

**Exploring the End-of-Life Care Perceptions of Older Gay, Bisexual, and Other Men
who have sex with Men**

by

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Dedication

To family and friends who supported me throughout this work, I offer my thanks.

To my thesis committee who were incredibly patient, I extend my gratitude.

To those who gave their time to participate in research, I am always appreciative.

To other graduate students who commiserated and celebrated with me, I praise you for your work and thank you for supporting mine.

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Abstract

Older gay, bisexual, and other men who have sex with men (gbMSM) face unique challenges in relation to end-of-life care and preparation. Using qualitative research methods, this study explored perceptions of older gbMSM in relation to end-of-life care planning. Data for this study are from a national study of older lesbian, gay, bisexual, and transgender adults and end-of-life service providers. Transcripts of five older gbMSM focus groups from across Canada were coded using qualitative description methodology and thematically analyzed. Major themes were mapped to an inverted social ecological model for health promotion interventions. This mapping created an understanding of where health promotion efforts can intervene to reduce barriers and strengthen facilitators for older gbMSM at end-of-life. Findings from this study offer recommendations to help reduce discrimination within health care services and supports a greater understanding of the complexities of end-of-life care for older gbMSM.

List of Abbreviations Used

The following is a list of abbreviations used either in this research or cited research.

- AIDS: acquired immune deficiency syndrome
- gbMSM: gay, bisexual, and other men who have sex with men
- GSA: gender and sexuality alliance
- HIV: human immunodeficiency virus
- LGB: lesbian, gay, bisexual
- LGBT: lesbian, gay, bisexual, transgender
- LGBTQ: lesbian, gay, bisexual, transgender, and queer/questioning
- LGT: lesbian, gay, transgender
- MAiD: medical assistance in dying
- SEM: social ecological model

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Chapter One: Introduction

A Note on Language. Throughout this thesis, there are a variety of terms used to describe those who are part of sexual orientation and gender identity minority populations. The most common term is ‘lesbian, gay, bisexual, and transgender’ abbreviated as LGBT.

This term is not inclusive of all identities. For example, it typically refers only to those who self-identify with these labels and does not include those who may engage in same-sex romantic or sexual behaviour. ‘LGBT’ also excludes other identities that are sexual and gender minorities including queer or two-spirit. Some literature cited is specific to sections of this broader community such as focusing only on lesbian, gay, and bisexual (LGB) individuals. In all cited research, the terms the authors have used in their work is the term that is when referring to said research.

The collective term ‘gay, bisexual, and other men who have sex with men’ abbreviated as gbMSM, is used to include all men who have sexual and/or romantic relationships with men, regardless of their self-identified sexual orientation.

Older lesbian, gay, bisexual, and transgender (LGBT) adults have often been labelled an “invisible population” (Brotman, Ryan, & Cormier, 2003; de Vries & Blando, 2004). The invisibility of this diverse group of communities is partly associated with the need to conceal sexual orientation and gender by remaining ‘in the closet’ to avoid stigmatizing interactions within health and social care institutions (Brotman, Ryan, & Meyer, 2006; Kochman, 1997; Kuyper & Fokkema, 2018). This enduring stigma within

institutions has resulted in members of these communities being overlooked and often neglected (National Senior Citizen's Law Center, 2011).

The exact number of the population that identifies as LGBT is still a matter of debate and research. In Canada, 2.1% of adult Canadians have self-identified as lesbian, gay, or bisexual (Statistics Canada, 2011). This measure only includes those who self-identify with these labels and not all persons who have sex with same sex partners publicly identify with one of the LGBT labels; particularly true of older persons and persons of marginalized racial groups (Adelman et al., 2006; Fredriksen-Goldsen et al., 2013). When research focuses on same sex behaviour and/or desire, estimates increase to between 4 and 6% (Institute of Medicine, 2011) but these are still likely underestimated numbers given the fear and distrust of institutions and research (Statistics Canada, 2011a). That fear and distrust is evident in a community consultation done with older LGBT adults by Egale, a national Canadian LGBT advocacy. Through this consultation, Egale (Plante, Filipenko, Bontje, & National Seniors Advisory Council, 2017) found that 52% of those participating feared being forced back into the closet for long-term care; 50% worried about their rights at end-of-life.

Research into the needs and experiences of this population of older LGBT adults has revealed unique demographic and health conditions – most of which can be attributed to a lifetime of stigma (de Vries, 2013). In comparison to age-matched heterosexual peers, older LGBT adults are up to three times more likely to live alone and more likely to be single (Adelman et al., 2006; Metlife Mature Market Institute & The Lesbian and Gay Aging Issues Network of the American Society on Aging [MMI & ASA], 2010; Wallace et al., 2011). Older LGBT adults are also less likely to have the familial support

network of children; they are five times less likely to have children (Statistics Canada, 2011).

For those older LGBT adults who are parents, they are less likely to be supported by their children (Fredriksen-Goldsen et al., 2013). It should be no surprise that older LGBT adults are more inclined to report feelings of loneliness and isolation (Kuyper & Fokkema, 2010). McLaren (2016) found in a study of older gay Australian men that in contrast to the sense of loneliness felt by those who lived alone, a sense of belonging with their friend circle helped act as a protective factor for depression. Improving mental health can lead to improved physical health outcomes. For example, a study of LGBT U.S. adults 50 and older, found good mental health was associated with better health behaviours which could then predict improved physical health (Fredriksen-Goldsen, Kim, Bryan, Shiu, & Emler, 2017).

Researchers in Canada and the United States have determined that the overall health of older LGBT adults is poorer than heterosexual peers in relation to physical and mental health indicators. Beyond isolation and loneliness, older LGBT adults are more likely to experience depression (Mills et al., 2004), contemplate suicide (Grossman, D'Augelli, & O'Connell, 2001), and experience violence at greater levels than their heterosexual age-matched peers (Fredriksen-Goldsen et al., 2011). Older LGBT adults face increased incidence of cancer with multiple studies finding higher rates among lesbians and gay men (Chin-Hong et al., 2004; Valanis et al., 2000). In a large study of community-residing older LGBT adults, almost 50% of the participants reported at least one disability (Fredriksen-Goldsen et al., 2011). In the overall older population, only approximately 26% report a disability (National Institute on Aging, 2010).

For older gbMSM, there is an increased likelihood of infection with human immunodeficiency virus (HIV). In the United States of America, the US Centers for Disease Control and Prevention (2010) projects that 25% of older gbMSM are HIV positive. They further predicted that by 2015 50% of all HIV positive persons in the nation would be over the age of 50 (2008). For many older gbMSM, there is also long-term traumatic stress related to the impact of HIV-related death of loved ones (including friends and former lovers) from years earlier (Mahmood, Manier, & Hirst, 2004).

Dealing with the processes of aging requires preparation for the end-of-life and there are several planning tools available. For this study, end-of-life care is used as a blanket term to include medical care plans and advanced care planning. End-of-life care medical plans are generally for those who are expected to die in the near/foreseeable future, including older adults (Canadian Institute for Health Information, 2011a). In a proposed best practice model, end-of-life care also extends to include the services needed by family members and friends of dying persons, including bereavement services (Wilson et al., 2008). Advanced care planning includes the discussion and acknowledgement of patients' goals regarding their own future care, including end-of-life preparations (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Advanced care planning seeks to help patients understand their own goals, values, and beliefs while considering possible future treatments, appointing legal decision makers, and documenting their plans (Detering, Hancock, Reade, & Silvester, 2010). While end-of-life concerns and advanced care planning are not unique to older individuals, they are frequently the target of such interventions, particularly among older individuals who foresee their own mortality or individuals who have life-threatening illness (Detering et al., 2010).

Research Design

This research is based on secondary data analysis from the *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults* study. The *Fostering* study was a cross-Canada study of older LGBT adults and end-of-life service providers conducted in 2014 and 2015 at five research sites across Canada. The key goal of this national study was to gain a better understanding of the needs of older LGBT adults in relation to end-of-life. The two main objectives of the *Fostering* study were: (1) to explore the ways in which older LGBT Canadians prepare for later life and end-of-life, seek and consider care, engage networks of support; and (2) the role that internet-based technology can play in supporting those activities.

The sites included Halifax (with local lead investigators Dr. Jacqueline Gahagan at Dalhousie University and Dr. Aine Humble at Mountain Saint Vincent University), the greater Toronto area (local investigator Dr. Steven Mock at University of Waterloo), Montreal (local investigator Dr. Line Chamberland at L'Université du Québec à Montréal), and Edmonton (local investigator Dr. Janet Fast of University of Alberta) and Vancouver (principal investigators Drs. Gloria Gutman and Brian de Vries at Simon Fraser University). At each of the five sites, potential participants were recruited into one of four focus groups: health care providers, older gay and bisexual men, older lesbian and bisexual women, and older transgender adults. Those recruited were screened to ensure they met the relevant inclusion criteria for their focus group (Appendix 1). Participants were invited to engage in semi-structured focus groups facilitated by members of the research team (Appendix 3). Prior to commencement of the focus group discussions,

participants completed demographic information forms (Appendix 2). Following the completion of the focus groups at each site, a town hall was held to report initial findings and engage community members in discussion around issues raised. Research team members at each site compiled a resource inventory that was distributed at a local town hall and shared with community partners.

Data from participants in the focus groups of self-identified gay and bisexual men, including transcripts and demographic data were the focus of this qualitative research study using qualitative description to better understand participants' experiences relating to end-of-life care planning. Further details on the research design can be found in Chapter Three.

Role of the Researcher

While qualitative research and interpretation strives to minimize the impact of individual researchers on data, "descriptions always depend on the perceptions, inclinations, sensitivities, and sensibilities of the describer" (Sandelowski, 2000, p. 335). I entered this research with the awareness gained as a middle-aged man who has been openly gay his entire adult life. I have the privilege of higher education with a Bachelor of Science (with honours) in health promotion. My academic research experience focused primarily on issues relating to marginalized sexual orientations and gender identities. I was personally motivated for this research as I will be a member of this population group in the not-so-distant future.

As an openly gay man, my positionality (my role as an 'insider') enriched the research process, helping reduce any potential power imbalance that might exist when

studying older gbMSM who have faced marginalization. I, too, have faced similar marginalization though not always in the same way. My ability to empathise with research participants as a peer, someone who has faced similar challenges, was very useful to understanding and interpreting meaning. Alternatively, there can be a disadvantage to an ‘insider status,’ in that I may not have been aware of my own implicit biases. This insider status was attenuated through academic rigour and the support of my thesis committee members who provided a more objective lens to identify any potential bias on my part and suggested measures to reduce such bias. My role in the original research (discussed below) informed my understanding of the data. Rather than simply reading transcripts, my first-hand experience of being in the room with older gbMSM during these discussions enriched my understanding of the emotional context in which discussions occurred. This helped provide a deeper perspective on participants’ concerns.

It is important to note that as a research assistant on the original *Fostering* study at Dalhousie University, I drafted and submitted the ethics proposal and amendments to the Dalhousie University Research Ethics Board (Appendix 8). A primary role as research assistant was to communicate with potential participants, answer questions related to the study, and screen them based on selection criteria if they were interested in participating. I participated in three of the four focus groups held in Halifax. I helped lead the focus group for older gay and bisexual men in Halifax in partnership with local investigator Dr. Humble. Dr. Humble and I alternated leading the discussion based on the focus group interview guide (Appendix 3); using prompting questions to draw out more detail when deemed appropriate. I transcribed the group discussion based on our audio recording and supplementary notes. I sat in on the focus group for service providers as a note-taker and

co-facilitated the focus group for older transgender adults with Dr. Gahagan. I compiled data from all participants at the Halifax site, including the screening tool (Appendix 1) and participant profile (Appendix 2). As part of the national research team, I engaged in teleconferences, face-to-face team meetings, and a national research conference supported by the study sponsor. These experiences helped shape my knowledge of the overall study and strengthened my ability to place the content into greater context.

The Problem

Given the challenges noted above that older LGBT adults face in health care and end-of-life care, it is crucial to note that many of the standard or stereotypical support systems are not applicable or available to LGBT populations (Cantor & Mayor, 1978). Most of these standard systems of social support rely on a heteronormative premise where care is expected from immediate family, followed by more distant relatives, and finally formal services (Cantor & Mayor, 1978). In a more recent study in the United States, 1 in 4 older LGBT respondents had cared for, or received cared from, a friend (MMI & ASA, 2010), a sharp contrast with the U.S. national average of 1 in 5 (MMI & ASA, 2010). Existing health care services that are specific to an aging population are often unaware or unprepared for older LGBT adults and rarely engage in outreach targeted in such a way that these services demonstrate an understanding of needs of older LGBT adults or their ability to meet those needs (Sussman et al., 2012; Hughes, Harold, & Boyer, 2011).

Research Purpose. The purpose of this qualitative research study was to better understand the perceptions of a sample of older gbMSM in relation to end-of-life care to

gain a clearer understanding of the related issues and contribute to the existing body of knowledge. Here, perceptions are defined as the processes by which people gain an understanding of their environment critical to survival (Cherry, 2017). Perceptions begin with basic sensory stimuli but are filtered by lived experience and knowledge, creating expectations, and impacting the ultimate action taken by an individual (Cherry, 2017). Study participants' perceptions were considered to help health promoters and end-of-life care providers develop responses that satisfy needs identified by older gbMSM. Using an examination of participant transcripts, the findings of this study helped develop an understanding of barriers and facilitators to end-of-life care faced by older gbMSM.

Research Question. The primary research question for this study was, “What are end-of-life care experiences and expectations of older gbMSM in Canada?” Other specific questions that were considered:

- What preparations are older gbMSM making for end-of-life?
- What barriers and facilitators do older gbMSM perceive (and/or have experienced) when making end-of-life care plans?
- Where within the inverted social ecological model are perceived barriers and facilitators located?
- What, if any, solutions to these perceived barriers and facilitators were proposed by research participants?
- How can health promotion intervene at different levels of the inverted social ecological model to reduce health inequities and provide improved care for older gbMSM?

With health promotion as the background for this research, structural and systemic changes to address these research questions were a key element of this study.

Health Promotion. Health promotion seeks to change the systems by which individual (and population) health is determined. One key framework of health promotion is the determinants of health (Mikkonen & Raphael, 2010). Although numerous lists of determinants of health exist, the Public Health Agency of Canada (2013) offers a list of 12 social determinants: income and social status, social support networks, education and literacy, employment/ working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture. Mikkonen and Raphael (2010) argue for a broader list of 14 determinants, including Aboriginal status, gender, disability, housing, early life, income and income distribution, education, race, employment and working conditions, social exclusion, food insecurity, social safety net, health services, unemployment and job security. Within these two Canadian lists, gender and health services are common, intersecting determinants of health. It is important to note that Mikkonen and Raphael (2010) explicitly include LGBT communities in their definition of those affected by gender discrimination whereas the Public Health Agency of Canada refers to the influence of gendered norms on health care systems (2013). Mikkonen and Raphael (2010) identify social exclusion as specific groups lacking the ability to fully participate in Canadian life and have less access to health care services.

While many health promotion efforts and interventions tend to focus on individual behaviour change, it is the intersecting nature of social determinants of health

that must be addressed to influence sustained change in health outcomes (Baum & Fisher, 2014). Specifically, policies are a key tool used to intervene on the determinants and their impact on population health, rather than focusing on individual behaviours (Baum & Fisher, 2014). Evidence shows that health promotion efforts that altered policies and systems/structures may decrease health inequities faced by marginalized populations, including gbMSM (Baum & Fisher, 2014).

Policy-related health promotion interventions focused on altering policies to be more LGBT-inclusive have shown success, leading to higher rates of interaction with the health care system and moderately improved health outcomes (Mule et al., 2009; Clark, Landers, Linde, & Sperber, 2001). While there is growing research on the health needs of LGBT communities in Canada and Nova Scotia (Colpitts & Gahagan, 2016a; Colpitts & Gahagan, 2016b; Gahagan & Colpitts, 2016; Gahagan & Subriana-Malaret, 2018), there is still a dearth of data on LGBT communities in health research, as they are often excluded, intentionally and unintentionally, in research projects leading to a limited understanding of their health (Boehmer, 2002; Sous, & Moleiro, 2015), especially relating to end-of-life care (Harding, Epiphaniou, & Chidgey-Clark, 2012). This can occur through methods and tools that are homophobic, biphobic, transphobic, and/or heterosexist or from discounting results for LGBT community members as not being ‘statistically significant’ due to low numbers (Boehmer, 2002; Meyer, 2001).

Glanz and colleagues (2008) argue that health promotion and health education need a greater emphasis to view health from a life-span approach that is holistic (recognizing that a person is a unified being, not able to be broken down into specific discrete units [Cottrell, Girvan, & McKenzie, 2009]) and focused on system-level

change. Yet the lack of attention in literature to sexual identities (including sexual orientation) of seniors is a striking absence (Henry & McNab, 2003). Sexual orientation and gender identity should be incorporated into health promotion programs to improve or maintain a good quality of life throughout the life span, including end-of-life with an emphasis on coping skills (Henry & McNab, 2003; Van Wagenen, Driskell, & Bradford, 2013). This research will reflect on existing health promotion and end-of-life policies that affect older gbMSM and suggest areas for improvement.

Chapter One Summary

This chapter introduced key concepts for this thesis. It began by clarifying the use of language of marginalized identities relating to sexual orientation and gender identity. A brief background of the issues that older gbMSM face was provided as justification for this research. The design of the research was outlined, clarifying data sources, theories, and conceptual framework. The role of the researcher and their reflexivity towards the research was explained. The chapter ended with an outline of the research problem, purpose, key research questions, and the role of health promotion. The following chapter will outline the literature reviewed as part of this study.

Chapter Two: Literature Review

The following section explores relevant factors that influence gbMSM in relation to end-of-life care planning. The first key concept to this research explored is defining “older.” This is followed by an exploration of the meaning of the term “end of life” and its origin in gerontology. The examination of literature continues with a historical perspective on the effects of homophobia and heterosexism that older gbMSM have faced over the last several decades and how these experiences may influence their perception of the health care system. Following that, an overview of the health issues that impact older gbMSM as they age, and a discussion on end-of-life planning specific to older gbMSM will be offered. This chapter concludes with identifying gaps in existing literature and a role for this research.

It bears mentioning that most of the literature reviewed for this thesis focused on countries that have legal protections in place for the expression of sexual orientation and gender identity (i.e., Canada, Australia, the United States of America). These protections are not a foregone conclusion and are, in fact, a privilege that many gbMSM (and LGBT) community members are not afforded globally. Protections for the free expression of true identities of sexual and gender minorities can vary greatly globally. The International Lesbian, Gay, Bisexual, Trans, and Intersex Association (ILGA) noted that progress has been made overall in the advancements of these rights and protections but that there were still many milestones to achieve for true equality (Carroll & Mendos, 2017). There are 72 nations that criminalize same-sex behaviour with the death penalty formally sanctioned by governments of 8 of those nations (Carroll & Mendos, 2017). ILGA found that 19 nations had laws specifically prohibiting the “promotion” of same-sex and transgender

identities (Carroll & Mendos, 2017). Twenty-five nations enacted barriers to prevent the formal founding and recognition of non-governmental organizations intended to support topics around same-sex issues (Carroll & Mendos, 2017). While this state-sponsored heterosexism may seem dated, many older gbMSM Canadians experienced similar challenges in their life times.

Defining “Older”

An important conceptual consideration for this research the varying definition of “older” found in the literature While considering the context of when research was conducted, generational differences can result in life experiences that will vary, possibly greatly. For example, the experiences of an older gay man who was 60 in 1980 are likely to be very different to a gay man who was 60 in 2010. It is also important to note that most of the literature used in this research was published in the last 10-15 years. Within that subset, some authors have developed their own definitions of what “older” constitutes. In a study of Canadian gay and bisexual men, the two relevant identified groups are ‘Generation Gay Legal,’ consisting of those born between 1944 and 1955, and ‘Generation Gay Pride,’ born between 1956 and 1970 (Trussler & Ham, 2016). Other authors used more commonly known labels such as ‘Baby Boomers,’ typically defined as being born between 1946 and 1964 (MMI & ASA, 2010).

Most authors, rather than using this generational model, applied a standard minimum age to participant selection which is often in keeping with health and social care policies used to determine eligibility for certain types of supports and programs (Almack, Seymour, & Bellamy, 2010; Grossman et al., 2001; Fredriksen-Goldsen &

Muraco, 2010). Many studies recruited those 65 or older in keeping with the notion of a ‘senior’ as defined by the Canadian Institute for Health Information (2011a). Some research expanded their inclusion criteria to 55 (Heyland et al., 2006) while others include those as young as 50 (Fenge & Hicks, 2011; Muraco & Fredriksen-Goldsen, 2011; Fredriksen-Goldsen & Muraco, 2010; Choi & Meyer, 2016; Fredriksen-Goldsen & Kim, 2017). The original study upon which this research is based, *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*, used a minimum age of 60 for participation (see Appendix 1) with an exception for those who were as young as 50 and providing care to another older LGBT adult. As such, while authors’ definitions of ‘older’ will be respected, this study will define older as 50 years of age and older.

End-of-Life Care & Gerontology

“End-of-Life” care is an issue typically faced by older adults or those with terminal illness as they prepare for death (even if the exact time of which is not known) (Heyland et al., 2006). While end-of-life considerations might be faced by younger adults, older adults are far more likely to face these realities as the infirmities of age set upon them (Fowler & Hammer, 2013). End-of-life care can be defined as the services a dying person and their family may need in the final years of their life (Wilson et al., 2008). This can include bereavement services for the family and loved ones of the deceased (Wilson et al., 2008).

End-of-life care includes up to five domains: medical and nursing care, communication and decision-making, social relationships and support, meaningful existences, and advance care planning (Heyland, 2006). Detering and colleagues (2010)

found that the primary goal for end-of-life planning was that the patient's wishes be known and respected. The important role of families and loved ones was also a consideration (Detering et al., 2010). Fowler and Hammer (2013) argue that normalizing discussions of end-of-life care will help improve the services provided at end-of-life through a better understanding of patient and family wishes.

Much of end-of-life research has fallen under the purview of gerontology. Gerontology is the study of aging which focuses on adults from middle age through later life and up to end-of-life (Academy for Gerontology in Higher Education, n.d.). It is an expansive field of study that includes understanding how society is shaped by older adults, changes older adults face (physiologically, mentally, and socially), and how knowledge in this field can impact policies (Academy for Gerontology in Higher Education, n.d.). The field has been cited as having a heteronormative focus or, as Brown (2009) refers to it, a 'silencing' of LGBT voices and experiences. In practice, similar challenges have arisen with the erasure of older LGBT adults in record-keeping and research into heteronormative long-term care facilities (QMunity, 2015). This erasing of LGBT identities is particularly pronounced for transgender adults through intentional avoidance of issues around gender identity (Namaste, 2000; Bauer et al., 2009).

Brown (2009) argues the exclusion of older LGBT adults is present in gerontology because of the actions within a position of power in the field. Brown (2009) posits that this is a not necessarily an intentional ignoring and silencing of an entire population, but the results are the same – the invisibility of older LGBT adults. Part of this silencing may come from the perception that sex is not for older adults (Henry & McNab, 2003), thus resulting a neutering of older adults, especially older LGBT adults

(de Vries & Blando, 2004). Including sexuality can expand the field of gerontology and offer a more holistic understanding of aging (de Vries & Blando, 2004). Studying older LGBT relationships can enhance knowledge of aging and stigmatized conditions (de Vries, 2007).

This field has been labelled “LGBT gerontology” which counters the heteronormative approach to research on aging and older adulthood (Henning, 2016). Henning (2016) argues that part of the exclusion of older LGBT adults has been the focus in social-focused gerontology on the family structure, primarily Caucasian heterosexual couple-based family units (de Vries & Brando, 2004). Much of gerontological research then focuses on “heterosexual aging” and is therefore neither properly defined nor appropriate to understand the aging experiences of older LGBT adults (Henning, 2016). Henning (2016) concludes that while the majority of existing gerontological research is still part of the *heteronormative panorama*, the field of LGBT gerontology is growing to address the needs of an aging LGBT community, better understanding their end-of-life and later life health care needs, using a holistic approach to the unique needs of these communities to recognize and honour their lived experiences.

Major Milestones for Older gbMSM

Key influences on the health of gbMSM come from stigma, discrimination, and a lifetime of minority stress resulting from heterosexism and homophobia in health care and social policies that exclude LGBT populations resulting in a lack of uptake of health care (Hash & Rogers, 2013; Meyer, 2013; Hoy-Ellis & Fredriksen-Goldsen, 2016; Fredriksen-Goldsen, Kim, Bryan, Shiu, & Emler, 2017). Heterosexism encompasses

attitudes and beliefs that favour opposite-sex relationships and heterosexuality, viewing these concepts as ‘normal’ and inherently superior (Hollenbach, Eckstrand, & Dreger, 2014). Homophobia includes negative reactions to the idea and reality of homosexuality, especially those who exhibit such behaviours (Hollenbach et al., 2014). These two elements combine over the course of a lifetime to generate minority stress for older gbMSM. Minority stress includes actual incidents of homophobia and heterosexism, expectations of those events, the internalization of these attitudes and the burden of concealing one's true identity (Kuyper & Fokkema, 2010). The long history of the psychopathologizing of same-sex desire and behaviour is reflected in the first edition of the *Diagnostic and Statistical Manual of Mental Disorders* when homosexuality was defined as a sociopathic personality disturbance akin to substance abuse (Institute of Medicine, 2011).

The inclusion of homosexuality as a mental health disorder in the *Diagnostic and Statistical Manual of Mental Disorders* was one of the major barriers to health care for gbMSM until it was removed in 1973 (Graham et al., 2011). In Canada, another milestone for improving the health of gbMSM came through the decriminalization of homosexuality in 1969 (Stinchcombe et al., 2017). During that same year, a major shift in public perception of LGBT communities, and the approach those communities used to advance their human rights, occurred with the Stonewall Riots which set the stage for the modern Gay Pride movement in North America (Knauer, 2010). Prior to Stonewall, the push for equal rights had been advanced by organizations such as the Mattachine Society and Daughters of Bilitis (Institute of Medicine, 2011). These organizations had mobilized

small public demonstrations and did not capture the attention of the larger community as happened with the Stonewall Riots (Institute of Medicine, 2011).

In 2005, same-sex marriage was legalized in Canada through the Civil Marriage Act which had significant legal implications for LGB couples (Humble, 2013; Stinchcombe et al., 2017). With the legalization of same-sex marriage, LGB couples had for the first time the opportunity to choose if legal marriage was right for them (Humble, 2013). Long-term couples were faced with challenging the internalized belief that marriage was ‘not for them,’ possibly due to internalized homophobia and a rejection of heteronormative institutions such as marriage (Humble, 2013). Legalization of same-sex marriage served as an indicator of the growing acceptance of same-sex relationships in many countries.

In a 2014 study of gay Australian men, 50 years and older, the increasing acceptance of homosexuality was cited as a significant change in their lifetime (Lyons, Croy, Barrett, & White, 2015). After years of remaining closeted for fear of criminal punishment, medicalization, or rejection by society and family, many found greater comfort in coming out (Lyons et al., 2015). The fear and expected rejection from loved ones and close friends was still strong for a significant portion of the study participants, especially those with ties to religious communities that were not accepting of homosexuality or gay marriage (Lyons et al., 2015).

Despite human rights advances, social stigma continues to influence the lives of many older gbMSM. In the *Sex Now Survey* of Canadian gay and bisexual men, Trussler and Ham (2016) found that gay and bisexual men aged 60+ were far less likely to be ‘out’ than younger gbMSM. In workplace settings, only 32% of those 60 or older would

be out as compared to 40% of those aged 45-59 and 49% of those aged 35-44 (Trussler & Ham, 2016). In community activities, only 30% of men 60 or older reported being out whereas in the next two closest age brackets, 45-59 and 35-44, 36% and 45% respectively, reported being out (Trussler & Ham, 2016).

This generational divide is further expanded by the experiences of older gay men with the onset of HIV/AIDS epidemic in North America (Lyons et al., 2015). Many older gay men lost the chosen family and friends they established in their 20s due to AIDS (Lyons et al., 2015). As many younger gay men today have not had this experience of massive community loss and view HIV as a manageable disease, these perceptions and attitudes further the generational gap (Lyons et al., 2015). For many older gbMSM, witnessing AIDS-related deaths resulted in psychological distress, including depressive symptoms and often traumatic stress related to cumulative losses (Mahmood et al., 2004). This bereavement can continue to have long-term effects as older gbMSM, having already witnessed difficult deaths, developed fears of experiencing such a death themselves, and watched other loved ones' experience such (Mahmood et al., 2004). The experience of caring for ill friends and partners helped gbMSM develop communities of care when government and other institutions did not act quickly enough to recognize the need for HIV/AIDS care in the 1980s (de Vries, 2015). Many of those who survived the AIDS epidemic continue to feel its effects, with or without an HIV diagnosis (Owen, Catalan, 2012). Careers may have been interrupted by illness and caregiving and social support networks corrupted (Owen & Catalan, 2012). For those living with HIV, the introduction of highly active antiretroviral treatment in 1996 meant an uncertain future as opposed to the certainty of death (Owen & Catalan, 2012). This included financial

insecurity and anxiety about their futures as many had used their financial resources on self-care and even with the introduction of highly active antiretroviral treatment many were unable to earn a stable income (Owen & Catalan, 2012). This added burden of years of increased anxiety and stress could impact the health of older gbMSM.

Health of Older gbMSM

While it is not ideal to compare older gbMSM to heterosexual men (or to other populations), this can help illustrate and clarify where and how they face unique health challenges. Despite self-reporting overall good health (Fredriksen-Goldsen et al., 2011), older gbMSM face several health challenges. Many older LGB adults contend with poor mental health, high rates of tobacco use, increased incidence of alcohol misuse, and greater levels of disability (Fredriksen-Goldsen, 2011; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). In one study, 44% of older LGBT adults reported limited physical activities due to health problems (Fredriksen-Goldsen et al., 2011). Older gay and bisexual men have higher rates of HIV, viral hepatitis (all strains), cardiovascular disease, diabetes, cancer, and hearing impairments than other older LGBT adults (Fredriksen-Goldsen et al., 2011). Even in basic health measures, older gbMSM fare at least slightly worse than national averages. In Canada, 52% of older gay and bisexual men report high blood pressure (Trussler & Ham, 2016) in contrast to the average of 48.9% for all Canadians (Canadian Institute for Health Information, 2011b).

Given the presence of these challenges, older LGBT adults may require additional formal social supports and services than heterosexuals (Brennan-Ing, Seidel, Larson, & Karpiak, 2014). Yet 38% of gay and bisexual Canadian men aged 60 or older are not out

to their primary health care provider; and 35% of those aged 45-59 are not (Trussler & Ham, 2016).

Further, loneliness is more common among older LGB adults than heterosexual peers, primarily stemming from past negative reactions and stigmatization (Kuyper & Fokkema, 2010). Over a 12-month period, 11% of gay and bisexual Canadian men aged 60 and older and 16% of those aged 45-59 have considered suicide (Trussler & Ham, 2016). This supports research in the United States that found 10% LGB adults aged 60 to 91 sometimes or often considered suicide (Grossman et al., 2001). Of those, Grossman and colleagues (2011) found that 29% related suicidality to sexual orientation with men reporting a stronger connection between suicidality and sexual orientation. Lyons and colleagues (2015) convey that older gay men found themselves being isolated from LGBT communities through ageism and the integration of the 'gay community' into the mainstream. Fredriksen-Goldsen and colleagues found that 29% of older gay men had depressive symptoms at a clinical level (2011). Older gay and bisexual men were also more likely to be lonely than lesbian and bisexual women (Fredriksen-Goldsen, 2011). Having a social network of other LGB adults helped reduce the minority stress that contributed to this loneliness (Kuyper & Fokkema, 2010).

Dying 'A Good Death'

According to Smith (2000), 'a good death' is more than being one that is free from pain. Smith outlines 12 key principles to a good death (2000). The most relevant to this study are: being able to retain control, being afforded dignity and privacy, control

over who shares the end, and the ability to issue advance directives to ensure wishes are carried out (Smith, 2000).

Wilson and colleagues (2008) propose that a best-practice model for end-of-life should include: a) universality; b) care coordination; c) access to a broad range of services; and d) end-of-life care in all settings. Universality recognizes that while individual needs for end-of-life vary, all patients need support for psychosocial, spiritual, and physical care (Wilson et al., 2008). Care coordination would help ensure that patients and their family/friends have access to services across sectors and settings (Wilson et al., 2008). Access to a broad range of services would ensure basic services such as transportation are included in end-of-life care along with health care concerns as not all patients have access to support networks to aid them with these tasks (Wilson et al., 2008). End-of-life care should include providing Canadians with services in their homes, hospitals, or hospices/palliative care homes (Wilson et al., 2008) ranging from health care to legal services.

A systematic review by Brinkman-Stoppelenburg and colleagues (2014) found evidence that advanced care planning has a positive impact on the quality end-of-life care. Complex advanced care planning, which involves more detailed discussions than the standard paperwork (i.e. funeral arrangements and legal wills), led to greater satisfaction and quality of life (Brinkman-Stoppelenburg et al., 2014). Complex advanced care planning resulted in greater adherence to the wishes of the end-of-life patient (Brinkman-Stoppelenburg et al., 2014).

In an Australian randomized controlled trial comparing those with and without advanced care planning, Detering and colleagues (2010) found advanced care planning

resulted in patients' wishes being better known and followed. For those patients in the intervention group who had advanced care planning, their families experienced less stress, anxiety, and depression (Detering et al., 2010).

In a study of Americans, more than 90% think it is important to talk to loved ones about their wishes relating to end-of-life care (Conversation Project, 2013). Yet less than 30% have had such discussions, with the primary reasons justifying this choice being the feeling it was not an issue at this stage in their life, their partner was not sick, the topic is uncomfortable, or fear of upsetting a loved one (Conversation Project, 2013).

In another study of American end-of-life patients (which did not break data down by sexual orientation), family members, and care providers, decisions about treatment preferences and being treated as a 'whole person' were rated as being important by more than 70% of respondents (Steinhauser et al., 2000). In the Canadian context, there is a desire for an end-of-life care plan that is focused on providing comfort to the dying person with a less aggressive treatment plan (Fowler & Hammer, 2013). Yet, the majority of deaths in Canada are occurring in hospitals where patients are often admitted to the Intensive Care Unit during their final days (Fowler & Hammer, 2013). This contradicts Canadians' wishes for a death that is non-institutionalized and less dependent on technology (Fowler & Hammer, 2013). Many end-of-life patients have expressed a desire of not wishing to die in a hospital (Canadian Institute for Health Information, 2011a) though up to 71% of Canadians are dying in hospital as part of their end-of-life treatment (Canadian Institute for Health Information, 2011a). This reliance on hospitals may reflect the inability with the Canadian health care system to keep up with the demand for palliative care specialties, hospices, or home hospice care options compared to other

countries (Fowler & Hammer, 2013). In 2015, the Supreme Court of Canada ruled that citizens had a right to medical assistance in dying (Dying with Dignity Canada, n.d.). The federal government then enacted legislation which includes the option of allowing qualified patients to be prescribed a substance that they can self-administer to cause their own death (Dying with Dignity Canada, n.d.) – an important step in relieving the reliance on hospitals for end-of-life. This can be an important option for older gbMSM as they may not have traditional family structures who can offer support for end-of-life.

Older gbMSM and End-of-Life

As they age and near end-of-life, older gbMSM find their experiences shaped by new and old social influences. The need for support and assistance from others becomes a more prominent concern. Aging often requires support structures and older gbMSM experiences with these structures may be unique, starting with their home life.

Family Structures

Older gay men are more likely to live alone – up to 2 to 3 times more likely as found in some studies (Fredriksen-Goldsen et al., 2010; Fredriksen-Goldsen et al., 2013; Wallace, Cochran, Durazo & Ford, 2011; Brennan-Ing et al., 2014). This stems from several factors including lack of partner, lack of children, and lack of familial relations. In comparison to age-matched heterosexual peers, older LGBT adults are up to three times more likely to live alone and more likely to be single (Adelman et al., 2006; MMI & ASA, 2010; Wallace et al., 2011). Research on the relationship status of older gay men echoes the data on their living status; they are less likely to have a partner or spouse when compared to older bisexual men, older lesbian/bisexual women, and older heterosexuals

(de Vries, 2006; MMI & ASA, 2010). Some studies have found that approximately half of older gay men are single (de Vries, Mason, Quam, & Acquaviva, 2009; Lyons et al., 2014; Hughes & Cartwright, 2015).

Beyond being single, older gay men are less likely to have children (up to five times less likely than heterosexuals) to offer support for end-of-life considerations (Almack, Seymour, & Bellamy, 2010; Statistics Canada, 2011). In the United States, approximately 1 in 4 older LGBT adults report having a living child (Fredriksen-Goldsen et al., 2011) though older gay men were less likely to report having children (Brennan-Ing, Seidel, Larson, & Karpiak, 2014). Other studies have compared childless rates to the general population and found older LGBT adults are 2.5 times less likely to have children, with older gay men being less likely than the general elderly LGBT population, with as few as a quarter of older gay men having children (Croghan, Moone, & Olson, 2014; Brennan-Ing, Seidel, Larson, & Karpiak, 2014). For those who do have children, they are less likely to have a supportive relationship with their children (Fredriksen-Goldsen et al., 2013) and other members of their biological families. Older LGBT adults find themselves facing homophobia and heterosexism from within their own family of origin (Orel, 2014). While some older LGBT adults may be distanced from their family of origin by estrangement or dispute, many also face the reality that their own relatives (e.g. siblings) are deceased (Almack et al., 2010). Given how few older gbMSM are parents and experience potential estrangement from siblings, this leaves many older gbMSM without familial support networks on which to rely.

As families of origin are not always an option, a great number of older LGBT adults create families of choice (or chosen family) as their support network (MMI &

ASA, 2010). Families of choice are defined as close friends who are “like family” and may be considered an extension of familial relations (MMI & ASA, 2010). Some older LGBT adults even think of families of choice as their primary family and their family of origin becomes ‘secondary’ (MMI & ASA, 2010). Friends who are identified as chosen family are loved and treated as family despite no formal/legal bond as family and often fulfill the role of caregivers that might be filled for others by biological family members (Almack et al., 2010; Muraco & Fredriksen-Goldsen, 2011).

Croghan and colleagues’ (2014) work supported others’ findings that older LGBT adults were less likely to have traditional sources of caregiver support (e.g. family and children). Family of choice members make up the primary source of support networks for older gay men (de Vries, 2006). Close friends in support networks typically provide basic support (such as transportation or assistance with daily tasks such as laundry) but the emotional and social support is recognized by the caregiver and care recipient as beneficial (Muraco & Fredriksen-Goldsen, 2011).

Support Networks

Support networks are a measure of perceived social support (Grossman et al., 2001) and can help gay men better understand their identity (Mallon, 1993). Those with robust and large support networks show decreased levels of loneliness and improved physical health outcomes (Grossman et al., 2001). In an Australia study of gay men aged 50 years or older, receiving emotional support correlated to lower psychological distress (Lyons, 2016). The strongest indicator of connectedness to combat isolation was not families but friendships, especially long-standing ones with other gay men (Lyons, 2016).

Social isolation in older gbMSM is associated with higher levels of mental health issues such as depression, anxiety, and suicidality (QMunity, 2015). Existing friendships and chosen family members can help counter isolation as there are limited social networks and opportunities for older LGBT adults (Almack, Seymour, & Bellamy, 2010). Support networks average six people, primarily made up of close friends, partners, relatives (including siblings), and social acquaintances (Grossman et al., 2001). The support networks that are made up primarily of close friends and chosen family are more common for a majority of older LGB adults (Grossman et al., 2001).

It is important to note that not all members the support network of an older LGBT adult will identify with the term 'caregiver.' In a 2007 Canadian study of those providing care to older LGBT adults, many participants saw the title as more formal than their relationship with those receiving care - providing care was an extension of their existing relationship (whether familial, romantic, or platonic) (Brotman et al., 2007). It is important to note that significant proportions of older LGBT adults were not able to identify someone on whom they might depend for care (de Vries, 2006), speaking to their social isolation and indicating challenges they may face as they grow older.

In another study, nearly half of older lesbians and gay men reported that their support systems were not able to aid them with the physical changes and needs expected as they age (McFarland and Sanders, 2003). Muraco and Fredriksen-Goldsen found that friends providing care for older LGB adults faced challenges that emerge with aging (2011). Difficulties between the caregiver and the older adult included the perceived burden that the care recipient feared they were becoming, fear from the caregiver that they would not be able to meet needs of their friend, especially as they aged and

perceived need increased (Muraco & Fredriksen-Goldsen, 2011). Many caregivers recognized that they could not always meet the needs of their friends, whether that be due to their own limited abilities or interest (Muraco & Fredriksen-Goldsen, 2011).

In a study of older LGBT adults in the United States, most caregivers were not a legal relation (Croghan et al.,2014). This could be influenced by the lack of legal protections through marriage that existed at the time (Humble, 2013). Thus, Croghan and colleagues' study (2014) might unintentionally have excluded partners. In an Australian study, most participants wanted a partner to be decision maker in end-of-life situations where they were incapable of making decisions (Hughes & Cartwright, 2015). Only approximately half of respondents had discussed this responsibility with their partner (Hughes & Cartwright, 2015) and there was no guarantee these partners would be legally recognized as spouses.

Given the variable level of legal recognition of chosen families, older LGBT adults may need to consider formal legal protections as part of their advanced care planning (Knauer, 2010). Tools such as wills, powers of attorney, medical directives, and burial instructions can help protect older gay men and ensure their end-of-life wishes are fulfilled (Knauer, 2010). For romantic partners without legal protection such as marriage the risks can be even greater, including losing access to their home or decision-making at end-of-life for their partner (Orel, 2004).

End-of-Life Preparations

For those who are partnered, there are increased rates of end-of-life and advanced care planning, typically involving increased legal protections for end-of-life. In a study of older LGBT adult Americans, approximately 70% of couples had completed a will

whereas only about 40% of single participants had (Riggle, Rostosky, Prather, & Hamrin, 2005). For power of attorney, nearly two-thirds of couples had arranged for power of attorney vs approximately 24% of singles (Riggle et al., 2005). For financial preparations, approximately 58% of couples had made such arrangements yet only 21% of single older LGBT adults had (Riggle et al., 2005). Despite the advantages older LGBT adults may gain from advanced care planning, an Australian study found that involvement in this planning was as low as the general population (Hughes & Cartwright, 2015).

In a meta-analysis of studies of older LGB adults in the United States, de Vries (2006) found that their financial resources were strained by those without partners and those living alone. As older gay and bisexual men were more likely than lesbian and bisexual women and heterosexuals to report being single, they do not have a two-income household to offset costs (de Vries, 2006). With up to 66% of older gay men being childless (de Vries, 2006), that is not an available source of financial support either. In a study in the United States, 70% of older gay men and lesbians reported not having the financial resources to meet their needs as they age (McFarland & Sanders, 2003). Seventy-three per cent had started making end-of-life plans such as life insurance, wills, power of attorney, and financial planning (McFarland & Sanders, 2003) yet there was less evidence of medical directives.

Interactions with Health Care

As older adults age, their need for social and health services are likely to increase and navigating these systems can be challenging (Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emler, & Hooyman, 2014). The complexity of end-of-life care is greater for older gbMSM due to discriminatory policies and a lack of recognition of their unique

needs (Fredriksen-Goldsen et al., 2014). Past experiences of discrimination discourage older gay men from seeking out formal services (Fredriksen-Goldsen et al., 2014). Even when services are geared to be LGBT-friendly, there is no guarantee that other clients will not display anti-LGBT attitudes (Fredriksen-Goldsen et al., 2014). One study of older LGBT adults in the United States found that being out to their provider led to improved services, a stronger relationship, and greater inclusion of partners in health care decision-making (Orel, 2004).

A good relationship with a health care or social service provider can be key to good health outcomes and peace of mind as older adults approach end-of-life. In a study of seriously ill Canadian patients and their family members, the most frequently reported 'extremely important' issue was that patients have trust and confidence in their doctors (Heyland et al., 2006). Yet many older LGBT adults continue to fear the health care system; nearly one quarter of participants included in a study of older LGB Californians reported their sexual orientation would be a source of discomfort in seeking social services targeted to older adults (Gardner, de Vries, & Mockus, 2014). Older LGBT adults reported their preference for LGBT-friendly services however this preference decreased with age; the older the participant, the less comfortable they would be using an LGBT-friendly service (Gardner, de Vries, & Mockus, 2014). Gardner and colleagues (2014) attribute this to their findings that the older the participant, the more likely they were to be closeted. "LGBT-friendly" was vaguely defined but respondents determined that the use of promotional material that included images of gay couples would strongly influence their use (Gardner, de Vries, & Mockus, 2014).

In a study in Michigan, more than one third (37%) of health care service providers who worked with older adults did not feel that the needs of older LGBT adults were different than those of the larger population (Hughes et al., 2011). Similarly, 36.7% of those survey respondents indicated that they did not want training on the issues facing older LGBT adults (Hughes et al., 2011). Most participants had ‘some knowledge’ across domains relating to end-of-life care and services for older LGBT adults while 25% knew nothing about the specific needs of older LGBT adults (Hughes et al., 2011). Professional care providers must recognize the importance of social support networks outside the traditional family to help older gay men avoid isolation (Fenge & Hicks, 2011).

Discrimination within the Canadian health care system is still a reality for older gay men; for example, being told to go back into the closet to receive care and avoid abuse (Brotman et al., 2007). Discrimination was often subtle which made it difficult to challenge or address such as in the form of negative attitudes or comments (Brotman et al., 2007). Caregivers of older LGBT adults cite these issues as reasons to reduce their trust in health care systems and providers (Brotman et al., 2007). This mistrust can be especially challenging when older gbMSM must rely more heavily on care providers as independence fades with age and reduce physical ability.

Long-Term Care

With advanced age, the need for continued care – including long-term care – becomes a greater reality. Many older adults feel hesitance and fear towards moving into long-term care and one of their main concerns regards the quality of treatment they might receive (Leggett, Davies, Hiskey, & Erskin, 2011). For older LGB populations, this resistance to giving up independence to move into a long-term care facility (such as a

nursing home) is amplified due to fear of staff lacking knowledge on the needs of aging LGB populations (McFarland & Sanders, 2003). In a study of older LGBT Americans' experiences with long-term care facilities, there was an overwhelming recurrence of issues relating to perceptions and fear of discrimination in health care (Jihanian, 2013). Participants cited the need for providers to be aware and to offer support systems that welcomed same-sex partners and included LGBT-positive religions (Jihanian, 2013). In a study of older lesbian and gay Canadian couples, couples were burdened with additional emotional and psychological labour to hide elements of their identity for fear of discrimination (Furlotte, Gladstone, Cosby, & Fitzgerald, 2016). The couples needed to remain vigilant to assess and perceive potential acts of discrimination while also placating others to minimize their own risk (Furlotte et al., 2016).

Gaps in the Literature

A significant amount of the literature on older LGBT populations reviewed for this thesis came from the field of social work, while little research has been done with a focus on health promotion and little focused on the specific needs of older gbMSM. In a literature review of healthy aging for LGBT seniors in Canada, the need was cited to collect additional information to support health promotion efforts for older LGBT adults with a specific need to look at the experiences of LGBT seniors (Murray, Numer, Merritt, Gahagan, & Comber, 2012). This notion was supported by Van Wagenen and colleagues who described the need to explore patterns of successful aging in older gay men (2013).

Orel (2014) cites the need for more research on the specific realities of older LGBT adults in a holistic manner, rather than focusing on individual needs (e.g. social

needs) in isolation. Future studies of older gbMSM need to include determinants of health (such as socioeconomic status and family composition) and how they influence the aging process (Fredriksen-Goldsen & Muraco, 2010). Research into understanding the diversity among older LGBT populations and the many forms of marginalization this community faces will lead to better efforts to address the resulting health care needs (Murray et al., 2011). Some older LGBT adults reported that their greater challenge is ageism; thus, understanding the unique challenges older LGBT adults face can benefit all older adults in end-of-life preparation (de Vries & Gutman, 2016).

There is limited data on the experiences of older LGBT Canadians with significant amounts of the literature contained in this review coming from the United States of America and Australia. Stinchcombe and colleagues (2017) recognized in their systematic review of literature on the end-of-life needs of older LGBT adults that there is a need for more Canadian data on how aging and end-of-life affect this community. Further, Fenge and Hicks (2011) cite the lack of research on the specific health needs of older gbMSM. In addition, Brotman and colleagues (2007) recommend expanding the definition of caregiver to be more inclusive of the reality of older LGBT adults as a potential research topic. This recommendation could also address that there is little research on community-based service providers and older LGBT adults (Hughes et al., 2011).

With the legalization of same-sex marriage in Canada in 2005 (Humble, 2013), there are considerations which have not been accounted for in past research. In a study in Massachusetts following the state's legalization of same-sex marriage, Hatzenbuehler and colleagues (2012) found that health care spending and visits decreased significantly for

gay and bisexual men, regardless of their partnered status. In Canada, a study of 26 same-sex married couples who wed following the federal legalization of same-sex marriage in 2005 found that the couples demonstrated increased relationship satisfaction and reduced attachment-related anxiety than data for heterosexual couples (Macintosh, Reissing, & Andruff, 2010). Brinkman-Stoppelenburg and colleagues (2014) cite the need for further study of advanced care planning in a variety of settings. Given the potential ‘built-in’ legal protections of same-sex marriage, this is a possible avenue of exploration for married couples.

Chapter Two Summary

This chapter outlined literature reviewed that is relevant to this study. It began with a discussion of ‘older’ and how different literature approaches this concept. The concept of gerontology and its lack of inclusion of the needs of older gbMSM adults was then explored. A brief history of some of the challenges that older gbMSM may have faced in their lifetimes, such as the AIDS epidemic, was summarized. Health concerns that older gbMSM face (and some of the causes) were highlighted. Following this, there was a discussion around end-of-life concerns for older gbMSM, including the impact of family, support networks, legal and financial preparations, the health care system, and long-term care considerations. The chapter concluded with an identification of gaps in the existing literature reviewed for this thesis and topics for future research. In the following chapter, the methods for this study are explored and explained.

Chapter Three: Methods

This chapter describes the research approach and methodology used to explore the perceptions of a sample of older Canadian gbMSM in relation to end-of-life preparation. Social constructivism, the guiding research paradigm, is outlined to inform the research methods. This chapter elaborates on the use of qualitative research with details regarding the methodological approach of this research. The conceptual framework of an inverted social ecological model will inform thematic analysis. An outline of the data collection and ethics considerations of the original study, *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*, is included and supplemented by ethics considerations for this research. The thematic analysis approach, including the use of MAXQDA software as a research tool, is included. This chapter ends with descriptions of knowledge transfer activities related to this research.

Research Paradigm: Social Constructivism

A research paradigm is the overarching and underlying worldview, including assumptions, about how the world and the people in it work (Rossman & Rallis, 2003). A paradigm represents the basic beliefs or worldview of the researcher (Guba & Lincoln, 1994) and guide the actions the researcher takes in their work (Creswell, 2013).

Social constructivism is a theory based on the idea that human knowledge and development is constructed through interaction (Vygotsky, 1978; McKinley, 2015). This sociological theory of knowledge suggests human development is socially situated (McKinley, 2015). Social constructivism is a useful framework in qualitative research as it reveals how people interact with the world (Creswell, 2013). Rather than using a theory

as a starting point, social constructivism generates patterns of meaning through the analysis of collected data (Creswell, 2013). In such cases, cause and effect cannot be concretely defined as social constructivism recognizes that phenomena are bound by the situational circumstances (Guba & Lincoln, 1994). Instead, context and culture are the stronger factors upon which knowledge should be based as reality is constructed through human activity (Brandon & All, 2010; Kukla, 2000; McKinley, 2015). Knowledge itself is a social product as individuals create meaning through their interactions with their environment (Ernest, 1999; Brandon & All, 2010; Kukla, 2000; McKinley, 2015).

Qualitative Research

This study used qualitative description, a qualitative approach, to address the research question. Qualitative description stems from inquiry into so-called ‘natural settings,’ using data reflective of subjects’ lives (Law, Mathai, Veinot, Webster, & Mylopoulos, 2015). This approach has been used in research with LGBT populations to develop results that have practical application (Law et al, 2015). Qualitative approaches focus on a specific social phenomenon (or clustered phenomena) and seeks to better understand its multifaceted contexts (Leedy & Ormrod, 2005; Baumgartner & Hensley, 2006). An advantage of qualitative approaches to research issues is that the participants’ understanding of an issue is kept as a priority, rather than the perspective of the researcher (Creswell, 2014). Qualitative research has also been cited as a good tool for understanding the complexities of context-rich phenomena such as family relationships (Orel, 2014).

Epstein (2003) highlighted that much research on LGBT communities has not been holistic, focusing instead on biomedical quantitative data. As qualitative research seeks to gain a context rich understanding of unique phenomena, rather than simply measure it as in quantitative data, it blends well with a series of open-ended questions such as those used in the focus group guide (Appendix 3). Those who work with LGBT clients have identified qualitative research as one means of moving to a more holistic approach to the health of gbMSM, rather than focussing solely on sexual health (Adams, Braun, & McCreanor, 2010). Qualitative description also gives voice to research participants, allowing their experiences to be reflected in the results.

Qualitative Description

Qualitative description entails presenting the facts of the data in accessible plain language (Sandelowski, 2000). Qualitative description is a useful approach in research that seeks to gain firsthand knowledge of patients' experiences with a specific topic (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Neergaard and colleagues (2009) argue that qualitative description should be used when a description of a phenomenon is desired. Qualitative description has the advantage of being suitable when time and resources are limited (Neergaard et al., 2009).

Sandelowski (2000) argues that basic or fundamental qualitative description is focused on a straightforward summary of data with less room for interpretation. Qualitative description involves 'low-inference' interpretation of content, that can be more easily agreed upon by members of a research team (Sandelowski, 2000, 2010). Rather, qualitative description seeks to present the facts in everyday language without

overanalyzing or interpreting participant experiences in other terms while still offering analysis and insight (Sandelowski, 2000, 2010). Researchers using qualitative description focus on their data and to the way participants express their ideas rather than the interpretation methods of phenomenological (which interprets the experience), ethnographic (thick description), grounded theory (focused on theory development), or narrative methodologies (Sandelowski, 2000; Neergaard et al., 2009). This does not exclude qualitative description from theoretical underpinnings as all inquiry and analysis is guided by theory (Sandelowski, 2010). While qualitative description has been criticized for a lack of rigour (Neergaard et al., 2009), there are several ways to strengthen rigour and credibility. These include authenticity and credibility (allowing participants to speak directly to the purpose of the study), ensuring participants' freedom to speak, ensuring participants' voices are heard, and accurately presenting participants' perceptions (including context) (Milne & Oberle, 2005; Neergaard et al., 2009).

In terms of research design, qualitative description works well with focus groups where there is purposeful sampling (Neergaard et al., 2009). are features of the data from *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*. This methodological approach has been used in other research involving gay men. Bilardi and colleagues used qualitative description in research on HIV self-testing among gay and bisexual men (2013). Han (2008) utilized qualitative description to explore which factors gay Asian Pacific Islander men found important when predicting unsafe sexual practices. Chapman and colleagues (2012) used qualitative description to understand the experiences of LGT parents relating to how health care systems treated their children,

drawing conclusions based on health care provider skills and knowledge based on parent experience.

Lincoln and Guba (1984, 1985) propose five criteria for trustworthiness in qualitative research: credibility, dependability, confirmability, transferability, authenticity. Credibility refers to the truth of the data from participant perspectives (Cope, 2014) and qualitative description, with its goal of reporting directly experiences of participants is a strong fit with this aspect (Sandelowski, 2000, 2010). Dependability is the consistency of results across similar circumstances or conditions and includes the ability for results to be reproduced by another researcher (Cope, 2014). Confirmability is the demonstration that results represent participant responses (Cope, 2014) which, is also a key element of qualitative description (Sandelowski, 2000, 2010). Transferability is the ability for results to be understood through outsider perspectives but is less emphasized in some qualitative research as unique circumstances may not provide transferable experiences (Cope, 2014). Authenticity is the degree to which participants' emotional experiences are expressed clearly and accurately (Cope, 2014).

As qualitative description seeks to reproduce and report the experiences of participants (Sandelowski, 2000, 2010), this methodology represents an approach that enables a researcher to meet these criteria for trustworthiness outlined (Lincoln & Goba, 1984, 1985; Cope, 2014). Kahlke (2014) argues that Sandelowski (2010) employs a constructivist epistemology as the individual interpretations is always mediated by the perspective of the researcher and lens of research. These lenses are less likely to be theoretical (Neergaard et al., 2009) but can include conceptual frameworks for application of findings.

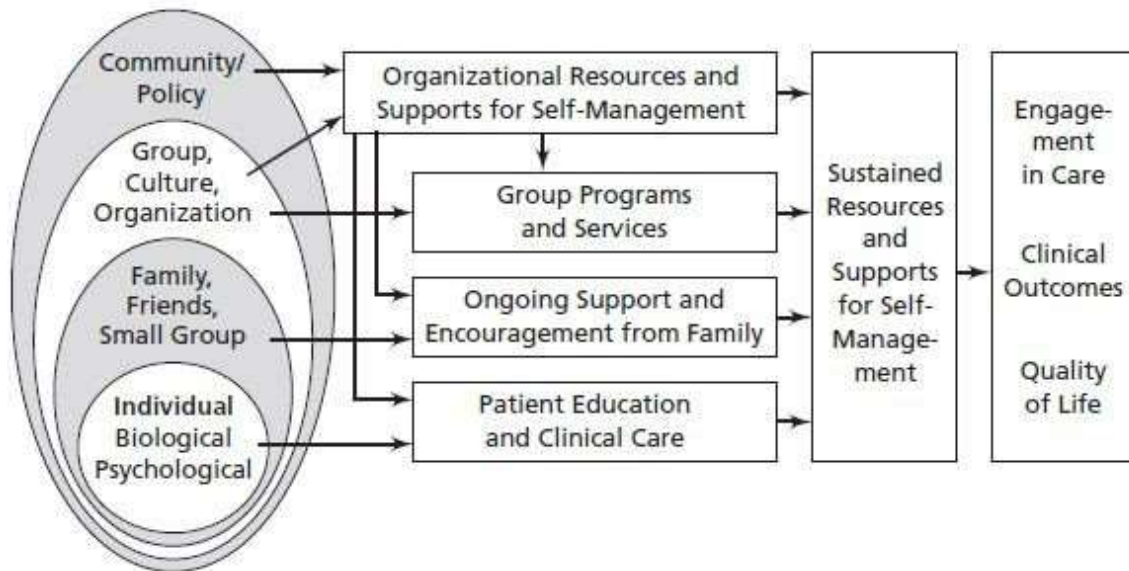
Conceptual Framework: Social Ecological Model

Conceptual frameworks are organizing devices of abstract concepts in research and application of knowledge (Ravitch & Riggan, 2016). A social ecological model (SEM) recognizes that there are multiple levels (or factors) influencing human behaviour (Sallis, Owen, & Fisher, 2008) as first proposed by Bronfenbrenner (Ceci, 2006). Depending on the model, labels will vary but they are all nested within one another, recognizing that their influence travels in directions (Sallis, Owen, & Fisher, 2008). SEM are often cited as good frameworks for understanding the interaction of determinants of health and can help develop interventions that target change at each level of influence (Sallis, Owen, & Fisher, 2008).

These models typically fall into two categories: 1) models designed mainly to explain behaviour; and 2) models designed mainly to guide interventions (Sallis, Owen, & Fisher, 2008). In 1998, McLeroy, Bibeau, Steckler, and Glanz proposed an ecological perspective for health promotion programs. Their model included five levels of influence: intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors, and public policy (McLeroy et al., 1988; Sallis, Owen, & Fisher, 2008). This model focuses attention on individual and societal environmental factors as potential targets for health promotion interventions (McLeroy et al., 1988). Of note is that this model included the population within the model to enable the affected community to consider its relationship to other factors (McLeroy et al., 1988). Interventions stemming from this model tend to address multiple levels of the model but with a focus on organizational factors (McLeroy et al., 1988).

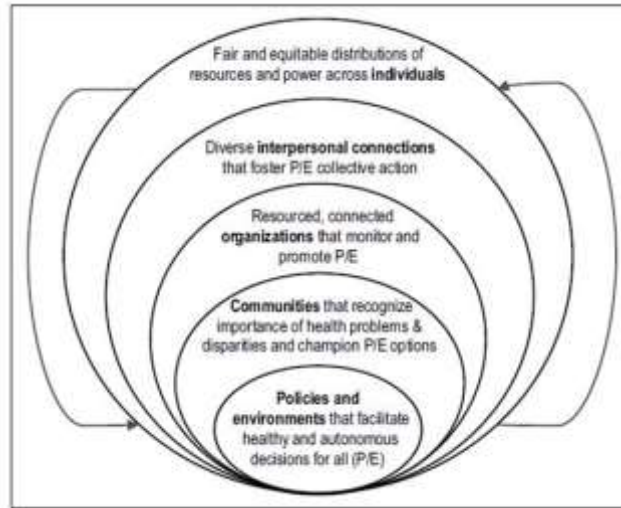
One example of an SEM cited by Sallis et al. (2008) is the Illustrative Model of Relationships among Organizational Factors and Supports for Diabetes Self-Management. This model (Figure 1) identifies the individual at the centre, recognizing biological and psychological influences with the individual as they impact health and health choices. The model then expands outwards to community and policy. At each level of the model, different health promotion interventions and resources are identified.

Figure 1: Illustrative Model of Relationships among Organizational Factors



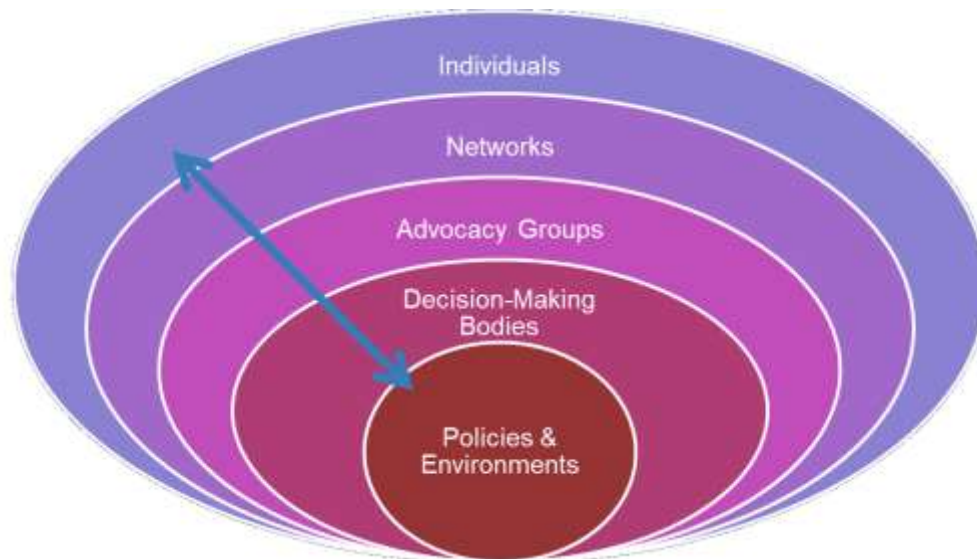
The typical layout of an SEM (with the individual at the centre) was recently “upended” with an inversion of the design where policy is in the centre and individual capabilities are the outermost ring (Golden, McLeroy, Green, Earp, & Lieberman, 2015). This revised model recognized the increasing effort to change policies and environments in which people live and placing greater emphasis on the context that is generated by individuals, their social networks, and organized groups (Golden et al., 2015). It is this model, hereafter referred to as an ‘inverted SEM for health promotion interventions’ or the ‘inverted SEM’, that was used in this research.

Figure 2: Inverted Social Ecological Model (SEM)



The model created by Golden and colleagues (2015), while complete, is not immediately accessible in terms of language and clarity. As such, to clarify the model and its role in this research, an alternate version with clarified levels is used (Figure 3).

Figure 3: Simplified inverted SEM for policy and environmental change.



The inverted SEM for health promotion interventions through policy and environmental change has five levels (Golden et al., 2015). Each of these levels is described below with the simplified title and the titles created by Golden and colleagues

(2015). As well, initial ideas as to how they might map onto issues arising from this study are included.

1. **Policies and Environments** (*Health-Related Policies and Environments*):

These policies and environments are created through intentional acts and include public health policy but also aspects of the environment such as access to transit (Golden et al., 2015). In relation to this study, this level may map to policies at the educational institutes relating to inclusiveness in education and training for care providers and access to transit for older adults who are not able to drive. Policies are thus, in this model, the core for health promotion interventions and change will radiate outward.

2. **Decision-Making Bodies** (*Community Contexts in Which Decisions About Policy and Environmental Changes Are Made*):

Here, ‘community contexts’ refers to decision-making groups such as elected bodies (Golden et al., 2015). This would extend to governmental bodies and regulatory bodies. This could include, for example provincial nursing regulatory bodies which govern the ways in which nurses engage in professional practice.

3. **Advocacy Groups** (*Organizations That Monitor and Promote Policy and Environmental Change*):

This level includes community advocacy groups (Golden et al., 2015); a relevant example might be Egale (cited above), a national LGBT rights organization. These differ from the next ring (Networks) in that they are formalized bodies with clear structure and organizational missions.

4. **Networks** (*Interpersonal Connections That Foster Collective Action*): This includes informal social groups and networks that foster collective action (Golden et al., 2015) and could include the communities of care noted in the literature review. Networks can be somewhat formalized (as in organized social support groups or recreational leagues) but includes loosely knit webs of personal connections.
5. **Individuals** (*Distributions of Resources and Power Across Individuals*): This ring recognizes the ability of individuals to influence policy or environmental change is largely dependent on how they meet their daily needs, exert control over lives and their resources, and can participate in public discussion (Golden et al., 2015). This may map to concerns by older adults about issues relating to infirmity that will prevent them from engaging in civil discussion but also the fear of repercussion if they are publicly out. With individuals at the outer ring of this model, they are not the primary target for creating change; rather they benefit from health promotion interventions aimed at the inner rings. Instead of putting the onus on individuals to create personal change, this inverted model sees them as the beneficiary of the work done within the inner rings.

This model is supported by the general trend in health promotion to combine government action and citizen participation (Golden et al., 2015). The World Health Organization, in their *Global Plan of Action on Social Determinants of Health*, identifies the first step in improving health outcomes as the need to include voices to all groups involved in addressing the determinants of health (n.d.).

Research Design

This thesis involved the analysis of secondary data from the *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*. This is a subset selection analysis as only the data on gbMSM from the larger study will be included (Hinds, Vogel, Clarke-Steffen, 1997). Subset selection analysis requires that the selected data is based on shared characteristics that distinguish the sample from the larger study population (Hinds, Vogel, Clarke-Steffen, 1997). The original study included four separate types of focus groups: a) self-identified gay and bisexual men; b) self-identified lesbian and bisexual women; c) transgender adults; and d) health care and end-of-life service providers. This thesis research included only data from the five focus groups of gay and bisexual men.

Use of Focus Groups. Focus groups were the means by which participants were interviewed in the original study. Given the potentially sensitive nature of the issues that were discussed, less structured approaches are beneficial to participants, giving them greater freedom to express their own insights and perspectives (Morgan, 1997). Additionally, focus group discussions can offer an appropriate and cost-effective method (Robinson, 1999), and this approach has been used in previous research with elderly gay and lesbian Canadians (Brotman et al. 2003). Group interaction allowed for comparison, collaboration, and contradiction among group participants, which can generate a level of depth not typically found in one-to-one interviews (Smithson, 2000).

Focus groups were conducted by members of the research team; often with two facilitators and a notetaker. In Halifax, the gbMSM focus group was led by Dr. Aine Humble and the author who shared facilitation responsibilities. Research assistants were

present at all focus groups to help facilitate the event, ensuring participant needs were met and logistical issues were addressed such as room bookings, functioning audio recorders, and the availability of snacks. Focus group discussion facilitators ensured that a variety of topics were discussed including preparations and explicit plans for later life care (including conversations about current and future care, housing, financial support and disposition of assets), issues and concerns about preparations to date or lack thereof, and the role of community (both formal and informal) in supporting and enacting such plans. These issues are outlined in the Focus Group Interview Guide (Appendix 3).

Each site sought to recruit 7 to 10 participants per focus group to help ensure theoretical saturation across all research sites. Previous research has found that this range of participants is often effective at eliciting a context rich discussion (Krueger & Casey, 2008). Focus groups were scheduled for two hours, including a break, if needed, for participants at the mid-way point.

Sample Selection. All participants selected to participate in *Fostering* could speak and read English (though only French-speaking participants were included in Montreal). Inclusion criteria for focus group participants included: minimum 60 years of age, reporting at least two chronic conditions and self-identifying as a gay or bisexual man. An exception to this age limit was made for older gbMSM who were 50-years-old and identified that they were caring for another LGBT friend or family member 60 or older. The age of 60 or older is based on World Health Organization criteria of ‘later life’ as well as literature on “accelerated aging” experiences within the LGBT community (de Vries & Herdt, 2012).

Sample Size. In total, 40 men participated in the five research sites with only one participant who self-identified as bisexual in the screening process (see Table 1).

Table 1: Breakdown of Participants by Sexual Orientation Across Research Sites

Male Participants	Halifax	Montreal	Toronto	Edmonton	Vancouver
Gay	8	6	5	5	15
Other	0	0	1	0	0
Total	8	6	6	5	15

Recruitment. In each city, research teams created a list of community partners (Appendix 4). Community partners were asked to distribute a recruitment poster (Appendix 5, Halifax version) via their social media, newsletters, or e-mail lists. If possible, printed versions of the recruitment poster were posted in local community spaces. Researchers shared recruitment material within their own social and community networks.

Potential participants could contact a research team member at a designated e-mail address or telephone number. Research team members would then screen participants to ensure eligibility for participation (Appendix 1 – Halifax version). Once determined eligible, participants were sent an e-mail with further information and a formal invitation to participate (Appendix 6) and an informed consent form (Appendix 7).

Compensation. Participants were given a \$25 gift card as compensation for their time, which was presented at the time of completing the informed consent form

(Appendix 6), just before the start of the focus group discussion. The specific type of gift card was pre-determined as part of the screening process, with up to three options available at each site (Appendix 1). If participants chose to leave the focus group, they were permitted to retain their gift card.

Data Collection

Data used for this thesis research were collected from the *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults* conducted at five sites across Canada in 2014 and 2015. Each of the five research sites (Dalhousie University and Mount Saint Vincent University, University of Waterloo, L'Université du Québec à Montréal, University of Alberta, Simon Fraser University) recruited their own focus group participants.

Screening. All potential participants for the LGBT Older Adults focus group(s) were screened by members of the national research team using a screening tool (Appendix 1 – Halifax sample). Data from this screening tool for each participant are used to help generate an understanding of the personal characteristics of participants (Chapter Four).

Participant Profile. Prior to the start of the focus group discussions, all participants were asked to complete a participant profile (Appendix 2) that included basic demographic questions such as age and marital/relationship status; sexual orientation, gender identity, and extent of end-of-life preparation to date (e.g. completion of a will, representation agreement, discussions with significant others). Data from the participant profile and screening tool are not the focus of this thesis research but are used to provide

a better understanding of the participants (e.g. median age). Further, some personal characteristics may prove relevant to further highlight the focus group results.

Specifically, questions 7, 17, and 18 which relate to status of being out of the closet and availability and use of support networks are of interest.

Interview Questions. As set out in the research protocol for the original study, focus group discussions were facilitated following a pre-established focus group guide (Appendix 3). The predetermined questions included issues such as preparations and explicit plans for later life care (including conversations about current and future care, housing, financial support, and disposition of assets), issues and concerns about preparations to date or lack thereof, and the role of community (both formal and informal) in supporting and enacting such plans. Focus group facilitators and participants expanded upon topics as relevant. As this thesis research did not seek to address the same questions as the broader *Fostering* study, the focus of analysis was on relevant questions. All transcript content will be considered in the analysis, however, to account for the organic nature of focus group discussions. Specifically, the questions included from the original focus group guide (Appendix 3) can be found in section II (“Interview”), sub-section A, questions a to d (“Plans for End of Life Care”), section II (“Interview”), sub-section B, questions a to c (“Community”), and section III (“Closing”). Discussions focusing primarily on the use of technology and internet resources in sub-section C of the focus group guide (“Technology”) are not included in this analysis except for using technology to access end-of-life and health care information.

Data Analysis

Focus group transcripts of older gbMSM from the five research sites were analyzed using a thematic analysis approach.

Thematic Analysis. This approach was used to identify major themes based on participants' comments and discussion within the focus groups. Thematic analysis is primarily used when analyzing data in primary qualitative research (where data is collected for a specific question and then analyzed based on the focus) (Thomas & Harden, 2008). Thematic analysis, sometimes called interpretive thematic analysis (Braun & Clarke, 2006), is a process that can be used with most qualitative research approaches (Boyatzis, 1998). The goal is to identify, analyze, and report patterns/themes in data (Braun & Clarke, 2006).

Thematic analysis begins with a researcher becoming familiar with the individual transcripts to understand the interview data (Braun & Clarke, 2006; Liamputtong, 2009). This includes reading transcripts multiple times before generating initial ideas (Braun & Clarke, 2006; Liamputtong, 2009). These initial ideas can then be translated into codes which can help explore and solidify potential themes emerging from the data (Braun & Clarke, 2006; Liamputtong, 2009). With inductive thematic analysis, concepts and themes are developed from the data presented, without an aim to test an existing theory or approach (Elo & Kyngäs, 2008). Codes from across all data sets (in this case focus group transcripts from different research sites) should be gathered by potential theme and themes can be revised for further clarification and accuracy (Braun & Clarke, 2006; Liamputtong, 2009). These themes must then be 'mapped' with definitions (Braun & Clarke, 2006; Liamputtong, 2009). Themes should be further revised throughout the

process so that their definitions are clear with each theme being unique from another (Liamputtong, 2009).

Descriptive Statistics. In addition to analyzing focus group transcripts, quantitative data from screening tools and participant profiles were analyzed. These data were analyzed using descriptive statistics which seek to summarize the nature of the data (Leedy & Ormrod, 2005). This can include how often certain measured variables occur, variability between similar points of data, and how closely to data characteristics may be connected (Leedy & Ormrod, 2005). For this research, the quantitative data analyzed (and discussed in Chapter Four) include data points such as average age, differing levels of education, self-reported end-of-life preparations, and more.

Analysis Tools. Transcripts of interviews were initially hand coded and analyzed before further analysis was completed using MaxQDA software. Descriptive statistics of quantitative data will be completed with the use of Microsoft Excel spreadsheets.

Ethical Considerations

Ethics approval for this study was granted through the Health Sciences Research Ethics Board at Dalhousie University using their Secondary Use of Information for Research process (Appendix 9). Ethics approval for the original study, *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*, was gained at each of the five research sites (Dalhousie and Mountain Saint Vincent University, University of Waterloo, L'Université du Québec à Montréal, University of Alberta, and Simon Fraser University) (Appendix 8).

Informed Consent. All focus group participants were provided an informed consent form (Appendix 7) following their initial eligibility pre-screening. The informed consent forms outlined that audio-recording was a required element of the focus group process. Participants were reminded that participation was fully voluntary and that there would be no repercussions for withdrawing from the study. They were additionally informed that they could participate to the level of their own comfort; declining to answer any of the questions.

Anonymity. Complete anonymity was not possible with this research, given the dynamics of focus groups. As part of the screening process, all participants were given the option to choose a pseudonym for the study during the screening process (Appendix 1). It was made clear in the informed consent form that all data would be de-identified and that pseudonyms would be assigned to those who did not choose one.

Confidentiality. All focus group participants were instructed to respect the confidentiality of other focus group participants. Any quotes attributed to a participant will be attributed to their pseudonym, age, and city (e.g. “Bob, 72, Halifax”). During focus groups, a member of the research team (typically a research assistant), made notes of who spoke, in which order, to allow for transcript content to be attributed to the correct participant. In occasions where there was confusion relating to which participant made a comment, their quotes will be attributed to their focus group (e.g., “Participant in Montreal.”).

Electronic copies of audio recordings of focus groups were stored at Simon Fraser University. All transcripts and personal data (e.g. consent forms) were password-

protected and stored at Simon Fraser University and individual research sites in secured spaces.

Knowledge Transfer

Results from this study were disseminated in ways that will reach community, academic, and policy audiences to further health promotion efforts for older gbMSM in Canada. These study results were published as a Master of Arts thesis at Dalhousie University.

The author planned to submit study results to academic conferences with a different focus on results for each conference to avoid academic self-plagiarism.

Conference presentations included:

- Crossroads Interdisciplinary Health Research Conference at Dalhousie University (March 2018),
- Canadian Public Health Association; annual research conference (May 2018),
- Canadian Association for Health Services and Policy Research; annual research conference (May 2018),
- Canadian Association of Gerontology conference (October 2018), and
- The Summit for Gay Men's Health (November 2018).

At the time of thesis submission, two academic journals were being considered for academic article publication; the *Journal of LGBT Health Research and Culture, Health, & Sexuality*.

Chapter Three Summary

This chapter outlined the role of social constructivism as an underlying research paradigm for this work. It clarified the importance of qualitative research in understanding the needs of older gbMSM and explained how qualitative description can meet that need. The conceptual framework of an inverted SEM that is focused on health promotion interventions was introduced. This was followed by an outline of the logistics of the research design, including how data was collected and analyzed. Ethical considerations relating to the protection of humans was addressed. Plans to disseminate the results and conclusions of this study were outlined. In the following chapter, results from the analysis of data are presented. Limitations of this research will be presented below in Chapter Six.

Chapter Four: Results

This chapter begins with a descriptive statistical overview of personal characteristics of the participants from the five focus groups. While demographic data (e.g. age, self-identified sexual orientation, prominent health conditions, etc.) are included, so too are details from participant profiles that indicate how comfortable older gbMSM are with being out of the closet to different people in their lives. There are several survey questions relating to care – in practical and emotional terms – that are compared and contrasted. Following this quantitative data, the major themes found in the transcripts are explored with examples of smaller sub-themes. Themes are broken into two major clusters. The first cluster centers around Heterosexism and includes Isolation, and Systemic Issues. The second cluster is built around Resilience and includes Survival, and Evolution of Identity.

Participants' Personal Characteristics

Using the eligibility screening tool (Appendix 1) and the participant profile (Appendix 2), it was possible to create an overview of the demographic and personal characteristics of participants (Appendix 10). The average age of the 40 participants was 70 years old. Most (32) were retired and education levels were high with 15 of the older gbMSM having graduate degrees, 7 having completed an undergraduate degree, 11 with some college/university experience. Six participants self-identified as being HIV positive. The most prevalent health issues for the 40 participants, in order of self-reported incidence, were:

- High blood pressure (22)

- High cholesterol (19)
- Arthritis (15)
- Cataract(s) (14)
- Anxiety (12)
- Depression (10)
- Challenges hearing (9)
- Challenges seeing (9)
- Diabetes (9)

For sexual orientation, 39 self-identified as gay/homosexual with one participant identifying as ‘other.’ Just over one-third of the men were in relationships (15/39¹), with varying degrees of commitment (married or domestic partnerships, 9; relationship or boyfriend, 6). The remaining (24/39) were single. This corresponds to a similar number (25/39) of older gbMSM who lived alone with the remainder living with their partner (7), partner and others (2), or friends (1).

In relation to family structures, 9 out of 39 older gbMSM who completed participant profiles were parents, all of whom identified themselves as being ‘mostly’ or ‘completely’ out to their children. For siblings, 25 of 39 older gbMSM were ‘mostly’ or ‘completely’ out and 4 were ‘not at all’ or ‘a little’ out. Given the average age of participants, 20 reported that being out to their parents was not applicable (suggesting their parents may have predeceased them or they do not have a current relationship to

¹ While 40 men participated in this study, not all participants fully completed their participant profile; at least one participant did not complete his profile in any way. This is the cause of the discrepancy between the cited numbers and percentages.

them) or they were unsure of their parents' knowledge of their sexual orientation. A further 6 older gbMSM indicated they were 'not at all,' 'a little,' or somewhat out to their parents. Approximately one-third (14) were 'mostly' or 'completely' out.

On average, participants had an average of 6 close friends and were 'mostly' or 'completely' out to them (36 out of 39). Two-thirds (25/39) indicated that they had a chosen family contrasted with 13 indicating who did not feel such a resource was in their lives. This connection to chosen family and close friends is indicated in the connection of older gbMSM to close friends in a series of questions about support. When seeking emotional support, 31 indicated they would go to close friends.

Other common supports were primary care doctors (12) and partners (9). Personal advice was also often directed to close friends (30) with primary care doctor and partner tied for second (9 each). Participants who had recently experienced illness and needed care were willing to seek assistance from close friends; 19 (of 28, 11 had indicated they had not experienced recent illness), 7 from their partner, 6 from their neighbour, and 3 from their primary care doctor. Encouragingly, 33 indicated that they were 'mostly' or 'completely' out to their current health care providers which may reduce barriers to care.

Isolation (a theme explored below) can also be noted in responses to the participant profile. When asked if they had recently experienced illness upon whom did they rely, 6 out of 28 older gbMSM (approximately one-fifth) had no one. As well, 12 indicated they had discussed end-of-life care and treatment with no one and 9 had not discussed care concerns with anyone. Further, 16 indicated that they were unsure who would be their primary caregiver should the need arise.

In preparation for end-of-life, almost all (31/39) participants had completed a will. Half had prepared a living will (20) and/or power of attorney agreement (21). Slightly more than one-third had pre-paid funeral arrangements (14) and informal caregiving arrangements (3). Only three participants had long-term or critical care insurance and only five had personal directives. Three participants were unsure of which arrangements they had completed for end-of-life. Preparation for end-of-life through existing systems and the challenges that older gbMSM face was a recurring topic of discussion in the transcripts and led to its Systemic Issues in the description of themes.

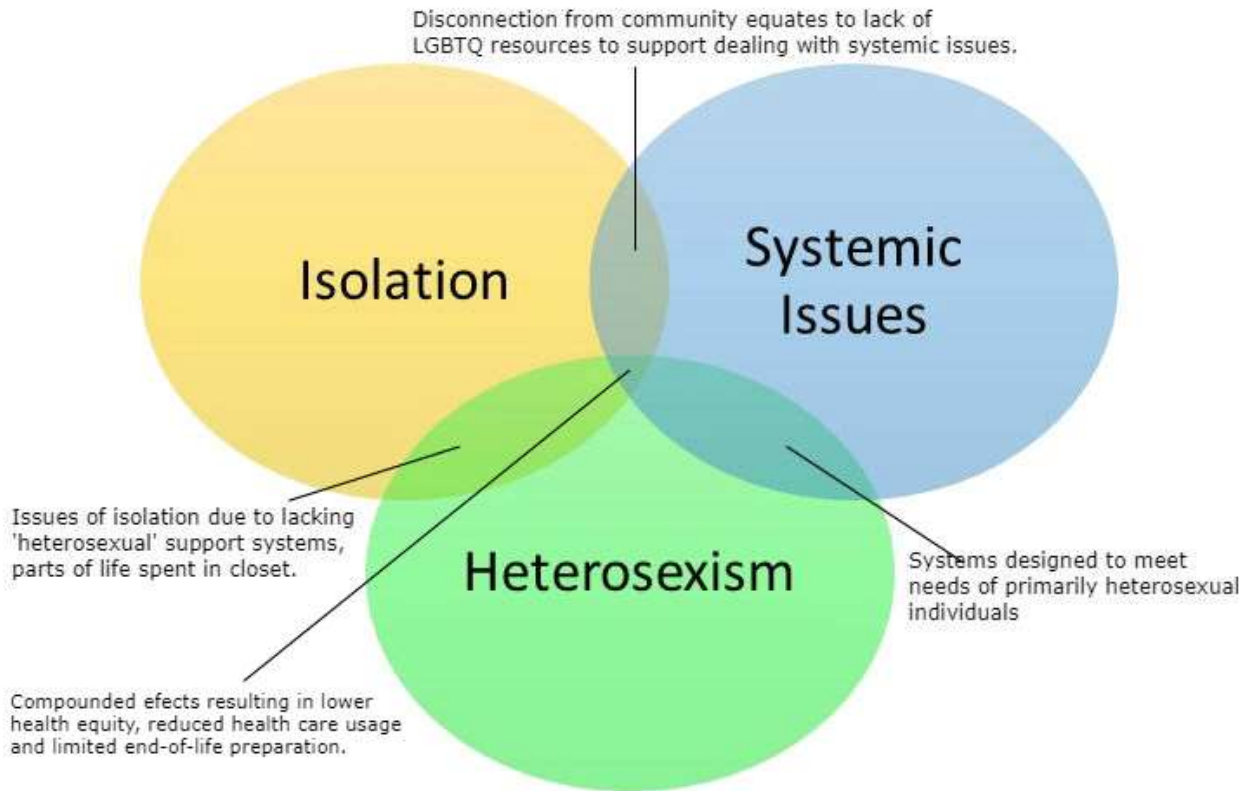
Major Themes

Following the coding of transcripts, six major themes were identified based on the content (and context) of the discussions held by each focus group in the original study after content was coded. Themes were clustered into barriers and facilitators based on how the discussions related to perceptions of end-of-life preparation and general health.

Each cluster is centered around the strongest theme identified within its respective cluster; heterosexism as a barrier and resilience as the facilitator. Themes were developed independent of the inverted SEM to ensure that themes were developed from the content and not proscribed to fit into the model. Discussion of how these themes interact with personal characteristics and the inverted SEM is presented in Chapter Six. The first of the two thematic clusters relate to barriers that older gbMSM faced in health care and end-of-life care and preparations.

Barriers: Heterosexism, Isolation, and Systemic Issues

Figure 4: Barriers



This first cluster focused on barriers created by broader social impact on individuals through the effects of heterosexism (including homophobia and biphobia) as an underlying cause of many of the challenges participants faced with isolation and systemic issues. While there is overlap, heterosexism is not the sole cause of isolation or systemic issues. Some of these challenges arise from the impact of aging or bureaucratic processes related to end-of-life. Isolation from community can influence challenges older gbMSM may encounter with systemic issues; without connection to community members, older gbMSM may have decreased access to resources to help them access culturally competent care and services, exacerbating systemic issues. At the centre of this

Venn diagram, the influence of all three barriers resulted in the compounded effects each barrier provided, resulting in lower health equity for older gbMSM, reduced health care usage, and limited end-of-life preparations. Each barrier, as defined by participants, is explored below beginning with isolation.

Isolation

Isolation in this context represents a sense of disconnection from others, including a sense of loneliness or lack of community. Participants raised the issue of isolation through direct discussion or as an underlying subtext to their discussions. Many older gbMSM indicated a sense of disconnectedness from the greater world and the LGBT community more specifically. Some of this isolation stemmed from their shrinking circle of friends as participants aged. This shrinkage resulted from friends and loved ones dying, limited capacity for social interactions due to aging (either on behalf of the participant or their loved one), and through relocation (e.g. someone may move in later life to be closer to a formal support network or move into a care facility where there is limited access). As participants aged, they faced increased transportation challenges – their own ability to move as well as access to motor vehicle transportation. This reduced their ability to engage with their friends and community.

Many indicated that they felt excluded from the LGBT community due to ageism among gbMSM. This is exemplified in a quote from Keith, *“I mean, I’m a 75-year-old man, nobody wants to be my close and intimate friend.”* (Keith, 75, Halifax) Beyond friendship, this isolation extended to romance and dating.

There was recognition that older gbMSM who were never fully out to all the people in their life would be further isolated as they aged. Without some connection to LGBT communities, they might be unaware of resources and services. Bernard in Edmonton raised the concern that this ‘hidden population’ would not come forward to provide their input into research studies on the needs of older gbMSM,

“I think one of the points that should be underlined here is the fact that you are talking with people who are active, and they’ve come out, most of them, themselves. . . And what is left out is a big crowd of gay seniors who have no contact with anybody.” (Bernard, 83, Edmonton)

There was concern that the lack of inclusion of these older gbMSM voices would further their exclusion as the needs of this hidden population would not be addressed in research studies.

The impact of being in the closet (a product of heterosexism, addressed below) among older gbMSM resulted in a sense of isolation and loneliness. Having grown up in a world that has stigmatized them to varying degrees throughout their life and burdened with a lifetime of minority stress, older gbMSM had long-standing feelings of isolation and loneliness that were intensifying as they age. In Toronto, a participant told the story of how, “. . . *one time I woke up in the middle of the night, I just went bolt up, and I thought, ‘I’m going to spend the rest of my life as a lonely old man with nobody to care for me’.*” (Heathcliff, 74, Toronto). This story outlined how the fear of aging in a heterosexist world fostered a sense of isolation.

The impacts of isolation on health care, end-of-life preparations, and possible approaches for health promotion interventions are explored in greater detail in Chapter 5.

As stated above a sense of isolation can create barriers for older gbMSM when they need to interact with existing systems to help prepare for end-of-life.

Systemic Issues

Systemic Issues represent challenges relating to advanced care planning and end-of-life preparation through interacting with health care, financial, and legal systems. Lack of inclusion of the needs of LGBT communities within these systems was viewed as a barrier to access and uptake. Participants viewed this exclusion as a knowledge gap on the part of the service providers towards their unique needs. The lack of inclusion indicated that these systems were not designed to accommodate the needs of older gbMSM. The resources developed by service providers to meet the needs of older (presumed heterosexual) adults can further exacerbate the exclusion of older gbMSM. Discussing advanced care planning resources presented at a public session at a long-term care facility, one participant noted, *“But when I read the guide, it’s talking to them. The words aren’t talking to me.”* (Keith, 75, Halifax) Keith addressed that end-of-life materials which he had been provided focused on heterosexual identities, and while not necessarily intentionally excluding, the lack of representation left him feeling his needs would not be met by this resource. This served as a prime example of the lack of inclusion participants experienced in interactions with resources and service providers.

Beyond many of these systems being non-inclusive, older gbMSM faced difficulties dealing with these systems because the systems themselves are complex. Most of the older gbMSM had engaged in some of the basic elements of their end-of-life

planning (e.g. will preparation). There was evidence that participants lacked knowledge of some elements of end-of-life planning as detailed in Halifax:

“You [focus group facilitators and members] brought up a couple things that I don’t really know too much about; the Caring Bridge, the Dying with Dignity, and the advanced directive. These are sort of new ideas for me and so I’m going to go home and look them up . . .” (Nicholas, 66, Halifax)

This spoke to the complexity of end-of-life and advanced care planning. Elements such as personal directives were unfamiliar to many focus group participants yet can be crucial for those who may not have supportive families or other legal protections.

The need to keep end-of-life and advanced care planning documents updated was a challenge that was raised in several focus groups. A Halifax participant who was HIV-positive noted that he had prepared all his legal, health care, and funeral arrangements when he was younger as he believed he would die soon after diagnosis. Ultimately, he lived for decades longer than expected and needed to update all his end-of-life plans, “. . . *I got the will done, living will, and prepaid funeral, everything. Luckily, the treatments were great then, so that’s why I’m sitting here today. Problem now is everything is outdated.*” (Mitchell, 63, Halifax) In addition to their own changing needs as they aged, many participants cited that as loved ones died, moved away, or became distant for other reasons, they needed to review and revise documents. As many of the designated individuals that older gbMSM had chosen as potential decisionmakers were not relatives, this meant they could not necessarily rely on familial bonds to ensure a continued role in the lives of the chosen decisionmaker. In Edmonton, Don discussed how he had prepared his end-of-life documents through a friendship with a lawyer. The two had a falling out

and Don was no longer confident in his preparations, “*And so, she phoned me and told me she wasn’t going to help me anymore. ... if she has done anything about the papers that we have grabbed on up, I don’t know.*” (Don, 88, Edmonton) This strained relationship highlighted the vulnerable position of many older gbMSM. Don completed the steps to prepare for end-of-life but decisions about his care became tenuous due to the reliance on a friendship.

While their own care needs were part of these end-of-life documents, the financial costs of aging in the Canadian context was also a point of concern in dealing with systemic issues. While many participants expressed disinterest in moving into long-term care facilities, they recognized this as a likely reality given their small support networks. This need for a long-term care facility was complicated by the perception that to receive quality, inclusive care, there was a need to stay at higher end, more expensive, facilities. These more expensive facilities were hoped to be safe spaces free from heterosexism.

Heterosexism

Heterosexism, defined as the attitudes and beliefs that favour opposite-sex relationships, viewing these as ‘normal’ and superior to same-sex relationships (Hollenbach et al., 2014), was an underlying theme to many discussions. Many older gbMSM did not come out until later life, having lived most of their lives in the closet to varying degrees, “*You lived two lives. One hidden and the other in front of everyone.*” (Gémeau, 73, Montreal) For those who had been out most of their life, they still felt that they had to live part of their life in the closet. Several spoke of the challenges they had

faced in coming out and continuing to live life as an out gbMSM. Many had been in relationships with women for a majority of their lifetime until coming out at a later age.

Having grown up in a culture that is primarily heterosexist, many of the older gbMSM participants displayed a great distrust towards institutions of power. After living in a world that told them they needed to conceal or change who they were which created a lifetime of minority stress, this attitude is understandable. This resentment was directed to society writ large, including religious institutions that have historically blocked LGBT rights advancements or the broadly defined health care system. Long-term care facilities were a common fear for older gbMSM who were afraid that they would have to go back into the closet for fear of mistreatment from staff. There was a strong desire for education and training of long-term care staff, “... *[I] think the long-term care facilities, retirement homes and so on, need to, and not just the Toronto ones, they really do need training in long-term care for LGBTQ folks . . .*” (Roderick, 74, Toronto) A common perception among participants was that most long-term care facilities were not welcoming or inclusive places. Training for staff was a common call to action by older gbMSM but did not address all their concerns.

Even if the staff were trained, older gbMSM were aware that they would be sharing living space with many people, similar in age but with backgrounds and experiences different from their own. Knowing their own experiences, older gbMSM feared that other residents might demonstrate homophobic or heterosexist attitudes and behaviours. This was complicated by the recognition by focus group members that other residents’ own existing health care issues (e.g. dementia) could play a factor as well. The often-cramped living conditions of long-term care facilities, where residents could share

rooms with someone homophobic was highlighted by Toronto participant Roderick who expressed concerns, “. . . *in the bed beside them, or in the room next to them, is somebody who was a real homophobe back in the days when it was politically correct to be a homophobe . . .*” (Roderick, 74, Toronto) This concern over other residents spoke to the vulnerable position that older gbMSM felt living in long-term care would automatically place them, with or without support from care providers.

While participants were overwhelmingly out to their health care providers, there was discussion relating to the length of relationship they had with those providers. The coming out process was not always an easy one for older gbMSM and their health care providers demonstrated discomfort. This exemplified in a comment from the Edmonton focus group

“I just came from my doctor today, it took me 5 years to get him to ask the question: are you sexually active with a [whispered] male or female? And I would say, ‘Pardon me?’ I want him to say it out loud.” (David, 67, Edmonton)

Getting to the stage of being out to their health care provider was often seen as a hard-fought battle. While all participants reported being out to their primary health care provider, data was not collected on when older gbMSM came out to said provider or if they intentionally sought out providers who established LGBT-supportive environments.

Many older gbMSM expressed optimism for the future, noting that some organizations and institutions were implementing change to create more welcoming LGBT older adults. Several participants discussed their experiences with such training. It became apparent that for many there was an unofficial ‘word of mouth’ communication system relating to which care facilities were welcoming and inclusive. Conversely, while

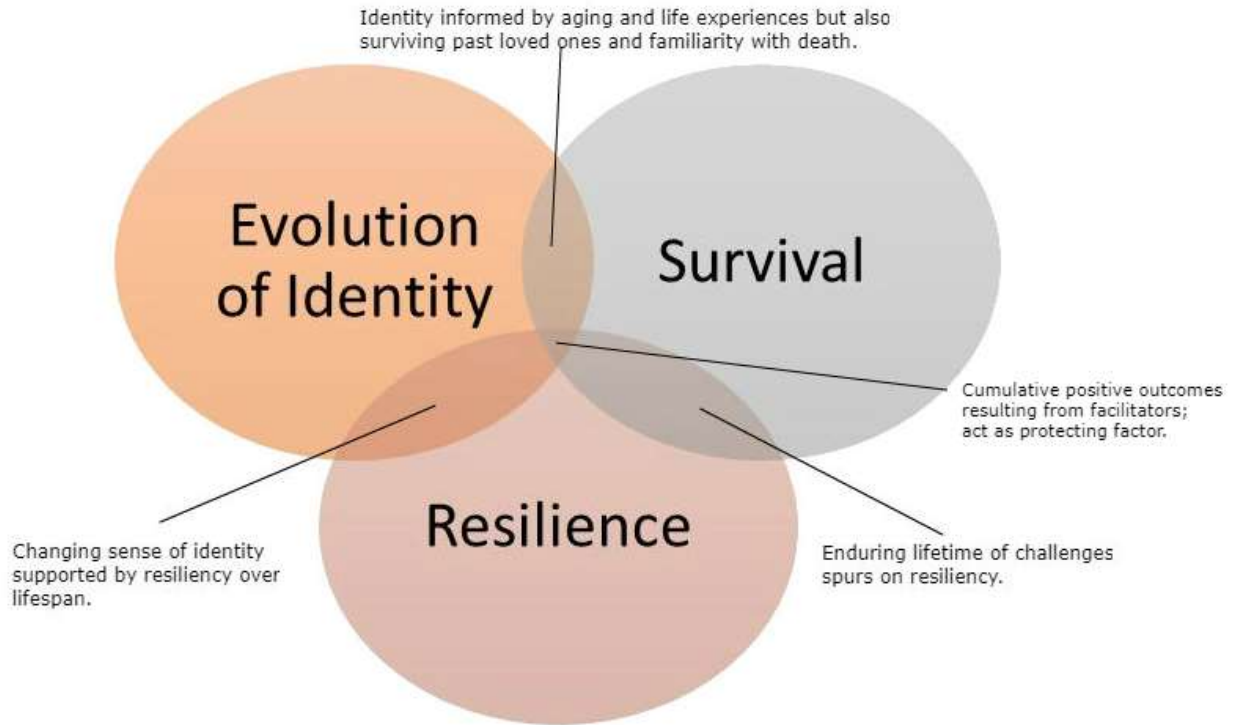
discussed less, there was mention of which facilities might not be the best fit. Despite recognizing the efforts of individuals and organizations to change long-term care facilities, most were concerned that these efforts are disparate and disorganized.

As mentioned above, there was concern that while staff might be trained, that does not address the education and attitudes of other residents. Individual focus group participants expressed a variety of reactions to such scenarios. The frustration at the thought of going back into the closet for long-term care was revealed in the sentiment, *“I’ve struggled all my life to become open and free and I don’t want to shut that down right now.”* (Adriaan, 67, Vancouver) In contrast, in Halifax, Brad saw an opportunity to discuss life more generally. Brad pondered, *“I’d go talk to everybody else. You talk to everybody else. Doesn’t necessarily have to be gay. Why?”* (Brad, 69, Halifax) His comments were interpreted by the Halifax group as advocating going back into the closet and the comments were not well received.

These differing perspectives could speak to past experiences as well as individual ability to be resilient in difficult circumstances. The discussion of going back into the closet evoked strong emotions and was seen by many as a betrayal of the lives that they had lived and battles they had fought. This resistance to the closet speaks to the many facilitators to end-of-life preparation that were found in transcript analysis.

Facilitators: Resilience, Survival, and Evolution of Identity

Figure 5: Facilitators



The facilitators cluster focused more on individuals, their sense of identity, and how that identity is shaped and influences health. Resilience (including problem solving) was a major theme that developed during the coding process. This theme is closely tied to the evolution of identity and survival which develop over the lifespan. Resilience is informed by and informs identity and is strengthened and tested by survival. While each factor was identified as an individual protective factor, those older gbMSM who demonstrated all three experienced a cumulative effect, which reduced the impact of cited barriers and helping foster positive aging as the focus groups participants approached end-of-life. Each factor will now be explored in detail, beginning with survival.

Survival

An underlying current to many of the experiences that older gbMSM discussed in focus groups were the challenges they faced in surviving to later life. This was often connected to the experiences of outliving others, whether in their peer cohort or loved ones. While the death of family members (including partners, parents, siblings, and other relatives) was a common topic of discussion, several participants discussed how they had witnessed lovers, friends, and peers die during the AIDS crisis. This was clarified, “*And we were also living within the survivors’ age. The people that died of AIDS during the AIDS epidemic are the people I might’ve expected to have as friends in my old age.*” (Keith, 75, Halifax) This demonstrated the generational trauma of grieving that several participants lamented, that the death of friends had shrunk their community and their circle of potential supports. The experience of ‘surviving their friends’ shaped their understanding of death and how dying was enacted.

There was an undertone of surprise among many of the older gbMSM focus group participants that they had survived into older adulthood. This was indirectly attributed to surviving the AIDS epidemic and the heterosexist world. Survival for participants meant more than just living, it meant living openly and happily. The topic of concealing one’s sexual identity and past during residence in long-term care facilities was raised in the Halifax discussion by Brad. This created heated exchanges which brought to light the importance of being out as part of surviving:

Brad: It’s not a matter of going back into the closet.

Mitchell: It is.

Brad: It’s a matter of, you know...

Ken: Survival.

Given that many (though not all) older gbMSM focus group participants cited their past activist work, this suggestion of returning to the closet was antithetical to the lives they had fought so hard to live. There were many small comments made about enjoying their older years and the implication perceived is that a life hidden in the closet is not one that was enjoyable, and not desired by most. As they became more aware of end-of-life concerns due to their advancing age, focus group participants expressed a desire to live their lives on their own terms at the end of their days.

Additionally, many felt that their experiences with death and dying in their past had helped prepare them for their own end-of-life preparation. They spoke of helping others with their end-of-life preparations and how it informed their own processes. Individual experiences with illness also informed several participants' perspectives on survival. Heathcliff spoke of his cancer diagnosis in 2009 and how he prepared for death, *"... and during that time my oncologist didn't think I was going to survive, and uh, so I made all my arrangements, I filled out all the forms."* (Heathcliff, 74, Toronto) This diagnosis encouraged him to engage in end-of-life preparations but over 5 years later, in the focus group, Heathcliff reflected on his own experiences as a cancer survivor:

"...I just turned 74, and I'm in remission but this cancer when it's in the lymph system it could hit anywhere, could hit the brain, it could hit anywhere and then I could have, I don't know what my future, or how long I've got, so I'm just trying to live the best way I can ..." (Heathcliff, 74, Toronto)

The comment by Heathcliff that he was ‘trying to live the best way [he] can’ spoke to the recurring belief of participants that after a lifetime of challenges, surviving included thriving, living life fully.

This desire for thriving was occasionally challenged through their own changing self-perception as they age. In Montreal, there was discussion about transitioning from working full-time to being retired and the challenges that presents to not only live but have a full and rich life. Hugo, now retired, offered advice for his younger boyfriend (55) who was planning to retire at 60, “*Do not tell me, because at age 60, you want to be retired. I said, you'll be at home doing nothing! I said, you have to find something. Think ahead.*” (Hugo, 68, Montreal) Hugo and others spoke of their own experience with the reduced engagement in life stemming from retirement and they felt less connected to life. In Toronto, Heathcliff recognized that as he aged, his opportunities dwindled but he continued to seek new experiences and connections. Heathcliff commented about his efforts to adapt to thriving with a changing sense of identity: “*I don't know what my future [is], or how long I've got, so I'm just trying to live the best way I can ... I joined this group ... to find friends as well.*” (Heathcliff, 74, Toronto) This desire to thrive might have been an act of defiance to all the challenges that older gbMSM had to overcome to as they have aged and developed a new sense of identity.

Evolution of Identity

Many participants indicated that their sense of self had changed with aging. Coding that formed this theme related directly to aging (e.g. resistance or denial of the impact of aging, realized limits due to aging). This might be common for all older adults

but older gbMSM had unique experiences related to their connection to the LGBT community. This was seen in the comment, *"Maybe I'm just old but not gay any more."* (Keith, 75, Halifax) Keith's comment addressed the sense of identity as defined by the gbMSM community. There was a disconnect from the LGBT community which participants perceived as being focussed on youth and sexual activity.

The changing nature of identity arose in comments relating to the nature of being out. Over their life, participants had been out of the closet in different aspects of their lives. Even for those who were fully out in most of their life, there were still references to concealing certain aspects of identity. As they grew older, the barriers that they had erected presented challenges. The barriers between chosen families and families of origin were cited as a potential source of conflict in end-of-life preparation. These barriers also added an additional emotional burden for older gbMSM as highlighted by the comment, *"...many older gay men will, what I call 'compartmentalize' their lives. In ways that straight people do not."* (Rick, 65, Vancouver) Here, Rick is addressing that older gbMSM may have led some part of their lives in the closet, concealing their true identity from others. This defence mechanism created barriers that limited their interactions with others and might have resulted in a mixed sense of identity; openly gay with some, closeted with others.

Several older gbMSM saw the defining aspect of their identity shifting from their sexual orientation to their age. This was demonstrated through equating their current needs with the needs of all older people as a priority rather than their needs as member of the LGBT community. In Halifax, Ken equated his life to that of opposite-sex couples, *"We just do the married kind of thing."* (Ken, 82, Halifax) This equating often came up

in discussions around the need for activism to defend the rights of older adults and advocate for their needs. When it was suggested that the needs of older persons without families might be similar to older gbMSM, Ken agreed, *“I just think the issues are the same.”* (Ken, 82, Halifax) Bradford in Vancouver, who had been an activist in the past, spoke about his experience in advocating for medical assistance in dying (MAiD), *“... the choice to end your life is something that I have been researching for a number of years and I’m involved with an organization that is fighting for that.”* (Bradford, 62, Vancouver) This shifting of priorities demonstrated the changing nature of older gbMSM conceptualization of identity, as it shifted to focus on the needs of an older adult, not a man who is gbMSM. This shift might have stemmed from experiencing the impacts and realities of aging.

Fear of aging and its potential impacts on abilities, physical and mental, were recognized by focus group participants. This was discussed in relation to the needs of friends and partners who had faced health issues. Several older gbMSM had been care providers for loved ones and seen the decline of their loved ones’ mental and physical health. The realization that participants were vulnerable to similar circumstances as they aged recurred throughout and across the focus group discussions. The impact of deteriorating health and the ability to engage in end-of-life preparation was a point of concern. These concerns included the dangers of poor mental health; *“...everybody here seems to be very clear thinking ... what about the people too depressed to think clearly?”* (Ray, 69, Vancouver) While poor mental health outcomes are not inherently linked with age, there is evidence of heightened risk for poor mental health outcomes for older

gbMSM. Other concerns included the ability to be in good enough physical condition to take care of oneself (and others).

Many of the concerns impacted participants' long-standing sense of identity as they felt their independence jeopardized by the impact of aging on their health. Some cited the benefits of aging (such as more leisure time) but these comments were far fewer. Most participants seemed to accept these changes were part of the aging process. Their desire to create change and advocate for improved welfare for all older Canadians spoke to the resiliency they developed through a lifetime of adversity.

Resilience

Resilience, as a concept, is complex but Longstaff, Koslowski, and Geoghegan (2013) identify four different types: the capacity to a) rebound and recover, b) maintain a desirable state, c) withstand stress; and/or d) adapt and thrive (Longstaff et al., 2013). A lifetime of challenges may have strengthened older gbMSM to deal with the challenges they faced as they age. This was noted by Kum (2017), “. . . there is an element of resilience that one develops from overcoming challenges faced earlier in life, such as racism and homophobia, which can be used to better cope with aging (p. 235).” There were several discussions around the need to organize and advocate for change.

The discussions often referenced past activist work group members had done in relation to HIV and AIDS and same-sex marriage legalization. In Halifax, Kurt spoke of past activist work,

“But most of us aren't gutsy enough to be outspoken enough as I am to get things done. And I have absolutely no fear about doing anything We fought tooth

and nail for the same-sex marriage issue. We're still fighting the blood issue. We'll fight until . . . the last nail goes in the coffin . . ." (Kurt, 76, Halifax)

This was echoed by Richard in Vancouver,

"There are various [groups doing advocacy work], there's about a dozen maybe 20 groups in this town and they're starting to coalesce, they're starting to smarten up they're starting to join together. But it's not going to happen unless there's political will, as Rick said, and we do have champions in the legislature, in the parliament for this activity." (Richard, 72, Vancouver)

The willingness and passion of older gbMSM to fight for change demonstrated their inner strength and resolve. Their ability to push for a 'desirable state' spoke to the resilience they developed over decades of difficulty and activism. In their lives, they developed the skills and abilities needed to challenge and overcome numerous threats to their existence through health issues, political foes, religious oppression, and more.

Despite many participants' past negative experiences with religion, several were still actively involved with organized religion. Their religious affiliation offered them community and support systems. Some older gbMSM were retired (or semi-retired) clergy members who had fought for change within their religious institutions. Beyond religious affiliation providing spiritual comfort, it provided applicable skills, *"I guess because I'm a church organist the whole concept of death... I've been doing that since I was 10 years old, so I don't find it the least bit [difficult to talk about]."* (David, 67, Edmonton) Organized religion provided coping skills for dealing with death and dying through ritualized behaviours that older gbMSM did not cite they found in other communities.

There was some tension around religion as many older gbMSM had negative past experiences. The sense of exclusion was felt in some churches more than others.

Roderick in Toronto left the Catholic Church, *“because there is no affirmation.”*

(Roderick, 74, Toronto) Even for those whom organized religion was a place of comfort, this sense of tension could exist. Ken in Halifax commented on his own experience,

“Now the institutional church is not overly enthusiastic about gay people but within our cathedral and Integrity [an LGBT-supportive group within the Anglican Church], we have a public service every month. There’s a group that comes and we’re perfectly accepted in the congregation and they know it. My partner and I have our joint picture in the cathedral as a couple. You know, which is amazing.” (Ken, 82, Halifax)

This experience was not universal and may have some bias from the long relationship that Ken had with the Anglican Church as a former pastor.

Ken further reflected that his church members helped him develop a community and sense of connection. He foresaw the community playing a role if he were ever to move into a long-term care facility. He explained, that *“[my religious community] will help me when I get older and if I have to go in to a nursing home. I know I’m going to have visitors.”* (Ken, 82, Halifax) This comment regarding visitors was important as several older gbMSM had expressed concerns about long-term care facilities. Beyond the loneliness that many feared, some reported rumours that long-term care residents who had fewer visitors were likely to receive a lower standard of care. Thus, the need for

building a defined community was a protective factor for battling isolation and potentially for ensuring adequate health care.

Connection to LGBT community was a source of resilience and identity for many. Knowing the history of how the community had struggled for acceptance and social change emboldened them with hope for continued improvement in their lifetime. Many found social support groups of older LGBT adults that helped them build connections and connect to resources. These groups were primarily in community settings though Roderick noted an organized group within a long-term care facility in Toronto.

Given the barriers that older gbMSM faced for end-of-life care, participants felt a need to create solutions on their own. Past romantic relationships were cited as a means to further support individual and community resilience. Whereas separated heterosexual couples frequently develop separate lives, many older gbMSM indicated ongoing friendships with their ex-partners.

Participants recounted stories of supplying aid to friends and chosen family who had no biological relatives to support them – either through being disowned, distanced, or through death of their relatives. Several participants cited their experiences taking care of parents and other relatives. Participants had been made keenly aware of the need for support networks and realized that biological relatives might not have been able or willing to provide these services. This lack of built-in support networks forced older gbMSM to be creative. One participant noted that he...

“ . . .purposively sought out someone who is almost 20 years younger than me. . . .he’s very computer savvy, he represents a kind of different view point, and so I just had everything turned there and I had a lawyer and accountant who are

exactly the same age, and I purposely chose that so that, if I live to be 90, which could happen, they'll still be 70, and it could be that I might have to do it again"

(David, 65, Edmonton).

David was not alone in noting that he had intentionally forged connections with younger people (including neighbours, friends, and relatives) in order that they might receive this care when they needed it. A generational change was noted by some participants in that when they were younger, older relatives stayed with families until death. They do not perceive that being a likely situation for them. To circumvent this, some intentionally made connections with younger community members as friends or even as romantic partners.

The reliance on friends (as indicated above) was also evident in the experiences shared by participants. Many participants cited that their friends comprised their core support networks and gave examples of times they provided or received care. This extended to informal legal and caregiving arrangements. John addressed this, describing discussions he had, "*. . . we have, among my friends we have talked about what happens, you know let's buy a big house so that we can all live there . . .*" (John, 67, Vancouver) Discussions around creating support networks and 'communities of care' frequently focused on the problem-solving around perceived barriers to care. Most participants recognized that LGBT-centric or -specific long-term care facility options were unlikely to be an option in their lifetime. Participants did, however, propose potential solutions to this issue, including creating their own facilities, advocating for LGBT-focussed spaces within existing facilities, and the more communal approach to long-term care such as John described in Vancouver.

Beyond caring for one another near the end, there was discussion on how death should arrive. In two of the focus groups, the topic of MAiD was raised. MAiD was perceived as giving greater control to older gbMSM as to how their lives ended. Several members were educated about these issues and advocated for this movement. This desire for control at the end-of-life echoes their experiences as survivors of the AIDS epidemic when they witnessed friends who had no control at the end.

One identified problem was that of collaboration between different interested parties. Several had witnessed this battle during the AIDS epidemic. For example, biological family members may have different interests and priorities than chosen family members. Biological family members may have outdated understandings of the life and lived experience of older gbMSM. Though several had negative experiences, most older gbMSM maintained a positive attitude towards these challenges which demonstrated their ability to rebound and recover, maintain desirable states, withstand stress; and adapt and thrive – all key elements of resilience (Longstaff et al., 2013).

Chapter Four Summary

This chapter began with an overview of the personal characteristics (including demographic information) of the older gbMSM included in this study. Analysis then shifted to the thematic clusters derived from transcript content. These themes were separated into two clusters: one centered around heterosexism (including isolation and systemic issues) and another around resilience (including survival and evolution of identity). Each theme was then explained through the qualitative descriptive process of situating participants' focus group content to clarify the theme and how it manifested in

discussions. The following chapter explores how these themes interacted and how they might be used with the inverted SEM for health promotion interventions to support older gbMSM in end-of-life.

Chapter Five: Discussion

This chapter provides interpretation of each of the six major themes discussed in the previous chapter. For each theme, the impact on the health and end-of-life preparations for older gbMSM is explored. Means by which the theme can be addressed using the inverted SEM are be outlined. Suggestions for multi-pronged approaches to address multiple themes across various layers are addressed in Chapter Six. This chapter concludes with a discussion on the limitations of this study.

Isolation

In the participant profile data, there was a demonstrated need for emotional and supportive care from close friends. Despite this, from a practical care point of view, there seemed to be an unwillingness to rely on others for care (i.e. transportation, caregiving). Older gbMSM demonstrated comfort seeking advice and emotional support from their friends. They exhibited hesitance to seek more practical care aid (i.e. transportation to/from medical appointments, receiving care when ill). As indicated by transcript content, this may be influenced by the reality that many of their peer group were older and had limited physical abilities and may not have been able to provide the care that they needed or expected to need. Thus, isolation is complex – even those who stated that they had many close friends may have felt isolated when it came to receiving care.

The Impact of Isolation on Health and End-of-life Preparations

Results in this study support and are reinforced by prior results discussed in the literature, such as the work of Almack, Seymour and Bellamy (2010) as well as Kuyper and Fokkema (2010), that recognized that isolation can have a significant impact on

individual health. It can lead to loneliness, resulting in poor mental health, which, in turn, leads to physical health side effects (Almack, Seymour, & Bellamy, 2010; QMunity, 2015; Lyons, 2016; McLaren, 2016). Depression, for example, can impact motivation of older gbMSM to seek help for other ailments, resulting in slowly declining health (Mills et al., 2004).

This lack of motivation can impact end-of-life preparations. As evidenced by comments from focus group participants, isolation can lead to a disregard or disinterest in end-of-life preparations. Without a strong connection to others, there may not be a perceived need to address these issues. This lack of preparedness can lead to a spiral of isolation; without proper plans in place for care in the case of severe illness (such as emergency contact lists, decision-makers), older gbMSM faced the risk being cut off from their existing connections and community. In keeping with the study findings of McLaren (2016) that demonstrate a sense of belonging as a protective factor for depression, connection and a sense of community can shield older gbMSM from the harms of isolation and lead to improved health.

Addressing Isolation with the Inverted SEM

Greater awareness of the impact of isolation might be a driver for health promotion interventions via **advocacy groups** and **personal networks**. These two layers of the inverted SEM can work together to foster more social connections among older gbMSM. To address isolation, one potential solution that can be taken up by advocacy groups is the creation of gender and sexuality alliances (GSAs) in long-term care facilities. One such organization was reported by a participant in Vancouver. He reported benefits including greater connection to other residents, ongoing education, and a needed

social outlet. The 519, a non-profit LGBT community centre in Toronto, recommended this option, based on the GSA model used in many Canadian high schools, to create safer spaces in long-term care facilities (519, n.d.). Health promotion practitioners can support this by developing resources and toolkits that can be distributed to advocacy groups. Advocacy groups can then distribute to personal networks (either through direct outreach or acting as a resource centre). Advocacy groups can seek funding to support the initial establishment of such groups in long-term care facilities where they feel there is a demonstrated need. Advocacy within long-term care facilities may be needed to create this change.

As there is no universal fit for such social groups, health promotion should work with older gbMSM volunteers to identify their needs, priorities, and capabilities to establish and maintain such social groups. The role of health promotion is to support this community-led effort. Once established, these social groups can, as reported by focus group participants, be a social outlet, a place of connection, and a place where participants can learn skills to deal with aging, including how to address end-of-life preparations within existing systems and structures.

The GSA can create a sense of connection within long-term care facilities but is as an internal network only. For those with chosen families outside of long-term care facilities, **policies** need to be changed to include a broader definition of ‘family’ to extend beyond biological family members and include chosen family. As a sense of connection and familiarity acts as a protective factor leading to better health outcomes, health promotion can argue for the benefit of this simple policy change within long-term care.

For those older gbMSM who live independent of long-term care, formalized social groups can act as a much-needed place of creating connection. Those practicing health promotion can work with and within existing advocacy groups and personal networks to gain a better understanding of local needs. Identifying advocacy and community groups that have ties to older gbMSM will be essential, with a recognition of areas of conflict and cooperation (Poland, Krupa, & McCall, 2009). Advocacy, coalition building, and community participation will be essential elements of the work of health promotion for older gbMSM in relation to end-of-life concerns (Poland et al., 2009). There are few advocacy groups focused on gbMSM and few national organizations. Egale is a national advocacy group for all LGBT Canadians and has engaged in work around older adults already. The Vancouver-based Community-Based Research Centre, which looks at gbMSM health through research, education, and advocacy, has recently moved to become a national organization. With their focus on health and gbMSM, they could engage in this process with a sharper focus. Advocacy groups for older adults need to bear some of this burden as well but starting with organizations that cater to gbMSM is a good first step.

Systemic Issues

Within focus groups, several participants remarked that they were unaware of existing resources and end-of-life preparations. This reinforces previous research that found that older gbMSM were not mindful and involved with all aspects of end-of-life preparations (Riggle et al., 2005; de Vries, 2006; Hughes & Cartwright, 2015). While not the intent, focus groups became places of learning. Individual members provided

resources to other participants following the discussion, with plans made to follow up on these resources after focus groups.

This lack of knowledge speaks to the challenges older gbMSM have interacting with existing systems and structures related to end-of-life preparations. While some of these challenges directly result from systems being inherently heterosexist, lack of ‘full’ preparation for end-of-life (e.g. having prepared for all aspects of end-of-life through legal and medical processes completely and comprehensively) is not out of the ordinary in Canada. The Canadian Hospice and Palliative Care Association found that only 70% of Canadians did not have a living will and 47% did not have a substitute decision-maker in health care matters (Ipsos-Reid, 2004). This speaks to the challenges older adults experience in dealing with existing systems and structures. These challenges may stem from several factors. Most systems are designed by adults who are at a stage in life who are not facing end-of-life and do not prioritize the needs of this population. Regulatory and legal requirements result in reduced readability through increased use of jargon and technical language with often complex elements that are not necessarily straightforward. Many forms and documents are produced in small font which can be a challenge for older adults with some vision loss. As well, older adults may have reduced attention and cognitive abilities, making this process even more frustrating as they navigate these complexities.

The Impact of Systemic Issues on Health and End-of-life Preparations

The frustration that older gbMSM faced dealing with these systems and structures can lead to increased stress and subsequent poor health impacts. There is a risk of emotional anguish resulting from the conflict between the knowledge that end-of-life

preparations are needed and beneficial but finding oneself unable to engage in the process.

A lack of knowledge and engagement in end-of-life preparations leaves older gbMSM at risk of not seeing their wishes fulfilled. This can include the types of care they receive, who is permitted to visit them, who makes decisions on their behalf, funeral arrangements, and the distribution of their material and financial assets after death.

Addressing Systemic Issues with the Inverted SEM

The lack of knowledge expressed by some older gbMSM on aspects of end-of-life preparations speaks to the need for **advocacy groups** to educate. In this case, advocacy groups includes organizations focused on the needs of gbMSM and organizations focused on the needs of older adults. Organizations focused on the needs of older adults, such as the Canadian Association of Retired Persons (CARP), already do outreach and education on advanced care planning. Their guide to end-of-life care does not speak to the specific needs of older gbMSM or other LGBT adults (CARP, n.d.). While LGBT advocacy groups have created their own guides relating to end-of-life, these may only reach those who are out and engaged in the LGBT community (a concern identified by focus group participants). Inclusion of the unique needs of older LGBT adults in the mainstream, national offerings could help foster a sense of welcoming and inclusion.

In *LGBT-Inclusive Hospice and Palliative Care*, Acquaviva (2017) proposes a four-stage process for creating spaces that reach and welcome LGBT communities. The four stages in that model closely reflect the inverted SEM, starting with **policies and environments** as the key area of change. The first stage is to create a non-discrimination statement that extends to service recipients and employees. This is tied to the second

stage which includes employee benefits that support LGBT employees and staff training (both at orientation and ongoing throughout employment) that addresses the needs of LGBT clients. Documentation, including intake forms and processes, are the third stage with the need to change the language to be more open-ended and inclusive (e.g. asking all clients about their sexual orientation in an appropriate manner to normalize the discussion and signal the organization is welcoming and supportive). The final stage is to do marketing and outreach to LGBT communities.

Numerous older gbMSM indicated that they felt organizations were ill-equipped to meet their needs based on a cursory perusal of their materials. Acquaviva argues that outreach to LGBT communities should be the last step after the previous three stages are complete. To do so otherwise, would be ‘false advertising;’ misleading LGBT individuals into thinking that an organization is nurturing or welcoming when they have not done the background work to ensure that they are. These various changes speak to the heart of the inverted SEM, **policy and environment**, while addressing the challenges of heterosexism and systemic issues that older gbMSM encounter.

Heterosexism

Older gbMSM have faced a lifetime of dealing with heterosexism in multiple modalities. Older gbMSM in this study indicated they were out and had strong relationships with their primary health care providers whereas many previous studies found rejection from health care services had negative impacts on health (Hash & Rogers, 2013; Hoy-Ellis & Fredriksen-Goldsen, 2016; Fredriksen-Goldsen, Kim, Bryan, Shiu, & Emler, 2017). This might be accounted for by the fact that many previous studies of older

gbMSM were in the United States that does not have universal health care and health is seen as less of a right than it is in Canada.

There was mixed reaction from participants to the continued presence of heterosexism in their lives. While some continued to rail against its impact, many had simply accepted it as a disappointing but not surprising aspect of their life. This resignation did not necessarily result in a sense of apathy so much as a recognition that things had improved overall and that there would be few, if any, major movements forward in their lifetimes. Those fighting ardently against the oppression they have faced their entire lives understood that as they faced the increased likelihood of long-term care they could very well encounter the type of people and attitudes they had sought to change in their younger days.

The Impact of Heterosexism on Health and End-of-life Preparations

As the root of much of the minority stress that older gbMSM experience, the impact of heterosexism on their lives cannot be understated. This stress, often starting when gbMSM realize their sexual orientation, was an ongoing health concern. Minority stress has long-lasting and deeply rooted impacts on health. Beyond the physical and emotional impact of a lifetime of stress, heterosexism can be the cause for isolation and creating barriers for accessing support systems and structures.

This exclusion can result in reduced tendencies to make use of health care systems, especially given the history of pathologizing, medicalization, and stigmatization of gbMSM identities. Without proper, full, and culturally competent health care, older gbMSM are faced an accumulation of a lifetime of stress without the full support of society. This societal judgement can also be internalized, reducing self-worth of older

gbMSM and increasing their reluctance to seek help. This exacerbates any underlying health issues, including mental health concerns, as there may be a perception that they are not wanted in health care systems.

This perceived lack of desirability extended to end-of-life preparations. As focus group members indicated, services are often seen as not being designed for older gbMSM or with their needs in mind. This continues their downward cycle as they avoid such systems with the expectation of rejection and exclusion of their needs.

Addressing Heterosexism with the Inverted SEM

To address older gbMSM needs, health promotion professionals should seek to intervene at the levels of **decision-making bodies** to influence their policies, training, and regulatory requirements. Decision-making bodies can include governmental organizations (e.g. government departments overseeing the needs of older adults). This would be the highest level within the decision-making bodies layer of the inverted SEM. As these organizations/departments are guided by policies, health promotion can advocate to create **policies and environments** that include the needs of older gbMSM. Government organizations can then enact these policies in their own programs and in those that they regulate.

Professional regulatory bodies, such as those overseeing the licensure of social workers, nurses, nurse practitioners, and doctors, are an avenue of change for health promotion interventions. These organizations often have annual training and education obligations for members in addition to entry-to-practice requirements. Including cultural competency as a requirement for practice and could reduce heterosexism through education of these professionals. As indicated above, the four-stage approach proposed

by Acquaviva can be applied to these regulatory bodies and would result in changes that reduce heterosexism.

While these activities may not reduce all socially constructed heterosexism, they can be a step towards providing a refuge for older gbMSM. Changing policies and organizations to reduce heterosexism can have a ripple effect outwards to reduce societal heterosexism, leading to improved health outcomes for all gbMSM and LGBT community members.

Survival

The adversity that older gbMSM have conquered through a lifetime of heterosexism is not often celebrated. While ‘mere survival’ may not seem noteworthy, many older gbMSM have lost their peers through self-harm and the AIDS epidemic. The prevalence of participants’ comments around HIV and AIDS demonstrate the value of past research into the needs of older gbMSM to address the long-term impact of this trauma in their lives (Mahmood, Manier, & Hirst, 2004; Owen & Catalan, 2012). Health care systems and structures often have a blind spot for the challenges that older gbMSM have faced, not recognizing the past trauma that older gbMSM have experienced. Treating ‘everyone the same’ belies that older gbMSM have faced a lifetime of marginalization and minority stress. Their unique experiences should be recognized as they engage in end-of-life preparations.

Many participants expressed surprise that they had lived to the age where they had to deal with the issues relating to advanced age. Having witnessed the deaths of their peer cohort during the AIDS epidemic, their understanding of mortality and expected

lifespan was inextricably altered. There was appreciation for the opportunity to live such long lives though this was often tied to survivors' guilt that they were 'lucky enough' to live this long when many of their peers and friends had not. This was often expressed through a desire to thrive; living life to the fullest, not just surviving.

The Influence of Survival on Health and End-of-life Preparations

This desire was often stymied by the impact of aging, the effects of which could be exacerbated due to a lifetime of minority stress. Given that many had not expected to live to the age they had, there was some denial relating to the aging processes and the imminence of death. Several participants acknowledged that they recognized that as they aged, they needed to engage in end-of-life preparations but found it challenging. There was a demonstrated desire to live life to the fullest out of respect for those who did not have the opportunity to do so.

The trauma of having watched almost their entire generation die early deaths can had long-lasting impacts on the health of individuals. As their needs were often ignored by the health care establishment, older gbMSM felt reluctance to now become dependent on those same systems or seek out help from same.

Addressing Survival with the Inverted SEM

While there is little that can be done to redress the past trauma of older gbMSM, health promotion can affect its impact in two ways. The first is to help older gbMSM come to terms with their own trauma. Acknowledging and understanding the impact of this trauma can help older gbMSM move forward in improving their own health and supporting emotional readiness for end-of-life preparations. **Advocacy groups** are an

ideal venue for such activities as they are often community-based and have connections to **personal networks**.

The second approach is through education of care providers. As indicated above, training in cultural competency can highlight the challenges that older gbMSM have faced. Combatting heterosexism within health care and end-of-life fields (such as gerontology, long-term care, palliative services) may enable individual professionals to understand the challenges that older gbMSM have overcome as they have moved through the world and grown older.

Evolution of identity

While evolution of identity is a natural part of the aging process, intergenerational connectivity between current older gbMSM and younger gbMSM might help prepare future generations of older gbMSM to tackle these changes. Intergenerational exchange was seen as a rare event by participants. Making these connections could also speak to Isolation; connecting older gbMSM through social formats to younger gbMSM. The GSA model could help facilitate this as well with a formalized structure through which connections could be made. Conversations might help build self-efficacy towards resilience as older gbMSM use the skills they have built over a lifetime. These skills include coping abilities to deal with adversity and the ability to advocate for change in their own self-interest.

The Influence of Identity on Health and End-of-life Preparations

This advocacy can address the changing nature of identity for older gbMSM as they may identify less with the LGBT community and more strongly with an older adult

identity. This can be a strength and protective factor as it fosters engagement and older gbMSM find alliances with other older adults in fighting for changes. With a focus on aging, older gbMSM can take up the battle for new issues related to end-of-life preparations, such as the interest in MAiD which appealed to many participants and other aging Canadians (and those who are younger facing end-of-life considerations). While these alliances can provide bridge-building opportunities for education and shared resources, it does expose older gbMSM to the risk of rejection due to heterosexism. The burden should not lie on older adults to advocate solely on their own behalf, though many focus group participants indicated activism as part of their sense of identity.

Despite this connection to the aging community, there is the risk of continued loss of identity as older gbMSM face disconnection from the LGBT community. This contributes to the sense of isolation they may feel. Given that older gbMSM often rely on their personal networks, frequently with other older gbMSM, for emotional support and care, this disconnection can have negative impacts on mental health.

Addressing Evolution of Identity with the Inverted SEM

To address these concerns, more information needs to be distributed to **personal networks** and **individuals** to prepare older gbMSM (and all older LGBT individuals) for the changing nature of identity. Health promotion cannot predict all personal experiences as part of the aging process but can provide tools and resources to individuals to help them prepare for these changes. Addressing the changing nature of individual identity may not resolve all the issues but acknowledging them can help individuals prepare for these changes and take protective steps. For example, if older gbMSM are aware that

their connection to peers is not only of positive social benefit but beneficial for health and wellness, they may be more likely to foster and maintain these relationships.

Identifying the ways that identities change as older gbMSM age can comfort them to understand that some of what they are experience is part of the natural aging process. Advice can be offered to individuals on how to integrate their identities, address unique challenges, and provide guidance on how to be resilience throughout this process. This knowledge of the changing nature of identity can be instrumental in dealing with younger gbMSM to help them prepare for the aging process and to give them a better understanding of their lives may change as they age.

Resilience

Despite the many challenges facing older gbMSM, they show tremendous resilience. Older gbMSM in this study displayed a positive attitude towards these challenges, demonstrated their ability rebound and recover, maintain desired states (e.g., how do they define their preferred level of stress, etc.), withstand stress, and adapt and thrive (Longstaff et al., 2013). Most participants did not inherently recognize or identify these skill sets as they have become an ingrained part of their identity through a lifetime of challenges. Several spoke to their activist past or fighting for change but demonstrated low self-efficacy with their own ability to enact change at this stage in their life. While these skills may not be top-of-mind for participants (and skill levels may have declined through lack of active use) resilience developed from past difficulties can better prepare older gbMSM for the challenges of aging and end-of-life preparation.

The Influence of Resilience on Health and End-of-life Preparations

As older gbMSM have found existing systems and structures do not suit their needs or wishes, they have found creative and unique solutions. By working within (e.g. writing wills) and outside (e.g. making younger friends to help with care) the typical systems for end-of-life preparations, older gbMSM are using their resiliency to find peace of mind and comfort with aging and end-of-life processes. This peace of mind can reduce their overall stress levels, yet the extra work required can be taxing as they research and create new processes.

These personalized solutions may face challenges during end-of-life preparations. As discussed, there can be conflict near end-of-life as different parties engage with older gbMSM. Their biological family and chosen family may have different understandings and priorities for provision of care, decision-making, and distribution of assets upon death. Relying upon individual resilience does not address larger societal issues that impact the health of older gbMSM as they age and begin to engage in end-of-life preparations but it was a protective factor against the unique impacts of aging that older gbMSM face.

Addressing Resilience with the Inverted SEM

Individual resilience can be bolstered to help gbMSM with the aging process and end-of-life preparations as part of health promotion programs and interventions. The organizing of GSAs by **advocacy groups** can be part of this. In discussions, several participants indicated that they once had the skills to tackle challenges but had lost some of their self-efficacy in their abilities in current practice. Programs and workshops to help older gbMSM re-establish their self-efficacy and update their skill sets will help them

engage with end-of-life preparations. These skill-building sessions may focus on individual but **personal networks** would benefit from such educational opportunities. These workshops could be places where new personal connections are made (another way of reducing isolation) but can be offered to groups of friends so that they may support the resilience of others. Building the resilience of older gbMSM can support the stated desire of many focus group participants to continue advocating for change.

While the ultimate goal of health promotion should be to reduce or remove barriers to health equity by changing existing systems and structures (often done through policy), enhancing individual resiliency is an important stopgap until (or if) such an event occurs. Health promoters can work to support tools that help foster resiliency (such as skill-building programs). It is important to recognize that individual resiliency can vary greatly, especially for those who are facing additional or intersectional adversity (i.e. racialized gbMSM, gbMSM with physical disabilities, those who are financially challenged) and health promoters should consider these factors when developing programs.

Limitations

Given the nature of this qualitative study design, the findings of this research cannot be generalized to broader populations of older gbMSM. Specific to the needs of bisexual men, they are recognized by members of at least one Canadian LGBT community as facing less acceptance as gay men which may impact their experiences in a significantly different way (Lewis, Bauer, Coleman, Blot, Pugh, Fraser, & Powell, 2015). As there was only one participant who did not identify as gay, the needs of bisexual older men may not

be fully represented by this research. The specific needs of older transgender gbMSM were excluded from this research as issues specific to the needs of older transgender adults were explored in separate focus groups of *Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults* and not a topic of discussion in the gbMSM men's focus group discussions.

As this was subset data analysis, there was no option to further explore themes in greater depth as they were developed through the analysis process. Evaluation of the content was limited to the data collected. The original participant profile did not ask questions regarding current socioeconomic status, nor questions relating to ethnicity or cultural identities. As such, certain parallels and comparisons could not be made.

The participant profile instrument may have led to some confusion. One of the first questions asked about romantic/sexual relationship status with a wide variety of options. Later questions simplified all relationships to 'partner,' which may not have been the language that participants used to describe their current romantic/sexual relationship. As well, the term 'close friend' might imply to some older gbMSM a romantic/sexual partner as the terms boyfriend or partner might be too modern a term which could confound results.

While this study focussed on end-of-life issues, its sole focus was on older gbMSM. These issues can impact gbMSM at any point in their life based on their health. For this study, older gbMSM were the subject as they were, by and large, more likely to have considered these issues as they aged. The experiences that younger gbMSM face in relation to end-of-life preparations would likely yield significantly different results.

Chapter Five Summary

This chapter connected the results from data analysis to the health of older gbMSM and provided context for potential future health promotion interventions. The inverted SEM demonstrated the various levels at which these interventions could take place. Limitations from this research and the original data upon which it was based were acknowledged. The final chapter provides an overall summary of the research, discussions of its significance, and areas for future research.

Chapter Six: Conclusions

Older gbMSM face many challenges as they age. This research found that while these challenges can hamper their ability to thrive and engage with health care and end-of-life preparations, it is not a foregone conclusion. Many participants demonstrated that they faced these challenges with the inner strength and resilience that they developed over a lifetime of such battles. Older gbMSM sought to improve the circumstances related to aging for themselves, other older adults, and for younger gbMSM generations. Several participants spoke to their desire to remain connected to the broader LGBT community and engage in intergenerational dialogue with younger gbMSM.

This passion for change within older gbMSM can be seized upon by health promoters. While there may not be a singular comprehensive solution to these complex issues, there are many areas where small changes can yield great results. Reducing health inequities can be completed within the lifespan of current older gbMSM and those changes can extend the lives of younger gbMSM. Using the inverted SEM gives health promotion practitioners and allied professionals a map for where to target their interventions based upon their individual abilities and area of focus. Centered around policy, creating change in how health care and end-of-life preparations are conceived and offered, long-lasting change can be made for generations to come.

While there is no ‘one size fits all’ solution to address all the needs identified by older gbMSM in this study, those who work in health promotion can seek to address key determinants of health that were evident as they impact the long-term health of older gbMSM and their end-of-life preparations. As identified by Mikkonen and Raphael (2010), social exclusion of specific groups such as gbMSM results in less participation in

health care services. This exclusion is built around two other determinants; culture and gender. Mikkonen and Raphael (2010) specifically include sexual and gender identity minorities in the overarching term of ‘gender.’ Those who work in health promotion can seek to shift the conversation around gender and hegemonic masculinity’s impact on how we interpret gender and the resulting heterosexism. Creating wide spread change to culture is not an easy task, especially given the diverse nature of Canadian society but it is an admirable and necessary goal to creating change.

The means by which older adults are studied (or *not* studied) in gerontology demonstrates the heteronormative bias cited by Henning (2016). Older gbMSM (and other members of the LGBT community) suffer from this bias. Challenging the hetero-centric and sex-negative approaches of gerontology are necessary steps to understanding the needs of older gbMSM. Programs and policies cannot be adequately created if the research and evidence does not exist to support culturally-informed development. Research of such cannot be fully informed if it does not recognize the varied and holistic nature of older adults, recognizing that sexual orientation is a lifetime lived experience and has significant impact on aging.

As health promotion and gerontology each have roles to play in advancing the health of older gbMSM (and all older LGBTQ individuals), professionals from each discipline could incorporate key concepts from the other into their work, especially relating to the needs of older gbMSM. Each discipline has a key focus on policies and how knowledge can foster change through policy change. Gerontology offers health promotion a focus on the inclusion of the changes of social realities as individuals age and how that shapes their identity and health. The critiques of the heteronormativity of

gerontology can be eased by using intersectional approaches that health promotion emphasizes through the recognition of the impacts of multiple determinants of health on individuals and communities. These two elements can improve circumstances for older gbMSM through improved research and application of knowledge that is culturally informed and competent. If sexual orientation was recognized as a determinant of health, the needs of older gbMSM would be more readily incorporated into health promotion and gerontology research, policy, and practice.

This research supported past calls to include sexual orientation as a unique determinant of health, given the complex and often overlapping nature of sexual orientation and its interactions with other determinants (Logie, 2012; Horner & Roberts, 2014; Muller & Hughes, 2016). The World Health Organization has already been called upon to consider inclusion of sexual orientation (Logie, 2012) and gender identity (Pega & Veale, 2015) as determinants of health given that sexual and gender identity minorities are disproportionately affected by health problems stemming from stigma and discrimination. Formal recognition as determinants of health would strengthen the argument that these issues should be key considerations in health promotion interventions.

Significance and Implications

To enact change, health promotion interventions are needed at all levels of the inverted SEM to reduce the inequities older gbMSM face in end-of-life health care and preparation. This research demonstrated that person-centered care, based on self-identified needs, can be enacted at all levels of the model to reduce health inequities.

Interventions at any one level should be recognized as having an outward effect, potentially creating improvements that will ultimately improve health outcomes for the individual and their cohort. Interventions can be focused on a single identified theme but can easily cross over into other themes (e.g. fostering GSAs can build resilience and reduce isolation) to meet the needs of older gbMSM near end-of-life.

Future Research

Given the progress of LGBT rights in the last several decades, research into the projected end-of-life needs and expectations of other age groups of gbMSM could yield very different results. While younger gbMSM might not be as likely to have considered end-of-life issues, research could help them to pre-emptively plan for their needs as they age. This might be expanded to include younger gbMSM who are experiencing (or expected to experience) end-of-life issues earlier in life due to illness.

Future studies should seek sample sizes with greater diversity (as measured on a variety of metrics including socioeconomic status, rural communities, intersectionally marginalized populations, and more) with more demographic data collected to better analyze and compare varying life experiences. For example, might it be demonstrated that those with higher socioeconomic status are more likely to have legal end-of-life preparations? What is the impact of living rurally for older gbMSM?

As well, while there was discussion of the ‘coming out’ process, there was no specific discussion related to the ages at which participants came out or their coming out experiences. The coming out process might have impact on individual experiences with building resilience and facing heterosexism. The experiences of out transgender gbMSM

would likely be very different than those of cisgender gbMSM (who made up the majority of participants in this study).

This research sought to understand older gbMSM experiences with end-of-life issues broadly to generate a holistic understanding in relation to health promotion interventions. This approach limited the depth to which each topic could be explored. Concepts identified in this study could be the subject of specialized research in the future. As an example, research on the resilience of older gbMSM could gain a better understanding of self-efficacy, skills, and how older gbMSM perceive their own development of resilience. Given that resiliency can be greatly variable by individual, health promotion research could seek to outline the underlying factors that foster individual and collective resilience. Further research could explore how gbMSM identify policies that would ultimately support and strengthen their own resiliency.

Given the importance of health promotion in effecting population-level change, research on the needs of older gbMSM should seek to understand which interventions impact policies and have the greatest impact on the end-of-life preparations for older gbMSM. This process could include comparisons between existing interventions that target different levels of the inverted SEM (i.e. changing policies at a regulatory body level, drafting inclusive mission statements for long-term care facilities, etc.) and attempting to gain a better understanding of the impact.

References

- 519, The. (n.d.). *Still Here, Still Queer: A handbook for affirming LGBTQ older adults*. Toronto, ON; Author. Retrieved from <http://www.the519.org/education-training/still-here-still-queer>
- Academy for Gerontology in Higher Education. (n.d.). *Gerontology/Geriatrics Definitions*. Washington, DC; Author. Retrieved from <https://www.aghe.org/resources/gerontology-geriatrics-descriptions>
- Acquaviva, K. D. (2017). *LGBTQ-inclusive hospice and palliative care - A practical guide to transforming professional practice*. New York, NY: Harrington Park Press.
- Adelman, M., Gurevitch, J., de Vries, B., & Blando, J. (2006). Openhouse: Community building and research in the LGBT aging population. In D. Kimmel, T. Rose & S. David (Eds.) *Lesbian, gay, bisexual, and transgender aging: Research and clinical perspectives* (pp. 247-264). New York: Columbia University Press.
- Almack, K., Seymour, J., & Bellamy, G. (2010). Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people. *Sociology*, 44(5), 908-924. doi: 10.1177/0038038510375739
- Barker, J. (2002). Neighbors, friends, and other nonkin caregivers of community living dependent elders. *Journal of Gerontology*, 57(3), 158-167.
- Bauer, G. R., Hammond, R., Travers, R., Kaay, M., Hohenadel, K. M., & Boyce, M. (2009). "I don't think this is theoretical; this is our lives": how erasure impacts health care for transgender people. *Journal of the Association of Nurses in AIDS Care*, 20(5), 348-361. doi: 10.1016/j.jana.2009.07.004
- Baum, F., & Fisher, M. (2014). Why behavioural health promotion endures despite its failure to reduce health inequities. *Sociology of Health & Illness*, 36(2), 213-225. doi: 10.1111/1467-9566.12112
- Boehmer, U. (2002). Twenty years of public health research: Inclusion of lesbian, gay, bisexual, and transgender populations. *American Journal of Public Health*, 92(7), 1125-1130. doi: 10.2105/AJPH.92.7.1125
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Sage: Cleveland.
- Brandon, A. F., & All, A. C. (2010). Constructivism theory analysis and application to curricula. *Nursing Education Perspectives*, 31(2), 89-92.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advanced care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000-1025. doi: 10.1177/0269216314526272

- Brennan-Ing, M., Seidel, L., Larson, B., & Karpiak, S. E. (2014). Social care networks and older LGBT adults: Challenges for the future. *Journal of Homosexuality*, 61(1), 21-52. doi: 10.1080/00918369.2013.835235
- Brotman, S., Ryan, B., & Cormier, R. (2003). The health and social service needs of gay and lesbian elders and their families in Canada. *The Gerontologist*, 43, 192-202.
- Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cormier, R., Julien, D., Meyer, E., Peterkin, A., & Richard, B. (2007). Coming out to care: Caregivers of gay and lesbian seniors in Canada. *The Gerontologist*, 47, 490-503.
- Brotman, S., Ryan, B., & Meyer, E. (2006). *The health and social services needs of gay and lesbian seniors and their families in Canada- Executive Summary*. Montreal: McGill University School of Social Work.
- Brown, M. T. (2009). LGBT aging and rhetorical silence. *Sexuality Research and Social Policy Journal of NSRC*, 6(2), 65-78. doi: 10.1525/srsp.2009.6.4.65
- Canadian Association of Retired Persons. (n.d.). *End-of-Life Care*. Toronto: Author. Retrieved from <http://www.carp.ca/priority/end-of-life-care/>
- Canadian Institute for Health Information. (2011a). *Health care use at the End of Life in Atlantic Canada*. Ottawa ON; Author.
- Canadian Institute for Health Information. (2011b). *Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions?* Ottawa, ON: Author.
- Carroll, A., & Mendos, L. R. (2017). *State-sponsored homophobia. A world survey of sexual orientation laws: Criminalization, protection and Recognition*. Geneva, Switzerland: International Lesbian, Gay, Bisexual, Trans and Intersex Association. Retrieved from <https://ilga.org/state-sponsored-homophobia-report-2017-ILGA>
- Ceci, S. J. (2006). Urie Bronfenbrenner (1917-2005). *American Psychologist*, 61(2), 173-174. doi: 10.1037/0003-066X.61.2.173
- Centers for Disease Control and Prevention (2008). *HIV/AIDS among persons 50 and older*. Retrieved from <http://cdc.gov/hiv/topics/over50/resources/factsheets/pdf/over50.pdf>
- Centers for Disease Control and Prevention (2010). Prevalence and awareness of HIV infection among men who have sex with men—21 cities, United States, 2008. *Morbidity and Mortality Weekly Report*, 59(37), 1201-1207.
- Cherry, K. (June 22, 2017). *Perception and the Perceptual Process*. Verywell Mind. Retrieved from <https://www.verywellmind.com/perception-and-the-perceptual-process-2795839>
- Clark, M., Landers, S., Linde, R., & Sperber, J. (2001). The GLBT Health Access Project: A state-funded effort to improve access to care. *American Journal of Public Health*, 91(6), 895-896.

- Colpitts, E., & Gahagan, J. (2016a). "I feel like I am surviving the health care system": understanding LGBTQ health in Nova Scotia, Canada. *BMC Public Health*, 16(1), 1005. doi: 10.1186/s12889-016-3675-8
- Colpitts, E., & Gahagan, J. (2016b). The utility of resilience as a conceptual framework for understanding and measuring LGBTQ health. *International Journal for Equity in Health*, 15(1), 1. doi: 10.1186/s12939-016-0349-1
- Cottrell, R. R., Girvan, J. T., & McKenzie, J. F. (2009). *Principles & foundations of health promotion and education* (4th ed.). Toronto: Pearson Benjamin Cummings.
- Creswell, J. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4th Ed.). Thousand Oaks, CA: Sage.
- Conversation Project, The. (2013). *The Conversation Project National Survey 2013*. Cambridge, MA: Author. Retrieved from <http://theconversationproject.org>.
- Cope, D. G. (2014, January). Methods and meanings: credibility and trustworthiness of qualitative research. In *Oncology Nursing Forum* 41(1).
- Croghan, C. F., Moone, R. P., & Olson, A. M. (2014). Friends, family, and caregiving among midlife and older lesbian, gay, bisexual, and transgender adults. *Journal of Homosexuality*, 61(1), 79-102. doi: 10.1080/00918369.2013.835238
- de Vries, B. (2006). Home at the end of the rainbow: Supportive housing for LGBT elders. *Generations*, 29(4), 64-69.
- de Vries, B. (2007). LGBT couples in later life: A study in diversity. *Generations*, 31(3), 18-23.
- de Vries, B., & Blando, J. (2004). The study of gay and lesbian lives: Lessons for social gerontology. In G. Herdt & B. de Vries (Eds.), *Gay and lesbian aging: Research and future directions* (pp. 3-28). New York: Springer.
- de Vries, B., & Gutman, G. (2016). End-of-Life Preparations Among LGBT Older Adults. *Generations*, 40(2), 46-48.
- de Vries, B., & Herdt, G. (2012). *Gay men and aging*. In T.M. Witten & E. Eyler (Eds.,) *Gay, lesbian, bisexual, and transgender aging: Challenges in research, practice and policy*. Baltimore: Johns Hopkins Press.
- de Vries, B., Mason, A. M., Quam, J., & Acquaviva, K. (2009). State recognition of same-sex relationships and preparations for end of life among lesbian and gay boomers. *Sexuality Research & Social Policy*, 6(1), 90-101.
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advanced care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ*, 340, c1345. doi: 10.1136/bmj.c1345
- Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Services Research & Policy*, 10(1), 45-53. DOI 10.1258/1355819052801804.

- Dying with Dignity Canada. (n.d.). *Get The Facts: Bill C-14 And Assisted Dying Law In Canada*. Toronto, ON: Author. Retrieved from http://www.dyingwithdignity.ca/get_the_facts_assisted_dying_law_in_canada
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x
- Ernest, P. (1998). *Social Constructivism as a Philosophy of Mathematics: Radical Constructivism*. Albany, NY: State University of New York Press.
- Fenge, L. A., & Hicks, C. (2011). Hidden lives: The importance of recognising the needs and experiences of older lesbians and gay men within health care practice. *Diversity in Health & Care*, 8(3).
- Fowler, R., & Hammer, M. (2013). End-of-life care in Canada. *Clinical & Investigative Medicine*, 36(3), 127-132.
- Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emlet, C. A., & Hooyman, N. R. (2014). Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of Gerontological Social Work*, 57(2-4), 80-107. doi: 10.1080/01634372.2014.890690
- Fredriksen-Goldsen, K. I., Kim, H. J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study. *American Journal of Public Health*, 103(10), 1802-1809. doi: 10.2105/AJPH.2012.301110
- Fredriksen-Goldsen, K. I., Kim, H. J., Bryan, A. E., Shiu, C., & Emlet, C. A. (2017). The cascading effects of marginalization and pathways of resilience in attaining good health among LGBT older adults. *The Gerontologist*, 57(suppl_1), S72-S83. doi:10.1093/geront/gnw170
- Fredriksen-Goldsen, K. I., Kim, H.-J., Emlet, C. A., Erosheva, E. A., Muraco, A., Petry, H., et al. (2011). *The aging health report: Disparities and resilience among lesbian, gay, bisexual and transgender older adults*. Seattle, WA: Institute for Multigenerational Health.
- Fredriksen-Goldsen, K. I., Kim, H.-J., Hoy-Ellis, C., Goldsen, J., Jensen, D., Adelman, M., Costa, M., & de Vries, B. (2013). *Addressing the needs of LGBT older adults in San Francisco: Recommendations for the future*. San Francisco, CA: Department of Public Health.
- Fredriksen-Goldsen, K. I., & Kim, H. J. (2017). The Science of Conducting Research with LGBT Older Adults-An Introduction to Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS). *The Gerontologist*, 57(s1), s1-s14. doi: 10.1093/geront/gnw212
- Fredriksen-Goldsen, K. I., & Muraco, A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on Aging*, 32(3), 372-413. doi: 10.1177/0164027509360355

- Furlotte, C., Gladstone, J. W., Cosby, R. F., & Fitzgerald, K. A. (2016). "Could We Hold Hands?" Older Lesbian and Gay Couples' Perceptions of Long-Term Care Homes and Home Care. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 35(4), 432-446. doi: 10.1017/S0714980816000489
- Gahagan, J., & Subriana-Malaret, M. (2018). Improving pathways to primary health care among LGBTQ populations and health care providers: Key findings from Nova Scotia, Canada. *International Journal for Equity in Health*. 17(76). doi: 10.1186/s12939-018-0786-0
- Gahagan, J., & Colpitts, E. (2016). Understanding and Measuring LGBTQ Pathways to Health: A Scoping Review of Strengths-based Health Promotion Approaches in LGBTQ Health Research. *Journal of Homosexuality*, 64(1), 1-27. doi: 10.1080/00918369.2016.1172893
- Gardner, A. T., de Vries, B., & Mockus, D. S. (2014). Aging out in the desert: Disclosure, acceptance, and service use among midlife and older lesbians and gay men. *Journal of Homosexuality*, 61(1), 129-144. doi: 10.1080/00918369.2013.835240
- Gendron, T., Maddux, S., Krinsky, L., White, J., Lockeman, K., Metcalfe, Y., & Aggarwal, S. (2013). Cultural competence training for health care professionals working with LGBT older adults. *Educational Gerontology*, 39(6), 454-463. doi: 10.1080/03601277.2012.701114
- Glanz, K., Rimer, B., & Biswanath, K. (2008). The Scope of Health Behavior and Health Education. In K. Glanz, B. Rimer, K. Biswanath (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (4th ed.) (pp. 465-486). San Francisco, CA: Jossey-Bass.
- Golden, S. D., McLeroy, K. R., Green, L. W., Earp, J. A. L., & Lieberman, L. D. (2015). Upending the social ecological model to guide health promotion efforts toward policy and environmental change. *Health Education & Behavior*, 42(IS), 8S-14S doi: 10.1177/1090198115575098
- Grossman, A. H., D'Augelli, A.R., & O'Connell, T.S. (2001). Being lesbian, gay, bisexual, and 60 or older in North America. *Journal of Gay & Lesbian Social Services: Issues in Practice, Policy & Research*, 13(4):23-40. doi: 10.1300/J041v13n04_05
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- Harding, R., Epiphaniou, E., & Chidgey-Clark, J. (2012). Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *Journal of Palliative Medicine*, 15(5), 602-611. doi: 10.1089/jpm.2011.0279
- Hash, K. M., & Rogers, A. (2013). Clinical practice with older LGBT clients: Overcoming lifelong stigma through strength and resilience. *Clinical Social Work Journal*, 41(3), 249-257. doi:10.1007/s10615-013-0437-2

- Hatzenbuehler, M. L., O'cleirigh, C., Grasso, C., Mayer, K., Safren, S., & Bradford, J. (2012). Effect of same-sex marriage laws on health care use and expenditures in sexual minority men: a quasi-natural experiment. *American Journal of Public Health, 102*(2), 285-291. doi: 10.2105/AJPH.2011.300382
- Henning, C. E. (2016). Is old age always already heterosexual (and cisgender)? The LGBT Gerontology and the formation of the "LGBT elders". *Vibrant: Virtual Brazilian Anthropology, 13*(1), 132-154. doi: 10.1590/1809-43412016v13n1p132
- Henry, J., & McNab, W. (2003). Forever young: A health promotion focus on sexuality and aging. *Gerontology & Geriatrics Education, 23*(4), 57-74. doi: 10.1300/J021v23n04_06
- Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., ... & Lam, M. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal, 174*(5), 627-633. doi: 10.1503/cmaj.050626
- Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research, 7*, 408-424. doi: 10.1177/104973239700306
- Hollenbach, A. D., Eckstrand, K. L., & Dreger, A. D. (Eds.). (2014). *Implementing curricular and institutional climate changes to improve health care for individuals who are LGBT, gender nonconforming, or born with DSD: A resource for medical educators*. Washington, D.C.; Association of American Medical Colleges.
- Horner, J., & Roberts, N. J. (2014). Time to recognise sexual orientation as a social determinant of health. *The Medical Journal of Australia, 200*(3), 137. doi: 10.5694/mja13.10464
- Hoy-Ellis, C. P., & Fredriksen-Goldsen, K. I. (2016). Lesbian, gay, & bisexual older adults: linking internal minority stressors, chronic health conditions, and depression. *Aging & Mental Health, 20*(11), 1119-1130. doi: 10.1080/13607863.2016.1168362
- Hughes, A. K., Harold, R. D., & Boyer, J. M. (2011). Awareness of LGBT aging issues among aging services network providers. *Journal of Gerontological Social Work, 54*(7), 659-677. doi: 10.1080/01634372.2011.585392
- Humble, A.M. (2013). Moving from ambivalence to certainty: Older same-sex couples marry in Canada. *Canadian Journal on Aging, 32*(2), 131-144. doi: 10.1017/S0714980813000196
- Institute of Medicine. (2011). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press.
- Ipsos-Reid. (2004). *Hospice Palliative Care Study*. Study commissioned by GlaxoSmithKline and the Canadian Hospice Palliative Care Association.

- Jihanian, L. J. (2013). Specifying long-term care provider responsiveness to LGBT older adults. *Journal of Gay & Lesbian Social Services, 25*(2), 210-231. doi: 10.1080/10538720.2013.782834
- Kahlke, R. M. (2014). Generic qualitative approaches: Pitfalls and benefits of methodological mixology. *International Journal of Qualitative Methods, 13*(1), 37-52.
- Kim, B. (2001). Social constructivism. *Emerging Perspectives on Learning, Teaching, and Technology, 1*(1), 16.
- Knauer, N. J. (2010). Gay and lesbian elders: Estate planning and end-of-life decision making. *Florida Coastal Law Review, 11*, 164-215.
- Kochman, A. (1997). Gay and lesbian elderly: Historical overview and implications for social work practice. In J. Quam (Ed.), *Social services for senior gay men and lesbians* (pp. 1-25). New York: Haworth Press.
- Krueger, R.A. & Casey, M.A. (2008). *Focus groups: A practical guide for applied research*. 4th edition. New York: SAGE.
- Kum, S. (2017). Gay, gray, black, and blue: An examination of some of the challenges faced by older LGBTQ people of color. *Journal of Gay & Lesbian Mental Health, 21*(3), 228-239, DOI: 10.1080/19359705.2017.1320742
- Kuyper, L., & Fokkema, T. (2010). Loneliness among older lesbian, gay, and bisexual adults: The role of minority stress. *Archives of Sexual Behavior, 39*(5), 1171-1180. doi: 10.1007/s10508-009-9513-7
- Law, M., Mathai, A., Veinot, P., Webster, F., & Mylopoulos, M. (2015). Exploring lesbian, gay, bisexual, and queer (LGBQ) people's experiences with disclosure of sexual identity to primary care physicians: A qualitative study. *BMC Family Practice, 16*(1), 175. doi: 10.1186/s12875-015-0389-4
- Leggett, S., Davies, S., Hiskey, S., & Erskin, J.A.K. (2011). The psychological effects of considering a move into residential care: An age-related study. *Journal of Housing for the Elderly, 25*, 31-49. doi: 10.1080/02763893.2011.545740
- Lewis, N., Bauer, G., Coleman, T., Blot, S., Pugh, D., Fraser, M., & Powell, L. (2015). Community Cleavages: Gay and Bisexual Men's Perceptions of Gay and Mainstream Community Acceptance in the Post-AIDS, Post-Rights Era. *Journal of Homosexuality, 62*(9), 1201-1227. doi: 10.1080/00918369.2015.1037120
- Liamputtong, P. (2009). Qualitative data analysis: Conceptual and practical considerations. *Health Promotion Journal of Australia, 20*(2), 133-139.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Logie, C. (2012). The case for the World Health Organization's Commission on the Social Determinants of Health to address sexual orientation. *American Journal of Public Health, 102*(7), 1243-1246. doi: 10.2105/AJPH.2011.300599

- Longstaff, P. H., Koslowski, T. G., & Geoghegan, W. (2013, June). Translating resilience: a framework to enhance communication and implementation. In *Symposium on Resilience Engineering* (pp. 12-23).
- Lyons, A. (2016). Social support and the mental health of older gay men: Findings from a national community-based survey. *Research on Aging, 38*(2), 234-253. doi: 10.1177/0164027515588996
- Lyons, A., Croy, S., Barrett, C., & Whyte, C. (2015). Growing old as a gay man: How life has changed for the gay liberation generation. *Ageing & Society, 35*(10), 2229-2250. doi: 10.1017/S0144686X14000889
- Mahmood, D., Manier, D., & Hirst, W. (2004). Memory for how one learned of multiple deaths from AIDS: Repeated exposure and distinctiveness. *Memory & Cognition, 32*(1), 125-134.
- Mallon, D. (1993). Social Support Networks of Gay Men. *The Journal of Sociology & Social Welfare, 20*(1), 10.
- McFarland, P. L., & Sanders, S. (2003). A pilot study about the needs of older gays and lesbians: What social workers need to know. *Journal of Gerontological Social Work, 40*(3), 67-80. doi: 10.1300/J083v40n03_06
- Macintosh, H., Reissing, E. D., & Andruff, H. (2010). Same-sex marriage in Canada: The impact of legal marriage on the first cohort of gay and lesbian Canadians to wed. *The Canadian Journal of Human Sexuality, 19*(3), 79.
- McKinley, J. (2015). Critical argument and writer identity: Social constructivism as a theoretical framework for EFL academic writing. *Critical Inquiry in Language Studies, 12*(3), 184-207.
- McLaren, S. (2016). The relationship between living alone and depressive symptoms among older gay men: the moderating role of sense of belonging with gay friends. *International Psychogeriatrics, 28*(11), 1895-1901.
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377.
- Metlife Mature Market Institute & The Lesbian and Gay Aging Issues Network of the American Society on Aging. (2010). Out and Aging: The MetLife Study of Lesbian and Gay Baby Boomers. *Journal of GLBT Family Studies, 6*(1), 40-57. doi: 10.1080/15504280903472949
- Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*(5), 674. doi: 10.1037/0033-2909.129.5.674
- Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. Toronto, ON: York University Press.
- Morgan, D. (1997). *Focus groups as qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

- Mule, N., Ross, L., Deepröse, B., Jackson, B., Daley, A., Travers, A., & Moore, D. (2009). Promoting LGBT health and wellbeing through inclusive policy development. *International Journal for Equity in Health*, 8(18). doi: 10.1186/1475-9276-8-18
- Muller, A., & Hughes, T. L. (2016). Making the invisible visible: A systematic review of sexual minority women's health in Southern Africa. *BMC Public Health*, 16(1), 307. doi: 10.1186/s12889-016-2980-6
- Muraco, A., & Fredriksen-Goldsen, K. (2011). "That's what friends do": Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults. *Journal of Social and Personal Relationships*, 28(8), 1073-1092. doi: 10.1177/0265407511402419
- Murray, E., Numer, M., Merritt, B., Gahagan, J., & Comber, S. (2011). Healthy Aging among LGBT Seniors in Canada: A Review of the Literature. *International Journal of Health, Wellness & Society*, 1(4), 179-192.
- Namaste, V. (2000). *Invisible lives: The erasure of transsexual and transgendered people*. Chicago, IL: University of Chicago Press.
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description— The poor cousin of health research?. *BMC Medical Research Methodology*, 9(1), 52. doi:10.1186/1471-2288-9-52
- Orel, N. A. (2004). Gay, lesbian, and bisexual elders: Expressed needs and concerns across focus groups. *Journal of Gerontological Social Work*, 43(2-3), 57-77. doi: 10.1300/J083v43n02_05
- Orel, N. A. (2014). Investigating the needs and concerns of lesbian, gay, bisexual, and transgender older adults: The use of qualitative and quantitative methodology. *Journal of homosexuality*, 61(1), 53-78. doi: 10.1080/00918369.2013.835236
- Owen, G., & Catalan, J. (2012). 'We never expected this to happen': Narratives of ageing with HIV among gay men living in London, UK. *Culture, Health & Sexuality*, 14(1), 59-72.
- Pega, F., & Veale, J. F. (2015). The case for the World Health Organization's Commission on Social Determinants of Health to address gender identity. *American Journal of Public Health*, 105(3), e58-e62. doi: 10.2105/AJPH.2014.302373
- Pietkiewicz, I. & Smith, J.A. (2012) Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii [A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology]. *Czasopismo Psychologiczne*, 18(2), 361-369.
- Plante, I., Filipenko, S., Bontje, F., & National Seniors Advisory Council. (2017). *Community Engagement Consult for LGBT Seniors - Online Consultation Brief*. Toronto, ON; Egale. Retrieved from <https://egale.ca/seniors/>

- Poland, B., Krupa, G., & McCall, D. (2009). Settings for health promotion: an analytic framework to guide intervention design and implementation. *Health Promotion Practice, 10*(4), 505-516. doi: 10.1177/1524839909341025
- Public Health Agency of Canada. (2013). *What Makes Canadians Healthy or Unhealthy?* Ottawa, ON: Author. Retrieved from <https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health.html>
- Ravitch, S. M., & Riggan, M. (2016). *Reason & rigor: How conceptual frameworks guide research*. Sage Publications.
- Riggle, E. D., Rostosky, S. S., Prather, R. A., & Hamrin, R. (2005). The Execution of Legal Documents by Sexual Minority Individuals. *Psychology, Public Policy, and Law, 11*(1), 138. doi: 10.1037/1076-8971.11.1.138
- Robinson, N. (1999). The use of focus group methodology—with selected examples from sexual health research. *Journal of Advanced Nursing, 29*(4), 905-913.
- Rossman, G. B., & Rallis, S. F. (2003). *Learning in the field: An introduction to qualitative research*. Sage.
- Sallis, J., Owen, N., & Fisher, E. (2008). Ecological models of health behavior. In K. Glanz, B. Rimer, K. Biswanath (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (4th ed.) (pp. 465-486). San Francisco, CA: Jossey-Bass.
- Sandelowski, M. (2000). Focus on research methods- Whatever happened to qualitative description?. *Research in Nursing and Health, 23*(4), 334-340.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84. doi: 10.1002/nur.20362
- Smith, R. (2000). A good death. *BMJ, 320*(7228), 129-130. doi: 10.1136/bmj.320.7228.129
- Smithson, J. (2000). Using and analysing focus groups: Limitations and possibilities. *International Journal of Social Research Methodology, 3*(2), 103-119.
- Sousa, M., & Moleiro, C. (2015). The inclusion of lesbian and gay populations in health research: a systematic review. *Ex Aequo, 32*, 169-182.
- Statistics Canada. (2011). *Gay pride by the numbers*. Ottawa, ON: Statistics Canada.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA, 284*(19), 2476-2482. doi: 10.1001/jama.284.19.2476
- Stinchcombe, A., Smallbone, J., Wilson, K., & Kortess-Miller, K. (2017). Health care and End-of-Life Needs of Lesbian, Gay, Bisexual, and Transgender (LGBT) Older Adults: A Scoping Review. *Geriatrics, 2*(1), 13. doi: 10.3390/geriatrics2010013
- Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook, 53*(3), 127-133. doi: 10.1016/j.outlook.2005.03.005

- Thomas, J., & Harden, A. (2008). Methods for thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45. doi: 10.1186/1471-2288-8-45
- Trussler, T., & Ham, D. (2016). *Gay Generations: Life Course and Gay Men's Health - Findings from the National Sex Now Survey*. Community-Based Research Centre for Gay Men's Health; Vancouver BC.
- Van Wagenen, A., Driskell, J., & Bradford, J. (2013). "I'm still raring to go": Successful aging among lesbian, gay, bisexual, and transgender older adults. *Journal of Aging Studies*, 27(1), 1-14.
- Vygotsky, L. S. (1978). *Mind in society. The development of higher psychological functions* (M. Cole, V. John-Steiner, S. Scribner, & E. Souberman, eds.; M. Cole & M. Lopez-Morillas, trans.). Cambridge, MA: Harvard University Press.
- Wallace, S. P., Cochran, S. D., Durazo, E. M., & Ford, C. L. (2011). The health of aging lesbian, gay and bisexual adults in California. *Policy Brief (UCLA Center for Health Policy Research)*, 1.
- Wilson, D. M., Birch, S., Sheps, S., Thomas, R., Justice, C., & MacLeod, R. (2008). Researching a best-practice end-of-life care model for Canada. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 27(4), 319-330. doi: 10.3138/cja.27.4.319
- World Health Organization. (n.d.). *Global Plan of Action on Social Determinants of Health*. Retrieved from http://www.who.int/social_determinants/action_sdh/en/

Appendix 1: Sample Screening Tool

Screening Tool

Thank you for interest in our project, “*Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults.*” This project is funded by the Technology Evaluation in the Elderly (TVN) National Centre of Excellence and we are conducting this study in conjunction with University and community partners across the country.

We have two primary goals:

- 1) to understand the barriers to preparing for later life and end-of-life among LGBT older adults;
- 2) to explore the role that internet-based technology can play in helping LGBT older adults in making informed decisions and taking appropriate action.

We will do this by hosting focus groups and town-hall meetings across the country and by setting up a test website.

At this point, we are hoping to recruit participants for one of our focus groups. To do so, I need to ask a few questions to make sure you meet our eligibility requirements. Please know that you don’t have to answer any of these questions, you can discontinue this conversation at any time and your participation is completely voluntary. If you decide not to participate or discontinue your participation, please know that it will not affect any of the personal services you or the person for whom you are providing care receive or your relationship with any organization which may have connected you to this project. If you withdraw from this study, these data will be destroyed.

May I go ahead and ask these questions?

1. **What is your current age, in years?**
 - a. **60+**
 - i. Proceed to Question 2.
 - b. **If 59**
 - i. “When do you turn 60?” If this is during the next few months, they may qualify. If turning 60 within data collection period, proceed to Question 2.
 - c. **50 to 58**
 - i. Proceed to Question 6.
 - d. **Under age 50**
 - i. Proceed to Ineligibility Response
2. **Do you identify as gay, lesbian, bisexual, or heterosexual? [CHECK ONE]**
 - a. **Lesbian, bisexual, gay, or homosexual**
 - i. Proceed to Question 3.
 - b. **Heterosexual (straight)**
 - i. Proceed to Question 3.

- c. **Other**
 - i. *“Could you please clarify how you identify?”*
 - 1. *If non-heterosexual and/or non-cisgender, continue to Question 3. Explain that we may not have a group that exactly matches their identity but we will do what we can to find them the right focus group (if they meet other selection criteria).*
3. **What is your current gender?**
- a. Female
 - b. Male
 - c. Other
4. **Is the gender with which you currently identify different from the gender that you were assigned at birth?**
- a. No
 - i. If participant identified as lesbian, gay or bisexual... Proceed to Question 4
 - ii. If participant identified as heterosexual... Clarify eligibility as LGBT older adult.
 - b. Yes
 - i. Are you or have you been transgender? Yes^[SEP] No
5. **Do you have any of the following chronic health conditions? (Read list of chronic conditions- see Appendix P)**
- a. No
 - i. Proceed to Question 6.
 - b. Yes
 - i. Proceed to Question 6.
6. **Are you currently or have you ever provided care on a regular basis to an LGBT friend or family member aged 60 or older?**
- a. No
 - i. If participant answered “No” to Questions 5, proceed to Ineligibility Response
 - ii. If participant answered “Yes” to Question 5, proceed to Question 9.
 - b. Yes
 - i. *“If yes, what is/was his/her relationship to you?”*
_____”
 - ii. Proceed to Question 7.
7. **Thinking about the person for whom you are providing care, do they have two or more chronic health conditions?**
- a. No
 - i. If participant answered “Yes” to Question 5, proceed to Question 9.
 - ii. If participant answered “No” to Question 5, proceed to - Ineligibility Response.
 - b. Yes

- i. Proceed to Question 8.
8. **With which chronic health conditions does he or she live? For example, impaired hearing or vision, arthritis, diabetes, osteoporosis, high blood pressure, cardio-vascular disease, dementia, HIV/AIDS?**
-
-

9. **Do you use the internet for things like email, staying in contact with friends and family, news and/or other activities?**
- a. **Yes**
- b. **No**

Thank you for answering these questions.

Eligibility Response

We would like to invite you to participate in a focus group during which we will talk about preparations for later life and end of life among LGBT persons ages 60 and older. Based on your responses, I would like to invite you to participate in one of our four focus groups. Which of the following focus groups would you feel most comfortable participating in; a) gay and bisexual men; b) lesbian and bisexual women; c) transgender people?

The focus group will last about 2 hours, take place in the HRM, and the exact date and time will be decided after the groups are formed so as to be convenient for the group. As I mentioned before, all of the information shared will be confidential; we will ask you to use a pseudonym or whatever provides you with the most comfort. We will conduct the focus group in a professional manner and ask the same of participants. Our focus groups will be audio-recorded but we will remove any personally identifying information.

Could you please choose a pseudonym (a name or number) that you feel comfortable using for further participation in this project?

When you come to the focus group, we will give you a \$25 gift card as a thank you for sharing your time and opinion with us. Which of the following would you prefer?

Sobeys _____ Atlantic Superstore _____ Chapters/ Indigo _____

Ineligibility Response

Thank you for taking the time to answer these questions. At this time, we do not have an appropriate focus group to which to invite you. We would, however, hope that you would consider attending the town-hall meeting that we will host in the HRM after the focus groups are finished. You can find out about when and where this meeting will take place by e-mailing LGBT-end-of-life-care-study@msvu.ca or calling 902-494-6620.

Thank you for your interest in this project. Please feel free to call or email with any questions, comments, or concerns you might have.

Appendix 2: Participant Profile

Participant Profile – LGBT Older Adults

Participant ID: _____

Introduction: Thank you for volunteering to participate in this study. The purpose of the study is to find out how older LGBT Canadians prepare for end-of-life, seek and consider care, engage their networks of support, and the role of technology in serving these needs. In order to describe who participated in the study, we need to ask you some questions about yourself – for example your age, about your living arrangement and health, and about your use of the internet. The information you give will be kept strictly confidential. Personal information will not be released. Participant characteristics will be reported in the aggregate only (e.g. the study participants ranged in age from 60 to __; __% were female).

Part A: Personal Characteristics

1. Which of the following best describes your current primary relationship status?

[PLEASE CHECK ONE]

- Single; If yes, please answer question below
- Legally married to a male
- Legally married to a female
- In a legally recognized registered domestic partnership with a male
- In a legally recognized registered domestic partnership with a female
- In a committed relationship with a male
- In a committed relationship with a female
- Have boyfriend
- Have girlfriend
- Other (Please specify):

If you answered “single” above, please respond to which of the following is most accurate. [PLEASE CHECK ONE]

- Never partnered
- Partners of short duration

- Separated
 - Divorced
 - Widowed
 - Other (Please specify):
-

2. How long have you been in your current primary relationship circumstances (e.g., single, married, partnered, boyfriend)?

_____ (years) or _____ (months)

3. Do you have any children? Yes No
If so, how many living children do you have? _____

4. Which of the following describes your current living arrangement?

- Live alone
 - Live with spouse/partner only
 - Live with spouse/partner and/or other family members (Please specify) _____
 - Other (Please specify):
-

5. Current Work Status:

- Self-employed
- Regular salaried-wage employee
- Casual wage employee
- Domestic duties (e.g. look after grandchildren while parents work)
- Retired
- Not employed

6. What was your highest level of education? [CHOOSE ONE]

- 8th grade or less

- Some high school
- High school graduation
- Technical or trade school
- Some college/university
- Bachelor's degree
- Graduate degree

7. To what extent, if any, are you “out” to the following people? Please place an “X” in the corresponding space.

	Not at all	A little	Somewhat	Mostly	Completely	Not sure	Not applicable
Parents							
Siblings							
Children							
Close Friends							
Acquaintances							
People at work							
Health Care Providers							

If you would like to explain or expand on any of your answers above, please do so here:

Part B: Social Support

8. Who is likely to be your **primary** caregiver when the need arises?
[CHOOSE ONLY ONE]

- Partner/Spouse/significant other
- Friend
- Parent
- Sibling
- Adult child
- Other biological relative
- Neighbor
- Paid in-home caregiver
- Volunteer caregivers from a community organization or faith community
- Other (Please specify _____)
- Not sure

10. Have you completed any of the following? **[CHOOSE ALL THAT APPLY]**

- Will
- Living will (A living will is a document that states what health care decisions you would want to have made for you should you become unable to do so; this may also be known as an Advance Directive)
- Durable power of attorney for health care or health care surrogate/proxy
- Representation Agreement or Personal Directive (allows you to appoint someone as your legal representative to handle your financial, legal, personal care and health care decisions)
- Pre-paid funeral plan
- Purchased long-term care insurance
- Purchased critical care insurance
- Informal caregiving arrangements (i.e., discussions with another person who would serve as your caregiver should the need arise)
- Not sure

11. With whom have you had *explicit* discussions about caring for you should/when the need arise? **By explicit discussions, we mean having discussed the circumstances under which you would receive care and/or the nature of care that you would prefer. [CHOOSE ALL THAT APPLY]**

- Partner
 - Parent
 - Adult Child
 - Sibling
 - Other biological relative
 - Close Friend
 - Neighbor
 - Primary care doctor
 - Counselor/therapist
 - Other health care professional
 - Spiritual/Religious advisor or clergy
 - Legal or financial professional
 - No one
 - Other (Please specify):
-

12. With whom have you had explicit discussions about end-of-life care and treatment preferences? **By explicit discussions, we mean having discussed what life-support treatment would you want (or don't want), for example. [CHOOSE ALL THAT APPLY]**

- Partner
 - Parent
 - Adult Child
 - Sibling
 - Other biological relative
 - Close Friend
 - Neighbor
 - Primary care doctor
 - Counselor/therapist
 - Other health care professional
 - Spiritual/Religious advisor or clergy
 - Legal or financial professional
 - No one
 - Other (Please specify):
-

13. When you think of a recent time (e.g., past six months) when you were feeling down and wanted to talk with someone, on whom did you rely?

[CHOOSE ALL THAT APPLY]

- Partner
- Parent
- Adult Child
- Sibling
- Other biological relative
- Friend
- Neighbor
- Primary care doctor
- Counselor/therapist
- Other health care professional
- Spiritual/Religious advisor or clergy
- Legal or financial professional
- Other (Please specify):

-
- No one
 - Not applicable

14. When you think of a recent time (e.g., past six months) when you needed help getting to or from a medical appointment, on whom did you rely?

[CHOOSE ALL THAT APPLY]

- Partner
- Parent
- Adult Child
- Sibling
- Other biological relative
- Friend
- Neighbor
- Primary care doctor
- Counselor/therapist
- Other health care professional
- Spiritual/Religious advisor or clergy
- Legal or financial professional
- Other (Please specify):

-
- No one
 - Not applicable

15. When you think of a recent time (e.g., past six months) when you needed advice on a personal matter, on whom did you rely? **[CHOOSE ALL THAT APPLY]**

- Partner
- Parent
- Adult Child
- Sibling
- Other biological relative
- Friend
- Neighbor
- Primary care doctor
- Counselor/therapist
- Other health care professional
- Spiritual/Religious advisor or clergy
- Legal or financial professional
- Other (Please specify):

-
- No one
 - Not applicable

16. When you think of a recent time (e.g., past six months) when you were ill and needed some care (e.g., getting groceries and/or a meal), on whom did you rely? **[CHOOSE ALL THAT APPLY]**

- Partner
- Parent
- Adult Child
- Sibling
- Other biological relative
- Friend
- Neighbor
- Primary care doctor
- Counselor/therapist
- Other health care professional
- Spiritual/Religious advisor or clergy
- Legal or financial professional
- Other (Please specify):

-
- No one
 - Not applicable

17. How many close friends do you have (that is, people who are not your relatives, but who you feel at ease with, can talk to about what is on your mind, or call on for help)? _____

18. Do you have a chosen family? By chosen family, we mean a group of people to whom you are emotionally close and consider “family” even though you are not biologically or legally related.

Yes No

PART E: INTERNET USE

19. How comfortable are you with everyday use of the computer?

- Not at all
- Somewhat
- Mostly
- Completely

20. Not counting checking e-mail, on a typical day about how many hours do you spend on the Internet for recreational purposes? (Mark one.)

- 0 hours
- Less than 1 hour
- 1 or 2 hours
- 3 or 4 hours
- More than 4 hours

21. How much do you rely on the Internet to: (Circle one number for each item.)

	Very much	Somewhat	Just a little	Not at all
1. E-mail with friends	3	2	1	0
2. E-mail with family	3	2	1	0

3. Chat, instant message or videoconference (e.g. AIM or Skype)	3	2	1	0
4. Stay in touch with people via social networking website (e.g. Facebook)	3	2	1	0
5. Contact people via dating websites	3	2	1	0
6. Keep up with the news	3	2	1	0
7. Find travel information	3	2	1	0
8. Find career information	3	2	1	0
9. Find health information	3	2	1	0
10. Find end of life information	3	3	2	1
11. Pay your bills	3	2	1	0
12. Find product information (e.g. window shopping)	3	2	1	0
13. Buy products	3	2	1	0

Appendix 3: Focus Group Interview Guide

FOCUS GROUP INTERVIEW GUIDE: LGBT OLDER ADULTS

Before starting, ensure informed consent process is reviewed and complete

I. Introduction

Welcome participants. Introduce participants to each other and introduce the research staff present. Let participants know that they should please feel free to use a nickname or pseudonym if they would prefer.

- Receive signed consent forms.
- Give gift cards
- Inform of break schedule (or develop such a schedule with the group).
- Have participants complete the participant profile sheet.
- Read the following protocol summary to the participants

This focus group has three main objectives. First we would like to hear your perceptions of the problems faced by older LGBT persons around issues of and preparations for care and end of life; second, we would like to discuss the roles of community in this process (e.g., support of and from friends and kin)—actual and anticipated; and third, we hope to speak about the role of technology in this process: How can technology be engaged to support care and end of life preparations? How can technology be engaged to support and encourage community? To facilitate discussion I will ask a series of questions. There are no right or wrong answers to these questions. We are interested in hearing everyone's opinions. You don't need to agree as a group. Do you have any questions before we begin?

We will record this discussion so that our attention may be focused on what is being said (e.g., not distracted by trying to take too many notes) and so that we might review these discussions at a later date. We will transcribe the recordings, removing identifying information such as the names of individuals and organizations from the transcripts.

Please know that this is meant to be a safe sharing environment, so please feel free to share as much or as little as you feel comfortable. [review consent form here] We do ask that what is discussed today remains confidential and that you don't discuss the personal information shared outside this discussion with others.

I will ask a series of questions to start our discussions.

II. Interview

A. Plans for End of Life Care

- a) How much thought have you given to how you will handle things (e.g., your affairs, what will happen to you) as you approach the end of your life?

(Prompts: Why is this the case? Do you think it is important to think about these things in advance? Why? What issues should we think about? What plans have you made for your future? i.e., will, durable power of attorney, health care directive, financial.)

b) Have you had discussions about caring for or receiving care from another person? Who is this person? (Prompts: Who would pick you up following a medical procedure such as a colonoscopy? Who would tell you that you have lost weight and need to see a doctor? Who would tell you that you should no longer drive?)

c) With whom have you had EXPLICIT discussions about care? Have you talked with anyone about coming in to provide personal care? Why or why not? What are these conversations like? (Do you discuss definite plans and/or strategies to support each other? If not, why do you think you don't have direct conversations?)

d) What would encourage people (you) to have such explicit discussions? What could we do/offer to assist in having such explicit discussions?

B. Community

a) Have you provided care for another person? Whom? How were you approached to be the caregiver? What were your experiences in caregiving?

b) Who are the people with whom you would talk about hopes, fear, plans for the future? (prompt: Do you have a "chosen family"?)

c) How do you stay connected with these individuals? (How do you maintain ties?) How could we encourage and support individuals (you) to sustain and nurture such relationships?

C. Technology

a) What role does technology play in your life?

b) Have you used any online resources (e.g., CaringBridge, Facebook) to stay in contact with your friends/family? Do you have meaningful discussions this way? Why or why not?

c) What would encourage people (you) to have such discussions online? What could we do/offer to assist in having such discussions?

III. Closing

Is there anything you would like to add?

Closing remarks: That's all the questions I have. Thank you very much for you time and for participating in this discussion.

Appendix 4: Community Partners

Organization	Designated contact	e-mail & telephone
Simon Fraser University Gerontology Research Centre	Andrew Sixsmith, Director	sixsmith@sfu.ca
Haro Park Centre	Jude Morrison, Director of Residential Services and Assisted Living	jmorrison@haropark.org
Qmunity: B.C.'s Queer Resource Centre	Bonnie O'Sullivan, Generations Community Developer	generations@qmunity.ca
West End Seniors Network	Eric Kowalski, Executive Director	executivedirector@wesn.ca 604-669-5051
Vancouver Coastal Health	Shannon Berg, Executive Director, Home and Community Care	Shannon.Berg@vch.ca 604-875-4673

Fraser Health	Anita Wahl, Clinical Nurse Specialist	Anita.Wahl@fraserhealth.ca 604-851-3031
Senior's Association of Greater Edmonton	Roger Laing, Executive Director	info@mysage.ca 780.423.5510
Institute for Sexual Minority Studies and Services, University of Alberta	Kristohper Wells, Director of Programs & Services	Kris.Wells@ualberta.ca 780.492.9908
The 519 Church Street Community Centre	Heather Bain, Coordinator, Community Development Services, 50+ LGBT	hbain@the519.org 416.355.6787
Rainbow Health Ontario	Devan Nambiar, Education and Training Coordinator	dnambiar@rainbowhealthontario.ca 416.324.4100
ARC: Aines et retraites de la communaute, Montreal	Gilbert Ouellet, Executive Director	

Project Changement, Montreal	Jean Ouellet, Director General	aines@projetchangement.com
Manuel Mendo, Photographie- realization, Montreal	Manuel Mendo, auteur et realisateur du projet "Dis papo, dis mamie, raconte-moi ta vie gai[e]"	Mendo@azul-fr.com
Aide aux trans du Quebec, Montreal	Mathieu-Joel Gervais, Membre du Consueil d'administration	
prideHealth, Halifax	Graeme Kohler, Manager, Primary Health Care, Capital Health	prideHealth@cdha.nshealth.ca
Nova Scotia Rainbow Action Project	Chris Aucoin, Administrative Coordinator	nsrap@nsrap.ca , (902) 444-3206
Nova Scotia Centre on Aging	Janice Keefe, Director	janice.keefe@msvu.ca 902.457.6546

Nova Scotia	Valerie White,	902.424.0065
Department of	Chief Executive	
Seniors	Officer	
Fada Research	Aine Humble,	fadaconsulting@gmail.com
Consulting	President	902-448-1663
North American	Ryan Woolrych,	rwoolry@sfu.ca
Chapter of	Secretary	
International		
Society for		
Gerontechnology		

Appendix 5: Recruitment Poster (Halifax)



Flyer/Poster/Ad Text

LGBT Persons Ages 60 and Older Sought for Research Study

Researchers at Dalhousie University and Mount Saint Vincent University, in conjunction with community partners in Halifax and academic centres and their partners in Edmonton, Toronto, Montreal, and Vancouver, are conducting a study to examine the ways in which LGBT older adults are looking ahead and preparing for later life and end-of-life.

The '*Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*' Project is seeking participants who:

- Self-identify as Lesbian, Gay, Bisexual, and/or Transgender
- Are at least 60 years of age
- Are fluent in English
- Have some email experience
- Of special interest are people coping with or caring for persons with two or more chronic conditions (e.g. impaired hearing or vision, arthritis, diabetes, osteoporosis, high blood pressure, dementia, HIV/AIDS)

The study involves sharing your experiences and opinions in a 2-hour focus group. A \$25 gift card will be offered as a thank you for your participation.

If you are interested in participating or want to get more information, please contact Kirk Furlotte at 902-494-6620 or Sarah Paterson at LGBT-end-of-life-study@msvu.ca

Jacqueline Gahagan, PhD	Áine Humble, PhD
Professor and Head of Health Promotion, Faculty of Health Professions Dalhousie University	Associate Professor, Chair, Family Studies and Gerontology Mount Saint Vincent University
Jacqueline.Gahagan@dal.ca	Aine.Humble@msvu.ca
(902) 494-1155	(902) 457-6109

Funded by TVN, supported by the Government of Canada through the Networks of Centres of Excellence (NCD) program.

Appendix 6: Invitation to Participate

Information Sheet/Invitation for Service Providers/Agency Representatives to Participate in “*Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults.*”

The project titled “*Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults*” is a one year study being conducted by Dalhousie University and Mount Saint Vincent University in conjunction with colleagues from Simon Fraser University, University of Alberta, University of Waterloo, and University of Quebec at Montreal, as well as community groups in all these cities.

This project is funded by the Technology Evaluation in the Elderly (TVN) National Centre of Excellence in support of two primary goals: 1) to understand the barriers to preparing for later life and end-of-life among LGBT older adults; 2) to explore the role that internet-based technology can play in helping LGBT older adults in making informed decisions and taking appropriate action. We will do this by hosting focus groups and town-hall meetings across the country and by setting up a test-website at SFU.

Currently, we are seeking people from groups or agencies that are involved with end-of-life care and the LGBT community, for example hospice, LGBT community groups, and public health care sectors. Participants should provide services to self-

identified LGBT individuals aged 60 or over who are living with or are caring for an LGBT friend or family member aged 60 or older with two or more chronic conditions. We invite you to join with 8-10 other service providers to participate in a focus group that will take about 2 hours of your time. The focus group will be held in [insert city] in an easy-to-get to location [insert place].

If you are interested in participating in this important national study, email [insert site secure e-mail address] or leave your telephone number at [insert phone number]. A member of our research staff will call you, go over details of the study and answer any questions you may have. In this early telephone conversation, you will be asked about the proportion of your clientele who identify as LGBT and the type of diseases with which they typically present. The exact date and time of the focus group will be decided after the group is formed so as to be convenient for the participants.

On the day of the focus group, before it starts, if you have not signed the attached consent form you will be asked to do. You will also be asked some basic demographic questions (e.g. your experience in working with older LGBT persons around end-of-life issues, your appraisal of their preparedness as well as barriers and supports of the same, as well as the role of the LGBT community in general in this area). The conversation will be audio-recorded and later transcribed for analysis – *agreement to be audio-recorded is required for this study*. Please know that your participation in this study is completely voluntary. You are free to withdraw or discontinue your participation at any time. If you

are uncomfortable with any of the questions asked, you do not have to respond. If you decide not to participate or discontinue your participation, please know that it will not affect your relationship with your organization or any organization associated with this project.

While there are no direct and immediate benefits to you personally for participating in the study, doing so gives you the opportunity to provide feedback and direction for the development and refinement of tools and approaches to late life and end-of-life that might make it better for LGBT persons. We hope that you will take this opportunity.

Again, please be assured your privacy will be respected. Your name, identity and anything we discuss will be held in strict confidence and we ask all focus group participants to respect the same agreement.

Confidentiality will be maintained in the following ways: your contact information will not be known to anyone except the person who schedules you for the focus group; when that person first makes contact with you, you will be asked to choose a Personal Identity Number (PIN) or pseudonym; that PIN or pseudonym will be your ID for the rest of the project. Your name will not be used in the focus group, or appear on any forms or reports. While reports may contain quotes from the focus groups or other parts of the study, all identifying information will be removed.

All computer files will be password protected, and access to study files will be restricted within the limits permitted by law.

A summary of the results of the study will be available for interested participants.

If you have any questions, or if you require more information about this project, please contact the Local Co-Investigators, Dr. Jacqueline Gahagan (at [contact information]) or Dr. Áine Humble (at [contact information]).

If you want to speak to someone uninvolved with the study, or talk about concerns regarding the study, please contact either Catherine Connors, Director of Research Ethics, Research Services, Dalhousie University at (902) 494-1462 or by e-mail at Catherine.connors@dal.ca or the chair of the Mount Saint Vincent University's Research Ethics Board c/o MSVU Research and International Office, at 902-457-6350 or by e-mail at research@msvu.ca.

Thank you in advance for your time and kind consideration.

Appendix 7: Informed Consent Form (Halifax)



Informed Consent Form for LGBT Participants
“Fostering End-of-Life Conversations, Community
and Care Among LGBT Older Adults”

<u>Local Investigators</u>	
Jacqueline Gahagan, PhD Professor and Head of Health Promotion, Faculty of Health Professions Dalhousie University Jacqueline.Gahagan@dal.ca (902) 494-1155	Áine Humble, PhD Associate Professor, Chair, Family Studies and Gerontology Mount Saint Vincent University Aine.Humble@msvu.ca (902) 457-6109

Principal Investigators

Dr. Brian de Vries, PhD
Simon Fraser University (SFU)
SFU Gerontology Research Centre &
Department of Gerontology
Email: dbrian@sfu.ca

Dr Gloria Gutman, PhD
Simon Fraser University (SFU)
SFU Gerontology Research Centre &
Department of Gerontology
email: Gutman@sfu.ca

Co-Investigators

Co-Investigator and Department Affiliation	Co-Investigator Institution	Co-Investigator Email
Janet Fast, Professor of Human Ecology	University of Alberta	jfast@ualberta.ca
Steven Mock, Assistant Professor, Recreation and Leisure Studies	University of Waterloo	Smock@uwaterloo.ca
Line Chamberland, Titulaire de la Chaire de recherché sur l'homophobie	University of Quebec, Montreal	Chamberland.line@uqam.ca

Description:

You are invited to take part in a project that seeks to gain a better understanding of the ways in which older LGBT persons prepare for later life and end-of-life, seek and consider care, engage networks of support, and the role that internet technology can play in supporting these activities. This project is conducted by researchers from Simon Fraser University, University of Alberta, University of Waterloo, University of Quebec at Montreal, Dalhousie University, and Mount Saint Vincent University, in partnership with community groups in these locations. This project is funded by Technology Evaluation in the Elderly Network.

As part of our project activities, we are seeking self-identified Lesbian, Gay, Bisexual, and/or Transgender (LGBT) persons, 60 years or older who are living with or caring for a person with a chronic health condition(s), and who have some email experience and access to voluntarily participate in a focus group.

Each focus group will aim to have between 7 and 10 participants and each research site will have four different types of focus groups (meaning our research study will have between 140 and 200 participants).

The focus group will take about two hours. A gift card of \$25.00 will be offered in gratitude for your participation in this study.

I understand the following:

1) Procedure:

I will participate in a focus group (approximately 2 hours) addressing issues about later life and end-of-life preparation. My participation is completely voluntary. I may refuse to answer any questions I am not comfortable answering. I can withdraw from the study at any time and any personal information I have provided (such as my participant profile) but excluding any audio recordings (*which would be de-identified*) will not be included in the final study. Withdrawal will not affect any of my personal services nor my relationship with any organization which is connected to this project.

My participation in the focus group will be audio recorded and later transcribed for analysis. My name will not be used in the focus group, or appear on any forms or reports. While reports may contain quotes from the focus groups or other parts of the study, all identifying information will be removed.

2) Privacy:

I will choose a number or pseudonym to be used during the project. All participants in

the focus groups will be asked to treat the discussions as confidential and respect the sensitivity of what others say. Data will be pooled for any reports that come out of this research and will not identify any individual participant by anything other than their pseudonym, location and focus group.

My privacy will be respected. Local data will be kept in a locked cabinet at Dalhousie University or Mount Saint Vincent University, while the researchers work with the information. The hard copies of these data will be destroyed two years after the project's completion.

Focus group interviews will also be sent outside Dalhousie University and Mount Saint Vincent University to the other members of the research team for transcription and/or analysis.

I will sign two copies of a consent form given to me: one copy is my own and the other is to be kept by the coordinator of this project. The consent forms will be kept separate from the project data, in a different secure area at Dalhousie University or Mount Saint Vincent University, and will also be destroyed within two years of the project's completion.

I understand that if I disclose that I have abused or neglected a child (or vulnerable adult), the members of the research team are required by law to report this information to the authorities. The research team member will make a report with the appropriate authorities and inform the Local and Principal Investigators of their actions.

3) Risks:

While there are no major risks to participants in this project, I understand that there may be some discomfort in thinking and/or talking about end-of-life issues. I understand that my participation is completely voluntary and that I may decline to answer specific questions, or withdraw from the study at any time.

4) Benefits and Outcomes:

Participation in this project is intended to provide information and direction to better assist researchers, community organizations and older individuals to understand and prepare for end-of-life within the LGBT communities. My participation in this survey

will make an important contribution to the “Fostering End-of-Life Conversation” project. I understand that I will receive a \$25.00 gift certificate in recognition of my participation in this project.

The results from this study may be published in journals and graduate theses, reported at conferences, used in web pages or brochures related to this topic, and discussed at a town hall meeting. Information from my contribution to the focus group, which has been removed of identifiers, may be used in this information dissemination.

5) Questions:

I may ask the project staff any questions that I have about the project. I am welcome to contact the Local Investigators, Drs. Gahagan and Humble, with any questions or concerns that I have about the project (using the contact information above).

If I want to speak to someone uninvolved with the study, or talk about concerns regarding the study, I can contact either Catherine Connors, Director of Research Ethics, Research Services, Dalhousie University at (902) 494-1462 or by e-mail at Catherine.connors@dal.ca, or the Chair of the Mount Saint Vincent University’s Research Ethics Board c/o MSVU Research and International Office, at (902) 457-6350 or by e-mail at research@msvu.ca.

My signature indicates my agreement and consent to be involved in this project.

Name: _____ (print)

Signature: _____

Date: _____

(yyyy/dd/mm)

Project Staff's Name: _____ (print)

Project Staff's signature: _____

Date: _____

(yyyy/dd/mm)

MSVU, Halifax Nova Scotia B3M 2J6 Canada

Tel 902 457 6321 • Fax 902 457 6314

msvu.ca

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Appendix 8: Dalhousie Letter of Approval for Original Study

REB # 2014-3290 Letter of Approval

sharon.gomes@dal.ca

7 July 2014 12:04

To: "Dr Jacqueline Gahagan (Primary Investigator)" <jgahagan@dal.ca>

Cc: Kirk.furlotte@dal.ca, sharon.gomes@dal.ca

Health Sciences Research Ethics Board
Letter of Approval

July 07, 2014



Dr Jacqueline Gahagan
Health Professions\Health & Human Performance

Dear Jacqueline,

REB #: 2014-3290
Project Title: Fostering End-of-Life Conversations , Community and Care Among LGBT Older Adults

Effective Date: July 07, 2014
Expiry Date: July 07, 2015

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Brenda Beagan, Chair

Appendix 9: Dalhousie University Research Ethics Board Approval



Health Sciences Research Ethics Board Letter of Approval

December 21, 2017

Kirk Furlotte
Health\Health & Human Performance

Dear Kirk,

REB #: 2017-4335

Project Title: Exploring the End-of-Life Care Expectations and Experiences of Older Gay, Bisexual, and other Men who have sex with Men

Effective Date: December 21, 2017

Expiry Date: December 21, 2018

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Tannis Jurgens, Chair

Appendix 10: Participants' Personal Characteristics

Demographics

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
<i>Average age</i>	68	78	68	72	70	70
65 or younger	7		3	1	3	14
66 to 70	4	1		1	2	8
71 to 75	3	1	3	3	1	11
76 to 80	1	1		1	1	4
81 to 85		1			1	2
86 and older		1				1
Gay	14	5	6	6	8	39
Other	1					1

Which of the following best describes your current primary relationship status?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Single	10	4	3	4	3	24
Legally Married (Male)	3	1	1	1		6
Legally Married (Woman)	1					1
Domestic Partnership (Male)				1	1	2
Domestic Partnership (Female)						0
Relationship (Male)	1		1		2	4
Relationship (Female)						0
Boyfriend			1		1	2
Girlfriend						0

* 1 participant did not complete participant profile

If you answered "single" above, please respond to which of the following is most accurate?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Never partnered		1			1	2
Partners of short duration	2	1	2	1		6
Separated	1		1			2

Divorced	1	1			1	3
Widowed	2	1		3	1	7
Other	4					4

Do you have any children?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Yes	3	2	1	1	2	9
No	12	3	5	5	5	30

Which of the following describes your current living arrangement?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Live alone	11	5	4	1	4	25
Live w spouse/partner only	3		1	2	2	8
Live w spouse/partner and/or other family members Other	1		1			2
Living with Friends					1	1
Other						0

Current Work Status:

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Self-employed		1	1		2	4
Regular salaried-wage employee	2					2
Casual wage employee	2				2	4
Domestic duties					2	2
Retired	11	4	5	6	6	32
Not employed	1					1

What was your highest level of education?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
8th grade or less		1				1
Some high school						0
High school graduation	3			1		4
Technical or trade school	1		1			2

Some college/university	5	1	1	3	1	11
Bachelor's degree	3		1	1	2	7
Graduate degree	4	3	3	1	4	15
						0

To what extent, if any, are you "out" to the following people? Please place an "X" in the corresponding space.

		Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Parents	"Not at all" or "A little"	2			2		4
	Somewhat			1	1		2
	"Mostly" or "Completely"	5		3	3	3	14
	"Not sure" or "Not applicable" or not answered	8	5	2		5	20
Siblings	"Not at all" or "A little"	1	1		2		4
	Somewhat						0
	"Mostly" or "Completely"	12	2	4	1	6	25
	"Not sure" or "Not applicable" or not answered	2	2	2	3	2	11
Children	"Not at all" or "A little"						0
	Somewhat						0
	"Mostly" or "Completely"	3	1	1		4	9
	"Not sure" or "Not applicable" or not answered	12	4	5	6	4	31
Close friends	"Not at all" or "A little"						0
	Somewhat						0
	"Mostly" or "Completely"	14	5	6	4	7	36
	"Not sure" or "Not applicable" or not answered	1			2	1	4
Acquaintances	"Not at all" or "A little"			1	1		2
	Somewhat	1		2			3
	"Mostly" or "Completely"	13	5	2	5	7	32
	"Not sure" or "Not applicable" or not answered	1		1		1	3
People	"Not at all" or "A little"				1	1	2
	Somewhat				1	1	2

	"Mostly" or "Completely"	9		3	4	2	18
	"Not sure" or "Not applicable" or not answered	6	5	3		4	18
Health care	"Not at all" or "A little"				2		2
	Somewhat				1		1
	"Mostly" or "Completely"	15	2	6	3	7	33
	"Not sure" or "Not applicable" or not answered		3			1	4

Who is likely to be your primary caregiver when the need arises?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner/Spouse/significant other	4		1	2	3	10
Friend	4	2	1	2	1	10
Parent						0
Sibling			1			1
Adult child			1			1
Other biological relative	1	1				2
Neighbor						0
Paid in-home caregiver		1	1			2
Volunteer caregivers from a community organization or faith community						0
Other						0
Not sure	11	1	1		3	16
N/A or No answer	1			2	1	4

Have you completed any of the following?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Will	11	4	6	4	6	31
Living Will	5	4	5	3	3	20
Power of Attorney	6	4	4	4	3	21
Personal Directive	1	1	1	2		5
Pre-Paid Funeral	4	2	3	3	2	14
Long-Term Care Insurance	2				1	3
Critical Care Insurance	2				1	3

Informal Caregiving Arrangements	6	3	2	1	1	13
Not sure	2			1		3

With whom have you had explicit discussions about caring for you should/when the need arise?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner	4		1	2	4	11
Parent	0				1	1
Adult Child	1		1	1	1	4
Sibling	7	1	3	2	1	14
Other biological relative	1	1	2	2		6
Close Friend	7	2	4	3	3	19
Neighbor	1					1
Primary care doctor	3	1	2	1	1	8
Counselor/therapist	2		1			3
Other health care professional	1					1
Spiritual/Religious advisor or clergy	0	1	1		1	3
Legal or financial professional	1	1	3		2	7
No one	5	1		1	2	9
Other			1			1
Not applicable						0

With whom have you had explicit discussions about end-of-life care and treatment preferences?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner	3		2	2	4	11
Parent	0					0
Adult Child	1		1	1	1	4
Sibling	5	1	1	1		8
Other biological relative	1	1	1	2		5
Close Friend	8	2	4	2	2	18
Neighbor	0					0
Primary care doctor	3	1	1	1	1	7
Counselor/therapist	0		1			1

Other health care professional	0					0
Spiritual/Religious advisor or clergy	0				1	1
Legal or financial professional	2	1	2		2	7
No one	6	1	1	2	2	12
Other	0		1			1
Not applicable						0

When you think of a recent time when you were feeling down and wanted to talk with someone, on whom did you rely?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner	4		2	1	2	9
Parent	0					0
Adult Child	0		1	1		2
Sibling	4	1	1		1	7
Other biological relative	0					0
Close Friend	13	4	5	5	4	31
Neighbor	3	1				4
Primary care doctor	7	1	3	1		12
Counselor/therapist	6		1			7
Other health care professional	1					1
Spiritual/Religious advisor or clergy	0	1	1		1	3
Legal or financial professional	0	1	1			2
No one	0		1		1	2
Other	0				1	1
Not applicable	0	1		1		2

When you think of a recent time (e.g., past six months) when you needed advice on a personal matter, on whom did you rely?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner	4		2	1	2	9
Parent	1					1
Adult Child	0		1	1		2
Sibling	4	1	2			7

Other biological relative	1	1				2
Close Friend	14	4	5	5	2	30
Neighbor	2	1	1			4
Primary care doctor	7	1	1			9
Counselor/therapist	3		1			4
Other health care professional	2					2
Spiritual/Religious advisor or clergy	0	1				1
Legal or financial professional	2	1	1		1	5
No one	1				2	3
Other	0	1	1		1	3
Not applicable	0			1	1	2

When you think of a recent time when you were ill and needed some care, on whom did you rely?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Partner	3		1	2	1	7
Parent	0					0
Adult Child	0		1	1		2
Sibling	1	1				2
Other biological relative	1					1
Close Friend	9	4	3	2	1	19
Neighbor	4			1		5
Primary care doctor	1		2			3
Counselor/therapist	0					0
Other health care professional	1			1		2
Spiritual/Religious advisor or clergy	0	1				1
Legal or financial professional	0					0
No one	3		1		2	6
Other	0				1	1
Not applicable	3	1	1	3	3	11

How many close friends do you have?

Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
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Average

6	5	4	5	4	6
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Do you have a chosen family?

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
Yes	13	3	4	2	3	25
No	2	2	1	4	4	13
N/A or No answer			1		1	2

(Prominent) Health Conditions

	Vancouver (15)	Edmonton (5)	Toronto (6)	Montreal (6)	Halifax (8)	Total
High blood pressure	9	5	1	5	2	22
High cholesterol	5	2	6	4	2	19
Arthritis	8	1	3	2	1	15
Cataract(s)	7	4		2	1	14
Challenges seeing	2	3	2	2		9
Challenges hearing	5	2	1		1	9
Depression	6		3	1		10
Anxiety	9		3			12
HIV	2		2		2	6
Diabetes	2	2	2	2	1	9