

Mount Saint Vincent University
Department of Family Studies and Gerontology

**End-of-Life Preparation and the Role of Online Technology:
A Comparison of Older Gay Men and Lesbians**

by
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Abstract

End-of-life literature reflects the social determinants, resources, and services that can influence how one experiences EOL and the ways in which to prepare. However, what is currently missing from the available literature is how sexual orientation can influence the ways in which individuals think about or prepare for EOL. If experiences of lesbians and gay men (LG) are mentioned within the literature it is often as a comparison to their heterosexual counterparts, and the experiences of older LG individuals are even less documented. This portrays the LG population as a homogenous group and overlooks the potential for diversity within this minority population. This qualitative study aims to bridge that gap by exploring the similarities and differences between older lesbians and gay men in the way they think about and prepare for EOL, as well as the role that online technology plays in these preparations.

A secondary data analysis of a subset of the “Fostering EOL Conversations, Community, and Care among LGBT Older Adults” research project was conducted, guided by minority stress theory and intersectionality. A content analysis of lesbian and gay men’s focus group interviews from British Columbia, Alberta, Ontario, and Nova Scotia was performed, assisted by the use of MAXQDA software for data management.

Three main themes emerged from the analysis: (a) ways in which the men and women prepared for EOL, (b) concerns they had about aspects of EOL preparation, and (c) the role that online technology played in keeping LG older adults connected. More similarities than differences were found between the men and women. The areas where variation occurred were the configuration of social networks, openness to new relationships in later life, motivations for putting EOL documentation in place, and

confidence in online technology abilities. These differences highlight the importance of looking deeper into the intersections of the older LG population.

The diversity recognised within this population also leads to a number of policy and practice implications, including a reconfiguration of policies that uphold the prioritization of blood and marriage ties over LG networks in legal and health care environments, long term care reform to redefine what is considered appropriate residential placement for older LG adults, and working towards a national approach to EOL documentation terminology.

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Chapter 1: Introduction

Our denial of death marries into what I call the “Peter Pan Syndrome”. We might age and we don’t want to think about this, instead of being practical and planning for it. People are scared of death, “It’s not going to happen to me.” (Cartwright, Hughes, & Lienert, 2012, p. 543)

Today’s dominant culture upholds youth, vitality, and beauty, which are attributes not readily associated with old age and the dying process (DeLamater, 2012). Even though there are ways to prepare for the end of life (EOL) and many agree that it is beneficial to start thinking about it while still healthy, this is often an experience that is overlooked and relegated to the margins of conversation (Canadian Hospice Palliative Care Association, 2015).

EOL literature reflects the social determinants, resources, and services that can influence how one experiences EOL and the ways in which to prepare. What is poorly documented in this literature is an understanding of the barriers, concerns, and preparations, including the role that Internet technology plays, of older lesbians and older gay men (LG), with regard to EOL preparation. These aspects may be different from those of the general population due to different life circumstances for aging LG individuals. However, if such experiences are acknowledged within the literature, it is often as a comparison to their heterosexual counterparts. This portrays LG individuals as a homogeneous subset of the population. Just as the diversity between experiences of EOL for older heterosexual men and older heterosexual women are well documented, so should any diversity between older gay men and older lesbians be documented.

For LG individuals who grew up in a heavily stigmatized and oppressive

environment, aging in a society that is radically more supportive of the LG community provides the opportunity for them to not only embrace their sexuality but also feel empowered by it (Mehra, Merkel, & Bishop, 2004). One domain in particular that can encourage this enlightenment is the use of online technology (Mehra et al., 2004). The influence that an online presence can have on ameliorating the stress of older LG adults through the ability to access services, resources, and social support with regard to the EOL has yet to be explored.

This study aimed to bridge this gap in the literature by providing an in-depth analysis of the similarities and differences between older lesbians and gay men in how they think about and prepare for EOL, as well as investigating the role online technology could play in these preparations in a Canadian context. The literature review is preceded by a description of the theoretical framework and followed by the methodology, findings, and discussion sections. The methodology for this study was guided by a social constructivist/interpretivist research paradigm, and informed by both intersectionality theory and minority stress theory. Secondary data analysis of qualitative data from the research project “Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults” was conducted.

Chapter 2: Theoretical Framework

This study was informed by a combination of minority stress theory and intersectionality theory. The rationale for using both theories was to provide a framework that took into account not only the impact that being part of a minority group could have on a person's wellbeing and life experience, but also the intersections that could occur within the dynamics of oppression and discrimination. This framework acknowledged the complexities of oppression and how it can be experienced differently within the same minority group.

Minority Stress Theory

Minority stress theory sheds light upon the effects that stigmatization and marginalization can have on minority populations (Meyer, 2003). Minority stress derives from the clash between minority populations and the values and beliefs of the dominant culture and the adverse effects that can occur when the two are incompatible (Meyer, 1995). LG individuals experience minority stress in part due to homophobic and/or heterosexist attitudes within society. Homophobia refers to the irrational fear and hatred of lesbian, gay, bisexual, and transgender individuals based solely on their sexual orientation (Addis, Davies, Greene, MacBride-Stewart, & Shepherd, 2009). Heterosexism is defined as "the assumption that all individuals are heterosexual and heterosexuality is more natural or normal than same sex sexuality" (Addis et al., 2009, p. 653).

Minority stress theory discusses stress processes that can ultimately lead to poor health outcomes (Meyer, 2003). The theory breaks these sources down into distal stressors and proximal stressors (Meyer, 2003). Distal stressors are the external sources of stress that one can be exposed to within their environment such as exposure to

discrimination (Meyer, 2003). Proximal stressors are internal sources of stress such as the anticipation or fear of discrimination (Meyer, 2003). Minority stress factors that pertain specifically to older LG adults consist of both distal and proximal sources of stress including external objective stressful events, expectations of those events, internalized homo-negativity and the hiding of one's LG identity (Meyer, 1995, 2003). External objective stressful events, classified as distal stressors, include negative attitudes towards their identity and sexual orientation, victimization, and discrimination (Meyer, 1995). As will be described further in the review of literature, some older LG adults are members of a cohort that grew up in the pre-liberation era. The pre-liberation era for LG individuals was signified by a lack of protection by law when homosexuality was considered to be a mental illness, and LG individuals were considered to be sexual deviants and criminals (Conger, 1975; Kuyper & Fokkema, 2010). This lack of protection resulted in exposure to many stressful events at the expense of their sexual orientation, a significant contributing factor to minority stress (Brotman, Ryan, & Cormier, 2003). Even with the changing climate of acceptance, these older adults may still find themselves in environments with peers who have maintained these negative views about homosexuality (Kuyper & Fokkema, 2010)

For older LG adults, knowing that these negative views still exist within society leads to the next contributing proximal factor of minority stress, the expectation of negative events (Meyer, 2003). Growing up in an atmosphere of intolerance for their sexuality prompts many LG individuals to live in anticipation of negative events or reactions from their heterosexual peers (Meyer, 2003). Having to remain vigil and be on guard at all times can put additional stress on these individuals (Meyer, 2003).

Internalized homophobia, another example of a proximal stress process, is described as negative attitudes felt by an LG individual towards homosexuality in others or themselves (Meyer, 2003). A negative correlation between age and internalized homophobia has been found within a number of American studies (Grossman, D'Augelli, & O'Connell, 2001; Otis & Skinner, 1996). This may be attributed again to the unique experiences of the pre-liberation cohorts that have reached older adulthood (Butler, 2004). Early socialization experiences can have a large impact on the development of one's identity (Meyer, 2003). Individuals growing up with significant exposure to anti-gay attitudes during their preliminary years may have allowed these views to infiltrate their perceptions of themselves resulting in internalized homophobia (Grossman et al., 2001). A correlation has been found between age and negative self-perception, showing the older the individual is, the more likely it is for them to hold a negative view toward their own sexual orientation, making internalized homophobia a very pertinent minority stress factor for this aging population (Grossman et al., 2001; Otis & Skinner, 1996).

When taking these three factors into account, it is no surprise that another proximal contributor to minority stress would be the attempt to conceal or hide one's true identity in order to avoid stigmatization and discrimination (Butler, 2004). For some, the solution to avoid negative reactions, attitudes, and events is not to disclose their sexual orientation at all (Butler, 2004). This may eliminate a degree of stress; however, not being able to express their true identity may create an alternative source of stress. This is an example of how proximal stressors can be by-products of distal stressors, as individuals begin to experience internal stress as a result of external stress (Meyer, 2003).

Intersectionality Theory

Given that this study was not looking at the EOL experiences of older LG adults as a group, but was rather comparing the experiences of lesbians and gay men, using intersectionality theory avoided a one-dimensional identity-based analysis (Hillsburg, 2013). From this perspective, oppression is not additive, it is not from single distinct factors that can be layered that will create an understanding of how one will experience oppression (Hankivsky, 2014). Instead, oppression is the result of an interaction of one's social location, power relations, and experiences (Hankivsky, 2014). This means that two people in the same minority group may experience oppression in different ways. Intersectionality allows for a closer look at the differences that may exist within minority groups instead of just between them and other groups (Hillsburg, 2013).

To intersectionality theorists, oppression is not fixed and instead can vary depending on many factors, including time and place (Hillsburg, 2013). For older LG adults, the concept of time can be a significant factor on how oppression is experienced. Within the field of gerontology, it is important to identify exactly what age group is being referred to when they speak of older adults. Common practice is that "young-old" refers to persons between the ages of 50 and 64 years. "Old" refers to those from 65-74 years of age, and "old-old" refers to those over 75 (Cronin & King, 2010). This is particularly important when trying to understand the experiences of older LG adults, as is described by Rosenfeld's construction of cohorts. According to Rosenfeld (2002) the old-old group reached adulthood prior to the Gay Liberation movement, but the young-old and the old groups reached adulthood during the movement or after it. In terms of constructing self-image, those born post-liberation era may have a significantly more positive sense of self entering old age as opposed to those born pre-liberation era, when society was

significantly less accepting of LG individuals (Butler, 2004).

Current literature referring to LG individuals has shifted away from using terms such as “the gay community” in order to shed light on the fact that this is not a homogenous population and to acknowledge that the experiences of lesbians also merit attention (Cronin & King, 2010). Instead identity-based acronyms are now used in areas such as policy development, to acknowledge the diversity within this population (Cronin & King, 2010). However, whether the use of the acronym and its intended goals have transcended beyond policy into the field of research is debatable. Research currently focuses more on the differences that exist between LG individuals and their heterosexual counterparts, as opposed to the differences that lie within the LG population (Cronin & King, 2010).

With that in mind, more attention must be paid to the multiple different realities within one minority group. It is also important to note that some individuals within a minority group may lack power in some areas and yet hold power in others (Hankivsky et al., 2012). For example, within the older LG population approaching the EOL, both gay males and lesbian females may experience ageism or heteronormativity. From a gender perspective however, gay men may have more power in society over lesbians. In other words, both gay men and lesbians may identify with the same minority group, but this does not mean that they share the same intersections of oppression. Due to the fact that this analysis will include a gender comparison within the older LG adult population, the categories that will be included in this intersectionality framework are sexuality, gender, and age. This will allow for an analysis of difference and will help to uncover intersections of disempowerment and/or empowerment between older gay men and older

lesbians with regard to EOL preparation.

As policymakers, decision makers, and activists begin to be more cognizant and inclusive of the needs of older LG adults, it becomes more important to have an accurate understanding of the diversity of experience within the older LG population. An oversimplification of the experiences of this population in research will translate into an oversimplification of the ways in which their needs are met within societal institutions and service provision.

Together, minority stress and intersectionality allow for an informed theoretical framework, which accounts for the wider dynamics of power that may oppress older LG adults, while simultaneously uncovering fine grained intersections of oppression to provide a greater understanding of the complexities of this population.

Chapter 3: Literature Review

This chapter takes an in-depth look at the available literature pertaining to general EOL, the experience of aging for LG individuals and older LG adults at the EOL. This review will emphasize a gap in knowledge regarding the similarities and differences between older gay men and older lesbians and how they think about, partake in, and use online technology with regard to EOL preparation.

End of Life

For a comprehensive understanding of EOL experiences and preparations for gay men and lesbians, a foundation of general knowledge about the EOL is necessary. The following sections discuss how society currently perceives and values the dying experience, how preparations are made leading up to or during this experience, the treatments and care options available for individuals preparing for EOL, the barriers to accessing this care, and the role that gender plays in how EOL is experienced.

Experience of dying. The concept of EOL and how it is prepared for and addressed, is influenced by the meaning and reception of the experience of death within society (Barry & Yuill, 2011). Modern society tends to be in denial of death by silencing or avoiding discussions, resulting in a taboo surrounding the topic (Barry & Yuill, 2011). Over time there has been a shift from death being seen as an inevitable experience to an experience that can be tamed and controlled (Barry & Yuill, 2011).

In the 18th century death was romanticized as being almost a beautiful experience, but an experience bathed in pathos and ideas of personal tragedy (Barry & Yuill, 2011). The main historical change was the move from public recognition of the dead and the dying to a privatised and hidden death (Kellehear, 2007). Death has now become an event

to be shunned or avoided and consequently relegated to the margins of conversation (Kellehear, 2007).

The avoidance of death is bolstered by the current medicalization of the dying experience, which strives for a prolongation of life (Moeller, Lewis, & Werth, 2009). Compared to 50 years ago, individuals are living longer but are still dying from the same top three leading causes of death, which are cancer, cerebrovascular disease (stroke), and heart disease (Moeller et al., 2009). Prolongation of life also alters the location in which death occurs, and when discussing EOL care this has a large impact on how death is experienced (Moeller et al., 2009). Despite the majority of people dying in institutional care settings, there is still a preference for dying at home (Hays, Galanos, Palmer, McQuoid, & Fint, 2001).

For people living in contemporary high income nations, the combination of a consumerist culture and a death denying culture results in values of youth, beauty, and vitality (Barry & Yuill, 2011), further devaluing the aging process and the acceptance of dying. The prolongation of life has also created a time and space for individuals to reflect on their lives and prepare for death, however now that death is less likely to be an unexpected swift event, making plans early on in life and preparing for the unexpected has lost its imminence (Barry & Yuill, 2011).

Preparation for end of life. EOL preparation is often assumed to only refer to medical precautions, however preparation for EOL can include discussions and decision making in a number of different facets, such as psychosocial, spiritual, legal, existential, or practical matters (Orel, 2004).

The majority of Canadians reach the point of death while receiving care from

health professionals, and a large proportion of these persons are deemed incapable of providing consent to make their own decisions near time of death (Canadian Hospice Palliative Care Association, 2012). Unfortunately it is near time of death that some of the most complex decisions come to light. Eight in ten Canadians agree that people should start planning for EOL when they are healthy (Canadian Hospice Palliative Care Association, 2012), however only 30% of Canadians have taken the appropriate steps to put EOL documents in place (Canadian Hospice Palliative Care Association, 2012).

Medical preparations for EOL can include anything from completing formal legal documents to having a discussion with loved ones or health professionals about care preferences. *Advance Care Planning* is the term used to describe the conversation or process one goes through to make their care preferences known for times of incapacity (Canadian Hospice Palliative Care Association, 2015). An *Advance Care Plan*, also referred to as a *living will*, is made up of a number of documents that differ according to provincial jurisdiction. The name and layout of the documents may change but within each Advance Care Plan, the creator will be prompted to create an advance care directive and assign a substitute decision maker (Canadian Hospice Palliative Care Association, 2015).

The advance directive is a document that sets out the detailed instructions, expressions, values, beliefs, and goals of care in preparation for the EOL (Wahl, Dykeman, & Gray, 2014). This document acts as a guideline for the care recipient's medical team or substitute decision maker (Wahl et al., 2014). A substitute decision maker is a third party identified by the care recipient to participate in the medical decision making process on their behalf in times of incapacity (Canadian Hospice

Palliative Care Association, 2015). If no substitute decision maker is identified by the care recipient, a temporary substitute decision maker is identified from a set list by law of potential representatives that the medical team can contact for assistance in time of need (Canadian Hospice Palliative Care Association, 2015).

A durable power of attorney for healthcare is the equivalent of an advanced directive where substitute decision maker is appointed (Irving, 2015). Depending on the province a substitute decision maker may also be referred to as an “agent”, “attorney of personal care”, “representative”, “delegate”, or “healthcare proxy” (Irving, 2015). These terms all refer to the individual who oversees the medical decision making on behalf of someone else in times of incapacity (Irving, 2015). A separate document is needed to appoint someone to be in charge of finance and property in times of incapacity, referred to in Canada as a durable power of attorney for finances (Irving, 2015). Having a conversation with these representatives about particular preferences on how affairs should be handled is important in order to eliminate uncertainty after the time of death. The more preparations that are made prior to the EOL, the less likely that family and friends will feel burdened by difficult decision making and the more likely the care recipient will have their wishes met (Detering, Hancock, Reade, & Silvester, 2010).

Concern about being a burden on loved ones can be a source of stress for care recipients even before the first signs of dependence. Some care recipients navigate their way through the EOL actively trying to alleviate this burden. This can include eliminating the uncertainty and financial stress of funeral arrangements (Canadian Virtual Hospice, 2015). Even for the most basic funerals, finances can add up quickly. To avoid loading this expense onto family after the time of death, funeral prearrangement is a

viable option. Prearranging a funeral is also recommended for those who have specific preferences of what they would like their funeral service to entail, who should be involved, and where it should be held (Canadian Virtual Hospice, 2015). It is important to leave these instructions with loved ones or to provide the funeral director with a copy of the document for safekeeping (Canadian Virtual Hospice, 2015).

After the death of a loved one, family members and friends must obtain a death certificate to be able to discuss benefits or assets (Canadian Virtual Hospice, 2015).

Death certificates can be ordered at the funeral home and the cost varies across Canada (Canadian Virtual Hospice, 2015). The specific information required to create a death certificate also varies by geographic location, and all of these details should be in place prior to the time of death to avoid complications when addressing financial and legal affairs (Canadian Virtual Hospice, 2015).

Preparations can eliminate confusion, complication, sadness, and guilt for both the care recipient and the caregivers when approaching or experiencing the EOL. One decision that can be difficult to make regardless of the preparations in place, is the appropriate time to switch from a curative medical approach to a caring approach when EOL care and treatments become necessary. The following section will discuss care and treatment options specific to the EOL.

End-of-life care and treatments. Due to advances in biomedical technology and the dominance of curative medicine, Canadians are living longer but at the expense of good health (Williams et al., 2010). This can be attributed to the high rates of chronic conditions among Canadians, accounting for nearly 70% of all deaths (Williams et al., 2010). Emotional and physical suffering throughout the EOL process can be significant

however a bio-physical approach does not provide health care personnel with the proper training to address the psycho-social or spiritual needs of their patients (Williams et al., 2010). The acknowledgement that the needs of our dying population are not currently being met by the health care system creates a demand for such services that would take a holistic approach to care, addressing the emotional, physical, psychosocial, and spiritual aspects of the dying process (Williams et al., 2010). These services exist in Canada in the form of hospice and palliative care.

Hospice and palliative care strive for an interdisciplinary approach in the treatment of terminally ill patients by making the quality of life of the patient and their support system paramount throughout the dying process (William et al., 2010; Rousseau, 1995). There is a point in the course of chronic illness when the effort to cure must be replaced by the effort to care for the patients dying needs, and it is at this point where closure and a personal acceptance of death becomes necessary (Rousseau, 1995). Good hospice and palliative care includes close attention to symptom control and pain management in order to provide comfort for the patient while eliminating the fear associated with dying (Rousseau, 1995).

It is important to note the difference between palliative care and hospice care, for the terms are often used interchangeably. Palliative care can be administered at any point along the continuum of care for someone with a serious chronic condition (National Institute of Senior Health, 2014). This highlights one of the biggest differences between palliative and hospice care. A person can receive palliative care while still receiving curative treatments, however the administration of hospice care marks the cessation of curative treatment (National Institute of Senior Health, 2014). In other words palliative

care is available to patients with serious chronic conditions as well as those at the EOL, whereas hospice care is provided specifically to those who have approximately six months or less to live (Moeller et al., 2009). If a patient chooses hospice care, they are welcome to resort back to curative treatment at any time, and because both palliative and hospice care are provided in a variety of settings including assisted living facilities, hospitals, and at home, a patient can request to switch approaches without the stress of relocation (National Institute of Senior Health, 2014).

In 1994, hospital deaths peaked in Canada at 80.5% (Wilson, Hewitt, Thomas, & Woytowich, 2014)), and since then there has been a shift towards remaining in the community when engaging in the EOL process (Williams et al., 2010). Remaining in the community can help to encourage independence and wellbeing among older adults for which a hospital environment may be less conducive (Shapiro & Havens, 2000). These community care and home care initiatives are beneficial in many ways, however underfunding can put pressure on family and social support networks to take on potentially unsustainable caregiving roles (Gregor, 1997; Saunders, Alibhai, Hogan, Maxwell, Quan, & Johnson, 2001).

Even with these care options in place, family caregivers in all regions of Canada still take on a significant amount of the care responsibility for their dying loved ones (Williams et al., 2010). To acknowledge the significant role that these caregivers play, hospice and palliative care programs also focus on the bereavement of family and friends to assist with the transition out of the caregiving role (Rousseau, 1995).

In 2012, at least 8 million Canadians were providing care to a friend or family member with a disability, chronic health condition, or aging needs (Statistics Canada,

2013c). To replace these unpaid caregivers with paid workers would cost approximately 25 billion dollars (Hollander, Liu, & Chappell, 2009). Demographically, family sizes are getting smaller and increasingly more mobile, meaning family members may no longer be living in the same geographical area (Canadian Healthcare Association, 2012). This may also put the stress of inadequate family resources on the caregiver who may lack additional support (Canadian Healthcare Association, 2012). In an attempt to relieve these caregivers of potential stress, who are often providing such care in order to allow their loved ones to remain in the community throughout the EOL process, respite services are available (Canadian Healthcare Association, 2012).

Respite services are in place as temporary relief from the responsibility of caregiving which is often taken on by family and friends (Canadian Healthcare Association, 2012). Respite care can be a combination of medical or social care, catered towards the specific needs of the care recipient (Canadian Healthcare Association, 2012). The flexibility of respite care is in place to honour the cultural, ethnic, religious, and geographic needs of each individual recipient, with the ultimate goal of reducing stress and supporting the functioning of both the caregiver as well as the care recipient (Canadian Healthcare Association, 2012).

Respite care can be provided in home or out of home, depending on the preference of the caregiver (Canadian Healthcare Association, 2012). Out of home respite offers 24-hour care for an extended period of time (generally 1-2 weeks), usually in a long-term care home setting (Canadian Healthcare Association, 2012). For shorter durations, day programs are available as well as in home assistance on an hourly basis (Canadian Healthcare Association, 2012). The combination of persons with chronic

conditions living longer than any other time in history, a higher demand in homecare and an increasingly older population has led Canada's seniors to be the fastest growing group of respite consumers (Canadian Healthcare Association, 2012).

Barriers to end-of-life care. EOL care, specifically palliative and hospice care are currently found in the margins of the health care system, with many Canadians experiencing barriers to accessing these services (Williams et al., 2010). Barriers to access include EOL treatments' contradictory nature to the dominating medical model, the informal support network needed in order to receive certain types of care, and lack of financial aid.

Canadians have accepted a culture of care primarily curative and biomedical in nature, therefore those who believe in the power of modern medicine may see hospice care as giving up on the patient or loved one (Rousseau, 1995). For health care providers, their professional lives have been focused on keeping patients alive (Rousseau, 1995) and a shift from a curative approach to care approach may be seen as failure. In addition, families and friends may feel guilty about choosing this care approach for their dying loved one (Novak & Campbell, 2006).

Those who do not have a support system to assist them when preparing for EOL may not view palliative and hospice based approaches favourably, because these services often require a primary caregiver to oversee and assist with care provision in between formal care visits (Gomes & Higginson, 2004). Quality community-based care throughout the EOL process requires a partnership between formal and informal caregivers that may leave some older adults ineligible for these services. Therefore, older adults who lack the necessary informal support or do not want to burden their loved ones

with the task of home care assistance, remaining in the home throughout the EOL process may not be a viable option (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004).

Although there is a national body developed for hospice and palliative care in Canada called the Canadian Hospice and Palliative Care Association (CHPCA), there is no standardized system of care provision (Williams et al., 2010). Fragmentation among provinces results in differences in quality and access to care across the country (Williams et al., 2010). These differences include the coverage that Canadians can expect to receive depending on their geographic location (Williams et al., 2010). In part due to funding shortages, only 16% to 30% of Canadians currently benefit from specialist hospice, palliative, and EOL care services (Albrecht, Comartin, Valeroiete, Block, & Scarpaleggia, 2011).

The discrepancies that exist regarding coverage for home and community based services are in part a result of the Canada Health Act's outdated definition, of what is considered to be "medically necessary care" (Williams et al., 2010, p. 5). This definition was created in 1983, but has not adapted to the new health care climate in Canada that is trying to accommodate a population in which 70% of its deaths are at least in part due to chronic conditions (Williams et al., 2010). Even with the current demand for better EOL care, a demand that is only expected to grow with Canada's aging population, this list does not identify hospice and palliative care services as medically necessary (Williams et al., 2010). Not being identified as a core service means that they are then embedded within pre-existing funding envelopes and receive a smaller allocation of funds and resources (Williams et al., 2010). Coverage for these services is therefore hard to come by, and for those who may have limited resources to begin with, trying to justify

additional costs may be a barrier to accessing these services (Rousseau, 1995).

Just as a person's geographic location can affect service coverage, it can also affect the quality of service provision. The current approach to administering hospice and palliative care is largely urban centric (Kelley, 2007). Even though roughly 70% of Canada's population is found in urban areas, this still creates a deficiency of quality service for Canadians living in rural areas (Kelley, 2007). The hospice and palliative care administration approach is currently the same in all regions of the country, disregarding the differences that exist between rural and urban communities (Kelley, 2007). This lack of specialized care can act as a barrier to service use for rural Canadians if their needs are not being met.

In addition to geographic location, there are many differences within the Canadian population that may contribute to a diverse range of experiences with regard to EOL preparation, one of which is gender. The following section looks at the similarities and differences between preparation for EOL for men and women.

Gender and preparation for end of life. In 2010, 56% of Canadians aged 65 and over, 67% of Canadians aged 85 and over, and 80% of centenarians were women (Statistics Canada, 2013a). Therefore, policies and services that are targeted towards older adults will apply to women for longer periods of time. Moreover, given that more than 80% of older Canadians report having one or more chronic health condition, this extension of life expectancy also increases the period of time that a woman must live with multiple chronic conditions (Lindsay & Almey, 1999). For example, women experience poorer health in later life, with higher rates of hypertension, arthritis, and rheumatism in comparison to men (Belanger, Martel, Berthelot, & Wilkins, 2002). The

variation between health status and the experience of chronic conditions between genders approaching EOL may significantly impact the ways in which preparations are made for these older adults. That being said, even though gender has been identified as a social determinant of health that can greatly impact the health outcomes of aging Canadians, it is not adequately addressed in mainstream health promotion policies and programs, especially those aimed at non-heterosexual older adults (Murray, Numer, Merritt, Gahagan, & Comber, 2011).

In addition to one's health, the financial status of Canadians entering later life can significantly impact their wellbeing, and different work patterns and consequently different income patterns between men and women in their working years can influence financial security in old age (Government of Canada, 2015). Work trends in the past have shown women often leaving their first job to raise children, and due to family responsibilities they spend three times longer than men between jobs (Connelly & MacDonald, 1990). The expectations that women will place family before their careers restricts them from getting high salary employment and from storing up pension credits (Street & Connidis, 2001). For female cohorts currently reaching old age, their low incomes have resulted in smaller CPPs (Canada Pension Plan) (Moen, 1996). Women therefore find themselves in later life with less financial stability and a longer life span that will require more resources to maintain quality of life (Martin-Matthews & Davidson, 1996). However, women's role in the workforce has changed, narrowing the labour market participation gap, as well as the wage gap between Canadian men and women (Government of Canada, 2015).

Married people stand the best chance of staying out of long term care because

they have someone to care for them in the home, but with the death of a spouse the surviving partner is at an elevated risk of being institutionalized (Cohen, Tell, & Wallack, 1986). Men are more likely than women to be married in later life, and even if they experience the death of their first spouse they are more likely to remarry (Lindsay & Almey, 1999). Due to traditional gender roles in a marriage, men focus more on work where as women focus more on relationships throughout their life span (Whitbourne & Powers, 1993). Consequently, when a husband loses his wife, he often loses a significant portion of his social network and ties to family members (Barrett & Lynch, 1999). Women have a larger social network to fall back on after the death of their spouse, but this loss of a “live-in support system” poses a risk for institutionalization (Connidis, 2001).

Research on EOL, especially gender specific factors that may influence preparations or experiences, is centered on traditional gender roles and the assumption that the individual in question has experienced normative age graded events such as marriage and retirement. What is currently missing from EOL literature is the acknowledgement of variation within EOL experiences, concerns, and preparations. Specifically, in same-sex partnerships there is an erosion of traditional constraints and conventions and the individual can redefine and pursue their own roles (Almack, Seymour, & Bellamy, 2010). Staying away and/or being excluded from gendered social norms, gendered responsibility, and obligations may result in different EOL experiences for older LG adults (Almack et al., 2010).

Men and women adapt differently to the aging process due to different life circumstances that ultimately impact the ways in which they experience the last stages of

life (Pinquart & Sörensen, 2001). Moreover, sexual orientation and the implications it can have on one's lifestyle, may also contribute to the way EOL is experienced for LG individuals. The remaining sections of this literature review look at the experience of aging for older LG adults as well as factors that may influence the experience, preparations, and concerns with regard to EOL.

LG Aging

Current EOL literature does not sufficiently address the potential impact that non-normative events and life experiences can have on EOL. To achieve a comprehensive understanding of the EOL experience of LG individuals, many of whom do not abide by society's traditional norms and conventions, it is important to broaden the scope of research to take elements of the aging process into account. Stigma, overall health, isolation, and relationships with institutions are aspects of the aging process experienced by the LG community examined in this section.

Stigma. A significant part of understanding the stigma and discrimination that older LG adults either experience or anticipate in today's society requires an in depth understanding of what their experience has been identifying with the LG community up to this point. Older LG individuals grew up in a time where homosexuality was considered to be a sin or sickness and there were few opportunities to meet other LG individuals (Kuyper & Fokkema, 2010). In their younger years they were discriminated against by institutions and laws, and homosexuality was considered to be a mental illness by the American Psychiatric Association and the American Psychology Association (Conger, 1975).

In the first two editions of the Diagnostic and Statistical Manual of Mental

Disorders (DSM), homosexual individuals were labeled as sexual deviants and classified as child molesters, voyeurs, exhibitionists, and people who committed destructive crimes (Kuyper & Fokkema, 2010). The attitude of the general population towards the LG population was overwhelmingly negative (Kuyper & Fokkema, 2010). It was in these hostile environments that many of these older LG adults grew up, and to address the particularly harsh reality of the time period, this cohort is commonly referred to as the pre-liberation cohort (Brotman et al., 2003). Many lived through enforced medical interventions and or experienced overt discrimination from professionals and the public (Brotman et al., 2003). These wounds of being socially marginalized remind older lesbian and gay individuals that it is unwise to place trust in individuals and social systems that have historically persecuted them (Brotman et al., 2003). Attitudes may have changed towards homosexuality and same-sex partnerships, however incidents of overt homophobia towards this population still exist, which reinforces a vigilance for older adults to maintain secrecy over their sexual orientation (Brotman et al., 2003).

Even with the changing attitudes in today's society, sectors of the aging network in which older people work (whether voluntary or social support organizations) or live, still expose older LG adults to further marginalization from contemporaries who continue to hold discriminatory attitudes reminiscent of the pre-liberation era (Daley, 1998). Due to this shame and stigma that was brought on in the pre liberation era, a survival technique for this population is to keep their sexual orientation private (Butler, 2004).

Since the Stonewall riots in 1969, which was a famous demonstration against police harassment of patrons at a New York City bar and the birth of the Gay Liberation movement in the United States in the 1970s, the experience of being LG has dramatically

changed (Butler, 2004). These riots created momentum in Canada, including the decriminalization of homosexuality in 1969 (Rau, 2014). However, despite this amendment, LG individuals still faced discrimination including ongoing police harassment (Rau, 2014). This led to what is known as Canada's Stonewall in 1981 (Rau, 2014). Three hundred men were arrested by Toronto police during a raid of four bathhouses, which led to mass retaliation (Rau, 2014). These riots led to the establishment of the Lesbian and Gay Pride Day in Toronto, now held annually in cities across the country (Rau, 2014). In 1982 the Canadian government adopted the Charter of Rights and Freedoms, laying a foundation for equality in Canada (Rau, 2014). However, it was not until over a decade later that the Supreme Court ruled that sexual orientation should be included in Section 15 of the Charter, guaranteeing equality to LG individuals and protection from discrimination (Rau, 2014).

Due to the shift in political and social acceptance of LG individuals after the gay liberation movement, the experiences of the current population of older LG adults may be significantly different from those who will come of age in the next 15 to 20 years. Today's older LG adults grew up in harsh conditions of discrimination that existed before the gay liberation movement resulting in particular strategies of hiding to survive (Butler, 2004). Future cohorts will have grown up in an environment of political and social solidarity and visibility that has emerged out of the gay liberation. They will have more likely identified themselves with a cultural community and had the opportunity to participate in a variety of organizations designed to promote their health and well-being, challenge discriminatory law and policy, and celebrate a sense of pride in their identity (Brotman et al., 2003).

When discussing cohort experiences of stigma and discrimination, there is a portion of today's older LG adults who may have come out in middle or old age and their experiences may therefore be different from those who came out during the earlier, more oppressive pre liberation years (Butler, 2004). In other words, it cannot be assumed that the discrimination associated with the pre-liberation era was experienced by all LG members within those cohorts.

The current cohort of older LG adults are described within the literature as being "twice hidden" representing the most invisible of an already invisible minority, also known as Gen Silent (Blando, 2001; de Vries, 2014). This label has been given to this group due to an intersection of ageism and heterosexism (Addis et al., 2009; Blando, 2001; Brotman et al., 2003; Hays, Fortunato, & Minichiello, 1997; Johnson, Jackson, Arnette, & Koffman, 2005; Price, 2005), further marginalizing this population. Due to the fact that the LG community is primarily viewed by their sexuality and society prefers to see older people as sexless, these older adults experience greater homophobia than their younger counterparts (Addis et al., 2009).

Sexuality is an intrinsic part of human identity and to be denied that can have detrimental effects on self-image, social relationships, and mental wellbeing throughout the aging process (Elias & Ryan, 2011). Price (2005) suggests that expressions of sexuality among older adults are often seen as problems to be managed or treated, and sexuality in general often goes unrecognized for older adults (Addis et al., 2009). Gay culture has been guilty of being particularly youth focused and what is old has been seen as less attractive and less worthy than what is young (Brotman et al., 2003). Due to this multi-level experience of oppression from both ageist and heterosexist attitudes, older LG

adults may not feel comfortable in both traditional agencies for fear of aversion to their sexual orientation or to LG specific organizations that may be less targeted towards the aging members of the community.

Brotman et al. (2007) describes two distinct ways to articulate discrimination similar to Meyers (2003) distal and proximal stress processes. Actual discrimination and anticipated discrimination. Although “actual” discrimination or experiences of hostility were more common in the past, discrimination continues although often more subtle and in the form of negative attitudes or comments (similar to Meyer’s distal stress process) (Brotman et al., 2007). Anticipated discrimination (similar to Meyer’s proximal stress process) plays an important mediating role in the willingness to access resources. Despite recent changes in social policy in Canada that have resulted in an increased recognition of the rights of the gay and lesbian population (most notably the passing of federal and provincial legislation recognising same sex couples as equivalent to common law couples outside of family law), discrimination continues to be apparent in many societal, social, and institutional environments. Discrimination in healthcare is particularly salient for today’s lesbian and gay older adults (Beeler, Rawls, Herdt, & Cohler, 1999; Boxer, 1997; Cahill, South, & Spade, 2000). Due to the fact that they have historically been socially defined within medical terms as mentally ill and that the health care system has been one of the primary arenas through which control over their lives was exerted, the anticipation and actual experiences of discrimination within these institutions play a key role in the capacity for older adults and their caregivers to access services (Brotman et al., 2003). The discrimination within the healthcare system and the ways in which this can influence the frequency at which older LG adults access health services may influence the overall

health of these individuals, which will be discussed in the following section.

Overall health. With advances in medical technology (among other factors) Canadians are living longer and with many complex health conditions (Canadian Hospice Palliative Care Association, 2012). Moreover, recent research suggests that older LG adults have significantly higher rates of both psychological and physical health conditions than their heterosexual counterparts (Mills, Paul, & Stall, 2004). The differences between overall health are seen more in the comparison of gay men and heterosexual men than their female counterparts (Wallace, Cochran, Durazo, & Ford, 2011). In a study controlling for social and demographic characteristics, gay men did not differ significantly from heterosexual men in their rates of heart disease, however the ratio of hypertension, diabetes, psychological distress symptoms, and an overall poorer health status was higher among gay men (Wallace et al., 2011). Although, there are fewer significant differences in health conditions between lesbians and heterosexual women, there is a sizeable portion of lesbians who experience poor health conditions, including being at a greater risk of experiencing psychological distress symptoms and physical disability (Wallace et al., 2011).

Significant variation exists in mental health.. Although gay men evidenced higher prevalence of depression, panic attacks, and psychological distress than heterosexual men, lesbians showed a greater prevalence of generalised anxiety disorder than heterosexual women (Cochran, Sullivan, & Mays, 2003).

Managing long-term stigma in the form of heterosexism and homophobia is suggested to contribute to higher risks of depression and suicide within the aging LG population (Russell & Joyner, 2001). The high prevalence rates of depression and the

elevated risk for poor physical health for gay men are frequently documented within the literature (Brotman et al., 2003; Cochran et al., 2003; de Vries, 2014; Shippy, Cantor, & Brennan, 2004; Wallace et al., 2011), and the prevalence of HIV among this population may be a contributing factor (Fredriksen-Goldsen, Kim, Emler, Muraco, Erosheva, & Hoy-Ellis, 2011). Additionally, given the effectiveness of anti-retroviral therapies, more adults are living into old age with HIV than ever before, which is likely to influence the level of overall poorer health for gay men (Fredriksen-Goldsen et al., 2011).

A frequent topic is whether LG individuals are more prone to substance abuse than their heterosexual counterparts. Managing long-term stigma across the life course may put older LG adults at an elevated risk of addiction and substance misuse (Rothblum, 1994; Russell & Joyner, 2001). For example, Hughes (2003) found that 16% of lesbians compared with 2% of heterosexual women reported being in recovery for alcohol use. Gay men who experienced negative feelings about being gay tend to overuse alcohol (D'Augelli, Grossman, Hershberger, & O'Connell, 2001), and older LG adults are more likely to smoke and engage in heavy drinking than their heterosexual counterparts (Fredriksen-Goldsen et al., 2011). In contrast, a large majority of older LG adults reported no evidence of drug use and relatively few classified as "problem drinkers" in a study by D'Augelli et al. (2001). This is just one aspect within the literature that alludes to the diversity and variation within the older LG population.

LG individuals not only experience the normal declines in health brought on by the aging process, including the elevated risk of chronic conditions towards the EOL (Lindsay & Almey, 1999), but also may face additional risks due to the social, psychological, and physical impacts of their sexual orientation on their health (Jackson,

Johnson, & Roberts, 2008). This is problematic because, as previously mentioned, older lesbian and gay adults are reported to be less likely to access health care services or disclose their sexual orientation to health care providers when they do (Brotman et al., 2003). Choosing not to disclose one's sexual orientation may make it difficult for health care personnel to suggest or administer the necessary treatment to meet their needs (Brotman et al., 2003).

Minimal research discusses good mental health among older LG adults. The research that is available associates good mental health with higher self-esteem, a sense of social interaction, and more people being aware of their sexual orientation (Addis et al., 2009). The ability to maintain a positive outlook despite potentially negative circumstances speaks to the resilience that can be found within the LG network. Despite all of the challenges that older LG adults face and contrary to myths of older adults being frail and lonely, many lesbian and gay older adults approach old age with unique resiliency and particular strengths (Butler & Hope, 1999; Healy, 2002).

One of the largest factors that contributes to the resiliency of this population is the group cohesiveness and large social networks that, if available, can help to reduce the negative effects of discrimination and social exclusion (Kuyper & Fokkema, 2010). Having these large LG networks can create a social context in which a person is not stigmatized or different from the dominant culture. These individuals therefore do not have to or are less likely to maintain vigilance about their identity when among others of the same group (Kuyper & Fokkema, 2010). These friends and social networks that lesbian and gay individuals create are referred to as "families of choice" (Addis et al., 2009). This provides a social advantage for these individuals in times of need by being

able to rely on a broad base of support (Barranti & Cohen, 2000). In addition, a tight-knit community allows these older adults to celebrate a sense of pride in their identity and for those that have taken the opportunity to participate in a variety of organizations and advocacy work, a number of these individuals will age with the benefits of solidarity (Brotman et al., 2003). This may encourage these older adults to be more proactive and involved in the way services are designed and delivered to ensure that their rights are being acknowledged, whether it be from a heterosexist standpoint or an ageist standpoint.

Three quarters of an American sample of LG boomers (born between 1946 and 1964) agreed that their sexual orientation has helped them prepare for aging (de Vries, 2014). A phenomenon called “crisis competence” describes how living through years of stress and negativity caused by discrimination and homophobic attitudes helps older LG adults prepare for the stress of potential ageist attitudes as they age (Cahill & South, 2002). Specific factors that may prepare LG individuals for aging are discussed in a study by Barranti and Cohen (2000). These include coping skills that are developed through the process of accepting their sexual identity, which may help LG seniors in the acceptance of aging (Barranti & Cohen, 2000). By experiencing the coming out process and learning to manage society’s perception of difference, LG individuals may be more prepared for aging in a youth oriented society (Barranti & Cohen, 2000).

In contrast to coping through acceptance, some LG individuals choose to remain invisible as a means of survival in a heterosexist society. Many older LG adults have learned to hide their orientation from family, friends, employers, and for some, even from themselves, and some have chosen heterosexual marriage and having children as a method of concealment (D’Augelli et al., 2001; Meyer, 2003). Even for those in same-

sex partnerships, older couples may choose to identify themselves as friends or co-habitants to ensure privacy and to avoid negative treatment (Brotman et al., 2003). The conscious effort to hide one's sexual orientation may also be a contributing factor to the isolation that some older LG adults experience.

Isolation. Important factors that can influence an older adult's wellbeing are loneliness and isolation (Kuyper & Fokkema, 2010). Many of the articles that address LG aging include or at least briefly acknowledge the theme of isolation and the impacts that isolation can have on the health status and quality of life of older adults. Research that supports the presence of isolation address the living arrangements, the lack of biological support networks, and the choice to withdraw from certain activities and institutions for fear of discrimination among the older LG population (Brotman et al., 2003). For example research states that 50% of aging gay adult men live alone compared to 13.4% of heterosexual men, putting gay men in a more susceptible position for isolation (Fredriksen-Goldsen et al., 2011; Wallace, Cochran, Durazo & Ford, 2011). About one third of older gay men are married or are living with a partner whereas more than three quarters of heterosexual older men are married or living with a partner (Wallace et al., 2011). One in four older lesbians live alone compared to one in five heterosexual women and this isolation can place them at a higher risk of self-neglect, decreased quality of life, and increased mortality (Herdt, Beeler, & Rawls, 1997; Peterson & Bricker-Jenkins, 1996; Quam & Whitford, 1992).

The tendency for lesbian and gay older adults to be less linked to their biological families or families of origin can also be a contributing factor to the experience of isolation for older LG adults by limiting their options for support in later life (Barranti &

Cohen, 2000). However, the relationships between LG individuals and their biological families is a topic of significant variation in existing literature. Research by Brotman et al. (2003) and Hays et al. (1997) showed that few LG participants have maintained positive relationships with members of their families of origin, and the reasoning behind the breakdown of these bonds was largely due to the disclosure of sexuality. In contrast, research by Shippy et al. (2004) examined the social networks of gay men aged 50 years and older and found that they largely consisted of partners and friends but these social networks also included members of their biological families. The men who had children within this study indicated that sexual orientation did not stand in the way of their relationships. White and Cant's (2003) findings were similar to that of Shippy et al. (2004), finding that there were very few cases of estrangement from biological families but that daily support was provided by partners, ex partners, or friends rather than biological family members. Even though there are contradictions among the literature to which degree older LG adults are tied to their families of origin, the primary source of support for many is sought outside the biological family network.

The perception of older LG adults as lonely and isolated is supported by only a limited amount of recent research and only represents a certain portion of this population (Butler, 2004). There is a distinct difference between living alone and being lonely (Butler, 2004). Just because a portion of older LG adults live alone does not necessarily mean they are isolated nor lonely. Many gay and lesbian older adults approach old age with unique resiliency and particular strengths due to their need through life to create alternative support and social networks, or from making it this far without the support of others (Butler & Hope, 1999; Healy, 2002). Literature available on the large informal

support networks within the LG community dismisses the myth that portrays older LG adults as lonely and isolated (Brotman et al., 2003). Instead there is a new focus on the development of alternative support networks referred to as “fictive kin” or “chosen family” (Barranti & Cohen, 2000). This broad base of support can act as a social advantage in times of loss and need and can counteract the risk of isolation and loneliness (Butler & Hope 1999; Healy 2002).

The importance of friendship and the implications that having such strong social networks can have on older LG individuals is discussed in de Vries and Megathlin’s work (2009). Friends and the support that they provide can serve a unique function in mitigating the impact of stigmatization:

Friendship groups for heterosexuals may be close and important but it occurs as an option in the context of a heterosexually dominant society. For the lesbian and gay population on the other hand, these individuals must create out of necessity a meaningful friendship group to cope with threats to identity and self-esteem. (Nardi, 1982, p. 86, as cited in de Vries & Megathlin, 2009)

Even though these relationships can play a significant role in the lives of older LG adults, they are currently unrecognized by social institutions and health care professionals (Brotman et al., 2003). It is due to this lack of recognition that friends are often limited as to how much care they can provide in professional settings, especially when medical decision making is required (Fredriksen-Goldsen et al., 2011).

Caregivers within the LG community are also at risk of isolation and lack of support, especially when having to contend with heterosexist institutions or values. In the

presence of heterosexism, the specific needs of LG caregivers may not be acknowledged (Addis et al., 2009). The challenges brought on by providing care in the context of reduced support, rejection by family, and invisibility are ubiquitous within the LG caregiving community (Brotman et al., 2007). Common issues for caregivers are managing responsibilities, experiencing emotional and physical strains, feeling tension in partner relationships, and experiencing conflicts with employment responsibilities (Cantor, Shippy, & Brennan, 2002). These issues are further exacerbated by LG caregivers trying to find a balance between showing love and maintaining a level of privacy so as not to put them at risk for discrimination (Cantor et al., 2002). In general caregiving literature, women provide the majority of care, however within the LG community men are as likely to provide care as women (Fredriksen-Goldsen et al., 2011), meaning all LG caregivers are at risk of experiencing these challenges.

Research suggests that family members who provide unpaid instrumental, physical, financial, and emotional support do not often identify themselves as caregivers, which is particularly true of spouses who see caregiving as a natural extension of their spousal role (Brotman et al., 2007). The support provided is instead something done out of love or obligation or as a result of a reciprocal relationship with the care receiver (Brotman et al., 2007). Caregivers within the lesbian and gay communities share the same sense of motivation and identity, but have expressed that coping with the decline in health of their partners can be severely hampered when partnerships cannot be openly dichotomy acknowledged, shared, or disclosed (Brotman et al., 2007). Older couples commonly identify themselves as friends or roommates as a coping mechanism in order to mediate negative treatment by others (Brotman et al., 2003). This choice to hide their

relationship with the care receiver is exacerbated by the worry and fear that is experienced when a caregiver must leave their spouse or partner unattended during interactions with health care professionals for fear of making the care receiver more vulnerable (Brotman et al., 2007). When care receivers are less “out” to the community and more averse to seeking professional support, they may inadvertently put more responsibility on the shoulders of their caregiver (Brotman et al., 2007). Caregivers may therefore experience a sense of isolation and invisibility in their attempts both to provide care to their loved ones and to identify support for their own needs (Brotman et al., 2007). Although LG caregivers may be able to access support groups in their geographic area, some may experience reluctance to join for fear of being ostracized as many of these groups are described as being limited to a heterosexual framework (Moore, 2002).

Even though some older LG adults are able to reap the benefits of a strong social network, there are also older LG adults who are without such large support systems and therefore do experience relative isolation (Brotman et al., 2007). The challenge of acquiring access to these older LG adults remains (Brotman et al., 2003). This highlights a potential limitation of research that is attempting to grasp the lived experience of older LG adults. It is often easier to recruit individuals who are more comfortable with their sexual orientation, and are more engaged in the community, making them more inclined to participate in a study (Addis et al., 2009). However, the needs of those who are isolated, or are choosing not to disclose their sexual orientation would be significantly different from those who are publicly self-identified (Orel, 2004). Samples often comprise those who are more willing to self-identify, and it is their needs and experiences that would be represented in the data.

All in all, isolation can be a significant contributor to the lack of well-being for older LG adults including its potential to keep them from accessing services in their time of need. The choice not to access services may be exacerbated by the negative relationships between LG individuals and the health care system, which is discussed in the next section.

Relationships with institutions. Negative relationships between LG individuals and health care providers stem from the pre-liberation era. During this time, health professionals were often charged with the task of “healing” gay and lesbian people from their “unhealthy” same sex attractions through means of electroshock therapy or aversion therapy (Daley, 1998). Even though the American Psychiatric Association (APA) removed homosexuality from its classification of mental disorders in 1973, the consideration of homosexuality as a mental disorder has not been as effectively eliminated from the attitudes and views of all health care providers (Harrison & Silenzio, 1996; Jones & Gabriel, 1999). Moreover, heterosexism can still occur within these institutions. The general consensus is that there is often mistrust felt towards the health and social services network due to these past experiences of discrimination (Brotman et al., 2003). Older LG individuals may therefore find it necessary or prefer to go back into hiding when they begin to require health care services in order to avoid the discriminatory behaviour on behalf of their sexual orientation (Brotman et al., 2003).

Researchers have documented examples of current challenges faced by older LG adults and barriers to feeling comfortable coming out within the service sector. Disclosing one’s sexual orientation has been met with a broad spectrum of negative reactions from healthcare providers, which include embarrassment, anxiety, rejection,

hostility, curiosity, pity, condescension, ostracism, withholding treatment, detachment, avoidance of physical contact, and breach of confidentiality or “outing” (Brotman et al., 2003).

The onset of disability in later life may contribute to a greater risk of outing of LG individuals by care providers. This breach of confidentiality is particularly significant among older adults living within assisted living facilities or long term care homes due to an exposure of domestic arrangements or living circumstances (Price, 2005).

Consequently, to protect one’s identity, older LG adults may prefer not to claim government benefits for a partner if their relationship is not public (Addis et al., 2009). They can also be anxious about completing official documents that require information about next of kin (Price, 2005).

For some LG individuals, their biological next of kin may not be the ones whom they wish to have assisting throughout the care process, but many older LG adults encounter difficulty in gaining recognition from healthcare and legal personnel for partners and families of choice (Wallace et al., 2011). Members of family of choice have noted this lack of recognition in areas of care such as visiting terms, decision making, and caring for their friend or partner (Irving, Bor, & Cataan, 1995; Turner & Catania, 1997).

Homophobia and heterosexism are even more common in elder care systems than within the healthcare system in general (Brotman et al., 2003). As previously noted, due to the environment and culture of long term care homes (e.g., shared housing), older LG adults may come into contact with other residents who may hold discriminatory attitudes (Daley, 1998; Peterson & Bricker-Jenkins, 1996). Another concern that may arise within the elder care network, however, is the way in which the notion of the “family” is

constructed (Brotman et al., 2003).

For heterosexual older adults, families play an increasingly important role within the care networks. Health care professionals, policy makers, and researchers have also recognised the role of families in providing care and support and in participating in decision making as an essential part of the process, but a prioritization of families constructed by marriage or blood ties is evident (Brotman et al., 2003; Manthorpe, 2003). This prioritization has reinforced the experience of marginalization and exclusion among lesbian and gay older adults (Brotman et al., 2003). Many health care professionals who come into contact with lesbian and gay older adults with few or no ties to biological family simply assume that they have no one to support them (Brotman et al., 2003). There is an overwhelming lack of recognition of fictive kin networks, which can lead to older LG adults being cared for by family members who actually show little support towards their identity or sexual orientation and therefore may not make health care decisions in the care receiver's best interest (Barranti & Cohen, 2000).

Experiences of discrimination discourage older LG adults to disclose their sexual orientations or to place trust in systems that have historically persecuted them (Brotman et al., 2003). Particularly as the reality of becoming dependent sets in, it seems unwise to put themselves in a more vulnerable position by disclosing their sexuality (Brotman et al., 2003). Conversations about sexuality are often overlooked and do not occur during assessments due to apprehension and fear of vulnerability on the care receiver's part but also due to the discomfort that health care professionals experience around discussing issues of sexuality with their aging clients (Brotman et al., 2003). The discomfort and apprehension around this topic of conversation within institutions promotes and

reinforces a cycle of oppression for aging LG individuals whose specific needs are largely unacknowledged within the service sector (Brotman et al., 2003).

Consequently, LG individuals may be less likely to access health services or to disclose their sexual identity when they do (Addis et al., 2009). Withholding information about one's sexual identity can further exacerbate the poor health status of some older LG adults by delaying or denying themselves client-centered care (Murray et al., 2011). Health care providers require full disclosure in order to make an accurate assessment and follow up with the most effective and appropriate care strategies (Murray et al., 2011). However, no statistical differences between measures of access to healthcare services between LG individuals and their heterosexual counterparts were found by Wallace et al. (2011). This analysis provided data on basic access measures and did not indicate whether or not the quality of that care was similar across populations (Wallace et al., 2011). This may suggest that it is the quality of care and the lack of cultural competence that is a root of mistrust among LG service users, which can impede the desire for LG individuals to seek assistance (Wallace et al., 2011). A gap in the literature pertaining to LG service access is whether there is a difference between how gay men and lesbians access these services. Currently the research available compares LG individuals to heterosexual individuals, but whether there is a difference of access rates or patterns within the LG community has yet to be identified.

Service providers have an obligation to become knowledgeable about the diversity among older adults based on class, race, gender, ability, religion, ethnicity, and sexual orientation, but heterosexism and homophobia are still widespread and are often symptomatic of a larger sex phobia associated with those providing services to seniors

(Addis et al., 2009). If physicians do not recognise patients' sexual orientation and patients do not disclose, it can result in serious medical problems (Fredriksen-Goldsen et al., 2011). The non-disclosure of one's sexual orientation can prevent discussions from occurring about sexual health, hormone therapy, breast cancer, hepatitis, HIV, or other potential risk factors (Fredriksen-Goldsen et al., 2011).

Relying on others for healthcare as a result of failing health can be a worrisome experience for older adults but the fear is even greater for older LG adults who are forced to depend on networks and social institutions not cognisant of their needs (Brotman et al., 2003). Whether this fear is increased at the EOL has yet to be identified due to a lack of explicit documentation on EOL care experiences for older LG adults (Almack et al., 2010). The following section will discuss the limited available literature on older LG adults and their concerns, preparations for, and barriers experienced with regard to end-of-life.

Older LG Individuals and End of Life

Literature is available on the aging experience of LG adults as well as on EOL preparation, but less literature on older LG adults and their experience with EOL preparation is available, especially within the Canadian context. This final section focuses on EOL preparation and coping, barriers to receiving and accessing EOL care, and acknowledgement of diversity with regard to LG individuals and EOL preparation.

End-of-life preparation and coping. Preparation for EOL can often be dominated by healthcare plans and medical decision making, yet there are a number of other aspects of EOL that must be prepared for. Seven life areas important to address with regard to EOL preparation for older LG adults are physical health, legal rights,

housing, spirituality, family, mental health, and social networks (Orel, 2004).

Specific legal concerns for older LG adults reported by Orel (2004) included domestic violence protection orders, automatic inheritance of jointly owned real and personal property, decision making power with respect to burial or cremation, bereavement or sick leave to care for a partner, joint filing of income tax returns, status of next of kin for hospital visits, immigration and residency for partners from other countries, joint leases with automatic renewal rights in the event one partner dies, spousal exemption to property tax increases upon the death of a partner and dissolution and “divorce” protections, and survivor benefits for same-sex lifelong partners. However, due to the fact that these data were collected in the United States, these legal concerns may not be directly applicable to older LG Canadians. In 1999, for example the Canadian Public Service Superannuation Act was amended, extending survivor pension benefits to same-sex couples and in the following year the Modernization of Benefits and Obligations Act took effect providing all common-law relationships (including same-sex) the same rights as heterosexual married couples (BC Teachers’ Federation, 2006). This ensured equality in areas such as pensions, tax, and employment insurance (BC Teachers’ Federation, 2006).

Progress has been made in Canada for LG rights, but uncertainty remains as to how far legal protections go and what steps are necessary to put these preparations in place. As one of Orel’s (2004) participants stated,

I’m still not sure what type of legal arrangements are needed to protect me and my partner. We heard about one lesbian who had to fight to get the ashes of her lifetime partner when she died. Her ashes were given to a niece. (p. 66)

In the United States a report called “Outing Age: Public Policy Issues Facing Gay, Lesbian, Bisexual, and Transgender Elders” was released in 2000 by Cahill, South, and Spade. This report, later updated in 2010 (Grant, Koskovich, Frazer, & Bjerk, 2010), was the first comprehensive report that addressed the social and public policy shortcomings experienced by LGBT older adults in the United States. This document looked in depth at the current policy in sectors such as services, social security, health, housing, anti-poverty, and discrimination and the extent to which they meet the needs of LGBT older adults (Cahill et al., 2000). The report also consists of a needs assessment section and recommendations for policy advocacy and activism. The comprehensive nature of this report is an important step for further legal progress, however the equivalent of this document is not currently available in Canada. Literature on EOL preparedness of older LG adults in general are often limited to Australian or American samples, highlighting the need for further steps to be taken to fill these gaps in the Canadian context.

From a health and wellness perspective, reasons for planning for EOL care for older LG adults are similar to those that would encourage the general population to engage in this process (Smolinski & Colon, 2006). Reasoning includes avoiding becoming a burden on loved ones, ability to cope with current health conditions, and increased feelings of security (Hash & Netting, 2007). However, despite similar reasoning for EOL preparation, in a MetLife study on the preparations boomers have taken for later life, LG boomers were reported to be significantly more likely to have engaged in EOL preparations than their heterosexual counterparts (de Vries, 2014).

Planning for future care by creating an advance directive can be especially useful for LG individuals due to the fact that anyone can be named a substitute decision maker

(aside from those under a certain age which differs by province). The substitute decision maker is not required to be a biological relative. This supports the agency of the older adult by providing control over their EOL care preferences as well as who will be speaking on their behalf in times of incapacity (Detering et al., 2010). Although family members related by blood or marriage play a primary role of support in the general population, most older LG adults care for one another and have distinct support networks that would not be recognised by the healthcare system unless made known through explicit advanced care plans (Hash & Netting, 2007).

The fear of family members not accepting their partner or relationship or trying to interfere with their plans is a frequently stated motivation for creating advance directives (Cartwright et al., 2012; Hash & Netting, 2007; Hughes & Cartwright, 2014). Creating these documents protects the recipient of care and the caregiver from unwanted interference from professionals in formal care settings as well as against unwanted involvement of informal parties (Hash & Netting, 2007). Therefore some LG individuals use advance directives as a way of communicating the nature of their relationship to health care providers and family members (Hash & Netting, 2007).

Even though in essence the advance directive meets the needs of LG individuals when preparing EOL documentation, the documentation process does lack suitability in some areas. For example, Speak Up, an organization campaigning to promote advance care planning in Canada, recommends meeting with a lawyer or health care provider to oversee the preparation of the documents in order to ensure validity and legitimacy (Canadian Hospice Palliative Care Association, 2015). This may pose as a barrier to creating valid documentation for members of the LG community who are apprehensive

about having these types of conversations with health care or legal personnel (Lawton, White, & Fromme, 2014). A British study provides evidence to support that healthcare professionals experience difficulty in communicating with people about sexuality and in recognising people with diverse sexual and gender identities (Pennant, Bayliss, & Meads, 2009). This can be discouraging for older LG adults to disclose their sexual orientation. Additionally, even if the topic is broached, the lack of time that health care practitioners have to facilitate such discussions may affect how beneficial the conversation is for the recipient of care (Bloomer, Tan, & Lee, 2010; Seymour, Almack, & Kennedy, 2010). Therefore opportunities to have conversations about specific LG EOL issues that would better prepare these individuals are lost or cut short (Hughes & Cartwright, 2014). A pressing example of this is although gay men with AIDS report wanting to discuss their preferences about life sustaining treatment with their physicians, these discussions are uncommon (Stein & Bonuck, 2001).

As previously mentioned, older gay men and lesbians often rely on fictive kin networks made up of partners and friends for support (Barranti & Cohen, 2000). Unfortunately, health care professionals will often call on the biological family to make health care decisions because of a current lack of recognition and trust in fictive kin networks or such “communities of care” (Barranti & Cohen, 2000). Consequently, in the absence of documentation that appoints a member of the fictive kin network as the SDM, the representative is chosen from a hierarchy of relatives and is referred to as a temporary substitute decision maker (Canadian Hospice Palliative Care Association, 2015).

As long as same-sex couples are legally married or in a common law partnership, there is no difference between how temporary substitute decision makers are identified

for LG individuals and their heterosexual counterparts (Canadian Hospice Palliative Care Association, 2015). However, if an LG member strictly depends on their fictive kin networks for support, and their partner is not considered their spouse or partner by law, that individual is left with few alternatives within the hierarchy to be spoken on behalf of someone within their chosen family. In 2011, out of almost 65,000 same-sex couples in Canada, approximately 3 in 10 couples were married by law (Statistics Canada, 2013b). This leaves about 70% of these couples at risk of misrepresentation, if hoping to rely on their partner or fictive kin networks in times of incapacity (Statistics Canada, 2013b). Table 1 depicts the temporary substitute decision maker hierarchy in the four Canadian provinces that were included in this study, showing a strong partiality towards blood relatives to be appointed in the absence of explicit documentation. British Columbia is the only province that recognises a close friend within the hierarchy. The difference between the medical decision making and advance care plan policies in these four provinces, and the different levels of coverage an advance directive provides may influence the ways in which LG individuals within these provinces prepare for end-of-life.

Even if one has completed an advance directive, having these documents in place may not be as reassuring for some LG Canadians as it is for others depending on the province they reside in. Out of the four provinces included in this study, British Columbia allows the care recipient to exercise the most individual control over their medical decision making process in times of incapacity. This is largely attributed to the fact that British Columbia is the only province in this study that allows for its advance directive to be legally binding (Dying with Dignity, 2011b). This means that if the care recipient has

created an advance directive and the guidelines and instructions provided in the document apply to the medical scenario at hand, the medical team does not have to contact the substitute decision maker (SDM) to receive verbal consent (Dying with Dignity, 2011b). It is only legally binding, however, if it is explicitly stated in the care recipient's representation agreement, which is an additional document required to complete the advance care plan (Dying with Dignity, 2011b).

In Alberta the advance directive is referred to as a personal directive and is conditionally legally binding. This means that one's personal directive is only legally binding if the care recipient has not identified a substitute decision maker (referred to as an agent in Alberta) (Dying with Dignity, 2011a). Similar to British Columbia, the scenario that requires medical decision making must be specifically addressed within the personal directive for it to be legally binding (Dying with Dignity, 2011a). If what is written in the personal directive does not apply to the current medical scenario and no agent has been identified, a temporary substitute decision maker is contacted (Dying with Dignity, 2011a). If an agent has been named within the personal directive, the personal directive immediately loses its legal binding, as verbal consent from the agent takes priority over written consent in Alberta (Advance Care Planning, 2014).

Ontario advance care directives are not legally binding under any circumstances and are only used as guidance for the substitute decision maker to make an informed decision in the best interests of the care recipient in times of incapacity (Wahl, 2006). Ontario's process is also similar to British Columbia in that a separate document, the power of attorney for personal care document, must be created in order to identify the substitute decision maker (Advance Care Planning, 2014).

Nova Scotia's personal directive is similar to Alberta's policy in that it is only conditionally legally binding, and will only apply if a delegate (the substitute decision maker in Nova Scotia) has not been identified and the medical scenario is directly applicable to what has been written in the personal directive (Dying with Dignity, 2011c). Also similar to Alberta, a delegate can be identified within the personal directive and does not need their own document as is necessary in British Columbia (Dying with Dignity, 2011c).

Even with EOL documentation in place to protect and respect the rights and wishes of the care recipient from unwanted interference, the wishes of an older LG adult may be jeopardized due to the combination of a complex documentation process and fictive kin networks going widely unacknowledged within the temporary substitute decision maker hierarchy (Lawton et al., 2014).

Table 1. *Hierarchy of Temporary Substitute Decision Makers by Province*

	British Columbia	Alberta	Nova Scotia	Ontario
1	Spouse	Spouse or adult interdependent partner	Spouse or the person with whom one cohabits as spouse	Spouse, common law spouse or partner
2	Child	Adult son or daughter	Adult son or daughter	Child (16 years or older) or parent
3	Parent	Father or mother	Parent or legal custodian	Parent with sole of access
4	Brother/sister	Adult brother or sister	Adult brother or sister	Brother or sister
5	Grandparent	Grandfather or grandmother	Grandparent	Relative by blood, marriage or adoption
6	Grandchildren	Adult uncle or aunt	Adult grandchild	Office of the public guardian and trustee
7	Relative by birth or adoption	Adult nephew or niece	Adult uncle or aunt	
8	Close friend		Niece or nephew	
9	Relative by marriage		Other relative	

Note. Sources: Advocacy Centre for the Elderly, 2013; Alberta Health Services, 2009; Province of Nova Scotia, 2013; Vancouver Coastal Health, 2013

This lack of recognition of fictive kin networks and specifically of same-sex partners can be stressful for the care recipient and can have a significant impact on the caregiving partner (Cartwright et al., 2012). It can cause additional grief, loss of dignity, and loss of property upon the death of same-sex partners (Cartwright et al., 2012). Thus due to the unique past and current experiences of the LG community, bereavement may

be different for LG individuals (Cartwright et al., 2012). Moreover, as a result of this potential for a different experience of bereavement, health professionals may not understand or support the role of same-sex partners and friends throughout the EOL process (Hash, 2006). When relationships are not recognised, bereaved partners and friends miss out on the social support necessary for coping with grief (Almack et al., 2010). This is known as disenfranchised grief, where the grief of a person is not considered to be legitimate (Doka, 1989). When these members do not feel appreciated or acknowledged as significant members, this can lead to isolation or delayed access of treatment, which can result in the need for crisis management, further complicating EOL experiences (Cartwright et al., 2012).

Barriers to receiving and accessing end-of-life care among LG older adults.

Similar to the heterosexual population, LG aging individuals face obstacles to receiving proper care throughout the EOL process, these obstacles however are often intensified for LG individuals due to a lack of support from social policies and practices (Brotman et al., 2003). Without culturally competent assistance in obtaining needed services, the experience or anticipation of discrimination and heteronormativity within EOL care settings can keep these older adults from accessing services (Cartwright et al., 2012). In addition, the failure to follow up with LG friendly environments to ensure proper care delivery leaves these older adults with few options (Cartwright et al., 2012). Moreover, for closeted rural LG individuals, couples deliberately do not engage in preparations or services that would assist the EOL process in order to maintain privacy within their residential community (Cartwright et al., 2012).

A significant barrier to receiving care for LG individuals is the configuration of

one's social network. Research in the field of EOL care emphasizes family support and informal caregiving as an available and inexpensive source of care (Manthorpe, 2003). However, when older LG adults need EOL care, these support networks may no longer be available. This speaks to the fact that personal networks do not remain static, whether referring to traditional familial bonds or chosen family bonds (Almack et al., 2010). As one gets older, personal networks may shift and shrink in ways out of one's control, and even though LG individuals may have developed informal social support networks, these networks may not be available to them in old age (Almack et al., 2010). In the absence of informal care supports, LG individuals may be required to rely on formal homecare services or be forced to consider assisted living facilities (Almack et al., 2010). These circumstances may bring them into contact with a range of people and settings not necessarily of their choosing, bringing the potential for discrimination or negative responses to their sexual orientation back into view (Almack et al., 2010).

A lack of informal support throughout the EOL process may also be a product of other barriers including geographic location, financial constraints, frailty, or failing health (Johnston, Hillier, Purdon, Pears, & Robson, 2012). However a positive EOL experience for older LG adults may involve the desire for life closure and reconciliation with these estranged members of their social network (Johnston et al., 2012). This may include making peace with loved ones, asking for and/or offering forgiveness, or just reconnecting with old friends and family to be at peace (Johnston et al., 2012). A way to eliminate these barriers to reconciliation can be through the use of technology, to provide audio visual contact with those that may not be otherwise readily accessible (Johnston et al., 2012).

The use of technology can involve barriers of its own by what is referred to as the digital divide (Mehra et al., 2004). The digital divide refers to the gap between those who have access to the internet and computer technology and those who do not (Mehra et al., 2004). The Internet has been identified as a tool to support and improve personal wellbeing for those in the margins of society, by giving them access to social support groups, programs, political events, and other online resources specific to their needs (Mehra et al., 2004). The access to these resources can help to achieve greater social equity and cultural empowerment for these marginalized individuals (Mehra et al., 2004). Online communication has been reported to help facilitate positive development of LG individuals' sexual orientation by giving them the space to express their identities and achieve social change (Mehra et al., 2004). Additional benefits can include access to EOL online resources, support groups, and programs that may ameliorate EOL stress (Brown, Maycock, & Burns, 2005).

The LGBT Technology Partnership is an American not-for-profit organization that strives to provide the LGBT community with online resources (LGBT Technology Partnership, 2013). This organization has identified a gap in research on the trends, uses, and benefits of technology within the LGBT community (LGBT Technology Partnership, 2013). Current research focuses on LGBT youth and the ways in which technology and cyber activity plays a role in their lives. For example, the Internet has been identified as advantageous for LG users due to its anonymity, as well as its ability to bring together a relatively small, geographically dispersed population (Mehra et al., 2004).

A disadvantage of online technology and a potential barrier to its use, is the victimization that can occur. One in every two LGBTQ (lesbian, gay, bisexual,

transgender, queer or questioning) adolescents are reported to have been victimized due to their sexual orientation through the use of the Internet (Varjas, Meyers, Kiperman, & Howard, 2013). These youth are more reluctant than their heterosexual peers to report this cyber victimization (Cooper & Blumenfeld, 2012). An advantage of the Internet is its growing reputation as a popular venue to develop relationships or to seek sexual partners for and by LG individuals (Brown et al., 2005; Varjas et al., 2013), but what is absent from the literature are the ways in which older LG adults use the Internet, and more specifically, the role that online technology can play in the preparation for EOL. Maintaining a sense of connection and support can enhance ones EOL experience, and a lack of access to these technological sources can prevent older LG adults from reaping these benefits.

Additionally, for some older LG adults, with increased age comes an increased devotion to spirituality and religion (Orel, 2004), however heteronormative attitudes within these organizations can raise issues of past mistreatment or exclusion, or can act as a barrier to participation altogether. When preparing for the EOL when external control over the dying process is largely out of their hands, some may look to faith and spirituality as a coping method, and to provide internal control over how death is experienced (Koenig, 2002). In a study identifying quality of life issues for older LG adults in the United States, a vast majority stated that they would be more involved in religious activities and organizations if the religious institutions were more inclusive and accepting of their sexual orientation (Orel, 2004). Just as it is important for some LG individuals to have their true identity accepted by friends, family, and the community, it was also important for these participants to feel as though they were accepted from a

religious perspective as well (Orel, 2004). As one participant states, “When you get closer to meeting your maker, you want to be sure that he knows who you are” (p. 67).

Acknowledgement of diversity. Currently EOL care and bereavement research mainly addresses the gay male population and their experiences with HIV/AIDS, so whether the experiences of the rest of the LG community differ either has yet to be examined in depth or is significantly under represented within the literature (Almack et al., 2010). One may assume that gay men and heterosexual men, and lesbians and heterosexual women share similar EOL experiences. In actuality, within the LG community, many of the trends applicable to the general population may not be accurately applied.

Within the general population older women are more likely than older men to live alone in poverty, less likely to remarry, more likely to take on a caregiving role, and rely heavily on alternative social networks in the absence of a spouse (Pinquart & Sörenson, 2001). Older women also have a greater life expectancy, increased financial difficulties, and increased risk of institutionalization (Martin-Matthews & Davidson, 1996; Statistics Canada, 2013a). The greater life expectancy among women also contributes to a greater likelihood for multiple chronic conditions throughout the EOL process (Lindsay & Almey, 1999). In comparison, heterosexual men are less likely to rely on friends and family for support and are therefore more likely to receive support primarily from their spouse (Pinquart & Sörenson, 2001). Widowed and divorced men are also more likely to remarry and are consequently less likely to live alone in old age (Arber & Ginn, 1994).

Within the LG community, gendered understandings as well as heteronormative conceptions of the family are constantly being challenged and consequently redefined

(Dalton & Bielby, 2000). Aging LG adults may therefore experience gender related bias because they do not fit into socially accepted male-female gender roles (Cahill & South, 2002). In comparison to lesbians, gay men are just as likely to be caregivers, are at an elevated risk and are more likely to live alone, and have developed just as large and supportive social networks compared to their lesbian counterparts (Brotman et al., 2007; Brotman et al., 2003; Fredriksen-Goldsen et al., 2011). Findings like these shed light on the differential life circumstances of gay men and lesbians, however research in this area is very limited, and the ways in which these circumstances may affect the ways these two groups prepare for EOL is a large gap within the literature.

A lack of documentation on the diversity within the LG population may in part be due to the structure of large population-based research that currently does not consider sexual orientation. The findings are separated into two all-encompassing gender categories as opposed to accommodating for the potential diversity of sexual orientation. The absence of emphasis on sexual orientation contributes to the invisibility of this population and impedes the development of programs, policies, and health interventions that are client centered, not only by gender but by sexual orientation.

Conclusion

Despite an abundance of general EOL literature, and the available research about the experience of aging for individuals within the LG community, EOL research is lacking the acknowledgement and understanding of diverse experiences within this minority group. This review has uncovered a need for a more comprehensive understanding of the thought process, preparations, and use of online technology with regard to EOL preparation for LG individuals, particularly in Canada. It also identified

the need to explore differences within and among LG community members. Thus, this study explored the similarities and differences between older lesbians and gay men in how they thought about and prepared for EOL as well as the role that online technology played in these preparations.

Chapter 4: Methodology

This chapter breaks down the research design. First, the paradigm and overall design of the study are described. Then, focus group methodology is explained. Next, I describe the content analysis approach and how MAXQDA was used to support the analysis. Finally, ethical guidelines to ensure the confidentiality and security of these data are described.

Design

A qualitative approach was used as it is particularly helpful when looking into the complexities of lived experiences (LaSala, 2005). The analysis was informed by a social constructivist/interpretivist paradigm due to its belief that meaning is found through interaction, and through this meaning-making process a researcher can hope to understand the reality of the participants (Daly, 2007). Due to this process and the role that the researcher plays in this interactive exchange, multiple realities can exist (Guba & Lincoln, 1994). The construction of meaning is an interpretation and may therefore be influenced by the values, standpoint, and positions of the researcher (Daly, 2007). The findings are therefore not to be used as predictions or generalisations but rather one of many potential interpretations of the experiences provided by the participants (Guba & Lincoln, 1994).

For social constructivists, conversation is relied on as a primary tool to develop an understanding of the meaning of experience (Daly, 2007). For this particular study, focus groups were used to encourage dialogue as means for the participants to make sense of their own reality through expression and discussion.

The data for this study were collected in the “Fostering End-of-Life

Conversations, Community and Care among LGBT Older Adults” research project led by principal investigators Gloria Gutman and Brian de Vries from Simon Fraser University. Therefore, this study was a secondary data analysis (Hinds, Vogel, & Clarke-Steffen, 1997). Researchers in Alberta, British Columbia, Ontario, Nova Scotia, and Quebec carried out four focus groups per provincial site with the following groups: (a) lesbian and bisexual women, (b) gay and bisexual men, (c) transgender individuals, and (d) service providers.

The type of secondary data analysis used in this research was a *subset selection analysis* (Hinds et al., 1997). Subset selection refers to the extraction of a portion of the data in order to undergo a similar but more focused analysis than the original study (Hinds et al., 1997). The original study included four types of focus groups in each of the locations: (a) gay and bisexual men, (b) lesbians and bisexual women, (c) transgender individuals, and (d) service providers. This thesis only included data from the gay and bisexual men’s and lesbian and bisexual women’s focus groups in order to explore differences in experiences between genders within the LG community.

Only one bisexual individual participated in the focus groups (a Halifax women’s group participant). Thus, this thesis focuses on lesbians and gay men to avoid misrepresentation of the bisexual population in an analysis that did not provide an adequate portrayal of their potentially unique experiences¹. To preserve the cohesive and

¹ From this point forward, the terms “gay men” and “lesbians” will be used rather than “gay and bisexual men” and “lesbians and bisexual women” when referring to the focus groups.

synergistic flow of conversation, however, this participant's comments were not removed from the transcript prior to analysis, and specific quotes from her were not used. This participant may have influenced the direction or topic of conversation, and therefore even though the bisexual perspective was not included in the analysis, a bisexual person's voice was still present within the dialogue.

Additionally, due to the fact that the transgender focus groups were not separated into male-to-female transgender individuals and female-to-male transgender individuals, it would be difficult to draw a clear comparison of male and female experiences. Moreover, the transgender experience may be completely different from the LG experience and warrants a separate analysis. As a result, data from the transgender focus groups was not included in this analysis. Due to the study's focus on the differences within the LG community, the service provider data was also excluded from this analysis.

Analysis also focused on English-speaking participants. Quebec's transcripts were only available in French and funding was unavailable for translation, therefore Quebec's data was not included in this analysis. In total, with two focus groups analysed from each of the other four provinces, eight focus groups were included in this analysis.

Prior to submitting the grant proposal for this research, each site was required to develop an advisory committee of community partners to consult for assistance and support throughout the duration of the project. A bridge between the research team and the LGBT community allowed for a collaboration of shared knowledge and experiences (Viswanathan et al., 2004). This partnership supported the development of a culturally appropriate research design that ensured quality data collection in an effective and efficient manner (Viswanathan et al., 2004). It was also beneficial when considering the

policy and practice implications of the research by ensuring that it reflected a need within the community or a gap in the understanding of the community's circumstances (Viswanathan et al., 2004).

The advisory committees were integral to the recruitment process, which followed a modified respondent-driven sampling approach, which used seeds and referrals (Heckathorn, 1997). This method reached out to the community and partnering organizations through marketing strategies including general announcements on websites, newsletters, advertisements, and participation incentives to recruit participants (Heckathorn, 1997). Potential participants were asked to contact the research teams by email or phone. Upon contact, they received an information sheet outlining the main goals of the project and the topics to be covered in the focus groups (Appendix A). Those who were interested in taking part in the study were screened to ensure eligibility (Appendix B). Those who were eligible to participate were offered a \$20 dollar gift card to one of three stores (gift card options varied by province) as compensation for participation. The gift cards were handed out at the start of each focus group.

Several criteria were used for eligibility for participation in the lesbian, gay men, and transgender groups. First, individuals had to be 60 years of age or older. Even though there is no general consensus on the criteria to which a person is considered "old", the United Nations has agreed to consider anyone 60 years of age or older, as being part of the older population (World Health Organization, 2015). Additionally, there is a theory of accelerated aging within the LG community according to Schope (2005) that describes a different outlook on the aging process, particularly for gay men who consider themselves "old" at a younger age than heterosexual men. Schope's theory of accelerated aging

(2005) further supports the age eligibility criteria of 60, rather than the age of 65 which most developed countries have accepted as the definition of “elderly” (World Health Organization, 2015). Additional inclusion criteria required that the participants be living or coping with at least one chronic condition (Appendix C), and have a basic foundation of computer literacy. If eligible, the participants were then invited to the focus group that they identified with: the gay and bisexual men’s, lesbian and bisexual women’s, or transgender individuals’ group.

The screening tool also included questions about age, sexual orientation, gender, chronic health conditions, and Internet use. Other basic information collected from the participant screening tool included whether or not the participant currently was or had ever been a caregiver to an LGBT family member or friend aged 60 and older and whether the gender to which they currently identified was different from the gender assigned at birth.

On the day of the focus group, participants completed a participant profile (Appendix D). This consisted of three sections: (a) personal characteristics, (b) social support, and (c) Internet use. A signed informed consent form was also required of each participant prior to the commencement of the focus group (Appendix E).

Focus groups were semi-structured, following an interview guide developed by the research team and not copyrighted (Appendix F). The focus groups covered three main topics: (a) issues of and preparations for care at EOL, (b) the roles of the community, and (c) the role of technology in this process. The interview guide included questions such as, “How much thought have you given to how you will handle things (e.g., your affairs) as you approach the end of your life?”, and “Who are the people with

whom you would talk about hopes, fears, and plans for the future?”. The focus groups were audiotaped (with consent), and transcribed verbatim with pseudonyms assigned and identifying information removed. Each group lasted between one and two hours.

As a research assistant on the “Fostering End-of-Life Conversations, Community and Care among LGBT Older Adults” research project, I submitted a data request form to the research team for approval (Appendix G). The request was approved and after the successful presentation of my thesis proposal, I gained access to the transcripts, participant profile sheets, and screening tools with all identifying information removed. I received only the data itself. I did not have access to any pre-existing findings or analysis, with the exception of the Halifax data analysis that I had been involved with as a research assistant to ensure an unbiased approach to my data analysis process.

Focus Group Methodology

For a complex and potentially sensitive topic such as EOL, less structure is useful for explanatory purposes by giving the participants the freedom to express their own insights and perspectives (Morgan, 1997). Thus, a focus group format presents an opportunity to potentially uncover aspects of an experience that may not have been anticipated.

The target number of participants per focus group for this research was 8 to 10. This fit within the recommended sample size, which is 6 to 10 participants (Morgan, 1997). On one hand, too many participants poses a risk for members to dominate the conversation while others did not have the opportunity to speak (Morgan, 1997). On the other hand, too few participants may not allow for the kind of synergy that is considered ideal for focus group discussions (Morgan, 1997).

The collaboration and contradiction of opinions and ideas were drawn out through this analysis, providing a range of group dynamics (Smithson, 2000; Stewart, 2007). This contributed to a level of depth in the dialogue often not found in individual interviews, group interaction being a fundamental aspect of focus group methodology (Smithson, 2000). This meant the ways participants influenced each other, new insights as the focus group progressed, and changed opinions had to be accounted for (Krueger, 1998). This was due to the evolutionary nature of focus group discussions in which participants were constantly building off of other's comments and points of view (Krueger, 1998).

Analysis

A content analysis of the data from the gay men's and lesbian women's focus group transcripts, and the accompanying screening tools and participant profiles was conducted. A content analysis approach was used in order to help pare down the large volume of text to allow for a more focused look at the themes and meanings within the transcripts that addressed this specific research question (Schreier, 2014). The data was analysed with the assistance of the qualitative data analysis software MAXQDA (version 12), using focus groups as the unit of analysis. Program features used were the logbook, basic coding, memos, retrieved segments window (see Appendix H for an example), and summary grid (see Appendix I for an example). The summary grid and the retrieved segments window were used to assist in the discovery of emerging themes by being able to activate coded segments and analyse them in a separate window.

Analytical coding was used to consider the meanings within the particular context rather than store information or identify topics within the text (Richards, 2009). An abstract approach was taken by constantly asking deeper questions and exploring the data

(Richards, 2009). As an idea or phenomenon was discovered within the data, open coding was demonstrated by attaching a code, and every time it reappeared within the data it was assigned the same code (Krueger, 1998). These pieces of data were then selectively retrieved, and viewed within the retrieved segments window in MAXQDA. This allowed for all of the coded segments from one category to be seen at once, which provided an opportunity to discover emerging themes (Richards, 2009).

A compare and contrast approach was used in this analysis by comparing the gay and bisexual men's groups with the lesbian and bisexual women's groups across the four data collection sites to identify the similarities and differences in how they thought about and prepared for EOL and the role that online technology played in these preparations. When patterns were not found within focus groups, focus groups were compared to observe bigger ideas or patterns (Krueger, 1998). Comparing and contrasting focus groups helped identify conceptual similarities that could not be identified at a micro level (Krueger, 1998).

An audit trail was used to ensure confirmability of the analytical processes and methodological decisions (Cutcliffe & McKenna, 2004). Qualitative research has been criticised for lack of control, bias, and a lack of validity (Cutcliffe & McKenna, 2004). An audit trail speaks directly to these claims by providing a detailed account of the conceptual progression of the findings (Cutcliffe & McKenna, 2004). A secondary party would then be able to track through the steps of the analytical process in order to follow, understand, and confirm the findings reported (Cutcliffe & McKenna, 2004). The audit trail was kept through the use of memos, a logbook in the MAXQDA program, and dating and saving every document draft to depict the progression of concepts and

analysis.

Memos helped organize ideas and emerging themes throughout the process. A secondary party should be able to look at the memos and see what was being considered at that point in the project (Richards, 2009). These notes were not neat or definitive but rather were a way to keep track of ideas as they grew and became more complex (Richards, 2009). All memos, no matter how small or seemingly insignificant they were at the time, could be an important contribution to the audit trail when trying to validate the data. Memos were therefore made about all aspects of the project, including the methodology, documents, codes, and emerging ideas (Richards, 2009). The logbook was used after every analysis session to keep track of what was done and what still needed to be accomplished. All memos and logbook entries were all dated to provide legitimacy as well as an explanation of the progress at that point in the process. These tools contributed to the development of an audit trail that support the trustworthiness of the findings.

The findings derived primarily from the analysis of the qualitative data. The quantitative data collected from the screening tools and participant profiles were examined in SPSS. This information was used for aggregate purposes to support the qualitative data and to provide a description of the sample.

Ethics

Prior to data collection, each site was required to receive their ethics approval from their respective Research Ethics Boards. Due to the nature of the study and broaching sensitive issues surrounding the EOL (e.g., lack of support and issues with service or community discrimination) the participants were at risk of anxiety and other negative emotions brought on by the subject area. These risks were managed by ensuring

that participants were fully informed of what the study consisted of prior to participation. These precautions were taken to prepare the participants and to minimize the chances of experiencing discomfort or shock throughout the interview. The participants were reminded that they were not obligated to engage in conversations that caused discomfort and that they could leave the study at any time without penalization. Participants were also provided with contact information for resources that would be able to assist them with any questions or concerns that emerged from the focus group discussions.

Confidentiality was ensured by removing all identifiers from the transcripts and by giving the participants the option to be referred to by a pseudonym throughout the duration of the focus group. The identities of the participants were also protected by not linking the data from the participant profiles and screening tools to the focus group transcripts. The data files were all password protected to ensure security and confidentiality throughout the analysis.

Chapter 5: Findings

The following three themes were identified: (a) the different ways in which one can prepare for EOL, (b) the concerns that may arise when considering and undergoing these preparations, and (c) the ways in which online technology can be used to facilitate these preparations and ameliorate these concerns. Preparedness for EOL was discussed from an emotional, legal, and care network standpoint, highlighting the mutual fear and uncertainty for men and women in regard to EOL, security and control versus a desire to relieve burden on others as motivators to put legal documentation in place, and the practical versus emotional approach to creating a strong care network. Financial and discriminatory concerns were emphasized by looking closely at financial stress surrounding housing and the specific concern for women about service and care provision costs, and the mutual fear and anger towards the climate of long term care for older LG adults. The last theme discusses the ways in which online technology can encourage communication and connection. More specifically, the different ways in which the men's and women's groups find online technology useful and the mutual desire for online resources pertaining to EOL preparation topics with more LG specific content are discussed. In each section the similarities and differences between the men's and women's focus groups are addressed.

Sample Description

In total, 34 men and 24 women participated across the four sites. Fifteen gay men and 12 lesbians participated in the Vancouver focus groups. Five gay men and two lesbian women participated in the Edmonton focus groups, whereas six gay men and four lesbians participated in the Toronto focus groups. Thus, the Vancouver focus groups were

larger than the recommended range of focus group participants and the ones in Toronto and Edmonton were smaller than the recommended range. Eight gay men, five lesbians, and one bisexual woman participated in the Halifax focus groups. In total the men reported approximately 173 chronic conditions and the women reported approximately 113 chronic conditions. Taking the smaller sample of women into account, both the men's and women's groups averaged 5 chronic conditions per person (4.70 for the women and 5.08 for the men). The most common for both genders was hypertension (reported by approximately 50% of the participants).

Table 2 provides demographic data for the men's and women's groups, using selected data from the participant profiles and screening tools. Participants ranged in age from 59 to 88 years, and only the men's groups had participants over the age of 79. The sample was highly educated, with approximately 60% of both groups having either a bachelor or graduate degree.

Characteristics such as living arrangements, whether or not they had children, the use of dating websites, and drafting representation agreements depicted a variety of different life circumstances among these participants. No apparent differences were found across the four cities but there were differences among the men and the women in their relationship status, living arrangements, and whether or not they have children. Men were more likely to report being single (58%) than the women (46%). This differential transcends into their living arrangements, showing that most of the men lived alone in comparison to less than half of the women. Of the participants who reported living with others, only one in five of the men lived with a spouse or partner, whereas half of the women reported doing so. Women were also twice as likely as the men to report having

children and almost twice as likely to report being a care provider for an LGBT family member or friend aged 60 or over (38%, 8 of the lesbians, and 21%, 7 of the gay men, provided care). Some additional findings from the participant profiles and screening tools will be referred to throughout the qualitative analysis, which is presented in the next section.

Table 2. *Sample Demographics by Gender*

	Gay Men (n)	Lesbians (n)
Number of Participants	34	24
Age Range	60-88	59 ^a -78
Sexual Orientation		
Bisexual		1
Gay, lesbian, or homosexual	33	20
Heterosexual or straight		
Other	1	3
Relationship Status		
Single	20	11
Legally married to man	5	
Legally married to woman	1	4
Legally recognised registered domestic partnership with man	1	
Legally recognised registered domestic partnership with woman		4
Committed relationship with man	4	
Committed relationship with woman		5
Boyfriend	2	
Girlfriend		
Not answered	1	
Children		
Yes	8	11
No	25	13
Not answered	1	

(Table 2 continues)

	Gay Men (<i>n</i>)	Lesbians (<i>n</i>)
Living Arrangements		
Alone	24	10
Spouse/partner	6	12
Spouse/partner and other family/friends	1	
Friend(s)	2	1
Family		1
Not answered	1	
Education		
8 th grade or less	1	
Some high school		1
High school diploma	2	1
Technical/trade school	2	
Some college/ university	8	7
Bachelor's degree	6	5
Graduate degree	14	10
Not answered	1	

^aAn eligibility exception was made for a 59-year old woman from Halifax who was turning 60 that year.

Table 3 describes how much the participants relied on the Internet for a range of purposes. Men and women had average scores that were similar on 10 of the 13 items. Men used the Internet more than women for dating and obtaining EOL information. Women were more likely than the men to use the Internet for keeping in contact with family.

Adding up scores on the 13 items and dividing by 13 provided an overall score for the extent to which the Internet was used by these participants. The average score of all of the participants was 1.27, falling in between 1 “just a little” and 2 “somewhat”. The women reported higher usage patterns (1.35) than the men (1.21), however this difference was not statistically significant, $t(51) = 0.84, ns$.

Table 3. *Frequency of Internet Use for Personal Tasks*

	Gay Men	Lesbians	Total
Email Friends	2.27	2.42	2.33
Pay Bills	2.00	1.92	1.96
Get News	1.73	1.83	1.77
Obtain Travel Information	1.58	1.87	1.7
Obtain Health Information	1.47	1.79	1.61
Obtain Product Information	1.3	1.5	1.39
Email Family ^a	1.28	1.83	1.51
Buy Products	1.03	1.00	1.02
Obtain EOL Information ^b	1.00	0.87	0.95
Engage in Social Networking	0.82	1.54	1.12
Send Instant Messages	0.82	0.75	0.79
Use Dating Websites ^c	0.73	0.04	0.44
Obtain Career Information	0.33	0.21	0.28

Note. Responses ranged from 0 (“Not at all”) to 3 (“Very much”) when referring to how much they used the Internet for these purposes.

^a $t(53) = 1.91, p = .05.$ ^b $t(54) = -0.47, p < .05.$ ^c $t(55) = -3.38, p < .05.$

Table 4 depicts which EOL documentation had been obtained by the participants. The three most common documents were a will, living will, and durable power of attorney—over half of all the participants had these in place. The least commonly obtained documents were critical care insurance, long term care insurance, a representation agreement, and a pre-paid funeral plan. A higher percentage of the men reported having made informal caregiving arrangements and having a pre-paid funeral

plan in place, whereas the women were more likely to have a representation agreement in place.

Table 4. *Documentation Obtained for EOL Preparation*

	Gay Men		Lesbians		Total	
	%	(n)	%	(n)	%	(n)
Will	81.8	27	75	18	78.9	45
Durable Power of Attorney	51.5	17	54.2	13	52.6	30
Living Will	51.5	17	54.2	13	52.6	30
Informal Caregiving Arrangements	36.4	12	16.7	4	28.1	16
Pre-paid Funeral Plan	33.3	11	4.2	1	21.1	12
Representation Agreement	9.1	3	25	6	15.8	9
Critical Care Insurance	9.1	3	0	0	5.3	3
Long Term Care Insurance	9.1	3	0	0	5.3	3
Not Sure	6.1	2	8.3	2	7.0	4

Table 5 lists themes and subthemes from the qualitative analysis, supported by quote excerpts. The data was analysed inductively. Second cycle coding, as described by Miles, Huberman, and Saldaña (2014), was used to group coded segments into smaller themes or constructs. Second cycle coding is used to identify patterns from the summarized segments of data that are created in first cycle coding (Miles et al., 2014). The subthemes represent codes that were grouped together into the three overarching themes.

Table 5. *Themes and Subthemes*

Theme 1: Variation in Emotional, Legal, and Care Network	
Subtheme 1: Feeling fear and uncertainty	<p>“I’m going to die alone.”</p> <p>“There’s no support whatsoever.”</p>
Subtheme 2: Pursuing security through legal documentation	<p>“We’ve done the paperwork but our main concern is how invasive is my family going to be?”</p> <p>“I was quite ill in 96 so I was strongly encouraged to do all of the preparations.”</p>
Subtheme 3: Creating and maintaining a strong care network	<p>“Government assisted programs only do so much.”</p> <p>“Everybody has these children that come in and look after you, we don’t have children.”</p>
Theme 2: Having Financial and Discriminatory Concerns	
Subtheme 1: Financial stress surrounding housing, service, and care provision	<p>“I think money colours a lot of our decision making.”</p> <p>“I was not prepared for the financial costs of [my partner’s] illness.”</p>
Subtheme 2: Fear of discrimination and exclusion in long term care and service provision	<p>“The horror of winding up in care and having to start again, pretending to find a gay joke funny.”</p> <p>“Just because I’m a lesbian doesn’t mean I don’t have the right to appropriate EOL care.”</p>
Theme 3: Using Online Technology as an Aid for Connectedness	
Subtheme 1: Online technology as a vehicle to support new and old relationships	<p>“It’s easier for me to do it that way than go to the bar.”</p> <p>“Whatever you’re into there’s a community on the net.”</p>
Subtheme 2: Access to online resources for practical and personal use	<p>“Afraid to get into it (online technology), and cut off from the world because of that.”</p> <p>“I can easily learn, but then I can just as easily forget about it.”</p>

(Table 5 continues)

Subtheme 3: Desire for online resources specific to LG EOL preparation	“She never once mentioned the situation that might apply to us.” “I’m not tech savvy but I would use a website that was geared toward the gay community.”
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Variation in Emotional, Legal, and Care Network Preparedness

This section discusses the similarities and differences between the men’s and women’s groups in the different ways they prepare for EOL. Specifically, the emotional, legal, and care network aspects of preparing for EOL are addressed, looking at the emotions related to EOL, legal documentation and preparations that were put in place to secure one’s EOL wishes, and care support that was needed and often required to help assist with EOL tasks and preparations. The subthemes, feeling fear and uncertainty, pursuing security through legal documentation, and creating and maintaining a strong care network, reflect the advantages of being prepared in all three aspects. These subthemes also address the adverse effects that neglecting to put these preparations in place can potentially have on one’s EOL experience.

Feeling fear and uncertainty. The majority of emotions expressed in all groups about EOL preparation were negative in connotation, and the most frequent emotion was fear. For example, one woman said, “I don’t have any friends, nobody I can call on, no neighbours, that’s scary.” (Women-Halifax, Mary). This uncertainty about where their care support would be coming was a significant source of fear. The unpredictable nature of life may require a person to completely rethink who would be part of their support network, but not knowing whether or not this would be the case made it difficult to know whether the configuration of their support network would stand the test of time.

I have a friend that knows everything about me, I know everything about

him, including financial, emergency, and health information and so on.

He is about 17 years younger than I am so that the assumption has always been that I will go before him. But it seems because of his health situation now, the risks are that he might go before me. So I am modifying very substantially my personal situation because he may not be around when my time comes. (Men-Edmonton, Bernard)

For some participants, the unknown referred to whether their social networks would last up until the time they would need them, but for others who found themselves isolated, they did not know whether they would have anyone there at all to care for them. Both the men's and women's groups expressed feelings of isolation and the sense of helplessness that came with it. Not having a partner, friends, or close family, and being at an age where it may be difficult to develop new relationships made preparing for EOL, which is typically so reliant on the support and foundation of unpaid networks, a big concern.

My biggest fear was that I'm going to die alone. And I remember one time I woke up in the middle of the night, I just went bolt upright and I thought, I'm going to spend the rest of my life as a lonely old man with nobody to care for me. (Men-Toronto, Harry)

Fear was not just directed at EOL in general but specifically the experience of preparing for EOL as a lesbian or gay man. For some participants this emotion was a manifestation of the realization that services were not tailored to their specific needs as an older lesbian or gay man.

If you're a lesbian or gay male, you get moved in with everybody in

general, and quite often there's no support whatsoever. Nor is there [pause] searching all night and discovering everything is very mainstream, there's nothing, nothing for us in the community for the gay and lesbian community, and it's scary. I'll be honest with you, for the first time in my lifetime I'm actually petrified. (Men-Toronto, Rod)

Being in denial, or choosing to think about EOL preparations as little as possible were expressed equally among the men and women. This emotion was closely associated to fear because some of the participants who expressed denial or a lack of caring may have resorted to such emotions as a way to avoid or cope with fear and uncertainty. For example, in the Halifax men's focus group, one participant had no idea how to prepare, so he chose not to think about it. EOL preparations can require a lot of work, and those who did not know where to start felt overwhelmed by the task, especially if they felt their specific needs as an older LG adult were not acknowledged within the preparation process. "So I'm having a difficult time. I know I have to do it. I'm having a hard time translating the documents into my reality." (Men-Halifax, Keith)

Another fear expressed by the men's and women's groups related to having responsibility for others' EOL plans. Being unsure about what to do with other people's arrangements was expressed by participants who were nervous about the responsibilities and complexities that came along with being a loved one's substitute decision maker.

Contradicting opinions occurred within both groups about whether being closer to or more exposed to death and EOL made a person more emotionally prepared or whether it made them more hesitant and fearful about what was to come. Both men and women were on either side of this debate. The difference however between those who felt more

comfortable about death and those who were more fearful came down to the actual association they had with EOL, or how it played a role in their lives. Participants who were comfortable with EOL explained their stance as a product of familiarity or exposure to death and dying through means of education or employment. For example one woman found comfort through palliative care classes and felt enlightened by what she had learned and therefore believed that the more one educated themselves on death the more comfortable that individual would be with life. One man found comfort with the idea of death as a result of working as a church organist and at a funeral parlour. By coming into contact with EOL issues that way, he felt that it didn't bother him anymore.

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 [pause] I've worked in a funeral parlour, those kinds of things, so that has never really bothered me. (Men-Edmonton, David)

The participants who expressed more concern about death were caregivers of loved ones who required a significant amount of care due to their chronic illnesses. These individuals therefore saw a very different side of EOL, the necessities of preparations, and the things that ultimately could not be prepared for including unforeseen struggles, burdens, and responsibilities. Even those who expected to be emotionally prepared found it difficult to remain positive under such circumstances. This was the case for one man who discussed how his job required that he provide help to others in similar situations and yet it would be him in the end who would seek help after having witnessed his loved ones go through the motions of EOL preparation. In the Vancouver women's group, a participant discussed how being a caregiver to her partner with early onset Alzheimer's

and other loved ones had opened her eyes to the number of things that could go wrong when trying to prepare. “Quite honestly I’m a bit scared about what will happen when it’s my turn, because I’m living so closely to EOL with Bridgette, and with Christine and Robin, that I see [pause] I know so much about what doesn’t work.” (Women-Vancouver, Chris).

In terms of differences between the women’s and men’s groups, men expressed more positive emotions than the women when EOL was discussed. This greater positivity seemed to stem from feeling secure and reassured by the preparations they had in place. “I’ve got my finances arranged and I’ve kept my sons informed on all of this. They have copies of my advanced directives and everything else. So, so far I’m quite comfortable with my EOL” (Men-Halifax, Ken). In addition, being reassured by the support of one’s identity by family members and being familiar and therefore comfortable with the presence and meaning of death were a few instances that evoked a positive outlook on the preparation process expressed by the men’s groups. Although the quantitative data (Table 4) showed that the women and the men were equally as likely to have a will, living will, and durable power of attorney in place, the men were more likely to have informal caregiving arrangements in place (36%) than the women (18%). These arrangements, in addition to the 33% of men having a pre-paid funeral plan in place (compared to 4% of the women), may have, in part, accounted for the greater sense of positivity voiced by the men.

In conclusion, fear was by far the most consistent emotion across groups, which was also expressed as being a motivator for lesbians and gay men to find security by means of legal documentation. Denial was present within the groups, potentially as a

coping method to deal with the fear and uncertainty of EOL issues and preparations. Whether or not the participant had been a caregiver for someone going through the stages of EOL also had an impact on their emotional preparedness. The men appeared to discuss EOL with more positivity than the women, which was attributed to feelings of security through protection of EOL documentation and the acceptance and support of family. The following section discusses motivators and barriers to putting legal documentation in place as another step to prepare for EOL.

Pursuing security through legal documentation. Participants described a number of motivators and barriers to obtaining legal documentation in order to prepare for EOL. The most common reasons for obtaining these documents included avoiding burden on others, having control over substitute decision makers and medical decision making, and gaining security from knowing a plan was in place. The barriers to obtaining documentation were EOL planning not being a priority, the inconvenience of continuously updating plans, and the overwhelming nature of all the recommended elements to put in place for EOL preparations.

Relieving other's burdens as a motivator for obtaining legal documentation was more prominent for the women compared to the men. This attempt to relieve burden included ensuring that all documents were organized, easy to access, and easy to follow to make the role of being an executor or power of attorney less of an imposition on whomever they entrusted. By having as much documentation in place and having it be as organized as possible, they hoped to relieve as much burden as possible. Words used by the women to describe the support that they asked of their friends and family made it appear as though they felt like an inconvenience to their loved ones. Phrases that

emphasized such a burden focused mindset included “unnecessary hassles”, “I approached her with trepidation”, “must make sure I’m minimalizing things”, “she’ll have to come dig through all my crap”, and “it just seems like a huge imposition”. For these women, having the right preparations in place seemed to be more for the sake of the convenience of others as opposed to for themselves.

Since my partner passed away, I’ve made those arrangements with my niece. So I have a will. I approached her with a little trepidation because at first she said she didn’t want to do this, so I was looking for a friend, I’m very aware that I don’t want to impose too much on my niece, so I have it organized. (Women-Toronto, DC)

Participants in the men’s groups less commonly made these kind of statements. Instead, a more prominent motivator for men putting legal documentation in order was the need for control over who their substitute decision makers were and who would be able to speak on their behalf in times of incapacitation. Specifically, legal documentation was put in place to prevent unwanted family interference.

We’ve done the paperwork but our main concern is how invasive is my family going to be? If I go first, what are they going to, pardon my French, screw around with him about doing things. Even though, yeah the i’s and t’s are crossed and dotted. (Men-Halifax, Kurt)

Despite these comments made in the men’s and women’s focus groups about the importance of naming a substitute decision maker, the participant profiles showed that only 8% of the men and 25% of women had actually put representation agreements in place. That being said, over 50% of the men and women reported having durable power

of attorney, which meant that their financial affairs would be delegated in times of incapacity. A durable power of attorney for healthcare exists, which would serve a similar purpose as the representation agreement, but the participant profile was not explicit about which document was being referenced. As a result, the exact percentage of participants that obtained documentation for protection in times of incapacity is not known.

Legal documentation was described as useful to have in place for the sake of prohibiting interference. Participants described the different places they were keeping their documents to ensure that they would be used, for example on the fridge, in their bedside table, on the wall, or in their wallet.

Don: Well, there's another thing that you can do too, and I'll throw this out at you, is that I've got a thing that fits on the wall, it's transparent, and I've got a booklet in there for emergency people to come in. As soon as you come in, it's in pink so you can't miss it, like this, and then they can get it there and they can take it with them to the hospital. And I make sure that I tell them that I need that document back again.

Bernard: You can have something in your wallet, which they would find straight away, which I have. (Men-Edmonton)

However there was also discussion about how these documents may not be as reliable as one would hope and that having these documents in place did not always provide the intended security and reassurance. Mitchell (Men-Halifax) described an incident in which a friend's EOL documentation was not used as intended due to the location of the document. The file had been created but kept on a computer for security

purposes. When the document was needed it could not be obtained because consent was required to access it but the individual was in a coma. Mitchell went on to describe the pressure the situation put on him and his friends to provide what they thought was the right guidance for their friend without access to his EOL documentation. Protocol could even be overlooked for those who did take the precautions that were recommended like having placed documents right by the door, or on the fridge so that emergency medical services could access it.

I had my mother's [EOL documents] posted right beside the doorway so when the EMS people went through the door they had to pick it up, and by the time my mother got to the hospital they'd performed three things already that they weren't supposed to. (Men-Edmonton, David)

Participants described the difficulties of being someone's substitute decision maker and having the responsibility of making sure their loved one's directives were followed in a time sensitive manner, highlighting the reality that in a time of crisis, the substitute decision maker may not be there in time to ensure that the documentation was found and followed. David also went on to discuss how the computers in the emergency room were not compatible with the hospital, and so all of the documents that had his mother's records from regular admittances could not be accessed by the emergency personnel. Such fragmentation among levels of health services made it difficult to know if the documentation arranged with a family doctor or physician would be accessible in time of emergency.

In addition to documents not being particularly reliable under certain circumstances, a number of barriers to drafting or maintaining documentation were

prominent within the focus group discussions. These barriers included personal prioritization, the potential to be overwhelmed by the magnitude of documentation options and the different requirements depending on location, and the constant effort required to maintain up-to-date documentation.

Whether or not a person had drafted documentation was mentioned in some focus groups as a matter of prioritization. Some individuals argued they had more immediate needs than taking the time and the resources to draft EOL documentation. This tied back to the participants who were not emotionally prepared and in denial about the importance of EOL planning. Those who thought they were still too young to be thinking about EOL suggested that the idea of drafting up documentation to prepare seemed unnecessary: “Can I just say that in the back of my mind, I know I’m not 20, but I’m still expecting a longevity of maybe 80 or something so I haven’t really put a lot of thought into a lot of this stuff.” (Men-Vancouver, Chuck).

Having to stay on top of the maintenance of those documents and remembering to update them every time something changed was also a barrier. The unpredictability of one’s health and the ever-changing nature of support networks left individuals with documents that did not actually apply to the scenario at hand. Even though they knew of the importance of the documents, having initially acquired them, the idea of having to go back through and update them was daunting.

I was quite ill in ’96 and so I was strongly encouraged to do all of the preparations. So I got the will done, living will and prepaid funeral, everything. Problem is now everything is outdated. I think the funeral home has closed down. I had it all ready, expecting [pause] I had a group

of friends lined up to look after me. And now it's all out of date. So it's having to get started again, and I'm putting it off. (Men-Halifax, Mitchell)

Many factors played into whether or not someone had taken the steps to get their documentation in place. Due to the sheer magnitude of documents and preparations that were recommended, the pursuit of security through legal documentation was overwhelming for some without assistance.

One difference between the men's and women's groups in terms of having legal documentation in place was the use of service providers and lawyers for assistance in this process. The men discussed relationships with service providers and lawyers and the benefits of seeking out this second opinion much more frequently than the women.

I have durable power of attorney which my son holds, not my partner, and he can only get that if I'm incapable of making a decision. He doesn't have a copy, it's with my lawyer and he has to go convince my lawyer that I'm, you know, incapable of making decisions. Cause I don't want [my son] making any for me if I can still make them. (Men-Halifax, Ken)

Meeting with a lawyer to draft EOL documentation was only discussed once by the women. Nancy (Women-Halifax) explained that she was able to consult with a lawyer because there was no cost to her.

I saw a sign for a pro bono will and a power of attorney. And I signed up for that and I got a real will and a real power of attorney, which, you know, I had never expected to have. God knows how much she bills an

hour.

The women's groups discussed having documentation in place but were not explicit about how they went about acquiring these documents and whether or not they sought external advice from a lawyer or service provider. Seeing a lawyer, as the segment above alluded to can be expensive. The fact that the presence of a lawyer was discussed more in the men's groups may speak to a difference in levels of disposable income between the genders.

The participant profiles showed that across all focus groups, the most common legal document put in place was a will, accounting for 75% of the women and 81% of the men. A will is useful to dictate decision-making after time of death, however documentation such as durable power of attorney and living wills are also important in regard to EOL to help ensure that wishes and needs are being met in times of incapacity. Having these documents in place in addition to a will were less common across the groups even though the importance of them were acknowledged. "So people say I have a will, but that's when you're dead, what about while you're alive and you're cognitively impaired or for whatever reason you can't communicate as you'd like to. A [living will] is really important." (Men-Toronto, RB). These arrangements would help dictate decision making for the participant as well as their care support networks in times of need, and yet almost half of these participants remained without these documents in place.

Even though almost half of the participants had not arranged a living will or durable power of attorney, those documents were still the two most commonly completed documents after the will. Documents that required higher financial contributions, such as critical illness insurance, long term care insurance, and a pre-paid funeral plan were more

likely to be purchased by men. Even though only 9% of the men reported having bought insurance, the fact that none of the women had may again suggest a potential difference in disposable income between the men and the women.

In conclusion, there were many motivators and barriers expressed by the participants to putting EOL documentation in place. The unreliability of documentation in certain circumstances, the absence of prioritization for EOL planning, the continuous effort required to keep documents updated, and the overwhelming nature of drafting the appropriate documents were barriers expressed by the participants. The motivators differed for the men and women. The men seemed more motivated by security and control whereas the women seemed more motivated to relieve the burden on others. Gaining the security of knowing a plan was in place also encouraged these men and women to draft EOL documentation.

Creating and maintaining a strong care network. An essential part of preparing for EOL is developing an unpaid care support network to provide care in times of need and to support the paid care support that an individual may end up receiving. The necessity and benefit of having a care team to fill in the gaps of paid service provision was fairly prominent among the men's and women's groups. Both genders agreed that it was difficult to navigate the healthcare system without having an advocate to ensure proper treatment or having a secondary care network altogether.

Even with the government assisted programs, whether it be home care or assisted living, you still need a social network to fill in the gaps around it. Cause the government assisted program only does so much. And you need that network of friends around you. (Men-Halifax, Mitchell)

In terms of professional caregivers and what we can [pause] what we get for free by our taxes [pause] and what we would have to pay for are very different. And so I certainly know for me that the need to have friends and people around who can assist me in providing support is huge.

(Women-Vancouver, Chris)

A reliance on unpaid care was frequently expressed throughout these discussions. However, many participants within these groups did not have these kind of networks available. According to the participant profiles, only 36% of the men and 18% of the women reported having informal caregiving arrangements in place. Even though the men were twice as likely to have these arrangements in place, the men and the women described a sense of stress from not knowing where they would be able to find new acquaintances to create these new bonds or whether or not they would feel comfortable doing so.

The women's groups more so than the men's groups discussed the unique position they were in as lesbian and gay older adults and the implications that this had on the structure of social networks and who they had to call on for support if necessary. The potential for having less biological kin to rely on for care was addressed, often referring to the absence of children within their care networks. Yet, even though more men's focus group participants had no children (24%) compared to the women's groups (46%), the women were more likely to speak about the disadvantages from a care perspective of not having children than the men.

The concern is we don't have children, I mean you see everybody that has

these children that come in and look after you and they help you out and shovel your snow and all these things, and I just think boy I hope I can keep doing these things, I am still able to do it for now. (Women-Halifax, Barbara)

Even the 11 female participants and 8 male participants who did have children discussed how these relationships with their children were not as supportive as they could have been. This speaks to biological family challenges. The women in particular discussed the hardships they faced with their children around topics of caregiving. For example one son said to his mother that she had to take care of herself because he did not want to. Her response was that it was fine and that she could take care of herself.

Knowing that biological kin, especially one's own child, did not want to be there to provide support was hard to accept. "The only son who lives in the city, for a long time said 'Well, you need help? Pay for it'. And that hurts because that's not love." (Women-Edmonton, Simone). Younger generations not wanting to be the ones to provide care and instead referring their loved ones to paid care services was discussed by the men as being a new generational trend in caregiving. This was very different from the mindset these participants felt they had as young adults and the responsibilities they had to take care of their older relatives.

My family looked after them [two of his older family friends] until they died because I refused to let them go into a nursing home and that was our pact with them. But we don't have that. Younger generations are not prepared to, I don't think, to do the same thing that we were prepared to do. (Men-Halifax, Kurt)

Not having the reassurance that these family members would provide that care created a sense of helplessness. For some it was a question of whether there would be anyone there at all to provide that care when needed. At an advanced age it may be difficult to make new friendships or bonds to create a new network.

The reality that social networks changed over time and that friends or family members who were once expected to provide care may not be there in time of need was addressed in both women's and men's groups. In some instances it was not that those relationships no longer existed, but rather that they were from the same age cohort and therefore were not in proper physical or mental state to provide care. Thus, the composition of the network was not conducive to putting together a care team. This added to the difficulty of acquiring new members for an individual's care network if they had experienced ageism within the community in the past and could not create bonds with younger, more able bodied acquaintances.

My contemporaries are generally my age. And they're going to die at the same time as I am. I don't have that 20-year younger group. And in our community, I mean, I'm a 75 year old man, nobody wants to be my close and intimate friend. (Men-Halifax, Keith)

Even participants who had a partner or a group of friends to rely on were still nervous or unsure about how much they could depend or rely on that one person or that small network of people. The fear of what to do or who to rely on if those few connections disappeared or were unavailable was unsettling for them.

I do have one friend who is up to his neck now taking care of somebody else. I don't know anybody else that I could even talk to. So in this city of

185,000 or whatever it is, I know one person- who's up to his neck as it is.

(Men-Halifax, Keith)

However, just as many comments from the men's and women's groups discussed feeling confident and secure about the networks that they had created and the support that they could expect from those groups. For example Mireille (Women-Toronto) and Ken (Men-Halifax) described the networks they felt they could rely on.

Friends forever. I mean, you, you meet people and you click or it doesn't click and you become friends. I've lived in Toronto for 45 years and I know the community, I know some friends that I've been friends for ages with. There's no problem here [referring to support network], for me anyway. (Toronto-Women-focus-group: 176-176/
Mireille)

I feel I have a real support group in that whole community [at church], which 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. So I've got that but everybody's got to determine their own kind of thing. (Men-Halifax, Ken)

A big difference between the men and women was in how and who they asked for help. With a few exceptions, the men talked about the deliberate choice to keep the company of younger acquaintances particularly to ensure that those individuals would be alive and able to provide support when needed.

I'm being very careful in looking at power of attorney and stuff like that because my thinking is don't get somebody your own age, because

they'll probably be gone before you are so what's the point? So I'm talking to somebody considerably younger than me. (Men-Vancouver, Adriaan)

In contrast, the women mentioned having younger friends who were available for support and expressed how grateful that they were for those bonds but were not as deliberate about the purpose of that friendship being precisely for caregiving. One woman, for example, addressed the fact that making younger friends would have been a good idea but the thought of seeking out younger friends for that purpose seemed too mercenary for her.

I'm on my own, I have only a niece as far as saddling somebody with all of this. I often think what I really should do is make younger friends, which seems so mercenary, so I haven't done anything about it. But, again, I am on my own. (Women-Vancouver, Barb)

When it came to care receiving and asking for help, even when considering some of their closest friends or family, the women's groups appeared to be more hesitant to ask members of their network for this type of assistance. The potential for burden and the potential negative implications of asking a family member or friend for assistance seemed to be a larger barrier for them, compared to the men.

The majority of the participants in the men's groups did not seem to make this process as complex as their female counterparts and appeared to be making these decisions about who they would ask more from a position of practicality rather than letting burden factor into their decision making. As a result, they seemed more comfortable developing relationships with younger people.

I purposely sought out someone who is almost twenty years younger than me. And I was lucky, a fellow that I play golf with, 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 an 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. (Men-Edmonton, David)

This difference in approach to asking for help was particularly evident when it came to asking those to whom they were not very close. For example a discussion in the Halifax women's focus group highlighted that if a bond or foundation of a friendship was not there, asking for help or asking someone to be a part of their EOL care network might seem inappropriate or uncomfortable. Interestingly, the participant profile data showed that of those women who identified as being a caregiver to someone else, 56% said it was for their partners or spouses. In contrast, 71% of the care provided by men was to friends within their social networks, suggesting a more open approach to a broader social network for the men.

You have to be willing to engage with somebody and ask them or talk to them and if you don't have somebody to talk to I guess you have to start thinking about what the options are and who you can develop relationships with. But I can't imagine myself kind of looking for people that are going to be friends so that they can look after me. (Women-Halifax, Barbara)

Overall women appeared to be more particular about who they had in their support networks and what they were willing to ask of these individuals whereas for some

of the men they would do what was necessary to develop a reliable network in preparation for EOL. The participant profile data reported on the degree of “outness” of the men and women (referring to the disclosure of their sexual orientation to others), and while majority of both groups were completely “out” to their close friends (85% of the men, and 83% of the women), the men were more likely to be completely “out” to their acquaintances (68% of the men, and 50% of the women). This tendency to be more open to acquaintances about their sexuality may be in part why the men were more comfortable asking more from the acquaintances in their social network than the women. If they are out to more members of their social network they may be less likely to hesitate to ask for help if, for example, the need for vigilance may be reduced.

Overall, barriers to a strong network included a lack of support from children or merely not having them at all to rely on and the challenges of developing new relationships as an older adult. Despite the different approaches to creating these networks and the barriers to doing so, the participants agreed that regardless of how a care network was formed, it was necessary and beneficial in order to navigate the health care system, especially when preparing for EOL. The next section discusses the financial and discriminatory concerns that can arise when thinking about and undergoing these EOL preparations.

Having Financial and Discriminatory Concerns

This section addressed concerns that participants expressed around financial and discriminatory aspects of preparation and service provision in regard to EOL. Preparations for EOL often entail seeking out or accessing care service options for assistance. It is through this process of seeking out services or new living arrangements

that many LG individuals become aware of not only the unaffordability of these services but also the lack of LG specific care and service options available. The limitations that high long term care and service costs can place on these individuals ability to access services are addressed when discussing the financial stress accompanied by the search for adequate and appropriate housing, service, and care provision. The mutual fear and frustration that is felt by the LG community towards the current climate of long term care for older LG adults is also addressed when discussing the discrimination and exclusion of LG individuals within these service provision environments.

Financial stress surrounding housing, service, and care provision. Finances and cost were a source of concern when trying to prepare for EOL due to the unpredictable nature of one's health, the services that would be required to meet one's health and lifestyle needs, and the length of time those services would need to be provided. Whether or not the person was approaching old age with significant or few financial resources had the potential to have a large impact on their quality of life.

Due to the significant role that money and care cost can play in EOL, the cost of EOL preparations, care support options, and desired care settings were acknowledged in both the men's and women's groups. That being said, the nature of the conversation about money and finance differed between the men's and women's groups. The women, again thinking about the implications of what they asked of their social network, were concerned about whether or not they were inconveniencing their female counterparts when asking for help. The relationship that women had with money was expressed differently from the men, as the women seemed to be more aware of the financial implications of community care.

I think women, or speaking for self, are constantly weighing, okay can I afford this. I think finances and our relationship with money is different than that of the male relationship with money and I think it colours a lot of our decision making in terms of what we're going to pay for, who were going to ask, are we taking them away from their income earning positions? (Women-Halifax, Susan)

The necessity of the support and care that friends, family, and other unpaid networks provided as an alternative to paid services was expressed more frequently by the women's groups. A number of these women discussed their experiences as caregivers and how if they did not have those unpaid networks and had to pay professional caregivers for the support that was being provided, they simply would not be able to afford it. Another alternative for seeking out affordable care was through government assisted programs, but even with available services, the participants expressed that it was still very limited in terms of what the government could provide.

I know with CCAC [Community Care Access Centre] um, you can get some support. Um, but it's, it's tight economic times and it's very limited as to what you can get. For people, but even if somebody comes into your home for a couple hours a day you still need other support. (Women-Toronto, DC)

Thus, even if these government assisted programs offered several hours a day of home care, the reality was that it would simply not be enough to keep an individual living in their own home. They would either have to pull together an unpaid care team or look into assisted living facilities.

Moving into long term care or an assisted living facility was also a source of financial concern that both the men's and the women's groups discussed. Approaching the transition from home to an assisted living facility with few resources could potentially translate into a lower quality facility, which was a big concern for participants in that their options were limited. "My concerns about EOL are I'm poor, I live on income assistance. Like what is going to happen to me? I'm going to be one of those people in a six bedroom at Northwood I guess."(Women-Halifax, Nancy). Even for those who may have had the money to pay for EOL services or quality assisted living facilities, the cost was still emphasized as being uncomfortably high and may be difficult to fund long term, which was expressed by both the men's and women's groups. Budgeting concerns for EOL were expressed in the women's groups along with the frustration and uncertainty around not knowing how long they would live and therefore not knowing how long they would have to make their resources last. Again even if they had tried to prepare financially, EOL could be so unpredictable that events, conditions, or illnesses could come up unexpectedly and derail financial plans or preparations currently in place. For example, as stated earlier the men had an average of 5.08 chronic conditions and the women had an average of 4.70. This averages out to approximately 5 chronic conditions per participant. The point at which these participants multiple chronic illnesses may become unmanageable is unknown, but if unprepared, the financial strain could be devastating. In the Vancouver women's group, one woman who was a caregiver for a partner in the final stages of early onset Alzheimer's discussed the financial implications of their situation and the hit that their finances took because of this unforeseen health condition.

We have all our papers in place. What I'm recognizing now at this point is that most of what we've done isn't going to work anyway. I was not prepared for the financial costs of Robin's illness. So there I was thinking that with the home I had and all of that kind of thing that I would be able to do certain things. I can't now, this disease has cost an enormous amount and I think that many of them do. (Women-Vancouver, Christine)

The cost of legal preparations also acted as a barrier to putting these documents in place. Those who were more affluent may have had an easier decision to make all of the advised arrangements, such as prepaying for a funeral or buying a cemetery plot in advance. The participant profiles showed that only one woman had prepaid for her funeral in comparison to 11 of the men. In addition, even though only 9% of the men had purchased long term care insurance and critical illness insurance, none of the women had. It may be easier to make those documents a priority without a more imminent need for that money, which may be the case for less affluent individuals. The men's groups discussed consulting a lawyer to ensure that documents such as a will were drafted properly. The participant profiles showed that men were more likely to be completely out to their health care providers than the women (82% of the men, and 71% of the women). This openness with health care providers may also have transcended into relationships with other service providers, making it potentially easier for men to have conversations of a sensitive nature that would require disclosing their sexuality. One male participant suggested to everyone in the group that if they had named an executor to their will, that it was a great idea to take that person to a lawyer who specialized in wills and to just spend

the money for half an hour with the lawyer so that he or she could explain to the executor all the details of their responsibility in that role. “Just spend the money” overlooked the fact that for many people, this would not be an affordable option.

It is important to note that the participant profile did not ask participants to report their income, so it cannot be determined whether the men or the women had higher incomes within this sample. That being said, a “more relaxed” attitude towards money seemed to be more commonly expressed by the men, compared to the women. For example, one man described how he did not need to work, but he had the option to when he wanted to because he owned his own business. He made it clear that he did not have to work for financial reasons but instead worked to get out of the house. Another man talked about using his financial stability in order to attract a partner. “I’d be the first to be looking for a young trick, I’ll be on the street buying a new partner, because I can afford it.” (Men-Toronto, Don). This nonchalant approach to money was present within the men’s groups, but concerns about finances and the affordability of services, care supports, and housing were more frequent in the women’s focus groups.

Overall, the women appeared to have a different relationship with money in comparison to the men. The necessity of unpaid care support as an alternative to paid care and the frustrations around budgeting and unforeseen service costs were mentioned more frequently by the women. The men were more likely to discuss consulting a lawyer about creating EOL documents and made more comments of a relaxed nature about spending money than the women. Despite these differences the men and women both agreed that the costs of long term care were uncomfortably high and would therefore be difficult to fund long term.

Fear of discrimination and exclusion in long term care and service provision.

The anticipation of or the actual experience of discrimination on the basis of sexual orientation within long term care and service provision settings was frequently expressed. These discussions alluded to the current lack of cultural competency among the staff and services that were not cognizant and accommodating of their needs. Aside from the services and staff, these participants also expressed fear of discrimination from the residents whom they would have to coexist with within these facilities. For these reasons, some participants expressed fear or anger towards the idea of having to go back into the closet, a choice that some residents may choose to consider in order to avoid negative interactions within assisted living facilities.

How about those [people who are] about 80 or 85, when those people are going back to the times when they were in the closet. Most of them would have been in the closet at some time, definitely stigmatized, definitely alienated, marginalized in society, but in 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. (Men-Toronto, RB)

For those of us kind of this age and older it was a deal to come out, and it was ongoing, it's not a one-time deal. So what looms large in my mind is that horror of having to wind up in care, which hopefully I won't but you know, having to start again, to pretend to find a gay joke funny. Because it's not just the staff that need training or the sensitivity, but it's the other

residents, and maybe that's the bigger challenge. (Women-Vancouver, Barb)

These participants discussed a prominent concern for this cohort when entering long term care in that it was not necessarily just the staff they had to be wary of, but also of the residents that they would have to co-exist with within these facilities. Not knowing how their peers would react to their sexual orientation led to a variety of suggested coping strategies for how to co-exist within long term care homes with heterosexual residents. The Halifax men's group had a conversation about this. One participant suggested not bringing up his sexuality in order to avoid any altercations within the living facility, and this comment was met with strong disagreement from the other participants.

Nicholas: If you're gathered around the table and you're talking about your past partners and your gay partners, with straight people who may not be understanding then it becomes a problem, it seems to me.

Brad: Well, it doesn't become a problem if you just don't talk about it.

[Overlapping voices, several group members voice disagreement]

Stephen: But you shouldn't have to.

Brad: You talk about generalities or something that everybody can relate to.

[Overlapping voices, several group members voice disagreement]

Kirk: I am hearing that a lot of people do not want to go back into the closet.

[Overlapping voices, general consensus, nodding of heads].

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. (Men-Halifax)

The anticipation of discrimination for some participants potentially stemmed from growing up in a pre-liberated society in which they were stigmatized, discriminated against, and marginalized by a homophobic and heterosexist society. Thus, their points highlighted the struggle they may potentially face when entering long term care between supporting their identity for the sake of quality of life, and choosing not to disclose their sexual orientation to a historically prejudiced cohort for the sake of safety and security.

Disappointment and frustration towards a lack of awareness of the needs of the LG population within health care settings were frequently discussed. Some were concerned about service providers being educated in the specific health complications or circumstances that may be unique to lesbians or gay men. For example in the Toronto men's group, one experience with a service provider began extremely positively but when the participant asked the doctor about whether or not anal sex would interfere with his medical situation, the mood completely changed.

I said well what does that mean for me in terms of anal sex. Well he started moving this over there, moving that away, and no more eye contact, I totally lost him on it. It just indicted to me that he's probably 40 at max, and he's got another 15, 20 years to go and he's got to learn how to talk to gay men. (Men-Toronto, RB)

The same frustration was felt when trying to find EOL care or a long term care facility that was aware of and educated to support the identities of older lesbian and gay men as opposed to pretending as though those individuals did not exist within the facilities. Many of the participants who were currently caregivers of individuals who

would be transitioning into long term care, expressed how it could be upsetting and frustrating knowing that they would have to hand over the responsibility of care to a number of staff members who may not have the education or compassion to address their loved ones specific needs. One woman in particular was trying to find a bed for her partner and was having a problem with the way the system was set up because the “first available appropriate bed” was the one they would place her partner in. She argued that an “appropriate” bed for them meant a location that had educated and trained staff on topics surrounding sexual orientation and gender identity. However the service providers would not make the effort to find a place for her partner that satisfied her needs. These were provincial sanctioned services that were allegedly supposed to support everyone, but she did not experience it as being there for the LG community.

Just because I’m a lesbian doesn’t mean that I don’t have the right to have appropriate EOL care that’s paid for by the state. (Women-Vancouver, Chris)

Due to these frustrations, the advantages and disadvantages of developing an LG friendly assisted living facility were discussed among the focus groups. Groups debated as to whether (hypothetical) funding would be better spent by putting resources toward making existing services more accommodating of their needs or on the development of an exclusive facility.

I’m not convinced that I want to see 7 million dollars put into a queer community centre. Uh I’m not convinced that I want to see a lot of resources put into a queer retirement facility. In my mind, we have reached a point in the evolution of our society that those resources

would be better spent on making sure that the facilities, the services, everything that's available now in the larger community were safe and inclusive for us. (Men-Vancouver, Kevin)

This dialogue also included comments about whether this should be approached as an old age issue or as an exclusively LG issue. "It's not just us gay people, there's this huge tsunami of older people out there... and they're dealing with physical illness, mental illness, everything, financial stresses, it's gonna be crashing down on us as a society." (Men-Vancouver, Rick)

The advantages of being in an LG exclusive home would include being able to avoid the stress and anticipation of discrimination by other residents. For most participants knowing that they would not have to be restricted in the way they acted or what they said would allow them not to be as vigilant on a day-to-day basis. The current climate in many of these facilities made these participants feel as though they may not be able to be themselves.

You feel weird when you're an outgoing person and all of a sudden you have to be restricted and that's what would happen if you weren't accepted in a senior home. Maybe you're a little less resilient because of the illness that you have, so I'm not looking forward to that. (Women-Edmonton, Simone)

Those who disagreed with the idea of an exclusive home believed that their issues and concerns were those of the aging population as a whole and therefore did not want their sexual orientation to be the deciding factor on where they should live and what services they should access. They did not want sexual orientation to be the only thing that

defined them. Brad (Men-Halifax) said, “We’re all getting older. You don’t have to, you know, actually stamp ‘gay’ or ‘straight’. We’re all in the same boat if we’re in that age bracket”, whereas Jean (Women-Edmonton) stated, “I don’t think I would want to be in an exclusively gay seniors’ home. You know I mean there’s much more to life than being gay.”

Overall, the fear and uncertainty about going into long term care and the vigilance that these participants resorted to in certain service provision environments were expressed as a result of a perceived lack of current understanding, education, and support of gender identity and sexual orientation. These participants anticipated discrimination from both staff and residents. Entering an environment with members of their cohort who were historically prejudiced toward them due to their sexual orientation produced feelings of frustration and fear. This left some to consider non-disclosure of their true identity for the sake of security upon entering long term care, and others to consider an exclusive LG friendly home to avoid the potential altercations altogether. Others believed resources would be of more use if they made already existing services more informed and supportive of LG needs. Despite these differing views on how to eliminate discrimination within these service provision settings, the desire for change was unanimous. The next section addresses how online technology was used by the participants to encourage connection, communication, and education in regards to EOL.

Using Online Technology as an Aid for Connectedness

This section discusses the different ways in which participants used technology as a vehicle to stay connected with people, accomplish tasks, and assist with EOL planning. As noted in Table 4, the men and women had similar overall levels in using Internet

technology—the men’s average was 1.20 and the women’s average was 1.35 on a scale ranging from 0 (not at all) to 3 (very much). However, differences were found within the focus group dialogues pertaining to (a) who they were communicating with through the Internet, (b) what online communication tools they were using, and (c) the availability of current online EOL resources with LG specific content. The current lack of online EOL resources with LG specific content is also discussed as a barrier to use of online technology as a primary source of information for this population.

Online technology as vehicle to support new and old relationships. Online technology was particularly useful for the maintenance and development of connections with friends, family, or new acquaintances where distance was a factor. Online tools that assisted with this were Skype, Facebook, Face Time or email.

The use of online technology to communicate with and meet new people was more frequently discussed in the men’s groups. Moreover dating sites were mentioned by the men’s groups but not at all within the women’s groups. For example, in the Toronto men’s group, a dating site called “Silver Daddies” was described. This site was used because it helped single older men make it in a “gay world” (Men-Toronto, Harry). This participant, for example, did not want to have to go to the bar to meet a partner because that environment made him uncomfortable. He used online dating sites as an alternative to find a potential match.

I’ve made a lot of friends actually around the world, doing the sites that I am a member of. It’s easier for me to do it that way than go to a bar because I’m not a bar person and the bar here is not very friendly as far as I’m concerned. In fact bars anywhere are not very friendly for me. So I

found the Internet to be a sexual release in many ways and to feel comfortable in my own skin, and be around other gay men, which is not always easy to find. (Men-Halifax, Nicholas)

Trying to develop or find a new partner or relationship was challenging for those who felt they became less desirable in the eyes of younger community members due to their age. This was expressed within the men's groups and alluded to the existence of ageism within the LG community that may make these individuals less inclined to pursue new romantic connections.

Ageism has a greater impact in the gay community than it is in the straight community. You will see widows and widowers get together. You don't see that kind of thing happening that often. . . . They're on the street looking for Prince Charming to come along, and he'll only come if you have a fat wallet." (Men-Toronto, Don)

Online dating can act as a solution by getting older LG individuals in touch with others seeking a partner with whom they may not have otherwise come into contact.

The women's groups did not discuss using the Internet for meeting new romantic partners. However, they did feel that online chat rooms could be quite beneficial for finding people to connect with on a number of different levels. Whether a person was in need of information or opinions about a particular illness, or was just looking for someone who was experiencing similar things, online chat rooms were expressed as being quite useful.

Particularly when you think you're alone and this has been true particularly for a lot of you know various, like no matter what you're

into, you're not alone, like whatever you're into there's a community on the net. Like if you're a left handed accountant that needs to dress up like a bunny. (Women-Halifax, Nancy)

Both positive and negative opinions were expressed by the women about the use of online technology for communication and staying connected with others. On the one hand, some felt that it was beneficial to be able to be in contact with someone at all times if necessary. On the other hand, some women felt as though real connections could not be made via communication through the Internet.

I spend so much time alone so it is such an important piece of just staying sane. But then you know isn't this such a totally artificial and kind of alienating construct anyway? . . . How much real connection am I having? Is there enough to sustain me in the future? You know I keep going back to the bowl, maybe it isn't really full of anything worthwhile, you know. You're still alone. (Women-Vancouver, River)

The men's and women's groups both expressed that email was their preferred communication method as opposed to other social media outlets such as Facebook or Twitter. The women, however, were more vocal about their dislike for social media whereas the men described it more positively.

A benefit of online communication expressed by the men's and women's groups was the ability to stay in contact with friends and family regardless of distance.

I send out a Christmas e-letter to I don't know, 120 people. So that more than Facebook really helps me, try and stay in touch with some people, that I don't anymore live within distance, you know, live so far away I

haven't seen some of them in many years, I don't want to forget them.

(Women-Toronto, Nancy)

For the women's groups, email was still primarily used for these long distance connections whereas the use of Skype came up more frequently in the men's groups as a great way to keep in touch.

Men's comfort with online communication may have come from familiarity and frequency of use. Some of the men's groups discussed their reliance on these modes of communication through technology as a product of using their computers for work. Thus, sending emails to communicate was just a natural extension of their jobs instead of taking the initiative to call or meet face-to-face. If the women were just using their computers for mainly communication purposes they may not feel as comfortable exploring other ways in which it can be of use. The following segment speaks to the frustration expressed in the women's groups of how quickly things change in the online world and therefore never quite feeling as though they were using the technology efficiently.

When there is a problem, I spend an increasingly large amount of time and frustration in trying to keep up, and my fear is everything is going to be online and I'm going to be stuck, I'm not going to be able to learn it, I'm not going to be able to update, I'm not going to be able to figure the new Facebook out or whatever it would be. And I don't have this grandson person for hire that they just come over and tell you what to do.

(Women-Halifax, Barbara)

Nevertheless, even though the men seemed to be more comfortable exploring different modes of online communication than their female counterparts, a general consensus was

found between the two genders that for sensitive topics such as EOL preparation, a face-to-face conversation would be more appropriate than sending an email. The men's groups suggested that the initial discussion should be in person and then follow up conversations could be over Skype or email.

I would do it face-to-face first and then maybe follow up online. But it would have to be a face-to-face thing. I'm not going to e-mail them and say, "By the way, I was thinking about my death the other day and I thought maybe you should know where to put me." (Men-Halifax, Nicholas)

In summary, technology for online communication was used differently by the men's and women's groups particularly in who they were contacting via these online tools and the variety of ways in which they were comfortable doing so. The men utilized online communication tools to create new bonds and maintain friendships and on a seemingly regular basis, alluding to a sense of comfort and familiarity not as present for some of their female counterparts. The women expressed their use of online communication tools mainly for keeping in touch with friends and family, using this outlet to maintain already formed relationships as opposed to using the Internet to seek out new relationships.

Access to online resources for practical and personal use. The convenience factor was expressed within the focus groups as one of the benefits to using online resources for practical purposes. The value of convenience for such tasks was supported by the participant profile data. For example, over half of the men and women used the Internet for online banking to some degree (this includes any participant who scored

above 0 for “online banking” on the Internet use scale). Even though using these online services seemed straight forward and therefore beneficial, some participants felt that remembering how to go through all the steps in order to relocate the web pages and follow the appropriate directions was a barrier to using the Internet for these purposes. Difficulty with remembering the necessary steps was addressed more often in the women’s groups preventing them from using online resources more often than they currently did.

I’m a dinosaur. And I’m struggling. I’m kind of caught in that place where I know that there are benefits to learning how this whole thing goes. But I am very resistant to it and so friends gave me their old computer over a year ago and I nearly threw it out the window yesterday. . . . I find the world is changing, I think a lot of disconnecting happening. There has got to be a lot of older people who are also feeling challenged by it, afraid to get into it and cut off from the world because of that.

(Women-Vancouver, Barb)

However, some comments from the men’s groups also alluded to some frustration over having to be told the instructions a number of times because they could not remember the necessary steps to complete the online tasks. “I’m using a computer, but not very much, the problem being that I can easily learn. But then I can just as easily forget about it. So it is a memory problem.” (Men-Edmonton, Bernard).

Despite this barrier to use, quite a few participants, both male and female, used online resources to look up various websites, support groups, and chat rooms as ways of mediating their stress. For example chat rooms were described as useful to discuss

medical circumstances, to navigate through tough or personal discussions before opening up to loved ones, and simply for finding a community of people like them to share stories or ask for advice.

I guess it's a website... that's called Lots of Helping Hands, and it's developed out of the United States – Alzheimer's Society, and it's a piece of technology that really allows you to connect and get people involved in your support. The other one that I'm connected to is called Talking Point, and it's out of England, and again it's one for people with dementia. And one of the interesting things that I've found about that is that they have a whole list of, like, different strands and there is one for people who are, who are queer, and there's another one for people who are supporting a spouse or a partner. (Women-Vancouver, Christine)

The difference between the men's groups and the women's groups was the women had found the websites and resources that worked for them or met their needs and sought those out. The men's groups talked about taking a more exploratory approach to the online databases for personal enjoyment, looking for resources, reading the news, and just merely "googling things". For example, one participant from the men's group expressed how fantastic it was to be able to type anything into a google search and receive thousands of answers. In contrast, the women discussed being frustrated with how many different sources were available online and one woman said she did not appreciate having to navigate through what she referred to as "all the garbage".

Interestingly enough, despite the women's tendencies to discuss the shortcomings and frustrations of the uses of online technology, the participant profile data showed that

not only did the women and men have similar levels of comfort with computers to each other, but the women actually report spending more time on the Internet for recreational purposes than the men (2.13 hours per day for the women vs. 1.64 for the men). The difference between the hours spent online daily is quite small and was not statistically significant.

Overall, the convenience of being able to accomplish practical tasks online encouraged these participants to benefit from this aspect of the technology. However, difficulty in remembering the steps by both the men and women prevented these participants from using online technology for more than they currently did. The uses of chatrooms were also discussed as being helpful for stress release as well as finding a sense of community for both the men and the women. The participant profile data showing similar comfort levels with computers, but the men expressed more of an exploratory approach to their Internet use in comparison to the women.

Desire for online resources specific to LG EOL preparation. The focus group discussions widely acknowledged the lack of EOL resources that were available for older LG adults on and offline. These discussions revealed a desire for information that spoke specifically to their needs and circumstances as aging LG community members, in order to feel reassured and secure about the EOL preparations that they had in place or wanted to create.

I did a workshop on a “just in case book”. It was ironic as heck because the woman that was doing it was sitting there and doing a very nice job of it. Except there were 8 people taking the thing and 7 were gay or lesbian. And she never once mentioned the situation that might apply to

us. (Men-Halifax, Keith)

Even though LG specific services and information were desired in all capacities and not just online, the focus group discussions emphasized the benefits of not only being able to find these documents on the Internet but also having such resources cater specifically to their LG cohort. For example, the Toronto women's focus group discussed the benefits of developing an online resource specific to LG needs. The conversation began by discussing how the resource would be used if it existed.

Facilitator So what kind of thing would you like to see? It sounds like you all use the internet to connect, what kind of platform would you like to see to provide support?

Annette: Practical information. Useful information. Where to find what. Where to get forms. Those kinds of things.

Nancy: So that would be local.

Annette: It would be most useful at the local level. What are the seniors homes that are queer friendly, you know, if it were specifically geared toward the queer community there are specific interests that we have.

However as the dialogue progressed, frustrations were voiced about trying to use government websites and how difficult it was to navigate, and how they could not figure out how to print off their advance directives and therefore had not yet done so.

Facilitator: Um. Any other ideas of how an online platform would be useful to you? What you would like to have available?

Annette: The government sites are just horrible to navigate. I've been trying to print off the last care directives, they won't even let me print it off.

Nancy: Really?

Annette: Having taken ages to find the site, and then plow through a hundred pages to find the pages I need, and now it won't let me print.

The Edmonton men's focus group talked about how people who were very technologically inclined designed websites that were just too advanced to be functional.

There is just one problem and that's sometimes you have people that know the computers inside and out, but the format they use, I can't follow it. . . . Get to the point, let's not have all this fancy stuff going on.

(Men-Edmonton, Don)

These dialogues were an example of the importance for the development of online resources to not only have useful content but also be user friendly. Even if these resources existed, they argued, if the targeted population could not navigate the website, the resource was still of no use.

The Toronto men's group discussed how a well-developed website could be used efficiently and effectively by this population when given the opportunity. An organization called "Prime Timers", which is a social group that organises educational and social activities for older gay and bisexual men, ran into financial difficulty and the solution was to transfer their newsletter into an online version to cut costs.

At the beginning about a third of the membership were able or willing to take on the online version, now we have very few who insist on the

printed version and it saved us thousands of dollars. . . . And there are so many more things that they can access online. I can put links in the online version. In fact, I've had people talk about that, how they can get to different things. (Men-Toronto, Gerry)

Even though the participant went on to explain that the transition online took about 8-10 years, the following they had developed showed that if the resources existed and were accessible to the population they were intended for, they would be used. The transition towards considering online technology as a reliable source for information may take time, but many participants expressed a willingness to overcome their technological apprehensions for the sake of having access to LG specific EOL resources if they became available. In the Vancouver men's focus group for example, a participant expressed his shortcomings with technological ability but was not willing to let that keep him from a potential resource. "I'm not very tech savvy, but I would use a website that was geared to gay community for information and health care." (Men-Vancouver, Mike).

The desire for information that was specific to their city or at the very least province was brought up more frequently in the women's groups than in the men's groups. The focus on how beneficial it would be to have information on not just LG specific content but instead local resources and services that were LG friendly seemed to stand out to these women as something that they were currently missing. For example, Annette (Women-Toronto) said, "It would be most useful at the local level. What are the seniors homes that are queer friendly, you know, if it were specifically geared toward the queer community, there are specific interests that we have". One group that was mentioned quite frequently by the men's groups was the Prime Timers organization,

which was described by the Edmonton men's focus group as being a great outlet for resources specific to EOL topics for gay and bisexual men. Prime Timers has chapters worldwide, including three of the four provinces in this study (the exception is Nova Scotia). This organization offers online links to club activities, news, and member resources, as well as links to gay friendly businesses and gay friendly doctors. The equivalent to this organization for lesbians was not addressed in women's focus group discussions and may not exist, which may have accounted for the more pressing need from the women for local sources.

Ultimately, available online resources regarding EOL preparation were dominated by heterosexually focused content, which some felt could still be valuable.

The one I'm connected to is called Talking Point, for people with dementia. . . . They have a whole list of different strands and there is one for people who are queer. When I went to the queer one there wasn't much. When I went to the spouse and partner one there was loads. . . . So if you're looking for support and information we needed to go to the heterosexual one. But people on there were all open so it all works well.

(Women-Vancouver, Chris)

For others, making do with what was available when it did not speak to their needs as LG individuals was not satisfactory enough. Instead ideas of how to create these LG specific resources were discussed in both the women's and men's groups. For example, the Vancouver men's group discussed a way to approach current organizations to encourage them to focus more on the needs of the aging LG population.

Instead of reinventing the wheel, find out what online resources currently

exist through Coast Mental Health or whoever and say okay well where's your LGBTQ section? Where does someone go for specific information and conversations around those concerns? And if you don't have one, what do we need to do to help you add that to your information? (Men-Vancouver, Kevin)

To conclude, both the men's and women's groups expressed a desire for acknowledgement that their EOL needs, experiences, and preparations may be different from those of the heterosexual population. This acknowledgement prompted similar dialogues within these groups on the current lack of LG specific content available online. Consequently the ways in which these resources could be developed and accessed through online technology to meet not only LG specific needs but also the needs of an aging cohort that may face unique technological barriers were frequently discussed.

Conclusion

This chapter discussed three themes that addressed the similarities and differences between the men's and women's focus groups. Overall more similarities than differences were found between the women and the men, showing commonalities in the mutual fear and uncertainty that the participants felt in preparation for EOL, the biggest source of uncertainty being the unknown of who would be there to look after them in their time of need. A shared fear and anger towards the current climate of long term care for older LG adults and the need for more educated staff and the development of more accepting living environments for these individuals were paramount within the groups. In addition, the desire for more online resources pertaining to EOL preparation topics with more LG specific content was expressed. Participants felt that available EOL resources were

largely geared towards the heterosexual population and accessing resources that did not acknowledge their specific needs or potential issues as older LG adults was not incentive enough to navigate potentially complex websites for information that did not speak to their reality.

Though there were more similarities than differences, the following variations in the ways to prepare for EOL and the uses of online technology to assist in the preparations showed diversity between lesbians and gay men. Looking at the different ways in which to prepare for EOL including legal documentation, emotional preparedness, and care network configuration revealed that the men's groups had tendencies towards security and control, whereas the women's groups were largely driven by the desire to relieve burden on others when discussing motivators for putting legal documentation in place. This focus on burden also transcended into the women's groups hesitation towards asking for help and therefore created a difference in the way the men's and women's groups went about creating and maintaining their care networks. The men's groups discussed a more practical approach to acquiring these individuals for support whereas the women were more affected by the implications of what they were asking their loved ones to do. When financial concerns were discussed, the frustrations about the unpredictability of care costs and the lack of governmental support for care services were heard more in the women's groups.

Exploring the ways in which online technology could be used as a vehicle of connectivity highlighted the different patterns of use between the men and the women. The women's groups seemed more direct in the ways in which they used online technology. They used sites and applications that they found worked for them and did not

necessarily experiment with other available options. The men were more exploratory in their approaches to online technology such as being open to using online dating sites, which was not discussed in the women's groups. Despite the benefits and convenience of using online technology to stay informed and connected, both the men and the women reported low scores for using the Internet to obtain EOL information. This shows that using online technology for the circulation of EOL services, preparations, and resources is not currently being used to its fullest potential.

In summary many similarities were found between the men's and women's groups, however the differences highlighted in this chapter support the need for acknowledgement of diversity within this minority population and the ways in which lesbians and gay men may consequently experience and prepare for EOL differently.

Chapter 6: Discussion

The findings section described three main themes addressing preparations for EOL, concerns associated with EOL, and the ways that technology can be used to assist with the preparation process. More similarities than differences between older lesbians and gay men were found in these themes. Similarities were found in the fear and uncertainty felt about EOL, the concern about the unaffordability and discrimination towards older LG adults within long term care and assisted living, the complexities and barriers of putting EOL documentation in place, and the desire for more online LG-specific EOL content. The differences found between the men and women contributed an additional layer of insight into how intersections of identity and social location can influence one's approach to EOL preparations. The differences were the configuration of social networks, openness to new relationships in later life, motivations for putting EOL documentation in place, and confidence in online abilities.

This chapter addresses the attempts this cohort is making to embrace the intersections of their identity as older LG adults to begin to overcome historically hostile relationships with institutions and health care providers. It also describes the establishment of new connections with unfamiliar practices like finding new romantic relationships online in later life, and using the Internet to enhance one's social capital. The ways in which the intersections of lesbians and gay men's identities and their adaptability to a changing technological society influences the way they think about and prepare for EOL are also discussed. Suggestions for future research, implications for practice, and limitations of the study conclude the chapter.

For lesbians and gay men it can be stressful knowing that the health care system

historically favours biological family networks over family of choice, and if there is estrangement from those biological networks, the urgency to make sure interference from those parties is prohibited is even more crucial (Barranti & Cohen, 2000; Cartwright et al., 2012; Hash & Netting, 2007; Hughes & Cartwright, 2014). The value of having a substitute decision maker to support the agency of the older adult and to help provide control over EOL care preferences including who will speak on their behalf (Detering et al., 2010) was emphasized within the focus groups. However, the quantitative data showed that only a quarter of the women, and even less of the men had representation agreements in place. By comparison, approximately a third of Canadians in the general population are reported to have these documents in place (Canadian Hospice Palliative Care Association, 2012). However, American LG-specific EOL literature reports that having documentation in place is more common within the LG community than in the general population (de Vries, 2014). If Canada's statistics are similar to the American data (the equivalent of the American study could not be found in a Canadian context), one factor that may play into these percentages of participants being lower than the general population average is the difference in document terminology used across provinces. For example in the participant profile, the term "representation agreement" was used to represent a document that asks the participant to name an SDM. However, this term is only used in British Columbia. In Alberta and Nova Scotia, substitute decision makers are appointed within personal directives, and in Ontario with the power of attorney for personal care. The same participant profile was used in all provinces without adjusting the terminology to reflect the proper terms for that location. This oversight may explain not only the low response rate but also why majority of those who

reported having a representation agreement were from the Vancouver focus groups. Therefore, these percentages may not accurately portray how many of these participants appoint substitute decision makers due to an unfamiliarity with the term used on the participant profile sheet.

Terminology differences are not the only way that EOL documentation differs across provinces. The number of documents required, the extent of their legal binding, and the level of involvement of the substitute decision maker also varies from province to province (Advance Care Planning, 2014; Dying with Dignity, 2011a, 2011b, 2011c). Due to the complexities of the preparation process, and the lack of a cohesive EOL approach across the country, even participants who have documentation in place still feel insecure about whether or not they will be protected in their time of need. Participants who are considering moving to be closer to family members or friends or to find a more active and supportive LG community, express the overwhelming nature of having to navigate a different health care system with different requirements for proper EOL preparation. Even though EOL documentation is in place to protect and respect the wishes of the care recipient, a combination of a complex documentation process as well as a lack of recognition of fictive kin networks (Brotman et al., 2003; Manthorpe, 2003; Wallace et al., 2011) leaves older LG adults with a sense of vigilance and insecurity when it comes to seeking protection through EOL documentation. These older adults may still find themselves in environments where heterosexist opinions occur, so having to navigate through such interactions without the security of proper documentation can put additional stress on these individuals as described by minority stress theory (Meyer, 2003).

Fear and uncertainty are two of the most consistent emotions expressed when

discussing EOL preparations. Fear is demonstrated in many ways including fear of interference by unwanted parties, discrimination in long term care and service provision, fear of not having any care support, and fear of EOL itself and the preparations it requires. The sources of fear discussed in the focus groups are anticipatory by nature, which according to minority stress theory are classified as proximal stressors (Meyer, 2003). For the LG population minority stress is felt in part due to homophobia and/or heterosexism within society (Addis, Davies, Greene, MacBride-Stewart, & Shepherd, 2009). The participants in this study are part of a cohort that grew up in and potentially came out in the pre-liberation era (Kuyper & Fokkema, 2010). Trying to foster their identity as a lesbian or gay man in such a hostile environment could have exposed them to a number of external objective stressful events such as marginalization, discrimination, segregation, and persecution due to their sexual orientation (Meyer, 1995). Even though the climate is changing for acceptance of all sexual orientations in society, these participants discuss how they are still anticipating this kind of behaviour, showing a transition from distal stress processes to proximal stress processes.

The transition into long term care and the reliance on services that are not cognizant of the needs of older LG adults are expressed as sources of proximal stress for all participants. Participants who were once immersed in an atmosphere of intolerance due to their sexuality discuss maintaining a level of vigilance in anticipation of negative events or reactions from their heterosexual peers. The imminence of such anticipatory measures is heightened when they discuss going into long term care where they will potentially once again find themselves in an environment with the same peers who considered lesbian and gay individuals as mentally ill, sexual deviants, and criminals that

should be persecuted by law during the pre-liberation era (Conger, 1975; Kuyper & Fokkema, 2010). Additionally, a significant amount of fear and distress is also expressed about the quality of care provision by long term care staff if those staff members disagree with their lifestyle and values on the basis of their sexual orientation. Transitioning into long term care should not require a person to change who they are, and the treatment and attitudes that these participants anticipate when having to stay in these facilities make these participants feel as though that would be necessary.

As a result of the negative feelings towards the current climate for older LG adults within long term care, discussions occurred about whether resources should be allocated towards an LG friendly long term care home or instead towards making living facilities that already exist more inclusive. The argument for not having an exclusive LG long term care home and instead making services that currently exist more sensitive to LG needs is to ensure that moving forward more initiatives are created to integrate LG individuals into all facets of society in a safe and inclusive way. Creating a home specifically for LG older adults ensures a safe environment but it does not work towards a more inclusive society and would instead be putting money and effort into further segregating this demographic from the rest of the population. That being said, existing research happens to agree with the participants who are in favour of an LGBT specific home (Lucco, 1987; Quam & Whitford, 1992). These sources however are not very recent and therefore may reflect opinions from a more heterosexist time period. A more recent study by de Vries (2006) shows that while respondents preferred an “LGBT-affirmative and predominant” living environment, it did not have to be exclusive to this population, and instead the inclusion of multiple generations and communities were encouraged. Views

for integration rather than segregation may be a product of today's more progressive and accepting society.

The fear of mistreatment and neglect in long term care transcends into further discussion about service providers and the lack of current training and education about sexual orientation within the health care system. Negative relationships between LG individuals and health care providers' stem from the pre-liberation era when health professionals were often provided with the task of "healing" gay men and lesbians through electroshock or aversion therapy (Daley, 1998). Thus, due to this history, some of the participants discuss being very careful about to whom they do and do not disclose their sexual orientation. This apprehension to discuss sexuality with service providers is consistent with the literature in that these conversations are often overlooked and do not occur during assessments (Brotman et al., 2003). Health care professionals may experience discomfort in discussing issues of sexuality with their aging clients (Brotman et al., 2003). Participants who are very open and honest about their sexuality with their service providers expressed disappointment with their interactions when service provider's showed discomfort about such health topics. LG individuals are often met with a broad spectrum of negative reactions from healthcare providers including embarrassment, anxiety, rejection, hostility, curiosity, pity, condescension, ostracism, withholding treatment, detachment, avoidance of physical contact, and breach of confidentiality or "outing" (Brotman et al., 2003). Service providers have an obligation to become knowledgeable about the diversity among older adults based on class, race, gender, ability, religion, ethnicity, and sexual orientation (Addis et al., 2009). Despite the comments made about fear of disclosure, or disappointment with the reactions of service

providers, the majority of the men and women report being completely out to their health care providers. This may speak to a change in dynamics between older LG adults and their health care providers and the level of openness that they are trying to achieve. At this point it may be a matter of the health care providers needing to make a more conscious effort to support and encourage these conversations. Until this service provision training is implemented, important discussions about sexual health, hormone therapy, breast cancer, hepatitis, HIV, or other potential health risks for LG individuals will continue to go unaddressed and untreated (Fredriksen-Goldsen et al., 2011).

Breaches of confidentiality or “outing” are even more likely for LG individuals who are living within assisted living facilities or long term care homes due to the exposure of their living circumstances (Price, 2005). Participants discussed the hardships of being a caregiver for their LG partner or friend because of the energy required to be an advocate for LG rights and appropriate care in a healthcare system dominated by heterosexist institutions and values. The examples described by these caregivers in the focus groups are consistent with other findings that describe common issues for caregivers of LG individuals as managing responsibilities, experiencing emotional and physical strain, and feeling tension in partner relationships in a context of reduced support and invisibility (Brotman et al., 2007; Cantor, Shippy, & Brennan, 2002). These caregivers expressed having to push the boundaries of services to make them applicable to the needs and wishes of their LG loved ones. For example, when looking for a vacant spot in long term care, the system looks for the “first available appropriate bed”. For an older LG adult, an “appropriate” bed may mean a location with educated and trained staff to ensure that all sexual orientations will be both accepted and supported within that

environment.

In the presence of a heterosexist system, the specific needs of older LG adults may not be acknowledged and the responsibility can then fall on the caregivers (if available) to ensure that proper care is provided. These feelings of obligation to ensure proper care are consistent with the literature that states caregivers often experience worry and fear when they must leave their loved ones unattended during interactions with health care professionals for fear of making them appear more vulnerable to mistreatment (Brotman et al., 2007). The caregiving participants expressed more negativity towards EOL and the preparations that it entails due to their close proximity to the ways in which the health care system and assisted living facilities were not meeting the needs of their LG partners or friends.

Having an advocate to help navigate the health care system is important to receiving proper care. The necessity of these supports is due to certain services requiring a primary caregiver to oversee and assist with care provision in between formal care (Gomes & Higginson, 2004). Quality care may therefore require a partnership between paid and unpaid caregivers that all older LG adults may not be able to provide. Due to reasons such as restricted access to traditional sources of caregivers, such as children or a spouse, older LG adults are less likely to have a caregiver to provide support than the general population (Croghan, Moone, & Olsen, 2014). In this study, many participants did not feel they had anyone in their lives to advocate for them, and the realization that this could restrict the kind of care they could receive was unsettling to them. It was these participants, both male and female, who exposed the presence of isolation within the older LG community and the fear that can come along with not having anyone to care for

them. The spectrum of social networks described is consistent with the literature that reports the presence of strong social networks but also significant relative isolation within the LG community (Brotman et al., 2007).

A contributing factor to the isolation of this population is the potential estrangement from biological networks (Barranti & Cohen, 2000). Participants varied in terms of how they described the strength and value of relationships with biological family members. According to Brotman et al. (2003) and Hays et al. (1997), few LG participants maintain positive relationships with members of their families of origin, largely due to the disclosure of sexual orientation. However for these participants, estrangement from biological networks due to sexual orientation was rarely discussed. Instead, they emphasised the varying degrees to which they felt they could rely on different members of their biological networks and this did not appear to be different for the lesbians or gay men. When difficulties with biological relationships were brought up it was to discuss the generational differences in care approaches. The current mentality towards caregiving for younger generations is that someone else will take care of it, and if support is needed there are services available to provide that care. The expectations of the participants who had children however, who grew up providing care for their friends and family, was that their children would be willing to do the same for them, and were upset and disappointed by this change in attitude. Even though this difference in attitudes towards support was apparent, complete estrangement from these family members was still not discussed, and instead these participants discussed the relationships that they could rely on in the absence of this support. These findings are therefore more consistent with White and Cant's (2003) finding that although few LG people report cases of estrangement from

biological families, daily support is instead provided by partners, ex partners, or friends.

Living arrangements are potential indicators of isolation for older LG adults (Brotman et al., 2003). For example, American research states that half of aging gay adult men live alone compared to about a sixth of heterosexual men, placing gay men in a more susceptible position for isolation (Fredriksen-Goldsen et al., 2011; Wallace et al., 2011). About one third of older gay men are married or are living with a partner, whereas more than three quarters of heterosexual older men are married or living with a partner (Wallace et al., 2011). One in four older lesbians live alone compared to one in five heterosexual women and this isolation can place them at a higher risk of self-neglect, decreased quality of life, and increased mortality (Herdt, Beeler, & Rawls, 1997, Peterson & Bricker-Jenkins, 1996; Quam & Whitford, 1992). In this study, the majority of the men and just below half of the women were single and lived alone. These percentages are higher than percentages found in other research (Fredriksen-Goldsen et al., 2011; Wallace et al., 2011), so using living arrangements and relationship status as measures of isolation would appear to describe this sample of older LG adults as significantly isolated. However, the presence of reliable social networks that occur within these focus groups contradicts the relative isolation that these percentages portray. This speaks to a number of other factors that can play into isolation. A person who lives alone or is not in a relationship may still have other meaningful relationships and aspects of their lives that keep them from an isolated lifestyle.

A useful avenue to help reduce the chances of isolation is the use of the Internet as a means to stay connected, engaged, and informed (Friemel, 2006). However, one point affirmed by many of these participants was about the desire for more online LG

specific content.

Due to the fact that being connected to the Internet is so closely linked to social inclusion, social support, and social capital in today's society (Morris, Goodman, & Brading, 2007), the lack of information available on usage patterns gives little indication of how much of the LG population is not currently online and consequently how many are being disadvantaged by a lack of access (Friemel, 2016). A barrier to Internet use is motivational indifference, meaning there is a perceived uselessness of the information on the Internet, or little perceived relevance to one's life (Friemel, 2016). This is a particularly salient issue within the focus groups for participants expressed that they would use the Internet as a source for finding EOL preparation information if that specific content was available. The content that is particularly relevant to their lives as LG individuals is either currently nonexistent or too difficult to find for it to be worth the effort. Even if useful sources are currently available, frustrations were expressed with websites that were not user friendly or too complex to navigate efficiently.

Having these resources cater to an aging LG population require not only LG specific content but also easy to navigate websites to prevent a complex website from deterring users. Online resources should be developed with an aging population in mind. In doing so, these older LG adults can use online resources to feel more informed instead of feeling disconnected as a result of a lack of online access.

Overall, the similarities between the lesbians and gay men are quite apparent when discussing the topics mentioned above, including the fear and uncertainty that these participants experience when thinking about and preparing for EOL, the concern about discrimination and the unaffordability of long term care, the complexities and barriers of

putting EOL documentation in place, and the desire for more online LG specific content.

There were fewer differences found between the women and men. However, the following section demonstrates that by looking at the different motivators for putting EOL documentation in place, the configuration of social networks, openness to new relationships in later life, and confidence in online abilities, diversity within this population is evident. Table 6 provides a brief overview of these differences. It describes the topic in which the difference lies, the theme it is associated with, and the ways in which the men and women differ in their approaches or beliefs.

Table 6. *EOL Preparation Differences between Gay Men and Lesbians*

	Theme ^a	Gay Men	Lesbians
Motivation for EOL documentation	1	Security	Avoid burden on others
Configuration of social networks	1	New and old bonds	Stronger reliance on old bonds
Willingness to ask for help	1	Open/Casual	Hesitant/Selective
Caregiving roles	1, 2	Friends	Spouse/Partner
Relationship with money	2	Varied	Stressed
Self-described approach to online technology	3	Explorative/Multi-purpose	Complex/Purpose-driven

^aTheme 1: Variation in Emotional, Legal, and Care Network Preparedness. Theme 2:

Having Financial and Discriminatory Concerns. Theme 3: Using Online Technology as an Aid for Connectedness.

Similar to the general population, older LG adults face obstacles to receiving proper care throughout the EOL process (Brotman et al., 2003). However these challenges are amplified for older LG adults due to a lack of support by social policies

and practices (Brotman et al., 2003). In an attempt to ameliorate the effects of a lack of institutional support, older gay men and lesbians often rely on fictive kin networks made up of partners and friends (Barranti & Cohen, 2000). This population is therefore encouraged to put EOL documentation in place to ensure that their wishes will be recognised by a health care system currently perceived to be neglecting the needs of a population with diverse sexualities and gender identities (Detering et al., 2010; Hash & Netting, 2007; Pennant, Bayliss, & Meads, 2009). The motivation behind putting these documents in place appear to be different for the men and women in this study. A significant motivator for the women to obtain legal documentation is to alleviate burden on others, and for the men it is more to ensure security and control over who will be involved in the decision making process in times of incapacitation. These two main findings are consistent with literature that discuss older LG adult's reasoning behind planning for EOL care (Cartwright et al., 2012; Detering et al., 2010; Hughes & Cartwright, 2014). For example, Hash and Netting (2007) discuss avoiding becoming a burden on loved ones, ability to cope with current health conditions, and increased feelings of security as motivators to engage in the documentation preparation process. The findings from this research however, allow for a closer look at how gay men and lesbians were motivated differently.

The motivations to develop new social networks also differed between the lesbians and gay men. Even though strong informal care networks are quite common within the LG community, the desire for an intimate relationship is expressed quite frequently by the men. In fact, wanting to find new romantic partners was only discussed within the men's groups. This could be because more of the men were single in this

sample than the women, or it could be a reflection of some of the patterns seen in the heterosexual community where men are more likely to remarry or re-enter a relationship in later life to maintain a strong social network, whereas women tend to rely on their friends and family in later life in the absence of a partner or spouse (Lindsay & Almey, 1999). Whatever the reasoning may be, the search for a partner and therefore the struggles of dating as an older gay male within the gay community were discussed across the men's groups. Gay culture is particularly youth focused, making the older cohorts of men appear less desirable (Brotman et al., 2003; Suen, 2015). Moreover, sexuality among older adults in the general population is often a taboo subject that often goes unrecognised due to society's preference to see older people as sexless (Addis et al., 2009). The intersection of these social identities creates a multi-level experience of oppression that leaves the older gay men feeling uncomfortable with pursuing new romantic connections. Finding younger men who would provide companionship in exchange for payment was discussed. Yet, developing a meaningful connection at that point in their lives was described by some as being difficult and having to pay for these interactions was acknowledged as an alternative to being alone.

In the effort to assuage the challenges of not only meeting other gay men but also those with similar intentions, some of these men discussed using online dating sites as an avenue to meeting new people. Meeting other lesbian or gay individuals may be difficult so for these men it may have been easier to meet other men online. When meeting people online, a person can find out if the potential partner has the same intentions without having to put themselves out there in public. This was important for those who would not usually attend or feel comfortable in typical meeting spots (Suen, 2015). Dating sites

have become quite a new phenomenon for the general population and research has been conducted on the ways in which lesbian and gay men present themselves on their online profiles (Morgan, Richards, & VanNess, 2010), however the frequency of use, the benefits of engaging with others online for this purpose, and the role it can play in EOL preparation have not yet been discussed.

It is important to note that just because online dating or seeking out new romantic partners are not discussed within the women's groups does not necessarily mean that it does not occur. However, the tendency for these men to be seeking new relationships does correspond with this study's findings about the differences in how men and women go about creating and maintaining their support networks as older adults. The women showed more hesitancy towards creating new bonds in older adulthood, feeling uncomfortable with the concept of making new connections for the purpose of having more people to rely on in times of need. The men however do not express this hesitancy to the same degree and appear to be more comfortable relying on people outside their close friends and family for support and social interaction. The men's apparent broader social networks and reliance on a variety of different people may contribute to the higher rates of positivity when discussing the emotional preparedness for EOL. Despite the reported levels of anxiety being very similar, and the average number of chronic conditions being similar between the men and women, the women expressed more negative emotions towards EOL and the preparations it entailed. The men expressed positivity through the confidence they had in their social networks, and the security they felt due to the preparations they had in place. The quantitative data also showed the men being more likely to be completely "out" to acquaintances than the women, potentially

suggesting they are more open to the possibility of expanding their networks and developing new bonds later in life. In contrast, the women seem more inclined to rely on the bonds they cultivated prior to entering older adulthood and putting effort into maintaining those bonds than creating new ones. That being said, little is known about the desire for intimacy and relationships for LG individuals within this cohort (Suen, 2015) and so it cannot be said for certain what the needs of these men and women are when the preferences and patterns of dating are inadequately addressed within available research.

Research states that married or cohabiting people typically stand the best chance of staying out of long term care because of a “live-in support system” (Cohen, Tell, & Wallack, 1986). For a heterosexual male, living alone and being single may be circumstances that would suggest the need for institutionalization at the point when EOL support was necessary due to the absence of spousal or familial care support within the home (Cohen, Tell, & Wallack, 1986). However, even though majority of the men in this sample reported being single and living alone, informal care networks available to some of these men may ameliorate the urgency of formal service provision when support is required.

When discussing patterns of caregiving between the lesbians and gay men, more women reported helping someone with care than the men. Additionally, the majority of the women who reported being caregivers were providing care for their partners or spouses. Yet majority of the men who reported being caregivers were providing care to friends within their social networks, implying that even in the absence of a live in partner or spouse, care may still be available to keep these men in their homes. Existing research

shows that the nature of the caregiving role (i.e., spousal vs. non-spousal caregiving) can have very different implications on the demands of caregiving, as well as the health and financial implications it can have on the caregiver (Reinhard, Levine, & Samis, 2014). Spousal caregivers can face the loss of their income as well as the income of their partner or spouse, shrinking of their savings due to unforeseen caregiving costs, as well as risking diminishing retirement income because of fewer pension contributions (Houser & Gibson, 2008; Reinhard, Levine, & Samis, 2014). Spousal caregivers are also less likely to accept help because they do not see themselves as caregivers and rather see their roles of care as an extension of their role as a spouse. As a result, they often try to take on the responsibilities of care alone and suffer financially and physically from doing so (Reinhard, Levine, & Samis, 2014). As a non-spousal caregiver, often times support is provided within a “circle of care”, meaning a group of friends come together to contribute to the care of their loved ones (Reinhard, Levine, & Samis, 2014). Caregiving in this role can still have its demands, but the financial burden and independent mentality may not be as common (Reinhard, Levine, & Samis, 2014).

Research on sexual orientation and income in Canada shows that the personal income of gay men is less than their heterosexual counterparts and the personal income of lesbians is more than heterosexual women (Carpenter, 2008). However, research that compares the financial status of lesbians and gay men in Canada could not be found. In addition, the participant profile did not ask specifically about income brackets to help provide financial context. Therefore, the fact that the women expressed concerns more often about the financial demands of EOL cannot be assumed to be a product of a difference in socioeconomic status. The concerns regarding finances expressed by the

women were most often in relation to high service costs, not enough government assistance, and unforeseen caregiving expenses. One factor that may influence the prevalence of financial concerns or comments that allude to high service costs is the role of caregiving. Of the women who identified as caregivers, the majority of them were caring for their spouses or partners. This type of caregiving is attributed to more financial demands than non-spousal caregiving roles (Reinhard, Levine, & Samis, 2014). The majority of the men providing care were supporting friends, which may not have elicited as many comments about the financial caregiving demands. Therefore, the financial concerns expressed by the women may not be due to lower socio-economic status, but rather as a result of more financial caregiving demands. If the men were in similar caregiving roles as the women, and were faced with similar financial demands, more comments about the financial aspects of care and service provision may have been made.

Older men and women may use online technology in different ways. The current research looking at patterns of online technology use for men and women suggests that a “digital divide” that used to exist is no longer a concern (based on a sample of participants ranging from age 18 to 81) (Hargittai & Shafer, 2006). A digital divide refers to the inequality in access that men and women have to the Internet (Hargittai & Shafer, 2006). Concerns about a digital divide refer to the fact that more daily activities are moving online and those who do not have access to the Internet, or the “non-users”, may be at a disadvantage by not being given the opportunity to benefit from the medium as “users” are (Dobransky & Hargittai, 2012; Friemel, 2016; Hargittai & Shafer, 2006).

Research from the United States demonstrates that this digital divide of access no longer exists, however, a difference of attitudes towards the use of online technology

remains (Hargittai & Shafer, 2006). Hargittai and Shafer (2006) found that the men had significantly more positive attitudes towards computers than the women, and it was the negative attitudes towards computers that discouraged the women from extensive computer use. The difference in attitude towards online technology from the men and women in Hargittai and Shafer's (2006) research are consistent with the attitudes of the participants in this study. The men discussed the use of technology in a positive manner and noted how they used the Internet for a variety of purposes. In contrast, the women were more vocal about the frustrations and faults of being online technology users. Yet, women reported just as high comfort levels with computers as the men did, despite their tendency towards negative feedback within the focus group dialogues. These two findings appear to be contradictory, however the participant profile asked the participants what their comfort level with computers was and was not explicit about what tasks they had to be comfortable performing. Furthermore, the women expressed that one of the main reasons they used online technology was to stay in contact with others, and as a result used email quite frequently. Therefore, if they used the computer primarily for emailing friends and family and they were quite comfortable doing so, their comfort level scores on the participant profile would be quite high. In the focus group discussions however, when asked about the different ways that they use online technology and when asked about performing tasks online that may be outside of their usual routine, feelings of discomfort and frustration were expressed.

The men reported a more exploratory approach to using the Internet, using the medium for a variety of reasons as opposed to just communicating with others, and therefore their high comfort level scores in the participant profile were more consistent

with what was expressed within the focus groups. These gendered attitudes towards online abilities discussed in the available literature (Dobransky & Hargittai, 2012; Friemel, 2016; Hargittai & Shafer, 2006) are apparent within the focus groups, because the ability of the women to use online technology is demonstrated, but the lack of confidence in themselves to explore the different ways in which it can benefit them leads to barriers of use (Hargittai & Shafer, 2006).

The digital divide may no longer be a concern between men and women but there is still a divide between younger and older cohorts, now referred to as the grey divide (Morris et al., 2007). Even though age is a significant variable in patterns of online use, it is not well represented within the online technology literature, and even fewer articles discuss Internet use patterns of older LG adults. Friemel (2016) also discussed one's social network as being a contributor to whether or not an older adult is an online user or not. Specifically, the support provided among one's social network can strongly influence whether or not a person adopts the use of the Internet (Friemel, 2016). Encouragement from children was the most significant source of support for an older individual to engage in online use compared to support provided by grandchildren, friends, siblings, and life partners (Friemel, 2016).

Older LG adults may not have children to provide this support and encouragement, and this was discussed more so in the women's groups, even though more of the men in the sample did not have children. The fact that the women were more aware of the absence of children to assist them with online technology problems may again be influenced by the lower level of perceived ability that women are reported to have when it comes to online technology skill in comparison to their male counterparts

(Hargittai & Shafer, 2006). This lower level of perceived ability may make the women more inclined to seek help as opposed to exploring the Internet on their own.

Many similarities existed between the lesbians and gay men in how they prepared for EOL and used online technology to assist in these EOL preparations. However, there were aspects of the preparation process to which these two groups differed. This variation speaks to the different experiences that can exist within one minority population as a result of the intersections of age, gender, and sexuality. The findings from this research were consistent with much of the literature on EOL for older LG adults (Cartwright et al., 2012; Detering et al., 2010; Hash & Netting, 2007; Hughes & Cartwright, 2014). However the differences found by taking an intersectional approach to this analysis provide a closer look at the heterogeneity within the LG community by addressing differences around motivations for pursuing legal documentation, the search for new romantic partners in later life via online dating sites, and the patterns of use of online technology to assist with EOL preparations.

In conclusion, more similarities were found between the lesbians and gay men in their preparations for EOL and their use of online technology for EOL purposes. However, even though there were only few differences found, looking further within the different intersections of the LG community was necessary to gather a better understanding of the heterogeneity of this population. Going forward, research that involves the LG community should be more cognizant of the different intersections that exist within this population in order to gather a more in depth understanding of their experiences and needs.

Policy and Practice Implications

More similarities than differences were found between older lesbians and gay men when looking at the ways in which they think about and prepare for EOL, and the role that online technology plays in these preparations, and because of this the importance of taking an intersectionality approach may be overlooked. However, by considering the intersections of age, gender, and sexuality and the ways in which they can create multiple different realities within one population (Hankivsky, 2014), a better understanding of EOL preparation emerges. This, in turn, can allow for a more comprehensive approach to developing resources, services, and policies that address the diverse range of needs and experiences within the older LG population.

This study shows that in regard to EOL resources, what is currently available online does not have enough LG specific content for these participants to consider them helpful. Additionally, online resources were not formatted in a way that these participants found user-friendly. Therefore, finding ways to encourage these older adults to consider online technology as a useful resource requires that there be content available that acknowledges and addresses the interests, questions, and experiences of older LG cohorts. To address this current content/format gap, more initiative needs to be taken to provide content that specifically caters towards the LG population and takes into consideration the life events, experiences, and abilities of this cohort. For EOL content in particular, if these participants are not comfortable discussing such topics with their healthcare or service providers, there must be an alternative way to access this information to ensure that EOL preparations are being made, and any potential concerns are being alleviated. A more comprehensive approach must be taken to develop a more inclusive online database to ensure that online technology can be a reliable and user-

friendly source for older LG adults.

The need for inclusivity and acknowledgment of the needs and values of the older LG population is not limited to the online technology forum. Significant progress has been made in the acknowledgement of the rights of the LG population, however within legal and healthcare environments the configuration of LG social networks are still unrecognised due to the prioritization of families constructed by marriage or blood ties (Brotman et al., 2003; Manthorpe, 2003; Wallace et al., 2011). Within these environments families of choice still may not be recognised in areas such as visiting terms and medical decision making (Irving, Bor, & Cataan, 1995; Turner & Catania, 1997). Even with EOL documentation in place, older LG adults may still feel insecure about whether or not their wishes, values, and intended role of their partner or loved ones will be respected in times of incapacity (Barranti & Cohen, 2000). Though research exists on further education of staff and service providers to be more culturally competent, inclusive, and aware of the needs of different sexual orientations (Eliason, Dibble, & DeJoseph, 2010; Makadon, 2006), a reconfiguration of the policies that uphold the prioritization of blood and marriage ties over the networks of LG individuals is also necessary.

Working towards creating safer and more inclusive long term care environments is paramount to older LG individuals' mental and physical wellbeing and peace of mind when discussing EOL preparations. Currently, due to the growing aging population there is a high demand for beds in long term care and assisted living facilities (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). The protocol for admission differs by province and depends on whether it is a private, not for profit, or government funded (Banerjee,

2007). Some long term care homes in Ontario, for example, offer services and/or prioritized placement for residents with specific needs (e.g. religious, spiritual, or ethno-cultural) (Government of Ontario, 2014), however evidence that the particular needs of older LG adults are factored into their LTC placement and service provision could not be found. For an older LG adult, this can mean that if the bed that becomes available is not in an inclusive environment that can ensure the older LG adults' identity would be supported and respected, there may be little room for negotiation depending on the circumstances. This calls for reform in what the system considers "appropriate" when placing an LG resident in a long term care facility. For example, if the staff have not gone through sensitivity training, and are not aware of the needs of older LG adults, this particular facility should not be considered an "appropriate" placement for this resident. Without sensitivity training, conversations between health care providers, staff, and residents may not take place due to a lack of awareness as well as a lack of knowledge on how to appropriately address the health issues and needs that may be unique to these individuals (Fredriksen-Goldsen, 2011). Thus, without a culturally competent care approach, these residents may be at risk of inadequate care.

Lastly, a barrier to preparation for EOL from a legal perspective is the overwhelming magnitude of recommended documents. When trying to find out which documents are necessary in order to develop a secure advance directive it is difficult to find clear and concise guidelines. This is in part due to the different requirements that each province has recommended in order to secure EOL plans. Due to its provincial jurisdiction, trying to work towards a national approach to EOL planning is currently not an attainable feat, however, working towards universal EOL documentation terminology

is a start to alleviating some of the stress and confusion when trying to ensure that all of the proper preparations are in place, especially in the event of having to move to a different province.

Limitations and Future Research

My role as a research assistant on the original research project, and my familiarity with the project acted as an advantage throughout the analysis process because I did not have to overcome the barrier that some face with secondary data analysis of feeling too far removed from the data (Boslaugh, 2007). However my involvement with the original study may also have acted as a limitation. Because I had worked closely at one site of data collection, I needed to approach the analysis process being cognisant of the need for dispelling my assumptions of what the other sites data would show. I had to approach the data set with an unbiased perspective to allow the analysis process to bring forth other themes, ideas, and patterns than what was seen in the Halifax data.

Another limitation relates to having focus group transcripts. In a focus group, much can be communicated through body language or even through the intensity of one's voice. The volume, the speed, and the emphasis on certain words in a sentence can change how it is interpreted (Krueger, 1998). Reactions like these can be lost in a transcript-based analysis. I only had access to the Halifax digital audio files if I had needed to go back to review anything.

Using focus groups as the unit of analysis also came with its own limitations. Focus group research uses group interaction as a fundamental aspect of its method, but this interaction can be influenced by the dominant opinions and ideas of certain participants (Morgan, 1997; Smithson, 2000; Stewart, 2007). In a group setting

participants may be more inclined to give responses influenced by social desirability or less inclined to voice an opinion that contradicts with the views of the majority (Stewart, 2007). Under these circumstances participants may feel pressured to “group think” or give way to the opinions of persuasive and dominant participants (Smithson, 2000; Stewart, 2007).

Participants can take a focus group conversation in many directions (Krueger, 1998), and this was the case in this study, even though there was an interview guide. In other words, the topics that were discussed were dictated by not only the moderator but also the participants themselves, giving the participants more control over the direction of the discussion than in many other methods of research (Smithson, 2000). In certain instances this made it difficult to decipher patterns or consistent views within the data (Krueger, 1998). For example, due to this study being cross-provincial, multiple research team members facilitated the focus group discussions. Some facilitators followed the interview guide more closely than others, allowing for the conversation to go in different directions exploring themes and experiences that were not addressed in other groups. In cases like those, the lack of pattern was an enlightening discovery in itself, and though it did not allow for a comparison with comments of a similar nature, the presence of such findings were still valuable.

Group size can be a limitation. Three of the four sites had sample sizes above or below the recommended number of participants per focus group, which may have influenced the synergy of the group discussion. On the one hand, the Edmonton women’s group, for example, consisted of just two women who were partners, which made conversation difficult to facilitate and the desired synergy of dialogue challenging to reach

(Morgan, 1997) did not occur. On the other hand, the Vancouver focus groups consisted of 15 men and 12 women, which led to a few participants dominating the conversation while the remaining participants did not have the opportunity to speak.

Focus group data has also been criticized as being difficult to interpret, but this was avoided by taking the appropriate methodological approach to using focus groups as the unit of analysis by not going about it as individual interview data (Stewart, 2007). This was achieved by focusing on the interaction of participants and the discourse that emerged from the context of the group as a whole, rather than treating each individual as a unit of analysis (Smithson, 2000).

Those who volunteered to participate in this study may have been more comfortable with their sexuality (Orel, 2004). This sample was limited to those who were prepared to self-identify. Moreover, because the research was about EOL preparedness, it may have been that older LG adults who were hard to reach or were not willing to self-identify may have had more challenges (Orel, 2004). The needs of those who did not readily disclose their sexuality may be considerably different than those who are active within the LG community (Orel, 2004).

Despite these limitations, the analysis of these data attempted to capture an understanding of the similarities and differences between how older lesbians and gay men prepare for EOL and use online technology with regard to EOL preparation. An advantage of addressing the limitations of a study is they often assist in deciphering the areas of opportunity for future research that fell outside the scope of the research project.

Several ideas emerge for future research. To start, obtaining a better idea of where the older LG population stands in terms of computer literacy and online access is an

important step to bridging the gap in access to more EOL resources. This study provided a good look at the different patterns of use of online technology for older LG adults, however one of the screening criteria was that these participants had to have a basic level of computer literacy in order to be eligible. Therefore the data from this sample looks at how older LG adults who are already online users engage with online technology. The experience of older LG adults who are not currently online and the reasoning behind this absence of an online presence have yet to be investigated. The digital divide existed between heterosexual males and females and is said to still exist between generational cohorts. Whether or not there is a digital divide within the older LG population requires further exploration. Internet access is closely linked to increased social capital, social support, and social inclusion (Morris, Goodman, & Brading, 2007). Thus, it is crucial if there is a subset of this population experiencing barriers to online technology access, that it be addressed in order to reduce the potential for stratification within the LG population.

Those who had the reassurance of a strong support network expressed more positivity and security towards EOL preparations. Therefore, whether or not these older LG adults had a social network to rely on when preparing for EOL impacted their emotional preparedness. One of the biggest differences found between the men and women when discussing social networks was the different degrees of willingness to create new relationships as they aged and the configuration of the networks that they felt comfortable relying on. The potential difference in how older lesbian and gay men create and maintain relationships in later life should be further explored to take a closer look at how the configuration of one's social network can influence their preparedness for EOL.

Finally, only one participant in this study resided in a rural area and therefore this

perspective was virtually absent from this data set. Research can be conducted in rural locations to see if there is a potential difference in access to resources, the degree of “outness”, and the configuration of one’s social networks in relation to EOL preparation for older LG adults in smaller communities (Lee & Quam, 2013). Whether or not the different characteristics of rural communities would influence the ways in which rural older lesbians and gay men think about and prepare for EOL, as well as the role online technology plays in these preparations, has yet to be explored.

Reflexivity

When working from a social constructivist/interpretivist paradigm, the researchers play a significant role, for it is through her or his interpretation of the data that meaning is created (Daly, 2007). It is therefore important for me to state my position, values, and background as the researcher who analysed this data. As a young heterosexual female, I did not have an extensive background of knowledge regarding the lived experiences of the LG community. Methodological sources referred to my position as a researcher as being “non-affiliated” or as an “outsider”, as compared to an LG researcher who would have been referred to as an “affiliate” or an “insider” (McClennan, 2003). My non-affiliated research position could have been seen as a disadvantage, and had actually been verbalized as an objection to me prior to the start of the study. To overcome doubts of my ability to produce a meaningful and culturally sensitive analysis of this topic, I educated myself on emerging strategies that other non-affiliated researchers have taken to overcome these barriers (McClennan, 2003; Viswanathan et al., 2004). The first strategy was to prepare for further objections. Having worked closely as a research assistant with the research teams and community partners involved in this research project, I gained a

significant amount of insight into the complexities of this topic area. In addition, several of the researchers affiliated with the project, both locally and nationally, identified as lesbian or gay, which reassured me that with their insight and contributions to the development of the research plan, the data that I was analysing was collected in a culturally sensitive way. That experience gave me more confidence about proceeding with the analysis of these data and made me secure in my capabilities as a non-affiliated researcher. Being a reliable non-affiliated researcher is dependent on “unbiased openness and honesty in the approach to understanding an unfamiliar culture” (McClennan, 2003, p. 38). To accomplish this, I sought the advice, support, and guidance of the network of experienced colleagues and community members that I had the privilege to meet throughout the duration of this project. My thesis committee was also a resource that was used for consultation, as it included two of the researchers in the original research project: Dr. Brian de Vries and Dr. Áine Humble. The analysis process benefitted from multiple insights and feedback from these committee members who were not only familiar with the original research project but also had expertise in this research area.

“Being knowledgeable, sensitive, and culturally unbiased can compensate for cultural difference” (McClennan, 2003, p. 38). This quote from McClennan’s experience as a non-affiliated researcher speaks to the advantage that this position can have in terms of providing an unbiased perspective. Compensating for cultural difference by a non-affiliated researcher also requires a cultural humility approach (California Health Advocates, 2016). This required constant self-awareness, reflection, and consideration as a non-affiliate while respecting that only an individual who identifies with the minority group would be able to truly understand their experience (California Health Advocates,

2016). “Inside” investigators bring previous knowledge and understanding to the content but this could have led to an assumption of what would be found within the data due to common cultural perceptions (LaSala, 2003). If a researcher expected to see certain themes come out in the data, they may have overlooked unique perspectives. The unfamiliarity with the culture as an “outside” investigator then became an advantage by eliminating any expectation of common themes (La Sala, 2003). It is important to note that all of the aspects that contributed to my position as a researcher on this project reinforce the social constructivist belief that this analysis was just one interpretation, and can therefore cannot be used as generalizations.

In addition, my undergraduate and graduate education have been dedicated to the field of gerontology, making the EOL a topic of familiarity. I believe the combination of these experiences helped me in my efforts as a researcher to maintain the integrity of the data and the meanings and interpretations that were constructed throughout the analysis process.

Conclusion

Older LG adults are known as a “twice hidden” population, a minority within a minority (de Vries, 2014). This is a subset of the population that has to work diligently to support their own identities in a youth driven society with historically heterosexist values, still upheld by institutions of power and influence within society. Research on the lived experiences of older LG cohorts is often limited to the understanding of this population by the ways in which they compare to the heterosexual population.

The experiences, life events, and social realities of this population are still being measured against the age graded normative events that structure the lives of many within the heterosexual population, projecting gender norms and expectations on to LG

individuals that are often incompatible with their lifestyles. This study, looking at the similarities and differences of older lesbians and gay men in the way that they think about and prepare for EOL, and the role that online technology can play in these preparations, was an attempt to branch away from the heterosexual comparison and instead explore the intersections that exist within this minority population.

Many similarities were found in the ways older lesbians and gay men prepare for EOL, the concerns they have when thinking about and undergoing these extensive preparations, and the ways in which they use, or at least desire to use online technology to stay connected and informed in regards to EOL. The similarities between the women and men included the overwhelming fear and uncertainty that accompanied their thoughts and preparations, the processes and complexities that kept them from obtaining proper EOL documentation, their concern about and anticipation of discrimination within long term care and service provision, the concern about the financial implications of EOL, and the need for more LG specific content online to answer their questions about EOL that speak to their experiences and life circumstances.

Many similarities existed between the gay men and lesbians, but the differences that emerged from this analysis spoke to a heterogeneity within this population that is often missing from current LG EOL literature. The differences were the configuration of social networks and the motivations behind maintaining and creating new bonds, openness to new romantic relationships in later life, motivations and barriers for putting EOL documentation in place, and confidence levels in their online technological abilities.

With the discovery of this diversity, policy and practice implications need to be established in order to encourage the reconfiguration of policies that uphold the

prioritization of blood and marriage ties over LG networks in legal and health care environments and to encourage efforts towards a national strategy for universal EOL documentation terminology to help eliminate some of the confusion and complexities around obtaining proper EOL documentation.

In conclusion, the diversity that lies within the older LG community can no longer be confined to comparisons with their heterosexual counterparts. Older lesbians and gay men may not only have different EOL plans, thoughts, and experiences from straight men and women, but may also approach EOL differently from one another. It is the different intersections of their identities, gender, age, and sexuality that must be further explored in order to ensure that their needs regarding EOL are no longer overlooked.

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Appendix A: Information Sheet

**Information Sheet/Invitation for LGBT Persons 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 researchers at Dalhousie University and Mount Saint Vincent University in conjunction with colleagues from the Simon Fraser University, University of Alberta, University of Waterloo, and University of Quebec at Montreal, as well as community groups in these cities.

This project is funded by the Technology Evaluation in the Elderly Network (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 Simon Fraser University.

Currently, we are seeking LGBT individuals from Nova Scotia, age 60 or over, who are fluent in English, who are living with or caring for a person with a chronic health condition(s), and who have some email experience and access, to participate in a focus group of approximately 8 to 10 persons. These focus groups will take about 2 hours of your time. The focus group will be held in the Halifax Regional Municipality in an easy-to-get to location.

If you are interested in participating in this important national study, please email LGBT-end-of-life-care-study@msvu.ca or leave your telephone number at 902-494-6620. A member of our research staff will call you, go over details of the study, answer any questions you may have and confirm that you are eligible to participate. Specifically, you will be asked to give your year of birth, to indicate if you self-identify as lesbian, gay, bisexual and/or transgender, and about the chronic conditions you or the person you are caring for may be living with and

about your internet experience and access. If you choose to participate, and depending on how you self-identify, you will be scheduled for one of three groups: (1) gay and bisexual men, (2) lesbians and bisexual women, or (3) transgender women and men. The exact date and time will be decided after the groups are formed so as to be convenient for the group.

On the day of the focus group, before it starts, if you have not yet signed the attached consent form you will be asked to do. You will also be asked basic demographic questions (e.g. marital/relationship status, housing and living arrangement), and extent of late life/end-of- life preparation to date, such as completion of a will or representation agreement, and discussions with significant others. The conversation will be audio-recorded and later transcribed for analysis. A gift card of \$25 will be offered in gratitude for your participation in 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 any of the personal services or your relationship with any organization which may have connected you to this project. If you choose to withdraw from the study, the data from your participant sheet will be destroyed.

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. You may choose to use your own name in the focus group meeting or use a pseudonym, but your real name will not appear in transcriptions or in 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 Jacqueline.Gahagan@dal.ca or (902) 494-1155 or Dr. Áine Humble at Aine.Humble@msvu.ca or (902) 457-6109.

If you want to speak to someone uninvolved with the study, or talk about concerns regarding the study, you 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/a 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 B: 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, proceed to Question 2.
 - c. **50-58**
 - 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 No

5. Do you have any of the following chronic health conditions? (Read list of chronic conditions- see Appendix M)

- a. No
 - i. Proceed to Question 6.
- b. Yes
 - i. _____
 - ii. 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 Question 5 , proceed to Ineligibility Response
 - ii. If participant answered “Yes” to Question 5, proceed to Question 9.

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?

Sobey's ____ 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 C: List of Chronic Conditions

Have you been told by a doctor that you have any of the following conditions?

[Read each category, offering conditions as examples]	<u>[If yes, Check below]</u>
<u>Heart/Circulation</u>	
Congestive Heart Failure	
Coronary Artery Disease	
Hypertension (High Blood Pressure)	
High Cholesterol	
Peripheral Vascular Disease	
<u>Neurological</u>	
Alzheimer’s Disease or other dementia	
Parkinsonism	
Stroke	
<u>Musculo-Skeletal</u>	
Arthritis/Rheumatism	
Hip Fracture	
Other Bone Fracture	
Osteoporosis	
<u>Senses</u>	
Cataract	
Glaucoma	

Problems reading or seeing distances even when wearing glasses	
Problems hearing everyday speech even when wearing a hearing aid	
<u>Mental Health</u>	
Depression	
Anxiety	
Other Psychiatric condition	
<u>Infections</u>	
HIV Infection/AIDS	
Hepatitis	
Pneumonia	
Tuberculosis	
Urinary Tract Infection (in last 30 days)	
<u>Other Diseases</u>	
Cancer, in the past 5 years (not including skin cancer)	
Diabetes	
Asthma, Emphysema, Chronic Obstructive Pulmonary Disease	
Gastritis	
Eating Disorder (obesity, anorexia)	
Renal Failure/Kidney Disease	
Thyroid Disease	
Substance Abuse Disorder (Drug/Alcohol abuse)	

None of the above	
Other current diagnoses [please specify]	

Appendix D: Participant Profile

**“Fostering End-Of-Life Conversations, Community and Care
Among LGBT Older Adults”**

LGBT Participant Profile

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
(specify)_____

Other (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	Some what	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

9. 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
- 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

10. 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_____**)

11. 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 _____**)

12. 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

13. 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

14. 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

15. 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

16. 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)? _____

17. 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 C: INTERNET USE

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

- Not at all
 Somewhat
 Mostly
 Completely

19. 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

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

	Very much	Somewhat	Just a little	Not at all
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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	2	1	0
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 E: Informed Consent Form



Informed Consent Form for LGBT Participants

“Fostering End-of-Life Conversations, Community and Care Among LGBT Older Adults”

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

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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), to voluntarily participate in a focus group. 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) 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.

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/a 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)

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Appendix F: 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 G: Qualitative Data Request

Requested By:

Sarah Paterson, MA student

Department and Institution:

Department of Family Studies and Gerontology, Mount Saint Vincent University

Requested from:

TVN Research Group “Fostering End-Of-Life Conversations, Community and Care Among LGBT Older Adults”

Purpose:

Master’s Thesis (for Master of Arts in Family Studies and Gerontology)

Thesis Supervisor:

Dr. Áine Humble

Data Requested:

I am requesting (a) focus group transcripts, (b) screening tools, and (c) participant profiles for the English-speaking gay and bisexual men’s groups and lesbians’s groups for which participants were screened prior to participating in their focus groups. This limits data to the following three cities: (a) Halifax, (b) Toronto, and (c) Vancouver. Data was also collected in Montreal, however this thesis will be limited to the focus groups that were transcribed in English due to a shortage of resources for translation of the French transcripts. Also the data will be limited to focus group for which screening took place prior to the focus groups so that the protocol for participation is consistent across the sites. If the Edmonton site does complete screening prior to its focus groups then, the Edmonton data would be requested as well.

Rationale for Data Request:

This master’s thesis will compare how older gay and bisexual men and older lesbians think about and plan for end-of-life decision making. Current literature discusses how within the general population older women are more likely to live alone and in poverty, less likely to remarry, are more likely to take on a caregiving role, and rely heavily on alternative social networks in the absence of a spouse (Novak & Campbell, 2006). Older women also have a greater life expectancy, increased financial difficulties and increased risk of institutionalization (Novak & Campbell, 2006; Martin-Matthews, 1999). The greater life expectancy among women also contributes to a greater likelihood for multiple chronic conditions at the end of life (Lindsay, 1999 as cited in Novak & Campbell, 2006). In comparison, heterosexual men are less likely to have developed the same extensive social networks throughout the life course and are therefore more likely to receive

support primarily from their spouse (Novak & Campbell, 2006). Widowed and divorced men are also more likely to remarry and are consequently less likely to live alone in old age (Novak & Campbell, 2006). These trends impact the kind of support that is available as well as how one experiences, plans and prepares for end-of-life.

Within the LGBT community, many of the trends applicable to the general population cannot be accurately applied. Aging LGBT adults may also experience gender related bias because they do not fit into socially accepted male-female gender roles (Cahill & South, 2002). In comparison to lesbians, gay men are just as likely to be caregivers, are at an elevated risk to live alone, and have developed just as large and supportive social networks as their lesbian counterparts (Fredriksen-Goldsen, Kim, Emler, Muraco Erosheva & Hoy-Ellis, 2011; Brotman, Ryan & Cormier, 2003; Brotman, Ryan, Collins, Chamberland, Cormier & Julien, 2007). This variation in life circumstances in older adulthood may impact how end-of-life is experienced and planned for by these individuals.

This qualitative analysis will allow for a closer look at the similarities and differences between how older lesbians and older gay and bisexual men think about and prepare for end of life. This thesis will also seek to understand the fact that these two groups represent a heterogeneous population, as the diversity within the LGBT population is often overlooked or underrepresented in current literature (Addis, Davies, Greene, Macbride-Stewart & Shepherd, 2009).

Time Frame:

I would require the data after I present my thesis proposal (April 2015) and obtain ethics approval from MSVU following the completion of their research ethics form “application for use of secondary data”.

References

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Novak, M. W., & Campbell, L. D. (2006). *Aging and society: A Canadian perspective* (6th ed.). Scarborough, Ontario: Nelson Canada.

Appendix H: Retrieved Segments Window

The screenshot displays the 'Retrieved Segments' window, which is organized into three main sections:

- Left Panel (Document System):** A hierarchical tree view showing the structure of the data. It includes folders for 'Documents' (Halifax, Toronto, Edmonton, Vancouver) and 'Code System' (Being 'Out' in Health Care Settings, Care Receiving, Care Providing, End-of-Life Concerns, Discrimination, Family Challenges, Family of Origin, Family of Choice, Unknowns, Resource Distribution, Isolation, Burden on Others, Cost, Social Safety Net).
- Middle Panel (List):** A table listing segments with columns for 'D', '#', and a color-coded status indicator.

D	#	Status
4513	1512	Yellow
320	692	Yellow
834	493	Yellow
341	1119	Yellow
541	578	Yellow
1048	354	Yellow
694	694	Yellow
- Right Panel (Detailed View):** A transcript of a conversation with segments highlighted in blue. The text includes:

I can't imagine like, well I don't know Nancy, you don't seem to mind this but I can't imagine myself kind of looking for people that are going to be friends so that they can look after me?

And my sister is probably a likely care giver, if she retires in three or four years so you know that might be the time in which I would start to need extra care, but my god that would be a terrible thing to do to her.

[Sharon laughs]

Carol: You know, leave your home, come in and sleep on my sofa bed and look after cranky old Carol.

And the other issue for me is making sure that everything is in order, so that my daughter doesn't have unnecessary hassles.

Yes I've also made, uh, since my partner passed away, um, made those arrangements with my niece. Um, so I have a will, and similar to what you said, um, and I approached my niece with a little trepidation because at first she said she didn't want to do this, so I was looking for a friend, um, and, and I'm very aware that I don't want to impose too much on my niece, so I have it organized and I'm trying to really, um, make sure that I'm

Appendix I: Summary Grid

Summary Grid

Women-Halifax-focus-group-transcript - Burden on Others

Code System	Wom...	Men...	Wom...	Men...	Edmo...	Edmo...	Wom...	Men...
End-of-Life Preparation								
Emotional Preparedness								
Denial								
Awareness								
Discussions								
Legal Documents								
End-of-Life Care								
Care Settings								
Being "Out" in Health Care Setti								
Care Receiving								
Care Providing								
End-of-Life Concerns								
Discrimination								
Family Challenges								
Family of Origin								
Family of Choice								
Unknowns								
Resource Distribution								
Isolation								
Burden on Others								
Cost								
Social Safety Net								
Community								
Partners								
Friends								
Family								
Information Resources								
LGBT Inclusive/ Exclusive								
Technology								
Online								
Communication								
Desired								
Accessed								

Coded segments

I've wanted to do as much as I possibly can to prevent someone else having to go through what I have had to go through
[70-70 \(0\) End-of-Life Concerns](#), [Burden on Others](#)

I know that it's really unfortunate when someone dies without a will, you fuck everybody else up. It's not just you being capricious.
[82-82 \(0\) End-of-Life Concerns](#), [Burden on Others](#)

I have been winnowing my possessions, so I have thrown away a huge amount of stuff because it'll be my sister with whom I am drifting apart or my best ex who will have to come and dig through all my crap. And so I want to, I want to make that task as easy as possible for them. So that's a, yah so the end of my life before it's the end where the hell am I going to be? And how can I make it as easy as possible for people who probably don't want to have anything to do with going through my stuff but by default will have to.
[82-82 \(0\) End-of-Life Concerns](#), [Burden on Others](#)

And my ex in [location removed] would give up her job and her wife for a certain length of time but....
[117-117 \(0\) End-of-Life Concerns](#), [Burden on Others](#)

Like I, like we have neighbours, you were talking about neighbours, we have a few neighbours in our little area, and they're very nice, we go for walks sometimes together and things like that, but they're also older and they're kind of like acquaintances rather than friends. I don't know if I want to ask somebody like that, you know it's kind of, it's more my sense of, doesn't seem right. You know? Like...

Jacquie: Like does it feel like it might be an inappropriate imposition or?

Summary

Burden on others is a strong theme, in that people make certain arrangements or plans, as well as reconsider asking people/ family/ friends for support in the hope to minimize the burden they are putting on them. They do not want to be an inconvenience to their loved ones.