

The Caring Experiences of LGBT Older Adults

“NONE OF US CAN GO IT ALONE”: THE INFORMAL CARING EXPERIENCES OF
LGBT OLDER ADULTS

By SOPHIE GEFFROS, B.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree Master of Arts

McMaster University © Copyright by Sophie Geffros, August 2019

MA Thesis – S. Geffros; McMaster University – Department of Health, Aging, and Society

McMaster University MASTER OF ARTS (2019) Hamilton, Ontario (Health, Aging, & Society)

TITLE: “None of us can go it alone”: The Informal Caring Experiences of LGBT Older Adults AUTHOR: Sophie Geffros, B.A. (McMaster University) SUPERVISOR: Dr. M. Griffin NUMBER OF PAGES: v, 115

LAY ABSTRACT

This paper examines the experiences of LGBT older adults giving and receiving informal care for physical or mental health conditions. It highlights themes of stigma and autonomy, the relationship between community caregiving and political advocacy, the legacy of the HIV/AIDS epidemic, and how LGBT older adults hold each other and the dead in personhood. Seven LGBT older adults from Southern Ontario were interviewed about their experiences with care, and the relationship between social structures and discrimination and their personal experiences with the medical system.

Abstract

This paper examines the caring experiences of 7 LGBT older adults in Southwestern Ontario. Up to 2 90-minute interviews were conducted with 7 participants which were then transcribed and analyzed using interpretive phenomenological analysis (IPA). Participants described life histories of discrimination and isolation, as well as contemporary experiences of medical discrimination. As a result, participants were highly skeptical of the formal care system, with only one indicating they would be willing to enter long term care.

Analysis was conducted according to four themes that were identified while engaging in the interpretive phenomenological process. The research was influenced by life course theory and cultural scripts: specifically, that the current cohort of LGBT+ older adults is perhaps the first to age openly in their identity and as a result lack cultural scripts as to what they should do as they age. Questions were open-ended and asked participants about their experiences giving or receiving care, life histories of discrimination, and how their care experiences influence their plans for the future. Although no questions were directly asked about the HIV/AIDS epidemic, the legacy of the HIV/AIDS epidemic on contemporary LGBT older adults became a major theme of this paper. Other themes identified include the role that stigma and concerns about autonomy play in their plans for the future, the importance of political advocacy and community caregiving for LGBT older adults, and how LGBT older adults have developed resiliency and the practice of holding loved ones in personhood in order to cope with medical issues and death.

Acknowledgements

I have received a great deal of support and assistance throughout the process of writing this thesis. I would first like to thank my supervisor, Dr. Meridith Griffin, for her enthusiasm and support throughout this project. I would also like to thank my committee members, Dr. Gavin Andrews and Dr. Randy Jackson.

Thank you as well to my participants and to the ONDP LGBTQ+ Committee, to the Toronto Bi+ Network, the 519, and the OPSEU Rainbow Alliance for their assistance in sourcing participants for this work.

Thank you to my mother Susan Suter for always taking my panicked phone calls and for listening patiently while I verbally restructured my entire thesis while we were unloading groceries. You believed in me even when I wasn't sure if I believed in myself.

Thank you to my grandparents, Dawn and Corie Suter, for showing me what love, caregiving, and a good death can look like. Thank you for always supporting my dreams. Grandpa, I wish you were alive to read this, but I think you would be proud.

Finally, thank you to my partner Olivia for your love, support, and willingness to listen when I needed you. I couldn't have done it without you.

Table of Contents

1. Chapter 1:	
Introduction	3
Literature Review	6
The Scope of the Problem....	6
Discrimination and Healthcare access	10
Unique Challenges for LGBT Older Adult Health	12
Transgender Aging and Embodiment	16
Stress Factors and the Minority Stress Model	19
Qualitative Experiences of Care	21
Reciprocal Caregiving and the Legacy of HIV/AIDS	26
2. Chapter 2: Methodology	31
Life Course Theory ...	31
Cultural Scripts...	33
Interpretive Phenomenological Analysis	35
Methods	38
Sampling & Sample Characteristics	39
3. Chapter 3: Stigma, Autonomy, and Care	46
Gender Nonconformity, Stigma, and Intersecting Oppressions	46
Sources of Stigma	54
Autonomy and Plans for the Future	57
Personal Care in LGBT Identity	61

4.	Chapter 4: Community Caregiving and Political Activism	68
	Health Justice and Health Advocacy	69
	Community Care Networks	69
5.	Chapter 5: Legacy of the AIDS Epidemic	81
	Long-Term Survivors of HIV	82
	Caregiving Legacy	84
	AIDS Survivor Syndrome....	91
6.	Chapter 6: Hope, Holding, and Letting Go: Resiliency and Personhood....	95
	Holding in Personhood....	95
	Battling an Imperfect Identity	96
	Personhood, Death, and Dying	97
	Holding the Dead in Personhood	100
	Advanced Directives and Medically Assisted Dying	103
	Communal Responsibilities	106
7.	Chapter 7: Discussion and Conclusions	108
	Limitations	113
	Recommendations for Community Care	117

1. Introduction

Over the next decade, it is anticipated that the population of older adults who identify as part of the 2SLGBTQ+ community will nearly double (Fredriksen-Golden et.al, 2015; Conron, Mimiaga, & Landers, 2010). Despite a lack of comprehensive studies of the 2SLGBTQ+ older adult communities in Canada, American studies indicate that there are currently more than 3 million Americans over the age of 65 who identify as members of the 2SLGBTQ+ community. While data remains limited, there is a scientific consensus that 2SLGBTQ+ individuals experience higher rates of physical and mental health issues, and that 2SLGBTQ+ older adults experience aging-related frailty at an earlier age than their cisgendered and heterosexual peers (Kimmel, Rose, & David, 2006). Despite these challenges, they are also significantly less likely to seek formal care, particularly in the form of long-term care facilities (Fredriksen-Goldsen et. al., 2015). Community care networks also play a larger role in the lives of 2SLGBTQ+ individuals: in the absence of positive kinship ties, fictive kin often step in to perform care that is usually provided by blood relations. These norms of community care are deeply political, and are experienced across the 2SLGBTQ+ population: the few studies that exist around community care for older 2SLGBTQ+ adults indicate extremely strong in-group ties and a suspicion of assistance from outside the communities, with one older Canadian lesbian saying “We have to take care of each other... I don’t trust anyone else.”(Aronson, 1998, pg.509).

The aim of this thesis is to highlight and analyse those caregiving relationships, and to consider what factors influence caregiving in LGBT older adults. I will look at the role of stigma and autonomy as factors that influence the kind of care that LGBT older adults seek, examine how fictive kin networks are formed and what kind of care structures exist, and reflect on how the legacy of the AIDS epidemic continues to shape norms of care and community in the LGBT older adult community.

A Note on Language

Whenever possible, and when referring to specific cases, I will indicate what specific subcommunity of the 2SLGBTQIA+ community to which an individual belongs. 2SLGBTQIA+ is usually understood to refer to 2-Spirit people, lesbians, gays, bisexuals, trans people, queer-identified people, intersex people, and asexual people. There is a great deal of diversity within the community, who are broadly linked by life experiences wherein they experience or perform gender identity and romantic/sexual attraction in a way that is outside of what is considered to be the norm by the cisgender and heterosexual majority. Despite this link, there is a great deal of diversity in terms of how these different communities, and members of those communities, experience heterosexism and cissexism. It is for this reason that I will indicate how participants identify and will use specific language whenever possible.

Although I actively sought participants from all parts of the broader 2SLGBTQ+ community, my sample reflects only the “LGBT” portion, as none of my participants identified as Two-Spirit, intersex, or asexual. While it is likely that many of the experiences expressed by the LGBT older adults in my sample are shared or experienced similarly by other members of the community, I cannot know for certain and

it would be inappropriate to imply otherwise. The use of LGBT, in contrast to the more inclusive 2SLGBTQIA+ should not be understood as a diminishment or erasure of those who identify as queer, Two-Spirit, intersex or asexual: it is instead an attempt to accurately represent the sample population without claiming knowledge of the experience of groups not included in the sample.

Literature Review

LGBT Older Adults: The Scope of The Problem

Research on the caregiving experiences of LGBT older adults is limited, particularly research with a qualitative focus or a Canadian location frame. When analysing the extant research, I found that nearly every paper shared one of four limitations: scope, diversity of sample, focus, and location frame. While some papers studied qualitative experiences of care in the gay and lesbian community, and some covered the general caregiving experiences of LGBT older adults from a quantitative perspective, very few considered the qualitative experiences of transgender people and only one, from 1998, considered community care for LGBT older adults in a Canadian context.

Despite a lack of comprehensive studies on LGBT older adults in Canada, it can be broadly assumed that the LGBT older adult community is large and growing (Teaster et al., 2011). American studies indicate that there are currently over 3 million Americans over the age of 65 who identify as members of the LGBT community, and that number is expected to more than double over the next decade as the comparably more sexually liberal Baby Boomer generation continues to age ([Erdley, Anklam, & Reardon, 2014](#)). This group has unique care needs that have not historically been well-accommodated by the mainstream medical system ([Muraco & Fredriksen-Goldsen, 2011](#)), and indeed older LGBTQ2SIA+ adults are significantly more likely to report a negative interaction with the medical system. For example, the Caring and Aging with Pride/CAGE Study (2011), which surveyed thousands of LGBT older adults, reported that over 80% of

transgender older adults indicated that on at least one occasion they had been denied care due to their gender identity.

In her 2014 paper *Friends, Family, and Caregiving Among Midlife and Older Lesbian, Gay, Bisexual, and Transgender Adults*, Catherine Croghan combined the data from the over 15,000 participants in the CAGE study with the MetLife (2010) survey of LGBT baby boomers in order to perform quantitative analysis on the LGBT older adult population, something which she was prompted to do after co-authoring a study on US Area Agencies on Aging (Knochel et al., 2012). This study had found that fewer than 13% of agencies conducted outreach to the LGBT community, fewer than 8% reported any LGBT-targeted services, and less than one third had any staff training on LGBT-specific aging issues (Knochel et al., 2012). Sixty percent of the agencies surveyed did not believe it was necessary to address issues specific to LGBT older adults, and although the majority indicated that LGBT older adults would be welcomed by their local services, a full 25% believed that they would not be welcomed or were unsure of the kind of welcome they would receive. Croghan (2014) therefore focused her efforts on the high rates of informal and non-kin caregiving present in the LGBT community, which she posits as being a response to the lack of service providers who are able to adequately care for LGBT older adults. In her analysis, she found that while about 10% of caregivers in the United States provide care to someone who is not legally related to them (Barker, 2002), about 27% of LGBT adults over 50 are providing informal care. Of the sample, about 35% are providing care to a partner or spouse, with 39% caring for a non-related friend or community member. The remaining 26% are providing care to a parent or an adult child with a disability. This is a significant concern: non-kin caregivers

experience higher levels of caregiver stress and burnout as many supports available for kin caregivers are not available to them (Fletcher & Fast, 2014). Despite the fact that the US National Family Caregiver Support Act provides assistance to all primary caregivers regardless of their relationship to the care recipient, many state laws relating to Family Medical Leave and other supports require that the caregiver be providing care to someone to whom they are legally related. In Canada, the Employment Insurance requires that employees have access to up to 26 weeks of compassionate care benefits when they must leave work to take care of a family member, while the Canada Labour Code requires federal employees have access to up to 28 weeks in paid leave in order to take care of a family member (Government of Canada, 2017). In Ontario, the *Employment Standards Act* allows employees 8 weeks of unpaid leave to take care of a family member who has a significant risk of death within in a 26 week period and the Family Caregiver Leave, added in October 2014, entitles employees to 8 weeks of unpaid leave to provide care or support for certain family members (Government of Ontario, 2014). None of these leaves are available to Ontarians engaging in non-kin caregiving (CHANGE Foundation, 2016).

In general, a spouse or an adult daughter is the most common source of informal care for an older adult. However, Croghan's analysis shows that LGBT older adults are over 21 times less likely to have children than the general population and are twenty percent less likely to have a spouse or partner (Croghan, 2014). This is not evenly distributed within the community: Croghan found that the members of the LGBT older adult community least likely to have children were cisgender gay men aged 50 to 65, while lesbians, bisexuals, and trans people are more likely to have children than gay

men but less likely than the general population. Cisgender gay men were also more likely to be single than the general population, while lesbians, bisexuals, and trans people were more likely to be partnered if not necessarily married. This is a plausible explanation for why, when asked to identify a potential caregiver, 73% of LGBT older adults indicated a partner to whom they were not married, a friend, or a neighbour. This population is also often estranged from their families of origin, with over 40% of the older adults surveyed indicating that their biological family was hostile or unaccepting of LGBT people (Croghan, 2014). However, even those who indicated that their families of origin were accepting or very accepting also indicated that they had a chosen family defined as a group of people to whom they were emotionally close and considered family but were not biological or legal relations. This may partially explain why Croghan (2014) found that LGBT older adults are nearly twice as likely to serve as caregivers and more than twice as likely to be acting as a caregiver for a non-kin friend or neighbour than the general population. Another aspect may be that in the United States, according to Croghan (2014), nearly 40% of LGBT older adults do not have long-term partners or spouses. Croghan suggests that these caregiving patterns point to the importance of friends and neighbours in successful LGBT aging. Drawing as it did from the two largest surveys of LGBT Baby Boomers and older adults, Croghan's (2014) analysis provides an important quantitative background for the scope of the research problem.

Discrimination and Healthcare Access

A meta-analysis of studies of community-dwelling LGBT people's perception of sexuality in long term care conducted by Mahieu, Cavolo, and Gastmans (2019) revealed that 73% of participants anticipate or suspect discrimination against LGBT people in long term care and nursing homes. Participants in studies conducted in Canada often distinguished between overt and covert discrimination, noting that they are less fearful of overt discrimination given the legal protections that are present for LGBT people in Canada. However, that does not mean that these participants did not anticipate discrimination in long term care: rather, they feared the more subtle covert discrimination that many LGBT people experience on a regular basis such as disparaging comments, stigmatisation, and heterosexism (Mahieu, Cavolo, & Gastmans, 2019). They also indicated fearing that their same sex partners would not be acknowledged or given the same weight as the spouse of a heterosexual person and that this might lead their partners to be ignored when it came time to make decisions about their care. The meta-analysis, which looked at papers from Canada, the UK, the United States, and Australia, also noted that nearly all participants in the studies indicated a high level of anxiety around long term care, and some studies suggested that this fear is rooted in previous life histories of medical homophobia (Mahieu, Cavolo, & Gastmans, 2019).

Access to healthcare remains a significant issue, particularly in the United States. As a group, LGBT older adults are significantly less wealthy than their cisgendered and heterosexual peers, although this varies strongly along racial and intracommunity lines:

the majority of older lesbians of colour live in significant poverty, while white gay men are often able to accumulate wealth at a similar level to their cisgendered heterosexual peers (Croghan, 2014). Transgender people in general, and transgender women of colour in particular, are significantly more likely to live in poverty than cisgendered members of the LGB community. This lack of wealth may be one of the primary causes of the fact that LGB adults are 16% less likely to have health insurance than their heterosexual peers, while transgender people are 30% less likely to have health coverage than the general population ([Croghan, Moone, & Olson, 2014](#)). Even for those individuals who are able to access care, the care that is available is often not culturally competent or equipped to deal with the unique experiences of LGBTQ2SIA+ elders: according to a 2017 survey by Sarah McCrone and OneColorado, 83% of trans people and 62% of LGB people reported that their health care providers were not adequately trained to deal with the LGBT community, and 87% of trans people and 71% of LGB people reported experiencing community fears and negative attitudes towards LGBT people in a healthcare setting.

These experiences vary greatly according to other factors such as race, class, gender, and geographic location, but the broad trends hold true across all subpopulations of the LGBT community: the aging LGBT population is more likely to be isolated, more likely to experience significant health problems, more likely to experience mental illness or substance use disorder, more likely to live in poverty, and less likely to have family caregiving available to them than cisgendered heterosexuals of the same age (Teaster et al., 2016).

Unique Challenges for LGBT Older Adult Health

In their 2018 paper, Fredriksen-Goldsen et al. note that LGBT older adults are at a higher risk for developing Alzheimer's disease and other dementias for a variety of reasons, including that some of the "modifiable risk factors" for developing dementia, such as smoking and depression, are more common in LGBT older-adult communities. Building from data collected by the *Aging with Pride* project, Fredriksen-Goldsen et al. (2018) identified that rates of cognitive impairment were higher in general amongst LGBT older adults than in the general population and that in particular, LGBT older adults who are African American, Hispanic, or HIV positive are more likely to experience significant cognitive difficulties. However, they also found that less than 1% of those surveyed reported a diagnosis of Alzheimer's disease dementia, which is surprising given that about one third of Americans aged 85 and over have been diagnosed with Alzheimer's disease alone (Alzheimer's Association, 2016b, as cited in Fredriksen-Golden et. al., 2018). They posited that this is likely the result of a number of factors, including the fact that individuals with dementia are less likely to complete a self-reported survey and that LGBT older adults are less likely to interact with formal health care systems (Fredriksen-Goldsen et al., 2018). They identified 5 key risk factors for LGBT older adults with regards to dementia: historical context, which may include life histories of medical and societal discrimination, unique family structures that may not be recognised as caregiving networks by medical or legal authorities, barriers to care which may include isolation and lower incomes, caregiving burden which is exacerbated by the fact that LGBT non-kin caregivers often have no legal right to make decisions for the

person they are caring for, and health factors including higher rates of HIV, depression, and rates of smoking (Fredriksen-Golden et al., 2018).

Fredriksen-Golden et al. (2018) then go on to make policy recommendations regarding the training of health professionals that treat LGBT older adult populations, but such recommendations are outside of the scope of this paper. The key point is that LGBT older adults are more likely to experience cognitive difficulties than their heterosexual peers but seem to lag far behind in formal diagnoses. The other point is the caregiving burden -- LGBT caregivers of LGBT patients often struggle when interacting with medical and legal systems as the fictive kin relationships which sustain the LGBT community even today are rarely given the same weight as kin relationships. This is experienced in addition to the regular stressors that all caregivers experience.

It is also worth noting that some individuals with traumatic experiences and cognitive decline find that the memories of traumatic experiences may become difficult to recall while the emotional reactions and triggers from said event remain intact. Fredriksen-Golden et al. (2018) note that given that most LGBT older adults have some experiences of trauma related to their sexual or gender identity, clinicians should take extra care to provide culturally safe environments for LGBT patients. However, despite the fact that many LGBT older adults express a strong desire for LGBT-centric or LGBT-positive healthcare and long-term care facilities, very few currently exist. This gap between supply and demand is often filled by informal community care, which is the subject of this paper.

Older adults of all sexual orientations and gender identities often fear the possibility of dementia, but there are particular concerns that come alongside aging as a

member of the LGBT community. In Price's (2012) paper *Gay and Lesbian Carers: Aging in the Shadow of Dementia*, Price interviewed gay and lesbian caregivers of individuals with dementia. The sample ranged in age from their early 30s to their mid-50s, and primarily were providing care to their aging parents while a minority provided care to partners or non-parental kin. In contrast to some of the other studies discussed here, Price (2012) was not interested in the specific experience of caregiving but rather in exploring how the experience of caring for someone with dementia affected their beliefs and plans for the future. Participants indicated that a loved one's diagnosis of dementia often caused them to reflect upon how their identity might be treated should they acquire dementia and require care. Many reported seeing care providers struggle to provide person-centred care for the primarily heterosexual and cisgender dementia patients, they expressed concern about how they may be treated by the same institutions as members of a marginalized community. One participant was concerned with the possibility of being diagnosed with dementia and had already considered how she would want her life and identity to be reflected:

Respondent: Hopefully, if I've got dementia, my son would hopefully make me my memory books like we made for mum and hopefully he would label them correctly, you know – 'Mum with her partner, Julie; Mum with her partner, Debbie'. Not just 'With friend', you know, my unknown 'friend', because that's what would happen if anybody else was labelling them, you know. You know if a stranger was trying to understand the photographs of my life they'd think I had an awful lot of women friends (laughter) ... it's horrible. So, I've actually already

started my memory book, it's already started ... make sure people know who's on those pictures." (Price, 2012).

Price's (2012) respondent anticipated heterosexist erasure of her life and romantic relationships and was counting on her son to respect and uphold her identity. Other participants agreed that if the task of holding them in their gay and lesbian identities was left to non-kin and non-friend caregivers, their identities would be erased. Some spoke about their concerns regarding entering state-run nursing homes, where they anticipated being isolated from gay and lesbian specific services, community events, media, and activities. Others suggested that they were concerned that leaving their personal care in the hands of a state-employed caregiver could possibly lead to them enforcing heteronormative standards of dress and behaviour, such as dressing them only in clothes that were concordant with heteronormative gender roles (Price, 2012).

While all caregivers, and particularly caregivers of people with dementia, often struggle with fears and anxieties not just about the person to whom they are providing care but with how those experiences may be reflective of their own older adulthood, the anxieties expressed by the gay and lesbian caregivers in Price's (2012) study were different. It is common for the caregivers of those with dementia to fear a future in which they, too, are diagnosed with dementia, however the gay and lesbian caregivers expressed concerns about their possible diagnosis that were intertwined with their concerns regarding the treatment of their sexuality in their older adulthood. This paper unfortunately only considers gay and lesbian histories, which prevents it from considering the particular concerns associated with transgender aging and dementia:

transgender people typically have higher modifiable risk factors for dementia such as substance use and are more likely to have experienced trauma related to their gender identity (Fredriksen-Golden et al., 2014). Transgender people also have unique concerns regarding long-term care, which will be discussed in the following section.

Transgender Aging and Embodiment

The anxieties about aging which are commonly expressed by LGB older adults are only amplified in transgender older adults. In her study *Aging Bodies That Matter: Gender and Embodiment in Older Transgender People's Life Stories*, Siverskog interviewed transgender older adults in both rural and urban Sweden (2015). The sample ranged in age from 62 to 78 and was socio-economically and geographically diverse. The degree to which they were publicly open about their transgender identity also varied. The majority were transgender women, with all but one of the remainder being transgender men. The remaining participant had a non-binary gender identity. The most common fear expressed by participants regarded the possibility of increased care needs as they age, which might result in them requiring in-home or institutional care. One older trans man indicated that there was a nurse in his small rural village who assisted him in administering his testosterone injections and feared that should she move away or change jobs he would be without a caregiver to help him administer his injections. Lena, 70, expressed the fear that should she have to move into a nursing home or long-term care facility, her ability to make choices concerning her own body and gender expression would be restricted. The other older women in the study had similar concerns, with several expressing the fear that they would be treated poorly were they to ask nursing home support staff to assist them in expressing aspects of

their gender identity via cosmetics, hair removal and other normative constructions of female gender expression. This fear is also present in the North American transgender populations surveyed by Cook-Daniels (2015) and is linked to life histories of discrimination and negative reactions to their gender transition.

Transgender older adults who transitioned earlier in life and who are not out in their trans identities often fear that entering institutional care contexts will result in their bodies being exposed as bearing scars and incongruencies that reveal their trans histories (Cook-Daniels, 2015). Other studies of transgender adults have indicated that trans people for whom this is a concern typically limit situations in which they may have to be naked or exposed in front of others, but institutional or homecare environments may limit the opportunity for trans adults to conceal these incongruencies. This may explain why Siverskog's participants only considered long term nursing care as a last resort. An important note is that this study took place in Sweden, where gender confirmation therapies have been available free of charge on their state health insurance since the 1970s. Similar therapies were available for a small percentage of transgender individuals in Ontario throughout the seventies and eighties, until sex reassignment surgery was delisted from OHIP coverage in 1998. They would not be covered again until 2008, in the wake of a number of human rights challenges (Benzies, 2012). Coverage for gender confirmation therapy remains incomplete throughout North America, and many transgender people in the United States struggle to access insurance coverage for gender confirming therapies such as hormone replacement therapy and SRS (Cook-Daniels, 2015). This is important, as it means that the overwhelming majority of older transgender people in North America may not have had

access to gender confirmation therapies until their adulthood, if then. An earlier medical transition for transgender people is associated with a more congruent gender presentation and lower rates of physical and mental distress related to gender transition (Cook-Daniels, 2015). It can therefore be inferred that the distress identified by the Swedish subjects of Siverskog's (2015) study relating to their non-normative bodies may be even greater in North American transgender older adults.

Indeed, some transgender older adults in the United States have indicated to researchers that their fears surrounding state care and long-term care are so significant that they would seriously consider suicide were those their only options for care (Cook-Daniels, 2015). While gay, lesbian, and bisexual older adults often access state care alongside community care, older trans people are often wholly reliant on fellow members of the LGBT community to meet their care needs. While transgender women are less likely than cisgender lesbians to have children, they are significantly more likely to do so than cisgender gay men (Croghan, 2014). They are also more likely to be estranged from their biological families, including their children. They are more likely to report negative interactions with state authority and less likely to indicate that they would consider accessing state authorities such as health care or the criminal justice system even when compared to cisgender LGB people, who already have lower rates of trust and higher rates of negative interactions with the state than their cisgender heterosexual peers (Cook-Daniels, 2015). To date, Siverskog's (2015) study remains the only of its kind to focus on the experiences of older trans people, and many of the studies which purport to address LGBT older adults in general often only addressed the concerns of LGB older adults. Transgender older adults are often invisible in the

literature, and qualitative research in this area is particularly lacking. The aim of this study is to fill these gaps and to consider how the life histories and identities of different members of the LGBT community interact with each other and effect their caregiving experiences.

Stress Factors and Minority Stress Model

The minority stress model was outlined by Meyer in his 1995 work *Minority Stress and Mental Health of Gay Men*. It was further detailed and updated in his 2007 piece *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual issues and Research Evidence*. This model provides a framework for understanding the impact of societal prejudice, including homophobia, on the mental health and well-being of marginalized individuals. Meyer proposes three forms of stressors relevant to the mental health of LGB people: (a) external, objective stressors and conditions, (b) expectations of such events and associated hypervigilance, and (c) the internalization of social attitudes. Meyer also notes that concealment of one's sexuality, which is associated with all the processes above, can also be seen as a proximal stressor as the associated stress impact is thought to be the result of internal psychological and neurological processes.

Being a member of a minority community can, in and of itself, also act as a psychologically protective factor: it has been shown that groups of out LGBT people who indicate that they have strong community ties are less likely to experience the negative health outcomes associated with experiences of discrimination. Studies of how the minority stress model can be used to describe experiences of racism have shown

that members of close-knit ethnic or racial communities are able to mitigate the negative impacts of racism on their members via community support and understanding (Cohen & Byers, 2015). This can be used to explain why being closeted in your sexual orientation or gender identity is associated with higher degrees of negative psychological stress and poorer health outcomes: a closeted LGBT person may experience or witness negative actions or behaviours towards LGBT individuals and internalize that stress while lacking the positive identity reinforcement that results from relations with other members of the LGBT community.

The minority stress model is cumulative, which is concordant with current understandings of how stressors can impact mental and physical health over the life course. This is key for understanding LGBT older adults for a number of reasons, the most important being that LGBT older adults lived a significant portion of their lives concealing their sexual orientation or gender identity.

Concealment of one's sexuality or gender identity is an exhausting process that requires a great deal of self-surveillance. Most LGBT older adults have already lived a significant portion of their lives engaging in this coping strategy and are often understandably reluctant to "return to the closet" (Wilson, Kortes-Miller, Stinchcombe, 2018). As a result, many of them are actively seeking out ways to access care that do not require them to return to a closeted life (Fredriksen-Golden & Murad, 2011), which has to date been a somewhat understudied phenomenon.

Qualitative Experiences of Care

Qualitative studies on the care experiences of LGBT older adults have begun to emerge over the last two decades. In her 1998 study *Lesbians Giving and Receiving*

Care: Stretching Conceptualizations of Caring and Community, Aronson interviewed 15 white professional-class lesbians from Southern Ontario about their experiences giving and receiving care for an illness. This study was focused on addressing a gap in the research as at the time very few studies had been done on lesbian experiences of caregiving relationships, and most research on gendered aspects of caregiving focused exclusively on those who provided care rather than those who received it (Aronson, 1998). Aronson acknowledged the limitations of her sample, as it was completely lacking in socioeconomic and ethnoracial diversity, but believed that this study would be an opening salvo into the world of research into lesbians giving and receiving care and hoped that further research would be done that addressed the weaknesses of her original study.

Aronson's (1998) study acknowledged that many lesbians exist outside of traditional heteronormative kinship structures, and further posited that exchanges of care and support look differently in communities not governed by heterosexual norms. While lesbians today are more likely to be married than they were in 1998, given the legalization of same-sex marriage in Canada in 2005, many LGBT people continue to live outside of traditional heterosexist norms and indeed older lesbians are significantly less likely to be married or have children than their heterosexual counterparts (Gates, 2015). Given that the population in question is not governed by traditional heterosexual kinship norms, Aronson (1998) posited that exchanges of care and support may be experienced differently. In the absence of traditional kin or spousal caregiving networks, the lesbians in question described having to "take conscious charge" of patterns of intra-community support and commitment. This conscious decision is of particular interest

when considering norms of reciprocity: of her 15 participants, 5 had been both caregivers and recipients of care, while 7 were exclusively providers and 3 exclusively recipients of care (Aronson, 1998). Aronson (1998) identifies this as being the result of strong in-group norms regarding caring for other lesbians.

Aronson (1998) found that it was rare for biological families of origin to be involved in the care of the participants interviewed, and in those rare cases where they were involved, they often prevented lesbian caregivers from making decisions about the care of the person in question as well as minimizing their contributions. This may explain why one participant indicated “We must always look after our own.” (Aronson, 1998, pg. 509) Aronson was aware of the limits of her sample and concluded with the hope that the topic would be studied by other researchers whose samples would have greater ethnic, socioeconomic, and geographic diversity. However, this does not seem to have occurred: at this time, Aronson’s (1998) work is the only paper that specifically studies and identifies lesbian communal caregiving in a Canadian context.

However, outside of the Canadian context there has been some movement. In her 2018 paper, *Older lesbians receiving home care: formal and informal dimensions of caregiving*, Sandra Butler (2018) of the University of Maine explored the experiences of 20 lesbians over the age of 65 who had used home care services for acute illness or chronic medical concerns. Butler notes the dearth of articles about older lesbians, noting that in her research she had only been able to find 28 published between 1997 and 2010 (Butler, 2018). She attributes this to the so-called “triple jeopardy” experienced by older lesbians: that is, dealing with ageism, sexism, and homophobia while being rendered largely invisible to the culture at large. She notes that the present

cohort of older lesbians largely came of age prior to the gay liberation movements of the 70s, although those who are between 60 and 70 were in their twenties at the time and were young adults or in early middle age when the US Supreme Court upheld Georgia's law banning sodomy. This context, she argues, is likely to have contributed to the higher rates of disability and mental health issues amongst older lesbians as well as their beliefs regarding the need to be cautious about revealing their identities to health-care providers (Dearing & Hequembourg, 2014, as cited in Butler, 2018).

Butler's (2018) sample of 20 middle class lesbians over the age of 65 all received in-home help from an outside agency. Nearly all also benefited from informal support and caregiving networks between friends, partners, and community members. Those who had long-term partners tended to receive quite significant levels of personal care and support from them, while the others existed on a continuum from strong community care and connection to relative isolation.

Seven participants reported some level of isolation, with difficulties connecting with their neighbours and community. At least two of the participants attributed this, at least in part, to homophobia: one participant, who had moved to the Chicago area after the death of her partner, reported the following interaction:

I was new here and I said, "Hello, my name is ____." The person says, "Are you Christian?" before she tells me her name. I say, "No." Then she says, "Are you married?" I say, "I was to a woman for 23 years." She says, "I have to go." And goes upstairs. Never spoke to me again[M1]. (Butler, 2018, pg. 100)

While homophobia played an aspect in the isolation of some participants, the majority reported strong support systems comprised of friends, neighbours, and other lesbians. One participant, who had recently moved into a senior's apartment complex where two other long-time lesbian friends lived, described the strong care ties she and the couple had, noting that throughout their friendships they had provided care for each other:

The three of us are taking care of each other for, I don't know, 25 years or something—going to each others' doctors' appointments and all that kind of thing. Ah, but of course now we're older—in 25 years, we're 25 years older—so that is not working well. We really aren't able to take care of each other anymore, and so we need some other people. (pg. 101)

Butler (2018) interviewed her participants about their experiences of receiving in-home help, with 25% reporting experiencing homophobia from home health workers. The majority were ultimately able to form good relations with their home care workers, and ultimately it was determined that the factors that influenced their ability to form good relationships with their home care workers were based less on their sexual identity and more on shared characteristics between the lesbian service users and their workers: participants were far more likely to report a positive experience when their home care worker was also older and where they shared common interests such as sports or religion (Butler, 2018). This is not a phenomenon unique to lesbians: service users in general are more likely to report positive experiences when their care workers are older, who often have more life experience as well as caregiving experiences (Butler, Brennan-Ing, Wardamasky, & Ashley, 2014). While Butler's (2018) article is useful in

considering the background against which many LGBTQ+ older adults turn to informal care after negative experiences or difficulty accessing formal care, it also highlights that for the most isolated LGBT older adults, in-home care is often the only option. In the absence of strong community or family ties, these older adults are often left as their own self-advocates, which is a difficult and exhausting process. As Fredriksen-Golden et al. (2015) found, isolation is often a key factor in the physical and mental well-being in LGBT older adults, something which will be discussed at length in Chapter 3: Community Caregiving and Political Advocacy.

Reciprocal Caregiving and the Legacy of HIV/AIDS

In the US, 32% of lesbians and gay men report providing informal care, with 61% of these caregivers providing it to friends (Fredriksen, 1999). Most studies show that gay men and lesbians are particularly willing to provide caregiving support within their own communities, with some caregivers identifying the act as a means of showing their strengths and commitment (Hash et al., 2003). Gay men and lesbians are more likely to provide care to their fellow gay men and lesbians, and although there is a gender split in care provision in the LGB community it is not statistically significant (Grossman et al., 2000). It is likely that the norms of caregiving are different in the LGB community both because of an acceptance of more fluid gender roles and because of the legacy of the AIDS crisis, whose LGB victims were predominantly male and young and were cared for by their gay male partners (Muraco & Fredriksen-Goldsen, 2009).

In their 2011 study “*That’s what friends do*”: *Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults*, Anna Muraco and Karen

Fredriksen-Goldsen were interested in identifying to what extent LGB caregiving dyads represented traditional caregiving dynamics in the broader community – where caregivers tend to be women, older, and straight – and to what extent they were reflective of HIV/AIDS caregiving dyads where caregivers tend to be younger, male, and gay (Turner & Catania, 1997). To identify the experiences and needs of those who care for LGB older adults and the older adults themselves, Anna Muraco and Karen Fredriksen-Golden (2011) interviewed 18 caregiver-care recipient dyads.

The participants were racially diverse and mostly made less than \$20,000 a year.

In about half the dyads, both care giver and care recipients were male; another quarter were female-female, and another quarter were of different genders. Muraco and Fredriksen-Golden (2011) posit that because this cohort did not meet the gender norms associated with normative heterosexual life, they were freer to defy other gender norms such as those governing who gives or receives care. Another possibility is that as gender norms for gay men do not necessarily abide by norms of hegemonic masculinity (Connell, 1992) -- which is of course not to say that perceptions of masculinity are unimportant in the LGBT community – it may be more socially acceptable for gay men to show love for and provide care to their loved ones. The legacy of AIDS caregiving may also have shaped social norms in LGB circles such that there is a culture of care for community members, which lasts through middle and older adulthood. Indeed, a large portion of Muraco and Fredriksen-Golden's (2011) sample is HIV positive, with 8 out of the 18 pairs having at least one HIV-positive participant. Caregiving for chronically ill LGB older adults seems to resemble the tradition of HIV/AIDS care by

friends in the LGB community, both for those with HIV/AIDS and those with other chronic conditions.

Muraco and Fredriksen-Golden (2011) note that the majority of gay men and lesbians indicate that they would first turn to a partner for care giving assistance, and that they would then turn to friends.

The current cohort of LGB elders experienced marginalization over their life course that included intense stigma, rejection by family members, and laws that prohibited same sex marriage and as a result they may not have the biological or legal networks present in heterosexual communities to provide necessary care (Muraco & Fredriksen-Golden, 2011). However, that also means that the caregivers in LGB older adult communities may not have access to legal or social supports available to others. Friends do not have the legal power to make decisions about medical care or end-of-life issues without the presence of a legal power of attorney or medical conservatorship document in place. For the low-income, often street-involved older adults in Muraco and Fredriksen-Golden's (2011) sample, these documents were prohibitively expensive to get and those who had attempted to obtain them had faced barriers from medical and legal professionals who questioned the role of the friend in the life of the care recipient (Muraco & Fredriksen-Goldsen, 2011). It is also important to note that most of the participants anticipated that a day might come when they were unable to continue to be the primary caregiver for their care recipients. In part, this is in recognition of the lack of instrumental support provided to informal caregivers as well as a recognition that most informal care arrangements may reach a point where the informal caregiver is no longer

able to provide the majority of care to their loved one. This is especially significant when, as in this sample, caregivers are also experiencing some form of health issue that they anticipate may become more severe in the future. There have been limited studies of caregiving arrangements where the caregiver is also experiencing diminished health status. However, Muraco and Fredriksen-Goldsen (2011) posit that this may be a more frequent problem in non-kin and LGBT caregiving, as research on HIV/AIDS caregiving indicates that people who provide care in such contexts are often also HIV positive.

The literature synthesized here that provides the background for the current project has several strengths and weakness. It frequently provided insights regarding the consistent life-histories of discrimination, isolation, and fear of discrimination across global populations of LGBTQ+ older adults. The quantitative studies were valuable both for their scope and for the diversity of their samples, however, none of them occurred in a Canadian context and the experiences of American and British LGBT+ older adults may not directly map onto the Canadian LGBT experience. In addition, the qualitative studies, with the exception of Siverskog's 2015 study, excluded transgender people, and as a result there is a need for qualitative studies of LGBTQ+ care, in a Canadian context, which include transgender participants.

This research project seeks to fill the gaps of these previous studies while laying out the groundwork for further research in this area. It is also an attempt to answer the following questions:

- 1) How do LGBTQ2SIA+ older adults experience the act of caring and/or of being cared for, and is it impacted by their identity?

- 2) How do LGBTQ2SIA+ older adults envision aging, dying, and death, and is it impacted by their identity?

Further, it is important to consider what the norms and values regarding caregiving are, in the LGBTQ2SIA+ older adult community. The personal narratives of older LGBT people are deeply valuable, both in informing future policy and in recording narratives that would be otherwise lost to history. The persistent invisibility of LGBTQ2SIA+ older adults is stark, in both in academic research on caregiving, which tends to focus on cisgendered and heterosexual older adults, and in academic research on the LGBTQ2SIA+ community, which typically focuses on middle aged or young adults. It is the aim of this project to highlight the experiences older LGBT people have giving and receiving care, and to preserve the personal narratives for these individuals for posterity.

Methodology and Methods

This qualitative project aims to highlight the experience of LGBT caregivers and care recipients, and to consider how their lived experiences interact with broader societal events, structures, and beliefs such as the HIV/AIDS epidemic and the role that medical homophobia and transphobia plays in influencing LGBT older adults experiences of care.

Life Course Theory

Life course theory has dominated many aspects of social science research for several decades (Elder, Johnson, and Crosnoe, 2004), and developed out of several key longitudinal studies of child development in the early 20th century. These cohorts of children and young adults had lived through a period of massive social change including

the Great Depression and the Second World War. Researchers found that these real-world events impacted the design of their studies: for example, participants in Terman's study of gifted children born between 1900 and 1920 were often veterans of the Second World War, and those who were would often write about aspects of their war experiences in the margins of questionnaires that did not ask explicit questions relating to the war, and Terman later expressed that some of the participants had been shocked at the seeming indifference researchers had to the war and its effects (Terman, personal correspondence 1985, in Elder, Johnson, and Crosnoe, 2004).

While early life course theorists were primarily interested with generational and cohort effects, later theorists began to link it with individual lives(Hutchison, 2010). Under this model, the life course is defined by social pathways, or the trajectories which individuals follow through life events and which can be impacted by large-scale social phenomena. Individual choices matter, but the nature and extent of those choices are constrained by larger forces.

Principles of Life Course Theory

1. Principle of Life-Span Development: Development never ends: aging and development go hand-in-hand.
2. The Principle of Agency: Although societal events and structures may constrain the number of choices available to them, individuals still have agency and make choices.
3. The Principle of Time and Place: An individual's life course is heavily embedded in the historical and societal structures that surround it, and cohort-level events are experienced differently depending on the time and place.

4. The Principle of Timing: Both individual transitions and societal events are experienced differently depending on the age of the individual in question.
5. The Principle of Linked Lives: All individuals are to some extent interdependent with each other and all experiences are to some degree relational (Elder, Johnson, and Crosnoe, 2004)

When considered through the lens of Life Course Theory, it is clear that LGBT older adults continue to be affected by life course disruptions and cohort level events, and it provides an interesting lens through which to view my participants' experiences of the HIV/AIDS epidemic. For members of the LGBT community, the HIV/AIDS epidemic was a cohort level event that touched nearly everyone, directly or indirectly. My oldest participants experienced the epidemic as adults and expressed a different relationship to it than those who were in their twenties during the height of the epidemic. I did not initially anticipate exploring the legacy of the HIV/AIDS epidemic except in passing, and had no formal written questions on it, but nearly all participants brought it up unprompted. Like Termans' participants, they could not talk about their own lives without also considering how it fit into larger cultural and geopolitical contexts. For my participants, the principle of linked lives is also important: participants often discussed the importance of acting in solidarity and engaging in community care and activism.

Cultural Scripts

Age is often used as the basis for assigning status and regulating social interactions, and age norms are culturally constructed (Neugarten, Moore, & Lowe, 1965). When taken together, the cultural norms that we assign to aging results in an expected "cultural life script" such that there is an expected timetable and pattern of

development that an individual is expected to follow (Pecchioni, 2012). Interruptions to this timetable are often the result of traumatic events that interrupt the idealised life script that an individual may expect: Pecchioni (2012) uses the example of young adult cancer patients: given that serious illness is culturally expected to occur in very old age, her participants expressed an interrupted life course and age relativism, many saying that they feel “older than their age”.

LGBT older adults have a different relation to the cultural scripts of aging than their heterosexual cisgender counterparts: they have often not attained the markers of adulthood or older adulthood that are considered to be part of the broader cultural script (e.g., marriage, owning a home, having children) and also find themselves outside of the subcultural scripts common to the LGBT community. LGBT identity is often considered to be synonymous with youth, even within the community (Gates, 2015), and the current cohort of LGBT older adults are in uncharted territory as perhaps the first generation to age openly in their LGBT identities. As a result, there are no accepted cultural scripts for LGBT aging: instead, LGBT older adults must create their own scripts and attempt to make sense of their own lifeworlds.

This study aimed to identify how care is experienced by LGBT older adults, and to understand the relationship that LGBT older adults have to formal healthcare. The role that stigma, life histories that include medical discrimination, and the presence of informal care networks effects the interactions between LGBT older adults and care systems were of particular interest. The target population was defined by three characteristics:

1. They were aged 60 or older

2. They self-identified as members of the 2SLGBTQ+ community
3. They had given or received care for a physical or mental health issue outside of a hospital setting

The age range was chosen after considering how to best define “older adult” for the purposes of this study. Because age and aging-related frailty has different effects on different populations, there is no strict, universal definition for what defines an “older adult”, although the United Nations generally uses “60 or over” as the criterion for being considered an older adult (World Health Organisation, 2015). In this study, 60 was chosen as the lower end of the age range because LGBT older adults who are over 60 broadly came of age prior to or during the gay liberation movements of the 1970s, giving them a distinctly different lifecourse history than LGBT people in their 50s.

Interpretive Phenomenological Analysis

Although forms of phenomenology have been explored by philosophers for centuries, phenomenology-as-disciplinary method is usually attributed to Edmund Husserl. Working in the early 20th century, Husserl responded to the dominance of logical positivism in Anglo-American philosophy by centering the inherent subjectivity of the human experience and noting that it is not possible to fully access the lifeworld of another person (Husserl, 1970). For Husserl, phenomenology is a descriptive exercise, one in which researchers are required to bracket their personal experiences and prior knowledge before exploring a subject. The research question may not be discovered until the end of the project, and the project should be entirely participant-driven as it aims to understand the holistic subjectivities of participants (Husserl, 1970). Because this project is concerned not just with the subjective experiences of participants but with

how those experiences interact with and are influenced by social and political norms and structures, descriptive phenomenological analysis was not considered appropriate. Instead, interpretive phenomenological analysis was taken as a starting point.

Smith and Osborne (2007) describe IPA as an explicitly interpretive endeavour, one which engages in multiple layers of interpretation and which searches for a so-called “gem”. Having been heavily influenced by Heidegger’s concept of *appearing* (Heidegger, 1962 in Eatough & Smith, 2017), IPA involves “mining” the data, or engaging in multiple levels of phenomenological analysis of the same text in order to reveal hidden meanings. These gems provide access to the lifeworld of the participant, but Smith and Osborne (2007) note that IPA researchers must be careful to note that you can never have full access to a participant’s lifeworld, only their experiences of it as experienced by the researcher. Interpretive phenomenological analysis (IPA) takes as read that the researcher is not neutral and that indeed access to the participants’ lifeworlds is a dynamic process involving interaction between the researcher, the participant, and their understandings of themselves and each other. To quote Smith and Osborn (2007, p. 3), “The participants are trying to make sense of their world; the researcher is trying to make sense of their world.”

This makes it an ideal frame to work within when one is trying to discover the interiority of participants, and how that interiority impacts their relationship with their broader lifeworld. IPA is also an ideal method of analysis for a small sample size as it requires detailed analysis of transcriptions to discover both surface and hidden meanings of the participants responses. While IPA does not allow us to make empirical general findings regarding a specific population, it instead aims at thick descriptions of

individual experiences and the possibility of theoretical generalizability (Eatough & Smith, 2017). In the case of this study, I considered the responses of participants in the context of the broader literature which identifies a number of trends regarding LGBTQ+ older adults' experience of care.

While IPA does not require researchers to bracket their personal experiences and knowledge of the subject, it does require a constant reflexivity on the part of the researcher (Smith et. al., 2004). Engaging in this reflexivity led me to discover an interesting phenomenon: my participants seemed to be engaging with me as a younger member of the LGBT community rather than simply as a researcher. This occurred regardless of whether or not I actively disclosed my connection: even when I did not say anything, participants correctly inferred that I was also a member of the community. This was highlighted by participants' occasional use of diminutives to speak with me and the way they often framed their own narratives: participants would occasionally pause mid-sentence to demand that I "write that down". Given that they were aware that the interviews were being recorded and transcribed, I took that instead as a direction to pay particular attention and care to a specific aspect of their story.

Relating to me as a fellow community member rather than as a researcher seemed to build trust with participants: the second interview was often significantly more casual than the first, and when given an opportunity to speak freely on any aspect of their experiences they often emphasized how important it was to them that LGBT young adults both understand their experiences and join them in their battles. I was often encouraged to "take care" of their narratives: it is for this reason that I have not fully anonymised the data or created composite figures: the individual identity and life history

of each participant affects how they experience old age and illness, and it would not be appropriate to separate them. Participants were made aware, both verbally and via consent forms, that I would be changing names and locations but little else in the narrative. They were given the option to review their transcripts as well as sections of this thesis that featured their stories and offered the opportunity to have aspects redacted or rewritten. 5 of 8 participants took me up on this option, and upon reviewing the transcripts none chose to withdraw their narratives.

Methods

Participants engaged in one-on-one interviews either in person (n=4) or over the phone (n=3) after orally completing a basic demographic questionnaire that asked for their current health status on a scale of 1-5, with 1 being “poor” and 5 being “excellent”. They were also asked their age, ethnic or racial background, profession or former profession, and the highest level of education they had completed. They then engaged in a semi-structured interview where they were asked questions relating to their personal life histories of illness, societal and medical discrimination, and experiences giving or receiving care. Three participants were primarily care recipients, although two of the three indicated that they had at some point also provided care to another individual, and four participants were primarily caregivers. The resulting discussion centred on how participants’ LGBT identity affected their experiences of care. Interviews were between 60 and 90 minutes in length, and after completing their first interview participants were invited to participate in another 60 to 90 minute interview to expand on

any of their experience. This method allowed me to not only collect rich data but provided participants with an opportunity to reflect on their experiences. Guided by the IPA method, the second interview was able to be more focused on the themes that arose in the initial interviews. Over half (n=5) agreed to engage in a second interview. Interviews were digitally recorded and transcribed immediately after they were complete. They then underwent a preliminary analysis for themes around autonomy, stigma, and life-histories of medical discrimination and caregiving. In accordance with the IPA method, these themes were chosen after a review of the current literature on the experiences of LGBT older adults, which identified that there are a number of common experiences in their life courses. Some of the themes were identified from the researcher's personal experiences and knowledge of the LGBTQ2SIA+ older adult community. After all interviews were complete, the transcripts were reviewed to see if further themes were discernable: accordingly, the legacy of the HIV/AIDS epidemic and the importance of personal identity and hope were added as themes to code for. Data was analysed using QDA miner, and each transcript underwent a minimum of 3 analyses in accordance with the IPA belief that access to the participants' lifeworlds is a dynamic process and that over time themes may emerge that were previously unknown to both researcher and participant (Smith et. al., 2003).

Sampling

The target population was 2SLGBTQ+ identified adults who were 60 or older and who had either given or received care for a health issue. Extant research on 2SLGBTQ+ older adults tends to over-represent white, professional, cisgendered gay

and lesbian people (Stoke, 2001). An explicit aim of this study was thus to try and ensure racial and socioeconomic diversity as well as the participation of bisexual and transgender participants. To ensure this, I employed purposive sampling, which involved explicitly involving community organisations that serve these groups. Recruiting occurred partially online, with the Toronto Bi+ network and the Toronto Prime Timers, a group for gay, bisexual, and queer older men. Two participants were recruited in this manner. The remainder were recruited after a presentation at an event for 2SLGBTQ+ union members.

This method of sampling resulted in a sample that is skewed in the opposite direction to most research on 2SLGBTQ+ older adults: the majority (n=4) had obtained their high school diploma or equivalent, while one was employed in a skilled trade and had gone through a formal apprenticeship. The remaining two participants had obtained university educations and were employed in the so-called “pink collar” professions of teaching and nursing.

The sample was skewed by the populations that the researcher had access to: as a White non-binary working-class lesbian, it was relatively easy to access White lesbian and gay participants, and older lesbians in particular (n=3). Two participants had a non-cisgendered gender identity.

Sample Characteristics		
Racial or Ethnic Background		
	<table> <tr> <td data-bbox="649 1709 1253 1885">Racial/Ethnic Background</td><td data-bbox="1253 1709 1325 1885">n=</td></tr> </table>	Racial/Ethnic Background
Racial/Ethnic Background	n=	

	White, Caucasian or European Descent	4
	Black, African-Canadian, or Afro-Caribbean Descent	2
	Latino/Latina/Latinx, Latin American Descent	1
Highest Level of Education Obtained	Level of Education	n=
	Some High School	1
	High School Diploma	3
	College or Apprenticeship	1
	University	1
	University + Professional or Graduate School	1
Age	Age Range	n=
	60-65	4
	66-70	1

	71-75	2
	76-80	0
	81+	1
Self-Identified General Health Rating	Health Rating	n=
	Poor	1
	Fair	2
	Average	1
	Good	3

While it was an aim of this project to recruit participants outside of major urban centres and the Greater Toronto Area, rural 2SLGBTQ+ populations are often difficult to access. One participant was recruited who lives in a town of less than 2000 people in rural southwestern Ontario. The remainder currently reside either in Toronto, or in mid-sized and smaller industrial cities in Southwestern Ontario (Hamilton, Windsor, Kitchener-Waterloo).

Information about the participants is below: all names have been changed and whenever possible other aspects were anonymised. However, it was neither possible

nor desirable to truly anonymise some aspects of the data because the personal narratives shared by participants were often directly linked to their personal identities. Participants were informed ahead of time, both in writing and orally prior to their interview, that their names would be changed but that other aspects of their personal identities and life histories would likely remain intact.

Name of Interviewee	Demographic Characteristics
Barbara	63, White, lesbian-identified, Health Rating of Good, Education attained: high school diploma Transit Operator Married (Windsor)
Ron	67, White, cisgendered, gay man Health Rating of Good Long-term survivor of HIV Highest level of education attained: BA and teaching certificate Retired teacher Married, spouse of Juan.

	(Toronto)
Elizabeth	63, Black, cisgender, lesbian Health Rating of average, Education Attained: B ScN Nurse Single (Hamilton)
Juan	65, Latino, cisgender, bisexual man. Health Rating of Fair Highest level of education attained: High school diploma freelance writer and critic. Married, spouse of Ron. (Toronto)
Oliver	80, Black, cisgender gay man Health rating of fair, Highest level of education: BA. Retired Non-Profit Director Married (GTA)
Melanie	70, White, genderqueer lesbian Health rating of good Highest Education: Apprenticeship

	<p>Mechanic Millwright</p> <p>Single</p> <p>(Windsor Area)</p>
Deborah	<p>63, White, transgender woman</p> <p>Health rating of poor</p> <p>some high school education,</p> <p>community organiser and activist</p> <p>Single</p> <p>. (Toronto)</p>

I

Chapter 3: Stigma, Autonomy, and Care

Although LGBTQ+ older adults are a heterogeneous population, nearly all of them have had experience dealing with medical and societal stigma. The CAGE study discussed in the review of the literature showed that over three quarters of LGBT older adults surveyed had experienced discrimination from a healthcare provider related to their sexuality or gender identity (CAGE, 2011). Trans and gender non-conforming individuals have even worse experiences, with nearly 90% reporting experiencing medical discrimination according to the same study. These experiences range from having their symptoms ignored by medical professionals to being refused treatment on the grounds that their gender identity makes their case “too complex”. (Interview, Deborah, 2018)

Medical discrimination against LGBTQ2SIA+ communities has a long and sordid history. Homosexuality was a diagnosable psychiatric condition until 1973, with gender identity disorder remaining in the DSM until the sixth edition, where it was replaced with gender dysphoria. The medicalization of human sexuality interacts with colonial, white supremacist, and patriarchal structures, and these structural oppressions often replicate themselves within the healthcare system (English, Rendina, & Parsons, 2018) .

Gender Nonconformity, Stigma and Intersecting Systems of Oppression

Despite a general societal trend of more accepting attitudes towards the LGBT community (Greenberg et al., 2019), the medical and healthcare profession are often seen as more conservative, and indeed, attitudes towards LGBT individuals, especially those who are also marginalized on other axes, are significantly more hostile in the healthcare setting (Cramer, 2015). Gender non-conformity is one of the factors most

strongly associated with hostility both within the healthcare system and society writ large. Trans women and femme or gender-nonconforming gay men are the primary targets of violent assault (Egale Canada, 2019), with trans women of colour and black and Indigenous transgender women in particular making up a disproportionate number of LGBTQ+ homicide victims (Egale Canada, 2010). In Canada, Indigenous 2SLGBTQ+ people, particularly Indigenous 2SLGBTQ+ sex workers, remain one of the most highly criminalized, surveilled, and marginalized groups in the country (Lyons et al., 2017). While hate crimes against cisgender bisexual women and lesbians are more likely to take the form of verbal threats or harassment, physical and sexual assaults are disproportionately directed at gender-nonconforming or butch women (Meyer, 2008).

Within a healthcare setting, enforcement of heterosexist and cisnormative gender roles are often cited by LGBT individuals as reasons for avoiding healthcare (Croghan, 2014, Siverskog, 2017). While many older adults feel discomfited by the prospect of long-term care as they fear the loss of autonomy (Lynch, 2009), this fear is only increased in LGBTQ2SIA+ populations. For a large percentage of the LGB community, and for the entire trans community, the enforcement of these norms can result in an epistemically violent attack on their personhood and identity. When these stigmas interact with other social structures like misogyny, racism, and ableism, they can be deadly. Elizabeth blames these intersecting stigmas and poor experiences in the healthcare system for the death of her friend from breast cancer.

Elizabeth: My friend K, she passed a couple years ago. She had stage 4 metastatic breast cancer. They didn't catch it until it was too late. I helped her out quite a bit.

Interviewer: How did you know her?

Elizabeth: We were good friends, we met at a feminist reading group back in the 80s... What happened to her was a damn shame. It could've been treated if they caught it earlier... it was just so frustrating. Breast cancer is treatable as long as you catch it early. But she was a bigger girl, and she was a dyke, and the doctor's office was just an awful place for her to be. She'd probably be alive today if that wasn't the case.

Interviewer: Do you think they didn't treat her appropriately?

Elizabeth: No, well, once she was diagnosed her care was fantastic. But she had been feeling sick for a while, and she had this terrible pain in her joints. But she'd gone to the doctor before with pain in her joints, and they told her to lose weight. And they were really snippy with her in general, because she didn't dress like they thought a woman should, I suppose. As a nurse, I'd like to think that my colleagues are better than that, that they don't treat patients differently because of their own views. But I also know that that's not always the case. I've heard some stuff over the years that would make your ears blister.

Interviewer: So just to rephrase what you said, you think that she didn't go to the doctor when she should have because she had had such bad experiences?

Elizabeth: I offered to get her in with mine, she's excellent, and it's always nice to have a lady doctor. But she didn't want that. I think she really thought it would get better on its own.

Here Elizabeth identifies two intersecting systems of oppression that ultimately resulted in her friend's untimely death: it is extremely common for medical professionals to dismiss women's pain (Hamberg et al., 2002), and it is also very common for doctors to simply direct overweight or obese patients lose weight even when their symptoms are completely unrelated to their weight (Kolata, 2016). Compounding this was her friend's lesbian identity and gender non-conforming appearance: gender non-conforming people, by and large, receive poorer treatment than those whose gender expression conforms with their sex-assigned-at-birth (Aparicio-Garcia et. al., 2017). Unfortunately, her friend's life history of past medical discrimination ultimately prevented her from seeking help for her breast cancer before it was too late.

Hospitalization and interactions with state apparatus can also be re-traumatizing for LGBT people with life histories of discrimination and violence. For example, Deborah, a 63-year-old transgender woman with a personal history of homelessness and experiences of transphobic and homophobic violence, describes her experience of being hospitalized thusly:

Deborah: ...I've had some dreadful experiences, and they don't -- I couldn't shave, I couldn't really put my face on, and in a hospital

gown. They said I could wear sweats, but I only wear nightgowns, and they were no good because I'd had an epidural for the pain. They needed access to my back, I guess. But it didn't -- in those places, it's almost like you don't have a gender. Like every difference is flattened between them, everyone is just in shapeless sweats and so on. But I didn't want -- it's very important to me to be able to control my appearance.

Interviewer: it's important for your identity.

Deborah: Exactly. But you can't explain that to a cis person, or at least a cis straight person. So then [the social worker I was assigned] said I was being difficult and was hard to place because I was so difficult. So I ended up just going home instead, even though I really needed more time to heal. I wasn't ready. I could barely get out of bed. I needed help getting dressed, help walking, help making food everything.

For Deborah, the lack of sensitivity to her identity and personhood reminded her of personal trauma she had experienced related to her gender identity. Given that she has historically experienced a great deal of hostility towards her gender identity, which will be explored further later in this chapter, her response is perfectly sensible. She had indicated earlier in the interview that she had come out as transgender in the mid 1980s, at a time when society was significantly less accepting of 2SLGBTQ+ people and transgender people in particular. She also indicated that this was what led to her experiencing several years of homelessness and survival sex work. During this time

period her interactions with medical professionals and most authority figures were broadly traumatic. She had been mocked by police when she attempted to report a sexual assault and had previously been denied medical care due to her gender identity, with multiple physicians refusing to treat her as her gender identity made her “too complex”. It was because of these experiences that she did not seek out treatment for a broken foot until it became a life-threatening bone infection that spread to her bloodstream:

Deborah: ...when I got sick --- I should have gone to the doctor earlier but I'd just had such awful experiences -- and I just didn't want to fight anymore. It's hard to fight when you're sick. I think that's part of why I had such a bad experience in the hospital. I didn't really have the energy to advocate for myself, and I didn't have a partner or family to advocate for me. But I was just too tired.

Here, Deborah highlights a problem that is common to LGBT older adults: in the absence of a long-term partner or children, many find themselves isolated and marginalized. I will return to this theme later.

Deborah also experienced discrimination while in the hospital and linked that discrimination with previous poor treatment at the hands of authorities.

Interviewer: Do you think that the healthcare providers treated you differently because you're a trans woman?

Deborah: I think so. It wasn't – they didn't say anything in particular, but it was hard to get a nurse to come see me when I pressed my

call button, and often it wasn't the nurse who was assigned to me according to the whiteboard. So I think that might have been related to my being a trans woman. And it's sort of difficult to explain, but I did feel a bit like I was a curiosity for the medical students, like I was on display in a zoo. Like "And here, next to the lions, we have an old tr*nny"

Interviewer: Did they use that language?

Deborah: No, but I've heard it enough times in my life to know that's what they were thinking. I've been beaten up, arrested, assaulted, you name it. But I'm still here, so I win.

Deborah's experiences with societal and medical transphobia led her to forgo a rehab or long-term care placement, against medical advice. However, hers is not a unique experience: many of the older LGBT people interviewed for this study were suspicious of formal medical care due to experiences of stigma.

Similar to the participants in Muraco's (2015) study on gay and lesbian caregivers of people with dementia, some participants with children were counting on them to hold them in their LGBT identity should they develop dementia. Here, Barbara, a White lesbian in her 60s who had previously provided care for her elderly mother and interacted with the home health care system as a caregiver, expresses a fear that her identity may not be respected if decisions about her care are not being made by friends or family members:

Barbara: I do worry about being taken care of by non-family members or [non-lesbians] if we need it, because there's so much good and bad, and most of the girls we had were lovely but a few were you just got the sense that they didn't really approve. And I don't want to spend my last years trying to seem less queer to make people more comfortable. Not gonna grow my hair, not gonna start wearing sweater sets and skirts, it's my work pants and smocks until I die. [My daughter] knows that, too.

Interviewer: That sort of thing is clearly very important to you.

Barbara: Yeah, well. I spent a lot of time trying to be something I'm not. Then I found who I really was, and I was so much more comfortable and happy. And I found it out so late! You're lucky, you have so much time. I'm not gonna waste another second being unhappy. I decided that a long time ago. And even if I get Alzheimer's, or if I can't speak -- **I don't trust the nurses not to doll me up, I've seen them do it in nursing homes. [emphasis mine]** I want to look like this until I die, I don't care if I'm in my right mind or not. It's that important.

Here Barbara hits on a number of important points -- not only does she not trust the healthcare system to affirm her in her lesbian identity and gender expression, but she indicates that she could not tolerate it because she had previously spent a large portion of her life "hiding". The emotional toll of the closet is significant, as discussed in the

literature review, and all participants in this study indicated that they would never consider ‘going back in the closet’.

Sources of Stigma

While some of the medical stigma discussed by participants involved doctors and nurses refusing care, particularly when the case involved AIDS-related caregiving (see Chapter 6, The Caregiving Legacy of the AIDS Epidemic), the more common and subtle experiences of homophobia, transphobia, and cisheterosexist norms came from personal support workers, RPNs, and others involved in the personal care of seriously ill individuals. For instance, Oliver indicated that it was common for personal support workers to attend to his seriously ill husband only once, before being replaced by a different caregiver. Elizabeth indicated that her friend’s PSW, in an attempt to cheer her up, had tried to dress her in the only dress that she owned, despite the patient’s personal animosity towards dresses. Melissa was outed as a lesbian when her PSWs who were also from her small town entered her home and met her live-in partner. When Barbara was caring for her ailing mother in her home, she also identified that it was common for them to rapidly cycle through personal support workers, and she also indicated that she believed this was based on their discomfort with her and her partner’s lesbianism. Determining why PSWs were the most common source of discrimination and heterosexism is beyond the scope of this paper: it is possible that this occurs simply because PSWs have more intimate and longer relationships with care recipients, giving them more opportunities to act in a heterosexist or homophobic manner. When not performed by partners, relatives, or friends, bathing, dressing, and other forms of personal care are most commonly performed by personal support workers and practical

nurses, who therefore exercise an outsized degree of influence on the individual presentation of the person who is being cared for. This led to problems for some participants, and all participants who had required or who had cared for someone who required the services of a PSW indicated that they felt that at least some of their assigned PSWs reacted poorly to their sexual orientation or gender identity, with Oliver saying:

“We had a few PSWs who only came once, and I suspect that is because they asked to be reassigned away from the gay guys.”

Inviting PSWs and other care workers into the home can be potentially problematic for closeted or semi-closeted older adults. Melanie, a 73-year-old retired mechanic millwright who has lived in the same small rural community for several decades, described the impacts of having PSW support on her social experiences:

Melanie: I had a lot of help, like I said. We had PSWs and things. That was an interesting experience!

Interviewer: In what way?

Melanie: Well, to start off, I knew some of them... We went to high school together. That was weird, we had to get new ones. And some of them -- well, small towns, you know. They knew I was gay, but they didn't like to see the evidence. Couple of them left some Jesus pamphlets! [laughs]

Interviewer: Wow, that must have been an uncomfortable experience.

Melanie: You just had to laugh really. Cause honestly -- and [my then-partner] didn't think this was funny, but I think it's hilarious -- if they were

looking for proof that God hates the gays, well, there was I with breast cancer!

...

Interviewer: Did the caregivers and assistants you had know you were gay? Or, sorry, were you living with [your partner] at this point?

M: I was, so just about every one that came in our house, and we were -- gossip travels fast, there probably isn't anyone in town who don't know.

Interviewer: Have you found that impacts how people interact with you? Including medical professionals?

M: Well, most of my doctors are in other places, the GP in town refused to see me after I left [my husband]. Said that it was a conflict of interest since he also treated [my husband], but I doubt it.

Interviewer: So if I'm getting this right, most of your medical team was in [city], but a lot of your PSWs and caretakers were local?

M: Yeah, a lot of the girls in town work as PSWs or RPNs. And it only takes a couple gossips. Not that it matters, I wasn't hiding, it was just a bit much to be dealing with when I was already dealing with all that.

Melanie was the only participant who lived in a rural area, as such, her experiences of healthcare discrimination varied based on where the treatment was taking place. Her experiences of discrimination were compounded by the fact that she was also dealing with a potentially life-threatening illness, making it more difficult for her to deal with the hostility surrounding her sexual orientation.

As a result, the majority of her healthcare team is located in urban areas that are at least 50km away by car. Although this is currently working for Melanie, it is not hard to see how this could become an untenable situation as she ages and experiences aging-related health issues.

Autonomy and Plans for the Future

The prospect of surveillance and enforcement of gender norms was a source of anxiety for many participants, and was explicitly named by Barbara, Elizabeth, and Deborah as a reason they intended to avoid entering a nursing home by whatever means necessary. This is a common sentiment amongst older adults, but it can be a more difficult problem to resolve for LGBT older adults. Statistically less likely to have children, who are typically the primary caregivers of their older adult parents, LGBT older adults may find themselves in a double bind wherein their fears and concerns about long term care are as strong or stronger than that of their peers while also finding themselves without an obvious primary caregiver or kin caregiving network.

The older adults I spoke to have a number of ways of coping with this issue: some, like Oliver or Ron and Juan, have been saving up for some time in order to finance private care or have strong insurance coverage from unionized jobs. Other participants, such as Elizabeth, envision their later life differently:

Interviewer: So what are your plans?

Elizabeth: Well, me and some of the girls – a few friends of mine, some of them go way back – we actually started talking about it around K's death, but recently, we've been getting a lot more serious about it, as we get closer to the age where we want to

retire. And I don't ever want to go to a nursing home, and I know that's what could happen when you don't have kids to take care of you. So we are gonna make our own.

Interviewer: your own nursing home?

Elizabeth: Well, I guess it's closer to a commune [laughs]. But yes, there are 6 of us who want to get a house together. We're actually meeting with the bank next week. It's real now!

...

Interviewer: Can I ask why you're so against going into a nursing home?

Elizabeth: I mean, I know that there are nice ones, or ones that are actively affirming of gay people, but I could never afford one of those. I know what kind of place I would go, and they aren't nice. Plus I would be away from my friends, and I'd have to give up my pets. And once you're in a nursing home, people kind of forget about you. And I don't want that.

Notably, what Elizabeth fears the most about aging and potentially needing long term care support is that she may find herself cut off from her community, and that she may be forgotten. At another point in the interview, she referenced a gay male friend of hers who was currently in a nursing home in Waterdown, even though his friends and community were in Toronto. At multiple points, she considered how her own lack of children would affect her aging process, noting that as a nurse she was aware that adult

daughters are the most common caregivers of their seriously ill parents. However, she perceived this childlessness and lack of traditional kin ties as a strength, saying:

“I do actually for sorry for [non-LGBT people], especially older women. Some of my colleagues – their families were their whole lives, and that’s fine until something goes wrong. A friend of mine is a widower and he’s just helpless, if I’m being honest with you. But being a lesbian, being part of the community – having seen us all come together over K’s death really heartened me. [Laughs] I know that if I found out tomorrow I was dying, there’s be 6 lesbians fighting over who got to sit at my bedside and hold my hands!”

Elizabeth, who was an only child and who immigrated to Canada on her own in her early twenties, said that most of her close friends were also members of the community, including several who she considered to be her family. However, she was aware that the medical and legal systems do not consider these ties as having the same weight as blood kin, noting that this was another reason she feared going into long-term care. While Local Health Integration Networks (LHINS), who are largely responsible for placing older adults in government-funded long term care and nursing home facilities, usually try and place individuals in their preferred long term care facility and when possible aim to place residents in facilities that are close to the homes of their spouse and/or family, she noted that in her professional experience it was extremely rare for the same consideration to be given regarding the access marginalized residents would have to their own communities.

It was after her circle of friends experienced the loss of one of their numbers to breast cancer that they began to consider how they would ensure they were able to support each other in illness and when they age. As childless women, they were concerned not just that they would not have natural caregivers but that their wishes may be denied without the presence of someone to advocate for them. These friends, most of whom met in the 1980s at a lesbian feminist reading group, have spent several decades together acting as an ersatz family. Deeply politicized, they engaged in significant activism during the AIDS epidemic, with a number of them providing hands-on care to gay men who were dying of the disease. Several were also active in the equal marriage movement. The result of this politicisation, in Elizabeth's opinion, is that they are much more equipped to advocate for themselves and each other in medical matters as they age. I will discuss more about Elizabeth's plans in the following chapter.

LGBT people are statistically less likely to invoke the state and its authority when dealing with problematic issues: while white LGBT people are more likely than LGBT people of colour to call the police in an emergency, white LGBT people are significantly less likely to do so than white cisgendered heterosexuals (Peterson & Panful, 2014). Controlling for income, education, and race, it has also been found that LGBT adults are less likely to have a family doctor, less likely to go to the emergency room for emergency care (although amongst LGBT people without a primary care provider, the emergency room is often their first and only point of access with the healthcare system), and less likely to complain about poor treatment at the hands of authorities (Peterson & Panful, 2014). The suspicion with which the LGBT community treats these structures

may well be justified: studies have continuously shown that doctors under-treat LGBT people (Knauer, 2016), and the history of negative interactions between the police and the LGBT community are both well-known and outside the scope of this paper.

However, these systems are of note precisely because they are connected in the experience of many marginalized peoples: hospitals and medical professions have historically been and often still are sites of trauma for many marginalized people.

Healthcare professionals who also occupy marginalized social locations have noted this for years: racialized healthcare professionals frequently attempt to bring attention to issues of systemic discrimination in the healthcare system, while LGBT healthcare professionals continue to highlight the poor treatment of LGBT patients, particularly transgender people (Cousteau, 2018). Hospitals are also sites of surveillance, linking them with negative experiences of heterosexist and cissexist surveillance that many LGBT people experience in their daily lives.

Personal Care in LGBT Identity

Many LGBT people consider their personal appearance, particularly choices in clothing, hairstyle, and cosmetics, to be an important part of expressing their identity (Reddy-Best & Peterson, 2015; Siverskog, 2015). For transgender people, it is even more important: being forced to perform the gender that they were coercively assigned at birth and which is incongruent with the gender they currently experience themselves to be can cause deep psychological distress (Gooren, 2014; Cook-Daniels, 2015).

Transgender people of all ages who are affirmed in their gender and encouraged to express it in a way that feels positive to them have significantly more positive mental

and physical health outcomes. This extends to some seemingly unnoticeable aspects of personal care: many transgender women seek out electrolysis of the hairs on their face, legs, and arms: a 2011 survey of over 600 trans people indicated that those women who were able to access said treatments had lower rates of gender dysphoria and improved mental health outcomes (Cole, 2011).

LGB members of the community also experience high levels of stress and distress around gender performance and expectations. In a survey of 18 queer-identified women conducted by Reddy-Best and Peterson (2018), all but two participants indicated that they had changed their physical appearance and gender expression after they came out, which predominantly meant wearing masculine-coded clothing, cutting hair, and in three cases binding their breasts so they achieved a more androgynous shape. Interestingly, the two who did not change their appearance indicated that they would like to, but that their family had been very hostile to their attempts to change their physical appearance.

The act of being cared for is very intimate, and also invites a level of surveillance into the lives of those who are being cared for. Relying on strangers for personal care is difficult for everyone, but in the case of LGBT older adults this medical surveillance can be even more problematic. Several participants had previously experienced medical professionals, and particularly personal support workers, who had been explicitly hostile towards their identities. This surveillance, and the associated enforcement of heterosexist gender norms, can negatively affect the mental health and outcomes of LGBT older adults.

Indeed, this surveillance is one of the reasons Juan gave for the level of attention he pays to his physical appearance. Although peripheral neuropathy in his hands and feet has made it difficult for him to groom himself, he and his husband work together to ensure that Juan's clothes are well-put together and that his facial hair is neatly trimmed. When asked about this, his response was a pointed "People are going to be looking at me anyways, I might as well give them something to look at." He referenced the surveillance he receives from strangers resulting both from his non-conforming gender presentation and because of his use of a cane. When pressed further, he acknowledged that he would not feel "put-together" if he did not maintain his grooming to a certain standard and expressed the belief that gay and bisexual men have an increased burden regarding expectations of dress and grooming.

All of the caregivers interviewed, including those who had held dual roles as caregiver and care recipient, indicated that personal care was an important aspect of their caregiving experience. Those who had received care indicated that some of the most valuable or meaningful care experiences occurred when their friends or partners assisted them with tasks that allowed them to maintain their personal identity and gender expression.

Juan is a long-term survivor of HIV. Like many long-term survivors, he has found himself experiencing aging-related health issues at an earlier age than the general population, and also experiences ongoing kidney and liver problems resulting from earlier treatments. Currently, Juan lives with Ron, his partner of many years, and continues to work as a freelance writer and critic. He describes his overall health as

“fair”, and experiences HIV as an iterative chronic condition which occasionally interferes with his ability to complete instrumental activities of daily living such as shopping. He has also experienced several hospitalisations over the years. While most of his daily care needs are met by himself or by his husband, he has a volunteer from a queer community centre to help him with some aspects of personal care.

Juan: There are only a few things that are really important to me that I can't do anymore, and one of them is making sure my hands and my feet are nice and my nails are well-cared for. So one of [the volunteers] comes every week to help me out. My usual girl is Maria, I like her. She always adds a sparkly topcoat! [laughs]

Maria, an HIV+ trans woman, is a volunteer peer support worker with an HIV/AIDS community organisation. On multiple occasions during our interview, Juan referenced her and the importance of her attention to detail.

Juan: Sometimes I'm not feeling so well, and I just want to stay in bed. And if it's a day when a volunteer is coming, well, it doesn't matter. It just doesn't feel possible. Not even Ron can get me up. But sometimes she comes, and she doesn't make me get out of bed, she just opens the window and pulls out her bag and gets to work. Then by the time she's done, she's usually convinced me to get up and walk to the living room at

least. She makes me feel better, just by acting like everything is normal and making little bits of my life better.

These small acts of personal care were also important to Deborah, who referenced her experience having her friends paint her finger and toenails while she was in the hospital and later as she was recovering as being deeply personally meaningful. Indeed, all of the caregivers and care recipients interviewed indicated that relatively small aspects of personal care, such as painting fingernails or trimming beards, were performed routinely by non-kin caregivers. It has been shown that maintaining personal hygiene and grooming standards is an issue of paramount importance for most individuals who require high levels of personal care: personal grooming reflects personal identity and remaining firmly rooted in one's own personal identity is often difficult in an institutional environment. LGB communities often experience personal aesthetic choice as an integral aspect of identity, with gender-nonconforming appearance being something that is of significant personal importance to those individuals who practice it (Reddy-Best & Peterson, 2018). Indeed, while some participants indicated that their greatest fear about long-term care involved being separated from a partner or other forms of homophobic stigma in a long-term care facility, all of the participants interviewed said that they feared the enforcement of gender norms onto them in a nursing home, with even those who were not personally gender non-conforming expressing concern for their gender non-conforming partners and peers.

The gender non-conforming behaviours of cisgender gay men, lesbians, and bisexuals often take the form of relatively small acts of rebellion against cissexist and

heterosexist norms. These behaviours include length of hair and hair style, the presence or absence of cosmetics, cut and style of clothing, or personal accessories. While the differences may be relatively minor in and of themselves, and indeed may not be apparent to members of the straight community, they are often practiced concurrently and taken in concordance constitute a distinctly non-heteronormative style of appearance (Reddy-Best & Peterson, 2018). Participants feared being unable to engage in these small acts of “rebellion”, which for many LGB people is not just an important expression of their self-image but also a way to signal to fellow community members that they are also LGB. Thus, enforcement of heterosexist gender norms onto LGB people can result not just in psychological distress but also in feelings of disconnect from their community (Cohen & Byers, 2015). For members of the trans community, the enforcement of cissexist gender norms by medical professionals or care providers can result in increased gender dysphoria, increased risk of mental illness, and increased risk of violence (McGuire et al., 2016).

In general, it has been shown that the level of care a person gives or receives is directly related to the strength of their bond with that person (Donovan et al., 2011). In North American society, these bonds are typically strictly defined via blood and marriage, with the highest expectations of care being partner to partner and adult child to parent. Caregiving is also typically a highly gendered act, with the overwhelming majority of informal caregivers being women (Pinquart & Sorensen, 2006). Male caregivers are also significantly less likely to provide personal care. However, as discussed in the literature review, these norms simply are not present in many LGBT

communities, likely as a result of the legacy of the AIDS epidemic. Most participants provided care for a member who shared their sexual orientation and/or gender identity, however three participants reported either giving or receiving care for another member of the LGBT community who was not a part of their own sub-group. In these cases, cis lesbians and trans women provided care to cis gay and bisexual men, suggesting that at least within the surveyed population the typically gendered aspects of caregiving may be more apparent when the caregiving relationship occurs on an inter-community basis. It is also important to note that while many caregivers find themselves in the position of needing to advocate on behalf of the individual they provide care for, all of the LGBT caregivers interviewed considered advocacy, and even political activity, as an integral part of providing care for a fellow member of the community. Indeed, the norms around community care in the LGBT community are highly tied to community action and political advocacy, resulting from previous community experiences of discrimination and poor care, particularly during the AIDS epidemic. This phenomenon is explored at length in the following chapter.

Chapter 4: Community Caregiving and Political Advocacy

*“If you are silent about your pain, they’ll kill you and say you enjoyed it” - Zora
Neal Hurston*

LGBT existence is heavily politicized: terms such as the LGBT community or the queer community arose out of an explicit political alliance between members of oppressed sexualities and gender identities (Sayers, 2015). This politicisation has been necessary to the community’s survival. Although the negative perceptions around LGBT people are seemingly less widespread than they were even ten years ago (Greenberg et al., 2019), there remains a dense and interconnected network of formal and informal discrimination and oppression, from the treatment of LGBT asylum seekers to the small but steady increase in violent hate crimes in Canada over the last ten years (Statistics Canada, 2019). In response, LGBT+ individuals form stronger social and emotional ties with other LGBT people than they do with cisgendered heterosexuals (Cook-Daniels, 2015), and like many marginalized communities LGBT communities often form their own networks of care outside of the traditional caregiving norms (Kim et al., 2017). For many participants in this study, community caregiving was also synonymous with political action or advocacy.

Health Justice and Health Advocacy

Marginalized communities, and in particular the multiply marginalized, often conceive of political advocacy or action as something that must be done in order to ensure the safety and wellbeing of their own community. Health justice is one such

issue: particularly in the United States, access to healthcare is intrinsically tied to social and economic capital which is difficult for marginalized people to accumulate (Reidman, 2007). Health justice is often a goal of marginalized community advocates, in part because members of marginalized communities are more likely to get sick than the general population. The cumulative impact of minority stress, higher rates of poverty and incarceration, and medical neglect often significantly impact the life expectancies of marginalized peoples. These stresses compound with multiple axes of marginalization: while LGB people in general have slightly lower life expectancies than straight people, transgender women of colour in America have an average life expectancy of just 35, primarily due to death by suicide and homicide (Carcano, 2014).

Advocacy is an integral part of all forms of care work in a neoliberal society (Seyers, 2012). Caregivers of all kinds as well as disabled people have repeatedly indicated that one of the most time-consuming aspects of care work or self-care is continued advocacy to healthcare professionals and the navigation of complex bureaucratic systems (Conwin et al, 2010). Navigating these systems alone was a consistently expressed fear amongst participants, and single participants had already made plans to ensure that they would not be alone if they became ill.

Community Care Networks

Barbara, an older lesbian who provided care to a gay male friend of hers, C, as he died of AIDS, described the community impact of C's illness and eventual death. His death and friendship were particularly meaningful to her as he was the first person she had met who publicly identified as being gay.

Interviewer: You mentioned C earlier. Can you tell me a bit about that relationship?

Barbara: C was the first gay person I ever knew. He was so funny, you know? He worked with me, and at the time I was a bus driver, and he always had the best jokes. And so we'd go out sometimes after work and grab drinks, he actually – he was L's godfather.

Interviewer: So you knew him before you came out.

Barbara: Yeah ... [after arguing with my ex] I called him... and told him that my ex thought we were sleeping together and he just paused and said "[B], you know I'm gay, right?"

And I just kinda didn't say anything, and then he asked if I was surprised and truth is I was, but only because I'd never met a gay person before.

And things were a bit awkward for a while, but afterwards things settled.

Heck, my ex even liked him by the time L was born. So we made him her godfather.

Interviewer: Wow. So when he got sick, what happened next?

Barbara: Well by then I was with M, and I had L, and we were just all so scared. We had made friends in the scene, and I've always said I'm glad I'm a lesbian and not a gay man. Lesbians respect their elders.

Interviewer: So when people started getting sick, what was that like for you?

Barbara: Well it was clear that it wasn't being spread to dykes, so we weren't too worried about ourselves really, but we were worried about our

friends. ...So when he was really sick, well, there was a casserole train from work, from all the bus drivers and their wives, and his partner would take care of his sort of daily care as much as he could but he had to work, it was – if C had been sick with anything except AIDS, literally anything, he would've had really good coverage from work. But he couldn't take LTD – long term disability – because AIDS wasn't on the list. So he had to quit. But we did the best we could, his friends in the union. We'd pass a hat at the end of meetings for the "C fund", and I'd count it and bring it to them. I know that they really appreciated it. When his partner worked days, then we would drive C to his appointments. And when his partner switched to the night shift we used to go over and stay the night on the couch, have a sleepover.

Interviewer: It sounds like you really cared about him.

Barbara: we all did. Everyone. The funeral – it was almost funny. His family wasn't there. He told me they weren't in touch. So the crowd was half people from the community, you know, and the other half were these big gruff union guys. But they loved him, he was such a — a positive force to be around, you couldn't help but love him.

Elizabeth described a similar case of the community -- in this case, the lesbian community -- coming together to care for one of its members.

Interviewer: So you mentioned earlier that you helped take care of her.

Can you tell me about that? What kind of things did you do?

Elizabeth: Oh, all sorts of things. I would drive her to her appointments, help her out with meals, and talk to her health care team. She liked to have me with her because I'm a nurse, so I understood everything.

Interviewer: Did she have any other people helping her out?

Elizabeth: Well she was single, and this was before we could get married anyway. And her family was far away, out in Nova Scotia, but her sister came towards the very end. And she had a lot of friends, everyone loves her.

Interviewer: Did they help out as well?

Elizabeth: Oh yeah, we had a calendar and everything.

Elizabeth's story demonstrates a crucial point regarding in-group care in the LGBT community: in the absence of biological kin or spouses, it is often friends from the community who step up to provide care of all kinds.

Deborah and Ron were perhaps the most overtly politicized participants, as both of them had been involved in a number of advocacy campaigns over the years. While Ron's participation was prompted by the AIDS epidemic, which will be discussed further in Chapter 5, Deborah's political action began when she came out as transgender in the 1980s. Although she had previously been involved in political action, and had been, in her own words, "aware of the issues," it was not until she began to explore her own identity that she began to make links with others in the LGBT community and developed strong ties with her fellow organizers. When she was discharged from the hospital following a significant operation on her foot, fellow trans women and activists formed the nucleus of her caregiving network.

Interviewer: It sounds like most of them were close friends. Can I ask how you met them?

Deborah: I met some of them in activism, the woman who helped me the most was also a member of the anti-poverty coalition, she was on ODSP and wasn't working so she had the time to help me out. [Another caregiver] – she's a lawyer, and a trans woman, and we met working on housing issues. Most of the people who helped me were either also trans women or disabled, often both, if we're being honest.

Asked to elaborate on her beliefs on community care, she highlighted a number of issues, including her belief that the medical system is ill-equipped to address health problems that are the result of marginalized people living under structural powers.

I: Can you tell me more about that?

Interviewer: It's simple. Doctors, hospitals, all these medical gatekeepers – they might know what they're talking about when it comes to diseases, but they don't have any idea how to deal with the real problems. They are too busy thinking about everything as a disease, they don't think about how a lot of our problems are problems of poverty and racism and discrimination.

She also noted that, despite her deep passion for and involvement with LGBT issues, there are barriers between her and other transgender older adults who came out later in life that can occasionally make it difficult for her to connect with them. As someone who came out long before being transgender was considered

even somewhat socially acceptable, and as someone who was deeply embedded in the queer community and particularly communities of queer sex workers in the 1980s and 1990s, her life history has been significantly different than that of many other transgender people her age. However, her strong belief in community care has helped her overcome these barriers to emotional connection.

Deborah: I'm aware – most of the other older trans people I know are people who lived a life, essentially, and then came out. I came out in my late twenties. I've outlived most of my friends from back then, they died of AIDS or by overdose or suicide or murder or just sickness that they didn't get treated. So there's always gonna be a bit of a difference between me and other trans women my age, but I still think we have to look out for each other. I look out for them, I volunteer at the senior's program at [an LGBTQ2SIA+ community group], and they look out for me.

Having lost friends and fellow community members to violence and illness, it is perhaps unsurprising that remembering the dead forms a core component of Deborah's beliefs around community care. Other participants' experiences of remembering the dead and caring for the dying will be discussed in Chapter 6, but Deborah's experience is recorded here because she explicitly views the act of remembrance as being inherently political. She also noted that her passionate advocacy for herself and for the broader community is often misidentified as aggression, something she links to societal beliefs around the inherently "masculine" nature of transgender women.

Deborah: I think the thing that worries me the most about aging and losing those people is that we lose so much of our histories and stories. We talk about the dead, but I don't think we do so enough. But I try and remember them, and I've written about them on my blog, and so when I say we have to take care of each other I don't just mean that we have to look out for one another when we're ill or dying, although of course we should. [It] also means making sure people don't fall through the cracks, and making sure that we are looking out for all marginalized people, because nobody is free until everyone is. And I've seen so much movement in my own lifetime, it's remarkable to really think about how far we've come. But we have to go further.

Interviewer: It sounds to me like you consider activism to be a really important part of your identity as well.

Deborah: Of course I do. There's a quote – I think it's bell hooks [sic] – that if you are quiet about your pain, people will kill you and say you enjoyed it. And that's absolutely true. If we aren't loud, and we aren't – there's a pretty nasty thing where people call trans women aggressive and use all kinds of masculine language about them – and so I try to be conscious of that, but we need to be aggressive. I'm proud to be aggressive. It means I'm a good advocate, and it's got nothing to do with my gender.

It is a testament to how linked the acts of community caregiving and political advocacy are that many participants referenced the importance of advocacy and support when asked about seemingly unrelated topics. When asked about how they envisioned caring for themselves as they aged, many participants expressed the belief that their partners or other members of their care networks would assist them with the necessary self-advocacy.

As discussed in the previous chapter, Elizabeth and her friends first began to consider how they would age and continue to hold each other in their identities after the death of a member of their close-knit lesbian community. As a nurse, she was also particularly well-situated to consider what would be necessary for their plans to work.

Interviewer: So you're choosing to work completely outside the system.

Does that scare you?

Elizabeth: No, I'm a pretty independent person [laughs]. But we're an educated bunch, one of the others is also a nurse, and I think we could take care of each other for a long time.

Nevertheless, Elizabeth was not naïve about the amount of care that may be required and the expenses they may incur as they age:

Elizabeth: We'll probably need more care towards the very end, but I think we can be self-sufficient for a while. We'll be able to renovate the place, make sure that it's accessible, in case any of us need a wheelchair or a walker as time goes on. We were all – I'm sure that we'll be able to get whatever it is that we need. We should have the funds to get it, and we

were all pretty political back in the day, we're pretty good at demanding that our needs be met.

While financial stability and the ability to meet each others medical needs was mentioned by Elizabeth as one of the primary motivators for their plan, the inbuilt community was another.

Interviewer: And what about the others? Why do they want to join you?

Elizabeth: Well, we're all scared shitless of going into a nursing home, and you start to think about it a you get older. But I really do think it comes down to K, and seeing her die, and seeing her have to fight with the system until she died just to get the care she needed – I think that we realized then that none of us could go it alone, not if we wanted to be happy.

Interviewer: What do you mean?

Elizabeth: Well, even with friends, and I know that if I woke up tomorrow and learned I was dying there would be half a dozen people trying to help me immediately. But it's still lonely. I stayed in K's house when she was dying, because she told me she was scared that she would be alone when the time comes. And I don't want that, and I want people in my corner to fight for me so I don't have to do it all myself. That fighting is so exhausting, and I don't want to have to think about it when I'm dying. If we were straight and had children, we'd have spouses or children to advocate for us. But we don't, so it's down to us to take care of each other.

Unknowingly, Elizabeth is echoing a statement made by another Hamilton lesbian over 20 years ago, when a participant in Aronson's study of lesbians giving and receiving care said, "We have to look out for each other." (Aronson, 1998, pg. 101).

It is impossible to discuss political action and care work in the context of the LGBT community without mentioning the AIDS crisis, when a diversity of tactics were used by activists in response to apparent societal indifference to the epidemic. While I will discuss the ways in which the AIDS epidemic continues to affect LGBT older adults and their care networks in the following chapter, I nonetheless must give some consideration to the intense and sudden politicization experienced by some of our participants who survived the HIV/AIDS epidemic.

Ron, a 67-year-old White gay man and retired teacher, indicated that he has provided care to multiple individuals over the span of decades, including friends and partners with AIDS as well as his dying estranged mother. He describes his politicisation thusly:

R: [When I] was in my twenties, I wanted to have fun, I wasn't interested in – activism or whatever, not in the way that I am now.

Interviewer: What changed that for you?

R: AIDS happened. And it was – people were getting sick, and nobody knew anything, nobody would help us. We were – we were on our own.

And that's what made it political to me.

Ron's experiences of caregiving during the HIV/AIDS epidemic will be discussed at length in the following chapter.

For Ron, acting as a patient advocate for his friends who were diagnosed with AIDS was as political as his involvement with groups like ACT-UP: from his perspective, the systemic discrimination against HIV+ people would only end with both sustained political pressure and sustained advocacy from patients and their loved ones. This early politicisation is a common experience for older LGBT people: many participants came of age during or slightly before the AIDS epidemic of the 1980s, resulting in many of them joining groups to fight for a cure or other political goals. Juan, who has been with Ron for nearly 30 years, describes how he brought this aspect of his activism into the classroom as a teacher.

J: ...in 2004 or so I had a really bad turn and we thought that was it, that I was done for. But we were civil partners and his union was really good, made sure that everyone with a civil partnership had the same rights to family leave as married couples. So he was able to take a few weeks off to take care of me.

Interviewer: That's good

J: ... he did a lot of work in making sure that they were accepting of gay people and people with HIV, you know? It would have been easier for him to hide. And it's not as though he ever brought it up -- but when he had to take leave, one of his students asked where he'd been, and he said that he was taking care of his partner, who had HIV and who was very sick, and did they have any questions? And it turned out quite a few of his students were from places that they -- where it was more common to have HIV.

And that was how they went on with it, you know?

Interviewer: That's lovely

J: Yeah, it was unexpected. A few of them came to our wedding, it was very nice. But after that he was more open with his students because he realised -- he realised that it was important for them to have a teacher who was queer, and he realised that it was important also to connect with the kids. And illness is a surprisingly good connection.

While participants often referenced the importance of the HIV/AIDS epidemic to their understandings of advocacy and political action, most did so in the past tense. Unlike the other participants, Juan and Ron continue to experience discrimination -- and in the case of Juan, active health effects -- as a result of their HIV+ status. As a result, HIV/AIDS remains a central component of their activism.

Chapter 5: Legacy of the HIV/AIDS

While much has been written about the legacy of the HIV/AIDS epidemic in MSM communities (Matthews, 2018; Enoch, 2017; Wilson et al., 2016) to date there is comparably less literature on the impacts and legacy of HIV/AIDS in communities who were not directly targeted by the virus: particularly, lesbians, bisexual women, and transgender men. However, these groups were part of AIDS caregiving and advocacy from the very beginning of the epidemic. All of the older adults I interviewed, who were from a variety of social locations and who represented different segments of the LGBT community, mentioned the HIV/AIDS epidemic as a formative event either in their understanding of their own sexuality, or in their politicisation and political understanding of caregiving. While two of the men interviewed are long-term survivors of HIV, one had been entirely asymptomatic while the other continues to experience side-effects from early HIV medications and earlier-onset issues of aging-related frailty. The other MSM participant interviewed was considerably older, and had been middle-aged during the epidemic, limiting the number of people in his social circle who suffered from HIV/AIDS--the majority of those diagnosed with HIV were in their 20s, a trend which holds true today. However, this does not mean that the epidemic did not affect him: he expressed feelings of tremendous guilt that he was not personally affected in the same breath as he described providing care for HIV/AIDS sufferers. All subjects referenced the HIV/AIDS epidemic as being a formative event in their understanding of caregiving and health advocacy.

Long Term Survivors of HIV

Long term survivors of HIV are broadly defined as individuals who were diagnosed with HIV prior to 1995, when HAART medication was developed, or as individuals who have lived with HIV for more than 20 years (Emlet, Gerken, & Orel, 2009). In North America, the majority of long-term survivors of HIV are currently older adults, and two of the participants in my sample can be defined as long-term survivors of HIV under both criteria. Long-term survivors of HIV, particularly those diagnosed prior to 1995, are as a group less likely to remain in the labour force for the same length of time as their peers, less likely to own their home or have accumulated wealth, and are broadly poorer, sicker, and more vulnerable than their HIV-negative peers (Slomka, Lim, Gripshover, & Daly, 2013). Long-term survivors of HIV often experience aging-related illness and frailty before their peers, a phenomenon some scientists refer to as “accelerated aging”. It is unknown at this time if this is the result of long-term HIV infection or long-term antiretroviral therapy use (Emlet et al., 2009).

Many government-run nursing homes and hospices are poorly equipped to deal with older adults with HIV. In 2017, Hughes and Alford found that misperceptions about HIV/AIDS are common among both residents and the medical staff of many general nursing homes. There is also an issue with treating these individuals in an acute-care setting, both because late-stage HIV/AIDS often involves multiple system failures and because people can now live with late-stage HIV/AIDS for quite some time, making hospital care an inappropriate treatment (Martin, Fain, & Klotz, 2008). Due to the high care needs associated with late-stage HIV/AIDS, medical professionals often refer

these individuals to general nursing homes which often lack the medical capacity and culturally safe environment necessary for the treatment of individuals with HIV/AIDS. Of the long-term survivors interviewed, one had been asymptomatic since his infection in the mid 1980s, while the other continues to experience side-effects from early treatment options including peripheral neuropathy and kidney damage. He continues to have his care needs met at home by his husband, with some support as necessary from community-led AIDS organisations. He indicated that they prefer this care to that provided by institutions (community nursing, PSW support, etc.) as they believe that negative attitudes towards people with HIV persist in the healthcare system, and the community volunteers were unlikely to react negatively. Juan also indicated that Ron had a strong personal identity as a caregiver, and so reacted poorly to the suggestion that outside help be brought in.

Juan: ...One of my really bad days, I suggested we take my doctor up on the offer to, you know, connect us with community nursing services. And uh it wouldn't be ideal for me, but I'd rather have a stranger help me than have Ron burn himself out.

Interviewer: What did he say?

Juan: He was almost offended! [laughs] He said something like [sarcastic voice] "Oh, suddenly I'm not a good enough nurse, is that it?" He was joking, but I think part of him was actually kind of hurt. We ended up with a sort of compromise, now there's um, a volunteer, or a couple of them actually.

Interviewer: Did you talk about that? You said you thought he was hurt.

Juan: No, uh, I just got the sense – he's an excellent nurse, he's probably spent as much of his life playing nurse as he has teaching. I think [pause], I think helping me makes him feel better.

The couple indicated that they both continued to experience both physical and mental health issues relating to the HIV/AIDS epidemic. While nearly all individuals interviewed indicated that the HIV/AIDS epidemic had either personally affected them or affected their thinking about the future, the couple were the only participants who disclosed that they have both been diagnosed with AIDS Survivor Syndrome, a form of complex post-traumatic stress disorder that will be discussed in more detail shortly. This caregiving dyad also showed a high level of reciprocal caregiving, with Juan indicating that he has at times hidden aspects of his illness from Ron in order to avoid overburdening him. Similarly, in addition to the physical care disclosed by Juan, Ron expressed high levels of anxiety over his long-term health and his ability to care for Juan.

Caregiving Legacy

Two other participants indicated that their first experiences with caregiving occurred during the HIV/AIDS epidemic, although they differed both in the level of care provided and their relationship to the disease. Oliver, who is now 81, was already middle aged during the epidemic, and the overwhelming majority of new infections occurred in people in their teens and twenties, a trend which holds true today. That said, as someone who was active in the community, he experienced the loss of several friends, and provided care for them in his own way.

Oliver: Well, when Brian got sick, it was like riding a bicycle, I remembered how to do much of it just from the old days... I don't want to misrepresent myself; I was extremely fortunate. I never lost a boyfriend or a partner. So I didn't do all of it, some of the more nitty gritty personal stuff was new. But just being in the community and being out at the time meant you would lose friends. I mean, I was in my late forties at the time, and it hit the younger men harder for a variety of reasons, but nobody was safe. We all lost people.

Interviewer: What kind of care did you do then? You mentioned you didn't do the "nitty gritty" stuff, which I'm guessing you mean like personal care, bathing, toileting, that kind of thing. What kind of care did you provide?

Oliver: Oh, well. I would help with shopping, I would cook these lovely meals and bring them round to people I knew, I would go and visit and read to them. I also – if they wanted a drink or a smoke, they knew that I would figure out how to make it happen even if they were in the hospital. They were dying, we all knew that, and I've always been able to charm a nurse.

This care experience, which combined assistance with instrumental activities of daily living and holding the dying in personhood, was invaluable when his husband was diagnosed with prostate cancer in 2009.

Interviewer: you mentioned that your husband was very ill recently ... do you remember what you were feeling then? Aside from shock?

Oliver: Grief. Anger. Frustration. It just seemed so unfair. We'd both survived the epidemic untouched, and, well, you can't help but think about that when something like that happens.

Despite the glaring absence of lesbians and transgender people from popular depictions of AIDS histories, the reality was quite different: during the crisis, both implicit and explicit networks of care were created and sustained by lesbians. Indeed, two notable historiographers of early AIDS activism and ACT-UP, have publicly discussed how as lesbian activists they feel a duty to carry on and memorialize the work that killed many of their gay male comrades in the AIDS activism movement (Levine 2010; Hager 2015). This sentiment is common in individuals who were active members of the LGBTQ2SIA+ community in the 1970s and 1980s and who survive to this day: in addition to dealing with long-term mental health effects and the ongoing physical challenges that some long-term survivors experience, many have taken on the additional burden of holding lost loved ones in personhood. As Ron, a long-term survivor of HIV married to another long-term survivor, both of whom lost friends and partners during the epidemic, said:

Some of these guys, they thought they were so grown up, but they were kids.

[emphatically] I was still a kid, and I was -- God -- 28, 29 maybe? Some of them

were 18 years old, their parents didn't want them, but they were-- they were kids. I hope -- some of them, I've had the opportunity to get in touch with their siblings, tell them about their brothers. I've kept -- I've done my best to keep them alive in that sense.

For Ron, the AIDS epidemic was transformative. Previously non-politicized, he engaged in a multitude of political activity and advocacy on behalf of his friends, and later, his partner, who had contracted HIV/AIDS. He participated in direct action for the first time, in the full knowledge that it could lose him his job as a public high school teacher. Interestingly, when asked about the care he provided to people in his social circles that were suffering from HIV/AIDS, he first emphasised his political activity.

R: I wasn't out until the 90s, not at work. Other staff probably knew my friends definitely did. But there was that constant fear, and you have to remember that I was in my twenties, I wanted to have fun, I wasn't interested in activism or whatever, not in the way that I am now.

Interviewer: What changed that for you?

R: AIDS happened. And it was people were getting sick, and nobody knew anything, nobody would help us. We were just -- we were on our own. And that's what made it political to me.

Interviewer: The political aspect is interesting, and I want to touch on it later, but just first how did you end up in the situation where you were providing care? What can you walk me through it?

R: The politics are important to understand what was happening. I was -- some of us were a bit older, university educated, and out. Very few people were all of those things, especially at the beginning of the epidemic. But I knew-- I knew how doctors worked, and I knew how to advocate, and I wasn't a kid.

Other participants who provided care to people with HIV/AIDS expressed similar sentiments. Barbara provided care to a fellow bus driver who passed away from AIDS in the early 1990s. This was discussed at length in Chapter 4: Community Caregiving and Political Advocacy, and is notable for the ways in which care was provided not just by Barbara and other members of the LGBT community but also by his cisgender heterosexual colleagues in the transit union.

Barbara: ... we did the best we could, his friends in the union. We'd pass a hat at the end of meetings for the "C fund", and I'd count it and bring it to them. I know that they really appreciated it. When his partner worked days, then we would drive C to his appointments. And when his partner

switched to the night shift we used to go over and stay the night on the couch, have a sleepover.

Barbara also noted how C's illness and eventual death affected the perceptions her cisgendered and heterosexual colleagues had of LGBT people and in particular people suffering from HIV/AIDS.

Barbara: ...after C had to quit, we were at a union meeting one night, and a newer guy made some kinda AIDS joke. You shoulda heard it. The room was so damn silent. And right when I was about to get my nerve up and say something, Dave, who was this big gruff guy, straight as they come, practicing catholic, all that -- stood up. And he was TALL, y'know? And he looked the new guy right in the eye [and] said "Don't you ever fucking say that again. You don't know what the hell you're talking about." And that was that.

Interviewer: Wow. Were you surprised?

B: I was surprised that it was Dave who said it. But then when I was driving home, I thought about it some more and I realized everyone liked C. And things are different when you know someone. I just -- a lot of those guys are a lot more understanding now, because of C.

Interviewer: Probably you as well, no?

B: Yeah, I suppose. Last time I saw one of the guys from the old days he told me that he has a transgender niece out in P.E.I. And he struggled with pronouns a bit, but it was very clear that he really wanted to help and be supportive and just wasn't sure how.

Here, the legacy of community care for someone suffering from HIV/AIDS led to a broader understanding of LGBT people in general amongst a group -- predominantly white, working class men -- who are often perceived as being unsupportive of LGBT issues and who indeed show higher levels of suspicion and aversion towards openly LGBT individuals, particularly gay men (Embrick et al., 2007). The impact was not just felt by the community, in this case C's union colleagues, but also by their families. Barbara often brought her then school--aged daughter with her to care for C. When she got older, her daughter chose to study nursing, and specifically mentioned her experiences with her mother and caregiving as the reason why she chose to enter nursing. She currently works at a transgender health clinic and volunteers at a safe injection / harm reduction site and informed her mother that she chose to work with stigmatized and marginalized populations because she recalled the treatment of her mother's friend as he died of AIDS.

AIDS Survivor Syndrome

Juan, who like Ron is a long-term survivor of HIV, continues to experience negative health effects associated with the virus and its treatment, but considers the

psychological burden associated with “AIDS Survivor Syndrome” to be the more serious condition.

Interviewer: I know I asked how your health was earlier, but could you maybe elaborate on that?

J: I was diagnosed with HIV in 1991, and I managed to stick around until the drugs got better. It was a close thing, though. And those early drugs did a lot of damage, but at the time -- at the time, we were all pretty sure we'd be dead soon, so long-term side effects... [laughs] weren't really a concern.

Interviewer: What kind of things are you experiencing?

J: Oh, you know ... fatigue, dizziness, osteoporosis --- I've got kidney trouble and bone trouble from the early drugs. I know I look like an old man! (laughs) And the first drugs they gave us, they were neurotoxins -- so I have nerve damage in my hands and feet, it makes it hard to walk and sometimes hard to type. It's painful. I'm always in pain. They've got me on a fentanyl patch, and I use cannabis to help. But it's hard.

Interviewer: Does Ron know about your symptoms?

J: Some of them -- I don't see the point in complaining all the time, but it's like, sometimes I'll be taking a shower and I just need to sit down for a few minutes. I've passed out a couple times, he knows about them. And he knows me well, he can tell when I'm in pain more-or-less. But I don't think he knows -- I mean, neither of us

sleep well. I get nightmares. He gets -- we both suffer from something they're calling "AIDS Survivor Syndrome", it's sort of a form of PTSD. He was lucky, he's been positive for decades, but he never got sick. He's done a bunch of studies, and I think that's something that gives him comfort -- they're using antibodies from guys like him to find a cure. But I think -- I might have gotten the worst of it, physically, but it really fucked him up... he took it upon himself to keep track of everyone, everyone he knows who died and what he knew about them. He wrote it all down.

AIDS Survivor Syndrome is a term coined by activist and long-term survivor of HIV, Tez Anderson (2015), to describe the constellation of mental health symptoms often experienced by long-term survivors of HIV. Those symptoms include: depression, lack of future orientation, panic from unexpected old age, suicidality, sexual risk-taking, self-destructive behaviour, substance abuse, social withdrawal and isolation, persistent negative self-image, survivor's guilt, cognitive impairment such as poor concentration and loss of immediate memory, anhedonia, anxiety, irritability, insomnia, nightmares and night terrors, personality changes, hypervigilance, low self-esteem, irritability, and self-stigma. While it is most common in pre-HAART HIV+ individuals, it has also been known to affect HIV- LGBT people in North America who lived through the initial AIDS epidemic.

Speaking on the causes of the syndrome, Anderson says "AIDS Survivor Syndrome is akin to Complex Post-traumatic Stress Disorder (CPTSD) because of the duration of the "Plague Years" filled with multiple casualties and a life-threatening illness. Now

survivors are aging with HIV, something most never imagined, much less planned for. There are numerous challenges to survival, including high levels of multimorbidity, persistent behavioural health issues, inadequate social supports, barriers to access community-based services, and truncated opportunities for employment and participation in society resulting in insufficient financial resources and poor quality of life.” (Anderson, 2017)

Long-term survivors of HIV/AIDS have experienced a double life course interruption: the first when they were diagnosed with HIV and prepared themselves to die young; and the second when they instead lived. Having psychologically prepared themselves for death, they instead found themselves living for decades with a chronic condition. This can be extremely traumatic and is likely one of the triggers for AIDS Survivor Syndrome: many long-term survivors have spoken of the psychological burden that comes with preparing for death and instead living. Pre-HAART survivors are more likely to have developed a medication-resistant form of HIV: early medications were unfortunately only moderately effective and had serious side-effects like peripheral neuropathy and kidney damage. The ramifications of the AIDS epidemic were both societal and personal for our participants. Some care networks that were formed then continue to exist to this day, and for some it was their first exposure to caregiving. Others were politicized during and because of the epidemic. Indeed, all but one participant spontaneously brought up the epidemic as something which influenced their experiences and histories with caregiving and health care. The legacy was felt most heavily by the two HIV+ participants, one of whom experiences significant health issues and disability from early treatment options,

and the other of whom experiences ongoing mental health issues and survivor's guilt related to his survival of the epidemic.

Chapter 6: Remembering, Hoping, and Letting Go: Resiliency and Holding in Personhood

Read how disgusting we are in the press/ *The Telegraph*, *People* and *Sunday Express*/
Molesters of children/ corrupters of youth/it's there in the papers/ it must be the truth."

- *Glad to be Gay*, The Tom Robinson Band, 1977

Holding in Personhood

Personhood is a fundamental component of any form of care work, and the maintenance of personhood via upholding personal identity. For my purposes, I will be using the narrative ethics constitution of personhood, as defined by Hilde Lindemann (2014) in her book *Holding and Letting Go: The Social Practice of Personal Identities*. Lindemann (2014) argues that personhood is a relational process of moral understanding that occurs, roughly, in the following way:

1. A human being has sufficient mental activity to constitute a personality
2. Aspects of this personality are expressed bodily, via identity-performance
3. Other persons recognize it as the expression of a personality
4. They respond to what they see

This definition of personhood as a relational ethical act is particularly useful for discussions involving the ill, dying, or dead. The impersonal nature of acute hospital care often leads to individuals who have experienced it feeling depersonalized, but their friends and family may hold them in personhood by both responding to and assisting them in their identity-construction. This is not a practice that is unique to the LGBT community, and indeed it is often an instinctual act that is part-and-parcel of care work: people often bring loved ones their favourite foods, or a beloved pair of pyjamas, when they are in the hospital or otherwise ill. This is a way of holding them in their personhood.

Recognition and response are the vital part of this, and that recognition often involves identifying an individual's personal narrative within the master narrative about 'people

like them’ (Lindemann, 2014). This can lead to an imperfect recognition: master narratives can be stereotypical or otherwise damaging, particularly for marginalized peoples. But what happens when the master narrative is absent, harmful, or contrary to the individual’s personal narrative? Lindemann posits that the individual is then stuck in an “impossible identity” (Lindemann, 2014, p. 128), something which she identifies as particularly affecting transgender people. The master narrative about transgender people posits that they are deceivers, that they are ill, or that they lack personhood. As a result, transgender people find themselves in a double-bind wherein they either “come out”, disclose their transgender identity, and be assumed to be a deceiver or pretender at their own identity, or to not disclose it and live in fear of being found out and identified as a deceiver. The end result of an impossible identity is that people will treat you as though you have no right to exist. The only way to combat an impossible identity is for there to be positive-identity constituting narratives about transgender people.

Battling an Imperfect Identity

The imperfect or impossible identity has historically been a hallmark of identifying as a member of the LGBT community: the master narrative has often been directly harmful to LGBT people. LGBT people have responded both with rejections of the master narrative historically and construction of positive descriptions of personhood. The song quoted at the beginning of this chapter is one example of this: identifying the negative master-narratives within the verses and rejecting them with a positive one in the chorus, which runs “Sing if you’re glad to be gay/ Sing if you’re happy that way//” etc. LGBT community pride has historically been a pride of defiance, not one of positive identity-construction: that positive identity construction has instead often occurred at the

interpersonal level. LGBT caregivers and care recipients often have to engage in both forms of recognition: rejecting harmful counter-narratives and holding people in their positive personal narratives.

The first aspect of recognition was discussed at length in Chapter 4 and will not be engaged with further in this chapter. Instead I will focus on the second aspect: the act of holding the ill and dying in personhood, and how said holding influences LGBT caregivers' feelings about their own death.

Personhood, Death, and Dying

All participants noted a time when they or their caregiver were particularly attuned to aspects of personhood and identity. Those who had received care often expressed that they found it particularly meaningful when their caregivers were able to assist them with tasks which may not have been directly linked to their health, but which improved their outlook and combatted feelings of isolation.

Deborah described being the beneficiary of one such act:

Deborah: I have a very good friend who would visit me in the hospital to paint my fingernails, and then when I was home, she brought me this beautiful stack of brand-new nightgowns from The Bay. It must've cost her a fortune.

Interviewer: Did you --- I mean, you said that you were having a hard time paying rent. I feel like I would've rather had the money.

Deborah: No, she knew I wouldn't have accepted that. Instead she stocked my fridge with really good, organic food, and brought me

beautiful nightgowns, and just generally tried to do the things that I couldn't afford to do but which really improved my quality of life.

Here Deborah's friend was attentive to her personal self-conception as someone who is independent and who dislikes being the recipient of what she sees as unearned largesse. Although she lived and lives in poverty, her friend was close enough to know that any outright gifts of money would likely be rejected. Instead, knowing that Deborah had just left the hospital where she had felt disconnected from any positive aspect of her trans identity (discussed in Chapter 3), she provided her with a gift that would both materially improve her comfort and would also reinforce her personal identity by gifting her with signifiers of femininity that she had not had access to in a hospital setting. Her friends were also very attentive to her feelings of pride, and while one or more of them did indeed pay her rent for the month, they were careful not to let her know who had done so.

Deborah: ...it ended up that someone paid my rent that month, anyway. None of my friends will admit to it, but it was such a huge relief. I had a roof over my head and good food and nice clothes and that was probably as important to my recovery as the physio. Being sick, especially really sick makes you feel like you're not a person, and I think that's a general thing, I think that everyone experiences it. And *I've been fighting for my entire life to be seen as a person, so when it's taken away, it hurts more than it would for someone else.* [emphasis mine]

Interview: I can understand that.

Deborah: So being at home and amongst friends was important because they treated me like a person, and they didn't make me do things that I didn't want to do. They were supportive but they didn't smother me. In any other situation I would have hated having an overnight guest for a few weeks. But I think because she was my friend, and because when she first arrived, I was still so sick, I didn't mind.

Here Deborah identifies two aspects of care that were even more critical because of her transgender identity. While holding in personhood is a vital aspect of all forms of care, Deborah's transgender identity means that she has been fighting all of her life against a master narrative that erases her personhood. Attendance to aspects of her identity which affirmed her personal narrative was thus even more vital for her due to her previous experiences of transphobic and cissexist violence and erasure (discussed at length in Chapter 3. In Deborah's case, she was able to heal outside of the hospital setting due to her friends who stepped up to provide care in the knowledge that she was unlikely to flourish in a long-term care setting. Having previously experienced homelessness, the significance of being "under her own roof" was important in her healing.

In one notable case, a caregiver's attempt at holding their care recipient in personhood resulted in them choosing not to disclose the level of care their partner required. Juan and Ron, whose experiences were discussed in more detail in Chapter 5, were interviewed separately, with Ron being interviewed first. At the time, when asked about his partner's care needs, he chose not to disclose the progression of Juan's illness or the fact that he occasionally required help with ADLs and IADLS due to

peripheral neuropathy in his hands and feet, a side effect of the earlier medications he took for his HIV. When asked about this, Juan indicated that it was likely that Ron had been “protecting him” by allowing him to “take the lead” (Interview, J.D., 2019). This kind of protection was not exclusive to Ron, the primary caregiver in their dyad: Juan also disclosed that he had, at some points, hidden his pain or otherwise disguised symptoms associated with his status as a long-term survivor of HIV. He also indicated that he did this in order to spare his husband the pain of knowing that Juan was in pain but being unable to help him. As discussed in Chapter 5, Ron was also a long-term survivor of HIV but had never experienced symptoms of the disease.

Holding the Dead in Personhood

Ron responded to the trauma of the AIDS epidemic by starting a practice of holding the dead in personhood: for many years he has maintained a series of notebooks which contain the biographical details of the individuals he knew who had died from AIDS-related complications.

Ron: I've tried to remember the little things, and I've kept track as best I could... every so often I will go on Facebook and look up the siblings and families of those guys, see if there might be a sister or a niece who wants to know more.

This form of caregiving is not easy: holding multiple deceased individuals in personhood is a heavy load, particularly when their deaths were traumatic. Scholars in the field of genocide studies who have studied first and second-generation survivors of the Holocaust have pointed to remembrance of the dead as being one of the most significant psychological burdens for survivors and their descendants (Van Alphen,

2006). It is difficult enough for most to hold a dead parent or grandparent in personhood: the memories are often marred by sadness and grief even if the person lived a full life and died comfortably. The AIDS epidemic, in contrast, struck the young -- then, as now, the majority of new infections occurred in individuals who were in their late teens and early twenties (ACT, 2019). In the previous chapter, I discussed how Ron provided assistance to individuals with AIDS when they were sick and dying, but like many caregivers he also views this continued remembrance and holding in personhood as being equally important to the act of caregiving. His partner, Juan, expressed that this act weighed heavily on Ron, and expressed his own fears about how he will be remembered after his death:

Juan: But I think -- I might have gotten the worst of it, physically, but it really fucked him up... he took it upon himself to keep track of everyone, everyone he knows who died and what he knew about them. He wrote it all down. Our apartment is full of these notebooks, and you open them, and they say things like, you know, "Ben, dx'd at 25, dead 26, loved hockey and parrots", shit like that. I suppose it helped him feel like he was in control of everything. I wrote my own memoirs, so he won't have to do that for me. He won't have to -- he won't have to remember me.

Interviewer: Do you think about that? How you'll be remembered when you're gone?

Juan: ... I have this horror of being reduced to a line in one of Ron's notebooks... I don't want to put that burden on him. I don't want to be another person he has to remember.

Interviewer: I mean, you're his husband, I'm sure he'll remember you no matter what.

Juan: that's not what I mean. I mean – he doesn't sleep, he has a lot of nightmares, and I don't – I don't want to be another life he feels like he has to carry and share.

Here, Juan is doing his best to retain his own personhood while demonstrating empathy and respect for that of Ron: he understands that his husband feels a duty to remember the dead, and instead of arguing with him he attempted to make it emotionally and practically easier for Ron to do the same for him when he dies by writing his own memoirs and explicitly sharing his personal narrative. Juan knows that his husband will consider it his duty to remember him, and so has attempted to ease his suffering by doing it for him. Reciprocal care and attentiveness to personhood is not exclusive to this particular caregiving dyad: Oliver indicated that there came a point in his husband's treatment for prostate cancer when his husband became extremely depressed and, in Oliver's words, "[I] had to believe that Brian was getting better, and I told him that it was ok if he didn't think so, because I'd believe it enough for both of us."

Advanced Directives and Medically Assisted Dying

The process of nursing Brian through his cancer treatment also prompted the two of them to consider what a good death would look like for them, and how best to ensure that it occurred:

Interviewer: You mentioned that you both have advanced directives. Can I ask what they say?

Oliver: Neither of us wants extreme levels of intervention if we are actively dying and the balance of probabilities is that we won't be in our right mind afterwards. But to be clear, I don't mean feeding tubes or catheters. As long as our minds are clear, we're here. But for example, if I had a stroke right now and the only way to save me was to do brain surgery, I don't want that. Just let me go in that case.

Interviewer: Does your husband feel the same way?

Oliver: Yes, he does. We spoke about it during his cancer treatment, although he ultimately decided that he wanted any and all possible treatments for his cancer, but now that we're older -- it's becoming increasingly unlikely that we would have a good quality of life after a major brain surgery or being put on a ventilator. So we changed them relatively recently, actually.

Interviewer: You talked about it, then.

Oliver: Oh yes, for a long time. We had to agree. I didn't want to be in the position of enforcing an advanced directive that I felt I couldn't legitimately support, and he didn't want that either.

Interviewer: Did you think you wouldn't be able to oversee it?

Oliver: Not exactly. I would have enforced his wishes, regardless of my own feelings about them, because they are his wishes and he has a right to them. But having to enforce something I didn't agree with, especially about Brian -- it would destroy me, and I know the opposite situation would

do the same to him. So we needed to be clear. And we eventually arrived at ADs that we both feel good about.

Up-close experience with death and dying was often influential in how the participants viewed their own potential deaths. The possibility of dementia often loomed large over them, as several participants feared being remembered imperfectly and the possibility of the erasure of their LGBT identity after their death or while they were dying. As a result, some considered the possibility of medically assisted dying (MAD).

Interviewer: So, I'd like to talk a bit more about your life now, and where you see it going. Do you think about growing older?

Ron: I wasn't supposed to get this old! I mean that both in the sense – I didn't think I'd be alive to have to worry about retirement, but also – my knees hurt, hun.

...

Interviewer: And have you talked about what you're going to do as you get older?

Ron: I have a pension. I don't want to go into a home. And I'm under strict orders to give A "poison pudding" if he gets dementia. And I worry about the same thing, I guess – my mom lived much longer than she should have, after the stroke. I worry about quality of life.

While many participants expressed concerns about their deaths related to experiences they had previously had with dead and dying friends and loved ones, Juan was particularly concerned with the kinds of deaths he had previously witnessed in

friends who died of AIDS-related complications. He was also very comfortable with the idea of medically assisted death and seemed to view it as the most likely way to ensure he had a “good death” and spoke at length about his plans.

Interviewer: Have you spoken about what will happen if you need more help?

Juan: [Ron is] gonna take care of me for as long as he can the thing that scares me the most is dementia. I saw it happen to too many guys, and it just -- it just about ripped the heart out of everyone involved. So if I get it, no matter how, whether it's AIDS or just age, it's the poison pudding for me.

Interviewer: [laughs] he mentioned the poison pudding!

Juan: Yeah. I won't -- there are some things it isn't necessarily prudent to talk about, but we knew guys who -- when they were dying, really truly dying, they went home. Had their friends around. They'd saved the morphine syringes, and the y injected him, he drank a few glasses of red wine, and he drifted off... that was a better way to go than scared and alone in the hospital.

Interview: So if medically assisted dying something you'd consider, given the option? It's legal now, after all.

Juan: Yeah, as long as they would let me do it at home. I also worry because the law doesn't cover advanced directives. You have to consent right before. So I couldn't be too far gone, I suppose

Interestingly, both Juan and Oliver spoke about the consideration they had given to their partner's emotional and mental health should they predecease their partners: an aspect of reciprocal care and holding in personhood that they may be able to practice even after their deaths.

Communal Responsibilities

While Oliver, Juan, and Ron all have partners that they can count on to hold them in personhood, the other participants were relying on community fictive-kin ties to both support and remember them in their old age and eventual deaths. Single participants were more likely to express the fear of dying alone or being misremembered. For example, in the previous section Elizabeth indicated that one of her primary motivations for moving in with a group of older lesbians was that as a single woman she was worried that she would not have anyone to advocate for her. Others worried that their LGBT identity may be completely erased after death.

Expressing this anxiety, Deborah said

“I have a recurring nightmare where I’m dead, and they deadname me in my obituary. I know that’s unlikely to happen -- I think my friends would make sure of it -- but it’s a real fear.”

Deadnaming is a term used in the transgender community to refer to the use of a trans person’s birth name as opposed to their chosen one: doing so can often result in misgendering of the trans person in question as the name given to them at birth may reflect the gender they were assigned at birth rather than that with which they identify. In the absence of traditional kin ties, LGBTQ2SIA+ people of all ages often rely on their fellow community members to affirm their personal narratives. However, this is particularly important for the acts of death and dying: we can express our wishes as frequently as we want, but there is no way for us to ensure that they are abided by from beyond the grave. This loomed large in the life histories of the participants: several described attending funerals for deceased members of the community where they felt

as though they did not know the person who was being remembered. Unfortunately, this is not one of the aspects of the LGBT experience that can be comfortably confined to the past: this researcher has personally attended the funeral of a trans community member where the deceased was repeatedly misgendered and deadnamed by their family.

Where does this leave the personhood of LGBT older adults? The maintenance of personhood is an active task, and one which can be overwhelming. As older adults continue to age, many of those who could conceivably hold them comfortably in personhood may die themselves. It is here, I believe, that the norms of community care in the LGBT community are so vital. The active construction and maintenance of intergenerational solidarity is a difficult but necessary task for the LGBTQ community if we wish to maintain the personhood and dignity of our elders: to be blunt, it is my belief that only younger LGBT people are equipped to hold these stories, and that to let them die out or to place them in cisgender and heterosexual hands would be a very grave mistake. This will be discussed further in the following chapter.

Chapter 7: Discussion and Conclusions

This thesis aimed to answer the following questions:

- 1) How do LGBT older adults experience the act of caring and/or of being cared for, and is it impacted by their identity?
- 2) How do LGBT older adults envision aging, dying, and death, and is it impacted by their identity?
- 3) What are the norms and values around caregiving in the LGBT older adult community?

Taking each question in turn, I will synthesise my findings. I will then identify some of the limitations of this study and identify where further research is needed. I will conclude with a call to action for community members, researchers, and the general public.

Our LGBT older adult participants' experiences of care were directly informed by their personal life histories, particularly experiences of medical discrimination. All participants indicated that they believed that they or the person they cared for had been discriminated against by health care providers as a result of their LGBT identity. These ranged from outright discrimination, such as the rejection of Melanie and Deborah by their primary care providers and Melanie's experience with homophobic PSWs, to more subtle forms: despite being on the list for a kidney transplant, Juan expressed doubt that he would ever be the recipient of a donor kidney, noting that it was his belief that "HIV+ people go to the bottom of the list". Whether or not this is actually true is immaterial: Juan believes it to be so, and it influences how he interacts with the healthcare system.

Some participants had experienced discrimination from nurses and doctors, and indeed Elizabeth, a nurse, indicated that she had heard her colleagues make demeaning comments about 2SLGBTQ+ patients, saying “I’ve heard things that would make your ears blister.” It is therefore unsurprising that no participant expressed high levels of trust towards the healthcare system, and all but one were completely opposed to ever entering a long-term care facility.

Contrary to general care norms, male participants indicated that they took part in personal care at the same rates as female participants, and participants were less likely to report providing significant care for an elderly parent. The participant who indicated that they had provided high levels of care for their ailing mother was also the only participant who indicated they expected to be cared for by their children. The other two participants with children indicated that they had been estranged from them for several years. Three participants indicated that they provided or received care from a partner or spouse, including one caregiving dyad where both members were interviewed. All other participants provided or received care from a friend, ex-partner, or fellow community member.

The norms of community care within the 2SLGBTQ+ community were to some extent set in stone after the AIDS epidemic. Research has consistently shown that gay, bisexual, and transgender men are significantly more likely to provide care than cisgendered heterosexual men. While some researchers have posited that this is due to the more fluid gender-roles within the 2SLGBTQ+ community, participants who provided care were less likely to attribute this as a cause. Instead, repeatedly, participants expressed sentiments like “it’s just what you do.” and “We have to look out for each

other.” These sentiments were heard from all participants, suggesting that the norms of community care are significantly stronger than in the general population. Several participants who were being interviewed about a more recent caregiving experience made an explicit link to their experiences during the HIV/AIDS epidemic. While the epidemic primarily took its toll on gay and bisexual men and transgender women, lesbians and bisexual women were often involved in the direct personal care provided to people with AIDS. Interestingly, attitudes towards community norms of care do not seem to have changed significantly from those described in Aronson’s work in 1998. Despite a society that is significantly more affirming of 2SLGBTQ+ identities, the LGBT older adults who were interviewed continued to express high levels of suspicion and distrust towards the healthcare system and were significantly more likely to seek/provide informal care.

All participants indicated that their LGBT identity influenced how they perceive and envision aging, care, and death. While negative perceptions about nursing homes and long-term care facilities are common in the general population, and concerns about autonomy are common amongst older adults considering long term care, participants indicated feeling deep anxieties around long-term care that were explicitly linked to their LGBT identity. Commonly expressed fears were that the participant may have to go back into the closet if they entered a nursing home with unsupportive residents or staff, that they may be separated from their partner, and that they may have their gender presentation aggressively policed. The last concern was deeply felt by the transgender and gender-non-conforming participants, who indicated that they had personally experienced or had had friends who had experienced efforts to force them into

conforming with gendered expectations of attire on the basis of the sex assigned at birth. Personal care and personal appearance are deeply linked, and many participants indicated that there were aspects of their identity that they expressed via attire or grooming. As a result, many participants indicated that personal care, including assistance with dressing and grooming, is a particularly important aspect of reinforcing the personhood of LGBT older adults.

The fears surrounding nursing homes and long-term care have resulted in a diverse set of solutions. Oliver, a participant with significant financial resources, indicated that he and his husband had saved money specifically for in-home private nursing care, should it become necessary. Another participant, Elizabeth, indicated that she and her friends had come up with an inventive solution to the dilemma: by moving in with several other older lesbians and pooling their financial resources, they would be able to both provide care for one and another and more easily pay for private care should it be required.

Participants' ideas of what a "good death" would look like was highly influenced by their caregiving experiences. In general, participants expressed a desire to die outside of an institutional setting, a strong aversion to long term care, and a fear of being forced to abandon their LGBT identities in order to receive care. Several expressed an interest in medically assisted dying. Participants who expressed a fear of dementia or Alzheimer's often also feared that their LGBT identity would not be preserved if they were not able to advocate for themselves. Incidentally, two of the caregivers interviewed indicated that they had had to fight for the autonomy and

personal identity of their care recipients when they were unable to advocate for themselves.

Multiple participants expressed a level of exhaustion associated with a life of dealing with societal homophobia and transphobia. Of the seven participants, four expressed sentiments such as “I’m too tired to deal with it anymore” (Barbara) or “I’ve been fighting all my life, I don’t want to still be fighting at my death” (Deborah). Participants who had survived the AIDS epidemic were likely to express similar sentiments, but directly related to their experience either as caregivers for people with AIDS or as long-term survivors of HIV.

Nearly all participants indicated that they felt political advocacy was a vital aspect of providing care to fellow LGBT people. For many, that advocacy began during the HIV/AIDS epidemic, but several participants interviewed discovered that it was necessary to engage in political advocacy while they were taking care of dying community members. This political advocacy was considered to be necessary to ensure that their loved ones received necessary care, as well as to ensure that the wishes of their loved ones were respected.

Despite the fact that LGBT older adults are often unwilling to engage with formal care systems, something which is directly linked with life-course histories of discrimination, the participants engaged in a great deal of community care. The participants were likely to have engaged in caregiving relationships with friends and community members, particularly during the height of the AIDS epidemic, and these caregiving networks continue to be built by LGBT older adults. Participants took a great deal of pride in their LGBT identities, and several expressed high levels of anxiety that

engaging in formal care would require them to “go back into the closet” or otherwise conceal their sexuality or gender identity. Participants placed a high value on personal narratives, particularly in maintaining the personhood of the dead and dying.

Participants also placed a high level of value on autonomy, respect, and personal expressions of identity. They perceived formal care, particularly long-term care, as something which would impinge on these values. This is consistent with Croghan (2014) and Butler (2018)’s findings: older LGBT adults, as a population, express high degrees of anxiety about relying on formal care for this very reason. In many ways, these participants’ experiences were reflective of the broader literature: life histories of discrimination and medical stigmatisation, comparative isolation, and distrust of healthcare system. What distinguished them from the literature were their strong community ties, and the closeness of their relationships - much of the literature depicts older LGBT adults as isolated (Fredriksen-Golden et. al., 2015), however, all participants had strong community ties and a high degree of involvement in their communities. While this is in part a result of selection bias -- it is hard to reach the most isolated members of a community -- it also provides an element of hope in an otherwise bleak landscape. It may also offer a way forward: if LGBT older adults are provided with the resources and opportunities to build and maintain strong community ties, they will likely do so, and this may mitigate the negative physical and mental health outcomes associated with isolation.

Limitations

This study has several limitations, the first being the relatively small sample size. While efforts were made to reach out to members of the community through several venues, including venues primarily targeted at the general older adult community and those targeting 2SLGBTQ+ populations in particular, the majority of the participants were recruited at an event for 2SLGBTQ+ union members. As a result, nearly all participants are or were employed in primarily blue collar or pink-collar jobs. The two participants who did not fall into this category were personally recruited, one being the spouse of another participant and the other being a relatively well-known community member who was personally recruited by the researcher. A racially diverse sample was also desired, in an attempt to remedy the frequent sampling bias towards white, middle or upper middle-class individuals in 2SLGBTQ studies. This was to an extent achieved: 3 of 7 participants were non-White, but the remainder were White Canadians of European descent whose families had been in the country for multiple generations.

Despite active attempts at recruitment in rural communities, only one participant lived in a rural community, and the majority were recruited from the GTA and Golden Horseshoe. Only one participant, aged 81, could be described as being amongst the “oldest old”, and the majority of participants were in their early-to-mid 60s. A larger sample, and one which had a more even age distribution, would have allowed for further analysis as to how attitudes towards aging might be different amongst LGBT older adults of different ages. This might particularly be valuable when considering events like the AIDS epidemic, as community-level events are experienced differently by people who were young adults at the time versus those who were middle aged or older.

Additionally, all but 2 participants were cisgender, and no participants were Indigenous. More research is desperately needed on the experiences of these groups, and in particular the experiences of transgender Indigenous people as they experience some of the highest levels of violence and incarceration amongst any group in Canada (EGALE, 2015). It is my hope that research can be conducted in partnership with these groups, and that their lifecourse histories will be recorded: this was regrettably outside of the scope of this paper.

When conducting research using interpretive phenomenological analysis, it is understood that the researcher does not “bracket” their own personal knowledge of the issue, and instead uses it to help understand the experiences of participants. This was necessary for this project: had I not disclosed my own membership in the community, it is unlikely that I would have gained access to the target population. Although there is always a power differential between researchers and participants, in this case that dynamic was influenced by the age difference between myself and participants. Rather than interacting with me on those terms, interviews often evolved into discussions where the dynamic was not one of researcher and participant but of elder and youth, something which I believe increased the richness of the data. When given the opportunity to speak freely at the end of the interviews about whatever was on their mind, they often directed me to take care of their stories and histories, while often expressing the belief that while a better future was possible it was unlikely they would live to see it. It was not uncommon for participants to refer to me by a diminutive -- four participants referred to me as “hon”, “sweetheart”, or similar terms. It is my belief that this was prompted by the age differential. I very consciously did nothing to either

encourage or discourage this behaviour, as I noticed that when the participants thought of me not as a researcher but as simply a younger fellow community member, the stories they told were both more personal and more detailed. Despite knowing that I was recording the interviews for transcription at a later date, on multiple occasions a participant stopped mid-anecdote to ask that I “write that down”. I took this as a special reminder to act with care and respect towards them and their stories, and as a request that I highlight that aspect of their personal narratives.

This respect is why, with the exception of changing names and in some cases cities of origin, I have endeavoured to leave their narratives unchanged. While it is common practice to combine interview data into a pastiche in order to anonymise it, I chose not to do so in this case both because I believe that in each case the individual life history and personal narrative of a participant is vital to understand their attitudes towards age and care, but also because I did not want to slice and dice the personal narratives I had been entrusted with. LGBT older adults are too often the victims of epistemic injustice: largely absent from both the disciplines of gerontology and queer studies, their existence is relegated to the margins. It is my hope that by centering them and their subjective experiences in this research, I have done something to remedy this.

I had hoped when beginning this research that I would be able to provide possible policy solutions to the problem, but after spending time with my participants and their stories I came to the conclusion that it is too late for policy inventions for the current cohort of older adults, or at least for my participants -- the trust between them and medical institutions has been irreversibly broken and has been for some time. This does not mean that there are no possibilities for this cohort, nor does it mean that policy

solutions are not needed here. Indeed, I also believe that policy changes such as improved training for healthcare workers and expanded LGBT specific services could yield positive change for younger LGBT baby boomers and the generations that follow them.

I return to the theme of community care, and consider that one explanation for why my sample was relatively positive about their futures is that definitionally in order to be participants in my study they must have had some community ties, ties which were strong enough to overcome the usual conventions about who provides care to whom.

My participants were strong believers in the ability and duty of the LGBT community to care for itself. Many of them viewed sharing their stories with me as being an element of that community care -- the sharing and recording of community histories that would otherwise be lost. They believed that institutions could be improved but that they would never be enough to save them. The emphasis on community care is likely a result of both historical community norms formed during the HIV/AIDS epidemic, as well as from a belief that when systems will not save you or those you love, you have a duty to step in and assist. Rather than policy implementation from the top down, this population requires community care and the best possible outcome for them is for those communities to be supported and provided with necessary resources in order to take care of one another.

Remedying the epistemic injustice that has been done to 2SLGBTQ+ older adults is also vital: fortunately, there are existing frameworks for recording the oral histories of people who survived the AIDS epidemic. These frameworks should be expanded, and every effort should be made to record these histories before they are gone. And most

importantly, younger 2SLGBTQ+ people must be vigilant and supportive as our elders age in an unforgiving world and must step up to help provide the necessary community care in their old age.

To echo a participant: “None of us can go it alone, not if we want to be happy.”

Works Cited

- Anderson, Tez. (2015). *HIV Long-Term Survivors Declaration: A Vision for Our Future*. Accessed June 2 2019 from <https://letskickass.hiv/with-courage-and-compassion-long-term-survivors-of-hiv-strive-not-only-to-survive-but-also-to-ee056d372994>
- Anderson, Tez. (2018). *What is AIDS Survivor Syndrome?* Retrieved June 5th 2019 from <https://letskickass.hiv/what-is-aids-survivor-syndrome-dc0560e58ff0>
- Aronson, J. (1998). Lesbians giving and receiving care: Stretching conceptualizations of caring and community. *Women's Studies International Forum*, 21(5), 505–519.
[https://doi.org/10.1016/S0277-5395\(98\)00065-X](https://doi.org/10.1016/S0277-5395(98)00065-X)
- Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cornier, R., Julien, D., Meyer, E., Peterkin, A., and Richard, B. (2007). Coming Out to Care: Caregivers of Gay and Lesbian Seniors in Canada. *The Gerontologist*, 47(4), 490-503. <https://doi.org/10.1093/geront/47.4.490>
- Benzie, R. June 13, 2012. Ontario Human Rights Code amended to protect transgendered people. *The Toronto Star*. Retrieved June 3, 2019 from https://www.thestar.com/news/canada/2012/06/13/ontario_human_rights_code_amended_to_protect_transgendered_people.html?li_source=LI&li_medium=star_web_ymbi
- Butler, S. (2018). Older lesbians receiving home care: formal and informal dimensions of caregiving. *Journal of Women & Aging*, 30(2) 91-110.
<https://doiorg.libaccess.lib.mcmaster.ca/10.1080/08952841.2017.1290977>

- Butler, S. & Brennan-Ing, M. (2014) Determinants of longer job tenure among home care aides: What makes some stay on the job while others leave? *Journal of Applied Gerontology*, 33(2), 164-188
- Cohen, J. N., & Byers, E. S. (2015). Minority stress, protective factors, and sexual functioning of women in a same-sex relationship. *Psychology of Sexual Orientation and Gender Diversity*, 2(4), 391–403. <https://doi.org/10.1037/sgd0000108>
- Conron, K., Mimiaga, M., Landers, S. (2010). A population-based study of sexual orientation identity and gender differences in adult health. *American Journal of Public Health*, 100(10), 1953-1960. Doi:// 10.2105/AJPH.2009.174169
- Connell, RW. (1992). A very straight gay: Masculinity, homosexual experience, and the dynamics of gender. *American Sociological Review*, 735-751
- Cook-Daniels, L. (2015). Understanding transgender elders. In D.A. Harley and P.B. Teaster (eds.), *Handbook of LGBT Elders*. Springer International Publishing. DOI 101007/978-3-319-03623-6_14
- Croghan, C., Moone, R., Olson, A. (2014). Friends, Family, and Caregiving Among Midlife and Older Lesbian, Gay, Bisexual, and Transgender. *Journal of Homosexuality*, 61(1) 79-102. Doi:// 10.1080/00918369.2013.835238
- Eatough, V. and Smith, J. (2008). Interpretive Phenomenological Analysis. In C. Willig and W. Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (1983-208). London: SAGE Publications Ltd.
- Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The emergence and development of life course theory. In *Handbook of the life course* (pp. 3-19). Springer, Boston, MA.

EGALE Canada. (2010) Blog Post. *Trans Day of Remembrance*, retrieved 04/05/2019 from

<https://egale.ca/trans-day-of-remembrance/>

EGALE Canada. (2012). Blog Post. *Hate Crimes Targeting LGBT Community Remain Most Violent*

in Canada. Retrieved 04/05/2019 from <https://egale.ca/hate-crimes-targeting-lgbt-community-remain-most-violent-in-canada/>

Embrick, D. G., Walther, C. S., & Wickens, C. M. (2007). Working class masculinity: Keeping gay men and lesbians out of the workplace. *Sex roles*, 56(11-12), 757-766.

Emlet, C.A. and Poindexter, C. (2004). Unserved, Unseen, and Unheard: Integrating Programs for HIV-Infected and HIV-Affected Older Adults. *Health & Social Work*, 29(2), 89-96

English, D., Rendina, H. J., & Parsons, J. T. (2018). The effects of intersecting stigma: A longitudinal examination of minority stress, mental health, and substance use among Black, Latino, and multiracial gay and bisexual men. *Psychology of Violence*, 8(6), 669–679. <http://dx.doi.org.libaccess.lib.mcmaster.ca/10.1037/vio0000218>

Erdley, S.D., Anklam, D.D, and Reardon, C.C. (2014). Breaking Barriers and Building Bridges: Understanding the Pervasive Needs of Older LGBT Adults and the Value of Social Work in Health Care. *Journal of Gerontological Social Work*, 57(2-4), 362-385.

<http://dx.doi.org/10.1080/01634372.2013.871381>

Fredriksen, K. (1999). Family caregiving responsibilities among lesbians and gay men. *Social Work*, 44(2), 142-155. <https://doi.org/10.1093/sw/44.2.142>

Fredriksen-Goldsen, K. (2014). Resilience and Disparities among Lesbian, Gay, Bisexual, and Transgender Older Adults. *Public Policy & Aging Report*. Doi://10.1093/ppar/21.3.3

Fredriksen-Goldsen, K. I., Kim, H.-J., Emlet, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P.,

Goldsen, J., Petry, H. (2011). [The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults. Seattle: Institute for Multigenerational Health.](#)

Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Muraco, A., Goldsen, J., & Kim, H.-J. (2015). The health and well-being of LGBT older adults: Disparities, risks, and resilience across the life course. In *The lives of LGBT older adults: Understanding challenges and resilience* (pp. 25–53). <https://doi.org/10.1037/14436-002>

Gates, G. J. (2015). Marriage and family: LGBT individuals and same-sex couples. *The Future of Children*, 67-87.

Glaesser, R. and Patel, B. (2016). Psychological Trauma and LGBT Caregivers: A Conceptual Framework to Guide Practice. *Journal of Evidence-Informed Social Work*, 13(5), 458-468

Grossman, A.H., D'Augelli, A.R., Hershberger, S.L. (2000). Social support networks of lesbian, gay, and bisexual adults 60 years of age and older. *Journal of Gerontology*, 55b(3), 171-9

Hamberg, K., Risberg, G., Johansson, E. E., & Westman, G. (2002). Gender bias in physicians' management of neck pain: a study of the answers in a Swedish national examination. *Journal of women's health & gender-based medicine*, 11(7), 653-666.

Hash, K., Cramer, E. (2003). Empowering gay and lesbian caregivers and uncovering their unique experiences through the use of qualitative methods. *Journal of Gay and Lesbian Social Services*, 15(1-2), 47-63

Hutchison, E. D. (2010). A Life Course Perspective. In *Dimensions of Human Behavior: The Changing Life Course* (4th ed., p. 38). Sage Publications.

- Husserl, E. (1970). *The Crisis of European Sciences and Transcendental Phenomenology* (D. Carr, Trans.). Evanston: Northwestern University Press. (Original work published 1936)
- Illa, L, Brickman, A., Saint-Jean, G., Echenique, M., Metsch, L., Eisdorfer, C., Bustamante-Avellano, V., Sanchez-Martinez, M. (2008). Sexual Risk Behaviors in Late Middle Age and Older HIV Seropositive Adults. *AIDS and Behavior*, 12(6), 935-942.
<http://dx.doi.org/10.1007/s10461-008-9370-8>
- Johnson, M., Jackson, N., Arnete, J., Koffman, S. (2005). Gay and Lesbian Perceptions of Discrimination in Retirement Care Facilities. *Journal of Homosexuality*, 49(2), 83-102
- Jue, S. (1994). Psychosocial issues of AIDS long-term survivors. *Families in Society*, 75(6), 324-332.
- Kimmel, D., Rose, T., & David, S. (2006). *Lesbian, Gay, Bisexual, and Transgender Aging: Research and Clinical Perspectives*. Retrieved from
<http://ebookcentral.proquest.com/lib/mcmu/detail.action?docID=908267>
- Kuyper, L. and Fokkema, T. (2010). Loneliness Among Older Lesbian, Gay, and Bisexual Adults: The Role of Minority Stress. *Archives of Sexual Behaviour*, 39(5), 1171-1180. Doi://
10.1007/s10508-009-9513-7
- Lindemann, H. (2014). *Holding and Letting Go: The Social Practice of Personal Identities*. Oxford: Oxford University Press.
- Mahieu, L., Cavolo, A., Gastmans, C. (2019). How do community-dwelling LGBT people perceive sexuality in residential aged care? A systematic literature review. *Aging & Mental Health*, 23(5), 529-540. Doi: 10.1080/13607863.2018.1428938

Martin, C. P., Fain, M. J., & Klotz, S. A. (2008). The Older HIV-Positive Adult: A Critical Review of the Medical Literature. *The American Journal of Medicine*, 121(12), 1032–1037.

<https://doi.org/10.1016/j.amjmed.2008.08.009>

McGuire, J. K., Doty, J. L., Catalpa, J. M., & Ola, C. (2016). Body image in transgender young people: Findings from a qualitative, community based study. *Body Image*, 18, 96–107.

<https://doi.org/10.1016/j.bodyim.2016.06.004>

Meyer, D. (2008). Interpreting and Experiencing Anti-Queer Violence: Race, Class, and Gender Differences among LGBT Hate Crime Victims. *Race, Gender & Class*, 15(3/4), 262-282.

<https://www.jstor.org/stable/41674664>

Meyer, I. (2003). Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence. *Psychology Bulletin*, 129(5), 674-697. Doi:// 10.1037/0033-2909.129.5.674

Muraco, A. and Fredriksen-Goldsen, K. (2014). The Highs and Lows of Caregiving for Chronically Ill Lesbian, Gay, and Bisexual Elders. *Journal of Gerontological Social Work*, 57(0), 251-272. Doi: [10.1080/01634372.2013.860652](https://doi.org/10.1080/01634372.2013.860652)

Muraco, A. and Fredriksen-Goldsen, K. (2011). “That’s what friends do”: Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults. *Journal of Social and Personal Relationships*, 28(8), 1073-1092 doi:10.1177/0265407511402419

Murray, S.J. and Holmes, D. (2014) Interpretive Phenomenological Analysis (IPA) and the Ethics of Body and Place: Critical Methodological Reflections. *Human Studies*, 37(1), 15-30

Neugarten, B. L., Moore, J. W., & Lowe, J. C. (1965). Age norms, age constraints, and adult socialization. *American journal of Sociology*, 70(6), 710-717.

- Pearlin, L., Mullan, J.T., Aneshensel, C., Wardlaw, L., and Harrington, C. (1994) The structure and function of AIDS caregiving relationships. *Psychosocial Rehabilitation Journal*, 17(4), 51-67
- Pecchioni, L. L. (2012). Interruptions to cultural life scripts: Cancer diagnoses, contextual age, and life narratives. *Research on Aging*, 34(6), 758-780.
- Pinquart, M., & Sorensen, S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(1), P33–P45.
<https://doi.org/10.1093/geronb/61.1.P33>
- Reddy-Best, K.L and Pedersen, E.L. (2015). The relationship of gender expression, sexual identity, distress, appearance and clothing choices for queer women. *International Journal of Fashion Design, Technology and Education*, 8(1), 54-65, doi://
10.1080/17543266.2014.958576
- Shiu, C., Muraco, A., & Fredriksen-Goldsen, K. (2016). Invisible Care: Friend and Partner Care Among Older Lesbian, Gay, Bisexual, and Transgender Adults. *Journal of the Society for Social Work and Research*, 7(3), 527-546
- Slomka, J., Lim, J., Gripshover, B., & Daly, B. (2013). How Have Long-Term Survivors Coped with Living with HIV? *The Journal of the Association of Nurses in AIDS Care : JANAC*, 24(5), 449–459. <https://doi.org/10.1016/j.jana.2012.09.004>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1(1), 39-54.

- Smith, J. And Osborn, A. (2007). Interpretive Phenomenological Analysis: Theory, method and research. J.A. Smith (ed) in *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE Publications Ltd.
- Stein, G., Beckerman, N., Sherman, P. (2010). Lesbian and Gay Elders and Long-Term Care: Identifying the Unique Psychosocial Perspectives and Challenges. *Journal of Gerontological Social Work*, 53(5), <https://doi.org/10.1080/01634372.2010.496478>
- Stotzer, R. (2009). Violence against transgender people: A review of United States data. *Aggression and Violent Behavior* 14(3), 170-179. doi:// 10.1016/j.avb.2009.01.006
- Turner, H., Pearlin, L., Mullan, J. (1998). Sources and Determinants of Social Support for Caregivers of persons with AIDS. *Journal of Health and Social Behavior*, 39(June): 137-151
- Van Alphen, E. (2006). Second-generation testimony, transmission of trauma, and postmemory. *Poetics Today*, 27(2), 473-488.
- Weitz, R. (1987) The Interview as Legacy: A Social Scientist Confronts AIDS. *The Hastings Center Report*, 17(3), 21-23, <https://www.jstor.org/stable/3562245>
- Wilson, K., Stinchcombe, A., Kortes-Miller, K., Enright, J. (2016). Support Needs of Lesbian, Gay, Bisexual, and Transgender Older Adults in the Health and Social Environment. *Counselling and Spirituality*, 1, 13-29, doi:// 10.2143/CS.35.1.3189089
- Wilson, K., Kortes-Miller, K., Stinchcombe, A. (2018) Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life. *Canadian Journal on Aging*, 37(1), 22-31. doi:10.1017/S0714980817000514