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AN ETHNOGRAPHIC STUDY OF AGING AND HEALTH EXPERIENCES OF LGBT
ELDERS: UNDERSTANDING DISCRIMINATORY CONTEXTS AND STRATEGIES

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Abstract

LGBT elders will be a subset of the aging population in the United States with unique needs as they age. During their lifetimes, LGBT elders have experienced social, political, and medical discrimination from their peers, the government, and their doctors. This accumulation of life experiences has led to a distinct fear of aging and finding the appropriate care needs. Much of the literature on LGBT aging and health focuses on the findings without embedding them in theoretical work or solely on theories of stigma without proposing intervention. In this dissertation, I look at three areas of navigating aging and health needs using established sociological theories, suggesting interventions and noting the resilience of older LGBT adults. Drawing on 80 in-depth interviews with both straight cisgender older adults and lesbian, gay, bisexual, and transgender adults over the age of 50 in the Chicago area; 300+ hours of community observation at a community center that assisted all elders, but specialized in LGBT needs; and secondary data analysis of online material denoting engagement with the LGBT community in Chicago area long-term care facilities, I show that care standards do not meet elders' needs to find LGBT-friendly providers, navigate care from their social networks, or find care in long-term care facilities. In Essay I I find that sometimes white, educated, economically privileged older adults can draw on their particular resources to find the care they need. In Essay II I find that in other cases, older LGBT adults who do not mirror traditional family structures must reach the depths of their social network for assistance during aging. Finally, in Essay III I show that when networks cannot care for LGBT elders, elders struggle to find care that will meet their needs, even in a large city like Chicago. Overall, this work considers how LGBT elders'

aging experience relates to the life course and health outcomes, proposing interventions along the way.

Chapter One

INTRODUCTION

For the better half of a century, sociologists have been concerned with issues of the life course (Ryder, 1965; Riley, 1987; Elder, 1994) and how context shapes various outcomes including health. This work largely focuses on socioeconomic status (Wilson, Shuey, & Elder, 2007) and race (Umberson et al, 2018). Yet since the end of the last decade notable scholars (Fredriksen-Goldsen & Muraco, 2012; Fredriksen-Goldsen, Jen, & Muraco, 2012) have called for applying the life course lens to the lives of lesbian, gay, bisexual, transgender, and queer (LGBT) people. The field of LGBT health has established poor health outcomes compared to their peers, citing discrimination stress and stigma (Meyer, 2003) along with historical and environmental experiences (Fredriksen-Goldsen, Bryan, Jen et. al, 2017). LGBT individuals have reportedly higher levels of poor mental health (Fredriksen-Goldsen et al, 2012), disability (Fredriksen-Goldsen et al., 2013), and physical health (Gonzales, Przedworksi, & Henning-Smith, 2016) compared to their straight, cisgender counterparts. The ways in which the life course has impacted health have been studied in terms of relationships in mostly quantitative studies (Leblanc et al., 2018; Denny, Gorman, & Barrera, 2013; Garcia & Umberson, 2019; Kim et al., 2017; Umberson et al., 2018), demonstrating the disparities in this community, but there is limited qualitative work that explicates how life course theories shape understanding of the aging process of LGBT older adults, particularly through the use of social networks. A more thorough understanding of this process may help scholars continue to apply life course theory to LGBT

populations, especially as we continue to shift policy, and provide practitioners with insights on how better to care for their older LGBT patients.

As LGBT populations have continued to receive greater political and media attention at the local and national levels, debate over health practice and policy for this population has risen to the forefront in conversations of caring for older and vulnerable groups. Scholars have linked discrimination towards LGBT adults (Fredriksen-Goldsen et. al, 2014) to impacts on health. Discrimination and stigma came in all historic (Berube, 2000), social (Duberman, 1994), political (Canaday, 2009), and medical (Hegarty, 2018) including prohibition from participating openly in society, barring from marriage and other legal contracts, exclusion from access to healthcare coverage and medical services, and issues accessing guaranteed protections in housing, employment, and healthcare. Seemingly then, LGBT elders may fail to age well and be unable to adequately prepare for old age. However, in a three-part essay I argue that life course theory offers us a lens to understand how despite the years of discrimination and stigma that LGBT elders have faced, there are ways that elders can contend with their fears based on their past experiences to age successfully. In these three essays, I address how LGBT elders navigate the healthcare system, utilize their social networks, and trust policy to help them receive care tailored to their needs. In doing so I also make an argument extending the value of a segment of life course theory of cumulative advantage and disadvantages, and also critiquing the theoretical utility of strong and weak ties for this population.

Using three data sources including in-depth interviews with ninety older adults (LGBT and not), over 300 hours of ethnographic data from observations at an LGBT older adult

community center, and document analysis of online marketing material of long-term care facilities, I seek to demonstrate how experiences and circumstances over the life course result in real fears and situations for LGBT individuals to navigate as they age. I do this in three distinct, but related essays. Essay I examines the relationships of white gay men and women navigating healthcare as shaped by their previous experiences. While these individuals have negative interactions with the healthcare system because of their sexuality, they are nonetheless able to use their accumulated advantages to harness resources to generate more positive interactions with the healthcare system. This essay demonstrates that though LGBT older adults as a group face health inequality, some segments are able to counteract their negative life course experience by leveraging benefits of social support, education, and financial resources. Essay II delves into the differences between social networks of LGBT and straight, cisgender older adults by observing the differences in their network formation and utilization. I find that the social and legal context in which LGBT older adults aged, such as the ban on same-sex marriage and the impact of the AIDS epidemic, left many LGBT adults without a partner and children in old age. I find the differences in social networks also explain limitations in who LGBT elders can turn to for assistance and care during the aging process. Finally, Essay III looks at the institutions that often provide the last stop before death in the life course. This essay builds on findings from Essay I and II, showing that because of their negative healthcare experiences deriving from discrimination related to their sexuality and the inability to draw from their social networks for caregiving, LGBT older adults are likely to need institutionalized care in old age, but that process is filled with fear about the quality of care they will receive. This essay examines how prepared

long-term care institutions are to care for LGBT individuals based on the wants and needs of this population and seeks to bridge the gaps with policy recommendations.

Background

For older LGBT adults, previous lived experience and society's structure shape their current strategies for navigating care. By applying Dale Dannefer's (2003) extension of Robert Merton's (1965) study of stratification, one can see those differences in receipt of social and legal benefits among sexual and gender minorities, in this case along health and access to healthcare. The experience of stigma results in significant health disparities because of macro level discrimination (Meyer, 2003), especially from the medical community. Gay men, women, and transgender individuals coming of age that are subjects in this dissertation were pathologized and psychologized (Hegarty, 2018) and deemed 'unnatural'; some were institutionalized in order to suppress their feelings for those of the same gender. In their formative young adult years, this cohort suffered immense loss and subsequent backlash from the medical community, resulting in fears of providers that continue to this day (Johnson et al., 2005; Lucco 1987). However, LGBT older adults also have resiliency that allows them to continue to survive and navigate what could be a daunting system. In Essay I, I find that despite systemic disadvantages experienced by LGBT older adults, with my observations of white privileged older adults are able to seek to navigate the healthcare system in a way that serves them, while simultaneously circumventing the discrimination that they have endured and still fear from providers and the medical system. A common solution for these elders includes finding gay friendly primary care physicians who can advocate for them as they age, which is especially important to those who are single. They also

prefer to avoid the system all together and have leveraged their financial assets to avoid institutionalization (the topic of chapter 4). Finally, they build LGBT friendly social support to call on as they age, rather than turning to the system for aid. However, as adroit as this privileged group is at navigating care, when a more comprehensive picture that includes race, gender, and sexuality is studied and compared to straight counterparts, it becomes clear that there are major gaps for this group, deriving especially from their social networks.

A qualitative study in Essay III that examines LGBT older adult networks compared to straight cis-gender counterparts reveals that LGBT older adults have sparser networks to pull from aging related needs, unless, their networks mirror those of straight partnerships with children. While most older adults have shrinking social networks (Cornwell, Laumann, & Schum, 2008), LGBT older adults are less likely to be partnered (Fredriksen-Goldsen, 2011) or have children (Erosheva et al., 2015), and are more likely to have networks made of friends (Breder & Brockting, 2022). This leaves LGBT older adults susceptible to lack of support for care needs and benefits that straight folks receive from their partnerships (Cornwell & Waite, 2009) and children (Kotwal et al., 2016). Though my sample had unusually high levels of partnership, it still followed that older LGBT adults with depleted networks reached to the depths of their networks (Antonucci, Ajrouch, & Birditt, 2014) for aging needs. However, in doing so the older adults complicated the theoretical functional premises of a long-standing weak tie and strong tie dichotomy, in which strong ties provided more consistent reliability in serious intimate matters than weak ties (Granovetter, 1973; 1983). This theoretical function most recently expanded on by Mario Small (2017) lends a deeper sociological examination of the networks of

these elders. I find evidence in this work that rather than networks comprised of strong ties and weak ties with specific functions, the ties are more fluid and unbound from a fixed meaning. In a system where we would expect intimate familial ties to implement the difficult labor of taking care of aging loved ones, other actors step into these roles in places where there are no intimate or familial ties. Thus, the inelastic definition of strong and weak ties does not map onto LGBT older adults with small, kinless networks. Finally, the lack of kin also poses a more practical than theoretical problem of sparking fear about institutionalization and how to navigate finding suitable care.

LGBT older adults fear harassment, mistreatment, and negligence on the part of their fellow residents or providers (Putney, Keary, Herbert, Krinsky, & Halmo, 2018; Dickson et al., 2022; Caraces et al., 2020). As many institutions in Chicago are also Catholic based, many fear the repercussions of being in the care of devout Christians in the United States (Wilson et al., 2018; Houghton, 2020; Westwood, 2022). Because of this, elders worry they will have to go back into the closet to stay safe (Jihanian, 2013; Wilson et al., 2018; Furlotte, Gladstone, Crosby & Fitzgerald, 2016). As a result of these fears, LGBT elders take actions looking for specific LGBT friendly attributes when considering long-term care. Sociologically, how the fear of an imagined feature results in lived consequences (Thomas & Thomas, 1928) provides a window into studying the fears, real or imagined, and subsequent actions of these elders. Using Robert Merton's essay on "Self-Fulfilling Prophecy" (1968), it is clear that these elders are navigating a system which casts them as an "outgroup" likely to face harm at the hands of the "ingroup". Thus, they look for LGBT-friendly institutions signaled by their advertisements of cultural

competency, LGBT friendly material, and non-discrimination statements. In documenting these fears and the process of finding care, combined with attempting to navigate the system as an elder would, I find that less than 1% of long-term care facilities in Chicago actively invest in and offer culturally competent care to LGBT elders. The findings lend credence to the possibility of inescapability of discrimination, harassment, and abuse, especially if the institutions that provide quality care are out of the price range of most elders. Thus, I spend a significant portion of the essay suggesting policy as remedies.

Data and Methods

My data came from three triangulated sources to compose three essays: interviews, participant observations, and field survey. Essay I relies on LGBT interviews only. Essay II relies on LGBT interviews and the field survey. Essay III relies on interviews with both LGBT and straight individuals. All my data came from Chicago, which is an ideal research case study as the third-largest urban LGBT population in the United States, located in one of the few states with guaranteed protections for LGBT elders, yet a place where elders still struggle. It is a racially diverse city that could help capture the LGBT elder experiences of Latinx, Black, and Indigenous populations. Chicago has a mix of older lesbians and gays who migrated from the South, East, and West Coasts and the surrounding Midwest, giving a snapshot of America. Finally, Chicago is economically diverse and has one of the most significant wealth gaps of any American city, allowing for studying some of the wealthiest and poorest individuals. Chicago has more aging resources for LGBT folks than cities like Los Angeles, New York, and Philadelphia. Additionally, Illinois in general and Chicago have some of the most progressive laws around

LGBT aging as evidenced by the creation of an LGBT aging counsel that will report to the Illinois Health Services Department. Yet, as will be seen, there are still huge barriers for older LGBT adults when it comes to finding accepting resources, creating a need for studies of where these policies are effective and might be improved for the over 380 long-term care and supportive care institutions in the area. Revisited in each chapter, data was derived from interviews, participant observation, and a survey. Data was collected shortly before the pandemic in the summer of 2019 for my first round of interviews, and then in summer and fall of 2021. There was a distinct shift in the lives of the elders during this time, as well as numerous deaths, Covid related and not.

Interviews

Participants came from a nonprobability sample, recruited in two waves in the summer of 2019 and autumn of 2021. The first group is the basis for Essay I. Both groups are used in Essay II and III. Participants were recruited from community centers, online announcements, and interpersonal or third-party interactions via Zoom. LGBT interviewees came from Chicago and the surrounding suburbs. Adults ranged in age from 57 to 87 years of age. The mean age for the participants at the time of the interview was 72. Fifteen identified as gay women or lesbians, and the remaining twenty-nine identified as gay men. Forty-five of the interviewees were cisgender, and one was transgender. Eight identified as Black or African American, three as Asian-American or Pacific Islander, two as Hispanic/Latinx, one as indigenous, and one unknown. The remaining thirty participants identified as white. Two were HIV positive. This sample was highly educated, all but four had some college education, and many had received graduate degrees.

Thirteen of the participants had children or grandchildren. Most of the sample was married or partnered, with six being widowed.

Interviews with thirty-three straight folks were conducted in the fall of 2021, recruited through LGBT individuals, churches, and online announcements. Cisgender interviewees ranged in age from 55 to 89 years of age. The mean age for the participants at the time of the interview was 70, two years younger than their LGBT counterparts. Eleven were men, and twenty were women. Seven were Black or African American, two were Asian-American or Pacific Islander, and one was mixed race and unknown heritage. The remainder identified as white or ethnic white (Swedish, Ukrainian, and Polish), with three participants raised in Europe and moving to Chicago as adults. The sample was also highly educated, with all thirty-three attending some college or more. Two-thirds were married, two of the other eleven were widowed, and the other nine were single or divorced. There were no single straight men. About 90 percent had children, and about half had grandchildren.

I developed and maintained a close relationship with many of the interviewees, especially those who were LGBT who would not become interviewees until I was a part of the community several months into my participant observation and understanding. In several cases, I became a chauffeur, a porter, and a confidant to these older adults. I spent a lot of time listening as a way to gain trust. To secure LGBT interviews, I also spent time attending community events, house parties, and zoom discussions among other events, often fielding uncomfortable questions such as “How are you related to the LGBT community?” or “Why would you want to study an old gay like me?” and the not infrequent solicitation. I settled on a version of the truth that was

satisfactory but not uncomfortable, while choosing to never explicitly define my gender or sexual orientation. Interviews with straight older adults were equally as uncomfortable, since they also wanted to know about my relationships and when I was planning to have kids. However, I was lucky in that most of these older adults understood that their participation could provide insights in relationship to their LGBT counterparts and acknowledged their privileged position. Funnily enough, given that LGBT individuals are understood to be hard to reach for studies, interviews with straight adults were hard to obtain and I would not have been as successful without an extremely well-connected informant whose porch provided my outdoor office and interview space at the height of the pandemic.

Interviews were mostly in-person, adhering to Covid protocols and restrictions, including masking, with a few occurring over the phone or on Zoom. The interviews lasted about an hour each. Each interview was semi-structured, touching on life course events such as recognizing their sexual identity, coming out or not, and finding a partner. The brief life history focused on experiences with discrimination, including violence, police interactions, health care interactions, family relationships, and similar experiences, paying special attention to their view of their social support. A second critical part of the interview covered health and health care, including what decisions have been made for aging, self-rated health, and experiences with health care professionals given their sexuality. The final focus was on aging and planning, which included questions on downsizing, making wills, naming executors of wills, advanced directives, and plans for long-term care or other types of care.

Participant Observation

During the summer of 2021, I conducted over 300 hours of participant observation for three months. Time was spent facilitating discussion groups, talking with elders who attended the weekly lunch programming, finding services for individuals on a case-by-case basis, and helping elders with whom I developed deeper bonds. During the observation sessions, I would keep shorthand notes to identify events and use these to detail longer memos written after each day. The themes reoccurring in these observations informed the interviews with community elders, some of whom attended the events at the center. Eighty of these hours were accumulated preparing for a resource fair for LGBT elders, called the “4th Quarter of Life,” specifically addressing plans for the end of life. The afternoon included a keynote address by the director of senior services and a presentation from a local organization specializing in connecting LGBT adults to resources. Lunch was served during the keynote and followed by a tabling of a dozen or so vendors. During this event, I was able to connect with many of the attendees to understand their motivations for coming and spent time listening to, talking with, and observing the attendees of the conversations with vendors. Finally, I was able to sit with a few vendors, taking notes on their perspectives and motives.

The work here was not laborious, except for the few times I schlepped heavy objects for the event while the elevator was in use. However, the work was emotionally taxing, as many individuals served were sick, lonely, and aging. During my time there I also learned how the Center operated and developed relationships with the volunteers, many of whom were LGBT elders themselves, but much healthier and more privileged than the ones receiving services from

the Center. I gained an understanding of the gaps that institutions like the Center filled between programs offered by the City of Chicago and efforts from other non-profits. I would not have been able to navigate the system without the guidance of a trusted informant who provided me with introductions, references, and coaching.

Survey

This study, in Essay II, relies on a field survey created from a preliminary review of websites to assess the LGBT friendliness of a dataset of long-term care facilities compiled from November 2021 to February 2022. I started with a publicly available list of institutions listing LGBT-friendly senior long-term care and supported living guides from the Center on Halsted, a community center dedicated to the health and well-being of the LGBT population of Chicago. This list was curated by the Center on Halsted's Senior Service team, which included information on 14 institutions. In addition, I accumulated organizations through the Long-Term Care Ombudsman Program, Illinois Department of Public Health, and *U.S. News*, extracting corporate names, addresses, and types of services offered.

Analysis

Interviews and Observations

I analyzed interviews using inductive data analysis with theories and interpretation from the data (Saldana, 2016). NVivo 12, a qualitative software, was used to store and code data. I first listened to the interviews, read each transcript, and consulted memos written after each interview to jog my memory about salient themes noted at the time. I then took several passes at the data, gathering patterns and categories in the transcripts, making sure to go back to recode

interviews when new categories were found. I conducted line-by-line coding for themes specifically related to aging and planning for long-term care. Categories were collated and connected by concepts aided by reflections and memos on each topic. A similar approach was used to synthesize findings from the memos and notes from field observations.

Survey

I verified the extracted data using a two-step process. First, I crosschecked the available data with existing addresses to confirm sites were operational and not double-listed due to a change in ownership since their listing. Second, I verified information by visiting each institution's website. Institutions had to have an online presence since the goal was to evaluate online marketing material. While more up-to-date data might be available or verifiable through phone calls or site visits, this search aimed to replicate an initial investigation by a consumer and was focused on online marketing material; it was also conducted during the height of the COVID-19 Omicron outbreak in 2021, limiting the opportunity for in-person visits. The inclusion criteria are institutions listed at a verifiable address within the City of Chicago, serving older adults as their main population rather than special needs adults or psychiatric patients, and offering long-term care services.

The initial list included more than 150 programs; however, seventy-three institutions were removed for catering to populations other than older adults. I removed twenty-eight institutions focused on adults with disabilities. Another eight institutions focused on mental health and psychological rehabilitation. Three institutions listed did not provide long-term care. Twenty-five were removed because they had merged with other organizations or had changed

names since the listing was made. Four were removed because they had permanently closed, and six had no verifiable information. There were eighty remaining verifiable institutions. Once I verified institutions, I collected data to measure the quality of service and care available based on three particular categories that general consumers use to distinguish and choose a long-term care option. These included location, quality of care, and quality of life. But for the purpose of this study, I focused on the range and quality of LGBT-specific marketing.

In future work, I would spend more time focusing on the quality of care and quality of life as the places where most LGBT individuals in this study could afford and ended up were not the ones that provided the best quality of care. Additionally, it became clear that straight older adults had different ways to evaluate care, leaning more towards proximity to their children and family and investing time to think about the quality of life they would have when they moved to an institution, as opposed to LGBT older adults who avoided institutional care as much as possible and tended to mostly care about the quality of care vis a vis their sexuality. I provide deeper coding and analysis outlined in Chapter 4.

Chapter Two

HOW OLDER WHITE GAY MEN AND LESBIANS LEVERAGE THEIR RESOURCES TO NAVIGATE HEALTHCARE

Introduction

One of the many ways that gay men and lesbians have historically been excluded from governmental and social forms of recognition and support is through the denial of legal marriage. Before 2015 gays and lesbian relied on civil unions, and state backed marriages due to the lack of access to national marriage equality. While the legalization of same-sex marriage ended this era of discrimination and provided more equitable access to resources, it did not erase the legacies of discrimination for older LGBT people. The legalization of same sex marriage is an example of changing disadvantage experienced by gay men and lesbian women. Gay men and women have historically faced disadvantages that impact their health, but less talked about is advantages some gay men and lesbians have. The application of a theory that looks at a series of advantages and disadvantages is called cumulative advantage/disadvantage (CAD) in social science which stems from Robert Merton's (1968) structural functionalism theory. Cumulative disadvantage applies to societies' systemic divergence between those with accumulated advantages on the top of the societal structure and those who accumulate disadvantages closer to the bottom. Across the aging experience, these two paths diverge, creating a ranked order with an ever-increasing gap. Merton's work was later adopted by life course theorists (O'Rand, 1996; Dannefer, 2003) in conjunction with other important contributions to life course studies (Ryder,

1965; Riley, 1987, Elder, 1994). CAD has been applied to health outcomes, with studies addressing socioeconomic status (Willson, Shuey, & Elder, 2007) and race/ethnicity (Umberson et al., 2017). Yet, gender and sexual minority health needs more attention in this body of work. In the last decade, there has been a call by scholars to apply an understanding of stigma and violence to the health of lesbian, gay, bisexual, transgender, and queer/questioning (LGBT) people (Fredriksen-Goldsen and Muraco, 2010; Fredriksen-Goldsen, Jen, & Muraco, 2019; Fredriksen-Goldsen et al., 2019), and CAD is a lens through which to examine the aging process for older gay men and lesbian women.

For older gay men and lesbians, past and present legal and social contexts shape their current strategies. Those with more advantages can challenge the structural disadvantages they have faced over their lifetimes by leveraging their social, political, and economic resources to assuage concerns about facing discrimination from the medical community as they age (Gorman, 2016). However, more theoretical work needs to be done examining how historic struggles for sexual equality alongside personal challenges people have faced with friends, family, and medical providers in the past influence preparations for aging. These fears are not easily alleviated with the legalization of marriage equality or shifting public attitudes and can help make sense of why gay men and lesbians persistently have worse health outcomes compared to their heterosexual peers (Fredriksen-Goldsen et al., 2011; Fredriksen-Goldsen et al., 2019).

These findings are analyzed through CAD to build a bridge between the robust body of work on stigma and health inequalities and the budding field of LGBT health research. Like other minority and disadvantaged communities, gay men and lesbians in this study with access to

higher levels of education, wealth, prestige, and social support have developed a way of navigating the healthcare system in response to long-lived discrimination and anti-gay attitudes. Understanding these processes may have implications for helping a growing number of LGBT identifying adults age successfully (Vincent & Velkoff 2010). In the study below, I analyze interviews with older gay men and lesbians. The work argues that CAD can apply to negative experiences related to sexuality over the life course, which in turn influence decisions around aging and health care. Here I argue that this localized privileged group can help extend the theory of health disparities by looking across the life course and demonstrating how social science concepts can be applied to research on LGBT aging.

Literature Review

Cumulative Advantage/Disadvantage

Social scientists and the medical community have studied inequalities in morbidity and mortality, particularly focusing on how sociopolitical factors are associated with disparities in health outcomes (McLeod, 2015; Gengler & Jarrel, 2015). The theory of cumulative advantages and disadvantages over the life course helps to elucidate health differences in old age along the axes of race/ethnicity, gender, SES, and sexual and gender minority status (Dannefer, 2003) based on the understanding of cohort studies introduced decades prior (Ryder, 1965). CAD has its roots in Robert Merton's ideas of structural functionalism, which reasoned that stratification by CAD processes was necessary for a stable society. As sociologist Dale Dannefer points out, CAD can further the knowledge of health inequity among older adults.

Important to understanding the impact of CAD, social structures have policies that reward those who already benefit from those replicable structures, putting more distance between the haves and have-nots (Dannefer, 2003; S330). CAD processes diverge along the lines of characteristics such as money, health, and status, to name a few. In the case of gender and sexual minorities, one example may be having access to marriage and the benefits conferred from this legal status, including accumulation of wealth, transfer of wealth and property, access to healthcare, and social security as mechanisms of stratification at various levels (Dannefer, 2003; S333). Thus, CAD can help explain some of the health inequities and outcomes of the LGBT community as a subgroup and individuals. Because of their experiences as LGBT people in a system where they are disadvantaged, some individuals may gain an advantage because of access to education, money, or social connections and others may lose out.

Additionally, and importantly for this work, inequality in old age is built on experiences over the life course, shaped by structural and institutional arrangements that work to stratify cohorts over their lifetimes (O'Rand, 1996). Thus, the choices available to one cohort of gay men and lesbians might look very different from those of another based on changing social attitudes and the era's legal circumstances. For example, those who came of age in the pre-Stonewall era versus those who came of age after Stonewall and during sexual liberation may have accumulated different reactions to their sexuality based on when they were born. Another example would be younger LGBT adults who since 2015 have access to legal marriage around the same time as their straight, cis-gendered peers, compared to older LGBT adults who married much later in life relative to their straight peers. Given the circumstances of marriage inequality,

older gay men and lesbians missed the ability to accrue wealth as a couple in the same way as their peers, could not receive each other's health benefits until recently, and in many cases could not legally partake in end-of-life rituals. Notably, the experiences of gay men and lesbians might be very different from those of gender-expansive and transgender older adults, who face an entirely different set of experiences compared to gay men and lesbians and are not addressed in this paper.

CAD has not been widely applied to studies on gender and sexuality. Some theories, such as minority stress, posit that social stress contributes to poor mental health through stigma, prejudice, and discrimination because of experiences hiding an identity, internalized homophobia, violence, and other coping mechanisms (Meyer, 2003). While the literature on minority stress accounts for structural factors and relationships, it does not necessarily discuss how stress and other disadvantages play out throughout life or maybe cumulative in old age. Again, Fredriksen-Goldsen, has produced the *Aging with Pride* study, arguing that the life course is crucial for LGBT individuals. Unlike Meyer's work, Fredriksen-Goldsen's work revolves around the idea of the 'iridescent life course.' The theory positions LGBT individuals and their health historically and structurally. Fredriksen-Goldsen and colleagues frame protective factors as resilience (Fredriksen-Goldsen et al., 2012; Fredriksen-Goldsen et al., 2013; Fredriksen-Goldsen et al., 2019). Resilience is the ability of a sexual minority to overcome negative outcomes through learned coping mechanisms. Resilience may be understood in terms of cumulative advantage, and disadvantage as a culmination of advantages accrued over the life course. The 'iridescent life course' includes the importance of linked lives, in other words, the

ability of social support in the form of family, friends, and chosen family to mitigate or offset the disadvantages associated with sexual and gender minorities.

This work applies CAD to a group of gay men and lesbians that have experienced social and political disadvantages throughout their life course and thus leverage their advantages in the form of socioeconomic and social supports to circumvent sociopolitical factors that might otherwise lead to negative health outcomes prevalent in the wider LGBT community.

LGBT Health Studies

Current research suggests that LGBT people face a higher risk of physical, emotional, and social stress than their heterosexual and cisgender peers. These outcomes are compounded by societal marginalization and stigma, making it more difficult to maintain health and manage or receive health services, especially with increasing age and declining health. Despite progress in LGBT health research (Fredriksen-Goldsen, et al., 2019; Fredriksen-Goldsen & Muraco, 2013) and clinical practice (Dickey 2012), there is still much to learn. We do know that gays, lesbians, and bisexuals have significant disparities in both mental and physical health compared to heterosexual, cisgender individuals (Fredriksen-Goldsen et al., 2011). They are more likely to struggle with mental health (Meyer, 2003; Stinchcombe et al., 2020), more likely to have a disability (Fredriksen-Goldsen et al., 2012), and more likely drink and smoke (Austin et al., 2004; Russell et al., 2002). LGBT people, in particular youths, young adults, and older transgender adults, are at increased risk for contracting or having negative health effects of the Human Immunodeficiency Virus (HIV) (Russell et al., 2002; Emlet, 2016).

Recent research on gay, lesbian, and bisexual health has posited why lesbian, gay, and bisexual people may be more prone to health issues than their heterosexual counterparts. One model proposed in Ilan Meyer's work (2003) argues that minority stress "explains the higher prevalence of mental disorders as caused by excess in social stressors related to stigma and prejudice," (p. 23) meaning that treatment by others based on race, sexuality, gender identity, or age—or as a correlate, stress induced by one's location in a sociocultural context—can influence health outcomes. Discrimination at macro levels can impact health by limiting resources (Berkman et al., 2000), like not having access to same-sex marriage or housing protections (Choi & Meyer, 2016). Individually, discrimination may mean rejection by family and friends (Weston, 1997). Research shows that negative physical and mental health outcomes among LGBT individuals are inversely associated with identity disclosure.; this was particularly true for older age groups (Fredriksen-Goldsen et al., 2015).

The LGBT community has a long history of social and institutional disadvantages (Foucault, 1978; Canaday, 2009; Katz, 1992). Gay men and lesbians faced sodomy charges (Eskridge, 2008) under a law that was only struck down in 2003 by *Lawrence v. Texas*. In addition, refusal to allow gay men and lesbians to serve in the military until the repeal of Don't Ask, Don't Tell came with the denial of certain government benefits such as honorable discharge if found to be gay and access to GI Bill benefits that applied to heterosexual families (Berube 2000). Gay men and lesbians have not been able to live openly until very recently owing to social movements like sexual liberation (Duberman, 1994; Faderman, 2011), before which time they could be fired for being gay or suspected of being 'homosexual.' Access to hospital

visitation, social security benefits, having a spouse on a bank account, and numerous other rights were not easily accessible until the more recent push for Marriage Equality (Hart-Brinson, 2018) in 2015. More directly, the LGBT community has been psychologized and pathologized by the medical community (Hegarty, 2018) and in popular culture. Furthermore, Acquired Immunodeficiency Syndrome (AIDS) devastated the gay community with unnamable loss, but resulted in a renewed backlash against the LGBT community, and residual fears from discrimination continue to influence healthcare providers (Johnson et al., 2005; Lucco, 1987). This all has contributed to legitimate fear and preferences for safe providers among LGBT individuals.

Additionally, LGBT individuals are more likely to face strain on important resources, including social support. While LGBT individuals report the importance of families of origin (Connindis, 2010; Heaphy, 2009), they are often strained, resulting in LGBT folks being hesitant to accept offers from family members, instead of asking gay and lesbian friends and neighbors (Hash, 2009). Same-sex couples are less likely to be married (Gates, 2014) and to have children (Erosheva et al., 2015) or grandchildren (Espinoza, 2011). LGBT individuals may rely on families of choice, non-kin networks created out of necessity (Muraco, 2006; Croghan, Moone, and Olson, 2014), because of discrimination by biological relatives or absence of caregivers like spouses and children (Weston, 1997; Price, 2011, Brennan-Ing et al., 2014). Even when partnered, gay men and lesbians take extra steps to protect themselves by creating fend of life documentation and legal plans (Thomeer et al., 2017), or seeking LGBT friendly services or physicians (Fogolia & Fredriksen-Goldsen, 2014).

While little research focuses specifically on LGBT older adults and their health and well-being, extant research focuses on social supports and networks. Research demonstrates that greater access to family, friends, and non-family ties is associated with better mental health (Kim et al., 2017). Other work has demonstrated the important benefits of marriage for gay men and lesbians (Umberson et al., 2018), including improved mental health (LeBlanc et al., 2018). The few studies that compare same-sex and different-sex couples indicate that lesbians receive mental health benefits from marriage (Garcia & Umberson, 2019). Despite recent publications, much still needs to be explored around how LGBT individuals utilize all their resources for health as they age, and how, if at all, a history of disadvantage plays into health inequalities.

Data and Methods

Data

This study is based on twenty-three in-depth interviews with individuals over the age of 60 who identify as gay or lesbian in the Chicago area. Interviews were collected in the summer of 2019. Participants were recruited through flyers posted in high-density LGBT neighborhoods, gay-friendly newsletters, and community centers, as well as through announcements at community events, which I attended in person, and through listservs for interest groups associated with LGBT and aging issues in Chicago and the surrounding areas. Recruits were offered coffee, tea, or a snack to be delivered at the time of the interview as a thank you. Participants contacted me, and we arranged a semi-structured interview in a location of their choice.

All participants reside in Chicago or its suburbs. My sample ranges in length of time living in Chicago from four years to more than 80, with half of the sample moving to Chicago from across the country in their twenties. They range from 60 to 87 years of age. Fourteen are Baby Boomers, born between 1946 and 1964, while seven are members of the Silent Generation, born between 1925 and 1945. With half of the sample between the ages of 69 and 74, the median age is 71. Six of the interviewees are lesbian, and seventeen are gay. Only one participant identifies as Black, and the remaining twenty-two respondents identify as white. All of my respondents completed high school, and all but one have some college education. Of the remaining twenty-two, nine have bachelor's degrees, and thirteen have post-baccalaureate or graduate school education. About half my interviewees (eleven) work full (2) or part-time (9), including all the women, and the remaining thirteen are retired. Ten interviewees are in a long-term marriage or partnership, defined as ranging from twenty to more than fifty years. Three people date or have an ambiguous partnership. Three participants lost their spouse or partner and have not re-partnered. The remaining participants are single. Only two of the participants ever had spouses of the opposite sex. Three have children or grandchildren; this includes two men who had children in a heterosexual relationship, and a lesbian who adopted an extended family member. All participants reported some connection to family, mostly siblings, cousins, or young nieces or nephews, but often these relationships were burdened with complications related to sexuality. The sample overall was highly-educated, white, and economically privileged (meaning they generally owned their homes, had been employed throughout their life without interruption, and had assets including pensions and savings).

Analysis

Interviews were held in offices, coffee shops, and homes. Interviewees verbally consented, and the conversations were recorded for transcription. Most interviews lasted about an hour, with some as short as twenty-five minutes and others lasting more than two hours. Interviews followed the same semi-structured guide for all respondents with the opportunity for clarification with follow-up questions. Questions included decisions about social support around healthcare such as, "Can you tell me about a time when you talked to someone about your health?" These were followed by probing questions such as: "What was the nature of your relationship with the person you were talking to?"; "How often do you talk to this person about your health?"; and "Have you talked to this person about other health-related issues as you age?" The respondent determined what was most relevant to share during the interview.

I analyzed interviews using traditional inductive data analysis with theories and interpretation developing out of the data (Charmaz, 2006). NVivo 12, a qualitative software, was used to store and code the data. I first listened to and read each transcript and consulted memos written after each interview to jog my memory about salient themes noted at the time. I then took several passes at the data gathering patterns and categories in the transcripts, making sure to go back to recode interviews when new categories were found. I conducted line-by-line coding for themes related to resources (social, financial, knowledge) and navigating healthcare. Categories were collated and connected by concepts aided by reflections and memos on each topic. The themes that resulted from this process were the final stage of analysis and writing are seen in the results that follow.

Results

Those interviewed expressed many worries about interacting with the medical community as they planned for declining health and aging, including: apprehension about discrimination from providers and professional caregivers due to institutional regulation of sexuality; lack of social support from family owing to strained relationship dynamics related to sexuality; and fear of facing stigma from medical providers. Interviewees sought to find acceptance in medical care and to avoid discrimination. They equated feeling comfortable being “out” to their doctors with quality care, since their sexuality remained salient to their identities as they aged.

In response to these concerns, gay men and lesbians leveraged resources in three main ways that bolstered their sexual identities: 1) finding gay-friendly primary care physicians (PCPs) that they can come out to and in turn gain a trusted ally in managing their care as they age; 2) drawing on their financial assets and homeownership to age at home as long as possible, and avoiding long term care (LTC) facilities; and 3) intentionally surrounding themselves with trusted partners, younger family members, chosen family, or friends to execute caregiving and end of life decisions.

Navigating Healthcare with the Support of Primary Care Physicians

Many elders were apprehensive about encounters with medical professionals stemming from physicians' prejudices towards gay men and lesbians. A part of this was related to past negative and uncomfortable experiences. Theo, for example, recounted an experience with his

dentist who accosted him after he saw him on television speaking for an LGBT event.

He says, "Mr. Theo, I saw you on television. And you were being interviewed, and you said you were gay." I said, "Yes." He says, "You never told me that." And I said, "I told you that the first day I came in here because if you don't want to handle gay people's teeth, I would find somebody else."

Theo, who had been seeing the dentist for more than twenty years, felt uncomfortable with his doctor bringing up his sexual identity when he provided the opportunity for it to be addressed decades earlier. Theo, 82, concluded that this dentist does not like gay people, and though he was uncomfortable, reluctantly continued with the same provider because finding another dentist was too difficult.

Other gay men and lesbians reported lasting emotional trauma from the AIDS epidemic; both the men and women had lost friends, partners, or brothers. Though all the participants were HIV negative survivors, the AIDS crisis profoundly shaped them and had implications for picking gay-friendly physicians. Richard, 74, struggled with acute distrust of doctors after being misdiagnosed with AIDS. Tom, 69, an attorney, felt compelled to fight against doctors refusing care to AIDS patients. Jody, 65, cared for her brother as he died of AIDS, and Jean, 71, cared for numerous dying gay friends one after another. Stan volunteered in hospitals after losing his partner to AIDS. Diane, 60, and Rhonda, 58, a lesbian couple, volunteered at an AIDS call line starting in the early 1980s. As a result of these experiences, elders avoided doctors with negative attitudes because of their ignorance or judgment towards those with AIDS. Wanting to avoid similar interactions, they sought gay-friendly providers, specifically PCPs, as resources for navigating the healthcare system. Therefore, they placed significant value on LGBT (friendly)

doctors found through social connections.

To find PCPs, elders relied on their social position and knowledge of the medical field to obtain recommendations and switch practices. For example, Seymour, 74, retired from decades in the sales display industry, used his connections to doctor friends.

But this friend of mine told me about two doctors who'd started the AIDS research and program at Illinois Temple. I decided to go to one of them. They were at that time located in Illinois Temple. I transferred over there.

Seymour leveraged his connections to top tier providers who were well versed in care for gay men and lesbians. Similarly, Martin, 73, obtained recommendations from his gay friend's brother. Additionally, those without specific social connections were informed about local institutions for LGBT people and made phone calls for referrals.

I was trying to think, what can I do to increase my chances. It was never important to me that my doctor be gay, but they had to be gay-aware, gay-sensitive, gay-friendly. So I called the gay health clinic, I said, I'm looking for a new doctor. Who are your volunteer doctors?

Martin, who wanted to remain proactive and avoid contracting HIV, decided to get a recommendation from a local gay health clinic, and could do so because he had knowledge and connections.

Using Resources to Age in Place

Another major concern for gay and lesbian seniors centered on fears related to aging in place or finding gay-friendly services. On numerous occasions, elders expressed fear about the treatment they could face in LTC facilities, citing their previous personal interactions and secondhand stories. Diane, 73, and Rhonda, 65, together for twenty-five plus years and living in

the same suburban home for fifteen, considered the future as Diane's health declined and she developed several chronic conditions. When asked if they considered a LTC facility, with her wife next to her, Diane responded:

We haven't checked that out. I hadn't checked that out. That would be something that would be interesting. Would they want us living in there, sharing their dining room, sharing their shuffleboard? There were some in the news. There was one, I think, last year in the news where they wouldn't let the [gay] couple live together. We wouldn't go somewhere like that.

Though Diane and Rhonda worried about managing Diane's deterioration, they were more concerned about discrimination. Based on the news they consumed and stories from friends, they feared discrimination from residents who might refuse to socialize with them. More jarring, they dreaded ending cohabitation because they were a lesbian couple. Like many participants, fear of what might happen to them in such environments prevented them from researching LTC possibilities. Stan, single and 60, who struggled with walking because of bad knees and a hip replacement, expressed a common concern.

We're ready to go back into the closet under any stress. You're in a nursing home. You're infirm for some reason yourself. You're isolated. And you're at the mercy of people who very well may be Catholics, Filipinos, and you're really at the mercy of people. You may just go back in the closet, especially if you can't find other gay people.

Stan echoed the vulnerability of older adults without family support, particularly elders who cannot advocate for themselves because of physical or mental ailments and must place trust in others to treat them with dignity and respect regardless of their sexuality. Stan had nieces and nephews whom he could turn to if his sister died, but Stan was not confident that they would be willing to care for him full-time as his health worsened, meaning he would have to seek care in

an institution.

Sydney, one of the oldest interviewees at 81 and recently widowed, expressed why it was so important for gay men and lesbians to be able to find gay-friendly providers. He said:

You may have heard it said that somebody could be out during his or her life, and then when they need care toward the end of their life, they end up going back into the closet because they're in places that are not gay-friendly.

For Sydney and other elders, going back into the closet produced a lot of anxiety, especially since, for many, the decision to come out was an arduous and decades-long process. To circumvent poor care and avoid discrimination, elders spent a large amount of time figuring out how to receive the same services they would in LTC facilities at home by leveraging various investments and assets.

Frederick, 71, spoke at length about his aging-in-place plan. Frederick lived in a large, manicured three-story home with his husband, Graham.

One thing I did with my life insurance policy with my spouse as a beneficiary, several years ago, I added a provision where you could draw on the cash value of your life insurance to pay for in-home services. All you need is a physician to say that you need these services, and you can withdraw the cash value.

Later he continued:

The other asset I have is this house; I'm still paying a mortgage on it but, if things got to a crunch, we could sell this house and realize a substantial profit and use the proceeds from that.

Frederick, like all interviewees, was acutely aware of the insurance programs and policies that he could take advantage of to age in place. Like most elders in this study, Frederick and his husband owned their homes. If assistance with daily activities was not enough, and they could

not navigate the three-story home, Frederick and Graham could sell and put the profits towards in-home care or a smaller, more accessible home, anything to avoid moving into an institution,

Other elders modified their home environments to avoid moving into any kind of assisted living or nursing home. Ernie, 71, and an active socialite, moved with his partner of several decades to a gay-friendly neighborhood, trading a multi-level home for a more accessible one within walking distance of several key services.

We recently moved to where I am now, and partly because I give speeches on aging for the gay community, and we had sort of planned on that. I previously had a single-family home, which meant [using] snow blowers and all that good stuff. But we moved into a high-rise, elevator building with indoor parking. Outside my door, for two blocks, there were restaurants, dry cleaners, bank, Walgreens.

Ernie and his partner had reached the age where using the snowblower during the winter was difficult, and they preferred a condominium to a single-family home. The building had an elevator, making it accessible, and nearby amenities. All were significant, but most importantly, the neighborhood was gay-friendly. Some gay men and lesbians thought about moving to nursing or long-term care facilities and hoped they could afford the few local gay-friendly institutions. But most understood there would be an exorbitant cost would prohibit this competent care, so instead dreaded a facility less equipped to handle LGBT patients.

Using Social Support for Alternative Caregiving

Though most participants had partners, only three elders had children, either from a previous straight marriage or by adopting a family member. Unable to marry and even less likely to raise children, gay and lesbian older adults developed a particular anxiety about aging.

Partnered individuals in the study assumed their partners would care for them or help them navigate healthcare setting. Still, they remained worried about how institutions would respond to their sexuality in old age, as we will see with Theo and Wally, and later with Clyde and Sam. In the absence of a traditional heterosexual family, single individuals in my study, as illustrated by Jean, intentionally pick others to fulfill specific caretaker roles to help them navigate healthcare.

Theo, 87, and Wally, 81, together for more than fifty years, relied on one another to advocate for their care. In 2001, Theo and Wally had issues with needing extra documentation while at the hospital. Theo recalled a conversation that he had with a nurse while his now-husband Wally was recovering from surgery. Theo insisted on being with Wally after surgery despite pushback from a nurse.

The nurse wondered who I was. I said, 'Well, I'm his partner.' And she said, 'What's that supposed to mean?' I said, 'I'm his partner. I'm his life partner.' And I said, 'I'm going to stay here tonight.' She said, 'No, you're not.' And I said, 'Yes, I am.' She wanted to know if I had papers [to prove we were partners]. We had papers.

Couples felt obligated to address their sexual identity with providers because, to them, it meant better care for their partner. Advocacy by one or both partners was particularly crucial in the days before same-sex partnership was more acceptable and certainly before the Supreme Court legalized same-sex marriage in 2015.

Even when partners cannot provide care, they can orchestrate care. Clyde, an 88-year-old veteran, looked after his partner Sam, in his late-seventies, who suffered from Lewy Body Dementia. Because of changes in Sam's health, Clyde chose a close friend to be the executor of their trust should Sam survive him. Finding an executor of their Will and healthcare Power of

Attorney was difficult for older adults: many friends preceded them in death from AIDS and old age, leaving fewer people to choose from, with even more limited options for those without extended family. Clyde was an only child, and most of his relatives were deceased, so Clyde turned to some of his best gay friends from church.

Finding someone to help with end-of-life caretaking was especially difficult for older single adults estranged from their prejudiced family members. This group of people in my study turned to close LGBT friends or younger distant relatives to act as Power of Attorney and Executor of the Will. Single LGBT individuals worried about hiding their identity from providers because they had no partner advocating for them and put more energy into finding people who could care for them in an emergency, after a procedure, and after death.

Jean's story illustrates this point. She was an animated, 71-year-old artist who built a community, including neighbors, close friends and former lovers, relied on them when she injured her knee. Jean actively engaged in the community—going to church, local political organizations, garden groups, and book groups to form community. In a time of need, she was able to rely on people with whom she had developed relationships.

I have a neighbor who's helped, I broke my knee last year, and it was in November. They provided anything I needed. I had another friend who's now moved to Florida, also. She went and got groceries for me. I called her, I said, Denise, I need your help. She was like what? She's the one that took me to the doctors when I broke my knee. It was on a Sunday night; she came Monday morning, took me there. My friend, Bobby, took me to see the surgeon. [My friend] Wanda would give me the tabloid every week.

Jean described how she intentionally cultivated a network of people in case of a health

crisis. Jean could rely on her neighbors. She had to trust multiple people to fulfill different roles. While partnered people in this study can reach out to their spouses, singles must work to create support in the absence of a spouse and children.

Discussion

Systemic disadvantages motivated how gay men and lesbians engaged with the healthcare system, leading them to maximize their advantages including social supports, financial assets, and knowledge to seek gay-friendly care as part of their imagined way to age successfully. This study demonstrates how one local group that faces overall social and political disadvantages can mitigate these effects by leveraging available advantages.

Cumulative Disadvantages and Advantages

Social science work connects inequalities in older age to advantages and disadvantages experienced over the life course (Ryder, 1965; Riley, 1987, Elder, 1994). CAD research has helped to expand health research on socioeconomic status (Willson, Shuey, & Elder, 2007), and race and ethnicity (Umberson et al., 2018). Life course models have been suggested by giants in the gender and sexuality fields (Fredriksen-Goldsen and Muraco, 2010; Fredriksen-Goldsen, Jen, & Muraco, 2019, Fredriksen-Goldsen et al., 2019) as there has been a call for more theory in sexual and gender minority work (Fabbre & Fredriksen-Goldsen, 2019). CAD suggests a way to understand how societal factors such as legal and social discrimination that disadvantage gay men and lesbians lead individuals to leverage their personal advantages. These advantages can lead to positive interactions with healthcare providers. Those with more advantages may have

more choice in how they confront the healthcare system, demonstrating stratification among gay men and lesbians (Dannefer, 2003).

Gay and lesbian elders who have experienced systematic and enduring disadvantages may be examined using cumulative advantages and disadvantages. There is a documented history of struggle related to sexuality captured by pivotal historical moments like Stonewall (Duberman, 1994), sexual liberation (Faderman, 2011), and the recent legalization of same-sex marriage. The enduring legacy of discrimination may translate to interactions with healthcare providers as seen in the cases of the elders interviewed for this paper. As such, gay men and lesbians, who faced significant disadvantages related to their sexuality throughout their life may rely on their advantages (social support, accrued wealth, and knowledge) to offset disadvantages when aging and receiving care.

Economically privileged, highly educated white gay men and lesbians in Chicago and surrounding suburbs are just one example of how having resources to draw upon when facing declining health in older age may make a difference. In this case, they used their social supports and institutional knowledge to find gay-friendly PCPs to act as their advocates within the system. This group employed assets in the form of finances, homeownership, and knowledge to age in place, thus avoiding unpleasant circumstances in LTC and other medical settings. Finally, these gay men and lesbians relied on their social supports like spouses, friends, relatives, and chosen family to ensure the best care was provided, but also to make sure that their wishes were respected when under medical care.

LGBT Aging and Health

Previous LGBT health and aging work names mechanisms for disparities such as stigma (Meyer, 2003) and calls for investigating how some LGBT individuals thrive despite discrimination through models such as the ‘iridescent life course’ (Fredriksen-Goldsen & Muraco, 2010; Fredriksen-Goldsen, Jen, & Muraco, 2019; Fredriksen-Goldsen et al., 2019). Negative life experiences are suggested to contribute to poor mental health outcomes (Meyer, 2003), a higher likelihood of disability (Fredriksen-Goldsen et al., 2012), and poorer health behaviors (Austin et al., 2004; Russell et al., 2002). My work, though focuses exclusively on gay men and lesbians, extends the literature in two ways. First, it helps to contextualize LGBT health and aging studies in an established social science theory, thus providing another model in a field where theory can be understated (Fabbre, Jen, & Fredriksen-Goldsen, 2019). Second, it considers how these previously identified mechanisms (such as discrimination, stigma, homophobia, prejudice and violence) can be labeled as disadvantages and suggests that many gay men and lesbians use the resources or advantages available to them to access the type of healthcare suitable for them.

My results suggest that understanding CAD for older gay men and lesbians may be vital to recognizing how they use their resources and lived experiences to navigate the healthcare system (Thomeer et al., 2017; Fogolia & Fredriksen-Goldsen, 2014). Thus, disadvantages in the form of social and legal contexts have shaped gay and lesbian healthcare interactions, making the health of LGBT elders a key future concern as the American population continues to age.

Disadvantages can motivate older LGBT individuals to use their advantages to seek safe and high-quality care that allows them to maintain their sexual identities.

This work looks at the body of health outcomes of LGBT people and seeks to consider the nuances of stress and discrimination faced by LGBT individuals and how their experiences lead to health outcomes that may be stratified based on a particular set of advantages and disadvantages experienced over the life course. Like previous literature, I find that minority sexuality can result in negative experiences or fear of negative experiences in health care. This work may help move the analysis forward, despite the extreme privilege of this group, by demonstrating how some gay men and lesbians use their advantages such as social supports, community connections, and knowledge to seek better quality care by finding a gay-friendly PCP. They maximize their financial assets and understanding of healthcare policies and systems to ensure they can age in place rather than face the uncertainty of entering a LTC. Finally, they rely on the support of their partners, friends, and family to prepare for care as they age, and in some cases, circumvent the medical community. I demonstrate that though there is inequality because of cumulative advantages/disadvantages in health outcomes for LGBT individuals, white, economically privileged, educated gay men and lesbians can leverage resources to strategize healthcare interactions for the better.

Limitations

The literature on LGBT health occasionally applies life course theories such as cumulative advantages and disadvantages, but infrequently applies such theories to health and

healthcare interactions or aging studies. I expand on gender and sexuality studies by linking life course theory to LGBT health work in a study of white, economically privileged, highly-educated gay and lesbian Chicago elders. While expanding on previous research to include gay men and lesbians' health and aging, there are some limitations but exciting ways to expand on the study in the future. First, this is an extremely localized group of privileged individuals. Additional work should explore beyond a homogeneous sample. Future research should examine elders with more diverse backgrounds, including lower SES, minority race/ethnicity, living in rural regions, and alternative living arrangements.

Second, there are ways that gay men and lesbians are similar to heterosexual individuals in how they utilize their networks as they age that cannot be fully captured in this work. Further research should interview LGBT individuals along with their straight peers to allow for more comprehensive comparisons (Umberson et al., 2016; Reczek et al., 2018). Finally, additional studies should focus on groups often excluded from LGBT research like bisexual, transgender, and nonbinary individuals.

Conclusion

My findings suggest that older, white, economically privileged, highly-educated gay men and lesbian adults leverage their advantages strategically to avoid negative interactions with healthcare providers on the basis of shared historic disadvantages experiences. Examining how older gay men and lesbians use their advantages to navigate the healthcare system is key to developing effective health policies and clinical responses to support the growing healthcare

needs of the older adult LGBT community. This is particularly important in the context of health disparities (Institute of Medicine, 2011; Fredriksen-Goldsen et al., 2011). There is the opportunity to explore CAD in relation to other life course and health outcomes of sexual and gender minorities in the increasing elderly American population. Beyond addressing health disparities of older gay men and lesbians, the extension of this inquiry to bisexual, transgender, and queer populations has the potential to broaden this theory. This work conceptualizes health inequalities for LGBT individuals and expands the growing body of literature on LGBT health. Finally, it demonstrates how some gay men and lesbians interface with the medical system, highlighting potential challenges and areas for further investigation when it comes to healthcare solutions for older LGBT adults.

Chapter Three

“FORCED BACK INTO THE CLOSET:” GAPS BETWEEN LGBT ELDERS’ FEARS AND AVAILABLE CARE

Introduction

The 2020 Census demonstrated that the United States continues to grow older, with more than a quarter of Americans predicted to be over the age of 65 by the year 2060, half of which are projected to need some long-term care (Rubin, 2022). Despite the dip in life expectancy due to the Covid-19 pandemic, Americans are living longer than in generations prior, and along with that comes the increased need for long-term care (LTC). That is, care meant for more permanent residence for individuals who will need continuous assistance with activities of daily living, which differs from temporary care or assisted living options that may or may not be available in a nursing home, and is not meant for types of care such as shorter term care, acute post-operative care, rehabilitation . As Baby Boomers age, it is projected that the population in long-term care will increase from one million to nearly 1.2 million in 2030 (Mather, Scommegna, & Kilduff, 2019). The yearly cost for an individual was nearly \$150,000 in 2015 and is continuing to increase due to inflation, especially post-pandemic. The market itself is expected to reach nearly \$800 billion by 2030, with an annual compound growth rate of over 5% (Grandview Research, 2022).

With that aging population, there is going to be increased scrutiny of long-term care facilities. For a particular set of older adults, the prospect of long-term care brings a unique set of

issues. Across the U.S., LGBT elders struggle with many social and medical issues (Fredriksen-Goldsen et al. 2019). When LGBT elders have interacted with providers, many have experienced mistreatment and stigma (Pierce, 2022) or vicarious trauma related to homophobia, transphobia, and fear of HIV (de Vries et al., 2022). Yet, LGBT folks are at higher risk for placement in long-term care than their straight counterparts (Hiedemann & Broddff, 2013), making the consequences of long-term care of heightened importance for LGBT older adults. Chicago, Illinois, makes an interesting case study because even though Chicago has vast resources for the LGBT community including Howard Brown, Center on Halsted, and support from major medical centers at the University of Chicago and Northwestern, as well as new legislation that extends protections for LGBT older adults, LGBT elders still struggle with fear and accessing care (AARP, 2022).

LGBT older adults have distinct fears about aging, including whether they will maintain their sexual identity as they age (Wilson, Kortés, & Stinchcombe, 2018), remain connected to their families, partners, and chosen family (Hash & Netting, 2003), and receive the care they deserve if they must be institutionalized. Many LGBT elders in this study face some level of discrimination leading to fear. How older adults in this study envision the care they receive as they age reflects how they conceptualize aging with their fears regarding the implications of their sexual orientation or gender identity. In other words, how LGBT older adults plan for finding long-term care demonstrates a response to their fears and anxieties about the discrimination they will face in old age because they are gay, lesbian, bisexual, and/or transgender. These plans or lack of planning are based on imagined futures conceptualized based on stories and stigma.

These constructed future realities, though imagined, are real in their "lived consequences" (Thomas & Thomas, 1928) because they have real-life implications for the behaviors of LGBT older adults in how they approach planning decisions. Perceptions of this marginalized community become manifest by responding to their interpretation of a 'prophecy' of real or perceived discrimination, "evoking a new behavior" (Merton, 1968, p. 477) of seeking affirming care they want.

In this paper, I ask: 1.) How do LGBT elders' perceived fears inform their very real search for long-term care? 2.) Based on these desires and approaches to searching, what are their care options? and 3.) How can we bridge gaps with policy? To answer this, I analyze interviews with elders about their aging plans and fears and conduct ethnographic work following elders seeking care and aging resources. Using a survey of online material assessing how LTC providers in Chicago engaged with LGBT older adults, I determine how well these materials meet the needs of what elders seek in their search. I find that LGBT elders have distinct fears related to their sexuality when thinking about long-term care and seek indicators of an LGBT-friendly environment, including disclosures of the levels of cultural competency training of their staff and administration. Second, I find there is a lack of online material for the LGBT community helping them navigate their research to make decisions about their care. Finally, while I find a chasm between what is desired and what is offered, I argue the gap can be filled with additional policy and enforcement of existing legislation.

Literature Review

LGBT Adults Fears of Care

Historically, long-term care facilities are not viewed as safe places, even by care teams (Stein, Beck, & Sherman, 2010). Given the context, LGBT elders fear mistreatment and neglect by institutions (Putney, Keary, Herbert, Krinsky, & Halmo, 2018) and expect discrimination (Dickson et al., 2022) especially transgender and nonbinary patients (Knockel & Flunker, 2021). LGBT older adults also reported worrying about the impact of caregivers' lack of training and qualifications to interact with LGBT individuals (Caceres et al., 2020). Many cite that they will have to go back into the closet to remain safe and avoid abuse or negligence (Jihanian, 2013; Wilson et al., 2018; Furlotte, Gladstone, Crosby & Fitzgerald, 2016) when staying out of the closet is tied to a sense of freedom, independence, and dignity (Wilson et al., 2018) as they age. Some also fear they are assumed straight (De Vries et al., 2022). They also worry about being invisible (Farchild, Carrino, & Ramirez, 1996; Fasullo, McIntosh, Buchholz, Ruppert, & Ailey, 2021) and suffering in silence (Wallace, 2019). Studies on LGBT elders in institutionalized care show elders focus on the quality of care they will receive if they are placed in a religious-based institution (Wilson et al., 2018; Houghton, 2020; Westwood, 2022) that repudiates LGBT individuals. Taken together, this has informed distinct fears and desires when it comes to anticipating long-term care needs.

In the past, studies on what LGBT elders desire in care find older adults just want to feel safe (Fredriksen-Goldsen & Satin, 2016; Gardner, de Vries, & Mockus, 2018), which in many cases means finding LGBT-friendly care (Brotman et al., 2007). Specifically, worries center on the inability to find a facility that will provide them care, or if they do find care, they fear that the quality of care will be compromised because of their sexuality (Stein et al., 2010).

Accompanying these fears, elders know what they would like to see when looking for quality long-term care options. At the highest level, LGBT individuals want legal protection from discrimination (Hoy-Ellis, Ator, Kerr, & Milford, 2016; Fredriksen-Goldsen, 2014). When looking at specific facilities, LGBT elders would like more LGBT-friendly options or LGBT-only facilities (Meyer & Choi, 2016; Buczak-Stec, Konig, Feddern & Hajek, 2023). LGBT elders want to know that the staff has LGBT cultural competency training (Arthur, 2015; Qureshi et al., 2019) and to see the staff demonstrate they are LGBT-friendly (Johnson, Jackson, Arnette, & Koffman, 2005) or LGBT themselves (Dickson et al., 2022), and they want more education to be offered to staff and administration (Hoy-Ellis et al., 2016; Furlotte et al., 2016, Fasullo et al., 2022). They would like to see LGBT inclusive material (Putney et al., 2018; SAGE, 2021), such as materials including rainbows, inclusive values in mission statements, or mentions of sensitivity training. This could be on advertisements, online postings, and human resources communications (Houghton, 2020; Gardner et al., 2014), indicating facilities have made an investment in understanding LGBT culture. Elders also suggest including material on intake forms that allow them to list a same-sex partner or spouse (Hafford-Letchfield, Simpson, Willis, & Almack, 2018).

Healthcare facilities have come a long way in providing care for LGBT individuals since this topic was first studied. Thirty years ago, providers were easily upset by knowing residents were engaged in same-gender sexual relationships (Fairchild, Cirrino, & Ramirez, 1996). By the 2010s, while the staff was found to be less supportive of gay and lesbian residents than their straight counterparts, there seemed to be greater support than before (Hinrichs & Vacha-Haase,

2010; Ahrendt, Sprankle, Kuka, & Mcpherson, 2017). Other work indicated support among staff for residents to disclose their sexuality (Villar, Serrat, Fabà, & Celdránm 2015). Additionally, more institutions began encouraging or requiring staff to go to training; much of the content, which previously focused on HIV/AIDS training (Hafford-Letchfield et al., 2018), has shifted to include more training on cultural understanding (Donaldson, Smith, & Parrish, 2017). A methodological drawback of many of the older studies is the focus on vignettes and self-reporting (Dickey, 2013), and to date there are no large-scale studies that this author is aware of. A study from 2016 (Garrison & Ibañez) showed that staff received less than 5 hours of training on LGBT individuals across four years.

As late as 2019 (Smith, Altman, Meeks, & Hinrichs, 2019) few staff had the chance to work with LGBT residents; as many as 40 percent of providers and staff had not interacted with known LGBT patients. However, when staff go to trainings, they report increased comfort with and knowledge of LGBT individuals, as well as increased ability to identify LGBT history, politics, and legal issues (Gendron et al., 2013; Donaldson et al., 2019).

The 2020s have seen cultural competency integrated into the curricula of nursing, medical, and social work programs. However, most undergraduate nursing programs have only about 2 hours of training across the entire program as of 2021 (Sherman et al., 2021). Similarly, medical schools are beginning to incorporate more training with the impetus often coming from students at schools like the University of Washington (Gibson et al., 2020). But medical educators call for more education as providers on average still receive only about 5 hours related to LGBT issues during their program unless they intentionally pursue more (Pregnall,

Churchwell, & Ehrenfeld, 2021). We know that while some studies have indicated various levels of support for patients, many facilities and staff report that they feel unprepared to care for LGBT patients (Ryan, Anarte, & Greenhalgh, 2022). Facilities know that more training and more inclusive material is necessary, but in some cases have opted not to include them due to repercussions from those who dislike it (Sussman et al., 2018), demonstrating that while the conversation has been started there is still work to do (Chaze et al., 2019).

Sociological Implications of Fear and Action

The above studies indicate that the perceived vulnerabilities of older LGBT individuals in medical settings motivate them to go to great lengths to find suitable long-term care (Burton, Lee, Waalen, & Gibbs, 2020). LGBT older adults' realities thus produce a set of actions in response to their fears. Elders who know about the possible risk of discrimination, even before they experience it, generate fears from these perceived risks. This fear, even without confirmation, guides their behaviors. LGBT elders' beliefs that they may be discriminated against are most important for interpreting their behaviors since their fears are real to them and, therefore, real in their consequences (Thomas & Thomas, 1928). For LGBT individuals, this means constructing their future through their particular institutionalized reality as discriminated and marginalized persons (Berger & Luckman, 1966). In response to the construction of this reality, elders make plans attempting to counteract negative and discriminatory outcomes. This paper describes how elders make efforts to research and find long-term care facilities that will provide affirming care for them when they cannot care for themselves and have no family or friends who can care for them. Their fears are abuse, poor quality of care, and neglect among

providers and in institutions (in-groups) and LGBT individuals (out-groups). institution. Thus, they actively seek LGBT-friendly institutions.

To extend this further, Robert Merton's 1948 essay "The Self-fulfilling Prophecy" states, "men respond not only to the objective features of a situation but also, and at times primarily, to the meaning a situation has for them." (Merton, 1948, p. 505) These objective features, or in the case of LGBT elders, fears of discrimination because of their identity and decentralization of that identity, may once have been subjective but now have realized consequences, as "the originally false conception come true." (Merton, 1948, p. 506)". For LGBT elders, the fear of discrimination is the prophecy they are protecting against.

The response to the perceived reality has consequences between "in-groups" and "out-groups," in this case, the providers and institutions (in-group) and LGBT individuals (out-group). This theory helps explain the behaviors of LGBT elders in response to their fears of discrimination as they age and the possible adverse outcomes. Merton goes on to say that the behavior of minority groups is in response to the majority group, and there is a "bisymmetrical prejudice" in which the "systemic condemnation of the out-grouper continues largely *irrespective of what he does* (p. 511)." Ultimately, as Merton demonstrates through an analysis of racial and ethnic prejudices of white Americans against Black Americans and non-Jewish Americans against Jewish Americans, "discrimination aimed at the outgroup is not a result of what the outgroup does but are rooted deep in the structure of our society." (Merton, 1948, p. 511)."

The outgroup of older LGBT individuals, is left with two defensive responses within this structure. The first is 'self-assertion,' which secures 'self-respect' and security by overachieving.

The second is 'self-effacement,' again out of the concern for safety, minimizing the visibility of the 'outgroup.' LGBT older adults' fears arise from stories and past discriminatory experiences and their reification in the institutions that seek to help older LGBT adults. Thus, the prophecy of discrimination leads older adults to choose a path of 'self-assertion' when planning for old age. By being proactive in research, coordinating with their care teams, and making appropriate decisions when choosing care options as far in advance as possible, they keep their dignity in the form of maintaining their sexual or gender identity and receiving affirming care. The other path wrought is of 'self-effacement,' in which case the elder, scared of discrimination, downplays their sexual orientation and ignores or hides their identity, hoping to remain undetected and thereby protected. This would be akin to wanting to go back into the closet, the act that I found was rare among participants, so in this study I focus on elders who choose the path of 'self-assertion.' LGBT older adults are potentially fated to mistreatment in old age regardless of their actions (in either case, self-effacement or self-assertion) the LGBT older adult could be the subject of discrimination from society's discriminatory structures, where 'phobias' dictate treatment, not the behavior of the older adult. Thus, there is the need for structural intervention, and this is where policy comes into play.

Data and Methods

This mixed-method study relies on 46 in-depth interviews with community-dwelling adults identifying as gay or lesbian over 50 in the Chicago area, which covered previous discriminatory experiences, fears around aging, and end of life care plans. I also pulled data from observations from a summer internship with an organization working to support the needs of

LGBT elders in Chicago, during which I planned and attended events relating to older LGBT adults finding the affirming and culturally competent care they need. And finally, I completed a preliminary survey of websites of Chicago's long-term care facility reviewing them for LGBT-friendliness and capacity to care for LGBT elders.

Interviews

Participants came from a nonprobability sample, recruited in two waves in the summer of 2019 and autumn of 2021. Participants were recruited from community centers, online announcements, and interpersonal or third-party interactions via Zoom.

Interviewees came from Chicago and the surrounding suburbs. Adults ranged in age from 57 to 87 years of age. The mean age for the participants at the time of the interview was 72. Fifteen identified as gay women or lesbians, and the remaining twenty-nine identified as gay men. Forty-five of the interviewees were cisgender, and one was transgender. Eight identified as Black or African American, three as Asian-American or Pacific Islander, two as Hispanic/Latinx, one as indigenous, and one unknown. The remaining thirty participants identified as white. Two were HIV positive. This sample was highly educated, all but four had some college education, and many received graduate degrees and were very successful in life. However, many had fallen into poverty in older age. A little less than half the sample felt poor, while the remaining felt very privileged. More than thirty interviewees participated in LGBT events, advocacy, or volunteering to stay connected.

Interviews were mostly in-person, adhering to Covid protocols and restrictions, including masking, with a few occurring over the phone or on Zoom. The interviews lasted about an hour

each. Each interview was semi-structured, touching on life course events such as recognizing their sexual identity, coming out or not, and finding a partner. The brief life history focused on experiences with discrimination, including violence, police interactions, health care interactions, family relationships, and similar experiences, paying special attention to their view of their social support. A second critical part of the interview covered health and health care, including what decisions have been made for aging, self-rated health, and experiences with health care professionals given their sexuality. The final focus was on aging and planning, which included questions on downsizing, making wills, naming executors of wills, advanced directives, and plans for long-term care or other types of care.

Participant Observation

During the summer of 2021, I conducted over 300 hours of participant observation for three months. Time was spent facilitating discussion groups, talking with elders who attended the weekly lunch programming, finding services for individuals on a case-by-case basis, and helping elders with whom I developed deeper bonds. During the observation sessions, I would keep shorthand notes to identify events and use these to detail longer memos written after each day. The themes reoccurring in these observations informed the interviews with community elders, some of whom attended the events at the center. Eighty of these hours were accumulated preparing for a resource fair for LGBT elders, called the “4th Quarter of Life,” specifically addressing plans for the end of life. The afternoon included a keynote address by the director of senior services and a presentation from a local organization specializing in connecting LGBT adults to resources. Lunch was served during the keynote and followed by a tabling of a dozen or

so vendors. During this event, I was able to connect with many of the attendees to understand their motivation for coming and spent time listening to, talking with, and observing the attendees of the conversations with vendors. Finally, I was able to sit with a few vendors taking notes on their perspectives and motives.

Survey

I chose to use online websites for three reasons. The first is that during the pandemic information about where to go was only available online. Second, as will be demonstrated in the ethnographic data, elders relied on online resources to evaluate institutions. As more online information has become available and there are ways to rate and evaluate institutions, consumers have responded in kind. In 2008, a 5-star rating system was developed by the Centers for Medicare and Medicaid (CMMS) services for nursing homes based on health inspection surveys, quality measures, and staffing information, most easily accessed online. Studies have evaluated the response, determining that, in some cases, it has helped increase the performance of care (Kim, 2016) and impacted the way consumers evaluate facilities (Konetzka & Perrailion, 2016). In addition, to these ratings, social media ratings have been a helpful way for the consumer to gain information and evaluate quality (Li, Cai, & Wang, 2019; Li, Lu, Xiaoyuan, & Feng, 2021). Quality reporting matters to consumers and rating responses are likely to increase (Perrailion, Konetzka, & Werner, 2019). Thus, this study uses a preliminary review of websites to assess LGBT friendliness. A dataset of long-term care facilities was compiled from November 2021 to February 2022. I started with a publicly available list of institutions listing LGBT-friendly senior long-term care and supported living guides from the Center on Halsted, a community center

dedicated to the health and well-being of the LGBT population of Chicago. This list was curated by the Center on Halsted's Senior Service team, which included information on 14 institutions. In addition, I accumulated organizations through the Long-Term Care Ombudsman Program, Illinois Department of Public Health, and *U.S. News*, extracting corporate names, addresses, and types of services offered. While this data is preliminary it is a starting point for other researchers to validate and expand on.

Analysis

Interviews and Observations

I analyzed interviews using inductive data analysis with theories and interpretation from the data (Saldana, 2016). NVivo 12, a qualitative software, was used to store and code data. I first listened to, read each transcript, and consulted memos written after each interview to jog my memory about salient themes noted at the time. I then took several passes at the data, gathering patterns and categories in the transcripts, making sure to go back to recode interviews when new categories were found. I conducted line-by-line coding for themes specifically related to aging and planning for long-term care. Categories were collated and connected by concepts aided by reflections and memos on each topic. A similar approach was used to synthesize findings from the memos and notes from field observations.

Survey

I verified the extracted data using a two-step process. First, I crosschecked the available data with existing addresses to confirm sites were operational and not double-listed due to a change in ownership since their listing. Second, I verified information by visiting each

institution's website. Institutions had to have an online presence since the goal was to evaluate online marketing material. While more up-to-date data might be available or verifiable through phone calls or site visits, this search aimed to replicate an initial investigation by a consumer and was focused on online marketing material and conducted during the height of the COVID-19 Omicron outbreak in 2021, limiting the opportunity for in-person visits. The inclusion criteria are being listed at a verifiable address within the City of Chicago, serving older adults as their main population rather than special needs adults or psychiatric patients, and offering long-term care services.

The initial list included more than 150 programs; however, seventy-three institutions were removed for catering to populations other than older adults. I removed twenty-eight institutions focused on adults with disabilities. Another eight institutions focused on mental health and psychological rehabilitation. Three institutions listed did not provide long-term care. Twenty-five were removed because they merged with other organizations or had changed names since the listing was made. Four were removed because they had permanently closed, and six had no verifiable information. There were eighty remaining verifiable institutions.

Once I verified institutions, I collected data to measure the quality of service and care available based on three categories that general consumers use to distinguish and choose a long-term care option. These included location, quality of care, and quality of life. But for the purpose of this study, I focused on the range and quality of LGBT-specific marketing.

I assessed how and if the institution marketed toward the LGBT population through a virtual assessment of information focused on LGBT marketing material. Assessments included

looking for inclusive language such as the mention of sexuality or gender identity, LGBT pride, or other related terms; images of same-sex couples; mention of cultural competency or training; naming the Human Rights Campaign or showing the stamp; mention or rating of the SAGE Longterm Care Index (which is an established system to assess institutions based on the needs of LGBT elders, including adopting culturally competent care); an image of the Rainbow flag or the Progress Flag; and other inclusive images including any type of flag, rainbow colors, or queer symbols. This material was then categorized into *passive* and *active* material. *Passive* material is defined as material that can be duplicated without making institutional investments. Examples of *passive* material are a nondiscrimination statement, including sexuality and/or gender identity, the inclusion of an HRC stamp, or a rainbow/progress flag. *Active* material has references to cultural competency training, an emphasis on LGBT individuals or celebration, intentional placement of same-sex couples, noting the SAGE LTC index, and HRC LTC index (though none were on this list) or inclusive language specifically naming the LGBT community. *Active* materials reflect an institution's commitment and investment in equitable treatment for LGBT patients.

Findings

Fear

Over and over in my interviews and ethnographic work, older adults expressed their fear of aging and being discriminated against in a facility because of their sexuality and not having the agency to protect themselves. Their fear spawned from stories they heard or experiences as an 'out-group' receiving mistreatment or discrimination from the 'in-group'. One of the most

feared fates was being forced to go into a nursing home. I got to know Elma, a 77-year-old white lesbian, through my ethnographic work. She was one of the attendees of the 'The Fourth Quarter.' Her conversation with me best illustrated the imagined fear older adults were creating when she said that people she knew from her community apartment building were terrified.

I don't know whether that is true of people in general, I think so, but I think it is more true of people in the gay community. Here [at this apartment building] because we're especially fortunate to have it be gay-friendly. Not completely, but we're concerned about having to go back into the atmosphere of a nursing home-type situation related. One of the social workers tried to have a program with people visiting [the facility], for instance, from here. But it failed because people were afraid. [They said,] "Don't send somebody who asks about being gay, don't have them bring me literature that is gay." It turned out the people who had been out of the closet for years were being forced back in because of their environment in that quote-unquote nursing home situation. I think people are really reluctant to give any concept that they've got to start looking at those things.

Elma pointed out that it was not just about being 'gay;' residents in a long-term care facility feared having gay visitors or materials because it would make them targets. It was stories like this, though not directly experienced by Elma, that informed how she and others like her conceptualized aging and drove their fears. These reservations from nursing home residents in the program then leaked back to the community members volunteering and reinforced the idea of the nursing home being an unsafe place. Stories like this illustrated the fear among older adults and were often followed by statements about how or why they were preparing for an LGBT-friendly institution, demonstrating how their imagined fear was shaping their current actions.

Interviewees talked about the stories that informed their decisions for avoiding discrimination, which included avoiding nursing homes, and what they might expect if they ended up there. For example, in my conversation with Theo, 87, and Wally, 81 – both white and

lifelong gay activists – they both mentioned trying to avoid long-term care despite worsening health. Wally was still sharp but had increased difficulty navigating the crowded rowhouse. His younger partner, too, was struggling with increasing heart health issues. Still, both were ingrained in the activist culture and aware of many of the issues in wider Chicago and thus were worried about going into a care facility, and envisioned how they would respond. They let me know they would speak their mind, but they were still frightened.

Theo: I have always been a little bit nasty and aggressive, and I've read about older gay people having problems in nursing homes and whatever. I won't have a problem. They will have a problem. They will have a problem with it. I know how to throw a shit fit in an instant.

Wally: They'll expel you.

Theo: I will.

Their initial response reflected their awareness of the milieu of fear and mistreatment of gay elders in facilities. With further probing, it was clear that they felt they needed to act and respond to this anxiety. Wally continued:

We always wanted some kind of protection because we know how far outside, we are of the mainstream, and so you've got to protect yourself. You've got to have a baseball bat, or you've got to have a piece of paper. And so, one or the other is going to protect you.

The meaning of this for Wally was that you need to protect yourself in some way from physical harm that could come to you as an LGBT older adult in a nursing home; thus, you needed a bat you might keep by a bed at night to protect yourself from an unwanted home intruder. Or, more realistically, for him, he needed a piece of paper that documented his relationship with his partner and outlined a care plan that respected him as an LGBT aging adult. Wally and Theo described the numerous times they had redone their marriage papers and

documents that would protect their relationship and each other as they aged. Despite their lifelong commitment to standing up to authority, repeatedly stating they were untouchable iconoclasts, they felt compelled to prepare for anything that could happen to them as they thought about long-term care placement and how they would be treated. In the end, by giving time to planning and documentation, the two men conceded their fear. Throughout my interviews, again and again, interviewees cited articles they had read, stories that they had heard, or experiences with loved ones which reinforced feelings of dread about going into a home and interacting with providers who did not know they were gay, lesbian, or transgender. In this way, the experience of discrimination at the hands of the 'in-group' fueled their anxiety, and thus drove informed their actions for 'self-assertion' and protection.

Action

To prevent discrimination from being realized, many elders chose 'self-assertion' through education and action. Some shored up legal documents, others planned to age at home. To do this they often turned to LGBT organizations, such as the one where I worked during the summer helping elders find the resources they needed, including accepting institutions. During my summer work with the senior services, a significant part of my role was planning a resource fair dubbed "The Fourth Quarter." Consistent with the institution's mission and Senior Services goals, this event helps facilitate the health and well-being of LGBT elders (in particular) by reaching elders interested in or in need of aging and end-of-life resources. The event included a coffee hour, a resource fair, and a keynote speaker event with a PowerPoint talk given over lunch. The attendance was around 60 to 70 people, about eighty percent of whom were first-time contacts

for the organization, and questions and comments during and after demonstrated their deep anxiety rooted in living as a member of an ‘outgroup’ and the need for this type of information to help them quell fear and resolve uneasiness.

During this event I helped with the administrative work, but I was also able to check many folks in to the event and ask them what brought them there. Many explained that they had heard too many negative stories from her LGBT friends and networks that she was convinced it was time to start planning. One Black lesbian, Opal, in her 70s, referenced the story of Marsha Wetzel, a lesbian older adult who was harassed and mistreated when she entered a care facility in the North Suburbs of Chicago. During this event, Wetzel’s story became shorthand for their motivation and was also used as a cautionary tale and as a way to drive 'buy-in' and engagement from the attendees by the social services staff. She also noted that this was a religious institution, and what scared Opal most was that she was hard pressed to find an affordable institution that was not religious—specifically Catholic. The social service providers and providers at the event reflected back to the elders their fears as a way to motivate them to take action on an imagined future, which the providers and attendees knew could be realized without taking protective action.

To find LGBT-friendly providers for long-term care, elders were told to ask a lot of questions, research, interview institutions, and build community. They were told to ask their family of choice, friends, and acquaintances where would be 'safe' for them or reach out to social service providers specializing in LGBT care. They were provided with a list of online LGBT-friendly databases and told to ensure each institution was well-rated among mainstream

organizations. If that was not enough to manage, the elders were encouraged to be open and upfront about what they wanted from a care facility and conduct visits and interviews, including asking questions about LGBT issues, but were warned out of an abundance of caution that they should bring someone with them. During the event, the elders were encouraged to use their networks as well as online resources to find places for care that were LGBT friendly. The Human Rights LTC index was cited as a source along with Sage. The presenters suggested beginning the research process through online forums, using social media and website databases, and looking on the websites themselves. They were coached to keep an eye out for inclusive language that referred to the LGBT community, rainbow flags, and other non-discrimination statements. The presentation and guidance from social services, much like the elders, assumed a negative outcome because of the potential for discrimination and stores like Marsha Wetzel's, and guided them to plan for the worst case scenario. Elma had attended the "4th Quarter" event and the presentation, and I was sitting with her at the table. She turned to me, with her hands full of handouts and notebook with notes, and said, "This is really overwhelming, I'm glad I got started on this." Earlier in an interview, Elma had said:

I started talking to [a senior service director] and talking to their social workers about care and where the next step is, assisted living, and looking into those sorts of things. They helped me find places to look at and research things for me.

Elma told me she knew how to do internet research and use databases, and could check her list with the social workers. But she was one of a few who could ask for help. Elma said she did not have much luck in what she was looking for with cursory research that she was taking more seriously, especially after the 4th Quarter event. However, she had the social services in her

building to turn back to. Given the fears that LGBT older adults expressed about going into a facility and how they were being advised to search for one, I wondered what they would find.

Searching

I attempted to replicate the search of LGBT elders in finding friendly long-term care. I followed the recommendations based on the 4th quarter of life and fears expressed by the elders I worked with. I found there is a clear disparity in the distribution of institutions across Cook County. Most of the facilities have Northside addresses in wealthier neighborhoods. Neighborhoods between Edgewater and North Halsted near the Lake on the Northside, known for being friendly to LGBT populations and predominantly white, have fifteen institutions. The West and South Sides of Chicago have thirty-four institutions with predominantly Hispanic and Black populations. I found that of the 80 long-term care facilities included in this study, only twenty-three facilities (28%) engaged with LGBT older adults.

Most did so with the use of passive material, which included easily replicable, low-stakes material like images and boilerplate nondiscrimination statements. Twenty-two institutions acknowledged LGBT individuals by including a small flag or an Equal Housing symbol (which includes sexuality and gender identity as a protected class in Illinois, but not at the Federal level); fifteen were large conglomerates, where website templates were used for each home, and the symbol was included at the bottom of the page along with the International Symbol of Access. The others were independent. This represents 35% of the market share in long-term care in Chicago. Only one institution included the image of the Pride Flag in addition to the Equal Housing symbol. No institution included additional imagery. Although many organizations

lacked identifying information in support of the LGBT affirming care, there is latitude imagination of poor quality of care for elders who are not reassured by positive signaling they are looking for.

Four institutions had inclusive language in the nondiscrimination statement under sex and gender or, in one case, with inclusive language that explicitly stated they are rooted in Quaker tenets that encourage diversity in all its facets. Not a single website included an image of same-sex couples. While websites included diverse images of straight people, they had no images of any gay people. In addition, only two websites included active language about the LGBT community. The website of the institution based on Quakerism noted the LGBT community as a cultural highlight:

Between its old-world architecture, bars and restaurants, and bustling main street, Andersonville is a charming urban neighborhood. You'll sense the vibrant community spirit of a diverse and LGBT-friendly culture.

A link at another institution, part of the Symphony Care Network and in the same area in the Northside of Chicago, led to a blog about how the organization recognized pride. The post, dated July 11, 2019, focused specifically on the Lincoln Park site and its partnership with Howard Brown, a nonprofit healthcare organization. The publication did note the organization had much more work to do. During the search process, again the elders' fears are reinforced because they cannot find signs of supportive care they desire to feel safe.

Finally, a single institution included cultural competency training through the mention of the SAGE Long-Term Care Equality Index (an established rating system and promoter of the needs of older LGBT adults). The Admiral at the Lake is the only one to include active language

alongside passive indicators of their commitment to serving the LGBT community, which may help alleviate the fears and anxieties of potential residents. Inclusive language on their Community Life page mentions, "The Admiral at the Lake is pleased to announce that our staff recently completed the SAGECare training program on creating fully LGBT-inclusive services in the senior living community." According to a press release on the website dated August 21, 2021, 80% of the staff and executives underwent cultural competency training, earning 'platinum status' from SAGECare. This is an hour-long training webinar for staff and a 4-hour in-person training for executives. None of the institutions were on the HRC's LTC index. There are downsides, though, to this active engagement. The Admiral's monthly rate is more expensive than most of Chicago's LTCs. Additionally, the Admiral, an expensive and exclusive institution, only had 93 rooms, whereas many other facilities had between 150 and 300 beds. The Admiral represents less than 1% of the market share, yet it is the standard that most LGBT older adults seek in long-term care when planning ways to navigate what feels safe. Thus, while elders in the 'outgroup' are taking plans to protect themselves from mistreatment and discrimination at the hands of providers in the 'ingroup' their fears are reinforced when their imagined realities come to fruition in the inability to locate institutions that will provide the type of care that will keep them safe.

Discussion

Circulating stories and institutional discussion create anxiety for LGBT older adults (Putney et al., 2018; Fredriksen-Goldsen & Satin, 2016; Gardner, de Vries, & Mockus, 2018) who fear negligence or assault from providers or fellow residents (Jihanian, 2013; Wilson et al., 2018; Furlotte, Gladstone, Crosby & Fitzgerald, 2016; Houghton, 2020; Westwood, 2022), who

represent Merton's (1948) 'ingroup'. Elders fear inability to access care because of their sexuality or gender identity (Dickson et al., 2022; Knockel & Flunker, 2021). The constructed reality of discrimination (Dickson et al., 2022), disrespect (Stein et al., 2010) or dismantling (Farchild, Carrino, & Ramirez, 1996; Fasullo, McIntosh, Buchholz, Ruppard, & Ailey, 2021; Wallace, 2019) of their sexuality means gay and lesbian older adults want to protect themselves. LGBT older adults find themselves in one of Merton's theorized 'outgroups' at the mercy of the ingroup with two behavior routes to protect themselves, one of self-assertion and one of self-effacement when it comes to preparing for making advanced care plans. They either attempt to work within the standards and expectations of the ingroup by overplanning to ensure they are cared for, and/or their wishes are respected upon their demise. To prevent negative outcomes, they want to find LGBT friendly care options (Meyer & Choi, 2016; Buczak-Stec, Konig, Feddern & Hajek, 2023) with cultural competence training and education (Arthur, 2015; Qureshi et al., 2019) that is signified by inclusive materials when they begin their search (Putney et al., 2018; SAGE, 2021). Yet, untold numbers of LGBT older adults struggle to find what they want because planning is too daunting, or they cannot find the resources to aid their search. As seen in detail with Elma, Wally, and Theo, stories around them have influenced their decision to begin thinking about care and planning. In each case, they explicitly state they expect discrimination and therefore are taking action to find suitable long-term care. Yet as illustrated above, even for Elma who had more resources and support than most, the process was still difficult.

Additionally, the 4th Quarter of Life event for many in the audience confirmed the fears that were driving them there in the first place. The presentation by experts in the field

unknowingly framed that LGBT people (the outgroup) face a unique set of concerns in old age and therefore need to identify what is important to them and be prepared ahead of time, because society (the ingroup) is not welcoming. The fear bringing elders to this event was reified through professional commentary and advice, whose strategies for planning aging and long-term care solutions were underpinned by the assumption that institutions were not safe, open, or inclusive of LGBT older adults. Therefore, the only response to the elders' fear, realized through the absence of acceptance of institutions and the solutions provided by social services, was to validate the fear and push for overplanning. Social workers at this organization were mostly reinforcing fears they heard from their concerned LGBT stakeholders; whether they have observed discrimination firsthand or not, social services are mirroring the fears back to concerned adults, but in doing so, also acting as the agent concertizing the abstraction of unrealized fear.

LGBT Long-term Care

Based on the findings from this research, it's important to note the impact of the long-term care location and environment in Chicago for LGBT individuals. Access to high quality care remains one of the biggest concerns for the LGBT community (Fredriksen-Goldsen & Satin, 2016; Gardner et al., 2018). In addition to issues around access to quality care, LGBT people fear going into long-term care facilities and seek LGBT-friendly facilities (Brotman et al., 2007). They worry about receiving the same quality of medical care and quality of life, fearing verbal and physical abuse or even denial of care (Justice in Aging, 2015; Brotman et al., 2007). They worry about being placed in religious institutions (Wilson et al., 2018; Houghton, 2020). Worst

of all, many fear going back into the closet (Jihanian, 2013; Wilson et al., 2018; Furlotte et al., 2016). As such, they look for places that are LGBT friendly through signaling of images, out staff, inclusive language, or mention of cultural competency training. As the results of this study show, less than one-third of the institutions in Chicago indicate that they consider the needs of LGBT older adults. Of the twenty-three institutions that do engage with LGBT individuals, only two actively recognize the LGBT community, and one that refers to the training of staff and inclusion of LGBT elders in their community. While the current numbers are dismal, long-term care facilities have plenty of opportunities to engage and market to elders, and there are possibilities for better policies to support this burgeoning community and their needs.

Meeting the Need

Based on the expression of need by the elders themselves, especially for cultural competency training (Arthur, 2015; Qureshi et al., 2019) and the lack thereof (Garrison & Ibañez, 2016), even in healthcare training (Gibson et al, 2020; Sherman et al., 2021; Pregnall, Churchwell, & Ehrenfeld, 2021), there is a missed opportunity that could also catalyze change (Hafford-Letchfield et al., 2018; Gendron et al., 2013). Though little literature has covered specifics, there seems to be a clear distinction between how elders in general evaluate long-term care and how LGBT people think about it. Many elders use online information for their initial evaluations (Li, Cai, & Wang, 2019; Konetzka & Perrailion, 2016) of LTC facilities; this was especially true during the height of the COVID-19 pandemic. This requires that facilities indicate how they engage with or think about LGBT individuals and, in the best-case scenario, indicate the level of cultural competency training their staff has. LGBT elders are looking for

quality assurance (Gardner et al., 2014). Based on the desires of LGBT individuals, this would mean using places like the Admiral as a model for other institutions to provide active, inclusive language and notation of competency training, in addition to passive marketing that includes images of rainbows or the HRC symbol.

Additionally, quality of life for LGBT people means socializing with other residents without fearing name-calling, exclusion, or battery because of their sexuality or gender identity (Justice in Aging, 2015). Additionally, it means being able to be out (Wilson et al., 2018; Fasullo et al., 2021). It means staying in the same room with their partner or spouse (Brotman, Ryan, & Cormier, 2003). This means there needs to be a culture of inclusion driven at the administrative level that permeates the caregivers and residents (Bell et al. 2010.) This should be indicated by inclusive statements and language visible in high-traffic website sections rather than relegated to a link at the bottom of a page. It should include expanding current nondiscrimination statements, making more inclusive materials such as images of residents that show all types of relationships, including same-gendered couples, and making it a priority to demonstrate cultural competency for all staff and administrators.

Yet, based on the online survey of long-term care facilities in Chicago, few facilities are inclusive, and only a handful meet the mark of what is most important for LGBT individuals. I found that twenty-three institutions in Chicago do engage, but to address the issues important to LGBT elders, we should see more institutions having active language. With an increasing percentage of people identifying as LGBT and nearly 150,000 LGBT older adults over the age of 50 in Chicago alone, there is a need for this, especially since we know that LGBT elders are

more likely to need long-term care (Hiedemann & Broddff, 2013). To do that means stepping beyond virtue signaling by actualizing change and eliminating potential barriers. This includes not only making updates to websites, but also advocating for policies at all levels of government and addressing internal changes. Policy is needed to ensure that elders have protections in LTC because currently, institutions are not taking the initiative to confirm and advertise those protections on their own.

Intervention

Overcoming barriers and protecting LGBT individuals requires more than institutions marketing toward LGBT individuals. There should be protections for LGBT individuals in housing, employment, and healthcare at the federal level. This means creating and enforcing comprehensive nondiscrimination protections. The federal government should continue to include LGBT older adults under the Older Americans Act, which helps fund and deliver services to LGBT older adults. The bill is renewed every four years and should continue to include LGBT populations as a priority. Further, additional policies should be worked through the legislature or executive branches to protect LGBT older adults from challenges to bills that limit the ability of conscientious objectors to avoid providing care for LGBT elders based on religious exceptions.

Illinois led the way in designating older adults as a group with the greatest social needs in 2019, as part of its states' rights under the Older Americans Act of 1965, providing funding, services, and research for older Americans. Additionally, due to advocacy across the state, the Illinois Legislature passed SB 3490, which created the Illinois Commission on LGBT Aging to study and report on the needs of LGBT elders across the state, with the input of stakeholders,

providers, and advocates. The bill provides an LGBT Older Adult advocate to work with the Director of the Illinois Department of Aging on LGBT needs. Finally, enacting solutions for LGBT elders requires providers that receive state funds to complete LGBT competency training. While this is the beginning, more targeted planning should be sought out. In addition, the state should adopt a Bill of Rights to protect LGBT older adults from bullying and harassment, guaranteeing the quality of care and requiring and enforcing cultural competency training. Illinois should continue targeted programming and outreach supported by data collection to meet LGBT elders' needs.

Private institutions play a part in this as well. As they continue to look at who their clients might be in the future, they should consider meeting the needs of older LGBT adults, especially those in areas with higher LGBT populations and more competitive markets. Because information is more salient in these markets with higher needs and greater competition like Chicago, it would behoove LTCs to require training as elders look to see which institutions are indexed in reports like Sage's Long-Term Care Equality Index. To begin, institutions could engage with organizations like SAGE, which advocate for LGBT rights, and partner with the Human Rights Campaign Foundation to work towards standards set by the Long-Term Care Equality Index. At the local level, they could also partner with organizations like AARP Illinois, Center on Halsted, AIDS Foundation of Chicago, Affinity Community Services, Center for Disability and Elder Law, Howard Brown Health, and The Care Plan, which are resources for the LGBT community.

Limitations and Future Directions

This research has several important limitations in terms of the interview and ethnographic work. First, the data presented here is from a subset of individuals in the Chicago area. Second, because of the location-based nature of the data, I cannot make extrapolations to other areas. The area of research on older adult health and end-of-life care will continue to increase as we see the Baby Boomer generation age and reach later life. Though Chicago is a liberal bastion in the Midwest, and Illinois and the city have many protections for LGBT folks, it is striking that in such a liberal environment, where protections are in place, elders still have these fears. Thus, future research may help determine the broader landscape of LGBT older adults' fears around aging and their responses. Work in geographic regions beyond Chicago should be pursued. Comparing it to other urban areas would be useful. Still, the voices of those in suburban and rural areas with less political and social support for older adults need attention. Finally, more work should look at the experience of going through the process of finding a home or large purposeful sample of elders in long-term care environments.

Regarding the online survey, despite considerable insights of this study, there are notable limitations. First, the results were gathered using lists from a limited set of resources, potentially missing institutions that were not included in these areas. If institutions were missed, this could give an inaccurate representation of the institutions that market towards LGBT individuals through their websites. The inclusion of other institutions could change the results of accessibility, cost, and location of long-term care institutions that are LGBT-friendly. Further, despite a rigorous validation and classification process, some institutions may be misclassified or missed by the researcher. The study was based on long-term care facilities. Still, it excluded

other institutions that could provide care for the same population, such as assisted living, retirement homes, etc. Future work should consider a more expansive definition of care.

Though this research is a starting point that evaluates online marketing of LGBT friendliness, this is only one factor of marketing. Additional factors could go into decision-making for LGBT elders in Chicago. This could include different avenues of collecting information, such as other online resources that were not investigated, like Google Ads, reviews on social media, and other platforms. Other marketing could include hardcopy materials such as brochures, flyers, and handouts. In addition, potential consumers could have learned about LGBT friendliness through their medical providers, friends, and family rather than beginning with online research. Future work should consider other material and information gathering methods.

Similarly, this study assumed a connection between previous studies and the needs and wants of LGBT elders in Chicago; however, the needs and wants of this population may be different from those in previous research. Future research should look into how LGBT elders make decisions about long-term care. Though there seem to be differences in the considerations of straight and LGBT older adults, additional work may look explicitly at how those decision-making processes differ from straight populations. Finally, a note must be made that only one individual was overseeing this process, and though there was input and review from experts in the field and professional advising it is possible that bias could impact the findings of the survey and its analysis.

Conclusion

LGBT elders face several barriers to accessing long-term care that will meet their needs as they age and face a unique barrier of needing care that is LGBT-friendly and competent. There are several challenges to their safety and quality of care in the current climate. LGBT elders fear being out because it could lead to a lesser quality of care by staff, discrimination, abuse, and denial of care. But institutionalization could also lead to low quality of life because of separation from a partner, harassment or abuse by other residents, potential isolation, and psychological distress. Studies indicate that providers lack training, do not feel prepared to care for LGBT elders, and fear for the safety of patients that are LGBT. Facing these fears, LGBT older adults seek LGBT-friendly care through the marketing of long-term care facilities.

Despite the need for LGBT-friendly care, many institutions in competitive markets like Chicago are not engaging with the growing and aging LGBT population. Only 1 of 80 institutions in Chicago market themselves on their website as LGBT-friendly with a high level of LGBT cultural competency training. This leaves a huge gap to be filled by marketing in Chicago long-term care institutions. We know that online material is used in the process of informing long-term care options and that for LGBT people, LGBT friendliness, inclusivity, and training of staff and administration matters. This differs from the priorities of the overall population, which relies more on location, qualitative measures of care and life, as well as the cost and outcomes of care.

Finally, while changing marketing to this population is part of the solution to meeting the demand, protecting LGBT older adults through federal, state, and local legislation is also

required. Providing funding for programs for LGBT elders, continuing to collect data and measure the delivery of programs, making LGBT elders a protected class, and mandating and enforcing cultural competency training for state and federally funded institutions would help protect this vulnerable group.

Chapter Four

UNCOVERING THE ROLE OF SEXUALITY IN SOCIAL NETWORKS AMONG OLDER ADULTS: A QUALITATIVE STUDY ON SEXUALITY AND AGING

Introduction

In December of 2022, the *New York Times* published an article, "Who Will Care for 'Kinless' Seniors?", that investigated the aging process of the kinless.ⁱ The article hints that some seniors are more at risk of depleted networks; however, one group not mentioned was LGBT elders, whose small social networks can have negative ramifications for health and aging. LGBT elders are already known to face health inequities (Fredriksen-Goldsen, 2019). They also have smaller, less dense social networks than those of their straight, cisgender counterparts (Hsieh & Wong, 2020). LGBT elders are less likely to have partners (Erosheva et al., 2016; Fredriksen-Goldsen et al., 2013) or a biological family (Croghan et al., 2014). As a result, older LGBT adults turn to their 'chosen family,' friends, or more distant relations when they need support (Breder & Bockting, 2022). This study of how LGBT elders decide who in their social network they can rely on for support for health and aging complicates traditional views of strong versus weak ties (Granovetter, 1973; 1983). It builds on the work of Mario Small (2017) suggesting strong and weak ties are not easily delineated and may lack analytical power for understanding individuals' social networks.

In conventional studies of weak versus strong ties, strong ties are thought to consist of social and emotional support (Wellman, 1981), mostly close familial and tight friendship bonds, to be called upon when an individual is in a vulnerable position, such as dealing with health

issues around aging. Weak ties are more transactional, conveying information between groups, and involve more casual friends and acquaintances (Granovetter, 1973). Mario Small, in his book *Someone To Talk To* (2017), argues that weaker ties can be relied on for emotional support, usually thought to derive from strong ties. In this reframing, Small calls for a reexamination of strong versus weak ties and asks if how people think about and turn to social networks is more fluid and contextual than previously thought. While Small studied graduate students, who, as young people, may have more tie variation, similar patterns of relying on weak networks may be visible and important for other populations. As LGBT elders consider who they can turn to as they age for important matters of health and aging, they may be less able than cisgender heterosexuals to turn to strong ties. Rather than depending on strong ties like children and spouses, LGBT elders look to further dispersed circles of ties of relatives, friends, and acquaintances (Antonucci, Ajrouch, & Birditt, 2014) because they can better fulfill needs in this context, thus obscuring the line between the function of strong and weak ties.

In this paper, I ask how sexuality impacts how older adults rely on their social networks to manage health related aging issues. To do so, I analyze 80 interviews and three months of participant observation with older adults over 50 using the lens strong and weak ties as well as implications for inequalities. I find that some older adults, especially LGBT ones, cannot rely on family; in the case of LGBT elders, this occurs because of strained relationships and stigma related to their sexuality. In comparison to straight adults, other strong ties do not exist because of discrimination or the prohibition on marriage that still existed for LGBT elders when they were younger. Instead, it makes sense for LGBT elders to turn to those who accept their sexuality

and understand the implications for aging. Those they know they can trust are often distant ties, who are the most logical choice for that role despite falling further down on the spectrum of strength of tie. In the end, I argue that while traditionally strong familial ties help many straight older adults age, for LGBT elders social networks cannot be easily defined as strong and weak nor have clear functional differences. Thus, I demonstrate the limits of a dichotomy of strong and weak ties and the theoretical limits to their use in the context of aging.

Literature Review

Social Networks

Social networks are traditionally defined as friends, family members, co-workers, acquaintances, and other relationships between individuals (Fischer, 1982; Simmel, 1950; Wellman, 1979), and the emphasis on the difference between strong and weak ties (Granovetter, 1973). Each type of tie offered distinct benefits: strong ties were a source of accessible, intimate emotional support (Wellman, 1981) during vulnerable times (Granovetter, 1973; Marsden & Campbell, 1984), and weak ties provided a wealth of information or connectors (Granovetter, 1983). Networks beyond strong ones could help span boundaries (Burt, 2004, Freeman, 2004), thereby providing more resources to the individual. These connections and relationships helped build social support via more diverse networks (Erickson, 2003; Granovetter, 1973). Studies (Krackhardt, 1992) also challenged Granovetter's definition of strong ties as a linear relationship comprised of a function of time and the reciprocity of emotion, intimacy, and services. Mario Small continues to dismantle some of the previously established literature on definition and function of strong ties. In his book *Someone to Talk to*, Small (2017) argues that how an

individual relies on their network is entirely situational. He argues that in practice, how the graduate students he observes choose who to rely on depends on a couple of factors. First, building on other sociological studies, sometimes relationships are complex, resulting in incompatible expectations (Blau, 1986), and thus an individual will depend on the entire network for support and can derive "sustenance from anywhere in their stream" (Small, p. 158). In other words, individuals can draw from anywhere in their network for support, if the strong ties are not a match for the individual's needs. For example, LGBT elders' family members reticent about their identity cannot be trusted to make supportive decisions on behalf of the elder. Second, Small argues that the strength and closeness of the tie are less important than the ability to relate to the individual under certain circumstances, e.g., a graduate student in an advanced degree program. Or in this paper, sharing or accepting a sexual identity. Most relatedly, deciding who to rely with decisions involves the utility that ties have for those particular topics (Perry & Pescosolido, 2010). LGBT elders seeking culturally competent care can only derive this from a limited number of resources that provide LGBT-friendly services. While Small challenges strong and weak ties by arguing ties do not always operate as theorized, it should also be considered that ties sometimes fail as a tool for sociological analysis.

Social Networks and Older Adult Health

Given all of this, it is important to recognize that there is an entire field of studies dedicated to the importance of social networks in old. Older men tend to have wider networks, while women have smaller familial based networks (Ajrouch, Blandon, & Antonucci, 2005). Older heterosexual adults gain social networks from community engagement retirement can lead

to a shrinking of social networks (Cornwell, Laumann, & Schum, 2008). People of color and immigrant elders also experience social networks differently than white Americans. For example, compared to their white counterparts, Black women are particularly vulnerable in old age (Umberson et. al, 2017; Verdery and Margolis, 2017). Social networks are critical components of aging as they provide a resource for health benefits, and those who have fewer social networks may have to depend on weaker ties as they age. Those who feel they have larger social networks and a community they can rely on have better overall self-rated mental and physical health (Hawkley, Kozloski, & Wong, 2017; Cornwell & Waite, 2009). Loneliness, from smaller networks and lack of support, is particularly damaging for older adults associated with chronic health, disability (Hawkley, Kozloski, & Wong 2017), depressive symptoms, mortality (Cornwell & Waite, 2009), and cognitive decline (Kotwal et al., 2016). Yet benefits differ by race, socioeconomic status, and gender; for example, marriage, especially a healthy one, is beneficial but benefits men more than women (Cornwell & Waite, 2009; Waite & Das, 2009). Men experiencing cognitive decline in one study reported more social support from their networks than women also experiencing cognitive decline (Kotwal et al., 2016). Men benefit even in negative marriages, according to one study by Hui, Waite, and Shen (2016), while women do not. This suggests that women orchestrate and do the work to mobilize the social network to provide support for men but do not receive the same support from their network.

For older straight adults, in addition to marriage, children and grandchildren are a critical part of the social network. Those with a higher volume of family ties and embeddedness have lower mortality risks. Higher survival rates and longer lives are associated with having biological

kids (Patterson, Margolis, & Verdery, 2020). While here ties can provide intergenerational care, increasingly more elderly people are expected to age without family care (Carr, 2020). This burden is greater for women, Black and Hispanic populations and those with lower socioeconomic status (Margolis & Verdery, 2017). In this way, those lacking familial networks must figure out how to utilize their distant family, perhaps siblings, neighbors, and other community members in their social networks, if they are to benefit from them as they age.

LGBT Older Adult Social Networks and Health

LGBT older adults have different types of social networks than their straight counterparts. Some studies demonstrate that as in the straight, cisgender population, being a woman, having a partner or child, or community involvement, religious or otherwise, resulted in larger networks for LGBT elders (Erosheva et al., 2016), but does not necessarily translate to health benefits as seen above. However, studies have repeatedly demonstrated the friend-centric models of older adult LGBT networks (Brennan-Ing et al., 2014; Dewaele et al., 2011; Hsieh & Wong, 2020), which includes more friends than partners and biological families (Breder & Bockting, 2022; Hsieh & Wong, 2020). Gay and lesbian adults are less likely to have partners or be married than straight, cisgender older adults (Erosheva et al., 2016; Fredriksen-Goldsen et al., 2013, Gates, 2014). Some of the oldest LGBT elders missed the opportunity to get married because companions in their cohorts have passed from AIDS and marriage was only legalized in 2015. LGBT adults are also less likely to have children (Erosheva et al., 2015) and grandchildren (Espinoza, 2011) though more lesbians and bisexual women tend to have children more than gay men (Croghan et al., 2014), many come from previously heterosexual relationships. While this

does not mean that these friendship ties are inherently weaker than family ties, it could put LGBT people at a disadvantage considering the benefits of support derived from strong familial ties.

Because older adults lack spouses and children to bear caretaking burdens (Chrogan, et al., 2014), LGBT adults turn to their friends, or their chosen family, as a substitute for biological family ties for social support usually offered by biological family members (Weston, 1997). Despite the support of friends or family, older LGBT adults' networks remain less dense and diverse than those of their straight counterparts, which has implications for their health (Ning & Wong, 2020). As with straight couples, marriage is important and supports positive mental health for same-sex couples (Denny, Gorman, & Barrera, 2013; Garcia and Umberson, 2019; Leblanc et al., 2018). But given that fewer older adults are married or partnered, they are less likely to receive these benefits. Moreover, gay and lesbian older adults have higher levels of loneliness (Hsieh & Lui, 2020) that we know is dangerous for older adults. Furthermore, stronger relationships with family, friends, and non-family are associated with better mental health for LGBT elders (Kim et al, 2017). Again, this depends on the existence of those relationships, which we know LGBT elders are less likely to have. Taken together, the lack of social connections means fewer places from which LGBT elders can derive social support, diminishing vital resources for positive and healthy aging (Hsieh & Shuster, 2021). It also means that LGBT individuals work from a deficit of traditional strong ties.

Because LGBT elders must rely on their 'chosen family', friends, and others for support rather than family as they age, there is the opportunity to revisit Granovetter's (1973) theory of

strong ties versus weak ties among this population. One tenant of strong ties is the utilization of strong ties in vulnerable or delicate situations such as sickness, frailty, aging, dying, and death. As argued by Small (2017), how one utilizes networks is situational. Since older LGBT adults cannot rely on their strong ties of biological family for support, especially in old age, they must rely on their friends and others, including trusted advisors like doctors and realtors, to execute end-of-life plans, reaching further and further from the 'strongest' ties (Antonucci, Ajrouch, & Birditt, 2014). These “weaker ties” become increasingly important and for many in the LGBT community take on the role of strong ties as they age. Additionally, LGBT elders making decisions about health prioritize their sexuality and thus seek support from others who are sensitive and knowledgeable about these issues, thus not looking to the closest person, but the most useful (Perry & Pescosolido, 2010). Strong ties only go so far for older LGBT adults in vulnerable situations as they age, when they are considering who to turn to for support when putting in place advanced care plans and determining who they would rely on in a health crisis. As a result, LGBT older adults more frequently turn to what may be considered weaker ties who are better suited to fulfill these roles historically belonging to strong ties, even when there are strong ties available in the network. Thus, the roles of strong and weak ties are harder to delineate and undermines the theory of distinction between strong and weak ties in networks of LGBT elders. This paper finds that both the theoretical underpinnings of the taxonomy and operationalization of strong and weak ties do not work as expected in LGBT elders and therefore suggest the limits of this theory.

Data and Methods

This mixed-method study relies on 89 in-depth interviews with community-dwelling adults over 50 in the Chicago area. I also pull data from observations from a summer internship with an organization working to support the needs of LGBT elders in Chicago. Participants came from a nonprobability sample, recruited in two waves in the summer of 2019 and autumn of 2021. Participants were recruited from community centers, online announcements, and interpersonal or third-party interactions via Zoom. After a brief screening and explanation of what the interview would consist of, a mutually agreed upon time and location was arranged for the interview.

All interviewees came from Chicago and the surrounding suburbs. LGBT elders ranged in age from 57 to 87 years of age. The mean age for the participants at the time of the interview was 72. Among LGBT participants, seventeen identified as gay women or lesbians, and the remaining twenty-nine identified as gay men. Forty-five of the interviewees were cisgender, and three were transgender. Eight identified as Black or African American, three as Asian-American or Pacific Islander, two as Hispanic/Latinx, one as indigenous, and one unknown. The remaining thirty-one participants identified as white or ethnic white (German, Polish, and Russian). Three were HIV positive. This sample was highly educated – all but four had some college education, and many had graduate degrees. Twenty-two were employed, either full or part-time, at the time of the interview. Seven of the participants had children or grandchildren. More than half of the sample was married or partnered, with six being widowed.

The thirty-three straight, cisgender interviewees ranged in age from 55 to 89 years. The mean age for the participants at the time of the interview was 70, two years younger than their LGBT counterparts. Eleven were men, and twenty were women. Seven were Black or African American, two were Asian-American or Pacific Islander, and one was mixed race and unknown heritage. The remainder identified as white or ethnic white (Swedish, Ukrainian, and Polish), with three participants raised in Europe and moving to Chicago as adults. The sample was highly educated, with all thirty-three attending some college or more. Two-thirds were married, two of the other eleven were widowed, and the other nine were single or divorced. There were no single straight men. About 90 percent had children, and about half had grandchildren. About a third of this group was also still working at least part-time.

Also, during the summer of 2021, I conducted over 300 hours of participant observation for three months. Time was spent facilitating discussion groups, talking with elders who attended the weekly lunch programming, and helping case managers find services for individuals. During the observation sessions, I would keep shorthand notes to identify events and use these to detail longer memos written after each day. The themes reoccurring in these observations informed the interviews with community elders, some of whom attended the events at the center. An additional eighty hours were accumulated preparing for a resource fair for LGBT elders, specifically addressing plans for the end of life.

Analysis

Interviews were mostly in-person, adhering to COVID protocols and restrictions in the fall of 2021, and the rest were conducted via phone or on Zoom. After obtaining a verbal

consent, the interviews were recorded for transcription and coding. The interviews lasted about an hour each. Each interview was semi-structured, touching on life course events such as recognizing their sexual identity, coming out or not, and finding a partner. The brief life history focused on experiences with discrimination, including violence, health care interactions, family relationships, and similar experiences, paying special attention to their view of their social supports. A second critical part of the interview covered health and health care, including what decisions have been made about aging, self-rated health, experiences with health care professionals given their sexuality, who was involved in making decisions, and with whom they discussed health issues. The final focus was on aging and planning, which included questions on downsizing, making wills, naming executors of wills, advanced directives, plans for long-term care or other types of care, and who they could rely on as they aged, including in the case of a health emergency. I analyzed interviews and field notes using inductive data analysis with theories and interpretation from the data (Saldana, 2016). NVivo 12, a qualitative software, was used to store and code data. I first listened to and read each transcript and consulted memos written after each interview to jog my memory about salient themes noted at the time. I then took several passes at the data, gathering patterns and categories in the transcripts, making sure to go back to recode interviews when new categories were found. I conducted line-by-line coding for themes specifically related to aging and planning for long-term care. Categories were collated and connected by concepts aided by reflections and memos on each topic.

Findings

My participants fell into four categories when it came to making decisions about aging and on whom they could rely. The first is what I call the *traditionalists*. Most straight participants fell into this category, and about half of LGBT participants as well. *Traditionalists* were married and had a close nuclear family, including children and grandchildren. They turned to these strong family ties for help with planning, aging, and health issues. The notable difference was that in straight marriages, women orchestrated the care networks, versus both partners actively caring for one another in same-sex relationships. In the other three categories, older adults had a more difficult time thinking of strong ties that were reliable actors of support compared to the *traditionalists*. As a result, the other three groups turned to further ties outside of their nuclear family, looking to more distant connections. However, pinning down the type of tie and the function was not always easy.

The second group, the *adapters*, comprised of LGBT elders and single straight adults, felt they could rely on some traditionally strong ties like family and other close ties but thought of mostly distant relatives and less close strong ties for support as they aged, including chosen family. Straight folks without partners or who were among the oldest old were in this group, as well as LGBT elders who were without partners or estranged from family members. For both straight and LGBT older adults, the most common arrangement was the enlistment of a younger female family member. LGBT elders recruited a younger relative that was more accepting and aware of the implications of their sexuality.

The next group, the *optimizers*, had no nuclear strong family ties such as partners or children they could rely on, nor more distant family ties like siblings, nieces, nephews, cousins, or chosen family. Instead, these elders had to construct networks of friends and acquaintances to depend on for support. LGBT elders were in this group for various reasons, including strained family relationships due to sexuality and the lost opportunity to partner, especially for gay men because of the AIDS epidemic. For straight women, they had outlived all their family members and had no children. This group talked about their distant ties functioning like stronger ties might. Going beyond Small's role of providing someone to listen to, these weaker ties played an actionable role of arbiter of the will, power of attorney, and care in times of medical needs – tasks usually left to family or professionals.

Finally, there were the *loners* who had only extremely weak ties and had to depend on a trusted advocate or 'best' choice in case of an emergency or 'next of kin'. All the *loners* in this study were gay men. In the last three groups, participants utilize distant ties for support because closer ties were incompatible with their needs or non-existent. Especially for LGBT elders, specialized knowledge and sensitivity about sexuality and aging were required.

The Traditionalists

Partnered participants, LGBT and straight, had strong ties with their partners. Cameron, 65, and Michael, 67, a married, white straight couple from the suburbs of Chicago, made plans around health and aging with each other and their two gay sons, one of whom was a doctor. During the interview, Cameron, a warm semi-retired schoolteacher, answered for her husband, Michael. Michael spoke a few times, but when he did, would say, "I could just say ditto."

Cameron and Michael, had a large social network; they were close with their neighbors, involved in their church, volunteered frequently, held get-togethers with their friends around the holidays, and participated in community performances. When we spoke of their plans for aging and health, Cameron said:

I jokingly say—and Sean's mom [her son-in-law's mother] as well—that our retirement plans are a room off of Daniel's [her son] house because they've got a nice, big ranch. They've got a nice room on the side. We just have to add a bath.

Though she was being facetious, Michael and Cameron have retirement funds they planned to use to age in place and would turn to their sons for help when they could no longer take care of themselves. Michael had just retired, so they were redoing their power of attorney and revisiting the allocation of their assets. More seriously, Cameron discussed that after naming each other as their respective Powers of Attorney, they enlisted their children and their children's spouses. Their sons were responsible for all helping them physically and legally age, their son's spouse Sean, a doctor was added as counsel for medical decision making. Cameron and Michael were unremarkable among the straight, married adults that I interviewed. They were college educated and had a plan for their health and assets that involved their spouse first and then their children. This meant if their health failed, they had a system they could turn to and that their health and well-being were assured as they continued to age.

LGBT elders also named their partner or child as individuals they could turn to. Julie, 76, white and an artist, was partnered with Florence, an 80-year-old Jewish businesswoman, and the two were representatives of the traditionalist group among LGBT elders, both gay and lesbian. When interviewed in their home near the suburbs of Chicago, they showed how 'conventional'

LGBT networks can be. Julie had been married before and had two grown adult children, Sarah and Justin. Florence had also been married before and adopted a distant relative as her own, Catherine. They had been together for several decades but had chosen not to marry, though they had drawn up documents to protect themselves legally and financially in the year before the legalization of same-sex marriage. Julie and Florence had a rich social network of friends and family. When they had health emergencies, they could call on their family:

Julie: Really, just a few years ago, I had a hernia that burst, and it was an emergency surgery kind of thing.

Florence: That was bad. But I've been lucky.

Grey: When that happens, do you call on your family?

Julie: It's us, but the kids are there, and her sister's there.

Florence: Now the grandgirls are there too.

Julie: Sarah is our helper; she doesn't want us to lift a finger; she carries us.

Florence: We have all the family big dinners.

Julie: We have the 20 and 30-people dinners.

Florence: We cook for it, but we do have a woman that comes and helps with the serving and cleaning and all that.

Julie: The cooking isn't the hardest part; it's the setup and getting ready.

Florence: Justin comes, and Sarah comes because they're the closest; my daughter lives in the suburbs. They come, and they slap all the chairs; they do all of that for us. Justin doesn't set tables, but Sarah does. Everybody pitches in, and Catherine does some of the cooking, too; she just brings it from her house. That's my daughter.

Julie: Her sister Lisa cooks too.

Julie and Florence's life reflects that of many heterosexual couples who have large family gatherings. Julie and Florence have close ties with their nearby siblings, children and grandchildren, actively relying on them during emergencies and as the couple continues to age. A few years before her hernia burst, Julie had breast cancer. Her health crisis had spurred them to update their plans for the end of life, naming their son Justin a power of attorney, and knew their

children and grandchildren would care for them. These couples are representative of those who had strong ties in their lives in the form of spouses and children, in addition to others, that they could rely on as they aged.

Adapters

Another group of individuals who had strong ties in their network like siblings, parents, and partners, but instead relied on more distant ties that blurred the distinction between strong and weak ties. Because adapters lacked or could not rely on nuclear families, they turned to their more distant familial ties who they felt were more equipped than their nuclear familial strong ties or close friends. For LGBT elders there was less of a conflict with more distant ties, especially their younger female relatives who were more accepting of diverse sexualities and gender identities.

Debbie, an Asian American woman in her late 60s, had no partner or children she could turn to, so as she aged, she turned to various family members to help her. Debbie never married; she had four brothers several years younger than her, one of whom lived across the border in Indiana, but this was not her closest brother. She had a male companion and best friend for a long time, who she turned to for support with all her important financial, aging, and health plans, but he died close to the time of our interview. Over the long term, she ended up providing most of the care to her family members and caring for her friend Zach as he died. For her aging plans, she turned to her younger brother, Jonathan, because he was the youngest and closest in proximity. Debbie had to shift her plan when her long-term companion and best friend died; she had to rethink who she would rely on.

But then here, this friend of mine [Zach], I probably was in love with him for a long time, even though he's so much younger than me. But you know, in some ways, I almost think that it was meant to be that I was to take care of Zach.

After Zach died, she started taking care of his affairs; she also reassessed who she would turn to in her time of need. Debbie was still a little unsure who she would rely on to help her age and care for her as she grew old and died, which she was increasingly worried about after her experience with Zach since it had taken a long time to access his bank account. Reeling from being his caregiver and thinking about caregiving for another brother, she decided that her new Power of Attorney would be her brother Jonathan, who lived in Indiana, because he was the youngest and the closest in age, even though he was not the closest in relationship. “Jonathan would probably be Power of Attorney. He is only two years younger than me. Well, Jonathan and then Jacob after that.” After some hesitance and consideration, she listed Jonathan first because he lived in Indiana and then Jacob because he lived on the East Coast. It was a choice of convenience not based on strength of ties. She thought briefly about her nieces and nephews, but she thought they were still too young to be reliable.

Another example of an adapter who adjusted to her life circumstances was Janae, a Black transgender health worker in her 50s who lived with her mother, who had a vibrant support network of chosen friends and family, yet was very cautious with whom she socialized and turned to for care. Though Janae had a mother, a partner, and close friends as strong ties, she felt those relationships were not very reliable sources for support in aging and health. The people she did have were her sister, who had recently died, and her goddaughter from her family of choice. “I have a very small family [of origin], and just a few people in my family I'm close to. My sister

and I were very close, and we did practically everything together. We were only three years apart. But my mother and I have never been close.” Janae had very few family ties she could turn to. Additionally, even if Janae could rely on her mother, she was worried about her mother’s age and her health. Janae was most worried about her wishes not being respected.

A lot of trans people I know have been buried by their family as their [sex] assigned at birth, or their friends were excluded from any ceremony. So, I also tell my friends and stuff. You have to prepare for that. You can't leave that up to anyone else.

She turned to those chosen family ties and close friends in her network to rely on and help her age because they had more specialized knowledge about the LGBT community, and could address her transgender identity and give her dignity as she aged. Janae is representative of this small group without trusted family members of origin who turned to families of choice. These families of choice provide trust for individuals in Janae’s case, and could assist as they aged by carrying out important duties such as executing a will and caring for them during an illness.. Debbie moved from her closest relationship, her best friend and companion, to her brothers that she named according to literal physical proximity. However, focusing on their caregiving took a back seat as they provided care to others.

Optimizers

The next group, the *optimizers*, had no strong ties to rely on for health issues as they aged, such as partners or children. Though they had what might be considered distant strong ties like siblings, nieces, and nephews, they had to construct networks of distant friends, neighbors, and acquaintances, depending mostly on weak ties for support to take on the role of strong tie duties. This group of LGBT elders was very intentional about who they socialized with because

they were cognizant of their vulnerabilities due to deficits in strong ties. Straight women also fell into this group and worked hard to establish connections and support to help them age.

Gerta, an 89-year-old white widowed German immigrant, took her interview in her living room where one of my informants and her friend, Joanna, was also present. Joanna was my ride there, and also Gerta was a little unsure of a strange graduate student coming to her home for an interview, so it became a social visit as well. Gerta met her husband on a passenger ship as she traveled to work in New York from Europe, and he moved from Chicago to Italy; they reconnected years and hundreds of letters later. Gerta's husband had died young and was "long dead" according to Gerta when we spoke. They had had no biological children; she had taken in a few children who needed help for a year or so but did not remain in contact. As she told me, all her family was in Germany. That did not stop Gerta, an optimizer, from cultivating a large, non-kin network of weak ties to help her. Gerta, nearing 90, needed a lot of help as she was living with cancer. She was debating about stopping treatment and had several doctors' appointments each week. She had named her neighbor a Power of Attorney, even though she called him "a worry" and thought she cared more for him than he cared for her. At her age, she felt she was much more sensible than most, and she felt she had a system to help her.

Gerta: Yes. I have a lot of people who would take care of me, who are willing, and every time, "If you need any help, let me know, let me know." I said, "Right now, I don't need help." I need help when I have a procedure, when they put me under, to take me there and bring me home.

Joanna: Call on me. I'll do that. [...]

Gerta: I know you would do that. Next time, maybe I'll ask you.

Joanna: Okay, good.

Gerta: Ginger [a neighbor and friend] takes me, and David [her neighbor] takes me. For the eye thing, David took me, and last time Ginger took me. I have

people. It's good. You need that. But I have enough people who are willing to do that. Just like I'm willing to do things for them if they need help.

Gerta made connections earlier in her life, had always been involved in some kind of community or social event, and still tried to keep up with social events and groups as much as possible. She actively worked to cultivate a sense of belonging because she was single for many years and thrived on companionship, but also because her biological family was so far away. She had cultivated a connection with the four units adjacent to her townhouse, even though one lady a few years older had just died and the home was empty. She also talked about her friends and clubs she tried to attend when she was not in the hospital. Gerta felt supported and loved, even though she worked at it, but for her it was not a chore because she enjoyed connecting with people, even as she became sick.

LGBT elders optimizers were acutely aware of their position and intention of cultivating a strong network. Jean, a 71-year-old white lesbian artist, lived in north Chicago. She had some family who were estranged from her due to her sexuality. However, when it came to her health and aging, Jean was adamant she could utilize her network and find folks to help her out. She pointed to one time a couple of years prior she had fractured her leg. After the fall, she names a dozen people who could help her in the course of the story. “My neighbor came” to immediately help her go. A friend who long since moved to Florida “went and got groceries for me.” Denise, “She’s the one that took me to [doctor].” Bobby, who “took me to see the surgeon.” Sandra, “who brought the tabloid.” And other neighbors, who “I could call.”

In an emergency, Jean had to rely on her neighbors and some friends to help her out. She could call on this group because she had cultivated these relationships, as she said, through her

'energy'. However, when pressed about who she could turn to about health or end-of-life preparations, she could name two people. Her power of attorney for her health was a distant friend, while her other occasional friend Kat, who she sometimes texted and conveniently happened to work in the medical field, was her medical power of attorney. Jean had met Kat through an ex-lover who lived on the same block and with whom she was still friendly. Unlike the traditionalists and the adapters, who could first rely on close family ties like partners and children, Jean could not even turn to the next closest circle of distant family for assistance and support during a health crisis or for helping her as she aged. Instead, she had to optimize her network and find available resources that matched her needs. For example, she picked Kat as her medical Power of Attorney because she was a medical assistant, knowledgeable on the topic, and knew that Jean was a lesbian.

For optimizers, using weak ties made sense because those ties were compatible with their expectations, but optimizers had to expand their networks to fulfill these roles. For example, my informant Ray, an outgoing Black man in his 70s, bridged the gap between the older Black and white LGBT communities, seeking ties between communities because he no longer was in touch with any of his family. Through many conversations, it became clear that Ray had been the caretaker of his parents during his middle-aged years. In taking this on, he had turned down opportunities for work advancement and accrued health issues of his own from stress. In addition, he had children he adopted from his sister and raised as his own as a single father. However, he lost contact with them. Ray had several health issues. But to ensure he had people he could rely on, he constantly volunteered to participate in social programs, speak at community

events, and sit in advisory roles for various communities. I saw this firsthand as he incorporated me into his network. Whenever there was a question to be answered, he could ask to meet in person and thereby get a ride to a doctor's appointment, run some errands, and then have a conversation over lunch. It was not uncommon for him to call me to ask how my dissertation was going or for him to suggest a time to meet to talk about my work. In doing so, he could also have his needs met. I usually ended up scheduling an entire afternoon off because I never knew what Ray might suggest I help him with. The time usually ended with him confiding how important our relationship was to him. In this case, like most in this group, Ray optimized weak ties, including our tie, to help him as he aged.

Loners

Loners are individuals who have no traditional strong ties in their network for various reasons including estrangement from family, death of partners or never having had a partner, and having few close or distant friends upon whom to rely. Loners rely on the farthest reaches of the outer circle of weak ties and complete strangers, turning to the “best” choice given their network deficits to rely on in an emergency or to help with advanced care plans.

Taylor stands out as a prime example of the loners I talked to during my time in the field. Taylor, who came to Chicago by way of Hawaii, was of Asian Pacific Islander decent. He had worked in computer information, as he proudly showed me pictures of himself from the 80s with oversized glasses, a large brown tie, and a white short sleeved button-down shirt. Taylor went to local churches and centers for most of his meals and lived in a sparse condo that he owned. Taylor's network was entirely depleted: his younger brother was in a nursing home, the rest of his

family had disowned him, and he never re-partnered after his partner died of AIDS. When asked about his social life and who he interacted with, he said "I had friends in Logan Square. They're not really friends. They're because of the club, I knew them." When pressed to think of social things he might do, he could not name any friends with whom he regularly interacted. When asked "Do you have any hobbies?" He answered, "Watching television. At my age not much hobbies. You're young. I'm 75." Further questioning elicited no further social activity.

Additionally, Taylor really struggled to get basic help. While I was at his condominium, I ended up doing some minor handyman jobs, including replacing a few lightbulbs he had been waiting a month to have someone put in because he didn't want to fall off the ladder. When asked about his advanced care planning, Taylor replied:

My Power of Attorney was set up with my 'friend' who is a Real Estate Agent who knows this lawyer because they've got to get lawyers when they sign all the forms and this and that. She did my Will, and everything is supposedly straightened out through the Will.

His assets would go to his brother's family, but Taylor was ambivalent about what happened to his assets after he passed. When pushed as to why the real estate agent was his Power of Attorney it became clear that what mattered to him most was that his real estate agent knew he was gay and more importantly could care for the connection he did have, his senior Schnauzer, who continually chimed in with loud barks from my lap during our entire interview. He knew this because the real estate agent talked about dogs.

Taylor had so few ties in his network he could rely on that something considered a significant decision by most was mentioned as a flippant comment addressed by his no name real estate agent. Though Taylor's nonchalance toward preparing for end of life was atypical of most

of the loners I interviewed, the fact that he had to turn to his real estate agent as a trusted other was characteristic of the loners I talked to. However, in his statement it was clear that he trusted the realtor because he had experience working with complicated affairs, as with other loners who relied on their primary care physician, their attorney, and accountants. Loners as a category were all single gay men and in general turned to a very distant ties that 1) likely, but not always knew they were gay and 2) had a respected career, such as a real estate agent, doctor, or attorney, with the assumption that they were learned and reliable for such complicated matters.

Discussion

Network Construction: Findings Compared to Literature

Based on the literature we would expect to see many patterns that did not hold for this sample. Beginning with sexuality, we would expect that older straight adults are more likely to be partnered than LGBT elders (Erosheva et al, 2016; Fredriksen-Goldsen et al., 2011; Gates, 2014) and thus less likely to be traditionalists. Yet in this sample most of the LGBT elders were married or partnered, and when they were partnered, and especially when they had children, straight and LGBT networks looked the same and operated similarly in terms of whom to turn to. Lesbian and gay relationships like Julie and Florence, look a lot like straight relationships like Cameron and Michael. Despite the expectation that LGBT elders have fewer children and grandchildren (Erosheva et al, 2015; Espinoza, 2011), removing a potential tie that could provide care of sexuality were likely to turn to a variety of distant ties when they had no partner or children. This was especially seen in the similarity of patterns among LGBT and straight adults in the adapter and optimizer categories.

The biggest difference expected between LGBT and straight older adults was the number of friends or reliance on chosen family compared to family of origin. Older LGBT adults have networks comprised mostly of friends (Breder & Bockting, 2022) and are thought to rely heavily on family of choice (Breder & Bockting, 2022; Weston, 1997). Yet both straight and LGBT elders turned to a variety of biological and non-biological ties as they aged, as seen among adapters and optimizers. Among the adapters, those like Debbie were turning to their extended family members and friends, and among the optimizers Gerta, Roy, and Jean cobbled together care with friends and neighbors. Furthermore, the notion of family of choice or cultivating an alternative familial model played a limited role for LGBT elders. Few LGBT elders constructed a network of “chosen family”. Janae was one of the very few LGBT older adults that constructed a network resembling a chosen family. As an important aside, all transgender older adults had a family of choice, a difference that warrants further investigation. Straight and LGBT adults turned to a mix of ties in similar patterns across adapters and optimizers, both turning to family, close friends, distant friends, and neighbors.

One consistency with the literature in this sample was that LGBT elders felt lonely, as we might expect given the higher levels of loneliness for LGBT elders as compared to straight adults (Hsieh and Lui, 2020). These LGBT elders had limited options when it came to someone to rely on, as we saw with the loners. What we might not expect is that this group would be entirely gay men. Men are expected to have wider, less familial based networks, while women have more familial networks (Ajrouch, Blandon, & Antonucci, 2005). Men, on the other hand, tend to be partnered even in old age and benefit from these partnerships (Cornwell & Waite, 2009; Waite &

Das, 2009) compared to women (Hui, Waite, & Shen, 2016; Kotwal et al., 2016). Certainly, women in this sample provided the role of caretaker, especially among straight traditionalist relationships, like Cameron did with Michael. Additionally, women in the adapter and the optimizer group were caregivers as we saw with Debbie as representative, but more so with lesbian women, and especially Black lesbians. Both straight and LGBT women were much better able to create a network and draw from it when in need as we saw with the optimizers like Gerta and Jean. Ray was one of a few men who was a caregiver earlier in life and now an optimizer. Many men were adapters, expecting to rely on their mothers, sisters, and nieces, or were loners. More gay men ended up single compared to lesbians, most likely resulting from the extensive loss of gay men due to AIDS. Combined with gendered differences of how networks are operationalized, this leaves gay men at a disadvantage.

Network in Action: Limitations of Theoretical Literature

The expected network construction and network utilization compared to what I found in my observations differs, which has implications for the health and aging of older adults. For many older adults who are not immediate nuclear families, defining ties in their network is difficult. Strong ties originally theorized as a function of time, reciprocity of emotion, intimacy and services, is complicated by many of the older adult relationships among adapters, optimizers and loners in this study that have relationships that do not function as theorized. In these groups familial, friendship, and neighborly relationships blurred the lines between strong and weak ties and were not easily labeled. For example, though we spent many hours together, provided reciprocal services, and shared intimate details with each other, Ray considered me a son, but for

me he was a distant friend. For older adults, having strong ties and building intimacy that is reciprocated and carried through decades limits them if they are depleted, but also reshapes the idea of what ties might be for them and how they function. Here, the traditional distinctions fail to fully capture how a relationship that seemingly fulfills strong tie roles for one person might be a weaker tie for the other, depending on the circumstances, despite satisfying the definition of time and reciprocity.

Several theorists have added to the definition of strong tie, notably *philos* (Krackhardt, 1992), which emphasizes frequency, positive affect, and history over the above definition. This on its own does not help provide more clarity for adapters, optimizers, and loners. Further complicating the original conception of strong and weak ties is the casual use of the term friend, where some might be strong and others might be weak, certainly following the close, closer, closest model (Antonucci, Ajrouch, & Birditt, 2014). Even this model failed to capture a systematic pattern of ties utilized in aging.

Based on Granovetter's work (1973; 1983) we would expect only strong ties to be called upon when it comes to issues of health and aging. Strong ties, mostly family and some very close friends, would be the ones to provide care, manage health issues, and take care of advanced care planning as they are both more easily intimate and accessible (Marsden & Campbell, 1984) during times of vulnerable affairs. Occasionally, we might expect influence from a weak tie to find caregivers, health care providers, or professional services for end-of-life matters (Burt, 2004; Freeman, 2004). However, that was only the case for the traditionalists in this study. Many

older adults, gay and straight, utilized a wide range of people for health and aging needs. In most cases, it is difficult to classify the type of tie, as discussed above.

Small suggested in his book *Someone to Talk to* that many students turned to weak ties for support because of compatibility. This was true for many older adults looking beyond nuclear family as adapters. The decision to choose one sibling over another could be physical proximity, like for Debbie, in whose case the younger brother could get there faster and was more likely to live longer than her older brothers. Similarly, gay men and lesbians turned to her nieces and nephews because of their age. Like Small's suggestion of why weak ties were turned to in conversation, pragmatic considerations could lead people to value certain ties more for actions and processes that don't fit with the pattern of strong versus weak ties. Jean made sense of turning to a casual friend because of her medical expertise. In most cases, the stories they told older adults drew from anywhere in their social network to get the support they needed. Additionally, Small contends that the strength of ties is less important than the utility of a certain person given the uniqueness of a circumstance. This bores out for many gay older adults who curated a network of people who could care for them. This was particularly important for the optimizers. Jean and Ray sought to pick people who were aware of their sexuality to assist them with medical, aging, and end-of-life planning.

In Small's work *Someone to Talk to*, his reconceptualization analyzes the case of graduate students and argues the function of weak ties in that case is to be a resource for conversation and emotional support—traditionally thought to be a function left to strong ties. This paper takes that a step further by questioning what, in some cases, may be considered weak ties and who is

providing the hard emotional and physical support of caring for an aging person. Caretaking like this certainly falls beyond the scope of the original theoretical definition of weak ties. In shifting the lens from that of graduate school experience and needed emotional support, I interrogate the realities, complexities, and tasks of care required for aging. In doing so, traditionally strong familial ties who are expected to do the intimate and emotional labor of caretaking are not always sufficient. Other actors in the social network must step in for these roles for elders without a traditional nuclear family with spouses and children. As Small pointed out, actors can pull from anywhere in their network for their needs. Rather than thinking about a network comprised of strong and weak ties, or a sphere going from strong to weak, the ties can be constantly reconfigured given the circumstances and the needs of the individual. The function of the tie is neither weak nor strong in the traditional sense, but the tie is dependent on the purpose. The traditional view is simplistic and the realities of lived experience leads to a fluid system of ties not confined to rigid definitions – rather it is an active and ongoing process.

Limitations

This research has several important limitations. First, the data presented here is from a subset of individuals in the Chicago area. This sample is unusual in that they are highly educated and seem to have more familial ties than what the literature indicates. Second, because of the location-based nature of the data, I cannot make extrapolations to other areas. The field of research on older adult health and aging will continue to increase as we see the Baby Boomer generation age and reach later life. Though Chicago is a liberal bastion in the Midwest, and Illinois and the city have many protections for LGBT folks, other areas may not be as open, and

thus may not provide LGBT elders with the same opportunities to create strong ties with accepting families or generate relationships among LGBT friends. Thus, future research may help determine the broader landscape of older adults' social network cultivation. Work in geographic regions beyond Chicago should be pursued. In particular, comparisons with other urban areas would be useful.

Still, the voices of those in suburban and rural areas with less political and social support for older adults need attention. This work develops an analysis under the current understanding of who people will rely on to take care of them based on past experiences, who has helped them complete paperwork, and who has been actively involved in support in the past. This paper assumes that past actions are the best predictor of the future. However, aging and dying are events in the human experience that are filled with unpredictability. When someone's family member is suddenly ill there may be a change of heart, or in some cases family might be moved to step in to help. Future work should follow acute cases and death and dying along the lines of sexuality, and observe who is present and takes on what role during this process. Finally, future work should include matched data that looks at straight and LGBT folks in a variety of relationship types and network structures along with differences by race and gender. This study could benefit from more straight, single men, who I suspect are also more likely to be *loners*.

Conclusions

This paper expands on Mario Small's critique of Granovetter's strong versus weak ties theory and questions the utility of the definitions of strong and weak ties, as well as the theoretical role each tie is supposed to play. As demonstrated in *Someone to Talk to*, I find that

older individuals look beyond their closest relationships for help. When thinking about who to pick, elders choose based on compatibility expectations, the need for specialized knowledge or expertise, and finally, whoever is in their stream. The fact that even in a time of great vulnerability elders turn to those outside of their family ties for support questions the very assumptions of the definition of strong and weak ties. First, to see who elders turn to and the benefits of networks in old age, I outlined how this sample challenges what an older adult network might look like, making sure to note important differences along the lines of gender and sexuality. I find that the traditional definition and operationalization of strong and weak ties only hold for older adults, gay and straight, in partnered relationships, and most likely with children.

Given that finding, this paper looks at all the other cases outside of the traditional family network, and finds three other categories that I name *adapters*, *optimizers*, and *loners*. It provides evidence that strong ties and weak ties were blurred, not fitting neatly in any one category. For straight adults, finding help meant finding the next closest person in their familial network for help, for whom the definition of strong tie may be appropriate or not. Older adults consistently turned to what might be considered weak ties when there were mismatched expectations with their family ties that were supposed to be strong, particularly around sexuality and gender identity for LGBT elders. LGBT individuals sought out ties that best matched their needs in that they could be trusted to carry out necessary tasks and understood the person's identity as central to providing support.

However, the paper also seeks to extend the reconsideration of weak and strong ties to the role of social support for the same reasons someone might depend on a weak tie for emotional

support. The reliance on a variety of ties is not limited to graduate students, but also exists for older adults at the other end of the life course, who traditionally have smaller social networks. In the cases illustrated in this paper, strong ties and weak ties operated along a blurred spectrum. For straight adults, finding alternative ties meant finding the best person in their network for help. And expanding on Small's work, this paper shows that in contrast to the theoretical work that assumes weak ties are just for emotional and conversational support, anyone can be asked to carry out support around health and aging.

This work justifies further research about older adults' social networks and the possible impacts on health and aging, as well as investment in policies to support the gaps in social networks for older adults who lack social support. For social science scholars, it provides evidence for revisiting social networks and how they function vis a vis strong and weak ties. It also calls for more work around which ties provide social support, as they are not as distinct in all cases as previously thought. Furthermore, this work asks scholars of gender and sexuality also studying social networks to update the literature as more LGBT individuals construct families that mirror traditional straight, cisgender ones in the form of a partner, children, and grandchildren to rely on. While straight individuals are increasingly having diverse networks as well, with single parent households, coparenting models among many parents, and adults choosing not to have children. It provides those in health, legal and service industries working with elders, a reframing of what kind of questions should be asked while in their care. Lastly, it asks policymakers to consider the needs of aging LGBT Baby Boomers who do not have a network to draw on and, looking to the future, what the needs of a generation choosing not to

marry or have children might be. As we continue to see a shifting landscape in the aging population, much like the *New York Times* article suggests, our services will need to shift as well to accommodate.

Chapter Five

CONCLUDING THOUGHTS

This dissertation, written as a collection of three papers, addresses the wide range of growing issues in the field of LGBT health care. This work is situated between sociology, health, gender studies, and aging, impacting healthcare providers, policymakers, and researchers. The current atmosphere for LGBT folks is one of uncertainty as many expansions of rights gained during the 2010s may be receding under the current barrage of legislation targeting, for now aimed at transgender youth. The battery of bills, however, could expand depending on who wins the 2024 election. Currently, the Biden administration views “sex” under Title IX as protecting LGBT individuals from receiving care, though there is controversy about whether this impacts religious freedoms. This protection under a Democratic administration could easily be flipped by a DeSantis Administration, and pushed to further extremes by Republican-led states. For example, legislation like the Lesbian, Gay, Bisexual and Transgender Long Term Care Facility Resident's Bill of Rights in California curtailed the intentional misgendering of transgender patients under penalty of fines and jail time. However, the statute was rejected in 2021 by the State's 3rd District Court, and allows caregivers to misgender among other acts, under the name of religious freedom. This could be easily instituted anywhere in the United States. Additionally, religious freedom bills could be forced through in many Republican-led states, giving providers the ability to turn away LGBT individuals – a major fear of many of the older adults in this study who know their options will be mostly from religious institutions. With the political timeliness of

this work, my first suggestion for this dissertation is to inform policy and protections of LGBT elders specifically, but of course, ideally, protect LGBT individuals from youth to old age.

As outlined in Essay II, this dissertation understands the need for legislation like that in Illinois that makes LGBT elders a protected class. It seeks to study their needs more closely and use the findings to inform legislation and action to help them age successfully. Such legislation, like that signed by Governor Pritzker in May of 2022, allows for better insights into housing, healthcare, social needs, caregiving, and assisted living, as seen in this work. It also ensures equal treatment regardless of sexuality or gender identity. It provides an Aging Commission to work closely with the State's health department that will continue to grow and respond to the needs of elders as they change over time. A few states have such resources for their elders, like Massachusetts, California, Illinois, Washington, and Maine, but those are the exceptions. It is highly recommended that more states take on this model and aim to research and protect the needs of LGBT elders, especially since some of the largest populations of LGBT elders are in Arizona and Florida. In addition, ideally, such a model would take place at the national level, directly protecting the health care and aging needs of older LGBT adults. Congress made progress in December of 2022 when it passed a bill protecting same-sex and interracial marriage. However, there needs to be more legislation explicitly protecting our LGBT older adults at the federal level, and to come at a time when the Left leads with ideology and not as a last reactionary measure.

While policy and legislation are needed, at a granular level, healthcare providers currently providing care to older adult populations need a better understanding of the needs of

LGBT elders, especially if they live in metropolitan areas like Chicago where there are higher populations of these elders. Here providers in long-term care, assisted living, nursing homes, and retirement communities could all benefit from understanding LGBT culture, history, and the fears of this population to better tailor care to their needs. One requirement could be that State-funded institutions should have to complete a basic level of cultural competency for LGBT populations, among others, that is more than 1 hour per year and requires continuing education. At the educational level, nurses, social workers, and physicians should be taught about the needs of LGBT individuals across the life course. In this dissertation's writing and editing process, many social workers shared with me that they did not know or would not know what to ask their LGBT patients, especially around issues of who in their network could provide care. Many actioners with whom I talked to about my work were shocked to find that many gay men were turning to their landlord, real estate agent, or attorney in the case of an emergency. These individuals attend a school that is a leading academic institution but produces students with limited knowledge and skills regarding the needs of LGBT elders. Moreover, while some schools are leading the way in the endeavor, this is not the norm.

Additionally, the curriculum for physicians may change more rapidly than that of nurses who can receive accreditation from a wider array of institutions, many of whom have religious affiliations and may not cover topics of gender and sexuality in the classroom. Therefore, nurses and nurses' aides who do most of the caregiving in this country for our elders may come from backgrounds with the most animosity toward LGBT elders and may not have the opportunity to learn about LGBT individuals and their needs. As a result, the quality of care is not what it

should or could be. Thus, at the fundamental level, providers across all institutions need more education and exposure.

Finally, to create legislation and design curricula, we need research from our social scientists, who will provide the data that will inform the basis of these changes. During the process of researching and writing the dissertation, I encountered many researchers, academics and professors, some in University of Chicago's sociology department, who believed that this research was futile because they were incredulous to know that the LGBT population could 1) have the fear they had about the medical community and 2) not receive proper treatment in places like Chicago because after all it is a liberal place and we are living in a progressive era. I also encountered comments from reviewers who pushed me to "update my literature to reflect the progress made in the healthcare community" in the last 30 years. I spent many weeks attempting to update the literature to reflect the progress made, but the work from 2020 to today reiterates the struggles, fears, and discrimination this population faces. While researchers like Karen Fredriksen-Goldsen push to find resiliency as I did throughout my research on elders who learned to navigate the system, from elders who used all their resources and research to find the care they needed to those that learned to design a network of care they could rely on, not all the stories were happy. Nor is resiliency a guaranteed way to avoid discrimination or to age well. More work needs to be done by scholars building on the work of the early 2000s and 2010s to test if there have been changes or if there are new fears elders face, followed by timely impact on the legislation, and faster turnaround of evidence for providers.

Despite the current political climate and the uncertain future for LGBT individuals aging into that future, this work hopes to address some of those concerns and fears as we move forward. I hope this work provides a steppingstone to examine and advance our academic, healthcare, and political systems to better serve the needs of LGBT elders. This is a small step in better informing the navigability and accessibility of healthcare and aging needs. Of course, more work needs to be done to help LGBT elders, both inside and outside the academy.

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