

Article

Shifting Social Context in the Lives of LGBTQ Older Adults

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Introduction

We are witnessing a time of profound change in the experiences of lesbian, gay, bisexual, transgender, and queer (LGBTQ) older adults in this country. The rapid shift in social attitudes and the legal ruling mandating the constitutional right to marry for same-sex couples profoundly increased the visibility and support of LGBTQ people. Yet, in June 2016 we also witnessed the brutal murder of 49 people, mostly LGBTQ, in a crowded Florida nightclub, which at the time was the largest mass shooting in U.S. history. How do we make sense of such a tragedy within the shifting context? And why is it that, despite the change in the larger social context, LGBTQ older adults remain an underserved and understudied population? They are largely invisible; yet, by 2060 their numbers will exceed 5 million, and will account for more than 20 million older adults when including those who do not publicly self-identify but have engaged in same-sex sexual behavior, or romantic relationships, and/or are attracted to members of the same sex (Fredriksen-Goldsen & Kim, 2017).

When I began my research on LGBTQ aging in the early 1990s, I was told by many that these older adults would not participate: that they were too closeted, too vulnerable, or too stigmatized to participate. Yet, that early research led to the first national longitudinal study of health, aging, and well-being of LGBTQ older adults, *Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS)*. When we sent out our first surveys with the help of community agencies across the country, the rate of response was quadruple the original estimate,

and we received handwritten notes from some who shared that it was the first time they had told anyone they were LGBTQ. Like most older adults, this population wants to tell its story, and our research seeks to understand their lives and their trajectories in aging, health, and well-being.

Health Inequities and Resilience

In the first national, population-based study to specifically investigate health disparities in chronic health conditions and other key health indicators among lesbian, gay, and bisexual adults aged 50 and older (Fredriksen-Goldsen, Kim, Shiu, & Bryan, 2017), we found that sexual minority older adults, compared to heterosexual older adults, showed significantly higher likelihoods of chronic health conditions, including low back or neck pain, weakened immune systems, and disabilities. In addition, lesbian and bisexual older women were significantly more likely than heterosexual older women to report strokes, heart attacks, asthma, arthritis, or multiple chronic conditions. Gay and bisexual older men were more likely to report angina pectoris and cancer compared to heterosexual men. We also found higher rates of disparities in cognitive impairments in lesbian, gay, and bisexual older adults, which as a health issue simply has not been addressed either in these communities nor in our existing health care systems. While transgender older adults are rarely identified in public health surveys due to the lack of gender identity and expression measures, they have elevated health disparities relative to lesbian, gay, and bisexual older adults (Fredriksen-Goldsen, Cook-Daniels, et al., 2014); LGBT older adults of

color and those living in poverty also have elevated rates of health disparities (Fredriksen-Goldsen et al., 2011).

Yet, despite the health disparities that exist, many health-care providers don't have the knowledge and skills necessary to provide culturally relevant care (Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emler, & Hooyman, 2014). Previous negative experiences also may inhibit LGBTQ people from being open with their physicians and other providers, and as a result restrict information about potential health concerns, such as breast or prostate cancer or HIV risks.

It's important to remember that, while a health-disparate population, most LGBTQ older adults are doing well despite the risks. More lesbian, gay, and bisexual adults, compared to heterosexual older adults, are engaging in preventive health measures, including obtaining blood pressure screenings and HIV tests (Fredriksen-Goldsen, Kim, et al., 2017).

Risk and Resistance Through the Life Course

But why are some LGBTQ people not only surviving but thriving despite the adversity of their lives? Our research revealed that relentless adversity, stigma, and social exclusion have accumulative and negative impacts on health. Unfortunately, the Orlando massacre reminds us that historical trauma exists for LGBTQ people; most of today's LGBTQ older adults have been persecuted and victimized throughout their lives. We found that more than two-thirds of LGBTQ older adults have experienced victimization and discrimination more than three times in their lives, including discrimination in health, aging, and disability services (Fredriksen-Goldsen et al., 2011). On average, they reported 6.5 lifetime victimization and discrimination events (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emler, 2015).

Yet, despite the challenges faced, or perhaps because of them, three quarters of LGBTQ older adults reported engaging in antidiscrimination activism, with particularly high rates among bisexual women and transgender older adults (Fredriksen-Goldsen, Bryan, Jen, et al., 2017). One third regularly attended religious or spiritual activities (Fredriksen-Goldsen, Bryan, et al., 2017).

Our research finds that both positive and negative life events influence the health and well-being of LGBTQ older adults through their lifespan (Fredriksen-Goldsen, Bryan, Jen, et al., 2017). Concomitantly, key events are tied to generational differences. Of the three generations of LGBTQ older adults currently living in the United States today, many assume that, given the changing social context, the youngest of these generations, the Pride Generation, would experience less discrimination and victimization than the older generations. They came of age during the civil rights and women's movements, which led to the Stonewall Riots and the gay liberation movement. As they came of age, they also experienced changes in social and political context,

reflected in such policy changes as the movement toward decriminalizing sodomy, the declassification of homosexuality as a mental illness (Fredriksen-Goldsen & Kim, 2017), and the dramatic activism sparked by the onset of the AIDS pandemic.

When compared with the two older generations, the Invisible Generation and the Silenced Generation, the Pride Generation experienced the highest rates of victimization and discrimination, most likely related to the higher likelihood of disclosing their sexual or gender identity (Fredriksen-Goldsen et al., 2015). The Silenced Generation, the middle of these three generations, was bombarded during their formative years with public anti-gay sentiments, including the mandated firing of gay and lesbian federal employees, the classification of homosexuality as a mental disorder, and the telecast of the McCarthy hearings.

The Invisible Generation, the oldest LGBTQ adults, on the other hand, came of age during a time when there was little public discourse regarding sexual and gender minorities. These older adults reported the lowest rates of lifetime victimization and discrimination, along with the lowest levels of positive sense of sexual identity and disclosure, and more limited social resources (Fredriksen-Goldsen et al., 2015).

Uniquely situated within these generational differences and the impact of historical and contemporary victimization and discrimination, LGBTQ older adults have been shaped by the collection of experiences through their lives. This intersection of age and life events illuminates the immense diversity within this population.

Support and Caregiving

Across the generations, these communities found ways to care for one another, building their relationships and support networks as they lived in the margins. Caregiving in these communities, for example, is most often provided by partners, spouses, and friends (Muraco & Fredriksen-Goldsen, 2014; Shiu, Muraco, & Fredriksen-Goldsen, 2016), and has helped us to better understand mutuality in care, with both members of the partnership caring for one another. In examining the important role of extended kin in care, we identified the often-unrecognized role of ex-partners in care. Interestingly, even though LGBTQ people may be ostracized from their families of origin, some research suggested they are more likely to be caregivers than adults in the general population (deVries, 2013). The theme of coming out can have important implications when applied to caregiving, since it is the antithesis of hiding: invisibility creates vulnerability for LGBTQ older adults, as well as caregivers and their loved ones. Such aspects of care in these communities may help to inform the field of caregiving, highlighting what is distinct as well as universal in care.

Evidence revealed that many LGBTQ older adults are isolated, especially given that most rely on age-based

peer support systems (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). As their peers aged, they too often experienced their own health challenges, leaving long-term survivors at extreme risk of social isolation and premature institutionalization and death. Both transgender (Fredriksen-Goldsen, Cook-Daniels, et al., 2014) and bisexual older adults (Fredriksen-Goldsen, Shiu, Bryan, Goldsen, & Kim, 2016) reported larger social networks yet lower levels of social support compared with gay men and lesbians. It is important to consider the differing configurations of support for the diverse subgroups in these communities in order to develop evidence-based interventions that are responsive to their unique needs.

LGBTQ older adults and their caregivers have had to traverse how they manage their identities, and to whom and under what conditions they disclose or conceal their sexual and or gender identities. We asked one of the oldest participants in our study, who was 95, “How old were you when you first knew you were gay?” He answered, “15 years old.” When we asked, “How old were you when you first told someone you were gay?,” he answered, “90 years old.” We also asked why those that were most invisible participated in our study, and they responded that they wanted to create a legacy for their future: so how do we count them?

Count Me in

The field of LGBTQ aging has been stymied by the lack of pertinent data collected (see Appendix A: Best Practices for Ascertainment of Sexual Orientation and Gender Identity and Expression among Older Adults, in [Supplementary Materials](#)). The inclusion of sexual orientation and gender identity and expression questions are necessary in gerontological and public health research to ensure we have data available to assess the needs and experiences of LGBTQ older adults, to make informed policy choices that address the existing disparities, and to work toward the goals identified in Healthy People 2020 (U.S. Department of Health and Human Services, 2012), which aim to improve the health, safety, and well-being of LGBTQ people.

Until recently, national data was not available in the U.S., but in 2013 a sexual identity question was added to the National Health Interview Survey (Ward, Dahlhamer, Galinsky, & Joestl, 2014). Most national and state health surveys do not ask about sexual orientation or gender identity and expression, and among the population-based surveys that include sexual orientation measures, many only ask them of young and middle-age adults, excluding older adults (Redford & Van Wagenen, 2012).

The rationale for not asking older adults sexual orientation and gender identity questions seems to be anchored by several assumptions, including that older adults will neither understand nor respond to such measures and that such measures are too sensitive for older age groups. Yet, using state-level data, we found that older adult participants were more likely to respond to a sexual identity

question than an income question (Fredriksen-Goldsen & Kim, 2015). We also observed a significant increase in responses to sexual orientation questions over time among adults aged 65 and older, from about 96 percent in 2003 to 98.5 percent in 2010, which is comparable to the response rates of other age groups. In addition, our research finds that some at-risk LGBTQ groups, including the LGBTQ oldest adults and those of color, are less likely to self-identify in federally-funded surveys.

The removal of voluntary questions about sexual orientation and gender identity was recently proposed in two federal surveys: the National Survey of Older Americans Act Participants and the Annual Program Performance Report for Centers for Independent Living. These surveys provide data to assist in the allocation of resources for senior services. While it was later decided to reinstate the sexual orientation question in the National Survey of Older Americans Act Participants, the gender identity question has been removed, as have both questions from the Annual Program Performance Report for Centers for Independent Living. Decisions to not ask sexual orientation and gender identity questions among older adults must be reconsidered, given documented health disparities, rapidly-changing social trends in the response rates to such questions, and the need to better understand aging in our increasingly diverse society. In addition, the inclusion of sexual orientation and gender identity and expression questions may allow for harmonization across studies and help to reduce the stigmatization of LGBTQ populations. And, to be responsive to relatively small sample sizes, other techniques can be used as well, such as pooling data and oversampling in geographic regions with high concentrations of LGBTQ older adults (Fredriksen-Goldsen, Kim, Shiu, & Bryan, 2017). See Fredriksen-Goldsen & Kim (2017) for measures on sexual orientation and gender identity and expression and other related constructs, developed and validated by Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS).

Policy Matters

Given the current social context, I see an uptick in fear among LGBTQ older adults, who have walked out of the shadow cast by bias and discrimination. Our research show that discrimination is the strongest predictor of poor health among LGBTQ older adults. As the climate for change has cooled, these communities are increasingly confronted with bias, such as limited access to bathrooms and, most recently, shifting policies aimed at limiting the right of transgender people to serve in the U.S. military. In our study, we found that serving in the military was a protective factor associated with good health of transgender older adults (Hoy-Ellis et al., 2017).

Policies embracing social inclusion can make a difference. For example, the impact of marriage equality was significant and positive: participants who were married

Shifting contexts are not new to LGBTQ older adults, who have historically weathered – and continue to experience– changing social mores.

LGBTQ older adults, though perceived, and sometimes targeted, as the “other,” represent the ordinary yet profound aspirations for community and connection that all older adults share.

reported better health, were more public about their sexuality, and had greater social and economic resources than couples who were not married (Goldsen et al., 2017). Yet, women who were married reported experiencing higher rates of everyday bias compared to those not married. And while federal benefits of marriage are vast, such as Social Security spousal and bereavement benefits, they are only available to those married; about half of LGBTQ older adults in long-term relationships are not legally married. Furthermore, federal nondiscrimination laws in employment, housing, and public accommodations do not yet exist, so many LGBTQ older adults do not have protections against discrimination.

Shifting contexts are not new to LGBTQ older adults, who have historically weathered—and continue to experience—changing social mores. The lives of LGBTQ older adults can provide important lessons learned for the field of gerontology as they continue to find creative ways to build their communities and thrive in the face of adversity. In the end, LGBTQ older adults, though perceived and sometimes targeted as the “other,” represent the ordinary yet profound aspirations for community and connection that all older adults share.

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