

Intervention Research

Key Determinants of Physical and Psychological Health-Related Quality of Life Over Time Among Midlife and Older LGBTQ and Sexual and Gender-Diverse Caregivers

Karen Fredriksen-Goldsen, PhD,^{1,*} Sarah Jen, PhD,^{2,◊} Charles A. Emlert, MSW, PhD,^{3,◊} Hyun-Jun Kim, PhD,^{1,◊} and Hailey H. Jung, PhD¹

¹School of Social Work, University of Washington, Seattle, Washington, USA. ²School of Social Welfare, The University of Kansas, Lawrence, Kansas, USA. ³Social Work Program, University of Washington, Tacoma, Washington, USA.

*Address correspondence to: Karen Fredriksen-Goldsen, PhD, School of Social Work, University of Washington, 4101 15th Avenue NE, Seattle, WA 98105, USA. E-mail: fredrikk@uw.edu

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Abstract

Background and Objectives: Prior research has shown informal caregiving among older adults can negatively affect the caregiver's physical and psychological health. However, little is known about protective and risk factors associated with the health-related quality of life (HRQOL) of lesbian, gay, bisexual, transgender, and queer (LGBTQ) caregivers.

Research Design and Methods: Informed by the Health Equity Promotion Model and Caregiver Stress Process Model and utilizing longitudinal data from Aging with Pride: National Health, Aging, and Sexuality/Gender Study, this analysis examined modifiable risk and protective factors associated with psychological and physical HRQOL over time among 754 LGBTQ caregivers aged 50–98.

Results: Psychological and physical HRQOL declined over a 3-year period. After controlling for background characteristics, mastery, social support, socialization, LGBTQ community engagement, and physical activity were positively associated with psychological HRQOL while day-to-day discrimination, identity stigma, and insufficient food intake were negatively associated. Steeper declines were observed for older and with no physical activity. Mastery, social support, socialization, and physical activity were positively associated with physical HRQOL while day-to-day discrimination and insufficient food intake were negatively associated. Steeper declines were found for those with high mastery and no physical activity.

Discussion and Implications: Although generalized factors including mastery, socialization, and social support are protective for HRQOL among LGBTQ caregivers, factors including day-to-day discrimination and identity stigma are more unique to historically disadvantaged populations and should be considered in future research and practice. Caregiving interventions incorporating physical activity are promising given its buffering effect for decreased physical and psychological HRQOL over time.

Keywords: Caregiving, LGBTQ, QOL, sexual/gender minority

Background and Objectives

It is estimated that 48.1 million adults are currently providing informal care to individuals aged 50 and older in the United States, a 25% increase since 2015 (AARP, 2020).

While caregiving is often a necessary and common social role, it negatively affects the physical and emotional health among caregivers through greater physical strain, higher prevalence of disease and disability, increased emotional

stress, and higher rates of stress and depression (AARP, 2020; Achilike et al., 2020; Beach et al., 2000; Yates et al., 1999). The interwoven nature of financial strain, social isolation, and barriers to accessing support creates a multi-dimensional cycle of burden such that caregivers' physical and psychological health are shaped by a wide variety of complex and often interrelated factors (Pearlin, 1999). For instance, caregivers report more negative physical and psychological outcomes, which have been found to be associated with higher demands of care provision (Achilike et al., 2020; Vaingankar et al., 2016), rates of caregiving burden (Or & Kartal, 2019), and less access to social and caregiving resources and supports (Hong & Harrington, 2016; Ong et al., 2018). These experiences are widespread; a recent national survey found one fifth of caregivers (19%) reported high levels of physical strain from caregiving, while over one third (36%) considered their caregiving situation to be highly emotionally stressful (AARP, 2020).

While we have gained considerable knowledge about caregiving in the United States and its impacts on caregivers, research in this area has focused primarily on heterosexual and cisgender populations, resulting in a dearth of information about caregivers who identify as lesbian, gay, bisexual, transgender, and queer (LGBTQ) or are sexual and/or gender-diverse. However, in the most recent AARP (2020) report on *Caregiving in the U.S.*, LGBTQ caregivers made up 8% of total respondents. There is reason to believe that caregiving will become a growing issue among this population. Current estimates suggest as many as 2.4% of older adults in the United States identify as a sexual minority, accounting for 2.7 million older adults (Fredriksen-Goldsen & Kim, 2017). These individuals may be more likely to require informal care due to high rates of early onset of disability and disease (Fredriksen-Goldsen et al., 2013) paired with the fact many lack biological or legal kin, including children, to take on caregiving roles (Fredriksen-Goldsen 2007). Additionally, recent growth in the United States caregiving population reflects in part a greater preference for home- and community-based services (AARP, 2020). This option may be particularly appealing for LGBTQ individuals who report concerns about accessing formal and residential long-term care services and supports due to a lack of welcoming facilities and fear of discrimination (Fredriksen-Goldsen 2007). In fact, evidence does indicate that LGBTQ individuals are acting in caregiving roles at relatively high rates (Knauer, 2016). In a recent national study of LGBTQ adults aged 50 and older, nearly one third of participants were caregivers for another adult (Fredriksen-Goldsen et al., 2011).

In addition to the growing scale of this issue, LGBTQ individuals experience caregiving in unique ways when compared to their heterosexual and cisgender counterparts (Fredriksen-Goldsen, 2007). While the general population is most likely to provide care to an adult relative (89% of caregivers; AARP, 2020), LGBTQ older adults are more likely to provide care to a friend or partner, or someone

with whom they do not share a legally recognized relationship (Croghan et al., 2014). Additionally, as a health disparate population compared to heterosexual counterparts of similar age (Fredriksen-Goldsen et al., 2013, 2017), the strain associated with caregiving may further exacerbate these existing inequities. For instance, LGBTQ caregivers are on average younger and report more financial strain than their non-LGBTQ counterparts and provide a greater amount of medical and personal care to their care recipient (Anderson & Flatt, 2018; Fredriksen-Goldsen, 2007), a characteristic linked to greater physical and emotional burden (Polenick et al., 2017). A more recent study indicated that LGBTQ caregivers, like caregivers in the general population, often experience high levels of stress, which has been associated with lower income, provision of personal care, a greater number of caregiving hours, and lower levels of social support (Fredriksen-Goldsen 2007). However, in this study, differing from the general population, caregiver strain was also predicted by prior experiences of LGBTQ-related victimization, and over half of those caregivers reported experiencing a disability themselves. In recent comparison studies, LGB caregivers have also reported poorer overall subjective health compared to non-LGB caregivers although transgender caregivers did not report poorer health compared to cisgender counterparts (Boehmer et al., 2019) and have reported lower stress than nontrans LGBQ counterparts (Anderson et al., 2021). Qualitative studies and literature reviews have found that LGBTQ caregivers face unique risks—they have battled invisibility and insensitivity in mainstream caregiving support services and often lacked legal protections for their relationships (Muraco & Fredriksen-Goldsen, 2014). Historical forces such as prior experiences with discrimination inform fears of negative treatment, which in turn shape current willingness to access formal caregiving services and supports, added stress in transitions in care, and fear of disclosing one's sexual orientation to providers (Butler, 2017; Cloyes et al., 2018; Di Lorito et al., 2021). Caregivers in these communities also have differing social networks and supports and are likely to depend heavily on LGBTQ communities and families of choice in the place of formal services (Knauer, 2016). Such challenges may be more pronounced among LGBTQ older adults of color and individuals facing financial insecurities, making their care access situations particularly fragile or tenuous (Butler, 2017; Jones et al., 2018).

Most caregiving literature to date has been guided by the Caregiver Stress Process Model (Pearlin, 1999; Pearlin et al., 1990), which predicts that caregiver stress results from the confluence of caregiver characteristics (e.g., socioeconomic status), primary stressors related to characteristics of the caregiving situation (e.g., relationship with recipient), and secondary stressors external to the caregiving situation (e.g., work responsibilities), which can be offset by available resources (e.g., social supports). In addition to the Caregiver Stress Process Model, in this paper we utilized the Health Equity Promotion Model

(HEPM; Fredriksen-Goldsen et al., 2014), a conceptual framework developed to understand social determinants affecting the health and well-being of marginalized populations. The model highlights key factors relevant to the lives of LGBTQ caregivers, including intersecting background characteristics (e.g., age, sexuality, and gender), the adverse historical and contemporary context (e.g., lifetime discrimination, everyday discrimination, and microaggressions), and psychological (e.g., identity stigma and mastery), social (e.g., LGBTQ community engagement), and behavioral (e.g., physical activity and insufficient food intake) factors. Derived from the HEPM, we assessed stressors and resources relevant to LGBTQ identities and life experiences, including internalized stigma, prior experiences of victimization or discrimination and LGBTQ community engagement. These stressors may exacerbate or contribute to caregiver strain, whereas LGBTQ-specific resources may alleviate it. We recognize these stressors and resources may exist in addition to previously identified characteristics based on the Caregiver Stress Process Model (Pearlin, 1999; Pearlin et al., 1990), although they must also be considered within the historical and environmental context.

Anticipated growth in population size and caregiving roles among LGBTQ individuals indicate a need for research examining their unique experiences, risk and protective factors, and how these factors may change over time. In order to build a literature base in this substantive area, conceptual framing is needed that accounts for both the general health-related factors common among aging populations and those specific to LGBTQ caregiving. Thus, by drawing upon *both* conceptual frameworks we can more fully understand the convergence of factors that influence the well-being of caregivers in general alongside the specific historical and environmental context of LGBTQ caregivers to shape supports and interventions for this underserved population. Thus, this study, as one of the first analyses to examine health-related quality of life (HRQOL) and its predictors over time in this population rather than cross-sectionally, is designed to address the following research questions: (a) What modifiable risk and protective factors are associated with psychological and physical HRQOL over time of LGBTQ caregivers, aged 50 and older, controlling for background characteristics? and (b) What modifiable risk and protective factors moderate the effects of time on psychological and physical HRQOL among these caregivers?

Research Design and Methods

Data and Sample

The data come from the first national longitudinal study of LGBTQ and sexual and gender-diverse older adults, Aging with Pride: National Health, Aging, and Sexuality/Gender Study ($N = 2,450$), which investigates the life-course experiences and trajectories of health, aging, and

well-being among this population. Participants were recruited utilizing both contact lists of 17 aging agencies across all U.S. Census divisions and social network clustering chain referral nationally with stratification goals by cohort, gender, race/ethnicity, and geographic location. Social network clustering chain referral was used to recruit LGBTQ midlife and older adults not affiliated with aging agencies and to fulfill stratification goals. The study sample was weighted to reduce potential sampling bias. The inclusion criteria included being born in 1964 or earlier (age 50 and older) and self-identifying as lesbian, gay, bisexual, transgender or sexual or gender-diverse or as someone who is attracted to or has engaged in sexual behavior or a romantic relationship with someone of the same sex or gender. According to participant preference, paper and online baseline surveys were completed in 2014. In this analysis we focused on the experiences of caregivers in detail to specify their unique experiences; as such, this analysis used a subsample of 754 participants who at baseline reported they regularly provided informal care to another individual. Longitudinal data collected among caregivers in 2014 ($n = 754$), 2015 ($n = 719$: 95.4% retention from 2014), and 2016 ($n = 699$: 97.2% retention from 2015) were analyzed with the sample size of 2,172. Data collection procedures were approved by the Institutional Review Board of the University of Washington.

Measures

Measures aligned with the Stress Process Model include characteristics of the caregiving situation, psychological (mastery), social (social support and socialization), and behavioral (physical activity and insufficient food intake) factors which may moderate the impact of primary and secondary stressors. The selection of measures specific to LGBTQ-related experiences was informed by the HEPM including experiences of stigma, discrimination and identity, historically and current, and community engagement specific to LGBTQ communities.

Psychological and physical HRQOL

Psychological and physical HRQOL were repeated measures assessed using the World Health Organization Quality of Life (WHOQOL)-BREF (Bonomi et al., 2000). Seven items of physical (e.g., energy level, physical pain, etc.) and six items of psychological (e.g., affect, self-esteem, etc.) HRQOL were rated by participants. Summary scores were calculated as recommended by WHO (World Health Organization, 2012), ranging from 0 to 100; higher scores indicated better HRQOL. In the sample, physical HRQOL summary scores ranged from 3.6 to 100 ($m = 66.5$, $SD = 19.9$) with Cronbach's α of 0.85, 0.86, and 0.87 for 2014, 2015, and 2016, respectively (hereafter presented in chronological order). Psychological HRQOL summary scores ranged from 4.2 to 100 ($m = 68.1$, $SD = 17.3$) with Cronbach's α of 0.85, 0.86, and 0.85.

Adverse life events

Lifetime experiences of LGBTQ discrimination and victimization were assessed at baseline for 14 types of discrimination (e.g., employment, housing, health care, etc.) and victimization (e.g., verbal, physical, sexual, etc.) experienced due to being perceived as LGBTQ (0 = never to 3 = three or more times; Fredriksen-Goldsen & Kim, 2017). Summed frequency scores ranged from 0 to 42; higher scores indicated more adverse experiences. In the sample, scores ranged from 0 to 40 ($m = 6.5$, $SD = 7.7$). *Day-to-day discrimination* repeatedly measured experiences of stigma and unfair treatment, which may occur daily (e.g., “People do things that devalue and humiliate you”; 0 = never to 5 = almost every day). Mean scores were calculated across six items, with higher scores representing more day-to-day experiences of bias (Fredriksen-Goldsen & Kim, 2017). Scores ranged from 0 to 5 ($m = 0.9$, $SD = 0.9$) with Cronbach’s α of 0.90, 0.91, and 0.91. *LGBTQ Microaggressions* also assessed repeatedly participants’ experiences of subtle and indirect forms of stigma and bias such as micro-invalidation, micro-assault, and hostile environment (Fredriksen-Goldsen & Kim, 2017) with the mean across eight items (e.g., “People use derogatory terms to refer to LGBTQ individuals in your presence”; 0 = never to 5 = almost every day). Higher scores represented more experiences of LGBTQ microaggressions, and scores ranged from 0 to 4.88 ($m = 1.2$, $SD = 0.8$) with Cronbach’s α of 0.85, 0.83, and 0.82.

Psychological factors

Identity stigma repeatedly measured negative attitudes and feelings toward one’s own sexual or gender identity with a mean of the eight-item identity appraisal scale (e.g., “I feel ashamed of myself for being LGBTQ”; 1 = strongly disagree to 6 = strongly agree; Fredriksen-Goldsen & Kim, 2017); higher scores indicated higher stigma. Scores ranged from 1 to 6 ($m = 1.7$, $SD = 0.8$) with Cronbach’s α of 0.88, 0.86, and 0.90. *Mastery* was measured at baseline by the four-item scale from Lachman and Weaver (1998) with items such as “what happens to me in the future mostly depends on me” (1 = strongly disagree to 6 = strongly agree). Mean scores were calculated across the four items. Higher scores represented greater mastery, ranging from 1 to 6 ($m = 4.5$, $SD = 1.0$) with Cronbach’s α of 0.84.

Social factors

Social support was repeatedly measured with the abbreviated four-item scale (Gjesfeld et al., 2008) of the MOS-Social Support Survey (Sherbourne & Stewart, 1991); items asked, for example, whether a participant had: “Someone to help with daily chores if you were sick” (0 = never to 4 = very often). A summary score was created by calculating the average across the four items; higher scores represented higher support. Scores ranged from 0 to 4 ($m = 2.8$, $SD = 1.0$) with Cronbach’s α of 0.85, 0.86, and 0.86. *Socialization* was assessed at baseline by asking how

often participants had gone out for enjoyment in the past month (1 = never to 5 = every day). Scores ranged from 1 to 5 ($m = 3.2$, $SD = 0.9$). *LGBTQ community engagement* was repeatedly assessed with the four-item Community Engagement Scale (Fredriksen-Goldsen & Kim, 2017) to measure the degree of engagement in LGBTQ communities (e.g., “I feel part of the community”; 1 = strongly disagree to 6 = strongly agree). A summary score was created by calculating the mean across items; higher scores indicated more engagement. Scores ranged from 1 to 6 ($m = 4.1$, $SD = 1.2$) with Cronbach’s α of 0.87, 0.87, and 0.84.

Behavioral factors

Physical activity was repeatedly measured using the physical activity guidelines by the Centers for Disease Control and Prevention (2015), that is, whether participants engaged in moderate and/or vigorous activities for more than 150 min in total per week (1 = yes, 0 = no). Over three quarters of the sample met the physical activity guidelines in all years (82.3%, 75.1%, and 76.9%). *Insufficient food intake* was also measured repeatedly by asking how often in the last 2 weeks participants experienced insufficient food intake due to loss of appetite, digestive problems, and chewing or swallowing difficulties (1 = never to 5 = always). Scores ranged from 1 to 5 ($m = 1.6$, $SD = 0.8$).

Background and caregiving characteristics at baseline

Age was measured by subtracting one’s birth year from 2014. *Gender* was assessed as self-identification of women (= 0), men (= 1), and gender nonbinary/diverse (= 2). *Household income* was assessed as whether it was at or below (= 1) or above (= 0) 200% of the federal poverty guidelines (U.S. Department of Health and Human Services, 2018). *Education* was a three-level categorical variable indicating high school or less (= 1), some college (= 2), and college graduate or more (= 3). *Caregiving relationship* was assessed dichotomously as partner/spouse care (= 1) versus others (= 0). *Types of care* was also a dichotomous measure of personal care (= 1, any of dressing, grooming, toileting, bathing, and eating) versus other types of care (= 0).

Statistical Analysis

All analyses were conducted using Stata/MP 16.0 (StataCorp, 2019). First, we generated descriptive statistics of baseline background and caregiving characteristics, including percentage distribution, frequency or mean, and standard deviation, as applicable. Second, we examined the risk and protective factors of psychological and physical HRQOL using three time points of data. We employed multivariate mixed models using maximum likelihood estimation to adjust the dependence among repeat measures over time within an individual, and variance between individuals. We selected random intercepts model for parsimoniousness over random slopes model with time effects as the random component, for both psychological ($\chi^2(1) = 0.0$, $p = .9$)

and physical ($\chi^2(1) = 2.5, p = .1$) HRQOL, based on the log-likelihood ratio tests. Independent sigma matrix was specified for residuals for the selected random intercepts model. Controlling for background and caregiving characteristics, linear changes over time in psychological and physical HRQOL were estimated in addition to the effects of the risk and protective factors (Model 1). No multicollinearity among independent variables was confirmed by the Variance Inflation Factor. Finally, we explored the risk and protective factors for their moderating effects on changes in psychological and physical HRQOL over time (2014, 2015, and 2016). Time interaction with the factors was first analyzed by dimension (i.e., adverse life events and psychological, social, and behavioral factors); those factors significantly interacting with time were selected and combined into a single model (Model 2). Significant interactions were further probed for patterns by calculating and visualizing predictive margins using margins function of Stata.

Results

Background and Caregiving Characteristics

As shown in Table 1, the 754 caregiving participants were 67 years old on average ($SD = 8.9$) ranging from ages 50 to 98. The majority were men (54.1%), 42.7% were women, and 3.2% were gender-diverse. Over a third (36.3%) lived at or below 200% of the federal poverty guidelines. The majority had some college education (90.8%) with almost half having graduated from college (45.6%). Over one third (37.5%) were caring for a spouse or partner with 62.5% assisting other individuals. Among caregivers, 13.9% provided personal care, including dressing, toileting, and eating.

Predicting Psychological HRQOL Over Time

The first two columns in Table 2 present findings from the random intercepts models predicting psychological HRQOL among caregivers. As shown in Model 1, psychological HRQOL followed a linear declining pattern over the 3-year period ($b = -0.9, p < .001$). When adjusted for this time effect and background characteristics, day-to-day discrimination ($b = -1.8, p < .001$), identity stigma ($b = -2.8, p < .001$), and insufficient food intake ($b = -3.0, p < .001$) were negatively associated with psychological HRQOL, while mastery ($b = 6.2, p < .001$), social support ($b = 2.2, p < .001$), socialization ($b = 2.5, p < .001$), LGBTQ community engagement ($b = 1.8, p < .001$), and physical activity ($b = 2.7, p < .001$) were positively associated. Significant effects were not found in relation to lifetime discrimination and victimization or ongoing microaggressions. Regarding background characteristics, providing personal care was associated with lower psychological HRQOL ($b = -2.5, p < .05$), while older age was associated with higher psychological HRQOL ($b = 0.1, p < .05$).

Table 1. Background and Caregiving Characteristics at Baseline ($N = 754$)

Variables	Mean (<i>SD</i>)	% (<i>n</i>)
Age	66.5 (8.9)	
Gender		
Women		42.7 (322)
Men		54.1 (408)
Gender-diverse		3.2 (24)
Household income		
200% FPG		36.3 (271)
>200% FPG		63.7 (476)
Education		
High school or less		9.2 (69)
Some college		45.2 (339)
College graduate or more		45.6 (342)
Caregiving relationship		
Partner/spouse		37.5 (282)
Other		62.5 (469)
Types of care		
Personal care ^a		13.9 (105)
Other		86.1 (649)

Notes: FPG = federal poverty guidelines; *SD* = standard deviation.

^aPersonal care includes any of dressing, grooming, toileting, bathing, and eating.

Moderators for declining psychological HRQOL

Model 2 for psychological HRQOL (Table 2) displays significant moderators for the over-time declining pattern of psychological HRQOL. Significant interactions with time were found for age ($b = -0.1, p < .01$) and physical activity ($b = 1.3, p < .05$); the other risk and protective factors maintained their statistical (non)significance found in Model 1 and in Model 2. Older ages accelerated the decline of psychological HRQOL, reducing over time the advantage of older ages, which led to little difference in psychological HRQOL in 2016. On the other hand, physical activity decelerated the decline of psychological HRQOL and increased the benefit of physical activity over time leading to significant difference in psychological HRQOL in 2016. Figure 1 shows a visual representation of these interactions—time by age and time by physical activity.

Predicting Physical HRQOL Over Time

The last two columns in Table 2 present findings from random intercepts models predicting physical HRQOL. As shown in Model 1, physical HRQOL showed a linear declining pattern over time ($b = -0.8, p < .01$). When adjusted for the time effect and background characteristics, physical HRQOL was negatively associated with day-to-day discrimination ($b = -1.5, p < .01$) and insufficient food intake ($b = -4.6, p < .001$) while positively associated with mastery ($b = 4.4, p < .001$), social support ($b = 1.3, p < .01$), socialization ($b = 3.2, p < .001$), and physical activity ($b = 4.5, p < .001$). Personal care provision, identity-related

Table 2. Multivariate Mixed Models Examining Predictors of Psychological and Physical Health-Related Quality of Life (HRQOL) Over Time

Variable	Psychological HRQOL				Physical HRQOL			
	Model 1		Model 2		Model 1		Model 2	
	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>
<i>Background characteristics</i>								
Age	0.1 (0.0)	.030	0.2 (0.1)	.001	-0.2 (0.1)	.001	-0.2 (0.1)	.001
Gender ^a								
Men	-0.3 (0.9)	.738	-0.2 (0.9)	.777	1.7 (1.1)	.123	1.7 (1.1)	.113
Gender-diverse	0.1 (2.4)	.978	0.1 (2.4)	.981	-2.4 (3.1)	.434	-2.4 (3.1)	.439
Household income, 200% FPG	0.1 (1.0)	.895	0.1 (1.0)	.912	-6.1 (1.3)	<.001	-6.1 (1.2)	<.001
Education ^b								
Some college	-1.4 (1.6)	.380	-1.5 (1.6)	.360	0.7 (2.0)	.724	0.8 (2.0)	.688
College graduate or more	1.3 (1.7)	.421	1.3 (1.7)	.436	2.5 (2.1)	.241	2.6 (2.1)	.223
Partner/spouse care	-1.4 (0.9)	.107	-1.4 (0.9)	.105	-3.6 (1.1)	.001	-3.7 (1.1)	.001
Personal care	-2.5 (1.2)	.042	-2.5 (1.2)	.043	-2.2 (1.6)	.150	-2.3 (1.6)	.143
<i>Adverse life events</i>								
Lifetime LGBTQ discrimination and victimization	0.0 (0.1)	.866	0.0 (0.1)	.811	-0.1 (0.1)	.092	-0.1 (0.1)	.103
Day-to-day discrimination ^c	-1.8 (0.4)	<.001	-1.8 (0.4)	<.001	-1.5 (0.5)	.001	-1.5 (0.5)	.002
LGBTQ microaggressions ^c	-0.3 (0.4)	.480	-0.4 (0.4)	.350	-0.8 (0.5)	.086	-0.9 (0.5)	.064
<i>Psychological factors</i>								
Identity stigma ^c	-2.8 (0.4)	<.001	-2.8 (0.4)	<.001	0.1 (0.5)	.845	0.1 (0.5)	.811
Mastery	6.2 (0.5)	<.001	6.2 (0.5)	<.001	4.4 (0.6)	<.001	5.1 (0.6)	<.001
<i>Social factors</i>								
Social support ^c	2.2 (0.3)	<.001	2.2 (0.3)	<.001	1.3 (0.4)	.001	1.3 (0.4)	.001
Socialization	2.5 (0.5)	<.001	2.5 (0.5)	<.001	3.2 (0.7)	<.001	3.2 (0.7)	<.001
LGBTQ community engagement ^c	1.8 (0.3)	<.001	1.7 (0.3)	<.001	0.4 (0.3)	.253	0.3 (0.3)	.315
<i>Behavioral factors</i>								
Physical activity ^c	2.7 (0.6)	<.001	1.3 (0.9)	.157	4.5 (0.7)	<.001	2.3 (1.0)	.027
Insufficient food intake ^c	-3.0 (0.4)	<.001	-3.0 (0.4)	<.001	-4.6 (0.4)	<.001	-4.6 (0.4)	<.001
Time	-0.9 (0.2)	<.001	3.8 (1.8)	.034	-0.8 (0.3)	.001	0.5 (1.3)	.683
Time × Age	—	—	-0.1 (0.0)	.001	—	—	—	—
Time × Physical activity	—	—	1.3 (0.6)	.031	—	—	2.2 (0.7)	.002
Time × Mastery	—	—	—	—	—	—	-0.7 (0.3)	.014

Notes: *b* = unstandardized coefficients; FPG = federal poverty guidelines; LGBTQ = lesbian, gay, bisexual, transgender, and queer; SE = standard error.

^{a,b}Reference categories were women (gender) and high school or less (education), respectively.

^cTime-variant factors.

stigma, and LGBTQ community engagement did not significantly predict physical HRQOL. Regarding background characteristics, older age ($b = -0.2, p < .01$), lower income ($b = -6.1, p < .001$), and partner/spouse care ($b = -3.6, p < .01$) were negatively associated with physical HRQOL.

Moderators for declining physical HRQOL over time

As shown in Model 2 for physical HRQOL, mastery ($b = -0.7, p < .05$) and physical activity ($b = 2.2, p < .01$) moderated the over-time declining pattern of caregivers' physical HRQOL; the other risk and protective factors maintained their statistical (non)significance found in Model 1 and also in Model 2. We found faster decline of physical HRQOL with higher mastery level. Thus, the advantages in physical HRQOL at baseline associated with high mastery decreased over time, leading to less

difference in physical HRQOL associated with mastery in 2016 than at baseline. Furthermore, as depicted in Figure 2, physical HRQOL of those with low mastery was not predicted to decline. Meanwhile, the moderating effect of physical activity was similar to psychological HRQOL. As seen in Figure 2, physical activity slowed down the decline of physical HRQOL over time, resulting in greater advantage in physical HRQOL in 2016 among those who engaged in physical activity compared to those who did not.

Discussion and Implications

This study contributes to an understudied area of research by providing foundational information regarding the factors influencing HRQOL of midlife and older LGBTQ

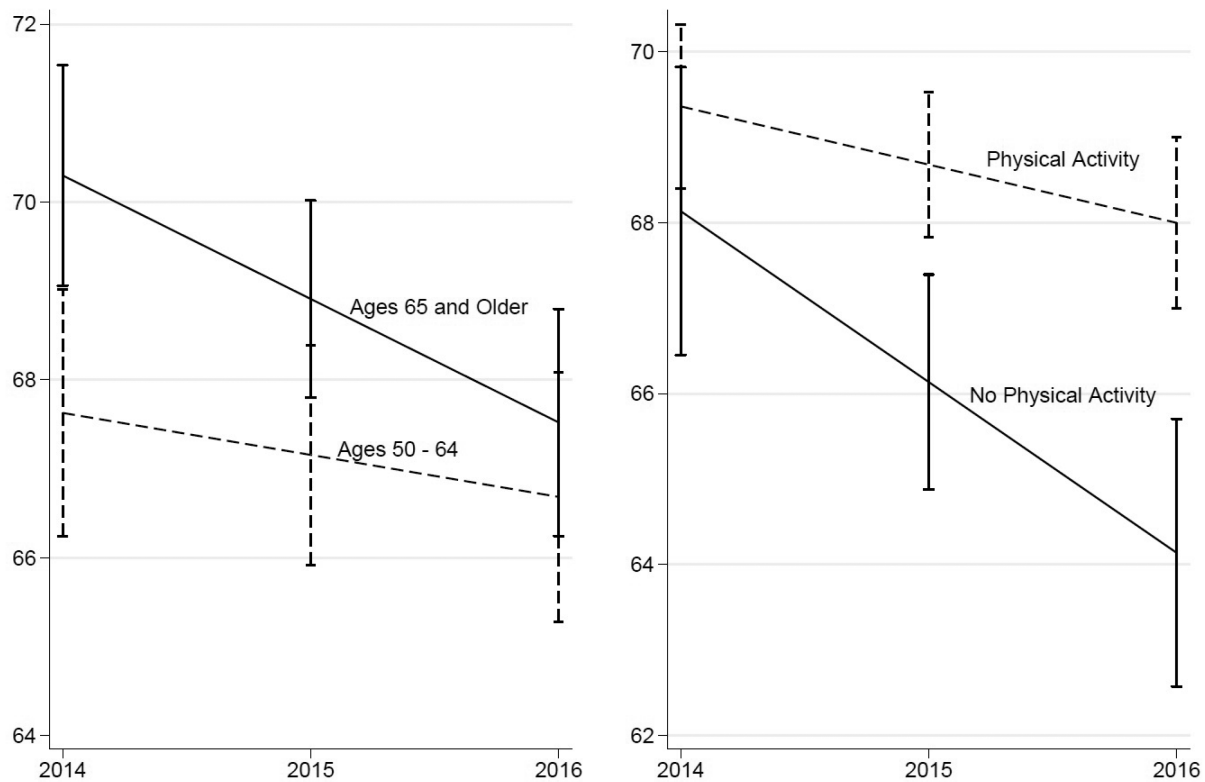


Figure 1. Moderating effects of age (left) and physical activity (right) in declining psychological health-related quality of life over time. *Notes:* Predictive margins and 95% confidence interval are presented on the y-axis. Slopes are -0.5 (ages 50–64), -1.4 (ages 65 and older), -0.7 (physical activity), and -2.0 (no physical activity).

caregivers. We contextualized these findings both within the broader caregiving literature and within the LGBTQ aging literature to assess lessons relevant to caregiving at large and the unique situations and needs of LGBTQ caregivers, including how their needs change over time.

While only preliminary evidence is available regarding the demographic characteristics of LGBTQ caregivers, somewhat surprisingly, this study indicated a slight majority of men were caregivers, 54% of the sample. This finding suggests the pattern of women assuming greater responsibility for caregiving roles does not hold among LGBTQ communities and reflects recent shifts toward greater balance across genders in caregiving (AARP, 2020). While gender-diverse individuals made up a small proportion of this sample (3.2%) and their experiences did not differ significantly from those of women in this case, their presence in the sample does indicate potential for future research specific to this population. It was also notable that one third of the sample reported living at or below 200% of the federal poverty guidelines, despite relatively high levels of education. This finding reflects a particular vulnerability among LGBTQ caregivers as financial hardships have been shown to contribute to the emotional strain associated with caregiving (Wight et al., 2003) and are also associated with lifetime victimization, poorer physical health, and barriers to health care access among LGBTQ older adults (Fredriksen-Goldsen et al., 2019).

Both psychological and physical HRQOL showed a linear declining pattern across the three points in time, likely reflecting the ongoing nature of care with the accumulation of caregiving-related strains (Beach et al., 2000), which distinguishes aging as a caregiver from aging without such roles and responsibilities. We drew from the Caregiver Stress Process Model to understand how background characteristics and primary and secondary stressors influenced caregiver health. To better understand the risk and protective factors associated with HRQOL among historically disadvantaged caregivers, we also employed the HEPM (Fredriksen-Goldsen et al., 2014), highlighting the interplay and intersectionality of background characteristics and the historical and environmental context in which these caregivers have lived and provided care. With the convergence of the Caregiver Stress Process Model and the HEPM, we examined potential psychological, social, and behavioral factors that may be associated with these caregivers' HRQOL. After controlling for background characteristics, we found day-to-day discrimination was a significant predictor of lower psychological and physical HRQOL, and identity stigma for lower psychological HRQOL, both of which are consistent with prior findings in which strain and the perception of adverse experiences have been found to predict quality of life and depressive symptoms among sexual and gender minority caregivers (Anderson et al., 2021). While identity stigma, lifetime

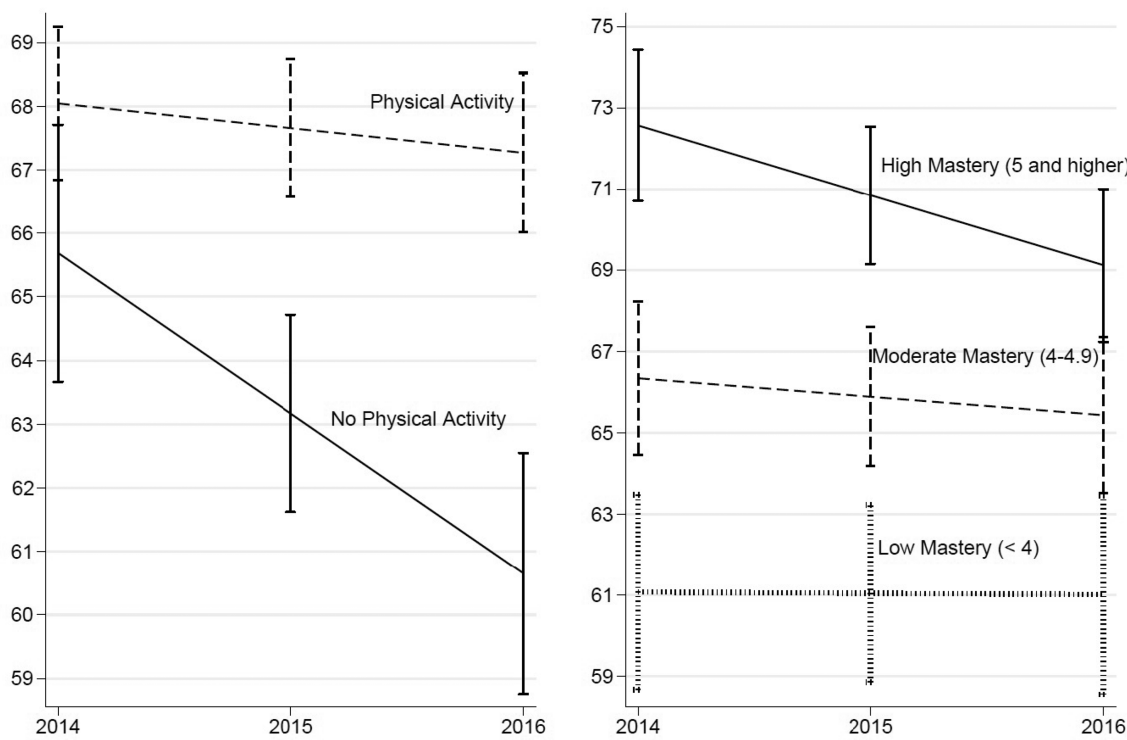


Figure 2. Moderating effects of physical activity (left) and mastery (right) in declining physical health-related quality of life over time. *Notes:* Predictive margins and 95% confidence interval are presented on the y-axis. Slopes are -0.0 (low mastery), -0.5 (moderate mastery), -1.7 (high mastery), -0.4 (physical activity), and -2.6 (no physical activity).

LGBTQ discrimination and victimization, day-to-day discrimination, and LGBTQ microaggressions are important factors in the lives of LGBTQ people in terms of predicting mental and physical health (Fredriksen-Goldsen et al., 2013, 2019), the findings in this study suggest ongoing bias and internalized LGBTQ identity stigma may have a unique cumulative effect for caregivers' quality of life. It is also possible caregiving places caregivers at risk for ongoing discrimination and bias in social service and health care settings, and identity stigma may lead to diminished support network and poor relationship quality (Frost & Meyer, 2009). These are significant predictors of psychological health among LGBTQ older adults, and practitioners and service providers should be trained to be more responsive to these unique risk factors among LGBTQ caregivers, so they can evaluate support needs and provide more appropriate resources (Fredriksen-Goldsen et al., 2018). These findings may also be extended to other marginalized populations who may have differing historical experiences, but shared reasons to be wary of formal supports.

Both psychological and physical HRQOL were positively associated with several psychological and social factors, including mastery, social support, and socialization indicating similar protective roles of social support among LGBTQ individuals as those found among cisgender and heterosexual samples in prior literature (Hong & Harrington, 2016; Ong et al., 2018) and as consistent with the Caregiver Stress Process Model. Uniquely to LGBTQ

caregivers, psychological HRQOL was also associated with LGBTQ community engagement. These factors indicate key areas for future intervention through enhancing resilience, promotion of social connections and participation, facilitation of physical activity, and creating opportunities for respite. In this analysis, socialization reflected one's ability to go out for purposes of enjoyment. This variable speaks to one of the key issues raised in caregiving literature, that of respite. When caregivers are able to access respite as a moderating supportive resource per the Stress Process Model (Pearlin, 1999), they have improved outcomes in reducing burnout and stress (Zarit et al., 2014). However, caregivers experience barriers to requesting assistance, such as a sense of responsibility or unwillingness on the part of the care recipient (van Exel et al., 2008). Additionally, LGBTQ individuals may hesitate to reach out to formal supports or experience policy-driven limitations if they are providing care to an individual with whom they share no legal relationship. To circumvent these barriers, the creation of welcoming respite services, provision of caregiver education on respite, and development of policies which recognize and define caregiving relationships broadly are needed.

Other areas for potential intervention include physical activity and insufficient food intake, both behavioral health factors that predicted psychological and physical HRQOL. In a recent longitudinal study comparing older caregivers with matched noncaregivers, caregivers were

less likely to meet nutrient intake recommendations and reported less physical activity than noncaregivers, which was mediated by caregiving hours (Snyder & Vitaliano, 2020). Given the importance of both nutrient intake and physical activity for maintaining optimal physical health (Nied & Franklin, 2002; Rullier et al., 2014), these caregiver health-related behaviors are important areas for targeted intervention.

The findings suggest physical activity is not only associated with overall higher HRQOL, both psychological and physical, but also slows their over-time decline, leading to larger difference in psychological and physical HRQOL in later years. Developing and implementing programs that assist and facilitate physical activity among LGBTQ caregiver older adults and provide education on the long-term benefits of physical activity are warranted.

Over-time decline of psychological HRQOL was also moderated by caregivers' age. The advantages of higher psychological HRQOL among older caregivers diminished over time because psychological HRQOL decreased faster with increasing age. Multifaceted changes often associated with age, such as physical constraints, compounded by caregiving responsibilities, may precipitate declines in psychological HRQOL, which is consistent with the Stress Process Model.

Surprisingly, physical HRQOL declined over time among LGBTQ caregivers with higher mastery. This finding suggests that advantages of physical HRQOL associated with higher mastery diminished over time. Mastery, a psychological factor, may have a more complex relationship with physical HRQOL as suggested by a previous study (Sargent-Cox et al., 2015) where positive association of mastery to physical health was indirectly mediated by physical activity. Future studies should further examine how longitudinal changes in physical HRQOL among LGBTQ caregivers are associated with mastery and other potential mediating factors.

Limitations and Future Research

While this study contributes key foundational knowledge related to significant health-related protective and risk factors among LGBTQ caregivers, there are some notable limitations that may be addressed through future research. Additional waves of longitudinal data will likely contribute to a more comprehensive understanding of trajectories of caregivers' psychological and physical HRQOL over time as will comparisons of the experiences and health outcomes of LGBTQ caregivers and noncaregivers. Also warranted are the examinations of HRQOL over time in relation to changes in functional limitations and/or other conditions in addition to the factors examined in this study (Thompson et al., 2012). The analytic methods used do not suit interpretations of causality, as more waves of data are needed to fully assess the risk and protective effects on HRQOL. For example, additional data are needed to tease

out if engaging in physical activity or having greater capacity for physical activity over time are related to higher HRQOL. Likewise, mastery may operate as a proxy of HRQOL rather than as a protective factor. Due to the nature of the initial study which was focused on overall life experiences and health of LGBTQ midlife and older adults, there were limited caregiving-specific measures to incorporate into this analysis which may be indicated by prior research on caregiver burden and health, such as detailed characteristics of the caregiving situation which are associated with physical and mental health (e.g., financial burden, caregiving demands, assessment of relationship strength, etc.). Such factors may further illuminate health-related pathways among LGBTQ caregivers in future research. Our analysis did not take into account the presence or absence of dementia. A recent study (Sheehan et al., 2021) compared caregivers of those with and without dementia and found caregivers of those with dementia reported higher appraisals of stress and burden, greater depression, and more behavioral problems among care recipients. Further research of the impact of dementia among LGBTQ caregivers and appropriate and acceptable interventions are needed. The importance of health behaviors in this study, particularly physical activity, suggests that research examining both the influence and interactions of such behaviors is needed to guide intervention efforts in this arena.

Conclusion

Diversity by sexuality and gender provides insights into the varied experiences of the heterogeneous population of U.S. caregivers and indicates specific prevention and intervention needs. LGBTQ people have a long history of caring for their own, as evidenced by the historical context of the HIV pandemic in which communities banded together to provide informal caregiving and bereavement supports amid egregious societal marginalization and discrimination. The aging population, and those caring for them, continues to grow in size and diversity; by studying this population, we gain insights into how these communities can optimize their strengths and be better supported by formal services, with the potential for lessons learned for all caregivers.

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Conflict of Interest

None declared.

Data Availability

Data used for this paper contain information that could compromise the privacy of research participants and are therefore not publicly available.

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