Stress and Resilience among Sexual and Gender Diverse Caregivers

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Abstract
Little is known about caregiving outcomes of sexual and gender diverse, including LGBT, caregivers. Informed by the Health Equity Promotion Model (HEPM) and Pearlin's Stress Process Model, we utilized data from Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS), to examine perceived stress among a sample of 754 sexual and gender diverse caregivers using regressions on background and caregiving characteristics and risk and protective factors. Among caregivers, 38% were providing care to a spouse or partner and about one-third to a friend (29%). Higher stress was associated with younger age, lower income, higher education, partner/spouse care, personal care provision, longer caregiving hours, and caregiver cognitive impairment. After including the risk and protective factors from HEPM, victimization, social support, and community engagement significantly predicted perceived stress. Findings contribute to emergent research on caregiving in diverse populations.

Introduction

Caregiving is a current and pressing public health and policy issue, as the number of Americans providing unpaid care has increased by 9.5 million over the past 5 years, from 43.5 million in 2015 to 53 million in 2020 (National Alliance for Caregiving [NAC], 2020). Caregivers (of someone 18 or older) now make up nearly one-fifth of the population at large (19.2%, up from 16.6% in 2015; NAC, 2020). The proportion of caregivers is anticipated to increase with the largest growth in the provision of unpaid informal older adult care, as the number of baby boomers aging into retirement continues to grow. The anticipated increase in those providing and receiving care necessitates a better understanding of caregiving dynamics, experiences, and impacts across diverse communities.

Challenging care-related issues tend to arise among informal caregivers, such as high rates of emotional strain, often operationalized as caregiver stress or burden, financial insecurity, and poor physical health, including physical strain, prevalence of disease and disability, and physical impairment (Beach et al., 2000; NAC, 2020; Schulz & Beach, 1999; Yates et al., 1999). Care characteristics and outcomes related to caregiving have been shown to vary according to the race and ethnicity, age, and gender of both the caregiver and recipient, indicating that unique issues arise among diverse communities (NAC, 2020). Yet, to date relatively few studies have examined the caregiving experiences of sexual and gender diverse caregivers.

Stress has been conceptualized and examined as a key mechanism through which characteristics of the caregiver, care recipient, and caregiving situation influence caregiver health and well-being (Blair & Perry, 2017; Truzzi et al., 2012; Zarit et al., 1980). In particular, Stress Process Model Pearlin's & Bierman (2013) has been utilized frequently to conceptualize linkages between stress, caregiving characteristics, protective factors, and health outcomes among caregivers (Judge et al., 2010; Lilly et al., 2012). For example, key caregiving factors including the type of caregiving relationship, type and hours of care provided, length of time providing care, and higher care needs, have been found to influence the stress experience among caregivers (Thornton & Travis, 2003; Walker et al., 1995). While this area of literature is empirically and conceptually well-developed, there remains a paucity of literature specific to understudied populations, especially among sexual and gender diverse caregivers, including lesbian, gay, bisexual, transgender, and queer (LGBTQ) older adults.

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A small body of extant literature indicates that the experience and impacts of caregiving may be unique among sexual and gender diverse older adults. For example, the initial need for care may be greater among this population. Based on population estimates, 2.4% of adults aged 50 and older openly identify as lesbian, gay, bisexual, or transgender, accounting for more than 2.4 million older adults in the U.S. (Fredriksen-Goldsen & Kim, 2017). Compared with heterosexuals of similar ages, these individuals are more likely to experience poor health, disability, and mental distress (Fredriksen-Goldsen et al., 2013), which may increase their need for care and support. As has been suggested by the Health Equity Promotion Model (HEPM; Fredriksen-Goldsen, Kim, et al., 2017), many sexual and gender diverse older adults have also experienced stigma and bias in mainstream healthcare, social services or residential long-term care settings (Fredriksen-Goldsen et al., 2017), often resulting in distrust (Jenkins Morales et al., 2014; Sullivan, 2014), which may place a higher burden on informal caregiving.

To better understand caregiving within this community, it is important to consider the key components in the HEPM. The model, seen in Figure 1, is unique in that unlike previous theories used to examine caregiving among sexual and gender diverse older adults, it highlights the importance of the historical and social context and addresses the complexity of the interaction between the context and individual lives (Fredriksen Goldsen et al., 2019). It signifies how unique challenges and strengths impact the full range of adverse and positive experiences that may influence sexual and gender diverse caregivers (Fredriksen-Goldsen & Kim, 2017). For example, experiences of stigma and violence are associated with poorer physical and mental health and disability (Fredriksen-Goldsen et al., 2013). Furthermore, social support, LGBTQ community engagement, and connection to sexual and gender diverse communities as protective factors have been found to be associated with positive outcomes in this population (Erosheva et al., 2016; Fredriksen-Goldsen et al., 2017).

A key component of the model focuses on intersectional identities, as such, in this paper we assessed the background characteristics of the sample including sexual and gender identity along with key factors identified in the caregiving literature, i.e., education, income, and relationship status (NAC, 2020). Moreover, while social isolation is a common concern among caregivers broadly (Poo & Conrad, 2009), sexual and gender diverse older adults report unique barriers to finding adequate support (Erosheva et al., 2016). Many have differing social networks and support systems (Kim et al., 2017) and many sexual and gender diverse people have reported estrangement from their biological families due to bias or stigma related to their sexual orientation or gender identity or expression, which can lead them to rely primarily on friends, partners, and other members of their families of choice (i.e., relationships offering care and support extending beyond those legally or biologically recognized) to provide care and to serve as supportive networks, most often peer-based supports (Muraco & Fredriksen-Goldsen, 2011). It is also important to note that while financial issues are common among caregivers of diverse backgrounds, sexual and gender diverse caregivers are more likely to report higher financial strain than heterosexual counterparts (27% vs. 18%; NAC, 2020). Researchers have also identified a reported lack of formal service provider "readiness" to support sexual and gender diverse caregiving, which further increases the felt strain and isolation among informal sexual and gender diverse caregivers (Brennan-Ing et al., 2013; Croghan et al., 2014; Muraco & Fredriksen-Goldsen, 2011; Orel & Coon, 2016; Valenti & Katz, 2014). Additional caregiving challenges may arise given their higher odds of health-risk behaviors such as substance use and lack of physical activity and of chronic conditions among sexual and gender diverse older adults (Fredriksen-Goldsen, Emlet, et al., 2013; Fredriksen-Goldsen, Kim, et al., 2013).
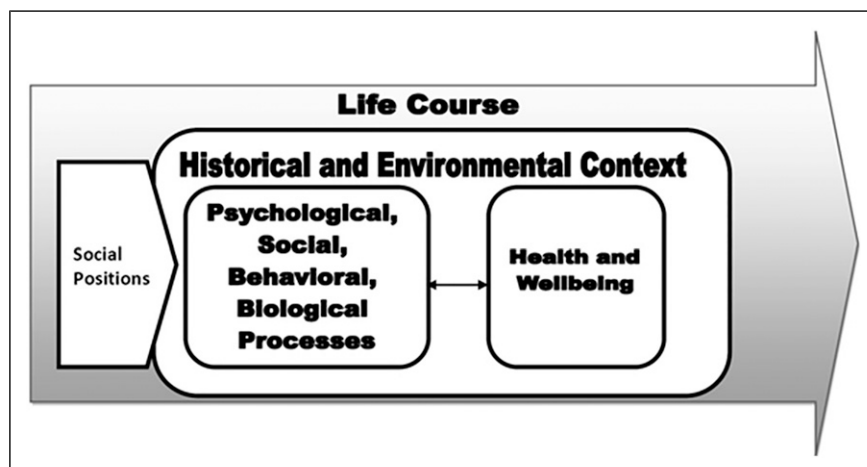

Figure 1. Health Equity Promotion Model (HEPM).

In conceptualizing the current analysis, we also draw upon the Stress Process Model (Pearlin & Bierman, 2013), which identifies sources of stress specific to the caregiving process. In this paper, perceived stress is the outcome of interest as it offers an important conceptual link to the broader body of research on caregiving (Montgomery et al., 1985; Pearlin & Bierman, 2013; Pearlin et al., 1990). Consistent with the Stress Process Model, this study examined specific characteristics of the caregiving context that have been found to be associated with perceived stress of caregivers, including the type of relationship between the caregiver and care recipient, type of care provided (e.g., personal, financial, instrumental, etc.), level and amount of care needed, and financial support (NAC, 2020). Social support has also been found to be a key protective factor in relation to caregiver stress (Haley et al., 2003; Pearlin et al., 1990). We integrate these key components of the Stress Process Model with the HEPM, which articulates key determinants of adverse outcomes and well-being in historically underserved and yet resilient populations (e.g., stigma, lifetime discrimination, victimization, and LGBTQ community engagement).

When caregivers are informally and formally supported, they report reduced stress, better quality of life, and more satisfaction with caregiving, and in turn provide better care (NAC, 2020; Pearlin et al., 1990). However, in the case of sexual and gender diverse caregivers, gaps in knowledge about their unique caregiving experiences may inhibit the development of effective preventative programming and culturally relevant interventions. The current study is therefore motivated by a need to better understand the stress related experiences of sexual and gender diverse caregivers. Specifically, we will address two research questions: (1) What are the characteristics of sexual and gender diverse informal caregivers, including their background and caregiving characteristics? (2) What background characteristics, caregiving characteristics, and caregiving risk and protective factors predict perceived stress among sexual and gender diverse informal caregivers?

Methods

Data

In the current analysis, we used 2014 baseline data from the ongoing Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS). National Health, Aging, and Sexuality/Gender Study is the first national longitudinal survey of sexual and gender diverse older adults aged 50 and older in the U.S. Participants self-identified as lesbian, gay, bisexual, transgender, or sexual or gender diverse, or have reported same-gender sexual behavior or romantic relationships to meet the study criteria. Participants ($N = 2450$) were recruited across all U.S. census divisions via contact lists of service organizations. In addition, social network clustering chain referral was utilized to secure sufficient proportions of

underrepresented subgroups including older adults of color and those not connected to service organizations. This entailed asking current participants to assist in recruiting individuals from their social networks into the study, through which an additional 238 participants were recruited. The sample was stratified by age cohort, gender, race/ethnicity, and geographic location. Mail-in or electronic surveys, according to participants' preference, were self-administered and available in either English or Spanish. Informed consent was obtained, and all research protocols were approved by the Human Subjects Division of the University of Washington. This research used a subsample of informal caregivers ($n = 754$, 31%) from the larger study, who indicated in the survey that they assisted a partner/spouse, friend, or family member who had a health issue or other needs.

Measures

Analyses included background characteristics, measures representing concepts from the Stress Process Model including perceived stress, social support, social network, and characteristics of the caregiving relationship, and measures drawn from the HEPM which are specific to LGBTQ populations (stigma, LGBTQ community engagement, and lifetime discrimination and victimization.).

Perceived Stress. *Perceived stress* was measured with the mean of the 4-item short form of the Perceived Stress Scale (PSS; Cohen et al., 1983; Cohen & Williamson, 1988). Items ask about general perceived stress (e.g., "How often have you felt that you were unable to control the important things in your life?") with each being rated on a Likert scale (1 = *Never* to 5 = *Very often*). In this sample, scores ranged from 1 to 4.8 with a mean of 2.3 ($sd = 0.8$; $\alpha = 0.78$). Higher scores indicated higher levels of perceived stress. The PSS' construct validity has been established in previous studies among older adults (e.g., Fredriksen-Goldsen et al., 2017; Luchesi et al., 2016).

Caregiving Risk and Protective Factors. *Stigma* was assessed with the mean of four items measuring negative attitudes toward their identity (e.g., "I feel ashamed of myself for being LGBT"; Fredriksen-Goldsen & Kim, 2017) rated on a Likert scale (1 = *Strongly disagree* to 6 = *Strongly agree*). Scores ranged from 1 to 6 with a mean of 1.5 ($sd = 0.8$; $\alpha = 0.82$), and higher scores indicated higher stigma. *Lifetime discrimination and victimization* were measured as summed frequencies of five discriminatory and nine victimizing events experienced over their lifetime for being or being perceived to be LGBT. Each event was assessed on a 4-point Likert scale (0 = *Never* to 3 = *Three or more times*). Items include "I was not hired for a job" and "I was prevented from living in the neighborhood I wanted" for discrimination, and "I was punched, kicked, or beaten" and "I had an object thrown at me" for victimization. Ranges were 0 to 15 and 0 to 27 with a mean of 1.6 ($sd = 2.8$) and 4.8 ($sd = 5.7$), respectively (α not reported for summed

scores), with higher scores indicating more experiences. *Social support* was measured by the abbreviated 4-item instrument (Gjesfjeld et al., 2008) of MOS-Social Support Scale (Sherbourne & Stewart, 1991) assessing frequency of available tangible, emotional-informational, affectionate, and interactional support on a 4-point Likert scale from 0 (= *Never*) to 4 (= *Very often*). It ranged from 0 to 4 with a mean of 2.9 (*sd* = 1.0; α = 0.90) with higher scores indicating more support. *Social network* was computed by summing the number of people who the participants reported having close relationships with for each of the following relationships: children, other immediate family members (e.g., brothers or sisters, parents, cousins, or grandchildren), ex-partners, friends, and neighbors (Fredriksen-Goldsen & Kim, 2017). The number reported for each relational type was truncated to 10 if 10 or higher to reduce the influence of outliers. The summed score was up by 1 for those with a close relationship with their partner/spouse, ranging from 0 to 44 with a mean of 9.1 (*sd* = 5.9). Higher scores indicated larger networks. *LGBTQ Community engagement* was assessed with a mean of four items measuring the degree of participants' engagement in their communities (e.g., "I help other people in the community"; 1 = *Strongly disagree* to 6 = *Strongly agree*; Fredriksen-Goldsen & Kim, 2017). Scores ranged from 1 to 6 with a mean of 4.1 (*sd* = 1.2; α = 0.87) and higher scores indicated stronger community engagement.

Caregiving Characteristics. *Care relationship* was dichotomous indicating whether participants provided care to partner/spouse or others (including friends, parent or parent-in-law, ex-spouse or ex-partner, child or grandchild, and other relatives). *Type of care* was assessed as personal care (including dressing, grooming, toileting, bathing, and/or eating) versus other types of care which were not mutually exclusive (e.g., instrumental care [transportation, grocery shopping, doing laundry, or preparing food], handling finances, financial support [less than $300 a month, $300 to $999, or $1000 or more per month], or managing care provided by others). *Hours of care* was measured by the number of hours in a typical week spent on caregiving as 15 or more hours-versus 14 or less hours. *Duration of care* was the length of time caregiving, i.e., less than 2 years or two or more years.

Background Characteristics. *Age* was calculated by subtracting birth years from 2014 and ranged from 50 to 98 (*m* = 66.5, *sd* = 8.9). *Race/ethnicity* was coded dichotomously, i.e., non-Hispanic white versus people of color. Sexual identity was assessed and coded as lesbian or gay, bisexual, and sexually diverse (heterosexual or notlisted). Gender was assessed and coded as woman, man, and gender diverse (not listed). *Gender identity was assessed by* whether participants identified as transgender. *Income* was assessed and coded dichotomously to indicate household income above versus at or below 200% of

federal poverty guidelines (FPG) (U.S. Department of Health and Human Services, 2013). *Education level* was high school or less versus some college or more. *Relationship status* was whether participants were married or partnered versus not married or partnered. *HIV status* was whether participants had ever been diagnosed with AIDS or HIV positive. *Cognitive impairment* was measured with the 6-item cognition subscale of the World Health Organization Disability Assessment Schedule (WHO-DAS) II (Üstün, et al., 2010). Participants indicated how much difficulty they had in the past 30 days with cognitive tasks such as "learning a new task" and "starting and maintaining a conversation" (0 = *None* to 4 = *Extreme difficulty or cannot do*). Scores ranged 0 to 90 with a mean of 17.2 (*sd* = 16.7; α = 0.87) as calculated according to the user manual with higher scores indicating more difficulty or impairment. *Disability* was based on the measure utilized by the U.S. Department of Health and Human Services (2011) with any of the following six areas coded as having a disability: (1) serious difficulty in seeing, (2) serious difficulty in hearing, (3) serious difficulty in walking or climbing stairs, (4) serious or extreme difficulty in concentrating, remembering, or making decisions, (5) difficulty in dressing or bathing, and (6) difficulty in running errands alone such as grocery shopping.

Analysis

Analyses were conducted using Stata/MP 16.1. First, background and caregiving characteristics and key risk and protective factors were descriptively analyzed using frequencies and percentages for categorical variables and means and standard deviations for continuous variables. Second, Pearson's correlations were run to examine bivariate associations among all study variables including perceived stress, background and caregiving characteristics, and risk and protective factors. Third, perceived stress was regressed on background and caregiving characteristics and risk and protective factors using a multiple hierarchical linear regression in two blocks. Model 1 regressed perceived stress on background and caregiving characteristics. Model 2 added the risk and protective factors to examine how these factors were associated with perceived stress after taking into consideration the background and caregiving characteristics. The change in R^2 from Model 1 to Model 2 was examined via the Wald tests. The absence of multicollinearity was confirmed using VIFs. The alpha was set to .05, but the exact *p*-values and the *p*-values corrected for potential inflation of Type I error in Model 2 (Anderson, 2008) were also reported. Nonetheless, it is thought that greater importance lies on detecting as many true differences as possible by reducing Type II error than correcting for Type I error given the area of research on informal caregiving in this population is vastly under explored.

Results

Background Characteristics

Table 1 shows descriptive statistics of the sample ($N = 754$). The vast majority (86%) were lesbian or gay, 9% were bisexual, and 5% reported other diverse sexual identities. Women and men made up 43% and 54% of the sample respectively and the other 3% were gender diverse. Transgender individuals made up 8% of the sample. Those aged 50 to 64, 65 to 79, and 80 or older comprised 44%, 47%, and 9%, respectively. Almost three quarters were non-Hispanic Whites (73%) whereas Hispanics, non-Hispanic Black, and other races respectively made up 10%, 9%, and 8%. Over a third reported an income at or below 200% of FPG while only 9% had high school or less education. The majority were married or partnered (56%). One in six were living with HIV and/or AIDS, and 52% had a disability.

Regarding caregiving characteristics, 38% provided care to their partner or spouse and 62% to others (29% friends, 12% parent or parent-in-law, 7% ex-partner or ex-spouse, 3% child

or grandchild, 8% other relatives, and 3% others). About 14% provided personal care (assistance with dressing, grooming, toileting, bathing, and/or eating) and 86% provided other types of care only (66% instrumental care [transportation, grocery shopping, doing laundry, preparing food], 31% handling finances, 30% financial support [41% of these spent less than $300 a month; 31% $300 to $999; and 28% $1000 or more per month], and 23% management of care provided by others). Regarding hours of care, 22% provided 15 or more hours of care per week (12% for 15–28 hours and 10% for 29 or more hours) and more than three-quarters (78%) spent 14 or less hours per week. In terms of duration of care, 72% had been providing care for 2 years or more (30% for 2–5 years and 42% for more than 5 years), with 28% providing care for less than 2 years.

Correlations among Study Variables

As Table 2 illustrates, there were moderate correlations with r being .30 or higher among study variables. Perceived stress had a positive correlation with cognitive impairment ($r = .53$) and a negative correlation with social support ($r = -.38$). Cognitive impairment was positively correlated with disability ($r = .34$). Social network had a positive correlation with social support ($r = .33$) and LGBTQ community engagement ($r = .30$). Among caregiving characteristics, personal care and partner care were correlated with longer weekly hours (≥ 15) of care ($r = .36$ and .29, respectively). More hours of care were correlated with lower LGBTQ community engagement ($r = -.08$) and higher perceived stress ($r = .14$). Longer duration of care (≥ 2 years) was positively correlated with partner care ($r = .16$), more hours of care (≥ 15 per week; $r = .11$), and disability ($r = .09$). Partner care and personal care was not significantly correlated. HIV-positive status was correlated with being male ($r = .36$), and lower income was correlated with less education ($r = .30$). Younger ages were correlated with being people of color ($r = -.31$). Transgender identity was correlated with sexually diverse ($r = .39$) and gender diverse identities ($r = .53$).

Predicting Perceived Stress among Caregivers

Model 1 of Table 3 presents the findings from the regression of perceived stress with the background and caregiving characteristics included. Higher perceived stress was associated with younger age ($b = -0.01$, $p = .003$), lower income ($b = 0.14$, $p = .02$), and cognitive impairment ($b = 0.02$, $p < .001$), and among caregiving characteristics, with providing personal care ($b = 0.16$, $p = .04$) and 15 or more hours of care per week ($b = 0.20$, $p = .002$).

The risk and protective factors of Model 2 accounted for significant additional variance of perceived stress beyond what was explained by the background and caregiving characteristics in Model 1 (R^2 change $= 0.07$, $F = 13.3$, $p < .001$). Victimization was associated with perceived stress,

Table 1. Background and Caregiving Characteristics and Caregiving Risk and Protective Factors among Caregivers ($N = 754$).

Background Characteristics	
Sexual identity, n (%)	
Lesbian and gay	645 (85.8)
Bisexuals	67 (8.9)
Other sexually diverse	40 (5.3)
Gender, n (%)	
Women	322 (42.7)
Men	408 (54.1)
Other gender diverse	24 (3.2)
Transgender, n (%)	60 (8.0)
Age, m (sd)	66.5 (8.9)
People of color, n (%)	199 (26.5)
Income ≤ 200% FPG, n (%)	271 (36.3)
High school or less, n (%)	69 (9.2)
Partnered/married, n (%)	417 (55.6)
HIV Positive, n (%)	127 (16.8)
Cognitive impairment, m (sd)	17.2 (16.7)
Disability, n (%)	380 (51.8)
Caregiving characteristics, n (%)	
Care relationship: Partner/spouse care	282 (37.6)
Type of care: Personal care	105 (13.9)
Hours of care (per week): ≥ 15 hours	154 (22.1)
Duration of care > 2 years	516 (71.5)
Caregiving risk and protective factors	
Stigma, m (sd)	1.5 (0.8)
Discrimination, m (sd)	1.6 (2.8)
Victimization, m (sd)	4.8 (5.7)
Social support, m (sd)	2.9 (1.0)
Social network, m (sd)	9.1 (5.9)
LGBTQ community engagement, m (sd)	4.1 (1.3)

Note. FPG = federal poverty guidelines.

Table 2. Correlations between Study Variables.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
1 Lesbian and gay	1																								
2 Bisexual	−.03 .48	1																							
3 Sexually diverse	.11 .004	.02 .54	1																						
4 Women	−.23 <.001	−.03 .40	−.13 .76	1																					
5 Men	−.37 <.001	.15 <.001	.39 <.001	.01 .71	1																				
6 Gender diverse	.09 .009	−.09 .02	−.03 .34	−.03 .34	−.20 <.001	1																			
7 Transgender	−.15 <.001	.12 .001	.09 .02	−.08 .02	.06 .10	−.07 .04	1																		
8 Age	−.18 <.001	.17 <.001	.06 .13	−.06 .08	.07 .04	.03 .44	−.16 <.001	1																	
9 People of color	−.07 .06	.06 .09	.03 .46	−.03 .36	.04 .33	−.01 .76	.12 .002	−.31 <.001	1																
10 Income ≤ 200% FPG	−.03 .42	.02 .57	.02 .59	−.36 <.001	.36 <.001	−.02 .56	.05 .14	−.08 .03	.27 <.001	1															
11 HS or less	−.16 <.001	.12 .001	.10 .005	−.10 .008	.09 .01	.02 .65	.13 .001	−.06 .08	.16 <.001	.30 <.001	1														
12 HIV positive	−.08 .02	.02 .57	.02 .59	−.26 <.001	.21 <.001	−.02 .56	−.01 .69	−.26 <.001	.21 <.001	.22 <.001	.18 <.001	1													
13 Cognitive impairment	.08 .03	.10 .005	.05 .15	−.10 .008	.09 .01	.02 .65	.13 .001	−.06 .08	.17 <.001	.22 <.001	.19 <.001	.18 <.001	1												
14 Disability	−.07 .06	.06 .09	.05 .15	−.03 .55	.02 .56	.03 .38	.02 .52	.11 .004	.12 <.001	.20 <.001	.09 .01	.19 <.001	.34 <.001	1											
15 Partner care	−.02 .69	−.04 .38	−.07 .05	−.02 .75	.04 .30	−.05 .20	−.002 .97	.07 .04	.02 .52	−.16 <.001	.01 .39	.03 .43	−.03 .42	.03 .45	1										
16 Personal care	−.06 .09	.05 .17	.04 .25	.05 .19	−.08 .03	.08 .08	.12 .007	−.07 .046	.03 .45	.15 <.001	−.06 .10	−.01 .85	.04 .33	.07 .07	.07 .06	1									
17 ≥15 hours/week		−.02 .63	−.02 .63	−.02 .55	.02 .73	−.01 .71	.05 .17	.003 .94	.15 <.001	.17 <.001	.03 .39	.01 .71	.02 .63	.06 .09	.29 <.001	.36 <.001	1								
18 ≥2 years		.04 .38	.07 .05	−.04 .24	.04 .30	.01 .70	−.02 .58	.05 .14	.15 <.001	.17 <.001	.04 .34	.01 .74	.003 .93	.09 .02	.16 <.001	−.01 .89	.11 .006	1							
19 Stigma	−.23 <.001	.15 <.001	.16 <.001	−.11 .003	.08 .02	.06 .09	.11 .002	.02 .67	.01 .52	.06 .13	−.03 .39	−.01 .88	.25 <.001	.06 .09	−.05 .50	−.04 .28	.01 .86	−.02 .65	1						
20 Discrimination	−.12 .002	.09 .01	.06 .09	−.02 .63	.01 .73	.01 .71	.23 <.001	−.17 <.001	.15 <.001	.17 <.001	.13 <.001	.05 .17	.25 <.001	.10 .01	.01 .70	.11 .004	.06 .11	.04 .25	.11 .002	1					
21 Victimization	−.04 .30	.03 .36	.02 .66	−.17 <.001	.17 <.001	−.01 .84	.12 .001	−.18 <.001	.12 <.001	.16 <.001	.02 .61	.14 <.001	.17 <.001	.09 .01	−.08 .03	.09 .01	.05 .17	.07 .06	.03 .40	.59 <.001	1				
22 Social support	.12 <.001	−.05 .16	−.13 <.001	.09 .01	−.09 .02	−.01 .81	−.10 .007	.08 .03	−.17 <.001	−.23 <.001	−.14 <.001	.24 <.001	−.25 <.001	−.04 .30	.27 <.001	−.06 .08	−.04 .26	.04 .23	−.21 <.001	−.17 <.001	−.12 .001	1			
23 Social network	.02 .52	.01 .72	−.05 .15	.09 .01	−.09 .01	−.01 .83	−.04 .24	−.004 .91	.07 .048	−.07 .05	−.14 <.001	−.14 <.001	−.11 .003	−.05 .16	−.03 .46	−.03 .45	−.07 .07	.01 .87	−.15 <.001	−.14 <.001	−.06 .08	.33 <.001	1		
24 LGBTQ community engagement	.06 .11	−.05 .18	.03 .45	−.02 .62	.02 .53	−.01 .70	.02 .55	.07 .07	.07 .046	−.005 .90	−.06 .13	−.04 .23	−.07 .04	−.05 .20	.01 .86	.01 .79	−.08 .03	−.001 .99	−.21 <.001	.02 .58	.10 .006	.18 <.001	.30 <.001	1	
25 Perceived stress	−.18 <.001	.13 <.001	.11 .002	−.05 .15	.04 .25	.03 .42	.13 <.001	−.15 <.001	.14 <.001	.22 <.001	.08 .03	.15 <.001	.53 <.001	.22 <.001	−.01 .72	.14 <.001	.14 <.001	.02 .59	.21 <.001	.26 <.001	.22 <.001	−.38 <.001	−.20 <.001	−.17 <.001	1

Note. Three decimal places for p values when needed for precision. Dummy-coded binary variables were used for categorical variables with three or more categories. Shaded areas are not reported because they are for correlations within same variable.

HS = high school. FPG = federal poverty guidelines.

*$p < 0.05$.

Table 3. Multiple Hierarchical Regressions of Caregiver Background Characteristics, Caregiving Characteristics, and Caregiving Risk and Protective Factors of Perceived Stress among Caregivers (N = 754), b (se).

	Model 1		Model 2		
	b (se)	p	b (se)	p	Corrected p[a]
Background characteristics					
Sexual identity					
Lesbian and gay (Reference)	—	—	—	—	—
Bisexual	0.07 (0.10)	.48	0.11 (0.09)	.24	.26
Sexually diverse	0.14 (0.13)	.25	0.04 (0.12)	.73	.55
Gender					
Women (Reference)	—	—	—	—	—
Men	−0.02 (0.06)	.68	−0.08 (0.05)	.16	.24
Gender diverse	−0.16 (0.16)	.32	−0.08 (0.16)	.62	.54
Transgender	0.08 (0.12)	.49	−0.02 (0.11)	.88	.56
Age	−0.01 (0.003)**	.003	−0.01 (0.003)**	.01	.06
People of color	0.01 (0.06)	.87	0.01 (0.06)	.84	.56
Income ≤ 200% FPG	0.14 (0.06)*	.02	0.09 (0.06)	.09	.15
High school or less	−0.17 (0.10)	.07	−0.20 (0.09)*	.02	.07
HIV Positive	0.09 (0.08)	.26	0.04 (0.07)	.55	.50
Cognitive impairment	0.02 (0.002)***	<.001	0.02 (0.002)***	<.001	.001
Disability	0.06 (0.05)	.26	0.07 (0.05)	.19	.24
Caregiving characteristics					
Care relationship: Partner/spouse care	0.003 (0.05)	.96	0.11 (0.05)*	.047	.097
Type of care: Personal care	0.16 (0.08)*	.04	0.13 (0.07)	.07	.13
Hours of care (per week) ≥ 15 hours	0.20 (0.07)**	.002	0.15 (0.06)*	.02	.07
Duration of care ≥ 2 years	0.03 (0.06)	.61	0.009 (0.05)	.86	.56
Caregiving risk and protective factors					
Stigma	—		0.01 (0.03)	.75	.56
Discrimination	—		0.004 (0.01)	.73	.56
Victimization	—		0.01 (0.01)*	.02	.07
Social support	—		−0.18 (0.03)***	<.001	.001
Social network	—		−0.01 (0.004)	.20	.24
LGBTQ community engagement	—		−0.05 (0.02)*	.02	.07
Adjusted R^2	0.34		0.42		
Change in R^2	—		0.074***		

Note. Relationship status was excluded due to conceptual overlap with partner/spouse care and high correlation (r = 0.68) of the two variables. Three decimal places were presented when needed for precision.
FPG = federal poverty guidelines.
*p < .05, **p < .01, ***p < .001.
[a] Correction for false discovery rate (FDR) for potential inflation of Type I error was made to Model 2 (Anderson, 2008), and corrected p-values are reported.

such that caregivers with more victimization experiences over their lifetime had higher perceived stress (b = 0.01, p = 0.02). Social support and LGBTQ community engagement were negatively associated with perceived stress as protective factors, such that higher reported social support (b = −0.18, p < 0.001) and LGBTQ community engagement (b = −0.05, p = 0.02) were associated with lower stress levels.

With the risk and protective factors included, income was no longer significantly associated with perceived stress. The association of younger age and cognitive impairment with perceived stress remained significant, and higher education was associated with higher stress (b = −0.20, p = .02). Regarding caregiving characteristics, while hours of care

remained significantly associated with perceived stress, care relationship, i.e., partner care (b = 0.11, p = .047), instead of type of care (personal care), was associated with stress. Corrected p-values to account for potential inflation of Type I error indicated significant association with higher perceived stress with cognitive impairment and social support at p < .05 level and the significant predictors without the correction remained significant at p < .10.

Discussion

As people live longer and the older adult population grows increasingly diverse, there is a critical need to highlight the

variety and impact of diverse caregiving experiences (NAC, 2020). Due to a range of historical and contextual factors, informal caregiving may be increasingly needed as well as distinctive among sexual and gender diverse older adults. While the broader literature on caregiver experiences and stress is relatively robust and growing, this analysis offers an in-depth examination of sexual and gender diverse caregiving, which highlights a number of key findings that provide important insights and needed information for the development of tailored caregiving interventions in these underserved communities.

It is critical to recognize that one-third of sexual and gender diverse older adults 50 and older were providing informal care to a family member or friend in need of assistance. It has been reported previously that sexual and gender diverse older adults are often called on to provide care to families of choice, particularly if no biological children are present or willing to provide such support (Brennan-Ing et al., 2013). While the largest proportion of participants were caring for spouses and partners (38%), friends (29%) were the second most likely individuals to be receiving care. Furthermore, ex-spouses and ex-partners made up over 7% of those receiving care. These findings highlight the importance of expanding the definition of family in caregiving and ensuring that access to caregiving-related services and programs which traditionally support spouses and adult children, extends beyond biological kin to incorporate other types of relationships, including friends and other important ties in the lives of those needing care.

Among the caregivers in this study over half were living with a disability themselves; more than one in six were living with HIV, and one-third were living at or below 200% of the FPGs. Such health and economic risks may increase the vulnerability of these caregivers and reduce the potential stability of their caregiving arrangements. Many sexual and gender diverse caregivers are providing care to age-based peers, and their advancing age combined with physical health limitations may pose a threat to their ability to provide long-term caregiving assistance.

Cognitive function and memory loss were significant predictors of stress, even when controlling for other background characteristics and risk and protective factors. Existing literature demonstrates that sexual minorities experience significant disparities in subjective cognitive impairment compared to heterosexuals of similar age (Fredriksen-Goldsen et al., 2021). Caregivers' difficulty tending to their own health needs is likely especially difficult for those that are experiencing their own challenges with memory loss and cognitive function (Buyck et al., 2011; Jones et al., 2011; NAC, 2020). Those experiencing memory loss, as a high-risk caregiver group, likely need specialized support to meet their care responsibilities as well as to receive their own needed care and support. This may be of a particular concern for those who do not feel they can trust or rely on formal services and therefore rely more heavily on informal networks of support within the LGBTQ community (De Vries, & Croghan, 2014; Hughes, &

Kentlyn, 2011). These findings suggest that caregiving may be an important factor to consider in order to better understand disparities in health among sexual and gender diverse individuals, which is, as of yet, underexplored (Fredriksen-Goldsen & Hooyman, 2007).

As would be predicted by the Stress Process Model and existing caregiving research (Pearlin & Bierman, 2013; Montgomery et al., 1985; NAC, 2020), we found that caregiver and caregiving characteristics, including having a lower income and providing personal care and more caregiving hours per week, predicted higher levels of perceived stress in this study. Research has also demonstrated that social support is associated with lower levels of stress among caregivers (Haley et al., 2003; Pearlin et al., 1990) and reduces the impact of caregiving demands and time spent providing care (Yates et al., 1999). However, in this study, while provision of personal care was no longer associated with stress given protective effects of social support, longer time per week spent providing care remained and partner or spouse care became predictive of higher stress after accounting for the protective effects of social support. This may be due to elevated strain from continuous caregiving demands associated with providing care to a partner or spouse given that partner or spouse care was significantly correlated with more caregiving hours per week. As caregiving interventions are developed in sexual and diverse communities it is imperative that steps be taken to alleviate the burden accompanied by the heightened demands of providing long hours of caregiving and personal care, and particularly partner or spouse care. It will also be important to further assess and identify what types of opportunities for support exist or are lacking for sexual and gender diverse caregivers providing extensive care responsibilities.

Older age was predictive of less stress among caregivers, which supports prior findings of less subjective burden among older caregivers (del-Pino-Casado et al., 2014). It is possible that this finding reflects the fact that older caregivers may have fewer other responsibilities competing with their caregiving as is seen among the "sandwich generation," those middle-aged caregivers who are often providing care to older adults in addition to paid employment and parenting (Montgomery et al., 1985; Poo & Conrad, 2009).

Lower income was no longer associated with higher stress after including the risk and protective factors. Significant protective factors like social support and LGBTQ community engagement might alleviate the strain of lower income impacting caregivers' perceived stress. On the other hand, higher education was already associated with higher stress with marginal significance in Model 1 although it gained statistical significance in Model 2 where the negative impact of lower income was mitigated. It is possible that education's positive association with caregiver stress was a suppression effect coming from the association between lower education and cognitive impairment. Additional analysis with education omitted did not change the other findings of Models 1 and 2 and that with cognitive impairment omitted left education not

associated with stress. Research addressing cognitive impairment should take caution interpreting findings involving education level and take appropriate measures when including education level in their analyses.

The findings also suggest that sexual and gender diverse caregivers face additional challenges, rooted in the social context and biases that they may encounter (Coon, 2005; Meyer, 2016) or fear they may experience if accessing support services. The HEPM illuminates how both the historical and contemporary experiences can impact caregiving in marginalized communities. In this study, lifetime victimization was found to be significantly associated with stress among sexual and gender diverse caregivers rather than their sexual identities or identity stigma, per se. These findings demonstrate how the social context of caregiving and experiences of bias may exacerbate difficulties experienced by caregivers from historically disadvantaged populations.

While previous research has suggested that one's sexual identity and level of identity stigma may impact one's willingness to access supportive services (Coon, 2005; Dunkle, 2018; Meyer, 2016), our findings suggest that violence and victimization experiences sexual and gender diverse caregivers have encountered in their lives significantly predict perceived stress, not their identity. Prior occurrences of violence, which is a relatively common lifetime experience among sexual and gender diverse older adults (Fredriksen Goldsen et al., 2020), likely trigger a trauma response associated with increased stress, which has been linked to potential adverse health outcomes for caregivers. The HEPM also directs us toward investigating resilience and strengths within these communities. We found that LGBTQ community engagement was significantly associated with lower level of stress among caregivers. The critical role of community resources, which is evident in historically disadvantaged communities (Brennan Ing et al., 2013; Fredriksen-Goldsen & Hooyman, 2007), may be an important caregiving protective factor that has not been thoroughly investigated in the broader existing literature. This important finding suggests that creating supportive networks and fostering community engagement beyond the immediate family may be an important point of prevention and intervention to improve caregiving outcomes in these and other traditionally underserved communities.

Limitations of the Study

While this study represents an important step toward understanding the caregiving experiences of older sexual and gender diverse caregivers, there are notable limitations in the study as well as remaining gaps in the literature that warrant further research. In the broader caregiving literature, stress is often conceptualized as caregiving-specific (Pearlin & Bierman, 2013). However, in this study we assessed the impact of perceived stress more generally. Thus, in future research it will be important to also measure caregiving specific stress and

compare findings to studies that measured stress more generally. Among caregivers, feelings of stress have impacted physical health and well-being as well as other aspects of life such as increasing feelings of loneliness (NAC, 2020). As such, stress itself has been found to be associated with serious negative health consequences that can include the physical toll on one's body, emotional challenges, and strains on relationships (Jones et al., 2011). In these ways, future research is needed that employs longitudinal designs so that we can better understand the trajectories of caregiving and fully investigate the role of stress overtime.

It will also be important to further explore the complexities of "service utilization," among these caregivers, both in terms of what would be most instrumental to support their service utilization as well as the training and education needed for the providers themselves to ensure provision of culturally relevant and equitable care (Coon, 2005; Hughes, & Kentlyn, 2011). This is a relevant issue given the current data set as the sample was in part recruited through community organizations and as such, the sample may have higher service use than sexual and gender diverse caregivers in general.

Further research is also needed to further explore how caregiving relationships are expressed and the impacts of these relationships on subgroups of sexual and gender diverse older people of color and transgender caregivers. Because these groups often experience distinct systematic barriers to care (Coon, 2005; Dentato, Spira, Walker, 2014; Orel, & Coon, 2016), additional research is needed to examine their caregiving experiences in more depth, the impact of existing structures and public policies, and the role of the potential economic insecurity they may face (Knauer, 2011). This intersectional approach is well-aligned with the HEPM and would likely deepen our understanding of the potential unique and distinct caregiving experiences among specific subgroups in these communities. In addition, future research on the interaction of gender and sexuality in caregiving characteristics, type, intensity, burden and stress is warranted. While this study focuses on caregiving, many sexual and gender diverse older adults may also lack caregiving support, since they are less likely to be married/partnered, and/or to have children, are more likely to live alone and rely heavily on age-based peers often with their own chronic health conditions. More research and early intervention for sexual and gender diverse older adults lacking caregiving support is also needed to reduce premature institutionalization, potential premature mortality, and reduce the cost and burden of higher levels of formal care than needed.

Conclusion

This study demonstrates the notable prevalence of caregiving among midlife and older sexual and gender diverse communities and the varied factors that are associated with stress and the experience of caregiving. The findings highlight the important role of distinct caregiving risks as they are

significantly associated with higher levels of perceived stress among sexual and gender diverse caregivers, including lifetime victimization as well as other factors such as financial insecurity, disability, and cognitive impairment. While these issues put caregivers at risk for higher levels of stress, they also present issues in the caregiving relationship itself, whereby the caregiver's disability could limit their ability to provide care in the long-term. Fostering culturally responsive and sensitive service provision is a crucial step to support these communities through formal service provision in addition to fostering the strength of informal social supports. In spite of the risks faced, the resilience of the sexual and gender diverse communities is evident, especially as this community has become a forerunner in articulating the much needed expansion of the concept of family in the provision of informal caregiving and support services. This is evident in the proportion of those providing care not only for a spouse or partner, but also for those they identify as friends and other personal ties, such as ex-partners and ex-spouses. These findings also highlight the potential important role of community engagement to offset the negative impact of bias and violence in historically disadvantaged communities. While the caregiving literature is robust, this study contributes to the growing area of research on caregiving in diverse populations. Key findings of this study identify important factors to be further interrogated in future caregiving research. As we witness the continued growth in the size of the caregiver population and those needing care, such cultural considerations are both timely and deeply needed as we work to better respond to increasing diversity in our aging population.

Declaration of conflicting interests

Funding

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