Physical and Psychological Burden among Caregivers of Latinx Older Adults with Stroke and Multimorbidity

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Objective: To investigate the association between Latinx older adults' stroke, multimorbidity, and caregiver burden.

Methods: For this retrospective cohort study, we used the Hispanic Established Populations for the Epidemiologic Study of the Elderly (H-EPESE) Wave-7 data set. The caregiver's physical burden was defined by using the Level of Burden Index. The caregiver's psychological burden was measured by using the Perceived Stress Scale (PSS-4). Multimorbidity was defined as the presence of 3 or more chronic conditions.

Results: The average age of the Latinx adults was 86 years, and the caregivers were 56 years. Latinx older adults and caregivers were more likely to be females (66% and 75%). Most caregivers were children (71%). Twelve percent of Latinx older adults presented with stroke, and 50% presented with multimorbidity. Caregiver physical burden was stratified into 3 levels: low (43%), medium (17%), and high (40%) burden. The cumulative logit model revealed that caregivers caring for those with stroke or multimorbidity had a high physical burden. Family caregivers and caregivers with a higher household income had a low physical burden. Caregivers with multimorbidity had a higher psychological burden. Caregivers who were interviewed in Spanish and those with higher household incomes had decreased psychological burden.

Conclusion: This study revealed that caregivers had a higher physical burden among caregivers of Latinx adults with stroke or multimorbidity. Future studies must investigate the relationship between Latinx adults' stroke and caregiver psychological health, and build culturally tailored policies and community interventions to support caregivers susceptible to high stress and burden. *Ethn Dis.* 2023;33(4):156–162; doi:10.18865/ed.33.4.156

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Introduction

Latinx are the largest minority population in the United States and make up 18% of the US population.[1,2] Latinx are the fastest-growing population among older age groups (65 years and older).[3] Mexican Americans are the largest Latinx subgroup population in the United States.[1] Stroke is one of the leading causes of long-term disability among adults in the United States.[4] Although Mexican Americans have a significantly higher risk of incidence of stroke than non-Latinx White persons, the stroke mortality rate has been declining among this population (Hispanic paradox).[5–7] Mexican elderly have a higher prevalence of chronic conditions such as diabetes mellitus, hypertension, cognitive impairments, and obesity than non-Latinx White persons.[8] Research has also shown that the prevalence of multiple chronic conditions (multimorbidity) among elderly Mexican Americans increases the likelihood of disability.[9,10]

Older Latinx adults are less likely to use formal long-term services and are known to "age in place," and their family members serve as caregivers. This has been attributed to familism, a set of cultural values where the family's needs are greater than theirs.[11] Compared to non-Latinx caregivers, Latinx caregivers provide greater weekly caregiving hours, encounter more intensive caregiving situations,[12] and are more likely to be unpaid. Latinx caregivers tend to neglect their health in favor of adherence to cultural beliefs such as familism, filial responsibility, and mistrust of the medical system.[13,14]

Caregivers of stroke survivors experience an increased burden, as stroke survivors develop a lasting dependency on their caregivers. Caregivers caring for stroke survivors often present with depression, anxiety, and cognitive decline.[15,16] Studies have indicated an increased caregiving burden among those caring for frail older adults with multimorbidity and caregivers with multimorbidity.[17,18] Paid caregivers are hired to decrease unpaid caregivers' burden, which increases burden among paid caregivers.[19] The current study explored the factors associated with caregivers' psychological and physical burden, specifically those caring for older Mexican Americans with stroke and multimorbidity.

Methods

Study Design

This retrospective cohort study used data from the seventh wave (2010-2011)

of the Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE).[20]

Study Sample

The HEPESE is a longitudinal study of elderly Mexican Americans (care recipients) and their caregivers from the 5 southwestern states: Arizona, California, Colorado New Mexico, and Texas.[20] The first wave of the HEPESE originally surveyed 3050 Latinx older adults, 65 years and older, during 1993-1994. The study sample included 1078 elderly Mexican Americans. Latinx older adults were asked to identify their caregiver as someone they would turn to for assistance with things they could not do independently. A total of 925 caregivers were surveyed about their perspectives on the health conditions of the individuals they cared for, their health, financial status, and sociodemographic information. Languages used for the interview included English and Spanish. The HEPESE study's data are available for access by the public, and hence this study was exempt by the Institutional Review Board.

We linked Latinx adults with caregiver data. We excluded participants who did not identify a caregiver (n=153). We extracted the Latinx older adults' stroke history from their caregivers' survey responses. We excluded Latinx adult and caregiver dyads with missing data on Latinx elderly stroke history (n=58). This resulted in a final sample size of 867 caregivers and Latinx elderly dyads.

Outcome

Assessment of caregiver stress and burden was not directly available from the HEPESE survey data. We adopted an external scale to define the physical burden of caregivers by matching equivalent HEPESE survey questions to items in the Level of Burden Index (LBI).[12] We evaluated caregivers' mental stress by using the Perceived Stress Scale-4 (PSS-4)[21] from the HEPESE survey.

Physical Burden: Level of Burden (LBI)

The LBI measures the intensity of caregiving and the resulting burden on the caregiver, based on the number of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) performed by the caregiver and weekly caregiving hours, which classifies caregiver burden into low, medium, and high burden.[22] LBI has been used to assess the caregiver burden among the Latinx population.[12] Although the LBI was not directly available in the HEPESE data, the items of LBI (number of ADL and IADL that the caregiver performed, caregiving hours) were matched with exact items from the HEPESE survey.

Mental Burden: Perceived Stress Scale

A shortened 4-item version of the Perceived Stress Scale was available from the HEPESE caregiver survey and was used to measure the mental stress of the caregiver.[21] The caregiver responded: Never (0), Almost Never (1), Sometimes (2), Fairly Often (3), and Very Often (4) to each of the 4 questions and the sum was taken to yield a score that could range from 0 to 16. A higher score on PSS-4 indicated higher caregiver mental stress.

Predictors

Sociodemographic Characteristics

For the caregivers' characteristics, we included age, sex (male/female), marital status (married, not married), annual household income (<$10,000, $10,000-$19,999, $20,000-$39,999, ≥$40,000) from the caregiver survey, and language in which the caregiver interview was completed. For the Latinx older adults' characteristics, we extracted age, sex (male/female), and the relationship between the caregiver and Latinx adult, which included child (son/daughter, son/daughter-in-law), spouse, another family member (head of household, grandchild, parent, brother/sister, nephew/niece, cousin, aunt/uncle, great-grandchild, other family members), non–family member (friend, boarder/roomer, all others), and paid employee.

Latinx Older Adults with Index Stroke

We recorded the Latinx older adults' stroke history reported by their caregiver from the caregiver survey.

Multimorbidity

Multimorbidity, or multiple chronic conditions, was dichotomized for caregivers and the Latinx older adults as having 3 or more chronic conditions.[9,23-26]

Latinx Older Adults with Multimorbidity

We extracted 9 chronic conditions other than stroke for calculating Latinx older adults' multimorbidity. Diabetes, myocardial infarction, arthritis, and cancer were extracted from the caregiver survey (caregivers reported the presence of these conditions among Latinx older adults). Hypertension (systolic ≥140 mm Hg or diastolic ≥90 mm Hg), emphysema/chronic obstructive pulmonary disease, heart failure, cognitive impairment (defined as Mini Mental Status Exam [MMSE] score ≤17), and depression (Center for Epidemiologic Studies-Depression [CES-D] score ≥16) were extracted from the Latinx older adults' survey.[27–30]

Caregiver Multimorbidity

Chronic conditions for caregivers were extracted from the caregiver survey, including diabetes, hypertension (systolic ≥140 mm Hg or diastolic ≥90 mm Hg),[27] stroke, myocardial infarction, arthritis, depression (CES-D score ≥16), and cancer (n=7).

Data Analyses

All statistical analyses were performed in R version 3.6.3.[31] Descriptive statistics were computed for all variables and across the levels of burden index. We then ran a cumulative logit model to understand the

factors associated with physical burden, using the LBI (low, medium, or high burden) as the outcome was categorical and ordered, and interpreted the results by using a cumulative odds ratio (OR) with CI. We performed the ordinary least square regression to examine the factors associated with caregivers' perceived stress, using the PSS-4. Latinx older adults' and caregivers' characteristics were included in the model for both the cumulative logit model to determine the physical burden and the ordinary least square regression to determine perceived stress (psychological burden).

Table 1. Descriptive statistics on the study sample

	Descriptive statistics
	Sample size (proportion %) or mean (SD)
Perceived Stress Scale-4	3.7 (2.6)
Level of burden	
Low burden	369 (42.6%)
Medium burden	151 (17.4%)
High burden	347 (40.0%)
Latinx adult with stroke	
Yes	106 (12.2%)
No	761 (87.8%)
Latinx adult with multimorbidity	
Yes	429 (49.5%)
No	438 (50.5%)
Caregiver multimorbidity	
Yes	69 (7.9%)
No	789 (92.0%)
Age (Latinx adult)	85.9 (3.9)
Age (caregiver)	55.9 (12.6)
Sex (Latinx adult)	
Male	299 (34.5%)
Female	568 (65.5%)
Sex (caregiver)	
Male	220 (25.4%)
Female	647 (74.6%)
Relation	
Paid employee	39 (4.5%)
Children	614 (70.8%)
Nonfamily	31 (3.6%)
Other family	119 (13.7%)
Spouse	64 (7.4%)
Household income (caregiver)	
≤$10,000	148 (18.7%)
$10,000-$19,999	242 (30.6%)
$20,000-$39,999	248 (31.3%)
≥$40,000	154 (19.4%)
Caregiver's language	
English	326 (37.6%)
Spanish	541 (62.4%)

Results

Descriptive Statistics

The descriptive statistics of our study sample are presented in Table 1 (and Table 2 for descriptive statistics stratified by level of burden). More than half (62%) of caregivers were interviewed in Spanish. Our analytic sample included 867 dyads of Latinx older adults and caregivers. The average age for Latinx adults was 86 years, and the average age for caregivers was 56 years. Most caregivers were female (n=647, 75%) and children (n = 614, 71%). Paid caregivers were younger (average age, 52 years) than informal caregivers (average age, 56 years) and more likely to be females. The income distribution among paid caregivers was similar to that of informal caregivers; however, no paid caregivers had a household income of $40,000 or more and had a smaller multimorbidity rate than informal caregivers (not shown in table). It is important to note the larger variance in these statistics due to the small sample size of paid caregivers. Most caregivers (61%) had a household income between $10,000 and $40,000. Twelve percent of Latinx older adults had a stroke. Fifty-one percent of Latinx older adults and 8% of caregivers had multimorbidity. Around 43% of caregivers had a low burden, 17% had a medium burden, and 40% had a high burden, as per the LBI.

Caregiver Physical Burden Using Level of Burden Index

Table 3 shows the results of the cumulative logit model, where the caregiver's physical burden was evaluated by using the LBI. The physical burden was greater among female caregivers (OR=1.50; 95% CI, 1.08-2.10) and caregivers of female older adults (OR=1.76; 95% CI, 1.27-2.45), and with increasing age of Latinx older adults (OR=1.15; 95% CI, 1.10-1.20). Caregivers of Latinx older adults with index stroke with or without multimorbidity were 2 times more likely to have a higher level of physical burden than caregivers of Latinx elderly with no stroke (OR=2.10; 95% CI, 1.10-4.41). Caregivers of Latinx older adults with multimorbidity with or without index stroke were 2 times more likely to have a higher level of physical burden than caregivers caring for Latinx older adults with no multimorbidity (OR=2.40; 95% CI, 1.76-3.29). The interaction of

Table 2. Descriptive statistics on the study sample by caregiver level of burden

	Descriptive statistics by level of burden		
	Sample size (proportion %) or mean (SD)		
	Low burden (N=369)	Medium burden (N=151)	High burden (N=347)
CSB: Perceived Stress Scale-4	3.4 (2.5)	3.9 (2.5)	4.1 (2.6)
Latinx adult with stroke			
Yes	30 (28.3%)	16 (15.1%)	60 (56.6%)
No	339 (31.0%)	135 (17.7%)	37.7 (82.7%)
Latinx adult with multimorbidity			
Yes	133 (31.0%)	79 (18.4%)	217 (50.6%)
No	236 (53.9%)	72 (16.4%)	130 (29.7%)
Caregiver multimorbidity			
Yes	31 (44.9%)	12 (17.4%)	26 (37.7%)
No	338 (42.4%)	139 (17.4%)	321 (40.2%)
Age (Latinx adult)	85.0 (3.4)	86.0 (3.8)	86.9 (4.2)
Age (caregiver)	56.2 (13.3)	55.0 (13.3)	55.9 (11.5)
Sex (Latinx adult)			
Male	151 (50.5%)	51 (17.1%)	97 (32.4%)
Female	218 (38.4%)	100 (17.6%)	250 (44.0%)
Sex (caregiver)			
Male	105 (47.7%)	45 (20.5%)	70 (31.8%)
Female	264 (40.8%)	106 (16.4%)	277 (42.8%)
Relationship			
Paid employee	7 (17.9%)	5 (12.8%)	27 (69.2%)
Children	261 (42.5%)	108 (17.6%)	245 (39.9%)
Nonfamily	15 (48.4%)	7 (22.6%)	9 (29.0%)
Other family	53 (44.5%)	19 (16.0%)	47 (39.5%)
Spouse	33 (51.6%)	12 (18.8%)	19 (29.7%)
Household income (caregiver)			
≤$10,000	39 (26.4%)	35 (23.6%)	74 (50.0%)
$10,000-$19,999	101 (41.7%)	39 (26.4%)	102 (42.1%)
$20,000-$39,999	107 (43.1%)	44 (17.7%)	97 (39.1%)
≥$40,000	85 (55.2%)	22 (14.3%)	47 (30.5%)
Caregiver's language			
English	154 (47.2%)	45 (13.8%)	127 (39.0%)
Spanish	215 (39.7%)	106 (19.6%)	220 (40.7%)

CSB, caregiver stress and burden

stroke and multimorbidity was not associated with caregivers' physical burden.

Factors that were associated with decreased caregiver physical burden included family caregivers: child (OR= 0.27 [95% CI, 0.10, 0.63]), another family member (OR=0.25 [95% CI, 0.09, 0.63]), or spouse (OR=0.29 [95% CI, 0.09, 0.85]) compared to paid employees. Caregivers with a higher household income (10,000 to ≥$40,000) had decreased physical burden as compared to those with income ≤$10,000.

Caregiver Psychological Burden Using Perceived Stress Scale-4

Table 4 shows the ordinary least square regression results to explore the factors associated with caregiver psychological stress (PSS-4). Caregiver multimorbidity was associated with increased caregiver psychological burden (beta = 0.96 [95% CI, 0.23, 1.68]). Increased caregiver household income alleviated psychological burden when the household income was 20,000 to ≥ $40,000. Caregivers interviewed in Spanish had lower psychological stress than those interviewed in English (beta = −0.87 [95% CI, −1.27, −0.48]). Latinx older adults' stroke and/or multimorbidity were not associated with caregivers' psychological burden.

Discussion

Latinx adults in the United States have a drastically increasing aging population.[3]

Caregivers of female older adults, female caregivers, and caregivers caring for those with stroke or multimorbidity had increased levels of physical burden. Previous studies have revealed that female caregivers of patients with chronic illnesses have an increased burden.[32] Females are known to have poorer health than their male counterparts of the same age.[33] This is because women assume caregiving responsibilities years before they present with comorbidities requiring caregivers' assistance.[34] These factors may contribute to an increased burden among female caregivers of elderly female adults. Women also experience increased caregiving burden owing to secondary stressors due to unequal distribution of resources and caregiving responsibilities that can be attributed to gender roles.[35] Interestingly, the physical burden of caregiving for stroke care recipients was equivalent to that of those caring for Latinx older adults with multimorbidity. The recovery post stroke is often challenging because of concomitant physical, cognitive, and psychological impairments following stroke, uncertain needs of stroke survivors, and variable and evolving caregiving tasks/ workload throughout stroke recovery.[36,37]

The current study revealed that compared to paid employees, caregivers who were family members of Latinx adults had lower level of physical burden. This is the first study to report a higher physical burden among paid caregivers of Latinx older adults. Previous studies report a higher caregiving burden

Table 3. Multivariate results: cumulative logit model of caregiver level of burden on Latinx adult with stroke and multimorbidity with odds ratio

	Caregiver level of burden *Cumulative logit model*	
	OR [95% CI]	**P value**
Latinx adult with stroke (with or without multimorbidity)	2.10 [1.01-4.41][a]	.048
Latinx adult with multimorbidity	2.40 [1.76-3.29][b]	.000
Latinx adult with stroke × multimorbidity	1.18 [0.45-3.10]	.733
Caregiver multimorbidity	0.984 [0.55-1.75]	.956
Age (elderly)	1.15 [1.10-1.20][b]	.000
Age (caregiver)	0.99 [0.97-1.00]	.115
Sex (rf: male) (elderly)	1.76 [1.27-2.45][c]	.001
Sex (rf: male) (caregiver)	1.50 [1.08-2.10][a]	.018
Marital status (rf: not married) (caregiver)	0.82 [0.61-1.12]	.213
Relationship (rf: paid employee)		
Children	0.27 [0.10-0.63][c]	.003
Nonfamily	0.36 [0.10-1.22]	.104
Other family	0.25 [0.09-0.63][c]	.005
Spouse	0.29 [0.09-0.85][a]	.027
Household income (rf: ≤$10,000) (caregiver)		
$10,000-$19,999	0.58 [0.38-0.89][a]	.014
$20,000-$39,999	0.59 [0.38-0.92][a]	.019
≥$40,000	0.35 [0.22-0.58][b]	.000
Caregiver's language (rf: English)	1.14 [0.84-1.57]	.400

[a] P<.05
[b] P<.001
[c] P<0.01

among paid caregivers caring for hospitalized patients[19] and those with dementia.[38] The burden among paid caregivers could have been higher as they had to navigate older adults with chronic conditions and their family members, making the care process complex.[39] Latinx culture has a history of aging in place and expectations of family members caring for their loved ones. Hence family members may underestimate their hours of caregiving and tasks, as they would assume it is their responsibility and not a caregiving-related task. Latinx older adults may have resorted to paid caregivers when the physical caregiving duties became burdensome for family caregivers. Increased household income was associated with decreased caregiving physical and psychological stress and burden. Previous studies have shown that stroke caregiver burden is attributed to lack of supportive resources, and financial burden.[40,41]

Our study revealed that caregivers with multimorbid conditions have higher levels of perceived stress. Caregivers of individuals with high needs often do not attend to their own physical and mental health, increasing their overall stress and burnout.[42] Studies have shown a higher prevalence of comorbid conditions among caregivers, including obesity, hypertension, depression, and sleep problems, which may contribute to increased perceived stress which can, in turn, lead to poorer health.[43,44] Our study also revealed that caregivers who used the Spanish language to interview had decreased psychological burden. Caregivers prefer to receive information about their loved ones' medical care in their preferred language, as it facilitates better communication with health care providers and families, and helps them navigate the health care system effectively.[45] Caregivers with limited English proficiency have challenges navigating the health care system effectively when they lack access to professional interpreters, which limits shared decision-making.[45]

In our study, caregivers of Mexican American older adults with both stroke and multimorbidity did not have a significant physical and psychological burden. This means preexisting multimorbidity did not modify the effect of the caregiving burden for those caring for individuals with stroke.

Our results call for developing and implementing policy changes and community support for caregivers to alleviate their stress and burden, such as expanding the Family and Medical Leave Act tailored to adapt to the work and life of Latinx caregivers. It is crucial to prepare caregivers for the role of caregiving proactively. We must develop and adopt culturally appropriate coping strategies for Hispanic caregivers. Knowing that Latinx individuals have an aging culture,[11] we must strengthen access to home and community-based services. Information technology–based community interventions may be cost-effective in delivering caregiver support material or therapy and decrease the burden on family caregivers.[46]

Limitations

The Hispanic EPESE study did not have an item that collectively measured caregivers' physical and psychological burden, which may have limited us from effectively studying caregiver burden across multiple dimensions. We used the LBI to assess the physical burden from multiple items collected in the Hispanic EPESE study and PSS to assess the psychological burden. We acknowledge the inherent limitations of the study while using secondary data. For instance, only comorbidities collected for the Hispanic EPESE study were included in the calculation of the multimorbidity variable. Because of this, we may have underestimated the number of people with multimorbidity in our study. The

Table 4. Multivariate results: ordinary least square regression of caregiver perceived stress on elderly stroke and multimorbidity

	Caregiver perceived stress *OLS regression*	
	Beta [95% CI]	**P value**
Latinx adult with stroke (without multimorbidity)	−0.04 [−0.98 to 0.90]	.936
Latinx adult with multimorbidity	0.23 [−0.17 to 0.63]	.260
Latinx adult with stroke × multimorbidity	−0.23 [−1.41 to 0.96]	.708
Caregiver multimorbidity	0.96 [0.23-1.68][a]	.001
Age (Latinx adult)	0.03 [−0.02 to 0.08]	.276
Age (caregiver)	−0.01 [−0.03 to 0.00]	.135
Sex (rf: male) (Latinx adult)	0.05 [−0.36 to 0.47]	.796
Sex (rf: male) (caregiver)	−0.03 [−0.46 to 0.39]	.873
Marital status (rf: not married) (caregiver)	−0.02 [−0.41 to 0.37]	.917
Relationship (rf: paid employee)		
Children	0.30 [−0.71 to 1.31]	.558
Nonfamily	0.51 [−1.00 to 2.03]	.505
Other family	−0.11 [−1.25 to 1.02]	.843
Spouse	0.77 [−0.54 to 2.08]	.248
Household income (rf: ≤$10,000) (caregiver)		
$10,000-$19,999	−0.44 [−0.99 to 0.11]	.120
$20,000-$39,999	−1.11 [−1.67 to −0.55][b]	.000
≥$40,000	−1.45 [−2.06 to −0.83][b]	.000
Caregiver's language (rf: English)	−0.87 [−1.27 to −0.48][b]	.000

OLS, ordinary least square regression
[a] P<.01
[b] P<.001

Hispanic EPESE study did not collect data on the race/ethnicity of caregivers, and the current study cannot imply the burden of Mexican American caregivers. However, considering 62% of caregivers had Spanish as their preferred language, most were Latinx.

Conclusion

Our results on the study sample demonstrated that stroke, multimorbidity, and increasing age of Mexican American older adults were associated with caregivers' physical burden. Female caregivers and caregivers of female Mexican American older adults had increased physical burden. Caregivers with multimorbid conditions had an increased psychological burden. Higher household income decreases caregiver physical and psychological burden. Family caregivers had decreased physical burden compared to paid caregivers. Caregivers who were not acculturated had decreased psychological burden. Our results indicate the need for culturally tailored coping strategies to support Latinx caregivers of Latinx adults with stroke who are susceptible to a high-level burden.

Author Contributions

Research Concept and Design: Krishnan; Analysis and Interpretation of Data: Krishnan, Chen, Rho, Caston; Drafting of Manuscript: Krishnan, Chen, Rho, Caston; Statistical expertise: Krishnan, Chen, Rho; Administrative, Technical, and Material Support: Krishnan, Caston; Supervision: Krishnan, Rho.

Conflict of Interest

All authors do not have any conflicts related to the study.

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