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Haobin Chen April 6, 2021

Caregiver Stress and Burden among Hispanic Elderly with Stroke and Multicomorbidity

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Abstract
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Background: Hispanic elderly has high prevalence of stroke and chronic diseases that result in impaired function. Caregivers caring for Hispanic elderly have higher caregiving duties than other ethnicities.(Benjamin et al., 2018; Rote, Angel, & Markides, 2015; Velasco-Mondragon, Jimenez, Palladino-Davis, Davis, & Escamilla-Cejudo, 2016)

Objective: The purpose of this study was to investigate the association between Hispanic elderly's demographics, stroke, multicomorbidity (MCM), interaction between stroke and MCM of elderly, and caregiver MCM, affecting caregiver stress and burden (CSB).

Method: Data was extracted from the Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE) study Wave 7. CSB was defined as stressor count using Bakas Caregiving Outcomes Scale and as level of burden using Level of Burden Index by matching items from each scale to HEPESE caregiver survey. Negative binomial regression was applied to model caregiver stressor count and cumulative logit model was applied to model caregiver level of burden.

Results: The outcome caregiver stressor count yielded a range from 0 to 12 and level of burden took on three levels: low burden, medium burden, and high burden. Negative binomial model on caregiver stressor count did not show an association between presence of stroke in elderly and CSB but demonstrated that caregivers who had MCM themselves had higher CSB and had higher household income had lower CSB. Cumulative logit model on caregiver level of burden revealed that caregivers caring for elderly with stroke or with MCM had higher CSB. Caregivers who were children, other family member, or spouse of elderly or had higher household income had lower CSB. The interaction between elderly stroke and multicomorbidity was not observed.

Conclusion: This study showed that Hispanic caregivers had higher stress and burden when caring for elderly who had stroke and multicomorbidity. Future studies must expand upon our results to build culturally tailored policies and community interventions to support Hispanic caregivers susceptible to high stress and burden. (Isakson, 2018)

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Introduction

Hispanic Americans are the largest minority population in the United States and make up 18% of the U.S. population (Lopez, Krogstad, & Passel, 2019; United States Census Bureau, 2018). Hispanic Americans are the largest ethnic minority populations in the U.S. among the older populations aged 65 and over, and Hispanic older population with age 65 and over is predicted to increase by 188% between 2017 and 2024 (The Administration for Community Living, 2019). Mexican Americans are the largest Hispanic subgroup population in the U.S. (United States Census Bureau, 2018). Mexican Americans have significantly higher risk of having ischemic stroke and intracerebral hemorrhage incidence than non-Hispanic Whites, and the stroke death rate has been increasing since 2013 among Hispanic population (Morgenstern et al., 2004; Yang et al., 2017). Hispanic elderly have higher prevalence of chronic conditions compared to non-Hispanic Whites, including diabetes mellitus, hypertension, and arthritis (Benjamin et al., 2018; National Center for Health Statistics, 2016; Samper-Ternent et al., 2012). Stroke is the leading cause of long-term disability among U.S. adults (Miller et al., 2010). Research has shown the prevalence of multiple chronic conditions (multicomorbidity), such as diabetes, together with stroke increases the odds for having disability of daily living (ADL) and instrumental disability of daily living (IADL) among Hispanic population (Collins et al., 2018; Otiniano, Du, Ottenbacher, & Markides, 2003). It is well established that caregivers of stroke survivors experience significantly increased psychological stress and life burden as stroke survivors develop a lasting dependency on their caregivers for ADLs. The negative emotional impact and burden on those caring for stroke survivors are well documented and include depression, worsened physical and mental health, loss of personal time, and declined quality of life (Jaracz et al., 2015; Kitson, Dow, Calabrese, Locock, & Muntlin Athlin, 2013; Lutz &

Young, 2010; Torregosa, Sada, & Perez, 2018; Tunney & Ryan, 2014). Some of the stress can be attributed to the unpreparedness of stroke caregiver and lack of supportive resources (Danzl et al., 2013; Tunney & Ryan, 2014). Additionally, stroke is a financially burdensome disease that incurs cost in hospitalization, medical treatment, long-term care, and expenses associated with morbidity, which may further burden the caregiver (Demaerschalk, Hwang, & Leung, 2010; Pei et al., 2016). Compared to non-Hispanic caregivers, Hispanic caregivers have lower education level, lower household income, more weekly caregiving hours, and intensive caregiving situations (Evercare and National Alliance on Caregiving, 2008). Previous study has explored the health of elderly Mexican Americans and depressive symptoms of their caregivers, but there has not been a study systematically examines the association between stroke, multicomorbidity and caregiver's overall stress and burden which includes physical and mental health, loss of personal time, and financial burden among the Hispanic population (Rote et al., 2015). This study aimed to assess the effect of stroke and multicomorbidity of elderly on caregiver stress and burden among Hispanic population in the U.S. We defined caregiver stress and burden using existing valid and reliable scales. We hypothesized that the presence of elderly stroke negative affected the caregiver stress and burden and that the presence of elderly multicomorbidity increased the impact of elderly stroke on caregiver stress and burden.

Methods

Study Sample

Data for this study was from the seventh wave (2010-2011) of the Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE). The HEPESE is a longitudinal study that included elderly Mexican Americans and their caregivers from the five

southwestern states: Arizona, California, New Mexico, and Texas.(Markides, Chen, Angel, Palmer, & Graham, 2016). The first wave of the HEPESE originally surveyed 3050 elderly Mexican Americans who were 65 and older during 1993-1994. 1078 elderly Mexican Americans continued to the seventh wave. The elderly Mexican Americans were asked to identify their caregiver as someone they would turn to for assistance with things which they were not able to do independently. A total of 925 caregivers were identified and interviewed about their perspective on health conditions of the elderly they cared for, their own health, financial status, and sociodemographic information. We linked the elderly data and the caregiver data and excluded elderly who did not identify a caregiver (n = 153). For this study, we extracted the elderly's stroke history from their caregivers' response on the health of elderly. We excluded elderly and caregiver dyads with missing data on stroke history of elderly reported by caregivers (n = 58). This resulted in a final sample size with 867 dyads of caregiver and elderly.

Outcome

Caregiver stress and burden (CSB) was not a variable directly available from the HEPESE survey data. We adopted two external scales to define CSB by matching HEPESE survey questions to them: the 15-items Bakas Caregiving Outcome Scale (BCOS) and Level of Burden Index (LBI) (Bakas & Champion, 1999; Evercare and National Alliance on Caregiving, 2008).

Caregiver Stressors (BCOS)

While previous studies focused primarily on the psychological well-being of caregivers, the BCOS holistically measures the caregiving burden outcome across various constructs that include social functioning, subjective well-being, and somatic health. The BCOS scale has been validated on a cohort of caregivers caring for stroke survivors, which aligned with the sample of

interest of this study (Bakas, Champion, Perkins, Farran, & Williams, 2006; Rote et al., 2015). We matched items from the HEPESE caregiver questionnaire to items from the BCOS based on previous literature evidence (Appendix 1.A, Appendix 1.B). Each BCOS item was originally measured in a Likert scale from -3 to 3, indicating changing for worse to changing for better due to caregiving. However, for our study, we dichotomized each item on BCOS as has the stressor (1) or does not have stressor (0). We were able to match 14 out of total 15 BCOS items with HEPESE survey items, except for "My relationship with my family" because the HEPESE dataset did not include items related to the relationship between caregiver and his or her own family. A HEPESE caregiver questionnaire item, daily caregiving time was matched to two items on BCOS "My time for family activities" and "My social time with friends"; hence we collapsed these two BCOS items to form one time-associated stressor. Similarly, another HEPESE caregiver questionnaire item, caregiver self-rated health was matched to two items on BCOS "My physical health" and "My general health"; hence, we collapsed these two BCOS items to form the stressor for general health. We finally identified 12 stressors of caregivers based on the BCOS scale and a caregiver could have 0 to 12 total stressors.

Level of Burden (LBI)

The Level of Burden Index measures the intensity of caregiving and resulting burden on caregiver based on number of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) the caregiver performed for elderly, and weekly caregiving hours, which classifies caregivers into Low burden, Medium burden, and High burden (National Alliance for Caregiving & AARP, 1997). See appendix (Appendix 2.A) for the construction of LBI. LBI has been used to assess caregiver burden among Hispanic population (Evercare and National

Alliance on Caregiving, 2008). All three items of LBI (ADL, IADL, caregiving hours) have exact matching items from the HEPESE survey.

Predictors

Stroke and Multicomorbidity: We recorded the elderly's stroke history reported by the caregiver. Multimorbidity (MCM), or multiple chronic conditions, was dichotomized for both caregivers and elderly as having three (3) or more selected chronic conditions (Collins et al., 2018).

Elderly MCM: Nine (9) chronic conditions were extracted for the Hispanic elderly. We extracted diabetes, myocardial infarction, arthritis, and cancer reported by the caregiver. We also extracted hypertension (systolic ≥ 140 mmHg or diastolic ≥ 90 mmHg (Whelton et al., 2018)), emphysema/chronic obstructive pulmonary disease, heart failure, cognitive impairment (defined as Mini Mental Status Exam (MMSE) score ≤ 17), depression (Center for Epidemiologic Studies-Depression (CES-D) score ≥ 16) from elderly's own response. (Folstein, Folstein, & McHugh, 1975; National high Blood Pressure Education Program, 2003; Radloff, 1977)

Caregiver MCM: Seven (7) chronic conditions were extracted for the caregiver, including diabetes, hypertension (systolic ≥ 140 mmHg or diastolic ≥ 90 mmHg (Whelton et al., 2018)), stroke, myocardial infarction, arthritics, depression (CES-D score ≥ 16), and cancer.

Sociodemographic: We extracted age, sex, marital status (married, not married), and annual household income for caregivers (Less than $10,000, $10,000-$19,999, $20,000-$39,999, $40,000 and More). We also extracted age and sex for the elderly and the relationship between the caregiver and the elderly, which included child (son/daughter, son/daughter in law), spouse, other family member (head of household, grandchild, parent, brother/sister, nephew/niece,

cousin, aunt/uncle, great grandchild, other family member), non-family member (friend, boarder/roomer, all others), and paid employee.

Statistical Analyses

All statistical analyses were performed in R version 3.6.3 (R Core Team, 2020). Descriptive statistics were calculated for the outcome: caregiver stressor count and level of burden and stroke history of elderly, multicomorbidity of elderly and caregiver, and sociodemographic variables of the elderly and caregiver.

Caregiver Stressors (BCOS)

The distribution of caregiver stressor count included non-negative integer values and was count data. As the first step, we estimated the quasi-Poisson model to relax the equivariance assumption of the regular Poisson model which has $Var(Y) = E(Y) = \lambda$. Specifically, we allowed the generalized linear model variance assumption in quasi-Poisson model with $Var(stressor|X) = \sigma^2 E(stressor|X)$. Depending on the sign of σ^2, the quasi-Poisson model can represent underdispersion, equidispersion, or overdispersion of the outcome caregiver stressor count. After estimating the quasi-Poisson model, we found evidence for the overdispersion of caregiver stressor count with estimated $\hat{\sigma}^2 = 1.32$.

Because the quasi-Poisson model indicated that caregiver stressor count was overdispersed, we also estimated the negative binomial model which specifically represents the overdispersion of outcome since the negative binomial distribution satisfies the following relation $Var(Y) = E(Y) + dE^2(Y)$ with $d > 0$ as the dispersion parameter.

Both quasi-Poisson model and negative binomial model were interpreted using incidence rate ratio (IRR).

Level of Burden (LBI)

The caregiver level of burden is an ordinal categorical scale including low burden, medium burden, and high burden. Since caregiver level of burden had discrete classes and was ordinal in nature, we modeled level of burden using cumulative logit model which was suitable for ordered multinomial outcome and interpreted the result with cumulative odds ratio and average partial effect (APE). Bootstrap standard error and confidence interval were obtained for APE estimates of each predictor.

Results

Descriptive statistics

The descriptive statistics of our study sample is presented in **Table 1.1** (and **Table 1.2** for descriptive statistics stratified by level of burden). Our analytic sample included 867 dyads (N = 867) of elderly and caregivers. The average age of elderly was 85.9 and the average age for caregivers was 55.9. Most caregivers were female (n = 647, 74.6%)and children (n = 614, 70.8%) and other family members (n = 119, 13.7%) of the elderly. Most caregivers (61%) had a household income between $10,000 and $40,000. 12.2% of elderly in our study sample had a stroke. 50.5% of the elderly and 7.9% of caregivers had multicomorbidity. The average stressor count of caregivers defined under BCOS was 2.0, where the possible range is 0 to 12. The most common stressor was loss of personal time which was reported by 376 caregivers, followed by worse health of caregiver which was reported by 371 caregivers. 42.6%, 17.4%, and 40.0% of caregivers had low burden, medium burden, and high burden defined under LBI.

Table 1.1: Descriptive statistics on the study sample

	Descriptive statistics
	Sample size (proportion %) or Mean (SD)
CSB: Stressor count	2.0 (1.7)
CSB: Level of burden	
- Low burden	369 (42.6%)
- Medium burden	151 (17.4%)
- High burden	347 (40.0%)
Elderly stroke	
- Yes	106 (12.2%)
- No	761 (87.8%)
Elderly multicomorbidity	
- Yes	429 (49.5%)
- No	438 (50.5%)
Caregiver multicomorbidity	
- Yes	69 (7.9%)
- No	789 (92.0%)
Age (elderly)	85.9 (3.9)
Age (caregiver)	55.9 (12.6)
Sex (elderly)	
- 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%)
- Non-family	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%)

Table 1.2: 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: Stressor count	1.4 (1.5)	2.1 (1.8)	2.7 (1.7)
Elderly stroke			
- **Yes**	30 (8.1%)	16 (10.6%)	60 (17.3%)
- **No**	339 (91.9%)	135 (89.4%)	287 (82.7%)
Elderly multicomorbidity			
- **Yes**	133 (36.0%)	79 (52.3%)	217 (62.5%)
- **No**	236 (64.0%)	72 (47.7%)	130 (37.5%)
Caregiver multicomorbidity			
- **Yes**	31 (8.4%)	12 (7.9%)	26 (7.5%)
- **No**	338 (91.6%)	139 (92.1%)	321 (92.5%)
Age (elderly)	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 (elderly)			
- **Male**	151 (40.9%)	51 (33.8%)	97 (28.0%)
- **Female**	218 (59.1%)	100 (66.2%)	250 (72.0%)
Sex (caregiver)			
- **Male**	105 (28.5%)	45 (29.8%)	70 (20.2%)
- **Female**	264 (71.5%)	106 (70.2%)	277 (79.8%)
Relationship			
- **Paid employee**	7 (1.9%)	5 (3.3%)	27 (7.8%)
- **Children**	261 (70.7%)	108 (71.5%)	245 (70.6%)
- **Non-family**	15 (4.1%)	7 (4.6%)	9 (2.6%)
- **Other family**	53 (14.4%)	19 (12.6%)	47 (13.5%)
- **Spouse**	33 (8.9%)	12 (7.9%)	19 (5.5%)
Household income (caregiver)			
- **≤ $10,000**	39 (11.7%)	35 (25.0%)	74 (23.1%)
- **$10,000 - $19,999**	101 (30.4%)	39 (27.9%)	102 (31.9%)
- **$20,000 - $39,999**	107 (32.2%)	44 (31.4%)	97 (30.3%)
- **≥ $40,000**	85 (25.6%)	22 (15.7%)	47 (14.7%)

Quasi-Poisson model and negative binomial model

A quasi-Poisson regression was fitted for the stressor count with all independent variables of the study. The dispersion parameter of quasi-Poisson model was $\widehat{\sigma}^2 = 1.32 > 1$ with $Var(stressor|X) = \sigma^2 E(stressor|X)$, which indicated overdispersion of caregiver stressor count. The result for quasi-Poisson model of stressor count on stroke history and multicomorbidity of elderly with sociodemographic variables is presented in **Table 2**. From negative binomial model, the dispersion parameter of caregiver stressor count was estimated to be d = 0.10 with $Var(stressor|X) = E(stressor|X) + dE^2(stressor|X)$. The result for negative binomial regression is presented in **Table 3**. There was no statistically significant association between caregiver stressor count and stroke and multicomorbidity of elderly. However, caregivers who had multicomorbidity had 79.6% more stressors (Incidence Rate Ratio (IRR) = 1.796, 95% Confidence Interval = [1.493, 2.154]) than those who did not have multicomorbidity; every year increase in age for caregivers was associated with 2.0% more stressor count (IRR = 1.020 [1.005, 1.035]); caregivers who were spouse of the elderly had 71.6% more stressor count (IRR 1.716 [1.145, 2.607]) compared to those who were paid employees. Increased caregiver annual household income was associated with less caregiver stressors and caregivers whose household income was more than $40,000 had 52.9% less stressor count (IRR = 0.471 [0.388, 0.570] for ≥ $40,000) compared to those whose annual income was less than $10,000.

Table 2: Multivariate results: Quasi-Poisson regression of caregiver stressors defined with BCOS on elderly stroke and multicomorbidity, caregiver multicomorbidity, and sociodemographic.

	Caregiver stressors (BCOS) *Quasi-Poisson Model*	
	IRR: exp(β) [95% CI]	**P-value (β)**
Elderly stroke	1.122 [0.093, 1.370]	0.131
Elderly multicomorbidity	1.057 [0.823, 1.494]	0.450
Elderly stroke × multicomorbidity	0.939 [0.652, 1.367]	0.404
Caregiver MCM	1.804 [1.498, 2.158] ***	<0.000
Age (elderly)	1.020 [1.004, 1.035] *	0.014
Age (caregiver)	1.000 [0.994, 1.006]	0.956
Sex (rf: Male) (elderly)	1.090 [0.951, 1.252]	0.219
Sex (rf: Male) (caregiver)	1.128 [0.981, 1.301]	0.094
Marital status (rf: Not married) (caregiver)	0.912 [0.807, 1.032]	0.144
Relationship (rf: Paid employee)		
- Children	1.229 [0.879, 1.782]	0.251
- Non-family	1.343 [0.819, 2.200]	0.240
- Other family	1.343 [0.754, 1.650]	0.631
- Spouse	1.708 [1.122, 2.658] *	0.015
Household income (rf: ≤ $10,000) (caregiver)		
- $10,000 - $19,999	0.696 [0.594, 0.816] ***	< 0.000
- $20,000 - $39,999	0.661 [0.562, 0.777] ***	< 0.000
- ≥ $40,000	0.471 [0.384, 0.576] ***	< 0.000

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 3: Multivariate results: Negative binomial regression of caregiver stressors defined with BCOS on elderly stroke and multicomorbidity and sociodemographics.

	Caregiver stressors (BCOS) *Negative Binomial Regression*	
	IRR: exp(β) [95% CI]	**P-value**
Elderly stroke	1.120 [0.836, 1.480]	0.427
Elderly multicomorbidity	1.063 [0.939, 1.203]	0.331
Elderly stroke × multicomorbidity	0.956 [0.672, 1.370]	0.804
Caregiver MCM	1.796 [1.493, 2.154] ***	<0.000
Age (elderly)	1.020 [1.005, 1.035] *	0.01
Age (caregiver)	1.000 [0.995, 1.006]	0.897
Sex (rf: Male) (elderly)	1.091 [0.957, 1.244]	0.194
Sex (rf: Male) (caregiver)	1.130 [0.989, 1.294]	0.075
Marital status (rf: Not married) (caregiver)	0.906 [0.806, 1.020]	0.102
Relationship (rf: Paid employee)		
- Children	1.235 [0.895, 1.742]	0.215
- Non-family	1.363 [0.850, 2.182]	0.196
- Other family	1.113 [0.775, 1.625]	0.570
- Spouse	1.716 [1.145, 2.607] *	0.01
Household income (rf: ≤ $10,000) (caregiver)		
- $10,000 - $19,999	0.696 [0.596, 0.813] ***	< 0.000
- $20,000 - $39,999	0.659 [0.563, 0.771] ***	< 0.000
- ≥ $40,000	0.471 [0.388, 0.570] ***	< 0.000

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Cumulative logit model

Table 4 shows the results of the cumulative logit model with caregiver level of burden matched with LBI as outcome on elderly stroke and multicomorbidity. Caring with elderly with stroke was associated with higher level of caregiver burden with an over two-fold increase in the odds for having higher level of burden compared to caregivers caring for elderly with no stroke (Odds Ratio (OR) = 2.097, 95% Confidence Interval = [1.008, 4.407]). Multicomorbidity was also associated with higher level of caregiver burden (OR = 2.414 [1.768, 3.305]) which increased the odds for having higher burden by 141.4%. However, the interaction between elderly stroke and multicomorbidity was not statistically significant so there was no evidence

that the presence of multicomorbidity of elderly affected the impact of elderly stroke on caregiver level of burden. Additionally, caregivers who were older (OR = 1.146 [1.100, 1.196]), were female (OR = 1.751 [1.263, 2.436]), or cared for elderly with increased age (OR = 1.502 [1.078, 2.101]) had higher level of burden. Factors correlated with decreased burden included being child (OR = 0.257 [0.101, 0.599]), non-family member (OR = 0.239 [0.087, 0.608]), or spouse of elderly (OR = 0.284 [0.091, 0.829]) compared to paid employee and higher caregiver household income (OR =0.341 [0.210, 0.551] for ≥ $40,000).

The average partial effects (APE) of predictors in the cumulative logit model was estimated as the change in probability of having higher burden level, and the results with bootstrap confidence interval were presented in **Table 5.** If the elderly had stroke, the probability of having low burden decreased by 0.158 (APE-Low Burden = -0.158) and the probability of having high burden increased by 0.170 (APE-High Burden = 0.170). Multicomorbidity of elderly decreased caregiver's probability of having low burden by 0.190 (APE-Low Burden = -0.190) and increased the probability of having high burden by 0.185 (APE-High Burden = 0.185). Additionally, the results also revealed that the probability of having high burden increased when the elderly was female (APE-High Burden = 0.111). The probability of having high burden decreased when caregiver was the child (APE-High Burden = -0.266), other family members (APE-High Burden = -0.239), or spouse of elderly (APE-High Burden = -0.219) or had higher household income (APE-High Burden = -0.201 for ≥ $40,000).

Table 4: Multivariate results: Cumulative logit model of caregiver level of burden defined with LBI on elderly stroke and multicomorbidity with OR.

	Caregiver Level of Burden *Cumulative Logit Model*	
	OR: exp(β) [95% CI]	**P-value**
Elderly stroke (Without multicomorbidity)	2.097 [1.008, 4.407] *	0.048
Elderly multicomorbidity	2.414 [1.768, 3.305] ***	0.000
Elderly stroke × multicomorbidity	1.165 [0.448, 3.056]	0.755
Caregiver MCM	0.967 [0.544, 1.718]	0.910
Age (elderly)	1.146 [1.100, 1.196] ***	0.000
Age (caregiver)	0.988 [0.974, 1.003]	0.126
Sex (rf: Male) (elderly)	1.751 [1.263, 2.436] **	0.001
Sex (rf: Male) (caregiver)	1.502 [1.078, 2.101] *	0.017
Marital status (rf: Not married) (caregiver)	0.836 [0.616, 1.133]	0.246
Relationship (rf: Paid employee)		
- Children	0.257 [0.101, 0.599] **	0.004
- Non-family	0.357 [0.101, 1.206]	0.101
- Other family	0.239 [0.087, 0.608] **	0.004
- Spouse	0.284 [0.091, 0.829] *	0.024
Household income (rf: ≤ $10,000) (caregiver)		
- $10,000 - $19,999	0.569 [0.370, 0.873] *	0.010
- $20,000 - $39,999	0.578 [0.375, 0.886] *	0.012
- ≥ $40,000	0.341 [0.210, 0.551] ***	0.000

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5: Multivariate results: Cumulative logit model of caregiver level of burden defined with LBI on elderly stroke and multicomorbidity with APE.

	CSB: Level of Burden *Cumulative Logit Model*		
	Average Partial Effect (APE) [95% Bootstrap CI]		
	Low Burden	**Medium Burden**	**High Burden**
Elderly stroke	-0.15796 ** [-0.28769, -0.02822]	-0.01212 [0.03998, 0.01574]	0.17008 ** [0.02675, 0.31341]
Elderly multicomorbidity	-0.19014 *** [0.27573, -0.10455]	0.00496 [-0.00874, 0.01866]	0.18518 *** [0.10195, 0.26841]
Elderly stroke × multicomorbidity	0.00530 [0.25741, 0.26801]	-0.04855 [-0.10785, 0.01076]	0.04325 [-0.25235, 0.33885]
Caregiver MCM	0.007 [-0.15403, 0.16762]	-0.000 [-0.01267, 0.012267]	-0.007 [-0.16196, 0.14877]
Age (elderly)		-0.00072 [-0.00245, 0.00101)	
Age (caregiver)		0.0000612 [-0.00015, 0.00027]	
Sex (rf: Male) (elderly)	-0.11686 ** [-0.20838, -0.0253]	0.00540 [-0.00520, 0.01601]	0.11146 ** [0.02657, 0.19635]
Sex (rf: Male) (caregiver)	-0.08461 [-0.17758, 0.00835]	0.00420 [-0.00420, 0.01259]	0.08042 [-0.00633, 0.16717]
Marital status (rf: Not married) (caregiver)	0.03670 [-0.04870, 0.12209]	-0.00076 [-0.00494, 0.00342]	-0.03594 [-0.01195, 0.04759]
Relationship (rf: Paid employee)			
Children	0.24565 ** [0.07303, 0.41827]	0.02016 [-0.02272, 0.06305]	-0.26581 ** [-0.48437, -0.04725]
Other family	0.27962 ** [0.06479, 0.49446]	-0.04061 [-0.09643, 0.01521]	-0.23901** [-0.40267, -0.07535]
Non-family	0.21052 [-0.10513, 0.52618]	-0.02848 [-0.10019, 0.04322]	-0.18203 [-0.044470, 0.08062]
Spouse	0.25654 * [-0.02032, 0.53341]	-0.03738 [-0.10328, 0.02851]	-0.21916 * [-0.43593, -0.00239]
Household income (baseline: ≤ $10,000) (caregiver)			
$10,000 - $19,999	0.11475 * [0.00715, 0.22235]	-0.00596 [-0.01695,0.00503]	-0.10879 * [-0.20803, -0.00954]
$20,000 - $39,999	0.11206 * [0.00014, 0.22397]	-0.00561 [-0.01610, 0.00489]	-0.10645 * [-0.21100, -0.00191]

$40,000	0.22323 *** [0.09318, 0.35327]	-0.02181 [-0.04880, 0.00518]	-0.20141 *** [-0.30929, -0.09354]

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Discussion

Hispanic in the US has a drastically increasing elderly population (The Administration for Community Living, 2019). The health of the Hispanic elderly has been shown to be associated with the depressive symptoms of their caregivers (Rote et al., 2015). This study uniquely filled a gap in the literature by investigating the association between the presence of stroke and interaction between stroke and multicomorbidity among Hispanic elderly and caregiver stress and burden, which was defined holistically rather than solely psychological outcomes. To create caregiver stress and burden as an outcome variable, we utilized two external scales: Bakas Caregiving Outcome Scale (BCOS) and Level of Burden Index (LBI) and matched individual items in each scale to items in HEPESE survey. We hypothesized that the presence of stroke in Hispanic elderly was associated with increased caregiver stress and burden and the presence of elderly multicomorbidity would interactively increase the impact of elderly stroke on caregiver stress and burden.

First, using the caregiver stressor count defined by BCOS as a measure for caregiver stress and burden, we did not observe a statistically significant association between the stroke history of elderly and caregiver stressor count from both quasi-Poisson regression and negative binomial regression. The quasi-Poisson regression and negative binomial regression yielded highly similar coefficient estimates for predictors on caregiver stressor count after adjusting the overdispersion of count data. This served a check for robustness of our regression results. Despite the nonsignificant results, the coefficient estimates for stroke (IRR = 1.120) and

comorbidity (IRR = 1.063) of elderly aligned with our hypothesis that stroke of elderly is associated with increased caregiver stressor count. The results showed that multicomorbidity of the caregiver and being the spouse of the elderly were associated with higher stressor count, convening with prior literature (Schumann, Alexopoulos, & Perneczky, 2019). Our results also confirmed the role of increased household income of caregiver in decreasing caregiver stressor count (Andrén & Elmståhl, 2007).

Second, our model results using caregiver level of burden as outcome showed that the presence of stroke on elderly was associated with a 110% increase in the odds of having higher level of burden for caregiver, which confirmed our initial hypothesis. We also found a 141% increase in odds of having higher caregiver level of burden associated with the presence of elderly multicomorbidity, similar to existing literature on the burden of caregivers caring for patients with chronic illness (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). However, a statistically significant interaction effect between stroke and multicomorbidity of elderly was not observed as we expected that stroke would have greater impact on increased caregiver burden with the presence of multicomorbidity of elderly. Additionally, the results showed that compared to paid employee, caregivers who were family members of elderly tended to have lower level of burden. We hypothesized that this was because elderly had to resort to paid employees once the physical caregiving duties became exceedingly burdensome for family caregivers. Lastly, our results for the negative correlation between caregiver household income and level of burden were similar to the results of negative binomial model.

The estimated multivariate results based on two different outcome measures: caregiver stressor count and level of burden yielded partly dissimilar results. In particular, when the caregiver stress and burden was measured by stressor count (BCOS), there was evidence that

multicomorbidity of caregiver affected the stressor count. Yet, we failed to observe significant association of elderly multicomorbidity and stressor count. On the other hand, when the caregiver stress and burden was measured by level of burden (LBI), there was evidence that elderly multicomorbidity affected the burden level, whereas there was no significant association between caregiver multicomorbidity and level of burden. This might be because caregiver stressor count defined by BCOS captured a broader scope of constructs, one of which was the caregiver's self-rated health that was correlated with multicomorbidity of the caregiver. On the contrary, the caregiver level of burden defined by LBI measured caregiver stress and burden based on the intensity of caregiving: type and length of care provided. Level of burden directly measured the burden outcome due to physical caregiving duties and did not include measures for psychological outcome of caregivers. However, the domains in LBI enabled us to exactly match items from HEPESE survey to recreate the level of burden with no information loss, which allowed us to have a more precise measure for caregiver stress and burden compared to stress count defined by BCOS.

Our study, particularly with caregiver LBI as outcome, identified a subset of Hispanic caregiver population who were caring for elderly with stroke or multicomorbidity that were susceptible to high caregiver stress and burden. Our results called for further policy and community support for those caregivers to alleviate their stress and burden, such as the expansion of the Family and Medical Leave Act tailored to adapt the work and life of Hispanic caregivers in the southwestern U.S. region. State and community level actions should also be taken by strengthening the Home & Community Based Services for Hispanic elderly population and also specially designing toolkits and guidelines for Hispanic caregivers caring for stroke survivors (Alzheimer's Association, 2021; Texas Health and Human Services Commission,

2021). Additionally, information technology-based community intervention might also be a cost-effective way to deliver caregiver support material or therapy, as it has been shown to be effective in moderating the depressive symptoms among family caregivers (Eisdorfer et al., 2003). Actions need to be taken to address caregiver stress and burden among Hispanic population with culturally tailored approaches.

One limitation of our study was the loss of information when matching HEPESE survey to BCOS which contains 15 questions, some of which did not have exact matching items in our survey. Nonetheless, extensive literature reviews were conducted to reduce inappropriate matching decision. The LBI was exactly matched from the HEPESE survey data. Matching to external scale could potentially be helpful in maximizing the utility of existing survey data to provide new insights. Our analysis also encountered missing data which caused 135 observations deleted in the final regression model. We plan to address the missing data as the immediate next step by examining missing data patterns and then employ a random forest-based algorithm to impute missing data. Lastly, the proportion of Hispanic elderly with stroke in our sample is 12.2% and with further stratification after multiple controls into subgroups in a generalized linear model, the regression model might not have been able to capture enough variations within the elderly stroke survivor's subsample. Future work needs to be conducted to examine the role that acculturation of Hispanic Americans played in our model to account for the association between elderly stroke and caregiver stress and burden. Acculturation has been shown to be linked to negative outcomes such as increased depressive symptoms of Hispanic caregivers and negative health behaviors, and positive outcomes such as increased self-esteem of Hispanic elderly and higher life satisfaction and resilience (Hahn, Kim, & Chiriboga, 2011; Marsiglia, Booth, Baldwin, & Ayers, 2013; Masel, Rudkin, & Peek, 2006; Meyler, Stimpson, & Peek, 2006).

Others contended that acculturation in U.S. had mixed effects for Hispanic health, which on one hand was associated with worse health behaviors and outcome and on the other hand was associated with increased healthcare use and better self-rated health (Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005). Out study could contribute to the current discussion of the effect acculturation on Hispanic health by including the HEPESE survey item: language used for interview (English or Spanish), a surrogate measurement for Hispanic acculturation, as a predictor for caregiver stress and burden in our model (Rote et al., 2015).

Conclusion

The Hispanic population in the U.S. has a rapidly growing elderly population (The Administration for Community Living, 2019). Survey items from HEPESE were matched to Bakas Caregiving Outcome Scale which yielded caregiver stressor count ranging from 0 to 12 and to Level of Burden Index which yielded caregiver level of burden which took on low burden, medium burden, and high burden as measures for caregiver stress and burden. Our results on the study sample demonstrated that stroke and multicomorbidity of the Hispanic elderly was associated with increased caregiver stress and burden, specifically physical burden measured by level of burden, but we did not observe the effect of stroke or multicomorbidity of elderly on the caregiver stress and burden measured by stressor count. Our results indicated the need for further culturally tailored policy and action from the federal, state, and community level to support caregivers caring for elderly with stroke who are susceptible to high level of stress and burden.

Appendix

Appendix 1.A

Table 1.A: Matching results from HEPESE Caregiver Survey to BCOS.

BCOS Items	HEPESE Caregiver Survey
1. My self-esteem	Just as good as others (CES-D item) Whole life failure (CES-D item)
2. My physical health	Self-rated health
3. My time for family activities	Total hours of daily or personal care provided per day
4. My ability to cope with stress	Neuropsychiatric Inventory Distress score Perceived Stress Scale-4
5. My relationship with friend	I felt lonely (CES-D item) People were unfriendly (CES-D item)
6. My future outlook	I felt hopeful about future (CES-D item)
7. My emotional well-being	Center for Epidemiological Study-Depression (CES-D) Total score
8. My social activities time with friend	Total hours of daily or personal care provided per day
9. My relationship with family	Dropped
10. My relationship with patient	How well informant get along with respondent
11. My Financial well being	If caregiving makes it difficult to provide any other expense
12. My physical function	Grip strength measurement
13. My general health	Self-rated health
14. My roles in life	Can't control important things in life. Life satisfaction
15. My level of energy	Everything I did was an effort (CES-D item)

Appendix 1.B

Matching Process to BCOS and Literature Evidence

The first BCOS item, “My self-esteem”, was matched to two “CES-D” subitems “I felt I was just as good as other people” and “I thought my life has been a failure” from HEPESE caregiver survey. We first collapsed CES-D scale 0 = rarely or none of the time, 1 = some or little of the time, 2 = occasionally or a moderate amount of time, and 3 = most or all of the time to yes (1) and no (0) where no (0) = 0: rarely or none of the time and 1: some or little of the time; yes (1) = 2: occasionally or a moderate amount of time and 3: most or all of the time. A caregiver would have this stressor if they had (1) for either of the two CES-D items.

The second BCOS item “My physical health” and the *thirteenth* BCOS item “My general health” were both matched to HEPESE caregiver survey item “caregiver self-rated health”, and we dichotomized this item as (1) = excellent or good and (0) = fair or poor. This stressor was counted only once.

The third BCOS item “My time for family activities” and the *eighth* BCOS item “My social time with friends” were both matched to daily caregiving hours. Daily caregiving hours was created by selecting the greater value between “daily personal care hours for care recipient” and “daily household tasks assistant hours for care recipient” from the HEPESE caregiver questionnaire item. Daily caregiving hours were dichotomized at 3.48 hours per day according to the average care providing hours by family caregiver in the U.S where (0) was assigned for daily caregiving hours less than 3.48 and (1) was assigned for daily caregiving hours greater or equal to 3.48. (Public Policy Institute & National Alliance for Caregiving, 2015).

The fourth item of BCOS “My ability to cope with stress” was matched to the total score of 4-items Perceived Stress Scale (PSS-4) HEPESE caregiver survey because PSS-4 was used to

assess the stress of the caregiver and a cut point at 5.6 was proportionally derived based on the original recommended cutoff for the complete 10-items Perceived Stress Scale (PSS-10) at 14 out of total score 40, and was applied to dichotomize PSS-4 out of total score 16 (Schwarz & Dunphy, 2003). A caregiver would have (1) if scored higher than 5.6 on PSS-4.

The fifth item of BCOS "My relationship with friends" was matched to two CES-D subitems "People were unfriendly" and "I felt lonely" from HEPESE caregiver survey. We first collapsed each item from its original scale (0, 1, 2, 3) into (1) and (0), with (0) = original 0 and original 1, (1) = original 2 and original 3. We then assigned the fifth stressor to the caregiver if he or she had (1) for either of the two CES-D subitems.

The sixth BCOS item was matched to the CES-D subitem "I felt hopeful about the future" from HEPESE caregiver survey. This stressor was dichotomized to (1) if the caregiver scored 3 or 4 for this CES-D subitem.

The seventh BCOS item "My emotional well-being" was matched to the CES-D total score which measures the overall depressive symptoms of the caregiver from HEPESE caregiver survey. We assigned the seventh stressor (1) to the caregiver if the CES-D score is greater than recommended threshold value 16 for CES-D scale and (0) otherwise (Lewinsohn, Seeley, Roberts, & Allen, 1997).

The ninth BCOS item "My relationship with my family" was dropped because a matching item from HEPESE survey could not be identified.

The tenth BCOS item "My relationship with patient" was matched with caregiver self-rated "how well do you and care recipient get along together" from HEPESE caregiver survey item. The eighth stressor was assigned to the caregiver if the caregiver responded "Not well/not at well, Not too well, or Somewhat" to this question.

The eleventh BCOS “My financial well-being” was matched to the question “Does the financial responsibility for care recipient make it difficult for you to save money for following expenses” from HEPESE caregiver survey item. The ninth stressor (1) was assigned to caregiver if the caregiver responded any financial difficulties due to caregiver to this question.

The twelfth item “My physical function” was matched to grip strength of caregiver (Taekema, Gussekloo, Maier, Westendorp, & de Craen, 2010) (Al Snih, Markides, Ottenbacher, & Raji, 2004). The tenth stressor (1) was assigned to the caregiver if the caregiver’s grip strength is less than 25.8 kg for male or less than 17.4 kg for female (Vasconcelos et al., 2016).

The fourteenth BCOS item “My role in life” was matched to “caregiver life satisfaction” from HEPESE caregiver survey The eleventh stressor (1) was assigned to the caregiver if they responded “Not at all”.

The fifteenth BCOS item “My energy level was matched to CES-D subitem “I felt everything I did was an effort”. The twelfth stressor (1) was assigned to caregiver if they scored 1, 2, or 3 for this subitem.

Appendix 2.A

Figure 2.A: Level of Burden Index (Evercare and National Alliance on Caregiving, 2008)

Hours of Care (weekly)	
0-8 hours	1 point
9-20 hours	2 points
21-40 hours	3 points
41 or more hours	4 points

Types of Care Provided	
0 ADLs, 1 IADL	1 point
0 ADLs, 2 or more IADLs	2 points
1 ADL, 0-7 IADLs	3 points
2 or more ADLs, 0-7 IADLs	4 points

Level of Burden Based on Points	
Sum of Points	**Level of Burden**
2-3 points 4 points	Low Burden
5 points	Medium Burden
6-7 points 8 points	High Burden

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