

Caregiving for Older Adults with Limited English Proficiency: Transitioning from Hospital to Home



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BACKGROUND: Although the family caregiver workforce is increasingly diverse, little is known about culturally and linguistically diverse caregivers and patients for whom they care. Caregiver roles include communicating with health care teams on behalf of patients with language barriers.

OBJECTIVE: Our objective is to describe characteristics and experiences of caregivers for patients with limited English proficiency (LEP) immediately following hospital discharge.

DESIGN: Cross-sectional.

PARTICIPANTS: Primary informal caregivers for Chinese- and Spanish-speaking patients with LEP discharged from a large academic medical center's orthopedic surgery, general surgery, and cardiovascular inpatient floors from June 2012 to August 2013.

MAIN MEASURES: Bilingual-bicultural research assistants conducted baseline structured interviews with patients or surrogates in the hospital, and 3 weeks after discharge, gathering demographic and health information. They then interviewed by phone informal caregivers, identified by patients, to determine caregiving experiences.

KEY RESULTS: One hundred fifty-eight caregivers were interviewed post-discharge. Two-thirds (69.0%) were adults caring for parents or grandparents, and 20.9% were spouses or partners. Sixty-nine (43.7%) caregivers had LEP themselves, yet only 12% of patients reported having access to professional interpreters at the time discharge instructions were provided. Ninety percent reported performing three or more caregiving roles for the patient (helping at home, helping with medical decisions, helping with medical forms, helping communicate with medical staff, and talking with doctors about medical care). Forty percent reported moderate/high levels of perceived stress (some, most, or all of the time) caring for the patient. Multivariate regression revealed caregivers for Chinese-speaking patients, and those for patients discharged to another hospital were most likely to report moderate/high levels of perceived stress.

CONCLUSION: Culturally and linguistically diverse caregivers perform multiple roles caring for patients with LEP, often have LEP themselves, and experience notable levels of stress. These results also demonstrate an opportunity to expand the use of professional interpreters at hospital discharge to avoid communication errors.

KEY WORDS: caregiving; care transitions; limited English proficiency; geriatrics.

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INTRODUCTION

Family (or informal) caregivers have a significant role in home care of elderly patients. In 2015, of the 43.5 million Americans who reported providing unpaid care during the past year, 79% cared for an adult age 50 or older.¹ Beyond assisting with activities of daily living, caregivers are often involved in medical decisions, patient advocacy, and communication with health care providers; they also provide emotional and social support to patients.^{2, 3} The volume of caregiver responsibility coupled with lack of formal support systems and training for these roles can lead to caregiver burden. A recent national survey found that 4 in 10 caregivers consider their caregiving situation to be highly emotionally stressful.¹ These caregivers may suffer from decline in their own physical health, emotional well-being, and socioeconomic status.⁴⁻⁶ Caregivers responsible for patients with chronic conditions, limited mobility, medical or nursing needs, and extended care needs appear to experience the highest levels of emotional stress.^{1, 7, 8}

Thus far, the majority of work examining caregivers and caregiver burden has focused on the outpatient setting, with limited data on experiences of culturally and linguistically diverse populations. Yet, over half of caregivers report that their care recipient was hospitalized at least once during the prior year and the caregiver workforce is increasingly diverse with Latinos accounting for nearly 20% of informal caregivers.¹ A systematic review of ethnically diverse caregivers demonstrated numerous differences in caregiver experiences

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exist across cultural groups; however, few caregiver intervention studies report their findings stratified by cultural groups.⁹ An analysis of the American Time Use Survey (ATUS), reporting stratified results, found that Latino caregivers tend to engage in more time-intensive and demanding caregiving roles when compared with non-Latino Whites. Asian caregivers had more care recipients than other racial/ethnic groups.¹⁰ Little attention, however, has been given to describing in detail characteristics of culturally and linguistically diverse caregivers.

Patients with limited English proficiency (LEP) face challenges during hospitalization, including risk of errors and adverse events due to communication barriers.¹¹ For caregivers with LEP, navigating the complexities of the health care system alongside patients with LEP compounds communication challenges and could lead to stress. The purpose of our study was to describe the demographic makeup, roles, and self-reported stress levels of caregivers for recently hospitalized Chinese- and Spanish-speaking patients with LEP, and to explore the characteristics of both caregivers and patients associated with elevated levels of caregiver perceived stress.

METHODS

Study Design and Setting

This was a cross-sectional study taking place at a large academic medical center with a diverse patient population. Approximately 24% of discharges per year involve patients with LEP.¹² We investigated the characteristics and perspectives of caregivers for Chinese- and Spanish-speaking patients with LEP and their experiences during the period immediately following hospital discharge. The affiliated academic institutional review board approved this study.

Study Population

The study population was drawn from a parent study examining communication strategies among hospitalized patients with LEP. Details of this recruitment were previously published.¹³ In brief, we prospectively recruited Chinese- (Cantonese or Mandarin) and Spanish-speaking patients from orthopedic surgery, general surgery, and cardiovascular inpatient floors from June 2012 to August 2013. We interviewed patients in the hospital and asked them to identify their primary informal caregiver, who was present at the time of hospital discharge. Approximately 3 weeks after discharge, we then interviewed the caregiver by telephone.

Research assistants screened eligible patients to confirm patient age, LEP status using a validated LEP algorithm,¹⁴ and cognitive status using the Mini-Cog.¹⁵ Patients with cognitive impairment were included if they met all other inclusion criteria and a surrogate consented to participate in the study. Thirty-nine percent of patients had a surrogate, most of whom

(90.3%) were also the identified primary caregiver. Patients were included in this analysis if they were alive at the time of post-discharge follow-up calls.

We conducted baseline structured interviews with patients or their surrogates in the hospital pre-discharge. Participants identified the primary caregiver, who was present at the time of hospital discharge. Caregiver was defined as “a relative, friend, or other caregiver present when you received instructions about your medicines, follow-up appointments, and how to care for yourself after leaving the hospital.” We contacted identified caregivers for telephone interviews post-discharge; the mean time between patient discharge and caregiver interview was 39.7 ± 15.8 (SD) days. During the interview, each caregiver was screened to verify their role as the caregiver according to our study definition or to provide the name of another caregiver who met this criterion.

Caregiver and Patient Characteristics

Through the baseline interviews, we obtained demographics for patients including age, gender, country of birth, and highest level of education; we obtained the same information for caregivers at the follow-up caregiver interview. We additionally inquired about caregiver self-reported health. For patients, we asked about comorbidities, scored using the Self-Administered Comorbidity Questionnaire (SCQ), a validated instrument that uses simplified language to assess the presence of, treatment for, and limitation related to 12 common medical problems (score, range 0–36).¹⁶ We inquired about functional status, including activities of daily living (ADLs) and independent activities of daily living (IADLs). We abstracted discharge destination (home, SNF/rehab/hospice, another hospital) from patient charts. We inquired about both patient and caregiver health literacy, preferred language, and English-speaking ability using validated instruments. Limited English proficiency was defined using an algorithm validated in the clinical setting, which classifies patients as having LEP based on the US Census English proficiency definition and preferred language for receiving medical care.¹⁴ Health literacy was categorized as adequate or inadequate using a brief validated 1 question screening tool.¹⁷ We asked all patients whether a professional interpreter was present at the time discharge medication and follow-up instructions were reviewed by the medical team.

During caregiver interviews, caregivers responded “yes” or “no” to assuming specific caregiving roles (helping at home, helping with medical decisions, talking to doctors about medical care, and helping communicate with the medical staff). We used a validated screening tool to assess caregiver global financial strain; specifically, we asked whether caregivers had difficulty paying monthly bills at any point over the past 12 months.¹⁸ Additionally, we used the Medical Outcomes Study of Social Support (MOS-SS) subscales of tangible and

emotional/informational support (score, range 0–5) to assess caregivers' perceived support networks.¹⁹ For our primary outcome, we asked caregivers: "In the past week, how often have you felt stressed caring for the patient?" with response options "none of the time," "a little of the time," "some of the time," "most of the time," and "all of the time."

Statistical Analysis

Descriptive statistics were used to present demographic and health characteristics for patients and caregivers. We used Chi-square and Student's T tests to examine bivariate associations between caregiver self-reported stress level, and caregiver and patient characteristics. Caregiver stress levels were dichotomized as low stress ("none of the time" and "a little of the time") and moderate/high stress ("some of the time," "most of the time," and "all of the time"). Using a backward stepwise elimination approach, with a significance level of $p < 0.20$, we selected variables to include in a multivariable logistic regression modeling the odds of reporting caregiver moderate/high stress versus low stress. Two-sided p values < 0.05 were considered statistically significant. We performed all statistical analyses using Stata 14 (StataCorp, LP, College Station, TX).

RESULTS

From the parent study recruitment, 254 patients were eligible to participate in the study and 84% ($n = 214$) initially agreed to participation. The 39 patients that refused participation did not differ significantly from participants in terms of age, gender, or preferred language to receive medical care. In total, 202 (94.4%) of 214 patients in the LEP cohort were alive at discharge. One hundred fifty-eight (78.2%) caregivers for these patients completed follow-up interviews and were included in this analysis. Among the caregivers not included in the analysis, 10 refused participation, 21 were unable to be contacted despite three attempts, 12 cared for patients who died after discharge but before follow-up, and 2 did not respond to the caregiver perceived stress question.

Caregiver Characteristics

Two-thirds were adult children or grandchildren in a caregiver role. The median age of caregivers was 47 years (range 19–81) and a majority (65.2%) were women. More than half reported living with the patient that they cared for. Overall, 41.7% of caregivers preferred to receive their own medical care in a language other than English, and 34.2% reported speaking English not at all or not well. Twenty-nine percent of caregivers had inadequate health literacy (mean HL score 2.14 ± 1.24). A quarter of caregivers did not have enough money to pay their monthly bills in the past year. Forty percent of caregivers felt stressed caring for their loved one at least some of the time (Table 1).

Caregivers reported multiple roles assisting patients post-hospitalization including helping at home (85.4%), helping with medical decisions (79.6%), helping with medical forms (77.2%), talking with doctors (88.6%), and communicating with medical staff (84.6%). Ninety percent of caregivers reported taking on 3 or more caregiving roles for patients (Fig. 1).

Patient Characteristics

Overall, among the 158 patients cared for, the median age was 70 years (range 41–95) and a majority were women (58.2%). Almost all patients preferred to receive medical care in a language other than English, and 83.8% had inadequate health literacy. Twelve percent of patients reported having a professional interpreter present at the time discharge medication and/or follow-up instructions were provided. The mean comorbidity score for patients was 8.7 (SD 4.9). Sixty-six percent of patients reported having difficulty with at least one IADL post-hospitalization. Forty-nine percent of patients reported having difficulty with three or more IADLs, and 35.1% had difficulty with three or more ADLs. Seventy-seven percent of patients were discharged to home, 19.6% to SNF/rehab/hospice, and 3.8% to another hospital (Table 2).

Association of Caregiver and Patient Characteristics with Caregiver Perceived Stress Level

In bivariate analysis, moderate/high caregiver perceived stress was significantly associated with older patients, more patient comorbidities, and patient preferred Chinese language (Tables 1 and 2). After backward stepwise elimination, our multivariate logistic regression model was adjusted for patient age, patient financial hardship, caregiver relationship to patient, caregiver MOS tangible support score, patient preferred language, hospital discharge floor, and discharge destination. Caregivers had greater odds of self-reporting moderate/high stress when caring for patients who preferred to receive medical care in Chinese rather than in English (OR 9.52; $p = 0.033$) or when caring for patients discharged to another hospital rather than those caring for patients discharged to home or SNF/rehab/hospice (OR 9.95; $p = 0.025$). No other characteristics were significantly associated with moderate/high self-reported stress in the multivariate model.

DISCUSSION

We found that a majority of informal caregivers for Chinese- and Spanish-speaking patients with LEP recently discharged from the hospital are adult children or grandchildren, who take on multiple roles caring for their family member, both in the health care environment and at home. A number of caregivers, who themselves had LEP, assumed a direct role coordinating their relative's care and communicating on their behalf.

Table 1 Characteristics of Caregivers for Patients with Limited English Proficiency Recently Discharged from the Hospital According to Caregiver Perceived Stress (n = 158)

	Total (n = 158)	Low caregiver stress (n = 95)	Moderate-to-high caregiver stress (n = 63)	p
Caregiver Characteristics				
Relationship to patient				0.422
Spouse/partner	33	20 (60.6)	13 (39.4)	
Adult child/grandchild	109	63 (57.8)	46 (42.2)	
Other family/friend	16	12 (75.0)	4 (25.0)	
Caregiver lives with patient	93	55 (59.1)	38 (40.9)	0.883
Age (years), mean ± SD	47.1 ± 14.7	45.7 ± 15.2	49.3 ± 13.6	0.136
Female	103	60 (58.3)	43 (41.7)	0.510
Place of birth				
USA	30	22 (73.3)	8 (26.7)	
Latin America	38	29 (76.3)	9 (23.7)	
Asia	89	43 (48.3)	46 (51.7)	
Preferred language to receive medical care				0.063
English	92	59 (64.1)	33 (35.9)	
Spanish	22	16 (72.7)	6 (27.3)	
Chinese	44	20 (45.5)	24 (54.5)	
English-speaking ability				0.131
Not at all	17	9 (52.9)	8 (47.1)	
Not well	37	23 (62.2)	14 (37.8)	
Well	49	24 (49.0)	25 (51.0)	
Very well	55	39 (70.9)	16 (29.1)	
Highest level of education				0.977
Some high school or less	37	22 (59.5)	15 (40.5)	
High school diploma	29	18 (62.1)	11 (37.9)	
Some college or more	89	54 (60.7)	35 (39.3)	
Health literacy				0.318
Adequate	108	67 (62.0)	41 (38.0)	
Inadequate	45	24 (53.3)	21 (46.7)	
Self-rated health				0.204
Excellent	18	11 (61.1)	7 (38.9)	
Very good	34	26 (76.5)	8 (23.5)	
Good	57	34 (59.6)	23 (40.4)	
Fair	42	23 (54.8)	19 (45.2)	
Poor	5	1 (20.0)	4 (80.0)	
Very poor	1	0 (0.0)	1 (100.0)	
Global financial strain: in the past 12 months, was there a time when you did not have enough money to pay your monthly bills?				
Yes	40	23 (57.5)	17 (42.5)	0.549
MOS score: tangible support (mean, SD)	4.3 ± 0.9	4.4 ± 0.8	4.2 ± 1.1	0.345
MOS score: emotional support (mean, SD)	4.0 ± 1.2	4.1 ± 1.1	4.0 ± 1.2	0.181

Percentages are based on non-missing values. Caregiver's response to the question: "In the past week, how often have you felt stressed caring for patient?" was dichotomized as low stress: "none of the time" and "a little of the time"; moderate/high stress: "some of the time," "most of the time," and "all of the time." All percentages shown are calculated from row proportions
 ADL, activities of daily living; IADL, instrumental ADL; MOS, Medical Outcomes Study (score, range 1–5); SCQ, Self-Administered Comorbidity Questionnaire (score, range 0–26)

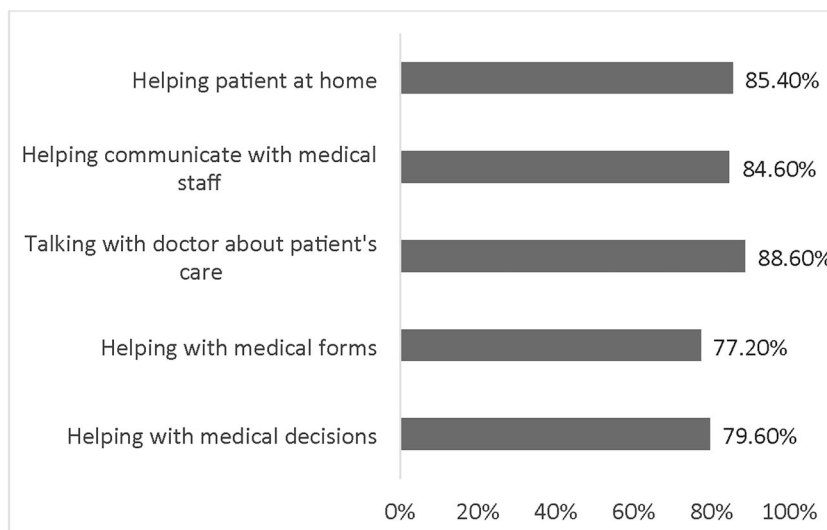
**Figure 1 Caregiver-reported roles assisting patients with LEP post-hospitalization.**

Table 2 Characteristics of Patients with Limited English Proficiency Recently Discharged from the Hospital According to Caregiver Perceived Stress (n = 158)

	Total (n = 158)	Low caregiver stress (n = 95)	Moderate/high caregiver stress (n = 63)	p
Patient characteristics				
Age (years), mean ± SD	69.6 ± 13.2	67.4 ± 12.9	73.0 ± 12.9	0.009
Female	92	56 (60.9)	36 (39.1)	0.822
Preferred language to receive medical care				0.008
English	14	10 (71.4)	4 (28.6)	
Spanish	37	30 (81.1)	7 (18.9)	
Chinese	107	55 (51.4)	52 (48.6)	
English-speaking ability				0.074
Not at all	78	41 (52.6)	37 (47.4)	
Not well	65	46 (70.8)	19 (29.2)	
Well	15	8 (53.3)	7 (46.7)	
Very well	0	0	0	
Professional interpreter present at discharge	19	13 (68.4)	6 (31.6)	0.431
Highest level of education				0.417
Some high school or less	113	68 (60.2)	45 (39.8)	
High school diploma	22	11 (50.0)	11 (50.0)	
Some college or more	20	14 (70.0)	6 (30.0)	
Health literacy				0.167
Adequate	24	17 (70.8)	7 (29.2)	
Inadequate	124	69 (55.6)	55 (44.4)	
SCQ comorbidity score (mean, SD)	8.7 ± 4.9	8.0 ± 4.7	9.8 ± 5.2	0.029
Baseline IADL function				0.070
No IADL impairments	54	36 (66.7)	18 (33.3)	
Difficulty with 1–2 IADLs	26	19 (73.1)	7 (26.9)	
Difficulty with ≥ 3 IADLs	78	40 (51.3)	38 (48.7)	
Baseline ADL function				0.276
No ADL impairments	43	26 (60.5)	17 (39.5)	
Difficulty with 1–2 ADLs	53	36 (67.9)	17 (32.1)	
Difficulty with ≥ 3 ADLs	52	23 (44.2)	29 (55.8)	
Hospital floor/service				0.099
Cardiology	89	47 (52.8)	42 (47.2)	
Orthopedics	28	20 (71.4)	8 (28.6)	
General surgery	41	28 (68.3)	13 (31.7)	
Hospital discharge destination				0.393
Home	121	74 (61.2)	47 (38.8)	
SNF/rehab/hospice	31	19 (61.3)	12 (38.7)	
Another hospital	6	2 (33.3)	4 (66.7)	
Global financial strain: in the past 12 months, was there a time when you did not have enough money to pay your monthly bills?				0.549
Yes	52	33 (63.5)	19 (36.5)	

ADL, activities of daily living; IADL, instrumental ADL; MOS, Medical Outcomes Study (score, range 1–5); SCQ, Self-Administered Comorbidity Questionnaire (score, range 0–26)

Percentages are based on non-missing values. Caregiver's response to the question: "In the past week, how often have you felt stressed caring for patient?" was dichotomized as low stress: "none of the time" and "a little of the time"; moderate/high stress: "some of the time," "most of the time," and "all of the time." All percentages shown are calculated from row proportions

Among these caregivers, particularly those caring for Chinese-speaking patients and patients discharged to another hospital, we found moderate/high self-reported stress related to their caregiving role.

National surveys have provided a general description of informal caregivers.^{1–3} Similar to caregivers in the general population, in our sample, caregivers were mostly late-middle-aged women caring for parents or grandparents. Almost all caregivers in our study had multiple roles caring for Chinese- and Spanish-speaking patients, including communicating with the health care team and assisting with medical decision-making. Notably, almost half of caregivers had a language barrier. For caregivers with LEP, navigating the complexities of the health care system alongside patients with LEP likely presents significant communication challenges.

Patients with LEP are at risk for adverse health events, longer hospital stays, and readmissions, compared with English-fluent patients.^{20, 21} These disparities may be

compounded for elderly patients, who often have complex health needs that require greater care coordination, particularly during the transition from hospital to home.²² Many caregivers in our study reported roles helping patients communicate with doctors and medical staff. We found that only 12% of caregivers with LEP had access to professional interpreters at the time discharge medication and follow-up instructions were provided. Although caregivers in our study had a relatively higher health literacy compared with the general population, many also had LEP.²³ Caregivers facing language barriers may have difficulty helping patients overcome challenges communicating with their health care team, particularly when the teams do not access professional interpreters.

Asian caregivers have been found to have more care recipients than other racial/ethnic groups.¹⁰ Asian caregivers in the National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP)

survey were also more likely to work full time while caregiving compared with White, Black, or Latino caregivers.¹ In our study, we found that caregivers caring for Chinese-speaking patients were more likely to report moderate/high stress compared with those caring for English- and Spanish-speaking patients. More than half of caregivers we studied had at least some college education. A recent California Health Interview Survey analysis found that while having more education mitigates general psychological distress among White caregivers, it has been associated with more distress for Asian caregivers.²⁴

While prior work has found an association between longer duration of caregiving and high caregiver stress, there has been a limited investigation of acute care scenarios.⁷ In our study, we focused on the experiences of caregivers in the acute post-hospital care setting. Post-hospital care is particularly important given the potential for patients having new, challenging functional limitations that increase caregiver burden. Among patients in our sample, nearly half had difficulty with 3 or more IADLs and one-third with 3 or more ADLs. Caregivers providing more assistance with ADLs are more likely in some cases to report overload in their caregiving role.²⁵ Latino caregivers, however, have been found to report less stress related to caregiving than non-Latino caregivers despite providing more ADL assistance and more hours caregiving.²⁶ In our bivariate analysis, we did not find a significant association of patient functional status with perceived caregiver stress levels. Given many of the patients in our study were discharged post-op, they likely had access to home health services or nursing at SNF/rehab/hospice, which may have alleviated caregiver perceived stress due to patients' functional limitations. Additionally, patients' functional limitations may in many cases have been temporary and improving during the post-procedure period.

Caregivers responsible for patients discharged to another hospital, as opposed to home, or SNF/rehab/hospice, reported moderate/high levels of perceived stress. This stress may have been due to these patients having more functional limitations or health complications, demanding a higher level of caregiver involvement upon discharge. In addition, given that caregivers were contacted 3 weeks after initial hospital discharge, these caregivers may have been interviewed soon after the patient's second hospital stay, further intensifying the perceived burden of care.

There are important limitations to consider when reviewing our findings. This is a small cross-sectional study, from which we cannot draw causal conclusions. Additionally, we relied on patients to identify one caregiver present at the time of discharge though these roles may have been dynamic or shared across caregivers. However, the vast majority of caregivers in our study reported performing three or more caregiver roles, suggesting that they were in fact the patient's primary caregiver. Also, by focusing on a distinct time period post-hospital

discharge, we were able to limit the likelihood of multiple caregivers being closely involved in the patient's care. An additional limitation is that all caregiver roles assisting patients were self-reported. Yet, in terms of assessing our primary outcome, caregiver stress, self-described roles, and responsibilities may be the most relevant. We had a significant number of surrogates or proxies, most of whom also served as caregiver, respond on behalf of patients. This is not surprising given our study population was primarily post-op and prone to acute delirium. Proxies have been shown to overestimate health and functional limitations, particularly among elderly and disabled populations.²⁷ Our interview questions, however, primarily focused on the caregiver's perceived quality of life and mood. We objectively measured patient comorbidities, demographic characteristics, admission, and discharge location. Only 6 patients in our study were discharged to another hospital so our finding that discharge to another hospital is associated with moderate/high caregiver perceived stress may not be clinically significant. For the assessment of caregiver perceived stress, we did not use a validated caregiver stress instrument in order to ease survey burden and because existing measures of caregiver burden have not been validated in populations with LEP. A national study of Latino family caregivers did, however, use a similar 1-question screen for caregiver stress as in our study.²⁶ Also, we separately asked caregivers about emotional and tangible support as well as self-reported health questions included in longer, validated caregiver stress assessment tools.

Despite these limitations, this is the first study, to our knowledge, to describe characteristics and roles of caregivers for Chinese- and Spanish-speaking patients with LEP. Our study contributes to the limited literature examining the experiences of racially/ethnically diverse caregivers by providing insight into their linguistic diversity and its relationship to caregiver stress. By doing so, we can begin to develop effective tools and systems that will support all caregivers in their roles as part of the patient care team. Our results also suggested a missed opportunity to access professional interpreters at the time of hospital discharge to communicate with both patients and their caregivers with LEP, so as to avoid potential communication errors.

Contributors: Study concept and design: Karliner and Napoles; acquisition of subjects and/or data: Karliner; analysis and interpretation of data: Livaudais-Toman, Semere, Karliner, and Gregorich; and preparation of the manuscript: Semere, Karliner, Livaudais-Toman, Napoles, and Gregorich. No other individuals contributed substantially to this research or to the preparation of this manuscript.

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Compliance with Ethical Standards:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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