


Identifying Sociodemographic Characteristics Associated With Burden Among Caregivers of the Urban Homebound: The Importance of Racial and Relationship Differences

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Abstract

Limited research has explored whether the burden associated with caring for homebound patients varies across racial groups or by relationship status. We examined these variations for this vulnerable population. Patients self-identified informal caregivers and caregiver burden/depression were assessed using the Zarit Caregiver Burden Scale and the Center for Epidemiologic Studies–Depression scale (CES-D). Forty-nine informal caregivers completed the interview. Mean age was 58 ($SD = 14$), 78% were female, 37% Black, 35% Hispanic, and 46% had completed high school. Over 60% of caregivers had moderate or severe caregiver burden and 30% had significant depression. White caregivers had greater burden than Black and Hispanic caregivers ($p = .02$). Mean caregiver burden was higher among spouse/partner caregivers, versus those who identified as children or other family or friends ($p = .004$). Additional research is needed to better understand the experience of racial and ethnic minorities and spouses in providing informal care to homebound adults.

Keywords

caregiver burden, house calls, race and ethnicity

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Background

In response to increasing costs of care in the United States, caregiving for frail older adults has shifted from institutional to home-based settings (“AAHCP Public Policy Statement,” 2005). This shift has greatly expanded the role of informal caregivers, particularly spouses, children, and other family members (Cameron, Franche, Cheung, & Stewart, 2002). Informal caregivers are defined as family members, friends, or neighbors who help someone regularly to manage the day-to-day tasks related to their health care. Due to poor functional status and multiple chronic diseases, homebound seniors often require routine home-based medical care, assistance with self-care, and daily supervision (Gammel, 2005; Kellogg & Brickner, 2000). Informal caregivers coordinate and provide this care, potentially making the difference between a patient remaining in the community and requiring institutionalization. As more than one fifth of the U.S. population will be older than 65 years of age by 2030, the need for informal caregivers will only grow (Muramatsu, Mensah, & Cornwell, 2004).

Although informal caregiving brings clear benefits, it can also take a significant toll on those providing the care. Numerous studies have demonstrated that informal caregivers have high levels of caregiver burden (Garlo, O’Leary, Van Ness, & Fried, 2010; Palos et al., 2011), depression (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000), and stressed social (Cameron et al., 2002) and professional relationships (Ho, Collins, Davis, & Doty, 2005). Caregiving for chronically ill patients also negatively affects informal caregivers’ self-rated health (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003;

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Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). Prior research has found that the level of burden may vary according to the racial and ethnic makeup of the informal caregivers, often being higher for African Americans than other groups (McCann & Hebert, 2000; Yaffe et al., 2002). However, little is known about racial and ethnic variation in caregiver burden among informal caregivers of homebound seniors. As patients who are non-White are more likely to be homebound, knowledge of the interaction between race and caregiver burden is important in addressing the complex health care demands and often long-term needs of this population (Ornstein et al., 2015).

With little data on informal caregivers of homebound seniors and the growing need to understand the demands they face as our population ages, we interviewed informal caregivers of homebound older adults to quantify their perceived level of burden and examined patient and caregiver characteristics (e.g., race/ethnicity, health status) associated with caregiver burden.

Method

Study Participants and Setting

We recruited homebound seniors for a larger study on quality and utilization in the homebound. As part of this enrollment, all homebound enrollees were asked whether they had an informal caregiver. If they were able to identify someone, we then approached the informal caregivers for enrollment into this part of our study. All patients were recruited from two home-based long-term care programs, the Mount Sinai Visiting Doctors program (MSVD) and the Lombardi nursing care program of the Visiting Nurse Service of New York (LVNS). The MSVD program was founded in 1995 and provides home-based primary care to approximately 1,000 homebound seniors in the upper Manhattan neighborhoods of New York City (Smith, Ornstein, Soriano, Muller, & Boal, 2006). To be enrolled in the program, patients must meet the Medicare definition of homebound which specifies that they are restricted in their ability to leave their place of residence except with the aid of supportive devices, special transportation, or another person. Patients in the MSVD program receive home visits by primary care physicians. They also receive visits from registered nurses, nurse practitioners, physical therapists, phlebotomists, and medical specialists as needed.

The LVNS program, funded by the Medicaid Long Term Home Health Care Program 1915(c) Home and Community Based Services waiver, provided services to homebound adults who would otherwise require long-term nursing home care but preferred to remain at home. Patients received home nursing care through the program, but their primary and specialty medical care was provided to them independently. Patients in the LVNS program were typically referred to the program by their primary care providers or by providers during acute hospital or

skilled nursing facility stays. The LVNS program did not directly provide primary or specialty medical care services, though LVNS nurses communicated with patients' physicians by mail and telephone. Patients were eligible if they participated in either program between June 2010 and February 2012. All study procedures were approved by the Icahn School of Medicine at Mount Sinai and the Visiting Nurse Service of New York institutional review boards.

All eligible patients were identified through a weekly report of new patients enrolled in the MSVD and LVNS programs. To obtain informed consent, each patient was screened by phone for cognitive impairment using the Short Portable Mental Status Questionnaire (SPMSQ). When patients screened positive for cognitive impairment (SPMSQ score ≥ 8), research coordinators recruited patients through their surrogate or health care proxy. Interviews were conducted in English or Spanish. Informal caregivers were identified by study patients or their proxies and were defined as a family member, friend, or neighbor who regularly helps manage the patient's health care. Formal (or paid) caregivers were not included in this study. Identified informal caregivers were recruited by telephone at the time of or following the recruitment of the patient.

Outcome Measures

We measured outcomes likely to reflect the negative impacts of caregiving, including caregiver burden and depressive symptoms. Caregiver burden was measured using the Zarit Caregiver Burden Scale, a widely used 22-item self-report inventory with good internal consistency and reliability (Zarit, Reever, & Bach-Peterson, 1980). It has been validated for use in community-based settings, for caregivers of adults with dementia, and for use with both English and Spanish speakers (Hébert, Bravo, & Prévaille, 2000). The Zarit scale was administered to informal caregivers and their responses with each item were summed to produce an overall score, ranging from 0 to 88 where a higher score indicates greater burden. By convention, scores of 21 to 40 indicate moderate burden and scores >41 indicate severe burden. We measured depression with the Center for Epidemiologic Studies–Depression scale (CES-D; Radloff, 1977). The CES-D is a 20-question screening tool that has been tested in both community and psychiatric settings and with older adults. Severe depression on the CES-D was defined as a score of 16 or higher. The CES-D has good internal consistency and validity and has been measured and applied in clinical and community populations (Miller, Anton, & Townson, 2008; Radloff, 1977).

Measures of Caregiver and Patient Demographics

We assessed several sociodemographic and health characteristics of informal caregivers and patients in relation to caregiver burden. Caregiver-level predictors of burden included the number of hours of care provided to the

patient, number of years of caregiving, relationship to the patient (spouse/partner, adult child, or other family member/friend), whether the patient and caregiver lived together, and employment status. Sociodemographic measures included age, sex, race/ethnicity, educational attainment, and marital status. Patient functional impairment was assessed using the Lawton activities of daily living measure (Lawton, 1988). This is a brief measure that assesses patient incontinence and his or her ability to feed, transfer, toilet, dress, and bathe independently. Patient self-rated health was assessed using the single-item Short Form-1 general health measure (DeSalvo, Fan, McDonnell, & Fihn, 2005), a validated measure taken from the Short Form (36) Health Survey. The presence of depression was assessed using the CES-D (20). Other covariates included the presence of a formal (paid) caregiver and patient sociodemographic characteristics, including age, sex, race/ethnicity, education, and income. Caregiver race/ethnicity was classified into one of four categories: White/non-Hispanic, Black/non-Hispanic, Hispanic, and Other.

Data Analysis

We used descriptive statistics, including means and proportions, to summarize the characteristics of informal caregivers and patients. We examined the association between patient and caregiver characteristics with level of caregiver burden (none or moderate) and depression among caregivers, using Fisher's exact test, the chi-square test, and the *t* test as indicated. Because of the small sample size, we did not conduct multivariate analyses. All analyses were conducted with SAS Version 9.3 (SAS Institute, Cary, North Carolina).

Results

Caregiver Demographic Characteristics

Of the 238 patients who were enrolled in the study, 76 (32%) had an informal caregiver. Forty-nine informal caregivers (64%) completed the baseline interview and were included in this analysis. Among the informal caregivers, the mean age was 58 (range = 44-72), and the majority was female (78%; Table 1). The informal caregivers in our study were racially and ethnically diverse. Thirty-seven percent were Black, 35% were Hispanic, and 27% were White non-Hispanic. Almost half (46%) had completed high school or an equivalent degree. Almost three quarters of caregivers (74%) were children of the patients for whom they provided care, 14% were spouses, and the remaining 12% were friends or other family members. Over two thirds (70%) provided more than 20 hr of care per week and half (54%) had been providing this care for 5 years or more. Despite substantial involvement in patient care, 37% worked full-time and 12% part-time.

Table 1. Caregiver Characteristics.

	All caregivers
	49 (100%)
Age <i>M</i> (<i>SD</i>)	58 years (14)
Sex	
Female	38 (78)
Race/ethnicity	
White, non-Hispanic	13 (27)
Black, non-Hispanic	17 (35)
Hispanic	19 (39)
Education	
<12 years	23 (46)
High school	22 (44)
>High school	4 (8)
Marital status	
Married/with partner	20 (41)
Never married	17 (35)
Widowed	12 (25)
Employment	
Full-time	18 (37)
Not working	25 (51)
Part-time	6 (12)
Relationship to patient	
Spouse or partner	7 (14)
Adult child	36 (74)
Other family member/friend	6 (12)
Lives with patient	
Yes	34 (69)
No	15 (33)
Hours of care provided per week	
≤20 hr	15 (31)
21-40 hr	15 (31)
≥41 hr	19 (39)
Number of years providing care	
<2 years	9 (19)
2-5 years	14 (29)
≥5 years	26 (53)
Zarit Caregiver Burden Scale	
No caregiver burden (≤20)	18 (37)
Moderate burden (21-40)	23 (47)
Severe burden (≥41)	8 (16)

Caregiver Burden

Almost half of informal caregivers (47%) had moderate caregiver burden and an additional 16% had severe caregiver burden (Table 1). The informal caregiver's relationship to the patient was associated with the level of caregiver burden, with higher Zarit scores observed among spouses/partners compared with other relations (Table 2; $p = .03$). Furthermore, 100% of spouses/partners described moderate or severe burden. The level of caregiver burden was also associated with race/ethnicity. Non-Hispanic White informal caregivers reported greater burden than Blacks and Hispanics (43 ± 10 vs. 24.5 ± 13.6 and 23.9 ± 13.3 , $p = .02$; Table 3). Other factors, including the amount of care provided and whether

Table 2. Characteristics of Caregivers, Stratified by Level of Caregiver Burden.

	All caregivers	Caregiver burden		<i>p</i> ^a
		None	Moderate or severe	
	49 (100%)	18 (36.7%)	31 (63.3%)	
Age <i>M</i> (<i>SD</i>)	57.5 (14.2)	54.5 (15.8)	59.7 (13.1)	.25
Sex				
Female	38 (77.6)	16 (88.9)	22 (29.0)	.18
Race				.17
White, non-Hispanic	13 (27)	2 (11.1)	11 (35.5)	
Black, non-Hispanic	17 (35)	7 (38.9)	10 (32.3)	
Hispanic	19 (39)	9 (50)	10 (32.3)	
Education ^a				
<12 years	23 (46.0)	10 (58.8)	13 (40.6)	.28
High school	22 (44.9)	5 (29.4)	17 (53.1)	
>High school	4 (8.2)	2 (11.7)	2 (6.3)	
Hours care				
≤20 hr	15 (30.6)	5 (27.8)	10 (32.3)	.99
21-40 hr	15 (30.6)	6 (33.3)	9 (29.0)	
≥41 hr	19 (38.8)	7 (38.9)	12 (63.3)	
How long care				
<2 years	9 (18.8)	3 (10.0)	0 (0.0)	.11
2-5 years	13 (27.1)	5 (27.8)	8 (26.7)	
≥5 years	26 (54.2)	7 (38.9)	19 (63.3)	
Employment				
Full-time	18 (36.7)	7 (38.9)	11 (35.5)	.99
Not working	25 (51.0)	9 (50)	16 (51.6)	
Part-time	6 (12.2)	2 (11.1)	4 (12.9)	
Marital status				
Married/with partner	20 (40.8)	7 (38.9)	13 (41.9)	.52
Never married	17 (34.7)	5 (27.8)	12 (38.7)	
Widowed	12 (24.5)	6 (33.3)	6 (19.4)	
Relationship to patient				
Spouse or partner	7 (14.3)	0 (0)	7 (22.6)	.03
Adult child	36 (73.5)	15 (83.3)	21 (67.7)	
Other family member/friend	6 (12.2)	3 (16.7)	3 (9.7)	
Live with patient				
Yes	34 (69.4)	12 (66.7)	22 (71.0)	.76
No	15 (32.6)	6 (33.3)	9 (29.0)	

^aFisher's Exact Test, except for age, which was assessed with the Wilcoxon Rank Sum Test.

or not the patient lived with the caregiver were not associated with having moderate or severe caregiver burden (Table 2; $p > .05$ for all associations).

Over one quarter (27%) of informal caregivers had a score of 16 or greater on the CES-D scale consistent with depression. Caregivers with depression were more likely to be a spouse or partner of the patient (86% vs. 17%, $p < .001$) compared with caregivers who did not report depression.

Patient Health Characteristics and Association With Caregiver Burden

Informal caregivers provided care for a generally ill and functionally impaired group of patients (Table 4). Patients receiving support from informal caregivers had

a mean age of 85 ± 9 years, 57% reported poor or fair health, and 88% were dependent for assistance with two or more activities of daily living (ADL). The majority of patients (90%) also had a formal caregiver, such as a home attendant or home health aide. No patient characteristics were associated with the level of burden experienced by caregivers, including the type of care needed or the presence of a formal (paid) caregiver ($p > .05$ for all associations).

Discussion

Little research has investigated how patient and caregiver characteristics are related to the level of burden experienced by informal caregivers of homebound seniors. Three quarters of the informal caregivers

Table 3. Characteristics of Patients, Stratified by Level of Burden of Their Caregivers.

	49 (100%)	Caregiver burden		<i>p</i>
		None-mild 18 (36.7%)	Moderate-severe 31 (63.3%)	
Age, <i>M</i> (<i>SD</i>)	85 (9)	87.0 (8.7)	83.5 (9.1)	.18
Female	40 (81.6)	17 (94.4)	23 (74.2)	.07
Race/ethnicity				
White	16 (32.6)	3 (16.7)	13 (41.9)	.30
Black	12 (24.5)	5 (27.8)	7 (22.6)	
Hispanic	19 (38.8)	9 (50.0)	10 (32.3)	
Other	2 (4.1)	1 (5.6)	1 (3.2)	
Education				
<12 years	22 (47.8)	11 (68.8)	11 (36.7)	.12
High school	10 (21.7)	3 (18.8)	7 (23.3)	
Some college	3 (6.5)	1 (6.3)	2 (6.8)	
College graduate	11 (23.9)	1 (6.3)	10 (33.3)	
Income				
≤US\$750/month	12 (30.0)	6 (35.3)	6 (26.1)	.56
US\$751-US\$1,350/month	20 (50.0)	9 (52.9)	11 (47.8)	
US\$1,351-US\$3,000/month	5 (12.5)	2 (11.8)	3 (13.0)	
≥US\$3,000/month	3 (7.5)	0 (0)	3 (13.0)	
General health				
Excellent-very good	7 (14.3)	4 (22.2)	3 (9.7)	.32
Good	14 (28.6)	6 (33.3)	8 (25.8)	
Fair-poor	28 (57.1)	8 (44.4)	20 (64.5)	
≥6 ADL impairments	42 (87.5)	16 (88.9)	26 (86.7)	
Depression				
Depressed	10 (20.4)	3 (16.7)	7 (22.6)	.72
Has a formal health aid	43 (89.6)	17 (94.4)	26 (86.7)	.63
>5 days per week of care	34 (78)	14 (82.4)	20 (76.9)	.99
≥8 hours per day	34 (79.1)	14 (82.5)	20 (86.8)	.99

Note. ADL = activities of daily living.

Table 4. Mean Caregiver Burden Score, by Caregiver's Race/Ethnicity and Relationship to Patient.

	<i>n</i>	Caregiver burden score		<i>p</i>
		<i>M</i>	<i>(SD)</i>	
Caregiver race				
White	13	36.5	(12.2)	.02
Black	17	24.5	(13.6)	
Hispanic	19	23.0	(13.3)	
Caregiver relation to patient				
Spouse/partner	7	43.3	(10.2)	.003
Child	36	24.1	(12.2)	
Other family/friend	6	26.2	(17.4)	

were female and adult children. More than two thirds provided at least 20 hr of care per week. This study found that almost two thirds of informal caregivers reported moderate or severe caregiver burden. Moderate or severe caregiver burden was more likely to be reported by spouses/partners as well as White non-Hispanic caregivers. Our results shed light on groups of informal caregivers who experience high

levels of burden and may help to inform future interventions that are designed to reduce burden among informal caregivers.

The level of caregiver burden and depression reported by informal caregivers in our study was comparable to that found in previous studies of informal caregivers of patients with specific illnesses like severe congestive heart failure (CHF) and chronic obstructive pulmonary

disease (COPD; Garlo et al., 2010), advanced dementia (Parker, Mills, & Abbey, 2008), and terminal cancer (Palos et al., 2011). Given the functional limitations and multiple medical illnesses in the homebound, informal caregivers likely face many of the same issues in caring for their patients as do the caregivers of non-homebound patients with serious or terminal illnesses. However, homebound patients in general are more dependent on assistance with more activities of daily living than non-homebound patients, and are by definition more isolated. This results in more complete reliance on informal caregivers for all aspects of their lives and health. In this study, almost all the patients had more than six ADL impairments and some amount of formal caregiving from a home attendant or home health aide.

Our results indicate that sociodemographic factors may contribute to the burden of informal caregivers in the home. Hispanic and Black informal caregivers reported less burden than White informal caregivers but were also more likely to identify as children or other family member of the homebound patient. Similarly, we also found that Latino and Black caregivers in our study population were on average more than 10 years younger than White caregivers, though age was not associated with caregiver burden. Furthermore, though the patients being cared for had high ADL impairments overall, there was no difference in ADL impairments between White, Black, or Latino patients to explain the difference in burden among their informal caregivers.

There may be ethnic group differences in both family structures and cultural attitudes toward caring for older generations that influence the amount of familial support available to a homebound adult. Prior studies have found a wider acceptance of care of extended family members among Latinos and Blacks in comparison with Whites and that the activities of caregiving are perceived as more burdensome among White groups even when the responsibilities performed are similar (Mui, 1995). Martin et al. (Martin, 2000) similarly found that Black caregivers were less likely to report burden than Whites, regardless of the presence of paid support or level of patient disease burden. Informal caregivers of Black patients are also less likely to institutionalize their relatives with dementia than White caregivers (Morycz, 1985).

In this study, informal caregiver spouses of the homebound elderly also experienced more burden than all other groups of caregivers. Prior literature has been mixed. Some studies have found that spouses have more burden than other family members or friends (George & Gwyther, 1986), whereas others have found spouses reporting less burden (Bass, Noelker, & McCarthy, 1999). Given that most of our informal caregivers were female, most were wives and it would be interesting to explore possible differences in burden for wives versus husbands in the future. Other research has found that patients with older informal caregivers are more likely

to be placed in nursing homes over a 3-year period (Yaffe et al., 2002), suggesting that aging spouses are less able to physically or cognitively care for their dependents. We found that spouses are at greater risk of experiencing caregiver burden, but age was not associated with burden. Additional research in larger cohorts of informal caregivers of the homebound is needed to better understand what factors make them particularly vulnerable to the stresses of providing care to the patient and how supports for these caregivers may need to be different than they are for caregivers of non-homebound patients.

This study has several limitations. The small sample of informal caregivers interviewed for our study limits generalizability of the study's findings. The small sample also reduced our ability to detect significant associations between caregiver burden and other variables and prevented us from performing multivariable regression analyses. In addition, several caregivers who enrolled in the study did not participate in the baseline interview. The extent to which this represents a bias in our results is not clear. Despite these limitations, the study highlights the heavy burden of care experienced by informal caregivers of homebound seniors and indicates a need for new research to better understand how the health and well-being of caregivers of homebound adults are affected by their roles and what interventions should be developed to better support them.

Conclusion

In conclusion, we found a high level of caregiver burden and depression among informal caregivers of homebound adults. White non-Hispanic caregivers and those who identified as spouses or partners of the homebound patient were especially at risk for these poor outcomes. As the population ages and the number of homebound individuals grows, informal caregiving and its resultant effects will be an increasing issue in the coming decades. It is important to understand the burdens this will place on families and friends of vulnerable patients and to tailor relevant interventions to different groups. Interventions and studies designed to further understand race/ethnic differences in caregiver burden and support the needs of spouse/partner caregivers for homebound older adults are warranted.

Declaration of Conflicting Interests

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