Published in final edited form as:

J Aging Health. 2013 September ; 25(6): 1036–1049. doi:10.1177/0898264313497509.

Health Care Utilization Among Homebound Elders: Does Caregiver Burden Play a Role?

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Abstract

Objectives—To describe informal caregiver and patient characteristics associated with high caregiver burden in homebound elders and to examine associations between high caregiver burden and patient health care utilization at the practice level.

Method—We used a cross-sectional and prospective cohort design to study 214 caregiver-patient dyads in a home-based primary care program.

Results—Informal caregivers with the highest burden were more likely to help with more activities of daily living and instrumental activities of daily living and spend >40 hr/week in caregiving. Patients whose caregivers experienced the highest burden were more likely to be non-White males without 24-hr paid homecare. There were no significant independent associations between high burden and high calls, high visits, or social work involvement.

Discussion—In this medically complex and highly dependent population, further study of how families and other caregivers impact health care utilization is needed.

Keywords

caregiving; families; health services; geriatrics; homebound

Introduction

As the population ages and the prevalence of individuals living with multiple debilitating chronic conditions continues to grow, the number of chronically ill elders who are homebound grow as well (Administration on Aging, 2011). Compared with their nonhomebound counterparts the homebound have a disproportionately high disease burden, significant functional limitations, unique psychosocial needs, and higher mortality (Cohen-Mansfield, Shmotkin, & Hazan, 2010; Kellogg & Brickner, 2000; Qiu et al., 2010). Home-based primary care programs attempt to meet the needs of these complex patients and are at

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

the forefront of innovative primary care delivery models (Kellogg & Brickner, 2000; Smith, Ornstein, Soriano, Muller, & Boal, 2006). For example, programs like Independence at Home (Center For Medicare And Medicaid Innovation, 2012) attempt to address the unique needs of the homebound to improve quality of care and reduce unnecessary health care utilization.

When caring for the homebound, a strong partnership between patients, their informal caregivers, and providers is essential. For many homebound individuals, informal caregivers such as unpaid family members or friends may be the primary (or in some cases, only) liaisons through which they engage the formal health care system. This act of providing care can be a significant stressor for caregivers and may result in significant caregiver burden (Pearlin, Mullan, Semple, & Skaff, 1990). Informal caregiver and patient characteristics influence the complex and subjective experience of caregiver burden (Bergvall et al., 2011; Garlo, O'Leary, Van Ness, & Fried, 2010; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). Informal caregivers for the homebound have not been characterized in the literature, but are likely at high risk for caregiver burden.

Proposed expansions of Anderson's behavioral model of service utilization have emphasized that psychosocial factors including societal norms about caregiving and caregiver burden should be considered as important predisposing factors to service utilization (Andersen & Newman, 1973; Bradley et al., 2002). Furthermore, in functionally dependent populations like the home-bound, this traditional model should be expanded to include the role that caregiver-related needs play in influencing patients' health care utilization (Bookwala et al., 2004). Evidence suggests that informal caregiver burden may be associated with various markers of patient health care utilization such as formal homecare service use (Nakagawa & Nasu, 2011), hospitalization (Kuzuya et al., 2011), and nursing home placement (Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Miller, Rosenheck, & Schneider, 2012; Yaffe et al., 2002). To our knowledge, there are no data that evaluate how caregiver burden influences health care utilization at the clinic or practice level.

The goals of this study are twofold: (a) to describe informal caregiver and patient characteristics associated with high caregiver burden in homebound elders, and (b) to examine associations between high caregiver burden and patient health care utilization in homebound elders. We hypothesized that in this functionally dependent population, high caregiver burden would be associated with higher utilization of the practice's services.

Method

Study Design

We used a cross-sectional survey to determine informal caregiver and patient characteristics associated with high caregiver burden. We used a longitudinal cohort study to examine the association between high caregiver burden and patient health care utilization for the 6 months following enrollment.

Sample

The Mount Sinai Visiting Doctors Program is a home-based primary care practice in New York City. It is the largest academic house call program in the country and provides care to an ethnically and socioeconomically diverse homebound population (Smith et al., 2006). To meet the complex biopsychosocial needs of the homebound, physicians and nurse practitioners can refer patients requiring further psychosocial assistance to staff social workers.

From July 2001 until April 2002, providers at Mount Sinai Visiting Doctors program screened all new and existing patients for the involvement of an informal caregiver. We recruited informal caregivers who spoke either English or Spanish and self-identified as the “primary person to provide, arrange, or oversee the needed services because of functional disabilities or health need” (Kane & Kane, 2000). We excluded those with severe hearing limitations, those under investigation for elder abuse, and those already participating in the study as an informal caregiver for another patient. After obtaining informed consent, we enrolled the informal caregivers and completed a 30-min telephone interview that asked questions about caregiver demographics and caregiver burden.

Because we determined health care utilization in the 6 months following enrollment, we excluded those with less than 6 months of follow-up and those with missing charts when evaluating the association between caregiver burden and health care utilization. The Mount Sinai Institutional Review Board approved all study procedures.

Measures

Caregiver burden—We measured caregiver burden using a modified version of the multidomain Caregiver Burden Inventory (CBI; Novak & Guest, 1989) that was administered during the informal caregiver interview. We included the burden domains of time-dependence, developmental, social, and physical burden; we did not ask caregivers about the emotional burden domain, because it applied only to informal caregivers of individuals with dementia (Ornstein, Smith, & Boal, 2009). Because there are no established cutoffs for the CBI above which caregiver burden is considered significant, we divided total caregiver burden scores and domain-specific scores into quartiles and dichotomized the results. We classified the upper quartile of caregiver burden scores as “high burden” and all others as “non-high burden.”

Patient and caregiver characteristics—During the informal caregiver interview, we obtained information about covariates related to informal caregivers. We used the practice’s clinical database to obtain patients’ demographic characteristics, medical conditions, and functional status.

Health care utilization—All measures of health care utilization were calculated in the 6 months following enrollment. The primary measures of health care utilization were (a) total number of phone calls to and from the practice and (b) number of home visits by the medical service provider. The secondary measure of health care utilization was social work home visits and calls.

We determined all measures of health care utilization by chart review. Investigator JR performed all chart reviews and investigator LD reviewed 10% of charts. Discrepancies between reviews were minimal and resolved by consensus. Based on provider chart documentation, we classified provider visits as urgent or routine. We also recorded who initiated each call: provider, patient, informal caregiver/family, paid caregiver/nurse, other (e.g., physical therapist, physician consultant) or unknown. Chart reviewers were blinded to caregiver burden classification at the time of review.

We divided the number of total calls and provider home visits into quartiles. We dichotomized the results classifying the upper quartile of total phone calls as “high total calls” and the upper quartile of provider visits as “high visits.” Because social workers are often asked to help address patient’s unmet psychosocial needs, we defined “social work involvement” as 2 or more social worker visits or calls in the 6 months following enrollment and we dichotomized patients into those with and those without social work involvement.

Data Analysis

We used chi-square and *t* tests to compare the prevalence of informal care-giver and patient characteristics between the high burden and non-high burden groups. We used multivariate logistic regression analyses to examine the associations between high caregiver burden (total and domain-specific) and high health care utilization while adjusting for age, gender, race, dependence in activities of daily living, and more than 1 year in program prior to care-giver assessment. We performed all analyses using SAS version 9.2 (SAS Institute, Inc., Cary, NC.).

Results

Of 474 patients screened, 315 had informal caregivers and met eligibility criteria. Nineteen informal caregivers refused to participate and 34 informal caregivers could not be contacted despite repeated attempts. A total of 262 informal caregivers were enrolled, and of these, 214 were active in the program for 6 months following enrollment. When evaluating for subsequent health care utilization, charts were missing for 40 individuals. Patients whose charts were missing were significantly more likely to be less than 85 years of age ($p = .04$) and non-English speaking ($p = .04$). However, there were no statistically significant differences in functional abilities, medical conditions, informal caregiver characteristics, or caregiver burden between the two groups.

Informal caregiver scores on the modified Caregiver Burden Index (CBI) ranged from 0 to 74 on an 80-point scale ($M = 27.68$, $SD = 16.81$). Scores related to time burden were the highest ($M = 10.80$, $SD = 5.75$) followed by developmental burden ($M = 7.84$, $SD = 6.22$), physical burden ($M = 6.52$, $SD = 6.22$), and social burden ($M = 3.83$, $SD = 4.46$). The interquartile range for the total CBI score ranged from 14 to 39. Interquartile ranges for the individual domains were as follows: time burden 6 to 16, developmental burden 2 to 13, physical burden 0 to 9, and social burden 0 to 7. As expected, individual CBI domains were highly correlated (range 0.31–0.70).

Table 1 describes the informal caregivers in the sample. Most were middle-aged women (mean age = 56.1, 70.2% female) of diverse ethnicities (35.8% White, 31.6% Latino, 27.4% Black.) The majority (60.0%) had been caregivers for more than 5 years and only 9.2% had been caregivers for less than 1 year. Nearly half (43.7%) spent more than 40 hr per week providing care. Those informal caregivers who experienced high burden were more likely to be non-White ($p = .02$) children ($p = .02$), or spouses ($p = .04$) of the patients. They were more likely to spend >40 hr per week in caregiving ($p < .01$) and help with a greater number of activities of daily living (ADLs; $p < .01$) and instrumental activities of daily living (iADLs; $p = .04$).

Table 2 describes the characteristics of patients in the sample. Most patients were elderly women (mean age = 76.5, 80.5% female) of diverse ethnicities (37.1% White, 31.9% Latino, 29.1% Black). They had significant medical comorbidities including 57.2% with dementia, 20.5% with diabetes, and 13.5% with congestive heart failure; 16.1% were dependent in all ADLs and 27.9% were dependent in all iADLs. Only 20.5% had no paid caregivers and 38.6% had 24-hr paid caregivers. Those cared for by informal caregivers who experienced high caregiver burden were more likely to be male ($p = .03$), married ($p < .01$), non-White ($p = .01$), and to live in public housing ($p = .05$). They were less likely to have 24-hr paid care ($p = .01$).

Table 3 describes the 6-month health care utilization of this group and Table 4 describes the association between caregiver burden and health care utilization. There were an average of 5 calls and 4 visits for each patient during the 6-month follow-up period, but the range was wide (from 0 to 30 calls, from 0 to 11 visits). Most calls were from either paid caregivers/nurses (37.7%) or informal caregivers/family (23.6%). Urgent visits accounted for 9.8% of total visits and 21.4% of individuals had social work involvement. In analyses adjusted for age, gender, race, ADL dependence, and more than 1 year in program prior to caregiver assessment, there were no significant associations between high burden and high total calls, (adjusted odds ratio 1.15 [95% Confidence Interval 0.51, 2.60]) or high visits, 0.48 [0.18, 1.32]. Likewise, there was no significant association between high burden and social work involvement, 1.64 [0.70, 3.86]. There were no significant associations between high burden in any of the burden domains and any utilization measure.

Discussion

This homebound population is highly functionally dependent, medically ill, and ethnically diverse. Their caregivers experienced higher levels of total burden and domain-specific burden as compared with other populations with published CBI scores: For example, the mean CBI score for caregivers of demented elders was 25.47, while the mean CBI score in our population was 27.68 (Novak & Guest, 1989; Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009).

High caregiver burden in this population was associated with several informal caregiver and patient characteristics including spouse or child caregivers and functionally dependent patients. This is consistent with previous literature (Bergvall et al., 2011; Pinquart & Sorensen, 2011). In our diverse population, non-White informal caregivers were more likely

to be burdened. The relationship between race and caregiver burden in the literature is variable, and it has been suggested that factors such as socioeconomic status and relationship to patient actually mediate much of this (Janevic & Connell, 2001).

Despite significant variability in number of calls and visits, high burden was not associated with high total calls, high visits, or social work involvement. This was true for high total burden and high burden in each of the burden domains. There are several potential explanations for this finding.

While caregiver burden increases utilization in some populations, the contribution of caregiver burden to health care utilization in our frail, medically ill population may be overshadowed by the contribution of medical illness. Further study should assess how specific medical illnesses and illness severity impact utilization among the homebound. While direct comparison is difficult, our study population tended to have more dementia and functional dependence than populations described in studies where an association between caregiver burden and utilization was found (Kuzuya et al., 2011). This may be because utilization among healthier patients is less closely tied to medical morbidity. It may also be that the measure of caregiver burden used in this study incorrectly or incompletely captured the informal caregiver factors that impact patient health care utilization. Studies have revealed that informal caregiver factors beyond burden such as caregiver mental and physical health (Bookwala et al., 2004) or caregiver satisfaction (Shugarman, Buttar, Fries, Moore, & Blaum, 2002) are associated with patient health care utilization. The relationship may be even more complex: Competent informal caregivers had increased hospitalizations, but decreased discharge delays (Wolff & Kasper, 2004).

Importantly, our data do not support the anecdotal observation of many clinicians that burdened caregivers tax the practice with phone calls and demands for visits. Rather than objective observation by the clinician, a phenomenon such as transference may be occurring (Hughes & Kerr, 2000): We expect burdened caregivers to behave in a particular way and subsequently interpret the behaviors we see as resulting from caregiver burden. While some burdened informal caregivers may react by frequently calling on support services, others likely suffer in silence, or worse, forgo indicated treatments and interventions that could potentially benefit their loved one. An analogy can be made to delirium: While hyperactive delirium never fails to get our attention, the full scope of delirium's clinical impact cannot be judged until cases of hypoactive delirium are acknowledged as well (Inouye, Foreman, Mion, Katz, & Cooney, 2001). While we work to standardize the assessment of caregiver burden (Family Caregiver Alliance, 2006), further study of physician perceptions of the presence and impact of caregiver burden is needed.

We were surprised to find that paid caregivers and nurses initiated nearly 40% of phone calls to the practice. Although our study was not designed to assess the role of formal caregivers in health care utilization, this finding suggests that formal caregivers may play a significant role in determining health care utilization in this homebound population. Prevalence of formal caregivers was high and nearly 40% of patients had 24-hr paid care. This is likely due at least in part to New York City's significant Medicaid expenditures on home attendants (Samis & Birnbaum, 2010). The contribution of formal caregivers to practice-

level health care utilization deserves further examination, particularly in light of recent evidence suggesting inadequate health literacy among many homecare workers (Lindquist, Jain, Tam, Martin, & Baker, 2011). Future research should further characterize both calls that come from nurses and calls that come from home health aides and home attendants; while nurses are often monitoring patients according to care plans developed in conjunction with their providers, home health aides and home attendants may be voicing the patient's unmet needs. Such research may help identify caregiver or patient needs that can be anticipated in advance and in doing so suggest ways in which interventions like outreach to formal caregivers may decrease the numbers of calls to the practice.

To better understand utilization among our homebound patients, we may need to move beyond focusing on single constructs such as caregiver burden and instead systematically analyze how patient, caregiver, and family factors together impact utilization. Importantly, this analysis should include input from caregivers themselves about if and how the practice is meeting their needs with an emphasis on the differing utilization patterns between new and established patients. While providing care for patients with complex chronic illness is often difficult, approaches such as team-based care and the Chronic Care Model have improved patient outcomes and quality of care for the most complex patient populations (Coleman, Austin, Brach, & Wagner, 2009; Grumbach & Bodenheimer, 2004). As we work to apply such models to the care of the homebound, attention to how such systems of care impact patients and caregivers is essential.

This study has several limitations. Charts were not available for 40 included individuals. Chart review depended on clinician documentation of visits and calls and underdocumentation may have limited our ability to detect differences in utilization. We collected data in only one home-based primary care practice and factors related to patient flow at that practice, such as visit scheduling or phone messaging protocols may have driven health care utilization at the practice level more than informal caregiver or patient characteristics. We measured caregiver burden and subsequent utilization at one point in time, and our results do not reflect the dynamic ways caregiver burden and health care utilization can change over time.

Yet despite these limitations, this study provides an important characterization of informal caregiver and patient characteristics associated with high caregiver burden in a homebound population. It also suggests that more research is needed to understand how caregiver factors impact patient health care utilization at the practice level. As the population of community-dwelling patients with multiple comorbidities becomes an increasing burden on our health care system, we need to continue to develop innovative care delivery models that deliver quality care and reduce unnecessary utilization. This study's findings provide a first step in understanding the role the family may play in impacting health care utilization. Future research should attempt to further elucidate how factors beyond the patient's own demographic and clinical characteristics predict health care utilization among the chronically ill. This is particularly important in the homebound, a population whose biomedical and psychosocial complexity tests the abilities of our current health care system.

Acknowledgments

The authors thank Alice Chen for her assistance with preliminary chart reviews and Grace Leu for her contribution to the background research.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by the Jacob and Valeria Langeloth Foundation. Dr. Kelley's work is supported by the National Institute on Aging Paul B. Beeson Career Development Award (1K23AG040774-01A1).

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Table 1Baseline Caregiver Characteristics by Caregiver Burden Index Category ($n = 214$).

Caregiver characteristic	Total $n = 214$	High burden $n = 53$	Non-high burden $n = 161$	p
Age in years: M (SD)	56.1 (14.4)	52.9 (12.6)	57.4 (14.8)	.63
Time (years) in program: M (SD)	1.28 (1.34)	1.10 (1.23)	1.36 (1.37)	.22
Female (%)	70.2	69.8	70.2	.96
Married (%)	45.1	43.4	43.5	.71
Less than high school (%)	19.1	20.8	19.2	.81
Works full-time (%)	41.4	43.4	41.0	.13
Ethnicity (%)				
White	35.8	22.6	39.8	.02*
Latino	31.6	35.9	30.4	
Black	27.4	34.0	25.5	
Lives with patient (%)	48.4	69.8	41.0	<.01*
Child of patient (%)	50.2	64.2	46.0	.02*
Spouse of patient (%)	12.6	20.8	9.9	.04*
>5 years caregiving (%)	60.0	54.7	61.5	.38
>40 hr/week caregiving (%)	43.7	62.3	38.6	<.01*
No other relatives assist (%)	57.2	66.0	54.7	.15
Assists with 3+ADLs (%)	32.6	58.5	24.2	.01*
Assists with 6+iADLs (%)	21.9	32.1	18.6	.04*

*
 $p < .05$.

Table 2Baseline Patient Characteristics by Caregiver Burden Index Category ($n = 214$).

Patient characteristic	Total $n = 214$	High burden $n = 53$	Non-high burden $n = 161$	p
Age in years: M (SD)	79.5 (14.9)	75.38 (15.68)	79.45 (14.57)	.08
Female (%)	80.5	69.8	83.9	.03*
Widowed (%)	51.2	43.4	54.0	<.01*
Lives alone (%)	23.3	17.3	25.5	.23
Public housing (%)	32.4	43.4	28.9	.05
Has Medicaid (%)	65.5	75.5	62.5	.09
Ethnicity (%)				
White	37.1	21.6	41.6	.01*
Latino	31.9	37.3	30.4	
Black	29.1	37.3	26.7	
Non-English speaking (%)	31.8	41.5	28.8	.08
Dependent all ADLs (%)	16.1	15.7	16.3	.91
Dependent all iADLs (%)	27.9	36.0	24.7	.12
No paid caregiver (%)	20.5	20.8	20.5	
24-hr paid caregiver (%)	38.6	24.5	43.7	.01*
Chronic conditions (%)				
Dementia	57.2	60.4	55.9	.57
Depression	37.2	41.5	36.0	.47
Diabetes mellitus	20.5	28.3	18.0	.11
Congestive heart failure	13.5	9.4	14.3	.36
Chronic obstructive pulmonary disease	9.8	9.4	9.9	.91
Cancer	12.1	18.9	9.9	.08
Difficulty walking	57.7	71.7	52.8	.02*

*
 $p < .05$.

Table 3Six-Month Health Care Utilization Among Homebound Patients ($n = 174$).

Service utilized over 6 months	Descriptor
Phone calls	
Number of calls: M (range)	5.04 (0 to 30)
Calls from provider (%)	11.80
Calls from patient (%)	8.00
Calls from informal caregiver/family (%)	23.60
Calls from paid caregiver/nurse (%)	37.70
Calls from other (%)	11.75
Calls from unknown (%)	8.20
Home visits	
Number of visits: M (range)	4.06 (0 to 11)
Urgent visits (%)	9.80
Social work (SW) involvement	
Number with 2+ SW visits or calls (%)	21.40

Table 4Association Between Caregiver Burden and Health Care Utilization Among Homebound Patients ($n = 174$).

Variables	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
High burden and high total calls	1.24 [0.57, 2.70]	1.15 [0.51, 2.60]
High burden and high visits	0.42 [0.16, 1.09]	0.48 [0.18, 1.32]
High burden and social work involvement	1.96 [0.90, 4.25]	1.64 [0.70, 3.86]

^a Adjusted for age, gender, race, ADL dependence, and more than 1 year in program. OR = odds ratio.