

Caregiver Objective Burden and Assessments of Patient-Centered, Family-Focused Care for Frail Elderly Veterans

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Purpose: There is a growing consensus that quality of care for frail elders should include family and be evaluated in terms of patient-centered, family-focused care (PCFFC). Family caregivers are in a unique and sometimes sole position to evaluate such care. In the context of caring for physically frail elders, this study examined the extent to which objective burden was associated with caregiver perceptions of PCFFC and the extent to which it mediated the influence of other variables on perceptions of PCFFC. **Design and Methods:** In a study of frail elderly veterans receiving care in U.S. Department of Veterans Affairs ambulatory primary care clinics, informal caregivers assessed quality of care with 13 questions. Factor analysis of these items revealed an eight-item scale that specifically assessed PCFFC ($\alpha = .90$). Regression analysis identified variables associated with caregiver ($N = 210$) assessments of PCFFC and the potential mediating effect of objective burden. **Results:** Caregiver assessments of PCFFC

were positively associated with care recipient instrumental activity of daily living limitations ($p = .04$) and perspectives on the quality of their own patient care ($p < .001$). Greater objective burden was negatively associated with caregiver assessments of PCFFC ($p < .001$) and mediated (i.e., reduced) the relationship between care recipient perceptions of the quality of their own patient care and caregiver assessments of PCFFC ($\Delta R^2 = .06$). **Implications:** These findings support recommendations for conducting caregiver assessments as part of routine care and highlight the importance of measuring objective burden and expectations for PCFFC in assisting physically frail elders. Primary care providers will require additional training in order to effectively implement and translate such caregiver assessments into clinical practice improvement.

Key Words: Family-focused care, Caregiver burden, Quality of elder care

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Introduction

Overview

There is a growing consensus that quality care for frail elders must be patient centered and must involve family members upon whom care recipients rely for physical and emotional support and assistance in seeking and receiving health care (Haug, 1994; Rose, Bowman, & Kresevic, 2000). These two components are at the core of patient-centered, family-focused care (PCFFC). Informal caregivers may be in the best position to assess such care, especially as it affects them (Musil, Morris, Warner, & Saeid, 2003; Silliman, 1989). Yet, to our knowledge, other than in studies on end-of-life care (Howell & Brazil, 2005;

Teno, Casey, Welch, & Edgman-Levitan, 2001), prior research has not specifically examined caregiver perspectives of PCFFC. Indeed, experts should evaluate the quality of geriatric care, perhaps especially primary care for frail elders, in these terms. We developed a measure of PCFFC based on data from community-dwelling frail veterans and their informal caregivers. We explored the relationships between caregivers' perceptions of PCFFC and background characteristics of the care recipient and caregiver and tested for mediating effects of caregivers' objective burden on these relationships.

Informal caregivers provide extensive assistance to their physically frail elderly relatives (Bowman, Rose, & Kresevic, 1998; Lim & Zebrack, 2004), and such support allows many individuals to avoid nursing home placement and remain in the community. Caregivers also continue to experience stress and burden associated with the provision of care to relatives in nursing homes, coupled with the competing demands of family, job, and society (Bowman, Mukherjee, & Fortinsky, 1994). Although these negative mental and physical health effects of caregiving are well documented (Donelan et al., 2002; Navaie-Waliser et al., 2002; Schulz, O'Brien, Bookwala, & Fleissner, 1995), there is evidence to suggest a lack of awareness among health care providers about caregiver perspectives on the needs and demands involved in assisting physically frail elders (Musil et al., 2003; Rose et al., 2000). PCFFC for these frail elders requires assessing real-time demands on family members who provide essential care and encouraging their involvement in patient-care decision making (Boise & White, 2004; Haug, 1994). Such PCFFC from physicians and other primary care providers has the potential to help ameliorate family members' burden and enhance their ability to maintain caregiving roles (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Fried, Bradley, O'Leary, & Beyers, 2005; MacKean, Thurston, & Scott, 2005; Musil et al., 2003).

Numerous studies about the burden experienced by families caring for frail elderly care recipients make a distinction between objective and subjective burden. *Objective burden* is defined as the "concrete events, happenings, and activities" related to actual provision of assistance, whereas *subjective burden* is described as the "feelings, attitudes, and emotions" that result from the caregiving experience (Montgomery, Gonyea, & Hooyman, 1985, p. 20). In previous research, subjective burden has been less distinguishable from other measures of perceived well-being, especially in predictive models. As it stands, researchers have given less attention to caregiving for physically frail versus cognitively impaired elders, for which objective burden may be the more important measure and the one more salient to family caregiver assessments of PCFFC.

In a study examining the relationship between caregiver burden and multiple dimensions of health-

related quality of life for caregivers of frail elderly veterans, researchers found that, compared to subjective burden, objective burden had a stronger negative association with all but one (mental health) of the components of health-related quality of life (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). Indeed, caregivers who have higher levels of objective burden may have a greater need for family-focused care, and their perceptions of PCFFC may reflect this need. Furthermore, the level of objective burden may mediate the effect of other variables on PCFFC. Independent variables that objective burden may mediate include attributes of family caregivers and frail elderly care recipients, intensity of health care utilization, or elders' perceptions of the quality of their own care.

The purpose of the current study was to explore the relationships between caregivers' perceptions of PCFFC and background characteristics (demographics, health status, frail elder health care utilization, and perceived quality of patient care) of the care recipient and caregiver and to test for mediating effects of caregivers' objective burden on these relationships. Figure 1 provides the conceptual model for examining relationships among characteristic variables, objective burden, and caregiver assessments of PCFFC for frail elderly veteran care receivers.

Background

Quality of Patient Care for Frail Elders.—As U.S. society ages and medical advances allow older adults to survive longer with greater physical impairment, the need to provide appropriate and high-quality care for frail elders is increasingly important (Atherly, Kane, & Smith, 2004; Geron et al., 2000). Recent work has focused on identifying key components associated with high-quality patient care, including the availability of competent and technically skilled health care professionals, the provision of well-coordinated care (Attree, 2001; Ware, Snyder, Wright, & Davies, 1983), and, more recently, assurances against medical errors (Sloss et al., 2000). Although instruments developed to assess satisfaction with the quality of patient care exist for each of these domains, concerns about their validity and reliability for frail elderly patients persist.

Informal Caregivers and Formal Care for Frail Elders.—Informal caregivers, primarily spouses or adult children, play a variety of key roles in pursuing medical care for frail elderly care recipients (Haug, 1994; Musil et al., 2003; Silliman, 1989). Elders often rely on them for practical aspects of receiving formal care (e.g., managing appointments, transportation, medications), as well as for communication about symptoms and care goals and for aid in decision

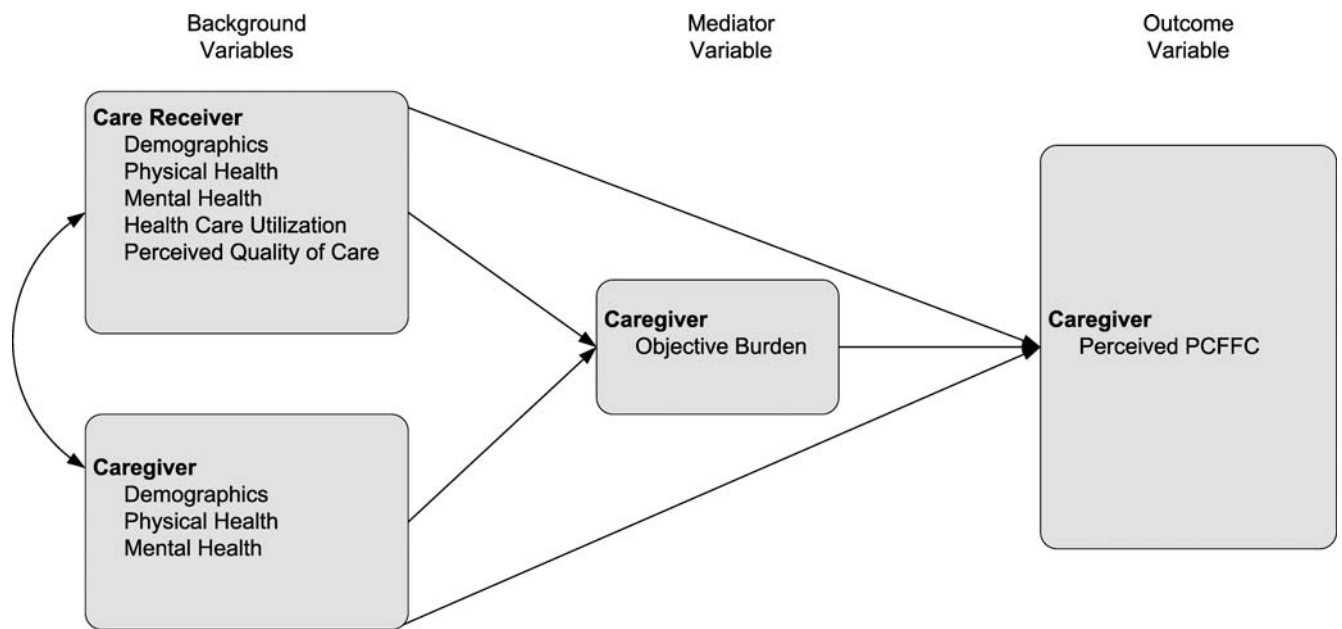


Figure 1. Conceptual model of caregiver perceived patient-centered, family-focused care (PCFFC).

making about treatments and procedures across health care settings (Boise et al., 1999; Boise & White, 2004; Donelan et al., 2002). Family caregivers are often present during care recipient encounters with the physician (Greene, 1994; Haug, 1994; Silliman, 1989). As informal caregivers are especially aware of the physical and emotional well-being and needs of their relatives—and because they may be the ones to follow up on the care plans and prescriptions provided by health care professionals—it is important for them to be heard and supported during health care encounters (Fried et al., 2005; Musil et al., 2003; Rose et al., 2000).

PCFFC for Frail Elders.—End-of-life care acknowledges the perspective that high-quality care requires being attentive to family members (e.g., Howell & Brazil, 2005; Teno, 1999); this is an important goal in chronic care (Kane & Kane, 2000). Drawing on the literature and focus groups with bereaved family caregivers, Teno and colleagues (2001) identified key domains in a model of PCFFC: (a) providing desired physical comfort, (b) achieving control over everyday decisions and shared control over treatment decisions, (c) easing the family's burden of advocacy for quality of care, (d) educating family members to increase their knowledge and confidence, and (e) providing emotional support before and after the patient's death (pp. 742–743). In evaluating the quality of end-of-life medical care, the most commonly used instruments assess such care from the perspective of bereaved family members a few months after the patient's death. Thus, experts measure the quality of end-of-life care against the goal of family inclusion (Howell & Brazil, 2005; Stewart, Teno, Patrick, & Lynn, 1999).

As chronic physical illness and disability increase, frail elders rely more and more on informal caregivers to remain in the community and maintain function and independence. Because these caregivers are strongly linked to elders' care systems, key standards for elder care should be both patient centered and family focused. Naturally, professionals should assess the quality of frail elder care, especially primary care services (Beck, Daughtridge, & Sloane, 2002), in this regard. However, outside of end-of-life care, brief and reliable measures to assess this concept are absent, and, thus, there is little information about the extent of such care.

Caregiver Assessments of PCFFC for Frail Elders.—Assessing the degree to which care is patient centered and family focused is hampered by the fact that elderly care recipients may not be able to respond to questions or evaluate these issues because of their frailty. As care recipients' health worsens, family caregivers often become the primary or sole source of information in assessing quality of care. Typically, caregivers are the best source for evaluating the extent to which family is involved in care services and supported for their knowledge and contributions to the patients' health and functioning. It remains unclear which factors influence informal caregiver assessments of the quality of patient care and the extent to which such care is family focused.

In summary, PCFFC is an important concept for the evaluation of the overall quality of care provided to impaired elderly adults. Optimally, care should be both patient centered and family focused. In the remainder of this article, we discuss a measure we have developed to assess family caregivers' perceptions of PCFFC, explore the relationship between

characteristics of both caregivers and care recipients to PCFFC, and examine how these relationships may be mediated by caregivers' objective burden.

Methods

Participants and Recruitment

Data for this study came from a larger project designed to evaluate the longitudinal effects of a care coordination model of all-inclusive long-term care for frail elderly veterans, conducted by the Dayton, Ohio, Veterans Affairs Medical Center (VAMC). Public Law 106-117, Section 102, required the U.S. Department of Veterans Affairs (VA) to implement three pilot programs to study the effectiveness of all-inclusive long-term care in reducing hospital and nursing home utilization by frail elderly veterans. In one of these programs (Model 1, VA as sole provider) the Dayton, Ohio, VAMC provided all of the long-term-care services for nursing-home-eligible veterans, including transportation to medical appointments, and homemaker/home, nursing home, assisted living, and adult day health care. In this project (referred to here as the Long-Term-Care [LTC] Coordination Study), the intervention was a nurse practitioner functioning as a care coordinator of long-term-care services whose goal was to identify services needed by the veterans across time.

Over a 2-year time period, from July 2001 through June 2003, 438 frail elderly veterans were enrolled and randomized into the intervention and control groups of the LTC Coordination Study. Eligible veterans were 55 years old or older, received care from an identified primary care physician in a VA ambulatory primary care clinic, and were nursing home eligible (State of Ohio criteria define eligible residents as those who have two or more activity of daily living [ADL] limitations or who need help taking medications). During a regularly scheduled appointment in the primary care clinic and prior to randomization into the LTC Coordination Study, veterans consented to participate and completed baseline in-person interviews with trained and experienced research assistants. During enrollment, study organizers asked veterans to identify the person upon whom they most depended for assistance with care and requested permission to contact this person. Researchers enrolled caregivers in the clinic (if they had accompanied the patient) or in a follow-up phone call. In order to avoid burden to the family during the clinic visit, organizers conducted caregiver interviews in follow-up phone calls subsequent to patient enrollment. All enrolled patients and family caregivers gave signed informed consent.

The current study excluded veterans who scored below 5 on the Pfeiffer (1975) mental status instrument. The total veteran sample contained 425 cognitively intact veterans who completed baseline

interviews. We limited our analyses to patient-family-caregiver dyads for whom covariate data were complete ($N = 210$); the demographic profile for this subsample did not differ from that for the total sample of veterans or caregivers.

Outcome and Mediating Variables

PCFFC.—At baseline, study organizers asked caregivers about quality of care based on the health services they had helped their frail elderly family member obtain during the past 3 months. The health services research team responsible for overall evaluation of model projects selected the 13 items, which were drawn from instruments previously developed to assess satisfaction with medical care (Ware et al., 1983) as well as frail elders' satisfaction with long-term care (e.g., Geron et al., 2000). Response options for 12 of these items were on one of the following scales: (a) 1 = poor to 5 = excellent, (b) 1 = not at all to 4 = all of the time (converted to a 5-point scale), or (c) 1 = strongly disagree to 5 = strongly agree (see Table 1). One item (which assessed whether the patient received services without mistakes or delays) used a 4-point scale, where 1 = not at all, 2 = some of the time, 3 = most of the time, and 4 = all of the time; we rescaled the responses to a 5-point scale by using linear extrapolation. We created the PCFFC measure based on exploratory factor analysis of 12 items (1 item dropped due to substantial missing data: "How would you rate the ease of making your relative/friend's appointments for medical care?").

Principal axis factoring with oblique rotation revealed a three-factor solution with a strong first factor (eigenvalue = 5.6) and two additional factors (eigenvalues = 1.2 and 1.1). Eight items had loadings greater than or equal to .55 on the first factor and a difference greater than .30 in loading on either of the other factors. These included four items that addressed quality of patient care and four items that assessed family-focused care. (The four items that did not meet criteria were (a) "Do you feel that your relative/friend's health care providers plan and discuss his/her care with one another?", (b) "How would you rate the availability of transportation for your relative/friend to health care destinations?", (c) "How would you rate the services available for getting prescriptions filled?", and (d) "My relative/friend often has to wait too long to get the services he/she needs.") The resulting eight-item scale had a coefficient alpha of .90 (see Table 1). Consistent with the theoretical underpinnings of the items (Attree, 2001; Haug, 1994; Howell & Brazil, 2005; MacKean et al., 2005; Teno et al., 2001), we labeled this measure PCFFC.

Missing Data and "Don't Know" Responses in the PCFFC.—Although some data were available for

Table 1. Quality of Care Measures (N = 210)

Item	Factor Loading	M (SD)	Range	Alpha
Caregiver Assessed Patient-Centered, Family-Focused Care Scale		29.9 (5.8)	(8–40)	.90
Overall, how would you rate the friendliness and courtesy shown to you by staff? ^a	.83	3.9 (1.0)	1–5	
Overall, how would you rate the quality of your relative/friend's care? ^a	.83	3.7 (1.0)	1–5	
Overall, how would you rate the skill, expertise, and training of the health care providers that care for your relative/friend? ^a	.79	3.7 (0.9)	1–5	
How would you rate the attention given to what you have to say by your relative/friend's health care providers? ^a	.79	3.5 (1.0)	1–5	
Overall, how would you rate the personal interest in you shown by staff? ^a	.75	3.7 (1.0)	1–5	
How would you rate the explanations that are given to you about your relative/friend's care or health? ^a	.70	3.6 (1.0)	1–5	
Health care is provided to my relative/friend in a coordinated and efficient manner. ^b	.58	4.0 (0.7)	1–5	
Do you feel your relative/friend receives the health care services he/she needs without mistakes or delays? ^c	.69	3.4 (1.0)	1–5	
Care Recipient Assessed Quality of Patient-Centered Care Scale		11.8 (1.9)	3–15	.77
Overall, how would you rate the quality of your care? ^a	.89	4.0 (0.9)	1–5	
My care is provided in a coordinated and efficient manner. ^b	.52	3.8 (0.6)	1–5	
Have you received the health care services you need without mistakes or delays? ^c	.69	3.9 (1.0)	1–5	

Notes: SD = standard deviation.

^aResponse categories were 5 = excellent, 4 = very good, 3 = good, 2 = fair, 1 = poor.

^bResponse categories were 5 = strongly agree, 4 = agree, 3 = not sure, 2 = disagree, 1 = strongly disagree.

^cResponse categories were 4 = all of the time, 3 = most of the time, 2 = some of the time, 1 = not at all (converted to a five-point scale).

316 caregiver–patient dyads in the study, only 254 yielded a complete set of eight definitive responses to the PCFFC scale items. For the 15 dyads with one or two missing items, we imputed the modal category. To impute responses for an additional 26 dyads with one or two “don’t know” responses, we built ordinal logistic regression models for each item to estimate the probability of each possible response. Predictors included the other seven PCFFC responses, as well as the patient’s age, race, education level, marital status, ADL limitations, instrumental ADL (IADL) limitations, total medications, Charlson comorbidity score, and patient/caregiver living arrangement. We created five new data sets, consisting of the 269 dyads without “don’t know” responses after missing value imputation, plus a draw from the modeled probability distribution to fill in responses for the 26 dyads with one or two “don’t know” responses. We used proc mianalyze in SAS Version 9.1 (SAS Institute, Cary, NC) to combine results, leaving a total of 295 dyads for which we could estimate the PCFFC scale. Our analytic sample (210 dyads) consisted of all dyads for which we could estimate the PCFFC scale and for which we had complete information on all covariates for the models.

Caregiver Objective Burden.—The LTC Co-ordination Study used the nine-item subscale of the Montgomery Caregiver Burden scale (Montgomery et al., 1985) to assess objective burden. This scale gauges the caregiver’s health and personal time away from the care recipient and includes privacy, income, personal time and freedom, energy, and relationships

with others. The health services research team evaluating the model projects deleted one item (“amount of vacation activities and trips you take”), reducing this scale to eight items. Response options for these items were 1 = extremely satisfied to 5 = not satisfied at all (range 8–40, with higher scores indicating higher objective burden).

We conducted confirmatory factor analysis for the objective and subjective subscales in the Montgomery Caregiver Burden scale to check whether factor loadings conformed to what would be expected on the basis of existing theory and extensive prior psychometric work on this measure. For the objective burden scale, factor loadings ranged from .32 to .77 (comparative fit index = .933, root mean square error of approximation = .092, $\chi^2 = 56$, degrees of freedom = 20). In contrast, for the subjective burden scale, factor loadings ranged from .20 to .82 (comparative fit index = .844, root mean square error of approximation = .088, $\chi^2 = 140$, degrees of freedom = 54). Thus, these analyses revealed a strong factor with distinct loadings for all items in the objective burden subscale and a weaker second factor in which only some items in the subjective burden subscale showed distinct loadings. Cronbach coefficient alpha for the eight-item objective burden scale was .87, indicating high reliability (see Table 1).

Background Variables for Frail Elderly Veteran Care Recipients

Care Recipient Sociodemographics.—Demographics included age (in years) and education level

(a categorical variable coded as 0–8 years, 9–11 years, 12 years, 13–15 years, or 16 or more years). We coded race as 1 = African American and 0 = White (including 1 Hispanic). All but 4 veterans were men.

Care Recipient Physical and Mental Health.—The LTC Coordination Study measured veteran functional health using the Index of Independence in ADLs (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) and the Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire–IADL (Fillenbaum, 1988). The Index of Independence in ADLs is six items, with dichotomous yes/no response categories that determine if the respondent can perform the functions of eating, bathing, dressing, transferring, toileting, and walking across a room. This measure ranges from 0 = no limitation to 6 = completely limited.

The Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire–IADL has seven items and assesses personal functioning. Scores range from 0 = no help needed to 14 = unable to perform any activity. Individual items include using the telephone, shopping, preparing meals, doing housework, using transportation, taking medications, and handling money. The IADL scale differentiates between people who 2 = are unable to perform the task, 1 = need some help, and 0 = can complete the task on their own. Scores range from 0 to 14. This scale has a coefficient alpha of .83.

Study organizers measured physical health in the 6 months prior to enrollment in the Model 1 LTC Care Coordination study by abstracting data from respondents' VAMC computerized medical charts or the Computerized Patient Record System. A trained research assistant conducted chart reviews, and a geriatric nurse practitioner reviewed them for accuracy. The measure used was the Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987). The Charlson is an additive scale calculated from a weighted checklist of diagnosed medical conditions that are predictive of mortality.

Study organizers assessed mental health by using the 15-item Geriatric Depression Scale–Short Form (Sheikh & Yesavage, 1986), with yes/no response categories. They reverse coded five of the items to indicate the presence of depression. Scores of 4 or less indicate normal functioning, those within the 5–9 range indicate mild depression, and scores of 10 or higher indicate moderate to severe depression (Sheikh & Yesavage, 1986). The depression scale coefficient alpha is .75.

Care Recipient Health Care Utilization.—The LTC Coordination Study derived health care utilization variables from computerized patient record reviews for counts of total medications and from Veterans Health Administration Decision Support System data for counts of encounters in primary care

clinics (with a physician or nurse), urgent care visits, and hospitalizations in the 6 months prior to enrollment. The Dayton Decision Support System Site Team produced utilization data on all enrolled patients. Because frail veterans were receiving care in VA ambulatory primary care clinics at time of enrollment and baseline interviews, these counts likely represent the majority of health services utilized during the time described by these analyses.

Care Recipient Perceived Quality of Patient Care.—To measure care recipients' perceptions of their own care, we focused on four items that directly assessed quality of patient care and were identical to items asked of caregivers in the PCFFC measure. These four items selected by the health services research team had been included in interviews with care recipients as well as with their informal caregivers. The items used the same five-point response option and rescaling procedures. Exploratory factor analysis with principal axis factoring and oblique rotation of these four items revealed a two-factor solution with eigenvalues of 1.70 for Factor 1 and 0.74 Factor 2. Three of the four items had loadings that were .50 or greater on the first factor and were formed into a scale. (One item, "How would you rate the skill, expertise and training of the staff?" did not meet criteria for inclusion.) The coefficient alpha for this three-item scale was .77 (see Table 1).

Background Variables for Informal Caregivers

Caregiver Sociodemographics.—Demographic variables included age (in years), gender, and whether the caregiver lived with the care receiver. Availability of family members or friends to help provide care for the frail elderly care receiver when the caregiver needed coded as 1 = usually or always available, 2 = sometimes available, 3 = rarely available, and 4 = never available.

Caregiver Physical and Mental Health.—Study organizers measured caregiver physical and functional health with a three-item scale in the Medical Outcomes Study Short Form-36 (Ware & Sherbourne, 1992). This scale measures, in the past 4 weeks, the extent to which the caregiver has had trouble climbing a flight of stairs or walking a block, or been limited in the kind of work or other activities performed as a result of physical health. Response options range from 1 = all of the time to 5 = none of the time. Cronbach coefficient alpha for this scale is .88. Study organizers asked caregivers a question in addition to the SF-36 (namely, to assess overall perceived health), with answer categories ranging from 1 = poor to 5 = excellent.

The LTC Coordination Study measured mental or emotional health by using another scale in the

Table 2. Characteristics of Frail Elderly Veteran Care Recipients (N = 210)

Variable	M (SD) or n (%)	Range
Sociodemographics		
Age	74.8 (7.2)	55–101
Race		
White	173 (82.4%)	
African American	37 (17.6%)	
Education		
0–8 years	48 (22.9%)	
9–11 years	43 (20.5%)	
12 years (high school graduate)	75 (35.7%)	
13–15 years	32 (15.2%)	
16+ years (college graduate)	12 (5.7%)	
Physical and mental health measures		
Depression	5.0 (2.9)	0–13
Activities of daily living	2.8 (1.7)	0–6
Instrumental activities of daily living	7.8 (3.1)	0–14
Comorbidities	3.3 (2.3)	0–16
Health care utilization measures^a		
Primary care visits with physician or nurse	3.9 (3.3)	0–14
Urgent care visits	1.0 (1.9)	0–16
Hospitalizations	0.6 (1.0)	0–7
Total medications	11.0 (4.9)	2–29
Perceived quality of patient care	11.8 (1.9)	3–15

Notes: SD = standard deviation.

^aHealth care utilization measures are counts of encounters 6 months prior to interview.

Medical Outcomes Study Short Form-36 instrument (Ware & Sherbourne, 1992). This three-item scale assesses the amount of time during the past 4 weeks that the caregiver has had a lot of energy, felt calm and peaceful, and felt downhearted or blue (reverse scored). Response options range from 1 = none of the time to 5 = all of the time. Cronbach coefficient alpha for this scale is .77.

Results

Background Variables

Frail Elderly Veteran Care Recipients.—The mean age of veterans was 75 years (range 55–101), and all but 4 veterans were men. Education levels were typical of the elderly veteran population, with 57% reporting high school graduation or higher and 6% reporting graduation from college. In all, 18% were African American, and the rest were White (including one Hispanic; see Table 2).

Frail elderly veterans' scores on the Geriatric Depression Scale ranged from 0 to 13, with a mean score of 5.0 ($SD = 2.9$), indicating that the majority were in normal to mild depression states. In terms of physical health, we observed moderate limitations on average, with substantial variability between veter-

ans that one can see in the ADL ($M = 2.8$, range 0–6) and IADL scores ($M = 7.8$, range 0–14). The mean score for the Charlson Comorbidity Index for frail elderly veterans was 3.3 (range 0–16).

We assessed health care utilization for the frail elders as the number of documented encounters over the 6 months prior to enrollment in the LTC Coordination Study and the baseline interview. On average, primary care clinic visits with a physician or nurse occurred approximately every 45 days (mean number of visits in prior 6 months = 3.9, range 0–14). Veterans had between 0 and 16 urgent care visits ($M = 1.0$, $SD = 1.9$) and from 0 to 7 hospitalizations ($M = 0.6$, $SD = 1.0$). On average, doctors had ordered approximately 11 medications (prescription and nonprescription drugs) for veterans over the 6 months (range 2–29).

Frail elderly veteran care recipients' perspectives on the quality of their own patient care were fairly positive ($M = 11.8$, $SD = 1.9$). As all respondents were receiving care in a VAMC outpatient primary care clinic during the time period studied, these assessments should reflect views specifically about such care.

Informal Caregivers.—The mean age for caregivers was 63 years (range 15–83), with 94% being family members (63% spouses, 22% adult children, 9% other family). We thus use the terms *informal caregiver* and *family caregiver* interchangeably throughout this article. In all, 191 (91%) caregivers were women, and 181 (86%) lived with the frail elderly veteran. A total of 56 (27%) caregivers reported that family or friends were never or rarely available to care for the frail elder when needed, whereas 65 (31%) said sometimes and 89 (42%) said usually or always available (see Table 3).

Caregivers' mean score on the mental health scale was 10.0 ($SD = 2.7$), and their mean score on the physical functional health scale was slightly higher at 11.8 ($SD = 3.9$). On average, caregivers perceived themselves as being in good (but not very good) health, with a mean score of 3.1 ($SD = 1.1$) for the single five-point assessment of overall perceived health.

Outcome and Mediating Variables.—There was considerable variation in caregiver assessments of PCFFC for frail elderly veteran care receivers. Scores on this scale ranged from 12 to 40 ($M = 29.9$, $SD = 5.8$). In general, caregivers also described substantial objective burden (range 9–37, $M = 22.4$, $SD = 6.3$).

Correlations of Mediating and Outcome Variables With Independent Variables

Table 4 shows zero-order correlations of outcome and mediating variables with all independent variables. We found significant associations between

caregivers' objective burden and care recipients' younger age, greater number of ADL and IADL limitations as well as urgent care visits, and perceived higher quality of their own patient care. Lower availability of informal help with care and poorer mental health of caregivers were associated with objective burden. Caregivers' higher levels of physical functioning and perceived overall health were associated with objective burden as well. Caregiver assessments of PCFFC showed a somewhat different pattern, including significant correlations with fewer care recipient comorbidities, urgent care visits, or hospitalizations. Higher perceived quality of their own patient care, better mental health of caregivers, yet lower perceived overall health also were associated with PCFFC.

Regression Approach to Testing Mediating Effects

After considering both regression and structural equation modeling strategies for testing mediating effects (Holmbeck, 1997), we settled on a regression approach to examine conceptualized relationships among background variables (caregiver and care recipient demographics, physical and mental health states and care recipients' comorbidities, health care utilization, and perceived quality of their health care), a mediating variable (caregiver objective burden), and a dependent variable (caregiver-assessed PCFFC). To test the mediating effects of caregiver objective burden, we followed the three steps outlined by Baron and Kenny (1986). First, we regressed caregiver-assessed PCFFC on all background variables listed above to establish the existence of relationships to be mediated. In the second step, we regressed caregiver objective burden, the potential mediating variable, on the same background variables. Finally, we regressed PCFFC on all background variables and caregiver objective burden. Table 5 presents *p* values for all variables to demonstrate trends. Figure 2 displays relationships that were significant at the 5% level.

The first regression model shown in Table 5 indicated that only a single variable (care recipients' perceived quality of patient care) had a highly significant relationship with caregivers' perceptions of PCFFC ($\beta = .41, p < .001$). Specifically, when elderly care recipients perceived the quality of their care to be higher, family caregivers perceived care to be more patient centered and family focused. This finding confirms the existence of a bivariate relationship capable of being mediated. We also observed indications of trends between PCFFC and care receivers' lower education ($\beta = -.12, p = .08$) and greater IADL limitations ($\beta = .12, p = .09$), as well as caregivers' older age ($\beta = .12, p = .09$).

The second equation verified that care receiver perceptions of quality of care were not only related to the PCFFC outcome, but also were significantly

Table 3. Characteristics of Informal Caregivers (*N* = 210)

Variable	<i>M</i> (<i>SD</i>) or <i>n</i> (%)	Range
Sociodemographics		
Age	62.6 (14.5)	15–83
Gender (female)	191 (91.0%)	
Lives with frail elderly veteran care recipient	181 (86.2%)	
Availability of family or friends to help provide care when needed		
Never	21 (10.0%)	
Rarely	35 (16.7%)	
Sometimes	65 (31.0%)	
Usually or always	89 (42.4%)	
Physical and mental health		
Mental health	10.0 (2.7)	3–15
Physical functional health	11.8 (3.9)	3–15
Perceived overall health	3.1 (1.1)	1–5
Caregiver objective burden	22.4 (6.3)	9–37
Perceived patient-centered, family-focused care	29.9 (5.8)	12–40

Note: *SD* = standard deviation.

related to caregiver objective burden ($\beta = -.12, p = .03$). In other words, care recipients' perceptions of greater quality of their own care were associated with caregivers' reports of less objective burden. Greater objective burden was also significantly associated with poorer mental health of the caregiver ($\beta = -.51, p < .001$), and with care recipient African American race ($\beta = .11, p = .04$) and limitations in ADLs ($\beta = .12, p = .04$). We also noted a trend between greater caregiver objective burden and more urgent care visits for the associated care recipients ($\beta = .12, p = .07$).

The final step tested the mediating effect of caregiver objective burden on the relationship between care receivers' perceptions of the quality of their care and caregivers' perceptions of PCFFC. When burden entered the model, the effect of care receiver perceptions of higher quality of their own care on PCFFC was reduced, but not significantly ($\beta = .37, p < .001$ vs $\beta = .41, p < .001$). Other variables associated with larger values of PCFFC included lower caregiver objective burden ($\beta = -.35, p < .001$) and more limitations in care receivers' IADLs ($\beta = .14, p = .05$).

When viewed together, perspectives of frail elderly care recipients about the quality of their own care were closely associated with caregiver assessments of PCFFC. Specifically, care recipient perceptions of higher quality care were associated with caregiver assessments of higher PCFFC. Our data suggest relatively independent relationships of objective burden and care receiver perceived quality of care to PCFFC. When informal caregivers were more burdened, care receivers' satisfaction with their own care had a smaller effect on caregiver perceptions of

Table 4. Correlation Matrix for Caregiver Perceptions of Patient-Centered, Family-Focused Care and Caregiver Objective Burden (N = 210)

Background Variable	Caregiver Perceived Patient-Centered, Family-Focused Care (Outcome Variable)		Caregiver Objective Burden (Mediating Variable)	
	Pearson Correlation Coefficient	<i>p</i>	Pearson Correlation Coefficient	<i>p</i>
Frail elderly care receiver variables				
Sociodemographics				
Age	.13	.052	-.21	.002
Race (African American = 1)	-.12	.085	.11	.113
Education	-.04	.568	-.02	.723
Physical and mental health				
Depression	-.12	.078	.12	.085
Activity of daily living limitations	-.10	.168	.25	.000
Instrumental activity of daily living limitations	.03	.635	.15	.028
Comorbidities	-.15	.025	.11	.103
6-month health care utilization ^a				
Primary care visits	.02	.741	-.09	.219
Urgent care visits	-.18	.009	.16	.022
Hospitalizations	-.16	.019	.10	.143
Total medications	-.10	.167	.11	.100
Perceived quality of patient care	.43	.000	-.21	.002
Caregiver variables				
Sociodemographics				
Age	.13	.055	-.07	.307
Gender (female = 1)	-.04	.523	.10	.158
Lives with care receiver	-.08	.251	.11	.123
Availability of informal help with care	.10	.131	-.25	.000
Physical and mental health				
Mental health	.21	.003	-.64	.000
Physical functional health	-.07	.306	.36	.000
Perceived overall health	-.15	.029	.41	.000

^aHealth care utilization measures are counts of encounters 6 months prior to interview.

PCFFC. Care recipient perceptions of poorer quality of care were related to higher caregiver burden.

Discussion

To our knowledge, no prior studies have specifically assessed patient-centered, family-focused aspects of care for physically frail elders. Our own prior work found a lack of congruence between family caregiver and health care provider perspectives on both the health care needs of physically frail elders and the demands of informal caregiving post hospitalization (Bowman et al., 1998; Rose et al., 2000). Our focus on objective burden was informed by this and other previous research and conceptual thinking about objective burden in caring for physically frail elders. To date, researchers have not easily distinguished subjective burden from other measures of perceived well-being. In contrast, ex-

perts consider objective burden (e.g., reported loss of privacy, income, personal time) to be more tangible and salient to family caregiver assessments of PCFFC. As a result of this research work, we focused here on objective burden and its impact on caring for physically frail elders.

This research developed an empirical measure of PCFFC using psychometric evaluations. Of particular importance was the emergence of a single cluster of items representing both patient-centered and family-focused aspects of care. Family caregivers appeared to see patient-centered and family-focused aspects of care as an integrated whole in assessing quality of care for their physically frail elders. We created a brief scale that equally weights patient-centered and family-focused aspects of care and that permits the direct examination of caregivers' perceptions of PCFFC. With this scale as our key outcome, we then proposed and tested a model in which caregiver objective burden mediated the

Table 5. Regression Analyses for Caregiver Perceptions of Patient-Centered, Family-Focused Care ($N = 210$)

Background Variable	Caregiver Perceptions of PCFFC		Caregiver Objective Burden (Mediating Variable)		Caregiver Perceptions of PCFFC (With Mediating Variable in Model)	
	β^a (SE)	p	β (SE)	p	β (SE)	p
Frail elderly care receiver variables						
Sociodemographics						
Age	-.05 (0.06)	.507	-.03 (0.05)	.595	-.06 (0.05)	.395
Race (African American = 1)	-.05 (0.99)	.474	.11 (0.88)	.041	-.01 (0.96)	.901
Education	-.12 (0.33)	.075	.04 (0.29)	.432	-.10 (0.31)	.106
Physical and mental health						
Depression	-.05 (0.13)	.438	-.01 (0.12)	.924	-.05 (0.13)	.403
Activity of daily living limitations	-.04 (0.25)	.625	.12 (0.22)	.042	-.01 (0.25)	.915
Instrumental activity of daily living limitations	.12 (0.13)	.089	.06 (0.12)	.284	.14 (0.13)	.037
Comorbidities	-.08 (0.17)	.252	.02 (0.15)	.688	-.07 (0.16)	.284
6-month health care utilization ^b						
Primary care visits	.06 (0.12)	.386	-.02 (0.11)	.688	.05 (0.12)	.435
Urgent care visits	-.08 (0.24)	.301	.12 (0.21)	.067	-.04 (0.23)	.605
Hospitalizations	-.07 (0.45)	.374	-.04 (0.40)	.580	-.08 (0.44)	.275
Total medications	-.00 (0.09)	.972	.02 (0.08)	.674	-.01 (0.08)	.928
Perceived quality of patient care	.41 (0.20)	.000	-.12 (0.18)	.032	.37 (0.20)	.000
Caregiver variables						
Sociodemographics						
Age	.12 (0.03)	.086	-.08 (0.03)	.191	.09 (0.03)	.165
Gender (female = 1)	.02 (1.34)	.726	.01 (1.18)	.811	.02 (1.28)	.769
Lives with care receiver	-.02 (1.05)	.785	.02 (0.93)	.688	-.01 (1.01)	.870
Availability of informal help with care	-.01 (0.39)	.934	-.06 (0.34)	.270	-.03 (0.38)	.647
Physical and mental health						
Mental health	.10 (0.16)	.179	-.51 (0.14)	.000	-.08 (0.18)	.351
Physical functional health	-.04 (0.12)	.668	.07 (0.11)	.314	.01 (0.12)	.883
Perceived overall health	-.13 (0.46)	.131	.11 (0.40)	.104	-.09 (0.44)	.283
Caregiver objective burden	—	—	—	—	-.35 (0.08)	.000
Multiple R^2	.295		.524		.355	
Adjusted R^2	.226		.477		.286	
Change in R^2 , Model 1 to Model 3					.060	

Notes: PCFFC = patient-centered, family-focused care; SE = standard error.

^aBeta is the standardized regression coefficient.

^bHealth care utilization measures are counts of encounters 6 months prior to interview.

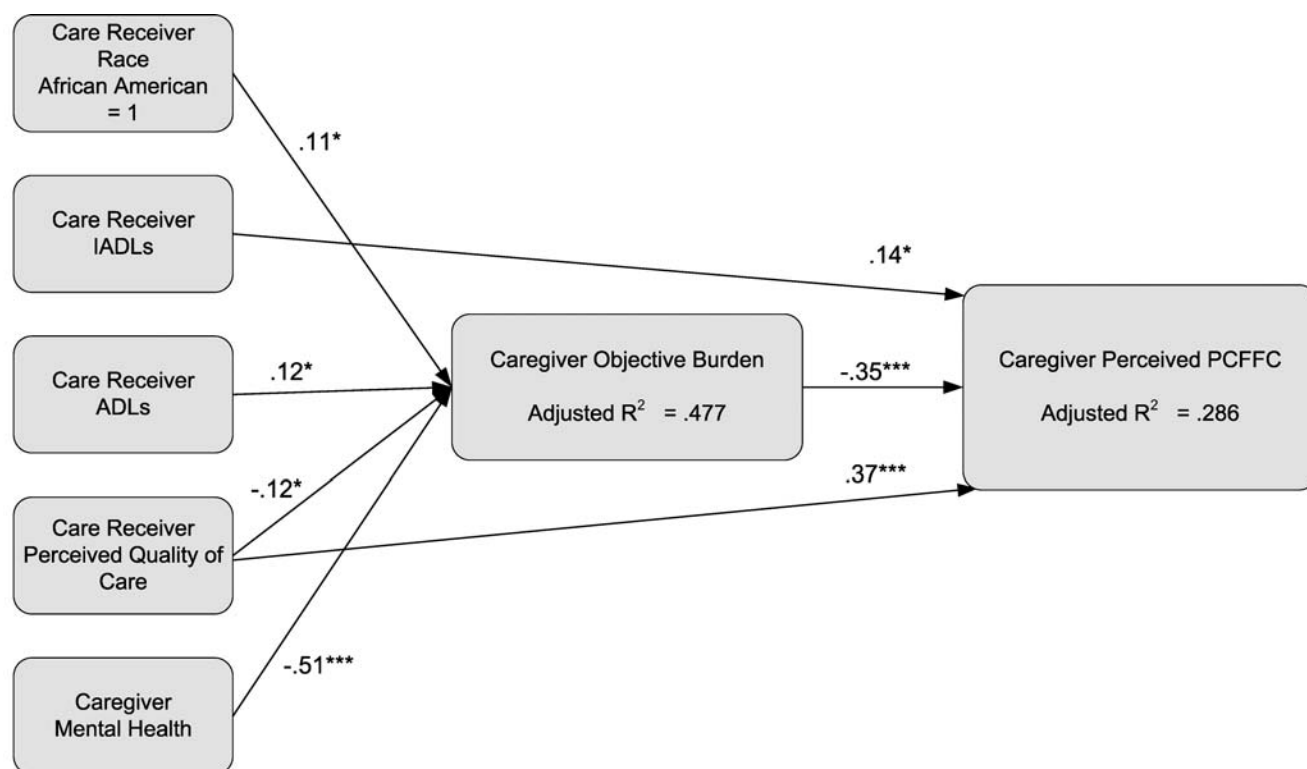
relationship between background caregiver and care receiver variables and PCFFC.

In regression analyses, the most important correlate of caregivers' assessments of PCFFC was care receivers' perceptions of quality of care, which appeared to have both direct and indirect effects. The perspectives of frail elders about the quality of their own care were generally consistent and positively associated with family caregiver assessments of PCFFC. Although this association weakened slightly when we included caregiver objective burden in the model, it still remained the most powerful correlate of PCFFC. This association provides important new evidence of shared thinking about quality of patient care for the chronically physically frail.

Whereas previous studies of agreement have focused more on accuracy of surrogate reports than

on quality of care, in comparing perspectives on quality of care for physically frail elders, agreement may be more important than accuracy (e.g., Horowitz, Goodman, & Reinhardt, 2004). Such comparisons require that both the caregiver and elder be cognitively intact, as in this study. Yet, these findings may inform related contexts of care. For example, although researchers have identified PCFFC as fundamental in end-of-life care evaluation, it has been difficult to explore such care receiver/caregiver agreement about quality of patient care because care recipients cannot participate in such studies.

Caregiver objective burden is the other key correlate of PCFFC. More burdened caregivers perceived care recipients' quality of care as less patient centered and family focused. Primary care provider teams must be attentive to the needs and perspectives



^a Conventionally statistically significant standardized regression coefficients (Beta) only
 * $p \leq .05$ ** $p \leq .01$ *** $p \leq .001$

Figure 2. Regression analyses of the mediating effects of caregiver burden on the relationship between care receiver and caregiver background variables and caregiver perceived patient-centered, family-focused care (PCFFC), $N = 210$. Figure depicts conventionally statistically significant standardized regression coefficients (β) only. ADL = activity of daily living; IADL = instrumental ADL. * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$.

of caregivers, including them in health care encounters and supporting and advising them about their own physical and mental health maintenance (Haug, 1994; Musil et al., 2003; Navaie-Waliser et al., 2002). It is likely that more burdened informal caregivers have greater needs and expectations for such support from physicians and primary care teams and that these needs are not always met. At a minimum, our findings argue for training programs that enhance provider skills in assessing and communicating with family caregivers about their expectations for such care and in addressing caregiver health problems and burden associated with assisting physically frail elderly patients (Fried et al., 2005; Lim & Zebrack, 2004; Rose et al., 2000).

In order to optimize the delivery of care, it is important for primary care providers to understand the ramifications of caregiver burden, for the informal caregivers themselves and for the care recipients as well. Of course, primary care providers must seek patient permission and guidance as to the extent to which to include specific informal caregivers. Although this patient-family unit of care is usually consistent with patient wishes, this is not inevitably the case, especially with patients who are

physically frail but cognitively intact. The challenges of providing high-quality care to this medically complex population are many, and recommendations for additional assessments and interventions should be based on demonstrated need and benefit whenever possible. In contrast with the common approach of developing training programs based on a presumed effect and then creating evaluative strategies to document this, our findings yield opportunities to construct training targeted at specific elements of care that demonstrate an association with an outcome of interest (perceived quality of care) at the outset.

Family caregivers of physically frail elderly veterans in this study were older and faced challenges in their own physical and/or mental health. Given this profile and the degree of functional limitations in frail elderly care recipients, daily demands on caregivers and objective burden are important considerations. Objective burden, as opposed to subjective burden, should capture the effects of more practical aspects of care for these elders.

Care provided by informal caregivers in this study was a key factor in avoiding nursing home placement for the community-based care recipient

population. Researchers may hypothesize the implications of successfully addressing objective burden on continued avoidance of nursing home placement based on results in this setting. However, it is unclear that professionals can extrapolate these findings to other care venues. For example, although family caregivers of patients in nursing homes continue to play an important role and experience stress and burden, these burdens are often substantially different than those observed in this study (Bowman et al., 1994).

Given the existence of an extensive literature on caregiver burden (Hughes et al., 1999; Montgomery et al., 1985), our discussion about burden here and its correlates is noteworthy, although secondary in light of our main findings. It is not surprising that our findings are consistent with previously demonstrated associations between poorer mental health and functional limitation and greater objective caregiver burden (Hughes et al., 1999; Navaie-Waliser et al., 2001; Sherwood, Given, Given, & Von Eye, 2005). In this study, it appears that mental health overrode other commonly reported caregiver attributes such as availability of family or friends to step in or living with the frail elder.

Another strength of this research is the inclusion of health care utilization; however, outside of an observed trend between more urgent care visits and greater objective burden, utilization displayed no significant impact. We were not able to assess utilization from the perspective of delayed or actual nursing home use nor could we include all of the potential financial (real and opportunity) costs of providing care in community. This may underscore the importance of caregiver burden assessment as part of a strategy to reduce health care utilization and social costs of caring for frail elders (e.g., Family Caregiver Alliance, 2006a, 2006b). At the very least, the observed correlation between health care utilization and burden requires further exploration.

Caregiver objective burden can and should be assessed by health care providers who may be able to reduce it in tangible ways, such as assisting with respite care needs. To provide optimal care for physically frail elders, health care providers need to understand the perspectives of family caregivers and involve them in discussions and problem solving about the challenges both they and their elderly care recipients face. Recognizing this, we anticipated that objective burden would be associated with caregiver perspectives on PCFFC and would potentially mediate the effects of other influences on caregiver perspectives. However, we were uncertain about the directionality of these relationships or about which specific background variables burden would mediate. Our finding that caregivers' reported objective burden did not fully explain their perspectives on PCFFC raises the possibility that their expectations may in fact be an additional important measure in PCFFC. Future researchers could modify the brief

PCFFC assessment scale reported herein to assess expectations as well as perceptions of such care.

Absent in this research, and a key factor in understanding actual care processes, is any documentation of physician–patient–family communication processes during actual encounters with primary care physicians, who provide the bulk of care for frail community-dwelling elders. To understand the relative importance of variables assessed in our models, future studies should include observational data on such encounters (Adelman, 2000; Haug, 1994; Silliman, 1989).

Although correlation analysis showed numerous care recipient and caregiver variables associated with the mediating and outcome variables, it is somewhat surprising that only a small number of these remained significant in multiple regression models. For example, we expected that greater depression and more health care utilization would relate to greater caregiver burden and their perspectives on PCFFC. We also were surprised by the lack of association between caregiver demographics (such as education, higher depression, or intensity of health care utilization) and either the mediating or outcome variables. Because these commonly available variables, which may be utilized in clinical settings to make judgments about burden, were not predictive, our findings support the use of practical and structured assessments of caregiver concerns that include known predictors of perceived burden.

Data on frail elders and their family caregivers were reported at one point in time, thus allowing us to investigate only one association in our regression analysis. Although we included as independent variables demographics and health care utilization during the 6 months prior to enrollment, causal assessments are beyond the scope of these data. Also, the available health care utilization data were limited to encounters in the VA system. Although all frail veterans received primary care in the VA, they may also have received undocumented care outside the system.

This study also has several substantial strengths. To our knowledge, this is the first study that assesses PCFFC in the context of primary care for frail elderly veterans and the first to examine the mediating effect of objective burden on caregiver perceptions of such care. The measurement of care recipient perceptions of the quality of their own patient-centered care as well as caregiver assessments of PCFFC permitted an examination of the association between perspectives, both direct and indirect.

Caregiver burden is an important component of PCFFC and relates to clinically relevant outcomes for frail elderly patients, at least in this study. Experts should consider its assessment to be a potential part of patient evaluation in the clinical setting. Our finding that caregivers' reported objective burden did not fully explain their perspectives on PCFFC raises the possibility that their expectations may in fact be

an additional important measure in PCFFC. We propose a brief PCFFC assessment scale that should be tested in larger populations and various settings in which appropriate patients receive care. An important remaining question is the extent to which assessments of PCFFC may be associated with utilization and quality-of-life outcomes for elderly patients and their caregivers over time, with increasing frailty.

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