Difficulty Assisting with Health Care Tasks Among Caregivers of Multimorbid Older Adults

Erin R. Giovannetti, PhD^{1,3}, Jennifer L. Wolff, PhD^{1,2}, Qian-Li Xue, PhD^{1,2}, Carlos O. Weiss, MD, MHS¹, Bruce Leff, MD^{1,2}, Chad Boulton, MD, MBA, MPH^{1,2}, Travonia Hughes, PhD¹, and Cynthia M. Boyd, MD, MPH^{1,2}

¹Division of Geriatrics, Johns Hopkins School of Medicine, Baltimore, MD, USA; ²Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; ³Johns Hopkins University School of Medicine, Baltimore, MD, USA.

BACKGROUND: Family caregivers provide assistance with health care tasks for many older adults with chronic illnesses. The difficulty they experience in providing this assistance, and related implications for their well-being, have not been well described.

OBJECTIVE: The objectives of this study are: (1) to describe caregiver's health care task difficulty (HCTD), (2) determine the characteristics associated with HCTD, and (3) explore the association between HCTD and caregiver well-being.

DESIGN: This is a cross-sectional study.

PARTICIPANTS: Baseline sample of caregivers to older (aged 65+ years) multimorbid adults enrolled in an ongoing cluster-randomized controlled trial (N=308).

MAIN MEASURES: The HCTD scale (0–16) is comprised of questions measuring self-reported difficulty in assisting older adults with eight health care tasks, including taking medication, visiting health care providers, and managing medical bills. Caregivers were categorized using this scale into no, low, medium, and high HCTD groups. We used ordinal logistic regression and multivariate linear regression analyses to examine the relationships between HCTD, caregiver self-efficacy, caregiver strain (Caregiver Strain Index), and depression (Center for Epidemiological Studies Depression Scale), controlling for patient and caregiver socio-demographic and health factors.

KEY RESULTS: Caregiver age and number of health care tasks performed were positively associated with increased HCTD. The quality of the caregiver's relationship with the patient, and self-efficacy were inversely associated with increased HCTD. A one-point increase in self-efficacy was associated with a significant lower odds of reporting high HCTD (OR, 0.64; 95% CI, 0.54, 0.77). Adjusted linear regression models indicated that high HCTD was independently associated with significantly greater caregiver strain (B, 2.7; 95% CI, 1.12, 4.29) and depression (B, 3.01; 95% CI, 1.06, 4.96).

CONCLUSIONS: This study demonstrates that greater HCTD is associated with increased strain and depression

among caregivers of multimorbid older adults. That caregiver self-efficacy was strongly associated with HCTD suggests health-system-based educational and empowering interventions might improve caregiver well-being.

KEY WORDS: caregiver; chronic disease; self efficacy; psychology.

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INTRODUCTION

Increasing prevalence of chronic diseases has led to a growing proportion of older patients with multiple chronic illnesses, which can be burdensome for patients to manage.^{1–4} The burden of chronic illnesses rests not only on an individual patient but can often affect an entire family.^{4–7} Caregiver assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) has been well documented, and this direct care provision can influence the caregiver's physical health through increased risk of injury, poor self-care, and elevated stress hormones.^{8–12} However, ADL and IADL measures fail to capture the full scope of caregiving which can include many tasks related to health care management.¹³

Qualitative research suggests that family caregivers often fill in the gaps in the disjointed medical system.⁵ They fill multiple roles which can include the following: coordinating care across transitions, accessing and coordinating medical care services, communicating with physicians and services, and providing information regarding patients' medical history.^{5,13} Caregivers who engage in these tasks often experience difficulty accessing helpful information, assessing the quality of services, understanding what information is necessary to get services, and anticipating what will be needed.⁵

Previous studies have used the Oberst Task Time and Difficulty scale to measure the amount of time and difficulty caregivers have assisting with various tasks, including health care related, ADL, IADL, and emotional support tasks.^{14,15} In two studies, indirect care such as managing health care bills or arranging transportation to doctor's appointments were rated as most time consuming.^{14,16} Increased caregiver-reported difficulty assisting with these types of task, among others, has been shown to be associated with increased negative emotional strain

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among caregivers to stroke survivors^{15,17,18} and heart failure patients.¹⁹ The generalizability of these studies is limited due to a disease-specific focus, small sample sizes, and lack of rigorous statistical testing using multiple regression models. What remain unclear are the frequency and magnitude of health-care-specific task difficulty among diverse populations of caregivers to multimorbid older adults, and the association between caregiver difficulty assisting with health care tasks and caregiver outcomes.

Findings are also mixed when it comes to understanding the relationship between patient and caregiver characteristics and caregivers' assessment of health care tasks as difficult. Studies of caregiver difficulty with medication administration and coordination showed that race and higher education, were associated with higher levels of difficulty.^{20,21} Studies of caregivers to cancer patients suggested that the level of patient dependency was the most significant predictor of caregiver difficulty with any type of task.^{14,18} Other disease-specific studies have shown factors such as family coping skills¹⁸ and a caregiver's belief in their ability to control outcomes (e.g., self-efficacy)¹⁶ were inversely correlated with caregiver-reported overall task difficulty. However, these studies have not differentiated between factors associated with direct care (such as ADL care) and indirect care (such as assisting with health care tasks).

This study strengthens the research on caregiver difficulty with health care tasks by (1) describing the scope of caregiver assistance and difficulty with health care tasks, (2) determining the patient and caregiver factors associated with caregiver self-reported difficulty assisting with health care tasks and (3) examining the effect of high difficulty on caregiver well-being. The conceptual model for this research is based on the Lazarus and Folkman stress, appraisal and coping model^{15,18,22} which posits that caregiver strain and depression is more likely explained by the caregivers' appraisal of the situation than the amount and type of assistance being provided, demographic factors, or illness characteristics of the care recipient (see Figure 1). We aim to test the hypotheses that (1) an increase in caregiver self-efficacy will independently predict a decrease in caregiver's appraisal of health care task difficulty (HCTD) and (2) caregivers who report greater HCTD will also report higher levels of strain and depression.

METHODS

Study Population. Data for this study were obtained from a cross-sectional baseline survey of caregivers to patients enrolled in the Guided Care randomized trial (see Wolff et al. for more details²³). This study enrolled 308 caregivers identified by patients enrolled in the Guided Care trial (N=904 patients). Patients were eligible for the study if they had been seen by a participating physician within the previous year and were predicted to be in the highest 25% of Medicare utilization services for the next year using the hierarchical condition categories (HCC) model.²⁴

Each patient who reported receiving assistance with ADLs, IADLs or health care tasks (HCTs) was asked to identify the person (family or unpaid friend) who assisted them the most. These caregivers were then contacted and, upon completing informed consent, were administered an in-person caregiver interview by a professional survey research interviewer. Each caregiver enrolled in the study provided care for only one patient enrolled in the study. Patients identified 353 eligible caregivers, and response rate among eligible caregivers was 86% (n=308).

Scope of Caregiver Assistance. Assistance was measured using caregiver-reported assistance with HCTs, IADLs and ADLs (e.g., "Do you help [person] with [task]?"). ADLs included dressing, eating, using the toilet, bathing, and transferring between a bed and chair. IADLs for this study included using the telephone, heavy housework, light housework, managing money and shopping. HCTs included eight tasks related to health care which all patients needed to perform and may have asked a caregiver to assist with (such as scheduling medical appointments), and 4 tasks which were considered "optional" because not all patients performed the task and therefore were never in the position of asking the caregiver for assistance (such as obtaining community services; see Table 1 for a complete list).

Caregivers in the study were categorized into three assistance groups: (1) helps with only HCT (N=43), (2) helps

Figure 1. Conceptual model of caregiver appraisal of health care task difficulty.

Table 1. Caregiver Task Difficulty (N=308)

	Does not do task (N (%)) [*]	No difficulty (N (%))	Some difficulty (N (%))	A lot of difficulty (N (%))
HCTD scale items				
Difficulty obtaining medications	62 (20)	209 (68)	37 (12)	0 (0)
Difficulty planning medication schedule	143 (46)	144 (47)	18 (6)	3 (1)
Difficulty administering medications	200 (65)	91 (30)	12 (4)	4 (1)
Difficulty deciding to change medication†	222 (72)	75 (24)	10 (3)	1 (0)
Difficulty managing medical bills	136 (44)	141 (46)	22 (7)	9 (3)
Difficulty scheduling medical appt	105 (34)	181 (59)	19 (6)	3 (1)
Difficulty arranging transportation	70 (23)	181 (59)	51 (17)	6 (2)
Difficulty getting information	62 (20)	203 (66)	40 (13)	3 (1)
HCTD optional items‡				
Difficulty following recommended diet	120 (39)	99 (32)	58 (19)	31 (10)
Difficulty monitoring patients health	44 (14)	206 (67)	55 (18)	3 (1)
Difficulty obtaining medical equipment	182 (59)	104 (34)	17 (6)	5 (2)
Difficulty obtaining community services	255 (83)	34 (11)	15 (5)	4 (1)

*Row percentages

†Included deciding to increase, decrease or skip a medication dose

‡Scale items refer to items which all patients needed either to perform themselves or ask for assistance. Items which were considered optional may not have been applicable to all patients in the study. These items were not included in the HCTD scale.

with IADL and HCT only (N=128), and (3) helps with ADL, IADL, and HCT (N=127). The ten caregivers who did not fit one of these three groups were added to the group which was most similar to their assistance pattern in a hierarchical fashion (see Table 2 for more detail). Sensitivity analyses showed that the inclusion of these ten caregivers did not influence results.

Health Care Task Difficulty. Our HCTD scale was based on the Oberst Task Difficulty scale^{14,17} and included eight HCTs applicable to all patients in the study (see Table 1). This scale has previously been validated in multi-morbid older adults and is strongly associated with health-related quality of life and quality of care.²⁵ For each HCT, caregivers were asked if they assisted the patient with the task and, if so, how much difficulty they had performing the task. Each item was then coded as 0=no difficulty or does not help, 1=some difficulty, and 2=a lot of difficulty. In the measurement of caregiver HCTD, “does not do task” was considered to be conceptually equal to “does task with no difficulty.”²⁶ A summary score was created by adding values across the eight questions (range, 0–16). Due to the skew in the distribution of responses (skewness=2.12), caregivers’ HCTD summary scores were categorized as follows: no difficulty (HCTD=0), low difficulty (HCTD=1), medium difficulty (HCTD=2), and high difficulty (HCTD=3+).

Caregiver Self-Efficacy. We used an eight-item scale, adapted from the chronic disease self-management efficacy scale,²⁷ in which caregivers reported how certain they were that they could handle different stressful caregiving situations using a scale of 0 to 10 (10 being very certain). The caregiving situations presented included managing general caregiving problems, maintaining a positive mood, improving mood, dealing with frustration, dealing with demands of caregiving, managing worries, getting information, and finding resources. A summary self-efficacy score was created by averaging all eight items.

Caregiver Outcomes. The modified Caregiver Strain Index (CSI) was used to measure strain^{25,28} and the Center for Epidemiological Studies Depression scale (CESD) was used to measure depression.²⁹ The CSI is a 13-item index (range, 0–24) used to screen for caregiver strain. The CESD is a 20-item scale (range, 0–60) used to self-report the presence of depressive symptoms. A score of 16 or above on the CESD is suggestive of clinically significant depression.

Independent Variables. Caregiver variables assessed were age, gender, relationship to the patient, education, employment status, co-residence with the patient, co-residence with a child under the age of 18, average hours of care provided in a typical week, number of years spent caring for the patient, and self-rated health. We additionally assessed the caregiver-reported quality of their relationship with the care recipient and the caregiver’s level of satisfaction with caregiving on a scale of 1 to 10 (10 being the best possible).

Patient variables assessed in this study were age, gender, race, financial situation, and education. Patient health variables included the SF-36,³⁰ number of chronic conditions out of the 14 most common chronic conditions in the Medicare population,³¹ number of days confined to bed and in a nursing home in the previous month, and the HCC risk for future utilization.²⁴

Statistical Analysis. Patients and caregivers across the three assistance groups and across the four difficulty groups were compared on the variables described above, using Cuzick’s non-parametric test for trends.

To test the hypothesis that caregiver self-efficacy was associated with health care task difficulty, ordinal multivariate logistic regression was used to determine the odds of caregivers reporting higher versus lower levels of difficulty for every unit increase in self-efficacy. This model can be considered as an extension of the logistic regression model for binary response variables to variables with ordered categories. Inherent in this model is the assumption of proportional odds (which was upheld in this analysis based on approximate likelihood ratio tests ($p>0.05$)). To control for potential confounding, we adjusted for the caregiver and patient characteristics related to caregiver self-efficacy which were also hypothesized to be related to HCTD. These variables included both caregiver characteristics (age, gender, education, health, and reported quality of relationship with patient), patient health-related quality of life (measured using the SF36³²), and the number of assisted HCTs. The number of assisted HCTs was included in the model to ensure the estimated coefficients reflected the relationship of each

Table 2. Patient and Caregiver Characteristics by Scope of Caregiver Assistance Group (N=308)

	Total	Scope of Caregiver Assistance Group*			
		HCT Help Only	HCT and IADL Help	HCT, IADL & ADL Help	Test for Trend
	N=308	N=43	N=129	N=136	P value
Patient characteristics					
Female (N (%))	169 (55)	12 (28)	75 (58)	82 (60)	<0.001
Caucasian (N (%))	148 (48)	24 (56)	66 (51)	58 (43)	0.08
Money problems (N (%))†	43 (14)	4 (9)	24 (19)	15 (11)	0.62
Education (N (%))—ref. high school					
No high school	101 (33)	8 (19)	51 (40)	42 (31)	0.40
More than high school	124 (40)	28 (65)	43 (33)	53 (39)	0.02
Age (mean, SE)	78.70 (0.41)	75.67 (0.69)	79.47 (0.64)	78.93 (0.67)	0.08
No. conditions (mean, SE)‡	4.57 (0.11)	4.02 (0.24)	4.50 (0.17)	4.82 (0.18)	0.04
SF36—Physical (mean, SE)	34.72 (0.59)	42.54 (1.75)	35.01 (0.89)	31.97 (0.77)	<0.001
SF36—mental (mean, SE)	46.93 (0.75)	51.09 (1.63)	47.31 (1.09)	45.27 (1.23)	0.01
HCC (mean, SE)§	2.31 (0.07)	2.00 (0.16)	2.22 (0.11)	2.49 (0.12)	0.01
Bed bound days (mean, SE)	2.11 (0.35)	0.37 (0.18)	1.16 (0.29)	3.56 (0.72)	0.01
Nursing home days (mean, SE)¶	3.72 (0.86)	0.14 (0.14)	1.57 (0.96)	6.88 (1.70)	0.01
Caregiver characteristics					
Female (N (%))	220 (71)	35 (81)	91 (71)	94 (69)	0.11
Relationship (N (%))—ref. other family					
Spouse	142 (46)	32 (74)	48 (37)	62 (46)	0.03
Son	39 (13)	2 (5)	17 (13)	20 (15)	0.07
Daughter	94 (31)	8 (19)	45 (35)	41 (30)	0.36
Education (N (%))—ref. high school					
No high school	43 (14)	6 (14)	12 (9)	25 (18)	0.14
More than high school	186 (60)	25 (58)	87 (67)	74 (54)	0.21
Co-reside with patient (N (%))	220 (71)	34 (79)	82 (64)	104 (76)	0.50
Poor self-rated health (N (%))	74 (24)	11 (26)	25 (19)	38 (28)	0.38
Presence of other helpers (N (%))	149 (48)	12 (28)	61 (47)	76 (56)	<0.001
Child in caregiver house (N (%))#	55 (18)	3 (7)	24 (19)	28 (20)	0.04
Employed (N (%))	125 (41)	14 (32)	62 (48)	49 (36)	0.63
Age (mean, SE)	61.72 (0.85)	64.93 (2.16)	60.5 (1.28)	61.84 (1.34)	0.22
Hours of caregiving (mean, SE)**	25.12 (1.57)	13.40 (3.14)	18.69 (1.95)	34.57 (2.61)	<0.001
Years spent caregiving (mean, SE)	6.41 (0.40)	8.58 (1.53)	5.87 (0.55)	6.20 (0.56)	0.64
Self-efficacy (mean, SE)	7.90 (0.09)	7.94 (0.22)	7.99 (0.14)	7.80 (0.15)	0.69
Quality of relationship (mean, SE)††	8.66 (0.09)	8.57 (0.29)	8.65 (0.14)	8.70 (0.14)	0.69
Satisfaction (mean, SE)‡‡	8.40 (0.11)	8.24 (0.26)	8.54 (0.15)	8.33 (0.17)	0.64
CSI—strain (mean, SE)	7.25 (0.34)	3.44 (0.58)	6.83 (0.46)	8.85 (0.55)	<0.001
CESD—depression (mean, SE)	7.06 (0.4)	7.44 (1.17)	6.59 (0.63)	7.38 (0.56)	0.34
Scope of assistance					
Number scale health care tasks (mean, SE)	4.13 (0.13)	3.19 (0.3)	3.71 (0.18)	4.82 (0.19)	<.001
Number optional health care tasks (mean, SE)	2.05 (0.06)	1.56 (0.13)	1.86 (0.09)	2.38 (0.09)	<.001
Number IADL tasks(mean, SE)	2.90 (0.12)	–	2.71 (0.14)	4.00 (0.15)	–
Number ADL tasks (mean, SE)	1.04 (0.08)	–	–	2.35 (0.12)	–

*HCT only group includes two caregivers who reported not assisting with any HCT, ADL, or IADL tasks; HCT, IADL, and ADL group includes two caregivers who assisted with only ADL tasks, and six caregivers who assisted with HCT and ADL tasks.

†Patient reported not having enough money to make ends meet at the end of the month

‡Total of 14 conditions assessed (diabetes, hypertension, heart attack, angina, congestive heart failure, other heart condition, asthma/COPD/emphysema, arthritis, sciatica, cancer, osteoporosis, hip fracture, and Alzheimer's disease)

§Hierarchical condition categories measures risk of heavy utilization

||Number of days patient was confined to bed in previous month

¶Number of days patient was in nursing home in previous month

#Child under the age of 18 living in caregiver's house

**Average number of hours caregiver reports assisting in a typical week

††CG self-rated relationship with Pt. on a scale of 1–10 (10 being best possible relationship)

‡‡CG self-rated satisfaction with caregiving on a scale of 1–10 (10 being highest possible satisfaction)

independent variable with HCTD, regardless of the number of HCTs being performed.

To test the hypothesis that HCTD is associated with depression and strain symptoms in the caregiver, multivariate linear regression models were constructed. Models were adjusted for the same covariates used in the previous model which have been shown to affect depression or strain and were theorized to affect HCTD. To clarify the magnitude of these effects, effect sizes (ES) were calculated using Hedges' *d*, taking into account the covariates adjusted for in the model. The ES statistic describes

the average change in standard deviation units of the outcome variable associated with one unite change in the independent variable (0.2, small ES; 0.5, medium ES; 0.8, large ES³³).

RESULTS

Caregivers reported assisting multimorbid older adults with a variety of HCTs (see Table 1). Prevalence of assisting with a

specific HCT ranged by activity, from 80% of caregivers who helped obtain medications, to 28% of caregivers who helped decide when to change a medication dose. The majority of caregivers did not report having difficulty with HCTs. Tasks that were most commonly reported as being difficult included helping the patient to follow a recommended diet (29% reported some level of difficulty), arranging transportation (19%), and monitoring patients' health (19%).

Table 2 describes patient and caregiver characteristics and the scope of caregiver assistance. An increasing scope of assistance

was associated with incrementally greater numbers of chronic conditions, HCC risk score, number of bed bound days and number of nursing home days among care recipients, as well as decreased patient quality of life (SF36; see Table 2). There was a trend toward females receiving more assistance (HCT, IADL, and ADL assistance) and individuals with higher education receiving less assistance (HCT only). Similarly, caregiver scope of assistance was significantly and positively associated with the presence of other helpers, presence of a child (age <18) in the house, increased hours of caregiving, and caregiving-related strain.

Table 3. Patient and Caregiver Characteristics by Caregiver-Reported Health Care Task Difficulty (HCTD) Score (N=308)

	Caregiver difficulty group*				
	None	Low	Med	High	Test for trend
	N=140	N=56	N=40	N=72	p value
Patient characteristics					
Female (N (%))	91 (65)	24 (43)	15 (38)	39 (54)	0.04
Caucasian N (%)	66 (47)	29 (52)	23 (58)	30 (43)	0.70
Money problems (N (%))†	23 (16)	3 (5)	4 (10)	13 (18)	0.91
Education (N (%))—ref. high school					
No high school	53 (37)	17 (30)	12 (30)	19 (26)	0.08
More than high school	47 (34)	28 (50)	20 (50)	29 (40)	0.21
Age (mean, SE)	79.00 (0.59)	78.41 (0.99)	78.23 (1.30)	78.59 (0.86)	0.52
No. conditions (mean, SE)‡	4.56 (0.17)	4.25 (0.23)	4.95 (0.38)	4.67 (0.24)	0.52
SF36—Physical (mean, SE)	34.15 (0.95)	36.46 (1.25)	33.76 (1.68)	34.98 (1.11)	0.52
SF36—mental (mean, SE)	47.79 (1.12)	49.21 (1.47)	45.06 (2.39)	44.51 (1.56)	0.05
HCC (mean, SE)§	2.33 (0.11)	2.14 (0.14)	2.22 (0.25)	2.43 (0.14)	0.33
Bed bound days (mean, SE)	2.49 (0.62)	1.03 (0.36)	2.10 (0.97)	2.21 (0.65)	0.02
Nursing home days (mean, SE)¶	3.16 (1.25)	0.93 (0.81)	4.10 (1.49)	6.75 (2.56)	0.02
Caregiver characteristics					
Female (N (%))	94 (67)	44 (79)	30 (75)	52 (72)	0.38
Relationship (N (%))—ref. other family					
Spouse	64 (46)	31 (55)	21 (53)	26 (36)	0.29
Son	17 (12)	6 (11)	5 (13)	11 (15)	0.53
Daughter	43 (31)	15 (27)	11 (26)	25 (35)	0.64
Education (N (%))—ref. high school					
No high school	22 (16)	7 (13)	8 (20)	6 (8)	0.27
More than high school	78 (56)	34 (61)	24 (60)	50 (69)	0.06
Co-reside with patient (N (%))	100 (71)	39 (70)	28 (70)	53 (74)	0.79
Poor self-rated health (N (%))	31 (22)	10 (18)	13 (33)	20 (28)	0.21
Presence of other helpers (N (%))	66 (47)	24 (43)	18 (45)	41 (57)	0.24
Child in caregiver house (N (%))#	21 (15)	7 (13)	9 (23)	18 (25)	0.05
Employed (N (%))	49 (35)	25 (45)	13 (33)	38 (53)	0.04
Age (mean, SE)	61.77 (1.42)	64.04 (1.66)	60.33 (2.86)	55.72 (2.33)	0.05
Hours of caregiving (mean, SE)**	26.12 (2.46)	18.85 (2.71)	26.35 (5.28)	22.75 (2.85)	0.92
Years spent caregiving (mean, SE)	5.91 (0.55)	6.96 (1.12)	8.61 (1.37)	5.75 (0.67)	0.57
Self-efficacy (mean, SE)	8.49 (0.12)	7.94 (0.19)	7.56 (0.26)	6.88 (0.20)	<0.001
Quality of relationship (mean, SE)††	9.14 (0.11)	8.74 (0.18)	8.13 (0.31)	7.97 (0.23)	<0.001
Satisfaction (mean, SE)‡‡	8.91 (0.13)	8.40 (0.21)	7.70 (0.30)	7.79 (0.26)	<0.001
CSI—Strain (mean, SE)	5.74 (0.48)	6.07 (0.63)	7.75 (0.90)	10.82 (0.66)	<0.001
CESD—depression (mean, SE)	5.55 (0.53)	5.69 (0.68)	7.90 (1.06)	10.62 (0.96)	<0.001
Scope of assistance					
Number of scale health care tasks (mean, SE)	4.05 (0.19)	3.76 (0.25)	3.75 (0.39)	4.76 (0.24)	0.08
Number of optional health care tasks (mean, SE)	1.80 (0.93)	2.00 (0.13)	2.05 (0.16)	2.56 (0.10)	<0.001
Number of IADL tasks(mean, SE)	2.86 (0.18)	2.18 (0.26)	2.95 (0.31)	3.51 (0.21)	0.03
Number of ADL tasks (mean, SE)	0.95 (0.12)	0.67 (0.14)	1.32 (0.27)	1.30 (0.19)	0.05

*None, HCTD=0; low, HCTD=1; med, HCTD=2; high, HCTD>3

†Patient reported not having enough money to make ends meet at the end of the month

‡Total of 14 conditions assessed (diabetes, hypertension, heart attack, angina, congestive heart failure, other heart condition, asthma/COPD/emphysema, arthritis, sciatica, cancer, osteoporosis, hip fracture, and Alzheimer's disease)

§Hierarchical condition categories measures risk of heavy utilization

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††CG self-rated relationship with Pt. on a scale of 1–10 (10 being best possible relationship)

‡‡CG self-rated satisfaction with caregiving on a scale of 1–10 (10 being highest possible satisfaction)

Table 4. Proportional Odds of Reporting Higher Difficulty Across Caregiver and Patient Factors: Ordinal Multivariate Logistic Regression Model (N=308)

Independent variables	Adjusted OR (95% CI)	p value
Caregiver female	1.15 (0.69, 1.92)	0.60
Caregiver age	0.98 (0.97, 0.99)	0.02
Caregiver fair/poor health (ref. good)	1.14 (0.66, 1.98)	0.64
Caregiver high school education (ref. no HS)	0.94 (0.43, 2.05)	0.87
Caregiver>high school education (ref. no HS)	1.18 (0.58, 2.26)	0.65
Quality of caregiver relationship	0.81 (0.69, 0.95)	<0.01
Caregiver self-efficacy	0.64 (0.54, 0.77)	<0.001
No. of health care tasks assisted with	1.17 (1.04, 1.31)	<0.01
Patient SF36—physical	1.02 (1.00, 1.05)	0.07
Patient SF36—mental	0.99 (0.98, 1.01)	0.73

Table 3 describes the characteristics of patients by categories of HCTD. Interestingly, we observed very little variation in patient health characteristics across caregiver HCTD summary scores (see Table 3). Only gender, number of bed bound days, and number of nursing home days were associated with increased HCTD at the significance level of $p<0.05$. Greater strain (CSI) and depressive symptoms (CESD) were observed with increasing caregiver HCTD. Caregivers' self-efficacy, satisfaction with caregiving, and quality of relationship with the patient were inversely associated with level of HCTD. HCTD was associated with increased assistance with optional health care tasks and IADL tasks, but not with ADL tasks.

Table 4 presents the ordinal multivariate logistic regression model of caregiver self-efficacy on odds of reporting a higher versus a lower level of HCTD. For every one-point increase in self-efficacy, the odds of reporting a higher versus lower levels of HCTD decreased by 36%. A 1-year increase in caregiver age and one-point increase in the quality of the caregiver's relationship were also associated with a decrease in the odds of reporting high versus low level of HCTD by 2% and 19% respectively. An increase in the number of health care tasks assisted with was associated with increased odds of reporting high versus low level of HCTD by 17%.

Table 5 presents results of the multivariate linear regression models that examine the association between caregiver HCTD

separately for caregiver strain (CSI) and depression (CESD). Models that adjusted for patient and caregiver characteristics indicate that high HCTD was independently associated with higher depression and strain. After adjustment for patient and caregiver characteristics, caregivers reporting high HCTD had an average CSI score 2.7 (95% CI, 1.12, 4.29) points greater than caregivers reporting no difficulty, with a corresponding effect size (Hedges' d) of 0.45 (95% CI, 0.18, 0.75). Caregivers reporting high HCTD also had an average CESD score 3.01 (95% CI, 1.06, 4.96) points higher, with a corresponding effect size of 0.41 (95% CI, 0.14, 0.69).

DISCUSSION

Caregivers in this study reported difficulty assisting multi-morbid patients with a range of health care tasks. Our hypothesis that caregivers with high HCTD would show greater evidence of strain and depression was supported by the independent relationship between high HCTD and increased strain and depressive symptoms, after controlling for possible confounders (number of assisted health care tasks, caregiver self-efficacy,^{32,34} and poor patient mental health-related quality of life^{35,36}). The strength of the relationship between HCTD and strain/depression is particularly striking. A meta-analysis of caregiver support and education-based interventions suggested an average effect size of 0.14–0.41 standard deviation unit decrease in burden and depression associated with a successful intervention.³⁷ The effect size of HCTD in our study on strain (0.45 standard deviation units) and depression (0.41 standard deviation units) approximates the effect of the most successful caregiver support interventions, suggesting the differences seen in our study are clinically significant.

As hypothesized, caregiver self-efficacy was strongly associated with decreased HCTD, suggesting that low caregiver self-efficacy could be an important indicator for caregivers experiencing HCTD assisting patients with complex treatment plans. Consistent with previous studies, high HCTD was found to be more common among younger caregivers.^{16,18} Researchers have hypothesized older adults consider illness to be a normal

Table 5. Caregiver Strain and Number of Depressive Symptoms Across Caregiver Difficulty Groups: Multivariate Regression Models (N=308)

Independent variables	Multivariate model 1—strain (CSI)		Multivariate model 2—number of depressive symptoms (CESD)	
	B (95% CI)	p value	B (95% CI)	p value
Low HCTD	0.51 (−1.08, 2.10)	0.53	−0.25 (−2.19, 1.70)	0.83
Medium HCTD	1.09 (−0.72, 2.90)	0.24	0.56 (−1.66, 2.78)	0.62
High HCTD	2.70 (1.12, 4.29)*	<0.001	3.01 (1.06, 4.96)†	0.01
Caregiver female	−0.04 (−0.07, 0.00)	0.03	−0.02 (−0.06, 0.02)	0.35
Caregiver age	0.09 (−1.15, 1.32)	0.89	0.28 (−1.23, 1.80)	0.72
Caregiver fair/poor health (ref. good)	0.06 (−1.28, 1.40)	0.93	5.26 (3.61, 6.92)	<0.001
Caregiver high school education (ref. no HS)	−0.58 (−2.46, 1.3)	0.55	−0.21 (−2.55, 2.12)	0.59
Caregiver>high school education (ref. no HS)	0.14 (−1.58, 1.87)	0.87	−2.05 (−4.20, 0.10)	0.06
Quality of caregiver relationship	−0.15 (−0.54, 0.24)	0.45	−0.36 (−0.84, 0.13)	0.15
Caregiver self-efficacy	−0.73 (−1.16, −0.30)	<0.001	−0.99 (−1.53, −0.46)	<0.001
No. of health care tasks assisted with	0.92 (0.65, 1.19)	<0.001	−0.08 (−0.41, 0.25)	0.63
Patient SF36—physical	−0.05 (−0.10, 0.01)	0.11	0.00 (−0.07, 0.06)	0.90
Patient SF36—mental	−0.08 (−0.12, −0.04)	<0.001	−0.07 (−0.12, −0.01)	0.01

*Effect size of coefficient—Hedges' d (95% CI)—0.45 (0.18, 0.75)

†Effect size of coefficient—Hedges' d (95% CI)—0.41 (0.14, 0.69)

experience of aging and thus can more easily adapt to the situation.³⁸ Also of interest was the strong independent relationship between high caregiver-reported quality of relationship with the patient and low perceived HCTD. The effect of the caregiver's relationship with the patient on outcomes for both the patient and caregiver has not been well studied to date and warrants further exploration.³⁹

In the bi-variate analyses, there was little association between patient socio-demographic characteristics and caregiver HCTD (only caring for a female patient was associated with greater caregiver HCTD). Although some patient health characteristics (bed bound days, nursing home days and mental health-related quality of life) were associated with caregiver HCTD, this relationship was not consistent across all measures of patient health (numbers of chronic conditions, physical health-related quality of life, and predicted health care utilization).

Collectively, these findings suggest that interventions aimed at increasing self-efficacy and reducing caregiver HCTD might lower strain and depression for caregivers. Physicians, nurses, and social workers may have a role to play in detecting family caregivers who are experiencing difficulty with specific HCTs and problem solving with patients and caregivers. Improving caregiver mental health through reduced difficulty with HCTs could also improve patient outcomes^{40,41} in that patients with effective caregivers often show better adherence to treatment plans^{42,43} and improved functioning.⁴⁴ However, it remains unclear how physicians can best support caregivers in the health care setting given the lack of available resources, knowledge of how to best support family caregivers, and the time constraints of an average visit.⁴⁰ A careful examination of a patient's treatment plan and the associated HCTD experienced by both the patient and the caregiver may help the physician to reduce needless complexity and prioritize which health care tasks are most important. Potential interventions aimed at improving caregiver self-efficacy to perform health care related tasks could also lead to a decrease in HCTD; however more research is needed to determine this.

The cross-sectional analysis used in this study limits our ability to comment on the directionality of the relationship between caregiver self-efficacy, HCTD and caregiver mental health outcomes. Further research is needed to determine how responsive caregiver outcomes are to changes in HCTD. The large number of bi-variate comparisons tested in Tables 2 and 3 warrant caution when interpreting the statistical significance of the test for trends. Performing multiple comparisons increases the likelihood that one or more of the tests for trends will reach a *p* values level of 0.05 by chance alone. Despite these limitations, the focus of this study on caregivers to a group of patients with multiple chronic conditions allows for greater generalizability of results than previous disease-specific studies. As physicians, nurses, and social workers look to reduce treatment burden, they should also be attentive to how the difficulty caregivers experience with a treatment plan may affect family caregivers.

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Corresponding Author: Erin R. Giovannetti, PhD; Johns Hopkins University School of Medicine, Mason F. Lord Building, Center Tower, Rm. 710, 5200 Eastern Ave., Baltimore, MD 21224, USA (e-mail: erandgi1@jhmi.edu).

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