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Health Care Task Difficulty among Older Adults with Multimorbidity

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Abstract

Background—Applying disease-specific guidelines to people with multimorbidity may result in complex regimens that impose treatment burden.

Objectives—To describe and validate a measure of health care treatment difficulty (HCTD) in a sample of older adults with multimorbidity.

Research Design—Cross-sectional and longitudinal secondary data analysis

Subjects—Multimorbid adults ages ≥65 from primary care clinics

Measures—We generated a scale (0–16) of self-reported difficulty with 8 health care tasks(HCTD) and conducted factor analysis to assess its dimensionality and internal consistency. To assess predictive ability, cross-sectional associations of HCTD and number of chronic diseases, and conditions that add to health status complexity (falls, visual, and hearing impairment), patient activation, patient-reported quality of chronic illness care (Patient Assessment of Chronic Illness Care; PACIC), mental and physical health (SF-36) were tested using statistical tests for trend (n=904). Longitudinal analyses of the effects of change in HCTD on changes in the outcomes

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were conducted among a subset (n=370) with≥1 follow-up at 6 and/or 18 months. All models were adjusted for age, education, sex, race and time.

Results—Greater HCTD was associated with worse mental and physical health (Cuzick's test for trend ($P<0.05$), and patient-reported quality of chronic illness care ($P<0.05$). In longitudinal analysis, increasing patient activation was associated with declining HCTD over time ($P<0.01$). Increasing HCTD over time was associated with declining mental ($P<0.001$) and physical health ($P=0.001$) and patient-reported quality of chronic illness care ($P<0.05$).

Conclusions—The findings of this study establish the construct validity of the HCTD scale.

INTRODUCTION

Growing numbers of older adults are living with and managing multiple chronic conditions, with concomitant complex treatments.[1–4] A person who also reports high treatment burden can be described as experiencing the aggregate influence of the direct consequences of those diseases in combination with prescribed or recommended care plans. Treatment burden is defined here as a patient's perception of the aggregate weight of the actions and resources they devote to their health care, including difficulty, time, and out-of-pocket costs dedicated to health care tasks such as adhering to medications, dietary recommendations, and self-monitoring.

The importance of treatment burden for decision-making is acknowledged by systems designed to develop clinical practice guidelines.[5] It is generally recognized that patients with multimorbidity face increased health care demands associated with adherence to treatment regimens.[6] However, even for many single diseases, how patients view treatment burden is poorly understood.[7] Treatment burden has been previously defined and measured for patients with terminal conditions and for patients with specific conditions based on characteristics of treatment (such as hospitalization), complications that arise, and self-reported burden of a specific aspect of treatment.[8–12] Despite the inherent relevance of treatment burden to decision-making for older patients with multimorbidity, comprehensive measures of treatment burden for this population do not exist.[7] Difficulty with health care tasks (HCTD) (e.g. difficulty planning medication schedule) is one aspect of treatment burden. HCTD may be addressed in part through targeting patient activation, defined as patients' knowledge, skills, and confidence for self-management.[1314] As described in the Chronic Care Model, patient-centered chronic illness care is particularly important when considering complex treatment plans in older adults with multimorbidity.[15]

What remain unclear are the frequency and magnitude of HCTD among diverse populations of older adults with multimorbidity, and the association between HCTD and quality of chronic illness care and health-related quality of life (HRQoL).

Therefore, we sought to describe and validate a measure of health care treatment difficulty (HCTD) in a sample of older adults with multimorbidity. Cross-sectionally, we examined whether lower patient activation was associated with greater HCTD and whether greater HCTD was associated with lower HRQoL and lower quality of chronic illness care. To further assess predictive validity of the HCTD scale, we analyzed the longitudinal associations between change in patient activation, change in the HCTD score and changes in mental and physical HRQoL as well as patient-reported quality of chronic illness care. We examined whether increases in patient activation over time were associated with declining HCTD and whether increasing HCTD was associated with declining patient-reported quality of chronic illness care and HRQoL.

METHODS

We examined baseline data collected in a cluster-randomized controlled trial of "Guided Care."[16] The Institutional Review Boards of Johns Hopkins University, Kaiser-Permanente Mid-Atlantic States, and MedStar Physician Partners approved the study.

Recruitment

Between 2006 and 2009, 904 older patients with multimorbidity and 308 of their informal caregivers were enrolled.[16] Community-dwelling, English-speaking patients aged ≥65 were eligible 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 for the next year using the hierarchical condition category predictive model.[1617] Potential participants were excluded if they had cognitive impairment (unable to verify age, address and spelling of name) and no legal representative, or were unable to participate in the baseline or follow-up interviews.[16] Among eligible patients, 38% consented to participate (n=904).

For longitudinal analyses, we restricted our sample to 419 of the 904 patients who were randomized to receive usual care. We restricted longitudinal analyses to usual care because Guided Care was originally hypothesized to affect patient-reported quality of chronic illness care and HRQoL. Patients were administered a baseline interview in-person and a phone interview at six-months and eighteen-months. Among the 419 patients receiving usual care who survived and received care from the same physician at follow up, 94.2% (n=370) had at least one follow-up interview and were thus eligible to be in this analysis. Patients in the longitudinal sample for this analysis (n=370) did not differ from the other participants who are not in the longitudinal sample (n=534) in terms of age, sex, or race, patient activation, or HRQoL, but the longitudinal sample did have slightly worse baseline PACIC scores (2.55 vs. 2.65, $p<0.05$).

Analyses of patient activation were restricted to study participants who self-reported responses at baseline and at least one follow-up (n=855 and 351, respectively). For all other measures, approximately 5% of the baseline sample (n=49) and longitudinal sample (n=19) were proxy responses.

Data Collection and Measures

In-person baseline interviews were conducted with patients and caregivers. Patient measures included socio-demographics, number and type of self-reported chronic conditions, physical, sensory, and cognitive functioning, number of medications, social support, and income sufficiency. Caregiver measures included relationship to patient, co-residence with patient, and hours of care provided. The Patient Activation Measure (PAM), assesses patient knowledge, skill, and confidence for self-management and provides a continuous score (0–100).[14] Quality of chronic illness care was assessed using the Patient Assessment of Chronic Illness Care (PACIC), a 20-item validated scale which measures patient-report of receiving aspects of care congruent with the Chronic Care Model. [18] (For example, questions assess whether the patient was "asked to talk about any problems with my medicines or their effects," "asked to talk about my goals in caring for my condition," etc.).[18] HRQoL is measured with the Physical and Mental Component Scores from the SF-36.[19]

Although treatment burden is a multidimensional construct, in this study we focus on a single dimension – perceived difficulty in performing health care management tasks. Health Care Task Difficulty (HCTD) was measured using 11 items which ask patients to identify the amount of difficulty they have performing health care tasks (Table 1). These items were generated through review of existing instruments, input from clinical experts in geriatric medicine, and testing in a pilot study of Guided Care.[20] A summary health care task difficulty (HCTD) scale was created from 8 out of 11 of the questions that all participants answered where 0=no difficulty, 1=some difficulty and 2=a lot of difficulty (range 0–16). Three questions were excluded from the summary scale because they included an additional response category of does not do" task. Participants who did not know or refused were recoded as having no difficulty (0).

Analytic Plan

Internal construct validity of the summary HCTD scale—Exploratory factor analysis (EFA) was used to assess the dimensionality of the summary HCTD scale (0–16, described above). Polychoric correlations were used to account for the ordinal response categories in the 8 tasks in the EFA. The "eigenvalue-greater-than-1" rule, the scree test, and the parallel test were used to select the number of factors to extract. The Comparative Fit Index (CFI), the Tucker-Lewis Index (TLI), and the root mean square error of approximation (RMSEA) were used to assess the model goodness-of-fit. The unidimensionality of the scale was further verified using a confirmatory factor analytic model (CFA) that allows the residual errors of the eight items to be correlated, and a likelihood-based chi-square difference test was used to compare the models with and without the correlated residual errors.[21] For a scale to be unidimensional, the correlations among the items must be fully explained by a single factor.[22] Therefore, nonsignificant difference between the two models will support the unidimensionality of the scale.

Predictive validity of the summary HCTD scale

Cross-sectional analyses: Patient and caregiver characteristics were compared across categories of HCTD for the combined usual care and intervention group participants. Categories were generated by dividing summary scale scores greater than or equal to one into tertiles resulting in the following four categories: no difficulty (score=0), low level of difficulty (score <2) (first tertile), medium level of difficulty (score=2–4.5) (second tertile) and high level of difficulty (score= 4.6 or more) (third tertile). Trends for continuous and binary characteristics were tested using the Cuzick's test and the Royston's *ptrend* test, respectively; and for multilevel characteristics, multinomial (insurer) or ordinal (number of medications) logistic regression was used treating HCTD category as a continuous variable (Table 2). Reports of HCTD for each question were compared between respondents with high levels of mental and physical HRQoL (SF36 score in the highest tertile) to those with low levels of mental and physical HRQoL (SF36 score in the lowest tertile).

We analyzed the independent association of HCTD categories with the PACIC, mental and physical HRQoL after adjusting for age, sex, education, and race using multiple linear regression analyses.

Longitudinal analyses: To further assess predictive validity of the HCTD scale, we analyzed the longitudinal associations between change in the summary HCTD score and changes in mental and physical HRQoL as well as the PACIC using random effects models, to account for the different follow-up time intervals and within-person correlation among the repeated measurements of the outcome variables over time.

The model is specified as follows:

$$\begin{gathered} y_{i1}=b_{i0}+b_c x_{i1}+\alpha_i s_{i1}+\varepsilon_{i1}; y_{i2}=b_{i0}+b_c x_{i1}+b_L(x_{i2}-x_{i1})+\alpha_i s_{i2}+\varepsilon_{i1}; \ldots ; \\ y_{iT}=b_{i0}+b_c x_{i1}+b_L(x_{iT}-x_{i1})+\alpha_i s_{iT}+\varepsilon_{iT}, \end{gathered} \tag{A}$$

where x_{it} and y_{it} respectively are subject i's continuous HCTD score and outcome score (e.g., mental HRQoL) at time t, t=1…T; s_{it} is the time gap between visit 1 and visit t; and ε is the error term. The coefficient b_c summarizes the population-average ‘cross-sectional’ effect of HCTD score recorded on mental HRQoL at baseline; whereas b_L summarizes the population-average ‘longitudinal’ effect of within-person change in HCTD score and change in mental HRQoL, so named because, for example, subtracting the first equation from the second in (A) results in an expression for y_{i2}-y_{i1} in terms of x_{i2}-x_{i1} and b_{iL}. To account for baseline between-subject heterogeneity in y_{i1} and within-subject correlation over time, we treat b_{i0} and α_i as random effects. Results of fitting Model (A) before and after adjustment for age, sex, education, and race are presented.

We analyzed the effect of baseline patient activation and change in patient activation (PAM) on change in the HCTD summary score using a random effects model similar to Model (A), with the exception that the HCTD score was modeled as a negative binomial outcome with a log link to account for the excess variability (i.e., over-dispersion) in the HCTD score. The coefficients b_c and $b_L$are presented as the percentage change in the HCTD score for one standard deviation unit change in PAM.

Sensitivity Analyses

Missing data were uniformly low; ranging from none on most items to 2.4% for difficulty knowing when to change medication dosages. Sensitivity analyses were conducted by 1) dropping those with missing data for difficulty items included in the HCTD score and 2) reassigning missing items a “3” (a lot of difficulty) as opposed to “0”. The results of both methods were similar to the original analysis which assumes missing is having no difficulty with the given task.

RESULTS

We generated and validated a scale (0–16) of HCTD based on 8 questions. The one-common factor model explains 50% of the total variance of all 8 difficulty items; and the goodness-of-fit statistics all suggested a reasonably good fit (CFI=0.91, TLI=0.96, RMSEA=0.05). While both the “eigenvalue-greater-than-1” rule and the scree test favored one-common factor model, the parallel test identified two factors. The CFA also revealed significant partial corrections among 3 out of 8 items (planning medication schedule, taking medications, and making decisions about changing medications) after removing the effect of the “difficulty” factor (likelihood-based chi-square different test statistics=34.476 with 3 degrees of freedom; P<0.01), suggesting the possibility of a second factor underlying these three items. However, given that (i) all three items had “very significant” loadings (≥0.7) on the “difficulty” factor in the one-factor model[23], (ii) each item was similarly affected by the “difficulty” factor with the percentage of variance of each item explained by the factor ranging from 40% to 53% with the exception of scheduling medical appointments (71%), and (iii) the ordinal coefficient alpha was 0.89 indicating strong interrelatedness among the eight items, the proposed summary HCTD scale may still be warranted for its simplicity and ease of interpretation.[24][25]

The prevalence of heart failure and stroke was significantly greater with increasing HCTD (Table 2). Hypertension and dementia showed a similar, but marginal, association. The numbers of diseases was significantly associated with increased HCTD. Conditions adding to complexity of clinical decision-making and understanding and implementing treatment regimens (falls, visual impairment, hearing impairment and sleep disturbances) were associated with increased HCTD. Insufficient funds at the end of the month was associated with increased HCTD. Among participants with a caregiver (n=308), greater caregiving hours was associated with increased HCTD. Among all participants, activation was strongly associated with HCTD; scores decreased in a stepwise manner by nearly 10 points from 58.8 among people with no HCTD to 49.3 among people with high HCTD. Greater HCTD was associated with lower PACIC scores, indicating worse quality of chronic illness care. Greater HCTD was associated with worse mental and physical HRQoL.

To explore how difficulty with specific health care tasks was associated with HRQoL, we examined tertiles of mental and physical HRQoL in relation to responses to individual questions about different aspects of a treatment regimen. Worse physical and mental HRQoL were significantly associated with greater HCTD for all but one question, where the relationship was in the expected direction but non-significant at the 0.05 level (physical HRQoL and difficulty planning a medication schedule, P=0.076).

We examined the associations of HCTD score with mental and physical HRQoL, and PACIC scores in three separate models adjusting for age, sex, education and race (Table 3). Compared to individuals with no HCTD, those with low, medium, and high HCTD had significantly worse physical and mental HRQoL (P<0.05). Individuals with high HCTD scored 11.86 points lower on the SF-36 mental health score (P<0.001) and 6.22 points lower on the SF-36 physical health score (P<0.001) compared to individuals with no HCTD. Individuals with HCTD (low, medium and high) also reported lower quality of chronic illness care on average (P<0.05); those with high HCTD rated the PACIC 0.24 points lower compared to individuals with no HCTD (P<0.001).

Longitudinal Analyses

Patient Activation—Patients with higher activation at baseline reported lower health care task difficulty at follow up (see Table 4). An adjusted random effects negative binomial model with random intercept and random time slope showed that a 1-SD unit (i.e. 12.8) higher baseline PAM score was associated with a 35% lower HCTD at follow-up (P<0.01). We also found that for every SD unit (i.e. 14.6) increase in PAM score over time, HCTD decreases by 12% (although these results were not statistically significant, P=0.08). In other words, for a person whose PAM score increases by 14.6 points over any two points of time, his/her HCTD score is expected to decrease by 12% during the same interval after adjusting for all other covariates including baseline PAM score. All results are adjusted for age, sex, race, education and follow-up time.

Physical and Mental Health Related Quality of Life—Patients with higher HCTD at baseline reported lower mental health-related quality of life at follow-up (Table 5). The SF-36 mental health score was lower by 2.42 points for every one point higher baseline HCTD (P< 0.001), a difference in magnitude that approaches clinical significance (3 points).[26] Similar, albeit weaker results were found for physical health. The SF-36 physical health score was lower by 1.09 points at follow-up for every one point higher baseline HCTD (P<0.001). We also found that patients who reported increasing HCTD over time reported decreased mental and physical health-related quality of life over time. Adjusted longitudinal analysis showed that for every one point increase in HCTD score over time, SF36 mental health score decreased 1.32 points (P<0.001) and SF36 physical health score decreased 0.59 points (P=0.001). All results are adjusted for sex, age, education, race and follow-up time.

Quality of Chronic Illness Care—Although we found a statistically significant relationship between HCTD and patient rated quality of chronic illness care (PACIC) at baseline, and between change in HCTD and change in PACIC at follow up, the effect size was small (Table 5). The PACIC score was lower by 0.04 points for every one point higher baseline HCTD score (P<0.05). Similarly, the longitudinal analysis showed that for every one point increase in HCTD score over time, the PACIC score decreased by 0.04 points (P<0.05).

DISCUSSION

This study describes and validates a measure of health care treatment difficulty (HCTD) in a sample of older adults with multimorbidity. We find HCTD to be strongly associated with greater disease burden, as well as conditions that add to complexity of decision-making and self-management. HCTD was also greater among older adults who were less activated and was associated with worse mental and physical HRQoL as well as worse quality of chronic illness care. From the perspective that HCTD was highly correlated with worse health status, lower education, and more limited financial resources; factors that are strongly associated with self-management challenges, study results lend support to construct validity of treatment burden. The association of HCTD over time with mental health-related quality of life approaches clinical significance (3 points).[26] Future work is needed to understand whether approaches to reduce difficulty with health care tasks lead to improvements in quality of life and quality of chronic illness care. A careful examination of a patient's treatment plan and the associated HCTD may help the physician to reduce needless complexity, enhance patient activation, and prioritize which health care tasks are most important. Although HCTD represents just one aspect of treatment burden, it is an important dimension that is broadly relevant to a large segment of the population, irrespective of specific illnesses and settings of care.[1327]

The concept of treatment burden has been largely used for, and developed from, end-of-life care whereas treatment burden and treatment outcomes have been defined as key components of patients' medical decision making.[102829] Studies of patients at the end of life have found that patients vary in their willingness to accept treatment with high degrees of associated treatment burden.[1030] Treatment burden has been explored in the context of single diseases or screening tests.[893132] Adult veterans with diabetes report significant burden associated with glycemic control therapies, and this burden is the primary predictor of adherence and willingness to accept insulin.[9] A qualitative study of middle-aged adults with multimorbidity suggests significant burden may result from medication-related treatments and that this in turn influences adherence, patient priorities, and self-management.[11] Thus, building on the concepts developed largely in the end-of-life and single disease literatures, treatment burden associated with treatment regimens for chronic conditions was defined in this study for a broader population who were not immediately confronting end-of-life care and encompassed both non-pharmacologic and pharmacologic treatment across all of their conditions.[8–10122730–32]

Well-informed patients vary in the burden they assign to treatments they are receiving and in their willingness to accept burdensome treatments. Some patients may intentionally prefer to depart from "best practice" treatments.[91130–35] Treatment burden related to just one disease may affect adherence, self-management and prioritization of therapies.[9–11] Currently, how to combine disease-specific evidence-based recommendations and patient preferences to create feasible, integrated, and appropriately prioritized treatment regimens for older patients with multimorbidity is unknown. Unlike comorbidity scales, an understanding of treatment burden has the advantage of being potentially actionable in a clinical setting. Assessment of treatment burden should directly affect decision-making because treatment burden is inherently part of how patients operationalize their priorities concerning their health care. Assessing and addressing treatment burden in clinical practice may serve to improve patient and caregiver empowerment, help identify situations where patients would benefit from additional assistance, and guide prioritization and decision-making in a patient-centered manner. The relationship between treatment burden and quality of chronic illness care observed here emphasizes the importance of this type of patient-centered care. Future work is needed to determine the best methods to assess and address treatment burden in a busy clinical practice, particularly among populations with heterogeneous patterns of multiple chronic conditions.[236] Such approaches may include screening for treatment burden ahead of time or during the visit, and providing prompts and tools for providers to discuss treatment burden with older patients, and guiding patients, caregivers and providers through strategies to improve activation, secure additional assistance with health care tasks, and inform prioritization of aspects of care plans to best align with patient goals.

Limitations

The measurement of HCTD does not address all potential dimensions of treatment burden.[27] However, this assessment is a worthwhile foundation from which the broader concept of treatment burden in medical decision making might be further explored. Our study sample was selected on the basis of their predicted future use of health services. Although they represent a vulnerable population, only a subset of all eligible people agreed to participate. This may introduce bias if non-participants differ from participants, but we are not able to assess the characteristics of non-participants. Although this study relies on a relatively small sample, study participants are from a diverse population of older adults with multimorbidity with different types of medical coverage. This is an observational study, and therefore we cannot draw conclusions about causality. We are using longitudinal data to examine concurrent relationship of changes in HCTD with changes in HRQoL and quality of chronic illness care. Available measures in this study are robust, though assessment of adherence, health literacy, and each component of treatment regimens and how they change over time would have been ideal to explore additional hypotheses. We do not have data on disease-specific quality standards. Given debate about the optimal measurement of quality of care for older patients with multimorbidity, a strength of this work is the use of a patient assessment of quality of chronic illness care.[37]

Understanding complexity of decision-making and self-management among older adults with multimorbidity, their families, and clinicians is important. Currently, clinicians are without explicit guidance or evidence on how to approach decisions for such patients. Older patients with greater difficulty with prescribed treatment regimens experience lower mental and physical HRQoL, worse quality of chronic illness care, and low levels of activation. Results from this study suggest that identifying HCTD may be feasible using broad-based approaches that are not disease-specific and that may be more widely applicable to older adults with multiple chronic conditions. Patient-centered approaches might help to improve patient activation, minimize interactions and complexity, and unify treatment recommendations coming from all providers and could ultimately affect patient-important outcomes like HRQoL and quality of chronic illness care.

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Table 1

Patient Task Difficulty (n=904)

		Patient – N (%)
Health Task Difficulty Scale Items		
Difficulty obtaining medications	No difficulty	846 (93.6)
	Some difficulty	51 (5.6)
	A lot of difficulty	7 (0.8)
Difficulty planning medication schedule	No difficulty	848 (93.8)
	Some difficulty	48 (5.3)
	A lot of difficulty	8 (0.9)
Difficulty administering medications	No difficulty	846 (93.6)
	Some difficulty	50 (5.5)
	A lot of difficulty	8 (0.9)
Difficulty deciding to change medication	No difficulty	836 (92.5)
	Some difficulty	58 (6.4)
	A lot of difficulty	10 (1.1)
Difficulty managing medical bills	No difficulty	746 (82.5)
	Some difficulty	116 (12.8)
	A lot of difficulty	42 (4.7)
Difficulty scheduling medical appt	No difficulty	816 (90.3)
	Some difficulty	72 (7.9)
	A lot of difficulty	16 (1.8)
Difficulty arranging transportation	No difficulty	788 (87.2)
	Some difficulty	80 (8.9)
	A lot of difficulty	36 (3.9)
Difficulty getting information	No difficulty	742 (82.1)
	Some difficulty	141 (15.6)
	A lot of difficulty	21 (2.3)
Health Task Difficulty Optional Items[1]		
Difficulty following recommended diet	Does not do task	351 (38.8)
	No difficulty	322 (35.6)
	Some difficulty	174 (19.3)
	A lot of difficulty	57 (6.3)
Difficulty obtaining medical equipment	Does not do task	454 (50.2)
	No difficulty	403 (44.6)
	Some difficulty	32 (3.5)

		Patient – N (%)
	A lot of difficulty	15 (1.7)
Difficulty obtaining community services	Does not do task	659 (72.9)
	No difficulty	187 (20.7)
	Some difficulty	30 (3.3)
	A lot of difficulty	28 (3.1)

[1] Items which were considered optional and may not have been applicable to all patients in the study. These items were not included in the HCTD scale.

Table 2

Characteristics by categories of health care task difficulty[1] (n=904)

	None (n=524)	**Low (n=166)**	**Med (n=91)**	**High (n=123)**	**p**
Patient Factors					
Age (mean)	77.3	78.2	78.3	78.1	0.175
Female, n (%)	288 (54.9)	86 (51.8)	52 (57.1)	69 (56.1)	0.073
Caucasian, n (%)	270 (51.6)	79 (47.9)	41 (45.1)	62 (50.4)	0.470
High School education or higher, n (%)	394 (75.2)	126 (75.9)	59 (64.8)	81 (65.9)	0.012
Insurer, n (%)					
FFS Medicare	180 (34.4)	49 (29.5)	34 (37.4)	44 (35.8)	0.514
USFHP	127 (24.2)	34 (20.5)	14 (15.4)	19 (15.5)	0.008
Kaiser	217 (41.4)	83 (50.0)	43 (47.3)	60 (48.8)	--
Not enough money left over at the end of the month, n (%)	49 (9.4)	16 (9.6)	18 (19.8)	28 (22.8)	<0.001
PAM score, mean (n=855)*	58.8	55.2	54.6	49.3	<0.001
Treatment					
Daily No. of Meds, n (%)					
<5	113 (21.6)	29 (17.6)	15 (16.5)	21 (17.1)	0.099
5–10	309 (59.0)	98 (59.4)	54 (59.3)	74 (60.2)	
More than 10	102 (19.5)	38 (23.0)	22 (24.2)	28 (22.8)	
Illness/Conditions					
Median number of self reported diseases (0–14) (range)	4.2 (0–13)	4.3 (0–12)	4.3 (1–8)	4.6 (0–9)	0.006
HTN, n (%)	434 (82.8)	126 (75.9)	72 (79.1)	93 (75.6)	0.046
Angina, n (%)	145 (27.7)	40 (24.1)	29 (31.9)	38 (30.9)	0.408
CHF, n (%)	89 (16.9)	34 (20.5)	13 (14.3)	35 (28.5)	0.022

	None (n=524)	Low (n=166)	Med (n=91)	High (n=123)	p
MI, n (%)	116 (22.1)	38 (22.9)	22 (24.2)	34 (27.6)	0.206
Other heart, n (%)	207 (39.5)	68 (40.9)	34 (37.4)	61 (19.6)	0.112
Stroke, n (%)	93 (17.8)	33 (19.9)	25 (27.5)	35 (28.5)	0.002
Asthma, COPD, n (%)	111 (21.2)	36 (21.7)	20 (21.9)	23 (18.7)	0.669
Arthritis, n (%)	355 (67.8)	137 (82.5)	57 (62.6)	85 (69.1)	0.833
Sciatica, n (%)	87 (16.6)	27 (16.3)	19 (20.9)	23 (18.7)	0.406
Diabetes, n (%)	267 (50.9)	69 (41.6)	50 (54.9)	60 (48.8)	0.772
Cancer, n (%)	146 (27.9)	47 (28.3)	25 (27.5)	35 (28.5)	0.928
Osteoporosis, n (%)	94 (17.9)	30 (18.1)	18 (19.8)	26 (21.1)	0.398
Hip Fracture, n (%)	29 (5.5)	17 (10.2)	4 (4.4)	12 (9.8)	0.152
Alzheimers/dementia, n (%)	20 (3.8)	7 (4.2)	3 (3.3)	11 (8.9)	0.048
Conditions adding to complexity					
At least one fall within the last 6 mos, n (%)	147 (28.1)	57 (34.3)	30 (32.9)	52 (42.3)	0.002
Unable to read newsprint, n (%)	35 (6.7)	19 (11.5)	16 (17.6)	16 (13.0)	0.001
Unable to hear most of what people say, n (%)	41 (7.8)	14 (8.4)	12 (13.2)	16 (13.0)	0.033
Frequent difficulty with sleep, n (%)	89 (16.9)	42 (25.3)	21 (23.1)	35 (28.5)	0.002
Outcomes					
SF36 physical (mean)	39.9	37.9*	36.9	33.5	<0.001
SF36 mental (mean)	52.1	49.5*	47.2	40.1	<0.001
PACIC (mean)	2.69	2.52*	2.53	2.43	0.001

	None (n=524)	Low (n=166)	Med (n=91)	High (n=123)	p
Family/Community Factors: This is an analysis of a subset of participants (n=308), including only those who both had a caregiver and whose caregiver consented to participate.					
Caregiver Relationship					
Spouse/partner	68 (48.6)	29 (50.9)	16 (40.0)	29 (40.9)	
Son/Son in law	13 (9.3)	6 (10.5)	7 (17.5)	13 (18.3)	0.035
Daughter/Dtr in law	47 (33.6)	13 (22.8)	14 (35.0)	24 (33.8)	0.484
Other *(n=308)*	12 (8.6)	9 (15.8)	3 (7.5)	5 (7.0)	0.974
Lives in the same house, n (%) *(n=308)*	99 (70.7)	42 (73.7)	26 (65.0)	53 (74.7)	0.756
Provides greater than 14 hrs of care, n (%)*(n=288)*	59 (45.47)	25 (46.3)	20 (51.3)	43 (65.2)	0.013

[1] Health Care Task Difficulty Score Questions

Considering any help that you may have, how much difficulty do you have….

1. Managing medical bills?
2. Scheduling medical appointments?
3. Arranging transportation to health care appointments?
4. Getting information from and talking with doctors, nurses and other health care workers?
5. Obtaining medications?
6. Planning your medication schedule?
7. Taking your medications?
8. Making decisions to skip, increase or decrease a dose or discontinue medication?

(0=no difficulty; 1= some difficulty; 2= a lot of difficulty)

Summary score: 0–16

[b] Each patient (or proxy) who reported receiving assistance with activities of daily living, instrumental activities of daily living, or health care tasks was asked to identify the person (family or unpaid friend) who assisted them the most. Patients identified 353 eligible caregivers; 86% consented to participate.

Abbreviations: FFS (Fee for Service), USFHP (United States Family Health Plan), PAM (Patient Activation Measure), HTN (hypertension), MI (myocardial infarction), CHF (congestive heart failure), COPD (chronic obstructive pulmonary disease), PACIC (Patient Assessment of Chronic Illness Care)

[*] Patient activation items not asked of proxies.

Table 3

Multiple linear regression of baseline associations of health care task difficulty score with HRQoL and patient-reported quality of chronic illness care: mean decline in physical and mental HRQoL and quality of care when comparing low, medium, and high health care task difficulty to reference category (i.e., none)

	Low		**Medium**		**High**	
		p value		**p value**		**p value**
Mental Health (SF36)	−2.69	0.010	−4.75	0.001	−11.86	<0.001
Physical Health (SF36)	−2.02	0.028	−2.73	0.040	−6.22	<0.001
Quality of Care (PACIC)	−0.16	0.015	−0.15	0.061	−0.24	<0.001

[*] Adjusted for age, sex, education and race

Table 4

Cross sectional and longitudinal association between patient activation and health care task difficulty (outcome) (n=351): results from the random effect negative binomial model with random intercept and random time slope

	Unadjusted Ratio (95% CI)	**p value**	**Adjusted Ratio[*] (95% CI)**	**p value**
PAM Score				
PAM Baseline Score in Standard Deviation Units (SD=12.8)	0.63 (0.54, 0.75)	<0.01	0.65 (0.55, 0.77)	<0.01
PAM Change Score in Standard Deviation Units (SD=14.6)	0.88 (0.76, 1.01)	0.07	0.88 (0.76, 1.01)	0.08

[*] Adjusted for age, sex, education, race and time

The results of the analyses shown here examine association of PAM with change in HCTD over time in standard deviation units. In the first set of models (unadjusted and adjusted PAM Baseline Score) the PAM unit is the SD of the baseline PAM score. In the second set of models (unadjusted and adjusted PAM Change Score) the PAM unit is the SD of the change over time in PAM. The average change in PAM across the sample was 0.97 (range −56.60 to 50.10; interquartile range 15.80).

N=351 (The PAM was not asked of 19 patients in the longitudinal sample who had proxy respondents).

Table 5

Cross sectional and longitudinal association between health care task difficulty and physical and mental HRQoL and quality of care(outcome) (n=370): results from model with random intercept and random time slope

	Unadjusted Coefficient (95% CI)	**p value**	**Adjusted Coefficient [*] (95% CI)**	**p value**
SF36 Mental Health				
Difficulty Baseline Score	−2.59 (−3.15, −2.04)	<.001	−2.42 (−2.97, −1.87)	<.001
Difficulty Change Score	−1.31 (−1.76, −0.87)	<.001	−1.32 (−1.76, −0.87)	<.001
SF36 Physical Health				
Difficulty Baseline Score	−1.26 (−1.80, −0.71)	<.001	−1.09 (−1.63, −0.54)	<.001
Difficulty Change Score	−0.59 (−0.95, −0.23)	.001	−0.59 (−0.95, −0.23)	.001
PACIC				
Difficulty Baseline Score	−0.04 (−0.07, −0.005)	0.022	−0.04 (−0.07, −0.007)	0.017
Difficulty Change Score	−0.05 (−0.09, −0.005)	0.026	−0.044 (−0.08, −0.004)	0.030

[*] Adjusted for age, sex, race, education, and time

Analyses are based on sample which was randomly assigned to usual care. The average change in SF-36 mental health (Mental Component Score) across the sample was 1.21 (range −46.11 to 43.86; interquartile range 12.09). The average change in SF-36 physical health (Physical Component Score) across the sample was −0.30 (range −35.63 to 34.25; interquartile range 10.15). The average change in PACIC across the sample was 0.20 (range −2.60 to 2.45; interquartile range 1.00).