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Measurement Properties of the CAPACITY Instrument to Assess Perceived Communication With the Health Care Team Among Care Partners of Patients With Cognitive Impairment

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Abstract

Background: The *CAREgiver Perceptions About Communication* with Clinical Team members (CAPACITY) instrument measures how care partners perceive themselves to be supported by the patient's health care team and their experiences communicating with the team.

Objectives: The objective of this study was to assess the measurement properties (ie, structural validity of the construct and internal consistency) of the CAPACITY instrument in care partners of patients with cognitive impairment, and to examine whether care partner health literacy and patient cognitive impairment are associated with a higher or lower CAPACITY score.

Research Design: This was a retrospective cohort study.

Subjects: A total of 1746 dyads of community-dwelling care partners and older adults in the United States with cognitive impairment who obtained an amyloid positron emission tomography scan.

Measures: The CAPACITY instrument comprises 12 items that can be combined as a total score or examined as subdomain scores about communication with the team and care partner capacity-assessment by the team. The 2 covariates of primary interest in the regression model are health literacy and level of cognitive impairment of the patient (Modified Telephone Interview Cognitive Status).

Results: Confirmatory factor analysis showed the CAPACITY items fit the expected 2-factor structure (communication and capacity). Higher cognitive functioning of patients and higher health literacy among care partners was associated with lower communication domain scores, lower capacity domain scores, and lower overall CAPACITY scores.

Conclusions: The strong psychometric validity of the CAPACITY measure indicates it could have utility in other family caregivers or care partner studies assessing the quality of interactions with clinical teams. Knowing that CAPACITY differs by care partner health literacy and patient impairment level may help health care teams employ tailored strategies to achieve high-quality care partner interactions.

Keywords

care partners; communication; health care team cognitive impairment; health literacy

An estimated 5.8 million Americans have Alzheimer disease and ~15%–20% of people aged 65 years or older have mild cognitive impairment (MCI) from any cause.¹ Care partners, that is, those identified by patients as the person they consider to be the most involved with decisions and support related to their health and health care, play a key role in the information exchange between patients and medical providers on the health care team.^{2–4}

Understanding perceptions about the quality of communication with the health care team from the care partner's perspective is important because care partners commonly help implement treatment plans² and support preferences of persons with cognitive impairment. Perceptions of poor communication could hinder the ability of care partners to contribute their expertise when interacting with the patient's health care team, thus inhibiting optimization of the health care choices and treatment plan. In other settings, poor patient communication has been found to be associated with worse outcomes among patients with dementia.^{5,6} In addition, little is known about shared decision-making and health communication when care partners are involved^{7–11} or the extent to which care partners perceive their interactions with the health care team to be productive or satisfying. A better understanding of care partner perceptions of their interactions with the health care team may

facilitate the development of person-centered and family-centered strategies to engage in shared decision-making with persons with memory problems, their care partners, and health care teams.

In this paper, we seek to understand care partner perceptions of quality in interactions with the health care team. The *Caregiver Perceptions About Communication with Clinical Team members* (CAPACITY) instrument was originally developed using a sample of 929 caregivers of young, primarily male, injured US veterans. It was found to represent 2 distinct domains that measure caregivers' perceptions of how well they are supported by the patient's health care team (capacity domain) and their experiences communicating with the health care team (communication domain).¹² There are concerns specific to care partners of older adults with cognitive impairment that warrant an assessment of measurement properties of the CAPACITY instrument among this particular group: for example, they are older and may have different preferences for team interaction, thus there is a need to confirm the underlying 2-domain factor structure. Thus, the first research question is whether CAPACITY has acceptable measurement properties among care partners of older adults with cognitive impairment.

The second research question is to examine how cognitive impairment of the patient and health literacy of care partners are associated with CAPACITY. A priori we did not have a strong directional hypothesis because there could be countervailing effects; thus, this second research question is exploratory. With greater cognitive impairment patients may not be able to successfully navigate the health care encounter alone. Thus, we expect that care partners will have a more active role in representing patient preferences, relaying symptoms and concerns to the team, and treatment planning. Care partners with low health literacy may perceive communication with the health care team to be of different quality compared with care partners with high health literacy. For example, patients with low health literacy have had lower satisfaction with health care teams and one pathway has been poorer communication with the team,¹³ yet it is unclear how health literacy is associated with care partner perception of the quality of communication.

METHODS

Study Setting and Participants

The participants in this study are from the CARE-IDEAS study, a supplemental survey study to the Imaging Dementia—Evidence for Amyloid Scanning or IDEAS study. Details of the IDEAS Study are reported elsewhere.^{14,15} In short, the IDEAS Study recruited 18,295 Medicare beneficiaries aged 65 years and older with progressive MCI and/or dementia of uncertain cause from 592 dementia practices over 22 months.¹⁶ Referring doctors believed that an amyloid positron emission tomography scan could help to guide their patients' care.

The IDEAS Study transferred the contact information of 3717 IDEAS patients who agreed to be contacted for the CARE-IDEAS supplemental study. Of these, 2228 of patients and 1872 of their care partners (dyads) completed the baseline telephone interview. To be included in this study, the following criteria was met: Patient and care partner completed a survey; care partner reported attending primary care check-ups or specialty care visits "1 =

Rarely,” “2 = Sometimes,” “3 = Most of the time,” or “4 = Always”; and care partner had < 2 individual missing values on the CAPACITY measure (n = 1746).

Measures

Dependent Variables—Care partners answered 12 Likert scale items from the CAPACITY instrument.¹² The overall CAPACITY score is calculated as the mean of all 12 items (range: 1–4), where a higher score indicates perceptions of better quality communication and capacity-assessment from the care team. Scores for the subscales capturing the “communication” and “capacity/preferences” domains were also calculated as the mean of each respective set of 6 domain-specific items.

Independent Variables—Cognitive status was assessed using an abbreviated version of the Telephone Interview Cognitive Status (TICS-M) administered to patients, one of the most frequently used telephone cognitive screening instruments to detect cognitive change and dementia.^{17,18} The possible scores range from 0 to 41, and the instrument includes items of immediate and delayed 10-noun free recall; serial 7 subtraction; counting backwards; recall of the date, naming the president and the vice-president; and naming 2 common items. A higher score for the TICS-M indicates better cognitive functioning. For regression analyses, we divided the score by 5 so as to model the average effect of a 5-U increment in TICS-M total score. We also report on the patient’s level of cognitive impairment using a diagnosis of MCI versus dementia reported by the IDEAS physician; this diagnosis variable was not used in the regression models due to collinearity with the TICS-M. We also administered the TICS-M to care partners, which has been a shortcoming of some prior studies focusing on care partner or caregiver-patient dyads.

Health literacy of the care partners was measured with a 5-point Likert scale response to the following question: “How often do you have someone (like a family member, friend, hospital or clinic worker, or caregiver) help you read medical forms or hospital materials?”¹⁹ Responses included “1 = Always,” “2 = Often,” “3 = Sometimes,” “4 = Occasionally,” or “5 = Never.” A higher value on this measure indicates higher health literacy.

Sociodemographic characteristics were obtained for both members of the patient/care partner dyad; however, due to high correlation within dyads, we included only care partners’ age (grouped for analysis as < 75, 75–84, or ≥ 85), sex, and race (grouped as “White” or “Other races”) in the analysis. We included educational attainment for each dyad member (grouped as “High school graduate or less,” “Some college,” “Bachelor’s degree,” or “Graduate degree”). The relationship of the patient to the care partner was characterized as either “Spouse or significant other” or “Parent/other.” Each respondent was also asked to self-assess their general health status on a 5-point Likert scale, with response options of “1 = Excellent,” “2 = Very good,” “3 = Good,” “4 = Fair,” or “5 = Poor.”²⁰

Care partner employment was measured by categorizing work for pay across all jobs into “Part-time (> 0–< 40 h/wk),” “Full-time (≥ 40 h/wk),” or “Not working for pay, don’t know, or refused.” Objective caregiving burden was measured as the number of hours the care partner provided care to the patient weekly, with response options including “5 hours or fewer a week,” “6–19 hours a week,” “20–39 hours a week,” “40 or more hours a week” or

“Not providing care.” Subjective caregiver burden was defined using the 12-item Zarit burden measure, described as the level of stress felt by a caregiver.^{21–23} Responses to each item range from 0 to 4, with 0 = “Never” and 4 = “Nearly always.” The Zarit scale total score is calculated as the sum of the 12 responses and can range from 0 to 48. A score > 16 suggests a clinically significant caregiver burden.^{21,24}

Care partner depressive symptoms were captured by selecting the PHQ-2 items from the Patient Health Questionnaire 8 (PHQ-8). The PHQ-2 is a screening instrument for further assessment for clinical depression.²⁵ Care partners responded how often during the past 2 weeks that they have been bothered by either of these problems: “Little interest or pleasure in doing things” and “Feeling down, depressed, or hopeless.” Responses range from 0 indicating “Not at all” to 3 indicating “Nearly every day.” The sum of the 2 response values was calculated and a sum of ≥ 3 was considered positive for this screening instrument for depression.²⁵

Statistical Analysis

We first described the total and domain-specific scores on the CAPACITY scale by reporting univariate statistics and plotting histograms. We then classified the population into tertiles of the total CAPACITY score and described the characteristics of the patients and care partners, overall and by CAPACITY tertile, using proportions for categorical variables and means with SDs for continuous variables. We tested for differences between tertile groups using Pearson χ^2 tests for categorical variables and Kruskal-Wallis tests for continuous variables.

We first assess the structural validity of the CAPACITY instrument in our sample, which the Consensus-based Standards for the selection of health status Measurement INstruments (COSMIN)²⁶ defines as one aspect of construct validity concerning specifically the adequate reflection of the dimensionality of a construct. We, therefore, estimated confirmatory factor analysis (CFA) to determine whether the scale yields the expected construct dimensionality and then checked reliability using tests for internal consistency, that is, the degree of interrelatedness among the items. We performed weighted least square CFA for ordinal items, testing both a 1-dimensional solution and the 2-factor structure for separate communication and capacity domains that was obtained in previous validation efforts among veterans.¹² We examined standardized factor loadings for each domain, whereby a value closer to one represents evidence that the majority of the variance in individual items is captured by the latent factor. High standardized factor loadings (above 0.50) constitute important evidence of a valid unobserved latent factor that drives shared variance in observed items.²⁷ The adequacy of a 2-factor model was examined using the following model fit statistics: χ^2 , root mean square error of approximation (RMSEA), the Comparative Fit Index (CFI), and Tucker Lewis Index (TLI). A lower and nonsignificant χ^2 indicates better fit, although this statistic is sensitive to sample size and considered too stringent among large samples. A lower value on the RMSEA indicates a better fit (< 0.05), while larger values (> 0.95) for CFI and TLI indicate a good model fit.²⁷ MPLUS was used for all CFA. As part of sensitivity analyses, we explored whether any modification indices proposed by the software might suggest conceptual improvements in this population, and checked the factor structure among different sub-groups for meaningful differences, namely

among care partners who reported always attending appointments with patients and across education levels. Internal consistency was examined using the omega for standardized factor loadings of the 1-factor solution, and for the separate subscales. Omega is interpreted the same way as Cronbach α , with values above 0.90 considered excellent, but has fewer limitations in the context of scales that are composed of ordinal items.²⁸

We fit 3 separate multiple regression models with normal distributions and log links (ie, log-normal models) to estimate the associations between the primary variables of interest, patient cognitive impairment and care partner health literacy, and either: (1) the communication domain; (2) the capacity domain; or (3) the total CAPACITY score. Categorical control variables, such as age group and relationship to the patient, were transformed into binary or multilevel indicator variables. Multicollinearity was assessed using the SAS VARCLUS procedure; the variables included in the final analysis and described here were not considered collinear. Parameter estimates for the associations between each variable and the CAPACITY total or domain score are presented as ratio measures and interpreted as the percent change per unit increment of the independent variable.

In addition to the 3 main regressions, we performed 2 sensitivity analyses. We reran these models among the 1557 care partners who reported attending the patient's medical visits "Most of the time" or "Always," because we hypothesized that the associations may be even stronger with CAPACITY. We also reran the models including the care partner's cognitive status, to ensure that covariates of interest were robust to the inclusion of this covariate.

RESULTS

The care partners in the 1746 dyads that met the study eligibility criteria were predominantly the spouses and significant others of the patient, though about 10% of them had other types of relationships, such as parent-child (Table 1). Most care partners were female (68%), White (96%), retired or not working (76%), and younger than 75 years (66%, mean age = 70.3 y). Educational attainment was high, with the majority of both patients and care partners having Bachelor's or Graduate degrees. While the majority of patients had MCI, 482 (27.6%) were classified as having dementia. Nearly half of care partners reported spending between 1 and 19 hours per week caring for the patient (44%), and another 10% of care partners reported spending over 20 hours per week providing such care. Care partner cognitive status, as indicated by the TICS-M, was in the normal range with an average of 27.9 (Table 1).

The results of the CFA revealed good standardized factor loadings in both the 1-factor and 2-factor solutions, with values above 0.50 throughout, and many above 0.75 (Table 2). The 2-factor model, with separate communication and capacity subscales, yielded better model fit statistics than the 1-factor solution, with an acceptable RMSEA of 0.09 and CFI and TLI values above 0.95, consistent with previous validation study findings.² The 2 factors had a correlation of 0.72. None of the potential modifications that were explored, such as dropping items or switching which scale they load on, improved the model fit. Sensitivity analyses among different groups based on the level of education or reporting always attending

patients' health care visits did not modify the findings substantively. The subscales also yielded omega values indicative of excellent internal consistency, with 0.90 for the communication domain, and 0.94 for the capacity domain. The omega value for the full 1-dimensional scale was also excellent at 0.95. Altogether, these results support previous findings indicating the 2-dimensional structure of the CAPACITY scale and confirm its structural validity (or dimensionality) and reliability in a population of care partners to older adults with cognitive impairment.

Overall CAPACITY scores had a mean of 2.35 (SD = 0.65) and median of 2.25 [quartile (Q) 1–Q3: 1.92–2.75] and had a slightly right-skewed but nearly symmetric distribution (Fig. 1). The component domains, however, were skewed in opposite directions; care partners tended to rate communication with the patient's health care team favorably but report that those same providers rarely assessed whether the care partner felt that they had the ability, desire, skills, and resources to provide care and manage the patient's health condition. Specifically, the communication domain scores were left-skewed, with a mean of 3.08 (SD = 0.68) and median of 3.17 (Q1–Q3: 2.67–3.67), while the capacity domain scores were right-skewed, with mean of 1.62 (SD = 0.79) and median of 1.33 (Q1–Q3: 1.00–2.00). On the basis of the factor analysis results supporting a 2-factor solution and the relatively high correlation between the factors, we present 3 regression models: the communication subscale, the capacity subscale, and an overall scale of CAPACITY. We present the overall scale to show the consistency of results between the subscales and the overall instrument.

The cognitive status of patients was measurably impaired, as indicated by a mean score of 20.4 (SD = 6.2) out of a possible total score of 41 on the TICS-M (Table 1). Adjusting for all other factors, a 5-point increase in the TICS-M score (ie, better patient cognition) was associated with a decrease of 2.3% [95% confidence interval (CI): 1.5%, 3.1%] on the communication domain score and a decrease of 4.5% (95% CI: 2.7%, 6.2%) on the capacity domain score (Table 3). In other words, care partners in dyads with more cognitively-intact patients tended to rate the patient's health care providers as being less likely to communicate effectively with the care partners and less likely to assess the care partners' capacity to care for the patient (Table 3).

Health literacy among care partners in this study was very high, with a mean of 4.5 (SD = 0.9) out of 5, meaning that, on average, they never or only occasionally needed help reading medical forms or hospital materials (Table 1). After adjustment, a 1-point increase in health literacy was associated with a 3.2% (95% CI: 0.9%, 5.5%) decrease in the capacity domain score, but was not significantly associated with the communication domain, and a 1.7% (95% CI: 0.3%, 3.1%) decrease in the overall CAPACITY score¹³ (Table 3). In plain language, care partners with higher health literacy tended to rate their interactions with patient's medical providers slightly less favorably overall and were slightly less likely to feel that the providers adequately assessed the care partner's capacity to care for the patient's condition.

Several other factors were identified as post hoc as being associated with CAPACITY after adjustment. Older care partners (> 75–84 or 85 vs. 75) rated the team less favorably overall and on each domain (Table 3). While there was no association between sex and

overall CAPACITY score, male care partners rated communication with the team 4% (95% CI: 1%, 6%) lower than females but rated the capacity-assessment of the providers 9% (95% CI: 4%, 14%) higher than females. Reporting a few hours of active caregiving (< 5 h a wk) was associated with lower CAPACITY overall and lower subscales. The overall and communication-specific CAPACITY scores of care partners who screened positive for depression on the PHQ-2 were 7% lower than those who were not depressed; however, depression was not statistically significantly associated with the capacity domain scores. A 5-point increment in subjective burden was associated with a 1% (95% CI: 0%, 2%) decrease in both the overall CAPACITY and communication domain scores.

Results did not change in the 2 sensitivity analyses (detailed results available upon request).

DISCUSSION

The CAPACITY instrument measures how well care partners perceive themselves to be integrated into the patient's health care team. Specifically, it assesses how well the health care team is perceived to communicate with care partners and the extent to which care partners feel the team asks them about their capacity and preferences for involvement in the patient's care. This study marks the first time the CAPACITY score has been tested in a sample of care partners of older adults with memory problems. CFA showed the CAPACITY items fit the expected 2-factor structure in our sample (communication and capacity). Furthermore, the 2-factor model, with separate communication and capacity subscales, yielded better model fit statistics than the 1-factor solution. We presented regression models for both subscales and the overall measure because we were interested in understanding consistency of the relationship between capacity domains and the independent variables of interest. We found some differences in the strength of the association between covariates of interest (eg, health literacy) and the individual CAPACITY domains versus the overall score, such that interpretation was aided by examining an individual domain. Given the results of the measurement properties of the instrument, other research teams should consider 2 separate domains of the CAPACITY score in their own study designs, either as separate dependent variables or using structural equation modeling for a multidimensional latent construct.

We also found that higher cognitive functioning of patients was associated with lower communication domain scores, lower capacity domain scores, and lower overall CAPACITY scores.

The negative association between higher cognition and communication merits comment. For patients with MCI, communication between the care team and the care partner may not be as essential as for more severe cognitive impairment; the patient likely can communicate directly with the team to state preferences, report concerns, and ask questions. Thus, the findings may not indicate the need for intervention. However, the communication items on the CAPACITY score may be viewed as important to care partners for future planning, so the perception that these items are neglected may represent a missed opportunity for the health care team to establish a high-quality relationship with the care partner. This would also allow teams to engage partners earlier in the disease course so that their decision-

making is as consistent as possible with patient preferences.¹⁶ The inverse relationship between care partner's perception of communication and patient's cognitive function could also be due to patients with MCI receiving a less definitive diagnosis and prognosis from providers; this uncertainty could have been unsatisfying and reduced care partner perceived quality of interaction with the health care team. In addition, that care partners' perceptions about interactions may track with worse quality of care more broadly is a concern given that people with cognitive impairment have been found to receive a lower quality of care.²⁹⁻³² Importantly, in our sample care partners had normal cognitive status, indicated by the mean TICS-M score. Yet future studies should collect care partner cognitive status and may want to include it in their multivariable models to understand whether perceived communication with health care teams differs by the care partner's own cognitive status (we thank a peer reviewer for making this important point). Several covariates were not significantly associated with perceived communication, such as the relationship between patients and care partners and work status. This could be due to a lack of variation in the covariate or other reasons and could be tested in other contexts.

We found that higher health literacy was associated with a lower capacity domain score on average, but had little relationship with quality of communication. Those with higher health literacy may also have higher expectations of the team,⁶ so this finding could be a proxy for some other quality expectation marker. Qualitative methods would be needed to fully interpret the reasons for our findings.

Our study has notable limitations, such as that it relies on cross-sectional survey data with respondents who have high access to care, as signified by them all receiving an amyloid positron emission tomography scan. Study participants were also predominantly White and more highly educated than the general US population of older adults, and care partners were predominantly spouses. In addition, we did not capture the provider's perspective.

The finding that the CAPACITY measure is structurally valid and reliable in care partners of older adults with cognitive impairment means that it could provide an assessment of person-centered care for a broader range of care partners, including adult children or friend caregivers, or including patients with more severe memory problems, such as Alzheimer disease.³³ In addition, CAPACITY affords the ability to shed light on the family experience of care for important populations of health care users, some of whom cannot report on their own. With so few measures quantifying the extent to which family members and friends feel integrated into the health care team, CAPACITY could be used more widely as a performance measure to assess the quality of health care teams.³⁴ Assessing CAPACITY more broadly would fill a major gap in obtaining quantitative data on the experience of care from the perspective of the family or friend caregiver or care partner. Importantly, evaluating the CAPACITY measure over time could help teams monitor and evaluate systematic efforts to improve communication. A modest first step, given the relatively lower capacity domain scores compared with the communication domain scores, would be to increase interactions with care partners about their ability, desire, skills, and resources to provide care and manage the patient's health condition. Addressing these unmet needs may then spill over to improve the communication domain. Substantially improving the perceived quality of communication and perceived support of care partners could, in turn, enable care partners to

facilitate shared decision-making and person-centered care if the care partner is able to represent the preferences and wishes of the person with memory problems.³⁵

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REFERENCES

1. Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures; 2019 Available at: www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf Accessed February 20, 2019.
2. DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol.* 2004;23:207–218. [PubMed: 15008666]
3. Laisaar-Powell RC, Butow PN, Bu S, et al. Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns.* 2013;91:3–13. [PubMed: 23332193]
4. Wolff JL, Roter DL. Family presence in routine medical visits: a meta-analytical review. *Soc Sci Med.* 2011;72:823–831. [PubMed: 21353358]
5. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract.* 2000;49:796–804. [PubMed: 11032203]
6. Stewart MA. Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J.* 1995;152:1423–1433. [PubMed: 7728691]
7. Barr PJ, Thompson R, Walsh T, et al. The psychometric properties of CollaboRATE: a fast and frugal patient-reported measure of the shared decision-making process. *J Med Internet Res.* 2014;16:e2. [PubMed: 24389354]
8. Garvelink MM, Ngangue PA, Adekpedjou R, et al. A synthesis of knowledge about caregiver decision making finds gaps in support for those who care for aging loved ones. *Health Aff (Millwood).* 2016;35: 619–626. [PubMed: 27044961]
9. Giguere AMC, Lawani MA, Fortier-Brochu E, et al. Tailoring and evaluating an intervention to improve shared decision-making among seniors with dementia, their caregivers, and healthcare providers: study protocol for a randomized controlled trial. *Trials.* 2018;19:332. [PubMed: 29941020]
10. Groen-van de Ven L, Smits C, Span M, et al. The challenges of shared decision making in dementia care networks. *Int Psychogeriatr.* 2016;30: 843–857. [PubMed: 27609338]
11. van de Pol MHJ, Fluit CRMG, Lagro J, et al. Shared decision making with frail older patients: proposed teaching framework and practice recommendations. *Gerontol Geriatr Educ.* 2017;38:482–495. [PubMed: 28027017]

12. Van Houtven C, Miller K, O'Brien E, et al. Development and initial validation of the Caregiver Perceptions About Communication With Clinical Team Members (CAPACITY). *Med Care Res Rev.* 2017;76: 1–23.
13. Levy H, Janke A. Health literacy and access to care. *J Health Commun.* 2016;21(suppl 1):43–50. [PubMed: 27043757]
14. Rabinovici GD, Gatsonis C, Apgar C, et al. Association of amyloid positron emission tomography with subsequent change in clinical management among Medicare beneficiaries with mild cognitive impairment or dementia. *JAMA.* 2019;321:1286–1294. [PubMed: 30938796]
15. IDEAS-Study Group. IDEAS: Imaging Dementia—Evidence for Amyloid Scanning; 2018 Available at: www.ideas-study.org/ Accessed February 12, 2019.
16. Jutkowitz E, Van Houtven CH, Plassman BL. Willingness to undergo a risky treatment to improve cognition among persons with cognitive impairment who received an amyloid PET scan. *Alzheimer Dis Assoc Disord.* 2020;34:1–9. [PubMed: 31414990]
17. Gallo JJ, Breitner JC. Alzheimer's disease in the NAS-NRC Registry of aging twin veterans, IV. Performance characteristics of a two-stage telephone screening procedure for Alzheimer's dementia. *Psychol Med.* 1995;25:1211–1219. [PubMed: 8637951]
18. Welsh KA, Breitner JCS, Magruder-Habib KM. Detection of dementia in the elderly using telephone screening of cognitive status. *Neuropsychiatry Neuropsychol Behav Neurol.* 1993;6:103–110.
19. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med.* 2004;36:588–594. [PubMed: 15343421]
20. Hays RD, Bjorner JB, Revicki DA, et al. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Qual Life Res.* 2009;18:873–880. [PubMed: 19543809]
21. Bedard M, Molloy DW, Squire L, et al. The Zarit Burden Interview: a new short version and screening version. *Gerontologist.* 2001;41: 652–657. [PubMed: 11574710]
22. Zarit SH, Orr NK, Zarit JM. *The Hidden Victims of Alzheimer's Disease: Families Under Stress.* New York, NY: New York University Press; 1985.
23. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist.* 1980;20:649–655. [PubMed: 7203086]
24. O'Rourke N, Tuokko HA. Psychometric properties of an abridged version of The Zarit Burden Interview within a representative Canadian caregiver sample. *Gerontologist.* 2003;43:121–127. [PubMed: 12604753]
25. Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: validity of a two-item depression screener. *Med Care.* 2003;41: 1284–1292. [PubMed: 14583691]
26. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Qual Life Res.* 2010;19:539–549. [PubMed: 20169472]
27. Kline RB. *Principles and Practice of Structural Equation Modeling.* New York, NY: Guilford Press; 2010.
28. Dunn TJ, Baguley T, Brunsden V. From alpha to omega: a practical solution to the pervasive problem of internal consistency estimation. *Br J Psychol.* 2014;105:399–412. [PubMed: 24844115]
29. Hsiao FY, Peng LN, Wen YW, et al. Care needs and clinical outcomes of older people with dementia: a population-based propensity score-matched cohort study. *PLoS One.* 2015;10:e0124973. [PubMed: 25955163]
30. Mecocci P, von Strauss E, Cherubini A, et al. Cognitive impairment is the major risk factor for development of geriatric syndromes during hospitalization: results from the GIFA study. *Dement Geriatr Cogn Disord.* 2005;20:262–269. [PubMed: 16103670]
31. Mukadam N, Sampson EL. A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *Int Psychogeriatr.* 2011;23:344–355. [PubMed: 20716393]
32. Naef R, Ernst J, Burgi C, et al. Quality of acute care for persons with cognitive impairment and their families: a scoping review. *Int J Nurs Stud.* 2018;85:80–89. [PubMed: 29859348]

33. Lynn Snow A, Cook KF, Lin PS, et al. Proxies and other external raters: methodological considerations. *Health Serv Res.* 2005;40:1676–1693. [PubMed: 16179002]
34. Van Houtven CH, Hastings SN, Colon-Emeric C. A path to high-quality team-based care for people with serious illness. *Health Aff (Millwood).* 2019;38:934–940. [PubMed: 31158020]
35. Mejia AM, Smith GE, Wicklund M, et al. Shared decision making in mild cognitive impairment. *Neurol Clin Pract.* 2019;9:160–164. [PubMed: 31041132]

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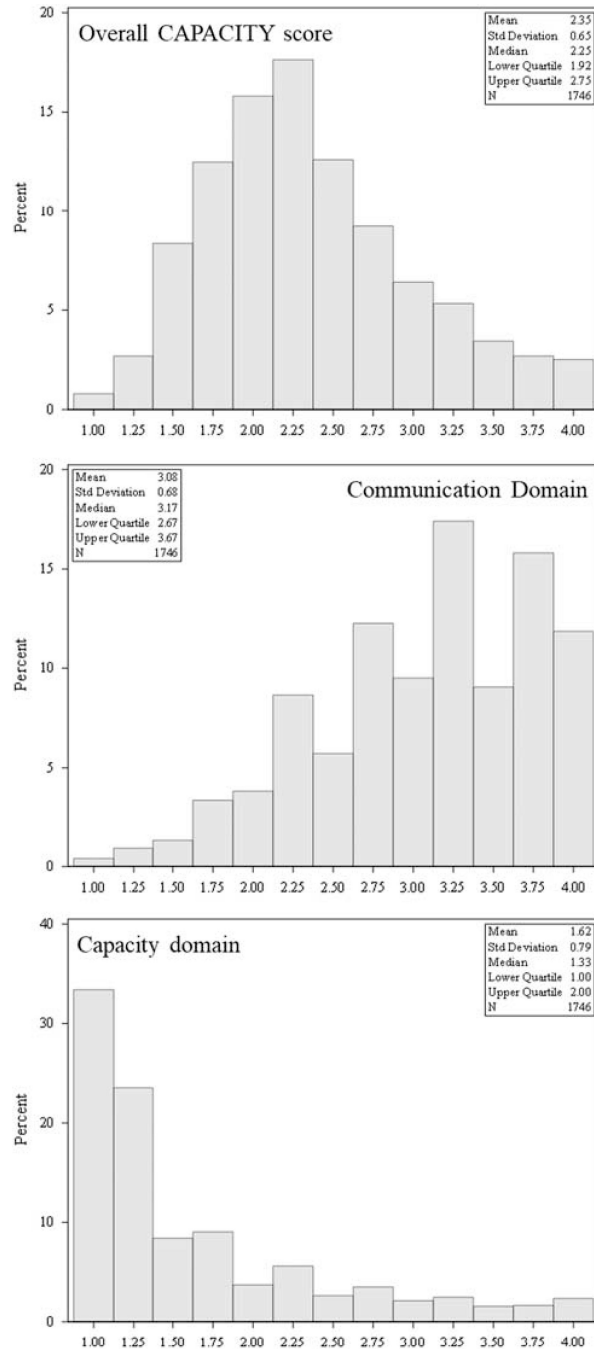


FIGURE 1. Histograms for the distributions in the CAPACITY scale overall and domain scores, with univariate statistics. CAPACITY indicates *C*Aregiver *P*erceptions About *C*ommun*C*a*T*ion with Clinical Team members.

TABLE 1. Characteristics of the Study Sample Overall and by Tertiles of the Overall CAPACITY Scale Score

Variables	n (%)				P*
	Overall	Tertile 1 (lowest)	Tertile 2	Tertile 3 (highest)	
N	1746	604	563	579	
CAPACITY scale					
Total score [mean (SD)]	2.4 (0.6)	1.7 (0.2)	2.3 (0.1)	3.1 (0.4)	NA
Median (Q1, Q3)	2.3 (1.9, 2.8)	1.8 (1.6, 1.9)	2.3 (2.2, 2.4)	3.0 (2.8, 3.4)	
Communication domain [mean (SD)]					
Median (Q1, Q3)	3.1 (0.7)	2.3 (0.5)	3.2 (0.3)	3.7 (0.3)	NA
Capacity domain [mean (SD)]					
Median (Q1, Q3)	3.2 (2.7, 3.7)	2.3 (2.0, 2.7)	3.2 (3.0, 3.5)	3.7 (3.5, 4.0)	NA
Capacity domain [mean (SD)]					
Median (Q1, Q3)	1.6 (0.8)	1.1 (0.1)	1.3 (0.3)	2.5 (0.8)	NA
Patient characteristics					
Median (Q1, Q3)					
Cognitive status (TICS-M) [mean (SD)]	1.3 (1.0, 2.0)	1.0 (1.0, 1.2)	1.2 (1.0, 1.5)	2.3 (1.8, 3.0)	
Impairment level					
Cognitive status (TICS-M) [mean (SD)]	20.4 (6.2)	21.4 (6.2)	20.8 (5.7)	18.9 (6.5)	< 0.001
Impairment level					
Mild cognitive impairment	1264 (72.4)	469 (77.6)	423 (75.1)	372 (64.2)	< 0.001
Dementia	482 (27.6)	135 (22.4)	140 (24.9)	207 (35.8)	
General health status (self-assessed) [mean (SD)]					
General health status (self-assessed) [mean (SD)]	2.5 (1.0)	2.5 (1.0)	2.6 (1.0)	2.5 (1.0)	0.66
Education					
High school graduate or less	278 (15.9)	79 (13.1)	82 (14.6)	117 (20.2)	0.03
Some college	439 (25.1)	156 (25.8)	139 (24.7)	144 (24.9)	
Bachelor's degree	409 (23.4)	139 (23.0)	138 (24.5)	132 (22.8)	
Graduate degree	620 (35.5)	230 (38.1)	204 (36.2)	186 (32.1)	
Care partner characteristics					
Health literacy [mean (SD)]					
Health literacy [mean (SD)]	4.5 (0.9)	4.6 (0.9)	4.6 (0.9)	4.5 (0.9)	0.19
Age group					
< 75	1152 (66.0)	375 (62.1)	380 (67.5)	397 (68.6)	0.07
75–84	539 (30.9)	203 (33.6)	167 (29.7)	169 (29.2)	
85+	55 (3.2)	26 (4.3)	16 (2.8)	13 (2.2)	
Age [mean (SD)]					
Age [mean (SD)]	70.3 (9.6)	71.0 (9.9)	70.2 (9.0)	69.5 (9.7)	0.01
Male					
Male	565 (32.4)	213 (35.3)	154 (27.4)	198 (34.2)	0.008

Variables	n (%)				P*
	Overall	Tertile 1 (lowest)	Tertile 2	Tertile 3 (highest)	
Race, White	1673 (95.8)	582 (96.4)	543 (96.4)	548 (94.6)	0.23
Education					0.41
High school graduate or less	246 (14.1)	93 (15.4)	72 (12.8)	81 (14.0)	
Some college	502 (28.8)	171 (28.3)	150 (26.6)	181 (31.3)	
Bachelor's degree	478 (27.4)	169 (28.0)	159 (28.2)	150 (25.9)	
Graduate degree	520 (29.8)	171 (28.3)	182 (32.3)	167 (28.8)	
Patient is spouse/significant other	1556 (89.1)	545 (90.2)	510 (90.6)	501 (86.5)	0.049
Employment, hours per wk					0.88
Part-time	260 (14.9)	87 (14.4)	89 (15.8)	84 (14.5)	
Full-time	156 (8.9)	50 (8.3)	51 (9.1)	55 (9.5)	
Not working or don't know/refused	1330 (76.2)	467 (77.3)	423 (75.1)	440 (76.0)	
Time providing care for the patient					<0.001
05 h or fewer a wk	521 (29.8)	214 (35.4)	170 (30.2)	137 (23.7)	
06–19 h a wk	241 (13.8)	64 (10.6)	81 (14.4)	96 (16.6)	
20–39 h a wk	98 (5.6)	25 (4.1)	33 (5.9)	40 (6.9)	
40 or more hours a wk	82 (4.7)	13 (2.2)	32 (5.7)	37 (6.4)	
Not providing care or don't know/refused	804 (46.0)	288 (47.7)	247 (43.9)	269 (46.5)	
General health status (self-assessed) [mean (SD)]	2.4 (0.9)	2.5 (1.0)	2.3 (0.9)	2.4 (0.9)	0.08
Depression (PHQ-2)	127 (7.3)	56 (9.3)	41 (7.3)	30 (5.2)	0.03
Subjective burden (Zarit) [mean (SD)]	10.8 (7.9)	10.6 (7.8)	11.0 (7.8)	10.8 (8.0)	0.55
Cognitive status (TICS-M) [mean (SD)]	27.9 (5.0)	27.8 (4.6)	28.0 (5.4)	27.9 (5.0)	0.25
Accompanies patient to PCP or specialist appointments most of the time or always	1557 (89.2)	483 (80.0)	515 (91.5)	559 (96.5)	<0.001

* Generated from Pearson χ^2 tests for categorical variables and from Kruskal-Wallis tests for continuous variables.

CAPACITY indicates Caregiver Perceptions About Communication with Clinical Team members; NA, not available; PCP, primary care provider; PHQ-2, Patient Health Questionnaire 2; Q, quartile; TICS-M, Modified Telephone Interview Cognitive Status.

TABLE 2.

Standardized Factor Loadings and Model Fit Statistics

Individual Items of CAPACITY Measure	One-factor Solution	Two-factor Solution
Communication domain		
Explain in way that is easy to understand	0.53	0.58
Understand the things that really matter to you	0.61	0.67
Ask your ideas about patient health	0.81	0.86
Give easy-to-understand instructions	0.73	0.78
Be responsive to your concerns about treatment plan	0.76	0.80
Ask for your ideas when developing/ adjusting treatment plan	0.82	0.88
Capacity domain		
Ask how much help you could give	0.84	0.89
Ask how much help you wanted to provide	0.83	0.87
Ask whether you have the skills or training you need to help	0.90	0.91
Assess you to see what care you could successfully provide	0.84	0.87
Ask if you needed help at home in managing patient condition	0.83	0.86
Talk to you about community resources	0.64	0.69
Model fit indices		
χ^2	1890.510	729.218
<i>df</i>	54	53
Root mean square error of approximation	0.140	0.085
Confirmatory Fit Index	0.928	0.973
Tucker Lewis Index	0.912	0.967

The χ^2 statistic and all factor loadings are significant at the *P* 0.001 level.

TABLE 3. Adjusted Estimates for the Associations Between the Study Variables and the CAPACITY Total Score, Communication Domain Score, and Capacity Domain Score

Description of Included Variables	Communication Domain		Capacity Domain		Overall	
	Ratio (95% CI)	P*	Ratio (95% CI)	P*	Ratio (95% CI)	P*
Primary variables of interest						
Cognitive impairment (TICS-M), per 5-point increase (patient)	0.98 (0.97, 1.00)	< 0.001	0.95 (0.94, 0.97)	< 0.001	0.97 (0.96, 0.98)	< 0.001
Health literacy (care partner)	0.99 (0.98, 1.00)	0.19	0.97 (0.94, 0.99)	0.008	0.98 (0.97, 1.00)	0.02
Patient characteristics						
General health status	1.00 (0.99, 1.01)	0.77	0.98 (0.95, 1.00)	0.05	0.99 (0.98, 1.00)	0.19
Education		0.10		0.11		0.049
High school graduate or less	Reference		Reference		Reference	
Some college	0.97 (0.94, 1.00)	0.07	0.94 (0.88, 1.01)	0.10	0.96 (0.92, 1.00)	0.04
Bachelor's degree	0.97 (0.94, 1.01)	0.14	0.94 (0.87, 1.00)	0.07	0.96 (0.92, 1.00)	0.05
Graduate degree	0.96 (0.93, 0.99)	0.01	0.92 (0.85, 0.98)	0.01	0.94 (0.91, 0.98)	0.005
Care partner characteristics						
Age		< 0.001		0.007		< 0.001
< 75	Reference		Reference		Reference	
75–84	0.97 (0.95, 0.99)	0.008	0.93 (0.88, 0.98)	0.007	0.96 (0.93, 0.99)	0.003
85+	0.90 (0.85, 0.96)	0.002	0.87 (0.76, 1.00)	0.046	0.89 (0.82, 0.96)	0.004
Male	0.96 (0.94, 0.99)	0.002	1.09 (1.04, 1.14)	< 0.001	1.01 (0.98, 1.04)	0.65
Race						
White	Reference		Reference		Reference	
Other race	1.00 (0.96, 1.06)	0.85	1.14 (1.03, 1.25)	0.01	1.05 (0.99, 1.12)	0.10
Education						
High school graduate or less	Reference		Reference		Reference	
Some college	1.02 (0.98, 1.05)	0.29	1.03 (0.96, 1.11)	0.45	1.02 (0.98, 1.07)	0.29
Bachelor's degree	1.02 (0.99, 1.06)	0.26	0.99 (0.92, 1.07)	0.77	1.01 (0.97, 1.05)	0.64
Graduate degree	1.04 (1.00, 1.08)	0.03	1.09 (1.01, 1.18)	0.02	1.06 (1.01, 1.11)	0.01
Relationship to patient						
Spouse/significant other	Reference		Reference		Reference	

Description of Included Variables	Communication Domain		Capacity Domain		Overall	
	Ratio (95% CI)	P*	Ratio (95% CI)	P*	Ratio (95% CI)	P*
Parent/other	1.00 (0.96, 1.03)	0.89	1.08 (1.00, 1.17)	0.06	1.03 (0.98, 1.07)	0.27
Employment	Reference	0.95	Reference	0.51	Reference	0.69
Not working or don't know/refused						
Part-time	1.00 (0.97, 1.03)	0.86	0.96 (0.89, 1.03)	0.27	0.98 (0.94, 1.02)	0.41
Full-time	0.99 (0.95, 1.04)	0.75	0.97 (0.88, 1.06)	0.51	0.99 (0.94, 1.04)	0.63
Time providing care for the patient		< 0.001		0.002		< 0.001
Not providing care or don't know/refused	Reference		Reference		Reference	
05 h or fewer a wk	0.97 (0.94, 1.00)	0.02	0.91 (0.86, 0.97)	0.003	0.95 (0.92, 0.98)	0.003
06–19 h a wk	1.03 (1.00, 1.07)	0.07	1.03 (0.96, 1.11)	0.44	1.03 (0.99, 1.08)	0.14
20–39 h a wk	1.04 (0.99, 1.09)	0.13	1.02 (0.92, 1.13)	0.70	1.03 (0.97, 1.09)	0.27
40 or more hours a wk	1.07 (1.02, 1.13)	0.004	1.07 (0.97, 1.19)	0.17	1.07 (1.01, 1.14)	0.02
General health status	0.98 (0.97, 0.99)	0.002	0.99 (0.96, 1.01)	0.32	0.98 (0.97, 1.00)	0.03
Depression (PHQ-2)	0.93 (0.89, 0.97)	0.001	0.94 (0.85, 1.03)	0.16	0.93 (0.88, 0.98)	0.01
Subjective burden (Zarit), per 5-point increase	0.99 (0.98, 1.00)	0.003	0.99 (0.97, 1.00)	0.12	0.99 (0.98, 1.00)	0.01

As a sensitivity analysis, we reran these models among the 1557 care partners who reported attending the patient's medical visits "most of the time" or "always," because we hypothesized that the associations may be even stronger with CAPACITY. In the interest of brevity, these results are available upon request, showing associations between the study variables and CAPACITY scores that were consistent with the main findings. We also reran these models including care partner cognitive status (TICS-M), and results were similar. These results are also available upon request.

* For categorical variables parameterized with binary indicator variables, the P-values shown on the unindented rows are for type 3 tests for the overall contribution of that variable to the model. Likelihood ratio χ^2 tests indicated the covariates included provided significant improvement in explaining the variance of the outcome (all $P < 0.0001$).

CAPACITY indicates Caregiver Perceptions About Communication with Clinical Team members; CI, confidence interval; PHQ-2, Patient Health Questionnaire 2; TICS-M, Modified Telephone Interview Cognitive Status.