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Magnitude and Causes of Bias among Family Caregivers rating Alzheimer's Disease Patients

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Abstract

Objective—Family caregivers generally underestimate the health and well-being of Alzheimer's disease (AD) patients when compared to patient self-assessments. The goals of this study were to identify caregiver, patient, and contextual factors associated with caregiver rating bias.

Methods—105 patients with AD and their family caregivers were assessed twice by trained interviewers one year apart. In separate interviews, caregivers were asked to rate the quality of life and suffering of their patient relative, and patients provided self-ratings using the same structured instruments. Multivariate cross-sectional and longitudinal analyses were used to identify predictors of caregiver-patient discrepancies.

Results—Caregivers consistently reported significantly higher levels of suffering and lower levels of quality of life than patients. Caregiver psychological well-being and health status accounted for a substantial portion of the difference in caregiver and patient ratings in both cross-sectional and longitudinal analyses. Caregiver depression and burden were consistently positively associated with the magnitude of caregiver-patient discrepancy, and caregiver health status was negatively associated with the size of the discrepancy.

Conclusions—Caregiver assessments of dementia patients may determine the type and frequency of treatment received by the patient, and caregivers' ability to reliably detect change in patient status can play a critical role in evaluating the efficacy of therapeutic interventions and pharmacologic agents. Clinicians and researchers working with dementia patients who rely on caregiver reports of patient status should be sensitive to the health and well-being of the caregiver

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and recognize that caregiver assessments may be negatively biased when the caregiver's own well-being is compromised.

Introduction

Proxy reports provided by family members are frequently used to characterize the health and well-being of older individuals. Although secondary reports of patient status may be better than having no information at all, it is important that we understand the limitations of these reports. For patients with dementia, family caregivers play critical roles in communicating patient status information to health care providers and advocating for patient care (1, 2). The validity and reliability of their assessment may determine the type and frequency of treatment received by the patient, and their ability to reliably detect change in patient status can play a critical role in evaluating the efficacy of existing therapeutic interventions and experimental pharmacologic agents. Inasmuch as improving the quality of life of dementia patients is a primary goal of treatment, having accurate assessments of patient status is essential.

The literature consistently shows that family proxies report worse health-related quality of life (HRQOL) and functioning for conditions such as stroke (3, 4), cancer (5), dementia (6, 7), and general health conditions (8) when compared to self-report measures from patients. Although several studies have shown that mild to moderately impaired patients with dementia can provide reliable self-report information about their health and well-being (6, 9-11), family members are frequently viewed as the primary source of patient status information (12). Unfortunately, agreement between patient and caregiver reports of patient status is low to moderate at best (6, 7, 9-11, 13), raising questions about the usefulness of family proxy reports as guides to patient treatment. Thus, treatment decisions based on proxy reports may not result in maximal benefits from the patient's perspective.

These findings beg the question, why do proxies infer worse health status than patients' acknowledge and how might this apparent bias be mitigated? Answering this question requires that we first identify factors that contribute to caregiver rating bias. Although not definitive, the literature suggests a number of candidate variables including caregiver depression (10, 13), burden (7, 10, 13), patient depression (10), patient cognitive status (6, 11, 14), and the domain being rated (e.g., subjective state vs. observable behavior) (6, 14). That is, larger discrepancies are reported when either the patient or caregiver is depressed, the patient is more cognitively impaired, the caregiver is more burdened, and the domains being rated are subjective states of the patient as opposed to observable behaviors such as physical functioning.

The present study sought to expand on these findings in several important ways. First, we compare caregiver and patient rating disparities for two widely used instruments, the Quality of Life in AD scale (QOL-AD) (10) and the Dementia Quality of Life scale (DEM-QOL) (15), to determine the level of proxy rater bias. Second, we extend proxy-patient comparisons to a recently validated measurement instrument designed to assess patient suffering in three domains: psychological, existential, and physical suffering (16). This enables us to assess variations in bias in both subjectively experienced (psychological and existential suffering) and objectively observed domains (physical suffering). Third, we systematically explore multiple caregiver, patient, and contextual factors associated with caregiver rating bias to identify key factors that predict bias. Finally, in longitudinal analyses we examine how changes in caregiver characteristics predict changes in caregiver bias. The latter analyses are unique in this literature and are critical to developing causal models for understanding and addressing caregiver bias.

Methods

Measures

Both caregivers and patients completed two quality of life instruments, the Quality of Life in AD scale (QOL-AD) (10) and the Dementia Quality of Life scale (DEM-QOL) (15) and a recently validated suffering scale comprised of three subscales assessing psychological, existential, and physical suffering (16). The QOL-AD consists of 13 items assessing multiple dimensions of quality of life (e.g., mood, energy, friends, ability to do things for fun) as either poor (1), fair (2), good (3), or excellent (4; range 13-52; higher scores indicate higher quality of life). The DEM-QOL is a 28 item scale assessing multiple dimensions of quality of life, including psychological status, memory, and daily activities. Respondents are asked to indicate how much they experienced each item during the last week (“a lot”=1; “quite a bit”=2; “a little”=3; “not at all”=4; range 28-112; higher scores indicate higher quality of life). Psychological suffering was measured with a scale assessing the frequency of 15 symptoms (e.g., confident, afraid, irritable, depressed, cheerful, hopeless, etc.) experienced during the last 7 days (not at all=0; a little {a few days, 1-3}=1; quite a bit {most days, 4-6}=2; very often {every day}=3; range 0-45; high scores indicate high levels of suffering). Physical suffering was measured with 9 items assessing symptoms such as pain, nausea, shortness of breath, dry mouth, etc., using the same response options as the psychological suffering scale. We calculated an index score by coding symptoms which occurred “quite a bit” or “very often” as 1 and all other responses as 0 (range=0-7). Spiritual/existential suffering was measured with 9 statements (I feel peaceful, My life has been a failure, I feel a sense of purpose in my life, Life is not worth living anymore, etc.). Respondents are asked to indicate how true each statement has been for them during the past 7 days (not at all=0, a little=1, somewhat=2, quite a bit=3, very much=4) yielding a score of 0 to 36 (high suffering). Positive items were reverse scored on all suffering scales. Patients were asked to rate themselves, and caregivers were asked to rate the patients on each of these scales. Patients were also administered the Mini-Mental State Examination which assesses cognitive functions of the patient (MMSE; range 0-30, high scores indicate high functioning) (17) and the Short-form 12 Question Health Survey (18) which yields two scores, one for mental health and one for physical health (range 0-100; high scores indicate better health), and caregivers completed the Center for Epidemiologic studies Depression Scale (19) (20 items; range 0-60; high scores indicate greater depression), the Zarit Burden scale (20) (12 items, range 0-48, high scores indicate greater burden), self-ratings of health, and provided information about demographic characteristics of the household.

Sample and Procedure

Patients with Alzheimer’s disease (AD) and their caregivers were recruited from the Alzheimer’s Disease Research Center at the University of Pittsburgh and the local chapter of the Alzheimer’s Association. Patients had to: (1) be 50 years old or older; (2) have consensus-based diagnosis of probable or possible AD or related dementia based on medical, behavioral and cognitive function performance data; (3) speak English; and (4) reside in the community with the primary caregiver. Caregivers had to: (1) be a family member/partner (e.g., spouse, child or fictive kin); (2) be 21 years of age or older; (3) provide a minimum of three months of in-home care prior to recruitment; (4) speak English; and (5) self-define as primary caregiver of the patient. A total of 129 dyads were referred to the study, and 121 met eligibility criteria. Of these, 16 declined participation because of lack of interest in the study (n=10), caregiver was too busy (n=2), patient too ill (n=1), patient too depressed (n=1), patient refused (n=1), or caregiver thought it would be too upsetting for the patient (n=1), leaving a baseline sample of 105 dyads. A total of 92 caregivers completed the follow-up assessment one year later. Seven caregivers were lost due to the death of caregiver or patient, and 6 refused participation. Seventy-eight patients completed the follow-up

assessments; of these, 7 were lost due to death of caregiver or patient, and 20 were too ill or refused to complete the assessment. Patients who completed the assessment were further evaluated for competency to provide reliable responses (see description of process below). A total of 79 dyads were able to reliably complete the baseline assessment and were included in the baseline analysis; 54 dyads were judged to provide reliable data at follow-up.

Data from caregivers and patients were collected via face-to-face interviews administered by a trained interviewer in the participant's home. Caregivers and patients were interviewed separately without the presence of other individuals. Visual cue cards were used to remind respondents of response options, and interviewers were asked to assess the respondent's comprehension by rating the ability of respondents to reliably answer questions and to ask follow-up questions when responses were unclear or inconsistent. If the respondent was judged to be incapable of completing the interview, the interviewer engaged the respondent in an informal conversation before terminating the interview. Based on interviewer ratings, MMSE scores, and analysis of responses to structured questions, it was determined that persons with dementia scoring less than 16 on the MMSE (N=26) could not provide reliable responses at baseline, and their data were, therefore, not used in the analyses.

Results

Demographics, Caregiver Relationships and Household Characteristics

The demographic characteristics of the AD patients (N=79) and their caregivers (N=79) are presented in Table 1. Patients' ages ranged from 55 to 95 (mean=76, s.d.=8.5) and were on average ten years older than their caregivers (mean=67, s.d.=11.0; range 42-87). Caregivers were disproportionately female (84%), with 98% of male patients having a spouse (90%) or daughter caregiver (8%) and nearly half of female patients cared for by a daughter (48%). On average, patients had lower levels of educational attainment than their caregivers, though this difference was only observed among those patients who had non-spouse caregivers. Overall, 42% of patients reported a high school degree or less compared to 29% of caregivers. The sample of patients is predominately White (89%), with all patient and caregiver dyads concordant on self-reported race/ethnicity. Thus, caregiver demographic factors including age, sex, race, and educational attainment are confounded with patient characteristics.

As shown in Table 1, other demographic and household factors such as the caregiver's employment status, total household income, and years living in the same household are largely determined by the relationship of the caregiver to the patient, with higher rates of current employment and higher incomes reported among non-spouse caregivers. Though a majority (57%) of non-spouse caregivers reported living in the same household as the patient for greater than 10 years prior to the interview, 24% had lived in the same household for less than 5 years. All spouse caregivers reported sharing the same household for a minimum of 5 years, with 97% having lived in the same household for 10 years or more. Though these household factors may be potential sources of discrepancy between caregiver and patient ratings, they are also largely mutually determined and confounded. Thus, in subsequent multivariate analyses, total years living in the same household and household income and race of the dyad are used to capture the shared aspects of the household environment, while relationship status was dropped as it was redundant and collinear when included in multivariate models with caregiver sex, caregiver age, and years living in the same household.

The analytic strategy was to first identify correlates of systematic over-rating of suffering and down-rating of quality of life by caregivers across a wide range of caregiver and patient characteristics as well as shared factors such as household income and years living together.

In order to control for Type 1 error at this stage of the analysis we adopted a conservative statistical significance criterion of $p < .01$. The next step was to assess the relative importance of these factors both individually and as blocks of related variables in explaining the residual difference between the caregiver and patient ratings in multiple linear regression models. For each linear regression model, the outcome variable is the caregiver's rating with the patient's rating entered at the first step. A final set of regression models assessed predictors of differences in ratings of change in patient suffering and quality of life.

Correlations and Concordance among Measures of Suffering and Quality of Life

The raw Pearson correlations between the caregiver and patient ratings across the five scales measuring the separate domains of patient suffering and quality of life are presented in Table 2. Correlations between caregiver and patient ratings were generally medium to low, with the highest observed correlation for the QoL-AD scale ($r = .354$) and the lowest level of agreement for the existential suffering scale ($r = .279$). These correlations suggest a similar pattern of concordance across the multiple measures of patient well-being and are generally consistent with findings of relatively low concordance among subjective measures of patient status and quality of life.

Using paired t-tests, caregivers reported significantly higher levels of patient suffering than reported by the patients across all three measures (see Table 2). On average, caregivers also reported a significantly lower patient quality of life than did the patients on the QoL-AD, but not for the DEM-QOL (see Table 2).

Predictors of Caregiver Bias at Baseline

Over-reporting of patient suffering and down-rating of quality of life by the caregiver at baseline was significantly associated with measures of caregiver depression across all scales except physical suffering (see Table 3). Caregiver burden and physical health status were also strong and significant predictors of discordance for all scales except for physical suffering with the additional exception that physical health status was not associated with psychological suffering. Years living together was negatively associated with the discrepancy in physical suffering, and higher income was associated positively with the discrepancy in quality of life as measured with the QoL-AD. Other demographic and household factors did not have statistically significant or consistent patterns of relationship with caregiver bias across the multiple scales using the conservative statistical significance criterion of $p < .01$.

After examining correlations among all predictor variables (see Table 4), we assessed associations among individual predictors and caregiver patient discrepancies using multivariate regression analyses. The results of these analyses are reported in Table 5. Because our sample size was relatively small and many key predictor variables were highly correlated (e.g., caregiver burden, depression, and health status), we also ran multivariate regression models in which we entered blocks of related variables in order to assess the relative contribution of those blocks predicting discrepancies (see Table 6). These analyses showed that psychosocial well-being and physical health status, including depression, burden, and general health status, collectively explained nearly a quarter of the difference between caregiver and patient ratings of existential suffering ($R^2 = .226$) and quality of life using the QoL-AD ($R^2 = .234$). By comparison, the physical and mental health status of patients explained less than 10% of the difference in ratings across all scales, suggesting that the degree of caregiver bias in measures of suffering and quality of life are not dependent on the absolute level of physical or mental health symptoms experienced by the patient. Caregiver demographic factors including age, sex, and educational attainment accounted for just 6% of difference in ratings of existential suffering and less than 3% of differences for all

other scales. Patient demographic factors were significantly associated with discordance in ratings of existential suffering but otherwise explained very little of the variability across the other scales. Household income, years living together, and race/ethnicity were not associated with caregiver bias after adjustment for other factors and collectively accounted for less than 5% of the difference in ratings.

Overall, the full models containing both caregiver and patient demographics, physical and mental health status variables, and shared household factors were able to explain a substantial portion of the caregiver bias in ratings of existential suffering ($R^2=.444$) and quality of life measured with the QoL-AD ($R^2=.366$). Multivariate models explained less than one-third of the observed differences in ratings of psychological suffering ($R^2=.316$), Dementia Quality of Life ($R^2=.296$), and physical suffering ($R^2=.208$), though the latter two measures had relatively low levels of discordance, leaving less to be explained.

Predictors of Caregiver Bias in Assessing Change

Agreement between caregiver and patient ratings of change between one year follow-up and baseline scores (Table 7) were also generally poor, although correlations for both psychological suffering ($r=.340$) and the QoL-AD ($r=.381$) were moderate. Though average changes in ratings of the DEM-QOL were similar between caregivers (mean =2.2, s.d.=10.9) and patients (mean =2.1, s.d.=8.5), the correlation between pairs of ratings of change is very poor ($r=.004$). Patients generally reported higher existential suffering at follow-up than at baseline (mean =1.6, s.d.=3.2), but this mean difference was not captured in caregiver ratings (mean =-0.06, s.d.=4.3). On average, both caregivers and patients reported little change in the average levels of physical suffering for the study cohort.

As was the case for baseline measures, the most important predictors of discrepancy between caregiver and patient ratings of change were changes in measures of caregiver physical and mental health status (Table 8). Of these caregiver factors, changes in caregiver depression was the most important for predicting bias in ratings of change in patient psychological suffering and QoL-AD, while changes in the caregiver's health status were relatively more important in predicting bias in assessment of change of existential suffering and the DEM-QOL. Thus, not only do caregivers with higher levels of depression and self-reported burden and poorer physical health tend to over-rate patient suffering and down-rate quality of life at baseline, changes in their own mental and physical health status may additionally bias measures of change in patient suffering and quality of life. Changes in the physical and mental health status of the caregiver accounted for a significant portion of the discrepancy between caregiver and patient ratings of psychological suffering ($R^2=.185$) and QoL-AD ($R^2=.153$) where the outcome is the residual between caregiver and patient ratings of change. Though not statistically significant, changes in caregiver well-being also explained the largest proportion of the discrepancy for existential suffering ($R^2=.096$) and DEM-QOL ($R^2=.111$) among the groups of variables measured. The bias related to caregiver psychological and physical well-being detected at baseline is, therefore, not a constant that can be simply subtracted out of the equation in subsequent ratings. Because the most important sources of bias are not fixed but may change over time, the ability to reliably assess changes in patient status may be undermined.

Discussion

Concordance between caregiver and patient ratings of patient suffering and quality of life was small to moderate. With the exception of the DEM-QOL, caregivers consistently reported higher levels of suffering and lower levels of quality of life than reported by patients. These differences were large and statistically significant. Multivariate analyses further showed that the caregiver's own physical and psychological well-being accounted

for a substantial portion of this difference between caregiver and patient ratings. Caregiver depression and burden were consistently positively associated with the magnitude of caregiver-patient discrepancy, and caregiver health status was negatively associated with the size of the discrepancy.

Agreement between caregiver and patient ratings of change between baseline and one year follow-up scores were also generally poor, although correlations for two scales, psychological suffering and QoL-AD, were moderate. As was the case for baseline measures, the most important predictors of discrepancy between caregiver and patient ratings of change were changes in measures of caregiver physical and mental health status. Of these caregiver factors, changes in caregiver depression was most important for predicting negative bias in ratings of change.

These findings both replicate and extend prior research in this area, and have important implications for both care of the patient and for clinical trials in dementia (21). Because of patient cognitive impairment, the caregiver is often the primary source of information on patient health and well-being in health care encounters. Caregivers with high levels of depressive symptoms and burden are likely to exaggerate negative aspects of patient status, resulting in potentially non-optimal and inappropriate medical interventions for the patient. For example, a depressed caregiver may exaggerate depressive symptoms in the patient and advocate unnecessary treatment for depression. Clinicians treating dementia patients who rely on caregiver reports of patient status should be sensitive to the health and well-being of the caregiver and recognize that caregiver assessments may be negatively biased when the caregiver's own well-being is compromised.

Our findings are particularly relevant to outcomes assessment in clinical trials involving dementia patients. The Food and Drug Administration (FDA) requires that the global impression of a clinician serve as a primary outcome in clinical trials in dementia. To address this requirement, researchers frequently use the clinician's interview based impression of change with the caregiver input scale (CIBIC-plus) (22). This instrument uses information obtained during an independent clinical interview to assess disease severity and progression in multiple domains. A blinded clinician conducts interviews with the patient and caregiver. Our findings suggest that caregivers may be a potential source of bias in these ratings, resulting in an underestimate of treatment efficacy. Clinicians who identify discrepancies between caregiver and patient during CIBIC administration should consider the caregivers' depressive status when interpreting these discrepancies.

Caregiver bias does not account for all of the discrepancy between caregiver and patient ratings of patient status. This begs the question, what else might account for these relatively large differences? One possible explanation concerns the different perspectives that patients and caregivers bring to the disease. Patients experiencing the disease may have a vested interest in downplaying its impact on them as a means for coping with it or in an attempt to reduce the burden on the caregiver. In addition, patients may find the reality of the disease to be less negative than their expectations about it. On the other hand, it would be socially inappropriate for caregivers to downplay patient symptoms, and caregivers are subject to the generally negative media-based characterizations of the disease since they have no first-hand experience with it. It has also been suggested that AD patients' lack of insight may contribute to more positive self-assessments (21).

Limitations

Given the large number of statistical tests carried out and the relatively small sample available for this study, the results should be viewed cautiously because of possible Type I error. Replication with a larger sample is warranted. Our findings also point to a number of

unanswered questions. It is noteworthy that we did not find significant caregiver/patient discrepancies on the DEM-QOL, which may be due to the fact this scale contains numerous items that rely on behavioral observation of the patients (e.g., keeps him/herself clean; looks after his/her finances) as opposed to inferring internal states. It would be useful to explore this distinction more systematically in future studies. Given the relatively advanced age of our caregivers, it is possible that they too might have suffered from mild cognitive impairment which affected their judgment. Future studies should formally assess the cognitive function of both caregivers and patients. Similarly, having caregivers and patients rate both themselves and their respective relative/friend would show whether these disparities are a general phenomenon regardless of which role one occupies. Answering these questions and obtaining a more fine-grained understanding of the causes and consequences of caregiver rater bias should receive high priority. Nevertheless, the growing literature in this area strongly suggests that caution be advised in making clinical decisions based on caregiver reports.

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Table 1

Caregiver and Patient Characteristics at Baseline

	Caregivers (n = 79)	Patients (n = 79)
Age, mean (s.d.)	66.5 (11.0)	76.0 (8.5)
Sex, N (%)		
Female	64 (81)	27 (34)
Male	15 (19)	52 (66)
Race, N (%)		
White	70 (89)	70 (89)
Black	8 (10)	8 (10)
Asian	1 (1)	1 (1)
Educational attainment, N (%)		
Less than high school	5 (6)	12 (15)
High school	18 (23)	21 (27)
Vocational or some college	20 (34)	19 (24)
College degree	22 (28)	9 (11)
Graduate degree	14 (18)	16 (20)
Caregiver Employment Status, N (%)		
Employed	17 (21)	
Homemaker	16 (20)	
Retired	36 (46)	
Unemployed	4 (5)	
Total Household Income, N (%)		
< \$20,000	18 (23)	
\$20,000 to < \$40,000	24 (30)	
\$40,000 to < \$60,000	16 (20)	
\$60,000 +	19 (24)	
Not reported	2 (3)	
Years Living in Same Household, N (%)		
< 5 years	5 (6)	
5-10 years	6 (8)	
>10 years	68 (86)	
Relationship		
Spouse	58 (73)	
Non-spouse	21 (27)	
Caregiver Physical & mental health status		
Depression (CES-D), mean (s.d.)	13.8 (11.2)	
Burden (ZBI), mean (s.d.)	14.8 (8.4)	
Self-rated Health		
Poor	4 (5)	
Fair	19 (24)	
Good	22 (28)	

	Caregivers (n = 79)	Patients (n = 79)
Very Good	25 (32)	
Excellent	9 (11)	
Patient Physical & mental health status		
Mental Health (SF-12)		44.1 (10.2)
Physical Health (SF-12)		47.2 (12.0)
MMSE		
16-19		14 (18)
20-24		33 (41)
25-29		32 (41)
mean(s.d.)		23.1(3.6)

CES-D = Center for Epidemiologic Studies Depression Scale.

ZBI = Zarit Burden Inventory.

MMSE = Mini-Mental State Examination.

SF-12 = Short-form 12 Question Health Survey, Mental Health (MCS) and Physical Health (PCS) summary scores.

Table 2

Suffering and Quality of Life Measures: Means, Standard Deviations, and Measures of Concordance between Caregivers and Patients

	Caregiver (n = 79)	Patient (n = 79)	Paired Difference ^a (CG - CR)	Correlation ^b <i>r</i>
Suffering Measures				
Psychological	11.3 (6.5)	7.3 (6.6)	4.0 (7.5)*	0.345*
Existential/Spiritual	11.0 (6.1)	6.4 (6.1)	4.6 (7.4)*	0.279
Physical (Index)	2.0 (1.5)	1.0 (1.3)	1.0 (1.7)*	0.288*
Quality of Life Measures				
QoL-AD	30.0 (5.3)	34.6 (4.9)	-4.6 (5.8)*	0.354*
DEMQOL	92.9 (13.4)	91.7 (11.2)	1.2 (14.5)	0.315*

QoL-AD = Quality of Life in Dementia.

DEMQOL = Dementia Quality of Life.

*
p < .01

^aPaired T-test (df = 78) comparing differences in raw scales scores between caregiver and patient rating.

^bRaw Pearson correlation (df = 77) between caregiver and patient ratings for each scale.

Table 3
 Correlations Between Selected Caregiver and Patient Characteristics and Discrepancy in Scale Ratings of Patient's Suffering and Quality of Life^a

	CR Suffering Measures			CR Quality of Life	
	Psychological	Existential	Physical	QoL-AD	DEMQOL
Demographic factors					
Caregiver					
Age (years)	-.194	-.069	-.119	-.098	.148
Sex (female)	-.051	.063	-.034	-.124	.004
Education	-.094	-.111	-.300	.138	.079
Patient					
Age (years)	-.108	-.098	.124	-.027	.175
Sex (female)	.144	.104	.109	.142	-.039
Education	-.203	-.249	-.269	.094	.123
Physical & mental health status					
Caregiver					
Depression (CES-D)	.435*	.452*	.236	-.337*	-.328*
Burden	.400*	.390*	.196	-.400*	-.293*
Health status	-.279	-.346*	-.076	.300*	.292*
Patient					
MMSE	-.127	.015	.087	-.053	.144
Physical health (SF-12)	-.027	.042	-.155	.150	-.064
Mental health (SF-12)	-.081	.044	-.059	-.064	-.051
Household or shared factors					
Race (non-White)	.068	-.036	-.064	-.005	.122
Non-spouse caregiver	.168	.121	.195	.043	-.108
Years living together	-.202	-.095	-.235*	.024	.116
Household income	-.124	-.127	-.165	.270*	.120

MMSE = Mini-Mental State Examination.

CES-D = Center for Epidemiologic Studies Depression Scale.

SF-12 = Short-form 12 Question Health Survey, Mental Health (MCS) and Physical Health (PCS) summary scores.

*
p < .01

^aPearson correlations (df = 77) are between the residual of the caregiver rating regressed on the patient rating and selected factors.

Table 4

Correlation Matrix of Selected Covariates and Predictors of Measures of Patient Suffering and Quality of Life.^a

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Demographic Factors																
Caregiver																
1 Age	1	-.039	-.050	.175	-.291*	.235	-.210	-.291*	-.050	.001	.094	.178	-.252	-.703*	.742*	-.100
2 Sex (Female)	-.039	1	.071	.120	-.604*	.009	.176	.253	-.150	.180	.013	.336*	-.001	0	-.078	-.090
3 Education	-.046	.071	1	-.020	-.050	.574*	-.170	.240	.189	-.040	.010	.110	-.002	0.036	-.075	.583*
Patient																
4 Age	.200	.120	-.020	1	.204	-.192	-.070	.059	-.040	.042	-.119	.089	0.118	.397*	-.008	-.010
5 Sex (Female)	-.291*	-.604*	-.050	.204	1	-.327*	-.030	.013	-.010	-.210	-.072	-.327*	0.207	.533*	-.179	.083
6 Education	.235	.009	.574*	-.190	-.327*	1	-.100	.110	.177	.010	.040	.034	-.003	-.379*	.082	.341*
Physical & Mental Health Status																
Caregiver																
7 Depression (CES-D)	-.200	.176	-.170	-.070	-.030	-.095	1	.606*	-.507*	.102	-.086	.051	-.018	0.054	-.186	-.180
8 Burden	-.291*	.253	.240	.059	.013	.110	.606*	1	-.231	.117	-.089	-.120	-.003	.225	-.347*	.037
9 Health Status	-.100	-.148	.189	-.040	-.010	.177	-.507*	-.231	1	.003	.073	.044	-.007	0.02	-.066	.267
Patient																
10 MMSE	.000	.180	-.040	.042	-.210	.010	.102	.117	.003	1	-.072	.126	-.017	-.130	-.090	.003
11 Phys. Health (SF-12)	.100	.013	.010	-.120	-.070	.040	-.090	-.089	.073	-.070	1	.054	-.015	-.110	.091	-.010
12 Mental Health	.200	.336*	.110	.089	-.327*	.034	.051	-.122	.044	.126	.054	1	-.385*	-.100	.133	.138
Household or Shared Factors																
13 Race (Non-White)	-.252	-.010	-.020	.118	.207	-.032	-.180	-.031	-.070	-.170	-.149	-.385*	1	.288	-.356*	-.288
14 Non-Spouse	-.703*	-.001	.036	.397*	.533*	-.379*	.054	.225	.020	-.130	-.106	-.01	.288	1	-.627*	.107
15 Yrs. of Caregiving	.742*	-.078	-.080	-.010	-.180	.082	-.190	-.347*	-.070	-.090	.091	.133	-.356*	-.627*	1	-.012
16 Household Income	-.100	-.090	.583*	-.010	.083	.341*	-.180	.037	.267	.003	-.012	.138	-.288	.107	-.119	1

MMSE = Mini-Mental State Examination.

CES-D = Center for Epidemiologic Studies Depression Scale.

SF-12 = Short-form 12 Question Health Survey, Mental Health (MCS) and Physical Health (PCS) summary scores.

* $p < 0.01$ level

² Pearson correlations ($df = 77$) between pairs of measures.

Multiple Regression Models Assessing Sources of Discrepancy Between Caregiver and patient Ratings of Patient's Suffering and Quality of Life^a

Table 5

	CR Suffering Measures			CR Quality of Life		
	Psychological	Existential	Physical	QoL-AD	DEMQOL	
Demographic factors	beta	beta	beta	beta	beta	beta
Caregiver						
Age (years)	.155	.341 *	.114	-.275	.021	.021
Sex (female)	-.094	.085	-.100	.070	.137	.137
Education	.005	.051	-.269	.019	-.012	-.012
Patient						
Age (years)	-.168	-.295 *	.130	.021	.157	.157
Sex (female)	.051	.232	-.015	.141	.063	.063
Education	-.186	-.311 *	-.051	.120	.110	.110
Physical & mental health status						
Caregiver						
Depression (CES-D)	.226	.355	.020	-.283	.012	.012
Burden	.328 *	.374 *	.162	-.530 **	-.243	-.243
Health status	-.207	-.414 *	.028	.377 *	.079	.079
Patient						
MMSE	-.140	.008	-.018	.014	.205	.205
Physical health (SF-12)	.159	.360 *	-.031	-.353 *	.240	.240
Mental health (SF-12)	.049	.288	.012	-.476 *	-.021	-.021
Household or shared factors						
Race (non-White)	.111	.100	-.194	-.080	.247	.247
Years living together	-.134	-.125	-.326	.129	.183	.183
Household income	-.020	.002	-.046	.177	.115	.115

MMSE = Mini-Mental State Examination.

CES-D = Center for Epidemiologic Studies Depression Scale.

SF-12 = Short-form 12 Question Health Survey, Mental Health (MCS) and Physical Health (PCS) summary scores.

* p < .05

p < .01

^aStandardized regression coefficients (beta) predicting discrepancy in score rating (the residual variance between caregiver and patient ratings). Tests of significance are based on t-tests in multiple regression model (df = 63).

Table 6
 Summary of Multiple Regression Models Assessing Sources of Discrepancy Between Caregiver and Patient Ratings of Patient's Suffering and Quality of Life

	CR Suffering Measures						CR Quality of Life	
	Psychological		Existential		Physical		QoL-AD	DEMQOL
	R ²	R ²	R ²	R ²	R ²	R ²	R ²	
Demographic factors ^a								
Caregiver	.025	.063	.029	.029	.029	.029	.007	
Patient	.046	.107**	.026	.014	.014	.039		
Physical & mental health status								
Caregiver ^b	.112*	.226**	.015	.234**	.047			
Patient ^c	.022	.062	.003	.066	.018			
Household or shared factors ^d	.016	.025	.053	.019	.029			
Full model, all factors ^e	.316*	.444**	.208	.366**	.296*			

Results showing R² and p-values from F-tests to assess the relative contributions of blocks of related variables in a multiple-regression model predicting discrepancy in score rating (the residual variance between caregiver and patient ratings). All R² tests (df₁ = 3, df₂ = 63) for blocks of related variables and for the full model were evaluated when entered into the model at the final step, adjusted for all other variables. Blocks of variables were as follows:

QoL-AD = Quality of Life in Dementia.

DEMQOL = Dementia Quality of Life.

CES-D = Center for Epidemiologic Studies Depression Scale.

MMSE = Mini-Mental State Examination.

* p < .05

** p < .01

^aTwo blocks, one for caregiver demographics (age (continuous); sex (indicator); educational attainment (ordinal)) and one for patient demographics (age (continuous), sex (indicator), educational attainment (ordinal)).

^bBlock includes three variables measuring caregiver mental and physical health status at the time of interview: caregiver depression score (CES-D); caregiver burden score; caregiver general health status score.

^cBlock includes three variables measuring patient's mental and physical health status: Patient's MMSE score; SF-12 physical health summary score; SF-12 mental health summary score.

^dBlock includes total household income (ordinal); years of living together (continuous); race/ethnicity (indicator). Non-spouse status was co-linear with total years living together and was removed from the model.

^eTest for full model based on F-test (df₁ = 15, df₂ = 63) evaluating the contribution of all variables above in explanation of residual of caregiver rating regressed on patient rating.

Table 7

Mean Change and Measures of Concordance of Change in Suffering and Quality of Life Measures (N=54)

	Caregiver (n = 54)	Patient (n = 54)	Paired Difference ^a (CG - CR)	Correlation ^b <i>r</i>
Suffering Measures				
Psychological	0.45 (5.3)	1.25 (5.2)	-0.81 (6.1)	0.340 *
Existential/Spiritual	-0.06 (4.3)	1.57 (3.2)	-1.63 (5.7)	-0.105
Physical (Index)	0.11 (1.5)	-0.15 (1.1)	0.26 (1.7)	0.179
Quality of Life Measures				
QoL-AD	-0.76 (4.2)	-1.06 (4.3)	0.30 (4.6)	0.381 **
DEMQOL	2.15 (10.9)	2.08 (8.5)	0.07 (13.8)	0.004

QoL-AD = Quality of Life in Dementia.

DEMQOL = Dementia Quality of Life.

*
p < .05**
p < .01^a Paired T-test (df=53) comparing differences in raw change scores between caregiver and patient rating.^b Raw Pearson correlation (df=52) between change in caregiver and patient ratings for each scale.

Table 8

Summary of Multiple Regression Models Assessing Sources of Discrepancy Between Changes in Caregiver Ratings and Changes in Patient Ratings of Patient's Suffering and Quality of Life (N=54)

	CR Suffering Measures (T2-T1)			CR Quality of Life (T2-T1)	
	Psychological	Existential	Physical	QoL-AD	DEMQOL
	R ²	R ²	R ²	R ²	R ²
Demographic factors ^a					
Caregiver	.011	.008	.043	.065	.003
Patient	.052	.090	.046	.123*	.003
Physical & mental health status					
Caregiver					
Baseline ^b	.013	.049	.085	.076	.040
Change ^c	.185*	.096	.019	.153*	.111
Patient					
Baseline ^d	.040	.124	.041	.149*	.049
Change ^e (MMSE only)	.015	.005	.005	.002	.077
Household or shared factors ^f	.078	.082	.041	.099 [†]	.011
Full model, all factors ^g	.469	.535	.326	.648**	.398

Results showing R² and corresponding F-tests to assess the relative contributions of blocks of related variables in a multiple-regression model predicting discrepancy in assessments of change (the residual variance between caregiver and patient ratings of change). All F-tests for blocks of related variables and for the full model were evaluated when entered into the model at the final step, adjusted for all other variables. Blocks of variables were as follows:

QoL-AD = Quality of Life in Dementia.

DEMQOL = Dementia Quality of Life.

MMSE = Mini-Mental State Examination.

CES-D = Center for Epidemiologic Studies Depression Scale.

* p < .05

** p < .01

^aTwo blocks, one for caregiver demographics (age (continuous); sex (indicator); educational attainment (ordinal)) and one for patient demographics (age (continuous), sex (indicator), educational attainment (ordinal) (F= df1 = 3, df2 = 34)).

^bBlock includes three variables measuring caregiver mental and physical health status at the time of the baseline interview: Caregiver depression score (CES-D); caregiver burden score; caregiver general health status score (F, $df_1 = 3$, $df_2 = 34$).

^cBlock includes the change in ratings of caregiver depression (CES-D), caregiver burden and caregiver general health status score (F, $df_1 = 3$, $df_2 = 34$).

^dBlock includes three variables measuring patient's mental and physical health status at baseline: Patient's MMSE score; SF-12 physical health summary score; SF-12 mental health summary score (F, $df_1 = 3$, $df_2 = 34$).

^eBlock includes change in patient's MMSE score only, SF-12 scores only captured at baseline (F, $df_1 = 1$, $df_2 = 34$).

^fBlock includes total household income (ordinal), years of living together (continuous), race/ethnicity (indicator), Non-spouse status was co-linear with total years living together and was removed from the model (F, $df_1 = 3$, $df_2 = 34$).

^gFull model evaluates the contribution of all variables above in explanation of residual of caregiver rating regressed on patient rating (F, $df_1 = 19$, $df_2 = 34$).