Using the EQ-5D-5L and EQ-VAS to Examine the Suitability of Patients' Proxy Assessments of Caregivers' HR-QoL

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Abstract

Objective: Decision makers increasingly recognize that innovative treatments benefit not only patients but also have spillover effects on caregivers. However, there can be logistic challenges to health outcomes assessments from not only the patients but also the caregivers. This study investigated the suitability of care-recipients as proxies by examining the level of agreement between caregivers' self and patients' proxy assessments of caregivers' HR-QoL using the EQ-5D-5L and EQ-VAS measures.

Methods: A US-based cross-sectional survey was conducted in 504 caregiver-patient dyads using an online Qualtrics panel between August 2022 and February 2023. Both caregivers and patients completed self and proxy versions of EQ-5D-5L and EQ-VAS. Directional bias was assessed using mean difference scores and strength of agreement was quantified using intraclass correlation coefficients (ICC), interpreted as poor (0-0.2), fair (0.2-0.4), moderate (0.4-0.6), substantial (0.6-0.8), and excellent (>0.8).

Results: Caregivers' mean (SD) age was 49.2 (±15.4) years and that of patients was 62.7 (±18.9) years. Dyads were most commonly spouses/partners (34.5%). Fair to moderate agreement between caregivers' self-assessment and proxy assessment by patients was observed across EQ-5D dimensions (ICC (95% CI) from highest to lowest: PD = 0.55 (0.50, 0.61); AD = 0.51 (0.45, 0.58); MO = 0.51(0.44, 0.57); SC= 0.41 (0.33, 0.48); UA = 0.37 (0.30, 0.45)) and summary scores (ICC (95% CI): VAS = 0.57 (0.51, 0.63); Index = 0.54 (0.47, 0.60)), whereas moderate to excellent agreement was observed between patient self-assessment and proxy assessment by caregiver across EQ-5D dimensions (ICC (95% CI) from highest to lowest: MO=0.82 (0.79, 0.84); SC=0.80 (0.76, 0.83); PD=0.71 (0.66, 0.75); UA=0.69 (0.64, 0.74); AD=0.59 (0.53, 0.64)) and summary scores (ICC (95% CI): Index=0.81 (0.77, 0.83); VAS=0.74 (0.70, 0.78)). Notably, caregivers tended to underestimate patients' HR-QoL (VAS and index score mean differences (SD), 2.32 (16.46) and 0.03 (0.23), respectively), and care-recipients tended to overestimate caregivers' HR-QoL (VAS and index score mean differences (SD), -6.35 (17.50) and -0.06 (0.26), respectively). Results did not differ based on relationship, time (hours/week) of caregiving, and baseline HR-QoL.

Conclusion: Results suggest the use of care-recipients as proxies is slightly less reliable than when caregivers serve as proxies for care-recipients. Notably, care-recipients tended to overestimate caregiver HR-QoL, whereas caregivers tended to underestimate patient HR-QoL. The threshold for acceptability where care recipients can serve as proxies for caregivers or at least provide valuable insight into spillover effects in terms of health outcomes using the EQ-5D and other measures of health warrants further research as a mechanism for capturing broader health effects of innovative health interventions.

Introduction

Health-related quality of life (HR-QoL) is a multidimensional concept that refers to how individuals perceive and function in their daily lives across physical, psychological, and social domains.[1] HR-QoL assessments rely on the respondents' self-report as the primary source of information, offering invaluable insights into the person's HR-QoL directly from their perspective. [1-5] However, in situations where self-reporting is difficult or impossible, such as with individuals facing cognitive impairments or communication barriers, a proxy may be asked to substitute or complement the individual's assessment of HR-QoL.[3,6] Traditionally, caregivers or family members have served as proxies, offering an alternative perspective on the patient's HR-QoL, helping to overcome obstacles like selection bias and the potential exclusion of respondents who cannot respond for themselves from research. This inclusivity is important for enhancing the power and generalizability of outcomes research and clinical trials, especially when HR-QoL serves as a primary endpoint. [7-9] Currently, proxy assessments by caregivers have been utilized to not only substitute for patients' assessment of HR-QoL in clinical trials to avoid missing data but also inform clinical decisions regarding caregiving by reinforcing and complementing information provided by self-assessments.[5] Despite the advantages, proxy assessment could raise issues when using self-assessments of HR-QoL as the gold standard. [7,10,11] For example, proxies often perceive patients' HR-QoL more negatively than the patients themselves, and those experiencing pain or depressive symptoms may offer more skewed assessments of these conditions.[7,9-11]

Informal caregivers are relatives, friends, or neighbors who provide ongoing assistance, typically unpaid, to someone with physical, mental, or cognitive limitations. [12,13] The impact of illness goes beyond the patient, affecting unpaid caregivers and other family members with out-of-pocket expenses, lost time, lost productivity, and decreased HR-QoL from caring for a sick family member.[14] These consequences known as "family spillover effects" are increasingly recognized in the literature and the importance of considering caregivers' HR-QoL in evaluating innovative medical interventions is growing. [15-19] Current guidelines and frameworks, such as the National Institute of Health and Care Excellence and the Second US Panel on Cost-effectiveness, emphasize the importance of measuring and valuing caregiver HR-QoL effects but provide limited guidance on which measures to use. [20,21] Furthermore, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Special Task Force on US Value Assessment Frameworks, known as the "ISPOR value flower", identifies "caregiver spillovers" as a core element of value, including caregiver QoL.[21] However, economic evaluations often overlook the costs and effects of informal caregivers, potentially affecting cost-effectiveness inferences and recommendations. Incorporating family spillover costs and health effects from CEAs can meaningfully influence cost-effectiveness outcomes for illnesses that have a high caregiving responsibility. [22]

Researchers often point to the lack of data as a reason for excluding family spillover effects in CEAs. [23,24] Gathering self-assessed HR-QoL data from informal caregivers is challenging due to their limited availability and accessibility in clinical trials or studies. This challenge raises the question of whether patients as recipients of care can provide a reliable proxy assessments of caregiver HR-QoL? Such an approach could be a pragmatic solution to get insight into caregiver HR-QoL without needing both the patient and caregiver to complete assessments. Previous studies have examined agreement between patients' self and caregivers' proxy assessments of patients' HR-QoL, alongside factors contributing to various levels of agreements.[10,25-30] However, the notable gap in the literature is the absence of studies exploring the reverse scenario – assessment of caregivers' HR-QoL using care recipients as the proxy. To bridge the gaps in literature, the primary objective of this study was to examine the level of agreement between caregivers' self and patients' proxy assessments of caregivers' HR-QoL using the EQ-5D-5L and EQ-VAS measures in a diverse sample of informal caregivers and patients in the U.S. Our hypothesis is that higher level of agreement would be observed in dimensions that are more observable, such as mobility, and lower level of agreement would occur in dimensions that are more subjective, such as anxiety/depression. A secondary objective was to explore the mean differences between self and proxy responses from both caregivers and patients to determine the direction and magnitude of the discrepancies between two assessments. Our hypothesis is that proxy assessments would rate HR-QoL more negatively than self-assessments which is typical of the literature on the assessment of patient HR-QoL by caregivers as proxies. This research is particularly significant as it evaluates the feasibility of patient proxy assessment for caregivers' HR-QoL, which could be valuable since it would require only a single respondent instead of needing both patients and caregivers to complete assessments. When EQ-5D is used, this introduces a novel methodological approach for use of proxy assessment in health technology assessments.

Methods

Research Ethics

The Institute Review Board at the University of Illinois at Chicago has granted exemption for this study (approval number: 2022-0490)

Design

This was a prospective cross-sectional study involving the administration of measures related to caregiver health and well-being to patient-caregiver dyads.

Participants

Eligible participants included caregivers aged 18 years or over who provided unpaid care to relatives, or friends aged 18 years or over for the past six months with at least an hour a week and had the patient willing and able to participate in the survey. Patients were required to confirm being at least 18 years of age and receiving care from their caregivers within the last six months.

Survey Development and Data Collection

The survey was developed, tested, and conducted on the Qualtrics survey platform (Provo, UT, USA) between August 2022 and February 2023. Participants recruited from Qualtrics were self-identified caregivers. The sequential linking method was selected for data collection as it allowed caregivers and patients to complete the survey consecutively during a single session, resulting in more efficient data collection. Several steps were taken for survey completion. First, caregivers provided informed consent, confirmed eligibility, and shared information about their caregiving relationships with their patients. Second, the caregivers self-completed the EQ-5D-5L measure (self and proxy assessment), followed by demographic, clinical and socioeconomic questions. Patients then completed the same sequence of survey sections (including self and proxy assessment of EQ-5D). A reminder page was included before caregiver and patient survey parts, asking participants to complete the survey without consulting their companion and refrain from discussing their answers until both members of the dyad had finished the survey.

Validity Checks and Data Quality

To assure the validity of caregiver-care recipient dyads and prevent situations where one participant completes the survey for both, certain checks based on demographic and relationship variables were implemented. These include the number of years the participants have known each other, the nature of their relationship, and the gender of the other participant.[31] A duplicate demographic question regarding age was also used for individual respondents.[32] Dyadic, individual, and quality check were implemented to ensure authenticity and to address potential issues, such as a participant not passing the survey to the other after completion. Based on recommendations from previous dyadic research, we carried out dyadic checks on demographic and relationship variables, such as years of knowing each other, nature of relationship, and the gender of the other participant. [31] In addition, age was used as a duplicate demographic question for individual validity checks. [32] Data quality was ensured through pre- and post-data collection checks to address the escalating issue of survey bots and inattentive respondents.[32-35] These included the use of Completely Automated Public Turing test to tell Computers and Humans Apart (CAPTCHA), cookies, I.P. address, geolocation data before data collection, invisible 'honeypot' questions, misspelled words, and image-based text questions. [33] To filter out inattentive respondents, commitment check, and attention-check questions tailored to the study were used. [34] Post data collection, we evaluated open-ended responses. Respondents who completed the survey in less than half of the median sample time (known as "speeders") were also excluded from the data set.

Measures

HR-QoL of caregivers were assessed using the EQ-5D-5L, a multi-attribute utility instrument comprising five dimensions: mobility (MO), self-care (SC), usual activities (UA), pain/discomfort (PD), and anxiety/depression (AD), accompanied by the Visual Analog Scale (EQ-VAS). [36,37] The EQ-5D-5L index scores were calculated using a scoring function based on the U.S. population preferences. [38] Both measures were implemented with both self-assessment and proxy assessment to caregivers and patients. Proxy assessments by caregivers for patients were listed for the purpose of mean difference comparisons.

Statistical Analysis

Descriptive analysis was conducted on caregivers' and patients' characteristics. The minimum sample size was determined using Flack et al.'s sample size formula.[39,40] Assuming the k=0.3 versus the alternative hypothesis k=0.5, with a significance level of 0.05 and power of 90%, a minimum of 173 dyads were required. The strength of agreement between caregivers' self- and patients proxy responses of the EQ-5D-5L were evaluated using the two-way random effects intraclass correlation coefficient, ICC (2, k). [41] The level of agreement was interpreted as follows: poor (0-0.2), fair (0.2-0.4), moderate (0.4-0.6), substantial (0.6-0.8), and excellent (>0.8). [42] Directional biases of dimensional and index scores between caregivers' self- and patients' proxy assessments were quantified with mean difference scores (self minus proxy assessment) and effect sizes (ES), interpreted with the following thresholds: small (d=0.2), medium (d=0.5), large (d=0.8), and very large (d=1.4). [43] In addition, 95% confidence intervals of ICCs were calculated with R package "irr". The analyses were conducted using SAS Version 9.4, Copyright SAS Institute., Cary NC, USA and RStudio Version 2021.09.

Results

Caregiver and Patient's Demographic Characteristics

Of 4,714 respondents who initiated the survey, 2,651 were screened out by eligibility questions, 244 by dyad validity checks, 957 by individual validity checks, and 317 by quality checks. Finally, 285 being excluded after quotas for race and gender were met. After fulfilling inclusion criteria and data quality checks, a total of 504 caregiver-care recipient dyads successfully completed the survey. [44] The average age for caregivers was 49.2 (SD, ±15.4) years, while that of patients was 62.7 (SD, ±18.9) years. **[Table 1]** The majority of caregivers were female (number, percentage; 290, 57.5%) and white (369, 73.2%), which reflects the demographics of informal caregivers in the U.S. [45] In addition, the racial and ethnic distribution of caregivers in our sample also largely aligns with U.S. informal caregiver statistics: 73.2% of white in our sample versus 67.2% in the U.S., 15.7% of black versus 12.9% in the U.S., and 12.3% of Hispanic versus 13.8% in the U.S. [44] Our sample also reflects the age distribution of caregivers in the U.S, with 45.2% under age of 45, 32.5% between age of 45-64, and 22.6% with age of 65 or older.[44] 34.5% of caregivers were spouses/partners of patients, 4.2% are children, 29.8% are parent(s), 6.2% are sibling(s), 6.0% are other relatives, 11.9% are friends/family friends, and 7.5% are grandparents. 68.3% of caregivers lived with the patients, and approximately 60% had the option to choose whether to take on the caregiver role. Caregivers' EQ-5D-5L Index and EQ-VAS score were 0.73 (SD = 0.28) and 71.45 (±20.63), respectively, while that of patients were 0.43 (SD = 0.40) and 55.33 (SD = 23.66), respectively. The lower health scores observed in our study compared to those of general population in the U.S (EQ-5D-5L Index: 0.85 (±0.21)) underscore the validity of our cohort, highlighting their pronounced functional limitations, and the need for optimal caregiving processes.[44,46]

Level of Agreement in Proxy Assessments

Overall, the level of agreement between caregivers' self and patients' proxy assessments was lower than the level of agreement between patients' self and caregivers' proxy assessments in all five dimensions, as well as the EQ-5D-5L Index and EQ-VAS score **[Table 2, 3/Graph 1]**. Fair to moderate agreement (ICC=0.37-0.60) was observed when patients' were proxies for caregivers across EQ-5D-5L dimensions from highest to lowest (ICC, 95%CI): PD = 0.55, (0.50, 0.61); AD = 0.51, (0.45, 0.58); MO = 0.51, (0.44, 0.57); SC= 0.41, (0.33, 0.48); UA = 0.37, (0.30, 0.45)) and summary scores (ICC, 95% CI): VAS = 0.57, (0.51, 0.63); Index = 0.54, (0.47, 0.60)). Moderate to excellent agreement (ICC=0.41-1.00) was observed in caregivers serving as patients' proxies across EQ-5D dimensions (ICC, 95% CI) from highest to lowest: MO=0.82, (0.79, 0.84); SC=0.80, (0.76, 0.83); PD=0.71, (0.66, 0.75); UA=0.69, (0.64, 0.74); AD=0.59, (0.53, 0.64)) and summary scores (ICC, 95% CI): Index=0.81, (0.77, 0.83); VAS=0.74, (0.70, 0.78)).

Mean Differences at Self and Proxy HR-QoL Assessments

Notably, from examining the mean differences between self and proxy assessments, we found that patients tend to overestimate caregivers' HR-QoL in all five dimensions (Dimension: mean difference (ES); MO: 0.06 (d=0.07); SC=0.11 (d=0.15); UA=0.24 (d=0.28); PD=0.20 (d=0.20); AD=0.24 (d=0.21)), EQ-5D-5L Index (Difference, Effect Size; -0.06, 0.22) and EQ-VAS score (-6.35, 0.32) **[Table 3/Graph 2]**. On the other hand, caregivers tend to underestimate patients' HR-QoL except the mobility dimension (Dimension/Index=Difference, Effect Size): MO=0.04, 0.04; SC=-0.04, 0.03; UA=-0.14, 0.12; PD=-0.04, 0.04; AD=-0.30, 0.26; EQ-VAS=2.32, 0.10; EQ-5D-5L Index=0.03, 0.09. Both the results from level of agreement and mean differences between self and proxy assessments of caregivers and patients' HR-QoL did not differ based on time of caregiving, baseline EQ-5D-5L Index score, living situation and memory issues of patients **[Supplement 2.1, 3.1, 4.1-4.5]**.

Discussion

This study is the first to investigate the agreement between caregiver's self-assessment and patient's proxy assessment of caregiver's HR-QoL using the EQ-5D-5L across a diverse sample of caregiver-patient dyads in the US. Our analysis revealed fair to moderate agreement between caregiver self-assessments and patient proxy assessments across all five dimensions of EQ-5D-5L as well as the VAS and index-based summary scores. Similar results were found when subgroup analyses were conducted, indicating that relationships to caregivers, time spent caregiving, caregivers', and patients' baseline HR-QoL had minimal effects on the level of agreement. These results challenge our initial hypothesis that higher levels of agreements would be observed in more observable dimensions of health, such as mobility and usual activities, and that lower levels of agreements would be found in more subjective dimensions, such as PD and AD.

The findings revealed interesting patterns in the agreements between self- and proxy-assessments of caregivers and patients. Caregivers, when acting as proxies, generally systematically underestimated (except the mobility dimension) patients' HR-QoL assessments, which is consistent with the current literature that proxy assessments tend to underestimate self-assessments of HR-QoL. [47] Conversely, patients, when serving as proxies for caregivers' HR-QoL assessments, systematically overestimated caregivers' HR-QoL. Markedly, based on the mean differences and effect size results, these systematic differences were larger and in the opposite direction when patients serve as proxies for caregivers compared to when caregivers are proxies for patients. These discrepancies suggest there is room for enhancing communication and understanding between caregivers and patients, aiming to fortify their relationships through better mutual recognition of each other's HR-QoL.

This research has important implications for both future studies and healthcare policy. Informal caregivers, who are invaluable in providing care for individuals with health conditions or disabilities, often experience a decline in their own HR-QoL due to the multifaceted strains of caregiving.[12,13] Accurately assessing caregivers' HR-QoL is therefore essential for comprehensive economic evaluations to capture the full value of healthcare interventions. The presence of trivial to small systematic biases in patient proxy reporting highlights the potential for these assessments at a group-level to offer valuable insights into caregivers' HR-QoL, whether alongside caregiver self-assessments or substituting self-reports when unavailable. This could be particularly relevant in situations where direct caregiver assessments are often unfeasible or logistically burdensome, like clinical trials. By utilizing patients as a single source for both their own and their caregivers' HR-QoL data, our study offers a viable method to include caregiver spillover effects in health technology assessments. Ultimately, this approach could lead to more informed research and policy-making that fully captures healthcare interventions' impacts, considering the broader effects on both patients and caregivers.

Several limitations should be considered when interpreting the results. First, the generalizability of the results could be limited due to the online format of recruitment and assessments, including internet access limitation for those with lower socioeconomic status or poorer baseline health state. Additionally, the self-reported nature of data from the self and proxy assessments may be subject to response biases. Lastly, this study had a cross-sectional study design so the extent to which these trends in responses persistent across time would be informed by further study using a longitudinal study design. Of note, our study utilized EQ-5D-5L for both self and proxy assessments from caregivers and patients, which is consistent with the current NICE (The National Institute for Health and Care Excellence) guideline recommends EQ-5D for caregivers' HR-QoL assessment.[48,49]

Conclusions

Our study makes a novel contribution as the first investigation of patient proxy assessment for caregiver HR-QoL using the EQ-5D-5L. Results suggest the use of care-recipients as proxies is slightly less reliable than when caregivers serve as proxies for care-recipients. Notably, care-recipients tended to overestimate caregiver HR-QoL, whereas caregivers tended to underestimate patient HR-QoL, a finding consistent with the substantial literature on caregivers as proxies. The threshold for acceptability where care recipients can serve as proxies for caregivers or at least provide valuable insight into spillover effects in terms of health outcomes using the EQ-5D and other measures of health warrants further research as a mechanism for capturing broader health effects of innovative health interventions.

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Table 1. Respondent Characteristics

Sociodemographic Characteristics (n=504)	Caregivers N (%)	Patients N (%)
Age (years), mean (±SD)	49.2 (15.4)	62.7 (18.9)
Age Group (years)		
18-44	226 (45.2)	102 (20.2)
45-64	164 (32.5)	114 (26.6)
65+	114 (22.6)	288 (57.1)
Gender		
Male	213 (42.3)	238 (47.2)
Female	290 (57.5)	264 (52.4)
Agender (self-described)	1 (0.2)	2 (0.4)
Race/Ethnicity[a]		
White	369 (73.2)	362 (71.8)
Black or African American	79 (15.7)	79 (15.7)
American Indian or Alaskan Native	13 (2.6)	5 (0.9)
Asian	27 (5.4)	26 (5.1)
Hispanic or Latino or Spanish Origin of any race	62 (12.3)	55 (10.9)
Native Hawaiian or Other Pacific Islander	1 (0.2)	0 (0)
Others	3 (0.6)	3 (0.6)
Employment Status		
Employed (full-time, part-time or self-employed)	311 (61.7)	58 (11.5)
Retired, homemaker	138 (27.4)	233 (46.2)
Student, unemployed (unable to work due to disability, looking or not looking for work)	55 (10.9)	213 (42.3)
Marital Status		
Married, engaged, living with partner	350 (69.4)	248 (49.2)
Widowed, divorced, or separated	71 (14.1)	184 (31.7)
Single, never married	83 (16.5)	72 (36.9)
Educational Attainment		

High school degree/GED or less	103 (20.4)	229 (45.4)
Technical school, associate or some college (no degree)	204 (40.5)	131 (26.0)
Bachelor’s degree	106 (21.0)	86 (17.1)
Master’s, professional, or doctorate degree	91 (18.1)	58 (11.5)
Difficulty in Meeting Monthly Household Expenses		
Not difficult	195 (38.7)	206 (40.9)
Slightly difficult	146 (29.0)	125 (24.8)
Somewhat difficult	81 (16.1)	83 (16.5)
Very difficult	52 (10.3)	55 (10.9)
Extremely difficult	30 (6.0)	35 (6.9)
Health and Relationship Quality		
General Health		
Excellent	48 (9.5)	10 (2.0)
Very good	144 (28.6)	37 (7.4)
Good	180 (35.7)	124 (24.6)
Fair	113 (22.4)	207 (41.1)
Poor	19 (3.8)	126 (25.0)
Instruments (Score, ±SD)		
EQ-5D-5L Index	0.73 (0.28)	0.43 (0.40)
EQ-VAS	71.45 (20.63)	55.33 (23.66)
Caregiving Situation		
Relationship to patients		
Spouse/partner	174 (34.5)	
Parent	21 (4.2)	
Child	150 (29.8)	
Sibling	31 (6.2)	
Another relative (not child, sibling, parent, grandparent)	30 (6.0)	
Friend/family friend	60 (11.9)	
Grandchild	38 (7.5)	

Reason for Aiding Patient [a]	
Physical condition (short-term)	75 (14.9)
Physical condition (long-term)	297 (58.9)
Emotional or mental health problem	148 (29.4)
Developmental or intellectual disability or delay	35 (6.9)
Behavioral issue	50 (9.9)
Memory problem	127 (25.2)
Old age, aging	237 (47.0)
Other	31 (6.2)
Duration of Caregiving (years)	
0.5-1	48 (9.5)
1-2	141 (28.0)
3-5	158 (31.4)
6-10	88 (17.5)
10+	69 (13.7)
Primary Caregiver	
Yes	439 (87.1)
No	10 (2.0)
Sharing caregiving responsibilities about equally with someone else	55 (10.9)
Average Weekly Time Spent on Caregiving (hours)	
≤5	35 (6.9)
6-10	69 (13.7)
11-20	176 (34.9)
21-30	99 (19.6)
31-40	28 (5.6)
41+	46 (9.1)
Living in the Same Household as Patients	
Yes	344 (68.3)
No	160 (31.7)

[a] not mutually exclusive category

Note: EQ-5D-5L index scores were calculated using US-specific utility values. Higher scores on EQ-5D-5L and EQ-VAS represent better HR-QoL.

Table 2. Level of Agreement Between Patients Proxy Assessment and Caregivers Self Assessment

	All Dyads [n=504]	**Primary Caregiver [n=439]**	**Same Household [n=344]**
Dimensions	**ICC (95% CI)**	**ICC (95% CI)**	**ICC (95% CI)**
Mobility	0.51 (0.44, 0.57)	0.53 (0.44, 0.60)	0.53 (0.45, 0.60)
Self-Care	0.41 (0.33, 0.48)	0.39 (0.31, 0.47)	0.40 (0.31, 0.49)
Usual Activities	0.37 (0.30, 0.45)	0.37 (0.50, 0.62)	0.39 (0.29,0.47)
Pain/Discomfort	0.55 (0.49, 0.61)	0.56 (0.50, 0.62)	0.56 (0.49, 0.63)
Anxiety/Depression	0.51 (0.45, 0.63)	0.55 (0.48, 0.61)	0.55 (0.48, 0.62)
EQ-VAS Index	0.57 (0.51, 0.63)	0.59 (0.53, 0.65)	0.58 (0.50, 0.65)
EQ-5D-5L Index	0.54 (0.47, 0.60)	0.57 (0.48, 0.61)	0.57 (0.48, 0.62)

Table 3. Level of Agreement Between Caregivers Proxy Assessment and Patients Self Assessment

	All Dyads [n=504]	**Primary Caregiver [n=439]**	**Same Household [n=344]**
Dimensions	**ICC (95% CI)**	**ICC (95% CI)**	**ICC (95% CI)**
Mobility	0.82 (0.79, 0.84)	0.80 (0.77, 0.83)	0.81 (0.78, 0.85)
Self-Care	0.80 (0.76, 0.83)	0.79 (0.75, 0.82)	0.78 (0.74, 0.82)

Usual Activities	0.69 (0.64, 0.74)	0.70 (0.65, 0.75)	0.70 (0.64, 0.75)
Pain/Discomfort	0.71 (0.66, 0.75)	0.71 (0.67, 0.76)	0.73 (0.67, 0.77)
Anxiety/Depression	0.59 (0.53, 0.64)	0.62 (0.56, 0.67)	0.63 (0.56, 0.69)
EQ-VAS Index	0.74 (0.70, 0.78)	0.75 (0.71, 0.79)	0.77 (0.73, 0.81)
EQ-5D-5L Index	0.81 (0.77, 0.83)	0.80 (0.77, 0.83)	0.80 (0.76, 0.83)

Graph 1. Level of Agreement Between Self and Proxy Assessment

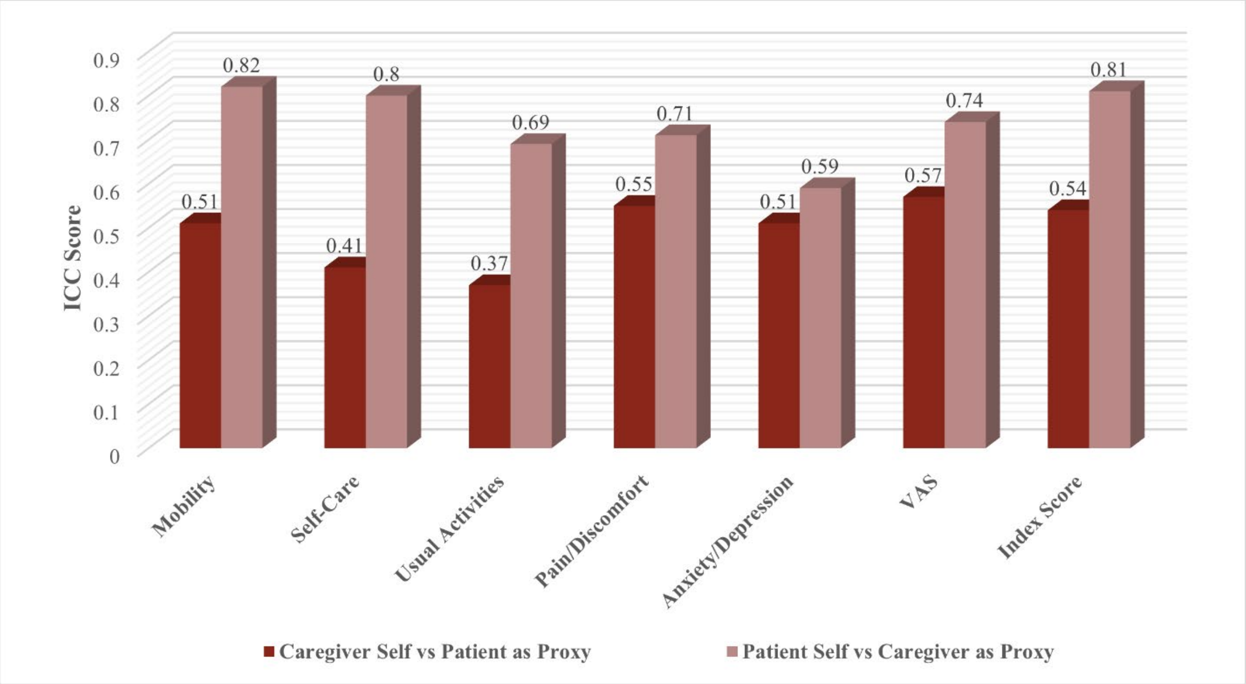
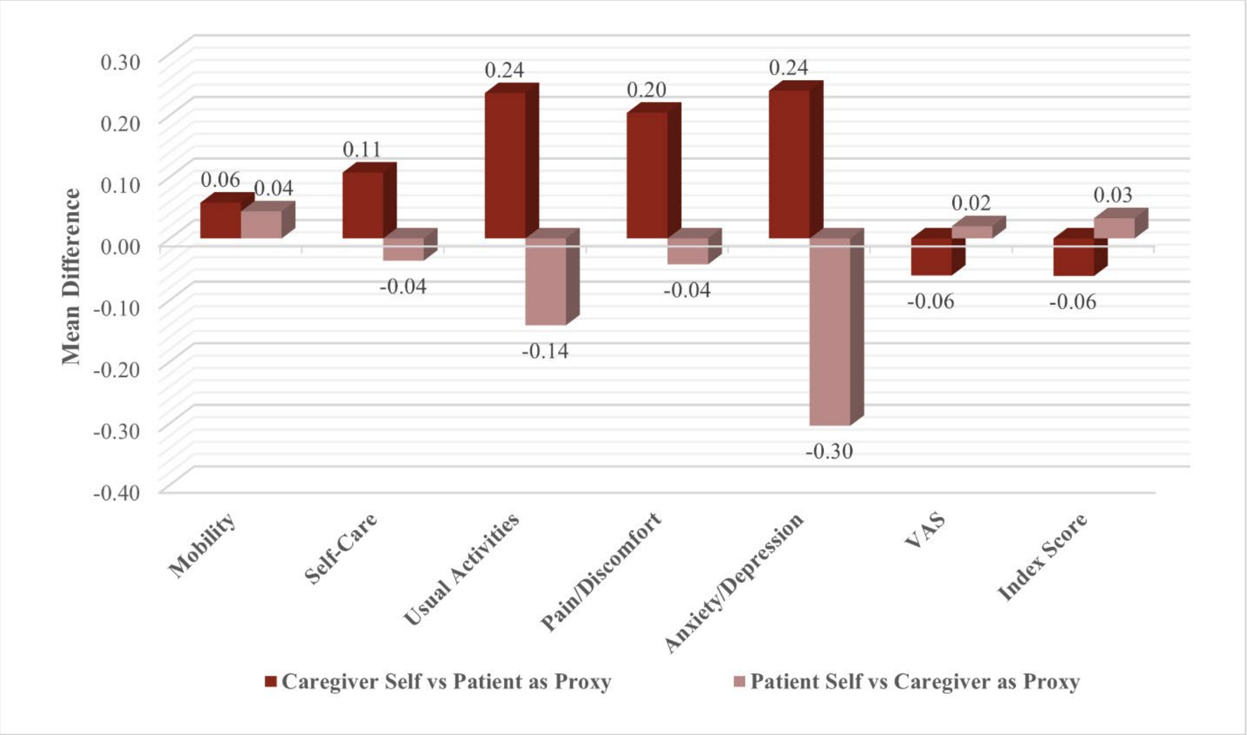


Table 4. Mean Differences Between Self and Proxy Assessments

	All Dyads			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**

Mobility	0.06 (0.84)	0.07	0.04 (1.23)	0.04
Self-Care	0.11 (0.70)	0.15	-0.04 (1.21)	0.03
Usual Activities	0.24 (0.84)	0.28	-0.14 (1.21)	0.12
Pain/Discomfort	0.20 (1.00)	0.20	-0.04 (1.08)	0.04
Anxiety/Depression	0.24 (1.12)	0.21	-0.30 (1.15)	0.26
EQ-VAS Index	-6.35 (19.87)	0.32	2.32 (22.92)	0.10
EQ-5D-5L Index	-0.06 (0.28)	0.22	0.03 (0.38)	0.09

Graph 2. Mean Differences Between Self and Proxy Assessment



Supplement

Supplement 2.1 Level of Agreement Between Patients Proxy Assessment and Caregivers Self Assessment

	Caregiver Index Score <1 [n=416]	**Patient Index Score <1 [n=476]**	**Patient without Memory Issues [n=362]**
Dimensions	**ICC (95% CI)**	**ICC (95% CI)**	**ICC (95% CI)**
Mobility	0.50 (0.43, 0.57)	0.52 (0.45, 0.58)	0.51 (0.43, 0.58)
Self-Care	0.42 (0.34, 0.50)	0.41 (0.33, 0.48)	0.46 (0.37, 0.53)
Usual Activities	0.33 (0.24, 0.42)	0.38 (0.30, 0.46)	0.40 (0.31, 0.48)
Pain/Discomfort	0.49 (0.42, 0.56)	0.55 (0.48, 0.61)	0.55 (0.48, 0.62)
Anxiety/Depression	0.46 (0.38, 0.53)	0.52 (0.45, 0.58)	0.52 (0.44, 0.59)
EQ-VAS Index	0.54 (0.47, 0.61)	0.56 (0.50, 0.62)	0.60 (0.53, 0.66)
EQ-5D-5L Index	0.53 (0.42, 0.56)	0.55 (0.47, 0.59)	0.57 (0.48, 0.62)

Supplement 3.1 Level of Agreement Between Caregivers Proxy Assessment and Patients Self Assessment

	Caregiver Index Score <1 [n=416]	**Patient Index Score <1 [n=476]**	**Patient without Memory Issues [n=362]**
Dimensions	**ICC (95% CI)**	**ICC (95% CI)**	**ICC (95% CI)**
Mobility	0.80 (0.76, 0.83)	0.83 (0.80, 0.85)	0.84 (0.80, 0.87)
Self-Care	0.78 (0.74, 0.81)	0.81 (0.77, 0.84)	0.79 (0.75, 0.83)
Usual Activities	0.67 (0.61, 0.72)	0.70 (0.65, 0.74)	0.67 (0.61, 0.72)
Pain/Discomfort	0.71 (0.66, 0.75)	0.71 (0.67, 0.75)	0.70 (0.64, 0.75)
Anxiety/Depression	0.56 (0.49, 0.62)	0.61 (0.55, 0.66)	0.60 (0.53, 0.66)
EQ-VAS Index	0.73 (0.68, 0.77)	0.75 (0.71, 0.79)	0.76 (0.71, 0.80)
EQ-5D-5L Index	0.79 (0.75, 0.82)	0.82 (0.79, 0.85)	0.81 (0.77, 0.84)

Supplement 4.1 Mean Differences between Self and Proxy Assessments: Primary Caregiver

	Primary Caregiver			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**

Mobility	0.07 (0.84)	0.08	0.02 (1.22)	0.02
Self-Care	0.12 (0.69)	0.17	-0.04 (1.20)	0.03
Usual Activities	0.25 (0.86)	0.29	-0.14 (1.21)	0.12
Pain/Discomfort	0.21 (1.01)	0.20	-0.05 (1.07)	0.04
Anxiety/Depression	0.22 (1.14)	0.20	-0.28 (1.16)	0.24
EQ-VAS Index	-6.00 (20.19)	0.30	2.29 (22.92)	0.10
EQ-5D-5L Index	-0.06 (0.28)	0.22	0.04 (0.38)	0.10

Supplement 4.2 Mean Differences between Self and Proxy Assessments: Same Household

	Same Household			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**
Mobility	0.07 (0.88)	0.08	0.01 (1.24)	0.00
Self-Care	0.14 (0.73)	0.19	-0.07 (1.21)	0.06
Usual Activities	0.26 (0.89)	0.29	-0.18 (1.21)	0.15
Pain/Discomfort	0.17 (1.02)	0.17	-0.05 (1.08)	0.05
Anxiety/Depression	0.21 (1.14)	0.19	-0.30 (1.17)	0.26
EQ-VAS Index	-5.93 (20.22)	0.29	2.44 (23.19)	0.11
EQ-5D-5L Index	-0.06 (0.29)	0.21	0.04 (0.38)	0.11

Supplement 4.3 Mean Differences between Self and Proxy Assessments: Caregiver Index Score <1

	Caregiver Index Score <1			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**
Mobility	0.10 (0.88)	0.12	0.06 (1.21)	0.05
Self-Care	0.15 (0.73)	0.21	-0.06 (1.18)	0.05

Usual Activities	0.31 (0.88)	0.35	-0.15 (1.18)	0.13
Pain/Discomfort	0.31 (0.99)	0.31	-0.03 (1.06)	0.02
Anxiety/Depression	0.35 (1.12)	0.31	-0.32 (1.14)	0.28
EQ-VAS Index	-7.88 (19.91)	0.40	1.87 (22.77)	0.08
EQ-5D-5L Index	-0.09 (0.28)	0.31	0.04 (0.37)	0.10

Supplement 4.4 Mean Differences between Self and Proxy Assessments: Patient Index Score <1

	Patient Index Score <1			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**
Mobility	0.05 (0.85)	0.06	0.08 (1.20)	0.07
Self-Care	0.11 (0.71)	0.15	0.00 (1.21)	0.00
Usual Activities	0.24 (0.85)	0.28	-0.09 (1.18)	0.08
Pain/Discomfort	0.20 (1.00)	0.20	0.00 (1.04)	0.00
Anxiety/Depression	0.21 (1.12)	0.19	-0.25 (1.14)	0.22
EQ-VAS Index	-6.28 (19.86)	0.32	1.36 (22.45)	0.06
EQ-5D-5L Index	-0.06 (0.28)	0.21	0.02 (0.47)	0.05

Supplement 4.5 Mean Differences between Self and Proxy Assessments: Patient without Memory Issues

	Patient Without Memory Issues			
Dimensions	**Caregiver Self – Patient Proxy**		**Patient Self – Caregiver Proxy**	
	Mean (Pooled SD)	**ES**	**Mean (Pooled SD)**	**ES**
Mobility	0.05 (0.84)	0.06	0.04 (1.20)	0.04
Self-Care	0.10 (0.67)	0.15	-0.02 (1.17)	0.01
Usual Activities	0.22 (0.85)	0.26	-0.12 (1.19)	0.10

Pain/Discomfort	0.19 (0.99)	0.19	-0.04 (1.08)	0.04
Anxiety/Depression	0.19 (1.11)	0.17	-0.29 (1.16)	0.25
EQ-VAS Index	-5.33 (19.49)	0.27	0.92 (21.89)	0.04
EQ-5D-5L Index	-0.05 (0.28)	0.19	0.03 (0.37)	0.07