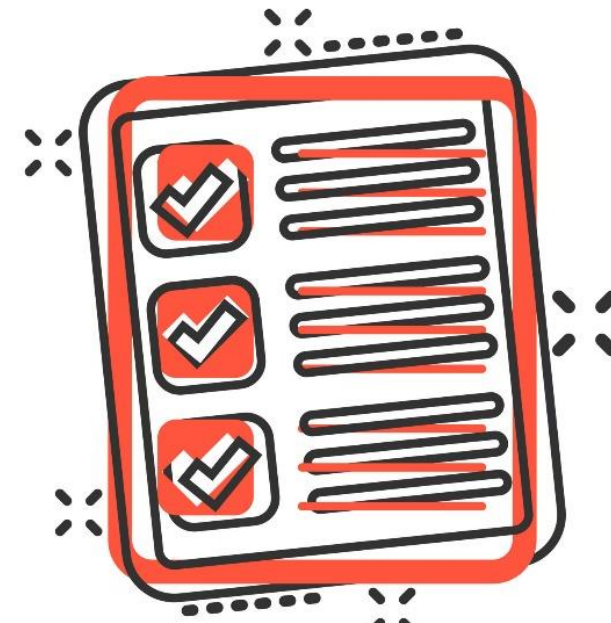


INTRODUCTION

- Value frameworks** for assessing innovative medical treatment include not only care-recipient (CR) outcomes but also caregiver (CG) spillover effects
- Outcomes assessments of both care-recipient and caregiver health and well-being are challenging to obtain. One option is to seek proxy ratings.**
- Most studies focus on level of agreement between care-recipients' (CR) self-assessments and proxy-assessments by caregivers to determine acceptability of proxy assessment.
- Care-recipients could potentially serve as a proxy source of information** on caregivers' health and well-being without having to get both care-recipients and caregivers to complete assessments.
- Few studies have ever examined whether the care-recipient is an acceptable proxy rater of caregiver health.

OBJECTIVE

To investigate the suitability of care-recipients as proxies by examining agreements between caregiver self and care-recipient proxy assessments of health and well-being.



METHODS

- Design:** A cross-sectional survey involving the administration of items and measures related to health and well-being of caregiver-care recipient dyads.
- Sample:** Data was collected from 504 eligible caregiver care-recipient dyads in the United States with an online Qualtrics panel between August 2022 and February 2023. Eligible caregivers were aged ≥ 18 years who provided unpaid care or assistant at least 1 hour per week to a relative or friend aged ≥ 18 years within the past 6 months. Eligible care-recipients were required to confirm receiving care from caregiver within the past 6 months and were able and willing to complete the survey.
- Measures:** Both caregivers and care-recipients completed self and proxy versions of a widely used and validated standardized measure of **health-related quality of life (HRQL)**, including the **EQ-5D-5L** (see below), a **multi-attribute utility instrument comprising five dimensions** and Visual Analog Scale (EQ VAS). EQ-5D-5L index scores were calculated using a scoring function based on U.S. population preferences.
- Statistical Analysis:**
 - Agreement between self and proxy assessments were quantified using intraclass correlation (ICC), interpreted as: Poor = 0-0.2; Fair = 0.21-0.4; Moderate = 0.41-0.6; Substantial = 0.61-0.8; Almost perfect = 0.81-0.99; Perfect = 1.0.
 - ICC 95% confidence intervals were calculated using R package "irr".
 - For means comparison, $\alpha=0.05$ (SAS version 9.4, R version 4.3.1)



RESULTS

TABLE 1: Caregiver and Care-Recipient Characteristics

Characteristics	CG N (%)	CR N (%)
Age (years), mean (\pm 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 ¹		
White	369 (73.2)	362 (71.8)
Black or African American	79 (15.7)	79 (15.7)
Hispanic/Latino	62 (12.3)	55 (10.9)
Others	44 (8.6)	34 (6.6)
Relationship to Care-Recipients		
Spouse/Partner	174 (34.5)	N/A
Parent	21 (4.2)	N/A
Child	150 (29.8)	N/A
Sibling	31 (6.2)	N/A
Others	128 (25.4)	N/A
Primary Caregiver		
Yes	439 (87.1)	N/A
No	10 (2.0)	N/A
Sharing responsibilities	55 (10.9)	N/A

¹: not mutually exclusive

FIGURE 1: Agreement Comparison of CG as Proxy vs CR as Proxy

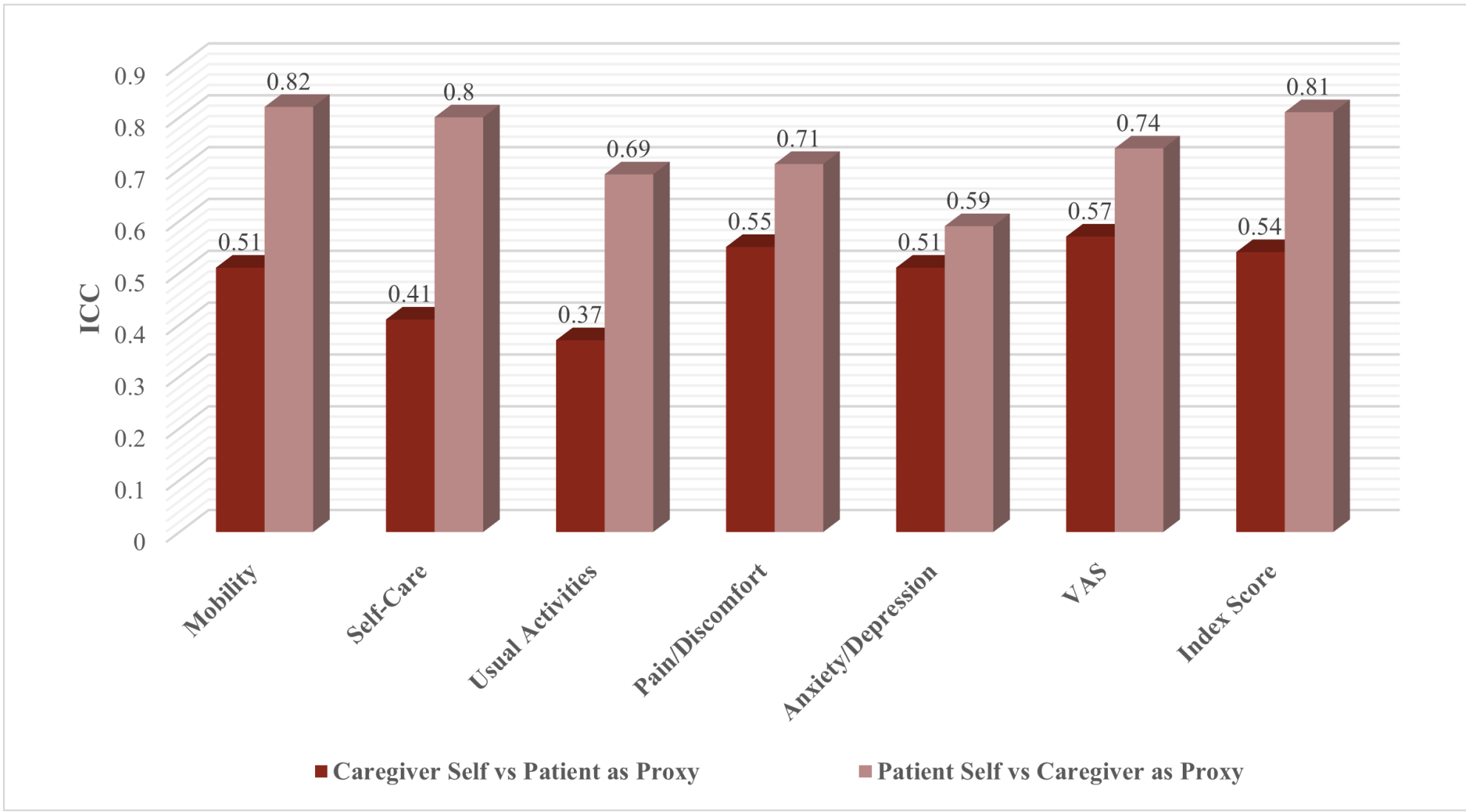


FIGURE 2: Mean Diff Comparison of CG as Proxy vs CR as Proxy

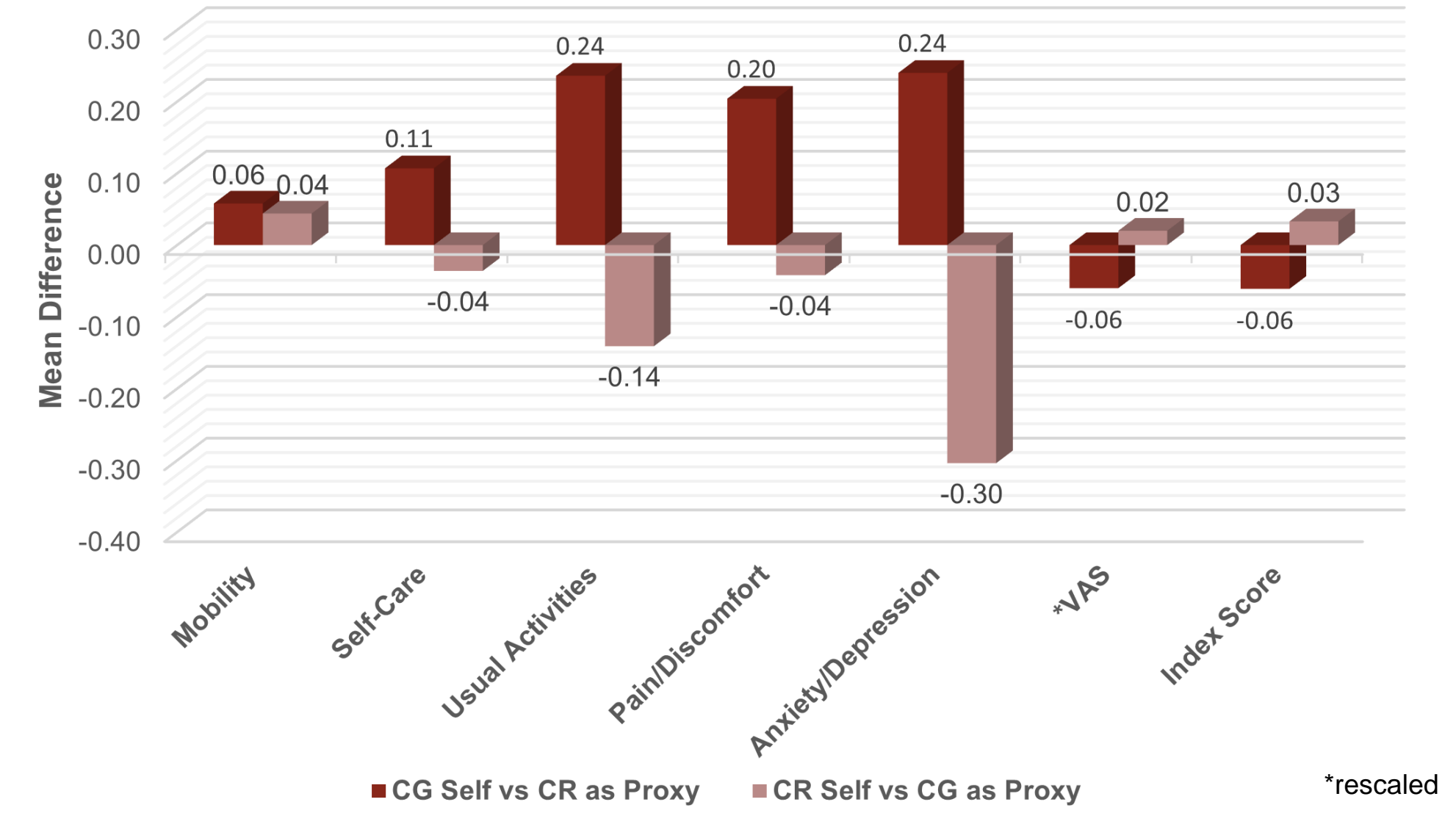
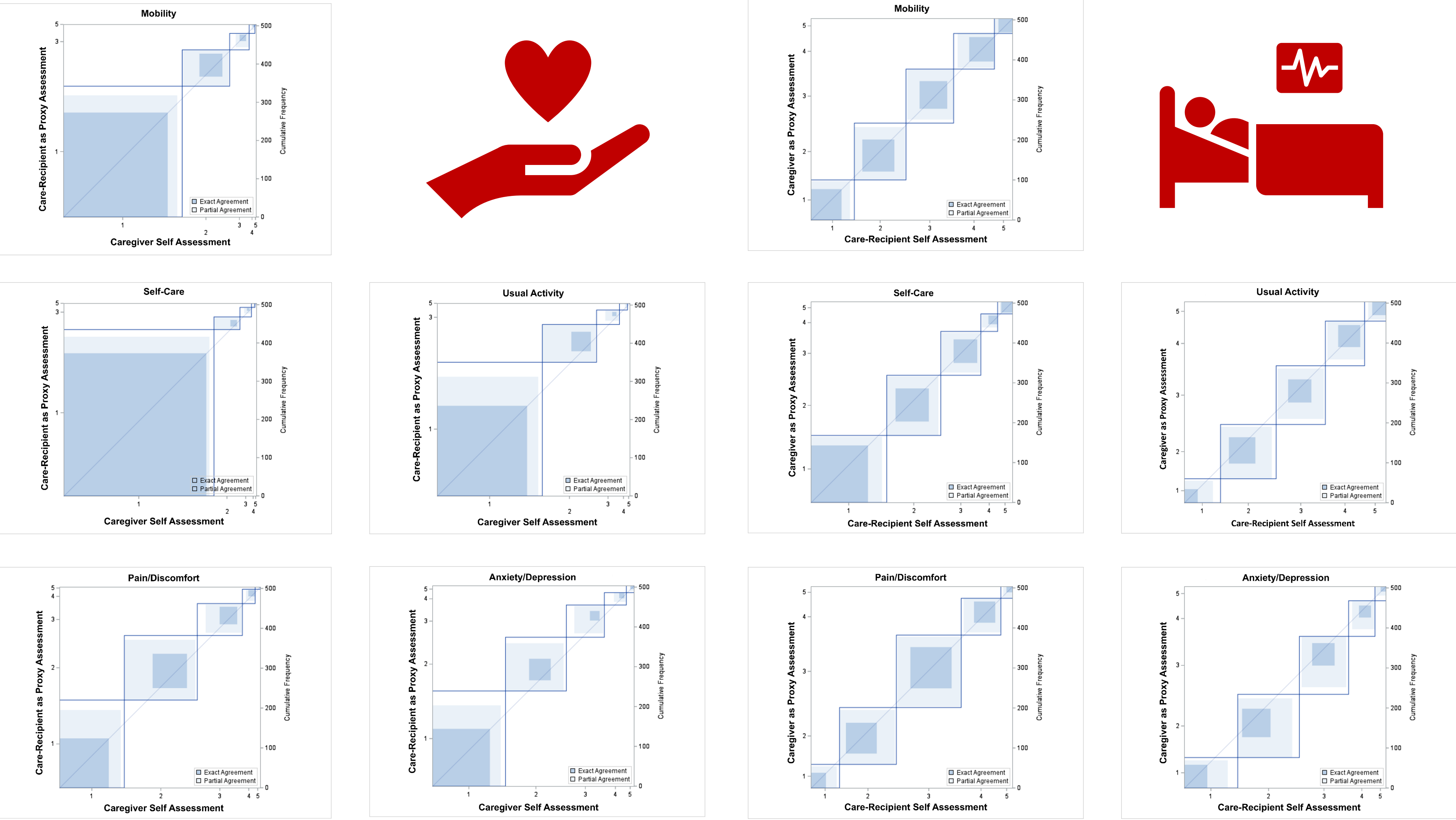
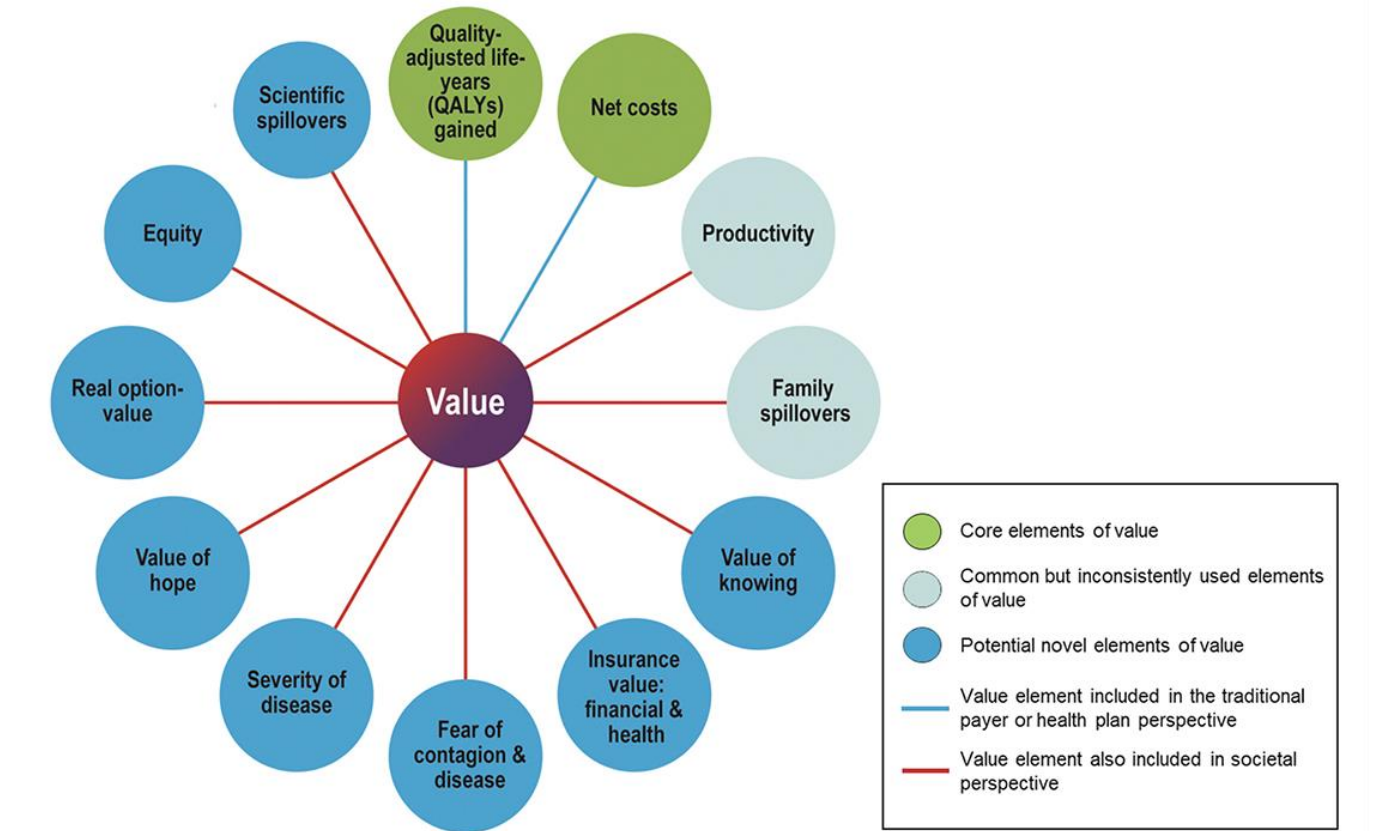


FIGURE 3: Cumulative Frequency of Exact & Partial Agreement in Caregiver-Care Recipient Dyads



DISCUSSION

- Fair to moderate agreements** were observed in all domains of **caregiver self versus care-recipient as proxy assessments.**
- Compared to caregivers' self assessment, care-recipients as proxy **overestimated** caregivers' health and well-being (HRQL), with **positive mean differences** in all five domain scores (1 = best, 5 = worst), and **negative mean differences** in the VAS (100 = best, 0 = worst) and index score (1 = best, 0 = worst).
- Moderate to almost perfect agreements** were observed in **all domains of care-recipients self vs caregivers as proxy assessments.**
- Compared to care-recipient self assessment, caregiver as proxy **underestimated** care-recipient's health and well-being (except mobility), with **negative mean differences** in the four domain scores, and **positive mean differences** in the VAS and index score.
- Higher agreements** were generally observed in **caregivers as proxies** for care-recipients compared to **care-recipients as proxies** for caregivers.
- Level of agreements **did not differ** based on caregivers' relationship to care-recipients, time spent caregiving, or health and well-being index.
- This study suggests that care-recipients as proxies for caregivers are slightly less reliable than when caregivers serve as proxies for care-recipients but may still be sufficient to serve as proxies.**
- Designing studies to use care-recipients as a proxy source to report caregivers' health and well-being holds promise as a mechanism for capturing broader effects of new innovative therapies on the family unit.



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