



# Do Parkinson's Disease Caregiver Proxy Reports Represent Patient Self-Reports?

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## INTRODUCTION

It is often difficult to corroborate patients' self-reports; the use of proxy responses may help. The purpose of this study was to evaluate patient-proxy agreement in a population of veterans with Parkinson's disease (PD) on measures of quality of life (QOL) and physical activity and to compare levels of agreement by patient subgroups of disease staging and depression.

## METHODS

We used a cross-sectional survey design conducted with PD patients seen at the MEDVAMC PADRECC. Proxies chose their answers based on the situation of their "friend or patient." Both patients and proxies independently completed the 8 components of the PD Questionnaire 39 (PDQ-39) and 3 questions related to physical activity. The Center for Epidemiologic Studies Depression Scale was given to both groups. Disease staging was measured by a neurologist using the Hoehn & Yahr (HY) and Schwab & England (S&E) instruments. Descriptive statistics were collected for demographics and the standardized measures. Confidence intervals were established for scores on all self-report measures. Intraclass correlation coefficients were calculated to estimate inter-rater reliability of patient and proxy responses and to compare responses by subgroups.

## RESULTS

| Depression (n=61)  | Score | n (%)      | Range |
|--------------------|-------|------------|-------|
| CES-D (patients)   | >16   | 46 (75.4%) | 0-53  |
| CES-D (caregivers) | >16   | 38 (62.5%) | 0-44  |

## Patient Characteristics

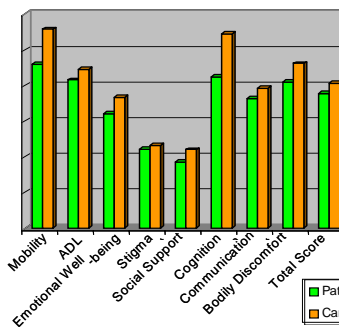
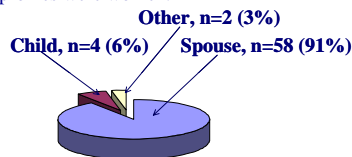
|                  | n  | Mean  | (SD)    | Range  |
|------------------|----|-------|---------|--------|
| Age of Veterans  | 64 | 74.41 | (5.72)  | 58-83  |
| Hoehn & Yahr     | 64 | 2.50  | (0.90)  | 1-5    |
| Schwab & England | 46 | 74.89 | (21.07) | 30-100 |

## Proxy Characteristics

### Proxies (n=64)

Gender: 59 (92%) of proxies were women.

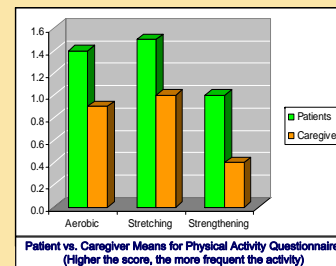
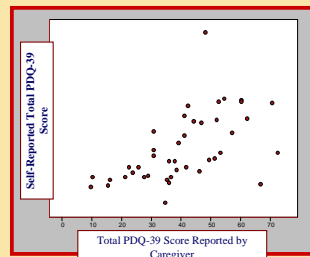
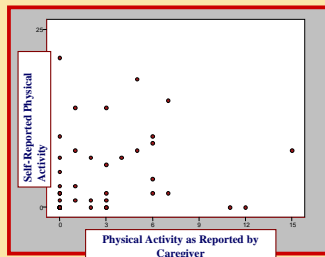
## Proxy Relationships



Patient vs. Caregiver Means for PDQ-39 Subscales, p>0.05 (Higher scores = lower QOL)

## CONCLUSIONS

- ▶ Since patients report a higher QOL and lower disability than proxies, caregivers may benefit from learning how patients perceive the experience of PD.
- ▶ Clinicians need to assess the level of depression in patients with PD and initiate referral/treatment as appropriate.
- ▶ PD patients need encouragement for physical activity.
- ▶ Clinicians and families need to reconsider their assumptions about the impact of PD disability on QOL, depression, and activity levels.
- ▶ Further research is needed to assess the validity of proxy reports for PD patients in all stages of illness.
- ▶ Caregiver characteristics and their impact on proxy reports need further study.



Patient vs. Caregiver Means for Physical Activity Questionnaire, (Higher the score, the more frequent the activity)



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