



PADRECC

# When Researchers in Parkinson's Disease Say, "Quality of Life," What Do They Measure?

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"Health is not only the absence of infirmity and disease but also a state of physical, mental and social well-being." World Health Organization

## INTRODUCTION

Interviews with patients who have Parkinson's disease (PD) indicate their concerns are not restricted to the motor functioning domain. Researchers often explicitly state the importance of "quality of life" (QOL) outcomes for understanding treatment effectiveness. However, there is no widely accepted definition of QOL.

The purpose of this study was to catalogue both the explicit and implicit definitions of QOL in PD studies.

## METHODS

**Data.** Using PubMed we identified all Medline citations that included the key words "quality of life" and "Parkinson's disease." From this database, we eliminated papers that: (1) did not target PD, (2) were measurement development papers, or (3) did not have an empirical component (e.g., letters, tutorials).

**Analyses.** The remaining studies were reviewed to determine if they included an explicit definition of QOL. In addition, we collected the outcome instruments used in each study (excluding ad hoc measures) and coded them according to the targeted domains. Based on these data, the studies were categorized by measured domains and summary statistics were calculated.

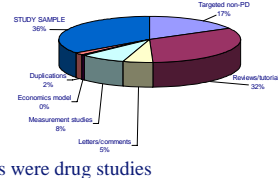
## RESULTS

### Case Identification

223 studies were reviewed, 78 (36%) met inclusion criteria

### Study Sample Characteristics

- 39 (50%) were intervention studies
- 20 (51%) of the 39 intervention studies were drug studies
- 53% of the studies only measured physical domains



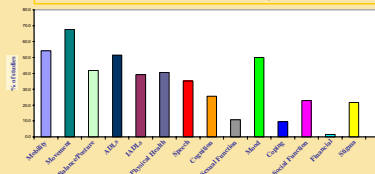
### Definitions of QOL

- Though all 78 studies referred to QOL, only 11 (14%) explicitly defined what was meant by the term.
- Sample definition:

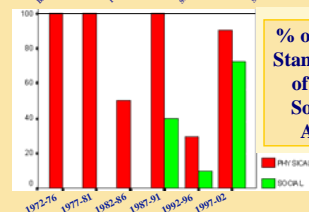
QOL is a broad and multidimensional concept including physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and self-reported general health.<sup>1</sup>

<sup>1</sup>L. D. Frazier. Coping with disease-related stressors in Parkinson's disease. *Gerontologist* 40 (1):53-63, 2000.

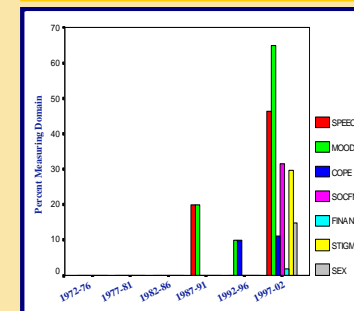
## % of Studies Measuring Domains



## % of Studies Using Standard Measures of Physical and Social Domains Across Years



## % of Studies Measuring Psychosocial Domains Across Time



## CONCLUSIONS

Though the term "quality of life" is often used in PD studies, it is seldom defined.

PD is often evaluated in terms of physical variables (e.g., function, mobility) and much less frequently in terms of psychosocial variables (e.g., coping, well-being).

There is an increasing tendency on the part of researchers to assess the impact of disease on psychosocial as well as physical outcomes. This is an encouraging finding since, from the perspective of the patient, PD impacts a wide range of physical and psychosocial domains. The measurement of these domains allows "patient-centered" evaluation of treatment effectiveness.

