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Measuring quality of life in palliative care for Parkinson's disease: a clinimetric comparison

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Keywords

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INTRODUCTION

Neuropalliative care is an emerging field with high relevance to neurodegenerative conditions [1,2]. Implementation of palliative interventions for Parkinson's disease (PD) has been increasing [3,4] given far-reaching effects of its motor and non-motor symptoms and relatively long disease duration. PD palliative care needs occur at all stages of the disease, but increase significantly at later stages, with worsening motor fluctuations, cognitive impairment, and caregiver strain [5,6]. In addition to symptomatic issues, people with PD also contend with practical problems, such as the need for better communication and education about the disease process [7]. In response, clinicians and researchers have become increasingly aware of the need for a palliative approach, including compassionate conversations around diagnosis and prognosis, discussion of goals of care and advance care planning, complex symptom management, and caregiver support, all with the goal of optimizing quality of life for the person living with PD and their loved ones [3].

As the application of palliative interventions for PD increases, so does the need for validated scales that measure outcomes targeted by palliative care, namely quality of life (QOL). QOL in the context of chronic conditions like PD encompasses a mix of physical, psychological, financial, spiritual, and socioeconomic factors [8]. Although a number of studies have

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examined QOL assessments in general PD populations [9–12], these scales have not been validated specifically in a PD population receiving palliative care nor evaluated for their responsiveness to palliative interventions. In light of the growth of neuropalliative care for PD and the lack of validated evaluation tools specific to the field, the present study aims to 1) describe the psychometric utility of four commonly used QOL scales in a population of PD patients receiving palliative care and 2) define and compare the minimal clinically important differences (MCID) and responsiveness to change for QOL scales in this population.

METHODS

People with PD and related disorders and their caregivers were enrolled into a larger three-year, multi-site, randomized controlled trial of outpatient palliative care [13]. This study received institutional review board approval from its three participating sites (University of Colorado, University of Alberta, and University of California San Francisco) [ClinicalTrials.gov], each of which had existing outpatient neuropalliative care clinics, and written informed consent was obtained from all participants. Participants were recruited from movement disorders specialists, community neurologists, and self-referral, and randomized to either outpatient palliative care intervention or usual medical care control. Participants and their caregivers completed a battery of outcome measures, including motor, cognitive, functional, mood, and quality of life assessments, every six months. The present study utilized cross-sectional baseline and repeat QOL data at six months post-palliative intervention.

Participants

210 participants with parkinsonian disorders, including PD (n=184), progressive supranuclear palsy (PSP) (n=13), corticobasal syndrome (CBS) (n=1), multiple system atrophy (MSA) (n=7), and dementia with Lewy bodies (DLB) (n=5), were included. Inclusion criteria were: fluent English, age 40 years and older, and identified palliative needs using the Palliative Care Needs Assessment Tool (PC-NAT), modified for PD. Caregivers were identified by asking the participant to name the “one person who helps most with their PD outside of clinic”. Exclusion criteria included: 1) immediate and urgent palliative care needs (these patients were not randomized and offered appropriate services immediately); 2) unable or unwilling to commit to study procedures; 3) presence of additional chronic medical illnesses which may require palliative services (e.g. metastatic cancer); or 4) already receiving palliative care and/or hospice services.

Administered Quality of Life Outcome Measures

Parkinson’s Disease Questionnaire-39 (PDQ-39)—The PDQ-39 is a 39-item self-reported measure assessing PD-specific health-related QOL over the previous month [14], using a five-point Likert scale with anchors of “never” and “always or cannot do at all”. The PDQ-39 has eight domains: mobility (10 items); activities of daily living (ADL) (6 items); emotional wellbeing (6 items); stigma (4 items); social support (3 items); cognition (4 items); communication (3 items); and bodily discomfort (3 items). Raw scores range from 0 to 156; higher scores on the PDQ-39 indicate worse patient-rated QOL. The PDQ-39 is

internally reliable and valid in PD [14,15], as well as sensitive to change, with established MCIDs for the overall scale and subscores [16]. Administration time is 15 to 20 minutes [10]. The PDQ-39 has not been validated in a PD palliative population.

Patient-Reported Outcomes Measurement Information System (PROMIS-29)— The PROMIS-29 is a person-centered measure that evaluates QOL across multiple domains. It is psychometrically validated in multiple health conditions, including PD [17,18]. Five-point Likert scales, anchored by “never” and “always”, measure severity or frequency of symptom domains, measured over the prior seven days: anxiety (4 items), depression (4 items), fatigue (4 items), sleep disturbance (4 items), pain interference (4 items), current physical function (4 items) and ability to participate in social roles and activities (4 items). A single pain intensity item is scored separately on an 11-point scale. Total raw scores on the PROMIS-29 range from 32 to 160; higher scores on the PROMIS-29 indicate worse patient-rated QOL. Administration time for the PROMIS-29 in older adults with chronic conditions ranged from 4 to 8 minutes [19]. In older adults with chronic musculoskeletal pain, the PROMIS-29 demonstrated good construct validity, internal consistency, test-retest reliability, and responsiveness over three months [20]. The PROMIS-29 has not been validated in PD.

Quality of Life in Alzheimer’s Disease Scale (QOL-AD)—The QOL-AD is a 13-item scale, completed individually by both patients and caregivers, with adequate internal consistency, test-retest reliability, and construct validity [21]. Symptoms are rated on a four-point Likert scale with anchors of “poor” and “excellent”. Total scores range from 13 to 52; higher scores on the QOL-AD indicate better patient- and caregiver-rated patient QOL. In Alzheimer’s disease, the QOL-AD demonstrates good inter-rater reliability and responsiveness to treatment [22]. The QOL-AD has good concurrent validity with other dementia scales [22,23]. The QOL-AD can be used to both integrate and compare patient and proxy ratings; caregiver ratings of patient QOL-AD are consistently lower than patient self-rated scores [24]. Administration time for the French language QOL-AD is 8 and 6 minutes for dementia patients and caregivers, respectively [25]. The QOL-AD has been used in secondary analysis of one LBD clinical trial [26], but has not been validated in PD [22].

McGill Quality of Life Questionnaire (McGill QOL)—The McGill QOL assess QOL for people with life-threatening illness and differs from other QOL measures by considering an existential domain, as well as positive contributions to QOL [27]. The McGill QOL also allows participants to provide qualitative details on symptoms with the greatest effect on QOL [28]. It is comprised of 16 items among four domains, plus a single-item global QOL scale: physical symptoms and wellbeing (4 items); psychological wellbeing (4 items); existential issues (6 items); and support (2 items) [29]. It measures symptomatic presence over the past two days on an 11-point Likert scale. Total raw scores on the McGill QOL range from 0 to 160; higher scores on the McGill QOL indicate better patient-rated QOL. Although predominantly used in oncology populations, the McGill QOL has been validated in palliative settings, exhibiting good psychometric properties [27,30]. Administration time ranges from 10 to 30 minutes in general palliative patient populations [31]. The McGill QOL has been validated in PD, but not in a PD palliative population [11].

Statistical Analysis

Summary statistics were computed to describe demographic features of participants at baseline visits, prior to randomization. Psychometric properties of the four QOL scales in this PD palliative population, including floor and ceiling effects, internal consistency, and concurrent validity, were examined. Floor and ceiling effects were tested for by plotting the data and examining their distribution. Internal consistency was established by calculating Cronbach's α. Concurrent validity was defined using Spearman correlation with well-validated scales of symptom burden in PD (Edmonton Symptom Assessment System Scale for PD (ESAS-PD)) and mood (Hospital Anxiety and Depression (HADS)-Depression scale), as well as with each of the other QOL scales. To investigate subdomain structure of the QOL scales in a PD palliative population, factor analyses were performed, utilizing an oblique (Promax) rotation. Number of factors was determined from Scree plots, eigenvalues, and number of previously established subdomains. To evaluate concurrent validity of resulting factors across the scales, Spearman correlations between similar symptomatic subdomains were calculated.

To define MCID, an anchor-based method was used as recommended in the literature [32]. Patient-based anchors were drawn from the Clinical Global Impression of Change (CGIC) scale [33], a single item, seven-point Likert scale. Six months after enrollment, after receiving palliative care (intervention group) or usual care (control group), patients were asked: "Compared to your condition at the time of enrollment, how much as your condition changed?". MCID was defined as the mean of the raw score change on each QOL scale for those who reported "minimal worsening" or "minimal improvement". For responsiveness, standardized response means (SRM) were calculated for each QOL scale administered at baseline and at six months for both the intervention and control groups. To test for differences in SRMs between the four scales, inferential statistics for the SRMs were obtained from bootstrapping. Using Cohen's criteria [34], an SRM > 0.8 is large, 0.5 to 0.8 is moderate, and 0.2 to 0.5 is small. Statistical analyses were performed using SAS 9.4 and R 3.1.0 software.

RESULTS

Demographics

The mean age of participants was 69.8 years (SD 8.3), ranging from 46 to 88 years, with a mean disease duration of 9.5 years (SD 6.4). 35.5% of the participants were female. On average, the PD participants included in this study had high levels of symptom burden and low self-reported quality of life at baseline. The mean raw PDQ-39 score at baseline was 91.7 (SD 26.8); baseline mean PROMIS-29 was 74.9 (SD 21.1); baseline mean McGill QOL was 117.8 (SD 28.3); and baseline mean QOL-AD was 34.0 (SD 6.3.

Internal and External Validity

All four QOL scales demonstrated good internal consistency in a PD palliative population: Cronbach's α for PDQ-39: 0.95; PROMIS-29: 0.93; McGill QOL: 0.88; QOL-AD: 0.83. There were no significant floor or ceiling effects for any QOL scale. For concurrent validity, all four QOL scales were significantly correlated with the ESAS-PD and the HADS, with

comparable correlation coefficients (Table 1). In addition, each of the scales was significantly correlated with each of the other QOL scales, with moderate to strong correlation coefficients.

Factor Analyses

There were some variations from established subdomains of the QOL scales in our PD palliative population (Table 2). For the PDQ-39, an additional item (item #11: Have you had difficulty washing yourself?) loaded onto the *Mobility* domain. Items of the *ADL* domain were scattered onto other factors, leading to a more defined basic, rather than instrumental, *ADL* domain (items #12, 13, 15, 16), which also included an excessive daytime sleepiness item (item #30). The *Social Support* domain was consistent with the defined scale, though with the addition of an item from *Communication* (item #36: Have you felt ignored by people?). The *Communication* domain gained an item from *ADL* (item #14: Have you had problems writing clearly?). *Emotional Wellbeing* and *Bodily Discomfort* items loaded together onto a single *Wellbeing and Pain* domain, and a new *Mood* domain emerged. The *Stigma* section remained consistent, but the *Cognition* domain was decreased to only two items with high face validity for cognition (item #31: have you had problems with your concentration? and item #32: have you felt your memory was bad?).

For PROMIS-29, there were two possible interpretations, one with two factors and one with six. For the two factor version, individual items loaded onto either *Physical Symptoms* or *Psychosocial Symptoms.* For the six factor version, most defined subdomains were maintained, though the domains of *Depression* and *Anxiety* loaded together onto a single *Mood* factor. For QOL-AD, three factors were identified: *Wellbeing, Home Life, and Daily Function* factors; the QOL-AD does not have defined sub-domains otherwise. For McGill QOL, three factors were also found, with *Existential Issues, Support*, and overall QOL rating loading together onto a single *Wellbeing* factor, in addition to the scale-defined subdomains of *Psychological Symptoms* and *Physical Symptoms.*

Correlations between factor-defined symptomatic subdomains of the four QOL scales demonstrated weak to strong correlations, depending on the scale and subdomain (Table 3). Overall, all three scales with a defined *Mood* subdomain correlated strongly, and all PDQ-39 and PROMIS-29 subdomains correlated well. However, McGill QOL correlated weakly with the other scales for similar symptomatic domains, including *Physical Symptoms* and *Wellbeing.*

Minimal Clinically Important Differences

90 participants in the treatment group had complete QOL and CGIC anchor data at the six-month time point and were used to calculate MCIDs. Patient-rated CGIC scores were weakly, but significantly, correlated with changes in McGill QOL (ρ=0.33, p=0.002) and PDQ-39 (ρ=−0.23, p=0.03), but not with QOL-AD (ρ=0.16, p=0.13) or PROMIS-29 (ρ=−0.19, p=0.07). The mean and standard deviation for difference scores in each anchor group, along with 95% confidence interval estimates, are displayed in Supplemental Data Table 1. For PDQ-39 and PROMIS-29, patient-defined “minimal worsening” was unexpectedly associated with a decrease in scale score, indicating an improvement in QOL by the scale.

For QOL-AD and McGill QOL, the direction of scale changes occurred in expected directions. Absolute MCID values were estimated as 12.7, 10.9, 3.9, and 18.9 for PDQ-39, PROMIS-29, QOL-AD, and McGill QOL, respectively.

Responsiveness

SRMs for each QOL scale in the intervention and control groups are presented in Table 4. The SRMs in both groups were small, indicating poor overall responsiveness. The PDQ-39 and PROMIS-29 demonstrated statistically significant SRMs in the intervention group, indicating they may be more responsive to the effects of palliative intervention in PD. When directly comparing pairs of QOL scales (Table 4b) , the QOL-AD demonstrated significantly better responsiveness to change than the PROMIS-29 or McGill QOL in the control group. Otherwise, the scales were comparable in their responsiveness for both groups.

CONCLUSIONS

All four examined QOL scales have good cross-sectional psychometric properties in a PD palliative population. The PDQ-39, PROMIS-29, QOL-AD, and McGill QOL demonstrated strong internal consistency, lack of floor or ceiling effects, and concurrent validity with validated scales of symptom burden in this population. Given our factor analysis, subdomains of the scales differ slightly in a PD palliative population; though while some items loaded with different subdomains than those defined, good face validity was maintained. Correlational analyses between factor-defined subdomains indicate that some scales (i.e. PDQ-39 and PROMIS-29) are measuring similar concepts of and contributions to QOL in this population, while others (namely McGill QOL) may be accessing QOL from a different lens, given weak correlations for the same types of symptoms. Interpretation of the QOL impact of certain symptoms may be different in a PD palliative population, therefore requiring a unique scoring scheme and purposeful selection of complementary, but not overlapping, outcome measures.

The PDQ-39 and PROMIS-29 demonstrated better responsiveness to change than the QOL-AD and McGill QOL in the intervention group and may be superior for detecting change in QOL in response to a palliative care intervention. However, even for these scales, there was a large amount of variability and small effect sizes overall. Previous studies have demonstrated asymmetric responsiveness of QOL outcome measures in PD; QOL scales seem more responsive to decline than improvement when compared to traditional measures of symptom burden in PD, such as the UPDRS [35]. It is unclear if this is related to the disease process or inherent biases in the scales. For a PD palliative population specifically, QOL could improve with palliative interventions due to changes not captured by extant scales, such as improved communication or strengthening of relationships with loved ones. Capturing such contributions through novel QOL scale development in a PD palliative population is a path for future study.

Unexpectedly, MCID analyses for the PDQ-39 and PROMIS-29 demonstrated a U-shaped distribution, with an improvement in scale-defined QOL associated with both patient-rated “minimal improvement” and “minimal worsening” of their overall condition. This apparent inconsistency further reflects the complexity of measuring relative improvements in the face

of a progressive, neurodegenerative condition; “minimal worsening” rather than “moderate worsening” may confer relative improvement in QOL. Exploring the underlying causes of these findings will be important in ensuring QOL outcome measures are capturing the full spectrum of patient experience. Importantly, despite this apparent inconsistency in results for the PDQ-39 and PROMIS-29, as well as wide confidence intervals for change score means overall, we hold that our calculated absolute MCID values for all four QOL scales are valid for this population and could be utilized in future clinical trials, given overall significant or near-significant correlations with our CGIC anchor. Currently, despite potential limitations, we recommend the PDQ-39 or PROMIS-29 for use as QOL outcome measures in clinical trials for a PD palliative care population. These two scales also correlated strongly with one another ($\rho=0.82$, $p<0.001$), indicating that either scale could be used to measure QOL changes in response to a palliative intervention in PD, but using both may be redundant.

Unlike the PDQ-39 and PROMIS-29, our results do not strongly support the use of the QOL-AD or McGill QOL scales as primary outcome measures in clinical trials of palliative care interventions in PD. However, despite non-significant responsiveness indices, the QOL-AD and McGill QOL have strong cross-sectional psychometric properties that would be useful for measuring QOL related to disease burden and progression in PD palliative populations. Moreover, the QOL-AD was significantly more responsive in detecting changes in quality of life for our control group, indicating this scale is likely superior for measuring changes in QOL associated with PD progression and that tempering this change could also be a marker of intervention effectiveness. Furthermore, the construct of QOL differs significantly between the PDQ-39 and PROMIS-29 (health-related QOL), the McGill (greater focus on palliative issues) and the QOL-AD (more general QOL); researchers should thus be cognizant that these scales are not interchangeable and choices should be tailored to the research question and the focus of interventions.

Strengths of this study include its large population of PD participants in palliative care, who were thoroughly assessed and well-characterized at baseline and post-intervention. Inclusion of patient-defined impressions of global change as an integral outcome measure is also a strength, ensuring a patient-centered focus. Relative limitations include the mixed parkinsonian population, including atypical parkinsonian disorders that may be due to different underlying pathologies. While palliative needs and QOL issues overlap significantly between these conditions, there may be differences in measurement of QOL and response to palliative care interventions. The lack of a well-validated, “gold standard” measurement of QOL in this population is also a limitation, in that concurrent validity had to be defined using separate, but related, validated outcome measures. Lastly, we only examined responsiveness to a single intervention and thus other types of palliative care interventions might have greater or lesser responsiveness.

In conclusion, the PDQ-39, PROMIS-29, QOL-AD, and McGill QOL are valid for cross-sectional use in a PD palliative population, given acceptable psychometric properties. The QOL-AD may be better for measuring longitudinal changes in QOL related to symptom burden and disease status, independent from treatment effect, in this population. The PDQ-39 and PROMIS-29 are more responsive to change in a treatment paradigm and are

therefore better supported for use as QOL outcome measures in clinical trials in PD palliative care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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HIGHLIGHTS

- Quality of life (QOL) is a fundamental outcome in PD, especially in palliative care
- Currently available QOL scales have not yet been validated in PD palliative care
- PDQ-39 and PROMIS-29 demonstrate better responsiveness to palliative intervention
- QOL-AD may be more responsive to disease progression in PD palliative care
- Each QOL scale has good cross-sectional psychometric properties in palliative PD

Table 1:

Concurrent validity (Spearman ρ) of QOL scales at baseline for entire cohort

	PDQ-39	PROMIS-29	QOL-AD	McGill QOL
PDQ-39	1			
PROMIS-29	0.82 (<0.001)	1		
QOL-AD	−0.58 (<0.001)	−0.59 (<0.001)	1	
McGill QOL	−0.58 (<0.001)	−0.62 (<0.001)	0.64 (<0.001)	1
ESAS-PD	0.65 (<0.001)	0.69 (<0.001)	−0.55 (<0.001)	−0.65 (<0.001)
HADS-Depression	0.60 (<0.001)	0.64 (<0.001)	−0.58 (<0.001)	−0.64 (<0.001)

Note: For PDQ-39, PROMIS-29, ESAS-PD, and HADS-Depression, a lower score indicates better QOL. For QOL-AD and McGill QOL, a higher score indicates better QOL

Table 2:

Factor analyses within each QOL scale in PD palliative population

Scale	N	Variance Explained	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
PDQ-39	176	67%	Mobility *Items #1-11*	Basic ADLs *Items #12, 13, 15, 16 & 30*	Social Support *Items #27-29 & 36*	Wellbeing & Pain *Items #19, 20, 33 & 37-39*	Stigma *Items #23-26*	Mood *Items #17, 18, 21 & 22*	Communication *Items #14, 34 & 35*	Cognition *Items #31 & 32*
PROMIS-29	191	47%	Physical Symptoms *Items #1-4 & 21-29*	Psychosocial Symptoms *Items #5-20*						
		73%	Mood *Items #5-12*	Pain *Items #25-29*	Physical Function *Items #1-4*	Fatigue *Items #13-16*	Social Roles & Activities *Items #21-24*	Sleep *Items #17-20*		
QOL-AD	166	54%	Wellbeing *Items #1-3, 5, 9, 13*	Home Life *Items #4, 6, 7 & 12*	Daily Activities *Items #8, 10 & 11*					
McGill QOL	141	57%	Wellbeing *Items #4, 9-16 & QOL Overall*	Psychological Symptoms *Items #5-8*	Physical Symptoms *Severity of symptom #1-3*					

Table 3:

Correlational analysis (Spearman ρ) for factor analysis-defined subdomains

		Physical Symptoms			Mood			Wellbeing			ADLs	
		PDQ-39	**PROMIS-29**	**McGill QOL**	**PDQ-39**	**PROMIS-29**	**McGill QOL**	**PDQ-39**	**McGill QOL**	**QOL-AD**	**PDQ-39**	**QOL-AD**
Physical Symptoms	PDQ-39	1	0.84(<0.001)	0.36(<0.001)								
	PROMIS-29	0.84 (<0.001)	1	0.27 (<0.001)								
Mood	PDQ-39				1	0.79 (<0.001)	0.72 (<0.001)					
	PROMIS-29				0.79 (<0.001)	1	0.71 (<0.001)					
Wellbeing	PDQ-39							1	0.14 (0.046)	−0.38 (<0.001)		
	McGill QOL							0.14 (0.046)	1	−0.23 (0.001)		
ADLs	PDQ-39										1	−0.50 (<0.001)

Table 4:

Comparisons of responsiveness indices for QOL scales

4a: SRMs for each QOL outcome measure

Scale	SRM For Intervention Group (95% CI)	SRM for Control Group (95% CI)
PDQ-39	**−0.30 (−0.49, −0.10)** *	−0.002 (−0.22, 0.21)
PROMIS-29	**−0.25 (−0.45, −0.06)** *	−0.07 (−0.28, 0.14)
QOL-AD	0.13 (−0.09, 0.34)	−0.22 (−0.42, 0.02)
McGill QOL	0.14 (−0.12, 0.35)	0.13 (−0.09, 0.34)

4b: Comparisons of SRMs

Scales	Difference in SRM for Intervention Group (95% CI)	Difference in SRM for Control Group (95% CI)
PDQ-39 vs. PROMIS-29	0.04 (−0.13, 0.20)	−0.07 (−0.28, 0.13)
PDQ-39 vs. McGill	0.18 (−0.05, 0.43)	−0.13 (−0.38, 0.12)
PDQ-39 vs. QOL-AD	0.20 (−0.03, 0.42)	0.23 (−0.03, 0.46)
PROMIS-29 vs. McGill	0.15 (−0.05, 0.37)	−0.06 (−0.30, 0.19)
PROMIS-29 vs. QOL-AD	0.13 (−0.10, 0.36)	**0.30 (0.05, 0.53)** *
McGill vs. QOL-AD	0.01 (−0.23, 0.21)	**0.34 (0.09, 0.58)** *

* p=0.05

For PDQ-39 and PROMIS-29, negative change indicates improved QOL

For QOL-AD and McGill QOL, positive change indicates improved QOL

* p=0.05

Note: Scales were reversed as necessary so positive numbers consistently refer to improvement in QOL.