Measuring quality of life in patients with Parkinson's Disease using the McGill Quality of Life questionnaire

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Introduction

- Multiple quality of life (QOL) assessment tools are validated for use in patients living with Parkinson's disease (PD)
- Existing tools evaluate the motor aspects of PD and the effects of motor disability on patient QOL
- Few tools are available that directly assess contributors to QOL such as:
  - psychosocial support
  - patient well-being
  - feelings/emotions
- The existential elements of QOL are less tangible and therefore more difficult to evaluate
- The McGill Quality of Life (MQOL) questionnaire is a tool originally developed for measuring QOL in palliative care patients and targets these aspects of QOL in addition to physical functioning

Objective

To determine the validity and reliability of internal consistency of the McGill Quality of Life questionnaire in a population of PD patients

Method

Approval

- Research Ethics Board at the University of Western Ontario (London, Ontario, Canada)
- Participants completed voluntary informed and written consent

Subjects

- Consecutive patients with PD from the movement disorder clinic at London Health Sciences Centre, London, Ontario Canada were recruited to participate in this study over a one year period

Inclusion criteria:

- Consenting patients over age 18 years
- Diagnosis of idiopathic PD
- Mini-Mental Status Examination score great than 26/30

Exclusion criteria:

- Patients unable to provide consent due to cognitive impairment or other cause

Procedure

- Questionnaires were de-identified by one author and data extracted by a different author in order to maintain patient confidentiality.
- Authors performing statistical analysis did not have access to clinical files
- Participants completed the questionnaire independently or with assistance from a caregiver if writing was impossible due to physical limitations
- Participants completed a series of assessment tools including:

Demographics questions	• age, age at diagnosis, disease stage, marital status, living arrangement, financial concerns
Unified Parkinson's Disease Rating Scale (UPDRS, motor component)	• used to grade severity of physical symptoms in Parkinson's disease • administered by study physician
Single-item scale	• a self-reported overall quality of life scale
McGill Quality of Life Questionnaire (1997)	• a self-reported QOL assessment questionnaire designed to existential aspects of QOL • originally validated in a general palliative care setting
Parkinson's Disease Questionnaire-39 (version 1.1, 1997)	• a valid and reliable QOL assessment tool for use in PD
Short Form -36 (2005)	• a valid and reliable overall QOL assessment tool
Free response area	• to identify component of the questionnaire package requiring further clarification • to determine acceptability of the questions to participants • to determine aspects of QOL not evalutated by the questionnaire package

- The McGill Quality of Life Questionnaire (MQOL) assesses multiple domains including:
  - physical symptoms
  - psychological well being
  - physical well being
  - psychosocial supports
  - existential aspects of life

Method

Statistical Analysis

- Statistical analysis was performed initially including **only** the **complete** data set
- Analysis was repeated including **all** data sets including those with **missing items**
- Any missing items were replaced appropriately depending on the assessment tool in question
- A scree plot, a plot of the eigenvalues by the eigenvalue number was created to determine the number of eigenvalues (the number of factors) contributing to each subscale in the MQOL
- A principal components analysis was completed
- A correlation analysis between the 4 identified MQOL subscales, the UPDRS, the PDQ-39 and the SF-36 was completed
- The free responses provided by participants were analyzed descriptively by two authors (HK, TG) The findings of this analysis appear in a separate poster "Measuring existential, psychological and physical contributors to QOL in PD using the MQOL"

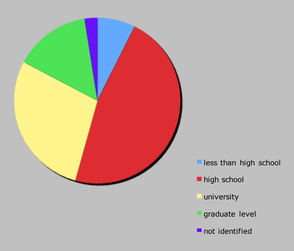
Results

Subjects and Demographics

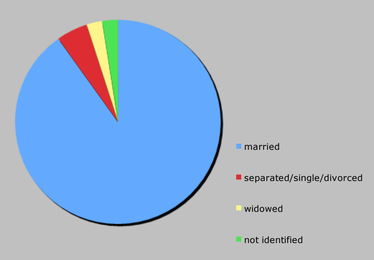
Table 1. Demographic information for study participants.

	n	%
Total patients	81	100
men	49	60.5
women	30	37
not identified	2	2.5
Age	**mean**	***SD***
mean age	65.2	8.4
self-reported age at diagnosis	60	9.2

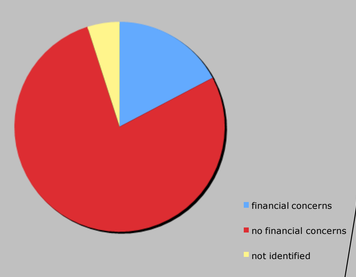
Level of Education



Marital Status



Financial Situation



Eigenvalues and Principal Component Analysis

Table 2. Numbers indicate items in the MQOL. Eigenvalues for data obtained from the MQOL (excluding the single item scale). The eigenvalues for complete data set (n=75) and imputed data set (n=81). Values approaching 1 or higher are used to generate the subscales.

	Eigenvalues	
Number	Complete Cases (n=75)	Imputed (n=81)
1	6.521	6.497
2	1.389	1.300
3	0.760	0.751
4	ITEM OMITTED	ITEM OMITTED
5	0.379	0.342
6	0.273	0.243
7	0.211	0.210
8	0.151	0.165
9	0.042	0.043
10	0.025	0.005
11	-0.054	-0.067
12	-0.097	-0.087
13	-0.131	-0.135
14	-0.165	-0.163
15	-0.192	-0.196
16	-0.200	-0.211

The data was analysed as *3 subscales* based on the scree plot and the eigenvalues obtained. Item 4 is not displayed and has been analysed separately.

Table 3. Principal component analysis of the MQOL in patients with PD. The loading for each item in the analysis is shown. Subscale 1 represents physical contributors to QOL, subscale 2 represents psychological and subscale 3 represents a combination of existential and support based on the MQOL.

	Complete Cases (n=75) Factor			Imputed (n=81) Factor		
MQOL Item	3	2	1	3	2	1
1. Physical Symptom 1	.18	.19	***.61***	.18	.20	***.62***
2. Physical Symptom 2	.22	.18	***.84***	.22	.16	***.82***
3. Physical Symptom 3	-.01	.16	***.75***	.03	.19	***.72***
5. Depressed	.37	***.69***	.21	.34	***.70***	.24
6. Nervous or worried	.28	***.69***	.21	.28	***.69***	.21
7. How often sad	.35	***.76***	.28	.31	***.77***	.27
8. Fear of future	.30	***.69***	.16	.34	***.63***	.17
9. Life meaningful	***.43***	.32	.29	***.41***	.32	.32
10. Achieve life goals	***.71***	.18	.11	***.70***	.20	.16
11. Life worthwhile	***.74***	.29	.01	***.74***	.28	.01
12. Control over life	***.60***	.39	.35	***.60***	.36	.38
13. Feel good about self	***.65***	.21	.05	***.66***	.19	.07
14. Every day a burden/gift	***.72***	.27	.17	***.72***	.27	.18
15. World is caring	***.73***	.25	.18	***.73***	.25	.19
16. Feel supported	***.48***	.24	.15	***.48***	.23	.14

Internal Consistency of the Subscales (Cronbach's alpha):

Subscale	Cronbach's alpha (with imputed data)
Physical symptoms	0.83 (0.82)
Psychological symptoms	0.59 (0.59)
Existential/Support symptoms	0.76 (0.76)

Results

Quality of Life Data Set:

Table 4. MQOL summary of results. Scores were transformed as previously published such that a score of 0 represents the worst possible score and 10 represents the best possible score.

	mean	*SD*	Range (0-10)
Single item scale	6.90	1.94	3-10
McGill Quality of Life Questionnaire			
Total Score	7.29	1.58	2.91
Physical symptoms subscale	6.42	2.49	2-10
Physical well being item	7.03	2.21	0-10
Psychological symptoms subscale	7.69	2.02	2-10
Existential and support subscale	8.02	1.33	4.63-9.75
Total physical symptoms	6.73	1.94	0.83-10

Table 5. PDQ-39 summary of results. The total score is 39, the remainder of the results are tabulated as transformed dimensions with a maximum of 100 representing the best possible score.

	mean	*SD*	Range (0-100.00)
PDQ-39 Total score	32.28	20.66	2-98.00
Mobility	22.43	21.79	0-75.00
Activities of daily living	19.48	16.50	0-70.83
Emotional well being	22.33	16.49	0-70.83
Stigma	16.66	22.30	0-75.00
Social support	9.40	16.14	0-83.30
Cognitive impairment	24.06	17.31	0-68.75
Communication	17.41	15.80	0-41.67
Bodily Discomfort	31.98	21.07	0-75.00

Table 6. SF-36 summary of results. Each score represents a transformed dimension of general quality of life.

	mean	*SD*	Range (0.00-100.00)
Physical function	67.69	26.07	0-100.00
Role-physical	44.72	42.08	0-100.00
Bodily pain	70.67	61.58	21.00-100.00
General health	59.77	21.69	1.65-100.00
Vitality	57.84	20.15	5.00-95.00
Social function	77.31	28.72	0-100.00
Role-emotional	67.93	40.80	0-100.00
Mental health	73.59	16.48	40.00-100.00

Correlation Analysis:

- With α = 0.01, correlation values between the subscales of the MQOL and the total score of SF-36:
  - Physical $p < 0.001$
  - Psychological $p < 0.015$
  - Existential/support $p < 0.002$
- With α = 0.01 correlations between the subscales of the MQOL and the PDQ-39 and motor UPDRS

	MQOL Physical	MQOL Physical Well Being	MQOL psychological	MQOL Existential/Support
PDQ-39	-0.56 (p<0.001)	-0.53 (p<0.001)	-0.60 (p<0.001)	-0.65 (p<0.001)
UPDRS	-0.258 (P<0.03)	-0.17 (p=0.16)	-0.22 (p<0.05)	-0.26 (p<0.02)

Acceptability of Questionnaires:

- Most participants had no concerns regarding the acceptability (77 of 81, 95.1%)
- Two did not answer demographic questions (questions administered for validation purposes, not intended for daily clinical practice)
- One stated that the area for free response in the MQOL, required a lot of writing for a patient with PD

Areas Not Addressed by Questionnaire:

- 16 stated significant influences on QOL not adequately addressed by the questionnaire (19.8%)
- Areas not addressed included:
  - cost of treatment and medications
  - the impact of medication and medication timing on QOL
  - the transition from employment to disability
  - the rate of disease progression
  - health of spouse
  - no direct questions pertaining to religious beliefs
  - no direct questions pertaining to specific supports or activities including family members or friends or community members.

Conclusion

- MQOL may be used in a clinical setting to assess existential aspects of QOL in PD.
- Psychological factors remain a challenge to measure. Further research into objective measures of the psychological symptoms in PD will help quantify their impact on QOL.
- MQOL can be analysed using three subscales in patients living with PD: 1) physical aspects, 2) psychosocial aspects and 3) existential and support aspects.
- This observation is different from the palliative care and HIV population where 4 subscales are found.
- In PD, the MQOL is a reliable measure of both physical symptoms and of existential/psychosocial support aspects of QOL (Cronbach's alpha = .82 and .76 respectively)
- MQOL is less reliable at measuring psychological symptoms in PD (Cronbach's alpha 0.59)
- Correlation between the MQOL subscales and the SF-36 and the PDQ-39, along with the principal component analysis demonstrates good construct validity for the MQOL in PD
- MQOL was acceptable to patients and the content was clear.
- Critical areas not addressed by the MQOL that impact QOL include medication, disease progression, health of spouse, faith based support and support of community/friends.