

Measuring existential, psychological and physical contributors to quality of life in Parkinson's disease using the McGill Quality of Life tool



TE Gofton, A South, H Kumar, MS Jog
University of Western Ontario, London (ON), Canada

Introduction

- Current QOL assessment tools focus primarily on physical symptoms and social supports for patients living with Parkinson's Disease (PD)
- The McGill Quality of Life (MQOL) questionnaire is designed to target more elusive domains of QOL, such as existential experience, using probe questions and free response
- The MQOL has been validated in a PD population (2010, unpublished data)

Objective

To study applicability of the MQOL for measuring physical, psychological, existential and support influences on quality of life (QOL) in PD

Method

Approval

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

Subjects

Recruitment:

- Consecutive patients with PD from a tertiary care movement disorder clinic at London Health Sciences Centre, London Ontario, Canada
- Duration = one year

Inclusion criteria:

- Consenting patients over age 18 years
- Mini-Mental Status Examination score > 26/30
- Idiopathic PD

Exclusion criteria:

- Patients unable to provide consent due to cognitive impairment

Design

- Descriptive, cross-sectional study

Procedure

- MQOL was completed independently either in the clinic or at home and returned by post
- Questionnaires were de-identified and data were extracted and tabulated by two authors
- Authors completing statistical analysis were blinded to clinical files/status
- MQOL was evaluated both quantitatively and qualitatively
- Quantitative analysis (Sections A-C; ratings): Items scored on 0-10 scale
- MQOL scores were transformed such that 10 always represents the best possible outcome
- Qualitative analysis (Section D; free response): Scoring method based Strauss using:
 - open coding*
 - selective coding*
 - comparison and categorization*
 - re-reading and modifying*
- Categories of emotional response were generated from the free responses
- Event rates for each category of patient reaction were calculated

Description of MQOL

Part A: Single-Item Scale (SIS)

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the last 2 days the quality of my life has been
Very bad (0).....Excellent (10)

Part B: Physical Symptoms or Physical Problems (symptom generated by individual and then rated)

Over the past 2 days, one troublesome symptom has been _____ (fill in the blank).
Question repeated three times
No problem (0).....Tremendous problem (10)

Over the past 2 days I have felt
Physically terrible (0).....Physically well (10)

Part C: Feelings and thoughts

Over the past 2 days.....
I have been depressed: Not at all (0).....Extremely (10)
I have been nervous or worried: Not at all (0).....Extremely (10)
How much of the time did you feel sad? Never (0).....Always (10)
When I thought of the future I was: Not afraid (0).....Terrified (10)
My life has been utterly: Meaningless (0).....Very purposeful (10)
When I thought about my whole life I felt in achieving goals I have
Made no progress whatsoever (0).....Progressed to complete fulfillment (10)
When I thought about my life, I felt that my life has been:
Completely worthless (0).....Completely worthwhile (10)
I felt that I have: No control over my life (0).....Complete control over my life (10)
I felt good about myself as a person: Completely disagree (0).....Completely agree (10)
To me the past 2 days were: A burden (0).....A gift (10)
The world has been an
Impersonal unfeeling place: (0).....Caring and responsive to my needs (10)
I have felt supported: Not at all (0).....Completely (10)

Part D: Free Response

Please list or describe the things which had the greatest effect on your quality of life in the past 2 days. Please tell us whether each thing you list made your quality of life better or worse during that time.

Results

Subject Demographics:

N = 81 (30 women; 49 men; 2 not identified)
Age = 65 +/- 8.4 year
Age of PD onset (self report) = 60 +/- 9.2

Table 1. Total scores on the SIS, MQOL and its subscales (A-C). 10 represents the best possible score.

	mean	SD	Range (0-10)
Single item scale (SIS)	6.90	1.94	3-10
McGill Quality of Life Questionnaire			
Total Score	7.29	1.58	2-9
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 2. Most frequently self-identified physical problems in patients with PD in rank order. A score of 10 represents the best possible QOL. Section B

Physical Problem	n	QOL score	Physical Problem	n	QOL score
Response 1			Response 2		
Fatigue or difficulty sleeping	18	4.8	Fatigue or difficulty sleeping	18	4.2
Pain	14	3.7	Impaired mobility	13	5.1
Tremor	9	5.7	Weakness	8	5.6
Impaired mobility	9	5.0	Constipation	4	4.3
Constipation	6	4.3	Pain	3	4.3

Physical Problem	n	QOL score
Response 3		
Fatigue or difficulty sleeping	8	4.0
Impaired mobility	5	6.4
Pain	4	4.3
Anxiety	3	4.3
Weakness	2	3.5
Nausea	2	3.5
Tremor	2	3.5
Diaphoresis	2	5.5
Constipation	2	10

Table 3 and 4 Frequency of free responses influencing QOL. Section D of the MQOL.

Positive Contributor to QOL	Total		Negative Contributor to QOL	Total	
	Total	%		Total	%
Family support	32	39.5	Poor sleep/fatigue	8	9.9
Friendships	14	17.3	Poor mobility	5	6.2
Ability to maintain hobbies	11	13.6	Pain	5	6.2
Faith/religious beliefs	8	9.9	Illness or death in family	5	6.2
Ability to exercise	7	8.6	Tremor	3	3.7
Being outdoors	7	8.6	Medication cost or schedule	3	3.7
Maintaining employment	3	3.7	Constipation, bladder or sexual difficulties problems	3	3.7
Medication	2	2.5	Weakness/lack of physical activity	2	2.5
Stable finances	2	2.5	Sexual difficulties	1	1.2
Other	4	4.9	Inability to pursue hobbies	1	1.2
			No longer employed	1	1.2

Results

Table 5. Frequency of other responses having an influence on QOL. Patient indicated neither a positive nor a negative influence.

Other Facets of QOL	Total	%
Embarrassed in public	3	3.7
Depression	2	2.5
Denial	1	1.2
Anger	1	1.2
Sadness	1	1.2
Frustration	1	1.2
Frightened about the future	1	1.2
Fear of PD altering relationships	1	1.2

Excerpts from patient narratives

"The greatest impact on my quality of life has been the inability to have a solid night's sleep."

"Not being in control of movements and feeling embarrassed when tremors occur in public."

"Having been away from my main support (my wife) for a few days and being on my own I have had time to dwell on our relationship. Have I become a burden? What would my life be like without her? Are my constant needs affecting my level of self-effort or her level of caring?"

"The thing that is paramount in my quality of life at any time is the unconditional support system that I have from my wife and daughters."

Conclusions

- Despite how poorly patients may feel on specific symptoms, overall, PD patients feel very good about all aspects of their life.
- The clinical experience of lack of correlation of the UPDRS score to a patients QOL is highlighted by this study. The QOL in PD cannot therefore be isolated simply to their motor dysfunction.
- **Therefore, using scales of this type may be much better at guiding initiation and dose changes in , medications in PD.**
- In patients living with PD, consistently identified physical contributors to quality of life include: **poor sleep** and **fatigue, impaired mobility** and **pain**
- Other contributors include: **tremor, weakness, constipation and anxiety**
- Further attention given to the clinical management of sleep hygiene and sleep disorders in PD as well as to the etiology of pain is likely to benefit patients and improve QOL in PD.

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Disclosures

The authors have no financial or other conflict of interest to disclose.