

From Guidelines to Action: Movement Disorders Care Through Regional & Multidisciplinary Collaboration

Miami, Florida, USA | November 7-8, 2026

International Parkinson and Movement Disorder Society
Pan American Section

In collaboration with:

Baptist Health

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Impact of Parkinsonian Symptoms on Quality of Life

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Objectives

1. Evaluate barriers to quality of life in the person living with Parkinson’s
2. Understand the domains that impact quality of life
3. Identify the limitations with current quality of life measures

QoL: The individuals' perceptions of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards, and concerns

QoL: The standard of health, comfort, and happiness experienced by an individual

It is a subjective evaluation of oneself and of one's social and material world

Van Munster M, et. al, Mov Disord 2024* Al-Khammash, et al, Cureus 2023



The problem with QoL measures

Healthcare providers tend to focus on the objective aspects of QoL with external assessments of an individual's functioning by measuring health-related symptom burden

This lacks a holistic approach

We must consider the person with Parkinson's perspective in order to facilitate patient-centered care and promote QoL

Van Munster M, et. al, Mov Disord 2024

Parkinson's Disease Quality of Life Measures – What we attempt to measure

Domain	PD QOL	PDQ-39	Parkinsons Impact Scale
Physical Health	✓		✓
Psychological/Emotional	✓	✓	✓
Social Functioning	✓	✓	✓
Sexuality	✓		✓
Independence	✓		
Urinary Function	✓		
Mobility		✓	
ADLs		✓	
Cognition		✓	
Sleep	✓		
Communication		✓	
Bodily Discomfort		✓	
Stigma		✓	

Blue = Core domains • Green = Psychosocial domains • Gold = Unique PD QOL domains • Gray = PDQ-39-specific domains

Most Relevant

Historically motor symptoms were identified as the most relevant manifestations of health-related quality of life, recent studies have demonstrated, that non-motor symptoms and other aspects such as activities of daily living may have a more significant impact on HRQoL than motor symptoms

Multi-center international study

3206 patients with Parkinsons

Comparison of MDS-UPDRS and PDQ-8

Findings:

The most significant correlations between the PDQ8 and MDS-UPDRS were found in part I and part II

Some areas emerged as the most important independent determinants of worsening HRQoL

1.3 DEPRESSED MOOD

0: Normal: No depressed mood.

1: Slight: Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.

2: Mild: Depressed mood that is sustained over days, but without interference with normal activities and social interactions.

3: Moderate: Depressed mood that interferes with, but does not preclude the patient's ability to carry out normal activities and social interactions.

4: Severe: Depressed mood precludes patient's ability to carry out normal activities and social interactions.

1.13 FATIGUE

Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad.

0: Normal: No fatigue.

1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people.

2: Mild: Fatigue causes me some troubles doing things or being with people.

3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.

4: Severe: Fatigue stops me from doing things or being with people.

2.5 DRESSING

Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?

0:	Normal:	Not at all (no problems).
1:	Slight:	I am slow, but I do not need help.
2:	Mild:	I am slow and need help for a few dressing tasks (buttons, bracelets).
3:	Moderate:	I need help for many dressing tasks.
4:	Severe:	I need help for most or all dressing tasks.

2.3 CHEWING AND SWALLOWING

Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped, or blended to avoid choking?

0:	Normal:	No problems.
1:	Slight:	I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.
2:	Mild:	I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.
3:	Moderate.	I choked at least once in the past week.
4:	Severe:	Because of chewing and swallowing problems, I need a feeding tube.

2.1 SPEECH

Over the past week, have you had problems with your speech?

0: Normal: Not at all (no problems).

1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.

2: Mild: My speech causes people to ask me to occasionally repeat myself, but not every day.

3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.

4: Severe: Most or all of my speech cannot be understood.

2.8 DOING HOBBIES AND OTHER ACTIVITIES

Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?

0: Normal: Not at all (no problems).

1: Slight: I am a bit slow but do these activities easily.

2: Mild: I have some difficulty doing these activities.

3: Moderate: I have major problems doing these activities, but still do most.

4: Severe: I am unable to do most or all of these activities.

Where is the Quality in Quality of Life?

Key Domains

🩺 **Illness Experience**
- Symptoms
- Disease burden
- Adaptation

🏥 **Health Care**
- Access to care
- Care coordination
- Treatment support

🏠 **Everyday Life**
- Daily activities
- Independence
- Routine participation

👥 **Social Life**
- Relationships
- Community engagement
- Social support

⭐ **Identity**
- Self-concept
- Purpose
- Personal roles

🙏 **Spirituality / Religion**
- Meaning
- Beliefs
- Coping resources

🌳 **Environment**
- Physical surroundings
- Accessibility
- Community resource

Illness Experience

Barriers

- Tremor
- Gait disturbance (risk of falls)
- Psychiatric symptoms
- Cognitive declining
- Unpredictability of symptoms
- Complications of treatments
- Thoughts of future (anxiety)

Everyday Life

Barriers

- Fatigue with daily tasks
- Inability to participate in hobbies or leisure activities
- Inability or difficulty with participation in exercise
- Inability to continue working
- Financial burden to person and family
- Difficulty performing self care
- Difficulty doing housework/yardwork



Social Life Barriers

- Social overload
- Social isolation
- Inability to live out intimacy and sexuality
- Experiencing stigma due to deviations from the norm
- Inability to go to the restroom independently
- Lack of motivation
- Cognitive changes
- Difficulty showing feelings

Identity Barriers

- Changes in self-perception
- Changes in interpersonal roles
- Dependence
- Self-perceived deviation from the social norm
- Loss of control
- Poor body image
- Difficulty with communication

Spirituality and Religion

Barriers

Difficulty participating at previous level

Coping Resources



Environment Barriers

- Lack of accessibility – home and community
- Safety
- Community Resources

Health Care Facilitators to a better QoL for the PwP

+ Education – especially at the time of diagnosis ***

+ Trusting relationship between patient and health care professional – feeling comfortable discussing problems openly

+ Receiving a holistic approach

+ Facilitating care that keeps the patient in their desired environment

Clinical implication:

Improving quality of life requires addressing not only symptom management, but also **identity**, participation, social connection, emotional well-being, and meaningful engagement.



Identity, purpose, & meaning = Quality of Life

Identity answers the question 'Who am I?' while purpose answers 'What gives my life meaning?' In Parkinson's disease, preserving valued roles and helping individuals find new ways to express themselves can support both identity and purpose, ultimately improving quality of life


Physician prescribes medication to reduce rigidity
Physical Therapy: Sit-to-stand performance and mobility
Speech-Language Pathology: Posture and respiratory support for communication
Occupational Therapy: Medication timing and participation in valued social activities
Patient is able to attend, engage in, and cheer at grandchild's soccer game
Quality of Life

Take home message



Quality isn’t in the reduction of the symptom; it’s in the accomplishment of the task that reducing the symptom allows



It takes a team

Thank you



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