Quality of Life in Parkinson's Disease – Patient, Clinical and Research Perspectives

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Abstract

Parkinson's disease (PD) has a severely negative impact on the quality of life (QoL) of patients and their caregivers. Health-related QoL (HRQoL) is a patient-reported component of QoL that includes physical, mental and social domains and in PD is an increasingly important part of patient monitoring. HRQoL in PD is assessed using a range of different generic (e.g. Short Form-36) and PD-specific (e.g. 39-item Parkinson's Disease Questionnaire) instruments/questionnaires. It is important that HRQoL is regularly determined in patients with PD to identify determinants of their HRQoL deterioration and appropriately manage them. The perspectives of PD patients, clinicians and researchers, however, can be different. In PD, motor symptoms such as slowness or tremor are the most visible manifestations of the disease and these tend to be concentrated on by doctors. PD patients, however, are likely to also have a range of non-motor symptoms such as nocturia, urinary frequency, fatigue, drooling and forgetfulness, which can be more troubling than motor symptoms. These can increase distress and social isolation but are often unreported or overlooked. In addition, morning akinesia and wearing-off phenomena may cause additional difficulty. However, these symptoms and patient concerns can be readily identified using simple HRQoL measures. The management of PD should therefore take into account patient, clinical and research perspectives of HRQoL in order to recognise and adequately address the consequences of motor and non-motor symptoms in PD.

Keywords

Parkinson's disease, health-related quality of life, assessment scales, patient perspective, clinical perspective, research perspective

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Parkinson's disease (PD) is a chronic condition that imposes a substantial burden on patients and their caregivers. The disease has a profound and progressive impact on various neurological functions, but its aetiology is not fully understood. There are an estimated seven to 10 million people with PD worldwide (including 1.2 million in Europe); it is the second most common neurodegenerative disease after Alzheimer's disease.[1-4] In PD, advancing age is a strong risk factor and its prevalence is likely to increase with demographic changes leading to increasingly elderly populations.[5] In Europe, the disease costs an estimated €13.9 billion per year (in 2012)[6,7] compared with an estimated €126 billion/year for cancer (in 2009)[8] and an estimated €196 billion/year for cardiovascular disease (in 2012).[9] An increasingly recognised and important factor in PD is its impact on quality of life (QoL) and its assessment is becoming more important in clinical trials and routine practice.[10] Perspectives of QoL in PD as seen by patients, in clinical practice and in research can be quite different. For example, PD involves prominent motor symptoms such as slowness (bradykinesia) and stiffness (rigidity) that are a primary concern for patients,[11] but also causes a variety of non-motor symptoms that are frequently overlooked and/or unreported.[12,13] It is important that these perspectives are aligned to fully assess the differing impact of the disease on each patient and better monitor the effects of treatment. This article considers QoL in PD from different perspectives and a companion article in this issue continues this theme with the effect of therapeutic measures and QoL outcomes in PD in clinical trials.[14] Both articles are based on the discussions of an expert panel on QoL in PD that was convened at the 20th World Congress on Parkinson's Disease and Related Disorders, Geneva, December 2013.

Table 1: Recommended Health-related Quality of Life Measures used in Studies of Parkinson's Disease

Acronym	Full Title	Type
EQ-5D	European Quality of Life (EuroQoL) 5-dimension questionnaire	Generic
NHP	Nottingham Health Profile	Generic
SF-36	36-item Short-Form Health Survey (with physical and mental component scales)	Generic
SIP	Sickness Impact Profile	Generic
PDQ-39	39-item Parkinson's Disease Questionnaire	Specific
PDQ-8	8-item Parkinson's Disease Questionnaire (short form)	Specific
PDQL	Parkinson's Disease Quality of Life questionnaire	Specific
PIMS	Parkinson's Impact Scale	Specific
SCOPA-PS	Scales for Outcomes in Parkinson's Disease – Psychosocial	Specific
PDQUALIF	Parkinson's Disease Quality of Life scale	Specific

Source: Martinez-Martin et al., 2011.[16]

Table 2: The Effect of Motor Complications on Quality of Life in Parkinson's Disease

	Early-morning Akinesia			Nocturnal Akinesia			End of Dose Fluctuations			Paradoxical Fluctuations			Unpredictable OFFs		
PDQ-39 Dimension	Yes	No	p	Yes	No	p	Yes	No	p	Yes	No	p	Yes	No	p
Mobility	52.2	41.6	0.019	58.2	37.9	<0.001	50.9	40.2	0.017	57.3	40.4	<0.001	60.6	41.0	<0.001
ADL	48.9	37.0	0.006	54.3	33.9	<0.001	48.4	34.2	<0.001	54.2	35.3	<0.001	55.1	37.1	<0.001
Emotional well-being	46.2	42.0	0.199	49.1	40.4	0.008	46.5	40.6	0.064	46.0	42.4	0.294	47.7	42.3	0.158
Stigma	44.8	32.0	0.003	44.8	32.0	0.003	44.8	28.4	<0.001	47.1	31.8	<0.001	50.9	32.4	<0.001
Social support	15.8	11.9	0.233	17.5	11.0	0.043	16.0	10.6	0.089	15.6	12.6	0.33	17.2	12.2	0.176
Cognition	38.0	32.5	0.085	41.3	30.5	<0.001	36.6	32.6	0.199	37.8	33.1	0.158	35.1	34.5	0.871
Communication	36.5	26.3	0.005	39.7	24.4	<0.001	35.3	25.0	0.004	40.2	25.6	<0.001	41.2	26.8	<0.001
Bodily discomfort	49.5	45.7	0.271	52.3	44.1	0.017	49.0	45.3	0.282	51.8	45.0	0.057	53.4	45.3	0.037
PDQ-SI	40.9	33.6	0.005	44.7	31.3	<0.001	41.0	31.6	<0.001	44.2	32.6	<0.001	45.5	33.5	<0.001

ADL = activities of daily living; PDQ-SI = Parkinson's Disease Questionnaire Summary Score. Source: Chapuis et al., 2005.[65]

What is Quality of Life and What Scales are used in Parkinson's Disease?

QoL is a general term relating to an individual's overall well-being and satisfaction. This is a holistic approach encompassing various aspects of a patient's condition and is gaining recognition as an important measure of disease impact and status. QoL is also a criterion that can be improved with treatment rather than simply concentrating on specific disease symptoms.[15] Health-related QoL (HRQoL) is a component of QoL and is a patient-reported outcome, with physical, mental and social domains that can be measured at single points and over time periods.

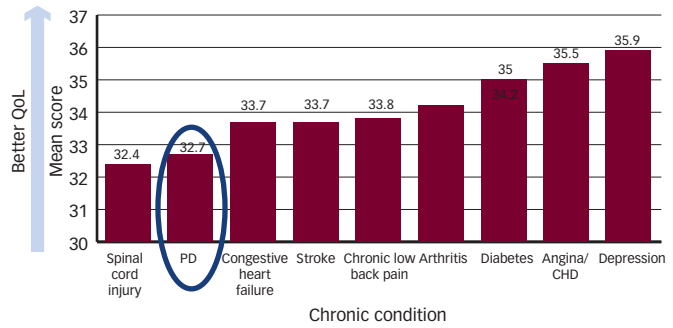
HRQoL scales may be generic and applicable to multiple different diseases, such as multiple sclerosis, Alzheimer's disease, stroke and depression and include, for example, the EuroQoL-5D (EQ-5D) or Short Form-36 (SF-36). Some scales, however, are PD-specific, such as the 8- and 39-item Parkinson's Disease Questionnaires (PDQ-8/PDQ-39), Parkinson's Impact Scale (PIMS), Scales for Outcomes in Parkinson's Disease – Psychosocial questionnaire (SCOPA-PS) or the Parkinson's Disease Quality of Life scale (PDQUALIF) (see *Table 1*).[16]

The most commonly used HRQoL instruments characterise patients in multiple dimensions, e.g., disease symptoms, physical functioning, emotional well-being and social activity.[17] In PD, these measures of HRQoL provide important global information for assessing the efficacy of medical interventions.[10] The SF-36 questionnaire is the most widely used generic measure and gathers information of the patient's physical and mental status, which are presented as two different sub-scores. The physical component summary encompasses physical functioning, physical role, bodily pain and general health; the mental health component encompasses vitality, social functioning, emotional role and mental health. This measure has been successfully used to assess the status of various diseases in clinical practice including PD. This scale, however, has limitations in assessing change in physical health but is useful in predicting the course of disease.[10,18,19]

The EQ-5D is another generic measure of HRQoL that is frequently used in PD and is a five-dimension questionnaire dealing with aspects related to mobility, self-care, usual activities, pain/discomfort and anxiety/depression.[20] Other prominent generic HRQoL scales in PD include: the Quality of Life Questionnaire 15D,[21] the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting[22] and the World Health Organization Quality of Life Assessment Short Version.[16]

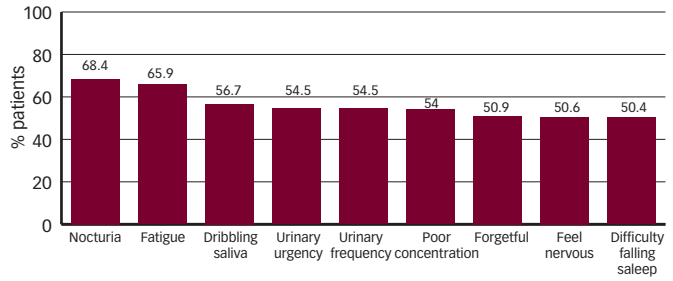
Among the PD-specific instruments, the PDQ-39[19,23] is the most widely used. This instrument captures the impact of both motor and non-motor symptoms and assesses 39 aspects of life including activities, feelings, support and capabilities. The PDQ-39, for example, includes items such as walking 0.8 km (0.5 mile) or 92 m (100 yards) carrying bags, getting around in public or in the home, fastening buttons or shoelaces and holding drinks without spillage.[23] This scale also captures the impact of motor fluctuations, it is convenient and can be completed within 15–20 minutes. The PDQ-8 is a short-form of PDQ-39 that in which each item represents a dimension of the extended scale. In PD, wearing-off of drug treatments is a common factor, but is not well defined and can be missed by clinicians. The 32-symptom Wearing-off Questionnaire (WOQ-32) and the shorter nine-symptom version (WOW-9) are useful instruments for determining treatment wearing-off.[24] In a critique of wearing-off scales, the authors recommended 19- and 9-item scales and suggested the 32-item scales but for determining wearing-off severity they recommended using patient diaries.[25]

Figure 1: Comparative Impact of Different Chronic Diseases on Health-related Quality of Life (SF-36 Physical Component Summary Score) in a Large-scale Survey of US Veterans



CHD = chronic heart disease; PD = Parkinson's disease; QoL = quality of life. Source: Gage et al., 2003.[27]

Figure 2: Prevalence of Non-motor Symptoms in a Sample of 411 Consecutive Patients with Parkinson's Disease



Source: Martinez-Martin et al., 2011.[46]

The Impact of Parkinson's Disease on Quality of Life from Three Perspectives

The Research Perspective

HRQoL is a comprehensive outcome that can be measured with appropriate generic or specific scales. Generic scales of HRQoL allow the evaluation of relevant aspects of general health and the comparison of diseases in different therapeutic areas, whereas specific scales are focused on particular aspects important for their respective targeted populations. In PD research, studies have used both types of scales, in addition to other clinical evaluations, to assess the impact of the disease manifestations on patients' HRQoL. Using these scales, it is apparent that the motor and non-motor symptoms of PD have a severe impact on patients and worsen as the disease progresses. Better reporting and management of these symptoms is needed if HRQoL in many patients with PD is to be improved. Various studies of PD patient populations have shown that motor complications and disability, together with a diversity of other symptoms, are determinant factors of poor HRQoL. Interventions that improve motor function, particularly medications, but also surgery, exercise programmes and other types of support are therefore also likely to improve HRQoL.[26]

HRQoL measures have shown that the impact of PD is worse than several other prominent chronic diseases. This was demonstrated in a large-scale survey of 887,775 US military veterans among whom 14,530 had PD.[27] The results showed that for SF-36 physical component scores of HRQoL, among nine chronic diseases or conditions, only spinal cord injuries had a worse impact than PD (32.38 versus 32.72) (see *Figure 1*). For SF-36 mental component scores, only depression had a worse impact than PD (35.94 versus 41.48). It was concluded that PD imposes a relatively heavy burden on individuals in the US Veterans Health Administration system.

Various classic studies have shown that as PD increases in severity, HRQoL worsens.[28,29] Studies in Finland, Norway and the UK have shown an inverse correlation between HRQoL and PD severity and that disability, motor (decreased mobility, instability and falls) and non-motor symptoms (depression, fatigue, pain and cognition) directly affect HRQoL.[30-32] The impact of the disease was further emphasised in a study of 227 patients with PD: health and HRQoL, as determined using the SF-36 health survey, was substantially worse than in the general population.[33]

The increasing recognition of non-motor symptoms in PD has necessitated greater use of several instruments in clinical trials and other research. The SCOPA scale consists of sets of different scales and questionnaires for the assessment of autonomic function, psychosocial function, cognition and sleep (day and night). These scales show good convergent validity with other scales when used to assess PD patients.[34-36] The Non-Motor Symptoms Scale (NMSS)[37] does not directly assess HRQoL but effectively captures many aspects that directly affect it. The scale is a 30-item instrument that is divided into nine domains: cardiovascular, sleep/fatigue, mood/cognition, perceptual/hallucination, attention, gastrointestinal, urinary, sexual function and miscellaneous. This rater-based scale has been widely used in PD and showed good correlation with the Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Part I – Non-Motor Aspects of Experiences of Daily Living (nM-EDL) scale, in a study on 434 consecutive PD patients who were assessed for non-motor symptoms.[37] The nM-EDL scale provides a useful measure of change in disease over the first decade of the disease.[38] The MDS-UPDRS: Part I scale consists of 13 items relating to aspects including cognition, mood, sleep, pain, urinary problems, constipation and fatigue. In addition to these general scales, there are scales that assess individual symptoms such as the Parkinson Fatigue Scale (PFS),[39] Parkinson's Disease Sleep Scale (PDSS)[40] and the Parkinson's Disease Cognitive Rating Scale (PD-CRS).[41] Another instrument that captures non-motor symptoms (and motor symptoms) in PD is the PS-23 scale. This novel instrument was shown to be valuable in determining these symptoms a large open-label study (n=871) of rasagiline monotherapy conducted in Germany.[42]

The advantage of using PD-specific instruments is that they can accurately capture the impact of both motor and non-motor symptoms. Some of these tools, however, may be too lengthy for routine clinical practice but shorter assessments have been shown to also provide valuable information. A survey conducted in the UK[43] assessed patients with PD (n=3,043) using the patient-based Non-Motor Questionnaire (NMS-Quest) and the PDQ-8 measure. The results showed that symptoms of digestion, memory, urinary tract, hallucinations, depression, sexual function, cardiovascular and sleep disorders were more common in patients with disease duration exceeding 10 years. These symptoms were more common in patients under 45 years compared with those over 85 years of age and were slightly more common in males compared with females (except for depression). There were also increased levels of nocturia, urinary urgency, constipation, loss of smell and taste before diagnosis with PD compared with a control population. The study showed worsening of NMS-Quest and PDQ-8 scores over

10 years following diagnosis but the findings from both questionnaires were consistent and therefore useful for patient monitoring.

Instruments for the assessment of HRQoL therefore, are simple to use and can be used to routinely monitor patients with PD. HRQoL results have been shown to correlate with both motor and non-motor symptoms of PD. Each of these measures provides an aggregated marker that is useful for comparisons across different areas and emphasise that PD imposes a high burden on the patient.

The Clinical Perspective

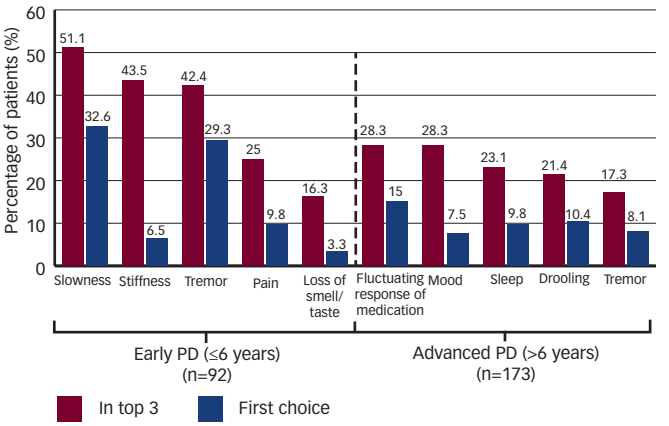
In clinical trials, motor symptoms and non-motor symptoms have been evaluated using specific scales including the SCOPA and UPDRS motor scales. These specific scales are lengthy and are more suited to the research environment. In routine practice however, the assessments needed may be simpler. Such simple procedures are important, and can assist the clinician in making management decisions and starting appropriate treatment.[44] Therefore, QoL can be improved as a result of understanding disease impact but this may not be apparent and may not be captured by any clinical assessment scales.

In routine clinical practice the symptoms that severely impact the patients evolve as the disease progresses and therefore different scales are needed. HRQoL assessments evaluate the impact of symptoms on daily life, irrespective of the nature of the symptoms. They therefore provide good markers of the patient status over the different stages of the disease and are indicative of the rate of deterioration.

To some clinicians, especially general practitioners, diagnosing PD can be challenging due to the variability in presenting symptoms, mistaking signs for those of other conditions and possibly limited experience of the disease – diagnosis can therefore be delayed.[45] For the clinician, keeping track of PD symptoms and their impact in patients can also be challenging; patients and their caregivers may not remember or record their experiences and may not be able to express the severity or extent of the effect during normal consultations. When assessing PD, it is important that clinicians gain an understanding of the patients' experience and question them on all aspects of the disease rather than focusing mainly on a limited number of motor symptoms. The non-motor symptoms are often not recorded or investigated because they are less visible than the motor symptoms[12] but collectively may have a greater impact. Non-motor symptoms are under-reported because patients may not associate them with PD or may concentrate on the motor symptoms during consultations. The symptoms can be a source of embarrassment and lower confidence, thus increasing social isolation. In an international, cross-sectional study on patients with PD (n=411) symptoms such as nocturia and fatigue were shown to be present in approximately two-thirds of patients and other symptoms including dribbling, urinary urgency and frequency, poor concentration, forgetfulness, nervousness and difficulties sleeping were reported in more than half of the patients (see *Figure 2*).[46]

In one study, non-motor symptoms were not identified by neurologists in over 50 % of consultations.[47] A better determination of both motor and non-motor symptoms may be achieved using HRQoL evaluations that assess multiple patient dimensions and assist overall understanding of the patient with PD. The PDQ-39 questionnaire, for example, has many questions on non-motor symptoms and its use provides a comprehensive assessment of the patient raising concerns that they may not otherwise report.

Figure 3: Patient Rating using PDQ-39 Assessments of their Three Most Troubling Symptoms/Conditions



PD = Parkinson's disease. Source: Politis et al., 2010.[11]

Such evaluations are increasingly recognised as informative global measures of patient status.[27]

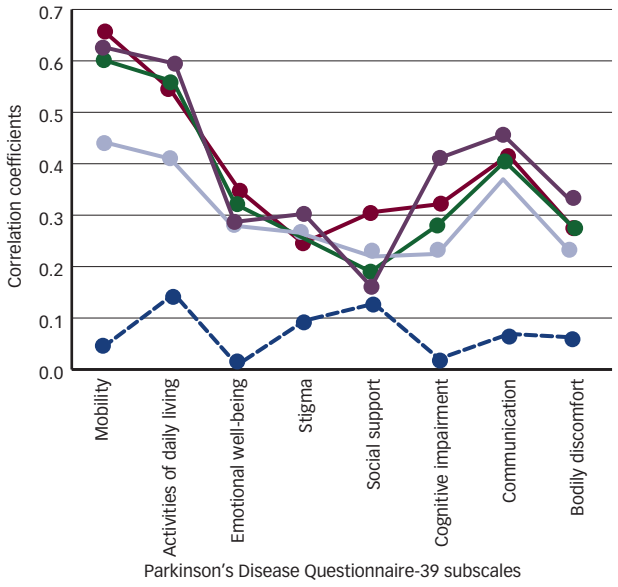
For many years PD has been routinely managed with levodopa but up to 50 % of older patients (aged over 60 years) and up to 100 % of younger patients (aged 21 to 39 years) receiving this treatment have motor complications within 5 years.[48,49] Estimates based on some studies indicate that up to 50 % of patients with PD will experience motor fluctuations within the first 2 years of treatments.[50] In addition, the Earlier versus Later Levodopa Therapy in Parkinson Disease (ELLDOPA) study showed that complications can occur within the first year.[51] A recent study designed to evaluate the presence of motor and non-motor fluctuations using a specific questionnaire, the 19-item wearing-off questionnaire (WOQ19) showed that 42 % of patients suffered from wearing-off within the first 2.5 years of disease (Early DEtection of wEaring off in Parkinson disease [DEEP] study).[52] Motor complications increase with disease progression and mainly appear as 'OFF' time, dose failures and dyskinesias. In patients whose HRQoL is deteriorated by motor complications, the situation can be managed by changing the timings and/or doses of levodopa, using adjunct therapies such as dopamine agonists, monoamine oxidase-B (MAO-B) inhibitors, catechol-O-methyl transferase (COMT) inhibitors or by considering other therapies, such as continuous infusion of apomorphine or levodopa or deep brain stimulation (DBS).[53,54]

Therefore, in the clinic, HRQoL assessments should be easy to use and complement traditional diagnostic evaluations used by physicians. Since these traditional approaches can be time-consuming, laborious and require specialist training, HRQoL scales may offer a broader evaluation of the disease in routine practice that is both simple and rapid.

The Patient's Perspective

Specific HRQoL measures have been developed to reflect the patient perspective on PD. An example is the PDQ-39 that was designed to be completed by the patient and captures various aspects of well-being.[55] For example, studies using PDQ-39 assessments have shown that during the course of the disease symptoms that are considered by patients to have the most serious impact on their lives tend to change. A study in the UK that also used PDQ-39 assessments showed that during the first 6 years of PD, patients rated slowness, stiffness, tremor

Figure 4: Agreement of Scales and Parkinsonian Symptoms with PDQ-39 Subscales



Sources: Dodel et al., 2001[58] and Schrag et al., 2000.[32]

and pain as their most troubling problems, but after 6 years they rated fluctuating response to medication, mood disorder, sleep problems and drooling as the worst symptoms (see *Figure 3*).[11] This study showed a range of patient experiences in PD and many symptoms and difficulties that are important to patients were not always recognised by clinicians, thus worsening the patients' situation.

In the treatment of PD, involving patients in management decisions is beneficial and gives them a sense of control. This was demonstrated in a UK survey of 117 patients in which consultation and involvement in treatment decisions was correlated with better satisfaction and compliance intent. In this study, HRQoL as measured using PDQ-39, showed significant negative association with depression, worse UPDRS scores and duration of PD, but was positively associated with compliance intent and satisfaction.[56]

Among neurologists, there is growing awareness that patient's perspective of HRQoL needs to be considered. This has been emphasised by the design of various clinical studies including the UK PD MED study.[57] This is a large 'real life' (pragmatic) trial that aims to reliably determine which class of drug provides the most effective control, with the fewest side effects, for both early and late PD. The trial has recruited 1,620 patients with early PD and 500 with late PD and one of the main outcome measures was PDQ-39. Results of this trial are to be published soon.

In PD, symptoms such as postural instability, rigidity, tremor and gait impairment are strongly correlated with poor HRQoL in PD (see *Figure 4*).[32,58] Many investigations have highlighted this relationship, including a population-based study in which 202 patients (124 with probable PD) were assessed using the PDQ-39 and the Beck Depression Inventory. Depression was most strongly associated with poor HRQoL ($p<0.0001$) but disability ($p<0.001$), postural instability ($p<0.001$) and cognitive impairment ($p<0.037$) also showed significant associations. Increasing severity of motor symptoms is correlated with worsening HRQoL but this effect is not always clear because HRQoL is also affected by non-motor symptoms. In addition, the types of motor impairment have differing impacts on HRQoL. A study in Florida in 639 patients with PD showed that all motor impairments generally worsened HRQoL but lower extremity impairments had a larger effect than upper extremity impairments.[59]

As indicated above, a common, and often the first type of motor fluctuation to develop during treatment, is an end-of-dose wearing-off.[60] As the name implies, the patient develops a loss of response to a dose of medication before taking the next dose. Patients commonly show a good response 30–60 minutes after taking an individual dose of levodopa, but their parkinsonian symptoms re-emerge before their next scheduled dose because the benefit of the last dose 'wears-off'.

Many patients also experience a re-emergence of symptoms before the first morning dose (early morning akinesia).[61] This is partly due to the short half-life of levodopa and reflects a deterioration in response to extensive use of the drug but also a change in the pharmacodynamic response due to post-synaptic mechanisms. Indeed, wearing-off effects have also been reported with dopamine agonists that are not retained in the presynaptic compartment.[62] With disease progression there is a tendency for fluctuations to become increasingly less predictable and as the wearing-off phenomenon becomes more complicated, dosing responses vary and patients may report a 'delayed-on' effect or dose failures. The delayed-on effect refers to a significant delay between the intake of a dose of levodopa and the commencement of its effects. This delay in the 'on' response reflects the delay in absorption of medication and its crossing the blood–brain barrier. Wearing-off can appear early in the course of the disease but often is not recognised by patients and doctors.[50]

Early morning symptoms, particularly akinesia, have been shown to be correlated with motor aspects of PD and have strongly negative effect on HRQoL as perceived by patients.[46,63,64] The impact of morning akinesia, nocturnal akinesia and biphasic dyskinesias can be effectively determined using the PDQ-39, Parkinson's Disease Quality of Life (PDQL) questionnaire and PIMS scales. The importance of morning akinesia was shown by a study conducted in France that included 143 patients with PD who were investigated using PDQ-39 assessment. The results showed that early-morning akinesia, nocturnal akinesia, end of dose fluctuations, paradoxical fluctuation and erratic OFF times were all significantly associated with poorer scores of mobility, activities of daily living (ADL), stigma, communication and PDQ summary scores (see *Table 2*).[65] In this study, therefore, motor complications, particularly early morning and nocturnal akinesia and biphasic dyskinesias, worsened the overall HRQoL of PD patients.

Among the non-motor symptoms of PD, sleep disturbance has a serious effect on HRQoL. This problem is believed to be a result of neurochemical and neurodegenerative changes in the brain and has been reported in up to 96 % of patients but is often not treated. Various studies have shown poor sleep in PD is exacerbated by frequent night-time awakening, sleep fragmentation, nocturia, restless legs syndrome/periodic limb movements, sleep breathing disorders and drug-induced symptoms. Sleeping difficulty also results from parasomnias associated with rapid eye movement sleep, sleep attacks, reduced sleep efficiency and excessive daytime sleepiness.[40,66]

Fatigue is a common symptom of PD and has been reported in 65.9 % of patients.[46] It is considered by patients as one of the most disabling PD symptoms with significant impact on QoL.[67] Fatigue is often seen early

in PD and is likely to progressively worsen over time. Recognition and monitoring of fatigue and appropriate treatment therefore are essential to maintain HRQoL.

A further non-motor symptom in PD that significantly impacts HRQoL is pain, which is reported in 40 % to 85 % of patients.[68,69] This symptom is increasingly recognised as a consequence of PD, but is frequently not reported and goes untreated. Pain in PD can be nociceptive, usually musculoskeletal and visceral. Musculoskeletal pain usually results from abnormal posture, rigidity and akinesia causing motor fluctuations and painful dystonia. Pain in PD can also be neuropathic, including radicular pain in the spine resulting from lumbar disc structure damage due to festination, kyphosis or dystonia.

Another aspect of PD that is often overlooked is that as the disease progresses and patient measures of HRQoL deteriorate, the strain on their caregivers is likely to worsen. This aspect was illustrated in a study that included 380 spouse caregivers at 23 sites of the Parkinson Study Group in the US. In the study, questionnaires were mailed to caregivers and found that they had to perform significantly greater numbers of tasks for the patient, their burden increased and their own health became significantly poorer as their charge's disease progressed.[70]

In PD management therefore, the patient's perspective is important and should be recognised. Several of the measures for assessing HRQoL in PD are designed to capture this perspective and their regular use enables better global assessment of all the symptoms that are causing difficulties and distress and informs better treatment choices.

Future Developments

In the future, increased awareness of HRQoL measures and their importance in determining PD impact and appropriate treatments among healthcare providers is likely to lead to an increasingly holistic approach to the disease and better maintenance of HRQoL. In addition, better public awareness of the negative effect of PD on HRQoL may reduce the stigma and isolation that many patients continue to experience and may increase public acceptance and reduce the burden on caregivers. HRQoL in PD is gaining greater prominence both in clinical trials and regular clinical practice and may become as important a criterion in drug efficacy as current measures of motor disability. The perspectives of patients, clinicians and researchers are not always consistent but ideally these will become more aligned enabling better recognition of the real impact of PD and finding better ways to address it. The development of improved assessment batteries and greater use of them in clinical practice may lead to better PD patient management, more timely and appropriate treatment and improved outcomes including patient independence.

Conclusions

In PD, while motor symptoms are the most obvious manifestation of the disease, motor fluctuations often are not recognised in the early stage of the disease. Non-motor symptoms are common and can remain substantially unrecognised too if they are not specifically assessed. Such lack of recognition often leads to poor HRQoL. The perspectives of the patients, clinical practitioners and researchers relating to symptoms, diagnosis, monitoring, treatment and management are often divergent resulting in misunderstandings, a failure to grasp the problem and inappropriate or insufficient treatment. In PD, HRQoL measures provide insights from patients on the impact of the disease and their use can rectify these shortcomings. Evidence from a wide range of studies on patients with PD indicates that both motor and non-motor symptoms significantly affect HRQoL and that maintaining or improving this aspect should be major aims in caring for people with PD. ■

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