

Enhancing Quality of Life in Indian Parkinson's Disease Patients with Improved Measurement of Psychological Domains: A Perspective

Ashima Nehra, Priya Sharma, Avneesh Narain, Shivani Sharma, Garima Joshi, Priyanka Bhat¹, Rajesh Kumar Singh¹, Roopa Rajan¹, Vinay Goyal², Achal Kumar Srivastava¹

Neuropsychology, Neurosciences Centre, ¹Department of Neurology, AIIMS, New Delhi, ²Department of Neurology, Medanta, Gurgaon, Haryana, India

Abstract

Parkinson's disease (PD) is the second most common progressive neuro-degenerative disorder. Research in PD is gradually increasing in India due to increased clinical cases, which could double by 2030 worldwide. Although its prevalence is low in India as compared to other countries, the total burden is much higher due to the large population size. PD is progressively debilitating, with pronounced motor and nonmotor symptoms (NMSs) that severely affect the quality of life (QoL) of patients and their caregivers. The progressive nature of the disease lays great emphasis on doctors to focus on the patients' QoL. As a consequence, Health-related QoL (HRQoL) has gradually become one of the main indicators for assessing health-related outcome. There is a growing need to pay attention to the NMSs and a pressing need to look at the QoL of Indian patients with PD through a culture and value specific lens. Research into the holistic QoL assessment with emphasis on psychological domains may allow for the early evaluation and intervention of depressive and cognitive symptoms in PD. This could result into increased productivity, reduced morbidity, and healthcare cost, which would in turn result into better QoL of Indian PD patients.

Keywords: Clinical Neuropsychology, Deep brain stimulation (DBS), HRQoL assessment, Neuropsychology, nonmotor symptoms

PD IN INDIA: AN OVERVIEW

Parkinson's disease (PD) is the second most common progressive neurodegenerative disorder.^[1-4] Research in PD is gradually increasing^[2] in India due to increased clinical cases that could double by 2030 worldwide.^[3,5-8] Although its prevalence is low in India as compared to other countries, the total burden is much higher due to the country's large population size.^[8] Comprehensive public health policies that cater to the needs of elderly are required to be cultivated, which would aid in decreasing the foreseeable economic burden.^[3] Measurement of PD's impact is of paramount importance in overall cost-benefit analysis^[9] especially in a developing country like India.

PD AND HRQoL: A PSYCHOLOGICAL VIEWPOINT

PD is progressively debilitating, with pronounced motor and nonmotor symptoms (NMSs) that severely affects the quality of life (QoL) of patients and their caregivers.^[1,6,10-14] Health-related QoL (HRQoL) is the patient's perception of the impact of an illness on physical, social, and psychological aspects of his life.^[12,15-18]

The fact that PD has no cure compels health care researchers to channelize most of their effort into refining and maintaining the QoL of the patients^[19] despite the rising difficulties. As a consequence, HRQoL has gradually become one of the main indicators for assessing health related outcome to the extent that, it is being made mandatory^[20] in most clinical studies to make optimal clinical interpretation and decisions^[20,21] and improve patient-physician communication.^[10,12,22]

COMPLEXITIES INVOLVING HRQoL

HRQoL is a theoretical concept that changes in accordance to different illnesses.^[12] Measuring PD-QoL is challenging due to the complex, deteriorating nature of PD and also because of the dynamic nature of the definition of the term QoL, which differs from one patient and caregiver to the next.^[23] It is bound to change over time with new interventions and disease progression.^[1,2,12,24] Defining a working definition of HRQoL of PD patients is the first step required towards the development of a new tool. It should be able to combine objective functioning along with the subjective perceptions and judgements of the patients.^[2,24-26] Since PD impacts a patients life varyingly – a mild tremor may be acceptable under a few circumstances however, it is extremely disabling for a worker whose job demands high level of dexterity.^[9]

Address for correspondence: Prof. Ashima Nehra,
Division of Neuropsychology, Room 718, 7th Floor, Neurosciences Centre,
AIIMS, New Delhi, India.
E-mail: dr.ashimanehra@aiims.edu

Submitted: 23-Apr-2020 **Revised:** 11-Jun-2020 **Accepted:** 11-Sep-2020

Published: 10-Apr-2021

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DOI: 10.4103/aian.AIAN_410_20

NMS IN PD

While rigorous research exists in the motor area, there is a growing need to pay attention to the NMS since, there is a high prevalence of NMS in Indian PD patients^[27] and also because of the fact that, the NMS may often precede PD diagnosis by several years.^[4] Research into this may allow for the early evaluation and intervention of depressive and cognitive^[28] symptoms associated with PD which could in turn result into increased productivity, reduced morbidity, and healthcare cost,^[25,29] which ultimately would translate into better QoL in Indian PD patients.

Moreover, it is also imperative to understand the increased probability of NMS resulting from disease progression and/or due to the increased concentrations of dopaminergic agonists.^[30] Understanding this is important since, pharmacology has been the main source of treatment thus far. Furthermore, in a study, nearly 100% of all PD patients had at least one NMS.^[31] Additionally, as compared to the controls, NMS in PD patients tend to be more recurrent and severe.^[16,17,26,27] It affects their QoL more severely^[32] as compared to motor, even in the early stages of PD.^[12,14,16,23,25,30-33] Moreover, the effect of perceived psychological burden in the QoL of PD patients is often greater than the severity of the illness by itself.^[4,9,14,22,25,27]

FACTORS IMPACTING QoL

There is a grave paucity of Indian population (IP).^[9,34] As compared to the world, the IP may differ in terms of epidemiology or response to treatment.^[8] In an extensive study, 34 professionals working with PD patients all over India were asked to report issues faced by PD patients in India. As a result, seven factors affecting QoL of Indian PD patients surfaced after intensive focus group discussions. Results demonstrated that bradykinesia, rigidity, postural problems along with fatigue, attention deficits, memory impairments,^[27,30] and psychiatric issues impacted the lives of the patients.

Likewise, among the several factors that negatively impact the QoL in PD such as anxiety, self-efficacy,^[14] fatigue, pain and motor issues,^[15,35] illness duration, and income,^[1,4,9,23,36,3] etc., cognitive^[27] and depressive factors are regarded as being the most significant.^[4,12,14,17,25,26,37,38] Since psychological factors play an extremely important role in improving the QoL of patients and are also an integral part of the continuum of care model,^[39] we should look beyond the physical Disabilities and towards the neuropsychological ones.^[9]

However, despite the growing awareness of QoL, the impact of psychological factors have not been addressed as the primary research concern in PD^[12] because researchers fail to realize the importance of this.^[9]

A systematic review of HRQoL scales in PD discerned that most of the existing tools assess the “*health status*” instead of *HRQoL*. *Health status* only indicates the perceived health functioning while outlining the limitations; however, *HRQoL*

also reflects the extent to which a patient is bothered by these limitations in daily life. The varying degree of importance patient gives to different aspects of functioning, limits the extrapolation of HRQoL from health status data. By the virtue of HRQoL scales providing more comprehensive view of patient’s health and functioning, there is a need to use such scales in PD.^[18]

QoL ASSESSMENT IN PD

While the *Movement Disorder Society Task Force* has “*recommended*” five out of nine QoL scales for PD patients, only one, Parkinson’s disease Questionnaire 39 (PDQ-39), is available in Hindi language.^[23,35] PDQ-39, despite being hailed as the most appropriate, thoroughly tested,^[19] and frequently used^[20,21,23] QoL tool in PD patients, has limitations in its summary scores validity and eight subscale dimensionality.^[20,23,40] Additionally, it also lacks items pertaining to sexuality and nocturnal sleep.^[1,16] Furthermore, PDQ-39 was developed on the basis of areas that were adversely affected rather than on a broader conception of QoL that consists of positive and negative areas. This tool negatively weighs QoL and predetermines life areas that are important to the patients. Many tools impose external value systems on the patients instead of letting them decide what is important to them individually.^[23] These tools imply that QoL has the same meaning for everyone which is not the case. In fact, emphasizing on other factors may end up causing more distress to the patients than they did previously before being asked certain questions. Many patients also attribute feeling distressed to the negative nature of the questions asked.^[23] While *none* of the “*recommended*” measures are sans limitations, the selection of the appropriate tool is mainly determined by research study’s objective, extent of PD Symptoms’ specificity, availability of the tool, and its cross-cultural validity.^[11,16,26]

NEED FOR PD-QoL ASSESSMENT IN INDIA

While a handful of reliable PD-QoL tools exist,^[35] none have been developed with the intention to cater to the needs of IP. There is a need for an appropriate QoL tool which is culturally accepted and which highlights the neuropsychological, socioeconomical aspects of IP instead of using measures that are designed in other countries on the basis of their respective population.^[19] Several cultures construct values and preferences for the degree of acceptance of particular illness and its symptoms and accordingly isolate or integrate the sick person. The outcome of this response is directly collated to the level of stress.^[41] Consequently, we require culture^[42]-specific assessment and treatment tools that are reliably validated as per Indian norms. Few of the reasons for the same have been enumerated in the following paragraphs.

In India, social and psychological issues are different. Lower QoL in Indian PD patients is associated with depression, worse disease intensity in off state, illness duration,^[9,17,30]

severity,^[14,26,36] dyskinesia, postural issues, cognitive impairment, work and financial insecurity,^[2,8,9,21,43] female gender,^[30] and high levodopa dosage.^[43] Furthermore, a study observed that, the cases of young-onset PD is gradually rising in India along with greater number of male patients actively seeking treatment as compared to females, with women perceiving their QoL worse than men^[1] in all dimensions of a QoL tool. This was despite their mean age and illness duration being lower. This may be because women in India notwithstanding of their illness are still required to complete household chores and rear their children with full responsibility. Even monetarily, women's treatment is not given the due importance since they are not the bread earners of the house in majority of the cases. Moreover, most Indian women feel that it is their duty to look after the family, but when the roles are reversed due to disability, they find it quite upsetting.^[43] It was also observed that male PD patients tended to gain the most attention from their family Members, being the "man of the household" probably because they are expected to support the family financially. Moreover, they also had a tendency to "avoid sharing their feelings" with their family and feel less important after their diagnosis^[19] due to their inability to support their family as per their set societal gender roles. Additionally, social support is another factor worth researching in the domains of QoL, Since strong extended family ties is a positive factor towards enhanced QoL in PD-IP. This highlights the importance of social functioning and cultural background,^[19] and such factors warrant a place in the thorough assessment of QoL^[36] for Indian Parkinson's patients.

Furthermore, researchers should also address culture specific factors while collecting sensitive data and forming items pertaining to depression and disturbance in familial and marital relationships and sexual life. These discussions are frowned upon, and in most cases such responses are inhibited.^[8,19] Many elderly patients are unwilling to talk about their emotional health and outright deny feelings of sadness despite experiencing them on a regular basis. As a result, depression in PD is often overlooked in clinical practice, and thus, frequently missed.^[2,25,31] This reflects the need of active participation of neuropsychologists as a part of the holistic team for more efficient standardized neuropsychological evaluation.^[25,27] For example, in a study conducted in India, it was stated that although approximately 38.5 PD patients appeared to have comorbid depression; it was not measured with the use of a standardized assessment tool.^[43] Depression symptoms and spiritual aspects of QoL are more often than not ignored by many physicians who instead tend to focus on their physical health.^[2]

A holistic input from the neuropsychologists is required^[27] to comprehend the less obvious but more debilitating signs of illness such as worries about being a burden, loss of interest in routine and nonroutine activities, and social withdrawal which leads to the patient feeling isolated and worthless. This is absolutely mandatory since depressive and its associated cognitive^[42] symptoms make it more difficult to deal with

PD, and thus reduce the QoL severely.^[25] Understanding of these issues is important and can result into enhanced QoL^[41] in Indian PD patients^[8] Professional neuropsychological assessment would help in the treatment of comorbid depressive and cognitive symptoms, which is likely to enhance QoL in Indian PD patients and "every effort should be recognized" to do so.^[43]

Along with the standardization and establishing the norms of the Indian PD-QoL tool, research is also needed in understanding the "minimal clinically important difference," which is the minimal change in scores that may not be scientifically significant as per the set norms but is clinically meaningful to physicians and subjectively to the patients.^[12,20] This reflects the need to standardize norms based on the functional needs of a large of Indian PD patients, which can later be used to serve as a point of reference for clinical decisions.

This would also allow us to establish a standard assessment protocol^[42] and, thus, make it easier to interpret the obtained scores^[24] and also compare various studies that observe the improvement of QoL in Indian PD patients after holistic neuropsychological rehabilitation, in a meta-analysis.^[1,11] This would be helpful since available literature on the efficacy of different interventions, gender differences,^[44] and neuropsychological determinants of QoL in PD patients are inconclusive^[1] due to the lack of consensus in a specific PD-QoL tool.

EXISTING PD ASSESSMENT TOOLS AND THEIR LIMITATIONS

Existing PD-QoL tools that have been used in IP consists of Fatigue Severity Scale^[11,33] that focuses mainly on the impact of fatigue in QoL; PDQ-39,^[8] the limitations of which have been aforementioned; and WHO QOL-BREF, which although has also been used in PD patients, it fails to assess the complexity of QoL factors like social support, individualistic coping strategy, cultural context^[18,25]; Parkinsonism impact scale^[10] is a yet another tool that can be used, which although is easy to use in the OPD setting has only 10 items that may provide with restricted results. None of these tools appear to be very holistically well adapted to Indian PD patients.

However, recently, Aggarwal *et al.*,^[45] developed a novel and meticulous culture-specific QoL tool which is deeply rooted in the rich literature review. Nevertheless, there is still a scope for improvement – in the tool, out of 47 items, only four address the psychological aspects, wherein cognitive characteristics have been completely neglected. A holistic comprehension of the inter-relationship between QoL and cognition is crucial for research and also for making informed decisions in healthcare and rehabilitative areas.^[11] Additionally, while they comprehensively tried to understand the factors underlying the QoL of Indian PD patients; we believe that they would have further benefited from a group trained neuropsychologists^[1,39] during the information extraction phase to obtain the vital personal and sensitive data skilfully via in-depth, unstructured

interviews from the PD patients that they might not have been comfortable sharing due to the taboo and stigma attached to it.^[9,26,27] Eliciting such sensitive data often requires the knowledge of rapport formation, active listening, empathy, and understanding the nonverbal cues of the patients, which can be deftly managed only by a trained neuropsychologist.^[39] We suggest that the due consideration of this psychological aspect would not only enhance the outcome of the tool but also prove to be beneficial for the patients' welfare.

PD-QoL ASSESSMENT IN DBS

Another important requirement of the HRQoL tool is evident during the pre- and post-deep brain stimulation (DBS) treatment. Since PD cannot be cured, the patient's QoL is the most important domain which determines the success of this procedure^[32] and several studies point towards the positive role of DBS in improving QoL^[46,47,44] of PD patients. Numerous studies point towards the strong relationship between QoL and NMS, wherein it was found that depression and cognitive^[48] level predicts whether patients would show clinically significant changes in PDQ scores postsurgery or not. This fact enhances the important influence of mood in self-reported QoL along with the significance of psychological care underlying surgical treatment and also guides best practices for patient selection pre-DBS.^[49] DBS has resulted into enhanced QoL as compared to best medical treatment.^[50] A study^[32] that aimed to assess whether DBS stimulation parameters setting may impact some NM aspects of QoL observed up to 32% improvement in PDQ-39 subscales of emotions, communications, and stigma, after altering the stimulation parameters (mean increase of amplitude of 0.35 V), despite no changes in UPDRS-III, in 3 months follow-up. This proved to have additional positive influence on QoL in PD patients. Such studies emphasize that routine meticulous QoL observation, focusing on the neuropsychological domains,^[46] can aid in DBS parameter settings and should be mandatory before and after DBS surgery.^[32] Being a fundamental part of such clinical protocols may help in identifying factors that affect the patient's QoL rather than only the motor activities^[32]

HRQoL assessment is an obligatory resource in clinical research, especially to understand the efficacy of novel interventions from the unique viewpoint of the patients,^[36] and thus plays a major role in making therapeutic decisions.^[42] It is more reliable than informal interviews alone^[35] and has become a chief concern for patient counseling.^[24] There is an urgent need for PD clinical trials to develop and utilize scientifically valid, standardized, and reliable QoL tools^[21] as the primary outcome measures^[1,4] for the use of Indian professionals.^[33] This would aid in comprehending the crucial underlying issues related to PD in IP, its impact,^[1] and also in designing personalized treatment regime, assessing its efficacy^[6,12,26,35] which is not viable through any other method.^[35] Examining personal determinants of HRQoL may provide vital information for setting the goals at the intervention planning phase and the change outcomes in the evaluation phase^[12,17,26] for patients, family, and professionals at different junctions of interventions and disease progression.^[23]

FACTORS TO BE CONSIDERED IN DEVELOPING PD-QoL TOOL FOR IP

While developing the QoL tool on Indian PD patients one must keep in mind the general limitations of other QoL tools, which is inclusive of: complex definition of QoL,^[25] low^[32] sample size,^[11,27,33] unbalanced distribution of sample as per the disease severity, restricted geographical area^[11] and socioeconomic status (all which impact generalization of results),^[27] changes in the disease state between the time frames of test-retest reliability, language, sociocultural differences for proper generalization,^[24] under reporting of sexual symptoms^[27] whether it should be generic or disease/symptom specific,^[16,20,26] its time requirement (scale length),^[9] sensitivity to changes over time,^[12] role of social environment,^[26] inclusion of all major QoL factors on the basis of the psychological interview; while at the same time understanding that it should not attempt to address every aspects of life that has an influence On its quality. It, it should be based on in-depth literature review, unbiased experts, should be solely based on "*patient reported outcomes*" to enable "*real time*" monitoring of symptoms, should have consistent HRQoL definition, nonvague language, gender appropriateness, and be easy for translation,^[22] should avoid cognitive symptoms overlap due to depression^[25] and include *casual and indicator domains* to improve the discriminatory sensitivity and responsiveness of the Tool.^[2] Lastly, it should also consider neuropsychological aspects to yield richer information.^[25]

In an attempt to establish such a tool, another recent systematic review^[2] of PD-specific scales was carried out. It established four main domains of HRQoL – physical, psychological, social/familial, and NMSs. The review emphasized that a PD-QoL tool should address the multidimensionality and dynamic nature of the QoL concept as it is influenced by nonmodifiable factors such as gender,^[14] educational qualification, and age. It should also address all of its important domains that ensure that they are self-reported by patients since HRQoL is an individualized concept and, thus, should not have a predefined criterion. It should depend on the needs of the patients as per their experiences and expectations.^[14] The patient reported subjective outcomes are accentuated to negate the chances of the responses being influenced by clinicians. We need to elicit the factors affecting QoL in Indian PD patients.^[2]

This new PD-QoL tool should address the limitations of existing tools and ensure the cultural and linguistic corroboration of the same. This would not only allow researchers to gain insight into the objective aspects of QoL like course, illness duration,^[32] number and intensity of social contacts,^[4,14] presence of comorbidities,^[12,14] but also allow a holistic insight into the subjective psychological aspects of QoL such as self-image, fitness level, familial satisfaction, economic condition, human interaction, and social support.^[15] It would help in focusing on enhancing the overall QoL with special emphasis on psychological factors, which is what matters the most to the patients.^[15,37] Additionally, it would also give us a better understanding of gender differences since

women are more prone to depressive and cognitive symptoms and thus tend to have a decreased QoL as compared to men.^[5]

CONCLUSION

A holistic assessment and treatment regime with interdisciplinary^[9,12] approach and interdisciplinary team support would profit PD patients. Ensuring that the assessment tool is in regional Indian languages and which also highlights the psychological aspects, would help us to understand the factors affecting the QoL in a subjective manner and thus come up with holistic tailor made, patient-centered^[12,27,36,43,48] treatment regime for the Indian PD patients in order to maximize their QoL and subjective well-being, which is the ultimate aim of any intervention.^[9,11] This will certainly help patients and their family cope better with the illness^[12] and “*add life to the years rather than merely adding years to life*”^{[9].}

Acknowledgements

We would like to thank the All India Institute of Medical Sciences (AIIMS, New Delhi) for their support as well as to the Department of Biotechnology (DBT), India (BT/PR 12587/MED/122/3/2016) for their funding.

Financial support and sponsorship

Department of Biotechnology (DBT), India.

Conflicts of interest

There are no conflicts of interest.

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