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PERCEPTION OF QUALITY OF LIFE IN INDIVIDUALS WITH PARKINSON'S DISEASE USING THE PDQ-39

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ABSTRACT

Parkinson's disease (PD) is a chronic degenerative disease of the central nervous system that affects mainly individuals older than 50 years of age. Studies evaluating quality of life (QOL) in individuals with PD have revealed that this disease has a significant negative impact. The Parkinson's Disease Questionnaire-39 (PDQ-39) has been indicated as one of the most appropriate instrument for evaluating QOL in individuals with PD. Objective: To evaluate the perception of QOL in individuals with PD at our Institution's outpatient service for movement disorders, using the PDQ-39. Method: Individuals with a diagnosis of PD who were aged 40 years and older and classified in stages 1 to 3 of the Modified Hoehn & Yahr scale were included in this study. Results: Thirty-three individuals of mean age 64.65 ± 10.44 years and mean duration of the disease of 9.27 ± 4.40 years participated in this study. The descriptive analysis showed that the median total score in the PDQ-39 was 25%, with worst perceptions of QOL in the dimensions of "Activities of Daily Living" (ADL) (41.67%) and "Mobility" (34.32%). A high association was found between the total score and the dimension of "Mobility" (r_s= 0.82) and a moderate association between the total score and the dimensions of "ADL" (r_s= 0.68) and "Communication" (r_s = 0.53). Conclusions: Motor limitations relating to mobility, ADL and communication were significantly related to the general perception of QOL among individuals with PD. These findings suggest that rehabilitation programs aiming to improve QOL among individuals with PD should focus on these limitations.

Key words: Parkinson's disease; quality of life; PDQ-39.

RESUMO

Percepção da Qualidade de Vida de Indivíduos com Doença de Parkinson Através do PDQ-39

A Doença de Parkinson (DP) é uma doença crônica e degenerativa do sistema nervoso central que afeta principalmente pessoas acima de 50 anos. Estudos que avaliaram a qualidade de vida (QV) em parkinsonianos revelaram significativo impacto negativo da doença nesses indivíduos. O *Parkinson Disease Questionnaire–39* (PDQ-39) tem sido indicado como instrumento mais apropriado para avaliação da QV do indivíduo com DP. Objetivo: Avaliar a percepção da QV de indivíduos com DP do Ambulatório de Distúrbios do Movimento da Instituição, através do PDQ-39. Método: Participaram deste estudo indivíduos com diagnóstico de DP, entre os estágios 1 e 3 da escala de Hoehn & Yahr Modificada e com idade igual ou superior a 40 anos. Resultados: Trinta e três indivíduos com média de idade de 64,65 (±10,44) anos e tempo médio de evolução da doença de 9,27 (±4,40) anos participaram deste estudo. A análise descritiva mostrou que a mediana do escore total no PDQ-39 foi 25%, ocorrendo pior percepção da QV nas dimensões "Atividade de Vida Diária (AVD)" (41,67%) e "Mobilidade" (34,32%). Encontrou-se alta associação entre o escore total e a dimensão "Mobilidade" (r_s= 0,82) e moderada associação das dimensões "AVD" (r_s= 0,68) e "Comunicação" (r_s= 0,53) com o escore total. Conclusões: As limitações motoras relacionadas à mobilidade, AVDs e comunicação possuem relação significativa com a percepção geral da QV dos indivíduos com DP. Estes achados sugerem que programas de reabilitação que tenham como objetivo a melhora da QV na DP devem enfocar tais limitações.

Palavras-chave: doença de Parkinson; qualidade de vida; PDQ-39.

INTRODUCTION

Parkinson's Disease (PD) is a chronic and degenerative disease of the central nervous system[1,2] which results from the death of motor neurons of the substantia nigra, causing a decrease in dopamine in the nigrostriatal pathway[1]. This is a slowly progressive disease which mainly affects people over 50 years old[1]. With the increased aging of the world's population, it is estimated that by 2020 more than 40 million people worldwide will have motor disorders as a consequence of PD[3].

PD is characterized by motor disorders and postural dysfunctions[3]. The main motor disorders are bradykinesia (slowing down of movements), hypokinesia (reduction in range of motion), akinesia (difficulty to initiate movements), tremors and stiffness[3,4], as well as deficits in balance and gait[3,5]. As the disease progresses, patients can suffer cognitive disorders, memory loss, problems related to visuospatial dysfunction, difficulty with sequential and repetitive movements, freezing and slowness in psychological response[3-5]. It is common for the individual to also present a diminished writing ability, lowering of the voice, and other complications in speech as well as in deglutition[3,5,6]. The mental, physical, emotional, social and economic damage associated with the signs, symptoms and side effects of PD affect the individual's level of disability[1] and can negatively influence their quality of life (QoL), causing isolation and lack of social interaction[7].

According to the World Health Organization, health is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"[8,9]. Recently, this concept became broader, and researchers began to use the term Health-related Quality of Life (HRQoL)[9,10]. HRQoL refers to an individual's perception of their disease and its effects on their life, including personal satisfaction associated with physical, functional, emotional and social well-being[10]. Therefore, QoL can be considered a multidimensional concept which reflects a patient's subjective assessment of personal satisfaction with life and other aspects such as family relationships, personal health and the health of friends and family, finances, housing, independence, religion, social life and leisure activities[9,11,12].

QoL can be measured by generic as well as specific instruments. The former are used to compare the impact of different diseases or a specific disease on QoL in the general population[9,11]. In the specific instruments, however, the items focus more on the characteristics of the disease in question. These instruments can also include items designed to measure the side effects of treatment, although they may contain the same domains assessed by the generic instruments[11]. The specific instruments are more sensitive to alterations in the individual's health condition as they focus on the symptoms which have greater impact on the disease in question[9].

The generic instruments used on PD patients include the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP), the Short-Form 36 - Medical Outcomes Study (SF-36), the Functional Status Questionnaire (FSQ) and the EuroQol instrument (EQ-5D). The 39-item Parkinson's Disease Questionnaire (PDQ-39)[13] stands out among the specific questionnaires and it has been recommended as the most appropriate instrument to evaluate QoL in PD patients[9]. Recent studies have indicated that PDQ-39 is sufficiently robust to be used in cross-cultural studies after its results revealed more similarities than differences between different countries[14,15].

Studies that evaluated QoL in PD patients showed the negative impact of the disease on the QoL of these individuals[4,7,16-18]. In spite of that, little is known about the real impact of the disease on the life of the patients and their families. In Brazil, only the studies of Camargos et al.[9], Rodrigues de Paula Goulart et al.[19], Rodrigues de Paula et al.[20] and Schestatsky et al.[21] focused on this theme.

The Movement Disorder Clinic, located at the institution where the present study was developed, has been operating for approximately eight years. It is a center of excellence in the multidisciplinary approach of individuals with different types of Parkinson's disease and other motor disorders. Considering the prevalence of PD, its impact on QoL and the lack of more specific information on the QoL of PD sufferers in Brazil, the present study sought to evaluate the perception of QoL of PD individuals treated at the abovementioned clinic, through the use of PDQ-39.

MATERIAL AND METHODS

Participants

Only individuals diagnosed with PD and treated at the Movement Disorder Clinic of the University by local neurologists were recruited. The participants had to be classified between stages 1 and 3 of the Modified Hoehn & Yahr (MHY) Scale[2], be 40 years old or more, show no difficulty in comprehending the questionnaire and agree to answer it. Thirty-three PD patients (18 men and 15 women) were recruited and included in the present study.

All participants were briefed on the objectives of the research and signed a free and informed consent. This study was approved by the University's Ethics in Research Committee (approval 045/99).

Instrumentation

Modified Hoehn & Yahr Scale

The Hoehn & Yahr Scale (Degree of Disability Scale) is a scale that evaluates disability in individuals with PD. It is capable of determining their general condition quickly and efficiently[19]. Its modified form includes seven classification stages to evaluate the gravity of PD and essentially covers global

measures of signs and symptoms to classify an individual as to their degree of disability[19]. The individuals classified in stages 1 to 3 presented slight to moderate disability, whilst those in stages 4 and 5 presented serious disability[2,19].

PDQ-39

The PDQ-39 is a specific scale that evaluates the QoL of PD patients and consists of 39 multiple-choice questions with five possible answers: "never"; "occasionally"; "sometimes"; "often"; "always" or "cannot do at all"[18]. The scores in each item vary from 0 (never) to 4 (always or cannot do at all). The PDQ-39 is divided into eight domains: Mobility (10 items), Activities of Daily Living - ADL (6 items), Emotional Well-Being (6 items), Stigma (4 items), Social Support (3 items), Cognition (4 items), Communication (3 items), Bodily Discomfort (3 items)[11,18]. Each individual's total score is calculated as follows: 100 x (the sum of the patient's scores in the 39 questions / 4 x 39). The domain scores are calculated in the same way as the total score[11,22]. The total score for the PDQ-39 varies from 0 (no problem) to 100 (severe problem), that is, a low score indicates a better perception of QoL on the part of the individual[5,18].

This scale was formally validated in American English, British English, German, Spanish, Chinese, Greek and French[11,14]. Translations are available in many languages, including Brazilian Portuguese[11]. It was adapted to Brazilian Portuguese by the Health Services Research Unit (Department of Public Health and Primary Care - University of Oxford), in 2005. This was the version used in the present study and was obtained through personal contact with the authors of the questionnaire.

Before PDQ-39 was used in this study, a pilot study was conducted to determine the instrument's intra-rater and inter-rater reliability. The results revealed adequate reliability both for intra-raters (ICI= 0.93) and inter-raters (ICI= 0.98) of the PDQ-39 in PD patients.

Procedures

Data were collected by two researchers specially trained in the application of this questionnaire. The interviews were scheduled in advance according to patient availability. Initially, the demographic data were collected, and the MHY stage was determined based on each patient's medical record and confirmed by the researchers during the medical appointment where the patient was recruited. The PDQ-39 was then applied in approximately 15 minutes. Due to the sociocultural characteristics of the sample, the questionnaire was applied in the form of an interview, and the questions were always asked in the same order. Any questions regarding the application of the PDQ-39 were brought directly to one of the authors of the original version for clarification so as to adjust the individual's answers to the answer system proposed in the questionnaire[15]. Records were kept in individual sheets, and the participants were told to provide only one of the possible answers. To ensure anonymity and data confidentiality, the participants received an identification number.

Statistic analysis

SPSS 13.0 for Windows was utilized for the descriptive statistics and the normality test (Shapiro-Wilk). As the majority of the variables were not normally distributed, the Spearman Coefficient Correlation was used to investigate possible associations between them. The association between each domain and the total PDQ-39 score was analyzed. The magnitude of the correlations were based on Munro's classification[23] (low= 0.26-0.49; moderate= 0.50-0.69; high= 0.70-0.89; very high= 0.90-1.00) for the interpretation of the correlation coefficients. The level of significance considered was $\alpha < 0.05$.

RESULTS

Thirty-three individuals participated in the present study, including 18 men and 15 women, with a mean age of 64.65 ± 10.44 varying from 42 to 83 years of age and a mean period of evolution of the disease of 9.27 ± 4.40 varying from 1 to 17 years. Among these individuals, one was in stage 1.0 of the HY Scale; another was in stage 1.5; 14 were in stage 2.0; five were in stage 2.5; and 12 were in stage 3.0. The minimum and maximum values and the median of the total score and the score obtained in each domain are presented in Table 1.

Statistically, the individuals demonstrated a worse perception of QoL in the "ADL" and "Mobility" domains (Table 1). The Spearman Correlation Coefficient found a high association between the total PDQ-39 score and the "Mobility" domain and a moderate association between the "ADL" and "Communication" domains (Table 2).

Table 1. Descriptive statistics (minimum, maximum and median values) of the total score and the scores for each dimension of the PDQ-39 (in percentage).

Domain	Minimum	Maximum	Median
1- Mobility	0.00	82.50	35.00
2- ADL	0.00	95.83	41.67
3- Emotional Well-Being	0.00	75.00	29.17
4- Stigma	0.00	62.50	12.50
5- Social Support	0.00	75.00	0.00
6- Cognition	0.00	56.25	12.50
7- Communication	0.00	75.00	16.67
8- Bodily Discomfort	0.00	100.00	25.00
Total Score	5.26	53.95	25.00

ADL= Activities of Daily Living; PDQ-39= Parkinson Disease Questionnaire-39.

Table 2. Spearman correlation coefficient (r_s) between the total PDQ-39 score and its domains, and the Munro[23] classification for correlations.

Domain	r_s	Classification
1- Mobility	0.82 **	High
2- ADL	0.66 **	Moderate
3- Emotional Well-Being	0.36 *	Low
4- Stigma	0.47 **	Low
5- Social Support	0.42 *	Low
6- Cognition	0.10 ^{NS}	—
7- Communication	0.53 **	Moderate
8- Bodily Discomfort	0.46 **	Low

** $p< 0.01$; * $p< 0.05$; ^{NS} Non-significant.

DISCUSSION

This study aimed to evaluate the perception of QoL in PD individuals through the use of the PDQ-39. This questionnaire was chosen because it is the most used in research on QoL in PD individuals[14,24,25]. It is also the most extensively validated and possibly the most appropriate to measure QoL in PD[14]. According to Hagell & McKenna[26], the PDQ-39 presents good content validity as a measurement of health, functionality and well-being, and also as an easy-to-understand instrument that takes important aspects of the disease into account.

Given that most participants presented a low educational level, the instrument was applied in interview form to avoid misinterpretation and to emphasize the main question – something that has been pointed out as a limitation of the instrument in studies that used the traditional form of application[14]. In addition to that, this method of application seeks to prevent the loss of data, encouraging the individual to answer the questionnaire completely[14].

In this study, a worse perception of QoL was observed in the "ADL" and "Mobility" domains (Table 1). Various studies in different countries analyzed QoL in PD using the PDQ-39[5,15,24,25,27-30]. The majority of these studies also documented a worse perception in the "Mobility" and "ADL" domains[5,15,27,28,30]. Other studies utilized generic instruments to evaluate QoL in PD individuals and found similar results to the ones found in studies with the PDQ-39[5,17]. Jenkinson et al.[5] and Karsen et al.[17] observed a more negative perception of QoL in the physical domains, through SF-36 and PSN, respectively. These findings corroborate the present study, indicating that the domains which relate to the physical aspects of the disease are the ones in which the PD individuals present a more negative perception of QoL. It is known that the main symptoms of PD are motor symptoms and that, coupled with a sedentary lifestyle and social isolation, they interfere significantly in the perceived QoL of the individual[13,17].

The participants of this study presented a low total score in the PDQ-39 (Table 1) that could indicate a good perception of QoL in this group. The fact that this sample was not in the more advanced stages of the disease, i.e. above stage 3 of the MHY[3], may have contributed to this result. However, in relation to the total PDQ-39 score, a cutoff point that indicates which values represent a good or bad perception of QoL is not yet available in the literature.

Correlation coefficients are used to quantitatively describe the strength and the direction of the relationship between two variables, indicating that the changes in one of the variables are proportional to the changes in the other[31]. In this study, the "Mobility" domain presented a high correlation with the total PDQ-39 score. The "ADL" and "Communication" domains presented a moderate correlation with this total score. Only the study by Martínez-Martín et al.[25] carried out this kind of analysis using the PDQ-39 data and reported a high correlation between the total score and the "ADL" and "Communication" domains and a moderate correlation with the "Mobility" domain. It is known that the motor aspects are the most damaged in DP[5,15,24,25,27-29], therefore the domains associated with them can be related to a worse perception in the total PDQ-39 score. The "Mobility", "ADL" and "Communication" domains present questions that include motor aspects of PD. These domains could thus present a more significant relationship with the general perception of QoL, as alterations in its scores may correspond to proportional alterations in the total PDQ-39 score. However, the lack of studies with this kind of analysis limits the discussion of this association and hampers the identification of the domains most related to the perception of QoL in PD individuals according to the PDQ-39.

It is important to note that, during the application of the PDQ-39, some limitations regarding the instruments were observed, such as the questionable relevance of some items which can be of little importance in the daily life of an individual (difficulty carrying bags) and the complexity of questions involving more than one concept, e.g. question 33 (Have you had any bad dreams or hallucinations?) and question 29 (Have you lacked support from your family or friends?). These observations were also reported in Hagell & McKenna[26] and Kim et al.[32], who also questioned the presence of double negatives in the text of two of the three items of "Social Support" and whether the use of walking aids should be considered for the answers in the "Mobility" domain. The real difference between "occasionally and "sometimes" has already been questioned. This problem exists in the Portuguese language version as well as in the British, Swedish and American versions[26,32]. Also, important aspects were not incorporated into the PDQ-39, such as medication, nutrition, mental aspects, dyskinesia, sexual problems, mobility in bed and sleeping problems[26,32].

It is known that the reliability and validity established in a language do not guarantee that these properties re-

main intact when the questionnaire is adapted to another language[26]. The PDQ-39 was validated in many countries and its potential use in cross-cultural studies has already been confirmed[11,14]. In a recent study, Carod-Artal et al.[33] discovered that the Brazilian version of the PDQ-39 is a reliable and valid measure for PD patients in Brazil.

The results of this study indicated that the motor limitations related to mobility, ADLs and communication present a significant association with the general perception of QoL by PD individuals assessed at the Movement Disorder Clinic where the study was carried out. These findings suggest that the approach to motor aspects during PD treatment is relevant to the modification of the perception of QoL by PD individuals, as an improvement in the perception of "Mobility" and "ADL" is associated with an improvement in the total PDQ-39 score.

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