Reproducibility of the multidimensional assessment questionnaire and factors associated for individuals with Parkinson disease

Reprodutibilidade do questionário de avaliação multidimensional e fatores associados para indivíduos com doença de Parkinson

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ABSTRACT

Objectives: To investigate the reproducibility of the Multidimensional Assessment Questionnaire for Individuals with Parkinson's Disease (MAQPD), applied remotely, based on an analysis of test-retest reliability, standard error of measurement (SEM) and minimum detectable change (MDC), and to investigate the associated factors.
Methods: The MAQPD was applied and re-applied via Google Forms to individuals with Parkinson. Personal and clinical variables (age, sex, number of associated diseases, number of medications, skin color, and sleep quality - number of times waking up at night) also was registered. Test-retest reliability for each section was determined by the intraclass correlation coefficient (ICC). With these values, the SEM (SEM%) and MDC were calculated. Spearman's correlation coefficient was used to assess the correlations between each section of the MAQPD and the associated factors.
Results: Sixty-one individuals were included, with a mean age of 61 years (SD 12) and a cognitive score of 17 (SD 3). All three sections showed high reliability (ICC≥0.90), and a SEM% lower than 15%. The MDC for the ADL section was 13.52, for cognition was 7.98, and for pain was 11.72. There was a significant correlation between: the ADL section and age (ρ=-0.371,p=0.004) and skin color (ρ=-0.324,p=0.011); the cognition section and the number of medications (ρ=-0.295,p=0.022); and the pain section and age (ρ=0.286,p=0.027) and sleep quality (ρ=-0.292,p=0.024).
Conclusion: The MAQPD is reproducible and capable of generating reliable measures in the self-assessment of this population. Furthermore, older and black individuals have worse performance in ADLs, individuals taking a higher number of medications have a worse cognitive state and, finally, younger individuals with a higher number of nocturnal awakenings have more pain.

Keywords: Parkinson's disease. Reproducibility. Remote assessment. Multidimensional assessment. Self-assessment.

RESUMO

Objetivos: Investigar a reprodutibilidade do Questionário de Avaliação Multidimensional para Indivíduos com Doença de Parkinson (MAQPD), aplicado remotamente, com base na análise da confiabilidade teste-reteste, erro padrão de medida (SEM) e mudança mínima detectável (MDC), além de explorar fatores associados.
Métodos: O MAQPD foi aplicado e reaplicado via Google Forms em indivíduos com Parkinson. Variáveis pessoais e clínicas (idade, sexo, número de doenças associadas, número de medicamentos, cor da pele e qualidade do sono - número de despertares noturnos) também foram registradas. A confiabilidade teste-reteste para cada seção foi determinada pelo coeficiente de correlação intraclasse (ICC). Com esses valores, foram calculados o SEM (SEM%) e o MDC. O coeficiente de correlação de Spearman foi utilizado para avaliar as correlações entre cada seção do MAQPD e os fatores associados.
Resultados: Sessenta e um indivíduos foram incluídos, com média de idade de 61 anos (DP 12) e escore cognitivo médio de 17 (DP 3). Todas as três seções apresentaram alta confiabilidade (ICC≥0,90) e SEM% inferior a 15%. O MDC foi de 13,52 para a seção de ADLs, 7,98 para cognição e 11,72 para dor. Houve correlação significativa entre: a seção de ADLs e idade (ρ=-0,371, p=0,004) e cor da pele (ρ=-0,324, p=0,011); a seção de cognição e número de medicamentos (ρ=-0,295, p=0,022); e a seção de dor e idade (ρ=0,286, p=0,027) e qualidade do sono (ρ=-0,292, p=0,024).
Conclusão: O MAQPD é reprodutível e capaz de gerar medidas confiáveis na autoavaliação dessa população. Além disso, indivíduos mais velhos e negros apresentam pior desempenho em ADLs, indivíduos que utilizam maior número de medicamentos apresentam pior estado cognitivo e, por fim, indivíduos mais jovens com maior número de despertares noturnos apresentam mais dor.

Palavras-chave: Doença de Parkinson. Reprodutibilidade. Avaliação remota. Avaliação multidimensional. Autoavaliação.

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INTRODUCTION

Parkinson's disease (PD) is characterized as a progressive neurological disorder, marked essentially by the degeneration of neurons in the ventral layer of the compact part of the substantia nigra[1]. Consequently, there is a decrease in the production of the neurotransmitter dopamine, generating a variety of motor symptoms, such as resting tremor, rigidity, and bradykinesia, which result in slow movements[2]. In addition, PD can be related to non-motor symptoms, including constipation, urinary dysfunction, memory loss, depression, orthostatic hypotension, pain, hyposmia, and sleep disorders[3]. Actually, PD is one of the most common neurological diseases, with a global prevalence of around 10 million people, making it an important cause of neurological disability [4-6] .

Motor and non-motor disorders in individuals with PD tend to progress, becoming increasingly evident and resistant to treatment, generating disability in daily activities, increasing the number of falls and hospitalizations, reducing quality of life, and favoring the onset of dementia[7]. Thus, it should be noted that regular assessment of these individuals is important to monitor the progress of the disease[8]. Questionnaires are an important tool for this assessment, as they allow patients to reflect on themselves and their general state of health, as well as providing information for the professionals, about the disease and its repercussions[9]. There are several questionnaires that are used to assess the functionality of individuals with PD. However, most of them do not assess several domains of functionality, or their application must only be carried in person, or are not specific to the disease [10-12] .

Considering these characteristics of PD, especially in relation to the decline in functionality, it is necessary to use questionnaires that can assess these individuals multidimensionally[13]. In addition, the questionnaires should also cover as many patients as possible, considering their specificities and limitations, i.e. also covering those who face difficulties in transportation and locomotion, live in places that are difficult to access, as well as in situations of isolation, such as a pandemic[13]. In this context, the Multidimensional Assessment Questionnaire for Individuals with Parkinson's Disease (MAQPD) was developed, to be applied remotely using Google Forms. Consisting of 71 questions, the questionnaire is divided into three sections: activities of daily living (ADL), cognitive aspects and pain[13]. It is currently considered the only self-applicable tool, used remotely, which enables a detailed assessment of the general state of health and functionality of the individuals with PD[13].

Although the MAQPD has been developed and validated, it is still necessary to assess whether it is reproducible. The reproducibility is understood as the degree of agreement of the results when the test is repeated under the same conditions and at different times and can be assessed by the test-retest reliability, standard error of measurement (SEM) and minimum detectable change (MDC)[14]. Test-retest reliability is related to the coherence and consistency of the results when the instrument is applied twice to the same group[15]. The SEM and MDC are parameters that supply important information on the reliability of the instrument in question by indicating the range in which the theoretical “true” score lies; and supply context when interpreting data from longitudinal measurements by indicating by how much the score needs to change before one can be reasonably certain that a true change has occurred[15]. These properties are called population dependent, and so it is important that are always investigated in every population group that the questionnaire is intended to be applied[16].

Other important knowledge is about the impact of which personal and/or clinical factors may possibly be associated with the functionality of patients with PD, providing to the physiotherapy professionals information of a profile of individuals at greater risk of developing a worse prognosis, helping them to draw up an appropriate treatment plan with greater precision. These factors include sex, age, sleep quality, diet, continuous use of medication, etc. Previous studies have shown that natural aging is a factor that can negatively affect the functionality of individuals with PD, with the possibility of its development in men and women increasing significantly after the age of 60 [17,18] . Age can also influence the severity of symptoms and the presence of morbidities that affect functionality [17,18] . Previous data has also revealed that the disease affects the non-Hispanic white population more and has a higher prevalence in males[17]. Furthermore, sleep is also affected in PD, with more than 60% of patients reporting insomnia caused by nocturnal motor symptoms[19], which can possibly affect functionality. Although these results represent an advance in the literature, studies that consider the three domains of functionality most affected by PD (pain, cognition, and ADLs) and their associated factors are still scarce.

Thus, the aim of this study was to investigate the reproducibility of the MAQPD questionnaire based on the analysis of test-retest reliability, SEM and MDC, in addition to investigating which personal or clinical factors (age, sex, associated diseases, number of medications, skin color, and sleep quality) may be associated with the functionality of individuals with PD, in the ADL, cognition and pain sections of the MAQPD.

MATERIALS AND METHODS

Design

This is a methodological observational study, approved by the Research Ethics Committee of the FUNCESI University (CAAE 68276323.3.0000.5110), which all participants signed the consent form digitally.

Participants

Individuals from the general community with a diagnosis of PD, who met the eligibility criteria, were recruited through social media, such as WhatsApp, Facebook and Instagram, as well as rehabilitation clinics. The inclusion criteria were: (1) individuals of both sexes aged 18 or over; (2) a clinical diagnosis of PD, provided in advance by a neurologist; (3) adequate cognitive ability, determined by the Montreal Cognitive Assessment (T-MoCA)[20]. The exclusion criterion was individual had any other condition that would interfere with the application and results of the questionnaire.

Procedures

All individuals were informed about the purpose of the study and agreed to participate. After, the inclusion criteria were checked, and clinical and demographic data was collected to characterize the sample. The MAQPD was applied remotely, using Google Forms, by two previously trained physiotherapists, and reapplied after six days, to assess test-retest reliability. The same physiotherapist who carried out the test also carried out the retest. This time interval was adopted as it has already been established that it is long enough to prevent individuals from remembering their previous answers, as well as short enough to prevent any changes in their clinical condition[16]. Personal and clinical data (possible associated factors) were also collected in the remote interview, including age, sex, associated diseases, number of medications, skin color, and sleep quality (number of times waking up at night) (Figure). The phase of medication ("On or Off") and/or dosage were not considered. However, the questionnaire was always reapplied at the same time to ensure the same conditions in the test and retest assessments.

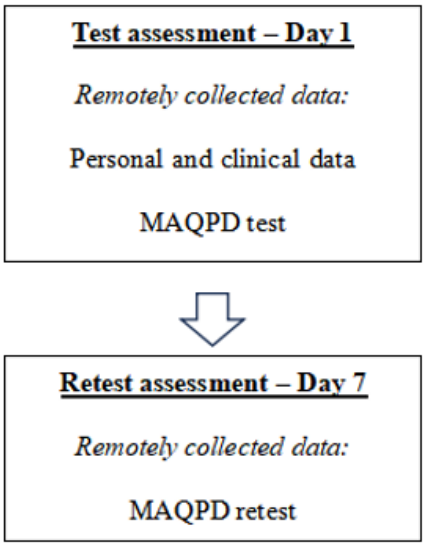

Figure . Assessment flowchart

MAQPD

The MAQPD consists of 71 questions, divided into three sections (A, B and C). Section A is related to the presentation of the research, while section B is divided into two modules, the first of which is related to ADL, and the second to cognition[13]. Section C concerns the impact of pain on the lives of the participants. This section is divided into three subgroups of questions, taken from the Portuguese version of the Multidimensional Pain Inventory[13].

The MAQPD uses two responses: a Likert scale with five rating levels, ranging from zero (totally disagree) to 4 (totally agree) used in Section B, and a Likert scale with seven rating levels, ranging from 1 (little pain) to 7 (a lot of pain) used in Section C[13]. The questionnaire also has optional open questions, if the participant wants to report their complaints in more detail or highlight any aspect that wasn't mentioned in the questionnaire. Regarding the score, the scale for section C must first be converted and inverted to the scale for section B, so that all the sections have the same order and the same number of alternatives, thus concluding that a low score indicates greater commitment[13]. After this standardization, each answer of the individuals must be multiplied by a specific factor. Once this is done, the scores found for each question are added up, to give the final score, which can vary from 0 to 209.36 points. The score for the ADL section ranges from zero to 126.84, for the cognition section from zero to 35.24, and for the pain section from zero to 47.28[13].

Sample size

Considering the inclusion of six independent variables (age, sex, associated diseases, number of medications, skin color, and sleep quality), and using the formula n=10k, where k is the number of possible predictor variables to be included, the minimum sample size found was 60 individuals[21]. This number is also sufficient to investigate the reproducibility of the MAQPD, since a sample size of at least 50 individuals need to be included, consistent with the minimum sample size guidelines recommended by COSMIN standards for the assessment of clinimetric properties for patient-reported outcomes[22].

Statistical analysis

Descriptive statistics were used to characterize the sample. The test-retest reliability of the MAQPD was assessed using the calculation of the intraclass correlation coefficient (ICC 2.1)[23]. This property was analyzed considering each of the three sections (ADL, cognition and pain), separately. The ICC was classified as follows: > 0.75, good reliability; 0.5 - 0.75, moderate reliability; < 0.5, low reliability [16].The SEM and MDC were calculated as follows: SEM = s√(1.00 - r), where "s" is the standard deviation (SD), "r" is the test - retest ICC; MDC = 1.96*SEM*√2 [16,24] . In addition, the SEM values were divided by the maximum

section scores and multiplied by 100% (SEM%), with values <15% being considered acceptable[25,26]. Spearman's correlation coefficient was used to assess the correlations between the possible factors and the score for each MAQPD section. The strength of the correlations was interpreted as follows: very high (≥ 0.90), high (0.70 ≤ rs ≤ 0.89), moderate (0.50 ≤ rs ≤ 0.69), low (0.26 ≤ rs ≤ 0.49), and very low (≤ 0.25)[27]. A significance level of 95% will be adopted, and the analyses will be carried out using the SPSS for Windows program (version 21.0).

RESULTS

Participants

Seventy-two participants were recruited, and a total of 61 were included in this study, with a mean age of 61 years (SD 12), and a T-MoCA score of 17 (SD 3). Of the 11 participants who didn't complete the retest, five refused and six had problems accessing the internet and missed the deadline. Among the participants included, 25 (41%) were men, 25 (41%) had associated diseases, and regarding the number of medicines used, there was a mean of 4 per person (SD 3). All the descriptive data on the individuals included is summarized in Table 1. The MAQPD score achieved by the sample was 100.63 for ADL section, 20.49 for cognition section, and 32.41 for pain section (Table 2).

Table 1 – Characteristics of the participants (n=61).

Sex, men, n (%)	25 (41)
Age, years, mean (SD)	61 (12)
Diagnosis time, years, mean (SD)	3 (4)
Associated diseases, n (%)	
No	36 (59)
Yes	25 (41)
Number of medicines, mean (SD)	4.4 (.5)
Skin color, n (%)	
White	32 (52,5)
Yellow	1 (1.6)
Black	4 (6.8)
Brown	22 (35.1)
Amerindian	2 (3.3)
Sleep quality (number of times waking up at night), mean (SD)	1.9 (0.8)
Montreal Cognitive Assessment (0-21), mean (SD)	17 (3)

* SD: Standard deviation; n: number; %: percentage.

Table 2 – Mean values, SD, ICC, SEM (SEM%) and MDC of each section of the MAQPD.

Section	Mean	SD	ICC (95% IC)	SEM (SEM%)	MDC
ADL	100.63	21.84	0.95 (0.92 – 0.97)	4.88 (4)	13.52
Cognition	20.49	9.13	0.90 (0.86 – 0.94)	2.88 (8)	7.98
Pain	32.41	14.10	0.91 (0.87 – 0.94)	4.23 (9)	11.72

* SD = Standard deviation, ICC = Intraclass correlation coefficient, SEM = Standard error measurement, MDC = Minimal detectable change, ADL = Activity of daily living.

Reproducibility of the MAQPD

Statistical analysis revealed that all three sections showed good test-retest reliability. The ICC for the ADL section was 0.95, for cognition was 0.90, and for pain was 0.91. The SEM (SEM%) for the ADL section was 4.88 (4%), for cognition was 2.88 (8%), and for pain was 4.23 (9%), which were also considered adequate and within the

Correlation between possible associated factors and MAQPD sections

The correlation analysis revealed a significant correlation between: the ADL section and the factors age (rs=-0.371, p<0.004) and skin color (rs=-0.324, p<0.011); the cognition section and the factor number of medications (rs=-0.295, p<0.022); and the pain section and the factors age (rs=0.286, p<0.027) and number of times the volunteer wakes up at night (rs=-0.292, p<0.024). No significant correlations were found for the other variables (p>0.05).

DISCUSSION

The aim of the present study was to investigate the reproducibility of the MAQPD questionnaire based on the analysis of test-retest reliability, SEM and MDC, in addition to investigating which personal or clinical factors may be associated with the functionality of individuals with PD, in the ADL, cognition and pain sections of the MAQPD. The results indicated that the questionnaire showed excellent test-retest reliability, with values starting at 0.90, as well as adequate SEM values. According to the MDC value, individuals must change by at least 13.52 points in the ADL section, 7.98 in the cognition section and 11.72 in the pain section in order to be able to affirm that there really has been a change in their functionality. Furthermore, age and skin color were associated with the ADL section, the number of medications was associated with the cognition section, and that the number of times that the individual wakes up at night and age were associated with the pain section.

The high test-retest reliability found in the MAQPD indicates that this instrument can be applied on different days and in different contexts, allowing effective monitoring of the individual with PD remotely, assessed by the same professional[14]. As observed, the ICC for the ADL section was higher than others. It is possible that the cognition section has more complex questions, and sometimes perhaps more difficult to answer, resulting in greater variability of responses. Furthermore, the pain section has a larger scale of response alternatives than the others, ranging from 1 to 7, which may also contribute to a greater variability of responses and, consequently, a lower ICC.

Regarding the SEM, the MAQPD showed adequate values, revealing that the questionnaire has the potential to provide more reliable results, with low variability and small error, which suggests its high effectiveness in generating accurate results and corroborates its increasingly widespread applicability in clinical practice[25]. Thus, considering the values found, if the individual changes the score up to 4.88 points in the ADL section, 2.88 points in the cognition section, and 4.23 in the pain section, this cannot be considered a clinical change, but a change that belongs to the instrument's error. Thus, according to the MDC results found, when individuals with PD are assessed and reassessed with the MAQPD, they must change by at least

13.52 points in the ADL section, 7.98 in the cognition section and 11.72 in the pain section, in order to be able to say that there really has been a change in their functionality.

A significant association was found between ADLs and age and skin color, indicating that older individuals and those with black skin color, perform worse in their activities. In fact, elderly people with PD, in addition to the progression of the disease, usually also must face greater frailty, resulting from a functional decline as a result of the ageing process[28]. Thus, the combination of the disease and age can result in greater limitations in the performance of ADLs, justifying the association found. Corroborating these results, previous data found in the literature demonstrated an association between ADLs and age in individuals with PD[28]. In a study with 17 elderly people diagnosed with the disease, it was found that most individuals had mild functional dependence in ADLs and a poorer perception of quality of life in mobility, social support, and bodily discomfort domains[28]. On the other hand, in relation to the association between ADLs and skin color, previous data has also shown that PD is more common among non-Hispanic whites, and individuals with darker skin color have worse functionality, which may justify greater difficulty in performing their ADLs[18].

In the present study, a significant association also was found between cognition and the number of medications used by the individuals, indicating that individuals using a higher number of medications have a worse cognitive condition. Previous studies, corroborating these findings, have correlated worsening cognition with excessive use of anticholinergic drugs, used to block cholinergic receptors from activating acetylcholine and thus reduce tremors and dyskinesia[29]. Such drugs, when used daily and over the long term, can increase the risk of dementia and worsening cognition, especially antidepressant drugs, antimuscarinic drugs for the bladder, and epilepsy drugs[30].

Finally, a significant association was found between the pain section and age and the number of times the individual wakes up at night, indicating that younger individuals with a greater number of nocturnal awakenings have more pain. However, the evidence found in the literature is controversial. Previous studies have shown that patients with pain are younger when compared to those without pain[31], as well as showing that PD-related pain is more prevalent in younger individuals[32]. On the other hand, there are also studies in literature that have reported no correlation between age and pain in individuals with PD[33,34]. Therefore, more studies are also needed to elucidate the real association between age and pain in this population. Regarding sleep quality, previous studies have also correlated it with the presence of pain, showing this association mainly with some subtypes of pain, such as musculoskeletal or nocturnal pain[35-37].

The limitations of this study include the fact that, although the sample was taken from the general community, it was not selected randomly (convenience sample) and, therefore, cannot be representative of the parkinsonian community in general. In addition, other variables not investigated in this study may also be associated with each of the sections of functionality investigated by the MAQPD, such as depressive symptoms and anxiety.

CONCLUSION

Based on the analysis of test-retest reliability, SEM and MDC, the MAQPD proved to be reproducible and capable of generating reliable results in the self-assessment of people with PD. This contributes to it being recommended and used by professionals in the field, both in research and clinical practice, given its importance in situations that require remote monitoring of the patient. Furthermore, the results showed that age and skin color are associated with ADLs, indicating that individuals with higher age and black skin color perform worse in their activities. In addition, the number of medications is associated with cognition, indicating that individuals taking a higher number of medications have a worse cognitive condition. Finally, the number of times the individual wakes up at night and age are associated with pain, indicating that younger individuals with a higher number of nocturnal awakenings have more pain. These results emphasize a real correlation between personal and clinical factors and the functionality of individuals with PD, and it is important to consider them in the rehabilitation process of this population.

Declaration of interest statement: We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or any other associated organization.

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