

QUALITY OF LIFE AND COGNITION IN PATIENTS WITH PARKINSON'S DISEASE DURING THE COVID-19 PANDEMIC

QUALIDADE DE VIDA E COGNIÇÃO EM PACIENTES COM A DOENÇA DE PARKINSON DURANTE A PANDEMIA DA COVID-19

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ABSTRACT

Introduction: Restrictive isolation contributes to the containment of the virus, but it also has negative consequences for mental health. This study aimed to assess the quality of life, during the pandemic, in patients with Parkinson's disease (PD), compare it with measures before the pandemic, and identify factors that may be associated with non-compliance with cognitive intervention activities.

Methods: The PDQ-39 questionnaire was reapplied in a sample of PD patients previously followed up in rehabilitation program. In addition, a questionnaire to assess the follow-up of cognitive training activities was elaborated.

Results: Twenty-two individuals with mean age of 62.72(7.49) years and a mean duration of the disease of 8.7(3.30) years participated in this study. There was a statistically significant difference in the total score of the PDQ-39($p=0.048$), as well as in the mobility ($p=0.038$), stigma ($p=0.035$), social support($p=0.045$), and cognition($p=0.026$) dimensions. When analyzing the questionnaire, it was observed that most of the sample was able to follow the guidelines received during the cognitive training group (77.3%), mainly reading activities (41%), games (35%), and applications (35%). However, 77.3% reported worsening cognition, with attention (50%) and memory (34%) being highlighted, as well as sadness, discouragement, and indisposition (72%), anxiety (77.27%), and difficulty falling asleep (68%). A total of 86.36% perceived the need for professional support in mental health.

Conclusion: This study showed the impact of the pandemic on individuals with PD, leading to a worse perception of quality of life and subjective complaints related to sleep disturbance, cognitive impairment, and neuropsychiatric symptoms (depression and anxiety).

Keywords: Parkinson's disease; COVID-19; Treatment Adherence and Compliance; Social Isolation; Quality of Life.

RESUMO

Introdução: O isolamento restritivo contribui para a contenção do vírus, mas também traz consequências negativas para a saúde mental. Este estudo teve como objetivo avaliar a qualidade de vida, durante a pandemia, em pacientes com doença de Parkinson (DP), compará-la com medidas anteriores à pandemia e identificar fatores que possam estar associados à não adesão às atividades de intervenção cognitiva.

Métodos: O questionário PDQ-39 foi reaplicado em uma amostra de pacientes com DP previamente acompanhados em programa de reabilitação. Além disso, foi elaborado um questionário para avaliar o acompanhamento das atividades de treino cognitivo.

Resultados: Participaram deste estudo 22 indivíduos com idade média de 62,72(7,49) anos e duração média da doença de 8,7(3,30) anos. Houve diferença estatisticamente significativa na pontuação total do PDQ-39($p=0,048$), bem como na mobilidade ($p=0,038$), estigma ($p=0,035$), suporte social ($p=0,045$) e cognição ($p=0,026$) dimensões. Ao analisar o questionário, observou-se que a maior parte da amostra conseguiu seguir as orientações recebidas durante o grupo de treinamento cognitivo (77,3%), principalmente atividades de leitura (41%), jogos (35%) e aplicativos (35%). No entanto, 77,3% relataram piora da cognição, com destaque para atenção (50%) e memória (34%), além de tristeza, desânimo e mal-estar (72%), ansiedade (77,27%) e dificuldade para dormir (68%). Um total de 86,36% percebeu a necessidade de apoio profissional em saúde mental.

Conclusão: Este estudo mostrou o impacto da pandemia em indivíduos com DP, levando a uma pior percepção da qualidade de vida e queixas subjetivas relacionadas a distúrbios do sono, comprometimento cognitivo e sintomas neuropsiquiátricos (depressão e ansiedade).

Palavras-chave: Doença de Parkinson; COVID-19; Cooperação e Adesão ao tratamento; Isolamento Social; Qualidade de Vida.

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INTRODUÇÃO

COVID-19 (Coronavirus Disease 2019), caused by SARS-CoV-2 (Severe Acute Respiratory Syndrome Coronavirus 2), has spread worldwide from reported cases in Wuhan, Hubei Province, China.

Symptoms such as fever, dry cough, and dyspnea were initially correlated with the disease, with the involvement of the respiratory, cardiovascular, gastrointestinal, and neurological systems being better understood later. Although 80% of cases are asymptomatic¹, presentations in the most severe symptomatic forms, characterized by pneumonia and severe acute respiratory syndrome (SARS), mainly in older individuals and/or those with comorbidities (such as hypertension, diabetes, cardiovascular diseases, and chronic respiratory diseases), result in complications that lead to prolonged hospitalizations and even death.

In Brazil, since the first case registered on February 2020 in São Paulo, until November 2022, there have been more than 689.665 deaths due to COVID-19 and about 35.227.599 million confirmed cases according to data from the Ministry of Health².

Given the high transmissibility, the complexity of the disease, and little evidence of effective treatments, governments, and health authorities began to adopt sanitary measures, as recommended by the World Health Organization (WHO). Among them, there was the use of disposable masks, regular hand hygiene, and social distancing aimed at preventing and containing the spread of the disease while scientists searched for a vaccine.

The impacts of social distancing, changes in work relationships and family dynamics, and closure of schools and services considered non-essential were observed from the beginning with repercussions on socioeconomic and psycho-emotional aspects³.

The stress caused by the fear of becoming infected with the coronavirus, combined with social distancing, difficulties to access health care services, and reduced stimuli, are factors that can impact the non-motor aspects associated with Parkinson's disease (PD), such as sleep disorders, anxiety, and depression. A study carried out by⁴ demonstrated greater sleep disturbance during the pandemic in PD patients compared to controls, including exacerbation of anxiety and motor symptoms. On the other hand,⁵ did not find negative effects of social distancing among PD patients, as they were with their families during confinement. A study with 568 patients with PD pointed out that they reported experiencing worsening symptoms during the pandemic⁶.

Restrictive isolation influenced containing the virus, but it also led to negative consequences for mental health. The main cause was the need to change habits and the drastic reduction in social life; thus, there was a worldwide increase in symptoms related to stress, anxiety, anguish, and depression. Confinement forced a change in

the routine of these older people, hindering the performance of physical activities and limiting external stimuli related to social life, thus leading to a marked worsening of neuropsychiatric symptoms.

Regarding the impacts of the pandemic on PD, a systematic review conducted by El-Qushayri et al. (2022) indicates no correlation between this condition as a specific risk factor for COVID-19 infection. Still, it points out that more unfavorable outcomes in PD, such as hospitalization and mortality, were correlated with advanced age and the presence of comorbidities⁷. In addition, direct/indirect effects of SARS-CoV-2 on the motor/non-motor symptoms of PD were evidenced, such as, for example, motor worsening and demand for an increase in the daily dose of levodopa⁸.

A multicenter study with 27 patients from the United Kingdom, Italy, Romania, and Mexico, also identified other long-term effects of COVID-19 among individuals with PD, such as fatigue, cognitive disorders (including brain fog, loss of concentration, memory deficits), sleep disorders such as insomnia, considering that, in some cases, prolonged isolation and reduced access to health services and rehabilitation treatments during this period may have influenced these outcomes⁹.

Such findings from different studies suggest impairment of quality of life (QoL) in individuals with PD, due to COVID-19 infection or even the situation of distancing or social isolation, in addition to economic and psychosocial variables, causing less stimulation and social interaction in this more vulnerable population. Studies also show unfavorable outcomes, including the difficulty of following up the interdisciplinary treatment.

Health-related quality of life (HRQoL) refers to the individual's perception of their disease and its effects on their own lives, including personal satisfaction associated with their physical, functional, emotional, and social well-being. Therefore, QoL can be considered as a multidimensional concept that reflects a subjective assessment of the patient's personal satisfaction with his/her life and other aspects such as relationship with the family, his/her own health, the health of close people, financial issues, housing, independence, religion, social life and leisure activities¹⁰.

In a systematic review and meta-analysis study, found that individuals with PD have a lower QoL when compared to healthy controls in most domains, especially in physical function and mental health¹¹.

Motor and non-motor symptoms present in this pathology are correlated with this worse perception of quality of life. Fatigue, a prevalent aspect of PD, was associated with a negative impact on quality of life in people with PD, in an analytical and cross-sectional observational study carried out by Nassif and Pereira (2022), who suggest that other non-motor symptoms can amplify this impact¹². The systematic review of the literature, identified anxiety as one of these non-motor

symptoms affecting the quality of life in PD and consider that research on these aspects can contribute to the promotion of well-being and QoL in this population¹³.

QoL can be assessed by both generic and specific instruments. Among the specific questionnaires, the Parkinson's Disease Questionnaire-39 (PDQ-39) is highlighted. The PDQ-39 has been indicated as the most appropriate instrument for assessing the QoL of patients with PD. In our country, this scale was validated and considered a reliable measure to be used in patients with PD¹⁴.

Recent studies have indicated that the PDQ-39 is sufficiently robust to be used in cross-cultural studies, since, in their results, greater similarities than differences were observed among different countries.

Most studies carried out in PD show that the individual has a worse perception of QoL with the progression of the disease and it is evidently associated with the stage of the disease¹⁵. Difficulty moving, such as gait, and freezing in social situations, can make the individual more dependent and less confident¹⁶.

A study by Sousa *et al.* (2021) showed the importance of early cognitive intervention in patients with mild cognitive impairment (PD-MCI) to PD, emphasizing improvement in the total score of the PDQ-39 and dimensions (mobility, activities of daily living, and body discomfort) when compared to the control group that only obtained improvement in the total score of the questionnaire¹⁷.

On the other hand, the literature has shown that the pandemic interferes with the perception of quality of life¹⁸, and therefore, the patient's involvement in performing cognitive training activities, but there are no studies with this outcome, that is, evaluating the impact on cognitive measures, with a longitudinal design, and after a non-pharmacological therapeutic approach (cognitive training).

Therefore, these and other studies indicate negative consequences of both SARS-CoV-2 infection and prolonged conditions of social isolation; in addition to economic and psychosocial variables, leading to less stimulation and social interaction within these more vulnerable populations, which signals the need to adopt strategies to improve management in such circumstances, minimizing these negative effects, among which is also the difficulty of follow-up of interdisciplinary treatment.

Considering the importance of cognitive training for this population, the objective of this study was to better understand and identify the dimensions of quality of life most affected during the pandemic in individuals with PD, treated at the Neurological Rehabilitation, in the SARAH Network of Rehabilitation Hospitals (Salvador/Bahia Unit, Brazil). It also aimed at verifying, through a multiple-choice questionnaire, clinical and psychosocial aspects, and the follow-up and related factors for the non-follow-up of the activities learned during the cognitive training group carried out before the pandemic.

METHODS

This was an observational, longitudinal study.

Participants and recruitment

Patients, according to UK Parkinson's Disease Brain Bank criteria, Hoehn and Yahr (H&Y) stages I-III and MCI according to the Movement Disorders Society (MDS) PD-MCI Level II diagnostic criteria, were selected from a sample who performed cognitive training from January to November 2019. All participants, during this study, participated in the general activities of the rehabilitation program for four weeks: physiotherapy, dance, reeducation in writing, speech therapy, information groups, manual skills workshops, physical activity. The current study has the following inclusion criteria: no cognitive-behavioral alteration that could interfere during the application of the questionnaires.

For greater adherence to the study, due to the difficulty of moving and residence in the inland cities of the State, the participants were invited to participate in the research through contact made by telephone, using virtual media or environment - video call through the application WhatsApp, to the telephone number informed in the respective medical record.

In this initial contact, there was clarification about the research and its objectives, the instruments to be used for data collection, the time to be spent to participate in the research, the virtual mode of assistance for data collection, the storage of data in physical documentation, and reading and clarification of the informed consent.

The participants were also informed about the acceptance of participation in the study through informed consent, which was forwarded by a Google Forms link. There was no recording or saving of information on devices or applications online. The study was approved by the ethics committee of the SARAH Network of Rehabilitation Hospitals (51795721.4.0000.0022).

Data collection

The data collection session took place through virtual consultations, via the WhatsApp application (in the period of May to November-2022) and in review consultation. Data collection time was approximately 30 minutes, with the respective instruments being shown to the participant and each participant marking their answers, which the investigators on the printed instrument simultaneously marked.

As instruments for this collection, the quality of life by the Parkinson's Disease Questionnaire-39 (PDQ-39) and a multiple-choice questionnaire (to evaluate the follow-up of cognitive training, elaborated by the researchers) were used.

The PDQ-39 is a specific QoL assessment scale in PD. It consists of 39 items that can be answered with five

different response options: "never", "occasionally", "sometimes", "often", "always", or "it's impossible for me". The scores on each item range from 0 (never) to 4 (always or impossible for me). The PDQ-39 is divided into eight dimensions: Mobility (10 items), Activities of Daily Living (6 items), Emotional Well-being (6 items), Stigma (4 items), Social Support (3 items), Cognition (4 items), Communication (3 items), and Body Discomfort (3 items). The total score for everyone is calculated using the following formula: $100 \times (\text{sum of the patient's scores in the 39 questions} / 4 \times 39)$. The score for each dimension is obtained in the same way as the total score. The total score on the PDQ-39 ranges from 0 (no problem) to 100 (maximum level of the problem); that is, a low score indicates a better perception of QoL by the individual¹⁴.

Aiming to understand the factors involved in the follow-up of cognitive guidelines better, a multiple-choice questionnaire was applied. It was prepared by the investigators responsible for the current study and consisted of 23 items, with dichotomous and coded answers (1: yes or 2: no).

The items are multiple-choice, six of which are made up of sub-items. Part I, with eight items, includes information related to the follow-up of activities, cognitive training, guided during the program. Part II is divided into questions related to psychosocial - how and with whom did the social distancing, for example (4 items), psycho-emotional (5 items) aspects, cognition (2 items), sleep (2 items), and medication adherence (1 item). For each item, the absolute frequency was obtained. The questionnaire was applied in three moments (T0: baseline, T1: post-intervention, immediately after; T1: peri pandemic, 2 years after the intervention).

Data analysis

For this analysis, the following was used: descriptive statistics (total value/percentage, mean, median, and standard deviation), according to the type of data; inferential statistics, with Fisher's exact test (as a function of sample size) for categorical/nominal variables; nonparametric repeated measure test (Friedman and Kendall), to compare the dimensions and the total score in the PDQ-39 questionnaire, in the three moments. To analyze the data from the cognitive follow-up questionnaire, responses were coded, and their frequencies and relative frequencies were calculated. These data were presented and summarized in the form of bar charts.

The level of significance for the inferential analyses was $p < 0.05$.

RESULTS

The sample consisted of 22 patients, with a mean age of 62.72 (7.49) years, 12.4 (3.12) years of education, a higher proportion of men (81%), a mean time of disease of

8.7 (3.30) years, and baseline H&Y (Stage 3=3).

The inferential analysis (Table 1) showed a statistically significant difference on the total score of the PDQ-39 ($p=0.048$) and mobility ($p=0.038$), emotional well-being ($p=0.053$), stigma ($p=0.035$), social support ($p=0.045$) and cognition ($p=0.026$), with a better perception score of quality of life at T1 (after cognitive intervention) when compared to T0; and lower perception in the dimensions total score, mobility, activities of daily living and body discomfort when compared to T0 and T1.

Table 1. Comparison of PDQ-39 during the follow-up.

	Friedman	Kendall	Valor de p
PDQ-Total	31.3597	0.4978	0.048
Mobilidade	33.8221	0.5369	0.038
Atividades de vida diária	23.5613	0.3740	0.315
Bem-estar emocional	32.3874	0.5141	0.054
Estigma	34.1225	0.5416	0.035
Suporte social	33.0949	0.5253	0.045
Cognição	35.3597	0.5613	0.026
Comunicação	23.1225	0.3670	0.338
Desconforto Corporal	27.3439	0.4340	0.160

The questionnaire analysis showed that most of the sample was able to follow the guidelines received during the cognitive training group (77.27%), mainly reading activities (41%), games (35%), and applications (35%). However, 77.3% reported worsening cognition, with attention (50%) and memory (34%) being highlighted, as well as sadness, discouragement, and indisposition (72%), symptoms of anxiety (77.27%), and difficulty falling asleep (68%). A total of 86.36% perceived the need for professional support in mental health.

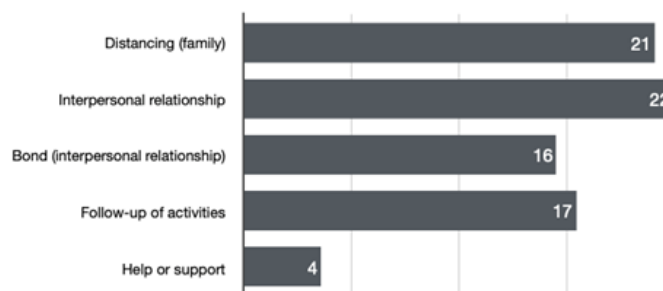


Figure 1. The pandemic, social life, and generalization of guidelines/activities.

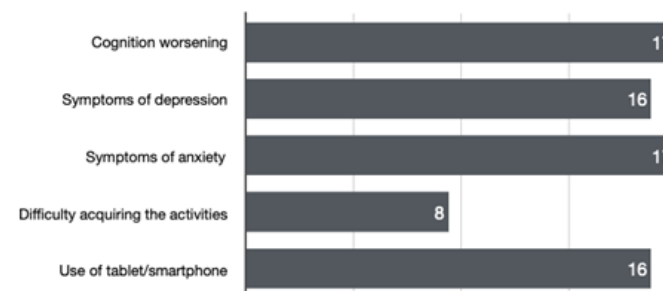


Figure 2. The pandemic and cognitive and psycho-emotional aspects.

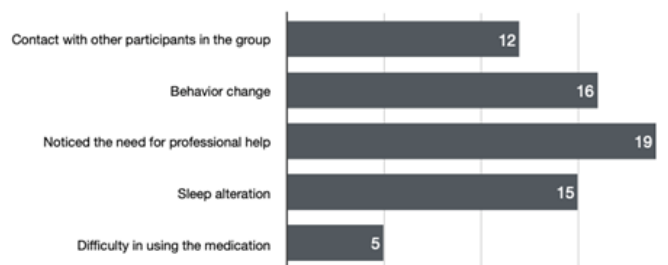


Figure 3. The pandemic and social/clinic aspects.

DISCUSSION

This study signaled the impact of the pandemic on individuals with PD, causing a worse perception of quality of life, both in the total score of the PDQ-39 instrument and in the dimension's mobility, stigma, social support, and cognition, as well as subjective complaints related to psycho-emotional aspects (symptoms of anxiety and depression), sleep disturbance, and cognitive deterioration.

The results found are in line with other studies, whose findings showed a worse perception of QoL among individuals with PD when compared to healthy controls, concerning dimensions that assess physical and mental health aspects¹¹ in different QoL assessment instruments.

Using the PDQ-39 in the evaluation of the same group of individuals in different temporal spaces, results found that mobility scores, activities of daily living, emotional well-being, stigma, cognition, communication, body discomfort, and total PDQ-39 scores were significantly higher during the period of social distancing than in the period of gradual release of distancing, indicating that quality of life was significantly impaired in this period¹⁹.

Even when the overall score analysis showed no change, it was possible to observe worsening of the "emotional well-being" domain in the qualitative analysis by domain²⁰. These data corroborate our findings regarding the worsening of QoL perception in pandemic conditions.

It is noted that, despite this result, there was a report of maintenance of cognitive training activities during the pandemic, but a reduction in the effect of these interventions, probably correlated with a lower frequency and little family support for such activities.

It appears that social distancing, deprivation of activities, difficulties in accessing materials, reduced physical activity, increased stress, and its implications for sleep quality can generally interfere with the patient's clinical condition and, therefore, with the effective follow-up of cognitive training activities and quality of life measures.

Reviewing the literature, we have not found studies to date correlating the effective follow-up of cognitive training and quality of life outcomes during the COVID-19 pandemic period.

This study provided data to help identify factors that may hinder/preclude the performance of cognitive training activities during the period of social distancing caused by the pandemic and verify therapeutic strategies for these patients. The main advantage of this study is the long-term follow-up during the two pandemic years.

With these findings, alternatives can be sought to manage the interference of social distancing, such as the use of tools that allow better monitoring of the patient in these situations, aiming at therapeutic listening and monitoring of activities to contribute to the generalization and maintenance of the effects of interventions aimed at cognition. There are limitations, such as absence of the control group, the non-performance of the formal cognitive assessment, through the reapplication of neuropsychological batteries and tests, and reduced sample size, but sufficient to give us some important insights concerning PD patients, cognitive training, and social isolation.

Author's contribution. NMFS: Study concept and design, literature search, acquisition of data, interpretation of data, statistical analysis, writing of the manuscript, final approval of the manuscript. ACMN: Design, acquisition of data and writing of the manuscript. SMDB: Guidance in the preparation and collection of data, corrections, and guidance of the manuscript.

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