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Quality of life and health profile in individuals with Parkinson's

Cristianne Confessor Castilho Lopes[1], Thaine Andressa Ruschel[2], Daniela dos Santos[3], Marilda Morais da Costa[4], Paulo Sergio Silva[5], Tulio Gamio Dias[6], Eduardo Barbosa Lopes[7], Lucas Castilho Lopes[8], Laisa Zanatta[9], Joyce Kelly Busoli Jardim[10], Caroline Lehnen[11], Vanessa da Silva Barros[12], Liamara Basso Dala Costa[13], Heliude de Quadros e Silva[14], Youssef Elias Ammar[15]

[1]University of the Region of Joinville - Joinville - SC
[2,3]High Valley University of Rio do Peixe - Hunter - SC
[4]Lutheran Educational Association - Faculty IELUSC - Joinville - SC
[5]Uni Sociesc/Joinville - SC
[6]USP School of Arts, Sciences and Humanities – São Paulo - SP
[7,9,10,11,12,13,14]Alto Vale University of Rio do Peixe - Caçador - SC
[8]Federal University of Santa Catarina - SC
[15]University of the South of Santa Catarina/Tubarão – SC

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Abstract *— Parkinson's disease is a pathology that affects the central nervous system (CNS) progressively causing its degeneration. This results in a decrease in the dopamine hormone, which is the neurotransmitter responsible for normal brain activity, its decrease directly linked to the appearance of the pathology. Therefore, it affects the quality of life, which is represented by the degree of satisfaction found in family, loving, social and environmental life. As a treatment, physiotherapy plays a fundamental role in improving the quality of life in order to relieve symptoms and disease progression. The aim of the study was to analyze the quality of life and the health profile of the individual with Parkinson's disease. The research is descriptive, with a cross-sectional design and a quantitative and qualitative approach. The sample consisted of 11 individuals with Parkinson's. Data collection was carried out through a mixed online questionnaire, developed through Google Docs®, containing information and general characteristics of the participants, a questionnaire on the health profile of Nottingham (PSN) and finally a questionnaire that evaluated the quality of individuals with Parkinson's (PDQ-39). The PSN questionnaire brought an average of 13.7 points indicating a worse perception of health and the PDQ-39 presented 45.8% in the average of the final score. With this study, it was possible to note that the quality of life of the participants is greatly affected due to the symptoms, degree and progression of the disease.*

I. INTRODUCTION

Parkinson's disease is a pathology that affects the central nervous system (CNS) causing its degeneration progressively leading to the decrease of the hormone dopamine, which is the neurotransmitter responsible for the normal activity of the brain. Its decrease is directly linked to the emergence of the pathology(GOULART et al., 2004).

Among the alterations present in Parkinson's disease are: tremor, described as at rest and usually involves mainly the hands; stiffness that leads to a limitation in range of motion and resistance to movement; bradykinesia due to slowing of movements; postural instability and musculoskeletal changes altering balance and causing postural deviations(SILVA; DIBAI FILHO; FAGANELLO, 2011).

These postural deviations lead to a decrease in lung expansion due to chest rigidity, which, in turn, compromises the natural movement of breathing, leading to progressive limitation of lung ventilation (PEREIRA, 2006).

Such changes require physical therapy treatment so that there is a process of rehabilitation of patients with Parkinson's disease. This treatment is developed with motor exercises, such as, for example, training in gait and activities of daily living, relaxation therapy and breathing exercises(ARAÚJO, 2007).

With this, the compromised quality of life can present a decline according to the symptoms, degree of the disease and its progression, therefore, it is necessary to elaborate an adequate intervention strategy in order to minimize the symptoms and slow down the disease progression, through knowledge of factors related to the perception of quality of life (SILVA; DIBAI FILHO; FAGANELLO, 2011).

Due to all the changes mentioned above, it is possible to observe the difficulty that people with Parkinson's disease have when it comes to quality of life and functional independence. Thus, the general objective of this research is to analyze through questionnaires if there is really a change in the quality of life and how this affects the lives of these individuals.

Taking into account the characteristics of the pathology and the above, the following question arises: Is there a decrease in the quality of life of the individual with Parkinson's? Is it possible to see which changes are present in these people's lives, measuring through specific questionnaires for this pathology?

In view of this, it motivated the choice of the research topic, as it is of great importance to collect data to analyze the quality of life of these individuals and how they behave in the situation.

Thus, the general objective of the research was to evaluate the quality of life and health profile in individuals with Parkinson's disease. The specific objectives were to assess the quality of life of these individuals and their health profile.

II. METHODS

TYPE OF RESEARCH

The survey is a descriptive one, with a cross-sectional design and a quantitative-qualitative approach.

As for the goals

The study was defined as descriptive and with a quantitative approach. In order to demand from the investigator information about what he wants to study, descriptive research intends to describe the facts and phenomena of a given reality. Seeks to answer questions without interfering with reality, observes the motivation for that action , and may aim to become familiar with a phenomenon or discover a new perception or analyze points of view from different sources(FONSECA, 2012).

As for technical procedures

For technical procedures, the study was characterized as a cross-sectional research, which is carried out through data collection that can be carried out through interviews, observations or search for information or data in databases and documents (SILVEIRA, 2009).

As for the approach

Finally, presenting a quantitative approach, which is based on the use of measurable data with the use of questionnaires, measurement and precision calculations, elaboration of indexes and scales and statistical procedures explaining its existence, relationship or influence on another variable, with concern with what is common to most situations. It seeks to analyze the frequency of occurrence to measure the veracity or not of what is being investigated(FONSECA, 2012).

This type of approach is tied to the formulation of hypotheses through verification, demonstration, tests and mathematical logic that require a relationship between cause and effect to support the conclusion in statistical data and thesis. (ZAMBELLO et al., 2018).

Sample and Location

The sample consisted of 11 individuals, of both sexes, aged between 40 and 80 years and diagnosed with Parkinson's disease.

Ethical procedures

The project was submitted for proper approval by the Ethics Committee of the Alto Vale of Rio do Peixe University (UNIARP) according to the recommendations of resolution 466/12 of the national health council for scientific research with human beings.

After proper approval, through opinion number 4,143.053/2020, data collection started, through the dissemination of the survey on the social networks Facebook®, Instagram® and Whatsapp®.

Procedures for data collection

To meet the objectives proposed in this study, data collection was performed through a mixed online questionnaire, developed on the Google Docs® platform, available at this link<https://forms.gle/ypDt1GoT2v3NLiwS8>.

The capitation of the participants took place through the dissemination of the questionnaire link on the academic and supervisor's social networks Facebook®, Instagram® and Whatsapp®. The collection period took place between the months of July to September/2020.

The evaluation consisted of questions referring to the general characteristics of the participants, applying the questionnaire on the Nottingham Health Profile (PSN) and another that assessed the quality of life (PDQ-39) in individuals with Parkinson's. These were answered by the participants with Parkinson's, and if the participant could not answer the questionnaire alone, it could be helped by a family member or even a professional responsible for their care. The questionnaires that were used are described below:

1. **Questionnaire of general characteristics of participants:**

It is a targeted questionnaire containing information that characterizes the participants, such as: name; age; education; physiotherapeutic treatment is performed; among other questions, being closed and multiple choice.

2. **Nottingham Health Profile Questionnaire (PSN):**

It is a comprehensive questionnaire to assess quality of life, originally developed to assess the quality of life in patients with chronic diseases. It uses an easy-to-interpret language and offers a simple measure of the individual's physical, social and emotional health, being considered clinically valid to distinguish patients with different levels of dysfunction and to detect important changes in the patient's health status over time. It refers to a self-administered questionnaire, consisting of 38 items, based on the disability classification described by the World Health Organization, with answers in the yes/no format. Items are organized into six categories that include energy level, pain, emotional reactions, sleep, social interaction, and physical skills(TEIXEIRA-SALMELA et al., 2004).

3. **Quality of Life Questionnaire for Individuals with Parkinson's (PDQ-39):**

It is a widely used questionnaire and a specific scale for this pathology. It consists of 39 questions and divided into domains, namely: mobility, consisting of 10 items; daily life activity, with 6 items; emotional well-being, 6 items; stigma of the disease, 4 items; social support; 3 items; cognition, 4 items; communication, 3 items; and physical bodily discomfort, with 3 items(BRIDGES et al., 2017).

As an alternative answer, it presents five options: “Never”; "rarely"; "sometimes"; “often” and “always” (VASCONCELOS et al., 2015). The score ranges from 0 to 4, which is never equal to 0; every now and then it equals 1; sometimes equals 2; often equals 3; always equals 4(BRIDGES et al., 2017).

The overall score ranges from 0 to 100, where 0 means less problem and 100 means a higher level of problem and worse quality of life. This score is divided by the domains mentioned above. In the emotional well-being domain, the score ranges from 0 to 24, which brings questions about how you felt in the last month; in the Stigma domain, where questions about situations that the person lived in the public are addressed, the score ranges from 0 to 16; in the social support domain, it ranges from 0 to 12; in the cognition domain, it ranges from 0 to 16, addressing issues related to concentration, memory, among others; in the communication item, it ranges from 0 to 12 and aims to assess whether the individual has the ability to communicate; in the body discomfort domain, it ranges from 0 to 12(BRIDGES et al., 2017).

The score for each domain is calculated according to the following formula: the sum of the patient's scores for each question, divided by the result of the multiplication of 4 (the maximum score for each question) and the total number of questions in each division. Your result should be multiplied by 100. The total score ranges from 0 to 100, where 0 means less problem and 100 means a higher level of problem and consequently worse quality of life(LANA et al., 2007).

III. RESULTS AND DISCUSSION

The sample consisted of 11 patients, aged between 70 and 80 years (45.5%), with complete higher education (54.5%), married or in a stable relationship (63.6%) who manifested the onset of symptoms between

60 and 70 years (63.6%), with a time of 5 to 10 years since the diagnosis of the disease (63.6%), practitioners of physical activity (90.9%) and physiotherapy (81.8%), these data appear in Table 1 below.

Table1 – Sample profile.

	N	%
Gender		
Feminine	3	27.3
Male	8	72.7
Age		
40 to 50 years	1	9.1
51 to 60 yearsold	two	18.2
61 to 70 yearsold	3	27.3
71 to 80 yearsold	5	45.5
education		
incompleteelementaryschool	two	18.2
Complete primaryeducation	two	18.2
Incomplete high school	1	9.1
completehighereducation	6	54.5
Marital status		
Married/consensual union	7	63.6
Divorced	4	36.4
Onsetofsymptoms		
30 to 40 years	two	18.2
41 to 50 yearsold	1	9.1
51 to 60 yearsold	1	9.1
61 to 70 yearsold	7	63.6
diseasediagnosis time		
between 1 to 5 years	3	27.3
between 6 to 10 years	7	63.6
between 11 to 15 yearsold	1	9.1
practicephysicalactivity		
Yea	10	90.9
No	1	9.1
Performphysiotherapy		
Yea	9	81.8
No	two	18.2

Source: Author (2020).

Table 2 shows the individual results obtained through the Nottingham Health Profile Questionnaire, where the maximum score is 38 points. When the score is closer to zero, it is indicative of the worst perception of health, and the closer to 38 the score, the better is the perception of health. Through the results, it is possible to observe that the sample reached an average score of 13.7 (±8.1) being indicative of a worse perception of health. The individual score is shown in Table 2 and Graph 1.

The concept of quality of life is related to several elements within self-esteem and personal wellbeing and encompasses several aspects such as functional capacity, socioeconomic level, emotional state, social interaction, intellectual activity, self-care, family support, lifestyle, among other factors. Its variable is the sociocultural level, age group and individual personal aspirations(VECCHIA et al., 2005).

In general, quality of life is represented by the degree of satisfaction found in family, love, social and environmental life, and with the changes resulting from the disease, there is a decrease in quality of life, resulting in limitation of activities and partial or total dependence (SILVA; DIBAI FILHO; FAGANELLO, 2011).

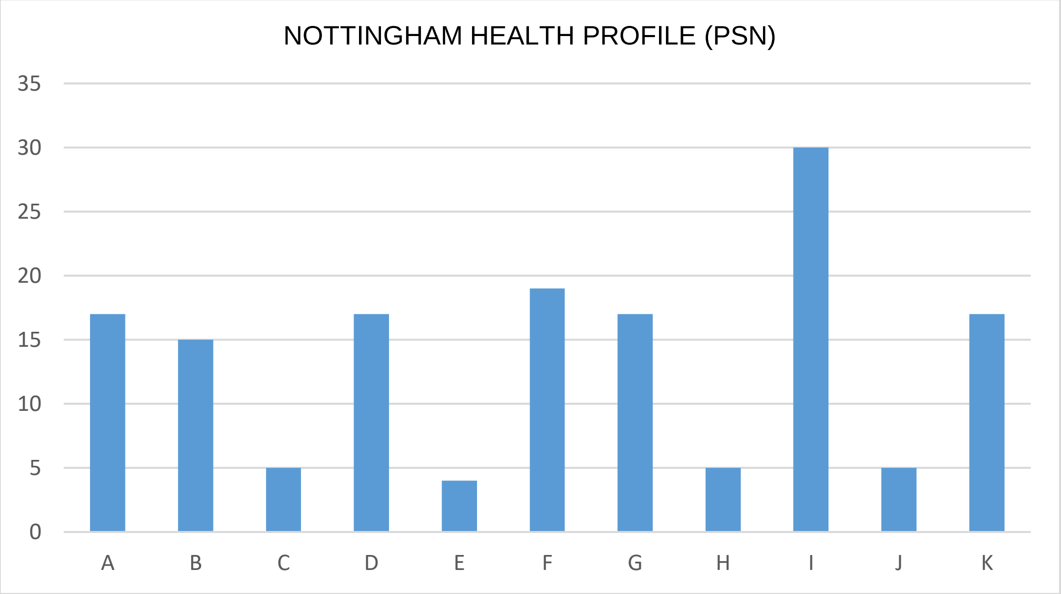
The results presented by the sample corroborate the work by Goulart et al. (2004), who carried out a study evaluating the functional performance and quality of life (PSN) among adults and elderly individuals and a group with Parkinson's patients, thus, the final analysis of the data also found a worse perception of quality of life in individuals with Parkinson's when compared to adults and the elderly.

Table.2:– Score from the Nottinghan Health Profile (PSN) questionnaire.

Participant	Individual score
A	17
B	15
C	5
D	17
E	4
F	19
G	17
H	5
I	30
J	5
K	17

Source: Author (2020).

Graphic 1 – Score from the Nottinghan Health Profile (PSN) questionnaire.



Subtitle: Individual Score

Source: Author (2020).

Table 3 shows the results obtained through the PDQ-39 questionnaire, in which the overall score values range from 0 to 100, where 0 means less problem and 100 means a higher level of problem, and consequently worse quality of life. It is possible to observe that the evaluated items were presented at a medium level, representing a regular quality of life, with 45.8% in the final score average.

The dimensions with the highest score were mobility and social support with 50%, activity of daily living with 55.4%, and body discomfort with 58.3%.

The quality of life of these individuals and their impairment may decline according to the symptoms, the degree of the disease and its progression, thus, it is necessary to develop an adequate intervention strategy in order to minimize symptoms and slow down the progression of the disease, through knowledge of factors related to the perception of quality of life (SILVA; DIBAI FILHO; FAGANELLO, 2011).

Thus, this individual's mental and emotional impairment is directly affected according to the evolution and secondary complications of the disease, resulting in a worsening in the quality of life and in his level of capacity. Because of this, by understanding the stage of the disease and seeking the appropriate treatment, it is necessary to maintain and improve the quality of life, aiming at the physical and psychological well-being of those who have the disease(VASCONCELOS et al., 2015).

With the evolution of the disease, new changes arise that lead to compromised quality of life within other dimensions of the questionnaire, such as motor symptoms, cognition, bodily discomfort, emotional well-being and communication. Thus, the dimensions of activity of daily living and cognition showed a difference between the mild and severe groups, and moderate and severe(NAVARRO-PETERNELLA; MARCON, 2012).

Disorders that detract from the perception of quality of life are related to the development of motor activities, thus, the two domains that presented the highest levels of impairment were mobility and the activity of daily living, involving situations of leisure or bathing, where the motor support must be adequate (SILVA; DIBAI FILHO; FAGANELLO, 2011).

In the study carried out by Souza et al., (2007)which aimed to assess the usefulness of the questionnaire in question, comparing groups of patients with and without motor fluctuation, found a higher score in the mobility, activity of daily living, communication and body discomfort domains in the group of patients with motor fluctuation. Thus, when compared to patients with more than 5 years of disease evolution and patients with 5 years or less of the disease, the first group shows a worse score in relation to the PDQ-39, when compared to the first years of the disease. Thus, the results presented by the sample confirm the study by this author.

Table 2 – Score result of the Quality-of-Life Questionnaire for Individuals with Parkinson (PDQ-39).

	Average score eachquestion	Final score (%)
Mobility	20.0	50.0
daily life activity	13.3	55.4
Welfare	9.3	38.8
Stigma	5.1	21.3
Social Support	14.0	50.0
cognition	5,6	46.7
Body Discomfort	7.0	58.3
total score	74.3	45.8

Source: Author (2020).

IV. FINAL CONSIDERATIONS

Parkinson's is a pathology that causes negative impacts on quality of life, self-esteem, social and economic aspects, but mainly physical and psychological changes to patients with the disease.

With this study, it was possible to analyze, through the questionnaires, that the quality of life of the participants is greatly affected due to the symptoms and degree of the disease, mainly in terms of mobility, activities of daily living and bodily discomfort, which can lead to depression and resulting in a worse perception of health.

The greatest difficulty faced in carrying out this study was the small number of individuals with Parkinson's to answer the questionnaire, in which those who participated were very helpful due to the level of complexity of the questionnaire. Another difficulty encountered was the scarcity of literature with the same methodology. It is suggested that the methodology of this study be associated with a treatment protocol, thus being able to observe the effectiveness of physiotherapy in restoring the quality of life of patients with Parkinson's.

Thus, physiotherapy has a fundamental role in the treatment, prevention of disease progression and especially the promotion of health for these patients, through exercises that help with mobility, balance and help maintain the individual's condition to reintegrate him into society with a good quality of life.

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