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PARKINSON'S DISEASE: QUALITY OF LIFE (QOL) AND EFFECTS OF HOME-BASED REHABILITATION

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ABSTRACT

Background: Parkinson's Disease (PD) causes increasingly significant disability and functional impairment, negatively influencing the quality of life of those affected by the disease. The tool widely adopted for assessment of quality of life in Parkinson's disease patients is the Parkinson's Disease Questionnaire (PDQ- 39). Study objectives: to assess the level of correlation of the PDQ-39 questionnaire with the clinical severity of PD patients; to assess changes in quality of life following home-based rehabilitation treatment.

Methods: Thirty patients residing in the province of Naples were enrolled in the study; the inclusion criterion was the presence of Parkinson's Disease, whilst patients with other neurodegenerative or chronic disorders were excluded. The participants were assessed utilizing: the medical history questionnaire, the Hoehn and Yahr scale to rate disease severity, the PDQ-39. They contemporaneously followed a home-based physiotherapy programme for 18 months. The readings were carried out in three stages: time zero, nine months, eighteen months.

Results: The Pearson test indicates a close correlation between clinical severity and quality of life (QoL) ($0.76 \leq R \leq 0.85$). Following rehabilitation treatment, the patients reported some improvement in quality of life, particularly in the psychological dimension: the stigma areas and psychological well-being had significantly improved ($p < 0.05$), whereas the mobility areas and Adl showed only a short-term improvement ($p > 0.05$). No significant change was found in the areas of cognitive impairment in the Parkinson's Disease patient.

Conclusion: HRQOL strongly correlate with disease progression; home physiotherapy can improve patients condition, especially from emotional point of view.

Keywords: Parkinson's Disease, quality of life, rehabilitation

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INTRODUCTION

Parkinson's Disease represents the second neurodegenerative disorder in the world after Alzeimer's disease[1], with an estimated prevalence of 3% in the elderly.[2,3] This condition, which causes degeneration of the dopaminergic neurons of the substantia nigra in the midbrain, is associated with motor symptoms (bradykinesia, rest tremor, rigidity and postural instability)[4] and non-motor symptoms (hyposmia, autonomic, sensory, gastrointestinal dysfunctions, neuropsychiatric symptoms and sleep disorder.)[5,6,7,8] PD compromises health-related quality of life (HRQOL), due to its progressive and chronic nature and to the consequences of the medication taken[9]; initially, the patient's physical dimension seems to be the most involved, due to the marked motor symptoms. Subsequently, there is a growing limitation in ADL performance[2,10] which, associated with the development of cognitive disorders, further compromises HRQOL from a physical, psychological, emotional and economic point of view.[11,12] Over time, several researchers proposed a specific HRQOL assessment tool for the PD patient: the tool to have received top international validation is the PDQ-39.[13,14,15] The PDQ-39 is a questionnaire containing 39 questions divided into 8 discrete scales: mobility, emotional well-being, activities of daily living (Adl), stigma, social support, cognitive impairment, communications, bodily discomfort; each question investigates how often the patient has experienced the onset of certain difficulties in the last month; some likely answers are: never, occasionally, sometimes, often, always. These answers are given a score from zero to four, which describes the different levels of difficulties encountered by the patient (0 = no difficulty; 4 = maximum difficulty or cannot do at all). At the end of the survey, it is possible to establish the final score obtained by the patient, expressed both in percentage points per area, and on the scale total.

METHODS

The study was conducted in compliance with the Declaration of Helsinki; we obtained approval by ethics Committee of Federico II University.

The primary objective of this study was to evaluate the degree of correlation between PD severity, studied using the classification proposed by Hoehn and Yahr[16], and the score of quality of life obtained via PDQ-39. Another of our objectives was to assess the changes in HRQOL following home-based physiotherapy treatment.

All patients were asked to sign informed consent; each one had the possibility to leave the study at any time. There weren't, however, losses during the follow up.

Criteria for inclusion

We examined, at first, 36 patients in home-based treatment for PD. The criterion for inclusion in the study was represented by the presence of Parkinson's disease; the element of exclusion from the study, however, was the concomitant presence of other associated neurodegenerative or chronic diseases. Four of examined people declined to participate at the study, and two did not meet the inclusion criteria, as shown in figure 1. Thirty patients, instead, satisfied the inclusion criteria.

Figure 1: Patients flow chart. We showed all patients examined for the eligibility to the research, and all ones excluded. There were no losses at follow up.
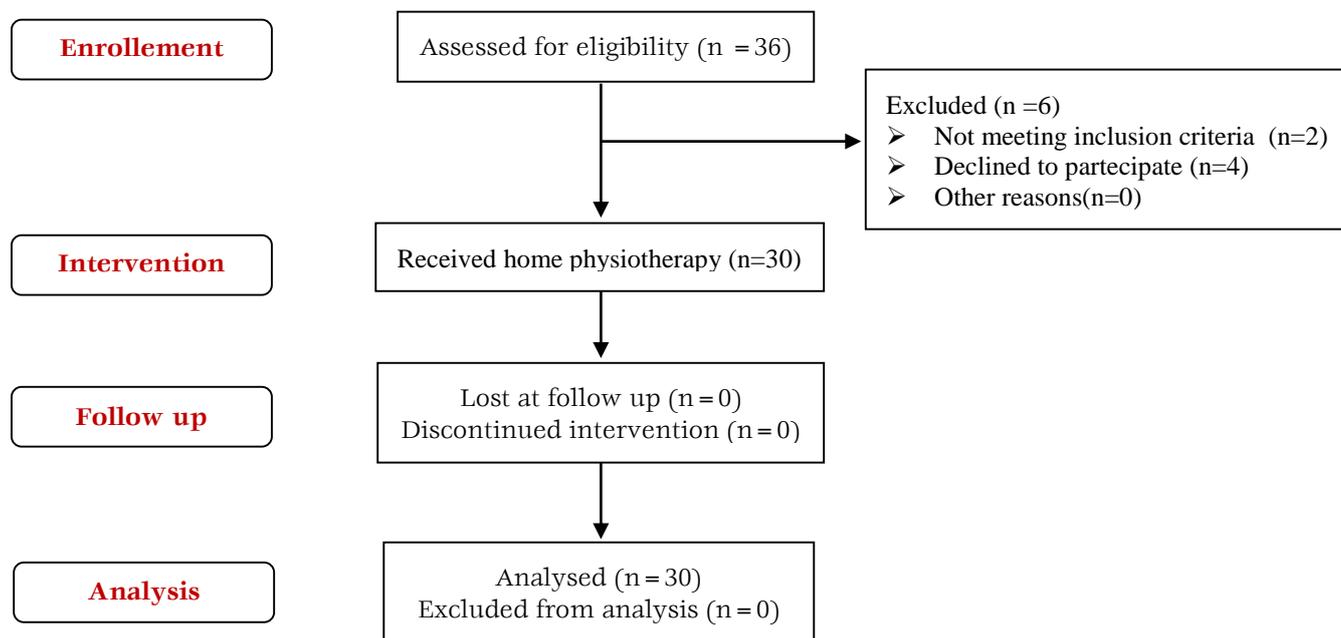
Data collection and intervention

Each of the individually examined study participants was given:

1. An anamnestic questionnaire, indicating:
   - First names, surname, place and date of birth, place of residence
   - Period of PD onset
   - Collection of the most frequent symptoms (tremor, pain, postural instability, motor deficits, bradykinesia)
   - Presence of other cardiac, respiratory, orthopaedic conditions
   - Medication taken over 24 hours
   - Dosage of drugs taken
   - Changes experienced since last neurological examination

2. The Hoehn and Yahr scale, a system for measuring the severity of the disease according to the symptoms presented by the patient. The original scale, published in 1967, divides the patients into seven categories:
   - Score 1: unilateral involvement with little or no functional disability;
   - Score 1.5: unilateral disease with involvement of the trunk;
   - Score 2: bilateral or axial involvement without functional balance disorder;
   - Score 2.5: bilateral disease with initial balance disorder;
   - Score 3: first signs of alteration of postural reflexes: some functional limitations, but the subject is able to live independently and eventually to work;
   - Score 4: full-blown disease, severely disabling;
   - Score 5: patient confined to a wheelchair or to bed.

   According to this scale, the disease is considered mild when the score ranges from 1 to 2, moderate between 2.5 and 3, serious from 4 to 5.

3. PDQ- 39 Scale

   Assessment was carried out at three different times: time zero (T_0), after nine months (T_1) and after eighteen months (T_2).

   All patients included in the study were regularly followed by a physical therapist who subjected them to a fortnightly home-based rehabilitation protocol. The exercises carried out were the following:

   1. Active and passive mobilization of the following joints:

   - Shoulder: flexion (0˚-45˚) /extension (0˚-180˚), abduction (0˚-90˚) /adduction (0˚-45˚), internal/external rotation (0˚-90˚)
   - Elbow: flexion/ extension (0˚-150˚);
   - Wrist: flexion (0˚-90˚)/ extension (0˚-70˚) radial deviation (0˚-20˚)/ulnar deviation (0˚-40˚)
   - Hip: flexion (0˚-100˚)/ extension (0˚-30˚); abduction (0˚-45˚)/adduction (0˚-20˚)
   - Knee: flexion (0˚-100˚)/extension (0˚-15˚)
   - Ankle: flexion (0˚-45˚)/ extension (0˚-20˚); prone movement (0˚-30˚); supine movement (0˚-20˚)

   All movement were reached starting by relaxed position.

   2. Respiratory gymnastics: Active Cycle of Breathing Techniques (ACTB)
   3. Upper and lower limb motor coordination
   4. Trunk control exercises (static control, extension towards an object, lateral oscillations)
   5. Step training exercise, following a traced walkway
   6. Independent/assisted gait with a moving point and utilization of sensory cues, choosing between three options: auditory (human voice), visual (laser pointers), sensory (vibration).

Each session lasted 60 minutes, and the interval between the weekly encounters was always three days.

The data were organized with the utilization of Microsoft Excel 2007 work sheets, while SPSS 20 was utilized for hypothesis testing.

RESULTS

Characteristics of the patients included
The main characteristics of the patients involved in the study are summarized in table 1; we will take a brief look at some of the peculiarities that emerged. It must first be noted that most of the patients participating in the study are male (20), and about two thirds of the patients are effected by PD with a high severity score (20); this represents the cause of the home-based treatment. More information on which to dwell is the pharmacological treatment: in fact, most of the patients appear to be divided into two macro areas: those taking only levodopa and those that accompany this drug with other substances (dopamine agonists such as pramipexole, rasagiline, rotigotine).

Table 1: characteristics of the patients included. Four sample characteristics were studied: gender, clinical severity (using the Hoehn and Yahr system), medications taken and main symptoms; for each one we reported the possible values, the numerical and percentage result.

Variable	Values	Result (%)
Sex		
	Man	20 (66,7)
	Woman	10 (33,3)
Disease progression		
	Mild (H/Y1-2)	0
	Moderate (H/Y 2,5-3)	10 (33,3)
	Severe (H/Y 4-5)	20 (66,7)
Taken drugs		
	Levodopa	12 (40)
	Levodopa + others	16 (53,4)
	Only other drugs	1 (3,3)
	No treatment	1 (3,3)
Main symptom		
	Bradykinesia	3 (10)
	Resting tremor	13 (43,3)
	Postural instability	11 (36,7)
	Rigidity	3 (10)

Table 2, on the other hand, describes the average age of the patients, time elapsed since diagnosed with PD and age at the onset of the disease.

Table 2: age at onset of Parkinson's Disease. Three factors were studied: age of the patient at T_0, number of years elapsed since diagnosis, age of the patient when diagnosed. Each detail was reported, therefore, as an average (1st column) and standard (2nd column) deviation.

	Mean	Standard Deviation
Age	77,53 years	7,8 years
Years of disease	8,2 years	4,4 years
PD's age of onset	68,6 years	9,86 years

Effects of the rehabilitation programme on HRQOL

An analysis was carried out relative to the HRQOL of the patients included in the study, as well as on its variations during home-based rehabilitation. The PDQ-39 questionnaire, as already indicated, is divided into eight specific areas, in each of which the attainment of the maximum score is indicative of a low quality of life reported by the subject. In Table 3 and in figure 2 are the patients' average scores in the three successive surveys, with indication of the level of significance obtained for the differences observed.

In accord with the Shapiro- Wilk test, all the areas of the questionnaire, except the one relating to social support, follow normal distribution; this enabled the Student t hypothesis test to be carried out in order to assess the weight of the differences observed over time. For the variable with abnormal distribution, the non-parametric Mann-Whitney test was used.

Thematic Area	T_0	T_1	T_2
Movement	25,2 ± 5,7	23,7 ± 7,4	25,8 ± 8,7
Adl	14 ± 5,6	12,46 ± 5,9	12,8 ± 5,7
Psychological well-being	12,3 ± 3,9*	9,8 ± 4,4*	7,5 ± 3,2*
Stigma	6,7 ± 5*	3,7 ± 3,7*	1,5 ± 2,8*
Social support	2 ± 2,6**	1,1 ± 1,5**	0,4 ± 0,6**
Cognitive impairment	7,4 ± 4,1	7,8 ± 3,5	7,2 ± 3,4
Communication	3,8 ± 2,9	3,2 ± (3,1)	3 ± 3,1
Physical discomfort	7,2 ± 2,9	7,1 ± 2,9	7,6 ± 3,1

Table 3: average scores in the Pdq-39 areas and statistical significance. For each of the Pdq 39 subject areas, the scores of patients in T_0, T_1 e T_2 were indicated, expressed as ± standard deviation average. The statistical significance of the differences observed was studied using the Student t test for all the areas which presented normal distribution, whereas the Mann- Whitney test was used for the "social support" are.
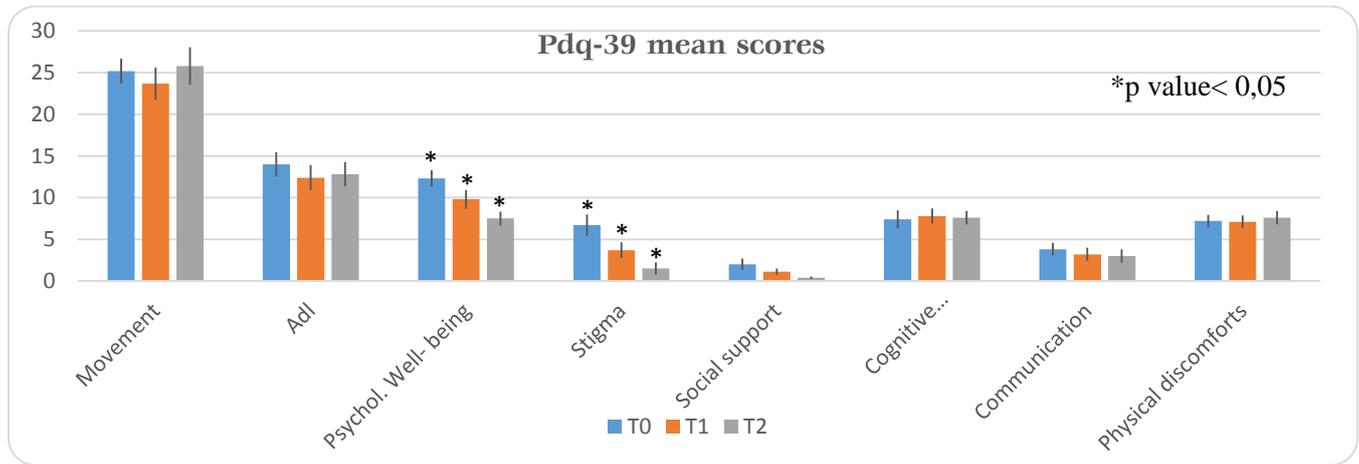
Figure 2: graphic representation of the average Pdq 39 scores with statistical significance. The subject areas were represented via three columns, corresponding to the average scores in T_0, T_1, T_2; each column indicates the standard error. The differences observed reached statistical significance in two areas only, stigma and psychological well-being.

The most important figure is definitely represented by the changes in the scores on the psychological dimension associated with PD: the areas of psychological well-being, stigma and social support noted a trend in constant decline, representative of a better HRQOL reported by the patients. In all the later surveys, the first two dimensions indicated reached a significant P value in the Student test, therefore the figure is reliable. The same significance, however, was not reached by the social support area. The rehabilitation treatment, therefore, exerts its main action on the emotional condition of the patient with Parkinson's disease, through the dynamics of taking charge and counselling.

As for the expressly physical dimension of PD, analysis of the mobility area and ADL scores indicates that the physiotherapy treatment can work in the short term (where a decline in average scores has been observed), but the progression of the disease nullifies the results obtained in the long period. This result, however, was not accompanied by statistical significance.

A final consideration regards the effect of the rehabilitation treatment on the cognitive abilities of patients with PD: mean scores of the communication and cognitive impairment areas indicated minimal and irrelevant changes, which practically annul the role of physiotherapy in this aspect of the clinical management. A similar consideration is to be applied to the score of the physical discomforts area, which has seen an increase.

HRQOL correlation- disease severity

For each survey, the degree of correlation was estimated by means of the Pearson's r coefficient, considering the total PDQ-39 score and the clinical severity score based on the Hoehn and Yahr scale; Figure 3 shows the distribution of patients with respect to the clinical severity observed.
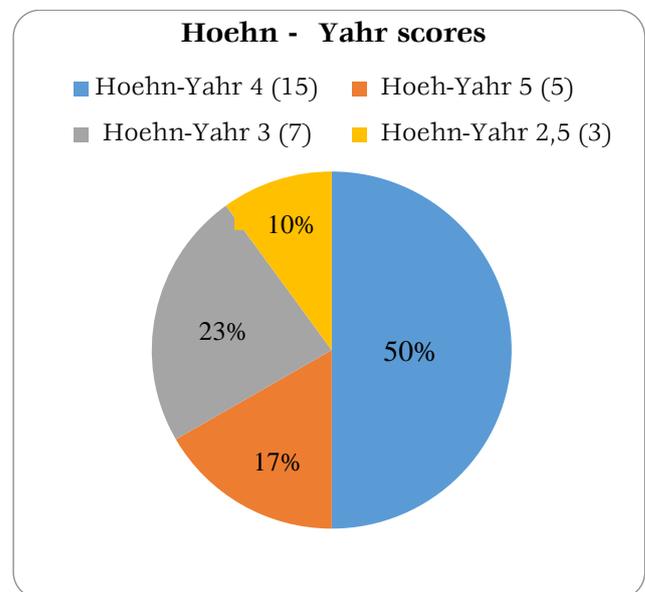

Figure 3: clinical severity in Parkinson's Disease in the sample studied, based on Hoehn e Yahr (H/Y) staging. The disease caused severe impairment in a total of 20 subjects, who received H/Y score 4 (15 subjects) and 5 (5 subjects), whilst the other 10 had a moderate degree of the disease. In fact, 7 people received H/Y 3, and, lastly, 3 received a score of 2.5. No-one showed mild impairment (H/Y 1-2).

The correlation test gave the following values:
- R (T_0) = 0.845
- R (T_1) = 0.85
- R (T_2) = 0.76

Pearson's r coefficient describes the degree of correlation between the two aleatory variables, and oscillates between – 1 (negative correlation) and 1 (full positive correlation). In our case, as explained,

R always assumes the indicative values of a strong correlation; however, it is necessary to make a clarification. As already explained, the patients reported an overall better quality of life in findings T_1 and T_2, following the improvement of the psychological dimension. The R value in T_2, therefore, decreases for the comparison between the lower HRQOL scores and unchanged clinical severity.

DISCUSSION AND CONCLUSION

Several issues arose from our study: if, in fact, on the one hand the research made use of physiotherapy protocols and evaluation tools widely recognized in literature [13, 14, 15, 17, 18, 19, 20, 21], emphasis is to be placed also on some methodological limitations identified. Firstly, the impossibility to carry out a study with control groups: this means the impracticality of leaving patients without physiotherapy treatment and of not assessing quality of life in part of them. On the first point, there would be a major ethical problem in not treating patients suffering from a progressive and degenerative disease. [22] Regarding quality of life, on the other hand, in the absence of findings, we would have no way of understanding whether what is being practised is correct or not. The same clinical validation studies of the PDQ-39 mentioned previously [13,14,17] have a control-free structure; this deficiency, therefore, is a regular problem for those who study quality of life in patients with Parkinson's Disease.

A second limitation is the lack of sensitivity of the Hoehn and Yahr scale which, focusing solely on the clinical manifestations of the disease, has not quite detected the psychological changes.

The results of our study deserve final reflection; to date, not many similar works can be found in literature, since most existing studies focus on the effectiveness of the rehabilitation treatment only on motor symptoms. A recent literary work, [23] in accord with ours, traces reports of extremely strong correlations between HRQOL and clinical severity, but there is no suggestion of rehabilitation intervention. Instead, in the light of our results, it becomes necessary to combine physical therapy and pharmacotherapy to achieve an active improvement in the subject's quality of life. Lastly, the issue of short-term effects of physiotherapy on the motor problems of PD was addressed by a systematic review of the literature, [24] in accordance with the evidence demonstrated by our trial.

In conclusion, therefore, our experience has demonstrated that:

– PD severity and the HRQOL perceived are in close correlation;

– The dynamics of taking charge and counselling of the patient contribute in a decisive manner to the perception of the patients' emotional resources and capability to improve their daily activities;

– Home-based physiotherapy in PD has short-term effects for motor problems, and even long term effects for emotional problems.

Our hope, ultimately, is that the study of HRQOL in PD may lead to broader case studies, overcoming the ethical and organizational issues connected with structuring control groups, and ensuring the adoption of standardized physiotherapy protocols; this would enable a more ample confrontation between different socio-health realities and the development of increasingly effective treatment strategies.

Conflict of interest

Author have no conflict to disclose; no found was obtained for the conduct of the study

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