



Individualized guidance and telephone monitoring in a self-supervised home-based physiotherapeutic program in Parkinson

Orientação individualizada e monitoramento telefônico em programa domiciliar fisioterapêutico autossupervisionado no Parkinson

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Abstract

Introduction: Home therapeutic exercises have been a target of interest in the treatment of the Parkinson's disease (PD). The way that the physical therapist guides and monitors these exercises can impact the success of therapy. **Objective:** To evaluate the effects of individualized orientation and monitoring by telephone in a self-supervised home therapeutic exercise program on signs and symptoms of PD and quality of life (QoL). **Methods:** Single-blind randomized clinical trials with 28 people with PD (Hoehn and Yahr 1 to 3). Patients were randomized into two groups: experimental and control. The experimental group had a meeting with individualized guidance about physiotherapy exercises present in a manual, received the manual to guide their activities at home and obtained subsequent weekly monitoring by telephone. The control group received the usual cares by the service. Both were orientated to carry out exercises three times a week during 12 weeks. Was evaluated: (1) activities of daily living (ADL) and motor examination sections of the Unified Parkinson's Disease Rating Scale (UPDRS) and QoL by the Parkinson Disease Questionnaire 39 (PDQ-39). The analysis between groups was performed by the Mann-Whitney test and intragroup through the Wilcoxon ($p < 0.05$). **Results:** Significant improvement in ADL ($p = 0.001$) and motor examination ($p = 0.0008$) of the UPDRS, PDQ-39

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total ($p = 0.027$) and dimensions mobility ($p = 0.027$), emotional well-being ($p = 0.021$) and bodily discomfort ($p = 0.027$) in the experimental group compared to the control group. **Conclusion:** The individualized guidance and weekly monitoring by telephone in a self-supervised home therapeutic exercises program promoted positive effects on ADL, motor examination and QoL of people in early stages of PD.

Keywords: Parkinson Disease. Exercise Therapy. Physical Therapy Specialty. Quality of Life.

Resumo

Introdução: Exercícios terapêuticos domiciliares vêm sendo alvo de interesse no tratamento da doença de Parkinson (DP). A forma como o fisioterapeuta orienta e monitora estes exercícios pode impactar no sucesso da terapêutica. **Objetivo:** Avaliar os efeitos da orientação individualizada e do monitoramento por telefone em um programa de exercícios terapêuticos domiciliares autossupervisionados sobre os sinais e sintomas da DP e a qualidade de vida (QV). **Métodos:** Ensaio clínico randomizado simples-cego com 28 pessoas com DP (Hoehn e Yahr 1 a 3). Pacientes foram randomizados em dois grupos: experimental e controle. O grupo experimental teve um encontro com orientação individualizada sobre os exercícios de fisioterapia de um manual, recebeu o manual para orientar atividades em domicílio e obteve posterior monitoramento semanal por telefone. O grupo controle recebeu cuidados usuais do serviço. Ambos foram orientados a realizar exercícios três vezes por semana durante 12 semanas. Foram avaliadas: seções atividades da vida diária (AVD) e exame motor da Escala Unificada de Avaliação da Doença de Parkinson (UPDRS) e QV mediante Questionário de Doença de Parkinson 39 (PDQ-39). Foi realizada análise intergrupos (Mann-Whitney) e intragrupos (Wilcoxon) com $p < 0.05$. **Resultados:** Melhora significativa nas seções AVD ($p = 0.001$) e exame motor ($p = 0.0008$) da UPDRS, PDQ-39 total ($p = 0.027$) e dimensões mobilidade ($p = 0.027$), bem-estar emocional ($p = 0.021$) e desconforto corporal ($p = 0.027$) no grupo experimental quando comparado ao controle. **Conclusão:** A orientação individualizada e o monitoramento semanal por telefone em um programa de exercícios terapêuticos domiciliares autossupervisionados apresentaram efeitos positivos sobre AVD, exame motor e QV em estágios iniciais da DP.

Palavras-chave: Doença de Parkinson. Terapia por Exercício. Fisioterapia. Qualidade de Vida.

Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disease associated with motor, cognitive, behavioral and social repercussions (1, 2). These can imply loss of autonomy and independence of the individual, negatively influencing their quality of life (QoL) (3-5).

The importance of multidisciplinary management and rehabilitation therapies as adjuvant to pharmacological and neurosurgical treatment has been demonstrated for the maintenance or improvement of QoL in PD (6, 7). The physiotherapist, a member of the rehabilitation team, must be inserted to maximize the individual's functional capacity and minimize secondary complications of the disease (8, 9).

Physiotherapy in PD includes aerobic exercises, transfers, posture, balance, strengthening, relaxation, movement strategies, gait training without and with

external stimuli, and education of the patient and caregivers (9-11). Recently, studies have evaluated the effects of therapeutic home exercise programs whose practice can be supervised by the patient (12-18).

Home therapeutic exercises with self-supervised practices seem to be an interesting alternative for patients with PD, since many have difficulty in locomotion or the cost of physiotherapy sessions (15, 19). However, these programs may have as a disadvantage the lack of assurance of the correct execution of the exercises since the patient and caregivers can understand the guidelines received in a limited way or present insufficient motivation and discipline (16, 17).

In these programs, individualized counseling can be used in the patient education session to provide information about the disease, rehabilitation, exercises and explanations on how to perform it in the most appropriate way (16). Also, the telephone can be a resource for motivation and control of self-supervised

practice (14, 16, 17). Randomized clinical trials that have evaluated effects of individualized guidance and weekly telephone monitoring in a self-supervised PD home program have not been found in the literature.

In view of the above, this study aims to evaluate the effects of individualized guidance and weekly telephone monitoring in a program of self-supervised home therapeutic exercises on signs and symptoms of PD and QoL. Our hypothesis is that such a program contributes to the improvement of activities of daily living (ADL), motor examination and QoL.

Methods

A randomized, simple-blind clinical trial consisting of a self-supervised home-based exercise program with individualized guidance and weekly telephone monitoring for a twelve-week intervention period. The study was approved by the Research Ethics Committee of the Federal University of Pernambuco (UFPE) (CAAE 38511314.0.0000.5208) and all the patients signed the informed consent form, according to the code of ethics of the World Medical Association (Declaration of Helsinki) for research involving human beings (20). The trial was recorded on ClinicalTrials.gov (trial registration number: NCT 02510833).

Sample

Patient recruitment occurred in the Pro-Parkinson's Program of the Clinic Hospital of the UFPE, Ambulatory of Neurology in Recife, Pernambuco, Brazil. Patients with idiopathic Parkinson's disease were listed and selected weekly, systematically, according to the agenda of the day during their routine visit to the service. The following system was considered: of every two patients scheduled, one was selected, starting with the first patient of the day. Randomization was performed by draw by groups in the experimental group or control group, each with 14 participants.

Eligibility Criteria

Patients of the female and male sex were included; not institutionalized; aged between 50 and 80 years;

clinical diagnosis of idiopathic PD attested by the neurologist of the Pro-Parkinson's Program according to Ordinance No. 228/2010 of the Brazilian Ministry of Health (21) and in the mild to moderate stages (classified between 1 and 3) according to the original version of the Hoehn and Yahr (HY) scale (22). Exclusion criteria were: cognitive impairment identified by the Mini Mental State Examination (MMSE) according to schooling (23); other associated neurological, orthopedic, or unstable cardiorespiratory pathology; medical or musculoskeletal contraindication for exercise; have undergone surgery for PD and undergoing physiotherapy during the study period.

Size of the sample

The Power Analysis and Sample Size (PASS) 2005 version was used for sample calculations. With 14 patients for the experimental group and 14 for the control group, it is possible to detect a reduction of three points in the PDQ-39 scale and in the ADL and motor examination subscales of the UPDRS with a test power of 82% and a significance level of 5% for the intervention group, comparing with no reduction for the control group. The expected mean and standard deviation parameters were based on previous studies (13, 16, 24) and on clinical experience in the Pro-Parkinson's Program.

Intervention

Experimental Group

The physiotherapist responsible for the research guided in an initial meeting each patient and her companion about a program of therapeutic exercises of the chapter of physiotherapy present in a manual of the Pro-Parkinson's Program. The manual has the sequence of the exercises, description of the exercises, number of repetitions and self-explanatory illustrations, being delivered as a way of guiding the practice at home. The exercises were based on the recommendations of the guide for Physical Therapy in patients with PD of the Royal Dutch Society of Physiotherapy (10). The physiotherapy chapter is divided into 4 parts: 1- stretches; 2- mobility exercises; 3- exercises for balance and strength and 4- orientations of everyday situations (Table 1).

The exercises were conducted at home three times a week (on intercalated days), for 12 weeks, a session of up to 60 minutes, and the on-going period of the medication (one hour after taking the medication). The exercises were supervised by the patient himself. Patients received an exercise diary and were

monitored weekly by phone calls to remind them of the exercises, clarify their doubts and motivate them to continue the practice. Patients and caregivers could attend the Physiotherapy lectures of the Pro-Parkinson's Program (group orientation) on the physiotherapy chapter of the handbook on medical consultation days.

Table 1 - Details of the therapeutic exercises present in the physiotherapy chapter of the program manual

Physiotherapy chapter exercises in the Program manual *	Description of exercises for the patient
1: Cervical flexor muscles, anterior trunk chain, hip flexors, and knee extensors	"Lie on your stomach, keep your elbows on the bed. Fix your eyes forward or slightly upwards. Keep one knee bent while counting to 20. Repeat the same with the other knee. Do 3 reps on each leg".
2: Hamstring and triceps surae	"Lying on your stomach, let your head rest and one knee bent. With the help of a band or a sheet under the foot, stretch the other knee, raising the lower limb. Your caregiver can help with this exercise. Count to 20. Repeat the same with the other knee. Do 3 reps on each lower limb".
3: Hip adductor muscles	"Lying on your belly up: keep your head resting on the bed and your upper limbs on the side of the body. Pull away, opening one of the lower limbs to its limit, without taking the other limb out of its position. Keep the limb away ("open") while counting to 20. Repeat the same action with the other limb. Do 3 reps on each lower limb".
4: Pectoralis major and minor	"Stand, support your upper limb with your elbow stretched or bent at a door in your home. At the same time turn your body in the opposite direction to its limit. Hold the position while counting to 20. Repeat the same with the other member. Do 3 reps on each upper limb".
5: Flexor muscles (lateral and anterior) and extensors of the cervical	"Sitting with your arms up, tilt your head sideways to one side, hold and count to 20. Then tilt your head sideways to the other side, hold and repeat the count. Then tilt your head forward, hold and count to 20. Then tilt your head back, hold and repeat the count. Do 3 reps for each move".
2-Mobility	
1: Head mobility	"Sitting with your arms up, turn your head from side to side. Repeat 10 times. Then tilt your head sideways from side to side. Repeat 10 times. Finally tilt your head back and forth and repeat 10 times".
2: Mobility of the upper limbs	"Sitting with your back straight, hold a stick or broom handle with your hands lifting it from your thighs up above your head with your elbows straight. Then return to the starting position. If you do not have difficulty, this movement can be done standing. Repeat 10 times".
3 and 4: Trunk mobility	"Sitting down, hold a stick or broom handle and turn the torso slowly from side to side. If you do not have difficulty, this movement can be done standing. Repeat 10 times". "Seated, with the trunk upright, tilt the trunk sideways as if to pick up an object on the ground. Then do the same to the opposite side. Repeat 10 times".
3-Balance and strength	
1: Sit and stand	"To get up from the chair or bed, approach the edge, with your hands lean on the arms of the chair, keep your feet away, lean forward and lift slowly. Repeat 10 times".
2: Movement strategies	"To get up from the bed, rotate your body to stand on the side, then with the help of your arms, raise your trunk and lower the legs of the bed by sitting. Then follow the guidelines from the previous exercise. Repeat 10 times".

Physiotherapy chapter exercises in the Program manual *	Description of exercises for the patient	(conclusion)
3: Bridge exercise	Lying down, with your upper limbs at your side and your knees bent, raise your hip. Then return to the starting position. Repeat 10 times.	
4- Orientations of everyday situations		
1: Strategies for freezing	"When locking ("freeze") while walking, think and program the movement to be performed. Count the steps or pretend you are climbing a ladder to unlock".	
2: Strategy for accomplishing tasks	"Avoid doing too many tasks at once".	
3: Strategies for imbalance while walking	"When you feel imbalance move your feet away from each other and hold onto safe objects. And when turning or changing direction make wider (open) curves".	
4: Importance of staying active	"Stay active. Moving is important".	

Note:* Therapeutic exercise program present in the physiotherapy chapter of the Pro-Parkinson's Program manual available at: <https://proparkinson.wordpress.com/>.

Control Group

Patients and companions could attend the Physiotherapy lectures of the Pro-Parkinson's Program (group orientation) about the physiotherapy chapter of the manual on medical consultation days and have the program manual, the usual procedure of the service. Patients did not receive individualized guidance or weekly telephone monitoring. The lectures took place twice a month on medical consultation days and had a maximum duration of 40 minutes. Patients and caregivers were instructed to do the therapeutic exercises at home three times a week (on intercalated days), with a maximum duration of 60 minutes each session and on the medication period.

Procedures for Data Collection

The physiotherapist responsible for the research and previously trained, evaluated at the beginning of the study period and reevaluated after 12 weeks all the patients. The Unified Parkinson's Disease Assessment Scale (UPDRS) and the Parkinson's Disease Questionnaire 39 (PDQ-39) were used.

Unified Parkinson's Disease Assessment Scale (UPDRS)

Considered the standard evaluation to measure signs and symptoms in practice and clinical research in PD (25). It covers 42 items, divided into four subscales: I- mental activity, behavior and mood;

II- activities of daily living (ADL); III- motor examination and IV- complications of drug therapy. For the present study, the subscores of the ADL section and motor examination of the UPDRS (ON medication states) were used through the summations of their respective items, as well as the total score obtained from the sum of the ADL and motor examination sections (UPDRSt). The score in each item ranges from zero to four, the maximum value being indicative of a greater impairment by the disease (15, 26).

Parkinson's Disease Questionnaire 39 (PDQ-39)

It is a specific instrument to evaluate the quality of life in PD. It comprises 39 items distributed in eight dimensions: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication and bodily discomfort. Scores range from 0-100 and the higher, the worse the perception of QoL (3, 4).

Data Analysis

Data was analyzed using statistical software Statistical Package for Social Sciences (SPSS) version 16.0. To verify the normality of the sample, the Shapiro-Wilk test was used. By means of non-normality, the results were compared intergroup using the Mann-Whitney test and intragroup using the Wilcoxon test. For the descriptive analysis of the data, mean, standard deviation, median and interquartile range were used. The level of significance was set at 0.05 for all analyzes.

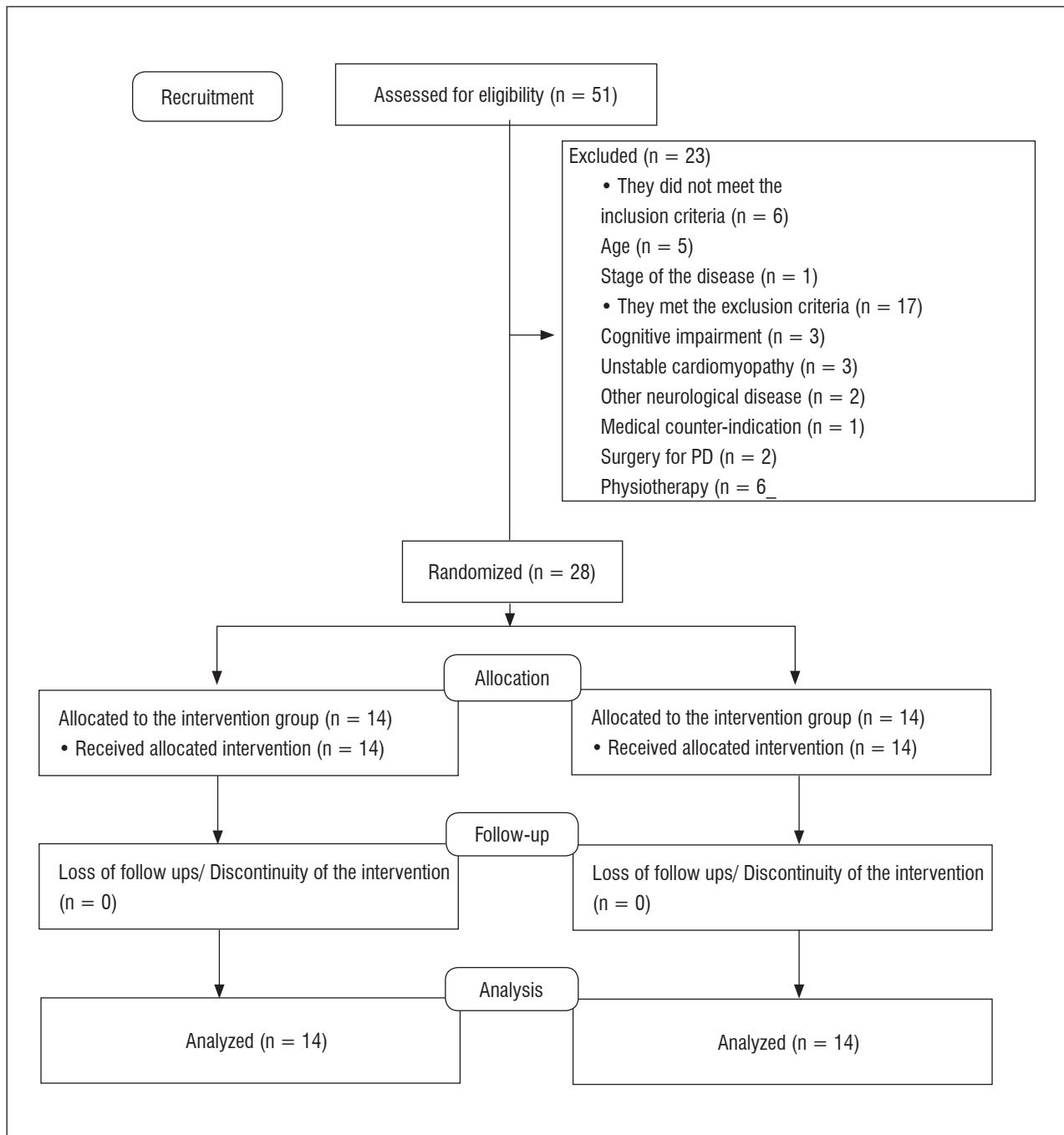


Figure 1 - Sample flowchart

Results

Fifty-one patients were recruited and evaluated for eligibility; however, 28 were randomized to the experimental or control groups (Figure 1).

After randomization, the groups were the same as the variables: sex, age, time and disease severity (Table 2).

Table 2 - Comparison of baseline characteristics between study groups

	Experimental group	Control Group	P
Sex (men/women)	8/6	8/6	-
*Age (years)	65 (8)	61 (7)	0.177
*Time of illness (years)	4 (2)	5 (3)	0.339
** Staging (HY)	2 (0)	2 (0)	1.000

Note: Sex expressed in absolute frequency; Mean age and time of disease (standard deviation) and disease staging at median (interquartile range). HY = Hoehn and Yahr. * Test T; ** Mann-Whitney Test.

Experimental group when compared to the control, presented a statistically significant reduction in the UPDRSt score and in the ADL and UPDRS motor examination sub scores after intervention. In the paired analysis, the experimental group had a statistically significant reduction in the UPDRSt score and in

the ADL and UPDRS motor examination sub scores after the intervention. On the other hand, the control group presented a statistically significant increase in all the evaluated scores of the UPDRS after the same period (Table 3).

Table 3 - Expresses the median (interquartile range) of the UPDRS scores before and after a home-based program of self-supervised therapeutic exercises, according to whether or not they use individual guidance and telephone remote monitoring

UPDRS	Experimental group		Wilcoxon P	Control Group		Wilcoxon P	Mann-Whitney P
	Before	After		Before	After		
UPDRSt	30 (10)	24 (11)	0.001*	27 (18)	38 (29)	-0.003*	0.0006*
UPDRS-ADL	14 (7)	9 (5)	0.002*	13 (8)	16 (12)	-0.003*	0.001*
UPDRS- motor examination	19 (7)	13 (9)	0.001*	16 (17)	24 (21)	-0.01*	0.0008*

Note: UPDRSt: Unified Parkinson's Disease Assessment Scale, sum of the sub-sections ADL and motor examination; UPDRS-ADL: Activities of daily living section of the UPDRS. UPDRS- motor examination: Motor examination section of the UPDRS. * $P \leq 0.05$.

In the comparison between the groups, statistically significant differences were observed for the total PDQ-39 score and their dimensions: mobility, emotional well-being and bodily discomfort. In the paired analysis, the experimental group presented a statistically significant

reduction in the total PDQ-39 score and in the dimensions: mobility, emotional well-being, stigma and cognition. On the other hand, the control group showed a statistically significant increase for the dimensions of cognition and bodily discomfort (Table 4).

Table 4 - Expresses the median (interquartile range) of the total PDQ-39 and its domains before and after the intervention in both groups

PDQ-39	Experimental group		Wilcoxon P	Control Group		Wilcoxon P	Mann-Whitney P
	Before	After		Before	After		
Total	30 (24)	19 (16)	0.005*	27 (36)	29 (29)	0.162	0.027*
Mobility	44 (27)	19 (16)	0.003*	53 (55)	40 (49)	-0.255	0.027*
ADL	27 (30)	27 (28)	0.694	33 (47)	31 (52)	0.838	0.260
Emotional well-being	25 (30)	10 (25)	0.041*	25 (32)	35 (33)	0.233	0.021*
Stigma	25 (36)	13 (23)	0.029*	9 (47)	13 (28)	0.789	0.662
Social Support	0 (0)	0 (0)	0.675	0 (17)	4 (21)	0.446	0.154
PDQ-39	Experimental group		Wilcoxon P	Control Group		Wilcoxon P	Mann-Whitney P
	Before	After		Before	After		
Cognition	34 (30)	9 (22)	0.006*	9 (13)	16 (28)	-0.035*	0.312
Communication	8 (29)	8 (17)	0.102	12 (48)	21 (37)	0.798	0.175
Bodily Discomfort	33 (25)	17 (23)	0.157	33 (23)	33 (23)	-0.041*	0.027*

Note: PDQ-39: Parkinson's Disease Questionnaire 39. ADL: Activities of Daily Living. * $P \leq 0.05$.

Discussion

Individualized counseling and weekly telephone monitoring in a self-supervised home-based therapeutic exercise program promoted positive effects on activities of daily living, motor examination and quality of life of people in the early stages of PD.

Reductions of the UPDRSt score and ADL and motor examination sub scores of the UPDRS were statistically significant in the experimental group when compared to the control after twelve weeks. These findings highlight the importance of intervention for the control of signs and symptoms of the disease, since the evaluated subscores, especially ADL, are considered important markers of PD progression (27). In addition, they suggest gain in the functional independence of these individuals, positively impacting their QoL (28).

Regarding QoL, statistically significant differences were observed for the PDQ-39 total score and their dimensions of mobility, emotional well-being and bodily discomfort. According to Lana et al. (4), the mobility dimension presents a high correlation with the overall score of the PDQ-39 and the emotional well-being and bodily discomfort dimensions a low correlation. In this sense, it is suggested that in our study the total PDQ-39 score decreased significantly, mainly due to the observed decrease in the mobility domain score. In addition, the intervention was effective for two domains related to physical aspects (mobility and bodily discomfort) commonly affected in PD (28) and for a non-motor symptom (emotional well-being), which usually plays an important role in the functionality and QoL (1).

Previous studies evaluating a self-supervised home-based exercise program found positive effects on the ADL and UPDRS motor examination sections (13, 15-17) as well as on QoL (15, 16, 18). All of them provided a manual with exercises on the program, but they varied in the form of monitoring and most of them did not make it clear whether the orientation of the exercises was individualized or in a group.

Dereli and Yaliman (16) and Lopes et al. (15) obtained gains on both the ADL and motor examination of the UPDRS and on the QoL. The first study was the one that most resembled the present protocol, since it guided patients and companions in an individualized way about the exercises and used the telephone as a way of monitoring. The second investigated the effects of a 10-week self-supervised home-based

program and used a diary as monitoring. It is possible that the diary contributed to reinforcing the regular practice of the exercises (12). However, when compared to the telephone as a form of monitoring, it is understood that the diary demands a higher level of schooling and a greater discipline of the patient or caregiver in view of requiring a detailed written record of the practice performed.

Santos et al. (17) observed a significant improvement on the UPDRS motor examination section in most of their patients and on the ADL section for a group of individuals under 60 years of age and diagnostic time less than five years. This study aimed to investigate a self-supervised program using weekly telephone monitoring and the same intervention time as ours. In spite of this, it was a series of cases with no presence of a control group.

Refuting positive findings about UPDRS, a randomized controlled trial of King et al. (18) did not find a statistically significant difference for the ADL and motor examination sub scores in a household group with an individualized self-supervised exercise program after four weeks. He did not report the use of exercise monitoring over the telephone. Also, it is important to include the presence of at least one PD-associated comorbidity to assess the impact of this on the success of the interventions proposed in the study. According to the authors, patients who have comorbidities and cognitive-behavioral impairments are poorly benefited by a home-based program, and a supervised outpatient program is preferable. In the present study, we chose to use a self-supervised program with individualized guidance and weekly telephone monitoring, but the stages of PD severity were controlled, the presence of unstable comorbidities and cognitive impairment, and opted for a longer intervention time. These factors may have positively influenced our findings.

It is believed that individualized orientation and weekly telephone remote monitoring have contributed to a better understanding of the program and to a more adequate execution of the exercises in the experimental group when compared to the control. The individualized orientation may have enabled the patient and companion to feel more at ease, favoring the dialogical exchange with the health professional (29). As for the telephone, it is understood to have been a viable monitoring resource capable of strengthening the relationship between the health professional, the patient and the caregiver, allowing the promotion of self-care (30-32).

Among the advantages of this program are the convenience of being able to perform the exercises at the desired moments, not having to go to a rehabilitation unit and reducing the direct cost to the patient (13, 15-17). The latter has assumed even greater importance in our population since it is predominantly low-income (33).

Concerning the disadvantages, we cannot guarantee the correct execution of the exercises and full compliance of the prescribed program (13, 15-17). Therefore, trying to minimize risks, we chose to plan a program for individuals with a higher degree of independence (HY 1 to 3) and adequate cognition for their level of education. For individuals more severely affected by PD (HY above 3) and with cognitive impairment, a supervised program is suggested. Finally, the main methodological limitation of this study is the absence of blinding for the researcher. Also, since the evaluation of long-term effects was not objective, it is suggested that controlled randomized trials be conducted for this purpose. In addition, since the telephone was used as a monitoring method, studies on its cost-effectiveness are necessary.

Conclusion

Individualized counseling and weekly telephone monitoring in a self-supervised home-based therapeutic exercise program had positive effects on ADL, motor examination and QoL in people in the early stages of PD.

This research has an original character for the scientific community, since it is the first randomized clinical trial on the subject in PD. Thus, more research is needed, especially double-blind randomized clinical trials on guidance and monitoring strategies in self-supervised PD programs.

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