

HEALTH MANAGEMENT PERFORMANCE OF OLDER PEOPLE WITH PARKINSON'S DISEASE: QUALITATIVE STUDY

Desempenho da gestão da saúde de pessoas idosas com doença de Parkinson: estudo qualitativo

Desempeño de la gestión de la salud de personas mayores con enfermedad de Parkinson: estudio cualitativo

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Abstract: Introduction: People with Parkinson's disease may have motor and non-motor symptoms that affect occupational performance. Studies in this area have not included the analysis of all occupations. **Objective:** To analyze the perception of older people with Parkinson's disease about their performance in the occupation of health management. **Methods:** Cross-sectional and qualitative study, carried out with participants of the Parkinson's Disease Study Group at the Federal University of Rio de Janeiro. Data were collected using: Montreal Cognitive Assessment, Hoehn & Yahr Scale, sociodemographic questionnaire, and an interview guide on health management were used. Data analysis was based on content analysis. **Results:** The study involved 10 participants in a mild to moderate stage of the disease, aged between 62 and 78 years, who reported regular health and good quality of life. Three themes were identified regarding health management: health management performance, barriers, and facilitators. Participants reported difficulties, mainly in managing nutrition, condition and symptoms and promoting/maintaining social and emotional health. The main barriers were accessibility, lack of access to health services and medicines. Environmental adaptations, technological devices and support networks were identified as facilitators. **Conclusion:** There are varied changes in health management occupational performance in people with Parkinson's disease. It is suggested that studies on this topic be expanded to include people with different levels of functioning and to monitor changes throughout the disease process.

Keywords: Aged. Parkinson's Disease. Occupational Therapy. Activities of Daily Living.

Resumo: Introdução: Pessoas com doença de Parkinson podem apresentar sintomas motores e não motores que impactam o desempenho ocupacional. Estudos na área não contemplam a análise de todas as ocupações. **Objetivo:** Analisar a percepção de pessoas idosas com doença de Parkinson sobre o seu desempenho na ocupação de gestão da saúde. **Métodos:** Estudo transversal e qualitativo, realizado com participantes do Grupo de Estudo de Doença de Parkinson da Universidade Federal do Rio de Janeiro. Para levantamento dos dados, foram utilizados: Montreal Cognitive Assessment, Escala de Hoehn & Yahr, questionário sociodemográfico e roteiro de entrevista sobre a gestão da saúde. A verificação dos dados foi baseada na análise de conteúdo. **Resultados:** A pesquisa envolveu 10 participantes em estágios de leve a moderado da doença, com idade entre 62 e 78 anos, que relataram condição de saúde regular e boa qualidade de vida. Sobre a gestão da saúde, foi possível identificar três temáticas: desempenho da gestão da saúde, barreiras e facilitadores. Os participantes relataram dificuldades, sobretudo em gerir a nutrição, a condição e os sintomas e em promover e manter a saúde socioemocional. As principais barreiras envolveram acessibilidade, acesso aos serviços de saúde e medicamentos. Adaptações ambientais, dispositivos de tecnologia e rede de apoio foram apontados como facilitadores. **Conclusão:** Há alterações variadas no desempenho da ocupação da gestão da saúde em pessoas com doença de Parkinson. Sugere-se ampliar os estudos sobre o tema com pessoas de diferentes graus de funcionalidade e acompanhar as mudanças ao longo da evolução da doença.

Palavras-chave: Idoso. Doença de Parkinson. Terapia Ocupacional. Atividades Cotidianas.

Resumen: Introducción: Las personas con enfermedad de Parkinson pueden presentar síntomas motores y no motores que repercuten en el desempeño ocupacional. Los estudios en este ámbito no analizan todas las ocupaciones. **Objetivo:** Analizar la percepción de las personas mayores con enfermedad de Parkinson sobre su desempeño en la ocupación de gestión sanitaria. **Métodos:** Estudio transversal y cualitativo realizado con participantes del Grupo de Estudio de la Enfermedad de Parkinson de la Universidad Federal de Río de Janeiro. Para la recopilación de los datos se utilizaron: Evaluación Cognitiva de Montreal, Escala de Hoehn & Yahr, cuestionario sociodemográfico y guión de entrevista sobre la gestión de salud. El análisis de los datos se basó en el análisis de contenido. **Resultados:** La investigación contó con 10 participantes en la fase leve a moderada de la enfermedad, con edades comprendidas entre los 62 y 78 años, que informaron de un estado de salud regular y una buena calidad de vida. Con respecto a la gestión de la salud, se identificaron tres temas: desempeño de la gestión de la salud, barreras y facilitadores. Los participantes informaron dificultades, sobre todo, en el manejo de la nutrición, las condiciones y los síntomas, y en la promoción/mantenimiento de la salud social y emocional. Las principales barreras estaban relacionadas accesibilidad, acceso a servicios sanitarios y medicamentos. Las adaptaciones del entorno, los dispositivos tecnológicos y una red de apoyo se consideraron facilitadores. **Conclusión:** Existen cambios variables en el desempeño de las ocupaciones de gestión sanitaria en personas con enfermedad de Parkinson.

Palabras-clave: Anciano. Enfermedad de Parkinson. Terapia Ocupacional. Actividades Cotidianas.

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Introduction

In Brazil, there is an observed growth in the population aged 60 years or older. This increase in longevity has been considered the major challenge of the century. Several studies show a high prevalence of multiple morbidities in this population (Camarano, 2021), including chronic-degenerative diseases such as Parkinson's disease (PD). PD has been identified as the neurodegenerative disease that has shown the greatest growth in prevalence, disability, and deaths over the past 25 years (GBD, 2018).

The clinical diagnosis is based on the identification of cardinal signs: bradykinesia plus rigidity and/or resting tremor. In addition to these signs, individuals with PD may present other motor symptoms, such as gait deficits, postural instability, freezing, micrographia, and hypomimia, as well as non-motor symptoms, such as cognitive deficits, depression, sleep disorders, sexual and urinary dysfunctions, apathy, and fatigue (Postuma *et al.*, 2015; Mammen *et al.*, 2023).

In this context, PD may affect engagement in occupations (Foster *et al.*, 2014; Murdock *et al.*, 2015; Silva & Carvalho, 2019). The concept of occupation refers to the daily activities that people perform individually, within families, and in the community, to organize their time and give meaning to life. In this sense, occupations can be categorized as activities of daily living, instrumental activities of daily living, health management, sleep and rest, education, play, leisure, and social participation (Gomes *et al.*, 2021).

There are studies on the impact of PD on activities of daily living, instrumental activities of daily living, sleep and rest, work, and leisure (Foster *et al.*, 2014; Murdock *et al.*, 2015; Silva & Carvalho, 2019; Welsby *et al.*, 2019; Sadural *et al.*, 2022; Oliveira *et al.*, 2024). However, despite these studies, there remains a need to explore aspects related to the impact of the disease on health management. Health management refers to "activities related to the development, management, and maintenance of health and well-being routines, including self-management, with the aim of improving or maintaining health to support participation in other occupations" (Gomes *et al.*, 2021, p. 32). These activities can be subdivided into: 1) promotion and maintenance of socioemotional health; 2) condition and symptom management; 3) communication with the health system; 4) medication management; 5) physical activity; 6) nutritional management; 7) management of personal care devices (Gomes *et al.*, 2021, p. 10). The literature demonstrates that occupational therapy interventions for people with PD are more effective when they use individualized, goal-oriented plans, focusing on meaningful activities, physical and functional approaches, and self-management strategies (Foster *et al.*, 2014; Welsby *et al.*, 2019; Oliveira *et al.*, 2024). However, gaps remain regarding how these individuals specifically experience health management as an occupation. Thus, the objective was to analyze the perception of older adults with PD regarding their performance in this occupation.

Methods

This is a descriptive and exploratory study with a qualitative approach, conducted with people with PD who were members of the Parkinson's Disease Study Group (GEDOPA) of the Institute of Neurology Deolindo Couto (INDC), Federal University of Rio de Janeiro (UFRJ), located at the Praia Vermelha campus. GEDOPA is a scientific institution with a social function that integrates teaching, research, and extension activities.

The research followed the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) and was approved by the Ethics Committee of the INDC, UFRJ, CAAE 66193422.3.0000.5261 (approval number 5.876.184). The team consisted of four researchers: an undergraduate student in Occupational Therapy (principal); an occupational therapist who was developing her doctoral research at GEDOPA (cosupervisor); and two faculty members (supervisor and coordinator of the study group in which the research was conducted).

The principal researcher, despite not having had prior contact with the participants, was familiar with the data collection setting and with other people with PD. During her participation in undergraduate scientific initiation at the same institution throughout her degree, she observed the application of measurement instruments and the conduct of interviews, which contributed to her familiarity with the procedures adopted in this study.

Participants invited to the study met the following inclusion criteria: 1) being a person with PD, regardless of sex; 2) being aged ≥ 60 years and being a member of GEDOPA. The exclusion criteria were: 1) presenting limitations that made communication impossible, according to the interviewer's perception; 2) presenting cognitive impairment, according to the Montreal Cognitive Assessment (MoCA), with cutoff points adjusted for schooling (César et al., 2019). All participants obtained scores above the cutoff points and did not present communication impairments, resulting in zero exclusions. Participants were invited in person by the principal researcher before or after weekly physical therapy activities at GEDOPA. All agreed to participate, with no refusals.

After the invitation and acceptance, participants took part in the following stages: 1) a sociodemographic and health perception interview; 2) a semi-structured interview on health management. In addition, based on data from medical records, PD staging was performed using the modified Hoehn & Yahr scale, which classifies disease progression into 8 stages: 0 – no signs of the disease; 1 – unilateral disease; 1.5 – unilateral and axial involvement; 2 – bilateral disease without balance impairment; 2.5 – mild bilateral disease; 3 – mild to moderate bilateral disease, with some postural instability; 4 – severe disability; 5 – confined to bed or wheelchair (Goetz *et al.*, 2004).

The identification form, developed by the researchers, included 14 items related to sociodemographic characteristics (age, sex, marital status, race, education, retirement status, and income), religion, type of health service used (public and/or private), self-reported diseases, hospitalizations, as well as self-perceived quality of life (very poor; poor; neither poor nor good; good; very good) and health condition (very poor; poor; neither poor nor good; good; very good). The semi-structured interview guide, also developed by the researchers, consisted of 26 questions on activity performance, barriers, and facilitators, constructed based on the health management topics described in the occupational therapy practice framework (Gomes *et al.*, 2021).

The interviews were scheduled according to participants' availability at the GEDOPA physical therapy outpatient clinic, in a private room with only the participant and the lead researcher present. In some interviews, the supervisor or the co-supervisor was also present. The interviews were conducted between 02/16/2023 and 04/27/2023, with an average duration of 45 minutes, audio-recorded and fully transcribed. Data collection was concluded when the principal researcher and the supervisors identified, in weekly supervision meetings, data saturation in relation to the initially proposed objective.

After transcription, the data were not validated with the participants, but confidentiality was ensured by replacing names with "P" followed by a number (P1–P10). In the presentation of results, information in square brackets [] within participants' quotes indicates authors' additions for contextual clarification and/or replacement of names of institutions and healthcare professionals, while ellipses in square brackets [...] indicate omissions of portions of the original statement that do not compromise the meaning of the message. The data were analyzed deductively based on Bardin's (2011) content analysis technique, carried out in the following stages: pre-analysis, with floating reading of the data to identify initial hypotheses and assumptions; exhaustive exploration of the material to perform coding and create context units and their categorization; and data treatment and the inferences necessary for the study (Minayo, 2010).

Results

Characterization of the participants

The research involved 10 participants aged between 62 and 78 years, who self-identified as white (n=3), black (n=2) and mixed race (n=5), mostly married (n=7) and living with others (n=7). They reported, on average, 14 years of schooling and a monthly income of 3 to 5 minimum wages (n=3) and 5 minimum wages or more (n=3), as shown in Table 1. All were professionally inactive, except for one (P4), who had not yet retired. Regarding religion, they were Catholic (n=6), Evangelical (n=2) and Spiritist (n=1). One preferred not to declare.

Table 1 – Sociodemographic characteristics of the participants

| P | Sex | Age (years) | Marital status | Family arrangement | Education (years) | Monthly income (in MW) |
|----|-----|-------------|----------------|--------------------|-------------------|------------------------|
| P1 | M | 67 | Married | Wife | 22 | 3 to 5 |
| P2 | M | 70 | Married | Wife and daughter | 12 | 3 to 5 |
| P3 | F | 67 | Single | Lives alone | 16 | 1 to 3 |
| P4 | M | 71 | Married | Wife | 12 | No income |
| P5 | M | 78 | Divorced | Lives alone | 16 | 5 or more |
| P6 | M | 62 | Married | Wife and daughter | 11 | 1 to 3 |
| P7 | M | 77 | Married | Wife | 12 | 5 or more |

| | | | | | | |
|-----|---|----|---------|----------------------------|----|-------------|
| P8 | F | 73 | Widow | Daughter and granddaughter | 11 | 5 or more |
| P9 | M | 64 | Married | Wife | 8 | 3 or 5 |
| P10 | M | 77 | Married | Wife | 16 | No response |

Source: prepared by the authors, 2025.

Legend: F – female; M – male; P – participant; MW – minimum wages.

Participants reported having, in addition to PD, up to 10 other comorbidities (mean = 2.9), highlighting: hypertension (n=4), gastritis (n=3), depression (n=3), and urinary incontinence (n=3). They were treated only in public services (n=6) and in both public and private services (n=4). Regarding self-reported health perception, they classified it as very good (n=1), good (n=3), neither bad nor good (n=4), and bad (n=2). In relation to self-reported quality of life, the assessment was very good (n=1), good (n=5), and neither bad nor good (n=4), as shown in Table 2. Only one reported hospitalization in the last year. All were in a mild to moderate stage of the disease, according to the modified Hoehn & Yahr scale.

Table 2 – Health/disease characteristics and quality of life of the participants

| P | Quality of life | Health assessment | Health service | Self-reported illnesses |
|-----|------------------------|------------------------|--------------------|---|
| P1 | Neither poor nor good; | Poor | Public and private | Gastritis, depression, urinary incontinence, and gastroesophageal reflux. |
| P2 | Good | Neither poor nor good; | Public | Colonic lipoma |
| P3 | Good | Very good | Public | Did not refer |
| P4 | Good | Poor | Public | Osteoarthritis, diabetes mellitus, hypertension, fecal and urinary incontinence, gastritis, asthma, panic disorder, Tourette syndrome, and atopic dermatitis. |
| P5 | Good | Good | Public and private | Heart problems, cataracts, and hypertension. |
| P6 | Good | Neither poor nor good; | Public | DM and hypertension |
| P7 | Neither poor nor good; | Neither poor nor good; | Public and private | Heart problems and depression |
| P8 | Neither poor nor good; | Good | Public and private | Depression and anxiety |
| P9 | Very good | Good | Public | Hypertension |
| P10 | Neither poor nor good; | Neither poor nor good; | Public | Arthritis, gastritis, urinary incontinence, and benign prostatic hyperplasia. |

Source: prepared by the authors, 2025.

Legend: DM – Diabetes mellitus; P – participant.

Based on the analysis of the interviews and in accordance with the Occupational Therapy Practice Framework – Domain and Process (Gomes, 2021), three thematic categories emerged: a central theme, "health management performance," and two sub-themes, "barriers" and "facilitators" (Figure 1).

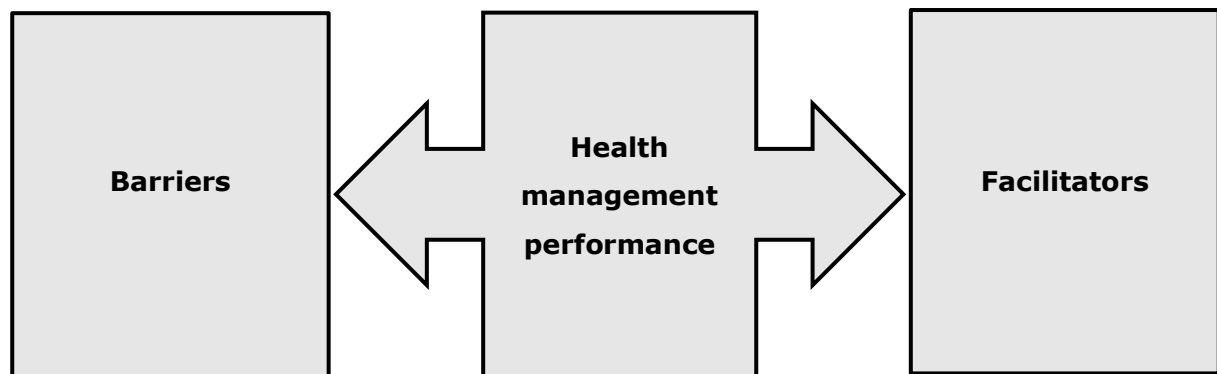


Figure 1: Thematic map representing the relationship between the overall theme and the sub-themes.

Source: prepared by the authors, 2025.

Performance in health management

This topic concerns how participants have been performing health management activities. No difficulties were reported in managing personal care devices, such as eyeglasses, orthotics, prosthetics, hearing aids, and other devices for checking health parameters.

The activity indicated as most difficult to perform was nutritional management, which involves adhering to and implementing recommendations on nutrition and hydration, as well as preparing meals to meet their health goals. The difficulty in maintaining hydration outside the home was linked to possible urinary emergencies.

I've been eating vegetables, but not greens, because I'm afraid of choking [...] I feel shaky when I cook [...] I'm very afraid of the stove. (P8)

At home I drink a lot of fluids, but not when I'm out, because I'm afraid I won't have time to go to the bathroom. (P9)

I drink little water because of a bladder problem. I drink little water when I go out so I don't have to go to the bathroom in the street. I don't eat vitamin tablets [...] I'm afraid of choking. (P10)

This restriction is not always exclusively related to Parkinson's disease and may originate from a history of lack of adherence to healthy habits in daily life.

The restriction that exists [...] is habit. The habit of eating bread in the morning, of eating a sweet... (P1)

It's laziness to eat... At home we have everything: vitamins, fruits, vegetables, greens... (P2)

In health management activities, such as managing the condition and symptoms, promoting and maintaining social health, and engaging in physical activities, participants reported difficulties related to both external issues (accessibility and characteristics of the community environment) and PD symptoms (tremor, rigidity, postural instability, bradykinesia, freezing, fatigue, and pain). Slowness in movements and, consequently, in activities, was a major highlight in the participants' accounts.

I know that some pains are due to stiffness [...] This is from Parkinson's. [...] I can no longer carry weight like I used to, I can no longer walk like I used to. I get tired very easily. [...] When I have pain, I have to stop what I'm doing. [...] I feel like I'm losing vitality. These things tire me more today than they used to. [...] I've lost the synchronicity of my movements. (P1)

It's... it doesn't have that development, it's slower, a bit shaky, a bit difficult. (P2)

The problem related to Parkinson's is the relationship between time and space. I'm much slower. (P4)

I haven't been walking outside as much, because as I walk, my stride gets shorter. If I push it, my hip hurts a lot [...] I don't have that speed anymore. I go slower, it freezes up [...]. This problem is like a car: you keep putting in gas to make it work [referring to medications], but when it runs out [the medication effect], it stops. (P6)

Parkinson's has made me move more slowly, it makes me more attentive to movement. My hand trembles at rest. [...] my speed has certainly changed. (P7)

Sometimes it's tiring. I arrive discouraged. You have to have a lot of willpower [...] there are days when I walk well, there are days when I'm tired. Halfway there, I'm already tired, I have to take a taxi. (P10)

These accounts illustrate how the presence of signs and symptoms of Parkinson's disease can lead to changes in previous routines, requiring, for example, interruptions in tasks, slower execution of activities, or reliance on alternative transportation. This impacts health management. Furthermore, some patients recognize that Parkinson's disease is progressing, impacting their involvement in activities that promote and maintain socio-emotional health.

Exchanging ideas, you understand, nowadays, that's very difficult. (P4)

I don't know if I'm capable of taking a very long bus trip. Taking a long trip is a barrier [...] I haven't been to the cinema. Once in a while, once a month, I go. (P10)

Despite this, regarding the management of the condition and symptoms, some participants mentioned strategies to minimize the impact of motor symptoms, fatigue, and pain.

When I'm in pain, I stop. When I'm tired, I rest. [...] do it slower... do a little bit each day, do a little less. These are things we modify in our daily lives. (P1)

I can cope with the illness. [...] Doing water aerobics, walking, watching television, going for a stroll... one thing at a time. I have physiotherapy twice a day... (P2)

It only gets better if I rest, if I finish lunch and lie down until 4 or 5 pm, then I feel calm. (P6)

I become more careful when I have an obstacle in front of me. I wasn't worried about speed. You need to slow down so you don't trip. If I used to run, now I have to start walking. I try to see [regarding the pain] how I adjust myself, I try changing sides, for example, I look for medication. (P7)

I use my other arm to reduce the tremor, when there is one. (P9)

There's tiredness, but it's lighter. I try to take a break, I try to sit down and rest. (P10)

These strategies reveal attempts to adapt to and preserve occupational performance in the face of changes resulting from the illness. Some of these strategies were learned by the participants throughout the treatment process.

Sometimes situations are accompanied by pain. I already know what to do, what exercise to do, how to prevent it. (P1)

When I have a constant pain, I try to do some activity. I do some exercises that I've learned throughout my life and the pain goes away. (P5)

When I wake up in the morning, I have more difficulty, it's not just because of the pain. You try to get out of bed and you start to slip. Then you have to lift your foot as if you were climbing a step. (P6)

I stretch, sigh deeply, release slowly and it relieves the pain. (P9)

The practice of physical activity as a health management activity was expressed in the participants' statements as routine.

In-person and distance physiotherapy, in addition to the Municipal Health Department's gymnastics program that takes place in the parks. I do it, it's very good, the teacher is nice. (P1)

Water aerobics two days a week, walking every day and physiotherapy twice a week, Tuesdays and Thursdays. (P2)

Three to four times a week. GEDOPA once a week. I just started a hydrotherapy project, three times a week. (P3)

I go cycling, resistance band exercises. I do physiotherapy with great pleasure, in the pool and walking. (P4)

Practically daily, walking and physiotherapy [...] currently, I have been taking senior dance classes. (P5)

I walk sometimes. The frequency in the week is two or three times. I do it here and at [a rehabilitation center]. (P6)

I was invited to come here. I was very happy and I'm also trying to join the gym. (P8)

These accounts illustrate how physical activity becomes a vital part of the participants' health management. However, it is crucial to recognize that performance in health management activities can be influenced by several factors, both negative and positive, topics that will be addressed below as barriers and facilitators, respectively.

Barriers

This topic concerns physical, social, and attitudinal barriers, which involve the following themes: changes in the community environment, urban accessibility, lack of access to or distance from health services, and lack of medication. The following excerpt mentions how a change in the community environment can influence the practice of physical activities.

The mayor took away the place where I did gymnastics, dancing, and stretching. (P8)

Regarding the lack of urban accessibility, according to the participants, physical barriers influence mobility.

There are usually no seats on the subway. I try to hold onto those bars. Depending on the seat, I refuse to, because I can't get up afterwards [...] I don't like asking for help to get up. I have to be extremely careful along the way because of the obstacles. (P1)

Participants also highlighted the difficulty in accessing health services, due to distance and the difficulty in scheduling appointments with some specialists, as well as the lack of medication.

The medicine is out of stock. Right now, Prolopa isn't available at the public pharmacy [...] I bought a month's supply. I paid a lot, but I prefer to use it when it's out of stock. (P1)

If you need a doctor, you have to plan ahead. Appointments are scheduled in distant, hard-to-reach places. (P2)

The barrier is the lack of availability of the medication at public pharmacies [...] I take Prolopa BD, which isn't available at the health center. They give me another one, but I have to keep breaking the pill in half. (P6)

It's not always available to schedule an appointment. If I need to schedule a cardiologist appointment in 2 or 3 months, I'll already be heartless. (P7)

The pharmacy is making it difficult because the demand is so high that they ask my wife to bring my ID. I already went to the notary to get a power of attorney, but she has to carry my ID. (P10)

These accounts demonstrate that factors related to the organization and availability of health services can compromise the continuity of care, as pointed out in the account below:

My gastroenterologist is in Copacabana, my urologist in Irajá, another one in Barra da Tijuca. It's impossible for this group to communicate [...] because my urological problem is from Parkinson's, so the urologist should talk to the neurologist. That doesn't happen. (P1)

Furthermore, aspects related to people's attitudes, including those of professionals, were mentioned.

My social life underwent a radical change after I was diagnosed [with PD]. I tried going to the gym, but the instructors have no idea of the needs that a person with Parkinson's has [...] when I say I have Parkinson's, they usually say I need a certificate from the neurologist clearing me [to practice physical activity]. (P1)

People's tolerance of your situation [with PD] changes. Instead of going out with 10 groups, you end up going out with 5. [The issue] is knowing where you won't hinder the group's performance. (P7)

These statements reveal how the lack of technical and attitudinal preparedness of the social environment can restrict users' participation in activities, contributing to experiences of exclusion and isolation. Despite this, in addition to the identified barriers, participants also highlighted resources, technologies, and family arrangements as facilitators of health management.

Facilitators

This category describes the facilitators of health management activities reported: environmental adaptations and technology resources, adaptation for efficient control of medication use, use of agendas and calendars, and effective communication with doctors, in addition to the support network formed, above all, by family members.

The use of environmental adaptations and technology resources is varied, such as grab bars, in addition to the use of household appliances.

I'm not much of a cook, but I manage. I buy pre-made meals and use the microwave. (P5)

Inside the bathroom, my son installed those grab bars. (P6)

Regarding the use of medications specifically, medication organizers, physical assistance from family members, reminders, and alarm clocks are used.

The wife helps with Prolopa. She uses a small box with markings for the days of the week. (P4)

I try to organize on the computer which medication to take. (P5)

My wife said: "You're trembling a lot, you're taking the wrong medication!" The doctor [name withheld] made a little note and said: "Here, stick it on the refrigerator." The note stays on the refrigerator door and a small container with the day's medication. (P6)

When needed, we always need help... I accept help. I have a cell phone that alarms me at all times and I keep my medications in the box. (P7)

I know the times for my medications. I use technology to remember: alarm at 9 pm. (P9)

In addition, other helpful resources for organizing and planning routines were mentioned, such as the use of agendas and calendars for scheduling appointments and other events.

I put everything in a planner so I can stay organized and not get lost. (P2)

There is a computer program that times the tasks you have to do. It identifies the task and how much time you need. (P4)

I use the computer and I have my planner. (P5)

My wife has a spreadsheet with the appointment times with the neurologist, cardiologist, and exams that were already arranged and scheduled. (P7)

I use a planner. (P10)

Regarding support for attending appointments, assistance from family and private transportation were mentioned.

I have transportation for a companion. (P6)

My daughter doesn't let me go to appointments alone. If I have to take public transport, she picks me up. (P8)

For long trips, I go with my wife. (P9)

Another aspect mentioned by the participants was the ease of communication with the healthcare professionals who care for them or with medical assistance services:

I talk to the doctor [name withheld], especially when the medication isn't working. (P6)

I send messages in the [instant messaging group with patients and professionals at] GEDOPA. I can [also] call to schedule [an appointment with my] private doctor. (P7)

Furthermore, participants cited the importance of family support for encouragement, supervision, and minimal physical assistance as a facilitator in health management, especially in relation to nutritional management.

I get encouragement from my daughter, who is a nutritionist... (P2)

My wife said: "You have to buy fruit!" [...] my wife tells me that I need to eat more vegetables... (P6)

I always have frozen food. My family makes lunch boxes and leaves them in the freezer. (P8)

In addition to the family support network, another form of care mentioned was the company of friends and people from the community, especially for physical activities and the promotion and maintenance of socio-emotional health.

I'm taking a Theology course, I go to church, I have dear friends. Every now and then, we go out, have a snack, a coffee, and chat. (P5)

I like to keep in touch with people. I go to the gym, I do weight training... Every now and then, I go to a music event. (P10)

These reports illustrate how health management is facilitated by multiple resources: technological and organizational strategies (mobile phones, alarm clocks, planners, spreadsheets), family support for medication management, accompaniment to medical appointments and organization of the household routine, as well as support from health professionals (guidance, clarification of doubts, continuous follow-up) and the community network (companionship in physical and social activities).

Discussion

The health management occupation of people with PD may undergo changes due to motor, process, and social interaction demands, performance patterns — such as habits and routines —, and the individuals' own client and contextual factors (Gomes *et al.*, 2021). Furthermore, the potential impact on activities of varying levels of complexity may progress with the evolution of the disease (Foster *et al.*, 2014; Murdock *et al.*, 2015; Silva & Carvalho, 2019). These findings point to the need for occupational therapists to use integrated, client-centered, and evidence-based approaches in PD (Welsby *et al.*, 2019), given that health management requires interventions that integrate performance components and meaningful activities.

In the area of nutritional management, difficulties are not limited to voluntary lack of adherence to healthy habits, but also include motor impairment, which may be present even in early stages and compromise activities such as shopping, food preparation, and consumption, affecting the adoption of a healthier diet (Sheard *et al.*, 2013). In view of the identified difficulties, occupational therapists can implement compensatory strategies and task modification, in addition to prescribing assistive technology. The approach may involve training in instrumental activities of daily living related to food preparation, with adaptations that minimize risks, such as the use of a microwave instead of a conventional stove (Oliveira *et al.*, 2024). In addition, educating patients and family members about compensation strategies and establishing structured routines for hydration and meals are essential in this area.

In other health management activities, such as condition and symptom management, participants reported the impact of motor symptoms, such as tremor, rigidity, postural instability, bradykinesia, and freezing. Rigidity, postural instability, and gait alterations were identified as factors influencing performance and safety in carrying out activities inside and outside the home. This finding is consistent with the literature, which associates these symptoms with an increased risk of falls (Mammen *et al.*, 2023), especially in older adults, such as the participants in this study.

Bradykinesia, characterized by slowness in the execution of movements and, consequently, activities, was emphasized by the participants. Even in the early stages of the disease, Morel *et al.* (2022) describe this "functional slowness" as a condition in which individuals are able to complete tasks, but with significantly longer time. This condition requires greater planning and organization of activities, since actions previously performed with agility now require more time and dedication. Such circumstances may generate frustration, in addition to compromising self-esteem and quality of life for these individuals (Morel *et al.*, 2022).

It should be noted, however, that all participants reported regular engagement in physical activity, a crucial element for maximizing functionality and preventing falls (Orcioli-Silva *et al.*, 2014; Bouça-Rev. Interinst. Bras. Ter. Ocup., 10, 3749 - 3767, 2026.

Machado *et al.*, 2022). Additionally, performing structured physical exercise by older adults with PD not only enhances the ability to carry out daily activities, but also contributes to improvements in quality of life (Orcioli-Silva *et al.*, 2014).

In addition to the motor symptoms mentioned above, participants also reported pain and fatigue, which are frequently reported in PD (Nassif & Pereira, 2022). Pain may be primary — present already at the onset of the disease — or secondary, presenting with greater frequency and intensity as muscle rigidity worsens and postural abnormalities are present (Valkovic *et al.*, 2015). In the present study, participants identified pain as the main cause of impact on performance in condition and symptom management, which reinforces the evidence that it is a distressing symptom that directly affects quality of life (Valkovic *et al.*, 2015).

Additionally, fatigue — defined as an abnormal, oppressive, and exhausting sensation of tiredness — represents a highly prevalent non-motor symptom in PD, with a negative impact on quality of life (Nassif & Pereira, 2022). Therefore, both pain and fatigue should be carefully considered in the assessment of performance of older adults with PD, with a view to strategies that optimize their participation in health management without intensifying the occurrence of debilitating symptoms.

Other non-motor changes, such as urinary incontinence, were mentioned by participants. Urogenital symptoms cause discomfort and may generate difficulties in performing activities (Bonnet *et al.*, 2012). Participants mentioned difficulties with adequate fluid intake, a factor that may limit older adults' ability to remain in external activities for prolonged periods. This alteration often compromises performance in health management, especially in aspects related to social promotion and maintenance. In this context, the impact of non-motor symptoms on health, functionality, and quality of life of people with PD is evident (Munhoz *et al.*, 2015).

The management of motor and non-motor symptoms in health management also requires a combination of intervention strategies by occupational therapists. Sadural *et al.* (2022) highlight the importance of multimodal interventions that integrate education, skills training, and environmental modification. In the context of this study, the implementation of energy conservation programs for fatigue management, relaxation techniques for pain control, and the use of cues to minimize freezing episodes during health management activities, such as traveling to medical appointments, are recommended. Non-immersive virtual reality, which has shown positive results for people with PD (Oliveira *et al.*, 2024), can be incorporated as a therapeutic resource for training motor components required for health management, such as manual dexterity for medication management and mobility for access to health services.

Moreover, the difficulties identified in health management performance point to the need for comprehensive assessments that consider all dimensions of this occupation, in addition to the analysis of contextual factors — personal and environmental — that function as barriers or facilitators, allowing the planning of individualized, goal-oriented interventions at any stage of the disease, with the aim of optimizing participation in health management throughout the progression of PD (Welsby *et al.*, 2019; Bouça-Machado *et al.*, 2022).

It should also be considered that the number of self-reported diseases among participants was above the national average, which is 1.8 chronic diseases and higher among women, with 2.4 diseases (Camarano, 2021). Morbidity is related to poorer perceived quality of life and the presence of disabilities in usual activities (Mammen *et al.*, 2023). This coexistence of multiple chronic conditions among participants with PD may increase the complexity of health management, as it requires the simultaneous management of multiple medications, monitoring of vital parameters and dietary plans, and consultations with different specialists. Thus, occupational therapists should assess not only the isolated impact of PD, but also the interaction between multiple morbidities on occupational performance to establish priorities (Sadural *et al.*, 2022).

Regarding barriers, participants mainly highlighted physical ones, such as lack of accessibility in external spaces and transportation systems, which are fundamental aspects for access to health services and participation in social and leisure activities. However, this issue goes beyond the physical dimension and also constitutes a social barrier, as the literature highlights the scarcity of health services for people with PD (Zaman, Ghahari & McColl, 2021). This, in turn, may compromise effective access to health maintenance activities.

It is also observed that the lack of access to medication, likewise reported, may impact treatment continuity and disease progression (Jenner, 2015). Access to diagnosis and medication prescription may be dependent on the availability of medical specialists, as well as on professionals' knowledge and practice (Gil *et al.*, 2024). In addition, lack of adherence may be affected by communication with health professionals and understanding of the treatment (Gil *et al.*, 2024). Participants mentioned that the distance required to attend follow-up appointments makes medication management difficult, which points to the fact that one activity within the health management occupation may influence performance in others.

Regarding the social barrier, the lack of investment in health actions for this population stands out. With the growth of the older population, public policies aimed at this group should emphasize health promotion and maintenance, foster autonomy, and strengthen social support networks that generate impacts on the various ways of providing care to the older population and, in particular, to older adults with PD (Silva & Carvalho, 2019). By understanding that the disease may compromise physical and cognitive abilities (Silva & Carvalho, 2019), preventing new barriers and providing greater access to health services and other spaces that may optimize engagement in occupations for people with PD are possible long-term coping strategies for the disease.

Furthermore, investment is needed to break down stigma, prejudice, and discrimination against people with the disease, as this factor was identified in the study. These feelings may significantly interfere with the daily lives of people with PD and their families, with negative consequences for functional status and for the promotion of well-being and quality health (Silva & Carvalho, 2019). Thus, reducing stigma and the limitations imposed by the disease may be favored by strengthening professional competencies for health management and guidance, in addition to encouraging educational actions that promote the sharing of information among patients, caregivers, and professionals (Silva & Carvalho, 2019; Geerlings *et al.*, 2022; Foster *et al.*, 2014).

Moreover, to minimize the identified barriers, occupational therapists should include, in their interventions, education of people with PD about their rights. In this sense, Sadural et al. (2022) emphasize the need for interventions that consider the social determinants of health and the care context of people with PD. Additionally, health education groups focused on self-management strategies have proven increasingly effective (Welsby *et al.*, 2019).

Conversely, in addition to the barriers mentioned by participants, several facilitators in medication management were identified, such as physical assistance from family members and the use of reminders, medication organizers, and alarms. Furthermore, participants reported various strategies to improve their performance in health management, including devices to remember appointments. From this perspective, environmental adaptation and the implementation of technologies can enhance functionality and promote participation in family and social contexts (Foster *et al.*, 2014).

Given the chronicity and progression of the disease, another facilitator cited in the present study was the role of family and friends, both for instrumental support — assistance in performing activities — and emotional support — listening and encouragement. The informal support network, especially formed by family members, constitutes the primary care group for people with PD and is essential to support coping with the difficulties imposed by the disease (Geerlings *et al.*, 2022).

The facilitators identified in this study provide direction for the clinical practice of occupational therapists. The use of assistive technology — from simple devices such as pill organizers and alarms, to more complex resources such as health management applications — should be incorporated into interventions. Oliveira *et al.* (2024) identified that adaptations and technological resources constitute specific categories of intervention in PD, which reinforces the importance of these elements. Furthermore, the central role of the family support network highlights the need for occupational therapists to include caregivers and family members in the therapeutic process as partners in promoting autonomy, independence, and safety for the person with PD (Welsby *et al.*, 2019).

Finally, it is worth noting that facilitators go beyond everyday resources and strategies. Empathy, understanding of difficulties and capabilities, and functional and psychosocial support are essential in the process of adapting to the various stages of the disease (Bermejo *et al.*, 2020).

This study was not without limitations. Participants in the present research, composed of older adults with PD, presented higher levels of education and income compared with the national average of the older population (Sousa *et al.*, 2021). In addition, data collection in a specialized reference service may have selected a sample with greater access to multidisciplinary care, which may not represent the reality of people with PD assisted exclusively in primary care or in regions with more limited service availability.

Conclusion

The present study achieved its objective of analyzing the perception of older adults with PD regarding their performance in the occupation of health management. It was identified that there are varied changes in the performance of this occupation. In this sense, it is necessary to optimize participation by reducing or eliminating barriers and investing in the proposition of facilitators.

The main barriers identified were the lack of accessibility in external spaces, lack of medication, and lack of investment in health actions. In contrast, the facilitators mentioned involved the use of technology, environmental adaptations, and other assistive technology resources, as well as effective communication with the team and the support network formed primarily by family members.

Occupations are carried out within a life context and are intertwined with activities from different occupations. Thus, the importance of investing in the understanding of this emerging topic of health management, both theoretically and practically, is emphasized. It is expected that the present study will contribute to research that addresses health management performance in people with PD, especially older adults, with different levels of functionality and care contexts.

It is noted that, as a contemporary topic, there is still a shortage of studies to support practices and research related to health management. It is suggested that more qualitative studies — such as the present one — and also quantitative studies be conducted on this topic, especially longitudinal ones, to monitor changes throughout the disease process. This may improve the information available to society and health professionals regarding how health management performance occurs in older adults with PD at all stages of the disease. In addition, the importance of investigating how other variables (for example, quality of life) are related to health management in older adults with PD is highlighted. Such investigation may provide a more comprehensive understanding of the interactions among different factors and allow the identification of critical areas requiring intervention, enabling the formulation of more effective strategies to improve health management performance.

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