



The psychosocial dimension of Parkinson's: A phenomenological study on patient experiences

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Abstract

Background The aim of this study is to evaluate the psychosocial dimension of Parkinson's disease and the life experiences of patients with a phenomenological approach.

Methods In this phenomenological study, semi-structured in-depth interviews were conducted with 20 Parkinson's patients who applied to the neurology outpatient clinic of a state hospital in a province in southern Turkey. Criterion sampling method, one of the purposive sampling methods, was used to reach the sample group. Interviews continued until data saturation was achieved. All interviews were recorded on a voice recorder after obtaining the necessary permissions from the patients and then transcribed. The data of the study were evaluated using thematic analysis. The study was conducted and reported according to the COREQ checklist.

Results Data analysis revealed three main themes (metaphors for Parkinson's disease, effects of Parkinson's disease, symptom management and psychosocial needs in Parkinson's disease) and eight sub-themes (metaphors for physical effects, metaphors for mental effects, metaphors for social effects, mental, physical, social, symptom management and psychosocial needs).

Conclusions As a result of this study, it was determined that Parkinson's disease negatively affects patients psychosocially and they have difficulty in coping. It is recommended to implement research and application centers for Parkinson's patients with a focus on psychosocial support and to carry out awareness and awareness-raising studies on Parkinson's disease. Studies on this subject are very limited and it is recommended that large-scale studies on psychosocial problems in individuals with Parkinson's disease be conducted in the future.

Keywords Parkinson's · Psychosocial dimension · Phenomenological study

Introduction

Parkinson's disease is a chronic, progressive, neurodegenerative disorder characterized by motor and non-motor symptoms. These symptoms have a serious impact on the

quality of life of patients, which highlights the importance of the treatment process. While the motor symptoms of Parkinson's disease usually cause difficulties with movements, non-motor symptoms are more widespread and affect many body systems (Saini et al., 2024; Still et al., 2024; Rawls &

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Okun, 2025). The most common motor symptoms of Parkinson's are the presence of bradykinesia, resting tremor, rigidity and loss of postural reflexes; non-motor symptoms include neuropsychiatric symptoms (depression, anxiety, apathy, hallucinations, delusions, impulse control disorders), sleep disorders (REM sleep behavior disorder, excessive daytime sleepiness, restless leg syndrome, insomnia), fatigue (central and peripheral fatigue); sensory symptoms (pain, olfactory impairment, hyposmia, visual impairment), autonomic dysfunction (bladder dysfunction (urgency, frequent urination, nocturia), sexual dysfunction, sweating abnormalities, orthostatic hypotension) and gastrointestinal symptoms (salivary dribbling, dysphagia, agusia, constipation, nausea, vomiting) (Shalash et al., 2020; Sveinbjornsdottir, 2016; Tibar et al., 2018; Tran et al., 2021; Váradi, 2020; van der Meer et al., 2025). The frequency and severity of disease-related symptoms increase over time. Initially mild symptoms become more pronounced over the years. Although the progression of Parkinson's disease varies in each individual, patients have more difficulty in performing activities of daily living in the later stages. Genetic, environmental and treatment response factors are key determinants of disease course and management. (Ball et al., 2019; Pang et al., 2019).

Parkinson's disease is associated not only with motor symptoms but also with serious psychosocial problems. Psychological symptoms and mood swings in Parkinson's patients are intertwined with cognitive and physical problems (Sjödahl Hammarlund et al., 2018). Factors such as lower quality of life, higher disability, earlier onset of the disease and shorter disease duration are important determinants of psychosocial difficulties (Schiavolin et al., 2017). Psychosocial problems such as fatigue, anxiety, depression, demoralization, hopelessness, pessimism, feelings of loss, changes in roles, relationships and self-concept, worries about the future and social isolation are common among people with Parkinson's disease (Ahn et al., 2022; Koszycki et al., 2022; Schiavolin et al., 2017; Sjödahl Hammarlund et al., 2018; Valcarengi et al., 2018). These problems cause some people with Parkinson's disease to have dark and destructive thoughts and even deliberately consider ending their lives (Sjödahl Hammarlund et al., 2018). The young-onset form of Parkinson's disease makes the psychosocial difficulties experienced by patients even more pronounced (Stephenson et al., 2023). One study found that younger-onset Parkinson's patients experienced more frequent job loss, disruption of family life, greater perceived stigma and depression than older-onset patients (Schrage et al., 2003).

Individuals with Parkinson's disease struggle to manage the demands of daily life (Sjödahl Hammarlund et al., 2018). Individuals with Parkinson's disease develop different strategies to cope with the disease. The severity of the disease,

available treatment options, physical and psychological symptoms, complications of the disease, and personal characteristics affect individuals' coping strategies (Liebermann et al., 2020; Prins et al., 2023). These patients cope with the disease through various strategies such as engaging in social activities (exercise, walking, poetry, dancing, painting), seeking social support, maintaining life satisfaction, focusing on the present, avoiding unexpected challenges, and preserving their independence. (Ambrosio et al., 2019; Haahr et al., 2021; Kalyani et al., 2020; Senter et al., 2024). People with Parkinson's disease try to maintain their normal life and self before the disease with different coping strategies (Haahr et al., 2021). Understanding the psychosocial status of individuals with Parkinson's disease by their families, friends and health professionals has an important place in their treatment process (Zarotti et al., 2021). Health professionals' adopting a holistic approach in the treatment of Parkinson's disease by taking into account not only the physical symptoms but also the psychosocial symptoms of Parkinson's patients can help them maintain their daily life activities and improve their quality of life. In this context, the aim of this study is to evaluate the psychosocial dimension of Parkinson's disease and the life experiences of patients with a phenomenological approach.

Method

Throughout this study, the authors followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) and reported accordingly (Appendix 1).

Study design and setting

This qualitative study was conducted between June and August 2024 using a descriptive phenomenological design. Phenomenological design aims to understand a phenomenon by exploring it from the perspective of people who have experienced it (Neubauer et al., 2019). This design allows for a phenomenological approach to assess the psychosocial dimension of Parkinson's disease and the life experiences of patients.

In determining the hospital where the research will be conducted, the fact that Adana province is one of the provinces located in the south of Turkey, the province with the highest population in the southern region, the accessibility of the researcher and the cooperation of the team with the researcher were taken into consideration.

Study participants

Criterion sampling method, which is one of the purposeful sampling methods, was used to determine the study group of

the research. Criterion sampling is the sampling of people, events, objects or situations that have the qualities determined for the problem (Başkaya & Demir, 2023; Nyimbili & Nyimbili, 2024). Semi-structured in-depth interviews were conducted with 20 Parkinson's patients who applied to the neurology outpatient clinic of a state hospital in a province in southern Turkey. Interviews were continued until the data were repeated and ended when data saturation was reached by interviewing 20 individuals.

Inclusion criteria

- Having Parkinson's disease for at least five years.
- Being open to communication,
- Voluntary participation in the research.

Exclusion criteria

Having a language, speech or hearing impairment that prevents communication.

Data collection

A semi-structured open-ended interview guide was used to collect data. The interview guide was prepared by the researchers based on the literature review and in line with the purpose of the study. In the interviews, patients were asked to describe their thoughts about the situations experienced by Parkinson's patients. The interview consists of two parts. The first section includes questions such as age, gender and how long the individual has had Parkinson's disease. The second part includes basic open-ended questions.

In order to ensure the content and face validity of the interview guide, the opinions of 3 faculty members specialized in neurology, mental health nursing and internal medicine nursing were obtained. The interview guide was finalized in line with the expert opinions (Table 1). The interview guide was prepared in Turkish and all interviews with the patients were conducted in Turkish.

Table 1 Questions in the semi-structured interview form

1.	What does the word Parkinson's mean to you?
2.	What are the effects of Parkinson's on the health of individuals? (What are the effects mentally, physically and socially?). What are your experiences?
3.	Do you think you are coping effectively with Parkinson's? What are your sources of support in this process? What are your experiences in this regard?
4.	What symptoms do you experience? What do you do to cope with these symptoms? What are your experiences in this regard?
5.	What are your psychosocial needs?

A pilot study was conducted with four patients diagnosed with Parkinson's disease in order to improve the comprehensibility and applicability of the data collection forms and the ability to obtain data appropriate to the research questions and to improve and standardize the interview skills of the researcher. As a result of the pilot study, no changes were required in the questions. However, due to the standardization of the interview, the patients included in the pilot study were excluded from the main study.

Study procedure

All potential participants were informed about the purpose and procedure of the study through announcements by the neurology physician one week before the interviews started. Those who met the study criteria were asked to read an information sheet and sign a consent form. The third researcher conducted all interviews after scheduling face-to-face interviews that were feasible for both the interviewer and the interviewee in private rooms in the outpatient department of the hospital. Each interview was conducted in Turkish, lasted 25–30 min and was recorded.

Data analysis

All interviews were transcribed by the third researcher and triangulation was checked by the other researchers. Thematic analysis was used to analyze the data. To do this, each transcript was read by the other researchers to find the most frequently repeated sentences in each interview. Codes were identified using a codebook and sub-themes were identified by combining similar codes; common themes were identified by combining similar sub-themes (Green et al., 2007). If the codes identified were not similar, a discussion was held between the two coders to resolve the difference.

Study rigor

In a qualitative study, it is important to ensure rigor and reliability. In this study, reliability is based on four criteria: credibility, dependency, verifiability and transferability (Cypress, 2017; Forero et al., 2018). For credibility, all participants were informed about the purpose and study procedure verbally and using an information sheet before inclusion in the study. All participants were asked to sign a consent form. Interviews were conducted at a time and place convenient for both the interviewer and the interviewees. The third researcher had basic knowledge about the conduct of the interview and data collection.

The interview tool was piloted before it was applied in the interview. All interviews were recorded with a digital recorder and transcribed on the day of the interview. For reliability, the

transcriptions were re-read to correct all possible errors. Two independent coders read all transcripts and separately identified codes and discussed differences. For verifiability, all researchers discussed and validated the identified codes, themes and sub-themes. Transcription was done using purposive sampling and continuing the interviews until data saturation was reached.

Institutional permission to conduct the interview was obtained from the selected public hospital. All participants were informed about the purpose and objectives of the study, possible benefits or harms, and their right to participate in the study using an information form. Those who met the study criteria were asked to sign the consent form. The information sheet and consent form were provided to the participants in Turkish. They were informed that participation in the study was completely voluntary and that they could terminate their participation at any stage. Participants were kept anonymous and all information was kept confidential (Moser & Korstjens, 2018; Saunders et al., 2018).

Research team and reflexivity

All three members of the research team work as active faculty members in nursing schools. One of the researchers also works as a specialized neurology physician in the state hospital where the interviews were conducted. One of the researchers has a PhD in psychiatric nursing and two in internal medicine nursing. All three researchers had experience working as clinical nurses in hospitals and received training in qualitative research methods. All four researchers have experience in qualitative interviewing and have qualitative studies in international journals.

Ethical considerations

This research was approved by the X University Scientific Research and Publication Ethics Committee (dated: 22.04.2023, numbered: E-95674917-108.99.99-248309). Written informed consent was obtained from the participants before starting the interview. Verbal informed consent was also obtained again at the beginning of the interview. Recordings and transcripts were stored on a password-protected device. The study was conducted in accordance with the Declaration of Helsinki and the ethical standards of the National Research Committee.

Results

Fourteen of the individuals included in the study were male and the average age was 66.80 ± 14.27 . Eighteen of the participants were married. Eighteen of the participants were

married. Table 2 presents the sociodemographic and clinical characteristics of the participants (Table 2).

Table 3 presents the themes, sub-themes, and codes identified through data analysis. (Tables 3).

Theme 1. Metaphors for Parkinson's

Sub-theme 1. Metaphors for physical effects

As a result of the interviews with the patients, it was determined that Parkinson's disease made individuals think of metaphors such as pain, problems with balance and tremors.

"When I think of Parkinson's, I think of tremors and decreased movement..." (P8).

"I tremble a lot all the time, my hands tremble a lot, that's what I know, that's what comes to my mind." (P10).

Sub-theme 2. Metaphors for spiritual effects

As a result of the interviews, patients expressed metaphors such as anxiety, depression and feelings of helplessness when they think of Parkinson's.

"I think Parkinson's means that your psychology deteriorates and becomes bad." (P11).

"Parkinson's means being dependent on others after a while, being alone..." (P14).

Sub-theme 3. Metaphors for social effects

As a result of the analyzes, it was determined that the patients also had social difficulties and some patients did not want to eat in the presence of people.

"Parkinson's is not picking up anything when people are around me, not going out much (P12).

"Lonely is not wanting to go out, not wanting to be alone at all and being a burden on people after a while, unfortunately Parkinson's..." (P9).

Theme 2. Effects of the disease

Sub-theme 1. Physical

As a result of the analysis, patients experience various difficulties such as tremors, impaired balance, urinary incontinence, problems with walking, and impaired speech.

Table 2 Distribution of the participants' sociodemographic and clinical characteristics

Participant number	Age	Gender	Education Status	Marital status	Comorbid disease	Year of diagnosis
P1	47	Male	University	Single	-	6 years
P2	55	Woman	Middle School	Married	Hypertension Type 2 Diabetes mellitus	5 years
P3	73	Woman	Primary School	Married	Hypertension	7 years
P4	62	Male	Middle School	Married	Hypertension	10 years
P5	82	Male	Illiterate	Married	Heart failure	5 years
P6	85	Male	Primary School	Married	Hypertension Heart failure Type 2 Diabetes mellitus	10 years
P7	66	Kadin	Primary School	Married	Type 2 Diabetes mellitus	12 years
P8	62	Male	Primary School	Single	Type 2 Diabetes mellitus Heart failure	5 years
P9	48	Male	Primary School	Married	Type 2 Diabetes mellitus Hypertension	5 years
P10	78	Male	Illiterate	Married	Heart disease	4 years
P11	81	Woman	Primary School	Married	Type 2 Diabetes mellitus	6 years
P12	68	Male	Primary School	Married	Type 2 Diabetes mellitus	6 years
P13	69	Male	Middle School	Married	Type 2 Diabetes mellitus Hypertension	5 years
P14	70	Woman	Illiterate	Married	-	5 years
P15	82	Male	Primary School	Married	Hypertension Type 2 Diabetes mellitus	5 years
P16	32	Male	Primary School	Married	-	6 years
P17	75	Male	Middle School	Married	Hypertension	6 years
P18	58	Male	High School	Married	Hypertension	13 years
P19	85	Male	Primary School	Married	Hypertension Type 2 Diabetes mellitus Heart failure	10 years
P20	58	Woman	High School	Married	Hypertension	8 years

"Of course, look at the effects, I can't do anything with my hands, now I have difficulty in speaking, I have difficulty walking, I can't stand up without help." (P10).

"I am very stressed and irritable, I am very sleepy, I have slowed down in walking. I am not very balanced. I have difficulty standing, I don't go out much, I am always at home." (P9).

Sub-theme 2. Spiritual

According to the data obtained from the interviews with the patients patients stated that they were highly affected psychologically.

"I have locking in the lower part of my legs, I have difficulty in walking, I cannot speak, I have difficulty in speaking, no one listens to me, I am an angry person lately, I am very troubled (P2).

"I sleep a lot, I have dullness, I am psychologically sluggish, unhappy and hopeless, I don't want to talk to anyone, I have drowsiness." (P4).

Sub-theme 3. Social

According to the data obtained from interviews with patients, patients stated that they were also socially affected and distanced themselves from the society.

"Socially, I started not seeing my friends anymore, I can't say that I am very social after the illness." (P1).

"I became very angry, I am nervous, I tremble a lot even when I talk, I don't want people with me, I am alone, I even came to the hospital alone." (P6).

Theme 3. Symptom management and psychosocial needs in Parkinson's disease

Sub-theme 1. Symptom management

As a result of the analysis, it was determined that patients had difficulty in symptom management and used different coping strategies.

Table 3 Themes, sub-themes, and codes identified through data analysis

Themes	Sub-Themes	Codes
Metaphors for Parkinson's	A. Metaphors for physical effects	A1. Tremor A2. Disruption of movement A3. Chewing/swallowing problems A4. Pain A5. Disease from the brain A6. Difficulty in standing A7. Body swaying movement
	B. Metaphors for spiritual effects	B1. Unhappiness B2. Anxiety B3. Depression B4. Loneliness B5. Despair B6. Uncertainty
	C. Metaphors for social effects	C1. Thinking that you will be dependent on others C2. Disease that reduces quality of life C3. A pity-evoking disease
2. Effects of Parkinson's	A. Physical	A1. Urinary incontinence A2. Hoarseness A3. Tremor A4. Dizziness A5. Balance problems A6. Locking problems in the jaw A7. Difficulty in speaking A8. Fatigue A9. Quitting the job A10. Sleep problems A11. Slurred speech A12. Forgetfulness
	B. Spiritual	B1. Future anxiety B2. Thinking that you will be alone B3. Being aggressive B4. Hopelessness B5. Feeling helpless B6. Hallucination B7. Depression
	C. Social	C1. Distancing from society C2. Introversion C3. Decrease in social activities
3. Symptom management and psychosocial needs in Parkinson's disease	A. Symptom management	A1. Regular medication use A2. Doing sports A3. Distancing from society A4. Use vitamins A5. Praying A6. Receiving psychosocial support from the family
	B. Psychosocial needs	B1. Increased social support from her family B2. Friend/friend support B3. Providing economic support B4. Transportation support to and from the hospital B5. Providing psychological support

"I try to cope, I go to sports 5 days a week, I get up early in the morning and do my sports, I use my medications regularly." (P20).

"I have difficulty coping, I take my medications regularly and pray to God that they work." (P19).

Sub-theme 2. Psychosocial needs

Interviews with patients revealed that they had different psychosocial needs. Patients stated that they expected their families to provide them with social and economic support, transportation support to and from the hospital and psychological support.

"I even came to the hospital alone, but I don't want to be alone, I really need someone to be with me." (P18).

"I really want my friends to come to me and talk to me, I am shaking from the waist down, my legs are cut off, I cannot walk, I am alone, I cannot go anywhere." (P5).

Discussion

The aim of this study is to deeply examine the psychosocial dimension of Parkinson's disease and the life experiences of patients. The psychosocial dimension of Parkinson's and life experiences are discussed in three categories.

In this study, it was found that Parkinson's disease made individuals think of physical metaphors such as pain, problems with balance, tremors, chewing/swallowing problems; emotional metaphors such as anxiety, depression and helplessness; and social metaphors such as thinking that they would be dependent on others, feeling pity, and not wanting to eat around people. In Parkinson's patients, cognitive and physical problems are reported to be intertwined with psychological symptoms and mood swings. These patients are often depressed, downhearted and worried about the future. Some have dark and destructive thoughts and contemplate deliberately ending their lives (Sjödahl Hammarlund et al., 2018). The inherent symptoms of Parkinson's disease, such as visible tremors and rigidity, can lead to stigmatization and discrediting of the individual by society. This contributes to social isolation and feelings of exclusion (Crooks et al., 2025). Based on this, the combined evaluation of physical, emotional, and social elements may enhance the effectiveness of treatment processes. Strengthening support systems provided to patients, rebuilding social connections, and supporting psychological well-being could play a significant role in improving the quality of life for individuals with Parkinson's disease.

In our study, while Parkinson's patients face physical problems such as tremors, balance disorders, urinary incontinence, walking difficulties and speech impairment, they also experience mental problems such as anxiety about the future, fear of being alone, aggressiveness, hopelessness, helplessness and depression. Socially, they experience difficulties such as withdrawal from society, introversion and decreased participation in social activities. The findings of this study indicate that the patients included in the research are significantly affected by the disease. Additionally, it is believed that the numerous physical problems experienced by the patients and their social withdrawal further deteriorate their emotional states and contribute to psychological issues. There are similar findings in the

literature; Parkinson's patients often experience a range of physical, emotional and social problems, including urinary urgency, nocturia (nocturnal urination), constipation, insomnia, attention problems, dizziness when standing up from a sitting or lying position, feelings of lightheadedness and weakness, cognitive and motor slowness, orthostatism (posture disorder), fatigue, sleep problems, falls, sadness, depression, anxiety, worry, fear and panic (Diaconu et al., 2024; Gubbiotti et al., 2025; Schiavolin et al., 2017; Sjödahl Hammarlund et al., 2018; Hasnain et al., 2025). The various symptoms experienced in Parkinson's disease significantly limit patients' activities of daily living and negatively affect their overall quality of life (Cassidy et al., 2024; Lubomski et al., 2021).

In the present study, it was found that Parkinson's patients face difficulties in symptom management and use various strategies to cope with these difficulties. These coping strategies include exercising, praying and taking regular medication. Parkinson's patients develop different approaches to cope with the physical and psychological effects of the disease. Similarly, it was found in the literature that Parkinson's patients use various strategies to cope with the disease. These strategies include exercising, going for walks, engaging in social activities such as writing poetry and painting, receiving social support, enjoying life, focusing on living in the present, avoiding unforeseen challenges, and remaining independent (Ambrosio et al., 2019; Haahr et al., 2021). Various coping strategies allow people with Parkinson's disease to preserve their sense of self during the disease process and maintain their normal life before the disease. (Haahr et al., 2021). As seen in this study and other studies, Parkinson's patients focus on social activities and thoughts that distract them. By increasing patients' mental focus, such strategies can alleviate the effects of physical symptoms, improve their stress management skills, facilitate social connections, provide emotional support and ultimately enhance their overall quality of life.

The motor and non-motor symptoms of Parkinson's not only challenge patients' daily lives, but also severely affect their social interactions, labor force participation and personal independence (Candel-Parra et al., 2022; Valcarenghi et al., 2018). Physical symptoms such as rigidity, tremors and fatigue and mental symptoms such as depression and hopelessness increase the need for social support (McDaniels & Subramanian, 2024). In this study, patients were found to have different psychosocial needs. Patients stated that they expected help from their families in terms of social and economic support, transportation support to and from the hospital, and psychological support. This shows that the symptoms related to Parkinson's disease prevent individuals from working as they used to, and thus they experience loss of economic power and become dependent on others.

Patients whose psychosocial needs are not adequately met may experience increased levels of loneliness, hopelessness, sadness and anxiety (McDaniels et al., 2025; Parveen et al., 2023). From this point of view, trainings can be provided to family members to help both the patient and the family cope with this challenging process in a healthier way and to meet the patient's emotional and psychosocial needs. These trainings can raise awareness about patient care strategies and psychological support methods. Thus, Parkinson's patients can have a better quality of life. Training can also enhance the ability of family members to cope with stress and enable them to respond more effectively to the emotional and psychosocial needs of patients.

Conclusions and recommendations

As a result of this study, it was determined that Parkinson's disease negatively affects patients psychosocially and they have difficulty in coping. It is recommended to implement research and application centers for Parkinson's patients with a focus on psychosocial support and to carry out awareness and awareness-raising studies on Parkinson's disease. Studies on this subject are quite limited and it is recommended that large-scale studies on psychosocial problems in individuals with Parkinson's disease be conducted in the future. It is recommended to increase the number of associations and organizations that assist especially younger patients with issues related to familial relationships, potential early retirement, income generation, compensation, and other financial matters. In addition, it is thought that the social support network for Parkinson's patients should be strengthened and structured psychosocial interviews with families should be made a systematic policy.

Limitations

One limitation of the study is that all participants were from the neurology outpatient clinic of a state hospital located in a city in southern Turkey. The results depend on the participants and the environment in which the research was conducted. The small participant group is not representative of the Parkinson's patient population. The fact that the study was conducted at a single hospital and that most participants were male are among the limitations of the study. This situation stems from the fact that male patients were admitted to clinics more frequently during the period when the study was conducted.

Implications for future research

It is believed that this study contributes to a deeper understanding of the psychosocial dimensions of Parkinson's disease. Developing holistic support programs that combine informational, emotional, and peer support is recommended, as these programs could better meet the various needs of Parkinson's patients. It is suggested that these programs focus on providing personalized interventions to help patients cope with the psychological challenges associated with their diagnosis. Additionally, investigating the effectiveness of specific interventions such as targeted counseling, digital health tools, or structured support groups, would provide valuable insights into improving mental health outcomes for this population. Lastly, examining the influence of family dynamics and caregiver support on mitigating Parkinson's disease psychological difficulties could offer new perspectives on holistic care approaches for Parkinson's disease patients.

Appendix 1

Table 4 Combined criteria for reporting qualitative research (COREQ)

Number	Item	Guiding questions	Explanations
Area 1: Research team and reflexivity			
Personal Characteristics			
1	Interviewer/facilitator	Which author(s) conducted the interview or focus group?	The third author conducted the interview.
2	Credentials	What were the credentials of the researcher, e.g. PhD,	Four authors have PhD
3	Profession	What was their occupation at the time of the study?	First author: Assistant Professor, Internal Medicine Nursing Second author: Associate Professor, Psychiatric Nursing Third author: Assistant Professor, Internal Medicine Nursing Fourth author: Neurology physician.
4	Gender	Was the researcher a man or a woman?	Three researchers were female One researcher was male
5	Experience and training	What experience or training did the researcher have?	All authors have taken qualitative courses, have experience in qualitative research and have published qualitative studies in international journals.
Relationship with participants			
6	Relationship status	Was a relationship established before the training started?	No relationship was established before the start of the study.
7	Interviewer's participant knowledge	What did participants know about the researcher, e.g. personal goals, reasons for doing research?	Individuals knew that the researcher had a PhD in internal medicine nursing.
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator, e.g. bias, assumptions, motives and interests in the research?	At the beginning of each interview, participants were informed about the purpose and objectives of the study.
Area 2. Study design			
Theoretical framework			
9	Methodological orientation and Theory	Which methodological orientation was specified to support the study, e.g. discourse analysis, ethnography, phenomenology, content analysis?	This was a qualitative study.
Participant selection			
10	Sampling	How were participants selected? e.g., purposeful, convenience, consecutive, snowball	Criterion sampling method, one of the purposive sampling methods, was used.
11	Approach method	How were participants approached, e.g. face-to-face, telephone, mail	The timing of the interviews was determined by the individuals who voluntarily agreed to participate in the study.
12	Sample size	How many participants were there in the study?	A total of 20 individuals were included in the study.
13	Disagree	How many people refused to participate or dropped out? Reasons? from the participants and the researchers?	There were no individuals who refused to participate in the study.
Setting			
14	The setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Detailed information is provided in the data collection section of the study.
15	Presence of non-participants	Was there anyone else present apart	There were no observers.
16	Description of the sample	What are the important characteristics of the sample, e.g. demographic data, history	Individuals who agreed to participate in the study were included in the study.
Data collection			
17	Interview guide	Were questions, prompts and guidelines provided by the authors? Has it been pilot tested?	Detailed information was given in the Methods section.
18	Repeat interviews	Have there been re-interviews If yes, how many	No.
19	Audio/visual recording	Was audio or visual recording used to collect data in the study?	Interviews were recorded with a voice recorder

Table 4 (continued)

Number	Item	Guiding questions	Explanations
20	Field notes	Were field notes taken during and/or after the interview or focus group?	Responses of all individuals and researcher observations were recorded.
21	Duration	How long were the interviews or focus groups?	Each interview lasted between 25 and 30 min.
22	Data saturation	Has data saturation been discussed?	Data saturation was discussed.
23	Transcripts returned	Have transcripts been returned to Participants for comments and/or corrections?	No.
Area 3: Analysis and findings			
24	Number of data coders	How many data coders coded the data?	Two researchers and a third individual coded the data.
25	Description of the coding tree	Did the authors provide a description of the coding tree?	The titles and subtitles in the results section represent the final coding tree.
26	Derivation of themes	Were the themes predetermined or derived from the data?	Themes were derived from the data.
27	Software	What software, if any, was used to manage the data?	Data were analyzed manually.
28	Participant control	Did participants provide feedback on the findings?	No.
Reporting			
29	Quotes provided	Were participant quotes presented to illustrate themes/ findings Was each quote identified, e.g. participant number	Source. Participant quotes are provided to illustrate themes/findings. e.g. participant number.
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31	Clarity of main themes	Were the main themes clearly presented in the findings?	Yes
32	Clarity of small themes	Was there an explanation of the different cases or a discussion of minor issues?	Yes

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Data availability The datasets generated during the study are not publicly available due to an ethical restriction but are available from the corresponding author on reasonable request.

Declarations

Conflict of interest The authors declared no potential conflicts of interest concerning this article's research, authorship, and publication.

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References

- Ahn, S., Springer, K., & Gibson, J. S. (2022). Social withdrawal in parkinson's disease: A scoping review. *Geriatric Nursing*, 48, 258–268.
- Ambrosio, L., Portillo, M. C., Rodriguez-Blazquez, C., Rojo, J. M., & Martinez-Martin, P. (2019). Influencing factors when living with Parkinson's disease: A cross-sectional study. *Journal of Clinical Nursing*, 28(17–18), 3168–3176.
- Ball, N., Teo, W.-P., Chandra, S., & Chapman, J. (2019). Parkinson's disease and the environment. *Frontiers in Neurology*, 10, 421551.
- Başkaya, E., & Demir, S. (2023). The problems and information needs of patients with bipolar disorder during the treatment process: A qualitative study in Turkey. *Archives of Psychiatric Nursing*, 42, 45–54.
- Candel-Parra, E., Córcoles-Jiménez, M. P., Delicado-Useros, V., Hernández-Martínez, A., & Molina-Alarcón, M. (2022). Relationship between motor and nonmotor symptoms and quality of life in patients with parkinson's disease. *Nursing Reports*, 12(1), 1–12.
- Cassidy, I., Doody, O., Richardson, M., & Meskell, P. (2024). Quality of life and living with Parkinson's disease: A qualitative exploration within an Irish context. *BMC Neurology*, 24(1), Article 275.
- Crooks, S., Mitchell, G., Wynne, L., & Carter, G. (2025). Exploring the stigma experienced by people affected by Parkinson's disease: A systematic review. *BMC Public Health*, 25(1), Article 25.

- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253–263.
- Diaconu, S., Monescu, V., Filip, R., Marian, L., Kakucs, C., Murasan, I., Chaudhuri, K. R., Jianu, D. C., Falup-Pecurariu, C., & Opritoiu, B. (2024). The impact of fatigue on sleep and other non-motor symptoms in Parkinson's Disease. *Brain Sciences*, 14, Article 397.
- Forero, R., Nahidi, S., De Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., & Aboagye-Sarfo, P. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *BMC Health Services Research*, 18, 1–11.
- Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L., & Daly, J. (2007). Generating best evidence from qualitative research: The role of data analysis. *Australian and New Zealand Journal of Public Health*, 31(6), 545–550.
- Gubbiotti, M., Ditunno, F., Brahim, E., Rosadi, S., & Rubilotta, E. (2025). Clinical features in Parkinson's disease: Characterization of urinary symptoms according to Parkinson disease subtype. *International Urology and Nephrology*, 57, 2495–2501.
- Haahr, A., Groos, H., & Sørensen, D. (2021). Striving for normality' when coping with Parkinson's disease in everyday life: A meta-synthesis. *International Journal of Nursing Studies*, 118, Article 103923.
- Hasnain, H., Shafiq, H., Qadeer, A., Azam, M., Khubab, M., & Arshad, F. (2025). Association of cognitive behavior and non-motor manifestations in Parkinson's disease. *The Healer Journal of Physiotherapy and Rehabilitation Sciences*, 5, 452–459.
- Kalyani, H. H., Sullivan, K. A., Moyle, G. M., Brauer, S. G., Jeffrey, E. R., & Kerr, G. K. (2020). Dance improves symptoms, functional mobility and fine manual dexterity in people with Parkinson disease: A quasi-experimental controlled efficacy study. *European Journal of Physical and Rehabilitation Medicine*, 56(5), 563–574.
- Koszycki, D., Taljaard, M., Kogan, C., Bradwejn, J., & Grimes, D. (2022). Interpersonal psychotherapy for depression in Parkinson's disease: A feasibility study. *Journal of Geriatric Psychiatry and Neurology*, 36(1), 52–62. <https://doi.org/10.1177/08919887221090220>
- Liebermann, J. D., Witte, O. W., & Prell, T. (2020). Association between different coping styles and health-related quality of life in people with Parkinson's disease: A cross-sectional study. *BMJ Open*, 10(7), Article e036870. <https://doi.org/10.1136/bmjopen-2020-036870>
- Lubomski, M., Davis, R. L., & Sue, C. M. (2021). Health-related quality of life for Parkinson's disease patients and their caregivers. *Journal of Movement Disorders*, 14(1), 42.
- McDaniels, B., & Subramanian, I. (2024). Psychosocial Challenges Associated with Parkinson's disease. *Handbook of the Behavior and Psychology of Disease* (pp. 1–27). Springer.
- McDaniels, B., Bradley, E. R., Pontone, G., Pushparatnam, K., Mathur, S., Miller, R., & Subramanian, I. (2025). From hopelessness to hope: Addressing demoralization in Parkinson's disease. *Movement Disorders Clinical Practice*. <https://doi.org/10.1002/mdc3.70209>
- Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, 24(1), 9–18.
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8(2), 90–97.
- Nyimbili, F., & Nyimbili, L. (2024). Types of purposive sampling techniques with their examples and application in qualitative research studies. *British Journal of Multidisciplinary and Advanced Studies: English Lang Teaching Literature Linguistics & Communication*, 5(1), 90–99.
- Pang, S. Y. Y., Ho, P. W. L., Liu, H. F., Leung, C. T., Li, L., Chang, E. E. S., & Ho, S. L. (2019). The interplay of aging, genetics and environmental factors in the pathogenesis of Parkinson's disease. *Translational Neurodegeneration*, 8(1).
- Parveen, S., Moore, J., Parveen, S., & Moore, J. (2023). Current perceptions and unmet needs of people with Parkinson disease and their families. *Clinical Archives of Communication Disorders*, 8(2), 57–69.
- Prins, E. M., Geerlings, A. D., Ben-Shlomo, Y., Meinders, M. J., Bloem, B. R., & Darweesh, S. K. (2023). Determinants of coping styles of people with Parkinson's Disease. *NPJ Parkinson's Disease*, 9(1), Article 99.
- Rawls, A., & Okun, M. S. (2025). Parkinson disease. *Continuum (Minneapolis)*, 31(4), 930–955.
- Saini, N., Singh, N., Kaur, N., Garg, S., Kaur, M., Kumar, A., & Sohail, H. S. (2024). Motor and non-motor symptoms, drugs, and their mode of action in parkinson's disease (PD): A review. *Medicinal Chemistry Research*, 33(4), 580–599.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52, 1893–1907.
- Schiavolin, S., Raggi, A., Quintas, R., Cerniauskaite, M., Giovannetti, A. M., Covelli, V., & Leonardi, M. (2017). Psychosocial difficulties in patients with parkinson's disease. *International Journal of Rehabilitation Research*, 40(2), 112–118.
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2003). Young-versus older-onset parkinson's disease: Impact of disease and psychosocial consequences. *Movement Disorders : Official Journal of the Movement Disorder Society*, 18(11), 1250–1256. <https://doi.org/10.1002/mds.10527>
- Senter, M., Clifford, A. M., O'Callaghan, M., McCormack, M., & Ni Bhriain, O. (2024). Experiences of people living with Parkinson's disease and key stakeholders in dance-based programs: A systematic review and meta-ethnography. *Disability and Rehabilitation*, 46(26), 6288–6301.
- Shalash, A., Hamid, E., Elrassas, H., Abushouk, A. I., & Salem, H. H. (2020). Sexual dysfunction in male patients with parkinson's disease: Related factors and impact on quality of life. *Neurological Sciences*, 41(8), 2201–2206. <https://doi.org/10.1007/s10072-020-04328-2>
- Sjödahl Hammarlund, C., Westergren, A., Åström, I., Edberg, A.-K., & Hagell, P. (2018). The impact of living with parkinson's disease: Balancing within a web of needs and demands. *Parkinson's Disease*, 2018, 1–8. <https://doi.org/10.1155/2018/4598651>
- Stephenson, C., Flynn, A., Overs, A., & Strickland, K. (2023). Support needs of people with younger onset parkinson's disease: An interpretative phenomenological analysis. *Collegian (Royal College of Nursing, Australia)*, 30(2), 335–342.
- Still, A., Hale, L., Alam, S., Morris, M. E., & Jayakaran, P. (2024). Relationships between physical activities performed under free-living conditions and non-motor symptoms in people with Parkinson's: A systematic review and meta-analysis. *Clinical Rehabilitation*, 38(11), 1534–1551. <https://doi.org/10.1177/02692155241272967>
- Sveinbjornsdottir, S. (2016). The clinical symptoms of Parkinson's disease. *Journal of Neurochemistry*, 139(S1), 318–324. <https://doi.org/10.1111/jnc.13691>
- Tibar, H., El Bayad, K., Bouhouche, A., Ait Ben Haddou, E. H., Benomar, A., Yahyaoui, M., Benazzouz, A., & Regragui, W. (2018). Non-motor symptoms of Parkinson's disease and their impact on quality of life in a cohort of Moroccan patients. *Frontiers in Neurology*, 9, Article 170. <https://doi.org/10.3389/fneur.2018.00170>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for

- interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.
- Tran, T. N., Le Ha, U. N., Nguyen, T. M., Nguyen, T. D., Vo, K. N. C., Dang, T. H., Ha, U. N. L., Trinh, P. M. P., & Truong, D. (2021). The effect of non-motor symptoms on health-related quality of life in patients with young onset Parkinson's disease: A single center Vietnamese cross-sectional study. *Clinical Parkinsonism & Related Disorders*, 5, Article 100118. <https://doi.org/10.1016/j.prdoa.2021.100118>
- Valcarenghi, R. V., Alvarez, A. M., Santos, S. S. C., Siewert, J. S., Nunes, S. F. L., & Tomasi, A. V. R. (2018). The daily lives of people with Parkinson's disease. *Revista Brasileira de Enfermagem*, 71(2), 272–279.
- van der Meer, F., Jorgensen, J., & Hiligsmann, M. (2025). Burden of non-motor symptoms of Parkinson's disease: Cost-of-illness and quality-of-life estimates through a scoping review. *Expert Review of Pharmacoeconomics & Outcomes Research*, 25(1), 17–27.
- Váradi, C. (2020). Clinical features of Parkinson's disease: The evolution of critical symptoms. *Biology*, 9(5), Article 103. <https://doi.org/10.3390/biology9050103>
- Zarotti, N., Eccles, F. J. R., Foley, J. A., Paget, A., Gunn, S., Leroi, I., & Simpson, J. (2021). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research and Practice*, 94(3), 760–797. <https://doi.org/10.1111/papt.12321>

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