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Self-care and its assessment in the patient–caregiver dyad in Parkinson's disease: a mixed-method study protocol

Monica Petralito,[1] Chiara Tedesco,[1] Ioannis Ugo Isaias,[2,3] Giovanni Muttillo,[4]
Anna Castaldo,[4] Gianluca Pucciarelli,[1] Rosario Caruso [5,6]

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For numbered affiliations see end of article.

Correspondence to
Professor Rosario Caruso;
rosario.caruso@unimi.it

ABSTRACT

Introduction Parkinson's disease (PD) is a chronic neurodegenerative condition that affects approximately 10 million people worldwide. As the second most common neurodegenerative disease, its prevalence is expected to double in the next 30 years. PD is characterised by both motor and non-motor symptoms that significantly impact patients' quality of life. The disease leads to physical disabilities and can strain the social and emotional well-being of patients and caregivers. While pharmacological and surgical treatments are essential, non-pharmacological approaches, including self-care strategies, play a critical role in managing the disease. This study protocol aims to describe methodological steps required to explore the self-care behaviours of patients with PD and their caregivers, with a particular focus on the dimensions of self-care maintenance, monitoring and management.

Methods and analysis This mixed-method study will involve dyads of patients with PD and their caregivers. Participants will be recruited from the PD and Movement Disorders Centre of the "Azienda Socio Sanitaria Territoriale (ASST) Gaetano Pini-Centro Traumatologico Ortopedico (CTO)". Validated questionnaires, such as the WHOQOL-Bref, the version 2 Self-Care of Chronic Illness Inventory, and the Caregiver Self-Efficacy in Contributing to Self-Care Scale, will be administered. The study will also include semistructured interviews to collect qualitative data on patients' and caregivers' perceptions of self-care. A non-probabilistic convenience sampling method will be employed, encompassing both patients at any stage of disease and their primary caregivers. The estimated sample size is 311 dyads, calculated to provide a 5% margin of error.

Ethics and dissemination The study has been approved by the Lombardia 3 ethics committee (identification (ID) study 5732 12.03.2025 P bis). All participants will sign a written informed consent document. Ethical considerations include ensuring participant confidentiality, voluntary participation and the right to withdraw at any time without consequence. The study results will be disseminated through national and international conferences and published in clinical research journals to contribute to the broader understanding of self-care in the management of PD.

Trial registration number NCT06953050 (clinicaltrials.gov).

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Including both patients and caregivers offers a comprehensive view of self-care dynamics and support systems in Parkinson's disease.
- ⇒ The use of validated tools, such as the World Health Organization Quality of Life – Brief version (WHOQOL-Bref) and the Self-Care of Chronic Illness Inventory, ensures reliable and comparable results.
- ⇒ The sample size was calculated using a precision-based approach, balancing statistical power and feasibility.
- ⇒ Limiting participation to Italian speakers may introduce linguistic and cultural bias, affecting generalisability.
- ⇒ Self-reported data may be subject to recall bias, social desirability bias and incomplete responses.

INTRODUCTION

Parkinson's disease (PD) is a chronic and progressive neurodegenerative disorder that affects approximately 10 million people worldwide (1). It is the second most prevalent neurodegenerative disease after Alzheimer's disease, with a projected doubling in incidence in the next three decades (2). According to the Global Burden of Disease study, neurological disorders are the leading cause of disability, with PD showing higher growth rates compared with other conditions.[1] PD is classified into two main types: a genetic form, inherited in an autosomal dominant or recessive manner, with common mutations in leucine-rich repeat kinase 2 (LRRK2) and glucocerebrosidase (GBA), and an idiopathic form, resulting from the interaction between genetic and environmental factors.[2] PD leads to depigmentation of the substantia nigra and the locus coeruleus, with associated loss of the substantia nigra in the pars compacta (5). This condition is characterised by various disturbances affecting multiple neurotransmitter pathways, particularly manifesting through both motor and non-motor symptoms.

The literature defines the main motor symptoms as tremor, rigidity, bradykinesia, balance disorders and posture issues, all resulting from dopamine deficiency.[3] Non-motor symptoms can be classified into seven distinct categories, which include[4 5]: (a) sensory symptoms such as pain, diplopia, hyposmia and altered colour vision; (b) neuropsychiatric symptoms such as hallucinations, psychosis, anxiety, depression, apathy and impulse control disorders; (c) cognitive symptoms such as early cognitive dysfunction and dementia; (d) sleep disorders, including rapid eye movement (REM) sleep behaviour disorder, restless leg syndrome, daytime sleepiness and sleep attacks; (e) cardiovascular disorders such as orthostatic hypotension, blood pressure variability, nocturnal hypertension and oedema; (f) gastrointestinal disorders such as reduced gastric emptying, constipation and sialorrhoea; and (g) genitourinary disorders such as nocturia, detrusor hyperreflexia, reduced libido and erectile dysfunction.

The typical symptoms of PD could lead to significant disability and a reduction in quality of life for both patients and their caregivers.[6] As the disease progresses, patients often require continuous support, typically provided by an informal caregiver, which has a significant impact on both psychological and emotional aspects, as well as physical, social and time-related demands (ie, time-intensive nature of being a caregiver).[7] To ensure improvements in quality of life and symptom management, it is crucial to encourage the use of self-management strategies.[8] Studies conducted in the context of chronic diseases have demonstrated that proper self-care improves key outcomes for patients with chronic conditions, such as reduced mortality, improved quality of life and a decrease in unnecessary hospitalisations.[9]

As described in the middle-range theory of self-care of chronic illness, self-care is defined as the set of behaviours carried out by patients with chronic conditions to ensure the psychosocial stability of the disease (self-care maintenance), monitor signs and symptoms (self-care monitoring) and respond quickly in case of exacerbation or severe complications (self-care management).[10] The three dimensions of self-care (self-care maintenance, monitoring and management) are also detectable in patients with PD. A study of Bloem *et al*[11] suggested that the ultimate goal of treating PD should be to improve patients' self-care abilities, particularly because, as the disease progresses, they are highly likely to become dependent people and may require increasing help from caregivers or family members to complete daily activities.[12]

Although research in PD has proliferated over time, studies on the lived experiences of dyads (patients and caregivers), their needs, motivations, perceptions and behaviours related to self-care are scarce and primarily focus on therapy adherence as a self-care behaviour.[13 14] The primary objective of this study protocol is to describe the methodological steps required to detect a proportion of self-care in the population with PD and their respective caregivers. Gaining an in-depth understanding of the phenomenon in its experiential and perceptual components, as well as the meanings attributed to it, is essential for developing and validating a new tool capable of assessing and measuring self-care in PD. The secondary objectives of the study described in this protocol are (a) to describe the proportions of self-care maintenance, monitoring and management in the population with PD and their respective caregivers; (b) to explore the meaning attributed by patients with PD to self-care in its three dimensions: self-care maintenance, monitoring and management; (c) to describe the attitudes and self-care behaviours adopted by patients with PD across different disease stages; (d) to explore the meaning attributed by caregivers of patients with PD to self-care in its three dimensions: self-care maintenance, monitoring and management; (e) to describe the attitudes and self-care behaviours adopted by caregivers of patients with PD across different disease stages; and (f) to identify the dimensions of self-care and the constructs that should be represented within the items of the new instrument, the Parkinson's Disease Self-care Questionnaire (PDSC-Q).

Methods and analysis

Study design

This protocol describes the methodological steps required to involve dyads consisting of a patient with PD and their caregiver. Specifically, it will be structured as a mixed-method study. The quantitative component will include the administration of validated scales from the literature, while the qualitative component will consist of semistructured interviews to explore the perception of self-care from both patients and caregivers, addressing the subjective meaning of self-care in its three dimensions (maintenance, monitoring and management). Participation in the interview phase will be optional: dyads may take part in the questionnaire study alone or additionally consent to the qualitative part. For this reason, a separate consent process will be used for the interviews. A preliminary topic guide has been developed based on the middle-range theory of self-care of chronic illness and existing qualitative literature in PD (see online supplemental file 1). It will be further refined through pilot testing with a small number of dyads before full implementation.

To enhance transparency and rigour in reporting, this protocol is guided by the checklist proposed by Fetters and Molina-Azorin,[15] which specifies the essential elements for reporting and integrating quantitative and qualitative components in mixed-methods research. This approach ensures that both the design and reporting of the study align with current methodological standards in mixed-methods research.

Recruitment procedures and selecting patients

Dyads will be invited to participate in the study through an informational letter outlining the study objectives. The letter will be provided by nurses working within the Parkinson's Disease and Movement Disorders Centre of the "Azienda Socio Sanitaria Territoriale" (ASST) Gaetano Pini-Centro Traumatologico Ortopedico (CTO), in collaboration with the referring neurologists. Eligible participants will be identified during routine clinical check-ups, based on the inclusion and exclusion criteria described above. All patients with primary or idiopathic PD who present at the centre and meet the criteria will be approached consecutively. This strategy ensures transparency while maintaining a non-probabilistic convenience sampling approach, which applies to both the quantitative component (questionnaire study) and the optional semistructured interviews (qualitative component). Dyads who decide to participate will complete the questionnaires immediately after their clinical visit. If interested, they will indicate their availability for the interview, which will then be scheduled at a convenient time. Participation in the qualitative part will require separate consent in addition to the main study consent.

Eligibility criteria

The study population consists of patients with PD and their respective informal caregivers who must participate together as a dyad. To be eligible, patients must have primary or idiopathic PD, be oriented in space and time and be proficient in the Italian language. They must also provide written informed consent. Patients at any stage of the disease, as classified by the Hoehn and Yahr (H&Y) scale, will be included. Both H&Y staging and the Unified Parkinson's Disease Rating Scale (UPDRS) will be assessed during the in-person neurological examination conducted at the Parkinson's Disease and Movement Disorders Centre on the day of recruitment. This ensures that eligibility and disease severity are determined using standardised clinical measures. Both those receiving standard treatment and those undergoing advanced therapies are eligible.

Caregivers must be identified as the primary informal caregiver of the patient, be oriented in space and time, proficient in Italian and willing to participate. If the patient does not have a caregiver or if the caregiver does not consent, the dyad will be excluded from the study.

Subjects will also be excluded if they present secondary forms of PD, cognitive impairment as determined by a Mini-Mental State Examination score <24/30 or inability to understand written and spoken Italian. Refusal to provide consent at any stage will also lead to exclusion.

A non-probabilistic convenience sampling method will be applied to both the questionnaire (quantitative) and interview (qualitative) components of the study. Recruitment will follow a consecutive strategy, whereby all eligible dyads attending routine visits at the Parkinson's Centre will be approached. This strategy aims to maximise the inclusion of participants with diverse sociodemographic and clinical characteristics and ensure the representation of under-represented patient and caregiver groups, thereby enhancing the generalisability of the findings.

Sample size

A precision-based approach for finite populations will be used to estimate the proportion of individuals with PD who theoretically maintain adequate vs inadequate self-care, based on previous published research.[12] The calculation follows the standard formula for sample size estimation, with a 95% confidence level (z=1.96), an estimated adherence proportion of 70% (p=0.70) and an error margin of 3%–5%:

$$n = \frac{N\times z^2\times p\times(1-p)}{E^2\times(N-1)+z^2\times p\times(1-p)} \tag{1}$$

The most representative proximity measure of the self-care maintenance construct is therapeutic adherence. This choice is justified by the fact that several items of self-care maintenance, assessed through validated scales, explore the degree of adherence to treatments, continuity in therapy management and the patient's ability to follow health recommendations.[16] In the absence of studies that have fully measured self-care maintenance in patients with PD, the therapeutic adherence proportion, estimated at 70%, derived from an Italian study, is used as a proxy estimate.[17] Therefore, considering an annual population of patients with PD managed at the Parkinson-CTO Gaetano Pini Centre, approximately 8000, and considering a margin of error of 5%, our sample should be 311 dyads (patients and caregivers). The interview phase (qualitative data collection), which may coincide with data collection using questionnaires, will proceed until data saturation is achieved.[18 19]

Data collection instruments

Patients with PD will complete the WHO Quality of Life questionnaire (WHOQOL-Bref, 26 items)[20] and the Self-care of Chronic Illness Inventory version 2 (SC-CII v2, 30 items).[21] Caregivers will complete the WHOQOL-Bref and the Caregiver Self-Efficacy in Contributing to Self-Care Scale (10 items).[22] The SC-CII v2 has not yet been specifically validated in the PD population, but it has been validated in patients with other chronic diseases. The WHOQOL-Bref, originally developed for the general population, has already been used in studies involving PD patients.

Participants will complete the questionnaires on a single occasion, immediately following their baseline neurological examination at the PD and Movement Disorders Centre. This study is therefore cross-sectional, with recruitment taking place over 12 months. After completing the questionnaires, dyads will be invited to indicate their willingness to participate in the optional semistructured interview.

If participants are unable to complete the questionnaires during the visit, they may return them at the next clinical check-up or submit them electronically via a dedicated study email address. To minimise missing data, if returned questionnaires contain unanswered items, participants will be contacted to clarify whether omissions were intentional or accidental.

To accommodate motor symptoms (eg, tremor, dyskinesia) that may limit self-completion, assistance will be provided by the caregiver or, if necessary, by trained nursing staff at the centre. This support ensures that patients can complete the questionnaires reliably without compromising their autonomy.

In addition to the evaluation questionnaires, dyads will complete a sociodemographic form (table 1). Clinical data for the patient will be extracted from medical records during the same visit (table 1). In addition to the questionnaires, each patient will undergo an in-person neurological examination conducted during their routine visit at the PD and Movement Disorders Centre. This examination will include the H&Y staging and the UPDRS, which are assessed directly by the referring neurologist. These measures will provide standardised information on disease stage and severity, complementing the self-reported data collected through the questionnaires.

Analytics

Quantitative data obtained from the questionnaires will be analysed using descriptive statistics. Measures of central tendency and dispersion will be calculated to summarise participant characteristics and key outcomes. Missing data will be handled under the Missing at Random (MAR) assumption, with multiple imputation techniques applied when missingness exceeds 5%. Central tendency and dispersion values will be calculated.

Self-care adequacy will be classified according to validated thresholds,[16] with scores below 70 indicating inadequate self-care and scores of 70 or above indicating adequate self-care. The proportions of participants demonstrating adequate vs inadequate self-care maintenance will be determined.

Subgroup analyses will examine differences in self-care behaviours and quality of life across key variables, including: (a) disease stage (as per H&Y classification), (b) disease severity (measured with the UPDRS), (c) type of therapy (standard vs advanced treatments, from clinical records) and (d) caregiver involvement (assessed via the Caregiver Self-Efficacy in Contributing to Self-Care Scale).

Statistical tests will include independent t-tests or analysis of variance (ANOVA) for continuous variables, and χ^2 tests or Fisher's exact tests for categorical variables. For non-normally distributed data, non-parametric tests such as the Mann-Whitney U test or the Kruskal-Wallis test will be used. To explore factors influencing self-care maintenance and quality of life, multiple linear regression models will be conducted, adjusting for demographic covariates (age, gender, education, occupation, marital status) and clinical covariates (disease stage, comorbidities, therapy type, psychiatric disorders). Logistic regression models will be applied to assess predictors of dichotomous outcomes, such as adequate vs inadequate self-care. Adjustments for multiple comparisons (eg, Bonferroni correction) will be performed as appropriate.

The dyadic nature of the data will also be considered by exploring associations between patient and caregiver self-care attitudes and behaviours, using correlation analyses and dyadic concordance assessments.

Qualitative data from semistructured interviews will undergo thematic analysis, applying a deductive approach grounded in existing self-care frameworks. A structured codebook will guide data coding, categorisation of significant statements and identification of emergent themes related to perceptions, experiences and meanings attributed to self-care. The integration of qualitative and quantitative findings will support a comprehensive understanding of self-care dynamics in PD dyads and inform the future development of the PDSC-Q.

For the preliminary psychometric validation of the PDSC-Q, item analysis will be performed to assess the quality of individual items. This will include examining

Table 1 Demographic and clinical variables

Domain	Variable	Source/method of assessment	Items
Sociodemographic	Age, gender, marital status, nationality, education, city, occupation, living situation, children	Sociodemographic form (self-report)	–
Clinical (patient)	Date of diagnosis, Hoehn & Yahr stage, UPDRS, MMSE, comorbidities, psychiatric disorders, medications & route, falls, sleep/urinary/constipation, swallowing/phonation disorders, physical activity, recreational activities/support groups.	Clinical record+in-person neurological exam	–
Quality of life (patient)	WHOQOL-Bref	Questionnaire	26
Self-care (patient)	Self-care of Chronic Illness Inventory v2 (SC-CII v2)	Questionnaire	30
Quality of life (caregiver)	WHOQOL-Bref	Questionnaire	26
Caregiver involvement	Caregiver Self-Efficacy in Contributing to Self-Care Scale	Questionnaire	10

MMSE, Mini-Mental State Examination; SC-CII v2, Self-care of Chronic Illness Inventory, version 2 ; UPDRS, Unified Parkinson's Disease Rating Scale; WHOQOL-Bref, World Health Organization Quality of Life – Brief version.

item-total correlations to ensure each item contributes meaningfully to the overall construct. Items with low item-total correlations (eg, <0.30) will be considered for revision or removal. Floor and ceiling effects will also be evaluated to identify potential issues with score distribution and sensitivity. Exploratory factor analysis (EFA) will be conducted to examine the underlying factor structure of the questionnaire and to identify distinct dimensions corresponding to the theoretical domains of self-care (maintenance, monitoring and management). Factor extraction will use principal axis factoring with oblique rotation, given the anticipated correlation among self-care dimensions. The number of factors retained will be guided by eigenvalues (>1), scree plot analysis and theoretical interpretability, as well as parallel analysis. Internal consistency reliability will be assessed using Cronbach's alpha coefficients for each identified factor or subscale, with values ≥0.70 considered acceptable for group comparisons. Where appropriate, McDonald's omega coefficients will also be calculated to provide a more robust estimate of internal consistency.

Study duration

The study will last 12 months. Data collection is anticipated to start in November 2025. Data will be entered into an electronic database progressively as collection advances, ensuring continuous monitoring and quality control throughout the study period.

Ethics and dissemination

The study has received approval from the Ethics Committee Lombardia 3 (identification [ID] study 5732, 12.03.2025_P_bis). All participants will be enrolled only after providing written informed consent, ensuring that they fully understand the study objectives, procedures, potential risks and their rights as participants.

Key ethical considerations include maintaining strict confidentiality of all personal data, respecting participants' autonomy and upholding the right to withdraw from the study at any point without any negative consequences. Data will be anonymised and securely stored in accordance with the General Data Protection Regulation (GDPR) and local regulations to ensure optimal privacy protection. Data collected up to the point of withdrawal will normally be retained and included in the analysis in anonymised form, unless the participant explicitly requests the removal of their data at the time of withdrawal.

We anticipate that this study will highlight varying levels of self-care maintenance, monitoring and management among patients with PD and their caregivers, revealing gaps, particularly in self-care monitoring and the implementation of proactive management strategies. We expect to observe a positive association between higher self-care adequacy and better quality of life scores, as well as higher self-efficacy among caregivers who actively contribute to patient self-care.[23] The qualitative findings are anticipated to provide rich insights into the subjective meanings and challenges of self-care in this population, informing the development of the PDSC-Q.

Results from this study will be disseminated through presentations at national and international scientific conferences and published in peer-reviewed clinical and nursing research journals. Additionally, lay summaries may be shared with patient advocacy groups and participating centres to ensure accessibility and support patient and caregiver engagement.

These dissemination strategies aim to maximise the research's impact, contribute to evidence-based practice and support the development of targeted interventions to enhance self-care and quality of life for patients with PD and their caregivers.

Limitations

This study has some limitations that should be acknowledged. First, participation is limited to Italian-speaking patients and caregivers, which may restrict the generalisability of findings to other linguistic and cultural contexts. Second, the use of self-reported questionnaires may introduce recall or social desirability bias. In addition, to ensure valid questionnaire completion, we included only patients without significant cognitive impairment (Mini-Mental State Examination, MMSE≥24), which may exclude individuals with more advanced disease and limit insights into this subgroup. Despite these limitations, the study will provide valuable insights into self-care dynamics in PD dyads and inform the development of the PDSC-Q.

Contribution to mixed-method research

This protocol demonstrates how a mixed-methods approach can enhance the understanding of self-care in PD dyads. While quantitative measures will provide standardised assessments of self-care and quality of life, the integration of qualitative interviews will capture the subjective meanings, experiences and challenges that cannot be fully explained by numerical scores alone. The combination of these approaches is expected to yield a richer, more comprehensive perspective than would be possible with a single method. Future mixed-methods studies in this field should further refine strategies for integrating quantitative and qualitative data, for example, through joint displays or procedural diagrams, to strengthen interpretation and comparability across studies.

Author affiliations
[1]Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Lazio, Italy
[2]Parkinson Institute, ASST Gaetano Pini-CTO, Milan, Italy
[3]Department of Neurology, University Hospital of Würzburg and Julius Maximilian University of Würzburg, Würzburg, Germany
[4]Healthcare Professional Management Department, ASST Centro Specialistico Ortopedico Traumatologico Gaetano Pini-CTO, Milano, Italy
[5]Department of Biomedical Sciences for Health, University of Milan, Milan, Italy
[6]Health Professions Research and Evidence Transfer Unit, IRCCS MultiMedica, Sesto San Giovanni, Italy

Social media Rosario Caruso, LinkedIn @rosario-caruso-92b633138

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ORCID iD

Rosario Caruso https://orcid.org/0000-0002-7736-6209

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