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Caregiver Contributions to Self-Care in Parkinson's Disease: A Qualitative Descriptive Study

Petralito Monica[1] | Caruso Rosario[2,3] | Tedesco Chiara[1,4] | Castaldo Anna[5] | Muttillo Giovanni[5] | Ioannis Ugo Isaias[6,7] | Bonvegna Salvatore[6] | Caniglia Arturo[6] | Cuoco Angela[8] | Vellone Ercole[1,9] | Pucciarelli Gianluca[1]

[1]Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Italy | [2]Department of Biomedical Sciences for Health, University of Milan, Milan, Italy | [3]Health Professions Research and Evidence Transfer Unit, IRCCS MultiMedica, Sesto San Giovanni, Italy | [4]Department of Nursing, Faculty of Health Sciences, University of Jaume I, Spain | [5]Healthcare Professional Management Department, ASST Centro Specialistico Ortopedico Traumatologico Gaetano Pini-CTO, Milano, Italy | [6]Parkinson Institute of Milan, ASST G.Pini-TO, Milan, Italy | [7]Department of Neurology, University Hospital of Würzburg and Julius Maximilian University of Würzburg, Würzburg, Germany | [8]ASL 3 Napoli Sud, Nola, Italy | [9]Division of Research Methodology, Faculty of Nursing and Midwifery, Wroclaw Medical University, Poland

Correspondence: Tedesco Chiara (tedesco@uji.es)

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ABSTRACT

Introduction: Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease, and is characterized by motor symptoms such as bradykinesia, rigidity, and reduced movement automaticity. Caregiver contributions (CC) to self-care in PD represent an important resource for supporting people with PD. However, this topic has not yet been fully explored.

Aim: To explore CC to self-care in PD across the domains of CC to self-care maintenance, monitoring, and management.

Method: A qualitative study design was conducted using a combined deductive and inductive approach. An initial deductive framework guided the analysis, while an inductive process allowed the identification of additional codes emerging from the interview data.

Results: Twenty semi-structured interviews were conducted. Caregivers of people with PD were 75% women, with a mean age of 63.7 years, and were 90% spouses and 95% living with the patient. The analysis showed that the CC to self-care emerges across all domains: in self-care maintenance, through support for medication adherence, physical activity, safety, and diet; in self-care monitoring, through support in daily activities, routine symptom monitoring, and alert system monitoring; and in self-care management, through symptom management strategies and caregiver attitudes. More broadly, this contribution also emerged in relation to caregiving difficulties, interactions with healthcare professionals, and the information that guides self-care.

Discussion-Conclusion: The findings from this study showed that caregivers of persons with PD play a significant role in CC to self-care maintenance, monitoring, and management, particularly through non-pharmacological strategies.

Clinical Relevance: These data are fundamental for guiding educational interventions aimed at the caregivers of patients with PD.

1 | Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease (Prajjwal et al. 2023). The frequency and risk of PD vary according to race and ethnicity, with higher prevalence and incidence among white individuals (Siddiqi et al. 2023). China and Japan, together with Canada, show a markedly higher burden of PD, with greater prevalence, incidence, and mortality rates in men than in women, with European countries such as Spain and Germany exhibiting a relatively high prevalence (Wang et al. 2026).

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PD is a multisystem neurological disorder characterized by motor symptoms such as bradykinesia, rigidity, and reduced movement automaticity (Mirelman et al. 2019) as well as non-motor symptoms including sleep disturbances, cognitive impairment, autonomic dysfunction, and sensory symptoms which, as they progress, lead to increased disability (Tanner and Ostrem 2024). The management of Parkinson's disease requires an integrated approach that includes several aspects, such as adherence to the therapeutic regimen, with particular emphasis on the use of levodopa, which is crucial for improving symptoms and reducing complications (Sumbul-Sekerci et al. 2023). In parallel, physical exercise is considered essential for improving mobility and slowing the progression of disability (Mcginley and Nakayama 2024). Another important aspect is the maintenance of an adequate nutritional regimen, which is essential to avoid interactions with drug metabolism (Tan et al. 2023).

Self-care, as defined by the Middle-Range Theory of Self-Care of Chronic Illness, is a process of maintaining health through health-promoting practices and managing chronic illness. The three fundamental concepts in the theory, articulated in three dimensions: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance pertains to the actions taken to enhance well-being, sustain health, or uphold emotional and physical stability (e.g., taking medications as prescribed). Self-care monitoring is the ongoing process of attentive observation of psychophysical changes, self-awareness, and attentiveness to one's body or body awareness (e.g., identifying off and on periods) Self-care management involves responding to signs and symptoms as they arise (e.g., through medication management or the use of practical symptom management strategies) (Riegel et al. 2012, 2026). Behaviors related to all three dimensions may be performed by patients but it has been demonstrated in many studies that indeed patients are supported by their informal caregivers in self-care (Prado et al. 2020; Rippon et al. 2023; Yorkston et al. 2017). This support has been defined as caregiver contribution (CC) to self-care (Vellone et al. 2019).

CC to self-care is a construct that was initially developed in heart failure (Vellone et al. 2019) but the three theoretical dimensions of CC, including CC to self-care maintenance, self-care monitoring and self-care management (i.e., caregiver support to maintain illness stability, to monitor signs and symptoms, and to respond to signs and symptoms, respectively) have been adopted to study caregivers' involvement in several chronic conditions (e.g., pulmonary diseases, inflammatory bowel disease, ostomy, diabetes, cancer). PD caregiver contributions to patient self-care were never studied but as PD patients need to perform self-care behaviors and caregivers play a fundamental role in PD it could be argued CC to self-care also regarding this disease. Indeed, the literature has highlighted that caregivers of persons with PD could represent an important resource in supporting the person and in engaging in self-care behaviors, as in other diseases (Vellone et al. 2013).

In Italy, care for people with PD is provided by public and private healthcare services that adopt a multidisciplinary approach aimed at early diagnosis, optimizing treatment, and disease management. These pathways involve various professionals, such as neurologists, nurses, speech therapists, and physiotherapists. In this context, nurses play a key role not only in patient assessment, monitoring symptoms, and promoting medication adherence, but also in caregiver education and counseling, strengthening patient management skills. This knowledge is essential for designing specific educational interventions for caregivers of patients with PD.

Numerous qualitative studies have explored distinct aspects of CC to self-care in PD, including medication administration, scheduling medical appointments, supporting dietary management, and providing emotional support (Hurt et al. 2017; Zaragoza Salcedo et al. 2014). Caregivers are also responsible for observing and monitoring the progression of the disease (Prado et al. 2020) and for providing direct support when symptoms arise in the person with PD (Davey et al. 2004). However, these studies offer only a partial representation of the CC to self-care, focusing on isolated dimensions rather than considering its multifaceted and dynamic nature, as highlighted in a recent metasynthesis (Petralito et al. 2025) based on Riegel's middle-range theory (Riegel et al. 2012, 2026). The complexity and evolution of the needs of individuals with PD, related to the continuous progression of the disease, require an approach that considers all aspects of caregiving in an integrated approach. Addressing this gap is essential to understanding the caregiver's contribution to self-care according to a comprehensive theoretical approach and to guide the development of tailored interventions, ultimately improving the quality of care for individuals with PD.

2 | Aim

The aim of the study was to explore the overall experience of caregiver contributions to self-care, specifically within the domains of self-care maintenance, self-care monitoring, and self-care management, among caregivers of persons with PD.

3 | Methods

3.1 | Study Design

A qualitative study design was adopted to explore caregivers' contributions to self-care and to obtain a description of the phenomenon among caregivers of persons with PD. The Middle-Range Theory of Self-Care of Chronic Illness guided the study by providing the theoretical framework for the development of the interview guide and the interpretation of the findings. Data were analyzed using a combined deductive and inductive approach (Mayring 2015). An initial deductive framework guided the analysis, while an inductive process allowed the identification of additional codes emerging from the interview data. Consolidated Criteria for Reporting Qualitative Studies were used for study reporting (Tong et al. 2007).

3.2 | Research Team and Reflexivity

The interviews were conducted by two researchers who were PhD students in Nursing Science (MP, CT). Both researchers had

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clinical experience managing people with PD and expertise in self-care. In addition, CT had previous experience in conducting qualitative research. No prior relationship was established between the researchers and the participants before the interviews. Participants were informed about the study's aim and the researchers' professional backgrounds before agreeing to participate. Efforts were made to minimize potential researcher bias throughout the data collection and analysis processes. To enhance the reflexivity of the analysis, the codes were independently identified and applied by two researchers (MP and CT), and any discrepancies were discussed until consensus was reached; the third researcher (AC) acted as an external adjudicator to resolve discordances. Furthermore, data analysis was methodologically conducted by two researchers (MP and CT) supervised by a third researcher (AC) with expertise in qualitative research and self-care, with no contact with caregivers and not involved in the primary review of the textual data (Olmos-Vega et al. 2023).

3.3 | Participant Recruitment and Sampling

Participants were recruited using a voluntary convenience sampling strategy. The inclusion criteria of caregivers were as follows: (a) being an informal caregiver (family members or friends of a person with PD regardless of Hoehn and Yahr (H&Y) level), (b) space and time orientation and good comprehension and use of the Italian language. Participants at the Parkinson Center were recruited between June and December 2025. Caregivers of persons with PD were initially approached face-to-face and, if interested in participating, were subsequently contacted by telephone to schedule the interview. A total of 20 caregivers were recruited, in accordance with a priori thematic saturation criteria, with data collection ending when additional interviews became redundant and adequately reflected the study's theoretical framework (Saunders et al. 2018). No participants refused to participate, and no dropouts occurred during the study.

3.4 | Data Collection

Interviews were conducted remotely in an online format via video calls. Only the researchers and the caregiver were present during the interview to ensure openness and facilitate the discussion. A semi-structured interview guide (Appendix S1) was developed to explore caregivers' contributions to the self-care of persons with PD. The guide interview included 11? open-ended questions aimed at exploring caregivers' experiences and roles in supporting self-care across the domains of self-care maintenance, self-care monitoring, and self-care management, according to Riegel's middle-range theory (Riegel et al. 2012) (Appendix S1). All interviews were audio video (using the appTeams) recorded with participants' consent. In addition, field notes were taken during the interviews by one of the researchers (MP) to capture contextual information and non-verbal or paralinguistic cues, such as mood, pauses, silence, and hesitations in speech, and were subsequently used to inform and deepen data analysis. The interviews had an average duration of 33 min and 30 s (MIN 15 min, MAX 50 min). The first three interviews were used as a pilot test to determine whether the question pool was suitable for investigating the research question and if it was well understood by the participants. As no changes were made to the interview guide after piloting, these interviews were retained and included in the final analysis. Interviews were transcribed applying a pure verbatim protocol (Mayring 2015).

3.5 | Data Analysis

A qualitative content analysis following the seven steps of structuring category assignment of Mayring was performed (Mayring 2015). Categories were formed in a deductive manner according to the assumptions of the Middle range theory of self-care proposed by Riegel et al. (Riegel et al. 2012) Therefore, we defined a priori the category system and built a codebook composed of 36 codes grouped in 10 categories and having as main themes the concepts of self-care. Each code was related to an anchor sample and a definition extracted from Riegel's self-care theory (Riegel et al. 2012) and previous studies about the experience of caregiver's person with PD. It was only once we had completed the assignment of codes deduced from the model that we inductively formulated codes to capture themes not reflected in the model, as they arose from the interviews.

3.6 | Rigor and Trustworthiness

Data analysis was conducted manually by two researchers (MP and CT) through an iterative deductive–inductive approach. The analysis was guided by the Mid-Range Theory of Self-Care of Chronic Illness and by concepts identified in the existing literature, which informed the initial coding framework. At the same time, new codes were generated from the interview data when participants' narratives revealed additional concepts or perspectives not captured by the initial framework. The researchers progressively reviewed and refined the codes, grouped them into categories, and discussed their interpretation throughout the analytic process. To enhance transparency, the occurrence of each code was documented during the analysis. For each participant, the number and type of codes identified in the transcript were recorded, and the frequency of occurrence of each code across interviews was summarized in the Supporting Information. These counts were used only to provide a descriptive overview of the distribution of codes across participants and were not interpreted as quantitative indicators of the relevance or importance of the identified categories. Representative quotations were selected based on their ability to illustrate the identified categories and to accurately reflect participants' experiences. Regarding inter-rater reliability, no formal statistical measure of agreement was calculated because the purpose of the analysis was not to quantify agreement between coders but to achieve interpretive consensus through an iterative qualitative process. Credibility was ensured through researcher triangulation, with two researchers involved in coding, analysis, and interpretation decisions. A third researcher (AC) reviewed the final coding framework and was involved in resolving discrepancies when consensus could not be reached between the two primary researchers. For transferability, a thick description of the context and sample characteristics was provided, utilizing the theoretical framework of Barbara

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Riegel's self-care theory and the concept of the caregiver's contribution to self-care (Cuoco et al. 2022). Dependability and confirmability were ensured by providing a transparent documentation of all research steps, from the initial planning to the development of the analysis (memoing) and the reporting of findings (raw quotations report). The researchers, experts in English, took care of the translation of caregivers' quotations. As none of the authors are native English speakers, the system helped ensure accurate and contextually appropriate translations, particularly given the presence of colloquial and dialectal expressions in the original texts.

3.7 | Ethical Considerations

The study was conducted under the authorization of the Ethics Committee.

3.8 | Characteristics of the Participants

Twenty semi-structured interviews were conducted until data saturation was reached. Data saturation was reached when repetition of themes was observed without the emergence of new relevant information. The sociodemographic characteristics of caregivers of people with PD are described in Table 1. The caregivers participating in the study were primarily caring for male patients (75%), with a mean age of 65.85 years. The mean disease duration was 14.6 ± 7.01 years, and the average disease severity, as assessed using the Hoehn and Yahr scale, was 2, with severity ranging from Stage 1 to Stage 4, and UPDRS III was 16.40 ± 7.28. The mean of Activities of Daily Living (ADL) score was 5.90 ± 1.07. With regard to current treatment, 50% of patients were receiving oral pharmacological therapy, while 25% were undergoing neurostimulation and a further 20% were receiving subcutaneous therapy, and 5% were receiving therapy by PED (Percutaneous Endoscopic Dijustomy). The individuals assisted by the interviewed caregivers showed a heterogeneous clinical profile in terms of comorbidities: 45% had no comorbidities, 20% had one concomitant chronic disease, 20% had two chronic diseases, and 15% had three chronic diseases (Diabetes, Heart Disease, Hypothyroidism). All patients were oriented to time and place (Mini Mental State Examination > 24). In addition, 10% presented with depressive syndrome, and 2 patients (10%) reported sleep disturbances compatible with REM sleep behaviors disorder. From a sociodemographic perspective, all assisted patients were Italian and married. In terms of educational attainment, 35% had a bachelor's degree, 40% had completed higher education, 20% had completed middle education, and 5% had completed elementary education. Regarding employment status, 30% were still in paid employment, whereas 70% were retired from work. The characteristics of specific ID caregivers were reported in Table 2.

TABLE 1 | Characteristics socio-demographic of the caregiver.

Total (20 caregiver)	*n* (frequency)	% (percentage)
Gender		
Male	5	25
Female	15	75
Marital status		
Married	19	95
Single	1	5
Area of residence		
North Italy	16	80
Central Italy	1	5
Southern Italy	3	15
Employment		
Paid Work	17	85
Retired	3	15
Education		
Elementary school	1	5
Middle school	6	30
High school	7	35
Bachelor's degree	4	20
Not reported	2	10
Cohabitation with the person with PD		
Yes	19	95
No	1	5
Relation with the person with PD		
Wife/Husband	18	90
Mother/Father	1	5
Brother/sister	1	5
Economic income		
Sufficient	5	25
Good	12	60
Excellent	1	5
Not reported	2	10

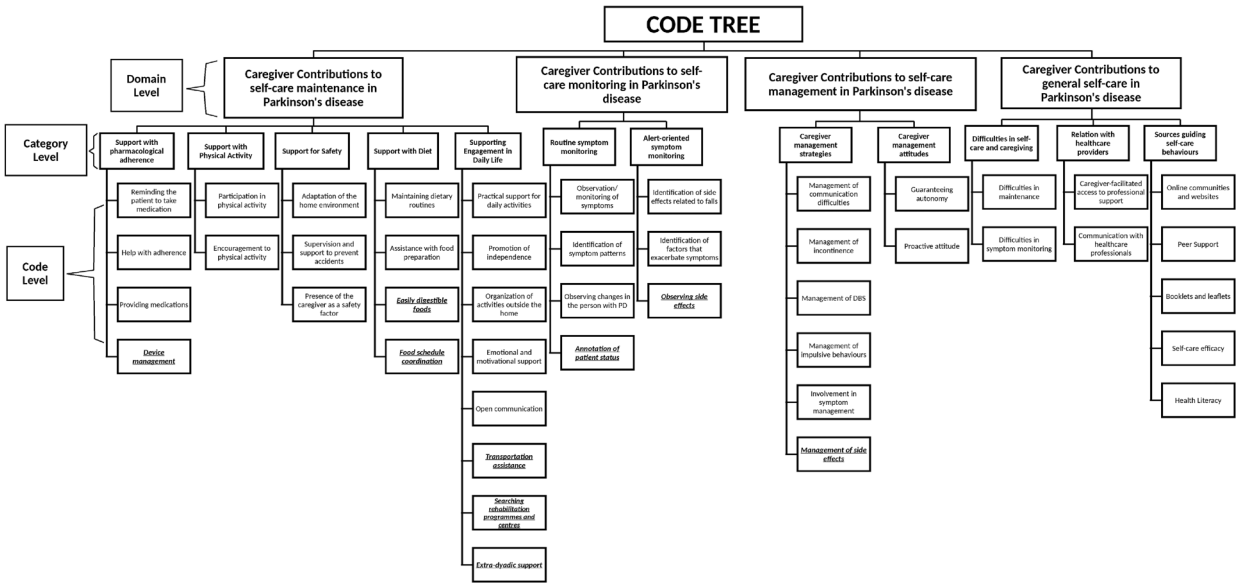
4 | Results of Qualitative Analysis

From the qualitative analysis, 36 codes were initially extracted through a deductive phase. Subsequently, through an inductive analysis of the interviews, 9 additional codes were identified describing caregivers' behaviors in contributing to the self-care of people with PD. Overall, four themes were identified in Figure 1 and Appendix S2. Relevant quotations for each predefined code were identified in the interview transcripts Appendix S3. A total of 448 quotations were associated with the codes, with frequencies varying widely across codes, ranging from a minimum of 2 occurrences (code) to a maximum of 47 (code) (Appendices S4, S5).

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TABLE 2 | Specific characteristics of ID Caregiver.

ID caregiver	Age caregiver	Sex caregiver	Relationship with patient	Duration of disease of patient	Hoehn and Yahr of patient	ADL of patient
ID01	58	F	Spouse	10	2	6
ID02	40	F	Spouse	4	1	6
ID03	60	F	Spouse	16	2	6
ID04	54	F	Spouse	23	2	6
ID05	55	F	Spouse	20	2	5
ID06	60	F	Sister	11	2	1
ID07	58	F	Spouse	12	2	6
ID08	56	F	Spouse	11	2	6
ID09	72	F	Spouse	7	2	6
ID010	73	M	Spouse	19	2.5	6
ID011	65	F	Spouse	31	3	6
ID012	38	F	Spouse	9	2	5
ID013	64	F	Spouse	11	2	6
ID014	75	F	Spouse	16	2	6
ID015	67	M	Spouse	19	2	6
ID016	72	M	Spouse	8	2	6
ID017	72	M	Spouse	6	2	6
ID018	72	M	Father	16	2	6
ID019	72	F	Spouse	17	2	5
ID020	62	F	Spouse	26	4	6



Note: The underlined codes correspond to the codes identified inductively based on the interviews

FIGURE 1 | Code Tree. The underlined codes correspond to the codes identified inductively based on the interviews.

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4.1 | Domain 1: Caregiver Contributions to Self-Care Maintenance in Parkinson's Disease

The domain related to caregiver contributions to self-care maintenance in Parkinson's disease includes 15 codes defined in the a priori codebook and enriched with 6 additional codes identified through an inductive approach. These codes are organized into five categories: (1) Support with pharmacological adherence, (2) support with physical activity, (3) support for safety, (4) Support with diet, and (5) supporting engagement in daily life.

4.1.1 | Category 1: Support With Pharmacological Adherence

The category Support with pharmacological adherence includes the codes *reminding the patient to take medication*, *help with adherence*, and *providing medications*. Caregivers reported performing daily activities related to the management of pharmacological therapy. In particular, they play a key role in reminding the person with PD to take medications, recognizing the complexity of the pharmacological regimen and the importance of respecting medication schedules.

> First of all, there is medication management. My husband takes many medications at very close intervals and they are practically difficult to remember because they are not connected to meals; so, this is my first concern. In fact, I ask him 'did you remember to take your medications?
>
> (ID 03)

> What I additionally do is remind him when he has to take his medications, because we have understood that it is important to pay attention to the timing.
>
> (ID016)

Caregivers also contribute to improving adherence to prescribed medications by encouraging person with PD to take them even when they are reluctant. They described implementing strategies to increase adherence, such as setting alarms or using pill organizers.

> The supplements I must encourage him to take those, the ones prescribed by the dietitians, because he gets a bit annoyed about them. He doesn't really understand that it is for his own good.
>
> (ID 04)

> Simply, I set the alarm on my phone, so it rings every time he has to take his medications. He has to take them at 9, 12:00, 18:00 and 21:00. At each of these times my phone rings and we remember together.
>
> (ID012)

> So, we have a list that both he and I check. Usually, he is very precise about this. I check if a medication is missing or if he forgot to put it in
>
> (ID019).

Within medication management, caregivers also reported contributing to medication procurement, preparation, and direct administration of medications, which in the sample vary among pills, infusion ecc.

> I had to take care of calling for the medication supply because he is not able to handle those things.
>
> (ID04)

> Until two weeks ago I went to pick them up at the hospital, but they told me that from the next supply I can go to the pharmacy in a nearby town about 6–7 km from mine, which would be much easier.
>
> (ID06)

> Sometimes I give them to him myself. For example, if he is sleeping, I take the pill, put it in his mouth and say 'look, it's time for you to take this
>
> (ID016).

> I take the cannabis out of the fridge because it's a bit cold, and I warm it up with a glass of hot water.
>
> (ID017)

An inductive analysis of the interviews also identified a new code related to device management, referring to activities through which caregivers contribute to the management of complex therapies associated with PD, such as continuous for levodopa infusion pumps or the management of percutaneous endoscopic gastrostomy (PEG) for intrajejunal levodopa administration.

> I put it on in the morning and remove it in the evening because we chose to have the infusion only during the day. So, at 6:45 in the morning I wake him up and then prepare everything; at 7 I start the infusion. This pump takes at least fifteen minutes. I load the syringe and apply the cannula. Then in the evening, around 11:00, I remove the needle until the next morning.
>
> (ID06)

> For me it has become normal to manage the PEG. I always clean it well and keep everything sterile. So far, I have not had any problems.
>
> (ID016)

> The pump has to be activated; my daughter and I do it together, but I do it primarily myself.
>
> (ID019)

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4.1.2 | Category 2: Support With Physical Activity

The category support with physical activity consists of two codes: *participation in physical activity* and *encouragement to physical activity*. Caregivers reported having an important role in supporting the engagement of the person with PD in physical activities, often participating in the activity themselves to promote adherence. These activities included both daily physical activities performed together and structured exercise programs.

> We go to the gym, then from 11:00 to 1:00 we have Feldenkrais, which is about relating to your body in movement. Then from 8:00 to 9:00 in the evening, two days a week, we have kickboxing, as Edda said, so we are already quite busy... We do kickbox for people with PD; I accompany her to the kickboxing sessions-
>
> (ID017).

> At my wife's request we go for a walk, when she feels like it, maybe half an hour or forty-five minutes, almost every afternoon when the weather allows.
>
> (ID010)

Caregivers sometimes played a motivational role by encouraging the person with PD to remain physically active.

> I try to stimulate him; when spring came, we had a friend who used to take him out walking.
>
> (ID04)

4.1.3 | Category 3: Support for Safety

Within the contribution to self-care maintenance, caregivers also played a key role in ensuring safety. Three codes were defined a priori: *adaptation of the home environment, supervision and support to prevent accidents, and presence of the caregiver as a safety factor*. Caregivers described modifying the home environment in response to the progression of PD to improve safety.

> There is also the aspect of the house itself, like the shower with modifications... mats outside the shower so he doesn't slip, removing rugs near the bed. You have to be careful... to create a safe environment, a sort of habitat for him.
>
> (ID04)

Caregivers also reported directly supervising the person with PD to prevent falls.

> I pay attention because I'm afraid, he might fall.
>
> (ID04)

> She needs me to accompany her with my arm while she walks.
>
> (ID010)

> I stay behind him during all the phases... when I see he is about to fall I hold him.
>
> (ID013)

The presence of the caregiver was also described as a general safety factor, not only in relation to mobility but also in monitoring the overall well-being of the person with PD.

> On his own he can do many things, even walk, but then he stops and I go toward him and observe him. There is always that glance.
>
> (ID014)

> I get up to check if he needs to be covered, if he is coughing, that he doesn't choke. I always do a little round.
>
> (ID011)

> Between us, I still keep an eye on him, but I feel more relaxed because I see that he is calmer.
>
> (ID019)

4.1.4 | Category 4: Support With Diet

The category support with diet includes two codes: *maintaining dietary routines* and *assistance with food preparation*. These codes describe the behaviors that caregivers adopt to support an appropriate diet for the person with PD, such as protein redistribution diets or reducing dairy intake.

> The only major change in our diet has been eating carbohydrates at 12:00. For the rest, since I am the daughter of a chef, we have always eaten very healthy food at home. Absolutely yes, lots of vegetables and fruit-well, fruit less, but vegetables a lot. At 12:00 always carbohydrates, varying them, and in the evening proteins with vegetables.
>
> (ID05)

> At lunch only pasta, the first course, and in the evening only meat or fish with vegetables or salad. This is the diet we usually follow.
>
> (ID016)

> We were advised to eat very little cheese. I already knew that, only Parmigiano Reggiano; other cheeses should be eliminated for people with PD.
>
> (ID017)

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Through inductive analysis, two additional codes were identified: easily digestible food and food schedule coordination. These codes reflect the caregiver's role in providing easily digestible food to avoid delays in medication absorption and coordinating meal timing with medication schedules.

> I try to avoid foods that are too difficult to digest because my husband also has some digestive difficulties. If digestion slows down, medication absorption also slows down.
>
> (ID03)

> First of all, we try to identify the right timing, making sure medications are taken before meals with an appropriate interval so that absorption is facilitated.
>
> (ID03)

4.1.5 | Categoty 5: Supporting Engagement in Daily Life

The category supporting engagement in daily life includes five codes defined a priori: *practical support for daily activities, promotion of independence, organization of activities outside the home, emotional and motivational support, and open communication*. Caregivers reported providing support in daily activities related to both personal care and household management.

> Among the practical behaviors, I would say first my presence the idea that whenever he is in difficulty he knows he can rely on me. Having someone at home to physically lean on is very useful for him.
>
> (ID012)

> I do the housework; the only thing I don't do is the laundry, but apart from that I do everything-cleaning, cooking. It's harder now because I have to follow him much more.
>
> (ID016)

> I empty the ileostomy bag twice, sometimes three times during the night.
>
> (ID017)

Caregivers also emphasized the importance of promoting the independence of the person with PD despite disease-related limitations.

> My husband is very independent; he manages everything himself, even his medications. As long as he can manage, I want him to remain independent from me.
>
> (ID04)

> He tells me he can do it by himself, that he is autonomous. Knowing his personality, whenever he can do something on his own he likes to do it.
>
> (ID012)

Caregivers also supported social participation and activities outside the home.

> If there is something like a lunch out, my son accompanies him.
>
> (ID014)

> We often go out together, sometimes we even go dancing.
>
> (ID015)

Emotional and motivational support was another important aspect of caregivers' contribution.

> Nothing extraordinary, simple things... but I try to motivate him and encourage him.
>
> (ID016)

Open communication within the dyad was also considered fundamental.

> Between us there is a lot of communication, very frank and open. He knows he can ask me for any help and that I will listen.
>
> (ID012)

Through inductive analysis, three additional codes emerged: *transportation, searching rehabilitation programmes and centers, and extra-dyadic support*. Caregivers frequently ensured transportation to healthcare services.

> Being able to accompany him to the dentist, to doctors, or even on trips where we can enjoy our free time is very important.
>
> (ID012)

Caregivers also reported searching for rehabilitation programs specifically designed for PD.

> I searched online for centres because everyone kept recommending physiotherapy, but physiotherapists often did not know what to propose for someone with PD.
>
> (ID03)

Finally, extra-dyadic support referred to the involvement of other family members or external aides assisting the caregiver.

> The lady who prepares lunch knows the rules, and I leave a note for each day of the week.
>
> (ID06)

> Luckily we have our daughters who are a resource, especially emotionally.
>
> (ID09)

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4.2 | Domain 2: Caregiver Contributions to Self-Care Monitoring in Parkinson's Disease

The domain related to caregiver contribution to self-care monitoring is organized into six codes defined in the a priori codebook and enriched with two additional codes through inductive analysis. These codes are grouped into two categories: (1) Routine symptom monitoring, and (2) Alert-oriented symptom monitoring.

4.2.1 | Category 1: Routine Symptom Monitoring

The category routine symptom monitoring includes four codes: *observation/monitoring of symptoms*, *identification of symptom patterns*, *observing changes in the person with PD*, and *annotation of patient status*. Caregivers reported having an important role in observing and monitoring both motor and non-motor symptoms experienced by the person with PD. This monitoring also includes aspects directly related to disease management, such as blood pressure measurement.

> Observing, I'm an observer. I look at every little thing he does, because in my opinion it is fundamental and very important.
>
> (ID04)

> Sometimes I notice that he looks more drowsy, more tired, more still, but the symptoms are always the same. They are mostly slowing down; he bends forward a bit.
>
> (ID09)

> This morning, I checked his blood pressure again, because I always monitor it. Today it was 152 mmHg, so he restarted the antihypertensive medication.
>
> (ID09)

> In the morning, with the first glance, I see whether he slept well or not, how he walks... my eye always goes there.
>
> (ID011)

Caregivers also described observing continuous fluctuations in the physical and psychological condition of the person with PD.

> One day it goes better, another day worse. One day everything seems to collapse, and the next day things improve significantly.
>
> (ID09)

> In the morning he might exercise and ride the stationary bike, but in the evening he is a completely different person.
>
> (ID014)

> She has become much more emotional... a friend of hers died and she cried as if it were a relative.
>
> (ID017)

Another code refers to the identification of symptom patterns, meaning the caregiver's ability to recognize factors that improve or worsen symptoms.

> If he freezes because it is digestion time after meals, there is nothing that can be done; he has to sit and wait.
>
> (ID06)

> During the day the symptoms follow a pattern related to medication intake.
>
> (ID015)

> When the effect of Madopar is ending I notice she struggles to open the car door.
>
> (ID017)

Through inductive analysis, the code annotation of patient with PD status emerged, referring to caregivers recording symptoms or other health-related information.

> We started keeping a diary where we recorded the intensity of dyskinesias and the time periods when they appeared.
>
> (ID012)

> I made a small diary to track his weight, from 54 kg initially to 49.5 kg now.
>
> (ID017)

> We fill in the chart together and decide how she feels that day.
>
> (ID019)

4.2.2 | Category 2: Alert-Oriented Symptom Monitoring

This category includes two codes identified deductively: *identification of side effects related to falls* and *identification of factors that exacerbate symptoms*. Caregivers described their role in recognizing side effects related to treatments that could increase the risk of falls.

> With the stimulation and medications, he takes, he sometimes walks in an unstable way.-
>
> (ID04)

Caregivers also identified environmental or contextual factors that may worsen symptoms.

> In summer, in my opinion, the situation gets worse.
>
> (ID09 Female)

> If he eats too much, like both first and second courses, he freezes for two hours.
>
> (ID016)

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> When he gets frightened or emotional the tremor starts.
>
> (ID04)

Inductive analysis also revealed a new code related to observation of medication side effects, such as dyskinesia, drowsiness, and constipation.

> Sometimes there is a peak effect of the medication that causes these involuntary movements.
>
> (ID012)

> He had problems with sleepiness every time he took Madopar.
>
> (ID013)

> I think that medication also caused constipation as a side effect.
>
> (ID017)

> Before starting pump therapy, he moved continuously, even at the table he could not stay still.
>
> (ID019)

4.3 | Domain 3: Caregiver Contributions to Self-Care Management in Parkinson's Disease

This domain includes seven codes from the a priori codebook and one additional code identified inductively. These codes are organized into two categories: (1) Caregiver management strategies, (2) Caregiver management attitudes.

4.3.1 | Category 1: Caregiver Management Strategies

This category includes five codes: *management of communication difficulties, management of incontinence, management of DBS, management of impulsive behaviors, involvement in symptom management*. Caregivers described strategies aimed at managing communication difficulties caused by PD.

> He tends to speed up his speech and then stumble over words, so I tell him to slow down and breathe.
>
> (ID09)

> Sometimes she wrote on the phone what she wanted to tell me because she had no voice.
>
> (ID015)

In managing urinary incontinence, caregivers described strategies such as planning access to bathrooms or helping with assistive devices.

> Before going out we try to check whether there are bars or places where she can go to the bathroom.
>
> (ID015)

> When necessary, I lift her to use the portable toilet.
>
> (ID018)

Caregivers also contributed to managing complex treatments such as Deep Brain Stimulation (DBS).

> Once the DBS device stopped working and we had to call technical assistance.
>
> (ID07)

Another code referred to management of impulsive behaviors, including behaviors associated with dopaminergic therapy.

> He developed gambling due to Requip; I had to take control of the situation and manage the consequences.
>
> (ID06)

> Sometimes he asks for more pills, and I have to tell him no.
>
> (ID06)

Caregivers also reported actively contributing to symptom management, through emotional support, physical assistance, or medication adjustments.

> When he gets anxious about symptoms, I try to minimize the situation.
>
> (ID02)

> If he freezes, I hold his hand and reassure him.
>
> (ID016)

> Sometimes I tell him to get in the car and go for a ride so he can relax.
>
> (ID03)

> Sometimes I tell him to get in the car and go for a ride so he can relax.
>
> (ID03)

> When he gets anxious about symptoms, I try to minimize the situation.
>
> (ID02)

> If he freezes, I hold his hand and reassure him.
>
> (ID016)

> Sometimes I tell him to get in the car and go for a ride so he can relax.
>
> (ID03)

4.3.2 | Category 2: Caregiver Management Attitudes

This category refers to caregivers' attitudes toward symptom management and includes two codes: *guaranteeing autonomy*

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and *proactive attitude*. Caregivers emphasized the importance of respecting the autonomy of the person with PD.

> He wants to remain autonomous and not depend on anyone.
>
> (ID019)

> Sometimes I contact the doctor for him, but generally he manages things quite independently.
>
> (ID02)

Caregivers also described a proactive approach to anticipating disease-related challenges.

> You have to be a bit forward-thinking and anticipate things.
>
> (ID011)

> We are already working on different strategies to minimize future problems.
>
> (ID04)

4.4 | Domain 4: Caregiver Contributions to General Self-Care in Parkinson's Disease

This theme includes nine codes organized into three categories: (1) Difficulties in self-care and caregiving; (2) Relation with healthcare providers; (3) Sources guiding self-care behaviors.

4.4.1 | Category 1: Difficulties in Self-Care and Caregiving

This category includes two codes: *difficulties in maintenance* and *difficulties in symptom monitoring*. Caregivers described challenges in maintaining lifestyle recommendations.

> To be honest, we have never been consistent with diet recommendations.
>
> (ID012)

> Doctors always recommend physical activity or psychological support, but we often fail to follow these recommendations.
>
> (ID016)

Caregivers also reported difficulty distinguishing between disease progression and medication side effects.

> I cannot really understand whether dyskinesias are due to medication or worsening of the disease.
>
> (ID03)

4.4.2 | Category 2: Relation With Healthcare Providers

This category includes two codes: *caregiver-facilitated access to professional support* and *communication with healthcare professionals*. Caregivers often facilitated access to healthcare services.

> We called and they sent us another pump because the old one was not working properly.
>
> (ID010)

> My supervision sometimes consists in helping my husband write messages to doctors.
>
> (ID012)

> We also had video calls with the nurse to check the device.
>
> (ID020)

Caregivers also played an active role in communication with healthcare professionals.

> Sometimes I contacted the doctor when there were severe freezing episodes.
>
> (ID05)

> I feel reassured knowing that I can call the nurse whenever I need help.
>
> (ID020)

4.4.3 | Category 3: Sources Guiding Self-Care Behaviors

This category includes five codes: *online communities and websites, peer support, booklets and leaflets, self-care efficacy, and health literacy.*

Caregivers described using multiple information sources to support their caregiving role

> I searched both medical sources and websites about PD.
>
> (ID07)

> When we discovered the disease, I spent days reading on the internet.
>
> (ID016)

> We received booklets and newsletters connected to the Parkinson's Association.
>
> (ID03)

> We manage the pump using the video recorded at the hospital and the brochures they gave us.
>
> (ID019)

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Peer support was also considered important.

> When I discovered my husband also had PD, I talked with another person who had already experienced it.
>
> (ID013)

> There is a social group for people with PD where caregivers share experiences.
>
> (ID017)

Two important aspects emerging from the interviews were self-care efficacy and health literacy, referring to the caregiver's perceived ability to effectively contribute to the self-care of the person with PD.

> It came quite naturally to me, like when you manage other illnesses in the family.
>
> (ID020)

> At the moment I feel confident in managing everything.
>
> (ID019)

> I constantly seek information on how to manage the disease.
>
> (ID020)

5 | Discussion

This study represents the first published study to comprehensively explore and define the contribution of caregivers to self-care of persons with PD, highlighting the importance provided by caregivers. These findings are important because they give new insights on how informal caregivers of persons with PD contribute to specific self-care behaviors. From the findings of the present study, it emerges that caregivers of persons with PD have a role within the three dimensions of self-care (Riegel et al. 2012, 2026), specifically self-care maintenance, monitoring, and management, highlighting the importance of carefully considering the role of the caregiver for persons with PD.

Regarding the caregiver's contribution to self-care maintenance, it emerged that caregivers contribute in many activities, particularly with respect to medication adherence and nutrition, two important aspects for the management of PD (Hurt et al. 2017; Zaragoza Salcedo et al. 2014). Specifically, caregiver support focused on the use of medication reminders, which is the cornerstone of symptom management for which studies report cases of non-adherence or suboptimal adherence (Shin et al. 2015). The introduction of a code such as device management highlights the important role played by caregivers in supporting the management of complex therapies, whose characteristics differ according to the type of device. Indeed, as reported in the literature, the caregiver burden associated with the management of enteral carbidopa/levodopa decreases at 6 and 12 months after treatment initiation. (Aamodt et al. 2024) whereas no reduction in caregiver burden is observed in patients undergoing DBS. Furthermore, as reported by one caregiver, support with medication administration may also involve off-label drugs, such as cannabis, namely medications used to alleviate motor symptoms, such as tremor, or non-motor symptoms, such as sleep disturbances (Costa et al. 2022). Within the domain of dietary support, the caregiver's role emerges in promoting dietary choices that are beneficial for the patient, such as protein redistribution, which is associated with an improvement in motor symptoms (Cereda et al. 2010) or ensuring appropriate coordination between food intake and therapy administration, given its crucial role in drug absorption. (Baruzzi et al. 1987), although this timing is not explicitly stated in the interviews.

The topic of psychological support offered by the caregiver to the person with PD is also present within the sample analyzed, fundamental for being able to face the challenges of the disease itself (Zaragoza Salcedo et al. 2014).

A topic discussed by the caregivers interviewed in this study is the action taken to monitor the person's changes and disease-related symptoms; this finding is also consistent with a previous literature review (Prado et al. 2020). In particular, the caregiver observes the onset and progression of symptoms, whether they are motor in nature; in this context, it is important to underline that in persons with PD, monitoring the frequency and severity is important (Antonini et al. 2023; Montgomery and Reynolds 1990).

The caregiver's contribution to self-care management involves the presence of strategies that we could classify as pharmacological and non-pharmacological, where physical and emotional support is crucial to cope with the "off" periods of persons with PD. The interventions discussed by caregivers primarily concern physical support in performing activities or the use of assistive devices for direct intervention; this finding is in line with what has been defined in a recent metasynthesis (Petralito et al. 2025).

The analysis of the interviews conducted with the interviewed caregivers allowed the identification of codes not previously described in the literature across all three dimensions of self-care. In particular, the role of the caregiver in ensuring the physical transportation of the patient, who, due to the nature of the disease, loses the ability to drive, and in the area of extra-dyadic support, which is crucial for managing the levels of burden, which in this target population range from mild to moderate (Zhao et al. 2024). The content analysis of the interviews highlights that caregiver contribution in person with PD cannot be considered an isolated phenomenon, but rather a broad set of behaviors (Petralito et al. 2025). The presence of an active caregiver contribution to the patient's self-care in terms of maintenance, monitoring, and management is fundamental to achieving a direct or indirect improvement in the patient's symptoms, as observed in other diseases (Locatelli et al. 2024). Among the self-care behaviors, there are also problematic aspects related to self-care maintenance, such as the difficulties encountered by the caregiver in helping to maintain a diet with reduced protein intake or in carrying out physical activities. In this regard, it is essential to educate both caregivers and persons

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on managing these aspects. Some studies show that dyads with shared knowledge are more effective in promoting adherence to diet (Bidwell et al. 2018). Caregivers also highlight a difficulty in monitoring, partly due to a lack of knowledge about the symptoms or side effects of the disease. In this regard, it is important to emphasize that the ability to contribute to self-care depends on caregivers' education, experience, and hours devoted to caregiving (Adëraj et al. 2025), as well as on the type of dyadic relationship established between the patient and the caregiver (Bidwell et al. 2015). These findings are consistent with other studies, where caregivers of persons with PD exhibit a low level of knowledge (Al Ofair et al. 2023); in this regard, it is essential to increase awareness and knowledge among caregivers to ensure better therapeutic outcomes, through peer mentoring interventions, which are considered effective for this specific target population (Fleisher et al. 2023).

Although our findings provide valuable information, further research is essential to more thoroughly explore how the actions and support of caregivers influence not only the symptoms and quality of life of the patient, but also the well-being and psychological health of the caregiver. A more detailed analysis of these reciprocal effects could contribute to the development of more targeted and sustainable interventions aimed at improving the overall condition of the patient-caregiver dyad. It is also important to investigate the barriers and facilitators to self-care contributions, particularly among caregivers of persons with advanced disease and considering the caregiver characteristics. It is important to consider the need for longitudinal studies that could assess the long-term impact of caregiver self-care contributions. In particular, the findings of this study could form the basis for the development of a theoretical tool to assess caregiver self-care contributions in persons with PD, which could facilitate the early identification of self-care difficulties, thus enabling the implementation of personalized interventions. The relationship between person with PD self-care and caregiver contribution could be considered a dyadic phenomenon, as reported for persons with chronic disease (De Maria et al. 2022); therefore, it is important to focus on identifying all the countless aspects involved in caregiving.

6 | Strengths/Limitations

A key strength of the study is its qualitative design, which led to the analysis of information on how caregivers contribute to the self-care of individuals with PD. Through individual interviews, the study provided in-depth insights, offering unique perspectives on the experiences of each caregiver, with a certain level of heterogeneity. Another strength was the use of a theoretical framework that guided the interview process, data organization, and the use of both inductive and deductive analysis. However, a potential limitation lies in the sampling method, which was voluntary and involved caregivers of persons with Parkinson's disease recruited from a single medical centre. Although the sample exhibited diverse characteristics in terms of age and education level, participants mainly cared for individuals with mild to moderate disease severity (Hoehn and Yahr Stages 1–4, with most participants within Stages 1–3), and caregivers of individuals with particularly disabling disease forms were not represented. Therefore, the findings and related implications for clinical practice should be interpreted within this specific context and may primarily apply to caregivers of individuals with early to mid-stage Parkinson's disease receiving care in similar healthcare settings. Further research including caregivers of individuals with more advanced disease stages is needed to better understand how caregiver contributions to self-care may evolve throughout the disease trajectory. Additionally, relying exclusively on video calls for data collection may have created a technological barrier, potentially excluding individuals who were unable to use digital devices or felt uncomfortable doing so.

7 | Conclusion

The findings of this study highlighted the caregiver's contribution to self-care in individuals with PD across the four identified themes, providing valuable insights for identifying interventions that could potentially enhance self-care contributions and offering guidance for future research. Therefore, healthcare providers should consider the importance of caregivers' role in supporting their loved ones, also taking into account their needs to avoid situations of overburden.

8 | Clinical Resources

Self-care Measures (n.d). Self-care of chronic illness instruments and resources. https://self-care-measures.com/.

Fondazione Pezzoli per la Malattia di Parkinson-ETS https://www.parkinson.it/fondazione-pezzoli-ets-per-la-malattia-di-parkinson/.

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Ethics Statement

The study was conducted under the authorization of the Ethics Committee of the Lombardy Region 1 (ID 5732_12.03.2025_P_bis). The study was conducted in the Centre of Parkinson in ASST Gaetano Pini-CTO.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

References

Aamodt, W. W., B. M. Kluger, M. Mirham, et al. 2024. "Caregiver Burden in Parkinson Disease: A Scoping Review of the Literature From

15475069, 2026, 6, Downloaded from https://sigmapubs.onlinelibrary.wiley.com/doi/10.1111/jnu.70141 by CochraneItalia, Wiley Online Library on [25/10/2026]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

2017-2022." *Journal of Geriatric Psychiatry and Neurology* 37, no. 2: 96–113. https://doi.org/10.1177/08919887231195219.

Adëraj, S., M. Saurini, R. Mazzotta, et al. 2025. "Caregiver Contribution to Patient Self-Care and Associated Variables in Older Adults With Multiple Chronic Conditions Living in a Middle-Income Country: Key Findings From the 'SODALITY-AL' Observational Study." *Nursing Reports* 15, no. 10: 360. https://doi.org/10.3390/nursrep15100360.

Al Ofair, A. A., M. Alamri, S. H. Alshehri, et al. 2023. "Level of Knowledge and Quality of Life Among Saudi Caregivers of Parkinson's Disease Patients: A Study From a Tertiary Hospital in Riyadh, Saudi Arabia." *Saudi Pharmaceutical Journal* 31, no. 10: 101765. https://doi.org/10.1016/j.jsps.2023.101765.

Antonini, A., H. Reichmann, G. Gentile, et al. 2023. "Toward Objective Monitoring of Parkinson's Disease Motor Symptoms Using a Wearable Device: Wearability and Performance Evaluation of PDMonitor." *Frontiers in Neurology* 14: 1080752. https://doi.org/10.3389/fneur.2023.1080752.

Baruzzi, A., M. Contin, R. Riva, et al. 1987. "Influence of Meal Ingestion Time on Pharmacokinetics of Orally Administered Levodopa in Parkinsonian Patients." *Clinical Neuropharmacology* 10, no. 6: 527–537. https://doi.org/10.1097/00002826-198712000-00004.

Bidwell, J. T., M. K. Higgins, C. M. Reilly, P. C. Clark, and S. B. Dunbar. 2018. "Shared Heart Failure Knowledge and Self-Care Outcomes in Patient-Caregiver Dyads." *Heart & Lung* 47, no. 1: 32–39. https://doi.org/10.1016/j.hrtlng.2017.11.001.

Bidwell, J. T., E. Vellone, K. S. Lyons, et al. 2015. "Determinants of Heart Failure Self-Care Maintenance and Management in Patients and Caregivers: A Dyadic Analysis." *Research in Nursing & Health* 38, no. 5: 392–402. https://doi.org/10.1002/nur.21675.

Cereda, E., M. Barichella, C. Pedrolli, and G. Pezzoli. 2010. "Low-Protein and Protein-Redistribution Diets for Parkinson's Disease Patients With Motor Fluctuations: A Systematic Review." *Movement Disorders: Official Journal of the Movement Disorder Society* 25, no. 13: 2021–2034. https://doi.org/10.1002/mds.23226.

Costa, A. C., H. P. G. Joaquim, J. F. C. Pedrazzi, A. d. O. Pain, G. Duque, and I. Aprahamian. 2022. "Cannabinoids in Late Life Parkinson's Disease and Dementia: Biological Pathways and Clinical Challenges." *Brain Sciences* 12, no. 12: 1596. https://doi.org/10.3390/brainsci12121596.

Cuoco, A., P. Arcadi, M. C. Figura, et al. 2022. "Designing and Conducting Qualitative Research Across Countries and Cultures: Challenges for Inclusiveness and Rigour." *European Journal of Cardiovascular Nursing* 21, no. 8: 873–879. https://doi.org/10.1093/eurjcn/zvac067.

Davey, C., R. Wiles, A. Ashburn, and C. Murphy. 2004. "Falling in Parkinson's Disease: The Impact on Informal Caregivers." *Disability and Rehabilitation* 26, no. 23: 1360–1366. https://doi.org/10.1080/09638280400000195.

De Maria, M., F. Ferro, E. Vellone, D. Ausili, M. Luciani, and M. Matarese. 2022. "Self-Care of Patients With Multiple Chronic Conditions and Their Caregivers During the COVID-19 Pandemic: A Qualitative Descriptive Study." *Journal of Advanced Nursing* 78, no. 5: 1431–1447. https://doi.org/10.1111/jan.15115.

Fleisher, J. E., M. Suresh, E. C. Klostermann, et al. 2023. "IN-HOME-PD Caregivers: The Effects of a Combined Home Visit and Peer Mentoring Intervention for Caregivers of Homebound Individuals With Advanced Parkinson's Disease." *Parkinsonism & Related Disorders* 106: 105222. https://doi.org/10.1016/j.parkreldis.2022.11.014.

Hurt, C. S., S. Cleanthous, and S. P. Newman. 2017. "Further Explorations of Illness Uncertainty: Carers' Experiences of Parkinson's Disease." *Psychology & Health* 32, no. 5: 549–566. https://doi.org/10.1080/08870446.2017.1283041.

Locatelli, G., P. Iovino, C. Y. Jurgens, et al. 2024. "The Influence of Caregiver Contribution to Self-Care on Symptom Burden in Patients With Heart Failure and the Mediating Role of Patient Self-Care: A Longitudinal Mediation Analysis." *Journal of Cardiovascular Nursing* 39, no. 3: 255–265. https://doi.org/10.1097/JCN.0000000000001024.

Mayring, P. 2015. "Qualitative Content Analysis: Theoretical Background and Procedures." In *Approaches to Qualitative Research in Mathematics Education*, edited by A. Bikner-Ahsbahs, C. Knipping, and N. Presmeg, 365–380. Springer Netherlands. https://doi.org/10.1007/978-94-017-9181-6_13.

Mcginley, J. L., and Y. Nakayama. 2024. "Exercise for People With Parkinson's Disease: Updates and Future Considerations." *Physical Therapy Research* 27, no. 2: 67–75. https://doi.org/10.1298/ptr.R0030.

Mirelman, A., P. Bonato, R. Camicioli, et al. 2019. "Gait Impairments in Parkinson's Disease." *Lancet Neurology* 18, no. 7: 697–708. https://doi.org/10.1016/S1474-4422(19)30044-4.

Montgomery, G. K., and N. C. Reynolds. 1990. "Compliance, Reliability, and Validity of Self-Monitoring for Physical Disturbances of Parkinson's Disease: The Parkinson's Symptom Diary." *Journal of Nervous and Mental Disease* 178, no. 10: 636–641. https://doi.org/10.1097/00005053-199010000-00004.

Olmos-Vega, F. M., R. E. Stalmeijer, L. Varpio, and R. Kahlke. 2023. "A Practical Guide to Reflexivity in Qualitative Research: AMEE Guide No. 149." *Medical Teacher* 45, no. 3: 241–251. https://doi.org/10.1080/0142159X.2022.2057287.

Petralito, M., C. Tedesco, E. Vellone, et al. 2025. "Self-Care Experiences and Behaviours in People With Parkinson's Disease: A Meta-Synthesis." *Journal of Geriatric Psychiatry and Neurology* 39, no. 4: 380–412. https://doi.org/10.1177/08919887251392139.

Prado, L., R. Hadley, and D. Rose. 2020. "Taking Time: A Mixed Methods Study of Parkinson's Disease Caregiver Participation in Activities in Relation to Their Wellbeing." *Parkinson's Disease* 2020: 1–18. https://doi.org/10.1155/2020/7370810.

Prajjwal, P., H. S. Flores Sanga, K. Acharya, et al. 2023. "Parkinson's Disease Updates: Addressing the Pathophysiology, Risk Factors, Genetics, Diagnosis, Along With the Medical and Surgical Treatment." *Annals of Medicine and Surgery* 85, no. 10: 4887–4902. https://doi.org/10.1097/MS9.0000000000001142.

Riegel, B., T. Jaarsma, and A. Strömberg. 2012. "A Middle-Range Theory of Self-Care of Chronic Illness." *Advances in Nursing Science* 35, no. 3: 194–204. https://doi.org/10.1097/ANS.0b013e318261b1ba.

Riegel, B., T. Jaarsma, and A. Strömberg. 2026. "An Update to the Middle-Range Theory of Self-Care of Chronic Illness." *Advances in Nursing Science* 49, no. 1: 14–25. https://doi.org/10.1097/ANS.0000000000000594.

Rippon, D., A. Hand, L. Dismore, and R. Caiazza. 2023. "The Impact of the COVID-19 Pandemic on Informal Caregivers of People With Parkinson's Disease Residing in the UK: A Qualitative Study." *Journal of Geriatric Psychiatry and Neurology* 36, no. 3: 233–245. https://doi.org/10.1177/08919887221135555.

Saunders, B., J. Sim, T. Kingstone, et al. 2018. "Saturation in Qualitative Research: Exploring Its Conceptualization and Operationalization." *Quality and Quantity* 52, no. 4: 1893–1907. https://doi.org/10.1007/s11135-017-0574-8.

Shin, J. Y., B. Habermann, and I. Pretzer-Aboff. 2015. "Challenges and Strategies of Medication Adherence in Parkinson's Disease: A Qualitative Study." *Geriatric Nursing* 36, no. 3: 192–196. https://doi.org/10.1016/j.gerinurse.2015.01.003.

Siddiqi, S., J. Li, Z. Ortiz, et al. 2023. Race and Ethnic Background in Parkinson's Disease: A Literature Review and Risk Factor Analysis.

15475069, 2026, 6, Downloaded from https://sigmapubs.onlinelibrary.wiley.com/doi/10.1111/jnu.70141 by Cochraneltalia, Wiley Online Library on [25/10/2026]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Sumbul-Sekerci, B., H. A. Hanagasi, B. Bilgic, Z. Tufekcioglu, H. Gurvit, and M. Emre. 2023. "Medication Management and Treatment Adherence in Parkinson's Disease Patients With Mild Cognitive Impairment." *Acta Neurologica Belgica* 123, no. 3: 823–829. https://doi.org/10.1007/s13760-022-01916-1.

Tan, Q. Y., H. C. Roberts, S. D. S. Fraser, K. Amar, and K. Ibrahim. 2023. "What Are the Modifiable Factors of Treatment Burden and Capacity Among People With Parkinson's Disease and Their Caregivers: A Qualitative Study." *PLoS One* 18, no. 3: e0283713. https://doi.org/10.1371/journal.pone.0283713.

Tanner, C. M., and J. L. Ostrem. 2024. "Parkinson's Disease." *New England Journal of Medicine* 391, no. 5: 442–452. https://doi.org/10.1056/NEJMra2401857.

Tong, A., P. Sainsbury, and J. Craig. 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, no. 6: 349–357. https://doi.org/10.1093/intqhc/mzm042.

Vellone, E., B. Riegel, and R. Alvaro. 2019. "A Situation-Specific Theory of Caregiver Contributions to Heart Failure Self-Care." *Journal of Cardiovascular Nursing* 34, no. 2: 166–173. https://doi.org/10.1097/JCN.0000000000000549.

Vellone, E., B. Riegel, A. Cocchieri, et al. 2013. "Psychometric Testing of the Self-Care of Heart Failure Index Version 6.2." *Research in Nursing & Health* 36, no. 5: 500–511. https://doi.org/10.1002/nur.21554.

Wang, S., Y. Che, Y. Lin, Y. Zhang, W. He, and W. Zhang. 2026. "Epidemiology of Parkinson's Disease – Global Burden of Disease Research From 1990 to 2021 and Future Trend Predictions." *Clinical Parkinsonism & Related Disorders* 14: 100421. https://doi.org/10.1016/j.prdoa.2026.100421.

Yorkston, K., C. Baylor, and D. Britton. 2017. "Incorporating the Principles of Self-Management Into Treatment of Dysarthria Associated With Parkinson's Disease." *Seminars in Speech and Language* 38, no. 3: 210–219. https://doi.org/10.1055/s-0037-1602840.

Zaragoza Salcedo, A., J. M. Senosiain García, M. Riverol Fernández, et al. 2014. "Key Elements for Patients and Caregivers in the Process of Living With Parkinson's Disease." *Anales del Sistema Sanitario de Navarra* 37, no. 1: 69–80. https://doi.org/10.4321/s1137-66272014000100008.

Zhao, Y., W. Wu, J. Wu, B. Shen, Y. Cao, and Y. Xu. 2024. "Risk Factors and Intervention of Caregiver Burden in Parkinson's Disease: A Systematic Review and Meta-Analysis." *Quality of Life Research* 33, no. 7: 1753–1766. https://doi.org/10.1007/s11136-024-03616-0.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Appendix S1:** Interview guiding questions. **Appendix S2:** jnu70141-sup-0002-AppendixS2.docx. **Appendix S3:** Anchor samples. **Appendix S4:** Total frequency for each code. **Appendix S5:** Total frequency for each code.

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