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Journal of Population and Social Studies (JPSS)

Understanding Caregiver Perspectives on the Management of Individuals With Parkinson's Disease in Thailand: A Qualitative Study

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Abstract

Caregivers' perspectives, knowledge, and coping strategies critically influence the care of individuals with Parkinson's disease. This study explores the experiences, challenges, coping mechanisms, and support needs of caregivers in Thailand. Ten caregivers from the Physical Therapy Centre at Mahidol University participated in face-to-face, in-depth interviews. Thematic analysis identified four key themes: understanding of Parkinson's disease, daily caregiving responsibilities, concerns and challenges in Parkinson's care, and unmet needs and expectations. Caregivers reported difficulties managing motor symptoms, particularly during medication 'off' periods, and identified physiotherapy as a significant concern. They described challenges in sustaining motivation and selecting appropriate exercises. Without formal training, caregivers relied on self-learning through online platforms, hospital brochures, and personal experience. Emotional strain, fear of causing harm, and time burdens related to medication and care routines were commonly reported. Significant unmet needs included access to stage-specific educational materials, practical physiotherapy guidance, and financial support. These findings highlight the multifaceted challenges faced by caregivers, particularly in terms of managing symptoms and accessing limited information and resources. Addressing these gaps through structured caregiver education, physiotherapy training, and support services is essential to enhance caregiving capacity and improve care outcomes for individuals with Parkinson's.

Keywords

Caregiver perspectives; caregiving challenges; coping strategies; Parkinson's disease; support needs

Introduction

Parkinson's disease is the second most common neurodegenerative disorder (Ou et al., 2021), with individuals over the age of 65 at a significantly higher risk of developing the condition (de Lau & Breteler, 2006). The four cardinal features of Parkinson's are resting tremor, rigidity, bradykinesia, and postural instability (Kalia & Lang, 2015). These symptoms are generally classified into two categories: motor and non-motor (Jankovic & Tolosa, 2007). Motor symptoms include impairments in speech, writing, facial expression, gait, posture, coordination, balance, fine motor skills, and muscle fatigue. Non-motor symptoms encompass dysfunction of the autonomic nervous system, cognitive impairment, emotional and behavioral disturbances, perceptual and sensory deficits, and sleep disorders. The severity of Parkinson's is commonly assessed using the Hoehn and Yahr staging scale (Hoehn & Yahr, 1967), with a modified version developed by the Movement Disorder Society (Goetz et al., 2004). Based on motor symptoms and functional impairment, Stages 1 to 2.5 are generally classified as mild, Stage 3 as moderate, and Stages 4 to 5 as advanced.

As Parkinson's progresses, individuals increasingly rely on support to perform daily activities and maintain a quality of life (QoL) (Kalia & Lang, 2015). In this context, caregivers—often family members—are crucial providers of physical, emotional, and social care. However, the caregiving role is frequently accompanied by substantial physical and psychological burdens, including fatigue, musculoskeletal strain, stress, anxiety, and depression, particularly as care demands intensify over time (Martínez-Martín et al., 2008; Mosley et al., 2017). Studies have shown that caregivers of individuals with Parkinson's commonly report reduced QoL and emotional exhaustion due to the complex and progressive nature of the disease, especially when managing both motor and non-motor symptoms of Parkinson's (Lageman et al., 2014; Mosley et al., 2017).

In Thailand, caregiving is deeply rooted in traditional family systems and shaped by cultural and religious values, particularly those derived from Buddhism and the concept of filial responsibility (Gray et al., 2016; Knodel et al., 2015; Teerawichitchainan, 2020). These values emphasize devotion, patience, and a moral obligation to care for elderly and ill family members. Therefore, these cultural and religious values can both buffer psychological stress and contribute to caregiver burden, particularly when expectations for care exceed available support or resources. Understanding caregiving within this sociocultural framework is crucial for comprehending caregiver psychology and developing culturally sensitive interventions.

Although physiotherapy is widely recognized as a key component in the comprehensive management of Parkinson's (Radder et al., 2020; Tomlinson et al., 2013), which also includes pharmacological and multidisciplinary medical interventions, the role of caregivers in this therapeutic process is often underacknowledged (Radder et al., 2020). Caregivers frequently assume responsibility not only for supporting exercise adherence but also for managing medication schedules, monitoring symptom changes, coordinating with healthcare professionals, and adapting care routines in response to the progressive and fluctuating nature of the disease (Dekawaty et al., 2019). Caregivers' perspectives, knowledge, and coping strategies play a critical role in influencing the engagement of individuals with Parkinson's in both medical and physiotherapy treatments, adherence to prescribed regimens, and the overall effectiveness of long-term management and rehabilitation interventions.

Understanding caregivers' perspectives is therefore essential for several reasons: it provides insight into their lived experiences, identifies coping mechanisms and support gaps, and highlights areas where additional education and resources are needed (Dekawaty et al., 2019; Tan et al., 2010). However, few studies have focused explicitly on caregiver experiences in the context of Parkinson's, particularly in low- to middle-income and culturally distinct settings such as Thailand. Therefore, this study aims to address this gap by exploring caregivers' perspectives on individuals with Parkinson's in Thailand, focusing on their experiences, challenges, coping strategies, and understanding of Parkinson's management, particularly regarding medical and physiotherapy interventions. By prioritizing caregivers' perspectives, this study contributes to the development of caregiver-informed and culturally appropriate physiotherapy programs to enhance caregiving capacity, promote caregiver well-being, and support more effective long-term care for individuals living with Parkinson's.

Method

Design

This qualitative research employed individual, face-to-face, in-depth interviews as the study design, utilizing semi-structured interviews and drawing on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007) (See Appendix 1). The study was focused on family members of individuals with Parkinson's who also serve as caregivers. A non-random sampling approach was used to select participants.

Participants

The sample size, ranging from 5 to 30 participants, was determined based on data saturation, following the recommendations of Nastasi and Schensul (2005). The inclusion criteria consisted of caregivers of individuals diagnosed with mid-to-advanced stages of Parkinson's disease by a neurologist based on clinical evidence and standard diagnostic criteria. Additionally, the diagnosis and disease staging were reviewed and confirmed by a physiotherapist specializing in Parkinson's. Caregivers were also required to be willing to participate in a recorded interview. The exclusion criteria included a clinical diagnosis of cognitive impairments or dementia, hearing problems that would affect the interview, and other severe neurological, cardiopulmonary, or other health issues that would impact the interview.

This study was approved by the local Ethics Committee on Human Experimentation of Mahidol University (COA No. MU-CIRB 2023/162.0211). Only caregivers who met the inclusion criteria were invited to participate in the study. Caregivers were informed about the researcher's personal goals and the reasons for conducting the study. Before the interview, a researcher informed participants of the study's aim to explore and understand caregivers' perspectives on caring for individuals with Parkinson's, focusing on carer-centric experiences, challenges, coping mechanisms, and support needs. The researcher also provided their information, as well as the interviewer's background in healthcare. This helped caregivers understand the purpose of the research and enhanced their comfort and confidence during the interviews. Following this, caregivers were informed about the purpose, procedure, and potential benefits of the study, and written informed consent was obtained from all caregivers before data collection.

Experimental procedures

Demographic and questionnaire data were recorded. All interviews were evaluated at the Parkinson Movement and Research Collaboration Laboratory, Faculty of Physical Therapy, Mahidol University, Thailand.

Interview protocol

The research team consisted of lecturers with extensive training in research methodologies and practical experience in caring for individuals with Parkinson's disease, as well as three practicing physiotherapists who conducted the interviews. At the time of data collection, all research team members were actively involved in the clinical practice of physiotherapy for individuals with Parkinson’s. Additionally, a relationship had been established between the research team and some caregivers of individuals with Parkinson’s before the commencement of the study. The research team members who conducted the interviews had not previously interacted with the caregivers through clinical practice, research projects, or community outreach.

To ensure consistency and quality in data collection, the research team underwent intensive training in qualitative interviewing techniques, which was facilitated over three months by two experienced qualitative researchers. One researcher has been conducting qualitative research since 2016 (Trongtortam et al., 2018), while another has been conducting qualitative research for over a decade (Sutiwong et al., 2021). Both researchers and the research team collaboratively designed the semi-structured interview guide, conducted coding audits, and engaged in reflexive discussions throughout the data collection and analysis process. The semi-structured interviews were conducted face-to-face in a private setting, with only the interviewer and the caregivers present to promote comfort and confidentiality. Interviews were audio-recorded using digital devices, and supplementary field notes were taken during each session to capture non-verbal cues and contextual information.

Separate interview guides were developed for caregivers to ensure the clarity, relevance, and depth of the data collection. To ensure the rigor and trustworthiness of the study, the interview questions were reviewed and refined by the co-authors and peer-reviewed by an external qualitative expert. The interviews focused on six core areas, each designed to align with the overarching themes of the study:

1) Demographic information: background details of the caregiver and the individuals with Parkinson’s, including age, relationship, and duration of caregiving.

2) Caregiving experiences and challenges: an exploration of the caregiving journey, including difficulties encountered, key challenges, and the evolution of care practices over time.

3) Daily tasks and responsibilities: Descriptions of routine caregiving activities, including physical assistance, supervision, and monitoring of the individual with Parkinson’s.

4) Emotional and psychological impact: reflections on the emotional toll and psychological consequences of long-term caregiving.

5) Coping mechanisms and support systems: strategies used to manage caregiving stress, and the availability of social, familial, and institutional support networks.

6) Treatment perspectives: caregivers' opinions and experiences regarding medical and physiotherapy treatments, including accessibility and perceived effectiveness.

Each interview lasted approximately 40 to 45 minutes. Methodological triangulation was employed to enhance the credibility, dependability, and transferability of the study's findings by integrating multiple data sources and analytical methods.

Data analysis

Thematic analysis was conducted following the six-phase approach outlined by Braun and Clarke (2006). First, all interview recordings were transcribed verbatim. The research team read and re-read the transcripts to become familiar with them. Initial codes were generated manually and inductively to capture meaningful units related to caregivers' experiences, perceptions, and challenges. Two researchers conducted coding independently, and discrepancies were resolved through discussion until a consensus was reached. The codes were then organized into potential sub-themes based on recurring patterns, conceptual similarities, and alignment with our research objectives. These sub-themes were reviewed, refined, and clustered into four overarching themes reflecting the broader dimensions of caregiving. Manual thematic mapping was used to visualize relationships between codes, sub-themes, and themes. Triangulation was applied through peer debriefing, team discussions, and cross-checking across transcripts to enhance the trustworthiness and credibility of the analysis. Themes were also validated through constant comparison with the full dataset to ensure consistency and representativeness of caregivers' perspectives.

Results

A total of 10 caregivers participated in semi-structured interviews, with no individuals declining to participate in the study. The respondent pool for these interviews also consisted of all 10 caregivers. Repeat interviews were not conducted; each participant was interviewed only once during the data collection. The majority of caregivers interviewed were between 55 and 65 years old. The relationships between caregivers and individuals with Parkinson's included family members, such as spouses and direct relatives (e.g., sons and daughters). Six caregivers had graduated to either a bachelor's or master's degree level. Four caregivers reported that they had received an education below a bachelor's degree, completed their primary school education, or held a vocational diploma. The current occupations included private business/trading, government official/retired government official, state enterprise, permanent employees, and housekeeper. The duration of caregiving for individuals with Parkinson's varies from 2 to 20 years. The characteristics of Parkinson's caregivers are shown in Table 1 below.

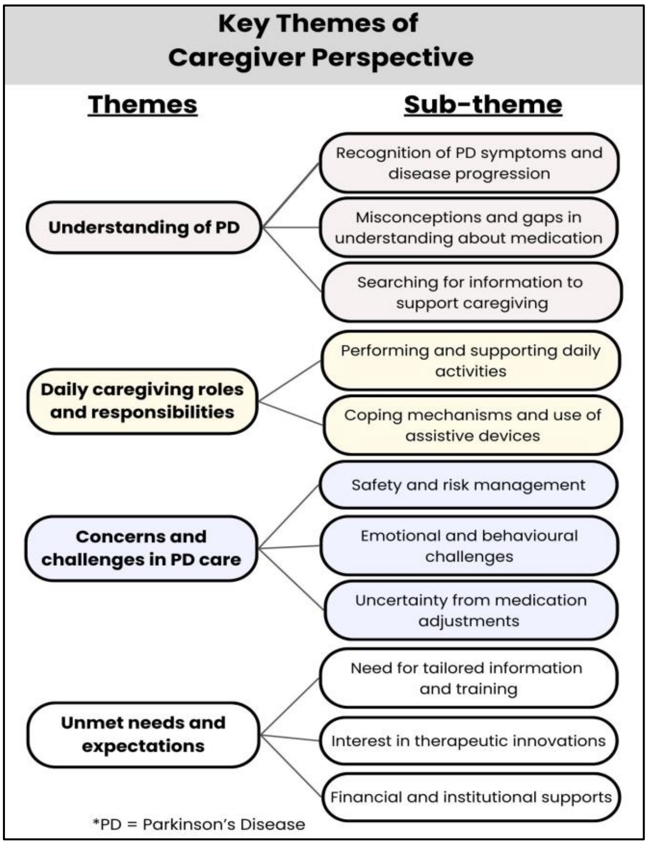
Table 1: Demographic Details of Caregivers (*n* = 10)

Characteristic of caregiver	*n*
Age (years)	
25–40	2

Characteristic of caregiver	*n*
55–65	6
70–75	2
Relationship with Parkinson's patient	
Spouse	4
Direct relatives	6
Education level	
Elementary school (and below)	2
Senior high school	2
Bachelor's degree	3
Master's degree or above	3
Occupation	
Private business/trading	3
Government official/Retired government official	3
State enterprise employee	2
Permanent employees	1
Housekeeper	1
Duration of caring for Parkinson's inpatient (years)	
2–4	3
8–9	3
10–15	2
16–20	2

Figure 1 presents the analysis and interpretation of the four core themes identified from the caregivers' perspectives on caring for individuals with Parkinson's. Additional caregiver sample quotes are included under the sub-themes of each core theme. The ten caregivers are anonymized and labeled Caregiver 00 to Caregiver 09.

Figure 1: Final Thematic Map of Caregiver's Perspective



The demographic characteristics of caregivers are relevant to their perspectives, as these factors may influence their ability to recognize Parkinson's symptoms, seek information, express concerns, and navigate the challenges of caregiving. These aspects are explored in Theme 1.

Theme 1: Understanding of Parkinson's

This theme examines caregivers' knowledge and awareness in caring for individuals with Parkinson's disease, focusing on the nature, symptoms, and management of the disease.

Sub-theme 1: Recognition of Parkinson's symptoms and disease progression

Results from the caregiver interviews revealed that most of them could identify and describe motor symptoms associated with Parkinson's, such as tremors, bradykinesia, rigidity, and postural instability. In addition, most caregivers linked these symptoms to abnormalities in the brain and nervous system, and some described difficulties in caregiving due to the progression of these motor impairments. For example:

> *"Parkinson's is a difficult disease to manage, and I have to stay with and take care of the Parkinson's patient at all times."*
>
> (Caregiver 01)

> *"Parkinson's is a neurological disorder that affects the brain and causes abnormal movements, such as difficulty walking and constant hand tremors."*
>
> (Caregiver 05)

> *"Parkinson's results in movement problems, beginning with tremors. After we noticed them, we decided to see a doctor."*
>
> (Caregiver 08)

> *"This disease cannot be fully controlled; sometimes, my husband is unable to walk because of impaired balance. To me, it feels like his brain and body are no longer connected when he tries to walk."*
>
> (Caregiver 09)

While most caregivers demonstrated an understanding of the motor aspects of Parkinson's and acknowledged its neurological origin, there was limited recognition of non-motor symptoms, such as loss of smell, constipation, cognitive changes, neuropsychiatric symptoms, or autonomic dysfunction, which are also cardinal features of Parkinson's (Pfeiffer, 2016). Furthermore, no caregiver explicitly described Parkinson's as a slow, progressive neurodegenerative disorder. Therefore, although caregivers were aware of common motor symptoms, their understanding of the full clinical spectrum and the progressive nature of Parkinson's appeared to be limited. This highlights an opportunity for improving caregiver education regarding the broader spectrum of Parkinson's symptoms and its progressive neurodegenerative course.

Sub-theme 2: Misconceptions and gaps in understanding about medication

Some caregivers expressed concerns and confusion regarding the effects and side effects of medication. Misunderstandings included beliefs that the medication no longer affected brain function or that it caused individuals with Parkinson's to behave irrationally, reflecting gaps in knowledge about drug efficacy, side effects, and dosage adjustments.

> *"When the doctor adjusts her medication, she ends up fainting throughout the day. It seems like her brain doesn't respond well to the pills, which makes me upset, and I don't know how to handle it."*
>
> (Caregiver 01)

> *"Madopar, which I believe was too strong. It caused hallucinations and made him completely irrational. He became aggressive, even hurting family members, and had to switch medications. Changing medications is always a major concern for us."*
>
> (Caregiver 03)

This sub-theme highlights misconceptions about the medication used for Parkinson's management, including misunderstandings about the efficacy of the drugs and the potential side effects. For instance, some caregivers believed that medication adjustments caused the patient to behave irrationally. In contrast, others expressed fear about the harsh side effects of certain medications, such as hallucinations or aggression. This further illustrates the gaps in knowledge about Parkinson's medication and its side effects, which should be addressed in caregiver education and support.

Sub-theme 3: Searching for information to support caregiving

Caregivers sought to bridge knowledge gaps through online resources, hospital-provided materials, and self-directed learning.

Most caregivers rely on the internet, particularly search engines, for information on Parkinson's symptoms, treatments, and caregiving. While these resources were easily accessible, their reliability varied.

> *"After learning about his Parkinson's diagnosis, I read the information provided by the doctor and searched on Google to understand the disease, its treatment, and how to care for him better."*
>
> (Caregiver 02)

> *"I often search for information on how to care for someone with Parkinson's. One of the main topics I look into is tremors. I want to understand why he shakes so much, even after taking his medication. I found that stress might be a contributing factor."*
>
> (Caregiver 05)

In addition to online resources, some caregivers relied on educational materials provided by hospitals or medical centers. These included handbooks, brochures, and, in some cases, online training programs. These resources were viewed as more reliable and helped caregivers understand medication regimens, monitor symptoms, and establish exercise routines.

> *"I read a book about Parkinson's from King Chulalongkorn Memorial Hospital that offers advice on caring for and providing exercise for individuals with Parkinson's. Additionally, I have also participated in online training sessions."*
>
> (Caregiver 03)

> *"I have received information from the hospital about medication management, symptom monitoring, and physical therapy guidelines."*
>
> (Caregiver 06)

Lastly, some caregivers emphasized that they learned by observing the individual's condition and adjusting their care strategies accordingly. These caregivers developed a personalized approach, tailoring care to the individual's unique symptoms and behaviors associated with Parkinson's.

> *"I tell her that the symptoms are related to the brain not functioning properly, so I try to find ways to care for her. Each person with Parkinson's experiences different symptoms, so I observe her closely and manage them in my own way. That's why I've taken it upon myself to learn as much as I can."*
>
> (Caregiver 01)

> *"I study and observe his symptoms, then try to care for him based on what I see."*
>
> (Caregiver 09)

These findings indicate that caregivers are highly motivated to understand Parkinson's disease and enhance their caregiving skills. However, their reliance on self-directed learning and non-specialist sources highlights the need for more accessible, comprehensive, and evidence-based caregiver education, particularly regarding disease progression, symptom management, and treatment-related effects at each stage of Parkinson's.

Theme 2: Daily caregiving roles and responsibilities

This theme describes caregivers' day-to-day experiences and responsibilities in managing the physical, emotional, and logistical needs of individuals with Parkinson's disease. This theme focused on the caregiving experience from the caregiver's perspective in addressing the patient's physical, emotional, and practical needs. The two sub-themes are:

Sub-theme 1: Performing and supporting daily activities

Caregivers assisted with basic activities, including toileting, eating, bathing, and mobility. While some encouraged independence to promote cognitive stimulation, others required constant support, depending on the individual's stage of the disease.

> *"I care for her all day, including helping her go to the toilet, eating, and taking pills. If she cannot do some activities, I will help her to complete them. In most cases, she can do it by herself, and I am only keeping an eye on her."*
>
> (Caregiver 01)

> *"I prepare everything for her, and she takes charge of her own self-management. I monitor from a distance because I believe that allowing her to do things herself helps develop her brain's function."*
>
> (Caregiver 07)

Some caregivers reported providing full-day care and participating in daily activities alongside individuals with Parkinson's.

> *"I have to take care of him since waking up because of his impaired balance. When he wanted to get up from his bed, I had to help him. He did not have enough strength to push himself up from the bed, and then I took him to the bathroom. I always monitor him during the morning routine of showering, brushing, and exercising. I prepare meals and drugs for him. I have just helped him try to do all activities by himself."*
>
> (Caregiver 02)

> *"I take care of him to do all daily routine, including eating, taking a pill, and physiotherapy, which I do with him."*
>
> (Caregiver 03)

Sub-theme 2: Coping mechanisms and use of assistive devices

Caregivers employed both emotional and practical strategies, including positive communication and physical support. Devices like wheelchairs and walkers were used for mobility, although some saw these as burdensome or ineffective.

When asked about coping and equipment use, some caregivers expressed experiencing constant fear and concern, managing both physical and psychological challenges in their caregiving role.

> *"He does not have enough strength to push himself up, so I always assist him, helping him move and sit."*
>
> (Caregiver 00)

> *"I care for my mom in all daily activities such as exercising, walking, and physiotherapy. In the emotional part, I always talk positively because I believe positive talking can improve and help her manage her symptoms better."*
>
> (Caregiver 04)

> *"I take care of my dad and let him exercise. Sometimes, he has great tremors; I will take him outside and positively talk to him to make him feel relaxed."*
>
> (Caregiver 05)

Many caregivers reported that assistive devices such as canes, walkers, and wheelchairs were essential tools that facilitated safer and more effective care for individuals with Parkinson's.

> *"I use a wheelchair when my dad and I need to go outside because when the medication wears off and becomes ineffective, his legs stiffen, and he*

> *walks slowly. The wheelchair helps and provides support during those times."*
>
> (Caregiver 00)

> *"I might use a wheelchair when he needs to go to the toilet because he walks slowly. I'm afraid he won't be able to make it there in time."*
>
> (Caregiver 03)

A few caregivers perceived assistive devices as burdensome or unnecessary, citing concerns about safety and practicality during use.

> *"I've never used any assistive devices before, and I find them burdensome. I don't think some devices are effective. For example, when individuals with Parkinson's faint and become unconscious, devices like walkers can fold, causing them to fall. Similarly, using a cane when they fall could cause injury. It feels dangerous for them."*
>
> (Caregiver 01)

Theme 3: Concerns and challenges in Parkinson's care

This theme captures the emotional, practical, and medical challenges caregivers face in their caregiving roles.

Sub-theme 1: Safety and Risk Management

Caregivers expressed concerns about the safety of Parkinson's patients, including falls, fainting, choking, and the unpredictability of symptoms, especially during medication wearing-off periods.

> *"I'm worried about the drug wearing off as his movements then become stiff… I was nervous that he was going to fall."*
>
> (Caregiver 00)

> *"I did not want him to stand up because whilst standing, he would faint and fall. So, I'm worried about syncope and that he would fall."*
>
> (Caregiver 09)

> *"When he was going somewhere, I would be worried that he might fall."*
>
> (Caregiver 04)

> *"He walked slowly, and sometimes his legs were stiff. He would not listen to guidance. For example, he insisted on climbing stairs. I was always worried about him falling because I never knew when it might happen."*
>
> (Caregiver 06)

Sub-theme 2: Emotional and behavioral challenges

Caregivers often described difficulties related to patient stubbornness, impatience, or mood changes. These emotional behaviors were perceived as obstacles to providing consistent care.

> *"He is stubborn and impatient, which is why I worry. It makes him difficult to care for."*
>
> (Caregiver 00)

> *"Sometimes he gets moody, so I have to be careful to speak gently and avoid offending him."*
>
> (Caregiver 03*)*

Sub-theme 3: Uncertainty from medication adjustments

Adjustments in drug regimens occasionally resulted in worsening symptoms or adverse events, leading to stress and confusion for caregivers, who felt ill-prepared to manage these effects.

> *"When the doctor adjusts the dosage of pills, a problem happens; she faints all day. I do not know how to deal with it."*
>
> (Caregiver 01)

Theme 4: Unmet needs and expectations

This theme highlights the resources and support that caregivers perceive as inadequate or insufficient.

Sub-theme 1: Need for tailored information and training

Caregivers requested information about disease progression, symptom monitoring, and stage-based care strategies. Individuals with Parkinson's also wanted better guidance in physiotherapy and symptom management.

> *"After he was diagnosed with Parkinson's, I wanted to learn more about how to care for him and help manage his tremors so I could better cope with and handle them. She mentioned that "informational guidelines could be found online or in books."*
>
> (Caregiver 02)

> *"I want to learn how to care for him at each stage of Parkinson's. Additionally, I am looking for an exercise guidance video in slow motion to help me understand the movements better."*
>
> (Caregiver 04)

Sub-theme 2: Interest in therapeutic innovations

Caregivers expressed interest in utilizing occupational therapy tools, such as cognitive games, to preserve mental function and promote engagement.

> *"I am looking for a game to help practice my dad's brain function, like matching games."*
>
> (Caregiver 00)

> *"Incorporating games into exercise can make it more enjoyable for patients while providing both physical activity and brain training."*
>
> (Caregiver 09)

Sub-theme 3: Financial and institutional supports

Caregivers emphasized the need for enhanced financial support, the establishment of Parkinson-specific services, and broader access to care within national healthcare systems.

> *"There should be advice regarding a specialized center for Parkinson's and health coverage."*
>
> (Caregiver 05)

Discussion

This study aimed to explore caregivers' understanding and experiences in caring for individuals with Parkinson's disease in Thailand, with a particular focus on their experiences, challenges, coping strategies, knowledge of Parkinson's management, and overall support requirements. The findings reveal several key issues critical for informing the development of targeted interventions, resources, and services to enhance the well-being of caregivers and individuals with Parkinson's.

Caregivers in this study reported facing multifaceted challenges that encompassed both physical and psychological dimensions. They were acutely aware of the progressive nature of Parkinson's and the associated changes in physical ability and emotional health that patients experience following diagnosis, consistent with previous findings (Lawson et al., 2018). Similarly, Kwok et al. (2021) reported that individuals with Parkinson's in Thailand struggle significantly with both physical limitations and mental health concerns, which, in turn, place considerable demands on caregivers. These responsibilities extend beyond physical assistance to emotional and social support (McLaughlin et al., 2011; Walga, 2019).

A prominent concern among caregivers was safety, particularly the risk of falling, fainting, and injuries in the absence of supervision. Many caregivers expressed heightened anxiety, often resulting from prior experiences with individuals' falls, an issue similarly reported by Tan et al. (2012). Mental health concerns were also prevalent, as caregivers frequently expressed apprehension regarding the emotional well-being and psychological deterioration of their loved ones, particularly when left unsupervised. These findings are consistent with previous research indicating that Parkinson's caregivers frequently face emotional distress due to concerns about disease progression and safety.

Regarding coping strategies, caregivers reported using positive communication and emotional support to help individuals with Parkinson's manage symptoms and maintain motivation. This aligns with Hjelle et al. (2024), who found that keeping a positive attitude is a key coping mechanism among individuals with Parkinson's. In addition, caregivers assumed significant responsibilities in physical caregiving, supporting activities of daily living such as bathing, meal preparation, and housework, especially as individuals' functional independence declined (Lawson et al., 2018). Assistive devices, such as walkers and wheelchairs, were occasionally used to support mobility and minimize the risk of falls.

However, some caregivers expressed reluctance to adopt these tools, even after fall incidents, a pattern also observed in previous research (Choo et al., 2020).

A significant theme identified was the need for information, particularly regarding physiotherapy, disease progression, and home care techniques. Due to limited access to structured physiotherapy programs or formal referrals, many caregivers turned to online sources to seek guidance, a finding consistent with previous studies (Choo et al., 2020; Hjelle et al., 2024; Kim et al., 2018). However, the availability and reliability of this information varied considerably, leading to uncertainty and a persistent sense of unmet needs among caregivers. As a result, caregivers emphasized the necessity of receiving practical, stage-specific information in various formats, such as videos, brochures, illustrated manuals, and easily accessible online resources, to support effective home-based care. This aligns with Tan et al. (2012) and Choo et al. (2020), who highlighted that reliable and accessible information is crucial for empowering caregivers and enhancing care outcomes.

While a few caregivers briefly mentioned the potential usefulness of alternative or innovative approaches (e.g., game-based cognitive training or healthcare system supports), these ideas emerged as prominent themes in the analysis (Kibra, 2018). Consistent with the literature on digital rehabilitation tools, financial and healthcare system supports (Basharat et al., 2023; Özgönenel et al., 2016; Riva et al., 2016; Tan et al., 2010), these aspects were consistently reflected in the narratives of Thai caregivers.

Overall, this study provides valuable insights into the lived experiences and unmet needs of Thai caregivers for individuals with Parkinson's. The findings highlight an evident interdependence between coping mechanisms and support needs, with caregivers' ability to implement effective strategies - such as maintaining emotional stability, engaging in positive communication, or utilizing assistive tools, often contingent upon the availability of appropriate support, including accurate information, financial assistance, and access to physiotherapy or counseling services. Without adequate support, even well-intended coping mechanisms may prove insufficient or counterproductive. In particular, caregivers emphasize that foundational needs, such as stage-specific disease education and access to care services, must be addressed before more advanced coping strategies, such as self-regulation and innovation in care routines, can be effectively employed.

These findings can inform healthcare professionals, policymakers, and product developers in designing tailored support systems and educational resources that respond to the specific challenges caregivers face. Access to precise, reliable, and practical caregiving information should be prioritized in improving Parkinson's care. While this study was conducted in Thailand, the caregiving challenges identified are broadly consistent with findings from international studies (Dekawaty et al., 2019; Tan et al., 2010), suggesting potential applicability across diverse cultural and healthcare settings. Future research could benefit from collaborative efforts to co-develop culturally appropriate and adaptable caregiver support tools and resources that are suitable for various contexts.

This study has several limitations. Firstly, interview transcripts were not returned to participants for their comments or corrections. Although participants were provided with a summary of their interviews to confirm their understanding, the lack of transcript review may have limited opportunities for clarification or elaboration. Future studies should consider this. Secondly, the sample size was relatively small. Although data saturation was achieved, the limited sample may affect the generalizability of the findings. Future research should consider recruiting a larger and more diverse population of caregivers to enhance representativeness and accuracy.

Additionally, most participants in this study had a relatively high socioeconomic status, which may not accurately reflect the broader Thai population. The absence of caregivers for individuals with younger-onset Parkinson's or those in the early stages of the disease also limits the transferability of the findings across all disease durations and age groups. The use of in-depth interviews may have introduced bias, as participants might have provided socially desirable responses or focused predominantly on their personal experiences rather than shared or community-wide perspectives (Latkin et al., 2017). Furthermore, several common clinical issues were not extensively addressed, such as the recognition and management of non-motor symptoms, challenges in medication management and adverse effects, polypharmacy and over-the-counter medication use, understanding of advanced therapies such as deep brain stimulation, access to medical and physiotherapy services, and caregiver burden related to lack of personal time and self-care. Although these topics did not emerge prominently within the specific cohort interviewed, their omission constitutes a limitation. Future studies should aim to explore these areas to provide a more comprehensive understanding of the multifaceted challenges encountered by both individuals with Parkinson's and their caregivers.

Conclusion

This study examines caregivers' perspectives on caring for individuals with Parkinson's disease in Thailand. Four key themes emerged: caregivers' understanding and experiences of Parkinson's, daily caregiving responsibilities, concerns and challenges in Parkinson's care, and unmet needs and expectations. The findings reveal that while caregivers generally recognized the motor symptoms of Parkinson's, there was limited awareness of its non-motor manifestations and progressive nature. Misconceptions regarding the effects and side effects of medication were also apparent, contributing to uncertainty and distress during drug adjustments. Caregiving responsibilities were found to be physically and emotionally taxing, with caregivers facing challenges related to patient mood changes, communication, and risk of falls.

Additionally, some caregivers reported skepticism towards using assistive devices due to perceived ineffectiveness or safety concerns. These experiences highlight the practical burdens of care and the emotional and psychological toll on caregivers. Beyond practical challenges, caregivers needed stage-specific information, physiotherapy guidance, cognitive rehabilitation tools, and improved financial and institutional support. These findings suggest that addressing unmet needs alone is insufficient; addressing unmet needs in conjunction with other factors is necessary for effective outcomes. Adequate caregiver support must also encompass efforts to correct misconceptions, alleviate emotional strain, and enhance caregivers' understanding and coping strategies through accessible training and culturally appropriate interventions. Ultimately, this study underscores the significance of understanding caregiver perspectives in informing the development of comprehensive, culturally sensitive, and practical strategies that support effective long-term care for individuals living with Parkinson's.

Ethics approval and consent to participate

The study was approved by the Ethics Committee on Human Experimentation of Mahidol University (COA No. MU-CIRB 2023/162.0211) and complied with the standards outlined in the Declaration of Helsinki. All participants signed an informed consent form before data collection. In addition, informed consent was obtained from all participants involved in the study, and all participants gave their permission for the publication.

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Appendix

Appendix 1: COREQ Checklist

Domain 1: Research team and reflexivity

Personal characteristics

Item	Guide Question / Description	Response	Page No.
1	Interviewer/facilitator – Which author(s) conducted the interview or focus group?	The research team consisted of lecturers with extensive training in research methodologies (ST and JS) and practical experience in caring for individuals with Parkinson's disease (FK and JT), as well as three practicing physiotherapists who conducted the interviews (NV, KS, and WS).	5
2	Credentials – What were the researcher's credentials? (e.g., PhD, MD)	FK, JS, and JT hold PhDs in research related to individuals with Parkinson's disease. ST holds a PhD in Computer Science and is an experienced qualitative researcher. NV, KS, and WS hold Bachelor of Science degrees and conducted the interviews.	5

Item	Guide Question / Description	Response	Page No.
3	Occupation – What was their occupation at the time of the study?	The research team consisted of lecturers with extensive training in research methodologies and practical experience in caring for individuals with Parkinson's disease, as well as three practicing physiotherapists who conducted the interviews.	5
4	Gender – Was the researcher male or female?	The research team included both male and female members. The interviewers were all female physiotherapists.	5
5	Experience and training – What experience or training did the researcher have?	All interviewers underwent intensive training in qualitative interviewing techniques, which was facilitated over three months by two experienced qualitative researchers.	5 - 6
Relationship with Participants			
6	The relationship established – Was a relationship established before the study commencement?	A relationship had been established between the research team and some caregivers of individuals with Parkinson's before the commencement of the study.	5
7	Participant knowledge of the interviewer – What did participants know about the researcher?	Participants were informed about the researcher's objectives and the rationale behind the study.	5
8	Interviewer characteristics – What characteristics were reported (e.g., bias, assumptions)?	Interviewers also provided their information, as well as details about their background in healthcare. Additionally, the two researchers had a personal interest in the research.	5

Domain 2: Study design

Theoretical framework

Item	Guide Question / Description	Response	Page No.
9	Methodological orientation – What methodological orientation was used? (e.g., grounded theory, thematic analysis)	Thematic analysis, guided by Braun and Clarke, was used.	7
Participant Selection			
10	Sampling – How were participants selected?	A non-random sampling approach was used to select participants.	4
11	Method of approach – How were participants approached?	The study focused on family members of individuals with Parkinson's disease who also served as caregivers and volunteered to participate in the research.	4

Item	Guide Question / Description	Response	Page No.
12	Sample size – How many participants were in the study?	Ten caregivers participated in semi-structured interviews.	8
13	Non-participation – How many refused or dropped out? Why?	No individuals declined to participate in the study.	8
Setting			
14	Setting of data collection – Where was the data collected?	All interviews were evaluated at the Parkinson Movement and Research Collaboration Laboratory, Faculty of Physical Therapy, Mahidol University, Thailand.	5
15	Presence of non-participants – Was anyone else present?	Only the interviewer and participant were present to promote comfort and confidentiality.	6
16	Description of sample – What are the key characteristics (e.g., demographics)?	Key demographic characteristics included their age, the nature of their relationship to the individual with Parkinson's (e.g., spouse, child, sibling), and the duration for which they had been providing care.	8–9
Data Collection			
17	Interview guide – Was it pilot-tested?	Yes, separate interview guides were developed for caregivers to ensure the clarity, relevance, and depth of the data collection.	6
18	Repeat interviews – Were any conducted?	Repeat interviews were not conducted; each participant was interviewed only once during the data collection.	8
19	Audio/visual recording – Was data recorded?	Interviews were audio-recorded with consent.	6
20	Field notes – Were notes taken during or after?	Field notes were taken during each session to capture non-verbal cues and contextual information.	6
21	Duration – What was the average length?	Each interview lasted approximately 40 to 45 minutes.	7
22	Data saturation – Was it discussed?	Data saturation was not discussed	Not applicable
23	Transcripts returned – Were transcripts shared for comment/correction?	Transcripts were not returned to participants due to anonymization and ethics constraints.	Not applicable

Domain 3: Analysis and findings

Data analysis

Item	Guide Question / Description	Response	Page No.
24	Number of data coders – How many people coded the data?	Two researchers (ST and FK) independently coded the data.	7–9
25	Description of the coding tree – Was one provided?	A coding framework was included in the methods.	7

Item	Guide Question / Description	Response	Page No.
26	Derivation of themes – How were they developed?	Themes were derived inductively from the data.	7–9
27	Software – What software was used?	No software was used for data analysis in this study.	Not applicable
28	Participant checking – Did participants review the findings?	No, participants did not review the findings.	Not applicable
Reporting			
29	Quotations presented – Were quotes used? Labeled?	Yes, direct quotations from participants have been presented throughout the results section. Each quotation is clearly labeled with participant codes, and quotes are organized and thematically grouped.	8–20, Fig. 1
30	Data and findings consistent – Was there alignment?	Yes, the findings were consistently supported with direct quotes from participants.	7–20, Fig. 1
31	Clarity of major themes – Were they presented?	Yes, major themes were clearly defined and supported by the data.	7–20, Fig. 1
32	Clarity of minor themes – Were diverse or deviant cases reported?	Yes, minority perspectives were reported and analyzed.	7–20, Fig. 1

Note: Developed from Tong et al. (2007)