

Caregiving experiences from the perspective of female caregivers of patients with Parkinson's disease in Cali, Colombia

Research Article

 Open access



Experiencias de cuidado desde la perspectiva de cuidadoras de pacientes con enfermedad de Parkinson en Cali, Colombia

Experiências de cuidado na perspectiva de cuidadores de pacientes com doença de Parkinson em Cali, Colômbia

How to cite this article:

Andrade Díaz Karla V, Salazar Villegas Billy, Malvaceda-Espinoza Eli. Caregiving experiences from the perspective of female caregivers of patients with Parkinson's disease in Cali, Colombia. Revista Cuidarte. 2026;17(3):e5582. <https://doi.org/10.15649/cuidarte.5582>

Highlights

- Caring for a person with Parkinson's disease requires personal sacrifices, unwavering commitment, and continuous adaptation to the patient's evolving needs.
- Emotional support, caregiver education, and the promotion of patient autonomy are essential pillars of effective care.
- The emotional impact of caregiving encompasses both exhaustion and stress, as well as feelings of fulfillment, compassion, and personal growth among caregivers.
- Caregivers expressed a need for accessible technological tools, support networks, and comprehensive care that addresses physical, emotional, and spiritual dimensions.

Revista Cuidarte

Rev Cuid. 2026; 17(3): e5582

<https://doi.org/10.15649/cuidarte.5582>



E-ISSN: 2346-3414

Abstract

Introduction: Parkinson's disease requires complex care. Caregivers, predominantly women, face substantial physical and emotional burden; however, they also find gratification. **Objective:** To understand the caregiving experiences of female caregivers of patients with Parkinson's disease in Cali, Colombia. **Materials and Methods:** A qualitative study with a reflexive thematic analysis design was conducted. A focus group was held with six caregivers. Data were analyzed using ATLAS.ti 25. **Results:** Three main themes were generated: (1) Sacrificed performance, in which caregivers expressed unconditional dedication to the patient, developed spiritual and emotional coping strategies, and sought to promote the patient's autonomy and participation; (2) Emotional impact, which included emotional exhaustion in response to the patient's demands, compassion in caregiving, and satisfaction with healthcare professionals; and (3) Experienced needs, which encompassed needs for training, information, knowledge of digital tools, comprehensive medical care, and human support. **Discussion:** Caregivers experience sacrificed performance, emotional impact, and diverse needs, which are consistent with the literature reported to date. Training, the promotion of patient autonomy, emotional and spiritual coping, as well as the value of human, technological, and interdisciplinary support, were highlighted. **Conclusions:** Caregivers make significant personal and emotional sacrifices, underscoring the need for interventions that provide comprehensive support and adequate resources. This study highlights the importance of recognizing and addressing caregivers' needs to enhance their well-being and the quality of care they provide.

Keywords: Parkinson's Disease; Caregivers; Caregiver Burden; Family Care; Qualitative Research.

Received: August 8th, 2025

Accepted: March 21st, 2026

Published: October 30th, 2026

 *Corresponding Author

Eli Malvaceda-Espinoza

Email: emalvaceda@usil.edu.pe

 Karla V Andrade Díaz¹

 Billy Salazar Villegas²

 Eli Malvaceda-Espinoza³

1. Institución Universitaria Antonio José Camacho, Cali, Colombia. E-mail: kvandrade@profesores.uniajc.edu.co

2. Institución Universitaria Antonio José Camacho, Cali, Colombia. E-mail: bsalazarv@profesores.uniajc.edu.co

3. Universidad San Ignacio de Loyola, Lima, Perú. E-mail: emalvaceda@usil.edu.pe

Experiencias de cuidado desde la perspectiva de cuidadoras de pacientes con enfermedad de Parkinson en Cali, Colombia

Resumen

Introducción: La enfermedad de Parkinson requiere cuidados complejos. Las cuidadoras, principalmente mujeres, enfrentan sobrecarga física y emocional; sin embargo, también encuentran gratificación. **Objetivo:** Conocer las experiencias de cuidado de cuidadoras de pacientes con enfermedad de Parkinson en Cali, Colombia. **Materiales y Métodos:** Se llevó a cabo un estudio cualitativo con diseño de análisis temático reflexivo. Se aplicó un grupo focal con seis cuidadoras. El análisis de los datos se realizó con el apoyo de ATLAS.ti 25. **Resultados:** Se generaron tres temas principales: 1. Desempeño sacrificado, en el cual las cuidadoras expresan una dedicación incondicional hacia el paciente, desarrollan estrategias de afrontamiento espiritual y emocional, a su vez, buscan promover la autonomía y participación del paciente; 2. Impacto emocional, que incluye el agotamiento emocional frente a las exigencias del paciente, la compasión por el cuidado y la satisfacción con el personal de salud; y 3. Necesidades experimentadas, que corresponden a las necesidades de capacitación, información, conocimiento de herramientas digitales, abordaje médico integral y el apoyo humano. **Discusión:** Las cuidadoras presentan un desempeño sacrificado, impacto emocional y diversas necesidades, lo cual coincide con la literatura señalada hasta el momento. Se destacó la capacitación, promoción de la autonomía, afrontamiento emocional y espiritual, así como el valor del apoyo humano, tecnológico e interdisciplinario. **Conclusiones:** Las cuidadoras enfrentan un alto nivel de sacrificio personal y emocional, lo que resalta la necesidad de intervenciones que ofrezcan apoyo integral y recursos adecuados. Este estudio subraya la importancia de reconocer y abordar las necesidades de las cuidadoras para mejorar su bienestar y la calidad del cuidado que proporcionan.

Palabras Clave: Enfermedad de Parkinson; Cuidadores; Carga del Cuidador; Cuidado Familiar; Investigación Cualitativa.

Experiências de cuidado na perspectiva de cuidadores de pacientes com doença de Parkinson em Cali, Colômbia

Resumo

Introdução: A doença de Parkinson exige cuidados complexos. Os cuidadores, principalmente mulheres, enfrentam sobrecarga física e emocional; no entanto, também encontram gratificação. **Objetivo:** Compreender as experiências de cuidado de cuidadores de pacientes com doença de Parkinson em Cali, Colômbia. **Materiais e Métodos:** Foi realizado um estudo qualitativo com delineamento de análise temática reflexiva. Um grupo focal foi conduzido com seis cuidadores. A análise dos dados foi realizada utilizando o software ATLAS.ti 25. **Resultados:** Três temas principais emergiram: 1. Desempenho altruísta, em que os cuidadores expressam dedicação incondicional ao paciente, apresentam estratégias de enfrentamento espiritual e emocional e buscam promover a autonomia e a participação do paciente; 2. Impacto emocional, que inclui exaustão emocional diante das demandas do paciente, compaixão pelos cuidados prestados e satisfação com a equipe de saúde; 3. Necessidades vivenciadas, que correspondem às necessidades de treinamento, informação, conhecimento de ferramentas digitais, assistência médica integral e apoio humano. **Discussão:** Os cuidadores demonstram um desempenho sacrificial, impacto emocional e necessidades diversas, o que coincide com a literatura revisada até o momento. Destacou-se a importância do treinamento, da promoção da autonomia, do enfrentamento emocional e espiritual, bem como o valor do apoio humano, tecnológico e interdisciplinar. **Conclusões:** Os cuidadores enfrentam um alto nível de sacrifício pessoal e emocional, o que reforça a necessidade de intervenções que ofereçam apoio abrangente e recursos adequados. Este estudo destaca a importância de reconhecer e atender às necessidades dos cuidadores para melhorar seu bem-estar e a qualidade do cuidado que prestam.

Palavras-Chave: Doença de Parkinson; Cuidadores; Sobrecarga do Cuidador; Cuidado Familiar; Pesquisa Qualitativa.

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease worldwide¹. Over recent decades, it has become an increasingly important public health concern². According to the World Health Organization (WHO), its global prevalence has doubled over approximately 25 years, reaching more than 8.5 million affected individuals in 2019, accompanied by a substantial increase in associated disability and mortality³. This trend is largely attributable to the progressive aging of the population, a phenomenon expected to drive a sustained increase in care needs over the medium and long term and to continue intensifying through 2050⁴.

In Colombia, PD exhibits a similar pattern, with a higher frequency among older age groups and an increase in cases reported in recent registries⁵. In this context, the impact of the disease extends beyond the patient and affects caregivers as well. Informal caregiving has been consistently associated with a high burden among those who assume this role, affecting their physical, emotional, and social dimensions⁶. The demographic profile of caregivers in Colombia typically includes women of working age living in vulnerable circumstances and devoting many hours each day to caregiving tasks⁷. In addition, they are often homemakers with incomplete primary education and a high degree of religious commitment⁸. Against this backdrop, the following research question was posed: What are the caregiving experiences of female caregivers of patients with Parkinson's disease?

Parkinson's disease is a neurodegenerative condition that affects motor function, manifesting as tremor, bradykinesia, muscle rigidity, and postural instability, and impairing an individual's ability to perform activities of daily living⁹. Patients require caregivers who can safeguard their well-being. A caregiver is typically a family member (spouse, adult children, or other relatives) or a friend who provides informal, unpaid support to the patient¹⁰. Such support includes providing physical assistance, offering emotional support, and facilitating daily activities, including mobility, communication, and personal hygiene¹¹.

The interaction between caregivers and patients influences the latter's self-care and quality of life. In this regard, interventions for Parkinson's disease include digital psychological support solutions¹² and digital care technologies that incorporate contributions from patients and caregivers¹³, among others. Such interventions indirectly benefit caregivers by reducing the emotional burden associated with caregiving¹². As the population ages, the need for care is expected to increase, underscoring the importance of ensuring ongoing support and resources so that caregivers can maintain their well-being and effectiveness in carrying out their caregiving tasks¹⁴.

Care is understood as a holistic process that integrates cultural and human dimensions, emphasizing the interconnectedness of life and the social context¹⁵. This study draws upon Leininger's Culture Care Theory¹⁶ and Watson's Theory of Human Caring¹⁷, both of which are essential for understanding care. The former focuses on activities aimed at assisting, supporting, or enabling one or more individuals to improve their human condition from a cultural perspective, whereas the latter conceptualizes care as a value and an attitude that should become a matter of will, intention, or commitment, manifested through concrete actions, and proposes a comprehensive and relational view of care¹⁵.

As Parkinson's disease progresses, caregivers require guidance on managing patients' symptoms, including both motor and non-motor symptoms, depression, and cognitive impairment¹⁸. Effective self-management strategies include medication management, physical activity, and psychological support, all of which should be tailored to the disease stage¹⁹. These strategies also include facilitating patient autonomy in self-care and participation²⁰ within the framework of occupational

and psychosocial interventions²¹. In this regard, educational programs are essential for equipping caregivers with the competencies required for effective patient management and for fostering a sense of competence and confidence in their caregiving role²², which in turn improves the quality of care and strengthens caregiver empowerment²³.

However, caregivers often encounter difficulties associated with treatment demands, medication management, scheduling medical appointments, and implementing lifestyle modifications for the patient. The emotional and physical demands of caregiving may generate or exacerbate stress²⁴, lead to social isolation and limited personal time²⁵, and contribute to depression and anxiety²⁶, particularly among women responsible for caregiving²⁶. These difficulties are influenced by factors such as the stage of the disease, the coping mechanisms used by caregivers, and their own mental health status^{26,27}. Likewise, caregiver burden is shaped by the cultural context, which influences the formation of caregivers' experiences and aspirations²⁸.

The foregoing highlights the importance of psychological support in reducing anxiety²⁷ and enhancing caregivers' coping strategies, which may be problem-focused, emotion-focused²⁹, or spiritually oriented³⁰. In this regard, mutual support programs among caregivers, as well as opportunities to share their experiences, help mitigate feelings of helplessness and inadequacy^{22,31}. Despite the challenges described, many caregivers perceive their role as a means of managing the disease, finding personal gratification, and experiencing personal growth through caregiving, which may be viewed as either a challenge or a rewarding experience³². As noted, caregiver burden may generate stress, anxiety, and isolation, particularly among women who provide care²⁶; however, positive aspects have also been identified, including personal growth and emotional gratification³².

Additionally, as Inaltekin and Kocatürk²⁷ have noted, *access to information* is important as it is necessary to identify the factors that contribute to caregiver burden. Likewise, understanding the *emotional impact on caregivers* is essential for understanding *caregivers' experiences*, given the various effects on well-being and the presence of indicators of anxiety.

Although the literature has extensively addressed caregiver burden and the need for psychoeducational support among caregivers of people with PD, these studies have primarily focused on the functional, clinical, and instrumental dimensions of caregiving. Thus, the senses, meanings, and tensions embedded in the everyday experience of caregiving have been explored less extensively⁶. In the Colombian context, although studies have examined caregiver profiles^{5,8} and caregiver burden⁷, there remains a need to explore the experiential component of this phenomenon further. In response to these gaps, the present study aimed to understand the caregiving experiences from the perspective of female caregivers of patients with Parkinson's disease in Cali, Colombia.

Materials and Methods

Study design

This was a qualitative study, epistemologically grounded in a constructionist posture. A reflexive thematic analysis design was employed, emphasizing the active reflexivity of the researchers, which enabled the generation of central themes from participants' narratives within a critical posture³³.

Participants

Six female caregivers of patients with Parkinson's disease participated in the study. Participants were selected through convenience sampling due to difficulties in accessing eligible participants³⁴. Female caregivers of patients in stages 1, 2, and 3 of the disease who had the technological skills required

to connect via videoconference were included. Individuals with comorbidities that could affect data collection were excluded. All participants were women affiliated with the Parkinson Foundation of Colombia in Cali. Their mean age was 63.5 years, and the mean duration of their caregiving experience was 6.6 years. Regarding their relationship to the patient, most were spouses; one was a daughter, and another was a nurse [Table 1](#).

Table 1. Participants' characteristics

Participant	Age	Years as a caregiver	Relationship to the Patient
Amber	69	5	Wife
Sapphire	85	7	Wife
Emerald	61	8	Wife
Onyx	71	3	Wife
Topaz	57	9	Daughter
Amethyst	38	8	Nurse

Data collection technique

A homogeneous focus group was used, as it was considered appropriate for understanding shared experiences among participants with similar characteristics. The focus group was conducted virtually to facilitate participant access³⁵. The focus group protocol was developed based on a review of the existing literature, with particular attention to the contributions of Inaltekin and Kocatürk²⁷, from which the topics of caregiving experiences, emotional impact, and information needs were identified. An introductory topic with sociodemographic questions was also included. The instrument was evaluated by six expert judges, who assessed the clarity, coherence, representativeness, and appropriateness of the questions for the study [Table 2](#).

Table 2. Focus group guide

Topic	Questions
Experiences and lived experiences as a caregiver	What feelings do you experience in relation to the process of caring for a patient with PD? Briefly describe what being a caregiver of a patient with Parkinson's disease means to you.
Emotional impact	Could you share a significant experience that you remember having as a caregiver of a patient with Parkinson's disease during the first three stages of the disease? (Explore: difficulties or needs.) What do you believe are the most important needs faced by caregivers when caring for patients with Parkinson's disease during the first three stages?
Information needs	What challenges or problems have you encountered when seeking information on how to manage basic activities of daily living for the care of a patient with Parkinson's disease in the early stages? What concerns or situations do you face in the day-to-day care of patients? What type of information do you consider crucial for providing effective care during the early stages of Parkinson's disease?

PD: Parkinson's disease

Procedures

The researchers contacted the Parkinson Foundation of Colombia, a healthcare institution that supports individuals with Parkinson's disease in Cali. This institution facilitated access to potential participants, who were informed about the purpose of the study. After verifying the inclusion criteria, six participants were recruited and provided written informed consent. Subsequently, in March 2024, a virtual meeting was held via Zoom to conduct the focus group. During this session, the first researcher served as moderator and the second researcher as assistant, ensuring a comfortable environment for the participants, who selected their own pseudonyms and the location from which they would

join the meeting (their homes). The session was conducted in Spanish, and no compensation was provided for participation. The focus group was not repeated, and no participants withdrew from the study. The focus group transcript was prepared manually.

Data analysis

Qualitative data were analyzed following the reflexive thematic analysis approach³³. First, the researchers familiarized themselves with the data through verbatim transcription and repeated readings, which enabled them to identify relevant excerpts addressing the research objective. Initial coding was then conducted inductively by assigning codes to the excerpts. Two coding cycles were carried out: the first involved open and thematic coding, and the second involved axial and pattern coding. Subsequently, themes were generated, reviewed, and defined. At this stage, a semantic map was developed to visualize the relationships among codes and themes. It should be noted that the reflexive nature of the design allowed the concepts and theories previously described (such as those of Watson and Leininger) to serve as guiding frameworks; however, the codes and themes were refined through the research team's ongoing reflection. In addition, reflexive notes were maintained throughout the analytic process to support interpretation.

Meaning-generation criteria, including representativeness, frequency, and thickness, were applied³⁶. Based on these criteria, the codes were filtered, prioritizing those considered most meaningful for reporting the findings. Although one of the participants was a nurse, no differential analysis was conducted in relation to the other participants because the unequal number of participants did not allow for comparisons between them. The analysis was conducted by the three researchers, with discrepancies resolved through consensus, and ATLAS.ti 25 was used to support the analytic process. The complete dataset is publicly available for free access through Mendeley Data³⁷.

With regard to ethical and quality considerations, approval was obtained from the Ethics Committee of Antonio José Camacho University (FEDV-003-24-01). The study adhered to ethical principles, including the *confidentiality* and *anonymity* of the information collected, respect for participants' rights and dignity, as stated in the informed consent form, and the protection of participants' *autonomy*. In addition, rigor criteria were incorporated, including *credibility* through participant validation of the transcript and *confirmability* through a rigorous, systematic analytic process that helped ensure the quality of the findings. Finally, the study was conducted in accordance with the *Consolidated Criteria for Reporting Qualitative Research (COREQ)*³⁸.

Results

The results presented below emerged from a reflexive thematic analysis, in which the codes and analytic themes were interpretive constructions developed through the reflexivity of the research team, drawing on the preceding sections. In this regard, the caregiving experiences of female caregivers of patients with PD can be understood through three significant themes: the caregiver's sacrificed performance, the emotional impact of caregiving, and experienced needs, which are described below [Figure 1](#).

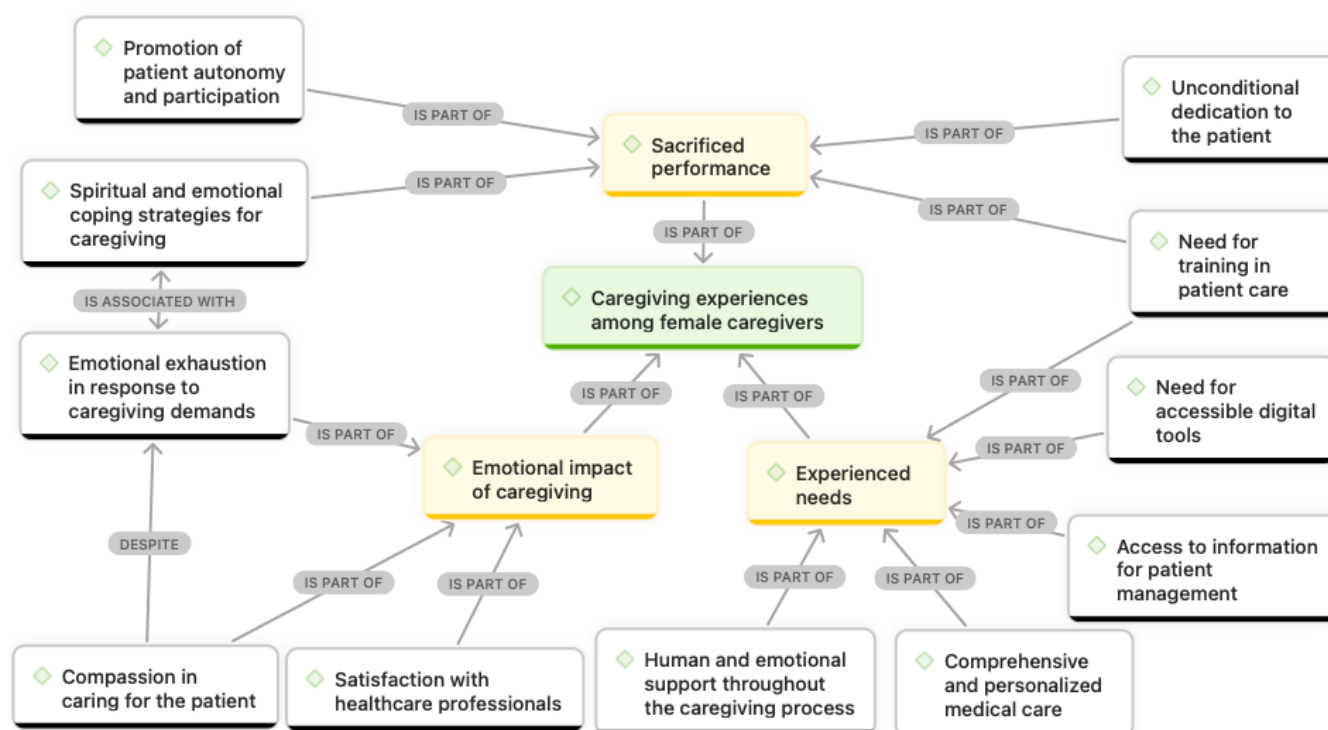


Figure 1. Thematic map of caregiving experiences among female caregivers

Sacrificed performance

The caregivers described their role as a comprehensive, ongoing commitment, marked by constant dedication to the patient, extending beyond their personal routines and requiring continuous availability. This commitment also involved adapting their daily lives to the patient's physical, emotional, and spiritual needs, assuming responsibility for the patient's well-being, and pursuing ongoing education to improve the care provided. At the same time, caregivers coped with the strain of caregiving through emotional and faith-based strategies, which provided strength and meaning to the act of caring.

According to the caregivers' accounts, sacrificed performance encompasses the following:

Unconditional dedication to the patient. This involves total commitment, without fixed routines, as personal activities depend on the patient's needs. Even when wishing to engage in recreational activities, caregivers reported that they must include the patient, who often requires their companionship for basic tasks. As such, they indicated that their caregiving responsibilities are constant and that they must remain available at all times, including for medication management.

"There's no such thing as a set routine, because you can be doing one thing and everything changes in an instant. [...] On top of that, they become a part of you. Even when I go to the bathroom, [...] he's constantly asking, 'Where are you?' And I say, 'I'm right here.' So you have to be paying attention all the time. You can't say, 'I have my routine. I'm going to get up and do this or that.' No. You get up and deal with whatever comes up throughout the day." (Amber, 69 years old, caregiver for 5 years).

Need for training in patient care. Participants sought to learn about the disease through their involvement in care centers and support groups. They attended courses and engaged in additional activities aimed at improving the patient's well-being. They recognized that although there was still much to learn, they adapted to each patient's needs, enabling them to provide better care and foster trust with patients.

"Yes, I've taken several courses. I learned about caring for a person with Parkinson's disease, including things like 'How to prepare for a neurology appointment.' For example, keeping a journal and updating it regularly so that, when the day of the appointment comes, you can provide a summary [...] and when the doctor sees it, he can make much better progress." (Topaz, 57 years old, caregiver for 9 years).

Promotion of patient autonomy. In this regard, participants indicated that caregiving involved not only careful medication management but also engaging patients in activities that promote their emotional and physical well-being. They also emphasized the importance of going for walks, playing games, and participating in activities such as dancing and crafts, which contributed to patients' development and active engagement. In addition, they highlighted the need to include patients in daily and family activities to avoid their exclusion. Participants further indicated that it is essential for patients to continue performing everyday activities independently, with support from the caregiver, thereby creating an environment conducive to their progress.

"If patients aren't taken out, if they don't spend time with other people, if no one plays with them [...] believe me, they're not going to improve. Medication does part of the job, but the emotional side, the soul part, is about connecting with them, listening to them [...] My mother told me, 'I don't need a psychologist anymore because you've become like my psychologist.'" (Sapphire, 85 years old, caregiver for 7 years).

Spiritual and emotional coping strategies in caregiving. Caregivers reported that faith-based strategies provided them with calmness and strength to face daily challenges, exhaustion, and uncertainty. They acknowledged the difficulty of accepting patients' dependency and vulnerability, which initially led them to suppress their emotions. However, many chose to focus on solutions and accompany patients with a more positive outlook rather than dwelling on suffering.

"I ask God every day for the wisdom to guide me and show me what to do, and believe me, it's helped. In eight months, the progress my mother has made [...] she couldn't move before, and now she does—she even dances. But you have to take action [...] It's not just about the intellectual or psychological side; you also have to care for the soul, because we are body, soul, and spirit." (Emerald, 61 years old, caregiver for 8 years).

Emotional impact of caregiving

According to the participants, the emotional impact of caregiving refers to the range of emotional experiences they face in response to the demands of providing ongoing support. These experiences included exhaustion, anxiety, and feelings of helplessness in the face of disease progression, as well as compassion, empathy, and satisfaction derived from the relationship with the patient and the professional support received. In this sense, caregivers experienced a complex emotional process characterized by both strain and personal fulfillment. The emotional impact of caregiving can be understood through emotional exhaustion, compassion in caregiving, and satisfaction with healthcare professionals.

Emotional exhaustion in response to caregiving demands. Caregivers were constantly tasked with shielding their family members from negative information in their surroundings, which led to fatigue as they sought to maintain a positive attitude. This strain intensified when their family members did not respond as expected. In addition, they expressed anxiety about the uncertain progression of PD, feeling that after resolving one situation, they had to start over again, which generated stress.

The unpredictable progression of PD elicited irritability, uncertainty, and feelings of helplessness among caregivers. They commonly expressed distress when witnessing patients' decline. Caregivers were also emotionally affected by observing other patients in more advanced stages of the disease,

which generated feelings of hopelessness regarding the future of their family members. Difficulties in understanding the causes and consequences of changes in the patient's health status contributed to their emotional strain, highlighting the need for greater emotional and psychoeducational support throughout the caregiving process.

"Because otherwise the caregiver ends up getting sick too, ends up feeling stressed [...] and the anxiety starts to build up, you know? Because all you want is for them to get better." (Topaz, 57 years old, caregiver for 9 years).

Compassion in caring for the patient. Participants emphasized the importance of supporting their family members through the caregiving process with patience and understanding. Compassion was expressed through empathy toward the patient's emotional process, recognizing that accepting the disease could be difficult and, at times, even denied. In this sense, caregivers demonstrated sensitivity to the emotions of those in their care. Within this context, they prioritized the patient's well-being, often above their own, demonstrating a profound commitment to providing daily support.

"[As a caregiver] I have three basic rules: understand them, support them, and care for them, because they're patients. You have to understand them because they can be very challenging, and even though they have Parkinson's disease, they may also have other conditions that can affect them." (Amethyst, 38 years old, caregiver for 8 years).

Satisfaction with healthcare professionals. Caregivers highlighted the emotional support they received throughout the care process. They reported that healthcare professionals not only provided medical guidance but also offered emotional support and guided caregivers during moments of distress. This facilitated access to support groups, which was perceived as a meaningful and compassionate form of support.

Caregivers valued the medical recommendations provided regarding physical, occupational, and psychological therapies. They highlighted that physicians provided clear guidance, responded to caregivers' questions, and organized educational programs focused on PD management. They also recognized that therapists tailored their interventions to the specific type of PD presented by each patient, which was highly appreciated.

"We have a treasure in the people who care for our patients, because we have a therapist who knows exactly what she's doing and understands how to work with people who have Parkinson's disease." (Amber, 69 years old, caregiver for 5 years).

Experienced needs

According to the caregivers, experienced needs refer to the requirements identified throughout the process of caring for people with PD. These include emotional and social support; access to support groups and psychological therapies; clear information about disease management and medical care; comprehensive and personalized care; accessible technological tools that facilitate communication, and ongoing learning and support. Together, these resources enable caregivers to strengthen both their own well-being and the patient's.

Human and emotional support throughout the caregiving process. Caregivers valued support groups because their establishment provided opportunities to share their experiences of living with the disease and exchange useful day-to-day strategies. They also emphasized the need to participate in psychological therapies and recreational activities that promote the emotional well-being of both the patient and themselves.

Access to support groups and psychological therapies. Participants recognized the role of foundations and support groups in providing spaces for interaction, education, and group activities that strengthen mutual support among peers. These groups also offered practical guidance on how to carry out therapeutic activities. In addition, participants emphasized the need for technological tools that facilitate interaction with others, as these would enable them to ask questions and receive responses from individuals with similar experiences, thereby strengthening support and information networks.

"The patient needs something to keep them engaged. So, you have to look for support from other people, stay in communication, and have people who can help you—that interaction we were talking about. [...] That's what a support group is." (Emerald, 61 years old, caregiver for 8 years).

Comprehensive and personalized medical care. Caregivers considered it essential for patients to have access to therapies such as occupational therapy, neurorehabilitation, and physical therapy from the early stages of the disease. Likewise, they emphasized the need for specialized therapists according to the stage of Parkinson's disease, as care needs vary depending on the specific presentation of the disease and the patient's personality, requiring a multidisciplinary team approach. Alongside physical treatment, caregivers viewed psychological support and acceptance of the diagnosis as essential components of care. They also highlighted the importance of promoting physical and cognitive activity to support the well-being of patients with PD.

"(We need) professionals with more specialized expertise in patients with Parkinson's disease [...] Every person should have a place where they feel comfortable and where their rehabilitation works for them, and a patient who needs truly comprehensive care." (Amber, 69 years old, caregiver for 5 years).

Access to information for the management of patients with PD. Caregivers emphasized the need for personalized informational support to understand their family members' situations better, as each case of Parkinson's disease is different and requires specific strategies. They also requested clear information about medications, how they work, and their interactions with food, given their impact on patients' health. In addition, caregivers expressed a need for more information, particularly at the time of diagnosis, as the information provided at that stage was perceived as primarily intended for healthcare professionals, making it difficult for them to understand. They also sought information about medication combinations, their effects, therapies, appropriate nutrition, and a comprehensive approach to the disease.

"You need to know how to manage all of their medications properly so you don't end up causing more problems down the road. [...] You have to know how to handle them. My doctor gave me a schedule that has worked really well for me. An internist helped me make sure the medications wouldn't harm his body either. That has helped me a lot in learning how to manage them." (Sapphire, 85 years old, caregiver for 7 years).

Need for accessible digital tools. Caregivers emphasized the need for user-friendly, intuitive tools that use clear, understandable language. They considered it essential for these tools to address their needs and be accompanied by practical training to facilitate their use. Although they used platforms such as Google and YouTube to search for information on the disease, nutrition, and medical recommendations, they found the information insufficiently specific. As a result, they expressed the need for an interactive space, moderated by a specialist, where they could share experiences, address questions, and feel supported.

"The most important thing about apps is that they have to be user-friendly [...] Some apps are impossible to use. They have too many features, and you can't get to the information you're looking for. So, it has to be simple, with language that I can understand." (Amber, 69 years old, caregiver for 5 years).

Discussion

This study sought to explore the caregiving experiences from the perspective of female caregivers of patients with PD. Through a focus group, experiences related to sacrificed performance, the emotional impact of caregiving, and experienced needs were identified. These findings expand the theoretical and empirical understanding of caregiving in the context of this disease. Sacrificed performance, reflected in unconditional dedication to the patient, was consistent with the findings of Risnarita et al.¹¹, who highlighted the broad range of tasks assumed by informal caregivers, from physical assistance to emotional support. However, the present study further demonstrates that caregivers not only faced these demands but also actively sought educational opportunities, such as training courses and recreational activities for patients, an aspect that has not always been made visible in previous research. This finding is consistent with Watson's theory¹⁷, which emphasizes the need for a holistic approach to care. It also underscores the importance of promoting patient autonomy, a finding that aligns with Tuijt et al.¹⁹ regarding the need to encourage physical and cognitive activity among patients with PD.

Regarding the promotion of patient autonomy and participation, caregivers reported making efforts to respect patients' wishes and decisions, which is consistent with previous studies showing that perceived autonomy improves quality of life and reduces depressive symptoms²⁰. This type of care fosters patients' sense of agency and strengthens relationships of trust. These findings are consistent with Watson's perspective¹⁷, which holds that caring involves recognizing the other person as an active participant in the relationship, thereby contributing to their psychoemotional well-being.

With regard to spiritual coping strategies, these findings were consistent with the sociocultural profile of Colombian caregivers, who tend to demonstrate a high level of religious commitment⁸. In this regard, Durán Badillo et al.³⁰ found that spirituality supports coping and may reduce caregiver burden. Closely related to this, caregivers also drew on emotional coping strategies, including humor, acceptance, and positive reappraisal, which have been associated with lower levels of depressive symptoms and better emotional well-being²⁹.

The emotional impact of caregiving revealed psychosocial implications such as emotional exhaustion and anxiety, which are consistent with previous research^{24,32}. However, the compassion and empathy developed by caregivers are particularly noteworthy, as they prioritized the patient's well-being and found satisfaction in their caregiving role, a finding that is consistent with Seshadri et al.³². This balance between challenges and rewards reinforces the need for interventions that address both caregivers' psychological well-being and their practical caregiving skills.

With regard to satisfaction with healthcare professionals, caregivers reported feeling heard and acknowledged, experiencing greater confidence, and reduced uncertainty. This finding is consistent with another study³⁹, which found that interdisciplinary collaboration led to better therapeutic outcomes and greater subjective well-being among both patients and their caregivers.

The needs experienced by caregivers reflected a demand for comprehensive support, both human and technological. The need for accessible digital tools supports the recommendations of Pinto et al.¹² and Monje et al.¹³, who highlighted the role of technology in improving care. In addition, caregivers emphasized the need for training and mutual support networks, which are essential for reducing stress, a finding consistent with previous studies^{22,31}. In the Colombian context, where caregivers are predominantly women living in situations of vulnerability⁷, these needs take on particular significance and underscore the importance of public policies that promote access to resources.

Regarding access to information, caregivers expressed the need for information about the disease and therapeutic options that is clear, up-to-date, and easy to understand, consistent with the findings of Hiseman and Fackrell¹⁸. In this regard, Tuijt et al.¹⁹ reported that a lack of information, or information presented in technical language, generated distress, insecurity, and feelings of helplessness. Conversely, training and adequate access to information facilitated coping and improved the quality of care²³. Caregivers also valued models of care that incorporate psychological and social dimensions, consistent with Watson's humanistic approach¹⁷, as these models enabled a more tailored response to the complex needs of individuals with PD and their caregivers. In line with these findings, Foster et al.²¹ supported this perspective by demonstrating that therapeutic approaches combining physical, occupational, and psychosocial interventions are more effective in maintaining patients' quality of life and reducing caregiver burden.

Human and emotional support was perceived as essential for long-term caregiving. In this regard, the absence of support networks may lead to emotional exhaustion and increased psychological vulnerability, as noted by Geerlings et al.³¹. Although not all studies focus specifically on formal or informal support networks, Watson¹⁷ emphasized that caring is a practice of human connection in which the emotional bond can be a source of both strain and meaning. In this sense, caregivers who were able to reframe their role as an opportunity for connection, personal growth, and dedication tended to experience the caregiving process more positively. These findings underscore the need for psychological interventions²⁷, particularly those aimed at strengthening coping strategies, whether problem-focused, emotion-focused²⁹, or spiritually oriented³⁰.

The results underscore the importance of a cultural and holistic approach to caregiving, consistent with the perspectives advanced by several authors^{16,17}. These findings reinforce the need to consider cultural context when designing interventions, as suggested by Achen et al.²⁸. This study provides a comprehensive understanding of caregiving experiences from the perspective of female caregivers of individuals with PD. These findings have important implications for the development of interventions aimed not only at improving patients' quality of life but also at enhancing caregivers' well-being, given the essential role caregivers play in the management of this disease.

Conclusions

Female caregivers of individuals with PD demonstrate unconditional dedication that involves profound personal sacrifices and a strong commitment to the patient's well-being. This sacrificed performance reflects the challenges of assuming an informal caregiving role, while also highlighting caregivers' ability to develop adaptive strategies, such as seeking training and promoting patient autonomy. Furthermore, despite the significant emotional impact they face, characterized by stress and exhaustion, caregivers find in their role a source of emotional gratification and personal growth, illustrating the dual nature of caregiving as both a challenging and an enriching experience.

Furthermore, caregivers expressed an urgent need for comprehensive support, particularly in contexts of vulnerability where caregiving is predominantly provided by women with limited resources. Addressing these needs, including access to accessible technological tools and mutual support networks, is essential to ensuring effective and sustainable care. The results also underscore the importance of a cultural and holistic approach, integrating spiritual and emotional dimensions into the design of interventions.

In summary, this study highlights the pivotal role of female caregivers in the management of Parkinson's disease and underscores the need to develop comprehensive support strategies that promote their physical, emotional, and social well-being.

Among the study's limitations are the small number of participants and the use of a single focus group, which limited triangulation across data sources and methods. In addition, the inclusion of caregivers affiliated with a single foundation may limit the transferability of the findings to other contexts. For future research, further exploration of the importance of educating close family members is recommended. Although this emerged as a minor theme in the present study, it may be highly relevant, as the way information is communicated can affect family communication and, consequently, the care provided to both the patient and the caregiver.

Conflicts of interest: The authors declare no potential conflicts of interest.

Funding: This article is part of the research project PI0624, *Support for Caregivers of Patients with Parkinson's Disease Through a Technological Tool*, approved under Resolution No. 080 of 2024 and endorsed by the Ethics Committee of the Institución Universitaria Antonio José Camacho.

Acknowledgments: The authors would like to thank the Parkinson Foundation of Colombia.

Author contributions: KVAD: Conceptualization; Data Curation; Formal Analysis; Investigation; Methodology; Project Administration. BSV: Conceptualization; Visualization; Writing – Original Draft Preparation; Writing – Review & Editing. EM-E: Investigation, Methodology, Software, Supervision, Writing – Review & Editing.

References

1. **Dorsey E, Elbaz A, Nichols E, Abbasi N, Abd-Allah F, Abdelalim A et al.** Global, regional, and national burden of Parkinson's disease, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*. 2018;17(11):939-953. [https://doi.org/10.1016/S1474-4422\(18\)30295-3](https://doi.org/10.1016/S1474-4422(18)30295-3)
2. **Feigin VL, Abajobir AA, Abate KH, Abd-Allah F, Abdulle AM, Abera DF, et al.** Global, regional, and national burden of neurological disorders during 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet Neurology*. 2017;16(11):877-97. [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(17\)30299-5/fulltext?platform=hootsuite](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(17)30299-5/fulltext?platform=hootsuite)
3. **World Health Organization.** Launch of WHO's Parkinson disease technical brief [Internet]. 2022 [cited 2025 Jan 15]. Available from: <https://www.who.int/news/item/14-06-2022-launch-of-who-s-parkinson-disease-technical-brief>
4. **Su D, Cui Y, He C, Yin P, Bai R, Zhu J, et al.** Projections for prevalence of Parkinson's disease and its driving factors in 195 countries and territories to 2050: modelling study of Global Burden of Disease Study 2021. *BMJ*. 2025;388:e080952. <https://doi.org/10.1136/bmj-2024-080952>
5. **Orozco JL, Valderrama-Chaparro JA, Pinilla-Monsalve GD, Molina-Echeverry MI, Pérez Castaño AM, Ariza-Araújo Y, et al.** Parkinson's disease prevalence, age distribution and staging in Colombia. *Neurol Int*. 2020;12(1):8401. PMID: 32774822; PMCID: PMC7378539
6. **Aamodt WW, Kluger BM, Mirham M, Job A, Lettenberger SE, Mosley PE, et al.** Caregiver Burden in Parkinson Disease: A Scoping Review of the Literature from 2017-2022. *J Geriatr Psychiatry Neurol*. 2024;37(2):96-113. <https://doi.org/10.1177/08919887231195219>
7. **Carreño SP.** Agrupaciones de cuidadores familiares en Colombia: perfil, habilidad de cuidado y sobrecarga. *Pensam Psicol*. 2017;15(1):87-101. <https://doi.org/10.11144/Javerianacali.PPS15-1.ACFC>
8. **Barreto Osorio RV, Coral Ibarra R del C, Campos MS, Gallardo Solarte K, Támara Ortiz V.** Cuidadores y cuidadoras familiares de personas con enfermedad crónica en Colombia: más similitudes que diferencias. *Salud Uninorte*. 2015;31(2):255-265. <https://doi.org/10.14482/sun.31.2.6988>

9. **Asuku AO, Ayinla MT, Olajide TS, Ajagun EJ, Ganiyu KO, Hamza YO, et al.** Diagnosis and Biomarkers of Parkinson's Disease. In: Mohamed W, editor. Zebrafish as a Model for Parkinson's Disease. Boca Raton: CRC Press; 2024. p.154-66. <https://doi.org/10.1201/9781003402893-15>
10. **Kisangala E, Mbivnjo EL, Webb EJD, Barrett B, Rukundo GZ, Namisango E, et al.** Health and economic impact of caregiving on informal caregivers of people with chronic diseases in sub-Saharan Africa: A systematic review. *PLOS Glob Public Health*. 2024;4(12):e0004061. <https://doi.org/10.1371/journal.pgph.0004061>
11. **Risnarita D, Pribadi T, Furqoni PD, Elliya R.** Depresi, kecemasan, stress dan beban perawatan pengasuh utama caregiver pasien dengan stroke. *Holistik J Kesehat*. 2022;16(7):625-35. <https://doi.org/10.33024/hjk.v16i7.8843>
12. **Pinto C, Brown J, Hurt C, Cubi-Molla P, Chowdhury S, McCracken L, et al.** Acceptability and feasibility randomised controlled trial of a digital mental health intervention for people with Parkinson's PACT: trial protocol. *Pilot Feasibility Stud*. 2025;11:32. <https://doi.org/10.1186/s40814-025-01594-9>
13. **Monje MHG, Grosjean S, Srp M, Antunes L, Bouça-Machado R, Cacho R, et al.** Co-Designing Digital Technologies for Improving Clinical Care in People with Parkinson's Disease: What Did We Learn?. *Sensors*. 2023;23(10):4957. <https://doi.org/10.3390/s23104957>
14. **Hailu GN, Abdelkader M, Meles HA, Teklu T.** Understanding the Support Needs and Challenges Faced by Family Caregivers in the Care of Their Older Adults at Home. A Qualitative Study. *Clin Interv Aging*. 2024;19:481-90. <https://doi.org/10.2147/CIA.S451833>
15. **McCance TV, McKenna HP, Boore JRP.** Caring: theoretical perspectives of relevance to nursing. *J Adv Nurs*. 1999;30(6):1388-95. <https://doi.org/10.1046/j.1365-2648.1999.01214.x>
16. **Leininger MM, editor.** Culture Care. Diversity & Universality: A Theory of Nursing. New York: National League for Nursing Press; 1991.
17. **Watson J.** Nursing: The Philosophy and Science of Caring. Revised ed. Denver: Boulder; 2008.
18. **Hiseman JP, Fackrell R.** Chapter Fourteen - Caregiver Burden and the Nonmotor Symptoms of Parkinson's Disease. *Int Rev Neurobiol*. 2017;133:479-97. <https://doi.org/10.1016/bs.irn.2017.05.035>
19. **Tuijt R, Tan A, Armstrong M, Pigott J, Read J, Davies N, et al.** Self-Management Components as Experienced by People with Parkinson's Disease and Their Carers: A Systematic Review and Synthesis of the Qualitative Literature. *Parkinsons Dis*. 2020;8857385. <https://doi.org/10.1155/2020/8857385>
20. **Kim E, Lee J, Chung M, Yoo S.** Self-care and quality of life in people with Parkinson's disease and their caregivers. *Innov Aging*. 2022;6(1):540-541. <https://doi.org/10.1093/geroni/igac059.2052>
21. **Foster ER, Bedekar M, Tickle-Degnen L.** Systematic review of the effectiveness of occupational therapy-related interventions for people with Parkinson's disease. *Am J Occup Ther*. 2014;68(1):39-49. <https://doi.org/10.5014/ajot.2014.008706>
22. **Cianfrocca C, Caponnetto V, Donati D, Di Stasio E, Tartaglini D, Lancia L.** The opinions and feelings about their educational needs and role of familial caregivers of Parkinson's Disease patients: a qualitative study. *Acta Biomed*. 2020;91(12):e2020002. <https://doi.org/10.23750/abm.v91i12-S.10264>
23. **Brooks DJ, Burn DJ, Clarke CE, Grosset DG, MacMahon DG, Playfer J, et al.** Updated guidelines for the management of Parkinson's disease. *Hosp Med*. 2001;62(8):456-70. <https://doi.org/10.12968/hosp.2001.62.8.1621>
24. **Tan QY, Roberts HC, Fraser SDS, Ibrahim K.** 1221 a cross-sectional study exploring the treatment burden in people with Parkinson's and their caregivers. *Age Ageing*. 2023;52(1). <https://doi.org/10.1093/ageing/afac322.054>

25. **Geerlings AD, Kapelle WM, Sederel CJ, Tenison E, Wijngaards-Berenbroek H, Meinders MJ, et al.** Caregiver burden in Parkinson's disease: a mixed-methods study. *BMC Med.* 2023;21(1):247. <https://doi.org/10.1186/s12916-023-02933-4>
26. **Carpinelli L, Savarese G, Luisi E, Pellegrino F, Pellicchia MT.** A Brief Report on the Caregiver Burden: Exploring the Risk and Psychological Factors in Caregivers of Patients with Parkinson's Disease. *Preprints.* 2024. <https://doi.org/10.20944/preprints202406.1384.v1>
27. **Inaltekin A, Kocatürk I.** Burden and associated characteristics in caregivers of Parkinson's disease patients. *Psychogeriatrics.* 2024;24(6):1297-304. <https://doi.org/10.1111/psyg.13191>
28. **Achen B, Terroba Chambi C, Bruno V.** P.022 Cross-cultural experiences and expectations from caregivers of people living with Parkinson's Disease: a comprehensive review. *Can J Neurol Sci.* 2023;50(S2):S63. <https://doi.org/10.1017/cjn.2023.126>
29. **Lazarus R, Folkman S.** Stress, Appraisal, and Coping. New York: Springer Publishing Company; 1984.
30. **Duran Badillo T, Donjuan-Díaz BE, Herrera Herrera JL, Llorente Pérez YJ, Cortes Montelongo DB, Guerra-Ordoñez JA.** Estrés y espiritualidad relacionado con la sobrecarga en cuidadores de adultos mayores con dependencia total. *Rev Cubana Enferm.* 2023;(39). <https://dialnet.unirioja.es/servlet/articulo?codigo=9923000>
31. **Geerlings AD, Meinders MJ, Bloem BR, van der Marck MA.** Using former carers' expertise in peer support for carers of people with Parkinson's Disease. *NPJ Parkinsons Dis.* 2022;8(1):133. <https://doi.org/10.1038/s41531-022-00381-0>
32. **Seshadri S, Contento A, Sugiura K, Abendroth M, Macchi Z, Kluger BM.** Parkinson's Disease Carepartners' Perceptions of the Challenges and Rewards of Caregiving. *Am J Hosp Palliat Care.* 2024;41(12):1442-50. <https://doi.org/10.1177/10499091231223739>
33. **Braun V, Clarke V.** Thematic Analysis: A Practical Guide. London: Sage Publications; 2022.
34. **Robinson OC.** Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qual Res Psychol.* 2014;11(1):25-41. <https://doi.org/10.1080/14780887.2013.801543>
35. **Turney L, Pocknee C.** Virtual Focus Groups: New Frontiers in Research. *Int J Qual Methods.* 2005;4(2):32-43. <https://doi.org/10.1177/160940690500400203>
36. **Malvaceda Espinoza E.** La generación de significado en el análisis cualitativo de información. In: Carrasco Tapia NE, La investigación cualitativa, sus aportes teóricos, metodológicos y prácticos. Ediciones Universidad Cooperativa de Colombia; 2023. p.177-202. <https://doi.org/10.16925/9789587604245>
37. **Andrade Díaz K, Salazar Villegas B, Malvaceda E.** Experiencias de cuidado, desde cuidadoras de pacientes con enfermedad de Parkinson. *Mendeley Data V1.* 2025. <https://doi.org/10.17632/py2hf28kv9.1>
38. **Tong A, Sainsbury P, Craig J.** Consolidated criteria for reporting qualitative research COREQ: a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-57. <https://doi.org/10.1093/intqhc/mzm042>
39. **Giladi N, Manor Y, Hilel A, Gurevich T.** Interdisciplinary Teamwork for the Treatment of People with Parkinson's Disease and Their Families. *Curr Neurol Neurosci Rep.* 2014;14:493. <https://doi.org/10.1007/s11910-014-0493-1>