

## Research report

# Statistical analysis and generative Artificial Intelligence (AI) for assessing pain experience, pain-induced disability, and quality of life in Parkinson's disease patients



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## ABSTRACT

The Parkinson's Disease (PD) is a chronic neurodegenerative condition characterized by motor symptoms such as tremors, rigidity, and bradykinesia, which can significantly impact various aspects of daily life. Among these aspects, pain is a prominent element. Despite the widespread use of therapies aimed at improving symptoms and quality of life, effective pain management is essential to enhance the quality of life of individuals affected by this disease. However, a detailed understanding of the factors associated with pain in PD is still evolving. In this study, we examined the disability caused by pain and the pain experienced by PD patients using two validated questionnaires, namely the Parkinson's Disease Questionnaire (PDQ) and the King's Parkinson's Disease Pain Questionnaire (KPPQ). Customized questions were also included to further explore the pain experience and management strategies adopted by PD patients. Through statistical analysis, we explored the relationships between questionnaire scores, socio-demographic data, and other relevant variables. Additionally, generative Artificial Intelligence (AI) was employed to gain a deeper understanding of patient responses. The results indicate the extent and impact of pain in PD and provide valuable insights for more targeted and personalized management. This study lays the foundation for future research and the development of interventions aimed at improving the quality of life for individuals affected by this condition.

## 1. Introduction

Parkinson's disease (PD) is one of the most rapidly growing neurological disorders, characterized by motor deficits preceded by non-motor peripheral dysfunctions and by the presence and progressive propagation of the alpha-synuclein (-syn) protein and loss of dopaminergic neurons. In 2020, more than 8.5 million patients suffering from PD were reported worldwide, and studies predict that the burden of this

disease will grow substantially in industrial countries (Author1 et al., 2023). PD causes numerous motor symptoms, some of which precede motor dysfunction by over a decade (Kalia and Lang, 2015). These include bradykinesia, hypomimia, rigidity, resting tremors, postural and gait changes. In addition to the cardinal motor symptoms, PD is characterized by a range of non-motor symptoms, the identification of which can improve clinical care, monitor disease progression, and enhance our understanding of its evolution. Among these, cognitive impairment,

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depression, anxiety, psychosis, apathy, and fatigue are notable examples. Among the increasingly recognized non-motor symptoms, pain is one of the most debilitating and disabling aspects of the disease. Painful phenomena are reported in 30–85% of the affected population, with an average of 66% (Marques and Brefel-Courbon, 2021). The significant variability can be explained by the lack of a validated tool for assessing pain in PD in clinical practice. This would also explain why pain remains undisclosed in 40.5% of PD patients, considering that up to 80% of patients experience chronic pain (Chaudhuri et al., 2015). Numerous studies reveal that pain has an extremely negative impact on both the physical and mental health of the patient, with clear correlations between the severity of the disease, depression, and reduced independence (Chaudhuri et al., 2015). The disparities in prevalence among different studies reflect the absence of clear diagnostic criteria and the limited awareness of this symptom among medical professionals. Pain experiences can indeed manifest with various characteristics in PD, making them challenging to describe for both physicians and patients. Furthermore, different types of pain can coexist in the same patient, leading to inadequate identification and treatment. Various characteristics are reported, such as muscle cramps, painful dystonia, numbness, tingling, burning, vibrating, or stabbing pain, which reflect the heterogeneity and complexity of these painful experiences (Williamson and Hoggart, 2005). There are no specific validated scales to identify and classify various types of pain in PD. In this study, we examine the pain experienced by individuals using the Parkinson's Disease Questionnaire (PDQ) (Anagnostis et al., 2004) and the King's Parkinson's Disease Pain Questionnaire (KPPQ) from King's College, London (Chaudhuri et al., 2015), two validated instruments designed to assess the disability due to pain and pain related to the disease. Additionally, we collected data through other questions to further explore the pain experiences and management strategies adopted by patients. Our results reveal the extent and impact of pain in PD, providing important insights for more targeted and personalized pain management strategies and lay the foundation for future research aimed at improving the well-being of individuals affected by this condition.

## 2. Methods

### 2.1. Design

From October 2022 to May 2023, a survey was conducted among a cohort of Italian individuals diagnosed with PD. A total of 89 participants willingly consented to participate in the study. The survey was administered through an anonymous questionnaire distributed on a voluntary basis. All sections of the questionnaire were digitized using a predefined template on the Google Drive platform, and the study was carried out through electronic distribution. We engaged with various Facebook groups and Instagram pages where computerized questionnaires were posted. The sampling strategy employed was (virtual) snowball sampling, continued until data saturation was achieved.

### 2.2. Survey instrument

The questionnaire comprises five sections: The first section (7 items) captures socio-demographic data of the patients, including gender, age, geographical area, marital status, level of education, employment status, and residential area. The second section (9 items) includes information about the disease management. The third section (15 items) investigates disease-related pain and includes two open-ended questions. Additionally, we integrated two validated questionnaires, PDQ and KPPQ, into the fourth and fifth sections.

The PDQ is a comprehensive tool designed to assess pain-related disability. It comprises 15 items divided into two subscales: "Functional Condition" (9 items) and "Psychosocial Component" (6 items). These subscales explore the physical and emotional dimensions of the disease's impact on individuals' daily lives. The Functional Condition

subscale has a maximum score of 90 points, while the Psychosocial Component has a maximum score of 60. The overall PDQ score, ranging from 0 to 150, is the sum of scores from these two components.

Similarly, the KPPQ plays a central role in evaluating pain specifically associated with PD. The questionnaire includes 14 items tailored to measure pain experienced by individuals with PD, providing insights into the nature, intensity, and impact of pain on their lives. The version we used consists solely of "Yes" or "No" questions that assess the presence or absence of specific types of pain (Martinez-Martin et al., 2018).

### 2.3. Ethical considerations

The study's ethical concerns were explicitly explained in the questionnaire introduction. The questionnaire's structure followed the guidelines established by the Italian Data Protection Authority (DPA). It was emphasized that taking part in the study was entirely optional, and participants had the freedom to discontinue their involvement at any point. Individuals who indicated their willingness to participate were provided with an informed consent form that reiterated the voluntary nature of their participation and guaranteed the confidentiality and anonymity of the gathered data. Additionally, to enhance the protection of participants' privacy, all responses in the questionnaire were anonymized.

### 2.4. Statistical analysis

Descriptive statistics were utilized to present participants' responses to questionnaire items. Continuous variables were summarized using mean and standard deviation (SD), while categorical variables were summarized using frequencies and percentages. Descriptive statistics for individual item responses in the validated questionnaires included item numbers, mean, median, standard deviation, skewness, as well as floor and ceiling effects. Additionally, Cronbach's alpha was employed to assess the internal consistency reliability of the scale. An analysis of variance (ANOVA) was performed to identify factors influencing pain in individuals with PD. To further analyze the influencing factors of PD pain, multiple linear regression analysis was conducted. Each questionnaire score served as the dependent variable, while the factors identified in the ANOVA analysis were utilized as independent variables. For questions with open-ended responses, generative AI (ChatGPT version 4) was employed to cluster similar answers and provide a summary of the results. The statistical analyses encompassed all qualitative and quantitative variables and were carried out using MATLAB software, with the significance level maintained at  $p < 0.05$ .

#### 2.4.1. Generative Artificial Intelligence

ChatGPT is a generative large language model (LLM) tool launched by OpenAI (OpenAI, L.Martinez-Martin et al., 2018, San Francisco, CA, USA), on November 30, 2022, trained on massive text datasets in multiple languages with the ability to generate humanlike responses to text input. ChatGPT reached 57 million users within the first month and 100 million users by January 2023 (Gilson et al., 2023), making it the fastest-growing consumer application of all time. The superiority of ChatGPT compared to its GPT-based predecessors can be linked to its ability to respond to multiple languages generating refined and highly sophisticated responses based on advanced modeling.

ChatGPT offers several advantages that contribute to its remarkable success and set it apart from its GPT-based predecessors. The model serves as an assistant for text writing, facilitating content creation across various contexts. Additionally, its ability to understand and generate responses can be harnessed to find solutions to specific questions. Users can pose complex questions and obtain detailed answers, leveraging the extensive knowledge base on which the model has been trained. ChatGPT's utility can also be extended to more specialized tasks, such as creating educational content, generating code, or solving specific problems in various industries. Its flexibility makes the model suitable

for multiple purposes, providing reliable support in diverse contexts.

One of the lesser-known applications highlighted in this article is using ChatGPT to interpret and categorize open-ended responses in surveys, where respondents provide answers in their own words. The model can provide consistent categorization of responses, reducing potential biases that might arise from human interpretation. This ensures a standardized approach in analyzing and organizing survey data. It can handle a large volume of responses quickly, aiding researchers in deriving insights from survey data in a timely manner and its versatility enables it to adapt to a wide array of survey questions across different domains. Incorporating ChatGPT for interpreting open-ended survey responses not only enhances the efficiency of data processing but also brings a level of standardization and consistency to the categorization process, ultimately facilitating more insightful and reliable analysis of survey data.

In our research, we utilized ChatGPT 4 to categorize responses to open-ended questions. Explanation of the Workflow:

- Data Collection: Gathered open-ended survey responses from participants, where they provided answers in their own words.
- Preparation: Cleaned and preprocessed the raw text data to ensure uniformity and remove any irrelevant information or noise.
- Input to ChatGPT 4: Fed the preprocessed survey responses as input to ChatGPT 4 for interpretation and categorization. The model's natural language understanding capabilities were employed to comprehend the diverse language used by respondents.
- Categorization: Leveraged ChatGPT 4's ability to generate refined and sophisticated responses to categorize the open-ended survey responses. Defined categories or themes beforehand, guiding the model in organizing the responses accordingly.
- Validation: Checked the model's output for accuracy and consistency. Validated the categorized responses against predefined criteria to ensure reliability.
- Iterative Refinement: Fine-tuned the model's categorization based on feedback and adjusted the categories as needed. Iterative refinement aimed to enhance accuracy and align with the research objectives.
- Results Analysis: Analyzed the categorized responses to derive insights and draw conclusions from the survey data. Examined patterns, trends, and variations within the categories.

Although the model's adaptability to diverse language nuances and its ability to handle large volumes of responses contributed to a comprehensive analysis of the survey data, we should take into account some limitations regarding ChatGPT.

We need to cautiously consider valid concerns, risks, and categorical failures experienced and cited in the context of LLM applications. Specifically, Borji comprehensively highlighted the caveats of ChatGPT use that included, but were not limited to, the generation of inaccurate content, the risk of bias and discrimination, lack of transparency and reliability, cybersecurity concerns, ethical consequences, and societal implications (Borji, 2023).

Therefore, the aim of the current use of ChatGPT was to explore open-ended questions surveys, where respondents freely express their thoughts.

### 3. Results

#### 3.1. Sample demographics and baseline characteristics

A total of 89 individuals diagnosed with PD voluntarily participated in this study. Baseline characteristics and sample demographics were collected and reported in Table 1. Among the respondent, 37% were female and 63% were male. The average age of the participants was 68.89 years (SD=11.52), with an age range spanning from 33 to 91 years. Geographically, the participants were distributed across the North (27%), Center (27%), and South (46%) regions of Italy. Most of the participants were married (58%) and had completed higher secondary education (39%). Employment status revealed a diverse range, with

**Table 1**

Socio-demographics characteristics of all respondents (n = 89).

BASELINE CHARACTERISTICS	N	%
<b>SOCIO DEMOGRAPHIC DATA</b>		
<b>Gender</b>		
Female	33	37
Male	56	63
<b>Age</b>		
Range	33-91	
Mean	68.89	
SD	11.52	
<b>Geographical Area</b>		
North	24	27
Center	24	27
South	41	46
<b>Marital status</b>		
Married	52	58
Single	9	10
Separated/Divorced	15	17
Widower	13	15
<b>Education level</b>		
No title	13	15
Junior high school diploma	28	31
High school graduation	35	39
Degree	10	11
Postgraduate training	3	3
<b>Employment status</b>		
Public employee	13	15
Laborer	5	6
Freelancer	6	7
Unemployed	7	8
Retired	56	63
Student	2	2
<b>Residential area</b>		
In the city/town, downtown	41	46
In the city/town, in the suburbs	1	1
By the sea	2	2
In the countryside, far from the urban center	14	16
In the countryside, near the urban center	11	12
On a hill, far from the urban center	6	7
On a hill, near the urban center	6	7
In the mountains, far from the urban center	2	2
In the mountains, near the urban center	6	7

15% as public employees, 6% as laborers, 7% as freelancers, 8% as unemployed, 63% as retired, and 2% as students. The participants resided in various types of areas, with 47% living in cities or towns (downtown or suburbs), 2% by the sea, 28% in the countryside (near or far from the urban center), 9% in the mountains (near or far from the urban center) and 14% on a hill (near or far from the urban center).

#### 3.2. Personalized questionnaire items

The survey questionnaire items were systematically evaluated for all participants, and the obtained data have been reported from Table 2 through Table 4.

Table 2 investigates disease management information and the sources from which participants obtained information about the disease. Patients were asked about various aspects of their health and living situation, including the duration of their illness, their living arrangements, level of independence, need for mobility assistance, history of falls, prior knowledge of the disease, sources of awareness, availability of local pain management services, and the accessibility of healthcare facilities from their home. The participants' experience with PD ranged from 1 to 38 years, with a mean duration of 7.02 years (SD=5.53), indicating a notable variability in the duration of disease across the sample. A significant proportion of participants lived with her/his husband/wife (56%) or reported having assistance from children/neighbors (17%) or caregivers (18%). A smaller percentage lived alone (9%). These results underscore the diversity in living arrangements among individuals with PD. Regarding the independence and assistance needs,

**Table 2**  
Information about disease management.

	N	%
<b>For how many years have you been affected by the disease?</b>		
Range	1-38	
Mean	7.02	
SD	5.53	
<b>Do you live alone?</b>		
No, I live with my wife/husband	50	56
Yes	8	9
Yes, but I have children/neighbors who help me	15	17
Yes, I am assisted by a caregiver	16	18
<b>Are you independent?</b>		
No, I need partial assistance	45	51
No, I need full assistance	12	13
Yes, I am completely independent	18	20
Yes, but only at home, while needing help to go out	14	16
<b>Do you need assistance to move?</b>		
No, I don't need anything	33	37
Yes, I use a cane	31	35
Yes, I use a wheelchair	8	9
Yes, I use a walker	17	19
<b>Do you experience falls?</b>		
No	22	25
Yes, occasionally	47	53
Yes, frequently	20	22
<b>Had you ever heard of this disease before the diagnosis?</b>		
No	10	11
Yes	79	89
<b>If you answered YES to the previous question, in what area did you hear about it?</b>		
<b>MASS MEDIA</b>		
Always	11	12
Often	17	19
Occasionally	33	37
Rarely	12	13
Never	16	18
<b>FAMILY</b>		
Always	13	15
Often	8	9
Occasionally	15	17
Rarely	27	30
Never	26	29
<b>SCHOOL</b>		
Always	5	6
Often	11	12
Occasionally	12	13
Rarely	10	11
Never	51	57
<b>FRIENDS</b>		
Always	13	15
Often	9	10
Occasionally	17	19
Rarely	26	29
Never	24	27
<b>SANITARY</b>		
Always	11	12
Often	20	22
Occasionally	27	30
Rarely	15	17
Never	16	18
<b>In the city where you live, are there local services that contribute to at-home pain management?</b>		
No	36	40
Yes	32	36
I don't know	21	24
<b>Are clinics, hospitals, and pharmacies easily accessible from your home?</b>		
No, but there are convenient transportation options (such as buses, etc.)	8	9
No, I need a car	18	20
No, I need someone to accompany me	18	20
Yes	45	51

a substantial number of participants reported needing partial assistance (51%) or full assistance (13%), indicating varying degrees of independence. On the other hand, 20% of participants were completely independent, while 16% expressed the need for help only outside their homes. Mobility assistance requirements varied, with 37% not needing any assistance, while 63% used a cane, wheelchair, or a walker. These findings highlight the range of mobility challenges faced by individuals with PD.

Falls are a prevalent issue among PD patients, with 53% participants experienced them occasionally and 22% frequently.

Eighty-nine percent of respondents state that they had heard about the disease, with most of the information coming from mass media (31%), friends (25%), their family (24%), or school (18%).

Regarding information about local services and accessibility, around 40% of participants reported the absence of local services for at-home pain management, while 36% had access to such services. Notably, 24% were uncertain about the availability of such services.

Regarding accessibility to healthcare facilities, 45% of participants indicated ease of reaching services with convenient transportation options, 20% relied on their own car, 20% required assistance for transportation, and 9% used public transportation options. In summary, Table 2 data highlights diverse living arrangements, assistance needs, and sources of disease information among individuals with PD. Falls are prevalent, and access to local pain management services varies.

Patients were also invited to share their perspectives on alternative pain management strategies and their satisfaction with their current treatments by responding to questions regarding the possibility of alternative strategies and the reasons behind any dissatisfaction with their treatment. These were open-ended questions, allowing respondents to provide free-form responses. The AI analysis aided in identifying and structuring different recurring themes, which are outlined and showcased in Table 3. Furthermore, an encompassing overview of the outcomes derived from ChatGPT's analysis has been integrated. In particular, participants have expressed a range of ideas and suggestions, spanning from the need to establish specialized centers, introduce unconventional therapies, ensure comprehensive care, and involve patients in their own treatment. The gathered opinions reflect the importance of multidisciplinary collaboration, personalized treatment plans, and patient education. Additionally, the significance of access to experimental treatments, support services, and improving information dissemination has been highlighted. Overall, the responses underscore the diversity of envisioned strategies to enhance pain management and the overall well-being of PD patients.

Table 4 investigates the pain management and healthcare support for PD patients. Patients were queried about the duration of their pain, whether they attended a Parkinson's Center or disease-related pain clinic, their satisfaction with the care received at these centers, their perceptions of the adequacy of the regional healthcare system, the need for psychological support, the utility of a Friendly Phone service, the provision of in-home healthcare assistance, the presence of local nursing figures for pain management, the potential implementation of telecommunication with specialized nurses, and the role of the Parkinson's Disease Nurse Specialist. Participants reported experiencing pain for a range of 0 to 20 years, with an average duration of approximately 4.94 years. The SD indicates some variability in the reported durations. A good number attended specialized Parkinson's centers or clinics for pain management (33%), while others lacked access to such facilities in their region (36%). Satisfaction levels with care at these centers varied, with some feeling satisfied (22%), partially satisfied (42%), or unsatisfied (36%).

Participants expressed mixed opinions about the adequacy of the healthcare system for meeting the needs of PD patients, reflecting beliefs in its partial or complete effectiveness, as well as concerns about inadequacy: a notable number (61%) believed that the healthcare system in their region partially meets the needs of patients, while only 17% expressed full confidence in the System. However, a portion (n = 22) felt

**Table 3**  
Generative Artificial Intelligence (ChatGPT) of open-ended responses and result summary.

Questions	ChatGPT-found categories:	ChatGPT Summary of Results
Do you think there could be alternative strategies or specific structures for managing pain? If yes, what kind? (Feel free to write what you would recommend or believe is crucial to change.)	<p><b>Alternative Unconventional Therapies:</b> Proposals for exploring non-conventional therapies for pain management.</p> <p><b>Lack of Information:</b> Statements indicating uncertainty about the existence of such strategies in their region.</p> <p><b>Specialized Centers:</b> Recommendations for specialized centers focusing on Parkinson's disease.</p> <p><b>Physical Exercise and Therapy:</b> Advocacy for tailored exercise programs, physical therapy, and psychological support.</p> <p><b>Need for Holistic Care:</b> Emphasis on comprehensive care that considers various aspects of the disease.</p> <p><b>Individualized Treatment Plans:</b> Demand for personalized treatment plans and patient involvement.</p> <p><b>Nursing Support:</b> Proposals for specialized nursing support for in-home pain management.</p> <p><b>Professional Collaboration:</b> Suggestions for professional collaboration between patients and experts.</p> <p><b>Access to Innovative Strategies:</b> Recommendations for innovative approaches in treatment.</p> <p><b>Access to Experimental Drugs:</b> Calls for easier access to experimental medications.</p> <p><b>Multi-Disciplinary Approach:</b> Proposals for multi-disciplinary teams to address different aspects of the disease.</p> <p><b>Regular Assessment at Home:</b> Advocacy for regular in-home assessments.</p> <p><b>Patient Empowerment and Education:</b> Advocacy for educating patients and involving them in their care.</p> <p><b>Complementary Therapies:</b> Proposals for complementary therapies like acupuncture.</p> <p><b>Increased Research:</b> Recommendations for more research to discover new techniques.</p> <p><b>Specialized Training for Professionals:</b> Emphasis on specialized training for healthcare professionals.</p> <p><b>Socio-Economic Support:</b> Advocacy for socio-economic support for patients.</p>	<p>Participants expressed a range of ideas for improving pain management strategies in Parkinson's Disease. Suggestions encompassed establishing specialized clinics, introducing unconventional therapies, ensuring comprehensive care, involving patients in their treatment, and enhancing the roles of healthcare professionals. Many participants emphasized the need for multi-disciplinary collaboration, personalized treatment plans, and education for patients. Some also highlighted the importance of access to experimental treatments, support services, and improved information dissemination. Overall, the responses underscored the diversity of strategies envisioned to enhance pain management and overall well-being in Parkinson's patients.</p>
If you find the treatments you receive unsatisfactory, can you indicate the reasons why?	<p><b>Medical Visits and Information:</b></p> <ul style="list-style-type: none"> <li>• The visit is too short.</li> <li>• Would like more information about pain therapies and the disease.</li> <li>• Would like to be involved in the therapeutic decision-making process</li> </ul> <p><b>Inadequate Treatment:</b></p> <ul style="list-style-type: none"> <li>• The therapy I'm receiving is not adequate.</li> <li>• Often the therapy is ineffective.</li> <li>• Too many medications, not enough rehabilitation.</li> </ul> <p><b>Accessibility and Satisfaction:</b></p> <ul style="list-style-type: none"> <li>• Not attending a center.</li> <li>• Often the therapy is ineffective.</li> <li>• Varying levels of satisfaction with received care.</li> </ul>	<p>This summary indicates that participants have provided feedback regarding the short duration of medical visits, desire for more information about pain therapies and the disease, a strong desire to be involved in therapeutic decision-making, concerns about the adequacy of treatment, and varying satisfaction levels with the received care. There is also a mention of difficulties with accessibility to treatment centers or dissatisfaction with the treatment being received.</p>

that the System does not adequately address these needs. Psychological support was strongly recognized as vital for addressing the challenges faced by the patients (81%), including pain management and a substantial number of participants (n = 73) found the idea of a "Phone Friend" beneficial for patients and their families. There was also consensus on the importance of introducing new telecommunication methods to access advice from specialized Parkinson's nurses for pain management [Table 4](#).

The majority endorsed the idea of qualified home-based socio-sanitary assistance for more severe patient, with 93% expressed the belief that the regional healthcare system should provide qualified home-based socio-sanitary assistance for more severe patients. A smaller portion (1%) did not see the necessity, and only a few (6%) had mixed opinions. While some participants acknowledged nurses' involvement in advising pain management strategies (70%), others reported not receiving such guidance (30%). Furthermore, awareness about the

**Table 4**  
Pain Management and Healthcare Support for Parkinson's Disease Patients.

	N	%
<b>For how many years have you been experiencing pain?</b>		
Range	0-20	
Mean	4.94	
SD	4.54	
<b>Do you attend a Parkinson's Center or a clinic for disease-related pain?</b>		
No, there are none in my region	32	36
Partly	28	31
Yes	29	33
<b>If you attend a center/clinic, do you feel satisfied with the care you receive?</b>		
No, I do not attend any center/clinic	32	36
Partly	37	42
Yes	20	22
<b>Do you believe that the Healthcare System in your Region adequately meets the needs of people affected by Parkinson's disease (including other forms of parkinsonism)?</b>		
No	20	22
Partly	54	61
Yes	15	17
<b>Do you believe that the support of a psychologist is necessary for people with Parkinson's Disease to manage all the difficulties, including pain?</b>		
No	6	7
Partly	11	12
Yes	72	81
<b>Do you find the support of a Friendly Phone service helpful for individuals with Parkinson's and their family members?</b>		
No	8	9
Partly	16	18
Yes	65	73
<b>Do you believe that the Regional Healthcare System should provide qualified social and healthcare assistance at the homes of severely affected patients? (periodic visits from specialized nurses, physiotherapists, and healthcare assistants)</b>		
No	1	1
Partly	5	6
Yes	83	93
<b>Is there a local nursing figure who follows up and administers specific pain-relieving medications in the hospital outpatient setting?</b>		
No	27	30
Yes	62	70
<b>Is there a local nursing figure who follows up and administers specific pain-relieving medications at home?</b>		
No	48	54
Yes	41	46
<b>Do you believe that new forms of telecommunication with specialized Parkinson's nurses should be implemented to access valuable advice for managing pain?</b>		
No	3	3
Yes	86	97
<b>At the reference outpatient clinic, does the nurse advise you on how to manage pain and what strategies to implement?</b>		
No	37	42
Yes	52	58
<b>Have you ever heard of the Parkinson's Disease Nurse Specialist role?</b>		
No	76	85
Yes	13	15

Parkinson Disease Nurse Specialist role varied, indicating differing levels of familiarity with this healthcare professional. Overall, the data underlines the complexity of pain management strategies and healthcare support for PD patients, highlighting the need for comprehensive approaches, psychological support, and enhanced communication channels to better address their needs.

### 3.3. Validated questionnaire analysis

Table 5 refers to the PDQ and KPPQ questionnaire responses and

their relative percentage, respectively. Frequency distribution of scores in percent were summarized in Fig. 1.

The Part A of Table 5 provides an overview of the descriptive statistics concerning the score distributions of the PDQ questionnaire, divided into its two domains. The *Functional Condition* subscale, composed of 9 items, evaluates a spectrum of functional abilities associated with PD. The mean score for this scale was 52.59 out of a total of 90, and the median score was 54. The score distribution exhibited a minor negative skewness ( $-0.16$ ), signifying a slight inclination towards lower scores. Additionally, the prevalence of scores at the lower (0.74%) and upper (1.29%) ends implies a well-distributed range of responses, thus avoiding extremities. The satisfactory internal consistency reliability for this scale is indicated by the Cronbach's  $\alpha$  value of 0.79. The *Psychosocial Component* subscale, also under Part A, comprises 6 items that gauge psychosocial facets of participants' well-being. The mean score for this scale was 35.83 out of a total of 60, with a median score of 40. A slight negative skewness of  $-0.57$  signifies a subtle bias towards lower scores in the data distribution. The distribution of scores at the floor (1.65%) and ceiling (2.49%) levels suggests a well-balanced array of responses. The scale exhibited very good internal consistency, as evidenced by a Cronbach's  $\alpha$  value of 0.90.

Transitioning to Part B, the KPPQ scale encompasses 14 items, with possible scores spanning from 0 (all "No" responses) to 14 (all "Yes" responses). The average score attained by participants on this scale was 7.91, and the median score was 8. The data distribution demonstrated a slight positive skewness of 0.12, indicating a marginal inclination towards higher scores. The distribution of scores at the floor (3.10%) and ceiling (4.03%) levels reflects a moderately varied range of responses. The Cronbach's  $\alpha$  value of 0.65 signifies an acceptable level of internal consistency reliability for this scale.

To determine the factors that influence the PD pain, ANOVA analysis was performed among socio-demographic characteristics and both the PDQ and KPPQ scores. Gender was found to be significantly associated to PDQ score while factors such as age range, level of education, and residential area were found to be significantly associated with KPPQ score. These results are shown in Table 6.

Table 7 also provides a comprehensive overview to assess the influence of various factors on PDQ and KPPQ scores. The factors analyzed include some information about disease management (factors from Table 2) and variables regarding pain management and healthcare support (factors from Table 3). Significant association were found between PDQ score and age range, educational level, residential area, being independent, need for mobility aid, familiarity with the disease through mass media and scholastics channels, availability of accessible local services, as well as perception of telecommunication as a tool for pain management. This underscores the multifaceted nature of the variables impacting PDQ scores and emphasizes the significance of factors extending beyond the disease itself, such as accessibility to information and local resources.

Similarly, significant associations were observed between KPPQ score and the years of illness, being independent, frequent falls, familiarity with the disease within the family or healthcare channels, as well as the perception of the Regional Healthcare System being adequate. It becomes evident that factors beyond the medical scope, like familial and healthcare context, contribute significantly to the pain experience reported by individuals with PD.

To further investigate the factors influencing the pain management found in the ANOVA analysis, a multiple linear regression analysis was conducted (Table 8).

For the PDQ Scale, the results indicate that all the found significant variables demonstrates a moderate ability to explain the variance in PDQ scores. Results suggest that around 24% of the variability in PDQ scores can be attributed to the combination of these independent variables. The F-statistic and associated p-value ( $p = 0.001$  \*\*\*) further support the statistical significance of the model.

Similarly, for the KPPQ Scale, the multiple linear regression analysis

**Table 5**

Descriptive statistics of score distributions for PDQ and KPPQ questionnaire. Cronbach's alpha was used to measure the scales' internal consistency reliability.

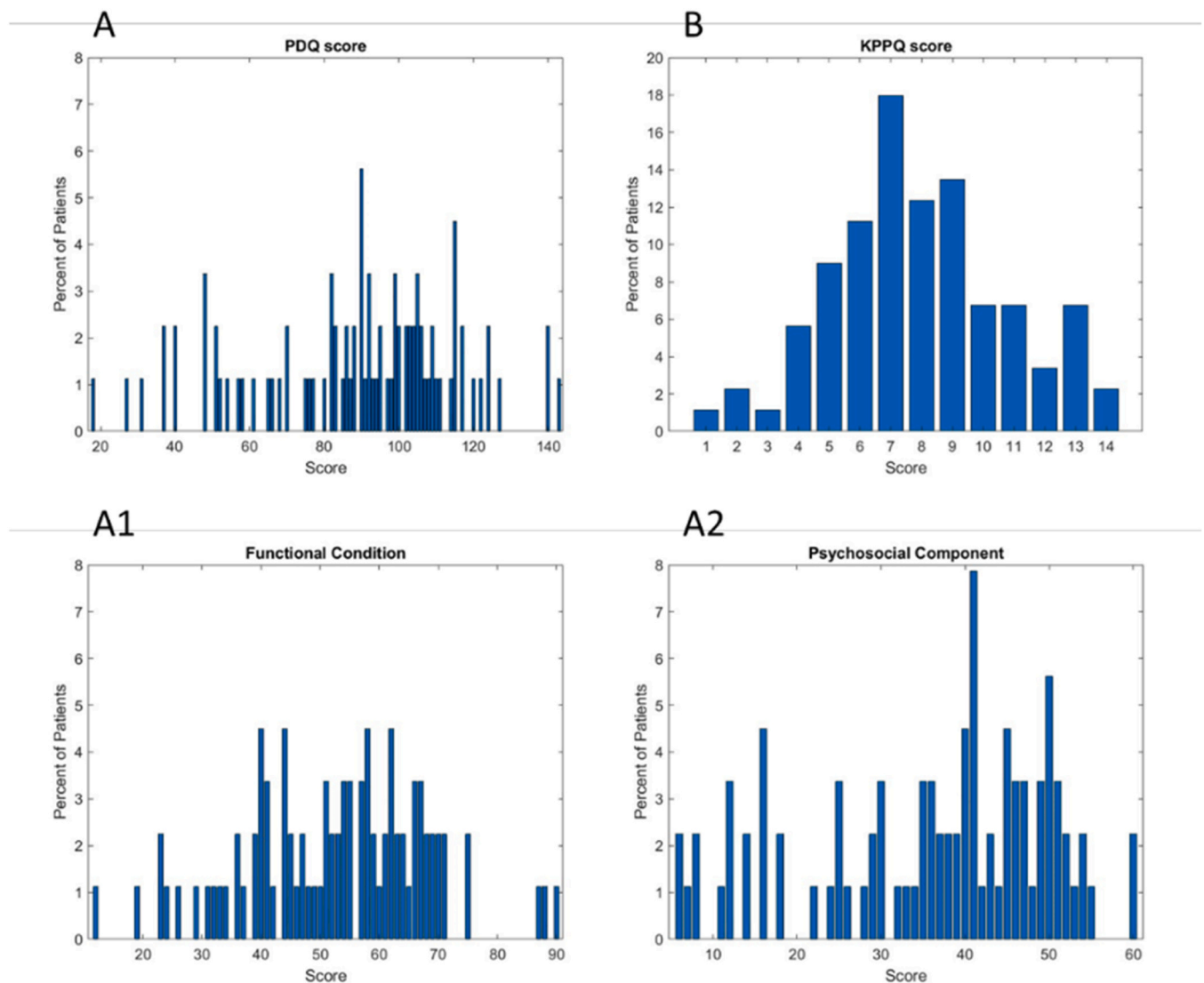
PART A:	No. of items	Score/ Total§	Score (mean)	Median	% floor†	% ceiling‡	Skewness	Cronbach's $\alpha$ *
<b>Scale PDQ</b>								<b>Total items = 0.89</b>
Functional Condition	9	0-90	52.59	54	0.74	1.29	-0.16	0.79
Psychosocial Component	6	0-60	35.83	40	1.65	2.49	-0.57	0.90
<b>PART B:</b>	<b>No. of items</b>	<b>Score min/max</b>	<b>Score (mean)</b>	<b>Median</b>	<b>% floor†</b>	<b>% ceiling‡</b>	<b>Skewness</b>	<b>Cronbach's <math>\alpha</math> *</b>
<b>Scale KPPQ</b>								
KPPQ items	14	0-14	7.91	8	3.10	4.03	0.12	0.65

§Score/total score

†Percentage of subjects with worst possible score.

‡Percentage of subjects with best possible score.

\*Measure of internal consistency.



**Fig. 1.** Frequency distributions (percent) for the PDQ and KPPQ scales (panels A to B) and details of PDQ subscales (Functional Condition and Psychosocial Component) (panel A1 to A2).

reveals significant associations between the KPPQ scores and all the found significant independent variables. Results suggest that approximately 24% of the variance in KPPQ scores is explained by the combination of these independent variables. The associated F-statistic and p-value ( $p = 0.005^{**}$ ) reinforce the statistical significance of the model.

In both cases, it's important to note that the adjusted  $R^2$  values (0.18 for PDQ and 0.16 for KPPQ) are slightly lower than the corresponding  $R^2$  values. This indicates that while the model explains a reasonable portion of the variance, there might be additional factors not included in the

analysis that could contribute to the observed outcomes.

Overall, these regression analyses provide valuable insights into the factors that influence the pain among individuals with PD. The identified associations highlight the importance of various socio-demographic and disease-related variables in shaping these outcomes. These findings can be utilized to develop more personalized and targeted interventions aimed at improving the well-being and pain management strategies for individuals living with Parkinson's disease.

**Table 6**

ANOVA analysis between socio-demographic characteristics and both the PDQ and KPPQ score with statistically significant correlation coefficients. A p-value < 0.05 was considered statistically significant (\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001).

Influencing factor	Group	μ±SD	PDQ F (p-value)	KPPQ F (p-value)
<b>Age range</b>	≤ 50	6.60 ±5.12	0.92 (0.45)	<b>4.81</b> (0.001***)
	51-60	46.23 ±27.77		
	61-70	44.87 ±22.61		
	71-80	47.26 ±28.08		
	>80	53.64 ±21.13		
		52.73 ±26.7		
<b>Gender</b>	Male	52.73 ±26.7	<b>8.68</b> (0.004**)	0.6 (0.4)
	Female	31.87 ±17.88		
<b>Education level</b>	No title	62.23± 20.55	0.15 (0.96)	<b>2.73</b> (0.03*)
	Primary school	46.42±		
	Secondary school	23.99		
	Degree	39.57 ±25.08		
	Post-graduate	43.9 ±31.43 24.00 ±27.87		
<b>Geographical Area</b>	North	49.12 ±25.66	0.04 (0.96)	0.14 (0.8)
	Center	51.91 ±23.32		
	South	38.53± 26.36		
<b>Marital status</b>	Married	42.00 ±26.51	2.14 (0.10)	0.49 (0.6)
	Not Married	42.11 ±25.53		
	Divorced	41.06 ±24.87		
	Widower	63.53 ±17.69		
<b>Occupational status</b>	Employee	37.76 ±27.87	0.55 (0.73)	2.21 (0.06)
	Laborers	44.6 ±42.34		
	Freelancer	36.66 ±22.93		
	Student	18.5 ±7.77		
	Retired	49.64 ±24.20		
	Unemployed	36.28 ±22.72		
<b>Residential area</b>	In the city/town, downtown	35.63 ±24.25	0.96 (0.48)	<b>2.23</b> (0.02*)
	In the city/town, in the suburbs	19±0		
	By the sea	81±0		
	In the countryside, far from the urban center	53.92 ±27.93		
	In the countryside, near the urban center	51.90 ±22.23		
	On a hill, far from the urban center	46 ±16.94		
	On a hill, near the urban center	48.33 ±30.32		
	In the mountains, far from the urban center	75 ±12.72		
	In the mountains, near the urban center	67±8.74		

**Table 7**

ANOVA analysis of both the PDQ and KPPQ scores according to information about disease and pain management." A p-value < 0.05 was considered statistically significant (\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001).

Influencing factor	μ±SD	PDQ F (p-value)	KPPQ F (p-value)
<b>Information about disease management</b>			
For how many years have you been affected by the disease?		1 (0.4)	<b>2.26</b> (0.01*)
Are you independent?			
No, I need partial assistance	46.88 ±23.41	<b>3.04</b> (0.03*)	<b>2.99</b> (0.03*)
No, I need full assistance	46.58 ±28.83		
Yes, I am completely independent	35.83 ±28.30		
Yes, but only at home, while needing help to go out	49.35 ±27.55		
Do you need assistance to move?			
No, I don't need anything	41.51 ±28.61	2.88 (0.04*)	2.47 (0.06)
Yes, I use a cane	46.82 ±25.44		
Yes, I use a wheelchair	57±25.05		
Yes, I use a walker	42.82 ±25.44		
Do you experience falls?			
No	41.59 ±28.35	0.91 (0.4)	<b>5.08</b> (0.008**)
Yes, occasionally	43.51 ±24.69		
Yes, frequently	52.25 ±25.54		
What area did you hear about the disease?			
<b>MASS MEDIA</b>			
Always	62.18 ±10.28	<b>2.38</b> (0.05*)	1.98 (0.10)
Often	55.05 ±19.06		
Occasionally	44.21 ±27.75		
Rarely	26±28.90		
Never	38.37 ±23.10		
<b>FAMILY</b>			
Always	59.84 ±13.78	0.41 (0.8)	<b>2.63</b> (0.03*)
Often	63.87 ±25.42		
Occasionally	48.13 ±20.48		
Rarely	40.18 ±27.53		
Never	34.96 ±26.25		
<b>SCHOOL</b>			
Always	67.6 ±2.07	<b>2.77</b> (0.03*)	0.43 (0.7)
Often	57.81 ±28.94		
Occasionally	56.83 ±24.45		
Rarely	31.2 ±26.97		
Never	39.94 ±23.65		
<b>FRIENDS</b>			
Always	61.61 ±6.18	0.48 (0.74)	1.86 (0.1)
Often	52.22 ±17.35		
Occasionally	39.41 ±21.43		
Rarely	37.46 ±30.68		

(continued on next page)



**Table 7** (continued)

Influencing factor	$\mu \pm SD$	PDQ F (p-value)	KPPQ F (p-value)
Never	45.41 $\pm 28.66$		
<b>SANITARY</b>			
Always	55 $\pm$ 25.45	0.78 (0.53)	3.29 (0.01*)
Often	56.4 $\pm 24.17$		
Occasionally	46.88 $\pm 23.99$		
Rarely	27.66 $\pm 26.007$		
Never	36.93 $\pm 22.17$		
<b>In the city where you live, are there local services that contribute to at-home pain management?</b>			
No	37.13 $\pm 25.84$	3.05 (0.05*)	0.59 (0.55)
Yes	61.56 $\pm 19.98$		
I don't know	33.23 $\pm 21.29$		
<b>Pain Management and Healthcare Support</b>			
<b>If you attend a center/clinic, do you feel satisfied with the care you receive?</b>			
No, I do not attend any center/clinic	44.21 $\pm 27.21$	0 (0.99)	1.86 (0.1)
Partly	41.45 $\pm 27.34$		
Yes	52.8 $\pm 19.40$		
<b>Do you believe that the Healthcare System in your Region adequately meets the needs of people affected by Parkinson's disease (including other forms of parkinsonism)?</b>			
No	41 $\pm$ 0	2.1 (0.12)	3.52 (0.03*)
Partly	35.4 $\pm 11.78$		
Yes	45.62 $\pm 26.52$		
<b>Do you believe that new forms of telecommunication with specialized Parkinson's nurses should be implemented to access valuable advice for managing pain?</b>			
No	35 $\pm$ 43.27	7.15 (0.009**)	1.95 (0.16)
Yes	45.34 $\pm 25.36$		

**4. Discussion**

The conducted study focused on the analysis of pain and quality of life in patients with PD, utilizing customized questions along with two validated questionnaires: the PDQ and the KPPQ, complemented by generative AI approaches.

While the scientific literature provides an increasingly clear picture of motor symptoms, healthcare professionals face numerous challenges with non-motor symptoms, including pain (Marques and Brefel-Courbon, 2021; Mostofi et al., 2021; Gandolfi et al., 2017). These challenges are exacerbated by the absence of validated and standardized methods for detection in studies. The difficulty arises from the fact that pain in PD is heterogeneous and often multifactorial in origin (Rana et al., 2017).

Through this study, an array of information regarding various living situations, care needs, and sources of information about the disease among patients have come to light. Various living arrangements have emerged, ranging from living with a partner to receiving care from

**Table 8**

Multiple linear regression analysis performed with the PDQ and the KPPQ scores as the dependent variable. A p-value < 0.05 was considered statistically significant (\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001).

Dependent variable	Independent variable	R <sup>2</sup>	R <sup>2</sup> adj	F-statistic	p-value
<b>PDQ Scale</b>	Gender	0.24	0.18	3.84	0.001 * **
	Being independent				
	Need for mobility aid				
	Familiarity with the disease through mass media				
	Familiarity with the disease through scholastics channels				
<b>KPPQ Scale</b>	Availability of accessible Local Services	0.24	0.16	2.91	0.005 * *
	Perception of telecommunication as a tool for pain management				
	Age range				
	Educational level				
	Residential area				
	Years of illness				
	Being independent				
	Frequent falls				
	Familiarity with the disease within the family				
	Familiarity with the disease through healthcare channels				
Perception of the Regional Healthcare System being adequate					

children or neighbors, and the presence of caregivers. These results emphasize the diversity of living situations among patients. Additionally, different levels of independence and care needs have been highlighted, ranging from partial or complete assistance to total self-sufficiency or only needing help outside the home.

Mobility support needs are equally diverse, with some people requiring no assistance while others use canes, wheelchairs, or walkers. The incidence of falls appears to be a widespread issue among Parkinson's patients, with a significant percentage of participants experiencing them occasionally or frequently. Furthermore, there is considerable heterogeneity in access to local services for managing pain in a home setting. While some participants report the absence of such services, others indicate they have access to them. Lastly, concerning accessibility to healthcare facilities, many participants report easy access to services due to convenient transportation options, while others rely on their own means of transportation or require assistance.

In summary, the data highlight the diversity of living situations, care needs, and sources of information about the disease among individuals with PD.

Through generative AI, the opinions expressed by patients regarding possible improvements for the disease and pain management have been uncovered. Respondents have provided a wide range of ideas, spanning from promoting specialized centers and unconventional therapies to emphasizing comprehensive care and patient involvement in treatment. The insights gathered underscore the importance of multidisciplinary teamwork, personalized approaches to treatment, and patient education. Additionally, the significant role of access to experimental treatments, support services, and improved information sharing has been highlighted. Overall, these responses illuminate a diverse range of envisioned strategies for enhancing pain management and the overall well-being of individuals with PD.

Regarding pain management, the data emphasize the need for

comprehensive approaches that can adequately address the individual needs of patients. Pain management in patients presents a complex challenge as it involves multiple physical, emotional, and social factors. These patients often face painful symptoms that can vary significantly in intensity and duration, requiring individualized and personalized attention. Furthermore, pain management must be integrated with effective psychological support, as PD can have a significant impact on the mental health and emotional well-being of patients.

Another crucial aspect highlighted by the data is the need for improved communication channels between patients, healthcare professionals, and caregivers. Clear and open communication is essential to ensure that patients understand their treatment options, care plans, and available services. Effective communication can also help reduce the anxiety and uncertainty that often accompany disease management. Access to accurate and timely information is therefore crucial to enable patients to make informed decisions and actively participate in their care journey.

The data obtained from the various scales provide an interesting overview of the different dimensions explored in the study. Concerning the *Functional Condition* subscale, achieving a score of 52.59 out of 90 suggests that participants reported a moderate assessment of their functional condition related to PD. This score indicates that there may be significant challenges in performing some daily activities, but at the same time, it suggests that there may be room for improvement through targeted interventions aimed at maintaining or improving physical functionality.

Moving to the *Psychosocial Component* subscale, a score of 35.83 out of 60 reflects a similar assessment by participants regarding the psychosocial aspects of their life related to the disease. This score suggests that there may be significant effects on mental health and quality of life, but it could also indicate that participants are facing these challenges with some degree of adaptability. However, further exploration of psychosocial stressors and the development of specific resources and support to address them more effectively may be necessary.

The KPPQ scale reports an overall score of 7.91 out of 14, indicating that participants experienced a moderate level of pain impact related to PD. This data highlights the importance of pain management in these patients and may suggest that there is room for improvement in pain management and access to more effective treatment strategies.

In conclusion, significant associations were found between the PDQ score and age range, level of education, area of residence, independence, need for mobility assistance, familiarity with the disease through media and educational channels, availability of accessible local services, as well as the perception of telecommunications as a valid tool for pain management. This highlights the complex nature of the variables influencing PDQ scores and underscores the importance of factors beyond the disease itself, such as access to information and local resources. Similarly, significant associations were observed between the KPPQ score and years of illness, independence, frequent falls, familiarity with the disease within the family or healthcare channels, as well as the perception of the Regional Healthcare System as adequate. It becomes evident that factors beyond the medical context, such as the family and healthcare environment, significantly contribute to the pain experience reported by people with PD.

These results have also identified correlations between socio-demographic factors and questionnaire scores, suggesting possible patterns for more targeted interventions. This study sheds light on under-explored facets of PD and suggests avenues for improving the quality of life for patients through more effective and informed pain management strategies.

The study's limitations encompass the choice to conduct an online investigation, which could have excluded respondents with limited IT skills. Consequently, the sample might not accurately represent the entire PD patient population, introducing potential selection biases inherent in the chosen study design.

The disease involves various aspects of the patient's life, including

physical health, quality of life, and emotional well-being. An approach that involves healthcare professionals from different specialties, therapists, social workers, and caregivers can ensure a more comprehensive and personalized treatment. Ultimately, the data reflect the need to address the challenges related to pain management in PD patients through holistic approaches, effective communication, and collaboration among different healthcare professionals. Further investigation is needed to delve into additional factors that may influence disease-associated pain and to confirm the trends identified within larger and more diversified patient groups. In essence, our study emphasizes the importance of personalized interventions and available tools aimed at enabling patients to competently manage their own condition.

## 5. Conclusions

In conclusion, this study focused on the analysis of pain in PD patients, utilizing a combination of customized questions and validated questionnaires. The results obtained provided a detailed picture of the challenges that patients face in pain management and the factors influencing their overall experience.

The research highlighted the importance of ensuring multidisciplinary approaches, individualized treatment plans, and active collaboration between patients and healthcare professionals. Additionally, the importance of improving access to information, support services, and experimental therapies emerged. The significant associations identified in the analyses confirm the influence of multiple factors, including socio-demographic factors, on pain management, suggesting possible personalized intervention models. The opinions expressed by the participants also highlighted a variety of innovative and personalized strategies for addressing pain and improving the overall well-being of patients.

These results can guide the development of targeted and personalized interventions that take into account the individual needs of Parkinson's patients, with the aim of enhancing quality of life and pain management.

## CRedit authorship contribution statement

**Lupo Roberto:** Conceptualization, Investigation, Methodology. **Lezzi Pierluigi:** Conceptualization, Data curation, Methodology. **Pedone Alessio:** Investigation. **Rubbi Ivan:** Methodology. **Lezzi Alesia:** Investigation, Methodology. **Vitale Elsa:** Methodology. **Fasano Antonio:** Validation, Visualization. **De Nunzio Giorgio:** Supervision, Writing – review & editing. **Conte Luana:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Writing – original draft, Writing – review & editing.

## Declaration of Competing Interest

None.

## Data availability

Data will be made available on request.

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