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ORIGINAL RESEARCH

Perceptions of the Provision of Pain Care Services from the Perspective of People with Parkinson's Disease: A Qualitative Descriptive Study

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Purpose: Pain is a common, debilitating, and complex non-motor symptom of Parkinson's disease (PD), often requiring input from healthcare providers across various disciplines for effective management. The aims of this study were to explore the perspectives of people with PD on the provision of pain care services.

Methods: A qualitative descriptive research methodology employing a maximum variation sampling strategy was used to recruit people with PD, living in Australia. Data were collected using individual, semi-structured interviews and analyzed thematically. To ensure trustworthiness, the study was conducted and reported in accordance with the Standards for Reporting Qualitative Research guidelines.

Results: Eighteen participants (10 female), with a median age of 71 years (IQR 68–77), shared their perceptions of the provision of PD pain care services. Thematic analysis of interview data resulted in five themes: empathy and understanding (care); acknowledging needs and concerns (listening); explaining diagnoses and treatment options (explaining); expertise in PD (knowledge); and responding to needs with tailored solutions (individualization). Participants' experiences were influenced by the presence, or the lack thereof, of these elements during clinical encounters. Furthermore, participants noted that these features were expressed to varying extents by different types of healthcare providers (neurologists, general practitioners, allied health professionals, and PD nurse specialists), which led to differing perceptions of the quality of pain care services.

Conclusion: The findings show that perceptions of pain care are influenced by a healthcare provider's ability to address both the emotional and physical needs of PD patients. The variability observed in participants' experiences highlights the need to ensure that all healthcare providers involved in PD pain care are equipped to deliver empathetic, individualized, patient-centered care that addresses the complex and multifaceted needs of this population.

Keywords: Parkinson's disease, pain, pain care, perceptions, healthcare providers

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Introduction

Pain is a common and debilitating non-motor symptom of Parkinson's disease (PD).[1–3] It is estimated that, at the time of writing, more than 65,000 people with PD in Australia experience persistent pain.[1,4] Research into PD pain mechanisms has found that disease specific neurodegenerative changes occur in the cerebral, spinal, and peripheral nociceptive pathways, and involves deficits in dopaminergic and nondopaminergic neurotransmitter systems as well as variations in several genes involved in the processing of nociceptive inputs.[5] These pathophysiological changes may interact with comorbidities associated with painful symptoms (ie, osteoarthritis) and PD motor symptoms (ie, bradykinesia and rigidity), and as a result, the clinical manifestations of pain in PD vary greatly.[6] Given the complexity of PD pain, a multimodal and multidisciplinary approach to PD pain management has been advocated,[7] and indeed, research has shown that people with PD typically consult a mix of healthcare providers who utilize a variety of therapies for its management.[8,9]

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While the effectiveness of various therapies for PD pain such as Parkinson's medication, analgesics, and physiotherapy has been reported,[10,11] to the authors' knowledge, no recent studies have explicitly investigated the experiences of people with PD regarding their perspectives of pain care services. Most previous studies in PD have either explored patients' experiences with healthcare services in relation to overall disease management or focused on aspects of care other than pain (ie, palliative care), and have been predominately conducted overseas.[12–17] Consequently, it would extend the existing literature and be clinically relevant to know the healthcare experiences of people with PD in the context of pain management and the Australian healthcare system. Understanding these experiences, for example, may aid in identifying what people with PD value in pain care as well as specific areas needing improvement, information which may be used to improve the quality of services in Australia. This study, therefore, aims to explore the perceptions of the provision of pain care services from the perspective of people with PD, as described and expressed by themselves, using their own words.

Methods

Methodology

This was a qualitative descriptive study.[18] A descriptive approach was deemed appropriate to address the aims of the study because the focus is not on increasing theoretical or conceptual understanding, such is the case with other forms of qualitative research (ie, phenomenology and grounded theory), but rather, contributing to clinical practice change and improvement.[19,20] The study was carried out and reported in accordance with the Standards for Reporting Qualitative Research (SRQR) guidelines.[21] The methods follow the approach outlined by Mezzini et al[22] (currently under peer review) and the methods description herein partly reproduces their wording.

Study Participants and Selection Procedures

To capture a broad range of perspectives, purposive maximum variation sampling[23] was employed to recruit participants. Participants were selected from a pool of individuals (n=52) who had previously taken part in a cross-sectional study on pain management practices in people with PD conducted by the authors that had indicated their willingness to participate in future research. The original cross-sectional study (n=206), conducted in 2023/24, employed a combination of sampling methods and was promoted through various PD advocacy and research funding organizations across Australia. Potential participants were initially contacted via email, which provided information about the study and included a brief questionnaire covering demographic (age, sex, and residential postcode) and clinical (disease stage and primary treating medical practitioner) details. Participants were selected from those that responded to the email (n=26) to reflect diverse demographic and clinical characteristics. Eligibility for the current study included: (a) a diagnosis of PD by a neurologist or movement disorder specialist; (b) self-reported pain symptoms in the past month; (c) currently living in Australia and holding either Australian citizenship or permanent residency; and (d) being 18 years or older. Given the absence of established sample size guidelines for descriptive qualitative research,[20] we adopted a pragmatic approach, deciding that the sample size was sufficient when novel data relevant to the study aims became so infrequent that further interviews were unlikely to meaningfully alter the study's outcomes.

Data Collection

Data were collected between March and April 2024 through individual, semi-structured interviews. The interview guide, which featured open-ended questions, was specifically developed for this study by the corresponding author (AM), an accredited exercise physiologist and PhD candidate conducting research investigating pain characteristics and management in PD, in collaboration with the research team members (SK, SS, and JH), who bring expertise in qualitative research, pain management, and PD. This method of data collection was chosen because it allows participants to focus on issues that are personally meaningful to them, providing a deeper and more individualized understanding of their experiences and perspectives.[24]

The interview guide questions broadly explored participants' perceptions of their experiences and interactions with providers of pain care and support services, as well as any unmet needs. It consisted of a comprehensive set of open-ended questions and follow-up questions for further exploration. The interview guide was reviewed by an external expert in qualitative research to ensure it was suitable and comprehensive for the study's aims.

To maintain consistency and reliability, all interviews were conducted by a single researcher (AM). The interview process was divided into two parts: an introduction and the interview questions. During the introduction, the interviewer provided information about the study, outlined their own background, ensured confidentiality and anonymity, and encouraged participants to share their experiences openly. In the second part, the interview allowed for flexibility, with deviations from the guide when necessary to keep the dialogue relevant and flowing. Interviews typically lasted between 45 minutes and 1 hour and were conducted either face-to-face or via video conferencing. With participant consent, all interviews were audio-recorded and transcribed verbatim by an independent external agency.

Data Analyses

Content and thematic analysis are argued to be valid techniques for qualitative descriptive analysis.[25] For this study, thematic analysis was conducted based on the six-phase framework proposed by Braun and Clarke,[26,27] with data analyzed concurrently by AM throughout the data collection process. To ensure the findings were relevant to the intended audience (ie, medical practitioners, allied health professionals, PD nurse specialists, and healthcare administrators) and aligned with the study's aims and methodology, a primarily 'semantic or explicit' approach to analysis was adopted.[26]

The transcribed data were first imported into NVivo (version 14), de-identified using pseudonyms, and cross-checked against the audio recordings for accuracy. The data were then re-read to gain an understanding of the content and to identify any interesting and relevant aspects. This process also helped refine the interview guide and pinpoint areas that might warrant further exploration in subsequent interviews. Coding was carried out using a largely inductive, descriptive approach. The initial coding involved annotating the data during a detailed reading to identify and label key concepts as codes. These codes were then grouped into sub-categories and broader categories (tentative themes) as they developed. A summary of each transcript was created and sent to the corresponding participant for review, allowing them to verify that the interpretation of their interview was accurate.

Once all transcripts were initially coded, they were revisited to ensure thorough exploration of their meaning, and the themes were refined to better reflect the entire dataset and meet the study's aims. The final themes were labeled based on their core meaning, and the results were reported descriptively, with supporting data excerpts. To confirm the interpretations and theme development, debriefing sessions were held with the research team.

Ethics

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Ethical approval for the study was granted by the University of South Australia Human Research Ethics Committee [ID: 205671]. Participants were provided with a Participant Information Sheet that explained the study's purpose, the requirements for participation, and the measures in place to ensure data confidentiality. The sheet also included contact details for support organizations in case any distress arose during the interview. It emphasized that participation was voluntary, and that participants could withdraw at any time without any negative consequences. Prior to the interview, participants were asked to provide informed written consent including publication of anonymized responses/direct quotes.

Results

The study included 18 participants (10 female), with a median age of 71 years (interquartile range, 68–77). Geographically, most participants were from South Australia (six), followed by New South Wales (five) and Victoria (four). The remaining three participants were from Queensland, Western Australia, and the Australian Capital Territory. Of the participants, 11 lived in metropolitan areas, while 7 resided in regional Australia. Regarding disease staging, six participants identified symptoms consistent with stage 1, six with stage 2, and six with stage 3 of the Hoehn and Yahr 5-point staging scale.[28] For PD treatment, 14 participants reported that their primary healthcare provider was a neurologist, three indicated a combination of neurologist and general practitioner, and one relied primarily on a general practitioner.

Participants' perceptions of the provision of PD pain care services were relayed through past and current experiences interacting with healthcare providers (neurologists, general practitioners, allied health professionals, and PD nurse specialists). Thematic analysis resulted in five overarching themes: empathy and understanding (care); acknowledging needs and concerns (listening); explaining diagnoses and treatment options (explaining); expertise in PD (knowledge); and responding to needs with tailored solutions (individualization).

Theme 1: Empathy and Understanding (Care)

Empathy and understanding (care) were important features of PD pain care for many participants when discussing their interactions with medical practitioners, particularly neurologists, but did not feature in discussions relating to allied health professionals and PD nurse specialists. Participants described empathy and understanding in the context of the clinical encounter as the ability of the provider to understand and share their experience of pain and PD. When describing interactions with neurologists, participants reported mixed experiences. One participant, for example, described empathy and understanding as an important but lacking feature of their interactions with neurologists when discussing pain management.

> Well, I think if you are a neurologist, and you're dealing with people with Parkinson's, then be empathetic. Be understanding. Don't just sit there and write scripts. Try and understand what they're going through. I haven't encountered that yet. (P7)

Participants also shared how some neurologists focused on the medical management of PD pain but did not address the emotional and physical challenges of living with it. This left some participants with the perception that their neurologist did not "care" about them as a person.

> I don't feel the neurologist is a bit interested in how I feel as a person. (P11)

Some participants shared positive experiences of empathy and understanding with neurologists. For instance, one participant vocalized appreciation for their neurologist's empathetic approach, which fostered a sense of comfort and reassurance for them and their spouse.

> The new [neurologist] that I have been seeing for a while… my wife and I are very comfortable with his empathy and his presentation. I felt very comfortable with him and that he was understanding of my situation. (P10)

Participants' experiences of empathy and understanding with general practitioners were, on the other hand, mostly positive. One participant's reflection of their interactions with their general practitioner reinforces empathy and understanding as holistic "care".

> And my general practitioner is just lovely. She really cares about the whole person, talks about everything. (P18)

Theme 2: Acknowledging Needs and Concerns (Listening)

Acknowledging needs and concerns (listening) was another key feature of PD pain care for many participants, who often referred to it as "listening". Listening was a feature of care that had several dimensions. For some participants listening meant having their symptoms recognized and believed by their healthcare provider.

> I am seeing a neurologist, [name redacted] and he was terrific. He listened to what I was saying, and he put me on pregabalin to see if that would help, and then I suppose gradually he's just added medication. But yeah, he certainly listens and hears me. (P17)

While, for another participant, listening was about the active engagement of the provider through questions and follow-up.

> The general practitioner, she's great, and she asked me all the questions and listens and follows up. (P9)

Like empathy and understanding, this feature of pain care was frequently mentioned in relation to medical practitioners. When participants believed that their needs and concerns were ignored, they sometimes used the term "dismissive". Once again, most of the negative sentiment regarding this feature of care was directed towards neurologists. Importantly, some participants reported that their neurologist had rejected pain as a symptom of PD altogether, and in some cases, was sufficiently motivating to seek an alternative provider.

> When I last saw my neurologist, I mentioned the pain. He was very dismissive of it. He said, "No, there's no pain associated with Parkinson's". (P6)

> I'm seeing a new neurologist tomorrow. I haven't been happy with my current neurologist, because when I've gone there with my concerns and my issues, he's been dismissive. (P7)

Some participants reported that they believed the non-recognition of pain symptoms was driven by an inordinate focus on the motor symptoms of PD by their medical practitioner.

> I think he's [neurologist] very much driven by the physical symptoms, and he's never asked me about pain. (P11)

> I think general practitioners are probably guilty of the old white man shaking syndrome, and that's not necessarily how we all present. (P1)

Theme 3: Explaining Diagnoses and Treatment Options (Explaining)

Explaining diagnoses and treatment options (explaining) was a feature of PD pain care common to neurologists, general practitioners, and allied health professionals. Across these provider types, participants' experiences were mixed.

> She [physiotherapist] explained a lot of stuff to me, what she was trying to do, which when I'd gone to physios before they hadn't. They just did things and never explained it. So, I thought she was quite good at telling you what she was trying to achieve and how she was trying to achieve it. (P12)

When this feature of care was present, some participants related it to the amount of time their provider was willing to spend with them during the clinical encounter.

> He [neurologist] summed me up fairly quickly and knew that I needed that knowledge, I needed the information, and he spent the time and continues to spend the time to make sure that I know what I need. (P15)

Other participants likened explaining with being treated as an equal, which some participants described as being treated like a human.

> He [neurologist] gives you a lot of his time, he talks to you on an equal level. (P18)

> I think from a patient's point of view, I respond well to doctors who treat me like a human, and they [allied health professionals] do that. They're very open, they're very friendly, they explain what's going on, what we're doing, why we're doing this exercise, what it does, and why it works. A lot of the people in the medical profession treat the patients as less than humans, shall we say. (P8)

In cases where there was a perceived lack of information sharing, participants reported that they felt disempowered and excluded from the therapeutic decision-making process.

> There was never any knowledgeable interaction with me. It was almost I'm the doctor and you're the patient, and that's exactly how it's going to be. (P15)

Theme 4: Expertise in PD (Knowledge)

Expertise in PD (knowledge) was a feature of PD pain care frequently mentioned by participants in relation to their experiences with general practitioners and PD nurse specialists. Regarding general practitioners, most participants reported that they had limited knowledge of PD and its specific pain management needs.

> I don't think my GP is really up on Parkinson's generally. (P14)

Despite that, participants often did not expect their general practitioner to have a great deal of expertise in PD and did not express ill feeling towards them for it.

> Sometimes I think they're a little bit in something they're not that familiar with. The general practitioners they cover everything. They're good, they're supportive, I'm not criticizing them, please don't think that for one moment. But to give that targeted information I need, it's not their area, and they're busy. (P6)

Other participants noted that their general practitioner had made efforts to improve their knowledge and deliver informed care when needed, which they valued.

> If there's something that she doesn't know that I'm asking about, she'll bring it up on the computer and we'll look together. (P17)

While limited expertise in PD was a characteristic of most participants' experiences with general practitioners, there were some exceptions: one participant, for example, reported that they believed their general practitioner had a high level of expertise in the field.

> As a general practitioner, he is extremely knowledgeable about what Parkinson's is and what it does. (P8)

Participants who had contact with PD nurse specialists consistently reported high levels of expertise in PD. One participant even reported that they believed their nurse had more knowledge than the medical practitioners they'd encountered.

> …The association nurse, she'll come to our home, I can go in there or email her a question and she'll get back to me straight away with an answer. And they just know so much more than the doctors. It's unbelievable. (P5)

In particular, participants noted that PD nurse specialists were able to provide practical information on living with and managing PD pain that other clinicians could not.

> She's given us lots of little hints and tips about things we could do. It really feels as though you're talking to someone who thoroughly understands the situation. (P10)

Theme 5: Responding to Needs with Tailored Solutions (Individualization)

Responding to needs with tailored solutions (individualization) was a feature of PD pain care commonly discussed by participants in relation to their experiences with allied health professionals and PD nurse specialists. Participants identified two primary ways in which allied health professionals delivered tailored solutions. First, they provided targeted therapy to address immediate and specific concerns. Second, they adjusted the mode and/or dosage of therapy to better meet the participants' needs. This second approach was particularly relevant in the provision of exercise therapy for pain management. Importantly, participants' reports of allied health professionals for this feature of care were almost always positive.

> My massage therapist, before I get on the bed, "Any particular spots this week?" I go to the physio, "What's the problem now?" I've got neuropathy in my foot. They work on whatever is applicable at the time, rather than being regimented and saying, "This is it". They've been good in that respect. (P1)

> They [exercise physiologists] tend to doctor the exercises to what you're capable of because of the different standards in the class. (P16)

PD nurse specialists, in contrast, provided solutions to participants in a somewhat different manner. Participants noted that these clinicians leveraged their clinical networks to help address the challenges they were facing. For instance, participants frequently described situations where a PD nurse specialist collaborated with other clinicians to gather information or to recommend – and occasionally – arrange appointments with other providers.

> She [PD nurse specialist] was another person who I could bounce off, particularly with my foot. I would say, look, my ankle is swollen, it's painful and I can't walk. And she would jump on the phone and ring the neurologist or liaise with my general practitioner or whoever. She was extremely resourceful. (P15)

> He [PD nurse specialist] also put me in touch with my speech therapist. I think that may be how I first got onto the physio as well. He also helped me with my NDIS application. They've been good for recommending support services. (P18)

Discussion

This is the first study to explicitly explore the perceptions of the provision of pain care services from the perspective of people with PD living in Australia. We found several themes that illustrate the varied experiences of participants' interactions with healthcare providers. The themes identified – empathy and understanding (care), acknowledging needs and concerns (listening), explaining diagnoses and treatment options (explaining), expertise in PD (knowledge), and responding to needs with tailored solutions (individualization) – provide valuable insights into how individuals with PD perceive the quality of pain care they receive, and highlight both strengths and gaps in the provision of these services.

In this study, empathy and understanding (care) were crucial components of participants' interactions with healthcare providers, particularly in relation to neurologists and general practitioners. Empathy was valued not only as a demonstration of care but also as a means of validating the emotional and physical struggles that accompany PD pain, and PD itself. Consistent with previous research, participants who felt their healthcare providers showed empathy were more satisfied with their care,[29] while those who perceived a lack of empathy often felt dismissed. In addition to patient satisfaction, physician empathy has also been associated with higher levels of therapeutic adherence[30,31] and improved clinical outcomes including pain relief,[32,33] and accordingly, is conceptualized and acknowledged as key component of medical practice.[34,35] Despite this, participants' reports of empathy varied both across and within medical disciplines, with empathetic interactions being the norm among general practitioners, but less so among neurologists. The discrepancy across health disciplines may reflect differences in the dynamics of the relationships. General practitioners, who typically see patients more frequently, and therefore, have more continuity of care, may have greater opportunities to connect on a personal level. In contrast, neurologists, whose specialist roles may emphasize disease management and work within time constraints, may engage differently with the emotional aspects of care. The variability found within neurology suggests that the presence of empathy in clinical interactions may also depend on individual provider practices and attitudes. Further research, however, to investigate why these variances exist is warranted.

Acknowledging needs and concerns (listening) was a finding that underscores the importance of healthcare providers being attentive to the symptoms and concerns of people with PD. Many participants believed that their needs were better addressed when healthcare providers, particularly medical practitioners, actively listened, validated pain symptoms, and engaged in meaningful dialogue through follow-up questions. This finding is consistent with previous literature advocating effective physician listening as an important feature of quality healthcare.[36,37] Negative experiences were reported by participants when neurologists dismissed pain as unrelated to PD. Given that pain is a prevalent and debilitating symptom of PD,[1,2] this is an important finding. The non-recognition of pain as symptom of PD has been previously reported in the literature. However, most studies have focused on the under-reporting of pain symptoms by people with PD,[38,39] rather than the acknowledgement of pain by healthcare providers as a symptom of PD. This study, therefore, contributes to the existing literature by offering a system-level perspective on the barriers to recognizing PD pain. It highlights that, despite ongoing efforts over the past few decades to raise awareness and improve the recognition of pain as a PD symptom,[40,41] there remains a critical need for continued work to bridge the gap between evidence and clinical practice.

Another important finding was the role of explaining diagnosis and treatment options (explaining) during the clinical encounter. Participants valued healthcare providers who took the time to clearly explain their clinical reasoning in a manner that was comprehensible. This emphasis on communication not only enhanced participants' understanding of their condition and treatment rationale but also played a crucial role in building a therapeutic alliance. Participants who felt treated as equals (those who were informed and involved in decision-making) were more likely to express satisfaction with their care. These findings align with previous research, which has highlighted various physiological, behavioral, and subjective health benefits linked to effective clinical communication[42–44] as well as with patient- and person-centered care principles that emphasize clear communication and shared decision-making as the foundation of high-quality healthcare.[45–47] However, some participants noted a lack of adequate explanation, that resulted in feelings of disempowerment. The contrast that we found between individual providers, may reflect a broader challenge in healthcare: the balance between providing comprehensive information and the constraints of time. While some studies, for example, have reported time constraints as a barrier to providing effective communication,[48] others suggest that effective communication does not require more consultation time and is associated with increased clinician satisfaction.[49,50] Moreover, the economic cost of poor communication in healthcare is estimated to be substantial,[51] emphasizing that improving communication in PD pain management should be a priority for healthcare providers.

Expertise in PD (knowledge) was a finding that emerged strongly particularly in relation to general practitioners and PD nurse specialists. Participants generally noted that general practitioners had limited knowledge of PD and its symptoms. This finding is consistent with previous research conducted in 2010 by Abbott, Naismith and Lewis[52] that found Australian general practitioners demonstrated significant deficits in PD knowledge across both motor and non-motor symptoms of the disease. Consequently, this study suggests that PD specific knowledge among general practitioners remains a persistent issue in Australia, emphasizing the need for continuing education within primary healthcare. In contrast, PD nurse specialists were universally praised for their expertise in managing PD and providing tailored, practical advice for managing symptoms, including pain. This suggests that PD nurse specialists play a crucial role in addressing the multifaceted needs of people with PD, particularly when it comes to non-motor symptoms such as pain. As a result, this study contributes to the existing, albeit limited, literature on the positive role of PD nurse specialists in the delivery of services to people with PD.[53]

The final key finding of this study, responding to needs with tailored solutions (individualization), emphasizes the importance of personalized care in managing PD pain. Allied health professionals, such as physiotherapists and exercise physiologists, were particularly noted for their ability to adapt treatments to the specific needs of patients, tailoring their interventions to address individual symptoms and concerns. PD nurse specialists were also praised for their ability to respond to patient needs by effectively coordinating care and connecting patients with the appropriate services. This approach of individualized care aligns with the growing recognition of the need to tailor chronic pain management to the unique needs of each patient,[54] which is particularly relevant in PD pain, given its multifaceted origin and presentation.[5,55] It also reinforces the importance of multidisciplinary teams in ensuring that PD patients have access to professionals with specialized knowledge to manage both the medical and practical challenges of the disease.[56,57]

A key strength of this study was the diversity of participants across various Australian states and locations, including metropolitan and regional areas, as well as diversity in age and sex, which collectively enhanced the richness of the data. The development of the interview guide through collaboration among the research team, bringing a range of skills and expertise, also contributed to the depth of the collected data. Furthermore, the study adhered to best practice standards for conducting and reporting qualitative research. However, this research does have limitations. Despite efforts to recruit a varied sample, the cohort did not include individuals with advanced-stage PD, as classified by the Hoehn and Yahr 5-point staging scale.[28] Additionally, participants were selected from a pool of participants from a previous study that were primarily recruited through PD advocacy groups, where individuals are usually seeking information and support for PD, potentially making them more informed and better connected to services than individuals with PD who are not engaged with such groups. The study findings, therefore, should be interpreted in the context of a demographically diverse and well-supported early to mid-stage PD cohort, while recognizing limitations in transferability due to the absence of advanced-stage participants and recruitment from PD advocacy groups.

Conclusion

This study provides valuable insight and understanding into the provision of pain care services from the perspective of people with PD living in Australia. The findings show that perceptions of care are influenced by a healthcare provider's ability to address both the emotional and physical needs of PD patients. The variability in participants' experiences underscores the urgent need for enhanced healthcare provider education to ensure all professionals involved in PD pain care are equipped to deliver empathetic, individualized, and patient-centered care that addresses the complex and multifaceted needs of this population.

Data Sharing Statement

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

Ethical Approval and Informed Consent

This study was conducted in accordance with the principles of the Declaration of Helsinki. Ethical approval for the study was granted by the University of South Australia's Human Research Ethics Committee (ID: 205671) and all participants provided written informed consent prior to participation including the publication of anonymized responses/direct quotes.

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Disclosure

The authors have no competing interests to declare that are relevant to the content of this article.

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