


# Challenges to Ethically Managing Parkinson Disease: An Interview Study of Patient Perspectives

Journal of Patient Experience  
2017, Vol. 4(4) 191-196  
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DOI: 10.1177/2374373517706836  
journals.sagepub.com/home/jpx  


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## Abstract

This study investigated the current ethical issues in relation to recognizing and managing Parkinson disease (PD) from the patient's perspective. **Methods:** Twelve patients living with PD who were from the medical school's Patients as Educators program were recruited. Semistructured interviews were conducted to record patient experiences in order to identify potential ethical issues in relation to recognizing and managing PD. Thematic analysis was applied to the interview transcripts. **Results:** Four key themes emerged from the interviews. These were information giving, coping, identity, and future medical treatment. These data indicate variable experiences in relation to communication between patient and health-care professional, better support for both planning end-of-life decisions and in coping with the disease's impacts on their identity. Patients with PD also struggle with access to support services and support for main carer. **Implications:** To ensure ethical practice in supporting patients with PD, these emerging themes need further investigation; and management guidelines relevant to PD must be informed by research in this area to ensure ethical care of patients with PD, their carers, and families.

## Keywords

Parkinson disease, neurodegenerative disorders, ethics, patient perspectives

Approximately 1 in 500 people in the United Kingdom are currently affected by Parkinson disease (PD; 1), and it is estimated that by 2030, the number of individuals with PD worldwide will be in the region of 9 million (2). Medical professionals are faced with many ethical challenges when treating a patient with PD because of the diverse presentation of symptoms over time and the late onset complication of dementia affecting older patients with prolonged disease duration (3). In addition to complications relating to dementia, progression of PD significantly impacts on the mental well-being of the patients, requiring sociopsychological issues to be considered in the long-term management of the patients (4,5). These inherent complexities point toward potential ethical considerations in ensuring best practice in caring for patients diagnosed with PD and their families. However, the recent literature largely focuses on non-data-driven analyses and novel therapies instead of issues related to practical day-to-day care (6). Little focus is given in the recent literature to the everyday ethical challenges and concerns from the point of view of the patient. In this article, we investigate the current ethical issues in relation to recognizing and managing PD from the patients' perspective.

## Methods

A literature review was firstly undertaken to investigate current ethical issues in PD. Conclusions from the literature review informed the structure of a semistructured interview to explore the ethical issues from the patients' perspective. Semistructured interviews with participants of the Patients as Educators (PAE) program who have a diagnosis of PD was then undertaken. The interview was composed of 4 standardized open-ended questions allowing the interviewee to reflect and detail their experiences in their own words (see Box 1 for the key questions employed in the interview). The exact wording and sequence of questions were determined in advance. The strength of this process was that it increased

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1. Who gave you your diagnosis and when did you receive this information?
2. Is the treatment you are receiving effective?
3. How has life changed and what are the challenges of living with your condition?
4. What plans have you made regarding your wishes for future medical treatment?

### Box 1. Interview Questions.

the comparability of responses with complete data for each participant. It reduced interviewer effects and bias (7). These interviews were transcribed and analyzed thematically.

### Participant Characteristics

The PAE database consisted of 763 patients at the time of data collection; of these, 24 patients had a diagnosis of PD. Patients were invited from the list for interviews on predetermined days when the lead author had availability. The only criterion for invitation was a diagnosis of PD. All invited patients consented to be interviewed. Of the 12 PAEs interviewed, 5 were female (their ages ranged from 51-70) and 7 male whose ages ranged from 60 to 86. The length of time since their diagnosis ranged from 11 months to 24 years. Four participants were of working age but were unable to work because of their PD, and 8 participants were retired. All participants lived with a partner, who was their carer, apart from 1 participant who lived alone.

The number of participants to interview was not established ahead of time. The data collection was continued until saturation of themes was reached and no new information emerged from the data. The semistructured interviews were audio recorded and transcribed. These data were then analyzed to look for patterns of meaning and topics of potential interest. Next came the production of codes, which aimed to organize the data into meaningful groups to indicate potential themes. It was attempted to code for as many potential themes as possible in order to ensure that the context of the data was not lost (8). Once coding was completed, the search for themes began. The codes were analyzed and a thematic map was produced to help sort the codes into themes and subthemes. The themes were then checked against the data to ensure that they accurately reflected the meanings evident in the transcripts. This was done to ensure a rigorous method of analysis had been undertaken in order to provide merit and validity to the findings.

### Discussion of the Key Themes From the Interviews

Four key themes emerged: information giving, coping, identity, and future medical treatment. Each theme contained subthemes, and the findings are supported by extracts from the transcripts to demonstrate that themes were grounded in

**Table 1.** Theme 1: Information Giving.

Theme 1: Information Giving	Quotes No.	Quotes From Patients
Diagnosis as closure	1.	"I knew something had been going on for a while . . . when I got the diagnosis I felt a bit better"
	2.	"It took 6 years from start to finish to actually get a diagnosis. I had a lot of different health problems"
	3.	"A young doctor saw me and said — how long have you had PD? I had a shake and I think he saw the stare. I was referred to a neurologist. They confirmed the diagnosis. It was a shock, but a relief that it was something that could be dealt with"
Experience of being given the diagnosis	4.	"There were 2 medical students in the room but he didn't introduce them before he told me. I would have preferred to be more private. It was a bombshell"
Information helped/hindered ability to cope	5.	"I had an interview with the PD nurse. She gave me all the information about PD and I felt OK at that stage"
	6.	"The nurses left me with lots of leaflets and I made the mistake of reading every one of them. I felt worse after my diagnosis and was devastated at first"

the data. The results are organized in Tables 1 to 4 by the 4 main themes.

### Theme 1: Information Giving

This theme had 3 subthemes of perceptions about "diagnosis as closure," "varying experience of how the diagnosis was given" and whether "the level of information helped with coping."

Most interviewees stated they felt better after full disclosure of their diagnosis. This was because in many cases, a delayed diagnosis had often been a cause for concern due to on-going unexplained physical symptoms and negative test results. Once patients were diagnosed with PD they accepted this, getting closure (Table 1: quotes 1–3). Several interviewees were satisfied with the way in which they were given their PD diagnosis whereas others had a negative experience such as being informed of their diagnosis in a nonprivate setting. This is against good practice in breaking bad news (9). Another patient felt the clinician was abrupt and impersonal when giving the PD diagnosis. This may be due to clinicians feeling guilty about not being able to offer a valid solution, which affects perceived appropriate timing and manner of disclosure (10) (Table 1: quote 4). Several

**Table 2.** Theme 2: Coping.

Theme 2: Coping	Area of Focus	Quotes	
		No.	Quotes From Patients
Medication management	Medication	1.	"The medication has only recently started working. It's taken a long time to get the dosage right. I am now more myself"
		2.	"I take medication every 4 hours. It is effective. Without it I would not get out of bed"
		3.	"It's horrendous (the medication). Made me feel worse. I worked on a switchboard then and I fell"
		4.	"It made me start gambling. I got into it really bad and I never had any addictions before"
		5.	"I had terrible nightmares before the patches, and hallucinations. I still have those, I see things going past me"
Support	DBS	6.	"Since the DBS, the stiffness and tremor have been better. I feel well. I have now halved the medication. My family are amazed and it has made a big difference"
	From a health professional	7.	"The PD nurse has been lovely and helped me to cope"
	From partner/family	8.	"I and my wife are a team, getting on with it. She does a lot for me, simple things"
Access	Lack of access to medical profession	9.	"She is 74, she has health problems. I leave her in bed for as long as I can"
		10.	"I cannot get a repeat prescription automatically and I need to see the doctor. Controversial as I can't get in to see the doctor."
Impact of intra team relationships	Falls	11.	"Not allowed to be left alone, no independence. She is frightened of me falling because my biggest fear is falling"
		12.	"The GP refers to the neurologist and then the GP always rings me back"
	Interdisciplinary relationships	13.	"The diabetic nurse says she would like to change things but the consultant says no, leave it as it is"

interviewees' felt that receiving as much information as possible helped them to cope with their diagnosis. Others felt that they were given too much information and this hindered their ability to cope with the devastating news (Table 1: quotes 5,6).

### Theme 2: Coping with PD

There were several factors/subthemes that encompassed coping and included medication management, support from health-care professional or family, poor access to health-care professionals, and impact of relationships within the team on the patient.

Compulsive behavior (gambling) and frightening nightmares occurred in 2 patients as a side effect of their PD medication. Both patients were eventually offered alternative medications and the problems stopped (Table 2: quotes 4–5).

The patients were prescribed 7 different PD medications overall, and it appears that most prescriptions were altered over time in order to find the right drug and dosage for each individual. The principle of beneficence appears to be working well here with these efforts being an indication to improve efficacy of prescribed medication. However, there is currently limited evidence exploring the interindividual differences in response to drug treatment (11,12). One patient, who before receiving deep brain stimulation (DBS) had suffered severe physical symptoms, was adapting well to the stimulator (Table 2: quote 6). This was despite the need

for continuous device activity that sometimes causes feelings of strangeness or change in identity (13). All patients who regularly saw a PD nurse held them in high regard and felt them to be caring and supportive (Table 2: quote 7). Several interviewees felt that a lack of interdisciplinary cooperation between health professionals led to unwarranted challenges to their care (Table 2: quotes 10,13). Most interviewees had a spouse who was also their carer. Some were elderly with health problems of their own. This was a source of worry for several patients who felt their spouses got little support (Table 2: quote 9).

### Theme 3: Identity

These data suggest that the disease impacted on self-identity through "self-esteem," "limit to independence" and "compromises in relationships."

Several interviewees felt that physical changes due to PD had changed their identity and they experienced low self-esteem or "worthlessness." (Table 3: quotes 1–3). Loss of independence was a major challenge for the interviewees. For example, most interviewees had made up their own minds to stop driving and they appeared to be aware they should no longer be on the road (Table 3: quote 5). This shows that when possible it is appropriate to let patients lead on such decision-making. All interviewees reported regular appointments with their General Practitioner (GP), PD nurse, and neurologist, but not access to the multi-disciplinary team (MDT) that is recommended for maintaining Quality of Life (QOL) (14).

**Table 3.** Theme 3: Identity.

Theme 3 : Identity	Quotes No.	Quotes From Patients
Self esteem	1.	"I really felt that my self-esteem went down . . . sometimes people stare, children are difficult. It was really tempting to hide myself away but I had to get on with my life, it's like punishing yourself otherwise"
	2.	"Biggest challenge, my feelings, trying to have value. It takes so long to do anything"
	3.	"I can't do things around the house as my fingers don't work properly and then I get frustrated. The biggest challenge is realizing I can't do what I took for granted"
Independence	4.	"The biggest challenge is that I can't go to town on my own. I have lost my independence"
	5.	"I decided to give up driving. Every time I went out I would be driving along the street and I would hit the kerb"
	6.	"I can't work now, had that many stays in hospital. My wife had to give up work as I was in and out of hospital, the bills were mounting and my oldest son is autistic"
Compromised relationships	7.	"My husband has got quite snappy, tells me to stop shuffling my feet. He finds it stressful. He tells me to speak up all the time"

#### Theme 4: Future Medical Treatment

This theme comprised of challenges in planning for "end of life" and "treatment choices" in the future.

Few interviewees had considered that at some stage they may develop cognitive dysfunction and most had not made any provision for this outcome (Table 4: quotes 1,3). Parkinson disease can leave patients unable to make legally binding decisions about future medical treatment, highlighting the importance of advance planning. Several interviewees had already prepared advance directives but most had never discussed this with anyone (Table 4: quotes 1,3). One patient who had made an advance directive did so as a result of mistaken views about the Liverpool Care Pathway propagated by the media (Table 4: quote 2). Another patient discussed "going to Switzerland when the time is right" showing an understanding of current UK law. Patients and families need to be well informed to make good decisions about future care, and when a patient lacks capacity, family has input in the decision-making process (Table 4: quote 1). The issue of inadequate End of Life (EOL) discussions raised by the participants here should be further explored to understand the prevalence and nature of the issues in a larger population. Several interviewees had been given information about DBS as a possible future treatment but

were not ready to consider this procedure (Table 4: quote 4). They felt they were either too young or not yet at an advanced stage of the disease. The patients have a right to refuse DBS surgery, which should be respected, even if the decision is not in their best interests.

The literature indicates, patients do prefer full disclosure when given a diagnosis of a neurological condition in the early stages of their disease; this helps them to understand the condition and what the future might hold (15). Older patients sought less detailed information and preferred less involvement in treatment decisions (16). When disclosing a neurological diagnosis, clinicians only tend to address the physical consequences of the disease, suggesting that clinicians might not want to burden the patient with the knowledge of possible psychological symptoms (17). These findings were supported by data collected from patients with PD (see Table 3). However, clinicians did aim to establish a good physician-patient relationship over time (10).

Ethical challenges to QOL when living with a neurological condition were discussed in the literature, in particular with regard to medication and its potential side effects. It is recognized that medication in patients with PD should be reviewed regularly and discontinued if causing behavioral dysfunction (18). This is supported by our data (Table 2: quotes 1, 3).

Clinicians should discuss potential life-changing decisions, such as giving up driving, with patient and family in order to avoid potential problems (18); patients with PD should be treated by a MDT to optimize QOL (14). However, lack of expertise among health professionals, little interdisciplinary cooperation, and decreased financial support are all barriers to successful MDT care (19). It is also important to treat patient and carer as a "unit," with the QOL of the carer linked to the physical and mental health of their charge (20). In relation to making advance plans for future medical treatment, it was found that health professionals felt it was of high importance to understand and implement the future wishes of their neurological patients (21). Perhaps, the unpredictability of neurodegenerative disease makes palliative care plans difficult and this may be a reason why discussions about EOL do not always take place. With the exception of 1 paper (22), we were unable to find literature that addresses how to help patients with PD cope with conflicts in their identity due to impact of the disease; this was the same with regard to supporting patients with PD about EOL issues indicating the need for further work in these areas.

#### Strengths and Limitations of the Data

This study provides an insight into the current ethical challenges related to supporting patients with PD. Information was gathered relating to how patients with PD receive their diagnosis, the ongoing QOL challenges the patients face and how they cope with day-to-day living, loss of identity, and their relationships with others. It also reflects on how patients with PD feel about their future. The findings show that key issues center on disclosure, pharmaceutical and

**Table 4.** Theme 4: Future Medical Treatment.

Theme 4: Future Medical Treatment	Area of Focus	Quotes No.	Quotes From Patients
End-of-life decisions	End-of-life issues	1.	"My daughter would know what I wanted. The family would not want me to suffer"
Advance decisions	Advance directives	2.	"In my living will I did say I did not want the Liverpool pathway. I don't mind being put down but I object to being starved and parched to death"
	No advance plans made	3.	"I am too young. I haven't got anything in place. I don't want to think about it yet"
	DBS	4.	"They have talked about DBS. No way would I let that happen!"

nonpharmaceutical treatment, and involving patients in EOL decisions. However, the interviewees are selected from 1 single site and chosen "conveniently" because they had PD (23) and were part of the PAE program at the medical school. It is important to consider how and whether PAEs differ from other patients with PD. The data collection was limited to patients and did not include clinicians and other stakeholders, preventing the opportunity to obtain a multistakeholder view.

### Implications for Future Research and Practice

In many areas, this small data set indicate mixed messages; for example, about satisfaction with receiving diagnosis, support with regard to future medical care or with end-of-life care planning. These maybe indicative of variable quality of experiences. To ensure that management of patients is ethical, equity in patients' experiences is important. Future research therefore needs to explore the issues emerging in this interview study further, both from patient as well as carer and the medical team's perspectives.

### Authors' Note

The project was reviewed and approved by the Sheffield Medical School Research Ethics Committee (SMBRER 004368).

### Acknowledgments

The authors acknowledge Sheffield Medical School Patients as Educator volunteers and The Sheffield Medical School Clinical Skills team.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research and/or authorship of this article.

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