

# The Perspectives of Patients with Parkinson's Disease: A Systematic Review and Thematic Synthesis

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## Research Article

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## Abstract

**Background:** Parkinson's disease has considerable impact on the quality of life of both patients and their caregivers. Patients' perspectives are a source of vital knowledge that informs health professionals' ability to provide individualised and patient-centered care. The aim of this systematic review was to identify the perspectives of patients with Parkinson's disease on treatment, care and rehabilitation.

**Methods:** We conducted a systematic review and searched the following electronic bibliographic databases: MEDLINE, EMBASE, CINAHL, PsycInfo and Scopus for original studies published before June 2020. Grey literature was searched at [www.parkinson.org](http://www.parkinson.org), <http://www.epda.eu.com>, [www.apdaparkinson.org](http://www.apdaparkinson.org) and in the OpenSIGLE and HMIC databases. We included studies focusing on patients with Parkinson's disease aged 18 or older that reported patients' perspectives on treatment, care and rehabilitation. Results were analysed using thematic synthesis.

**Results:** Ten studies were included, each of them applying qualitative methods and including between 1 and 28 patients. A total of 156 codings led to 17 descriptive themes which resulted in three analytic themes: *Significance of self*, *Significance of informal caregivers and peers*, and *Significance of professionals*.

**Conclusions:** Our findings could be important in helping healthcare professionals plan and deliver treatment, care and rehabilitation based on patients' priorities in the context of suffering from a chronic disease. The results might also guide future research regarding patient perspectives, as well as how and why to incorporate patients' perspectives in healthcare delivery.

**Systematic review registration:** The protocol was registered in Prospero (183551).

## Introduction

Parkinson's disease (PD) is a progressive neuromuscular disorder and a fairly common cause of movement disorders among elderly individuals (1, 2). The most prevalent movement disorders caused by PD are bradykinesia (slowness and inertness), rigidity and tremor due to a loss of dopaminergic neurons in the brain (2, 3), not to mention symptoms such as insomnia (4), urinary urgency (5), changed sex drive (6), and constipation (7). Moreover, PD is often accompanied by cognitive challenges, such as concentration problems and memory impairment (8). Despite these common features of PD, it is important to be aware that as a neurodegenerative disease, PD will develop and escalate differently in each individual. The cause of PD is mostly unknown, though genetic risk factors have been identified; environmental risk factors such as smoking, alcohol and vitamin D exposure are, despite uncertain evidence, also assumed to increase the risk of PD (2). PD is currently considered incurable, and patients with PD can expect to be in frequent contact with the healthcare system due to the overwhelming number of symptoms.

Despite a considerable amount of evidence on recommendations for treatment, care and rehabilitation of patients with PD (9, 10), the literature appears to lack meaningful identification of patients' perspectives on the disease. To fully accommodate the recommendations for evidence-based practice, patients' perspectives are of paramount importance to complement clinical expertise and research evidence (11). By including patients' perspectives, care, treatment, and rehabilitation can be planned and delivered based on what patients consider to be their priorities in dealing with a chronic disease such as PD. Thus, the aim of this systematic review was to identify and synthesise results from original studies examining the perspectives of patients with PD in terms of 1) treatment, 2) care and 3) rehabilitation.

## Methods

The protocol was registered in Prospero (183551) and remained unchanged during the review. Findings are reported according to the PRISMA Group - Preferred Reporting Items for Systematic review and Meta-Analysis guidelines (12).

## Eligibility criteria

We included primary studies of any design focusing on our population and reporting patients' perspectives on treatment, care and rehabilitation of PD. As such, we imposed no restrictions regarding design despite anticipating that our aim would be met only by studies with a qualitative design. If studies included patients both over and under 18 years of age or included patients with PD and other types of chronic or neurodegenerative illnesses, the studies were considered for inclusion only if the data were stratified by age or diagnosis, respectively. Likewise, if studies included both patient perspectives and the perspectives of spouses and/or formal or informal caregivers, the studies were included only if patients' perspectives were presented separately.

## Information sources and search strategy

The search was performed June 26th, 2020. An information specialist was consulted for the design of search strategy and identification of databases and keywords. We searched the electronic bibliographic databases MEDLINE, EMBASE, CINAHL, PsycInfo and Scopus with block search and pearl search strategies. Additionally, personal article collections and libraries of researchers and health experts were screened for relevant literature. Grey literature was searched at [www.parkinson.org](http://www.parkinson.org), [www.epda.eu.com](http://www.epda.eu.com), [www.apdaparkinson.org](http://www.apdaparkinson.org) and in the OpenSIGLE and HMIC databases. No restrictions were placed in terms of publication year, design, or language. Finally, PROSPERO was searched for ongoing or recently completed systematic reviews.

Initially, search terms were structured using the PEO framework (13) (see Table 1). However, as PD research appears to be a relatively narrow field, we used only two blocks in the final search: *patient* and *outcome*. The remaining block, *exposure (treatment, care and rehabilitation)*, would have increased the risk of excluding potentially relevant studies and was therefore not included in the final search but instead used for guiding the TiAb-screening to ensure included studies focused on either *treatment, care or rehabilitation*.

Table 1  
PEO framework for Medline

MEDLINE					
	P		E		O
SEARCHTERMS	PATIENT	AND	EXPOSURE	AND	OUTCOME
	Patients with Parkinson's disease		Treatment		Patients perspectives
OR	Parkinson disease (MeSH) or		Care		<i>exp Consumer Participation/ or Patient Acceptance of Health Care/ or exp Attitude to Health/ or *exp consumer satisfaction/ or patient preference/ or cooperative behavior/ or exp Adaptation, Psychological/ or exp health education/ or patient education as topic/ or exp attitude to health/ or health knowledge, attitudes, practice/ or *Quality of Life/ or Quality of Life/px or Personal Autonomy/ or consumer advocacy/ or Needs Assessment/ or Patient Advocacy/ or Self-Help Groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/ or Self Care/ or focus groups/ or narration/ OR (((patient or consumer*) adj3 (participat* or decisi* or decid*)) or patient-focused or (patientcentred or patient-centered)).mp. or (patient adj3 (attitude? or preference)).ti,ab. or patient satisfaction.ti. or coping.ti,ab. or self perception.ti,ab. or (informed choice or shared decision making).ti,ab. or empowerment.ti,ab. or (focus group* adj3 (patient* or parent* or famil* or spouse*)).ti,ab. or (QoL or Quality of life).ti. or self-management.ti. or ((patient* or consumer* or parent* or famil* or spouse*) adj (attitude* or involvement or desir* or perspective* or activation or view* or preference*)).ti,ab. or expert patient*.ti,ab. or focus group*.ti,ab. or qualitative.ti OR exp Decision Making/ or exp Communication/ or Stress, Psychological/ or Emotions/ or vignette*.ti,ab. and (exp Patients/px or patient*.ti. or consumer*.ti.)</i>
	Parkinson disorders (MeSH) or		Rehabilitation		
	Parkinson disease, secondary, (MeSH) or				
	((Parkinson* adj3 (disease* or Disorder* or syndrome*)) or parkinsonism)				

Treatment is broadly defined as the management and care of a patient to combat disease or disorder [www.wisconsin.edu/](http://www.wisconsin.edu/) (29.05.2020), and therefore does not refer to specific procedures or medications. Care is defined as 'The services rendered by members of the health profession and non-professionals under their supervision for the benefit of the patient',(14) and includes information, patients' involvement, personal care, discharge and planning. Finally, rehabilitation is defined as a treatment designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible (<https://medical-dictionary/> 29.05.2020).

The search strings (blocks) were customised towards the specific databases and their structures. An example is presented in Table 1. (For complete search string, see Appendix.)

## Screening and study selection

Search results were uploaded to Endnote (<https://endnote.com/>). Doublets were removed both prior to importation to the reference programme Covidence ([www.covidence.org](http://www.covidence.org)) and in Covidence. In Covidence, three reviewers (BN, SBT and MM) independently screened and identified studies that met the inclusion criteria.

To increase the consistency among reviewers, 50 publications were screened by the three reviewers and discussed prior to final screening.

The exclusion criteria were wrong study design (i.e., protocols or opinion papers without data), population or outcomes, respectively. Any disagreement among the reviewers concerning the eligibility of studies was resolved through discussion to reach consensus. Studies meeting the inclusion criteria were retrieved for full text analysis. None of the reviewing authors were blinded to journal articles, study authors or institutions. The process followed is shown in Fig. 1.

## Data extraction and data items

Prior to data extraction, a customised spread sheet was developed, piloted and refined to extract data for study characteristics. Two reviewers (BN and MM) independently extracted data, with a third reviewer (SBT) available to resolve conflicts. The following study characteristics were extracted: bibliographic information, including country (based on first author's affiliation); study aims; study design and data collection methods; inclusion and exclusion criteria; time and place of interview; participants' characteristics and data analysis techniques.

Data on patients' perspectives were extracted from the results sections (or findings) by three authors (BN, SBT and MM) to identify emerging themes across studies (15).

## Quality assessment

The quality assessment was based on the Critical Appraisal Skills Programme (CASP) checklists (Critical Appraisal Skills Programme (2019). CASP Qualitative Checklist. [online] Available at: [https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018\\_fillable\\_form.pdf](https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf) (Accessed: 2020.10.01)) as well as user guidelines as described by Butler et al. (2016) (16). In the scoring, 1 point was allocated for 'Yes', 0.5 points for 'Can't tell' (unsure) and 0 points for 'No'. To ensure a rigorous and fair assessment, we considered all italicised prompts listed under each question in the checklist, placing particular emphasis on Question 3 (the presence of a justification of research design), Question 7 (clear statements concerning the researchers' detailed explanations of the research to study participants) and Question 8 (the presence of an in-depth description of the analysis process).

All articles were assessed independently by authors BN, SBY and MM. Disagreement occurred only concerning unclear criteria fulfilment, and consensus was reached after discussion.

## Data synthesis and interpretation

The purpose of this study was to synthesise the perspectives of a specific group of users of healthcare services (here, patients diagnosed PD). Thus, we searched for themes or constructs from existing studies in order to generate new knowledge (17). Data were extracted and analysed by three authors (BN, SBT and MM) using thematic analysis. This approach, as described by Thomas, includes three steps: coding text, developing descriptive themes and generating analytical themes (15). The analytical strategy included coding and extraction of findings from the results section (or findings) of each study (Step 1). Data extraction was approached inductively, and the extracted data were then grouped according to similarity in meaning as judged by all authors. Through this process, the descriptive themes emerged (Step 2). In labelling the descriptive themes, it was important to ensure that these themes were not guided by predefined labels. Thus, we put a parenthesis around our research aim, allowing the descriptive themes to emerge through the grouping based on similarities. In doing so, we remained close to the original findings and did not interpret or create additional understandings. However, in Step 3, we went beyond the data in the included studies and generated analytic themes.

We looked for relationships between the descriptive themes and defined analytic themes, gathering the descriptive themes in fewer major groups (themes) that addressed the overall aim of the review: to identify patients' perspectives.

Steps 1 and 2 were conducted by three authors (BN, SBT and MM), whereas Step 3 was drafted by BN and later discussed, tested, validated and approved by SBT and MM. However, the final themes reflect a consensus agreement among all the authors.

## Results

### Study selection

After removing duplicates, 14,002 studies were identified, of which 13,905 were excluded based on title or abstract. Of the 97 remaining studies, 87 were excluded after full-text reading, leaving ten studies for inclusion. For further details, see Fig. 1.

### Study characteristics

The ten included studies were published from 2004 to 2020, with one study from 2004 (18) and the remaining nine studies from 2014 to 2020. There were three studies from the US (19–21), two each from the UK (22, 23) and Australia (24, 25) and one from each of Sweden (18) the Netherlands (26) and New Zealand (27).

Most of the studies reported a specific purpose – e.g., how patients view the role of their GP (26), or patients' perceptions of a specific exercise (20, 24, 27) or prevention program (19), or of their perioperative experiences (21).

All studies applied a qualitative design with interview data; one study supplemented this with video recordings (26). Most of the studies used coding and thematic analyses, though one study applied saliency analysis (25), one used grounded theory (24) and one used a constant comparative approach for analysis (26). Details of study characteristics are presented in Table 2.

Table 2  
Study characteristics

Author, year of publication and location*	Aim	Design/data collection method	Inclusion and exclusion criteria	Time and place of interview	Sampling strategy	Participants' characteristics (Sex, Age, Living)	Data analysis techniques
Shaw, 2017 (UK)	To investigate the current ethical issues in relation to recognizing and managing PD from the patients' perspective	Semi-structured interviews / 12 patients	Participation in the PAE Program (Patients as Educators)	Time range since diagnosis: 11 months to 24 years	Interviews until saturation	5 female / 7 male Age range 51–86	Thematic analysis, including coding and a thematic map
Read, 2019 (UK)	To explore experiences of service use and unmet needs of those with late stage Parkinson's who have high degrees of disability	Interviews / 10 patients	<b>Inclusion:</b> Diagnosed for the last 7 years , stage 4 or 5 (Hoehn and Yahr Scale) a score of 50% or below (Schwab and England Scale) <b>Exclusion:</b> dementia, drug-related Parkinson or unable to communicate	Time since diagnosis: mean: 18 years range. 9–28 years interviews were conducted at the patients' place of residence	Purposive sampling from the English cohort of the European 'Care of Late Stage Parkinsonism	3 female / 7 male Mean age: 77 years Living: ordinary housing: 9 / nursing home: 1	Thematic analysis using an inductive approach
Plouvier, 2017 (NL)	To clarify the role community-dwelling PD patients see for their GP in PD care	Video recordings graded to reflect patients' feelings followed by semi-structured interviews	Diagnosis of PD  Community-dwelling No apparent cognitive dysfunction Capable of handling a video camera	Mild stage disease	Purposive sampling through GPs (gender and location)  15 patients or until saturation	12 patients, 8 male / 4 female Mean age: 69 years Community-dwelling	Content comparative approach
O'Brien, 2015 (Australia)	To explore the relationship between the meaning of exercise and other influences that underpinned the exercise behaviour of individuals with PD	In-depth semi-structured interviews	Participants in a 6-month exercise arm of a falls prevention trial  Idiopathic PD; 40 years or older; ability to walk independently; stable PD medication; one or more falls the past year or in risk of falling	Disease duration: 3–11 years  Interviews were conducted in the participants' home	Purposeful sampling	8 patients, 6 male / 2 female; age range: 64–82 years	Grounded theory using an interpretivist, constructivist framework
Milligan, 2018 (NZ)	To explore the perceptions of participants of ... a small group exercise program...	Semi-structured interviews in small groups or individually	Participation in an RCT and idiopathic Parkinson's	Disease duration: 1–23 years	Patients randomised to the intervention group of an RCT	21 patients – 13 male / 8 female Age range: 61–82 years	Inductive approach including coding and thematic analysis
Greviskes, 2018 (USA)	To gain a better understanding of the nature of caring in a secondary prevention program setting from the perspective of individuals with PD	Semi-structured interviews	18 years or older, sufficient cognitive ability, participation in an SPP for the last 4 weeks	Median stage 3 H&Y	Patients enrolled in an SPP	10 patients – 3 male / 7 female Mean age 73 years	Inductive content analysis
Edwards, 2014 (Australia)	To explore perceptions of one patient's hospital experience, identifying what mattered to the patient...	A qualitative descriptive approach / case study	In-patient	Hospitalized for planned deep brain stimulation	Ease of recruitment... during hospitalization	One 49 year old male patient	Saliency analysis

\*Location = 1st author affiliation

Author, year of publication and location*	Aim	Design/data collection method	Inclusion and exclusion criteria	Time and place of interview	Sampling strategy	Participants' characteristics (Sex, Age, Living)	Data analysis techniques
Cleary, 2020  (USA)	To explore the reasons a group of people with PD continued to regularly attend a community-based group exercise program	Phenomenology research design	PD diagnosis, H&Y stage 1–3, regular attendee in the program	H&Y stage 1–3	A predetermined sample of 25 patients	18 patients – 9 male / 9 female  Mean age: 67.3	Content analysis
Birgersson, 2004 (Sweden)	To describe persons with Parkinson's disease and their partners' experience of support received	Open-ended interviews	Confirmed diagnosis of PD, married or co-habiting	Disease duration 5–24 years	Persons with PD recruited from two out-patient services specialised in care for patients with PD	Six couples – of those 2 male and 4 female with PD	Content analysis
Anderson, 2013 (USA)	To hear directly from surgical patients with Parkinson's disease about their perioperative experiences	Descriptive design – interviews	Adults with Parkinson's disease, having elective surgery (not PD surgery), age between 50 and 80 years, a score of 7–10 on SPMSQ	Interviews conducted in the participants' homes		13 patients – 10 male / 3 female	Coding
*Location = 1st author affiliation							

The studies included a total of 105 participants with between 8 and 21 participants (patients) per study, with the exception of one case study of a single patient (25). Of the included participants, 64 were men and 41 were women. The mean participant age from nine of the studies was 68.4; Shaw et al. presented only an age range (i.e. 51–86) (23).

While the included studies appeared relatively homogenous in terms of study design and analytic approach as well as gender and age of participants, they were characterised by noticeable heterogeneity in terms of *when* the interviews were conducted (i.e., during hospitalisation or community-dwelling with participation in exercise programs in primary care); time elapsed since diagnosis (from 11 months to 28 years); and stage of disease (Hoehn & Yahr and/or high degrees of disability/ability to walk independently).

## Quality assessment

Although the level of methodological quality varied slightly, the studies were rated positively, with scores between 8 and 10 out 10. However, half of the included studies failed to address the researcher-participant relationship and four failed to describe ethical considerations, particularly regarding information to participants. Nevertheless, we found that the results of each study were applicable and contributed to informing our research aim. In Table 3, we present the appraisals of the included studies.

Table 3  
Quality assessment

Study	Clear statement of aim	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection addressed research issue	Researcher-participant relationship adequately considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	Valuable research
Shaw, 2017 (UK)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Read, 2019 (UK)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Plouvier, 2017 (NL)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
O'Brien, 2015 (Australia)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mulligan, 2018 (NZ)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Greviskes, 2018 (USA)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Edwards, 2014 (Australia)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cleary, 2020 (USA)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Birgersson, 2004 (Sweden)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Anderson, 2013 (USA)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes

## Thematic synthesis

In Step 1, a total of 39 main themes, 76 sub-themes and 41 additional findings were coded line-by-line and extracted to allow the descriptive themes to emerge (Step 2). In this portion, the aim of the review was set aside to avoid causing our a priori framework and assumptions to influence the analysis. The process resulted in 17 descriptive themes. The number of codes in the single descriptive themes varied substantially, with, for instance, two codes defining 'The value of patients' knowledge', four codes defining 'Continuity', and 14 codes defining 'Physical challenges' and 'Individualised treatment, care and rehabilitation', respectively. However, we consider all codes to be of equal value – and consequently all descriptive themes to be of equal value as well. In Step 3, three analytic themes were generated: *Significance of self*, *Significance of informal caregivers and peers*, and *Significance of professionals*. Findings are presented according to these analytic themes. In Table 4, we list the studies that reported on the themes.

Table 4  
Analytic themes identified in each study

Study/Analytic theme	The significance of self	The significance of informal caregivers and peers	The significance of professionals
Shaw, 2017	Yes	Yes	Yes
Read, 2019	Yes	Yes	Yes
Plouvier, 2017	Yes	-	Yes
O'Brien, 2015	Yes	Yes	Yes
Mulligan, 2018	Yes	Yes	Yes
Greviskes, 2018	Yes	Yes	Yes
Edwards, 2014	Yes	-	Yes
Cleary, 2020	Yes	Yes	Yes
Birgersson	Yes	Yes	Yes
Anderson, 2013	Yes	Yes	Yes

## Significance of self

The analytic theme 'Significance of self' was composed of the five descriptive themes: *adaptation and coping*, *physical challenges*, *value of patients' knowledge*, *self and mind*, and *impact of own effort*. Although the descriptive themes at might appear diverse at first glance, they all concerned not only the value of the patients' own efforts but also the importance of *adaptation to and coping* with their new and constantly changing situation. 'Coping and adapting' was in most cases related to the *physical challenges* patients with Parkinson's disease experience continuously. One overarching theme was fear of falling, but other challenges were mentioned as well: apathy, fatigue and other health and memory problems such as forgetfulness, hopelessness and hallucinations. A single study reported patients' wish to be seen as individuals *having knowledge* about themselves and their disease, and therefore as individuals who sometimes know best regarding the best medication regimen. In other words, they wished to contribute actively to ensure their optimal treatment, care and rehabilitation, and consequently their own wellbeing.

However, the most pervasive descriptive theme within this broader analytic theme was *Self and mind*, which focuses on patients' continuous struggle to cope with the changes wrought by PD to their identity, self-reliance and autonomy, as well as their struggle to maintain a sense of self and normality in the face of disability and unpredictability. Many of the patients in the included studies cared deeply about self-efficacy, control and empowerment, independence, and autonomy. They cared about being confident, having high self-esteem, pursuing self-actualisation, and being respected. On the dark side of this theme, patients mentioned the importance of overcoming themselves in order to not be disappointed in themselves and underscored the *impact of their own effort* both in relation to physical and psychological challenges and also in relation to more concrete training and rehabilitation goals. They hoped for a holistic, lasting benefit, a more active future, physical comfort and functional gains resulting from their undertaking exercise regimes. Overall, this theme is composed of the physical and mental challenges caused by PD and the importance of accepting the inevitable changes and adapting to a new situation.

## Significance of informal caregivers and peers

The three descriptive themes *Support from peers*, *Motivation* and *Support from informal caregivers* fed into this analytic theme. *Motivation* was the most concrete of the themes, revolving primarily around the importance of motivating oneself or being motivated by others to undergo training and rehabilitation as well as the importance of making sense of the exercise experience. Motivation was closely related to another descriptive theme in this analytic theme: *Support from peers*. This theme revolved around being among equals during training with friends and in comparison with others; gaining strength, inspiration and knowledge; the influence of others; and encouragement received and given within the group. But patients in the included studies also mentioned more relational features, such as shared understanding, socialisation and inspiration, camaraderie between group members, the accountability that came with belonging to the group, an understanding and supportive environment, and experiencing solidarity and community. Furthermore, patients also expressed a desire for empathy (not to be confused with pity), which they experienced among peers who understood the challenges of living with PD.

Last but not least, *Support from informal caregivers* fell within this analytic theme. This descriptive theme is characterised by both vulnerability due to patients' dependency and concerns regarding the burdens on their caregivers. Patients with PD were very much aware of their dependence on their informal caregivers, from whom they received vital support; they recognized the need for caregivers to advocate for them as patients and to act as organisers and mediators regarding contact with healthcare. On the other hand, patients worried that their disease and its attending physical and mental challenges would result in compromised relationships and substantial caregiver burden. Overall, this is a rather complex theme: it captures the joy of being among peers; the dependency on, and need for, help from significant others; and the worry that their caregivers will be burdened by living with a person with PD.

## Significance of professionals

This analytic theme was a core theme regarding the aim of this review and a recurring theme in the included studies. It was also the analytic theme with the most codes (97/156). Within this theme, we identified the following descriptive themes: *Loss and end of life*; *Not being met and suffering*; *Information*; *Medication*; *Continuity*; *Professional professionals*; *Access to medical expertise*; *Individualised treatment, care and rehabilitation*; and *Kindness*.

Some of these themes were relatively concrete. *Access to medical expertise*, for example, covered experiences surrounding the diagnosis, such as the relief in viewing the diagnosis as closure, as well as access to medical specialists when needed. Medical specialists were defined in relation to PD, and the need for expertise changed over time. Thus, this could refer to access to the GP, neurologist or multidisciplinary team, or else acute care if needed. But patients also requested access to help more generally in terms of assisting with their care decisions. In other words, they wished that their GP or other medical specialist would stay in touch with them and be accessible when needed. Another example of a relatively concrete theme was *Medication*. This theme reflected that patients with PD were quite knowledgeable about their disease and keen to follow a medication routine that suited their particular needs, even if it did not conveniently fit organisational routines. Patients greatly wished for *individualised treatment* and care and, as a consequence, *continuity*. *Individualised treatment* was a broad theme covering the desire for a changing and challenging workout routine and modified exercise programmes to challenge patients as individuals. However, the themes also included a desire for relational individuality, i.e., that healthcare professionals should provide them with one-on-one attention and recall personal details and that care should be tailored and individual. This theme was also expressed in terms of a lack of individualised treatment and institutional inflexibility – patients stated that the fact that they, as individuals, were supposed to fit into the regimented healthcare system was detrimental to their normality, independence, and sense of self. This was again closely related to the theme of *Not being met and suffering* – a descriptive theme covering both organisational inadequacy (such as lack of privacy and empathy, being offended, feeling misunderstood and humiliated) and also more existential themes such as worthlessness and insecurity. Though patients mentioned *information* only a few times, this was a key theme, too – both in terms of their desire for sufficient, individualised and tailored information, and also regarding the fact that information helped them cope with their disease (or prevented them from doing so, if the information was not provided). Regarding the behaviour of the professionals, *kindness* stood out as being particularly important for patients with PD. This was expressed through a number of terms describing helpful caregiver reactions: showing interest and benevolence, creating a supportive atmosphere, asking questions and making patients feel welcomed and supported were all actions that helped provide warmth and a positive experience for patients. Patients with PD wanted a kind staff that was not in a hurry.

The descriptive theme *professional professionals* represented a variety of codes reflecting what patients with Parkinson's disease expected – or at least hoped to see – from healthcare professionals. The codes cover treatment, care and rehabilitation, as well as both positive and negative features (i.e., they included what patients *did not* want from healthcare professionals). On the positive side, patients expressed an overall trust in professional guidance, but they worried and suffered when they encountered a lack of expert knowledge and skills. They deeply wished to be seen by professionals, not amateurs. Regarding treatment, patients mentioned that expertise was of paramount importance in the process of diagnosing PD, while emotional security was most important in relation to care. When patients attended training and rehabilitation interventions, they hoped to meet with physiotherapists who paid attention to them as individuals and who were knowledgeable about how PD affects the body and daily activities. The last descriptive theme within *Significance of professionals* was *Loss and end of life*. This descriptive theme dealt with heavier topics, such as suffering through diagnosis, end-of-life decisions, fear of dying, and feeling unprepared for death. When patients went through this phase, they felt a need to sort out their affairs and make decisions in advance. They experienced physical disability, loss of ability and loss of identity, and they sought to focus on not losing more. In going through this process, they desperately needed professional and kind professionals.

This theme can be roughly condensed into three core aspects: the need for timely and sufficient information, the need for professionals that are true professionals and the desire to be met with empathy and kindness.

## Discussion

Three analytic themes – *Significance of self*, *Significance of informal caregivers and peers*, and *Significance of professionals* – emerged through the thematic analysis across 156 codings and 17 descriptive themes. Despite the heterogeneity in terms of time elapsed since diagnosis, we found all three themes present in almost all included studies, indicating that patients' perspectives are related to universal human traits rather than to disease-related details. This finding underlines the fact that we nearly lost track of our overall aim for the review – that is, to identify patients' perspectives on *treatment, care, and rehabilitation*. However, reviewing and synthesising the perspectives of patients with PD reveals that while an analytic view on treatment, care and rehabilitation might be helpful for creating a focused search protocol to include (only) relevant studies and focus the analysis, it might not make sense to force critically ill patients' perspectives into a narrow analytic frame. For patients with PD – and perhaps for patients in general – treatment, care and rehabilitation are intertwined and rarely separable. Furthermore, suffering from PD is a far more complex experience than any analytic frame can capture, and is not limited to contact with healthcare delivery. Rather, it is about their entire life: as identified by Edwards et al., '... the hospital experience is not limited to the admission' (25).

Nevertheless, the analytic theme *Significance of professionals* is the theme closest to our aim and also the most unique, as both *Significance of self* and *Significance of informal caregivers and peers* (in different descriptive themes yet in similar analytic themes) are reported in a recent review focusing on the real-life experiences of patients with PD (28). *Significance of professionals* includes a multiplicity of descriptions of what patients with PD want to see from healthcare professionals – and also what they *do not* want to see. The three core aspects within this theme – the need for timely and sufficient information, that professionals be true professionals and the desire to be met by empathy and kindness – correspond to what people with disabilities in general underscore as important to them, as found by Fadyl et al.: the technical competence of care service and professionals, a 'human' approach to service provision and context-appropriate response to needs (29). Furthermore, a study by Veronese et al. investigating the needs of individuals with neurodegenerative disorders found that they suffer from a multiplicity of symptoms and side effects, and that the dependency on family and the need for specialists was dominant (9).

However, it is also worth mentioning that aside from the substantial amount of physical, social and emotional suffering borne by patients with PD, these patients also have significant concerns regarding the burden their care places upon (informal) caregivers, as explained in *Significance of informal caregivers and peers*. This is supported by multiple studies documenting substantial caregiver burdens for families of patients with PD (30–33), underscoring that the patients' concern is both realistic and hopeless.

## Strengths and limitations

Despite our rigorous process in terms of search, screening, and analysis, we acknowledge the existence of a number of limitations for this study. First of all, even though all review processes were doubled (or tripled), the authors realise that the findings could be influenced by their previous research experience and their backgrounds as health professionals.

Despite the overall homogeneity of the included studies, the noticeable heterogeneity regarding the timing at which the interviews were conducted, ranging from 11 months to 28 years after diagnosis, might compromise the overall credibility of our findings. As credibility in qualitative studies addresses how well the findings reflect the perspectives of the informants (34), de-contextualising and re-contextualising findings from qualitative studies might include a risk of presenting wrong assumptions of importance (15). However, acknowledging the value of qualitative research does also include acknowledging a synthesis of qualitative research. Furthermore, the question of what 'counts' as data is crucial to the outcome of a qualitative systematic review. We decided that, in principle, all text in the results sections of the included studies counted as data. We could have chosen to include text from the discussions sections as well. However, recommendations for defining data in thematic analyses are not unambiguous: some recommend using only key concepts (not defined) (35), whereas others choose to include all text labelled as 'Results' or 'Findings' (15). We acknowledge that this choice is decisive for the conclusion; however, we chose to follow the recommendations of Thomas et al. (15) rigorously through the analysis.

## Conclusions

During our thematic synthesis, three analytic themes emerged: *Significance of self*, *Significance of informal caregivers and peers* and *Significance of professionals*; all of them contained multiple nuances revealing the complexities of living with Parkinson's disease. The findings of a qualitative systematic review concerning patients' perspectives could be important in helping healthcare professionals plan and deliver treatment, care and rehabilitation based on patients' priorities in the context of suffering from a chronic disease. The results might also guide future research regarding patient perspectives as well as why and how to these perspectives into healthcare delivery.

## Declarations

### *Conflicts of interest*

None declared.

### *Ethics approval and consent to participate*

n/a

### *Consent for publication*

n/a

### *Availability of data and material*

All data generated or analysed during this study are included in this published article and its supplementary information files.

### *Competing interests*

The authors declare that they have no competing interests

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### *Authors' contributions*

All authors have contributed substantially to this paper.

Design of protocol BN, SBT, MM

Search strategy and search STB, BN

TiAb screening BN, SBT, MM

Full text reading BN, SBT, MM

Quality appraisal BN, SBT, MM

Data extraction, analysis, and synthesis BN, SBT, MM, CSA

Manuscript BN, SBT, MM, CSA

## References

1. Takahashi K, Kamide N, Suzuki M, Fukuda M. Quality of life in people with Parkinson's disease: the relevance of social relationships and communication. *J Phys Ther Sci*. 2016;28(2):541-6.
2. Tysnes OB, Storstein A. Epidemiology of Parkinson's disease. *Journal of neural transmission (Vienna, Austria : 1996)*. 2017;124(8):901-5.
3. Tollár J, Nagy F, Kovács N, Hortobágyi T. A High-Intensity Multicomponent Agility Intervention Improves Parkinson Patients' Clinical and Motor Symptoms. *Arch Phys Med Rehabil*. 2018;99(12):2478-84.e1.
4. Wells T, Sawatzky JA, McMillan DE. Sleep disturbance in Parkinson's disease: a human response to illness. *Can J Neurosci Nurs*. 2009;31(4):24-32.
5. Vaughan CP, Burgio KL, Goode PS, Juncos JL, McGwin G, Muirhead L, et al. Behavioral therapy for urinary symptoms in Parkinson's disease: A randomized clinical trial. *NeuroUrol Urodyn*. 2019;38(6):1737-44.
6. Bronner G. Sexual dysfunction and Parkinson's disease: a need for further understanding. *European journal of neurology*. 2008;15(11):1146-7.
7. Rossi M, Merello M, Perez-Lloret S. Management of constipation in Parkinson's disease. *Expert Opin Pharmacother*. 2015;16(4):547-57.
8. Gill DJ, Freshman A, Blender JA, Ravina B. The Montreal cognitive assessment as a screening tool for cognitive impairment in Parkinson's disease. *Movement disorders : official journal of the Movement Disorder Society*. 2008;23(7):1043-6.
9. Veronese S, Gallo G, Valle A, Cugno C, Chiò A, Calvo A, et al. The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study. *Progress in Palliative Care*. 2015;23(6):331-42.
10. Tomic S, Rajkovic I, Pekic V, Salha T, Misevic S. Impact of autonomic dysfunctions on the quality of life in Parkinson's disease patients. *Acta Neurol Belg*. 2017;117(1):207-11.
11. Satterfield JM, Spring B, Brownson RC, Mullen EJ, Newhouse RP, Walker BB, et al. Toward a transdisciplinary model of evidence-based practice. *Milbank Q*. 2009;87(2):368-90.
12. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009;6(7):e1000097.
13. Moola S, Munn Z, Sears K, Sfetcu R, Currie M, Lisy K, et al. Conducting systematic reviews of association (etiology): The Joanna Briggs Institute's approach. *Int J Evid Based Healthc*. 2015;13(3):163-9.
14. Newman Dorland WA, Anderson DM. *Dorland's Illustrated Medical Dictionary*. 28th ed: Elsevier Health Sciences; 1994 01.09.1994.
15. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8:45.
16. Butler A, Hall H, Copnell B. A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. *Worldviews Evid Based Nurs*. 2016;13(3):241-9.
17. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J*. 2009;26(2):91-108.
18. Birgersson AM, Edberg AK. Being in the light or in the shade: persons with Parkinson's disease and their partners' experience of support. *International journal of nursing studies*. 2004;41(6):621-30.
19. Greviskes LE, Podlog L, Newton M, Dibble LE, Burns RD, Pillow W, et al. Caring Interactions in Secondary Prevention Programs: A Qualitative Inquiry of Individuals With Parkinson's Disease. *J Geriatr Phys Ther*. 2019;42(3):167-75.
20. Cleary AS, Rossi A, States RA. Parkinson's Disease: Exploring Motives for Long-Term Adherence to a Group Exercise Program. *Rehabil Nurs*. 2020;45(3):131-9.
21. Anderson LC, Fagerlund K. Original research: The perioperative experience of patients with Parkinson's disease: a qualitative study. *Am J Nurs*. 2013;113(2):26-32; quiz 3.
22. Read J, Cable S, Löfqvist C, Iwarsson S, Bartl G, Schrag A. Experiences of health services and unmet care needs of people with late-stage Parkinson's in England: A qualitative study. *PLOS ONE*. 2020;14(12):e0226916.
23. Shaw S, Vivekananda-Schmidt P. Challenges to Ethically Managing Parkinson Disease: An Interview Study of Patient Perspectives. *Journal of Patient Experience*. 2017;4:237437351770683.
24. O'Brien C, Clemson L, Canning CG. Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson's disease: a qualitative enquiry. *Disabil Rehabil*. 2016;38(5):472-81.
25. Edwards KJ, Duff J, Walker K. What really matters? A multi-view perspective of one patient's hospital experience. *Contemp Nurse*. 2014;49:122-36.
26. Plouvier AOA, Olde Hartman TC, Verhulst CEM, Bloem BR, van Weel C, Lagro-Janssen ALM. Parkinson's disease: patient and general practitioner perspectives on the role of primary care. *Family Practice*. 2017;34(2):227-33.
27. Mulligan H, Armstrong A, Francis R, Hitchcock H, Hughes EFH, Thompson J, et al. Engagement in exercise for people with Parkinson's: What is meaningful? *New Zealand Journal of Physiotherapy*. 2018;6(1):19-28.
28. Tomagová M, Lepiesová M, Bóriková I, Cáp J, Nemcová J, Zanolitová M. Real-life experiences of patients with Parkinson's disease. *Journal of nursing and social sciences related to health and illness*. 2019;21(3):9.
29. Fadyl JK, McPherson KM, Kayes NM. Perspectives on quality of care for people who experience disability. *BMJ Qual Saf*. 2011;20(1):87-95.

30. Vatter S, McDonald KR, Stanmore E, Clare L, Leroi I. Multidimensional Care Burden in Parkinson-Related Dementia. *Journal of geriatric psychiatry and neurology*. 2018;31(6):319-28.
31. Vatter S, McDonald KR, Stanmore E, Clare L, McCormick SA, Leroi I. A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age Ageing*. 2018;47(4):604-10.
32. Vatter S, Stanmore E, Clare L, McDonald KR, McCormick SA, Leroi I. Care Burden and Mental Ill Health in Spouses of People With Parkinson Disease Dementia and Lewy Body Dementia. *Journal of geriatric psychiatry and neurology*. 2020;33(1):3-14.
33. Abendroth M, Lutz BJ, Young ME. Family caregivers' decision process to institutionalize persons with Parkinson's disease: a grounded theory study. *International journal of nursing studies*. 2012;49(4):445-54.
34. Tong A, Palmer S, Craig JC, Strippoli GF. A guide to reading and using systematic reviews of qualitative research. *Nephrol Dial Transplant*. 2016;31(6):897-903.
35. Campbell R, Pound P, Pope C, Britten N, Pill R, Morgan M, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social science & medicine (1982)*. 2003;56(4):671-84.

## Figures

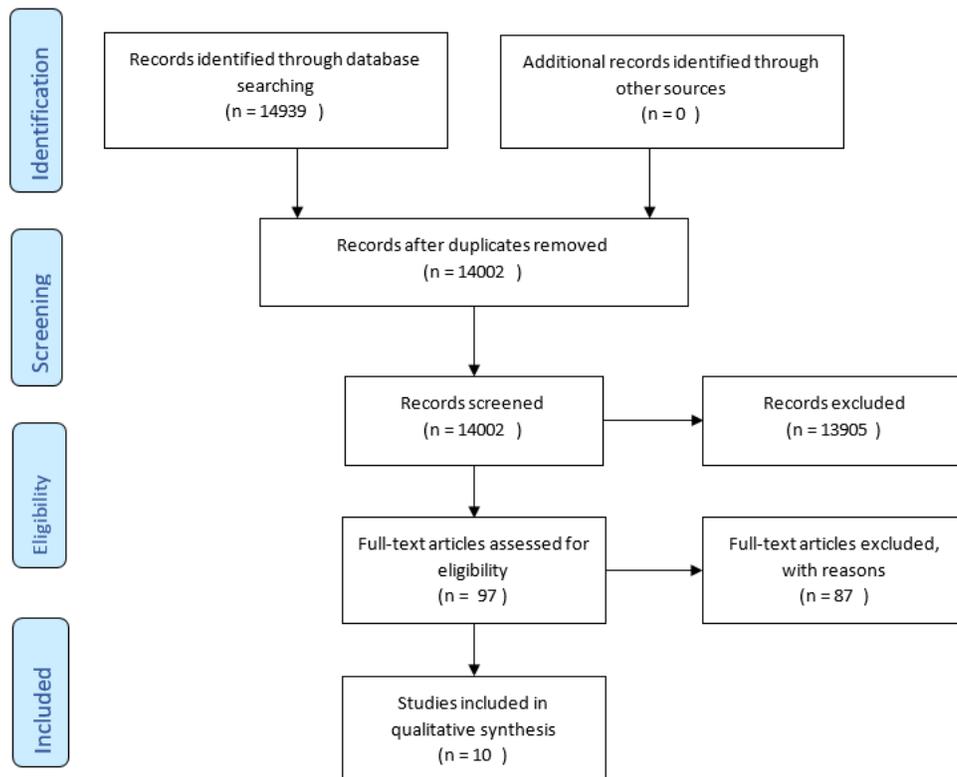


Figure 1

PRISMA flow diagram (12)

## Supplementary Files

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