






ORIGINAL ARTICLE

Facing and dealing with emotional turbulence: Living with newly diagnosed Parkinson's disease

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Abstract

Introduction: The experiences of living with Parkinson's disease (PD) from the perspective of newly diagnosed persons with PD (PwPD) have not been previously described.

Aim: This study aimed to gain a better understanding of the impact of living with the early stages of PD.

Methods: A qualitative interview study was conducted among nine persons, seven men and two women, from southern Sweden. Participants had a median age of 71 (min–max, 64–77) years and had been diagnosed with PD for a median of 5 (min–max, 2–12) months. Interviews were recorded and analysed using systematic text condensation.

Results: The analysis resulted in one core category, *Facing and dealing with emotional turbulence*, and four categories with 2–3 subcategories each: Something is wrong (*Vague signs of change; Losing control*); The going gets tough (*Recalling; Lack of motivation*); Losing direction (*Uncertainties; Frightened of disease progression*) and Dealing with life (*Avoiding social situations; Hope and despair; Ease worries*).

Conclusion: Newly diagnosed PwPD face emotional turbulence with increasing challenges in managing everyday basic needs. Impaired functioning affects self-esteem and identity, which calls for strategies to overcome emotional reactions of embarrassment, frustration and worry. A sense of lost control and direction increased as the future became more uncertain. The participants' emotional burden and struggle to find a reason to go on or some solution to their new situation left them with both hope and despair. Our results suggest that a person-centred needs-based approach may help newly diagnosed PwPD deal with their new life situation.

KEYWORDS

de novo, impact, newly diagnosed, Parkinson's disease, qualitative research

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INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disorder characterised by loss of dopaminergic neurons in the substantia nigra and clinical motor (e.g., tremor, rigidity, bradykinesia and postural impairment) and non-motor symptoms (e.g., depression, anxiety, fatigue, dysautonomia and pain) [1, 2]. The symptoms and progression of PD vary among individuals and so far, no cure is available. The occurrence of motor symptoms, such as tremor, bradykinesia and impaired walking [2–5], is the most common cause for seeking medical advice leading to the diagnosis of PD. Nevertheless, a number of non-motor symptoms may occur before or at the time of diagnosis [6], e.g., executive dysfunction [7], anxiety [8], visual impairment [9], olfactory dysfunction [10], gastrointestinal symptoms [11], as well as sleep disturbances [12]. Early symptomatic treatment may involve levodopa or dopamine agonists depending on therapeutic considerations based on the individual's situation [13]. Over time, treatment may become less beneficial and increased dyskinesias and fluctuating drug response may occur [1].

The experiences of living with PD from the perspective of persons with PD (PwPD) have been explored in a number of qualitative studies. These have studied the overall impact of living with PD [14, 15] as well as specific aspects, such as communication, swallowing, breathing, eating, walking and daily activities [16–23]. For example, PwPD have described the physical and psychological impact of symptoms and problems in daily life as a single dimension with intermingled motor and non-motor aspects. Furthermore, a shift from an internal to an external locus of control in order to manage lost control and unpredictability has been described [15]. This external locus of control was suggested to be in general accord with self-determination theory (SDT), according to which there may be a shift from intrinsically towards extrinsically motivated behaviours when needs become thwarted [24, 25]. SDT states that three fundamental psychological needs are essential for people's well-being and health: competence, relatedness and autonomy [24, 25]. SDT generally agrees with the needs-based quality of life model, which proposes that life gains its quality from the extent to which an individual's needs are met [26, 27]. If, as previously suggested, the experience of living with PD can be understood from a needs-based perspective this can have important implications for a better understanding of PD from the perspective of PwPD [15].

Recent qualitative work in early PD has been conducted to develop conceptual models of motor and non-motor symptoms and their impact from the perspective of PwPD, aiming to improve outcome assessment in clinical

research and practice [28, 29]. However, to the best of our knowledge, studies regarding the experiences in the daily life of persons with newly diagnosed PD appear to be lacking. Therefore, we conducted a qualitative interview-based study to better understand the impact of living with early stages of PD.

METHODS

Participants

Participants were recruited from the prospective Swedish BioFINDER study (www.biofinder.se). Nine persons, seven men and two women, with newly diagnosed PD, were strategically selected and consecutively recruited during a period of three months by a neurologist and PD specialised nurse [30]. Persons diagnosed with PD no more than 12 months ago and without significant cognitive decline (both according to an experienced movement disorders/PD specialised neurologist) were eligible for inclusion in the study.

Procedure

Data were collected through individual face-to-face interviews without the involvement of caregivers/family members. Each participant was interviewed once. The interviews lasted for 60–90 min each and were performed in a separate quiet room, by the same researcher (CSH). We used a semi-structured interview guide developed for a previous study [15, 31].

The interview guide aimed to cover a broad range of aspects of everyday life to further understand the consequences of living with newly diagnosed PD. The semi-structured interview covered activities at home, at work and at leisure time, as well as personal relationships, social life, personal care, cognitive ability, sleep and rest. If not covered spontaneously by the respondent, these areas were explored by open-ended questions. When needed, prompts were used to encourage respondents to explore and expand statements in greater depth. Each interview started with an introductory sentence: 'We are interested in learning more about how you have experienced the consequences of Parkinson's disease in your daily life. Could you please tell me how you first noticed the disease?' The interviews were guided by the list of topics mentioned earlier, which were introduced unless spontaneously covered by the interviewees. Follow-up probes such as: 'Can you give an example?' and 'Could you elaborate on this subject?' were used to get more in-depth answers and narratives. Brief field notes were made during the interviews.

All interviews were audio recorded and transcribed verbatim. No more interviews were conducted when data saturation was experienced, i.e., when new participants tended to repeat previously given narratives and the information became redundant.

Data analysis

Data were analysed using systematic text condensation as described by Malterud [32]. First, the interview transcripts were read to get a general impression of the whole and to identify and categorise the primary themes. Next, meaning units were identified and formulated into codes representing the essence and meaning of the statements. During this phase, three of the authors (AK, AW and CSH) worked individually and independently to discover more perspectives and nuances of associations in the material. Then the coded data were compiled into one set of data, organised into subcategories and duplicated codes were removed. The content of the meaning units of each category was reviewed and the abstracted meaning was formulated into aspects representing the content. The subcategories were then organised into categories. To validate the categories and ensure that every essential aspect was noticed, the subcategories were referred to the raw data, which were read through once again by all authors. The re-contextualised data were then formulated as conceptual descriptions of the understanding and meaning of each category, and representative quotes were selected for each category and subcategory.

Finally, given the results from a previous study among persons with more advanced PD [15], a deductive theory-based analysis was performed in relation to SDT [24, 25]. In this step, all interviews and quotes were reviewed with respect to their relationship to the three fundamental

psychological needs that are important for people's well-being and health according to SDT: competence (a sense of confidence and feeling effective in interacting with the surrounding society); relatedness (feeling connected to others) and autonomy (acting from interest and integrated values).

All authors have clinical experiences of caring for PwPD, either as nurses (AK, AW, PLH and PH) or as physiotherapist (CSH). These experiences were used and taken advantage of in the analysis and interpretation of data.

RESULTS

Participants

The participants' median age was 71 (min–max, 64–77) years, and they had been diagnosed with PD for a median of 5 (min–max, 2–12) months. Given the early stage of the disease, the diagnosis was tentative [33], but had in all cases been made by an experienced movement disorders/PD specialised neurologist. Five persons were not yet on any pharmacological treatment and four had tried oral levodopa (three persons with benserazide, one person with carbidopa) but had discontinued their medication pending a new consultation due to side effects and/or no improvements.

Results of the analysis

The analysis resulted in one core category, *Facing and dealing with emotional turbulence*, as diverse reactions and feelings constantly changed, representing an emotional rollercoaster that the participants found themselves trapped in and had to deal with. From this core category, four categories with 2–3 subcategories within each category was found (Figure 1). Each category is summarised

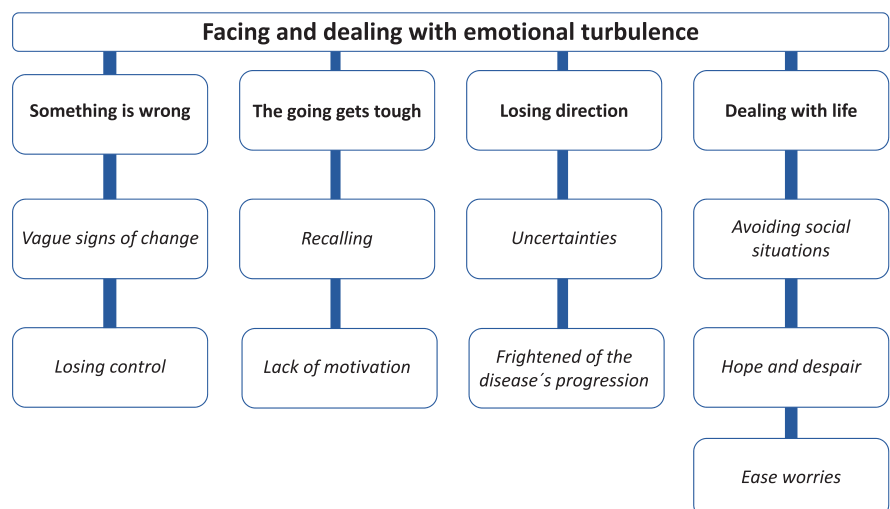


FIGURE 1 An overview of the overarching core category, categories (bold) and subcategories (italics) of the impact of living with newly diagnosed Parkinson's disease.

under their respective subheadings, including descriptions of subcategories (indicated in italics).

Something is wrong

Although difficult to define, a sense that something is wrong was described. Such *vague signs of change* were often difficult to separate from normal ageing. Commonly described changes included loss of smell, dullness, difficulties concentrating, being tired and listless, postponing activities, reduced mobility, and stiffness. The participants vaguely sensed something was different from how it used to be and that something was going on.

I was tired and listless, couldn't take care of my home, postponed things... it can wait until tomorrow... didn't vacuum for two weeks... I bought ready meals and settled for that, but [to me]... something's not right when you start doing things like that... P8

Inability to control and coordinate fine movements was also described, which caused problems in various everyday situations, such as buttoning shirts, putting on a bra, signing papers, using the wallet, transferring food to the mouth and leisure activities such as carving or knitting.

When I write my name then... the first name is ok and the beginning of my family name, but the end of the name is just like a tremble, just very tiny letters... I've never had that before... P2

A sense of *losing control* over one's body, senses and mind was apparent in various situations, and could also be a source of embarrassment. For some, reading had become more challenging as their vision had become blurry and it was not easy to concentrate. It was also described that their voices had changed and that they had started to mumble and stumble over words. Swallowing difficulties were also described as the throat felt tighter at times, especially when eating dry food. Another disturbing experience was drooling, which could occur during the night as well as during the daytime.

And then... well ... I drool as well... that's also most disturbing. At night, I can wake up and find that my pillow is all wet from dribbling... It may also happen during daytime when I'm just sitting down... all of a sudden, I start dribbling, you know... P4

An increased tendency to doze off during the daytime when sitting down to read the newspaper or watching television was described. Once sleepiness and yawning had begun there was nothing to do not to fall asleep.

I can feel tired during the day on several occasions and doze off...I'm aware of when I start to get tired and of course that's not something I just feel, but I also yawn quite a lot... But once it starts, there's not much you can do about it... P1

Feeling weak and having uncontrollable tremors within one's body or displayed as constant shaking was found very disturbing. Those who experienced uncontrolled tremors felt that working and doing the job was hard. Some were also troubled and frustrated when they were tired and wanted to go to bed as the shaking continued through the night.

.... It feels as if something inside my body is shaking and trembling all the time too... in my arms, although they are not shaking, but... it's like there are nerve fibres deep inside ... I don't know... P4

The body was experienced as unreliable and uncooperative regarding impaired coordination and balance. Walking had become more difficult with diminished control of pace, step length and coordination of arms and legs. Some participants occasionally felt that movements could not be controlled, and things were pushed over at times, which was embarrassing and brought about feelings of being clumsy.

I've become a bit clumsier maybe... whatever you mean by that... When I'm moving and when I'm standing up and... and... eh... to go out and put on my jacket.... Then there's always a risk that there's something that I may push over... But... it doesn't happen very often, which I'm grateful for... but it happens.... P9

The going gets tough

The narratives revealed experiences of various cognitively related problems, such as augmented memory and the ability to plan. Learning new skills (e.g., using the internet) or maintaining old skills (e.g., driving), could also be challenging. Lack of motivation affected the ability to carry out activities previously considered enjoyable.

Recalling what they had done the day before could be tricky, and a need to make notes to remember what to do

was described. Difficulties reading books and keeping track of the plot were described. Everyday practical things, such as paying bills online or doing maths, had slowly become more complex.

That's the problem... before I could always remember... now I will do this and then I can do that... but today... What I did yesterday would have been gone if I hadn't sat down and made notes... That's a big difference actually ... P3

Things that only required a little planning before, such as an outing, had become complicated and scrutinised. Some felt like they were overthinking such activities. Maintaining old skills that required thinking ahead and planning had become difficult. Some expressed that they no longer felt safe when driving a car.

It doesn't feel safe to drive... I don't feel that I'm in control when I do it... well. You know, where the verge of the road is and where you have the centre line... so that I'm in the correct position... It feels... It's exactly like... like you've become a little bit ... not having the strength and ability...P4

Lack of motivation was also described, as the lust or motivation to do things were not what it used to be. Activities that previously were seen as enjoyable were no longer attractive or desirable. Even though activities and chores were planned, they were often postponed to the next day; at the end of the week, it could feel as if nothing had been accomplished.

And then you... then you have sort of lost the lust too a little bit... the lust to do things you know... so that... It doesn't feel important either somehow... P4

Both men and women described a negative and frustrating impact on their sexual life, involving a lack of lust, impaired mobility and problems in performing sexually.

Losing direction

It had become clear that longer-term plans might not be possible to pursue and worries about what might occur if the disease worsens led to increased frustration, anger and discouragement.

The participants had already made plans for activities that were important to them, such as travelling, hiking,

or developing artistic work. Since such activities require physical skills, they realised that the future they had planned and hoped for might not come to pass, which was disturbing.

Well, it's really disturbing that you can't live life the way you had expected and hoped for... so that's really... you become restricted, you know.... P4

Not being able to foresee and predict what would happen in the future was worrying and they felt *frightened of the disease's progression*. Some noticed that they had deteriorated quickly in just a few months and were afraid and uncertain whether it would continue at the same pace. Some expressed that they could accept physical impairment but were afraid of being mentally affected and no longer able to care for themselves. They were preparing for the worst, and becoming aware of deteriorating functions led to bitterness, frustration and hopelessness.

A physical handicap, that's something I can handle, even if it would lead to an inability to walk.... I could manage that...but if my brain would suddenly go crazy and I should become obtuse, that's... that's worse... and not being able to care for myself... that's hard for me... it's a big question mark for the future if Parkinson's will get worse or if it stops now... P1

Dealing with life

Various approaches in managing the situation and finding strategies were used. It was difficult to talk to others about having PD and participants were *avoiding social situations* as they felt that people tended to judge and define them by their symptoms rather than seeing them as a person. Managing cutleries at dinner parties could also be a social problem that could make them avoid such situations. When meeting friends and acquaintances, they tried to hide their symptoms by changing positions or holding shaking arms.

I don't want to shake...partly because I'm tired of it and partly because I feel like everybody stares at me so... they don't see me.... they see that my body shakes... P7

Medication was central and expressed as a lifeline of *hope and despair*. Even though there is no cure for PD, there was hope that medication would improve everything and that they could pick up activities that they had quit.

I was consulting with one of the physicians about how things are going to work out once I start with my medication, and he told me that everything would go back to normal and function as before... so this is what I'm hoping for... that I'll be able to go skiing again for example...P4

However, after some time, those who had been on anti-parkinsonian medication had experienced disappointments, as the medicine had not been experienced as effective as desired or led to side effects that had made them stop treatment. Some also feared that the medication might be harmful.

The medicine made me so tired... didn't have the strength to do anything and that's when I thought that I'd rather die right now than to continue taking this... and I also read that there were lots of side-effects ... P8

The most common strategies to *ease worries* were to avoid thinking about the consequences of the disease and its progression. Other strategies were minimising by thinking that the symptoms might not progress further or that they might have been misdiagnosed and that the symptoms were not due to PD. They compared themselves to others who were worse off, which could invoke a sense that everything was still manageable. Asking children and grandchildren for help was one strategy that could be helpful, while others felt hesitant to depend on others.

...I'm not interested in reading about how it gets worse and worse and how it becomes so bad that you no longer can manage on your own. So, I think that... There's no point in me thinking about what might happen... maybe nothing will happen, and everything will stay as it is now... P2

I've seen people that have... that can't walk, can't move... but there's nothing you can do... If that's what will happen, then so be it... There's nothing anyone can do because there's no cure for this... P5

Deductive theory-based analysis

Although the participants were newly diagnosed with PD they expressed how their decreased capacity already had affected almost all aspects of their life and compromised their ability to satisfy basic needs. Examples of the linkage between data (using example quotes reported above

as well as other quotes from the interviews) and needs according to STD are provided in [Table 1](#).

DISCUSSION

The aim of this study was to better understand the impact of living with newly diagnosed PD. The narratives in this study suggest that living with early PD can be understood as facing and dealing with emotional turbulence associated with vague signs that something is wrong as well as lost control and direction in terms of uncertainty and fear of disease progression. This change in everyday life needs to be dealt with, e.g., by avoiding social interactions, and both hope and despair are experienced in the quest to ease worries. Taken together, the impact of PD compromises basic needs already early after the diagnosis. These findings are, to the best of our knowledge, unique and have important implications for the care of people with newly diagnosed PD.

The early onset of vague signs of both non-motor and motor problems, reported previously as early signs of PD [1, 2, 4, 6, 10], were described as evolving quite fast among some of the participants. The participants felt that such signs, e.g., loss of ability to smell, postponing things that needed to be done, and feeling dull and listless could well be mistaken for normal ageing. Many suffer from tremors and bradykinesia, the most common causes for seeking medical consultation, leading to a PD diagnosis [2]. Other difficulties were for example, managing shirt buttons, signing papers and putting food in the mouth, previously reported among people with advanced PD [2, 15]. A sense of losing control also involves finding oneself in embarrassing situations, such as dozing off during daytime and drooling due to swallowing difficulties [1]. The vast number of symptoms and complaints mentioned by our interviewees are in accordance with recent findings from studies aiming to develop conceptual models to improve outcome assessment in early PD [28, 29]. However, in contrast to those studies, our findings pertain to understanding the impact of living with newly diagnosed PD from the perspective of the affected person.

Only months after the diagnosis, motor control, including balance and coordination, had deteriorated. Walking was affected as the step length was shorter and coordinating arms and legs was increasingly tricky. This could vary during the day, which aroused feelings of insecurity, in line with findings from previous studies among people with advanced PD [17, 22, 34]. Impaired ability to walk has previously been shown to be linked to an individual's social identity, emotional well-being, and independence and is also the prerequisite for an autonomous life [22] and maintaining normality [35], which is in accordance with

TABLE 1 Example linkages between qualitative data and thwarted fundamental needs (competence, relatedness and autonomy) according to self-determination theory.

Competence (a sense of confidence and feeling effective in interacting with the surrounding society)	Relatedness (feeling connected to others)	Autonomy (acting from interest and integrated values)
I was tired and listless, couldn't take care of my home, postponed things... it can wait until tomorrow... didn't vacuum for two weeks... I bought ready meals and settled for that... P8	I don't want to shake... because I feel like everybody stares at me so... they don't see me... they see that my body shakes... P7	The medicine made me so tired... didn't have the strength to do anything and that's when I thought that I'd rather die right now than to continue taking this... P8
I've become a bit clumsier maybe... whatever you mean by that.... When I'm moving and when I'm standing up and... and... eh... to go out and put on my jacket.... P9	A physical handicap, that's something I can handle.... I could manage that...but if my brain would suddenly go crazy and I should become obtuse, that's... that's worse... P1	Well, I had planned to work more with handicraft and painting and things that I've done... but eehh... Now, I can't....it's not working... can't do the movements anymore.... P6
When I write my name then... the first name is ok and the beginning of my family name, but the end of the name is just like a tremble, just very tiny letters... I've never had that before... P2	I've always taken the initiative when meeting people and telling them why I shake... well, then they know... otherwise they'll just go behind my back... P7	It doesn't feel safe to drive... I don't feel that I'm in control when I do it... well. You know, where the verge of the road is and where you have the centre line... so that I'm in the right position... It feels... not having the strength and ability... P4
That's the problem... before I could always remember... now I will do this and then I can do that... but today... That's a big difference actually ... P3	I can meet people that I've known for many years, and suddenly, I don't remember their names... that's really hard... P1	I've seen people that have... can't walk, can't move... but there's nothing you can do... If that's what will happen, then so be it... There's nothing anyone can do because there's no cure for this... P5

the results of the present study. Hence, impaired walking has profound consequences on a person's self-esteem and sense of independence, which is vital to consider when caring for people also in the early stages of PD. According to SDT, such symptoms may well thwart basic needs and affect psychological health [24], which was shown here. Also, from a needs-based perspective, the ability to, e.g., walk may satisfy several needs such as exercise, shopping or running errands, activities that also may be important for a sense of control and autonomy [36].

The experiences of impaired cognitive skills or even the risk of losing one's cognitive abilities were more devastating than physical impairments. Losing cognitive and executive skills was regarded to increase the risk of no longer being able to manage everyday life and becoming dependent on others [1, 15]. Similarly to what previously has been found among people with more advanced PD [23, 35], maintaining old skills or learning new skills was challenging, and some skills needed to be abandoned. This was experienced as frustrating and affected everyday life. The most daunting and disappointing aspect related to disease progression that aroused worry, anger, sadness and disbelief, was that there is no cure for PD. Furthermore, the participants felt forlorn as they learnt that no evidence or signs might predict how severe the disease progression would become. With a sense of having lost direction and

control of the situation, the participants felt very let down and disheartened, leaving them with a great extent of emotional turmoil and mental burden.

According to SDT, such reactions of helplessness may result in a shift from intrinsic towards extrinsic behaviours, which may thwart the fundamental psychological needs that are important for well-being and health. When these needs are thwarted, the individual may no longer be capable of changing the situation (thwarted competence and autonomy) and feelings of loneliness and misery might develop (thwarted relatedness) [24]. Such feelings are important to acknowledge when caring for people in the early stages of PD. Support should therefore be based on the individual person's situation, needs and preferences and involve activities that promote a sense of reclaiming control of the situation, such as information seeking, exploring new activities better suited to engage in, and supporting basic needs [36, 37].

Lack of lust and motivation affected activities that used to be joyful and pleasant. Such activities were postponed or ignored. Similar results have been reported previously in people with advanced PD, which resulted in comparable feelings of increased frustration, anger, and sadness [15, 22, 35, 38]. Since these thoughts and reactions appear early in PD, health professionals, in dialogue with the affected individual, might consider finding positive

experiences that may promote optimistic feelings and behaviour and including cognitive training to preserve the intellectual capacity for as long as possible. Such interventions would also support the need of being self-sufficient and maintain a sense of competence and autonomy [6, 38]. The lack of lust, reduced mobility and performance problems affected the participants' sexual life which was described as frustrating, in line with a previous study [39]. In that study, involving people who had had PD for an average of about 9.5 years, women with PD were more satisfied with their sex life than men were, which was not confirmed here.

Feeling embarrassed in different situations led to avoidance behaviour. The participants mostly avoided socialising, which may lead to a lack of social contacts and limited ability to interact with others. Feelings of unease, embarrassment, and drawing the unwanted attention of strangers led to a sense of reluctance to socialise and eventually a need to isolate oneself [15, 34, 35, 40]. In a recent study, social belonging was found to be a primary concern among PwPD (mean time since diagnosis, 3.4 years) and to regain or achieve social belonging, they used various strategies to comprehend, accept, adapt and balance and that uncertainty is a continuous challenge in this process [41]. Our findings show that this process starts already very early in the disease.

The narratives also related to other coping strategies used by newly diagnosed PwPD. This is in line with a study among persons diagnosed with PD for 1–7 years by Rosengren et al. [42], who identified two groups concerning adaptation: those who used general acceptance and those who struggled to resist the disease. Furthermore, the findings of a previous study indicated that higher levels of sense of coherence supported PwPD to cope more effectively with stressful situations [43]. In our study among people with earlier PD, a common coping strategy was to avoid thinking about the consequences of the disease to ease their worry, which is often used in early stages of chronic diseases [44, 45]. Other strategies were minimising the potential consequences if the disease progressed and social comparisons with others who were worse off [15, 44–46]. These strategies are important to mitigate worry and might need to be considered when working with persons with newly diagnosed PwPD. However, such emotion-focused strategies tend to be energy consuming and are mainly useful in a short-term perspective [47, 48]. From a needs-based approach, more problem-focused strategies should be introduced in order to focus on needs that are attainable. Examples of such strategies include aids to facilitate leisure activities, planning ahead, cognitive training and socialising in safe environments [37, 49]. For instance, an outpatient five-week program for PwPD, including dialogues and physical training, reported that

the intervention improved self-reported sleep and psychosocial functioning, as well as motor functioning [50].

Although the participants were recently diagnosed, they expressed how almost all aspects of their life had been affected and their ability to satisfy basic needs had been compromised. Already early on following the PD diagnosis our participants experienced considerable impact on their self-image and identity. The ability to manage everyday life including family, work, social and leisure time activities had become restricted as well as the ability to maintain personal relationships, and physical and psychological needs. Feelings of losing direction and the need to deal with life were expressed as concerns about the future, loss of control, fear, discouragement, constraint and frustration. Hence, the disease seriously hampered their ability to satisfy basic needs. The narratives also reflected that relatedness to others had changed; they felt estranged from family and friends and lost their social identity and previous sense of belonging. In line with SDT [24, 25], these findings suggest that their sense of autonomy had shifted from an internal to an external locus of control and thwarted needs. Therefore, and in accord with what previously has been suggested regarding more advanced stages of PD, our findings suggest using a person-centred needs-based approach to better understand the situation from the individual's perspective in the care and management of persons with newly diagnosed PwPD [15, 35, 38].

Strengths and limitations

Participants represented different ages, genders and time since the diagnosis and provided rich data that contributed to improving the understanding of the impact of living with newly diagnosed PD. Although our pre-understanding as clinicians and researchers was seen as a strength, this may also have created a bias. Interpretations were therefore continually discussed to stay neutral to our findings. In addition, the different steps of the analysis are described, and each quote has a participant code to enhance transparency and strengthen the trustworthiness of the findings. Furthermore, it is possible that some participants suffered from atypical parkinsonism despite a preliminary clinical PD diagnosis. However, this is unavoidable when studying *de novo* or very early PD and reflects clinical reality, where care needs to be provided regardless of the final diagnosis.

CONCLUSION

Newly diagnosed PwPD face increasing challenges in managing everyday basic needs. Impaired functioning

due to both non-motor and motor problems affects their self-esteem and identity, calling for strategies to overcome emotional reactions of embarrassment, frustration, worry and sadness. Our results suggest that the participants had decreased capacity to change their situation due to thwarted competence, autonomy and relatedness. Therefore, a person-centred needs-based approach may help newly diagnosed PwPD deal with their new life situation. This involves individually tailored support and interventions to encourage the PwPD to regain control by use of problem-focused strategies that involve accepting aids, seeking information, cognitive training, positive thinking, socialising and engage in activities.

AUTHOR CONTRIBUTIONS

CSH and PH designed the study. CSH conducted the data collection. CSH, AK, AW, PLH and PH analyzed the data. CSH wrote the first draft of the manuscript. AK, AW, PLH and PH contributed to the entire manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon reasonable request to the authors. The data are not publicly available due to privacy or ethical restrictions.

ETHICS

All participants were examined by an experienced movement disorders/PD specialised neurologist, who found no cognitive or other symptoms that would prohibit their ability to provide informed consent or participate in the study. The principles of the Declaration of Helsinki were followed, and the study was approved by the Regional Ethical Review Board (Dnr: 2008/290 and 2014/519). All individuals gave their written informed consent to participate after receiving detailed written and oral information about the study, including, e.g., that they had the right to decline participation, assurance of confidentiality, and

that data would be stored for at least 10 years after the conclusion of the study.

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