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**The subjective experience of Parkinson's disease:
A qualitative study in 60 people with mild to moderate Parkinson's in 11 European
countries**

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Abstract

Objective: To describe the experience of being diagnosed and living with mild to moderate Parkinson's disease (PD).

Method: Semi-structured in-depth interviews with people with Parkinson's (PwP) in 11 European countries.

Results: Interviews with 60 PwP (52% male) with a mean age of 63 (SD 8.1) years and a disease duration of 9.6 (SD 6.9) years were analysed. PwP often delayed help-seeking due to lack of awareness of symptoms, and there was sometimes a delay in specialist referral. The diagnosis typically came as a "*shock*", making PwP unable to absorb all the information, but having a diagnosis for the symptoms was sometimes described as a "*relief*". Prompt referral to a specialist, a clear and sensitively communicated diagnosis with reassurance about life expectancy, and a follow-up appointment with a PD nurse or other health care professionals a short interval after diagnosis were all positively viewed. Many reported worries and negative experiences with medications and wished for more time and information before initiating these. Reactions from family, friends, and work colleagues when communicating the diagnosis were typically positive. During ongoing care, longer appointments with specialists and provision of information from health care professionals, patient organisations, and self-help groups were considered important to many PwPs and helped them feel as if they could "*take control*" and manage their disease more effectively.

Conclusions: Taking into account these findings has the potential to improve the experiences of PwP through improved communication, tailoring of appointments and information provision including self-help approaches.

Introduction

The impact of Parkinson's disease (PD) on patients health-related quality of life has been studied extensively, demonstrating that all aspects of physical and emotional functioning can be affected in PD even at the earliest stages of the disease (Schrag *et al.*, 2000). Management of PD aims at improving quality of life in people with Parkinson's (PwP) using pharmacological, surgical and non-pharmacological strategies (Ferreira, et al. 2013). In order to improve quality of life in PwP, research has primarily focussed on quantitative assessments of motor and non-motor symptoms to optimise their medical treatment and thereby PwP' wellbeing (Nicoletti *et al.*, 2017). However, relatively little is known on the experience of being diagnosed with and living with PD from the point of view of PwP. This is particularly relevant when advising health care providers and clinicians on the non-medical aspects of managing PwP in current health care systems.

We here report the results of a qualitative study in 60 individuals with a diagnosis of PD from 11 European countries on their experiences of being diagnosed and living with this disorder.

Methods

In 2014 and 2015, a qualitative research study was conducted as part of the "My PD Journey" project by the European Parkinson's Disease Association (EPDA). Semi-structured interviews on the experiences of being diagnosed and living with PD were conducted with people with Parkinson's (PwP) in 11 countries.

Principles of Grounded Theory were used to guide the sampling, data collection, and data analysis (Glaser & Strauss, 2009).

Recruitment and Sampling

Participants were identified through national Parkinson's Associations who asked for volunteers to take part in the study. Although the number of in-depth interviews to be conducted should not be pre-determined in Grounded Theory and recruitment should continue until data saturation is reached (Seale, 1999), a number of 5-10 participants from each of the 11 countries was agreed before the study commenced due to financial constraints. Nevertheless, data saturation was reached early and confirmed with additional interviews at the later stage of the project.

Data Collection

The individual interviews were conducted face-to-face or over the telephone (if preferred by the participant). All participants were interviewed once and the mean length of the interview was 41 minutes.

All interviews were recorded. Participants were informed of the intention to record in the study information sheet and the recorder was placed in a position clearly visible to each participant. Verbal informed consent was sought and obtained from all participants before the interview commenced. The interviews were transcribed verbatim and translated into English (if applicable) for analysis.

Interview Guide. Semi-structured interviews were conducted. RM developed the interview discussion guide, with input from the EPDA and AS. Topics covered included initial experiences of symptoms; help seeking behaviour; feelings before and after diagnosis;

attitudes towards medication/treatment; the role of the family and friends; support and care requirements; and informational and communication needs.

Data Analysis

All interviews were transcribed verbatim. The transcripts used accepted procedures for indicating exclamations, pauses and emotion (Field & Morse, 1985). Transcriptions were imported into NVivo (QSR International Pty Ltd, 2012). Analysis of the individual interviews used the constant comparative method. Two researchers conducted the analysis and coded the data into the initial themes, which were then further refined to five key themes. In discussing the results, using quantitative descriptions to describe qualitative data was deemed inappropriate, therefore, frequency of a response is indicated by such terms as, “all,” “most,” “many,” “some,” “a few,” or “one.”

Two researchers from different disciplines developed the study (RM and AS) and analyzed the data (RM and SH). However a total of ten interviewers were involved in the data collection, due to the interviews being conducted in participants’ own languages. The use of multiple interviewers and coders assured that the findings are not a result of personal bias or leading questions and that the analysis is grounded in the data.

Results

In-depth interviews were conducted with 60 PwP from 11 countries (Table 1). The average age was 63 years, with the youngest aged 45 and oldest aged 78 years. 52% of those interviewed were male. The average age at diagnosis was 55 years, with the youngest age at diagnosis being 29 and the oldest 73 years. Mean duration since diagnosis was 9.6 years (range 1 to 33) years.

Table 1: Participant details by country

Country	Number of participants	Male: Female ratio	Current age at time of interview (average)/ range (years old)	Age at diagnosis (average)/ range (years old)
Denmark	5	3:2	68.25/ 62-77	58.5/ 55-64
France	5	1:4	69.6/ 62-78	55.25/ 34-73
Germany	5	2:3	63.2/ 46-78	48.4/ 34-65
Hungary	6	1:5	63.2/ 57-68	57/ 46-67
Ireland	6	4:2	58/ 49-67	47/ 38-57
Italy	5	2:3	71.2/ 60-82	64.8/ 56-72
Netherlands	5	3:2	54.2/ 45-61	47.2/ 41-54
Slovenia	5	3:2	57.2/ 53-64	44.6/ 29-54
Spain	5	3:2	59/ 48-64	43.2/ 40-53
Sweden	5	3:2	64.6/ 50-73	61/ 58-68
UK	8	6:2	65/ 53-74	60/ 45-73

All participants were in the mild to moderate stages of the disease, and at least moderately independent, i.e. not reliant on others for most tasks.

Similar themes were identified across all 11 countries included in the study; the results are therefore presented combined for all countries.

Reported barriers to diagnosis

Delays in help-seeking

Most PwP did not seek help immediately, and reported waiting up to two years before seeking medical help. The delay was often caused by the PwP attributing the symptoms to stress, tiredness (caused by a virus) or nerve problems. Many commented on the lack of a tremor, which was the only symptom they usually associated with Parkinson's.

"I didn't think about it much [some of the earlier symptoms he experienced], I worked with computers and I thought it [the stiffness] was a result of that work." (PwP, Sweden)

"I have this nephew who has advanced Parkinson's and his symptoms compare to mine were different, so I didn't link them to Parkinson's....I didn't have the tremor." (PwP, Italy)

From first presentation to diagnosis

Most of the PwP initially saw their GP, and were very positive if they were referred quickly to secondary care. Whilst some of the participants reported that the GP suspected Parkinson's immediately and made the referral promptly, others reported that the GP failed to realise there was anything seriously wrong.

"I went to the GP first and after three years of getting no answers I changed GPs as she was not listening to me and he said 'have you ever been to a neurologist?' And I said 'no' and he said, 'well you are going to one now.'" (PwP, Ireland)

A few participants mentioned the seeming lack of specialist knowledge around PD: *"I was three years at general neurologist and then I decided to pay myself [to see a specialist neurologists] as the waiting times were too long. There the diagnosis was immediately made."* (PwP, Slovenia).

Experience of diagnosis

Communication of diagnosis

Although many of the PwP were happy with their specialist's clinical decisions (for example, what medication to try first), their communication and personal skills were often criticised.

"I was a bit disappointed with the neurologist, because the diagnosis was given quite abruptly. She said, 'You have Parkinson's, nobody has died of this disease yet'." (PwP, Slovenia)

"He [the neurologist] said: You should be happy, you don't have cancer, you don't have AIDS and not everyone gets dementia. That was quite a hit in the face I thought." (PwP, Germany)

This sometimes made them feel unable to discuss their true feelings with the specialists, or ask them questions as they feared the questions would be regarded as "stupid".

Those who reported that the neurologist spent time discussing the disease and treatment options were overall more satisfied with the initial consultation. Many however reported not having wanted too much information at the time of diagnosis as they did not feel it would be helpful to know what might happen in the future and it was hard for them to take in whilst also dealing the shock of the diagnosis. They reported their main requirement was an overview of the treatment options and what they could do to help themselves.

“He [the neurologist] sat down with me for one hour explaining. That really helped. If I had left immediately I would not have coped so well.” (PwP, Germany)

PwP reported appreciating if there was a Parkinson’s disease nurse specialist (PDNS) present at the appointment, and many felt it was easier to ask the nurse questions than the consultant.

“The PD nurse was very caring, especially. She can never do anything wrong to me again in my whole life!” (PwP, Netherlands)

Many PwP would have valued a follow-up appointment with the neurologist or PDNS a few days after the diagnosis to answer questions and give information about the treatment, following the initial shock of the diagnosis and when they felt more able to take in the information. At this point, they were also eager to understand what they could do to help themselves, such as living a healthy lifestyle.

“It’s important to fight against Parkinson’s with a healthy lifestyle, to do sports, to ease the negative symptoms with all the physiotherapeutic techniques. I do Pilates, yoga, Nordic walking.” (PwP, Slovenia)

Emotional reaction

Being told they had Parkinson’s was a “huge shock” for most, although, by the time of diagnosis, they knew “something was wrong”. They reported feeling “numb”. They reported knowing nothing or very little about the disease and their first question had often been: “Will I die from Parkinson’s?” However, they reported being quickly reassured by healthcare professionals that this was not the case and was greatly appreciated by the PwP.

“My doctor told me it was Parkinson’s disease, and I probably looked worried, or I don’t know, because she told me that there was no reason to be frightened because although this is an incurable disease, it does not cause death. She said that for certain.” (PwP, Hungary)

Despite the reported feeling of shock, some PwP reported a feeling of relief; they had feared it was something terminal, such as a brain tumour, and they had only a short time to live. Others talked about the relief of having an actual diagnosis, as they felt that once they knew what it was, they could start to deal with the disease.

“My initial reaction was mixed. I had been for three brain scans at a cancer clinic and so I was prepared for a worse diagnosis.” (PwP, UK)

“First I thought the world goes down. My husband had a positive reaction. We finally knew what it was. If I had known then how good I would feel now, I would not have worried so much.” (PwP, Germany)

Attitudes to starting medication

Most of the PwP started medication quickly (often immediately). There were however common concerns about starting antiparkinsonian medication, often fearing that the side effects would be worse than the PD symptoms.

A lack of information about the side effects was the most common concern. PwP often felt that side effects had not been explained to them clearly enough. Some acknowledged that they might have been, but as it was during the appointment where they had been diagnosed it was hard for them to take in this information.

“The appointment [where Parkinson’s was diagnosed] was a blur really. I got home and started taking the pills and...I don’t know what happened, but soon I started to have very bad side effects. My wife called for an ambulance, she thought I was going to die. They should have warned me....I don’t think they did, I just can’t remember” (PwP, Ireland)

The many medication choices made a few of the participants wonder about the evidence-base of treatment and wished for more specific treatment for themselves.

“I hope they find a cure or the right medical dose. Doctors shouldn’t be guessing, they should be better with making decisions about the prescribed medicine and the side effects they cause. The disease is something extremely individual.” (PwP, Denmark)

Experiences of ongoing care by healthcare professionals

Most of the PwP, once a diagnosis had been made, had consultations with a neurologist every 6-12 months. In the countries where PD nurse specialist were available, they usually also saw a nurse every 6-12 months (sometimes at the same time as their neurologist appointment, others on separate occasions). These regular follow-up appointments were highly valued by the PwPs (and their carers, who often also attended). However, as their disease progressed, they often felt longer appointments were needed to discuss treatments.

“After they had my medication sorted, the [neurologist] appointments were short, often just ten minutes and that was fine as the medication didn’t need changing. But after a while they had to change the drugs and then I had a million and one questions and I didn’t feel I could ask them. I always felt I was clock watching.”

Support needs

Informational needs

Whilst most PwP reported not wanting to receive too much information at the time of diagnosis about problems they might encounter in the future, they wanted to have basic information about the disease and information on the treatments available (and associated pros and cons).

“I wanted to know the facts [about Parkinson’s]....to feel prepared. That was important for me...I suppose you might say it empowered me, helped me feel a bit more in control.” (PwP, UK)

“Information is important, but you have to be strong enough yourself also when you receive some bad information, you have to handle it well. You hear about what’s happening to somebody and then you ask yourself, am I ending up this way too?” (PwP, Slovenia)

Parkinson's Associations and support groups

Views about attending support groups varied. Those that attended groups, often greatly valued the emotional and social support they gained from joining the meetings (usually held monthly). They also gained information about their disease and, in particular, benefitted when healthcare professionals attended the groups and gave presentations about new research findings or treatment options.

"It [the self-help group] was a blessing for me. It took my fear away seeing what other people can do with their lives despite PD." (PwP, Germany)

"It's quite interesting. You meet others with Parkinson's and you can have chats plus you can listen to the specialists from the field that are conducting research within PD...You can ask them questions in a more informal setting, less stressful than your hospital consultation where I often forget what I needed to ask." (PwP, Sweden)

The fear of seeing people who were at a later stage with their Parkinson's prevented a number of PwP attending such groups.

"No I don't go [to a support group]. There is a local one and...if it was full of people like me [at same stage of disease], then I would go. But I think it would be depressing seeing what life has in store for me." (PwP, UK)

However, many reported that this changed as the disease progressed, and they found the groups provided emotional support though connecting with other PwP, feeling understood and sharing experiences.

"I didn't want to go at first. I needed to process [my diagnosis] and preferred to just try and carry on as normal. But...well, as I got worse...I started to feel more isolated and going to the groups, I felt less alone." (PwP, Ireland)

Self-help

Many of the PwP, especially those who had been diagnosed with young onset Parkinson's, had explored ways to help themselves. They reported that they found that keeping active, both physically and mentally, was very important and improved their quality of life immensely. By turning to self-help activities, they also felt more *"in control"* of their disease and this in turn made them feel more confident to manage any future challenges and remain positive about the future.

"I felt that I needed to take control of the situation. I didn't want to disease to win and I felt...if I just sat back and let it take a hold of my body, then that was me simply giving up. I'm not naïve, I know things will get worse eventually, but by helping myself, I feel I can fight it off for longer." (PwP, UK)

A few of the participants took up a new hobby, such as stamp collecting, whilst many others took up some form of exercise, such as swimming, yoga, dancing, or Nordic walking.

"It's important to fight against Parkinson's with a healthy lifestyle, to do sports, to ease the negative symptoms with all the physiotherapeutic techniques. I do Pilates, yoga, Nordic walking." (PwP, Slovenia)

Reactions and support by family, friends and work environment

Family and Friends

Participants reported that although shocked and often very upset by the diagnosis initially, most family members and friends started to try and support the PwP, either by helping with their task/jobs, searching information on the internet, and/or attending support groups with the PwP.

“Good friends asked us: ‘What does this mean? And what can we do for you? What will help you?’ Then I held a kind of brain storming session with two friends about what I need and how I could make life easier for myself.” (PwP, Netherlands)

It was also reported that although family members and friends were trying to help, it could cause frustration to the PwP if they did tasks that the PwP still wanted to do, e.g. being constantly asked: ‘Can you still manage to do that?’ and ‘Why don’t I just do it as I can do it quicker?’ The PwP stated that they wanted to keep active and retain independence for as long as possible.

“I said to my friend, ‘until I really knockdown or until I ask for it, stay here with your hands in your pocket, even though your fingers are already itching.’” (PwP, Netherlands)

Work environment

Most PwP did not mention their Parkinson’s diagnosis to work colleagues until the symptoms became obvious and/or they needed to reduce their hours or change the type of work they did as part of their day-to-day job.

“In the beginning, when the signs weren’t visible yet, I didn’t say anything to work because I was afraid I will be seen as less capable of work and my future status will be negatively impacted.” (PwP, Slovenia)

However, some reported that if one of their symptoms was to “appear drunk”, they told their colleagues earlier in order to avoid their colleagues assuming they had an alcohol dependence problem.

“I told my immediate family straight away. I debated about telling people at work. But sometimes I seem as if I am drunk, so I would rather they know.” (PwP, UK)

Overall, PwP reported that work colleagues were accepting and positive once they were told about the diagnosis.

“They reacted positively in terms of reassuring me about the length of time I could work. They showed empathy and kindness in handling the situation.” (PwP, France)

Differences across the 11 countries

Overall, the findings were consistent across the 11 countries, despite the different health systems and access to specialist care. However, there were some interesting differences which should be noted. Once the referral had been made, a few of the respondents decided to seek private healthcare as they had been warned by their GP of the long waiting times to see a neurologist (general and/or specialist). These differences in waiting times were seen within the same country as well as from country to country. In Denmark and Sweden, PwPs

were seen quickly (usually within one month after referral). However this was not the case in other countries, in particular Ireland, Slovenia, Italy and Hungary.

“I was three years at a general neurologist and then I decided to pay myself [to see a specialist neurologists] as the waiting times were too long. There the diagnosis was immediately made.” (PwPs, Slovenia)

Some of the PwPs expressed concern and questioned whether Parkinson’s was genetic. Although at least one participant from most of the included countries questioned the genetic link, concern was most prominent in Ireland and Denmark where nearly all of the participants talked, unprompted, about this fear.

“I’m mostly interested to read more, as it strikes me although they say Parkinson’s is not inherited, we have so many cases in my family. It would be good to be informed whether there are methods, which could detect Parkinson’s even when you are young.” (PwPs, Denmark)

The PwPs from Spain and Ireland talked about the benefits of attending the national association’s support groups as through these groups they were able to access services not available via the health service. For example, in Spain services such as physiotherapy and a psychologist were only accessible through the Association, in contrast to other countries (e.g., UK) where these were often included in the standard healthcare offer.

“Those treatments are accessible, thanks to the association.” (PwPs, Spain)

Discussion

This study, which conducted qualitative interviews with 60 people with mild to moderate PD, provides new insights into the experience of PwP from the time of diagnosis and during continued follow-up in mild to moderate disease stages. The results are entirely focussed on PwP’ own perspective and take into account the range of experiences related to having Parkinson’s, of services provided and of support needs during this phase across differing health care settings. Providing in-depth information on these aspects in a large sample in several European countries can help inform service and support provision to better meet the needs of PwP in Europe and help them manage their disease.

Recognising the factors which facilitate satisfaction and wellbeing at time of diagnosis.

Factors experienced as positive at the time of diagnosis were prompt referral to a specialist, clear and sensitive communication of the diagnosis, reassurance about life expectancy, and sufficient time either at the initial consultation or at a follow-up appointment with a PD nurse or other health care professionals soon after the diagnosis is made. Reactions by family, friend and work environment were large positive and disclosure of diagnosis to others experienced as helpful by many. At the time of diagnosis as well as during ongoing care, adequate and timely provision of treatment information, and sign-posting to available patient support organisations and self-help groups were important to many PwP, as many felt that information helped them gain greater control over their symptoms. With the progressing nature of the disease, many felt longer appointments were required after a longer disease duration to discuss the more complex symptoms. Conversely, PwP reported negative experiences if there was a delay in referral, insensitive communication and poor information provision without sufficient opportunity to understand the diagnosis and future prognosis and options. Restricted resources make it difficult for most health care settings to provide

long specialist clinic appointments at the time of diagnosis. However, adequately training and supervising staff such as PDNS or other health care professionals on the disease and on the treatment and support options available to PwP could meet this need for tailored information at or shortly after the initial diagnosis. Similarly, the need for longer appointments during later follow-up and access to information and support options is an important unmet need. It has been shown that networks of health care professionals such as physiotherapists with ongoing supervision, guidance and training in PD can improve outcomes and reduce costs to health care systems (Ypinga et al, 2017). Developing such networks guided by centres with expertise in the management of PD, with the training of health care staff in the specific issues in the management of PD, is likely to improve overall wellbeing, meet the needs of PwP whilst reducing costs.

Understanding the importance of self-help and self-management.

Many PwP also explored and emphasised the importance of maintaining independence and the role for self-help and self-management. The ability to understand, control and manage aspects of life with Parkinson's represented an important need from PwP point of view, together with the emphasis on importance of support from health care professionals and social contacts. These experiences mirror the results from a report by the Kings fund "Delivering better services for long term conditions": which found that partnership between health care professionals and patients, promoting self-help and self management are important aspects to consider when designing services for long-term conditions, and that longer and more flexible appointments should be provided (Coulter, 2013). Similarly, a British Lung Foundation study found that self help group at which health professionals spoke were highly valued and informative for people with lung conditions and suggested that integrating such approaches and self-management might be more feasible than providing more frequent and available specialist appointments (Merritt et al., 2016). In Parkinson's disease, enabling PwP to help manage their own disease better through support and information is not only likely to improve disability but is likely to also improve the subjective experience of having PD. Enabling such self-management to supplement specialist care may require rearrangement of health care provision, but may not necessarily be associated with greater costs, and has the potential to have make a major contribution to improved quality of life for PwP.

Strengths and limitations of the study

This paper reports on a large qualitative study, which followed the principles of Grounded Theory. However, due to the recruitment of participants mostly through national Parkinson's Associations, the sample may have overrepresented more informed and active PwP, whereas less actively involved PwP may have less requirement for greater levels of information. The population interviewed in this study was also relatively young compared to the average age of PD. The average of a person at diagnosis is 62 years (Schrag, 2000), whereas in this study the average age at diagnosis was 53 (range 29-73 years old). This may be due to the fact that recruitment was mainly through online channels, which are less likely to be used by older individuals, or due to greater involvement of younger PwP in patient organisations. The issues raised in this study may therefore be not fully representative of older people with PD. Finally, none of the participants was in the advanced stages of the disease where additional experiences are likely to become relevant. Therefore, the results should be considered representative only for PwP in mild to moderate disease, and other studies will need to address experiences of PwP in the advanced stages of PD.

Conclusions

Prompt referral, clear and sensitive communication of the diagnosis, tailoring and extending consultations and information on positive steps that can be taken, including to self-help approaches with health professionals' input, are likely to improve the experience at diagnosis and during follow-up in early and moderate PD. As many PwP find it difficult to take in all information at the time of diagnosis, follow-up appointments with a health care professional in the PD service a short time after diagnosis can be helpful to allow appropriate provision of discussion of treatment options and open questions to be answered. Information including from self-help groups and patient organisations help many PwP feel they can manage their disease more effectively.

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DECLARATION OF INTEREST

AbbVie (the only funder of this study) did not have any role in the design, conduct, interpretation, review or approval of the study and this article. S.H. and A.S. have no competing interests. R.K.M. has received funding for presenting lectures on the findings of this study from AbbVie.

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