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Support needs of people with younger onset Parkinson's disease: An interpretative phenomenological analysis

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Title: Support needs of people with younger onset Parkinson's disease: an interpretative phenomenological analysis

Abstract

Background: People with younger onset Parkinson's disease reported trouble navigating the health system and managing their Parkinson's disease symptoms. This impacted their everyday responsibilities, such as: maintaining employment, caring for children, or meeting financial commitments.

Aim: To understand the experiences of the unmet support needs of people diagnosed with younger onset Parkinson's disease and allow a deeper understanding of their lived experiences.

Methods: Data were collected by interviewing four (n=4) participants about their perceptions of the current supports available. Interpretative phenomenological analysis was applied for in-depth exploration of the participant's experience, allowing the participant and the researcher to 'make sense' of their descriptions. The COREQ criteria for reporting of qualitative research were used to guide this study.

Findings: Four clear overarching themes were identified: 1) 'The pre-diagnosis of Parkinson's: denial', 2) 'What is next?', 3) 'Knowledge is power, mostly', 4) 'Loss and acceptance of identity'.

Discussion: This study has highlighted the demoralisation people with younger onset Parkinson's disease experience when they are left in a state of not knowing what is next. People with younger onset Parkinson's disease experienced a range of changing emotions and described the emotional turmoil experienced when not supported.

Conclusion: This research highlighted that a diagnosis of younger onset Parkinson's disease causes significant distress, particularly if trying to maintain employment or care for children. People with younger onset Parkinson's disease highlighted the need for psychosocial support to be instigated at the point of diagnosis.

Keywords: Parkinson's disease, younger onset Parkinson's disease, support needs, nursing, phenomenology, qualitative research, psychosocial nursing, diagnosis, self-identity.

Summary of Relevance

Problem

People with younger onset Parkinson's disease have different health care demands to their older counterparts. Yet the care offered is the same, which negatively impacts on their health outcomes.

What is already known

People with younger onset Parkinson's disease have trouble navigating a health care system designed for older people with Parkinson's disease.

What this paper adds

This study informs development of interdisciplinary care for people living with younger onset Parkinson's disease tailored to the needs of this population. This research 'gives voice' to the lived experience of people with younger onset Parkinson's disease and recognises their recommendations for innovative solutions.

Introduction

Parkinson's disease has been identified as the most rapidly increasing neurological disorder globally with an estimated 3.2 million disability adjusted life years attributed to the diagnosis (Dorsey et al., 2018, p.942). It is highlighted that 18% of people in Australia living with Parkinson's disease are of working age (Deloitte Access Report, 2015, p.22).

People with younger onset Parkinson's disease (YOPD) have reported having trouble navigating the system and coming to terms with how a diagnosis of Parkinson's disease and the associated complexities of managing symptoms impacts their everyday life. Calne and Kumar (2008) advocated for health care professionals to better understand the often-diverse needs of people with YOPD across all domains of their lives.

Literature review

Previous research has shown that people with YOPD experienced a higher loss of employment, disruption to family life and an increased stigmatisation resulting in a greater depression rate as compared to their older onset counterparts (Knipe et al., 2011; Schrag et al., 2003; Smith & Shaw, 2017). These factors may lead to a greater impairment in quality of life for the person living with YOPD. Smith and Shaw (2017) expanded on this work by exploring how people learned to live with Parkinson's disease. Smith and Shaw (2017) identified the themes of emphasising the need to continually adapt to changing mobility or immobility, exploring the kinship within couples after diagnosis and the shift in relationship dynamics, and belonging experienced through attendance at support groups.

Although these studies have indicated that there is a change in a person's lived experience once diagnosed, neither have specifically looked at how a health service could potentially address these factors to improve the patient experience. It is hypothesised that compared to their older onset counterparts people with YOPD may require a different approach to managing their symptoms, or accessing information, so they can maintain these important life responsibilities and continue to maintain a reasonable quality of life.

Participants

Inclusion criteria required participants to either be employed, have significant financial or child rearing responsibilities, or a combination of any of these and a diagnosis of Parkinson's disease. Participants were excluded if they were deemed to be experiencing cognitive impairment, and/or unable to consent, and/or participate in the interview process. It is important to note that while YOPD is usually classified as people who are under the age 50 (Elkouzi, 2021), this study took a broader approach to the definition by classifying people as YOPD based on life circumstance rather than age.

Ethics

The project was approved by the organisation's Human Research Ethics Committee on 24th January 2020. Informed consent was gained prior to interviews.

Methods

Design

Interpretative phenomenological analysis (IPA) was chosen as a method of interpreting the data relevant to the topic. IPA is a relatively new, but increasingly popular approach to exploring the lived experience and the meaning behind the explanations provided by the participants (Smith, Flowers & Larkin, 2009). IPA achieves this by using three key foundations: phenomenology, hermeneutics, and ideography (Smith, Flowers & Larkin, 2009). Larkin, Watts, and Clifton (2006) described IPA as an approach which allows for in-depth exploration of the participant's experience, allowing the participant and the researcher to 'make sense' of their descriptions.

Data collection

Four participants were recruited using a purposive sampling strategy: people attending clinics in a metropolitan area of Australia. Flyers were distributed to these people on attendance, and they were asked to contact a member of the research team for further information.

An in-depth, semi-structured interview schedule was utilised to support data collection. The participants, after giving full written consent, were asked to attend interviews at a mutually convenient time and place. The interviews took place over a period of six months (August 2020 – January 2021). The lead researcher conducted all the interviews, which ranged in length from 49 to 80 minutes. All interviews were recorded and transcribed verbatim. Each participant was interviewed once with no repeat interviews being required. All participants were from English speaking background and the researcher used reiteration techniques to ensure that the information was being correctly interpreted. The lead researcher was involved in the direct care of one of the participants and had an informal working relationship with another (through meeting at a support group), and no prior relationship with the remaining two participants.

Analysis

Smith, Flowers, and Larkin (2009) described a seven-step process to analyse data according to their IPA process (see Table 2). These authors described the importance of maintaining an individualised analysis for each transcript, maximising the potential for identifying themes

which are truly 'within the living' for each participant before developing master themes (Smith, Flowers & Larkin, 2009). This process, in theory, is thought to allow the researcher to be completely naïve to the prospective themes of each transcript prior to analysis (Larkin, Watts & Clifton, 2006; Smith, Flowers & Larkin, 2009).

The lead researcher was responsible for all the data collection and most of the analysis. This process allowed the lead researcher to become familiar with the data by collecting, reading, and rereading the data during the collection and analysis phases of the project. However, to minimise any bias and increase the validity and credibility of the findings two other members of the research team analysed some of the data separately using the hermeneutic process as described by Smith, Flowers, and Larkin (2009). The research team met on a regular basis throughout the analysis process to ensure qualitative methods were adhered to and to reflect on concepts as they were discovered throughout the analysis process. The lead researcher compiled the data into a spreadsheet, which was further analysed by the research team to identify the trends and led to the development of themes.

Findings

Four participants were recruited ranging in age from 49 to 61 years, three men and one woman. Three participants were employed on a full-time basis at diagnosis, with one participant unable to continue their employment because of their diagnosis, this participant was a chef and could no longer safely operate in a kitchen. The fourth participant was not formally employed but assisted their partner to operate a small self-managed business and received a disability pension. Three participants had children, with two participants having children under the age of 15. Three participants had a mortgage on their home. (Table 1). At the time of the interviews the median time since diagnosis was three and a half years. None of the participants were managed by the same neurologist.

Several themes were identified with four clear overarching themes: 1) 'The pre-diagnosis of Parkinson's: denial', 2) 'What is next?', 3) 'Knowledge is power, mostly', 4) 'Loss and acceptance of identity'. Each of the themes encompassed further subthemes (Table 2).

The pre-diagnosis of Parkinson's: denial

Every participant described noticing early symptoms of Parkinson's disease, such as a tremor, micrographia, and stiffness, and attributing these symptoms to something other

than Parkinson's disease or ignoring them completely, despite others telling them that it may be Parkinson's disease. Each person described a thought process by which they eliminated Parkinson's disease as an option based on their age or by comparison to others their age, *"it [Parkinson's disease diagnosis] happened to people who are so close to me, have the same thing, but mine was sinuses and a pinched nerve in my shoulder"* (Sally) (pseudonyms used to maintain confidentiality). Sally's mindset seemed to be one of rationalisation of illogical thoughts; she was able to accept that it may happen to other people her age, but it surely couldn't happen to her even if she did have all the symptoms.

Bob's initial thought process was also to dismiss the potential diagnosis of Parkinson's disease and attribute the symptoms to something else, despite the fact he was speaking to someone who was familiar with the symptoms of Parkinson's disease.

Peter's description of his thoughts is perhaps indicative of the fact he is still at the pre-diagnosis stage, and although the symptoms may be present, they do not have any value towards his self-identity at this stage. He does not prioritise the symptoms as they do not have any context within his pre-morbid self-concept.

"in the early days I supposed I had no-no idea what, um, what was going on. Um, so it was difficult. I think, um, I've lost, um-- A lot of things were happening in my life at the time. My daughter was very young. Um, I know I probably didn't manage a lot of the things very well, because I wasn't in the best physical condition or mental condition really".

Sally had to remain in a state of denial to be able to come to terms with the diagnosis driven by a fear that it would change her life forever and take away such a key part of her identity, her career. Being diagnosed with Parkinson's disease did not come as a surprise to the participants, however they were unable to accept the diagnosis due to the fact it would interfere with their life as it was. This had no impact on the way people dealt with their grief once finally diagnosed though. Being diagnosed caused all the participants to engage in catastrophic thinking, instinctively thinking the worst.

What is next?

Receiving a diagnosis of Parkinson's disease affected all participants in a way that made them reconsider their current sense of self and question their future self, with each

participant creating very gloomy outcomes to varying degrees. Bob described this as 'spiralling', describing a feeling that made him feel as though he was no longer in control of his life. He went on to describe that he entered the five stages of grief and ultimately, in his mind, accepted death. The metaphorical depiction of how he felt is very powerful in describing a sense of loss of control, spiralling downwards without any real ability to halt the process.

Three of the participants were very descriptive about the way the initial diagnosis left them feeling and described a sense of hopelessness and loss. *"My life's changed forever. What do I do next?"* (Bob), *"I-I didn't know what I wanted. Um, uh, it took a while to-to-to come to-- well, to become familiar with what the possible consequences of the diagnosis were."* (Michael). *"[I had a] really awful experience, he could tell me what a million other doctors could have said, 'You have Parkinson's, but that wasn't the important part. The important part- the important part was, what do you do now'"* (Sally). It was strongly emphasised by all the participants that they did not know where to seek help or what to do next. Each of the participants described this using negative terms and analogies. Bob stated: *"I was left in the dark, not knowing which way to face"*, he was given a diagnosis which in his mind meant he was going to die prematurely. Bob's comments conveyed a sense that he no longer trusted his body, he felt lost and alone and didn't trust himself to be able to regain a sense of direction as it pertained to his life. Bob described feeling lost for a long time and fearful of crossing the threshold from living with symptoms to living with YOPD, *"I was going through the five stages of grief because by actually taking the tablets I was accepting that I had Parkinson's and there was no turning back"*. He described being faced with an existential crisis, where taking the medications forced him into affirmation of his diagnosis of YOPD. This concept is perhaps the most important aspect of understanding the impact of YOPD. It highlights that so much more life is taken from someone at a younger stage in their life when diagnosed. The natural progression of coming to terms with a reduced quality and length of life is expedited in someone who is diagnosed with a life-limiting illness such as YOPD.

Knowledge is power, mostly

Every participant admitted to seeking information on the internet and although they all wanted to know more about their symptoms, and subsequently their diagnosis, every participant described feeling engulfed by the information. All participants described the confronting experience of seeking information on the internet where they were faced with images of older people, people they did not relate to. Interestingly Bob and Michael both referred to the search engine as “Dr Google”, perhaps in a sense creating a persona out of the internet to feel less lonely, or perhaps because this was the type of information they wished they would have received from their doctor.

All the participants described feeling fearful of allowing YOPD to become a ‘thing’ within their life, attributing this to a lack of support and understanding of what it meant to live with YOPD and how this would affect their future. Peter compared the ease of access to support and information for people with end stage renal failure, which he had also experienced. He highlighted that attendance at a dialysis centre, and therefore access to a wealth of knowledge, enabled the acceptance and understanding of the disease in a different manner than with YOPD, where the contact with other patients, nurses and clinicians is very limited.

Sally felt a certain resentment towards the neurologist for giving her a diagnosis which she subconsciously knew she had in a manner which she felt was for the purpose of making them feel superior. Michael ensured he had thoroughly researched his diagnosis prior to arriving at the appointment to avoid missing out on information because of potential perceived disrespect.

The data illustrated the innate desire to understand what the future holds after receiving a life-altering diagnosis, but also the fear that accompanies this. There is a distinct feeling expressed by all participants in that they did not feel well supported in seeking information or navigating the health system. Three of the participants described this feeling using similar terms, such as: *“left in the dark”*, *“the dark side of every piece of news”*, *“moving further into the dark”* (Bob), *“completely in the dark about everything”*, *“being kept in the dark”* (Michael), *“didn't have, uh, I didn't have any knowledge. I had nothing”* (Sally).

Loss and acceptance of identity

One of the key messages conveyed by people with YOPD is that they could not relate to the generic representation of people with Parkinson's disease. Bob explained, *"Okay, well, I kind of, I googled Parkinson's, but again, with Google, this Doom gloom and all in a kind of YouTube fitness videos for Parkinson's which they generally aimed at retirement age people"* The process of ageing and accepting one's natural progression of life is not a new concept, but people with YOPD feel they are pushed towards this prematurely.

Another concern expressed by the participants is the public image associated with Parkinson's disease and how they didn't identify with that image. For Michael, not identifying with a feeble, old, shuffling person enabled him to establish a new sense of self-concept by proving that he was not that person. He explained that for him it was almost uplifting to see those people, recognising that he was not at that stage.

Sally further described the importance of becoming empowered to understand that the diagnosis did not mean that she would lose her pre-morbid self. Sally explained that accepting the diagnosis was not the issue, it was about understanding where the diagnosis would take her and what her future would look like. By recognising the aspects of her life that she identified most strongly with and using this to relate to others who were also facing the journey of acceptance of YOPD, she was able to re-establish her self-identity and a positive outlook on her future.

Sally and Peter both described the impact YOPD had on their social identity, describing the issues they faced when their symptoms impacted their ability to participate in activities which others their age would do, such as dancing and attending concerts. Sally described a dissociation between the supports needed and the person she aims to portray herself as.

All participants described feeling as though their disease was a hinderance to being able to relate to people their age, or participate in activities that others their age would participate in. Interestingly, Michael's own perception of Parkinson's disease is inadvertently hindering him from being able to share his diagnosis.

Bob's description of the impact YOPD had on his life was particularly moving, as he described the disease robbing him of his identity as a chef. He had worked in the hospitality industry for more than 30 years, which represents his entire adult life. Bob's acceptance of

having YOPD signified more than an epistemological shift from someone without YOPD to someone with YOPD, as it put into question his whole self-identity. Bob described the fear of losing his independence, both physically and financially, as a motivating factor in seeking solutions for his future. He discussed the importance of crossing the barrier from fear of the unknown to confidently understanding his new abilities and prospects. Michael described how the diagnosis has opened him up to new opportunities, such as retraining in a different profession. He has used the acceptance of his diagnosis as a motivation to explore the option of training as a counsellor to assist others in accepting life changing events, essentially enriching his life through the diagnosis of YOPD. Sally too described a sense of newfound confidence and control through accepting the diagnosis by becoming a role model for others and taking control of her future.

It is evident that everyone approached the invisible threshold from pre-morbid identity to someone living with YOPD at different rates and with different fears. All participants managed to navigate their own way to finding empowerment and acceptance and this is a crucial aspect of recovering from the initial shock of receiving the diagnosis and continuing to live with YOPD.

Discussion

This research explored the lived experience of younger people diagnosed with Parkinson's disease and how this affected their sense of being within their world. Furthermore, it explored the unmet support needs of people with YOPD who are living with this diagnosis. The use of IPA enabled the researchers to use a lifeworld-led approach to understanding the ontological changes faced by the participants when coming to terms with a diagnosis of YOPD (Ekeburgh & Lindberg, 2020; Galvin et al., 2020). Several themes were identified with four clear overarching themes: 1) 'The pre-diagnosis of Parkinson's: denial', 2) 'What is next?', 3) 'Knowledge is power, mostly', 4) 'Loss and acceptance of identity'.

Parkinson's disease is generally diagnosed once symptoms such as tremor, shuffling gait, or loss of motor skills become evident (Schrag et al., 2015; Sveinbjornsdottir, 2016). However, Parkinson's disease has a distinct prodromal phase, where symptoms are present but not yet attributed to any disease process, or potentially not even recognised by the person experiencing them (Schrag et al., 2015). This research has demonstrated that the presence

of prodromal symptoms, followed by the emergence of visible symptoms is a crucial part of each person's journey towards diagnosis. Each participant described a period during which they were aware of symptoms, and subconsciously even worried, but attributed the symptoms to something else. Petrucelli (2010) described this phenomenon as 'sort-of-knowing', a state of awareness that is more implicit than explicit. 'Sort-of-knowing' is described as a mechanism of protecting oneself from the truth (Petrucelli, 2010). This research has highlighted that for people with YOPD it is often easier to dissociate from the symptoms by creating explicit reasons for their existence rather than seeking the true reason for their presence.

All the participants went through a phase of denial in their journey towards being diagnosed with Parkinson's disease, associated with their self-concept of being too young to have Parkinson's disease. Self-concept relates to the way in which a person perceives themselves and is influenced by various life aspects of oneself, e.g., one's occupation or family role (Bock, 2020). The diagnosis of a chronic illness challenges a person's self-concept by creating an additional element that contributes to their sense of self (Bock, 2020). This concept is further supported by Watanabe (2017) who identified the importance of providing positive support during negative experiences (receiving the diagnosis) and the way in which this can affect the person's self-concept and sense of identity moving forward.

A diagnosis of a chronic illness is often associated with numerous losses across all domains of the person's self (Gökler-Danışman, Yalçınay-İnan, & Yiğit, 2017). Being diagnosed with YOPD has been highlighted by all the participants as causing them to feel lost, hopeless, and overwhelmed by a diagnosis that they don't see as part of their identity. Gökler-Danışman, Yalçınay-İnan and Yiğit (2017) emphasised the importance of understanding a person's pre-morbid identity and the way in which a diagnosis has the potential to change a person's identity.

This study has highlighted the demoralisation people with YOPD experience when they are left in a state of not knowing what is next. Each participant described a complex process of reimagining their lives with YOPD, facing existential crises along the way that made them feel demoralised. Demoralisation has previously been attributed to an increased risk of developing depression, especially in younger people with Parkinson's disease (Koo et al., 2018; Zhu et al., 2021). These authors separately described the importance of recognising

demoralisation in Parkinson's disease to ensure accurate treatment is provided, acknowledging that while demoralisation increases prevalence of depression, the treatment approaches vary.

It was hypothesised that people with YOPD may require a modified approach to their care since they still had many competing priorities in life, such as financial, occupational, and family commitments. This research has highlighted that this is a reasonable hypothesis based on the reported need for easier and more tailored information to support the person living with YOPD across the continuum of their diagnosis. People with YOPD experienced a range of changing emotions towards their diagnosis and described the emotional turmoil they felt when they were not supported to come to terms with this diagnosis. This is represented in Figure 1, which highlights that although the continuum of symptoms, emotional responses, and adjustments to living with YOPD is not avoidable, it can be improved by understanding these responses as they relate to the individual and providing appropriate supports across the continuum.

[INSERT FIGURE 1 HERE- *Figure 1: Representation of the experiences across the continuum of living with YOPD*]

Conclusion

This research has further highlighted the importance of adopting an individualised approach when supporting people with YOPD, taking into consideration not only their immediate physical and medical needs, but also the psychological and social supports they may need to be able to live their best lives in the context of their diagnosis. Recognising that the physical aspect of Parkinson's disease is only a small part of the overall lived experience should inform the way in which services are provided, not only to younger people with Parkinson's disease, but people with Parkinson's disease in general.

One conclusion of this research is the need for support at the initial stages after diagnosis and the need for this to be initiated by health care professionals at the point a diagnosis is given. People with YOPD have strongly emphasised that this referral process needs to come with support to move forward in accepting their diagnosis; it is not just about referring, but also following up. Importantly, the support people feel they need and want at this stage is not necessarily medical. The participants highlighted that the need for access to social and

psychological support is imperative for people who are employed, have children, or significant financial responsibilities, throughout the lifetime of their Parkinson's disease journey. Furthermore, it is important for clinicians and Parkinson's disease services to recognise that these responsibilities will change over the course of someone's life with YOPD and that this should be taken into consideration when planning care. One of the key messages conveyed by the participants was the fact that they still had a lot of life ahead to plan, however now it looked very different than before.

Relevance for clinical practice

Health care access and provision for chronic conditions continues to strive towards the development of coordinated care and implementation of technological advances. This research has highlighted that people with YOPD want to have access to an easily accessible resource to assist with their initial diagnosis and throughout their journey with Parkinson's disease. This resource needs to be initiated by the health care professional at the point of diagnosis. People with YOPD advocated for this to be a resource that could be accessed through an online platform, which has been highlighted by this study as the preferred method for information seeking by people with YOPD. It is important for people with YOPD to have access to clinical and social support that does not require them to encounter older people with Parkinson's disease as this is confronting and counterproductive to their care. Providing access to social and psychological supports is the most important aspect of care as perceived by people with YOPD and this should take priority in the development of a service for people with YOPD. These supports should be initiated and followed up regularly by the health care team and adopt an interdisciplinary approach. Participants voiced that they wished for follow up to be flexible and innovative, rather than the current medical clinic follow up. It was suggested that a multidisciplinary telehealth consultation could be a preferred approach. This research has strengthened the health care consumer's voice when it comes to the development of services related to YOPD.

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