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"A young person in an old person's body": A reflexive thematic analysis of the experience of living with young onset Parkinson's disease.

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Abstract

Background: People with young-onset Parkinson's disease (YOPD), a term for those diagnosed with Parkinson's disease (PD) under the age of 60, face unique challenges compared to those diagnosed with PD later in life. A better understanding of the lived experience of those with YOPD is essential to delivering bespoke rehabilitation and improving quality of life.

Purpose: To provide insight into the emotional and social lived experience of individuals with YOPD.

Method: Semi-structured interviews were completed with twelve adults diagnosed with YOPD, aged between 30 and 59. Reflexive thematic analysis was used to analyse the data.

Results: Three major themes were developed: Theme 1: *"I'm not drunk or stupid, I'm just a young person with Parkinson's"*: A daily dose of stigma; Theme 2: *"I often feel like I've done something wrong, like I am wrong"*: The heavy weight of shame; and Theme 3: *"I was mourning my future, it felt like a death"*: Grieving what has been, and what will be, lost.

Conclusion: Grief and social stigma can result in shame and self-criticism in YOPD. Implications for healthcare professionals include the recommendation to routinely offer psychological support for individuals living with YOPD. Awareness campaigns about YOPD are needed to reduce stigma.

Keywords: Parkinson's disease, young-onset, reflexive thematic analysis, qualitative research

Implications for Rehabilitation

- Individuals with Young Onset Parkinson's disease (YOPD) are a unique group with their own set of challenges compared to those diagnosed with PD later in life.
- People with YOPD experience social stigma which can result in shame and self-criticism.
- Individuals with YOPD would benefit from psychological support tailored to their needs to maximize rehabilitative outcomes and enhance quality of life.

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative condition after Alzheimer's disease and is estimated to affect 1 percent of the overall population (Parkinson's Disease Foundation, 2019). PD is typically characterised by motor symptoms including tremor, akinesia (the loss of spontaneous, voluntary muscle movement), and rigidity; however, other symptoms, such as depression and anxiety are common and have a significant impact on the health-related quality of life (QoL) of people with PD (Schrag et al., 2000; Santos-García & de la Fuente-Fernández, 2013). PD is traditionally viewed as a disease that affects older adults, with 67 as the average age at diagnosis (Raket et al., 2022). However, it is estimated that approximately 10% of those with PD are diagnosed before the age of 60 and considered to have young-onset PD (YOPD) (Parkinson's Europe, 2018). The view that PD is a disease of older people may result in people with YOPD going undiagnosed or experiencing significant delays in diagnosis (McDaniels et al., 2023).

The symptoms experienced by people with YOPD differ from those with older age at onset of PD. Individuals with YOPD tend to have slower progression of the disease, fewer comorbidities and a higher incidence of dystonia and levodopa-induced dyskinesia (Eisinger et al., 2017; Thenganatt & Jankovic, 2014). A higher genetic contribution to PD is also observed among individuals with YOPD. The YOPD population tend to typically have a slower pace of cognitive decline (Schrag et al., 1998) and fewer gait disturbances and falls (Wickremaratchi et al., 2009) than the older-onset PD population. The number of people diagnosed with YOPD is increasing (Willis et al., 2013), likely due to improved recognition of YOPD symptoms.

Receiving a PD diagnosis at a younger age can be perceived as 'out of sync' with typical life transitions (McDaniels et al., 2023). Individuals with YOPD are likely of working age with significant career and family responsibilities and may face a unique set of psychosocial challenges and complexities (McDaniels et al., 2023; Mehanna & Jankovic, 2019). Higher levels of psychological and QoL difficulties are reported in YOPD compared to those diagnosed with PD at an older age of onset

(Calne et al., 2008; Post et al., 2020). There are several psychosocial differences between people diagnosed with YOPD and those diagnosed with PD later in life, including potentially having children at home, being employed, greater social isolation, financial responsibilities, and a lack of access to age-appropriate support groups (McDaniels et al., 2023). Individuals with YOPD are more likely to have increased marital discord and worse marital satisfaction, considered to be related to mood and adjustment difficulties, and challenges in accepting the PD diagnosis (Post et al., 2020).

People with YOPD are more likely to experience a poorer quality of life than individuals with conventional age of PD onset of over 60 years (Mehanna & Jankovic, 2019). This poorer QoL in YOPD may be associated with higher levels of anxiety, depression, and psychosocial issues and may also be affected by social stigma and social isolation (Calne et al., 2008; Quelhas & Costa, 2009).

Exploring the everyday difficulties that underpin psychological distress and low QoL is critical to fully understanding the experiences of people with YOPD, as they remain a relatively neglected group with little research conducted in this population specifically (McDaniels et al., 2023). Qualitative research could enhance our understanding of the unique emotional and adjustment experiences and impact. This could help health professionals in supporting people with YOPD and inform the development of interventions that would be effective in improving psychological distress and QoL for people living with YOPD (Knipe et al., 2011).

This research will focus on the experience of living with YOPD, diagnosed under the age of 60. The research question was: "What are the emotional and social experiences of people living with YOPD?"

Method

Ethical approval was received from the University Hospital Research Ethics Committee (SVHG REC Ref No: RS21-063).

Design

Through a qualitative design, we adopted an experiential (as opposed to critical) orientation. We are interested in how people experience and make sense of their world (Braun & Clarke, 2021). In particular here, how people with YOPD understand their social and emotional experiences. Within this broad paradigm, we take a contextual position i.e., that knowledge generated will be to some extent local and influenced by a participant's situation and context. Data was collected from semi-structured interviews with twelve participants with YOPD and analysed via reflexive thematic analysis (Braun & Clarke, 2021). Participants were asked to explain what living with YOPD was like for them with prompts such as "what did you make of that?" or "how was that for you"? These data in turn were interpreted by the researchers to generate the findings. Thus the researchers' experiences and orientations are also important to understand, as outlined below.

Researchers' position

A key aspect of reflexive thematic analysis and a contextualist position is considering the researchers' positions and experiences and their impact on the data (Braun & Clarke, 2021; 2022). Four of the authors, who led on the analysis, are clinical psychologists (the first author was a trainee psychologist at time of data collection) and therefore the interview guide and interpretation had a psychological lens. Two authors regularly research chronic illness, including neurological conditions, and this knowledge (e.g. of difficulties common to chronic illness generally) will have influenced the findings. None of the authors had YOPD. Three of the researchers work clinically with people with PD, including YOPD, as a Clinical Neuropsychologist, a Consultant Neurologist and Clinical Nurse Specialist in

Parkinson's and thus helped ensure the analysis had sensitivity to context, as well as impact and importance, as per Yardley's (2000) quality criteria.

Participants and Procedure

Participants were recruited via convenience sampling from an adult tertiary university teaching hospital neurology department from August 2022 to November 2022. Three of the researchers worked clinically in this neurology department. The inclusion criteria were as follows: individuals 18-59 years old with a confirmed diagnosis of PD, sufficient understanding of the English language to partake in a detailed interview, cognitive ability to give informed consent, and access to a computer or phone with internet to accommodate Microsoft Teams. Participants were excluded if they were aged over 60 at time of diagnosis or at time of participation, did not have a confirmed diagnosis of PD and had advanced severe cognitive impairment that would make their engagement with the consent, information, and interview process difficult.

Individuals who met the inclusion criteria were informed of the aim of this study during routine clinical contact with hospital clinicians. Fourteen individuals provided verbal consent to clinicians and agreed to a follow up phone call from the lead researcher. Two people were later unable to be contacted by the lead researcher at follow-up, approximately 1-2 weeks after initial contact. The lead researcher, who was not a clinician in the hospital, obtained informed consent and organised a suitable time to complete a semi-structured research interview virtually, using Microsoft Teams. Twelve participants with YOPD consented to take part.

Interview Topic Guide

A semi-structured interview topic guide was created by examining key topics of relevance in the existing literature (Calne et al., 2008; Knipe et al., 2011; McDaniels et al., 2023). Questions

regarding demographic and clinical variables were also incorporated into the guide. Interviews lasted on average 81 minutes, between 55 and 106 minutes on Microsoft Teams. A debrief was completed at the end of each interview between the interviewer and the participant. A debrief sheet was provided to all participants. Microsoft Teams software was used to record the interviews, which were then transcribed verbatim by the lead researcher. Identifying details (names and specific locations) were pseudonymized.

Data Analysis

Because this study was interested in the meanings that participants attributed to living with YOPD, with a particular focus on their social and emotional experiences, data was inductively analysed using reflexive thematic analysis. This was guided by the six phases outlined by Braun and Clarke (2021), and with consideration of the research questions. Using this approach allowed us to identify patterns across the entire data set, as well as to interpret it theoretically. The first step involved familiarisation of the data, where the lead researcher immersed themselves in the data, re-reading and making notes on the content of the interviews. After identifying relevant passages of text, the lead researcher coded inductively using Microsoft Word, identifying words, phrases and paragraphs that were relevant to the research question (i.e., on emotional and social experiences) and giving these a descriptive label. Initially codes were more semantic (Braun & Clark 2021), thus directly related to participants' description (e.g. worries about cognitive impairment), but as analysis progressed, some were also latent and more interpretive (e.g., age-related stigma). Codes were reviewed and discussed by the research team. Following the coding, the lead author collated the codes in order to develop candidate themes. These were reviewed and discussed with the research team, drawing on the wider team's experience of chronic illness more generally and working with people with Parkinson's and young onset Parkinson's specifically. Yardley's principles of commitment and rigour, but also transparency and coherence (Yardley, 2007) were borne in mind, ensuring the final themes

told a coherent story. The developing themes were also tested in connection with coded extracts and across the entire data set by returning to the interview transcripts. To produce the report, the final step involved revisiting the research questions, coding extracts, and defining themes, as well as establishing connections between the data and literature (Braun & Clarke 2019).

Results

Participant characteristics

Demographic and clinical features of each of the twelve participants are presented in Table 1. The mean age at time of participation was 47 years and mean time since diagnosis of PD was 8.6 years. The participants were Seven women and five men. All participants were white Irish or white British.

Table 1

Participant Demographics

Participant pseudonym	Gender	Age	Relationship status	Employment status	Time since diagnosis (years)
Phoebe	Female	45	Married	Employed	4
Eleanor	Female	40	Married	Employed	8
Geraldine	Female	48	Married	Employed	1
Kate	Female	54	In a relationship	Employed	2
Lucy	Female	41	Single	Employed	12
Michelle	Female	59	Married	Employed	4
Niamh	Female	50	Married	Home maker	21
Billy	Male	41	In a relationship	Employed	5
Nick	Male	30	Single	Employed	11
Peter	Male	58	Married	Employed	9
Pearse	Male	57	Married	Employed	8
Stewart	Male	44	In a relationship	Employed	18

Overview of themes

The data analysis process identified three themes: 1) *"I'm not drunk or stupid, I'm just a young person with Parkinson's"*: A daily dose of stigma; 2) *"I often feel like I've done something wrong, like I*

am wrong": The heavy weight of shame; and 3) *"It felt like a death"*: Grieving what has been, and what will be, lost.

Theme 1: *"I'm not drunk, I'm just a young person with Parkinson's":* A daily dose of stigma.

This theme depicts participants' experience of embarrassment and anxiety associated with judgements made by others and a fear of how others view them in social contexts. All participants interviewed discussed their experiences and perceptions of daily stigma from others, familiar and unfamiliar to them.

Some participants spoke about how others misinterpreted their symptoms, especially tremors, in public and in more intimate settings such as when with friends and family. These interactions caused participants to feel uneasy and self-conscious.

> *"People at work ask me if I'm anxious or cold, it's very embarrassing. I don't know what to say. What do you say when someone calls you a nervous Nellie? No, I'm just lacking in the dopamine department, don't worry about me!" (Kate).*

When a tremor was viewed as an effect of drinking alcohol or taking drugs, embarrassment was greater compared to if the participant was viewed as anxious or cold. Several participants described their conflicting feelings regarding telling others about having PD.

> *"People stare at you with sceptical eyes like they're wary of you. They look at you like you're on some sort of substance or drunk. I sometimes tell them that, no, I'm not drunk, I'm just a young person with Parkinson's. This is just a symptom of a disease. The wariness quickly turns to pity then." (Michelle).*

They also noted the idea that others were unlikely to suspect PD due to their age.

> *"People don't think of Parkinson's because I'm so young. To them, I just look weird or strange" (Eleanor).*

All participants highlighted the perception that others viewed them as *"older"*, perhaps due to some of the PD symptoms.

> *"My niece got a new treehouse and told me I wouldn't be able to climb up to it because I was 'too old' but had no issue thinking that my brother, her dad would be able to climb it and he's five years my senior." (Stewart).*

Many participants noted the stigma associated with having a PD diagnosis at a young age. Some participants noted that others who were aware of the PD diagnosis, perhaps assumed there were cognitive impairments following diagnosis disclosure.

> *"I was in a meeting at work and a colleague said to me 'do you need to write that down?', as if I would forget it 30 seconds later." (Billy)*

This made some participants more likely to try and hide symptoms or withhold disclosure from friends, family, and colleagues. Many participants called in sick to work or cancelled social events so as not to *"reveal"* themselves after experiencing stigma associated with being perceived as cognitively impaired.

> *"It's not like saying you have diabetes or an autoimmune disease. People automatically assume because your brain is involved that you're not all there. I began to avoid the office on bad days and only wanted to see family who knew me well enough to know I was still sharp as a tack." (Nick)*

Participants hesitated to tell others about having PD. This caused anxiety due to thoughts of what others might think if they knew about the diagnosis. Some participants described the disclosure of their diagnosis to friends, family, and colleagues as a *"coming out of the closet moment" (Kate).*

In terms of socialising, many participants reported experiencing social anxiety prior to and during social events due to stigma they had experienced previously. This high level of anxiety often made physical symptoms worse. Participants described feeling anxious and vulnerable when eating

out in a restaurant at the possibility of spilling food or drink on themselves. They also described the judgement that would follow if this happened. Geraldine discussed feeling like *"a child"* in a restaurant with her husband who had to assist her with cutting food and pouring tea. Other participants also gave examples of feeling anxious and subsequently vulnerable in social situations similar to this.

> *"There was a regression type feeling, like I had all of a sudden gone back to being a child. I could feel people looking at me and I was very embarrassed." (Geraldine)*

Similarly, Niamh discussed her experience of being in social situations and described feeling like she stood out to others around her when she could not adhere to social norms for example, eating, drinking or trying to use cutlery. Other participants also reported isolating themselves socially due to social embarrassment. This elicited conflicting feelings from participants who craved social interaction but felt they could not engage due to this perceived negative social attitude to difference.

> *"I constantly feel like I'm going against the grain and breaking the rules of society. I tend to lock myself away when feeling like this. It's lonely and it enrages me that this is how it is." (Niamh)*

Theme 2: *"I often feel like I've done something wrong, like I am wrong":* The heavy weight of shame.

The theme of shame was prominent in all interviews and infiltrated many aspects of the participants' life. All participants reported feeling an element of shame in relation to their PD diagnosis. Many spoke about having PD as misaligning with their values such as health. Some spoke about the idea that they had received a PD diagnosis as a form of *"punishment" (Niamh).* Others felt shame regarding their physical deterioration and sexual and body image. There were several indications of this shame during the interviews: using the word directly or equivalent words such as *"disgrace", "embarrassment"* or *"awkward"* in relation to themselves or their bodies; Indirect references referring to trying to *"hide"* aspects of their disease, their bodies, or their personalities.

Some participants described feeling like they had done something to warrant a PD diagnosis such as living an unhealthy lifestyle or having done something they perceived as morally wrong. Eleanor reflected on her feelings when telling her friends and family about her diagnosis and recounted a deep shame that she was now a young person with a health condition. She explored the idea that mistakes she had made in her life may have resulted in this diagnosis as a consequence of not always being a *"good person".*

"I often feel like I've done something wrong, like I am wrong. Did I not take care of myself well enough, is this karma or did I do something bad enough to deserve this?" (Eleanor).

Billy also reported feeling shame as being an *"unhealthy young person"* as it did not align with how he viewed himself or how he valued his health. Similarly, other participants described this notion of incongruence between how they felt about themselves and who they perceived themselves to be and the reality of being a young person with a progressive neurodegenerative disease.

"I feel like a hypocrite sometimes, preaching about living a healthy lifestyle which is a huge part of who I am. Now, I'm not healthy and feel like I can't be that person anymore." (Billy)

The notion of the changing self elicited a great deal of shame from participants, specifically in relation to body image. Participants described feeling *"out of sync"* or *"disconnected"* from their body following symptom onset. Lucy described feeling as if she was living in an older person's body despite feeling young on the inside. Many participants felt like their body no longer represented who they were, especially as a young person with a stereotypically older person's disease.

"I feel so wrong sometimes like I'm a young person trapped in an old person's body. I feel old and not myself anymore. I feel very disconnected." (Lucy).

This physical deterioration led many participants to feel shame as they lost their sense of autonomy and self-efficacy. This was the case with participants who needed to reduce hours in work or who were unable to play with their children in the same way that they used to. Some participants

reported feeling shame as they no longer played the same role in their family, for example, no longer being the breadwinner of the family or being in the role of the caring mother.

> *"Sometimes I don't recognise myself anymore. I was running the show before, taking care of everyone, making sure everything was done. I'm not able to keep that up anymore and I feel useless like I'm now relying on other people to do what I should be doing". (Niamh)*

Several participants discussed hiding these feelings from spouses and partners and described it as embarrassing or shameful to talk about one's shame.

> *"I just want to retreat, to hide like I don't want to be seen as anything less than what I once was. I can't talk about it either because it's embarrassing." (Peter)*

Shame in relation to sexual self-image was also a prominent topic discussed by participants. Many reported feeling a loss of libido and avoidance of sexual activity due to a poor sexual self-image. Kate described avoiding intimacy with her husband as she did not feel desirable any longer. Other participants felt that their partners had lost interest in them due to their diagnosis and being perceived as "old".

> *"I just lost interest; I didn't want my body on display like who would want to see it." (Kate).*

Several participants noted experiencing their bodies as *"disgusting" (Billy)* and *"untrustworthy" (Phoebe)* with many describing attempting to hide that they had a motor degenerative disease. This was difficult for participants due to the physical symptoms associated with PD which made it impossible to hide. Many participants reported withdrawing from those around them and not disclosing their diagnosis as a form of coping with overwhelming feelings of shame. Some participants noted denial or avoidance as another coping strategy.

> *"Some days I just had to pretend like it wasn't happening because it made me feel so embarrassed like to the point that I couldn't look in the mirror or look at people in the eye. I had to block it out to function." (Nick)*

Theme 3: *"I was mourning my future, it felt like a death"*: Grieving what has been, and what will be, lost

The experience of grief and loss was discussed among the majority of participants, around past and current losses, and specifically grief associated with losses related to anticipated loss of future plans they may have had. These centred around family, career and goals or opportunities participants may have wanted to achieve.

Past and current losses were also explored. Some participants described grieving the loss of previous functioning, abilities, and health. Many others spoke of the loss of financial security, control, and predictability that they once possessed before they got their diagnosis. This caused participants great distress which manifested itself in the form of anger, sadness, and denial.

> *"When I think of what I had once upon a time, a healthy body, a full-time job and knowing I would be able for my day. It makes me so angry and sad to know I've lost that." (Michelle)*

Many described this grief as unexpectedly intruding into their everyday life, *"popping up"* when they least expected it. Other participants spoke of *"moving in and out"* of grief, spending some time yearning for what has been lost, remembering what they once had and imagining what the future will hold.

> *"Some days, thinking about what I don't have any more and what I am going to lose infiltrates my life without my permission. I don't know it's going to happen and there it is." (Pearse)*

One participant described experiencing an intense sadness as well as periods of anxiety when thinking about their future with PD.

> *"I feel like PD has robbed me of so many different things. The way I was before this and who I'm going to be during it and in the future. It comes with so much sadness and worry when I think about it." (Eleanor)*

Several other participants described sleeping problems and loss of appetite when thinking about the future.

"Sometimes I can't eat or sleep thinking about what's to come and what I'll lose that I didn't even know I would have." (Peter)

Most participants felt this grief about their future. For example, one participant reported feeling loss about what way she would be with her family in the future, foreseeing being able to be present with her family in a way that was anticipated before she received a PD diagnosis and feeling that this had been taken away from her.

"I imagined helping my children with my grandchildren. Pushing them on swings and baking Christmas cakes. That's all gone now. The dream is dead." (Phoebe)

Other participants spoke of loss in terms of their planned future careers, describing their career goals as unattainable due to PD symptoms including fatigue, pain, and tremor. Several participants were concerned as to how their jobs would be impacted in the future as their PD symptoms progressed. One participant described reduced productivity due to PD which will limit his future progress in his field.

"I was doing so well in work, I got promoted and could see my career progression really clearly. It felt so attainable. Now I'll have to retire early, and my performance has been impacted by my symptoms. My future is restricted now" (Stephen)

Many participants described feelings of uncertainty and anxiety about their future and what was to come.

"I feel so nervous about what comes next. It's unsettling to not know what will happen or what way I will be. How bad will my symptoms get and will I not be able to do what I'm able to do now". (Lucy)

Participants also spoke of being able to remove themselves from this loss-oriented state into a more present state, describing focusing on their current situation. Many described shifting from focusing on their loss to focusing on their present as a coping strategy that allowed them to function.

> *"I'll get stuck in that pool of loss for a while thinking about the past and the future but will be able to bring myself out of it too after a while. It's like I'll dip in and out. That's the only way to survive because you could get lost in it". (Geraldine)*

However, several participants described thinking and discussing what might lie ahead in the future as a coping strategy, allowing them to plan and orient themselves to the reality of the potential disease progression. Information gathering was particularly helpful for these participants. Phoebe described feeling contained by being warned of what was to come, for example, worsening symptoms, medication desensitisation and financial difficulties. Others reported that this allowed them to grieve ahead of time as well as prepare their family and friends for what was to come.

> *"It was comforting to know what might happen and be able to sort things out for it financially and health wise. It was helpful to be forewarned and to have to time to let it sink in. For me and for my loved ones." (Phoebe).*

Discussion

This study explored the emotional and social experiences of living with young onset Parkinson's disease (YOPD). Findings identified three major themes: 1) *"I'm not drunk or stupid, I'm just a young person with Parkinson's":* A daily dose of stigma, 2) *"I often feel like I've done something wrong, like I am wrong":* The heavy weight of shame, and 3) *"I was mourning my future, it felt like a death":* Grieving what has been, and what will be, lost. The results explored the participants' experience of judgements made by others and the anxiety resulting from that. This appeared to be associated with non-accepting social attitudes to difference. The experience of internal and external shame linked to

having YOPD, and grief associated with what has been lost and anticipating what may be lost in the future was also identified. The themes relate to each other by considering the impact of external judgements from others and stigma and social expectations more generally (theme 1), which might lead to internalised shame (theme 2). Grief, loss and other complex emotions exist alongside and are potentially exacerbated by the societal external stigma and internalised shame.

Previous research has indicated that people with YOPD have a poor quality of life (Knipe et al., 2011; McDaniels et al., 2023). Our study provides unique insight into possible reasons why, with results revealing significant levels of shame, stigma and grief communicated by participants. The present study also identified a range of difficult emotions, including embarrassment, frustration, anger, low mood, and anxiety, that are likely to have negatively affected the quality of life for participants living with YOPD. These findings support Calne (2008) and Knipe's (2011) proposition that such psychological difficulties are an accompanying feature of PD in younger people. Our study allows greater understanding of how and why these emotions may occur.

A common unmet need identified by people with YOPD is having a community of others with YOPD around them (McDaniels et al., 2023). Our findings highlight that high levels of stigma experienced by people with YOPD may in part explain this unmet need for community. This stigma experienced without the support of an understanding community may increase the likelihood that an individual will feel alone and shame (Dolezal, 2022), which could in turn lead to avoidance of social situations and further isolation.

Although there is a body of literature suggesting all people with PD may experience stigma (Maffoni et al., 2017), it is possible that this may be amplified for younger people as neurodegenerative diseases like PD are typically associated with older adults. As our results suggest, when presented with someone displaying PD motor symptoms, others may assume a younger person is drunk or under the influence of drugs compared to an older adult over 60.

Individuals with PD of all ages face judgement regarding assumptions about their cognitive abilities (Posen et al., 2001). Those with YOPD are less likely to experience cognitive impairment and dementia overall compared to older people with PD (Schrag et al., 1998). However, some participants in our study noted that following their diagnosis disclosure, other people associated PD with dementia and assumed cognitive impairments. This assumption regarding cognitive impairments with PD may be particularly difficult for those with YOPD, as they are more likely to be of working age with different social and familial responsibilities than later onset PD (McDaniels et al., 2023; Post et al., 2020).

Post et al. (2020) highlighted numerous areas which can be impacted by YOPD, including work, physical state, relationships, finances and mental health. Considering all these changes and losses, the experience of significant grief in our YOPD participants as noted in theme 3 makes sense. Bishop (2005) found that psychological wellbeing and QoL are more likely to be negatively affected if chronic illnesses impact those life domains valued by individuals, such as the family domain, and if chronic illnesses take away an individual's ability to change an unsatisfactory lifestyle. This may be amplified for younger people with a chronic conditions like PD as many are at a stage in life where they are engaged in numerous valued activities such as a career, traveling, and possibly raising a family with children (Knipe et al., 2011; McDaniels et al., 2023)

Feeling unable to fulfil ideal representations of oneself can lead to shame and guilt (Katzir & Eyal, 2013). Participants' own perceptions may also have contributed to their feelings of anxiety, embarrassment, and shame, in addition to perceptions of others as seen in theme 1 and 2. Gilbert (2009) proposed that shame is an evolutionary response that helps people identify and correct aspects of their behaviour that are likely to result in social exclusion. Shame arises when the self is perceived to have undesirable characteristics that others might feel are insufficient or unattractive (Gilbert, 2009). There was an awareness among participants in this study that they could not change how PD manifested; as a result, some participants did not feel safe in social environments, perhaps feeling that their social position would be criticized or rejected. This can be defined as external shame by

Gilbert (2002), as participants felt devalued and at times avoided by others. Some participants may have internalized this shame (Gilbert, 2009) because they felt inferior to others in society which was evident in theme 2.

According to Gilbert (2002), there are two major defences or safety strategies to external shame, one being the internalised shame response which is evident from the findings of this study as identified in theme 2. Gilbert (2002) stated that the internalised shaming response is where an individuals will take on a "subordinate, submissive strategy associated with self-monitoring and self-blaming". This can be found in participants account of feeling responsible for their illness. This may be a way of coping with the stigma and external shame participants were experiencing.

The participants in this study reported experiencing grief associated with future losses. Anticipatory grief is defined as a grief that occurs before a loss, in contrast to grief that occurs during or after a loss (Sweeting & Gilhooly, 1990). Anticipatory grief has been traditionally applied to family and caregivers experiencing a bereavement; however, it can be relevant to individuals diagnosed with chronic illness and their families (Walker et al., 1995). Hottenson (2010) describes anticipatory grief as a response to threats of loss of role, loss of identity or loss of the ability to function in the future, all of which is applicable to the participants in this study. Rando (1986) stated that anticipatory grief is not only concerned with future losses and can be focused on past and current losses also. Losses associated with a life-changing diagnosis include the loss of former functioning, health, abilities, and body parts; the loss of security, predictability, and control, and the loss of invulnerability (Rando, 1986) which participants described in theme 3.

Interesting findings from this study show that some participants experienced thinking about the future and information about progression of PD as positive, allowing them to plan and adjust to their new circumstances. Rando (1986) argued that anticipatory grief may be used as a coping mechanism to deal with the losses experienced by the individual, with other researchers arguing that it may result in a shorter and easier grief period once the actual loss takes place (Fulton & Gottesman,

1980). However, Lindeman (1944) stated that anticipatory grief may have adverse effects, possibly intensifying grief once the loss takes place.

Participants described a shift from being loss-focused to focusing on the present as a coping mechanism to allow them to function daily. Stroebe & Schut's (1999) dual process model of grief illustrates those individuals experiencing grief switch from "loss orientated stressors" which are stressors that originate from focusing on the loss to "restoration-orientated" which refers to the secondary sources of stress and coping e.g., everyday tasks having to be completed despite the loss. This is referred to as "oscillation". This model highlights the necessity of rebuilding everyday life after a loss and emphasises that healthy grieving requires shifting or "oscillating" between the two modes. Although originally published to reflect those who were experiencing a bereavement, it can be applied to individuals experiencing anticipatory grief (Carr, 2010).

Clinical implications

Previous research suggests that individuals diagnosed with PD are not routinely offered psychological support during or after the diagnostic process (Dobkin et al., 2013). Guidance from the UK National Institute for Health and Care Excellence (NICE, 2017) describes that when diagnosing PD, health professionals should provide support, information, and advice on PD. In the context of YOPD, this guidance seems especially relevant given that participants described feeling uncertain and anxious about what the future holds for them. This distress could be alleviated with support and information on the condition at different time points.

Dobkin at al. (2013) reported that barriers to mental health care utilisation for people with PD include inadequate understanding of mental health challenges associated with PD, access difficulties, the failure of medical providers to screen for psychological distress and the need to offer more

effective interventions to this population. These barriers may be more of a difficulty for a YOPD population considering PD is a disease typically associated with older age.

Because of the impact of PD on their lives, participants with YOPD in this study experienced a wide range of distressing emotions, including shame, anxiety, uncertainty, embarrassment, frustration, anger, low mood, and grief. In the context of YOPD, Acceptance and Commitment Therapy (ACT) may potentially be beneficial for individuals experiencing these difficult emotions. ACT utilizes mindfulness skills to empower one to take valued- based actions that enriches one's life, even in the presence of distressing or uncomfortable emotional or physical experiences (Harris, 2009). There is increasing evidence supporting the use of ACT with chronic health conditions, including neurological conditions (Graham et al, 2016). The values-based approach of ACT may be helpful with the psychological distress and grief that people with YOPD experience. Although the evidence base for ACT and PD is currently limited, preliminary positive findings on its use indicate further research is warranted (Zarotti et al., 2020). These findings are corroborated by Nagatsu (2020) who found that ACT may improve anxiety and depression for those with PD. Other emerging evidence is also indicative of positive effectiveness of ACT in working with people with PD (Gwak & Park, 2024; Javidtash et al., 2024; Ghielen et al., 2017). Future research could explore the potential effectiveness of ACT with people living with YOPD.

In addition, participants in this study reported a distressing level of internal and external shame. An intervention model aimed specifically at addressing shame is Compassion-Focused Therapy (CFT) (Gilbert, 2009). Self-loathing, intense self-criticism, and active devaluation are characteristics of individuals who are susceptible to feeling ashamed. In contrast to harsh self-criticism and self-loathing, they do not know how to engage in self-compassion. The goal of CFT is to help individuals examine their shame-based self-attacks and replace them with a healthier stance, namely compassionate self-correction (Angulo et al., 2019). CFT has been found to be effective in treating anxiety and improving quality of life in individuals with MS (Aboutalebi et al., 2022).

Similarly, to the use of ACT with a PD population, there is limited research examining the effectiveness of CFT with a PD population. This may be because the experience of shame for people with PD is an under-researched area, particularly for individuals under 60. This paper highlights the need for interventions that focus on shame, particularly with a YOPD population as findings indicate they experience a distressing level of shame.

In McDaniels et al., (2023) study exploring unmet needs of those with YOPD, findings indicated that a universally unmet need for all participants was the need for a community of similarly affected people. This was for a variety of reasons, including receiving more information about PD, help with mental health difficulties and support with diet and nutrition. The findings of this study may be applicable to the results of this paper. Having a community of people around you that are experiencing similar difficulties can be helpful in reducing health related stigma (Heijnders & Van Der Meij, 2006) and shame (Nkosi & Rosenblatt, 2019). This unmet need of community may be met by facilitated peer support group for people with YOPD. In addition, these groups could be organised for those at the same stage of the disease as to not distress those who are in the early stages.

Furthermore, a lack of awareness of PD may have contributed to the stigma participants experienced. As PD is among the most common neurological conditions, more public awareness campaigns are needed around the condition of PD in general, particularly YOPD as it is a disease typically viewed as an older person’s disease. (Parkinson's Disease Foundation, 2019; McDaniels et al., 2023). This may lead people to assume that a younger person does not have PD and attribute their symptoms to something else e.g., alcohol and drugs as previously discussed.

Enhancing public awareness of the holistic needs of people diagnosed with PD is crucial. Clinical psychologists should work alongside other health care professionals to promote awareness of the psychological and physical impacts of Parkinson's disease. It may also be possible to reduce some of the stigma associated with people making assumptions about alcohol and/or drugs, which can lead to psycho-emotional disablism (Simpson et al., 2013), by raising the profile of this common

neurological disorder. Moreover, clinical psychologists have a role to play in providing psychological input to individuals with PD who desire it and further understanding shame, stigma and emotional distress experienced by people with YOPD and how to intervene.

Limitations and future research

Participants in the study were recruited from an adult tertiary hospital in Ireland, therefore, the findings may be specific to this context. For example, experiences may differ for those who do not have regular access to a tertiary neurology service, but are largely managed by their general practitioner. Although general practitioner's typically offer comprehensive, whole-person care, they may not have such specialised knowledge or access to wider multidisciplinary team health care professionals. Furthermore, findings are likely to differ in countries where medical care and diagnosis procedure may differ, such as in lower income countries. The results of this study discuss the participants' experience of stigma; the experience of stigma with YOPD may also vary in other cultures and other parts of the world (e.g., Africa, Asia) as the cultural meanings associated with YOPD and its symptoms may be different. Future qualitative empirical research could focus on the experience of stigma in non-western countries and across more diverse ethnicities than those represented by our participants Our participants were also all either White Irish or White British. People with YOPD from traditionally socially excluded and otherwise disadvantaged groups, including migrants, are likely to potentially experience additional stigma. Furthermore, two of twelve participants identified as single. Whether participants relationships or living arrangements impacted the findings from our research was outside the scope of the current research. However, considering the informal caregiver role has been found to play a key role in supporting people with PD (Prizer et al., 2020), exploring the informal caregiver role in the experience and outcomes in YOPD is a valuable area of future research. Future research with a more nuanced perspective focussing on intersectionality of multiple demographic and systemic factors with YOPD would be helpful to increase our understanding of the impact and

experience of YOPD and crucially to best support those living with YOPD and their rehabilitation and support teams.

This research aimed to explore the experience of people diagnosed with YOPD regardless of disease stage or duration. Participants ranged from those diagnosed in the past year (1 year) to those who were diagnosed several years ago (up to 21 years). Participants were at different stages of PD progression and their experience of living with symptoms of YOPD may have been influenced by time since PD onset. We also did not specifically explore the impact of time of symptom onset to accurate PD diagnosis. To better understand the trajectory of PD experience in individuals under 60, future research could collect specific information on functional impairments associated with stages of PD, including the diagnosis process, which can be particularly difficult for YOPD. Longitudinal studies could better capture how the experience of being diagnosed with and living with YOPD changes over time.

The focus of this research was the experience of YOPD broadly, as it has been identified as an under-researched area. We therefore did not specifically consider the potential variation within or between themes based on the gender of the participants (7 women and 5 men). Emerging evidence regarding the impact of PD on women compared to men includes poorer quality of life, higher levels of psychological distress, depression and anxiety, greater fatigue, sleep difficulties, and worse autonomic functioning (Crispino et al, 2021; Subramanian et al, 2022). There are also fundamental gaps in knowledge about how YOPD specifically affects women throughout their hormonal life cycle, resulting in further unmet needs and further adversely impacting women with PD's quality of life (Subramanian et al, 2022). McDaniels et al (2023) had almost 70% women respondents to their survey about YOPD, and noted the top five unmet needs of women were slightly different compared to men. Future research focussing specifically on women with PD and women with YOPD is critical and would help meet some of these unmet needs.

There were strengths in this study in terms of recruiting a sample of participants who provided rich data and an in depth analysis, with contribution from several authors to ensure coherence, rigour and transparency (Yardley, 2007). However, a weakness was not having community engagement with those with YOPD. While Braun and Clarke (2022) caution against member checking per se (as this is not congruent with a reflexive thematic analysis approach), nonetheless, it would have be useful to have involved people with YOPD to help design the study (e.g. the interview topic guide) and to provide comment on the final themes from a lived experience perspective.

Considering the findings from this study, specifically, participants' experience of internal/external shame and anticipatory grief, future research should focus on interventions to support people with PD under 60 with these difficulties. Recent studies have indicated that CFT and ACT has been found to reduce psychological distress, including shame and self-criticism in those with chronic illnesses, including Crohn's disease, lupus, and ulcerative colitis (Carvalho et al., 2022) and other neurological conditions including stroke, TBI, dementia (Ashworth et al., 2015; Collins et al., 2018; Majumdar & Morris, 2019). Future research could examine the effectiveness of these therapies for people with YOPD under 60 struggling with shame. Findings also suggest people with YOPD struggle with anticipatory grief. There is limited research on individuals with chronic illness and their experience of anticipatory grief with studies mainly focusing on the experience of family members and carers. It would be beneficial for future research to examine anticipatory grief in individuals diagnosed with a life-altering diagnosis like PD.

Conclusion

This study investigated the emotional and social lived experiences of individuals diagnosed with YOPD, diagnosed under the age of 60. The study has provided unique insights into some of individuals' difficult day-to-day experiences and the distressing emotions that result from them. Findings from this study show that people with YOPD experience stigma, shame and anticipatory grief. This has implications for health care professionals regarding access to bespoke appropriate

psychological support for individuals living with YOPD. Furthermore, more awareness campaigns about PD and YOPD are needed to reduce stigma and enhance understanding of this condition. Future research should focus on appropriate interventions such as ACT and CFT to alleviate the psychological distress experienced by those living with YOPD. It is important that such insights are used to help inform interventions and strategies for those with YOPD who might require additional support.

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