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# Quality of life and living with Parkinson's disease: a qualitative exploration within an Irish context

Irene Cassidy<sup>1\*</sup>, Owen Doody<sup>1</sup>, Margaret Richardson<sup>2</sup> and Pauline Meskell<sup>1</sup>

## Abstract

**Background** Parkinson's disease is incurable, and the rate of progression varies meaning that people face a long future with an unpredictable condition that can significantly influence their quality of life. To date, much of the international research has focused on measuring and describing quality of life in Parkinson's from a quantitative perspective. Given its multidimensional nature, the present study aims to explore the concept using a qualitative approach so factors influencing self-reported quality of life can be understood in greater depth.

**Methods** Using a qualitative descriptive approach, people with Parkinson's disease who were survey participants in the first phase of a mixed methods study exploring factors influencing health-related quality of life were invited to participate in semi-structured interviews. Eighteen participants with high ( $n=6$ ), average ( $n=6$ ), and low ( $n=6$ ) health-related quality of life (PDQ-39 SI scores) were purposively invited to participate in this study. Audio recordings were transcribed and thematically analysed using Braun and Clarke's steps (familiarisation, generating initial codes, searching for themes, reviewing, defining, naming themes, and producing the report).

**Results** Thematic analysis revealed four overarching themes; 'Living an interrupted life,' 'Striving for 'I' in independence,' 'Unravelling identities, roles, and relationships' and 'Reconfiguring life'. These themes illuminated participants' experiences of living with Parkinson's disease and what influenced their overall quality of life.

**Conclusions** These findings add to the international literature by helping to achieve a deeper understanding of what it means to live with Parkinson's disease and how it influences quality of life. Participants experienced a range of fluctuating, and interconnected motor and non-motor symptoms. This finding draws attention to the impact of the often-unpredictable nature of the condition on the physical, functional, psychological, social, and spiritual dimensions of life. Quality of life was positively influenced by perceptions of independence and negative feelings of dependence. Being independent was associated with freedom to plan, autonomy of choice, and freedom from feeling stressed, strained, or fearful. Having a positive outlook, using problem-focused strategies, and participating in hobbies, holidays, work, and involvement in local community committees were perceived positively across interviews as accentuating social dimensions of life. Resourcing self-management strategies, advanced nursing roles, and developing personalised models of community support may assist healthcare professionals in meeting the unique needs of people with Parkinson's disease thereby supporting quality of life.

\*Correspondence:  
Irene Cassidy  
Irene.Cassidy@ul.ie

Full list of author information is available at the end of the article



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**Keywords** Parkinson disease, Quality of life, Experience, Qualitative

## Background

Globally, Parkinson's disease exemplifies a rapidly growing multifactorial neurodegenerative condition [1, 2] that is currently incurable with varying rates of progression [3, 4]. Ageing remains one of the most significant risk factors for developing Parkinson's [5]. These features mean that individuals can face a long future with an unpredictable condition that may significantly influence their quality of life [4, 6]. Research has highlighted challenges to maintaining personal equilibrium and self-concept and the need to preserve a stable identity, feel in control, and have a positive mindset [7, 8]. Additionally, self-caring challenges and fear of becoming disabled have also been described [9]. Augmenting quality of life for older people with Parkinson's disease requires multifaceted and multidisciplinary care input [10] that can provide symptom relief, care, and rehabilitation that meets the health care needs of the person, their family, and society [11, 12]. Hence, consideration of older adults' experiences of living with this condition and evaluating what influences their quality of life is significant for appraisal, service improvement, and provision of evidence-based health and social care resources [13, 14].

To date, much of the international research has focused on measuring and describing quality of life in Parkinson's disease from a quantitative perspective [15, 16]. Qualitative studies have been explored to a lesser extent. Older findings have shown that biopsychosocial factors, sense of autonomy, adaptation, communication, and social integration [17] along with interrelated factors connected with their health, interpersonal relationships, personalised care, communication, and society influence quality of life [18]. Investigating people's experiences in Ireland can add significantly to the current evidence, provide greater clarity to the meaning of quality of life, and offer a fuller and richer understanding of the impact of this condition on people's lives. This is paramount to inform evidence, healthcare policy, and practice so that healthcare professionals can respond effectively to influences shaping individuals' perceptions, goals, expectations, standards, and concerns.

## Methods

### Design

This paper presents a qualitative study exploring the experiences of men and women in Ireland living with Parkinson's disease and what influenced their quality of life. Using a qualitative descriptive approach, [19] survey participants in the first phase of a mixed methods study that explored factors influencing health-related quality of life [20] were invited to participate in a semi-structured

interview. The study is reported in line with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines [21] (Additional file 1).

### Sampling and recruitment/ participants and setting

A stratified purposive sampling approach was used to invite people with Parkinson's disease to describe their experiences of living with this condition and to explore in greater depth factors associated with high, average, and low self-reported health-related quality of life. To prepare for this approach, the PDQ-39 single index (SI) scores from all participants in the survey phase [20] were ordered from 0 to 72.76 and then divided into three groups. The initial fifty-eight scores ranged from 0 to 19.38 and represented people with higher health-related quality of life. The median score in this participant group was 12.81. The next fifty-seven PDQ-39 SI scores ranged from 19.69 to 37.29 and represented people with average health-related quality of life. The median score in this group was 27.42. The final fifty-eight of the 173 scores ranged from 37.4 to 72.76 and represented people with lower health-related quality of life. The median score in this participant group was 48.54.

In total,  $n=150$  survey respondents completed and returned an 'expression of interest' on their survey to participate in a follow-up semi-structured interview. These participants' scores were cross-checked against the median scores for people with high, average, and low self-reported health-related quality of life. A sample of survey participants ( $n=18$ ) who had completed an expression of interest to participate in a semi-structured interview and whose PDQ- SI scores centred on or near the median scores in each of the three groups were invited to participate in this study (high  $n=6$ , average  $n=6$ , and low  $n=6$  health-related quality of life). Equal numbers of men and women were invited to augment representativeness. There were no refusals to participate and no withdrawals from the study. Tailoring the sampling strategy offered a distinctive approach to reveal multifaceted, and multifactorial influences on quality of life for men and women with Parkinson's disease who had high, average, or low self-reported health-related quality of life.

Recruitment ceased at 18 participants (Additional file 2) when data sufficiency was reached. Participants chose their interview location; participants' homes ( $n=11$ ), nursing home ( $n=1$ ), hotels ( $n=2$ ), and university venues ( $n=4$ ). Data was collected using one-to-one, face-to-face semi-structured interviews except on one occasion where a primary carer was present. They contributed to the interview by supporting the participant to communicate their experiences of e.g. altered balance, falls, and

medication dosages along with offering their perspective on the value of the nurse specialist and the Parkinson's support group. The interview guide was developed by the research team in collaboration with three Parkinson's disease/Movement disorder nurse specialists to support content validity (Additional file 3). Following the pilot interview, reflections identified the need to include an additional question in the semi-structured interview guide related to the influence of work/roles and participation on quality of life.

Data was collected within a PhD study. The researcher (IC) was a nursing educator with a specific interest in Parkinson's care and was experienced in qualitative interviewing. Each participant was interviewed at one point in time and the interviews varied from thirty to fifty minutes but lasted on average forty-five minutes. Interviews were audiorecorded and typically opened with broad questions to ease participants into conversation e.g. 'Tell me your experiences of living with Parkinson's' and 'Can you share with me what you feel influences your quality of life?'. The researcher's role also entailed listening, responding, and introducing interview guide questions, prompts and probes to allow participants to expand on their experiences (Additional file 3). Following each interview, field notes and reflections on participant data were recorded (IC) as introspective processes of becoming aware. Reflections captured the 'context of reflection,' 'trigger for reflexivity,' 'researcher thinking,' and 'outcomes of reflexivity' [22].

Interviews were analysed inductively using thematic analysis [23]. Analysis was supported using NVivo 11.0. Interview recordings were transcribed verbatim, initially pseudonymised, and verified for accuracy by reading transcriptions and listening to recordings concurrently. Member checking was achieved by requesting a selection of participants ( $n=6$ ) to check their interview transcripts

for accuracy, interpretation, and completeness. One participant requested some minor changes to reflect changed life circumstances. Following member checking all transcripts were then anonymised. The principal investigator (IC) undertook coding of each interview transcript. Codes were generated from each interview transcript while simultaneously listening to each recording. Codes were then cross-checked and reviewed to ensure that coding for each interview was inclusive, thorough, and systematic. The final codes ( $n=304$ ) were stored under an open coding folder in NVivo. Data collated for each code were reviewed by the research team to identify similarities and overlap between codes. Where researcher interpretations varied, discussion and reflection enhanced insight into the meaning behind data until subthemes and themes were refined and crafted by the research team (IC, PM, OD). Consistent with an interpretive lens that recognises researcher subjectivity in data interpretation, thirteen subthemes were developed which amalgamated to form four overarching themes (Fig. 1 Additional file 4).

#### Ethics

Ethical approval was granted by the University Hospital Research Ethics Committee. There was no formal caring relationship between participants and the researcher (IC) who recruited, collected, and analysed participant data before or after the study. Participants were informed of the nature of the study, the researcher's responsibilities, and their right to decline to partake in the study or withdraw at any time without risk of incurring penalties or prejudicial treatment. Participants were also given the contact details of a nurse specialist if they felt they needed additional support. The right to full disclosure ensured that individuals received information outlining

#### Living an interrupted life

Visible intrusions  
Hidden invasions  
Unexpected interruptions

#### Striving for 'I' in independence

Cherishing independence  
Balancing medication effects/side-effects  
In the system  
Being informed

### Quality of Life and Living with Parkinson's disease

#### Unravelling identities, roles, and relationships

Unravelling identities  
Viewpoints and representations of Parkinson's  
Occupiers and outliers  
Reflections on roles, relationships

#### Reconfiguring life

Tackling Parkinson's  
Making connections

**Fig. 1** Four overarching themes with related candidate themes

the type of study, and likely risks and benefits; all participants provided their written informed consent.

## Findings

### Participant demographics

An equal number of men ( $n=9$ ) and women ( $n=9$ ) participated in the study. The age and years since diagnosis categories for all eighteen participants and each of the health-related quality of life groups (high, average, low) are included in Additional file 2. Depression symptomology data revealed that all those with high health-related quality of life reported normal/no depression symptomology while those with low health-related quality of life reported normal/no depression symptomology ( $n=1$ ), mild ( $n=2$ ), moderate ( $n=2$ ), and severe depression symptoms ( $n=1$ ). (Additional file 2).

### Overarching themes

Through thematic analysis, thirteen subthemes were identified, and these were hierarchically connected to four overarching themes namely, 'Living an interrupted life,' 'Unravelling identities, roles and relationships,' 'Striving for 'I' in independence,' and 'Reconfiguring life' (Fig. 1).

### Living an interrupted life

'Living an interrupted life' represented experiences from all eighteen participants that life with Parkinson's disease was punctuated with interruptions, which influenced quality of life daily. This theme contained three subthemes, 'Visible intrusions,' 'Hidden invasions,' and 'Unexpected interruptions.'

For participants in the high health-related quality of life group, motor fluctuations typically included slowed movement, joint stiffness, or feeling 'stumbly.' Participants with average health-related quality of life reported additional fluctuations including freezing of gait and altered balance. For those in the low health-related quality of life group, motor fluctuations also included freezing, difficulty standing/walking that often resulted in falls.

Freezing episodes were described as "just a weird sensation" or a "shutdown" (P16), where "...the mind, everything isn't coordinating together" (P17), or being "stuck to the ground" (P14). For some, unpredictability resulted in powerlessness, not feeling in control of self during 'freezing' interruptions, or embarrassment, particularly in social situations where "... you feel everyone is looking at you" (P11). Interruptions to life in the guise of fluctuations in functioning or "the way of Parkinson's" (P1), impacted ability to plan, reducing control and perceived quality of life.

The impact of fluctuations on functioning was perceived as less intense for participants with higher

self-reported health-related quality of life such as "there are days when I drop things and I'm frustrated; I can't open a button or something silly like that" (P2). Whereas for a person with lower health-related quality of life, their experience of a freezing episode resulted in symptoms being misinterpreted as "I'm not drunk but I've a medical disorder" (P11). Fluctuations meant that individuals could transform between different states of functioning throughout the day. Metaphorically it was compared with "a light switch you turn on and off. It's scary" (P13). For several participants, the morning, or times when medication was wearing off were the worst part of their day.

Interruptions to conversation or dialogue influenced engagement with others "Interacting with other people my voice goes lower" (P4). As voice becomes affected, people can withdraw from group conversation as they may feel they are not articulating themselves clearly. This may create a sense of isolation leading to situations where,

*"I don't like going out in public anymore because my speech is gone very bad" (P16).*

Participants reported that sleep and tiredness were problematic and acted as considerable disruptions to life. However, interruption to sleep often stemmed from other hidden problems such as pain and restless legs, highlighting the interconnectedness of non-motor symptoms; one symptom triggering another symptom resulting in a 'chain' or 'pain' reaction. Invariably these resulted in unpredictable disturbances to what should be otherwise routine activities, stopping the person in their tracks and disrupting life.

Only one participant relayed the impact of Parkinson's disease on sexuality. This individual indicated that their outgoing personality assisted them in availing of clinic appointments to divulge sexual issues. However, they felt that religious influences in Ireland, embarrassment, fear of being labelled a "dirty old man" or general hesitancy in discussing sexual issues, still joined forces to cause many people to suffer "in the darkness" (P7). Non-motor symptoms were described as 'hugely intrusive,' and 'tortuous' (P1). Rather than being a long-term condition affecting bodily movement, the condition "...affects everything in your body" (P7), and "I think it makes everyone depressed" (P13). The significance of hidden symptoms on spiritual dimensions of life was also emphasised, "I suppose they're not life-threatening but they're spirit-threatening" (P1).

### Striving for 'I' in independence

This theme represented the person (as in 'I') pursuing or seeking an identity encapsulating independence. Four subthemes contributed to this theme, 'Cherishing

independence,' 'Balancing medication effects/side-effects,' 'In the system,' and 'Being informed.'

Good quality of life related to "being independent" (P13), or "To me, quality of life starts and finishes there, [independence]" (P11). Being independent entailed freedom to plan, autonomy of choice, and freedom from feeling stressed, strained, fearful of feeling like a burden to family. Conversely, fading independence conveyed a complex array of losses, including social freedom and independent travel "Oh, I can walk around the house I can, but I wouldn't be able to go to town now on my own" (P12). Another participant with low health-related quality of life stated,

*"My own independence is gone...Like, what is independence – to be able to go when you want to, to do what you want to do. So, if you can't do that ... I don't like to be dependent"* (P18).

Medication was pivotal to comfort, and retaining a sense of self, "they keep the shaking and the whole lot to a minimum, at least you can fit in as a normal person..." (P9). Concerns around medication, related not just to side effects, but to taking multiple daily tablets "...sometimes the cure is worse than the disease" (P1), or "Oh gosh I'm taking too many tablets" (P15). Hence, preserving independence demanded organisation, responsibility, and diligence to follow up on frequent dose schedules.

Being in the health system and having a patient identity brings an inevitable need to interact with a myriad of healthcare professionals such as neurologists, consultant geriatricians, and allied therapists (physiotherapists, speech and language therapists, occupational therapists, nurse specialists, and general practitioners). Receiving encouraging comments and linking with practitioners who could refer to related therapies was valued for helping participants settle into life with Parkinson's disease.

*"I've got great confidence in the neurologist"* (P2).  
*"The physio and OT, they'll listen to you, and they'll advise you on whatever"* (P15).

Participants seemed to appreciate emotional support provided by Parkinson's nurse specialists, including additional support during times of hospitalisation, "I called on [nurse specialist] and she came and helped me and gave me some moral support, that was great" (P10). Overall, participants perceived the nurse specialist as knowledgeable and 'tuned into' (P6) the whole person.

The importance of community health services was highlighted to 'keep [people] out of nursing homes and to keep them at home' (P18). While structures were identified for personal health care needs, deficiencies in home-based social care supports were highlighted as a barrier

to supporting independence and citizenship within local communities. One participant suggested that it would be of greater benefit if the form of support from community services reflected individual needs, rather than a one size fits all approach.

*"I didn't see any point in somebody coming in and helping me shower when I was able to do it myself. By doing the shower for me, it was making me less independent. What I was looking for was somebody to go with me, to do the shopping, but they don't do that"* (P17).

### **Unravelling identities, roles, and relationships**

Living with Parkinson's disease was a life-changing journey that involved unravelling many identities, roles, and relationships that influenced quality of life and was formed by the subthemes, 'Unravelling identities,' 'Viewpoints and representations of Parkinson's,' 'Occupiers and outliers' and 'Reflections on roles, relationships.'

For people with good health-related quality of life or those in earlier stages, being able to dissociate from the condition to some degree, was facilitated by having minimal outward features. For others, ignoring they had it was a means of adapting and coping with the diagnosis, which facilitated escape and detachment. Having a 'label' was viewed positively by one participant.

*"It was good to get a name for it, it has an identity, and you just say you have Parkinson's and that's it"* (P8).

Nevertheless, the condition contributed to only one aspect of identity; people were more than patients. For another participant, 'Parky' (P7) was a named identity or force separate from the person's 'true' identity, who invaded their life, controlled them, and caused havoc "You'd swear there was somebody inside in your head pulling the switches" (P7). Contrastingly, "when you feel good, Parkinson's is over here you don't need it, it isn't controlling you" (P16).

One participant with high health-related quality of life was clear that the condition was 'not as bad' as what the label portrayed (P2). This participant aspired to remain 'ordinary' and retain normality. However, another participant with low health-related quality of life recounted occasions where interfacing with others caused feelings of discomfort and categorisation, "you find people are staring at you when you go shopping" (P17).

Participants seemed to affiliate with and occupy 'groups' they self-categorised themselves as belonging to. Interestingly, participants i.e., P2 and P3 who had better health-related quality of life seemed to embrace

(non-Parkinson's) groups. Participants identified with Parkinson's-specific groups (e.g., local support groups and specific therapy groups) and membership if they offered a source of needed knowledge, expertise, or network opportunities. 'Mental categorisation' provided a basis for defining if a group was relevant. Categorisation was primarily influenced by appearances and perceived severity of existing group members' health as in, "there are different grades of it you'd notice that inside at the meetings" (P15). Hence, some participants whose stage was milder remained 'outliers' from support groups and spoke in terms of differentiating self-identities from existing group members.

*"I probably don't think I'm old enough or frail enough to join" (P2).*

Participants with different health-related quality of life scores (high, average, and low) used adjectives like 'scary' (P10) when they witnessed another person in a more advanced stage. This event created fears of what their future and future identities might hold.

*"If I saw somebody with advanced Parkinson's disease, I would avoid that ..., that's my coping skill" (P6).*

Participants including those with poorer health-related quality of life discussed loss of previous functioning, roles, and increased social isolation. Underlying fears about deteriorating health grounded perceived quality of life within a physical health agenda.

*"Parkinson's itself is creeping up on me. I've fallen down the stairs. I don't like going out in public anymore because my speech is gone bad" (P16).*

Changing roles from carer to being cared for and feeling like "... I'm a burden" (P15), along with changing partner roles were perceived as affecting life quality. Moreover, reduced activity or independence to travel outside the home creates a negative spiral where people become self-conscious, retreat further into themselves, become uneasy in social situations, or become "...a bit slow on ...linking in" (P9). Isolation creates uneasiness, presenting another vicious circle where nervousness results in further isolation from engagement in social situations because,

*"... if we're in this environment [home] 7 days a week, 24 hours a day and not meeting [others] ... you do go further and further back [into yourself]" (P18).*

### Reconfiguring life

Reconfiguring life was presented as a non-linear process of confronting, adjusting, and reshaping life with Parkinson's. This theme contained two subthemes, 'Tackling Parkinson's' and 'Making Connections.'

Tackling Parkinson's meant adopting an outlook imbued with, "positivity and good mental attitude" (P2). Positivity was an active rather than passive process stemming from conscious efforts to put the bright side out, "I think I have come to terms with it. But it was all adopting a positive attitude to it" (P8). Taking the positives from life, rationalising that there were more serious conditions, and recognising abilities rather than debilities, "I have a good quality of life outside of it [Parkinson's disease]" was also highlighted (P7). Remarkably, one participant (P14) who recorded only average health-related quality of life scores felt they had good quality of life highlighting inadequacies in health-related tools in evaluating global quality of life.

Confronting Parkinson's head-on, meant finding a purpose, acknowledging restrictions imposed on life, and working around these to move forward, "since I have faced up to it and turned my life around and said I have Parkinson's, that's just it. Parkinson's on board!" (P8).

Adjusting to life changes extended to accomplishing new ventures, challenging oneself, and moving forward. It also meant pursuing passions or pastimes, beginning new ventures, continuing previous interests, and blending old and new identities. Participants' accounts of hobbies and holidays demonstrated enthusiasm for life and learning. While this was described across groups, it was more frequently cited by participants diagnosed less than 6 years, with normal or mild depression symptomology and good or average health-related quality of life.

*"I'm with the drama group... cycling... you make lots of friends and I suppose it's the camaraderie of it" (P3).*

However, pursuing interests wasn't easy for all participants "because you wouldn't have the strength to do anything" (P17), may feel hesitant to link in with others (P9) or may experience diminishing confidence.

*"... one of the things people lose is confidence... you go back into yourself ... you do feel you've lost your value" (P18).*

Participants shared innovative and meaningful rituals they used to manage everyday life, which incorporated personal ways of knowing. These ranged from shaking holy water on their bed to prevent nightmares (P17), to doing "my five times tables in my head..." to divert attention from a shaking hand (P7) or getting up "...an hour

earlier” (P13) to reduce stress. Adapting and reconfiguring wasn’t easy for all participants, particularly those with poorer health-related quality of life, “I can’t go up the stairs and that kills me” (P15). Another participant who was “very house-proud” (P15), found it extremely difficult to cope with not being able to participate in housework. Being positive and wishing to get on with life wasn’t a stable attribute; it was sometimes hard to relinquish control, as it’s hard to be balanced all the time (P1).

Tackling Parkinson’s required mental strength and resilience to take on a challenge and battle to win out and beat ‘Parky’ (P7), using problem-solving approaches in the face of adversity. Participant emphasis on words ‘have to’ implied that rather than mental strength being optional or occasionally added-on, it was a daily requirement reinforcing the importance of mental health and well-being to reconfigure and adapt. Being in control and not letting the condition take over personhood was imperative to good quality of life, summed up by,

*“I might have Parkinson’s, but it doesn’t have me”  
(P11).*

In response to ‘What you think improves your quality of life,’ one participant answered, “Well, I think participating” (P8). Building group involvement around specific activities can have beneficial spin-off effects, including augmenting social dimensions of life. What was particularly striking was participant involvement in community life, for example, active engagement in reclaiming local history and community committees, with the sentiment being to “Get out there and mix with the people” (P7). One participant summed up the importance of making connections, “It’s the whole social aspect of it..., chatting away to people, it’s brilliant” (P2). Having purpose meant that participants didn’t define their lives solely through this neurological condition but through engagement in leisure activities or work as it is “very important for people to join things and have their own life” (P2).

Barriers to connecting were evident and wide-ranging, including transportation issues, psychological impediments, physical effects of Parkinson’s like freezing, altered gait, and difficulty doing activities. These barriers reflect the complex range of factors, including physical, functional, psychological, environmental, and social influencing quality of life.

*“When I’m among crowds ...I have to keep an eye on myself just so that I wouldn’t be pushed over” (P5).*

## Discussion

A key finding from this study was the fluctuating, unpredictable, and intrusive nature of Parkinson’s disease and how it influenced quality of life, particularly for those with lower health-related quality of life. Previous evidence [24] has highlighted how the fluctuating, unpredictable nature of the condition leads to activity curtailment adversely impacting people’s lived experience. Participants reported that freezing episodes affected mobility, movement predictability, and ability to plan. Internationally, the occurrence of freezing of gait is recognised as intrusive, impacting life quality [25–28]. With freezing, falls or psychosocial effects, such as fear, anxiety, embarrassment, vulnerability, and inability to undertake social roles may impact daily living [29]. This finding has clinical relevance for nurses and healthcare professionals and underscores the importance of undertaking individualised assessments and managing interconnections between freezing of gait and other symptoms [30] to reduce their intrusiveness on perceived quality of life.

In this study, the intrusiveness of ‘hidden’ non-motor symptoms was discussed not only by their physical threat or distress to daily living but also by their psychological, social, and spiritual impact. The broader research reinforces findings from this study that these symptoms can also extend beyond mere health-related effects and encroach into broader realms of quality of life [31, 32] highlighting for health care professionals and researchers the inadequacies of health-related tools in evaluating the everyday impact of Parkinson’s disease [20]. Encouraging people with Parkinson’s to complete a straightforward tool like the NMSQuest [33, 34], a patient diary [35], consultation aid [36], or home-based self-management interventions such as smartphone-based text messaging and information [37] can be effective methods of detecting problems influencing quality of life and emphasise the importance of health care professionals empowering people with Parkinson’s to be active participants in their care. For multidisciplinary teams, fostering choice about consultations such as who attends, what is discussed [38, 39], and how they are facilitated can encourage people to report sensitive non-motor symptoms. Hence, independent factors influencing quality of life can be revealed, and comprehensive multidisciplinary interventions incorporating holistic care can be devised [40–44].

All participants with poorer health-related quality of life discussed loss of previous functioning, roles, and increased social isolation. This resonates with the wider literature where fear of becoming disabled is a primary concern [9]. Access to exercise-based rehabilitative interventions and multidisciplinary team input (nursing, physiotherapy, occupational therapy, speech, and language therapy, GP, and neurologist) were recognised

as important to moderate the impact of the condition, maintain function, support independence, well-being, and quality of life. Within this, nurse specialists were valued for their accessibility, holistic perspectives, and generalised guidance. In the wider literature, Wright [45] asserts that nurse specialists play a crucial role in evaluating patients throughout the disease trajectory, from diagnosis to the complex stages of palliative and end-of-life care. Their remit incorporates care of patients with complex therapies, continuity of care, specialised clinics, education, counselling, advocacy, and multidisciplinary collaboration [46–49]. However, recent findings from a national survey on experiences of health service access and use in Ireland found that only 20.7% ( $n=290$ ) of participants reported having access to a Parkinson's nurse specialist [50]. Indeed, access to specialised nursing and continuing contact with a nurse specialist is a key recommendation [49]. Given the drive to use mechanisms and processes to deliver safe and effective healthcare at the lowest level of complexity [51], it is imperative that health policy and service planning, prioritise the resourcing of specialist and advanced community nursing roles to enhance the health and social care needs of people with Parkinson's disease within their community.

In this study, qualitative data suggested that increasing dependency or care needs often necessitated more formal community care support. Living at home is the preferred choice for many older people with research and policy documents in Ireland supporting the importance of community or home-based care [52, 53]. Bolenius et al. [54] stated that older adults living at home with support from home care services have better quality of life if their care and service needs are met. For some participants in this study, formal supports like home help, which typically involve 'doing for' the person, were perceived as jeopardising independence; devoted help being disabling rather than enabling. Von Heideken-Wägert et al. [55] also raised this point in that as far as home help was considered a 'helping hand,' it was also potentially inhibiting. Barken [56] also highlighted that valuing the involvement of older people with disabilities in their care muddies dichotomous understandings of independence as capacity to do things for oneself and dependence as the need for help. According to Tracy and Robles [57], altercasting an individual as helpless or ill often takes the way of others providing "excessive" help, which may impinge on an independent identity. Thus, like Wilde and Glendinning's [58] findings on home care re-ablement services, understanding individuals' and carers' priorities for recovery and daily living is fundamental to successfully regaining skills, confidence, and independence for people with Parkinson's disease.

In Ireland, the long-term vision for health and social care and the direction of health policy recommends

increasing community homecare provision [51]. Browne [52] proposed that for older people in Ireland, the 'money follows the person' principle needs to be extended to all services and funding provided on an individualised basis so interventions can be personalised to individuals' current and changing needs. From a health policy perspective, this requires a commitment to change focus, from a biomedical to a needs-based approach to understand the impact of living with Parkinson's and enable more person-centred care and outcomes [59].

In this study, participating in hobbies, holidays, and involvement in local community committees was perceived positively across interviews as accentuating social dimensions of life. Similarly, enthusiasm and fulfilment from active engagement in community committees and being part of interest 'groups' were highlighted. Qualitative data showed that participants with good or average health-related-quality of life, no or mild depression symptomology, and those diagnosed for shorter timeframes (i.e., 1–6 years) more frequently described pursuing activities. Hence, the importance of anticipating the impact of perceived health-related quality of life, depression symptomology, and length of time diagnosed on activity engagement and overall quality of life. Even if physical health becomes poor, evidence suggests that quality of life can often remain high if individuals find value and enjoyment in other dimensions of life [13]. For healthcare professionals, this raises the challenge of how best to promote activity and community engagement in people with Parkinson's disease who have been living with the condition for prolonged timeframes while also experiencing declining health.

Language is a powerful tool to influence how society and culture construct disabilities [60]. Findings from this study also illuminated determination and commitment to tackle the effects of Parkinson's disease and the importance of not letting this get in the way of everyday living. In this study, one participant (good health-related quality of life), used creative and innovative emotion-confronting skills and determination by personifying the condition as 'Parky,' an intruder to be battled. Personification can change an event or situation from an external hindrance into an internal sense of purpose and meaning [61]. Having a sense of focus and fortitude may help cultivate a sense of mastery or control for living with the condition [62]. What was particularly interesting was the can-do attitude, which from a societal agenda, underlines the importance of health-care professionals in partnership with people living with Parkinson's disease challenging discourse to draw more considerable attention to abilities rather than disabilities.

The study did not primarily seek to compare perceived quality of life between people with differing health-related quality of life scores. Nonetheless, inviting a



stratified sample of men and women with high, average, and low health-related quality of life [20] offered a distinctive and representative approach to reveal multifaceted, and multifactorial influences on quality of life for men and women with Parkinson's disease. It is recommended that future research focuses on developing an instrument that embraces wider dimensions of life quality and the everyday impact of Parkinson's disease to overcome inadequacies in health-related quality of life instruments [20]. Empowering individuals to self-monitor for the presence and impact of non-motor symptoms along with promoting choice on follow-up consultations may assist with reporting and follow-up of these symptoms. A 'personalised' community support model that addresses not just physical dimensions of health, but also social dimensions is recommended to promote independence. Additionally, resourcing advanced nursing roles may assist healthcare teams in meeting the needs of people with Parkinson's disease thereby promoting independence and supporting overall quality of life.

This research was conducted in one area of Ireland; hence participants' experiences are specific to an Irish context and a limitation of this study is that the findings may not reflect the entire population of people living with Parkinson's disease. Furthermore, including data on cognitive status, stage, and severity of Parkinson's may have shaped the research findings by furthering insight and analysis of participant perspectives.

## Conclusions

This study explored the experiences of people with Parkinson's with high, average, and low health-related quality of life around what it means to live with this condition and how it influenced their perceived quality of life. While all participants experienced fluctuating and unpredictable symptoms, participants with lower health-related quality of life reported more concerns relating to mobility and non-motor symptoms including anxiety and depression. Encouraging self-monitoring may empower individuals to increase help-seeking intentions thereby supporting self-management and independence. Quality of life was positively influenced by perceptions of independence and negatively by feelings of dependence. Being independent was associated with freedom to plan, autonomy of choice, and freedom from feeling stressed, strained, or fearful. Funding self-management strategies, advanced nursing roles, and personalised community care models, may assist healthcare professionals in meeting the goals, expectations, standards, and concerns of people with Parkinson's disease.

Having a positive outlook, using problem-focused strategies, and participating in hobbies, holidays, work, and involvement in local community committees were perceived positively across interviews as accentuating

social dimensions of quality of life. Consequently, healthcare professionals should capture opportunities to support individuals to engage with valued groups and activities, thereby promoting community engagement and contributing to life quality.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12883-024-03769-y>.

Supplementary Material: Additional File 1: COREQ guidelines

Supplementary Material: Additional File 2: Participant demographics

Supplementary Material: Additional File 3: Interview guide

Supplementary Material: Additional File 4: Thematic tree

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## Author contributions

Authors' contributions: IC designed the study, she conducted the interviews, coded, and analysed the data and she led the writing of the manuscript. OD provided feedback throughout and assisted with the writing of the manuscript. MR provided feedback on the writing of the manuscript. PM contributed to the study design and provided feedback throughout.

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## Data availability

Availability of Data: The data that support the findings of this study is not openly available due to reasons of sensitivity but may be available from the corresponding author upon reasonable request. Data is in controlled access data storage at the University of Limerick.

## Declarations

### Ethics approval and consent to participate

The study was conducted according to the guidelines of the Declaration of Helsinki. The research protocol was approved by the University Hospital Research Ethics Committee, Limerick, Ireland which also provided approval to undertake the research. This approval was based on ethical principles including beneficence/non-maleficence, justice, and autonomy. Consistent with ethical standards, participants were informed of the nature of the study, the researcher's responsibilities, and their right to decline to partake in the study or withdraw at any time without risk of incurring penalties or prejudicial treatment. All participants provided informed, written consent to participate in the interviews. Research methods were conducted with reference to relevant regulations and study reporting was informed by COREQ guidelines (Additional file 1).

### Consent for publication

Is not required as all participants are unidentified and there are no individual details reported within the manuscript.

### Competing interests

The authors declare no competing interests.

## Author details

<sup>1</sup>Department of Nursing and Midwifery, Faculty of Education and Health Sciences, Health Research Institute, Ageing Research Centre, University of Limerick, Limerick, Ireland

<sup>2</sup>University Hospital Limerick, Limerick, Ireland

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