Exploring Factors That Influence Hrqol For People Living With Parkinson's In One Region Of Ireland; A Cross Sectional Study

Irene Cassidy (✉ irene.cassidy@ul.ie)

University of Limerick

Owen Doody

University of Limerick

Pauline Meskell

University of Limerick

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Abstract

Background: The diversity of symptoms associated with Parkinson's and their impact on functioning have led to an increased interest in exploring factors that impact Health-Related Quality of Life (HRQoL). Although the experience of Parkinson's is unique, some symptoms have a greater impact than others, e.g. depression. Moreover, as the risk of Parkinson's increases with age, the financial and public health impact of this condition is likely to increase with the growing aging population. In Ireland, research is ongoing in the pursuit of causes and effective treatments for Parkinson's; however, its impact on everyday living, functioning and HRQoL is largely under examined. This study aims to describe factors that influence HRQoL for people with Parkinson's (PwP) in one region of Ireland.

Methods: A cross-sectional postal survey was conducted of people (n=208) with Parkinson's in one region of Ireland. This survey included socio-demographic questions, Nonmotor Symptoms Questionnaire for Parkinson's disease (NMSQuest), the Geriatric Depression Scale (GDS-15) and the Parkinson's disease Questionnaire (PDQ-39). Descriptive and inferential statistics were conducted using SPSS, IBM version 25 (SPSS Inc., Chicago, IL, USA).

Results: Participants reflected a predominantly older population who were married and lived in their own home (91%). Participants diagnosed the longest reported poorer HRQoL regarding mobility, activities of daily living, emotional wellbeing, social support, cognition, and communication domains and overall HRQoL. Lower HRQoL correlated with higher depression scores $p \leq 0.001$ and participants in the lower HRQoL cohort experienced 2.25 times more non-motor symptoms (NMSs) than participants with higher HRQoL. Hierarchical multiple linear regression analysis predicted Geriatric Depression Scale (GDS 15) score, non-motor symptom burden, and years since diagnosis to negatively impact HRQoL. Principal component analysis also indicated that for the population in this study, components measuring 1) independence/dependence 2) stigma 3) emotional wellbeing and 4) pain were central to explaining core aspects of participants' HRQoL.

Conclusions: Findings help to achieve a deeper understanding of the effects of Parkinson's symptoms in Ireland, and direct future research priorities to identify interventions required to support people and improve their HRQoL. This study includes data on HRQoL influences and a conceptual person-centred guide for nurses and healthcare professionals in supporting care and QoL for people living with Parkinson's.

Background

Parkinsonism is a complex range of symptoms used to describe the motor features of resting tremor, bradykinesia, and muscular rigidity [1], [2]. The incidence of Parkinson's is approximately 1.5 times higher in men compared with women [3] with delayed onset in women is credited to neuroprotective effects of oestrogen on the nigrostriatal dopaminergic system [2]. Parkinson's is the second most common multifactorial neurodegenerative disorder after dementia [3], with an estimated 6.1 million people worldwide living with Parkinson's [4]. In Ireland, the incidence is 1-2:1,000 of the general population and 1:100 in those over 80. With a population 4,761,865 [5] there is an estimated 12,000 people living with Parkinson's in Ireland [6].

Idiopathic or classic Parkinson's is the most common form of Parkinsonism, which is a slowly progressive neurodegenerative condition [7]. Parkinson's pathology includes not only dopaminergic cells but also cholinergic, noradrenergic, serotonergic, histaminergic, and glutaminergic cells, explaining the wide clinical spectrum of features associated with the condition [8]. Consequently, Parkinson's can result in progressive disability characterised by motor and nonmotor features [2] that have significant impact on health [9]. Motor symptoms include shuffling gait and gait fenestration [1], facial masking, dysphagia [10], [11], poor balance, and stooped posture [12]. Furthermore,

difficulty standing and turning, freezing (brief inability to move) [13], 'off periods' [14] and speech that is low, slow, or difficult to understand [15] along with small handwriting are additional motor symptoms [1]. The clinical spectrum of Parkinson's is much broader than a classical movement disorder. It encompasses many non-motor impairments like depression, sleep disturbances, anxiety, dementia, pain, constipation, sexual and urinary dysfunction [16], [17]. These non-motor symptoms are extremely prevalent and often present before the onset of motor symptoms [18].

Ageing remains one of the most significant risk factors for developing Parkinson's [19]. As more people are living into old age, the overall number of people living with Parkinson's is also set to rise. European estimates have predicted that Parkinson's will double by 2030, primarily due to ageing populations [20], [4]. Living longer poses challenges for planning and providing health services [21], including living with chronic illness, isolation, cognitive loss, financial hardship, and presents a challenge for policymakers, society, service-delivery, and families. Consequently, health care professionals including nurses need to accommodate expected age-related changes, comorbidities, effects of long-term medication, possible cognitive decline, and caregiver support when leading and managing the care of people with Parkinson's [22]. Given that the complex interplay of factors influencing HRQoL in Parkinson's predominantly occurs within the context of advancing age, it also strengthens the importance of planning for and delivering multifaceted interdisciplinary care to meet these individuals' health care needs.

HRQoL normally indicates not only the influence of disease and treatment on disability and daily functioning but also the influence of perceived health on an individual's capability to live a satisfying life [23], [24]. HRQoL is a broad, multidimensional concept that includes symptoms of disease or a health condition, treatment side effects, and functional status across physical, social, and mental health life domains [25]. Critical aspects of HRQoL are physical and sensory functioning, agility, cognition, pain, emotional and psychological wellbeing i.e., "all within the skin", making it a multifaceted dynamic concept [26]. HRQoL evaluation helps us to understand a person's condition, identify the main issues affecting HRQoL deterioration, and determine individual needs and priorities [23] to guide health care management decisions. Research findings have shown the impact of symptoms and predictors on HRQoL for PwP [27]. These findings have included exploration of issues associated with a decreased HRQoL [28]. For example, the specific impact of NMSs on HRQoL [29], impact of stigma [30] multidisciplinary care [31] and excessive daytime sleepiness [32] on HRQoL. From a nursing perspective, understanding key factors influencing HRQoL can focus assessments and support interventions to reduce the negative impact of this chronic debilitating condition [33].

Methods

Aim and objectives

To explore HRQoL for people living with Parkinson's in one region of Ireland. This understanding is important to inform health policy, practice, education, and research so health care professionals in Ireland and internationally can respond effectively using person-centred approaches to support and care for PwP. The study objectives were to; i) describe demographic characteristics ii) describe types and frequencies of NMSs, iii) investigate reported depression symptomology, iv) examine baseline HRQoL data (PDQ-39 scale), v) explore associations between socio-demographic variables, NMSs, depression symptomology and perceived HRQoL and vi) examine factors influencing HRQoL scores.

Design

This research was part of a larger mixed methods study exploring QoL and living with Parkinson's. A cross-sectional postal survey design using a self-reporting 91-item questionnaire across four scales. Scale one demographics 7 items consisted of gender, age, marital status, time since diagnosis, living arrangements e.g., where participants lived, whom participants lived with and their sources of support. Scale two the NMSQuest consisted of 30-items focused on participants' accounts of non-motor symptoms with yes/no responses to each question [34], [35]. Scale three GDS-15 [36] was used to draw attention to the presence of depression symptomology [37]. The GDS-15 frames 15 questions within the past week and responses require a yes/no answer. Cut off scores used for this study reflect suggestions of 0-4 as normal or no clinical concern, 5-8 mild depression symptomology, 9-11 moderate, and 12-15 severe depression symptomology [36]. The fourth scale, PDQ-39 is a disease-specific, self-reporting HRQoL questionnaire designed to assess aspects of functioning and wellbeing adversely affected by Parkinson's [38]. PDQ-39 is composed of 39 items across eight subscales/domains, including: mobility, activities of daily living, emotional wellbeing, and stigma, social support, cognition, communication, and bodily discomfort [38] and has tested strongly psychometrically [39]. The University Hospital Limerick Research Ethics Committee, provided approval to undertake the survey.

Participants and setting

A purposive sample of the total population (n=358) of PwP accessing a neurological service at a model 4 hospital diagnosed with idiopathic Parkinson's in one region of Ireland were invited to participate and a response rate of 58% (n=208) was achieved. Model 4 hospitals provide 24-hour care 7 days a week for acute surgery, acute medicine, critical care, tertiary care, and bidirectional care between surrounding model 1, 2, and 3 hospitals [40] including inpatient/outpatient neurology services. Reasons for nonresponse included noncoverage (members of the population not included as limited to one region), item nonresponse or partial nonresponse (missing data). Data was collected within a PhD study completed in 2020.

Statistical methods

Data were analysed using data analysis software, Statistical Package for the Social Sciences (SPSS), IBM version 25 (SPSS Inc., Chicago, IL, USA). Descriptive analyses summarised responses to demographic, non-motor symptoms, depression and PDQ-39 questions. Non-parametric inferential statistics (e.g. Chi-square, Mann Whitney-U, Kruskal-Wallis H, and Spearman's) were used for positively skewed data [41, 42]. Analysis also included odds, principal component analysis (PCA) and hierarchical multiple linear regression.

Results

Demographics

Three hundred and fifty eight PwP were invited and 208 returned surveys (response rate of 58.1%). Of the respondents, 61.5% (n = 128) were men and 38.5% (n = 80) were women, 89.9% (n = 187) were over 60 years and 95.2% (n = 197) were diagnosed 2 years or longer. Over 72% (n = 150) were married, 70.7% (n = 147) lived with their spouse and 90.9% (n = 189) lived in their own home. Mean rankings indicated husband, wife, or partner as the most important source of support (mean rank 3.34) (Table 1, Table 2).

Table 1
Demographics

Variable	Frequency %	n (total n = 208)	Variable	Frequency %	n (total n = 208)
Gender			Marital Status		
Male	61.5	128	Married	72.1	150
Female	38.5	80	Widowed	14.9	31
			Divorced	2.4	5
			Separated	3.4	7
			Single	7.2	15
Age Category			Who - usually live with?		
20 or under	0	0	Spouse	70.7	147
21–30	0	0	Alone	17.8	37
31–40	0.5	1	Daughter	1.4	3
41–50	0.5	1	Son	2.9	6
52–60	9.1	19	Relative	1.4	3
61–70	29.8	62	Friend	1.0	2
71–80	43.8	91	Nursing home	3.4	7
81 or older	16.3	34	Other	1.4	3
Years since diagnosis			Where usually live		
1 year or less	4.8	10	Own home	90.9	189
2–6 yrs	43.5	90	Partner's home	0.5	1
7–11 yrs	25.1	52	Relative's home	2.4	5
12–16 yrs	16.4	34	Nursing home	3.4	7
17–21 yrs	4.3	9	Other	2.9	6
22 yrs or more	5.8	12			

Table 2
Sources of support

Sources of Support (Lowest mean = most important source of support)	Mean Rank
Husband, wife, or partner	3.3421
Son or daughter	3.8984
Friend or neighbour	6.6616
Brother or sister	6.8150
Home help	7.1960
Professional carer	7.2525
Son-/daughter in law	7.3069
Other Family	7.7330
Grandchild	7.7951
Identified health care professionals	7.7971
Other community services	7.9324
Mother or father	7.9420

Types and frequencies of NMSs

The top five NMSs identified were: a sense of urinary urgency 68.8% (n = 139), getting up regularly at night to pass urine 59.4% (n = 117), problems remembering or forgetting 58.3% (n = 119), unpleasant leg sensations 57.6% (n = 114) and constipation 51.3% (n = 102) (Fig. 1).

Overall, results highlighted differing gendered impacts of NMSs on HRQoL. Symptoms relating to dribbling of saliva $p \leq 0.001$ (sexuality symptoms $p \leq 0.001$ (small-medium effect) and talking or moving about in sleep $p = 0.033$ (small effect) were significantly associated with male gender. Alternatively, nausea/vomiting $p < 0.001$ (small effect) was statistically correlated with female gender (Table 3).

Table 3
Non-motor symptoms

30 Non-Motor Symptoms	Total % NMS	% in Males	% in Females	P ≤	Effect size phi
1 Dribbling of saliva	42.6 (n = 84)	52.9	26.3	0.001	-2.62
4 Vomiting or feelings of nausea	19.9 (n = 38)	10.3	34.7	0.001	.298
18 Feeling less/more interested in sex	41.4 (n = 72)	52.3	22.2	0.001	- .293
19 Finding it difficult to have sex	43.6 (n = 72)	61.1	10.5	0.001	- .485
25 Talking or moving about in your sleep, 'acting' out a dream	39.3 (n = 77)	45.8	29.5	0.033	- .163

GDS-15 results identified 51.1% (n = 97) of respondents documented normal scores or did not report symptomology of depression, 30% (n = 57) of participant scores indicated mild depression, 10.5% (n = 20) moderate depression and 8.4% (n = 16) reported scores indicating severe depression. Of note within the results was that while 81.1% (n = 154) of respondents reported symptoms of either no or mild depression combined frequencies for moderate and severe depression symptomology was 18.9% (n = 36).

Of the respondents 83.2% (n = 173) completed the PDQ-39 Single Index (SI) and scores ranged from 0-72.76. The mean score was 30.34, median was 28.02, mode 6.77 and standard deviation was 17.2. Higher PDQ-39 SI scores mean lower HRQoL and Lower PDQ-39 SI scores mean higher HRQoL. Table 4 presents the scores from each of the eight PDQ-39 dimensions along with the PDQ-39 SI score.

Table 4
PDQ-39 descriptive statistics

	Mobility	ADL	Emotion	Stigma	Social support	Cognition	Communication	Bodily discomfort	SI
n	187	194	187	199	193	193	197	200	173
Mean	45.01	41.66	28.9	18.4	12.3	31.7	24.3	37.9	30.3
Median	42.5	37.5	25	12.5	0	31.25	16.67	33.33	28
Mode	0	8.33	0	0	0	18.75	0	25	6.77
SD	30.87	31	21.99	19.43	18.8	21.19	23	23.7	17.2
Variance	953	964	483	377.68	354	449.4	531.7	562	296
Range	100	100	100	87.5	100	87.5	100	100	72.76
Centile 25	17.5	12.5	12.5	0	0	12.5	0	25	17.4
Centile 50	42.5	37.5	25	12.5	0	31.25	16.67	33.33	28
Centile 75	72.5	67.7	45.8	31.25	16.7	50	33.33	50	43.6

Results from a Mann-Whitney-U test revealed a small effect significant relationship between PDQ-39 dimension 7 (Communication) score of females (Md = 16.67, n = 77) and males (Md = 25.00, n = 120), U = 3646, Z = -2.527, p = 0.012, r = 0.180 indicating women reported better HRQoL in the communication dimension than men.

In this study, the influence of movement and mobility alterations were reflected in the PDQ-39 survey data, where several respondents reported having trouble looking after their home (39.2%, n = 78) or getting around their house (27.7%, n = 56). Changes to movement, mobility, and bodily functioning also spanned beyond home to the community with some respondents reporting difficulty walking short distances (100 yards). Kruskal-Wallis analyses of PDQ-39 survey revealed statistically significant differences across age and years since diagnosis. A Kruskal-Wallis test revealed a statistically significant difference in PDQ-39, dimension 1 'Mobility' scores across age groups, (Gp 1, n = 0: 20 years or under, Gp 2, n = 0: 21–30 years, Gp 3 n = 1: 31–40 years, Gp 4 n = 0: 41–50 years; Gp 5, n = 17: 51–60 years, Gp 6, n = 57: 61–70 years, Gp 7, n = 86: 71–80 years, Gp 8, n = 26: 81 or older. X^2 (4, n = 187) = 12.4, p = 0.015.

Illustrating that people 81 years and older recorded a higher median score ($Md = 60$) than other age categories. Median values ranged from 2.5–47.5 meaning that people in the oldest age category (81 years and older) had lower HRQoL in the mobility subscale of the PDQ-39 scale.

Survey participants diagnosed the longest (22 years or more) scored poorer HRQoL with mobility $p \leq 0.001$, activities daily living scores $p \leq 0.001$, social support $p \leq 0.019$, communication $p \leq 0.001$ and the overall Single Index (SI) scores $p \leq 0.001$ than other years since diagnosis cohorts. Respondents diagnosed 7–11 years scored poorer HRQoL for emotional wellbeing than other years since diagnosis cohorts ($p = 0.004$) and participants diagnosed 12–16 years and 22 years reported poorer HRQoL with cognition ($p = 0.008$).

The relationship between the number of NMSs (NMS Burden) and overall HRQoL score (PDQ-39 SI) was investigated using Spearman's test. There was a strong positive correlation between the two variables, $r = .660$, $n = 173$, $p \leq 0.001$, with high levels of NMS Burden associated with higher PDQ-39 SI scores meaning the higher the number of NMSs the lower the HRQoL.

Three even centiles were created from the available 173 PDQ-39 Single index (SI) scores. The first centile group represented people with higher HRQoL with PDQ-39 SI scores ranging from 0–19.69. The second centile represented people with average HRQoL with scores ranging from 19.84–37.4. The third centile included participants with lower HRQoL and scores ranging from 38.86–72.76. A Kruskal-Wallis test revealed a statistically significant difference in NMS burden scores across three HRQoL cohorts (high, average, low HRQoL) Gp 1, $n = 57$: high HRQoL, Gp2, $n = 56$: average HRQoL, Gp3, $n = 60$: low HRQoL, $X^2 (2, n = 173) = 55.66$, $p \leq 0.001$. The low HRQoL group recorded a higher median score ($Md = 121.6$) than the other two HRQoL cohorts which recorded medians of 85 (average HRQoL) and 52.7 (high HRQoL). These results suggest that respondents in the low HRQoL cohort reported higher NMS burden.

Respondents in the high HRQoL cohort reported experiencing 391 NMSs in the previous month. Those in the average HRQoL cohort reported experiencing 591 NMSs and those in the low HRQoL cohort reported 880 symptoms in the previous month. The NMS burden was 1.51 times higher for people in the average HRQoL cohort (average PDQ-39 SI scores) compared with those with those in the high HRQoL cohort (low PDQ-39 SI HRQoL scores). The NMS burden was 1.49 times higher for people in the low HRQoL cohort (Low PDQ-39 SI scores) compared with those with those in the average HRQoL cohort (average PDQ-39 SI scores). Overall respondents in the low HRQoL cohort (High PDQ-39 SI scores) experienced 2.25 times more NMSs than respondents with high HRQoL.

For each HRQoL cohort, the odds ratios (frequency of an event occurring/non-occurrence) for experiencing individual NMSs were calculated through examining the proportion of respondents in each HRQoL cohort high, average, and low likely to experience each of the 30 NMSs [41]. As odds ratios can only be undertaken in a 2 by 2 table, three binary variables were used 1) 'high' HRQoL and 'not high' HRQoL 2) 'average' HRQoL and 'not average' HRQoL and 3) 'low' HRQoL and 'not low' HRQoL. The odds of NMSs such as difficulty concentrating (OR 7.77), incomplete bowel emptying (OR 6.49), feeling anxious (OR 5.78, seeing or hearing things that others say are not true (OR 5.73) were more likely to be experienced by participants with lower HRQoL (than participants in high and average HRQoL cohorts). Figure 2.

A Kruskal-Wallis test revealed a statistically significant difference in GDS-15 scores across three HRQoL cohorts (high, average, low HRQoL) Gp 1, $n = 52$: high HRQoL, Gp2, $n = 50$: average HRQoL, Gp3, $n = 55$: low HRQoL, $X^2 (2, n = 172) = 62.1$, $p \leq 0.001$. The low HRQoL group recorded a higher median score ($Md = 7$) than the other two HRQoL cohorts which recorded medians of 40 (average 4) and 1 (high HRQoL). These results suggest that respondents in the Lower HRQoL cohort reported higher GDS-15 scoring for depression symptomology. The relationship between

overall HRQoL scores (PDQ-39 SI scores) and depression symptomology scores (GDS-15 depression scale) utilising Spearman's Rank Order Correlation (ρ) identified a strong positive correlation between the two variables $\rho = 0.609$, $n = 177$, $p \leq 0.001$, with high PDQ-39 SI scores associated with high depression scores (higher PDQ-39 SI scores indicate poorer HRQoL) (Fig. 3).

Hierarchical multiple regression was used to assess the ability of four control measures (Gender, Where participants usually live, Who they usually live with, Marital status) to predict overall HRQoL as measured by the PDQ-39 Single Index score after controlling for the influence of the GDS-15 score, NMS burden, Years Since diagnosis and Age. Preliminary analyses ensured no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. GDS-15 score, number of NMSs reported (NMS burden), years since diagnosis and age were entered at step 1 explaining 53.9% of the variance in HRQoL, $F(4, 152) = 44.373$, $p \leq 0.001$. R^2 change = 0.539, F change (4, 152), = 44.373, $p \leq 0.001$.

After entry of the variables where participants usually lived, who they usually lived with, marital status and gender at step 2 the total variance explained by the model was 56.9% $F(8, 148) = 0.030$, F change (4, 148) = 2.610, $p = 0.038$. Hence, the second block of control measures only explained a further 3% of the variance in HRQoL after controlling for GDS-15 score, NMS burden and years since diagnosis and age thereby supporting model 1 as the model that most accurately explains the effects of key variables including demographics, NMSs and reported depression symptomology on participants' HRQoL.

Model 1 with four variables GDS-15 score, NMS burden, years since diagnosis and age were predicted to negatively influence HRQoL. Three of the four control variables were statistically significant. The NMS burden measure recorded the highest beta value (beta = 0.415, $p \leq 0.001$) followed by the GDS-15 measure (beta = 0.374 $p \leq 0.001$). The lowest significant beta measure was Years since diagnosis (beta = .151 $p = 0.008$). These results strengthen understanding around the impact of depression symptomology, number of NMSs experienced and the length of time diagnosed, in predicting HRQoL for individuals living with Parkinson's (Table 5, Table 6, Table 7).

Table 5
Regression model summary

Model	R	R square	Adjusted R Square	Std. Error Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change $p \leq$
1	.734 ^a	.539	.527	11.83959	.539	44.373	4	152	.001
2	.754 ^b	.569	.546	11.59645	.030	2.610	4	148	.038

Table 6
ANOVA results

Model		Sum of Squares	df	Mean Square	F	Sig. P≤
1	1. Regression	24880.190	4	6220.047	44.373	.001
	Residual	21306.722	152	140.176		.001
	Total	46186.912	156			
2	2. Regression	26284.221	8	3285.528	24.432	.001
	Residual	19902.692	148	134.478		
	Total	46186.912	156			
a. Dependent variable : PDQ-39 SI (total score).						
b. Predictors: (Constant) , Age ≤ 80 or 81 and older, Years since Diagnosis ≤ 11 years or 12 years and older, GDS-15 Score, NMS Burden. c. Predictors: (Constant) Age < 80 or 81 and older, Years since diagnosis < 11 years or 12 years and older, GDS-15 score, NMS burden, Gender, Usually lives own home/doesn't usually live own home, Usually lives spouse/partner/doesn't usually live spouse/partner, Married/not currently married						

Table 7 Coefficients

Additional file 1

File format -Word file

Title of Table- Table 7 Regression data coefficients

Details- Landscape presentation of table

The 39 items of the PDQ-39 were subjected to PCA using SPSS version 25. Prior to performing PCA the suitability of data for PCA was assessed and verified. Analysis initially revealed the presence of seven components with eigenvalues exceeding 1, explaining 65.5% of the variance in total. Examination of the rotated component matrix involved removing eight questions from the Principal Component Analysis that had patterns of low coefficient loadings < 0.6. The analysis was rerun with the presence of six components explaining 67.9% variance with four factors accounting for 60.1% of this.

The rotated solution identified that there were loadings on four components with the highest loadings on component 1 and 2 and all variables loaded substantially on only one component. The four-component solution explained 60.1% of the variance with Component 1 contributing 40.2% of the variance, Component 2 contributing 8.5%, Component 3 contributing 6.1% and Component 4 contributing 5.4%.

Results of Principal Component Analysis indicate that for the population in this study, components measuring 1) Independence/dependence 2) Experiencing stigma when communicating with others, 3) Emotional wellbeing and 4) Experiences of Pain are central to explaining core aspects of participants' HRQoL. This analysis provides some unique and tangible dimensions to explaining HRQoL and strengthens recognition of it as more than just physical impacts such as pain. From these findings' health and HRQoL, also encapsulate social dimensions stemming from

interactions with others and the impact on self, emotional wellbeing as well as feelings of being in control, feeling independent.

Discussion

Respondents included a predominantly older population who were married, lived in their own home with their spouse/partner and had been diagnosed with Parkinson's for two years or longer. Consistent with international literature, there were more men than women in the sample [43]. Interestingly, a large proportion of survey respondents in this study reported never having problems with close personal relationships or lacking support from family or close friends. Indeed, the profile of long-term survivors with Parkinson's for over 20 years suggested that the majority lived at home with a family caregiver [44]. Elsewhere, "social relationships" (with family, friends, and neighbours) were revealed as most significant for PwP [45]. Karlstedt et al. [46] found that although PwP may deteriorate over time, high relationship quality can produce gratification, meaning, and support, enhance negative consequences, and improve QoL. This emphasises the importance of establishing a profile of available supports to guide and facilitate pathways for individualised person-centred care [47] that can support HRQoL of people with Parkinson's. Hence, interventions such as social support, respite care, couple therapy, or counselling may help caregivers and individuals adapt and adjust to ever-changing care situations and find inward strength to cope [46].

In this study, presence, type, and disruptions caused by NMSs, often referred to as invisible symptoms, and manifested their influence on HRQoL. Results indicated the differing gendered impacts of NMSs on HRQoL, with symptoms relating to talking or moving about in sleep, dribbling of saliva, and sexuality were statistically significant for men and nausea/vomiting for women. Concurring reports have suggested that NMSs influence long-term HRQoL for PwP [48]. Moreover, findings showed how they may influence HRQoL more than motor symptoms [49], and psychological wellbeing [50] thereby highlighting the impact of NMSs and their relationship to HRQoL.

Within this study, respondents living with Parkinson's for longer timeframes, recorded a higher NMS burden, a finding supported by Sanchez-Martinez et al. [17]. There was also greater than a two-fold increase in the NMS burden for those in the low HRQoL cohort compared with participants in the high HRQoL cohort. Results indicated that the odds of experiencing individual NMSs were more likely in participants with lower HRQoL. Indeed, NMS burden can negatively affect HRQoL [51]. Furthermore, people with more severe NMSs have reported more unmet needs such as accessibility to health care professionals [22]. Given that respondents were community-dwelling, this highlights the vital role of primary and community nurses in providing impeccable assessment and therapeutic care that alleviates the impact of NMSs on PwP [22].

As detailed in the results most survey respondents reported either no depression or mild depression; nonetheless, combined frequencies for moderate and severe depression symptomology were clinically significant. This supports earlier findings [52], [53] signalling the prevalence of major depressive disorders in PwP. Principal component and regression analyses established depression score as a significant contributor to and determinant of HRQoL. Symptoms of depression have emerged as one of the most important determinants of poor HRQoL for PwP [27] [54].

Of interest within this study was the finding which revealed a statistically significant difference in HRQoL scores (high, average, low HRQoL cohorts) across GDS-15 depression symptomology categories. Respondents in the low HRQoL cohort recorded more severe depression symptomology. From a health-professional perspective, two simple questions are recommended to assist identification of depression symptomology in the previous month, 'have you often been bothered by feeling down, depressed or hopeless?' and, 'Have you often been bothered by having little interest or pleasure in doing things?' [55] Undoubtedly, being vigilant to depression symptomology, employing

listening skills, along with ascertaining a comprehensive history are fundamental nursing skills. Furthermore, referral to practitioners competent to undertake more in-depth physical and mental health assessments using validated instruments (e.g., GDS-15 or the combined Hospital Anxiety and Depression Scale HADS) to indicate presence of psychological difficulties severity, family and social supports and individual preferences is advised [56], [57]. This is particularly important given the negative impact of depression and anxiety on the lives of people with Parkinson's [58].

In the wider literature, the direct influences of motor control and mobility as strong contributors to HRQoL are reported [59]. More recently, it was reported that 'locomotion dysfunction' (gait and balance difficulties) scored highest in motor characteristics underscoring the importance of gait deficits to HRQoL [28]. One common dysfunction, freezing of gait, is a complex motor fluctuation connected with advancing Parkinson's [60]. In this study, the influence of Parkinson's on mobility went beyond mere estimates of walking distance; many participants indicated they would need someone to accompany them in public. Furthermore, almost a third of survey participants reported that they felt frightened (often or always) about falling over in public. Horning et al. [61] reported gait deterioration, falls, and functional decline as key symptoms challenging home safety. These cause noticeable restrictions in a range of activities, disability, and altered autonomy [62] and highlight the interwoven nature of mobility, fear and dependence. Falls are significantly related to reduced HRQoL [33], [63].

As motor fluctuations also have direct and indirect effects on HRQoL (directly affecting pain and fatigue, and indirectly mood and sleep), assessing and managing these effectively could improve overall QoL [64]. Recommendations from this study include the need to supplement HRQoL research instruments such as the PDQ-39 by including additional instruments to capture the everyday impact of Parkinson's such as freezing of gait (e.g. The Freezing of Gait Questionnaire FOGQ), and other influences such as falls incidence and fear of falling (FOF) e.g. Fall Efficacy Scale-International (FES-I).

Findings from this study also emphasised the everyday impact of Parkinson's not just on motor fluctuations but on ambulation, where almost half (48.5%) of respondents reported difficulty walking ½ mile. Findings from the wider literature highlight that exercise may help motor and nonmotor symptoms and prevent secondary complications of immobility (cardiovascular, osteoporosis) [65]. Additionally exercise can help optimise function and performance of life activities [66]. Developing exercise and walking capacity, balance, muscle power, and compensatory methods to alleviate pain during ambulation, could also reduce the work of walking from a rehabilitation perspective [67]. Through rehabilitation, growth in knowledge and skills can increase personal control, self-management, role participation, and satisfaction [68]. This emphasises the importance of resource planning and long-term healthcare professional commitment to sustaining rehabilitative therapy initiatives for PwP that truly foster independence and augment QoL.

It was evident that physical effects of Parkinson's made it difficult for some respondents to complete everyday activities like doing up buttons or laces, writing clearly and cutting up food. Participants diagnosed the longest (22 years or more) showed poorer HRQoL with mobility, activities of daily living, emotional wellbeing, social support, cognition, communication and overall HRQoL. Furthermore, there was a significant association between feeling helpless and poorer HRQoL scores. Self-care activities contribute most to and are strong predictors of HRQoL [33]. From the wider literature, a decline in ADL performance over a period of 8 years [69] along with ability to engage in leisure activities, household work, walking, and getting around in public have been attributed to Parkinson's [70].

Principal component analysis in this study (PDQ-39 scale) revealed one of the four components determining HRQoL was independence/dependence. Previously, perceived autonomy was reported to affect HRQoL [71]. Being dependent

on others causes feelings of insecurity and reduces confidence in self-image and identity [72]. The idea that Parkinson's impacts on meaningful activities was previously linked to losses associated with previous social identities evident such as gardener, cook, mother/father, or being able to wear heeled shoes [73]. Without sufficient personal control, people also find adaptation problematic [74]. Subsequently, they may experience increased effects of chronic illness and its treatment, resulting in even lower QoL. Findings from Gusdal et al.'s [75] delphi study described having a social life, feeling safe and being able to retain one's control as requirements for healthy and independent living among older people generally. Social care is valued for allowing choice, control, and enabling people to maintain independence [76]. Hence, more creative community supports, based on individual needs in line with an active ageing concept [77], are required that facilitate social and advocacy needs around independence to sustain and improve HRQoL rather than just a focus on physical care services. This is further supported by aspirations to support people to live independently in the community for as long as possible and to co-design population service requirements [21]. Udo's (2016) [78] analysis of active ageing also incorporates continued participation in life and health to enable individuals to enjoy a positive QoL, as they grow older. Hence, promotion of independence and participation must be primary considerations for health care policy development and service delivery to preserve HRQoL for PwP.

In this study, PCA revealed stigma was a significant component of HRQoL. Moreover, there was a positive correlation between GDS-15 scores and the stigma dimension score (PDQ-39, with higher scores, suggest lowered HRQoL). A Kruskal Wallis test also showed a statistically significant difference in the GDS-15 category, and the stigma dimension score, revealing that participants in the severe depression category recorded the highest median stigma score. Salazar et al. [79] reported that for men, younger age and higher depression scores and for women higher depression scores were significant predictors of stigma, suggesting that treatments for Parkinson's should also target emotional responses to alleviate perceived stigma.

Difficulty participating in preferred leisure activities were reported by over a third of respondents in this study. Kennedy-Behr and Hatchett [80] identified engagement in meaningful occupation as supporting wellbeing, relationships, and identity. Participation in a wide range of activities is also a useful rehabilitation goal [81]. Involvement in physical and social activities can help individuals recover previous routines, ease and shape transition to a new life or fill losses in building self-esteem and identity [82].

Survey findings indicated over a third of respondents had difficulty getting around in public, and/or needed someone to accompany them. Over half the respondents indicated a preference for staying at home rather than socialising. In addition, poorer HRQoL in the domain of social support was evidenced by respondents with longstanding Parkinson's. Social isolation independently influences the prospect of depression or anxiety, with loneliness being a cyclical risk factor for declining social life [83]. All these situations ultimately reduce social roles, wellbeing, and QoL.

While the largely inevitable physical consequences of disease take hold, social withdrawal and isolation should not be viewed as inevitable nor intractable [83]. From a health and social perspective, activities that engage PwP where they feel valued, and part of communities is essential for QoL. This is especially important for individuals diagnosed for longer periods where social isolation may creep in. This again emphasises the importance of addressing loneliness and social network size to improve mental health of older PwP [83]. It is vital that barriers to participation are removed for older people generally and more opportunities emerge for continued involvement in cultural, economic, and social dimensions of life and communities according to needs, preferences, and capabilities [21]. From a HRQoL perspective, healthcare professionals should be mindful of the positive influence of feeling part of a community of people be that a committee or group.

Most survey respondents with good to average HRQoL reported feeling happy most of the time, as did two-thirds of those with poorer HRQoL. Sperens et al. [84] also found a positive outlook was necessary for coping with Parkinson's. Moreover, Hurt et al. [85] explored relationships between illness perceptions, optimism, and well-being. Holding positive views of illness predicted better well-being; being optimistic offered some protection from undesirable illness perceptions [85]. Gardenhire et al. [86] observed 'emotional optimism' was expressed through hope, happiness, and gratitude. Consequently, interventions should focus on enhancing positive perceptions of Parkinson's and general optimistic attitudes to maximize well-being. This finding reiterates the importance of healthcare interventions that support adaptation to Parkinson's incorporating psychological therapies into pathways of care.

Results explored reliability of and relationships among variables in the PDQ-39 scale relative to an Irish context using principal component analysis (PCA). Results from PCA indicated that for the population in this study, components measuring 1) Independence/dependence 2) Experiencing stigma when communicating with others, 3) Emotional wellbeing and 4) Experiences of Pain were central to explaining core aspects of participants' HRQoL. This finding strengthens recognition of HRQoL determinants as more than just physical but encapsulating sense of self, emotional wellbeing, feelings of control and social dimensions of interacting with other people. Statistical analysis in this study's population also uniquely established a framework of regression that strengthens understanding around the impact of depression symptomology, number of NMSs experienced and the length of time one is diagnosed in predicting HRQoL for PwP.

Limitations And Recommendations

This research was conducted in one area of Ireland; therefore, participants' responses and experiences may not be generalised to the whole population of people living with Parkinson's. The survey reflected self-reports at a single point in time with no follow-up survey. The stage of Parkinson's was not clinically assessed during the research, hence, progression patterns and severity could not be objectively assessed and subsequently related to key research variables and subjective meanings of HRQoL. Missing data was omitted from the analysis.

The NMS Quest, and GDS-15 described presence of symptoms and the PDQ-39 assessed aspects of functioning and wellbeing adversely affected by Parkinson's. However, these instruments did not examine participants' experiences and feelings around NMSs, depression and HRQoL. This calls for more indepth qualitative exploration to expand breadth and range of inquiry and provide fuller and deeper understandings of the impact of Parkinson's on participants' lives.

Focused multidisciplinary rehabilitative programmes targeting walking ability, balance, FOG, falls and FOF should be available in primary care to prevent and address sedentary lifestyle, and falls. It is also recommended that the PDQ-39 as a Parkinson's specific HRQoL instrument is revised to capture the everyday impact of Parkinson's on individuals' lives such as dyskinesias, FOG, falls and fear of falling. Future research should consider sampling and recruitment within the context of gender representation to identify if gender sensitive health care interventions may be effective in ameliorating the impact of NMSs on perceived HRQoL. Health care policy keeps promotion of independence a central consideration when resourcing service delivery for PwP to support people to live independently in their own community for as long as possible.

Conclusions

This study aimed to explore the factors that influence Health-Related Quality of Life (HRQoL) for people with Parkinson's (PwP). From a broader perspective, the findings allude to the positive benefits of close relationships in providing a supportive context moderating the psychological wellbeing of participants particularly within the context of living within one's own home. Overall, findings indicated the differing impact of NMSs on HRQoL of men and women, those with a longer disease duration, and people with poorer self-reported HRQoL. The impact of depression was identified, stressing the need for vigilance, comprehensive assessment, and referral for individualised follow-up care. This is important given the evidence illuminating the powerful influence of depression to overall QoL in Parkinson's. The influence of movement and mobility alterations were reflected in the PDQ-39 survey data, which also revealed Independence/dependence as a key component determining HRQoL. As Parkinson's progresses, it may generate communication-inhibiting symptoms and, as people present, negotiate, and manage their identity through communication; it is likely that such symptoms may contribute to perceived stigma. Consequently, interventions should focus on enhancing positive perceptions of Parkinson's and general optimistic attitudes to maximize well-being.

List Of Abbreviations

FoF - Fear of Falling

GDS - Geriatric Depression Scale

HRQoL - Health-Related Quality of Life

NMSQuest - Nonmotor Symptoms Questionnaire for Parkinson's disease

PDQ - Parkinson's disease Questionnaire

PwP - People with Parkinson's

Declarations

Ethics approval and consent to participate: The research protocol was approved by University Hospital Limerick Research Ethics Committee, Limerick, Ireland who also provided approval to undertake the research. This approval was based on the ethical principles of 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 consented to complete the survey based on the invitation letter, information sheet and return of completed questionnaire. Research methods were carried out in accordance with relevant regulations and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [87].

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

Availability of data and materials: The datasets used and analysed during the current study are not publicly available as participants have not given consent for public availability of their data. But it is available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: IC designed the study, collected and analysed the data and led the writing of this manuscript. OD contributed to the study, provided feedback throughout and assisted with the manuscript writing. PM contributed to the study and survey design, provided feedback throughout and assisted with the manuscript writing. All authors read and approved the final manuscript.

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Figures

Figure 1

Types and Frequencies of NMSs reported by all participants

Figure 2

Odds ratios NMS and HRQoL cohorts

Figure 3

Spearman's correlation GDS-15 scores and PDQ-39 SI scores

Supplementary Files

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