

Research Report

Challenges of Improving Patient-Centred Care in Parkinson's Disease

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Abstract.

Background: Parkinson's disease is a neurodegenerative condition with a complex pattern of motor and non-motor symptoms. Of several clinical scales used to measure patient experience few are delivered by patients themselves.

Objective: The present study reports the results of an online survey to establish (a) factors that most influence QoL (quality of life) for people with Parkinson's and (b) areas where self-monitoring may help.

Methods: A 27 question online survey (using Survey Monkey) was developed by The Cure Parkinson's Trust, comprising four main sections (demographics, monitoring, symptoms and communication).

Results: 492 patients participated. 97% felt it 'very' or 'moderately' important to understand their own Parkinson's symptoms and recognise patterns in their condition ($n=420$). Although, 87% ($n=467$) were interested in recording information about their Parkinson's to monitor their well-being, only 49% of respondents were actually doing so. Slowness of movement (82% $n=432$) and lack of energy (61% $n=432$) were the most reported motor and non-motor symptoms, respectively. These symptoms were also commonly reported to impact QoL ($n=407$). In monitoring these symptoms 75% ($n=409$) thought it would help improve their understanding of their condition, 64% thought it would improve their wellbeing and ability to cope, 61% thought it would improve their treatment and 59% thought it would improve communication with their healthcare team.

Conclusion: Collectively, the data suggest that a measurement tool supporting a patient-centred care model would be a combination of objective and accurate measurement of the most bothersome symptoms for patients towards the end goal of improving patients' QoL.

Keywords: Parkinson's disease, measurement, patient reported outcome measures

INTRODUCTION

Lord Kelvin, the Irish mathematical physicist and engineer best known for determining the correct value of absolute zero, is quoted as saying "To measure is to know" and "If you cannot measure it, you cannot

improve it" [1]. Although spoken in the context of thermodynamics, it is a sentiment relevant to many other disciplines in science, including medicine. This is reflected by the degree to which patient management decisions often rely heavily on measurement tools, as is the case in treating hypertension or diabetes where blood pressure measurement and glucose monitoring respectively, are integral to treatment choices.

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This is not the case in Parkinson's disease. In fact one of the complicating issues in the management of this neurodegenerative illness is that there are no objective markers. There is no measure of how the disease is progressing and how it responds to treatment. Lack of such a definitive marker also affects research into potential treatment modalities where the lack of sensitivity in the existing rating scales make it difficult to study accurately the effect of an intervention. A marker that accurately correlates with clinical results would be valuable as a surrogate outcome when trying to demonstrate clinical efficacy. Identifying such a biomarker will likely have compelling research and clinical impact.

Although no such marker currently exists, a number of scales have been designed to allow clinicians and researchers to assess their patients by measuring aspects of the patient experience of Parkinson's. In addition to their observational skills and the patient's narrative, these scales help clinicians in the on-going evaluation as the illness progresses.

The four most characteristic, clinically measured symptoms of Parkinson's are all motor based – tremor, bradykinesia, postural instability and rigidity. Although disabling, there is a significant diversity in the symptoms and their impact in patients with Parkinson's that extend beyond those affecting movement. This is reflected in the reported symptoms that patients find the most bothersome which in one study were cited as being not only tremor, lack of mobility and imbalance but pain, fatigue, mood issues and anhedonia as well [2].

Factors in determining life experience for patients have previously been addressed using the Satisfaction with Life Survey (SWLS) where a strong correlation was found between a patient's quality of life and their satisfaction with their life experience [3]. Quality of life (QoL) may be defined as the perceived quality of a person's daily life, including the physical, emotional and social aspects of their life experience. Health-related quality of life (HRQoL) is the extent to which one's usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment [4]. In a large study of Parkinson's patients, HRQoL was measured against disability. Researchers found that psychosocial well-being had a larger impact on HRQoL compared to physical symptoms. Of those patients whose management was directed mainly to motor symptoms of the disease, non-motor symptoms had a large impact on HRQoL. These included axial motor symptoms, gastrointestinal and urinary complications and depressive symptoms [5].

Although these measures purport to describe the patient experience of Parkinson's, this is nonetheless transduced by healthcare workers and not patients themselves. And although they do quantify patient experience, they are impersonal healthcare tools rather than the route to symptom self-awareness. There appears to be some discordance between what aspects of Parkinson's disease are measured by current evaluation tools and the symptoms that are particularly impactful. If "to measure is to know", then an accurate assessment tool that measures how this disease truly impacts patients is the first step in improving the relevance of treatment from a patient's perspective which in turn may improve QoL for patients. The present study reports the results of an online survey, designed in consultation with people with Parkinson's (PwP) for PwP, to establish those factors that most influence QoL for people with Parkinson's and areas where self-monitoring may be helpful.

METHOD

A twenty-seven question online survey (using Survey Monkey) was developed by Parkinson's Movement (www.parkinsonsmovement.com), an international patient-driven action group created by a UK research charity, The Cure Parkinson's Trust (www.cureparkinsons.org.uk). The survey was shaped with input from an advisory group of six transatlantic Parkinson's advocates who range from 5 to 22 years post-diagnosis. This is broadly representative of the study sample demographic (see results).

An invitation to participate was sent out to the charity's database of PwP via The Cure Parkinson's Trust website, the Parkinson's Movement HealthUnlocked page (6471 members), Facebook (over 3000 likes) and Twitter (over 7000 followers) as well as to over 2500 people who receive regular updates via E-News. It was sent to the major English-speaking charitable organisations in the US and UK representing the interests of patients (namely in the US Michael J Fox Foundation, Parkinson's Disease Foundation, Davis Phinney Foundation, Brian Grant Foundation, Northwest Parkinson's Association and, in the UK, Parkinson's UK). The survey was also distributed to those attending the *Grand Challenges in Parkinson's* conference in Grand Rapids, Michigan, USA organised by the Van Andel Research Institute (VARI). The survey was active from 13/07/2015 to 07/09/2015.

The survey consisted of 5 broad sections:

1. Background information (questions 1–8)
2. Monitoring (questions 9–13)
3. Symptoms (questions 14–20)
4. Communication (questions 21–25)
5. Future correspondence (questions 26 & 27)

Section 1 gathered general background information including gender, age, year of diagnosis and year of first symptoms. Further information was collected on responder's Parkinson's-related symptoms, the current medications they take, whether they live alone or with others and in what type of dwelling.

Section 2 assessed attitudes towards technology and technology-based solutions for monitoring Parkinson's. Questions also covered whether respondents are interested in recording information about their Parkinson's to monitor well-being and whether they currently do so. If they do monitor, the question was then posed as to what methods/tools they use (for example, diary, apps and monitoring devices). And finally, information was also gleaned on how interested they are in using technology and what devices they already use (for example, computer, TV, smartphone).

Section 3 gathered important information about symptoms; what movement and non-movement symptoms respondents currently experience, what five symptoms most affect their QoL and what outside factors affect the state of their Parkinson's (for example, stress, diet, change in medication, time of day). Within this section, respondents were also asked how important it is to them to understand their own Parkinson's, what five symptoms they would continuously monitor if they had to and in monitoring these five symptoms what they think it might improve (for example, understanding of Parkinson's, understanding of own condition, treatment).

The final data-gathering section concerned communication between PwP and their healthcare team. The questions posed investigated the importance attributed by PwP to communication with their Parkinson's consultant, who respondents see when they have a Parkinson's appointment and whether they communicate the full range of symptoms at their appointment. As well as, whether they think their healthcare team have a clear understanding of what PwP hope to achieve from their Parkinson's treatment and frequency of appointments.

Questions were a mixture of YES/NO, multiple choice and free text. All multiple choice questions had an 'other-please specify' option. See Appendix 3 for all the data-gathering survey questions.

RESULTS

Response rates per question were between 399 (81%) to 492 (100%) with 224 (47%) male, 254 (53%) female ($n=478$) respondents. Respondents were predominantly (88%, $n=344$) UK and USA based but in total responses covered 9 countries and 5 continents, the majority of which are English speaking. The mean age was 62.3 ± 10.4 y (range 26–91, $n=479$) and respondents on average were diagnosed 7 years ago (range 1963–2015, $n=475$). 84% lived with someone, mostly with a spouse (94% $n=477$) and 63% lived in a dwelling with 2 or more floors ($n=480$). The majority of respondents are currently taking some form of levodopa medication (84%, $n=492$), 53% are taking some form of dopamine agonist and 26% are self-prescribing which included pain killers, vitamins, caffeine and Botox for example.

88% were 'very' or 'moderately' interested in using technology ($n=466$). Device/gadget use was high with 94% of respondents using some kind of device regularly, for example computer (92%), TV/DVD (78%) or smartphone (57%). 87% were interested in recording information about their Parkinson's to monitor their well-being ($n=467$). 97% felt it was 'very' or 'moderately' important to them to understand their own Parkinson's symptoms and recognise patterns in their condition ($n=420$). 49% of all respondents use a range of methods, from keeping a written diary (27%) to using technology such as apps (15%), to record information about their Parkinson's to monitor their wellbeing.

Figure 1 shows the motor and non-motor symptoms the respondents currently experience. Slowness of movement (82%, $n=432$) and lack of energy (61%, $n=432$) were the most reported motor and non-motor symptoms, respectively. These symptoms are also commonly reported in the 5 symptoms that most impact on QoL ($n=407$). That said, neuropsychiatric symptoms were the most commonly reported, followed by postural instability & gait dysfunction symptoms and fatigue (Fig. 2). Neuropsychiatric symptoms and postural instability & gait dysfunction symptoms were also the most commonly reported symptoms respondents ($n=399$) would like to monitor continuously over a period of time if they had to, however this was followed by sleep and tremor (Fig. 3). Further differences in responses for symptoms most affecting QoL and symptoms that respondents would most like to monitor are shown in Fig. 4. In monitoring these symptoms 75% of 409 respondents thought it would help improve their understanding of their own condition, 64% thought

Motor

Slowness of movement	82.41% (356)
Tremor	61.57% (266)
Rigidity	56.71% (245)
Dyskinesia (involuntary movements)	38.89% (168)
Dystonia (uncontrollable and sometimes painful muscle spasms)	36.81% (159)
Balance problems	60.19% (260)
Restless legs	31.25% (135)
Festination (alteration in walking pattern e.g. quickening and shortening of normal strides)	35.88% (155)
Difficulty instigating movement/Freezing	34.95% (151)
Falling	29.17% (126)
Others	17.13% (74)

Non-motor

Lack of energy	61.34% (265)	Memory problems	34.26% (148)
Difficulty sleeping	54.86% (237)	Difficulties with thinking	29.86% (129)
Daytime sleepiness	51.85% (224)	Dementia	5.09% (22)
Tiredness/exhaustion	54.40% (235)	Depression	27.31% (118)
REM sleep behavioural disorder	17.82% (77)	Anxiety	40.28% (174)
Constipation and other gut problems	49.31% (213)	Delusions	2.55% (11)
Difficulty swallowing	27.31% (118)	Hallucinations	10.19% (44)
Dribbling	31.71% (137)	Obsessive compulsive behaviour	10.65% (46)
Loss of sense of smell/taste	51.16% (221)	Changes in behaviour/mood	21.06% (91)
Nausea or vomiting	9.72% (42)	Inability to organise	24.54% (106)
Bowel incontinence	8.56% (37)	Urinary urgency	48.38% (209)
Excessive sweating	29.17% (126)	Confusion	13.66% (59)
Dizziness	21.99% (95)	Repetitive behaviour	8.10% (35)
Hyper sexuality	6.02% (26)	Impulsive behaviour (e.g. gambling)	4.63% (20)
Need to get up in the night	46.76% (202)	Poor attention span	23.84% (103)
Dry eyes	25.69% (111)	Blurred vision	19.68% (85)
Erectile dysfunction	20.83% (90)	Double vision	12.73% (55)
Tingling sensations	21.99% (95)	Weight gain	19.68% (85)
Difficulties with speech	41.67% (180)	Weight loss	16.20% (70)
Pain	38.89% (168)	Other	15.28% (66)

Fig. 1. Motor and non-motor symptoms currently being experienced by respondents ($n = 432$).

it would improve their wellbeing and ability to cope and 61% thought it would improve their treatment. A further 59% thought continuous monitoring of these symptoms would improve communication with their healthcare professional, 55% thought it would improve their expectations for the future and 49% thought it would improve their understanding of Parkinson's.

The majority (91% $n=417$) think communication with their Parkinson's consultant is 'very' or 'moderately' important, yet more than 20% only see/communicate with healthcare professionals or their Parkinson's care team once every 7+ months and 11% once every 1-2 years. What's more, 22% ($n=415$) do not think their healthcare team have a clear understanding of what they hope to achieve from

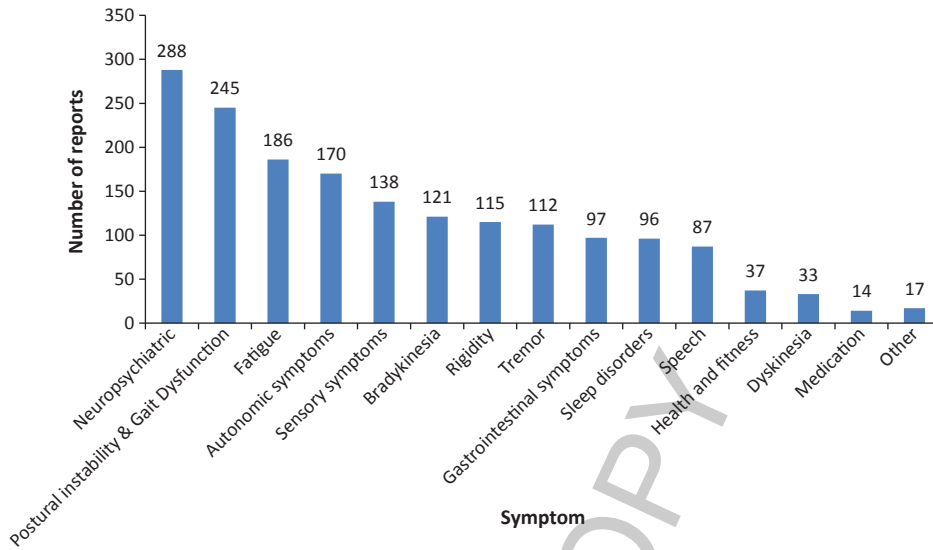


Fig. 2. The number of reports of different types of symptoms that most affect respondents quality of life ($n = 407$). See Appendix 1 to view the symptoms included in each category.

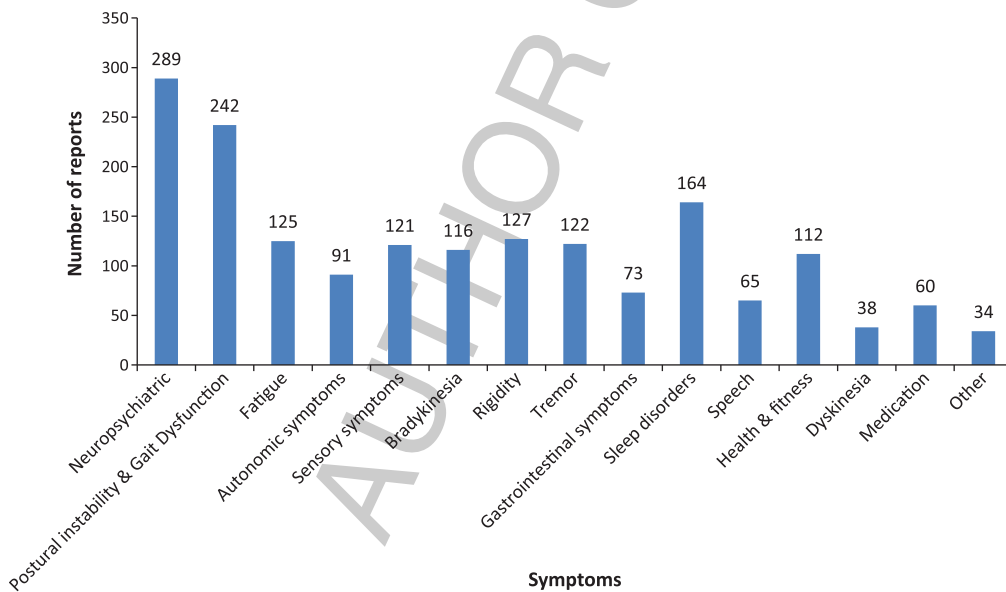


Fig. 3. The number of reports of different type symptoms that respondents would most like to monitor ($n = 399$). See Appendix 2 to view the symptoms included in each category.

their Parkinson's treatment. Reasons for this included appointments being too short or feeling rushed. Interestingly, 24% ($n = 415$) feel they do not communicate the full range of symptoms they experience in their appointment due to reasons such as forgetting, lack of time and the lack of interest in non-motor symptoms.

DISCUSSION

“If you cannot measure it, you cannot improve it”. To address this challenge faced by both the Parkinson's medical and research communities, Rallying to the Challenge was held in September 2015. With over 100 PwP in attendance, this conference,

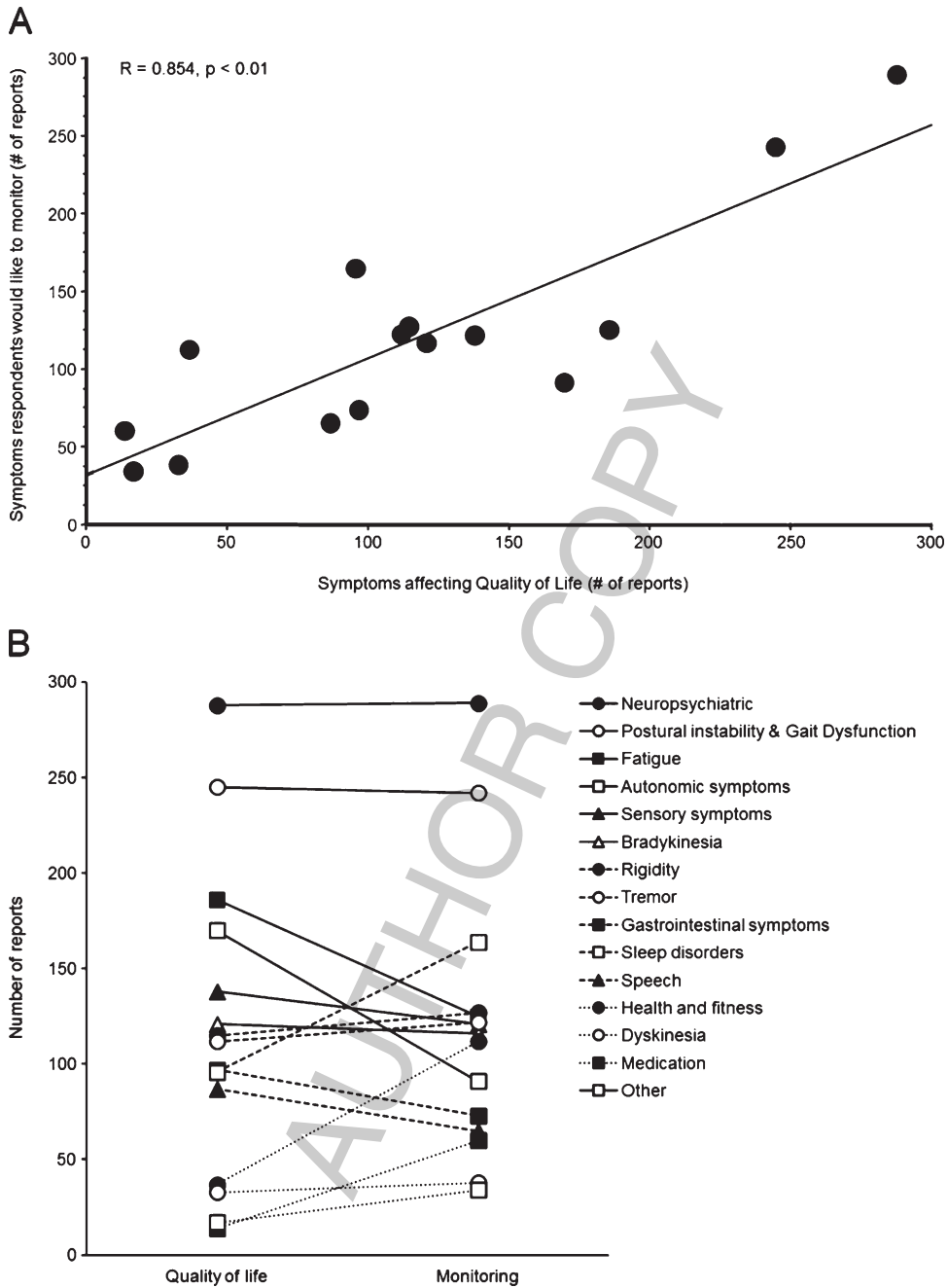


Fig. 4. A) Correlation of symptoms respondents would like to monitor and symptoms affecting QoL. B) The difference in responses for symptoms most affecting quality of life and symptoms that respondents would most like to monitor if they had to.

organised by VARI in association with Parkinson's Movement, served as a platform to discuss the results of the survey designed to look at outcomes and measures in Parkinson's disease. Its purpose was to determine which outcomes are most important to patients and how they may be measured.

There are a number of evaluation scales currently in use for Parkinson's assessment. In addition to clinical exam and patient narrative these measurement tools are used to guide management decisions. Despite the fact that 91% of respondents feel that communication with their PD consultant is impor-

tant, few respondents feel that their physician has a clear understanding of their treatment goals and admit to not communicating the full range of symptoms they experience. These barriers to communication were attributed to lack of time, poor memory, feeling rushed and so forth. There is clearly a discord between what is important to patients and what information is being relayed to their clinicians.

Looking at outcomes of Parkinson's evaluations, the survey sought to document those symptoms of the disease that impact patients the most. Impact was defined in the context of QoL; the perceived quality of a person's daily life, including the physical, emotional and social aspects of their life experience. Health-related quality of life (HRQoL) attempts to capture QoL in the context of one's health and illness. There is a strong positive correlation between a patient's QoL and their satisfaction with their life experience. Conversely there is a strong association between Parkinson's disease severity and reduced quality of life and increased disability.

The presence of non-motor symptoms also seems to have an adverse effect on QoL. Unlike the traditional tenet that Parkinson's is solely a movement disorder, this disease is now known to be far more pervasive. Respondents to this survey identified at least one non-motor symptom in the top five symptoms that patients feel are impactful with almost half reporting a non-motor symptom as having the greatest effect on their QoL. Neuropsychiatric symptoms were reported most often as significantly impacting QoL with postural instability and gait issues being the second most bothersome. Fatigue followed by autonomic effects and sensory symptoms rounded out the top five symptoms listed as impacting QoL. Although neuropsychiatric symptoms were reported most often, this category was made up of 28 individual symptoms, some of which are quite different from each other (see Appendix 1). Grouping them together in this way explains why it was so highly reported, especially as other categories did not include so many symptoms. The individual symptoms included in the neuropsychiatric symptom category as well as the number of times they were reported to affect QoL can be found in Appendix 1.

The use of QoL as an end-point can help move management from a clinician-centred medical model to a patient-centred care model. From a model where patients are followed and receive management for issues related to the disease, symptoms or treatment, to a model which focuses on the needs of

the individual, assisting them to live well with a currently incurable, progressive neurodegenerative disease. This type of approach places emphasis on how the patient is functioning with the disease, how they are able to function not only physically but psychologically and socially.

Identifying symptoms that are most impactful for patients is important but the degree to which patients are affected ultimately needs to be communicated to those responsible for their disease management. Due to the lack of an objective biomarker and the lack of a proper method of self-assessment, clinicians often rely on patient narrative or their recollection of symptoms and sporadic clinic visits when assessing the status of a patient's Parkinson's. Although 91% of respondents felt that communication with their PD consultant is "very" or "moderately" important, more than 20% see their physician only once every 7 + months with 11% making a visit every 1 – 2 years. Along with high inter-rater variability, the current measurement tools used during these patient evaluations are inherently subjective. This results in an incomplete, inaccurate snapshot of a patient's clinical status.

Combined with the heterogeneous nature of this disease and fluctuations in symptoms that patients experience, a more comprehensive and accurate measurement tool that provides a clearer picture of the variability of this disease on a daily basis is important. This requires input from patients. Currently our study showed that the majority of patients who responded are interested in recording information about their Parkinson's to monitor their well-being and almost all participants felt it is "very" or "moderately" important to understand their own Parkinson's symptoms and recognize patterns in their own condition. Among benefits to this increased personal understanding, improvements in wellbeing, ability to cope, communication with their healthcare professional, and an improved treatment plan were cited.

When asked which symptoms patients would like to monitor, the results were generally similar to those deemed most bothersome (Fig. 4A) with possibly the exception of sleep disorder (Fig. 4B). Figure 5 shows that the majority of factors give ratios very close to 1.00, meaning that symptoms deemed most bothersome and symptoms patients would like to monitor are highly correlated, with the exception of sleep disorder (1.71) which is reported more commonly as a symptom patients would like to monitor than as one of their most bothersome symptoms. On the other hand, the ratios for fatigue (0.67) and autonomic symptoms

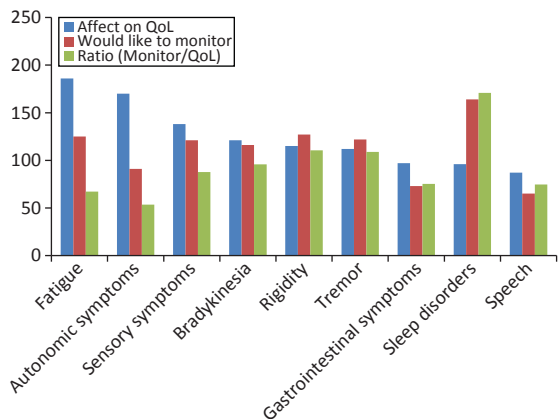


Fig. 5. Comparison of the number of reports of different types of symptoms that most affect respondents quality of life and those that respondents would most like to measure. Health and fitness, dyskinesia, medication and other were excluded as they all had very low scores with little correlation between monitoring and QoL. Ratio is shown as a percentage [(monitoring/QoL)*100].

(0.54) are low, meaning that more people reported them as bothersome symptoms than as symptoms they would like to monitor (Fig. 5). These discrepancies may be a reflection of patients' perceptions that the manifestation of sleeping problems are easier to measure than other symptoms that they find more bothersome such as fatigue and autonomic symptoms.

Of those that responded to the survey 37% of patients were already using a drug diary as a record of their disease, with 27% extending this concept to include a written diary of symptoms and responses to interventions while 20% relied on the recollection of their caregivers. Again any of these methods are limited by their subjectivity. The advent of technology and wearable devices may help to improve accuracy and efficiency by helping to record more objective results. Of those surveyed 88% were "very" or "moderately" interested in using technology with 94% already using some kind of device regularly for other tasks. Initial studies have shown that measuring Parkinson's symptoms is feasible using smartphone technology and may play a role as a diagnostic support tool. Parkinson's tracker apps have also shown promise in the area of self-management and initially have been linked to increased adherence to treatment and QoL.

In the Handbook of Neurologic Rating Scales, author Robert Herndon describes the characteristics of useful scales [6]. From his description, a useful

measurement tool should be appropriate to the task, should be valid (must measure what it purports to measure), must be accurate, must be reliably reproducible, should be efficient and easy to use (with little special training), should be sensitive to change in the underlying condition yet relatively insensitive to symptom fluctuation and should be consistent over time. Unfortunately no such measurement tool currently exists in the field of Parkinson's disease.

As this survey was created by PwP for PwP, the symptoms found to be the most bothersome could be used to create a measurement tool that truly supports a patient-centred care model. It would use a combination of objective and accurate measurement of those symptoms that are most bothersome for patients towards the end goal of improving patients' QoL.

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CONFLICTS OF INTEREST

The authors confirm that no financial or material support was provided in the production of this paper and there are no commercial or other conflicts of interest in connections with its submission.

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APPENDIX 1

Table 1

Symptoms included in the symptom categories created from the free text answers of the respondents in response to the quality of life question. The numbers in brackets relate to the number of reports

Category	Symptoms included
Neuropsychiatric (288)	Memory issues (68), Anxiety (54), Depression (42), Difficulty thinking (19), Organisation difficulties (17), Confusion (16), Change in mood an behaviour (13), Apathy (11), Poor attention span (7), Poor concentration (6), Stress (5), Lack of motivation (4), Difficulty with social interaction (4), All mental health issues (3), Hypersexuality (3), Hallucinations (2), Dementia (2), Impulsivity (2), OCD (2), Lack of patience (1), Attitude (1), Panic attacks (1), Frustration (1), Unstable Emotions (1), Lack of confidence (1), Executive dysfunction (1), Self-isolation (1)
Postural Instability & Gait Dysfunction (245)	Balance & falling (125), Difficulty walking (64), Freezing (52), Poor posture (3), Camptocormia (1)
Fatigue (186)	Tiredness (57), Lack of energy (46), Fatigue (42), Exhaustion (38) Lack of stamina (2), Weariness (1)
Autonomic Symptoms (170)	Urinary urgency (73), Incontinence (37), Erectile dysfunction (23), Excessive sweating (18), Dizziness (10), Dry eyes (5), Hot flushes (2), Dry mouth (1), Low blood pressure (1)
Sensory Symptoms	Pain (85), Blurred vision (18), Loss of sense of smell (17), Loss of sense of taste (12), Overstimulated by noise, lights and activity (2), Leg ache (2), Migraines & headaches (2)
Bradykinesia (121)	slowness of movement (106), Bradykinesia (8), poor mobility (6), legs not moving (1)
Tremor (112)	Tremor (112)
Rigidity (115)	Rigidity (55), Stiffness (37), Dystonia (13), Turning in bed (4), Muscle tightness/tension (3), Excessive sitting (2), Mask-like face (1)
Gastrointestinal Symptoms	Constipation (51), Swallowing (22), Drooling (18), Nausea (4), Choking (1), Diarrhoea (1)
Sleep Disorders (96)	Difficulty sleeping (41), Daytime sleepiness (22), Lack of sleep (11), Insomnia (7), REM sleep disorder (5), Sleep issues (4), sleep disturbance (4), Nightmares (2)
Speech (87)	Speech issues (87)
Dyskinesia (33)	Dyskinesia (33)
Health & Fitness (37)	Muscle weakness (15), Weight gain (11), Weight loss (5), Breathlessness (4), Exercise (1), General wellbeing (1)
Medication (14)	Medication wearing off (10), Effect of food on medication (4)
Other (43)	Fine motor difficulties (23), General restrictions of daily activities (7), Poor coordination (3), Having to give up work (2), Eyelid apraxia (2), Embarrassment (1), Lack of consideration (1), Gambling (1), Dignity (1), Clumsiness (1), Loss of control of dominant hand (1)

APPENDIX 2

Table 2

Symptoms included in the symptom categories created from the free text answers of respondents in response to the monitoring question. The numbers in brackets relate to the number of reports.

Category	Symptoms included
Neuropsychiatric (289)	Memory (45), Anxiety (45), Mood (38), Depression (29), Stress (24), Cognitive abilities (21), Thinking (18) Mental state (11), Concentration (10), Apathy (8), Confusion (8), Motivation (5), organisation (5), Impulsivity (4), Hallucinations (3), Behavioural changes (2), Attitude (2), Emotion (2), Confidence (2), Finishing things (1), Panic attacks (1), Delusions (1), OCD (1), Phobias (1), Aggression (1)
Postural Instability & Gait Dysfunction (242)	Balance & falling (120), Gait (71), Freezing (43), Posture (6), Arm swing (2)
Sleep disorders (164)	Sleep (163), Alertness (1)
Fatigue (125)	Energy (20), Lack of energy (18), tiredness (32), Exhaustion (16), Fatigue (37), lethargy (1), lack of stamina (1)
Rigidity (127)	Stiffness (26), Rigidity (52), Dystonia (45), Flexibility (3), Reaction time (1)
Bradykinesia (115)	Bradykinesia (5), Slowness of movement (56), mobility (10), movement (36), speed (5), Facial mask (3)
Tremor (122)	Tremor (122)
Health & Fitness (112)	Exercise & activity (36), Diet (16), Strength & weakness (16), Weight (14), Fitness (11), Wellbeing (9), Hydration (7), illness/injury (2), Progress of disease (1)
Sensory Symptoms (121)	Pain (78), Restless leg (14), Taste (6), Smell (7), Blurred vision (11), Tingling (2), Cold feet and legs (2), Migraine (1)
Autonomic Symptoms (91)	Urinary urgency (45), Incontinence (12), Sweating (10), Blood pressure (7), Dizziness (7), Erectile dysfunction (4), Need to get up at night (2), Dry eyes (2), Premature ejaculation (1), Dry mouth (1)
Gastrointestinal Symptoms (73)	Constipation (38), Swallowing (15), Gut problems (8), Dribbling (8), Nausea (4)
Speech (65)	Speech issues (65)
Medication (60)	Medication (reminder, time, amount, missed doses)/on/off periods (51), Effect of food on medication (8), Effect of non-PD medication (1)
Dyskinesia (38)	Dyskinesia (38)
Other (34)	Fine motor movements (22), Coordination (5), Sociability (3), Lack of power (1), Expectation for the future (1), Frustration (1), Patience (1)

APPENDIX 3 – SURVEY QUESTIONS (SECTIONS 2–4)

Monitoring Parkinson's

In this section we would like to get an idea of your attitudes to technology and technology-based solutions for monitoring.

9. Are you interested in recording information about your Parkinson's to monitor your well-being?

Yes No

10. Do you currently record information about your Parkinson's to monitor your well-being?

yes no

11. If you answered yes to Question 10, Which of the following methods/tools do you use to assess your well-being? Please tick all that apply

- Keep a written diary
- Record times of meds taken: use an alarm for timing of meds Recollection and opinion of family and carers
- Self-Assessment Tool
- Plot information on a chart Quality of Life Dial
- Monitor from day to day only Own personal scale
- Apps (for mobile phones/tablets)
- Monitoring devices/sensors (e.g. speedometer, pedometers, heart-rate monitor, stop watch etc) Typing exercises
- Memory or logic games None
- Other (please specify)

12. How interested are you in using technology?

- Very interested
- Moderately interested
- Not very interested
- No interest at all
- Other (please specify)

13. What devices do you already use? (Choose any that apply or add your own)

- Computer (e.g. desktop, laptop, ipad) TV, DVD
- i-phone or smart phone Mobile phone
- Wii-fit
- Video/computer games
- Other (please specify)

Symptoms

This section is where we get to the nitty gritty of symptoms - really useful data

*14. What movement symptoms do you currently experience? (Please mark all that apply)

- Slowness of movement Tremor
- Rigidity
- Dyskinesia (involuntary movements)
- Dystonia (uncontrollable and sometimes painful muscle spasms)
- Balance problems Restless legs
- Festination (alteration in walking pattern e.g. quickening and shortening of normal strides)
- Difficulty instigating movement/Freezing Falling
- Others (please specify)

*15. Which non-movement related symptoms do you experience? (Please mark any that apply)

- Difficulty sleeping
- Hypersexuality
- Hallucinations
- Lack of energy
- Need to get up in the night
- Obsessive compulsive behaviour
- Daytime sleepiness
- Dry eyes
- Changes in behaviour/mood
- Tiredness/exhaustion
- Erectile dysfunction
- Inability to organise
- REM sleep behavioural disorder
- Tingling sensations
- Urinary urgency
- Constipation and other gut problems
- Difficulties with speech
- Confusion
- Difficulty swallowing
- Pain
- Repetitive behaviour
- Dribbling
- Memory problems
- Impulsive behaviour (e.g. gambling)
- Loss of sense of smell/taste
- Difficulties with thinking
- Poor attention span
- Nausea or vomiting
- Dementia
- Blurred vision
- Bowel incontinence
- Depression
- Double vision
- Excessive sweating
- Anxiety

- Dizziness
- Delusions
- Weight gain
- Weight loss
- Other (please specify)

16. In order of importance, what are the 5 symptoms (both movement and/or non-movement) which most affect your quality of life? (Please list the most important first)

17. What outside factors affect the state of your Parkinson's (negatively, positively or both)? (Please mark all that apply)

- Stress
- Sleeplessness/Sleep deprivation Diet
- Hydration
- Timing of medication Missing doses of medication Change of medication
- Allergies (e.g. hay fever, food)
- Injuries
- Non-Parkinson's medication e.g. for pain relief Weather
- Lack of exercise
- General sense of well-being Other illness
- Time of day Mood Relationships Pain
- Other (please specify)

18. How important to you is it to understand your own Parkinson's symptoms and recognise patterns in your condition?

- Very important
- Moderately important
- Not very important
- Not important at all
- Other (please specify)

19. If you had to choose any 5 symptoms to monitor continuously over a period of time, what would they be in order of importance? (Please list the most important first)

20. In monitoring these five symptoms, do you think they would help you improve your..... (Please tick all that apply)?

- Wellbeing
- Ability to Cope
- Understanding of Parkinson's
- Understanding of your own condition
- Expectations for the future
- Communication with your healthcare professional

- Treatment
- Other (please specify)

Communications

This section addresses communication between YOU and your healthcare team.

21. How important/beneficial is communication with your Parkinson's consultant?

- Very important
- Moderately important
- Not very important
- Not important at all
- Other (please specify)

22. When you have a Parkinson's appointment, who do you see? (Please tick all that apply)

- A Parkinson's specialist
- A neurologist
- A GP
- A Parkinson's Nurse Specialist
- A physiotherapist
- A speech therapist
- Other (please specify)

23. Do you communicate the full range of symptoms you experience in your appointment? If no, please explain why?

- Yes No
- Why?

24. Do you think your healthcare professional has a clear understanding of what you hope to achieve from your Parkinson's treatment? If no, please explain why?

- Yes No
- Why?

25. Approximately how frequently do you see/communicate with healthcare professionals or your Parkinson's healthcare team?

- Every month
- Every 2-3 months
- Every 4-6 months
- Every 7-11 months
- Once a year
- Other (please specify)