

Perceptions of People with Parkinson's on Non-motor Symptoms and Functional Ability

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ABSTRACT

Parkinson's is the fastest-growing neurological disorder worldwide, exhibiting motor and non-motor symptoms. The condition impacts individuals at multiple levels with both motor and non-motor symptoms (NMS). This study qualitatively explored perceptions of people with Parkinson's (PwP), NMS, and functional ability. Ten PwP took part in semi-structured phone or Zoom interviews. Data were analysed using the General Inductive Approach. Four major themes were identified: (a) diagnosis as a turning point; (b) non-motor symptoms and functional ability; (c) self-management; and (d) significant others. The themes were further classified into 13 subthemes and 10 categories. Interaction between the four themes also emerged from the data. A complex nuanced impact was found on the relationships between the individual and their significant others. People with Parkinson's experienced either a "vicious cycle" or a "virtuous cycle" of symptoms, which were dependent on a multitude of factors, for example, whether it is a "good" or "bad" day and the corresponding actions taken on these days. The findings provide key insights into tailoring advice and support into self-management of Parkinson's, particularly of actions that can be taken for better outcomes.

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INTRODUCTION

Parkinson's is one of the most common neurodegenerative disorders among the ageing population (de Lau & Breteler, 2006; Khan et al., 2017). The global prevalence of Parkinson's has increased by almost 2.5 times from 1990 to 2016 and is expected to rise exponentially (GBD 2016 Parkinson's Disease Collaborators, 2018).

The pathophysiology of Parkinson's is characterised by the death of dopaminergic neurons in the nigrostriatal pathway (Dauer & Przedborski, 2003), causing the cardinal motor symptoms of rigidity, bradykinesia, and resting tremors. Postural instability in Parkinson's, along with the cardinal motor symptoms, adversely affects the functional ability of the individual (Diab et al., 2014). However, non-motor symptoms (NMS) are also integral defining elements of the disease and include depression, anxiety, cognitive impairments, sleep disorders, and fatigue, which can also impact functional ability and quality of life (QoL) (Khedr et al., 2013).

While NMS are often more disabling than motor symptoms (Berganzo et al., 2016; Hermanowicz et al., 2019; Pfeiffer, 2016), they may remain unrecognised and unaddressed in the health care management, as the primary focus is usually on the motor aspects of the disease (Martinez-Martin et al., 2011). Moreover, as NMS reportedly appear years before motor

symptoms (Chaudhuri et al., 2006) individuals may not report them, as they may not be aware of their association with Parkinson's (Bostantjopoulou et al., 2013).

Previous studies show that NMS have a significant negative impact on health status and health-related quality of life (HR-QoL) (Hinnell et al., 2012; Soh et al., 2011). Quantitative research exploring the correlation between NMS and motor function in Parkinson's suggests that increased severity of NMS reflect decreased functional ability (Avanzino et al., 2018; Khoo et al., 2013; Lo Buono et al., 2021; Still et al., 2021). Although not very assertive, earlier studies with quantitative outcome measures suggested that functional ability and general wellbeing may be affected by the NMS (Khoo et al., 2013; Lo Buono et al., 2021). More recent quantitative findings suggest that functional disability was correlated with self-reported measures of depression and anxiety (Still et al., 2022). However, the insidious effect of NMS on health and wellness, and function, is not well understood or easily measured (Still et al., 2022).

Qualitative literature to date appears to have only explored individuals' perspectives following diagnosis with Parkinson's or the lived experiences of PwP (Gardenhire et al., 2019; Rutten et al., 2021; Soundy et al., 2014). While a range of themes have been identified, the common themes that are notable

across these studies are the lack of identity or new identity since diagnosis, recognition, acceptance, and readjustment to this new identity.

Collectively, it is inferred that exploring the perceptions of PwP would form a first step towards the recognition, acceptance, and readjustment to their NMS and functional abilities. This provides the rationale to qualitatively explore the extent of NMS impact upon functional ability in PwP. An improved understanding of individuals' perceptions could base the strategies that promote autonomy more clearly on people's needs, values, and beliefs (Zizzo et al., 2017). Therefore, this study aimed to explore PwP's perceptions of their disease, NMS, and functional ability with a qualitative study design by giving more emphasis to the voice of PwP.

METHODS

Study design

This study followed a qualitative design using one-on-one semi-structured remote (either via telephone or Zoom call) interviews with participants so that the breadth as well as richness of the perceptions of PwP could be captured (DeJonckheere & Vaughn, 2019). Data were then analysed with the General Inductive Approach (Thomas, 2006). Recruitment, data collection, and analysis occurred over 6 months in 2020. The study was approved by the University of Otago Human Ethics Committee (reference H20/048) and this report adheres to the standards for reporting qualitative research (O'Brien et al., 2014).

Participants

Recruitment

Participants were recruited from the New Zealand community primarily via electronic circulation of the recruitment flyers through the local Parkinson's Society. Participants were recruited and interviewed until data saturation was reached (Saunders et al., 2018). While a purposive sampling with people with range of functional abilities/disabilities was aimed for, due to the COVID-19 situation prevailing at the time, a convenience sampling of all participants who expressed interest and met the minimum criteria were included in the study.

Inclusion and exclusion criteria

Participants of any age, with a diagnosis of Parkinson's and with a range of motor symptoms and NMS were included. Participants with a severe cognitive disability and who were therefore unable to follow instructions or answer questions were excluded. The criteria for the cognitive impairment (item 1.1) described in the Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) was used to determine the "severity" of the participant's cognitive ability. According to this scale, "severe" cognitive dysfunction is when cognitive impairment precludes any "ability to carry out normal activities and social interactions" (Goetz et al., 2008, p. 2142). This criterion was used for ease of administration and to reduce participant burden by not undertaking an explicit cognitive assessment. The cognitive screening was completed by the primary researcher (CL, Honours research student) who was involved in the recruitment, scheduling, and conduct of the interviews. Participants who were unable to hold a conversation for more than 10 min (self-reported) were also excluded, as the

interview was estimated to be about 20–30 min long. No other criteria based on MDS-UPDRS were considered for inclusion/exclusion in the study.

Participant descriptors

The self-reported sections of the MDS-UPDRS were used to enable the description of participants. These sections were Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL) and Part II: Motor Aspects of Experiences of Daily Living (M-EDL). The MDS-UPDRS is a recommended descriptive measure of disease severity and is an improved version of the UPDRS which is the most widely used clinical rating scale for Parkinson's disease (Ramaker et al., 2002). Studies have also shown that the MDS-UPDRS has good reliability and validity, supporting its use in this study as a descriptive measure (Abdolahi et al., 2013). Participant demographic information, duration since Parkinson's diagnosis, and whether participants were taking medications for anxiety and/or depression were also collected.

Procedure

All potential participants who expressed interest were provided with the information sheet, consent form, and screening questionnaires (demographics and MDS-UPDRS). Individuals interested in participating returned the signed consent form and screening questionnaires. Participants returned the demographic questionnaire and self-reported parts of the MDS-UPDRS via email and any incomplete sections and questions were then clarified prior to the interview.

Twenty-eight participants showed interest in the study. Nobody was excluded for not meeting the criteria. After 10 interviews were completed, participants not interviewed but still interested in the study were advised they would be contacted should a second round of interviews be needed for data saturation. Due to the COVID-19 situation at the time all participants were interviewed either by telephone or video conferencing (Zoom). Regardless of the mode of the interview, all interviews were audio-recorded.

A semi-structured interview guide (Table 1) was developed by the first author (CL) in consultation with the other authors. All interviews were conducted by two researchers (CL and PJ), with CL as the lead interviewer and PJ as the second interviewer, documenting field notes. The interview guide comprised five open-ended questions and related prompt questions. While the open-ended nature of the questions allowed participants to elaborate on what was important to them, if they deviated too far from the research aim, the interviewer used the guide to steer them back to the core discussion. To ensure the interviewer and the interview guide were eliciting appropriate information in an unbiased, encouraging, and easy way, the interview was trialled and refined with an experienced qualitative researcher (LH) (Kallio et al., 2016).

The field notes made during each interview were used to verify and refine the questions for subsequent interviews (Morse et al., 2002) and to determine data saturation. The duration of each interview ranged from 19 to 38 min. No new information appeared to emerge at interview eight and this was confirmed by the subsequent two interviews (nine and 10). Therefore, data collection was concluded after the tenth interview.

Table 1*Interview Guide*

Major questions

1. What does Parkinson's disease mean to you?
2. Tell us how has Parkinson's disease affected your ability to do things that you usually do?
3. What is your understanding surrounding your emotions/feelings (*or any other related to apathy*) and your functional ability?
4. What worries you most about your Parkinson's disease? And tell us about your ability to manage it?
5. How has Parkinson's disease affected your overall general health?

Probing questions

1. You mentioned ... how did you feel about that? Could you tell me a little more?
2. How do you deal with that? What kind of things do you do to get around that?
3. Why is that important to you?
4. Please explain further.
5. Can you give us an example of that? When did you experience this?

Data analysis

The audio recordings of the interviews were transcribed verbatim by CL and, where Zoom was used, Zoom auto-transcription was downloaded and verified word by word by CL. Transcribed data were then analysed using the General Inductive Approach (Thomas, 2006). This approach was used as it allowed findings to emerge from the recurring themes in the data without being restrained by structural methodology or theoretical thematic analysis.

The following steps were employed in the analysis process: The transcribed interviews were initially read independently by two researchers (CL and PJ) to gain familiarity and an overall impression of the data. Several preliminary themes evolved during this process. After careful multiple readings of the transcripts, an initial set of 91 codes were identified independently by the two researchers. Subsequently, through multiple meetings and discussions between the two researchers, the codes were collapsed into categories and the categories were then collated as themes and subthemes. As an inductive thematic analysis approach was undertaken, themes in addition to the research aim were also developed from the data. Microsoft Office package tools were used in the data analysis and themes deduction process – with colour codes and smart art graphics.

Trustworthiness of data

Member checks ensured the accuracy, credibility, and validity of the findings. These checks involved seeking feedback from participants on a two-page summary of the findings.

Reflexivity

The research team comprised three individuals with physiotherapy backgrounds and one person with a health psychology background (NS). Two physiotherapists (PJ and LH) have both quantitative and qualitative research experience in Parkinson's and at least 10 years of clinical experience in working with PwP. The third physiotherapist (CL) was a research student who also has a clinical exercise science qualification. CL and PJ had an integral part in data collection and analysis, and in interpretation of the findings. LH and NS were involved as advisors at each stage of the study.

RESULTS

Ten participants who met the inclusion criteria were interviewed. Participant demographics are summarised in Table 2 and all participants have been given pseudonyms in the quotes to maintain their anonymity.

Table 2*Descriptive Characteristics of the Participants*

Characteristic	<i>M</i>	<i>SD</i>	<i>n</i>
Age (years)	63.7	10.8	
Sex			
Female			3
Male			7
Ethnicity			
New Zealand-European			8
Māori			1
British			1
Time since diagnosis (years)	3.4	2.1	
Medications for anxiety or depression			
No			9
Yes			1
MDS-UPDRS – non-motor symptoms	11.0	4.4	
MDS-UPDRS – motor symptoms	11.2	7.3	

Note. MDS-UPDRS = Movement Disorder Society Unified Parkinson's Disease Rating Scale.

From the analysis four themes emerged: (a) diagnosis as a turning point; (b) NMS and functional ability; (c) self-management; and (d) significant others. Under these four themes were 13 subthemes and accompanying categories (Table 3). Each theme and its subthemes are detailed below, illustrated by key supportive quotes. Further supporting quotes are detailed in Appendix A. Throughout the results and discussion section, the subthemes and categories are identified with italics and underlined phrases, respectively.

Table 3*Themes, Subthemes, and Categories*

Themes	Subthemes	Categories
Diagnosis – A turning point	Outlook in life (Perceived) societal stigma Loss of independence Worries about the future	A challenge in life A new beginning
Non-motor symptoms and functional ability	“Good” and “bad” days When “something goes wrong” Worse with comorbidities	Vicious cycle Virtuous cycle
Self-management	Exercise and staying active Successful coping strategies Understanding responses to medication	Acceptance Staying positive Active coping “Get on with it”
Significant others	Need for external support Being a burden Social interaction	Social interaction is helpful Social life is affected

Note. MDS-UPDRS = Movement Disorder Society Unified Parkinson’s Disease Rating Scale.

Diagnosis – A turning point

Diagnosis with Parkinson’s marks a turning point and affects an individual’s *outlook in life*. As Parkinson’s is a progressive long-term condition, many participants understandably perceived diagnosis as an added challenge causing difficulty in life. Peter commented that “I slowly but surely won’t be able to lead a normal life”. For others, however, a diagnosis with Parkinson’s brought about the chance for a new beginning and to try new things in life: “It means a brand-new direction ... it also means that life is better” (Jose) and “I have been exploring crazy things ... enjoying the freedom to do things” (Miriam).

The diagnosis also invariably led to loss of independence as symptoms often made it difficult to complete activities of daily living unaided causing a concern. Mary commented that “What worries me the most ... being not able to do things for myself”.

Many participants also had worries about the future due to the progressive nature of the condition. For example, “I don’t know what’s going to happen. I don’t know when it’s going to happen. And I find that the hardest to deal with” (Rod). Unsurprisingly, several participants reported the *feeling of being stigmatised by society* because they had Parkinson’s: “I have met a couple here that sort of looked at me differently. You know, they kind of judge me” (Christy); “concerned, a little bit about what they might be thinking” (Mark).

NMS and functional ability

In this theme, participants described how their NMS and motor symptoms interacted with each other causing them to have “good” and “bad” days, and how events that happen

on these days and the corresponding actions they took could either culminate in a vicious or virtuous cycle. A vicious cycle to participants was defined as a negative series of events that reinforced each other. For example, Paul said:

I’d sit down at the piano, feel great about playing and within a few minutes, my hands would start locking up and I’d lose the motivation to do that thing that I used to love doing. It was like feeding back into each other.

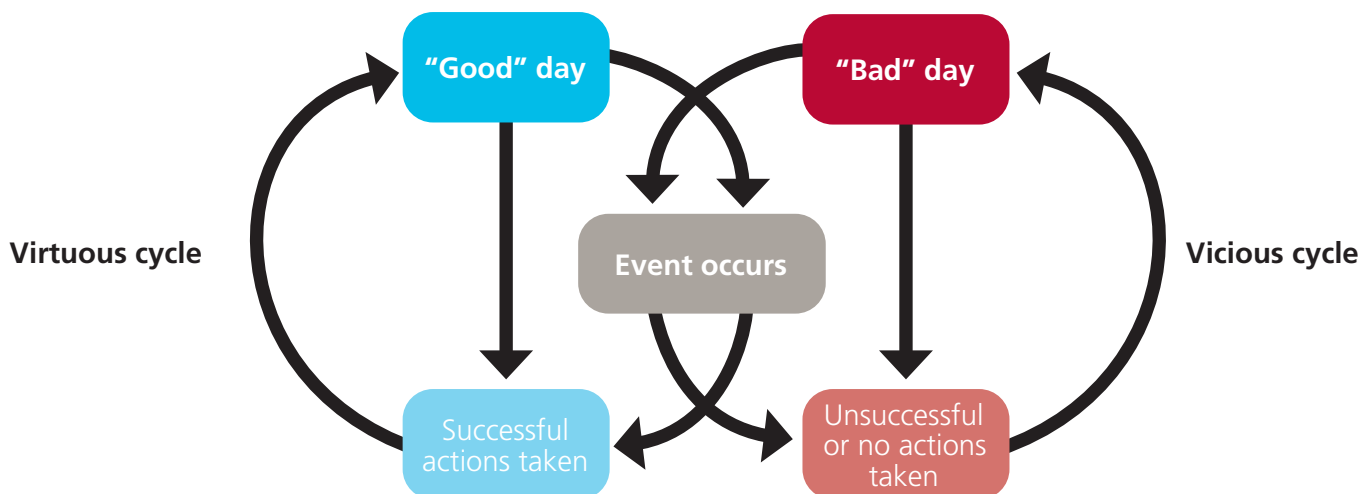
On the other hand, a virtuous cycle was a positive feedback loop where one positive occurrence led to and reinforced another positive experience.

You might get up in the morning and feel a bit depressed, like feel sorry for yourself, that you’ve got Parkinson’s, and it just gets you down, but then you get out and do something and you come round again. (Peter)

A vicious or virtuous cycle, however, could happen on either a “good” or “bad” day (Figure 1). The most important factor leading to the culmination of a vicious or virtuous cycle was the actions taken by the individual on that day, and whether those actions ended up being successful to remedy the situation or not. Participants also commonly reported that symptoms are exacerbated when something goes wrong. This could refer to any unexpected occurrence, and usually worsened NMS, motor symptoms, or both: “If something kind of comes out that I wasn’t expecting, suddenly my anxiety goes through the roof. I might start feeling a bit of depression, I kind of really struggle” (Jose).

Figure 1

Vicious and Virtuous Cycle of "Good" and "Bad" Days



Christy also said that:

I've always done a lot of craft work and I keep doing it because I don't really want to lose the use of my hands. Most of the time I manage, but there are some times that when things go drastically wrong, I get really angry.

The symptoms of Parkinson's were also worse with comorbidities such as a coexisting medical condition, or even a common illness such as the cold or 'flu. For example, Christy, who also suffers from gluteal tendinopathy, mentioned that "... the thought of having to put up with this for the rest of my days, as well as the Parkinson's is a bit much, really".

Self-management

Most participants considered self-management of the symptoms and condition to be key in Parkinson's. The chronic and progressive nature of the condition prompted individuals to do something to help themselves by improving their situation or symptoms. *Exercise and staying active* was reported to be vital, and several participants agreed. The use of various *coping strategies* such as acceptance, staying positive, active coping, and to simply get on with it was beneficial to help individuals cope with managing their condition. For example, Peter said "I'd go for a bike ride and some exercise, go for a walk, just get on with life, basically. Go out in the garden, you can't just sit there and feel sorry for yourself". This combination of staying positive, using an active coping style, and to "get on with it" helped him manage his condition. This was also supported by two others: "Never mind what you used to be able to do, it's what can I still do?" (Ben) and "I'm just taking it as it comes. I mean, it's a new normal for me and I gotta accept that" (Mark).

Of further importance for self-management was understanding individual responses to medication. Most participants talked about the trial and error process of working out when or not to take their medications, as suggested by Mark and Miriam: "It's a matter of working out the best means of when to take medication, when and when not to eat it separate, because

eating does tend to interfere ..." (Mark). "That's been really important experimenting with the dosage to get that right and learning when I can eat with meds, with the pills and when I can't" (Miriam).

Significant others

Many participants talked about needing *external support* to help in managing their condition, be it from the government, healthcare professionals, or family members, as Miriam explained: "Because I just know that I can't do it. So, I'm going to get someone else to do as much as I need". Because of this, some individuals worried about *being a burden* to others since they needed help a lot of the time. For example, Mary said "being not able to do things for myself, you kind of think you're going to be a burden".

Living with Parkinson's also *affects the individual's social life*. Participants reported fatigue as a notable NMS that incited the need to reduce socialising time or significantly modify their social habits. For example, Paul said: "Socialising usually happens towards the end of the day, and that's where I'm struggling the most to actually move around". Conversely, some participants saw *social interaction* with significant others in a more positive light and talked about enjoying it and using it as a helpful means of coping with the condition. For example, Jose said that "socialising has been great. I have a very good social network of support. So, I talked to people a lot. Not necessarily about the disease although that's helpful".

Interaction of the four major themes

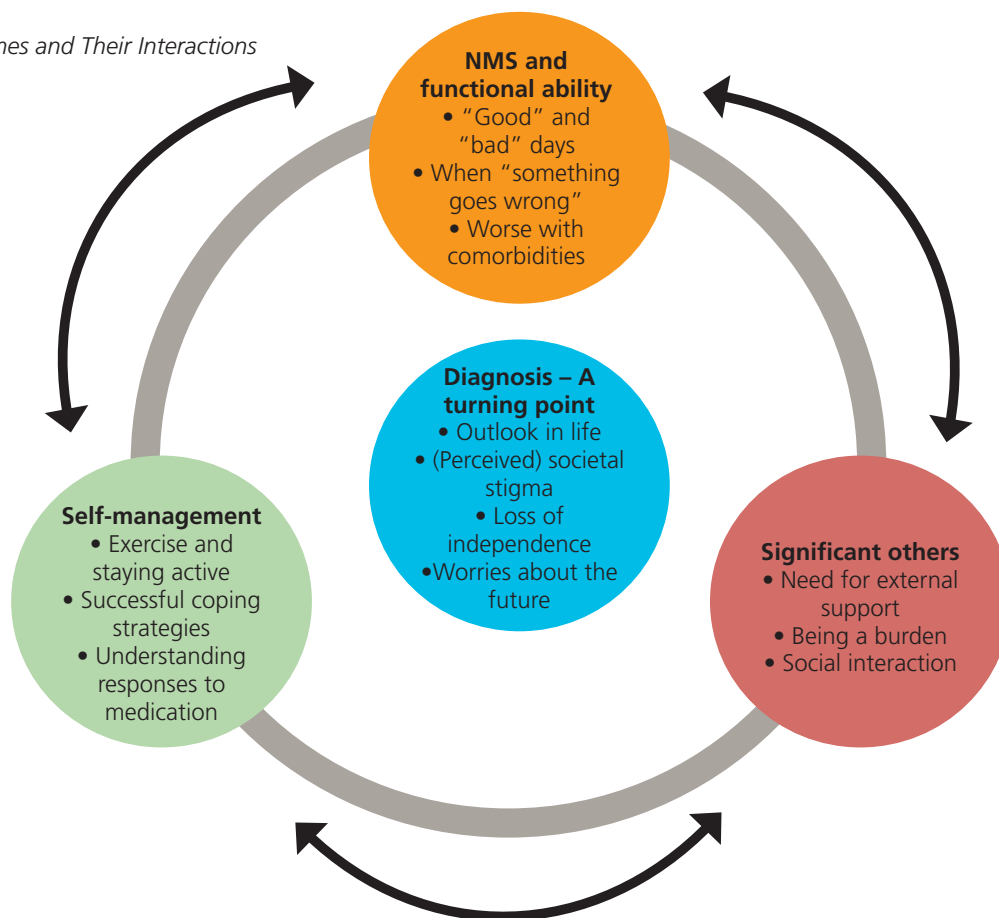
We further identified an interaction between the four themes (Figure 2) and this is elaborated on in the Discussion section.

Trustworthiness of data

Four participants responded to the summary of our key findings, and all agreed with the findings. Two agreed strongly with the findings and said, "could identify with almost all the quotes" (Miriam) and "the quotes overall really do seem to summarise how (they) personally feel about this accursed disease" (Ben).

Figure 2

Four Major Themes and Their Interactions



This is significant as these participants could identify with things they did not personally talk about in the interview but were brought up by others.

DISCUSSION

The purpose of this study was to better appreciate the lived experiences and perceived relationship between NMS and functional ability in PwP. Four themes were identified: (a) diagnosis as a turning point; (b) NMS and functional ability; (c) self-management; and (d) significant others. These themes had a complex interaction (Figure 2) which is discussed below.

This study showed that *diagnosis* was the cornerstone, marking a turning point in the individual's life, echoing findings of previous studies that explicitly explored participants' thoughts and feelings of their diagnosis of Parkinson's (Gofton & Jog, 2008; Maffoni et al., 2019) Although the initial response was one of negative emotions, most participants then either ended up seeing Parkinson's as an added challenge in life or a new beginning, which is similar to the findings of Soundy et al. (2014). For several participants, the diagnosis of Parkinson's was one of relief, as it provided them with an explanation for the various changes they had been experiencing.

Apart from affecting the individual, Parkinson's also impacts upon their relationship with significant others, as shown in previous literature (Caap-Ahlgren & Dehlin, 2002; Kessler

& Liddy, 2017; Roland et al., 2010). However, rather than a one-way dependence of those with Parkinson's on others, as previously reported, the age range (41–79 years) of participants in this study meant some were the main carers for people such as children, highlighting an interdependence and mutual reliance with their significant others.

As Parkinson's is a progressive long-term condition, it initiates the need for *self-management* of the symptoms and the condition. Whether participants saw their diagnosis as a challenge in life or a new beginning, all shared their experiences of using strategies to cope with and self-manage their condition. Previous research has shown that enabling and supporting PwP to self-manage is an effective strategy and supports a paradigm shift in healthcare from clinician-focused to person-centred (Lim et al., 2020; Tickle-Degnen et al., 2010).

There was a mutual interaction between *NMS and functional ability* and *self-management*. The finding that the complex array of NMS, and changes in functional ability necessitated participants' self-management, to cope with their situation or to improve symptoms, agreed with previous studies (Hellqvist et al., 2018; Kessler & Liddy, 2017). For example, when participants felt down, they talked about using exercise or active coping strategies to improve mood and wellbeing. No participants overtly identified what self-management they did to deal with their condition. However, the various strategies

cited appeared to be a reactive coping mechanism to deal with the symptoms of Parkinson's and thus could be described as "self-management". While self-management programmes have been promoted in the move towards active person-centred care (Chenoweth et al., 2008; Lyons, 2004), no participants mentioned having received advice from healthcare professionals on "self-management strategies", which is in alignment with the previous findings of Vlaanderen et al. (2019). Our findings demonstrate how participants had developed their own ways of dealing with their condition, signifying advancing self-management skills that could still be unmet as reported earlier (Vlaanderen et al., 2019). Although participants were not aware they were demonstrating self-management behaviour, they perceived their coping strategies as useful and effective to improve their mood and wellbeing.

There was also a mutual interaction between *self-management* and *significant others*.

As reported in past research, significant others also played a major role in participants' self-management journey (Gallagher et al., 2008; Kessler & Liddy, 2017). Participants talked about the importance of interacting with health professionals for managing their condition, or the use of social interaction as a successful active coping strategy to improve symptoms, which is supported by other study findings (Chenoweth et al., 2008; Gallagher et al., 2008; Lim et al., 2020). As participants did not explicitly state they had learnt self-management skills via their health care provider, it appeared their social interactions with their peers helped in self-managing their condition. Social self-management is not a new concept in Parkinson's and has been reported earlier (Tickle-Degnen et al., 2020).

A mutual interaction between *NMS* and *functional ability* and *significant others* was also evident. A novel finding of this study was that the social interaction could possibly trigger a vicious cycle of worsening NMS and/or functional ability. For example, one participant talked about comparing their current ability to other people in their life and getting angry at themselves, their negative emotions, and feelings of depression. A similar emotion was reported by another participant ("... so, singing in a choir or whatever, I tend to get a bit nervous" (Mark)) which worsens his tremors and in turn increases his feelings of anxiety and nervousness.

As reported by other studies, the presence of symptoms increases the need for external support from others, such as a health professional, friends, or family members (Hermanns, 2013; Lyons, 2004; Ma et al., 2016; Soundy et al., 2014). This reliance causes PwP to worry about whether they are a burden to the people around them (Gupta & Bhatia, 2000; Hermanns, 2013; Verity et al., 2020). The complexity of the impact of social interactions is shown in the apparent contradiction of social interaction sometimes being helpful in improving mood (Gupta & Bhatia, 2000; Tickle-Degnen et al., 2020) and sometimes being unhelpful in causing more fatigue (Gupta & Bhatia, 2000).

Strengths and limitations of the study

This is the first known qualitative study to explore the perceived relationship between NMS and functional ability in PwP. While the primary interviewer was a research student, they were trained

prior to data collection and an experienced qualitative researcher was present during all 10 interviews to ensure rigour of data collection. Independent parallel coding was performed to account for different interpretations of data and enhance consistency in the data analysis process. In addition, member checks were performed to improve trustworthiness and credibility of analysis; both processes are considered strengths of the study.

It is however important to note that this study was undertaken during COVID-19 and findings may reflect the situation of that period. Although data saturation was reached, the findings are the perceptions and experiences of 10 individuals living in New Zealand and these participants did not have a wide range of NMS, functional limitations, or disease duration.

By highlighting the interplay between function and NMS, findings from this study may guide future research in management strategies for health practitioners and PwP. It may also help to encourage the contemporary paradigm shift to a point where disease evaluation and management always consider the perspectives of the individual.

CONCLUSION

This study highlights the importance and the need for supporting PwP to build strategies, skills, and confidence to self-manage their condition. A key finding to inform clinical practice is that individuals experience either a "vicious cycle" or a "virtuous cycle" of symptoms, which is dependent on a multitude of factors. However, the outcome of a day being a "good" day is dependent on positive action regardless of whether it was a good or a bad day to begin with.

KEY POINTS

1. The relationship between NMS and functional ability in people with Parkinson's is still largely underexplored.
2. Four themes were identified in this qualitative study, with complex interaction between the themes.
3. Individuals generally experience either vicious or virtuous cycles of symptoms, which influence their functional ability.
4. An outcome of "good" day is dependent on positive action regardless of how good or bad a day it was to begin with.

DISCLOSURES

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

This study was approved by the University of Otago Human Ethics Committee (reference H20/048).

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CONTRIBUTIONS OF AUTHORS

Conceptualisation, CL and PJ; methodology, CL, LH, NS and PJ; validation, CL, LH and PJ; formal analysis and investigation, CL and PJ; data curation, CL; writing—original draft preparation, CL; writing—review and editing, LH, NS and PJ; visualisation, CL; supervision, LH, NS and PJ.

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REFERENCES

- Abdollahi, A., Scoglio, N., Killoran, A., Dorsey, E. R., & Biglan, K. M. (2013). Potential reliability and validity of a modified version of the Unified Parkinson's Disease Rating Scale that could be administered remotely. *Parkinsonism & Related Disorders*, *19*(2), 218–221. <https://doi.org/10.1016/j.parkreldis.2012.10.008>
- Avanzino, L., Lagravinese, G., Abbruzzese, G., & Pelosin, E. (2018). Relationships between gait and emotion in Parkinson's disease: A narrative review. *Gait & Posture*, *65*, 57–64. <https://doi.org/10.1016/j.gaitpost.2018.06.171>
- Berganzo, K., Tijero, B., González-Eizaguirre, A., Somme, J., Lezcano, E., Gabilondo, I., Fernandez, M., Zarranz, J. J., & Gómez-Esteban, J. C. (2016). Motor and non-motor symptoms of Parkinson's disease and their impact on quality of life and on different clinical subgroups. *Neurologia*, *31*(9), 585–591. <https://doi.org/10.1016/j.nrl.2014.10.010>
- Bostantjopoulou, S., Katsarou, Z., Karakasis, C., Peitsidou, E., Milioni, D., & Rossopoulos, N. (2013). Evaluation of non-motor symptoms in Parkinson's disease: An underestimated necessity. *Hippokratia*, *17*(3), 214–219. <https://www.ncbi.nlm.nih.gov/pubmed/24470730>
- Caap-Ahlgren, M., & Dehlin, O. (2002). Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging Clinical and Experimental Research*, *14*(5), 371–377. <https://doi.org/10.1007/BF03324464>
- Chaudhuri, K. R., Healy, D. G., Schapira, A. H., & National Institute for Clinical Excellence. (2006). Non-motor symptoms of Parkinson's disease: Diagnosis and management. *The Lancet. Neurology*, *5*(3), 235–245. [https://doi.org/10.1016/S1474-4422\(06\)70373-8](https://doi.org/10.1016/S1474-4422(06)70373-8)
- Chenoweth, L., Gallagher, R., Sheriff, J. N., Donoghue, J., & Stein-Parbury, J. (2008). Factors supporting self-management in Parkinson's disease: Implications for nursing practice. *International Journal of Older People Nursing*, *3*(3), 187–193. <https://doi.org/10.1111/j.1748-3743.2008.00123.x>
- Dauer, W., & Przedborski, S. (2003). Parkinson's disease: Mechanisms and models. *Neuron*, *39*(6), 889–909. [https://doi.org/10.1016/s0896-6273\(03\)00568-3](https://doi.org/10.1016/s0896-6273(03)00568-3)
- de Lau, L. M., & Breteler, M. M. (2006). Epidemiology of Parkinson's disease. *Lancet Neurology*, *5*(6), 525–535. [https://doi.org/10.1016/S1474-4422\(06\)70471-9](https://doi.org/10.1016/S1474-4422(06)70471-9)
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health*, *7*(2), Article e000057. <https://doi.org/10.1136/fmch-2018-000057>
- Diab, K. S., Hale, L. A., Waters, D. L., & Skinner, M. A. (2014). Factors contributing to postural instability in patients with idiopathic Parkinson's disease. *Physical Therapy Reviews*, *19*(5), 302–327. <https://doi.org/10.1179/1743288x14y.0000000148>
- Gallagher, R., Donoghue, J., Chenoweth, L., & Stein-Parbury, J. (2008). Self-management in older patients with chronic illness. *International Journal of Nursing Practice*, *14*(5), 373–382. <https://doi.org/10.1111/j.1440-172X.2008.00709.x>
- Gardenhire, J., Mullet, N., & Fife, S. (2019). Living with Parkinson's: The process of finding optimism. *Qualitative Health Research*, *29*(12), 1781–1793. <https://doi.org/10.1177/1049732319851485>
- GBD 2016 Parkinson's Disease Collaborators. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *The Lancet. Neurology*, *17*(11), 939–953. [https://doi.org/10.1016/S1474-4422\(18\)30295-3](https://doi.org/10.1016/S1474-4422(18)30295-3)
- Goetz, C. G., Tilley, B. C., Shaftman, S. R., Stebbins, G. T., Fahn, S., Martinez-Martin, P., Poewe, W., Sampaio, C., Stern, M. B., Dodel, R., Dubois, B., Holloway, R., Jankovic, J., Kulisevsky, J., Lang, A. E., Lees, A., Leurgans, S., LeWitt, P. A., Nyenhuis, D., ... Movement Disorder Society, U. R. T. F. (2008). Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale presentation and clinimetric testing results. *Movement Disorders*, *23*(15), 2129–2170. <https://doi.org/10.1002/mds.22340>
- Gofton, T. E., & Jog, M. (2008). Diagnosing Parkinson's disease: The patient perspective. *The Canadian Journal of Neurological Sciences*, *35*(4), 510–512. <https://doi.org/10.1017/s0317167100009227>
- Gupta, A., & Bhatia, S. (2000). Psychological functioning in patients with Parkinson's disease. *Parkinsonism & Related Disorders*, *6*(3), 185–190. [https://doi.org/10.1016/s1353-8020\(00\)00010-9](https://doi.org/10.1016/s1353-8020(00)00010-9)
- Hellqvist, C., Dizdar, N., Hagell, P., Berterö, C., & Sund-Levander, M. (2018). Improving self-management for persons with Parkinson's disease through education focusing on management of daily life: Patients' and relatives' experience of the Swedish National Parkinson School. *Journal of Clinical Nursing*, *27*(19–20), 3719–3728. <https://doi.org/10.1111/jocn.14522>
- Hermanns, M. (2013). The invisible and visible stigmatization of Parkinson's disease. *Journal of the American Association of Nurse Practitioners*, *25*(10), 563–566. <https://doi.org/10.1111/1745-7599.12008>
- Hermanowicz, N., Jones, S. A., & Hauser, R. A. (2019). Impact of non-motor symptoms in Parkinson's disease: A PMDAAlliance survey. *Neuropsychiatric Disease and Treatment*, *15*, 2205–2212. <https://doi.org/10.2147/NDT.S213917>
- Hinnell, C., Hurt, C. S., Landau, S., Brown, R. G., Samuel, M., & PROMS-PD Study Group. (2012). Nonmotor versus motor symptoms: How much do they matter to health status in Parkinson's disease? *Movement Disorders*, *27*(2), 236–241. <https://doi.org/10.1002/mds.23961>
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965. <https://doi.org/10.1111/jan.13031>
- Kessler, D., & Liddy, C. (2017). Self-management support programs for persons with Parkinson's disease: An integrative review. *Patient Education and Counseling*, *100*(10), 1787–1795. <https://doi.org/10.1016/j.pec.2017.04.011>
- Khan, M. A., Quadri, S. A., & Tohid, H. (2017). A comprehensive overview of the neuropsychiatry of Parkinson's disease: A review. *Bulletin of the Menninger Clinic*, *81*(1), 53–105. <https://doi.org/10.1521/bumc.2017.81.1.53>
- Khedr, E. M., El Fetoh, N. A., Khalifa, H., Ahmed, M. A., & El Beh, K. M. (2013). Prevalence of non motor features in a cohort of Parkinson's disease patients. *Clinical Neurology and Neurosurgery*, *115*(6), 673–677. <https://doi.org/10.1016/j.clineuro.2012.07.032>
- Khoo, T. K., Yarnall, A. J., Duncan, G. W., Coleman, S., O'Brien, J. T., Brooks, D. J., Barker, R. A., & Burn, D. J. (2013). The spectrum of nonmotor symptoms in early Parkinson disease. *Neurology*, *80*(3), 276–281. <https://doi.org/10.1212/WNL.0b013e31827deb74>
- Lim, K. E., Kim, S. R., Sung, Y. H., Oh, S.-Y., Kim, M. S., & Chung, S. J. (2020). Factors influencing self-management in Parkinson's disease: A cross-sectional study. *Geriatric Nursing*, *41*(3), 254–260. <https://doi.org/10.1016/j.gerinurse.2019.10.005>

- Lo Buono, V., Palmeri, R., De Salvo, S., Berenati, M., Greco, A., Ciurleo, R., Sorbera, C., Cimino, V., Corallo, F., Bramanti, P., Marino, S., Di Lorenzo, G., & Bonanno, L. (2021). Anxiety, depression, and quality of life in Parkinson's disease: The implications of multidisciplinary treatment. *Neural Regeneration Research*, 16(3), 587–590. <https://doi.org/10.4103/1673-5374.293151>
- Lyons, K. D. (2004). Self-management of Parkinson's disease: Guidelines for program development and evaluation. *Physical & Occupational Therapy In Geriatrics*, 21(3), 17–31. https://doi.org/10.1080/J148v21n03_02
- Ma, H.-I., Saint-Hilaire, M., Thomas, C. A., & Tickle-Degnen, L. (2016). Stigma as a key determinant of health-related quality of life in Parkinson's disease. *Quality of Life Research*, 25(12), 3037–3045. <https://doi.org/10.1007/s11136-016-1329-z>
- Maffoni, M., Pierobon, A., Frazzitta, G., Callegari, S., & Giardini, A. (2019). Living with Parkinson's—past, present and future: A qualitative study of the subjective perspective. *British Journal of Nursing*, 28(12), 764–771. <https://doi.org/10.12968/bjon.2019.28.12.764>
- Martinez-Martin, P., Rodriguez-Blazquez, C., Kurtis, M. M., Chaudhuri, K. R., & the NMSS Validation Group. (2011). The impact of non-motor symptoms on health-related quality of life of patients with Parkinson's disease. *Movement Disorders*, 26(3), 399–406. <https://doi.org/10.1002/mds.23462>
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13–22. <https://doi.org/10.1177/160940690200100202>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251. <https://doi.org/10.1097/acm.0000000000000388>
- Pfeiffer, R. F. (2016). Non-motor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders*, 22(Suppl 1), S119–S122. <https://doi.org/10.1016/j.parkreldis.2015.09.004>
- Ramaker, C., Marinus, J., Stiggelbout, A. M., & Van Hilten, B. J. (2002). Systematic evaluation of rating scales for impairment and disability in Parkinson's disease. *Movement Disorders*, 17(5), 867–876. <https://doi.org/10.1002/mds.10248>
- Roland, K. P., Jenkins, M. E., & Johnson, A. M. (2010). An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's disease. *Movement Disorders*, 25(2), 189–193. <https://doi.org/10.1002/mds.22939>
- Rutten, S., van den Heuvel, O. A., de Kruijff, A. J. T. C. M., Schoonmade, L. J., Schumacher, E. I. M., Vermunt, K., Hagen, R., van Wegen, E. E. H., & Rutten, K. (2021). The subjective experience of living with Parkinson's disease: A meta-ethnography of qualitative literature. *Journal of Parkinson's Disease*, 11(1), 139–151. <https://doi.org/10.3233/JPD-202299>
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Soh, S.-E., Morris, M. E., & McGinley, J. L. (2011). Determinants of health-related quality of life in Parkinson's disease: A systematic review. *Parkinsonism & Related Disorders*, 17(1), 1–9. <https://doi.org/10.1016/j.parkreldis.2010.08.012>
- Soundy, A., Stubbs, B., & Roskell, C. (2014). The experience of Parkinson's disease: A systematic review and meta-ethnography. *TheScientific World Journal*, 2014, Article 613592. <https://doi.org/10.1155/2014/613592>
- Still, A., Hale, L., & Jayakaran, P. (2022). The inter-relationship between various non-motor symptoms and with habitual physical activity in Parkinsonism: A scoping review protocol. *Physical Therapy Reviews*, 27(6), 444–452. <https://doi.org/10.1080/10833196.2022.2133885>
- Still, A., Hale, L., Swain, N., & Jayakaran, P. (2021). Self-reported depression and anxiety are correlated with functional disability in Parkinson's disease. *New Zealand Journal of Physiotherapy*, 49(1), 40–49. <https://doi.org/10.15619/NZJP/49.1.06>
- Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, 27(2), 237–246. <https://doi.org/10.1177/1098214005283748>
- Tickle-Degnen, L., Ellis, T., Saint-Hilaire, M. H., Thomas, C. A., & Wagenaar, R. C. (2010). Self-management rehabilitation and health-related quality of life in Parkinson's disease: A randomized controlled trial. *Movement Disorders*, 25(2), 194–204. <https://doi.org/10.1002/mds.22940>
- Tickle-Degnen, L., Stevenson, M. T., Gunnery, S. D., Saint-Hilaire, M., Thomas, C. A., Sprague Martinez, L., Habermann, B., & Naumova, E. N. (2020). Profile of social self-management practices in daily life with Parkinson's disease is associated with symptom severity and health quality of life. *Disability and Rehabilitation*, 43(22), 3212–3224. <https://doi.org/10.1080/09638288.2020.1741035>
- Verity, D., Eccles, F. J. R., Boland, A., & Simpson, J. (2020). Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease? *Journal of the Neurological Sciences*, 414, Article 116841. <https://doi.org/10.1016/j.jns.2020.116841>
- Vlaanderen, F. P., Rompen, L., Munneke, M., Stoffer, M., Bloem, B. R., & Faber, M. J. (2019). The voice of the Parkinson customer. *Journal of Parkinson's disease*, 9(1), 197–201. <https://doi.org/10.3233/JPD-181431>
- Zizzo, N., Bell, E., Lafontaine, A. L., & Racine, E. (2017). Examining chronic care patient preferences for involvement in health-care decision making: The case of Parkinson's disease patients in a patient-centred clinic. *Health Expectations*, 20(4), 655–664. <https://doi.org/10.1111/hex.12497>

APPENDIX A

THEMES, SUBTHEMES, CATEGORIES, AND SUPPORTING QUOTES

Figure A1

Diagnosis – A Turning Point

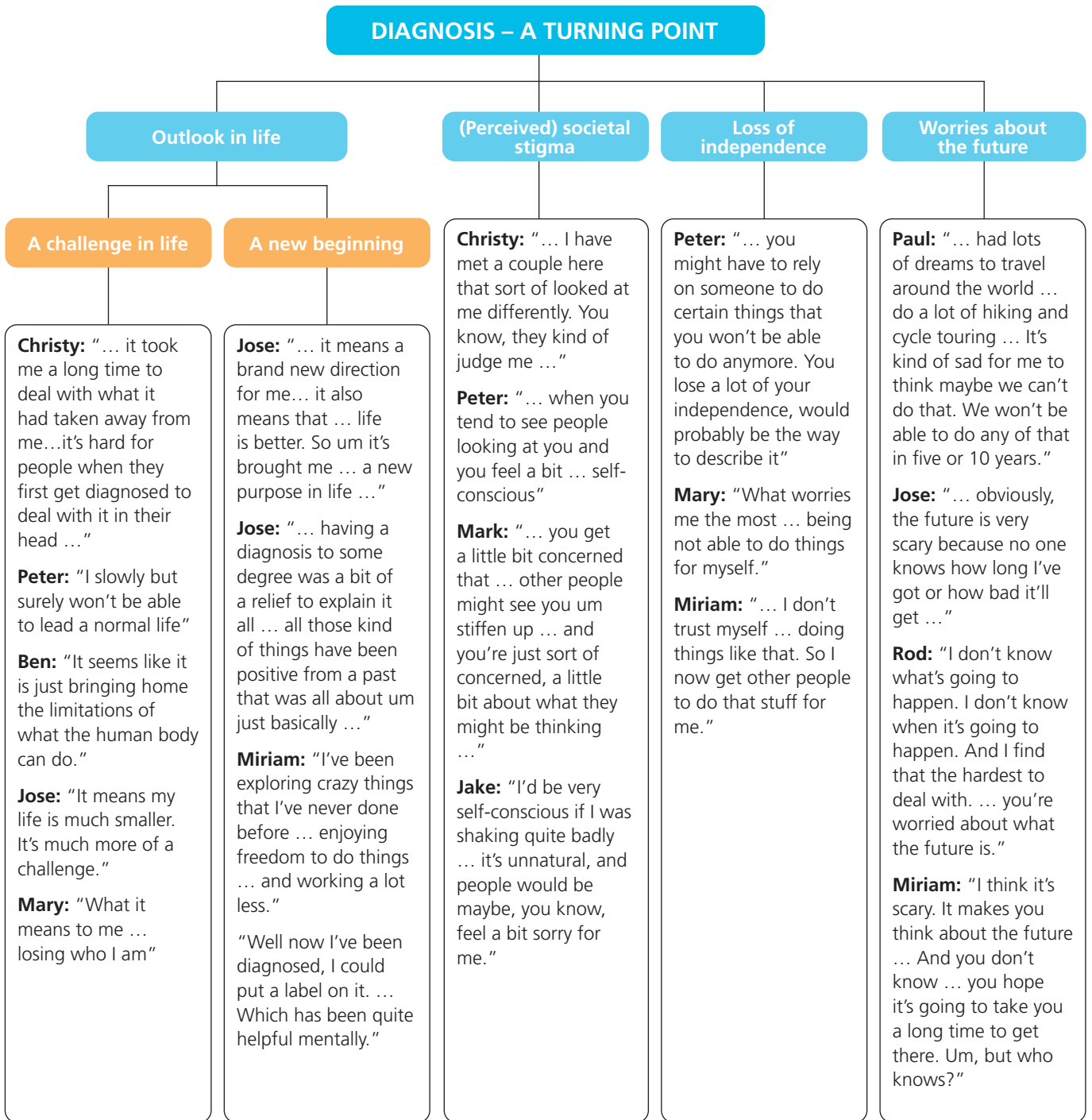


Figure A2
Self-management

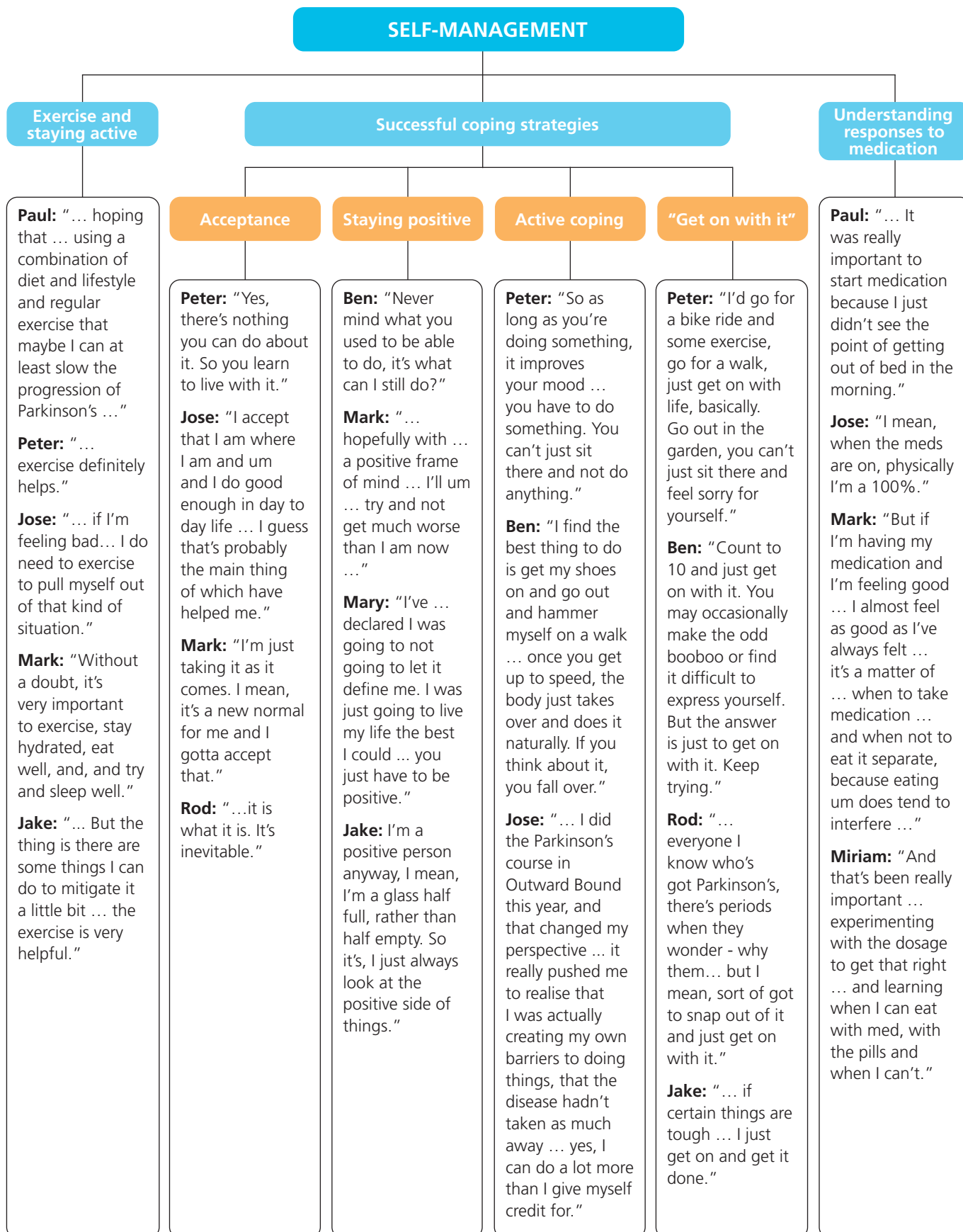


Figure A3

Non-motor Symptoms and Physical Function

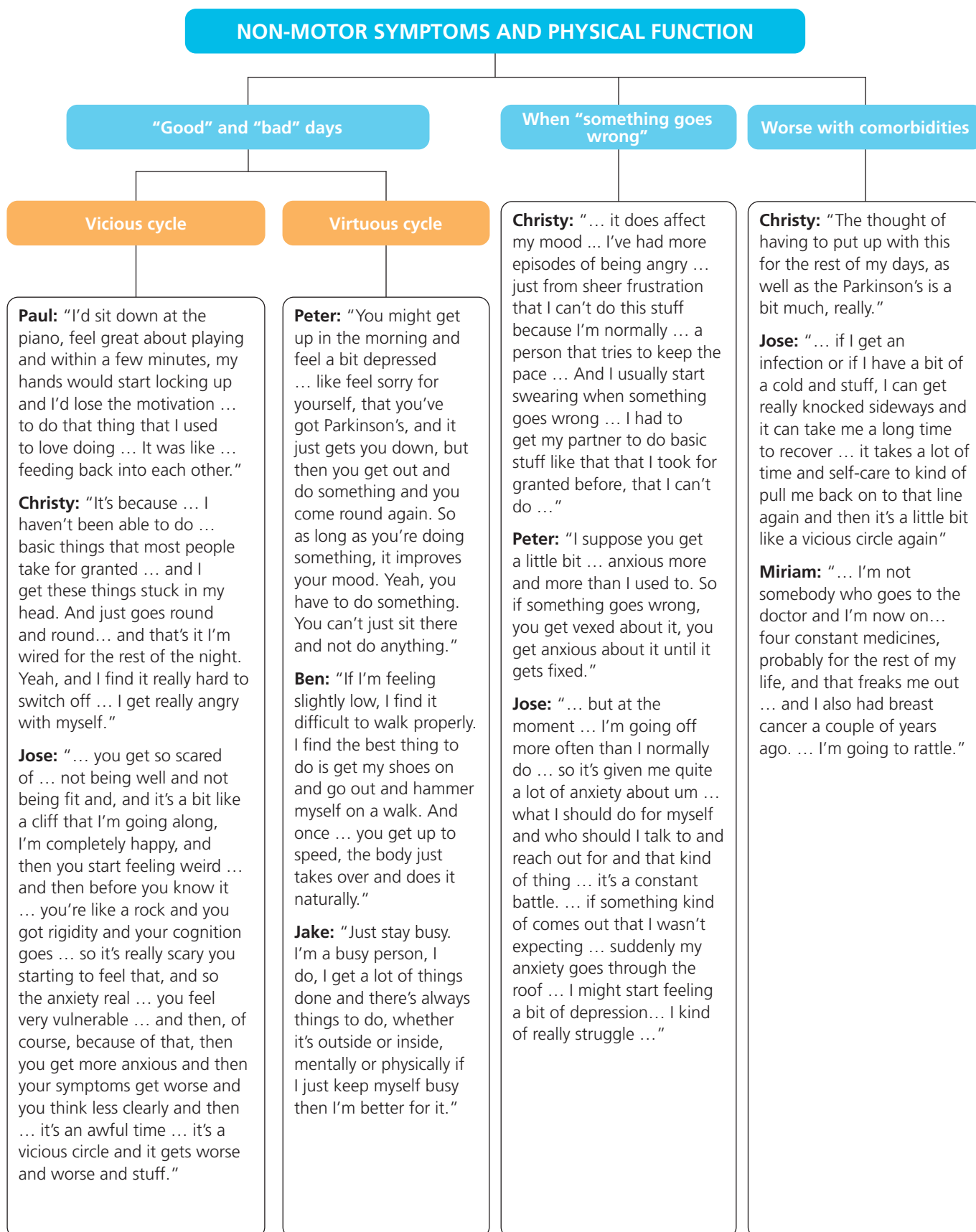


Figure A4
Significant Others

