

Supporting the journey to empowerment for people with Parkinson's through the person-centred lens of those living with Parkinson's.

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## **Abstract**

A therapeutic challenge arises when, consciously or unconsciously, a person relinquishes their active sense of personal autonomy for the passive role of 'patient'. This is particularly problematic in Parkinson's, an incurable neurodegenerative condition, but where a good quality of life is possible through patient self-efficacy and empowerment.

**Aims:** To explore through secondary data analysis 1) people with Parkinson's experiences from diagnosis to living with Parkinson's, including enabling and hindering factors for successful living with Parkinson's; and 2) the role and impact of healthcare professionals within this journey.

**Approach:** The data were generated originally as part of a Live Project marketing exercise conducted by undergraduate marketing students. Secondary analysis of this data was co-constructed by three people living with Parkinson's seeking to understand the impact of a Parkinson's diagnosis, and exploring internal and external factors influencing development of effective long term coping strategies.

**Findings:** Themes arising from this secondary analysis suggest that people with Parkinson's transition through four distinct stages to achieve empowerment, with progression and regression influenced by multiple variables, highlighting that the journey is not linear. Instrumental to progression is timely support from the Parkinson's community, healthcare professionals and peers. Levels of empowerment are associated with people with Parkinson's capacity to control their own management, and, crucially, the willingness and skills of healthcare professionals to adopt and encourage a partnership approach, grounded in person-centred practice. Paternalistic approaches reinforced patients' learned helplessness and deference, which risked blocking their journey towards self-empowered well-being.

**Conclusions:** Successful living depends upon developing empowered individuals facilitated through timely access to Parkinson's specialist healthcare professionals, support networks and peers. We suggest that services be reconfigured to promote true person-centred care, in which healthcare professionals:

- Adopt a person-centred approach to healthcare, fostering partnership
- Value people with Parkinson's lived experience,
- Provide them with knowledge and strategies for self-management

**What is already known on this topic:**

- Receiving a diagnosis of Parkinson's has a significant impact on health and well-being
- People with Parkinson's (PwP) often feel disempowered, helpless and in denial following diagnosis
- People who are empowered report better health outcomes

**What this paper adds:**

- A combination of peer support networks and Parkinson's specialist healthcare professionals (HCP) are integral in supporting PwP to achieve acceptance, autonomy and a sense of self-empowerment
- PwP progress through a series of stages on their way to living successfully with Parkinson's. However, this progression can fluctuate owing to physical changes in motor and non-motor symptoms, cognitive changes especially in mood, and psychological changes in their attitude towards their condition.
- PwP wish to be active partners in their care, recognising the expertise that both PwP and HCP bring to guide treatment and management decisions.
- Changes to service delivery are required to foster a participatory and integrative approach to healthcare delivery for PwP, founded on person-centred practice.

**Key Words:** Empowerment, self-efficacy, partnership, Parkinson's, peer support, and person-centred healthcare.

**Quotations:** All quotations in italics are from people with Parkinson's (PwP). Permission to use participants anonymous quotes was sought and approved through the Parkinson's UK Branch.

**Background:**

Globally Parkinson's is the second most common neurodegenerative condition, after Alzheimer's (Dorsey and Bloem, 2018). In 2016, worldwide, over 6.1 million people were living with Parkinson's (Dorsey et al, 2018). The prevalence of Parkinson's is predicted to rise by 50% by 2030 (Parkinson's UK, 2018), highlighting the need for effective healthcare interventions and services to manage this condition. Person centred care is central to UK and International healthcare policy, which encapsulates patients' preferences, values and advocates shared decision-making and partnership working (Scottish Government, 2019, World Health Organisation, 2013). However, translation of policy into practice is poor, with a European survey involving over 1500 participants reported that only 11.6% of PwP (n=2068) felt involved in their treatment decisions (Bloem and

Stocchi, 2015), with similar findings reported within North America (van der Eijk et al, 2015). Similar findings demonstrate that PwP want to be more actively involved in their management (Vlaanderen et al, 2019, Tennison et al, 2020), and identify the inability to self-manage as a key unmet need (Vlaanderen et al, 2019) suggesting changes to service delivery remain unmade. Rather than be recipients of care, PwP wish to be treated as equal partners, actively involved in decision-making. Self-management is a dynamic not a passive process, and reflects an ethos of empowerment, with patients taking personal responsibility for their own well-being *“50% of my wellness is down to my medication, but the other 50% is down to me”*. Self-management interventions endeavour to enhance the ability of individuals to improve their health status. A recent systematic review demonstrated that self-management is more successful when a person-centred approach between PwP and healthcare professionals is adopted (Peek et al, 2016), in which PwP are enabled to be active partners, and are treated as such.

Reliance on a provider led model disempowers and instils passivity among PwP (Vaartio-Rajalin et al, 2019, van der Eijk et al, 2013, Cockram et al, 2014). The World Health Organisation (WHO) advocates that health interventions should follow an integrated model, in which interventions are managed and discussed, with patients making health- and condition-related choices according to their needs (WHO, 2016). Implicit to integrated care is the emphasis upon collaboration between those living with the condition and service providers to optimise function and QoL. Adopting an integrative model requires a shift from an authoritative or paternalist model, to a participatory model of health, with equality between PwP, their carers, and healthcare professionals. The success of a participatory approach is dependent on well-informed, empowered PwP who have the tools and strategies to adapt and change as their condition changes, supported by staff with expertise in self-management and Parkinson’s (Kessler et al, 2017, Davies et al, 2017). While this approach is welcomed, it is not without challenge. A significant proportion of PwP report feeling disempowered, with over 50% (n=57) reporting that mechanisms to support self-management are *“generally not”* or *“never occurring in practice”* (Kessler et al, 2019), suggesting changes are required in how current services are configured to enable the practice of person-centred care. Achieving an integrated approach should be arguably be viewed as the health intervention goal, not as a starting point. Person-centred care allows for the HCP to be flexible, depending on a person’s need. Adopting a traditional medical model approach may be required initially to provide reassurance, to promote the development of self-confidence and capacity to become active partners in their care. However, the success of this is dependent upon PwP acquiring the

necessary knowledge and skills to enable active participation in their management. Adoption of effective self-management is essential to promote sustained behaviour change, and is the proposed mechanism to transition from healthcare provision, to a participatory integrated approach to health care delivery globally.

Patient empowerment and patient involvement in decision-making are central tenets of the international and national healthcare policies (WHO, Scottish Government, 2019). Rappaport (1987) defined empowerment as a process whereby “people gain mastery over their affairs”. Applied within the health context Funnel et al (1991) described empowerment as “helping patients discover and develop inherent capacity to be responsible for one’s own life”. The meaning of empowerment can infer a sense of power, a sense of control of their condition, which is frequently lacking in current service provision (Cockram et al, 2014) and is a principal determinant of poor quality of life (QoL) (Vandenberg et al, 2019). Rawlet (2014) proposes that empowerment is determined by one’s self-efficacy. Social cognitive theory proposed by Bandura (1998) associates self-efficacy with the ability to perform a task or behaviour. It is a person’s belief and capabilities to plan and take appropriate action to achieve personal goals. Self-efficacy is akin therefore to self-confidence or self-belief in one’s own ability or competence, to deal with prospective situations. However, the journey to achieving empowerment or enablement for PwP is poorly researched. While policy may advocate empowerment, in reality PwP report loss of identity, social isolation, loss of self-confidence, and low mood following diagnosis, suggesting a discord between what policy advocates and the real-life experience of PwP. A greater understanding of the experiences of PwP would inform the design and development of health interventions which integrate and support the needs of PwP, and support the adoption of an integrative person-centred approach to management. Empowerment in itself is not enough, PwP need to be: involved in treatment decisions; self-motivated to undertake/continue with activities such as exercise, volunteering, and the arts; and supported to build the resilience needed to continue activities when things are tough.

Qualitative studies can provide valuable information on lived experience, with potential to develop understanding, which could shape and inform developments towards a more integrative and equal relationship between healthcare providers and those with Parkinson’s. Moreover, enhanced understanding of the lived experience of Parkinson’s may help inform responsive services to support PwP as their condition evolves with time (Plouvier et al, 2018). The purpose of

this study was to explore the factors which influence the development of empowerment amongst PwP, in turn leading to effective long term coping strategies in lifestyle and attitudinal changes, and hence to improved wellbeing and quality of life.

### **Study Context**

In 2016 a project was conducted by undergraduate marketing students on behalf of a Branch of Parkinson's UK, exploring how the Branch might expand and diversify its active membership to better support PwP in the local area. The students' project was governed by their University's planned research guidelines, and their findings were presented to the Parkinson's community at a regular Branch monthly meeting. Immediately following the marketing students' presentation, the Branch members present at the meeting discussed the students' findings, generating ideas around the question: "What do I value about the Branch?" All views, opinions and perceptions were captured on post-it notes by scribes at each table. As these discussions were not part of the Live Project itself, the exact number of members present at the meeting, and taking part in the discussions was not recorded.

The discussions generated 74 post-it notes, each containing a single comment. These were subsequently transcribed and examined by AW, JS, and BW who are all individuals living with Parkinson's. The post-it notes were clustered in like-for-like groupings, and three main marketing themes, with suggested actionable sub-themes, emerged:

1. Who to target as new members
2. How to target/reach them
3. What activities/benefits would make it worth their while/entice them to join in.

The report was then passed to the Branch committee for further action.

This paper is based on the data gathered from the 74 post-it note comments from the Branch discussions. The authors had no prior expectation of anything other than marketing ideas emerging from the data. However, as they were working with the 74 post-it notes, ordering and re-ordering them into different clusters and categories, the authors recognised that as well as suggesting market approaches, the data were charting the approaches needed by PwP at different stages of their Parkinson's journey. It is from this observation that the model emerged on which this paper is based. Once their marketing findings were submitted to the Parkinson's UK Branch committee, the authors asked the committee for, and were granted, permission to analyse the

data further. Permission was also granted to use members' comments written on the post-it notes. Figure 1 illustrates the study's background, and how it emerged

Figure 1: attached as a separate file

The Branch meeting discussion groups were, in effect, a convenience sample of members from the Parkinson's UK branch. There were approximately 30 members present (PwP, carers and volunteers) ranging in age from 40 to 80 years with most members being 60 or over, and encompassing those who had been recently diagnosed, to those having lived with the condition for over 15 years.

### **Data analysis:**

The authors approached the data by physically laying out the post-it notes in like-for-like clusters, categorising themes as they started to emerge (for example, there were two distinct streams of data – those referring to newly-diagnosed PwP, and those referring to people finding it increasingly difficult to take part in Branch activities due to disease progression). The next stage – constructing concepts as the analysis progressed – saw the emergence of what was needed by newly-diagnosed PwP, including *“buddying (for newbies especially, and for others)”*, *“peer support”*, and *“proper plan for organising buddy contacts (needs a volunteer to get it started).”* The key contributions by health professionals (Parkinson's nurses, physiotherapists, and consultants) was also noted; as was *“Encourage newly diagnosed people to ‘come out’ that they have Parkinson's.”*

As the analysis progressed, the data revealed PwP needs at different stages of their condition, and the extent to which those needs had – or had not – been met. Needs identified included: *“Humour – more comedy about Parkinson's – can we get quotes from Paul Mayhew-Archer, Wobbly Williams, John McPhee??”* and *“How to advertise the fun side of the Parkinson's branch”* and *“emphasise and work on the changes to life, the new avenues to be explored.”* There was a strong theme of *“capturing experiences that help”* and *“moving from negative to positive”*. The three PwP authors also contributed their own data – their lived experience of Parkinson's – particularly reflecting on the role of mentoring, and being mentored by, other PwP.

The initial categories and themes that emerged were refined and developed through discussion, ensuring agreement in their identification. This process led to some of the original categories becoming subthemes of an overarching theme. A final check of the full set of themes was undertaken by re-testing them against the data to ensure that no key ideas had been omitted. Finally, four main themes were defined and named, as illustrated in the results section.

### **Findings:**

As the categories emerged from the data, it became clear that there were themes about support and community, and how PwP and partners coped with Parkinson's from diagnosis onwards. Interrogating the data, clustering and re-clustering the post-it notes, creating diagrams and drawings, a four-stage model emerged and was further informed by the three PwP's own experience of their respective Parkinson's journeys. *Figure 2* illustrates an early cluster set.

Figure 2: Early cluster set (attached as a separate file)

The analysis revealed several themes, which illustrated both the impact and psychosocial experiences of PwP following diagnosis. The emergent themes illustrated the needs of, and support required by, PwP in order to successfully transition from a state of impairment and isolation to one of empowerment, and belonging. The themes would suggest that PwP transition through four distinct stages as illustrated in figure 3. Subtheme analysis indicated that transition from isolation to empowerment was almost wholly dependent upon timely support from the Parkinson's community, HCP and peers. In stage 1, for example, the support from HCP was expected and sought, but support from peers – other PwP and their care-partners and local Parkinson's specific support groups – was either not known about or deliberately avoided: *"I don't want to know what my future might look like."* It was notable that as the PwP moved from one stage to the next, access to emotional support shifted from being predominantly HCP dependent in the first stage with little or no peer support, to being predominantly peer support in the latter stages. Through the stages, the nature of the HCP support changed from disease management (for example medication, symptom management advice) to wellbeing maintenance (for example exercise provision, links to therapies (eg voice therapy), information and research).

Figure 3: four staged journey to empowerment (attached as separate file)

### **Theme One: The shock of diagnosis**

In general, receiving a diagnosis of Parkinson's was associated with shock, even among those who had suspected that they had Parkinson's. The effect was dichotomous, associated with either a state of denial or fear of what the future holds. Regardless of direction, there was a sense of paralysis, isolation, and sudden and irreversible change in identity *"Will my husband still love me if I'm 'damaged goods'?"*. A sub theme of reliance and dependency for support during this stage of bewilderment emerged. For some this reliance was attributed to lack understanding of the condition, whereas for others it was due to apathy, denial, and disbelief: *"I found the nearest bucket of sand and stuck my head in it for eighteen months"*. While all PwP could relate to this period of bewilderment, and isolation, the duration varied. For some this period was brief, lasting a matter of weeks, with others reporting months. It is notable that some PwP who have attained stage 3 or 4 report regressing back to this first stage when they experience significant changes in motor and non-motor symptoms affecting their everyday lives. This suggests that the impact of Parkinson's on well-being is fluid, and determined by many complex and inter-related variables.

The second sub-theme which emerged was the value placed upon interventions during this first stage. Seeing healthcare professionals (HCPs) with expertise in Parkinson's was valued not only by those with Parkinson's but also by their families. Informed HCP's were perceived as catalysts, which enabled PwP to move out of a phase of bewilderment, and start to see life *with* Parkinson's as opposed to dwelling on life *before* Parkinson's. The role of the Parkinson's Specialist Nurses was particularly valued. PwP associated this stage with passivity, dependency, and reliance upon HCP's to make decisions of their behalf, as information was often overwhelming or simply too much to take in at this time. Parkinson's support groups, often in the form of cafes, dance classes, support groups and singing groups offered a non-threatening environment to develop understanding of Parkinson's, providing a safe forum to ask questions and an opportunity to meet fellow PwP. Others preferred to remain anonymous researching online websites to gain information. This would suggest a range of support is required from diagnosis, which is clearly signposted, and delivered by those with Parkinson's expertise either professional or lived experience or in combination.

### **Theme Two: Beginnings of hope.**

Analysis depicted a cautious transition for PwP from the fragility of diagnosis, to an exploratory mind-set of where this new perceived identity may lead them. Emotions of shock were replaced



by those of curiosity, and openness to new information, underpinned by a sense of moving forwards. PwP reported that this was a decisive step forwards in their Parkinson's journey, recognising having Parkinson's, but not yet accepting it. This was illustrated in the continued reliance on healthcare professionals, for support and guidance. PwP sensed a shift in the balance of the relationship, to one where they may ask questions, challenge assumptions, and seek clarity on Parkinson's as applied to them, not as an abstract condition that one may have. The stage was akin to raising one's head above the parapet. For many this was a bold, and confident step forwards, for others it was a demoralising endeavour. Success appeared dependent upon HCP's who were positive, adopting a supportive approach, enabling the development of self-efficacy and providing the building blocks to re-establish self-confidence. As such the relationship with HCP's shifted from complete reliance, to one whereby a HCP's ability to signpost, guide, be a sounding board, acting as a credible source was welcomed, while PwP explored, questioned, and challenged their new identity.

Shift in dependency away from HCPs was also evident in that PwP sought guidance from charities such as Parkinson's UK, whose local advisors offered a less medicalised environment to seek support, guidance and clarity, especially about practical and bureaucratic issues like benefits and blue parking badges. The perception that local advisors were willing to spend time, reduced anxieties about asking questions, or clarifying understanding. Others valued local advisors as a means to triangulate and verify their understanding of Parkinson's from what they had been told by HCP's and what they had read. Highlighting again the need for access to multiple support network from diagnosis.

A key sub-theme which also arose was willingness to explore support groups. The extent of exploring varied from attending branch meetings, cafes, discussion groups, research interest groups, carers groups, and self-management courses. These groups were diverse in nature and scope, with those focussed on Parkinson's and those not, valued in equal measure. Being among others provided opportunity for shared learning and experience, which remedied feelings of isolation, offering a sense of community. Support groups offered an informal environment, allowing people to freely articulate their concerns without fear of judgement or recrimination. The support groups were seen as somewhere to learn about the minor inconveniences of living with Parkinson's, for example, getting a radar key for accessing disabled toilets, a common craving for chocolate, and the impact of REM sleep disturbance (the standard Parkinson's joke is "I went to

bed, slept like a log, and woke up in the fireplace!”) At this point, PwP realised that their experiences were very often shared, and others had hints about how to manage them. The extent of participation varied with some simply attending, whereas others embarked on taking on informal roles, which served to fulfil a sense of purpose, and self-worth.

Overwhelmingly what emerged within this theme, was the importance of this early shift in relationship with HCP’s, support agencies such as local advisors, and with support groups. In combination, they provided PwP not only with a secure foundation to develop self-confidence but also, and arguably more importantly, provided PwP with the tools to rebuild their lives. Without which PwP often lacked direction, focus and a goal.

### **Theme 3: Growing trust and confidence**

Although Figure 3 illustrates the person with Parkinson’s journey as a cycle, the path and time taken to reach this stage of growing trust and confidence varied enormously. Factors such as strong support network for example from a partner and or family, and access to specialist HCP’s and services were associated with a quicker transition. Lack of support of any means, and significant changes in health either Parkinson’s related or not, were perceived as key barriers to achieving this stage.

In contrast to the prior two themes, this theme was associated with a sense of autonomy, and taking responsibility for oneself. The analogy of no longer sitting in the back seat of a car, rather PwP felt a sense of sitting in the front seat, with an established sense of the road ahead. This signalled a clear shift from dependency, facilitated by the development of knowledge acquired in the earlier phases, which enabled people to participate in decisions in relation to their own health and well-being. While notably positive, following the prior car analogy, PwP did not report being in the driving seat, therefore while PwP felt more informed, they remained as passengers, and as such not responsible for the direction of their care, or the decisions involved to direct this.

This new sense of confidence, also manifested in PwP having the confidence to attend group-based exercise, re-establishing old hobbies or discovering new ones, taking on more formal volunteering roles, identifying themselves as people who have something to offer, and are of value. This change appeared self-perpetuating in that the more PwP got actively involved, the greater the sense of achievement they felt, which served as a catalyst to take on more. This

promoted a sense of a new positive identity within the group, which had previously been lacking. This new-found confidence sprang from being amongst like-minded others, developing a positive ethos of peer support, friendship, underpinned by camaraderie, and humour. The support groups offered a sense of belonging to a community, and a secure place of support.

*“Friendship from a wonderful group of people, useful source of information, support for each other, interesting talks accompanied by tea, coffee and biscuits.”*

*“Our branch is most valuable asset for all of us with PD. It provides incredible number of activities for all tastes and abilities. We get support from each other.”*

*“Friendship, information and support for PwP AND CARERS. Sense of community. Hard work (but enjoyable).”*

Over half of the comments for members emphasised the importance of connection with people, particularly in shared understanding, belonging, feeling normal, being able to share experiences and tackle difficult subjects, like death. People appreciated the activities, particularly the variety of physical exercise classes, with specific mention of Tai Chi, Pilates, yoga, and neurodynamics, with the Branch widely perceived as a source of trusted information.

#### **Theme 4: Self-authority, and self-confidence**

There were two subthemes within theme 4. The first subtheme, self-authority and acceptance, is defined by participants’ perspectives on living with Parkinson’s. The second subtheme, giving back, is defined by participants’ perspectives providing mentorship, guidance and sharing their experiences with others with Parkinson’s.

Central to this theme is the reaching a sense of acceptance of having Parkinson’s. For PwP this represented a view that they were living with their Parkinson’s, as opposed to suffering from it. It is a state where they acknowledged that it has become part of who they are, but importantly not what defines them. In parallel to acceptance was a sense of self-authority or control over one’s own life, leading to a sense of empowerment. However, while this sense of enhanced control was widely acknowledged, conversely, frustration also existed. Discord appears to exist between

an activated and informed Parkinson's community, who wish to be actively involved in decisions central to the management of their Parkinson's, and the management approached adopted by HCP. Despite person-centred care being the central tenet of national healthcare policy, PwP experiences would suggest that some current service provision remains entrenched in paternalistic or authoritative approach to management *"It is almost impossible to get my consultant to spend more than five or ten minutes on a tick-box exercise, far less have a proper conversation"*. It can appear that staff are ill-prepared to accommodate informed patients, who wish to be active partners in their own care.

PwP wished to assume a partnership role in the direction of their care, but instead remained a passenger, with many HCPs failing to acknowledge the valued contribution PwP can make to the decision making process. Shared decision-making was unanimously supported, underpinned by mutual respect for the skill sets of both HCPs and those living with Parkinson's, thus adopting a more integrative approach.

Having reached stage four, many participants felt enabled and empowered to "give back", taking those new to living with Parkinson's under their wing. This giving back was done informally, but also involved more formal roles such as delivering the First Steps programme, which is a Parkinson's UK educational programme for people newly diagnosed, delivered by people with Parkinson's. This sense of empowerment was also reflected in participation in research, either as a participant, or co-designing future research ensuring research design is shaped to meet the needs of the Parkinson's community. The extent of confidence also led some to initiate and lobby for the development and enhancement of sustainable and accessible services for PwP.

Collectively, PwP drew strength from their involvement with the Parkinson's community, which offered a constant source of friendship, and support, which was valued in a non-linear condition such as Parkinson's. Shared experience galvanised the group, promoting self-efficacy, empowerment, and autonomy individually and collectively. While achievement of this stage could be perceived as the ultimate goal, PwP recognised that remaining in this stage was not guaranteed. For some, this served as a powerful motivator to take control of their future. This manifested in participation in regular exercise, adopting more physically active lifestyles, changing their diet, seeking non-pharmacological management options and researching further the

pathophysiology of Parkinson's. For others, the inevitability of regression was a source of anxiety, and fear. Time allowed PwP to develop strategies to live effectively with Parkinson's, yet progressing time was a tangible threat to maintaining this acceptance state. Changes to Parkinson symptom profiles or co-existing health or social circumstances, initiated a spiral of emotional decline, fuelled by associated anxiety, and changes to physical abilities. The impact of this decline resulted in feelings of anxiety, isolation and an overwhelming sense of fear that they will not be able to bounce back from this. The reality that changes to Parkinson's symptoms had the capacity to take people back to stage one was widely recognised. For some, having accepted living with Parkinson's, subsequent changes in their Parkinson's were a powerful reminder that they are not entirely in control of their Parkinson's, which psychologically was hard to accept. Moreover, recovering and rebuilding from this change in their condition was commonly perceived as harder than dealing with the initial diagnosis. This highlights the need for services to be responsive to changes in status and the wider psychosocial impact that this has.

#### **Discussion:**

This research co-constructed by PwP, explored the impact of being diagnosed with Parkinson's and the strategies adopted by PwP to cope with the impact Parkinson's has upon them and their wider support network. This article illustrates the significant and wide-reaching impact of receiving a Parkinson's diagnosis. Moreover, it highlights that successful transition from the diagnosis to acceptance is dependent upon timely involvement of professions who understand Parkinson's, and access to support from other PwP and the wider Parkinson's community.

While this work is based on the views of a small group of people living with Parkinson's in Scotland, the themes that emerge, map closely with Frank's (2013) three illness narratives: the *chaos narrative* in which the patient is overwhelmed by what is happening to and around them, typically triggered at diagnosis; the *restitution narrative* in which the HCP assumes control and responsibility for the patient's recovery, most often in the weeks and months post-diagnosis; and the *quest narrative* in which the patient reasserts their personhood, their right "to avoid living a life that is diminished, whether by the disease itself or by others' responses to it" (Frank 2013: pp16-17) that is, a self-empowered approach to living successfully with illness.

The impact of diagnosis reported by participants in this study, adds to the current body of research, which highlights the feelings of loss of identity and autonomy experienced by PwP at diagnosis (Soundy et al, 2014, Maffoni et al, 2019). In addition, this study demonstrates the sudden irreversible change in identity that Parkinson's brings is significant even among those who already suspected they had Parkinson's. Diagnosis was associated with a period of bewilderment, akin to Frank's *chaos narrative*. Lack of knowledge, low perceived sense of well-being and lack of access to specialist healthcare teams were key factors in determining time spent in shock.

Prolonged periods of low perceived well-being are negatively associated with motor impairments and perceived disability (Vescovelli et al, 2018), highlighting the need for improved access to specialist multidisciplinary teams (MDT) from diagnosis. The National Institute for Health and care Excellence (NICE) recommend access to Parkinson's specialist MDT (NICE, 2017); however the 2019 Parkinson's UK service audit highlighted that this is an area which requires improvement. Moreover, 50% of Physiotherapists and Occupational therapists participating in the audit, who deliver care to PwP reported having had no specialist Parkinson's training in the last 24 months (Parkinson's UK, 2019), highlighting the need for post registration training to optimise care.

Current healthcare policy, advocates shared decision-making, and partnership between patient and professional. However, PwP in this study welcomed a more directive approach immediately following diagnosis. Emotional and psychological fragility was a common theme exacerbated by fear of the future and potential dependency. Participants drew comfort and reassurance from seeing a Parkinson's specialist who could make decisions on their behalf and offer guidance at this time. Within this stage of bewilderment, PwP did not feel enabled to make informed decisions about the direction of their care. However, as they progressed in their Parkinson journey, with evolving sense of self-efficacy, the desire for a partnership approach was clear. This highlights the need for more integrative approaches to healthcare delivery, which are multidimensional and responsive to changing needs over time (Valcarenghi et al, 2018). Adopting a person-centred approach, HCP can appreciate that PwP are juggling evolving physical, mental and emotional changes (Maffoni et al, 2019), which threaten their sense of autonomy and control. Therefore, emphasis needs to be placed upon active listening and understanding (Maffoni et al, 2019), rather than focussing upon symptoms and treatment (Ambrosio et al, 2019). This adds further support for adopting an integrative approach to care, where team composition reflects individual need, which is co-ordinated and delivered by Parkinson's specialists best suited to manage a person's

need at any given time (Valentijn et al, 2015). For some this maybe seeing a physiotherapist who through physical activity can provide motivation and strategies to positively live with their Parkinson's. For other this maybe seeking possible options from their consultant or Parkinson's nurse, prior to being able to consider treatment approaches.

Possessing a sense of control of one's own life is associated with successfully living with Parkinson's (Kang and Ellis-Hill 2015); however this study demonstrated a sense of fragility where control was delicately held in the balance. Achieving control requires positivity, determination, and social support built over time (Kang and Ellis-Hill, 2015). It was commonly acknowledged this could be lost at any time, heightening anxiety (a common Parkinson's symptom), and fear for the future. Support groups offer a safe and supportive environment, whereby the Parkinson's community can nurture those new to living with the condition to re-build their identity, autonomy, and take positive steps to living with Parkinson's not in spite of it. Support groups offer a therapeutic environment of like-minded people (Andrejack et al, 2020), providing opportunity for social connection with others (Kessler, 2019, 2017, Hellqvist et al, 2018, 2020). Social connection reduces the sense of isolation, and providing opportunity to share experiences and coping strategies (Embuldeniya et al, 2013). Development of social connections facilitates acceptance of diagnosis, supports lifestyle adjustments (Hellqvist et al 2018,), and developed self-efficacy (Mulligan et al, 2018), which is essential for successful self-management (Kessler et al, 2019). This highlights the key role of HCP and Parkinson's ambassadors to signpost people when they are ready to attend support groups.

This study demonstrated the need for HCP professions to be dynamic and flexible to manage the individual, diverse and evolving needs of PwP. Approach to management needs to evolve with the person, with the need for HCP not to view patients through a Parkinson's lens rather see them as individuals. Recognition that management needs to be problem focussed, with PwP valuing open communication with an emphasis on problem solving, information sharing, providing PwP the knowledge and skills to empower themselves to effectively address their problems (Kessler et al, 2017, 2019). This requires a paradigm shift from HCP feeling the need fix patient problems, to one which requires understanding, amalgamating the lived-in expertise of PwP, with that of medicine, and science. This highlights the need not for changes to service design, but a desire from the Parkinson's community for change in the relationship between PwP and their HCP. While, shared

decision-making may form central tenets of healthcare policy, translation into practice is not universally experienced.

## Conclusions

In conclusion, the findings from the current study provide insight into the experience of people living with Parkinson's, which has implications for current clinical practice. Those involved in this study voiced the desire for a flexible and individualised approach to management, based on a partnership model between PwP and HCP, where there is mutual respect for the experience both parties bring to a consultation. Moreover, they expressed that living well with Parkinson's is dependent on PwP being enabled to empower themselves, which is facilitated by social connections with the Parkinson's community provided by support groups, and by specialist HCP who adopt a partnership approach to care delivery. The findings of this study highlight provides a platform for future research to explore how services can be optimised to meet the needs of the Parkinson's community.

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### **Roles and Contributions:**

Alison Williams, Judith Shepherd, and Bill Wright were involved in data collection and data analysis and development of the original four-stage model. Julie Jones and Alison Williams undertook data synthesis and manuscript development and write up. This paper is dedicated to the memory of Judith Shepherd, who was passionate about the messages conveyed in this paper.

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