

Running head: BEING DIAGNOSED WITH PARKINSON'S DISEASE.

The Experiences of Being Diagnosed with Parkinson's Disease

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Abstract

Being diagnosed with a chronic illness such as Parkinson's disease (PD) can have a considerable psychological impact on a person's life. However, this has been little explored and therefore it is unclear what support may be most beneficial at this time. This study therefore explored personal experiences of being diagnosed with PD. Six participants were interviewed and data analysed using thematic analysis. Three over-arching themes emerged: 1) "*Understanding it is an important thing*" – The value of knowledge; 2) "*You've got to get used to accepting the fact that you need help*" - The social implications of being diagnosed with PD; and 3) "*I think you need to talk to somebody*" - The importance of supportive others. The process of diagnosis was complex and often challenging for participants, with respect to their own understanding and that of others. Recommendations for future practice within specialist PD services are made, to improve the support that is offered at this time.

*Keywords:* Parkinson's disease, diagnosis, nurse, specialist services, support, social, psychological

### The Experiences of Being Diagnosed with Parkinson's Disease.

It is generally agreed that the process of giving a medical diagnosis has the potential to have long term ramifications for how individuals understand and manage the condition (Bunn et al., 2012). For example, Baile et al. (2000) reported that poorly delivered bad news can affect patients' "comprehension of information, satisfaction with medical care, level of hopefulness and subsequent psychological adjustment" (p. 304). Patients' experiences of the receipt of a diagnosis have been researched in a number of different conditions (Fallowfield & Jenkins, 2004), however much of the research has been conducted on serious but potentially curable conditions such as cancer (e.g., see Hack et al., 2005, for a review).

While results from other studies are useful, it is also important to focus on the diagnosis of specific conditions as this specific knowledge can help practitioners refine their own practice (e.g., Theed et al., in press). Parkinson's disease (PD) is a neurodegenerative condition typically characterised by four clinical features: resting tremor, physical rigidity, slowness of movement (bradykinesia, often resulting in 'freezing') and postural instability (Jankovic, 2008). Despite PD being known predominantly as a movement disorder, non-motor consequences are also common; changes in senses of smell and taste are evident (Shah et al., 2009), as well as varying forms of pain (Wasner & Deuschl, 2012), sleeping difficulties (Gjerstad, et al, 2007) and cognitive impairments (McKinlay et al., 2010). The condition can have a profound impact on many aspects of a person's lifestyle; for some this can lead to a significant reduction in quality of life (Tan et al., 2014) and, in the more advanced stages of the disease, activities of daily living become very restricted.

Currently, the diagnostic procedure of PD is based entirely on clinical examination and diagnosis can be difficult to ascertain; indeed there have been reports of inaccuracy in approximately 25% of patients (Tolosa et al., 2006). This can lead to diagnostic uncertainty

for clinicians but also for people with PD (Eccles et al., 2011). In current practice, three defining features of PD (bradykinesia, rigidity and tremor at rest) need to be present before a diagnosis is made, however these features can also be found in other variants of parkinsonism and many other conditions (Hughes et al., 1992), making idiopathic PD very difficult to ascertain confidently.

Despite PD being the second most common neurodegenerative disease after dementia, a limited body of research has considered first-hand experiences of receiving a diagnosis of PD. Gofton and Jog (2008) used a free response questionnaire to ask people with PD about their feelings during the diagnostic process. The authors found that PD diagnosis had prompted a range of emotional responses including anxiety for the future, denial, shock and sadness. However, although participants were allowed the freedom to write their own words, the authors acknowledged that this was an exploratory project and they were not able to explore these ideas in any depth. Phillips (2006), however, interviewed 11 people who had been given a diagnosis of PD and in her qualitative analysis she found an overarching theme of “dropping the bomb”, whereby participants felt the burden of having to reconstruct their lives following the damaging after-effects of the diagnosis. Indeed, this theme has also been identified in other chronic health conditions, such as motor neurone disease research (Mistry & Simpson, 2013). However, since participants in Phillips's study had lived with their diagnosis for up to 15 years ( $M$  years = 6.5), their descriptions of their diagnostic experiences were less current and are likely to have been subject to some natural reconstruction given the passage of time.

Consequently the aim of this study was to explore in more detail the experience of diagnosis in people with Parkinson's disease with a relatively recent diagnosis (in the last one to 18 months). A qualitative research methodology, thematic analysis (Braun & Clarke,

2006), was used to capture participants' experiences in a detailed and meaningful way. The research question was: how do people experience the diagnosis of Parkinson's disease?

## **Method**

### **Design**

The study used a qualitative approach in which all data were collected through semi-structured interviews. The data collection was guided by an interview schedule, which included broad, open-ended questions, allowing each participant to express their experiences in a detailed way. The data were analysed using thematic analysis (TA, Braun & Clarke, 2006). This type of analysis was considered appropriate given that the focus was on the personal experiences of receiving a diagnosis. Qualitative methodologies are increasingly used in chronic illness research; indeed a growing number of studies have used qualitative methods in understanding experiences of PD. For example, Charlton and Barrow (2002) used thematic analysis to explore the experiences of people with PD who participated in a self-help group, and reported that this type of approach added new elements to their understanding of the topic. Similarly, Drey et al. (2012) used thematic analysis to explore adherence of medication in people with PD.

Purposive sampling methods were used to gain a homogeneous sample of participants who had recently experienced being diagnosed with idiopathic PD. Samples in qualitative research tend to be small and homogeneous to allow for the detailed exploration of experiences. The sample in this study was considered of sufficient size for the construction of meaningful themes (Guest et al., 2006). Small sample sizes can often be criticized in qualitative research; however, the aim is not to produce 'generalisable' findings but to create insightful accounts which might have theoretical generalizability.

### **Participants**

A total of six participants (one female and five males) were interviewed individually. Participants' ages ranged from 64 to 89 years ( $M$  years = 74.6). The time since PD diagnosis ranged from 5 to 17 ( $M$  = 11.3) months although the majority of participants believed they had been experiencing the symptoms of PD for a significant period prior to their diagnosis. Participants generated their own pseudonyms in order for them to have ownership over their words while still maintaining confidentiality. While in some research participants are given a number or a pseudonym by the researcher, this did not happen in this study. It was decided to take account of research by Grinyer (2002), for example, who discusses how it was important for the cancer patients in her study not to lose ownership of their contributions. Consequently, having agreed with the research ethics committees which approved the study that participant data would not be identifiable, it was decided to offer participants the opportunity to choose their own pseudonym. The names selected were interesting – and might seem unusual to the reader – but captured a real part of each person. Moreover, the participants were informed that their pseudonyms would be used if the work was published, in order to respect the above.

Demographic details are included in Table 1.

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Participants were required to be aged 18 years or over and had been given a diagnosis of idiopathic PD in the last one to 18 months. The requirement for a diagnosis of idiopathic PD, rather than a variant of the disease with known causes (e.g. vascular or drug-induced parkinsonism), prevented the potential for differing diagnoses (and possibly therefore different kinds of experiences) to influence the results.

### **Data Collection**

The study was approved by a UK NHS Research Ethics Committee and by the relevant NHS Trust Research and Development committee. Participants were offered flexibility on interview location and all participants chose to have the interview within their own home. Before the interview, participants were reminded that all data would remain confidential, with the service from which they were recruited only having access to the final anonymised aggregated data. Interviews lasted between 32 and 67 minutes ( $M = 52.6$ ). With consent, participant interviews were digitally audio-recorded to ensure accuracy of data and so that they could be subsequently transcribed verbatim. Data were then transcribed by the first author.

### **Data Analysis**

The interviews were analysed by the first author using thematic analysis (Braun & Clarke, 2006). The first author identified common themes among the experiences and constructed meaning around these themes. Audit trails were created throughout analysis to ensure the analysis was rigorous and traceable and these were validated with the second and fourth authors (Guest et al., 2012). Braun and Clarke (2006) identify six main phases in analysing data using TA. These are outlined briefly as follows. Firstly, the first author became familiar with the data by listening to and reading the transcripts several times. The first author then attached labels to sections of the data that appeared relevant to the research question; these 'codes' helped capture meaning within the data. In the third phase, the first author looked for themes or patterns within the data that were relevant to the research question, using the coded data described above. The themes were reviewed by checking that they were consistent with the data set. In the fifth phase a 'story' was constructed about the data by defining and naming themes in an informative but succinct way. Finally, data extracts were used to help present a coherent narrative of the data.

### **Findings and Discussion**

Participants' experience of being diagnosed with PD was captured in three overarching themes. 1) "*Understanding it is an important thing*" – The value of knowledge; 2) "*You've got to get used to accepting the fact that you need help*" - The social implications of being diagnosed with PD; and 3) "*I think you need to talk to somebody*" - The importance of supportive others. Self-selected pseudonyms have been used throughout to preserve anonymity and where information has been removed from quotes (e.g. to protect identifiable information or to aid readability), this is indicated with the use of ellipses.

Participants gave a wide range of views on various aspects of PD, including details of their journey from before they were diagnosed to the present time. The three themes presented below reflect those that were most useful in contributing to an increase in understanding about the experiences of being diagnosed with PD (see Yardley, 2000). The incorporation of discussion into the findings section allows the integration of relevant theory and research.

### **Theme One: "Understanding it is an important thing" – The Value of Knowledge.**

This theme captures a topic that was salient for all participants: how their own level of knowledge and understanding was key in their experience of diagnosis. Two distinct temporal phases were discernible and form two subthemes within this theme: *Bewilderment* and *Elucidation*.

**Bewilderment.** When speaking of initially recognising their symptoms as unusual, participants indicated the complexity of knowing when to approach health services due to their (then) limited understanding of PD: "I couldn't put a name to it I couldn't, understand what was happening" (Shandy). This lack of understanding seemed to contribute to a misattribution of symptoms; there had been little awareness of the symptoms as being anything other than old age or clumsiness: "I started falling over and I thought, oh it's me not picking my feet up" (Mrs Rabbit); "I was just thinking it was normal process of ageing that

was all" (Mr R). Further, this misattribution resulted in a delay in seeking advice and thus in getting diagnosed. Other research has also suggested that the delay in PD diagnosis is largely attributable to the length of time between symptom onset and the individual approaching a primary care physician (e.g., Breen et al., 2013; Saunders-Pullman et al., 2011).

While it has been argued that public awareness of PD is comparatively high, mainly due to information presented in the media (Flynn et al., 2009), the public perception of PD is perhaps skewed towards a representation of the advanced stages of the disease, which gain more media interest (Prince, 2014). As a result, the less severe early stage symptoms are likely to go unrecognised. Indeed this is a common problem among practitioners too, since early PD symptoms are often mistaken for more common conditions present in the older adult population (Hayes & Surendranath, 2014), thus prolonging the diagnosis process. For many participants, the prompt to address the physical changes in their bodies came from others: "She [massage therapist] said that's not arthritis she said that's something else she said you better go and see your doctor she said and find out what it is" (Mrs Rabbit).

However when participants did come to raising their issues with their doctor, the majority described being somewhat dismissed: "He said oh ladies of a certain age, spine shrinks, that's what he said to me... and I was annoyed, because I thought they're always blaming it onto old age" (Mrs Rabbit). These shared experiences raise concern about the reasons why physicians respond in this way initially to symptoms and it has been suggested that general practitioners do not have sufficient training on PD diagnosis (Höglinger et al., 2004; Schrag et al., 2015).

Nevertheless, these descriptions from participants are again also consistent with the acknowledged difficulties in diagnosing PD (Berg et al., 2013) and this ambiguity is another possible contributor to the resultant perplexity amongst people with PD. While this is an undeniably complicated issue for physicians, it is often leaving the people who are seeking

help for their health in a state of impasse. Indeed, this uncertainty and subsequent lack of diagnosis sometimes led participants to express frustration:

Well I thought, God, I've been coming 18 months to find out what was wrong with me, what was going on with me and for the opticians has to find out first. Was a bit disappointed with the doctors, you know... Because you think 'oh am I going bloody barmy?' ... And you make an appointment cause you think there's sommat' [something] wrong with me so I've got to get the doctor to diagnose me, and they're reluctant to tell you, or they appeared reluctant, or they hadn't got the experience to diagnose. (Shandy)

As such, the majority of participants spoke with appreciation about having finally had a comprehensive assessment, whereby their own understanding and that of the healthcare professionals involved could begin to be developed.

**Elucidation.** Following on from the issues discussed in *Bewilderment*, participants seemed to benefit from a deeper personal understanding of their diagnosis, both in relation to its meaning and its aetiology. This sub-theme represents the explanation and clarification that many participants sought. Even after diagnosis, participants' understanding of their symptoms was complex, particularly when symptoms were not exclusive to PD. There seemed to be a combination of wanting to alleviate symptoms and also wanting to understand them. The majority of participants indicated a desire to distinguish which aspects were attributable to PD and which were not: "It's difficult trying to determine whether a symptom is because of the Parkinson's or because of the diabetes" (Baron Hardup). This attribution of symptoms was important because they believed PD symptoms could be managed with medication.

Similarly, most participants wanted further information about the diagnosis process: "I was interested to know from the doctor why she'd, how she'd diagnosed it and I did ask

the question – why are you heading to this position?” (George). Moreover, one participant was still in the process of wanting to learn more and asked the first author directly: “What is this? When I take these tablets what is it that comes out of tablets that has to go to my brain to replace what is not being made in my body?...What causes that?” (Shandy). This is consistent with other research (e.g., Phillips, 2006) where participants were also keen to learn more about their condition during the process of diagnosis.

More specifically, participants expressed a common desire to know what might have caused their condition or when it may have started: “You’re always looking back at where it could have come from... You look back you think was it that, was it that, or was it that?” (Shandy). This is consistent with research by Eccles et al. (2011) who also found that the search for a cause seemed to be an integral part of the adjustment process.

On a similar note, for most participants, learning that PD was not a terminal illness was a significant part of understanding the consequences of having the disease: “But I mean I found out since that, you don’t, nobody dies from Parkinson’s. I mean, it’s a debilitating illness, but nobody dies from Parkinson’s... So since then, I’ve not worried about it so much.” (Mrs Rabbit). It is interesting that these participants’ search to understand specific dimensions of their illness experience - i.e. cause and consequences - which have also been identified in theoretical accounts (e.g., Leventhal et al., 1992).

Unsurprisingly, an awareness of death can have a significant psychological impact on an individual. One theory which acknowledges this, Terror Management theory (Greenberg et al., 2008; Solomon et al., 1991), suggests that when people are reminded of their inevitable death, the resultant anxiety causes them to alter their behaviour in favour of living. It is possible that being diagnosed with a chronic health condition such as PD might prompt a person to have thoughts about death as a consequence of the illness, leading to a more positive attitude following their learning that this is unlikely. This is consistent with

Goldenberg and Arndt's (2008) proposal of a health model of terror management whereby health-related circumstances prompt such thoughts about death and result in taking either proactive or avoidant action. This was evident among participants too, for example some of them commented that they had sometimes been actively avoidant: "I've buried my head in the sand basically" (Baron Hardup), whereas others had been prompted to behave in ways that might prevent worsening of the disease, such as exercising to keep muscles from stiffening.

A further way of explaining these types of behaviours is in terms of acceptance (proactive behaviours) and denial (avoidant behaviours) of the diagnosis. However, the idea that a person must respond to chronic illness with either acceptance or denial has been disputed. For example, Telford et al. (2006) suggest that the use of the labels 'acceptance' and 'denial' by healthcare professionals in relation to chronic illness may be perceived as a negative judgement and impede the development of a person's sense of self-identity. This has also been noted in relation to diagnoses such as dementia where physician descriptions of 'denial' actually represent a far more subtle and nuanced understanding on the part of the patient (Matchwick et al., 2014).

### **Theme two: "You've got to get used to accepting the fact that you need help." - The Social Implications of Being Diagnosed with PD**

This theme represents some of the personal meaning of PD to participants, with close attention paid to the narratives spoken in relation to social implications. Much of the content of this theme could be a foundation for the issues discussed in theme one, in terms of how the need for such understanding may be rooted in societal attitudes and constraints.

The majority of participants expressed frustration following diagnosis in relation to losing of particular abilities and no longer being able to do things in the same way. This was particularly discussed in relation to social activities, "Well my lifestyle has changed vastly,

because I've always been a very active man. Life's been full of dancing, bowling, gardening, that all that's had to go out of my life" (Mr R), as well as general day to day activities: "You can't plan, you can't organize, and you can't do, you get yourself in a muddle when you try and do 2 or 3 different things at the same time... I used to multi-task and now I can't" (Saturnskies). However there was a sense that the changes they had experienced in their body had social consequences as well as personal: "I thought I would be a burden on them" (Baron Hardup). For Saturnskies, this was the driving force for approaching services: "It got to the stage where it used to annoy people. So I thought right I'm gonna go and see the doctor". Indeed the notion that a person having PD affects others in their life is one that has been recently explored (Martinez-Martin et al., 2012; McLaughlin et al., 2011; Peters, 2014) and the idea that symptoms are an irritation to other people is not a new one (Rintamaki et al., 2006).

In particular, one of the strongest findings that came from the data, discussed by most participants with vehemence, was a worry about becoming dependent on others: "I'm a very proud person and pride comes before a fall they say, don't they, but I can't stand the thought of being dependent on somebody else. I just can't" (Baron Hardup). As illustrated here, there was a strong sense that the concept of independence was an important part of life. Furthermore, some participants described the prospect as embarrassing: "Luckily at the moment I'm independent, but I think, God what happens when I can't sort of do these things myself? It's embarrassing isn't it?" (Shandy). There seemed to be an assumption that these negative feelings towards dependence were common feelings shared with all people in society, not just those with PD. Pertinently, Fine and Glendinning (2005) discuss the negative connotations associated with the discourse of 'dependency'; that it is often assumed to be "a negative state that should be alleviated wherever possible by public policy measures, treatments or other interventions... a negative attribute among adults, in which psychological

and moral failings compound issues of legal, social or economic status.” (p. 607). This is despite dependency being a very common, indeed necessary, social circumstance. As a result, participants' experiences of seeing their dependence as problematic and worrying about the prospect may stem from the wider societal pressures that often leave people feeling as though they are a burden on others (e.g. Aberg et al., 2005).

Views were similar in relation to dependence on services: “We're independent and, we plod on, on our own, as long as we can. And, my daughter, she'll step in if my wife can't do it” (Mr R); “the loss of my independence was, very very hard to bear I think. Not earning a living, was really really difficult... the stigma of the social paying me for doing nothing”. In certain Western countries the potentially stigmatising nature of receiving statutory help is well-recognised. For example, Fraser and Gordon (1994) describe how welfare dependency evolved in the US from having merely economical meaning to a sense of powerlessness and stigma. This is also similar in the UK welfare system, which often depicts the economically dependent individual as lacking in the necessary skills for a productive economy (Taylor et al., 2012). This is compounded by statements from the World Health Organisation (WHO 2003), advocating a definition of mental health as “a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (WHO, 2003, p. 7).

On a similar note, some participants discussed the impact on their working lives since being diagnosed with PD. Being in employment was an important part of life and again there were social implications to this change, for example:

I was desperate to get back to work, I'd been off for 6 months, I was going onto half pay and, I was desperate to get back to work. Erm, purely, well, I say purely, probably to prove to myself and other people I could still do my job. (Baron Hardup)

It was evident that there was a sense of stigma associated with not working or being unable to work. This is consistent with research that illustrates the presence of stigma in relation to physical illness and unemployment. For example, Reeder and Pryor (2008) describe 'self-stigma' as the private part of stigma, whereby people can feel shame, grief and a lack of self-esteem. They discuss 'public stigma' as the negative behaviours and attitudes that are so often directed at the stigmatised individual. Indeed, participants gave a sense that the impact of their condition was both personally distressing and perceived negatively by the public.

Consequently, with many participants making internal attributions – i.e. judging the distress as being caused by Parkinson's – as opposed to societal expectations, there was a focus on attempts to alleviate such physical limitations, mainly through the use of medication. That is, participants seemed to want to gain back aspects of independence and abilities with the use of medication: "they wasn't really having the effect they should have had, so she increased it from 1 every 4 hours to 2 every 4 hours... then I found more strength" (Shandy).

Moreover, immediately after the diagnosis, some participants commented that treating the symptoms was more important to them than the actual diagnosis:

I mean, does it matter that I've got it? I haven't got it?... Parkinson's is just this shake – without that I wouldn't, I would be quite happy just to get on with life... I'm not sure the diagnosis is necessary really. (George)

This suggests that the presenting symptoms and subsequent frustrations (e.g. from losing abilities) were more important than being diagnosed with a chronic health condition, a finding which contradicts previous findings (Phillips, 2006) and perhaps emphasises how views on diagnosis are not static but are influenced by contextual factors, including time. Moreover, it is likely that such frustrations and the desire to eliminate symptoms were grounded in a need to fit in with social norms. For example, one participant spoke in more

detail about 'fighting' the disease in an attempt to control the symptoms in some way, or prevent them from progressing:

Fighting it in my mind is being independent, doing things what, appear to be impossible to do. And overcoming the, say well having a shower, you're unsteady, you, you feel as though at times you have to be clinging to something, you know. But you want to be independent so you fight it so, you have a shower and, get in the shower and get it sorted... So when you've had a shower you think you've won you see. Gives you confidence to do other things. (Shandy)

Indeed the concept of 'fighting' has been found and discussed previously within chronic illness research (Jessup & Parkinson, 2010; McWilliam et al., 1996) and has been understood as an additional pressure on people with a chronic illness (Reeder & Pryor, 2008). Indeed, as discussed earlier, adjustment to a chronic health condition can be made more difficult by perceptions embedded in negative societal attitudes (de Ridder et al., 2008; Simpson et al., 2013).

### **Theme Three: "I think you need to talk to somebody" - The Importance of Supportive Others**

Despite the suggestion throughout theme two that societal expectations can hinder individuals' abilities to adjust to changing circumstances, it was also apparent that the presence of others was a contributing factor for participants' well-being. The key message of this theme is the influence that other people could have on people with PD, in relation to the diagnosis, including negative and positive experiences. The theme consists of two sub-themes: *Interactions with professionals* and *Family and friends*.

**Interactions with professionals.** Participants spoke about feeling happy with the care they had received from the specialist nursing service they had received. In particular participants described that they had sought (and received) reassurance and comfort from their

PD nurse specialist: “[PD nurse] goes through everything and puts your mind at rest and assures you know... so if you're getting, you get down a bit, you know a bit of advice, just ring her up and she comforts you” (Shandy).

While the on-going support that participants received from the PDNS was described positively, there were also some negative experiences reported in relation to other professionals, particularly in relation to the delivery of diagnosis. For example, participants expressed having felt a lack of compassion or sensitivity at this significant time in their life:

I was disappointed in how it was broken to me. I really was... when I was told, and the manner in which I was told, it just, it knocked me for six. And then I wasn't in the room much more than a couple of minutes after that before I was out the door and walking ...I was pretty disgusted with it really, the way it was delivered. The diagnosis, the words. I wouldn't tell anybody like that... they kind of forget the impact that their words are going to have on you... a bit more empathy is needed, I would say... I think a few kind words, before it was blurted out, you know soften the blow somewhat. Particularly as I wasn't expecting that... I had to be diagnosed, but I think it could have been done a little, or, a little bit more sensitively. A bit more sensitivity should I say. Or in this case, a lot more. (Baron Hardup)

There was a sense that some professionals did not have sufficient time for this important consultation. These difficulties are consistent with report of the delivery of diagnoses within other chronic health conditions (Edwards et al. , 2008). For example, one participant expressed the importance of simply being listened to: “I read his report when it came back, the first one and I said to [wife], do you know, every single detail that I mentioned is in there, everything that he thinks about those details is recorded” (Saturnskies). Therefore it would seem that people with PD not only appreciate it when the time, effort and compassion is

afforded to them during their contact with health services, but feel much more positive about their condition following such experiences.

**Family and friends.** The topic of family and friends was a frequent one among participants in terms of being a source of emotional and practical support. On speaking about what had helped them through the process of diagnosis, many participants referred to those in their environment: "I've had good advice really from all the family. With being close they always, they'll always talk to me just see how you are" (Shandy). Therefore it was evident that living with or being near to family or friends meant greater accessibility to support that was, for the majority, invaluable. This is consistent with Simpson et al. (2006) who found a positive correlation between the number of close relationships and positive affect.

However this raises concern about those people who do not have such embedded support systems. Many participants relied on their closest family members at the time of diagnosis for emotional support: "But when I get out the room and there's only [wife] and me, it's suddenly like somebody pulled the plug and let the air out" (Saturnskies). Therefore the use of family as an inherent support resource seemed an important contributor to their well-being and ability to cope. Lakey and Cohen (2000) discuss how social relationships influence an individual's well-being, and they propose three different perspectives for why this may be the case. The first is that social support reduces stress (by protecting against it) and promotes coping, for example through the provision of reassurance. This is certainly consistent with participant reports in this study, as the need for reassurance to reduce worry was something that was evident across the majority of participants. Their second perspective suggests that social support promotes individual self-esteem and self-regulation rather than the mediation of stress itself, an idea that was not particularly reflected by participant descriptions in this study. Alternatively, they suggest that there are aspects or qualities of the social relationships through which support is obtained which may be predictive of the

emotional well-being of the individual concerned. Indeed, some participants did speak about particular qualities that their spouse possessed in terms of this being somewhat compatible with their way of coping or in helping them to manage. Therefore the interpersonal interactions that result from these relationships are likely to be a significant part of social support (Reis & Collins, 2000). These differing perspectives have implications for how social support is accurately measured among people with PD, since there are several potential contributing factors to consider. However knowledge of the presence or absence of such support would assist professionals working with people with PD in understanding how they may be best helped by the service.

### **Clinical Implications and Recommendations**

A number of initiatives could help the process of diagnosis – including the need for professionals to continue to offer a compassionate approach and to give all options for support, even where these might not be accessed. However, less easily achieved solutions relate to the societal issues raised throughout this research given participants' discourse about not wishing to be a 'burden' or 'dependent'. The engrained values and attitudes within western society make it very difficult for people with PD (as with other chronic illnesses) to adjust to their changing circumstances and as such they find themselves 'fighting' to be as physically and cognitively able as they were previously. While it is important for healthcare professionals to help people with PD achieve their desired independence, they may wish to challenge some of the implicit societal messages and, for example, endeavour to increase accessibility and support for people with PD. Furthermore, if healthcare services had more awareness and understanding of the inherent societal messages about dependency, they may gain a meaningful insight into how this might be impacting upon each individual person with PD and their ability to adjust psychologically to their life-long health condition.

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brother-says.html](http://www.telegraph.co.uk/sport/othersports/boxing/muhammad-ali/11157484/Muhammad-Ali-is-so-ill-from-Parkinsons-that-he-cannot-speak-his-brother-says.html)

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Table 1. Participant information including pseudonyms

Pseudonym	Age (years)	Gender	Months elapsed since diagnosis	Reported family history of PD
Mrs Rabbit	67	Female	9	No
George	83	Male	12	Yes
Baron Hardup	64	Male	17	Yes
Mr R	89	Male	5	No
Shandy	81	Male	12	No
Saturnskies	64	Male	13	Yes