

## The recognition and management of psychological difficulties in individuals with Parkinson's disease: Perspective of the Parkinson's disease nurse specialist

Parkinson's disease nurse specialists (PDNSs) are often the key healthcare professionals involved in the management of Parkinson's Disease (PD), with regards to both motor and psychological aspects of PD. The voice of the PDNS however is not often heard. This study sought to investigate the experiences of PDNSs recognising and managing psychological difficulties in people with PD. Semi-structured interviews were conducted to gain their perspective and subsequently analysed using thematic analysis. Five overarching themes were developed summarising participants' experiences: (1) "*You can't tell whether it's related to the condition*" - Understanding the causes of psychological difficulties; (2) "*The resources just aren't there*" - Accessing psychological support; (3) "*Just listening to people is really important to me*" - How PDNSs recognise and manage psychological difficulties; (4) "*It's an area that I can't profess we completely address at all*" - Management could be improved and (5) "*I just get on with it*" - Resilience of PDNSs. These findings indicated a recognised need for psychological input both for PDNSs and people with PD.

While Parkinson's disease (PD) is most commonly recognised as a motor disorder, psychological difficulties are also prevalent yet are both under-recognised and underestimated by healthcare professionals (Barbosa, 2013), even in routine specialist practice (Hu et al., 2011). Individuals with PD may experience a number of psychological difficulties including depression and anxiety (Chaudhuri, Odin, Antonini & Matrinez-Martin, 2011), which occur throughout the progression of the disease (Bonnet, Jutras, Czernecki, Corvol & Vidailhet, 2012). These difficulties may subsequently result in a further deterioration in quality of life in individuals with PD who may already be experiencing reduced functioning as a result of their motor problems (Shulman, Taback, Rabinstein, & Weiner, 2002).

Given the consequences of psychological difficulties, increasing awareness of their importance is crucial (Rabinstein & Shulman, 2001). By recognising that someone may be experiencing psychological difficulties, the appropriate referrals and interventions may be offered in order to reduce the impact they may have and improve quality of life. If psychological difficulties are recognised early on in their occurrence then an individual may be able to receive the appropriate support and develop effective coping mechanisms to manage the daily problems they may encounter as a result of PD (Hagell, 2007). In terms of health professionals working with people with PD, psychological difficulties in people with PD are often most likely to be recognised by PDNSs (registered general nurses who have specialist experience in PD).

There is limited research looking at the perspective of the PDNS, particularly with regards to how they recognise and manage psychological difficulties in individuals with PD. There is therefore an absence of understanding regarding how PDNSs feel they recognise and manage psychological difficulties in people with PD. As PDNSs are often the primary, and most accessible, source of contact for someone with PD it is important to understand their perspective of recognising and managing psychological difficulties.

Therefore, the aim of the current study is to investigate PDNSs' experience of recognising and managing psychological difficulties in individuals with PD. The focus is on gaining insight into what PDNSs understand about the psychological needs of people with PD, whether they recognise a need for psychological input, both for themselves and people with PD, and what services and support are currently available to manage psychological difficulties.

## **Method**

### **Design**

The study employed a qualitative methodology to obtain the experiences of PDNSs in recognising and managing psychological difficulties in people with PD.

### **Ethics**

Prior to recruitment, ethical approval was gained from the researcher's University Research Ethics Committee (UREC). To ensure the interviews did not cause any distress to participants, information regarding the research was provided prior to the interviews and at the beginning of each interview time was given for any questions to be asked.

### **Recruitment**

Recruitment took place across the North West of England. The study was initially advertised at a PDNS meeting by the lead researcher. A recruitment email was sent out to the lead Parkinson's disease nurse and forwarded onto a total of 32 PDNSs with the participant information sheet attached.

### **Participants**

To be included in the study participants were required to have been in the role of a PDNS for a minimum of two years. Neurology nurses were also eligible for inclusion on the condition that around 50% or more of their caseload were people with PD. Five participants agreed to take

part in the research. Participants consisted of four PDNSs and one neurology nurse specialising in PD. Participants were all female and had been in their roles for between 2.5 and 14 years.

## **Data Collection**

Data were collected using semi-structured interviews which were guided by an interview schedule developed with the consultant to the study. Interviews were conducted between October 2014 and January 2015. All interviews were conducted face to face at non-NHS community locations of the participants' choice and lasted between 45 and 65 minutes.

## **Analysis**

Interviews were transcribed verbatim and anonymised, using pseudonyms, to protect participants' confidentiality. Data were then analysed following Braun and Clarke's (2006) process of thematic analysis to develop an understanding of PDNSs' experiences of recognising and managing psychological difficulties in individuals with PD. Themes were then created across participants to generate the major themes of the study by grouping codes from within and across the transcripts. Each theme was then named and described.

## **Findings**

A total of five over-arching themes were derived from the interview data. Each theme is described below.

### **Theme 1: “*You can’t tell whether it’s related to the condition*” - Understanding the causes of psychological difficulties.**

This theme describes participants' perceptions and understandings of psychological difficulties in people with PD. Different understandings of the causes of psychological difficulties in people with PD were discussed. It also encompasses the idea of the complexity of knowing what is causing the psychological difficulties and how this has the potential to influence how

psychological difficulties are managed. All participants spoke of recognising an increase in the number of people with PD experiencing psychological difficulties.

All participants had numerous understandings of the causes of psychological difficulties in people with PD. It was generally understood that people with PD could experience psychological difficulties for different reasons with four main causes becoming apparent. Firstly, a common understanding across participants was that psychological difficulties were, in part, a result of PD medication. Secondly, over half of participants also understood psychological difficulties to be a “symptom” of PD, in particular “anxiety being one of them” (Alex), caused by a “chemical imbalance” (Alex). Alternatively there was a third understanding expressed by over half of participants that psychological difficulties in people with PD could be related to any previous mental health difficulties they had experienced prior to receiving a diagnosis of PD. Fourthly, a few participants also acknowledged that psychological difficulties may also develop as an individual’s response to the condition whereby they “start having more psychological problems as their physical state deteriorates” (Deborah) because of a “difficulty adjusting to the condition” (Emily).

While it may be difficult to extrapolate what the cause of an individual’s psychological difficulty is, it was acknowledged by a few participants that this determined the best, most successful approach in supporting people with PD. It further influenced what support they either provided themselves or what they would access for them.

### **Theme 2: “*The resources just aren’t there*” - Accessing psychological support.**

This over-arching theme describes participants’ experiences of accessing the necessary support for people with PD experiencing psychological difficulties. Firstly, it incorporates participants’ experiences of the process of referring people with PD to the necessary healthcare professional. Secondly, participants spoke about the accessibility of the services that people with PD require.

**Referrals.** Over half of participants acknowledged that the main pathway for referrals regarding psychological support was through the individual's General Practitioner (GP). Some participants would "advise them to go to their GP" (Emily) and discuss either their psychological well-being with them, whether this be related to depression or anxiety. This was with the view that the GP could then decide whether the person would need medication or a further referral to a specialist service.

However, the referral process via the GP was described by many participants as taking too long. This slow and sometimes ineffective referral process was frustrating for PDNSs who were recognising mild psychological distress and trying "to be proactive about referrals" rather than "avert disaster when it's got to the point where they can't continue" (Emily).

**What is accessible and by who?** While participants aimed to be proactive and worked to ensure people were referred to receive the appropriate support, it was evident across all participants that there is "just a general lack of psychological support" (Alex) available to people with PD. Not only was there an identified lack of psychological support but there was also ambiguity regarding knowing what was available.

When people were able to access psychological support, one participant explained how "the waiting list's so long" (Emily) to see a psychologist and receive the support the PDNS felt they needed. In the meantime, PDNSs would provide as much psychological and emotional support as they felt able. Consequently participants consistently recognised that the psychological needs of people with PD were not being met. There was recognition that, with regards to people's psychological well-being and being able to access the necessary support "there's more that could access it and benefit from it" (Brenda).

**Theme 3: "*Just listening to people is really important to me*" – How PDNSs recognise and manage psychological difficulties.**

This theme encompasses what participants feel helps them to both recognise and manage psychological difficulties in people with PD. Four things were commonly identified by participants which supported them to recognise and manage psychological difficulties in people with PD; formal assessment tools, listening to and giving people with PD time to talk, the importance of the PDNS being available for contact, and the importance of the therapeutic relationship.

Formal assessment tools such as the Hospital Anxiety and Depression Scale (HADS) and Geriatric Depression Scale (GDS), were available for all participants to assess the presence of some psychological difficulties. Some identified them as facilitating them to “pick up mood related disturbance” (Alex) or as confirming suspected anxiety or depression. Others, however, did not “use any kind of formal tool to assess depression” (Emily). The latter spoke about how their ability to recognise and manage psychological difficulties was facilitated by “just listening to people” (Emily) with PD, giving them time. This was felt to provide them with more information than that within a questionnaire.

Participants described the therapeutic relationship as facilitating the recognition and management of psychological difficulties in people with PD. Emily explained “I usually pick up if someone’s mood’s changed by familiarity with the patient”, highlighting how important knowing each person is in terms of recognising when they may be struggling psychologically. Having a good relationship and knowing each client individually seemed especially important given that the majority of participants saw PD as “a very individualistic condition” (Deborah), including the psychological aspects. There was an understanding that no one approach would fit all, therefore knowing and understanding each person with PD allows them to recognise when someone may be struggling psychologically and subsequently decide on the best way to manage any distress.

**Theme 4: “It’s an area that I can’t profess we completely address at all” - Management could be improved.**

This theme generally refers to the current management of psychological difficulties in PD, acknowledging the limits to management and what could facilitate improved management.

**A medication management approach.** This sub-theme refers to participants' experiences of the current management approach. It was evident across all participants that medication is often the first approach to attempt to reduce psychological distress in people with PD. As some participants recognised psychological difficulties such as anxiety to be a result of PD medication, it was accepted that in the first instance the PD medication should be addressed. Caroline explained that if the alterations in PD medications did not have an impact on the psychological aspects of PD then "it would be a matter of considering anti-depressants", which was often the next step due to the lack of access to other support pathways such as psychological therapy. However, medication was often ineffective.

**Limits, knowledge and training.** Despite the main approach seeming to be medication based, participants also described what they believed limited their scope of management and what could facilitate their recognition of psychological difficulties and subsequent management. The main barrier to participants being able to provide the best holistic care and support to people with PD was the lack of training around the psychological aspects of PD. Some participants explained how there was not any formal training provided and if they wanted to access any training they had to initiate this themselves. Most participants thought training around the psychological difficulties that can occur in PD would be helpful.

#### **Theme 5: "*I just get on with it*" - Resilience of PDNSs**

This theme describes the impact recognising and managing psychological difficulties in people with PD has on PDNSs. It encompasses any support they receive and how they manage this impact themselves.

Many participants identified the process of managing psychological difficulties as stressful and frustrating. It was frustrating from the perspective that they wanted to be able to “address the psychological aspects of it better” (Caroline), however due to the combination of a lack of resources and lack of mental health training this was seen as difficult.

With regards to the support participants themselves receive, this also appeared to be lacking. The majority of participants noted that they did not receive regular supervision to support them in their role. Alternative supervision was often sought in the form of peer support by all participants. Although this was clearly beneficial for participants, it was identified that this was not often enough and that they would benefit from more frequent peer supervision time.

Overall, it was apparent that the task of recognising and managing psychological difficulties in particular was stressful for most.

### **Clinical Implications**

In order for PDNSs to be able to confidently manage the psychological difficulties associated with PD, an increase in access to psychological support should be made available. This could be having a psychologist or psychological therapist within the team or within the community who PDNSs know they can refer people to. As psychological services are seen to be under-resourced for people with PD, this increases the likelihood that those who require psychological support may not be able to access it.

Additionally, the limited availability of access to psychological therapies is placing more stress on PDNSs to manage psychological difficulties such as anxiety and depression which they feel under-trained to manage. As such, there is the potential for PDNSs to experience burn out due to working long hours, often being the sole PDNS in their area and increasing job roles. Axelrod et al. (2010) proposed that PDNSs should be provided with more help, acknowledging that this should take into consideration what PDNSs themselves would find most helpful. Training courses to

address the gap in psychological knowledge, specific to PD, could be made available to manage this. Indeed, if PDNSs were provided with some level of mental health training with regards to the potential psychological difficulties experienced in PD then they may feel more confident in recognising and managing psychological difficulties.

Furthermore, support for the PDNS, whether this be an assistant nurse or additional PDNSs, may reduce their workload to enable them to focus on providing people with PD with the best care possible. Alternatively, access to psychologists for supervision or consultation, for example, could provide PDNSs with the necessary support and advice to recognise and manage psychological difficulties that occur in PD. In addition, there may be more scope for incorporating a psychological model of care into PD care. It was evident that a more medical model is currently adopted when caring for people with PD and by incorporating the psychological model into PD care, psychological difficulties may receive increasing attention.

## **Conclusion**

As there is very limited research investigating the perspective of the PDNS, these findings provide an initial understanding of how PDNSs perceive the recognition and management of psychological difficulties in PD. There was recognition by PDNSs that people with PD need access to psychological input to support them with the psychological difficulties such as depression and anxiety that they may experience due to having PD. Despite this acknowledgement it is clear that the necessary resources to meet the psychological needs of people with PD are currently not available. Additionally, an increase in support and training regarding psychological difficulties for PDNSs may enable them to feel more confident in recognising and managing people with PD who experience psychological difficulties.



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