The recognition and management of anxiety and depression in individuals with Parkinson's disease: perspectives of the Parkinson's disease nurse specialist

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Abstract

Aim: Parkinson's disease (PD) is a neurodegenerative disease, most usually associated with motor problems, although psychological difficulties are also commonly experienced. In the UK Parkinson's disease nurse specialists (PDNSs) are often the key healthcare professionals involved in the management of PD, with regards to both the motor and psychological aspects of PD. This qualitative study sought to investigate the experiences of Parkinson's disease nurse specialists (PDNSs) in recognising and managing psychological difficulties in people with PD.

Design: Five female participants - four PDNSs and one neurology nurse specialising in PD – from the North West of England took part in the study. Participants were all female and had been in their roles for between 2.5 and 14 years. The study used a qualitative methodology aimed at providing a detailed account and analysis.

Method: Individual semi-structured interviews were conducted and subsequently analysed using thematic analysis.

Results: Five overarching themes were developed summarising participants' experiences. These included understanding the causes of psychological difficulties; accessing psychological support; the recognition and management of psychological difficulties; the improvement of psychological care and the personal resilience of the nurse specialists.

Conclusions: The specialist nurses were closely involved in the assessment and support of anxiety and depression of people with PD but concerns were expressed that there were limited resources for further help and management.

Key Words: Parkinson's disease; recognition; management; psychological; anxiety; depression; Parkinson's disease nurse specialists

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Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease, characterised by motor problems such as tremor, rigidity and bradykinesia (Dakof and Mendelsohn, 1986). While 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 specialist practice (Hu et al., 2011). Individuals with PD may experience a number of psychological difficulties including depression and anxiety (Chaudhuri et al., 2011), which occur throughout the progression of the disease (Bonnet et al., 2012). These difficulties may subsequently result in a further deterioration in quality of life in individuals who may already be experiencing reduced functioning as a result of their motor problems (Shulman et al., 2002) and the severity of psychological difficulties are a key predictor of health-related quality of life (HrQoL) (Soh et al., 2011).

Psychological difficulties in PD are likely due to a combination of psychological and neurobiological factors (Weintraub and Burn, 2011). Nonetheless research has tended to emphasise numerous neural systems causing these psychological difficulties in individuals with PD (e.g. Barbosa, 2013; Sung and Nicholas, 2013) as opposed to more psychological explanations (Brown and Jahanashi, 1994; Simpson et al., 2013). Moreover, while medication is often used to reduce the impact of psychological difficulties, for example anti-depressants, increasing evidence has made a case for the effectiveness of psychological interventions in people with PD (Fitzpatrick et al., 2010; Charidimou et al., 2011; Dobkin et al., 2011).

In addition, effective management of psychological difficulties in PD also depends on early recognition and action (Shulman et al., 2002). One way to try and deliver this is through care being organised within a multidisciplinary approach (Skelly et al., 2012). Members of a multi-disciplinary team (MDT), for example, may include a neurologist, speech and language therapist, physiotherapist, an occupational therapist and a Parkinson's disease nurse specialist (PDNS) (Skelly et al., 2012). However, psychological difficulties in people with PD are often most likely to be recognised by PDNSs.

PDNSs tend to be registered general nurses who have specialist experience in PD (http://www.parkinsons.org.uk/content/parkinsons-nurses). They were introduced to improve the care provided to individuals with PD (Royal College of Physicians, 1990) and can work in the community, hospital settings or a combination of both (Hagell, 2007). PDNSs provide a unique role, with their key roles and responsibilities being to provide education to and support the individual and their family, rehabilitate, monitor the illness, co-ordinate their care and encourage referrals to specialist therapists if and when appropriate (MacMahon, 1999; Reynolds, Wilson-Barnett & Richardson, 2000). Reynolds et al. (2000) also found that PDNSs dealt with explaining and managing the potential difficulties associated with PD, aspects that were not addressed by neurologists (Reynolds et al., 2000).

Indeed the PDNS is often the main consistent healthcare professional from whom individuals with PD will seek support, enabling them to access specialist care more readily (Axelrod et al., 2010; Parkinson's UK, 2011). The PDNS may therefore be able to recognise any psychological difficulties an individual is experiencing by exploring how the person feels they are managing and encouraging them to discuss any problems they are having that may not be related to PD (Vernon, 2009). However, while the PDNS may see people with PD on a more regular basis than other professionals, it may remain difficult for the PDNS to recognise psychological difficulties. This may not only be due to the overlap in symptoms

but due to their large caseloads, limited clinic time and the other aspects of health they have to monitor (Axelrod et al., 2010). Through surveys, PDNSs have reported numerous roles, large caseloads and a concern about workload pressures impacting on the level of care individuals with PD receive (Axelrod et al., 2010). Barriers are therefore apparent which may impact on the ability of the PDNS to recognise and manage psychological difficulties in the individuals they see.

Limited research has examined the perspective of the PDNS, particularly with regards to how they recognise and manage psychological difficulties in individuals with PD. Furthermore, the majority of research accessing the perspective of the PDNS either adopts a quantitative approach and thus ignores the direct voice of the PDNS or evaluates the effectiveness of the PDNS (Reynolds et al., 2000; Jarman et al., 2002). The aim of the current study is to investigate PDNSs' experience of recognising and managing psychological difficulties in individuals with PD.

Method

Design

The study employed a qualitative methodology to obtain the experiences of PDNSs in recognising and managing psychological difficulties in people with PD. Thematic analysis (Braun and Clarke, 2006) was used to analyse the data. Prior to recruitment, ethical approval was gained from the first author's University Research Ethics Committee.

Recruitment and participants

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 forwarded onto a total of 32 PDNSs with the participant information sheet. Five nurses responded to the email. 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. Of the five participants, four were PDNSs and one a 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 PDNS 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. Thematic analysis was an appropriate form of analysis as it is a flexible research tool which enables the development of a detailed and rich account of the data by identifying and analysing patterns, across participants, in detail (Braun and Clarke, 2006).

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 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: "we used to think that psychological problems and psychiatric problems were, were erm not that frequent but now most of our patients, in time, will have problems of one nature or another" (Deborah). With this was an understanding that the physical and psychological aspects of PD are related whereby "the psychological symptoms make the physical symptoms worse and the physical symptoms make the psychological symptoms worse" (Alex). One participant acknowledged that psychological difficulties such as anxiety and depression are "things that you don't see" (Emily), thus making them more difficult to recognise in comparison with the physical aspects of PD such as tremor.

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: "we think some of it was to do with medication…dopamine agonist treatment causing some of the psychological therapy needs" (Brenda). 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) with the further understanding that "they've got to replace the chemical" (Caroline). Alternatively there was a third understanding 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, with one participant noting "some of our patients have had really bad depression in the past" (Caroline). This may therefore increase the likelihood that someone would develop psychological difficulties at some point during their PD journey. 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).

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 this referral process, via the GP, was described by many participants as taking too long. Some participants recognised that while they had initiated a referral via the GP, the next time they saw the person "nothing's been done" (Caroline). 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). While this seemed to be a barrier to people accessing the necessary support in a timely manner, one participant acknowledged that they "should refer a lot more" (Brenda). Brenda went on to explain that due to time constraints "I pick the ones that I think I'm gonna struggle with", ensuring that those with psychological difficulties, not able to be managed by the nurses themselves, were being referred for the necessary support.

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. Another nurse described how "what is available for psychological support is so poor…often you're leaving your patient to just get on with it" (Deborah). Deborah also explained that, despite having a psychologist available to them, this was only for the assessment of psychological difficulties such as depression. This was therefore felt to be inadequate as they were not provided with "a treatment arm" (Deborah) to support people with any psychological difficulties identified should it be felt they needed some psychological support.

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. Again, this meant that by the time people were able to receive some psychological support their level of need was likely to be greater than at the point of referral. In the meantime, PDNSs would provide as much psychological and emotional support as they felt able. Additionally, as an alternative, many participants identified having supportive Parkinson's groups in their local areas that they advised people with PD to attend in order to help them manage their psychological difficulties; "we've got a good Parkinson's group" (Brenda). However, most participants recognised that this was not always an option that

people with PD felt to be accessible, predominantly due to not wanting to "see people who are worse off than themselves" (Caroline).

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 felt helped them both recognise and manage psychological difficulties in people with PD. Three aspects 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. Participants' experiences differed with regards to the use of formal assessment tools as a means of recognising when someone may be struggling psychologically. 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.

Being available for contact was identified by all participants as important in the management of psychological difficulties. Several participants spoke about how they "don't

discharge anybody" (Brenda), therefore people with PD would always have access to a specialist healthcare professional. Some participants described how they would "keep my phone on over the weekend" (Brenda) and have an "open door policy" (Alex) which they recognised as helping to "reduce anxiety" (Alex) in people with PD. It seemed that just knowing someone was available, if needed, helped manage people's psychological difficulties, in particular anxiety.

Participants described the therapeutic relationship as facilitating the recognition and management of psychological difficulties in people with PD; "I get to know patients really well" (Alex); "I know them so well, I've known them for years (Brenda)". This was felt to be particularly important in cases where someone may not openly tell their PDNS that they were struggling psychologically. However, it seemed that more often than not people would talk to their PDNS about any difficulties they felt they were experiencing. Trust was important to some participants, which developed as part of the therapeutic relationship; "building up a good relationship and trust is a big thing" (Alex). Again, this was a development that was felt to improve recognition of psychological difficulties and facilitate management. Indeed, 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.

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 was 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; "we try maybe tweak the medication for the Parkinson's if they're under-treated,

for help with the psychological symptoms" (Alex); "I think that's probably the first thing,

making sure the medicines are right" (Brenda). 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". It was identified that this was often the next step

due to the lack of access to other support pathways such as psychological therapy. Not only

this but one participant described a general focus from consultants on "the movement

disorders and Parkinson's medication" (Caroline) which subsequently influenced the

management of the psychological aspects of PD. Additionally, it was also acknowledged by

one participant that "it's much easier as medical professionals to be able to say right we'll

give you a tablet for that" (Emily), however recognised that "when it's not able to be changed

it's about changing how they deal with things and how they adapt".

Participants' approach to the management of psychological difficulties appeared

consistent. After both PD medication and psychiatric medication had been tried, if it had not

helped the person "then it's through to psychological therapies" (Brenda). Brenda also spoke

about "realising it's not working because the anxiety is the root". There was an

understanding across participants that medication, while often the first option, was often

ineffective; "I've lost faith in that really…I don't think it does anything" (Caroline); "some of

them could cause more problems than they solve" (Deborah). Some participants felt the

medication did not address the cause of the psychological distress, particularly when it was

related to adapting to the condition, understanding their distress and supporting people to cope.

However, different perceptions on the benefits of psychological therapy to address psychological difficulties in PD were apparent. Most participants recognised that not all individuals were happy to take medication, particularly when they are already taking medication for the motor difficulties experienced in PD. Psychological support was therefore seen as an alternative for such people; "it'd be better if they had some sort of psychological counselling" (Caroline). Alternatively it was felt by some, from feedback, their understanding of the research and advice from medical consultants that "CBT doesn't really work on patients with Parkinson's" (Alex). Another felt that current "talking therapies just seem to be a too general approach", particularly when delivered by someone without experience and knowledge about PD.

Limits, knowledge and training. Despite the main approach seeming to be medication based, participants also described what they believed limits 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.

Participants' experiences were that there was inadequate training regarding psychological difficulties in PD for PDNSs, with one nurse identifying that there was not a course available "that recognises psychological symptoms" (Alex). Some explained how there was not any formal training provided and if they wanted to access any training they had to initiate this themselves. Additionally, even when participants actively sought further training it was difficult for them to access this due to either work demands or financial

barriers. Alex explained how she wanted to attend a psychology and CBT course but "the resources just aren't there" while Deborah spoke of wanting to attend a Parkinson's conference, however "being allowed to go to things like that is increasingly difficult in today's healthcare system".

As a result of the lack of training around psychological difficulties in PD, many participants described feeling as though they did not have the necessary skills to manage psychological difficulties as well as they should and felt as though they struggled; "I haven't got them skills" (Brenda); "I struggle with the psychological, you know the anxiety and things" (Caroline). Caroline went on to explain that she offers "some psychological support but I'm not a qualified counsellor so it can be quite difficult for me". While PDNSs felt able to recognise and manage some psychological difficulties through the experience they had developed over time, it was felt that more training and knowledge would allow them to do so with the confidence that they were doing the right thing and providing the appropriate and necessary support.

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. This appeared to have an impact on participants who acknowledged feeling as though they had

"failed" (Emily) or as though there were "not a good nurse" (Caroline) if they were not able to support someone psychologically.

Methods for coping more, frequently mentioned, were "switching off" (Brenda) and trying to "get on with it" (Caroline). However, there were differences in how participants perceived their involvement. Some felt they were easily able to switch off and not get too involved with their patients; "I don't let there be an impact on me…you have to be detached otherwise you'd be too involved" (Alex), which allowed them to manage the impact of managing psychological aspects of PD. 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 or "know anybody who receives weekly supervision" (Caroline). Some did however mention they were able to drop in on the medical consultant to discuss cases if needed but there was no access to any specialist psychological input. Alternative supervision was often sought in the form of peer support by all participants. This was recognised as being the most beneficial support available to them.

Discussion

The current analysis of PDNS's experiences of recognising and managing psychological difficulties in people with PD identified five overarching themes. Findings suggest that PDNSs' understandings of the causes of psychological difficulties in people with PD are varied. Individual PDNSs described different causes of psychological difficulties across their caseload consistent with the different theories of anxiety in PD (Prediger et al., 2012). This confirms a commitment to individualised understandings of difficulties, although the care planning approach (from medication to therapy) was similar across all participants.

Furthermore, while there was acknowledgement by PDNSs that psychological difficulties were sometimes a response to being diagnosed with PD, the dominant view was

that psychological difficulties were due to either a chemical imbalance or in response to the Parkinson's medication. These findings suggest that psychological models are adopted far less than medical models in the care of people with PD. Moreover, this is consistent with research on the psychological aspects of PD which predominantly focuses on biological causes (Ferreri, et al., 2006). A psychological approach may only be adopted once a medical approach to managing psychological distress has been attempted.

However, this research study identifies that the current psychological input for people with PD and PDNSs themselves is limited, under-resourced and under-funded. This seemed to be further impacted by a slow and sometimes ineffective referral process. PDNSs described referring for psychological input via a person's GP. If PDNSs were consistently able to directly refer someone for psychological input then this may reduce the time it takes to access any available support. However, it is also important to consider how this would create an additional task for PDNSs to complete in the limited time they already have.

The British Psychological Society (BPS) acknowledges that "access to psychological assessment and intervention for people with PD is inconsistent across the UK" (BPS, 2009), which is consistent with the findings of this research. While overall access was recognised as being poor, some participants identified being able to access some psychological input while others felt this was, on the whole, absent. Findings indicated that this lack of psychological support influenced the level of emotional and psychological support PDNSs felt they had to try to provide for people with PD. However, as a result, this increased the level of stress in PDNSs due to not feeling skilled enough to manage the psychological difficulties which subsequently impacted on how well they felt able to do their jobs. Additionally, due to the difficult and challenging nature of their job, PDNSs may be at risk of burnout (Gandi et al., 2011). PDNSs in the present study acknowledged feeling stressed, however also noted that they did not receive regular supervision to be able to process or receive support for this.

Although access to psychological support was recognised as being limited, findings indicated that PDNSs tried to bridge this gap. PDNSs acknowledged how contact and availability were particularly important in helping them to manage the psychological aspects of PD. Contact, availability and trust may be important tools in developing a therapeutic relationship in order to facilitate the recognition and management of psychological difficulties in PD. A meta-analysis by Martin, Garske and Davis (2000) provided support for the concept that the therapeutic relationship has an impact on the outcomes of therapy. While this research was focussed on therapy specifically, it may also be applicable to the relationship PDNSs develop with people with PD. Cooley and Lajoy (1980) noted how clients value being listened to and understood, something which PDNSs in the current research identified as being a crucial part of their role. Although some people may not want to discuss psychological difficulties such as anxiety or depression (Shulman et al., 2002), developing a strong therapeutic relationship in which the person with PD feels able to trust the PDNS may increase the likelihood of discussing such difficulties. Therefore, in the absence of adequate psychological services for people with PD, the PDNS may be able to use the skills they have to reduce their level of distress.

Findings also indicated a preference for initial medication management of psychological difficulties such as anxiety and depression, both in terms of adjusting a person's PD medication and introducing anti-depressants. This is consistent with the idea that if psychological difficulties in PD are a result of either a chemical imbalance or a response to PD medication then the adjustment of anti-parkinsonian medication is a useful first step before considering any psychiatric medication or psychological therapy (Ferreri et al., 2006). Furthermore, within NICE (2006) clinical guideline 35 for PD, there is no mention of psychological therapy as a key intervention for people with PD. The focus is on, in addition to the PDNS, occupational therapy, physiotherapy and speech and language

therapy. Therefore, for PDNSs following NICE (2006) guidelines, this does not appear to be a priority. Consequently, if psychological support is not outlined as a key intervention by NICE (2006) then it may be that this has an impact on what services are prioritised and funded.

However, NICE (2009) clinical guideline 90 for depression in adults advises that "the least intrusive, most effective intervention" (p.15) should be offered first, adopting a stepped-care model. Within the general population it is recommended that a low-intensity psychological intervention such as CBT or computerised cognitive behavioural therapy (CCBT) should be offered prior to medication (NICE, 2009). If this is not effective then a high-intensity psychological intervention, medication or a combination of the two is recommended. Therefore, people with PD should be able to access the same level of support as that recommended for the general population, enabling them to start with the least intrusive approach. In addition, there is an increasing evidence base for the effectiveness of psychological interventions in people with PD (e.g., Fitzpatrick et al., 2010; Dobkin et al., 2011).

Limitations

Interviews were conducted by the first author, a trainee clinical psychologist. There may be the potential that some follow up questions asked were influenced by the interviewer's own interests and assumptions. However, all attempts were made to be consistent across interviews and ensure the questions asked remained focussed on the major research questions of the study. Additionally, the themes developed are, on some level, a reflection of the authors' interpretations. This is part of the qualitative research process but can be unfairly criticised by using a more quantitative positivist perspective. Therefore, there could also be different interpretations made of the interview data obtained in the present

research. However, the researchers remained aware of their potential influence on the data and aware of the context in which participants were situated. A full audit trail was created to ensure that the interpretations were supported by the data. The small sample could also be argued to limit 'generalisability' of the findings. However, small samples are accepted within qualitative research and while no attempt is made her for sampling generalisabilty, it is argued that there is theoretical generalisability in that the findings can be used to inform theory and understandings in similar groups (e.g., Yardley, 2008). Participants were aware that the interviewer was a trainee clinical psychologist but a range of opinions on the source of and relevant approaches to psychological difficulties was articulated. This suggests that there was no concerted attempt to provide data which could be seen to be more acceptable to the specific professional background the interviewer.

Conclusion

As limited research has currently been conducted on the perspective of the PDNS, these findings provide an initial understanding of their approach to 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.

References

Axelrod L, Gage H, Kaye J, Bryan K, Trend P, Wade D (2010) Workloads of Parkinson's specialist nurses: implications for implementing national service guidelines in England. Journal of Clinical Nursing 19(23-24): 3575-80

Barbosa, ER (2013) Non-motor symptoms in Parkinson's disease. Arquivos de Neuro-psiquiatria 71(4): 203-4

Bonnet AM, Jutras MF, Czernecki V, Corvol JC, Vidailhet M (2012) Nonmotor symptoms in Parkinson's disease in 2012: relevant clinical aspects. Parkinson's Disease 2012

Braun V, Clarke V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 3(2): 77-101

Brown R, Jahanshahi M (1994) Depression in Parkinson's disease: a psychosocial viewpoint. Advances in Neurology 65: 61-84

Charidimou A, Seamons J, Selai C, Schrag A (2011) The role of cognitive-behavioural therapy for patients with depression in Parkinson's disease. Parkinson's Disease, 2011

Chaudhuri KR, Odin P, Antonini A, Martinez-Martin, P (2011) Parkinson's disease: the non-motor issues. Parkinsonism & related disorders 17(10): 717-23.

Cooley EJ, Lajoy R (1980) Therapeutic relationship and improvement as perceived by clients and therapists. Journal of Clinical Psychology 36(2): 562-570

Dakof GA, Mendelsohn GA (1986) Parkinson's disease: The psychological aspects of a chronic illness. Psychological Bulletin 99(3): 375

Dobbie M, Mellor D (2008) Chronic illness and its impact: considerations for psychologists. Psychology, Health & Medicine 13(5): 583-90

Dobkin RD, Menza M, Allen LA et al (2011) Cognitive-behavioral therapy for depression in Parkinson's disease: a randomized, controlled trial. American Journal of Psychiatry 168(10): 1066-74

Ferreri F, Agbokou C, Gauthier S (2006) Recognition and management of neuropsychiatric complications in Parkinson's disease. Canadian Medical Association Journal 175(12): 1545-52

Fitzpatrick L, Simpson J, Smith A (2010) A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease. Psychology and Psychotherapy: Theory, Research and Practice 83(2): 179-92

Gandi JC, Wai PS, Karick H, Dagona ZK (2011) The role of stress and level of burnout in job performance among nurses. Mental Health in Family Medicine 8(3): 181-94

Hagell P, (2007) Nursing and multidisciplinary interventions for Parkinson's disease: what is the evidence?. Parkinsonism & Related Disorders 13: S501-8

Hu M, Cooper J, Beamish R et al (2011) How well do we recognise non-motor symptoms in a British Parkinson's disease population?. Journal of Neurology 258(8): 1513-7

Jarman B, Hurwitz B, Cook A, Bajekal M, Lee A (2002) Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. Bmj 324(7345): 1072

Macht M, Schwarz R, Ellgring H (2005) Patterns of psychological problems in Parkinson's disease. Acta Neurologica Scandinavica 111(2): 95-101.

MacMahon DG (1999) Parkinson's disease nurse specialists: an important role in disease management. *Neurology*, *52*(7 Suppl 3), pp.S21-5.

Martin DJ, Garske JP, Davis MK (2000) Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. Journal of Consulting and Clinical Psychology 68(3): 438.

National Institute for Health and Care Excellence (2006) Parkinson's disease: Diagnosis and management in primary and secondary care. NICE guideline (CG35)

National Institute for Health and Clinical Excellence (2009) Depression in adults: the treatment and management of depression in adults. NICE guideline (CG90)

Parkinson's UK (2011). *Parkinson's nurses – affordable, local, accessible and expert care: A guide for commissioners* [online]. Available at: http://www.parkinsons.org.uk/content/parkinsons-nurses-guide-commissioners-england

Prediger RD, Matheus FC, Schwarzbold ML, Lima MM, Vital MA (2012) Anxiety in Parkinson's disease: a critical review of experimental and clinical studies. Neuropharmacology 62(1): 115-24

Reynolds H, Wilson-Barnett J, Richardson G (2000) Evaluation of the role of the Parkinson's disease nurse specialist. International Journal of Nursing Studies 37(4): 337-49

Royal College of Physicians (1990) Standards of care for patients with neurological disease: A consensus report of a working group. Journal of the Royal College of Physicians of London 24(2): 90-97

Shulman LM, Taback RL, Rabinstein AA, Weiner WJ (2002) Non-recognition of depression and other non-motor symptoms in Parkinson's disease. Parkinsonism & related disorders 8(3): 193-97

Simpson J. Lekwuwa G. Crawford T (2013) Illness beliefs and psychological outcome in people with Parkinson's disease. Chronic Illness 9(2): 165-76

Skelly R, Lindop F, Johnson C (2012) Multidisciplinary care of patients with Parkinson's disease. Progress in Neurology and Psychiatry 16(2): 10-4

Soh SE, Morris ME, McGinley JL (2011) Determinants of health-related quality of life in Parkinson's disease: a systematic review. Parkinsonism & related disorders 17(1): 1-9

Sung VW, Nicholas AP (2013) Nonmotor symptoms in Parkinson's disease: expanding the view of Parkinson's disease beyond a pure motor, pure dopaminergic problem. Neurologic clinics 31(3): S1-16

The British Psychological Society (2009) *Psychological services for people with Parkinson's disease* [online]. Available at: www.bps.org.uk

Vernon GM (2009) Parkinson disease and the nurse practitioner: diagnostic and management challenges. The Journal for Nurse Practitioners 5(3): 195-206

Weintraub D, Burn DJ (2011) Parkinson's disease: the quintessential neuropsychiatric disorder, Movement Disorders 26(6): 1022-31

Yardley L (2008) Demonstrating validity in qualitative psychology. In: Smith J, eds. Qualitative psychology: A practical guide to research methods. Sage, London: 235-51