The involvement of people with Parkinson's in designing a study of the lived experience of anxiety

Christopher J. LOVEGROVE, Katrina BANNIGAN, Debbie CHEESEMAN and Jos M. LATOUR

British Journal of Occupational Therapy

Accepted 27th February 2017

Christopher J. LOVEGROVE, BSc (Hons)[1,2]
Clinical Lead Occupational Therapist in neurology, stroke and rehabilitation,
[1] Royal Devon & Exeter NHS Foundation Trust, Exeter, United Kingdom
[2] School of Health Professions, Faculty of Health & Human Sciences, Plymouth University, Plymouth, United Kingdom.

Katrina BANNIGAN, SFHEA, PhD
Associate Professor (Reader) of Occupational Therapy
School of Health Professions, Faculty of Health & Human Sciences, Plymouth University, Plymouth, United Kingdom.

Debbie CHEESEMAN, RGN, MBA, BSc (Hons)[1,2]
Consultant Nurse for Older People
[1] Royal Devon & Exeter NHS Foundation Trust, Exeter, United Kingdom
[2] School of Health Professions, Faculty of Health & Human Sciences, Plymouth University, Plymouth, United Kingdom.

Jos M. LATOUR, RN, PhD
Professor in Clinical Nursing
School of Nursing and Midwifery, Faculty of Health & Human Sciences, Plymouth University, Plymouth, United Kingdom

Corresponding author:
Christopher J. LOVEGROVE,
Clinical Lead Occupational Therapist in Neurology, Stroke & Rehabilitation,
Therapy Department, Royal Devon & Exeter NHS Foundation Trust, Barrack Road,
Exeter, Devon, United Kingdom EX2 5DW
Phone: +441392 402287
E-mail: christopher.lovegrove@nhs.net or
christopher.lovegrove@postgrad.plymouth.ac.uk
Twitter: @Clovegrove_OT

Research ethics: Ethical approval was obtained from Plymouth University's health student ethics sub-committee, reference number (16/17)-244, 04/11/2016. All participants provided written consent via email.

Declaration of Conflicting Interests: The authors confirm that there is no conflict of interest.

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Acknowledgements: The authors would like to thank the participants for sharing their experiences and their time, Daffyd Wilson-Evans for his contribution to the triangulation process and Isabelle Abbey-Vital at Parkinson's UK for her support with the PPI consultation process.

Authorship: All authors agreed on the final version and meet the criteria recommended by ICMJE (http://www.icmje.org/recommendations/):
1) Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
2) Drafting the article or revising it critically for important intellectual content.

Abstract

Introduction: Anxiety is a common non-motor symptom of Parkinson's and is an important consideration for occupational therapists working with this population. Little is known about how people with Parkinson's experience anxiety. A pragmatic inquiry framework and inductive approach were used to perform a patient and public consultation round to inform future occupational therapy research exploring anxiety in people with Parkinson's.

Methods: Seven telephone and two Skype interviews were conducted with people with Parkinson's who were accessed and recruited through the charity Parkinson's UK. They were selected on the basis of their previous experience and training to participate in a consultation exercise. Thematic analysis was used to develop codes using an inductive approach.

Findings: Three key themes emerged: experiences of anxiety in Parkinson's; coping with anxiety in Parkinson's; and considerations for future research. These include timing with regards to medication 'wearing-off' phenomena, easy access to medications and providing a safe, sensitive research environment. Occupational therapists need to take these findings into account when designing intervention studies.

Conclusion: This patient and public involvement consultation round proved valuable and the participants' contributions will directly improve the design of future occupational therapy research exploring the lived experience of anxiety for people with Parkinson's.

Keywords

Parkinson's, neurology, qualitative research

Introduction

Occupational therapists working with people with Parkinson's (PWPs) often encounter anxiety that acts as a barrier towards effective treatment. Developing an intervention that takes into account a condition with several interacting components requires a rigorous scientific process as outlined by the Medical Research Council guidance for developing complex interventions (Craig *et al.*, 2008). Beginning the journey towards developing a more holistic complex intervention for PWPs experiencing anxiety it is crucial to lay a strong scientific foundation. Putting the experiences of PWPs at the center of such a process ensures future work to develop the intervention is less influenced by researcher or healthcare professional assumptions. Occupational therapists are ideally placed to fulfill this role, with holism and person-centered practice being central concepts of the profession's philosophy.

Patient and public involvement

Patient and public involvement (PPI) in research has been shown to have positive benefits in terms of participant recruitment, feasibility, study design, and dissemination of findings (Whitstock, 2003). It has been stated that PPI provides a cornerstone to a truly patient-led national health service (NHS) in the UK (Hogg, 2007). Patient and public contributions can provide alternate views from those of researchers and the workforce (NIHR, 2014). Those involved are able to form judgments and recommendations based on experiences of their condition. They may have differing aims and opinions about health which researchers and healthcare professionals may not have considered (Whitstock, 2003; NIHR, 2014). As well as increasing representation and equity in public services, PPI contributes towards health services that are more accessible and acceptable to the public (Hogg, 2007). Improvements in the overall quality and relevance of health research have also been highlighted, as well as a perception of increased patient acceptance of research findings (Whitstock, 2003). However, there is a view that the impact of PPI in individual projects is weak and supported by methodologically poor research (Staniszewska *et al,* 2008). Despite this service users, involved in

PPI, report increased feelings of empowerment and value (Brett *et al.,* 2014) which echoes the philosophical underpinnings of occupational therapy. Research funders, such as the National Institute for Health Research (NIHR) in the UK, now consider PPI an essential requirement of funding applications (NIHR, 2014).

Literature review

In the UK there are approximately 127,000 people with Parkinson's (Parkinson's UK, 2014), and 98.6% experience non-motor symptoms that can be defined as a collection of neuropsychiatric symptoms specifically linked with Parkinson's (Barone *et al.,* 2009). These can include gastrointestinal issues, cognitive problems and mental health issues (Barone *et al.,* 2009). Of those people experiencing these non-motor symptoms, 43-56% live with stress and anxiety (Barone *et al.,* 2009; Breen & Drutyte, 2013). Whilst there is evidence that briefly touches upon anxiety, multiple references in the literature refer to the lack of anxiety-specific research in Parkinson's (Barone *et al.,* 2009; Breen & Drutyte, 2013).

Stress and anxiety are terms often used either together or interchangeably, in relation to Parkinson's; yet these terms need clarification. Bystritsky and Kronemyer (2014) emphasizes that stress is an external process that arises from an individual's environment. In contrast Sylvers, Lilienfeld and LaPrairie (2011) define anxiety as an ever-present internal feeling of excessive fear and worry that is invasive in everyday existence; often having a negative impact on one's quality of life. It is appropriate to focus solely on anxiety, rather than a combination of the terms, because it focuses on the individual and their experience rather than the wider external environment over which they may have little control. The presence of anxiety is linked to decreased quality of life and an increase in motor symptoms in PWPs, yet authors have noted a lack of anxiety specific research in Parkinson's (such as Barone *et al.,* 2009; Breen and Drutyte, 2013). Wressle, Engstrand and Granérus (2007) interviewed seven older PWPs (64-77 years) in a qualitative study to identify factors affecting their quality of life. Consistent reports of increased emotional sensitivity leading to higher anxiety emerged. For example PWPs experienced anxiety about being unable to care for their partner should they

become unwell. These experiences resulted in people planning to avoid stress wherever possible. Sunvisson (2006) interviewed a single PWP using a phenomenological approach at intervals over a five-year period. This paper identified similar themes to Wressle, Engstrand and Granérus (2007), such as experiencing a fear of the future, increased sensitivity to stress, and increased anxiety associated with the unexpected. These themes explored anxiety provoked by declining skills and the pressure of maintaining social involvement. The single participant design means these findings have limited transferability. Given the high prevalence of anxiety in Parkinson's, and limited research, an understanding of the experience of anxiety amongst PWPs is required. Deane *et al.* (2014) concur; they identified anxiety as the second highest unmet research need in Parkinson's in collaboration with the charity Parkinson's UK. None of the papers reported clearly stated an included PPI component in their design.

This suggests a future exploratory study using in-depth phenomenological face-to-face interviews to explore the lived experience of anxiety among people with Parkinson's is required to respond to this research gap. Some methodological issues appear self-evident e.g. purposive sampling used with a maximum variation strategy to capture a wide range of participant experiences (Emerson, 2015). However, to design such a study well a PPI consultation phase was required using a qualitative approach to provide a richer understanding of PWPs views about how the study should be conducted.

Method

Aim

The aim of this PPI consultation was to explore PWPs opinions regarding the need for anxiety research, and any methodological considerations they felt would be important for future research studies. This work provides the foundation for occupational therapists to develop more robust research into constructing a future complex intervention to support PWPs experiencing anxiety.

Design

The methodology for this PPI consultation was founded upon a constructivist epistemological framework, which views an individual's reality as a construct of the human mind formed from interacting with experience in the real world (Elkind, 2004). A pragmatic inquiry framework, along with an inductive approach was used to focus the PPI participants to look for actionable findings. Pragmatism itself is conceptually consistent with the philosophical underpinnings of occupational therapy (Ikiugu and Schultz, 2006). This further serves to make this a suitable research framework to be implemented by occupational therapists. The findings of this PPI consultation will be used to inform the development of future occupational therapy research. Semi-structured telephone and Skype interviews were conducted in this PPI consultation to facilitate the description of retrospective experiences and opinions towards the future research. The interviews were conducted in February and March 2016.

Sample

Parkinson's UK provide their own "Research Support Network" that helps researchers recruit participants with the charity's support. PWPs that are interested in engaging with PPI consultations receive training for the specific purpose of engaging with researchers. Contact was made with the charity's PPI coordinator via an electronic online form, and a subsequent recruitment email was developed with the PPI coordinator to e-mail out to volunteers. This email included a brief description of the proposed study and the purpose of the PPI consultation. The information sent out was explicit in stating that this PPI consultation focused on anxiety and an anxiety study. Also offered were choices for how the PPI consultation interview could be conducted, considering that communication problems are a common difficulty for PWPs (Barone *et al.,* 2009). Choices offered included telephone interviews, Skype interviews, e-mail or any other suggestions the volunteer had. If participants consented to engage in the consultation by responding to the e-mail, the main author contacted them to arrange a mutually convenient time for the interview.

Papers reporting similar consultations had sample sizes ranging from seven to 17 participants (Kleme *et al.,* 2014; Daveson *et al.,* 2015). Considering the wide

range of sample sizes presented in the literature a sample of 10 was deemed large enough to provide a potential saturation point for this PPI consultation whereby enough rich data could be extracted (Creswell 2003). Participants were recruited using convenience sampling. The first 10 PWPs to respond were included in the consultation. These participants had received training for PWPs interested in being involved in research consultations.

Ethical considerations

Ethical approval was provided by Plymouth University's health student ethics sub-committee, ref number (16/17)-244. Participants gave written consent via e-mail, which included a clear statement that the work would be published.

Data collection

The PPI consultation was completed in line with the process laid out in the NIHR handbook (NIHR, 2014). Seven participants chose to undertake a telephone interview and two participants chose to engage in a Skype interview using a webcam. One participant stopped responding to e-mails. The PWPs suggested no other interview methods. The first author, who is an occupational therapist, conducted all interviews.

A short six-question interview schedule was used for all PPI consultation interviews (Figure 1). The Parkinson's UK PPI coordinator reviewed the interview schedule prior to use. Taking advice from the PPI coordinator, minor changes to the wording of questions were made. The first question was a general question to open up the interview and relax the interviewee, with the second question being used to focus the interview. This was in line with the guidance presented in the NIHR handbook (2014). Audio recordings were made during all interviews with participants' consent and were destroyed following transcription. Field notes were taken during all interviews to ensure richness of data. The shortest interview lasted nine minutes and the longest interview lasted 35 minutes, with mean average interview duration of 18 minutes.

Figure 1. Interview guide and prompt sheet

1. **Please tell me a bit about yourself, and your experience of anxiety and Parkinson's.**
   Why do you say this?
   Can you explain a bit more about this?

2. **Do you think anxiety and Parkinson's is an area that needs research?**
   Why do you say this?
   Can you explain a bit more about this?

3. **What areas of anxiety and Parkinson's should this research focus on? For example, it's impact on freezing, communication, social isolation, or anything else?**
   Why do you say this?
   Can you explain a bit more about this?

4. **In the proposed study we aim to conduct face-to-face interviews with people with Parkinson's about their experiences of anxiety. What things are important to consider when interviewing a person with Parkinson's?**
   Why do you say this?
   Can you explain a bit more about this?

5. **Is there anything else you would like to tell me that we haven't discussed?**
   Why do you say this?
   Can you explain a bit more about this?

6. **Do you have any questions?**

Data analysis

Data was analysed using thematic analysis to identify, analyse and report patterns emerging from the data (Braun and Clarke, 2006). An inductive approach was adopted to allow frequent, dominant and significant themes to emerge from the raw data without the restrictions of a predefined framework. The transcribed interviews were then uploaded to the computer assisted qualitative software NVivo (version 10). This was used to facilitate coding and to take advantage of its ability to manage, organise and track data. Next, three researchers (CL, DC & DWE) read the interview transcripts to immerse themselves within the data. They then independently formulated initial codes (subthemes) across the data. The researchers then examined their defined codes together until agreement was

reached. Several codes were renamed or merged provide a deeper understanding of the participants meaning and experience. The third step was collating and reviewing the codes to identify potential themes. The final step was the search for vivid quotations to illustrate the themes that related back to the PPI consultation's aim. The rigour and credibility of the data analysis was assured by two senior researchers (JL, KB). The senior researchers provided constructive feedback until consensus was achieved on the text fragments, subthemes, and themes. These themes are illustrated with quotes that have been anonymised with pseudonyms to protect confidentiality, and presented with corresponding transcript (T) and line numbers for transparency.

Rigour

The criteria proposed by Lincoln and Guba (1985) were used to promote rigour and credibility in the PPI consultation's findings. Once interviews were transcribed verbatim, member checking was employed to ensure the validity of the accounts. Three of the nine interviewees consented to checking their respective interview transcripts; they confirmed their accuracy. Peer-review triangulation was used to ensure increased credibility in the coding process. This was achieved using two independent reviewers, of different professional backgrounds who did not work directly with PWPs to code a sample of transcripts (four of nine transcripts). Member checking was also employed following thematic analysis. Three of the original participants assessed the adequacy of the data analysis and confirmed its validity. Findings were triangulated with Sunvisson (2006) and Wressle, Engstrand and Granérus (2007) to ensure that the developed themes were rich, robust and valid.

A reflexive field journal was used to assess that the researchers assumptions had as minimal an influence on the findings as possible. On two occasions, participants asked the author unexpected and challenging questions regarding the authors opinions on familial genetic testing for Parkinson's. Whilst adequate answers were given redirecting the participants to their GP's and a short debrief with the Parkinson's UK PPI coordinator occurred, it has highlighted the need for comprehensive planning for such unexpected questions. Being reflexive it

is surmised that the participants might have been introducing a new topic that was more important to them, and perhaps more of a priority for research than anxiety. This is a subject that warrants further exploration as a potential area of research.

Findings

Following the initial e-mail appeal, 10 volunteers expressed interest (six male, four female). The mean age of all participants was 65 (age range 33-79). One male participant initially responded to a follow up e-mail, and then stopped answering emails with no reason given. It was assumed he had declined to participate in the consultation, and no further contact was attempted. The final number of participants was nine (five male, four female).

Thematic analysis identified 566 relevant codes, which were grouped into 10 sub-categories. These were further clustered into three main themes; experiences of anxiety in Parkinson's; coping with anxiety in Parkinson's; considerations for future research (Table 1).

Table 1. Table showing clustering of sub-categories into three main themes

Theme	Experiences of anxiety in Parkinson's	Coping with anxiety in Parkinson's	Considerations for future research
Sub-categories	• Anxiety and the diagnostic process • Interpretations of anxiety • Descriptions • Perceptions and feelings of others	• Positive approaches • State of mind • Physical wellbeing	• The need for research • Methodological considerations • Personal considerations

Experiences of anxiety in Parkinson's

All participants expressed anxiety as a negative experience associated with Parkinson's that has a detrimental impact on quality of life, which should be the focus of future research. Three participants in the opening question described certain roles, e.g. jobs, as 'stress' and 'stressful', but none ever directly described

themselves as stressed or used the term in any other way. Anxiety was often described as "crippling", and one of the most disabling aspects of Parkinson's. For example: "*…my own experience of anxiety is that it can be a crippling illness. I used to have panic attacks and the fear of getting one was almost worse than actually having a panic attack. I think anxiety can be a real scourge for people with Parkinson's who suffer from it."* [Irene, T9, line 94].

All participants felt that anxiety and Parkinson's was connected in some manner either as a result of biochemistry or attributed to knowing that they have an incurable, progressive and degenerative condition. It was sometimes experienced with depression, but not always. Whatever the perceived root cause of the anxiety, it was experienced as a ubiquitous and unpredictable presence that affected their daily lives: *"It's there in the background all of the time, and I was always fearful of it reoccurring, it was a very painful experience having anxiety to the extent that I did. It was, it was just an awful."* [Harry, T8, line 38].

The impact of anxiety on other symptoms in Parkinson's was a recurring element of this theme that participants felt needed addressing in future study. Participants expressed how anxiety negatively affected a variety of symptoms including freezing, hallucinations and communication. All participants experienced anxiety when considering the future, with three explicitly stating 'none of us know what the future holds' and that having Parkinson's made this very 'nebulous'. Finally, a persistent sub-theme regarded the impact of anxiety on other people. Participants reported feeling anxious regarding increased carer burden on their families and partners. They could feel trapped in a cycle of anxiety in public, becoming the subject of unwanted attention.

Coping with anxiety in Parkinson's

A variety of coping strategies were identified. Four participants identified internal resilience as an important coping strategy or mechanism, and that this was something that was either developed prior to being diagnosed with Parkinson's or after: "*…possibly that I have had a career which is not a conventional career in terms of progression through the same field of work over a large number of years. I*

have totally changed course from time to time and in, at those change points there has been some apprehension about what is going to be happening next. And it's possible that I have learnt to cope with those situations over time, even before I had Parkinson's. Therefore, when I now look at myself and the last three years there must be some coping mechanism somewhere which means that I don't quite feel anxiety the way that I've noticed some people seriously suffer from who have Parkinson's." [Eric, T5, line 20].

All participants discussed state of mind as an important coping mechanism. Maintaining a positive outlook and not mentally viewing oneself in a disabled role was seen as crucial to successfully managing anxiety. Despite all participants viewing a positive state of mind as an important coping strategy there was no consensus about how to sustain this. All participants agreed that more research was needed in this area: "*…when I got diagnosed first I mentally put myself into a little electric buggy which my mother had had when she had rheumatoid arthritis, and I mentally drove around in this buggy for about three days, then a good friend of mine said heh, my aunts had Parkinson's for 18 years and she plays badminton three times a week and get over yourself. I burst out laughing and realised what I'd been doing, I ditched the buggy."* [Abigail, T1, line 344].

Every participant identified that they tried to remain engaged in physical and social occupations to manage their Parkinson's symptoms, and that this was an important coping strategy for managing anxiety. It was more effective for some than others. Some participants were aware that they may not necessarily be exercising hard enough but stated they tried to be active to the best of their physical abilities. Interestingly, remaining engaged in social occupations was perceived by participants to be more valued than physical activity in managing anxiety. This is an important implication for occupational therapists, particularly in physical health settings where the management of bodily symptoms can often be the priority. Participants reported that making an effort to go out and socialise reduced feelings of anxiety, and also reported feelings of belonging to a 'club', and 'camaraderie' amongst PWPs, that improved their sense of wellbeing.

Considerations for future research

Every participant stated that anxiety in Parkinson's needs further research and that they felt that future research in the area was relevant: *"Oh absolutely because the PWPs that I hang out with and talk to, for us this is a big area and a very debilitating area."* [Abigail, T1, line 72].

The impact of anxiety on social interaction and communication were felt to be key areas that participants believed that research should focus on. Participants reported that social situations that they previously had no issue with or even excelled, now either caused or were affected by anxiety causing emotional distress and loss of quality of life. Furthermore, this often led to the loss of occupational roles for participants. This was closely related to communication in that people often felt becoming more anxious affected their voice, which in turn made them more anxious and continued the cycle: *"In my case, my voice changes. It gets weaker. I think uh, people tend to um, worry about what people think of them. And then that makes my voice worse"* [Gordon, T7, line 244].

Participants highlighted a number of considerations for researchers interviewing a PWP, which also have additional implications for occupational therapists and other healthcare professionals. For example, of primary importance was to consider "*the impact of the interview*" [Charlie, T3, line 102] and "*get to know the person*" [Daniel, T4, line 124]. Suggested solutions for these were to provide multiple choices for where, when and how the interview is performed and having a pre-interview telephone call to make sure the person is having a good day. Logistical considerations were consistent across all participants, for example ensuring there are adequate breaks, considering the time of day, timing the interview with respect to on/off phases, allowing additional time for slowed thinking and communication, and easy access to drinks and medication. Several participants highlighted the importance of establishing a safe environment. It was important to frame the researcher-participant relationship as collaborative and mutually beneficial to achieve research aims: "*I feel very strongly that I am the expert in my own body, and in my own life, and I get cross when medical*

professionals and whatever feel, try to tell me what I am or should be feeling. So, creating an atmosphere of partnerships and mutual benefit." [Abigail, T1, line 221].

Discussion and implications

This PPI consultation showed that PWPs interviewed considered the proposed study to be important, needed and relevant, which corresponds with the findings of Deane *et al.* (2014). Some of the themes uncovered in this consultation have been noted in relation to coping with anxiety in Parkinson's before. Sunvisson (2006) identifies the conscious structuring of daily habitual routines and activities to reduce anxiety. Furthermore, Wressle, Engstrand and Granérus (2007) identified activity restriction and decreased socialisation as contributors to increased anxiety and fear. Considerations for future research specifically regarding experiences of anxiety in Parkinson's have not previously been discussed in the literature.

The participants stated that anxiety was invasive and had a detrimental impact on their quality of life, as confirmed in other studies (Lindesay *et al.,* 2012). The specific sub-themes regarding the fear of the future and unpredictability were indicated in the works of Sunvisson (2006) and Wressle, Engstrand and Granérus (2007), although these studies were not focused on anxiety in Parkinson's. However, as these themes have also appeared in papers discussing anxiety in general populations (Cisler *et al.,* 2009) it suggests that future research should focus on determining more precisely how anxiety is experienced for PWPs than those without the condition. This intelligence could inform the design of discrete, effective anxiety interventions and approaches for people with Parkinson's (Deane *et al.,* 2014) and presents an opportunity for occupational therapists to become pioneers in the development of such treatments.

Coping strategies were an area that all participants felt required more research. Whilst some studies have explored coping with anxiety for people without Parkinson's (Krohne and Hock, 2011), literature regarding coping mechanisms for anxiety in PWPs has been limited to outcome measurement or experiences regarding deep brain stimulation that only affect small numbers of individuals (Hurt *et al.,* 2011). Researchers have only just started to focus on Parkinson's specific

anxiety interventions (Bloem *et al.,* 2015,) and in particular mindfulness techniques are emerging as potential anxiety treatments for PWPs (Pickut *et al.,* 2015). However it has been acknowledged that mindfulness is not a solution for everyone (Holmes, 2009). The views of participants in this consultation suggest that future research should explore coping strategies in more depth to highlight alternative avenues of research.

The concept of establishing a safe and sensitive research environment was important to participants, to enable them to feel both physically and psychologically supported. This will be valuable to not only maximise validity but also minimise any risk of bias or potential harm in the proposed study (Morris *et al.,* 2009). An important consideration raised in the consultation was the need for a "culturally safe research environment". This will be important for interview schedule planning: to protect participants from potential indirect harm, and experiences of feeling demeaned, or under-represented by a dominant research methodology, epistemology or even socio-cultural lens (Elmir *et al.,* 2011). Furthermore, participants identified wanting a "mutually beneficial" rapport with researchers in this consultation. Guillemin and Heggen (2009) argue that establishing this type of rapport early is necessary for generating rich data and ensuring respect is sustained between researchers and participants. In addition, Varga-Dobai (2012) details how a strong researcher-participant rapport can provide mutual benefits in self-learning and reflection. Alongside the concrete logistical suggestions put forth by participants, this suggests that establishing a safe research environment and strong researcher-participant rapport early on should be key practice in future research. As the suggestions of collaborative working and rapport building are key concepts of occupational therapy, this places the profession in an ideal position to lead such research.

Limitations

Despite successful recruitment through the Parkinson's UK PPI network, it must be acknowledged that by limiting to one recruitment method this has narrowed the potential sample and potentially introduced bias. That is, only those individuals with

access to a computer, an Internet connection and an e-mail account were able to participate. Furthermore, the participants accessed through the Parkinson's UK network have all received training in PPI, therefore whether they can truly be considered 'lay people' is debatable (Mockford *et al.,* 2012).

It may be argued that only subjecting a small sample of the transcripts to peer-review triangulation reduced the credibility of the findings. However there was close agreement between reviewers, which increases confidence in the findings. The fact that not all participants chose to be involved with member checking may impact on the robustness of these findings (Morse, 2015). However those who did respond agreed with the analysis suggesting it represented their views. It is acknowledged that there is controversy surrounding the validity of multiple-source triangulation; the assumption weaknesses in one method will be compensated for in another are unlikely (Morse, 2015).

Finally, a particular challenge of this consultation is the nature of PPI itself. Both Staniszewska *et al.* (2008) and Mockford *et al.* (2012) highlight that there is little evidence supporting the effectiveness of PPI. Furthermore, in their systematic reviews both Mockford *et al.* (2012) and Brett *et al.* (2014) highlight the little impact that PPI has in terms of real world benefits to date. Our PPI was specifically performed to inform a proposed research proposal. The participants were PWPs acting as consultants and not research participants (NIHR, 2014) but were able to provide valuable contributions to improve the research protocol.

Conclusion

Despite the evidence suggesting PPI has little impact on real world healthcare or research, this consultation work has provided valuable insights into important issues related to anxiety in Parkinson's. The findings should inform the design of future studies. Working in collaboration with Parkinson's UK proved to be a valuable resource for recruitment. The methods used for interviewing participants (telephone and Skype interviews) worked well but from the feedback received in this consultation it would be beneficial for occupational therapy researchers to provide more choice or novel ways in which participants can engage. With this in

mind, it is important for researchers to also plan to access support for participants should unexpected and challenging questions arise. Finally, the philosophy of occupational therapy complements the identified recommendations in such a way that occupational therapists are ideally placed to take research into anxiety in Parkinson's forwards.

Key messages

Key findings:

- This consultation round with people with Parkinson's strengthens the argument that anxiety needs more research.
- People with Parkinson's identify anxiety as a ubiquitous, detrimental presence in their lives which they cope with in a variety of ways.
- Establishing a safe and supportive research environment for participants with Parkinson's is important for occupational therapists to consider when designing and conducting research.

What the study has added:

Anxiety is experienced by people with Parkinson's and it should be a consideration when developing interventions with, and the design of research about, people with this condition.

References

Barone, P., Antonini, A., Colosimo, C., Marconi, R., Morgante, L., Avarello, T. P., Bottacchi, E., Cannas, A., Ceravolo, G., Ceravolo, R., Cicarelli, G., Gaglio, R. M., Giglia, R. M., Iemolo, F., Manfredi, M., Meco, G., Nicoletti, A., Pederzoli, M., Petrone, A., Pisani, A., Pontieri, F. E., Quatrale, R., Ramat, S., Scala, R., Volpe, G., Zappulla, S., Bentivoglio, A. R., Stocchi, F., Trianni, G. and Del Dotto, P. (2009) 'The PRIAMO study: A multicenter assessment of nonmotor symptoms and their impact on quality of life in Parkinson's disease', *Movement Disorders*, 24(11), 1641–1649. doi: 10.1002/mds.22643.

Bloem, B. R., de Vries, N. M. and Ebersbach, G. (2015) 'Nonpharmacological treatments for patients with Parkinson's disease', *Movement Disorders*, 30(11), 1504–1520. doi: 10.1002/mds.26363.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), 77–101. doi: 10.1191/1478088706qp063oa.

Breen, K. C. and Drutyte, G. (2013) 'Non-motor symptoms of Parkinson's disease: The patient's perspective', *Journal of Neural Transmission*, 120(4), 531–535. doi: 10.1007/s00702-012-0928-2.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. and Suleman, R. (2014) 'A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities', *The Patient - Patient-Centered Outcomes Research*, 7(4), 387–395. doi: 10.1007/s40271-014-0065-0.

Bystritsky, A. and Kronemyer, D. (2014) 'Stress and anxiety: Counterpart elements of the stress/anxiety complex', *Psychiatric Clinics of North America*, 37(4), 489–518.

Cisler, J. M., Olatunji, B. O. and Lohr, J. M. (2009) 'Disgust, fear and the anxiety disorders: A critical review', *Clinical Psychology Review*, 29, 34–36. doi: 10.1016/j.cpr.2008.09.007.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., Health, P., Unit, S., Michie, S., Nazareth, I. and Petticrew, M. (2008) 'Developing and evaluating complex interventions : new guidance', *BMJ (Clinical research ed.)*, 337, p. a1655. doi: 10.1136/bmj.a1655.

Creswell, J. W. (2003) *A Framework for Design*. Second edition, *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Second edi. London: SAGE Publications. doi: 10.3109/08941939.2012.723954.

Daveson, B. A., de Wolf-Linder, S., Witt, J., Newson, K., Morris, C., Higginson, I. J.

and Evans, C. J. (2015) ‘Results of a transparent expert consultation on patient and public involvement in palliative care research.’, *Palliative medicine*, doi: 10.1177/0269216315584875.

Deane, K. H. O., Flaherty, H., Daley, D. J., Pascoe, R., Penhale, B., Clarke, C. E., Sackley, C. and Storey, S. (2014) ‘Priority setting partnership to identify the top 10 research priorities for the management of Parkinson’s disease’, *BMJ Open*, 4(12), e006434–e006434. doi: 10.1136/bmjopen-2014-006434.

Elkind, D. (2004) ‘The problem with constructivism’, *The Educational Forum*, 68(4), 306–312. doi: 10.1080/00131720408984646.

Elmir, R., Schmied, V., Jackson, D. and Wilkes, L. (2011) ‘Interviewing people about potentially sensitive topics’, *Nurse Researcher*, 19(1), 12–16. doi: 10.7748/nr2011.10.19.1.12.c8766.

Emerson, R. W. (2015) ‘Convenience Sampling, Random Sampling, and Snowball Sampling: How Does Sampling Affect the Validity of Research?’, *Journal of Visual Impairment & Blindness*, 109(2), 164–168.

Guillemin, M. and Heggen, K. (2009) ‘Rapport and respect: Negotiating ethical relations between researcher and participant’, *Medicine, Health Care and Philosophy*, 12(3), 291–299. doi: 10.1007/s11019-008-9165-8.

Hogg, C. N. L. (2007) ‘Patient and public involvement: What next for the NHS?’, *Health Expectations*, 10(2), 129–138. doi: 10.1111/j.1369-7625.2006.00427.x.

Holmes, L. (2009) ‘Mind over matter.’, *Occupational Health*, 61(12), 36–38.

Hurt, C. S., Thomas, B. A., Burn, D. J., Hindle, J. V., Landau, S., Samuel, M., Wilson, K. C. M. and Brown, R. G. (2011) ‘Coping in Parkinson’s disease: An examination of the coping inventory for stressful situations’, *International Journal of Geriatric Psychiatry*, 26(10), 1030–1037. doi: 10.1002/gps.2634.

Ikiugu, M. and Schultz, S. (2006) ‘An argument for pragmatism as a foundational philosophy of occupational therapy’, *Canadian Journal of Occupational Therapy*, 2(73), pp. 86–97. doi: 10.2182/cjot.05.0009.

Kleme, J., Pohjanoksa-Mantyla, M., Airaksinen, M., Enlund, H., Kastarinen, H., Peura, P. and Hameen-Anttila, K. (2014) ‘Patient Perspective in Health Technology Assessment of Pharmaceuticals in Finland’, *International Journal of Technology Assessment in Health Care*, 30(3), 306–311. doi: 10.1017/S0266462314000282.

Krohne, H. W. and Hock, M. (2011) ‘Anxiety, coping strategies, and the processing of threatening information: Investigations with cognitive-experimental paradigms’, *Personality and Individual Differences*, 50(7), 916–925. doi:

10.1016/j.paid.2010.08.001.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: SAGE Publications.

Lindesay, J., Stewart, R. and Bisla, J. (2012) 'Anxiety disorders in older people', *Reviews in Clinical Gerontology*, 22(03), 204–217. doi: 10.1017/S0959259812000019.

Mockford, C., Staniszewska, S., Griffiths, F. and Herron-Marx, S. (2012) 'The impact of patient and public involvement on UK NHS health care: a systematic review', *International Journal for Quality in Health Care*, 24(1), 28–38. doi: 10.1093/intqhc/mzr066.

Morris, N., Armstrong, V. and Balmer, B. (2009) 'Constructing a safe research environment: Technology talk between researchers and volunteer research subjects', *Health, Risk & Society*, 11(2), 99–116. doi: http://dx.doi.org/10.1080/13698570902784299.

Morse, J. M. (2015) 'Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry', *Qualitative Health Research*, 25(9), 1212–1222. doi: 10.1177/1049732315588501.

NIHR (2014) *Patient and public involvement in health and social care research: A handbook for researchers*. Available at: http://www.rds.nihr.ac.uk/wp-content/uploads/RDS-PPI-Handbook-2014-v8-FINAL.pdf, date accessed: 1st February 2016

Parkinson's UK, (2014). *Parkinson's and You*. Retrieved from http://www.parkinsons.org.uk/content/parkinsons-and-you-booklet, date accessed: 1st February 2016

Pickut, B., Vanneste, S., Hirsch, M. A., Van Hecke, W., Kerckhofs, E., Mariën, P., Parizel, P. M., Crosiers, D. and Cras, P. (2015) 'Mindfulness Training among Individuals with Parkinson's Disease: Neurobehavioral Effects', *Parkinson's Disease*, 2015, 1-6. doi: 10.1155/2015/816404.

Staniszewska, S., Herron-Marx, S. and Mockford, C. (2008) 'Measuring the impact of patient and public involvement: The need for an evidence base', *International Journal for Quality in Health Care*, 20(6), 373–374. doi: DOI 10.1093/intqhc/mzn044.

Sunvisson, H. (2006) 'Stopped within a track: embodied experiences of late-stage Parkinson's disease', *International Journal of Qualitative Studies on Health and Well-being*, 1(2), 91–99. doi: 10.1080/17482620500487547.

Sylvers, P., Lilienfeld, S. O. and LaPrairie, J. L. (2011) 'Differences between trait fear and trait anxiety: Implications for psychopathology', *Clinical Psychology Review*, 31(1), 122–137. doi: 10.1016/j.cpr.2010.08.004.

Varga-Dobai, K. (2012) 'The relationship of researcher and participant in qualitative inquiry: From "self and other" binaries to the poststructural feminist perspective of subjectivity', *The Qualitative Report*, 17(47), 1–17.

Whitstock, M. T. (2003) 'Seeking evidence from medical research consumers as part of the medical research process could improve the uptake of research evidence', *Journal of Evaluation in Clinical Practice*, 9(2), 213–224. doi: 10.1046/j.1365-2753.2003.00376.x.

Wressle, E., Engstrand, C. and Granérus, A.-K. (2007) 'Living with Parkinson's disease: Elderly patients? and relatives? perspective on daily living', *Australian Occupational Therapy Journal*, 54(2), 131–139. doi: 10.1111/j.1440-1630.2006.00610.x