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# What is the lived experience of anxiety for people with Parkinson's? A phenomenological study

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**HEALTH  
PROFESSIONS  
WITH  
PLYMOUTH  
UNIVERSITY**

**MClinRes Masters in Clinical Research**

**MCR703 Research dissertation module**

What is the lived experience of anxiety for people with  
Parkinson's? A phenomenological study

**Chris Lovegrove**

**15<sup>th</sup> August 2017**

*What is the lived experience of anxiety for people with  
Parkinson's? A phenomenological study*

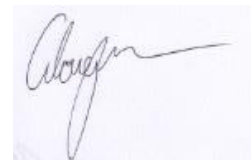
Submitted by Chris Lovegrove (325408)

To Plymouth University as a dissertation towards the degree  
of Master of Clinical Research

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I certify that all material in this dissertation which is not my own work has been identified and that no material is included for which a degree has previously been conferred on me.

A handwritten signature in black ink, appearing to read 'Chris Lovegrove', is written over a light blue rectangular background.

*Chris Lovegrove*

## Abstract

**Aim:** To explore the lived experience of anxiety for people with Parkinson's.

**Background:** Anxiety is a non-motor symptom of Parkinson's. While there is ample evidence demonstrating the incidence and prevalence of anxiety in people with Parkinson's, there is little specific research documenting how individuals with this condition experience anxiety. Current evidence of behavioural treatments is limited to small, specific populations or non-condition specific interventions. It is important to explore the experiences of people with Parkinson's to identify potential issues for consideration in developing future interventions.

**Methods:** This study used a qualitative research approach underpinned by a social constructivist epistemology. A phenomenological research design was selected to explore the participants' lived experience of anxiety in their 'lifeworld' using face-to-face interviews. Six participants were recruited through the charity Parkinson's UK using a maximum variation sampling strategy. Data was analysed using heuristic inquiry and thematic analysis.

**Findings:** Three key themes emerged: coping, amplification and perceptions. 'Coping' indicates high value on self-reliance and mixed views towards shared experiences. 'Amplification' concerned the effect of anxiety on physical and non-physical symptoms, and the challenging of self-identity. 'Perceptions' explains how participants viewed anxiety as both a negative and a positive experience. Researchers and healthcare professionals should take these findings into account when designing future studies and interventions.

**Conclusions:** Anxiety is a complex experience constructed of interlinked parts. It affects people with Parkinson's in a myriad of ways. Healthcare professionals and researchers should consider the broader issues of the lived experience of anxiety, such as its challenge to self-identity. Further research is required to illuminate the lived anxiety experiences of the discrete populations not included in this study.

(Abstract word count: 270 including subheadings)

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**This work is dedicated to the 127,000 people with Parkinson's currently living in the UK.**

## Abbreviations

BE	Ben Elliott (gatekeeper)
COREQ	COnsolidated criteria for REporting Qualitative research
FOG	Freezing Of Gait
KB	Katrina Bannigan (senior researcher)
MeSH	Medical Subject Headings
NHS	National Health Service
PIS	Participant Information Sheet
PPI	Patient and Public Involvement
PWPs	People With Parkinson's/ Person With Parkinson's
SPIDER	Sample, Phenomena of Interest, Design, Evaluation, Research type
NIHR	National Institute for Health Research



# 1 Chapter one

## 1.1 Introduction

15.4 million people live with a long-term condition in England and their care accounts for 70% of total NHS spending (NHS England, 2016). Parkinson's disease, more commonly referred to as Parkinson's, is a long-term neurodegenerative condition. The common symptoms include tremor, loss of automatic movement and bradykinesia (slowed movement) (Kalia and Lang, 2015). Parkinson's is the second most common neurodegenerative condition in the UK, affecting approximately 127,000 people with Parkinson's (PWPs) in the country (Parkinson's UK, 2014). Of these people, 98.6% experience non-motor symptoms that can be defined as a collection of neuropsychiatric symptoms associated with Parkinson's (Barone *et al.*, 2009). These can include sleep disorders, sensory disturbances, and autonomic dysfunction (Ou *et al.*, 2014). Of this number 43-56% experience stress and anxiety (Barone *et al.*, 2009; Breen and Drutyte, 2013).

Stress and anxiety are often used interchangeably in Parkinson's research, yet these terms need clarification. Bystritsky and Kronemyer (2014) explain that stress tends to be an external stimulus arising from the environment. Alternatively, Hallion and Ruscio (2013) describe anxiety as a persistent internal feeling of fear and worry that is intrusive in daily life. Clarifying these terms suggests it is more appropriate to focus solely on anxiety rather than a combination. PWPs who experience anxiety are more at risk of falling, experiencing a lower quality of life, loss of independence, loss of social roles and increased health burden (Karlsen *et al.*, 2000; Hanna and Cronin-Golomb, 2012; Duncan *et al.*, 2014). Several authors have highlighted a lack of anxiety specific research in Parkinson's (Pontone *et al.*, 2009; Breen and Drutyte, 2013; Erro *et al.*, 2013; Todorova, Jenner and Chaudhuri, 2014; Lutz *et al.*, 2016). With such high prevalence but a lack of specific research, it is vital to gain an understanding of the experience of anxiety for PWPs to lay a foundation to develop future complex interventions with scientific rigour (Craig *et al.* 2008). Anxiety has also been identified as a research priority in collaboration with the charity Parkinson's UK (Deane *et al.* 2014).

## 1.2 Aim of Research

This study aimed to develop an understanding of the lived experience of anxiety for PWPs to identify potential issues to consider in developing future interventions.

## 1.3 Literature review

### 1.3.1 Search strategy

A literature search was completed to identify current and relevant research regarding the experience of anxiety for PWPs. The following databases were searched between 10<sup>th</sup> September 2015 and 1<sup>st</sup> December 2016: CINAHL, MEDLINE, AMED, SocINDEX, PsycINFO, Web of Science and PubMed.

A SPIDER question was developed with the following keywords considered as pertinent and meaningful search terms (Cooke, Smith and Booth, 2012):

**Sample-** people with Parkinson's, male and female, no age limit

**Phenomenon of Interest-** anxiety, in relation to living with Parkinson's

**Design-** qualitative interviews, self-reported questionnaires, mixed methodology research, cross-sectional studies

**Evaluation-** experience of anxiety for people with Parkinson's, how does this affect them? How are symptoms affected? How is quality of life affected?

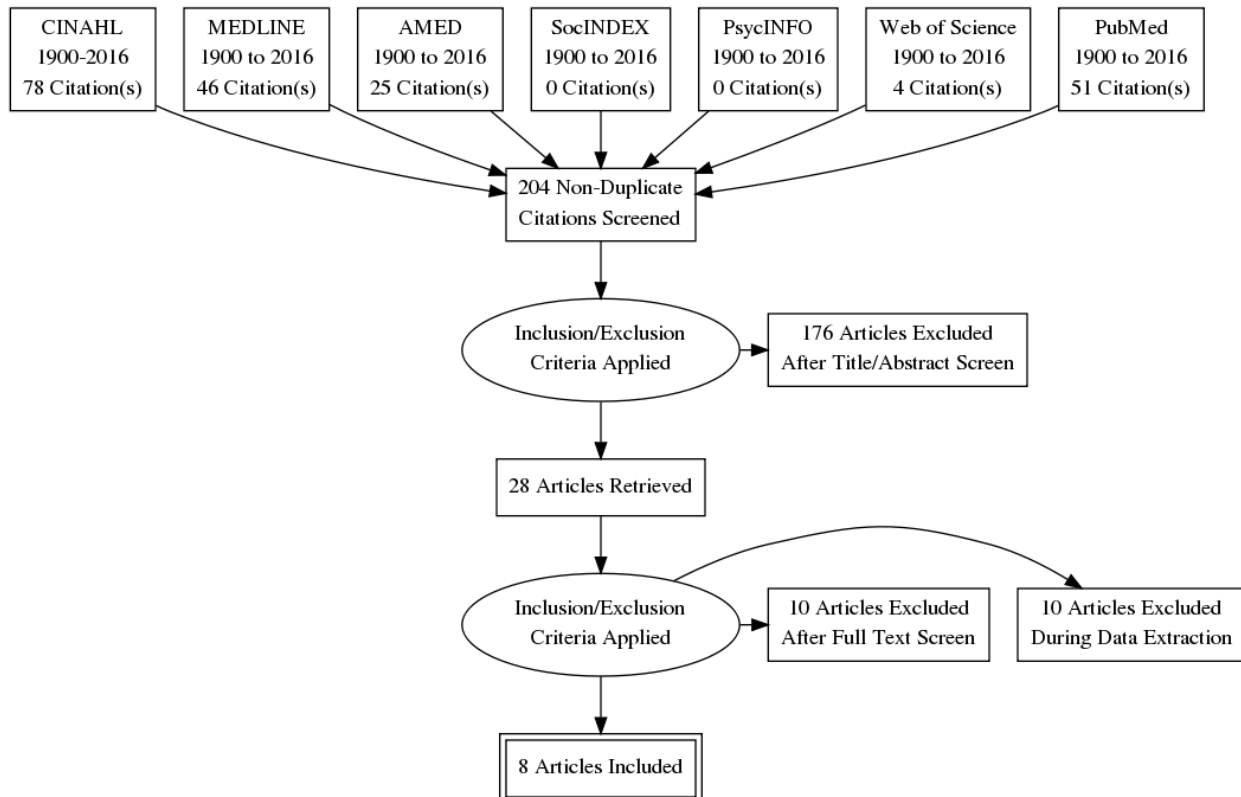
**Research type-** qualitative, quantitative and mixed methodology research all considered

From these keywords, MeSH search terms included:

- Parkinson's disease OR Parkinson\*

- Anxiety OR worry
- Qualitative OR interviews OR experiences OR views

A search with a combination of MeSH terms found a total of 204 potentially relevant papers. Hand searching identified no further research not already found. Figure 1 shows the literature search process.



**Figure 1: Flow chart outlining study selection**

The final number of articles chosen for discussion was eight. None of the papers directly answered the SPIDER question, highlighting a gap in the research literature as supported by Todorova, Jenner and Chaudhuri (2014). These articles remained in the final selection due to providing the most transferrable evidence towards answering the SPIDER question. Table 1 provides a brief overview of the included studies.

**Table 1: Overview of studies included in review**

<b>Study reference</b>	Walsh and Bennett (2001)  UK	Sunvisson (2006)  Sweden	Wressle, Engstrand and Granérus (2007)  Australia	Barone <i>et al.</i> (2009)  Italy	Pontone <i>et al.</i> (2009)  USA	Burn <i>et al.</i> (2012)  UK	Leentjens <i>et al.</i> (2012)  Inter.	Ehgoetz Martens, Ellard and Almeida (2014)  Canada
<b>Aim of study</b>	Present overview of anxiety in people with Parkinson's (PWPs)	Explore the experience of late-stage Parkinson's	How Parkinson's affects daily living	Assess prevalence of non-motor symptoms	To identify correlations between anxiety and Parkinson's	To identify links between mood and Parkinson's	Describe relationship between anxiety and motor fluctuations	To see if anxiety causes freezing of gait
<b>Methods</b>	Literature review	Phenomenology	Qualitative	Multicentre survey	Cross-sectional study	Cross-sectional study	Cross-sectional study	Randomised controlled trial
<b>Data collection</b>	Not specified	Interviews over five year period	Interviews	Surveys	Clinical assessment	Self-reported	Clinical assessment	Experimental
<b>Participants</b>	Nil	One 72 year old PWPs	Seven PWPs	1,072 PWPs	127 PWPs	513 PWPs	250 PWPs	31 PWPs
<b>Findings</b>	Further research required	Anxiety is a part of the lived experience	Anxiety affects PWPs in lots of ways	Anxiety is common for PWPs	Anxiety is linked to motor fluctuations	Onset age affects anxiety	The relationship is complex	Anxiety increases freezing of gait

This literature review considers the wider research related to the experience of anxiety in Parkinson's to provide the rationale and background for this study. The outcomes of the eight studies that are directly relevant to the study have been critically evaluated.

### 1.3.2 Critical analysis of relevant literature

During the literature review several broad themes emerged about the experience of anxiety for PWP's. This demonstrates the complex picture that anxiety in Parkinson's presents.

#### *Anxiety and age*

The experience of anxiety in Parkinson's has been thought to be related to age (Richard, 2005). A higher prevalence of anxiety problems has been identified in older people (Lindesay, Stewart and Bisla, 2012), particularly the fear of falling and the future. In their large multicentre survey, Barone *et al.* (2009) found that approximately 40% of PWP's in their seminal study experienced anxiety that affected their everyday life. They identified that a high prevalence of this non-motor symptom was related with longer disease duration, higher disease severity and cognitive dysfunction. Interestingly they were unable to establish a link between the experience of anxiety and the age of the PWP. However, there are limitations to this study affecting the transferability of the conclusions. The study was performed in Italy, which introduces a cultural bias. This limits transferability to the UK as an individual's cultural background influences their emotional expression (Hofmann, Asnaani and Hinton, 2010; Hofmann and Hinton, 2014). Additionally, the authors did not survey any form of a control group, making it hard to establish if this is an accurate representation of anxiety prevalence compared to a general population. Despite these limitations, this study was the first large-scale effort at developing the awareness of non-motor prevalence. It has led to the development of several future areas of enquiry by highlighting the prevalence of non-motor symptoms in PWP's (Leentjens *et al.*, 2014; Todorova, Jenner and Chaudhuri, 2014).

Burn *et al.* (2012) dispute the notion that there is no link between age and anxiety in Parkinson's. In a cross-sectional mixed-methodology study, they used a combination

of self-reported questionnaires and phenomenological, semi-structured interviews. Burn *et al.* (2012) demonstrated a strong relationship between the age of Parkinson's onset and anxiety, specifically that younger age of onset resulted in higher anxiety levels. The authors present a robust suite of inferential statistics supporting their claim. For example, they calculated an odds ratio of 0.63 with a 95% confidence interval (0.26-1.51) to demonstrate a link between younger onset Parkinson's and higher scores on the Hospital Anxiety and Depression Scale, irrespective of the presence of cognitive impairment. Their recruitment process is certainly of a convenience sample. This limits generalisation to the whole population (Sedgwick, 2013) and is not necessarily an accurate representation of anxiety in Parkinson's.

Similarly, the self-reported nature of the questionnaire introduces a degree of recall bias. This means that the findings could have reduced accuracy if events happened a long time ago or self-reported experiences may even be exaggerated or distorted (Hassan, 2005). Likewise, Burn *et al.* (2012) present no clarity regarding their qualitative thematic analysis method and the results are only briefly discussed. As there is no transparency regarding data analysis, it is unclear how the authors decided on what themes to include in their paper. This reduces the credibility of the qualitative component (Patton, 1999, 2015). These areas need consideration when contemplating transferability to practice.

However, Walsh and Bennett (2001) lend support to the claims of Burn *et al.* (2012). In their comprehensive literature review, they found a higher prevalence of anxiety in PWP's compared to the general population. The authors analysed several claims supporting a link between a younger age of onset and higher levels of anxiety. Walsh and Bennett (2001) are not transparent about their literature search process and did not outline their inclusion or exclusion criteria. Therefore, this reduces the confidence that the paper's conclusions are not influenced by selection bias (Berk, 1983; Gluud, 2006).

These studies support the notion that anxiety is more common in PWP's than previously believed (Picillo *et al.*, 2013). Burn *et al.* (2012) and Walsh and Bennett (2001) suggest that age of onset is particularly crucial. While Parkinson's can be a chronic stressor for all PWP's, the loss of social, familial, occupational and motor

function could be greater in those developing the disease earlier in life. Walsh and Bennett (2001) highlight that PWPs experience more anxiety than people with multiple sclerosis. This suggests that PWPs experience anxiety differently to other populations, and that an earlier age of anxiety onset in Parkinson's could be an indicator of higher levels of anxiety.

### *Anxiety and motor performance*

The impact of non-motor symptoms, particularly anxiety, has only become of interest to researchers within the last 20 years, including how anxiety affects motor symptoms (Todorova, Jenner and Chaudhuri, 2014). In a cross-sectional observational study using self-reported questionnaires, Pontone *et al.* (2009) identified that excessive anxiety in PWPs resulted in a higher frequency of motor fluctuations. The authors recruited from a specialist Parkinson's clinic. This means it is more likely that PWPs experiencing neuropsychiatric problems participated in the study, leading to a higher degree of prevalence being noted (Gluud, 2006). Additionally, the screening process purposefully excluded individuals who were not suffering from a mood disorder. This further skews the results, as there is no comparison presented. Additionally, the self-reported nature of the methodology introduced a degree of recall bias that further affects the study findings so they may be less accurate or distorted (Hassan, 2005). As a result, these findings initially provide little relevance to practice.

Leentjens *et al.* (2012) support the work of Pontone *et al.* (2009) with their cross-sectional study investigating anxiety and motor fluctuations. Participants underwent standardised clinical assessments as well as a questionnaire, adding further reliability to the findings. The authors found that high scorers on several anxiety scales experienced more motor fluctuations and related this to anxiety subtypes. This suggests that 'wearing-off' phenomena may only apply to a small number of people (Pontone *et al.*, 2009). The study is limited as inter-rater validity is not accounted for meaning there is reduced confidence that all researchers were consistent in their data collection (Kimberlin and Winterstein, 2008). Additionally, the subjectivity of some of the outcome measures used further reduces the reliability of the findings, especially as inter-rater validity had not been established (Richter and Werner, 2015). Finally, the research only identifies the presence of motor

fluctuations, not the severity. This would have been useful intelligence to further establish the link between anxiety and motor fluctuations.

More recently research has attempted to focus on motor fluctuations and anxiety in Parkinson's, specifically freezing of gait (FOG) episodes. Ehgoetz Martens, Ellard and Almeida (2014) performed a randomised controlled trial to investigate if anxiety caused FOG in Parkinson's. Virtual reality environments were used to stimulate anxiety-provoking situations while maintaining safety. They found that an increase in anxiety resulted in an increase in FOG episodes in both 'freezers' and 'non-freezers' ( $p < 0.001-0.013$ ). These results suggest that anxiety is an important mechanism underpinning FOG. This is a significant implication for clinicians and researchers to consider when developing interventions (Shah and Nolen, 2006; Goodwin *et al.*, 2015).

Despite this, the study has several limitations affecting its reliability. Firstly, there was no blinding present, which may have skewed the data (Psaty and Prentice, 2010). Using an independent and blinded assessor could have rectified this. This assessor would not be invested in the study. Therefore the findings would be less susceptible to confirmation bias as results would not be interpreted preferentially to meet the research hypothesis (Karanicolas, Farrokhyar and Bhandari, 2010). Also, the inferential statistics presented lack any confidence interval calculation. This means that despite the presented significant p-values ( $p < 0.001-0.013$ ) there is reduced reliability in the accuracy of the results (Norman and Streiner, 2012). Finally, the participants were unable to see their limbs when wearing the virtual reality headsets. The authors of the paper themselves previously identified visual feedback and sensory processing to be a factor in FOG (Ehgoetz Martens, Pieruccini-Faria and Almeida, 2013). This may have resulted in a misrepresentation of FOG episodes being falsely attributed to anxiety, subsequently reducing the transferability of the results (Rothwell, 2005).

Despite several limitations, all of these studies suggest a negative relationship between anxiety and motor performance of some form. The authors of all of the studies are in agreement that the relationship between anxiety and motor performance requires further research (Pontone *et al.*, 2009; Leentjens *et al.*, 2012; Ehgoetz Martens, Ellard and Almeida, 2014). The implication of this is if PWP's are



more anxious they will likely find mobilising more difficult. Clinicians and researchers should consider this as reduced mobility has a negative correlation with quality of life (Moore, Peretz and Giladi, 2007; Stegemöller *et al.*, 2014).

### *Anxiety and quality of life*

The effect of anxiety on quality of life can be broad for PWPs (Lutz *et al.*, 2016). In a qualitative study Wressle, Engstrand and Granérus (2007) interviewed seven older PWPs (64-77 years) to identify factors affecting their quality of life. It is important to acknowledge that they also interviewed relatives of PWPs, but this information was not relevant for this study. The researchers found consistent reports of increased anxiety and emotional sensitivity to stress. This results in avoiding anxiety-provoking situations whenever possible. They also noted the link to motor performance in that the participants were highly anxious about falling, which has been supported by other studies (Shah and Nolen, 2006; Rahman *et al.*, 2011). An unexpected finding was excessive worry about being unable to care for their partner should they become unwell, which supports themes highlighted in previous studies (Lindesay, Stewart and Bisla, 2012).

This study shows that there are numerous ways that anxiety impacts on the lives of PWPs, yet there are several limitations that have a bearing on its credibility. There is no clear explanation or examination of the researcher and participant relationship; therefore, it is unclear if there was any inherent bias within the results (Patton, 1999; Harvey, 2014). There is only a thin description of thematic analysis that is not placed within any particular qualitative inquiry framework, hence credibility is again diminished (Houghton *et al.*, 2013; Carter *et al.*, 2014). Finally, there is no discussion of credibility or triangulation methods, which further limits the trustworthiness and credibility of this study (Patton, 1999; Shenton, 2004; Carter *et al.*, 2014).

Wressle, Engstrand and Granérus (2007) presented results with reduced credibility and limited transferability, but Sunvisson (2006) supports their findings. In this paper, a single PWP was interviewed using a phenomenological approach at intervals over a five-year period (age 72-77). Themes mirrored in this article are the fear of the future, increased sensitivity to stress and increased anxiety associated with the unexpected. These ideas are expanded to explore anxiety around changes in habitual skilfulness and pressure from striving for involvement. This study provides

high credibility with transparency throughout the methodological process (Stanley and Nayar, 2014). In spite of this, there are questions around how the researcher maintained a bias-free relationship with the participant, as issues of reflexivity are not discussed. This is important to consider ensuring that the assumptions of the researcher are not influencing the participant or the findings (Clancy, 2013). Finally, the single participant design could be argued to limit transferability of these findings. Whether this is the actual purpose of a phenomenological study is a topic for another discussion (Giorgi, 2006).

These papers suggest that anxiety is not experienced as a singular entity but as a set of complex, multi-dimensional interactions with the world (Sunvisson, 2006; Wressle, Engstrand and Granéus, 2007). It is important that these papers identified the relationship between anxiety in Parkinson's and social participation, with particular consideration for motor difficulties. Interestingly, both studies (Sunvisson, 2006; Wressle, Engstrand and Granéus, 2007) established no link with age as previously identified (Walsh and Bennett, 2001; Burn *et al.*, 2012), but it must be noted that these studies focused mainly on older people so are inherently biased. This does not make the experiences reported any less valid. Rather, it demonstrates that anxiety can affect PWP's of all ages. This is an important implication to consider for practice and research design. Early evidence suggests that younger PWP's are the primary population affected by anxiety (Walsh and Bennett, 2001; Barone *et al.*, 2009; Burn *et al.*, 2012), however clinicians and researchers need to be aware that anxiety also affects older PWP's.

This literature search and critique have highlighted that there is no specific evidence looking at the experience of anxiety for PWP's. Research was selected that provided the most transferrable evidence to the original SPIDER question. Each study used considerably different designs and methodologies further highlighting the gap in the research literature. It is concluded that there is currently no qualitative evidence specifically exploring the lived experience of anxiety of PWP's. Further research of high methodological quality is needed in this area to further health-care practice and research.

Anxiety is a research priority for PWP's (Deane *et al.*, 2014; Todorova, Jenner and Chaudhuri, 2014). These studies suggest that if PWP's experience anxiety early in

life, they will likely experience higher levels of chronic anxiety (Walsh and Bennett, 2001; Barone *et al.*, 2009; Burn *et al.*, 2012). Consequently, these people are likely to experience an increase in fluctuations in their motor symptoms (Pontone *et al.*, 2009; Leentjens *et al.*, 2012; Ehgoetz Martens, Ellard and Almeida, 2014). Anxiety in Parkinson's can have an overall negative effect on quality of life in all age groups of PWP's (Sunvisson, 2006; Wressle, Engstrand and Granérus, 2007). There are limitations in all of the above studies that mean that the transferability of their conclusions must be considered.

## **Summary**

This critical analysis of eight relevant studies has found no research exploring the lived experience of anxiety for PWP's. There is reference in the literature to the lack of anxiety-specific research in Parkinson's, particularly of a qualitative nature (Pontone *et al.*, 2009; Breen and Drutyte, 2013; Todorova, Jenner and Chaudhuri, 2014). The research that is available only bears moderate relevance or is marred by methodological problems causing issues of reliability. This study, therefore, aimed to gain an in-depth understanding of the lived experience of anxiety for PWP's.

## **1.4 Research question and objectives**

### *Research question*

What is the lived experience of anxiety for people with Parkinson's (PWP's)?

### *Research objectives*

1. To develop an understanding of the lived experience of anxiety for PWP's.
2. To identify potential issues to consider when developing future anxiety interventions for PWP's.

## **2 Chapter two- Research Methodology**

### **2.1 Research approach**

Qualitative research is an approach that aims to illuminate and interpret how people attach meaning to their experiences. This is achieved by capturing and exploring people's stories to understand their perspectives (Creswell, 2013; Patton, 2015). The qualitative approach was considered most appropriate for this study due to the

nature of the research question and the identified lack of understanding of anxiety from the perspective of PWPs in the research literature. A quantitative research approach was deemed inappropriate for this study. This method implements the systematic investigation of observable phenomena using numerical data. Quantitative research uses statistical, mathematical or computational techniques to analyse the data to test hypotheses and identify relationships (Creswell, 2003; Shields, 2003). Using a quantitative approach could potentially limit the rich interpretation of the meaning of the participants' experiences. Despite the inherent differences in qualitative and quantitative research approaches, Fisher and Stenner (2011) highlight that these approaches could be used to complement each other. This could lead to research frameworks and health practices that are more meaningful and precise overall. As there is pre-existing evidence predominantly supporting the incidence and prevalence of anxiety for PWPs, a qualitative approach was selected for this study to focus on and explore the lived experience of anxiety for PWPs.

## **2.2 Philosophical Worldview**

When using any research approach, it is important to identify the philosophical framework that underpins it. This understanding is required as the underpinning philosophical framework shapes the formulation of the research question and how the researcher goes about seeking information (Creswell, 2013). The methodology of this study is founded upon a constructivist epistemological worldview. This decision was made based on the researcher's academic experience and understanding, the philosophical position of occupational therapy and clinical experience from working with PWPs who experience anxiety. The constructivist worldview is based on the assumption that people seek an understanding of the world in which they live and operate. An individual's reality is viewed as a construct of the human mind formed from interacting with and experiencing the real world (Creswell, 2003; Elkind, 2004). Since the meaning of human experience is complex, that we have evolved the capacity to construct and interpret reality; constructivist researchers rely on social interaction with participants to investigate the perceptions of reality shared by different groups of people (Creswell, 2013; Patton, 2015). The participants' own social, cultural and historical experiences affect their perception and experience of reality. Constructivism recognises that the researchers' own experiences will

influence their data interpretation and the inductive generation of meaning (Creswell, 2013; Patton, 2015). Through discussion with a senior researcher the main researcher was able to reflexively identify that their professional background, values and beliefs as an occupational therapist, along with the experience of working within NHS specialist neurological services, may influence the interpretation of findings.

### **2.3 Patient and public involvement**

Patient and public involvement (PPI) in research comprises the active collaboration between researchers, patients and/ or members of the public (NIHR, 2014). PPI in research has been shown to have positive benefits on overall study feasibility, participant recruitment and dissemination of findings (Whitstock, 2003). Researchers may not have direct experience of the health condition under investigation and PPI participants may have alternate aims or thoughts, which researchers have not considered (NIHR, 2014).

A PPI consultation was completed to verify the need for this research with PWPs and to seek their opinions on how the study should be conducted (Lovegrove *et al.*, 2017). Ethical approval was granted by Plymouth University, ref number (16/17)-244 (appendix 1). Telephone and Skype interviews were completed with participants accessed as a convenience sample through Parkinson's UK 'Research Support Network'. A pragmatic inquiry framework, coupled with an inductive approach, was used to look for actionable findings within a practical timeframe (i.e. to implement within this research study) (Mounce, 2000; Ikiugu and Schultz, 2006). A six-question interview schedule was developed in collaboration with a Parkinson's UK PPI coordinator and was used for all consultation interviews (figure 2). Thematic analysis was used to highlight, assess and report on patterns developing from the data (Braun and Clarke, 2006).

- 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?**

**Figure 2: PPI interview schedule**

All participants stated that they felt anxiety in Parkinson's needed more research, thus strengthening the rationale for this study. Participants also provided practical recommendations for how the study should be conducted. These included performing the proposed research interviews in the participants' own homes to increase comfort and being considerate of on/ off periods related to medication. Additionally, it was suggested that the researcher call the participant on the morning of the interview to check they were having a 'good day'. Of particular importance to the PPI participants were establishing a safe and sensitive research environment that enabled collaboration. These recommendations were used to directly improve the design of the main research study.

## 2.4 Research design

Qualitative research comprises paradigmatic, philosophical and theoretical orientations that Patton (2015) refers to as 'qualitative inquiry frameworks'. Al-Busaidi (2008) states that classifications of qualitative research approaches provide a sense of direction and focus for the researcher, however some authors argue that this overly simplifies the qualitative research process (Atieno, 2009).

Grounded theory (Glaser and Strauss, 1967) was a qualitative inquiry framework considered for this study. Pope, Ziebland and Mays (2011) describe grounded theory as an inductive approach of defining themes for analysis as they emerge from the data, rather than identifying them a priori. Grounded theory was considered for use in this study as it generates data richness and depth, as well as providing a framework to conceptualise this data (Levers, 2013). Conversely, (Hussein *et al.*, 2014) identify grounded theory as having the potential for methodological error, suggesting this may be exacerbated by writing the literature after data collection and analysis. Furthermore, both Misco (2007) and Hussein *et al.* (2014) identify the potential for grounded theory's limited external validity. Due to these factors, it was decided that grounded theory was not an appropriate framework for this study.

Narrative research was also considered a possible qualitative inquiry framework for this study. As an approach, narrative research seeks to not only capture the stories told by people but allow interpretation of the life and culture it is based in (Hendry, 2009). Despite the profound insights offered by this framework, its focus is on the experience of the individual (Clandinin and Connelly, 2000). Therefore, this would not fulfil the research objective for this study.

The qualitative inquiry framework deemed most appropriate for this study was phenomenology. The focus of phenomenology is what people experience regarding a particular phenomenon and how they interpret those experiences (Creswell, 2013; Wagstaff and Williams, 2014). In phenomenological research, the researcher attempts to gain an understanding of people's perspective, perception and understanding of that particular phenomenon (Finlay, 2014). This is referred to within phenomenology as the 'lived experience' (Reid, Flowers and Larkin, 2005).

Phenomenology has strong philosophical foundations and involves collecting the views of several people before culminating in describing the 'essence' of that experience (Moustakas, 1990). In his original work, Husserl (1931) defined 'essence' as the core meaning of the experienced phenomenon. Phenomenology is popular with healthcare researchers, being used to help make sense of service-users experiences and to ascertain the meaning they associate to them (MacKey, 2005; Al-Busaidi, 2008). This resonated with the researcher, mirroring their therapeutic listening style in clinical practice to apprehend and understand meaning in everyday experiences (Finlay, 2000).

Two main approaches exist within phenomenology- descriptive and interpretative. Descriptive phenomenology concentrates on people's experiences and perception of a phenomenon without attempting to construe meaning using preconceived ideas (Balls, 2009). Later, this approach was further developed to enable researchers to use their experience to interpret meaning from the data, giving rise to interpretative phenomenology (Dowling, 2007; Reiners, 2012). Interpretative phenomenological analysis aims to offer deeper insights into how people in a given context make sense of a particular phenomenon (Reiners, 2012). Additionally, it allows the researcher to generate some theory relating to their interpretation of the data (Callary, Rathwell and Young, 2015). Interpretative phenomenology was deemed most suitable for this study as the researcher has relevant clinical experience and knowledge in Parkinson's. Moreover, the interpretative approach will allow the generation of tentative patterns and theory. These will be grounded in PWPs experiences, providing a sound foundation upon which to develop future research (Callary, Rathwell and Young, 2015).

## **2.5 Research methods**

Research methods are a further element that contributes to the qualitative research approach alongside the philosophical worldview and inquiry framework (Creswell, 2003, 2013). This chapter includes discussions of the sampling technique, specific method of data collection and data analysis used for this study.



### 2.5.1 Sampling

There are no published studies recommending sample sizes for this type of qualitative study. Similar studies have used sample sizes ranging 1 to 16 (Sunvisson, 2006; Wressle, Engstrand and Granérus, 2007). Participant numbers required careful consideration as too few may have risked adequate depth and breadth, yet too many participants may have produced superficial or unwieldy volumes of data (Marshall *et al.*, 2013; Cleary, Horsfall and Hayter, 2014). Therefore, six participants were selected for this small exploratory study as it fits within the range used by previous researchers and will allow an adequate depth of data to be gained from the resources of the project (Creswell, 2013). This number and sampling strategy provides a more accurate representation of the lived experience of anxiety in Parkinson's. The end of life stage was excluded due to ethical concern. It was anticipated that these individuals may be more likely to experience anxiety due to being at the end of their life, or experiencing anxiety caused by another life-limiting illness e.g. cancer (Mystakidou *et al.*, 2005; Spencer *et al.*, 2010). Figure 3 details the inclusion and exclusion criteria used to focus the sampling process and help to identify information-rich participants that would meet the aims of the study (Patton, 2015).

*Inclusion criteria:*

- Diagnosis of Parkinson's made by a consultant in movement disorders, healthcare for older people or neurology (on participant information sheet)
- Have had a diagnosis of Parkinson's for a minimum of one year
- Aged 18 years or over
- Experiences anxiety that they feel is caused by their condition

*Exclusion criteria:*

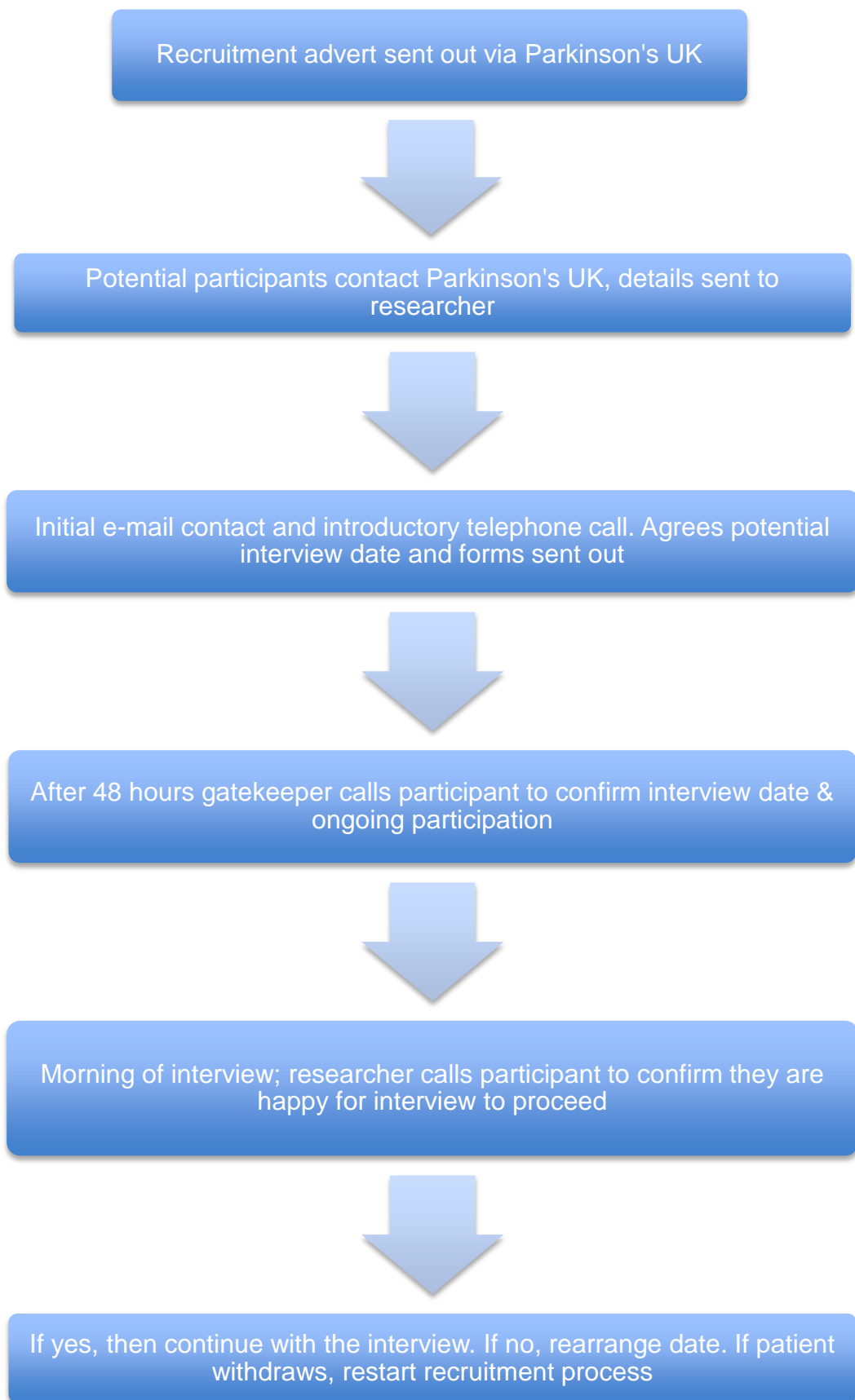
- People who are unable to give informed consent- i.e. who have a pre-existing significant cognitive deficit, or are unable to understand the purpose of the study, retain this information, and consider this information as part of a decision making process when in discussion with the researcher
- Diagnosis of 'Parkinsonism'-type disorder (these are atypical variants, such as Multiple Systems Atrophy, that may not have all the features of Parkinson's, have different underlying aetiology, or may even be reversible in the case of some drug-induced types)
- 'End of life stage' of Parkinson's or other potentially life limiting condition- for example cancer, which is likely to be a main source for anxiety

**Figure 3: Inclusion and exclusion criteria used to support sampling**

Once ethical approval was received (reference number (16/17)-244, appendix 2) PWP's in the South West of England were recruited through Parkinson's UK's 'Research Support Network' (Parkinson's UK, 2016). This network was used as the sampling frame. The researcher e-mailed Parkinson's UK and completed the required form to access the 'Research Support Network'. The Parkinson's UK Research Involvement Officer advertised the study via their network using e-mail, social media and newsletters between November 2016 and January 2017. Interested participants responded to the Research Involvement Officer, and their contact details were sent on to the researcher. Email contact was initiated with the participants to arrange an introductory telephone call where the researcher ensured they met the inclusion criteria. If the participant met the inclusion criteria the research process was started. Over-recruitment was not implemented. The aim of this sampling strategy was to provide a more accurate representation of the lived experience of anxiety in

Parkinson's. Recruiting through specialist NHS services may have been more likely to present a bias in the study findings. Participants recruited through clinics are more likely to be experiencing a health issue that may provoke its own anxiety (Tyrer *et al.*, 2011).

A potential interview date and time were mutually agreed between the participant and researcher during the introductory telephone contact. Once verbal consent was gained, participants were sent a participant information sheet (PIS) and consent form (appendix 3). An independent gatekeeper (BE) contacted participants after a 48-hour cooling off period to confirm consent and the proposed interview arrangements. At this stage, all six participants consented to continue with the study. On the morning of the interview, the main researcher contacted the participant by telephone to check they were happy to continue with the interview. As PWP's can experience daily variability in their condition, this was employed as a direct recommendation from the PPI consultation as a support mechanism for participants (Lovegrove *et al.*, 2017). If participants did not feel well enough, the interview would be rearranged for a later date. All six participants proceeded with their original interviews. Figure 4 shows a visual representation of the sampling process.



**Figure 4: Flow chart to illustrate sampling process**

## 2.5.2 Data collection

This research was conducted in accordance with the 'consolidated criteria for reporting qualitative studies' (COREQ) guidelines (Tong, Sainsbury and Craig, 2007). Interviews were held in the participants' homes in an area where they felt comfortable. The aim of this was to increase convenience and privacy, as it is suggested that if participants are comfortable, they are more likely to reveal the nature of their lived experience (DiCicco-Bloom and Crabtree, 2006; Elmir *et al.*, 2011). Furthermore, PPI participants suggested that this would enable participants to manage their conditions more efficiently and possibly experience less anxiety as a result of the interview itself (Lovegrove *et al.*, 2017). Participants were greeted warmly and the study aims explained in plain English. Each participant was asked to read the PIS again before two consent forms (for researcher and participant) were signed and witnessed. The participants were given the opportunity to ask any questions before the interview started and the encrypted Dictaphone was switched on.

During the interviews, the researcher referenced an interviewing schedule (figure 5) based on the proposed phenomenological interviewing framework of Bevan (2014). This had been adapted based on the findings of the PPI consultation. A semi-structured approach was utilised to allow participants to elucidate and explore matters considered important to them (DiCicco-Bloom and Crabtree, 2006). Using an interview schedule allowed the researcher to investigate the research question in each interview while giving participants the opportunity to illustrate their own 'lifeworld' (Easton, McCormish and Greenberg, 2000; Englander, 2012; Bevan, 2014). A digital Dictaphone with encryption capability was used for all audio recording and field notes were taken during and immediately after each interview. The purpose of this was to aid in developing understanding and meaning of the studied phenomenon by documenting observed behaviours, thoughts and feelings (Patton, 2015).

### **Opening**

My name is Chris Lovegrove and I'm doing this research with Plymouth University. I would like to ask you some questions about your background, your condition, some experiences you have had, and about you. You do not have to take part if you do not want to.

I hope to use this information to help develop more anxiety interventions specific to people with Parkinson's. The interview should take about one hour, but may be a little shorter or longer. Please feel free to ask for any breaks that you might need during the interview. Are you happy to continue?

Transition: Let me begin by asking you some questions about where you live and your family. Are you still happy to proceed?

### **Contextualisation**

- Can you tell me about yourself?
- Please can you tell me about your diagnosis with Parkinson's.

*Prompts as needed*

### **Apprehending the phenomenon**

- Please can you tell me about your typical day?
- What is your experience of anxiety?
- How does anxiety affect you?

*Prompts as needed*

### **Clarifying the phenomenon**

- Can you describe how anxiety makes you feel?
- How do you react to anxiety?

*Prompts as needed*

### **Closing**

I really appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know? *(Time for answers)*

Do you have any other questions for me? *(Time for answers)*

Would you like a summary of the findings? *(Time for answers)*

Thank you, I have all the information I need. I will now stop the recording. Thank you again.  
*(Recording stops, start debrief)*

**Figure 5: The interview schedule**

### 2.5.3 Data analysis

Before data collection, the researcher went through a 'bracketing' process. The aim of this process was to set aside the researcher's preconceived notions and previous experiences about anxiety in Parkinson's to avoid influencing the research findings (Tufford and Newman, 2012). To achieve this, the researcher used the strategies outlined by Chan, Fung and Chien (2013) to prepare mentally, decide the literature review scope and plan data collection & analysis.

The heuristic inquiry approach (Moustakas, 1990) was used to support the data analysis process by providing a systematic method to focus on the idea of the experience under investigation (Gerhard Kleining and Harald Witt, 2000). Heuristic inquiry has been identified as providing a structure that deepens reflection and understanding (Kenny, 2012). Conversely, it has been argued that heuristic inquiry shifts the research emphasis from the explication of a phenomenon to researcher self-development (Giorgi, 2006). Heuristic inquiry was selected for this study as it offered the potential for deep insight through systematic reflection that could help the emergence of meaningful order from the complex, rich data collected (Finlay, 2009, 2014). Table 2 outlines the phases of heuristic inquiry.

Thematic analysis was chosen as the main data analysis method for this research study. This method provides a flexible but robust process of analysis using coding to identify ideas from raw data and then using these codes to identify patterns across a dataset (Braun and Clarke, 2014). Thematic analysis was identified as appropriate for this study as it identifies, analyses and reports patterns (known as themes) within a dataset. This helps to develop a deeper understanding of the participant's comments, which can be lost with other analysis methods (Braun and Clarke, 2006; Vaismoradi *et al.*, 2016). Thematic analysis is considered an accessible, flexible data analysis method for novice researchers that produce findings that can be applied to health settings (Braun and Clarke, 2014; Chapman, Hadfield and Chapman, 2015). Despite these strengths, some have stated that thematic analysis lacks substance compared to other data analysis methods and is only descriptive in nature (Alhojailan, 2012).

**Table 2: Phases of heuristic inquiry** (Moustakas, 1990; Kenny, 2012)

<b>Phase</b>	<b>Description</b>
<b>Initial engagement</b>	Researchers contact with the subject and question
<b>Immersion</b>	Researcher fully involves themselves in the phenomena experience in the form it takes (e.g. interview recording and transcripts)
<b>Incubation</b>	Retreating from focused attention on the research question in unrelated activity
<b>Illumination</b>	Expanded awareness and deepened meaning allow themes and patterns to emerge
<b>Explication</b>	Examining what has arisen and coming to understanding the meaning it may hold
<b>Creative Synthesis</b>	The threads of meaning and experience that have emerged through the research are brought together to form a coherent whole

Following each interview, the researcher prepared the data for analysis. This involved verbatim transcription of the encrypted audio recordings into a word-processing document, formatted to support the coding process. Each transcript was completed within 24 hours. Braun and Clarke (2006, 2014) emphasise the importance of transcription as the beginning of the data analysis process. The researcher reread the transcripts and listened to the audio recordings, on several occasions simultaneously. This was part of the immersion phase to involve the researcher in the participant's experiences and increase their familiarity with the data (Moustakas, 1990). Following this, the researcher entered the incubation phase where they purposely stepped away from the research for one month with the aim of allowing the expansion of tacit knowledge (Moustakas, 1990; Kleining and Witt, 2000).

The researcher next entered a phase of illumination, approaching the coding process with expanded awareness and meaning of the phenomenon (Moustakas, 1990;



Kleining and Witt, 2000). At this stage, the qualitative data analysis software Nvivo v10 (QSR International, 2012) was used to support data analysis and project management. Woods *et al.* (2015) states that using computer software for this purpose distances the researcher from the data analysis. Yet, Pope, Ziebland and Mays (2000) affirm that a thorough immersion phase minimises this risk. Nvivo v10 (QSR International, 2012) was selected for its user-friendly qualities and features that facilitated the coding and management of the data. The codes chosen used the participant's own words as closely as possible with the aim of supporting participant's voices to come through in the analysis (Braun and Clarke, 2006; Reilly, 2013). Following this, the codes were grouped into sub-categories and then themes.

During the explication stage (Moustakas, 1990), the researcher underwent a peer review process with a senior researcher (KB) to assure the rigour and credibility of the data analysis (Patton, 1999, 2015; Houghton *et al.*, 2013). During this stage, constructive feedback and interrogation resulted in several themes being collapsed further or renamed. Next, all six participants were given an opportunity to view a summary of the findings to check for accuracy in a member checking process (Creswell, 2003). The purpose of this is to avoid misrepresentation of the participant's views and ensure a balance between researcher interpretation and participant experience (Birt *et al.*, 2016). Four of the six participants responded, agreeing with the overarching themes and offering additional insights into each theme for the researcher to consider. Morse (2015) questions the usefulness of member checking; in particular, its practicality and benefit to the interpretation process. Nevertheless, it is seen as a useful method for establishing credibility and as a triangulation method for reducing error in findings (Harvey, 2014; Birt *et al.*, 2016).

The final data analysis phase was creative synthesis, where themes were illustrated with vivid quotations from the interview transcripts to explore the phenomenon of anxiety in Parkinson's (Moustakas, 1990; Patton, 2015). The quotes are presented with the participant pseudonym and line numbers for transparency, explored in chapter three.

## 2.6 Ethical considerations

The Medical Research Council (2012) recommends that research be conducted with integrity, honesty, transparency, and respect for ethical and professional standards and principles. The Declaration of Helsinki (World Health Association, 2013) outlines a core set of ethical principles that include respect for autonomy, protection from harm, justice, and the promotion of benefit. This study was designed following the above principles. Ethical approval was granted through Plymouth University's Faculty of Health and Human Sciences (reference number (16/17)-244) before any participants were recruited.

### **Informed consent**

Participants recruited into the study were required to sign a consent form before inclusion (appendix 3). A written PIS was sent to potential participants at least two days before consent was obtained in line with good practice, to allow for sufficient time to process the information (Johnson *et al.*, 2015). This allowed participants to consider the personal implications of participating, such as being asked potentially distressing questions. After participants had agreed to their inclusion, consent forms were completed with the assistance of the researcher and a family member if requested.

### **Openness and honesty**

Deception was not used at any point during this study. This means transparency was delivered in the PIS and consent form. Participants were also provided with the contact e-mail of the researcher, as well as those of the supervisor and School research lead should they have required any further information or if they wanted to make a complaint. A telephone number was included for participants who felt more comfortable with this method of communication. The researcher arranged a time with the participant for an introductory telephone call, which allowed another opportunity for further questions to be asked. Finally, the researcher called each participant on the morning of the interview as previously identified, providing another opportunity to ask questions.

### **Right to withdraw**

Interviews were not formally organised for 48 hours to allow for a cooling off period after initial contact. This allowed participants to consider the personal implications of participating and being asked potentially distressing questions. Participants could

withdraw during this period and at any time during the study. Their data would be destroyed (i.e. transcriptions and recordings electronically shredded) if the data analysis had not started. If analysis had started the researcher would have been unable to remove participant-specific data, as it would have been anonymised at this point and interview recordings electronically shredded. This was explained on the PIS (appendix 3) and was also clarified at the start of the interview.

### **Protection from harm**

PWPs can experience cognitive deficits (Cosgrove, Alty and Jamieson, 2015), which can hinder their ability to give informed consent regarding individual decisions as defined by the Mental Capacity Act (2005). During the introductory phone call, the researcher was able to assess whether the participant had the capacity to make a decision to participate in the study. Namely whether they were able to retain and understand information relevant to the study, use this as part of a decision-making process and communicate this decision (Mental Capacity Act, 2005). The main researcher was an occupational therapist by background with experience and training in completing capacity assessments.

Cognitive deficits most often affect people in the later stages of the condition (Aarsland and Kurz, 2010), so this was less likely to be an issue during this study. As participants were volunteering for this research, thus self-selecting, this further diminished this risk, as participants with an advanced cognitive deficit were less likely to volunteer (McKeown *et al.*, 2010; Taylor *et al.*, 2012). Participant's GPs were informed of their involvement in the study. This provided an additional layer of protection should participants experience heightened anxiety after the study finished (appendix 4).

### **Debriefing**

Participants were offered an immediate debrief at the end the interview, as well as an additional telephone debrief 24 hours later. Once the analysis was completed, participants were provided a summary sheet of the findings if they indicated that they would like one. This was asked as part of the interview schedule.

### **Confidentiality**

Participant information was managed according to the Data Protection Act (1998). Confidentiality was guaranteed through the allocation of anonymised pseudonyms. Interview recordings were made with a digital Dictaphone with 256-bit encryption capabilities. Interview recordings were electronically shredded with the app 'FileShredder' once all verbatim transcriptions were made and were no longer required for analysis. All electronic research materials will be stored on a password-protected computer with an encrypted hard drive for 10 years. All physical research data and materials (e.g. paper transcriptions, field notes, journals, consent forms) will be kept in a separate physical location in a locked cabinet and accessible only to the researcher and supervisor. All research material will be held for 10 years in line with Plymouth University's "Research Ethics Policy" (Plymouth University, 2013). After this time, all research data will be physically shredded and any necessary files deleted from computer systems.

### **Professional bodies whose ethics policies apply to this research**

This research was performed in accordance with the College of Occupational Therapists 'Code of Ethics and Professional Conduct' (2015) and the Health & Care Professions Council 'Standards of conduct, performance and ethics' (2014). The PIS (appendix 3) explains that any sensitive or risk issues disclosed by the participant would have to be acted on by the researcher, as this is a legal and professional obligation. If any issues were to arise, they would be discussed with the supervisor to make a plan of action in accordance with local policy and practice.

The researcher was lone working in participants' own homes. A procedure, developed based on the outline provided in the Plymouth University "Research Ethics Policy" (2013), was put in place. When the main researcher was collecting data away from their place of work, the participant contact details and the mobile phone number of the researcher were emailed as a password protected document to the supervisor. The password was emailed separately. The interviewer contacted the supervisor on completion of each interview. If there was no contact from the researcher within three hours, the supervisor would open the document and seek to locate them. If the researcher was not located the supervisor would then try to locate them by calling through a list of three contacts. If this remained unsuccessful the police would have then been contacted.

## 2.7 Rigor

Lincoln and Guba (1985) proposed an evaluative criterion to establish the trustworthiness and credibility of a research study. The 'Criteria of Trustworthiness' (Lincoln and Guba, 1985) was used to determine credibility, transferability, dependability and confirmability within this study.

### **Credibility**

Member checking was used to check the accuracy of the data analysis and findings (Pope, Ziebland, and Mays, 2000). Member checking is a form of data triangulation that allows for interpretations and conclusions to be tested against the group that it was initially obtained from (Birt *et al.*, 2016). Findings have also been triangulated back to sources identified in the literature review to increase their credibility (Patton, 1999; Carter *et al.*, 2014).

### **Transferability**

Transferability was maximised through thick description to support external validity of the study findings (Shenton, 2004). For example, biographical sketches are used to illustrate the sample as opposed to presenting quantitative demographic data. This allows the reader to appraise the extent to which the study conclusions are transferable to other times, settings, situations, and people.

### **Dependability**

Shenton (2004) explains that if a study were repeated using the same methods and produced similar findings, this would be an example of dependability. This can be difficult to establish in qualitative research due to the changing nature of the explored phenomenon (Houghton *et al.*, 2013; Morse, 2015). Lincoln and Guba (1985) emphasise that if steps are taken to improve credibility, this also increases dependability.

### **Confirmability**

Confirmability refers to the extent to which the findings are shaped by the participants and not the assumptions and biases of the researcher (Houghton *et al.*, 2013; Patton, 2015). In this study, the researcher underwent a process of peer review with a senior researcher (KB) to check the findings and reflect on any biases that may have influenced the data analysis. The researcher's field notes and

reflective journal reinforced this process. Both Creswell (2013) and Patton (2015) state that using a variety of sources when establishing themes enhances confirmability.

The potential limitations of this study are discussed in Chapter 3.2.

### **3 Chapter three- Findings and Discussion**

Following the email advertisement, six participants expressed interest (three male, three female). All participants met the study inclusion criteria on initial screening and gave consent at each stage of the research process with no adjustments required. The shortest interview was 26 minutes, and the longest interview was 56 minutes. The participants (names are pseudonyms) are illustrated below in the form of short biographical sketches.

#### **Alan**

Alan is a 60-year-old man in the maintenance stage of Parkinson's. He is currently awaiting an appointment to see if deep brain stimulation may be suitable for him. Alan described his initial diagnosis experience as traumatic. Alan previously worked in a senior position in construction when he first started to notice his symptoms, which he initially attributed to a pulled muscle. He no longer works in this job but maintains self-employment as a handyman to contribute towards the household finances. Alan did not highlight finances as a concern at the moment. Alan's wife is younger than him and works as a dentist. They enjoy active holidays together. He is worried about the effect his condition may have for his wife in the future.

#### **Beth**

Beth is an 86-year-old woman in the complex stage of Parkinson's. She takes multiple doses of various Parkinson's medication each day, and experiences postural instability, which has resulted in falls. Beth described her diagnosis experience as "expected", but eventually sought a second opinion. Beth is a retired teacher; a career she enjoyed but found stressful at times. She lives with her husband who is registered blind and has dementia. Beth enjoys a good relationship with her daughter but does not get on with her son-in-law. Beth is supported at home by a care package but strives to be as independent as possible. Beth is computer

literate and enjoys shopping online. While Beth reports she spends a little too much money shopping, she says that finances are not a worry.

### **Clare**

Clare is a 63-year-old woman in the maintenance stage of Parkinson's. She takes one Parkinson's medication a few times a day. Clare described her diagnosis experience as very prompt and "good". She is a retired teacher. Clare explained that she took great pride in being a teacher but found the final six to twelve months very difficult following her Parkinson's diagnosis. She eventually took ill-health retirement. Clare is a widow of 18 years. She has two daughters that live close by and another a short distance away. Clare enjoys playing tennis, something Clare admits is a little harder to get motivated for recently, and going out for lunch with her girlfriends. Clare explained that she is financially more comfortable than she was while working, describing "financial security".

### **Daniel**

Daniel is a 59-year-old man in the diagnosis stage of Parkinson's, having received a diagnosis in the previous 24 months. Daniel described his diagnosis experience as efficient. He recently retired from running an established family business, a decision that he took to help manage his condition, though he still manages a property portfolio. Daniel lives with his partner who has experience with a family member with Parkinson's. He reports that she is a great support to him. Daniel is very active within his local Parkinson's community, being the treasurer for a local exercise class. Daniel described himself as being in a financially fortunate position to be able to take early retirement.

### **Edward**

Edward is a 68-year-old man in the complex stage of Parkinson's. He takes several medications multiple times a day. Edward described his diagnosis experience as going reasonably well. He is retired from the IT industry and has two adult children living some distance away. Edward states he has previously had a "bad hip revision" and this, coupled with his previous career, steers him towards sedentary occupations. Edward lives with his wife and does not receive a care package. He attends several Parkinson's groups with his wife where they have made friends. He has recently started to learn to play the snare drum to help keep his hands and mind

active. Edward did not explicitly state his financial situation but alluded that this was not a concern.

### Gillian

Gillian is a 73-year-old woman in the diagnosis stage of Parkinson's, having received her diagnosis a little over 24 months ago. She is currently distressed at her diagnosis and the way it is affecting her and feels there must be something else going on. She described her diagnosis experience as long and a struggle. Gillian lives at home with her partner and currently does not receive a care package. Previously, Gillian used to work as a receptionist in a doctor's surgery and described herself as full of confidence; she now feels she is a "totally different person" and a "mess". Gillian suggested that things had become more financially difficult for her and her partner since she had to give up work.

### 3.1 Themes

Thematic analysis identified 1,776 codes. The researcher extracted 16 sub-categories from the codes from which three overarching themes were identified (Braun and Clarke, 2006). Table 3 illustrates these groupings.

**Table 3: Grouping of sub-categories into three overarching themes**

Theme 1	Theme 2	Theme 3
<b>COPING</b>	<b>AMPLIFICATION</b>	<b>PERCEPTIONS</b>
Being committed	Social and public life	Anticipatory
Importance of achievement	Cognitive impact	Negative perceptions
Losing ability to cope	Emotions	Positive perceptions
Ways of coping	Physical effects	Causes of anxiety
The shared experience	Changing self-identity	Depression experience
		Presence of anxiety

During data analysis, a sub-category of finances was identified and is discussed here as part of the research study audit trail (Lincoln and Guba, 1985; Carcary, 2009). While participants did not directly attribute financial status in the context of their anxiety experience, it is included in the individual biographical sketches to provide additional detail. Furthermore, during the data analysis, a variety of sub-



categories were identified that were discarded as they did not pertain to the lived experience of anxiety. This is part of the thematic analysis process (Braun and Clarke, 2006). These sub-categories included "medication" and "miscellaneous". "Medication" was excluded as this sub-category related to participants superficial comments regarding their historical or current drug regimes. It was not related to the anxiety experience. The "miscellaneous" sub-category consisted of unique codes that did not fit under any other sub-category. They included participant's opinions of research funding in Parkinson's and superficial descriptions of leisure occupations. Participants did not relate these to their experience of anxiety in Parkinson's; thus they were deemed redundant. Despite being discarded these sub-categories could be worth investigating in the future (Tuckett, 2005; Vaismoradi *et al.*, 2016).

### 3.1.1 “Try not to let it rule your life” - Coping

Throughout the interviews, it became apparent that all of the participants valued coping and coping strategies as important parts of managing anxiety in Parkinson's. The participants all expressed different views regarding this. 'Coping' is a complex concept. It can be defined as habitual and enduring patterns of behaviours displayed by a person when confronted by a situation needing a response (Beutler, Moos and Lane, 2003). This research study used this definition. The differences in perspectives to coping offered by the participants have been identified across cultures by people living with a multitude of health conditions including anxiety (Beutler, Moos and Lane, 2003; Gárriz *et al.*, 2015). Coping strategies for anxiety in PWP's are not directly addressed in these works. It could be seen that the development of alternative coping strategies is not unique to the Parkinson's anxiety experience and more an expression of human response to confrontation (Barnes *et al.*, 2013; Bain, McGroarty and Runcie, 2015; Drummond and Brough, 2016).

All participants discussed the importance of developing alternative coping strategies to manage their anxiety, with five participants highlighting the importance of self-reliance and self-confidence:

*“In the end I’ve got to be answerable for myself. Other people cannot be responsible for me. And I think you’ve got to have trust in yourself. Faith in yourself. In the long run it comes to you.” Beth, lines 576-581*

*“Then I came home and told the girls, and they, unbeknown to me they had a secret meeting about it hahaha because they’re good at that hahaha! They had an emergency family meeting on my behalf, but I just thought you’ve got to get on with it as much as you can, as well as you can. And try not to let it rule your life.” Clare, lines 201- 210*

Self-reliance and self-confidence have been identified as essential components in managing anxiety, empowering people to seek out advice and implement strategies (Gino, Brooks and Schweitzer, 2012). However, it has similarly been noted that people experiencing anxiety demonstrate impaired cognitive information processing (Krohne and Hock, 2011) which is a known non-motor symptom of Parkinson’s (Hurt *et al.*, 2012). This can result in eroded self-confidence leading to people trying to reduce uncertainty in their lives and becoming more reliant on others (Murphy and Leighton, 2009).

In contrast, some participants emphasised how they felt that the support of other people was important in their anxiety experience:

*“I’m very lucky with my partner <name>. Whose granddad died, or had Parkinson’s when he died. Erm so she’s experienced it and will jokingly tell me don’t be so stupid and buck up you know. She kicks me up the bum now and then if I’m feeling anxious or worried about something I shouldn’t be worried about.” Daniel, lines 257-267*

Participants reported that the support of other people was a necessary driver for overcoming anxiety. Triangulating with the literature; the work of Sunvisson (2006) also acknowledged the prominence of the support of others when encountering increasingly stressful situations (see section 1.3.2). Rapee *et al.* (2015) recognised that family support or significant others is not only a protective factor in anxiety but also a positive influence in reducing distress and accessing support. Conversely, this may have potentially adverse consequences for PWP’s managing anxiety, such as increased social avoidance due to reliance on others (Kinderman *et al.*, 2015; Rapee *et al.*, 2015). The focus of current anxiety-related research on resilience (Ozbay *et al.*, 2007) could explain the importance of social support. The variety of experiences voiced by participants’ means that further studies in this area could be beneficial.

The participants saw shared experiences with other PWP's in both positive and negative lights. On the one hand, participants described the benefits of sharing their experiences with other PWP's as positively influencing their wellbeing:

*"Which is very beneficial, a because it's six guys we started out with and we are close knit family if you want to call it that and that's good camaraderie and that's good for your own wellbeing and physical exercise has been proven in Parkinson's to to, to help and suppress the anxiety things" Alan, lines 168-174*

*"Parkinson's is a big neurological disease. No one knows how it's going to pan out and there's a certain amount of nervousness about it. But if you're with other people who are similarly affected you can discuss, talk to themselves, their carers, their wives, their husbands. There's a few people younger than me not many. And we share experience. To be fair you become very friendly with them. " Daniel, lines 282-290*

On the contrary, other participants shared negative feelings towards shared experiences of anxiety with other PWP's; some participants even valuing experiencing their anxiety alone:

*"Um, I'm not very happy within the group, I mean it's not a huge group there's usually only five or six of us but it does get a bit monotonous. And that they are all older than me and it's a bit like being at a pensioners lunch haha! Which sounds very negative and horrible, but there's a lot of repetition and people are very forgetful which is again then something else that is probably typical." Clare, lines 558-568*

*"Soothing words, pfft, its that's not gonna help. So it doesn't help the person in front of me if there's someone there, and it doesn't really help me. Some say it clears out the stables it releases feelings, well for me something like that doesn't. It just makes it worse." Edward, lines 501-507*

Peer support is seen as a beneficial complement to other management strategies in mental health conditions including anxiety (Chinman *et al.*, 2014; Gidugu *et al.*, 2015). The notion of sharing experiences between peers going through a common phenomenon is established as a support mechanism and could be linked to the psychology of upwards and downwards social comparison (Legg *et al.*, 2011; Reynolds, Griffiths and Christensen, 2011). Wills (1981) explains downwards social comparison as a typically defensive propensity where the person looks at another individual they consider worse-off to feel better about their situation. Conversely, Collins (1996) describes upwards social comparison as a person consciously or

subconsciously comparing themselves to those they perceive as better off or coping better, to create a more positive perception of their reality. It may be that participants employ a combination of social comparison to manage their anxiety. As social comparison has been linked to positive and negative outcomes, including those related to anxiety, this may be an area of future research interest when developing a targeted Parkinson's anxiety intervention (Legg *et al.*, 2011; Yip and Kelly, 2013).

While the elements discussed so far pertain to more active ways of coping with anxiety in Parkinson's, participants identified that losing the ability to cope with anxiety was an important component of their lived experience of anxiety:

*"I feel a little bit like I have lost that capacity. And maybe perhaps, thinking about it, perhaps I am getting cross with myself that I can't deal with it as well as I used to." Clare, lines 625-629*

Losing the ability to cope, and reduced locus of control, is associated with anxiety (Frazier and Waid, 1999; Skidmore *et al.*, 2014), and the participants reflected this. These issues have also previously been identified in PWP's by Sunvisson (2006) and Wressle, Engstrand and Granérus (2007). It could be argued that the younger participants were more likely to experience this feeling as younger PWP's are more liable to experience severe anxiety (Burn *et al.*, 2012). However, this viewpoint is countered by Gillian's story:

*"And I know all the answers and I know that I should do more. Because the less you do the less you want to do. I've lost confidence to do things you know. I hate it, I hate the way I am. I absolutely hate it." Gillian, lines 38-43*

Despite being an older person who feels she knows what she should be doing to feel better, Gillian explains she is unable to cope with her anxiety. Her experience echoes those of other older adults (McInnis, 1999; Wolitzky-Taylor *et al.*, 2010). While a younger age of Parkinson's onset is likely related to an early commencement of anxiety symptoms (Burn *et al.*, 2012; Lutz *et al.*, 2016), PWP's of all ages experience a loss of coping and control. This is a consideration for the development of future interventions.

To summarise, participants identified coping as an important part of their anxiety experience. Being self-reliant but also receiving the support of others was valued, while sharing the experience of anxiety with PWP's was viewed both positively and

negatively. All participants reported losing the ability to cope and losing control. These are important concerns when developing a future Parkinson's-specific anxiety intervention.

### 3.1.2 “...are these things going to be haunting you forever more?” - Amplification

The second theme identified from the data was how anxiety affected the participants' Parkinson's symptoms. In all descriptions, anxiety exacerbated or amplified pre-existing symptoms, had an impact on daily occupations, and participation:

*“And-and you're trying inadvertently not to be conspicuous because it's not normal is it. It's not normal to be different at the meal table we'll say. Or it's not normal to be when you go to pick up a glass of orange squash or so or beer and you and, yeah.” Alan, lines 673-679*

*“So I now make sure, the way the way I engage with the outside world is predominantly in social context now. If I give a talk to my Probus group or my PD group, it's low profile it's not a big issue. It's something I've done before, it's something I can rehearse.” Edward, lines 288-297*

These quotes suggest that anxiety affected participants' engagement in public and social life. The findings align with other studies exploring the experience of Parkinson's. For example, Sunvisson (2006) highlights how increased situational anxiety can result in a “closing down” experience, possibly leading to reduced drive to socialise by PWPs (Karlsen *et al.*, 2000). However, Wressle, Engstrand and Granérus (2007) acknowledge that it is perhaps not viable to conclude that the effects on social and public life are solely because of anxiety in Parkinson's. Adverse effects on social and public life may occur irrespective of anxiety in Parkinson's, but may not have had such a high impact as described by participants (Cornwell and Waite, 2009). It could also be that the participants are experiencing slowed cognitive processing that is impacting on social interactions. Mild cognitive deficits can be detected in PWPs before motor symptoms even appear (Biundo, Weis and Antonini, 2016) so this may be a contributing factor in this experience.

Participants openly expressed the experience of anxiety on cognition, and this was experienced in different ways in a variety of circumstances:

*“Yes I have always thought I was quite a clear thinker but if I’m pushed, or if I’m stressed now, I just, I just forget basic ordinary things. And I just can’t, I just can’t think logically I need to wait until I settle. And go back to a problem.”  
Clare, lines 402- 407*

Similarly, Edward shared his experience of how anxiety affects his cognition and mimicked the physical symptom of freezing of gait (FOG):

*“And the thought process then gets, in the same way as you physically stuck I can get mentally stuck. I can only like it it’s not a vicious circle because that indicates motion. The brain stops!” Edward, lines 420-425*

*“Um you have to let it pass. I mean it passes, it’s not it’s not five minutes it can be 15 seconds. It’s almost as if the brain has to stop in order to reboot. I don’t mean mentally reboot or physically reboot it stops and then it starts again.”  
Edward, lines 440-445*

Research has described the cognitive consequences of anxiety, particularly in spatial and working memory (Maloney, Sattizahn and Beilock, 2014). In Parkinson’s, the relationship between anxiety and working memory has been noted particularly in PWP’s with left hemibody onset (Foster *et al.*, 2010). It might be that participants are experiencing an overload of their working memory contributing to their manifest experience (Vytal *et al.*, 2013). It is interesting that Edward described an experience that mirrored FOG. It has been recognised that PWP’s who experience FOG episodes have dysfunction in brain areas that interact with mobility (Peterson *et al.*, 2016). Edward describes the reverse of this experience i.e. his brain freezes not his mobility, possibly identifying a novel avenue for future research.

Participants described anxiety as having a negative effect on their emotions. The anxiety experience was never described as positive but as amplifying feelings of fear, nervousness and derealisation:

*“My experience of it is, it can leave you nervous, it can make you nervous. It can make you very concerned about issues that might not be so difficult to deal with but they become a problem more than they really are.” Alan, lines 526-530*

*“Well I sort of, sweaty. And I feel, I feel I go starey. A bit like a rabbit in the headlights. Sometimes. And I just feel that I’m there but I’m not part of what’s going on. I feel like I’m an outsider looking in, an observer of a situation rather than being part of it...” Clare, lines 459-465*

Issues with emotional regulation involving dopaminergic pathways have been identified in PWP (Blonder and Slevin, 2011), so this may be a contributing factor to participants' experiences. The effect of anxiety on emotions and emotional regulation is well recognised, particularly those of nervousness, fear and even anger, in individuals without the condition (Cisler, Olatunji and Lohr, 2009; Cisler and Olatunji, 2012). This suggests these occurrences are not isolated to PWPs. It may be argued that the underlying pathology of Parkinson's, coupled with the experience of living with an incurable neurodegenerative condition that affects participation in daily occupation, could amplify this experience (Wressle, Engstrand and Granérus, 2007; Pachana *et al.*, 2013; Wen *et al.*, 2016).

Clare's experience has been described in other studies exploring anxiety and derealisation in other populations (Kolev, Georgieva-Zhostova and Berthoz, 2014; Michal *et al.*, 2016). Derealisation is an altered perception or experience of oneself and their surroundings, resulting in the person feeling detached from the world they participate in (Hunter, Sierra and David, 2004). This could be interpreted as a protective experience; a disconnect from the anxiety stimulating constant worry (Michal *et al.*, 2016). While the findings of Sunvisson (2006) touch upon some themes linked to Clare's experience of derealisation, this is not explicitly investigated in the wider Parkinson's literature. This is relevant as it identifies another area of potential future research.

According to participants, anxiety amplified their physical symptoms:

*"It manifested itself as these pains in my legs and they're not shaking so much I don't shake a lot I am at the moment this is because I'm talking to you. But that's not, it's stiffness really. And my foot is turned out completely." Beth, lines 144-149*

*"I think it makes me slower, speech wise it-it appears to change my gait when I get tired and anxious. My gait changes, my walking pattern changes. To small steps. That's probably it if I get anxious, if I get tired that happens as well. So, so they seem to be linked somehow..." Daniel, lines 241-247*

Previously, it has been suggested that anxiety primarily affects motor performance as a result of the 'wearing-off' of medications (Siemers *et al.*, 1993). The stories

shared by participants suggest a more complex relationship between anxiety and motor symptomology that cannot be explained by 'wearing-off' phenomenon alone (Leentjens *et al.*, 2012). The link between anxiety and physical symptoms in Parkinson's has previously been explored in the context of FOG (Ehgoetz Martens, Pieruccini-Faria and Almeida, 2013; Ehgoetz Martens, Ellard and Almeida, 2014). There is less evidence regarding how anxiety affects other physical symptoms, such as pain and tremor in Parkinson's (Leentjens *et al.*, 2012; Lutz *et al.*, 2016) yet these are a vivid component of the participant's experiences. FOG (and the falls related with it) are a primary concern of healthcare professionals and researchers (Deane *et al.*, 2014). PWP's highlight their other symptoms as often being equal if not more important to them (Todorova, Jenner and Chaudhuri, 2014). Therefore, perhaps a shift in perspective is required so that healthcare professionals and researchers are more aware of the priorities of PWP's.

During the interviews, the idea that anxiety in Parkinson's changes one's self-identity and relationship with other people was a core component of the lived experience. Often this experience was negative:

*"I was surprised when I had stopped working, that I missed the sense of purpose. I still do miss having something to get up for. Although I've got bits and pieces that I do, plenty to keep me busy but I still miss having that, goal because I worked while 25 years. I was never previously off sick I was the sort of person who was never ill and worked most of the year without any days off sick. So it was a bit of a shock."* Clare, lines 302-311

*"And lately I feel like I've changed completely I'm a totally different person..."* Gillian, lines 26-27

*"I just feel that I'm a different person and I'm afraid to go anywhere because I'm afraid I'll feel ill or something you know..."* Gillian, lines 162-165

Self-identity is challenged on a daily basis through a variety of dynamic processes, such as consistency and clarity in life roles and personal standards (Schwartz *et al.*, 2011). If anxiety is experienced on a long-term basis, this can result in increased social isolation that challenges one's self-identity (Lee and Robbins, 1998; Ozbay *et al.*, 2007). PWP's have a higher risk of losing their ability to participate in meaningful life roles, which fosters vulnerability towards social isolation and can negatively influence their self-identity (Wressle, Engstrand and Granérus, 2007; Soundy, Stubbs and Roskell, 2014). This suggests that PWP's experiencing anxiety may be at



increased risk of losing their self-identity, which was reflected in the participants' stories.

Interwoven with changing self-identity were the participants' experiences of changing relationships with others. This included significant others, wider family and other people:

*"...as I say I've always been a sociable outgoing person but, um, I think twice now before I accept an invitation. Or going out to dinner with friends I feel more, more uncertain and insecure than I ever have done and I usually still go, but I'm looking for an excuse quite often." Clare, lines 149-155*

*"And those who, well my wife is increasingly in role of carer with a capital c rather than a small c." Edward, lines 320-323*

The participants' stories suggest that these changing relationships are in part due to the change in physical functioning brought about by Parkinson's as well as anxiety. Perhaps, as the condition increasingly affected the participant's ability to participate in the world, making them more static, it made it more effortful and challenging for them to adjust and respond to unexpected demands (Sunvisson, 2006). This may result in relationships with others altering, which further challenges self-identity (Schwartz *et al.*, 2011; Soundy, Stubbs and Roskell, 2014):

*"You can't help it and then it leaves you feeling as a man, are these things going to be haunting you forever more. Then you can have performance anxiety because of the Parkinson's and not sleep right. Then you've got the business of how does your wife feel about that. You've got the problem of being able to walk with her and hold her hand or be able to lay your hand across her body or something without the hand shaking. And, it-it's really unpleasant and that causes anxiety, definitely. Definitely. You just wish you could, you just wish you could go to sleep and wake up and you're ok." Alan, lines 614-628*

Problems related to intimacy and sexual dysfunction are a frequently recorded complication for PWP's, but remain poorly investigated (Meco *et al.*, 2008). It can lead to relationship dysfunction and subsequent breakdown (Hand *et al.*, 2010). Alan expresses how this challenges his identity as a man, as well as a husband. Gender identity issues are also under-explored, with some suggesting it may be a manifestation of hypersexuality i.e. sexual dysfunction leading to excessive sexual demand (Odiyoor *et al.*, 2009). Thinking reflexively, it was interesting that Alan raised

intimate relationships and illustrated his feelings about this in depth, yet this was not identified by the researcher or in the literature review. As the researcher did not question other participants around this, the findings are limited regarding this and further research is warranted.

In summary, the participants express that anxiety has a detrimental effect on their physical and non-physical Parkinson's symptoms, as well as regulation of their emotions. Self-identity is a core issue in anxiety for PWP's and is linked to changing relationships with other people. Intimate relationships in Parkinson's are under-investigated but had a significant impact on one participant's life, highlighting a possible avenue for future research.

### 3.1.3 “Anxiety is a funny thing”- Perceptions

The final theme explores the participants' perceptions of anxiety; what they thought about it, how they perceived it. Most participants voiced that they saw anxiety as a negative, ubiquitous presence and described it in a myriad of ways:

*“It’s emotionally draining it it’s also physically draining depending by the end of the week what sort of week you’ve had, you can just feel whacked by Friday lunchtime.” Alan, lines 355 to 359*

*“A sort of compression really I think. You feel everyone is watching you, you’re looking around. Lack of confidence I think, perhaps comes in with anxiety as well...” Daniel, lines 330-333*

*“I’ve lost confidence to do things you know. I hate it, I hate the way I am. I absolutely hate it.” Gillian, lines 40-43*

The participant's identified anxiety as a negative experience that had a detrimental impact on their quality of life. This aligns with findings of the recent PPI consultation for this study (Lovegrove *et al.*, 2017). Anxiety is overwhelmingly seen as a negative entity in Parkinson's literature, associated with issues such as fearing falling, and uncertainty in family and employment roles (Rahman *et al.*, 2011; Hanna and Cronin-Golomb, 2012; Lutz *et al.*, 2016). The participants' experiences reflect this, placing the negative perception as an aspect within the lived experience of anxiety in Parkinson's (Husserl, 1931; Sokolowski, 1999).

Interestingly, not all participants shared the perception of anxiety as a negative. Beth strongly felt that her anxiety experience was not negative and indeed she gained positives from it:

*“Anxiety in a way helps because I don’t do silly things. I mean I was doing silly things before. I was taking risks. And anxiety of keeping myself intact is important, it makes me be careful. I’ve got to think about the next move. I sometimes get in position and think, now they make me have this on <points to pendant alarm> that I don’t want to call them whereas before I was falling stupidly all over the place and being silly about things, now my anxiety is useful. It’s not pleasant. It’s very unpleasant but it’s useful.” Beth, lines 406-418*

Beth elaborated on this point, explaining how her anxiety was a driver for her to engage and participate in life:

*“Undoubtedly I could be sat having a peaceful life not doing anything but I’ve always, I make myself anxious sometimes. I do anxious making things. Because they’re interesting, they give you life. If you have nothing to worry about what you, you could just sit there like a zombie couldn’t you.” Beth, lines 544-551*

During the member checking process, Beth voiced this feeling further, explaining that her anxiety gave her a stronger sense of self-identity as it drove her to cope. Beth likened it to the *“climb of Everest on a daily basis”*. As the only participant reporting a lifetime history of anxiety, it is unclear if this is an authentic piece of the lived experience of anxiety in Parkinson's or unique to Beth. However, Bower *et al.* (2010) report that pre-existing anxiety is likely a predictor of increased Parkinson's risk, meaning many more PWP's may experience anxiety before the condition developing. There is little literature exploring positive perceptions and implications of anxiety. Kashdan, Weeks and Savostyanova (2011) suggest that social anxiety may play a role in shaping positive experiences and events, yet this conclusion is limited to a particular anxiety-subcategory and general populations. In Parkinson's populations, Sotgiu and Rusconi (2013) suggest that investigating the positive experiences of emotional events, such as anxiety, could lead to a greater understanding of the complex emotional landscape experienced by PWP's. Beth's story seems to have revealed a new facet of the lived experience of anxiety in Parkinson's that it would be beneficial to research further.

The causes of anxiety in Parkinson's were perceived in many different ways, relating to physical symptoms, control and unfamiliarity:

*"you find the urgency to go for a pee all the time. And that in itself if you're out travelling, that's another thing you have to think about 'cos you can't go too far without needing the loo and it's instantaneous so all those things. Personal things. They come into play." Alan, lines 569-575*

*"There's anxiety there to a certain extent, am I going to do this properly? And sometimes the anxiety is really there when you're out-of-control and you've got no control of your body." Beth*

*"I got anxious about finding the seat. It was really strange statement I've not really had before. It was a strange stadium I didn't know where I was going. I was anxious of the loss, I was by myself and I was anxious about where my seat was." Daniel, lines 198-204*

These findings are echoed in other works exploring experiences in Parkinson's (Sunvisson, 2006; Wressle, Engstrand and Granérus, 2007). Fluctuating physical symptoms and their impact on independence and safety have previously been associated with causing anxiety in PWP's (Wressle, Engstrand and Granérus, 2007; Rahman *et al.*, 2011). Though Sunvisson (2006) suggested that the sense of loss of control manifests in late-stage Parkinson's, the participants' stories reveal that this is also evident in the early stages of the condition.

All participants reported anxiety about having a progressive condition with an unpredictable course. This fear of the future was an important aspect of participant perception and lived experience of anxiety:

*"And it's it's always a constant thing in the back of your mind what's going to happen in the future which also makes you think about things in a different light as well." Alan, lines 221-224*

*"Parkinson's is a big neurological disease. No one knows how it's going to pan out and there's a certain amount of nervousness about it." Daniel, lines 282-285*

*"I can see depending on the way the condition goes I could be more and more anxious about me and those around me. But I hope to hang on to the fact that it's the way it is." Edward, lines 325-329*

This experience has been identified in previous works exploring the experience of Parkinson's, including anxiety (Wressle, Engstrand and Granéus, 2007). It could be that the fear of future is linked to worries wider than just physical deterioration, such as being unable to support a relative if they become sick or uncertainty regarding family and work roles (Wressle, Engstrand and Granéus, 2007; Ravenek, 2014). While a neurological basis for anxiety in Parkinson's is theorised but not confirmed, psychosocial and situational contributors to anxiety are expressed by PWPs (Soundy, Stubbs and Roskell, 2014; Wen *et al.*, 2016). This suggests interventional studies should move away from investigating strictly neurobiological solutions and encompass these psychosocial and situational factors. Alan expresses this stance:

*“And you can always be given tablets for things but that that isn't the answer it's about being able to overcome...” Alan, lines 239- 242*

Anxiety and depression are linked in the research literature; indeed, they often coexist (Richard, 2005b; Gallagher and Schrag, 2012; Tan, 2012). Participants described episodes of depression after diagnosis but did not identify themselves as currently feeling or being depressed:

*“Aaand yeah I've had times where I've felt depressed. And I haven't taken medication I mean I've always been one for, I've always been a one to make sure I don't look down that avenue I don't suffer with depression or haven't had depression.” Alan, lines 158-163*

Considering the strong link between anxiety and depression in PWPs in the quantitative literature (Barone *et al.*, 2009; Todorova, Jenner and Chaudhuri, 2014), it is interesting that participants' stories did not reflect this. It could be that the participants felt it was not relevant to the study, or the interview schedule required adapting to take this into account (Elmir *et al.*, 2011; Wagstaff and Williams, 2014). It should be considered that anxiety could exist as a phenomenon unique to depression yet existing in a complex dyadic relationship (Pachana *et al.*, 2013; Coventry, Dickens and Todd, 2014). Nevertheless, the participants perceived anxiety in Parkinson's as a ubiquitous, detrimental presence in their everyday lives:

*“And it's it's a cycle like that more or less everyday.” Alan, lines 359-360*

*“And that's an anxiety which is, it is always there but I would say up to now it's background. Background noise. I can see depending on the way the condition*

*goes I could be more and more anxious about me and those around me.”*  
*Edward, lines 323-328*

PWPs also expressed the ever-present nature of anxiety in the PPI consultation for this study (Lovegrove *et al.*, 2017). Due to the pathophysiology of Parkinson's, it could be that the participants experience this feeling of omnipresent anxiety due to irreversible changes in brain biology (Chaudhuri and Schapira, 2009; Wen *et al.*, 2016). As previously cited, neurobiological theories for anxiety in Parkinson's remain unconfirmed while psychosocial factors have been clearly expressed (Wolitzky-Taylor *et al.*, 2010; Soundy, Stubbs and Roskell, 2014; Maillet *et al.*, 2016). As a tentative suggestion, perhaps the underlying brain pathology of the condition coupled with the psychosocial factors identified in the literature means that PWPs are more vulnerable to experience the feeling of anxiety as ever-present (Sunvisson, 2006; Chaudhuri and Schapira, 2009; Soundy, Stubbs and Roskell, 2014).

To briefly summarise the final theme: anxiety was perceived both negatively and positively. To some it was seen as a ubiquitous, unhelpful presence limiting people's lives, while to others it was considered a driver for people to achieve. Two participants only directly mentioned depression, suggesting the lived experience of anxiety is a unique phenomenon.

### **3.2 Strengths and limitations**

This study has some points of methodological strength. The research implemented the COREQ guidelines (Tong, Sainsbury and Craig, 2007). The guidelines improved the quality and transparency in the reporting of the study context, method, interpretations and findings. Additionally, the research implemented Lincoln and Guba's (1985) 'criteria of trustworthiness' to improve the rigour of the study. This process included audit trail, peer review and member checking. The peer review process between the researcher and senior researcher allowed for debriefing and testing of the data analysis and emerging interpretation. This informed the results and contributed to the credibility of the findings by providing deeper insight into the studied phenomenon (Patton, 2015). Additionally, to check the accuracy of the researcher's interpretation of the data, member checking was conducted (Birt *et al.*, 2016). All participants agreed to take part in member checking and responded to follow-up contact. Two participants did not complete the process, possibly due to

reluctance to criticise the researcher's summary or a busy schedule (Houghton *et al.*, 2013; Birt *et al.*, 2016). Four participants confirmed the researcher's interpretation and offered clarifying comments, suggesting the interpretation represented their experience. Finally, the PPI consultation provided valuable contributions to the design of this study with one participant saying the design had reduced their anxiety about participating.

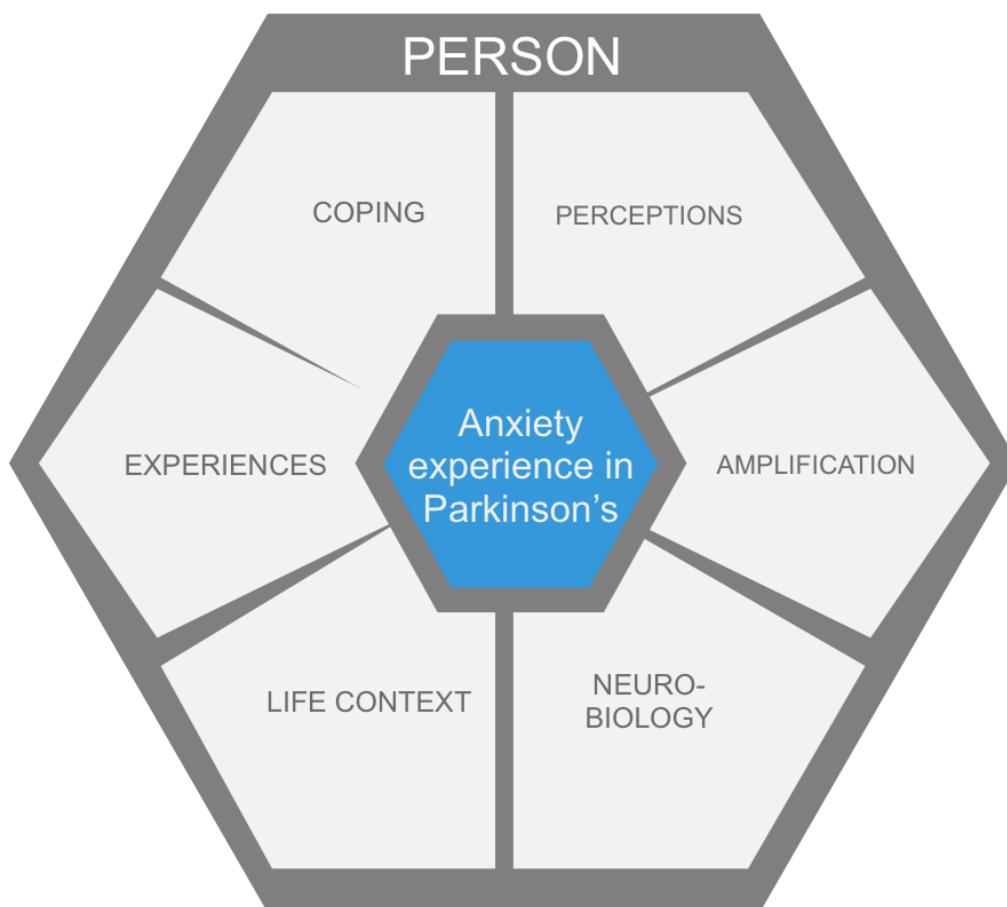
This study also has several limitations. The researcher aimed to sample PWP's who experience anxiety purposively, but it could be that convenience sampling is a more accurate term. Convenience sampling was achieved; as all of the PWP's self-volunteered and were interested in participating in research, and were the first to respond to the recruitment emails. While the maximum variation criteria were met, this is likely a fortunate coincidence and should not be relied upon in future studies. To achieve true purposive sampling with a maximum variation strategy in future will require more in-depth design (Luborsky and Rubinstein, 1995; Emerson, 2015). Furthermore, the research only included six participants. This was deemed a suitable saturation point based on similar work (Hennink, Kaiser and Marconi, 2016). During data collection and analysis it became apparent that the sample was limited to a particular age range, social class and ethnic group. That is, white heterosexual English people in the South West of England who are financially stable and live in their own home. As Parkinson's affects people across all backgrounds, this study may be seen as an overture, and further work is required to apprehend the complete picture of the lived experience of anxiety in Parkinson's.

It may have been useful to pilot the interview schedule with a PWP in addition to a postgraduate peer or healthcare professional. While the PPI consultation contributed to an improved interview schedule, a pilot would have allowed the researcher to check the schedule was meaningful to PWP's and bias had not tinted the design (Creswell, 2003). Due to time constraints, there was limited scope for additional formal piloting, but it should be considered for the future. During the interviews, the researcher found that participants required some prompting that could be construed as leading (Kvale, 1994; Agee, 2009). This could have been minimised if the interview schedule was piloted.

Finally, the researcher found the heuristic inquiry and thematic analysis processes exhausting. Other researchers have echoed this sentiment (Djuraskovic and Arthur, 2010). This is an important reflection for further research. The heuristic inquiry process was very demanding, requiring the researcher to engage in lengthy and tiring periods of self-reflection. While the researcher was supported throughout the process, under-prepared researchers may run into problems of struggling to accurately interpret and capture significant meanings of experiences (Moustakas, 1990; Djuraskovic and Arthur, 2010).

### 3.3 Conclusion and implications for practice

Tentatively, this study suggests that PWP's inhabit a lifeworld where anxiety is an experience that is multi-faceted. These facets are shaped by the individual's neurobiology, experiences and life context. This concept is represented in figure 6.



**Figure 6: Diagram presenting the proposed multiple facets of the lived experience of anxiety in Parkinson's**



Coping is a theme identified as an important part of the anxiety experience. It proposes that PWPs place importance on being self-reliant in managing and coping with their anxiety, indicating that self-management strategies may be a valued intervention within this population. These interventions could focus on maintaining the feeling of control that participants reported they felt was lost. Sharing the anxiety experience with other PWPs was perceived positively and negatively, with some valuing being with others while other participants felt this was not helpful and preferred to live their anxiety experience alone. This is an important consideration for healthcare professionals in the NHS, where the current emphasis is a move towards group working with service users, as this approach may not be therapeutic for everyone.

An important part of the anxiety experience described in Parkinson's was the amplification of Parkinson's symptoms. This study adds support to the notion that anxiety has a detrimental effect on Parkinson's symptoms (Ehgoetz Martens, Ellard and Almeida, 2014; Lutz *et al.*, 2016). It is suggested that the lived experience of anxiety in Parkinson's has a detrimental effect on cognitive and emotional wellbeing; it does not just affect motor symptoms, and that these effects can be more important to PWPs. Challenged self-identity can arise as a result of the experience of anxiety in Parkinson's. For one PWP, this tested their own gender identity, especially when intimate relationships are involved. Healthcare professionals working with PWPs should consider that PWP self-identity extends beyond family, social and work roles.

Areas for research have been highlighted throughout this text. While this study is not of sufficient power or design to change existing practice it has highlighted issues healthcare professionals may wish to consider, such as PWPs perceiving anxiety both negatively and positively. As a negative experience, PWPs experience anxiety as a ubiquitous presence that limits their lives. It is always there even though PWPs may not look outwardly anxious. On the other hand, anxiety in Parkinson's may be utilised by PWPs as a driver to help them achieve when they feel limited by their condition. It may be that healthcare professionals need to work collaboratively with PWPs to help them manage their anxiety so that they continue to maintain this perceived benefit. This may require a change in perspective from one that believes that anxiety is solely a negative experience.

## **Conclusion**

Anxiety is a non-motor symptom of Parkinson's commonly experienced by PWP's. There is quantitative research into this area, but a lack of qualitative evidence. The aim of this research study was to develop an understanding of the lived experience of anxiety for PWP's to identify potential issues to consider in developing future interventions. This study has started to illuminate the complex lived experience of anxiety for PWP's. Coping is an important aspect of the anxiety experience, with the value placed on self-reliance. It is important to recognise that not all PWP's find sharing their experience with others to be either positive or beneficial. PWP's experience anxiety in Parkinson's as amplifying not only their physical signs but also their cognitive and emotional symptoms. This can often be more important to them; an important consideration particularly in hospitals where the management of physical symptoms takes precedence. It is crucial that self-identity is considered with a deeper meaning, expanding beyond those of family and social roles. Anxiety is perceived both negatively and positively by PWP's. It is viewed as an ever-present, negative influence in PWP's' lives but can also be viewed as a positive force for people to initiate action. This may require a shift in perspective of healthcare professionals changing their beliefs about anxiety in Parkinson's.

The strengths and limitations of this study have been explored. Potential ways of expanding or improving upon this research have been identified. The implications of the findings for clinical practice and further research have been highlighted and discussed. Due to the limitations identified, the findings of this study should be considered preliminary and an invitation for further research to explore the lived experience of anxiety in Parkinson's in richer depth. This intelligence could then be used to develop an intervention for PWP's focused on their experiences and less influenced by healthcare professional or researcher assumptions.

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## 5 Appendices

### 5.1 Patient and public involvement ethical approval



Plymouth University

Faculty of Health, Education and Society

Health Student Ethics Sub-Committee

APPLICATION FOR ETHICAL APPROVAL OF RESEARCH

**Retrospective Ethical approval; Chairs action**

04/11/2016

Title of research: What is the lived experience of anxiety for people with Parkinson's?  
A phenomenological study

Student Name: Chris Lovegrove

Course/Programme for which project is being carried out: MClinRes

Email address and other contact details:

[Christopher.lovegrove@postgrad.plymouth.ac.uk](mailto:Christopher.lovegrove@postgrad.plymouth.ac.uk)

Supervisor/Chief Investigator/Independent researcher Name: Katrina Bannigan

Dear Chris,

Thank you for your revised Ethics application, including electronic consent.

**Decision:** Approved, permission to commence research granted

Wishing you every success with your studies and publication.

Kind Regards

Sylvia

Dr Sylvia Terbeck (Assistant Professor/Lecturer in Psychology)

Chair, Health Student Ethics Committee

Faculty of Health and Human Sciences

Email: [sylvia.terbeck@plymouth.ac.uk](mailto:sylvia.terbeck@plymouth.ac.uk)

## 5.2 Research study ethical approval



Katrina Bannigan

Wed 26/10/2016, 21:04

Graham R Williamson; hhsethics; (pg) Christopher Lovegrove ✕



↻ Reply all | ▾

Anxiety study

You forwarded this message on 27/10/2016 13:01



Action Items



Dear Chris,  
Ethics application reference number 15/16-239

Thank you for your revised application. I have checked the revised submission and confirm I am happy with the proposal and you have permission to proceed.

Best wishes,  
Katrina

Dr Katrina Bannigan

Associate Professor (Reader) of Occupational Therapy | School of Health Professions | Faculty of Health and Human Sciences | Peninsula Allied Health Centre | Derriford Road | Plymouth | Devon | PL6 8BH | UK | phone: +44 (0)1752 587550 | skype: katrina.bannigan | [www.plymouth.ac.uk/faculties/health](http://www.plymouth.ac.uk/faculties/health)

**Would you like to work with the occupational therapy team?** Closing date for applications 13<sup>th</sup> November 2016 - Find out more here <https://www.plymouth.ac.uk/your-university/jobs>

## 5.3 Study documents sent to participants



### **PARTICIPANT INFORMATION SHEET**

Title of Project: What is the lived experience of anxiety for people with Parkinson's? A phenomenological study

Name of Researcher: Chris Lovegrove

Researcher contact: christopher.lovegrove@postgrad.plymouth.ac.uk or 07514 692975.

#### **You are invited to take part in a research study.**

- I want to find out how people with Parkinson's feel about anxiety and how it affects their lives. This is important because there is currently no research evidence about this subject. I will do this by asking you questions in an interview.
- I would like to speak to six people with Parkinson's for this study.
- I want to speak to a male and female from the early/ diagnosis, maintenance and advanced stages of Parkinson's.
- I need to speak to people who have had a formal diagnosis of Parkinson's from a consultant doctor in neurology, movement disorders or healthcare for older persons and have had their diagnosis for at least a year. It is important that I speak to people who have experienced anxiety that they feel is caused or made worse by their Parkinson's.

#### **What is involved?**

- Before you decide whether to take part it is important for you to understand why this research is being done and what it will involve.
- Please read the following information carefully. Discuss it with friends and relatives if you want to. You will have two days to read this information and to think about it before ~~someone~~ contacts you again.
- It is your choice to decide whether or not to take part in this study. If you choose not to take part this will not affect the care you get from anyone involved in your care.
- Ask the researcher if there is anything that is not clear or if you would like more information.
- If you have religious or cultural needs that I need to be aware of, please let me know and I will accommodate them during the interview.

**CONSENT FORM**

Title of Project: What is the lived experience of anxiety for people with Parkinson's? A phenomenological study

Name of Researcher: Chris Lovegrove

Please tick box

1. I confirm that I have read the information sheet called 'What is the lived experience of anxiety for people with Parkinson's? participant information sheet' for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
3. I understand it may not be possible to extract my data from the study if I withdraw after data analysis has begun.
  
4. I understand that I will be asked to review the analysis of the findings (member checking). I understand that it is my right to choose not to take part in this aspect of the study.
  
5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
  
6. I agree to my General Practitioner being informed of my participation in the study.
  
7. I understand that my anonymised data will be kept securely for 10 years.
  
8. I agree to take part in the above study.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of family member/ friend	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

#### **What would taking part involve?**

- You will be taking part in a face-to-face interview with the researcher. The interview will take place in your home.
- The researcher will call you to arrange a date and time for the interview. One the morning of the interview the researcher will call you again to check that you still want to carry on with the interview.
- When the researcher arrives you will complete a consent form with them and a friend or family member if you wish. The researcher will interview by yourself. The interview will be recorded and the researcher will also take notes during the interview.
- At the end of the interview the researcher will offer you the opportunity to talk about the interview. You will also be offered an opportunity to talk on the telephone 24 hours later.
- You will be asked if you would check the researcher's analysis at a later date. There is no obligation to do this.
- It is your right to withdraw from the study at any time by contacting the researcher. If you choose to withdraw your information will be destroyed. This will not affect the help you get from anyone involved in your care. After 48 hours I will have anonymised your data. This means I will not be able to destroy it after this time.

#### **What are the possible benefits in taking part?**

- There are no expected benefits to taking part in this study. This study may help to understand more about anxiety in Parkinson's.

#### **What are the possible disadvantages and risks in taking part?**

- This study might make you feel more anxious. The researcher will spend time with you after the interview to talk about this, and any concerns or points you would like to make. You will also be offered a follow up telephone call for the next day.
- If you talk about anything of a serious nature the researcher will make it clear that they will have to take action on this. This is a legal and professional obligation.

## 5.4 GP letter

**RESEARCH  
WITH  
PLYMOUTH  
UNIVERSITY**

<DATE>

Dear Dr \_\_\_\_\_

**RE: What is the lived experience of anxiety for people with Parkinson's? A phenomenological study**

Your patient, **PATIENT NAME**, has agreed to participate in a research study named 'What is the lived experience of anxiety for people with Parkinson's? A phenomenological study'. This is a qualitative study exploring the lived experience of anxiety for people with Parkinson's. There is currently little research in this area and it is hoped that this research will be used in the future to inform larger scale research studies to assess and evaluate comprehensive treatments for anxiety in Parkinson's. Enclosed with this letter is a copy of the information sheet that has been supplied to the patient about this study.

For queries relating to your patients involvement please contact the researcher, as detailed on the accompanying correspondence.

Yours sincerely,

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Chris Lovegrove

Clinical Lead Occupational (neurology, stroke and rehabilitation), main researcher

Dr Katrina ~~Bannigan~~, supervisor