

University of Bath



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

Stephens, Emma

Award date:
2016

Awarding institution:
University of Bath

[Link to publication](#)

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

University of Bath
Department of Psychology

May 2016

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Abstracts

Main Research Project

OBJECTIVE: This study aimed to replicate previous findings regarding the influence of recovery style and attachment on engagement and help seeking in first episode psychosis (FEP). It also aimed to explore self-compassion and shame as new potential moderators of engagement, and in terms of their relationship with attachment and recovery style.

DESIGN: A cross-sectional between groups design was used to compare 'high' and 'low' engagers on key variables. Whole sample correlational analysis was also undertaken to further explore associations with self-compassion and shame in FEP.

METHODS: Twenty-two individuals with psychosis under the care of Early Intervention (EI) Services completed four questionnaires. Care Coordinators were subsequently sent a questionnaire on engagement to complete. RESULTS: No significant group differences on the predicted variables were found, with only time in service reaching significance. Although non-significant, avoidant attachment did result in a small to medium effect size whereby 'low' engagers scored higher on avoidant attachment, and a trend towards more non-white individuals in the 'low' engagers group was nearing significance. In the secondary analysis, avoidant attachment was associated with shame and problems help seeking, even when positive symptoms were controlled for. Anxious attachment was associated with lower self-compassion and higher shame. None of the variables were significantly correlated with recovery style.

CONCLUSIONS: The small sample size limits the conclusions which can be made, however it is of interest that no significant differences were found between the two groups on the expected variables. Although self-compassion and shame did not appear to effect engagement in this sample, strong and distinct associations were found between these variables and insecure attachment dimensions, indicating a possible area for further exploration.

Service Improvement Project

This paper outlines the development and evaluation of a professionals training day focussing on understanding and treatment of Obsessive Compulsive Disorder (OCD). The training included talks from experts in OCD, and was organised by

OCD-UK (a national service-user led OCD charity) with consultation and input from the researcher. The training day was developed in an attempt to target common unhelpful therapist beliefs about OCD. An evaluation of the day found that attendees' confidence in understanding and treating OCD increased significantly from pre to post training. The training was also found to significantly increase attendees' optimism about the treatment of OCD, and significantly decrease beliefs of OCD being a biological (rather than psychological) problem. Implications and links to relevant literature are considered.

Literature Review

BACKGROUND: Anxiety in Parkinson's Disease (PD) is highly prevalent yet frequently underdiagnosed, undertreated, and historically overshadowed in research by a focus on depression. More recently there has been increasing interest in anxiety as its significant impact on quality of life in PD is increasingly recognised. However anxiety is frequently conceptualised purely as one of many 'non-motor' manifestations of neurological change, with minimal consideration of potentially useful psychosocial factors.

OBJECTIVE: This review aimed to identify and synthesise the available evidence for psychosocial risk factors for anxiety, and to provide an alternative conceptualisation through development of a hypothetical cognitive behavioural model of anxiety in PD.

METHODS: This is a narrative review utilising a systematic search strategy to identify relevant papers relating to psychosocial factors and anxiety in PD.

RESULTS: Thirty relevant papers were located and reviewed, and demographic, disease/pharmacological and psychosocial risk factors for anxiety in PD were identified. A prominent finding was that individuals with motor fluctuation appeared to be more vulnerable to anxiety. A hypothetical cognitive behavioural model of anxiety in PD is offered.

CONCLUSIONS: Research focusing on anxiety in PD beyond just the biomedical perspective has only recently started to increase, and a number of methodological considerations have been highlighted by this review. The current shift in perspective on anxiety in PD from one of diagnostic overshadowing to a more psychologically informed one, has the potential to address the current problems with under-recognition and lack of treatment, which would potentially benefit a wide range of PD patients.

Word Count

Literature Review.....	7,430
Service Improvement Project.....	3,562
Main Project.....	5,278
Executive Summary.....	573
Connective Narrative.....	2,604
Case study 1.....	4,080
Case Study 2.....	4,212
Case Study 3.....	4,409
Case Study 4.....	3,892
Case Study 5.....	4,286
Total.....	40,326

Contents

Title.....	1
Abstract.....	2
Word Count.....	4
Contents.....	5
Tables.....	8
Figures.....	8
1 Diagnostic overshadowing of anxiety in Parkinson’s Disease: Application of a cognitive behavioural model.....	9
1.1 Abstract.....	10
1.2 Keywords.....	10
1.3 Introduction.....	11
1.4 Method.....	16
1.5 Results.....	17
1.5.1 Demographic Factors.....	17
1.5.2 Severity.....	18
1.5.3 Disease & Pharmacological Motor Symptoms.....	18
1.5.4 Cognitive Factors.....	22
1.5.5 Social Support.....	24
1.6 Discussion.....	32
1.6.1 A cognitive model of anxiety in PD.....	35
1.6.2 Limitations.....	38
1.6.3 Future Directions & Conclusions.....	38
1.7 Acknowledgements.....	39
1.8 Conflicts of interest.....	39
1.9 Reference.....	40
2 The impact of an OCD-UK Professionals Conference Day on Therapist beliefs about OCD.....	50
2.1 Abstract.....	51
2.2 Introduction.....	52
2.3 Research questions.....	54
2.3.1 Consultation.....	54
2.3.2 Evaluating the conference.....	54

2.4 Method.....	54
2.4.1 Consultation.....	54
2.4.2 Conference day.....	55
2.4.3 Measures.....	55
2.5 Results.....	57
2.6 Analysis.....	59
2.6.1 Confidence ratings.....	59
2.6.2 Beliefs data.....	59
2.6.3 General Conference feedback.....	62
2.6.4 Follow up.....	63
2.7 Discussion.....	63
2.8 Summary of main points.....	65
2.9 References.....	66
3 Insecure attachment, self-compassion and shame in the context of engagement and help seeking in first episode psychosis.....	68
3.1 Abstract.....	69
3.2 Introduction.....	70
3.3 Hypotheses.....	73
3.4 Method.....	74
3.4.1 Design.....	74
3.4.2 Measures.....	74
3.4.3 Participants.....	76
3.4.4 Procedure.....	77
3.4.5 Power Analysis.....	78
3.5 Results.....	78
3.5.1 Engagement.....	79
3.5.2 Attachment style.....	80
3.5.3 Self-compassion, shame & recovery style.....	81
3.6 Discussion.....	82
3.7 Clinical Implications.....	85
3.8 References.....	86
4 Executive Summary.....	92
5 Connective Narrative.....	94

5.1 Service Improvement Project.....	94
5.2 Literature Review.....	95
5.3 Main Project.....	97
5.4 Case studies.....	99
Appendix A Research Invite Letter.....	101
Appendix B Participant Information Sheet.....	102
Appendix C Questionnaire Pack.....	104
Appendix D Ethical Approval & R&D Correspondance.....	109
Appendix E Amendment Correspondance.....	118
Appendix F Literature Review process flow chart.....	123
Appendix G OCD-UK Questionnaire Pack.....	124
Appendix H Literature Review Journal: Instructions to Authors.....	128
Appendix I Service Improvement Project Journal: Instructions to Authors.....	129
Appendix J Main Research Journal: Instructions to Authors.....	130

Tables

Table 1.1: Summary Table of Reviewed Papers.....	25
Table 2.1: Table of mean pre and post confidence ratings and analysis results...	61
Table 2.2: Table of mean change and statistical outcomes for OCD beliefs factors.....	61
Table 3.1: Participant demographic and service related data.....	78
Table 3.2: Median (Mdn) and Range (R) scores of High and Low Engagers.....	79
Table 3.3: Pearson Correlation Coefficients of Attachment related variables....	81

Figures

Figure 1.1: Hypothetical Cognitive Behavioural Model of Anxiety in PD.....	36
Figure 2.1: Frequency graph showing spread of participants' professional roles.....	57
Figure 2.2: Frequency graph of participant ratings of experience treating OCD.....	57
Figure 2.3: Mean pre and post conference belief in OCD as psychological and optimism.....	62
Figure 2.4: Frequency graph of ratings of content.....	63
Figure 3.1: Consort Diagram of Recruitment flow.....	77

**Diagnostic overshadowing of anxiety in Parkinson's Disease:
Application of a cognitive behavioural model.**

Word Count: 7,050

Emma Stephens

Supervisor: Dr James Gregory

External Supervisor: Dr Leon Dych

Journal aimed at: Journal of Parkinson's Disease

1.1 ABSTRACT

BACKGROUND: Anxiety in Parkinson's Disease (PD) is highly prevalent yet frequently underdiagnosed, undertreated, and historically overshadowed in research by a focus on depression. More recently there has been increasing interest in anxiety as its significant impact on quality of life in PD is increasingly recognised. However anxiety is frequently conceptualised purely as one of many 'non-motor' manifestations of neurological change, with minimal consideration of potentially useful psychosocial factors.

OBJECTIVE: This review aimed to identify and synthesise the available evidence for psychosocial risk factors for anxiety, and to provide an alternative conceptualisation through development of a hypothetical cognitive behavioural model of anxiety in PD. **METHODS:** This is a narrative review utilising a systematic search strategy to identify relevant papers relating to psychosocial factors and anxiety in PD.

RESULTS: Thirty relevant papers were located and reviewed, and demographic, disease/pharmacological and psychosocial risk factors for anxiety in PD were identified. A prominent finding was that individuals with motor fluctuation appeared to be more vulnerable to anxiety. A hypothetical cognitive behavioural model of anxiety in PD is offered.

CONCLUSIONS: Research focusing on anxiety in PD beyond just the biomedical perspective has only recently started to increase, and a number of methodological considerations have been highlighted by this review. The current shift in perspective on anxiety in PD from one of diagnostic overshadowing to a more psychologically informed one, has the potential to address the current problems with under-recognition and lack of treatment, which would potentially benefit a wide range of PD patients.

1.2 KEY WORDS: Anxiety, Parkinson's Disease, Psychosocial, Cognitive Behavioural.

1.3 INTRODUCTION

Parkinson's disease (PD) is a chronic and progressive neurodegenerative disease affecting approximately 127,000 people in the United Kingdom (Parkinson's UK, 2013). Clinical diagnosis is a complex and often lengthy process frequently over more than a year. Diagnosis is based on evidence of: the physical effects of PD (e.g. tremor, rigidity, akinesia/bradykinesia and postural disturbance); ruling out of other possible conditions; and monitoring for the effect of medications and of disease progression. Brain imaging is also sometimes utilised. The majority of those diagnosed with PD are 50 and over, however PD can also affect people at a younger age. When diagnosis occurs prior to age 50 this is generally labelled 'early onset' PD (Parkinson's UK, 2013). The exact symptoms and the speed at which the condition deteriorates can be unpredictable and varies from one person to the next.

Progressive loss of dopaminergic neurons in the substantia nigra due to build up of Lewy bodies have long been linked to physical impairments in PD, and treatment involves administration of dopaminergic medications (most commonly L-Dopa). Maintaining optimal levels of L-Dopa medication is often complex however, and as the disease progresses individuals frequently experience increasing fluctuation in their physical symptoms as dopamine levels rise and fall when medication is 'wearing on' and 'wearing off'. Excess dopamine due to medication can also lead to disruptive uncontrolled movement (dyskinesia).

As diagnosing and treating PD as early as possible slows the disease progression more effectively, there is increasing interest in identifying early warning signs or 'prodromal' PD symptoms. A large prospective study (Schrag et. al, 2014) found that a range of symptoms of; tremor, balance impairments, constipation, hypotension, erectile dysfunction, urinary dysfunction, dizziness, fatigue, depression, and anxiety may signify prodromal symptoms. Further research is required however due to a lack of accuracy in PD diagnosis in this sample. It will also be important to explore whether depression and anxiety in prodromal stages are in fact a reaction to experiencing a range of worrying and troublesome symptoms, or are symptoms of neurological changes themselves.

Although the physical effects of PD are considered the core of the disease, there is an on-going shift from viewing PD as a "single chemical neurodegenerative disease" (Goetz, 2010, p.S105), to a neuropsychiatric disorder with motor symptoms; acknowledging a wider focus that includes a variety of common and often disabling 'non-motor' symptoms. These can include problems such as fatigue, apathy, pain, cognitive change or sleep disturbance, but psychological difficulties are now recognised as one of the most commonly reported non-motor symptoms of PD (Gallagher, Lees, & Schrag, 2010). Despite this, problems like anxiety or depression have historically been subjected to diagnostic overshadowing by the more physically apparent motor symptoms, and rarely identified as a potential target of psychological treatment. There is a growing acknowledgement however of the extensive impact of such potentially treatable difficulties on the everyday functioning of patients with PD. Paradoxically, it increasingly appears that it is the *non*-motor symptoms of PD that most influence the perceived quality of life of people living with this disorder (Barone et al., 2009; Quelhas & Costa, 2009).

Prevalence of anxiety in PD

Although there is a clear consensus that psychological difficulties are frequent and significant in PD, challenges remain regarding obtaining accurate prevalence rates. In their review of psychosis, apathy, depression and anxiety in PD, Gallagher and Schrag (2012) highlight the complexity of establishing accurate prevalence rates for mood problems and anxiety in PD, and this concern is repeated in much of the available research. Complicating factors are listed as: overlap with disease symptoms; possible qualitative differences in psychological disorders in this population; comorbid cognitive problems; medication side effects; the presence of motor and non-motor fluctuations; and the different diagnostic frameworks available (Gallagher & Schrag, 2012).

One review suggests a range of estimates for diagnostic anxiety *disorders* in PD of between 20-49% across studies (Gallagher & Schrag, 2012). Meanwhile 'clinically significant' anxiety has been identified in 40% to 60% of individuals with PD (Starkstein, Robinson, Leiguardia & Preziosi, 1993; Richard, Schiffer & Kurlan, 1996; Pachana et. al., 2013). In a review of non-motor fluctuations in PD, Bayulkem

& Lopez (2010) report that the “most common type of mood fluctuation is off period anxiety” (p.90), which is anxiety that occurs as medication wears off and motor symptoms increase; they state that up to 75% of patients may report this type of anxiety. A large scale Italian study found anxiety to be second only to fatigue out of the most commonly reported non-motor symptoms with 56% of the sample reporting anxiety difficulties (Barone et. al., 2011). A high prevalence of panic disorder (Stein et al., 1990; Goetz, 2010), generalised anxiety disorder (GAD) and social phobia (Gallagher & Schrag, 2012; Pachana et al., 2013; Stein et al., 1990, Bolluk, 2010) has been identified.

Despite methodological challenges, there is growing and consistent evidence of a high prevalence rate of anxiety in patients with PD, including when compared with both age-matched non clinical controls (40% anxiety rate versus 15% in controls; Chaudhuri, et al., 2006) and to individuals with other chronic health conditions (38% versus 11%; Pincus & Tucker, 2002). Considering these high rates, it is perhaps surprising that anxiety remains often under-recognised and untreated within PD.

Comorbidity with depression & anxiety subtypes

Depression is also common in PD, although prevalence estimates have varied widely from 2.7-90% across studies (Gallagher & Schtag, 2012). A large systematic review of depression in PD found an overall prevalence rate for *major* depression to be 17% (Reijnders et al., 2008), compared to 13.5% of the general population in later life (Beekman, Copeland & Prince, 1999). The broader category of ‘clinically significant depressive symptoms’ in PD was estimated at 35% (Reijnders, et al., 2008). Until more recently, depression has frequently overshadowed anxiety within PD literature. This may be because theories of depression linked to the dopaminergic systems have been more forthcoming. Goetz (2010), admits that there has been an ‘assumption’ that anxiety in PD relates to “the same neurochemical systems implicated for depression” despite the fact that these systems are not the same as those targeted by anxiolytic medications (Goetz, 2010, p.S105).

Although there is significant evidence that anxiety and depression in PD often do occur together (Gallagher & Schrag, 2012; Pachana et al., 2013; Goetz, 2010; Bayulkem & Lopez, 2010, Armento et. al., 2012) there is growing evidence that they

should not be viewed as one entity, or assumed to solely be manifestations of the same neurological change. A recent large-scale study with a sample of 513 PD patients identified four anxiety or depression subtypes using Latent Class Analysis. These included an ‘anxiety alone’ subtype (22.0%), an ‘anxiety co-existing with prominent depressive symptoms’ subtype (8.6%), a third subtype (8.9%) of depressive symptoms without significant anxiety, and a final subtype (60.4%) with no prominent affective symptoms (Brown et al, 2011). Indeed Brown et al. (2011) went even further to hypothesise that the phenotypic similarities found in patients in their ‘anxiety alone’ and ‘anxiety co-existing with depressive symptoms’ subtypes suggest there may be a progression from persistent GAD-like anxiety symptoms leading to a deterioration in mood and development of anxiety with depression over time- although they admit further longitudinal research is required to test out such an association (Brown et al., 2011). Such findings support the need for further study of anxiety as a primary symptom within the context of PD, contrary to the historical focus of literature on depression in PD.

Biomedical understanding of anxiety in PD

As with depression, anxiety in PD has historically been viewed as a symptom of underlying neurological changes associated with Parkinson’s disease (e.g. Menza et al., 1993), and biomedical explanations have predominated. Evidence is limited and conflicting regarding the relationship of anxiety with the dopaminergic system, with most research pointing more strongly to links with depression, psychosis and drug abuse (see Millan, 2003 for comprehensive review). However, research has begun to identify possible neurological changes in a number of other areas in PD more commonly associated with mood and anxiety. This includes neurological pathways to the amygdala and wider limbic system, which have been implicated in a range of anxiety disorders (Etkin & Wager, 2007) as well as being central to posture and balance (Balaban & Thayer, 2001).

Relatively few neuroimaging studies aimed at anxiety in PD have been completed (Aminian & Strafella, 2013), and the available research has varied in its findings. Unsurprisingly the neurological impact of PD is highly complex, however the implication is that neurodegeneration of other transmitter systems in the cortex and

brainstem (e.g. cholinergic, adrenergic and serotonergic neurons) may represent an underlying cause of a variety of non-motor symptoms including anxiety (Bassetti, 2011; Prediger, 2012; Walsh & Bennett, 2001). Despite increased interest in possible neurological explanations of anxiety in PD however, the picture remains complex and poorly understood, (Bassetti, 2011; Millan, 2003). It is also increasingly acknowledged that psychosocial factors are also highly relevant (Bassetti, 2011) and perhaps especially within certain groups, such as young-onset PD (Aminian & Strafella, 2013).

Anxiety as a psychological response to PD

PD is a progressive and deteriorating disease, however there is uncertainty and unpredictability about the speed of disease progression, and living with PD often involves considerable day- to-day variability and uncertainty. A significant proportion of individuals experience fluctuation in their motor symptoms as a result of dopamine medication ‘wearing off’ or ‘on’ over time. ‘Wearing off’ symptoms can involve slowing of movement, or incidents of motor block/freezing of gait (FOG) which can be sudden, unpredictable and frightening. If dopamine levels get too high in ‘on’ periods however, this causes excessive and uncontrolled movements (dyskinesia). Patients also often have symptoms such as tremor or gait problems, which may have social implications and can be misunderstood as evidence of alcoholism or drunkenness.

Anxiety is increasingly reported as one of the most common, if not *the* most common, non-motor symptom in PD (e.g. Pachana et al., 2013; Witjas et al., 2002; Barone et al, 2009), the presence of which correlates with degree of reported disability (Witjas, 2002; Quinn, 1998). Anxiety has also been found to reduce self-rated quality of life in individuals with PD (Barone et al, 2009; Dissanayaka et al, 2010; Martinez-Martin et al., 2011), and represents an additional significant burden and barrier to those already imposed by the disease (Quelhas & Costa, 2009). Yet the historical assumption that anxiety problems in PD are *solely* a symptom of underlying neurological changes associated with the disease (e.g. Menza et al., 1993), has had important implications for both patients and clinicians. Individuals with PD often fail to receive psychological intervention for anxiety despite the fact that a meta-analysis of randomised controlled trials found no significant effect of

pharmacological treatment on either anxiety or depression in PD (Troeng, Egan & Gasson, 2013), whilst Cognitive Behavioural Therapy has been identified as a potentially effective psychological approach (see Yang et. al., 2012; Armento et al., 2012 for reviews of psychosocial/CBT treatment for anxiety and depression in PD). Anxiety in PD remains frequently under-diagnosed (Dissanayaka et. al., 2014) and under-treated (Pachana et. al., 2013).

The psychosocial risk factors for anxiety in PD may also represent a promising target for psychological intervention considering the lack of evidence for any pharmacological treatment of anxiety in PD, and the risks of side effects from polypharmacy considering the numerous medications PD patients are frequently prescribed (Prediger, 2012; Walsh & Bennett, 2001). Various models of anxiety, such as a number of cognitive-behavioural models, have developed as useful theoretical explanations of anxiety with strong evidence bases. These models have also started to be applied to the experience of anxiety within chronic illnesses (e.g. Kehler & Hadjistavropoulos, 2008), and in other neurological diseases such as MS, the role of psychological factors in adjustment and coping are increasingly explored and understood (Dennison, Moss-Morris & Chalder, 2009). In comparison to MS, psychological perspectives of anxiety in PD which contrast the biomedical viewpoint lag behind, and very little attempt has been made to apply psychological models of anxiety in the context of PD specifically.

With increasing interest in anxiety in PD, and in identifying the factors that may impact on an individual's vulnerability to anxiety, this review will attempt to synthesise the available evidence and offer a theoretical model of anxiety in PD which draws on existing research and evidence based anxiety models. It is hoped that this review and model will identify:

- a) Risk factors/potential moderators of anxiety in PD (either disease factors e.g. motor fluctuation, or psychosocial factors e.g. illness beliefs or social support)
- b) The potential interaction between motor symptoms and anxiety in PD

1.4 METHOD

This review is narrative in nature, however a systematic search strategy was utilised and incorporated advice from consultation with a specialist librarian. The databases of PsychINFO and PUBMED were searched by the first author. Due to the limited research on anxiety in Parkinson's, broad search criteria were adopted to obtain as many relevant papers as possible. MeSH terms of 'Parkinson's Disease' and 'Anxiety' were therefore used in order to remain broad but also to ensure that anxiety was a major and substantial topic. No limits were set except that an inclusion criteria of 'human population' was applied. See Appendix for mapping of search process.

A total of 185 papers were identified. A title/abstract search of these papers was conducted and a number of papers were excluded due to:

- 1) Duplication in both searches
- 2) Not a journal article
- 3) Not English language
- 4) Single case study
- 5) Not directly relevant (e.g. only looked at depression or other non-motor symptom e.g. sensory changes).

The remaining 104 papers about anxiety in PD were then reviewed in more detail. Papers conceptualising anxiety in PD purely from a biological or pharmacological perspective were excluded. Papers focussed solely on treatment of anxiety (either pharmacological or psychological) were also excluded due to the existence of other available reviews of treatment approaches (e.g. Armento et. al., 2012). The remaining papers were included if they explored risk factors for anxiety in PD (e.g. disease related or psychosocial) or the interplay between motor symptoms and anxiety.

In total, 30 papers were included. The 30 identified papers were critically reviewed regarding methodological variations (e.g. design, sample size, control group etc) and relevance to the review aims of identifying possible factors influencing anxiety in PD, and the interaction between motor symptoms and anxiety in PD. This analysis identified three main areas of focus in the current research; motor

symptoms/fluctuations (and their interplay with anxiety), cognitive factors (such as metacognitions or illness beliefs), and disease severity. A fourth category of demographic factors were also identified and deemed relevant to include due to the recognition that PD patients are not a highly homogenous group, and that different factors may have more or less influence on anxiety across demographic groups e.g. at different ages.

1.5 RESULTS

1.5.1 *Demographic factors*

PD is considered ‘Young-onset’ when it occurs prior to age 40. A number of studies have identified that younger individuals (Dissanayaka, 2010; Pontone, 2011; Stefanova et al., 2013) and younger women with PD are more likely to experience anxiety (Nègre-Pagès et al., 2010; Pontone, 2011; Stefanova, 2013). Younger PD patients may also experience more social anxiety (Bolluk, 2010). Experiencing a degenerative disease earlier in life may increase risk of anxiety due to the possibility that illness may be more ‘socially acceptable’ or comprehensible at an older age, when society tends to expect health to decline. One study found gender, disease duration & severity, and social support explained 31% of variance in anxiety in younger PD patients but not in older patients (Ghorbani Saeedian et al., 2014).

Results suggesting a link between younger age of PD onset and anxiety fit with the findings of other reviews into PD (e.g. Bayluken & Lopez, 2010). Lifetime prevalence rates of anxiety disorders in the general population have been found to be higher in women (30%) than men (19%), so these findings may simply reflect this wider tendency (Kessler et. al., 1994), or may reflect increased caring responsibilities. One study using retrospective chart analysis identified ethnicity as being associated with anxiety (Rana et. al., 2012), but this was not replicated in any of the other studies included here.

1.5.2 *Severity*

A number of studies identified severity of PD as an important factor associated with anxiety levels (e.g. Dissanayaka, 2010; Ghorbani Saeedian et al., 2014; Manor et al., 2009; Pontone, 2011; Quelhas & Costa, 2009; Simpson et al., 2013; Stefanova et al., 2013). This is unsurprising considering the increasing burden and restriction likely

imposed by the disease as it progresses, as well as further development of neurological degeneration and associated complications e.g. fatigue. Motor fluctuation also tends to increase with severity of illness, as the effectiveness of dopaminergic medications reduce, leading to longer and more pronounced ‘off’ periods and less well controlled motor symptoms. Crucially however to support the role of psychosocial factors, severity by no means explains all variation in anxiety, and some studies with large sample sizes have found no significant relationship with anxiety (e.g. Brown & Fernie, 2015).

1.5.3 Disease & Pharmacological Motor Symptoms

On/Off Period Fluctuation

Richards et al. (2004) report that 24% of their PD sample experienced motor fluctuation, and that 75% of those with fluctuations also reported experiencing mood and/or anxiety fluctuation. Although Richards’ research involved only a small sample, a considerable range of studies have also found increased anxiety levels in those experiencing motor fluctuations. Although cross sectional, Dissanayaka et al.’s 2010 telephone interview study was thorough and in depth, including checking for psychiatric history and controlling for a variety of factors (e.g. psychiatric history, family psychiatric history). They also utilised a structured diagnostic measure (MINI) as well as a more specific anxiety rating scale (STAI).

Stefanova’s large study of 360 consecutive outpatients with PD found high rates of anxiety without depression (37%), and that patients with severe, unpredictable wearing on/off fluctuations had significantly higher anxiety scores (Stefanova et al., 2013). Another large scale study found those who experience motor fluctuations were more likely to meet the criteria for GAD than those without fluctuation (Leentjes et al., 2012). Higher unpredictability and severity of fluctuation may increase anxiety and susceptibility to problems such as GAD. One study comparing anxiety levels in on versus off period found higher overall anxiety during off period, and in particular changes in ratings of ‘tranquillity perception’ and ‘concern with the future’ from the State Anxiety Inventory (Caillava-Santos, Margis & Mello Rieder, 2015), suggesting a shift in cognitions and a possible increase in worry. Although this study involved a small sample and no control group, they also found a reduction in performance on some cognitive assessments during off phase (Caillava-Santos et.

al, 2015). Cognitive functioning in PD has been associated with anxiety but not depression, and it is theorised that increased anxiety may lead to higher cortisol levels which then impact on cognitive ability (Ryder et. al., 2010). Another small study but with a control group found that while mild depression was consistent across groups, those that experienced motor fluctuations had significantly higher anxiety levels than those without (Erdal, 2001). A stronger relationship may therefore exist between motor fluctuation and anxiety in particular, as compared to depression. The consistency of this pattern of increased anxiety in those with motor fluctuation make this a prominent finding (Erdal, 2001; Dissanayaka et al., 2010; Leentjes et. al., 2012; Stefanova et al., 2013).

Whether the relationship between motor symptoms and anxiety is a straightforward temporal one remains unclear (e.g. mood changes fluctuate as motor symptoms do). Richards (2001) utilised a diary method to monitor motor and emotional fluctuation in a small sample size of 16. Motor and mood symptoms were not consistently correlated, but where they did, this almost always involved a reduction in mood, increase in anxiety and simultaneous decrease in motor function. Replication with a larger sample of 87 PD patients and 19 spouse controls (Richard et al., 2004), found similar results whereby those experiencing fluctuations were more likely to experience psychological problems and anxiety, but that a simple temporal relationship was not always present (Richards et al, 2004; Leentjens et al., 2012). Both studies utilised unvalidated visual analogue scales, and relied on participants' consistent use of diaries.

Conversely, other studies-again with small sample sizes- have found evidence of a more direct relationship, with improvement in psychological measures and anxiety over time from 'off' to 'on' period (Siemens et. al, 1993, Menza, 1990), correlation of anxiety with a symptom diary (Siemens, 1993), and with onset of dyskinesia (Menza, 1990). There may be a number of reasons for inconsistent findings. These include methodological challenges whereby both motor symptoms and anxiety have been measured with diaries and subjective rating scales, relying on the accuracy and frequency of self-reports, and replication with larger samples is required.

Dyskinesia

Another motor symptom linked to PD treatment is dyskinesia (excess and

uncontrolled movement) occurring during ‘on’ periods. Research so far into dyskinesia and anxiety is limited, but it has been associated with anxiety (e.g. Dissanayaka et al., 2010; Menza, 1990). One study (Leentjens et al., 2012) looking at temporal links between motor symptoms and mood identified a minority of patients who reported anxiety exclusively during episodes of ‘on’ stage dyskinesia. Another study which compared anxiety during on/off phases found lower variation in anxiety scores between on and off periods for those patients with dyskinesia, possibly because dyskinesia is likely to occur in ‘on’ periods so that less relief is provided by the transition from off to on phase (Caillava-Santos et. al., 2015).

Bradykinesia, Akinesia

Bradykinesia is a cardinal symptom of PD and involves slowing of movement, whilst Akinesia is the absence of movement (‘freezing’). These symptoms can affect the ability of patients to vary facial expressions or make spontaneous gestures and hand movements when talking, which can affect social interaction. In a study of social anxiety, PD patients were found to be significantly more anxious and depressed, and more likely to experience social anxiety than healthy controls. Social anxiety was also associated with severity of symptoms and with Bradykinesia (Bolluk, 2010).

Lauterbach, Freeman and Vogel (2003) compared anxiety in a small sample of PD patients and individuals with another movement disorder (Dystonia), and identified panic as particularly common in PD. They found a positive relationship between panic disorder/secondary panic attacks and freezing of gait (FOG) frequency in PD when controlling for individuals’ life prevalence of GAD and Panic. Another, larger study (Lieberman, 2006) found that those with FOG (compared to PD patients without FOG) were more disabled, with more severe "wearing off", dyskinesia and postural instability. They were also more anxious as a group and more likely to experience panic in particular.

Such consistent findings are encouraging, however the cross sectional designs restrict conclusions regarding causation and exact mechanisms. There is supportive emerging evidence however of the impact of anxiety on frequency of FOG. A small but creative experimental study (Ehgoetz Martens et. al, 2014) utilising virtual reality goggles assessed FOG during ‘low anxiety’ (walking a plank at floor level) and ‘high anxiety’ (walking a plank at apparent height). Individuals with PD who experience

FOG were found to freeze more frequently and for longer during the high anxiety condition compared to low anxiety, and more than those who do not typically experience FOG. The impact of anxiety on FOG was most pronounced during ‘off’ phase, indicating a potentially critical period during which motor symptoms and anxiety are more likely, and whereby increased anxiety may exacerbate already problematic symptoms.

A similar study (Pasman et. al., 2011) with the same size sample found increased anxiety, fear, lower balance confidence and poorer perceived stability in the ‘anxiety’ condition. Anxiety and fear also significantly correlated with changes in actual postural control. In this case PD patients were not affected more than controls; this may be due to the PD patients only being tested during their ‘on’ phase, and the exclusion of PD patients taking anxiety medication (and therefore perhaps being a low anxiety group). Exploring FOG and festination (quickening and shortening of gait), Starkstein et al. (2015) found that stress and distress associated with these symptoms appeared to increase the severity of the gait problems and was associated with higher frequency of reported falls. Surprisingly however, and conversely with results described previously, no significant correlations were found between these motor symptoms and *any* psychiatric disorders as measured by the Mini International Neuropsychiatric Interview (MINI). The authors suggest their results may be due to their use of a stringent diagnostic-based instrument (MINI), however studies have found an association between motor fluctuations and anxiety disorders when using the same or similar diagnostic measures (e.g. Dissanayaka, Lauterbach et. al. 2006; Pontone et. al. 2011). Despite some variation in findings, such studies suggest the possibility of a complex interplay existing between motor symptoms and psychological factors, and the potential for significant vicious cycles to develop over time as anxiety deteriorates functioning and perceived confidence.

1.5.4 Cognitive Factors

There is emerging evidence that cognitive and metacognitive variables may be important moderating factors of anxiety in PD. Some research has focussed on the high prevalence rates of worry and GAD in PD samples (Gallagher & Schrag, 2012; Pachana et al., 2013; Stein et al., 1990). One study investigating metacognitive beliefs about worry in PD found that beliefs focusing on the uncontrollability and

danger of worry were associated with elevated levels of distress (Allott et al., 2005). Although involving a small sample size which limited the analysis possible, the results are supported by a larger study (Brown & Fernie, 2014) in which anxiety correlated significantly with: impact on activities of daily living, intolerance of uncertainty, positive beliefs about worry, negative metacognitions about thought uncontrollability and danger, and lack of cognitive confidence. The strongest relationships were with intolerance of uncertainty and beliefs about uncontrollability and danger, with a regression model of these factors predicting 56% of variance in anxiety.

A further regression analysis including only the data from the 93 individuals reporting motor fluctuation, surprisingly found no association between the reported predictability of 'off' periods and psychological distress but again found that negative metacognitive beliefs about thoughts being uncontrollable and dangerous were associated with higher levels of off period distress, even when motor symptoms and intolerance of uncertainty were controlled for (Brown & Fernie, 2014). Off period 'distress' in this research was measured by an un-validated five-point likert scale, which asked patients to rate 'distress during off periods' more generally rather than anxiety. Use of a validated and reliable measure of anxiety related specifically to motor fluctuation and off periods would be beneficial in future research. Brown and Fernie (2014) also acknowledge that the measure of metacognitive style focussed on worry rather than beliefs regarding illness or symptoms. The results regarding metacognitions are strengthened however by their consistency with evidence regarding similar beliefs (e.g. Wells, 2000) and intolerance of uncertainty (Carleton et. al., 2012) in anxiety disorders generally.

The only qualitative study reported here (Wright et al, 2015) utilised the Catastrophising Interview to compare worry content in high and low worriers with and without PD. The number of worry topics was not significantly different between PD and non-PD samples. In terms of content however, while health worries were found to distinguish between high and low worriers within the non-PD group, both high and low worry PD groups reported health worries. An exploration of catastrophic worries however identified that high worriers with PD were more likely to have concerns about relationships, negative self-perception, and death or severe

incapacity. There was also more significant differences in the content of catastrophic worries between the high and low worriers in the PD group than non PD group (Wright et al, 2015). As a qualitative study involving a small sample size, such results cannot be generalised and require replication. They are useful however in this early stage of research in order to highlight potential areas for future exploration- such as the role of catastrophic thoughts in anxiety in PD, and the possibly ubiquitous nature of health concerns in this group.

Illness representations are also an area of growing interest within PD literature but again there has been limited research so far. One study utilising a prospective design explored illness representations in relation to anxiety and depression in PD (Evans & Norman, 2009). Anxiety was found to correlate significantly with beliefs from the Revised Illness Perception Questionnaire regarding: a higher number of symptoms attributed to PD; a cyclical timeline (of disease); more perceived negative consequences of PD, and higher perceived impact of PD on emotions. Two coping styles of avoidance and resignation were also significantly correlated with anxiety (as measured by the Medical Coping Modes Questionnaire). A regression model of the correlated illness beliefs explained 42% of variance in concurrent anxiety, and the addition of coping via avoidance and resignation significantly increased the proportion of variance explained. At 6 month follow up, initial anxiety and belief in personal control (negative relationship) were found to be significant predictors of anxiety (Evans & Norman, 2009). Although involving a relatively small sample this study controlled for a wide variety of other correlates and is rare in including a prospective element. A later study with a larger sample of 81 (Simpson et al, 2013) also explored illness beliefs and identified belief in a psychosocial cause of PD (e.g. caused by stress, conflict etc) as an independent predictor of anxiety in PD, along with poor social support and PD severity.

An area linked to illness beliefs is the concept of Sense of Coherence (SOC) which explores a person's typical viewpoint on the comprehensibility, manageability (e.g. belief in control and problem solving), and meaningfulness of life events and challenges, and is thought to impact on coping skills in ill health. One study (Gison et. al., 2014) has explored SOC in a PD sample (50) and healthy controls (55), and found a significant negative correlation between SOC and emotional distress as

measured by the Health Anxiety and Depression Scale (HADS total). Interestingly, the anxiety subscale had the strongest negative correlation with SOC. Anxiety and Depression were also negatively correlated with quality of life (as measured by the WHO-5 Well-being Index) more powerfully than SOC itself. Diagnosis of the PD participants was confirmed through medical interview and MRI scan. Information on severity and duration of illness was also obtained and individuals with cognitive impairment and high medical comorbidity were excluded. No data on lifetime prevalence of anxiety or depression was obtained, and unfortunately anxiety was not included separately in the final regression analysis performed. A one point increase in SOC was found to predict a 3% decrease in distress (total HADS including anxiety score) and increase QoL by 2%.

1.5.5 Social Support

Social support has been identified as a potential factor influencing anxiety in PD (Ghorbani Saeedian et al., 2014). Simpson et al., (2006) found that positive affect in PD was associated with social factors of more children, employment, and close relationships. Greater reported problems in social support were associated with higher levels of depression, anxiety and stress. As described above, Simpson et al. (2013) also found dissatisfaction with social support, a higher belief in psychosocial cause and a higher severity score to predict anxiety.

Table 1.1: Summary Table of Reviewed Papers

Demographics						
Paper	Anxiety Measure	Sample	Control Group?	Method	Key Findings*	Strengths/ Limitations
Nègre-Pagès, L., Grandjean, H., Lapeyre-Mestre, M., Montastruc, J. L., Fourrier, A., Lépine, J. P., & Rascol, O. (2010).	HADS	n=548	Yes (PD=450, other disorders=98)	Cross sectional	Age, Gender. “Anxiety and depressive symptoms were more frequent in PD patients than in medical control group”. “Patients with anxious symptoms were more frequently female and younger than those without such symptoms.”	Cross sectional, very large sample. Controls with other disorders.
Bolluk, B., Ozel-Kizil, E. T., Akbostanci, M. C., Atbasoglu, E. C. (2010)	Liebowitz Social Anxiety Scale, HARS	n=100	Yes (50 healthy matched controls)	Cross sectional	Social Anxiety and Age: Social anxiety, Anxiety and Depression significantly more common in PD group compared to healthy controls. Social anxiety correlated with depression and age- younger patients more likely to be socially anxious.	Cross sectional but large sample and age & gender matched controls.
Rana, A. Q., Athar, A., Owlia, A., Siddiqui, I., Awan, N., Fattah, A., & Rana, M. A. (2012).		n=314	No	Retrospective chart analysis	Ethnicity: Anxiety was correlated with ethnicity	Retrospective chart analysis
Disease Severity						
Paper	Anxiety Measure	Sample	Control Group?	Method	Key Findings	Strengths/ Limitations
Quelhas, R., & Costa, M. (2009).	HADS	n=43	No	Cross-sectional	“HADS and Short Form-36 Health Survey scores significantly correlated with H&Y stage 2 Parkinson's disease (severity measure), anxiety strong correlation with physical score. Multivariate analysis found anxiety was the strongest predictor of QoL.”	Cross sectional, fairly small sample
Shulman, L. M., Taback, R. L.,	BAI	n=99	No	Cross sectional	“Only 12% of the sample had no non-motor symptoms. Fifty-nine percent two or more non-motor symptoms, and nearly 25% had four or	Cross sectional

Bean, J., & Weiner, W. J. (2001).					more. Increased comorbidity was associated with greater PD severity (P < 001).”	
Manor, Y., Balas, M., Giladi, N., Mootanah, R., & Cohen, J. T. (2009).	Spielberger manual for the trait anxiety	n=69	Yes (With and without swallowing disorders)	Cross sectional	Patients with Swallow Disorders experienced increased anxiety and depression compared to patients without SDs. “In addition, the most anxious patients had significantly increased disease severity and decreased MMSE scores compared with the least anxious patients.”	Cross sectional, self report, controls (without swallow problem). Focus on swallow disorders.
The following papers listed in another main category also add evidence for severity of illness:						
Ghorbani Saeedian, R., Nagyova, I., Krokavcova, M., Skorvanek, M., Rosenberger, J., Gdovinova, Z., ... van Dijk, J. P. (2014). Dissanayaka, N. N. W., Sellbach, A., Matheson, S., O’Sullivan, J. D., Silburn, P. A., Byrne, G. J., ... Mellick, G. D. (2010). Stefanova, E., Ziropadja, L., Petrović, M., Stojković, T., & Kostić, V. (2013). Bolluk, B., Ozel-Kizil, E. T., Akbostanci, M. C., Atbasoglu, E. C. (2010)						
Motor Symptoms						
Paper	Anxiety Measure	Sample	Control Group?	Method	Key Findings	Strengths/ Limitations
Richard, I. H., Frank, S., McDermott, M. P., Wang, H., Justus, A. W., LaDonna, K. A., & Kurlan, R. (2004).	Questionnaires , rating scales and diaries.	n= 106: (87 PD)	Yes- n=19 spouses	Cross-sectional	“Twenty-nine percent of patients had fluctuations in anxiety, 24% motor, and 21% mood; 65% had no fluctuations. Seventy-five percent of patients with motor fluctuations had mood and/or anxiety fluctuations, but 5 subjects reported emotional fluctuations without motor fluctuations. Visual inspection of diaries revealed that not all patients exhibited a temporal relationship between emotional and motor fluctuations.”	Control group small and spouses, cross sectional, use of visual analogue scales
Stefanova, E., Ziropadja, L., Petrović, M., Stojković, T., & Kostić, V. (2013).	Hamilton Anx Rating Scale	n= 360 outpatient cohort with PD Mean age 63. Males 65%	No	Cross sectional	A total of 136 (37.8%) patients with PD manifested only anxiety, whereas 20 patients (5.6%) had both depression and anxiety. All other patients (56.7%) had scores below cut-off either on HARS or HDRS. “Anxiety might be present as an isolated symptom.....and not only as a feature of depression in PD population.” The best predictors for anxiety were motor disability, core depression variable, and female gender. Patients with severe, unpredictable on/off fluctuations had higher HARS scores	Outpatient series- less severe? Cross sectional. Large sample. Ecological Validity.

Richard, I. H., Justus, A. W., & Kurlan, R. (2001).	Hourly diaries for 7 days	n=16, Age 62, all have fluctuation	No	Cross-sectional	“Motor and emotional states were not consistently correlated. When they were correlated, the most frequent pattern was the common occurrence of decreased mood, increased anxiety, and reduced motor function.”	Self report diaries-reliant on accuracy of diaries, small sample size, cross sectional
Caillava-Santos, F., Margis, R., & de Mello Rieder, C. R. (2015).	STAI-State	n=24	No	cross-sectional	Anxiety and depression higher in 'wearing off' stage. In particular, increase in STAI items 'tranquillity perception' and 'concern with future' from on to off period.	Cross sectional, small sample no controls
Dissanayaka, N. N. W., Sellbach, A., Matheson, S., O'Sullivan, J. D., Silburn, P. A., Byrne, G. J., ... Mellick, G. D. (2010).	Mini International Neuropsychiatric Interview (MINI-plus) and State section of STAI	n=79. Male=42. Mean Age= 67.2	No	Cross sectional telephone interview	25% current Anxiety disorder (10% Depression). Severity of PD symptoms, on/off fluctuations and dyskinesias were associated with anxiety. Anxiety disorders contributed to a poor quality of life. Younger patients were significantly more likely to experience anxiety disorder.	Collected LOTS of info to control and test for- detailed & thorough including psychiatric history. Australian sample however, cross sectional. Self-report.
Erdal, K. J. (2001).		n=36 (on-off: n=14, controls: n=22)	Yes (patients without on-off)	Cross sectional	PD with on-off group = significantly higher anxiety levels than PD without. Both groups were mildly depressed.	Small sample, cross sectional. Self-report. But comparison group
Lauterbach, E. C., Freeman, A., & Vogel, R. L. (2003).	SCID	n=56 (28 PD 28 Dystonia)	Yes (Dystonia sample)	Cross sectional	GAD more common “after dystonia onset (i.e., secondary generalized anxiety) while panic attacks developed more commonly after Parkinson disease onset.” “Exploratory analysis in Parkinson disease indicated a relationship of panic disorder and secondary panic attacks to motor block frequency.”	Smallish sample, Cross sectional, self-report but did have controls (dystonia)
Leentjens, A. F. G., Dujardin, K., Marsh, L., Martinez-Martin, P., Richard, I. H., & Starkstein, S. E. (2012).	Hamilton Anx Rating Scale	n=250 (118 with motor fluctuations)	Yes (PD patients with or without motor fluctuations)	Cross sectional	“Patients with motor fluctuations suffer from generalized anxiety disorder more often than patients without motor fluctuations. When patients with motor fluctuations have anxiety symptoms, the majority report that these have no temporal relationship with specific motor states. When there was a relationship, symptoms were almost always related to 'off' periods. However, a minority of patients experience anxiety symptoms during 'on' or "on with dyskinesia" periods exclusively.”	Big sample. Cross sectional, self-report, PD controls without fluctuation.

Lieberman, A. (2006).	Hamilton Anx Rating Scale	n=109	Yes (With/without Freezing of Gait)	Cross sectional	“Patients with FOG were more disabled, had more "wearing off", dyskinesia, leg dystonia, and postural instability. They were also more anxious and more likely to panic. FOG, in many patients, is increased by anxiety and panic.”	Q big sample. Cross sectional, self-report, not matched controls
Ehgoetz Martens, K. A., Ellard, C. G., & Almeida, Q. J. (2014).	Self assessment - in vivo	n=31	Yes- 14 'freezers' 17 'non-freezers'	Experimental	Virtual reality walking plank either low or high anxiety. “Freezers reported higher levels of anxiety compared to Non-Freezers and all patients reported greater levels of anxiety when walking across the HIGH plank compared to the LOW. Freezers experienced significantly more freezing of gait episodes and spent a significantly greater percentage of each trial frozen when crossing the HIGH plank. This finding was even more pronounced when comparing Freezers in their OFF state. Freezers also had greater step length variability in the HIGH compared to the LOW condition, while the step length variability in Non-Freezers did not change.”	Experimental- creative method (virtual reality) control group comparison. But small sample, specific around freezing of gait.
Pasman, E. P., Murnaghan, C. D., Bloem, B. R., & Carpenter, M. G. (2011).	Anxiety and fear of falling rating 0-100 galvanic skin response State anxiety questionnaire and PANAS-X anxiety subscale.	n=30 (PD=14 controls=16) women=3 PD, 7 controls, mean age = 68	Yes Age matched healthy controls	Experimental, small sample. Ecologically valid?? Healthy Controls matched.	“Manipulations of apparent surface height were accompanied by significant changes in self-reported ratings of state anxiety, fear, balance confidence and perceived stability in both PD patients and controls.” “Changes in state anxiety and fear were found to be significantly correlated with changes in postural control across groups”	PD patients only tested during 'ON' phase where anxiety may be less. Also any PD patients taking anxiety medication excluded- so may have been an unusually low anxious PD group.
Menza, M. A., Sage, J., Marshall, E., Cody, R., & Duvoisin, R. (1990).	Profile of Mood States and visual analogue scales	n=10	No	Cross sectional	“Significant changes in mood and anxiety were found to parallel changes in motor fluctuations. One patient rated his moods as consistently improving from the "off" state to the "on" state and finally to the "on with dyskinesia" state, a finding that is consistent with concomitant central dopaminergic changes. All other patients showed moods that improved significantly from the "off" state to the "on" state but then worsened significantly in the "on with dyskinesia" state, a finding that is consistent with the fact that patients feel worse when impaired by dyskinesias.”	Cross sectional, small sample, self-report, non-validated analogue scales - in moment mood ratings
Siemers, E. R., Shekhar, A., Quaid,	Spielberger anxiety state	n=19	No	Cross sectional	“Spielberger anxiety state scores were higher during off periods than on periods....magnitude of change in anxiety correlated with the change in	Cross sectional, small sample, no controls,

K., & Dickson, H. (1993).				repeated measures	[PD Symptom Diary] scores.” “Anxiety trait scores also correlated with disease duration”. Results “support existing data suggesting anxiety can contribute to morbidity in Parkinson's disease and.....that anxiety varies with fluctuations in motor performance.”	tested during on and off phases, used diary - accuracy?
Starkstein, S., Dragovic, M., Brockman, S., Wilson, M., Bruno, V., & Merello, M. (2015).	MINI; HAM-Anx*	n=95	No	Cross sectional	“A linear regression analysis showed that both motor blocks and festination were significantly associated with emotional distress and deficits on activities of daily living. Conversely, there was no significant association between motor blocks or festination and generalized anxiety disorder, panic disorder, agoraphobia, social phobia, or depression. Motor blocks and festination are significantly associated with emotional distress, but no significant associations were found with anxiety or affective disorders.”	Gender bias in sample - more men but did not report whether any effect of gender found. Also used HAI but only on 62 of 95 participants.
Pontone, G. M., Williams, J. R., Anderson, K. E., Chase, G., Goldstein, S. R., Grill, S., ... Marsh, L. (2011).	SCID, panel of psychiatrists, and questions about fluctuation-associated anxiety	n=249, M=166, F=83, Age=66	No	Cross sectional	“Anxiety disorder in 42%, Non-DSM specific anxiety 22%. Thirty subjects (12%) had multiple anxiety diagnoses. Co-morbidity with depression was high; (55% of anxiety disorders comorbid). Fluctuation associated anxiety linked to several anxiety disorder diagnoses, also more common in females, younger onset, longer disease duration, higher l-dopa dose, more complications of therapy. Only fluctuation-associated anxiety was independently associated with HS in the final multivariate model which accounted for 48% of the variance.”	No control group, large sample, cross sectional

The following papers listed in another main category also add evidence for severity of illness:

Bolluk, B., Ozel-Kizil, E. T., Akbostanci, M. C., Atbasoglu, E. C. (2010)

Cognitive Factors

Paper	Anxiety Measure	Sample	Control Group?	Method	Key Findings	Strengths/ Limitations
Brown, R. G., & Fernie, B. A. (2015).	HADS, distress during off period likert scale	n=106 (Fluc=93, control=13). Overall M=73	Yes - fluctuators and non fluctuators	cross-sectional	“Anxiety was not significantly associated with motor symptom severity or cognitive functioning, while metacognitive factors were significantly related to anxiety when controlling for motor experiences of daily living and intolerance of uncertainty. For participants with motor fluctuations, no association was found between predictability of, and distress associated with, off-periods. Metacognitions of uncontrollability and danger significantly related to off-period distress when controlling for	Cross sectional, self-report, metacognitive measure designed for worry not use with health population. Possible change in severity from

		F=33, Age=65			motor experiences, intolerance of uncertainty, and other metacognitive factors.”	assessment to data collection.
Wright, A., Hurt, C. S., Gorniak, S., & Brown, R. G. (2015).	Penn State Worry, Catastrophising Interview	n=39: 20 PD (10 high worry, 10 low), 19 controls (10 high worry 9 low)	Yes- 19 middle aged and older adults (high and low worry)	Cross sectional. Qualitative	“High worriers showed a greater diversity of worry topics” (both groups). “Health worries differentiated high/low worriers” but only in control group- health worries across PD groups. CI: “PD high worriers more likely to have concerns about negative self-perception and death/severe incapacity.”	Sample size limited analysis btw groups, control group participants may have had other chronic health conditions. Qualitative method-subjectivity.
Simpson, J., Lekwuwa, G., & Crawford, T. (2013).	DASS	n=81, Age 66, M=72%	No	Cross-sectional	More dissatisfaction with social support, a higher belief in psychosocial cause and a higher H&Y score predicted greater levels of anxiety.	Cross-sectional, no control group, self-report
Allott, R., Wells, A., Morrison, A. P., & Walker, R. (2005).	HADS	n=44, m=33, Age 68	No	cross-sectional	Maladaptive metacognitive style associated with heightened distress in Parkinson’s disease: “stronger negative beliefs about worry, focusing on its uncontrollability and danger....more likely to report elevated levels of distress”.	male bias, SS drawn from study of hallucinations
Gison, A., Rizza, F., Bonassi, S., Dall’Armi, V., Lisi, S., & Giaquinto, S. (2014).	HADs	n=100 (50 PD, 50 controls)	Yes (Healthy matched controls)	Cross sectional	“A statistically significant positive correlation was found between SOC and Qol and a negative significant correlation between SOC and emotional distress. The multivariate regression analysis confirmed the negative effect of SOC on total emotional distress and positive effect on Qol.”	q big sample and control group of healthy matched Ss. Cross sectional, SOC effect on 'distress' self-report.
Evans, D., & Norman, P. (2009).	HADS	n=58, m=28, f=30, Age 58	no	Cross-sectional & prospective	The illness representations measures (i.e. identity, cyclical timeline, consequences, emotional representations and psychological attributions), identity and avoidance explained majority of anxiety variance. “..final regression equation explained 56% of the variance in time 2 anxiety, with time 1 anxiety and personal control (negative relationship) emerging as significant independent predictors.”	Small-ish sample, self-report, cross sectional, no controls but 6 month follow up (prospective).
The following papers listed in another main category also add evidence for cognitive factors:						

Pontone, G. M., Williams, J. R., Anderson, K. E., Chase, G., Goldstein, S. R., Grill, S., ... Marsh, L. (2011). Anxiety and self-perceived health status in Parkinson's disease. *Parkinsonism & Related Disorders*, 17(4), 249–54. doi:10.1016/j.parkreldis.2011.01.005

Social Support

Paper	Anxiety Measure	Sample	Control Group?	Method	Key Findings	Strengths/ Limitations
Ghorbani Saeedian, R., Nagyova, I., Krokavcova, M., Skorvanek, M., Rosenberger, J., Gdovinova, Z., ... van Dijk, J. P. (2014).	HADs	n=124 (Male 52%, mena age= 68)	No	Cross sectional	“Gender, disease duration & severity, and social support explained 31% of variance in anxiety in younger PD patients but did not contribute to depression explanation.” In older group “model explained 41% of variance in depression [but not anxiety]”. In younger group disease duration plays primary role in anx, in older group poor social support assoc with depression.	Large sample, Cross sectional, self-report
Simpson, J., Haines, K., Lekwuwa, G., Wardle, J., & Crawford, T. (2006).	DASS	n=34 (M=24, F=10), Age=64	No	Cross sectional	“Positive affect is associated with more children, current employment and a greater number of close relationships. On the other hand, higher levels of depression, anxiety and stress were only significantly associated with greater reported problems in social support.”	Cross sectional, small sample, self-report

The following papers listed in another main category also add evidence for social support:
 Simpson, J., Lekwuwa, G., & Crawford, T. (2013).

*For clarity, summaries are largely in the original authors own words; however where direct quotes are not indicated summaries are in this authors words.

1.6 DISCUSSION

Anxiety in PD has only recently been seen as an important topic in its own right. There is no doubt however that anxiety and anxiety disorders are highly prevalent in those living with PD (Gallagher & Schrag, 2012). In fact, the evidence suggests that large numbers of people with PD develop anxiety without depression (Brown et al, 2011), and there are some hints that anxiety may precede later mixed anxiety and depression (Brown et al, 2011), although further research is required. Although some consider anxiety to be a purely biological manifestation of neurological change, the evidence for this is so far weak (Bassetti, 2011; Millan, 2003). This review has explored instead a range of disease, pharmacological and psychosocial risk factors in the development of anxiety in PD, and the potential complex interplay between anxiety and motor symptoms.

Although neurological changes are commonly theorised to increase vulnerability to anxiety in PD, the effect of living with PD from day to day would also appear to be fertile ground for a range of anxiety disorders to develop. It would seem probable that anxiety in PD may develop through several possible routes; one route may be as a direct result of neurological changes (for example that may be theorised to increase an individual's sensitivity to anxiety or impact on their ability to self-regulate); another may be as a direct result of the stress and uncertainty involved in living with PD from day to day (such as anxiety and panic about getting 'stuck' and the personal meaning of symptoms); finally for another group there may be a combination or interaction of both neurological vulnerability and psychosocial factors.

One of the most prominent findings of this review was that those who experience motor fluctuation, a symptom of pharmacological treatment, appear significantly more vulnerable to anxiety and anxiety disorders (e.g. Richards et al., 2004; Erdal, 2001; Dissanayaka et al., 2010; Stefanova et al., 2013), highlighting the importance of good medical management to reduce on/off fluctuation and dyskinesia as much as possible. Further research is needed to explore whether different cognitions or beliefs about PD (that could feed into anxiety) are held in those who experience on/off fluctuations. However most models of anxiety identify beliefs about a perceived

threat as being central; Brown & Fernie's (2015) research on metacognitions in PD generally found that intolerance of uncertainty and more catastrophic worries were present in the more anxious PD group, whilst Stefanova (2013) found that more unpredictable and severe on/off fluctuations led to higher levels of anxiety. Ratings of 'perceived tranquility' and 'concern for the future' have also been found to change significantly along with overall anxiety level between on and off periods (Caillava-Santos et. al., 2015), and provide evidence for a potential shift in cognitions and an increase in threat based interpretations triggered by off symptoms.

The results suggested that anxiety (particularly during off periods) has a negative feedback effect on symptoms, increasing severity and frequency of FOG and falls (Lieberman, 2006; Ehgoetz-Martens et. al., 2014; Pasma et. al., 2011). The mechanisms for this have yet to be confirmed (e.g. are anxious PD patients using maladaptive behaviours to try and avoid/control symptoms that non anxious patients do not) however the findings are commensurate with a cognitive behavioural perspective on anxiety, where increased arousal leads to further symptoms and 'safety behaviours' (such as tensing up or consciously focussing on an action) which can unintentionally increase the risk of the feared event taking place (e.g. increasing freezing/falls). A classic example being the cognitive behavioural panic cycle, (Clark, 1986) whereby anxiety symptoms trigger a catastrophic interpretation (e.g. a heart attack), that results in safety behaviours (e.g. hyperventilating, lying down) that often worsen panic but also reinforce the belief in such symptoms as dangerous and threatening.

It is of interest therefore that symptoms of motor block in PD are associated with panic attacks in particular. Unfortunately no research so far has explored the cognitions experienced by individuals who have panic attacks during motor block, however apparently higher rates of catastrophic worries about death and incapacity in individuals with PD and high anxiety (Wright et. al., 2015) may reflect an increased susceptibility to develop panic-type catastrophic interpretations of their symptoms. Evidence of increased social anxiety in younger PD patients and those with more severe symptoms and bradykinesia (Bolluk, 2010) also requires further exploration; theoretically this may represent an increased sense of threat or fear of

misunderstanding in younger patients, but again no measures of beliefs or cognitions were utilised.

A range of psychosocial factors with the potential to be important in moderating anxiety in PD were identified. Unsurprisingly, this included levels of (and satisfaction with) social support (Simpson, Lekwuwa & Crawford, 2013; Simpson et al, 2006), a finding supported by research into other health conditions (e.g. MS; Costa, Sa & Calheiros, 2012, Diabetes; Strom et. al., 2012). Certain metacognitive beliefs about the danger and uncontrollability of thoughts and worries appear important to anxiety in PD (Allott et al, 2005; Brown & Fernie, 2015) as they are more generally in anxiety (e.g. Wells, 2000) and in one study such metacognitive beliefs predicted off period distress (Brown & Fernie, 2015). Wider views about the predictability, manageability and meaning of life events (sense of coherence) have also been found to predict anxiety in PD (Gison et. al., 2014). There is some evidence of a high frequency of health worries within PD (Wright et. al., 2015) which warrants further investigation, especially since health anxiety has been found to be common in other conditions with fluctuating and unpredictable symptoms. In a diabetes sample, those with high health anxiety tended to be younger, female, or recently diagnosed, and anxiety was associated with poorer adherence and self-care, and lower quality of life (Claude, Hadjistavropoulos & Friesen, 2014). In MS, health anxiety has been associated with less adaptive coping styles, increased disability and GAD (Kehler & Hadjistavropoulos, 2008), as well as lower quality of life and increased misinterpretation of sensations as MS symptoms (Hayter et. al., 2016).

Illness related beliefs have been extensively studied in other chronic health conditions (e.g. Sharloo & Kapstein, 1997) and are just starting to be explored in this context. Illness representations involving a psychosocial cause (Simpson et al 2013), low personal control and serious negative future consequence (Evans & Norman, 2009) have been linked to higher anxiety levels in PD, as have maladaptive coping strategies of avoidance and resignation (Evans & Norman, 2009). Such findings are again comparable to wider cognitive behavioural anxiety literature and theory, where both meaning/appraisal and safety behaviours (such as avoidance) are at the core of many evidence based anxiety models (e.g. panic (Clark, 1986); health anxiety (Salkovskis, Warwick & Deal, 2003)). Early evidence of the possible role of

intolerance of uncertainty, catastrophic worries, and concern for the future (Brown & Fernie, 2015; Wright et. al., 2015) also fit with the cognitive behavioural GAD model which highlights intolerance of uncertainty as a key underlying factor in the development of chronic worry (Dugas et. al., 1998).

Over the longer term, avoidance strategies such as those found by Evans & Norman (2009) are conceptualised to strengthen anxiety related beliefs, but also to erode an individual's confidence and quality of life over time, and diminish their sense of self control; in other words the solution becomes the problem. As would be predicted, individuals with PD and high anxiety have been found to report lower levels of activities of daily living (ADLs) (e.g. Dissanayaka, 2010, Bolluk, 2010), and lower quality of life (e.g. Quelhas et. al., 2009), however due to the cross sectional nature of current research, the direction of this relationship is not yet confirmed.

1.6.1 A cognitive behavioural model of anxiety in PD

Below (Fig.1.1) is presented a hypothetical model of anxiety in PD, which attempts to synthesise the main review findings, as well as propose some mechanisms through which anxiety in PD may develop and be maintained. The top section of the model provides a visual summary of the factors that may increase an individuals' vulnerability to anxiety, incorporating demographic, disease, and psychosocial factors. The lower part of the model is based on Clark's Panic model (Clark, 1986) and attempts to apply cognitive behavioural theory to anxiety in PD, focussing on the role of appraisal/cognition and maladaptive coping/safety seeking behaviour. The model is illustrated with two examples based on clinical experiences: (1) off period anxiety/panic regarding fear of freezing and getting 'stuck' in a public toilet, and (2) anxiety regarding the experience of tremor in a social situation (a meal out). A great proportion of individuals with PD will experience symptoms such as motor block and tremor, however how they conceptualise and respond to the symptoms will vary considerably. It is likely that it is the attributions a person gives to those symptoms which determines the level of anxiety experienced and coping responses utilised.

The hypothetical model offered here highlights the development of negative beliefs and appraisals of situations or triggers as threatening and uncontrollable (e.g. 'I won't be able to control my tremor and will drop/spill my food') leading to high

levels of anxiety, which in turn increase both PD symptom (e.g. tremor) and anxiety symptom severity and encourage even more catastrophic interpretations ('They think I'm a drunk and a fool'), leading to maladaptive coping through avoidance, withdrawal or safety seeking behaviours (e.g. gripping utensils and focusing all attention on trying to suppress tremor). This combination of anxiety, increased symptoms and avoidance may then feedback into a strengthening belief in PD symptoms as threatening and uncontrollable, risking resignation, reduction in wider quality of life, and withdrawal from valued activities. If such a progression is accurate, then this may also support the concept of depression in PD emerging over time and preceded by anxiety symptoms (Brown et. al, 2011)

Such a cycle could help conceptualise the development of a range of anxiety disorders in PD such as panic, social anxiety and health anxiety. The hypothetical model described here is perhaps more suited to conditions where the interaction with physical symptoms is more pronounced 'in the moment'. It may therefore be less effective at conceptualising GAD in PD. Despite this, the vulnerability factors identified remain relevant, and considering the links between motor fluctuation and increased risk of GAD, off period symptoms may still trigger catastrophic thoughts about the *future* e.g. of death and incapacity, which then feed into safety behaviours such as the perceived need to worry *more* about the future to avoid or prepare for feared outcomes (offering a conceptualisation of off period worry with similarities to that of Brown & Fernie, 2014).

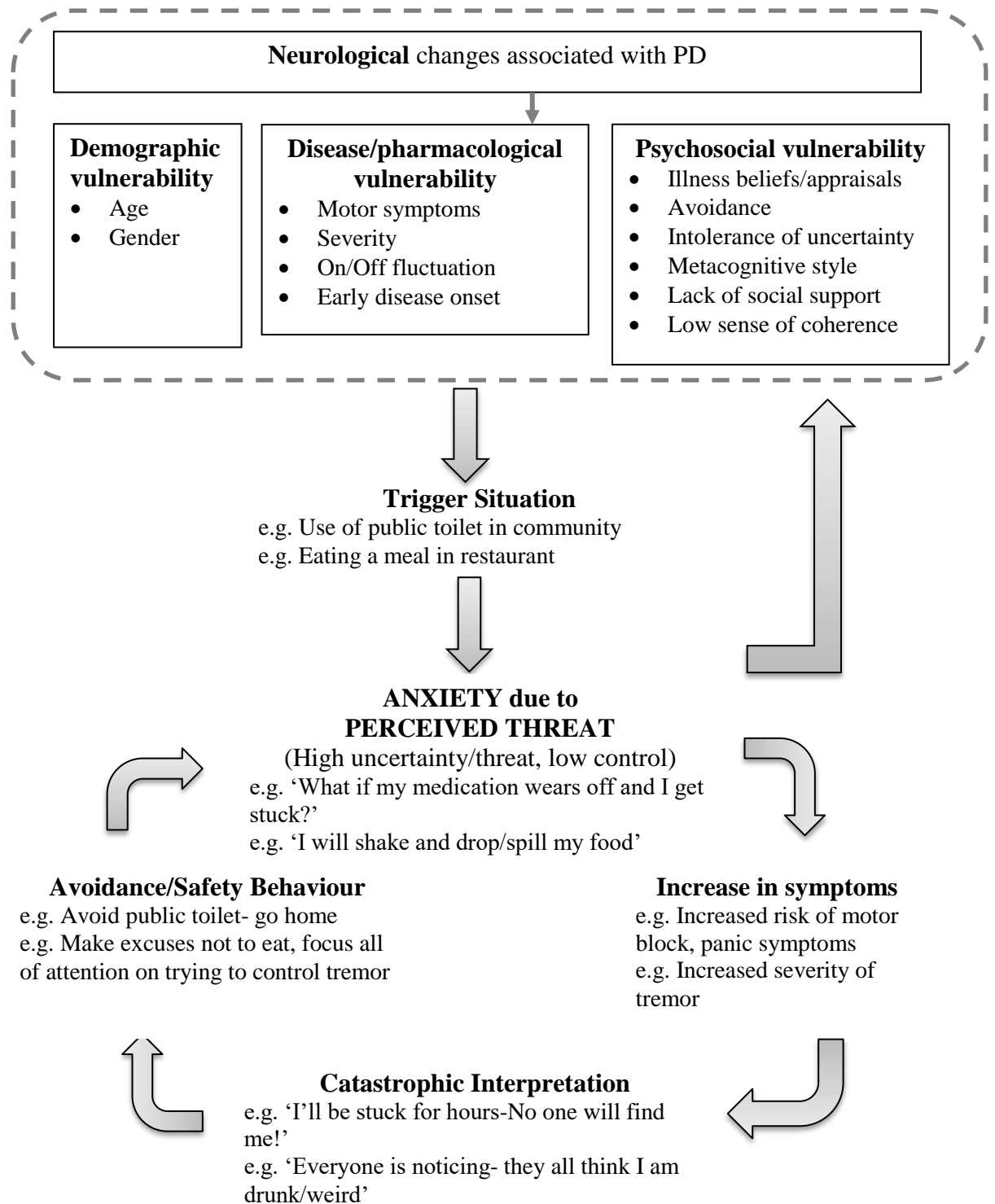


Fig. 1.1: Hypothetical Cognitive Behavioural Model of Anxiety in PD

1.6.2 Limitations

Research focusing on anxiety in PD beyond just the biomedical perspective has only recently started to increase, and a number of methodological considerations have been highlighted by this review. These include the predominance of cross-sectional designs, wide variation in sample sizes, and a lack of validated PD-specific anxiety measures. Such limitations within the wider literature also restrict the strength of conclusions that can be drawn from this review, due to a lack of randomised controlled studies, and the wide variety of anxiety measures utilised making direct comparisons difficult. Future longitudinal research with specifically designed and validated anxiety measures (for example that incorporate variation in on/off phases) is required. Although effort was made to conduct the search in a systematic way, one of the aims of this narrative review was to generate a rationale for a psychological framework for anxiety in PD, and an element of reviewer bias is therefore possible. Although developed from currently available research and based on well-evidenced cognitive behavioural models (e.g. Clark, 1986), many aspects of the model of anxiety in PD presented here would benefit from a great deal more research.

1.6.3 Future Directions & Conclusions

Potential areas for future research include further exploration of the appraisal and meaning of motor symptoms for individuals, and behavioural reactions to symptoms (such as avoidance and safety behaviours) which likely feed back into anxiety and significantly reduce the quality of life of individuals living with PD. Another area of potential interest could be exploring not just risk factors but also potential protective factors that may reduce the psychological impact of PD.

PD is a progressive condition which, along with its treatment, incorporates certainty about degeneration combined with significant variability of day to day functioning and uncertainty about the speed of deterioration. Examination of the available evidence has highlighted the significant psychological burden of both PD and its medical treatment. A number of possible demographic, disease/pharmacological and psychosocial factors are identified that may increase the risk of anxiety in PD, and a cognitive behavioural model of the complex interplay of anxiety with motor symptoms is offered. It is hoped this conceptualisation will encourage further application of psychological theory to

anxiety in PD, and in turn support the utilisation of well-grounded psychological treatments, adapted as required to incorporate the individual challenges and complications of PD. Although further research is required, CBT has been identified as a potentially effective psychological approach to anxiety and depression in PD in the few randomised controlled trials that have so far been completed, and compares favourably to evidence for pharmacological interventions (Yang et. al., 2012; Armento et al., 2012). If the perspective on anxiety in PD were to shift from one of diagnostic overshadowing to a more psychologically informed one, it is likely that the current problems with under-recognition (Dissanayaka et. al., 2014) and lack of treatment (Pachana et. al., 2013) would improve and potentially benefit a wide range of PD patients.

1.7 ACKNOWLEDGEMENTS: Acknowledgement goes to Dr James Gregory (University Supervisor) and Dr Leon Dysch (External Supervisor) for their considerable help and support in completing this review.

1.8 CONFLICTS OF INTEREST: The authors have no conflict of interest to report.

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The impact of an OCD-UK Professionals Conference Day on Therapist beliefs about OCD.

(Service Improvement Project, Oct 2016)

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Word Count: 3,897

Supervisors: Prof Paul Salkovskis, Dr Josie Millar (University of Bath), Ashley Fulwood (OCD-UK).

Proposed Journal: The Cognitive Behavioural Therapist. This journal has an interest in publishing research relating to the training of mental health practitioners.

2.1 ABSTRACT

This paper outlines the development and evaluation of a professionals training day focussing on understanding and treatment of Obsessive Compulsive Disorder (OCD). The training included talks from experts in OCD, and was organised by OCD-UK (a national service-user led OCD charity) with consultation and input from the researcher . The training day was developed in an attempt to target common unhelpful therapist beliefs about OCD. An evaluation of the day found that attendees' confidence in understanding and treating OCD increased significantly from pre to post training. The training was also found to significantly increase attendees' optimism about the treatment of OCD, and significantly decrease beliefs of OCD being a biological (rather than psychological) problem. Implications and links to relevant literature are considered.

2.2 INTRODUCTION

OCD-UK is a national charity which prides itself on being run *by* people with experience of Obsessive-Compulsive Disorder (OCD), *for* people with experience of OCD. OCD-UK envisions a time and place where “everyone affected by OCD should receive the most appropriate and the highest quality standards of care, support and treatment” (OCD-UK Website, Retrieved from: <http://ocduk.org/about-ocduk>, 05/01/2015).

Historically the OCD-UK Annual Conference has been designed primarily for people with experience of OCD and provides information and support, as well as an opportunity to voice concerns and experiences. OCD-UK members have frequently reported negative experiences of treatment to the organisation in support groups and online forums (A. Fulwood, Personal communication, 8/05/2014), some of which have also been highlighted by the limited empirical research in this area. Complaints included therapists taking intrusive thoughts as indicators of actual risk to others (e.g. Glazier et al., 2013; Veale et al., 2009); minimising the challenges associated with dropping OCD rituals, or appearing pessimistic about their chances of recovery (Stobie, 2009). OCD-UK therefore planned an additional day for professionals at their 2014 Conference, with the aim of sharing new advances in the understanding and treatment of OCD, combating unhelpful beliefs about OCD, and emphasising evidence based treatment supported by decades of quality research. OCD-UK’s stance as a strong advocate for individuals with personal experience of OCD, puts it in a unique position to educate and promote best practice whilst retaining a focus on personal stories about OCD and its impact on people’s lives. We were asked to support OCD-UK in this endeavour through consultation on the content of the day, and through evaluation of the impact of the training on a group of mental health professionals in attendance.

People with OCD often experience a long delay from symptom onset to effective treatment due to professional misidentification (Glazier et al, 2013) or reluctance to disclose symptoms (Torres et al, 2000). People experiencing OCD are often burdened by feelings of shame, embarrassment, and sadly justified fears of aggressive/sexual obsessional thoughts being taken at face value (Glazier et al, 2013; Veale et al., 2009). The recommendations of the National Institute for Health and Clinical Excellence (NICE) for OCD even refer to intrusive thoughts of harm to others frequently being

“misinterpreted as risk” (National Collaborating Centre for Mental Health, 2005: p. 15). It is therefore vital that people with OCD who ask for treatment are seen by someone with appropriate training, who understands the condition well, and does not confirm their fears about how they will be perceived.

A 2013 audit suggested that the majority of people experiencing OCD *are* offered treatment in line with NICE guidance (National Audit, 2013). However the same audit also showed high rates of drop out of people with OCD from treatment, and a significant ‘treatment gap’ remains in the UK between the true prevalence of OCD and the proportion of individuals in treatment (Kohn et al, 2004).

A previous study of mental health professionals’ beliefs found that OCD was rated as the most ‘difficult-to-treat’ anxiety disorder, the problem most likely to relapse, and the least successful in their experience of treatment (Stobie, 2009). Empirical evidence contradicts these perceptions however with a review of treatment trials showing CBT to be more effective for OCD than for many other anxiety disorders (Hofmann & Smits, 2008). Even the authors of the above review reported surprise, stating that the results “counter the general notion that OCD is the most treatment-resistant anxiety disorder” (Hofmann & Smits, 2008, p.629).

CBT and Exposure and Response Prevention (ERP) for OCD have the potential to be highly effective. However negative ‘general notions’ and unhelpful beliefs as described above may lead to therapists lacking in confidence/optimism, and lead to poor adherence to evidence based treatment (Shafran et. al., 2009), risking ‘therapist drift’ and impacting on treatment outcomes (Waller, 2009).

Social psychology research has shown that negative group beliefs toward a health problem can reinforce a “collective stigma that affects whether and how individuals seek care and how communities.....prioritize and deliver care to persons with this condition” (Mendel, Meredith, Schoenbaum, Sherbourne, & Wells, 2008, p.27).

Evidence however suggests that targeted training of professionals can improve outcomes and that even short training interventions can shift beliefs and expectations (DeRubeis et al., 2005; Stobie, 2009).

2.3 RESEARCH QUESTIONS

2.3.1 Consultation

- What aspects of OCD treatment are not well understood by professionals (from the perspective of OCD-UK members and of professionals)?
- How could the professionals' day be used to address this?

2.3.1 Evaluating the conference

- Have attendees increased their confidence in understanding OCD and how to treat it?
- Do attending professionals show a shift in beliefs about OCD and its treatment from pre to post conference day?
- How successful/useful was the day generally, and what changes or improvements do attendees suggest for the future?

2.4 METHOD

2.4.1 Consultation

Consultation on the proposed content of the Professionals Conference day was undertaken with members of OCD-UK, people with personal experience of OCD and mental health professionals. Regular one to one and small group meetings with members of OCD-UK (in person and via Skype) were used to discuss proposed topics, share relevant feedback and maintain regular contact.

As the OCD-UK members' forum represented an important 'safe place' for people with personal experience of OCD, it was agreed that it would be inappropriate for the researchers to join and post messages. However, a member of OCD-UK who was closely involved in the project and in the development of the conference, and who was also a known moderator of the forum posted a forum topic. This requested feedback from OCD-UK members on what they felt was most important for therapists to know about OCD or what they wished their therapist had known. It was made clear to OCD-UK forum users that any comments would be anonymised completely and sent to the researcher to be summarised and used to develop the OCD-UK professionals' day.

Mental health professionals were approached by the researcher by emailing previous attendees of an OCD-UK event for therapists, and also posting in online forums for

trainee psychologists and IAPT workers. Professionals were asked the following questions:

- What would you want to see at an OCD-UK health care professionals' conference day? E.g. content of talks, workshops, topics etc.
- From your experience, are there any aspects of the nature or treatment of OCD that you feel are less well understood by yourself or other health care professionals?
- What do you think would be the possible benefits of OCD-UK running a conference day for healthcare professionals?

Feedback was again anonymised, summarised and sent to OCD-UK to inform and help shape the content and format of the conference day.

2.4.2 Conference Day

Participants

Participants were recruited from attendees of the OCD-UK Professionals Day Conference in Nottingham. Fifty-two people attended the conference, and thirty-five agreed to take part in the study.

Measures

Conference Day Evaluation Questionnaires

Pre and Post evaluation questionnaires were designed through a process of consultation with key members of OCD-UK involved in the planning of the conference.

The priority for OCD-UK was to:

- Measure the overall impact and success of the new conference day
- Gather feedback from attending professionals on the content/topics offered
- Assess whether the day positively influenced professional's confidence in understanding and treating OCD.

In order to meet these goals, a range of general feedback questions and specific ratings were included. Once draft pre and post questionnaires were developed, these were sent to OCD-UK for feedback. Some changes were made on the request of OCD-UK, including a question about how welcomed the attendees felt, and how they had heard about the day.

The questionnaires were then finalised and distributed to attendees as part of their welcome pack on arrival at the Conference. Attendees were asked to read the information sheet and sign the consent form if they were happy to take part (see Appendix). Participants were prompted by the OCD-UK speakers to complete their pre questionnaire at the start of the day and prompted again to complete their post questionnaire at the end of the day.

Pre Questionnaire

The Pre- Questionnaire consisted of an initial question asking participants to select their role from a list of options e.g. CBT therapist, counsellor, etc. This was followed by a question asking them to use a Likert scale to rate their previous *experience* of working with individuals with OCD (from very experienced (4), quite, not very and not at all experienced (1)). Five further questions used a similar Likert scale (very (4), quite, not very, not at all (1)) to rate how *confident* they currently felt about:

1. Working clinically with someone experiencing OCD.
2. What the evidence-based treatments for OCD are.
3. Assessing risk in OCD e.g. thoughts of harming others.
4. Having some insight into what it feels like to experience OCD.
5. Involving family/carers in the treatment of OCD.

These were followed by a YES/NO question about whether they had any personal experience of OCD, and two open ended questions asking how they heard about the conference, and what their expectations for the day were.

See Appendix I for full copies of the pre and post questionnaires.

Therapy Beliefs Questionnaire

OCD-UK were also keen to adopt a more in depth method for evaluating the day's impact on professionals. For this reason the 'Therapist OCD Therapy Relevant Beliefs Scale', (Stobie, 2009) was included as a part of both the pre and post questionnaires. This questionnaire assesses professionals' *beliefs* about OCD and its treatment. The Therapist OCD Therapy Relevant Beliefs Scale (TRBS) consists of 21 items and has been found to include six factors; Optimism; OCD as a Biological problem; Poor patient progress due to past life problems; OCD as a difficult problem with insufficient therapy; Perceived poor past therapy; OCD as a chronic problem intrinsic to personality (Stobie, 2009).

Post Questionnaire

The post questionnaire included Likert style questions asking attendees to rate the conference day *content* (Very Good (4), Quite Good, Not Very Good, Not at all Good (1)) on:

1. Interest of topics
2. Relevance to your role/work
3. Helpful for developing therapeutic skills
4. Positive impact on your feelings about OCD treatment

The five *confidence* ratings from the Pre Questionnaire were then repeated to assess for any change in confidence.

Attendees were also asked to rate how well the day met their expectations (Very Well, Quite Well, Not Very Well, Not at all Well) and had the opportunity to expand on their answer with comments. Two other open questions asked what attendees would like to see in future professionals' conferences, and how the OCD-UK team had made them feel welcomed. The TRBS was again included in order to assess any changes in OCD therapy relevant beliefs from pre to post conference day.

Follow Up Questionnaire

Follow up of professionals was conducted three months following the conference (end of January 2015). The aim of the follow up was to assess for the maintenance of belief changes over time, or any further modification/reversal of beliefs about OCD since the conference. Those participants who had given permission in the consent form were contacted via the email address they provided, and asked to follow a link to an online follow up questionnaire. Professionals were also asked to once again complete the confidence ratings, and were asked whether they felt they had made any changes in the treatment for OCD that they provided following the conference, and if so, what they were doing differently.

2.5 RESULTS

Participants

The professionals' day conference was aimed at those working therapeutically with individuals with OCD, and included therapists from a range of training backgrounds. The conference day had fifty-two attendees, which was significantly lower than originally predicted to attend. Thirty-five of the attendees filled in both the pre and post questionnaires on the day. The largest group of participants were 'high intensity therapists/CBT therapists', but counsellors, trainee therapists and students also took part. See Fig. 1 for graph of participant roles.

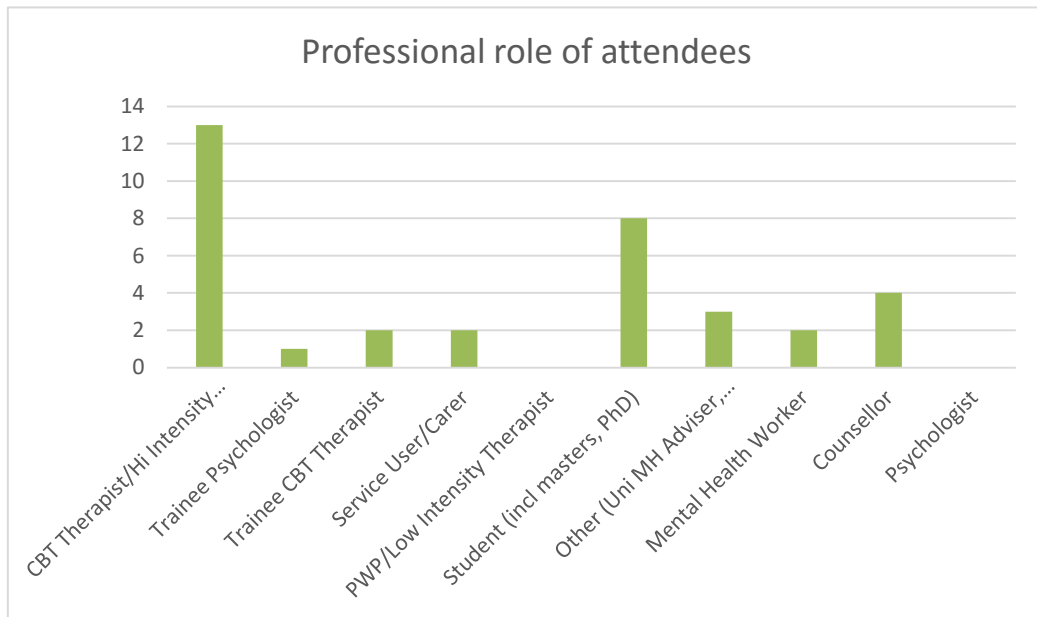


Fig. 2.1: Frequency graph showing spread of participants' professional roles.

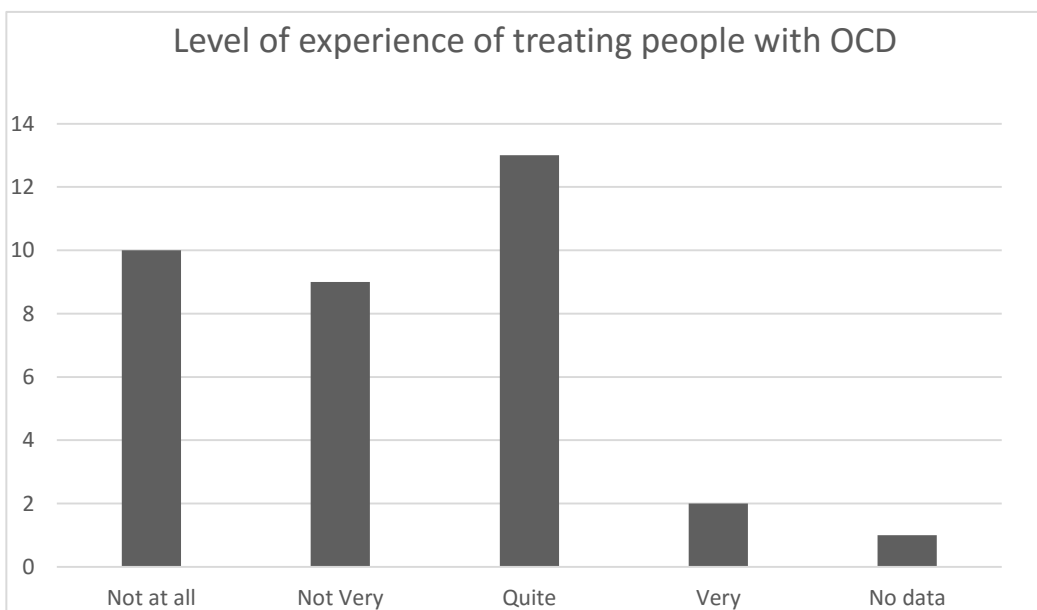


Fig. 2.2: Frequency graph of participant ratings of experience treating OCD

Twenty-one of the attendees reported no personal experience of OCD, but six reported some personal experience. Two of the attendees described themselves as also being service users/people with personal experience or carers. The level of experience of participants in working with people with OCD varied, likely due to variations in roles and length of time working clinically. The majority of individuals who reported no experience were students. Fig. 2 above shows the level of reported clinical experience of participants.

2.6 ANALYSIS

2.6.1 Confidence Ratings

The five clinician confidence ratings (working clinically with OCD, knowing evidence based treatments, assessing risk in OCD, working with families, and having insight into what it feels like to experience OCD) were checked for reliability and were found to have a good internal consistency (Cronbach's $\alpha = .89$). A total confidence rating from these five areas was calculated and compared from pre to post using paired sample t-tests. The results showed that clinician's overall confidence in the above aspects of understanding and treating OCD had increased significantly from the start to the end of the Conference day (pre: $M=7.47$; $SD=3.65$; $N=30$; post: $M=11.10$; $SD=2.26$; $N=30$), $t(29) = -7.72$, $p < .001$).

As well as the combined confidence ratings increasing significantly, further paired samples t-tests showed that participants' confidence also increased significantly in each of the individual five areas of OCD understanding/treatment. See Table. 1 for means standard deviations and t-test results showing change in each confidence rating from pre to post conference.

2.6.2 Beliefs Data

The beliefs data was used to compute the six factors of the OCD therapy relevant beliefs scale (TRBS) (Stobie, 2009). One factor (Optimism) was altered slightly from that used in Stobie (2009) as question 20 was not included in calculating this factor. This was due to a relatively weak negative loading of only $-.41$ found in the original factor analysis (Stobie, 2009).

Data were analysed to determine whether the OCD TRBS factor scores changed significantly from pre- to post-Conference. A repeated measures ANOVA was completed, with Time (Pre/Post) and the six Beliefs Factors as the within-subjects factors. Mauchly's test of sphericity was found to be significant for the interaction of Time by Beliefs Factor, so the Greenhouse Geiser calculation was used for this interaction.

A repeated measures ANOVA revealed a main effect of Subscale (Belief Factor) whereby the ratings for each factor differed significantly, $F(5, 110) = 112.59, p < .05$, and a significant interaction between pre- and -post conference changes on the Beliefs Factors scores, $F(5, 110) = 3.64, p < .05$. The main effect of Time was not significant.

As the interaction was significant, this was further explored with paired sample t-tests. These multiple comparisons indicated that two Beliefs Factors has changed significantly from pre- to post Conference, whereby Factor 1: Optimism had *increased* significantly (pre: $M=80.14; SD=13.11; N=24$; post: $M=84.84; SD=11.60; N=24$), $t(23) = -3.38, p = .003$, and Factor 2: OCD as a Biological Problem had *decreased* significantly (pre: $M=-18.80; SD=14.54; N=32$; post: $M=-25.73; SD=11.87; N=32$), $t(31) = 4.04, p < .0001$. Fig.3 shows the change in optimism factor and OCD as biological factor (transformed into belief in OCD as psychological to avoid negative values).

Changes in the remaining four Beliefs Factors (Poor patient progress due to past life problems; OCD as a difficult problem with insufficient therapy; Perceived poor past therapy; OCD as a chronic problem intrinsic to personality) were not found to be significant. See Table.2 for details of mean changes and statistical outcomes for all six belief factors. New variables of total change in Beliefs Factors from pre- to post Conference were computed and again included in a Repeated Measures ANOVA. Mauchly's test was again significant. The results confirmed the previous findings whereby there was a main effect of Subscale (Belief Factor changes); $F(5, 110) = 3.64, p < .05$. A correlational analysis was completed to assess for correlation between the two significant Beliefs Factors (Optimism and OCD as Biological). No significant correlation was found, identifying that the two Belief Factor changes represented separate effects.

Table 2.1: Table of mean pre and post confidence ratings and analysis results.

Confidence rating	N	Mean	SD	Mean	SD	t	P
		Pre		Post			
Working Clinically	31	1.29	.90	2.06	.68	-6.99	.000**
Evidence Base	34	1.53	.82	2.44	.56	-6.41	.000**
Risk Assessment	34	1.47	.96	2.15	.61	-5.77	.000**
Insight into experience	34	1.82	.72	2.47	.56	-4.45	.000**
Involving Family	32	1.25	.95	1.91	.64	-4.72	.000**

Note: **= significant to $p < .001$

Table 2.2: Table of mean change and statistical outcomes for OCD beliefs factors.

Belief Factor	N	Mean	SD	Mean	SD	t	P
		Pre		Post			
Optimism	24	80.15	13.11	84.84	11.60	-3.38	.003*
Biological	32	-18.80	14.54	-25.73	11.87	4.04	.000**
Past Life Problem	24	34.48	22.67	29.33	24.63	1.18	.252
Insufficient Therapy	24	45.90	25.00	49.72	27.30	-1.24	.229
Poor Therapy	24	34.17	18.80	39.26	23.71	-1.61	.121
Chronic Problem	24	17.15	14.42	11.31	12.77	2.01	.056

Note: *= statistically significant to $p < .01$ **= $p < .001$

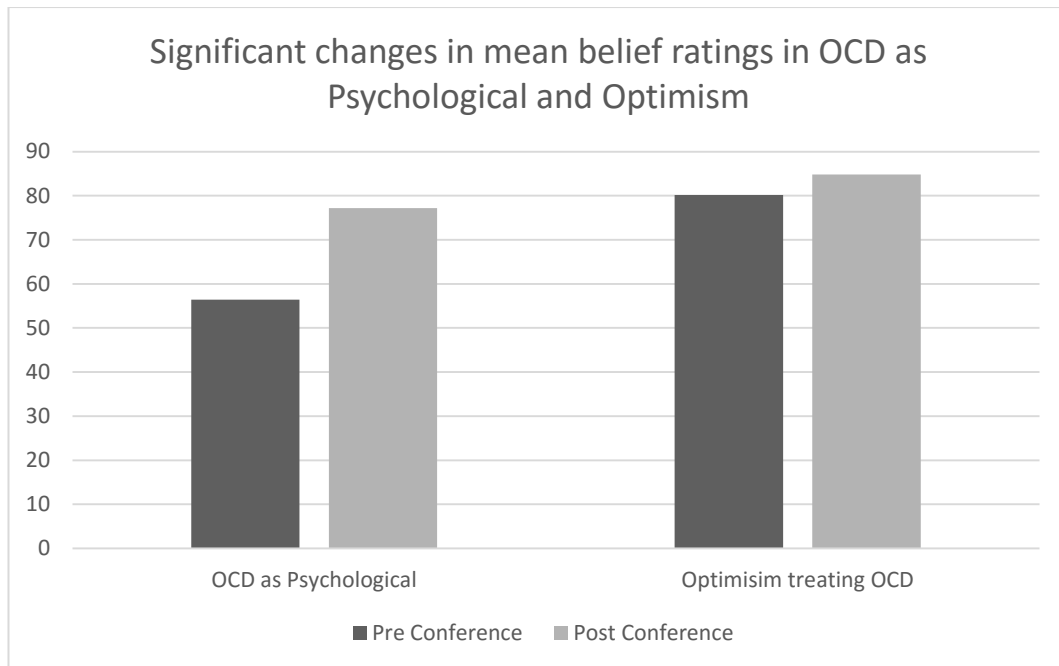


Fig.2.3: Mean pre and post conference belief in OCD as psychological and optimism.

2.6.3 General Conference Feedback

Overall ratings of the conference day were extremely positive. As discussed earlier, attendees were asked to rate the content of the day on interest of topics; relevance to role/work; helpfulness for developing skills; positive impact on feelings about OCD treatment. The vast majority (96%) of overall ratings for the content of the day were either ‘very good’ or ‘quite good’.

A frequency graph of ratings in each four areas can be found in Fig. 5, below. The day also appeared to successfully meet the expectations of attendees, with 83% of respondents indicating that the day met their expectations ‘very well’, and the remaining 17% ‘quite well’.

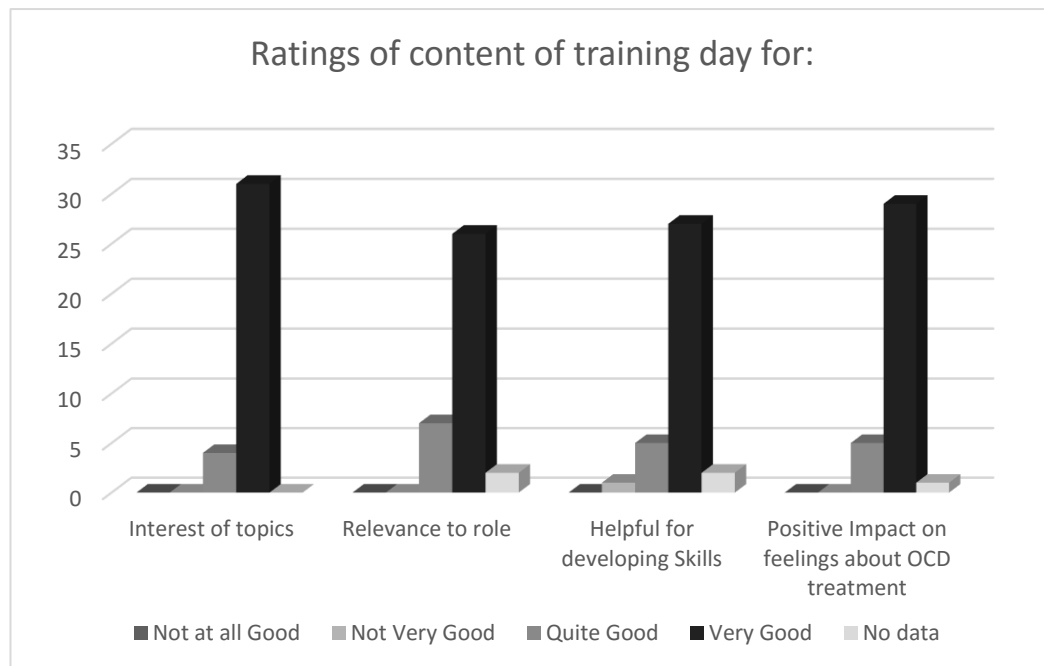


Fig.2.4: Frequency graph of ratings of conference content

2.6.4 Follow Up

Unfortunately very few professionals completed the follow up questionnaire (n=9), possibly due to technical issues accessing the form from some trust computers, which was not identified until after the final reminder was sent. This very poor response rate of follow up questionnaires meant that the data could unfortunately not be analysed statistically, however those who did respond continued to express positive comments about the day, and 8/9 stated that they had modified their treatment approach of OCD following the conference.

2.7 DISCUSSION

Although on paper people with OCD are offered appropriate treatment, something about how this is undertaken in practice appears to be leaving many feeling like their problems are not well understood. One potential explanation for this discrepancy is that many mental health professionals may hold biases and unhelpful beliefs about OCD and its treatment, which could negatively effect therapeutic alliance, adherence to evidence based treatment, and subsequent outcomes.

This research has focussed on a one day professionals conference provided by national charity OCD-UK, inspired by reports of unhelpful treatment experiences from people with personal experience of OCD. Consultation with OCD-UK; professionals; and people with personal experience of OCD helped to shape the topics provided on the day,

and the event was also evaluated with questionnaires developed by the researchers in consultation with OCD-UK.

2.7.1 Strengths & Limitations

Some limitations of the study are that although the beliefs questionnaire has been found to be reliable and valid in a patient format, the therapist format utilised has not yet been validated. Validation of this measure would be a potentially useful area of future research. Another limitation is a lack of useable follow up data, which prevents us from commenting on the longer term impact of the day. This is however something that OCD-UK could pursue in future Professionals Conferences. There is also the potential for expectation effects whereby individuals may have felt pressure to report a change in beliefs or to rate the day highly. However, these professionals had also paid money to attend the event, and therefore may be more likely to be honest and open should they have found the day to be less helpful. Finally, there was also a group of students who attended the day; and it is not clear if they were currently working therapeutically with individuals with OCD- however such students may in the future go on to work clinically, and any change in beliefs obtained is still likely to benefit individuals with OCD. Strengths of this research include the collaborative nature of the project with a service user group. The conference also represented an opportunity to get an insight and ‘snapshot’ into current beliefs and biases held by mental health professionals about OCD, and has provided a more interesting and in-depth evaluation of the day than a basic feedback form would have been able to.

The results found that attendees of the conference day reported significantly increased confidence ratings post conference in all of the five factors relating to understanding and treatment of OCD, such as confidence in knowing the evidence based treatments for OCD, and in completing risk assessments of intrusive thoughts in OCD. Importantly, participants also reported significantly increased confidence in having insight into the experience of OCD, and it is highly likely that the conference talks offered by people with personal experience played an important part in this, enriching the training day in a way that may not be the case in many non-service user led training events.

Similarly to the results of Stobie (2009), the professional sample were found to hold varied beliefs about OCD, some of which are likely to be unhelpful in maximising

treatment effectiveness, such as belief in OCD as a largely biological rather than a psychological problem, or one that is chronic and linked to an individual's personality. Encouragingly, even a one day conference day appears to have shifted some of these beliefs to a more positive stance, with statistically significant changes found in terms of an increase in optimism and decrease in belief in OCD as biological.

These results are encouraging in suggesting that relatively brief training interventions can significantly alter professionals' confidence and understanding of some of the more frequently troublesome areas of OCD treatment, such as intrusive thoughts unfortunately being viewed as evidence of actual risk (Glazier et al, 2013), as well as ensuring a good understanding of the current evidence base to avoid therapist drift and increase likelihood of successful treatment (Waller, 2009).

The conference evaluation suggested that professional attendees highly regarded the conference day, with excellent ratings of the day and over 95% of attendees rating the day as either 'good' or 'very good' overall.

This novel OCD-UK event was successful in significantly impacting both confidence levels and unhelpful beliefs about OCD and its treatment in a sample of mental health professionals. The feedback has been passed on to OCD-UK, who plan to run another professionals conference on a bigger scale in Autumn 2016. OCD-UK have requested to again utilise the beliefs and outcome questionnaires developed here to monitor change and evaluate subsequent professionals' conferences, as well as to highlight areas of beliefs about OCD that they might not currently be addressing. This study also highlights the important role that service user groups could and *should* play in leading the way in the training and continuing development of mental health professionals, with uniquely engaging talks about personal experiences of OCD undoubtedly enriching the conference experience for all involved.

2.8 SUMMARY OF MAIN POINTS

1. A sample of mental health professionals were found to have varied beliefs about OCD, some of which were unhelpful and may have negatively impacted on treatment.
2. A one day training event was found to significantly increase professionals' self-ratings of confidence in important areas of OCD understanding and treatment.

3. The training day also had a significant impact on professionals' beliefs about OCD whereby optimism about treating OCD increased significantly from pre to post training, and belief in OCD as a biological rather than psychological problem decreased significantly pre to post training.
4. This successful training/conference day held by OCD-UK supports continued collaboration between service-user led organisations and mental health professional training, which may represent a powerful way to educate and promote good practice.

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**Insecure attachment, self-compassion and shame in the context of
engagement and help seeking in first episode psychosis.**

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Candidate: Emma Stephens

Word Count: 5,047

Journal aimed at: Psychology & Psychotherapy: Theory, Research & Practice

3.1 ABSTRACT

Objective: This study aimed to replicate previous findings regarding the influence of recovery style and attachment on engagement and help seeking within the context of first episode psychosis (FEP). It also aimed to explore self-compassion and shame as new potential moderators of engagement, and in terms of their relationship with attachment and recovery style.

Design: A cross-sectional between groups design was used to compare ‘high’ and ‘low’ engagers on the key variables. Whole sample correlational analysis was also undertaken to further explore associations with self-compassion and shame in FEP.

Methods: Twenty-two individuals with psychosis under the care of Early Intervention (EI) Services completed four questionnaires. Care Coordinators were subsequently sent a questionnaire on engagement to complete via secure email.

Results: No significant group differences on the predicted variables were found, with only time in service reaching significance. Although non-significant, avoidant attachment did result in a small to medium effect size whereby ‘low’ engagers scored higher on avoidant attachment, and a trend towards more non-white individuals in the ‘low’ engagers group was nearing significance. In the secondary analysis, avoidant attachment was associated with shame and problems help seeking, even when positive symptoms were controlled for. Anxious attachment was associated with lower self-compassion and higher shame. None of the variables were significantly correlated with recovery style.

Conclusions: The small sample size limits the conclusions which can be made, however it is of interest that no significant differences were found between the two groups on the expected variables. Although self-compassion and shame did not appear to effect engagement in this sample, strong and distinct associations were found between these variables and insecure attachment dimensions, indicating a possible area for further exploration.

3.2 INTRODUCTION

Early intervention services are designed to engage and support individuals experiencing a first episode of psychosis (FEP), and have a growing evidence base for reducing hospitalisation, relapse and symptom severity (Bird et al, 2010). It is recognised that increased duration of untreated psychosis impacts significantly on later outcomes (Singh, 2007), however the engagement of individuals into such services can be challenging.

Evidence suggests that a ‘sealing over’ recovery style (McGlashan, 1987) reduces engagement with services and increases risk of relapse (Tait, 2003) whilst ‘integration’ (McGlashan, 1987) predicts better outcomes (Thompson et al, 2003). ‘Sealing over’ is conceptualised as involving a fixed negative view of psychotic experiences, their minimisation, and an unwillingness to consider and explore their personal meaning. ‘Integration’ meanwhile is seen as involving curiosity and reflection on the experience of psychosis, and the integration of psychosis into their wider life experiences (McGlashan, 1987). Recovery style can also vary over time, and has been linked to changes in psychological adjustment to psychosis (Tait, 2003).

Attachment models (Bowlby, 1980) have also been applied to engagement and recovery in psychosis. Generally, insecure attachment represents a transdiagnostic vulnerability factor for much psychopathology (Dozier, Stovall-McClough & Albus, 2008), and in psychosis has been associated with ‘sealing over’ and lower engagement in services (Dozier, 1990; Korver-Nieberg et. al., 2014; Gumley et. al., 2014; Tait, Birchwood & Trower, 2003). A recent review of attachment and psychosis (Gumley et. al., 2014) included 8 studies which explored insecure attachment and engagement in services and reported effect sizes ranging from medium to large ($r= 0.32$ to $r= 0.55$). Attachment style is conceptualised as developing in early life and remaining relatively stable over time, meaning that the development of therapeutic approaches to attempt to modify attachment style directly is challenging. There is therefore a need to identify underlying mechanisms and other moderators of engagement which link to attachment style but represent additional targets of psychological intervention in order to encourage integration and engagement.

Social mentality theory provides a theoretical framework of innate motivation systems which, when activated, organize a range of psychological functions such as attention,

emotion, cognition, and behaviour (Gilbert, 1997). Social mentalities also have a critical role in appraising threat, enhancing safeness, and in regulating affect. In this framework, psychosis is characterised by high threat processing (Freeman, 2002; Gumley et al, 2010), and individuals experiencing FEP may be conceptualised as being particularly vulnerable to the threat of perceived shaming or stigmatising from others, as well as possible internal threats of self-criticism and negative self-evaluation (Birchwood et al. 2007; Gilbert et al., 2001).

Stigma, shame and engagement

Many individuals experiencing psychological problems avoid engaging with mental health services due to fear of discrimination (public stigma) or due to internalizing negative stereotypes (self-stigma) (Corrigan, 2004; Clement et. al., 2015; Evans-Lacko et al. 2012; Vogel, Wade, & Haake, 2006). The experience of shame is strongly related to stigma and is considered its predominant emotional consequence (Hinshaw, 2007). As one of the ‘self-conscious emotions’ developed in childhood (Muris & Meesters, 2014), shame is increasingly recognised as a risk factor for a variety of psychological problems (Gilbert & Andrews, 1998; Stuewig & McCloskey, 2005), and has also been linked to more insecure attachment style (Wells, 1996; Gross & Hansen, 2000) and difficulty help-seeking (Rüsch et. al., 2013, Clement et. al, 2015).

Like stigma, shame can involve both external and internal components. External shame is linked to concepts such as stigma awareness (Pinel, 1999), and is characterised by negative conceptions of how others view the self: as defective, unattractive, or vulnerable to attack (Gilbert & Andrews, 1998). Internal shame includes self-focussed attention, self-evaluation as ‘bad’ or as being flawed in some important way (Gilbert, 2006). Shame is also associated with self-criticism, low self-compassion (Gilbert et. al., 2008) and depressive rumination (Cheung, Gilbert, Irons, 2004).

In social mentality theory, shame-proneness has been linked to a preoccupation with social ranking and to either submissive or aggressive behaviour as a response to loss of face or social standing (Gilbert, 2000; Gilbert et. al., 2001). The experience of psychosis in a society where stigma about the condition remains high could lead to such a perceived loss of social rank, and cognitive appraisals of psychosis involving loss of social role, shame and perceived low social status are common, and have been found to predict post-psychotic depression (Iqbal et al., 2000) and social anxiety in FEP

(Birchwood et al, 2007, Michail & Birchwood, 2013). It is hypothesised therefore that higher shame may also lead to more problems with help seeking and engagement in FEP.

Compassion and psychosis

Compassion focused therapy has specifically been developed for individuals with high levels of shame and internal self-criticism. Drawing on social mentality theory, it aims to reduce focus on social ranking and on potential threat from others, and instead activate cooperative, caring and affiliative processes towards self and others.

Self-compassion, unlike self-esteem, does not imply self-evaluation or comparisons with others. It is instead conceptualised as a way of relating helpfully to oneself even in instances of failure or perceived inadequacy. Key elements of self-compassion include extending kindness and understanding to oneself rather than harsh self-criticism and judgment; seeing one's experiences as part of the larger human experience rather than as separating and isolating; and holding one's painful thoughts and feelings in balanced awareness rather than over-identifying with them (Neff, 2003, 2009). Compassion has begun to be accepted as an important factor within psychological health and wellbeing (Barnard & Curry, 2011), and may represent an important protective factor for a range of psychological problems (MacBeth & Gumley, 2012). Theoretically, one might expect individuals with psychosis and higher self-compassion to report a more integrated recovery style following psychosis, rather than a minimising 'sealing over' style.

Researchers have recently begun to apply compassion based approaches to psychosis with some promising results (e.g. Braehler et al, 2013; Gilbert & Procter, 2006; Laithwaite et al, 2009). A case series of compassion focussed therapy for individuals with malevolent voices found participants initially experienced compassion as 'frightening and untrustworthy', but over time were able to access compassion more successfully and reported their voices becoming more compassionate and less malevolent (Mayhew & Gilbert, 2008).

An experimental study has explored the concept of fear of compassion in a high shame non-psychotic sample, and found increased heart rate and cortisol levels in individuals with insecure attachment and high self-criticism when asked to generate self-compassionate imagery (Rockliff et al, 2008). Social mentality theory would argue that

warmth and kindness, for example in the context of engagement with psychological therapy or a Care-Coordinator, may feel threatening and trigger feelings of distress, sadness and grief in individuals who are threat-focussed and may lack previous positive affiliative experiences in early life (Gilbert, 2009, Gilbert et al, 2011, Gilbert et al, 2008).

Despite growing interest in both shame and compassion in mental health research, and specifically in psychosis, no known study has thus far explored self-compassion in FEP, and only two studies have explored shame in FEP in the context of co-morbid social anxiety (Birchwood, 2007; Michail & Birchwood, 2013). This research therefore has aimed to explore for the first time levels of both shame and self-compassion in an FEP population. It has also aimed to explore the theoretical position that those who show more difficulty engaging with EI services will also show lower levels of compassion, higher levels of shame, and utilise more avoidant coping in the form of a ‘sealing over’ recovery style. As attachment style has consistently been found to be influential in FEP, and has also been linked in some literature with shame and self-compassion, the relationships between these variables and insecure (avoidant/anxious) attachment dimensions are also explored.

3.3 HYPOTHESES

Primary Hypotheses

The primary hypotheses focused on variables predicted to be associated with engagement with services in FEP. Lower engagers with services were hypothesised to report (a) more avoidant attachment (b) less ‘integrated’ recovery style (c) lower self-compassion and (d) higher shame. It was also hypothesised that shame and self-compassion may mediate any relationship between attachment style and engagement in services.

Secondary Hypotheses

Attachment style has frequently been recognised as influential in psychosis research and FEP. Relationships between attachment style, self-compassion and shame have not previously been explored in a FEP sample however. Secondary hypotheses for this research predicted that avoidant adult attachment style would be associated with (a)

shame, (b) a more ‘sealing over’ recovery style, and (c) problems with the ‘help seeking’.

Anxious attachment was hypothesised to be associated with lower self-compassion and higher shame, but not with problems in help seeking.

Self-compassion and shame have not previously been explored in relation to recovery style in FEP, therefore exploratory analyses were planned. It was predicted that a more ‘sealing over’ recovery style would be associated with higher levels of shame and lower levels of self-compassion.

3.4 METHOD

3.4.1 Design

A between groups cross sectional design was utilised for the main evaluation, with correlational components evaluated in the entire group. Participants were therefore divided into high and low engagement groups, and comparisons made between the two groups for the primary hypotheses.

3.4.2 Measures

Attachment

The Psychosis Attachment Measure (PAM; Berry et al., 2006) is a self-report measure using a four-point Likert scale which assesses dimensions of anxious and avoidant attachment. Total scores are calculated for each dimension with higher scores indicating more insecure attachment style. The PAM has acceptable levels of internal consistency (Cronbach’s alpha from 0.70 to 0.86 for anxiety and 0.60 to 0.91 for avoidance) (Berry et al, 2008).

Shame

The ‘Other as Shamer Scale’ (OAS; Allan, Gilbert, & Goss, 1994) is a self-report scale comprising 18 statements scored with a five-point Likert scale. Higher scores indicate higher levels of shame. The scale has high internal consistency (Cronbach’s alpha of 0.92).

Self-Compassion

The Self Compassion Scale (short form) (SCS-SF; Neff et al., 2003) is a 12-item self-report measure of compassionate responding to oneself. The SCS-SF has demonstrated adequate internal consistency (Cronbach's $\alpha \geq .86$ in all samples) and a near-perfect correlation with the long form SCS ($r \geq .97$ all samples).

Recovery Style

The Recovery Style Questionnaire (RSQ) was developed as a brief self-report form of McGlashan's Integration Sealing Over Scale and consists of 39 statements, which are dichotomously rated (disagree/agree). Higher scores represent an increasingly 'integrated' style of recovery. The RSQ has been shown to have adequate psychometric properties (Cronbach's alpha coefficient of .73 for total score, and test-retest reliability correlation coefficient of .81 (Berry et al, 2006)) and was validated against the interview version (Drayton et al, 1998).

Engagement in Services

The Service Engagement Scale (SES) is a 14 item measure consisting of statements about client engagement with services which are rated on a four point Likert scale. The measure consists of four subscales exploring availability, collaboration, help-seeking, and treatment adherence, and is designed to be completed by Care Coordinators. Higher scores indicate more problems with engagement. The scale has been shown to have good reliability, high internal consistency and retest reliability, including discrimination between criterion groups in an assertive outreach team (Cronbach's $\alpha = .76-.90$ for subscales) (Tait, Birchwood and Trower, 2002).

Psychosis Severity

The Clinical Global Impression Scale for Schizophrenia is a short severity scale for psychosis symptoms involving rating five symptom areas on a likert scale ('Normal, not ill' to 'Among the most severely ill'). This scale has been shown to have good reliability and validity (Cronbach's $\alpha > .70$ for all dimensions except depressive dimension which was $\alpha = .64$). Correlation coefficients with other much lengthier assessments of psychosis severity e.g. Positive and Negative Symptoms Scale are high (most above 0.75; Tait, Birchwood, & Trower, 2002).

3.4.3 Participants

A number of inclusion/exclusion criteria were set for involvement in the research:

- All participants were required to be under the care of one of the identified EI services, and considered to be experiencing psychosis by the service.
- Aged between 18 and 35
- No primary diagnosis of substance misuse or organic disorders- although some use of substances/alcohol would not exclude individuals from the study.
- In first year of contact with service (initial criteria that was later removed)

Twenty-eight individuals were referred by Care Coordinators from Early Intervention services in North Somerset, South Gloucestershire, Bath, Bristol, and Gloucestershire. Twenty-two individuals (79%; 13 males and 9 females) were successfully recruited to the study. The majority of participants described themselves as White British (14/22), with a small number reporting other ethnic backgrounds: Mixed White/Caribbean (3); Black (2); British Asian (1); British Indian (1). Participant ages ranged between 18 and 31 (mean 23) and none had a primary diagnosis of substance misuse or organic disorders.

Initially, participants were recruited only if they were within the first year of contact with the EI service (as this was expected to be a time when difficulties with engagement may be most prevalent and where individuals may be struggling most to come to terms with their experiences). However, due to significant recruitment challenges, an amendment was obtained to remove this inclusion criteria in order to widen recruitment opportunities. The mean length of time in contact with the service was just under two years (22 months), and the mean duration of untreated psychosis prior to contact with services was 1.3 months (range 0-6 months). Care Coordinators were asked to specify primary and secondary diagnoses. Primary diagnostic labels reported were; Unspecified nonorganic psychosis (n=11); First episode psychosis (n=6); Drug induced psychosis (1); Schizophrenia/ 'probable Schizophrenia' (n=4). Four participants were reported to have a co-morbid mental health difficulty (anxiety & depression, depression or panic).

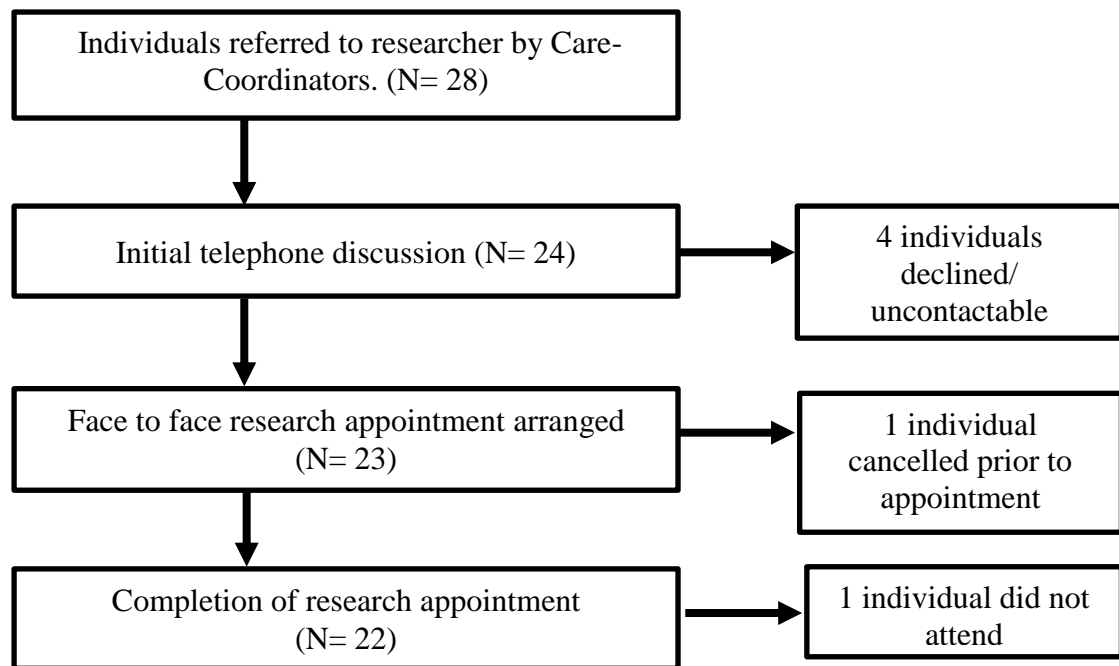


Fig.3.1: Consort Diagram of Recruitment flow

3.4.4 Procedure

Ethical approval was granted by the University of Bath and NHS Research Ethics Committee (Appendix D). Approval was also further obtained from individual trust Research and Development departments of Avon and Wiltshire NHS Trust and 2Gether NHS Trust (Appendix D). The study adhered to British Psychological Society Code of Human Research Ethics (2010).

Visits were made to all five of the EI services involved and team meetings attended to describe the research. Care Coordinators were asked to pass a letter from the researcher and an information sheet (Appendix A-B) to eligible clients they are working with, in which those clients were offered the opportunity to take part in the research with brief details of the study. Following a later amendment (see Appendix E), the researcher also attended some groups run by two EI services (e.g. Recovery groups, occupational therapy groups) to explain the research and distribute information about the study. Any group members interested in the research were asked to inform the staff member leading the group or their Care Coordinator, who again passed on their details to the researcher who contacted those interested via phone after at least 24 hours and provided further information. If interested, a face to face meeting with the individual was subsequently arranged at least 48 hours later, where full consent to take part was obtained before

completing the questionnaire pack (see Appendix C). For those recruited through a group setting, the researcher always contacted the participants' Care Coordinator prior to arranging an appointment to check eligibility.

Completion of questionnaires took around 20 minutes. Research meetings took place either in participants own homes or in an NHS setting, depending on the choice of participants. Participants were encouraged to request a break whenever needed, and were offered a small reimbursement of £5 for their time and contribution. Participants' data was given a unique identifying code to preserve confidentiality. A full debrief was provided to participants following administration of the questionnaires. Participants were also provided with a debrief sheet which included contact details for their EI team, the crisis team, the researcher, and information on relevant websites e.g. anti-stigma campaigns, compassion for voices. The Care Coordinators of participants were subsequently sent the Engagement in Services and Psychosis Severity Questionnaires to complete and return.

3.4.5 Power Considerations

A large meta-analysis of internalized stigma (a different but related concept to shame) found moderate to large negative correlation with treatment adherence and a meta-analysis of links between compassion and psychopathology found a large overall effect size ($p = -0.61$; $Z = -34.02$; $p < .0001$; MacBeth & Gumley, 2013). A recent review of attachment and psychosis (Gumley et al, 2014) included 8 studies which explored insecure attachment and engagement in services and reported effect sizes ranging from medium to large ($r = 0.32$ to $r = 0.55$). Given the sparsity of comparable studies looking at compassion and shame in FEP, an apriori power calculation to estimate required sample size has been completed but should be treated as tentative. In line with available reported effect sizes, a moderate to large effect size of 0.35 was entered into the power analysis. With significance level set as .05 and power at 0.80 a required sample of approximately 60 (30 in each group) was suggested, indicating that the current study is likely to be underpowered.

3.5 RESULTS

Prior to analysing data for the main hypotheses of this study, a comparison of the high and low engager groups in terms of demographic factors and other potentially important variables was completed. Duration of untreated psychosis (DUP); time in service and

overall severity of symptoms (including subscales of Positive, Negative and Depressive symptoms) were explored using Fishers Exact/Mann Whitney U (Exact). There were no significant differences in age, gender or comorbidity between groups. Ethnicity was nearing significance (Fishers Exact, $p = .056$) whereby there was a non-significant trend towards a higher proportion of non-white participants in the low engagers group. All other results were non-significant with the exception of duration of time in service, whereby high engagers had been in contact with services for longer than low engagers ($U = 23.00$, $Z = -2.46$, $p = .012$). See Table 1 for further details of demographic and service related variables.

Table 3.1: Participant demographic and service related data.

	High Engagers N=12	Low Engagers N=10
Gender: Male/Female	6/6	7/3
Age: <i>M</i> (SD)	24.58 (3.67)	22.1 (3.98)
Range	18-31	19-30
Ethnicity:	White British (91.7%) Other (8.3%)	White British (50%) Other (50%)
Comorbidity present:	33%	33%
Service:	Bristol 25% South Glos 25% Bath 25% Gloucester 25%	Bristol 30% South Glos 40% Bath 10% North Somerset 10%
DUP (months): <i>M</i> (SD)	0.91 (SD 0.99)	1.9 (2.07)
Time in Service: <i>M</i> (SD)	29.25 (17.98)	15.70 (6.61)
Severity: <i>M</i> (SD)	10.33 (4.90)	10.25 (5.35)

3.5.1 Engagement

The SES is reported to have a bi-modal distribution, with little overlap in scores between reported High and Low engagers in the original study (High: M 4.7, SD 5.4, range 0-13; Low: M 19.7, SD 9.10, range 6-29, Tait, Birchwood & Trower, 2002). A similar pattern was found in this data with clustering of scores either below 7 or above 10. Individuals scoring 7 or below were therefore considered ‘high engagers’ and those

scoring 10 and above ‘low engagers’. Twelve high (M 3.08, SD 1.97, range 0-7) and ten low engagers (M 15.55, SD 3.83, range 10-21) were identified.

Split groups analysis was used to explore variables for normality. No severe skewness or kurtosis was present, and Kolmogorov-Smirnov tests were not significant. Despite this, non-parametric tests (Mann-Whitney U) were utilised due to the small sample size. The primary hypothesis was explored by comparing group differences between high and low engagers on variables of self-compassion, shame, recovery style, avoidant attachment style and time in service (see Table 2 for Means and Standard Deviations). The ‘Exact’ test *p* values were utilised to determine significance due to its increased accuracy with small sample sizes.

No significant group differences on the predicted variables were found, with only time in service remaining significant ($U = 23.00, Z = -2.46, p = .012$) with a small effect size ($r = -.11$). Although non-significant ($U = 43.5, Z = -1.094, p = .144$ (one-tailed)), avoidant attachment did result in a small to medium effect size ($r = -0.23$). Due to the small sample size and lack of significant differences between high and low engagers, the planned regression analysis was not completed.

Table 3.2: Median (Mdn) and Range (R) scores of High and Low Engagers

	High Engagers N=12	Low Engagers N=10
Self-Compassion (SCS): Mdn (R)	2.87 (1.92)	3.04 (2.75)
Shame (OAS): Mdn (R)	27.50 (48.00)	26.00 (31.00)
Recovery Style (RSQ): Mdn (R)	76.90 (30.50)	76.90 (54.00)
Avoidant Attachment (PAS): Mdn (R)	1.31 (1.75)	1.62 (1.75)
Time in Service (Months): Mdn (R)	10.00 (14.00)	8.00 (14.00)

3.5.2 Attachment style

A correlational analysis was used to explore the secondary hypotheses around insecure attachment dimensions and predicted associations. The avoidant attachment and anxious attachment variables; shame; self-compassion; recovery style and help seeking problems were checked for normality. All had acceptable levels of skewness and kurtosis, and Kolmogorov-Smirnoff was not significant for any of the variables. A Pearson Correlation was therefore utilised. Psychosis symptom dimensions (positive or

negative symptoms) have frequently been associated with attachment style in previous research, so these variables were explored for any significant associations with attachment in this sample. Positive symptoms were found to correlate significantly with avoidant attachment.

a) As predicted, avoidant attachment was positively associated with shame and problems with help seeking. Contrary to expectation however, the small to medium correlation of avoidant attachment with integrated recovery style was not significant. When positive symptoms were controlled for in a partial correlation, avoidant attachment remained significantly and strongly associated with help seeking problems but the remaining medium effect size of shame was no longer significant. See Table 3.3 for statistical figures.

b) As predicted, anxious attachment was negatively associated with self-compassion and positively associated with shame. As self-compassion and shame are theoretically closely related and were also highly correlated, partial correlational analysis were used to further explore the associations as reported above. Shame remained significantly correlated with anxious attachment (but to a lesser extent) when controlling for self-compassion. When controlling for shame, self-compassion was no longer significant. See Table 3.3 for statistical figures.

Table 3.3: Pearson Correlation Coefficients for secondary hypotheses

Variables	1	2	3	4	5	6	7
1. Self-Compassion	—						
2. Shame	-.646**	—					
3. Problem Help Seeking	.297	-.090	—				
4. Integration (RSQ)	.185	-.189	-.130	—			
5. Positive Symptoms	-.461*	.403	-.209	.123	—		
6. Anxious Attachment	-.620**	.706**	-.199	-.012	.254	—	
7. Avoidant Attachment	-.215	.505*	.427*	-.234	.455*	.205	—

*Correlations significant to $p < .05$ level (two-tailed).

**Correlations significant to $p < .01$ level (two-tailed).

3.6.3 *Compassion, shame & recovery style*

A Pearson correlation was completed to explore associations between variables and to test hypothesis 3. Shame was found to be significantly and strongly negatively associated with self-compassion, however contrary to predictions neither shame nor self-compassion were significantly correlated with recovery style. See Table 3.3 for statistical figures.

3.6 DISCUSSION

This research aimed to replicate previous findings regarding the relationship between insecure attachment, sealing over recovery style and engagement in services, as well as explore the potential role of more novel factors drawn from social mentality theory; namely self-compassion and shame. As self-compassion had not previously been measured in an FEP sample, and shame had only been measured in two previous studies, the associations between these variables and attachment and recovery style were also explored.

Engagement

The comparison of high and low engagement groups did not find any significant differences in the expected variables of recovery style, attachment, self-compassion or shame, with the only significant between groups difference being longer time in service in the high engagement group, suggesting (as would be hoped) that the quality of engagement with services improves over time.

It is surprising that no significant relationship was found between avoidant attachment and engagement, as a number of previous studies have successfully linked avoidant attachment with engagement related variables, such as poor help seeking and poor use of treatment (Dozier, 1990) and poorer therapeutic alliance (Berry et. al., 2008). Secure attachment has been associated with overall engagement in services (MacBeth et. al., 2010), treatment adherence (Dozier, 1990, MacBeth et al, 2011) and reduced likelihood of disengaging (Tait, Birchwood & Trower, 2004). The lack of significant relationships between avoidant attachment and engagement in this sample may be due to the small sample size and subsequent lack of power, as although non-significant, a small to medium effect size for avoidant attachment was present. A variety of different measures of attachment have also been utilised in previous research including narrative approaches e.g. Adult Attachment Interview, as well as a range of self-report measures

(including the PAM utilised here), which may result in differing attachment dimensions that may relate slightly differently with engagement.

Although it has successfully been linked to attachment in the past (e.g. MacBeth et. al., 2011), another factor may be the broad nature of the SES engagement questionnaire utilised in this study. Engagement itself is clearly a highly complex area, and a range of engagement related subscales make up the overall SES score. These include questions around availability for appointments and medication adherence, with less emphasis on more subtle interpersonal factors than measures of therapeutic alliance, for example. It is of interest that in this study the help-seeking subscale of the SES in particular was significantly associated with avoidant attachment in the secondary hypotheses, the results of which will be discussed in more detail below. Finally, although previous studies have found associations between adult attachment and key worker relationships (Berry et al, 2007), suggesting that ratings of close relationships in general are meaningful in conceptualising relationships to professionals, the extent to which the psychiatric staff in this study represent attachment figures to the participants is unknown.

There is less available research exploring the influence of recovery style on engagement, however a more sealing-over recovery style has also been associated with insecure attachment (Tait, Birchwood & Trower, 2004), and sealing over at 3 months post psychotic episode significantly predicted engagement as measured by the SES at 6 months (Tait, Birchwood & Trower, 2003). One possible reason for a lack of significant effect in this sample is that the majority of participants reported a more integrated recovery style, with only one participant falling within the highest possible category of ‘predominantly sealing over’ recovery style, thereby limiting the ability to detect a relationship with engagement (or with self-compassion and shame in the secondary analysis). Although there was a wide range in engagement scores in this sample, the mean score of the low engager group was less than the low engager group in the SES validation study; so the most difficult to engage individuals (and perhaps those with more extreme sealing over style) may not have agreed to take part in this study. Another potential reason for less ‘sealing over’ in this sample may be due to widening of the inclusion criteria beyond individuals in their first year of contact with services. Several studies (Thompson et al, 2003; Tait, Birchwood & Trower, 2003), found the recovery style of their FEP sample shifted over the first 6 months/year of treatment, generally in

the direction of increased integration. The shortage of individuals during earlier phases of treatment may have contributed to the predominance of integration in this study.

It is surprising how similarly the high and low engagement groups scored on the variables of self-compassion and shame. Although theoretically it would be expected that those with higher shame would struggle to engage and seek help, such a relationship was not found in this sample. It would have been of interest to be able to compare a measure of more *internal* shame with the more *external* shame measure utilised here; however one would expect self-compassion to relate to internalised shame, and self-compassion also had no association with engagement. Social mentality theory proposes that threat based mentalities may lead to either an aggressive/rejecting stance or a submissive reaction. It may be therefore that a proportion of those experiencing shame in this sample responded submissively and therefore would be relatively easy to engage (but may not engage in the most helpful way). It would be of interest in future research to assess for any relationship between self-compassion and shame and more subtle/interpersonal engagement related variables, such as therapeutic alliance or therapy interfering behaviours.

Factors about the services themselves and its staff (which were not explored in this study) are clearly variables that may greatly influence an individuals' ability to engage. The identified non-significant trend towards more non-white individuals in the low engagement group is potentially important. Although no strong conclusions can be drawn from this data alone, they may hint at a need for services to ensure they are meeting the needs of individuals from minority ethnic and cultural backgrounds in order to maximise their engagement.

Self-Compassion, Shame & Attachment Style

Attachment style has frequently been explored in psychosis samples, with findings that individuals with psychosis/schizophrenia are more likely to have insecure attachment styles than individuals with affective disorders (Dozier, 1990), and that insecure attachment can predict key worker and parental relationships (Berry et. al, 2007); and has been linked to psychosis symptomatology (Wickham, Sitko & Bentall, 2014).

Although (as we have discussed) avoidant attachment was not significantly associated with engagement as a whole, it was significantly associated with the help seeking subscale of the engagement questionnaire, replicating previous findings (Dozier, 1990).

This subscale involves questions around seeking help when in a crisis or individuals contacting their Care Coordinator on their own impetus when things become difficult to avert worsening of symptoms. Such actions are arguably some of the most important in terms of managing risk and reducing the chances of relapse, and it is therefore of interest that individuals with more avoidant attachment may require additional support around seeking help when needed. Avoidant attachment was also significantly correlated with external shame as predicted, supporting the conceptualisation of avoidant attachment as representing a tendency to view others negatively e.g. as judgemental or critical. Anxious attachment is conceptualised as involving a tendency to view the self negatively, and to fear abandonment from others. As predicted, anxious attachment was found to be associated with high levels of shame and low levels of self-compassion, but was not associated with problems help seeking.

3.7 STRENGTHS & LIMITATIONS

A limitation of this study is the fairly concrete definition of engagement measured by the SES questionnaire. Although useful, the focus on practicalities e.g. making and attending appointments, likely oversimplifies the complexity of both defining and measuring engagement in a meaningful way. A measure which also explored more subtle interpersonal factors such as working alliance (e.g. Working Alliance Inventory: WAI, Horvath & Greenberg, 1989) may have produced further interesting results. Engagement is also dyadic, however the SES measure is clinician-rated, and does not explore patient views or staff and service related variables which may impact engagement. A relatively new measure of engagement in psychosis (SOLES: O'Brien, White, Fahmy & Singh, 2009) may have been a beneficial addition as a patient report measure which has been validated in psychosis samples. Finally, due to the need to widen recruitment beyond the first year of contact, there are indications that the sample acquired was relatively stable and with a more integrated recovery style, limiting the ability of this study to identify the impact of more sealing over perspectives. Strengths of this research include the use of novel measures in a FEP sample e.g. shame and self-compassion, and the identification of strong associations between these variables and attachment. The feedback from participants was also highly positive, with reports that the research had made them think and reflect on some of their beliefs e.g. about psychosis. The drop-out rate in this sample was also low, suggesting good acceptability of the research to participants.

3.8 CLINICAL IMPLICATIONS

Whilst research has shown strong links between adult attachment and psychosis, little is known about the mechanisms which may underlie these relationships. Further exploration of shame and self-compassion as potentially important factors relating to attachment style in FEP samples could help identify areas for future intervention. The use of short adult attachment self-report measures could help services to identify individuals with differing attachment styles that may benefit from slightly different approaches from EI teams. Although further research is required and a link with more general engagement was not found, there is some evidence supported by this study that individuals with psychosis and a more avoidant attachment style may need extra support around help seeking in particular (e.g. during a time of difficulty or crisis). Further research into the possibility that a more anxious attachment presentation in FEP may represent a risk factor for low self-compassion and more shame could also lead to more tailored interventions. The use of attachment style by services has the potential to lead to modifications in approach which could better meet the varying needs of individuals with FEP and hopefully maximise the helpfulness of the service.

3.9 RESEARCH IMPLICATIONS

Although attachment style has frequently been explored in psychosis samples, the relationship of these variables with self-compassion and shame has not previously been explored in a FEP sample. The fact that attachment dimensions were significantly correlated with self-compassion and shame in the directions predicted even in this small sample, and when using a short self-report measure rather than more detailed and lengthy adult attachment interview (AAI) suggest that further research into these relationships is important.

Due to the limitations of power in this small sample, further replication of results would be required, particularly the somewhat surprising negative results concerning the lack of a relationship between predicted variable and engagement. As discussed previously, further research exploring more subtle and interpersonal engagement in FEP would also be beneficial, and continued development of a meaningful definition of engagement would further research in this area.

4.0 CONCLUSIONS

This study aimed to replicate previous findings regarding the influence of recovery style and attachment on engagement and help seeking within the context of first episode psychosis (FEP). It also aimed to explore self-compassion and shame as new potential moderators of engagement, and in terms of their relationship with attachment and recovery style.

The small sample size limits the conclusions which can be made, however it is of interest that no significant differences were found between high and low engagers on the expected variables. Although self-compassion and shame did not appear to effect engagement in this sample, strong and distinct associations were found between these variables and insecure attachment dimensions, indicating a possible area for further exploration, particularly as some dimensions were associated with difficulty accessing help in a crisis. With further replication, these findings have implications for Early Intervention services that may wish to utilise short self-report attachment measures to better identify and meet the needs of their service users.

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Executive Summary

Early intervention (EI) services provide evidence-based support to individuals experiencing a first episode of psychosis (FEP) (Bird et al, 2010). A key aim of EI

services is to engage people and support them to get help, as there is strong evidence that a longer duration of untreated psychosis (DUP) can lead to poorer long-term outcomes compared to those who get help quickly. However those experiencing FEP vary in their help-seeking behaviour. When people feel threatened, they may find it hard to trust others and to ask for help.

There is strong evidence that someone's early experiences of being cared for can affect how easy it is for them to trust others later in life and to open up to other people. Those who received good and stable care in childhood often feel OK about themselves and think others are generally trustworthy (this is called secure attachment). However if early care was not ideal, was inconsistent or confusing, this can lead people to struggle to trust and open up to others (insecure avoidant attachment) and/or can lead to feelings of inadequacy and anxiety that others will abandon them (insecure anxious attachment). Previous research has found that factors such as an insecure avoidant attachment style and a 'sealing over' recovery style (minimising and shutting away psychosis experiences) have been associated with more problems help-seeking, engaging with services, and poorer outcomes.

This research aimed to see whether these results could be replicated, but it also wanted to explore other factors that may link to engagement. Despite growing interest in self-compassion and shame in the context of psychosis, no previous study has measured self-compassion in an FEP sample, and only a handful of studies have explored shame. The relationships between these variables and the more established factors in psychosis samples (insecure attachment style and recovery style) were therefore also explored.

People with psychosis being seen by EI services completed questionnaires, and their Care Coordinators from the service were asked about how easy or hard they felt the person was to engage. No significant differences were found between those who were easier and harder to engage overall on our measures of attachment, integration, self-compassion or shame. Those who were harder to engage did score higher for insecure avoidant attachment, and there were more non-white people in this group but both these trends were not statistically significant. It was found that those who engaged more had been in the service significantly longer- so engagement in services improved over time.

An exploration of attachment in more detail found that avoidant attachment was associated with difficulty asking for help in difficult times, and higher shame. Anxious attachment was also associated with shame, and also lower self-compassion. These findings fit with the pattern we would expect from attachment theory.

It is hoped that these findings might encourage other researchers to explore further how individuals' different attachment styles may affect how they cope with having psychosis, how they think others see them, and how they view themselves in the context of FEP (e.g. self-compassionately or not). It is possible that in the future services could tailor their approach to suit an individuals' attachment style in order to best support them and meet their needs- more research would help to support services to do this.

Connective Narrative

5.1 LITERATURE REVIEW

My literature review was inspired directly by a lady I worked with in my older adult placement (I also wrote up this therapeutic work in Case Study 2). She had Parkinson's disease (PD), and was also suffering with panic attacks. Her doctors had prescribed her antidepressants and had informed her that panic attacks are very common in PD. She was under the impression that her doctors felt the panic was simply a common symptom of the neurological effects of PD, and that it was unlikely they would get any better. She felt distressed that she was expected to just 'live with it' along with all the other challenges and motor symptoms. Through talking to her I realised that although complicated by her PD symptoms, and often triggered by them, her panic was also comprehensible through the cognitive behavioural model. We commenced a slightly modified CBT intervention for panic; her panic decreased and her mood lifted. No one had previously explained to her what panic was, that it was not dangerous, and that lots of people without PD also experience it.

Albeit pleased with the outcome of treatment, my client was also frustrated by the unnecessary anxiety she had experienced through a complete focus on the medical management of PD and a lack of acknowledgement of additional psychological needs. When my initial literature review proposal (about vagal tone and other physiological links to psychopathology) was deemed unwise due to a lack of high quality papers, I refocussed on this issue that had struck me through my clinical experience. I therefore decided to focus on trying to write the review I had wished I could find when I first started working with my panic patient.

I soon realised that research into anxiety in PD was still limited; and there was insufficient research to focus specifically on panic. The topic therefore widened to include anxiety in general within the context of PD. I looked into existing reviews and with the support of James Gregory my supervisor developed an idea of what was missing; a review of evidence for a more psychological perspective on anxiety in PD, and possibly even a model to further illustrate a psychological conceptualisation. After several months of refining and literature searches, James suggested inviting Dr Leon Dysch (Neuropsychologist) to get involved, as a clinician working in a Neuropsychology service and with insight into the particular client group. As the review

was primarily aimed at supporting clinicians, it felt useful to have a clinician on board to ensure the review remained relevant to practice. Following a useful meeting with Leon and James, and also a discussion with a Consultant and Doctor involved in Movement Disorder services in Bath in September 2015, the focus of the review finally came together. From now on it was a case of reviewing 30 papers in detail, summarising them and starting to organise and synthesize the results. I found writing the lit review probably the most challenging of all my research write ups. I found the process very time consuming and complex due to the need to try and absorb and analyse what felt like a huge amount of information, and then produce a coherent outcome. What I found most challenging was the need to fit in my literature review work on odd days or hours when I had time; it was really hard to write without a large chunk of time to dedicate; at times it felt like one step forward and two back. On reflection the neuropsychology topic probably added an additional challenge, as it required considerable learning ‘on the job’ about PD as a disease. It was really helpful however to end up on placement with Leon in my first elective placement, as this allowed me to gain additional neuropsychological understanding. My interest in developing a model also greatly increased the challenge- and there were times when I wished I had not suggested it! However I am very pleased and satisfied to have included a model which I know I would have found helpful and encouraging at the time of the clinical work that inspired the whole project. I would have really struggled (even more) to complete this review without the vital periodic support of both James and Leon, who despite many demands on their time, have been reliable and timely in their review of drafts, and who have offered (at times much needed) encouragement.

5.2 SERVICE IMPROVEMENT PROJECT

My service improvement project stemmed from my interest in service user groups and the potential of such organisations to enhance and energise clinical practice and NHS services. An opportunity arose through Prof Paul Salkovskis to get involved with OCD-UK; a service user group and national charity of people with personal experience of OCD designed to offer support, accurate information and advice to OCD sufferers and their family and friends. Paul had been involved with the organisation for many years, and regularly spoke at their Annual Conference for people living with OCD. However OCD-UK had discussed with Paul their concerns that they continued to hear distressing accounts of the poor understanding of many therapists about OCD and the misleading

information or unhelpful treatments that were still offered. OCD-UK had decided they wanted to do something about this; by adding an additional day to their Annual Conference aimed at mental health professionals. OCD-UK wanted help with this however; to help decide on what topics would be most important to include, and to find a way to somehow evaluate the day to assess whether this addition to the Conference was successful, and whether it would be something they should continue. A fellow trainee also became involved with a parallel project of introducing an evaluative component to the standard Conference day for people with OCD.

I was introduced to Ashley Fulwood (Director) and another OCD-UK and Conference team member via Paul initially, and ‘met’ with them both regularly via skype to plan and implement the project. Initially this involved collecting information about what topics would be useful at the professionals day- through a brief questionnaire posted on mental health professionals’ websites and the OCD-UK forum for a service user perspective. Responses were then summarised and sent to OCD-UK to help shape the day. Some topics appeared particularly urgent, such as training and advice on risk assessment of intrusive thoughts (which if misinterpreted can lead to distressing intrusive thoughts being taken as evidence of risk e.g. to others). Alongside this began the development of a way to evaluate the new conference day. In consultation with OCD-UK we identified the key general feedback they required, including ratings of interest, relevance of topics etc, but also wanted to attempt to gather more meaningful data about any change in beliefs or attitudes of attending professionals. Helpfully, Paul had previously supervised a PhD which had involved the development of a therapist beliefs scale about OCD. With some minor adaptations this scale was incorporated into a ‘Pre’ and ‘Post’ questionnaire for conference attendees. Following final consultation with OCD-UK and minor revisions, myself and the other trainee involved with the service user conference set off to Nottingham for the Conference. On the professionals day, Ashley (who was starting the day off with a brief introduction) encouraged professionals to complete the forms and explained their importance, the final speaker also reminded attendees to complete their ‘post’ questionnaires. Attending the conference was a real highlight- the quality of speakers was fantastic and included not only well known researchers in the field, but also personal stories and insights from people with their own very personal understanding of OCD. It was a fantastic example of true collaboration between ‘service users’ and ‘professionals’ that helped me to see

how the barriers and sense of ‘them and us’ which so often sadly occurs can be broken down; and that when this does happen, it empowers both groups.

It was unfortunate that the numbers attending the professional’s day were fewer than expected (largely due to delays in advertising the event). However a large percentage of those that attended did complete the questionnaires, and I was able to provide OCD-UK with highly positive feedback from professionals. The day appeared to be a great success, with very high ratings on all aspects. Even more proof of this perhaps was that significant and positive change was found in the professionals’ beliefs about OCD- after only one day of lectures and discussion. It was fantastic to see that factors like therapist confidence about treatment and optimism about working with OCD improved- and it felt particularly meaningful that the whole event was initiated, planned and developed by experts through experience, rather than experts by position or training. I feel this project has encouraged and strengthened my interest in service user involvement, and likely influenced my later involvement with the People with Personal Experience Committee at the University, and the subsequent consultation project for that committee on service user involvement on training programmes. I hope to continue working with service users to benefit and shape research and services long into my future career.

5.3 MAIN RESEARCH PROJECT

My main research project was also influenced by clinical work, this time in my first placement where I experienced working with people with psychosis, and was introduced to an approach that has gone on to influence me greatly; Compassion Focused Therapy (CFT). When learning about CFT and seeing it in practice through a group intervention, I immediately became fascinated with the transdiagnostic nature and power of self-compassion and its polar opposite, shame.

My initial research ideas were around whether high shame and low self-compassion might predict those at higher risk of post psychotic depression; however this would involve a significant follow up period, and was therefore unrealistic in the timeframe available. I then met with a member of staff with an interest in CFT research, who introduced the idea of looking at shame and self-compassion in oncology patients- an area where he worked clinically. However when this tutor ended up leaving the course, I returned to my original focus on psychosis.

After meeting with Lorna Hogg to discuss different ideas, I started to read current literature on compassion, shame and psychosis. I became interested in social ranking theory, and how this could be applied to a research study. Clear themes from available literature on psychosis became apparent and I started to develop a hypothesis that drew on social ranking theory about how self-compassion, shame, attachment and recovery style might relate to each other and to engagement in psychosis services.

With advice from my supervisor, I anticipated from the start difficulty in recruiting people with psychosis from Early Intervention (EI) services. For this reason I contacted and included six EI services in my ethics application. I found the process of obtaining ethical approval extremely slow, frustrating and complex, and there was little guidance available because the process appeared to have changed since the last cohort of trainees. Despite these difficulties, the research passed through proportionate review by early April 2015. This felt very early, and I was hopeful that I had given myself plenty of time, however once I contacted R&D, I was told that the EI services should have been listed as research sites, not SIPs. Although a small error, AWP R&D required an amendment form to be completed, which took many weeks to process and delayed recruitment starting for two months. Final approval was gained on 8th July 2015. Despite using the delay to get back in contact with all the EI services, the psychologists in the teams, and attending meetings to inform about the study, recruitment was (and would continue to be) very slow. Despite getting a list of all service users in their first year and then sending personalised emails to each individual Care Coordinator about those on their caseload, only four participants had been referred from the five services currently involved by the end of September 2015. It was clear that my initial restriction to individuals in their first year of contact with services was further reducing my chances of recruitment.

I therefore decided to remove this restriction to widen my opportunities, and also to allow me to organise joint research appointments with another trainee recruiting from EI services- so that we could complement rather than compete with each other. A further amendment was therefore submitted, again taking several weeks, being completed in November 2015. Although referrals picked up slightly following this, partly due to frequent reminders to teams and individuals within the services, referrals ground to a halt over the Christmas period, and by the end of January I was facing a worrying picture.

In discussion with teams and my supervisor, myself and the other trainee both submitted yet another amendment to be able to attend groups run by the EI services to distribute information directly to service users. Again after several weeks this was approved at the end of February 2016. Although only two of the services were currently running groups, we were able to attend several, and this resulted in a final modest flurry of participants, some of whom were recruited directly by us, and others who were referred by Care Coordinators we met at the groups.

Despite two amendments to modify approaches, countless emails of encouragement and requests, and linking in with key individuals within teams, recruitment to this research project has been hugely challenging. Ironically, or those referred, the number of participants refusing to take part or not responding to contact was extremely low. It felt that the main barrier to recruitment was Care Coordinators feeling overworked, overwhelmed and unable to dedicate time and energy to research. The period of my recruitment may have been particularly challenging due to simultaneous changes to targets and goals required by EI services (first contact with new referrals needed to happen faster, and starting to also work with 'at risk' clients) at a time when resources and staffing was tight. Although understandable, the impact on research has been frustrating and at times disheartening.

Despite not being able to reach my recruitment target (and thereby limiting my statistical power), I have really enjoyed conducting this research. Meeting individuals face to face allowed the research to feel much more personal, and I hope made participants feel more valued and listened to, due to opportunities for discussion and reflection. Feedback from participants has been very positive, with some reporting that the questionnaires had encouraged them to think about things differently, such as how little compassion they may give to themselves. Although some participants found the process tiring, none of the participants appeared or reported being emotionally upset or distressed by taking part, and it was a pleasure to meet every one of them.

5.4 CASE STUDIES

I have referenced several of my case studies already above, as my clinical work has often helped to inspire and direct my research interests. I believe that the process of writing up clinical work has ensured reflection and wider consideration of the heuristic value of therapeutic experiences. I hope that I will carry forward this curiosity and drive

and continue to be inspired by the people I work with to explore further research opportunities, such as writing up future clinical work or introducing evaluation and outcomes to group interventions. I would also like to add to the growing evidence base for third wave CBT therapies (such as Compassion Focussed Therapy), and to be involved with and promote service user led research in the future.

APPENDIX A- Research Invite Letter

Hello.

Thank you for taking the time to read this letter!

My name is Emma Stephens, I am a trainee Clinical Psychologist, studying at Bath University and working in the NHS. This is me!



I am writing wondering whether you might be interested in some research I am doing. Your Care Coordinator kindly agreed to pass this letter on to you. If you think you might be interested I'd be very happy to arrange a convenient time to ring you and we could talk more about it.

My research

Through working with people who are going through hard times, I have become really interested in how we all cope with difficult experiences in our lives, and whether we are hard/critical or kind to ourselves when things may be tough.

I am really interested in whether the different ways we all deal with our experiences can make asking for and receiving help and support (e.g. from NHS services or friends/family) easier or harder.

I would really like to meet with people who are attending the Bristol service for a short individual interview (30min- 1hour) to fill out some questionnaires together. The questionnaires are about:

- Recovery style (which is the way people cope with difficult experiences)
- Attachment style (how someone relates to and feels towards other people)
- How people feel about themselves in difficult times (self-critical or kind and understanding).

Taking part in the research would be completely optional. It is totally your choice whether or not you'd like to take part. Whatever you decide is absolutely fine and of course will not affect your care in any way.

What would happen next?

- If you think you may be interested, I wonder if you could kindly let your Care Coordinator know and s/he will pass the message onto me. I would then ring you some time the following week to arrange a convenient time to chat.
- On the phone I could answer any questions you may have and if you decide you would like to go ahead we would then arrange a convenient time to meet up (normally your home).
- At the meeting we would go over the details of the research and I would check that you're still happy to go ahead. If so we would then complete the questionnaires together. I estimate this would take about 45 minutes (but it could be a little more or less)
- You would receive £5 as a small token of appreciation for your time and energy in completing the questionnaires.

Thank you very much for reading this letter. If you would like to know more about the research you are very welcome to read the 'Information Sheet'. If you decide you would like to meet up we would also go through this information together then, to check everything is clear before you decide whether to take part.

If you are interested and would be happy for me to phone you, I'd be very grateful if you could let your Care Coordinator know.

Thanks very much for your time.

Best Wishes,

Miss Emma Stephens
Trainee Clinical Psychologist
University of Bath

Dr Lorna Hogg
Clinical Psychologist
University of Bath

APPENDIX B- Participant Information Sheet

Factors associated with Engagement in First Episode Psychosis.

You are being invited to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please ask if there is anything that is not clear or you would like more information about. You can talk to your Care Coordinator, family or friends and take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are inviting you to take part in a study looking at factors such as recovery style (which is the way people adapt to their experience of psychosis e.g., push it to the back of their minds or explore experiences), attachment style (how someone relates to others) and how they tend to feel about themselves in difficult times (e.g. self critical or kind and understanding). This project is being completed as part of a doctorate in clinical psychology.

Why have I been invited to take part?

We are approaching all patients who have been referred to a local Early Intervention service within the past year to ask if they want to help us explore what makes engaging with these services easier or harder. Your Care Coordinator has agreed for us to approach you.

Do I have to take part?

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. Staff involved in your care will not be upset and your treatment will not be affected. If you take part but later change your mind, you can withdraw at any time from the study without affecting your care.

What will happen to me if I take part?

If you decide to take part, you will be asked to meet with a researcher to complete some questionnaires about your experiences of mental health problems, and your viewpoints on recovery and relationships. The interview will take around one hour in total. We will try to make appointments at times which suit you. Interviews will normally take place in your own home but may be able to be arranged in a room in at the Early Intervention Service if you prefer.

Expenses and Payments

You will receive £5 in cash for taking part in the research study.

What are the possible disadvantages and risks of taking part?

The questions we ask are about things that you may have been asked before (e.g., about your mental health). It is possible that these questions might cause some distress. You do not have to answer any questions you do not want to and can stop the interview at any time. If you do feel distressed as a result of the interview you can contact your Care Coordinator on 0117 919 2371 or the researcher at the University via es555@bath.ac.uk. If you are feeling very distressed during out of office hours, you can contact out of hours services such as the Samaritans 08457 90 90 90 or Crisis Team on 0300 555 0334.

What are the possible benefits?

We hope the information we get from this study will help services better meet the needs of people experiencing psychosis, and ultimately lead to better outcomes for patients. You will receive £5 reimbursement for your time.

What happens when the research study stops?

The study will be written up as partial fulfilment of a Doctorate in Clinical Psychology at the University of Bath. All personal contact details (address, phone number etc) will

be destroyed as soon as they are no longer needed (after interview has taken place). After the study is completed, the anonymous questionnaire data will be kept securely for 10 years after publication of the study, in accordance with the University of Bath policy on storage of research data. Consent forms from the study will also be kept securely for this time, after which all study data will be destroyed.

Will my taking part in the study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential, and none of the questionnaires will not have your name or address so that you cannot be recognised. We will follow ethical and legal practice and we will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction.

As you are under the care of a mental health NHS Trust, a copy of your consent form will be copied into your usual medical notes. Your Care Coordinator has seen a copy of this information sheet. We have a responsibility to inform your Care Coordinator if you tell us information that suggests you or someone else might be harmed.

What will happen to the results of the research study?

The study will be written up as partial fulfilment of a Doctorate in Clinical Psychology at the University of Bath and a paper will be submitted to a relevant scientific journal. An overview of the results will be sent to all services who took part to be distributed if requested.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact the researchers Emma Stephens or Dr Lorna Hogg who will do their best to answer your questions (Emma Stephens- es555@bath.ac.uk Dr Lorna Hogg- l.i.hogg@bath.ac.uk). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (Details can be obtained from your Primary Care/NHSTrust) or you can contact the Research Governance Sponsor of this study, University of Bath. Please write to: Research Governance, University of Bath, Claverton, Bath, BA3 7AY.

Who is organising and funding the research?

Money for participants and for the researcher's travel and photocopying expenses will come from a research budget available via the Department of Clinical Psychology within the University of Bath.

Who has reviewed the study?

The study has been reviewed by an NHS Research Ethics Committee. The study protocol was also reviewed and approved by a research sub-committee constituting senior staff from the Department of Clinical Psychology within the University of Bath.

Thank you very much for considering taking part in our research. Please discuss this information with your family, friends or mental health team if you wish before deciding. Please let your Care Coordinator know if you are happy to be contacted by the researcher on the phone so that they can answer any questions and book in a face to face visit if you decide to go ahead.

Questionnaire Pack

Thank You
for agreeing to take part in this
research project.

Please remember:

- **Your answers will be anonymous**
- **Take a break at any time!**
- **You can decide not to answer questions you don't want to**
- **If you prefer I can read the questions out to you?**

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

**Almost
never**
1

2

3

4

**Almost
always**
5

- _____ 1. When I fail at something important to me I become consumed by feelings of inadequacy.
- _____ 2. I try to be understanding and patient towards those aspects of my personality I don't like.
- _____ 3. When something painful happens I try to take a balanced view of the situation.
- _____ 4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.
- _____ 5. I try to see my failings as part of the human condition.
- _____ 6. When I'm going through a very hard time, I give myself the caring and tenderness I need.
- _____ 7. When something upsets me I try to keep my emotions in balance.
- _____ 8. When I fail at something that's important to me, I tend to feel alone in my failure
- _____ 9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.
- _____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
- _____ 11. I'm disapproving and judgmental about my own flaws and inadequacies.
- _____ 12. I'm intolerant and impatient towards those aspects of my personality I don't like.

HOW I FEEL OTHERS SEE ME (OAS)

We are interested in how people think others see them. Below is a list of statements describing feelings or experiences about **how you may feel other people see you**.

Read each statement carefully and circle the number to the right of the item that indicates the frequency with which you find yourself feeling or experiencing what is described in the statement. Use the scale below.

0 = NEVER 1 = SELDOM 2 = SOMETIME 3 = FREQUENTLY 4 = ALMOST ALWAYS

- | | | | | | |
|---|---|---|---|---|---|
| 1. I feel other people see me as not good enough. | 0 | 1 | 2 | 3 | 4 |
| 2. I think that other people look down on me | 0 | 1 | 2 | 3 | 4 |
| 3. Other people put me down a lot | 0 | 1 | 2 | 3 | 4 |
| 4. I feel insecure about others opinions of me | 0 | 1 | 2 | 3 | 4 |
| 5. Other people see me as not measuring up to them | 0 | 1 | 2 | 3 | 4 |
| 6. Other people see me as small and insignificant | 0 | 1 | 2 | 3 | 4 |
| 7. Other people see me as somehow defective as a person | 0 | 1 | 2 | 3 | 4 |
| 8. People see me as unimportant compared to others | 0 | 1 | 2 | 3 | 4 |
| 9. Other people look for my faults | 0 | 1 | 2 | 3 | 4 |
| 10. People see me as striving for perfection but being unable to reach my own standards | 0 | 1 | 2 | 3 | 4 |
| 11. I think others are able to see my defects | 0 | 1 | 2 | 3 | 4 |
| 12. Others are critical or punishing when I make a mistake | 0 | 1 | 2 | 3 | 4 |
| 13. People distance themselves from me when I make mistakes | 0 | 1 | 2 | 3 | 4 |
| 14. Other people always remember my mistakes | 0 | 1 | 2 | 3 | 4 |
| 15. Others see me as fragile | 0 | 1 | 2 | 3 | 4 |
| 16. Others see me as empty and unfulfilled | 0 | 1 | 2 | 3 | 4 |
| 17. Others think there is something missing in me | 0 | 1 | 2 | 3 | 4 |
| 18. Other people think I have lost control over my body and feelings | 0 | 1 | 2 | 3 | 4 |

You are half way through, Thank You. You may want a break?

The Recovery Style Questionnaire (RSQ)

Written below are a list of statements about your illness. Please read them carefully and tick the box to show if you agree or disagree.

	Agree	Disagree
1. There was a gradual build-up to me becoming ill.		
2. My illness is not part of my personality.		
3. I am responsible for what I think when I am ill.		
4. I am not interested in my illness.		
5. My illness taught me new things about myself.		
6. I need help to solve the problems caused by my illness.		
7. My illness was caused by my difficulties in coping with life.		
8. I have had a nervous breakdown.		
9. I can see positive aspects to my illness.		
10. My illness has had a strong impact on my life.		
11. I am not frightened of mental illness.		
12. I liked some of the experiences I had when I was ill.		
13. My illness has helped me find a more satisfying life.		
14. My illness came on suddenly and went suddenly.		
15. My illness is part of me.		
16. I am not responsible for my actions when I am ill.		
17. I am curious about my illness.		
18. I understand myself better because of my illness.		
19. I can manage the problems caused by my illness, alone.		
20. Others are to blame for my illness		
21. I have had a medical illness.		
22. Nothing good came from my illness.		
23. My illness has had little effect on my life.		
24. I am frightened of mental illness.		
25. I didn't like any of the unusual experiences I had when I was ill.		
26. It's hard to find satisfaction with life, since I was ill.		
27. My illness came on very suddenly.		
28. My illness is alien to me.		
29. I am responsible for my thoughts and feelings when I am ill.		
30. I don't care about my illness, now that I am well.		
31. I want to be the person I was before my illness.		
32. Others can help me solve my problems.		
33. My illness was caused by stress in my life.		
34. I have suffered an emotional breakdown.		
35. Being ill had good parts too.		
36. I'm not really interested in my illness.		
37. I liked some of the unusual ideas I had when I was ill.		
38. My life is more satisfying since my illness.		
39. My attitude to mental illness is better now, than before I was ill.		

HOW I RELATE TO OTHERS

We all differ in how we relate to other people. This questionnaire lists different thoughts, feelings and ways of behaving in relationships with others.

PART A

Thinking generally about how you relate to other key people in your life, please use a tick to show how much each statement is like you. Key people could include family members, friends, partner or mental health workers.

There are no right or wrong answers

	Not at all	A little	Quite a bit	Very much
1. I prefer not to let other people know my 'true' thoughts and feelings.	(..)	(..)	(..)	(..)
2. I find it easy to depend on other people for support with problems or difficult situations.	(..)	(..)	(..)	(..)
3. I tend to get upset, anxious or angry if other people are not there when I need them.	(..)	(..)	(..)	(..)
4. I usually discuss my problems and concerns with other people.	(..)	(..)	(..)	(..)
5. I worry that key people in my life won't be around in the future.	(..)	(..)	(..)	(..)
6. I ask other people to reassure me that they care about me.	(..)	(..)	(..)	(..)
7. If other people disapprove of something I do, I get very upset.	(..)	(..)	(..)	(..)
8. I find it difficult to accept help from other people when I have problems or difficulties.	(..)	(..)	(..)	(..)
9. It helps to turn to other people when I'm stressed.	(..)	(..)	(..)	(..)
10. I worry that if other people get to know me better, they won't like me.	(..)	(..)	(..)	(..)

Continued on last page.....

	Not at all	A little	Quite a bit	Very much
11. When I'm feeling stressed, I prefer being on my own to being in the company of other people.	(..)	(..)	(..)	(..)
12. I worry a lot about my relationships with other people.	(..)	(..)	(..)	(..)
13. I try to cope with stressful situations on my own.	(..)	(..)	(..)	(..)
14. I worry that if I displease other people, they won't want to know me anymore.	(..)	(..)	(..)	(..)
15. I worry about having to cope with problems and difficult situations on my own.	(..)	(..)	(..)	(..)
16. I feel uncomfortable when other people want to get to know me better.	(..)	(..)	(..)	(..)

PART B

In answering the previous questions, what relationships were you thinking about?

(E.g. relationship with mother, father, sister, brother, husband, wife, friend, romantic partner, mental health workers etc)

Thank You...

I really appreciate your help. We hope that this research will help us understand better what can affect people's recovery from difficult times, and how services may be able to support people in the best way.

APPENDIX D- ETHICAL APPROVAL & R&D CORRESPONDANCE

24 April 2015
Miss Emma-Jane Kirsten Stephens
Trainee Clinical Psychologist
Taunton NHS
Department of Clinical Psychology
University of Bath
Claverton Down
Bath
BA2 7AY

Dear Miss Stephens

Study title: **The influence of self compassion and shame on engagement with services and recovery style in first episode psychosis.**
REC reference: **15/NW/0311**
Protocol number: **n/a**
IRAS project ID: **162293**

Thank you for your submission responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee. We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Rachel Katzenellenbogen, nrescommittee.northwest-haydock@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance

should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover Letter]	1	12 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Confirmation]	1	25 March 2015
Letter from sponsor [Sponsorship Approval]	1	25 March 2015
Letters of invitation to participant [Invite letter]	1	25 March 2015
Other [Care Coordinators Questionnaire Pack]	1	25 March 2015
Other [liability certificate]	1	25 March 2015
Other [letter academic approval]	1	25 March 2015
Other [Debrief sheet]	1	25 March 2015
Other [Field Supervisor CV]	1	25 March 2015
Other [Demographic Sheet]	1	25 March 2015
Other [Site information]		26 March 2015
Other [Data clarification]	1	14 April 2015
Participant consent form [Patient]	1	25 March 2015
Participant consent form [Care Coordinator]		26 March 2015
Participant consent form [Consent Form]	2	13 April 2015
Participant information sheet (PIS) [Patient]	1	25 March 2015
Participant information sheet (PIS) [Care Coordinator]		26 March 2015
Participant information sheet (PIS) [Participant Info sheet]	2	25 March 2015
REC Application Form [REC_Form_26032015]		26 March 2015
Research protocol or project proposal [Protocol]	1	25 March 2015
Summary CV for Chief Investigator (CI) [Emma Stephens CV]	1	25 March 2015

Summary CV for supervisor (student research) [Lorna Hogg CV]	1	25 March 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay Summary]	1	25 March 2015
Validated questionnaire [Questionnaire pack]	1	25 March 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0311 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

Dr Tim S Sprosen
Chair

Email: nrescommittee.northwest-haydock@nhs.net

Copy to:

Ms Lorna Hogg, University of Bath
Ms Hannah Antoniadou, Avon & Wiltshire
Partnership NHS Trust

29th June 2015

Our R&D ref: 15/017/2GT

Department of Clinical Psychology
University of Bath
Claverton Down
Bath, Somerset
BA2 7AY

Dear Emma

RE: The influence of self-compassion and shame on engagement with services in first episode psychosis.

Participating Organisation: 2gether NHS Foundation Trust

This letter should be presented to each participating organisation before you commence your research at that site. The participating organisation is 2gether NHS Foundation Trust.

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on 29th June 2015 and ends on completion of all research activity for the named study, unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from 2gether NHS Foundation Trust. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving confirmation from the individual organisation(s) of their agreement to conduct the research.

The information supplied about your role in research at the organisation(s) has been reviewed and you do not require an honorary research contract with the organisation(s). We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Evidence of checks should be available on request to the organisation(s).

You are considered to be a legal visitor to the organisations premises. You are not entitled to any form of payment or access to other benefits provided by the organisation(s) or this organisation to employees and this letter does not give rise to any other relationship between you and the organisation(s), in particular that of an employee.

While undertaking research through the organisation(s) you will remain accountable to your substantive employer, the University of Bristol, but you are required to follow the reasonable instructions of the organisation(s) or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required

to co-operate fully with any investigation by the organisation(s) in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with the organisations policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with the organisation(s) in discharging its/their duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each organisation prior to commencing your research role at that organisation.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the organisations premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) do not accept responsibility for damage to or loss of personal property.

This organisation may revoke this letter and any organisation(s) may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated.

Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in each participating organisation and the R&D office in this organisation.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Mark Walker', written over a faint blue horizontal line.

Mark Walker
Senior Research Governance Manager

Gloucestershire R&D Consortium)
(Gloucestershire Hospitals NHS Foundation Trust/2gether NHS Foundation Trust/Gloucestershire Care Services/Gloucestershire Clinical Commissioning Group)

Our Reference: 887AWP

Emma-Jane Stephens
Department of Clinical Psychology
University of Bath
Claverton Down
Bath
BA2 7AY
8th July 2015

Dear Emma,

Title of study: The influence of self-compassion and shame on engagement with services and recovery style in first episode psychosis.

Approval date: 08 July 2015

End date: 01 April 2016

Thank you very much for applying to undertake your research in AWP, we pride ourselves on a straight forward and rapid process for research governance and project management.

We are pleased to advise that we have been able to grant R&D Permission at Avon and Wiltshire Mental Health Partnership NHS Trust ("the Trust").

We also require you to document any study activity on RiO for the relevant patient records. *Please refer to the attached document for guidance.*

We now use EDGE (a Clinical Management System) to manage our research studies. As part of your approval you will be issued with an account and guide and will be expected to upload AWP recruitment figures regularly. This is a requirement from 01 April 2014 for all research recruiting in the Trust. Failure to comply with this will result in your research being suspended, so please make sure you complete this on a monthly basis.

The R&D Permission in the Trust is valid until 01 April 2016. If you require any extension to this in the future please contact us to arrange. The documentation listed below has been received and all the relevant governance checks have now been completed. I am therefore happy to provide R&D Permission for the above study across all locations within the Trust parameters.

You are reminded that you must report any adverse event or incident whether or not you feel it is serious, quoting the study reference number. This requirement is in addition to informing the Chairman of the relevant Research Ethics Committee. You are also required to submit to the Research and Development Operations Manager (Hannah Antoniadou) a final outcome report on completion of your study, and if necessary to provide interim annual reports on progress. Should publications arise, please also send copies to Hannah Antoniadou for inclusion in the study's site file.

You must also abide by the research and information governance requirements for any research conducted within the NHS:

- Work must be carried out in line with the Research Governance Framework which details the responsibilities of everyone involved in research.
- You must comply with the Data Protection Act 1998 and where required, have up to date Data Protection Registration with the Information Commissioners Office. Where staff are employed, this includes having robust contracts of employment in place and

ensuring that staff are made aware of their obligations through training and similar initiatives.

You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice:

(http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253)

You must have appropriate policies and procedures in place covering the security, storage, transfer and disposal of information both personal and sensitive, or corporate sensitive information. Any information security breach must be reported immediately to the Trust.

Where access is granted to sensitive corporate information, this must not be further disclosed without the explicit consent of the Trust unless there is an override required by law. Where disclosure is required under the Freedom of Information Act 2000, the Trust will assist you in processing the request.

Please note that, as a public authority, the Trust is obligated to comply with the provisions of the Freedom of Information Act 2000, including the potential disclosure of information held by the Trust in connection with this study. Where a request for potential disclosure of personal, corporate sensitive, or contract information is made under the Freedom of Information Act 2000, due regard shall be made to any duty of confidentiality or commercial interest.

Yours sincerely

Hannah Antoniades
Research & Development Operations Manager
Avon and Wiltshire Mental Health Partnership NHS Trust

CC:

Lorna Hogg (Bath University Academic Supervisor)
Dr. Kate Chapman (AWP Local Collaborator)

APPENDIX E- Amendment Correspondance

Our Ref: AWP 887
Miss Emma Stephens
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Bath
Claverton Down
Bath
BA2 7AY
27 November 2015

Hannah Antoniades
Research and Development
Avon & Wiltshire Mental Health Partnership NHS
Trust
Fromeside
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 1EG
0117 378 4267
hannah.antoniades@awp.nhs.uk

Dear Emma,

Title of study: The influence of self-compassion and shame on engagement with services and recovery style in first episode psychosis.

REC ref: 15/NW/0311
Amendment no: 01
Approval date: 27 November 2015
End date: 01 April 2016

I am pleased to advise you that I have reviewed the amended documents (listed below) for the above study, and am happy for Avon and Wiltshire Mental Health Partnership NHS Trust to continue to be a site for this project.

I can confirm that we have received the Research Ethics Committee favourable opinion dated 27 November 2015 with the amendment approval request.

Document

Participant information sheet (PIS)

Yours sincerely,
Hannah Antoniades
Deputy Director of Research & Development
Avon and Wiltshire Mental Health Partnership NHS Trust
CC:
Lorna Hogg (Bath University Academic Supervisor)
Dr. Kate Chapman (AWP Local Collaborator)

**Miss Emma-Jane Kirsten Stephens
Trainee Clinical Psychologist
Taunton NHS
Department of Clinical Psychology
University of Bath
Claverton Down
Bath
BA2 7AY**

11 February 2016

Dear Emma

Study title:

The influence of self-compassion and shame on engagement with services and recovery style in first episode psychosis.

REC reference: 15/NW/0311

Protocol number:n/a

Amendment number:2

Amendment date: 20 January 2016

IRAS project ID: 162293

Summary:

Approval is sought for changes made to protocol to include researchers to attend groups run by the Early Intervention service (e.g. Recovery groups, Occupational therapy groups) to briefly inform members about the research and distribute information sheets. The above amendment was reviewed at the meeting of the Sub-Committee held on 09 February 2016.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0311: Please quote this number on all correspondence

Yours sincerely

Ewan Waters

REC Assistant

PP: Dr Tim S Sprosen

Chair

E-mail: nrescommittee.northwest-
haydock@nhs.net *Enclosures:*

Our Ref: AWP 887
Miss Emma Stephens
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Bath
Claverton Down
Bath
BA2 7AY
01 March 2016

Dr Julian Walker
Research and Development
Avon & Wiltshire Mental Health Partnership NHS
Trust
Fromeside
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 1EG
0117 378 4267
julian.walker@nhs.net

Dear Emma,

Title of study: The influence of self-compassion and shame on engagement with services and recovery style in first episode psychosis.

REC ref: 15/NW/0311
Amendment no: Sub Amend 02
Approval date: 01 March 2016
End date: 01 April 2016

I am pleased to advise you that I have reviewed the amended documents (listed below) for the above study, and am happy for Avon and Wiltshire Mental Health Partnership NHS Trust to continue to be a site for this project.

I can confirm that we have received the Research Ethics Committee favourable opinion dated 20 January 2016 with the amendment approval request.

Yours sincerely,

Director of Research & Development
Avon and Wiltshire Mental Health Partnership NHS Trust

CC:
Lorna Hogg (Bath University Academic Supervisor)
Dr. Kate Chapman (AWP Local Collaborator)

OUR R&D REF: 15/017/2gt

Miss Emma-Jane Stephens
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Bath, Claverton Down,
Bath, Somerset
BA2 7AY

Dear Miss Stephens,

Study Title:	The influence of self-compassion and shame on engagement with services and recovery style in first episode psychosis.
REC Ref. N ^o	15/NW/0311
IRAS Ref. N ^o	162293
Amendment Ref. N ^o	Substantial Amendment 1 12.11.2015 and Substantial Amendment 2 20.01 2016

Thank you for notifying me about the above study amendments for review by the Gloucestershire Research Support Service on behalf of 2gether NHS Foundation Trust.

These amendments have been reviewed and approved by the Senior Research Governance Manager, Mark Walker. The trust is able to support this amendment to the above study on the basis of the information provided and as per the REC Amendment Favourable Ethical Opinion Letters, dated 26th November 2015 (Amendment 1) and 11th February 2016 (Amendment 2).

The documents reviewed and approved were:

Amendment 1

- Notice of Substantial Amendment (non-CTIMP) 1 12 November 2015
- Participant information sheet (PIS) 3 12 November 2015

Amendment 2

- Notice of Substantial Amendment (non-CTIMP) 2 20 January 2016
- Research protocol or project proposal 2 dated 22 January 2016

Please don't hesitate to contact me if you have any queries.

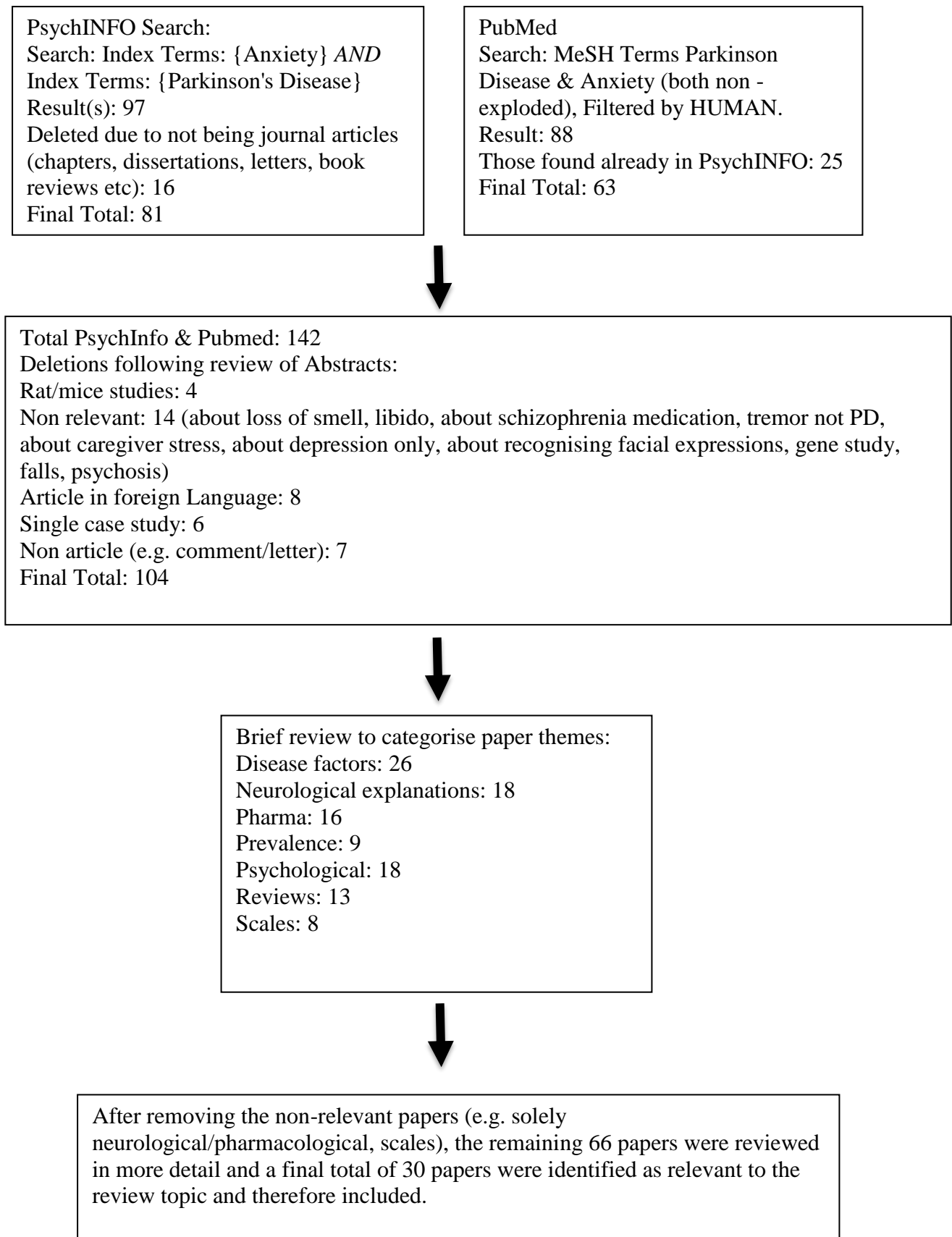
We continue to wish you well with your study.

Kind Regards
Nigel

**Nigel Johnson | Research Governance Support Officer | Gloucestershire Hospitals NHS Foundation Trust/2gether NHS Foundation Trust/Gloucestershire Care Services/Gloucestershire Clinical Commissioning Group
Gloucestershire Research Support Service | Leadon House | Great Western Road | Gloucestershire Royal Hospital | Gloucester | GL1 3NN**

Tel: 0300 4225467(GRH 5467) | Fax: 0300 4225469

APPENDIX F: Flow diagram of literature search and identification of papers



APPENDIX G- OCD-UK Questionnaire Pack
Pre Questionnaire 1- Experience & Expectations of the Day
What is your current role?

CBT Therapist/High Therapist	
Trainee CBT Therapist	
Trainee Clinical/Counselling Psychologist	
Clinical/Counselling Psychologist	
Counsellor	
PWP/Low Intensity Worker	
Mental Health Nurse	
Other...Please specify:	

Please rate how *experienced* you currently feel you are at working with people with OCD:

Very Experienced	Quite Experienced	Not Very Experienced	Not at all Experienced
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate how *confident* you currently feel about:

	Very Confident	Quite Confident	Not Very Confident	Not at all Confident
Working clinically with someone experiencing OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What the evidence-based treatments for OCD are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assessing risk in OCD e.g. thoughts of harming others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having some insight into what it feels like to experience OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involving family/carers in the treatment of OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any personal experience of OCD?: YES NO (Please circle)

<p>How did you hear about the conference?</p> <p>What are your expectations/hopes for the day?</p>

Pre-Questionnaire 2- Therapy Relevant Beliefs

People develop beliefs about a condition from past experience, the media, and other influences. Please complete the following anonymous questionnaire about you beliefs about OCD. Please rate each item on a scale from 0 to 100, where **0 indicates “Do not agree at all”** and **100 indicates “Completely agree”**.

Question	Rating 0 to 100:
1. OCD is caused by a chemical imbalance in the brain.	
2. OCD is a psychological problem	
3. I believe that obsessional problems can be overcome.	
4. I am certain that only psychological therapy can help people to beat OCD.	
5. I am certain that only medication therapy can help people to beat OCD.	
6. There's something wrong with the personality of obsessional people which means they're unlikely to overcome their problems.	
7. People with OCD have something physically wrong with them.	
8. I have dispensed good therapy for the OCD in the past.	
9. I have dispensed the wrong therapy for the OCD in the past.	
10. I have not given the obsessional patients I have seen enough therapy.	
11. OCD is a chronic condition which can be managed but not cured.	
12. I am optimistic about people's abilities to overcome the OCD.	
13. In my experience, most therapists don't understand OCD.	
14. My patients have not made as much progress in beating OCD as I would have liked them to, because of faults of their own.	
15. My patients have not made as much progress in beating OCD as I would have liked them to, because of my therapy not being good enough.	
16. My patients have not made as much progress in beating OCD as I would have liked them to, because OCD is a difficult problem to beat.	
17. My patients have not made as much progress in beating OCD as I would have liked them to, because of other life difficulties which they have.	
18. My patients have not made as much progress in beating OCD as I would have liked them to, because of bad things that happened to them when they were younger.	
19. The therapy I have done in the past has not focussed sufficiently on the obsessional problem.	
20. Over time I have become more and more pessimistic about the chances of treating OCD successfully.	
21. Over time my understanding of how OCD works has increased.	

Post Questionnaire 1- Feedback

Please rate the overall *content* of the day on the following:

	Very Good	Quite Good	Not Very Good	Not at all Good
Interest of topics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relevance to your role/work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful for developing skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Positive impact on your feelings about OCD treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please rate how *confident* you feel about:

	Very Confident	Quite Confident	Not Very Confident	Not at all Confident
What the evidence based treatments for OCD are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working clinically with someone experiencing OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assessing risk in OCD e.g. thoughts of harming others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having some insight into what it feels like to experience OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involving family/carers in the treatment of OCD?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How well did the day meet your expectations?

Very Well	Quite Well	Not Very Well	Not at all Well
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What would you like to see in future Professionals' Conferences? Please give details:

How did the OCD-UK team make you feel welcomed today? Please give details:

Post Questionnaire 2- Therapy Relevant Beliefs

People develop beliefs about a condition from past experience, the media, and other influences. Please complete the following anonymous questionnaire about you beliefs about OCD. Please rate each item on a scale from 0 to 100, where **0 indicates “Do not agree at all”** and **100 indicates “Completely agree”**.

Question	Rating 0 to 100:
1. OCD is caused by a chemical imbalance in the brain.	
2. OCD is a psychological problem	
3. I believe that obsessional problems can be overcome.	
4. I am certain that only psychological therapy can help people to beat OCD.	
5. I am certain that only medication therapy can help people to beat OCD.	
6. There's something wrong with the personality of obsessional people which means they're unlikely to overcome their problems.	
7. People with OCD have something physically wrong with them.	
8. I have dispensed good therapy for the OCD in the past.	
9. I have dispensed the wrong therapy for the OCD in the past.	
10. I have not given the obsessional patients I have seen enough therapy.	
11. OCD is a chronic condition which can be managed but not cured.	
12. I am optimistic about people's abilities to overcome the OCD.	
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14. My patients have not made as much progress in beating OCD as I would have liked them to, because of faults of their own.	
15. My patients have not made as much progress in beating OCD as I would have liked them to, because of my therapy not being good enough.	
16. My patients have not made as much progress in beating OCD as I would have liked them to, because OCD is a difficult problem to beat.	
17. My patients have not made as much progress in beating OCD as I would have liked them to, because of other life difficulties which they have.	
18. My patients have not made as much progress in beating OCD as I would have liked them to, because of bad things that happened to them when they were younger.	
19. The therapy I have done in the past has not focussed sufficiently on the obsessional problem.	
20. Over time I have become more and more pessimistic about the chances of treating OCD successfully.	
21. Over time my understanding of how OCD works has increased.	

APPENDIX H- Literature Review Journal Instructions for Authors

PREPARATION OF MANUSCRIPTS

Research Reports

Organization and style of presentation

Manuscripts must be written in English. Authors whose native language is not English are recommended to seek the advice of a native English speaker, if possible, before submitting their manuscripts. Manuscripts should be double spaced throughout with wide margins (2.5cm or 1in), including the abstract and references. Every page of the manuscript, including the title page, references, tables, etc., should include a page number centered at the bottom.

Manuscripts should be organized in the following order with headings and subheadings typed on a separate line, without indentation.

Title Page

1. Title (should be clear, descriptive and concise).
2. Full name(s) of author(s).
3. Full affiliation(s). Delineate affiliations with lowercase letters.
4. Present address of author(s), if different from affiliation.
5. Running title (45 characters or less, including spaces).
6. Complete correspondence address, including telephone number, fax number and e-mail address. Leave the author information blank if double-blind peer review is wished for, but do include the information in the submission letter to the editor.

Abstract and Keywords

The abstract for research papers should follow the “structured abstract” format:

BACKGROUND: OBJECTIVE: METHODS: RESULTS: CONCLUSIONS:

The abstract should try to be no longer than 250 words.

For other papers such as Reviews, the abstract should be clear, descriptive, and self-explanatory, and no longer than 250 words.

Include a list of 4-10 keywords. These keywords should be terms from the [MeSH database](#).

Introduction

Materials and Methods

There is no word limit to the materials and methods section, as the journal’s policy is that methodological rigour and reproducibility is of great importance.

Results

Discussion

Acknowledgments including sources of support

Conflict of Interest

If there is no conflict of interest to declare, do still include this section and insert “The authors have no conflict of interest to report”

Reviews

Reviews should be authoritative and topical and provide comprehensive and balanced coverage of a timely and/or controversial issue. Reviews should be prepared as detailed above for a Research Report omitting Introduction through Discussion, and include a Conclusion. When submitting a Review, clearly signify the article as such in the submission title by using: "REVIEW: full article title".

APPENDIX I- Service Improvement Project Journal Instructions for Authors

Style Guide

- **Title page.** The title should phrase concisely the major issues. Author(s) to be given with departmental affiliations and addresses, grouped appropriately. A running head of no more than 40 characters should be indicated.
- **Abstract.** The abstract should include up to six key words that could be used to describe the article. This should summarize the article in no more than 250 words, references should not to be included in the abstract.
- **All articles must include a set of 3-5 learning objectives** that will be achieved through reading the paper. At the end of each paper a summary of the main points from the paper must be included with suggestions for follow-up reading. This stipulation is in keeping with the practitioner and professional development aims of the journal.
- **Text.** This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal. Attention should be paid to the Editorial Statement. References within the text should be given in the form of (Jones & Smith, 1973). When there are three or more authors the first citation should be given as Williams et al. (1973). The appropriate positions of tables and figures should be indicated in the text. Footnotes should be avoided where possible.
- **References should be in the APA style.** All citations in the text should be listed in strict alphabetical order according to surnames. Multiple references to the same author should be listed using a, b, etc., for entries within the same year.
Note: Authors are encouraged to include digital object identifiers (dois) in their citation listings, as follows: Kaltenthaler, E., Parry, G. and Beverley, C. (2004). Computerised cognitive behaviour therapy: a systematic review. *Behavioural and Cognitive Psychotherapy*, 32, 31–55. doi:10.1017/S135246580400102X.
- **Declaration of interests** should be included with all papers, if there are none this should be stated.
- **Acknowledgements.** May include previous unpublished presentations (e.g. dissertation, meeting paper), financial support, scholarly or technical assistance etc.

APPENDIX J- Main Research Journal Instructions for Authors

Psychology and Psychotherapy: Theory, Research and Practice

Author Guidelines

All papers published in Psychology and Psychotherapy: Theory, Research and Practice are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The journal operates a policy of returning any papers that are over this word limit to the authors. The word limit does not include the abstract, reference list, figures and tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length (e.g., a new theory or a new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

- Research articles: 5000 words
- Qualitative papers: 6000 words
- Review papers: 6000 words
- Special Issue papers: 5000 words

Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded [here](#).
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- Manuscripts describing clinical trials must be submitted in accordance with the CONSORT statement on reporting randomised controlled trials (<http://www.consort-statement.org>).

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.