Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych)



Dr Poppy Brown

Harris Manchester College

University of Oxford

July 2024

Word Counts

Systematic Review of the Literature: 6,841

Service Improvement Project: 5,015

Theory Driven Research Project: 5,032

Executive Summary: 670

Connecting Narrative: 996

Total word count: 18,554 (Limit: 19,000)

Contents

ABSTRACTS 5

SYSTEMATIC REVIEW OF THE LITERATURE 10

ABSTRACT 11

INTRODUCTION 12

METHOD 14

RESULTS 19

DISCUSSION 48

REFERENCES 53

SERVICE IMPROVEMENT PROJECT 66

ABSTRACT 67

INTRODUCTION 68

METHODS 73

RESULTS 75

DISCUSSION 81

REFERENCES 87

THEORY DRIVEN RESEARCH PROJECT 91

ABSTRACT 92

METHODS 97

ANALYSIS 102

RESULTS 104

DISCUSSION 113

REFERENCES 118

EXECUTIVE SUMMARY 127

CONNECTING NARRATIVE 130

ACKNOWLEDGEMENTS 134

SYSTEMATIC REVIEW OF THE LITERATURE: APPENDICES 136

Appendix A: Mixed methods appraisal tool items and instructions 136

Appendix B: Risk of bias appraisal itemised results (MMAT scoring) 139

Appendix C: Schizophrenia Research: guide for authors 141

SERVICE IMPROVEMENT PROJECT: APPENDICES 143

Appendix D: Approved clinical audit form 143

Appendix E: Staff survey 146

Appendix F: Training summary sheet 148

Appendix G: Summary of service user feedback and how this was implemented *149*

Appendix H: The Cognitive Behaviour Therapist: guide for authors *150*

Appendix I: Key learning, practise points and further reading for The Cognitive Behaviour Therapist *153*

THEORY DRIVEN RESEARCH PROJECT: APPENDICES 155

Appendix J: Evidence of ethical approval *155*

Appendix K: Participant questionnaire pack *156*

Appendix L: Summary of feedback from PPI and how this was implemented *177*

Appendix M: Qualitative comments added by participants *178*

Appendix N: Further details on statistical analysis *189*

Appendix O: Journal of Parkinson's disease: guide for authors *194*

Abstracts

Systematic Review of the Literature

Sleep and Paranoia: a systematic review and meta-analysis

Background: Sleep dysfunction commonly co-occurs with paranoia and is hypothesised to be a contributory causal mechanism in its development and maintenance.

Objectives: To systematically review and quantitatively evaluate the evidence for the relationship between sleep dysfunction and paranoia across the spectrum of severity.

Method: A systematic search was conducted to identify studies investigating the relationship between aspects of sleep and paranoia across clinical and non-clinical groups. A random effects model using a Fisher r-to-z transformed correlation coefficient was used for meta-analysis.

Results: 41 studies were included in the review and 13 in the meta-analysis. The literature supports a clear link between sleep dysfunction and paranoia across the spectrum of severity. The meta-analysis suggested this link is small-to-moderate in size (r=0.29, 95% CI: 0.15-0.42 for the six studies using the most robust measures of insomnia and paranoia). There was significant heterogeneity across studies but no evidence of publication bias. The results of the review also provided evidence that the relationship is to some extent causal, with sleep disruption leading to increased paranoia, though there is also evidence of a bi-directional relationship. Negative affect is frequently seen as a mediator of this relationship.

Conclusion: This review and meta-analysis for the first time separates out and examines the significant relationship between sleep and paranoia individually from any other psychotic experience. Studies are needed that further assess the potential for early intervention on sleep dysfunction in those experiencing paranoia.

Service Improvement Project

20 years versus 20 minutes: increasing the understanding of delusions from a cognitive behavioural perspective in two older adult community mental health teams

The last two decades have seen considerable development in our understanding of delusions, with medical perspectives broadening into more holistic bio-psychosocial models. Of particular relevance to services is the increasing evidence base for cognitive-behavioural models and treatments. A number of national initiatives have aimed to ensure these developments are reflected in services. Primarily these have targeted adult services, yet delusions are still prevalent in older adults. Across two older adult services this study assessed the number of patients experiencing delusions, explored staff perspectives regarding delusions, and delivered a brief training on cognitive behavioural approaches to delusions. Three service users contributed to the training content. Endorsement of theoretical perspectives regarding delusions were measured pre and post training. Results showed over 20% of patients in the service may be experiencing paranoia or delusions, but less than 1% of these were referred for CBT. Of 27 staff participants, less than half had received training on working with delusions, most of which was from as many as 20 years ago. Nearly all reported a lack of knowledge prevented them from considering psychological perspectives. No immediate changes in outcome measures were seen after the training, with a striking diversity in approach to delusions according to professional background. All staff qualitatively reported finding the training valuable, though engagement was dampened by high levels of stress and burnout. Promoting change within stretched systems to reflect the developing cognitive behavioural evidence base is challenging but necessary. Where full interventions are not possible, small but consistent nudges may provide a path forward.

Theory Driven Research Project

Paranoia and Unusual Sensory Experiences in Parkinson's Disease

Background: Psychotic experiences (PEs) in Parkinson's disease (PD) are reportedly common. However, there is a lack of knowledge regarding the specific nature of these experiences, and limited understanding of their development and maintenance.

Aims: First, to comprehensively assess the severity, nature, and associated distress of paranoia and unusual sensory experiences (USEs) in PD. Second, using structural equation modelling (SEM), to assess what variables are significantly associated with these experiences, focussing on the psychological processes central to understanding PEs in non-PD groups.

Method: A questionnaire battery was completed by 369 individuals with PD with a mean age of 66 years and mean time since diagnosis of 5 years. For a subset of measures, comparisons were made to an age-matched control group.

Results: 182 (49%) participants reported USEs, including almost half of those not taking any dopaminergic medication. For 83 (23%), the experience was distressing. Paranoia across the sample was significantly lower than in age-matched controls. However, specific paranoid concerns around abandonment and spousal betrayal were prevalent (16% and 10% respectively). Half of those experiencing more frequent PEs wanted greater support for their symptoms. Rates of depression, anxiety, loneliness, and stigma were high across the sample, and almost all psychological variables tested were significantly associated with USEs and paranoia in individual SEMs. In unified SEMs, depression and anxiety were retained as the most significant predictors of USEs, as were negative beliefs about others and anxiety for paranoia.

Conclusion: PEs in PD are common, even in those not taking dopaminergic medication. For a subset, these experiences are distressing and not resolved by existing treatment. Psychological processes like negative cognition and affect could play a maintaining role in PEs in PD thus providing easy avenues for trialling intervention. Longitudinal data to explore the direction of effects, and further exploration to understand the rates and types of paranoia is now required.

Published Work

This thesis is submitted in alternative format with three papers. To maximise dissemination, the systematic review of literature and service improvement project papers have been submitted to peer-reviewed journals and the theory driven research project is due to be submitted.

The systematic review is under review at *Schizophrenia Research.*
The service improvement project is under review at *The Cognitive Behaviour Therapist.*
The theory driven research project is under review at *The Journal of Parkinson's Disease.*

Systematic Review of the Literature

Sleep and Paranoia: a systematic review and meta-analysis

Poppy Brown

The Oxford Institute of Clinical Psychology Training and Research

Oxford Health NHS Foundation Trust

University of Oxford

poppy.brown@hmc.ox.ac.uk

Word count: 6,841

Submission to course: January 2024

Internal Supervisor: Prof Craig Steel, craig.steel@hmc.ox.ac.uk
The Oxford Institute of Clinical Psychology Training, Oxford Health NHS Foundation Trust
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

Proposed Journal: This manuscript is under review in *Schizophrenia Research*. This journal was selected due to its focus on psychosis and prior publication of reviews of a similar scale.

Declaration of Interest: None

The trainee confirms that supervisors have read and provided feedback on the work, deeming it suitable for assessment.

Abstract

Background: Sleep dysfunction commonly co-occurs with paranoia and is hypothesised to be a contributory causal mechanism in its development and maintenance.

Objectives: To systematically review and quantitatively evaluate the evidence for the relationship between sleep dysfunction and paranoia across the spectrum of severity.

Method: A systematic search was conducted to identify studies investigating the relationship between aspects of sleep and paranoia across clinical and non-clinical groups. A random effects model using a Fisher r-to-z transformed correlation coefficient was used for meta-analysis.

Results: 41 studies were included in the review and 13 in the meta-analysis. The literature supports a clear link between sleep dysfunction and paranoia across the spectrum of severity. The meta-analysis suggested this link is small-to-moderate in size (r=0.29, 95% CI: 0.15-0.42 for the six studies using the most robust measures of insomnia and paranoia). There was significant heterogeneity across studies but no evidence of publication bias. The results of the review also provided evidence that the relationship is to some extent causal, with sleep disruption leading to increased paranoia, though there is also evidence of a bi-directional relationship. Negative affect is frequently seen as a mediator of this relationship.

Conclusion: This review and meta-analysis for the first time separates out and examines the significant relationship between sleep and paranoia individually from any other psychotic experience. Studies are needed that further assess the potential for early intervention on sleep dysfunction in those experiencing paranoia.

Keywords: insomnia, sleep-dysfunction, paranoia, psychosis, persecutory delusions, review

Introduction

Sleep disturbance has long been recognised as a common occurrence in those experiencing psychosis, ever since schizophrenia was first clinically described by early psychiatrists Kraepelin and Bleuler (Bleuler, 1950; Kraepelin, 1919). Studies repeatedly find that sleep dysfunction – a term used broadly to include all of self-reported low quality sleep, objectively measured sleep difficulties, and diagnosed sleep disorders – to be highly prevalent in those with psychotic experiences (PEs) such as paranoia (Bagrowska et al., 2022; Freeman et al., 2009). Improved sleep has also been reported as a preferred treatment target for many patients experiencing delusions and other PEs (Freeman, Taylor, et al., 2019).

More recently, evidence has emerged for the role of sleep dysfunction as a contributory causal factor and treatment target in PEs, particularly delusions and hallucinations (Freeman, 2016; Reeve et al., 2015). For instance, experimental sleep deprivation studies show that restricting the sleep of healthy individuals to, for example, four hours a night for three consecutive nights, significantly increases paranoia, as well as hallucinations, grandiosity, and cognitive disorganisation (Reeve et al., 2017). Moreover, evidence suggests that treating sleep dysfunction improves paranoia. In a large randomised controlled trial of cognitive behavioural therapy (CBT) for insomnia versus treatment as usual in over 3,500 students with insomnia, those who received the intervention showed reduced paranoia post-treatment, mediated by improved sleep (Freeman et al., 2017). Similarly, in a trial of CBT for insomnia in patients with persecutory delusions, there was evidence of reduced paranoia in some of those who received the intervention compared to

controls, although the trial was insufficiently powered to truly assess effects (Freeman et al., 2015).

Overall, there is considerable evidence for the importance of sleep in PEs such as paranoia. Unsurprisingly therefore, there have been a number of systematic reviews and meta-analyses assessing the role of sleep in psychosis (Chan et al., 2017; Chouinard et al., 2004; Reeve et al., 2015). However, none are from recent years – despite significant growth of literature in this area – and no review or meta-analysis has focussed solely on paranoia. Yet the importance of investigating individual PEs one at a time rather than psychosis or even positive symptoms of psychosis as a whole has become increasingly recognised. There is significant empirical evidence showing that individual PEs load onto independent factors (Kessler & Wang, 2008; Peralta & Cuesta, 1999; Vazquez-Barquero et al., 1996; Wigman et al., 2009) and have differing levels of environmental and genetic risk (Zavos et al., 2014). For instance, heritability is estimated to be higher for paranoia (h^2=0.52) than for hallucinations (h^2=0.15). As a result, there are separate cognitive models for individual PEs such as delusions and hallucinations, and individualised treatments targeting each experience.

The clinical picture, role, or mechanisms of sleep dysfunction in the occurrence of delusions versus hallucinations, for example, may therefore differ, making it important to review the role of sleep for each PE individually. This review and metanalysis focusses on paranoia, given sleep dysfunction is a clear part of cognitive theorising in paranoia (Freeman, 2016) and there is no existing review in this area. Given paranoia lies on a spectrum of severity in the general population ranging from mild suspiciousness and social-evaluative concerns at one end, to persecutory delusions at the other (Bebbington et al., 2013; Freeman

et al., 2011; Wong et al., 2014) with a similar factor structure across the spectrum (Shevlin et al., 2017), both clinical and non-clinical studies are included.

The present study reports both a systematic review and meta-analysis. The primary question addressed by the meta-analysis is: how strong is the relationship between sleep dysfunction and paranoia? The systematic review also qualitatively addresses this question, as well as looking at the extent to which sleep dysfunction has been found to be a causal mechanism in the occurrence of paranoia by assessing whether sleep dysfunction predicts the onset and persistence of paranoia, and whether treating sleep dysfunction helps reduce paranoia. The systematic review also explores what variables have been shown to be mediating and moderating the relationship between sleep and paranoia.

Method

Systematic Review

Search strategy and information sources

The project was conducted with reference to the preferred reporting items for systematic reviews and meta-analyses (PRISMA) (Page et al., 2021). The protocol was registered on the international prospective register of systematic reviews (PROSPERO: CRD42022381709). A systematic search of the literature was conducted, searching Pubmed, Medline, PsychINFO and Embase for English Language papers using the following search terms: (Sleep OR insomnia OR nightmare* OR dream) AND (paranoi* OR delus* OR persec* OR psychotic OR psychosis OR “ideas of reference”) appearing in the title. No date restriction was applied.

Inclusion criteria for systematic review

Papers were required to meet all of the following criteria:

- English language papers
- Published in a peer-reviewed journal
- Measure of paranoia
- Measure of sleep disturbance
- Analysis assessing the relationship between the measures of paranoia and sleep

Exclusion criteria for systematic review

Papers meeting any of the below criteria were excluded:

- Qualitative studies
- Single case studies
- Studies relating primarily to
    - Neurological conditions such as dementia
    - Bipolar or other affective psychoses including post-partum psychosis

Selection, data collection, and double rating

This search found 822 papers (February 2024). Titles and abstracts were screened then full texts as necessary. Reference lists of included studies and previous systematic reviews on sleep and psychosis were scanned to identify any missed papers. Mendeley and Covidence were used for managing references. Figure 1 presents a PRISMA diagram summary (Page et al., 2021) of the search process. The study selection process was completed by two authors (PB and NS), with NS reviewing and rating 20% of title and abstracts (achieving a kappa of

0.83 – near perfect agreement) and 25% of full texts (achieving a kappa of 1.00 – perfect agreement). Data extraction of included papers was completed by PB, with 50% double rated by NS. The following data were extracted: citation, sample size and characteristics, measures of sleep and paranoia used, and a summary of the study findings regarding the relationship between sleep and paranoia.

Quality Appraisal

The quality of included studies was assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). This measure is useful for assessing quality across a range of methodological designs unlike many other tools that are specific, for instance, to randomised controlled trials (RCTs). It has good psychometric properties, with intra-class correlations ranging from 0.7-0.9 (moderate-to-perfect agreement between reviewers) (Pace et al., 2012). The MMAT's latest version (2018) includes two screening questions and 25 criteria, appraising five categories of study designs. Two categories are for qualitative designs, so only three categories were used for the present review: RCT, quantitative nonrandomised (e.g. non-randomised experiments, cohort studies, experience sampling methodology (ESM) studies) and quantitative descriptive studies (e.g. cross-sectional studies and case series). The MMAT items and instructions can be viewed in Appendix A. The appropriate category was chosen for each study. If the screening criteria were met, then the study was assessed on the five items in its category, leading to a score of between 0/5 and 5/5. Fifty percent of studies were double rated (PB, NS) with a Cohen's kappa of 0.93 – near perfect agreement. Disagreements were discussed and resolved to arrive at a final decision.

Meta-analysis

A meta-analysis was conducted to synthesise the extent of the relationship between paranoia and sleep disturbance. The primary meta-analysis included studies where a cross-sectional correlation between self-reported sleep disturbance and paranoia was reported, or access to data where such a correlation could be calculated. Any measure of sleep and paranoia was permitted in the initial analysis, so long as the measures of paranoia and sleep contained a minimum of five items. Measures of 0-4 items were considered very brief and less likely to form a coherent continuous factor, whereas a minimum of five items was considered sufficient to be combined as a measure.

Following this, a subgroup analysis was conducted where studies were separated according to a stricter set of criteria applied to the measures that were included. A list of all measures used in initial meta-analysis was compiled and from these it was decided a priori which measures would be considered the most robust, homogeneous, and well-validated dimensional measures. For sleep there were four measures of insomnia fitting these more specific criteria: The Insomnia Severity Index (ISI) (Bastien et al., 2001), Sleep Condition Indicator (SCI) (Espie et al., 2014), Sleep-50 questionnaire (Spoormaker et al., 2005), and PROMIS Sleep Disturbance Scale (Buysse et al., 2010). Measures such as the Pittsburgh Sleep Quality Index (Buysse et al., 1998), or studies reporting on sleep quality and duration, were excluded due to their low specificity as clinical measures. Applying similar criteria to the paranoia measures, studies were retained that used the Green et al., Paranoid Thoughts Scale (GPTS) (Green et al., 2008), the Revised Green et al., Paranoid Thoughts Scale (R-GPTS) (Freeman, Loe, et al., 2019a), Paranoia Checklist (Freeman et al., 2005) or the paranoia subscale of the Specific Psychotic Experiences Questionnaire (SPEQ) (Ronald et

al., 2014). Again, these are dimensional and well-validated measures specific to paranoia, rather than, for example, the Comprehensive Assessment of At-risk Mental States (CAARMS) (Yung et al., 2005) or Positive and Negative Syndrome Scale (PANSS) (Kay, 1991) which do not provide thorough assessment specific to paranoia. The subgroup analysis therefore separated out studies that used one measure from both of these lists versus those that had neither or just one measure from each list.

Statistical Analysis

Statistical analysis was performed using jamovi version 2.0 to comprehensively synthesise the extent of the relationship between paranoia and sleep disturbance (The jamovi project, 2024). Pearson's *r* correlation coefficient was used as the primary metric. Where studies reported a different effect size, e.g. an odds ratio, this was converted using escal.site based on recommended computational methods (Cohen, 2013). Where multiple effect sizes were reported, effect sizes unadjusted for mediators were chosen over adjusted, and where multiple robust measures were reported on, the one reported on first (i.e. primary outcomes) was chosen. The analysis was carried out using the Fisher r-to-z transformed correlation coefficient as the outcome measure. A random-effects model was fitted to the data. Heterogeneity of studies was assessed using the restricted maximum likelihood estimator (tau^2), where $tau^2>0$ suggests the presence of heterogeneity (Viechtbauer, 2005). The I^2 statistic was also assessed, with I^2 values of 0%, 25%, 50%, and 75% indicating no, low, moderate, and high heterogeneity (Higgins et al., 2003). If substantial unaccounted heterogeneity was found in the outcome of interest across studies, it was planned to complete a meta-regression in order to try and explain the variance.

Publication bias was assessed via funnel plot inspection, Egger's test (Egger et al., 1997), Begg's test (Begg, 1994), and calculation of Orwin's fail-safe index (Orwin, 1983). An asymmetrical funnel plot, significant Egger or Begg tests, or a low fail-safe index can be suggestive of publication bias. The analysis was first completed for all studies included in the meta-analysis, then repeated for the subgroup analysis where studies were separated based on the measures used.

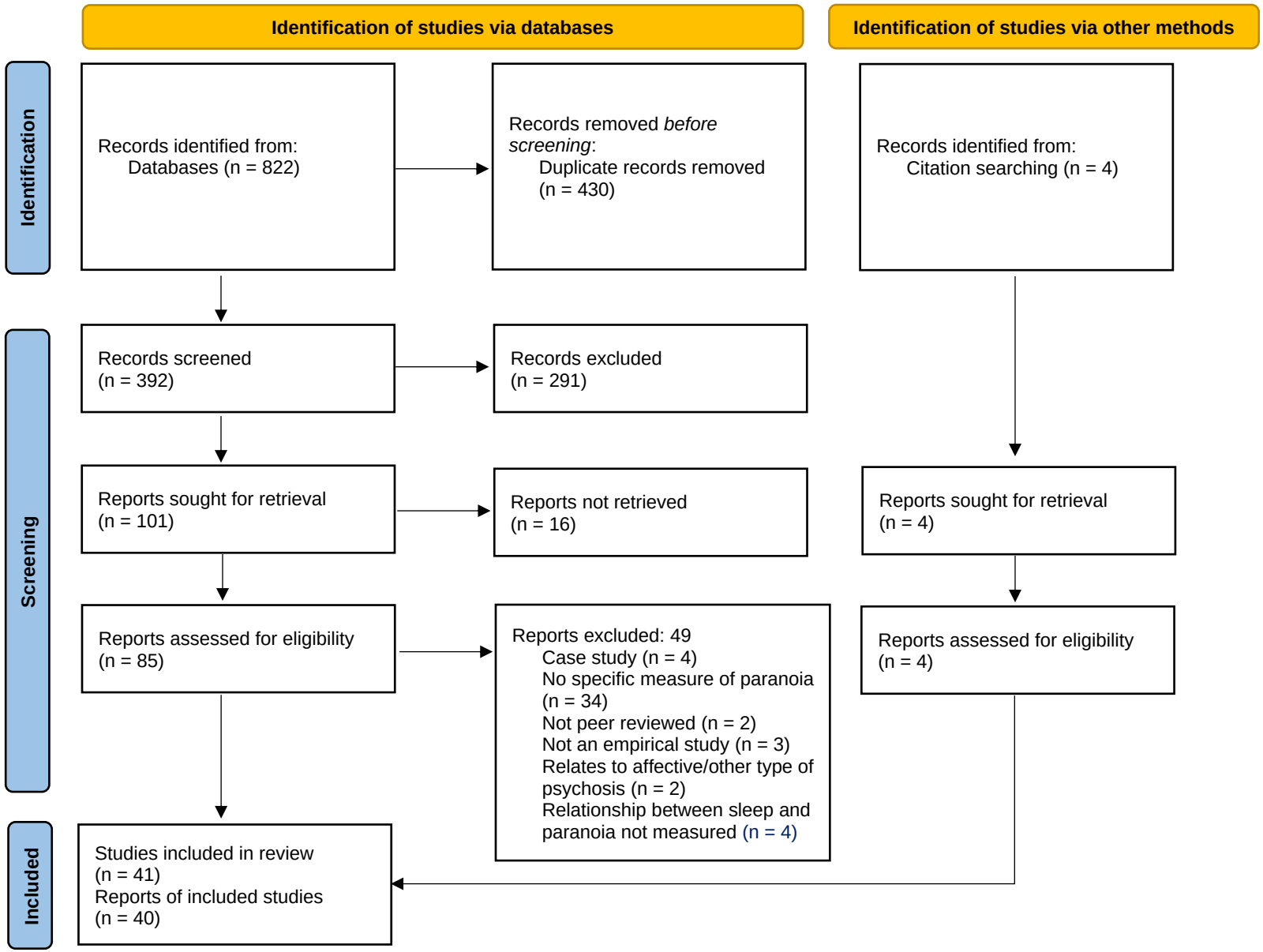
Results

Systematic Review

Search Results

A total of 41 studies (40 manuscripts, with one study reporting on two separate studies (Rehman et al., 2018)) meeting the inclusion criteria for the systematic review were found. This totalled 291,394 participants (range 6-261,547, and total 29,847 when removing one particularly large study). Over a third of studies were based in the UK, with a number of other studies run in Germany, Poland, America, and one study recruiting samples from over 50 different countries. Thirteen studies recruited clinical participants from clinical mental health services, 23 studies recruited non-clinical samples, and 5 recruited both, leading to a total of 1,565 clinical participants and 289,829 non-clinical participants. There were 18 cross-sectional studies, two cohort studies, one longitudinal study, four case series, five experimental studies, six ESM studies, and five RCTs. Summaries of the studies organised by design can be viewed in Tables 1-3.

Figure 1. Prisma flow diagram of the search process



Quality appraisal

All studies scored at least 1 out of 5 on quality appraisal, with only seven scoring a full 5/5. RCTs typically scored the highest, though some had lower scores due to incomplete outcome data and low adherence to the intervention. Where experimental studies scored low this was typically due to not controlling for potential confounders and not recruiting a representative sample, the latter of which was also a limitation of most cross-sectional studies. The cross-sectional studies also rarely assessed for nonresponse bias, which was also a limitation of two of the four case series. The total score for each study can be viewed in Tables 1-3, and itemised scoring for each study in Appendix B.

Cross-sectional studies

All but one of the 18 cross-sectional studies found a positive association between sleep problems and paranoia. Quality ratings varied, with studies of this design generally scoring lower on sample representativeness and lack of information on potential non-response bias. The largest study analysed data from 261,547 members of the general population from across 56 different countries (Koyanagi & Stickley, 2015). Although the measure of paranoia was only two items (one measuring ideas of persecution and one measuring ideas of control by others), the presence of sleep problems was associated with a significantly higher odds of reporting paranoia (2.38, CI: 2.31-2.96), which remained significant after controlling for anxiety and depression.

Similar findings were reported in other large studies of both adult and adolescent populations. For example, in a study of 8,580 adults, insomnia was associated with a two to threefold increase in paranoia, partially mediated by negative affect, and to a smaller degree,

cannabis use (Freeman et al., 2010). Similarly, in a study of 5000 16-year old twin pairs, paranoia was significantly correlated with insomnia and sleep quality, and also partially mediated by negative affect, with both paranoia and sleep dysfunction sharing similar genetic and environmental influences (Taylor et al., 2015). This study received the only 5/5 quality rating within the set of cross-sectional studies. A smaller study run in Tunisia, although primarily assessing the relationship between internet gaming disorder and psychotic experiences, also found a significant positive relationship between insomnia and paranoia (Fekih-Romdhane et al., 2023) though this study scored only two out of five on quality appraisal due to the student sampling and lack of reporting on non-response bias.

Where some aspect of negative affect was measured (typically anxiety and depression), it was generally found to be a mediator of the relationship. Most studies found only partial mediation, although some studies found that after controlling for depression and anxiety, the association between paranoia and sleep was no longer significant (Blanchard et al., 2021; Scott et al., 2017). A few studies identified other specific mediators of the relationship between sleep and paranoia beyond anxiety and depression. For instance emotional suppression and lack of reappraisal (Grezellschak et al., 2017), and alexithymia and perceptual anomalies (Rehman et al., 2018).

Five studies recruited patients with psychosis with two of these specifically also exploring the prevalence of sleep dysfunction or disorder. Freeman et al., (2009) found moderate or severe insomnia was present in over half of those participants with persecutory delusions, and Reeve et al., (2019) found that 80% of the patient sample received a positive screen or diagnosis of at least one sleep disorder, with fewer than one-third reporting having received any treatment for sleep problems. Two of the clinical studies also compared sleep

dysfunction in clinical versus non-clinical samples, with Goines et al., (2019) finding that their patient sample reported significantly more sleep dysfunction than their control group, and Grezellschak et al., (2017) finding that the correlation between sleep dysfunction and paranoia, although both significant, was higher for their patient sample (r=0.47) than their control sample (r=0.38). These studies scored slightly higher on quality appraisal due to more representative sampling of their target population (i.e. clinical groups).

Four studies focussed more specifically on nightmares in non-clinical populations with sample sizes ranging from 116-1403, predominantly recruiting students or young adults. All four studies found significant correlations, between paranoia and nightmare occurrence and severity (Rek et al., 2017), and nightmare frequency and distress (Kammerer, Bub, et al., 2021; Levin & Fireman, 2002; Sheaves et al., 2016), even after controlling for sleep quality (Kammerer, Bub, et al., 2021). Several mediators were also analysed by Rek et al., (2017), who found that the relationship remained significant after controlling for negative affect but was no longer significant after controlling for PTSD symptoms and stressful life events. Similarly, Kammerer, Bub, et al., (2021) found the relationship was partially mediated by stress and that the specific content of nightmares was related to the frequency of paranoia. For example, nightmares about workspace bullying predicted more frequent paranoia, whereas nightmares about horror films or car accidents did not. Quality appraisal scores were somewhat low for these studies due to the potential lack of representation in the sampling.

Two studies also used objective measures of sleep (Reeve, Sheaves, et al., 2019; Scott et al., 2017), though only one analysed these data's relationship to paranoia. Despite significant positive associations between self-reported sleep problems and increased paranoia (a relationship that analysis suggested was fully mediated by negative affect), Scott et al.,

(2017) found no direct association between objectively measured delayed sleep onset or sleep maintenance and paranoia.

The only study not reporting a significant relationship between sleep and paranoia was Cosgrave et al., (2021). They recruited 1,789 adults from the general population and found that the presence of insomnia as measured by the SCI did not significantly predict the presence of persecutory ideation as measured by an item within the Prodromal Questionnaire. The study was limited by use of single-item measure of paranoia, however, receiving 3/5 on the measure of quality appraisal.

Table 1. Cross-sectional studies

Citation	N	Participant characteristics	Paranoia measure	Sleep measure	Comment on findings	Included in meta-analysis?	Risk of Bias score (out of 5)
Goines 2019	1020	740 individuals aged 12-30 at clinical high risk for psychosis and 280 healthy controls	Items from the SOPS	Items from the SOPS	The patient group reported significantly more sleep dysfunction than controls. Within the patient group, sleep dysfunction was significantly positively correlated with paranoia, which was partially explained by depression.	N	4
Freeman 2009	330	300 individuals from the general population and 30 individuals with persecutory delusions	GPTS-B	ISI, Sleep-50 Questionnaire	Among the non-clinical sample, symptoms of insomnia were significant positively correlated with paranoia, a relationship that was partially explained by the presence of anxiety and depression. Moderate or severe insomnia was present in over half of those participants with persecutory delusions.	Y	3
Grezellschak 2017	336	46 patients with psychosis, 23 relatives of patients with psychosis, 267 healthy controls	Paranoia Checklist (German version)	ISI (German version)	Paranoia and insomnia were significantly positively correlated in the total sample. The relationship was partially explained by the use of emotional suppression and lack of reappraisal in both the total sample and patient only sample.	Y	3
Reeve 2019	60	Patients with psychosis	SPEQ	Sleep-50 and Consensus sleep diary, Actigraphy	80% of patients received a positive screen or diagnosis of at least one sleep disorder, though fewer than one-third reported having received any	N	4

Citation	N	Participant characteristics	Paranoia measure	Sleep measure	Comment on findings	Included in meta-analysis?	Risk of Bias score (out of 5)
					treatment. Having at least one sleep disorder was significantly associated with more severe paranoia.		
Blanchard 2021	90	Patients with psychosis	GPTS	PROMIS Sleep Disturbance and Sleep-Related Impairment short form scales	Sleep dysfunction was significantly positively correlated with paranoia.	Y	3
Levin 2002	116	Students	Items from the Symptom Checklist-90-Revised	21-day dream log	Nightmare frequency and distress was significant positively correlated with paranoia.	N	1
Sheaves 2016	1403	Students	SPEQ paranoia subscale	SCI-8, dream log	Paranoia was significantly positively correlated with sleep dysfunction, nightmare frequency, and nightmare distress.	N	2
Freeman 2010	8580	Healthy adults	Items from the PSQ	Items from the CIS-R and SCID-II	Insomnia was associated with a two to threefold increase in paranoia. Path analysis showed the association between insomnia and paranoia was partially explained by negative affect, and to a smaller degree, cannabis use.	N	4
Koyanagi 2015	261,547	Adults from the general population from 56 countries. Sample size	Single item question assessing paranoid feelings	Single item question assessing subjective sleep problems	Self-reporting sleep problems was associated with a significantly high odds of reporting paranoia, which remained significant after controlling for anxiety and depression.	Y	4

Citation	N	Participant characteristics	Paranoia measure	Sleep measure	Comment on findings	Included in meta-analysis?	Risk of Bias score (out of 5)
		within countries ranged from 700-38,746					
Taylor 2015	5000	16-year old twin pairs	SPEQ paranoia subscale	PSQI, ISI	Paranoia was significantly correlated with insomnia and sleep quality. Paranoia and sleep dysfunction shared similar genetic and environmental influences. Negative affect partially mediated the relationship between paranoia and sleep dysfunction, also playing a role in both genetic and environmental influences.	Y	5
Scott 2017	348	Healthy adults	GPTS-B	Sleep-50 insomnia subscale, Zeo Sleep Manager (subset of 91 participants)	No direct association between objectively measured delayed sleep onset or sleep maintenance problems and paranoia was seen in the subset of 91 participants wearing the Zeo Sleep manager. Self-reported sleep problems were however significantly associated with increased paranoia. This relationship was fully mediated by increased negative affect.	Y	3
Rehman 2018a	401	Healthy adults	GPTS-B	PSQI	Paranoia was significantly positively correlated with sleep dysfunction. The relationship was partially mediated by alexithymia, perceptual anomalies, and negative affect.	Y	2
Rehman 2018b	402	Healthy adults	GPTS-B	PSQI	Paranoia was significantly positively correlated with sleep dysfunction. The	Y	2

Citation	N	Participant characteristics	Paranoia measure	Sleep measure	Comment on findings	Included in meta-analysis?	Risk of Bias score (out of 5)
					relationship was fully mediated by alexithymia, perceptual anomalies, and negative affect.		
Kammerer 2021	486	Young adults (aged 18-27)	Paranoia Checklist (German version)	PSQI, bespoke measures of nightmare frequency and contents, NDQ	Nightmare frequency and distress were significantly associated with paranoia, even after controlling for sleep quality. This relationship was partially mediated by stress. The specific content of nightmares was related to the frequency of paranoia e.g. nightmares about workspace bullying predicted more frequent paranoia.	Y	2
Bagrowska 2022	604	Healthy adults	R-GPTS	PSQI	Sleep quality was significantly negatively associated with paranoia, mediated by negative affect.	Y	3
Rek 2017	846	Healthy adults	SPEQ	Nightmare Severity Scale	After controlling for negative affect, both nightmare occurrence and severity were significantly associated with higher paranoia. The association between nightmare occurrence and paranoia was no longer significant after controlling for PTSD symptoms and stressful life events but remained significant for nightmare severity.	N	3
Cosgrave 2021	1789	Healthy adults	Paranoia subscale of Prodromal Questionnaire (16 item version)	PSQI and SCI	Presence of insomnia did not significantly predict the presence of persecutory ideation.	Y	3

Citation	N	Participant characteristics	Paranoia measure	Sleep measure	Comment on findings	Included in meta-analysis?	Risk of Bias score (out of 5)
Fekih-Romdhane 2023	851	Students	Paranoia subscale of the BSI	Arabic version of the ISI	Paranoia and insomnia were significantly positively correlated.	Y	2

Key: SOPS = Scale of Prodromal Symptoms, GPTS = Green Paranoid Thoughts Scale, ISI = Insomnia Severity Index, SPEQ = Specific Psychotic Experiences Questionnaire, SCI = Sleep Condition Indicator, PSQ = Psychosis Screening Questionnaire, CIS-R = Clinical Interview Scale Revised, SCID = Structured Clinical Interview for DSM-IV, PSQI = Pittsburgh Sleep Quality Index, NDQ = Nightmare Distress Questionnaire, BSI = Brief Symptom Inventory

Case-series

Four case series evaluated the impact of sleep interventions on patients with psychosis and sleep difficulties with sample sizes of between six and 15. Three of these case studies (Bradley et al., 2018; Myers et al., 2011; Sheaves et al., 2015) preceded RCTs also included in this review (Freeman et al., 2015; Sheaves et al., 2019; Waite et al., 2023).

In one case series, eight sessions of CBT for sleep problems showed feasibility, acceptability and large effect size changes in both sleep and paranoia in 12 young people at ultra-high risk of psychosis (Bradley et al., 2018). Similarly, following four sessions of CBT-I with 15 adults, Myers and colleagues found over two-thirds of participants made significant improvements in insomnia and half showed significant reductions in persecutory ideation (Myers et al., 2011). At a group level, reductions in insomnia and paranoia were significant and showed large effect sizes.

In a study of a six-week smartphone CBT-I-based intervention, Taylor and colleagues recruited 14 patients, 11 of whom completed the intervention and assessments (Taylor et al., 2022). Referral rates and qualitative feedback suggested good acceptability and feasibility, with large effect size improvements in insomnia and sleep quality also seen. Improvements in paranoia showed small (ideas of persecution) to moderate (ideas of reference) effect sizes. Confidence intervals for ideas of persecution crossed zero.

In a case series of between four and six sessions of Imagery Rehearsal Therapy for nightmares, four out of five patients showed improvements in delusions and sleep quality, though only the changes in delusions were indicative of statistically reliable change (Sheaves et al., 2015).

All four case series scored four or five out of five on quality appraisal, with the only possibilities for concern being risk of non-response bias in Myers et al., (2011) and Taylor et al., (2022), due to possible differences between participants who were contactable and consented to taking part versus those who were not or did not.

Cohort and longitudinal studies

Three studies looked at the relationship between sleep and paranoia over time. In 2,382 adults from the 2000 British National Psychiatric Morbidity Survey insomnia predicted both the persistence of existing paranoid thinking over time and the onset of new paranoid thinking (Freeman et al., 2012). Insomnia was a stronger predictor of paranoia than both anxiety and depression.

In a much smaller clinical study of 29 patients with psychosis, current insomnia was significantly positively associated with current paranoia, but when measured over the course of three months, insomnia and paranoia also significantly predicted each other over time in a bi-directional relationship partially mediated by negative affect (anxiety and depression) (Reeve et al., 2018). Finally, in a clinical study of 160 young people (aged 14-35) with at risk mental state for psychosis, shorter sleep duration was associated with more severe delusional ideas both cross-sectionally and longitudinally (across 12-24 months), however the measure of delusions combined both persecutory and grandiose ideas so there is less specificity regarding paranoia in this study (Reeve et al., 2019).

Table 2. Case series, cohort, longitudinal, and ESM studies

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Myers 2011	Case series	15	Patients with persistent persecutory delusions and insomnia	GPTS, PSYRATS delusions subscale	ISI, PSQI	4 sessions of CBT for insomnia led to significant reductions in insomnia, paranoid thoughts, and persecutory delusions with large effect sizes. Changes were maintained at a one-month follow-up.	N	4
Sheaves 2015	Case series	6	Patients with psychosis and frequent distressing nightmares	PSYRATS delusions subscale	PSQI, dream log	Following imagery rehearsal therapy for nightmares, sleep quality improved and delusions scores decreased for four out of five patients who received treatment. Two of these participants' changes in delusion severity were indicative of a statistically reliable change.	N	5
Bradley 2018	Case series	12	Young people at ultra-high risk of psychosis with sleep problems	GPTS	ISI, PSQI, actigraphy, sleep diaries	Patients were offered 8 sessions of CBT for sleep problems. Treatment was acceptable and feasible, and led to large effect size improvements in sleep, negative affect, and paranoia, though the case series was not powered to assess significance of changes.	N	5

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Taylor 2022	Case Series	14	Patients with psychosis experiencing current sleep difficulties	RGPTS	ISI, PSQI	A smartphone-based CBT intervention targeting sleep problems was feasible and acceptable. Across the 11 patients included in analysis, there were improvements in insomnia and sleep quality with large effect sizes, and improvements in paranoia with small (ideas of persecution) to moderate (ideas of reference) effect sizes. Confidence intervals for ideas of persecution crossed zero.	N	4
Reeve 2019	Cohort	160	Young people aged 14-35 with at risk mental state for psychosis	CAARMS Unusual Thought Content subscale	Sleep items within EPQ interview	Sleep duration was not significantly associated with unusual thought content (ideas of reference, thought insertion, and delusional mood). Shorter sleep duration was associated with more severe delusional ideas cross-sectionally and longitudinally, however the measure of delusions combined both persecutory and grandiose ideas.	N	2

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Freeman 2012	Cohort	2382	Adults from the 2000 British National Psychiatric Morbidity Survey	Items from PSQ and SCID-II	Items from the CIS-R	Insomnia predicted both the persistence of existing paranoid thinking over time and the onset of new paranoid thinking. Insomnia was a stronger predictor of paranoia than both anxiety and depression.	N	5
Reeve 2018	Longitudinal	29	Patients with psychosis	SPEQ paranoia subscale	Sleep-50	Current insomnia was significantly positively associated with current paranoia. Insomnia and paranoia also significantly predicted each other over time in a bi-directional relationship mediated by negative affect (anxiety and depression).	Y	4
Hennig 2020	ESM	82	Young adults (ages 18-24), 41 with elevated psychosis proneness	State adapted Paranoia Checklist	Items from the German Sleep Society Diary, Actigraphy	Shorter sleep time and negative dream valence predicted paranoia. The relationship between poor sleep and paranoia was bidirectional.	N	3

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Mulligan 2016	ESM	22	Patients with psychosis and insomnia	PSYRATS delusions subscale (baseline), single item assessing persecutory thinking (ESM)	ISI (baseline), actigraphy and CSD (ESM)	Objectively measured sleep fragmentation and reduced subjective sleep quality predicted great paranoia, which was partially mediated by negative affect on awakening.	N	5
Hennig 2018	ESM	61	Adolescents aged 14-17	Items from the SPEQ	Items from the German Sleep Society sleep diary, Actigraphy	Shorter sleep time and more dreaming predicted greater paranoia over time. The former relationship was partially mediated by negative affect. Paranoia did not significantly predict any sleep parameters.	N	2
Meyer 2022	ESM	36	Patients with psychosis	Mean of 'suspicious' and 'others dislike me' items of PANSS	PSQI, ISI	Sleep quality was significantly negatively correlated with paranoia, over a time lag of 1-5 days. Paranoia also predicted sleep quality. No relationship with sleep duration and paranoia was found. While negative affect and cognitive symptoms mediated the relationship between sleep and total psychosis symptoms, mediation was not assessed with paranoia only.	N	2

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Kammerer 2021	ESM	106	67 patients with persecutory delusions and 39 healthy controls	PDI (German version)	ISI, Actigraphy	The patient group reported significantly lower sleep quality but significantly high actigraphy-measured sleep duration and efficiency than controls. Circadian disruption was associated with more severe paranoia.	N	2
Kasanova 2020	ESM	82	Young adults (ages 18-24), 41 with elevated psychosis proneness	4 bespoke Likert scales measuring state paranoia	Bespoke Likert scale measuring subjective sleep quality	Across the whole sample, poor sleep quality predicted higher paranoia the following morning. This relationship was fully mediated by negative affect. Paranoia in the evening did not predict sleep quality that night.	N	2

Key: GPTS = Green Paranoid Thoughts Scale, PSYRATS = Psychotic Symptoms Rating Scale, ISI = Insomnia Severity Index, PSQI = Pittsburgh Sleep Quality Index, RGPTS = Revised Green Paranoid Thoughts Scale, CAARMS = Clinical Assessment of At Risk Mental State, EPQ = Economic Patient Questionnaire, PSQ = Psychosis Screening Questionnaire, SCID = Structured Clinical Interview for DSM-IV, CIS = Clinical Interview Scale, SPEQ = Specific Psychotic Experiences Questionnaire, CSD = Consensus Sleep Diary, PANSS = Positive and Negative Syndrome Scale, PDI = Peters Delusions Inventory.

ESM studies

Six studies used ESM methodologies. All reported significant associations between some aspect of sleep and paranoia, though there were differences in the exact sleep variable showing a significant relationship and whether the relationship was bi-directional. Where negative affect was measured, it was generally found to be a mediator.

In two studies, one with 82 young adults (aged 18-24) and one with 61 adolescents (aged 14-17) Hennig and colleagues found that shorter sleep time predicted paranoia over 14 days (Hennig et al., 2020) and 8 days (Hennig & Lincoln, 2018). In the former study the relationship between sleep and paranoia was bi-directional, whereas in the latter, paranoia did not significantly predict any sleep parameters. Dreaming, (specifically negative dream valence in Hennig et al., 2020 and greater dreaming in Hennig & Lincoln, 2018) also predicted the presence of paranoia over time in both studies. Negative affect was not measured in the 2018 study but was a significant mediator in the 2020 study. Mulligan (2016) had similar findings, with reduced sleep quality predicting greater paranoia over seven days, partially mediated by negative affect (Mulligan et al., 2016). This study also used actigraphy and found sleep fragmentation also predicted greater paranoia.

Interestingly, a significant negative bi-directional relationship was found between sleep quality and paranoia in Meyer et al., (2022), but not for sleep duration and paranoia as was seen in the studies by Hennig and colleagues. In another study, poor sleep quality predicted higher paranoia the following morning (mediated by negative affect) but did not find a relationship in the reverse direction, with evening paranoia not predicting sleep quality that night (Kasanova et al., 2020).

The largest ESM study recruited 67 patients with persecutory delusions and 39 healthy controls (Kammerer, Mehl, et al., 2021). The study found that the patient group reported significantly lower sleep quality, but higher sleep duration and efficiency (objectively measured through actigraphy), than controls, with low actigraphy-derived sleep efficiency across the total sample being associated with more severe next-day paranoia.

Experimental sleep deprivation studies

Five studies used sleep deprivation to experimentally assess the relationship between sleep and paranoia. Meyhöfer and colleagues recruited 17 individuals reporting unusual experiences and 19 controls reporting no unusual experiences, finding that across both groups, 24 hours of wakefulness led to increased paranoia as compared to baseline (Meyhöfer, Steffens, et al., 2017). Similarly, Kahn-Green et al (2007) found 56 hours of wakefulness led to increased paranoia from baseline in 25 adults. Conversely, a study by Petrovsky et al., (2014) found that one night of total sleep deprivation (equating to a minimum of 12 hours for all participants) did not lead to any significant changes in paranoia. Results were possibly impacted by a floor effect of baseline paranoia and the total sleep deprivation window being shorter and more varied in total time between participants than in other studies. All three of these studies were rated as slightly low in methodological quality (scoring 2 or 3 out of 5) due to their sampling and chosen measures.

Two further sleep deprivation studies used randomised cross-over designs. Reeve et al., (2017) randomised 68 adults to four hours of sleep for three consecutive nights or normal sleep in a cross-over design and found that sleep loss led to significant increases in paranoia, 90% of which was mediated by changes in negative affect (depression, anxiety, and stress)

(Reeve et al., 2017). The second study randomised 32 adults to have one night of total sleep deprivation followed by a normal night's sleep, or vice versa (Meyhöfer, Kumari, et al., 2017). Interestingly, paranoia decreased from evening to morning following sleep deprivation, but only in one of the groups (those who underwent sleep deprivation followed by normal sleep condition rather than those following the conditions in reverse). Otherwise, no changes in paranoia were seen. This study scored only 3/5 on quality appraisal due to poorer reporting of sample representativeness and confounders.

Treatment RCTs

Three of the five RCTs were developed from case series reported earlier (Bradley et al., 2018; Freeman et al., 2015; Sheaves et al., 2019). In a trial of 24 participants with nightmares and persecutory delusions, Sheaves et al., (2019) found their CBT intervention for nightmares led to improvements in nightmares and insomnia, and reductions in paranoia, all with large effect sizes. In 40 young people at ultra-high risk of psychosis, Waite et al., (2023) found that a 12-week sleep intervention led to improvements in insomnia and also paranoia, the latter of which were significant at follow up (9 months after baseline) but not at 3 months. The same pattern was observed for anxiety and depression, consistent with the potential mediating role of affective symptoms in the relationship between sleep and paranoia. In a trial of 50 patients, Freeman et al., (2015) similarly found large effect size improvements in insomnia following CBT-I, with improvements maintained at a 12-week follow up. However, there were wide confidence intervals for the effects of the treatment on persecutory delusions, with some patients' delusions improving while others experienced a worsening of their delusions. A more highly powered phase three trial would be required to determine the

effects on delusions with greater precision. All three studies were rated as having a low risk of bias, scoring the highest possible score for their category.

Freeman et al., (2017) conducted the largest RCT of 3,755 university students with insomnia. The study found that compared to a control group, the digital CBT-I intervention significantly reduced insomnia with a large effect size, and significantly reduced paranoia with a small effect size. Changes in insomnia partially mediated changes in paranoia over time, where-as mediation in the reverse direction was very small. While it scored slightly lower on quality appraisal (3/5) this was due to relatively low treatment uptake (30% of the intervention group did not access any of the modules) and high dropout rates (50%), which may be considered unsurprising given the online nature of the study and the student sample, many of whom potentially had a low need for care.

Finally, one study of 124 patients with distressing delusions or hallucinations and insomnia embedded experience sampling assessments into a cross-over trial of an online psychological intervention (Lüdtke et al., 2021). The intervention (EviBaS) targeted psychotic symptoms as well as potential precursors of psychosis using guided self-help modules on topics such as sleep, worry, self-esteem, and depression. Results showed that 30% of participants accessed the sleep module and 30% accessed the persecutory delusions module. While the intervention did lead to a significant reduction in a composite score of positive psychotic symptoms, it did not lead to significant changes in sleep quality, or paranoia. The ESM data, however, was able to show that across the whole sample (whether delayed or immediate access to treatment), decreased sleep quality significantly predicted subsequent momentary paranoia during the course of the intervention. As is common in ESM studies, there was lower adherence to measure collection, and as is common in online

interventions, there was also somewhat low adherence to treatment. Thus, this study scored slightly lower on quality appraisal (3/5).

Meta-analysis results

Primary meta-analysis

Thirteen studies were included in the primary meta-analysis. There was a significant positive association between sleep and paranoia, with a pooled effect size of 0.27 (95% CI: 0.19-0.35, $p<0.001$; $tau^2 = 0.017$ [SE = 0.01], $I^2 = 96.61\%$). Converted back into Pearson's *r* this gave a small effect size of 0.26. Figure 2 presents a forest plot showing the variance between studies and the overall measure of effect. There was no indication of publication bias according to funnel plot inspection. Neither Begg's rank correlation nor Egger's regression test indicated asymmetry ($p = 0.77$ and $p = 0.14$ respectively). The fail-safe index was large, at 15,066.

The significant heterogeneity statistics suggest that a large proportion of the variance in effect size was attributable to between-study variance. However, a meta-regression or sensitivity analysis to explore this further was not considered appropriate for two reasons. First, while it is possible that variables such as sample size (which ranged between 26 and over 26,000) and population (clinical, non-clinical, or both) were contributing to the heterogeneity, with only 13 studies included there would not be particularly high power to explore potential predictors. Second, given all studies found a positive effect, with only two having confidence intervals crossing zero, further analysis would be unlikely to change the direction of the concluded effect, and only potentially impact the magnitude of the effect by a small amount.

Table 3. Experimental studies and RCTs

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Petrovsky 2014	Experimental (1 night of sleep deprivation vs usual sleep)	24	Healthy adults	PSI paranoia and delusions subscales	SSS, one-night total sleep deprivation	Baseline levels of paranoia and delusional thinking were low and did not significantly change following a minimum of 12 hours sleep deprivation.	N	3
Kahn-Greene 2007	Experimental (56 hours of wakefulness)	25	Healthy adults from the military	Items from the PAI	Adherence to sleep deprivation/wakefulness	Sleep deprivation (56 hours of wakefulness) led to an increase in paranoia compared to baseline.	N	2
Meyhöfer, Steffens, 2017	Experimental (24 hours of wakefulness vs usual sleep)	36	17 adults reporting unusual experiences and 19 controls reporting low levels of unusual experience	PSI	Adherence to sleep deprivation/wakefulness	24 hours of wakefulness led to increased paranoia compared to baseline.	N	2

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Reeve 2017	Experimental (sleep reduced to 4 hours a night for three nights vs usual sleep)	68	Healthy adults	SPEQ	Adherence to sleep restriction, Actigraphy	Sleep deprivation to four hours sleep for three consecutive nights led to significant increases in paranoia, 90% of which was mediated by changes in negative affect (depression, anxiety, and stress).	N	4
Meyhöfer, Kumari, 2017	Experimental (1 night of sleep deprivation vs usual sleep)	32	Healthy adults	PSI paranoia subscale	SSS, SPEM	Paranoia decreased from evening to morning after one night of total sleep deprivation only when sleep deprivation was the first night, and not when the normal sleep control condition was first.	N	3
Sheaves 2019	RCT (4 weeks of CBT for nightmares vs usual care)	24	Patients with persecutory delusions and nightmares	GPTS	DDNSI, SCI, PSQI	A CBT intervention for nightmares led to improvements in nightmares and insomnia and reductions in paranoia, all with large effect sizes.	N	5

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Freeman 2017	RCT (10 weeks of digital CBT for insomnia vs usual care)	3755	Students with insomnia	GPTS-B	SCI-8 (primary), ISI, DDNSI (secondary)	Digital CBT for insomnia significantly reduced insomnia with a large effect size, and significantly reduced paranoia with a small effect size, compared to controls. Changes in insomnia partially mediated changes in paranoia over time. Mediation in the reverse direction was very small.	N	3
Freeman 2015	RCT (8 sessions of CBT for insomnia vs usual care)	50	Patients with persistent distressing delusions or hallucinations and insomnia	GPTS and PSYRATS delusions subscale	ISI	CBT for insomnia led to reductions in self-reported insomnia severity with large effect sizes by the end of treatment. Benefits were maintained at a 12 week follow up. Effect sizes for improvements in actigraphy data were moderate. Confidence intervals for the effects of treatment on delusions were wide suggesting some patients experienced more severe paranoia and others less severe.	N	5

Citation	Design	N	Participant characteristics	Paranoia Measure	Sleep measure	Comment on findings	Included in Meta-analysis?	Risk of Bias score (out of 5)
Ludtke 2021	RCT (8 week EviBaS intervention vs usual care)	124	Patients with psychosis	PANSS (baseline), Single item assessment of state paranoia (follow-up)	Single item assessment of sleep quality	Intervention on psychotic experiences did not lead to changes in sleep quality. Sleep quality predicted subsequent paranoia.	N	3
Waite 2023	RCT (12 weeks of SleepWell intervention vs usual care)	40	Young people (14-25 years) at ultra-high risk of psychosis	R-GPTS	ISI	12 weeks of a targeted psychological sleep intervention led to reductions in insomnia and paranoia. The reduction in paranoia had confidence intervals crossing zero at 3 months, but not at 9 months.	N	5

Key: PSI = Psychotomimetic States Inventory, SSS = Stanford Sleepiness Scale, PAI = Personality Assessment Inventory, SPEQ = Specific Psychotic Experiences, SPEM = Smooth Pursuit Eye Movements, GPTS = Green Paranoid Thoughts Scale, DDNSI = Disturbing Dream and Nightmare Severity Index, SCI = Sleep Condition Indicator, PSQI = Pittsburgh Sleep Quality Index, PSYRATS = Psychotic Symptoms Rating Scale, ISI = Insomnia Severity Index, PANSS = Positive and Negative Syndrome Scale

Subgroup analysis

Six studies included the specific, continuous, clinically relevant, and therefore more homogeneous measures of paranoia and insomnia and six did not. For the set of homogeneous measures, the average correlation coefficient showed a significant positive association between insomnia and paranoia, with a pooled effect size of 0.30 (95% CI: 0.15-0.46, $p<0.001$; $tau^2 = 0.03$ [SE = 0.02], $I^2 = 88.9\%$). Conversion back into Pearson's *r* gave a small-to-medium effect size of 0.29. Neither the rank correlation nor the regression test indicated any funnel plot asymmetry ($p = 1.00$ and $p = 0.271$ respectively) and the fail-safe index was large, at 592. The variance between the studies and the overall measure of effect can be viewed in Figure 2.

For the seven studies with less homogeneous measures, the average correlation coefficient showed a significant positive association between insomnia and paranoia, with a pooled effect size of 0.25 (95% CI: 0.16-0.34, $p<0.001$; $tau^2 = 0.01$ [SE = 0.01], $I^2 = 95.34\%$). Converted back into Pearson's *r*, the effect size remained at 0.25. Neither the rank correlation nor the regression test indicated any funnel plot asymmetry ($p = 0.38$ and $p = 0.46$, respectively) and the fail-safe index was large, at 9,115. The forest plot for this set of studies can also be viewed in Figure 2.

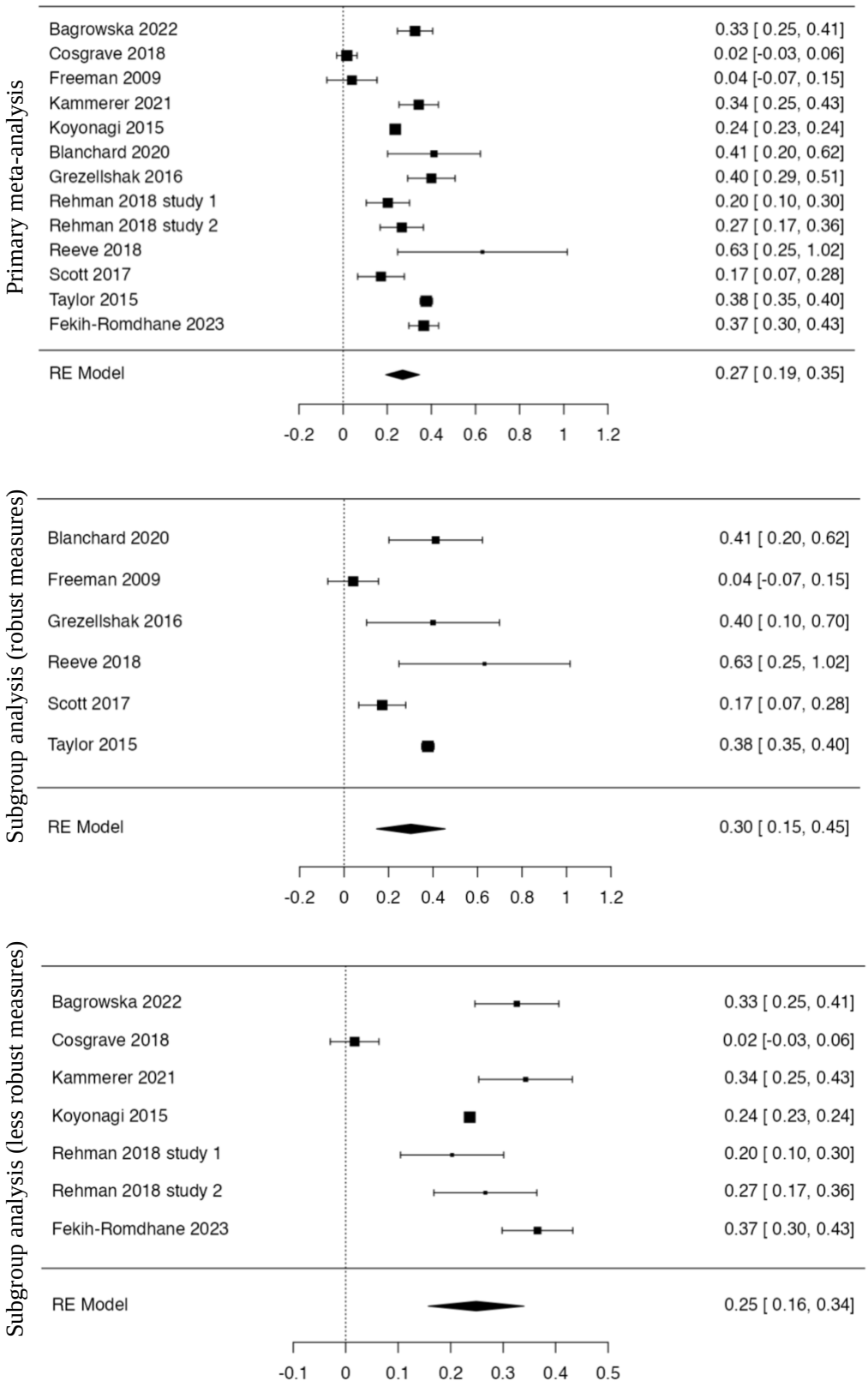


Figure 2. Forest Plots

Discussion

This review aimed to comprehensively synthesise the relationship between sleep and paranoia, including assessing the magnitude of its association through a meta-analysis for the first time. All meta-analyses demonstrated a significant moderate association between insomnia and paranoia, and the systematic review showed this association can be reliably discovered through multiple designs and has at least some causal element to it.

While cross-sectional designs were unsurprisingly by far the most commonly used, the few longitudinal and cohort studies also found significant positive associations between sleep dysfunction and paranoia, and experimental studies showed that when sleep is manipulated in either direction (i.e. improved or decreased) this has a subsequent effect on paranoia (i.e. decreases or increases). These latter findings of the impact of manipulating sleep offer evidence to suggest that sleep dysfunction could be a contributory causal factor in the development and/or maintenance of paranoia. Further weight is provided to this conclusion by the four clinical treatment RCTs that demonstrated that when cognitive therapy for sleep problems successfully led to improvements in sleep, this had a subsequent impact on reducing paranoia. Given the relative ease of intervening to improve sleep dysfunction and the motivation patients often have to improve sleep (Freeman, Taylor, et al., 2019), providing sleep interventions to those with an at risk mental state for developing psychosis would seem a useful avenue of research. Such interventions could be one way of reducing the likelihood of transition to psychosis. The SleepWell case series and pilot RCT (Bradley et al., 2018; Waite et al., 2023) provide initial evidence of this, with a full RCT still needed to assess efficacy.

The studies that used mediation analysis were able to shed further light on the nature of the relationship between sleep and paranoia. In a number of studies, it appeared that the relationship from sleep to paranoia was primary (Kasanova et al., 2020, Hennig & Lincoln, 2018), whereas in others, there was evidence of a bi-directional relationship (Meyer et al., 1990; Hennig et al., 2020). Typically, it is hypothesised that bidirectional relationships between paranoia and its causal factors become embedded (Freeman, 2016). An interesting avenue of future research would therefore be to assess whether interventions that successfully reduce paranoia also lead to a subsequent improvement in sleep, and if they do not, whether this increases the likelihood of paranoia relapsing.

Aspects of negative affect e.g., anxiety and depression, were also frequently identified as mediators, but there has been little investigation into other potential mediating variables. Larger longitudinal studies would be useful for robustly measuring and assessing the potential role of a range of cognitive, affective, and behavioural variables. Assessment of sleep dysfunction in those with paranoia could also be broadened to cover a wider range of sleep difficulties, including, for example, parasomnias. There is emerging evidence and a clear theoretical model for the role of nightmares in increasing paranoia (Sheaves et al., 2019), but also the potential of other parasomnias like sleep paralysis and sleep-related hallucinations to play a significant role in causing or maintaining daytime paranoia, that require further investigation.

It is helpful to note that the results of the primary meta-analysis as well as the two sub-group analyses were similar. This suggests that measure quality is unlikely to have a large impact on finding a reliable association between sleep and paranoia. The pooled correlation was highest for the analysis of more specific and clinically valid measures,

however, which could imply that those studies using less robust measures may actually be slightly diluting the true effect. There was at no point any evidence of publication bias, including a very high fail-safe index in the primary meta-analysis, which is also useful for demonstrating the reliability of the relationship and how likely it is to be a true effect even if there were considerable publication bias.

Visual inspection of the forest plots indicates potential moderators that could be examined in more detail. For example, a number of the clinical studies appeared to have slightly larger effects than the non-clinical studies. While both paranoia and sleep difficulties exist on a spectrum of severity across the population, with differences at the clinical end often representing more quantitative than qualitative differences (Elahi et al., 2017; Freeman, Pugh, et al., 2010), studies recruiting entirely non-clinical samples may sometimes be biased by a floor effect, as was thought to potentially be the case in e.g. Petrovsky et al., (2014), which might make the relationship easier to discover in clinical groups.

Age could also be explored as a moderator in greater detail. While there were no obvious differences in the findings reported by studies with adolescent populations as compared to adults, adolescents are more suspectable to certain sleep difficulties. For example, they experience both delayed and reduced feelings of needing to sleep at night due to differences in their release of melatonin (Blake et al., 2017; Feinberg et al., 2006) yet typically still need to rise early in the morning for school, leading to insufficient sleep duration. It is therefore possible that the strength of the relationship between sleep and paranoia and the mechanisms underlying it could be different for adolescents as compared to adults.

There are several limitations of the review and meta-analysis to consider. First, there is no way to guarantee that the search strategy identified every study that would meet inclusion criteria. Methods to reduce this likelihood were employed, such as scanning past reviews and reference lists of included studies, but a number of studies may not have been found. Furthermore, we chose to exclude case studies and unpublished or non-peer reviewed studies, but including these may have provided further insight into some areas of the relationship between sleep and paranoia. Second, the meta-analysis only quantitatively assessed and pooled the *r* correlation coefficients for the association between sleep and paranoia, with no quantitative analysis of e.g., intervention effect sizes or group differences. This was because of the limited number of studies using experimental designs but would be a useful area of future research as more studies in this area emerge. Similarly, the review only focussed on paranoia because of the importance of considering psychotic experiences individually, but it would also be useful to meta-analytically assess the relationship between sleep and other psychotic experiences such as hallucinations and anhedonia. Finally, the narrative review also gave considerably more focus to the findings with regard to subjective measures of sleep than objective ones. With the advent of increasingly easy ways to objectively measure aspects of sleep and many individuals opting to track their sleep using at-home devices, this may be an important area to focus future research.

In conclusion, it has been increasingly recognised in recent years that sleep dysfunction is not only a common occurrence in those with psychosis including paranoia specifically, but that it also plays a contributory causal role in its development and maintenance. This review and analysis provide an up-to-date synthesis of this evidence so far and provides a number of avenues for whether to focus future research. These include

investigating sleep difficulties beyond insomnia (e.g., parasomnias), assessing the sleep to paranoia relationship in reverse, (e.g., does successfully reducing paranoia also lead to a subsequent improvement in sleep), and conducting larger longitudinal studies using clinically relevant measures that allow in depth investigation into pathways that may more clearly explain the mechanisms by which sleep and paranoia are causally related.

References

Bagrowska, P., Pionke-Ubych, R., Majchrowicz, K., & Gawęda, Ł. (2022). The mediating effect of negative emotions on the relationship between subjective sleep quality and paranoia-like thoughts. *Journal of Psychiatric Research*, *145*(December 2021), 132–136. https://doi.org/10.1016/j.jpsychires.2021.12.003

Bastien, C. H., Vallières, A., & Morin, C. M. (2001). Validation of the insomnia severity index as an outcome measure for insomnia research. *Sleep Medicine*, *2*(4), 297–307. https://doi.org/10.1016/S1389-9457(00)00065-4

Bebbington, P. E., McBride, O., Steel, C., Kuipers, E., Radovanovič, M., Brugha, T., Jenkins, R., Meltzer, H. I., & Freeman, D. (2013). The structure of paranoia in the general population. *British Journal of Psychiatry*, *202*(6), 419–427. https://doi.org/10.1192/bjp.bp.112.119032

Begg, C. B. (1994). Publication bias. *The Handbook of Research Synthesis*, *25*, 299–409.

Blake, M. J., Sheeber, L. B., Youssef, G. J., Raniti, M. B., & Allen, N. B. (2017). Systematica Review and Meta-analysis of Adolescent Cognitive–Behavioral Sleep Interventions. *Clinical Child and Family Psychology Review*, *20*(3), 227–249. https://doi.org/10.1007/s10567-017-0234-5

Blanchard, J., Andrea, A., Orth, R., Savage, C., & Bennett, M. (2021). Sleep disturbance and sleep-related impairment in psychotic disorders are related to both positive and negative symptoms. *Psychiatry Research*, *14*(11), 1–15. https://doi.org/10.1016/j.psychres.2020.112857.Sleep

Bleuler, E. (1950). *Dementia praecox or the group of schizophrenias.* (J. Zinkin & N. Lewis (eds.)).

Borenstein, M., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2021). Converting Among Effect Sizes. *Introduction to Meta-Analysis*, 43–47. https://doi.org/10.1002/9781119558378.ch7

Bradley, J., Freeman, D., Chadwick, E., Harvey, A. G., Mullins, B., Johns, L., Sheaves, B., Lennox, B., Broome, M., & Waite, F. (2018). Treating sleep problems in young people at ultra-high risk of psychosis: A feasibility case series. *Behavioural and Cognitive Psychotherapy*, *46*(3 PG-276–291), 276–291. https://doi.org/https://dx.doi.org/10.1017/S1352465817000601

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1998). The Pittsburgh Sleep Quality index: a new instrument for psychiatric practice and research. In *Psychiatry Research* (Vol. 28, pp. 193–213).

Buysse, D. J., Yu, L., Moul, D. E., Germain, A., Stover, A., Dodds, N. E., Johnston, K. L., Shablesky-Cade, M. A., & Pilkonis, P. A. (2010). Development and validation of patient-reported outcome measures for sleep disturbance and sleep-related impairments. *Sleep*, *33*(6), 781–792.

Chan, M. S., Chung, K. F., Yung, K. P., & Yeung, W. F. (2017). Sleep in schizophrenia: A systematic review and meta-analysis of polysomnographic findings in case-control studies. *Sleep Medicine Reviews*, *32*, 69–84. https://doi.org/10.1016/j.smrv.2016.03.001

Chouinard, S., Poulin, J., Stip, E., & Godbout, R. (2004). Sleep in untreated patients with schizophrenia: A meta-analysis. *Schizophrenia Bulletin*, *30*(4), 957–967. https://doi.org/10.1093/oxfordjournals.schbul.a007145

Cohen, J. (2013). *Statistical power analysis for the behavioural sciences. Routledge.*

Egger, M., Smith, G. D., Schneider, M., & Minder, C. (1997). Bias in meta-analysis detected

by a simple, graphical test. *Bmj*, *315*(7109), 629–634.

Elahi, A., Perez Algorta, G., Varese, F., McIntyre, J. C., & Bentall, R. P. (2017). Do paranoid delusions exist on a continuum with subclinical paranoia? A multi-method taxometric study. *Schizophrenia Research*, *190*, 77–81. https://doi.org/10.1016/j.schres.2017.03.022

Espie, C. A., Kyle, S. D., Hames, P., Gardani, M., Fleming, L., & Cape, J. (2014). The Sleep Condition Indicator: a clinical screening tool to evaluate insomnia disorder. *BMJ Open*, *4*(3).

Feinberg, I., Higgins, L. M., Wong, Y. K., & Campbell, I. G. (2006). The adolescent decline of NREM delta, an indicator of brain maturation, is linked to age and sex but not to pubertal stage. *American Journal of Physiology - Regulatory Integrative and Comparative Physiology*, *291*(6), 1724–1730. https://doi.org/10.1152/ajpregu.00293.2006

Fekih-Romdhane, F., Lamloum, E., Loch, A. A., Cherif, W., Cheour, M., & Hallit, S. (2023). The relationship between internet gaming disorder and psychotic experiences: cyberbullying and insomnia severity as mediators. *BMC Psychiatry*, *23*(1), 1–14. https://doi.org/10.1186/s12888-023-05363-x

Freeman, D. (2016). Persecutory delusions: a cognitive perspective on understanding and treatment. *The Lancet Psychiatry*, *3*(7), 685–692. https://doi.org/10.1016/S2215-0366(16)00066-3

Freeman, D., Brugha, T., Meltzer, H., Jenkins, R., Stahl, D., & Bebbington, P. (2010). Persecutory ideation and insomnia: Findings from the second British National Survey Of Psychiatric Morbidity. *Journal of Psychiatric Research*, *44*(15), 1021–1026.

https://doi.org/10.1016/j.jpsychires.2010.03.018

Freeman, D., Garety, P. A., Bebbington, P. E., Smith, B., Rollinson, R., Fowler, D., & Kuipers, E. (2005). Psychological investigation of the structure of paranoia in a non-clinical population. *British Journal of Psychiatry*, *186*, 427–435. https://doi.org/10.1192/bjp.186.5.427

Freeman, D., Loe, B. S., Kingdon, D., Startup, H., Molodynski, A., Rosebrock, L., Brown, P., Sheaves, B., Waite, F., & Bird, J. C. (2019). The revised Green et al. , Paranoid Thoughts Scale (R-GPTS): psychometric properties, severity ranges, and clinical cut-offs. *Psychological Medicine*, 1–10. https://doi.org/10.1017/s0033291719003155

Freeman, D., McManus, S., Brugha, T., Meltzer, H., Jenkins, R., & Bebbington, P. (2011). Concomitants of paranoia in the general population. *Psychological Medicine*, *41*(05), 923–936. https://doi.org/10.1017/S0033291710001546

Freeman, D., Pugh, K., Vorontsova, N., Antley, A., & Slater, M. (2010). Testing the continuum of delusional beliefs: An experimental study using virtual reality. *Journal of Abnormal Psychology*, *119*(1), 83–92. https://doi.org/10.1037/a0017514

Freeman, D., Pugh, K., Vorontsova, N., & Southgate, L. (2009). Insomnia and paranoia. *Schizophrenia Research*, *108*(1–3), 280–284. https://doi.org/10.1016/j.schres.2008.12.001

Freeman, D., Sheaves, B., Goodwin, G. M., Yu, L. M., Nickless, A., Harrison, P. J., Emsley, R., Luik, A. I., Foster, R. G., Wadekar, V., Hinds, C., Gumley, A., Jones, R., Lightman, S., Jones, S., Bentall, R., Kinderman, P., Rowse, G., Brugha, T., … Espie, C. A. (2017). The effects of improving sleep on mental health (OASIS): a randomised controlled trial with mediation analysis. *The Lancet Psychiatry*, *4*(10), 749–758.

https://doi.org/10.1016/S2215-0366(17)30328-0

Freeman, D., Stahl, D., McManus, S., Meltzer, H., Brugha, T., Wiles, N., & Bebbington, P. (2012). Insomnia, worry, anxiety and depression as predictors of the occurrence and persistence of paranoid thinking. *Social Psychiatry and Psychiatric Epidemiology*, *47*(8), 1195–1203. https://doi.org/10.1007/s00127-011-0433-1

Freeman, D., Taylor, K. M., Molodynski, A., & Waite, F. (2019). Treatable clinical intervention targets for patients with schizophrenia. *Schizophrenia Research*, *211*, 44–50. https://doi.org/10.1016/j.schres.2019.07.016

Freeman, D., Waite, F., Startup, H., Myers, E., Lister, R., McInerney, J., Harvey, A. G., Geddes, J., Zaiwalla, Z., Luengo-Fernandez, R., Foster, R., Clifton, L., & Yu, L.-M. M. (2015). Efficacy of cognitive behavioural therapy for sleep improvement in patients with persistent delusions and hallucinations (BEST): A prospective, assessor-blind, randomised controlled pilot trial. *The Lancet Psychiatry*, *2*(11), 975–983. https://doi.org/10.1016/S2215-0366(15)00314-4

Green, C. E. L., Freeman, D., Kuipers, E., Bebbington, P., Fowler, D., Dunn, G., & Garety, P. A. (2008). Measuring ideas of persecution and social reference: the Green et al. Paranoid Thought Scales (GPTS). *Psychological Medicine*, *38*(01), 101–111. https://doi.org/10.1017/S0033291707001638

Grezellschak, S., Jansen, A., & Westermann, S. (2017). Emotion regulation in patients with psychosis: A link between insomnia and paranoid ideation? *Journal of Behavior Therapy and Experimental Psychiatry*, *56*, 27–32. https://doi.org/10.1016/j.jbtep.2016.08.001

Hennig, T., & Lincoln, T. M. (2018). Sleeping paranoia away? An actigraphy and

experience-sampling study with adolescents. *Child Psychiatry & Human Development*, *49*(PG-63-72), 63–72. NS -

Hennig, T., Schlier, B., & Lincoln, T. M. (2020). Sleep and psychotic symptoms: An actigraphy and diary study with young adults with low and elevated psychosis proneness. *Schizophrenia Research*, *221*(Adan, A., Almirall, H. (1991). Horne & Ostberg morningness-eveningness questionnaire: a reduced scale. Personal. Individ. Differ. 12(3), 241-253 https://dx.doi.org/10.1016/0191-8869(91)90110-W https://dx.doi.org/10.1016/0191-8869(91)90110-W 1991-23162-0), 12–19. https://doi.org/https://dx.doi.org/10.1016/j.schres.2019.09.012

Higgins, J. P. T., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. *Bmj*, *327*(7414), 557–560.

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M. P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M. C., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, *34*(4), 285–291. https://doi.org/10.3233/EFI-180221

Kammerer, M. K., Bub, K., & Lincoln, T. M. (2021). The relationship between nightmares and psychotic experiences in young adults. *Sleep Medicine*, *77*(Benjamini, Y., Hochberg, Y. (1995). Controlling the false discovery rate: a practical and powerful approach to multiple testing. J R Stat Soc Ser B 1995;57:289-300.Blagrove, M., Farmer, L., Williams, E. (2004). The relationship of nightmare frequency), 315–322. https://doi.org/https://dx.doi.org/10.1016/j.sleep.2020.08.014

Kammerer, M. K., Mehl, S., Ludwig, L., & Lincoln, T. M. (2021). Sleep and circadian

rhythm disruption predict persecutory symptom severity in day-to-day life: A combined actigraphy and experience sampling study. *Journal of Abnormal Psychology*, *130*(1 PG-78–88), 78–88. https://doi.org/https://dx.doi.org/10.1037/abn0000645

Kasanova, Z., Hajdúk, M., Thewissen, V., & Myin-Germeys, I. (2020). Temporal associations between sleep quality and paranoia across the paranoia continuum: An experience sampling study. *Journal of Abnormal Psychology*, *129*(1), 122–130. https://doi.org/10.1037/abn0000453

Kay, S. R. (1991). *Positive and negative syndromes in schizophrenia: assessment and research* (Issue 5). Psychology Press.

Kessler, R. C., & Wang, P. S. (2008). The descriptive epidemiology of commonly occurring mental disorders in the United States. *Annual Review of Public Health*, *29*, 115–129. https://doi.org/10.1146/annurev.publhealth.29.020907.090847

Koyanagi, A., & Stickley, A. (2015). The Association between Sleep Problems and Psychotic Symptoms in the General Population: A Global Perspective. *Sleep*, *38*(12), 1875–1885. https://doi.org/10.5665/sleep.5232

Kraepelin, E. (1919). *Dementia praecox and paraphrenia.* (R. Barclay & G. Robertson (eds.)). Chicago Medical Book Co.

Levin, R., & Fireman, G. (2002). Nightmare prevalence, nightmare distress, and self-reported psychological disturbance. *Sleep*, *25*(2 PG-205–212), 205–212. NS -

Lüdtke, T., Pfuhl, G., Moritz, S., Rüegg, N. L., Berger, T., & Westermann, S. (2021). Sleep problems and worrying precede psychotic symptoms during an online intervention for psychosis. *British Journal of Clinical Psychology*, *60*(1), 48–67. https://doi.org/10.1111/bjc.12270

Meyhöfer, I., Kumari, V., Hill, A., Petrovsky, N., & Ettinger, U. (2017). Sleep deprivation as an experimental model system for psychosis: Effects on smooth pursuit, prosaccades, and antisaccades. *Journal of Psychopharmacology*, *31*(4), 418–433. https://doi.org/10.1177/0269881116675511

Meyhöfer, I., Steffens, M., Faiola, E., Kasparbauer, A., Kumari, V., & Ettinger, U. (2017). Combining two model systems of psychosis: the effects of schizotypy and sleep deprivation on oculomotor control and psychotomimetic states. *Psychophysiology*, *54*(11 PG-1755–1769), 1755–1769. NS -

Mulligan, L. D., Haddock, G., Emsley, R., Neil, S. T., & Kyle, S. D. (2016). High resolution examination of the role of sleep disturbance in predicting functioning and psychotic symptoms in schizophrenia: A novel experience sampling study. *Journal of Abnormal Psychology*, *125*(6), 788–797. https://doi.org/10.1037/abn0000180

Myers, E., Startup, H., & Freeman, D. (2011). Cognitive behavioural treatment of insomnia in individuals with persistent persecutory delusions: A pilot trial. *Journal of Behavior Therapy and Experimental Psychiatry*, *42*(3), 330–336. https://doi.org/10.1016/j.jbtep.2011.02.004

Orwin, R. G. (1983). A fail-safe N for effect size in meta-analysis. *Journal of Educational Statistics*, *8*(2), 157–159.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies*, *49*(1), 47–53.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D.,

Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ*, *372*, 2020–2021. https://doi.org/10.1136/bmj.n71

Peralta, V., & Cuesta, M. J. (1999). Dimensional structure of psychotic symptoms: an item-level analysis of SAPS and SANS symptoms in psychotic disorders. *Schizophrenia Research*, *38*, 13–26. www.elsevier.com/locate/schres

Reeve, S., Emsley, R., Sheaves, B., & Freeman, D. (2017). Disrupting Sleep: The Effects of Sleep Loss on Psychotic Experiences Tested in an Experimental Study With Mediation Analysis. *Schizophrenia Bulletin*, *November*, 1–10. https://doi.org/10.1093/schbul/sbx103

Reeve, S., Nickless, A., Sheaves, B., & Freeman, D. (2018). Insomnia, negative affect, and psychotic experiences: Modelling pathways over time in a clinical observational study. *Psychiatry Research*, *269*(Baron, R. M., Kenny, D. A. 1986. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. J. Pers. Soc. Psychol. 51, 1173-1182. . 1987-13085-001. https://dx.doi.org/10.1037/0022), 673–680. https://doi.org/https://dx.doi.org/10.1016/j.psychres.2018.08.090

Reeve, S., Nickless, A., Sheaves, B., Hodgekins, J., Stewart, S. L. K., Gumley, A., Fowler, D., Morrison, A., & Freeman, D. (2019). Sleep duration and psychotic experiences in patients at risk of psychosis: A secondary analysis of the EDIE-2 trial. *Schizophrenia Research*, *204*(Afonso, P., Brissos, S., Figueira, M.L., Paiva, T. (2011). Schizophrenia

patients with predominantly positive symptoms have more disturbed sleep-wake cycles measured by actigraphy. Psychiatry Res. 189, 62-66 https://pubmed.ncbi.nlm.nih.gov/21257208 http), 326–333. https://doi.org/https://dx.doi.org/10.1016/j.schres.2018.08.006

Reeve, S., Sheaves, B., & Freeman, D. (2015). The role of sleep dysfunction in the occurrence of delusions and hallucinations: A systematic review. *Clinical Psychology Review*, *42*, 96–115. https://doi.org/10.1016/j.cpr.2015.09.001

Reeve, S., Sheaves, B., & Freeman, D. (2019). Sleep disorders in early psychosis: Incidence, severity, and association with clinical symptoms. *Schizophrenia Bulletin*, *45*(2 PG-287–295), 287–295. https://doi.org/https://dx.doi.org/10.1093/schbul/sby129

Rehman, A., Gumley, A., & Biello, S. (2018). Sleep quality and paranoia: The role of alexithymia, negative emotions and perceptual anomalies. *Psychiatry Research*, *259*(April 2016), 216–222. https://doi.org/10.1016/j.psychres.2017.09.066

Rek, S., Sheaves, B., & Freeman, D. (2017). Nightmares in the general population: identifying potential causal factors. *Social Psychiatry and Psychiatric Epidemiology*, *52*(PG-1123-1133), 1123–1133. NS -

Ronald, A., Sieradzka, D., Cardno, A. G., Haworth, C. M. A., Mcguire, P., & Freeman, D. (2014). Characterization of Psychotic Experiences in Adolescence Using the Specific Psychotic Experiences Questionnaire: Findings From a Study of 5000 16-Year-Old Twins. *Schizophrenia Bulletin*, *40*(4), 868–877. https://doi.org/10.1093/schbul/sbt106

Scott, A. J., Rowse, G., & Webb, T. L. (2017). A structural equation model of the relationship between insomnia, negative affect, and paranoid thinking. *PLoS ONE*, *12*(10 PG-). https://doi.org/https://dx.doi.org/10.1371/journal.pone.0186233

Sheaves, B., Holmes, E. A., Rek, S., Taylor, K. M., Nickless, A., Waite, F., Germain, A., Espie, C. A., Harrison, P. J., Foster, R., & Freeman, D. (2019). Cognitive behavioural therapy for nightmares for patients with persecutory delusions (nites): An assessor-blind, pilot randomized controlled trial. *The Canadian Journal of Psychiatry / La Revue Canadienne de Psychiatrie*, *64*(10 PG-686–696), 686–696. NS -

Sheaves, B., Onwumere, J., Keen, N., & Kuipers, E. (2015). Treating your worst nightmare: A case-series of imagery rehearsal therapy for nightmares in individuals experiencing psychotic symptoms. *The Cognitive Behaviour Therapist*, *8*(Afonso, P., Figueira, M. L., Paiva, T. (2014). Sleep-wake patterns in schizophrenia patients compared to healthy controls. World Journal of Biological Psychiatry 15, 517-524. 2014-40141-002. https://dx.doi.org/10.3109/15622975.2012.756987 https://pubmed). NS -

Sheaves, B., Porcheret, K., Tsanas, A., Espie, C. A., Foster, R. G., Freeman, D., Harrison, P. J., Wulff, K., & Goodwin, G. M. (2016). Insomnia, nightmares, and chronotype as markers of risk for severe mental illness: results from a student population. *Sleep*, *39*(1 PG-173–181), 173–181. NS -

Shevlin, M., McElroy, E., Bentall, R. P., Reininghaus, U., & Murphy, J. (2017). The psychosis continuum: Testing a bifactor model of psychosis in a general population sample. *Schizophrenia Bulletin*, *43*(1), 133–141. https://doi.org/10.1093/schbul/sbw067

Spoormaker, V. I., Verbeek, I., van den Bout, J., & Klip, E. C. (2005). Initial validation of the SLEEP-50 questionnaire. *Behavioral Sleep Medicine*, *3*(4), 227–246.

Taylor, K. M., Bradley, J., & Cella, M. (2022). A novel smartphone-based intervention targeting sleep difficulties in individuals experiencing psychosis: A feasibility and acceptability evaluation. *Psychology and Psychotherapy: Theory, Research and*

Practice, *95*(3), 717–737. https://doi.org/10.1111/papt.12395

Taylor, M. J., Gregory, A. M., Freeman, D., & Ronald, A. (2015). Do sleep disturbances and psychotic-like experiences in adolescence share genetic and environmental influences? *Journal of Abnormal Psychology*, *124*(3 PG-674–684), 674–684. https://doi.org/https://dx.doi.org/10.1037/abn0000057

The jamovi project. (2024). *jamovi (version 2.5)*. https://www.jamovi.org

Vazquez-Barquero, J., Lastra, I., Nuez, M., Herrera, S., & Grahamdunn, C. (1996). Patterns of Positive and Negative Symptoms in First Episode Schizophrenia. *British Journal of Psychiatry*, *168*, 693–701. http://bjp.rcpsych.org/content/bjprcpsych/168/6/693.full.pdf

Viechtbauer, W. (2005). Choosing between the fixed-, random-, and mixed-effects model in meta-analysis: An analysis of existing and new model selection methods. *Journal of Statistical Software*, *36*, 1–48.

Waite, F., Černis, E., Kabir, T., Iredale, E., Johns, L., Maughan, D., Diamond, R., Seddon, R., Williams, N., & Yu, L.-M. (2023). A targeted psychological treatment for sleep problems in young people at ultra-high risk of psychosis in England (SleepWell): a parallel group, single-blind, randomised controlled feasibility trial. *The Lancet Psychiatry*, *10*(9), 706–718.

Wigman, J. T. W., Vollebergh, W. A. M., Raaijmakers, Q. A. W., Iedema, J., Van Dorsselaer, S., Ormel, J., Verhulst, F. C., & Van Os, J. (2009). The Structure of The Extended Psychosis Phenotype in Early Adolescence—A Cross-sample Replication. *Schizophrenia Bulletin*, *37*, 850–860. https://doi.org/10.1093/schbul/sbp154

Wong, K. K., Freeman, D., & Hughes, C. (2014). Suspicious young minds: Paranoia and mistrust in 8- To 14-year-olds in the UK and Hong Kong. *British Journal of Psychiatry*,

205(3), 221–229. https://doi.org/10.1192/bjp.bp.113.135467

Yung, A. R., Yung, A. R., Pan Yuen, H., Mcgorry, P. D., Phillips, L. J., Kelly, D., Dell'Olio, M., Francey, S. M., Cosgrave, E. M., & Killackey, E. (2005). Mapping the onset of psychosis: the comprehensive assessment of at-risk mental states. *Australian & New Zealand Journal of Psychiatry*, *39*(11–12), 964–971.

Zavos, H. M. S., Freeman, D., Haworth, C. M. A., Mcguire, P., Plomin, R., Cardno, A. G., & Ronald, A. (2014). Consistent etiology of severe, frequent psychotic experiences and milder, less frequent manifestations: A twin study of specific psychotic experiences in adolescence Objective—Investigate degree of genetic and environmental influences on specific psychoti. *JAMA Psychiatry*, *71*(9), 1049–1057. https://doi.org/10.1001/jamapsychiatry.2014.994

Service Improvement Project

20 years versus 20 minutes: increasing the understanding of delusions from a cognitive behavioural perspective in two older adult community mental health teams

Poppy Brown

The Oxford Institute of Clinical Psychology Training and Research

Oxford Health NHS Foundation Trust

University of Oxford

poppy.brown@hmc.ox.ac.uk

Word count: 5,015

Submission to course: June 2023

Internal Supervisor: Dr Kathryn Evans, kathryn.evans@hmc.ox.ac.uk
The Oxford Institute of Clinical Psychology Training, Oxford Health NHS Foundation Trust
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

External/Field Supervisor: Dr Rebecca Dow, rebecca.dow@swft.nhs.uk
South Warwickshire University NHS Foundation Trust

Proposed Journal: This manuscript is under review at *The Cognitive Behaviour Therapist*. This journal was chosen given its cross-cutting focus on all aspects of cognitive behavioural approaches, including service projects, and its wide readership of clinicians and researchers.

Declaration of interest: None.

The trainee confirms that supervisors have read and provided feedback on the work, deeming it suitable for assessment.

Abstract

The last two decades have seen considerable development in our understanding of delusions, with medical perspectives broadening into more holistic bio-psychosocial models. Of particular relevance to services is the increasing evidence base for cognitive-behavioural models and treatments. A number of national initiatives have aimed to ensure these developments are reflected in services. Primarily these have targeted adult services, yet delusions are still prevalent in older adults. Across two older adult services this study assessed the number of patients experiencing delusions, explored staff perspectives regarding delusions, and delivered a brief training on cognitive behavioural approaches to delusions. Three service users contributed to the training content. Endorsement of theoretical perspectives regarding delusions were measured pre and post training. Results showed over 20% of patients in the service may be experiencing paranoia or delusions, but less than 1% of these were referred for CBT. Of 27 staff participants, less than half had received training on working with delusions, most of which was from as many as 20 years ago. Nearly all reported a lack of knowledge prevented them from considering psychological perspectives. No immediate changes in outcome measures were seen after the training, with a striking diversity in approach to delusions according to professional background. All staff qualitatively reported finding the training valuable, though engagement was dampened by high levels of stress and burnout. Promoting change within stretched systems to reflect the developing cognitive behavioural evidence base is challenging but necessary. Where full interventions are not possible, small but consistent nudges may provide a path forward.

Keywords: delusions, psychosis, staff training, cognitive models, older adults

Introduction

Cognitive behavioural approaches to delusions

There have been significant changes in the way we understand psychosis in the last two decades (Health Education England, 2020). Historic understanding of psychosis being a chronic biological illness treatable only via medication has broadened into a more patient-centred understanding, where psychosis is an umbrella term for varied experiences existing on a spectrum of severity within the general population, much like anxiety and depression (Garety et al., 2001). Delusions are one key psychotic experience, of which persecutory delusions (the severe end of the paranoia spectrum) are the most common. Evidence-based cognitive models have now been developed that posit a number of common, understandable, and treatable factors that cause and maintain paranoia and delusions, such as sleep dysfunction, negative cognition, high levels of worry, and reasoning biases (Freeman, 2016; Garety & Freeman, 1999).

Based on these models, increasingly tailored cognitive behavioural therapies are showing new ways of improving delusions, reducing distress, and increasing quality of life for patients with psychosis (Bighelli et al., 2018). Most recently, the Feeling Safe Programme showed the largest treatment effects ever seen for patients with persistent delusions when tested in a randomised controlled trial against another psychological intervention (befriending) (Freeman et al., 2021). Work is ongoing to consider whether cognitive-behavioural treatments should be considered more frequently without the use of medication at all (Morrison et al., 2020), particularly given the negative side effects of anti-psychotics

such as weight gain, drowsiness, and movement disorder, among others. Many of these side effects are also of particular risk to older adults (Leon et al., 2010).

Psychosis and delusions in older adults

Despite psychosis having a peak of onset during adolescence and early adulthood, a proportion of patients first experience psychosis later in life, with some estimates suggesting a quarter of first episode psychosis occurs in those aged over 65 (Mitford et al., 2010). Older adults experiencing psychosis typically do not have the same access to care as younger adults (Mitford et al., 2010), yet the cost of caring for older adults experiencing psychosis is simultaneously higher than for younger age adults (Gallagher-Thompson et al., 2008). The number of older adults experiencing and needing treatment for psychosis is expected to increase dramatically given our ageing population, thus a greater focus on how to care for older adults with psychosis is essential. Paranoia and delusions in particular may also be more prevalent and severe in older onset psychosis as compared to younger onset, potentially due to the overlap with increasing cognitive decline and neurodegenerative disorders like dementia (Suen et al., 2019). There is limited evidence to support the use of antipsychotic medications in late-onset psychosis, suggesting that psychological treatments might be important to explore, regardless of whether the psychosis is considered primary or secondary to another disorder (Reinhardt & Cohen, 2015).

Implementation into services

It is important for our mental health services to incorporate and reflect developing evidence bases. Most obviously this includes Psychologists being trained to deliver CBT for psychosis

(CBTp), including specific interventions like the Feeling Safe Programme. However, when first accessing a service, patients are typically seen by Community Mental Health Teams (CMHTs) made up of a diverse range of professionals. There are therefore a number of more nuanced ways that incorporating cognitive behavioural approaches into multi-disciplinary teams could be of benefit. For example, being aware of cognitive explanations of delusions could aid staff in gaining helpful additional information at general assessment. For instance, asking questions about the content and distress associated with delusions rather than challenging the unusual beliefs or viewing them as an epiphenomenon of the psychosis that is safest left alone, as might have been encouraged in earlier models of delusions (Berrios, 1991).

National initiatives have begun trying to incorporate more psychological models of delusions into mainstream mental health care. The NHS Long Term Plan (NHS England, 2019b) and Mental Health Implementation Plan (NHS England, 2019a) set out new models for more integrated and personalised community mental health care, including increased access to psychological therapies and upskilling the NHS workforce to deliver better care for individuals with psychosis. Health Education England have also commissioned a two-day training on 'Understanding Psychosis and Bi-polar disorder' for CMHTs (Health Education England, 2020). The training covers a broad range of social and psychological perspectives on psychosis, including, but not limited to, cognitive behavioural models. This training is available to older adult services although adaptations specific to the needs of older adults with psychosis are not included in the training.

There is no in-built evaluation of the training package, and indeed across the literature there is limited recent examination of CMHT staff perception of either their training needs or

the usefulness of training that has been provided. There is, however, general evidence that healthcare staff can lack confidence in working with those experiencing psychosis (Copello et al., 2012; Kramarz et al., 2021; Yung et al., 2003) and that despite the diverse professional background of staff working in CMHTs, knowledge of empirical psychological models is often not standard (Brooker, 2001). Evidence from some years ago suggests some positive outcomes from staff training in this area, however (Laube & Higson, 2000). For instance, training community psychiatric nurses to deliver psychosocial interventions for psychosis led to reductions in patients' positive and negative symptoms (Brooker et al., 1994), with similar studies showing significant overall NHS cost savings for those services (Brooker, 2001; Brooker et al., 1997). Conversely, despite positive outcomes, these studies raised questions over whether services have the capacity to have non-psychology staff delivering these interventions, and whether it led to poorer care being delivered in other areas. Certainly, within our service the aim was not to train CMHT staff in how to provide CBT. Staff shortages meant there was no capacity for staff to be delivering more interventions, with the aim instead to offer a brief training to increase knowledge and confidence to approach clinical work while holding cognitive-behavioural perspectives in mind, and to guide staff-patient interactions and care planning.

The current study

The study took place across two multi-disciplinary Older Adult CMHTs (OA CMHTs) serving one county within an NHS trust. These services provide care for adults aged over 65 with severe mental health needs. In each service there is also a step 4 team providing psychological therapies, predominantly CBT. Psychology staff identified a need for

increasing CMHT staff's understanding of and confidence to work with patients experiencing delusions, particularly from cognitive-behavioural perspectives, echoing the need identified at a national level. The service was not commissioned to receive the HEE Psychosis and Bi-polar training, and if they were to receive it in future, staff shortages would likely preclude attendance given its two-day length. Consequently, a smaller scale assessment of staff needs and training delivery, was planned. Prior to training delivery, it was also necessary to better understand the current service need through an audit and staff survey.

Overall, the aims were as follows: First, to assess the number of patients within the two teams who over the last year have been experiencing paranoia or delusions, and to identify what proportion of these individuals were referred to the Step 4 Psychological Service. Secondly, to assess staff knowledge and confidence in delivering care to patients experiencing delusions, and their understanding of psychological perspectives on delusions. Finally, to design a staff training session based on the identified need and deliver this intervention, as well as gaining feedback from staff on its impact.

The project took place post the Covid-19 pandemic where teams were trying to return to face-to-face work. Both teams began experiencing severe difficulties maintaining staffing levels, with significant numbers of staff recruited as locums without previous experience of working with older adults. Adding to this, the training was scheduled during a time where services unexpectedly experienced an extended outage of Carenotes, the trust's clinical notes system, adding to pressures and workloads. Given these challenges, it was clear that to engage staff, the training needed to be brief, straightforward, and have a practical focus.

Methods

Audit

Using routinely collected data, information was collated regarding the number of patients within the two teams who were experiencing delusions or paranoia and the number of which were then referred to the Psychology team. Clinical Record Interactive Search (CRIS), a service providing deidentified access to clinical notes, was used to search care notes, including free text data, from both teams. Search terms comprised: 'delus*' or ''paranoi*' or 'grandios*' or 'unusual belief' or 'unusual idea' or 'unusual thought', with notes excluded if 'no' proceeded any of the terms. Given the authors' observations that clinical notes regarding delusions often described staff's attempts to 'challenge' patients regarding their beliefs, a search was also conducted to see how frequently the word 'challenged' was included with clinical notes that included the search terms.

Staff survey

All CMHT staff were invited to take part. Demographic data included age, gender, job role, and length of time in the team. Further questions asked about the numbers of patients on caseloads experiencing paranoia or delusions, any past training in understanding or working with delusions, and questions about what staff typically do or ask when assessing individuals with delusions e.g., do they aim to challenge delusions and do they assess distress. Finally, staff were asked to list and rank the most helpful treatments for delusions, and perspectives on psychological approaches to delusions were gained. Free text boxes were included to allow staff to elaborate on their answers. The survey can be viewed in Appendix E.

Training

All CMHT staff were invited to take part. The training was devised based on the survey results and the contributions from service users, and suitable times were chosen for the training through liaising with service managers. Two lunchtime training slots were offered, with a recording of the session also distributed to those unable to attend. Slides and a summary sheet (see Appendix F) were also distributed and put on display in the offices.

Measures

Increased ability to consider cognitive-behavioural perspectives when caring for patients with delusions is something that would primarily be expected to develop over time, across in-the-moment staff-patient interactions. This is challenging to measure in a standardised way, which may be one reason why no evaluation or outcome measures are currently planned within the HEE commissioned psychosis training. For this project, staff were instead asked to complete four analogue scales measuring endorsement from zero (not at all) to 100 (completely) of biological versus psychological perspectives of delusions immediately before and after the training. The statements were: delusions are a symptom of a chronic neurological disease that can be managed but not cured; it's important to challenge patients' delusions to help bring them back into reality; delusions always require treatment by medication; there is value in using psychological approaches with people experiencing delusions. At the end of the training staff were also asked to provide feedback on what they found helpful about the training, what could be improved, and any further training or support they would like access to.

Service User Involvement

Two patients with experience of delusions and one carer of a patient with delusions from within the service fed into training content. They were asked questions such as ‘what would you like staff to know or understand about the experience of feeling unsafe or worried around others’ and ‘what are some of the things that have been most helpful or unhelpful regarding your interactions with staff?’. A summary of their input and how this was incorporated can be viewed in Appendix G.

Ethical approval

Trust service evaluation/audit approval was received (see Appendix D). NHS ethical approval was not required given the project fell within a service evaluation remit.

Results

Audit

4,065 patients were being held under the two teams between April 2021 and April 2022. Over a quarter (n=1,161) had clinical notes hitting at least one search term (n=807 for delusion; n=839 for paranoia; n=121 for grandiose; n=19 for unusual belief; n=23 for unusual idea; n=79 for unusual thought, with notes excluded if ‘no’ proceeded any of the terms). Of these, there were only six referrals to Psychology. There were 166 clinical notes that had the search terms present as well as the word ‘challenged’ within the same note.

A random selection of five patients who each had five or more notes mentioning paranoia or delusions (the two most common search terms) was made, yielding 89 clinical

notes, of which five were randomly selected using an online randomiser. There were five patients who had five or more notes containing one of the search terms as well as the word 'challenged'. A random sample of five of these notes was selected. Table 1 presents extracts from the notes.

Table 1. Extracts from clinical notes referring to paranoia or delusions

Note number	**Extract**
1	'He is not eating and when prompted expressed persecutory delusion about the food, yet would eat when assured and spoon fed'
2	'She has thoughts of being overtaken by the devil but this appeared to be more of an overvalued idea on the background of Christian faith, rather than a delusion'
3	'Issues with paranoia. She will not leave the house and has even changed the locks. The family has been accused as she thinks things are going missing'
4	'Likely persecutory beliefs around neighbor. Denies hallucinations'
5	'Home visit didn't go well from last week. Will need another home visit to assess delusions and still discussion on LPA after financial assessment. X still keeps pushing for a date for psychology assessment.'
Note number	**Extract mentioning the search terms alongside the word 'challenged'**
6	'She didn't feel she was a threat to anyone and was remarkably calm when challenged re delusions'
7	'X does have the tendance to be verbally aggressive especially if he is challenged regarding his grandiose thoughts or in regard to mental health interventions'
8	'He became aggressive when challenged about being mentally ill'
9	'Objectively, X was reassured when challenged on the irrationality of these thoughts, but seemed to be finding it difficult to be convinced and he needed reassurance throughout the shift'

10	'X asserted he was related to the royal family and when challenged on this stated that his dad is a black ops MI6 operator who has killed people in the past'

Staff survey

27 members (equating to over a quarter of staff) of staff completed the survey: eight psychology staff, three psychiatrists, five nurses, five occupational therapists, three social workers, and one manager. Staff turnover in both CMHTs was high, with half of respondents having been in their team for under a year. The number of patients on caseloads ranged from zero to half the entire CMHT area, with the estimated numbers of patients on caseloads experiencing severe paranoia or delusions ranging from 0-10 (an average response of 2, though several staff responded with 'not sure').

Half reported having never had training on working with paranoia or delusions and for those that had, this was typically limited to what had been within their general professional training as e.g., psychiatrists. As such, with the exception for a few staff members who qualified recently, most training was from many years ago.

Nine respondents wrote medication as the most helpful intervention for individuals experiencing delusions, with all others listing psychological or social approaches as the topmost helpful intervention. Despite this, 14 out of the 19 non-psychology staff members reported they may not consider psychological perspectives or interventions due to a lack of knowledge or confidence, with other reasons including the patient being too unwell or not wanting it. Most reported being open to talking to a patient about their delusions, but almost 20% reported that they do not typically ask about the distress associated with a patient's delusion. 60% (equating to almost all non-psychology staff) said it was 'sometimes'

important to challenge a patient's delusion in order to help them see that their belief is not true.

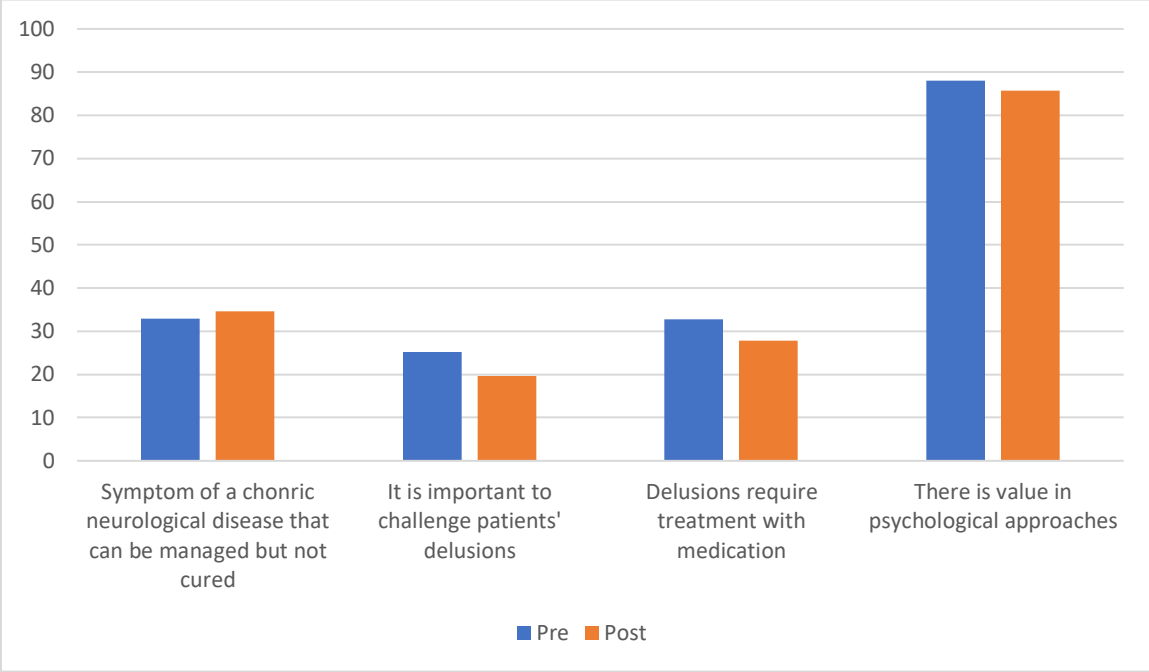
Qualitative comments included multiple concerns that agreeing with a patient's delusions could increase the patient's belief and conviction in their delusion and that even just talking to or asking a patient about their delusion may cause distress or aggression. Conversely, some respondents did think it important to ask detail about a patient's delusions in order to understand their perspective and create a care plan. Multiple respondents felt psychological approaches could be helpful with a patient who is well enough and who has tried medication, but primarily in order to help them test/check their reality.

Staff training

The training was devised and delivered by the trainee and comprised two parts. The first concerned rethinking delusions as an experience rather than just a symptom, by presenting evidence for their existence on a spectrum of severity across the population and a discussion of how different types of unusual or false beliefs may be considered normal or acceptable in different contexts. An evidence based cognitive model of persecutory delusions was presented to illustrate six common, understandable, and easily treatable factors that can contribute to delusions (Freeman, 2016). Evidence of the effectiveness of CBTp was then presented. Part two concerned how CMHT staff can work with patients experiencing delusions, starting with straightforward ways to engage patients by asking meaningful questions from a cognitive behavioural approach. Common concerns and myths about delusions as well as specific considerations for older adults were then explored.

Roughly a quarter of staff attended the training. Eleven staff members attended the first training session and nine attended the second, including two consultant psychiatrists, four social workers, four assistant psychologists, three clinical psychologists, and seven nurses (two holding senior leadership and management roles). Several additional members of staff watched the recording of the training in their own time. In total, 23 responses were gained for the pre-training questionnaire, and 25 responses for the post-training questionnaire. To preserve anonymity, pre and post responses were not linked, and several staff joined each training session late or had to leave early. Consequently, it was unclear how many individuals completed both the pre and post measures and thus how similar the two groups of staff were. Figure 1 summarises the results on the measures. For question 1 the mean endorsement pre-training was 32.88 (range: 0-71) and post-training was 34.64 (range: 0-90). For question 2 mean endorsement pre-training was 25.13 (range: 0-80) and post-training was 19.68 (range: 0-89). For question 3 mean endorsement pre-training was 32.76 (range: 0-94) and post-training was 27.81 (range: 0-78). For question 4 mean endorsement pre-training was 88.08 (range: 42-100) and post-training was 85.65 (range: 52-100). Overall, on average there was limited change across the group pre-post training, with high ranges in scores demonstrating significant diversity in views and approaches to understanding delusions.

Figure 1. Endorsement of statements pre- and post-training.



In the post-survey qualitative comments, 22 respondents described the training as relevant and helpful, with the remaining three people not completing this question. The most helpful parts reported were historical perspectives for older adults with psychosis, causal and treatment mechanisms in paranoia, summarising the evidence base, encouragement of validation rather than challenging patients, checking whether any reported persecution could be real, and the practical aspects of what to actually say to patients.

In terms of what staff wanted more access to in the future, 17 wanted more training, 14 wanted case formulation sessions, 6 wanted supervision groups, 7 wanted 1:1 consultation with a clinical psychologist, 6 wanted Q&A sessions, and 11 wanted access to more resources. Suggested topics for further input included working on insight, working on delusions in the context of severe comorbid depression or dementia, and full access to

training on CBTp. However, a number of staff also noted that engaging with this kind of training was difficult due to being in a state of 'just trying to keep heads above water'.

Discussion

This project aimed firstly to identify the number of patients within the service experiencing paranoia or delusions, secondly to assess the theoretical approach typically taken by staff when working clinically with delusions, and thirdly to deliver a training incorporating an up-to-date cognitive-behavioural understanding of delusions and assess its impact. There was a striking number of patients in the service (over 20%) who were identified to have the search terms present in their notes. While there may be some false positives (e.g., notes where paranoia or unusual thoughts were mentioned but in a different context or discussed in terms of their absence), none of the randomly selected notes showed evidence of this. A number of patients were likely experiencing paranoia or delusions in the context of a dementia rather than, for example, first episode psychosis, but a psychological understanding in this context may still be important (Collerton & Dudley, 2004). It would be interesting to investigate further whether there are significantly more older adults experiencing these symptoms than previously recognised, or whether there is something about the way paranoia is reported in clinical notes that is misrepresentative or overinflated.

The randomly selected notes also provided insight into the way delusions are recorded. While one of the notes (note 2 in Table 1) provided a helpful example of a clinician considering a patient's context and religious background as a way to understand their unusual ideas, other notes contained little information on the content, context, or impact of the patient's beliefs. Table 1 also confirmed that patients with delusions are sometimes being

‘challenged’ directly on their delusional beliefs despite several examples of this proving unhelpful and distressing to the patient.

The high number of patients with clinical notes mentioning delusions and paranoia was in stark contrast to the number of referrals received in the Psychological Therapies teams, despite NICE guidance to offer all patients with psychosis psychological therapy (NICE, 2015). From the present data alone, it isn’t clear if there were in fact many more patients who would have been suitable and benefited from psychological therapy, but this is certainly one plausible interpretation. We could have chosen to measure whether referrals to Psychology increased following the training. However, it was felt that this outcome can become tokenistic when used as a metric of change and in fact the real aim was to improve staff-patient interactions at all levels.

Results from the survey showed there was definite room for providing further training in understanding psychosis, and feedback after delivering the training further showed that this was welcome and relevant. However, the high staff turnover that was apparent meant that without continued delivery, any changes or improvements might be short-lived. Interpreting the wider impact of the training was also not straightforward. Both the training and associated measures were required to be brief to increase the likelihood of staff engaging and attending. The measures of perspectives on delusions showed almost no average group change after the training, suggesting a brief intervention is not sufficient for helping to merge perspectives and understanding of delusions. A more striking result from the measures was just how different individual responses were. Ranges for each question were large, with some respondents completely disagreeing with the first three questions (i.e. scoring their agreement at or close to zero), and others almost completing agreeing (i.e. scoring their endorsement

above 90%). The smallest range was for question four, regarding the value of psychological approaches, but even this ranged from 42-100% agreement. Given NICE guidance recommends psychological treatments as a first line intervention for psychosis alongside medication it is surprising that some staff members rated the value of psychological treatments so low (NICE, 2015). While a key strength of multi-disciplinary working is the integration of care from multiple perspectives, the question must be asked about whether consistent, reflective, and evidence-based team working, and patient care, can successfully be achieved in the face of such stark differences in conceptualisation and approach. Regular team case discussions and supervision should mitigate against these concerns, but for this to succeed all staff must feel valued and empowered to speak up and reflect in these contexts, which may not be the case in every service. Moreover, not every patient can be discussed by the whole team.

There was considerable positive qualitative feedback regarding the helpfulness of the training and the gap staff felt it was helping to fill. Following the training, the trainee was contacted by several staff members to discuss cases and seek advice on how to work with particular patients with delusions. Having a staff member within CMHTs emerging as a champion in a particular area allows staff members to seek advice quickly and easily. With high rates of staff turnover this can be challenging, however. Indeed, the trainee herself was only on short-term placement in the service which ended shortly after the project was completed. However, following the presentation of the results back to the team, it was agreed with senior management that a psychologist would re-facilitate the training to CMHT staff every six months in order to help reduce the difficulties associated with high staff-turnover.

The training materials and further resources were also added into an induction pack for new starters, and into other relevant resource folders held on Microsoft Teams.

There were several mentions of burn out and stress in the qualitative comments, adding to the narrative of it being challenging to make change within a context of high stress and understaffing. Despite this, there were also requests for more help in this area with lots of staff stating they would like further training sessions, potentially with the recognition that enhancing knowledge can often bring about time savings in the long run.

Implications

The data on numbers of older adults experiencing delusions was not easily available. Many staff were unsure of how many of their patients were experiencing paranoia or delusions, and the psychology team received very few referrals. It would be easy to have initially concluded, then, that this is not an area of particular importance. However, upon searching for the data, it became clear that this is not the case. It was evident that staff are often working with severe paranoia or delusions, but do not necessarily feel confident in doing so. Most significantly, staff approach their clinical work regarding delusions from vastly different theoretical positions. Service leaders need to be aware of these differences and find ways of bringing staff together to provide holistic and consistent care.

Supporting change within CMHTs is a fine balance, however. While 20 minutes of training could never set out to compete with 20 years of professional practice, even training as brief as this felt too much for many staff members to find the time to engage with. At times of high stress, it is more common to rely on well ingrained knowledge from core training than to fish for more recent learning that may not have previously been put into

practice. A sustained approach may therefore be required, for example using ideas from nudge theory (Thaler & Sunstein, 2009), in addition to formal training enforcement. Nudges might include having a champion associated with the training and as an expert in the area who is able to offer consultation, training reminders, and resources, and encouraging joint working and case presentations facilitated by both MDT and psychology staff together. As staff start to see the benefits to their learning, incorporation of learning is likely to be reinforced, thereby gradually allowing for wider and more significant change.

Limitations

There were a number of limitations to this study. The most significant was the difficulty in using standardised outcome measures to assess the impact of the intervention. Qualitatively it was clear that staff found the training relevant and helpful, and it did lead to 1:1 follow up consultations where the trainee was able to provide advice regarding cases, but there was no way to clearly measure long-term changes in staff's conceptualisation of delusions. A further limitation is that with regard to the endorsement of medical versus psychological perspectives, the large ranges combined with not all the same people completing pre and post measures meant the group changes (or lack of) were not necessarily meaningful, and it was not possible to assess change at the individual level for those who did complete both sets, given pre and post responses were not linked.

Thirdly, it was challenging to accurately measure the number of patients experiencing paranoia and delusions. The search terms may have missed some patients where paranoia or delusions were qualitatively described without using the named terms, yet also included

others whether the terms paranoia or delusions were discussed but in terms of their absence rather than presence. These data can therefore only be seen as an estimate.

Conclusion

In 2001 an article summarising the previous decade of psychological training available to mental health staff described the situation as 'hectic', with little consistency across trusts or professions. Twenty years on it's not clear that the situation has hugely improved, evidenced here by the inconsistency in staff's prior training on delusions and the fact that neither CMHT were accessing the wider HEE commissioned training. Delivering a brief training as was done in this project may be considered to only add to the 'hectic' situation, especially given the limited follow up of measurable outcomes. However, we argue the project provides a timely example of the difficulties of promoting change within CMHTs with consideration of what is still possible within a stretched system. Where larger interventions – such as the HEE training – are not possible, smaller scale nudges towards up-to-date evidence-based practise may be paramount.

References

Berrios, G. E. (1991). Delusions as ″Wrong beliefs″: A conceptual history. *British Journal of Psychiatry*, *159*(NOV. SUPPL. 14), 6–13. https://doi.org/10.1192/s0007125000296414

Bighelli, I., Salanti, G., Huhn, M., Schneider-Thoma, J., Krause, M., Reitmeir, C., Wallis, S., Schwermann, F., Pitschel-Walz, G., Barbui, C., Furukawa, T. A., & Leucht, S. (2018). Psychological interventions to reduce positive symptoms in schizophrenia: systematic review and network meta-analysis. *World Psychiatry*, *17*(3), 316–329. https://doi.org/10.1002/wps.20577

Brooker, C. (2001). A decade of evidence-based training for work with people with serious mental health problems: Progress in the development of psychosocial interventions. *Journal of Mental Health*, *10*(1), 17–31. https://doi.org/10.1080/09638230020023589

Brooker, C., Falloon, I., Butterworth, A., Goldberg, D., Graham-Hole, V., & Hillier, V. (1994). The outcome of training community psychiatric nurses to deliver psychosocial intervention. *British Journal of Psychiatry*, *164*(AUG.), 222–230. https://doi.org/10.1192/bjp.165.2.222

Brooker, Charlie., Molyneux, P., Deverill, M., & Repper, J. (1997). An audit of costs and outcome using HoNOS-3 in a rehabilitation team: A pilot study. *Journal of Mental Health*, *6*(5), 491–502. https://doi.org/10.1080/09638239718581

Collerton, D., & Dudley, R. (2004). A cognitive behavioural framework for the treatment of distressing visual hallucinations in older people. *Behavioural and Cognitive Psychotherapy*, *32*(4), 443–455. https://doi.org/10.1017/S1352465804001626

Copello, A., Walsh, K., Graham, H., Tobin, D., Fellows, S., Griffith, E., Day, E., &

Birchwood, M. (2012). The impact of training within a comprehensive dual diagnosis strategy: The Combined Psychosis and Substance Use (COMPASS) experience. *Mental Health and Substance Use: Dual Diagnosis*, *5*(3), 206–216. https://doi.org/10.1080/17523281.2012.660191

Freeman, D. (2016). Persecutory delusions: a cognitive perspective on understanding and treatment. *The Lancet Psychiatry*, *3*(7), 685–692. https://doi.org/10.1016/S2215-0366(16)00066-3

Freeman, D., Emsley, R., Diamond, R., Collett, N., Bold, E., Chadwick, E., Isham, L., Bird, J. C., Edwards, D., Kingdon, D., Fitzpatrick, R., Kabir, T., Waite, F., Carr, L., Causier, C., Černis, E., Kirkham, M., Lambe, S., Lister, R., … Twivy, E. (2021). Comparison of a theoretically driven cognitive therapy (the Feeling Safe Programme) with befriending for the treatment of persistent persecutory delusions: a parallel, single-blind, randomised controlled trial. *The Lancet Psychiatry*, *8*(8), 696–707. https://doi.org/10.1016/S2215-0366(21)00158-9

Gallagher-Thompson, D., Steffen, A., & Thompson, L. W. (2008). *Handbook of behavioral and cognitive therapies with older adults*. Springer.

Garety, P. A., & Freeman, D. (1999). Cognitive approaches to delusions: a critical review of theories and evidence. *The British Journal of Clinical Psychology*, *38 (Pt 2)*, 113–154. https://doi.org/10.1348/014466599162700

Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological Medicine*, *31*(02), 189–195. https://doi.org/10.1017/S0033291701003312

Health Education England. (2020). *Understanding psychosis and bipolar disorder*.

Kramarz, E., Lyles, S., Fisher, H. L., & Riches, S. (2021). Staff experience of delivering clinical care on acute psychiatric wards for service users who hear voices: a qualitative study. *Psychosis*, *13*(1), 58–64. https://doi.org/10.1080/17522439.2020.1781234

Laube, R. E., & Higson, F. M. (2000). Staff training in cognitive-behavioral family intervention in mental illness, using the multiple-family group approach: A pilot study. *Community Mental Health Journal*, *36*(5), 477–490. https://doi.org/10.1023/A:1001959613430

Leon, C., Gerretsen, P., Uchida, H., Suzuki, T., Rajji, T., & Mamo, D. C. (2010). Sensitivity to antipsychotic drugs in older adults. *Current Psychiatry Reports*, *12*(1), 28–33. https://doi.org/10.1007/s11920-009-0080-3

Mitford, E., Reay, R., McCabe, K., Paxton, R., & Turkington, D. (2010). Ageism in first episode psychosis. *International Journal of Geriatric Psychiatry*, *25*(11), 1112–1118. https://doi.org/10.1002/gps.2437

Morrison, A. P., Pyle, M., Maughan, D., Johns, L., Freeman, D., Broome, M. R., Husain, N., Fowler, D., Hudson, J., MacLennan, G., Norrie, J., Shiers, D., Hollis, C., James, A., Birchwood, M., Bhogal, R., Bowe, S., Byrne, R., Clacey, J., … Yung, A. (2020). Antipsychotic medication versus psychological intervention versus a combination of both in adolescents with first-episode psychosis (MAPS): a multicentre, three-arm, randomised controlled pilot and feasibility study. *The Lancet Psychiatry*, *7*(9), 788–800. https://doi.org/10.1016/S2215-0366(20)30248-0

NHS England. (2019a). *NHS Mental Health Implementation Plan 2019/20-2023/24*. https://www.longtermplan.nhs.uk/publication/nhs-mental-health-implementation-plan-2019-20-2023-24/

NHS England. (2019b). *The NHS Long Term Plan*. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

NICE. (2015). Psychosis and schizophrenia in adults: prevention and management. *Nice Guidelines*. https://www.nice.org.uk/guidance/cg178/evidence/full-guideline-490503565

Reinhardt, M. M., & Cohen, C. I. (2015). Late-Life Psychosis: Diagnosis and Treatment. *Current Psychiatry Reports*, *17*(2). https://doi.org/10.1007/s11920-014-0542-0

Suen, Y. N., Wong, S. M. Y., Hui, C. L. M., Chan, S. K. W., Lee, E. H. M., Chang, W. C., & Chen, E. Y. H. (2019). Late-onset psychosis and very-late-onset-schizophrenia-like-psychosis: an updated systematic review. *International Review of Psychiatry*, *31*(5–6), 523–542. https://doi.org/10.1080/09540261.2019.1670624

Thaler, R. H., & Sunstein, C. R. (2009). *Nudge: Improving decisions about health, wealth, and happiness*. Penguin.

Yung, A. R., Organ, B. A., & Harris, M. G. (2003). Management of early psychosis in a generic adult mental health service. *Australian and New Zealand Journal of Psychiatry*, *37*(4), 429–436. https://doi.org/10.1046/j.1440-1614.2003.01196.x

Theory Driven Research Project

Paranoia and Unusual Sensory Experiences in Parkinson's Disease

Poppy Brown

The Oxford Institute of Clinical Psychology Training and Research

Oxford Health NHS Foundation Trust

University of Oxford

poppy.brown@hmc.ox.ac.uk

Word count: 5,032

Submission to course: May 2024

Internal Supervisor: Dr Louise Johns, louise.johns@psych.ox.ac.uk
The Oxford Institute of Clinical Psychology Training & Research, Oxford Health NHS Foundation Trust, Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX

External/Field Supervisors: Dr Rebecca Dow[1] and Prof Daniel Freeman[2]
[1]rebecca.dow@swft.nhs.uk, South Warwickshire University NHS Foundation Trust
[2] daniel.freeman@psy.ox.ac.uk, University of Oxford and Oxford Health NHS Foundation Trust

Proposed Journal: *Journal of Parkinson's disease*. This journal publishes research across all aspects of Parkinson's disease.

Declaration of interest: None.

The trainee confirms that supervisors have read and provided feedback on the work, deeming it suitable for assessment.

Abstract

Background: Psychotic experiences (PEs) in Parkinson's disease (PD) are reportedly common. However, there is a lack of knowledge regarding the specific nature of these experiences, and limited understanding of their development and maintenance.

Aims: First, to comprehensively assess the severity, nature, and associated distress of paranoia and unusual sensory experiences (USEs) in PD. Second, using structural equation modelling (SEM), to assess what variables are significantly associated with these experiences, focussing on the psychological processes central to understanding PEs in non-PD groups.

Method: A questionnaire battery was completed by 369 individuals with PD with a mean age of 66 years and mean time since diagnosis of 5 years. For a subset of measures, comparisons were made to an age-matched control group.

Results: 182 (49%) participants reported USEs, including almost half of those not taking any dopaminergic medication. For 83 (23%), the experience was distressing. Paranoia across the sample was significantly lower than in age-matched controls. However, specific paranoid concerns around abandonment and spousal betrayal were prevalent (16% and 10% respectively). Half of those experiencing more frequent PEs wanted greater support for their symptoms. Rates of depression, anxiety, loneliness, and stigma were high across the sample, and almost all psychological variables tested were significantly associated with USEs and paranoia in individual SEMs. In unified SEMs, depression and anxiety were retained as the most significant predictors of USEs, as were negative beliefs about others and anxiety for paranoia.

Conclusion: PEs in PD are common, even in those not taking dopaminergic medication. For a subset, these experiences are distressing and not resolved by existing treatment. Psychological processes like negative cognition and affect could play a maintaining role in PEs in PD thus providing easy avenues for trialling intervention. Longitudinal data to explore the direction of effects, and further exploration to understand the rates and types of paranoia is now required.

Key words: Parkinson's disease, paranoia, hallucinations, unusual sensory experiences, psychotic experiences, psychological

Introduction

Parkinson's disease (PD) is a chronic and progressive neurodegenerative condition affecting one in 100 adults aged over 65 [1]. It is partly caused by the death of dopaminergic neurons, leading to a dopamine deficiency that causes movement disorder, the hallmark symptom of PD. The biggest risk factor for PD is age, reaching a peak after the age of 80 years old [2]. Given our ageing population, diagnosis of PD is expected to increase by 50% by 2030 [3]. PD has wide ranging impacts beyond motor control. An impact on cognition is common, with an increased prevalence of dementia, [4] as well as impulse control disorders [5], and sleep, gastrointestinal and autonomic dysfunction. Anxiety disorders and low mood are also common, which are both associated with greater caregiver burden [6]–[9].

Psychotic experiences

A range of psychotic experiences (PEs) are frequently reported in PD. Early on in disease progression it is common to experience unusual sensory experiences (USEs) such as illusions, passage hallucinations (the presence of an animal or person in peripheral vision), and presence hallucinations (the sense that someone is present nearby) [10]–[13]. More extreme visual hallucinations can then occur as PD progresses, with varying degrees of insight into the experience depending on cognitive decline [14], as well as auditory, olfactory and tactile hallucinations [15], [16]. Although less common, delusions are also reported in a significant minority of individuals with PD, with fears of abandonment and jealousy the most common themes [12] although this has been assessed less frequently in detail in the literature. The experience of psychosis in PD is associated with poor outcomes, including

increased morbidity and mortality, transition to dementia and into care, and increased care-giver burden [17]–[19].

Treatment

NICE guidance recommends pharmacological management of motor symptoms in PD primarily through dopamine agonists, Levodopa, or inhibitors [20]. Modification of dopaminergic therapy is also the first line recommendation for management of PEs, given the increase in dopamine triggered by these medications is thought to be the cause of PEs. Use of antipsychotics is also recommended. However, patients may not find their PEs decrease following reduction of dopaminergic medication, instead suffering more greatly due to the increase in their Parkinson's symptoms [21]. While evidence for the safety of anti-psychotics in this population is beginning to increase, the significant side effects mean they are still not always considered an ideal treatment option [22], [23].

Moreover, while PEs have been associated with dopaminergic medication [24], this is not always the case, with some patients experiencing PEs without dopaminergic medication [25], [26]. There is also no clear dose-response effect regarding dopaminergic medication and PEs [27], [28], with one study concluding that dopaminergic medication is not a risk factor for the development of USEs in PE at all [29]. Consequently, it has been argued there is an important need to examine psychological alternatives to the understanding and treatment of PEs in PD [30]. Non-pharmacological risk factors for developing PEs in PD include age, duration of illness, cognitive impairment, disease severity and sleep disturbance [21], [24]. However, findings have not always been consistent and studies limited by small samples [27], [31].

Theoretical models of primary psychotic experiences

Theoretical models of delusions and hallucinations have identified a number of psychological mechanisms as causal and maintenance factors, thus providing clear mechanisms to be targeted in therapy [32], [33]. These include negative beliefs about the self and others, sleep dysfunction, emotional processes such as anxiety, depression and worry, reasoning biases, anomalous experiences, secondary appraisals (likely to be influenced by stigma), and use of safety seeking and coping behaviours. Each of these mechanisms alone is insufficient to cause psychotic experiences, but increases the likelihood of their occurrence, persistence, and associated distress. For example, sleep dysfunction exacerbates low mood and anomalous perceptions, and negative self-beliefs lead to individuals feeling inferior and different to others, and therefore vulnerable, allowing paranoia to build.

Delusions and USEs have been increasingly demonstrated to exist on a spectrum of severity, with more extreme experiences differing more in quantity than quality to milder ones [34]–[36]. The variables included within cognitive models are therefore common psychological processes and could be relevant to individuals with PD experiencing PEs, whether mild or severe. The impact of having a degenerative health condition such as PD could also plausibly contribute to a number of psychological processes described in the models, and thus paranoia and USEs.

Research questions and hypothesis

While research into PEs in PD is gradually increasing, there has been less exploration of phenomenology, associated distress, meaning-making, and treatment desires. The first set of research questions were therefore: what types of paranoid thoughts and USEs are

experienced by individuals with PD, how frequent and distressing are they, and what associated support is received and desired? Our hypothesis was that these experiences would be prevalent and distressing for at least a significant minority, and that support would be desired. Given there is initial qualitative evidence for the importance of psychosocial factors in the understanding of PEs in PD [30], the second set of research questions concerned whether psychological variables are significantly associated with paranoia and USEs in PD. We assessed variables from psychological models of psychosis that are reliably measured by self-report and amenable to intervention. Our hypothesis was therefore that depression, anxiety, worry, sleep dysfunction, negative self-beliefs, negative beliefs about others, stigma, and loneliness would all be significantly associated with both USEs and paranoia.

Methods

Ethical approval was received from the Central University Research Ethics Committee: R82914/RE001. Six individuals with PD and one carer inputted into the study at multiple stages, recruited through Parkinson's UK. A summary of their input and the associated changes is provided in Appendix L.

Participants

Participants were recruited from across the United Kingdom through Parkinson's UK, social media, and local Parkinson's groups, community centres, and care homes. Inclusion criteria were: aged over 18, self-reported PD diagnosis, able to provide informed consent, and sufficient English Language ability to complete the questionnaires. There were no exclusion

criteria. Questionnaire completion was possible online via Qualtrics or by hand via post. Participants were informed participation would take 30-60 minutes and were encouraged to complete the questionnaires during 'on' periods of medication where relevant. Participants received no payment for taking part.

Measures

Participants reported their age, gender, ethnicity, living status, diagnoses, auditory and visual difficulties, years since PD diagnosis, and current PD medication. Severity of PD, PEs, and psychological constructs were also measured (see Table 1). The questionnaire battery is provided in Appendix K. Space was provided throughout for qualifying qualitative comments.

Table 1. Measures

Construct	Name of measure	Detail of measure
Severity of PD	Self-report version of the Hoehn and Yahr scale [37]	A single item scale that rates disease progression ranging from 0 (no signs of disease) to 5 (wheelchair/bed bound). The self-report version has a high correlation with clinician scores (r=0.7) [38]. The scale has been used widely in previous cross-sectional studies, often as a gold standard for comparing the validity of other scales [36]. Its use is recommended by the Movement Disorder Society Task Force for Rating Scales for Parkinson's disease given its correlation with neuroimaging studies of disease progression and other standardised scales of impairment [39].
Independence	Self-report version of the Schwab and England scale for Independence [40]	A single item scale that rates independence from 0 (where the individual has no control over things like swallowing, bladder, and bowels), to 10 (where they are completely independent). The

		self-report version has a high correlation with clinician scores (r=0.82) [38]. The scale has been used widely in previous cross-sectional studies on Parkinson's as an additional global measure of impairment vs independence, that typically correlates well with the Hoehn and Yahr Scale [41].
Delusions and USEs	Psychosis and Hallucinations Questionnaire (PsycH-Q) [42]	A 20-item measure of PEs developed specifically for use with individuals with PD. Respondents rate the frequency of experiences from 'never' (0) to 'daily' (4). If they score at least 1 on frequency, they also score associated distress from none (1) to severe (4). Only the first 13 items were included as these cover USEs (10 items) and delusions (3 items) where-as latter items assess difficulties with cognition such as concentration and daydreaming. Two additional paranoia items were added to capture the unique delusions previously reported in people with PD [12]. These asked about thinking your spouse/partner is betraying you despite them assuring you otherwise, and thinking loved ones will abandon you despite them assuring you otherwise. Internal consistency for the full 20-item measure is a=0.900 for frequency and a=0.908 for distress [42]. A sum score that multiplies the frequency and distress scores can also be reported. The measure benefits from explicit questioning on the types of unusual sensory experiences that are commonly experienced by individuals with PD that are not always captured by measures not specific to PD.
Paranoia	The revised Green Paranoid Thoughts Scale (R-GPTS) [43]	This measure was included as a longer and fully validated measure of paranoia. The scale includes eight items measuring ideas of reference (Part A) and ten items measuring ideas of persecution (Part B). The scale has excellent psychometric properties with high reliability across the spectrum of paranoia severity (a>0.90) [44]. Higher scores denote greater paranoia. Scores on Part A range from 0-32 and scores on Part B range from 0-40.

Further details on USEs	Bespoke items	Triggers of USEs were measured by asking the following: Do any of these often proceed the unusual experiences (tick all that apply): low mood, boredom, being alone, being around lots of others, night-time, other (please specify), there is nothing obvious before. Endings of USEs were measured by asking: What typically brings the unusual experience to an end (tick all that apply): time, I deliberately distract myself, I get distracted by someone or something else, other (please specify), not sure. Two items from The Questionnaire for Psychotic Experiences -Visual Hallucinations subscale [45] were also included in order to assess duration of USEs and the impact on functioning, adapted to ask about all USEs, not just visual hallucinations.
Appraisals of USEs	Brief Illness Perceptions Questionnaire (Brief IPQ) [46]	An 8-item scale assessing beliefs and understandings regarding an illness, symptom, or difficulty, with questions covering illness identity, causes, timeline, impact, control over symptoms/illness, and coherence and emotional representations. Participants were asked to complete this in relation to their perceptions of their USEs. The brief scale items all demonstrate significant (p<0.001) correlations with the full IPQ scale items, and has good predictive validity with other outcomes, e.g., quality of life.
Sleep dysfunction	Parkinson's Disease Sleep Scale (PDSS) [47]	A 15-item self-report measure of nocturnal and sleep disturbance for individuals with PD. Each item is rated on a scale from 0-10 regarding whether the particular sleep difficulty is present (0) or absent (10). To prevent confounding in analysis, one item about night-time hallucinations was excluded, allowing a maximum score of 140. Higher scores depict better sleep. In a review of sleep rating scales for PD it was found to have good psychometric properties (e.g. a=0.77) [48] and to discriminate well between those with and without PD [47].

Negative beliefs about the self and others	Negative subscales from the Brief Core Schema Scale (BCSS) [49])	The BCSS measures evaluations about the self and others. Respondents rate to what extent they believe statements such as 'I am worthless' and 'Others are bad' from 0 (not at all) to 4 (totally). Only the negative subscales (six items for self and six items for others) were used given negative cognition is more pertinent within models of psychosis, and the subscales can be used independently. Scores for each subscale range from 0-24. Higher scores denote higher endorsement of the negative belief. The scale has good psychometric properties, e.g. internal consistency for the negative-self scale is a=0.87 and a=0.88 for negative-other scale.
Worry	Dunn Worry Questionnaire (DWQ) [50]	A 10-item scale assessing worry with excellent psychometric properties (e.g. a>0.95 for internal consistency across the distribution of worry). Scores range from 0-40, with higher scores denoting greater levels of worry. A score of 21 and above is considered to reflect clinically severe levels of worry [50].
Anxiety	The Persistent Anxiety Subscale of the Parkinson's anxiety scale (PAS) [51]	A five-item subscale measuring persistent general anxiety. Latter subscales measure panic and social anxiety but these are less pertinent to theoretical models of psychosis, and all subscales of the PAS can be used independently. In a review of anxiety rating scales in PD the PAS was found to have good psychometric properties compared to other anxiety scales (e.g. good convergent validity with other scales and Cronbach's alpha=0.88 for the self-reported persistent subscale) [52]. Higher scores denote greater anxiety, with possible scores ranging from 0-20. A score of 10 and above can be used to define probable caseness [51].
Depression	Geriatric Depression Scale (GDS) [53]	A 15-item scale developed and validated for use with older adults, including those with cognitive impairments and moderate medical illnesses. It has been used extensively in community, acute and long-term care settings [53]. It has 92% sensitivity and 89% specificity when evaluated against diagnostic criteria. Each item is rated as

		either yes (1) or no (0), meaning scores range from 0-15 and higher scores denote lower mood. Internal consistency is good *a*=0.75 [54]. Scores of 5-8 indicate mild depression, 9-11 moderate depression, and 12-15 severe depression [53].
Loneliness	Three-item loneliness scale [55]	A three-item scale developed from the Revised UCLA loneliness scale to succinctly collect information on social isolation. It has been validated for use with older adults and has good internal consistency (*a*=0.72) and a high correlation with the full R-UCLA scale (*r*=0.82) [55]. Scores range from 0-9, with higher scores denoting greater loneliness.
Felt and enacted stigma	Stigma Scale for Chronic Illness 8-item version (SSCI-8) [56]	An 8 item version of the original 24-item scale that was designed and validated for use with individuals with PD [57]. Higher scores denote greater stigma with scores ranging from 0-40. The scale measures enacted and internalised stigma with good internal consistency (*a*=0.89).

Analysis

R version 4.3.2 was used for analysis. The first set of research questions concerned comprehensive assessment of PEs. For this, as large a sample as could be recruited within a 12-month timeframe was aimed for and descriptive statistics were reported. Cronbach's alpha was calculated for measures that were adapted or had not been previously validated with older adults.

To assess whether the psychological variables were significantly associated with USEs or paranoia, structural equation modelling (SEM) was employed on the full dataset. SEM is valuable when investigating complex relationships among variables and has advantages over traditional regression in dealing with measurement error and multicollinearity because of its incorporation of individual item scores rather than sum

scores. An a priori power calculation for SEM suggested to detect a medium effect size of 0.3 with up to eleven latent variables (eight psychological and three control variables), 95% power and alpha=0.05, a minimum sample of 277 was required. However, a bigger sample would support greater model stability.

SEM comprises two parts: a confirmatory factor analysis (CFA) which estimates the relationships between latent constructs and their observed indicators, and a structural model that is used to estimate the relationships among the constructs. The 'laavaan' package was used [58] and missing data were accounted for using the full information maximum likelihood (FIML) estimation. CFAs were first run on all eight psychological variables and both response variables (paranoia and USEs). Indicators of poor fit, such as low factor loadings (<0.4) and lack of theoretical alignment with factors, were used as criteria for assessing the stability of the CFA models. For the SEMs, adequate fit was considered achieved when the root mean square error of approximation (RMSEA) and standardised root mean square residual (SRMR) values were below 0.08, and the comparative fit index (CFI) and Tucker-Lewis Index (TLI) were above 0.90 [59]. Where adequate fit was not achieved, modification indices were assessed, and if necessary, item residuals correlated, to reach adequate fit.

Initially, separate SEMs were run, regressing each of paranoia and USEs separately onto each hypothesised predictor. Second, all predictors were entered into a unified SEM separately for paranoia and USEs, in order to account for the correlation between predictors. Gender, age, and severity of PD symptoms were controlled for if found to be significant in individual SEMs. A backwards stepwise elimination technique was employed, removing

explanatory variables that were not statistically significant or demonstrated a suppressor effect [60] and stopping when only significant predictors were retained.

Post hoc analysis

To allow comparison of scores on psychological variables in our PD sample to an age matched control dataset, a subset of data was randomly drawn from a recent study that recruited a nationally representative cohort of individuals [61]. The drawn dataset was required to be N=369, and to match the mean, standard deviation, and range of age of our dataset, using a weighted model with 2% tolerance. Further details of the matching process, t-tests, and a post-hoc power calculation are provided in Appendix N.

Results

Demographic and clinical data

Three-hundred-and-sixty-nine individuals (343 online, 26 postal) completed over 90% of the questionnaire and were included for analysis. Partial-completers (those completing 10-90% of questions, N=110) were not included for analysis, and did not differ to full-completers (above 90%) in age ($t(477)=0.75$, $p=0.45$), years since diagnosis ($t(477)=0.86$, $p=0.39$), or PD severity ($t(477)=1.05$, $p=0.29$). Table 2 presents clinical and demographic data. Participants were mostly White-British and living with family and/or a partner. The average age was 66-years (range: 36-92), and average time since diagnosis 5.2-years (range: one week-30years). Two-thirds reported no current diagnosis of a mental health or cognitive problem. Ten people reported a psychosis related disorder, the diagnosis of which proceeded Parkinson's diagnosis in all cases.

The average independence score was 7.9 out of 10, and severity of PD symptoms 1.7 out of 5, similar to past cross-sectional studies [42], [62]. Most were taking levodopa (307), with smaller numbers taking dopamine agonists or inhibitors. Twenty-four participants were not taking any medication for their Parkinson's.

Cronbach's alphas were good for the Brief-IPQ (a=0.78), BCSS-self (a=0.74) and PDSS (a=0.85), and excellent for the PsycH-Q paranoia items (a=0.90), PsycH-Q USE items (a=0.92), R-GPTS-A (a=0.92), R-GPTS-B (a=0.96), BCSS-other (a=0.90), and DWQ (a=0.96). The questionnaire battery had also included a measure of coping styles, but due to below acceptable levels of internal consistency on each subscale (a<0.6) the measure was excluded from further analysis. Further detail is provided in Appendix N.

Table 2. Summary of participant demographic and clinical data

	N=369
Age: mean (SD, range)	66.2 (9.7, 36-92)
Gender	
Male	187 (51%)
Female	182 (49%)
Ethnicity	
White British	333 (90%)
Any other White Background	23 (6%)
Asian	8 (2%)
Black	1 (<1%)
Any other ethnic background	4 (1%)
Living status	
With partner and/or family member	306 (83%)
Alone in independent housing	58 (16%)
Alone in supported housing	5 (1%)
Years since diagnosis: mean (SD, range)	5.2 (4.8, 1 week-30 years)
Independence score: mean/max* (SD, range)	7.9/10 (2.1, 0-10)
Parkinson's severity: mean/max* (SD, range)	1.7/5 (1.3, 0-5)
Current self-reported comorbid diagnoses: n (%)	
None	255 (69%)
Dementia	18 (5%)
Depression	77 (21%)

Anxiety disorder	56 (15%)
Psychosis	10 (2.7%)
PTSD	19 (5%)
Depression score	
Mean/max*, SD	5.6/15 (4.30)
No depression n (%)	188 (51%)
Mild n (%)	82 (22%)
Moderate n (%)	45 (12 %)
Severe n (%)	54 (15%)
Anxiety score	
Mean/max*, (SD)	7.2/20 (4.90)
Caseness: n (%)	108 (29%)
Worry	
Mean/max*, (SD)	13.5/40 (9.70)
Caseness: n (%)	78 (21%)
Negative self-beliefs: mean/max*, (SD)	2.4/24 (3.51)
Negative beliefs about others: mean/max* (SD)	1.3/24 (3.46)
Sleep: mean/max* (SD)	82.4/140 (2.77)
Stigma: mean/max* (SD)	19.7/40 (4.30)
Loneliness: mean/max* (SD)	4.2/9 (1.79)

**max = maximum possible score for specified scale*

Psychotic experiences

Table 3 shows the numbers of participants scoring on each item of the PsycH-Q measure. Almost two-thirds of participants reported one or more paranoid thought or USE. For USEs, the average sum score (frequency x distress) was 6.76 (SD=15.79) with half the sample (182, 49%) reporting one or more USE in the past month, and almost a quarter (83, 23%) reporting weekly USEs. The most commonly endorsed items were corner vision hallucinations (29% of the total sample), general misperception (26%) and presence hallucinations (23%). A significant minority also experienced non-visual hallucinations: auditory (17%), tactile (12%), olfactory (20%), and gustatory (6%). Forty-eight participants (26% of those reporting USEs) reported moderate or severe distress associated with at least one of their USEs.

Regarding paranoia/delusions, the mean sum score (frequency x distress) on the PsycH-Q across the sample was 2.46 (SD=8.8) with just under quarter reporting at least one

paranoid concern in the past month, and a fifth (69, 19%) reporting weekly thoughts. The most commonly endorsed thoughts concerned spousal betrayal (13% of those living with a spouse) and being abandoned by loved ones (16%) despite reassurance to the contrary. Sixteen participants (19% of those reporting paranoia) reported moderate or severe distress associated with their worries. Table 3 also reports the prevalence of PEs by gender. For all items except auditory, olfactory, and gustatory USEs, rates were similar, with a small but consistent preponderance in men.

Of the 24 participants not taking any medication, 10 reported USEs, and 10 reported one or more paranoid thoughts. Of those reporting visual hallucinations (151), 23 (15%) reported vision difficulties that not sufficiently corrected by glasses. Of those reporting auditory hallucinations (63), 10 (16%) reported hearing difficulties not sufficiently corrected.

Table 3. Number of participants scoring for each hallucination and delusion item

Item	n in present sample (N=369)	% of present sample (% of men / % of women)	% sample from original PsycH-Q validation paper (N=197) [42]
Presence hallucinations	83	23 (24/21)	21
Corner vision	108	29 (31/27)	26
Passage hallucinations	58	16 (16/15)	15
General misperception	97	26 (28/25)	21
Object misperception	68	18 (20/17)	17
Animal misperception	78	21 (23/19)	18
Auditory	63	17 (14/20)	15
Tactile	43	12 (13/10)	8
Olfactory	72	20 (12/27)	9
Gustatory	22	6 (4/8)	2

Persecutory delusions	30	8 (9/8)	5
Threatening delusions	43	12 (13/11)	5
Social delusions	16	4 (5/4)	3
Spousal betrayal delusions	37	10 (12/8)	-
Abandonment delusions	59	16 (19/14)	-

Comparison of psychotic experiences to previous samples

As can be seen in Table 3, findings were similar to those previously reported [42]. Mean scores on the R-GPTS, however, were significantly lower than in age-matched control data (R-GPTS-A: $t(736)=4.20$, $p=<0.001$, $d=0.3$; R-GPTS-B: $t(736)=4.91$, $p=<0.0001$, $d=0.2$), with few in our sample scoring above the average range for either sub-scale. Table 4 also shows a comparison to the general population (all ages), which shows that generally older adults report less paranoia, but our sample scored lower still.

Table 4. Comparison of GPTS scores to age matched data

	Current sample (N=369)	Age-matched data (N=369)	General population average (Part-A N=774; Part-B N=7297)
rGPTS-A			
Mean (SD)	2.24 (4.88)	3.94 (6.05)	6.77 (5.54)
Average score (0-9)	343 (93%)	317 (86%)	77%
elevated score (10-15)	12 (3%)	24 (7%)	23%
moderately severe score (16-20)	7 (2%)	17 (5%)	8%
severe score (21-24)	4 (1%)	7 (2%)	3%
very severe score (25+)	3 (<1%)	4 (1%)	2%

rGPTS-B			
Mean (SD)	2.48 (5.05)	3.80 (7.54)	4.52 (6.74)
average score (0-4)	336 (91%)	286 (78%)	73%
elevated score (5-10)	15 (4%)	34 (9%)	27%
moderately severe score (11-17)	10 (3%)	18 (5%)	15%
severe score (18-27)	4 (1%)	21 (6%)	7%
very severe score (28+)	4 (1%)	10 (3%)	1%

The nature of USEs reported

For those reporting USEs, triggers included night-time or falling asleep (29%), being alone (24%), low mood (13%), boredom (6%), and being around others (4%), although many were unsure (35%). USEs lasted only briefly for 49%, a few minutes for 25%, up to an hour for 7%, for several hours or continuously for 5%, with others unable to estimate due to variability. In terms of bringing the experience to an end, 25% were unsure, 25% reported deliberately distracting themselves, and 33% reported them naturally ending with time or by getting distracted. A small majority (57%) reported thinking the experiences are real when they occur, and over a quarter (27%) reported being frightened by their USEs. Qualitative comments (a full list is provided in Appendix M) described concerns primarily around losing control and being in danger. Of those experiencing weekly USEs, 54% reported no significant impact on daily functioning, 31% reported slight impact, and 15% reported considerable or severe impact.

Appraisals

Table 5 summarises the data on appraisals for those reporting weekly PEs. Scores on the Brief-IPQ were generally low, with the exception of the timeline item, with participants scoring 7.3 out of 10 on average, suggesting they expected the USEs to be an ongoing experience. Both perceived personal and treatment control were low, suggesting participants felt there is little they can do to control the experiences. However, the consequences/impact and concern items were also low, meaning participants on average did not feel the USEs were overly burdensome.

Table 5. Appraisals of USEs (Brief IPQ completed in relation to USEs)

	Those reporting weekly USEs (n=83) Mean (SD)
Consequences (how much they impact your life)	2.7 (2.8)
Timeline (how long you think they will continue)	7.3 (3.3)
Personal control (how much perceived control)	2.7 (3.5)
Treatment control (how much treatment can/does help)	2.3 (2.6)
Identity (how much do you feel you experience them)	3.6 (3.0)
Concern (how concerned you are)	3.2 (3.5)
Understanding (how much you feel you understand them)	3.7 (3.6)
Emotional response (how much they impact you emotionally)	3.6 (3.5)

Support and treatment for psychotic experiences

Only 12% of those with USEs had received support or intervention for their experiences, which in all but two cases was pharmacological. Of those with weekly USEs, 43% wanted further support. Of all those wanting support, 66% wanted information provision, 43% wanted peer support, 41% wanted talking therapy or management strategies from a psychologist, and 32% wanted further medication management.

A similar proportion (15%) reporting paranoia had received support or intervention regarding their worries, either medication management (11 people) or input from a psychologist (20 people). Of those with weekly paranoid thoughts, 54% wanted further support. Of all those wanting support, 62% wanted talking therapy or management strategies from a psychologist, 54% wanted information provision, 51% wanted peer support, and 30% wanted medication management.

Psychological variables

Scores on all psychological variables can be viewed in Table 2. Consistent with past reports in PD [6], [8], almost half met criteria for mild, moderate, or severe depression. This is higher than found in past epidemiological surveys of older adults, which report 1-5% with severe depression and 15% with milder depression [63]. Almost a third of our sample met criteria for generalised anxiety disorder and a fifth met caseness for clinically significant levels of worry, though this was lower than the 33% of individuals meeting caseness in the age-matched sample. The mean difference in mean worry scores between the two samples was not significant, however ($t(736)=0.103$, $p=0.918$).

The group mean for negative self-beliefs was 2.38 out of 24 (SD=3.51) and for negative beliefs about others 1.31 (SD=4.46). Both scores were lower than the average scores reported in student samples in the initial validation of the measure [49], and the negative-self score was significantly lower than the age matched group (M=3.05, SD=4.27, $t(736)=2.33$, $p=0.020$).

Reported stigma was on average 19.65 out of 40 (SD=4.30), significantly higher than has been reported previously for Parkinson's on this scale (M=12.07, SD=4.28, $t(499)=7.06$, $p<0.000$) as well a range of other chronic illnesses [56]. Mean loneliness was 4.62 out of 9 (SD=1.79), which is significantly higher than has been reported in a prior sample of older adults (M=3.89, SD=1.43, $t(2549)=9.17$, $p<0.000$) [55].

The mean total sleep score was 82.38 out of 140 (SD=27.7). In the initial validation of the PDSS, after also excluding the hallucinations item, 143 individuals with Parkinson's scored a mean of 92.90 and age matched controls 110.50 [47]. Our participants were therefore experiencing greater sleep dysfunction. Standard deviations of only the 14 items could not be calculated therefore t tests were not possible.

SEM results

The CFA results for each measure can be viewed in Appendix N. In individual SEMs, all the psychological variables were significantly associated with USEs, and all but sleep were significantly associated with paranoia (see Table 6). Negative beliefs about others explained the most variance in paranoia (43%), and depression (15%) and anxiety (14%) explained most variance in USEs.

Table 6. Parameter estimates of the SEMs

Explanatory variable	B	SE	Adjusted P value	β	R^2
Paranoia Individual SEMs					
Depression	0.45	0.11	<0.0001*	0.41	0.17
Anxiety	0.15	0.05	0.001*	0.38	0.15
Worry	0.20	0.05	<0.0001*	0.41	0.17
Sleep	-0.04	0.02	0.067	-0.16	0.03
Stigma	0.24	0.09	0.009*	0.56	0.21
Negative other-beliefs	0.69	0.25	0.006*	0.04	0.43
Negative self-beliefs	0.52	0.16	0.001*	0.42	0.17
Loneliness	0.30	0.10	0.003*	0.40	0.16
Age	-0.00	0.00	0.595	-0.02	0.00
Gender	-0.01	0.04	0.764	-0.02	0.00
PD severity	0.08	0.03	0.007*	0.28	0.08
USEs Individual SEMs					
Depression	0.73	0.15	<0.0001*	0.39	0.15
Anxiety	0.27	0.05	<0.0001*	0.38	0.14
Worry	0.31	0.06	<0.0001*	0.36	0.13
Sleep	-0.11	0.03	0.001*	-0.25	0.06
Stigma	0.27	0.08	<0.0001*	0.30	0.09
Negative other-beliefs	0.60	0.21	0.004*	0.33	0.11
Negative self-beliefs	0.69	0.27	0.010*	0.30	0.09
Loneliness	0.36	0.11	0.001*	0.28	0.08
Age	0.01	0.00	0.008*	0.14	0.02
Gender	-0.06	0.08	0.399	-0.05	0.00
PD severity	0.23	0.04	<0.0001*	0.43	0.18

*significant result at $p<0.05$

Following stepwise elimination in the unified SEM with paranoia as the response variable and controlling for PD severity, beliefs about others (B=0.66, SE=0.24, p=0.006, β=0.60) and anxiety (B=0.04, SE=0.02, p=0.035, β=0.11) were retained as significant predictors. The model indicated a good fit to the data, (Robust $\chi 2$ (112)=198.69, p<0.000, RMSEA=0.05; SRMR=0.07; CFI=0.95; TLI=0.94), overall explaining 45.6% of the variance in paranoia. For USEs as the outcome (controlling for age and PD severity), depression (B=0.31, SE=0.13, p<0.014, β=0.17) and anxiety (B=0.18, SE=0.05, p<0.000, β=0.26) were retained as significant predictors. The final model indicated a good fit to the data, (Robust $\chi 2$ (319)=648.47, p< 0.000, RMSEA=0.05; SRMR=0.08; CFI=0.92; TLI=0.91), overall explaining 26.3% of the variance in USEs. Further details on the full SEM results can be viewed in Appendix N.

Discussion

This study reports the largest comprehensive assessment of USEs and paranoia in PD. It is clear that USEs, primarily visual hallucinations, are common in this group. As was hypothesised, there was a clear subset of individuals for whom USEs were frequent, severe, and distressing, and additional support was desired. Conversely, for many individuals, the experiences were neither distressing nor associated with severe functional impact. This could be for a number of reasons. Principally, given participation required the completion of a large questionnaire battery, our sample primarily comprised those with less severe PD progression and without dementia. The neuropathology of PD in its earlier stages is most consistent with preserved insight and less distress, possibly due to less cortical lewy body involvement than is seen in later stages of PD and in those with dementia [64]. Additionally, few of the sample

lived alone. In contrast to patients with primary psychosis, who often live alone and have few social contacts [65], having a family member around for support and to reassure or question experiences may help reduce distress. Moreover, the type of USEs most commonly experienced, e.g., corner vision hallucinations and general misperception, are perhaps inherently less distressing and threatening than the USEs most commonly experienced by individuals with primary psychosis, such as critical voices.

The story was similar for paranoia. Contrary to our hypothesis, across the sample paranoia was low, including significantly lower than in an age-matched control group. Conversely, it was clear that a number of specific paranoid thoughts (namely fears around spousal betrayal and abandonment), not captured by the R-GPTS, were experienced by a significant minority. Moreover, over half of those experiencing regular paranoid thoughts wanted additional support for them.

What explains why only some individuals experience more frequent and distressing PEs? Previously, the literature has been dominated by the view that PEs are simply a side effect of the dopaminergic medication used to treat PD. However, much of this evidence is based on old research where dopamine was given to patients in large and sudden doses, and it is becoming increasingly clear that the picture is more complex. More recent literature has found little evidence of a dose-response effect with dopamine treatments, nor that a reduction in dopaminergic medication always resolves PEs [28]. Moreover, in our study, although the total number of individuals not taking dopaminergic medication was small, almost half still reported USEs. The qualitative comments also revealed that while some participants noted an association between their USEs and beginning dopaminergic medication, others reported

their USEs began prior to their official diagnosis and therefore prior to taking any dopaminergic medication.

A significant minority of individuals did report hearing or vision difficulties that were not satisfactorily resolved, but not enough to explain the rates of PEs reported. It seems important therefore to look to the psychological variables as potential contributory factors and treatment targets. Levels of anxiety, depression, stigma, and loneliness in particular were high across the sample. In line with our hypotheses, the individual SEMs demonstrated that almost all psychological variables were significantly associated with USEs and paranoia/delusions. Mechanistically, the unified SEMs suggest these relationships could be explained by anxiety and negative other-beliefs for paranoia, and depression, anxiety, and negative other-beliefs for USEs. Causality cannot be inferred from the current data, but it is possible that a bi-directional relationship exists between PEs and psychological processes like negative affect, as has been well documented generally in the psychosis literature [32]. Regardless of whether we see their original cause as neuropsychiatric or psychosocial [66], brief low intensity psychosocial interventions to improve e.g., mood and anxiety are increasingly being shown to be effective for many mental health difficulties, including in older adults, [67] and so may be an important additional treatment option in PD. Such interventions may be particularly helpful for current cohorts of older adults, who grew up with considerably different attitudes to mental health problems, meaning they may be less likely to help-seek than younger individuals [68]. Over a third of participants also reported being unsure of what triggers their USEs, and a quarter were unsure what brings them to an end. If support could be offered to help identify and intervene on triggers and modifiers – for

example, using monitoring forms supported by Parkinson's nurses – this may help to reduce the severity of USEs for some.

It is unclear why the R-GPTS scores were lower than in age-matched controls. One explanation is that our sample was skewed in some way. For example, those interacting with Parkinson's UK may be a non-representative group of the population in terms of, e.g., income or education level, leading to bias in the reported levels of paranoia (paranoia is negatively associated with income and education level [69]). Alternatively, the difference may be a true one, meaning having a diagnosis of PD is in some way protective against common paranoid thoughts. Perhaps people with PD, due to their care needs, spend more time around close family and friends, and less time around strangers where paranoia often thrives. Instead, paranoid concerns may focus on these close family and friends on whom they depend – hence the higher scores on the PsycH-Q items about fears of betrayal and abandonment by loved ones – concerns that are not captured in the R-GPTS. If so, then further work to consider how to measure the unique paranoid concerns experienced by individuals with PD may be required. Currently, the adapted five-item PsycH-Q measure could be used as a screening tool in services.

Limitations

The study has a number of limitations. First, advertising materials stated we were investigating PEs. Individuals with PEs may have been more motivated to take part, leading to bias in conclusions regarding the exact proportions of people experiencing them. Second, despite contacting care homes and carers groups to reach people with more severe PD, the average PD severity score of the sample was fairly low. Given the burden of questionnaires

this is unsurprising, and not inconsistent with previous studies [62]. However, the findings may not generalise to those with more severe symptoms including those experiencing cognitive decline. Third, the ethnic diversity of the sample was limited. Health outcomes vary considerably across ethnicities, and research conducted with predominantly White-British samples perpetuates structural inequality. Some research suggests PD may be more prevalent in white populations, but it is difficult to disentangle the impacts of possible recruitment biases [70]. Future research may benefit from more active outreach to individuals with PD among ethnic minorities. Finally, and most crucially in terms of interpreting the SEM results, the data are cross-sectional. Exploration of causal factors was therefore not possible. However, a number of avenues for future longitudinal and intervention studies are clearly identified.

References

[1] M. C. de De Rijk *et al.*, “Prevalence of Parkinson’s disease in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group.,” *Neurology*, vol. 54, no. 11 Suppl 5, pp. S21-3, 2000.

[2] J. A. Driver, G. Logroscino, J. M. Gaziano, and T. Kurth, “Incidence and remaining lifetime risk of Parkinson disease in advanced age,” *Neurology*, vol. 72, no. 5, pp. 432–438, 2009, doi: 10.1212/01.wnl.0000341769.50075.bb.

[3] E. R. Dorsey *et al.*, “Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030,” *Neurology*, vol. 68, no. 5, pp. 384–386, 2007, doi: 10.1212/01.wnl.0000247740.47667.03.

[4] M. Emre *et al.*, “Clinical diagnostic criteria for dementia associated with Parkinson’s disease,” *Mov. Disord.*, vol. 22, no. 12, pp. 1689–1707, 2007, doi: 10.1002/mds.21507.

[5] D. Weintraub *et al.*, “Impulse Control Disorders in Parkinson Disease,” *Arch. Neurol.*, vol. 67, no. 5, pp. 589–595, 2010.

[6] I. H. Richard, “Anxiety disorders in Parkinson’s disease.,” *Adv. Neurol.*, vol. 96, pp. 42–55, 2005.

[7] K. H. O. Deane *et al.*, “Priority setting partnership to identify the top 10 research priorities for the management of parkinson’s disease,” *BMJ Open*, vol. 4, no. 12, 2015, doi: 10.1136/bmjopen-2014-006434.

[8] J. S. A. M. Reijnders, U. Ehrt, W. E. J. Weber, D. Aarsland, and A. F. G. Leentjens, “A systematic review of prevalence studies of depression in Parkinson’s disease,” *Mov. Disord.*, vol. 23, no. 2, pp. 183–189, 2008, doi: 10.1002/mds.21803.

[9] J. J. Chen and L. Marsh, “Anxiety in Parkinson’s disease: Identification and management,” *Ther. Adv. Neurol. Disord.*, vol. 7, no. 1, pp. 52–59, 2014, doi: 10.1177/1756285613495723.

[10] G. Fénelon, T. Soulas, L. C. De Langavant, I. Trinkler, and A. C. Bachoud-Lévi, “Feeling of presence in Parkinson’s disease,” *J. Neurol. Neurosurg. Psychiatry*, vol. 82, no. 11, pp. 1219–1224, 2011, doi: 10.1136/jnnp.2010.234799.

[11] J. Pagonabarraga and J. Kulisevsky, “Cognitive impairment and dementia in Parkinson’s disease,” *Neurobiol. Dis.*, vol. 46, no. 3, pp. 590–596, 2012, doi: 10.1016/j.nbd.2012.03.029.

[12] B. Ravina *et al.*, “Diagnostic criteria for psychosis in Parkinson’s disease: Report of an NINDS, NIMH Work Group,” *Mov. Disord.*, vol. 22, no. 8, pp. 1061–1068, 2007, doi: 10.1002/mds.21382.

[13] R. A. Wood, S. A. Hopkins, K. K. Moodley, and D. Chan, “Fifty percent prevalence of extracampine hallucinations in Parkinson’s disease patients,” *Front. Neurol.*, vol. 6, no. DEC, pp. 1–9, 2015, doi: 10.3389/fneur.2015.00263.

[14] D. H. Ffytche *et al.*, “The psychosis spectrum in Parkinson disease,” *Nat. Rev. Neurol.*, vol. 13, no. 2, pp. 81–95, 2017, doi: 10.1038/nrneurol.2016.200.

[15] C. G. Goetz, G. T. Stebbins, and B. Ouyang, “Visual plus nonvisual hallucinations in Parkinson’s disease: Development and evolution over 10 years,” *Mov. Disord.*, vol. 26, no. 12, pp. 2196–2200, 2011, doi: 10.1002/mds.23835.

[16] W. L. Toh, C. Yolland, C. Gurvich, J. Barnes, and S. L. Rossell, *Non-visual hallucinations in Parkinson’s disease: a systematic review*, vol. 270, no. 6. Springer Berlin Heidelberg, 2023.

[17] C. G. Goetz and G. T. Stebbins, “Mortality and hallucinations in nursing home patients with advanced parkinson’s disease,” *Neurology*, vol. 45, no. 4, pp. 669–671, 1995, doi: 10.1212/WNL.45.4.669.

[18] D. H. ffytche *et al.*, “The psychosis spectrum in Parkinsons disease,” *Nat. Rev. Neurol.*, vol. 13, no. 2, pp. 100–106, 2017, doi: 10.1038/nrneurol.2016.200.The.

[19] J. G. Goldman and S. Holden, “Treatment of psychosis and dementia in parkinson’s disease topical collection on movement disorders,” *Curr. Treat. Options Neurol.*, vol. 16, no. 3, 2014, doi: 10.1007/s11940-013-0281-2.

[20] NICE, “Parkinson ’s disease in adults,” *Natl. Inst. Heal. Care Excell.*, no. July 2017, pp. 1–14, 2017, [Online]. Available: https://www.nice.org.uk/guidance/ng71/.

[21] J. R. Sanchez-Ramos, R. Ortoll, and G. W. Paulson, “Visual hallucinations associated with Parkinson disease,” *Arch. Neurol.*, vol. 53, no. 12, pp. 1265–1268, 1996, doi: 10.1001/archneur.1996.00550120077019.

[22] D. D. Truong, R. Bhidayasiri, and E. Wolters, “Management of non-motor symptoms in advanced Parkinson disease,” *J. Neurol. Sci.*, vol. 266, no. 1–2, pp. 216–228, 2008, doi: 10.1016/j.jns.2007.08.015.

[23] M. Rogowska *et al.*, “Implications of adverse outcomes associated with antipsychotics in older patients with dementia: a 2011–2022 update,” *Drugs Aging*, vol. 40, no. 1, pp. 21–32, 2023.

[24] J. Barnes and A. S. David, “Visual hallucinations in Parkinson’s disease: A review and phenomenological survey,” *J. Neurol. Neurosurg. Psychiatry*, vol. 70, no. 6, pp. 727–733, 2001, doi: 10.1136/jnnp.70.6.727.

[25] R. Sandyk and M. A. Gillman, “Depression as a cause of hallucinations in Parkinson’s

disease.," *Clinical neuropharmacology*, vol. 8, no. 2. pp. 199–200, 1985, doi: 10.1097/00002826-198506000-00015.

[26] G. Fénelon, F. Mahieux, R. Huon, and M. Ziégler, "Hallucinations in Parkinson's disease. Prevalence, phenomenology and risk factors," *Brain*, vol. 123, no. 4, pp. 733–745, 2000, doi: 10.1093/brain/123.4.733.

[27] J. R. Sanchez-Ramos, R. Ortoll, and G. W. Paulson, "Visual Hallucinations Associated With Parkinson," *Arch. Neurol.*, vol. 53, 1996.

[28] G. Fénelon and G. Alves, "Epidemiology of psychosis in Parkinson's disease," *J. Neurol. Sci.*, vol. 289, no. 1–2, pp. 12–17, 2010, doi: 10.1016/j.jns.2009.08.014.

[29] D. Merims, H. Shabtai, A. D. Korczyn, C. Peretz, N. Weizman, and N. Giladi, "Antiparkinsonian medication is not a risk factor for the development of hallucinations in Parkinson's disease," *J. Neural Transm.*, vol. 111, no. 10–11, pp. 1447–1453, 2004, doi: 10.1007/s00702-004-0209-9.

[30] D. Todd, J. Simpson, and C. Murray, "An interpretative phenomenological analysis of delusions in people with Parkinson's disease," *Disabil. Rehabil.*, vol. 32, no. 15, pp. 1291–1299, 2010, doi: 10.3109/09638280903514705.

[31] S. Papapetropoulos *et al.*, "A questionnaire-based (UM-PDHQ) study of hallucinations in Parkinson's disease," *BMC Neurol.*, vol. 8, pp. 1–8, 2008, doi: 10.1186/1471-2377-8-21.

[32] P. A. Garety, E. Kuipers, D. Fowler, D. Freeman, and P. E. Bebbington, "A cognitive model of the positive symptoms of psychosis," *Psychol. Med.*, vol. 31, no. 02, pp. 189–195, 2001, doi: 10.1017/S0033291701003312.

[33] D. Freeman, "Persecutory delusions: a cognitive perspective on understanding and

treatment," *The Lancet Psychiatry*, vol. 3, no. 7, pp. 685–692, 2016, doi: 10.1016/S2215-0366(16)00066-3.

[34] P. E. Bebbington *et al.*, "The structure of paranoia in the general population," *Br. J. Psychiatry*, vol. 202, no. 6, pp. 419–427, 2013, doi: 10.1192/bjp.bp.112.119032.

[35] A. Elahi, G. Perez Algorta, F. Varese, J. C. McIntyre, and R. P. Bentall, "Do paranoid delusions exist on a continuum with subclinical paranoia? A multi-method taxometric study," *Schizophr. Res.*, vol. 190, pp. 77–81, 2017, doi: 10.1016/j.schres.2017.03.022.

[36] H. M. S. Zavos *et al.*, "Consistent etiology of severe, frequent psychotic experiences and milder, less frequent manifestations: A twin study of specific psychotic experiences in adolescence Objective—Investigate degree of genetic and environmental influences on specific psychoti," *JAMA Psychiatry*, vol. 71, no. 9, pp. 1049–1057, 2014, doi: 10.1001/jamapsychiatry.2014.994.

[37] M. M. Hoehn and M. D. Yahr, "Parkinsonism: Onset, progression, and mortality," *Neurology*, vol. 57, no. 10 SUPPL. 3, pp. 427–442, 2001, doi: 10.1212/wnl.50.2.318.

[38] A. Schrag, A. Hovris, D. Morley, N. Quinn, and M. Jahanshahi, "Young-versus older-onset Parkinson's disease: impact of disease and psychosocial consequences," *Mov. Disord. Off. J. Mov. Disord. Soc.*, vol. 18, no. 11, pp. 1250–1256, 2003.

[39] C. G. Goetz *et al.*, "Movement Disorder Society Task Force report on the Hoehn and Yahr staging scale: Status and recommendations," *Mov. Disord.*, vol. 19, no. 9, pp. 1020–1028, 2004, doi: 10.1002/mds.20213.

[40] R. S. Schwab and A. C. England, "Projection technique for evaluating surgery in Parkinson's Disease.," in *Third Symposium on Parkinson's disease*, F. J. Gillingham and M. C. Donaldson, Eds. Edinburgh: Williams and Wilkins, 1969.

[41] M. M. Hoehn and M. D. Yahr, “Parkinsonism: onset, progression, and mortality,” *Neurology*, vol. 17, no. 5, p. 427, 1967.

[42] J. M. Shine *et al.*, “Validation of the Psychosis and Hallucinations Questionnaire in Non-demented Patients with Parkinson’s Disease,” *Mov. Disord. Clin. Pract.*, vol. 2, no. 2, pp. 175–181, 2015, doi: 10.1002/mdc3.12139.

[43] D. Freeman *et al.*, “The revised Green et al. , Paranoid Thoughts Scale (R-GPTS): psychometric properties, severity ranges, and clinical cut-offs,” *Psychol. Med.*, pp. 1–10, 2019, doi: 10.1017/s0033291719003155.

[44] D. Freeman *et al.*, “ The revised Green et al. , Paranoid Thoughts Scale (R-GPTS): psychometric properties, severity ranges, and clinical cut-offs ,” *Psychol. Med.*, pp. 1–10, Nov. 2019, doi: 10.1017/s0033291719003155.

[45] S. L. Rossell *et al.*, “The Questionnaire for Psychotic Experiences: An Examination of the Validity and Reliability,” *Schizophr. Bull.*, vol. 45, no. 1, pp. S78–S87, 2019, doi: 10.1093/schbul/sby148.

[46] E. Broadbent, K. J. Petrie, J. Main, and J. Weinman, “The Brief Illness Perception Questionnaire,” *J. Psychosom. Res.*, vol. 60, no. 6, pp. 631–637, 2006, doi: 10.1016/j.jpsychores.2005.10.020.

[47] K. R. Chaudhuri *et al.*, “The Parkinson’s disease sleep scale: A new instrument for assessing sleep and nocturnal disability in Parkinson’s disease,” *J. Neurol. Neurosurg. Psychiatry*, vol. 73, no. 6, pp. 629–635, 2002, doi: 10.1136/jnnp.73.6.629.

[48] B. Högl *et al.*, “Scales to assess sleep impairment in Parkinson’s disease: Critique and recommendations,” *Mov. Disord.*, vol. 25, no. 16, pp. 2704–2716, 2010, doi: 10.1002/mds.23190.

[49] D. Fowler *et al.*, “The Brief Core Schema Scales (BCSS): Psychometric properties and associations with paranoia and grandiosity in non-clinical and psychosis samples,” *Psychol. Med.*, vol. 36, no. 6, pp. 749–759, 2006, doi: 10.1017/S0033291706007355.

[50] D. Freeman *et al.*, “The dunn worry questionnaire and the paranoia worries questionnaire: New assessments of worry,” *Psychol. Med.*, vol. 50, no. 5, pp. 771–780, 2020, doi: 10.1017/S0033291719000588.

[51] A. F. G. Leentjens, K. Dujardin, G. M. Pontone, S. E. Starkstein, D. Weintraub, and P. Martinez-Martin, “The Parkinson anxiety scale (PAS): Development and validation of a new anxiety scale,” *Mov. Disord.*, vol. 29, no. 8, pp. 1035–1043, 2014, doi: 10.1002/mds.25919.

[52] N. N. W. Dissanayaka, E. Torbey, and N. A. Pachana, “Anxiety rating scales in Parkinson’s disease: A critical review updating recent literature,” *Int. Psychogeriatrics*, vol. 27, no. 11, pp. 1777–1784, 2015, doi: 10.1017/S1041610215000885.

[53] S. A. Greenberg, “Geriatric Depression Scale,” *Hartford Inst. Geriatr. Nursing, New York Univ. Coll. Nurs.*, vol. 69 Suppl 8, no. 4, pp. 455–458, 2012, doi: 10.3109/9780203213896-32.

[54] B. Friedman, M. J. Heisel, and R. L. Delavan, “Psychometric properties of the 15-item geriatric depression scale in functionally impaired, cognitively intact, community-dwelling elderly primary care patients,” *J. Am. Geriatr. Soc.*, vol. 53, no. 9, pp. 1570–1576, 2005, doi: 10.1111/j.1532-5415.2005.53461.x.

[55] M. E. Hughes, L. J. Waite, L. C. Hawkley, and J. T. Cacioppo, “A Short Scale for Measuring Loneliness in Large Surveys: Results From Two Population-Based

Studies," *Res aging*, vol. 26, no. 6, pp. 655–672, 2004, doi: 10.1109/ICIT.2017.7913066.

[56] Y. Molina, S. W. Choi, D. Cella, and D. Rao, "The stigma scale for chronic illnesses 8-item version (SSCI-8): Development, validation and use across neurological conditions," *Int. J. Behav. Med.*, vol. 20, no. 3, pp. 450–460, 2013, doi: 10.1007/s12529-012-9243-4.

[57] D. Rao *et al.*, "Measuring stigma across neurological conditions: The development of the stigma scale for chronic illness (SSCI)," *Qual. Life Res.*, vol. 18, no. 5, pp. 585–595, 2009, doi: 10.1007/s11136-009-9475-1.

[58] Y. Rosseel, "lavaan: An R package for structural equation modeling," *J. Stat. Softw.*, vol. 48, pp. 1–36, 2012.

[59] R. B. Kline, *Principles and practice of structural equation modeling*. Guilford publications, 2023.

[60] R. Smith, J. W. Ager, and D. L. Williams, "Suppressor variables in multipleregression/correlation," *Educ. Psychol. Meas.*, vol. 52, pp. 17–29, 1992.

[61] D. Freeman and B. S. Loe, "Explaining paranoia: cognitive and social processes in the occurrence of extreme mistrust," *BMJ Ment. Heal.*, vol. 26, no. 1, pp. 1–8, 2023, doi: 10.1136/bmjment-2023-300880.

[62] J. K. Garlovsky, J. Simpson, R. A. Grünewald, and P. G. Overton, "Impulse control disorders in Parkinson's disease: Predominant role of psychological determinants," *Psychol. Heal.*, vol. 31, no. 12, pp. 1391–1414, 2016, doi: 10.1080/08870446.2016.1218879.

[63] A. Fiske, J. L. Wetherell, and G. Margaret, "Depression in older adults," *Annu. Rev.*

Clin. Psychol., vol. 5, no. 11, pp. 363–389, 1009, doi: 10.1097/01.NAJ.0000422251.65212.4b.

[64] D. H. ffytche and D. Aarsland, *Psychosis in Parkinson's Disease*, 1st ed., vol. 133. Elsevier Inc., 2017.

[65] C. Gayer-Anderson and C. Morgan, "Social networks, support and early psychosis: A systematic review," *Epidemiol. Psychiatr. Sci.*, vol. 22, no. 2, pp. 131–146, 2013, doi: 10.1017/S2045796012000406.

[66] J. Simpson, H. McMillan, and D. Reeve, "Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism," *Parkinsons. Dis.*, vol. 2013, 2013, doi: 10.1155/2013/608562.

[67] G. Cremers, E. Taylor, L. Hodge, and A. Quigley, "Effectiveness and Acceptability of Low-intensity Psychological Interventions on the Well-being of Older Adults: A Systematic Review," *Clin. Gerontol.*, vol. 45, no. 2, pp. 214–234, 2022, doi: 10.1080/07317115.2019.1662867.

[68] C. Adams, E. Gringart, and N. Strobel, "Barriers to mental health help-seeking among older adults with chronic diseases," *Aust. Psychol.*, vol. 59, no. 2, pp. 154–165, 2023, doi: 10.1080/00050067.2023.2282540.

[69] D. Freeman, S. McManus, T. Brugha, H. Meltzer, R. Jenkins, and P. Bebbington, "Concomitants of paranoia in the general population," *Psychol. Med.*, vol. 41, no. 05, pp. 923–936, 2011, doi: 10.1017/S0033291710001546.

[70] A. Ben-Joseph, C. R. Marshall, A. J. Lees, and A. J. Noyce, "Ethnic Variation in the Manifestation of Parkinson's Disease: A Narrative Review," *J. Parkinsons. Dis.*, vol. 10, no. 1, pp. 31–45, 2020, doi: 10.3233/JPD-191763.

Executive Summary

Background

Psychotic experiences, like seeing unusual things or having unusual beliefs or worries, are thought to impact many people with Parkinson's. For some, these experiences are mild and not particularly distressing, where-as for others they can be more severe, frightening, and have a significant impact on daily life. Previously, it has been thought these experiences are simply a side effect of the dopamine that is contained in most anti-Parkinson's medication. However, not everyone on anti-Parkinson's medication develops these experiences. Moreover, some people with Parkinson's do experience them despite not being on any anti-Parkinson's medication. It is therefore possible that factors apart from medication are also playing a role. If we better understand what these factors are, it will help us to know how to manage psychotic experiences in Parkinson's.

We know from research in other populations that psychotic experiences can be exacerbated by a number of everyday factors, like sleeping badly and feeling low or anxious. As a result, improving things like sleep and mood through psychological interventions can then also positively impact psychotic experiences. Such interventions are a particularly useful avenue of support given they have fewer negative side effects than medication management. However, the role of these factors has not been investigated in Parkinson's. We therefore explored whether any of these types of variables (like anxiety and mood) might be linked to the severity of psychotic experiences in Parkinson's. Before addressing this question, we also wanted to make sure we fully understood the nature of psychotic experiences in Parkinson's, e.g., how common are they, what is the experience like, and is it something people want

more support with. In total, 369 people took part in this research by completing a survey that asked about Parkinson's, psychotic experiences, and aspects of psychological health and wellbeing like sleep and mood.

Results

We found that psychotic experiences were indeed common among participants. Half of participants reported at least one unusual sensory experience, including many of those who were not taking any dopamine medication. For a quarter of those reporting the experiences, they were distressing, and greater support beyond the existing medication management options was desired. A small proportion of participants (10-20%) also reported struggling with feeling suspicious or worried about specific topics, such as that their spouse could be betraying them or that loved ones would abandon them. Understandably, having these worries was distressing for many people, and again further support was desired. Low mood, anxiety, sleep difficulties, loneliness, and stigma were also common among participants, and all these variables were significantly correlated with the psychotic experiences. For example, sleeping badly or feeling depressed was more common in those with psychotic experiences, and these variables helped to explain some of the differences in why only some people had psychotic experiences and others did not.

Conclusions

These findings are important. That some of those not taking any dopamine medication still had psychotic experiences confirms that there are other factors that contribute to their development. Additionally, given the high rates of e.g., low mood and anxiety, and the fact

that these were correlated with severity of psychotic experiences, it is plausible that these factors play an important role in the development and maintenance of psychotic experiences. Further work remains to be done to test whether this relationship is indeed causal, i.e. whether low mood and sleep difficulties actually make psychotic experiences worse and more frequent over time, as we know is the case in other populations. If they do, then this adds an additional benefit to offering people with Parkinson's interventions and tools to help improve difficulties like low mood and sleep, which are already likely to be of importance given how many people were struggling with them.

Overall, this research took the first step towards exploring what psychological factors could explain why some people with Parkinson's develop psychotic experiences. The nature of the experiences was also comprehensively assessed and reported on for the first time, and the potential role of psychological variables explored. Clear avenues of further research are now opened up.

Connecting Narrative

SRL

Having followed for some time the development of our understanding of sleep dysfunction as not only a consequence of mental health problems, but actually a contributory causal mechanism in their development, I was keen to delve into this topic in more detail for myself. I noticed that previous reviews on sleep and psychosis often did not separate out individual psychotic experiences. Given the extensive literature showing the independence of different psychotic experiences, throughout this thesis I wanted to ensure I focused on individual experiences rather than just psychosis as a whole. The SRL was no exception, and focussing specifically on paranoia allowed me to fill a gap that seemed to be present in the literature.

I was also keen to conduct a meta-analysis, given this was not a form of analysis I had previously conducted, meaning it would be a useful opportunity for additional learning. Although I knew there would likely only be enough studies to do a meta-analysis on the cross-sectional relationship between sleep and paranoia, and not on the size of the causal relationship between them, I felt this would still be a helpful starting point.

Having previously conducted a systematic review I felt relatively confident getting going with this project. The meta-analysis, however, gave rise to many interesting theoretical questions when required to make decisions about, e.g., inclusion criteria. While the final statistical calculation was fairly straightforward, the steps to get to this point were challenging, and required careful thought and precision.

SIP

My first placement was in the older adult service where I conducted the SIP. Being in this service and working with older adults for the first time opened up a whole area of research that I had not previously considered. I enjoyed our teaching days that helped us to think about the unique aspects to older adulthood and how this impacts mental health and associated treatment, and as someone with previous experience of working in psychosis, I was immediately called upon to apply this experience in the older adult service. This allowed me to see first-hand how the wider multi-disciplinary team (MDT) thought, talked about, and worked with psychosis and delusions in particular.

Having come, prior to training, from a team of clinical psychologists researching patient-centred and theoretically driven new psychological treatments for psychosis, I was able to see the stark contrast in views held by the MDT. Reflecting on this with the psychological lead and my supervisor, it was a useful reminder that psycho-social models of psychosis are still comparatively new, and that the training many mental health professionals have received in the past still places psychosis as a chronic, incurable, neurological disease that requires treatment by medication and little else. A plan for a SIP in this area was therefore easily formed. I have always enjoyed teaching, training, and supervising others, particularly in the areas I am most passionate about – psychological approaches to psychosis being one such area – and so the project was an ideal fit. Again, to highlight the independence of individual psychotic experiences, I chose to only focus on delusions, and within this, primarily persecutory delusions. Useful groundwork had also previously been laid by a prior trainee's SIP on hallucinations.

Although the SIP had a straightforward design, I learnt a lot from considering different ways to easily convey useful information within a difficult context of high staff burnout and turnover, as well as how to try and measure change. In some ways, the write up of this project was the most challenging given its many intersecting themes: cognitive behavioural approaches to delusions, older adults, staff training, challenging service contexts.

TDRP

The idea for the TDRP flowed naturally on from my thinking about older adults and psychosis that began while formulating my SIP proposal. It struck me that both delusions and hallucinations were extremely common among many of our patients with dementia and other degenerative neurological diseases, but that these symptoms, although reported, were largely ignored in terms of treatment planning. A quick literature search showed me that there had been little investigation into understanding these experiences in this context, which again opened up interesting discussions with our psychological lead, who also had an interest in psychosis. We considered three different groups of neurological disease where psychotic experiences were common: Alzheimer's disease, lew body dementia, and Parkinson's disease. Research into any of these groups would be of value, but I decided that as a starting point, individuals with Parkinson's would be a more easily recruitable group who may be best suited to completing a battery of questionnaires. Approximately half of those with Parkinson's go onto develop dementia, but if I could capture individuals prior to this stage, I would have participants who were able to complete self-report questionnaires, but who are nonetheless vulnerable to psychotic experiences. Holding in mind cognitive models of delusions and hallucinations, where common and relatable psychological processes such as

worry and low mow mood have significant impacts on causing and maintain symptoms, I wondered that these same processes could surely be also playing at least some role in 'organic' psychoses such as in Parkinson's. Within the confines of the doctorate, it seemed unfeasible to collect data that went much beyond cross-sectional. However, given the lack of existing research in the area this was still a useful starting place, and provided useful opportunities for me to consider measure choice with great care, and to perform a type of analysis I was new to.

Conclusion

Psychological approaches to psychotic experiences are where I began my career in clinical psychology and is the area that I have kept returning to throughout training. Nonetheless, the content, particularly of my TDRP and SIP, took me in new directions from my past research, in considering psychosis in an often-forgotten population. All three projects presented unique challenges and opportunities for learning, and helped solidify not only my research skills, but my knowledge and love of a growing clinical research field that I am excited to continuing contributing to.

Acknowledgements

Thank you to the many clinicians and academics that have supported both my research and clinical work. There are more than I can name, and it's been a privilege to learn from so many talented individuals. A particular thank you to Louise Johns, as both my specialist placement and main research project supervisor – may your email inbox now be slightly less busy, and paperwork pile smaller, at least temporarily!

As ever, I owe thanks to Daniel Freeman and Felicity Waite, as well as the wider O-CAP team, who have continued to go above and beyond to support me professionally and personally. During my periods of ill-health, your care and proximity was a particular source of comfort.

I feel very lucky to have trained alongside a wonderful cohort. Peer supervision is a gemstone, and these three years have been the start of lifelong friendships. To the friends across cohorts in particular who helped with shopping, cooking, and cleaning, when I wasn't able, you know who you are, and I am grateful.

To the pioneering doctors and patients alike who made their growing understanding of long covid dysautonomia freely available online long before health services were able to catch up, I owe much of my recovery so far, and as a result, the completion of this doctorate. When life as I knew it was entirely transformed, the work of individuals like Dr Boon Lim provided hope. There is still a very long way yet to go, but without the efforts of these people, and the extensive rehabilitation this allowed me to access, life today would be in a very different place, and this research certainly not complete.

To Ali, my almost husband, thank you for everything. Second doctorate around, we yet again find ourselves having to board a plane to see each other. But exciting journeys across the pond await.

Finally, to the many patients and participants that contributed to this work, I am exceptionally grateful. As always, without them, this research would not have been possible. This work is dedicated to them.

Systematic Review of the Literature: Appendices

Appendix A: Mixed methods appraisal tool items and instructions

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

2. Quantitative randomized controlled trials	Methodological quality criteria
Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins and Green (2008); Higgins et al. (2016); Oxford Centre for Evidence-based Medicine (2016); Porta et al. (2014)	2.1. Is randomization appropriately performed? Explanations In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance. Researchers should describe how the randomization schedule was generated. A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient to judge if randomization was appropriately performed. Also, assignment that is predictable such as using odd and even record numbers or dates is not appropriate. At minimum, a simple allocation (or unrestricted allocation) should be performed by following a predetermined plan/sequence. It is usually achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer. Also, restricted allocation can be performed such as blocked randomization (to ensure particular allocation ratios to the intervention groups), stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics). Another important characteristic to judge if randomization was appropriately performed is allocation concealment that protects assignment sequence until allocation. Researchers and participants should be unaware of the assignment sequence up to the point of allocation. Several strategies can be used to ensure allocation concealment such relying on a central randomization by a third party, or the use of sequentially numbered, opaque, sealed envelopes (Higgins et al., 2016).
	2.2. Are the groups comparable at baseline? Explanations Baseline imbalance between groups suggests that there are problems with the randomization. Indicators from baseline imbalance include: "(1) unusually large differences between intervention group sizes; (2) a substantial excess in statistically significant differences in baseline characteristics than would be expected by chance alone; (3) imbalance in key prognostic factors (or baseline measures of outcome variables) that are unlikely to be due to chance; (4) excessive similarity in baseline characteristics that is not compatible with chance; (5) surprising absence of one or more key characteristics that would be expected to be reported" (Higgins et al., 2016, p. 10).
	2.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field and apply this uniformly across all the included studies. For instance, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for a follow-up of more than one year (Viswanathan and Berkman, 2012).
	2.4. Are outcome assessors blinded to the intervention provided? Explanations Outcome assessors should be unaware of who is receiving which interventions. The assessors can be the participants if using participant reported outcome (e.g., pain), the intervention provider (e.g., clinical exam), or other persons not involved in the intervention (Higgins et al., 2016).
	2.5 Did the participants adhere to the assigned intervention? Explanations To judge this criterion, consider the proportion of participants who continued with their assigned intervention throughout follow-up. "Lack of adherence includes imperfect compliance, cessation of intervention, crossovers to the comparator intervention and switches to another active intervention." (Higgins et al., 2016, p. 25).

3. Quantitative non-randomized studies	Methodological quality criteria
Non-randomized studies are defined as any quantitative studies estimating the effectiveness of an intervention or studying other exposures that do not use randomization to allocate units to comparison groups (Higgins and Green, 2008). Common designs include (this list if not exhaustive): **Non-randomized controlled trials** The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups. **Cohort study** Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). **Case-control study** Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). **Cross-sectional analytic study** At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population subgroups according to the presence/absence (or level) of the intervention/exposure. Key references for non-randomized studies: Higgins and Green (2008); Porta et al. (2014); Sterne et al. (2016); Wells et al. (2000)	3.1. Are the participants representative of the target population? Explanations Indicators of representativeness include: clear description of the target population and of the sample (inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the intervention/exposure and outcome of interest are used, or variables are measured using 'gold standard'.
	3.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field (and based on the targeted journal) and apply this uniformly across all the included studies. For example, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for follow-up of more than one year (Viswanathan and Berkman, 2012).
	3.4. Are the confounders accounted for in the design and analysis? Explanations Confounders are factors that predict both the outcome of interest and the intervention received/exposure at baseline. They can distort the interpretation of findings and need to be considered in the design and analysis of a non-randomized study. Confounding bias is low if there is no confounding expected, or appropriate methods to control for confounders are used (such as stratification, regression, matching, standardization, and inverse probability weighting).
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended? Explanations For intervention studies, consider whether the participants were treated in a way that is consistent with the planned intervention. Since the intervention is assigned by researchers, consider whether there was a presence of contamination (e.g., the control group may be indirectly exposed to the intervention) or whether unplanned co-interventions were present in one group (Sterne et al., 2016). For observational studies, consider whether changes occurred in the exposure status among the participants. If yes, check if these changes are likely to influence the outcome of interest, were adjusted for, or whether unplanned co-exposures were present in one group (Morgan et al., 2017).

4. Quantitative descriptive studies	Methodological quality criteria
Quantitative descriptive studies are "concerned with and designed only to describe the existing distribution of variables without much regard to causal relationships or other hypotheses" (Porta et al., 2014, p. 72). They are used to monitoring the population, planning, and generating hypothesis (Grimes and Schulz, 2002). Common designs include the following single-group studies (this list if not exhaustive): **Incidence or prevalence study without comparison group** In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). **Survey** "Research method by which information is gathered by asking people questions on a specific topic and the data collection procedure is standardized and well defined." (Bennett et al., 2011, p. 3). **Case series** A collection of individuals with similar characteristics are used to describe an outcome. **Case report** An individual or a group with a unique/unusual outcome is described in detail. Key references: Critical Appraisal Skills Programme (2017); Draugalis et al. (2008)	4.1. Is the sampling strategy relevant to address the research question? Explanations Sampling strategy refers to the way the sample was selected. There are two main categories of sampling strategies: probability sampling (involve random selection) and non-probability sampling. Depending on the research question, probability sampling might be preferable. Non-probability sampling does not provide equal chance of being selected. To judge this criterion, consider whether the source of sample is relevant to the target population; a clear justification of the sample frame used is provided; or the sampling procedure is adequate. 4.2. Is the sample representative of the target population? Explanations There should be a match between respondents and the target population. Indicators of representativeness include: clear description of the target population and of the sample (such as respective sizes and inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population. 4.3. Are the measurements appropriate? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used, variables are measured using 'gold standard', or questionnaires are pre-tested prior to data collection. 4.4. Is the risk of nonresponse bias low? Explanations Nonresponse bias consists of "an error of nonobservation reflecting an unsuccessful attempt to obtain the desired information from an eligible unit." (Federal Committee on Statistical Methodology, 2001, p. 6). To judge this criterion, consider whether the respondents and non-respondents are different on the variable of interest. This information might not always be reported in a paper. Some indicators of low nonresponse bias can be considered such as a low nonresponse rate, reasons for nonresponse (e.g., noncontacts vs. refusals), and statistical compensation for nonresponse (e.g., imputation). The nonresponse bias is might not be pertinent for case series and case report. This criterion could be adapted. For instance, complete data on the cases might be important to consider in these designs. 4.5. Is the statistical analysis appropriate to answer the research question? Explanations The statistical analyses used should be clearly stated and justified in order to judge if they are appropriate for the design and research question, and if any problems with data analysis limited the interpretation of the results.

Appendix B: Risk of bias appraisal itemised results (MMAT scoring)

Quantitative randomised controlled studies					
Study	Is randomization appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?
Meyhöfer 2017	0	0	1	0	1
Reeve 2018	0	1	1	1	1
Waite 2023	1	1	1	1	1
Freeman 2017	1	1	0	1	0
Freeman 2015	1	1	1	1	1
Sheaves 2019	1	1	1	1	1
Ludtke 2021	1	1	0	1	0
Quantitative non-randomised studies					
	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?
Meyhöfer 2017	0	1	1	0	1
Kahn-Greene 2007	0	0	1	0	1
Hennig 2018	0	0	1	1	1
Petrovsky 2014	0	1	1	0	1
Reeve 2018	0	1	1	1	1
Reeve 2019	0	0	0	1	1
Hennig 2020	0	1	1	0	1
Kammerer 2021	0	1	0	1	1
Meyer 2022	0	0	1	1	0
Freeman 2012	1	1	1	1	1
Kasanova 2020	1	0	0	1	1
Kyle 2016	1	1	1	1	1
Quantitative descriptive studies					
	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of non-response bias low?	Is the statistical analysis appropriate to answer the research question?
Fekih-Romdhane 2023	0	0	1	0	1
Rek 2017	1	0	1	0	1
Levin 2002	0	0	0	0	1

Sheaves 2016	0	0	1	0	1
Freeman 2009	1	0	1	0	1
Freeman 2010	1	1	1	0	1
Myers 2011	1	1	1	0	1
Koyonagi 2015	1	1	0	1	1
Sheaves 2015	1	1	1	1	1
Taylor 2015	1	1	1	1	1
Scott 2017	0	0	1	1	1
Grezellschak	1	0	1	0	1
Rehman 2018	0	0	1	0	1
Bradley 2018	1	1	1	1	1
Reeve 2019	1	1	1	0	1
Goines 2019	1	1	1	0	1
Blanchard 2020	1	0	1	0	1
Kammerer 2021	0	0	1	0	1
Bagrowska 2022	1	0	1	0	1
Taylor 2022	1	1	1	0	1
Cosgrave 2018	1	0	1	0	1

Yes = 1
No or can't tell = 0

Appendix C: Schizophrenia Research: guide for authors

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of').

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do

not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof-reading the article, etc.).

Figure captions
Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables
Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References
Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference style
Text: All citations in the text should refer to:
1. *Single author:* the author's name (without initials unless there is ambiguity) and the year of publication;
2. *Two authors:* both authors' names and the year of publication;
3. *Three or more authors:* first author's name followed by 'et al.' and the year of publication.
Citations may be made directly (or parenthetically). Groups of references can be listed either first alphabetically, then chronologically, or vice versa.

Supplementary material
Supplementary material such as applications, images, and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file.

Service Improvement Project: Appendices

Appendix D: Approved clinical audit form

Oxford Health NHS Foundation Trust

Quality Improvement/Clinical Audit Proposal Form

Please register your audit or service evaluation with your directorate Quality lead before you start your project who maintain a central database of all audit activity.

Title	Improving skills and confidence of Older Adult Community Mental Health Team staff in working with patients experiencing delusions		
Directorate	**Buckinghamshire older adult Psychological therapies/community mental health team**	**Team / Ward / Unit**	**Bucks Older Adult CMHT**
Name and Title of project lead(s)		**Dr Poppy Brown**	
Contact telephone number		**07775612290**	
Contact email address		**poppy.brown@oxfordhealth.nhs.uk**	
Supervising Consultant / Service Manager		**Dr Rebecca Dow**	
Proposed start date		**February 2022**	
Proposed finish date		**December 2022**	
This project is a:			
☒ First audit/ quality improvement	☐ Re-audit/ quality improvement If yes, date of last audit/ quality improvement _____		
What is the resource implication for carrying out project (estimate staff hours, designation, grade and cost)	Time for staff to attend the training (1-2 hours) and complete the pre and post training questionnaire		
Reason for audit or evaluation (tick all that are applicable)			
☒ National priority HEE commission (see bekiw)	☐ Trust priority	☐ Directorate priority	☐ CCG priority

☐ NICE guidance	☐ SIRI recommendation	☒ Other (please state) Identified as by project lead and supervisor as a knowledge gap within the service

If NICE guidance, please state which guidelines: _____

Background to Project

Psychology staff have identified a need for upskilling CMHT staff regarding their understanding of and confidence to work with patients experiencing severe paranoia or delusions. There is also wider recognition that upskilling the NHS workforce to deliver better care for patients with psychosis is essential. As such, Health Education England have commissioned a two-day training titled Understanding Psychosis and Bi-polar disorder that should be delivered members of mental health teams (Health Education England, 2020). This training is available to older adult CMHTs although adaptations specific to the needs of older adults with psychosis are not included in the training package. The Buckinghamshire Older Adult CMHT is not currently commissioned to receive the training, and, given the length of the training many staff may not feel able to attend if they were to be offered it. Consequently, a smaller scale assessment of staff need and training delivery was thought to be a helpful initial step to upskilling the workforce within this service. Prior to delivering the training an audit is required in order to assess the number of patients in the service experiencing delusions, if these patients receive a referral to psychological therapies, which staff record and how and where they record information about a patient's delusion. These results will then inform the training required.

Standard(s) for audit or quality improvement

(please list all the standards which will be assessed)
Number of patients experiencing severe paranoia and delusions
Number of these patients who are referred to the Psychology team
Please state source of standards
NICE guidance (2014) state that all adults with psychosis should be offered psychological intervention (CBT or FI). No specific guidance for older adults is given.

Scope and Methodology for Project

Using routinely collected data information will be collated regarding the number of patients within the North and South Bucks OA CMHT who are experiencing delusions or severe paranoia and the number of which are then referred to the Psychology team. CRIS will be sued to search care notes, including free text data, from both the North and South teams (therefore including teams that the lead researcher is not directly attached to) in order to find this information and record demographic information about those reported to be experiencing delusions.
A staff survey will then be distributed to find out current levels of staff understanding of delusions. The exact questions to be asked are still to be determined, but demographic data will likely include age, gender, job role and length of employment in current role. Further questions will assess participants' confidence to engage with older adults experiencing delusions, participants' understanding of the causes of delusions, and participants' understanding of the best treatments for delusions.
Based on the data collected in these first two stages a training session will be devised. This will then be delivered to available staff in the community team. Multiple training slots will be offered if possible to allow more staff to be able to attend. Training materials will also be made available for staff to look at in their own time after the delivery of the training.

How are you going to collect the data (tick all that are applicable)

☒ Case notes (paper/ electronic)	☐ Observations	☒ Patient/ Staff Survey	☐ Other (please state)

Data Protection Act

Please tick to confirm "yes" you will comply with:

☒ All data collected will be anonymised ☐ No patient or staff identifiable data will be reported

Ethics Screening	
Gather any information about a patient beyond that collected in routine patient care ☐ Yes ☒ No	
Pose any risk for or burden on a patient beyond those of his/her routine patient care ☐ Yes ☒ No	
Infringe on any patient's rights ☐ Yes ☒ No	
Risk breaching any patient's confidentiality or privacy ☐ Yes ☒ No	
Involve the use of any untested clinical or systems intervention ☐ Yes ☒ No	
Do you intend to publish the findings? ☒ Yes ☐ No	
Does National Data Opt Out need to be applied to the resulting data set prior to analysis? ☐ Yes ☒ No	
Requested Support from the Quality and Audit Team (tick all that are applicable)	
☐ Design data collection tool	☐ Data collection
☐ Data analysis	☐ Report writing
☐ Power point presentation design	☒ None
Quality and Audit Team Contact Details	
Emma Lofthouse – Tel: 07500 784 326 Liz Cheal – Tel: 07900 657 607 (maternity leave until June 2021) Clinical.audit@oxfordhealth.nhs.uk	**Corporate Directorate (Quality & Audit Specialists)**
Steve McCourt Steven.McCourt@oxfordhealth.nhs.uk	**Lead for CQC Standards & Quality**
Sandra Parker - Tel: 07770 346 493 CommunityServices.QualityTeam@oxfordhealth.nhs.uk	**Community Services Directorate**
Jelena Ampofo - Tel: 07787 002 849 AdultDirectorateGovernance@oxfordhealth.nhs.uk	**Mental Health Directorates**
Rene Sidorov – Tel: 07881 512 409 Ayo Akinbola – Tel: 07554 517 959 Governance.ForensicService@oxfordhealth.nhs.uk	**Specialised Directorate (Forensic, Dental, LD, Pharmacy)**
Dr Samantha Sadler – Tel: 01865 901222 Senior Locality Lead, Clinical Psychologist, Cognitive Behavioural Psychotherapist and Dynamic Interpersonal Psychotherapist www.talkingspaceplus.org.uk Dr David Tilbrook CPsychol AFBPsS – Tel: 01865 901620 Principal Clinical Psychologist, Bucks PTP Step 4, DIT Therapist	**Psychology Therapies Pathway (PTP)**
CRIS.Admin@oxfordhealth.nhs.uk	**Clinical Record Interactive Search (CRIS) Team**

Appendix E: Staff survey

You have been invited to participate in a project carried out by Dr Poppy Brown with Dr Becci Dow at South and North Bucks Older Adults Psychological Services.

We are interested in your views and experiences in the CMHT regarding patients experiencing delusions/severe paranoia. This survey is entirely anonymous. The results will be used to inform a training session on working with delusions.

Thank you for your time!

Q1 What is your age in years?

Q2 What is your gender?

Male □ Female □ Gender nonbinary □ Prefer not to answer □

Q3 What is your job role/profession?

CPN □ Social worker □ Staff nurse □ Psychiatrist □ Care co-coordinator □
Support worker □ Team manager □ Occupational therapist □ Psychologist □ Other (please specify) □ _____

Q4 What is your length of employment within the team?

< 1 year □ 1-2 years □ 3-5 years □ 6-10 years □ > 10 years □

Q5 Approximately how many patients do you have on your caseload at the moment?

Q6 Of the patients on your case load, how many would you say have severe paranoia or delusions?

Q7 Have you received any training in delusions/psychosis?

□ Yes, please specify what training
□ No

Q8 Do you ever ask questions about the distress associated with a patient's delusion?

□ Always/most of the time □ Sometimes □ No

Q9 Do you think it's important to challenge someone's delusion? For example, to help them see that their belief is not true?

□ Always/most of the time □ Sometimes □ No

Q10 Would you ever think it would be appropriate to agree with someone's delusion?

□ Always/most of the time □ Sometimes □ No

Q11 Please elaborate on your reasons for your previous answer

Q12 Do you prefer to not talk to patients about their delusions?

□ Always/most of the time □ Sometimes □ No

Q13 What are the reasons for preferring to talk or not to talk to patients about their delusions?

Q14 Do you ever ask a patient's family members what sense they make of the delusions?

□ Always/most of the time □ Sometimes □ No

Q15 What interventions for delusions are most helpful? Rank your first three in order

Q16 Do you think psychological approaches/interventions for delusions can be useful?

□ Yes □ Sometimes □ No

Q17 Please elaborate on your reasons for your previous answer

Q18 Do you think psychological intervention has a place for organic psychosis e.g. psychosis in the context of dementia or Parkinson's?

□ Yes □ Sometimes □ No

Q19 Please elaborate on your reasons for your previous answer

Q20 What are the reasons you might not consider psychological perspectives? Tick all that apply

□ Not my job role
□ Psychological perspectives not relevant in psychosis/delusions
□ Lack of knowledge/confidence
□ Other, please specify

Appendix F: Training summary sheet

RETHINKING DELUSIONS – QUICK TIPS

Quick facts about delusions

- Worries about other people and feeling unsafe is common across the general population
- A paranoid/persecutory delusion is the severe end of the spectrum of paranoia, like depression is the severe end of low mood
- A delusion is a person's attempt to make sense of what's happening and how they're feeling
- False/not widely held beliefs are surprisingly common among healthy individuals
- Psychological therapy can be really effective for helping people re-engage with life, even when acutely unwell

Six things that make paranoia/delusions worse – ask about them!

1. High levels of worry 2. Low self-esteem 3. Unusual experiences/hallucinations
4. Disrupted sleep 5. Jumping to conclusions 6. Safety behaviours e.g. avoidance

Improving these areas, even without working on the delusion itself, can reduce delusional conviction

What to say and do when working with delusions:

Connect with the feeling and show empathy

✓ 'That must be really terrifying. I'm really sorry to hear that'
✓ 'It's so understandable you don't want to leave the house'

Listen, ask questions, and reflect back

✓ 'You said you think someone is out to get you. Would you be able to tell me more?'
✓ 'You've seen someone following you. What do you worry might happen?'
✓ 'You're worried about being arrested. How certain are you that this will happen?'
✓ 'Have these scary things happened before?'

Be curious rather than challenging

✓ 'That sounds really scary. Is there anything that would help to make you feel safer?'
✗ 'That's not going to happen. They won't hurt you. There's no evidence for that'

Increase meaningful activity and remind them of their strengths

✓ 'It was really brave of you to give that a go when you were feeling so scared'
✓ 'Is there anything that helps you feel relaxed?
✓ 'What are your hobbies? What did you used to enjoy before you had these worries?'

Appendix G: Summary of service user feedback and how this was implemented

Service User Feedback	How this was addressed in the training
Staff often do not comprehend just how terrifying the experience is and how alone it leaves you given you can rarely talk about your worries with other people.	A number of service user quotes were included in the training with staff asked to reflect on these, as well as times in their own lives where they have felt unsafe or worried around other people.
Importance of staff explaining themselves patiently, calmly, and clearly, as well as coming across as knowledgeable and hopeful.	A step-by-step approach of ways to interact and respond to someone experiencing delusions was provided, including examples of how to phrase questions and information.
Importance of considering whether the side effects of medication might be worse or as bad as what the medication is aiming to treat.	Discussion about the unique challenges of anti-psychotics in older adulthood including difficulties with side effects and polypharmacy.

Appendix H: The Cognitive Behaviour Therapist: guide for authors

Aims and Scope

The Cognitive Behaviour Therapist is published for the British Association for Behavioural and Cognitive Psychotherapies and is the sister Journal to *Behavioural and Cognitive Psychotherapy*
The Cognitive Behaviour Therapist is an interdisciplinary peer reviewed journal aimed at CBT practitioners. Published online, the journal will publish a range of types of papers (see below for a full description of each) that support CBT therapists in improving their delivery of CBT, supervision and training and/or develop our knowledge and understanding of CBT across all areas.
A particular feature of the journal is that its electronic nature is designed to ensure timeliness of publication and professional debate whilst also ensuring rigorous standards in the dissemination of high-quality materials with relevance to the practice of the cognitive and behaviour therapies.

Editorial Governance

The Cognitive Behaviour Therapist encompasses most areas of human behaviour and experience, and represents many different research methods, from quantitative to qualitative research, how to flexibly implement specific clinical interventions right through to detailed case studies. Under the guidance of its editorial board *the Cognitive Behaviour Therapist* aims to reflect and influence the continuing changes in the concepts, methodology, and techniques within the cognitive and behaviour therapies.

Articles must be original and focused upon cognitive and/or behaviour therapy. There is no formal word limit, but concision is recommended.
In terms of subject areas, our scope includes
the delivery of CBT
supervision of CBT
training in CBT
service model and forms of delivery of CBT.

Types of Paper

Original Research*

Research evidence is at the heart of the practice of cognitive and behavioural psychotherapists. Original research will be published that directly relevant to the practice of CBT, such as the therapeutic relationship, therapeutic process and the evaluation of therapeutic strategies and techniques. It is expected that such reports meet both the necessary standards of scientific rigour and the journal's requirement of clear implications for the practice of CBT. Consequently, the description of the research and the presentation of results should be sufficiently brief to enable sufficient discussion of the practice implications. Consideration will be given to quantitative, qualitative, and mixed approaches given appropriate fit between the question, methodology and research methods chosen.

Preparing your materials

All articles must include the following sections:

Key Learning Aims (3 – 5 bullet points)
- Position – After the Abstract and Keywords
- Intention – What will the reader learn through reading the paper?

Key Practice Points (3 – 5 bullet points)
- Position – before the references
- Intention – a summary of the papers with clear and practical implications for the day-to-day practice of CBT therapists

Further Reading
- Position – before the references and after the Key Practice Points
- Intention – to direct the reader to other relevant follow up literature

This stipulation is in keeping with the practitioner and professional development aims of the journal. The main types of articles published are detailed below as a guide. Many of these will be therapy related but tCBT also welcomes papers related to subject areas such as CBT supervision and training. Most papers will have a subject area (e.g. therapy, assessment, supervision, training, service development) and a paper type (e.g. Original Research, Case Study, Review) e.g. a single case study looking at the impact of supervision, an empirically grounded clinical guidance paper focussing on a training method.

Title page
This should uploaded as a separate file the main text to ensure blind review.
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.

Acknowledgements
You may acknowledge individuals or organizations that provided advice, support (non-financial).

Conflicts of Interest
Authors should include a Conflicts of Interest declaration in their title page. Conflicts of Interest are situations that could be perceived to exert an undue influence on an author's presentation of their work. They may include financial, professional, contractual or personal relationships or situations. Authors should declare any real or perceived Conflicts of Interest in order to be transparent about the context of their work. If the manuscript has multiple authors, the author submitting the title page must include Conflicts of Interest declarations relevant to all contributing authors.

Data Availability Statement
This is a brief statement about whether the authors of an article have made the evidence supporting their findings available, and if so, where readers may access it. More information on Data Availability Statements and example statements can be found here. Please note that if you are not making your data publicly available, we ask you to state the reason why in your cover letter to the Editor.

Financial support
Please provide details of the sources of financial support for all authors, Including grant numbers. For example, "This work was supported by the Medical research Council (grant number XXXXXXX)".

Abstract
This should summarize the article in no more than 250 words, references should not be included in the abstract.

Keywords
Please include up to six key words that could be used to effectively search for the article.

Key Learning Aims
Body of paper
This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal.

References
Please use APA style for the in-text citations and references.

Tables
Use APA style. Tables should be provided in editable Word format. They should be numbered and given explanatory titles.

Figures
Use APA style. All artwork should be submitted as separate TIFF format files.

Supplementary Files
Where unpublished material e.g. behaviour rating scales or therapy manuals are referred to in an article, copies should be submitted as an additional document (where copyright allows) to facilitate review. Supplementary files can be used to convey supporting or extra information to your study, however, the main manuscript should be able to 'stand-alone'.

Authorship and contributorship
All authors listed on any papers submitted to this journal must be in agreement that the authors listed would all be considered authors according to disciplinary norms, and that no authors who would reasonably be considered an author have been excluded. For further details on this journal's authorship policy, please see this journal's publishing ethics policies.

Author affiliations
Author affiliations should represent the institution(s) at which the research presented was conducted and/or supported and/or approved. For non-research content, any affiliations should represent the institution(s) with which each author is currently affiliated.
For more information, please see our author affiliation policy and author affiliation FAQs.

Competing Interests
All authors must include a competing interest declaration in their title page. This declaration will be subject to editorial review and may be published in the article.

Appendix I: Key learning, practise points and further reading for The Cognitive Behaviour Therapist

Key Learning Aims

- To understand the developing cognitive-behavioural evidence base for understanding and treating delusions.
- To understand the need for this growing evidence base to be reflected in services, not only in structured interventions offered by psychologists, but also in patient interactions and care planning by all professions working in multi-disciplinary teams.
- To understand some of the key challenges in assessing and improving current understanding of cognitive behavioural approaches to delusions within services.
- To consider ways to overcome these challenges by providing small but consistent nudges towards psychologically informed practise.

Key Practice Points

- A significant proportion of older adults within mental health services may be experiencing paranoia or delusions. More thorough assessment of paranoia would allow better treatment signposting.
- CMHT staff often do not feel confident working with patients with delusions, and may have had little training in the cognitive behavioural approaches to delusions that have developed over the last two decades. It is important to assess this across individual services.
- Training in cognitive-behavioural approaches should not be limited to Psychologists delivering therapy, as being able to hold these models in mind can help all staff to better care plan, assess, and build rapport with patients. This is regardless of whether delusions are being experienced in the context of typical psychosis or a neurodegenerative condition such as dementia. As set out in the CMHT transformation agenda, leadership and management teams must a play a role in ensuring equity of access to training for all staff.
- Delivering training to stretched services is challenging. Using ideas from behavioural insights and nudge theory, small but consistent nudges towards evidence-based practise led by a named champion to gradually increase staff confidence may be an important additional path forward.

Further Reading

Freeman, D. (2016). Persecutory delusions: a cognitive perspective on understanding and treatment. *The Lancet Psychiatry*, *3*(7), 685–692. https://doi.org/10.1016/S2215-0366(16)00066-3

Freeman, D., Emsley, R., Diamond, R., Collett, N., Bold, E., Chadwick, E., Isham, L., Bird, J. C., Edwards, D., Kingdon, D., Fitzpatrick, R., Kabir, T., Waite, F., Carr, L., Causier, C., Černis, E., Kirkham, M., Lambe, S., Lister, R., … Twivy, E. (2021). Comparison of a theoretically driven cognitive therapy (the Feeling Safe Programme) with befriending for the treatment of persistent persecutory delusions: a parallel, single-blind, randomised controlled trial. *The Lancet Psychiatry*, *8*(8), 696–707. https://doi.org/10.1016/S2215-0366(21)00158-9

Mitford, E., Reay, R., McCabe, K., Paxton, R., & Turkington, D. (2010). Ageism in first episode psychosis. *International Journal of Geriatric Psychiatry*, *25*(11), 1112–1118. https://doi.org/10.1002/gps.2437

Health Education England. (2020). *Understanding psychosis and bipolar disorder*. *March*.

Brooker, C. (2001). A decade of evidence-based training for work with people with serious mental health problems: Progress in the development of psychosocial interventions. *Journal of Mental Health*, *10*(1), 17–31. https://doi.org/10.1080/09638230020023589

Theory Driven Research Project: Appendices

Appendix J: Evidence of ethical approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Dr Louise Johns & Poppy Brown
Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre
Warneford Hospital
Oxford

3 January 2023

Dear Dr Johns and Poppy,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R82914/RE001

Study title: Cognitive-affective variables associated with unusual experiences and paranoia in Parkinson's disease

Short title: Understanding unusual experiences in Parkinson's

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **2 years**, commencing on **3rd January 2023.**

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for
Dr Helen Barnby-Porritt
Research Ethics Manager

Appendix K: Participant questionnaire pack

Italicised subheadings are provided for identification of questionnaires to the reader, and were not shown to participants

Thank you for volunteering to take part. Before you begin the questionnaires, please read the information sheet and tick the two boxes at the end to certify your agreement. You may then proceed to the questionnaires. If needed, you may complete the questions in more than one sitting but please aim to complete the questionnaires within a one week period. You may find it easier to complete the questions during an 'on' period if such periods are relevant to you.

Please note many of these questions have been chosen because they are what are called 'standardised questionnaires' i.e. they are used as standard across research and clinical settings and have been shown to be helpful questions for many people with Parkinson's. However, everyone is different, and some questions may not feel like a good fit for you. Please don't worry about this and just answer them the best you can. Feel free to annotate a question if you feel the need to clarify something.

Once complete please put the pack into the pre-paid envelope provided and post it back by dropping it off at any post box (or return to your named contact if you have been given this option).

Section 1.

Age in years	_____years
Gender	☐ Male ☐ Female ☐ Intersex
Living Status (tick all that apply)	☐ Live alone in independent housing
	☐ Live alone in supported housing
	☐ Live with Partner
	☐ Live with family member(s)
	☐ Other, please specify: _____
What best describes your ethnicity	**White** ☐ English, Welsh, Scottish, Northern Irish or British ☐ Irish ☐ Gypsy or Irish Traveller ☐ Roma ☐ Any other white background

	Asian or Asian British ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background
	Black, Black British, Caribbean or African ☐ Caribbean ☐ African ☐ Any other Black British, Caribbean or African background
	Mixed or multiple ethnic groups ☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other Mixed or multiple ethnic background
	Other ethnic group ☐ Arab ☐ Any other ethnic group
Roughly how many years ago did you receive your Parkinson's disease diagnosis?	_____years
Have you ever received a diagnosis of any of the following mental health or cognitive disorders? Tick all that apply	☐ I have no current diagnosis of a mental health or cognitive problem
	☐ Dementia ☐ Schizophrenia or psychosis related disorder (e.g. schizoaffective disorder, delusional disorder, psychosis)
	☐ Bi-polar affective disorder
	☐ Depression
	☐ Post-Traumatic Stress Disorder
	☐ Anxiety disorder (including OCD, Social Anxiety, a severe phobia, Generalised Anxiety Disorder) ☐ Other mental health or cognitive problem (not including physical health problems). Please specify:
Do you feel the above diagnosis/diagnoses still apply to you?	☐ Yes
	☐ No
	☐ Not applicable as no diagnosis reported above
Did you receive your diagnosis of the above before your diagnosis of Parkinson's?	☐ Yes
	☐ No
	☐ Not applicable as no diagnosis reported above

Do you have difficulty with your hearing?	☐ No
	☐ Yes, but a hearing aid or other device satisfactorily corrects the problem
	☐ Yes; the problem is not satisfactorily corrected by a hearing aid or other device
Do you have difficulty with your vision?	☐ No
	☐ Yes but glasses/or equivalent satisfactorily correct the problem
	☐ Yes; the problem is not satisfactorily corrected by glasses or equivalent

Medication for <u>Parkinson's disease</u> ONLY
(List each medication you take and the amount that you take each day)

Drug	**Strength**	**Frequency**
<u>example</u>. *levodopa*	*100mg*	*Once a day at night*

Schwab & England measure of independence:

Please tick **ONE** answer below that most correctly describes your level of **independence**.

I am completely independent. I am **able to do all chores/daily activities** without slowness, difficulty, or impairment, and I am **unaware of any difficulties**.	☐ 10
I am completely independent, and I am **able to do all activities**. However, there is **some slowness**, difficulty or impairment, and chores/activities might take twice as long.	☐ 9

I am completely independent in **most** activities, but I am aware of difficulties and slowness and **chores usually take twice as long**.	☐ 8
I am **not** completely independent. Some chores/daily activities take three to four times as long.	☐ 7
I depend on other people **to some degree**. I can do most chores/daily activities, but exceedingly slowly and with much effort. **Some chores/daily activities are impossible**.	☐ 6
I depend on other people for **help with half of the chores/daily activities**. **I have difficulty with everything**.	☐ 5
I am very dependent on other people. I can assist with all chores/daily activities, but **can do few things alone**.	☐ 4
With effort, now and then I can do a **few chores/daily activities alone** or begin alone. I **need much help**.	☐ 3
I can do nothing alone, but I can be a **slight help with some things**	☐ 2
I am **totally dependent**, and more or less helpless.	☐ 1
I have no control over swallowing, bladder control, and bowel functions, and I am **bed-ridden**.	☐ 0

Hoehn & Yahr measure of PD severity:

Please tick which answer below most correctly describes the degree of your problems related to your **Parkinson's disease**. Read all answers before you decide on one and tick **only one** answer. We are interested in whether your Parkinson's disease affects one or both sides of your body and whether you have problems with your balance.

If you experience different symptoms depending on if your medication is working or not working, complete PART A and PART B below. Otherwise ONLY complete PART A.

PART A: No change in symptoms due to medication OR Medication WORKING	
I have **no** tremor, stiffness or slowness	☐ 0
I have tremor, stiffness or slowness only **on one side** of my body	☐ 1
I have tremor, stiffness or slowness **on both sides** of my body, but no problems with my balance	☐ 2
I have tremor, stiffness or slowness on both sides of my body, **and** I have **problems with my balance**, but I am independent	☐ 3

I have **great problems** due to my Parkinson's disease, but **I am still able to stand or walk without help**	☐ 4
I am in a **wheelchair (or bed)** unless I have help	☐ 5

PART B: Medication NOT WORKING (If applicable)

I have **no** tremor, stiffness or slowness	☐ 0
I have tremor, stiffness or slowness only **on one side** of my body	☐ 1
I have tremor, stiffness or slowness **on both sides** of my body, but no problems with my balance	☐ 2
I have tremor, stiffness or slowness on both sides of my body, **and** I have **problems with my balance**, but I am independent	☐ 3
I have **great problems** due to my Parkinson's disease, but **I am still able to stand or walk without help**	☐ 4
I am in a **wheelchair (or bed)** unless I have help	☐ 5

Section 2.
PsycH-Q measure of USEs:

Please complete the following questions relating to changes in vision that can sometimes occur in the normal progression of Parkinson's disease.

Please respond regarding the last month, rating how often you experienced it (on the left), and also how distressing it was if you did experience it (on the right).

Over the past month, how often did you:

If you experienced the symptom, how distressing was it?

1. Feel like someone is in the room with you that's not really there?



2. Feel like something is lurking in the corner of your vision?



3. Feel that something is passing by you that you can't make out?

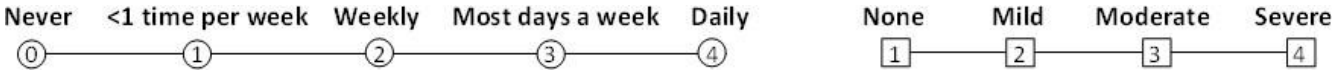
Never <1 time per week Weekly Most days a week Daily
0 1 2 3 4

None Mild Moderate Severe
1 2 3 4

4. See shadowy forms that aren't really there?



5. Mistake an object for something else e.g. a snake instead of a hose?

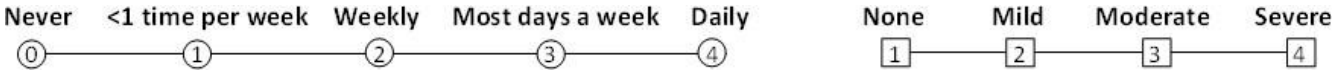


6. See people or things (e.g. animals) that aren't there?

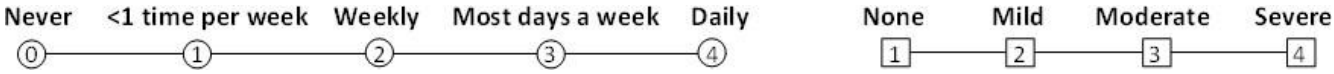
Never <1 time per week Weekly Most days a week Daily
0 1 2 3 4

None Mild Moderate Severe
1 2 3 4

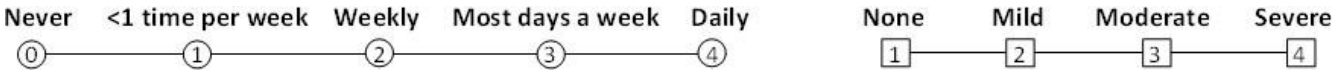
7. Hear voices or things that aren't real?



8. Touch or feel things touching you which aren't real?



9. Smell odours which aren't real?



10. Taste things which are not there?



The previous questions asked about these experiences in the last month. Have you experienced any of these symptoms before the last month? Provide as much detail as you would like.

_____

This is part of the survey complete. You may now wish to take a short break before continuing. You may want to set an alarm to remind you to return.

Further items within the PsycH-Q scale:

Please answer the next questions in regard to the unusual sensory experience(s) you reported above. This is really helpful even if all you reported experiencing was something mild on a couple of brief occasions. If you did not report any unusual sensory experiences, i.e. if you put 'never' to all of the questions above in Section 2 (pages 5-6), and therefore feel this section does not apply to you, you may skip to Section 3 on Page 11.

Did you experience any of the symptoms only when you were about to fall asleep?	☐ Yes ☐ No
Did you think that these experiences could be real?	☐ Yes ☐ No
If you thought they could be real, could you have been convinced otherwise?	☐ Yes ☐ No
Did the experiences frighten you?	☐ Yes ☐ No

Further details on USEs:

Are there any times or situations when you are more likely to have these experiences? Tick all that apply	☐ Boredom ☐ Being alone ☐ Being around other people ☐ Night-time (e.g. when it gets dark or when you try to go to sleep) ☐ There is nothing obvious/I'm unsure ☐ Other, please specify
What typically brings the experience to an end? Tick all that apply	☐ Time ☐ I deliberately distract myself

	☐ I get distracted by someone or something else
	☐ There is nothing obvious before
	☐ Other, please specify
How long does the unusual experience typically last?	☐ Very brief; just an instant
	☐ A few seconds
	☐ A minute or a few minutes at most
	☐ 10 minutes to an hour
	☐ Between one and several hours
	☐ Continuously
	☐ The length is very variable. Please elaborate:
Do the unusual experiences impact your functioning, activities or relationships?	☐ No impact
	☐ They interfere slightly but most things can be done normally
	☐ They interfere with several activities
	☐ They prevent me from doing most things
	☐ They cause huge disruption and prevent me from doing anything
Have you received any professional support (e.g. medication changes or input from a Psychologist) for these experiences? Tick all that apply	☐ Yes, change in dose to existing medication
	☐ Yes, begun a new medication e.g. antipsychotic
	☐ Yes, Seen a Psychologist or other mental health professional for support
	☐ Other, please specify
	☐ No
	☐ Yes
	☐ No

Would you find it helpful to have more support for these experiences?	
If so, what support would you like? Tick all that apply	☐ Access to more information about understanding the experiences
	☐ Talking therapy/input from a Psychologist on how to manage or reduce them
	☐ Medication to manage or reduce them
	☐ Peer support i.e. talking to others with similar experiences
	☐ Other, please specify

Coping orientations:

Please continue to answer the next set of questions in relation to coping with the unusual sensory experiences only.	**not at all**	**a little bit**	**a medium amount**	**a lot**
I've been expressing my negative feelings and/or getting emotional comfort from others	☐	☐	☐	☐
I've been accepting the reality of the experiences	☐	☐	☐	☐
I've been trying to get advice from others and to come up with a strategy or some steps about what to do	☐	☐	☐	☐
I've been trying to see the experience in a different light e.g. looking for any alternative perspectives	☐	☐	☐	☐
I've been giving up trying to deal with them	☐	☐	☐	☐
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	☐	☐	☐	☐

Illness Perceptions/Appraisals of USEs:

Overall, how much do these unusual experiences affect your life?

0 1 2 3 4 5 6 7 8 9 10

Not at all severely

If you had to provide your best estimate, how long do you think the experiences will continue?

0 1 2 3 4 5 6 7 8 9 10
a very short time forever

How much control do you feel you have over the experiences?

0 1 2 3 4 5 6 7 8 9 10
none Fully

How much do you think treatment can/does help with these experiences?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely helpful

How much do you feel you experience the symptoms overall?

0 1 2 3 4 5 6 7 8 9 10
no symptoms at all many severe symptoms

How concerned are you about the experiences/symptoms?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely

How well do you feel you understand the experiences/symptoms?

0 1 2 3 4 5 6 7 8 9 10
not at all very well

How much do they affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0 1 2 3 4 5 6 7 8 9 10
not at all Extremely

Section 3.

PsycH-Q measure of delusions

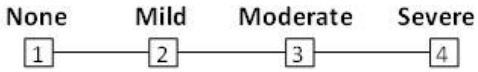
Please complete the following questions relating to changes in thoughts about other people that can occur in the normal progression of Parkinson's disease.

Please respond regarding the last month, rating how often you experienced it (on the left), and also how distressing it was if you did experience it (on the right).

Over the past month, how often did you: ***If you experienced the symptom, how distressing was it?***

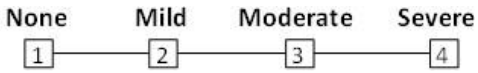
1. Think people are acting against you?
   e.g. stealing, hiding things





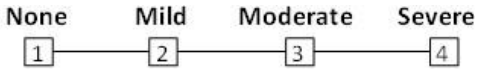
2. Feel threatened by the people around you?





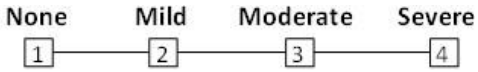
3. Think people are trying to trick you? e.g. pretending
   to be other people





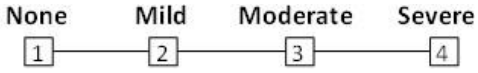
4. Have fears running through your mind that your spouse/partner
   has been betraying you even though they assured you that
   this is not so?





5. Have fears running through your mind that your loved ones
would abandon you, even though they have assured you they won't?





R-GPTS:

For the next questions, think about the last month and indicate the extent of these feelings from 1 (Not at all) to 5 (Totally) by ticking or circling an answer.

	Not at all (1)	(2)	(3)	(4)	Totally (5)
I spent time thinking about friends gossiping about me.	○	○	○	○	○
I often heard people referring to me.	○	○	○	○	○
I have been upset by friends and colleagues judging me critically.	○	○	○	○	○
People definitely laughed at me behind my back.	○	○	○	○	○
I have been thinking a lot about people avoiding me.	○	○	○	○	○
People have been dropping hints for me.	○	○	○	○	○
I believed that certain people were not what they seemed.	○	○	○	○	○
	Not at all	2	3	4	Totally
People talking about me behind my back upset me.	○	○	○	○	○
Certain individuals have had it in for me.	○	○	○	○	○

People wanted me to feel threatened, so they stared at me.	○	○	○	○	○
I was sure certain people did things in order to annoy me.	○	○	○	○	○
I was convinced there was a conspiracy against me.	○	○	○	○	○
I was sure someone wanted to hurt me.	○	○	○	○	○
I couldn't stop thinking about people wanting to confuse me.	○	○	○	○	○
I was distressed by being persecuted.	○	○	○	○	○
It was difficult to stop thinking about people wanting to make me feel bad.	○	○	○	○	○
People have been hostile towards me on purpose.	○	○	○	○	○
I was angry that someone wanted to hurt me.	○	○	○	○	○

The previous question asked about these experiences in the last month. Have you experienced any of these worries before the last month? Provide as much detail as you would like.

_____

Please answer the next questions in regard to the concerns/worries about other people and what they might be saying or doing that you reported above. This is helpful for us to know even if your worries/concerns have been very small/mild.

If you did not report concerns or worries at all, reporting 'never' or 'not at all' to **all of the questions above in Section 3 from pages 10-12**, and therefore feel this section does not apply to you, you may skip to Section 4, page 17.

Have you received any professional support (e.g. medication changes or input from a Psychologist) for these experiences? Tick all that apply	☐ Yes, change in dose to existing medication
	☐ Yes, begun a new medication e.g. antipsychotic
	☐ Yes, Seen a Psychologist or other mental health professional for support
	☐ No
	☐ Other, please specify

Would you find it helpful to have more support for these experiences?	☐ Yes
	☐ No
If so, what support would you like? Tick all that apply	☐ Access to more information about understanding the experiences
	☐ Talking therapy/input from a Psychologist on how to manage or reduce them
	☐ Medication to manage or reduce them
	☐ Peer support ie. talking to others with similar experiences
	☐ Other, please specify

Coping Orientations:

	not at all	**a little bit**	**a medium amount**	**a lot**
I've been expressing my negative feelings and/or getting emotional comfort from others	☐	☐	☐	☐
I've been accepting the reality of the experiences	☐	☐	☐	☐

I've been trying to get advice from others and to come up with a strategy or some steps about what to do	☐	☐	☐	☐
I've been trying to see the experience in a different light e.g. looking for any alternative perspectives	☐	☐	☐	☐
I've been giving up trying to deal with them	☐	☐	☐	☐
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	☐	☐	☐	☐

The next section is the final part of the survey. **You may now wish to take a short break before continuing. You may want to set an alarm to remind you to return**

Section 4.

Depression:

Choose the answer below that best describes how you felt over the <u>past week</u>.

Are you basically satisfied with your life?	☐ Yes ☐ No
Have you dropped many of your activities and interests?	☐ Yes ☐ No
Do you feel that your life is empty?	☐ Yes ☐ No
Do you often get bored?	☐ Yes ☐ No
Are you in good spirits most of the time?	☐ Yes ☐ No
Are you afraid that something bad is going to happen to you?	☐ Yes ☐ No
Do you feel happy most of the time?	☐ Yes ☐ No
Do you often feel helpless?	☐ Yes ☐ No
Do you prefer to stay at home, rather than going out and doing things?	☐ Yes ☐ No
Do you feel that you have more problems with memory than most?	☐ Yes ☐ No
Do you think it is wonderful to be alive now?	☐ Yes ☐ No
Do you feel worthless the way you are now?	☐ Yes ☐ No
Do you feel full of energy?	☐ Yes

	☐ No
Do you feel that your situation is hopeless?	☐ Yes ☐ No
Do you think that most people are better off than you are?	☐ Yes ☐ No

Anxiety:

Over the past two weeks, to what extent did you experience:

	Never	*Rarely*	*Sometimes*	*Often*	*Always*
Feeling anxious or nervous	☐	☐	☐	☐	☐
Feeling tense or stressed	☐	☐	☐	☐	☐
Being unable to relax	☐	☐	☐	☐	☐
Excessive worrying about everyday matters	☐	☐	☐	☐	☐
Fear of something bad, or even the worst, happening	☐	☐	☐	☐	☐

Worry:

Please circle the numbers that best describe your experience in the *past month.*

	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been worrying a lot	0	1	2	3	4
2. In my mind I have been going over problems again and again	0	1	2	3	4
3. There was little I could do to stop worrying	0	1	2	3	4
4. I have been worrying even though I didn't want to.	0	1	2	3	4
5. Worry has stopped me focusing on important things in my day	0	1	2	3	4
6. Worry has stopped me sleeping	0	1	2	3	4

7. Worry has caused me to feel upset	0	1	2	3	4
8. Worry has made me feel stressed	0	1	2	3	4
9. Worry has made me feel anxious	0	1	2	3	4
10. Worry has made me feel hopeless	0	1	2	3	4

Beliefs about the self and others:

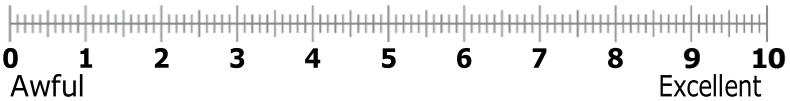
Please indicate whether you hold each of the following beliefs. Try to judge the beliefs on how you have generally, over time, viewed yourself and others. Do not spend too long on each belief. There are no right or wrong answers and the first response to each belief is often the most accurate.

	Please select Yes or No		***If you selected Yes, please also answer below***			
	No	Yes	*Believe it slightly*	*Believe it moderately*	*Believe it very much*	*Believe it totally*
I am unloved	○	○	○	○	○	○
I am worthless	○	○	○	○	○	○
I am weak	○	○	○	○	○	○
I am vulnerable	○	○	○	○	○	○
I am bad	○	○	○	○	○	○
I am a failure	○	○	○	○	○	○

	Please select Yes or No		*If you selected Yes, please also answer below*			
	No	Yes	*Believe it slightly*	*Believe it moderately*	*Believe it very much*	*Believe it totally*
Other people are hostile	○	○	○	○	○	○
Other people are harsh	○	○	○	○	○	○
Other people are unforgiving	○	○	○	○	○	○
Other people are bad	○	○	○	○	○	○
Other people are devious	○	○	○	○	○	○
Other people are nasty	○	○	○	○	○	○

Sleep:

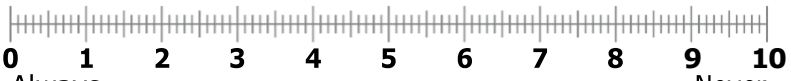
1. The overall quality of your night's sleep is:



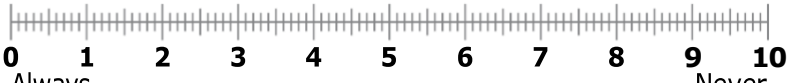
2. Do you have difficulty falling asleep each night?



3. Do you have difficulty staying asleep?



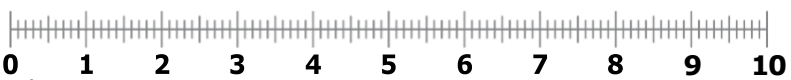
4. Does restlessness in your legs or arms at night or in the evening disrupt your sleep?



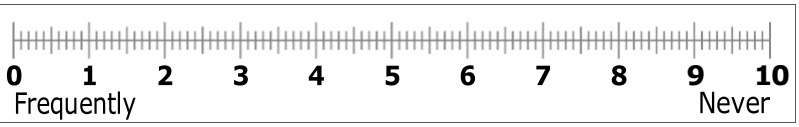
5. Do you fidget in bed?



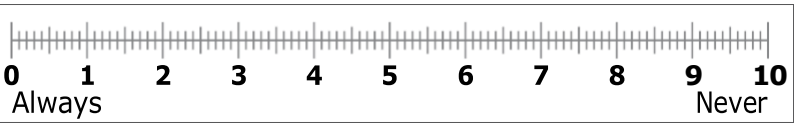
6. Do you suffer from distressing dreams at night?



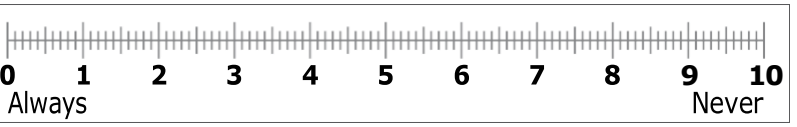
7. Have you unexpectedly fallen asleep during the day?



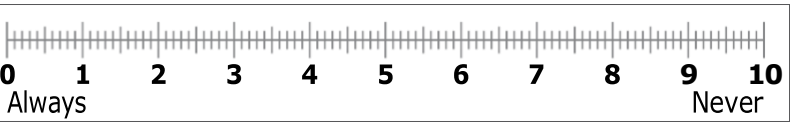
8. Do you get up at night to pass urine?



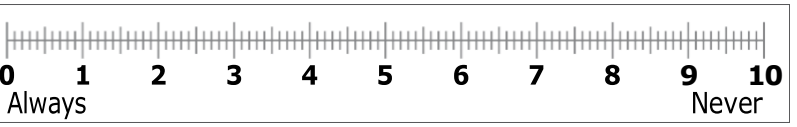
9. Do you have incontinence of urine because you are unable to move due to "off" symptoms?



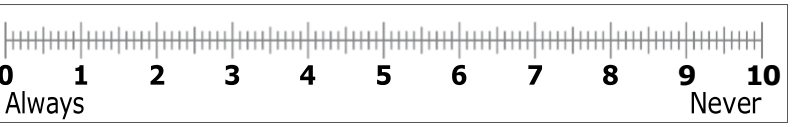
10. Do you experience numbness or tingling in your arms or legs, which wakes you from sleep at night?



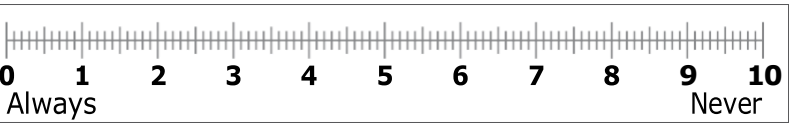
11. Do you have painful muscle cramps in your arms or legs which wake you from sleep at night?



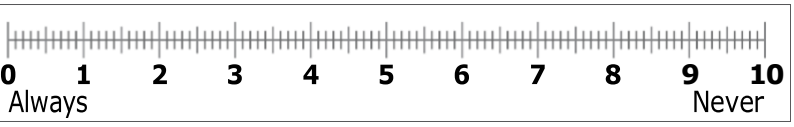
12. Do you wake early in the morning with painful posturing of your arms or legs?



13. On waking do you experience tremor?



14. Do you feel tired and sleepy after waking in the morning?



Loneliness:

The next questions are about how you feel about different aspects of your life. For each one, tell me how often you feel that way.

	Hardly ever	*Some of the time*	*Often*
How often do you feel that you lack companionship?	☐	☐	☐
How often do you feel left out?	☐	☐	☐

How often do you feel isolated from others?	☐	☐	☐

Stigma:

	Always	***Often***	***Sometimes***	***Rarely***	***Never***
Because of my illness, some people seemed uncomfortable with me	☐	☐	☐	☐	☐
Because of my illness, some people avoided me	☐	☐	☐	☐	☐
Because of my illness, I felt left out of things	☐	☐	☐	☐	☐
Because of my illness, people were unkind to me	☐	☐	☐	☐	☐
Because of my illness, people avoided looking at me	☐	☐	☐	☐	☐
I felt embarrassed about my illness	☐	☐	☐	☐	☐
I felt embarrassed because of my physical limitations	☐	☐	☐	☐	☐
Some people acted as though it was my fault I have this illness	☐	☐	☐	☐	☐

Thank you for your time completing the questionnaires!

Please return them in the freepost envelope.

Should you have any questions please contact the researcher using the information on this pack.

When the results of the study become available they will shown on the study's twitter page @PD_psychosis.

If you have been affected by any of the questions in this survey and would like to seek further support please contact your GP or for more urgent support see some options below.

SAMARITANS

Samaritans

Contact the Samaritans on: 116 123 or email jo@samaritans.org



NHS 111 – when it's less urgent than 999 But you need medical help quickly

Appendix L: Summary of feedback from PPI and how this was implemented

Feedback was provided during study design and on a drafted questionnaire pack.

Feedback	What was implemented
Long surveys can be overwhelming to complete	Trying to minimise the total number of questions, allowing completion over a 1-week period, and signposting to parts where respondents are encouraged to take a break
Motor difficulties can make completing questionnaires difficult	Encouraging participants to only complete the questionnaire during 'on' periods of medication where relevant
Questions from standardised measures often feel restrictive or like they don't fully capture what people would like to respond	Having free text boxes to allow qualitative comments where participants can expand on responses and explaining at the start of the questionnaire why we use standardised questionnaires (and what this means)
It's frustrating if you have to answer multiple questions that ask about the same thing	Only including one questionnaire per construct, even if there would be benefits to the analysis in having more than one
Questionnaires nearly always take longer than advertised	The advertised estimated time to complete was overestimated
Some people struggle with completing things online	Offering a postal option
Mixed views from the group about whether offering an option to go through the questionnaire battery with a researcher on zoom would be preferable	This was not offered as an option given the significant time burden it would be, and that the majority of the group said they would not opt for this option
QR codes would not be used by many people especially as requires a smartphone and then means you can't transfer to a laptop to complete it. Having a phone number would be helpful.	QR code not included on advertising materials, instead providing an email address, phone number, and website link
Certain types of question can feel difficult to respond to on the keyboard/mouse. - Sliders are okay, so long as you can use the keyboard to move it left and right, especially with the 'snap to grid option' - Matrix tables are clearer than side by side questions	Maximising the number of questions using these types of question, including snap to grid and checking the keyboard can be used to move the slider left and right
Framing the message positively e.g. we hope to be able to be able to develop better treatments is preferred and making it clear what the purpose of the study is	Advertising materials were framed positively, and the purpose made clear

Appendix M: Qualitative comments added by participants

Comments are direct, unedited quotes

Qualitative comments provided in response to Psych-Q hallucination items

Regarding types of visual experience:
Once I saw someone out the corner of my eye walk into the wall.
Once in the kitchen
Always think my sister here when she not few times in the werk
I say where is my sister and she has not even been In my house that day
I see shadows
Spoke as if to someone and on a couple of occasions it seemed like someone ghosted pastiest in the corner of my eye
Double vision
Horrific/ grim reaper
just a shadow at very edge of vision
It is usually on my left side I see shadows, ghosting.
May be a dog also or occasionally a large insect
Not some lurking but moving past
I sometimes see shadows from the corner of my eyes as if mice run across the floor
Animals, insects, people moving
I see a cat darting in my peripheral vision
Slight touch or change of air space.
At night I see shadow forming into flowers
I sometimes see shadows from the corner of my eyes as if mice run across the floor
Cat shapes in my peripheral vision
I can usually 'see' the object with clarity
I see Persian carpet patterns or carbon fibre sheets
i have 2 dark cats. Inanimate objects sometimes briefly resemble a cat, but not 'a fully formed vision'
plant is an animal
See cat faces in piles of laundry
my dog who past last year
Usually people or spiders
See black wiggly spider-like object that moves across my vision
See cats in my peripheral vision
grim reaper
Get that sometimes when housecquiet
I hear faint music - choral pieces or orchestral pieces - especially in the bathroom or in the car
I often hear my dog sniffling behind me when I turn to look nothing is there
on a couple of occasions I have turned because I thought I heard my name called
I think can hear a radio in another room or outside the house at night but I cannot find the source
Like spider crawling
Things passing me.

At random times I feel someone tap me or my dog scratching the back of my leg which is something he actually does too
I often feel like I've walked into a spiders web across my face and hair.

Regarding when visual experiences occur:
Often occurs when asleep but when I wake the person is still there
At random times
At random times especially if I'm stressed
usually tiredness in eyes
Mostly in the dark
When it happens, it happens in a dream, then I awake with the voice clear.

Regarding distress associated with visual experiences:
I've been seeing them before diagnosis so I'm used to it.
I quickly realised it was imaginary
Think I'm going crazy when that happens
I know it to be a symptom of PD
I know it's not there and that it can happen
I'm used to it. Thought I was going nuts when it first happened.
I am surprised when this occurs but not distressed.
I'm used to it.
I'm a spiritualist. I can tell the difference
I turned my head and immediately realised it was nothing
It makes me turn.
Not distressing, just irritating
This makes me anxious when I am driving at night
It's rather nice
Irritating

Regarding olfactory and gustatory experiences:
At random times. Usually very offensive smell of fart or death
Burning
It's a smell I can't describe, an acid/chemical
rarely I detect cidery/apples scent
had this for many years, can't rely on smell
i smell smoke when it isn't there and also experience loss of smell
Typically a strong smell of cat wee or cigarette smoke
Often smells bad lije rotten potatoes
I feel like there's a sweet scent surrounding me but it's not perfume or deodorant
Can't smell
cannot smell for over 15 years
have no sense of smell or taste
I can't even smell real odours
I do not have a sense of smell anymore
I have a very bad sense of smell
I have no sense of smell
I lost my sense of smell in an accident at work 14 years ago
Lost all sense of smell

Lost sense of smell
lost sense of smell 3 years ago
no sense of smell
Very little sense of smell
food being bland
Strong taste of sweets frequently and occasionally a taste of copper pennies

Regarding distress associated with olfactory and gustatory experiences
It's more irritating than distressing as I know it's not possible
Irritating when I can't find the answers.
More annoying
Only Smell, seeing someone walk into the wall was bizarre but I was aware what it was
As I think it's me that smells
I hate this happening.
Used to it

Qualitative comments reported after completing the PsychQ USE items, including those experienced outside of the past month
the grim reaper in front of me and feeling like it is real. 2 occasions some unnatural thing taking over me and controlling my body
A year or 2 ago I used to regularly see shadowy people in a half light. Now it's more occasional, But now I feel someone regularly cuddling in to my back in bed, but if I try to touch them there's nothing there but bedclothes.
About twice a year everything smells/tastes of candy floss
At night I get morbid visitors standing beside the bed. They started before commencing medication and were quite upsetting. They disappeared when I started on Sinamet and started to return earlier this year. An increase dosage strength has more or less removed them at this time.
become more aware of them in past few months
been going on longer than a month, don't usually remember severe occasions
Burning smell intermittent for 4 years
Daily for the last 6 months plus I always think I am holding something (knife fork cup for example) that's are not there
Earliest would be around three or four years ago...if tired, I would see glowing green writing on flat surfaces. Nothing I could read...it was like trying to focus on a floater in your eye.
Experienced over last 12 months usually when alone in the house
Experience night terrors and crystal clear nightmares convinced real on waking
Fleeting hallucinations two or three times a week for many months.
For a while now
For longer than had PD diagnosis
For nearly two years.
for some time I have occasionally been aware of a moving shadow at the edge of my vision that comes and goes very quickly
For the last 3-4 months
For years
Had more symptoms before diagnosis - medication seems to have reduced occurrences

I am bed ridden and see people and shadows in the room, mainly when I wake up. This has been going on for approx 6 months. I don't smell things as I lost my sense of smell approx 30 years ago following a stroke.
I am often awoken by voices which sound like a radio but on checking no radio is on in the house and there is no-one outside either.
I feel like some things smell and taste different to what they used to.
I first noticed when I was taking entapacone
I had numerous hallucinations, confusion and balance problems (falls) and fatigue when I was prescribed a high dose of Sinemet 8 then down to 6 x 25mg/250mg tablets per day and 1 x Half Sinemet 25/100mg modified-release tablets. This was changed when we moved area and has improved the symptoms.
I had one week of frequent symptoms but am now its much milder. Have always seen animals out of the corner of my eye
I had the odd frightening feelings along time ago
I have a loss of smell and i also smell smoke which isn't there
I have acted out several dreams and recently injured myself while sleep walking
I have had symptoms since being diagnosed. I think my medication affects what I 'see' especially when a dose has changed.
I have had these prior to my official diagnosis for several years
I have had to live with this for years and doctors can’t help.
I have heard music and singing for a couple of years
I have no sense of smell and sometimes find it hard to identify a familiar taste
I have no taste and continually smell burning which my consultant is aware of and stated this is a hallucination. I have had to make my family aware of as I could ignore a potential fire. This I find quite frightening as I burn food when cooking but not aware of the food burning. This means I no longer cook meals unless husband is present.
I often see people talking to me, this happens mostly when I am in bed.
I often see things in the corner of my eye especially in low light or at night. The loss of my sense of smell has been present since well before my diagnosis. Smelling smoke was present 12 months before my diagnosis. I have become very anxious when driving at night for many months. I get startled by head lights and feel my reactions are slowed
I once saw a horse in the bedroom about the time I was diagnosed
I put it down to the medication. Whe I am focused I am alert and pick up on sounds and movement like reflections. The main reason is I think there is someone outside my window. This is why I have answered a few times to most of the questions. I was getting violent vivid dreams. These have eased with Clonazepam. Now I know that I am more aware it is not an issue. The medication has stabilised my physical symptoms I am just a lot slower and need a stick to get around.
I seem to get a strong smell of Cigarette smoke & sometimes Petrol, occasionally I will mistake a tree or branch for a person or animal in the distance.
I sometimes see a shape and misinterpret it eg, I think a shape in foliage is a cat.. This has been the case for about 1 year.
I thought that a laundry basket was moving towards me
I used to see my children passing in front of me and actually they were in another place
I've had shadowing for a number of years and admit I thought we had ghosts In the house.
In the first few months after diagnosis, I did experience smell hallucinations! Usually bacon or wet dog.
Involving travel, sometimes aggression
It has been ongoing for a number of years but the experience is always only mild and only fleeting.

It runs at a pattern and gone on for several months now
July 2023 - thought wife had become another person (a male friend). Caused distress and agitation. I refused sedation. Became violent towards wife (very out of character). Went into hospital, diagnosed acute kidney infection. Since then have had continual hallucinations, including ones of wife. Stopped one medication (selegeline) as thought this may be causing the hallucinations and delusions. Prescribed quetiapine which did not help, nor rivastigmhine, and now on combo of both. This has lessened the hallucinations and delusions a little bit. Nurses now suggesting increasing quetiapine and reducing PD meds further
My smell hallucinations have been happening for about 10 years. Started as a smell of burning
Normally just a dark patch In my peripheral vision but I ignore them. I occasionally mistake objects but through reasoning know they are not real.
Not frequently but over the last 3-6 months I have had an occasional experience
occasionally
Occasionally I feel tickles on my arms or hands that makes me look to see if a fly or ant is crawling on me but there isn't. Once I look I realise there was no track or progression so it couldn't have been a creature.
Occasionally. >2 years
occasional odd smells which I can't explain and don't know whether they are real or not
occurs usually in bed imagining someone with you or under bedclothes
On occasion I have thought I saw something move in corner of vision but nothing there. I do have floaters in eye at times so have put it down to that
On rare occasion I may imagine I see something that may not actually be there. This is indeed quite rare though
Once when trying to sleep, felt disorientated.
One single occasion where I imagined a scorpion on my curtains in the dark. I bolted awake, switched the lights on- there was nothing
possibly experienced the apples scent about 6 months ago 3-4 times
Probably been experiencing some of these for years but not that often,
Probably for the last two years
Regularly see people who are not there. Two white Yetis jumping up and down in a neighbours garden etc
right feet sensory problem
Roughly once a month I may imagine I can smell food which in fact isn't there.
Same as in earlier answer but over several months now.
see/experience shadows of animals and have seen dead husband at the end of my bed
Seeing things that aren't there for a few years before diagnosis, thought we had ghosts In the house.
People touching or walking past me the same. Smells recent.
Since before my diagnosis
smell of smoke
smelling smoke that may not have been there
Smells
Hearing
Symptoms have been present since diagnosis (May 2018)
The cats for many years, first saw in my teenage years (my gran with Parkinson's also saw them) but more frequently from 2007 (diagnosed with hiv then). The smells and tastes began in 2020 after I lost my sense of smell.
The feeling of walking through a spiders web started about a year ago and has gotten worse in the last couple of months.

These sensory experiences have also occurred previously.
Too difficult to qualify but they were so real
unusual smells for last 8 years
Very occasionally, shadowy forms in bedroom when waking up in darkness; could just be the patterns of shades of darkness!
when almost asleep or sometimes during night experience doorbell phone ringing or people talking and clothing being moved
When I first lost my sense of smell about 15 years ago I used to smell phantom smells.
When Ropinerole was increased
When under stress or worn out
Woke wife saying there's a rat in the bedroom
Yes I have occasionally had nightmares
Yes whilst sleeping, have REM which manifests in different ways whilst sleeping

Qualitative comments provided in response to questions about the nature of USEs

Did you experience any of the symptoms you have reported above most commonly when you were about to fall asleep? - Yes - Text
A feeling that something else was close by
always nodding off
And during the night
Especially when nodding off in my armchair or taking a nap
falling asleep is a problem. the Mirtazapine helps with this problem.
Following a general anaesthesia in regard to a kidney stone removal
I see shapes like forming into flowers
I think so I sleep a lot
Restless feet
Seeing any bit on the floor as bugs that will bite and harm.
The green writing especially.
when drifting off or waking up
When very tired

Did you experience any of the symptoms you have reported above most commonly when you were about to fall asleep? - No - Text
1 when i woke up and 2 in the middle of the night, feeling very real
But very often in the evenings or when I wake at night
Could be at any time although most prevalent when asleep
It can happen at any time.
Noticed most often when tired and/or busy environment
Usually when I wake up.
When I wake up during the night, not when I go to sleep initially

When you had/have any of these experiences do you think they are real? - Yes – Text
At first I honestly thought there was people in the house or following me.
At the time.
Because it feels so real
But in a bewildered state in a noisy ward

but only briefly
Fleetingly, quickly realised they are not there.
For split second, ie double take
Had a conversation with my granddaughter but later realised she wasn't there
I think I've been bitten but there are no marks.
initially but then they disappear quickly
It's long night
Just for a moment before they disappear
occasionally
on very few occasions
Smell, yes. Vision, no.
Sometimes and I will go to check the kitchen.
Takes hrs to calm down I've Armed myself thinking I was under attack
They are real at the moment but as soon as I wake properly I know they are not real.
They feel so real
They look so real beautiful lighted up
they were all death related
thought someone was breaking in my car
Till I look at my arm or hand, yes.

When you had/have any of these experiences do you think they are real? - No – Text
After searching for voices or looking. Where the animals or man have gone
I am aware there is nothing there
I did initially but have got used to them
I react but immediately realise they are a figment of my imagination because I know I am alone
Known complication of PD
Logic says they can't be... But the "corner of the eye" stuff seems very real sometimes.
Not now as I am aware that I mistake things

Could you have been convinced that the experiences were not real? - Yes - Text
Because i trust my husband to be honest with me
My wife convinces me they are not real.
Only based on experience
Smell: my wife had to convince me before I would go out
Sometimes
Sometimes
they seem shadowy and quickly vanish
Yes when I am made alert and shown

Could you have been convinced that the experiences were not real? - No - Text
During the first 6 months or so.
I argued with the nurses
I saw them so they were there.
My experience was real, but the object was not
My wife takes photos to show me but I can't believe they are not real
No because at the time seemed so real
Not sure

Are there any times or situations when you are more likely to have these experiences? Tick all that apply - Other, please specify - Text

After eating when very tired
After I have been with family members eg weekend visits.
after waking in bed in the mornings
After/during periods of poor/disturbed/no sleep
At home with my wife. It doesn't happen at other people's home or when my carer is here. Only with my wife
at night when sleeping
bad light
Daytime nap in front of TV
Dozing
During or after large social gatherings.
Evening
evening sitting quietly
evening sitting quietly
First thing in morning as I wake up
I also occasionally see the ginger cat or undetermined movement during the day
I continually smell burning. I am used to this now as it has gone on almost since I was first diagnosed with PD. Being unable to taste things has not been for as long. When I eat I remember tastes from my past. I try to remind myself from my memory what they taste like.
I sometimes notice that my smell hallucinations are happening around the time my medication is due or just after I have taken it.
Night time when I am asleep, the noise wakes me
In low light
Just as I wake up and open my eyes
Late evening when I'm tired
Low ambient light
new situations
Normally when l sleep during the day and have just woken up
Only at night
Smell of cooked breakfast in the morning
sometimes waking up from daytime naps
Stimulating environment, when I'm tired
Stressed
These feelings, occurred when Ropinerole was increased
They happen any time of day and night
Usually in the early evening
Very tired or in a busy environment
When asleep or just woken up
When cycling or walking the dogs in the countryside
When doing jobs
When moving my head round
When my wife's not there and when I wake up following naps at any time of day or in the morning.
When tired
When waking from a nap rather than deep sleep

What typically brings the experience to an end? - Other, please specify - Text

As I live on my own I know there is nobody there. The violent dreams were frightening. Whenever something strange happens I discuss it with my Parkinson's nurse. Now things are under control. I think everything I experienced was the side effects of new drugs. Everything has now settled down.
Changing the situation e.g going outside
Happens very quickly and goes just as quickly.
I am only mistaken very briefly
I am only mistaken very briefly
I become aware that it is not real
I check on them to confirm they are not real
I concentrate, stare he thing out and it goes
I get out of bed and put the light on
I get out of bed expecting to find a radio has come on. Find nothing in any room in the house and realise that all is silent and I am fully awake
I ignore them they are too subtle to be a problem up to now
I look at problem as expected it's something else
I look at problem as expected it's something else
I rationalise that it is not real
I realise not real
I shout at them to go away
I think it is a matter of poor visual scanning of moving traffic or people.
I turn my head or glance and nothing is there.
I wake quickly
I wake up or am woken by my partner
If it is a visual flash or I think I see a person in the corner of my eye it makes me jump and when there isn't anyone there when I look I just tell my Parkinson's off for teasing me! If I hear a sound I look at my doc and if he hasn't reacted then I know I imagined it.
Is just disappears
It can go on for hours or a distraction may help.
It took about 24 hours to come round.
It's fleeting so it didn't bother me
Just keep my eyes closed so that I fall asleep
Logical objectivity. Some stuff is scary at first, but then when it disappears when examined closely, it loses its threat.
Looking at my arm or hands
Me looking at it to see what it is moving
My family try to touch the objects to prove they are not real
My wife talks it through with me to assure me all is ok
Never comes to an end it is continuous
Rare and easily ignored
Scared and sweating and unsure what has happened to me
Shake my arm
Talk myself down
The cats dart so they aren't there for lengths of time, the smells and tastes and last for hours though.
The experience is always only fleeting and ends as abruptly as it starts.
There's always someone in my peripheral vision so I turn my head in the opposite direction.
They are transitional
They disappear if I try to touch them, speak to them or switch the light on
they just fade

Waking startled at night I know immediately they are not real
waking up
Waking up fully
What typically brings the experience to an end? - Other, please specify – Text

How long does the unusual experience typically last? - The length is very variable. Please elaborate below. - Text
Can't remember
Corner of eye visuals last a few seconds but some soundsare fleeting but happen a lot close together
From dusk until dawn
If I think I see something in the corner of my eye, barely seconds. If I dream a rat is on my chest it's a bit longer
If in daylight minutes if sleep dream tim
once it was for a few hours, once it lasted over 24 hours
Smell smoke /burning randomly
Sometimes a few moments, but others much more persistent
Sometimes the smell continues for a few days
The cats in the vision dart quickly so they are moments, though I can see two or three. The smells and tastes can last from a few minutes to an hour or so.
Things being mistaken or just out of field of view only last until closely examined or focused on directly. The green writing can be more persistent, taking 10-30 secs to fade. Hearing is permanent, but may be Tinnitus
Voices - I can hear while conversations. Seeing items as someth8ng different - a few seconds

What support have you received? Tick all that apply and you may provide further detail in the text boxes if you wish.
Addition of Melatonin and Mirtazapine to my drugs, to interrupt the REM actions
Commenced on Melatonin 3mgs
Mirtazapine 15mg
Begun a new medication e.g. antipsychotic

What support have you received? Tick all that apply and you may provide further detail in the text boxes if you wish. - Other, please specify – Text
None
prescribed memantine 10mg tablets but this made me worse
Psychiatrist
Spoken to a Psychotherapist.
Stopped night sinimet but the had orobs getting out of bed next day
Support from doctor and Parkinson's nurse

What support would you like? Tick all that apply - Other, please specify – Text
Are aneasthetists aware of the effect of PD drugs?
Help for my wife to deal with them as she finds it incredibly hard
Links with sleep specialist especially night terrors
More time from my Parkinson’s nurse or my neurologist or my neurologist

Qualitative comments provided in response to Psych-Q paranoia items
breaking in house

I work in a toxic workplace- everyone wants my job
My shouting and swearing affected neighbours
Money and jewellery missing
i know it not real but it upsets me
I'm on probation, following 15 months in prison for a crime I didn't commit. My suspicion may have nothing to do with Parkinson's!
Happens when unknown people buzz my entry phone or ring doorbell at night on numerous times
i do not cope well around a lot of people, i would avoid at all costs it is to overwhelming
Usually when the cleaner is in
Not physically threatened but extremely uncomfortable in larger groups.
It is because of my poor eyesight
When money and items are missing
It's more about their language
Always on my guard
She did I got divorced
See previous comment...one officer said if it wasn't me, could it have been my partner...made me wonder.
I spoke with my siblings and we're preparing
Mainly in dreams that feel very real

Appendix N: Further details on statistical analysis

Exclusion of measure of coping

Six items from Abbreviated Coping Orientations to Problems Experienced Inventory (Brief COPE) (Carver, 1997) were included in the questionnaire battery with participants asked to complete the questions in regard to how they cope with their USEs or worries about others (paranoia). The original Brief COPE scale includes 28 items spanning three types of coping: problem focussed, emotion focussed, and avoidant coping. Each type includes multiple questions with near identical wording, so to reduce participant burden, near identical items were combined. Questions that could present a confound were also removed. For example, 'I've been saying to myself this isn't real' is considered an avoidant strategy in the scale yet could be considered a problem-focussed strategy in regard to USEs. Two items per coping style were retained. However, upon analysing the data and testing the internal consistency of the items, Cronbach's alpha was found to be below acceptable levels in nearly every case. Only the problem focussed items had an alpha of above 0.6, (a=0.62 in relation to paranoia and a=0.64 in relation to USEs) but given this is still below what is considered 'good' internal consistency (a>0.7) and using this scale alone would not allow comparison to how often other coping styles were used, the measure was deemed insufficiently reliable to warrant further analysis.

Comparison to age matched control data

The comparison dataset taken was a large cross-sectional non-probability survey of 10,382 UK adults, quota sampled to match the population for age, gender, ethnicity, income, and region (Freeman & Loe, 2023). The study was advertised as being about trust in others and included measures of paranoia (the R-GPTS) and cognitive and social processes. The comparison was planned post-hoc after viewing the mean R-GPTS scores in our dataset and seeing them to be lower than expected. We aimed to assess if the low scores were reflective of older adults in general, or specific to individuals with Parkinson's. A post-hoc power analysis showed that to achieve detection of even small effect sizes (Cohen's d=0.3) with 95% power in two tailed tests, a sample of 290 people per group would be required. Therefore, we had good power to detect effects. Our main aim was to allow comparison of the R-GPTS scores, but where relevant we then also made comparisons between other measures in order to better contextualise all results. For example, we were also able to compare scores on the Dunn Worry Questionnaire and Brief Core Schema Scale – Negative Self Subscale to that reported in the age-matched sample given the same measures were used. Further Bonferroni corrected t tests were additionally run between our data and scores on psychological measures reported for similar samples in prior literature to allow similar contextualisation for other measures not used in Freeman & Loe (2023).

CFA results

Predictor variables

Depression

The initial model fit was good but items 6, 10, and 13 had low factor loadings (<0.4). After examining the items, it was agreed that they were less theoretically aligned with the remaining items and could be removed. Item six concerns fear of something bad happening, which has more overlap with anxiety than low mood, item 10 is about memory, and item 13 is about energy (which may confound with PD symptoms). Removing these items retained a good model fit: $\chi 2(54, N = 369) = 155.04$, $p<0.0001$, RMSEA = 0.07; SRMR = 0.05; CFI = 0.92; TLI = 0.91). The composite reliability was 0.89.

Anxiety

An initial model fit was inadequate (RMSEA=0.166) and indicated that items 4 and 5 (excessive worrying and fear of something bad happening) had high modification indices. We therefore correlated the residuals of those items in the model, which then gave a good model fit: $\chi 2(4, N = 369) = 12.22$, $p<0.016$, RMSEA = 0.07; SRMR = 0.02; CFI = 0.99; TLI = 0.98). The composite reliability was 0.88.

Self-schema

A one factor CFA indicated good model fit: $\chi 2(9, N = 369) = 14.60$, $p=0.102$, RMSEA = 0.04; SRMR = 0.04; CFI = 0.97; TLI = 0.95). The composite reliability was 0.73.

Other-schema

A one factor CFA indicated good model fit: $\chi 2(9, N = 369) = 32.23$, $p<0.0001$, RMSEA = 0.08; SRMR = 0.05; CFI = 0.91; TLI = 0.90). The composite reliability was 0.96.

Worry

An initial model fit was inadequate (RMSEA=0.1) and indicated that items 8 and 9 (worry has made me feel stressed, and worry has made me feel anxious) had high modification indices. We therefore correlated the residuals of those items in the model, which then gave a good model fit: $\chi 2(34, N = 369) = 104.79$, $p<0.0001$, RMSEA = 0.08; SRMR = 0.02; CFI = 0.96; TLI = 0.97). The composite reliability was 0.96.

Loneliness

Given this item had only three items, the model fit was redundant, as all fit indices were set to zero or 1.0. However, factor loadings were high, and the composite reliability was 0.86.

Sleep

In the initial validation of the sleep measure, the scale is described as multifactorial. However, a large enough sample was not collected in their study to run an exploratory factor analysis (EFA) in order to identify the number of factors. It was clear from the factor loadings in our data that the model was likely to have a better fit with more than one factor. However, we too did not have a large enough sample to run EFA. Therefore, the items with the lowest loadings and that from examination appeared to assess constructs not directly associated with difficulty sleeping at night, were removed. These were items, 8 (getting up in the night to pass urine), 9 (incontinence of urine due to PD symptoms), 13 (experiencing tremor upon waking), and 15 (unexpectedly falling asleep during the day). The model also suggested that a number of items had high modification indices and therefore we correlated their residuals. These were: items 10, 11, and 12 (which all ask about painful muscle and motor symptoms specific to PD disrupting sleep), and items 4 and 5 (which both ask about restlessness/fidgeting in bed). By doing so, good model fit was achieved: $\chi 2(31, N = 369) = 93.28$, $p<0.000$, RMSEA = 0.07; SRMR = 0.06; CFI = 0.94; TLI = 0.91). The composite reliability was 0.75.

Stigma

The initial model fit was inadequate (RMSEA=0.2). All factor loadings were high but further analysis revealed several high modification indices meaning residuals needed to be correlated in order to achieve a good model fit. These were: items 6 and 7 (which both ask about embarrassment), items 4 and 8 (which both ask about unkindness of others), and items 1 and 2 (which both ask about other people avoiding me or being uncomfortable around me). Doing so led to a better model fit (RMSEA=0.09), but to improve it further the residuals of items 3 (feeling left out) and 5 (people avoided looking at me) were also correlated. This led to a good model fit: $\chi 2(16, N = 369) = 46.51$, $p<0.0001$, RMSEA = 0.07; SRMR = 0.03; CFI = 0.98; TLI = 0.96). The composite reliability was 0.81.

Response variables

Paranoia

Although the R-GPTS is a more established and well validated measure of paranoia, due to the low average score the skew of the data towards zero was significant. Moreover, a CFA demonstrated that the five-item measure was a significant predictor of PD severity where-as the R-GPTS-A and B were not, suggesting the predictive validity of the PsycH-Q measure was higher. The internal reliability of the five-item measure was also high (Cronbach's alpha=0.9), and the correlation with R-GPTS-A was 0.66 and GPTS-B 0.71, suggesting good construct validity (values above 0.7 are considered outstanding, and values 0.5-0.7 acceptable (Mukherjee et al., 2022). The 5-item modified PsychQ-H was therefore used as the paranoia response variable for the SEMs. In the original validation paper, although a sum score is also reported, the frequency and severity subscales were validated separately,

(Cronbach's alpha was 0.900 for frequency and 0.908 for severity), therefore we used only the frequency scores.

A CFA of the five items initially demonstrated an inadequate model fit (RMSEA=0.1, TLI=0.83) and revealed that items 4 and 5 (thoughts about of spousal betrayal and abandonment by loved ones) had high modification indices. We therefore correlated these residuals which led to good model fit: Robust $\chi 2$ (5, N=369) =5.86, p<0.0001, RMSEA=0.4; SRMR=0.01; CFI=0.99; TLI=0.98 . The composite reliability was 0.86.

USEs

For USEs, there was only one measure that could be used (items 1-10 of the PsycH-Q). A CFA demonstrated items 9 and 10 (gustatory and olfactory hallucinations) had low factor loadings with the overall USE items. Removing these items retained a good model fit (Robust $\chi 2$ (35, N=369) =79.26, p<0.000, RMSEA=0.4; SRMR=0.01; CFI=0.99; TLI=0.98, therefore we continued with using only items 1-8 as the response variable. The SEM results therefore apply only to visual, auditory, and tactile USEs.

Unified SEM results

Through the backward elimination procedure with paranoia as the response variable and controlling for severity of PD symptoms, review of the beta estimates suggested that several explanatory factors (worry, self-schema, and loneliness) may act as suppressors and were thus removed from the structural model. Two further variables were reduced (depression, stigma), resulting in two remaining significant predictors in the model: anxiety and negative beliefs about others. The final SEM model indicated a good fit to the data (Robust $\chi 2$ (112, N=369) =198.69, p<0.0001, RMSEA=0.05; SRMR=0.07; CFI=0.96; TLI=0.94) and the variance explained by the structural model was 44.8%.

Through the backward elimination procedure with USE as the response variable and controlling for age severity of PD symptoms, review of the beta estimates suggested that several explanatory factors (worry, self-schema, and loneliness) may again be acting as suppressors and were thus removed from the structural model. Three further variables were reduced (negative beliefs about others, stigma, and sleep), resulting in two remaining in the model: anxiety and negative beliefs about others. The final SEM model indicated a good fit to the data (Robust $\chi 2$ (319, N=369)=648.47, p<0.0001, RMSEA=0.05; SRMR=0.08; CFI=0.92; TLI=0.91) and the variance explained by the structural model was 26.3%.

References

Carver, C. S. (1997). You want to measure coping but your protocol'too long: Consider the brief cope. *International Journal of Behavioral Medicine*, *4*(1), 92–100.

Freeman, D., & Loe, B. S. (2023). Explaining paranoia: cognitive and social processes in the

occurrence of extreme mistrust. *BMJ Mental Health*, *26*(1), 1–8. https://doi.org/10.1136/bmjment-2023-300880

Mukherjee, S., Chittipaka, V., Baral, M. M., Pal, S. K., & Rana, S. (2022). Chapter 2 - Impact of artificial intelligence in the healthcare sector. In A. E. Hassanien, J. M. Chatterjee, & V. B. T.-A. I. and I. 4. . Jain (Eds.), *Intelligent Data-Centric Systems* (pp. 23–54). Academic Press. https://doi.org/https://doi.org/10.1016/B978-0-323-88468-6.00001-2

Appendix O: Journal of Parkinson's disease: guide for authors

Research Reports

Organization and style of presentation

Manuscripts must be written in US English. Authors whose native language is not English are recommended to seek the advice of a native English speaker or English language service before submitting their manuscripts. Word count: There are no specific limits, but the Editors-in-Chief ask that all articles are as concise and succinct as possible. As a broad guideline, research articles are usually between 2000-4000 words. Manuscripts should be double spaced throughout with wide margins (2.5cm or 1in), including the abstract and references.
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 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.

Acknowledgments

Include individuals or companies which have assisted with your study, including advisors, administrative support and suppliers who may have donated or given materials used in the study. If there are no acknowledgments, then do still include this section and insert: "The authors have no acknowledgments to report."

Funding

Include all funding sources for the study. If there is no funding involved, then do still include this section and insert: "The authors have no funding to report."

Conflict of Interest

All affiliations or financial involvement (e.g., employment, consultancies, honoraria, stock ownership or options, expert testimony, grants, patents received or pending, royalties) with any organization or entity with a financial interest in, or in financial competition with, the subject matter or materials

discussed in the manuscript must be completely disclosed in the submitted manuscript.
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".

Datasets/Data Availability Statement (Required for Research Reports, Short Communications, and Systematic Reviews/Meta-Analyses)
All datasets and data articles cited in your manuscript should be included in the reference list of your article (not in a separate box or in the article text). Data references should include: author name(s), dataset title, data repository, version (where available), year, and identifier (DOI/URL/etc.).
Authors should include a Data Availability statement at the end of the manuscript (before the References) to describe the availability or the absence of shared data. Authors are required to deposit sequence or proteomic data into a public repository (eg. GEO, Chorus) and include a link to the repository and data, and encouraged to publicly archive their research data including, but not limited to: software, algorithms, protocols, methods, and/or materials. Exceptions are made if sharing data compromises ethical standards or legal requirements.

References

- Click here to download the EndNote reference style file for JPD articles. A .csl file (for our sister journal with an identical reference style) is available here.
- Place citations as numbers in square brackets in the text. All publications cited in the text should be presented in a list of references following the text of the manuscript. Only articles published or accepted for publication should be listed in the reference list. Submitted articles can be listed in the text as (Author(s), unpublished data).
- All authors should be listed in the reference list.
- References should be listed in the order of appearance in the following style:

[1] Alzheimer Research Forum, Drugs in Clinical Trials: AAB-001, http://www.alzforum.org/drg/drc/detail.asp?id=101, Last updated May 29, 2007, Accessed on January 29, 2008.
[2] Zetterberg H, Blennow K (2018) From cerebrospinal fluid to blood: the third wave of fluid biomarkers for Alzheimer's disease. In *Alzheimer's Disease: New Beginnings*, Perry G, Avila J, Moreira PI, Sorensen AA, Tabaton M, eds. IOS Press, Amsterdam, pp. 269-277.
[3] Owen CL, Ibrahim K, Dennison L, Roberts, HC (2019) Falls self-management interventions for people with Parkinson's disease: a systematic review. *J Parkinsons Dis* **9**, 283-299.
[4] Langston JW, Palfreman J (2014) *The Case of the Frozen Addicts*. IOS Press, Amsterdam.
[5] Palfreman J (2017) Toward Personalized Medicine for Those with Parkinson's, *Jon Palfreman's Blog*, https://www.journalofparkinsonsdisease.com/blog/palfreman/toward-personalized-medicine-those-parkinson's, Posted May 1, 2017, Accessed January 29, 2018.

Tables
Number according to their sequence in the text. The text should include references to all tables. Provide each table on a separate page of the manuscript after the references.
Include a brief and self-explanatory title with any explanations essential to the understanding of the table given in footnotes at the bottom of the table. Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.

Figures
Number the figures according to their sequence in the text. The text should include references to all

figures.
For the file formats of the figures please take the following into account:

- Line art should have a minimum resolution of 1200 dpi, save as EPS or TIFF.
  - Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
  - All lines should be at least 0.1 mm (0.3 pt) wide.
- Grayscales (incl photos) should have a minimum resolution of 300 dpi, or 600 dpi for combination art (lettering and images); save as TIFF.
- Do not save figures as JPEG, this format may lose information in the process
- Do not use figures taken from the Internet, the resolution will be too low for printing
- Do not use color in your figures if they are to be printed in black & white, as this will reduce the print quality (note that in software often the default is color, you should change the settings)

Figures should be designed with the format of JPD in mind and preferable sized as they will appear when printed. A single column of the journal is 77mm and two columns are 165mm. Figures should be cropped to include the figure only (no blank space). On figures where a scale is needed, use bar scales to avoid problems if the figure needs to be reduced. Each illustration should have a brief self-explanatory legend that should be typed separately from the figure in the section of the manuscript following the tables.

Supplementary Data

Supplementary data can be submitted with the manuscript, included within the manuscript after the Figures and Tables (or otherwise after the References). Each supplementary item should have a legend and should not exceed the file size of 10MB. Supplemental videos can be submitted separately (see top of page for submission guidelines of videos). A short description of the supplementary items should be included under the header of “Supplementary Material” within the manuscript before the “References”. Large datasets should be hosted on the author’s own or institute’s website or in an appropriate database and should be properly cited within the manuscript.