

Doctoral Thesis

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Abstracts

Systematic Review of the Literature

What psychological interventions are effective for individuals with prolonged post-concussion symptoms of at least 12 months following mild traumatic brain injury? A Systematic Review

Background: For some, post-concussion symptoms following a mild traumatic brain injury are prolonged in nature, lasting for a minimum of 12 months, and up to many years. There remains limited insight into the effectiveness of psychological interventions for the treatment of prolonged post-concussion symptoms (PPCS) following mild traumatic brain injury (mTBI) of 12 months or longer.

Aim: To conduct a systematic review of the literature to evaluate the effectiveness of psychological interventions for PPCS (>12 months post mTBI).

Method: A systematic search was performed across five peer-reviewed databases (PsychINFO, Medline, Web of Science, *Cumulative Index to Nursing and Allied Health Literature* (CINAHL), & PubMed). Two independent researchers assessed the studies against pre-defined eligibility criteria and the studies were quality appraised. Eleven studies were included in the final selection of papers in this review and underwent narrative synthesis.

Results: A narrative synthesis across the eleven papers identified four psychological intervention approaches for PPCS. 1. Cognitive Behavioural Therapy (CBT). 2. Neurofeedback Therapy. 3. Psychoeducation. 4. Mindfulness-based therapy. The results suggest that psychological interventions may be effective in reducing certain PPCS.

Conclusions: Psychological interventions appear effective in reducing various PPCS and improving overall quality of life (QoL). CBT appears to have the strongest evidence base and to be the most effective in improving anxiety, anger and overall mental well-being. Further

research with more robust methodological designs is required to further explore the effectiveness of psychological interventions for individuals with PPCS following a mTBI.

Keywords*: Mild Traumatic Brain Injury, Post Concussion, Psychological Intervention, Cognitive Behaviour Therapy, Head Injury*

Service Improvement Project

Investigating and understanding how multiple re-referrals can be reduced and support improved for service users with multiple referrals into Berkshire Talking Therapies

Background: Talking Therapies (TT), previously called Improving Access to Psychological Therapies (IAPT), support individuals with mental health difficulties in England. Research suggests that greater clinical complexity increases the likelihood of re-referring to TT, which results in poorer clinical outcomes. Berkshire Talking Therapies (BTT) raised concerns about service users (SUs) with multiple referrals; they wanted to understand the factors surrounding re-referral rates.

Method: A mixed-methods design was used. A binomial logistic regression explored 'clinical characteristics' and demographics variables on the likelihood of being a 'high' or 'low' referrer to BTT. Secondly, interviews with previous SUs with multiple referrals to BTT were conducted, and thematic analysis used to analyse the findings.

Results: The logistic regression model suggested several variables increased the likelihood of being a 'high referrer' to BTT (i.e., individuals of 'other' religious groups, being single, having a long-term condition, high scores on the PHQ-9, and being discharged due to having 'dropped out of treatment'). Thematic analysis identified four key themes, 1. Support and connectedness, 2. Managing mental health dips, 3. Expectations not met and 4. Barriers to engagement.

Conclusions: This study identified factors which significantly increased the likelihood of re-referring to BTT and explored SUs perspectives on why they re-referred on multiple occasions. Recommendations to BTT included additional staff training, utilising the Practical Support Service and liaison with the Long-Term Conditions Pathway.

Keywords*: Talking Therapies, Re-referrals, IAPT, Service User Experience*

Theory Driven Research Project

Exploring the Prevalence and Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease

Background: Chronic Obstructive Pulmonary Disease (COPD) is a debilitating lifelong condition affecting the respiratory system. COPD is a major cause of mortality worldwide, with an ever-increasing prevalence across the population (Devine, 2008). Previous studies indicate that people with COPD experience high rates of anxiety, including health anxiety (HA). Studies of other chronic physical health conditions found that high HA leads to greater negative misperceptions of physical functioning and impacts quality of life, mental health, and self-rated disability (Carrigan et al., 2018; Daniels et al., 2017; Diamond et al., 2022; Hayter et al., 2016).

Method: Participants were recruited from a community-based NHS population. Forty-two participants with COPD were screened for HA and assigned to either a high or a low-health anxiety group. Participants completed a physical functioning task, alongside measures for perception of physical performance, mood, quality of life and disability. Comparisons were made with a healthy control (HC) group.

Results: COPD participants with high HA misperceived themselves as performing poorer on a physical functioning task. Participants with high HA and COPD reported a greater self-reported disability compared to the HC group.

Conclusion: HA is highly prevalent within those diagnosed with COPD, which can impact on perceptions of physical performance and self-reported disability. Given this, further research is needed to explore the effectiveness of psychological interventions to reduce HA in individuals with COPD.

Keywords*: chronic obstructive pulmonary disease, health anxiety, quality of life, mental health*

Systematic Review of the Literature

What psychological interventions are effective for individuals with prolonged post-concussion symptoms of at least 12 months following mild traumatic brain injury? A Systematic Review

Word count: 6,975 (Excluding references and appendices, tables & figures as 100 words or less)

Submission Date: May 2024 (Re-submitted for corrections August 2024).

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Proposed Journal: Brain Injury; a peer reviewed journal which focuses on research related to acquired brain injury and related interventions.

Abstract

Background: For some, post-concussion symptoms following a mild traumatic brain injury are prolonged in nature, lasting for a minimum of 12 months, and up to many years. There remains limited insight into the effectiveness of psychological interventions for the treatment of prolonged post-concussion symptoms (PPCS) following mild traumatic brain injury (mTBI) of 12 months or longer.

Aim: To conduct a systematic review of the literature to evaluate the effectiveness of psychological interventions for PPCS (>12 months post mTBI).

Method: A systematic search was performed across five peer-reviewed databases (PsychINFO, Medline, Web of Science, *Cumulative Index to Nursing and Allied Health Literature* (CINAHL), & PubMed). Two independent researchers assessed the studies against pre-defined eligibility criteria and the studies were quality appraised. Eleven studies were included in the final selection of papers in this review and underwent narrative synthesis.

Results: A narrative synthesis across the eleven papers identified four psychological intervention approaches for PPCS. 1. Cognitive Behavioural Therapy (CBT). 2. Neurofeedback Therapy. 3. Psychoeducation. 4. Mindfulness-based therapy. The results suggest that psychological interventions may be effective in reducing certain PPCS.

Conclusions: Psychological interventions appear effective in reducing various PPCS and improving overall quality of life (QoL). CBT appears to have the strongest evidence base and to be the most effective in improving anxiety, anger and overall mental well-being. Further research with more robust methodological designs is required to further explore the effectiveness of psychological interventions for individuals with PPCS following a mTBI.

Introduction

Mild traumatic brain injury (mTBI) occurs following an external impact force to the head which results in acute changes in brain functioning (Katz et al., 2015). Immediate symptoms may include a loss of consciousness for thirty minutes or less, post-traumatic amnesia for twenty-four hours or less, confusion, disorientation and transient neurological deficits such as epilepsy (Carroll et al., 2004). The Glasgow Coma Scale is a brief measure designed to assess the level of consciousness in a patient with an acute brain injury; a score of 13 to 15 indicating a mTBI, compared to 8 or lower for severe brain injury and a score between 9 to 12 for moderate brain injury; this is assessed no longer than 30 minutes post-injury (Teasdale & Jennett, 1976). mTBI is highly prevalent, occurring in 700 in every 100,000 hospital cases each year, often as a result of road traffic accidents (RTA), sports-related injuries, falls or assault (Lefevre-Dognin et al., 2021).

Following a mTBI adults may experience an acute phase of post-concussion symptoms (PCS) within the first three months post-injury. PCS can include self-reported dizziness, headaches, fatigue, neck pain, difficulty with sleeping, confusion, and memory/concentration problems (Carroll et al., 2004). Typically the majority of adults recover from this acute phase, however, approximately 15 to 30% may develop more persisting PCS which may continue for weeks, months or even years (Hou et al., 2012). These can include the acute symptoms of mTBI alongside additional symptoms such as irritability, anxiety, and depression (Emanuelson et al., 2003; Williams et al., 2010). Persistent PCS is defined as long-lasting PCS of at least three months or greater (Polinder et al., 2018) and prolonged post-concussion symptoms (PPCS) have been defined as those lasting beyond 12 months (King & Kirwilliam, 2013).

Development of PCS

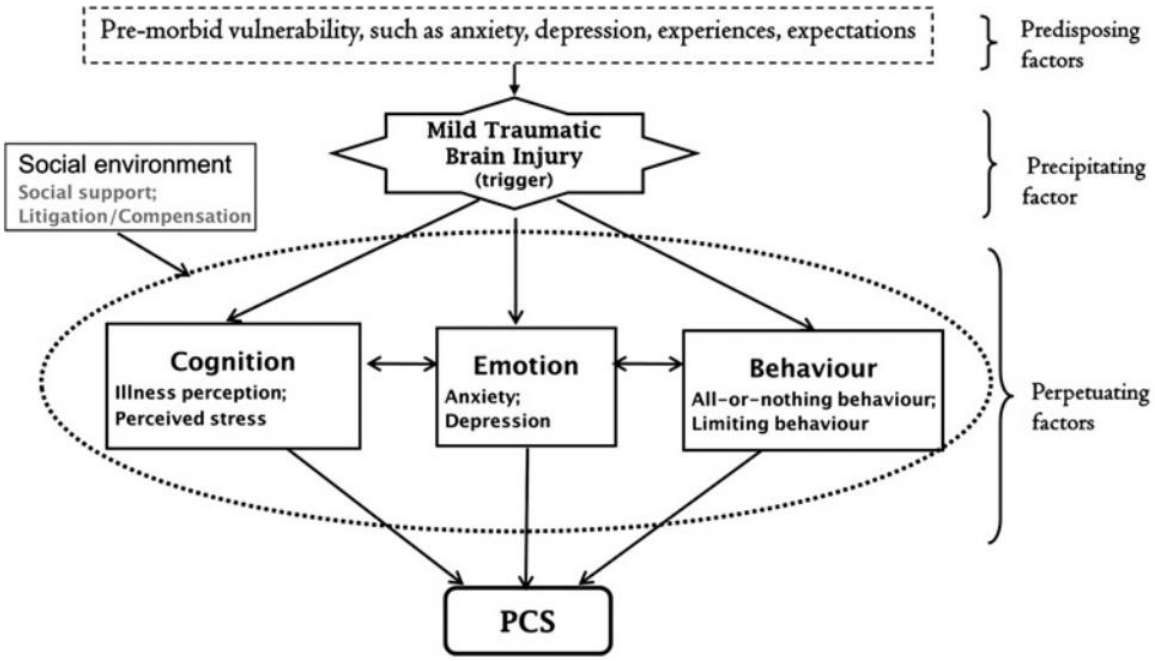
The exact cause of PCS is heavily debated within the literature; however, some research suggests an interplay between biological, psychological and social factors which maintain

symptoms long term (Hou et al., 2012). Hou et al. (2012) developed a cognitive behavioural model to explain the development and maintenance of PCS following a mTBI (see Figure 1). The model suggests that predisposing risk factors (e.g., pre-morbid anxiety and a history of somatic complaints) may result in persisting or even prolonged PCS following a head injury. Furthermore, the cognitive behavioural model suggests that cognitive, behavioural and emotional factors all contribute to perpetuating and maintaining PCS following the mTBI.

In addition to this, psycho-social factors external to the individual have been identified as contributing to the possible maintenance and persistency of PCS. Factors include ongoing litigation cases, long-term sick leave, and functional outcomes along with overlapping symptoms of Post-Traumatic Stress Disorder (PTSD), insomnia, anxiety, depression and cognitive impairments (e.g., concentration & attention) (Polinder et al., 2018). Furthermore, King (2003) identified that a lack of understanding of mTBI, difficulty in adjustment to a long-term disability and unhelpful secondary coping strategies are factors which are likely to contribute to persisting and prolonged PCS.

Figure 1.

Cognitive Behavioural Model of the Development and Maintenance of PCS (Hou et al., 2012).



Interventions for PCS following mTBI

Due to the heterogeneity of symptoms associated with PCS, there remains a lack of clear guidance for the treatment of PCS following a mTBI. Part of this challenge is the change in underlying causes which contribute to and maintain PCS over time. Initially, the mTBI would contribute to acute PCS, however, more persisting or prolonged symptoms can be exacerbated, perpetuated and/or maintained by factors such as stress, pain, PTSD, anxiety, depression, insomnia and so on.

Within the acute phase following a mTBI, recommended interventions include psycho-education, support and optimistic reassurance on the expected symptoms and recovery period (Marshall et al., 2015; Prince & Bruhns, 2017). Individuals are supported to return to usual activities and physical exercise over the twelve weeks post-mTBI. The guidance recommends

a psycho-social evaluation (i.e., support system, mental health history, the injury impact on employment status, substance misuse and co-occurring physical health conditions) due to the increased risk of developing persisting or prolonged PCS (Ontario Neurotrauma Foundation, 2018).

If PCS symptoms do not improve within the acute period, or the individual presents with complex physical and contextual factors, a referral for multidisciplinary treatment within a specialist brain injury service is advised with the aim to prevent the development of persisting or prolonged PCS. Treatment for persisting PCS may involve psycho-education, counselling, telephone support, graded return to physical activity, pharmacological treatment (e.g., pain management, sleep difficulties and symptoms of anxiety, depression or PTSD), cognitive rehabilitation and psychological intervention (Heslot et al., 2022).

Given existing knowledge and understanding of the relationship between stress, cognitive, behavioural and emotional factors on the development and maintenance of PCS following a mTBI, it is understandable that Cognitive Behaviour Therapy (CBT) has been recommended. CBT aims to improve the patients understanding of their mTBI and management of anger, anxiety, depression and Post Traumatic Stress Disorder symptoms as a consequence of the mTBI (Gómez-de-Regil et al., 2019). CBT has been highlighted as being effective in reducing symptoms of persisting PCS (Heslot et al., 2022; Prince & Bruhns, 2017) and improving symptoms of depression and anxiety and increasing social integration (Chen et al., 2020). However, Chen et al. (2020) found that CBT did not improve severe PCS, fatigue or cognitive difficulties such as problem-solving or executive functioning. This may suggest that CBT is more effective at managing the maintaining factors associated with PCS, or the mood symptoms which develop after a mTBI.

Clinical Implications

Previous meta-analyses and systematic reviews suggest that psychological interventions, in particular CBT, have shown promising results for people with PCS (Al Sayegh et al., 2010; Rytter et al., 2021; Sullivan et al., 2020; Teo et al., 2020). However, many of these reviews were conducted some time ago, only include randomised controlled trials (RCT) or have excluded PPCS of twelve months or longer post-injury. A majority of studies have focussed on interventions addressing acute or persisting PCS of less than twelve months, thus insight into the effectiveness of interventions for PPCS is lacking.

Individuals with PPCS are known clinically to be the most impaired group of patients in comparison to those with acute or persisting symptoms. This is due to PPCS having a significant impact on QoL in the long term (Emanuelson et al., 2003) and impacting physical health, mental health, social activities and energy levels. Furthermore, fatigue, depression, impaired concentration and irritability are likely to impact employment status and social relationships in the long term (Chen et al., 2020). Thus, it is essential that sufficient, valid and effective psychological interventions are offered to treat and manage PPCS following mTBI to improve QoL.

Purpose and aims of the present review

To the author's knowledge, there is no current systematic review of the effectiveness of psychological interventions on PPCS. Understanding which, if any, psychological interventions are effective in reducing and managing such symptoms shall be beneficial for services supporting individuals with PPCS. This systematic review aimed to identify which, if any, psychological interventions have been implemented to address PPCS of at least twelve months or longer following a mTBI, and how effective these were in reducing PPCS.

The papers which met the criteria were systematically identified and critically appraised using a narrative synthesis approach. The key findings from the narrative synthesis are presented, with a consideration of the clinical implications and possible next steps for clinical intervention for PPCS after mTBI.

Methods

Search Strategy

A review protocol was registered in PROSPERO (registration number: CRD42023338502). The study selection process followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021). On the 12th of October 2022, the first author conducted a systematic search of published studies across the following five databases: PsychINFO, MEDLINE, Web of Science, CINAHL and PubMed. A second search, using the same key terms and eligibility criteria, was ran by the first author on the 19th of April 2024 to check for any literature published since the initial search. An additional 351 papers had been published since the first search, however none of these studies met the inclusion criteria and thus were not included in this review. Key terms for the search included "mild head injury", "post concuss* symptom*" and "psychological treatment"; refer to Appendix 1A for full key terms used.

In addition to the key terms search for each database, a thesaurus search was used with the key terms. Additional terms identified by the thesaurus search included 'Brain Concussion', 'Traumatic Brain Injury', 'Psychotherapy', and 'Cognitive Behavior Therapy'. No filters were applied to the date range or language with the criteria that non-English papers must have a translated version available. Studies were filtered for peer-reviewed journals. Additional searches for relevant articles were conducted through Google Scholar, reviewing the reference lists of other relevant systematic reviews and through discussion with an expert in the field.

Inclusion Criteria

I. Adults aged 18 years and over. In several studies, a range of adolescents and adults may have been included in the participant sample. In these instances, the studies were required to explicitly state a mean of the participant's age, and this needed to be a minimum of 18 years old to be included in this review;

II. Standardised outcome measures having been used in the study which assessed for PCS or secondary symptoms associated with PPCS. Including PCS-specific measures such as the Rivermead Post-Concussion Symptoms questionnaire which assesses physical symptoms of PCS (i.e., headache, fatigue, sleep), cognitive (i.e., concentration, processing speed) and mental health (i.e., depression, irritability) (Eyres et al., 2005). Additionally, outcome measures which assessed symptoms associated with PCS were included, such as measures assessing specifically for depression, headaches, pain, anxiety, self-reported disability and quality of life;

III. Paper written in English or if non-English a translated version would be sought and included;

IV. Quantitative methodological approach was used;

V. A diagnosis of mTBI using standardised clinical measures, for example, the use of the Glasgow Coma Scale. Where both mild and severe head injuries were included more than 50% must have been in the mild category;

VI. Experiencing prolonged PCS for at least 12 months post the mTBI. In the instances where studies included participants with a wide range of duration post-injury, the study must have reported the mean time post-injury and this mean must be a minimum of twelve months post-injury;

VII. Human participants only;

VIII. A psychological intervention was delivered to address the PPCS symptoms after a mTBI.

Exclusion Criteria

I. Co-morbidity of other head injuries or an existing neurodegenerative disorder diagnosis;
II. Significant or severe co-morbid mental health or physical health diagnoses (e.g., PTSD, Psychosis, Schizophrenia, Bipolar)
III. Papers which have not been published in a peer-reviewed journal;
IV. Qualitative methodological approach only;
V. The study did not report on novel findings, for example, the study was a review, meta-analysis, or proposal.

Study Selection

A PRISMA (Moher et al., 2009) flowchart was utilised to outline the systematic review process. Firstly, any duplicates of studies were identified and removed. Next, the studies underwent title and abstract screening against the inclusion and exclusion criteria outlined above. At this stage, two independent reviewers screened 20% of the papers. Using Cohen's Kappa Statistic to determine the scoring agreement, substantial inter-rater reliability was attained (k = 0.8) with an agreement of 95%. The lead author screened the remaining studies. Next, the two independent reviewers screened 25% of the full texts against the eligibility criteria. Agreement between the two reviewers was a perfect 100%, (k =1.0*).* The lead author independently screened the remaining full texts.

Data Extraction

The data from the studies were systematically extracted by two independent reviewers using a Microsoft Excel Spreadsheet. Key elements of the studies extracted included the

authors, year of publication, country, study design, participant demographics, sample size, the independent and dependent variables, outcome measures, diagnosis tool for mTBI, cause of mTBI, duration of PPCS following mTBI and findings. Two independent reviewers extracted 30% of the key findings (k =1.0), and the first author extracted the remaining information from the studies.

Risk of Bias Assessment

The studies included in this review were systematically evaluated and analysed for risk of bias using The Standard Quality Assessment Criteria for Evaluating Primary Research (SQAC-EPR) (Kmet 2004). Two independent raters used the SQAC-EPR risk of bias tool to assess the quality of the studies; 92% agreement between independent reviewers was reached. Discrepancies between the reviewers were addressed through discussion to improve agreement (see Appendix 1B for the quality ratings on the SQAC-EPR).

Each study was analysed across fourteen questions and rated on a 3-point scale; a score of 2 (yes meets the criterion), 1 (partially meets criterion), 0 (does not meet the criterion) or non-applicable if not relevant for that study. If a study met all of the criteria, the highest possible score would be 28, the higher the score the higher the quality of the study. The total score for the quality rating of each study was converted into a percentage, which was used to label the overall quality of the study (i.e., >80% 'Strong Quality'; 70-79% 'Good Quality'; 50-69% 'Adequate Quality'; <50% 'Poor Quality') (Hakkarainen et al., 2023).

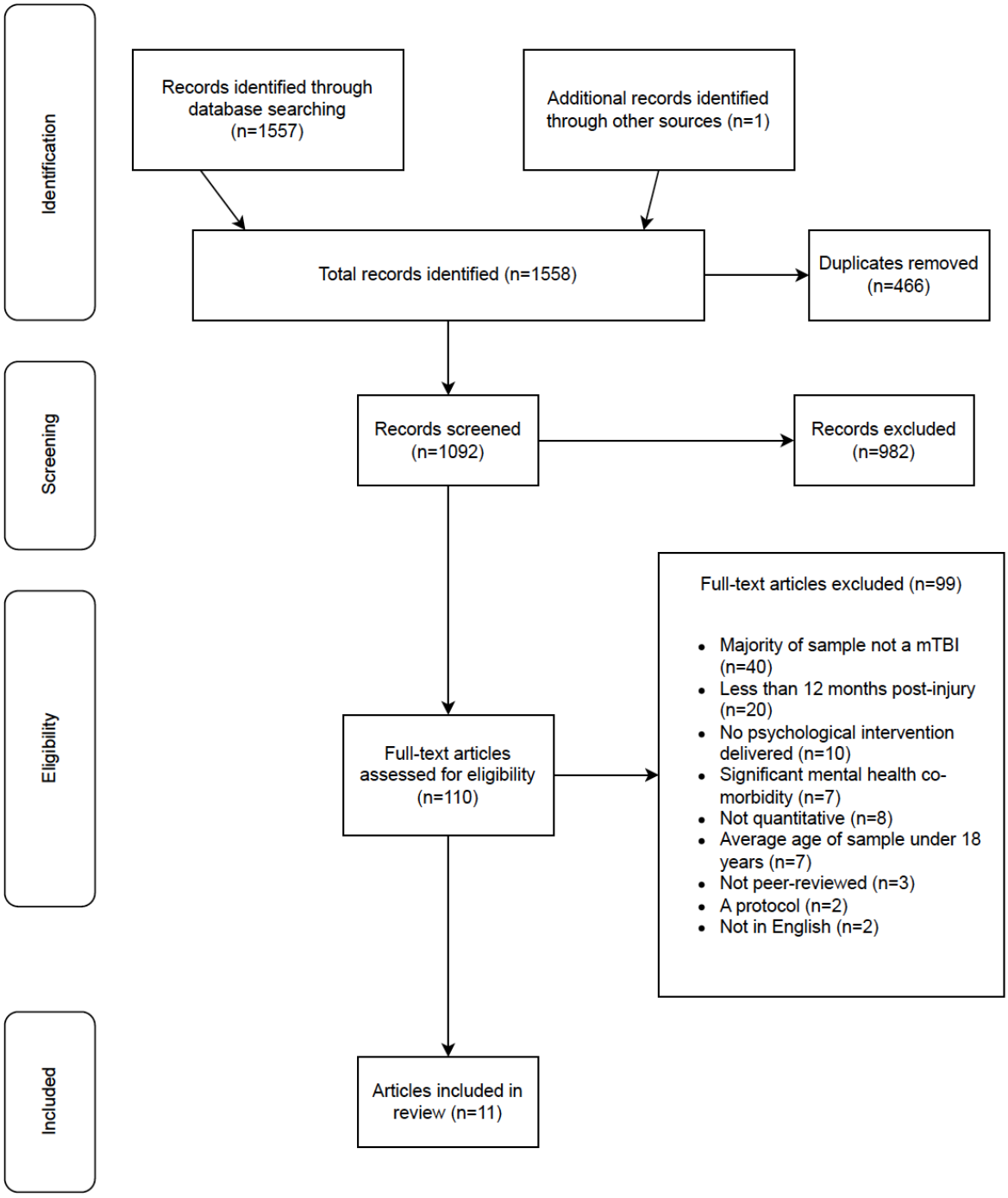
Results

The search strategy identified 1,558 studies and eleven studies met the criteria to be included in this review. Due to the diversity across the studies in this review (i.e., the clinical population, sample, methodology, intervention, and outcome measures), the quantitative results were synthesised using a narrative synthesis approach. The findings from the studies were

synthesised and grouped according to the intervention offered. No studies were excluded based on the quality assessment; however, the quality of each study was taken into consideration when interpreting and synthesising the findings (see Appendix 1B). The conduct of this narrative synthesis followed the guidance posited by Popay et al. (2006). The study selection process is presented in Figure 2.

Figure 2.

PRISMA flow diagram of the study selection process



Study Characteristics

Overlapping samples were found across the two papers by J. Hershaw et al. (2020) and J. N. Hershaw et al. (2020). Although these two papers share an identical participant sample and intervention approach, they report on different outcome measures across the two papers. The participant characteristics from these two papers were considered once, and the findings from each article are considered separately.

A summary of the main study characteristics is presented in Table 1. Across the eleven studies in this review, there was a total of 415 participants at pre-intervention. The participant sample sizes ranged from 7 (Tsaousides et al., 2014) to 90 participants (Kjeldgaard et al., 2014). Studies were conducted across the following high-income countries, Denmark (Kjeldgaard et al., 2014; Rytter et al., 2019), the United States of America (Azulay et al., 2013; J. Hershaw et al., 2020; King et al., 2013; Polich et al., 2020; Tsaousides et al., 2014) Canada (Topolovec-Vranic et al., 2010) and the United Kingdom (Potter et al., 2016). The dates of the collected data ranged from 2005 to 2020. Five of the papers were RCTs (Kjeldgaard et al., 2014; Polich et al., 2020; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005) and six were single-group experimental designs (Azulay et al., 2013; J. Hershaw et al., 2020; King et al., 2013; Topolovec-Vranic et al., 2010; Tsaousides et al., 2014). All papers included baseline and post-intervention outcomes, with six papers including an additional follow-up at 1 month (Tiersky et al., 2005; Tsaousides et al., 2014), 3 months (J. Hershaw et al., 2020; Tiersky et al., 2005), 6 months (Rytter et al., 2019) and 12 months (Topolovec-Vranic et al., 2010).

Table 1.

Study characteristics and participant demographics across the eleven studies.

Study ID, authors (year), location	Study Design	Intervention description	Sample Size	Ascertainment of mTBI diagnosis & cause of injury (%)	Time since injury in months (Mean, SD)	Gender (% male)	Age	Ethnicity
1. Rytter et al. (2019) Denmark	RCT Between groups Design Control sample received standard care.	A 22-week programme using individual, and group based neuropsychological intervention alongside exercise therapy and physiotherapeutic coaching compared to standard care. Based on Cognitive Therapy framework.	Total Sample (n= 89) Intervention (n= 45) Control standard care (n= 44)	Diagnosis of commotio cerebri (concussion) by a primary clinician or from A&E attendance documented in clinical notes. **Intervention Group:** Falls (46%) Sports related (33%) Occupational accident (4%) RTA (4%) Violence/assault (4%) Unknown (6%) **Control Group:** Falls (34%)	29 (16.3)	35%	18-29 (n= 24) 30-43 (n= 45) 44+ (n= 20)	Not reported

				Sports related (25%) Occupational accident (2%) Road traffic accident (RTA) (9%) Violence/assault (5%) Unknown (25%)				
2. J. N. Hershaw et al. (2020) USA	Single Group Experimental Design	Neurofeedback therapy using live Z score training over a 6-week period. Participants received positive feedback via visual and auditory cues when their EEG data aligned within normative values in real time.	Total Sample (n= 38) Treatment completers (n= 27) Non-completers (n= 11) Follow up outcomes (n= 23)	Previously documented diagnosis of a mTBI on medical records. Cause of injury not reported	14 (13.16)	81.6%	Total sample: Mean Age 33 (SD 8.04) Completers (Mean 36, SD 7.58) Non-completers (Mean 27, SD 5.18)	Total sample: African American (18%) Asian (3%) White (76%) Hispanic (8%) Other (3%) **Completers**: African American (11%)

								Asian (3.7%) White (81.4%) Hispanic (7.4%) Other (4%) **Non-completers:** African American (36%) Asian (0%) White (64%) Hispanic (9%) Other (0%)
3. Kjeldgaard et al. (2014) Denmark	RCT Between Groups	Group based CBT over 9 weekly sessions	Total Sample (n= 90)	Pre-existing diagnosis of chronic post-traumatic headache attributed to a mTBI, in reference to criteria in the International	27 months	44%	Mean Age 34 (SD 11.3)	Not reported

	Waiting list control sample			Classification of Headache Disorders. RTA (45%)				
4. Azulay et al. (2013) USA	Single Group Experimental Design	A Mindfulness-based stress reduction program	Total Sample (n= 22)	American Congress of Rehabilitation Medicine Criteria for mTBI Cause of injury not reported.	Authors did not report mean of time post injury for sample. 13-36 months (75%) >36 months post (5%)	50%	Mean Age 48.9 years (SD 8.3)	African American (9.1%) Asian (4.5%) White (68.2%) Hispanic/ Latino (18.2%)
5. J. Hershaw et al. (2020) USA	Single Group Experimental Design	Neurofeedback therapy using live Z score training over a 6-week period. Participants received positive feedback via visual and auditory cues when their EEG	Total Sample (n= 38) Treatment completers (n= 27)	Previously documented diagnosis of a mTBI on medical records. Cause of injury not reported	14 (13.16)	81.6%	Total sample: Mean Age 33 (SD 8.04) Completers (Mean 36, SD 7.58)	Total sample: African American (18%) Asian (3%) White (76%)

		data aligned within normative values in real time.	Non-completers (n= 11) Follow up outcomes (n= 23)				Non-completers (Mean 27, SD 5.18)	Hispanic (8%) Other (3%) **Completers**: African American (11%) Asian (3.7%) White (81.4%) Hispanic (7.4%) Other (4%) **Non-completers:** African American (36%) Asian (0%) White (64%)

								Hispanic (9%) Other (0%)
6. Polich et al. (2020) USA	RCT, between groups design.	Comparing focussed attention meditation to meditation with mobile EEG-based neurofeedback. Participants meditated at least 12 minutes a day for 6 weeks, using a meditation coaching app and real-time EEG neurofeedback.	Total Sample (n= 20) mNF intervention (n= 10) Control focused attention group (n= 10)	Participants must have a pre-existing diagnosis of mTBI. RTA (55%) Blunt trauma (25%) Fall (20%)	55.6 (11.4)	15%	Mean 45.4 years	White (85%) Hispanic (5%) African American (10%)
7. Tsaousides et al. (2014) USA	Single group experimental design	Online group CBT for improvement of emotional regulation following mTBI.	Total Sample (n= 7)	Diagnosis obtained through medical records and use of the American Congress of Rehabilitation Medicine Criteria for both presence and severity rating of the TBI	43.7	14%	Mean 42.8 years (range between 23-63)	White (42%) Asian (42%) Other (14%)

				RTA (85%) Fall (14%)				
8. Topolovec-Vranic et al. (2010) Canada	Single Group Experimental design	Online CBT based 6-week program called MoodGYM. Participants received weekly phone calls to monitor progress.	Total Sample (n= 21)	Glasgow Coma Scale RTA (57%) Fall (10%) Assault (5%) Sport-related (29%)	25	62%	Mean 42.5 (range 19 – 72)	Not reported
9. Tiersky et al. (2005) USA	RCT Between groups experimental design Waiting list control sample	Neurorehabilitation program involving CBT and cognitive remediation. 11 weekly individual sessions.	Total Sample (n= 20) Intervention (n= 11) Control (n= 9)	Glasgow Coma Scale, self-report, medical documentation and general clinical and historical presentation RTA (65%) Falling object (15%) Falls (10%) Sports related (5%) Pedestrian in motor vehicle collision (5%)	75 (6.02)	45%	Mean 45.85, SD 10.51	White (90%)

10. King et al. (2013) USA	Single Group Experimental Design	Computer-based intervention providing psychoeducation and information to participants about TBI	Total Sample (n= 25) Acute (<3 months post injury) (n= 14) Chronic (>3 months post injury) (n= 11)	History of a mTBI with posttraumatic amnesia of less than 1 day, and/or loss of consciousness less than 30 minutes. No specific diagnostic tool reported. Assault (20%) Fall (20%) RTA (32%) Blast/Rocket-propelled grenade (24%) Sports-related Injury (4%)	13.4	84%	Mean 31.92 (SD 8.91)	White (76%)
11. Potter et al. (2016) UK	RCT Between groups experimental design. Waiting list control sample.	12 individual session CBT program, with personalised formulation for vicious cycles maintaining PPCS.	Total Sample (n= 45) Intervention (n= 25) Control (n= 20)	Severity retrospectively assessed using the Rivermead protocol for classification of TBI severity. Intervention: RTA (62%) Assault (12%) Other (27%)	25 Intervention 12-24 months (23%) >24 months (54%) Control	54%	Mean 41.4 (SD 11.6) Intervention: Mean 40.1 (SD 10.3) Waiting List control: Mean 43.1 (SD 13.1)	Not reported

				Control: RTA (55%) Assault (10%) Other (35%)	12-24 months (15%) >24 months (50%)			

Table 2.

Extracted data of outcome measures used and timepoints administered, summary of relevant findings and quality rating for each study using The SQAC-EPR (Kmet et al., 2004).

Study ID and authors (year)	**Quality Rating**	**Measurement of PCS outcomes following intervention**	**Timepoints outcomes administered**	**Summary of relevant findings**
Rytter et al. (2019)	Strong Quality (25/28)	Rivermead Post-Concussion Symptoms Questionnaire (RPCSQ) The Headache Impact Test (HIT)	Baseline (T1) Immediately post intervention (T2)	Participants in the intervention group (S-REHAB) showed improvement overall, except on measures of energy and fatigue levels. Significant reduction of symptoms measured by the RPCSQ for the S-REHAB group compared to the control group immediately after

		Multidimensional Fatigue Inventory Major Depression Inventory (MDI) The 36-item Short Form Inventory	6 month follow up (T3)	treatment (F(1, 86) = 6.44, p = 0.013) (effect size (d) = 0.29) and at 6-month follow up (F(1, 86) = 8.17, p = 0.005) (d = 0.26). Immediately following intervention the S-REHAB showed significant improvement, compared to control group, on HIT (F(1, 86) = 4.40, p = 0.039, ES = 0.38), mental fatigue (F(1, 86) = 5.72, p = 0.019) (d = 0.42), social functioning (F(1, 86) = 5.47, p = 0.022) (d = 0.31). At 6 months follow up, the S-REHAB showed significant improvements, compared to controls, on headache symptoms (F(1, 86) = 8.94, p = 0.004, d = 0.68, increased activities (F(1, 86) = 9.88, p = 0.002, d = 0.74, and more satisfaction with 'leisure life' (F(1, 86) = 11.18, p = 0.001, d = 0.56. No significant differences immediately following the intervention were found across the MDI (F(1, 86)= 1.18, p=0.2810 (d = 0.38), general fatigue (F(1, 86) = 2.20, p=0.142, d=0.43, emotional wellbeing (F(1, 86) =0.03, p=0.870, d =0.05.
2. J. N. Hershaw et al. (2020)	Strong Quality (18/22)	Patient Health Questionnaire (PHQ-9) Neurobehavioral Symptom Inventory (NSI)	Baseline (T1) Post-intervention (T2) between 1-4 weeks after treatment	PHQ-9 scores were significantly reduced at T3 compared to T1 F(2,44) = 9.992, p= <0.001, effect size (n_p^2) = 0.312. NSI was significantly reduced at T3 compared to T1 F(2,44)= 6.974, p=0.002, n_p^2 = 0.241.

		Medical Outcomes Study Sleep Scale (MOS) Chronic Pain Grade Questionnaire Migraine Disability Assessment Scale Satisfaction with Life Scale (SWLS) Self-Efficacy for Symptom Management Scale (SEsX)	Follow up (T3) 11-15 weeks post-treatment	Significant reduction in Chronic Pain Grade Disability sub-scale $F(2,44) = 5.427$, $p=0.008$, $n_p^2 = 0.198$. Significant improvement in SEsX, $F(2,44) = 6.649$, $p=0.003$, $n_p^2 = 0.232$. No significant differences were found for MOS sleep, $F(1.5, 34.6) = 1.004$, $p=0.360$, $n_p^2 = 0.044$. No significant differences found for SWLS $F(2,44) = 1.307$, $p= 0.281$, $n_p^2 = 0.056$.
3. Kjeldgaard et al. (2014)	Strong Quality (22/24)	Headache Diary recording frequency, duration, and intensity of headaches Short form Survey (SF-36); QoL measure Rivermead Post Concussion Symptoms Questionnaire (RPCSQ) The Symptom Checklist (SCL-90-R)	Baseline T1 Post intervention T2	No significant differences were noted in intervention group for headache and pressure pain threshold post-intervention compared to baseline in terms of frequency at baseline (M 26.4, SD 4.39) to post intervention (M 26, SD 5.13) p= 0.551, ES (d) = 0.067 Headache intensity and duration at baseline (M 2341, SD 1110) and post-intervention (M 2261, SD 1140), ES 0.072, p= 0.621 Pain threshold at baseline (M 221, SD 96.4) compared to post-intervention (M 215, SD 98.7), p= 0.979, d = 0.067

				Results showed a slight improvement in self-reported QoL SF-36 for the intervention group at follow up, compared to control group. However, this improvement did not reach significance. Physical functioning at baseline (Mean T-score 68.6, SD 18) compared to post-intervention (Mean T-score 70.7, SD 15.7), p= 0.434, d= 0.127 General Health at baseline (Mean T-score 51.7, SD 19.8) compared to post-intervention (Mean T-score 52.5, SD 20.8), p= 0.355, d= 0.035 Social functioning baseline (M 35.8, SD 41.2), post intervention (M 44.1, SD 24) p= 0.588, d= 0.347 RPCSQ showed an improvement in somatic, emotional and cognitive elements for the intervention group at T2, but this was not significant from T1 (Mean T score 33.4, SD 13.8) to post-intervention (mean T score 32, SD 12.6), p= 0.054, d= 0.107. Control group had significantly less somatic symptoms from baseline (M 1.83, SD 0.822), compared to follow-up (M 1.57, SD 0.754), p= 0.027, ES 0.331, and cognitive symptoms from baseline (M 2.5, SD 1.47), compared to follow-up (M 2.16, SD 1.42), p= 0.039, d = 0.237.

				SCL-90-R- intervention group showed significant improvement across interpersonal sensitivity (p= 0.015), depression (p= 0.03) and hostility (p= 0.003) at T2 versus T1. Control group showed improvement on phobic anxiety (p= 0.028) compared to baseline measures. After adjustment for group differences at assessment, intervention group showed significant improvement on interpersonal sensitivity, from baseline (M 55.7, SD 9.45) to post-intervention (M 52.7, SD 11.1), p= 0.05, d= 0.3.
4. Azulay et al. (2013)	Good Quality (17/22)	Perceived quality of life scale (PQOL) Perceived self-efficacy scale (PSE) Neurobehavioral symptom inventory (NSI) Neuropsychological tests - Continuous performance test of attention (CPTA) - Paced auditory serial addition test (PASAT)	Baseline (2 weeks before intervention) (T1) 2 weeks post intervention (T2)	Significant improvement noted on PSE at post-test compared to pre-test (M 13, SD 16.3), p= 0.001, ES (d) = 0.5 Significant improvement on the PQOL at T1 compared to T2 (M 8.6, SD 12), p=0.003, d= 0.43 Reduction in symptoms on the NSI from pre and post intervention, though not significant (M 4.6, SD 11.3(, p= 0.07, d = 0.32. Significant improvement from baseline to post-intervention on attention on the PASAT (M 11.5, SD 14.3), p= 0.001, ES 0.32 and the CPTA, (M 4.6, SD 7.9), p= 0.01, d = 0.31

		- California verbal learning test-II alternative form Social problem-solving inventory revised short form Mindful Attention awareness scale		No significant effect on verbal learning and memory, (M 1.8, SD 5), p= 0.11, d = 0.02 from pre to post intervention score difference. No significant differences of improvement on rational problem-solving skills following the intervention compared to pre-test scores, (M 1.0, SD N/A), p= 0.134, d = 0.25.
5. J. Hershaw et al. (2020)	Good Quality (17/22)	Weschler Adult Intelligence Scale (WAIS-IV) Delis Kaplan Executive Functioning System (DKEFS) Hopkins Verbal Learning Test Revised (HVLT-R) Weschler Memory Scale Logical Memory Subtest (WSM-IV) Brief Visual Memory Test Revised	Baseline (T1) Post-intervention 1-4 weeks after treatment (T2) Follow up 11-15 weeks post-treatment (T3)	Following the LZT intervention, there were improvements in executive functioning tests (such as number-letter sequencing, $F(2,44) = 7.07$, $p= 0.002$, ES (n_p^2) = 0.243, inhibition, $f(2,44)=15.176$, $p=<.001$, $n_p^2 = 0.408$ and digit span sequencing $F(2,44)=6.299$, $p=0.004$, $n_p^2 = 0.223$ Improvements reported across attention and processing speed tests (Digit Symbol Coding $F(2,44)=11.682$, $p=<.001$, $n_p^2 = 0.347$ and Symbol Search, $F(2,44)=7.665$, $p= 0.001$, $n_p^2 = .258$ Free recall significantly improved across the three timepoints for both immediate recall $F(2,44)=12.594$, $p=<.001$, $n_p^2 = .364$ and delayed $F(2,44)=26.132$, $p=<.001$, $n_p^2 = .543$ No significant differences were reported between T1 and T3 for letter fluency attention $F(2,44)=1.632$, $p=.207$, $n_p^2 = 0.069$, attention and working memory as measured by the backwards digit span $F(2,44)=1.243$, $p=.298$, $n_p^2 = 0.053$.

6. Polich et al. (2020)	Adequate Quality (17/28)	Neurobehavioural Symptom Inventory (NSI) Beck Anxiety Inventory (BAI) Beck Depression Inventory (BDI) Self-Efficacy Questionnaire Cognitive and Affective Mindfulness Scale-Revised Digit Span Forward and Backward Symbol-Digit Coding	Baseline (T1) Immediately post intervention (T2)	When comparing the intervention and control group, no significant differences in scores were found between pre and post intervention across all outcome measures. No significant difference was found between groups on NSI between T1 to T2, $F(1,18) = 0.04$, $p = .838$ No significant differences were found between groups across all measures T1 to T2. When combining outcomes for both groups together and considering pre and post intervention scores, significant differences were found on the NSI $F(1, 38) = 4.51$, $p = .04$, BAI $F(1, 38) = 7.04$, $p = .012$ and BDI $F(1, 38) = 4.66$, $p = .037$ only.
7. Tsaousides et al. (2014)	Adequate Quality (12/22)	Difficulties in Emotion Regulation Scale (DERS) The Brain Injury Rehabilitation Trust Regulation of Emotions Questionnaire (BREQ) The Problem-Solving Inventory	Baseline (T1) Intervention (T2) 4 week follow up (T3)	No reported significant differences between baseline and post-intervention scores on the DERS, BREQ, Problem-Solving Inventory, Social Problem-solving inventory revised short form. Note. The authors did not report which statistical test was used, nor the specific statistical outputs.

		The Social Problem Solving Inventory Revised Short Form		
8. Topolovec-Vranic et al. (2010)	Strong Quality (19/22)	Centre for Epidemiological Studies Depression Scale (CES-D) Patient Health Questionnaire (PHQ-9)	Baseline (T1) 12 month follow up (T2)	At the 12-month follow up, the mean CES-D score significant decreased from T1, (M 30.7, SD 2.3) to T2 (M 20.6, SD 4.7), p= <0.05 At the 12 month follow up, the mean PHQ-9 score significantly decreased from T1, (M 17.4, SD 0.9) to T2 (M 11.6, SD 2.4), p= <0.05
9. Tiersky et al. (2005)	Strong Quality (22/26)	Coping Response Inventory (CRI) Symptom Checklist 90 Revised (SCL-90R) Assessment of Client Functioning Inventory (ACFI) The Attention Questionnaire	Baseline (T1) Immediately post intervention (T2) 1 month post intervention (T3)	Participants in the intervention group showed a significant improvement on scores on the SCL-90R Global Severity Index (M 0.86, SD 0.41) compared to the control group (M 1.74, SD 1) at follow up, p= 0.045 Participants in the intervention group showed significant improvement across depression scores on the SCL-90R (M 1.12, SD 0.45) compared to control (M 2.11, SD 1.14) at follow up, p= 0.046 No significant difference was reported on problem solving between the intervention group (M 13.06, SD 2.67) compared to the control group (M 12.58, SD 2.21), p= 0.685

			3-month post intervention (T4)	No significant difference was reported on the Attention Questionnaire between intervention (M 10.42, SD 11.56) and control group (M 29.29, SD 9.94) at follow up, p= 0.082
10. King et al. (2013)	Good Quality (16/22)	Patient Health Questionnaire (PHQ-9) Posttraumatic Stress Disorder Checklist Civilian Version (PCL-C) Neurobehavioral Symptom Inventory (NSI)	Baseline (T1) Follow up 1 month later (T2)	Significant improvement on the NSI at T2 compared to T1, F(1, 23)= 18.40, p= .001, ES (d) = .99. Factors such as demographics, PHQ-9 baseline score and PCL-C baseline score were not significantly associated with a change in PCS reporting on the NSI following the intervention, p= >0.05
11. Potter et al. (2016)	Strong Quality (22/24)	Rivermead Post Concussion Symptoms Questionnaire (RPCSQ) Brain Injury Community Rehabilitation Outcome Scale (BICRO) Quality of Life Assessment Schedule (QOLAS) Hospital Anxiety and Depression Scale (HADS – A)	Baseline (T1) End of treatment or after 4 months in control arm (T2)	Before controlling treatment duration as a covariate: Significant improvement on the QOLAS for the intervention group from T1 (M 43, SD 8.3), to T2 (M 24.5, SD 12), compared to the control group T1 (M35.8, SD 6.8) to T2 (M32.7, SD 9.9), F(1,42)=5.886, p=0.02, ES (d) =0.73 No significant differences were found between groups at T2 compared to T1 on: The RPCSQ F(1,42)=0.51, p=0.481, d =0.21 The checklist of individual strength, F(1,41)=2.112, p= 0.153, d =0.44

		(HADS-D) McGill Pain Questionnaire State-Trait Anger Expression Inventory 2 Checklist of individual strength		The HADS-A, F(1,42)=0.654, p=0.423, d =0.25 The HADS-D, F(1,42)=0.882, p=0.353, d =0.28 BICRO, F(1,42)=1.387, p=0.245, d =0.36; though significant improvement noted on the psychological wellbeing subscale for the intervention group at T2, F(1,42)=5.429, p=0.025, d =0.7 State Trait Anger= F(1,42)=1.317, p=0.258, d =0.34 McGill Pain questionnaire= F(1,42)=0.112, p=0.739, d = -0.1 After controlling for treatment duration as a covariate, the following outcome measures showed a significant improvement for the intervention group at T2 versus T1, compared to the control group: RPCSQ, F (1,41)= 4.578, p=0.0038, d = 0.81 QOLAS F(1, 41)= 11.120, p=0.0002, d = 1.26 HADS-A, F=1,41)= 8.003, p=0.007, d =1.06 Checklist of individual strength, F(1,41)=5.441, p=0.025, d = 0.89 STAXI-2, F(0,41)=6.384, p=0.015, d =0.95 No significant difference were reported on the: HADS-D, F=(1,41)= 2.513, p=0.121, d = 0.6 MPQ, F(1,41)=0.001, p=0.974, d = -0.1

				BICRO, f(1,41)=1.1117, p= 0.297, d= 0.4. However, the following subscales showed significant improvement for the intervention group at T2: socialising F(1, 41)= 7.325, p=0.01, d = 1.03 and psychological wellbeing, F(0, 41) = 13.069, p=0.001, d = 1.37

Note: The Standard Quality Assessment Criteria for Evaluating Primary Research (SQAC-EPR) (Kmet et al., 2004) quality ratings range from >80% 'Strong Quality'; 70-79% 'Good Quality'; 50-69% 'Adequate Quality'; <50% 'Poor Quality') (Hakkarainen et al., 2023). Effect Size (EF)

Participant Demographics

Participant demographics are summarised in Table 1. Ten of the studies reported a mean age of their sample, which ranged from 31 to 48 years. All studies reported on the gender of their sample, with a percentage of male participants ranging from 14% - 84%. Only five studies reported participant ethnicities of their total sample size (Azulay et al., 2013; J. Hershaw et al., 2020; King et al., 2013; Polich et al., 2020; Tiersky et al., 2005; Tsaousides et al., 2014); White (42% - 90%), Asian (3% - 42%), African American (9% - 18%) and Hispanic (5% - 18%).

Brain Injury

In terms of head injury, all studies reported the mean time since injury which ranged from 13.5 months to 75 months. Eight of the studies reported the cause of the head injury (King et al., 2013; Kjeldgaard et al., 2014; Polich et al., 2020; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005; Topolovec-Vranic et al., 2010; Tsaousides et al., 2014); the main cause being by a RTA (32% - 85%). Other causes of injury across participants were falls (10% - 34%), sports-related injury (4% - 29%), blunt trauma (25%), blast or rocket-propelled grenades (24%), assault (5% - 20%), falling objects (15%), and occupational accidents (2%). Eight of the studies were recruited from an outpatient community based-population (King et al., 2013; Kjeldgaard et al., 2014; Polich et al., 2020; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005; Topolovec-Vranic et al., 2010; Tsaousides et al., 2014), two from a veteran population (J. Hershaw et al., 2020; King et al., 2013) and one from an acute rehabilitation centre (Azulay et al., 2013).

Outcome Measures

Across the studies, 46 different validated outcome measures were used to assess PCS and the impact of PCS on QoL or mental health. Overlapping outcome measures included the Patient Health Questionnaire (PHQ-9) which was administered by three studies (J. N. Hershaw

et al., 2020; King et al., 2013; Topolovec-Vranic et al., 2010) four studies used the Neurobehavioral Symptom Inventory (Azulay et al., 2013; J. N. Hershaw et al., 2020; King et al., 2013; Polich et al., 2020), three studies used the Rivermead Post-Concussion Symptoms Questionnaire (Kjeldgaard et al., 2014; Potter et al., 2016; Rytter et al., 2019) and two studies used the 36-item Short Form Inventory (Kjeldgaard et al., 2014; Rytter et al., 2019).

Quality Assessment

Six studies scored >80% deeming the paper as of "strong quality" (J. N. Hershaw et al., 2020; King et al., 2013; Kjeldgaard et al., 2014; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005; Topolovec-Vranic et al., 2010), three studies scored between 70-79% and were deemed "good quality" (Azulay et al., 2013; J. Hershaw et al., 2020) and two papers scored between 50-69% and were considered as "adequate quality" (Polich et al., 2020; Tsaousides et al., 2014).

"Strong Quality" Studies

Many of the studies included in this review were rated as being of "strong quality". These studies mostly reported clear objectives and study design and reported on sufficient participant demographics. Outcome measures were often well-defined and described, and statistical approaches were in sufficient detail.

"Good Quality" Studies

Both the study by Azulay et al. (2013) and King et al. (2013) were rated as "Good Quality"; this was due to lower scores across the sample sizes being too small, only partially controlling for confounders and partially reporting results and conclusions. Both studies did not report on power for their chosen sample size, nor did they include a control sample.

One of the papers by J. Hershaw et al. (2020) partially met quality standards due to an insufficient sample size for the given study and a lack of power analysis to justify the sample

size. The authors did not describe the neuropsychological assessments in sufficient detail for the reader to infer the procedure used in this study. Hershaw and colleagues partially controlled for possible confounders. A further criticism of the paper by J. Hershaw et al. (2020) was the reporting of pairwise comparisons for certain outcome measures, but not others. It was unclear the reasoning behind these decisions and made it difficult to interpret their findings.

"Adequate Quality" Studies

The study by Polich et al. (2020) was proposed as a RCT in their study design, however, due to significant differences between the two randomised samples, the authors decided to allocate participants to groups stratified by scores on a depression scale. Furthermore, the sample size appeared small (N= 20) and power analysis to determine an adequate sample size was not reported. Finally, this study did not meet quality standards for reporting results, due to insufficient detail for the reader to make interpretations of the findings.

Similarly, Tsaousides et al. (2014) scored adequately on quality due to the small sample size (N= 7). The authors also did not report on what statistical analysis was used, and although stated their findings were non-significant, they did not provide any detail of the statistical output. There was no mention of controlling for any confounding variables in this study.

Intervention for PPCS

Across the eleven papers included in this review, four psychological interventions were used to address various symptoms of PPCS. Interventions included CBT, Neurofeedback Therapy (NFT), Psychoeducation and a Mindfulness-based therapy. The findings from each intervention are discussed in more detail below.

Neurofeedback Therapy

NFT is a non-invasive biofeedback of neuronal activity, (Marzbani et al., 2016) which has been used within a range of clinical populations (e.g., schizophrenia, insomnia, depression,

pain management) and to improve cognitive functioning (e.g., attention and memory) (Marzbani et al., 2016). Live Z score training is a type of NFT which uses a 'real-time' calculation of Z-scores of EEG activity (Hershaw & Hill-Pearson, 2022). NFT with live Z score training involves using positive and negative reinforcement, in the form of visual and auditory feedback, to encourage the individual's neuronal activity to be more aligned with that of a 'typical neuronal activity' from a normative database (Collura, 2016).

Three studies used NFT for the treatment of PPCS following a mTBI (J. Hershaw et al., 2020; J. N. Hershaw et al., 2020; Polich et al., 2020). The studies by Hershaw and colleagues included the same participant sample, however, both papers reported on different outcome measures and findings. The two studies by Hershaw et al. used live Z score training with positive auditory and visual feedback over 6 weeks. The studies by Hershaw et al. suggest that NFT significantly improved PCS, pain levels and low mood and that improvements were also noted in levels of attention, processing speed, and recall (immediate, delayed and free). No improvements were found in ratings of sleep, QoL, working memory or letter fluency attention.

The studies were rated of "Strong Quality" (J. N. Hershaw et al., 2020) and "Good Quality" (J. Hershaw et al., 2020) implying that overall, the papers were well-written and provided readers with sufficient detail. Large effect sizes for significant findings were found ($n_p^2 = 0.24 - 0.36$). However, the studies did not include a control sample and did not report on the controlling of other rehabilitative interventions participants may have previously, or concurrently, been receiving. Furthermore, the sample size was relatively small (n= 38) with a high rate of attrition; 29% of the sample did not complete the intervention.

Contradictory to the findings by Hershaw et al. (J. Hershaw et al., 2020; J. N. Hershaw et al., 2020), Polich et al. (2020) found that using NFT and meditation, compared with meditation only in a control group, did not improve PCS, mood, anxiety, processing speed, working memory or self-efficacy. They did, however, find that when combining the

intervention and control group significant improvements were found for NSI, anxiety, and depression levels; however, performing multiple statistical tests on the data to explore possible significance can increase the risk of finding false positives, and thus validity of these conclusions are limited. They concluded that a meditation intervention may result in improvements for PPCS, but that NFT did not contribute to any significant improvements. The study by Polich et al. received an 'adequate quality' rating. The study did not report on the use of blinding for investigators or participants and the inadequate sample size may have contributed to the non-significant findings and the possibility of a type 2 error. Had this study been sufficiently powered, there may have been a different outcome.

Mindfulness-based intervention

One paper looked at a mindfulness-based intervention for the treatment of PPCS (Azulay et al., 2013). Within this study, participants received a 10-week mindfulness-based group programme. Azulay et al. found a significant improvement in participants' perceived QoL with a small effect size (d= 0.43) and self-efficacy for their management of cognitive and emotional symptoms associated with the PCS, with a moderate effect size (d= 0.5). In terms of specific PCS outcome measures, although they found some improvements following the intervention, these did not meet significance. There was a significant improvement in the rate of attention, albeit with a small effect size (d= 0.31 - 0.32). No improvements were found in verbal learning, memory and problem-solving skills.

This study was assessed as being of a "good quality", however, study limitations include the absence of a control sample and a small sample size (n= 22). Furthermore, participants were concurrently receiving rehabilitation alongside the mindfulness-based intervention which the authors did not report controlling for and so improvements noted may not be solely attributable to the mindfulness-based intervention.

Psychoeducation

One study conducted a single-group experimental design to explore the impact of psychoeducation on reducing PPCS (King et al., 2013). Within this study, a one-off computer-based intervention was delivered, whereby participants were informed about TBI's, the impact of these and the expected periods for recovery. The participants with PPCS showed a significant reduction in self-reported PCS following the intervention with a large effect size (d = 0.99).

The study by King et al. was rated of a 'good quality' due to the clarity and detail of study design and findings. However, this study only partially met quality standards due to a relatively small sample size with no mention of power analysis (n=11), no control sample or follow-up, and not controlling for other concurrent rehabilitation. Furthermore, this study measured PCS by the NSI outcome measure only, which may have somewhat limited insight into other secondary or chronic symptoms people with PPCS may experience. Given this, the findings of this study may be limited in their application.

Cognitive Behaviour Therapy (CBT)

Six of the eleven studies explored the use of CBT for the treatment and management of PPCS (Kjeldgaard et al., 2014; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005; Topolovec-Vranic et al., 2010; Tsaousides et al., 2014). Four of these studies used an RCT approach with a comparison control group (Kjeldgaard et al., 2014; Potter et al., 2016; Rytter et al., 2019; Tiersky et al., 2005), and two studies did not include a control group sample (Topolovec-Vranic et al., 2010; Tsaousides et al., 2014). Two studies used a group-based intervention (Kjeldgaard et al., 2014; Tsaousides et al., 2014), three used individual sessions (Potter et al., 2016; Tiersky et al., 2005; Topolovec-Vranic et al., 2010) and one used a combination of both (Rytter et al., 2019). Four studies assessed for CBT intervention only

(Kjeldgaard et al., 2014; Potter et al., 2016; Topolovec-Vranic et al., 2010; Tsaousides et al., 2014) compared to those which incorporated CBT alongside other rehabilitation interventions such as cognitive remediation (Tiersky et al., 2005), physiotherapy coaching and exercise therapy (Rytter et al., 2019).

Mental Health Symptoms

Three studies found that CBT improved symptoms of depression (Kjeldgaard et al., 2014; Tiersky et al., 2005; Topolovec-Vranic et al., 2010), however, in contrast, two studies did not find significant improvements in depression symptoms (Potter et al., 2016; Rytter et al., 2019). Improvements were noted in overall psychological well-being and distress (Potter et al., 2016; Tiersky et al., 2005) and one study found improvements in both anxiety and anger (Potter et al., 2016).

Quality of Life

One study found CBT to significantly improve self-reported QoL with a large effect size (d= 1.26) (Potter et al., 2016). Kjeldgaard et al. (2014) found an improvement in QoL but this did not reach significance. CBT also appeared effective in improving overall leisure life satisfaction (d= 0.56), social functioning (d= 0.31) and in increasing of activities (d= 0.74) (Rytter et al., 2019).

Physical Symptoms

Rytter et al. (2019) found significant improvement in headaches immediately post-intervention albeit with a small effect size (d= 0.38), and at 6 months post-intervention with a medium effect size (d= 0.68). In contrast, Potter et al. (2016) and Kjeldgaard et al. (2014) found no significant improvement in self-reported headaches or pain following CBT. One study by Rytter et al. (2019) explored levels of physical and mental fatigue using the Multidimensional Fatigue Inventory; they found significant improvements in mental fatigue (d = 0.42) but not in

general fatigue levels. All three of these studies were RCTs and were rated as being of "strong quality" in this review. However, the study by Rytter et al. (2019) delivered CBT alongside exercise therapy and physiotherapeutic coaching. Thus, we cannot conclude that the improvement in mental fatigue and headaches were as a direct result of the CBT compared to other rehabilitative interventions. Unfortunately, the authors did not control for this within their study.

PCS-specific Outcome Measures

Three studies included a PCS-specific outcome measure (Rivermead Post Concussion Symptoms Questionnaire) (Kjeldgaard et al., 2014; Potter et al., 2016; Rytter et al., 2019). Two studies found a significant improvement in PCS following the CBT intervention immediately following the intervention (d= 0.29 - 0.81) and at a 6-month follow-up (d= 0.26). Kjeldgaard et al. (2014) found an improvement in participants' self-reported PCS, specifically in areas of somatic, emotional and cognitive domains, however, this did not reach significance.

Emotion regulation

One study measured emotion regulation before and after a group-based CBT intervention (Tsaousides et al., 2014). This group-based CBT intervention aimed to specifically target and improve emotion regulation skills for individuals with PPCS following a mTBI. No significant improvement in emotion regulation skills was reported in this study at the 4-week follow-up. However, this study was deemed as "adequate quality" in this review, due to the small participant sample (n=7) and lack of reporting of statistical analysis and outputs. This study was likely underpowered, and thus the risk of a type 2 error is high. We are unable to interpret the effectiveness of CBT for emotion regulation for individuals with PPCS following mTBI.

Cognitive Symptoms

Two studies measured the effect of CBT-based intervention on cognition. The results indicated that CBT did not result in an improvement in problem-solving skills (Tiersky et al., 2005; Tsaousides et al., 2014) or attention (Tiersky et al., 2005). The study by Tsaousides et al. (2014) was deemed "adequate quality" due to the small sample size (n= 7) and lack of a control sample. Furthermore, this study focussed the CBT intervention on improving emotion regulation skills and not on improving problem-solving skills specifically. The study by Tiersky et al. (2005) was rated as of "strong quality", however they implemented cognitive remediation alongside CBT. This can therefore make it difficult to interpret the relationship between CBT and cognitive-based skills as the authors did not control for this within their statistical analysis.

Discussion

This systematic review aimed to explore what psychological interventions had been offered to individuals with PPCS (>12 months post a mTBI) and the effectiveness of these on reducing PPCS. Due to the limited number of studies published, this review undertook an explorative approach. This meant that inclusion criteria were relatively broad, including papers from various study designs, year of publication and type of psychological intervention. Across the eleven studies included in this review, six were of a "strong quality" and three of a "good quality". Two studies were deemed as being of "adequate quality" but were retained in this review, due to the paucity of studies available to synthesise findings. Four psychological interventions were identified, CBT, NFT, psycho-education and mindfulness-based therapy.

Cognitive Behaviour Therapy

CBT was identified as being the most researched psychological intervention for PPCS following a mTBI. Five of the six studies were of a "strong quality" and thus findings can be interpreted with a degree of confidence. CBT was effective at improving mental health symptoms (e.g., anxiety, anger and mental well-being). This aligns with previous reviews on the effectiveness of CBT for persisting PCS (Al Sayegh et al., 2010). However, the effectiveness of CBT for depression symptoms in relation to PPCS remains debatable, due to contradictions in findings across the studies in this review. This reflects the cognitive behavioural model of PCS posited by Hou et al. (2012) suggesting that CBT may be effective at targeting the 'emotion' perpetuating factor of PCS even for individuals with PPCS.

CBT was not effective at improving physical symptoms of PPCS, such as headache, pain or fatigue. Elements of pain are unlikely to have been directly addressed in CBT, and the cognitive behavioural model does not account for pain in perpetuating and maintaining PCS. In addition, research into chronic pain suggests that alternative psychological approaches, such as Acceptance and Commitment Therapy (ACT) are effective for helping individuals to accept and manage pain (Sturgeon, 2014). Future research could explore the effectiveness of ACT in reducing PPCS, specifically pain and headaches.

In terms of fatigue, it could be argued that 'all or nothing' behaviour (e.g., pushing oneself when symptoms reduce and spending prolonged periods recovering) outlined in the cognitive behavioural model (Hou et al., 2012) may contribute to and maintain fatigue in PPCS. Based on this model, we would have expected CBT to improve fatigue for PPCS. Unfortunately, it was not always clear from the studies what protocols, if any, were followed and what areas were specifically addressed in CBT sessions. It would be interesting to explore whether CBT which focusses on addressing 'all or nothing' behaviours would be effective in improving fatigue in PPCS following a mTBI.

Other Psychological Interventions

Aside from CBT, the effectiveness of a brief psycho-education intervention demonstrated interesting findings on the improvement of PPCS following a mTBI. This aligns with a previous review which found psycho-education to be an effective intervention for persisting PCS following a head injury (Heslot et al., 2022). In consideration of the cognitive model of PSC (Hou et al., 2012), psycho-education may play a role in the cognitive perpetuating factors, mainly around illness perception. Delivering psycho-education may challenge some of these cognitions around illness perception, and may allow for cognitive shifts to occur. However, due to the limitations of the study by King et al. (2013) further research with larger sample sizes and a control sample is required to test the robustness of psycho-education for PPCS following a mTBI.

A mindfulness-based intervention appeared effective in reducing secondary symptoms associated with PCS, mainly Qol and self-efficacy. Unfortunately, this study did not include a follow-up, and thus longer-term effects of the intervention are unknown. It may have been interesting to investigate whether significant improvement of QoL and self-efficacy in the management of symptoms associated with PCS may significantly reduce PCS at a later point; especially given that PCS outcomes had improved somewhat at the post-intervention timepoint but did not reach significance.

From this review, there are limited studies investigating NFT as an intervention for PPCS following mTBI. The findings by J. Hershaw et al. (2020) suggest a promising impact of NFT on PPCS, pain, low mood and cognition (i.e., attention, processing speed and recall). However, the relatively small sample size and lack of a control condition limit the conclusions being drawn. Further studies are required to explore NFT on PPCS.

Strengths

All the studies included in this review were at least of an "adequate quality", with a majority of the papers being rated as "strong quality". A rigorous systematic approach was used involving two independent raters at the various stages of this review process (i.e., title and abstract screening, full-text screening, data extraction and quality assessment). A third independent rater was consulted during any discrepancies or queries throughout this review. This review has provided an up-to-date overview of the current studies looking at psychological interventions for PPCS. The inclusion of any psychological intervention enabled insight into other intervention approaches, such as mindfulness-based interventions and NFT, which may have been excluded had the review only focussed on CBT.

Limitations

Despite aiming to keep the inclusion criteria for this systematic review broad, to be explorative, few studies were identified as meeting the criteria for this review. A key factor for this was the exclusion of papers which included significant co-morbidity, such as PTSD. Due to this, several papers did not meet the high "strong quality" standard as would be expected to include within a review. Thus, the interpretations we can draw from "adequate quality" papers are limited.

A further limitation being that some of the participant samples in this review included those which may have PCS of less than 12 months post injury or may have presented with moderate or severe head injuries. Where possible, the results were only interpreted for participants with PPCS from a mTBI, but unfortunately most authors did not differentiate this within their overall results. This review took the approach of an overall mean post-injury of at

least 12 months, and a majority of the sample being a mTBI. However, there is the possibility that results may not explicitly reflect outcomes on the intended population.

Conclusion

In conclusion, this systematic review explored the effectiveness of psychological interventions for the treatment of PPCS following a mTBI. The narrative synthesis indicates that CBT did result in improved PCS for individuals with >12 months of symptoms following a mTBI. Mainly, CBT appears effective at improving symptoms of anxiety, anger and overall mental well-being. Although improvements for PPCS were found for NFT, mindfulness-based therapy and psycho-education, the conclusions drawn are tentative due to the very low number of studies in this area.

This systematic review has provided an up-to-date insight into quantitative research which aimed at reducing PPCS following a mTBI. This review has highlighted that psychological interventions at a prolonged period following the mTBI can be effective in reducing symptoms, and hopefully improving quality of life. Future research is required to continue exploring the effectiveness of psychological approaches for individuals with PPCS following a mTBI. Stronger and more robust methodological designs are required, preferably with longer term follow-ups, control samples and controlling for confounding variables.

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Service Improvement Project

Investigating and understanding how multiple re-referrals can be reduced and support improved for service users with multiple referrals into Berkshire Talking Therapies

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Abstract

Background: Talking Therapies (TT), previously called Improving Access to Psychological Therapies (IAPT), support individuals with mental health difficulties in England. Research suggests that greater clinical complexity increases the likelihood of re-referring to TT, which results in poorer clinical outcomes. Berkshire Talking Therapies (BTT) raised concerns about service users (SUs) with multiple referrals; they wanted to understand the factors surrounding re-referral rates.

Method: A mixed-methods design was used. A binomial logistic regression explored 'clinical characteristics' and demographics variables on the likelihood of being a 'high' or 'low' referrer to BTT. Secondly, interviews with previous SUs with multiple referrals to BTT were conducted, and thematic analysis used to analyse the findings.

Results: The logistic regression model suggested several variables increased the likelihood of being a 'high referrer' to BTT (i.e., individuals of 'other' religious groups, being single, having a long-term condition, high scores on the PHQ-9, and being discharged due to having 'dropped out of treatment'). Thematic analysis identified four key themes, 1. Support and connectedness, 2. Managing mental health dips, 3. Expectations not met and 4. Barriers to engagement.

Conclusions: This study identified factors which significantly increased the likelihood of re-referring to BTT and explored SUs perspectives on why they re-referred on multiple occasions. Recommendations to BTT included additional staff training, utilising the Practical Support Service and liaison with the Long-Term Conditions Pathway.

Introduction

One in six adults in England has a common mental health disorder, such as anxiety-related difficulties or depression (McManus et al., 2016). Between 2021 and 2022, the National Health Service (NHS) in England spent £14.9 billion on mental health services, 13.8% of the local NHS funding allocations (NHS Digital, 2022). The number of people reporting a common mental health disorder continues to rise (Baker & Kirk-Wade, 2023). In 2008 the Improving Access to Psychological Therapies (IAPT) programme (now termed 'NHS Talking Therapies') was launched with the intent to increase access to evidence-based psychological therapies for adults living in England who were suffering from common mental health disorders (Clark, 2011).

Re-referral into IAPT

Within mental health services, studies have sought to understand and explain the "revolving door" phenomenon of patients who return to services following discharge. Joyce et al. (1981) found that a greater number of previous admissions were predictive of further referrals. Other research found that patients who were re-referred were more likely to rely on others for financial support, be single, divorced or separated, misuse substances and engage in fewer valued activities (Franklin et al., 1975).

More recently, Cairns (2014) compared SUs who re-refer to those who do not; SUs with multiple referrals presented with greater clinical complexity and had specific 'clinical characteristics' (i.e., suicidality, substance misuse, a mental health diagnosis, debt, childhood or sexual abuse & unemployment). Having particular 'clinical characteristics' alongside multiple referrals has been associated with an increased likelihood of early treatment dropout (Cairns, 2014; Verbist et al., 2022).

Greater clinical complexity and at least one re-referral has been found to reduce treatment outcomes (Wakefield et al., 2021) with around 30% of SUs with re-referrals being less likely to 'move to recovery' (i.e., dropping below the clinical threshold on outcome measures, (Clark et al., 2009)) compared to SUs with no re-referrals (Verbist et al., 2022). SUs with multiple referrals and who identified as being on long-term sick or disabled were 74% less likely to 'move to recovery'.

Service Context

BTT received a total of 27,672 referrals in 2021, with 35% of these referrals recorded as 'completed treatment'; this being below the national average of 50% from 2021 to 2022 (NHS Digital, 2022). From these referrals, approximately 47% had at least one prior referral and 4.1% had six or more previous referrals to BTT. Although no national guidelines exist to suggest a target rate of re-referrals into TT, service leads identified the rate of re-referral and non-completion of treatment as areas of concern due to the possible impact on service resources, staff well-being and the SUs mental health journey. To date, no clinical audit or previous service evaluation has explored re-referral to BTT.

Study Rationale

There appears to be a link between greater clinical complexity and an increased chance of re-referral into TT. People with multiple referrals to TT appear at an increased likelihood of not meeting clinical recovery, not engaging in treatment and treatment dropout. TT are reporting an increased number of referrals with greater clinical complexity and increased re-referrals due to SUs not feeling their needs were met (Health Education England, 2022).

This study used a mixed-methods design of retrospective data analysis alongside collecting qualitative data from previous SUs with multiple referrals to BTT. This information

was collected and analysed to better understand the cohort of individuals with multiple referrals to BTT and to suggest recommendations for service improvement.

Aims

i. To explore and better understand why people re-refer on multiple occasions.
ii. To make service improvement recommendations to BTT to reduce the likelihood of multiple referrals and to support SUs with multiple referrals.

Research Questions

i. What is the current rate of re-referrals into the BTT, and what proportion of these are considered a 'high rate of re-referrals'?
ii. What is the profile of SUs who have a high rate of re-referral to BTT compared to a low or non-rereferral cohort?
iii. What is the SUs perspective of being re-referred into BTT service and their experience of the service?

Method

Service User Involvement

Experts-by-experience in using BTT were consulted via a focus group to shape the participant-facing documents and interview questions. Documents were amended in response to feedback provided.

Design and participants

This study used a mixed-methods design across two phases to explore clinical characteristics and previous SUs' perspectives of multiple referrals to BTT.

Phase 1.

Retrospective collection and analysis of data from SU who had previously been referred to BTT within a set period. The participants are those who were discharged following their first referral episode.

There are no clinical guidelines on what constitutes the threshold of a 'high referrer'. Following a consultation with the service, it was agreed that having four or more referrals to BTT since 2018 was considered a 'high referrer' to the service. The 'low referrer' category was defined as having one referral to BTT since 2018.

Phase 2.

One-to-one interviews with previous SUs who met the 'high referrer' criteria (i.e., four or more referrals to BTT) were conducted. Semi-structured interview questions were developed by the researchers with input from experts-by-experience (see Appendix 2A for the interview schedule). Participants were asked to share their previous experience of their multiple referrals to BTT, factors contributing to these referrals and their experience of the intervention offered.

Procedure & Analysis

Phase 1.

Data inputted between the 1st of April 2018 and the 31st of March 2019 was collected from the Mayden IAPTus reporting software. Data from all SUs discharged following their first referral episode were collated; a total of 11,855 discharges within this period met this criterion. SUs had consented for their data to flow to NHS Digital and be analysed for service improvement purposes. Next, the total number of referrals each of the 11,855 SUs had to BTT from the first referral to the 1st of April 2023 was produced, determining if they met the criteria of a 'low referrer' or a 'high referrer'.

The total data sample included 8,529 SU data entries; 8,103 discharges did not come back to the service (‘low referrer’) and 426 returned to the service for a minimum of four occasions (‘high referrer’). Those with two or three referrals were removed from the dataset. Each of the first referral episodes was analysed and descriptive statistics were produced.

For data analysis, descriptive statistics were explored and summarised. Secondly, a binomial logistic regression was run using the Statistical Package for the Social Sciences (SPSS) statistical software program.

Phase 2.

Significant and clinically important findings from Phase 1 were taken into consideration when designing the Phase 2 interview questions and for participant recruitment. For example, ensuring that the participants recruited would reflect the ‘clinical characteristics’ which significantly increased the likelihood of being a ‘high referrer’ in Phase 1 analysis. This would provide greater insight into their experiences of re-referring to Talking Therapies on multiple occasions.

Out of the fifty-seven people who were contacted, twenty consented to take part. Eleven people did not attend or withdrew before the interview. In total, nine people consented and attended an interview. The researcher (A.S) emailed the participant information sheet and consent form and the signed consent form was returned before the interview. Interviews took place between May and July 2023 either over the phone or by Microsoft Teams video call. Interviews ranged from 20 to 50 minutes, and involved prompts and follow-up questions. Interviews were audio recorded and transcribed verbatim by a researcher (A.S).

Braun and Clarke (2006) thematic analysis (TA) was used to analyse and interpret the qualitative data. Audio recordings and transcripts were reviewed several times to familiarise with the data before coding began. After coding the data, similar codes were grouped for initial

sub-themes and overarching themes to be developed. Final themes were discussed in a meeting with the supervisors of the project. Credibility checks involved supervisors reviewing codes and quotes from transcripts, all researchers were involved in developing the themes which underwent several stages of revision following discussion following an inductive process. A reflective diary was kept throughout. Refer to Appendix 2B for the process through the six phases of TA.

Study Approval

This study received approval from the Berkshire NHS Trust Clinical Audit Team (Appendix 2C) from the clinical director. All participants within Phase 2 provided written consent to take part; any personally identifiable data was either anonymised or removed, and a unique participant number was assigned.

Results

Phase 1.

When analysing 'low referrers' and 'high referrers' the descriptive statistics of the pre-collected data found that around 5% of the sample met the criteria of being a 'high referrer', and 95% had only one referral (see Table 1). Within the 'high referrer' group there was a greater percentage of those with a LTC, higher scores on outcome measures and a greater risk rating as rated by an allocated clinician (the risk ratings: no risk, medium risk, or high risk). In addition, a greater percentage of 'high referrers' dropped out of treatment by ending the therapy sessions earlier than planned, compared to the 'low referrer' category.

Table 1.

Descriptive Statistics from the data on referral types.

Demographics	**Referral Type**	
	High n=426 (%)	Low n= 8103 (%)
Age		
Under 18	28 (6.57)	584 (7.21)
18 to 35	269 (63.15)	3597 (44.39)
36 to 64	111 (26.06)	3253 (40.15)
65 and over	18 (4.23)	669 (8.26)
Gender		
Male	130 (30.52)	3096 (38.21)
Female	294 (69.01)	5006 (61.78)
Missing Data	2 (0.47)	1 (0.01)
Ethnicity		
White	320 (75.1	5886 (72.64)
Black	14 (3.29)	196 (2.42)
Asian	48 (11.27)	806 (9.95)
Other	32 (7.51)	324 (3.4)
Missing Data	12 (2.82)	891 (11)
Religion		
Christian	100 (23.47)	1932 (23.84)
Muslim	38 (8.92)	336 (4.17)
Other	24 (5.63)	495 (6.11)
No Religion	235 (55.16)	3740 (47.16)
Missing Data	29 (6.81)	1600 (19.75)
Employment Status		
Employed	167 (39.2)	4460 (55.04)
Unemployed	43 (10.09)	621 (7.66)
Long-Term Sick or Disabled	13 (3.05)	113 (1.39)
Other	71 (16.67)	1497 (18.47)
Missing Data	132 (30.99)	1412 (17.43)

Relationship Status		
In a relationship	122 (28.64)	3217 (39.7)
Single	198 (46.48)	2155 (26.6)
Separated	31 (7.28)	617 (7.61)
Missing Data	75 (17.61)	2114 (26.09)
Long-term condition status		
Yes	117 (27.46)	1526 (18.83)
Not Recorded	309 (72.53)	6577 (81.17)
Disability Status		
Has a disability	50 (11.74)	649 (8.01)
Not Recorded	376 (88.26)	7454 (91.99)
Mental Health Diagnosis		
Depressive Episode	150 (35.21)	3354 (41.39)
Generalised anxiety disorder	68 (15.96)	2162 (26.68)
PTSD	23 (5.4)	213 (2.63)
Recurrent depressive episode	7 (1.64)	116 (1.43)
Other	32 (7.51)	877 (10.82)
Missing Data	146 (34.27)	1381 (17.04)
Risk rating		
High	3 (0.7)	18 (0.22)
Medium	11 (2.58)	156 (1.93)
Low	222 (52.11)	4594 (56.57)
None	45 (10.56)	1633 (20.15)
Missing Data	145 (34.04)	1702 (21)
Caseness		
At Caseness	304 (71.36)	5928 (73.16)
Not at caseness	23 (5.4)	1268 (15.65)
Missing Data	99 (23.24)	907 (11.19)
Referral source		
G.P	28 (6.57)	584 (7.21)
Self	348 (81.69)	6700 (82.69)
Other	50 (11.73)	819 (10.11)
Discharge Reason		
Completed treatment	126 (29.58)	3267 (40.32)

Dropped out of treatment	180 (42.25)	2253 (27.8)
Not suitable	32 (7.51)	471 (5.81)
Advice and support	79 (18.54)	2026 (25)
Missing Data	9 (2.11)	86 (1.06)
PHQ-9		
None	17 (3.99)	785 (9.69)
Mild	39 (9.15)	1463 (18.06)
Moderate	74 (17.37)	1942 (23.97)
Moderately Severe	93 (21.83)	1674 (20.66)
Severe	104 (24.41)	1333 (16.45)
Missing Data	99 (23.24)	906 (11.18)
WSAS		
Low	68 (15.96)	1765 (21.78)
Moderate	102 (23.94)	2559 (31.58)
Severe	148 (34.74)	2423 (29.90)
Missing Data	108 (25.35)	1356 (16.73)
GAD-7		
Minimal/None	12 (2.82)	913 (11.27)
Mild	57 (13.38)	1615 (19.93)
Moderate	89 (20.89)	2115 (26.10)
Severe	169 (63.15)	2547 (31.43)
Missing Data	99 (23.24)	913 (11.27)

Note. Abbreviations PHQ-9 = Patient Health Questionnaire 9 Item; WSAS = Work and Social Adjustment Scale; GAD-7 = Generalised Anxiety Disorder 7 Item

A binomial logistic regression was performed to ascertain the effects of categorical variables on the likelihood that an individual will be a 'high referrer' to BTT. The data met the assumptions (i.e., multicollinearity and no highly influential points) for a binomial logistic regression using categorical variables.

Standardised residuals with values of greater than 2.5 (ZResid) were investigated for extreme data cases; extreme data cases which appeared to be problematic would be removed

or transformed. After reviewing the values, they were not considered to be of an extreme data case and so were retained for the analysis.

The percentage of missing values across the 16 variables ranged from 0.01% to 54%. Missing data was a result of incomplete data entry and service user dropout. Multiple imputation was used to analyse the existing data and impute missing values. Multiple imputation has been deemed a reliable and accurate approach to managing missing data in sample sizes larger than 1,000 (Austin & van Buuren, 2022).

All five imputations were statistically significant; see Table 2 for the statistical output of the logistic regression model. Imputation five of the logistic regression model was statistically significant, $\chi 2(28) = 265.402$, $p < .001$, the model explained 9% (Nagelkerke R^2) of the variance in referral type and correctly classified 95% of cases.

Table 2

Statistical outputs of the binomial logistic regression across each imputation number.

Imputation Number	Chi Square	df	Significance	Nagelkerke R^2
Original Data	75.517	28	<.001	0.082
1	258.901	28	<.001	0.091
2	256.906	28	<.001	0.091
3	262.047	28	<.001	0.092
4	258.757	28	<.001	0.091
5	265.402	28	<.001	0.094

In the unadjusted analysis, 13 variables were associated as predictors of either high or low referrer categories: Age, Ethnicity, Gender, Religion, Relationship Status, Employment Status, Disability Status, LTC, Recovery, Risk Rating, PHQ-9 Score, Primary Presentation, and Discharge Reason (See Table 3). When controlling for inter-relationships between the

variables, Ethnicity, Employment Status, Disability Status, Recovery, Risk Rating and Primary Presentation were no longer significantly associated with referral type.

Table 3

Binomial logistic regression predicting likelihood of being a 'high referrer' to BTT

Exposure Variable	Parameter Coding	Model I: Unadjusted odds ratios			Final Model: Adjusted odds ratios		
		Odds Ratio (OR)	95% CI	*P*	Odds Ratio (OR)	95% CI	*P*
Age (Years)	Under 18 (0)						
	18 to 35 years (1)	**0.46**	**0.36-0.57**	**<.001**	**0.53**	**0.39-0.71**	**<.001**
	36 to 64 years (2)	**0.36**	**0.22-0.58**	**<.001**	**0.38**	**0.18-0.80**	**0.013**
	65 years and over (3)	0.64	0.43-0.96	0.03	0.78	0.36-1.71	0.51
Ethnic Group	White (0)						
	Asian (1)	1.11	0.81-1.52	0.51	0.69	0.42-1.15	0.15
	Other (2)	**1.65**	**1.20-2.66**	**0.002**	1.13	0.80-1.60	0.50
Gender	Male (0)						
	Female (1)	**0.72**	**0.58-0.88**	**0.002**	**0.71**	**0.57-0.89**	**0.003**
Religion	Christian (0)						
	Muslim (1)	0.81	0.64-1.04	0.11	1.01	0.76-1.32	0.97
	Other (2)	**1.82**	**1.24-2.67**	**0.003**	**2.00**	**1.14-3.52**	**0.017**
	No Religion (3)	0.76	0.51-1.15	0.19	1.04	0.61-1.72	0.89
Relationship Status	In a relationship (0)						
	Single (1)	**2.31**	**1.79-2.97**	**<.001**	**1.59**	**1.19-2.12**	**0.002**
	Separated (2)	1.11	0.50-2.45	0.77	1.04	0.47-2.28	0.92
Employment Status	Employed (0)						
	Unemployed (1)	**1.79**	**1.31-2.45**	**<.001**	1.26	0.90-1.76	0.18
	Long Term Sick or Disabled (2)	1.80	0.40-8.17	0.37	1.45	0.62-3.40	0.36
	Other (3)	1.14	0.86-1.52	0.35	1.04	0.71-1.52	0.82
Disability Status	Not Recorded (0)						
	Recorded (1)	**1.57**	**1.15-2.12**	**0.004**	1.25	0.86-1.82	0.24
Long Term Conditions Status	Not Recorded (0)						
	Recorded (1)	**1.63**	**1.31-2.03**	**<0.001**	**1.98**	**1.54-2.55**	**<.001**
Recovery	At Recovery (0)						
	Not at Recovery (1)	**1.66**	**1.22-2.24**	**0.003**	1.05	0.74-1.50	0.76

Risk Rating	None (0)						
	Low (1)	**1.85**	**1.36-2.52**	**<0.001**	1.24	0.88-1.75	0.23
	Medium (2)	**2.66**	**1.32-5.36**	**0.007**	1.01	0.45-2.27	0.97
	High (3)	1.80	0.30-10.77	0.44	1.70	0.37-7.86	0.43
PHQ-9 Score	None to Mild (0)						
	Moderate (1)	1.50	0.63-3.56	0.30	1.42	0.86-2.34	0.16
	Moderately Severe (2)	2.15	0.92-5.03	0.07	**1.80**	**1.21-2.68**	**0.004**
	Severe (3)	**2.90**	**1.39-6.05**	**0.011**	**2.13**	**1.38-3.29**	**0.001**
GAD-7 Score	Mild (0)						
	Minimal (1)	0.53	0.13-2.22	0.32	-	-	-
	Moderate (2)	1.04	0.63-1.71	0.88			
	Severe (3)	1.64	0.95-2.81	0.07			
WSAS Score	Low (0)						
	Moderate (1)	0.98	0.61-1.58	0.94	-	-	-
	Severe (2)	1.46	0.90-2.38	0.11			
Primary Presentation	Other (0)						
	Generalised Anxiety (1)	0.66	0.43-1.02	0.06	0.84	0.58-1.22	0.35
	Depression (2)	0.82	0.45-1.48	0.46	0.92	0.58-1.47	0.73
	PTSD (3)	**2.22**	**1.18-4.15**	**0.017**	1.80	0.95-3.40	0.07
Discharge Reason	Completed Treatments (0)	**2.12**	**1.68-2.67**	**<0.001**	**1.60**	**1.13-2.30**	**0.01**
	Dropped out of treatment (1)	1.16	0.90-1.51	0.26	1.05	0.74-1.49	0.80
	Unsuitable for IAPT (2)						
Caseness	At Caseness (0)						
	Not at Caseness (1)	0.51	1.56-1.66	0.20	-	-	-

In the initial unadjusted analysis, a range of variables were significantly associated with referrer type (i.e., age, ethnicity, gender, religion, relationship status, employment status, disability, LTC status, recovery rate, risk rating, PHQ-9 score, primary presentation and discharge reason). GAD-7 scores, WSAS scores and caseness were not significant predictors of referrer type.

In the final model of adjusted odds ratios, several variables were significant predictors of referrer type. Individuals of 'other' religious groups (i.e., Hindu, Sikh, Buddhist, Jewish) were twice as likely (OR=2.00, 95% CI 1.14-3.52) of being a high referrer. Individuals who reported being single were one and a half times more likely (OR= 1.59, 95% CI 1.19-2.12) of being a high referrer. Having a LTC were almost twice as likely (OR= 1.98, 95% CI 1.54-2.55) of being a high referrer. On the PHQ-9, individuals who scored 'moderately severe' were almost twice as likely (OR= 1.80, 95% CI 1.21-2.68), and 'severe' were twice as likely (OR= 2.13, 95% CI 1.38-3.29) of being a high referrer. Finally, having a discharge reason of 'dropped out of treatment' was around one and a half times more likely (OR= 1.6, 95% CI 1.13-2.30) of being a high referrer.

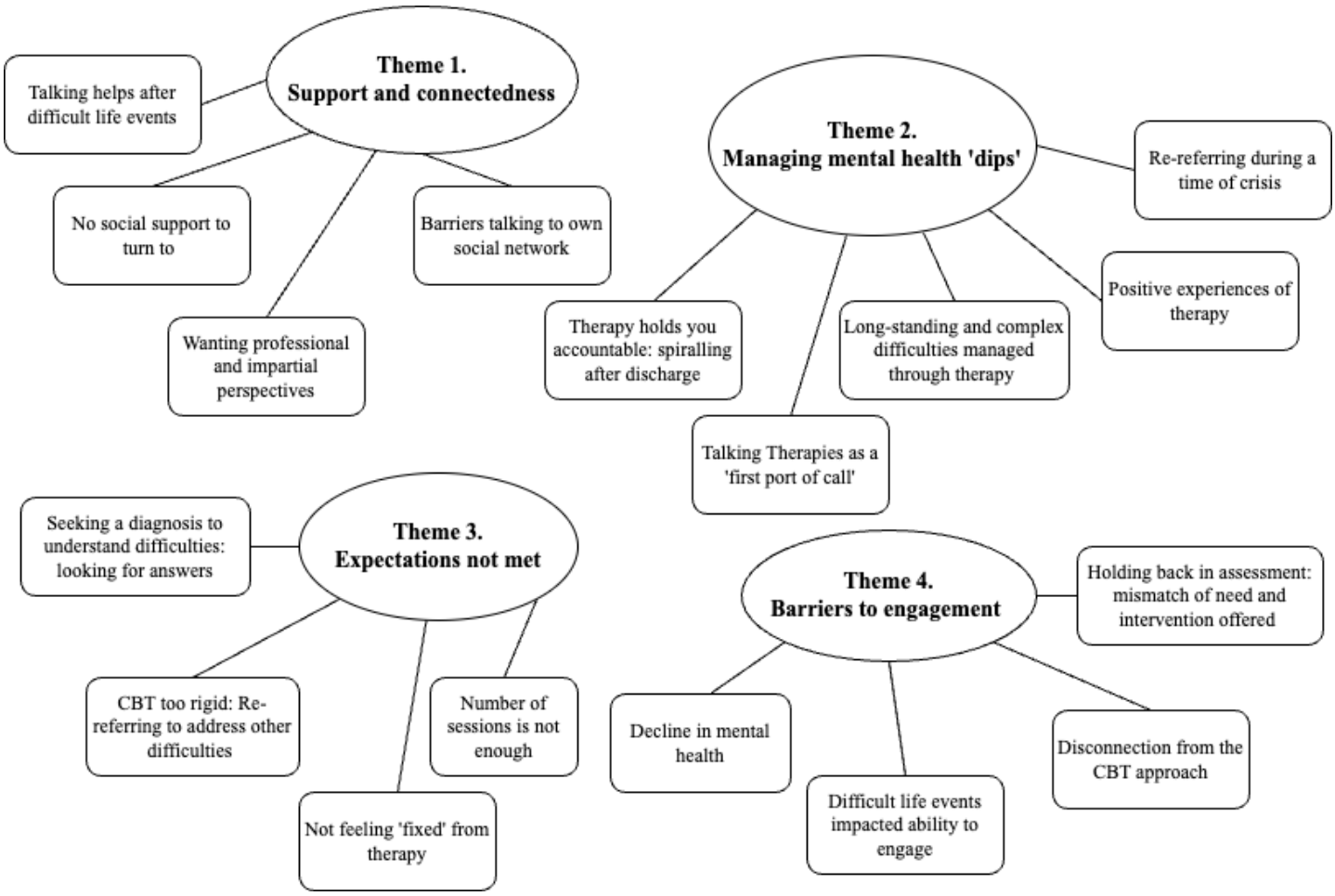
Being aged between 18 to 64 years and female was significantly associated with a reduction in the likelihood of being a high referrer to BTT. After controlling for inter-relationships between all variables, ethnicity, employment status, disability status, recovery, risk rating, and primary presentation were no longer significantly associated with referral type.

Phase 2. Semi-structured interviews

Across the nine participants (six identified as female and three as male) there was a mean age of 34 years (standard deviation 11) and an age range of 22 to 56 years (see Appendix 2D for demographic data). 55% of the sample identified as having a LTC, 44% as being single, 44% as disabled and 66% identified as being either unemployed or on long-term sick. The number of referrals to BTT ranged from four to eleven. Following the TA, four overarching themes were identified, see Figure 1 (Refer to Appendix 2E for quotes under each theme).

Figure 1

Thematic map of the themes and sub-themes devised from the TA of participant interviews.



Theme 1. Support and connectedness

Talking Helps after difficult life events

Participants spoke about experiencing difficult life events, in particular bereavement, and seeking support through BTT by self-referring; *"When I'm going through a particularly difficult time, and I know I'm struggling because I'm crying more... I think um, maybe I should go back and discuss this thing... it's been my pain, it's been my divorce, it's been… my parents dying"* (P6).

No social support to turn to

Participants spoke about using BTT as a social support network when they did not have one in their personal life; *"I don't have like, say friends... I have no support system"* (P5). One participant spoke about BTT being like a supportive partner; *"In the way you would... get home from work and moan to your other half ... I know I use talking therapies in a similar sort of way"* (P7).

Barriers talking to own social network

Participants spoke about feeling unable to seek support from their social network during difficult times. One participant explained their difficulties being enmeshed within the family system, *"there's nobody that you can talk to in your immediate family, cause it's all entangled"* (P1). Participants felt unable to talk to their partners or friends due to upsetting them or feeling like a burden; *"If I talk to my partner... or if I talked to my mum, I probably upset her with the way I was feeling"* (P8).

Wanting professional and impartial perspectives

Participants preferred talking to a professional who offered impartial and non-judgemental perspectives; *"Good talking to someone that was able to connect with me on a personal level but then also be professional"* (P8) and *"listen to you unbiased and um with no judgement"* (P7).

Theme 2. Managing mental health 'dips'

Therapy holds you accountable: spiralling after discharge

Participants spoke about therapy holding them accountable to maintain well-being; "*Having someone there to like, hold you to account, to sort of keep using these um tools and techniques*" (P1). Unfortunately, several participants discussed their mental health declining

following discharge, "*I get to the end of that 16-week course, I thought, yeah I'm feeling better, and then left on my own again I would just end up back down that spiral … finding myself at a point where I'm like I need to refer back*" (P4) and feeling uncertain as to how to manage their mental health when no longer having therapy; "*I've had this certain amount of free sessions, ... gone to all of those and then not known what to really do after*" (P2).

Talking Therapies as a 'first port of call'

Participants consider BTT as a reliable service to turn to during times of difficulty; "*It* (BTT) *always the first port of call if I'm feeling like I can't do this anymore, can't take this, it's Talking Therapies ... that's my go to*" (P5) describing re-referring as "*a no brainer*" (P8). One participant chose BTT over alternative services due to consistency; "*Talking Therapies was better because ... it's a constant thing*" (P8).

Referring during a time of crisis

Several participants noted that times of re-referral to BTT had been at a point of crisis; "*Most of the times I've been referred, I've been in crisis mode*" (P1) and noticing a significant decline in their mental health resulting in them re-referring for support; "*When I feel like it seems like things are getting bad in my head again … I usually contact them*" (P7).

Positive experiences of therapy

Participants spoke about their positive experiences of therapy from BTT and recognised the significant improvements following therapy completion; "*Every time I've gone* (to BTT) *I've come away thinking like that was worth it*" (P6) and "*Everything that I've got from Talking Therapies myself has always been spot on and has helped me"* (P5).

Long-standing and complex difficulties managed through therapy

Across all participants, there were shared experiences of long-standing and complex difficulties which they sought to address and manage within therapy; "*For my depression which I've had over the last 30 years, I've used talking therapies on and off"* (P7). Experiencing severe mental and physical health diagnoses was a shared experience amongst participants, "*I recently had PTSD from abuse as a child"* (P9) and "*Stress also triggers my multiple sclerosis symptoms"* (P5).

Theme 3. Expectations not met

Seeking a diagnosis to understand difficulties: Looking for answers

Participants spoke about re-referring to BTT on multiple occasions because they felt the previous referral did not provide them with an answer; "*I ... ended up coming back was because we hadn't managed to figure out what the actual issue was*" (P4). Participants spoke about seeking a diagnosis and coming back to BTT on multiple occasions to be diagnosed; "*I was in a pretty desperate state trying to get properly diagnosed*" (P2).

CBT too rigid: Re-referring to address other difficulties

Participants expressed that the approach in CBT was too rigid, often feeling unable to talk about wider difficulties outside of the goals of CBT; "*I tend to want to talk more about in-depth things... but in CBT it felt like... if you tried to talk to them about anything else ... they were kind of um that's not my script and they would cut you off*" (P7). Due to this, participants reported having to re-refer to the service on multiple occasions to address different problems in each new referral; "*I've had to refer back in for different things, um problems each time, about three or four times"* (P9).

Not feeling "fixed" from therapy

Participants discussed feeling that therapy with BTT they felt that therapy did not provide answers or fix their difficulties; "*There were no answers"* (P3) and "*Therapy for me seems to have given me the tools to cope with it, but it's never really sorted it out*" (P7).

Number of sessions is not enough

Most of the participants reported that the sessions were good but ended too soon; *"It should be more than 6 sessions... it certainly wasn't enough for me*" (P9). They became aware of disclosing more in sessions but not having enough time to address these problems sufficiently before discharge; "*I started opening up more and getting a bit deeper but not have enough time to work on it*" (P7).

Theme 4. Barriers to engagement

Decline in mental health

Discussions noted that a significant decline in their mental health often got in the way of engaging in therapy and resulted in treatment with BTT ending early; "*It just stopped abruptly, as I was put into a psychiatric hospital*" (P9).

Difficult life events impacted ability to engage

Many of the participants discussed difficult life events getting in the way of treatment engagement and completion. Factors included working full-time or preoccupation; "*It wasn't the right point in time*" (P3) and "*I was working full time... I didn't have much time to do it... it didn't go in*" (P1). Caring responsibilities and sudden bereavement were reported as a barrier for several participants; "*I had a really traumatic bereavement... I was doing CBT and it was actually going really well but when that event happened it just became apparent that I was not in the right headspace to continue*" (P1).

Disconnection from the CBT approach

Participants reflected on their experience of having CBT within BTT, often expressing an uncertainty around the fit of CBT for their presenting difficulties; "*Each time I've had CBT ... I still don't know whether that's the right thing for me*" (P1). Participants spoke of not feeling that connection with CBT, which resulted in early disengagement from treatment; "*So the CBT one... I felt that disconnect and I felt it was just wasting my time*" (P8).

Holding back in assessment: mismatch of need and intervention offered

Participants found it challenging to disclose in the assessment and so did not share the severity or breadth of their difficulties; "*I just didn't feel comfortable telling a complete stranger that over the phone, so they definitely only got half the story*" (P3). On previous referrals, participants felt the intervention offered did not meet their needs which led to re-referring; "*Had I gotten EMDR you know, back in the beginning, I might not have to come back so many times*" (P4).

Discussion

This project aimed to explore and understand multiple re-referrals to BTT and to make recommendations for the service. A mixed-methods approach combining retrospective analysis and semi-structured interviews was used.

Findings suggest that several variables significantly increased the likelihood of having multiple referrals to BTT (i.e., 'other' religious group status, being single, having a LTC, scoring 'moderately severe' or 'severe' on the PHQ-9). Those within a 'high referrer' category had a higher percentage of treatment dropout compared to the 'low referrer' group, which corroborates with previous research (Verbist et al., 2021). In the unadjusted model, significant differences were noted in risk rating or employment status between the two groups, which supports previous research (Cairns, 2014).

Findings from the TA suggest that participants view BTT as a supportive service. Participants held mismatched expectations, often expecting to be 'fixed' from therapy for long-standing complex difficulties or seeking a diagnosis from BTT. Participants referred to BTT for social support during difficult times, often not having specific expectations or goals from their therapy sessions. Many participants felt CBT was unhelpful or too rigid for their needs. Participants reflected several of the significant 'clinical characteristics' identified in Phase 1, such as being unemployed, single and having a LTC. However, despite efforts in recruitment, the sample was homogenous in terms of their ethnicity and religious background. This means we were unable to explore the possible factors contributing to multiple referrals from people of different backgrounds, specifically those of 'other' religions which was highlighted within Phase 1 findings. It would have been of value to have had participants in Phase 2 identify as being Hindu, Sikh, Buddhist or Jewish to explore their perspectives on why they re-referred.

The findings suggest that having a LTC increases the likelihood of having multiple referrals to BTT; this aligns with previous research which found that having a LTC contributed to poorer clinical outcomes, reduced the likelihood of reaching 'recovery', and increased the risk of re-referral (Bona et al., 2014; Seaton et al., 2022; Verbist et al., 2022). Having a LTC is linked to greater mental health difficulties (Cimpean & Drake, 2011), and an increased risk of missing health-related appointments (McQueenie et al., 2019). Missing mental health appointments increases the risk of treatment dropout and results in a further decline in mental health (Mitchell & Selmes, 2007). Therefore, the increased likelihood of discharge from BTT due to non-attendance may be linked to wider difficulties of attendance due to having mental health difficulties alongside a LTC, resulting in multiple referrals to have needs met.

SUs used BTT as a form of social support during difficult times, comparing their therapist to a friend/partner. After discharge SUs felt uncertain of where to seek support, likely contributing to further re-referrals during difficult life events. Research shows that a supportive

social network mitigates the need to require mental health services (Thotis, 2011). The lack of a social support network, or being single, can negatively impact an individual's mental health (Grundström et al., 2021; Harandi et al., 2017), especially following discharge from mental health services (Ernala et al., 2022). Research suggests that clinicians who develop personalised interventions addressing SUs need for social support outside of mental health services were found to improve the social network and mental well-being (Beckers et al., 2023).

SUs found the assessment process difficult, resulting in withholding information and consequently being offered an intervention which did not align with their expectations. This supports previous research whereby SUs find assessments to be challenging, uncomfortable and the therapy offered not being the 'right type' (Omylinska-Thurston et al., 2019). Midgley et al. (2016) found that individuals often struggle to understand what therapy is and what can be offered, which can result in mismatched expectations and unrealistic goals; mismatched expectations can result in therapy disengagement (Marshall et al., 2016; Mitchell & Selmes, 2007). Holding back in assessment, mismatched expectations and unsuitable interventions may result in early treatment dropout, and the subsequent re-referrals due to unresolved mental health difficulties.

The variables inputted into the logistic regression model explained 9% of the variance for whether someone was a 'high referrer' or 'low referrer', implying that 91% of possible contributing variables were not assessed by TT in their routine assessments. Within phase 2 of the project, participants shared their experiences of early life adversities and long-standing chronic mental health difficulties as factors contributing to seeking support from TT. Adverse childhood experiences (ACEs) are significant life events during childhood which may impact development, such as physical, emotional or sexual abuse, living in a household and witnessing violence or substance misuse or a carer being incarcerated or experiencing mental health difficulties (Scott, 2020). Adults with multiple ACEs are at an increased risk of experiencing

chronic mental and physical difficulties, including LTCs, and have increased use of mental health services compared to people with no or fewer ACEs (Scott, 2020; Tidmarsh et al., 2022; van der Velden et al., 2022). It would be interesting to explore the potential role of ACEs on the chronicity of mental health problems and re-referrals to TT; TT may benefit from using a short outcome measure to screen for ACEs, such as the Adverse Childhood Experiences Questionnaire (Felitti et al., 1998).

Strengths and Limitations

The pre-collected data had a relatively high percentage of missing data. This may limit our understanding of the different variables between 'high' and 'low' referrers. Furthermore, referrals were for both high and low intensity interventions and were not considered as two separate groups; it is likely differences between the referral types may be present. Interest in participating in interviews was low, with many SUs refusing to take part. Of the nine who did attend, all identified as White British. Thus, a representation of ethnicities was limited in second phase of this study.

This study had several strengths. Firstly, a mixed-methods approach was taken. Secondly, a large dataset was used for phase one of retrospective data analysis. Thirdly, nine interviews went ahead, which provided rich qualitative data to understand factors surrounding re-referrals. The interview sample was varied in terms of gender, age and employment status and around half the sample identified as having a LTC or disability. This has furthered our understanding of multiple referrals to BTT and helped to shape recommendations for service improvement.

Service Recommendations

A researcher (A.S) met with the BTT staff to discuss the study method, findings and recommendations. Staff feedback and responses were considered when developing the final recommendations (see Table 4).

Table 4

Findings and recommendations developed from the project, with an outlined action plan for next steps.

	Finding	Recommendation	Action Plan
1.	Service users reported having referred on multiple occasions for social support. They reported either not having access to a social support system or feeling unable to turn to this system. Service users felt 'lost' once discharged from the service and no longer knew who to turn to for support. A lack of social support can result in poorer mental health and increased likelihood of referring to mental health services. It is likely that service users would therefore re-refer during difficult times to seek that social connection and support.	• Staff training to be provided in recognising service users without a social support network outside of BTT, the impact of limited social support on mental health, ways to address this and how to conduct this within initial assessment. • Clinicians to familiarise themselves with BTT signposting services, particularly those associated with befriending services. • Offering service users with multiple referrals and limited social support the Practical Support Service (PSS) for active use of signposting. Clinicians to continue 'checking in' with service users on their engagement and progress with the PSS.	Grace Jell (Research Lead/SIP supervisor) to link in with the Berkshire TT signposting champions at PWP/S3. Grace Jell (Research Lead/SIP supervisor) to link in with Kelly Jarratt (PSS lead)
2.	Service users reported uncertainty about what support BTT can offer, and what these interventions look like. Due to this, some service users felt that it took multiple referrals to BTT to learn the language and what interventions could be offered. Some service users also had multiple referrals to BTT because they felt the previous intervention offered did not meet their expectations or their needs.	• Providing service users with information about what BTT can and cannot offer in an accessible way. • Involving both staff and service users with experience to create informative videos to be uploaded to the BTT website to inform of what interventions can be offered. • Encouraging service users access information on what can be offered for different presentations both following referral and prior to the assessment. • Following referral, service users to be sent information on 'what to expect from therapy' covering what therapy can and cannot offer.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with the Berkshire TT Comms manager (Susie Hartley)
3.	Service users explained that they felt the assessment was too impersonal. As a result, they often did not open up about their difficulties which resulted in an	• BTT to begin to discuss and consider how the Psychological Wellbeing Practitioner (PWP) assessments are being	Dr Grace Jell (Research Lead/SIP supervisor) to link in with Berkshire TT Business Manager

	intervention being offered that did not address their difficulties appropriately. Service users felt this added to them coming back to the service again following discharge, due to feeling their difficulties not being full addressed by the intervention they were provided.	conducted (i.e., over the phone, video call, face to face) with the aim of improving engagement and disclosure of current difficulties to triage. • BTT service to consider the feasibility of offering flexible assessment approaches for service users with multiple referrals (e.g., method of assessment, duration of assessment or conducting the assessment over several sessions).	(Nicola Farrin) and the Step 2 Service Lead (Carole Mortlock)
4.	Service users with long-term health conditions were more likely to be a 'high referrer' compared to those without a long-term health condition.	• Assessing and screening for service users who identify as having a long-term condition and the possible impact this is having on their mental health. • The Long-Term Conditions (LTC) workstream within BTT offers training to clinicians around working with a long-term condition. Recommendation for BTT to ensure regular reviews and input for clinicians if offered, with training around multiple referrals and long-term conditions and reminding clinicians to make use of specialist LTC supervision. • High Intensity Therapists and clinicians and PWPs to familiarise themselves with assessment questionnaires on the WHO-DAS-2 regarding the impact on a long-term condition and disability on daily life. This can help shape assessment structure and questions when considering the impact of a long-term condition on mental wellbeing. • Clinicians to consider using condition specific outcome measures (i.e., Pain Index) to better assess and understand the impact of the LTC on everyday functioning. • PWPs and High Intensity therapists to be aware of the LTC and to consider with the service user whether therapy goals should reflect the impact of the LTC on everyday functioning.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with LTC workstream leads (Abi Wroe, Judy Pritchard, Jordan Cuthbert)
5.	Service users expressed either having no expectations from their therapy sessions, or not feeling that they had attained their goals from	• Supporting service users, in particular those with multiple referrals to BTT, to have clear expectations from their therapy sessions and attainable and realistic SMART goals.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with Step 2 service leads (Carole Mortlock, Emma Hayden, Kelly Barnard)

	therapy. Some goals may have been unattainable, such as being 'fixed from therapy'	• Encouraging early identification of expectations from BTT at the point of self-referral • Staff training for clinicians and PWPs around supporting service users with identifying clear expectations and goals from therapy sessions, during PWP Orientation Program (POP) training sessions and to outline how clinicians can articulate what BTT can offer. • Clinicians to regularly review and refine service user goals across the first few sessions of the intervention. • Inclusion of an additional question on the online self-report referral form to prompt individuals to outline what they are hoping to gain from BTT, and if uncertain prompts can be outlined of what BTT can offer. • Clear expectations of what BTT can and cannot offer through comms with G.P practices and other primary or secondary care mental health services who often complete referrals to the service.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with Business managers (Bridget Elkington/Nicola Farrin) and Admin managers (Kate Blagrave, Georgia Webb) around adding a question to the online self-referral form.
6.	Service users who were discharged due to dropping out of treatment were around 1.5 times more likely to come back to the service on multiple referrals compared to those who were discharged due to treatment completion or being unsuitable for IAPT.	• Further service evaluation as to the reason why service users with multiple referrals to BTT dropped out of treatment previously. • Management of expectations of both assessment and treatment offered by BTT. • Flexibility in delivering treatment approaches. • The service to consider reviewing the DNA policy and procedure and to consider what approaches are being taken with SUs with multiple referrals to improve flexibility or increase engagement following a DNA.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with BTT senior leadership team.

7.	Service users with multiple referrals felt they were required to share their life histories every time they re-referred. They felt this was distressing and uncomfortable and may contribute to not opening up during assessment and thus not being offered an appropriate intervention leading to further referrals in the future.	• Awareness of historical referrals to BTT and discussion of this within clinical assessment. • Adaptation for history taking of assessment to explore previous therapy input from previous referral. • BTT to review the current approach that clinicians take when reviewing historical notes prior to assessment. • Offering staff training for clinicians to re-cap on assessment skills in relation to covering previous referral history and exploring with service users what they are hoping to gain from the re-referral to the service.	Dr Grace Jell (Research Lead/SIP supervisor) to link in with Step 2 Service Leads (Carole Mortlock, Emma Hayden and Kelly Barnard)

Conclusion

This study has provided insight and SU perspectives on multiple referrals to BTT. It is hoped that the findings and recommendations for service improvement can be implemented to improve clinical outcomes for SUs with multiple referrals. Ongoing evaluation and a 6-month review of recommendations are suggested.

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Theory Driven Research Project

Exploring the Prevalence and Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease

Word Count: 5,348 (Excluding references and appendices, tables & figures as 100 words or less, and including 10% for corrections)

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Proposed Journal: Behavioural and Cognitive Psychotherapy; experimental and clinical work contributing to the theory, practice and development of cognitive and behaviour therapy.

Abstract

Background: Chronic Obstructive Pulmonary Disease (COPD) is a debilitating lifelong condition affecting the respiratory system. COPD is a major cause of mortality worldwide, with an ever-increasing prevalence across the population (Devine, 2008). Previous studies indicate that people with COPD experience high rates of anxiety, including health anxiety (HA). Studies of other chronic physical health conditions found that high HA leads to greater negative misperceptions of physical functioning and impacts quality of life, mental health, and self-rated disability (Carrigan et al., 2018; Daniels et al., 2017; Diamond et al., 2022; Hayter et al., 2016).

Method: Participants were recruited from a community-based NHS population. Forty-two participants with COPD were screened for HA and assigned to either a high or a low-health anxiety group. Participants completed a physical functioning task, alongside measures for perception of physical performance, mood, quality of life and disability. Comparisons were made with a healthy control (HC) group.

Results: COPD participants with high HA misperceived themselves as performing poorer on a physical functioning task. Participants with high HA and COPD reported a greater self-reported disability compared to the HC group.

Conclusion: HA is highly prevalent within those diagnosed with COPD, which can impact on perceptions of physical performance and self-reported disability. Given this, further research is needed to explore the effectiveness of psychological interventions to reduce HA in individuals with COPD.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a physical health condition affecting the lungs and respiratory system. Individuals with COPD experience persistent limited airflow and alveolar abnormalities (Mirza et al., 2018), coughing, dyspnea (i.e., shortness of breath, the sensation of suffocation and tightness of chest), obstructed airflow, excessive sputum production, wheezing and fatigue (World Health Organisation, 2022). COPD is incurable, with a worsening of symptoms over time (National Institute for Health and Care Excellence, 2016) alongside exacerbation episodes (i.e., sudden and severe worsening of symptoms, risk of hospitalisation, mortality and faster disease progression) (Wedzicha & Seemungal, 2007). COPD is the third leading cause of death worldwide, with approximately three million people diagnosed in the UK (National Institute for Health and Care Excellence, 2016; World Health Organisation, 2022) and a prevalence rate of 4.9% in UK adults aged over 40 years (Stone et al., 2023). Treatments aim to manage symptoms, with pulmonary rehabilitation (PR), inhalation therapy and medication recognised as gold standard interventions for COPD (National Institute for Health and Care Excellence, 2021).

COPD & Anxiety

The prevalence of anxiety ranges from 16% to 65% within a COPD population, this being higher compared to the general population (Husain et al., 2021; Kunik et al., 2005; Willgoss & Yohannes, 2013). High anxiety and COPD have been associated with poorer management of the disorder, increased risk of mortality, hospital admission duration, symptom severity and a lower quality of life (Harryanto et al., 2018; Pumar et al., 2014). Despite the high prevalence and significant impact on well-being in people with COPD, approximately 30% receive mental health treatment (Baraniak & Sheffield, 2011; Kunik et al., 2005). Despite NICE guidelines recommending clinicians assess and manage mental health in people with COPD, clinicians feel that the treatment of COPD is overly medicalised with physical health

being the priority above mental health (Ogunbayo et al., 2017). Although research has highlighted the high prevalence of anxiety within the COPD population, less is known about specific anxiety sub-types.

Health Anxiety & Chronic Physical Health Conditions

Health Anxiety (HA), also known as hypochondriasis, is defined as a persistent worry or fear about having, or developing, a serious or progressive life-threatening illness (World Health Organisation, 2019). This excessive fear and preoccupation towards physical health persists despite reassurance from medical professionals (Diamond et al., 2022). Those with a pre-existing diagnosis of a serious or progressive chronic physical health condition (CPHC) could develop HA (Lebel et al., 2020). Individuals with a CPHC and HA have shown persistent worrying about the worsening of their health condition and misinterpret ambiguous physical sensations as being related to their health condition or a sign of their condition worsening (Daniels et al., 2017; Diamond et al., 2022).

Previous studies found a high prevalence of HA within CPHC (i.e., stroke, multiple sclerosis, and chronic fatigue syndrome), (Carrigan et al., 2018; Daniels et al., 2017; Diamond et al., 2022; Hayter et al., 2016). Having a CPHC and high HA resulted in increased bodily vigilance of symptoms, misattribution of benign physical sensations to their diagnosis and catastrophic cognitions around a worsening of their condition (Carrigan et al., 2018; Ratcliffe et al., 2006) which were exacerbated further when the physical symptoms of anxiety were similar to symptoms of the CPHC (Diamond et al., 2022; Ratcliffe et al., 2006).

Furthermore, individuals with a CPHC and high HA, compared to low HA, were more likely to perceive their performance on physical and cognitive functioning tasks as being more impaired, when objectively their performance was intact and were more likely to attribute the cause of their perceived impairment to their CPHC (Carrigan et al., 2018; Hayter et al., 2016).

Individuals with a CPHC and high HA were found to be more likely to experience a lower quality of life, increased risk of depression, and higher self-reported disability compared to low HA people (Carrigan et al., 2018; Daniels et al., 2017; Diamond et al., 2022).

Health Anxiety & COPD

There is limited research exploring HA within COPD, especially within a community-based setting. Existing research suggests that COPD patients are at an increased risk of developing HA; 20% of patients attending a respiratory medicine clinic and 48% of hospitalised 'complex COPD' patients met the diagnostic criteria for HA (Craig, 2016; Tyrer et al., 2011) compared to only 3.4% of the general population (Sunderland et al., 2013).

The cognitive model of HA (Salkovskis et al., 2001) suggests it is hypervigilance towards and misinterpretation of bodily sensations, that are seen as evidence of having, or being at risk of developing, a serious physical health condition, which develops and maintains the HA. This catastrophic misinterpretation and misattribution of threat-related stimuli result in a range of emotional, cognitive, behavioural, attentional and physiological responses, as well as safety-seeking behaviours (i.e., heightened anxiety, physiological arousal, selective attention to bodily cues, symptom checking, avoidance, and reassurance-seeking). These safety-seeking behaviours, such as continued checking for symptoms of serious illness, maintain and exacerbate the HA over time. In the context of COPD, people have a serious illness, but symptoms such as dyspnea can trigger the development and maintenance of anxiety (Livermore et al., 2010). For example, people with COPD may misinterpret breathlessness and chest tightness (symptoms of anxiety) as being catastrophic or indicative of an exacerbation of their illness. Individuals with COPD are more sensitive to changes in their breathing than controls (Sage et al., 2008), hence their hypervigilance to changes in physical sensations are likely to contribute to HA.

Clinical Implications

People with COPD and high anxiety are at a higher risk of disengaging from PR and dropping out of treatment (Eisner et al., 2010). Hayton et al. (2012) found that 32% of patients with COPD would not attend a single PR session and 29% dropped out of the PR program before completion due to anxiety. Given that PR is the recommended intervention for COPD management, it is concerning that HA may play a role in the avoidance of this treatment. Similarly, Borgmann et al. (2020) found that psychological factors negatively impacted the performance of a 6-minute walking test (6MWT) in people with COPD. It may be that misperceptions of physical functioning may be impacting PR engagement if health-anxious patients with COPD perceive themselves as being less physically able to complete the exercises than they really are. Exploring whether HA impacts perceptions of performance, general well-being and quality of life (QoL) in patients with COPD can help shape service provision and support individuals who meet HA criteria to attend PR programs to manage their COPD. Management of COPD is vital for improving overall well-being, reducing breathlessness and health care utilisation such as hospitalisation (Corhay et al., 2014).

Current Study

This study aimed to explore the prevalence of HA in a community sample of patients with COPD referred for PR. Similar to previous studies exploring HA in CPHCs, it was hypothesised that participants with COPD and high health anxiety (HiHA) would rate their performance on a physical health task (the 6MWT) as poorer than participants with COPD and low health anxiety (LoHA). Additionally, they would be more likely to attribute their performance to COPD to a greater extent than the LoHA group. Given this impact on perceived physical and cognitive functioning, as well as general mental wellbeing, it was further predicted the HiHA group would self-report lower QoL, higher disability, greater scores on mood and generalised anxiety compared to the LoHA group and a healthy control (HC) group.

Method

Design

This study aimed to replicate the methodology used in similar research (Carrigan et al., 2018; Hayter et al., 2016). It used an independent groups design, with the level of HA and HC as a between-subjects factor.

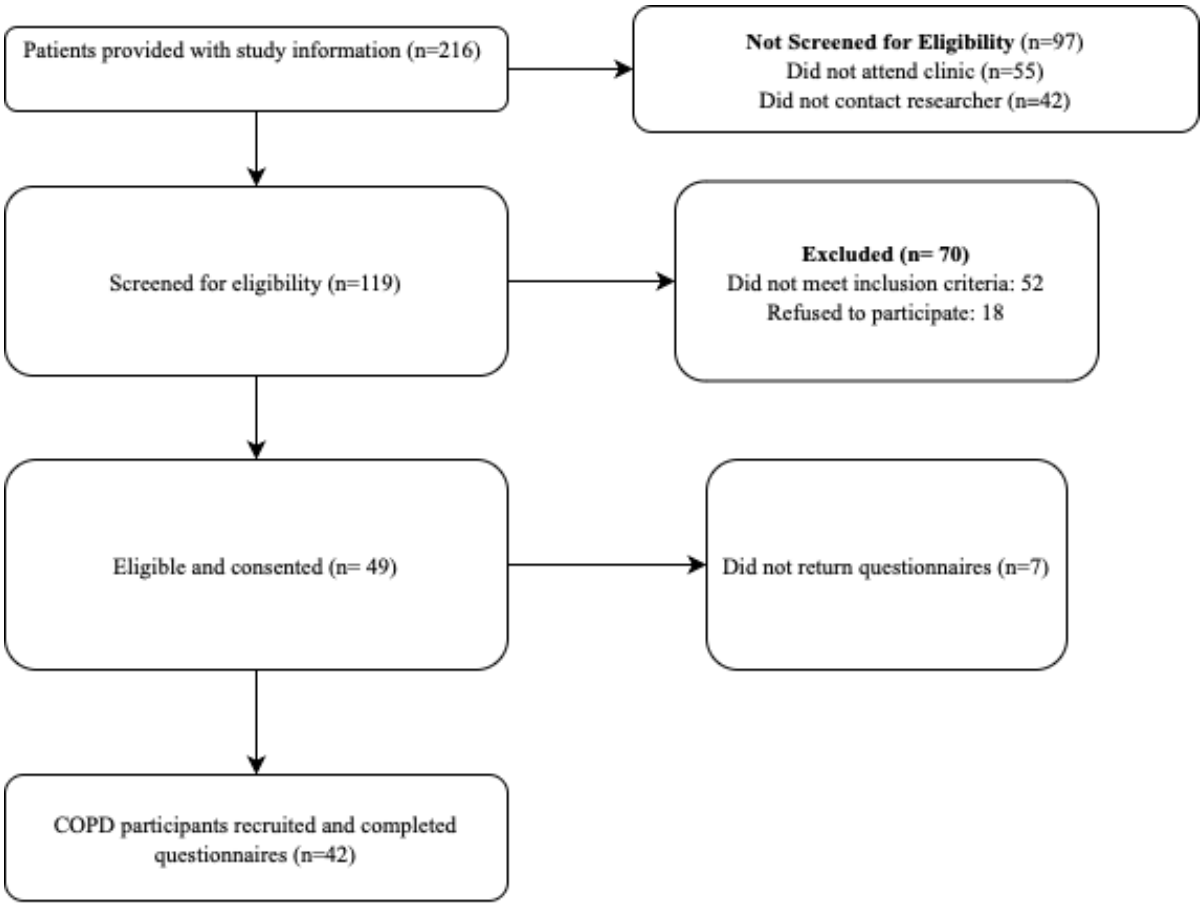
Participants

Participants with COPD were recruited from an NHS community Integrated Respiratory service. All patients with respiratory conditions invited to attend an initial assessment for PR were provided with the study information. The first author or a research assistant attended in-person at the clinic across various sites to invite and screen for eligibility. Participants with a COPD diagnosis, no other chronic physical health diagnoses, aged 18 years and over, not experiencing severe mental health difficulties and fluent in English were eligible to take part. Patients with more than two COPD exacerbations in the past year or co-morbidity of other respiratory or rheumatological conditions were excluded from taking part. See Figure 1 for a participant flow diagram of COPD patients.

HC were recruited through community advertisement and contacted the first author if they were interested in participating; HC eligibility included being 18 years and over, fluent in English, having no chronic health conditions and not experiencing severe mental health difficulties.

Figure 1.

Participant recruitment flow diagram of COPD patients recruited through the NHS community Integrated Respiratory service.



Measures

Health Anxiety. HA was assessed using a modified version of the Short Health Anxiety Inventory (SHAI), used by Carrigan et al. (2018). The modified version included the statement 'other than COPD' at the end of several items (i.e., 5, 9, 11 and 12) so participants with COPD would answer without their diagnosis impacting their responses. The SHAI is a reliable and valid measure of HA within non-clinical populations and with individuals with CPHC (Abramowitz et al., 2007; Alberts et al., 2012) with a Cronbach's alpha range from 0.74 to 0.96 (Alberts et al., 2012). The SHAI includes 14 items assessing HA symptoms, with scores ranging from 0 to 42. A higher score indicates greater HA symptoms, with a score of 18 and

above indicating clinically diagnosable levels of HA, and a score between 15 to 17 indicating some symptoms of HA, (Salkovskis et al., 2002).

Physical Functioning. Physical functioning was measured by the 6MWT, a standardised routine measure to assess the functional status of individuals with respiratory conditions by measuring the distance walked in meters over a 6-minute duration. The 6MWT has been identified as a valid and reliable measure (Celli et al., 2016). Physiotherapists completed this 6MWT with patients within the assessment clinics. The first author completed the 6MWT with participants in the HC group, recording the distance walked in meters.

Misperception and Misattribution. Misperception of performance (MOP) on the physical functioning task was measured using an adapted self-report measure, developed by Hayter et al. (2016) and used by Carrigan et al. (2018). After the 6MWT, participants were asked to evaluate how they felt they performed compared to others with COPD on a scale from -50 ('extremely badly in comparison to others') to +50 ('extremely well in comparison to others'). Participants rated how much better they felt their performance on the 6MWT would be if they did not have a COPD diagnosis from 0 ('no better') to 100 ('very much better').

Quality of Life (QoL). The St. George's Respiratory Questionnaire (SGRQ) is a 50-item self-report measure to measure health-related QoL in people diagnosed with a respiratory condition, including COPD (Meguro et al., 2007). The SGRQ measures across three domains (Symptoms, Activity and Impact) and produces a total score. A higher score indicates a poorer QoL caused by the respiratory condition. The SGRQ is a valid and reliable measure for individuals with respiratory conditions including COPD (Jones et al., 1992).

Mood. The participant's mood was assessed using the Patient Health Questionnaire (PHQ-9) self-report questionnaire. The nine items assess symptoms of clinical depression, with a score of 10 or higher indicating depression symptoms being present (Kroenke et al., 2001).

The PHQ-9 has high validity and reliability across clinical populations (Sun et al., 2020), Cronbach's alpha of 0.89 and test-retest reliability of r= 0.84 (Kroenke et al., 2001).

Generalised Anxiety. Generalised anxiety was measured using the Generalised Anxiety Disorder (GAD-7) self-report questionnaire. The seven items assess the frequency and severity of generalised anxiety disorder (GAD) symptoms, with a score of 10 or higher indicating a clinical diagnosis of GAD (Spitzer et al., 2006). GAD-7 is routinely used within healthcare settings and has high reliability and validity (Johnson et al., 2019) with Cronbach's alpha at 0.92 and test re-test reliability of r=0.83 (Spitzer et al., 2006).

Disability. The impact of COPD on self-reported disability was measured using the World Health Organisation Disability Assessment Schedule 2.0 (WHO-DAS-36). The WHO-DAS-36 is a 36-item self-report measure of health and disability (Üstün et al., 2010). Items are rated from 'none' to 'extreme or cannot do'; each domain is scored separately alongside an overall general disability score, ranging from 0 (no disability) to 100 (full disability). The WHO-DAS-36 has high reliability and validity within a COPD population, a Cronbach's alpha of 0.98 and generalisability across cultures (Üstün et al., 2010; Zacarias et al., 2022).

Demographics. Demographic information was collected from each participant, including age, gender, ethnicity, employment status, relationship status and education level.

Procedure

All patients invited to attend an assessment within the Integrated Respiratory Service received study information in their assessment packs. The lead physiotherapist identified patients who may meet the criteria (i.e., a COPD diagnosis) and asked whether the patient was interested in talking to a researcher. Those interested were screened for eligibility by the first author or research assistant; those who met the criteria signed the consent form. Participants completed their routine assessment, which included the 6MWT with a physiotherapist, the

GAD-7 and PHQ-9. They then completed the remaining questionnaires in the clinic (i.e., SHAI, MOP ratings, WHO-DAS-36, SGRQ, and demographics). The routine assessment alongside the additional study-specific measures had a completion time of up to 90 minutes, with study specific questionnaires taking between 15 to 45 minutes. Due to time constraints, some participants opted to take home the questionnaires and return them.

HC participants were recruited via community advertisement. This involved distributing the HC recruitment poster across libraries, local community information boards, online community groups and attending places of worship. The researcher screened individuals over the phone and those eligible were invited to attend an in-person session. The researcher administered the 6MWT and the outcome measures (i.e., SHAI, MOP ratings, WHO-DAS-36, PHQ-9 and GAD-7).

Statistical Analysis

Statistical analysis was conducted using the IBM Statistical Package for the Social Sciences (SPSS) statistics program for Mac (version 29). Descriptive statistics were used to compare participant demographic factors (*N,* mean, SD, %) alongside scores across the outcome measures (*M, SD).* To test the main hypotheses, a median-split of the SHAI scores was used to allocate COPD participants to the HiHA or LoHA groups. Where parametric assumptions were met, a one-way ANOVA was used to compare means of the three groups across measures. For COPD specific analysis, independent-sample t-tests explored differences between the HiHA and LoHA groups.

When parametric assumptions were not met, a non-parametric alternative were used (i.e., Mann-Whitney U and Kruskal-Wallis tests). A Bonferroni correction was used to adjust for multiple comparisons. Based on the effect size from a methodologically similar study (Hayter et al., 2016), a priori power analysis using G* Power (Faul et al., 2009) with an alpha

level of 0.05, 95% power and effect size of Cohen's f = 0.725, a minimum sample size of 33 participants across the three groups. To increase the likelihood of meeting parametric assumptions (e.g., normally distributed data) and to account for attrition the sample size was increased to 60 participants across the three groups.

Results

Sixty-two participants took part in the study: forty-two with COPD and twenty HC's. Four HC participants were identified as outliers due to scoring above clinical cutoff on the SHAI and so were removed from the analysis. The ages of the total sample ranged from 27 to 90 (mean 65.74, SD 17.17), with an even number of males (n=30, 51.73 %) and females (n= 28, 48.28%). A majority of the sample identified as white (n= 51, 87.93%), married (n=25, 43.10%), retired (n=31, 53.45%) and educated to a standard grade level (n=18, 31.03%). See Table 1 for individual group demographic data. In terms of HA, the scores on SHAI in the HiHA group were an average of 16.27 (SD 4.15) compared to 6.4 (SD 2.91) in the LoHA and 7.05 (SD 2.26) in the HC groups.

Table 1.

Demographic factors across the three groups.

	Participant Group		
	HiHA (*n* = 22)	**LoHA** (*n* = 20)	**HC** (*n* = 16)
Age (Mean, SD)	68.59 (12.54)	74.95 (11.01)	46.69 (15.43)
Gender (*n*, %)			
Female	11 (50)	10 (50)	7 (44)
Male	11 (50)	10 (50)	9 (56)
Ethnicity (*n*, %)			
White	20 (90.91)	20 (100)	11 (68.75)
Asian/Asian British	2 (9.09)	-	3 (18.75)
Mixed Ethnicity	-	-	1 (6.25)
Other	-	-	1 (6.25)
Education (*n*, %)			
SATS	2 (9.09)	1 (5)	1 (6.25)
Standard Grades/GCSE/O-levels	8 (36.36)	8 (40)	2 (12.5)
Highers/A-level/BTEC	5 (22.73)	3 (15)	-
National Vocational Qualification	2 (9.09)	2 (10)	1 (6.25)
Undergraduate Degree	-	3 (15)	7 (43.75)
Postgraduate Qualification	-	1 (5)	5 (31.25)
Unknown	5 (22.73)	2 (10)	-
Employment Status (*n*, %)			
Employed	1 (4.55)	3 (15)	12 (75)
Unemployed	3 (13.64)	-	2 (12.5)
Long Term Sick	1 (4.55)	-	-
Disabled	1 (4.55)	-	-
Retired	15 (68.18)	16 (80)	-
Student	-	-	1 (6.25)
Self-employed	1 (4.55)	1 (5)	-
Other	-	-	1 (6.25)
Relationship Status (*n*, %)			

Married	12 (54.55)	8 (40)	5 (31.25)
Divorced/Separated	1 (4.55)	5 (25)	1 (6.25)
Single	3 (13.64)	2 (10)	5 (31.25)
Widowed	6 (27.27)	4 (20)	-
Other	-	1 (5)	5 (31.25)

A Kolmogorov-Smirnov test for normality on the primary dependent variable of MOP comparison to others, was significant, $D(58) = 0.18$, $p = <0.001$, indicating that the data was not normally distributed across groups. Hence non-parametric analyses were used to compare the groups.

Demographic factors across the groups were compared using either a Kruskal Wallis test or Chi-square test. Significant differences were found between the groups on age, $H(2) = 24.79$, $p = <0.001$, however there was no difference between the HiHA and LoHA groups, $H(2) = -8.02$, $p = 0.37$. Furthermore, employment status X^2 (7, N = 58) = 114.41, $p = <0.001$, ethnicity X^2 (3, N = 58) = 123.24, $p = <0.001$, relationship status X^2 (5, N = 58) = 33.66, $p = <0.001$ and education X^2 (5, N = 51) = 12.41, $p = 0.03$ were significantly different between groups. No differences were found for gender, X^2 (1, N = 58) = 0.07, $p = 0.79$ or the number of COPD exacerbations, $H(1) = 0.81$, $p = 0.77$.

Age, employment status and ethnicity were considered theoretically relevant covariates to control for within the analysis based on previous literature identifying the impact of these variables on mental health, QoL and physical functioning, (Gerolimatos & Edelstein, 2012; Jimenez et al., 2010; Park et al., 2020). These three covariates were controlled for by a Quade non-parametric ANCOVA.

Misperceptions of Performance

Table 2 presents the means (SD) for perceived performance on the 6MWT across groups. The HiHA participants (M 7.5, SD 27.24) perceived their physical performance on the

6MWT as being poorer than the LoHA (M 24.15, SD 27.56) and HC participants, (M 19.06, SD 12.94); this difference was statistically significant, $F(2, 55) = 3.35$, $p = 0.042$ (see Table 4). Pairwise comparisons using Bonferroni corrections showed that this difference was between the HiHA and LoHA groups, $t(55) = -2.59$, $p = 0.012$, $d = 0.64$.

For perceived performance on the 6MWT had they not been diagnosed of COPD, HiHA participants (M 79.09, SD 23.48) rated this as higher than the LoHA participants (M 58.5, SD 36.31), however no significant difference between the two groups was found, $F(1, 40) = 2.37$, $p = 0.13$, $d = 0.67$.

The HiHA group expressed greater worry about their physical performance (M 24.55, SD 25.58) compared to the LoHA (M 8.25, SD 14.44) and HC group (M 8.56, SD 16.54), a significant difference between groups was found, $F(2, 55) = 3.36$, $p = 0.04$. After controlling for pairwise comparisons with Bonferroni corrections, the differences between the HiHA and LoHA were no longer significant, $t(55) = 2.41$, $p = 0.02$, $d = 0.78$.

HC participants walked furthest on average (M 521.06, SD 127.82), followed the HiHA group (M 385, SD 63.64) and the LoHA group (M 225.15, SD 119.29). A significant difference was found between groups on distance walked, $F(2, 55) = 5.10$, $p = 0.01$. Pairwise comparisons of groups with Bonferroni corrections indicated that this difference was between the HC and the HiHA group, $t(55) = -3.04$, $p = 0.004$, $d = 1.35$. There was no significant difference between the HiHA and LoHA groups, $t(55) = -0.47$, $p = 0.64$, $d = 1.67$.

Table 2.

Means (SD) of participants' perceived performance on the 6MWT, degree of worry before completing the 6MWT, how much better their performance would have been without a COPD diagnosis and distance walked in meters.

	Participant Group		
	HiHA	**LoHA**	**HC**
Perceived performance on 6MWT (-50 to +50)	7.5 (27.24)	24.15 (27.56)	19.06 (12.94)
Worry about physical performance (0 to 100)	24.55 (25.58)	8.25 (14.44)	8.56 (16.54)
Perceived performance if no COPD (0 to 100)	79.09 (23.48)	58.5 (36.31)	-
Distance walked in meters	385 (63.64)	225.15 (119.29)	521.06 (127.82)

Secondary Outcomes

Table 3 presents participants score on mood, generalised anxiety, disability and QoL. In terms of mood (PHQ-9), the HiHA participants (M 7.18, SD 5.93) and LoHA participants (M 6.15, SD 5.18) scored higher than the HC group (M 2.13, SD 2.53). There was no statistically significant difference between groups, $F(2, 55) = 1.24$, $p = 0.30$ (see Table 4).

The HiHA (M 4.5, SD 4.93), LoHA (M 3.35, SD 4.30) and HC (M 2.75, SD 2.57) participants showed similar scores on generalised anxiety (GAD-7); there was no statistically significant difference across the groups, $F(2, 55) = 0.40$, $p = 0.67$.

As shown in Table 3, the HiHA (M 0.92, SD 0.63) showed a higher level of self-reported disability (WHO-DAS) compared to the LoHA group (M 0.71, SD 0.53) and the HC group (M 0.16, SD 0.16), and there was a statistically significant difference across groups, $F(2, 55) = 7.90$, $p = .001$. Pairwise comparisons of groups with Bonferroni corrections indicated a significant difference between the HiHA and HC, $t(55) = 3.91$, $p = <0.001$, $d = 1.65$ however

no significant differences were found between the HiHA and LoHA groups, $t(55) = 2.38$, $p = 0.021$, $d = 0.36$, or the LoHA and HC group, $t(55) = 1.64$, $p = 0.11$, $d = 1.40$.

In terms of QoL (SGRQ), the HiHA participants (M 45.42, SD 14.99) and LoHA group (M 42.49, SD 14.65) had similar scores, with no statistically significant difference between the two groups, $F(1, 40) = 0.32$, $p = 0.57$, $d = 0.2$. When comparing the number of exacerbation episodes as measured on the SGRQ, there was no significant difference between the HiHA (M 0.77, SD 0.87) and the LoHA (M 0.8, SD 0.70) groups, $F(1, 40) = 0.12$, $p = 0.73$, $d = 0.04$.

Table 3.

Means (SD) of the self-reported outcome measures across mood, generalised anxiety, quality of life and disability across the three participant groups.

	Participant Group		
	HiHA	**LoHA**	**HC**
PHQ-9	7.18 (5.93)	6.15 (5.18)	2.13 (2.53)
GAD-7	4.5 (4.93)	3.35 (4.30)	2.75 (2.57)
WHO-DAS (M, SD)	Mild (0.92, 0.63)	Mild (0.71, 0.53)	None (0.16, 0.16)
Understanding and Communication	Mild (0.70, 0.60)	None (0.43, 0.59)	None (0.33, 0.29)
Getting Around	Mild (1.23, 1.03)	Mild (1.15, 0.98)	None (0.08, 0.14)
Self-Care	Mild (0.55, 0.80)	None (0.33, 0.61)	None (0.05, 0.14)
Getting Along with People	Mild (0.58, 0.61)	None (0.49, 0.41)	None (0.25, 0.37)
Life Activities (Household)	Mild (1.43, 1.05)	Mild (0.89, 0.97)	None (0.16, 0.24)
Life Activities (Work/School)	None (0.33, 0.55)	None (0.35, 0.69)	None (0.05, 0.10)
Participation in Society	Mild (0.95, 0.70)	Mild (0.76, 0.57)	None (0.12, 0.19)
SGRQ	45.42 (14.99)	42.49 (14.65)	-
Symptoms	51.23 (20.84)	52.02 (20.73)	-
Activity	64.45 (17.87)	63.41 (21.16)	-
Impacts	32.71 (15.95)	28.35 (14.91)	-

Table 4.

Statistical outputs from the Quade non-parametric ANCOVA with Pairwise Comparisons between groups whilst controlling for co-variates (i.e., age, employment status and ethnicity).

Measures	**Quade Non-parametric ANCOVA**			**Pairwise Comparisons**			
				Comparison	***t***	**df**	***p****
	F	**dfh/dfe**	***p***				
MOP Comparison	**3.35**	**2/55**	**0.04**	HiHA - LoHA	**-2.59**	**55**	**0.012**
				HiHA - HC	-1.16	55	0.25
				LoHA - HC	1.25	55	0.22
MOP Worry about performance	**3.36**	**2/55**	**0.042**	HiHA – LoHA	2.41	55	0.019
				HiHA – HC	1.93	55	0.059
				LoHA - HC	- 0.33	55	0.746
MOP Performance without COPD	2.38	1/40	0.13	-	-	-	-
WHODAS Global	**7.90**	**2/55**	**0.001**	HiHA - LoHA	2.38	55	0.021
				HiHA - HC	**3.91**	**55**	**<0.001**

				LoHA - HC	1.64	55	0.11
Domains							
Understanding Communication	3.08	2/55	0.054	-	-	-	-
Getting Around							
	6.68	**2/55**	**0.003**	HiHA - LoHA	1.45	55	0.15
				HiHA - HC	**3.65**	**55**	**0.001**
				LoHA - HC	2.24	55	0.029
Self-Care							
	1.72	2/55	0.19	-	-	-	-
Getting Along with People							
	1.63	2/55	0.21	-	-	-	-
Life Activities Household							
	7.75	**2/55**	**0.001**	**HiHA - LoHA**	**3.05**	**55**	**0.004**
				HiHA - HC	**3.60**	**55**	**0.001**
				LoHA - HC	0.72	55	0.45
Life Activities Work							

	3.85	**2/29**	**0.033**	HiHA - LoHA	0.87	29	0.39
				HiHA - HC	**2.65**	**29**	**0.013**
				LoHA – HC	1.61	29	0.11
Participation in Society							
	6.12	**2/55**	**0.004**	HiHA - LoHA	1.20	55	0.05
				HiHA - HC	**3.46**	**55**	**0.001**
				LoHA - HC	1.55	55	0.13
6MWT Distance	**5.10**	**2/55**	**0.009**	HiHA - LoHA	-0.47	55	0.64
				HiHA - HC	**-3.04**	55	**0.004**
				LoHA - HC	**-2.54**	**55**	**0.014**
PHQ-9	0.28	2/55	0.30	-	-	-	-
GAD-7	0.40	2/55	0.68	-	-	-	-
SGRQ	0.32	1/40	0.57	-	-	-	-

*Note. * Adapted p value of using Bonferroni corrections for multiple comparison.*

Discussion

This study aimed to explore the prevalence and impact of HA on a community population of individuals diagnosed with COPD and referred for PR. Clinically significant levels of HA (i.e., scores above 18 on the SHAI) were present in 16% of the COPD group, with 31% showing borderline symptoms of HA (i.e., scores between 15 to 17 on the SHAI). This finding is comparable to previous studies exploring the prevalence of HA in individuals with COPD (Tyrer et al., 2011) and higher than the general population (Sunderland et al., 2013). Findings suggest that individuals with COPD and HiHA misperceive their ability on a physical functioning task as being poorer than it really was. This finding is consistent with previous studies other CPHC's (Carrigan et al., 2018; Hayter et al., 2016). There was no difference between groups on the perception of performance without COPD, aligning with research by Carrigan et al. (2018), however the HiHA group expressed greater worry about their physical performance than the LoHA group, even though this difference was not statistically significant (see Table 2).

No difference was found between the HiHA and LoHA groups on QoL; this finding does not align with previous studies (Carrigan et al., 2018; Hayter et al., 2016). The results suggest that participants with COPD, regardless of HA, experienced impaired health-related QoL. There was no significant difference across age, mood or COPD severity (i.e., number of exacerbations) between the COPD groups. Participants with COPD in this study are on average older (M 71.62, SD 12.12) compared to studies by Hayter et al. (2016) and Carrigan et al. (2018) whose participants mean ages ranged from 36 to 42. Older, compared to younger, people with COPD have been found to report significantly poorer QoL across a range of domains (Qadire et al., 2023; Rizal et al., 2022), which may have overshadowed the impact of HA on QoL. Additionally, when comparing COPD participants with clinically significant HA (M 57.35, SD 12. 15) to non-clinically significant HA (M 41.36, SD 13.84), there is a greater

difference between the two groups. Those with clinically significant HA reported a poorer QoL. It can be hypothesised that clinically significant HA impacts QoL in individuals diagnosed with COPD, but further research is required to explore this.

There was no difference in mood across the three groups suggesting that HA or having COPD did not significantly impact on mood. However, participants with COPD were within the 'mild' range of low mood symptoms which does not reflect previous research which found that around 40% of people with COPD had signifcant depression (Stage et al., 2006). Low mood has been recognised as a risk factor for disengagement from physical health interventions (DiMatteo et al., 2000; Zeng et al., 2020) so it may be that those who did not attend or dropped out of PR were lower in mood.

The HiHA group had higher self-reported disabiltiy compared to the HC, and were significantly more impaired on household activities compared to the LoHA despite there being no significant difference in the number of exacerbations (i.e., COPD severity) or distance walked on the 6MWT. This suggests that having higher HA may negatively impact some aspects of self-reported disabiltiy in individuals with COPD. This aligns with previous literature which found that high HA was associated with increased physical impairment and reported disability compared to indivduals with no HA (Diamond et al., 2022; Sunderland et al., 2013).

Clinical Implications and Future Research

Given that 31% of the COPD individuals presented with symptoms of HA and the impact on misperceptions of physical ability, these results would suggest that HA be routinely screened for and treated in patients with COPD. The misperceptions of physical ability may impact engagement in the PR and treatment dropout, which may explain high rates of attrition from PR programs (Hayton et al., 2012). Research is required to explore the underlying

cognitions associated with the misperceptions of performance in participants with HiHA and COPD.

Further research would benefit from exploring the effectiveness of psychological interventions to reduce symptoms of HA within a COPD population and consider whether doing so increases patients' engagement with PR. Previous studies have demonstrated promising results of an adapted cognitive behavioural therapy for HA in CPHCs' (Carrigan et al., 2018; Petricone-Westwood et al., 2019; Tyrer et al., 2014).

Limitations

This study used a median-split on the SHAI to allocate COPD participants to the HiHA or LoHA groups due to only seven participants meeting clinically significant symptoms of HA and five being borderline. A limitation of this study is that although the HiHA group experienced a greater number of HA symptoms compared to the LoHA group, they did not meet a clinically significant level of HA. This may explain why no difference was found in QoL, disability or mood between the two groups, contrasting with previous findings (Hayter et al., 2016). It could be predicted that of the 25% of patients who dropped out of attending the assessment, some may have met clinically significant levels of HA and held cognitive biases and misperceptions of the PR program. Reflecting previous research on COPD patients not attending PR appointments due to anxiety (Eisner et al., 2010; Hayton et al., 2012).

Secondly, although this study aimed to control for symptom severity by excluding patients with more than two exacerbations in the past 12 months, there was no measure of disease severity. There was a disparity in how patients were assessed and diagnosed with COPD, subsequently impacting how their severity was recorded clinically. Some patients had objective measures of COPD severity (e.g., spirometry, X-rays), but unfortunately this was inconsistently reported. A measure of symptom severity, such as the COPD Assessment Test

(CAT) (Jones et al., 2009) may have been of benefit due to being able to more thoroughly control for severity as a covariate in the analysis. However self-reported COPD severity measures are subjective and rely on patient self-reporting which are highly correlated with symptoms of anxiety (Harryanto et al., 2018) making the measure invalid.

There were several limitations regarding the HC group. The HC group were not age-matched to the COPD participants and were significantly younger. Despite this study aiming to recruit an age-matched sample. Further to this, the HC participants had overall low HA (i.e., below the median-split) and so a four-way comparison could not be made between the HiHA and LoHA across disease status.

Conclusion

The findings of this study suggest that participants with HiHA and COPD misperceived themselves as being more impaired in physical functioning than they really were, supporting similar studies by Carrigan et al. (2018) and Hayter et al. (2016). COPD participants were also lower in mood compared to HC's. The high prevalence of HA and its impact on misperceptions of physical performance may explain the high dropout from PR. Further research to explore the effectiveness of psychological interventions on HA within a COPD population, and the possibility of increased PR engagement, would be beneficial.

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Connecting Narrative

Before starting the doctorate course, I had limited experience and knowledge of designing and running clinical research. Although apprehensive about completing three research projects, I was looking forward to the experience these opportunities offered.

My interests within the field of clinical psychology are varied, and the three research projects reflect this broad range of interest. I was keen to gain experience of designing and implementing research within NHS settings, due to having an interest in pursuing further research opportunities as a qualified Clinical Psychologist. Both the SIP and TDRP projects taught me about the challenges and barriers of designing and implanting clinical research within NHS services which are often under-staffed and under-funded. These experiences shall be carried forward when approaching NHS research opportunities in future endeavours.

Furthermore, I was passionate that my research explored mental health within underrepresented populations. When designing and choosing projects, I sought to include research which had not been vastly explored previously, or at least not within my target populations. It felt important to gain insight into these areas to improve services and reduce stigma for individuals who may often feel unseen and underrepresented.

TDRP

Whilst on my Older Adult placement, I worked with a gentleman diagnosed with COPD. Despite several invitations to attend pulmonary rehabilitation as part of the management of his COPD symptoms, he did not take part. Whilst considering my topic for the TDRP, I reflected on my experience working with this gentleman, and what appeared as high health anxiety getting in the way of him engaging in the pulmonary rehabilitation program rather than his severity of COPD; his COPD severity was considered mild in comparison to patients attended pulmonary rehabilitation. His cognitions about experiencing breathlessness exacerbating his COPD resulted in him not using the stairs in his own home.

This aligned with Dr Neil Carrigan's previous research exploring health anxiety in other chronic physical health conditions.

There were several challenges I experienced during the TDRP. Service staff offered to support the identifying and initial contacting of patients on the waiting list who may be interested and eligible to participate, however, this offer was revoked due to staff capacity. Thus, I had to re-write my protocol and recruitment strategy which delayed sponsorship and NHS ethics applications and meant that all recruitment was reliant on advertisement via the post and researcher presence at the assessment clinics. No participants were recruited via the advertisement; all were recruited via a researcher in the assessment clinics. Not only was this time-consuming but there was a chance we missed out on recruiting participants who may have had high HA who did not attend their initial assessment appointment.

Out of the three projects, the TDRP provided the biggest opportunity for development. Although I recruited participants for my SIP, the process was supported by the service, so recruitment was more straightforward. Although challenging and arduous at the time, I am glad to have had the opportunity to undergo the NHS ethics process as I feel this has prepared me for taking on further research based within NHS services in the future.

SIP

The SIP topic was first suggested by Dr Grace Jell as concerns had been raised by senior staff around the number of re-referrals some patients had within the Talking Therapies. The limited research in this area was mainly data-driven, and from my understanding, no research had sought patient perspectives as to why they re-refer. I was therefore determined to have a balance between exploring pre-existing data and hearing from service users.

I enjoyed hearing the perspectives of service users and felt honoured listening to their life stories and the factors leading them to re-refer. Working with the qualitative data felt meaningful, and the process of Thematic Analysis although overwhelming at times, was

rewarding. This was my first experience conducting qualitative analysis. I enjoyed this process and felt that this element of the project held more meaning for the service than the quantitative aspect. This was reflected by the service lead and external researcher who felt that the themes and sub-themes with verbatim quotes held significant meaning and insight.

In terms of challenges, I had to learn about the different terminology and system processes within Talking Therapies. Although I was aware of what Talking Therapies offer on a surface level, I have never worked in a Talking Therapies service and so I felt out-of-touch with certain aspects the service provision. I overcame this by being curious, asking questions, doing additional reading around service and being led by service users in interviews. Secondly, the pre-existing service user dataset was large with thousands of cases and a wide number of variables. This was a daunting task of understanding and cleaning up the dataset and understanding the best approach for data analysis. I used the research team on the course to support and guide me through this analysis.

SRL

I have always had an interest in neuropsychology and was keen to have one of my research projects within this area. Although I had prior experience in completing literature reviews, I have not conducted a systematic review before. Dr Nigel King presented the initial idea and current gap in literature, based on his extensive and in-depth knowledge of neuropsychology. Through initial discussions, it became clear that there were limited papers exploring the topic area and a too strict search criteria may result in too few papers to draw meaningful conclusions from. Thus, we decided to broaden our search criteria to take a wider approach to this SRL (i.e., any psychological intervention rather than only CBT and including any methodological approach and not only randomised controlled trials). However, this meant increased challenges when interpreting the data and synthesising the findings across the included studies, as papers which were not randomised controlled trials often held

many biases due to uncontrolled variables, and due to the diversity of the findings. This SRL developed my critical appraisal skills of published research, and to apply this knowledge when developing my TDRP and SIP projects.

Executive Summary

Why was the study conducted?

Health anxiety (HA), also known as hypochondriasis, can be a debilitating mental health condition. When someone has HA, they may worry excessively about their physical health, with fears that they may develop a serious and life-threatening illness. Research has shown that people with pre-existing chronic physical health conditions, such as multiple sclerosis or stroke, can also experience HA. People with HA and a chronic physical health condition interpret ambiguous physical health symptoms as indicating that their chronic physical health condition is worsening or that they are developing a life-threatening condition.

Previous studies have explored HA in people with chronic physical health conditions, comparing those with high levels of HA to those with low HA. People with chronic health conditions and high HA were more likely to perceive themselves as being more impaired on a physical functioning task than they really were and were more likely to attribute their performance to their chronic health condition. Additionally, the high HA groups generally had lower mood, greater self-reported disability and a lower quality of life compared to people with the same chronic health condition but lower HA. These groups often did not significantly differ in terms of their physical health symptoms or severity.

There is not enough research exploring the impact or prevalence of HA on people diagnosed with Chronic Obstructive Pulmonary Disease (COPD) in a community setting. COPD is a chronic health condition which affects the lungs and results in breathing difficulties, coughing, wheezing and increased risk of chest infections. Symptoms of COPD progressively get worse over time. The primary recommended intervention to manage COPD symptoms is pulmonary rehabilitation. Based on previous research, it was predicted that individuals with high HA and COPD, compared to low HA and COPD, will be more likely to misperceive themselves as being more physically impaired on a routine walking task and

more likely to attribute their performance to the COPD. Additionally, those with high HA will report a lower quality of life, poorer mood, and greater self-reported disability compared to those with low HA.

What was done?

This study recruited 62 participants; 22 participants had COPD and high HA, 20 with COPD and low HA and 20 healthy control participants. COPD participants were recruited from a community NHS service and invited for their initial assessment for pulmonary rehabilitation. All patients invited to the assessment clinic received study information in the post before attending the clinic. Healthy control participants were recruited from the community. All participants completed a physical task (6-minute walking test); COPD patients completed this with a trained physiotherapist in the clinic whereas the chief investigator delivered the physical task with healthy control participants. Following this, participants completed several questionnaires exploring to measure their level of HA, mood, generalised anxiety, quality of life, self-reported disability, and perceptions of physical functioning.

What was found?

Out of the participants with COPD, 16% met clinically significant levels of HA and 31% showed a high number of HA symptoms, this is a much higher prevalence of HA compared to the general population.

Participants with COPD and high HA were more likely to misperceive their performance on a physical walking test as being more impaired compared to the low HA group and healthy controls. When comparing the distance walked during the walking test, there were no significant differences between the COPD participants, in fact, the high HA group walked further on average compared to the low HA group.

Participants with COPD, compared to health controls, had greater self-reported disability. Participants with high HA and COPD were also lower in mood compared to a healthy control group. No difference was found between the COPD participants in terms of quality of life, suggesting that HA did not impact this population.

Implications

Given the high prevalence of HA and it's on mood and perceptions of physical performance, it would be beneficial to routinely screen for and treat HA in individuals diagnosed with COPD. If individuals with high HA perceive themselves as performing more poorly on physical tasks, they may be less likely to engage in a pulmonary rehabilitation program and avoid physical activity. Both of which would negatively impact their functioning and increase the risk of exacerbations and disease progression. High HA may explain why people drop out of pulmonary rehabilitation programs, and this needs to be explored further. Further research is needed to understand the underlying cognitions people with high HA and COPD may hold about their health and physical tasks. Additionally, to explore the effectiveness of a psychological intervention on symptoms of HA in people with COPD.

Acknowledgements

Firstly, I would like to thank all the participants who gave their time to take part in my research projects Without your help this research would not have been possible. Also, to thank all the experts by experience who shared with me their knowledge and expertise to help shape the TDRP and SIP projects, your insight was invaluable.

Secondly, I would like to thank the staff teams who supported my research and recruitment. Louise Dosanjh and Claire Woolams, your knowledge and support throughout my projects was much appreciated. I am very grateful to my research supervisors, Dr Nigel King, Dr Neil Carrigan, Dr Susannah Jenner, Dr Grace Jell and Dr Clare Daniels for their guidance, advice, support and encouragement over the last three years. Thank you to my course tutors, Nigel for the first two years and Fin for the final year of training for your continued support and being a listening ear during challenging periods on the course.

To my fellow trainees in the 2021 cohort, thank you for being a warm, inspiring and supportive group of people. I am so grateful for having experienced the training journey alongside you all and look forward to seeing where all your career journeys take you.

Lastly, I would like to extend my gratitude towards my family and friends. You have been by my side from my undergraduate psychology degree, through years of clinical work during the COVID pandemic and the journey of training. You have supported me throughout some of the toughest periods of my life, and always brought a smile and laughter into my life. You reminded me that there was a life outside of the course, and to not lose oneself in the process of clinical training.

Appendices

Appendix 1A: SRL Search Strategy

(mTBI OR "mild head injury" OR "mild brain injury" OR MHI OR "mild traumatic brain injury" OR "post-concussive" OR "post concuss* symptom*" OR "post concussi* syndrome" OR "prolonged post concuss* symptom*" OR "prolonged post concuss* syndrome" OR "persist* post concuss* symptom*" OR "persist* post concuss* syndrome")

AND

(non-pharmacological OR mindfulness OR psychotherapy OR "psychological approach" OR "psychological intervention" OR "psychological treatment" OR "cognitive behavio?r* therapy" OR CBT OR "dialectical behavio?r* therapy" OR "compassion focussed therapy" OR DBT OR "talking therapy" OR "cognitive therapy" OR "acceptance commitment therapy" OR "psychological therapy" OR "psychological treatment" OR "schema therapy" OR EMDR)

Appendix 1B: Quality assessment ratings (Kmet et al., 2004).

	1. Rytter 2018	2. Hershaw 2020	3. Kjeldgaard 2014	4. Azula y 2013	5. Hershaw 2020	6. Polich 2020	7. Tsaousides 2014	8. Topolovec-Vranic 2010	9. Tiersky 2005	10. King 2013	11. Potter 2016
Question / objective sufficiently described?	2	2	1	2	2	2	2	2	2	2	2
Study design evident and appropriate?	2	2	2	1	2	2	2	1	2	1	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	2	2	2	2	2	2	2	2	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	1	2	2	2	2	2	2	2	2	2	2
If interventional and random allocation was possible, was it described?	2	N/A	2	N/A	N/A	0	N/A	N/A	2	N/A	2
If interventional	2	N/A	N/A	N/A	N/A	0	N/A	N/A	2	N/A	N/A

and blinding of investigators was possible, was it reported?											
If interventional and blinding of subjects was possible, was it reported?	2	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A
Outcome and exposure measure(s) well defined and robust to measurement/ misclassificatio n bias?	2	1	2	2	1	1	2	2	1	2	2
Sample size appropriate?	1	1	2	1	1	0	0	1	1	1	1
Analytic methods described/justi fied and appropriate?	2	2	2	2	2	1	0	2	2	2	2
Some estimate of variance is reported for the main results?	2	2	2	2	2	2	0	2	2	1	2
Controlled for confounding?	2	1	2	1	1	2	0	2	2	1	2
Results reported in	2	1	1	1	1	1	0	1	1	1	1

sufficient detail?											
Conclusions supported by the results?	1	2	2	1	1	2	2	2	1	1	2

Appendix: Service Improvement Project

Appendix 2A: Phase 2 Interview Schedule

- Introductions to the interview
- Discussing consent and confidentiality
- Checking for questions prior to interview beginning

1. Could you tell me about the reason why you came back to IAPT? *(Prompts: situation has changed, needed longer term support, new difficulty with their mental health or hoping for a different outcome, no other service to turn to)*
2. What were your expectations from Talking Therapies? *(Prompt: Do you feel that Talking Therapies provided you with what you needed at each time?)*
3. What was the reason that these treatments ended? (*Prompts: did you complete treatment? Did you need to drop out for life reasons? Did you choose to drop out of treatment?)*
4. What, if any, ways of managing your difficulties did you learn from treatment? *(Prompt: Did you continue to use these after your discharge to manage your wellbeing?)*
5. In what ways has Talking Therapies been helpful? How could it be improved?
6. Do you think it is likely you would use Talking Therapies again in the future?

Appendix 2B:Thematic Analysis process across the six phases

Phase	Process
1. Familiarisation with the data	The first author (A.S) completed all nine interviews with participants. A.S was responsible for audio recording and transcribing all interviews by hand. A.S became familiar with the data throughout this process and read and re-read the transcripts to become familiar with the data. During the transcription process, A.S began to write down possible codes and themes. The supervisors involved in the project were involved in reviewing the codes and verbatim quotes from the transcriptions.
2. Generating initial codes	Each transcription was analysed separately, and initial codes were generated for individual quotes or statements across the interview transcripts. A bottom-up, data driven approach was used. Once all nine transcripts had been fully coded, A.S reviewed the list of codes and began to group together same or similar codes. Codes were reviewed by both supervisors and A.S involved in this project. This process helped to identify whether the themes identified for a particular section or statement felt appropriate and reflective of underlying meaning.
3. Searching for themes	Same or similar codes were collated together to begin to shape similar themes. The frequency of codes, similarity of coded and significance were taken into account when grouping and beginning to draft initial themes. Initial sub-themes and overarching themes were drafted and discussed with supervisors of the project.
4. Reviewing themes	Once the first ‘draft’ of the themes and sub-themes were produced these were discussed and reviewed with both supervisors and an

	external researcher of the project. The codes and initial theme ideas were discussed and reviewed. Following this process, there were several changes and iterations to ensure the themes were reflective of the underlying sub-themes and codes. Any differences in opinion were discussed until a consensus was reached amongst researchers.
5. Defining and naming themes	The naming of themes underwent several revisions through discussions as a research team and amendments were agreed to reflect the nuances of each theme.
6. Producing the report	The report was written by A.S, with reviews and amendments by both supervisors involved in the project. Verbatim quotes were implemented into the report write up to reflect the sub-themes and themes.

Appendix 2C: Study approval

Emma Walsh
Local Project 9830: Final Registration of Project
To: Adele Smith, Cc: Louisa Dosanjh

27 October 2022 at 13:13
Details

Dear Adele,

Thank you for completing your project registration via Datix, entitled "SE - Evaluating the High Rates of Re-referrals into the Improving Access to Psychological Therapies (IAPT) Service" and for your completed planning document. The project has now been registered by the team and allocated the ID number 9830. Please use this number in any correspondence to help us track the project.

- **Please could you clarify who your defined population is for your project? E.g. all service users referred to the IAPT service in Berkshire Healthcare …**

The relevant Clinical Director has been made aware of your audit being undertaken within their division. Please ensure that you liaise with the relevant Service Manager responsible for the service as they will need to be aware that you are undertaking this project within their area.

Once your audit has been completed, please send a copy of the project report and action plan to the Clinical Audit department by the review date stated. It is also expected that the completed report and action plan should be sent to the divisional PSQ meeting relevant to the audit for monitoring.

If you need any further information, please contact the Clinical audit team: clinical.audit@berkshire.nhs.uk.

Kind Regards,

Emma

Emma Walsh
Clinical Audit & Effectiveness Facilitator
Clinical Audit Department
Working from Home – please contact via Microsoft Teams or email
emma.walsh@berkshire.nhs.uk
Level 5, Fitzwilliam House, Skimped Hill Lane, Bracknell, Berkshire, RG12 1BQ.

CareQuality Commission Inspected and rated Outstanding
GDE
NHS Berkshire Healthcare NHS Foundation Trust

Appendix 2D: Participant Demographics

Characteristics	Number of participants
Gender	
Male	3
Female	6
Age	
22-26	3
27-36	4
50-56	2
Disability Status	
Yes	4
No	5
Long Term Condition	
Yes	5
No	4
Employment Status	
Employed	3
Unemployed	5
Long Term Sickness	1
Relationship Status	
Long Term Relationship	3
Single	4
Widowed	1
Cohabitating	1
Ethnicity	
White British	9
Primary Presentation	
Depressive Episode	5
Recurrent Depression	1
PTSD	1
Social Phobia	1
Generalised Anxiety Disorder	1
Caseness	

At Caseness	9
Discharge Reason	
Completed Treatment	7
Discharged following advice & support	2
Recovery Status	
At Recovery	4
Not at Recovery	5
Improvement	
Reliable Improvement	6
No Reliable Improvement	2
Reliable Deterioration	1
Number of Referrals to BTT IAPT	
4	4
8	2
9	1
11	2

Appendix 2E: Thematic analysis participant quotes

Subtheme	Participant Quotes
Theme 1. Social support and connectedness	
Talking helps after difficult life events	"To have someone to talk to about the worst stuff. The stuff I struggled to even think clearly, let alone put into words and admit to someone ... I just wanted someone" (P6)
	"When I'm going through a particularly difficult time and I know I'm struggling because I'm crying more often ... I think um, maybe I should go back and discuss this thing... it's been my pain, it's been my divorce, it's been my processing the grief of both of my parents dying" (P6)
	"After my wife there ... it was a lot worse so I contacted them (BTT) which allowed me to sort out my ongoing mental health problems" (P7)
	"I just wanted someone to talk to" (P8)
No Social support to turn to	"In the way you would... get home from work and moan to your other half about ... crap that happened in the day. You would get it off your chest, I know I use talking therapies in a similar sort of way" (P7)
	"I don't have like, say friends as such. So it was nice to go in and see somebody which obviously ... made me feel a lot better" (P5)
	"I don't really have what I call any friends, it's just me and my three sons and they're all grown up ... so it was like I have no support system in place" (P5)
Barriers talking to own social network	"I was just looking for ... to vent or another perspective of someone who's not, uhm ... personal to me. You know, it's someone else" (P8)
	"She (girlfriend) finds it hard to talk about it ... for me, it was really about having somebody to talk to who was kind of an unbiased person as well" (P9)
	"These issues that I have had throughout my life are not issues that I can speak with my family ... because a lot of them are within my family" (P1)
	"If I talk to my partner, I'll probably upset her with the stuff that I'd say... or if I talked to my mum I probably upset her with the way I was feeling" (P8)

	"Just talking with your friends is often not enough because you feel guilty about taking their time and their energy and worrying them and them having to watch you cry" (P6)
	"It was a really traumatic and stressful time for a number of months ... there's nobody that you can talk to in your immediate family, cause it's all entangled" (P1)
Wanting professional and impartial perspectives	"Good talking to someone that was able to connect with me on a personal level but then also be professional" (P8)
	"Always been the most helpful part of it is having someone ... to listen to you unbiased and um with no judgement" (P7)
	"Someone who is both being paid to be there but also is good at knowing how to unpick what you're saying or get to the root of the problem" (P6)
Theme 2: Expectations not met	
Seeking a diagnosis to understand difficulties: looking for answers	"A lot of why I ... ended up coming back was because um we hadn't managed to figure out what the actual issue was, it turns out I have ADHD" (P4)
	"I expected to speak to somebody who could diagnose me" (P2)
	"I was in a pretty desperate state trying to get properly diagnosed" (P2)
	"I was sort of adamant to get properly diagnosed" (P2)
	"I was hoping I might be able to do that (in reference to a bipolar diagnosis from BTT) but it sees that... someone else would have to do that" (P7)
CBT too rigid: re-referring to address other difficulties	"My counsellor... referred me back to the service because she was like, I don't think you're quite ready" (P1)
	"I've had to refer back in for different things, um problems each time, about three or four times" (P9)
	"There was loads of stuff going on at the time and we're only allowed to focus on one thing at a time. So I was having a bit of a breakdown but I could only talk about one issue" (P9)
	"I tend to want to talk more about in-depth things but the people I dealt with in CBT it felt like... if you tried to talk to them about anything else they were a little

	bit uninterested... they were kind of um that's not my script and they would cut you off" (P7)
	"I said I'm struggling and they said well we can't really focus on that at the minute, we have to focus on one thing at a time... my other situation just got worse and worse and that led to a breakdown" (P9)
Not feeling "fixed" from therapy	"That's why I referred (to BTT) myself thinking maybe if I obviously talked about things more then the pain could ease off or things might be slightly different but it's not obviously made any difference" (P3)
	"I've got to stage where I just thought, well this is it, this is how it's going to be. There's no cure I just have to deal with it every day" (P7)
	"I just felt with Talking Therapies there were no answers" (P3)
	"Therapy for me seems to have given me the tools to cope with it, but it's never really sorted it out. That's kind of where I've been stuck for the last 30 years" (P7)
Number of sessions is not enough	"I think it should be more than 6 sessions. Guess sometimes 6 isn't enough ... it certainly wasn't enough for me" (P9)
	"It was a bit of a shocker to receive the, ohh it's ended now, when I'm like, oh sh*t you know, has it? ... I was probably like could have done with a couple more" (P5)
	"I did have a chance to get a bit deeper... I started opening up more and getting a bit deeper but not have enough time to work on it" (P7)
Theme 3. Managing mental health 'dips'	
Therapy holds you accountable: spiralling after discharge	"I came back to the service as my mental health had dipped quite significantly and I um needed some help" (P8)
	"I then went through a really really bad point after that, and then self-referred again" (P1)
	(In the context of being discharged) "It's like back to reality, BAM, you're on your own again" (P5)
	"That's partly why I sort of kept like referring back because I get to the end of that 16-week course, I thought, yeah yeah I'm feeling better, and then left on my

	own again I would just end up back down that spiral and then I'm finding myself at a point where I'm like I need to refer back" (P4)
	"I've had this certain amount of free sessions, ... gone to all of those and then not known what to really do after" (P2)
	"Having someone there to like, hold you to account, to sort of keep using these um tools and techniques" (P1)
Talking Therapies as a 'first port of call'	"It's (BTT) always the first port of call if I'm feeling like I can't do this anymore, can't take this, it's talking therapies ... that's my go-to" (P5)
	"I was thinking of maybe referring back to talking therapies again, like, because of what just happened" (P5)
	"I'd been with talking therapies before it was just a no brainer sort of thing" (in the context of re-referring for support) (P8)
	"So when stuff happens you go back (to BTT), it's the same way you would maintain if you had a health condition" (P6)
	"I sort of felt as though talking therapies was better because ... it's a constant thing" (in reference to preferring BTT over other services) (P8)
Referring during a time of crisis	"Most of the times I've been referred, I've been in crisis mode" (P1)
	"I was in talking therapies and it failed horrendously... there was a lot of stuff going on at the time... I was having a bit of a breakdown" (In reference to ending therapy early) (P9)
	"When you're in a moment of crisis, for example, and you get referred, it's brilliant and it's a massive relief" (P1)
	"Every now and against when I feel like it seems like things are getting bad in my head again and I have this ... underlying depression and of the feeling of not wanting to be here all the time... I usually contact them (BTT)" (P7)
Positive experiences of therapy	"I believe in therapy. I believe that it does actually help" (P6)
	"Every time I've gone (to BTT) I've come away thinking like that was worth it" (P6)

	"Everything that I've got from talking therapies myself has always been spot on and has helped me and I've taken it on board" (P5)
	"I've had, you know, fairly good experiences with talking therapies... all the therapists have been really good, it's just been really nice, to be honest" (P1)
Long-standing and complex difficulties managed through therapy	"Stress also triggers my multiple sclerosis symptoms cause stress obviously is a main point to avoid... I was at the point of thinking, I just need to try it again (BTT)" (P5)
	"I've had a lot of bereavement in the last 5 years, which has sort of then triggered me to relapse into my normal which is a cesspit of negative thoughts and anxiety and depression" (P1)
	"Usually for me depression which I've had over the last 30 years, I've used talking therapies on and off" (P7)
	"I recently had PTSD from abuse as a child" (P9)
	"I've been in and out of therapy since I was five" (P1)
	"I've had quite a difficult life" (P6)
Theme 4. Barriers to engagement	
Decline in mental health	"It just stopped abruptly, as I was put into a psychiatric hospital" (in relation to sessions with BTT ending) (P9)
	"The other situation just got worse and worse and that's what led to a breakdown" (P9)
Difficult life events impacted the ability to engage	"Things got more on top of me that I couldn't really think straight" (P9)
	"I tried it (BTT) I think a few years earlier but I was at a point in my life where my wife was quite bad and trying to do that at the time I just couldn't commit the time to do it so well" (P7)
	"The most recent one (referral to BTT) came to an end because I had a really traumatic bereavement experience ... I was doing CBT and it was actually going really well but when that event happened it just became apparent that I was not in the right headspace to continue" (P1)

	"I was working full time... so I didn't have much time to do it and that was kind of an issue... it didn't go in" (in response to CBT) (P1)
	"The first lot, I don't think I done very many sessions... maybe it wasn't the right point in time" (P3)
Disconnection from the CBT approach	"I mean each time I've had CBT ... I still don't know whether that's the right thing for me" (P1)
	"It was like CBT based and I don't think I learnt any specific techniques that helped me" (P2)
	"So the CBT one... I felt that disconnect and I felt it was just wasting my time and ... wasting the therapist's time" (reason for ending therapy early) (P8)
	"I just didn't get that connection with CBT" (P8)
Holding back in assessment: mismatch of need and intervention offered	"If I had gotten EMDR you know, back in the beginning, I might not have to come back so many times" (P4)
	"Third times the charm because ... I knew what to say to get to the right services where I could then express what I needed more specifically. Without it, I might have ended up back in like talking therapy ... entirely inappropriate for what I needed" (P4)
	"When I'm in there ... I don't act like there is anything wrong" (P5)
	"I have no idea what any of that is or CBT is sounds weird. You're like I'll just ... go with you know, normal therapy... which was entirely unhelpful and not um what I really needed" (P4)
	"They (person assessing) are your life and death or whether you get a referral or not. So you've got to impress them but without opening up too much because that's just too raw ... it's a horrible horrible balancing act" (P4)
	"I just didn't feel comfortable telling a complete stranger that over the phone, so they definitely only got half the story" (P3)
	"Always feel like I'm holding back a bit" (P7)
	"It's just very difficult to be able to convey seriously what's going on. I know people who downplay their sort of issues, so if they are downplaying it the person

	on the other side of the phone who doesn't know this person, won't be able to identify oh they're holding back" (P4)
	"Unless you happen to know what the magic words are you don't know what you're gonna get offered" (P4)

Appendix 2F: Participant Information Sheet

Understanding experiences of people with multiple referrals into Berkshire Talking Therapies Improving Access to Psychological Therapies service (BTT-IAPT)

Participant Information Sheet

We invite you to take part in an audit of the BTT-IAPT service. Before you decide to take part, it is important that you understand why the project is being done and what it will involve. Please take the time to read the following information carefully. You may wish to discuss with friends, family or your G.P.

Purpose of the project

We are interested in understanding and hearing from people who have received treatment for their mental health from BTT-IAPT service. We wish to talk to people who have been referred multiple times to BTT IAPT. We want to explore your experiences, perspectives and recommendations for the service. We would like to know:

- What is your perspective on why you have been re-referred into BTT IAPT service for mental health treatment?
- What was helpful or unhelpful from the service you received?
- What skills you learnt from the treatment, and how you may have used these skills since treatment ended?
- What suggestions, if any, you could make around service improvement?

Research suggests that people who have multiple referrals to Talking Therapies are less likely to recover from a mental health condition. They may also end treatment early or drop out of treatment. This project aims to better understand why this may be the case. We want to hear from previous service users about their experience and what improvements could be made.

Taking part in the study

If you are interested in participating, we would like to hear from you. If you decide to participate, you will be asked to sign a consent form. This consent form would be stored confidentially on your patient record.

If you no longer wish to participate, you can withdraw at any time up until the data collected is made anonymous and the identifiable data destroyed. Withdrawing will not affect the care you receive from any NHS service.

Your participation in this project will be kept confidential. Any information will be made anonymous and not form part of your clinical records. However, if you disclose any information which implies yourself or someone else is at risk of harm the researchers will have a duty of care to pass this information on to relevant services.

Description of the Study

If you agree to participate, you will be invited to attend an informal remote meeting with a researcher. This meeting will be held on Microsoft Teams and is expected to be around 30 - 45 minutes in duration. You will need access to:

- A stable internet connection
- A confidential and private room
- A personal computer or laptop, with a video camera and microphone

You will be asked questions about your views of being re-referred to BTT-IAPT. We will explore your experience of the treatment and your recommendations for service improvement.

You will not be asked, or expected to, provide personal details concerning your mental health or personal history.

Your answers will be audio-recorded via Microsoft Teams on an NHS password protected laptop. All data will be securely stored on an NHS remote server. The researcher will transcribe the interviews, ensuring no identifiable data is included and all data will be kept anonymous. Anonymised quotes from the interview may be included in the audit write-up and published report.

Following completion of the project and report write-up, all identifiable data and audio recordings shall be disposed of in adherence to NHS Data Protection policies.

We would like to thank you for reading the patient information sheet and for considering taking part in this project. If you are interested in participating, please sign and complete the consent form. If you have any further questions, please contact researchers Adele Smith (adele.smith@stx.ox.ac.uk) or Louisa Dosanjh (TalkingTherapiesLTC@berkshire.nhs.uk)

Appendix 2G: Participant Consent Form

Healthcare from the heart of your community

Berkshire Healthcare NHS
NHS Foundation Trust

CONSENT FORM

Title of Project: Understanding experiences of people with multiple referrals into Berkshire Talking Therapies Improving Access to Psychological Therapies service

1. I have read and understood the information sheet for the above project. I have had time to consider the information, ask questions and received answers.
2. I understand that my participation is voluntary. I can withhold or withdraw consent at any time prior to, and during, participation in the interview without giving any reason and without penalty.
3. I understand that research data will be collected during the project, and it will only be shared with those connected to the project. I give permission for these individuals to access my data.
4. I understand that all information will be kept strictly confidential except in rare circumstances it is judged that I, or someone else, is at immediate risk of serious harm, or where information is requested by a court of law.
5. I understand that this project has been registered by the Berkshire Health Clinical Audit Department and received approval to proceed as part of a service evaluation to review and improve upon the quality of assessment and treatment provided.
6. I understand that information provided will be anonymised and may form part of the audit report provided to Berkshire Talking Therapies service and/or part of a published paper.
7. I understand any audio recording will not form part of my clinical record and will be stored on a secure NHS server which will be deleted within 3 months of creation. Unless explicit consent to continue retention and use of the recording is gained.
8. I understand that by signing below, I am providing consent to take part in this project.

Name of Participant	Date	Signature
Researcher	Date	Signature

Appendix 3A: TDRP Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Adele Smith
17 Wilsdon Way
Kidlington
Oxfordshire
OX5 1TN

Email: HCRW.approvals@wales.nhs.uk

18 October 2023

Dear Miss Smith

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)**
IRAS project ID:	**325752**
Protocol number:	**000000**
REC reference:	**23/WA/0290**
Sponsor	**University of Oxford/ Research Governance, Ethics and Assurance**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **325752**. Please quote this on all correspondence.

Yours sincerely,
Sue Byng

Approvals Specialist

Email: HCRW.approvals@wales.nhs.uk

Copy to: *N/A University of Oxford Research Governance, Ethics & Assur*

Appendix 3B: Approval of Funding

The Oxford Institute of Clinical Psychology Training and Research

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Oxford OX3 7JX
Tel: +44(0)1865 226431
Website: https://oxicptr.web.ox.ac.uk/home

31 May 2023

To Whom It May Concern

Confirmation of Funding Support – Adele Smith, Trainee Clinical Psychologist

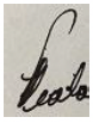
I can confirm that, Adele Smith, Trainee Clinical Psychologist, has full support for her research dissertation project as follows:

Study Title: The impact of Health Anxiety in Chronic Obstructive Pulmonary Disease
IRAS ID: 325752
Research Student: Adele Smith

Adele has been allocated a budget to run her study and any costs incurred will be covered by the Oxford Institute of Clinical Psychology Training and Research.

Please let me know if there is any further information you require.

Yours sincerely



Theresa Pedlar
Senior Institute Administrator

Appendix 3C: Sponsorship Approval

RESEARCH SERVICES
UNIVERSITY OF OXFORD

Research Governance, Ethics & Assurance
Boundary Brook House
Churchill Drive
Headington, Oxford
Oxon
OX3 7GB

To whom it may concern

Date: 11/09/2023

Title: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease

PID: 17062

Protocol Date/Version: 08.09.2023 Version 1.0

The above study has been designed by Miss Adele Smith and colleagues at the University of Oxford and funded by the Departmental Resources (Internal Funding). I confirm that the University will accept the role of Research Sponsor of this Study and will comply with the requirements of the UK Policy Framework for Health and Social Care Research October 2017.

Insurance-provided indemnity arrangements are in place for the project with Newline Underwriting Management Ltd., at Lloyd's of London.

Sponsorship is confirmed subject to the condition that the following are sent to Research Governance, Ethics & Assurance for review prior to submission to the Research Ethics Committee. Failure to do so may compromise insurance cover for the project.

- Any minor or substantial amendments
- Any extension to the study end date
- Addition of any new research site or patient identification centre

In addition, annual progress reports, the end of study notification and final report must be copied to Research Governance, Ethics & Assurance.

Lastly, where they exist, University Core SOPs must be followed by default for all clinical research sponsored by the University. Further information can be found here: https://researchsupport.admin.ox.ac.uk/ctrg/resources

Any communications relating to Research Sponsorship should be directed to the undersigned.

Yours faithfully

DocuSigned by:
BA168DF4624B463...

11 September 2023

Carol Cornelius
[PP Dr Karen Melham, RGEA Sponsorship & Ethics Lead]

Appendix 3D: Participant Information Sheet (COPD)

Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Buckinghamshire Healthcare NHS Trust

Bucks Integrated Respiratory Service

Participant Information Sheet

Study Title: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

You are being invited to take part in a research study. Before you decide, it is important you understand why the research is being done and what it will involve. Please take your time to read the following information carefully. You may want to talk to others about the study before agreeing to take part. This study involves looking at health anxiety in adults diagnosed with COPD.

Key Facts

- To explore whether people with COPD have anxiety about their physical health.
- To understand how experiencing anxiety about your physical health might impact on different areas of your life.

<u>What is the purpose of the study?</u>

We wish to better understand the role of health anxiety in the lives of adults diagnosed with COPD. Similar research has found that adults with long term physical health conditions often experience anxiety, in particular anxiety about their health.

There is little research looking at health anxiety in adults diagnosed with COPD. We would like to understand how health anxiety may affect people with COPD's lives.

Why have I been invited?

You are currently on the waiting list for support from the Bucks Integrated Respiratory service and have a diagnosis of COPD.

We are aiming to recruit around 90 people for this project, with 60 people having COPD.

Do I have to take part?

It is up to you to decide whether to take part or not. If you decide you would like to take part, you will be asked to sign a consent form. Even if you give consent, you have the right to withdraw at any time without giving a reason. If you decide not to take part, this will not impact on any care you are currently, or may, receive from the NHS.

Can I take part?

You can take part if you meet the following:

- Have a COPD diagnosis.
- Have had no more than two COPD exacerbations in the last year.
- Not have any other long term physical health conditions.
- Not have any severe mental health difficulties (e.g., psychosis, PTSD).
- Can read and write in English.
- Aged 18 years and over.

What will happen to me if I take part?

Patients who have expressed an interest in taking part in the study will first receive a phone call from a researcher. The researcher will explain the study and you will have the opportunity to ask questions. If you want to take part, you will provide consent either verbally over the phone or by filing in a consent form online.

As part of your routine assessment with the Bucks Integrated Respiratory Service you will be fill in questionnaires about your mood and complete a 6-minute walking task. These are part

of your standard care in the NHS. If you agree to take part, you will agree for the service to share your scores on the mood questionnaires and 6-minute walking task with the researchers of this study.

Afterwards, the researchers will collect some study specific questionnaires from you. There will be four questionnaires you will complete for the purpose of this research study. These will cover topics of health, daily life and how you felt you performed on the walking task. These are expected to take around 30 to 45 minutes and would be completed in the waiting room immediately after your routine assessment. If you can't complete these after your assessment, you will instead receive a website link to your email address to complete the questionnaires online. If you need support completing these, a researcher will offer a phone call or Microsoft Teams video call to complete these with you.

What are the possible disadvantages and benefits of taking part?

There are no disadvantages in taking part in this study, although we are asking you to give up some of your time. Your willingness to participate in this study will be an important contribution to the research base in helping us understand more about mental health and COPD. This can support future research in finding new ways of supporting people who have this physical health condition.

Some questionnaires may ask you to think about your mental health or current life circumstances. It is possible you may find answering some of these questions upsetting. You can take a break from the study and return to it later or withdraw at any point. At the end of the study, or if you withdraw early, you will be provided with contact details of services which can offer you support.

Will I be reimbursed for taking part?

Any reasonable travel expenses for any visits additional to normal care will be reimbursed on production of receipts, or a mileage allowance provided as appropriate.

What will happen if I don't want to carry on with the study?

If you decide you would no longer like to take part in the study, you can withdraw at any time. If you withdraw after you have completed the questionnaires, we will not collect any more data from you. We will use the already completed questionnaire data. This data will be anonymised,

meaning there will be no identifiable information. Withdrawing from the study will not affect the care you receive from any NHS service.

Will my General Practitioner (GP) be informed of my participation?

No, they will not be informed.

Will my taking part in the study be kept confidential?

Yes. All study records and samples will be identified only by an ID number. We will only use personal details (such as name, contact number, email address) where this is necessary to contact you.

Information that can identify you will only be held securely by the researchers involved in this study, or with clinicians involved in your care within the Bucks Integrated Respiratory service, for the purposes of the study.

Confidentiality will be maintained as far as it is possible, unless you tell us something which implies that you or someone you mention might be in significant danger of harm. In this case, we would have to inform the relevant agencies, but we would aim to discuss it with you first.

Relevant sections of your medical notes and any data collected for the purpose of the study may be looked at by responsible members from the University of Oxford, from regulatory authorities and from the Buckinghamshire NHS Trust, this would be for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

All the information we collect about you during the research project would be kept confidential. You will not be able to be identified in any reports or publications. Each participant will be given assigned an ID number, meaning the data will be pseudonymised. Participants will always be referred to by this ID number, and not by their name or other identifiable information. Collected data using the ID number will be stored on a password protected Excel spreadsheet and stored separately from any personal information. We will not audio record or video record any of the phone calls or tasks.

What happens with my information?

UK data protection regulation requires that we state the legal basis for processing information about you. The University of Oxford, based in the United Kingdom, is the sponsor for this study

and the data controller and is responsible for looking after your information and using it properly. The information you provide during the study is 'research data'. Any research data which can be identifiable (i.e., email address or telephone number) is known as 'personal data'.

Personal data: For participants under the Bucks Integrated Respiratory service, we will be using information from the clinical records of this NHS service. We will aim to use the minimum personally identifiable information possible. Any personal data will be stored on a password protected device on a secure University of Oxford server. Any information shall be stored on a password protected file and only used by the research team on this project. Personal data will be stored for 3 months after the study has finished and then deleted.

Other research data (e.g., consent forms, questionnaire data): will be stored for at least 3 years after the publication or public release of the work of the research. This information will then be shredded or permanently deleted or destroyed after this time.

Once you have consented to taking part in this study, your name, phone number and email address will be shared with the researchers from this study. They may use this data to contact you about taking part or to send an online link to access the questionnaires.

A copy of the consent form from this study will be kept in your medical records for as long as those records are retained in the Bucks Integrated Respiratory service. They will keep any other identifiable information about you from this study for up to 3 months after the study has finished.

Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.

The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.

Data protection regulation provides you with control over your personal data, and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at

https://compliance.web.ox.ac.uk/individual-rights. You can find out more about how we use your information by contacting the Chief Investigator on adele.smith@stx.ox.ac.uk.

What will happen to the results of this study?

Researchers involved in this project will have access to the research data. All personal information which may identify you would be removed before information is shared with other researchers or results are publicised. Using the research data, we hope to report our findings in academic journals and present them to other health professionals at conferences. The findings will also contribute to Adele Smith's Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the study.

What happens if something goes wrong?

Steps have been taken to ensure your safety during participation in this study. The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

However, if you have any concerns about an aspect of this study, please contact the members of the research project who will do their best to answer your questions. You can contact either Adele Smith (adele.smith@stx.ox.ac.uk) or Dr Neil Carrigan (neil.carrigan@hmc.ox.ac.uk).

If you remain unhappy and wish to complain formally you can do this by contacting the University of Oxford Research Governance, Ethics & Assurance (RGEA) on 01865 616480, or the director of RGEA at rgea.complaints@admin.ox.ac.uk.

Who is organising and funding the study?

The University of Oxford is sponsoring this study. The researchers involved in organising this study include the Chief Investigator (Adele Smith) and two supervisors (Dr Neil Carrigan & Dr Clare Daniel), alongside a research assistant. The Oxford Institute of Clinical Psychology Training and Research is the funder of this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given a favourable opinion by HRA and Health and Care Research Wales Research Ethics Committee.

I'm interested in participating, what's next?

If you would like to take part, please contact the researcher Adele Smith directly via email (adele.smith@stx.ox.ac.uk). Adele or a research assistant will then be in touch by phone to answer any questions and check eligibility in taking part.

Or you can let the clinicians in the Bucks Integrated Respiratory Service know you would like to take part and verbally consent to the service sharing your contact details with the research team who shall be in touch with you.

Thank you for considering taking part.

Appendix 3E: Consent Form (COPD)

Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Oxford Health NHS Foundation Trust

Oxford Health Foundation Trust's Respiratory Service

Participant identification number:

CONSENT FORM

Title of Project: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

If you agree, please initial in the box below

1. I confirm that I have read the information sheet (Version 1.0, dated 29.01.2024) for this study. I have had time to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that participation is voluntary, and I am free to withdraw at any time without giving any reason and without my NHS care or legal rights being affected.	

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Oxford, from regularity authorities and from the Oxford Health NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I wish to receive a written summary of the study findings after the study has been completed.	
5. I agree to take part in this study.	

_____	_____	_____
Name of participant	*Date*	*Signature*
_____	_____	_____
Name of person taking consent	*Date*	*Signature*

When completed: 1 copy for participant; 1 for researcher site file (original); 1 copy to be kept in medical notes (if participant is a patient)

Appendix 3F: Recruitment poster (COPD)

The Oxford Institute of Clinical Psychology Training and Research
Email:adele.smith@stx.ox.ac.uk
Ethics Approval Reference: 23/WA/0290

NHS
Buckinghamshire Healthcare
NHS Trust

UNIVERSITY OF OXFORD



Participants Needed

Impact of Health Anxiety in COPD

You are able to take part if you are:

- Aged **18 years and over**
- Can read and write in English
- Have a diagnosis of **Chronic Obstructive Pulmonary Disease** (COPD)
- Have been referred to the Bucks Integrated Respiratory Service for Pulmonary Rehabilitation
- Had no more than two COPD exacerbations in the past year
- You **do not** have any other chronic health condition or serious mental health diagnosis

Studies show having a chronic physical health condition can increase someone's worry about their health. We want to explore whether having a COPD diagnosis increases anxiety about one's health. Understanding this can improve what support we offer to people with COPD.

We are looking for people with COPD who are under the Bucks Integrated Respiratory Service. You would **already be completing some of the questionnaires as part of a routine assessment.** We would ask you to **complete 4 more questionnaires as part of taking part in this research.** These questionnaires would be about your mood, lifestyle and health.

Taking part should take between **30 to 45 minutes**.
You can complete the 4 questionnaires immediately after your routine assessment in the waiting room.
Or, you can complete online using a personal computer or via a phone call with the researcher.



Interested in taking part?
Please contact us via email: adele.smith@stx.ox.ac.uk
or Text/Call: 07749 073590

Or let your clinician in the Respiratory Service know you're interested

Date and Version number: V1.1, 29/01/24

Appendix 3G: Participant Information Sheet (HC)





Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Buckinghamshire Healthcare NHS Trust

Bucks Integrated Respiratory Service

Participant Information Sheet

Study Title: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

You are being invited to take part in a research study. Before you decide, it is important you understand why the research is being done and what it will involve. Please take your time to read the following information carefully. You may want to talk to others about the study before agreeing to take part. This study involves looking at health anxiety in adults diagnosed with COPD.

Key Facts

- To explore whether people with COPD have anxiety about their physical health.
- To understand how experiencing anxiety about your physical health might impact on different areas of your life.

<u>What is the purpose of the study?</u>

We wish to better understand the role of health anxiety in the lives of adults diagnosed with COPD. Similar research has found that adults with long term physical health conditions often experience anxiety, in particular anxiety about their health.

There is little research looking at health anxiety in adults diagnosed with COPD. We would like to understand how health anxiety may affect people with COPD's lives.

Why have I been invited?

We wish to recruit a control sample of participants. This means people who **do not** have COPD or Health Anxiety. This will help us to understand any differences between the group of people with COPD and Health Anxiety compared to those without COPD and Health Anxiety.

We are aiming to recruit around 90 people for this project, with 30 people within the control sample.

Do I have to take part?

It is up to you to decide whether to take part or not. If you decide you would like to take part, you will be asked to sign a consent form. Even if you give consent, you have the right to withdraw at any time without giving a reason. If you decide not to take part, this will not affect your legal rights.

Can I take part? You can take part if you meet the following criteria:

- Not have a COPD diagnosis or other respiratory disorders
- Not have any other long term physical health condition
- Not have a diagnosis of Health Anxiety
- Not have any severe mental health difficulties (e.g., psychosis, PTSD)
- Can read and write in English
- Aged 18 years and over
- Able to attend for a one-off meeting with the researcher (either in person or via Microsoft Teams) to complete the questionnaires and a 6-minute walking task

What will happen to me if I take part?

If you are interested in taking part in the study, you will receive an online link to read an information sheet and sign a consent form. You will give consent before any study procedure takes place. If you have consented to taking part in this study, you will complete some questionnaires and a 6-minute walking task.

The questionnaires will cover topics such as your mood, health, and daily life. You will be asked to complete a total of 6 questionnaires. It is expected to take approximately 45 to 60 minutes to complete along with the 6-minute walking task. This meeting will be offered in person and is likely to take place at the Education Centre. Warneford Hospital, Headington, Oxford OX3 7JX. Alternatively, a remote meeting via Microsoft Teams may be possible if you have access to a working camera and can keep the camera on for the duration of the walking task.

What are the possible disadvantages and benefits of taking part?

There are no disadvantages in taking part in this study, although we are asking you to give up some of your time. Your willingness to participate in this study will be an important contribution to the research base in helping us understand more about mental health and COPD. This can support future research in finding new ways of supporting people who have this physical health condition.

Some of the questionnaires may ask you to think about your mental health or current life circumstances. It is possible you may find answering some of these questions upsetting. You can take a break from the study and return to it later or withdraw at any point. At the end of the study, or if you withdraw early, you will be provided with contact details of services and voluntary organisations which can offer you support.

Will I be reimbursed for taking part?

Any reasonable travel expenses for any visits will be reimbursed on production of receipts, or a mileage allowance provided as appropriate.

What will happen if I don't want to carry on with the study?

If you decide you would no longer like to take part in the study, you can withdraw at any time. If you withdraw after you have completed the questionnaires, we will not collect any more data from you. We will use the already completed questionnaire data. This data will be anonymised, meaning there will be no identifiable information. Withdrawing from the study will not affect the care your legal rights.

Will my General Practitioner (GP) be informed of my participation?

No, they will not be informed.

Will my taking part in the study be kept confidential?

Yes. All study records and samples will be identified only by an ID number. We will only use personal details (such as name, contact number) where this is necessary to contact you. Information that can identify you will only be held securely by the researchers directly involved in this study. We will not audio record or video record any of the phone calls or tasks.

Confidentiality will be maintained as far as it is possible, unless you tell us something which implies that you or someone you mention might be in significant danger of harm. In this case, we would have to inform the relevant agencies, but we would aim to discuss it with you first.

Relevant sections of your medical notes and any data collected for the purpose of the study may be looked at by responsible members from the University of Oxford and from regulatory authorities, this would be for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

All the information we collect about you during the research project would be kept confidential. You will not be able to be identified in any reports or publications. Each participant will be given assigned an ID number, meaning the data will be pseudonymised. Participants will always be referred to by this ID number, and not by their name or other identifiable information. Collected data using the ID number will be stored on a password protected Excel spreadsheet and stored separately from any personal information.

What happens with my information?

UK data protection regulation requires that we state the legal basis for processing information about you. The University of Oxford, based in the United Kingdom, is the sponsor for this study and the data controller and is responsible for looking after your information and using it properly. The information you provide during the study is 'research data'. Any research data which can be identifiable (i.e., email address or telephone number) is known as 'personal data'.

Personal data: Any personal information will be provided by yourself in order to undertake this study. We will aim to use the minimum personally identifiable information possible.

Any personal data will be stored on a password protected device on a secure University of Oxford server. Any information shall be stored on a password protected file and only used by

the research team on this project. Personal data will be stored for 3 months after the study has finished and then deleted.

Other research data (e.g., consent forms, questionnaire data): will be stored for at least 3 years after the publication or public release of the work of the research. This information will then be shredded or permanently deleted or destroyed after this time.

Once you have consented to taking part in this study we will share your contact details such as your name, phone number and email address, with the researchers from this study. They may use this to contact you about taking part or to send an online link to access the questionnaires.

Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.

The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.

Data protection regulation provides you with control over your personal data, and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at https://compliance.web.ox.ac.uk/individual-rights. You can find out more about how we use your information by contacting the Chief Investigator on adele.smith@stx.ox.ac.uk.

What will happen to the results of this study?

Researchers involved in this project will have access to the research data. All personal information which may identify you would be removed before information is shared with other researchers or results are publicised. Using the research data, we hope to report our findings in academic journals and present them to other health professionals at conferences. The findings will also contribute to Adele Smith's Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the study.

What happens if something goes wrong?

Steps have been taken to ensure your safety during participation in this study. The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

However, if you have any concerns about an aspect of this study, please contact the members of the research project who will do their best to answer your questions. You can contact either Adele Smith (adele.smith@stx.ox.ac.uk) or Dr Neil Carrigan (neil.carrigan@hmc.ox.ac.uk).

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you remain unhappy and wish to complain formally you can do this by contacting the University of Oxford Research Governance, Ethics & Assurance (RGEA) on 01865 616480, or the director of RGEA at rgea.complaints@admin.ox.ac.uk.

Who is organising and funding the study?

The University of Oxford is sponsoring this study. The researchers involved in organising this study include the Chief Investigator (Adele Smith) and two supervisors (Dr Neil Carrigan & Dr Clare Daniel), alongside a research assistant. The Oxford Institute of Clinical Psychology Training and Research is the funder of this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given a favourable opinion by the Health Research Authority and Health and Care Research Wales Research Ethics Committee.

I'm interested in participating, what's next?

If you would like to take part, please contact the researcher Adele Smith directly via email (adele.smith@stx.ox.ac.uk). Adele or a research assistant will then be in touch by phone to answer any questions and check eligibility in taking part.

Thank you for considering taking part.

Appendix 3H: Consent Form (HC)

Buckinghamshire Healthcare NHS Trust

Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Buckinghamshire Healthcare NHS Trust

Bucks Integrated Respiratory Service

Participant identification number:

CONSENT FORM

Title of Project: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

If you agree, please initial in the box below

6. I confirm that I have read the information sheet (version 1.1, dated 13/10/23)) for this study. I have had time to consider the information, ask questions and have had these answered satisfactorily.	
7. I understand that participation is voluntary, and I am free to withdraw at any time without giving any reason and without my legal rights being affected.	
8. I understand that data collected during the study may be looked at by individuals from the University of Oxford and from regularity authorities where it is relevant to my taking	

part in this research. I give permission for these individuals to have access to my records.	
9. I wish to receive a written summary of the study findings after the study has been completed.	
10. I agree to take part in this study.	

_____	_____	_____
Name of participant	*Date*	*Signature*
_____	_____	_____
Name of person taking consent	*Date*	*Signature*

When completed: 1 copy for participant; 1 for researcher site file (original); 1 copy to be kept in medical notes (if participant is a patient)

Appendix 3I: Adapted Misperception of Performance measure





Perception of Performance

Compared to others, how well do you feel you performed on the 6 minute walk test? (Please tick)

Extremely badly in comparison to others										Extremely well in comparison to others
-50	-40	-30	-20	-10	0	+10	+20	+30	+40	+50
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How worried were you about your performance on the 6 minute walk test? (Please tick)

Not at all worried										Extremely worried
0	10	20	30	40	50	60	70	80	90	100
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much better would you have performed on the tasks if you did not have COPD? (Please tick)

Not better										Very much better
0	10	20	30	40	50	60	70	80	90	100
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Appendix 3J: Adapted version of the SHAI

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, OVER THE PAST SIX MONTHS. Identify the statement by ringing the letter next to it i.e., if you think statement (a) is correct, ring statement (a); it may be that more than one statement applies, in which case, please ring any that are applicable.

1. (a) I do not worry about my health
   (b) I occasionally worry about my health
   (c) I spend much of my time worrying about my health
   (d) I spend most of my time worrying about my health

2. (a) I notice aches/pains less than other people (of my age)
   (b) I notice aches/pains as much as most other people (of my age)
   (c) I notice aches/pains more than most other people (of my age)
   (d) I am aware of aches/pains in my body all the time

3. (a) As a rule I am not aware of bodily sensations or changes
   (b) Sometimes I am aware of bodily sensations or changes
   (c) I am often aware of bodily sensations or changes
   (d) I am constantly aware of bodily sensations or changes

4. (a) Resisting thoughts of illness is never a problem
   (b) Most of the time I can resist thoughts of illness
   (c) I try to resist thoughts of illness but I am often unable to
   (d) Thoughts of illness are so strong that I no longer even try to resist them

5. (a) As a rule I am not afraid that I have a serious illness [other than COPD]
   (b) I am sometimes afraid that I have a serious illness [other than COPD]
   (c) I am often afraid that I have a serious illness [other than COPD]
   (d) I am always afraid that I have a serious illness [other than COPD]

6. (a) I do not have images (mental pictures) of myself being ill
   (b) I occasionally have images of myself being ill
   (c) I frequently have images of myself being ill

(d) I constantly have images of myself being ill

7. (a) I do not have any difficultly taking my mind off thoughts about my health
(b) I sometimes have difficulty taking my mind off thoughts about my health
(c) I often have difficulty taking my mind off thoughts about my health
(d) Nothing can take my mind off thoughts about my health

8. (a) I am lastingly relieved if my doctor tells me there is nothing wrong
(b) I am initially relieved but worries sometimes return later
(c) I am initially relieved but the worries always return later
(d) I am not relieved if my doctor tells me there is nothing wrong

9. (a) If I hear about an illness, other than COPD, I never think I have it myself
(b) If I hear about an illness, other than COPD, I sometimes think I have it myself
(c) If I hear about an illness, other than COPD, I often think I have it myself
(d) If I hear about an illness, other than COPD, I always think I have it myself

10. (a) If I have a bodily sensation or change I rarely wonder what it means
(b) If I have a bodily sensation or change I often wonder what it means
(c) If I have a bodily sensation or change I always wonder what it means
(d) If I have a bodily sensation or change I must know what it means

11. (a) I usually feel at very low risk for developing a serious illness [other than COPD]
(b) I usually feel at fairly low risk of developing a serious illness [other than COPD]
(c) I usually feel at moderate risk for developing a serious illness [other than COPD]

(d) I usually feel at high risk of developing a serious illness [other than COPD]

12. (a) I never think I have a serious illness, other than COPD
(b) I sometimes think I have a serious illness, other than COPD
(c) I often think I have a serious illness, other than COPD
(d) I usually think that I am seriously ill with something, other than COPD

13. (a) If I notice an unexplained bodily sensation I never do anything to try and get rid of it
(b) If I notice an unexplained bodily sensation I sometimes try to get rid of it
(c) If I notice an unexplained bodily sensation I often try to get rid of it
(d) If I notice an unexplained bodily sensation I always try to get rid of it

14. (a) My family/friends would say I do not worry enough about my health
(b) My family/friends would say I have a normal attitude to my health
(c) My family/friends would say I worry too much about my health
(d) My family/friends would say I am a hypochondriac

Appendix 3K: Debrief Sheet (COPD)

Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Buckinghamshire Healthcare NHS Trust

Bucks Integrated Respiratory Service

Participant Debrief Sheet

Study Title: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

Thank you for taking the time to take part in this study.

This research project aimed to investigate whether individuals who have health anxiety and COPD are more likely to perceive their performance on a physical exercise task as being worse than people without health anxiety.

If you would like any further information about this research project, or have any questions, please get in touch with Adele Smith (Chief Investigator) via email address (adele.smith@stx.ox.ac.uk).

If you have any concerns about an aspect of this study, please contact the members of the research project who will do their best to answer your questions. You can contact either Adele Smith (adele.smith@stx.ox.ac.uk) or Dr Neil Carrigan (neil.carrigan@hmc.ox.ac.uk).

If you remain unhappy and wish to complain formally you can do this by contacting the University of Oxford Research Governance, Ethics & Assurance (RGEA) on 01865 616480, or the director of RGEA at rgea.complaints@admin.ox.ac.uk.

If you feel distressed or upset after having taken part in this study and you feel you need additional support, please contact one of the organisations below for support:

- Speak to a clinician within the Bucks Integrated Respiratory Service and ask for some support
- You can contact the NHS 24/7 mental health helpline by calling 111
- Arrange for an appointment with your G.P or allocated healthcare worker
- SHOUT, a texting service for 24/7 support or if you are in a crisis, text SHOUT to 85258.

Thank you again for taking part in this study

Appendix 3L: Debrief Sheet (HC)

Oxford Institute of Clinical Psychology Training and Research

Chief Investigator: Adele Smith

Buckinghamshire Healthcare NHS Trust

Bucks Integrated Respiratory Service

Participant Debrief Sheet

Study Title: The Impact of Health Anxiety in Chronic Obstructive Pulmonary Disease (COPD)

Thank you for taking the time to take part in this study.

This research project aimed to investigate whether individuals who have health anxiety and COPD are more likely to perceive their performance on a physical exercise task as being worse than people without health anxiety.

If you would like any further information about this research project, or have any questions, please get in touch with Adele Smith (Chief Investigator) via email address (adele.smith@stx.ox.ac.uk).

If you have any concerns about an aspect of this study, please contact the members of the research project who will do their best to answer your questions. You can contact either Adele Smith (adele.smith@stx.ox.ac.uk) or Dr Neil Carrigan (neil.carrigan@hmc.ox.ac.uk).

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- Arrange for an appointment with your G.P or allocated healthcare worker
- SHOUT, a texting service for 24/7 support or if you are in a crisis, text SHOUT to 85258.

Thank you again for taking part in this study