School of Psychology
Ysgol Seicoleg

A Mixed Methods Systematic Review of Factors Impacting Help-Seeking in OCD, and an Empirical Study of Psychological Flexibility and Resilience in Care Seeking and Non-Care Seeking Voice Hearers Exposed to Trauma

Thesis submitted in partial fulfilment of the requirement for the degree of:

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Owen Lane

Supervised by: Dr Heledd Lewis and Dr James Gregory

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Preface

Mental health difficulties are estimated to impact a quarter of people within the United Kingdom every year, however, only 1 in 8 of those people receive support for their mental health. Research has demonstrated that therapeutic interventions are effective at treating mental health difficulties and improving quality of life. This suggests that there are other factors which influence the care seeking patterns of people with mental health difficulties. Developing a better understanding of why people do or do not seek care is imperative to ensure that people are getting the support they need for any mental health difficulties that may be present.

The systematic review investigated the barriers and facilitators to care seeking for those with obsessive compulsive disorder (OCD). This is a highly relevant issue as OCD affects up to 3% of population but less than 40% of those with OCD in the UK actually seek support. Additionally, OCD has been recognised to be one of the most debilitating health conditions and rates of diagnosis have been increasing over recent years. It has been suggested that people may not seek support for OCD due to stigma; the process of labelling, stereotyping, and judging people. This review searched databases and reference lists, finding a total of 22 studies conducted across 12 countries. These studies were a mixture of qualitative and quantitative allowing for the development of rich findings that reflect the wide OCD population. Six integrated findings were produced that encapsulated both barriers and facilitators to help-seeking. These were treatment beliefs, stigma, making sense of own experiences, I am responsible, helplessness, and external support. Treatment beliefs referred to the negative or positive past experiences with support seeking and ideas about treatment effectiveness, alongside fears of cost and time implications. Stigma focused on the internal, external, and structural judgements that can be made about mental health and OCD, and that these can both motivate or prevent people from seeking support. A common theme related to people making sense of their own experience often stemmed from difficulties recognising OCD symptoms which are made more difficult by complex pathways to seeking support. Personal responsibility is a frequently held belief within OCD which was identified to be associated with people's identity and values. Helplessness referred to the belief that OCD was either too severe or not severe enough to seek help, and that another mental health condition was required to be able to access support. Finally, external support outlined the role of family, friends, professionals, and religion in the process of seeking help. These findings appeared to present on a continuum with factors acting as facilitators or barriers dependent on the strength of the factor. Furthermore, the findings align with models of therapy and highlight areas for broader intervention to encourage help seeking for those with OCD.

The empirical study recognised that some people who experience traumatic events may go on to hear voices, some of whom seek support while others do not. This study investigated the differences between these groups in relation to psychological flexibility and resilience. It is estimated that up to 15% of people will hear something, such as a voice, that is not there, with those who have been exposed to trauma reporting much higher rates of voice hearing. However, not all of these people will go on to seek mental health support, suggesting that there are other factors that need to be considered in relation to hearing voices. One theory, called psychological flexibility, is that an individual's ability to adapt to situations while balancing one's own needs. Another relates to resilience which is the ability to use personal and social resources to respond to challenging situations. This study used a range of questionnaires in an online study with adults who hear voices and have sought care alongside those who have not to investigate these factors. The results showed that there was a difference between the groups based on the repeated exposure to the same trauma alongside the distress caused by voices and traumas. Additionally, those who sought care reported much lower levels of resilience and psychological flexibility. These results support the use of a range of interventions including cognitive behavioural therapy, family therapy, social prescribing, and open dialogue to foster skills in resilience, alongside acceptance and commitment therapy to develop the ability to respond in a psychologically flexible manner. The study identified possible avenues for future research and highlighted that voice hearing may be more frequent than expected in university populations, with additional support required.

Both the empirical study and systematic review furthers our understanding of help seeking across OCD and voice hearing populations. The combination of these results with the wider literature and future research, could allow services to provide effective interventions to those in need to a wider proportion of the population.

Paper 1: Systematic Review

The Barriers and Facilitators to Accessing Support for OCD – A Mixed Methods Systematic Review

Running title: Help-Seeking in OCD

Owen Lane[a]

[a] South Wales Doctoral Programme in Clinical Psychology, School of Psychology, Cardiff University, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT

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This paper was prepared in accordance with the author guidelines for the Journal of Obsessive-Compulsive and Related Disorders (see Appendix A)

Abstract

Background

Obsessive-compulsive disorder (OCD) is a debilitating mental health difficulty with rising prevalence rates. Despite the presence of effective interventions, the majority of those with OCD do not access support. Stigma has been suggested to play a large role in preventing help-seeking. This review aimed to better understand the barriers and facilitators to help-seeking for those experiencing OCD.

Methods

A convergent integrated approach to mixed methods review was used to combine qualitative and quantitative findings. Electronic databases were searched (PubMed, PsychINFO, and Web of Science) to identify studies that included barriers and/or facilitators with OCD populations. The papers were quality assessed using the Mixed Methods Appraisal Tool.

Results

Twenty-two papers met the inclusion criteria. Six integrated findings were identified to encapsulate the barriers and/or facilitators to help-seeking: treatment beliefs, stigma, making sense of own experience, I am responsible, helplessness, and external support.

Conclusions

Many of the findings were found to act as barriers or facilitators to help-seeking depending on the strength of impact on the individual, supporting the use of a continuum model when considering access to support. Possible ways to improve access to support include stigma reduction interventions, integration of therapeutic and community resources, and improved cultural awareness.

Keywords: obsessive-compulsive disorder, OCD, barriers, facilitators, help-seeking, mixed methods, systematic review.

Introduction

Common mental health conditions negatively impact emotional state and daily function (McManus et al., 2016) which costs the United Kingdom an estimated £70 billion each year (OECD, 2014). Obsessive compulsive disorder (OCD) is estimated to be the fourth most prevalent mental health (MH) condition (Kessler et al., 2005) which is most often see in 20- to 24-year-olds (Bebbington, 1998) with lifetime prevalence rates of 1.6% to 3% (Subramaniam et al., 2012). OCD is defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013) as the presence of obsessive, intrusive and uncontrollable thoughts, images, or urges alongside a pattern of compulsive, ritualised mental or physical behaviours aimed at reducing the associated anxiety. The World Health Organization (1999) place OCD amongst the most debilitating conditions and there have been increasing rates of diagnosis over the past 6 years which may be due to events such as Coronavirus-19 (COVID-19; Newlove-Delgado et al., 2022).

The COVID-19 pandemic impacted services and existing physical and MH conditions with estimated rates of anxiety and depression increasing by a quarter (Santomauro et al., 2021). The pandemic recommendations of increased handwashing because of possible contamination and theoretical overlap with symptoms of OCD, it was hypothesised that OCD rates would increase, and treatment efficacy would reduce (Fontenelle & Miguel, 2020). Surprisingly, initial research demonstrated that COVID-19 was found to have little to no effect on those experiencing OCD during the height of the pandemic (Chakraborty & Karmakar, 2020) or at a one year follow up (Moreira-de-Oliveira et al., 2022). One hypothesis is that due to the high level of anxiety experienced as a result of the OCD, there is less capacity for increased worry and therefore, no worsening of symptomology (Pinciotti et al., 2022). However, the pandemic and the accompanying guidelines were found to create a sense of legitimising the compulsions (Tandt et al., 2021) and interrupted the treatment process (Wheaton et al., 2021).

The National Institute for Health and Care Excellence (NICE, 2005) recommend cognitive behavioural therapy (CBT) and exposure response prevention (ERP) as the initial treatment option for OCD. ERP is an established, effective treatment option for OCD (Havnen et al., 2014; Meyer, 1966; Stanley & Turner, 1995) which focuses on exposing the individual to anxiety inducing situations without engaging in compulsions. Research into cognitive therapy techniques demonstrates similar successes to ERP, indicating that both may be effective in the treatment of OCD (Cottraux et al., 2001; Freeston et al., 1997; McLean et al., 2001; Whittal et al., 2005). The combination of both interventions has formed the basis of CBT for OCD (Abramowitz, 2006), with Clarke (2005) emphasising the importance of maintaining key elements of cognitive therapy within the CBT approach. Medication has been used as an alternative intervention (Pittenger & Bloch, 2014) although an estimated 50% of individuals do not experience positive effects for OCD (Kellner, 2010). Research suggests that CBT alone or in combination with medication can produce positive outcomes (Foa et al., 2005; Skapinakis et al., 2016; Watson & Rees, 2008).

Comorbid depression is present in a large proportion of individuals with OCD as it is highly correlated with anxiety, avoidance, and obsessional beliefs (Yap et al., 2012), and is associated with poor treatment outcomes (Sharma et al., 2021). The perceived severity of OCD and comorbid depression is associated with a worse quality of life (Masellis et al., 2003; Pozza et al., 2018). The enduring nature of OCD has significant negative impacts upon quality of life (Subramaniam et al., 2013) to a greater extent than most other groups (Bobes et al., 2001). Furthermore, quality of life is associated with lower levels of social functioning in OCD (Koran et al., 1996).

Despite the advances in treatment options and the significant quality of life impact that OCD has, many individuals do not seek support or access treatment. It is estimated that, worldwide, around 60% of individuals who would meet the clinical criteria for OCD do not receive treatment (Kohn et al., 2004). In the United Kingdom, this ranges from 60-68% meaning that only 32-40% of individuals are receiving the support required for OCD. Additionally, many individuals experiencing OCD have not sought support or spoken to anyone about their symptoms (Mayerovitch et al., 2003). This is compounded by the time taken to seek or receive support globally ranging from 3.28 years to 25.8 years (Costa et al., 2022; Cullen et al., 2008; García-Soriano et al., 2014). This is of particular importance as research has demonstrated that delays in accessing support of two years or greater are correlated with worse treatment outcomes (Dell'Osso et al., 2009).

A possible reason behind low levels of help-seeking behaviour in OCD is related to stigma. Despite the increasing awareness of MH, stigma continues to present a challenge some of which may stem from the trivialisation of OCD in modern media (Pavelko & Myrick, 2015). The stigma experienced in OCD can vary dependent on the type of obsessions experienced. For example, aggressive obsessions are often viewed as taboo and may be more difficult to seek support (McCarty et al., 2017; Simonds & Thorpe, 2003). Individuals experiencing OCD may be concerned about the safeguarding or legal repercussions that they worry could arise if they were to disclose their experiences or may not have their experiences recognised as symptomatic of OCD (Homonoff & Sciutto, 2019). Stigma is also experienced by the family members of individuals with OCD (Stengler-Wenzke et al., 2004) which can lead to the accommodation of OCD behaviours, maintaining the difficulties but relieving the short-term distress which may reduce the likelihood of seeking help (Storch et al., 2007).

Conducting a review into help-seeking behaviour in OCD, and collating our existing knowledge, will deepen our understanding and help develop initiatives to improve access to support. This systematic review aimed to answer the following questions:

1. What are the barriers to accessing help for individuals experiencing OCD?
2. What are the facilitators to accessing help for individuals experiencing OCD?
3. Can the current research identify any factors that might mitigate some of the barriers and enable individuals to access support more easily for their OCD?
4. How may some of the facilitators be applied to wider mental health services to improve access?

Methodology

The review followed the a priori methodology registered with Prospero (CRD42023388929). Three databases were searched to identify studies including PubMed, PsychINFO, and Web of Science. The searches were conducted from 8th until 19th January 2023. A combination of the following key words were used to search titles and abstracts: OCD, obsessive compulsive disorder*; and seek* advice, advice seek*, seek* help, help seek*, access* support, seek* treatment, treatment seek*, barrier*, facilitator*, enabler*, or predictor*. In addition, the reference lists of included papers were reviewed for relevant research that may have been missed.

Inclusion Criteria

It was established that a mixed methods approach to the review was necessary with both qualitative and quantitative studies were eligible for inclusion. The additional inclusion and exclusion criteria used for this review can be found in Table 1.1.

Table 1.1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Lived experience of OCD	Review papers
Report on barriers/facilitators to care seeking	Individual case reports
English transcript	Guideline or recommendation articles
Peer reviewed or academic research	Policy papers
	General commentary or opinion
	Discussion reports
	Conference proceedings

The first author independently reviewed all papers retrieved through database and reference searches, screening based on the title and abstract. Full texts were then screened based on the inclusion and exclusion criteria. During the full text screening process, 30% were reviewed by an additional independent reviewer with any disagreements regarding eligibility at this stage being resolved through discussion.

Quality Appraisal

As the review employed a mixed methods design to incorporate both qualitative and quantitative data, the Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong et al., 2018) was used to appraise the included studies (see Appendix B). The MMAT was developed with the aim of creating a single tool to be used to appraise a range of study designs without the need to search for and learn how to use new tools, which can be time consuming (Pluye et al., 2009). It has been through three revisions based on feedback, findings from the literature, and an e-Delphi study (Hong, 2018). The MMAT has been found to be a brief tool with an average appraisal time of 14 minutes, with good pre-discussion (κ = .717) and excellent post-discussion (κ = .936) inter-rater reliability (Pace et al., 2012).

The MMAT was selected as it allows for the methodological quality of qualitative, randomised controlled, nonrandomised, quantitative descriptive, and mixed methods studies to be critiqued, which would likely encompass the majority of the studies in this review. The tool comprises of two initial screening questions to be used for all study types, before separating out into five relevant questions for each of the five different methodologies. All responses are scored with a ‘yes’, ‘no’, or ‘can’t tell’ with space to include comments to consider. The authors discourage the use of an overall score to be calculated favouring instead, a more detailed description where necessary, as is recommended by research and best practice guidance within the area (Viswanathan et al., 2017). Additionally, the authors discourage the exclusion of studies with low methodological quality but for that data to be interpreted with some caution. As such, the MMAT was used to establish the baseline quality of the papers to sufficiently support the findings of this review, rather than a commentary of the impact of said quality. An independent researcher appraised 30% of the papers with disagreements resolved through discussion.

Data Extraction

Quantitative and qualitative data were extracted from eligible full texts including study design, research aims, population, key barriers and facilitators to accessing support, and any additional key findings of significance to the review questions. The data extraction was carried out solely by the first author, using the data extraction form recommended by the Joanna Briggs Institute (JBI) convergent integrated approach to mixed methods review guidelines (Lizarondo et al., 2020). Study characteristics were recorded including the study type, methodology, participant number and characteristics, and relevant context information such as cultural or geographical settings. Both qualitative and quantitative data relevant to the original aims of this review were recorded including key barriers or facilitators to accessing support for OCD, and any additional findings of significance to the review question. Data on the measures used within each study were also collected.

Data Transformation, Synthesis, and Integration

All quantitative data extracted was transformed into 'qualitized data' which involved converting quantitative results into textual descriptions. The convergent integrated approach according to the JBI guidelines for conducting a mixed methods systematic review was followed to guide this process (Lizarondo et al., 2020). This began by entering the appropriate quantitative data from each paper into an Excel spreadsheet, before being initially transformed into a textual format with some numerical data, and then a final transformation into fully qualitized data. To support with the quality of this process, examples were taken to supervision and discussed. This allowed the qualitized data to be combined with the data extracted from qualitative papers, providing a consistent dataset to answer the review questions. Data were then pooled based on similarity of themes to produce a range of integrated findings.

Results

Study Inclusion

The completed search carried out across four databases, yielded 1,506 studies which resulted in a total of 942 studies after duplicates were removed. Of these identified studies, 84 were assessed as full texts for eligibility to be included, following the title and abstract screening phases. This resulted in the final 22 studies being included in the review, consisting of 7 qualitative and 15 quantitative studies (see Figure 1.1). As 30% of the full texts were reviewed by an independent researcher, an inter-rater reliability was assessed (κ = .689) as a moderate level of agreement (McHugh, 2012) which, following a discussion, led to a consensus of 100%.

Methodological Quality

Table 1.2 demonstrates the qualitative quality appraisal results using the MMAT, and Table 1.3 displays the quantitative. The inter-rater reliability score indicated a moderate level of agreement (κ = .689) with all disagreements resolved through discussion. Regarding the quantitative data, the main limitation noticed was in relation to the lack of reporting on non-response bias. The majority of the studies did not provide any information relating to reasons or compensations for nonresponses (73.33%) with one study noting the effects of nonresponses in their limitations. One paper lacked clarity in regard to the research questions, with another using a non-representative sample, and one using a sampling strategy that was not relevant to the research question. For the qualitative research, papers were assessed to have good methodological quality. However, it was unclear as to whether the data collection methods were adequate to address the research questions as a small and biased sample of participants were used.

Characteristics of Included Studies

A summary of the characteristics of the included studies are displayed in Table 1.4. A total of 4,784 participants with OCD or OCS took part in these projects with the majority reporting on the adult population, with two studies reporting on child and adolescent populations. These research papers were published across 20 years (2002-2022) and conducted in 12 countries spanning five continents (Africa = 2 studies, Asia = 5 studies, Australasia = 1 study, Europe = 9 studies, and North America = 5 studies). They ranged in design from interview based qualitative or quantitative methodologies, to longitudinal and cross-sectional methods.

Figure 1.1

PRISMA Flowchart

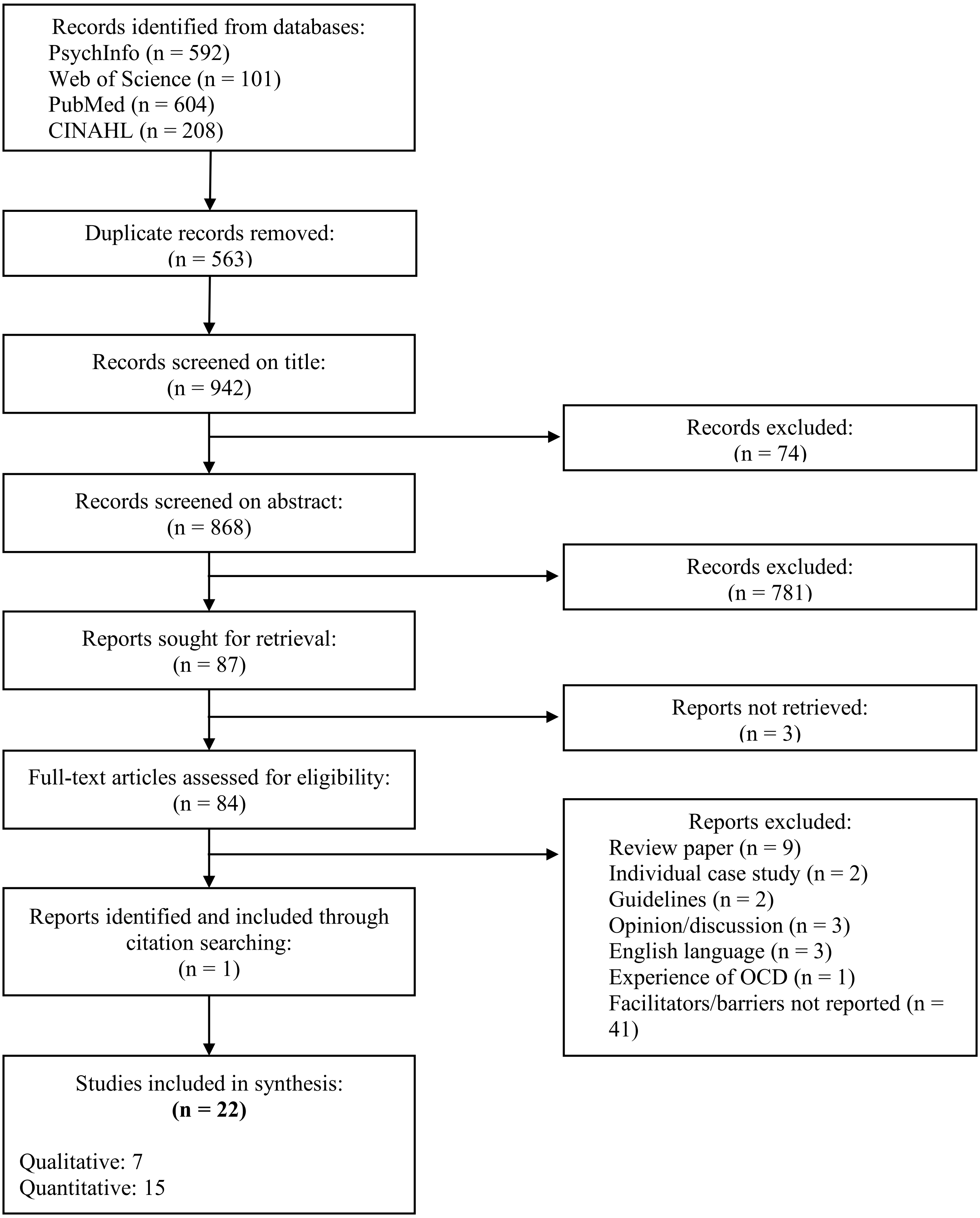


Table 1.2

Quality Appraisal of Qualitative Studies

	Yes (n = 48)	Mahintorabi et al. 2017	Burton 2021	Pedley et al. 2019	Sravanti et al. 2022	Al-Solaim & Loewenthal 2011	Robinson et al. 2017	Keyes et al. 2018
Are there clear research questions?	7	Y	Y	Y	Y	Y	Y	Y
Do the collected data allow to address the research questions?	7	Y	Y	Y	Y	Y	Y	Y
Are the qualitative data collection methods adequate to address the research question?	6	CT	Y	Y	Y	Y	Y	Y
Are the findings adequately derived from the data?	7	Y	Y	Y	Y	Y	Y	Y
Is the interpretation of results sufficiently substantiated by data?	7	Y	Y	Y	Y	Y	Y	Y
Is there coherence between qualitative data sources, collection, analysis and interpretation?	7	Y	Y	Y	Y	Y	Y	Y
Is the qualitative approach appropriate to answer the research question?	7	Y	Y	Y	Y	Y	Y	Y

Table 1.3

Quality Appraisal of Quantitative Studies

	Yes (n = 91)	Williams et al. 2012	Marques et al. 2010	Perris et al. 2021	Poyraz et al. 2015	Hathorn et al. 2021	Goodwin et al. 2002	Angst et al. 2004	Mancebo et al. 2011	Demet et al. 2010	Okasha et al. 2021	del Valle et al. 2017	Beşiroğlu et al. 2004	Belloch et al. 2008	Torres et al. 2007	Mayerovitch et al. 2003
Are there clear research questions?	14	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Do the collected data allow to address the research questions?	15	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is the sampling strategy relevant to address the research question?	15	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is the sample representative of the target population?	14	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Are the measurements appropriate?	14	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	Y	Y
Is the risk of nonresponse bias low?	4	CT	CT	Y	CT	CT	Y	CT	Y	CT	CT	CT	CT	CT	N	Y
Is the statistical analysis appropriate to answer the research question?	15	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 1.4.

Characteristics of Included Studies

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Williams et al. (2012)	*N* = 179 (*n* = 71 focus sample) 56.3% female M_{age} = 41.3 years Y-BOCS = $\geq$ 16	Center for the Treatment and Study of Anxiety, University of Pennsylvania, Philadelphia, USA	Cross sectional	OCD; barriers to treatment; African Americans	Barriers to Treatment Questionnaire (BTQ); Multigroup Ethnic Identity Measure (MEIM); Structured Clinical Interview for DSM-IV Axis I Disorders (SCID); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS); Barriers to Treatment Participation Scale (BTPS); Post Assessment Checklist
Marques et al. (2010)	*N* = 175 79.4% female M_{age} = 30.92 years *M* Y-BOCS = 21.69	Massachusetts General Hospital, Boston, USA	Cross Sectional	OCD; barriers to treatment	Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale – Self-report (Y-BOCS-SR); Quality of Life Enjoyment and Satisfaction Questionnaire-Short Form (Q-LES-Q-SF); Sheehan Disability Scale (SDS); Treatment History Questionnaire (THQ); Barriers to Treatment Questionnaire (BTQ)
Perris et al. (2021)	*N* = 83 48.2% female	OCD specialist unit,	Longitudinal	OCD; duration of untreated illness; OCD severity	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I);

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Perris et al. (2021) cont.	M_{age} = 31.5 years *M* Y-BOCS = 27.1	Department of Psychiatry, University of Campania "Luigi Vanvitelli", Naples, Italy			Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS); Hamilton Rating Scale for Depression (HDRS); Brown Assessment of Beliefs Scale (BABS); Family History Research Diagnostic Criteria
Mahintorabi et al. (2017)	*N* = 5 100% female M_{age} = 39 years Range Y-BOCS = 15-32	Australia	Semi-structured interviews - thematic analysis	Washing OCD; Muslim women; treatment seeking practice	Dimensional Obsessive-Compulsive Scale (DOCS); Duke Religion Index (DRI); Yale-Brown Obsessive Compulsive Scale (Y-BOCS)
Poyraz et al. (2015)	*N* = 96 57.3% female M_{age} = 32.49 years *M* Y-BOCS = 20.79	Cerrahpaşa Medical School, University of Istanbul, Turkey	Cross Sectional	OCD; barriers to treatment; insight; duration of untreated illness; treatment outcomes	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I); Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS)

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Hathorn et al. (2021)	*N* = 50 58% female M_{age} = 36.5 years	South Africa	Cross Sectional	OCD; Health Belief Model; help-seeking intention; barriers to help-seeking	Florida obsessive-compulsive inventory (FOCI); Attitudes Toward Seeking Professional Psychological Help Scale-Short Form (ATSPPH-SF); Barriers to Access Care Evaluation (BACE) scale; General self-efficacy scale (GSES);
Goodwin et al. (2002)	*N* = 14860 (*n* = 3069 with OCD) 69% female	USA	Cross Sectional	OCD; predictors; readiness to seek treatment	National Anxiety Disorders Screening Day (NADSD) survey
Burton (2021)	*N* = 5 100% female M_{age} = 33.6 years *M* DOCS = 38.6	University of Warwick, UK	Semi-structured interviews – interpretive phenomenological analysis	Established OCD; pregnancy and postpartum experience	Dimensional Obsessive Compulsive Scale (DOCS)
Pedley et al. (2019)	*N* = 16 62.5% female Age range = 16-64 years	UK	Semi-structured interviews - thematic analysis	OCD; illness perception; Common-Sense Model of Self-Regulation	Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS)

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Pedley et al. (2019) cont.	*M* Y-BOCS = 20.2				
Sravanti et al. (2022)	*N* = 10 40% female Age range = 10-17 years *M* CY-BOCS = 2.7	National Institute of Mental Health and NeuroSciences, Bengaluru, India	Semi-structured interviews – interpretive phenomenological analysis	OCD; experience; child and adolescent; remission	Mini International Neuropsychiatric Inter- view for Children and Adolescents (MINI KID); Children's Yale-Brown Obsessive–Compulsive Scale (CY-BOCS); Clinical Global Impression-Severity Scale (CGISS)
Angst et al. (2005)	*N* = 591 (*n* = 111 with OCD/OCS) 50.5% female Age range = 40-41 years	Zurich, Switzerland	Longitudinal	OCD; comorbidity; distress; impairment; treatment	Interviews
Mancebo et al. (2011)	*N* = 202 57% female M_{age} = 39.7 years *M* Y-BOCS = 11.8	Brown University, Rhode Island, USA	Longitudinal	OCD; treatment adherence; CBT	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I); Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS); Longitudinal Interval Follow-up Evaluation (LIFE); Modified Hamilton Rating Scale for

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Mancebo et al. (2011) cont.					Depression (MHRSD); Treatment Adherence Survey–Patient Version; Behavioural Therapy Inventory (BTI)
Al-Solaim & Loewenthal (2011)	*N* = 15 100% female Age range = 14-30 years	Royal Holloway, University of London, UK, and Saudi Arabia	Semi-structured interviews - thematic analysis	OCD; religion; Islam	Interviews
Demet et al. (2010)	*N* = 132 68.9% female M_{age} = 31.9 years *M* Y-BOCS = 20.9	OCD outpatient clinic or dermatology clinic, Manisa, Turkey	Cross Sectional	OCD; risk factors; delay treatment	Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Turkish Version; Yale-Brown Obsessive-Compulsive Scale (Y-BOCS); Y-BOCS Symptom Checklist; Beck Depression Inventory (BDI); Semi-structured Demographic Information Form
Okasha et al. (2021)	*N* = 93 46.2% female M_{age} = 29.66 years	Okasha Institute of Psychiatry, Ain Shams University, Egypt	Cross Sectional	OCD; traditional healers; help-seeking behaviour	Mini-International Neuropsychiatric Interview (M.I.N.I.) version 5; Yale-Brown Obsessive-Compulsive Scale (Y-BOCS); Custom designed questionnaire
Robinson et al. (2017)	*N* = 17 64.7% female	King's College, UK	Semi-structured interviews - thematic analysis	OCD; factors encouraging help-seeking; reasons to not seek help	Yale-Brown Obsessive-Compulsive Scale (Y-BOCS); Y-BOCS Symptom Checklist

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Robinson et al. (2017) cont.	M_{age} = 36 years *M* Y-BOCS = 18.2				
Keyes et al. (2018)	*N* = 10 50% female M_{age} = 15.58 years	UK	Semi-structured interviews - thematic analysis	OCD; experience; child and adolescent	Interviews
del Valle et al. (2017)	*N* = 156 (*n* = 71 with OCD) 60.6% female M_{age} = 34.17 years *M* Y-BOCS = 27.01	National Health System and Research and Treatment Unit for OCD, Valencia, Spain	Cross Sectional	OCD; comparison; Agoraphobia; depression; anorexia nervosa; cocaine dependence; help-seeking	Yale-Brown Obsessive-Compulsive Scale (Y-BOCS); Agoraphobia Inventory; Beck Depression Inventory-II (BDI-II); Eating Disorder Inventory- II; Cocaine Selective Severity Assessment; semi-structured interview; Interview on Help-Seeking for Mental Health (IHS-MH); Goldberg General Health Questionnaire-28; Anxiety Disorders Interview Schedule for DSM-IV: Lifetime version (ADIS-IV-L)
Beşiroğlu et al. (2004)	*N* = 48 39.6% female	Konya Epidemiological Study for OCD or Psychiatric Outpatient	Cross Sectional	OCD; healthcare seeking; depression; comorbidity; quality of life; predictors	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS); Hamilton Depression Rating

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Beşiroğlu et al. (2004) cont.	Care-seeking M_{age} = 28.3 years Non-care-seeking M_{age} = 31.4 years Care-seeking *M* Y-BOCS = 24.7 Non-care-seeking *M* Y-BOCS = 21.0	Clinic of Selçuk University Hospital in Konya, Turkey			Scale (HDRS); World Health Organization Quality of Life Measurement Instrument Turkish Version (WHOQOL-103 TR)
Belloch et al. (2009)	*N* = 26 61.5% female M_{age} = 32.85 years Y-BOCS Range = 16-40	National Health System, Valencia, Spain	Cross Sectional	OCD; help-seeking	Maudsley Obsessive Compulsive Inventory (MOCI); Thought Control Questionnaire (TCQ); Interview on Help-Seeking (IH-S); Yale-Brown Obsessive-Compulsive Checklist and Severity Scale (Y-BOCS)
Torres et al. (2007)	*N* = 114 64.9% female	England, Wales, and Scotland	Cross Sectional	OCD; treatment; comorbidity; gender	Clinical Interview Schedule (CIS-R)

Authors	Sample characteristics	Location	Design	Phenomena of interest	Measures
Torres et al. (2007) cont.	Age range = 16-74				
Mayerovitch et al. (2003)	*N* = 172 65.1% female M_{age} = 36.3 years	Edmonton, Canada	Cross Sectional	OCD; comorbidity; help-seeking	Diagnostic Interview Schedule (DIS version III)

Table 1.5.

Integrated Findings, Categories, and Findings

Integrated findings	Categories	Findings	
Treatment beliefs	Past experience of treatment	**Qualitative findings**	
		Successful help	“My psychiatrist prescribed clomipramine and then changed it to Fluoxetine which I have taken since then and my washing symptoms got less severe afterward … I am more relaxed now.” (Mahintorabi et al., 2017)
		Unhelpful support	“I did try to talk to a religious advisor (Imam) which was not helpful. Eventually … I sought professional help and went to see a psychiatrist.” (Mahintorabi et al., 2017)
		Too challenging	“I could not tolerate that way of doing things or stop washing my hands and body … It made me sick and I did not continue seeing him as it was too much for me.” (Mahintorabi et al., 2017)
		Effective	“Gradually it became easier … that motivated me and gave me the courage to continue therapy.” (Sravanti et al., 2022)
			“This is my third visit to the doctor and I already feel better.” (Al-Solaim & Loewenthal, 2011)
			“He gave me some pills, symptoms are much better …” (Al-Solaim & Loewenthal, 2011)
		Wider effects	“… once I agreed to taking treatment for this – I started being open to trying more things.” (Sravanti et al., 2022)
		Lack of clarity	“… I don’t know what those pills are doing to me.” (Al-Solaim & Loewenthal, 2011)

Integrated findings	Categories	Findings	
		Need additional support	"They give me experiments and expect me to go home and I'm going to be on my own again - it's like, no. It's a bit like prison - if you go into prison you are going to be good, because you are being watched. But as soon as you go out of prison no one is watching you. And you're like, 'oh, I'm free' … I need some- one to watch me ... yeah I need mum to watch me. Or some- one, anyone, and teachers." (Keyes et al., 2018)
		Quantitative findings	
		Unsuccessful	Treatment did not work (Williams et al., 2012) CBT not helpful in the past (Mancebo et al., 2011) Psychiatric history 3-fold higher risk for delaying treatment than no history (Demet et al., 2010) I received treatment before and it didn't work (Marques et al., 2010)
		Clinician problem	Did not think the CBT provider was good (Mancebo et al., 2011)
		Diversity	Treated unfairly because of race or ethnicity (Williams et al., 2012)
	Financial Implications	**Qualitative findings**	
		Unable to afford	"…my fear was that if I sought help, it would not be good because I couldn't afford it." (Williams et al., 2012)
		Quantitative findings	
		Income restrictions	Previous access to treatment were more likely to have a high income (Williams et al., 2012) Moderate income less likely to access treatment (Williams et al., 2012) Moderate income 3.12-fold higher risk of delaying treatment than high income (Demet et al., 2010)
		Employment	Unemployed less likely to seek treatment (Perris et al., 2021)

Integrated findings	Categories	Findings	
		Overall cost	Financial factors reported as a barrier by 12.5% (Poyraz et al., 2015)
			Not being able to afford the financial costs involved (Hathorn et al., 2021)
			Can’t afford treatment (Goodwin et al., 2002)
			Could not afford CBT cost and health insurance did not cover CBT (Mancebo et al., 2011)
			I was worried about how much it would cost (Marques et al., 2010)
		Insurance	No insurance (Goodwin et al., 2002)
			Could not afford CBT cost and health insurance did not cover CBT (Mancebo et al., 2011)
			Health insurance would not cover treatment (Marques et al., 2010)
	Expectation	**Qualitative findings**	
		Fear of side effects	“I did stop taking my medication because I had known there were certain cases … it had caused, like, heart defects … realistically I need the medication to function properly but then I can’t cause something that’s going to impact on my baby’s life.” (Burton, 2021)
		Treatment is safe	“I could probably do it (not check) if I knew that I was in therapy.” (Pedley et al., 2019)
		Medication reliance	“It [medication] helps with the symptoms and it does help. But it doesn’t really deal with the problem, so if you come off them all of a sudden it’s bad.” (Pedley et al., 2019)
		Medication concern	“You don’t know whether they’re going to give you medicines, and you know, that might seem a bit of a sledgehammer to crack a nut.” (Robinson et al., 2017)

Integrated findings	Categories	Findings	
		Treatment will be hard	“Not having to go through the hard process of CBT … not having this long process of getting better.” (Robinson et al., 2017)
		Quantitative findings	
		Effectiveness	Treatment will not be effective (Williams et al., 2012)
			Perception that the treatment will be ineffective (Poyraz et al., 2015)
			Perceived benefits of treatment predicted help-seeking intention (Hathorn et al., 2021)
		Commitment	I will disengage (Williams et al., 2012)
		Uncertainty	Possibility of using medication reported as a barrier by 24% (Poyraz et al., 2015)
			Reluctance to start treatment even after seeing a psychiatrist (Poyraz et al., 2015)
			Concerns about the treatments available (e.g., medication side effects) (Hathorn et al., 2021)
			Afraid to take medication (Goodwin et al., 2002)
			Fear to treat (del Valle et al., 2017)
		Different to reality	Lower response to all barriers after engaging with treatment (except for too busy or treatment inconvenient, CBT would not teach me anything new, and other reasons) (Mancebo et al., 2011)
	Logistics	**Quantitative findings**	
		Time availability	Lower income means no time for treatment (Williams et al., 2012)
		Age	Younger age means no time for treatment (Williams et al., 2012)
		Prioritisation	Too busy or treatment inconvenient (Mancebo et al., 2011)
			I thought it would be too inconvenient or take too much time (Marques et al., 2010)

Integrated findings	Categories	Findings	
	Choice	**Qualitative findings**	
		Different clinicians	Would prefer to go to a neurologist/psychologist or spiritual healer instead of psychiatrist (Poyraz et al., 2015)
		Multiple approaches	“You definitely need the therapy, I really don’t believe for one minute you would ever recover from OCD with just tablets.” (Pedley et al., 2019)
			“My parents decided to take me to a faith healer who started reading verses of the Qur’an to me, this gave me temporary relief, but the symptoms persisted.” (Al-Solaim & Loewenthal, 2011)
		Availability of treatments	CBT not available (Mancebo et al., 2011)
			I could not get an appointment (Marques et al., 2010)
			I was not satisfied with the services that were available
		Cultural options	“My family understands, they know that [my] obsessionality is caused by Satan, but they still believe I should take the pill, and also, read verses of the Qur’an on myself.” (Al-Solaim & Loewenthal, 2011)
			“I don’t really care about the level of religiosity of the psychiatrist who is treating me; he is not a family member or a friend so why should I feel protective of him. But it would be better if he was religious, since he will have fear of God, and thus be more dedicated in doing his job.” (Al-Solaim & Loewenthal, 2011)
			“I certainly prefer a Muslim psychiatrist, a non-Muslim would not understand what I am going through, would not understand my problem.” (Al-Solaim & Loewenthal, 2011)

Integrated findings	Categories	Findings	
		Finding someone similar	“When my symptoms started two or three years ago, going to a female faith healer was the first thing I did…” (Al-Solaim & Loewenthal, 2011)
Stigma	Internal judgement	**Qualitative findings**	
		Self-hatred	“I remember I hated myself during my period because of being impure. I was really scared of not performing religious rituals in a right way, especially five-time daily prayer.” (Mahintorabi et al., 2017)
		Guilt	“I felt guilty because I thought I do not correctly perform my rituals, God won’t accept them…” (Mahintorabi et al., 2017) “I decided to talk to an Imam … he reassured me God will help me if I ask for God’s forgiveness.” (Mahintorabi et al., 2017)
		Weakness	“I felt embarrassed at times, I felt weak at times.” (Pedley et al., 2019) “I just wasn’t strong enough to talk about it at the time. Um, like when I told the doctor, I cried . . . I wasn’t strong enough to talk about it and think about it, I guess. Um, so that was part of it as well, I was so exhausted, I was so ill, and stressed.” (Robinson et al., 2017)
		Selfish	“It’s [OCD] made me into, quite a, not self-centred person, but I spend a lot of time on me ... But it feels like I’m very selfish.” (Pedley et al., 2019)
		Disgust	“I was scared what the doctors will think if I talked about what was happening to me because it was really disgusting thoughts, not nice things. So, I felt shy to talk about it.” (Sravanti et al., 2022)
		Envy	“I have a thought – ‘if I didn’t have OCD just like my friends, then … I could have had a nice time and spent it more nicely and productively like they have’.” (Sravanti et al., 2022)

Integrated findings	Categories	Findings	
		Shame	“I would never have gone … it is a sense of shame of it.” (Robinson et al., 2017)
		Exposed	“… don’t do it … you’d feel a bit exposed, that sort of feeling.” (Keyes et al., 2018)
		Quantitative findings	
		Shame	Ashamed of symptoms and needing help (Poyraz et al., 2015)
			Feeling embarrassed or ashamed (Hathorn et al., 2021)
			Shame as a barrier to help seeking (del Valle et al., 2017)
			I felt ashamed by the thought contents (Belloch et al., 2009)
			Long delay in help seeking group more frequently reported feeling ashamed than short delay group (Belloch et al., 2009)
			I felt ashamed of needing help for my problems (Marques et al., 2010)
		Exposed	Embarrassed others would find out (Mancebo et al., 2011)
		Guilt	Guilt about the symptoms (del Valle et al., 2017)
		Crazy	Fear of being crazy as a motivator for help seeking (del Valle et al., 2017)
		Self-view	Being a bad person was a motivator (del Valle et al., 2017)
			I thought I was a bad person for having these thoughts facilitated help seeking (Belloch et al., 2009)
	External judgement	**Qualitative findings**	
		Race and culture	“Getting this type of help has, and continues to be, like a sore thumb in the African American community.” (Williams et al., 2012)
		Being an outsider	“I once spoke to my wider family … but I sometimes felt like the black sheep of the family because I was the one with the mental illness.” (Pedley et al., 2019)

Integrated findings	Categories	Findings	
		Not enough change	“There’s still a big stigma I suppose about it, about anything mental health, and I know it’s a lot better than it’s been before, but it’s still there.” (Pedley et al., 2019)
		Family views	“I wanted to talk but I was worried about what my parents would think about me if I talked to them about my problem. So, initially I held back from talking about it.” (Sravanti et al., 2022)
			“Maybe they [parents] felt they’d somehow failed if I was carrying on like this. And maybe they thought what if there’s something really wrong about, what, [s/he’s] mental or something. Just try and ignore it and [s/he] might stop.” (Robinson et al., 2017)
		Concealment	“I told my parents not to tell my relatives or friends. I don’t want anyone to know about my disease.” (Sravanti et al., 2022)
			“Nobody knows – nobody had ever known I had it … And you don’t want people to know.” (Robinson et al., 2017)
			“… through this time … my family … didn’t know really anything that was going on.” (Robinson et al., 2017)
		Professionals	“I didn’t know sort of what it would be like and I suppose what they [GP] would think.” (Robinson et al., 2017)
		Afraid	“I just thought ... other people would think, ‘Oh my God’, you know, ‘What a monster’. That’s why I never told anybody.” (Robinson et al., 2017)
		Quantitative findings	
		Diagnosis	Afraid to have a diagnosis of a mental illness (Poyraz et al., 2015)

Integrated findings	Categories	Findings	
			Long delay in help seeking group more frequently reported fear of stigma associated with mental disorder than the short delay group (Belloch et al., 2009)
		Race and culture	Those in receipt of treatment more likely to be Caucasian (Goodwin et al., 2002)
		Gender difference	Those in receipt of treatment more likely to be female (Goodwin et al., 2002)
		Age	Younger age increased likelihood of being ready to seek help (Goodwin et al., 2002)
		Fear	Afraid of what others would think (Goodwin et al., 2002) Worried about stigma of mental illness (Mancebo et al., 2011) Fear of being considered crazy (del Valle et al., 2017) Fear of social rejection (del Valle et al., 2017) I feared being considered a mentally ill person I worried about what people would think if they knew I was in treatment (Marques et al., 2010)
		Family	I was afraid of being criticised by my family if I sought psychiatric help (Marques et al., 2010)
	Experience of judgment	**Qualitative findings**	
		Not putting enough effort in	“The first time I asked for help, I talked to an Imam … and he recommended that I read the Quran more.” (Mahintorabi et al., 2017) “First time I talked to my father about what was happening to me. He told me that I should control it and do meditation.” (Sravanti et al., 2022)

Integrated findings	Categories	Findings	
		Family	“My elder sister once shouted at me for removing all petals of a flower. I did so in an attempt to make it look proper, because I felt something was not okay about it. I feel quite bad about it.” (Sravanti et al., 2022)
		Friends	“Once I went out with friends to eat ice-cream and I felt the ice-cream cone was not in a proper manner. [...] the ice-cream cone was not really round in shape so I just asked the shopkeeper to change it. My friends said, ‘what are you doing, we are feeling embarrassed, we are their regular customer, what they will think? This is a very bad thing that I embarrassed my friends!” (Sravanti et al., 2022)
		Significant other	“He [partner] gets very uncomfortable and he doesn’t like it. Erm, because he likes to do things his own way.” (Pedley et al., 2019)
		Quantitative findings	
		Race and culture	Treated unfairly because of race or ethnicity reported as a barrier (Williams et al., 2012)
		Gender differences	Women experience more stigmatising or negative beliefs about mental health than men (Williams et al., 2012)
Making sense of own experiences	Recognition of needing help	**Qualitative findings**	
		Identification of symptoms	“I didn’t realise I had a problem” (Williams et al., 2012)
		Comparison to others	“It probably then started hitting me that ‘This isn’t right that I’m doing these type of things’ because other people seem to be able to leave, you know, just be able to live with that, deal with that, without doing X, Y and Z.” (Pedley et al., 2019)

Integrated findings	Categories	Findings	
		Interference in daily life	"… there's a point on that spectrum where it becomes abnormal, it becomes disordered, it becomes chaotic, erm, and it becomes life intrusive." (Pedley et al., 2019) "To me it didn't affect me enough." (Robinson et al., 2017) "He immediately referred me and I was so surprised because I thought what I told him was not sort of, of much sort of significance almost." (Robinson et al., 2017)
		Quantitative findings	
		Identification of symptoms	Unaware of having OCD reported as a barrier (Williams et al., 2012)
			I thought I had a serious problem (an illness) motivated help seeking (Belloch et al., 2009)
		Interference in daily life	Interference of anxiety symptoms in daily life predicted treatment (Goodwin et al., 2002) Symptoms do not interfere with life (Williams et al., 2012) Low disturbance by symptoms and little importance given to symptoms (del Valle et al., 2017) Low interference of symptoms (del Valle et al., 2017) Interference in daily life motivates help seeking (del Valle et al., 2017) People who sought help scored lower on all quality-of-life domains (del Valle et al., 2017) The problem did not interfere with my daily activities (Belloch et al., 2009) The problem (thoughts and/or behaviours) interfered with what I was doing (Belloch et al., 2009)

Integrated findings	Categories	Findings	
			Short delay in help seeking group experienced their symptoms to interfere more in daily activities than long delay group (Belloch et al., 2009)
		Significant changes	Faster onset from a major incident, resulting in seeking help quicker (Poyraz et al., 2015)
			Frequency of symptoms increases, or fear of symptoms increases (del Valle et al., 2017)
			The problem (thoughts and/or behaviours) became more frequent (Belloch et al., 2009)
			Short delay in help seeking group were aware of changes in their behaviour caused by symptoms (Belloch et al., 2009)
		Denial	I don’t have an anxiety disorder (Goodwin et al., 2002)
	Insight into OCD	**Qualitative findings**	
		Being crazy	“I honestly thought I was going mad. That I was losing my mind, losing control of my mind.” (Pedley et al., 2019)
			“I just thought I was going mad, I didn’t know there was actually … this disorder if you like … had a name for it so that.” (Pedley et al., 2019)
			“I thought I was going crazy.” (Robinson et al., 2017)
		Understanding OCD as a mental health difficulty	“It’s definitely a mental illness to me now. And I know I’m sure there’s very logical ways of treating it.” (Pedley et al., 2019)
		Normalised symptomology	“Both my parents have little quirks and I’ve picked them up and taken them to the next level, like they’re both very organised and rigid in how they like things.” (Pedley et al., 2019)
			“I do believe that everyone has it [OCD], but whether or not you’d label that OCD …” (Pedley et al., 2019)

Integrated findings	Categories	Findings
		"I think everybody has a certain level of it [OCD] … I think that also demeans, like everyone is like 'urgh, everyone has it a bit'." (Pedley et al., 2019)
	Confusion	"One of the reasons I didn't ask for help when everything started is because I had no idea of what was going on." (Robinson et al., 2017)
	Public representations	"I seen that lady on the tele ... I watched her tell her story and I thought, 'Oh my God!' It was just like a revelation! ... relief poured down …" (Robinson et al., 2017)
	Quantitative findings	
	Fear	Fear of being crazy motivates help seeking (del Valle et al., 2017)
	Religious origin	Thinking that symptoms are related to religious problems/being a sinner (Poyraz et al., 2015)
	Education	Higher education predicts readiness for treatment (Goodwin et al., 2002) Short delay group had a lower education level than the long delay group (Belloch et al., 2009)
	Insight is required	Poor insight 2.13-fold higher risk for delaying treatment than good insight (Demet et al., 2010) Lower insight significantly associated with health care seeking behaviour (del Valle et al., 2017) Short delay in help seeking group had more insight than the long delay group (Belloch et al., 2009)
	Speaking into existence	Thought-action fusion beliefs both barrier and motivator (del Valle et al., 2017)

Integrated findings	Categories	Findings	
			I feared that if I disclosed the thoughts to someone, the thoughts would come true acted as a barrier (Belloch et al., 2009)
			I believed my thoughts could come true was a motivator (Belloch et al., 2009)
		Normalised symptoms	Thought that 'it's common' (or usual) (del Valle et al., 2017)
			Obsessive compulsive symptoms thought not to be an illness associated with longer duration without treatment (Poyraz et al., 2015)
	Next steps	**Qualitative findings**	
		Implications of disclosing	"I would never … have [er] admitted the, the thoughts that I was having because of the concern that they would take the baby away." (Burton, 2021)
		Optimism	"OCD will affect my journey from here on too. I am sure about it … but still life will be okay, it'll be nice." (Angst et al., 2005)
		Ignoring the problem	"I think maybe it was just kind of, if we don't focus on it, it will go away. If we pretend it's not happening, it's not really there." (Robinson et al., 2017)
		Quantitative findings	
		Fear of diagnosis	Afraid to have a diagnosis of mental illness (Poyraz et al., 2015)
		Unsure of what to do	Not being sure of where to go (Goodwin et al., 2002)
			Unsure of who to see or where to go (Williams et al., 2012)
			Statistically significant relationship between lower education and increased tendency to seek advice from traditional healers (Okasha et al., 2021)
			I was unsure about who to see or where to go (Marques et al., 2010)
			Don't know who to tell (del Valle et al., 2017)
		Religion will help	Consider religious commitment to help treatment therefore access traditional healer (Okasha et al., 2021)

Integrated findings	Categories	Findings	
		Time	The thought ‘symptoms will not last’ (del Valle et al., 2017) It did not go away (del Valle et al., 2017) I was convinced that the problem was temporary (it would pass over the time) (Belloch et al., 2009)
I am responsible	Independence	**Qualitative findings**	
		I need to protect others	“Don’t want him to see me doing this and think, ‘Well, this is the normal’ when we were going out and he, I was locking the inside doors, I just think, I don’t know that this should carry on so that’s why I actually started to have CBT.” (Burton, 2021) “I didn’t want my children to be like me. I didn’t want them to pick things up like that.” (Pedley et al., 2019) “… at first I was avoiding people. Because when I interacted with them, I had thoughts that were distressing.” (Sravanti et al., 2022) “The fear of like admitting to your parents as well, that you’ve got that problem, and wondering whether, whether your parents would be, they might be upset about knowing their child has a psychological issue.” (Robinson et al., 2017) “I felt like it was all my responsibility. I felt it was my responsibility to keep everyone safe. And if I didn’t do these things, bad things would happen.” (Keyes et al., 2018) “So I didn’t want to like put anyone at risk … I just wanted to stay by myself.” (Keyes et al., 2018)

Integrated findings	Categories	Findings	
		I can manage alone	"I didn't have any guilt but like I said I just thought I can do it myself. I can handle the situation myself. Every time I used to feel – 'I can do it myself, I don't need anyone's help'." (Sravanti et al., 2022) "I think for a long time I felt maybe I could deal with it myself. I felt I wanted to deal with it myself." (Robinson et al., 2017)
		Losing control	"… it was in control of me and I wasn't going to be able to stop it doing the things it wanted to do which was frightening, very frightening, terrifying." (Pedley et al., 2019)
		Personal responsibility	"I had to grow up before I should have really, because at age 12 I was making serious decisions. And my brother and sister were a lot younger, so I had to just be mature, because I was speaking to adults and I felt like right, I have to be mature about this ... I was taking on all the responsibility myself and I was taking on the responsibility of everything, every single thing …" (Keyes et al., 2018)
		Safer alone	"I just wanted to stay in my room because [it] kind of felt safer. I didn't want to like do anything …" (Keyes et al., 2018)
		Quantitative findings	
		I can manage alone	Could manage or handle symptoms on own as a barrier (Poyraz et al., 2015) Wanting to solve the problem on my own reported as a barrier (Hathorn et al., 2021) Can handle it on own reported as a barrier (Goodwin et al., 2002) I felt I could control the problem was reported to be a barrier (Belloch et al., 2009) I wanted to handle it on my own (Marques et al., 2010)

Integrated findings	Categories	Findings	
		I know best	CBT would not teach me anything new reported as a barrier for those in and out of treatment (Mancebo et al., 2011)
		Unable to manage alone	Lower level of independence significantly associated with health care seeking behaviour (Keyes et al., 2018)
		Losing control	The problem didn’t disappear, I couldn’t control it reported as a facilitator of help seeking (Belloch et al., 2009)
	OCD identity	**Qualitative findings**	
		It is my fault	“Finding out what my diagnosis was, was a relief to me, to know that the harm thoughts and the religious thoughts weren’t me, and that they didn’t mean anything necessarily, so to get that diagnosis was quite a relief.” (Burton, 2021)
		Innateness	“I do think that you can be predisposed to it by the kind of temperament you’re born with.” (Pedley et al., 2019)
		Acceptance of OCD	“I’m used to it, it’s part of me now. I’ve accepted it as part of me.” (Pedley et al., 2019)
			“Even though I don’t like it, it does make me me, so I would miss it a little bit.” (Pedley et al., 2019)
		OCD is useful	“… it helps me see different points of view, and look into things.” (Pedley et al., 2019)
		I need it	“It’s very paradoxical this sort of symbiotic relationship where … it’s part of my identity so I need it and it needs me.” (Pedley et al., 2019)
		It changed me	“I was feeling sick! … I was totally off my character when I was suffering from OCD … I stayed away from people, alone and everyone around were like – ‘what happened to you?’” (Sravanti et al., 2022)

Integrated findings	Categories	Findings	
		Envious of others	“I have a thought – ‘if I didn’t have OCD just like my friends, then … I could have had a nice time and spent it more nicely and productively like they have’.” (Sravanti et al., 2022)
		Conflict with personal values	“All the symptoms were distressing, but religious symptoms were the ones that made me come to the psychiatrist.” (Al-Solaim & Loewenthal, 2011)
		Used to it	“I didn’t realise what I was doing but to me it was part of life.” (Keyes et al., 2018)
			“It’s just, if I didn’t it would seem weird and if you break something you have been doing your whole life, say it’s a tradition and you sort of don’t do it, you get sort of [an] odd feeling … Sort of as if you have been doing something your whole life.” (Keyes et al., 2018)
		Quantitative findings	
		Used to it	Earlier onset of OCD associated with going longer without treatment (Perris et al., 2021)
			Duration of OCD acted as a factor for delaying treatment (Demet et al., 2010)
			Statistically significant relationship between earlier onset of symptoms and visiting traditional healers instead of medical support (Okasha et al., 2021)
		OCD is useful	Thinking that the symptoms are necessary in order to be tidy/orderly (Poyraz et al., 2015)
		Always present	Significant relationship between early age of OCD onset with delay in help-seeking and worse insight (Belloch et al., 2009)
			Non-health care seeking group had a significantly longer duration of OCD compared to the health care seeking group (Beşiroğlu et al., 2004)

Integrated findings	Categories	Findings	
		Conflict with personal values	Health care seeking group had significantly more aggressive and religious obsessions than the non-health care seeking group (Keyes et al., 2018)
	Implications	**Qualitative findings**	
		Diagnostic burden	"… what if my GP knows, and then, if I go for interviews and it goes on the Occupational Health form [inaudible] against me?" (Robinson et al., 2017)
		Permanence	"Also I didn't want it on my record … I didn't want to have to be admitting to it for the rest of my life … I felt if I went to the doctor, that was it, it was official, and I would always have to put that from then on, it was always going to a reality." (Robinson et al., 2017)
		Quantitative findings	
		Permanence	Did not want a 'record' of treatment for OCD (Mancebo et al., 2011)
Helplessness	Severity	**Qualitative findings**	
		Help does not work	"I have tried taking Fluoxetine which could not help me at all. My symptoms are not under control according to my psychiatrist." (Mahintorabi et al., 2017)
		No one can understand or help	"I was very obstinate about any kind of support or therapy because I don't, I didn't really trust that anyone would understand how I was feeling or what I was thinking." (Burton, 2021)
			"Nobody's ever going to understand why I'm doing this, and what I'm doing, which I guess is another reason you don't go and tell people." (Robinson et al., 2017)
			"No, I never thought about it [someone would be able to help] … No, never entered my head." (Robinson et al., 2017)

Integrated findings	Categories	Findings	
			“OCD isn’t just having your pens in a like coordinated order … It’s more serious than that ... It’s a lot of stuff. It’s a much wider broader thing than people think really and that it’s much more serious.” (Keyes et al., 2018)
		Paralysed by fear	“When it started, I was just scared. Very scared gripped in fear as thoughts were very unpleasant. I couldn’t talk about it to anyone.” (Sravanti et al., 2022)
		It is not bad enough	“I don’t feel it becoming worse. And therefore … you know, the NHS spirit, rightly or wrongly I call it, that … that other people’s needs are greater than mine and if they sign up and get it first, then it’s probably they deserve to, or need to, more than I do.” (Robinson et al., 2017)
		Quantitative findings	
		Help will not work	Perception that treatment will be ineffective (Poyraz et al., 2015)
			Treatment won’t help (Goodwin et al., 2002)
			Did not think CBT would work for my OCD (Mancebo et al., 2011)
			I didn’t think treatment would work (Marques et al., 2010)
		It is too severe	Higher severity of symptoms results in longer without treatment (Perris et al., 2021)
			OCD was too severe to participate in CBT (Mancebo et al., 2011)
		It is not bad enough	OCD not severe enough to justify CBT (Mancebo et al., 2011)
			I believed my behaviours and/or thoughts were not serious (Belloch et al., 2009)
			Thought that ‘it’s not dangerous’ (del Valle et al., 2017)
		It needs to be severe	Increased severity of OCD predicted likelihood of initiating CBT (Mancebo et al., 2011)

Integrated findings	Categories	Findings	
			Health care seeking group scored significantly higher on the Y-BOCS than the non-health care seeking group (del Valle et al., 2017)
		Paralysed by fear	I was afraid (of the thought contents) which acted as a barrier (Belloch et al., 2009)
		Overwhelming	Total number of OCD symptoms was significant treatment seeking variable in multivariate analysis (Mayerovitch et al., 2003)
	Comorbidity	**Quantitative findings**	
		Other mental health difficulties are needed	Receiving treatment more likely to have personality disorder, generalised anxiety disorder, or post-traumatic stress disorder (Goodwin et al., 2002)
			Higher treatment rates in obsessive-compulsive symptoms with borderline personality disorder than pure obsessive-compulsive symptoms (Angst et al., 2005)
			Significantly more likely to receive treatment if OCD is present with a comorbid disorder (Torres et al., 2007)
			Seeking treatment group were significantly more likely to have comorbid depression, mania, panic, generalised anxiety disorder, or post-traumatic stress disorder (Mayerovitch et al., 2003)
			Comorbid obsessive-compulsive symptoms had 2-3 times increased likelihood of lifetime treatment (Angst et al., 2005)
		Increased distress	Severity of psychological comorbidity was strongly associated with being in treatment (Torres et al., 2007)
			Comorbid obsessive-compulsive symptoms had 10 times higher suicidality (Angst et al., 2005)
	Crisis	**Qualitative findings**	

Integrated findings	Categories	Findings	
		Traumatic advice	“The faith healer I went to, who I know now is a shaman, asked me to get a goose, with specific features, slaughter it, and bathe in its blood. I can’t believe I did that, it was torture.” (Al-Solaim & Loewenthal, 2011)
		Suicidality	“I got to another stage where, um, the head wasn’t coping again, and I was getting extremely depressed. The only reason I went to the doctor in the first place was I left my [partner] a note … and I’d been drinking one night, and left [her/him] a note, ‘I want to die’. I couldn’t cope. And I thought I wanted to take an overdose. So my [partner] took me to see my doctor. Which was a good thing.” (Robinson et al., 2017)
		Fear of OCD	“… I was scared of doing like bad things, like violent things, because of the OCD.” (Keyes et al., 2018) “… it was in control of me and I wasn’t going to be able to stop it doing the things it wanted to do which was frightening, very frightening, terrifying.” (Pedley et al., 2019) “At this stage ... I thought my children were in immense danger … firstly for my children ... I thought you’ve got to be a decent person.” (Robinson et al., 2017)
		Quantitative findings	
		Traumatic event	Faster onset of OCD from a major incident (e.g., traumatic event) results in help seeking quicker (Poyraz et al., 2015)
		Suicidality	Having experienced suicidal thoughts was strongly associated with being in treatment (Torres et al., 2007) Comorbid obsessive-compulsive symptoms had 2-3 times increased likelihood of lifetime treatment with higher distress and 10 times higher suicidality (Angst et al., 2005)

Integrated findings	Categories	Findings	
External support	Family and friends	**Qualitative findings**	
		Encouraged by friend	“I decided to see a psychiatrist in advice of one of my friends.” (Mahintorabi et al., 2017)
		Family traits	“Both my parents have little quirks and I’ve picked them up and taken them to the next level, like they’re both very organised and rigid in how they like things.” (Pedley et al., 2019)
		Family judgement	“I once spoke to my wider family … but I sometimes felt like the black sheep of the family because I was the one with the mental illness.” (Pedley et al., 2019) “I wanted to talk but I was worried about what my parents would think about me if I talked to them about my problem. So, initially I held back from talking about it.” (Sravanti et al., 2022) “My elder sister once shouted at me for removing all petals of a flower. I did so in an attempt to make it look proper, because I felt something was not okay about it. I feel quite bad about it.” (Sravanti et al., 2022)
		Significant others	“He [partner] gets very uncomfortable and he doesn’t like it. Erm, because he likes to do things his own way.” (Pedley et al., 2019)
		Negative friend experience	“Once I went out with friends to eat ice-cream and I felt the ice-cream cone was not in a proper manner. [...] the ice-cream cone was not really round in shape so I just asked the shopkeeper to change it. My friends said, ‘what are you doing, we are feeling embarrassed, we are their regular customer, what they will think? This is a very bad thing that I embarrassed my friends!” (Sravanti et al., 2022)

Integrated findings	Categories	Findings	
		Persistence	“I did not want to go to a doctor. Not for this problem. My mother kept telling like me ‘You should go. It won’t be embarrassing, they will help you get better’. I still didn’t want to go, but finally I was convinced to go.” (Sravanti et al., 2022) “She had said you must have treatment. There’s treatment out there ... she kept on, I mean it was over a period, for about a year she kept on at me … but you know every time she mentioned it, I wouldn’t talk about it ... I’d brush it off. I’d be so, so horrendously embarrassed ... but it was through her pushing me ... to do something about the OCD. There could be something done about it. I wasn’t aware of treatment till she started telling me.” (Robinson et al., 2017)
		Accompaniment	“I went to a faith healer with my parents.” (Al-Solaim & Loewenthal, 2011)
		Taking charge	“My parents decided to take me to a faith healer who started reading verses of the Qur’an to me, this gave me temporary relief, but the symptoms persisted.” (Al-Solaim & Loewenthal, 2011) “… my mother she took me to a motawaa (faith healer) … after a while my father brought me to the hospital.” (Al-Solaim & Loewenthal, 2011) “I got to another stage where, um, the head wasn’t coping again, and I was getting extremely depressed. The only reason I went to the doctor in the first place was I left my [partner] a note … and I’d been drinking one night, and left [her/him] a note, ‘I want to die’. I couldn’t cope. And I thought I wanted to take an overdose. So my [partner] took me to see my doctor. Which was a good thing.” (Robinson et al., 2017)

Integrated findings	Categories	Findings	
		Lack knowledge	“Mum was sort of bordering on, maybe there is something there, but she is not sure. If she was more aware of what OCD was ... she might have seen the boxes and ticked them ... because we were a bit clueless in what OCD was it dragged on a bit longer than it should have.” (Keyes et al., 2018) “In those days people didn’t know about OCD and you know, my parents certainly didn’t.” (Robinson et al., 2017)
		Understanding	“I can remember sitting there, and they [parents] said to him, Oh, [s/he’s] got the weight of the world on [his/her] shoulders.” (Robinson et al., 2017) “My family understands, they know that [my] obsessionality is caused by Satan, but they still believe I should take the pill, and also, read verses of the Qur’an on myself.” (Al-Solaim & Loewenthal, 2011)
		Quantitative findings	
		Family accommodation	Lack of family support to overcome OCD reported to be a barrier (Poyraz et al., 2015)
		Parental education	Nonsignificant but trending correlation between increasing parental education and reducing duration to seek treatment (Demet et al., 2010)
		Significant other recognition	Single/divorced 2.29-fold higher risk for delaying treatment than married (Demet et al., 2010)
	Professional	**Qualitative findings**	
		Reduce fear	“I suppose the exposure response prevention thing is the main one [treatment] and I don’t think anybody would do that off their own back because … Some of the things you’re supposed to do are incredibly scary and you wouldn’t think of doing that.” (Pedley et al., 2019)

Integrated findings	Categories	Findings	
			“I was nervous before I went, obviously, um, but I felt that I can do this … I got there and … at that point I sort of crouched, and I was like ‘I’ve got OCD’, and I just burst into tears basically. But she was really good … I was lucky, because she knew a lot about OCD, she knew about treatments ... and she was very kind.” (Robinson et al., 2017)
		Belief in ability	“This is my third visit to the doctor and I already feel better.” (Al-Solaim & Loewenthal, 2011) “Doubting whether the doctors would know what it was and be able to help…” (Robinson et al., 2017)
		Bad experiences	“I must have seen at least 10 doctors … I used to tell them that I was scratching my hands and that was my problem … Actually, when anyone touched me, I would brush over that area but I didn’t talk about my thoughts. I was not asked, and I didn’t talk … simply we were going to different doctors and they were prescribing creams for application.” (Sravanti et al., 2022) “I had a bit of a bad experience with a doctor. My doctor actually didn’t help at all. He laughed to be honest. I think with normal GPs they don’t tend to understand the mental health side of things.” (Keyes et al., 2018)
		Need to provide clarity	“He gave me some pills, symptoms are much better but I don’t know what those pills are doing to me.” (Al-Solaim & Loewenthal, 2011)
		Similar characteristics preferred	“I don’t really care about the level of religiosity of the psychiatrist who is treating me; he is not a family member or a friend so why should I feel protective of him. But it would be better if he was religious, since he will have fear of God, and thus be more dedicated in doing his job.” (Al-Solaim & Loewenthal, 2011)

Integrated findings	Categories	Findings	
			“I don’t think I would still be with my psychiatrist had she not been a religious woman. It assures me that her opinions are correct because she is knowledgeable about how Islam views my illness and what I should or should not do. I don’t think I would have trusted her had she been not religious.” (Al-Solaim & Loewenthal, 2011)
		Trust is needed	“I feel that that the level of the professional’s religiosity correlates with how much I trust her/him. I have more admiration if I think the person who is treating me is religious, I listen to her/him, I accept what they say, I become much more receptive of what they say than if she/he was not religious.” (Al-Solaim & Loewenthal, 2011)
			“I didn’t know sort of what it would be like and I suppose what they [GP] would think.” (Robinson et al., 2017)
		Cultural understanding	“I certainly prefer a Muslim psychiatrist, a non-Muslim would not understand what I am going through, would not understand my problem.” (Al-Solaim & Loewenthal, 2011)
		Need for supplementary support	“They give me experiments and expect me to go home and I’m going to be on my own again - it’s like, no. It’s a bit like prison - if you go into prison you are going to be good, because you are being watched. But as soon as you go out of prison no one is watching you. And you’re like, ‘oh, I’m free’ … I need some- one to watch me ... yeah I need mum to watch me. Or some- one, anyone, and teachers.” (Keyes et al., 2018)
		Quantitative findings	
		Poor provision	Did not think the CBT provider was good acted as a barrier (Mancebo et al., 2011)

Integrated findings	Categories	Findings	
	Groups	**Qualitative findings**	
		Symptom contagion	“They have a lot of depression support groups and things, it’s knowing other people might help. I’d worry about picking up other people’s obsessions though.” (Pedley et al., 2019)
		Need for peer support	“It may have helped talking to other people that actually have OCD, because it’s hard talking to a psychologist that doesn’t actually have it, because although they sort of understand, they don’t. They understand, but they don’t know what it feels like. It’s hard to take advice from someone that doesn’t know what you’re going through. I think if you have OCD … there should be like forums or some way to connect or Facebook or something, some form of community to sort of talk about your compulsions and things you do.” (Keyes et al., 2018)
	Other	**Qualitative findings**	
		Religious support unhelpful	“I did try to talk to a religious advisor (Imam) which was not helpful. Eventually … I sought professional help and went to see a psychiatrist.” (Mahintorabi et al., 2017) “The faith healer I went to, who I know now is a shaman, asked me to get a goose, with specific features, slaughter it, and bathe in its blood. I can’t believe I did that, it was torture.” (Al-Solaim & Loewenthal, 2011)
		Religion and coping	“I believe having God in my world always helps me tolerate many difficult situations.” (Mahintorabi et al., 2017) “… be loved by God which made me tolerate my symptoms more and to be more satisfied and happier.” (Mahintorabi et al., 2017)

Integrated findings	Categories	Findings	
			“Had I not been a Muslim I would have gone! Religion is the foundation; it even alleviates the distress of illness since God will commend our endurance.” (Al-Solaim & Loewenthal, 2011)
		Religious alternative	“When my symptoms started two or three years ago, going to a female faith healer was the first thing I did…” (Al-Solaim & Loewenthal, 2011)
			“I used to feel very comfortable when she read the Qur’an.” (Al-Solaim & Loewenthal, 2011)
			“My parents decided to take me to a faith healer who started reading verses of the Qur’an to me, this gave me temporary relief, but the symptoms persisted.” (Al-Solaim & Loewenthal, 2011)
		Online reassurance	“I can remember writing on the forums on the websites, saying, you know, I’m going to the GP and … everyone thought, ‘Oh, well done’. You know. ‘You’ll be fine’. ‘Don’t be scared’. And getting loads of replies back.” (Robinson et al., 2017)
		No school recognition	“No one helped me in school.” (Keyes et al., 2018)
		Quantitative findings	
		Religious understanding	Thinking that symptoms are related to religious problems/being a sinner prevented people seeking professional support (Poyraz et al., 2015)
			Considered disease related to religion therefore access traditional healer (Okasha et al., 2021)
			Consider religious commitment to help treatment therefore access traditional healer (Okasha et al., 2021)
		Traditional healers less stigmatising	Statistically significant relationship between sexual and religious obsessions with higher tendency to seek advice from traditional healers (Okasha et al., 2021)

Integrated findings	Categories	Findings	
			High stigma of seeking psychiatric advice therefore access traditional healers (Okasha et al., 2021)
		External encouragement needed	Someone tells me to get help reported as a motivator for seeking support (del Valle et al., 2017)
			Someone advised me to seek treatment reported as a facilitator to help seeking (Belloch et al., 2009)
		Self-help use	OCD without comorbidity used self-help more (Torres et al., 2007)

Findings of the Review

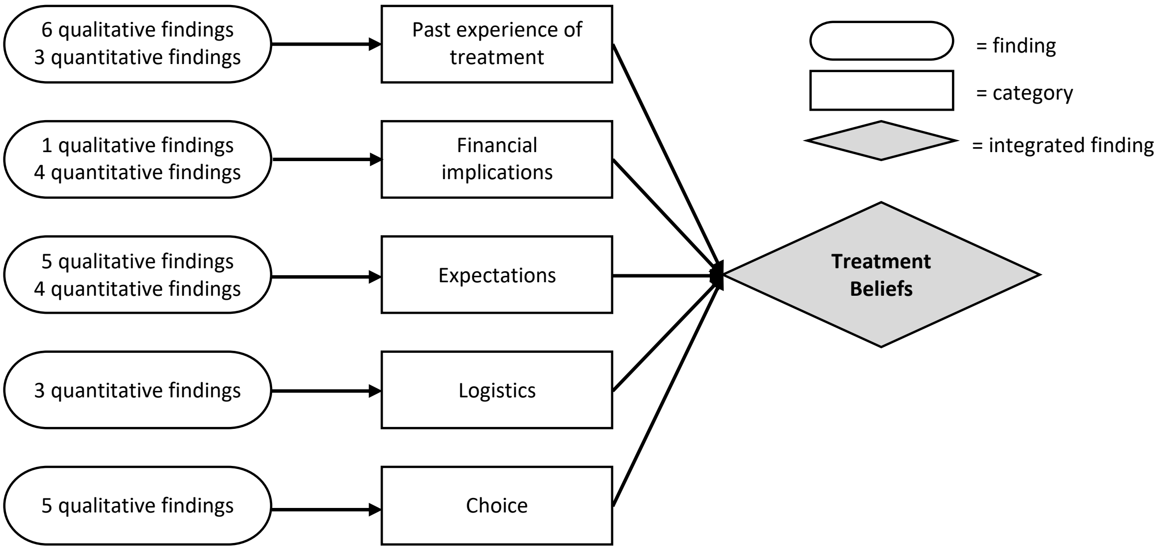
From the 22 papers included in this review, 6 integrated findings were synthesised from 21 categories. A total of 291 individual pieces of data contributed to the 164 unique findings of which 68 were quantitative (see Appendix C) and 96 were qualitative (Table 1.5). These integrated findings represent the spectrum of barriers and facilitators to accessing support for those that experience OCD as well as encompassing some suggestions of how services can improve their support of such individuals.

Integrated Finding One: Treatment Beliefs

The included studies demonstrated a range of beliefs which individuals held about the process of treatment, with Figure 1.2 displaying the categories which led to the generation of this integrated finding.

Figure 1.2

Integrated Finding One: Treatment Beliefs



Beliefs about treatment stemming from past experience of unsuccessful support was reported as a barrier for many individuals (Demet et al., 2010; Mahintorabi et al., 2017; Mancebo et al., 2011; Marques et al., 2010; Williams et al., 2012). Studies also reported that treatment had been too challenging (Mahintorabi et al., 2017) with clinicians whom individuals did not have faith in (Mancebo et al., 2011). One study found that people had a history of being treated unfairly based on race or ethnicity which acted as a barrier to accessing future support (Williams et al., 2012). In contrast, experiencing effective treatment (Al-Solaim & Loewenthal, 2011; Sravanti et al., 2022) and recognising the wider effects it had on life (Sravanti et al., 2022) were both reported as motivators for seeking further support. A need for increased clarity around treatments was reported (Al-Solaim & Loewenthal, 2011) alongside additional support outside of the therapeutic room (Keyes et al., 2018) to improve engagement.

The cost of treatment was another barrier (Goodwin et al., 2002; Hathorn et al., 2021; Mancebo et al., 2011; Marques et al., 2010; Poyraz et al., 2015; Williams et al., 2012) which was supported by moderate income households being less likely to access treatment than those with higher incomes (Demet et al., 2010; Williams et al., 2012). Similarly, those with lower incomes reported time constraints as did those from younger age groups (Williams et al., 2012) while others found it difficult to prioritise treatment (Mancebo et al., 2011; Marques et al., 2010). Unemployed people were less likely to access treatment (Perris et al., 2021,) along with those whose insurance would not cover MH interventions (Goodwin et al., 2002; Mancebo et al., 2011; Marques et al., 2010).

Expectations of medication side effects (Burton, 2021; Goodwin et al., 2002; Hathorn et al., 2021; Poyraz et al., 2015) or over reliance on medication (Pedley et al., 2019, Robinson et al., 2017) were reported as major barriers. Additionally, there was an expectation that treatment would not be effective (Hathorn et al., 2021; Poyraz et al., 2015; Williams et al., 2012) and would be a difficult process (Robinson et al., 2017) in which people may disengage (Williams et al., 2012). However, it was identified that believing in the effectiveness of treatment predicted help-seeking intention (Hathorn et al., 2021). There appeared to be a difference between expectations of treatment and reality as responses to most barriers reduced once people engaged with treatment (Mancebo et al., 2011).

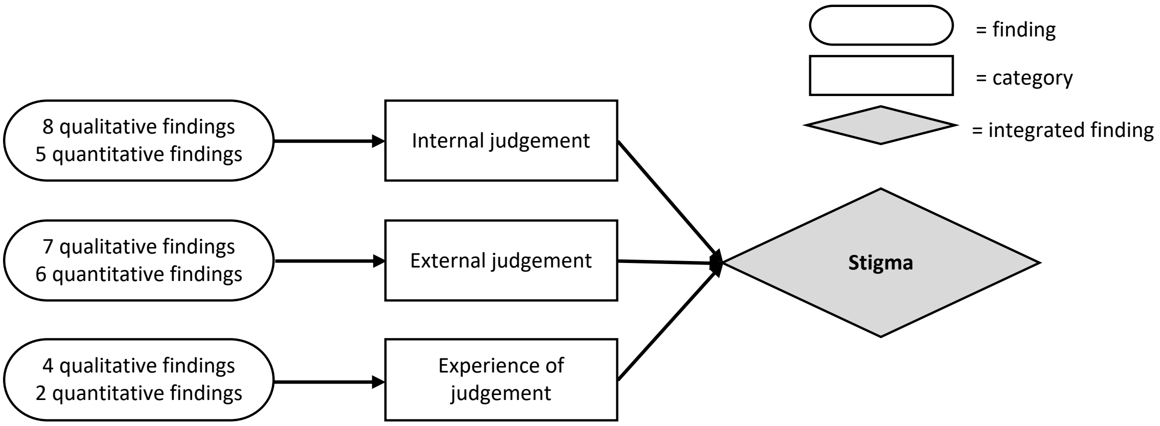
The availability of treatments (Mancebo et al., 2011, Marques et al., 2010) or types of clinicians (Poyraz et al., 2015) acted as barriers to accessing support. A common theme related to the importance of multiple approaches being used to treat OCD (Al-Solaim & Loewenthal, 2011; Pedley et al., 2019) alongside the integration of cultural practices to better match the individual (Al-Solaim & Loewenthal, 2011).

Integrated Finding Two: Stigma

Fear of judgements based on MH difficulties was a prevalent barrier throughout the studies included with Figure 1.3 displaying the categories that contributed to this integrated finding.

Figure 1.3

Integrated Finding Two: Stigma



Internalised judgement of OCD acted as a barrier to accessing support services with shame being the most frequently reported (Belloch et al., 2009; Hathorn et al., 2021; Marques et al., 2010; Poyraz et al., 2015; Robinson et al., 2017; del Valle et al., 2017). Other internalised narratives included feelings of guilt (Mahintorabi et al., 2017, del Valle et al., 2017), self-hatred (Mahintorabi et al., 2017), disgust (Sravanti et al., 2022), being weak (Pedley et al., 2019; Robinson et al., 2017), selfishness (Pedley et al., 2019), or envious (Sravanti et al., 2022), along with the idea of being exposed (Keyes et al., 2018; Mancebo et al., 2011). However, some of the reported internal judgements motivated people to seek support such as a fear of being crazy (del Valle et al., 2017) or concern that they were a bad person (Belloch et al., 2009; del Valle et al., 2017).

Many studies reported on the fear of judgment from external sources (Belloch et al., 2009; Goodwin et al., 2002; Mancebo et al., 2011; Marques et al., 2010; Robinson et al., 2017; del Valle et al., 2017) such as family members (Marques et al., 2010; Pedley et al., 2019; Robinson et al., 2017; Sravanti et al., 2022) or professionals (Robinson et al., 2017), leading the concealment of symptoms of OCD (Robinson et al., 2017; Sravanti et al., 2022) and the fear of diagnostic consequences (Belloch et al., 2009; Poyraz et al., 2015).
There were reports on changes in MH stigma with younger age groups more ready to seek help (Goodwin et al., 2002) but it still lingered (Pedley et al., 2019) especially for Black, Asian or minority ethnic groups (Goodwin et al., 2002; Williams et al., 2012).

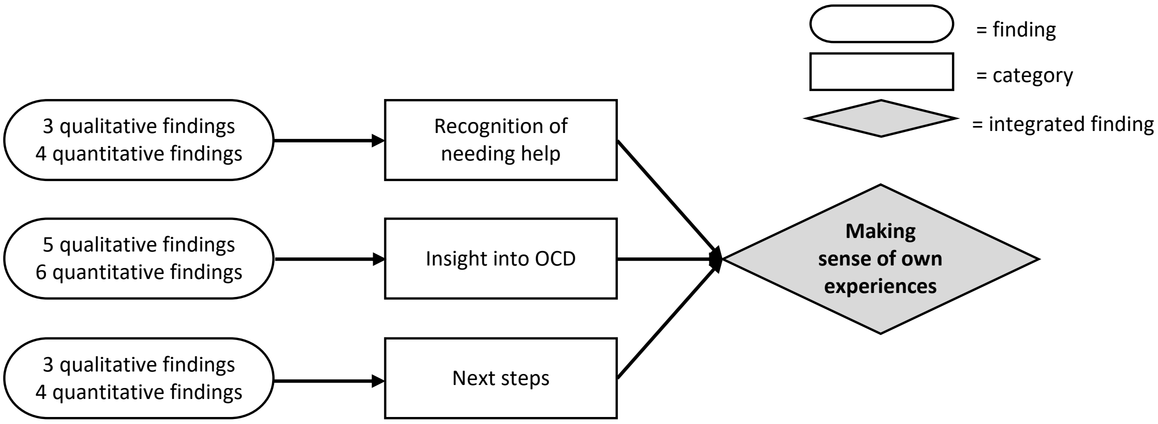
The final category within this integrated finding related to the lived experience of stigma. Reports of negative experiences from family or friends (Pedley et al., 2019; Sravanti et al., 2022) contributed to individuals being reluctant to disclose their symptoms. Additionally, people reported being told that they were not doing enough to manage their OCD (Mahintorabi et al., 2017; Sravanti et al., 2022). Sociodemographic factors acted as barriers with unfair treatment based on race or ethnicity and women experiencing more stigmatising beliefs about MH (Williams et al., 2012).

Integrated Finding Three: Making Sense of Own Experiences

Many studies reported on the individual experiences of the participants and how they made sense of these. Figure 1.4 depicts the categories on which this finding was constructed.

Figure 1.4

Integrated Finding Three: Making Sense of Own Experiences



The ability to recognise that help was needed was dependent on several factors. The main one relates to the interference of symptoms in daily life (Goodwin et al., 2002). If there was little to no obstruction caused by the OCD symptoms many reported not seeking support (Belloch et al., 2009; Robinson et al., 2017; del Valle et al., 2017; Williams et al., 2012), whereas a greater level of interference acted as a motivator to seek support (Belloch et al., 2009; Pedley et al., 2019; del Valle et al., 2017). Similarly, those who recognised having a serious problem were more motivated to seek support (Belloch et al., 2009) than those who were unaware of having OCD (Williams et al., 2012) although this could be altered if there was a recognition of being different to other people (Pedley et al., 2019). A significant change in symptoms acted as an indicating leading to faster help-seeking (Belloch et al., 2009; Poyraz et al., 2015; del Valle et al., 2017) although some denied the existence of OCD altogether (Goodwin et al., 2002).

Poor understanding of OCD was a significant barrier to help-seeking with some thinking that they were crazy (Pedley et al., 2019; Robinson et al., 2017). However, for some the fear of being crazy motivated help-seeking (del Valle et al., 2017). Some reported that OCD symptoms were normal in their experience (Pedley et al., 2019; Poyraz et al., 2015; del Valle et al., 2017) or felt confused about their experience (Robinson et al., 2017). Public representations of OCD aided in understanding their experiences (Robinson et al., 2017) which can lead to a recognition of how support could help (Pedley et al., 2019). The lack of understanding and self-awareness of OCD was identified as a risk factor for not seeking support (Belloch et al., 2009; Demet et al., 2010) although, one study reported the opposite with lower insight leading to increased help-seeking (del Valle et al., 2017). It is possible that education could play a role in the understanding of OCD, but the direction of effect is conflicted (Belloch et al., 2009; Goodwin et al., 2002).

Once people recognised having a difficulty there was some confusion about the next steps with reports of uncertainty of how to access support (Goodwin et al., 2002; Marques et al., 2010; Okasha et al., 2021; del Valle et al., 2017; Williams et al., 2012). Some turned to religion for support (Okasha et al., 2021) whereas others felt that difficulties would disappear on their own over time (Belloch et al., 2009; Robinson et al., 2017; del Valle et al., 2017) which could reflect the difference between avoidant and proactive styles of coping. A key barrier related to the implications of disclosing symptoms (Burton, 2021) and having a diagnosis (Poyraz et al., 2015), however, an optimistic view could motivate help-seeking (Angst et al., 2005).

Integrated Finding Four: I am Responsible

A reoccurring theme across the studies included related to a sense of responsibility and interconnectedness with OCD and the symptoms, with Figure 1.5 demonstrating the construction of this integrated finding.

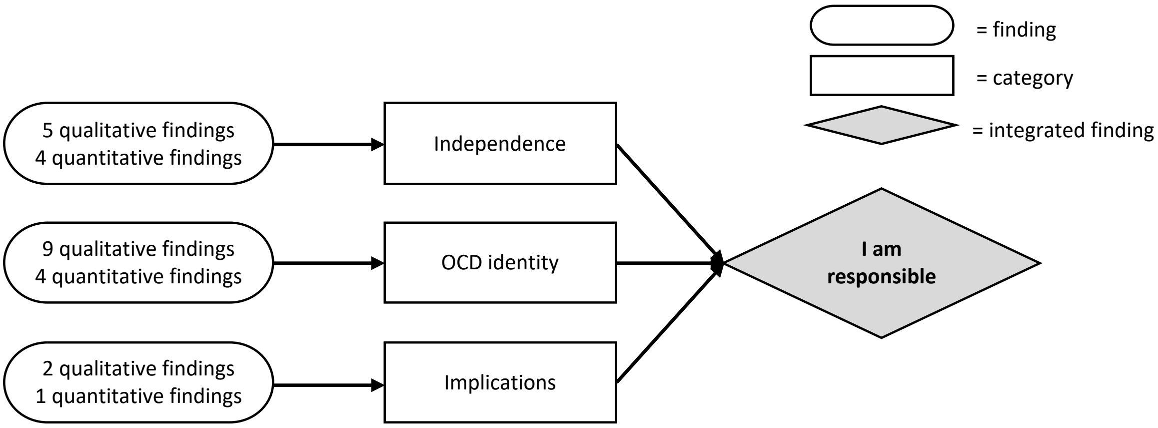
A sense of independence or personal responsibility (Keyes et al., 2018) experienced by many with OCD acted as a barrier to treatment. Some felt that they could or should be able to manage alone (Belloch et al., 2009; Goodwin et al., 2002; Hathorn et al., 2021; Marques et al., 2010; Poyraz et al., 2015; Robinson et al., 2017; Sravanti et al., 2022) with one study citing the idea that the individual knew best (Mancebo et al., 2011). Lower levels of independence were related to an increased likelihood to engage in help-seeking behaviour (Keyes et al., 2018) which could be caused by a loss of control of symptoms (Belloch et al., 2009; Pedley et al., 2019). Some reported taking actions to protect others such as isolating themselves and avoiding talking about their symptoms which acted as a barrier (Burton, 2021; Keyes et al., 2018; Robinson et al., 2017), however, others reported accessing help so they could protect people (Pedley et al., 2019).

One's identity being related to OCD (Pedley et al., 2019) acted as a barrier and may be due to the early onset and resultant habituation to OCD symptoms (Belloch et al., 2009; Beşiroğlu et al., 2004; Demet et al., 2010; Keyes et al., 2018; Okasha et al., 2021; Perris et al., 2021). Some held the belief that OCD was needed or was useful (Pedley et al., 2019; Poyraz et al., 2015) with a reluctant to change that. Additionally, others felt that OCD was innate (Pedley et al., 2019) or that they were to blame for the symptoms (Burton, 2021).

However, when OCD altered who they were (Sravanti et al., 2022) or conflicted with personal values (Al-Solaim & Loewenthal, 2011; Keyes et al., 2018), there was an increased likelihood to seek support.

Figure 1.5

Integrated finding four: I am Responsible



The last category related to the implications of OCD such as the diagnostic permanence or burden (Mancebo et al., 2011; Robinson et al., 2017) which may be tied to one's identity, and act as a barrier to help-seeking.

Integrated Finding Five: Helplessness

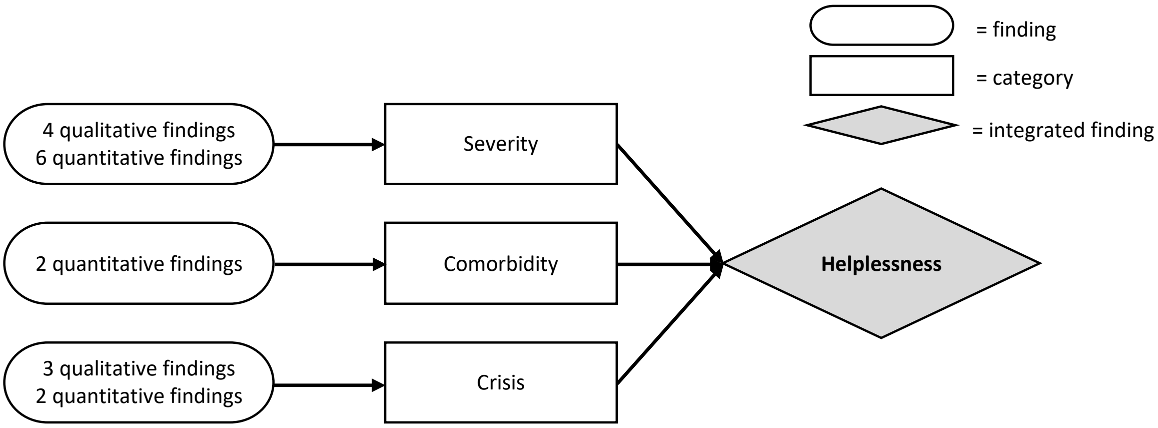
Studies reported various ways in which individuals felt helpless in relation to their OCD or that there needed to be additional reasons to seek support. The development of this integrated finding can be seen in Figure 1.6.

Helplessness was a barrier in the context of severity with people reporting that help would not work (Goodwin et al., 2002; Mahintorabi et al., 2017; Mancebo et al., 2011; Marques et al., 2010; Poyraz et al., 2015) or that people could not understand or help (Burton, 2021; Keyes et al., 2018; Robinson et al., 2017; Sravanti et al., 2022). OCD was perceived to be too severe for help (Mancebo et al., 2011; Perris et al., 2021) or not severe enough

(Belloch et al., 2009; Mancebo et al., 2011; Robinson et al., 2017; del Valle et al., 2017). Two studies reported that increased severity was linked with help-seeking (Mancebo et al., 2011; Mayerovitch et al., 2003; del Valle et al., 2017). However, higher severity made people feel paralysed by fear (Belloch et al., 2009; Sravanti et al., 2022).

Figure 1.6

Integrated Finding Five: Helplessness



One factor associated with help-seeking was co-morbid MH difficulties (Angst et al., 2005; Goodwin et al., 2002; Mayerovitch et al., 2003; Torres et al., 2007) suggesting that other difficulties are required for support to be provided or that they are easier to identify. The severity of the comorbid condition was associated with being in treatment (Torres et al., 2007). Comorbidity was also linked with increased suicidality (Angst et al., 2005).

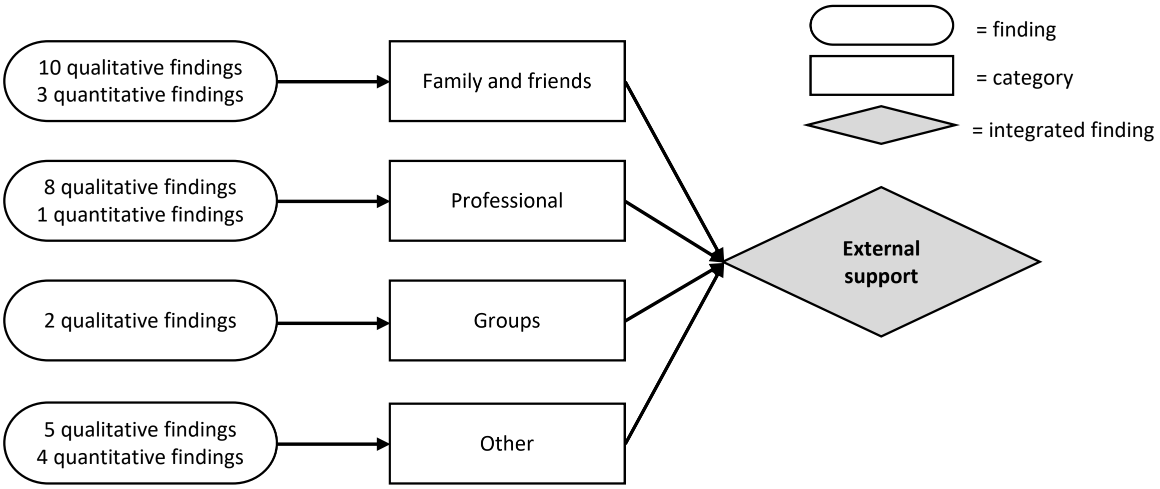
Crises, such as suicidal thoughts, were linked with increase help-seeking (Angst et a., 2005; Robinson et al., 2017; Torres et al., 2007) as was the presence of a traumatic event (Poyraz et al., 2015) or extreme advice (Al-Solaim & Loewenthal, 2011). Fear of symptoms led some to avoid contact with people while others went on to seek support (Keyes et al., 2018; Pedley et al., 2019; Robinson et al., 2017).

Integrated Finding Six: External Support

External support from a variety of sources can be a hindrance or encourager for OCD help-seeking. Figure 1.7 displays the way in which this integrated finding was constructed.

Figure 1.7

Integrated Finding Six: External Support



Family and friends can have a positive influence on accessing support (Mahintorabi et al., 2017) for problems that are persistent in nature (Robinson et al., 2017; Sravanti et al., 2022) and can aid in developing an understanding of the difficulties (Robinson et al., 2017). They can accompany people to appointments (Al-Solaim & Loewenthal, 2011) or in some cases take charge to ensure the correct support is accessed (Al-Solaim & Loewenthal, 2011; Robinson et al., 2017). However, they may struggle recognising OCD (Robinson et al., 2017, Keyes et al., 2018) or may be judgemental (Pedley et al., 2019; Sravanti et al., 2022). There were limited, contradictory findings relating to increased help-seeking and parental education or having a partner (Demet et al., 2010).

Seeking professional advice can provide reassurance or reduce treatment fears (Al-Solaim & Loewenthal, 2011; Pedley et al., 2019). The matching of cultural background or demographic characteristics with the professional increased trust in their ability which acted as a motivator to continue with support (Al-Solaim & Loewenthal, 2011). However, some reported negative experiences in which the professional did not recognise OCD (Sravanti et al., 2022) or did not understand MH difficulties (Al-Solaim & Loewenthal, 2011) which created a barrier. Additionally, the belief that the treatment provider was not effective could lead to disengagement from treatment (Mancebo et al., 2011).

Other sources of external support cited as being helpful were religious beliefs which enabled people to cope with their MH difficulties (Al-Solaim & Loewenthal, 2011; Mahintorabi et al., 2017). Religious support was perceived as less judgmental (Al-Solaim & Loewenthal, 2011; Okasha et al., 2021) and was sought in cases where OCD experiences were believed to have originated from religious causes (Okasha et al., 2021; Poyraz et al., 2015). In some instances, this support was perceived to be unhelpful (Al-Solaim & Loewenthal, 2011; Mahintorabi et al., 2017).

A need for support from peers through online groups or social media was identified (Keyes et al., 2018), however, there were concerns raised about symptoms being contagious in these social settings (Pedley et al., 2019) which could result in a worsening of symptoms. Reassurance from online communities acted as a motivator to help seeking (Robinson et al., 2017) with a recognition that many people require some form of external encouragement (Belloch et al., 2009; del Valle et al., 2017). Lastly, one study identified the possibility of using self-help resources, although these were mostly used by those without comorbid MH difficulties (Torres et al., 2007).

Discussion

This systematic review aimed to better understand the barriers and facilitators to help-seeking for individuals experiencing OCD. Secondary aims for the review were to identify any factors that may mitigate some barriers, enabling individuals to access support and how the facilitators can be applied to wider MH services to improve access. The studies included in this review report on a range of findings from a diverse population. Six integrated findings were identified to encapsulate the barriers and/or facilitators to help-seeking: treatment beliefs, stigma, making sense of own experience, I am responsible, helplessness, and external support.

Treatment Beliefs

Beliefs about OCD, MH, and seeking help were commonly discussed in the reviewed papers. Research has shown that positive past experiences of support can predict future help-seeking behaviour (Gulliver et al., 2010; Sherwood et al., 2007) by fostering a sense of comfort with professionals and challenging negative beliefs (Doll et al., 2021; Mackinnon et al., 2010). Conversely, negative past experiences with therapy can have enduring adverse effects (McQuaid et al., 2021). Some beliefs regarding treatments, medication side effects, and intervention efficacy exist without personal experience (Salaheddin & Mason, 2016). These beliefs can be persistence and hinder treatment adherence reinforcing existing beliefs that treatment is ineffective (De Las Cuevas et al., 2018). Belief in treatment effectiveness significantly contributes to help-seeking behaviours, as highlighted in prominent health behaviour models (Johnson & Possemato, 2019). Additionally, research demonstrates that engaging in psychotherapy can lead to improvements in quality of life (Crits-Christoph et al., 2008), although higher perceived treatment benefits have been associated with lower treatment utilisation (Lilly et al., 2020).

Other commonly reported beliefs relate to structural barriers which are recognised as significant global issues which require attention, although their impact has been debated (Andrade et al., 2014). The time commitment required for engaging in therapeutic interventions for OCD, such as 10 sessions of talking therapy or adherence to medication for 12 months as recommended by NICE guidelines (2005), represents a notable structural barrier. Another commonly reported structural barrier is the perceived financial cost associated with help-seeking, as well as concerns about treatment coverage by medical insurance (Mojtabai, 2021). While these barriers are mostly reported in countries without a nationalised health service, research indicates that individuals in the UK are increasingly reporting cost as a barrier due to heightened pressures and funding gaps in the NHS (Salaheddin & Mason, 2016). These pressures can present additional barriers with longer waiting times and limited intervention availability. Moreover, the process of accessing support within MH services poses ongoing difficulties, often involving contacting multiple services, repeating one's story, and encountering potential misdiagnoses or dismissal of presentations (MacDonald et al., 2021). These complex pathways contribute to delays in help-seeking (MacDonald et al., 2018) and act as persistent barriers in the future.

Structural factors can also serve as facilitators for help-seeking by providing individuals with choices in their treatment journey, including the selection of clinicians, approaches, and trusted characteristics. Choice is considered a fundamental element in healthcare services, and models like The Choice and Partnership Approach (CAPA) have integrated it as a core component in MH treatment (York & Kingsbury, 2009). CAPA has demonstrated effectiveness in child and adolescent services worldwide (Pajer et al., 2022), with choice influencing service engagement (Laugharne & Priebe, 2006).

Stigma

Stigma has been defined as a multi-component experience comprised of labelling, stereotyping, separation, status loss, and discrimination which occurs in a situation with power (Link & Phelan, 2001). Stigma related to OCD can manifest at different levels: intrapersonal, involving feelings of shame, guilt, or weakness; interpersonal, encompassing fears of judgment and experiences of being judged by others; and structural, influenced by factors such as race and gender (Knaak et al., 2017). Research indicates that these fears can lead to symptom concealment (Robinson et al., 2017; Sravanti et al., 2022) and subsequent delays in seeking treatment. The hiding of symptoms has been associated with increased symptom severity and the endorsement of negative beliefs about support (Wheaton et al., 2016). Moreover, seeking support necessitates trust, which can be undermined by concerns about being perceived negatively, experiencing social exclusion (Morgan et al., 2007), or encountering racism within services (Alang, 2019). Individuals with OCD who experience contamination, sexual, or violent thoughts may face heightened stigma and social rejection (Steinberg & Wetterneck, 2017), further impeding their help-seeking efforts.

Research has extensively explored the negative impact of stigma on MH and utilisation of services. However, recent studies have indicated a decline in stigma levels for certain MH conditions (Pescosolido et al., 2021). That same longitudinal research demonstrated that the millennial generation holds more progressive attitudes toward MH compared to older generations. These positive shifts in societal perceptions may facilitate easier access to support services for individuals experiencing challenges such as OCD, without the fear of judgment. Interestingly, this review identified that internal fears of being labelled as "crazy" or a "bad person" can actually motivate help-seeking behaviours. Kilk et al. (2019) proposed a theory suggesting that when MH is embraced as part of one’s social identity, stigma can serve as a motivator for action, aiming to mitigate the impact of stigmatising beliefs.

Making Sense of Own Experience

A core aspect to being able to make sense of one's own experience is the recognition of a difficulty present. This is one of the central aspects of mental health literacy (MHL) which is defined by Jorm et al. (1997) as knowledge and beliefs about MH difficulties that can aid in their recognition, management, and prevention. Research indicates that lower MHL levels are associated with increased stigma and delays in help-seeking (Tay et al., 2018). These findings have been linked to higher MH-related mortality rates and poorer recovery outcomes. Conversely, higher MHL levels are significantly correlated with increased help-seeking behaviour (Gorczynski et al., 2017). Moreover, increased MHL is associated with higher educational attainment (Jansen et al., 2018), which, in turn, is positively linked to increased help-seeking (Mackenzie et al., 2006). This suggests that enhanced education can facilitate help-seeking for individuals with OCD by fostering awareness of the need for support.

Recognition of the presence of a difficulty is a crucial component of MHL. However, research indicates that both the general population and health professionals struggle to recognise OCD symptoms (Stahnke, 2021). Normative beliefs or the perception of symptoms as common traits within close-knit social networks may contribute to poor recognition of OCD, thereby reducing the likelihood of seeking support (Birkel & Reppucci, 1983).

Once an individual is able to recognise the need for support, they must be able to identify a pathway to seeking help. The COVID-19 pandemic resulted in a notable increase in emergency service visits for MH difficulties (Ramadan et al., 2022), as traditional avenues like primary care providers were unavailable (Dalabih et al., 2022). This emphasises the importance of establishing clear pathways to MH support, not only for individuals but also for broader healthcare systems.

I am Responsible

The notion of personal responsibility in managing OCD without seeking support is another relevant factor. Salkovskis (1996) defines responsibility as the belief in one's ability to cause or prevent negative outcomes, with potential real-world and moral consequences. Choudhry et al. (2016) support the association of responsibility with OCD, noting that many individuals prefer relying on willpower rather than professional assistance. Additionally, responsibility is a central belief in the CBT maintenance formulation for OCD and plays a crucial role in the therapeutic intervention (Salkovskis et al., 1998).

The perception of personal responsibility in managing OCD may stem from its connection to identity and perceived necessity. Pedley et al. (2017) report that a close relationship to OCD can lead to a decreased belief in recovery. This aligns with the model of illness identity proposed by Yanos et al. (2010), suggesting that accepting the identity of having a MH condition positively influences various aspects of recovery. However, conflicts between symptomatology and identity can expedite help-seeking (Farmer et al., 2012). Prioritising values such as self-transcendence, openness to change, and conservation has been associated with increased help-seeking due to a reduction in stigma (Lannin et al., 2020). High self-reliance is linked to decreased help-seeking (Beukema et al., 2022), with the inverse being demonstrated within this review. Although it appears that a reduced level of independence may facilitate help-seeking, this may not be appropriate to encourage in

Western communities which often promote independence. Instead, social support can mediate the effects of self-reliance and foster help-seeking behaviour (Ishikawa et al., 2022).

Helplessness

The results relating to helplessness align with existing literature indicating that the interference of OCD symptoms with daily functioning serves as a motivator for help-seeking (Mojtabai et al., 2002). The DSM-V (APA, 2013) recognises functional impairment as a key criterion for diagnosing OCD. Impairment is considered an indicator of severity, associated with higher distress levels and increased help-seeking behaviour (Cauce et al., 2002). Many people report beliefs that accessing support requires a high severity of symptoms, possibly influenced by strict clinical thresholds within MH services. Empirical evidence supports the relationship between symptom severity, help-seeking behaviour (Aldalaykeh et al., 2019; Doll et al., 2021; Richardson & Rabiee, 2001), and reduced waiting times for treatment (Edbrooke-Childs & Deighton, 2020). However, relying on symptoms worsening to meet the threshold for seeking support may pose increased risks. Findings regarding the impact of suicidality on help-seeking are conflicting, with some studies suggesting little to no effect (Lueck, 2021). Other research indicates that suicidality can facilitate help-seeking (Biddle et al., 2004), yet it may lead to passive engagement in services (Han et al., 2018). Despite the association between increasing severity and treatment probability, 35.5% to 85.4% of individuals worldwide with severe MH difficulties remain untreated (Demyttenaere et al., 2004).

Comorbidity is a contributing factor to the perceived severity of MH needs, with MH difficulties predicting the development of further MH problems (Plana-Ripoll et al., 2019). The compounding effects of multiple difficulties negatively impact quality of life and perceived impairment, leading to increased help-seeking (Chiang et al., 2021). However, findings on the impact of psychiatric comorbidity on help-seeking are conflicting, with some presentations showing a positive effect while others show no effect (Magaard et al., 2017). These differences may be influenced by the recognisability of common MH issues and reduced stigma surrounding them, enabling more open discussions with professionals. Additionally, the higher rates of helplessness in OCD (Sun et al., 2015) and lower rates of remission (Burchi et al., 2018) may contribute to the perception that help is ineffective. Henshaw and Freedman-Doan (2009) propose that the belief in treatment ineffectiveness and the notion that difficulties must be severe are inhibitory help-seeking factors based on the Health Belief Model (HBM; Becker, 1974).

External Support

Professionals are a source of support, however there are reports of poor recognition of OCD resulting in misdiagnosis, inappropriate medication, and worsening of OCD (Stahnke, 2021). General Practitioners (GPs) face challenges in confidently recognising MH, resulting in a reluctance to diagnose specific conditions (Ford et al., 2016; Sinnema et al., 2018). Trust in GP services has declined in recent years, potentially influenced by decreased face-to-face appointments due to increased pressures (NHS England, 2022). Trust is crucial for establishing a positive therapeutic relationship (Laugharne & Priebe, 2006), and has a bidirectional association with the therapeutic process, influencing engagement with MH treatments (Maidment et al., 2011). The combination of inadequate trust and difficulties in recognising OCD symptoms can hinder individuals from receiving necessary support, leading to disengagement from interventions and avoidance of future help-seeking.

The HBM of healthcare utilisation indicates a role for external sources, such as media or family, acting as cues for action and motivating help-seeking (Henshaw & Freedman-Doan, 2009). Social networks have been found to encourage the initiation of help-seeking with higher levels of trust and stronger relationship ties producing better care responses (Green & Pescosolido, 2023). These support the theory proposed by Freidson (1960) which states that help-seeking is a process that involves navigating through various consultants, from intimate family members through more distant lay people until a professional is reached. This suggests a reliance on medical service knowledge held by close contacts (Rogler & Cortés, 1993).

Religious beliefs may perpetuate the idea of personal responsibility with some leaders attributing MH difficulties to signs of weakness or poor engagement with religious practices (Ali & Milstein, 2012; Payne, 2009). Religious individuals are also more likely to report lower levels of trust in MH systems and experience an increased concern about the stigma of MH (Nakash et al., 2019), indicating the effect of religiosity as a barrier. However, individuals often report a preference to meet with professionals from the same cultural background (Marsella, 2011) which supports a greater understanding of the cultural impacts of the difficulties. This improved understanding has been found to be a significant factor in treatment engagement (Chu et al., 2022).

Clinical and Research Implications

One intriguing finding from this review is the continuum nature of barriers and facilitators in relation to OCD symptoms and the initiation of help-seeking. The severity of OCD symptoms influenced individuals' perceptions of whether their symptoms were too severe or not severe enough to engage in CBT (Mancebo et al., 2011). This highlights the importance of considering the strength of effect on an individual when assessing barriers and facilitators. This perspective aligns with the shift in psychological practice from a diagnostic model to a continuum model of MH, emphasising the fluidity of symptoms and their impact (Keyes, 2002).

The adoption of a continuum model of MH has several advantages. It is associated with lower levels of stigma and can help reduce public stigma surrounding MH issues (Peter et al., 2021). Furthermore, this model has been linked to more positive treatment outcomes (Persson et al., 2021) and is applicable across the lifespan (Westerhof & Keyes, 2010). The continuum approach aligns with the stepped care model recommended by organisations like NICE (2011) which suggests tailoring interventions to match individuals' changing needs. This approach has been embraced by major MH support services and has informed governmental guidance documents worldwide (Cross & Hickie, 2017; National Assembly for Wales, 2010; National Psychological Therapies Management Committee, 2017). This approach provides a flexible framework that can be adjusted to meet the evolving needs of individuals, with intensity of intervention increasing in line with changes in the need.

This review underscores the significance of reducing stigma surrounding OCD and MH issues, as it serves as a major barrier to accessing support for individuals. Efforts to reduce stigma have gained recognition in the UK Parliament with the Mental Health (Discrimination) Bill (2014) and collaborative charity initiatives like Time to Change (2019). Increasing social contact between equal status individuals with and without MH conditions is an effective stigma-reduction strategy (Thornicroft et al., 2016). Another avenue to tackle stigma is to enhance knowledge and understanding of MH conditions through the provision of information (Simmons et al., 2017). However, limited research exists regarding stigma reduction interventions for OCD. Given the substantial number of individuals with OCD who do not seek help and the profound impact of stigma, it is crucial to prioritise research in this area.

Furthermore, MHL research proposes that improvements to knowledge, understanding, and recognition of MH difficulties can lead to prevention and better management (Tay et al., 2018). Interventions targeted at improving MHL have shown some signs of effectiveness with additional positive effects to stigma (Fretian et al., 2022) although the impact to help-seeking is limited (Brijnath et al., 2016) with school-based interventions reporting no strong evidence of change (Yan et al., 2022). Further research might target MHL interventions which would be a beneficial contribution to the research base.

The review emphasises the significance of religious and cultural understandings in motivating help-seeking behaviours. Healthcare services have increasingly recognised the importance of cultural competence in treatment provision and have implemented cultural competence training programs aimed at improving awareness, knowledge, skills, desire, and encounters related to diverse cultures (Stubbe, 2020). However, limited evidence exists regarding the effectiveness of these training programs, potentially due to a lack of data collection rather than the impact of the training itself (Bhui et al., 2007).

Regarding religious understanding, this review highlights that religious leaders may serve as the initial point of contact for individuals experiencing MH difficulties, as they are often perceived as less stigmatising than medical services. Some research has demonstrated successful integration between religious groups and MH services (Singh et al., 2012), with certain studies reporting a positive relationship between participation in formal, social religious practices and the utilisation of MH services (Harris et al., 2006). Considering these findings and the information presented in this review, integrating MH support with local religious groups may be beneficial for individuals experiencing OCD.

Collaboration with local communities can extend beyond cultural or religious contexts. The emphasis on personal responsibility among individuals experiencing OCD, highlighted in this review, and supported by the CBT formulation of OCD (Salkovskis, 1996), suggests a potential need for community-based interventions to reduce this sense of responsibility and facilitate access to support. For wider MH presentations, various promising interventions have been explored across different socio-ecological levels, ranging from parent and family support to initiatives within the criminal justice system (Castillo et al., 2019). One potential form of community intervention is the integration of MH services with primary care provisions which has demonstrated increased access to care and improved health outcomes (Funk et al., 2008). Additionally, it enhances staff satisfaction by fostering collaboration between services, particularly in areas such as assessment or triage (Vickers et al., 2013). By integrating MH services within primary care, individuals experiencing OCD and other MH difficulties can benefit from a more comprehensive and coordinated approach to their care within their local communities.

Strengths and Limitations

One limitation concerns the exclusion of non-English language studies as there were restrictions on translation abilities such as time and financial constraints. However, only three papers were excluded because of this restriction which, alongside the diverse range of studies included, suggests that this limitation had little impact on the findings presented.

A strength of this review is the use of the mixed methods approach as it allowed for the integration of a range of research methodologies which in turn, facilitated the development of richer findings (Bressan et al., 2017). Using a mixed approach incorporates the strengths from both qualitative and quantitative methodologies while balancing some of the weaknesses in order to answer a complex issue of help-seeking within OCD (Tariq & Woodman, 2013). Mixed methods approaches have been used with similar review questions as it allows for the broad, cross-sectional, quantitative research to aid in understanding the wider OCD population, which is then supported by smaller, more detailed qualitative findings (Johnston et al., 2021). Furthermore, the use of the JBI approach to mixed methods reviews aids in avoiding some of the common issues with similar style reviews (Lizarondo et al., 2022).

One additional limitation of this review may concern the quality appraisal process used. The appraisal tool used ensured consistency in ratings and was a brief tool, however, an alternative quality appraisal measure may have been used to facilitate a more detailed assessment of the extant literature. Furthermore, the quality of the papers could have been considered in relation to the themes, with those of higher quality having increased weight within the findings.

Although supervision was used throughout the development of the findings within this review, there was no second reviewer to check the reliability of the analysis which presents as a limitation of the review. As such, the findings should be treated with a degree of caution.

Finally, there is an underrepresentation of specific types of OCD (e.g., paedophile OCD) which may experience different barriers to accessing support. Some of these presentations are accompanied by significantly higher levels of stigma, thus preventing them from being included in initial research and having a snowball effect of not being included in wider reviews or policy guidelines.

Conclusion

This review, following the JBI convergent integrated approach to mixed methods review guidelines, found a range of barriers and facilitators to help-seeking for those experiencing OCD symptoms. These ranged from stigma, which further supported the findings within the wider literature, to broader recognition of OCD symptoms. The barriers highlighted within this review have broad clinical implications for individual therapeutic interventions and wider, community-based strategies. Further research may be required to evaluate the efficacy of strategies to reduce barriers to help-seeking.

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Paper 2: Empirical Paper

The Difference in Psychological Flexibility and Resilience Between Care Seeking and Non-Care Seeking Voice Hearers Following Exposure to Trauma

Running title: Psychological Flexibility, Resilience, and Voice Hearing

Owen Lane[a]

[a] South Wales Doctoral Programme in Clinical Psychology, School of Psychology, Cardiff University, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT

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Abstract

Objectives

It is estimated that up to 15% of the population will experience an auditory hallucination with many of these taking the form of voices. Hearing voices has been frequently associated with a historic traumatic experience, however, many people who hear voices do not seek support. Two hypothesised differences are in relation to psychological flexibility and resilience. This study aimed to explore the differences between care-seeking (CSVH) and non-care seeking voice hearers (NCSVH) in relation to these two variables alongside auditory hallucination distress and trauma.

Methods

One-hundred-and-forty-nine adult voice hearers (81.21% female, 88.59% aged 18-24 years, 76.51% white) were recruited online to complete self-report measures relating to trauma, voice-related distress, psychological flexibility, and resilience.

Results

CSVH reported significantly higher levels of voice and trauma related distress. CSVH were more likely to report repeated exposure to the same traumatic event, however, the total number of different traumatic experiences did not differ compared to NCSVH. NCSVH scored significantly higher on most areas of psychological flexibility apart from valued action where there was no significant difference. Similarly, NCSVH scored higher on most aspects of resilience aside from family cohesion and structured style where there was no significant difference.

Conclusions

These findings support the use of a range of therapeutic interventions, such as cognitive behavioural therapy, family therapy, acceptance and commitment therapy, to support voice hearers and reduce the need to seek support in the future. Further research in this area could investigate the direction of relationship between these variables.

Keywords: hearing voices, psychological flexibility, resilience, trauma, care seeking.

Introduction

Hallucinations are perceived sensory experiences that occur in the absence of an external stimulus. Commonly, hallucinations have been associated with clinical mental health diagnoses, in particular under the umbrella term of schizophrenia spectrum and other psychotic disorders in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association; APA, 2013). These psychiatric conditions are categorised as severe and enduring and have been frequently associated with an increased risk of suicide (Sher & Kahn, 2019) as well as historically being referred to as a "dreadful condition" due to the perceived detrimental impact upon an individual's life. (Bentall & Morrison, 2002). It is recognised that hallucinations can occur in a wider range of mental and physical health conditions including, but not limited to, affective disorders, Alzheimer's disease, borderline personality disorder, alongside some eye and ear conditions (Chaudhury, 2010; Thakur & Gupta, 2021; Waters et al., 2018). Over recent years, the psychological community have begun to increasingly adopt a continuum-based approach to mental health experiences, with this being applied to psychosis and the accompanying symptomology with experiences in the general population ranging from sub-syndromal to clinically significant (DeRosse & Karlsgodt, 2015). This move to recognise that hallucinations are a part of the wider human experience has been supported by research estimating a prevalence rate of between 6-15% for all types of hallucinations which is significantly greater than the rate for psychotic disorders (Blom, 2012; Linscott & van Os, 2012).

Auditory hallucinations have been repeatedly reported to be the most common sensory modality for hallucinations (Ivana & Dunja, 2021; Lim et al., 2016) most frequently taking the form of voices (Linszen et al., 2022) also referred to as auditory verbal hallucinations (AVH; Waters, 2010). It is estimated that around between 5-15% of the general population will experience some form of auditory hallucination during their lifetimes with particular peaks during childhood and adolescence (Cooke, 2017; Johns et al., 2014; Kråkvik et al., 2015; Maijer et al., 2017). The movement to a continuum model for hallucinations de-pathologises voice hearing which in turn opens the door to a variety of research into the differences between care-seeking voice-hearers (CSVH) and non-care-seeking voice hearers (NCSVH). Johns et al. (2014) reported that individuals receiving support from mental health services and those that do not, share similarities in the underlying mechanisms of their AVH but also demonstrate key differences in behavioural response and emotional valence. These may lead to several differences including increased levels of distress which has been found to be a key differentiator between CSVH and NCSVH.

There are many different explanations for AVH including a range of neurological mechanisms (Hugdahl, 2009; Hugdahl, 2017; Hurlemann et al., 2007; Kompus et al., 2011), however, there appears to be a lack of specific clarity regarding their role and long-term reduction of auditory hallucinations. Alternatively, significant research has investigated some of the environmental and psychological factors leading to the experience of AVH. One of the possible explanations for AVH is social isolation and withdrawal especially in vulnerable or older adult populations, as the lack of sensory stimulus may prompt the occurrence of compensatory stimulation of the perceptual network in an effort to meet the needs of the individual (Hoffman, 2007). Hypervigilance, especially in the context of anxiety, has been reported to be another factor in the persistence of AVH as there is a reduced barrier for perceiving ambiguous information as real alongside a heightened awareness for new stimuli (Campbell & Morrison, 2007). Research has demonstrated that individuals who view AVH as culturally viable, such as in religious contexts, may engage in training or purposeful cultivation of experiences in which these hallucinations occur including mental imagery work and prayer, however these experiences are often associated with a reduced level of distress in comparison to AVH occurrences in psychosis (Luhrmann, 2012; Luhrmann, 2017; Luhrmann et al., 2013).

The most highly researched explanation of the occurrence of AVH is in the area of trauma. A wealth of research has found a significantly higher rates of traumatic experiences and related psychological sequelae in populations experiencing psychosis when compared with the general population (Bebbington et al., 2004). Research has demonstrated that even in the non-clinical groups, traumatic events can trigger hallucinatory experiences with around 80% of recently bereaved reporting a hallucination relating to their loved one within the first month following their passing (Grimby, 1993). Traumatic experiences, especially those in childhood, are thought to contribute to the development of AVH with 70% of voice hearers first hallucinatory experience occurring following a traumatic event (Romme & Escher, 1989). A large-scale population study reported that the risk of experiencing AVH doubles if there is an exposure to traumatic events during childhood (Whitfield et al., 2005). These traumatic events can range from bullying (Arseneault et al., 2009; Lardinois et al., 2010) to sexual abuse (Read et al., 2005). Daalman et al. (2012) investigated this further reporting that both care seeking voice hearers and non-care seeking voice hearers experienced more sexual and emotional abuse during their childhood than the healthy controls, however, no difference in the occurrence of traumatic experiences was found between the two groups of voice-hearers. As psychological distress associated with traumatic events leads to a higher prevalence of AVH, developing an understanding of the factors that may shield against said distress could guide future treatment interventions. This combined with the awareness of the differences between CSVH and NCSVH could support in the adaptation of service provision (Brettet al., 2014; Johns et al., 2014).

One hypothesised difference between CSVH and NCSVH is their level of psychological flexibility. Psychological flexibility is defined as the measure of how an individual adapts to fluctuating situational demands, reconfigures mental resources, shifts perspective, and balances competing desires, needs, and life domain (Kashdan and Rottenburg, 2010). These flexible processes are often absent in many forms of psychopathology, and therefore it is thought that psychological flexibility may act as a protective factor for many individuals. This has been shown to be significant for voice-hearers as experiential avoidance, a key process in Acceptance Commitment Therapy which is based on the development of psychological flexibility, has been associated with distress related to AVH (Varese et al., 2016). Psychological flexibility has also been found to act as a mediator between early life trauma and psychological symptoms of depression and PTSD (Richardson & Jost, 2019) as well as reduce the effects of PTSD symptoms (Dutra & Sadeh, 2018).

Another possible difference is related to resilience which is a term frequently used in the field of psychology and mental health and can be defined as 'the act of rebounding or springing back' (Oxford University Press, 2010). However, this definition can be viewed as reductionist, missing impactful components. An alternative definition has been suggested to define it as 'the potential to exhibit resourcefulness by using available internal and external resources in response to different contextual and developmental challenges' (Pooley & Cohen, 2010). Research has found that there is a genetic, epigenetic, neuroanatomical, and neurochemical component to resilience (Feder et al., 2010) and has been examined extensively in participants with PTSD through neuroimaging studies (New et al., 2009). On a behavioural and psychological level, it is suggested that resilience is a key factor in understanding how individuals manage stress (Connor, 2006) with resilient coping found to be the most common response to possible traumatic events instead of a recovery pathway (Bonanno, 2005).

Current research has identified that resilience and psychological flexibility can significantly impact an individual's experience following a traumatic experience. When combined with the evidence that experiences of trauma increase the risk of developing AVH, it may be inferred that resilience and psychological flexibility may reduce the level of distress experienced by an individual following a traumatic experience. This would, in turn, be expected to reduce the severity of AVHs experienced. The improved understanding of these connections may inform future treatments provided to individuals who hear voices.

One of the central theories that underpins this research is the dissociation model of hallucinatory experiences (Longden et al., 2012; Moskowitz & Corstens, 2008). This theory suggests that AVH should be viewed more as a dissociative experience than a psychotic one as it may serve a protective function following traumatic experiences. An additional theory supporting this research is the cognitive appraisal of coping outlined within cognitive behavioural theory. This posits that individuals assess and respond to stressors based on their subjective evaluations, leading to the selection of coping strategies and emotional responses, with the outcome influenced by ongoing reappraisal. The last main theory upon which this research is based, relates to psychological flexibility as adapted from Acceptance and Commitment Therapy (Hayes et al., 1999). It is suggested that those with greater psychological flexibility have an improved capacity to adaptively cope with challenging situations through accepting, mindfully observing, and aligning one's values to guide purposeful actions while maintaining emotional regulation and a flexible problem-solving approach.

The aim of this research is to explore psychological wellbeing factors in the context of care seeking and non-care seeking voice hearers who have experienced one or more traumatic events. To do so, a cross-sectional methodological design was employed with an online survey-based approach to examine differences between these groups in levels of psychological flexibility and resilience. The following hypotheses are addressed in this study:

1. Non-care-seeking voice-hearers will report a significantly lower level of AVH distress than care-seeking voice-hearers.
2. Non-care-seeking voice-hearers will report a significantly lower level of trauma than care-seeking voice-hearers.
3. Non-care-seeking voice-hearers will report a significantly higher level of psychological flexibility than care-seeking voice-hearers.
4. Non-care-seeking voice-hearers will report a significantly higher level of resilience than care-seeking voice-hearers.

Table 2.1

Demographic Information of Participants

	CSVH (*n* = 51)		NCSVH (*n* = 98)		Total (*n* = 149)	
	n	%	n	%	n	%
Gender						
Female	39	76.47	82	83.67	121	81.21
Male	10	19.61	13	13.27	23	15.44
Non-binary / third gender	2	3.92	2	2.04	4	2.68
Prefer to self-describe	0	.00	1	1.02	1	0.67
Age						
18-24 years old	39	76.47	93	94.90	132	88.59
25-34 years old	7	13.73	3	3.06	10	6.71
35-44 years old	2	3.92	1	1.02	3	2.01
45-54 years old	3	5.88	0	0.00	3	2.01
No response	0	.00	1	1.02	1	.67
Education						
Completed primary school	0	.00	1	1.02	1	.67
Completed secondary school	15	29.41	33	33.67	48	32.21
Some university but no degree	22	43.14	54	55.10	76	51.01
University bachelor’s degree	6	11.76	1	1.02	7	4.70
Graduate or professional degree (MA, MS, MBA, PhD, JD, MD, DDS)	5	9.80	3	3.06	8	5.37
Vocational or Similar	3	5.88	4	4.08	7	4.70
Prefer not to say	0	.00	1	1.02	1	.67
No response	0	.00	1	1.02	1	.67
Ethnicity						
Asian (Indian, Pakistani, Bangladeshi, Chinese, any other Asian background)	4	7.84	10	10.20	14	9.40
Black/African/Caribbean	4	7.84	0	.00	4	2.68
Mixed two or more ethnic groups	3	5.88	4	4.08	7	4.70
Other (Arab or any others)	1	1.96	3	3.06	4	2.68
White	36	70.59	78	79.59	114	76.51
Prefer not to say	3	5.88	2	2.04	5	3.36
No response	0	.00	1	1.02	1	.67
Employment Status						
A homemaker or stay-at-home parent	0	.00	1	1.02	1	.67
Retired	1	1.96	0	0.00	1	.67
Student	25	49.02	77	78.57	102	68.46
Unemployed and looking for work	2	3.92	3	3.06	5	3.36
Working full-time	5	9.80	3	3.06	8	5.37
Working part-time	17	33.33	12	12.24	29	19.46
Other	1	1.96	1	1.02	2	1.34
No response	0	.00	1	1.02	1	.67

Methods

Participants

A total of 181 participants agreed to take part in this questionnaire-based study through the completion of an online consent form. The majority of these participants were recruited through the Cardiff University Experimental Management System for undergraduate psychology students (*n* = 150, 82.87%). Of those who completed the consent form, 82.32% completed all questions within the study, with 17.68% being excluded as they completed less than 90% (less than 68%) of the research questions. Data from the remaining 149 participants was included in further analysis. These participants were allocated to one of two groups, care-seeking voice hearers (CSVH; *n* = 51, 34.23%) or non-care seeking voice hearers (NCSVH; *n* = 98, 65.78%). Allocation to the CSVH group was based on the participants having sought support from mental health services for their voices in the past 6 months. No information was gathered regarding mental health diagnoses as it was possible that NCSVH would not have received a diagnosis, therefore, contact with mental health services was thought to be a more valid indicator. Demographic information for the total sample alongside the CSVH and NCSVH groups are displayed in Table 2.1.

Measures

Basic demographic information was collected with a study specific questionnaire which included gender (male, female, non-binary, write-in box), age, ethnicity, education, employment status, contact with mental health services in the past 6 months, and the mental health service contacted, if at all.

The *Trauma and Life Events Checklist* (TALE) is a 20-item questionnaire encompassing a range of traumatic events across the lifespan (Carr et al., 2018; see Appendix

E). The TALE was designed as a measure aimed to improve trauma-informed care in psychosis services, and as such it includes items relating to hospital admission and common psychotic symptoms. Research has demonstrated that the TALE has good convergent and construct validity when compared to existing trauma measures alongside good temporal stability (κ = .43 – 1.00). It is also the only trauma measure that includes events specific to psychosis such as hospitalisations or unusual experiences.

The *Auditory Vocal Hallucination Rating Scale Questionnaire* (AVHRS-Q) has 17 items, the majority of which are rated on a four- or five-point scale, with two items rated on a ten-point scale (Steenhuis et al., 2019; see Appendix F). The AVHRS-Q was developed from the Auditory Vocal Hallucination Rating Scale (AVHRS) which is a structured interview aimed at collecting detailed information regarding hearing voices over the past month (Jenner & Van der Willige, 2002). The AVHRS collects a range of information regarding the voices experienced including the qualitative characteristic, the severity, the content and form, and the number of voices which was unique compared to other common voice hearing measures. The AVHRS-Q has a strong correlation (r = .90) with the AVHRS, suggesting the developed questionnaire measure is a valid measure and was found to measure auditory hallucination severity distinct from general psychological distress. Additionally, the original Dutch version has been reported to have good internal consistency (α = .78 - .87) and has since been translated into multiple languages, including the English version used in this study.

The *Resilience Scale for Adults* (RSA) is a multi-dimensional 33-item measure, each item using a 5-point Likert response, comprised of six factors which can be analysed as separate subscales: perception of self, perception of future, social competency, social resource, family cohesion, and structured style (Friborg et al., 2003; see Appendix G). The original Norwegian version has been found to have adequate reliability (α = .70 - .85) and was able to differentiate between healthy controls and those requiring additional support. The RSA has been translated into a variety of languages and used across the world, with research demonstrating good cross-cultural validity and supporting the original reports of internal consistency (Hjemdal et al., 2011; Hjemdal et al., 2015).

The *Comprehensive assessment of Acceptance and Commitment Therapy* (CompACT) is a 7-point Likert based measure with 23 items (Francis et al., 2016; see Appendix H). The CompACT was developed as a questionnaire that covered all aspects of the acceptance and commitment therapy hexaflex (Hayes et al., 2011). and was a true measure of psychological flexibility, whereas the measures that came before it focused on psychological inflexibility. The CompACT is comprised of three subscales, each encapsulating two aspects of psychological flexibility: openness to experience, behavioural awareness, and valued action. It has been found to measure all of the six processes of psychological flexibility and has been demonstrated to have good reliability, validity, convergent validity, and concurrent validity. Additionally, it has no significant correlation with social desirability which improves the trust in the measure. The questionnaire has been translated into a variety of languages, with research demonstrating the maintenance of good content validity (Giovannetti et al., 2022; Musa et al., 2022).

Procedure

Ethical approval was gained from the Cardiff University School of Psychology Ethics committee (EC.22.02.08.6528R2A; see Appendix I). As this study required participants to think back to any traumatic events they experienced, ethical considerations were made to limit the distress or any impact it may have had. To reduce the risk of distress and re-traumatisation being caused, the questionnaire to measure the traumatic experiences, TALE, was selected as it requires the minimum amount of information regarding the traumatic event to be able to complete accurate analysis of the data. This questionnaire has been used by some of the leading researchers in the field of trauma and psychosis with no re-traumatisation or negative impacts on participants reported (Campodonico et al., 2021). Additionally, it was recognised that requesting individuals to focus on their auditory hallucinations through the answering of questionnaires may result in the intensity of the hallucinations increasing. To ensure these risks were managed appropriately, a self-care and support document was made available at the start and end of the study which included contact details for support services, alongside self-help resources, and online links (see Appendix J).

Participants were recruited from December 2022 to April 2023 through experience sampling via a range of sources. Key services across the UK who support individuals who hear voices were contacted via email to advertise the study which included Hearing Voices Networks, spiritualist organisations, and hearing voices research groups. The study was also advertised through social media services such a Twitter and Reddit with some posts being promoted or shared by relevant individuals. Leading researchers in the area were contacted to seek advice around recruitment and to request them to share the research where possible. Participants were also recruited through online research participation services such as Call for Participants and Survey Circle. Finally, the Cardiff University Experimental Management System was used to recruit psychology students at the university. Inclusion criteria alongside the study information (see Appendix K), consent form (see Appendix L), debrief (see Appendix M), and questionnaires were all distributed and hosted on Qualtrics, a secure online research platform. Those who consented to take part were presented with the option of receiving university credits as compensation or to be entered into a raffle to win one of six Love2Shop vouchers worth up to £50.

Statistical Analysis

An a priori power analysis was calculated using G*Power version 3.1 for Mac (Faul et al., 2007) to establish the minimum sample size required to achieve 80% power, at a significance criterion of $\alpha = .05$. The results demonstrated that $N = 51$ was needed for *t*-tests to be conducted to investigate the differences between the CSVH and NCSVH groups.

Data analysis was conducted using IBM SPSS Statistics (version 27) for Mac and Windows. To assess the normality of the data, a Shapiro-Wilk test was used with comparisons against Q-Q plots where there were possibilities of non-normal distributions. To improve the confidence in the normality of the data, 95% percentile bootstrap confidence intervals were used based on 1,000 bootstrap samples. Homogeneity of variance was also assessed initially using Levene's test, with confirmation using Hartley's $F_{\max}$. To test the hypotheses, *t*-tests were conducted to establish the differences between the CSVH and NCSVH groups. Due to multiple tests being carried out, a more conservative $\alpha = .01$ was used, with the results from these tests being used to calculate the strength of effect. Cohen's *d* of .50 and over indicates a large effect size, with over .30 demonstrating a medium effect, and above .10 being small. When evaluating the internal consistency of the measures using Cronbach's alpha, the criteria of above .90 demonstrates excellent internal consistency, over .80 is good, above .70 is acceptable, over .60 is questionable, above .50 is poor, and anything below .50 is viewed as unacceptable.

Results

Hypothesis 1 - Non-care-seeking voice-hearers will report a significantly lower level of AVH distress than care-seeking voice-hearers .

The AVHRS-Q consisted of 17 items and was found to have good internal consistency ($\alpha = .89$). The variance of the data was assessed using a Levene's test which identified that the variances between the CSVH and NCSVH groups on the AVHRS-Q severity ($F(1, 147) = 15.04$, $p = <.001$) was unequal. This was ratified by comparing it to Hartley's $F_{\text{max}}(50) = 3.22$ confirming that equal variances will not be assumed and should be reflected in the *t*-test results.

On average severity of voices, as recorded by the AVHRS-Q overall distress score, was significantly higher in the CSVH group ($M = 4.08$, $SE = .53$) than in the NCSVH group ($M = 2.03$, $SE = .21$) $t(66.56) = 3.59$, $p = <.001$, with a difference of 2.05, BCa 95% CI [.86, 3.10] and represented a large effect size, $d = .97$.

Hypothesis 2 - Non-care-seeking voice-hearers will report a significantly lower level of trauma than care-seeking voice-hearers.

The TALE consisted of 22 items and was found to have acceptable internal consistency ($\alpha = .74$). Hartley's F_{max} which identified that the variances between the CSVH and NCSVH groups on the count of traumatic events still affecting participants ($F(1, 147) = 6.29$, $p = .013$) was unequal, and as such, equal variances will not be assumed and reported in the *t*-test results.

The CSVH group reported still being affected by more of the traumatic events ($M = 2.59$, $SE = .38$) than the NCSVH group ($M = 1.51$, $SE = .18$). This difference, 1.08, BCa 95%

CI [.24, 1.95], was not statistically significant *t*(72.79) = 2.57, *p* = .012, but it did represent a moderate effect size *d* = .61. The distress currently experienced from these traumatic events was higher in the CSVH group (*M* = 5.78, *SE* = .44) than the NCSVH group (*M* = 4.00, *SE* = .29). This difference, 1.78, BCa 95% CI [.72, 2.80], was statistically significant *t*(147) = 3.46, *p* = <.001, which also represents a moderate effect size *d* = .61.

The response rates to individual traumatic experiences can be seen in Table 2.2. There was a difference in the number of repeated exposures to trauma with the CSVH group experiencing more traumatic events that repeated (*M* = 4.90, *SE* = .57) than the NCSVH group (*M* = 3.32, *SE* = .30). This difference, 1.59, BCa 95% CI [.29, 2.91], was statistically significant *t*(147) = 2.72, *p* = .007, which represents a moderate effect size *d* = .54. Furthermore, CSVH experienced more of the 20 different traumatic events (*M* = 6.73, *SE* = .67) than the NCSVH group (*M* = 5.16, *SE* = .37). However, this difference, 1.56, BCa 95% CI [.09, 3.13], was not statistically significant *t*(147) = 2.24, *p* = .027, which represents a moderate effect size *d* = .43.

Table 2.2

Response Counts and Percentages for the TALE

	CSVH			NCSVH			Total		
Event	No	Yes	%	No	Yes	%	No	Yes	%
1. Exposure to war, either in the military or as a civilian?	94	4	4.08	49	2	3.92	143	6	4.03
2. Loss of, or permanent separation from someone close to you such as a parent or caregiver?	72	26	26.53	39	12	23.53	111	38	25.50
3. A period of separation from someone close to you such as a parent or caregiver?	64	34	34.69	31	20	39.22	95	54	36.24
4. Sudden or unexpected move or change in circumstances?	71	27	27.55	30	21	41.18	101	48	32.21
5. Bullying or harassment at school, work or on the street?	48	50	51.02	21	30	58.82	69	80	53.69
6. Discrimination at school, work or on the street?	70	28	28.57	35	16	31.37	105	44	29.53
7. Someone close to you insulting you, putting you down or humiliating you?	52	46	46.94	26	25	49.02	78	71	47.65
8. Someone close to you being physically violent or aggressive towards you?	72	26	26.53	34	17	33.33	106	43	28.86
9. Witnessing physical violence or verbal aggression in your home?	61	37	37.76	31	20	39.22	92	57	38.26
10. Someone you did not know being physically violent or aggressive towards you?	87	11	11.22	41	10	19.61	128	21	14.09
11. Feeling unsafe, unloved, or unimportant during childhood?	67	31	31.63	25	26	50.98	92	57	38.26
12. Going hungry or thirsty, not having clean clothes or a safe place to stay during childhood?	95	3	3.06	47	4	7.84	142	7	4.70
13. Someone having any sexual contact with you, before your 16th birthday, that either at the time or looking back on it now was unwanted?	73	25	25.51	33	18	35.29	106	43	28.86
14. Someone having any sexual contact with you, since your 16th birthday, that either at the time or looking back on it now was unwanted?	60	38	38.78	26	25	49.02	86	63	42.28
15. Unusual experiences, such as hearing voices, seeing visions, or having worries about other people causing you harm, that made you feel in danger or distress?	62	36	36.73	24	27	52.94	86	63	42.28
16. Acting in ways that put you or someone else in danger or were strange or embarrassing?	73	25	25.51	30	21	41.18	103	46	30.87
17. Contact with mental health services (e.g., being admitted to hospital) that involved threatening or upsetting events?	90	8	8.16	42	9	17.65	132	17	11.41
18. Any other contact with health or criminal justice services which was upsetting or frightening?	87	11	11.22	42	9	17.65	129	20	13.42
19. Any other events that were accidental or did not involve people intending to cause you harm?	89	9	9.18	38	13	25.49	127	22	14.77
20. Apart from the above, has anything else happened in your life that you found distressing?	67	31	31.63	33	18	35.29	100	49	32.89
21a. Do any of the events you have mentioned, still affect you now?	48	50	51.02	16	35	68.63	64	85	57.05

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Hypothesis 3 - Non-care-seeking voice-hearers will report a significantly higher level of psychological flexibility than care-seeking voice-hearers.

The CompACT has three subscales: openness to experience, behavioural awareness, and valued action. The openness to experience subscale consisted of 9 items with questionable internal consistency (α = .68), the behavioural awareness subscale consisted of 5 items with good internal consistency (α = .82), and the valued action subscale consisted of 8 items with excellent internal consistency (α = .91). Overall, the CompACT questionnaire consisted of 17 items and was found to have good internal consistency (α = .89).

From the overall scores on the CompACT, the CSVH group scored lower (*M* = 60.55, *SE* = 1.84) than the NCSVH group (*M* = 70.85, *SE* = 1.29) which was significant *t*(147) = -4.63, *p* = <.001, with a difference of -10.30, BCa 95% CI [-14.72, -6.01], and a large negative effect size, *d* = -.81. A similar result was found on the CompACT openness to experiences subscale with the CSVH on average scoring lower (*M* = 19.71, *SE* = 1.19) than the NCSVH group (*M* = 24.33, *SE* = .63) which was also significant *t*(147) = -3.79, *p* = <.001, with a difference of -4.62, BCa 95% CI [-7.10, -1.94], and a large negative effect size, *d* = -.75. The CompACT behavioural awareness subscale also produced a significant result with the CSVH scoring lower (*M* = 10.84, *SE* = .75) than the NCSVH group (*M* = 14.47, *SE* = .54), *t*(147) = -3.94, *p* = <.001, with a difference of -3.63, BCa 95% CI [-5.42, -1.81], and a large negative effect size, *d* = -.68.

However, the CompACT valued action subscale produced a non-significant result with the CSVH group scoring slightly lower (*M* = 28.31, *SE* = 1.22) than the NCSVH group (*M* = 29.84, *SE* = .91), *t*(147) = -.92, *p* = .35), with a difference of -1.42, BCa 95% CI [-4.42, 1.64], which represented a small, negative effect size, *d* = -.16.

Hypothesis 4 - Non-care-seeking voice-hearers will report a significantly higher level of resilience than care-seeking voice-hearers.

The RSA is comprised of six subscales: perception of self, perception of the future, structured style, social competence, family cohesion, and social resources. The perception of self subscale consisted of 6 items with acceptable internal consistency (α = .74), the perception of the future subscale had 4 items with acceptable internal consistency (α = .77), and the family cohesion subscale with 6 items had good internal consistency (α = .83), However, the structured style subscale consisting of 4 items had poor internal consistency (α = .57), the social competence subscale with 6 items had questionable internal consistency (α = .61), and the social resources subscale consisted of 7 items with questionable internal consistency (α = .65). Overall, the RSA questionnaire consisted of 33 items and was found to have good internal consistency (α = .88).

The total score on the RSA produced a significant difference between the CSVH group (*M* = 3.05, *SE* = .07) and the NCSVH group (*M* = 3.48, *SE* = .05) *t*(147) = -4.88, *p* = <.001, with a difference of -.43, BCa 95% CI [-.61, -.26] and represented a large effect size, *d* = -.84. Similar results were found with the majority of the subscales apart from structured style and family cohesion. The difference between the CSVH group (*M* = 3.12, *SE* = .12) and the NCSVH group (*M* = 3.43, *SE* = .08) on the structured style subscale was not significant *t*(147) = -2.18, *p* = .031, with a difference of -.31, BCa 95% CI [-.60, -.01] and represented a medium effect size, *d* = -.38. The scores on family cohesion were also not significant between the CSVH (*M* = 3.27, *SE* = .11) and the NCSVH (*M* = 3.60, *SE* = .09) *t*(147) = -2.14, *p* = .034, with a difference of -.32, BCa 95% CI [-.62, -.05] and represented a medium effect size, *d* = -.35. The results from all of the *t*-tests across each hypothesis can be seen in Appendix N.

Discussion

Summary of Findings

The focus of this research was to identify the effects of psychological flexibility and resilience on care seeking for individuals who experience AVH following a traumatic experience, with clear implications for clinical practice. The initial aim was to confirm findings from previous research that AVH distress differs between CSVH and NCSVH, and to establish whether there is a difference in traumatic experience between the two groups. The main aim was to explore the differences in psychological flexibility and resilience between CSVH and NCSVH.

AVH Distress

This study supports previous research indicating that individuals who seek support for hearing voices experience higher levels of distress compared to those who do not seek support (Powers et al., 2017). The content of the voices has been identified as a significant predictor of distress and help-seeking behaviour (Beavan & Read, 2010). These findings align with the Health Belief Model, which suggests that the perceived severity and impact of difficulties motivate individuals to seek help (Becker, 1974). However, it is important to note that the Health Belief Model does not account for individual beliefs, and the cognitive model of auditory verbal hallucinations emphasizes the role of appraisals in distress (Chadwick & Birchwood, 1994). Appraisals of voices have been found to contribute to the experience of distress (Johns et al., 2014; Rammou et al., 2022), although other factors are likely involved (Tsang et al., 2021).

Trauma

The CSVH group reported higher rates of distress caused by hallucinations compared to the NCSVH group, 52.95% compared to 36,73%. This difference may be related to the absence of specific triggers for auditory verbal hallucinations (AVH), which reduces their frequency, severity, and distress (Bless et al., 2018).

Multiple traumatic experiences were associated with higher rates of hallucinations (Morrison & Petersen, 2003), but the number of different types of traumas did not significantly impact hallucination rates in this study. However, previous research, such as the ACE study, has shown that experiencing multiple types of traumas increases the likelihood of hallucinations (Begemann et al., 2021; Whitfield et al., 2005). The findings in this study suggests that there may be alternative factors which effect the likelihood of hearing voices following traumatic experiences that are not encapsulated within previous research. The attachment and cognitive models (e.g., Ehlers & Clark, 2000) may explain some of the differences, and may suggest that when trauma originates from a single source, individuals may have fewer negative global appraisals and feel more trusting, thus facilitating help-seeking.

The study found a significant difference between the CSVH and NCSVH groups in terms of distress related to traumatic experiences. Post-trauma appraisals, including disconnection from oneself and the world, are associated with distress and the development of trauma-related mental health difficulties (DePrince et al., 2011; Foa et al., 1999). Dissociation, defined as the impairment of mutuality between internal and external worlds, is linked to traumatic experiences and is associated with hallucinatory experiences (Sar & Öztürk, 2006; Wearne et al., 2020). Some propose that AVH should be conceptualized as a dissociative experience rather than a symptom of psychosis (Longden et al., 2012; Moskowitz & Corstens, 2008). These theories are supported by the higher prevalence of AVH in individuals who have experienced trauma compared to the general population (Clifford et al., 2018; Kråkvik et al., 2015; Pearson et al., 2008; Scott et al., 2007).

The Adverse Childhood Experiences (ACE) study found that the presence of ACEs increased the risk of hallucinations by 20-150%, with emotional abuse being the most impactful ACE (Whitfield et al., 2005). Similar findings were reported in this study with emotional harm from someone close (47.65%) and experiences of bullying or harassment (53.69%) reported as the most common traumatic experiences. These findings support the literature suggesting that peer rejection and bullying from childhood into young adulthood are associated with a higher risk of hallucinations (Steenkamp et al., 2021; Mackie et al., 2013; Wolke et al., 2014). Insecurity during formative social and developmental years may contribute to increased paranoid ideation, a characteristic of psychotic difficulties, and the likelihood of seeking professional support (Valmaggia et al., 2015). Young adults who have experienced bullying and trauma also find their AVH more distressing, which is linked to help-seeking (Løberg et al., 2019).

Psychological Flexibility

The study found that individuals with CSVH reported significantly lower levels of psychological flexibility compared to NCSVH, except for valued action. This supports previous research linking psychological flexibility to the emotional experience related to voice hearing (Morris et al., 2014). Low mood has been correlated with experiential avoidance, the opposite of acceptance (Hayes et al., 1996). When compared to psychosis, depressive symptoms are much more easily recognised within the general population with more positive attitudes, making it less stigmatising to seek support (Svensson & Hansson, 2016). Individuals with lower levels of openness to experiences may have increased depressive symptoms and be more likely to seek care due to better recognition of their difficulties. Alternatively, those with higher levels of openness may have a higher tolerance for uncertainty and feel less burdened by their voices, enabling them to cope better.

Research on personality traits suggests that hallucinatory experiences may result from extreme openness, which can lead to making connections that do not exist (DeYoung et al., 2012). This overlaps with the definition of openness in psychological flexibility. Previous studies have found that individuals with hallucinatory experiences often use thought-suppression strategies (Popa et al., 2020), contradicting acceptance, and that acceptance is associated with reduced distress and compliance with voice commands (Shawyer et al., 2007).

The lower levels of behavioural awareness reported by CSVH in this study may be attributed to the distress caused by hallucinations, which can hinder present moment focus and lead to immersion in the hallucinatory world (Dudley et al., 2018). This distorted experience of reality is strongly associated with affective dysregulation (Myin-Germeys & Van Os, 2007) and an increased likelihood of meeting clinical criteria for psychotic experiences (Van Rossum et al., 2011). These factors help explain the differences in behavioural awareness observed in the CSVH group.

One intriguing finding is the lack of significant difference between CSVH and NCSVH in valued action. It has been hypothesized that hallucinations interfere with an individual's life and hinder living according to personal values (Ashry et al., 2021). However, the participant sample in this study may not fully represent the wider voice hearing population, as there is a minimum level of mental well-being required to participate in an online study. The participants may not be experiencing as much distress or interference from their voices, allowing them to focus more on their goals. Research into psychological flexibility has demonstrated that an awareness of personal values is required to engage in goal-directive behaviour (Forman et al., 2012). Additionally, the majority of the sample consisted of university students, who may be more motivated and goal-oriented, which could contribute to higher scores on valued action (Alasqah, 2022).

Resilience

Significant differences were found between CSVH and NCSVH across most domains of resilience in this study, aligning with previous research showing that voice hearers tend to have a poorer perception of themselves, and the future compared to non-voice hearers (Laloyaux et al., 2020). Other studies have also shown that young adults who experience negative self-worth and less family support tend to find their AVH more distressing, leading to increased care-seeking behaviour (Løberg et al., 2019). These findings are consistent with cognitive models of mental health difficulties, which emphasise negative perceptions of self, the world, and the future.

While no significant findings were observed regarding family cohesion, aspects of family support were encompassed within the social resources domain of resilience, which did show a significant difference. Compared to research on non-voice hearing populations, both groups in this study had considerably lower mean scores, suggesting that voice hearers or those exposed to traumatic events may experience greater difficulties in their family lives than the general population (Cowden et al., 2016; Kutlutürkan et al., 2016). It is possible that NCSVH individuals have found support through voice hearing groups, which provide a safe space to explore coping strategies and different appraisals of voices, leading to improved social resources and coping skills (Ruddle et al., 2011).

The recent COVID-19 pandemic may have lasting impacts on the resilience of voice hearers. Research has shown that individuals with higher perceptions of social support, who engage in outdoor activities more frequently and have better sleep, tend to report greater resilience scores during the pandemic (Killgore et al., 2020). However, psychosis pathology, including hearing voices, has been associated with worse experiences in all of these areas, such as lower perceptions of social support (Gayer-Anderson & Morgan, 2013), higher rates of social isolation (Bornheimer et al., 2020; Butter et al., 2017), and poorer sleep (Davies et al., 2017). This suggests that there may be self-perpetuating negative effects on resilience among all individuals who hear voices, with greater effects on those experiencing higher levels of distress and increased concern about social stigma.

Clinical Implications

The findings of this study highlight the potential for interventions targeting psychological flexibility to benefit individuals with AVH or those exposed to trauma. Acceptance and Commitment Therapy (ACT; Hayes et al., 1999), which focuses on developing flexible responding through language, cognition, and functional contextualism, has shown promising results in the treatment of psychotic conditions (Gaudiano et al., 2017; O'Donoghue et al., 2018; Wakefield et al., 2018) as well as trauma (Bean et al., 2017). Mindfulness, a commonly used technique in ACT, has been defined as the deliberate practice of paying attention to the present moment, nonjudgmentally (Kabat-Zinn, 2003). Historic views of mindfulness exacerbating hallucinatory symptoms has been argued to be unfounded and stems from 'othering' of individuals with psychotic experiences. More recently, mindfulness has been found to reduce distress in individuals experiencing AVH and challenge the negative content of voices (Louise et al., 2019; Silver et al., 2023).

Early intervention services implemented by the NHS in England and Wales since 2001 have shown effectiveness in addressing psychotic experiences (Marwaha et al., 2016), including early recognition, reduced treatment delay, and providing effective treatment for individuals experiencing first-episode psychosis (Marshall & Rathbone, 2011; Csillag et al., 2018). While CBT and family therapy are the main therapeutic interventions offered within these services, incorporating ACT-based interventions could be a valuable addition. Considering the significant impact of childhood trauma, early intervention services may benefit from continuing to embed trauma informed approaches, such as the At Risk Mental State Services, to support those who experience traumatic events who may be at risk of psychosis or other mental health difficulties (Kassam-Adams, 2014).

Resilience is another important factor to consider in interventions for voice hearers and individuals exposed to trauma. The significant difference in resilience between CSVH and NCSVH may suggest the need to incorporate resilience-focused approaches in therapy. This idea is supported by research that has found a link between severity of psychosis, resilience, and suicidality (Harris et al., 2021) demonstrating a high level of need for support. CBT is well-established as a therapeutic intervention for voice hearers (Garety et al., 2001) built on the foundation of Beck’s (1976) cognitive triad which postulates that changing appraisals about the self, world, and future may improve one’s current mental state. The cognitive model is still evolving to better understand the differences between clinical and non-clinical voice hearers (Waters et al., 2012) and may benefit from the inclusion of psychological flexibility as some variables may be better explained through different lenses (Morris et al., 2014).

Despite the lack of significant difference relating to family cohesion, family therapy, which focuses on the strengths of support networks and views resilience as a developmental process, can also be beneficial (Hawley, 2000). It is possible that the blueprint established within family relationships could support individuals to feel more comfortable in social environments as they develop (Hauser-Cram et al., 2001). The family relationship can predict acceptance within peer groups throughout childhood (Nassau & Drotar, 1995) and support the development of abilities to adapt to challenging situations (Kolb & Hanley-Maxwell, 2003). Approaches such as Open Dialogue, which empower individuals within their social networks, and social prescribing, which addresses social determinants of health inequality, have also been recommended (National Psychological Therapies Management Committee, 2023). These interventions foster resilience within the wider community (Chatterjee et al., 2018) and have the potential to enhance resilience while reducing social isolation (Howarth et al., 2020).

The participants in this study were predominantly recruited from Cardiff University's undergraduate psychology program, indicating a potential need for mental health support within university populations. University counselling referrals have been increasing in recent years (Macaskill, 2013), with factors identified that place students at higher risk of developing psychosis (Sanderson et al., 2020). University students may be motivated to study psychology to better understand their own experiences or contribute to the field of mental health. It is important to conduct further research across a range of higher education settings and courses to gain a better understanding of mental health needs in this population.

Future Research Recommendations

This study highlights the heterogeneity among voice hearers and emphasises the need for further research to investigate the role of psychological factors in moderating the relationship between psychological flexibility, resilience, AVH distress, and trauma. Future studies should also explore the specific types of trauma experiences in CSVH and NCSVH to identify individuals at higher risk for developing psychotic pathology and enhance early intervention strategies. By delving deeper into these areas, we can gain a better understanding of the factors influencing voice hearing and improve support for those affected.

Strengths and Limitations

One limitation of this study is the lower internal reliability of some subscales, particularly the structured style subscale of the RSA, which raises concerns about the accuracy of its measurement and calls for cautious interpretation of the corresponding findings. However, a strength of this study is the use of the CompACT measure of psychological flexibility, which aligns well with the hexaflex and facilitates the connection to therapeutic interventions like ACT. This enhances the confidence in the interpretation of the results pertaining to psychological flexibility compared to previous research which often used measures that may capture psychological inflexibility (Rolffs et al., 2018) or general distress (Wolgast, 2014).

The study's sample composition, predominantly consisting of participants from Western, educated, industrialised, rich, and democratic (WEIRD) backgrounds, limits the generalisability and internal validity of the findings (Tindle, 2021). The overrepresentation of young (88.59%), female (81.21%), educated (61.08%), and white (76.51%) participants in both the CSVH and NCSVH groups suggests that the results may not fully represent the broader voice hearing population. Data from the UK government (2014) reports that individuals who identify as Asian or Black are more likely to receive a diagnosis of a psychotic disorder than those who identify as being White, with a similar pattern emerging around the positive screening of PTSD (McManus et al., 2016). However, the presence of diversity in responses and the significant differences observed suggest that the findings may still have relevance beyond the sample.

The study's online nature and recruitment through social media and university channels introduce accessibility-related limitations. The study primarily reached individuals with technology access and proficiency, highlighting digital inequality. This is a continuing pattern within research prior to, and since the COVID-19 pandemic (Watts, 2020). Conducting the study in person would have posed its own limitations, potentially excluding those lacking time and resources, once more resulting in a potentially biased sample.

Another limitation pertains to the allocation of participants to the CSVH and NCSVH groups based on self-reported support accessed in the past 6 months. The subjective nature of defining mental health support and the variability in participants' interpretations could introduce variability in the groups. Furthermore, the CSVH group may have felt more psychologically flexible and resilient due to recent care, while the NCSVH group may have faced difficulties accessing timely support, potentially influencing their outcomes. Additionally, the study's hypotheses focus on the need for care, which may change over time, and participants in the NCSVH group may have received extensive support beyond the 6-month period captured in this study. The operationalisation of care-seeking varies across the research base with strengths and limitations to each approach, and there is no clear standardised method which may be beneficial for further research.

Conclusions

This study demonstrated significant differences in trauma experience, AVH distress, psychological flexibility, and resilience between care-seeking and non-care-seeking voice hearers, although allocation to these groups may not accurately represent the wider voice hearing population. This highlights the need for further research to investigate the relationship between these variables, and the possible moderating effects of both psychological flexibility and resilience. These results have been produced from a majority student sample which may suggest a need for additional support within university settings for those who hear voices.

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Journal of Obsessive-Compulsive and Related Disorders Author Information Pack

JOURNAL OF OBSESSIVE-COMPULSIVE AND RELATED DISORDERS

AUTHOR INFORMATION PACK

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Journal of Obsessive-Compulsive and Related Disorders (JOCRD) is an international journal that publishes high quality research and clinically-oriented articles dealing with all aspects of **obsessive-compulsive disorder** (OCD) and related conditions (**OC spectrum disorders**; e.g., **trichotillomania**, **hoarding**, **body dysmorphic disorder**). The journal invites studies of clinical and non-clinical (i.e., student) samples of all age groups from the fields of psychiatry, psychology, neuroscience, and other medical and health sciences. The journal's broad focus encompasses **classification**, **assessment**, **psychological** and **psychiatric treatment**, **prevention**, **psychopathology**, **neurobiology** and **genetics**. Clinical reports (descriptions of innovative treatment methods) and book reviews on all aspects of OCD-related disorders will be considered, as will theoretical and review articles that make valuable contributions.

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John Piacentini, University of California Los Angeles, Department of Psychiatry and Biobehavioral Sciences, Los Angeles, California, United States of America
Pediatric OCD and Spectrum, Tourette’s and Anxiety Disorders, Randomized controlled trials, Treatment mechanisms
Christine Purdon, University of Waterloo, Waterloo, Ontario, Canada
OCD, Obsessions, Compulsions, Cognitive Behaviour Therapy, Anxiety, Anxiety Disorders

Adam Radomsky, Concordia University, Montréal, Quebec, Canada
OCD, Anxiety disorders, Experimental psychopathology, Cognitive therapy, CBT, Treatment development
Eric G. C. Rassin, Erasmus University Rotterdam, Rotterdam, Netherlands
Decision making, Bias, Thought control
Scott L. Rauch, Harvard Medical School, Boston, Massachusetts, United States of America Neuroimaging, OCD, PTSD, Telehealth
Lillian Reuman, Stonehill College, Faculty of Psychology, Easton, Massachusetts, United States of America Obsessive Compulsive Disorder, Cognitive Behavioral Therapy, Symptom dimensions, Posttraumatic stress disorder, Family accommodation
Emily Ricketts, University of California Los Angeles, Los Angeles, California, United States of America
Sleep and circadian disturbance and intervention (i.e., Behavior therapy, Light therapy, Novel and alternative therapies) in youth and adults with persistent tic disorders, Body focused repetitive behavior disorders and OCD
Bradley Riemann, Rogers Behavioral Health Oconomowoc Main Campus, Oconomowoc, Wisconsin, United States of America
Anxiety Disorders, OCD
Karen Rowa, McMaster University and St. Joseph's Healthcare Hamilton, Anxiety Treatment and Research Clinic, Hamilton, Ontario, Canada
Cognitive Behavioural Therapy, Family Accommodation, Treatment Outcome, Hoarding Disorder
Paul Salkovskis, University of Oxford, Department of Experimental Psychology, Oxford, United Kingdom OCD, Cognitive Behavioural Theory, Hoarding
Claudio Sica, University of Florence, Department of Health Sciences, Firenze, Italy
Obsessive-Compulsive Disoders, Anxiety, Personality, Disorders, Psychopathy, Cognitive-Behavior Therapy, Psychopathology, Cognitive Constructs, Experimental Psychopathology
Jedidiah Siev, Swarthmore College, Department of Psychology, Swarthmore, Pennsylvania, United States of America
OCD, Scrupulosity
Gregoris Simos, University of Macedonia, Thessaloniki, Greece
Anxiety, Uncertainty, CBT, Emotion Regulation, Perfectionism
H. Blair Simpson, New York State Psychiatric Institute, New York, New York, United States of America
How to improve treatments for people with obsessive-compulsive disorder (OCD) and related disorders, Effects of medication and cognitive-behavioral therapy to brain imaging studies
Dan Stein, University of Cape Town Division of Emergency Medicine, Cape Town, South Africa
Anxiety and related disorders, Psychiatry in Africa, Philosophy of psychiatry
Gail Steketee, Boston University School of Social Work, Boston, Massachusetts, United States of America Hoarding, Obsessive Compulsive Spectrum Disorders
Eric A. Storch, Baylor College of Medicine, Houston, Texas, United States of America
Obsessive-compulsive disorder
Laura J. Summerfeldt, Trent University, Peterborough, Ontario, Canada
Incompleteness, NJRES, Cognitive Processing, Personality
Berta J. Summers, University of North Carolina Wilmington, Department of Psychology, Wilmington, North Carolina, United States of America
Obsessive-compulsive disorder, Body dysmorphic disorder, Anxiety pathology, Cognitive biases, Safety behaviors, Virtual reality, Treatment outcome

Steven Taylor, The University of British Columbia, Vancouver, British Columbia, Canada
Psychology of Pandemics, Anxiety Disorders, OCD, PTSD, Health Anxiety
Johanna Thompson-Hollands, Boston Medical Center, Department of Psychiatry, Boston, Massachusetts, United States of America
PTSD, Family interventions, Social support, Accommodation, Veterans
Kiara Timpano, University of Miami, Coral Gables, Florida, United States of America
Anxiety, OC Spectrum Conditions, Transdiagnostic Risk
Odile Van den Heuvel, Amsterdam UMC Location VUMC, Department of Anatomy & Neuroscience, Amsterdam, Netherlands
Obsessive-Compulsive Disorder, Anxiety, Transcranial Magnetic Stimulation, Parkinson's Disease, Neuroimaging
David M. Veale, King's College London, London,
United Kingdom body dysmorphic disorder
Hilary M. Weingarden, Massachusetts General Hospital & Harvard Medical School, Cornell Institute for Reproductive Medicine, Boston, Massachusetts, United States of America
Emotion-Based Risk (e.g., for Suicide, Substance Use) in Obsessive-Compulsive Related Disorders, Use of Technology to Enhance Assessment and Intervention
Michael G. Wheaton, Barnard College, Department of Psychology, New York, New York, United States of America Obsessive-Compulsive Disorder, Cognitive-Behavioral Therapy, Hoarding disorder, ObsessiveCompulsive Personality Disorder
Stephen P. H. Whiteside, Mayo Clinic, Scottsdale, Arizona, United States of
America Pediatric, OCD and Anxiety Disorders
Sabine Wilhelm, Massachusetts General Hospital, Department of Psychiatry, Medford, Massachusetts, United States of America
OCD, Body Dsymoprhic Disorder, Digital health, Smartphone based treatment
Monnica Williams, University of Ottawa School of Psychology, Ottawa,
Ontario, Canada OCD, PTSD, Cultural Diversity, Racism
Shiu Fung Wong, La Trobe University, Melbourne, Victoria, Australia
Experimental methodology to examine the causal and maintaining factors underlying obsessivecompulsive and related disorders
Douglas W. Woods, Marquette University, Milwaukee, Wisconsin, United States of America
Behavior therapy, OC-spectrum disorders, Trichotillomania, Tic disorders, Tourette disorder, Excoriation disorder
Kevin Wu, Northern Illinois University, Dekalb, Illinois, United States of America
Obsessive-Compulsive Disorder, Anxiety, Assessment,
Keong Yap, Australian Catholic University - Strathfield Campus, Strathfield, Australia
Obsessive-compulsive disorder, Compulsive buying, Hoarding disorder, Mindfulness and compassion, Acceptance and Commitment Therapy
Chencheng Zhang, Shanghai Jiao Tong University School of Medicine and Ruijin Hospital, Center for functional neurosurgery, Shanghai, China
Neuromodulation, Clinical Neuroscience, Brain-Machine Interface, Compulsive Behavior, Neuropsychiatry
Joseph Zohar, Sheba Medical Center, Tel Aviv, Israel
PTSD, OCD, Depression

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Appendix B

Mixed Methods Appraisal Tool version 2018 Guidelines

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

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

Appendix C

Summary of Quantitative Findings

Authors	Summary of Quantitative Data
Williams et al., 2012	• European Americans perceived receiving treatment before that did not work as a barrier 38.89% significantly more than African Americans 12.68%. • African Americans perceived being unsure of who to go see or where to go as a barrier 76.06% significantly more than European Americans 50.00%. • African Americans perceived being treated unfairly because of race or ethnicity as a barrier 22.54% in a way that trended toward significantly more than European Americans 7.41%. • People who have had treatment before tended to have a higher income. • Significant correlations between: o Cost of treatment ▪ Age ▪ Insurance coverage ▪ Ethnic belonging o Stigma and judgement ▪ Gender ▪ Education level o Clinician unable to help ▪ Age ▪ Education level ▪ Ethnic belonging o Too busy for treatment ▪ Age ▪ Income • Those without any insurance were significantly more likely to be concerned about the cost of treatment than their poorer State/Federal or wealthier private insurance plan counterparts. • Stigmatising and negatives beliefs about mental health experienced by women more than men. • Serious concerns about treatment effectiveness: o Treatment will fail to meet expectations. o Lose interest in following through. • Lower sense of ethnic affirmation and belonging significantly correlated with belief that clinician would be unable to help. • No need for treatment as symptoms does not interfere with life. • Half participants unaware of having OCD. • Younger and lower income participants = too busy for treatment.
Poyraz et al., 2015	• DUI > 4 years = older. • DUI > 4 years = early onset (<12 years) • Potential barriers to treatment: o Not being considerably disturbed by OC symptoms = 33.3% o Family support for overcoming symptoms = 12.5% o Logistic or financial factors = 12.5%

	o Belief that OC symptoms are not associated with an illness = 60.4% o Belief that one could manage or handle symptoms on own = 55.2% o Possibility of using medication = 24% o Not comfortable discussing OCD related symptoms with the psychiatrist = 8.3% o Ashamed of symptoms and needing help = 21.9% o Spontaneous fluctuation of symptoms = 61.5% o Feeling depressed/hopeless = 15.6% o Preferring to go to a neurologist/psychologist or spiritual healer = 15.6% o Afraid to have a diagnosis of mental illness = 12.5% o Not starting treatment even after seeing a psychiatrist = 6.3% o Thinking that symptoms are related to religious problems/being a sinner = 15.6% o Perception that treatment will be ineffective = 14.6% o Thinking that symptoms are necessary in order to be tidy/orderly 17.7% • Believing that OCD symptoms were not an illness significantly associated with longer DUI (p = .039). • DUI not significantly associated with disturbed by OCD (p = .065). • DUI significantly shorter when a faster onset due to a major precipitating condition (trauma, postpartum depression, major depression, bereavement) (p = .002).
Marques et al., 2010	• Logistic and financial barriers o I was worried about how much it would cost – 57.1% o I was unsure about who to see or where to go – 50.4% o Health insurance would not cover treatment – 37.8% o I thought it would be too inconvenient or take too much time – 31% o I could not get an appointment – 16.2% • Stigma, shame, and discrimination barriers o I felt ashamed of needing help for my problems – 58.2% o I wanted to handle it on my own – 54.2% o I felt ashamed of my problems – 53.2% o I worried about what people would think if they knew I was in treatment – 39.3% o I was afraid of being criticised by my family if I sought psychiatric help – 38.6% • Treatment perception and satisfaction barriers o I didn't think treatment would work – 48.9% o I received treatment before and it didn't work – 41.6% o I was not satisfied with the services that were available – 30.7%
Perris et al., 2021	• DUI significantly associated with: o Unemployment. o Earlier onset. o Greater severity of OCD symptoms. • Hoarding OCD = longer DUI.
Hathorn et al., 2021	• Facilitator o Perceived treatment benefits significantly predict help-seeking intention (*B* = 1.37, t = 5.16, p = <.001)

	o Age, gender, education, symptom severity, self-efficacy, and treatment barriers did not predict help-seeking intention. • Barriers o Wanting to solve the problem on my own – 62% o Feeling embarrassed or ashamed – 30% o Not being able to afford the financial costs involved = 40% o Concerns about the treatments available (e.g., medication side effects) – 46%
Goodwin et al., 2002	• Received treatment more likely to: o Be older. o Be female. o Be Caucasian. o Be divorced/separated. o Have comorbid PD (most significant), GAD, or PTSD. • No correlation between gender or education with treatment. • No difference in prevalence of major depression or suicidal ideation in treatment/non-treatment. • Employment status did not have an effect. • Perceived need (readiness for treatment and interference of anxiety symptoms in daily life) significantly predicted treatment. • Younger age was the only socio-demographic factor that increased likelihood of being ready to seek help. • Higher education predicts readiness for treatment. • Barriers: o Not being sure of where to go – 39.8% o Can handle it on own – 28.4% o Can't afford treatment – 24.9% o Afraid what others would think – 20.5% o No insurance – 16.7% o Afraid to take medication – 14.7% o Treatment won't help – 5.7% o Don't have an anxiety disorder – 4.5%
Angst et al., 2005	• More severe the comorbidity among adults with OCS, the more likely it was that they had a positive family history of OCD. • Those with comorbid OCS were more severely affected than adults with pure OCS with 2-3 times increased likelihood of lifetime treatment, significantly higher overall distress, 10 times higher suicidality. • Higher treatment rates in OCS and BP than OCS pure or anxiety.
Mancebo et al., 2011	• 31/120 (26%) failed to initiate CBT after being recommended. • Endorsed reason did not initiate: o Environmental barriers - 69.3% ▪ CBT not available – 10.2% ▪ Could not afford CBT cost – 24.4% ▪ Health insurance did not cover CBT – 32.6% ▪ Too busy or treatment inconvenient – 40.8% o Perceived utility of CBT – 32.6% ▪ CBT not helpful in the past – 8.1% ▪ Did not think CBT would work for my OCD – 18.3% ▪ CBT would not teach me anything new – 12.2%

	o Too anxious or fearful to participate in CBT – 30.6% o Beliefs regarding severity of illness – 30.6% ▪ OCD not severe enough to justify CBT – 14.2% ▪ OCD was too severe to participate in CBT – 16.3% o Relationship with clinician – 12.2% ▪ Did not think CBT provider was good – 4.0% ▪ OCD symptoms too personal to discuss – 8.1% o Stigma/confidentiality – 8.1% ▪ Did not want a “record” of treatment for OCD – 4.0% ▪ Worried about stigma of mental illness – 6.1% ▪ Embarrassed others would find out – 6.1% o Other reasons – 10.2% • Endorsed reason dropped out of CBT: o Environmental barriers – 53.5% ▪ CBT not available – 0% ▪ Could not afford CBT cost – 17.8% ▪ Health insurance did not cover CBT – 7.1% ▪ Too busy or treatment inconvenient – 42.8% o Perceived utility of CBT – 32.1% ▪ CBT not helpful in the past – 3.5% ▪ Did not think CBT would work for my OCD – 17.8% ▪ CBT would not teach me anything new – 14.2% o Too anxious or fearful to participate in CBT – 28.5% o Beliefs regarding severity of illness – 10.7% ▪ OCD not severe enough to justify CBT – 7.1% ▪ OCD was too severe to participate in CBT – 3.5% o Relationship with clinician – 7.1% ▪ Did not think CBT provider was good – 3.5% ▪ OCD symptoms too personal to discuss – 3.5% o Stigma/confidentiality – 3.5% ▪ Did not want a “record” of treatment for OCD – 0% ▪ Worried about stigma of mental illness – 3.5% ▪ Embarrassed others would find out – 0% o Other reasons – 14.2% • Increased OCD severity predicted likelihood of initiating CBT (x^2 = 11.27, p = .023) (every 1-point increase on Y-BOCS, 10% increase likelihood in initiating CBT) • Age, gender, education, OCD duration, Modified Hamilton Rating Scale for Depression, comorbidity, CBT history did not significantly impact likelihood to be recommended or initiate CBT.
Demet et al., 2010	• Correlation between increasing level of parental education and reducing duration to seek treatment – insignificant. • BDI, YBOCS, and total number of obsessions and compulsions – insignificant. • Sex, level of education, place of birth, integreity of family, number of children, origin of patients, presence of comorbidity, types of obsessions (aggression, contamination, doubting, sexual religious, symmetry, somatic) and compulsions (repetitive rituals, checking, washing/cleaning, counting, ordering, hoarding, misc) were statistically insignificant in delaying treatment.

	• Moderate income had 3.12-fold higher risk of delaying treatment seeking than high income. • Single/divorced had 2.29-fold higher risk for delaying treatment seeking than married. • Psychiatric history = 3 times higher risk than no psychiatric history for delaying treatment seeking. • Poor insight for symptoms had 2.13-fold higher risk for delaying treatment seeking than good level of insight. • Hoarding obsessions, a factor in applying for treatment early. • Motivation and misc obsessions were statistically near significant for extended application for treatment. • Regression model – psychiatric history a strong predictor for early application for treatment. • Regression model – duration of OCD a factor for delaying treatment (increase of each year of duration, delayed further).
Okasha et al., 2021	• Statistically significant relationship between lower education and increased tendency to seek advice from traditional healers. • Age, sex, religion, occupation, marital state, or residency showed no significance. • Statistically significant relationship between presence of sexual obsessions and religious obsessions with higher tendency to seek advice at traditional healer. • Other obsessions (aggressive, contamination, hoarding, symmetry and exactness, somatic) and compulsions (cleaning, checking, repeating, counting, ordering, and hoarding) non-significant. • Went to traditional healer: o Stigma of seeking psychiatric advice – 89.2% o Considered disease related to magic or superstitions – 45.9% o Considered disease related to religion – 81.1% o Consider religious commitment to help treatment – 75.7% • Did not go to traditional healer: o Stigma of seeking psychiatric advice – 50.0% o Considered disease related to magic or superstitions – 0.0% o Considered disease related to religion – 1.8% o Consider religious commitment to help treatment – 17.9% • Statistically significant relationship between earlier in onset of symptoms visiting traditional healers.
del Valle et al., 2017	• Reasons for recognising the problem: o Symptom frequency increases – 59.5% o Anxiety/distress increases – 78.6% o Greater interference in daily life – 71.6% o Sadness increases – 50.0% o Disturbing behaviour changes – 59.5% o Symptoms' uncontrollability – 75.3% o Someone said it wasn't normal – 35.1% • Barriers to helps seeking: o Shame – 50.9% o Low disturbance by symptoms – 16.2% o Guilt about the symptoms – 20.6%

	o Low frequency of symptoms – 8.8% o Thought-action fusion beliefs – 5.5% o Give little importance to symptoms – 45.5.% o Fear of being considered crazy – 43.6% o Low interference by symptoms – 17.3% o Can keep symptoms under control – 54.5% o Pleasant sensations – 0.0% o Fear to treat – 11.8% o The thought “the symptoms will not last” – 63.5% o Fear of social rejection – 29.4% o Mistrust in health professionals – 11.8% o Nobody to trust – 5.9% o Don’t know who to tell – 14.7% o Thought that “it’s not dangerous” – 39.1% o Thought that “it’s common” (or usual) – 4.5% • Motivators of help seeking: o Frequency of symptoms increases – 68.6% o Anxiety – 81.4% o Interference in daily life – 71.4% o Thought-action fusion – 45.7% o It didn’t go away – 71.4% o Fear of being crazy – 47.7% o Out of control – 77.1% o Being a bad person – 18.6% o Sadness – 57.1% o My health is in danger – 30.0% o Fear of the symptoms increasing – 62.5% o Someone tells me to get help – 40.6% o Thought that it was something bad – 43.5% o Fear – 59.6% o It had control over my life – 62.1%
Beşiroğlu et al., 2004	• No significant difference between HCS and NHCS in age, gender marital status, educational level, or economically active/inactive. • NHCS duration of illness significantly longer than HCS. • NHCS scored significantly lower on YBOCS. • NHCS significantly higher insight. • No significant difference in age of onset, YBOCS compulsion subscale, or number of obsessions/compulsions. • HCS significantly more aggressive and religious obsessions. • Compulsions frequency no significant difference. • Subjects with comorbid disorders significantly less frequent in the NHCS. • MDD only significant difference between groups. • NHCS higher on all QoL domains. • Difference in psychological health and level of independence significantly different. • No differences in physical health, social relationships, environment, spiritual, and social pressure domains, or health and social care (accessibility and quality), physical safety and security, home environment, financial resources, opportunities for acquiring new information and skills, participation in and

	opportunities for recreation/leisure, physical environment (pollution/noise/traffic/climate) and transport. • Degree of insight and level of independence significantly associated with health care seeking behaviour. • Sex, total Y-BOCS score, psychological health, social relationships scores, presence of aggressive, religious obsessions, and comorbid diagnosis were not significant predictors of health care seeking behaviour.
Belloch et al., 2009	• How did you realise you had a problem? o I couldn’t control (my behaviour and/or thoughts) – 84.6% o It interrupted what I was doing – 80.8% o I felt sad – 65.4% o I noticed changes in my behaviour – 61.5% o Someone told me that my behaviours (and/or concerns) were unusual or strange – 23.1% o I have information about my disorder – 3.8% • Why did you delay in seeking treatment for your problem? o I was convinced that the problem was temporary (it would pass over the time) – 50.0% o I felt I could control the problem – 34.6% o I believed my behaviours and/or thoughts were not serious – 34.6% o I felt ashamed by the thought contents – 34.6% o I feared being considered a mentally ill person – 30.8% o I thought it was not a problem requiring professional help or treatment – 23.1% o I was afraid (of the thought contents) – 19.2% o The problem did not interfere in my daily activities – 7.69% o I was afraid someone would tell me I was a bad person for having these thoughts – 3.8% o I feared that if I disclosed the thoughts to someone, the thoughts could come true – 3.8% • Why did you seek treatment for your problem? o The problem didn’t disappear, I couldn’t control it – 77.0% o The problem (thoughts and/or behaviours) interfered with what I was doing –77.0% o The problem (thoughts and/or behaviours) became more and more disturbing – 73.1% o The problem (thoughts and/or behaviours) became more frequent – 65.4% o I felt sad – 65.4% o I was afraid of what was happening to me – 57.7% o I believed that my thoughts could come true – 57.7% o I thought I had a serious problem (an illness) – 46.2% o Someone advised me to seek treatment – 38.5% o I thought I was a bad person for having these thoughts – 30.8% • The most frequently selected answers to the question about the reasons for seeking help can be clustered in four types: the interference caused by the disorder was too high; mood changes (dysphoria); dysfunctional beliefs attached to the thoughts; and having increasing insight about the illness basis of the problem.

	• Significant relationship between early age of OCD onset and delay in help-seeking and worse insight. • Short delay in help seeking group had more insight, experienced symptoms as interfering more in daily activities, and aware of changes in their behaviour caused by symptoms. • Long delay in help seeking group more frequently reported feeling ashamed, and feared stigma associated with mental disorder. • No differences between long and short delay groups on reasons for seeking treatment. • Short delay group had lower educational level. • No difference in other sociodemographic data in short and long delay groups. • Delay in help seeking was related to social control and reappraisal on thought control measure.
Torres et al., 2007	• OCD and comorbid disorder significantly more likely to receive treatment. • Self-help/support groups used more by OCD without comorbidity. • No difference between obsessions only, compulsions only, or obsessions and compulsions in treatment received. • No significant differences in sociodemographic factors. • Comorbidity with other neurotic disorders, overall severity of psychological comorbidity, and having experienced suicidal thoughts were all strongly associated with being in treatment.
Mayerovitch et al., 2003	• Those with severe obsessions of violence and other unpleasant thoughts were significantly more likely to seek treatment. • Those with obsessions only and obsessions and compulsions were significantly more likely to seek treatment than compulsions only. • Seeking treatment group were significantly more likely to have comorbid depression, mania, panic, GAD, or PTSD. • Severe obsessions of violence and other unpleasant thoughts and total number of OCD symptoms were only significant treatment seeking variables in multivariate analysis.

Appendix D

Journal of Clinical Psychology Publication Guidelines

1. Submission and Peer Review Process

New submissions should be made via the **Research Exchange submission portal**. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the “My Submissions” button. For technical help with the submission system, please review our **FAQs** or contact **submissionhelp@wiley.com**.

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- The title page of the manuscript, including statements relating to our ethics and integrity policies (see information on these policies below in Section 1):
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- funding statement
- conflict of interest disclosure
- ethics approval statement
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- Acknowledgments;
- Abstract structured (objective(s)/methods/results/conclusion)
- Up to six keywords;
- Main body:
    1. regular section formatted as introduction, materials & methods, results, discussion, conclusion
    2. In Session (invitation only) formatted as introduction, Case Illustration (including separate sections on Presenting Problem & Client Description, Case Formulation, Course of Treatment, Outcome and Prognosis), Clinical Practices and Summary, and Selected References & Recommended Readings
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Appendix E

Trauma and Life Events Checklist

Part A. TALE Checklist

(Trauma And Life Events Checklist, Carr, Hardy & Fornells-Ambrojo, 2018)

This checklist includes a list of common traumatic or stressful life events. We would like to know whether or not you have ever experienced these events and, if so, which has the most impact on you now. If you choose to answer, please just indicate which events you experienced, if they happened more than once, and how old you were when they happened. Thank you.

Have you ever experienced…? (Please see brackets for some examples)	**Yes (✓) or No (×)**	**More than once? Yes (✓)/ No (×)**	**Age(s) -** range if repeated
1. Exposure to war, either in the military or as a civilian? (e.g. combat, ongoing civil unrest, torture, becoming a refugee or political prisoner)			
2. Loss of, or permanent separation from someone close to you such as a parent or caregiver? (e.g. due to death, being placed in care, conflict, divorce)			
3. A period of separation from someone close to you such as a parent or caregiver? (e.g. due to being placed in care, illness, conflict, divorce)			
4. Sudden or unexpected move or change in circumstances? (e.g. changing school, loss of home)			
5. Bullying or harassment at school, work or on the street? (e.g. people saying hurtful things, hitting or shoving)			
6. Discrimination at school, work or on the street? (e.g. being ignored or treated differently)			
7. Someone close to you insulting you, putting you down or humiliating you? (e.g. someone you live with / partner / family member/ caregiver)			
8. Someone close to you being physically violent or aggressive towards you? (e.g. parent / partner, hitting / kicking / throwing things)			
9. Witnessing physical violence or verbal aggression in your home? (e.g. parents fighting, seeing siblings being beaten or hurt)			
10. Someone you did not know being physically violent or aggressive towards you? (e.g. mugging, assault, fight)			
11. Feeling unsafe, unloved or unimportant during childhood? (e.g. no one to look out for you)			
12. Going hungry or thirsty, not having clean clothes or a safe place to stay during childhood?			
13. Someone having any sexual contact with you, before your 16th birthday, that either at the time or looking back on it now was unwanted? (e.g. talking, looking, touching, penetration)			
14. Someone having any sexual contact with you, since your 16th birthday, that either at the time or looking back on it now was unwanted? (e.g. talking, looking, touching, penetration)			
15. Unusual experiences, such as hearing voices, seeing visions or having worries about other people causing you harm, that made you feel in danger or distress?			
16. Acting in ways that put you or someone else in danger or were strange or embarrassing? (e.g. wandering the streets at night, violence, risky sexual behaviours)			
17. Contact with mental health services (e.g. being admitted to hospital) that involved threatening or upsetting events? (e.g. being restrained, coerced, secluded, assaulted, forced to take medicine, or witnessing such events)			
18. Any other contact with health or criminal justice services which was upsetting or frightening?			
19. Any other events that were accidental or did not involve people intending to cause you harm? (e.g. serious illness, accidents, fire, natural disaster)			
20. Apart from the above, has anything else happened in your life that you found distressing? Please specify:			
21a. Do any of the events you have mentioned, that ended at least 1 month ago, still affect you now? 21b. Which event or events currently affect you most? Event number(s):		Yes / No	
21c. Overall, how much are you affected now by the event or events select in 21b (from 0 = not at all to 10 = extremely)?			

Carr, Hardy & Fornells-Ambrojo (2018) The Trauma and Life Events (TALE) checklist: Development of a tool for improving routine screening in people with psychosis; *European Journal of Psychotraumatology*

Appendix F

Auditory Vocal Hallucination Rating Scale Questionnaire

AVHRS-Q ─ A self-report questionnaire about hearing voices

Gender*: **M / F**

Date of Birth: ________________

Today's Date: ________________

**please circle the correct answer*

The AVHRS-Q (Van de Willige G, Bartels-Velthuis AA and Jenner JA, 2010) is the self-report version of an interview about hearing voices, the Auditory Vocal Hallucination Rating Scale (AVHRS; Jenner JA and Van de Willige G, 2002). Translation into English: B.D. Ostafin, L.A. Steenhuis and A.A. Bartels-Velthuis (2017).

In this questionnaire you will be asked about the experiences you have had with hearing voices. Your answers should reflect your ***average*** experiences in the **past month**. Please select the answer that is most applicable to you. For each question only one answer should be selected.

---

(1) In the past month, did you always hear just one voice or did you sometimes hear more than one voice?

☐ always just one voice
☐ more than one voice: number of different voices = ...

In case you always heard just one voice in the past month, you can skip question 2.

(2) When you heard more than one voice, were these voices speaking separately (one at a time) or together at the same time?

☐ the voices were always speaking separately (one by one)
☐ the voices were speaking *both* separately *and* together at the same time
☐ the voices were always speaking together at the same time

The next questions are written in the form of hearing more than one voice. In case you hear just one voice, please answer the questions about that one voice.

(3) How often do you hear voices?

☐ not more than once in the past month
☐ about once a week
☐ about once a day
☐ about once an hour
☐ more than once an hour

(4) How long do the voices generally persist?

☐ briefly, only a few seconds
☐ a few minutes
☐ more than a few minutes to about 15 minutes
☐ 15 minutes to about an hour
☐ more than one hour to (almost) constantly

(5) When do you hear the voices?

☐ only when falling asleep (when I am almost asleep)
☐ only when waking up (when I am not yet fully awake)
☐ both when falling asleep and when waking up, but not at other times ☐ the voices occur at all times of the day

(6) Do the voices seem to come from inside your head or from outside your head?

☐ usually from inside my head
☐ usually both from inside my head and from the outside environment
☐ usually from the outside environment, in the immediate vicinity ☐ usually from the outside environment, from further away

(7) Do the voices speak to you or about you? Or do they usually say what you are thinking?

☐ the voices usually are saying what I am thinking
☐ the voices usually are speaking to me
☐ the voices are both speaking to me and about me
☐ the voices usually are speaking about me or commenting on what I am doing

(8) How loud are the voices?

☐ usually a soft whispering or murmuring
☐ usually louder than a soft whisper but more quiet than my own voice
☐ usually about as loud as my own voice
☐ usually noticeably louder than my own voice
☐ usually much louder than my own voice (also yelling, shouting or screaming)

(9) Are the voices positive or negative?

☐ always positive
☐ mostly positive, but occasionally negative, unpleasant or annoying
☐ mostly neutral or equally positive and negative
☐ mostly negative, unpleasant or annoying
☐ always negative, unpleasant or annoying

When you have selected ‘always positive’ for this question, you can skip question 10 and move to question 11.

(10) How unpleasant are the negative things that the voices are saying?

☐ the voice are unpleasant indeed, but they do not say negative things about myself or others
☐ the voices mostly say negative things about what I am *doing* (or what others are doing)
☐ the voices mostly say negative things about what or how I *am* (or how others are) ☐ the voices are threatening me or are giving commands to hurt myself or others

(11) Do the voices make you feel anxious or frightened at times?

☐ never
☐ occasionally
☐ about half of the time
☐ most of the time
☐ all of the time (or sometimes I completely panic because of the voices)

(12) Do the voices interfere with your daily life? Do they disturb or hinder the daily routine?

☐ never
☐ occasionally
☐ about half of the time
☐ most of the time
☐ all of the time

(13) Do the voices control or interfere with your thoughts, so that you cannot think well or clearly?

☐ never
☐ occasionally
☐ about half of the time
☐ most of the time
☐ all of the time

(14) Do you feel that you can manage your voices? Do you have them under control? For example, can you evoke them or make them disappear?

☐ I always have control over my voices
☐ I have control over my voices most of the time
☐ I have control over my voices about half of the time
☐ I do not have control over my voices most of the time
☐ I never have control over my voices

(15) What do you think is the cause of your voices?

Are they caused by things that concern you (for example your own thoughts, feelings or distress) or are they caused by outside influences (for example other people, computers, ghosts or extraterrestrial beings)?

- ☐ the voices only concern myself
- ☐ the voices mostly concern myself
- ☐ the voices equally concern myself as much as they are caused by outside influences
- ☐ the voices are mostly caused by outside influences
- ☐ the voices are fully caused by outside influences

(16) Please indicate on the scale (ranging from 1 to 10) how *often* you were bothered by the voices in the past month; '1' means 'never' and '10' means 'always'.

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

never……………………………………………………………………………………always

(17) Please indicate on the scale (ranging from 1 to 10) how *severely* or how *much* you suffered from the voices in the past month; '1' means 'not at all' and '10' means 'extremely'.

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

not at all…………………………………………………………………………extremely

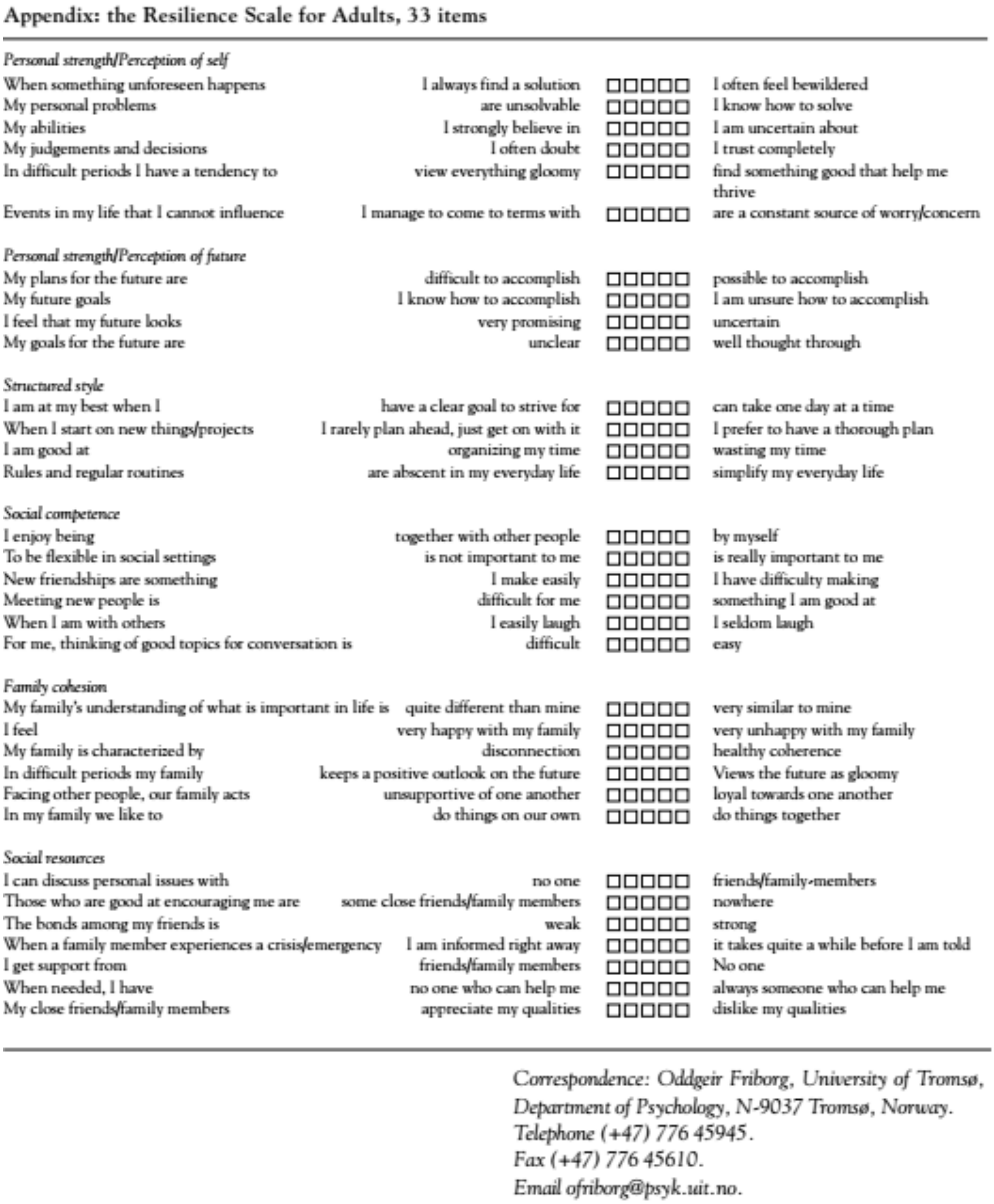
Finally:

When was the first time you heard one or more voices?

Number = ... **months / years ago** *(please circle the answer that is applicable)*

Appendix G

Resilience Scale for Adults



Appendix: the Resilience Scale for Adults, 33 items

Personal strength/Perception of self			
When something unforeseen happens	I always find a solution	☐☐☐☐☐	I often feel bewildered
My personal problems	are unsolvable	☐☐☐☐☐	I know how to solve
My abilities	I strongly believe in	☐☐☐☐☐	I am uncertain about
My judgements and decisions	I often doubt	☐☐☐☐☐	I trust completely
In difficult periods I have a tendency to	view everything gloomy	☐☐☐☐☐	find something good that help me thrive
Events in my life that I cannot influence	I manage to come to terms with	☐☐☐☐☐	are a constant source of worry/concern
Personal strength/Perception of future			
My plans for the future are	difficult to accomplish	☐☐☐☐☐	possible to accomplish
My future goals	I know how to accomplish	☐☐☐☐☐	I am unsure how to accomplish
I feel that my future looks	very promising	☐☐☐☐☐	uncertain
My goals for the future are	unclear	☐☐☐☐☐	well thought through
Structured style			
I am at my best when I	have a clear goal to strive for	☐☐☐☐☐	can take one day at a time
When I start on new things/projects	I rarely plan ahead, just get on with it	☐☐☐☐☐	I prefer to have a thorough plan
I am good at	organizing my time	☐☐☐☐☐	wasting my time
Rules and regular routines	are abscent in my everyday life	☐☐☐☐☐	simplify my everyday life
Social competence			
I enjoy being	together with other people	☐☐☐☐☐	by myself
To be flexible in social settings	is not important to me	☐☐☐☐☐	is really important to me
New friendships are something	I make easily	☐☐☐☐☐	I have difficulty making
Meeting new people is	difficult for me	☐☐☐☐☐	something I am good at
When I am with others	I easily laugh	☐☐☐☐☐	I seldom laugh
For me, thinking of good topics for conversation is	difficult	☐☐☐☐☐	easy
Family cohesion			
My family's understanding of what is important in life is	quite different than mine	☐☐☐☐☐	very similar to mine
I feel	very happy with my family	☐☐☐☐☐	very unhappy with my family
My family is characterized by	disconnection	☐☐☐☐☐	healthy coherence
In difficult periods my family	keeps a positive outlook on the future	☐☐☐☐☐	Views the future as gloomy
Facing other people, our family acts	unsupportive of one another	☐☐☐☐☐	loyal towards one another
In my family we like to	do things on our own	☐☐☐☐☐	do things together
Social resources			
I can discuss personal issues with	no one	☐☐☐☐☐	friends/family-members
Those who are good at encouraging me are	some close friends/family members	☐☐☐☐☐	nowhere
The bonds among my friends is	weak	☐☐☐☐☐	strong
When a family member experiences a crisis/emergency	I am informed right away	☐☐☐☐☐	it takes quite a while before I am told
I get support from	friends/family members	☐☐☐☐☐	No one
When needed, I have	no one who can help me	☐☐☐☐☐	always someone who can help me
My close friends/family members	appreciate my qualities	☐☐☐☐☐	dislike my qualities

Correspondence: Oddgeir Friborg, University of Tromsø,
Department of Psychology, N-9037 Tromsø, Norway.
Telephone (+47) 776 45945.
Fax (+47) 776 45610.
Email ofriborg@psyk.uit.no.

Appendix H

Comprehensive Assessment of Acceptance and Commitment Therapy

CompACT

Name:

Date:

Please rate the following 23 statements using the scale below:

0	**1**	**2**	**3**	**4**	**5**	**6**
Strongly disagree	Moderately disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Moderately agree	Strongly agree

1. I can identify the things that really matter to me in life and pursue them	0	1	2	3	4	5	6
2. One of my big goals is to be free from painful emotions	0	1	2	3	4	5	6
3. I rush through meaningful activities without being really attentive to them	0	1	2	3	4	5	6
4. I try to stay busy to keep thoughts or feelings from coming	0	1	2	3	4	5	6
5. I act in ways that are consistent with how I wish to live my life	0	1	2	3	4	5	6
6. I get so caught up in my thoughts that I am unable to do the things that I most want to do	0	1	2	3	4	5	6
7. I make choices based on what is important to me, even if it is stressful	0	1	2	3	4	5	6
8. I tell myself that I shouldn’t have certain thoughts	0	1	2	3	4	5	6
9. I find it difficult to stay focused on what’s happening in the present	0	1	2	3	4	5	6
10. I behave in line with my personal values	0	1	2	3	4	5	6
11. I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations	0	1	2	3	4	5	6
12. Even when doing the things that matter to me, I find myself doing them without paying attention	0	1	2	3	4	5	6
13. I am willing to fully experience whatever thoughts, feelings and sensations come up for me, without trying to change or defend against them	0	1	2	3	4	5	6
14. I undertake things that are meaningful to me, even when I find it hard to do so	0	1	2	3	4	5	6
15. I work hard to keep out upsetting feelings	0	1	2	3	4	5	6
16. I do jobs or tasks automatically, without being aware of what I'm doing	0	1	2	3	4	5	6
17. I am able to follow my long-term plans including times when progress is slow	0	1	2	3	4	5	6
18. Even when something is important to me, I’ll rarely do it if there is a chance it will upset me	0	1	2	3	4	5	6
19. It seems I am "running on automatic" without much awareness of what I'm doing	0	1	2	3	4	5	6
20. Thoughts are just thoughts – they don’t control what I do	0	1	2	3	4	5	6
21. My values are really reflected in my behaviour	0	1	2	3	4	5	6
22. I can take thoughts and feelings as they come, without attempting to control or avoid them	0	1	2	3	4	5	6
23. I can keep going with something when it’s important to me	0	1	2	3	4	5	6

Scoring instructions (administrative use only)

- Scores are derived by summing responses for each of the three subscales (Openness to Experience; Behavioral Awareness; Valued Action) or the scale as a whole (CompACT Total score).
- Twelve items are reverse-scored before summation (items 2, 3, 4, 6, 8, 9, 11, 12, 15, 16, 18, and 19).

Openness to Experience (OE) subscale

Calculated as the sum of scores for items: 2 (reversed), 4 (reversed), 6 (reversed), 8 (reversed), 11 (reversed), 13, 15 (reversed), 18 (reversed), 20, and 22.

Subscale scores range from 0-60, with higher scores indicating greater openness to experience (willingness to experience internal events [thoughts, feelings, sensations, etc.] without trying to control or avoid them)

Behavioral Awareness (BA) subscale

Calculated as the sum of scores for items: 3 (reversed), 9 (reversed), 12 (reversed), 16 (reversed), and 19 (reversed).

Subscale scores range from 0-30 with higher scores indicating greater behavioral awareness (mindful attention to current actions)

Valued Action (VA) subscale

Calculated as the sum of scores for items: 1, 5, 7, 10, 14, 17, 21, and 23.

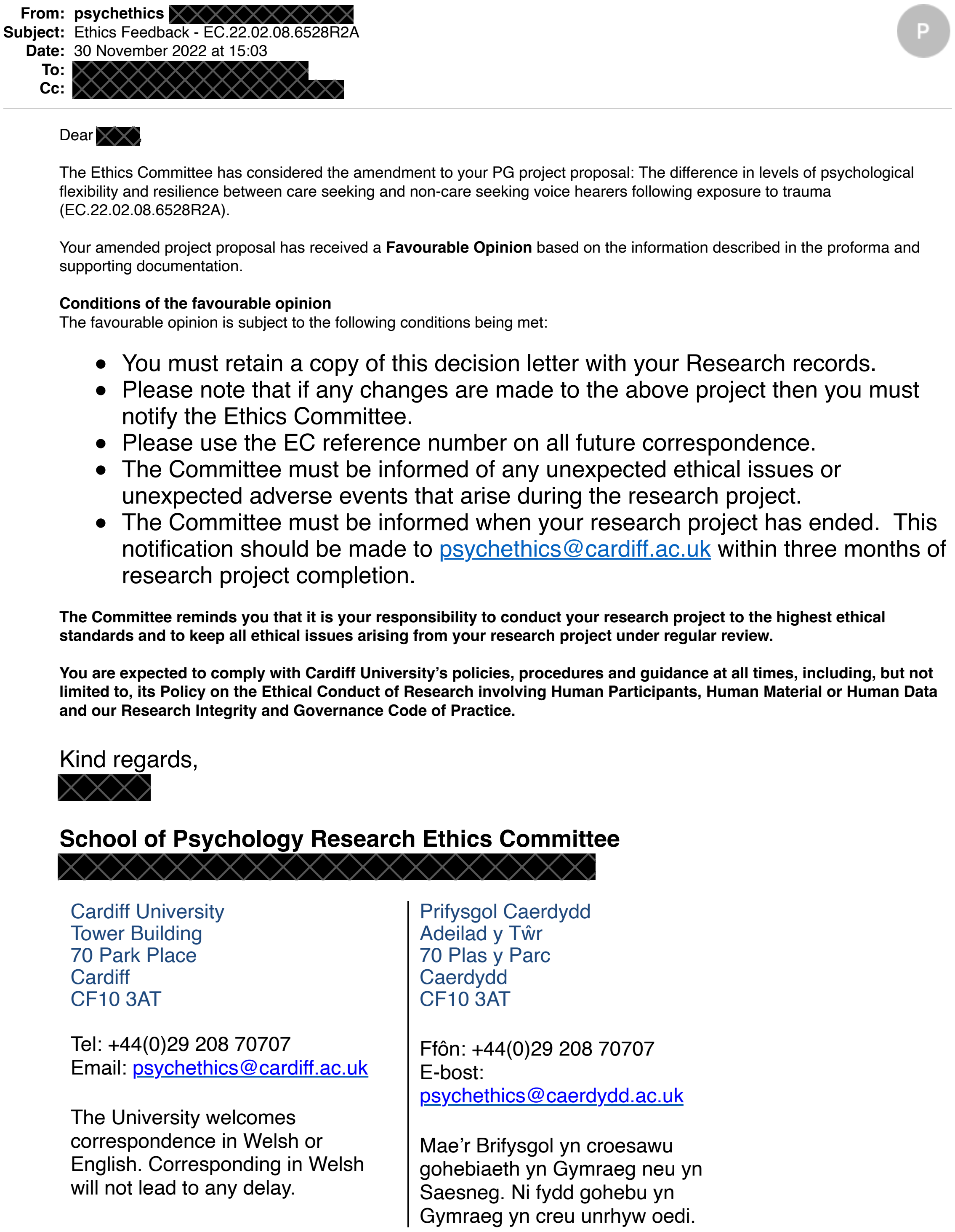
Subscale scores range from 0-48 with higher scores indicating greater engagement in valued actions (meaningful activity)

CompACT Total

Calculated as the sum of the three subscale scores, the full-scale CompACT Total score ranges from 0-138, with higher scores indicating greater psychological flexibility.

Appendix I

Letter of Ethical Approval



From: psychethics [redacted]
Subject: Ethics Feedback - EC.22.02.08.6528R2A
Date: 30 November 2022 at 15:03
To: [redacted]
Cc: [redacted]

Dear [redacted]

The Ethics Committee has considered the amendment to your PG project proposal: The difference in levels of psychological flexibility and resilience between care seeking and non-care seeking voice hearers following exposure to trauma (EC.22.02.08.6528R2A).

Your amended project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,
[redacted]

School of Psychology Research Ethics Committee
[redacted]

Cardiff University
Tower Building
70 Park Place
Cardiff
CF10 3AT

Tel: +44(0)29 208 70707
Email: psychethics@cardiff.ac.uk

The University welcomes correspondence in Welsh or English. Corresponding in Welsh will not lead to any delay.

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd
CF10 3AT

Ffôn: +44(0)29 208 70707
E-bost:
psychethics@caerdydd.ac.uk

Mae'r Brifysgol yn croesawu gohebiaeth yn Gymraeg neu yn Saesneg. Ni fydd gohebu yn Gymraeg yn creu unrhyw oedi.

Appendix J

Support and Self-Care Document

Self-Care and Support

It can be common for people to experience some big emotions when asked to think or talk about challenging times in their lives. These feelings can be difficult to manage and may feel uncomfortable. If you find yourself in this situation, we encourage you to use your existing coping strategies. Also, some people find that their voices increase in intensity temporarily when they think or talk about hearing voices, and this may cause you distress. You can cope with this temporary increase by using your usual coping strategies. If you find your current strategies are not working or you would like some additional ideas/support, there is a list of self-care ideas and signposting options.

Immediate Contact Details

If you feel that you need someone to talk to immediately then please contact your GP to discuss any concerns with your mental wellbeing and they will be able to refer you for psychological therapy or may provide medications to help manage your distress. If you are concerned that the distress your experiencing may require urgent support and you are unsure if you are able to keep yourself safe, then please contact **999** or visit your local **Accident and Emergency department.**

Additionally, you could contact any of the following services who are available to contact 24 hours a day, 365 days a year:

- Samaritans: UK wide charity that is available as a listening service available 24 hours a day, 365 days a year.
    - Telephone: 116 123
    - Email: jo@samaritans.org
    - Website: https://www.samaritans.org
- Community Advice and Listening Line (C.A.L.L.) Helpline: Wales only helpline offering emotional support and information and mental health and related matters available 24/7, 365 days a year.
    - Telephone: 0800 132 737
    - Text: 81066
    - Website: https://www.callhelpline.org.uk/
- National Suicide Prevention Helpline: UK wide helpline that offers a supporting listening service to anyone with thoughts of suicide open 24/7.
    - Telephone: 0800 689 5652
    - Website: https://www.spbristol.org/NSPHUK

Self-Care

- Eat nutrient rich food that you enjoy, and that you might like to cook yourself.
- Drink plenty of water and make yourself your favourite hot drink like tea or hot chocolate.
- Make sure you are getting enough sleep by creating a comfortable sleep environment.
- Go for a walk outside into fresh air and maybe try some exercise.
- Read your favourite books, stories or poems.

- Try drawing your thoughts and feelings.
- Listen to your favourite music, podcast, or audio book.
- Take a bath or a long shower.
- Play your favourite video game or board game.
- Watch your favourite tv show, movie, online videos etc.
- Look through photographs of happy memories.
- Use some breathing exercises (see below for links to guided breathing exercises).
- Use some grounding exercises such as hugging yourself, massaging your hands, feeling different textures etc. (see below for links to grounding exercises).
- Contact your friends, family, or someone you care about.
- Join an online support group.

Additional Links

- General Support/Advice: https://www.mind.org.uk/information-support/tips-for-everyday-living/
- General Support/Advice: https://111.wales.nhs.uk/encyclopaedia/m/article/mentalhealthandwellbeing
- Mental Health Support/Advice: https://www.mentalhealth.org.uk/your-mental-health/looking-after-your-mental-health
- Mental Health Support/Advice: https://www.getselfhelp.co.uk/
- Support for Hearing Voices: http://www.voicecollective.co.uk/coping/
- Sleep Support: https://www.sleepio.com
- Breathing Exercise: https://www.nhs.uk/mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress/
- Breathing Exercise: https://www.youtube.com/watch?v=tEmt1Znux58
- 1 Minute Breathing Exercise: https://www.youtube.com/watch?v=c1Ndym-IsQg
- 5 Minute Breathing Exercise: https://www.youtube.com/watch?v=nmFUDkj1Aq0
- Grounding Exercise: https://www.youtube.com/watch?v=tEmt1Znux58

Signposting

- SANEline: UK wide charity working to improve the quality of life for people affected by mental health difficulties available 4:30pm-10:30pm every day.
  - Telephone: 0300 304 700
  - Email: support@sane.org.uk
  - Website: http://www.sane.org.uk
- Campaign Against Living Miserably (CALM): UK wide charity making a stand against suicide offering a free and confidential helpline available from 5pm until midnight with an online webchat also available.
  - Telephone: 0800 58 58 58
  - Website: https://www.thecalmzone.net/
- Switchboard: UK wide support, information, and referral service for lesbian, gay, bisexual, and trans individuals and anyone considering issues around their sexuality and/or gender identity available 10am-10pm every day with an online chat also available.
  - Telephone: 0300 330 0630
  - Email: chris@switchboard.lgbt
  - Website: https://switchboard.lgbt

Appendix K

Participant Information Sheet

Participant Information Sheet

TITLE: Exploring the differences in levels of psychological flexibility and resilience between care seeking and non-care seeking voice hearers following exposure to trauma.

We would like to invite you to take part in this research project (henceforth referred to as the *project)*. Before you decide whether or not to take part, we want to tell you more about the project.

Please read this Participant Information Sheet carefully as it is important that you fully understand why we are running the project and what it would involve if you decided to take part. You do not have to decide now whether you would like to take part.

If you would like to take part in the project, please complete the consent form on. Completion of the consent form will automatically submit the results to us and you will be able to access questionnaires for the project.

Title of the project

Exploring the difference in levels of psychological flexibility and resilience between care seeking and non-care seeking voice hearers following exposure to trauma.

Why have I been asked to take part?

We are asking people who have heard one or more voice, that no one else is able to hear, within the last month and people who have experienced one or more traumatic experiences in their life. If you feel that you meet these criteria, then we would like to give you more information about this project.

What is the purpose of the project?

We understand that there is a link between traumatic experiences and hearing voices, however, we would like to find out whether resilience and psychological flexibility affect the likelihood that an individual requires support for their voices.

Do I have to take part?

Your involvement in the project is completely voluntary and you will only be involved in the project after reading this information sheet, virtually signing, and completing the consent form to confirm your participation in the project. If you decide to take part, but later change your mind, you can withdraw from the project at any time, without giving any reason. All information you give will be anonymised, so if you decide that you want to withdraw from the project after completing the questionnaires, the researcher will not be able to remove any information you have given, and your data will be analysed with other participants' data.

Withdrawing after completing the consent form will not affect your entry to the prize draw or Cardiff University Experiment Management System (EMS) participation credits.

What will taking part in the project involve?
You will be asked to complete four questionnaires and a selection of demographic questions which should last no more than one hour. These questionnaires cover a range of topics including your experience of hearing voices, your experience of traumatic event(s), psychological flexibility, and resilience. The questionnaires will be available following the completion of the consent form and will be completed digitally through Qualtrics.

How will the information obtained during the project be used?
The information gathered might be used in a number of ways:

- The results of the project will be shared with staff at Cardiff University.
- The results will be written up and presented as the research aspect of the South Wales Doctorate of Clinical Psychology Course.
- It is also hoped that the results will be published in a scientific journal and presented at conferences.
- All participants will be offered the opportunity to receive a summary of the project when the results of the project are finalised.

Whilst the project does collect demographic information, please be assured that this information will not be used to identify you so you will not be identified in any report/publication related to this project.

What are the benefits of taking part?
Once you have completed the consent form, you will be placed into a prize draw to have the opportunity to win one of six Love2Shop vouchers (1 x £50 and 5 x £10 to be won). If you are an undergraduate student at Cardiff University, you will have the opportunity to opt out of the prize draw and, instead, receive EMS participation credits. To do this, you will be asked to provide your university number.

We hope that your participation in this project will help to further our understanding of hearing voices and expand the research field. Furthermore, we hope that this improved understanding will inform the development of future support or treatment options, improving the care and support provided to yourself and others in similar situations.

We hope that by taking part in this project, it will give you an opportunity to reflect on your experiences and provide you with an opportunity to share your knowledge with the wider community.

Are there any disadvantages of taking part?
Some of the questions within this project may provoke distressing thoughts or memories. The questionnaires have been selected to minimise the amount of detail and, in turn, the amount of distress caused. It is important to know that taking part in the study will involve answering questions about your experience of hearing voices. Some people find that their voices increase in intensity temporarily when they think or talk about hearing voices, and this may cause you distress. If you do become distressed while completing the questionnaires, please take the time to look after your needs and use your usual coping strategies. If you feel that

the questions are too distressing to continue, then we would like to remind you that you may withdraw at any stage.

Whilst you are completing the questionnaires, there will be a Self-Care and Signposting document available to you which provides a list of contact details and strategies that you may use to manage any distress.

If you have any questions regarding the nature of the questions and the project, the details of the lead researcher are below, however, it should be noted that they will be unable to provide any direct support.

Will my taking part in the project be confidential?
All information collected from you during the project will be kept strictly confidential and any personal data you provide will be held in accordance with data protection law (please see ‘What will happen to my personal data’ below for further information).

The answers to the individual questions will only be viewable by the research team whilst analysing the data. All data will be anonymised to protect your identity. The data will be stored in accordance with GDPR regulations and in line with Cardiff University data governance and records management policy.

As an exception, if the investigator or a member of the project team has concerns about your safety, or the safety of others, they may be legally required to override confidentiality and report this to appropriate persons. The investigator would try and discuss this with you in the first instance if appropriate to do so.

What will happen to my personal data?
Cardiff University is the sponsor for this project based in the United Kingdom. Cardiff University will be using information from you in order to undertake this project and will act as the data controller for this project. This means that the university is responsible for looking after your information and using it properly. The University is registered as a Data Controller with the Information Commissioner's Office (ICO) to process personal data for research purposes. Registration No.: Z6549747.

Under data protection law, Cardiff University must specify the legal basis that we are relying on to process your personal data. In providing your personal data for this project we will process it on the basis that doing so is necessary for our public task for scientific and historical evaluation purposes in accordance with the necessary safeguards and is in the public interest.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the results to be reliable and accurate. If you withdraw from the project, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

For more information on how the Cardiff University uses data for projects, please use the following link: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

Who has reviewed this project?
This project has been reviewed by Cardiff University Psychology Ethics who have provided approval for this service evaluation to go ahead.

Contact for further information
If you wish to obtain further information about this study, or if you have any queries, please contact Owen Lane, using the contact details below.

Raising a concern and complaints
If you wish to raise a concern, or complain about the project, please contact Owen Lane, using the contact details below.

If we cannot resolve your concerns or problems, then Cardiff University Research Ethics has a complaints procedure. Please write to:

The Secretary,
School Research Ethics Committee,
School of Psychology,
Cardiff University,
Park Place,
CF10 3AT
Email: psychethics@cardiff.ac.uk
Tel: +44 (0) 029208 70707

Thank you for taking the time to read this information sheet.

<table>
<tr><td colspan="2" align="center"><u>The Project Team</u></td></tr>
<tr><td colspan="2" align="center"><u>Principal Researcher</u>
Owen Lane
Trainee Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology, Cardiff University
laneo@cardiff.ac.uk</td></tr>
<tr><td align="center"><u>Lead Supervisor</u>
Dr Heledd Lewis
Consultant Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology, Cardiff University</td><td align="center"><u>Supplementary Supervisor</u>
Dr James Gregory
Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology, Cardiff University</td></tr>
</table>

Appendix L

Consent Form

Consent Form

TITLE: Exploring the differences in levels of psychological flexibility and resilience between care seeking and non-care seeking voice hearers following exposure to trauma.

Please read each statement and select 'Yes' to consent to take part in the project. Selecting ‘No’ on one or more of the following statements will indicate that you do not wish to take part in the project.

1. I confirm that I have read and understood the Participant Information Sheet for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at any time without giving reason. If I choose to withdraw from the study, there will be no adverse consequences.
3. I consent to completing the study questionnaire asking about my experience of hearing voices.
4. I consent to completing the study questionnaire asking about my experience of one or more traumatic events.
5. I understand that my participation is anonymous, and my responses will be recorded without any identifiable information.
6. I understand that my information and responses to the questionnaire will be stored securely.
7. I understand that the research is looking at patterns across groups of people who hear voices and I understand I will not receive any feedback on my responses.
8. I understand that the research findings will be written up into a report and this will be submitted to an academic journal to be published.
9. I agree to take part in the project titled ‘Exploring the differences in levels of psychological flexibility and resilience between care seeking and non-care seeking voice hearers following exposure to trauma’.

This tick box is used in place of a signature:

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner’s Office should you wish to complain, can be found at the following: https://intranet.cardiff.ac.uk/staff/supporting-your-work/manage-use-and-protect-data/data-protection

Appendix M

Debrief Sheet

Thank you for participating in this project. Your anonymised responses have been recorded and combined with other participants' data.

Thank you for sharing your experience hearing voices and exposure to a traumatic event. We hope that the information you shared with us today will further the understanding of voice hearing and provide pathways to develop support and treatment to support individuals with similar experiences.

Once all the data has been collected and analysed, the results will be written up and presented as part of the South Wales Doctoral Programme of Clinical Psychology. We also would like others to know about and learn from this project. Therefore, we are hoping to share these findings in the health board and beyond by presenting at conferences and publishing it in scientific journals.

The researchers involved in this project will not use the responses to the questionnaires to diagnose any mental health disorders and will use the data solely for research purposes. Therefore, you should not regard completion of the mental health questionnaire as a clinical screening procedure. If you want help for any personal issues, then please contact your GP or consider any of the options outlined in the Self-Care and Signposting document.

If you wish to raise a concern, or complain about the project, please contact Owen Lane, using the contact details below.

If we cannot resolve your concerns or problems, then Cardiff University Research Ethics has a complaints procedure. Please write to:

The Secretary,
School Research Ethics Committee,
School of Psychology,
Cardiff University,
Park Place,
CF10 3AT
Email: psychethics@cardiff.ac.uk
Tel: +44 (0) 029208 70707

The Project Team
Principal Researcher Owen Lane Trainee Clinical Psychologist South Wales Doctoral Programme in Clinical Psychology, Cardiff University laneo@cardiff.ac.uk

Lead Supervisor	**Supplementary Supervisor**
Dr Heledd Lewis Consultant Clinical Psychologist South Wales Doctoral Programme in Clinical Psychology, Cardiff University	Dr James Gregory Clinical Psychologist South Wales Doctoral Programme in Clinical Psychology, Cardiff University

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: https://intranet.cardiff.ac.uk/staff/supporting-your-work/manage-use-and-protect-data/data-protection

Appendix N

Results from *t*-tests with Cohen's *d*

	CSVH		NCSVH		Mean Δ	BCa 95% CI					
	M	*SE*	*M*	*SE*		Low	Up	*df*	*t*	*p*	*d*
TALE											
Still affecting*	2.59	.38	1.51	.18	1.08	.24	1.95	72.79	2.57	.012	.61
Distress	5.78	.44	4.00	.29	1.78	.72	2.80	147	3.46	<.001	.61
Repeated	4.90	.57	3.32	.30	1.59	.29	2.91	147	2.72	.007	.54
Total count	6.73	.67	5.16	.37	1.56	.09	3.13	147	2.24	.027	.43
AVHRS-Q											
Severity*	4.08	.53	2.03	.21	2.05	.86	3.10	66.56	3.59	<.001	.97
CompACT											
Openness to Experiences	19.71	1.19	24.33	.63	-4.62	-7.10	-1.94	147	-3.79	<.001	-.75
Behavioural Awareness	10.84	.75	14.47	.54	-3.63	-5.42	-1.81	147	-3.94	<.001	-.68
Valued Action	28.31	1.22	29.84	.91	-1.42	-4.42	1.64	147	-.92	.357	-.16
Total	60.55	1.84	70.85	1.29	-10.30	-14.72	-6.01	147	-4.63	<.001	-.81
RSA											
Self	2.58	.10	3.16	.07	-.58	-.83	-.33	147	-4.66	<.001	-.81
Future	2.98	.13	3.41	.09	-.43	-.73	-.12	147	-2.84	.005	-.51
Structured Style	3.12	.12	3.43	.08	-.31	-.60	-.01	147	-2.18	.031	-.38
Social Competence	3.05	.10	3.47	.06	-.42	-.66	-.18	147	-3.66	<.001	-.67
Family Cohesion	3.27	.11	3.60	.09	-.32	-.62	-.05	147	-2.14	.034	-.35
Social Resources	3.24	.09	3.73	.07	-.49	-.71	-.27	147	-4.41	<.001	-.76
Overall	3.05	.07	3.48	.05	-.43	-.61	-.26	147	-4.88	<.001	-.84

CSVH = Care-Seeking Voice Hearers; NCSVH = Non-Care-Seeking Voice Hearers; TALE = Trauma and Life Events checklist; AVHRS-Q = Auditory Vocal Hallucination Rating Scale Questionnaire; CompACT = Comprehensive Acceptance and Commitment Therapy measure, RSA = Resilience Scale for Adults, *M* = mean, *SE* = standard error, Δ = change, *df* = degrees of freedom, BCa CI = bootstrapped confidence intervals.