Rebbeca Paulus (BSc Hons., PGDip)

OBSESSIVE-COMPULSIVE DISORDER (OCD) HELP-SEEKING INFLUENCES AND THE RELATIONSHIP BETWEEN DISTRESS TOLERANCE, MINDFULNESS, SELF-COMPASSION AND OCD.

Section A: Thematic synthesis of influences on seeking and engaging with help for obsessive-compulsive difficulties from the experiences of people living with OCD and their relatives.

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Section B: An exploration of the conceptual overlap between distress tolerance, mindfulness and self-compassion and the relationship to levels of obsessive-compulsive difficulties.

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Acknowledgements

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Summary

Context of project: The original part B project, focused on understanding obsessive-compulsive difficulties in Black Caribbean communities encountered recruitment difficulties, and a new part B project had to be commenced. Time constraints resulted in a new project using archival data. Therefore, while part A and part B both relate to obsessive-compulsive difficulties, they focus on different topics related to this.

Section A: The thematic synthesis explored influences on help-seeking for obsessive-compulsive disorder (OCD), identified through qualitative study findings regarding the experiences of people experiencing OCD and their relatives or carers. Five themes, including eleven subthemes, were identified: understanding and recognition of OCD, deciding if help is needed, stigma associated with disclosure, searching for appropriate intervention and support outside professional networks. Clinical implications and research recommendations are discussed.

Section B: The study initially explored the level of overlap between mindfulness, self-compassion, and distress tolerance through exploratory and confirmatory factor analysis on validated measures of the constructs. Eight factors were identified, and hierarchical multiple regression was used to consider how the latent factor structure predicted self-reported levels of obsessive-compulsive difficulties. General distress tolerance and factors related to mindfulness predicted levels of obsessive-compulsive difficulty; however, regulation of distress and self-compassion factors were non-significant predictors. Limitations of the study and clinical implications are discussed.

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Abstract

Background: Research and reviews have often overlooked the qualitative findings regarding potential influences on help-seeking for obsessive-compulsive disorder (OCD).

Method: A systematic literature search of seven databases was conducted, resulting in 1029 papers. Fourteen qualitative papers and one mixed methods paper focused on the perspectives and experiences of people living with OCD and their relatives were extracted for thematic synthesis. The quality of studies was assessed using the Critical Appraisal Skills Programme (CASP) framework.

Results: Thematic synthesis resulted in five themes, including ten subthemes: understanding and recognition of OCD, deciding if help is needed, stigma associated with disclosure, and searching for appropriate intervention and support outside professional networks. The findings give a lived experience voice to existing findings from quantitative reviews.

Conclusions: Whether people sought and engaged with help was influenced by individual, social, public health systems, and wider societal influences. The interconnected nature of these influences needs to be considered in clinical and research implications. Limitations of the review include transferability due to the predominantly White-Eurocentric focus of participants contributing to included studies and limited explicit focus on the topics of seeking and engaging with help.

Keywords: Obsessive-compulsive disorder, help-seeking, barriers, facilitators, qualitative

Introduction

Obsessive-compulsive disorder (OCD) is a diagnosis describing the experience of involuntary distressing thoughts or images that repeatedly enter someone's mind (obsessions), which are followed by repetitive behaviours or mental acts (compulsions) to alleviate distress about the obsessions or to prevent feared adverse outcomes (American Psychiatric Association [APA], 2013). OCD affects functioning in various domains of people's lives (Cole et al., 2013; Jones et al., 2012). The concept of a 'disorder' can be controversial in psychological professions (Widiger & Sankis, 2000). Some lived experience accounts have indicated that people experience an identity based around deficit because of living with OCD while at the same time valuing a medical diagnosis for getting support, indicating the importance of considering psychosocial explanations and origins of obsessive-compulsive manifestations of distress (Murphy & Perera-Delcourt, 2012). In this review, the term OCD will be used to reflect the literature being considered while holding in mind the limitations of a medical perspective of such difficulties.

Experiences of obsessive-compulsive difficulties are heterogeneous (McKay et al., 2004), with varied content of obsessions; for example, themes of obsessions include contamination, causing violent or sexual harm to others, and obsessions about relationships or sexuality (Sasson et al., 1997). Compulsions vary in the extent to which they are visible to others, with compulsions such as checking being overt and others such as mental rituals more covert. There is a suggestion that the way OCD is expressed and perceived may vary culturally (Fernandez de la Cruz et al., 2016; Glazier et al., 2015; Katz et al., 2020; Kolvenbach et al., 2018; Williams et al., 2012; Williams et al., 2020), although some reviews suggest commonalities across cultures (Hunt, 2020).

Exposure with response prevention (ERP) is the recommended intervention for OCD in National Institute for Health and Care Excellence (NICE) guidelines (NICE, 2005). Evidence supports the effectiveness of ERP with or without cognitive therapy, with psychological intervention found to be more effective than pharmacological intervention (Ferrando & Selai, 2021; Olatunji et al., 2013; Ost et al., 2015; Reid et al., 2021). Pharmacological intervention is recommended as an option to be offered to people when OCD experiences cause higher levels of impairment in daily living or where psychological intervention alone was not effective (NICE, 2005).

In line with emotional processing theory, ERP was postulated to interrupt conditioned fear responses via habituation to anxiety (Kozak & Foa, 1997). However, many people may not respond to such interventions or re-experience difficulties, which raised criticism about this being considered the process (Samantaray et al., 2018). Inhibitory learning theory instead indicates that ERP leads to the development of new associations that inhibit rather than break existing threat associations (Jacoby & Abramowitz, 2016). Cognitive theory offers the adjunctive theoretical explanation that obsessive-compulsive related distress is a result of people giving meaning and importance to the everyday human experience of unwanted intrusive thoughts (Obsessive Compulsive Cognitions Working Group, 2003; 2005). For example, people may interpret thoughts as indicating personal responsibility for causing or preventing harm (Salkovskis, 2007). Compulsions are theorised to be driven by these appraisals and completed to try and seek safety by preventing the intrusive thought from occurring, thus alleviating distress (Salkovskis & McGuire, 2003).

Even though effective interventions exist, obsessive-compulsive difficulties often go unrecognised or untreated (Coles et al., 2013), perhaps for up to ten years, a finding that has persisted over time (Stengler et al., 2013; Stahnke, 2021). There is some indication that the length of time without intervention correlates with increased level of obsessive-compulsive difficulties (Zheng et al., 2021).

Help-Seeking for OCD

Garcia-Soriano et al. (2014) completed a systematic review of factors associated with delayed intervention-seeking for people experiencing OCD. This identified that socio-demographic variables were not reliably associated with help-seeking, as studies reported variability in findings. However, interference with quality of life was associated with help-seeking, with people with lower quality of life seeking help sooner. Some studies suggested the content of obsessions influenced help-seeking (Besiroglu et al., 2004), but this was not a consistent finding (Levy et al., 2013; Mayerovitch et al., 2003; Torres et al., 2007). Since this review, some research has continued to suggest people with lower quality of life seek help sooner (Gentle et al., 2104) and delays in seeking intervention have been found to vary by the content of obsessions, with longer periods of difficulty without seeking help being associated with aggressive obsessions (Dell-Osso et al., 2015). The content of obsessions is also associated with differences in how well obsessive-compulsive difficulties are recognised (Poyraz et al., 2015; McCarty et al., 2017), including misidentification by professionals (Glazier et al., 2013). Stereotypical perceptions of OCD being solely about cleaning or handwashing may result in other forms of obsessive-compulsive difficulty being overlooked (Stewart et al., 2019).

Garcia-Soriano et al. (2014) found shame and stigma to be potential barriers to help-seeking that were present across cultures, including concerns about discrimination (Williams et al., 2012), which was shaped by previous experiences of seeking help. Shame and stigma may also be related to the content of obsessions or public perceptions of OCD (Cathey & Wetterneck, 2013; Glazier et al., 2015; Homonoff & Scuitto, 2019). Social stigma may arise from certain attributes being more rejected by society, being considered discreditable or unacceptable (Goffman, 1963). Alternatively, attributions about causes and controllability of a person's experience may lead to inferences about responsibility, with people judged as having the ability to control their experience being more stigmatised (Weiner, 1995). This parallels general mental health findings that stigmatising beliefs can be a barrier to seeking help (Salaheddin & Mason, 2016).

Additionally, Garcia-Soriano's (2014) review highlighted that people experiencing OCD may perceive themselves as not needing help or feel able to cope alone. If people did recognise the need for help, they were unsure where to seek it. Similar findings are present in more recent research (Hathorn et al., 2021). Finally, the 2014 review indicated financial costs as a possible barrier to treatment and logistical barriers such as taking time off work or travel issues, findings persisting in research since the review (e.g. Kolvenbach et al., 2018; Hathorn et al., 2021).

Relationships to help may also be influenced by cultural stories of people seeking help, their families and professionals, and interactions between those seeking help and the places where help is sought can be important to understand (Reder & Fredman, 1996). Variation has been found in cultural explanations for obsessions and associated help-seeking (Fernandez de la Cruz et al., 2016; Glazier et al., 2015; Katz et al., 2020; Kolvenbach et al, 2018; Williams et al., 2012). This reflects common mental health research findings that people may have conceptualisations of distressing experiences that are more diverse than the psychological models that services are framed around (Elyem et al., 2020; Memon et al., 2016; Shefer et al., 2013). The self-regulatory model (Leventhal et al., 1992) and the theory of planned behaviour

(Ajzen, 1985) indicate that beliefs about an experience may be one factor linked to people's ways of seeking and engaging with help.

Rationale and Aims

The studies reviewed by Garcia-Soriano et al. (2014) were all quantitative, mainly using surveys as the data collection method. Some studies in the review (Goodwin et al., 2002; Marques et al., 2010; Williams et al., 2012) explicitly asked participants about barriers to treatment. However, all the data was quantitative. While statistical associations were explored, the perspectives of participants living with OCD and their views about or experiences of seeking and engaging with help were not represented in the review. Help-seeking for OCD has remained an area of interest in research and clinical practice (e.g. Elliott et al., 2018; Glazier et al., 2015; Swisher et al., 2023), but reviews summarising purely qualitative findings in this area are limited. Exploring the findings of qualitative studies will help deepen the understanding of how factors influencing help-seeking are experienced, including how previous experiences of help may influence the relationship to future help-seeking (Reder & Fredman, 1996) and help services improve their accessibility.

Additionally, the National Institute for Health and Care Excellence (NICE, 2005) guidelines for the treatment of OCD address the needs of individuals across the lifespan, including how families and carers can support them. Therefore, it is important to consider the experiences and perceptions of both individuals with OCD and their families to inform clinical practice and guidelines. The review focussed on answering the question what do the experiences of people living with OCD and their relatives indicate about influences on seeking help and engagement with help? Therefore, the current review aimed to:

- Explore the experiences of people living with OCD and their relatives to identify potential influences on help-seeking.
- Further develop understanding about influences on seeking help and engagement with help.

Method

Eligibility Criteria

Papers were included if they focussed on the experiences or perspectives of people living with OCD or family or friends who supported a person living with OCD. This included papers where qualitative data was collected as part of mixed-method approaches. Table 1 outlines the full eligibility criteria.

Search Strategy

PubMed, MEDLINE, PsycINFO, Web of Science, CINHAL, ASSIA and Scopus databases were searched on 13th November 2023. Boolean operators were used across three search categories: obsessive-compulsive disorder, help-seeking, and methodology. Terms for the help-seeking category were developed from noted keywords in exploratory literature searches, discussions with supervisors with expertise in OCD, and discussions with consultant experts by experience. No date limits were set, resulting in the inclusion of studies since the databases' commencement. However, a limit was set to include only studies published in English. Table 2 details the search strategy.

The search terms related to OCD were limited to the title if the database allowed, as it was considered that this key category would be contained in the title of relevant research. Databases that did not allow for 'title only' to be specified were searched using the abstract search field. The abstract search field was applied to the other search term categories.

Table 1.

Eligibility criteria

Inclusion criteria	Exclusion criteria
- Studies with participants experiencing OCD or family/friends of someone experiencing OCD - Studies that reported qualitative findings with demonstrative quotes - Studies reported on barriers or facilitators to seeking help; experiences of seeking help; experiences of living with or supporting someone with OCD; support needs related to living with OCD or supporting someone with OCD - Studied published in peer reviewed journals - Written in English	- Studies focussed solely on symptoms. - No results related to seeking intervention for OCD - Studies where participants were all professionals or people from whom help was sought - Studies that reported on the development or validation of a measure, scale, or questionnaire - Not empirical research, such as reviews, books, opinion pieces, news articles, and conference papers - Dissertations and theses

The reference lists of chosen papers were also screened for relevant citations, as well as searching of papers that cited the chosen papers since publication. Additionally, a search of citations of the Garcia-Soriano et al. (2014) review was completed. This resulted in the identification of five additional papers, which were screened for inclusion. One was included. The PRISMA diagram (Page et al., 2021) in Figure 1 outlines full details of the search process.

Study Selection

Citations were imported into the reference management software Zotero. The duplication tool was used before the screening. During the screening of titles, studies related to experiences or perceptions of OCD and/or help-seeking were retained. Abstracts of the retained studies were reviewed, and those meeting the inclusion criteria were extracted. Studies were full-text screened when it was uncertain from the abstracts if they met the inclusion criteria. When the extracted studies were full-text screened, those not meeting the inclusion criteria were excluded, as shown in Figure 1.

Table 2.

Boolean search strategy.

Search terms
Title: OCD or obsessive-compulsive disorder or obsession*
AND
Abstract: Help-seeking or treatment-seeking or access help or health care seeking behavi* or treatment delay or untreated illness or barriers to treatment or enablers or support
AND
Abstract: Qualitative or survey or experiences or views or interviews or content analysis or grounded theory or thematic analysis or interpretive phenomenological analysis or IPA or discourse analysis or narrative analysis)

Data Extraction

The selected papers focus on experiences of living with OCD from the perspectives of people who experience obsessive-compulsive difficulties and their families/caregivers, including some specifically focused on help-seeking. Qualitative data was extracted from the results sections. Qualitative data representing professional views was not extracted, including ambiguous data when parent and professional views were combined (e.g. Sowden et al., 2023). The extracted data consisted of direct participant quotes and authors' text describing themes, alongside key study characteristics, shown in Table 3.

Quality Assessment

It is debated which criteria should be applied to assess the quality of qualitative research, but an emphasis on relevance and validity are indicated (Mays & Pope, 2000). The Critical Appraisal Skills Programme (CASP) framework provides a structured format for critically evaluating qualitative research evidence (CASP, 2024). The tool requires reflexivity during judgments of the quality of studies, given it is more subjective than quantitative appraisal tools (Dixon-Woods & Smith, 2004; 2006.).

Data Synthesis

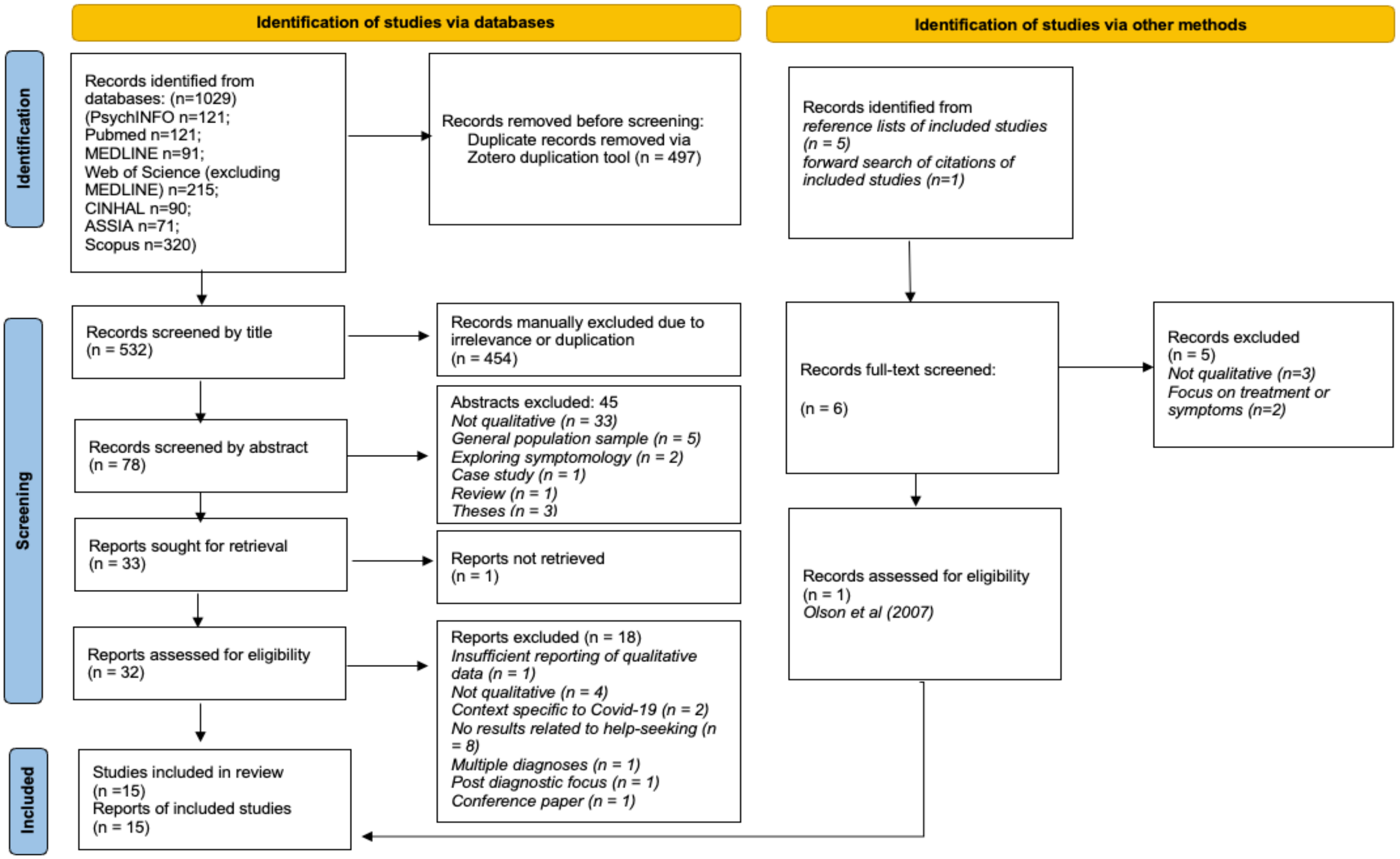
Thematic synthesis followed Thomas and Hayden's (2008) framework, informed by thematic analysis (Braun & Clarke, 2006). All data from study results was analysed to prevent the meaning of data from being restricted early in analysis (Thomas & Hayden, 2008). Data was coded line by line in NVivo software. Initial codes were created inductively at semantic and latent levels, with multiple codes sometimes assigned to single lines of text. As coding was likely influenced by existing knowledge of prior literature, particularly Garcia-Soriano et al.'s (2014) review, codes were regularly reviewed for alternative meanings. Codes were then grouped into descriptive themes based on similarities and differences, which were used to develop interpretative themes that 'go beyond' the content of studies' results to address the review question. Some themes inferred influences on help-seeking based on reviewer interpretation, which is at times considered a controversial part of thematic synthesis (Thomas & Hayden, 2008). This approach mirrors the use of third-order constructs in meta-ethnography (Thomas & Hayden, 2008), inferential themes in thematic analysis (Wiltshire & Ronkainen, 2021) and the idea of analysis being about "interpreting and creating" (Braun & Clarke, 2019, p. 591). The lead researcher summarised interpretative themes, which were discussed with the wider research team. Efforts have been made to be explicit where researcher interpretations were made and where points were explicit in the included papers.

Reflexivity

Supervision sessions and peer discussions, including with qualified psychologists not involved in the research, were the main methods employed regarding reflexivity. The lead researcher and the people consulted were all White British, predominantly identifying as female. Given some of the included papers did not focus on a White Western perspective, interpretations of the findings of these papers were given greater reflection by the lead researcher during analysis to consider bias from working in a Western medical model mental health system. The lead researcher has professional experience working with people experiencing OCD difficulties and personal lived experience of difficulties that could be described as OCD. This was important to reflect upon during analysis to reduce the likelihood of seeing more meaning in some of the published text than may have been expressed by the original papers, given aspects of the reviewer impact different stages of systematic reviews (Sandelowski et al., 2008).

Figure 1.

PRISMA diagram of the systematic literature search process (Page et al., 2021)



Results

Overview of Included Studies

Fifteen studies were selected as eligible for quality assessment, published between 2004-2023. Four focussed specifically on help-seeking for OCD (Kolvenbach et al., 2018; Mahintorabi et al., 2017; Robinson et al., 2017; Vuong et al., 2016).

The remaining studies focussed on lived experiences or perspectives of OCD more generally; two on children and adolescents (Keyes et al., 2018; Sravanti et al., 2022) and five on adults (Al-Solaim & Loewenthal, 2011; Burton et al., 2021; Kohler et al., 2018; Olson et al., 2007; Pedley et al., 2019). Four studies focussed on the perspectives and experiences of relatives of people with OCD (Chessell et al., 2023; Skarphedinsson et al., 2023; Sowden et al., 2023; Stengler-Wenzkee et al., 2014). Fourteen studies involved qualitative designs, and one used a mixed-methods approach (Vuong et al., 2016). Only the qualitative data of this paper was considered. A detailed overview of the studies can be found in Table 3.

Quality Assessment Outcomes

The CASP framework areas were applied to assess the quality of the included studies. An overview is shown in Table 4. The findings of the quality assessment are summarised according to research aims and design, recruitment and participants, data collection, data analysis and findings and reflexivity and ethics.

Research Aims and Design

All papers indicated the aims of the research or research questions, and qualitative methods seemed appropriate to address these, including the study that used mixed methods (Vuong et al., 2016). As shown in Table 3, most studies used Thematic Analysis (TA) as a methodology, with a variety of other methods in other studies. There was variability in the details of the decisions regarding design.

Recruitment and Participants

Most studies focussed on adults experiencing OCD (k= 8), while others included young people (k = 2), relatives or professionals (k= 5). All but four studies required participants to have a formal OCD diagnosis (Chessell et al., 2023; Robinson et al., 2017; Sravanti et al., 2022; Vuong et al., 2016). Eight of the 15 studies recruited participants from the United Kingdom, while others recruited from various other countries (see Table 3). One study conducted semi-structured interviews with a subset of participants from a larger study but did not detail how they were recruited from this larger pool (Kohler et al., 2018).

Participant gender was reported in all studies, with most participants being female. Nine studies included ethnicity data, with most participants identifying as White. One study explicitly recruited ethnically minoritised participants (Kolvenbach et al., 2018) and two studies focussed on Muslim women's experiences (Al-Solaim & Loewenthal, 201; Mahintorabi et al., 2017). While qualitative research does not prioritise representativeness and generalisability, this limited variability in participants reduced transferability (Korstjens & Moser, 2018; Noble & Smith, 2015).

Data Collection

Many studies used semi-structured interviews (SSIs) to collect data, detailing topic areas but not providing sample questions, while others used minimal questioning in line with the methodology (Stengler-Wenzke et al., 2004). Vuong et al.'s. (2016) open-ended survey questions were limited compared to the closed questions for the quantitative data collection. Limited reporting of the questions hindered the evaluation of data collection quality. Three studies used co-production to develop the SSI schedules or topic guides with experts with experience (Chessell et al., 2023; Keyes et al. 2018; Sowden et al., 2023), and one piloted the method to account for cultural factors (Al-Solaim & Loewenthal, 2011). Most studies using interviews recorded and transcribed these. Robinson et al. (2017) transcribed what was deemed ‘relevant’; it was unclear how relevance was determined before analysis.

Stengler-Wenzke et al. (2004) used ‘quasi-theoretical sampling’ due to the study’s connection to a larger quantitative project and reported being unable to reach theoretical saturation due to variability in participant relationships to relatives experiencing OCD. While theoretical saturation is traditionally recommended for Grounded Theory (Glaser & Strauss, 1967; Aldiabat & Le Navenec, 2018), conceptual depth and theoretical sufficiency are now increasingly seen as adequate criteria (Charmaz, 2006; Morse, 2007; Nelson, 2016).

Data Analysis and Findings

All studies using TA had an appropriate number of participants (Fugard & Potts, 2015), with Mahintorabi et al. (2017) having the smallest sample of five. While some recommend a greater number for such a homogenous sample (Guest et al., 2006), the focus on the generation of meaning in TA means data saturation is not universally considered integral to the process (Braun & Clarke, 2019). The studies using IPA were in line with sample size recommendations (Smith et al., 2021). Sowden et al.’s (2023) choice to combine parents’ and professionals’ responses in analysis reduced the extent to which the specificity of findings could be understood.

Table 3.

Details of extracted studies

	Author and date	Study aim	Participants and demographics	Context	Design and analysis	Main findings
1	**Al-Solaim & Loewenthal (2011)**	To explore the role of religion in OCD.	15 women - aged 14-30. - Muslim - Living in Saudi Arabia	People with religion themed OCD living in Saudi Arabia, recruited through psychiatric clinics.	Qualitative. Semi-structured interviews. Thematic Analysis.	Religion seen as an area of expression for OCD, rather than a casual factor. Understanding of what experiencing shaped help-seeking. Faith healer was primary source of help-seeking, providing temporary relief. Mental health services were a last resort.
2	**Burton (2021)**	Describe the pregnancy and postpartum experiences of women with existing OCD.	5 women - aged 26-40. - White British.	Recruited through Facebook OCD support groups and Twitter.	Qualitative. Semi-structured interviews. Interpretative Phenomenological Analysis	Some women experience an increase or changes in distress related to OC. Strategies and support for women with OCD is required before, during and after pregnancy to enable access to healthcare for exacerbation of OCD.
3	**Chessell et al. (2023)**	To explore experiences of parents seeking help for children with OCD.	22 parents of children with OCD aged 7-14. - ages 35-56 -15 mothers, 7 fathers - 16 white British, 2 white other background, 2 Asian background and 2 not stated ethnicity	Recruited through two Southeast England CAMHS, UK mental health charities, social media and UK private treatment providers.	Qualitative. Semi-structured interviews. Thematic Analysis	Parents indicated a battle to access support for their children. OCD was viewed as in control, their experienced a journey in learning how to navigate OCD and experienced their own emotional turmoil. Clear, accessible and scalable support is required for parents of children with OCD.

	Author and date	Study aim	Participants and demographics	Context	Design and analysis	Main findings
4	**Keyes et al. (2018)**	To investigate the issues young people face in the lead up to the development of OCD and their experiences of living with OCD.	10 young people - ages 13-18 years - 5 male and 5 female - 9 white British and 1 South American. - formal diagnosis of OCD by a MH professional.	Young people receiving treatment in three UK tier 3 CAMHS.	Qualitative. Semi-structured interviews. Thematic Analysis	Traumatic experiences may be an important onset factor for OCD and could relate to preventative work. Shame and stigma are common and needs addressing to reduce help-seeking delays. Wider societal education about OCD is a priority.
5	**Kohler et al. (2018)**	Explore perspective regarding quality of life and daily functioning among adults living with OCD.	20 adults in South Africa - aged over 18 (mean 45.65) - 5 male, 15 female - Ethnicity nor reported - primary diagnosis of OCD	Recruited from a larger South African university quantitative study on phenomenology and biological underpinnings of OCD.	Qualitative. Semi-structured interviews. Thematic Analysis.	Quality of life and daily functioning perceived as reduced by living with OCD. Acceptance of OCD is an important factor in treatment and help-seeking.
6	**Kolvenbach et al. (2018)**	To describe the barriers that parents from different ethnic group identify regarding accessing specialist OCD services and variation across groups.	20 parents of children with OCD - aged 36-58 - 14 mothers, 6 fathers - 10 white British - 5 Black African, 1 Black Caribbean, 1 Indian, 1 Iranian, I Malaysian, 1 Pakistani	Recruited from National and Specialist OCD clinic in South London, United Kingdom	Qualitative. Semi-structured interviews. Thematic Analysis	There were commonalities in barriers faced by parents across ethnic groups. There were some barriers specifically identified by minoritised ethnicity parents, but not parents of white backgrounds, including mistrust of health systems, stigma and discrimination within their cultural group and discrimination within the system.
7	**Mahintorabi et al. (2017)**	To explore the expression of OCD and help-seeking for religious OCD by Muslim women.	5 adults with OCD - aged 33-45 - all women - immigrated to Australia from Afghanistan, Iran, Iraq and Turkey.	Recruited via advertisement in psychology clinics, a university medical centre and medical practices in one Australian city.	Qualitative. Semi-structured interviews, Thematic analysis.	The most common compulsions were excess washing and repeating rituals before prayer, to prevent punishment from God. Participants sought help from a Imam before seeking help

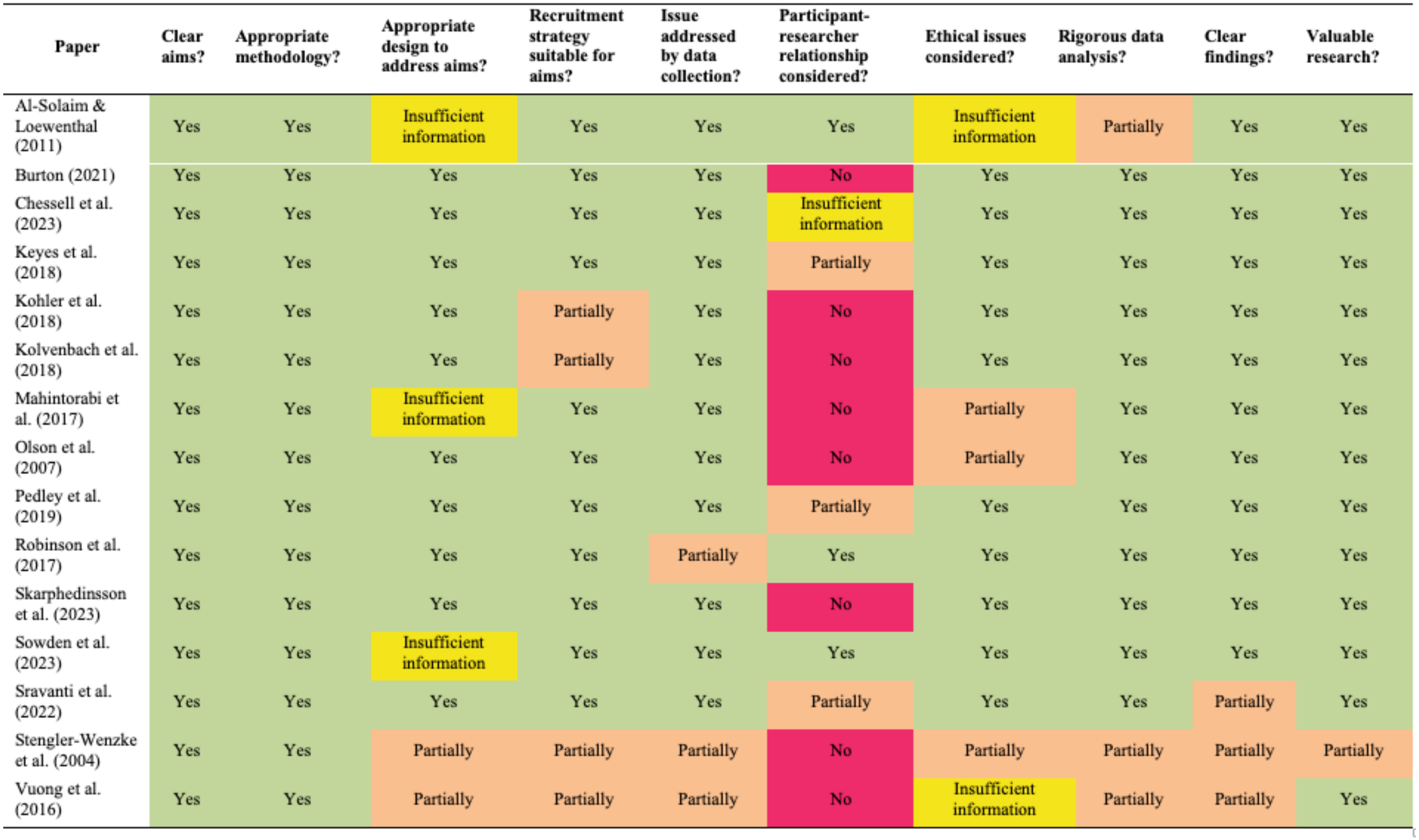
	Author and date	Study aim	Participants and demographics	Context	Design and analysis	Main findings
			- experienced ‘washing’ subtype of OCD			from mental health professionals.
8	**Olson et al. (2007)**	To describe the lived experience of adults in Hawaii diagnosed with OCD and explore health disparities.	10 adults with OCD diagnosis - aged 30-62 - 5 men, 5 women - 3 Asian, 7 White	Recruited from an OCD support group in Hawaii.	Qualitative. Interviews. Consensual qualitative methods (Hill et al., 1997)	Participants had had trouble identifying what they experienced and receiving evidence-based treatment other than medication. There is a need for education about OCD, including for clinicians. These factors contribute to delays in recovery.
9	**Pedley et al. (2019)**	Understand illness perceptions in people with OCD	16 adults with OCD - aged 16-64 - 6 men, 10 women - White British and White Scottish.	Recruited from social media and charity websites and a multi-site OCD treatment trial in the United Kingdom.	Qualitative. Semi-structured interviews. Thematic Analysis.	Identifying OCD may be hindered by failure to see experiences as ‘symptoms’ and may come to be seen as part of self. People are concerned about impact on others and attempt to minimise consequences of OCD. Public and professional knowledge about OCD needs extending to support help-seeking.
10	**Robinson et al. (2017)**	To identify the barriers to seeking treatment and factors that encourage people to seek help for OCD (enablers)	17 adults with OCD - aged 21-57 - 11 women, 6 men - 15 white British, 1 white Other, 1 Other - diagnosis and self-identified	Recruited through the charity OCD-UK, in the United Kingdom.	Qualitative. Semi-structured interviews. Thematic Analysis	There are a range of barriers and enablers that impact on decisions to seek help for OCD. This gives indicators regarding like reasons for delays in help-seeking and ways people can be encouraged to seek help.
11	**Skarphedinsson et al. (2023)**	To examine the parents experiences and perceptions	7 parents of children with OCD - 6 women, 1 man.	Recruited by approaching parents who had sought	Qualitative. Semi-structured interviews.	Obtaining assessment and treatment for children with OCD in a national health

	Author and date	Study aim	Participants and demographics	Context	Design and analysis	Main findings
		mental health care for children with OCD symptoms within the Icelandic health system.	- no other parental demographic data reported	national health service support in Iceland before seeking private treatment.	Framework Analysis	service can be a challenging process for parents. Several factors affected seeking help, including various obstacles, and contributed to a decision to seek private treatment.
12	**Sowden et al. (2023)**	To understand the support needs of parents with children with an OCD diagnosis	20 parents - aged 31-60 - all female - 19 white British, 1 white American 25 professionals - 20 female, 5 male - 11 CBT therapists, 5 clinical psychologists, 3 mental health practitioners, 2 mental health nurses, 3 other professionals	Recruited from NHS trusts in England, third sector organisations, multi-agency educational trust and social media. Part of a larger UK based study on support strategies for parents.	Qualitative. Semi-structured interviews for parents, focus groups or interview with professionals. Framework Analysis.	Parent support needs related to coping with the impact of OCD, getting help for the child, understanding their role in support, making sense of OCD and joint up care between parents and professionals.
13	**Sravanti et al. (2022)**	To explore the experiences of diagnosis, treatment and the meaning of recovering in children and adolescents with an OCD diagnosis. To use information about barriers and facilitators to develop a recovery model.	10 children and adolescents - aged 10-17. - 4 girls, 6 boys - ethnicity data not reported - diagnosis of OCD by a mental health professional	Recruited from out-patient and inpatient settings of a psychiatry department in India.	Qualitative. Semi-structured interviews. Interpretative Phenomenological Analysis.	Participants perceptions of OCD and treatment evolved overtime, disclosure of OCD occurs on a spectrum, there are cascading effects of OCD and OCD has varies factors that require navigation.
14	**Stengler-Wenzke et al. (2004)**	To explore experiences of burden in relatives of people living with OCD and the	22 relatives of adults with OCD - aged 19-80 - 9 male, 13 female - ethnicity data not reported	Recruited from an outpatient facility and day clinic of a university psychiatry department in Germany	Qualitative. Open ended question interviews.	Relatives' experiences of burden varied between relationship roles and they developed different coping strategies.

	Author and date	Study aim	Participants and demographics	Context	Design and analysis	Main findings
		coping strategies they developed.			Thematic Analysis and Grounded Theory.	
15	**Vuong et al. (2016)**	To explore the factors that influences how, when and why people sought help issues they encountered in the help-seeking process.	88 people aged over 18 identifying as having OCD. - 73% female. - mean age 33. - 75 white, 7 Asian, 1 Black ethnicity, 1 multiple ethnic group, 4 other ethnic group. - 15% (n=13) had no diagnosis	Recruited via advertisement through an OCD charity website, website forums, social media, and newsletters in the United Kingdom.	Mixed methods survey. Thematic analysis of open questions.	Most participants sought help from a GP, as well as websites and private services. Lack of understanding and awareness of OCD in health professionals is a problem, alongside waiting time for referral and accessing treatment.

Table 4

CASP Ratings



Paper	Clear aims?	Appropriate methodology?	Appropriate design to address aims?	Recruitment strategy suitable for aims?	Issue addressed by data collection?	Participant-researcher relationship considered?	Ethical issues considered?	Rigorous data analysis?	Clear findings?	Valuable research?
Al-Solaim & Loewenthal (2011)	Yes	Yes	Insufficient information	Yes	Yes	Yes	Insufficient information	Partially	Yes	Yes
Burton (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Chessell et al. (2023)	Yes	Yes	Yes	Yes	Yes	Insufficient information	Yes	Yes	Yes	Yes
Keyes et al. (2018)	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Yes
Kohler et al. (2018)	Yes	Yes	Yes	Partially	Yes	No	Yes	Yes	Yes	Yes
Kolvenbach et al. (2018)	Yes	Yes	Yes	Partially	Yes	No	Yes	Yes	Yes	Yes
Mahintorabi et al. (2017)	Yes	Yes	Insufficient information	Yes	Yes	No	Partially	Yes	Yes	Yes
Olson et al. (2007)	Yes	Yes	Yes	Yes	Yes	No	Partially	Yes	Yes	Yes
Pedley et al. (2019)	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Yes
Robinson et al. (2017)	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Yes	Yes
Skarphedinsson et al. (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Sowden et al. (2023)	Yes	Yes	Insufficient information	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sravanti et al. (2022)	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Partially	Yes
Stengler-Wenzke et al. (2004)	Yes	Yes	Partially	Partially	Partially	No	Partially	Partially	Partially	Partially
Vuong et al. (2016)	Yes	Yes	Partially	Partially	Partially	No	Insufficient information	Partially	Partially	Yes

All papers presented findings relevant to the aims and research questions of the studies. Some presented fewer excerpts of participant responses (Sravanti et al., 2023) or were unclear on how many participants had contributed to findings (Vuong et al., 2023). Each paper discussed the findings in relation to existing relevant literature and made statements regarding clinical implications and/or research recommendations.

Ethics and Reflexivity

Ethics were referred to in all but two papers (Al-Solaim & Loewenthal, 2011; Vuong et al., 2016), though the level of detail varied. Some mentioned ethical processes without specifics (Mahintorabi et al., 2017; Olson et al., 2007; Stengler-Wenzke et al., 2004), while others detailed measures like managing participant distress (Burton, 2021). Reflexivity, crucial in qualitative research as the researcher is the "research instrument' (Dodgson, 2019), was rarely addressed specifically. Some studies mentioned reflexivity in interview question design (Sravanti et al., 2022), while others highlighted it through lived experience researchers (Robinson et al., 2017) or co-production to reduce bias (Keyes et al., 2008; Sowden et al., 2023).

Summary

There is a lack of clear methods for deciding to exclude qualitative studies from syntheses based on their quality appraisal (Carroll et al., 2012; Dixon-Woods et al., 2006; Daly et al., 2007). All assessed studies were included for thematic synthesis, despite the variability in the quality appraisals for each. A decision was made to retain two lower-quality studies as Vuong et al.'s (2016) findings specifically relate to help-seeking, the focus of the review, and specific findings could be extracted from Stengler-Wenzke et al. (2004) to ensure the data analysed remain relevant to the review. To protect against the negative impact of including lower-quality studies, during synthesis it was noted if a code or theme relied heavily on data from poorer-quality studies.

Thematic Synthesis

Coding of the data resulted in 192 initial codes, the grouping of which resulted in nineteen descriptive themes, for example, ‘responding to OCD’. See Appendix B for NVivo coding samples. The thematic synthesis resulted in five interpretative themes, including eleven subthemes, displayed in a thematic map in Figure 2, where bidirectional arrows indicate themes that interconnect. Additional example quotes from the papers are shown in Appendix B.

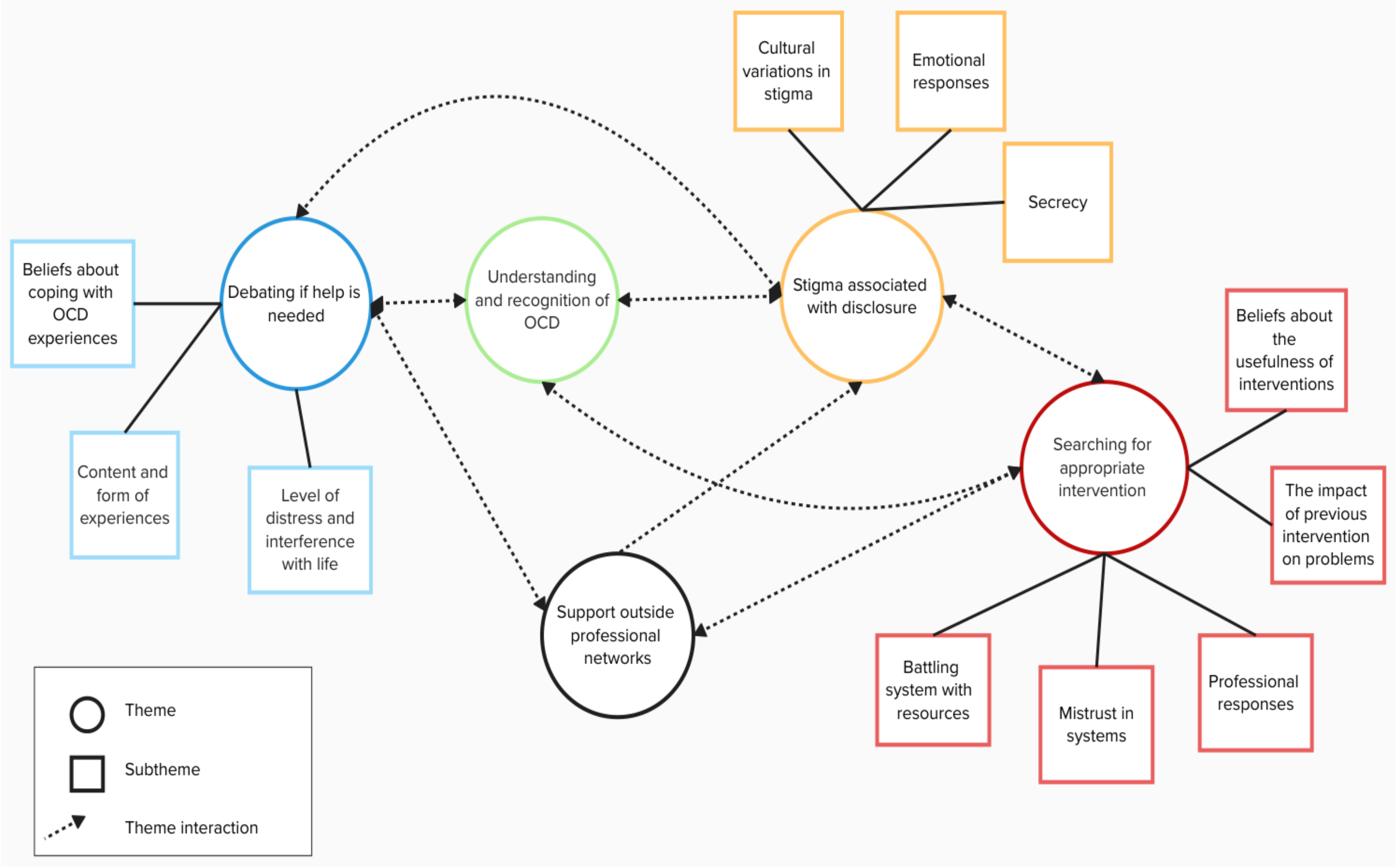
Understanding and Recognition of OCD

This theme represented that people *“struggled to understand what the problem might be”* (Pedley et al., 2019, p. 6). The onset of OCD in childhood at times resulted in a struggle to *“differentiate between normative childhood development and disordered behaviour”* (Chessell et al., 2023, p.74), or difficulties being seen as a *“quirk” (Pedley et al., 2019, p. 20), “features of their personality”* (Stengler-Wenzke, 2004, p.37), or “*their behaviour was ‘normal; as it was so habitual from a young age”* (Keyes et al., 2018, p.180). Participants’ cultural group related to how OCD may be explained in their communities, influencing how people understood the problem and how to seek help:

> *“Definitely the culture plays a role on how they look at it, it is about education. They will not see it as something physical, they will think it is something spiritual, to taking them to the doctor will have no impact, you have to take them to the church and pray. (Male, 47, Black African)” (Kolvenbach et al., 2016, p. 103).*

Figure 2.

Thematic map



"*Misdiagnosis and lack of understanding"* (Voung et al., 2016, p. 8) by professionals including medical doctors, educational professionals, and therapists was implicated in delays in getting help (Chessell et al., 2023; Olson et al., 2007; Pedley et al., 2019; Robinson et al., 2017; Sowden et al., 2023; Sravanti et al., 2022; Voung et al., 2016). However, recognition by others in personal relationships may positively influence help-seeking, and media information about OCD and accessible information for relatives was suggested to increase recognition and help-seeking (Robinson et al., 2023; Sowden et al., 2023; Vuong et al., 2016).

Debating If Help Is Needed

Debating whether to seek help for OCD was influenced by **the level of distress and interference with life** in areas such as activities, social relationships, work, education, self-care, sense of self and perceptions of personality (Chessell et al., 2023; Keyes et al., 2018; Mahintorabi et al., 2017; Olson et al., 2007). Experiences of OCD that were "*very distressing, time-consuming and physically exhausting…. [and] were observed as causing the most interference with normal life activities [were] the leading reason for seeking treatment"* (Mahintorabi et al., 2017, p. 6). This included the emotional impact of living with OCD, including *"resentment towards their OC symptoms and the intrusive nature of their OCD over time. This persistent intrusiveness led to irritability, anger, sadness, discomfort, disgust and embarrassment"* (Kohler et al., 2018, p. 5).

"Reaching a crisis/crunch point" (Robinson et al., 2017, p. 204) where *"symptoms became so intense that they could no longer be kept a secret"* (Stengler-Wenzke, 2004, p. 37) at times defined a transition to seeking help. For some people, it took until the point of suicidal ideation before help was sought (Skarphedinsson et al., 2023).

The **content and form** of intrusions and compulsions were mentioned by adult, youth, and relative participants. Thoughts that are *"perceived as extremely threatening and provoked high levels of anxiety"* (Al-Solaim & Loewenthal, 2011, p. 178) may be harder to speak about with others, but this was not consistent. For example, there was variability in views and experiences of seeking help for thoughts related to harm to others (Burton, 2021; Keyes et al., 2018; Sravanti et al., 2022). The notion of responsibility for protecting others from harm was linked to the content of OCD obsessions (Al-Solaim & Loewenthal, 2011; Keyes et al., 2018; Olson et al., 2007; Pedley et al. 2019; Robinson et al., 2017) but also related to protecting others from being affected by OCD, which was at times linked to help-seeking.

> *"Other women accessed treatment for their OCD in order to prevent their child from being affected, steps which they might not have taken otherwise."* (Burton, 2021, p. 319).
>
> "They sought help (one immediately and two after lengthy delays) to try to prevent the harm they feared they were capable of doing; "*And at this stage … I thought my children were in immense danger."* This participant sought help, *"firstly for my children … I thought you've got to be a decent person.""* (Robinson et al., 2017, p. 206).

Beliefs about coping with OCD experiences included seeing experiences as mild, ingrained, not needing or not deserving intervention (Robinson et al., 2017), or unlikely to change related to seeking and engaging with help:

> *"Additionally personal beliefs also acted as a barrier to treatment, such as believing it not to be the right 'time' to receive therapy (e.g. being too stressed)."* (Pedley et al., 2019, p.11)

If people believed *"they could manage the problem themselves"* (Robinson et al., 2017, p. 201) and relied on self-help techniques (Olson et al., 2007), this linked to decisions not to seek external help. This was expressed as related to accommodation and avoidance as coping responses (Burton, 2021; Chessell et al., 2023; Keyes et al., 2018).

Stigma surrounding disclosure

Emotional responses were repeatedly linked to stigma. Embarrassment and shame were referenced as reasons for not wanting to speak to professionals (Robinson et al., 2017; Sravanti et al., 2022) and for hiding experiences from others:

> *"..it's also a bit embarrassing, because your child is, so completely different from her friends . . . so she's saying all these really weird things, that, I would pretty much only like tell my best friend . . . how can you say to people "does your child think they have weed on light bulbs?"* (Chessell et al., 2023, p. 76).

Negative responses such as bullying were linked to emotional responses for some (Kolvenbach et al., 2016; Sravanti et. al., 2022), but feelings of shame may be present even in the absence of negative reactions from others:

> *". . . but I sometimes felt like the black sheep of the family because I was the one with the mental illness. . ." (P.8, m)" (Pedley et al., 2019, p. 14).*

Concerns about judgement from family and friends was sometimes linked to delayed disclosure (Burton et al., 2021; Keyes et al., 2018; Robinson et al., 2017; Sravanti et al., 2022; Stengler-Wenzke et al., 2004):

> *"I wanted to talk but I was worried what my parents would think about me if I talked to them about my problem. So, initially I held back from talking about it." (P10, 17 yr old girl)" (Sravanti et al., 2022, p. 6)*

The perceived threat of stigma resulted in being *"gripped in fear as thoughts were very unpleasant"* (Sravanti et a., 2022, p. 6) and fear about the real-world consequences, such as employment impacts or safeguarding responses, further inhibited disclosure (Kolvenbach et al., 2016; Robinson et al., 2017):

> *"One mother went further, explaining that her fear of others misunderstanding her OCD symptoms might lead to her losing custody of her children. To prevent this consequence, she was careful not to reveal too much about her condition to others." (Pedley et el., 2019, p. 14).*

Cultural variations in stigma were explored in three papers. This centred around people being worried about community judgement and responses (Chessell et al., 2023l Olson et al., 2007), which related to delays in disclosure and seeking professional help.

> *The first thing you think is: what will people say? It took me some time to tell my mother because I knew that she would not understand. In our culture, this is not something you wish on your enemy, let alone your family member.* (Male, 47, Black African)." (Kolvenbach et al., 2018, p. 102).

Others interpreted symptoms through cultural lenses, such as the Islamic notion of the "evil eye," which provided a non-stigmatising explanation of developing obsessions due to having positive qualities (Al-Solaim et al., 2011).

Secrecy emerged as part of stigma. Trying to understand OCD experiences *"…when combined with the stigma in society related to psychiatric problems, leads persons to hide their OCD as much as possible."* (Olson et al., 2007, p. 4). Experiencing OCD and disclosing experiences was framed as a *"personal affair"* (Sravanti et al., 2022, p. 7) that could result in secrecy that explained *"why most participants delayed seeking help for their OCD behaviours"* (Keyes et al., 2018, p. 181). There was encouragement for others supporting those with OCD to hold this in mind and not apply pressure regarding disclosure (Keyes et al., 2018).

Support outside professional networks

Support from personal relationships was an influence in relation to help-seeking. The importance of people moving towards acceptance of OCD was voiced by those experiencing OCD (Kohler et al., 2018; Sravanti et al., 2022), marked by some as part of the help-seeking process:

> *"…just getting parents feeling comfortable with the whole condition and making them realise that they need help and that they need, the child needs some sort of assistance . . . [ID39, father]"* (Chessell et al., 2023, p.75).

Peer support was referred to as helpful as *"it's hard to take advice from someone that doesn't know what you're going through"* (Keyes et al., 2018, p. 181), and could also give a sense of meaning to living with OCD (Olson et al., 2007). Parents of children with OCD indicated peer support as valuable to their role in supporting a child to get help, and a lack of such options was disappointing (Chessell et al., 2023; Kolvenbach et al., 2018). Some people expressed peer support as a vital avenue to their choice to seek professional help (Robinson et al., 2017), seemingly lessening the impact of stigma:

> *"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, p. 204).

Searching for appropriate intervention

The theme searching for appropriate intervention was present internationally. This linked to influences on first-time help-seeking, engagement with help and the prospect of seeking further help. **Beliefs about the usefulness of interventions** seemed to be an influence on how people may seek help. This included varied beliefs about medication (Mahintorabi et al., 2017; Skarphesinsson et al., 2023). On some occasions, ambivalent beliefs about intervention options were explicitly related to help-seeking or engagement with help:

> *"Two participants described concerns about the treatment they might be offered as contributing to their delay in seeking help. For one participant, this was about medication; for the other, it was about psychological treatment…"* (Robinson et al., 2017, p. 203).

Cultural factors also influenced preferences, with some communities prioritising faith-based approaches before health care, with psychiatric services sometimes positioned as a "*last resort"* (Al-Solaim & Loewenthal, 2011; Mahintorabi et al. 2017). Additionally, mental health practitioners' level of religiosity may be influential in working relationships and engagement with help:

> *''I've never thought about the level of religiosity of mental health professionals, but 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, 2017, p. 177).*

There were repeat references to **battling with system resources**, which included delays due to waiting lists (Chessell et a., 2023; Keyes et al., 2018; Kolvenbach et al., 2016; Skarphedinsson et al., 2023; Vuong et al., 2016) and "*miscommunication between different services or a lack of engagement from staff and continuity in treatment"* (Kolvenbach et al., 2018, p. 101). This led to an "*ambivalent relationship to help-seeking"* (Keyes et al., 2018, p. 182) and a *"battle involving pushing, fighting"* (Sowden et al., 2023, p. 6).

Some participants wondered about services *"trying to keep costs down"* (Olson et al., 2007). Parents of children experiencing OCD indicated time and money as barriers to getting help in the public mental health system or privately, in the UK (Kolvenbach et al., 2018) and Iceland (Skarphedinsson et al., 2023):

> *"More than half of the participants commented on time as an important factor when accessing services, specifically transport time or having to take time off work, and nine of the interviewees acknowledged that money could also be a significant barrier for them, as they were for instance not able to access private services due to funding issues." (Kolvenbach et al., 2018, p. 101).*

There were concerns about a lack of specialist clinicians as a resource and how this impacted identification and intervention (Skarphedinsson et al., 2023), with *"variation in the quality of therapist, or difficulty with continuity of treatment due to staff 'turnover'… seen as reducing the potential benefits of treatment"* (Pedley et al., 2019, p. 11).

In terms of **professional responses**, positive responses from professionals can be a *"remarkable source of strength"* (Olson et al., 2007, p. 6), positively influencing help-seeking.

> *"One participant, after delaying seeking treatment for over three years, deliberately chose to see a doctor who s/he "had a vague memory was good at listening to people" (Robinson et al., 2017, p. 206).*

Conversely, some experienced negative or inconsistent responses from professionals when seeking help, which might reinforce concerns prior to seeking help about *"what they would think"* (Robinson et al., 2017, p. 203):

> *"I had a bit of a bad experience with a doctor. My doctor actually didn't help at all. He laughed to be honest..." (Keyes et al., 2018, p.180).*

Invalidating responses by professionals and the associated misrecognition contributed to feeling *"misunderstood, unsupported, isolated and mistreated while others reported that such issues hindered their recovery" (*Voung et al., 2016, p. 7).

> *"It's quite insulting when like someone like that [CAMHS professional], who hasn't been there at 3 o'clock in the morning, every morning when your child is, you know, blinking at the ceiling otherwise she is going to be, a lesbian, telling me that she hasn't got OCD' [ID40, mother]" (Chessell et al., 2023, p. 77).*

The **impact of previous interventions on problems** was present across some studies. Some initially sought help from faith healers, but temporary relief resulted in seeking help from healthcare professionals (Al-Solaim & Loewenthal, 2016). Some people discontinued psychological interventions such as ERP, finding them too distressing.

> *""In the beginning, it went well, but then it stopped… she didn't seem to have any results with the OCD symptoms" (participant 1). "Although I was happy to have the service*

> *available, I was very disappointed. I felt I was wasting my time… it wasn't doing anything for us" (participant 2)."* (Skarphedinsson et al., 2023, p. 6).

For those with ongoing difficulties, some sought further help, and others experienced hopelessness (Vuong et al., 2016), indicating the impact of help on problems may influence later help-seeking.

Mistrust in systems seemed to contribute to reservations about seeking help, including fears about criminalisation due to the content of obsessions (Robinson et al., 2017). For some the battle with resources contributed to a sense of mistrust, with some deterred from seeking help and *"reluctant to return to the doctor if my symptoms worsen"* (Vuong et al., 2016, p. 8).

For parents from backgrounds minoritised based on ethnicity, experiences of being failed by systems as communities, and racial discrimination contributed to mistrust, highlighting how intersectionality between systemic discrimination and mental health are important considerations:

> *"You are supposed to have some trust in the system, which I guess we don't have now because the system has failed us so badly. (Male, 47, Black African)."* (Kolvenbach et al., 2018, p. 103).

Discussion

This systematic review aimed to explore the experiences of people living with OCD and their relatives to identify potential influences on help-seeking and to further develop an understanding of influences on seeking help and engagement with help. Thematic synthesis allowed for data reported across qualitative studies to be combined and the influences inferred from the experiences shared by the range of participants. The resultant themes are discussed in relation to the wider research literature, including clinical and research implications. There are limitations to this review that are worthy of consideration.

The theme ***understanding and recognition of OCD*** highlights the challenges posed by OCD's heterogeneity, which can hinder public and professional recognition of OCD experiences. Spiritual or religious beliefs linked to spiritual help-seeking, as shown elsewhere (Grover et al., 2014) and seeing OCD as a 'part of life or self' may also influence help-seeking. The attributions about cause that people make have often been linked to the way help is sought (O'Neill et al., 2023).

While many people are familiar with the term OCD (Stewart et al., 2019), research shows both the public (Coles et al., 2013; Garcia-Soriano & Roncero, 2017; McCarty et al., 2019) and professionals struggle to recognise OCD (Wahl et al., 2010; Glazier et al., 2013; Mulcahy et al., 2020). Increasing knowledge of OCD is frequently suggested to address this barrier (Warman et al., 2015; Chaves et al., 2021; Munslow-Davies & Anderson, 2022a, 2022b), but persistent gaps in understanding are evident in research (e.g. Coles et al., 2023), contributing to the maintenance of stigma and contributing to ***debating if help is needed.*** This theme highlighted **level of distress and interference with life** appears to influence help-seeking; high distress or impact on functioning may result in seeking help for difficulties sooner. This reflected findings that people with higher levels of OCD difficulty are more likely to be receiving intervention (Cullen et al., 2008; Belloch et al., 2009). People's **beliefs about coping with OCD experiences**, such as feeling undeserving of intervention, may deter help-seeking. Additionally, accommodation and avoidance, known for exacerbating OCD experiences (Lebowitz & Bloch, 2014), were identified in this review as potentially detrimental influences on help-seeking.

Furthermore, the **content and form** of OCD experiences may influence willingness to seek help. This builds on Garcia-Soriano et al.'s (2014) findings by offering some insight into why this may be the case. Variability in help-seeking responses to harm-related obsessions suggests content and form can act as barriers or motivators. While "taboo" thoughts, such as those involving themes of harming others and 'morally scrupulous behaviour', often delay help-seeking, fear of endangering others can prompt it, as also found by Mayerovitch et al., 2003) Inflated responsibility and control, linked to the onset of OCD (Salkovskis et al., 2000; Moulding & Kyrios, 2006), motivate some to seek help out of concern for others' safety, while others adopt hyper-independent coping. This review suggested that fear of losing control may also hinder help-seeking depending on the meaning it has for someone, contrary to assumptions that it would encourage it.

Furthermore, OCD obsession content that is less well understood or recognised has been related to higher levels of ***stigma surrounding disclosure*** (Cathey & Wetterneck, 2013; Homonoff & Sciutto, 2019; Glazier et al., 2015; McCarty et al., 2019; Ponzini & Steinman, 2022; Simmonds & Thorpe, 2003; Weigarden & Renshaw, 2015; Wetterneck et al, 2014). Again, this review extended previous findings by identifying aspects of what people fear being stigmatised for and by who. **Emotional responses** were an influence on help-seeking. Emotions such as guilt, embarrassment or shame may manifest to protect social identity (Klik et al., 2019), and the concept of seeking help may be too much of an emotional burden. There is a substantial literature base exploring the role of stigma and shame in healthcare seeking, both for OCD (e.g. Belloch et al., 2009) and mental-health care more generally (Clement et al., 2015). This, in some ways, makes it unsurprising that the perspectives and experiences in the papers of this review reflected such existing findings, and links to the idea of **secrecy** being a barrier to seeking help.

Support outside professional networks holds the potential to be a significant facilitator of help-seeking, given the review highlighted this as an experience that encouraged some to seek help. Conversely, invalidating social responses such as bullying may hinder disclosure and help-seeking. Similar findings are present in general mental health research (Gulliver et al., 2010). The journey towards others being accepting of experiences seemed to be a response that could facilitate seeking help.

Searching for appropriate intervention encompassed individual and system-level influences, including **battling with system resources**, such as waiting lists and a lack of specialist responses. Resources hold the potential to be barriers to or facilitators for help-seeking, depending on variability in the system, including social inequalities impacting the capacity to engage with the help offered by mental health systems, in line with findings by Garcia-Soriano et al. (2014) and general mental health research (Kantor et al., 2017; Salaheddin & Mason, 2016). **Mistrust in systems** based on concerns about racial discrimination was a barrier to help-seeking in this review and has been found elsewhere in OCD research (Williams et al., 2012). This concern may partially explain existing findings that people from racially oppressed backgrounds are underrepresented in mental health services despite the prevalence of OCD experiences being similar across ethnic identities (Fernandez de la Cruz et al., 2015a, 2015b; Katz et al., 2020). Additionally, higher marginalisation has been linked to higher difficulties with OCD and lower quality of life, even following treatment (Wadsworth et al., 2020). Systemic discrimination in public mental health systems is, therefore, a significant negative influence on help-seeking behaviour that needs to be addressed from within the system beyond research that repeats these findings.

Beliefs about intervention, both pharmacological and psychological, influenced how people sought help, as found elsewhere (Garcia-Soriano et al., 2014; Wheaton et al., 2016; Hathorn et al., 2021). This seemed to reflect some aspects of Leventhal et al.'s (1992) common sense model of responses to illness, with cognitions and affect influencing coping responses, and general mental health findings that attitudes about seeking help predict future use of mental health interventions (Mojtabai et al., 2016). The way people cope with difficulties seemed in part related to the **impact of previous interventions on problems**, with people finding some interventions challenging to engage in as they conflicted with existing ways of coping with distress. In general mental health literature across the lifespan, prior positive intervention-seeking experiences have been indicated as a facilitator of help-seeking (Gulliver et al., 2010; Elshaikh et al., 2023).

Across the themes, findings suggest that people with spiritual, religious, or cultural beliefs not represented by Western medical and psychological models may prefer help from people who hold similar beliefs or show an understanding of their beliefs. This has been indicated in OCD research that involved people from ethnic backgrounds who experience discrimination, where a lower sense of ethnic affirmation was linked to doubts about a clinician's effectiveness (Williams et al., 2012). Williams et al.'s (2020) guidelines on cultural competency in OCD support concluded that treatment providers need diverse and culturally competent staff that are willing to integrate treatment approaches to align with the client's values and beliefs, integrating their explanations for their experiences and working collaboratively with wider communities. The findings in this review support such a stance.

The findings of this review mirrored many of the findings from the quantitative review by Garcia-Soriano et al., (2014). However, the qualitative nature of the data extended the findings by offering greater insight into the meaning behind the influences that people identify as affecting seeking help and indicated how these influences relate to engagement with help.

Strengths and Limitations of Review

The analysis of all data reported in the findings of papers meant data was not limited by an initial researcher bias of what was ‘relevant’ to extract. While this allowed for comprehensive consideration of themes across findings, some of the analysed data did not explicitly relate to help-seeking. As such some influences were more inferred than explicitly stated by participants or authors, which holds the potential for bias being introduced at this point. While consultation with the wider research team and peers was used to mitigate bias, the White-centric nature of the research team may have maintained the bias of a White-British lead researcher.

The review considered papers with participants across the life span, and relatives of people with OCD experiences. The inclusion of people who had and those who had not sought help allowed for a fuller exploration of influences on the process of seeking and engaging in help for obsessive-compulsive difficulties. This allowed consideration of the breadth of influences on help-seeking and identified commonalities across groups. The main weakness of the included papers related to the variability in the level of participant quotes, limited detail about reflexivity processes, and predominantly White participants.

The initial analysis generated many codes, which indicated a specificity that helped maintain the diversity of findings, but working to synthesise this may have resulted in differences being overly subsumed in later stages of analysis.

Clinical and Research Implications

Repeated findings highlight that understanding, recognising OCD and addressing stigma are crucial to encouraging help-seeking behaviour. Further work is required to help people understand what OCD experiences are and that it is acceptable to seek help for such difficulties. Public psychoeducation, such as OCD Awareness Week (International OCD Foundation, 2024), is often recommended, but clinician awareness and skills also need enhancement. Services should focus on training front-line clinicians and updating outdated professional guidelines, such as the 2005 NICE guidelines, to improve cultural competency and integration of client beliefs with evidence-based practices.

How health professionals respond can determine whether people seek help or persist with seeking help. Listening to and validating people's experiences seems to be important for people staying engaged in the help-seeking process, reflecting findings about the importance of common factors in professional caregiving (Wampold, 2015a, 2015b) and of positive experiences of help-seeking (Mitchell et al., 2017). Additionally, system and personal resources can present barriers to seeking and engaging with help, supporting calls for psychologist training to include an increased focus on addressing social determinants of mental health difficulties (Woods-Jaeger et al., 2024). As peer support was identified as a valuable aspect of help-seeking, public health services may benefit from increasing their use of co-production or working with charitable organisations, as part of increasing access and improving the services they offer. This includes incorporating Williams et al.'s (2020) recommendations on developing culturally competent services.

Given the limited focus specifically on help-seeking for OCD in qualitative research, it would be useful for future research to focus more specifically on this area. This would include a higher level of ethnic and gender diversity in research participants, as well as researching experiences of seeking help for obsessions with a variety of thought content. The findings of this review could be used to identify further research questions that focus on experiences of seeking help across differing forms of OCD, as well as considering how to understand the perspectives of people who have never sought help for OCD.

Conclusion

The findings of this thematic synthesis of the experiences of people experiencing OCD and their relatives indicated several influences on help-seeking. The resultant themes included individual, social, public health systems, and wider societal influences. The review extended previous findings by explaining why these may be influences on seeking and engaging with help, including how some can be both barriers and facilitators. The studies reviewed were mainly robust, although were limited in the key aspect of reflexivity in qualitative research. The implications of the findings need to be considered with the limitations in mind, particularly the racial and cultural limitations in the range of participants in papers and the researchers involved in this review.

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Rebbeca Paulus (BSc Hons., PGDip)

OBSESSIVE-COMPULSIVE DISORDER (OCD) HELP-SEEKING INFLUENCES AND THE RELATIONSHIP BETWEEN DISTRESS TOLERANCE, MINDFULNESS, SELF-COMPASSION AND OCD.

Section B: An exploration of the conceptual overlap between distress tolerance, mindfulness and self-compassion and the relationship to levels of obsessive-compulsive difficulties.

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Abstract

Purpose: Mindfulness, self-compassion, and distress tolerance have been identified as predictors of levels of obsessive-compulsive difficulties. The definitions of these constructs appear to share conceptual overlap and may be explained by fewer overarching constructs. Understanding how potential conceptual overlap predicts obsessive-compulsive difficulties may support further development of psychological intervention.

Method: An exploratory and confirmatory factor analysis was completed on data from intervention-seeking and non-intervention-seeking adult samples, using measures of mindfulness, self-compassion and distress tolerance to identify and confirm a latent factor structure across the measures. A hierarchical multiple regression using the latent factor structure was applied to a self-report measure of obsessive-compulsive difficulties.

Results: Eight factors were identified and confirmed through factor analysis. *General distress tolerance, describe inner experience, non-judging of inner experience, acting with awareness* and *non-reactivity to experience* were small, significant independent predictors of levels of obsessive-compulsive difficulty. *Regulation of distress, uncompassionate self-responding*, and *compassionate self-responding* were non-significant predictors.

Conclusions: Concepts related to distress tolerance and mindfulness may be the most significant to consider in psychological intervention for obsessive-compulsive difficulties. The role of self-compassion may benefit from further exploration. Limitations of the findings and clinical and research implications are discussed.

Keywords: Mindfulness, self-compassion, distress tolerance, obsessive-compulsive.

Introduction

Obsessive-compulsive disorder (OCD) is a diagnosis describing distress caused by intrusive, repetitive thoughts (obsessions) and behaviours (compulsions) aimed at reducing the distress or preventing feared outcomes (Goodman et al., 1989). Such experiences are heterogeneous with various themes of obsession that can be linked to distress, including symmetry, contamination, violence, religious scrupulosity and sexual behaviour (McKay et al., 2004). Although diagnostic labels are contentious when describing mental health experiences, people with an OCD diagnosis typically report finding this useful (Hughes & Kinderman, 2023), and the term OCD is used in this study to align with such views and wider literature. National Institute for Health and Care Excellence (NICE) guidelines recommend exposure with response prevention (ERP) with or without cognitive strategies as the main intervention approach for OCD (NICE, 2005). The mechanism of change in ERP is proposed to occur due to inhibitory learning, where new non-threat associations are learnt through ERP tasks that compete with past threat associations between obsessions and compulsions (Abramowitz et al., 2014, 2015; Jacoby & Abramowitz, 2016). Many people terminate engagement in this type of therapy, finding the short-term distress of exposure too difficult or struggling to engage in homework tasks, affecting the benefit derived (Simpson et al., 2008; Strauss et al., 2015).

In connection to this, the cognitive model suggests certain beliefs lead to misappraisal of normal intrusive thoughts as more meaningful than they are, resulting in distress and the performance of compulsions, that in turn maintain distress by preventing disconfirmation of the thoughts (Salkovskis, 1985, 2007), including beliefs about high levels of responsibility, control, over-estimation of threat and perfectionism (Steketee et al., 1998; Tolin et al; 2003; Wheaton et al., 2010). However, obsessive beliefs do not fully explain the variation in OCD severity or forms (Abramowitz et al., 2009; Wheaton et al., 2010), indicating other psychological factors may play a role in the onset and maintenance of obsessive-compulsive difficulties and responsiveness to frontline intervention options. Other therapeutic approaches such as compassion-focused therapy (Gilbert, 2009) and mindfulness-based interventions (Twohig & Smith, 2015) show promise but have limited evidence of effectiveness. Additionally, low distress tolerance has been indicated as a possible factor related to people finding it difficult to live with the unpleasant emotions associated with obsessions, and the resultant difficulty resisting the urge to engage in compulsions (Robinson & Freeman, 2014).

Mindfulness

Mindfulness is grounded in Buddhist philosophy and became explicitly applied in psychology via mindfulness-based stress reduction (Kabat-Zinn, 2003) and mindfulness-based cognitive therapy (Segal et al., 2002). It refers to non-judgmental, purposeful observation and description of experience in the present moment (Kabat-Zinn, 2003). Mindfulness can support people to disengage from negative thinking processes such as rumination and worry and to decentre from thoughts and feelings, relating to them as transient events (MacKenzie & Kocovski, 2016). A higher disposition towards mindfulness, sometimes referred to as trait mindfulness, has been linked to enhanced well-being and psychological resilience (Conversano et al., 2020; Paul et al., 2013; Tomlinson et al., 2017), in clinical (Hofmann et al., 2010; Keng et al., 2011) and non-clinical samples (Chiesa & Serretti, 2009). Mindfulness may help promote non-reactive responses to intrusive thoughts (Barcaccia & Couyoumdian, 2019), although evidence of mindfulness-based interventions effectiveness in reducing OCD-related distress is mixed (Cludius et al., 2015; Hertenstein et al., 2012; Key et al., 2017; Küllz et al., 2019; Selchen et al., 2018; Strauss et al., 2018). A meta-analysis indicated a medium effect size pre-to-post intervention, including when mindfulness was offered to people with residual OCD difficulties following other interventions (Riquelme-Marin et al., 2022).

Self-compassion

Self-compassion, often defined as a kind and non-judgemental attitude toward personal suffering, is positioned as important for mitigating the negative mental health impacts of self-criticism (Stutts, 2022). Neff (2003a) outlined self-compassion as taking a kind and open approach to self-suffering, seeing this as part of common humanity rather than exclusive to self and avoiding over-identification with painful experiences by taking a non-reactive stance towards observing one's inner experience. Mindful self-compassion interventions posit that mindfulness is required to recognise suffering and take compassionate action (Neff & Germer 2012).

Similarly, Gilbert (2009) identifies self-compassion as a non-judgemental attitude towards personal suffering that involves a desire to understand and alleviate it, situated in a biopsychosocial model that focuses on helping people balance the brain's threat, drive and soothe systems by considering social context as part of self-soothing (Gilbert, 2009; 2014; 2022). Compassion-focused therapy (CFT) was designed for people experiencing high shame or self-criticism that did not fully benefit from existing therapeutic approaches (Gilbert & Proctor, 2006), aiming to strengthen the self-soothing system to counteract the negative effects of over-activated threat and drive systems (Gilbert, 2009).

Self-compassion-based approaches have been indicated as effective for people experiencing a range of mental health challenges (Craig et al., 2020; Cuppage et al., 2017; Kirby et al., 2017; Millard et al., 2023; Stroud & Griffiths, 2019; Wilson et al., 2019). Lower levels of self-compassion are associated with higher levels of obsessive-compulsive difficulties (Steinberg et al., 2012; Wetterneck et al., 2013; Eichholz et al., 2019), with people experiencing OCD often highly self-critical about the obsessions they experience (Eichholz et al., 2019). This may link to the thought-action-fusion notion that people may believe having a negative intrusive thought is equivalent to acting on it (Rachman, 1993), something which may lead to shame if they view the thought as morally reflecting them as a ‘bad person’ (Rachman, 1997). Shame has been associated with OCD (e..g. Cândea & Szentagotai-Tatar, 2018), particularly for themes of obsession that may come with more moral judgement (Weingarden & Renshaw, 2015). Group self-compassion interventions have been linked to a reduction in obsessive-compulsive difficulties (Petrocchi et al., 2021).

Distress tolerance

Distress tolerance refers to the ability to withstand and cope with negative emotions rather than focusing on reducing emotional intensity and is an aspect of emotional regulation (See et al., 2022; Simons & Gaher, 2005). Low distress tolerance indicates discomfort with internal experience, and interventions focus on changing someone’s relationship with inner experiences (Robinson & Freestone, 2014). Dialectical behaviour therapy (DBT; Linehan, 1993) includes distress tolerance skills, such as ‘radical acceptance’, which postulates that acceptance of and engaging with the present moment can assist in tolerating distress by focusing on facts rather than a perceived ’should not’ of experience (Swales & Heard, 2017), helpful when people feel out of control because they cannot change a situation (Chapman et al., 2011).

Lower levels of distress tolerance are associated with greater levels of difficulties with post-traumatic stress responses, mood, and anxiety (Akbari et al., 2020; Bernstein et al., 2011; Michel et al., 2016), as well as with higher levels of obsessive-compulsive difficulties in both clinical and non-clinical samples (Blakey et al., 2016; Cougle et al., 2011, 2012; Garner et al., 2017; Keough et al., 2010; Laposa et al., 2015; Macatee et al., 2013; Verónica del-Valle et al., 2022), and distress tolerance can be uniquely related to such difficulties (Keough et al., 2010). In OCD, this may reflect inhibitory learning suggestions that learning distress can be tolerated is an important outcome of ERP interventions (Jacoby & Abramowitz, 2016). There is some suggestion that improving distress tolerance may be a mechanism of change in OCD interventions (Godfrey et al., 2024), and treatment approaches such as DBT may reduce obsessive-compulsive difficulties in clinical samples (Ahovan et al., 2016; Khayeri et al., 2019), though this likely overlaps with wider emotional regulation ability that includes more than distress tolerance (Conway et al., 2021).

Rationale for the study

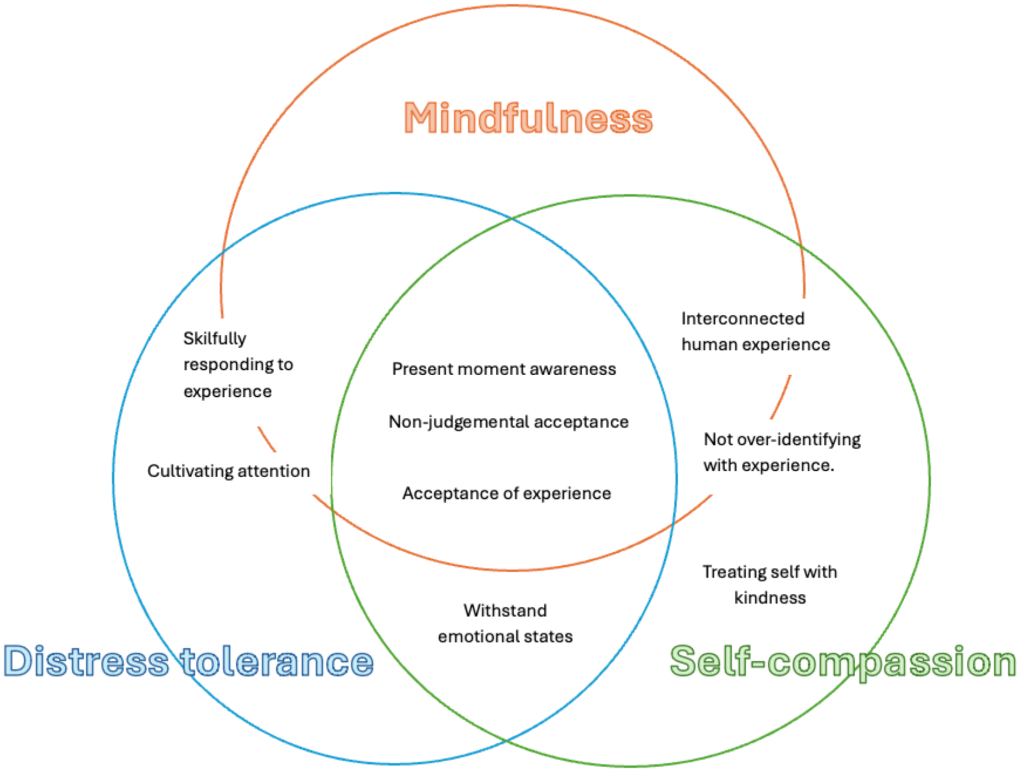
As indicated above, self-compassion, mindfulness and distress tolerance are often positioned as distinct yet interconnected ‘third-wave’ psychological constructs that focus on the influence of the context of thoughts and feelings linked to distress (Hayes, 2004). There are shared theoretical concepts within the definitions of the constructs (e.g. the notion of being non-judgemental, being accepting of experience, withstanding rather than avoiding experience). Figure 1 highlights proposed conceptual overlaps between the constructs, using the literature findings outlined above.

For example, both mindfulness and self-compassion consider the connected nature of human experience. They also emphasise responding intentionally to experiences rather than reacting automatically, which shares the distress tolerance position of initially tolerating distress before skilfully responding (Lynch & Mizon, 2011). This relationship between constructs is also seen in intervention manuals; for example, Segal et al. (2013) indicated in MBCT that self-compassion is an aim of the therapy and Linehan (1993) included aspects of mindfulness in

DBT, such as in the STOP skill, which encourages people to observe experience to respond mindfully. Self-compassion interventions encourage people to tolerate distress by attending to self-compassionate responses (Gilbert, 2009; 2022).

Figure 1.

Proposed overlap between mindfulness, self-compassion, and distress tolerance



Ideas of clinical change also support the potential conceptual overlap between the constructs. Increases in self-compassion have been indicated as a possible change mechanism in mindfulness-based therapies (Gu et al., 2015), while mindfulness training was linked to improvements in distress tolerance in non-clinical samples (Carpenter et al., 2019; Shaw & Kelly, 2024). Both mindfulness and distress tolerance may indirectly affect the relationship between a DBT intervention and improvement in clinical outcomes (Zeifman et al., 2020), suggesting that while the constructs may have overlap there may also be unique elements contributing to change. In relation to OCD, emotional regulation, which includes distress tolerance, may mediate the effect of self-compassion on level of OCD difficulties (Chase et al., 2019; Eichholz et al., 2020).

Empirical findings indicate associations between measures of these three constructs and OCD symptom severity. Leeuwerik et al. (2020) found that individuals with obsessive-compulsive difficulties scored lower on mindfulness and self-compassion than those with anxiety or depression and a student control group. In the clinical sample, mindfulness and self-compassion were negatively correlated with OCD severity, suggesting that higher levels of these constructs may be associated with fewer OCD difficulties. However, when controlling for distress tolerance, their predictive strength diminished, highlighting distress tolerance's potential role in OCD.

Understanding the relationship between mindfulness, self-compassion, and distress tolerance in obsessive-compulsive difficulties could uncover unique influences on symptoms. For instance, individuals low in the "act with awareness" mindfulness component might benefit more from mindfulness-based therapies than people already higher in such skills (Carpenter et al., 2019). Understanding the empirical and theoretical overlap between these constructs could help improve assessments and support the tailoring of intervention for people experiencing OCD.

Research aims

The project aimed to explore whether items from validated measures of mindfulness, self-compassion, and distress tolerance reflect fewer underlying constructs than would be expected from the original measures. Using exploratory and confirmatory factor analyses, the project sought to identify overlapping factors and examine their relationships with levels of self-reported obsessive-compulsive difficulties.

Hypotheses

The project is presented across three studies to address three hypotheses:

1) A theory-free factor structure of items from measures of mindfulness, distress tolerance and self-compassion will indicate a conceptual overlap between the constructs.
2) The overlapping factor structure will be confirmed in both intervention-seeking and non-intervention seeking samples.
3) The identified latent factors will vary in whether they are predictors of self-reported levels of obsessive-compulsive difficulties.

Previous study data

The following summarises the method and samples of the previous study by Leeuwerik et al. (2020), from which the data for the current project was drawn. Ethical approval for the data to be used in a further project is shown in Appendices D and E.

Design and procedure

Data was collected using a quasi-experimental design, comparing self-selected intervention-seeking and non-intervention seeking samples. Participants completed measures of multiple psychological variables and obsessive-compulsive difficulties.

Participants

Table 1 outlines the demographics of the intervention-seeking, non-intervention seeking and total samples in the archival data from Leeuwerik et al. (2020). Participants were considered to have OCD if they scored above the clinical threshold on the Obsessive-Compulsive Inventory-Revised (OCI-R; Foa et al., 2002).

Intervention-seeking sample. An intervention-seeking sample was recruited from 28 NHS Improving Access to Psychological Therapies (IAPT) services across England (*n* = 1871), services now known as NHS Talking Therapies. Inclusion criteria were: i) over the age of 18; ii) able to read and write in English; iii) assessed and offered intervention by an IAPT service. The majority were White, female, with at least a secondary education and identified as employed.

Non-intervention seeking sample. A non-intervention seeking sample was represented by students (*n* = 540) from a South England university. Inclusion criteria were: i) over the age of 18; ii) able to read and write in English. Students were excluded if they were waiting for or receiving intervention in an NHS service. A student sample was reported by Leeuwerik et al. (2020) as being used rather than a community sample due to the resources required to compensate a large sample of community participants. As per the intervention-seeking sample the majority were White, female, and identified as having secondary-level education. Given the recruitment pool, the majority identified as students.

Procedure

Leeuwerik et al. (2020) recruited the non-intervention seeking sample via a university research system, student forums, emails sent by academic staff, flyers and posters. The intervention-seeking sample was recruited via IAPT services, which distributed invitation letters with a survey link or an option of a paper version, with 15% of participants completing the paper version. Surveys were anonymous, designed to take 20-30 minutes and assumed consent when submitted. The Bristol Online Survey Platform (BOS, Bristol, UK) was used for survey completion by the intervention-seeking sample, while Qualtrics (Qualtrics, Provo, UT) was used for the student sample.

Table 1.

Sociodemographics of overall samples from Leeuwerik et al. (2020), total (N=2411), intervention-seeking (n=1871) and non-intervention seeking (n=540) samples.

Variable		Intervention seeking (*n*, %)	Non-intervention seeking (*n*, %)	Total (*N*, %)
Age	18-24	338 (18.1)	526 (97.4)	864 (35.8)
	25-34	386 (20.6)	8 (1.5)	394 (16.3)
	35-44	303 (16.2)	3 (.6)	306 (12.7)
	45-54	329 (17.6)	1 (.2)	330 (13.7)
	55-64	303 (16.2)	1 (.2)	304 (12.6)
	65+	190 (10.2)	0	190 (7.9)
	Prefer not to say	11 (.6)	0	11(.5)
	Missing	11 (.6)	1 (.2)	12 (.5)
Gender	Female	1332 (71.2)	442(81.9)	1774 (73.6)
	Male	508 (27.2)	92 (17)	600 (24.9)
	Other	7 (0.3)	1(.2)	7 (.3)
	Prefer not to say	6 (0.4)	2(.4)	9 (.4)
	Missing	18 (0.1)	3 (.6)	21 (.9)
Highest education	Secondary	1019 (54.5)	402 (74.4)	1421 (58.9)
	Higher	764 (40.8)	133 (24.6)	897 (37.2)
	Prefer not to say	69 (3.7)	4 (.7)	73 (3)
	Missing	19 (1)	1 (.2)	20 (.8)
Employment status	Employed/self-employed	1050 (56.1)	22 (4.1)	1072 (44.5)
	Looking for work	126 (6.7)	8 (1.5)	134 (5.6)
	Not looking for work	88 (4.7)	12 (.7)	92 (3.8)
	Unable to work	174 (9.3)	0	174 (7.2)
	Student	127 (6.8)	503 (93.1)	630 (26.1)
	Retired	243 (13)	0	243 (10.1)
	Prefer not to say	44 (2.4)	2 (.4)	46 (1.9)
	Missing	19 (1)	1 (.2)	20 (.8)
Ethnicity	White background	1748 (93.4)	453 (83.9)	2201 (91.3)
	Other background	95 (5.1)	78 (14.4)	173 (7.2)
	Prefer not to say	19 (1)	8 (1.5)	27 (1.1)
	Missing	9 (.5)	1 (.2)	10 (.4)
Intervention status	Not yet started intervention	1442 (77.1)	n/a	n/a
	Received some intervention	353 (18.9)	n/a	n/a
	Prefer not to say	48 (2.6)	n/a	n/a
	Missing	28 (1.5)	n/a	n/a
Previous experience of mindfulness	Yes	337 (18)	49 (9.1)	386 (16)
	No	1437 (76.8)	471 (87.2)	1908 (79.1)
	Prefer not to say	65 (3.5)	19 (3.5)	84 (3.5)
	Missing	32 (1.7)	1(.2)	33 (1.4)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

Study 1

Method

Design

Study one used a correlational design via exploratory factor analysis (EFA), focussed on exploring the potential overlap between items from three measures of the psychological constructs to address hypothesis one.

Measures

The measures reported are those from Leeuwerik et al.'s (2020) data collection used in the current study's data analysis.

The **Five-Factor Mindfulness Questionnaire- Short Form** (FFMQ-SF; Bohlmeijer et al., 2011) is a 24-item scale designed to measure mindfulness skills, using a 5-point Likert scale (1 = never, 5 = always true). It includes five subscales: observe, describe, act with awareness, non-judging of inner experience, and non-reactive to inner experience, developed from the original 39-item FFMQ (Baer et al., 2006). Internal consistency ranges from adequate to excellent (α = .71–.91; Bohlmeijer et al., 2011) and was found in the clinical (α = .83) and student samples (α = .84) by Leeuwerik et al., (2020). A meta-analysis (Carpenter et al., 2019) suggested the "observe" subscale may correlate less with affective symptoms and it cannot be qualified whether it measures observation of external or internal stimuli, leading to the exclusion of its items (6, 10, 15, 20) from this analysis.

The **Self-Compassion Scale- Short Form** (SCS-SF; Raes et al.; 2011) is a 12-item scale measuring self-compassion on a 5-point Likert scale (1 = almost never, 5 = almost always). Developed from the 26-item Self-Compassion Scale (Neff, 2003b), it includes six subscales: self-kindness, self-judgment, common humanity, isolation, mindfulness, and over-identification.

Negatively worded subscales (self-judgment, isolation, over-identification) are reverse-scored. The SCS-SF strongly correlates with the original scale (r = .98; Raes et al., 2011), as do language-specific versions (r = .92; Garcia-Campayo et al., 2014). Subscale correlations range from .89 to .93 (Raes et al., 2011). While construct validity is well-supported (Hayes et al., 2016; Kelly et al., 2013; Kotera & Sheffield, 2020), internal consistency of some subscales is moderate to acceptable (.54–.75). Thus, Raes et al. (2011) recommend using the full-scale score. Full-scale internal consistency was α = .83 in the clinical and α = .86 in student samples (Leeuwerik et al., 2020).

The **Distress Tolerance Scale** (DTS; Simons and Gaher (2005) is a 15-item measure of distress tolerance using a 5-point Likert scale (1 = strongly agree, 5 = strongly disagree). It includes four subscales: tolerance of emotional distress, absorption by negative emotions, appraisal of emotional distress responses, and regulation. Internal consistency is good (α = .83–.85; Simons & Gaher, 2005) and was excellent in the clinical (α = .93) and student samples (α = .92; Leeuwerik et al., 2020). However, the four-factor structure shows poor factor discrimination and low construct validity for the tolerance, absorption, and appraisal subscales (Galiano et al., 2024; Rogers et al., 2020).

Participants

Sample for study one. To address the hypotheses across studies one and two, the participants from the intervention-seeking and non-intervention seeking samples were combined, as the psychological constructs being explored apply to people living with or without clinical levels of psychological distress. Additionally, a heterogenous rather than homogenous sample has been recommended for EFA due to homogeneity lowering the variance and factor loadings (Kline, 2014). Participants were randomly allocated to two groups via SPSS random data splitting to create independent samples for each study, resulting in an initial sample of n = 1214 for study one (Appendix J).

Missing data. An overview of overall missing data can be found in Leeuwerik et al. (2020). Missing data analysis was conducted for the study one sample. Each item on the SCS-SF, FFMQ-SF, and DTS had 1% missing data. A total of 131 cases (10.7%) had missing data on at least one item, with 19 cases missing over 10% of data. Little's Missing Completely At Random (MCAR) test suggested data were not missing completely at random ($X^2(3302) = 2616.30$, $p < .001$). Only 355 of 57,058 possible values (0.01%) were missing, all from the intervention-seeking group, likely due to survey platform design not prompting participants if an answer had not been completed. Imputation methods were considered, however missing data were treated as completely at random due to the reason seemingly due to design (Kang, 2013). Cases with missing data were deleted listwise, resulting in a final sample of 1083 participants. Demographics are detailed in Table 2.

Data Analysis

Preliminary analysis. To test the data for normality and outliers, skew and kurtosis values, histograms and plots were reviewed using SPSS version 29. The correlation matrix, Bartlett's test of sphericity, and Kaiser-Meyer-Olkin (KMO) test assessed EFA suitability. Box plots showed no outliers, but the Kolmogorov-Smirnov test indicated non-normality. Inspection of Q-Q plots and histograms was conducted due to the large sample size (Field, 2024), and indicated skew and kurtosis in SCS-SF and DTS items.

Table 2.

Sociodemographic variables in the EFA total (N=1083), intervention-seeking (n=828) and non-intervention seeking (n=255) samples.

Variable		Total (*N*, %)	Intervention seeking (*n*, %)	Non-intervention seeking (*n*, %)
Age	18-24	387 (35.7)	141 (17.0)	246 (96.5)
	25-34	184 (17.0)	180 (21.7)	4 (1.6)
	35-44	141 (13.0)	138 (16.7)	3 (1.2)
	45-54	161 (14.9)	161 (19.4)	0 (0.0)
	55-64	138 (12.7)	137 (16.5)	1 (0.4)
	65+	63 (5.8)	63 (7.6)	0 (0.0)
	Prefer not to say	4 (0.4)	4 (0.5)	0 (0.0)
	Missing	5 (0.5)	4 (0.5)	1 (0.4)
Gender	Female	789 (72.9)	582 (70.3)	207 (81.2)
	Male	282 (26.0)	236 (28.5)	46 (18.0)
	Other	4 (0.4)	3 (0.4)	1 (0.4)
	Prefer not to say	3 (0.03)	3 (0.4)	0 (0.0)
	Missing	5 (0.5)	4 (0.5)	1 (0.4)
Highest educational qualification	No educational qualification	37 (3.4)	37 (4.5)	0 (0.0)
	Secondary	623 (57.5)	434 (52.4)	189 (74.1)
	Higher	391 (36.2)	228 (39.6)	63 (24.7)
	Prefer not to say	28 (2.6)	26 (3.10)	2 (0.8)
	Missing	4 (0.4)	3 (0.4)	1 (0.4)
Employment status	Employed/self-employed	500 (46.2)	489 (59.1)	11 (4.3)
	Looking for work	57 (5.3)	55 (6.6)	2 (0.8)
	Not looking for work	47 (4.3)	44 (5.3)	3 (1.2)
	Unable to work	76 (7.)	76 (9.2)	0 (0.0)
	Student	290 (26.8)	52 (6.3)	238 (93.3)
	Retired	87 (8.0)	87 (10.5)	0 (0.0)
	Prefer not to say	18 (1.7)	18 (2.2)	0 (0.0)
	Missing	8 (0.7)	7 (0.8)	1 (0.4)
Ethnicity	White background	986 (91.0)	775 (93.6)	211 (82.7)
	Asian background	30 (2.8)	14 (1.7)	16 (6.3)
	Black background	16 (1.4)	10 (1.2)	6 (2.4)
	Mixed background	23 (2.2)	13 (1.6)	10 (4.0)
	Other background	15 (1.4)	6 (0.7)	9 (3.6)
	Prefer not to say	10 (0.9)	8 (1.0)	2 (0.8)
	Missing	3 (0.3)	2 (0.2)	1 (0.4)
Intervention status	Not yet started intervention	634 (58.5)	634 (76.6)	N/A
	Declined NHS intervention	4 (0.4)	4 (0.5)	N/A
	Received some intervention	155 (14.3)	155 (18.7)	N/A
	Not asked as controls	255 (23.5)	N/A	255 (100)
	Prefer not to say	25 (23.5)	25 (3.0)	N/A
	Missing	10 (0.9)	10 (1.2)	N/A
Previous experience of mindfulness	Yes	176 (16.3)	148 (17.9)	28 (11.0)
	No	866 (80.0)	645 (77.9)	221 (86.7)
	Prefer not to say	32 (3.0)	27 (3.3)	5 (2.0)
	Missing	9 (0.8)	8 (1.0)	1 (0.4)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

Exploratory factor analysis (EFA). EFA was conducted via SPSS version 29 to explore the latent factor structure of items from the FFMQ-SF, DTS and SCS-SF. EFA was chosen over principal component analysis due to the aim of identifying factors that may represent latent constructs and an assumption of the presence of measurement error in the scales used (Field, 2024). Due to non-normality, principal axis factoring was chosen, which is more robust to such violations (Fabringer et al., 1999; Brown, 2015). Item-level analysis allowed a theory-free exploration of the relationships between measured constructs, addressing the above concerns about some subscale construct and discriminant validity.

A sample of 1083 participants met a recommended minimum case-to-variable ratio of 5:1 for the 47 items (Costello & Osborne, 2005). Inter-item correlations were reviewed, and no values exceeded 0.8, so all items were retained. Spearman rho coefficients, used due to the presence of non-normality, showed correlations above 0.3, confirming suitability for EFA. A Kaiser-Meyer-Olkin (KMO) test (KMO= 0.94) and Bartlett's test of sphericity (p= <.001) indicated that the data was adequate for factor analysis (Field, 2024).

Oblique rotation (direct oblimin) was used, as factors were expected to correlate given the theoretical overlap in the literature. Factor extraction prioritised the scree plot over eigenvalues >1 if discrepancies arose (Cattell, 1966). Factor loadings of ≥.32 were deemed meaningful for the sample given it was over 300 participants (Tabachnick & Fidell, 2007). Items with cross-loadings were assigned to the factor with the highest loading.

Results

Principal axis factoring with oblique rotation (direct oblimin) revealed an eight-factor model, with eigenvalues >1 and confirmed by the scree plot, accounting for 50.52% of variance. All items had communalities >0.3 after extraction, although eleven items loaded <0.4. After rotation, all factors had at least three items loading ≥0.32 within the pattern matrix, except FFMQ-SF item 24. Within the structure matrix this item had a coefficient loading >0.4 on two factors, indicating this item may be strongly influenced by other factors (Watkins, 2018). Removing this item did not alter the model, so all 47 items were retained, and the structure matrix was used for interpretation. The pattern and structure matrices are shown in Appendices K and L. Names were assigned to the factors using the content of the items they contained, as shown in Table 3, which also shows the correlations between factors.

The first factor, labelled 'general distress tolerance', was composed of most items of the tolerance, appraisal and absorption subscales of the DTS, and accounted for 26.7% of variance. Factor two reflected the 'describe inner experiences' subscale of the FFMQ-SF, while factor three comprised the items of the 'non-judging of inner experience' FFMQ-SF subscale. Factor four consisted of the 'regulation of distress' DTS subscale items and had a moderate positive correlation with the 'general distress tolerance' factor (.605). Factor five represented the items of the 'acting with awareness' FFMQ-SF subscale, which had weak correlations with other factors.

The sixth factor 'uncompassionate self-responding' contained the items of the isolation, over-identification and self-judgement subscales of the SCS-SF and FFMQ-SF item 24 *'I disapprove of myself when I have illogical ideas'*. This factor had moderate negative correlations with 'general distress tolerance' (-.476) and 'non-judging of inner experience' (-.460), as well as factor seven (-.409). Factor seven contained the items of FFMQ-SF subscale 'non-reactivity to experience', which also had a positive moderate correlation with 'general distress tolerance' (.451). The final factor 'compassionate self-responding' contained items from the mindfulness, self-kindness and common humanity subscales of the SCS-SF and had positive moderate correlation with 'non-reactivity to experience' (.484).

Table 3.

EFA factor structure and correlations between factors.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Factor 1 General distress tolerance	-	-	-	-	-	-	-	-
Factor 2 Describe inner experiences	.226	-	-	-	-	-	-	-
Factor 3 Non-judging of inner experiences	.291	.108	-	-	-	-	-	-
Factor 4 Regulation of distress	***.605***	.101	.148	-	-	-	-	-
Factor 5 Acting with awareness	-.307	-.330	-.264	-.152	-	-	-	-
Factor 6 Uncompassionate self-responding	**-.476**	-.223	**-.460**	-.240	.386	-	-	-
Factor 7 Non-reactivity to experience	**.451**	.159	.142	.188	-.193	**-.409**	-	-
Factor 8 Compassionate self-responding	.312	.264	.031	.058	-.188	-.339	**.484**	-

* p<.001, bold indicates moderate correlation above .4, bold and italicised indicates strong correlation above .6

Study 2

Method

Participants

This study used the remaining independent sample from Leeuwerik et al.'s (2020) data, namely the remaining halves of the intervention-seeking (n= 913) and non-intervention-seeking (n= 284) samples that were not included in Study 1, shown in Appendix M.

Missing data. Missing data was explored on SPSS version 29, to determine the sample for ongoing analysis. For the non-intervention seeking sample, four of the 47 items had one case missing each (1.4%). Little's MCAR test indicated data were missing completely at random ($X^2(184) = 196.770$, $p = .247$). The intervention-seeking sample had missing data for each of the SCS-SF, FFMQ-SF and DTQ items, with the highest percentage of missing data being 1%. Overall, 103 cases (11.3%) contained missing data on at least one item, with 14 cases (1.5%) missing over 10% of data. Little's MCAR test indicated data were not missing completely at random ($X^2(2908) = 3228.71$, $p = .000$). Only 259 out of 42,911 values (0.6%) were missing, mirroring patterns observed in Study 1, likely due to the intervention-seeking survey platform not prompting missing responses. Table 4 presents the sample demographics.

Data analysis

Preliminary analysis. Preliminary analysis was conducted using SPSS version 29. As per study one, normality tests were significant, but histograms and Q-Q plots were reviewed to assess normality due to the large sample size (Field, 2024). Skew and kurtosis appeared present for items in the SCS-SF and DTS, therefore breaching the normality assumption.

Confirmatory factor analysis (CFA). CFA tests hypotheses about proposed factor structures (Costello & Osbourne, 2005) and was completed on MPlus version 6.12 (Muthén & Muthén, 1998-2010). Using the factors identified in study one, the analysis tested five models: 1) a one factor model with all EFA factors entered simultaneously 2) a three-factor uncorrelated model combining factors from study one into distinct factors represented by their original measures of mindfulness (EFA factors two, three, five, and seven), self-compassion (EFA factors six and eight) and distress tolerance (EFA factors one and four), 3) a three-factor correlated model with the same factors, 4) a hierarchical eight-factor model using the EFA factors, and 5) a non-hierarchical eight-factor correlated model based upon the EFA findings, given the number of correlations between factors in the EFA. Given preliminary screening, the CFA used listwise

Table 4

Sociodemographic variables in the total (N=1090), intervention-seeking (n=810) and non-intervention-seeking (n= 280) samples for study two.

Variable		Total sample (N, %)	Intervention seeking (n, %)	Non-intervention seeking (n, %)
Age	18-24	438 (40.2)	163 (20.1)	275 (98.2)
	25-34	183 (16.8)	179 (22.1)	4 (1.4)
	35-44	119 (10.9)	119 (14.7)	0 (0.0)
	45-54	132 (12.1)	131 (16.2)	1 (0.4)
	55-64	128 (11.7)	128 (15.8)	0 (0.0)
	65+	82 (7.5)	82 (10.1)	0 (0.0)
	Prefer not to say	6 (0.6)	6 (0.7)	0 (0.0)
	Missing	2 (0.2)	2 (0.2)	0 (0.0)
Gender	Female	820 (75.2)	590 (72.8)	230 (82.1)
	Male	255 (23.4)	209 (25.8)	46 (16.4)
	Other	2 (0.2)	2 (0.2)	0 (0.0)
	Prefer not to say	5 (0.5)	3 (0.4)	2 (0.7)
	Missing	8 (0.7)	6 (0.7)	2 (0.7)
Highest educational qualification	No educational qualification	40 (3.7)	40 (4.9)	0 (0.0)
	Secondary	598 (54,9)	387 (47.7)	211 (75.3)
	Higher	421 (38.6)	354 (43.7)	67 (24.0)
	Prefer not to say	26 (2.4)	24 (3.0)	3 (1.1)
	Missing	5 (0.5)	5 (0.6)	2 (0.7)
Employment status	Employed/self-employed	465 (42.7)	454 (56.0)	11 (3.9)
	Looking for work	62 (5.7)	56 (6.9)	6 (2.1)
	Not looking for work	40 (3.7)	39 (4.8)	1 (0.4)
	Unable to work	75 (6.9)	75 (9.3)	0 (0.0)
	Student	320 (29.4)	60 (7.4)	260 (92.9)
	Retired	104 (9.5)	104 (12.8)	0 (0.0)
	Prefer not to say	19 (1.7)	17 (2.1)	2 (0.7)
	Missing	5 (0.5)	5 (0.6)	0 (0.0)
Ethnicity	White background	1001 (91.9)	762 (94.1)	239 (85.4)
	Asian background	25 (2.1)	15 (1.8)	7 (2.5)
	Black background	9 (0.9)	6 (0.8)	3 (1.1)
	Mixed background	26 (2.4)	15 (1.8)	11 (3.9)
	Other background	18 (1.6)	3 (0.3)	15 (5.3)
	Prefer not to say	11 (1.0)	6 (0.7)	5 (1.8)
	Missing	3 (0.3)	3 (0.4)	0 (0.0)
Intervention status	Not yet started intervention	623 (57.2)	623 (76.9)	N/A
	Declined NHS intervention	2 (0.2)	2 (0.2)	N/A
	Received some intervention	163 (14.9)	163 (20.1)	N/A
	Not asked as controls	280 (25.7)	N/A	280 (100)
	Prefer not to say	16 (1.5)	16 (2.0)	N/A
	Missing	6 (0.6)	6 (0.7)	N/A
Previous experience of mindfulness	Yes	173 (15.9)	153 (18.9)	20 (7.1)
	No	871 (79.9)	625 (77.2)	246 (87.9)
	Prefer not to say	40 (3.7)	26 (3.2)	14 (5.0)
	Missing	6 (0.6)	6 (0.7)	0 (0.0)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

deletion and maximum-likelihood estimation with robust standard errors due to violations of normality.

The fit of the model to the data was assessed using the following fit indices: root mean square error of approximation (RMSEA; Steiger & Lind, 1980), standardised root mean square residual (SRMR; Bentler, 1995), comparative fix index (CFI, Bentler, 1990), Tucker-Lewis index (TLI; Tucker & Lewis, 1973) and Akaike information criterion (AIC; Akaike, 1974). As the chi-square test is sensitive to larger sample sizes (Kline, 2023), it is reported but was not used to assess model fit. As fit statistics can be influenced by sample size, number of variables, non-normality of data and model complexity, cut-offs for assessing goodness of model fit can be subjective and are advised not to be considered rules (Chen et al., 2008; Marsh et al., 2004). As used by Williams et al. (2014) and Gu et al. (2020), the following liberal and conservative cut-offs were used to assess the acceptability of model fit: RMSEA .10 or less (liberal) or .06 or less (conservative), SRMR less than .10 (liberal) or 0.5 (conservative), and CFI and TLI close to or greater than .90 (liberal) or .95 (conservative). AIC was used to compare model fits, with superior fit indicated by lower values.

Results

Fit indices for tested CFA models are shown in Table 5. A one-factor model was a poor fit, with incremental indices below the liberal cut-off, indicating variance was not explained by one overarching factor. The three-factor model testing mindfulness, self-compassion and distress tolerance as uncorrelated constructs was also a poor fit, as was the three-factor correlated model. The hierarchical eight-factor model showed improved fit, but was still below liberal cut-offs for incremental indicates. The eight-factor correlated model had a higher fit on incremental indicates, close to the liberal 0.9 cut-off. Consideration was given to a hierarchical correlated eight-factor model using maximum likelihood estimation with robust standard errors; this resulted in an improper solution and attempts to correct this were unsuccessful. This model was re-run using Bayesian estimation and indicated a poor fit (PPP = 0), failure to converge (PSR = 1.1), and large residuals. Due to this, it seemed the hierarchical model was not warranted, and the non-hierarchical eight-factor correlated model was retained and explored for modifications. Factor loadings were reviewed to explore ways to improve the model, with all items loading above 0.4. Modifications indices (MIs) were reviewed to consider how item cross-loadings may improve model fit, given the presence of some cross-loadings above 0.4 in the EFA structure matrix. MIs above 20 and with an expected parameter change (EPC) >.3 were reviewed, and theoretical justifications were considered to decide if to pursue a modification (Brown, 2015). The cross-loadings in Table 6 were theoretically supported in terms of the content of items and the corresponding factors.

Modifications specifying the cross-loadings improved model fit (RMSEA = 0.05, SRMR = 0.05, CLI = 0.90, TLI = 0.90), supported by the lower AIC figure. As this remained close to the liberal thresholds for the incremental indices, it was considered that some items within the factors could have theoretically supported pairwise correlations. Therefore, pairs of items were reviewed, using MIs above 20 and EPCs >.3 to consider covariance in the error variance that may improve model fit. Table 7 displays the pairs considered and the theoretical links proposed.

Items SCS7 and SCS3 in factor eight tap into the notions of having balanced views and emotions, which may explain some shared error covariance. Similarly, items FFMQ14 and FFMQ4 in factor three both focus on telling the self not to think or feel a certain way and, therefore may share error covariance. Items FFMQ22 and FMMQ23 in factor five both focus specifically on inattentiveness.

Table 5.

Fit indices for models tested on full sample (N = 1090)

Model	**RMSEA [90% CI]**	**SRMR**	**CFI**	**TLI**	***χ^2 (df)***	**AIC**
One factor	**.091 [.089, .092]**	**.095**	.566	.547	10299.57 (1034)	143146.31
Three factor uncorrelated	**.082 [.080, .083]**	.199	.650	.634	8522.17 (1034)	140992.11
Three factor correlated	**.076 [.075, .078]**	**.082**	.695	.680	7554.25 (1031)	139898.64
Hierarchical eight factor	**.050 [.048, .052]**	**.069**	.870	.863	3813.38 (1081)	135568.93
Eight factor correlated	**.046 [.045, .048]**	**.057**	.890	.882	3357.95 (1006)	135089.72
Eight factor correlated model with four cross-loadings	**.045 [.043, .046]**	**.054**	.899	.891	3167.19 (1002)	134877.05
Eight factor correlated with four cross-loadings and error covariances	**.038 [0.037, .040]**	**.048**	**.926**	**.919**	2581.03 (991)	134220.34

RMSEA = root mean square error of approximation; CI = confidence intervals; SRMR = standardised root mean square residual; CFI = comparative fit index; TLI = Tucker-Lewis Index. AIC =Akaike information criterion. Indices in bold indicate acceptable fit based on liberal cut-off criteria at two decimal places.

While the DTS items had shared variance in terms of the factors they loaded on to, the wording of some items reflected shared processes regarding concepts such as coping and therefore may share error variance. This also reflected original scale findings of correlated residuals (Galiano et al., 2024). Some indicated modifications were not pursued due to the content of items describing differences in response to psychological distress. For example, in factor seven ‘non-reactivity to inner experience’, FFMQ21 referred to a passive reaction, whereas FFMQ18 referred to complete non-reactivity. Allowing correlation between this error variance did not improve the model fit.

Table 6

Item cross-loading modifications

Item	Current factor	Cross-loaded factor	Support for cross-loading
FFMQ24: *I disapprove of myself when I have illogical ideas*	Factor six: self-focussed judgement	Factor three: non-judging of inner experience	Both factors relate to the concept of self-judgement.
DTS7: *My feelings of distress or being upset are not acceptable*	Factor one: general distress tolerance	Factor three: non-judging of inner experience	The wording of the item may measure both judgement of personal inner experience as well as views regarding the concept of distress being unacceptable.
DTS11: *I am ashamed of myself when I feel distressed or upset*.	Factor one: general distress tolerance	Factor six: self-focussed judgement	The item may measure both sense of shame and how this relates to intolerance of distress.
SCS7: *When something upsets me, I try to keep my emotions in balance*	Factor eight: acceptance of experience	Factor seven: non-reactivity to experience	The concept of balance in the item words may reflect both the idea of accepting experience and non-reactivity.

Modifications allowing for the covariance of error variance improved the model fit to close to good (RMSEA = 0.04, SRMR = 0.05, CFI = 0.93, TLI = 0.92), with a lower AIC. All factor loadings were significant. The model was re-run with all cross-loading of items removed, and this decreased model fit slightly (RMSEA = 0.04, SRMR = 0.05, CFI = 0.92, TLI = 0.91, AIC = 134433.55).

Table 7.

Pairwise correlations of item error variances

Pair of items	Factor	Theoretical basis of correlation
FFMQ14 I tell myself I shouldn't be thinking the way I'm thinking FFMQ4 I tell myself that I shouldn't be feeling the way I'm feeling.	Factor three: non-judging of inner experience	Statements may reflect a harsh judgement of cognitive and affective states.
FFMQ23 I find myself doing things without paying attention. FFMQ22 I do jobs or tasks automatically without being aware of what I'm doing.	Factor five: acting with awareness	Shared more content than other items in the factor, focussing on inattention to current experience.

SCS7 When something upsets me I try to keep my emotions in balance. SCS3 When something painful happens I try to take a balanced view of the situation.	Factor eight: Compassionate self-responding	Statements may reflect a shared attitude to cognitive and affective states.
SCS12 I’m intolerant and impatient towards those aspects of my personality I don’t like. SCS11 I’m disapproving and judgmental about my own flaws and inadequacies.	Factor six: Uncompassionate self-responding	Statements both focus on the idea of judgement of personal characteristics.
DTS2 When I feel distressed or upset, all I can think about is how bad I feel (absorption) DTS1 Feeling distressed or upset is unbearable to me (tolerance)	Factor one: general distress tolerance	Statements may reflect a shared intolerance to cognitive and affective states.
DTS3 I can’t handle feeling distressed or upset (tolerance) DTS2 When I feel distressed or upset, all I can think about is how bad I feel. (absorption)	Factor one: general distress tolerance	Statements may reflect a shared approach to cognitive and affective states.
DTS4 My feelings of distress are so intense that they completely take over (absorption) DTS3 I can’t handle feeling distressed or upset (tolerance)	Factor one: general distress tolerance	Statements may reflect a shared approach to cognitive and affective states.
DTS15 When I feel distressed or upset, I cannot help but concentrate on how bad the distress actually feels. (absorption) DTS1 Feeling distressed or upset is unbearable to me (tolerance)	Factor one: general distress tolerance	Statements may reflect a shared approach to cognitive and affective states.
DTS3 I can’t handle feeling distressed or upset (tolerance) DTS1 Feeling distressed or upset is unbearable to me (tolerance)	Factor one: general distress tolerance	Statements may reflect a shared approach to cognitive and affective states.
DTS12 My feelings of distress or being upset scare me. (appraisal) DTS11 I am ashamed of myself when I feel distressed or upset (appraisal);	Factor one: general distress tolerance	Affective states in response to experiencing distress.
DTS 15 When I feel distressed or upset, I cannot help but concentrate on how bad the distress actually feels. (absorption) DTS 2 When I feel distressed or upset, all I can think about is how bad I feel (absorption);	Factor one: general distress tolerance	Shared concept of consuming focus on emotional distress.

Table 8.

Final model fit statistics

Sample	**RMSEA [90% CI]**	**SRMR**	**CFI**	**TLI**	χ^2 *(df)*	**AIC**
Combined	**.039 [.037, .041]**	**.049**	**.924**	**.917**	2612.57 (992)	134254.82
Intervention seeking	**.039 [.037, 0.42]**	**.053**	**.915**	**.907**	2238.72 (992)	100378.02
Non-intervention seeking	**.042 [.038, .047]**	**.057**	**.909**	**.901**	1489.60 (992)	33280.95

RMSEA = root mean square error of approximation; CI = confidence intervals; SRMR = standardised root mean square residual; CFI = comparative fit index; TLI = Tucker-Lewis Index. AIC =Akaike information criterion. Indices in bold indicate acceptable fit based on liberal cut-off criteria at two decimal places.

The sample was then split into intervention-seeking and non-intervention seeking samples to see if model fit was affected by clinical status, with modification indices retained. The model showed a close to good fit for both the intervention-seeking sample (*n*= 810, RMSEA = 0.04, SRMR = 0.05, CFI = 0.92, TLI = 0.91) and the non-intervention seeking sample (*n* = 280, RMSEA = 0.04, SRMR = 0.06, CFI = 0.91, TLI = 0.90). In the latter sample, item DTS11 had a non-significant factor loading on factor six, ‘uncompassionate self-responding’, which may have reflected people not seeking intervention experiencing distress at a level they did not find shameful or viewing distress in a way that did not lead to shame. However, DTS11 also had the lowest factor loadings across the model. Given this, the model was revised and DTS11 was retained only for factor one, ‘general distress tolerance’, as per the EFA findings of study one. The final model is shown in Figure 2; fit statistics for the full and split samples are in Table 8. All factor loadings (Appendix N) and factor correlations (Table 9) were significant. The factor correlation pattern above 0.4 found in study one was confirmed in the CFA.

Table 9.

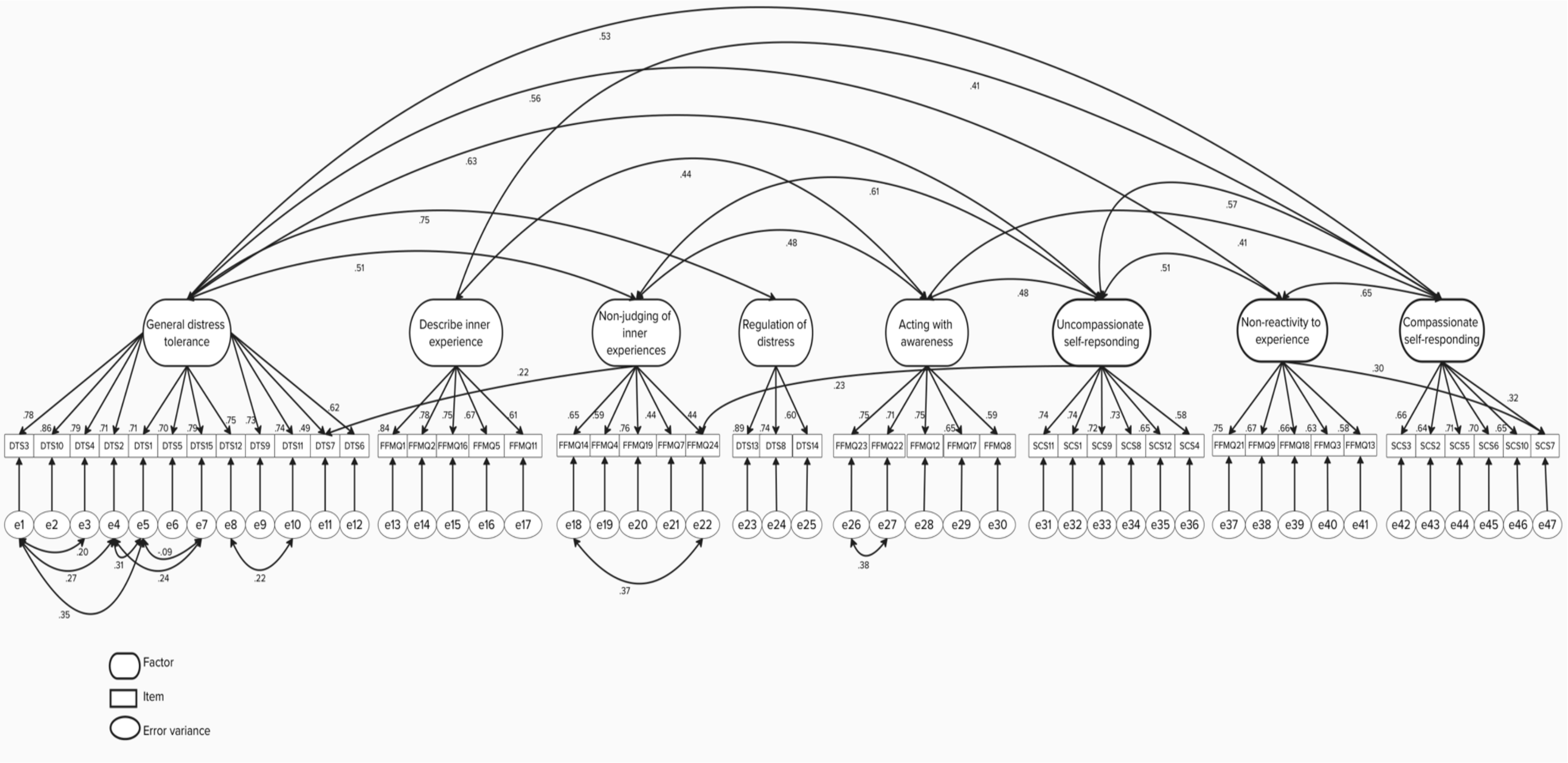
Factor correlations for final CFA model

	1	2	3	4	5	6	7	8
Factor 1 General distress tolerance	-	-	-	-	-	-	-	-
Factor 2 Describe inner experiences	.342*	-	-	-	-	-	-	-
Factor 3 Non-judging of inner experiences	**.509***	.314*	-	-	-	-	-	-
Factor 4 Regulation of distress	***.745****	.280*	.380*	-	-	-	-	-
Factor 5 Acting with awareness	.361*	**.435***	**.482***	.275*	-	-	-	-
Factor 6 Uncompassionate self-responding	***.626****	.393*	***.613****	.375*	**.481***	-	-	-
Factor 7 Non-reactivity to experience	**.560***	.327*	.337*	.296*	.304*	**.507***	-	-
Factor 8 Compassionate self-responding	**.530***	**.407***	.398*	.277*	**.411***	**.565***	***.648****	-

* p<.001, bold indicates moderate correlation above .4, bold and italicised indicates strong correlation above .6

Figure 2

Final CFA model path diagram



Factor correlations above 0.4 shown

Study 3

Hypotheses

Based on the CFA results in study two, the hypotheses below were developed to examine the relationship between the factors and self-reported obsessive-compulsive (OCD) symptoms. Distress tolerance has shown predictive value for OCD symptoms as a single factor in clinical and non-clinical samples (Cougle et al., 2011, 2012; Keough et al., 2010) but was not consistently an independent predictor when controlling for other variables (Blakey et al., 2015; Laposa et al., 2015; Macatee et al., 2013; Michel et al., 2016; See et al., 2022). Study two supported two highly correlated factors of distress tolerance rather than a single factor. Self-compassion has been reported as a non-significant predictor of OCD symptom level (Eichholz et al., 2019; Sher et al., 2023; Wetterneck et al., 2013), suggesting self-compassion's role is through its impact on emotional regulation (Odou & Brinker, 2014; Sher et al., 2023). Mindfulness facets such as acting with awareness, describing inner experience, and non-judging of experience have been linked to lower OCD symptoms (Crowe & McKay, 2016; Hawley et al., 2017), and non-reactivity predicted decreased symptoms post-intervention (Hawley et al., 2017).

Given the previous research findings and the findings of studies one and two the specific hypotheses for study three were:

1) The eight conceptual factors will show significant negative correlations with self-reported levels of OCD symptoms.

2) The two conceptual factors of distress tolerance (factors one and four) will be significant independent predictors of level of OCD symptoms.

3) The conceptual factors of mindfulness (factors two, three, five and seven) will be significant independent predictors of levels of OCD symptoms once distress tolerance factors are controlled for.

4) The conceptual factors of self-compassion (factors six and eight) will not be statistically significant independent predictors of levels of OCD symptoms once distress tolerance and mindfulness factors are controlled for.

Method

Materials

Study three utilised the factor structure from studies one and two, and the OCI-R (Foa et al., 2002) data from Leeuwerik et al. (2020). The OCI-R is an 18-item scale with six subscales (washing. checking, ordering, obsessing, neutralising, and hoarding) designed to measure level of obsessive-compulsive symptoms, developed from the original 34-item measure (Foa et al., 1998). Items are rated on a 5-point Likert scale ranging from not a lot (1) to extremely (4). Hoarding has been classified separately in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) since the OCI-R development. The scale has not been explored without the hoarding subscale other than by Wootton et al. (2015) and thus was retained in this analysis. Leeuwerik et al. (2020) found internal consistency of a = .90 in the intervention-seeking and a = .92 in the non-intervention seeking samples.

Participants

This study combined the samples from studies one and two (N = 2173), which already excluded participants missing values on the measures explored in those studies.

Missing data. Missing data for the OCI-R total score was explored on SPSS version 29. Fifty-seven cases (2.6%) contained missing data for the OCI-R. Little’s MCAR test indicated data were not missing completely at random ($X^2(5669) = 6539.86$, $p = .000$), likely due to the intervention-seeking participants survey platform not prompting missing answers. Cases were deleted listwise in ongoing analysis leaving a final sample of N = 2116. Demographic details are provided in Table 10.

Data analysis

The sample size was deemed adequate when applying Katz's (2011) 10:1 cases-to-variable ratio. Correlations between factors one to eight and total OCI-R score were analysed and applying the final CFA model to the regression sample indicated comparable fit to the original CFA sample (RMSEA = 0.04, SRMR = 0.05, CFI = 0.92, TLI = 0.91). Factor scores for each case were computed in MPlus, to assign a linear score. Correlational and multiple regression analyses were conducted on SPSS version 29.

Screening identified < 1% of cases were multivariate outliers, with no influential cases as Cook's distance was all below one (Cohen et al., 2002; Cook, 1977). Despite factor correlation exceeding 0.7 for some factors, VIF and tolerance statistics were in acceptable ranges for multicollinearity. The Durbin-Watson statistic (2.013) indicated independence of residuals (Durbin & Watson, 1951). Residuals showed acceptable kurtosis (1.02) but positive skew (0.89), with scatterplots confirming the skew and indicating potential homoscedasticity violations. To address these issues, robust bootstrapping regression was applied (Field, 2024). A hierarchical multiple regression model was constructed in three steps: distress tolerance factors (step 1), mindfulness factors (step 2), and self-compassion factors (step 3). Changes in R^2 at each step were analysed to determine the additional variance explained by each factor group.

Table 10.

Sociodemographic variables in the total (N=2116), intervention-seeking (n=1581) and non-intervention-seeking (n= 535) samples for study three.

Variable		Total sample (N, %)	Intervention seeking (n, %)	Non-intervention seeking (n, %)
Age	18-24	819 (38.7)	298 (18.8)	521 (97.4)
	25-34	360 (17.0)	352 (22.3)	25-34 (1.5)
	35-44	249 (11.8)	246 (15.6)	3 (0.6)
	45-54	280 (13.2)	279 (17.6)	1 (0.2)
	55-64	252 (11.9)	251 (15.9)	1 (0.2)
	65+	139 (6.6)	139 (8.8)	0 (0.0)
	Prefer not to say	10 (0.5)	10 (0.5)	0 (0.0)
	Missing	7 (0.3)	6 (0.4)	1 (0.2)
Gender	Female	1570 (74.2)	1133 (71.7)	437 (81.7)
	Male	521 (24.6)	429 (27.1)	92 (17.2)
	Other	6 (0.3)	5 (0.3)	1 (0.2)
	Prefer not to say	7 (0.3)	5 (0.3)	2 (0.4)
	Missing	12 (0.6)	9 (0.6)	3 (0.6)
Highest educational qualification	No educational qualification	73 (3.4)	73 (4.6)	0 (0.0)
	Secondary	1191 (56.3)	791 (50.1)	400 (74.2)
	Higher	791 (37.4)	661 (41.8)	130 (24.3)
	Prefer not to say	52 (99.6)	48 (3.0)	4 (0.7)
	Missing	9 (0.4)	8 (0.5)	1 (0.2)
Employment status	Employed/self-employed	937 (44.3)	915 (57.9)	22 (4.1)
	Looking for work	115 (5.4)	107 (6.8)	8 (1.5)
	Not looking for work	83 (3.9)	79 (5.0)	4 (0.7)
	Unable to work	144 (6.8)	144 (9.1)	0 (0.0)
	Student	610 (28.8)	112 (7.1)	498 (93.1)
	Retired	182 (8.6)	182 (11.5)	0 (0.0)
	Prefer not to say	34 (1.6)	32 (2.0)	2 (0.4)
	Missing	11 (0.5)	10 (0.6)	1 (0.2)
Ethnicity	White background	1936 (97.8)	1486 (94)	450 (84.1)
	Asian background	51 (2.4)	28 (1.8)	23 (4.4)
	Black background	26 (2.2)	16 (1.0)	9 (1.7)
	Mixed background	47 (2.3)	26 (1.7)	21 (3.9)
	Other background	33 (1.6)	9 (0.6)	24 (4.5)
	Prefer not to say	18 (0.8)	11 (0.7)	7 (1.3)
	Missing	6 (0.3)	5 (0.3)	1 (0.2)
Intervention status	Not yet started intervention	1213 (57.3)	1213 (76.7)	N/A
	Declined NHS intervention	6 (0.3)	6 (0.4)	N/A
	Received some intervention	307 (14.6)	307 (19.4)	N/A
	Not asked as controls	535 (25.3)	N/A	535 (100.0)
	Prefer not to say	40 (1.9)	40 (2.5)	N/A
	Missing	15 (0.7)	15 (0.9)	N/A
Previous experience of mindfulness	Yes	337 (15.9)	289 (18.3)	48 (9.0)
	No	1695 (80.1)	1228 (77.7)	467 (87.3)
	Prefer not to say	70 (3.3)	51 (3.2)	19 (3.6)
	Missing	14 (0.7)	13 (0.8)	1 (0.2)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

Results

As predicted, all correlations between the eight factors identified in studies one and two and OCI-R total score were significant, ranging from small to moderate negative correlations (Table 11). The same correlation pattern between factors was found as in the CFA.

The results of the hierarchical regression are shown in Table 12. The step-1 model was significant (R^2 = .190*,* ΔR^2 =.190*,* $F(2, 2113)$ = 248.36*,* p <.001), showing the distress tolerance factors explained 19% of the variance in OCI-R scores. Contrary to hypotheses, the predictive ability of these factors varied. *General distress tolerance* was a small but significant negative independent predictor of OCI-R score (pr = -.03, sr^2 = .08), indicating that higher levels of distress tolerance were associated with lower OCI-R scores (p<.001). *Regulation of distress*, however, was not a significant predictor (p = .486, ns).

At step two mindfulness factors were entered, and explained variance increased by seven percent to 26%, indicating the model had significantly increased explanatory power with these new predictors (*F*-change (4, 2109) = 50.56, p < .001, ΔR^2 = .071). *General distress tolerance* remained a small, significant predictor (p = <.001) and *regulation of distress* remained a nonsignificant predictor (p = .20, ns). All additional factors introduced in step two were statistically significant predictors, though with small effects. *Non-reactivity to experience* had a marginally significant effect (p =.02), as shown in Table 12.

In the final model, the inclusion of *uncompassionate* and *compassionate self-responding* did not significantly increase explained variance (*F*-change (2,2107) = 1.41, p =.245, ΔR2=.000), aligning with hypotheses that these factors would not predict OCI-R scores after controlling for other factors. In this final model, *regulation of distress* remained a nonsignificant predictor (p=.211, ns). *General distress tolerance, describe inner experience, non-judging of* *inner experience, acting with awareness* (all at p <.001)*,* and *non-reactivity to experience* (p = .04) remained significant, small predictors, showing that these factors uniquely predicted OCD symptom level when controlling for each of the other factors.

Table 11.

Correlations between factors 1-8 and OCI-R total score

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Factor 1 General distress tolerance	-	-	-	-	-	-	-	-
Factor 2 Describe inner experiences	.322*	-	-	-	-	-	-	-
Factor 3 Non-judging of inner experiences	**.581***	.306*	-	-	-	-	-	-
Factor 4 Regulation of distress	***.794****	.246*	**.407***	-	-	-	-	-
Factor 5 Acting with awareness	**.438***	**.486***	**.561***	.309*	-	-	-	-
Factor 6 Uncompassionate self-responding	***.679****	.357*	***.713****	**.432***	**.565***	-	-	-
Factor 7 Non-reactivity to experience	***.624****	.330*	**.415***	.364*	.372*	***.614****	-	-
Factor 8 Compassionate self-responding	***.602****	**.456***	**.477***	.310*	.500*	***.693****	***.777****	-
Total OCI-R	**-.436***	-.312*	**-.403***	-.338*	-.386*	**-.415***	-.342*	-.355*

* p<.001, bold indicates moderate correlation above .4, bold and italicised indicates strong correlation above .6

Table 12.

Hierarchical regression of distress tolerance, mindfulness and self-compassion factors on to OCI-R total score

Outcome	Model	Predictor	*B*	Lower CI	Upper CI	*SE*	*β*	*p*	ΔR^2	*Pr*	sr^2
OCI-R Total *N*= 2116	1	General distress tolerance	-6.27	-7.18	-5.49	0.42	-0.45	<.001	.190*	-0.29	.076
		Regulation of distress	0.27	-0.49	1.05	0.38	0.02	.486		0.02	.000
	2	General distress tolerance	-2.58	-3.81	-1.52	0.57	-0.19	<.001	.071*	-0.10	.007
		Regulation of distress	-0.48	-1.21	0.30	0.37	-0.04	.204		-0.03	.001
		Describe inner experience	-1.75	-2.46	-1.05	0.35	-0.11	<.001		-0.11	.009
		Non-judging of inner experience	-3.20	-4.29	-1.95	0.61	-0.14	<.001		-0.12	.011
		Acting with awareness	-2.71	-3.79	-1.67	0.54	-0.13	<.001		-0.12	.010
		Non-reactivity to experience	-1.31	-2.46	-0.16	0.58	-0.07	.020		-0.06	.002
	3	General distress tolerance	-2.46	-3.65	-1.31	0.59	-0.18	<.001	.001	-0.09	.006
		Regulation of distress	-0.47	-1.24	0.31	0.38	-0.04	.211		-0.03	.000
		Describe inner experience	-1.83	-2.53	-1.13	0.36	-0.12	<.001		-0.11	.009
		Non-judging of inner experience	-2.77	-4.08	-1.36	0.68	-0.12	<.001		-0.09	.007
		Acting with awareness	-2.65	-3.77	-1.52	0.57	-0.13	<.001		-0.11	.009
		Non-reactivity to experience	-1.46	-2.84	-0.15	0.68	-0.07	.037		-0.05	.002
		Uncompassionate self-responding	-0.94	-2.21	0.39	0.67	-0.05	.157		-0.03	.001
		Compassionate self-responding	0.69	-0.90	2.08	0.78	0.04	.381		0.02	.000

BCa 95% CI, *SE* and *p*-values based on 1000 bootstrap samples

OCI-R obsessive compulsive inventory-revised, ΔR^2 (change) explained variance*, pr* partial correlation*, sr^2* semi-partial correlation squared

* *F*-change statistic significant at *p* = < .001

Discussion

The project's first aim was to examine if items from validated measures of mindfulness, self-compassion, and distress tolerance load onto a smaller number of underlying constructs than would be expected from the original measures. The additional aim was to examine how the identified factors related to levels of self-reported obsessive-compulsive difficulties.

Hypothesis one predicted that a theory-free factor structure of items from measures of mindfulness, distress tolerance and self-compassion would indicate an overlap between the constructs. Contrary to this, the EFA revealed limited overlap between items on the FFMQ-SF, DTS, and SCS-SF, finding eight factors, with only one FFMQ-SF item loading on a predominantly SCS-SF factor. This suggested that the measures assess distinct constructs, further confirmed by the CFA's poor fit for one- and three-factor models contrary to hypothesis two that an overlapping factor structure would be confirmed. However, some factors combined items originally separated into subscales, notably splitting distress tolerance across two factors instead of the DTS's four-factor model. This supports previous findings that a four-subscale DTS may be redundant, with a regulation subscale possibly independent from a general distress tolerance subscale (Galiano et al., 2024; Rogers et al., 2020).

Distress tolerance factors showed the highest intercorrelations in studies one and two, indicating closer conceptual overlap than with other constructs. The SCS-SF items grouped into two factors ('uncompassionate' and 'compassionate' self-responding) rather than the components proposed by Neff (2003a, 2003b). This is consistent with previous suggestions that this measure of self-compassion may encompass both positive (self-compassion) and negative (self-criticism or self-coldness) elements (Babenko & Guo, 2019; Brenner et al., 2017; Costa et al., 2016; Kotera & Sheffield, 2020; López et al., 2015). Critiques suggest this two-factor model might reflect only positive versus negative item wording, where negatively worded items measure self-criticism, a lack of which cannot be assumed to indicate self-compassion (Muris et al., 2024).

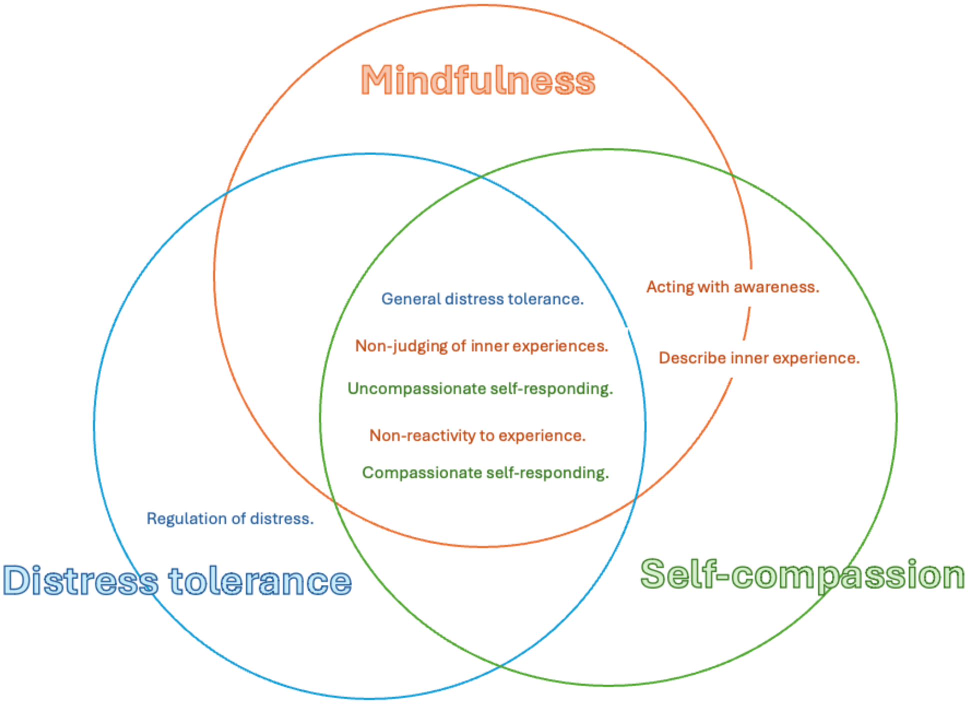
The correlations between the self-compassion and mindfulness factors were similar to correlations found between the constructs when using other measures of mindfulness in mental health literature (Baer et al., 2006). SCS-SF mindfulness items (‘*when something painful happens I try to take a balanced view of the situation’, ‘when something upsets me I try to keep my emotions in balance’*) did not align with FFMQ-SF items, likely due to the SCS-SF’s focus on intention compared to the FFMQ-SF items’ focus on behaviour. The four FFMQ-SF factors correspond with existing findings that using FFMQ-SF subscales is preferential to using a total score (Baer et al., 2006; Hawley et al., 2017; Williams et al., 2014).

The best-fitting CFA model, an eight-factor correlated structure, confirmed some potential conceptual overlap through cross-loadings and factor correlations, with no correlations above 0.8. This again suggested that while there are related aspects across measures, they remain sufficiently distinct, without fewer overarching constructs. Error covariance improving model fit seemed to be explained by items measuring related aspects of some concepts, such as cognitive and affecting states. Figure 3 illustrates the potential conceptual overlaps, based on the final CFA model correlations above 0.4, between factors from different scales.

Overarching hypothesis three predicted that the identified latent factors would vary in whether they are predictors of self-reported levels of obsessive-compulsive difficulties, a hypothesis that was confirmed. The factors that uniquely predicted the level of OCD symptoms when other factors were controlled for were *general distress tolerance, describing inner experience, non-judging of inner experience, acting with awareness,* and *non-reactivity to* *experience. Regulation of distress, uncompassionate self-responding,* and *compassionate self-responding* were not unique predictors.

Figure 3.

Proposed areas of conceptual overlap based on factor correlations.



Blue- DTS factors; Green- SCS-SF factors; Orange- FFMQ-SF factors

Regarding the specific hypotheses developed after identifying the factor structure, one distress tolerance factor predicted OCD severity but the other did not. The finding that *general distress tolerance* is a significant negative predictor of OCI-R scores aligns with existing literature suggesting that higher distress tolerance is associated with fewer OCD symptoms (Abdi et al., 2023; Laposa et al., 2015; Robinson & Freeston, 2014), also linked to lower quality of life in people with OCD (Garner et al., 2018). The ability to withstand emotional discomfort without resorting to maladaptive behaviours (Leyro et al., 2010), may reduce overwhelm, in turn perhaps reducing the urge to use compulsive actions to cope with distressing obsessions. In relation to

OCD intervention, the ability to tolerate distress related to obsessions without engaging in compulsions is integral to the ERP approach, which allows inhibitory learning to occur (Jacoby & Abramowitz, 2014). In contrast, the *regulation of distress* factor did not significantly predict OCI-R scores when controlling for other factors across models, indicating that the capacity to control emotional distress may not directly mitigate OCD symptoms over and above other factors. This finding might be due to the nature of OCD, where compulsions are often employed specifically to manage distress caused by intrusive thoughts, making distress tolerance (endurance) more relevant than regulation (modulation) in intervention to develop inhibitory learning (Abramowitz & Arch, 2014).

People experiencing OCD react strongly to intrusive thoughts, by definition, part of the maintenance cycle of obsessions and compulsions (Salkovskis, 1985, 2007). *Non-reactivity to experience's* marginal role in uniquely predicting OCD symptom severity aligns with research suggesting that improving non-reactivity through intervention may alleviate the intensity of intrusive thoughts (Hawley et al., 2017), although such findings of greater difficulties with non-reactivity for people with OCD compared to people without mental health difficulties are not consistent (Crowe & McKay, 2016). *Describe inner experience* has been found elsewhere as being lower in people experiencing OCD than people without mental health difficulties (Crowe & Mckay, 2016), which may link with suggestions that a relative lack of such meta-cognitive skills may contribute to alexithymia that predicts obsessive-compulsive difficulties (Abdi et al., 2023; Robinson & Freeston, 2014).

Non-judging of inner experience and *acting with awareness*, a concept focussed on choosing how to respond rather than automatically reacting, have been linked in previous research to experiencing fewer OCD symptoms (Crowe & McKay, 2016; Didonna et al., 2019;

Emerson et al., 2018), possibly due to people higher on these attributes being more able to choose not to engage in compulsions. Cognitive models of OCD often emphasise cognitive distortions, such as inflated responsibility or thought-action fusion (Rachman, 1997; Shafran et al., 1996); increasing ability in these areas of mindfulness may support people to detach from such thoughts and reduce the level of compulsions.

The finding that *uncompassionate* and *compassionate self-responding* did not uniquely predict OCD severity when controlling for other factors may be explained by self-compassion generally being related to the mitigation of shame and self-criticism (Gilbert, 2009), which as such may not be a direct influence on the cognitions proposed to underlie OCD. This is also supported by existing findings that compassionate self-responding is not an independent predictor of internalising symptoms once uncompassionate self-responding is controlled for, and use of the total SCS-SF score may inflate self-compassion's relationship with affective difficulties (Muris & Petrocchi, 2017). Given OCD compulsions are posited to alleviate perceived threats rather than mitigate self-criticism, self-compassion may, therefore, have a limited direct impact on the level of symptoms. However, this may vary depending on the nature of obsessional content, given suggestions that some obsessional content is associated with higher levels of shame (Weingarden & Renshaw., 2015; Wetterneck et al., 2014) and self-compassion may be an important factor in reducing shame as a barrier to engagement in interventions (Glazier et al., 2015; Weingarden & Renshaw., 2015).

Strengths and limitations

The inclusion of both intervention-seeking and non-intervention-seeking participants enabled the exploration of potential conceptual overlaps in constructs within a more diverse population, enhancing generalizability. However, the sample's predominantly female, White

British, and student demographic limits the findings' applicability. Distress tolerance, often conceptualised variably (Leyro et al., 2010), was narrowly assessed using the DTS scale, focusing only on the idea of withstanding emotional states. A broader measure might have provided deeper insights into the construct. Additional factors such as obsessive beliefs (Wheaton et al., 2010), depression (Overbeek et al., 2002), and anxiety sensitivity (Laposa et al., 2015; Robinson et al., 2014) may also influence how the eight factors predict OCD symptoms but were beyond the study's scope. Investigating relationships based on intervention-seeking status could have shed light on the factors' roles in help-seeking behaviours.

Implications

The studies have several implications for clinical practice and research, related to the impact of investigating multiple constructs within one investigation.

Clinical implication

The project identified mindfulness, distress tolerance and self-compassion as distinct constructs with some conceptual overlap, evidenced by correlated factors. The small effect sizes for the identified predictors may reflect the complexity of OCD symptoms. Additionally, given that the factors are correlated, the small effect sizes reflect the unique contribution of each factor. This is consistent with findings that OCD is multifaceted, influenced by cognitive, emotional, and behavioural components (Taylor et al., 2007), supporting multifaceted treatment approaches. Currently, ERP is the dominant psychological intervention for OCD, which focuses on increasing distress tolerance and may include adjunct cognitive restructuring (Foa et al., 2012; Jacoby & Abramowitz, 2016; NICE, 2005; Salkovskis, 2007). Similarly, third-wave interventions are generally designed with one construct foregrounded over the others, for example, CFT focusing on self-compassion and MBCT on mindfulness. The shared concepts across the constructs, as shown by shared variance, and their role as unique predictors in OCD severity advocate for the development and evaluation of a theoretically integrated therapy tailored to the individual needs of some people experiencing obsessive-compulsive difficulties.

The finding that self-compassion does not independently predict level of OCD difficulties raises questions regarding the effectiveness of such intervention being used with people with OCD. However, the correlations with OCD symptom level and other factors, indicates that while not a unique predictor that requires an explicit focus in intervention, self-compassion may be implicitly involved in mindfulness and distress tolerance focussed interventions. Additionally, given previous findings that it mediates the relationship between emotional regulation and OCD symptoms (Eicholz et al., 2020) and that shame impacts quality of life for with experiencing OCD (Singh et al., 2016), self-compassion may be an important intervention target for people who have persistent difficulties after psychological intervention or to address other related areas of difficulty.

Research implications

Given there may be variation in predictors and associations depending on the form of obsessional content people experience, further research may benefit from investigating how self-compassion, mindfulness and distress tolerance predict OCD symptoms in differing subgroups of OCD obsessional content. Additionally, it may be possible that self-compassion has a delayed effect on OCD symptom levels as people may learn to be more accepting of their experiences during interventions and develop higher levels of self-compassion; longitudinal studies may help understand the role of this construct in OCD. As identified above, the influence of other constructs on the relationship between the factors and level of OCD symptoms warrants further investigation.

Future research would also benefit from considering how the definitions of the constructs and the way they relate to OCD experiences vary across cultural groups. Given variations in OCD experiences and shame depending on cultural background (e.g. Fernandez de la Cruz et al., 2016; Williams et al., 2017) it may be the role of self-compassion as a predictor of obsessive-compulsive difficulties compared to mindfulness and distress tolerance may be an area important to understand further for delivering culturally competent interventions (Williams et al., 2020).

Conclusion

This project used measures of mindfulness, distress tolerance and self-compassion to explore if they could be explained by a smaller number of constructs and how the identified constructs related to levels of OCD. Eight correlated factors were identified, two composed of distress tolerance concepts, four by mindfulness concepts and two by self-compassion concepts. All were small but significant, unique predictors of levels of OCD, except for the self-compassion concepts. The findings have clinical implications, such as supporting the development and evaluation of theoretically integrated interventions, and highlight the importance of future research considering cultural variations in how the constructs may relate to OCD experiences.

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Section C: Appendices

Appendix A: NVivo Coding Examples

ACCEPTANCE OF OCD	4	12
Journey to acceptance	2	3
Others should accept...	1	1
ACCOMMODATION OF O...	7	22
Accommodating OCD =...	1	3
Accommodating vs cha...	4	14
Accommodation of OC...	4	4
Support vs dependency	1	1
AVOIDANT STRATEGIES	4	7
Deny problem	2	2
BATTLE	6	15
Battle for support	3	3
Battle of living with OCD	2	5
Crisis is subjective	1	1
Fighting back at OCD	1	5
Identifying help a strug...	1	1

CONTROL	6	28
Control through OCD	2	5
Controlling OCD	4	6
Fear of losing control	2	3
Lack of diagnosis is lac...	1	1
OCD in control	2	10
Sense of losing control	1	3
COPING	6	11
COPING ALONE	5	10
Lack of support	1	1
PEOPLE AS SUPPORT	0	0
CULTURE	5	16
cultural beliefs influenc...	1	1
Cultural differences in...	2	7
Cultural gender norms	1	1
Cultural responses to d...	1	2
Cultural ties important	1	1
Psychiatric services as...	2	4

BELIEFS & PERCEPTIONS	10	61
Belief in change	1	1
causes of difficulties	3	10
Changes in perception	1	2
individual factors link t...	1	2
It will pass without help	1	1
Life experiences link to...	1	10
OCD is negative	1	1
OCD permanent	4	13
Perceived causes vary	1	2
Still noticing positives	1	2
Timing for therapy	2	2
Trauma or stress linked...	2	10
Undeserving of treatm...	1	1
Viewing problem as mild	2	4
BLAME	3	6
Blame from others	3	3
Blame reduced by exte...	1	1
self-blame	1	1
CONNECTION TO PLACE	1	3

EMOTIONS	10	22
Embarrassment	3	6
Emotional strain of help...	1	2
Guilt and anxiety about...	1	2
Negative emotional imp...	1	1
Pressure of compulsion...	1	1
Shame	5	10
FUNCTIONING AND LIFE	10	77
Emotional impact of bei...	2	5
Everyday life	4	10
Flexibility = functioning	1	1
Impacts activities	7	14
Impacts goals	1	2
Impacts self-care	3	5
Impacts social relations...	5	8
Life dissatisfaction and...	3	6
OCD affects others lives	3	18
Silver linings of OCD	5	7
Ways of supporting aff...	1	1

Appendix B: Additional quotes from the analysis

Theme	Subtheme	Papers	Selection of extracts *
Understanding and recognition of OCD		12	"For some, there was a sense of unfamiliarity, *'didn't even know it was OCD . . . it just didn't make any sense'* [ID43, father], whereas others struggled to differentiate between normative childhood development and disordered behaviour. *'I think a lot of it I didn't really notice for a while because . . . kids are always running their hands along walls and tapping things and touching things, that's what kids do when they are young'* [ID28, father]" (Chessell et al., 2023, p. 74). "Most participants thought that their behaviour was 'normal' as it was so habitual from such a young age. For example, Charles states: '*I didn't realise what I was doing but to me it was part of life...'*." (Keyes et al., 2018, p. 180). "Also, most of the participants, like Gemma, reported that their parents thought their behaviour were childhood quirks and would pass without seeking help: 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., p. 180). "One of the most prominent barriers to accessing help was a lack of knowledge of and information regarding mental health issues in general, and OCD specifically, both within the participants' communities and from their schools and health providers. One participant noted: *I had never heard about OCD and it is not like any other illness…..* (Female, 43, Indian)". (Kolvenbach et al., 2018 p. 101). "In describing her efforts to seek help for her hoarding behavior, "K" stated "*I found that the therapist or the people in the health care profession did not have the picture at all. I guess they just didn't either believe me what I was saying or they just minimized it so severely that I could be having the kind of the, you know, the magnitude of the problem that I have. I don't know what."* (Olson et al., 2007, p. 4). "Similarly, "T" fully appreciated the neurobiological basis of his OCD, yet insisted, *"in a spiritual way, I feel like God gave me this disorder to see how tough it can be and to test my strength and to test me.'*" (Olson et al., 2007, p. 5). "One participant believed that her mother's insistence on excessive and meticulous care of the home during her upbringing, had led her to believe that *"all that was normal."* The participant recalled that her 'symptoms' only started to become evident when she became older and started to spend more time with a partner, whose behaviour contrasted significantly to her own: *"It probably then started hitting me that 'This isn't right that I'm doing these type of things'*….""". (Pedley et al., 2019, p. 6). "Participants often cited a combination of both 'internal' factors (e.g. the "connection in the back ofyour head", "serotonin levels", or genetics), and external factors, such as their upbringing (e.g.

Theme	Subtheme	Papers	Selection of extracts *
			learnt behaviour), significant events or traumas. Internal causes could be biological or even the participant's own personal characteristics, such as their way of thinking (e.g. someone who "thinks deeply"), their 'character' or 'personality'…" (Pedley et al., 2019, p. 8). "Six participants said that, at least for a period, it had not occurred to them to seek help. Two of these participants linked this with their OCD having become so much a part of their everyday life. One said their OCD, *"had always been there. Yeah, it's like ... every day.'"*" (Robinson et al., 2017, p. 202). "It was felt by most participants that members of the public and even many professionals, failed to recognise OCD as a serious and debilitating mental health condition: *"I know society will joke about OCD, but unless you're living with it, I don't think you can have any idea as to how controlling it is really of your life."* (Parent 12: interview, female, age 40–44)." (Sowden et al., 2023, p. 8). "Presentations of OCD, which did not often map onto stereotypes of the condition (including thoughts around harm or sexually intrusive thoughts or where their child's ritual involved seeking reassurance), left some parents feeling distressed and confused about what was wrong with their child". (Sowden et al., 2023, p. 8). *"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."* (P5, 14 yr old boy)" (Sravanti ey al., 2022, p. 6). *"I didn't know that the illness exists at all and always thought, well, it's just his own personal quirks, just as everybody has their own little eccentricities."* (Stengler-Wenzke et al., 2004, p. 37). "Participants generally felt more information regarding the lesser known symptoms of OCD, such as the sexual obsessions or 'pure O', was required to help patients identify their OCD: "*there's so much more to washing your hands lots of times a day, which is all I knew about it at the time* (participant 85, female, age 30)." (Vuong et al., 2016, p. 9).
Debating if help is needed	Content and form of experiences	8	"For some interviewees, religious symptoms seemed to be the reason for actively seeking help. This was the case with H., 17 years old: *"All symptoms were distressing, but religious symptoms were the ones that made me come to the psychiatrist."*" (Al-Solaim & Loewenthal, 2011, p. 177). "In addition to changing in severity, participants often explained that the content of their obsessions and compulsions shifted over time: *". . .through my life, it's metamorphosised, it's changed, it's gone into different things. The only thing I've never had a problem with is symmetry. I've never had a problem hoarding. I've never had a problem going in and out of doors and things like that. But the checking, the contamination, the intrusive thoughts, all them things I have had."* (P.3, f)" (Pedley et al., 2019, p. 13).

Theme	Subtheme	Papers	Selection of extracts *
			“A participant whose intrusive thoughts were about sexually abusing children feared the authorities might think s/he was a paedophile. *“Oh … I really thought that if I told them what I was thinking that I’d be either sectioned or sent to prison … Really, that was like the scariest thing … I don’t think anyone wants to be sectioned or sent to prison, do they? … So that’s why. 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, p. 203-204). “Three participants were driven to seek treatment because they had intrusive thoughts about harming children. They were very frightened by these thoughts and mistakenly interpreted them as meaning they were capable of harming children.” (Robinson et al., 2017, p. 206). “A fourth participant was driven to talk to a health professional about her / his OCD for the first time because of her / his intrusive thoughts related to scrupulosity; “*At the point I got the permanent job I had to fill in an Occupational Health form … and one of the bits was anxiety disorders. And … I guess with the confessing thing, having to be 100% clear I was telling the truth, which I also understand is an OCD thing, and so I felt I had to fill it in … but I was really wound up by that, and upset, because I’d never told anybody’”*” (Robinson et al., 2017, p. 206).
	The level of distress and interference with life	12	“The five daily prayers, and their preceding ablution rituals (wodoo), followed by repeating the mandatory prayers five times a day. All interviewees thought that these symptoms were most distressing, time-consuming, and physically exhausting. As a result, they were perceived as most interfering with normal life activities and the main reason for seeking treatment.” (Al-Solaim & Loewenthal, 2011, p. 178). “Gina, on the other hand, mentioned a lack of control…which made her distressed and angry, and deeply affected how she saw herself as a person.” (Sear, 2021, p. 320). *“I think surprising as well because, um he has gone from being a very placid, very affectionate child to being quite aggressive, and angry, really angry [ID23, mother]” (Chessell et al., 2023, p. 79).* “Parents identified that OCD controlled their own lives – for example, through the need to provide constant reassurance or to vigilantly monitor their child’s difficulties.” (Chessell et al., 2023, p. 79) *“‘it’s wrecked the family life . . . the way everybody used to interact changed an awful lot, and it’s you know, as parents you try to keep harmony between everybody, and it was very difficult to get that’ [ID34, father]”* (Chessell et al., 2023, p. 80). “Tobias explains: “*Well, [for] ages I just wanted to stay in my room because [it] kind of felt safer. I didn’t want to like do anything, because I was scared of doing like bad things, like violent things, because of the OCD. So I didn’t want to like put anyone at risk... I just wanted to stay by myself. It’s ruined everything’”*” (Keyes et al., 2018, p. 181)

Theme	Subtheme	Papers	Selection of extracts *
			"Participants' lack of sleep meant that they were tired often, and not emotionally or physically available for active engagement with their family and friends." (Kohler et al., 2018, p. 5). *"… I've had enough of it, like I've been dealing with it since junior school and I hate my thoughts, I hate my little tics, so some days maybe a teensy bit satisfied but overall I'm not satisfied, no (Kelsey, a 31-yearold female)."* (Kohler et al., 2018, p. 5). "All interviewees found these symptoms to be very distressing, time-consuming, and physically exhausting. Consequently, their religious OCD symptoms were observed as causing the most interference with normal life activities and the leading reason for seeking treatment." (Mahintorabi et al., 2017, p. 6). "One participant, DD, did not want to seek help at all, until she realised that her symptoms were impacting on her family members, As DD stated: *'I did not want to ask for help, I was fine to do things like that . . . But when I was 18, my mom passed away, my symptoms got worse afterwards, and my little sister and brother tried to convince me not to wash things and myself excessively . . . I remembered my little sister used to come to the bathroom with me, watching me and trying to stop me from washing more. After few months, I realised that my behaviours are extreme, and I have put too much pressure on my family members, so I did try to talk to a religious advisor (Imam) which was not helpful. Eventually, at the age of23, I sought professional help and went to see a psychiatrist; he did diagnose me with OCD'."* (Mahintorabi et al., 2017, p. 8). "…taking steps to maximise their wellbeing through good self-care (e.g. eating and sleeping well) and strategies to promptly access treatment and manage pressure when symptoms started to worsen: '*. . .I let the doctor know very quickly that this [increase in symptoms following difficult life event] is what was going on. I booked in myself into counselling very quickly that I accessed. I booked time off work to have a few days away. And because of all those steps that I took, I felt safe. . .'* (P.8, m)" (Pedley et al., 2019, p. 11). "Eight participants said that it was reaching a crisis / crunch point that finally pushed them to seek treatment. '*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 I 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, p. 204).
	Beliefs about coping with OCD experiences	11	*"I went to a faith healer with my parents, he read verses from the Qura'an and said it was evil eye that caused the symptoms, but recently he said that there is wind in my head that is causing some noise."* (Al-Solaim & Loewenthal, 2011, p. 174). "Young people wanted those in their systems to accommodate their OCD related behaviours, but acknowledged in the long-term that this was unhelpful, as Amy explains: *Well, normally I'm with my parents and my family, so they will do it... They know that I won't*

Theme	Subtheme	Papers	Selection of extracts *
			touch them, so they'll sort of just touch it for me. My mum always carries an anti-bacterial hand gel so if I don't have one my mum's always got one. Not in the long term probably, but in the short term it's nice to know that there is something there that she can help me." Again, this conflicting experience led to ambivalence in relation to gaining help." (Keyes et al., 2018, p.182). "… strategies that would not be recommended as part of modern exposure and response prevention-based approaches, such as avoidance or by asking others for reassurance: *"I rang my mum up the day before and went, 'do you think the world's going to end tomorrow? She went, 'no'. I was like, 'thanks mum'. That's all I needed. She's very well trained. . ."* (P.13, f)." (Pedley et al., 2019, p. 10). "Four participants described delaying seeking help because they felt they could manage the problem themselves; *"I think for a long time I felt maybe I could deal with it myself.""* (Robinson .et al., 2017, p. 201). Five participants described how they, or their parents, did not accept that they had a problem, or thought that it would go away; *"But 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, p. 202). "…discrepancies could occur between parents' understanding and approach to caring, which could exacerbate the disruption caused by a child's OCD symptoms: *"My husband and I, you know, were at loggerheads about how we were dealing with [our daughter's] challenging behaviour"* (Parent 4: interview, female, age 45–49)." (Sowden et al., 2023, p. 9). *"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'. (P6, 12 yr old girl)* (Sravanti et al., 2022, p. 6). *"I thought it will not go at all. It will be with me forever. I was afraid. I had a lot of questions about it, but I couldn't find answers." (P5, 14 yr old boy)…. It took time but I realised it is something I can work on and I can get better." (P9, 11 yr old boy). (Sravanti et al., 2022, p. 6).*
Support outside professional networks		6	*"'immediately as soon as a parent, understands that their child has got OCD, I think they should be put in a room with other parents with children with OCD, because immediately it's really, it's such a lonely experience . . ." (Chessell et al., 2023, p. 81).* "Bradley states: *"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…""* (Keyes et al., 2018, p. 181). *"…when I was diagnosed with OCD they were very supportive, very very supportive. In terms of financially supporting my therapy, financially supporting my education, and emotionally supporting me etc."* (Stuart). (Kohler et al., 2018, p. 6).

Theme	Subtheme	Papers	Selection of extracts *
			"Humour, in particular, was perceived as a supportive gesture and helped some participants to function and feel accepted—socially and at work—despite OCD. One participant mentioned how her and her friends would humour her situation, *…For example, a story like Dr. Monk, who is obsessive–compulsive, then I always said to them, "I'm Mr. Monk, "then they laugh, then they click and say," Yes, yes, now we know exactly why you were like that…* (Sandra, a 39-year-old female)." (Kohler et al., 2018, p. 7).
			"Several parents shared their disappointment with the absence of support within the community or outside the public health system and suggested for instance instituting support groups for parents and patients to ensure ongoing emotional and practical support." (Kolvenbach et al., 2016, p. 101).
			"Thus, "G" explained, in regard to the symptoms described above, *"I thought, okay, I've got this illness for a reason. I'm supposed to do something with it, you know."* "The reason," she found, came in helping others through the OC support group." (Olson et al., 2007, p. 5)
			"*"I would like to speak to other people who experience it, the same, or similar sort of things as [name of son]. Because I think, as a parent, it is quite frightening, yeah, it is very frightening…"* (Parent 5: interview, female, age 45–49)." (Sowden et al., 2023, p. 6)
Stigma surrounding disclosure	Secrecy	4	"This fear of going 'going crazy' was informed by a powerful sense of losing control of themselves and their lives, and these concerns added to secrecy and the delay in seeking help." (Keyes et al., 2018, p.181).
			"Don't put too much pressure on them. It can be very personal. It can be thoughts in your head which you just don't want anyone to know about." (Keyes et al., 2018, p. 181).
			"Nine participants spoke of the efforts they made to hide their OCD from other people, including friends, family and work colleagues. "*Nobody knows – nobody had ever known I had it … And you don't want people to know.*"" (Robinson et al., 2017, p. 199)
			"Two participants described keeping the illness secret from their family; "*But you know all …through this time ….. my family … didn't know really anything that was going on. Then I did take sick leave. Obviously I had to sort of let them know. And then that was the first time in my life that I told them."* "(Robinson et al., 2017, p. 199)
			Two participants described not telling their partners, over many years, about their OCD. Asked about telling her / his partner, one participant who had intrusive thoughts about harming their children, replied; *"No, never … but I was very open about it once I was diagnosed.'*"' (Robinson et al., 2017, p. 199).
			""I told my parents not to tell my relatives or friends. I don't want anyone to know about my disease." (P9, 11 yr old boy)." (Sravanti et L., 2022, P. 6)

Theme	Subtheme	Papers	Selection of extracts *
	Emotional responses	10	“Moreover, parents commonly experienced blame, either self-blame (e.g. feeling they had caused/ exacerbated their child’s difficulties or not sufficiently helped them) and/or blame from their wider community. *‘you feel a bit of a failure, like you haven’t done the best for your child, I do, I feel a real failure’* [ID33, mother]” (Chessell et al., 2023, p. 80). “All participants described being secretive about their obsessive and compulsive thoughts and behaviour, hiding it from family and peers…A further reason for secrecy was due to the stigma and shame around having a mental health ‘disorder’. This secrecy also further explains why most participants delayed seeking help for their OCD behaviours.” (Keyes et al., 2018, p. 180-181). “Several parents expressed their worry about whether officially recording their children’s difficulties might have an impact on their options for work or further education in the future.” (Kolvenbach et al., 2016, p. 101). “For one participant, the degree of shame experienced was such that he concealed his OCD from his partner and health professionals for many years, leading to delays in help-seeking. In contrast to participants who spoke of relief when receiving diagnosis, the sense of shame continued after confiding in a health professional: *“I was completely ashamed ifI’m honest. I didn’t get a magical sense ofrelief[disclosing OCD], which I was possibly hoping I would. After you think for so long that you can’t. . .’no I’m not going to tell anyone, not going to tell anyone’, and then it was only because ofthe state I was in that I actually said anything. . .”* (P.15, m).” (Pedley et al., 2019, p. 14-15). “One of these participants delayed seeking help for twenty years because of fear of discrimination; fear that a mental health record would jeopardise her / his career.” (Robinson et al., 2017, p. 199) “Participants also spoke specifically about not wanting to tell the doctor. Five participants said this was because they felt embarrassed. *“I felt embarrassed as well about it, cos I didn’t understand why I was doing it. That’s one of the main reasons why I did delay for so long because I was embarrassed.’”*” (Robinson et al., 2017, p. 199). “Three participants spoke of not wanting to tell the doctor because they felt ashamed, and one spoke of feeling humiliated if she went to the doctor. *“I would never have gone … it is a sense of shame of it.’”*” (Robinson et al., 2017, p. 199). *“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’.”* (Sravanti et al., 2022, p. 6). *“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”* (P1, 10 yr old boy)” (Sravanti et al. 2022, p. 6). *“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*

Theme	Subtheme	Papers	Selection of extracts *
			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!" (P7, 16 yr old girl). (Sravanti et al., 2022, p. 6).
	Cultural variations in stigma	4	"Obsessional symptoms were explained the same way any negative event or problem was explained, by evil eye. This explanation can have a number of implications: (a) obsessional symptoms were not particularly stigmatised…. *"I have very beautiful hair. My mom always told me to put it up so I wouldn't attract [an] evil eye, but once I put it down at a wedding party and perhaps I was struck by evil eye, and developed those obsessions.'"*" (Al-Solaim et al., 2011, p. 176). "Among participating parents who identified from non-White British backgrounds, there appeared to be a disparity between their own, and their wider culture's views of mental health difficulties, adding to their challenges. *'it's not really recognised no, they see it as, I wouldn't say a sign of weakness, they just see it as, just get on with it . . . it's not really spoken about . . . it's a very different way of thinking'* [ID withheld to preserve anonymity]." (Chessell et al., 2023, p. 76). *"'but it's trying to live with other people's accepting it, so . . . coming from an Asian culture, the first thing somebody said to me was, "oh, what did you do to him?"' [ID withheld to preserve anonymity]"* (Chessell et al., 2023, p.80). "Stigma within the community seemed to lead some parents to employ secrecy regarding their child's mental health problems, as one parent commented: *We made a decision that we were not going to discuss this with anybody (.. .). Maybe if I was English, I would have told school, but I still think it is not right, because this is something private.* (Female, 51, Iranian)." (Kolvenbach et al., 2016, p. 99) "Nine parents from ethnic minorities groups (vs. two White parents) reported that their families or communities presented an important barrier in accessing services. Participants were especially worried about what other people in their community might think and how they might treat the child if they found out about their mental health issues." (Kolvenbach et al., 2018, p.101). "All 3 of the Asian participants, but none of the Caucasian participants, emphasized the ongoing importance of cultural and ethnic ties…. Another participant, "J," a Chinese-American, highlighted her cultural and ethnic connectedness as follows: *Although privacy is a major factor in the islands, it was a huge major factor growing up in my family … my father would feel a sense of shame that "it" (OCD) was in his (family), which is why he's asked me not to mention my OCD to anyone outside of my siblings, and which is why I'd honor his request as long as he lives. I think that "keeping up appearances" is the norm among the majority of the Chinese families in the islands … I'm sure that this secretiveness within the island families prevents an earlier diagnosis and treatment of OCD for some.*" (Olson et al., 2007, p. 7).

Theme	Subtheme	Papers	Selection of extracts *
Searching for appropriate intervention	Battling with system resources	7	“Most participants discussed how they experienced long waiting lists for mental health service input and how this delayed getting help. This led to an ambivalent relationship to help-seeking due to the young people wanting therapy, but feeling frustrated at the long waiting times.” (Keyes et al., 2018, p. 182) “Most parents also commented on a lack of resources within the public health system, leading to long waiting times in the referral process and overstretched staff and forcing parents to push and ask for help repeatedly, as described by one parent: “*One always has the sense that the service is not as well resourced as it might be (...). So probably we didn’t see the most expert people as quickly as we should have.”* (Male, 50, White)” (Kolvenbach et al., 2018, p. 101). “More than half of the participants commented on time as an important factor when accessing services, specifically transport time or having to take time off work, and nine of the interviewees acknowledged that money could also be a significant barrier for them, as they were for instance not able to access private services due to funding issues.” (Kolvenbach et al., 2018, p. 101). “Participants emphasized the struggle to identify effective care and treatment, For instance, “L” replied *“not really,”* when asked if he had received exposure response prevention, a type of cognitive-behavior therapy that has been shown to be highly effective for persons with OCD. He added, the medical center’s *“trying to keep costs down and what is cost effective is to medicate people and kick them out the door. I know that.””* (Olson et al., 2007, p. 5). “Variation in the quality of therapist, or difficulty with continuity of treatment due to staff ‘turnover’, were seen as reducing the potential benefits of treatment.” (Pedley et al., 2019, p. 12). “When asked about how their child’s symptoms were assessed, the five participants with some form of assessment did not describe the use of evidence-based assessment tools to evaluate the problem at hand. Parents expressed frustration on not knowing what their child was dealing with: "*I never got a definite answer on what we were dealing with… until we went to the private clinic"* (participant 2).” (Skarphedinsson et al., 2023, p. 5). “ “*Overall the service needs to be better… accessible to those who can’t pay 250–300 thousand (Icelandic krona; 1600– 2000 Euros) for private sessions"* (participant 5).” (Skarphedinsson et al., 2023, p. 6). “…parent’s overwhelming priority was to get the right help for their child, which parents frequently depicted as a battle involving pushing, fighting and which required extensive energy, resources, and determination: *“…if you are proactive and you push and fight and fight and fight, you will finally start to get some help, and that is the problem”* (Parent 9: interview, female, age 40–44).” (Sowden et al., 2023, p. 6). “Last, a significant call for OCD specialists was made. This relates back to understanding, and a lack of support as participants felt treatment would have been better if an OCD specialist provided it rather than a CBT therapist that did not have the speciality. *Doctors*

Theme	Subtheme	Papers	Selection of extracts *
			and CBT therapists don't specialize in OCD or understand it and how many different forms of it there are. Would have liked to speak to an OCD specialist (participant 82, female, age 35)." (Vuong et al., 2019, p. 8).
	Mistrust in systems	4	"Parents from both groups also referenced a lack of trust in the mental health system and stated that they were not entirely comfortable with the way the system was set up or dealt with them and their children. (Kolvenbach et al., p. 101) "Lack of trust in the mental health system. Seven parents from ethnic minority groups (vs. one parent from the White group) talked about a lack of trust in the mental health system, especially as it related to their cultural group compared to the White majority. As one parent explained: *"It can be difficult for people from my background to trust them, unless they have knowledge about mental health people, so it is difficult for them to understand and trust it"* (Female, 36, Black African)." (Kolvenbach et al., 2018, p. 103) *"They just do not see or recognise that person beyond their color, and it takes a while, even with my daughter it took a while, for them to see past her culture, and see her as a person. (Female, 51, Black Caribbean)."* (Kolvenbach et al., 2018, p. 103). "Two participants described concerns about the treatment they might be offered as contributing to their delay in seeking help. For one participant this was about medication, for the other it was about psychological treatment; *"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. p. 203). "I am not very enthusiastic about this medication stuff" (participant 1). "I would have liked my child rather to have that kind of treatment (psychological treatment) than medication…" (Skarphedinsson et al., 2023, p. 6). "Participants' attitudes and trust levels towards healthcare professionals were affected, sometimes deterring any desire to seek help…. "*The NHS waiting lists severely affected my treatment and attitude to treatment. I waited six months for counselling, then was diagnosed . . . and put on a different waiting list, which lasted a year. This . . . made me very suspicious of medical professionals . . . I am reluctant to return to the doctor if my symptoms worsen.*" (participant 65, female, age 21)." (Vuong et al., 2016, p. 8).
	Beliefs about intervention	10	"All interviewees who took part in this study said that their first attempt to seek outside help was going to a faith-based healer. In all cases, interviewees took this step willingly and did think of faith-based healers as an appropriate outlet for help." (Al-Solaim & Loewenthal, 2011, p. 174). "G., 21 years old, gave a further a more idealistic view of religious professionals: "*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, p. 176).

Theme	Subtheme	Papers	Selection of extracts *
			Similarly, for some parents, helplessness improved over time, whereas for others, this persisted 'so now . . . we are not sending her to any therapist . . . because she'll get therapy um fatigue, and um, we need to just make sure . . . it's going to be, as useful as it possibly can be, you know, otherwise we don't want another wasted eight sessions' [ID43, father]. (Chessell et al., 2023, p. 81) "All interviewees stated that their first approach to seeking help for their OCD symptoms was to speak to an Imam. Four of the participants considered the Imam to be an appropriate source for help and followed the advice provided." (Mahintorabi et al., 2017, p. 7). "Even for "G," whose scrupulosity was a major part of her OCD, positive aspects of her relationship to God were pivotal in letting go of persistent, unfounded fears that she had hit a young girl with her car: *"And at that point, I said, okay ... I'm not going to pursue this (doubts about having harmed the young girl) anymore. I'm going to place my hands, my life—I said, "God, you're in charge." I said, "I can't do it anymore" ... And I said, "You know, if you want me to keep living and to raise this family, then you've got to help everyday because I can't do it by myself." I made that decision at that point that I was going to take the medicine and I was going to not pursue turning myself in'"*. (Olson et al., 2007, p. 7). "Many perceived medications (e.g. antidepressants) as a useful treatment, which had helped to reduce their symptoms: *"..when I first started taking the tablets, I definitely felt more relaxed. Whether it's just to get rid oft that anxious feeling, because obviously when you're not anxious, I believe I don't check as much. . ."* (P.11, m)" (Pedley et al., 2019, p. 11). *"Two participants described concerns about the treatment they might be offered as contributing to their delay in seeking help. For one participant this was about medication, for the other it was about psychological treatment; "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. "I think in a sense ... not having to go through the hard process of CBT ... not having this long process of getting better."* (Robinson et al., 2018, p. 203). "The central theme about treatment is that it helps and this forms the hub of the perception of treatment processes. Although there is initial reluctance to seek treatment, children not only perceive therapy as helpful but helpful beyond illness." (Sravanti et al., 2022, p. 7).
	Professional responses	8	"Gemma states: *I felt crazy at the time. I was thinking, you know, things like that. But for my GP to say, 'right, it's OCD.. .' He's actually saying something. I'm not going crazy, it's all good.*" (Keyes et al., 2018, p. 180). "Another parent got upset by her GPs reaction to her child's symptoms when seeking access to a psychologist at the PHC, leaving the parent very upset: "*We went together (with the child) to talk about this and apply for him to get assistance. And just, No. She said, this is much more serious, and you never know…. He could just start (does a stabbing motion). He needs to go private… I*

Theme	Subtheme	Papers	Selection of extracts *
			was so angry I walked out crying. It was just ridiculous!" (participant 6).” (Skarphedinsson et al., 2023, p. 5). “The following parent spoke of the positive difference compassion and sensitivity made when it was eventually encountered: “*The first person who was helpful and showed compassion. She admitted she didn’t know anything about OCD and spent a lot of time on the phone letting me explain. Felt supported and that she was genuinely interested.”* (Parent 1: journal entry, female, age 45–49).” (Sowden et al., 2023, p. 6). “Having their concerns heard and taken seriously was a key priority for parents, yet many felt they were not listened to as they tried to seek professional help for their child: “*I just felt like I was banging my head on a brick wall, and nobody was really listening, and as his mum, I knew what was happening to him, but I was powerless to help him”* (Parent 17: interview, female, age 40–44).” (Sowden et al., 2023, p. 6-7). “*“Only the doctor opened my eyes that this is really serious.”* [Spouse]”. (Stengler-Wenzke et al., 2004, p. 37). “Some indicated this resulted in them not having the opportunity to discuss their difficulties: *I felt that my GP was in too much of a hurry to prescribe antidepressants rather than offer me the chance to talk about my obsessive thoughts* (participant 74, female, age 44).” (Voung et al., 2016, p. 8).
	The impact of previous help on problems	6	*“My parents decided to take me to a faith healer who started reading verses ofthe Qura’an to me, this gave me a temporary relief, but the symptoms persisted. This is my third visit to the doctor and I already feel better.”* (Al-Solaim & Loewenthal, 2011, p. 174). “BB did not tolerate ERP well and discontinued treatment. She explained: ‘*In the second session my psychologist asked me to touch anything in the bathroom, like the floor and hand basin, and do not wash my hands or take a shower after that as a take home task. 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, p. 8). “Although the parents who had access to psychological treatment were thankful for having this service available for their child, they expressed frustration about the treatment effects as it did not affect the OCD symptoms. *"In the beginning, it went well, but then it stopped… she didn’t seem to have any results with the OCD symptoms"* (participant 1). *"Although I was happy to have the service available, I was very disappointed. I felt I was wasting my time… it wasn’t doing anything for us"* (participant 2).” (Skarphedinsson et al., 2023, p. 6). “*“They actually went and got a book, they had the book in front of them, and they’re saying, well, this is how we do CBT. I was like, but he’s not at that level. He’s got autism; he doesn’t understand what you’re saying to him. So, they didn’t adapt anything. The*

Theme	Subtheme	Papers	Selection of extracts *
			language or anything, adaptations for him." (Parent 6: interview, female, age 50–54)." (Sowden et al., 2023, p.8)
			"*"After initial sessions, I got clarity that it was something I was suffering from. Although initially it seemed complex and I thought it would be very hard to come out of. [..] I learnt ways to handle it and kept trying. Gradually it became easier.. [....] I worked on it and felt better. So, that motivated me and gave me the courage to continue therapy and work on improving myself."* (P3, 11 yr old boy)". (Sravanti et al., 2022, p. 5).
			"*'It's just that the CBT didn't work. I tried two courses, but if anything my fears worsened. I think I would have benefited from one-to-one sessions, but these were group courses. But I do appreciate there aren't the resources for every sufferer to have one-to-one sessions'* (participant 86, female, age 30). Some participants commented that treatment helped to a point, but then no further progress was made, or recurrence of symptoms resulted in the help-seeking process recommencing." (Vuong et al., 2016, p. 8).

Appendix C: ethical approval for original part B

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Appendix D: Ethical approval for Leeuwerik et al. (2020) study

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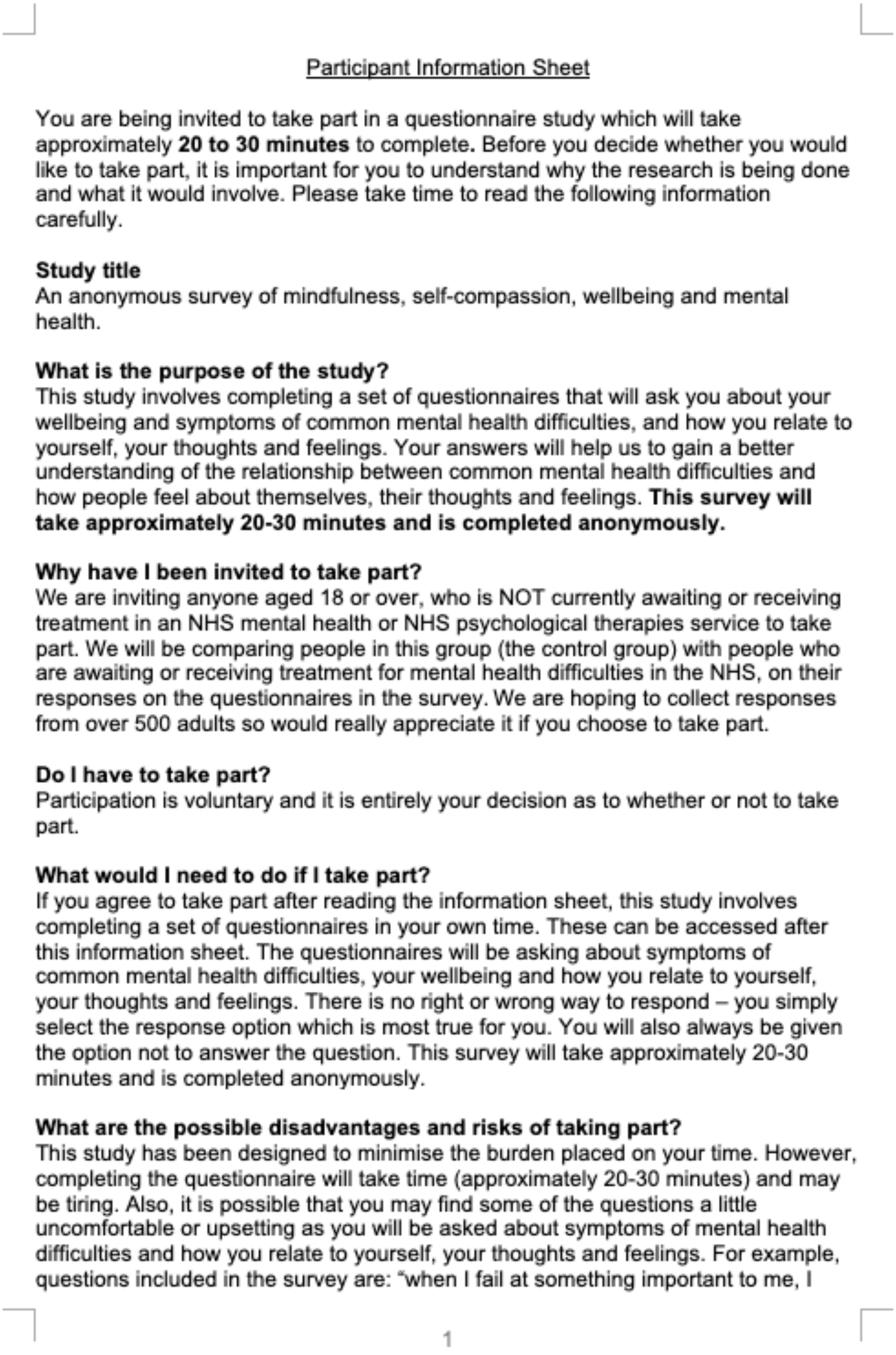
Appendix E: Participant information sheets



Participant Information Sheet

You are being invited to take part in a questionnaire study which will take approximately **20 to 30 minutes** to complete. Before you decide whether you would like to take part, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully.

Study title
An anonymous survey of mindfulness, self-compassion, wellbeing and mental health.

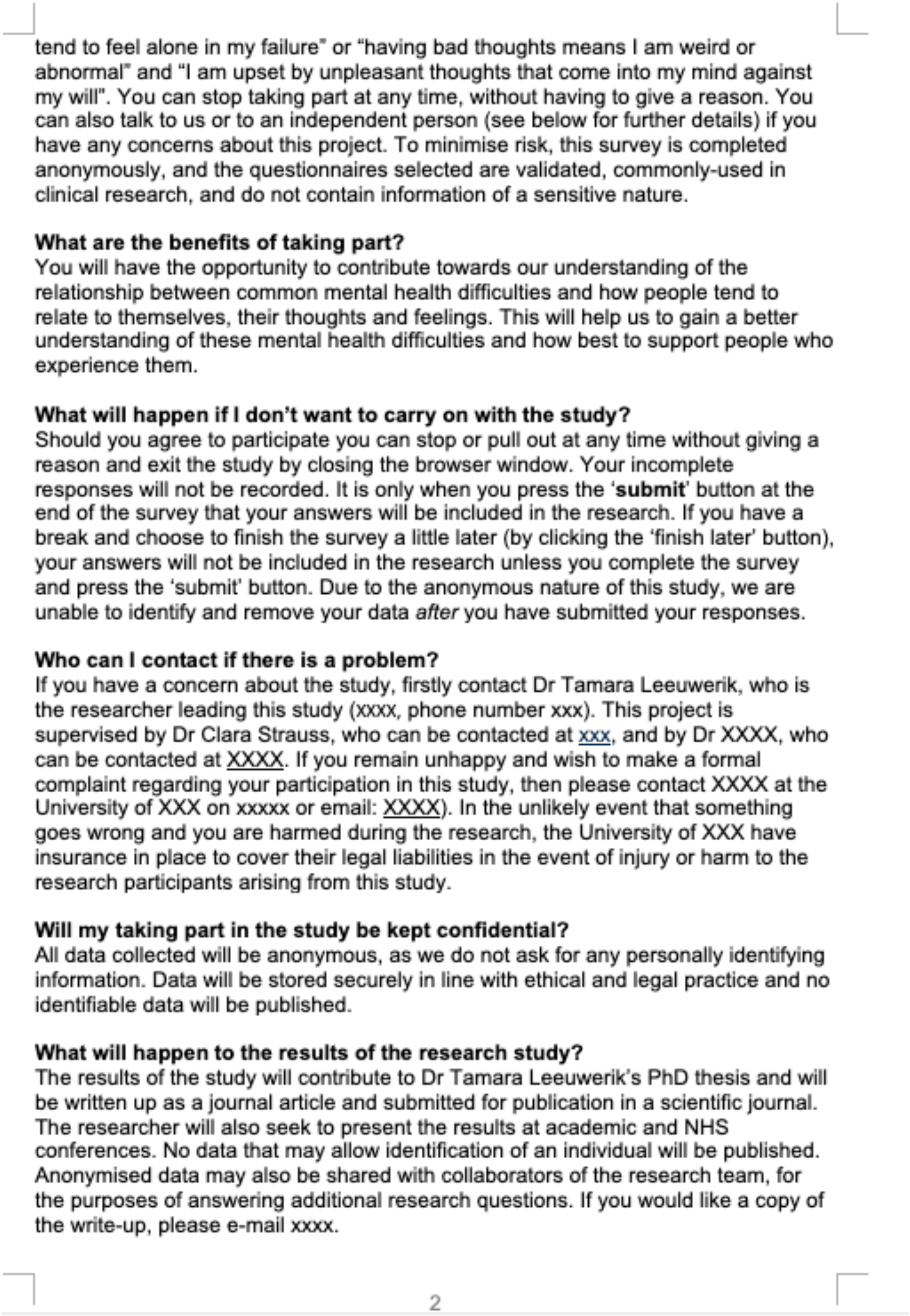
What is the purpose of the study?
This study involves completing a set of questionnaires that will ask you about your wellbeing and symptoms of common mental health difficulties, and how you relate to yourself, your thoughts and feelings. Your answers will help us to gain a better understanding of the relationship between common mental health difficulties and how people feel about themselves, their thoughts and feelings. **This survey will take approximately 20-30 minutes and is completed anonymously.**

Why have I been invited to take part?
We are inviting anyone aged 18 or over, who is NOT currently awaiting or receiving treatment in an NHS mental health or NHS psychological therapies service to take part. We will be comparing people in this group (the control group) with people who are awaiting or receiving treatment for mental health difficulties in the NHS, on their responses on the questionnaires in the survey. We are hoping to collect responses from over 500 adults so would really appreciate it if you choose to take part.

Do I have to take part?
Participation is voluntary and it is entirely your decision as to whether or not to take part.

What would I need to do if I take part?
If you agree to take part after reading the information sheet, this study involves completing a set of questionnaires in your own time. These can be accessed after this information sheet. The questionnaires will be asking about symptoms of common mental health difficulties, your wellbeing and how you relate to yourself, your thoughts and feelings. There is no right or wrong way to respond – you simply select the response option which is most true for you. You will also always be given the option not to answer the question. This survey will take approximately 20-30 minutes and is completed anonymously.

What are the possible disadvantages and risks of taking part?
This study has been designed to minimise the burden placed on your time. However, completing the questionnaire will take time (approximately 20-30 minutes) and may be tiring. Also, it is possible that you may find some of the questions a little uncomfortable or upsetting as you will be asked about symptoms of mental health difficulties and how you relate to yourself, your thoughts and feelings. For example, questions included in the survey are: "when I fail at something important to me, I



tend to feel alone in my failure" or "having bad thoughts means I am weird or abnormal" and "I am upset by unpleasant thoughts that come into my mind against my will". You can stop taking part at any time, without having to give a reason. You can also talk to us or to an independent person (see below for further details) if you have any concerns about this project. To minimise risk, this survey is completed anonymously, and the questionnaires selected are validated, commonly-used in clinical research, and do not contain information of a sensitive nature.

What are the benefits of taking part?
You will have the opportunity to contribute towards our understanding of the relationship between common mental health difficulties and how people tend to relate to themselves, their thoughts and feelings. This will help us to gain a better understanding of these mental health difficulties and how best to support people who experience them.

What will happen if I don't want to carry on with the study?
Should you agree to participate you can stop or pull out at any time without giving a reason and exit the study by closing the browser window. Your incomplete responses will not be recorded. It is only when you press the '**submit**' button at the end of the survey that your answers will be included in the research. If you have a break and choose to finish the survey a little later (by clicking the 'finish later' button), your answers will not be included in the research unless you complete the survey and press the 'submit' button. Due to the anonymous nature of this study, we are unable to identify and remove your data *after* you have submitted your responses.

Who can I contact if there is a problem?
If you have a concern about the study, firstly contact Dr Tamara Leeuwerik, who is the researcher leading this study (xxxx, phone number xxx). This project is supervised by Dr Clara Strauss, who can be contacted at xxx, and by Dr XXXX, who can be contacted at XXXX. If you remain unhappy and wish to make a formal complaint regarding your participation in this study, then please contact XXXX at the University of XXX on xxxxx or email: XXXX). In the unlikely event that something goes wrong and you are harmed during the research, the University of XXX have insurance in place to cover their legal liabilities in the event of injury or harm to the research participants arising from this study.

Will my taking part in the study be kept confidential?
All data collected will be anonymous, as we do not ask for any personally identifying information. Data will be stored securely in line with ethical and legal practice and no identifiable data will be published.

What will happen to the results of the research study?
The results of the study will contribute to Dr Tamara Leeuwerik's PhD thesis and will be written up as a journal article and submitted for publication in a scientific journal. The researcher will also seek to present the results at academic and NHS conferences. No data that may allow identification of an individual will be published. Anonymised data may also be shared with collaborators of the research team, for the purposes of answering additional research questions. If you would like a copy of the write-up, please e-mail xxxx.

Who is organising and funding this study?
The study is being organised and part funded by XXXX NHS Foundation Trust and The University of XXX. The Economic and Social Research Council (ESRC) have also provided funding.

Who has approved this study?
The project has been approved by the XXXX Research Ethics Committee (xxxx). The University of XXX is the sponsor of the study.

Further information and contact details
For further information or if you have any concerns about the study, please email XXX or phone [xxxx]. This project is supervised by Dr Clara Strauss, who can be contacted at xxxx, and by Dr XXXX, who can be contacted at XXXX.

Thank you for taking the time to read this information page. Please click on the ‘continue’ button to confirm that you have read and understood the Information sheet and wish to now begin the study. **Please note** that by completing the survey and **submitting** your responses (by pressing a ‘submit’ button at the end of the survey) you are agreeing to take part and for your responses to be included in the study.

Participant Information Sheet

You are being invited to take part in a questionnaire study which will take approximately **20 to 30 minutes** to complete**.** Before you decide whether you would like to take part, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully.

Study title

An anonymous survey of mindfulness, self-compassion, wellbeing and mental health.

What is the purpose of the study?

This study involves completing a set of questionnaires that will ask you about your wellbeing and symptoms of common mental health difficulties, and how you relate to yourself, your thoughts and feelings. Your answers will help us to gain a better understanding of the relationship between common mental health difficulties and how people feel about themselves, their thoughts and feelings. **This survey will take approximately 20-30 minutes and is completed anonymously.**

Why have I been invited to take part?

You have been invited as someone who has been offered psychological therapies in the NHS. We will be comparing people in this group with people who are not currently awaiting or receiving treatment for mental health difficulties in the NHS (the control group) on their responses on the questionnaires in the survey. We are hoping to collect responses from over 1000 adults so would really appreciate it if you choose to take part.

You will need to be **aged 18 or over** to take part in the study.

Do I have to take part?

Participation is voluntary and it is entirely your decision as to whether or not to take part. Whether you decide to take part or not will not affect the care you are currently receiving from the NHS in any way.

What would I need to do if I take part?

If you agree to take part after reading the information sheet, this study involves completing a set of questionnaires in your own time. These can be accessed after this information sheet. The questionnaires will be asking you about symptoms of common mental health difficulties, your wellbeing and how you relate to yourself, your thoughts and feelings. There is no right or wrong way to respond – you simply select the response option which is most true for you. You will also always be given the option not to answer the question. This survey will take approximately 20-30 minutes and is completed anonymously.

What are the possible disadvantages and risks of taking part?

This study has been designed to minimise the burden placed on your time. However, completing the questionnaire will take time (approximately 20-30 minutes) and may be tiring. Also, it is possible that you may find some of the questions a little uncomfortable or upsetting as you will be asked about symptoms of mental health difficulties and how you relate to yourself, your thoughts and feelings. For example, questions included in the survey are: "when I fail at something important to me, I tend to feel alone in my failure", "having bad thoughts means I am weird or abnormal", and "I am upset by unpleasant thoughts that come into my mind against my will". You will have the option to save your answers and come back to the survey a little later if you want to have a break. You can stop taking part at any time, without having to give a reason. You can also talk to us, the psychological therapies team that are caring for you or an independent person (see below for further details) if you have any concerns about this project. To minimise risk, this survey is completed anonymously, and the questionnaires selected are validated, commonly-used in clinical research, and do not contain information of a sensitive nature.

What are the benefits of taking part?

You will have the opportunity to contribute towards our understanding of the relationship between common mental health difficulties and how people tend to relate to themselves, their thoughts and feelings. This will help us to gain a better understanding of these mental health difficulties and how best to support people who experience them.

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

Should you agree to participate you can stop or pull out at any time without giving a reason and exit the study by closing the browser window. Your incomplete responses will not be recorded. It is only when you press the '**submit**' button at the end of the survey that your answers will be included in the research. If you have a break and choose to finish the survey a little later (by clicking the 'finish later' button), your answers will not be included in the research unless you complete the survey and press the 'submit' button. Due to the anonymous nature of this study, we are unable to identify and remove your data *after* you have submitted your responses.

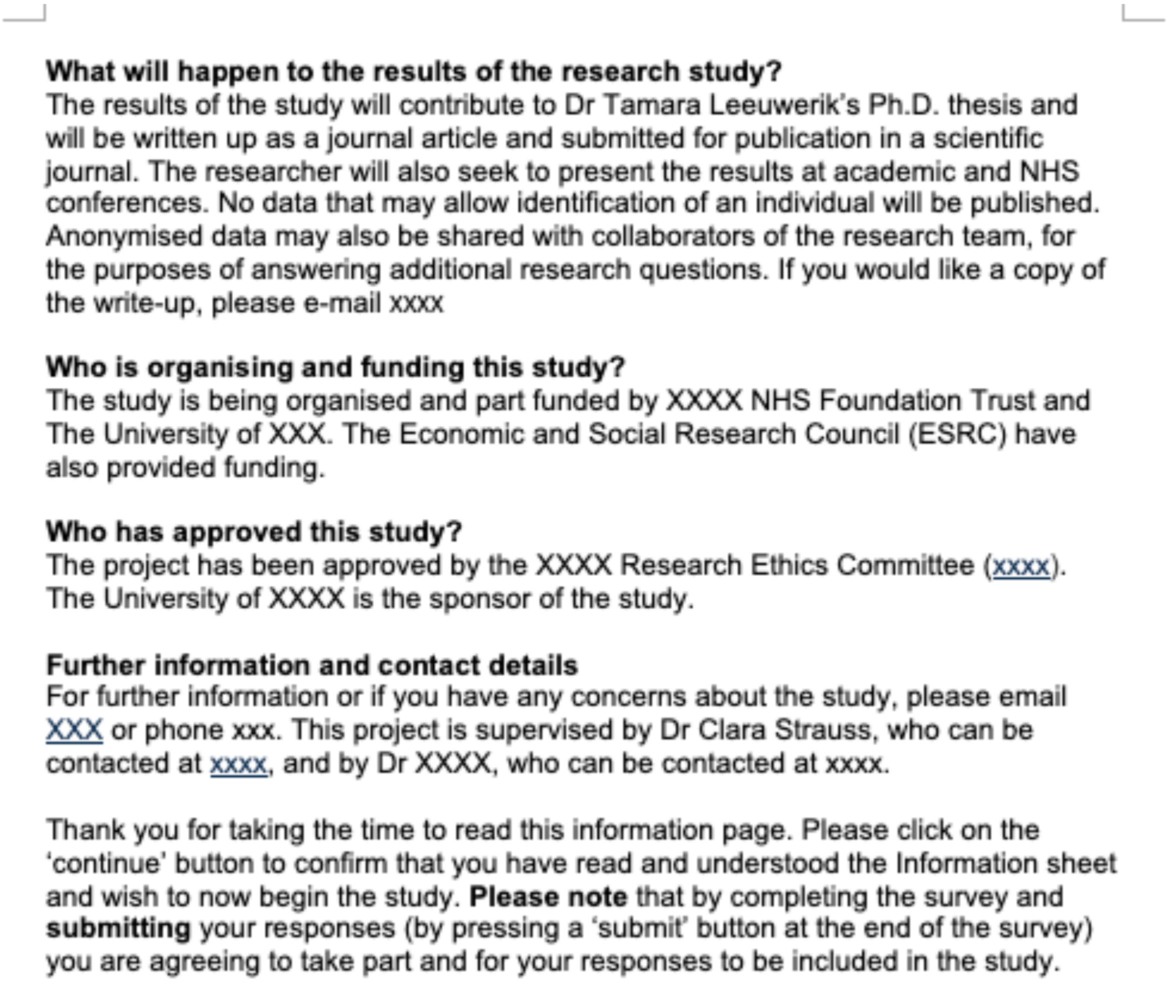
Who can I contact if there is a problem?

If you have a concern about participating in the study, firstly contact Dr Tamara Leeuwerik who is the researcher leading this study (xxxx; xxxx). This project is supervised by Dr. Clara Strauss, who can be contacted at xxx, and by Dr XXX, who can be contacted at xxx. If you remain unhappy and wish to make a formal complaint, you can do this by contacting the Research Governance Officer at the University of XXX, XXX (xxxx or xx). You may also wish to seek advice or use the more general NHS complaints mechanisms: The Patient Advice and Liaison Service (PALS) on xxxx.

In the unlikely event that something goes wrong and you are harmed during the research, the University of XXXX have insurance in place to cover their legal liabilities in the event of injury or damage to the research participants arising from this study.

Will my taking part in the study be kept confidential?

All data collected will be anonymous, as we do not ask for any personally identifying information. Data will be stored securely in line with ethical and legal practice and no identifiable data will be published.



What will happen to the results of the research study?
The results of the study will contribute to Dr Tamara Leeuwerik's Ph.D. thesis and will be written up as a journal article and submitted for publication in a scientific journal. The researcher will also seek to present the results at academic and NHS conferences. No data that may allow identification of an individual will be published. Anonymised data may also be shared with collaborators of the research team, for the purposes of answering additional research questions. If you would like a copy of the write-up, please e-mail xxxx

Who is organising and funding this study?
The study is being organised and part funded by XXXX NHS Foundation Trust and The University of XXX. The Economic and Social Research Council (ESRC) have also provided funding.

Who has approved this study?
The project has been approved by the XXXX Research Ethics Committee (xxxx). The University of XXXX is the sponsor of the study.

Further information and contact details
For further information or if you have any concerns about the study, please email XXX or phone xxx. This project is supervised by Dr Clara Strauss, who can be contacted at xxxx, and by Dr XXXX, who can be contacted at xxxx.

Thank you for taking the time to read this information page. Please click on the 'continue' button to confirm that you have read and understood the Information sheet and wish to now begin the study. **Please note** that by completing the survey and **submitting** your responses (by pressing a 'submit' button at the end of the survey) you are agreeing to take part and for your responses to be included in the study.

Appendix F: Self-Compassion Scale Short Form

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Appendix G: Distress Tolerance Scale

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Appendix H: Five Facet Mindfulness Questionnaire Short Form

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Appendix I: Obsessive-Compulsive Inventory Revised

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Appendix J: Table of initial study one sample

Sociodemographic variables in the total (N=1214), intervention-seeking (n=958) and non-intervention seeking (n=256) initial samples for study one.

Variable		Total (*N*, %)	Intervention seeking (*n*, %)	Non intervention seeking (*n*, %)
Age	18-24	407 (33.5)	160 (16.7)	247 (96.5)
	25-34	199 (16.4)	195 (20.4)	4 (1.6)
	35-44	166 (13.7)	163 (17.0)	3 (1.2)
	45-54	185 (15.2)	185 (19.3)	0 (0)
	55-64	158 (13.0)	157 (16.4)	1 (0.4)
	65+	86 (7.1)	86 (9.0)	0 (0)
	Prefer not to say	5 (0.4)	5 (0.5)	0 (0)
	Missing	8 (0.7)	7 (0.7)	1 (0.4)
Gender	Female	878 (72.3)	670 (69.9)	208 (81.3)
	Male	320 (26.4)	274 (28.6)	46 (18.0)
	Other	4 (0.3)	3 (0.3)	1 (0.4)
	Prefer not to say	3 (0.2)	3 (0.3)	0 (0)
	Missing	9 (0.7)	9 (0.8)	1 (0.4)
Highest educational qualification	No educational qualification	44 (3.6)	44 (4.6)	0 (0)
	Secondary	681 (56.1)	492 (51.3)	189 (73.8)
	Higher	436 (36.0)	372 (38.9)	64 (25.0)
	Prefer not to say	40 (3.3)	38 (4)	2 (0.8)
	Missing	13 (1.1)	12 (1.3)	1 (0.4)
Employment status	Employed/self-employed	568 (46.8)	557 (58.1)	11 (4.3)
	Looking for work	63 (5.2)	61 (6.4)	2 (0.8)
	Not looking for work	48 (4.0)	45 (4.7)	3 (1.2)
	Unable to work	85 (7.0)	85 (8.9)	0 (0)
	Student	298 (24.5)	59 (6.2)	239 (93.4)
	Retired	114 (2.1)	114 (11.9)	0 (0)
	Prefer not to say	25 (2.1)	25 (2.6)	0 (0)
	Missing	13 (1.1)	12 (1.3)	1 (0.4)
Ethnicity	White background	1015 (83.6)	842 (87.9)	173 (67.6)
	Other background	178 (14.7)	99 (10.3)	79 (30.8)
	Prefer not to say	15 (1.2)	12 (1.3)	3 (1.2)
	Missing	6 (0.5)	5 (0.5)	1 (0.4)
Intervention status	Not yet started intervention	n/a	734 (76.6)	n/a
	Received some intervention	n/a	176 (18.3)	n/a
	Prefer not to say	n/a	29 (3)	n/a
	Missing	n/a	19 (2)	n/a
Previous experience of mindfulness	Yes	195 (16.1)	167 (17.4)	28 (10.9)
	No	958 (78.9)	736 (76.8)	222 (86.7)
	Prefer not to say	39 (3.2)	34 (3.5)	5 (2)
	Missing	22 (1.8)	21 (2.2)	1 (0.4)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

Appendix K: EFA pattern matrix

Pattern matrix of item loadings on to factors

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
	General distress tolerance	Describe inner experiences	Non-judging of inner experiences	Regulation of distress	Acting with awareness	Uncompassionate self- responding	Non-reactivity to experience	Compassionate self-responding
DTS3. I can't handle feeling distressed or upset	.845							
DTS4. My feelings of distress are so intense that they completely take over.	.809							
DTS2. When I feel distress or upset all I can think about is how bad I feel.	.760							
DTS1. Feeling distress or upset is unbearable to me.	.742							
DTS10. Being distressed or upset is always a major ordeal for me	.706							
DTS5. There's nothing worse than feeling distressed or upset.	.700							
DTS9. Other people seem to be able to tolerate feeling	.548							

distressed or upset better than I can.		
DTS15. When I feel distressed or upset, I cannot help but concentrate on how bad the distress actually feels.	.545	
DTS12. My feelings of distress or being upset scare me.	.498	
DTS6. I can tolerate being distressed or upset as well as most people	.447	
DTS7. My feelings of distress or being upset are not acceptable.	.440	
DTS11. I am ashamed of myself when I feel distressed or upset.	.397	
FFMQ1. I’m good at finding words to describe my feelings.		.846
FFMQ2. I can easily put my beliefs, opinions, and expectations into words.		.768
FFMQ16. Even when I’m feeling terribly upset, I can find a way to put it into words		.669

FFMQ5. It’s hard for me to find the words to describe what I am thinking.	.635				
FFMQ11. When I feel something in my body, it’s hard for me to find the right words to describe it.	.555				
FFMQ14. I tell myself that I shouldn’t be thinking the way I am thinking.		.816			
FFMQ4. I tell myself that I shouldn’t be feeling the way I am feeling.		.701			
FFMQ7. I make judgements about whether my thoughts are good or bad		.483			
FFMQ19. I think some of my emotions are bad or inappropriate and I shouldn’t feel them.		.470			
FFMQ24. I disapprove of myself when I have illogical ideas.		.314			-.313
DTS13. I’ll do anything to stop feeling distressed or upset.			.824		

DTS8. I'll do anything to avoid feeling distressed or upset.	.668		
DTS14. When I feel distressed or upset, I must do something about it immediately.	.608		
FFMQ23. I find myself doing things without paying attention.		-.861	
FFMQ22. I do jobs or tasks automatically without being aware of what I'm doing.		-.801	
FFMQ17. I rush through activities without being really attentive to them.		-.656	
FFMQ12. It seems I am "running on automatic" without much awareness of what I'm doing.		-.616	
FFMQ8. I find it difficult to stay focussed on what's happening in the present moment.		-.384	
SCS11. I'm disapproving and judgemental about my own flaws and inadequacies.			-.783

SCS8. When I fail at something that’s important to me I tend to feel alone in my failure.	-.708	
SCS1. When I fail at something important to me I become consumed by feelings of inadequacy.	-.680	
SCS9. When I’m feeling down I tend to obsess and fixate on everything that’s wrong.	-.610	
SCS12. I’m intolerant and impatient towards those aspects of my personality I don’t like.	-.534	
SCS4. When I’m feeling down, I tend to feel like most other people are probably happier than I am.	-.369	
FFMQ21. When I have distressing thoughts or images, I just notice them and let them go.		.750
FFMQ18. Usually when I have distressing thoughts or images I can just notice them without reacting.		.663

FFMQ9. When I have distressing thoughts or images, I don’t let myself be carried away by them.	.587	
FFMQ13. When I have distressing thoughts or images, I feel calm soon after.	.494	
FFMQ3. I watch my feelings without getting carried away by them.	.379	
SCS3. When something painful happens I try to take a balanced view of the situation.		.568
SCS2. I try to be understanding and patient towards those aspects of my personality I don’t like.		.531
SCS5. I try to see my failings as part of the human condition.		.519
SCS10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.		.513

SCS6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	.480
SCS7. When something upsets me, I try to keep my emotions in balance.	.412

Appendix L: EFA Structure matrix

Structure matrix outlining the correlations between items and factors.

Item	Factor 1 General distress tolerance	Factor 2 Describe inner experiences	Factor 3 Non-judging of inner experiences	Factor 4 Regulation of distress	Factor 5 Acting with awareness	Factor 6 Uncompassionate self-responding	Factor 7 Non-reactivity to experience	Factor 8 Compassionate self-responding
DTS3. I can't handle feeling distressed or upset	.842			.518		-.362	.381	
DTS10. Being distressed or upset is always a major ordeal for me.	.821			.576		-.426	.390	
DTS4. My feelings of distress are so intense that they completely take over.	.820			.462		-.418	.428	.307
DTS2. When I feel distress or upset all I can think about is how bad I feel.	.778			.456		-.413	.387	
DTS1. Feeling distress or upset is unbearable to me.	.745			.514		-.314		
DTS5. There's nothing worse than feeling distressed or upset.	.731			.521				
DTS15. When I feel distressed or upset, I cannot help but concentrate on how	.729			.532		-.435	.396	

bad the distress actually feels.								
DTS12. My feelings of distress or being upset scare me.	.706		.324	.535	-.307	-.442	.340	
DTS9. Other people seem to be able to tolerate feeling distressed or upset better than I can.	.676			.393		-.429	.402	.347
DTS11. I am ashamed of myself when I feel distressed or upset.	.656		.374	.476	-.305	-.526	.319	.306
DTS7. My feelings of distress or being upset are not acceptable.	.599		.335	.424		-.366		
DTS6. I can tolerate being distressed or upset as well as most people	.542					-.377	.406	
FFMQ1. I'm good at finding words to describe my feelings.		.828						
FFMQ2. I can easily put my beliefs, opinions, and expectations into words.		.727						
FFMQ16. Even when I'm feeling terribly upset, I can find a way to put it into words		.684						

FFMQ5. It’s hard for me to find the words to describe what I am thinking.		.661			-.330	
FFMQ11. When I feel something in my body, it’s hard for me to find the right words to describe it.		.582			-.321	
FFMQ14. I tell myself that I shouldn’t be thinking the way I am thinking.			.786			-.336
FFMQ4. I tell myself that I shouldn’t be feeling the way I am feeling.			.695			-.321
FFMQ19. I think some of my emotions are bad or inappropriate and I shouldn’t feel them.			.584		-.338	-.449
FFMQ7. I make judgements about whether my thoughts are good or bad.			.530			
DTS13. I’ll do anything to stop feeling distressed or upset.	.613			.887		-.312
DTS8. I’ll do anything to avoid feeling distressed or upset.	.498			.719		

DTS14. When I feel distressed or upset, I must do something about it immediately.	.465			.674				
FFMQ23. I find myself doing things without paying attention.					- .833			
FFMQ22. I do jobs or tasks automatically without being aware of what I'm doing.					- .770			
FFMQ12. It seems I am "running on automatic" without much awareness of what I'm doing.		.340			- .691	-.346		
FFMQ17. I rush through activities without being really attentive to them.					- .643			
FFMQ8. I find it difficult to stay focussed on what's happening in the present moment.	.346	.314			- .520	-.356		
SCS11. I'm disapproving and judgemental about my own flaws and inadequacies.	.373		.398			- .796	.302	.316
SCS1. When I fail at something important to me I become	.374		.327		-.318	- .728	.353	.307

consumed by feelings of inadequacy.						
SCS9. When I’m feeling down I tend to obsess and fixate on everything that’s wrong.	.469	.320	-.333	- .714	.423	
SCS8. When I fail at something that’s important to me I tend to feel alone in my failure.	.361			- .714	.326	
SCS12. I’m intolerant and impatient towards those aspects of my personality I don’t like.	.378	.378		- .651		.324
SCS4. When I’m feelings down, I tend to feel like most other people are probably happier than I am.	.382			- .515	.343	
FFMQ24. I disapprove of myself when I have illogical ideas.	.300	.489	-.315	- .511		
FFMQ21. When I have distressing thoughts or images, I just notice them and let them go.	.376			-.357	.760	.342
FFMQ9. When I have distressing thoughts or images, I don’t let	.368			-.329	.663	.387

myself be carried away by them.								
FFMQ18. Usually when I have distressing thoughts or images I can just notice them without reacting.							.637	
FFMQ13. When I have distressing thoughts or images, I feel calm soon after.	.323					-.301	.562	.317
FFMQ3. I watch my feelings without getting carried away by them.	.304	.347				-.304	.519	.432
SCS3. When something painful happens I try to take a balanced view of the situation.	.369	.322					.449	.686
SCS2. I try to be understanding and patient towards those aspects of my personality I don’t like.						-.398	.418	.635
SCS5. I try to see my failings as part of the human condition.						-.344	.373	.605
SCS6. When I’m going through a very hard time, I give	.345					-.456	.384	.604

myself the caring and tenderness I need.				
SCS10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.		-.314	.384	.588
SCS7. When something upsets me, I try to keep my emotions in balance.	.378		.433	.557

Appendix M: Table of initial study two sample

Sociodemographic variables in the initial total (N=1197), intervention-seeking (n=913) and non-intervention seeking (n= 284) samples for study two.

Variable		Total sample (N, %)	Intervention seeking (n, %)	Non intervention seeking (n, %)
Age	18-24		178 (19.5)	279 (98.2)
	25-34		191 (20.9)	4 (1.4)
	35-44		140 (15.3)	0 (0)
	45-54		144 (16.0)	1 (0.4)
	55-64		146 (16.0)	0 (0)
	65+		104 (11.4)	0 (0)
	Prefer not to say		6 (0.7)	0 (0)
	Missing		4 (0.4)	0 (0)
Gender	Female		662 (72.5)	234 (82.4)
	Male		234 (25.6)	46 (16.2)
	Other		3 (0.3)	0 (0)
	Prefer not to say		4 (0.4)	2 (0.7)
	Missing		10 (1.1)	2 (0.7)
Highest education	No educational qualification		46 (5)	0 (0)
	Secondary		437 (47.8)	213 (75.0)
	Higher		392 (43)	69 (24.3)
	Prefer not to say		31 (3.4)	2 (0.7)
	Missing		7 (0.8)	0 (0)
Employment status	Employed/self-employed		493 (54)	11 (3.9)
	Looking for work		65 (7.1)	6 (2.3)
	Not looking for work		43 (4.7)	1 (0.4)
	Unable to work		89 (9.7)	0 (0)
	Student		68 (7.4)	264 (93.0)
	Retired		129 (14.1)	0 (0)
	Prefer not to say		19 (2.1)	2 (0.7)
	Missing		7 (0.8)	0 (0)
Ethnicity	White background		802 (87.8)	190 (66.9)
	Other background		100 (11%)	89 (31.3)
	Prefer not to say		7 (0.8)	5 (1.8)
	Missing		4 (0.4)	0 (0)
Intervention status	Not yet started intervention		708 (77.5)	n/a
	Received some intervention		177 (9.4)	n/a
	Prefer not to say		19 (2.1)	n/a
	Missing		9 (1)	n/a
Previous experience of mindfulness	Yes		170 (18.6)	21 (7.4)
	No		701 (76.8)	249 (87.7)
	Prefer not to say		31 (3.4)	14 (4.9)
	Missing		11 (1.2)	0 (0)

Secondary education= 11+, GCSE, A-Level, Higher = equivalent to undergraduate degree or above

Appendix N: CFA factor loadings

Standardised factor loadings for the final eight-factor correlated model with three cross-loadings and error variances for total sample, intervention-seeking and non-intervention seeking

	Total sample	Intervention seeking	Non-intervention seeking
General distress tolerance			
DTS3. I can't handle feeling distressed or upset	0.78 (0.02)*	0.78 (0.02)*	0.71 (0.04)*
DTS10. Being distressed or upset is always a major ordeal for me.	0.86 (0.01)*	0.85 (0.01)*	0.80 (0.03)*
DTS4. My feelings of distress are so intense that they completely take over.	0.79 (0.02)*	0.76 (0.02)*	0.75 (0.04)*
DTS2. When I feel distress or upset all I can think about is how bad I feel.	0.71 (0.02)*	0.70 (0.02)*	0.66 (0.04)*
DTS1. Feeling distress or upset is unbearable to me.	0.71 (0.02)*	0.69 (0.03)*	0.60 (0.04)*
DTS5. There's nothing worse than feeling distressed or upset.	0.70 (0.02)*	0.72 (0.02)*	0.56 (0.05)*
DTS15. When I feel distressed or upset, I cannot help but concentrate on how bad the distress actually feels.	0.79 (0.02)*	0.77 (0.02)*	0.77 (0.03)*
DTS12. My feelings of distress or being upset scare me.	0.75 (0.02)*	0.72 (0.02)*	0.72 (0.04)*
DTS9. Other people seem to be able to tolerate feeling distressed or upset better than I can.	0.73 (0.02)*	0.69 (0.03)*	0.74 (0.03)*
DTS11. I am ashamed of myself when I feel distressed or upset.	0.74 (0.02)*	0.73 (0.02)*	0.61 (0.04)*
DTS7. My feelings of distress or being upset are not acceptable.	0.49 (0.03)*	0.47 (0.04)*	0.41 (0.08)*
DTS6. I can tolerate being distressed or upset as well as most people	0.62 (0.02)*	0.55 (0.03)*	0.74 (0.04)*
Describe inner experiences			
FFMQ1. I'm good at finding words to describe my feelings.	0.84 (0.02)*	0.84 (0.02)*	0.83 (0.03)*
FFMQ2. I can easily put my beliefs, opinions, and expectations into words.	0.78 (0.02)*	0.79 (0.02)*	0.72 (0.05)*
FFMQ16. Even when I'm feeling terribly upset, I can find a way to put it into words	0.75 (0.02)*	0.76 (0.03)*	0.74 (0.04)*
FFMQ5. It's hard for me to find the words to describe what I am thinking.	0.67 (0.03)*	0.65 (0.04)*	0.73 (0.04) *
FFMQ11. When I feel something in my body, it's hard for me to find the right words to describe it.	0.61 (0.03)*	0.63 (0.03)*	0.47 (0.04)*

	Total sample	Intervention seeking	Non-intervention seeking
Non-judging of inner experiences			
FFMQ14. I tell myself that I shouldn't be thinking the way I am thinking.	0.65 (0.03)*	0.58 (0.04)*	0.78 (0.05)*
FFMQ4. I tell myself that I shouldn't be feeling the way I am feeling.	0.59 (0.03)*	0.53 (0.04)*	0.66 (0.06)*
FFMQ19. I think some of my emotions are bad or inappropriate and I shouldn't feel them.	0.76 (0.03)*	0.74 (0.04)*	0.73 (0.04)*
FFMQ7. I make judgements about whether my thoughts are good or bad.	0.44 (0.04)*	0.48 (0.05)*	0.54 (0.05)*
FFMQ24. I disapprove of myself when I have illogical ideas.	0.44 (0.05)*	0.43 (0.06)*	0.47 (0.09)*
DTS7. My feelings of distress or being upset are not acceptable.	0.22 (0.04)*	0.21 (0.04)*	0.24 (0.07)*
Regulation of distress			
DTS13. I'll do anything to stop feeling distressed or upset.	0.89 (0.02)*	0.90 (0.02)*	0.82 (0.04)*
DTS8. I'll do anything to avoid feeling distressed or upset.	0.74 (0.02)*	0.75 (0.03)*	0.71 (0.04)*
DTS14. When I feel distressed or upset, I must do something about it immediately.	0.60 (0.03)*	0.56 (0.03)*	0.64 (0.05)*
Acting with awareness			
FFMQ23. I find myself doing things without paying attention.	0.75 (0.03)*	0.80 (0.03)*	0.71 (0.06)*
FFMQ22. I do jobs or tasks automatically without being aware of what I'm doing.	0.71 (0.03)*	0.73 (0.03)*	0.69 (0.05)*
FFMQ12. It seems I am "running on automatic" without much awareness of what I'm doing.	0.75 (0.02)*	0.74 (0.03)*	0.70 (0.06)*
FFMQ17. I rush through activities without being really attentive to them.	0.65 (0.03)*	0.64 (0.03)*	0.65 (0.05)*
FFMQ8. I find it difficult to stay focussed on what's happening in the present moment.	0.59 (0.03)*	0.55 (0.04)*	0.58 (0.06)*
Uncompassionate self-responding			
SCS11. I'm disapproving and judgemental about my own flaws and inadequacies.	0.74 (0.02)*	0.73 (0.03)*	0.72 (0.04)*
SCS1. When I fail at something important to me I become consumed by feelings of inadequacy.	0.74 (0.02)*	0.71 (0.03)*	0.74 (0.04)*
SCS9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	0.72 (0.02)*	0.71 (0.03)*	0.70 (0.04)*
SCS8. When I fail at something that's important to me I tend to feel alone in my failure.	0.73 (0.02)*	0.71 (0.03)*	0.75 (0.04)*
SCS12. I'm intolerant and impatient towards those aspects of my personality I don't like.	0.65 (0.03)*	0.57 (0.04)*	0.71 (0.04)*

	Total sample	Intervention seeking	Non-intervention seeking
SCS4. When I'm feelings down, I tend to feel like most other people are probably happier than I am.	0.58 (0.03)*	0.55 (0.04)*	0.64 (0.04)*
FFMQ24. I disapprove of myself when I have illogical ideas.	0.23 (0.05)*	0.22 (0.06)*	0.19 (0.09)**
Non-reactivity to experience			
FFMQ21. When I have distressing thoughts or images, I just notice them and let them go.	0.75 (0.02)*	0.72 (0.03)*	0.76 (0.05)*
FFMQ9. When I have distressing thoughts or images, I don't let myself be carried away by them.	0.67 (0.03)*	0.64 (0.04)*	0.71 (0.04)*
FFMQ18. Usually when I have distressing thoughts or images I can just notice them without reacting.	0.66 (0.03)*	0.64 (0.03)*	0.64 (0.06)*
FFMQ13. When I have distressing thoughts or images, I feel calm soon after.	0.63 (0.03)*	0.57 (0.06)*	0.64 (0.05)*
FFMQ3. I watch my feelings without getting carried away by them.	0.58 (0.03)*	0.57 (0.04)*	0.60 (0.05)*
SCS7. When something upsets me, I try to keep my emotions in balance.	0.30 (0.05)*	0.31 (0.06)*	0.31 (0.08)*
Compassionate self-responding			
SCS3. When something painful happens I try to take a balanced view of the situation.	0.66 (0.02)*	0.63 (0.03)*	0.66 (0.06)*
SCS2. I try to be understanding and patient towards those aspects of my personality I don't like.	0.64 (0.03)*	0.64 (0.03)*	0.62 (0.05)*
SCS5. I try to see my failings as part of the human condition.	0.71 (0.02)*	0.73 (0.03)*	0.73 (0.05)*
SCS6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	0.70 (0.02)*	0.61 (0.03)*	0.64 (0.04)*
SCS10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	0.65 (0.03)*	0.62 (0.03)*	0.64 (0.05)*
SCS7. When something upsets me, I try to keep my emotions in balance.	0.32 (0.05)*	0.27 (0.06)*	0.47 (0.09)*

* p<.001 **p<.05

Appendix O: Feedback to ethics panel for terminated part B

Reference: V:\075\Ethics\2020-21

Dear Ethics Panel

I am writing to advise of the closure of the following research project.

Impact of form of obsessive thoughts and diagnostic label on stigma and help-seeking preferences for obsessive-compulsive difficulties in Black Caribbean communities and the impact of concerns about racism.

Introduction

The project was designed upon an expert by experience living with obsessive-compulsive disorder (OCD) identifying that within her cultural community people had limited awareness of OCD and this made it difficult for people to seek help. Research identifying that both the general public and professionals have difficulty recognising OCD support this lived experience, particularly identification varying depending on the content of the obsessions someone experiences. It was also identified that levels of concern about racist responses from professionals may impact on stigma of OCD and concerns about seeking help.

Aim

To develop and understanding of how stigma towards obsessions and views about help-seeking varies depending upon the form of obsessive thoughts and presence of an obsessive-compulsive diagnostic label in Black Caribbean communities, and the way this be affected by concerns about racism.

Methodological difficulties

The study design used an online anonymous survey. Initial was promising. Despite safeguards built into the survey to protect against the impact on online bots, some responses appeared to be automated and the survey was paused to add further safeguards. The survey was re-launched and was again shared by several people and elicited responses. When this reached around 40 responses it was difficult to recruit further respondents. The difficulties related to the recruitment process being devised with experts by experiences as central to the recruitment plan, whom due to their own circumstances unexpectedly decreased contact and were not actively involved in recruitment. Additionally, experts by experience and psychological professionals from Black Caribbean communities had opposite views on how the project should be framed, with experts by experience identifying it as needing to be framed as understanding difficulties recognising OCD by their community and professionals wanting to support a project that deconstructed diagnoses. As the project was devised from an expert by experience idea this was kept central to the framing, which in turn affected how comfortable or willing some professionals felt to share the project on their professional online platforms.

This combined set of circumstances meant recruitment was slower than anticipated and was unlikely to be successful in the time frame given for a Major Research Project. As a result, the project had to be terminated for a new part B project to be completed in the lifetime of my qualification.

Rebbeca Paulus

Trainee Clinical Psychologist