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Abstract

Systematic Review of the Literature: Structural barriers to help-seeking in first-episode psychosis: a systematic review and thematic synthesis

Aim: Access to timely treatment is key to early intervention in psychosis. Despite this, significant barriers to treatment remain. In this review we aimed to identify the structural barriers that patients and caregivers face in help-seeking for first-episode psychosis, and the recommendations provided to address these.

Methods: We conducted a systematic review (PROSPERO: CRD42021274609) of qualitative studies reporting structural barriers to help-seeking from the patient or caregiver perspective. Searches were performed in March 2023, restricted to studies published from 2001. Study quality was appraised using Critical Appraisal Skills Programme. Data were analysed using thematic synthesis.

Results: Nineteen papers from 11 countries were included. Across all papers, participants reported experiencing structural barriers to receiving healthcare. For many patients and caregivers, the process of accessing healthcare is complex. Access requires knowledge and resources from parents, caregivers, and healthcare providers, yet too often there is a misalignment between patients' needs and service resources. Expertise amongst healthcare providers vary, and some patients and caregivers experience negative encounters in healthcare. Participants highlighted earlier caregiver involvement and greater peer support are potential routes for improvement.

Conclusion: Patients and caregivers face multiple structural barriers, with legislative practices that discourage family involvement, and healthcare and transport costs found to be particularly problematic. Understanding these barriers can facilitate the design of more accessible services for first-episode psychosis. Further research is needed focusing not only on the perspectives of patients and caregivers who have accessed professional help, but crucially on those who have not.

Keywords: schizophrenia, caregivers, systematic review, help-seeking behaviour, healthcare

Abstract

Service Improvement Project: Improving access to secondary mental health services for young Pakistani women: a qualitative study

Background: Almost three quarters of mental health problems start by the age of 25, yet youth are often underrepresented in UK services. This is particularly true for those of ethnic minorities. In this service improvement project, we aimed to understand how young Pakistani women and their parents make decisions to seek help for mental health problems, and the barriers and facilitators that may exist to them accessing professional help.

Methods: Young Pakistani women with experience of severe mental health problems and their parents were recruited from a community sample. Semi-structured interviews were conducted with six young people and two parents. Data were analysed using reflexive thematic analysis.

Results: Pakistani culture and its interplay with British culture strongly influenced the decisions and ability of young Pakistani women and their parents to help-seek, largely through the role of stigma. External stigma, low mental health literacy, and lack of culturally informed services were identified as the most common barriers to accessing care. These barriers fed into the internalised stigma these young women experienced which, through fear of damaged reputation and personal prejudices, posed further barriers to seeking help. Participants highlighted recommendations for both individual-level (e.g., increased education and awareness) and service-level change (e.g., greater choice over care) to facilitate accessibility of professional help.

Conclusions: Young Pakistani women face multiple challenges to accessing care for mental health difficulties, largely surrounding the cultural tensions and stigma they face. Addressing both individual and service-level challenges may facilitate the development of services that are more inclusive and accessible.

Keywords: youth mental health; help-seeking; diversity; ethnic minority; access

Abstract

Theory Driven Research Project: Fighting OCD together: an experimental study of the effectiveness and acceptability of seeking and receiving emotional support for OCD

Excessive reassurance-seeking in OCD has been linked to the maintenance of OCD, functioning as a type of checking ritual. Current treatments recommend the imposition of the extinction of seeking and providing reassurance; however, this is not well tolerated. Although it has been suggested that the provision of support may provide a more helpful alternative, there is no empirical evidence for this. In the present study, 36 participants with OCD engaged with two personalised semi-idiographic scenarios in which they imagined seeking and receiving reassurance and seeking and receiving emotional support in counterbalanced order. The primary outcome measure was urge to seek reassurance, which was found to significantly decrease in the support condition relative to the reassurance condition regardless of order of presentation. Emotional support was perceived as significantly more acceptable when compared to imagining reassurance in terms of higher ratings of perceived helpfulness in managing emotions, feelings of calmness and closeness, and the sense that they were fighting OCD together. These findings provide preliminary evidence for the value of encouraging the seeking and giving of emotional support as an alternative to reassurance. Implications for clinical work and further research are discussed.

Keywords: obsessive-compulsive disorder; excessive reassurance-seeking; help-seeking; emotional support; cognitive behavioural therapy.

Systematic Review of the Literature

Structural barriers to help-seeking in first-episode psychosis: a systematic review and thematic synthesis

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Proposed Journal

Early Intervention in Psychiatry is an international journal with an impact factor of 2.721, that promotes the importance of early intervention in psychiatric practice and welcomes submissions of systematic reviews. Prior publications have included research in schizophrenia and other psychoses, health services and biological, psychological, and social mechanisms that influence the onset of mental health disorders. Author submission guidelines are presented in Appendix A.

Acknowledgements

This work was supported by the Oxford Institute for Clinical Psychology Training and Research. No funding was sought specifically for this project. FW is funded by a Wellcome Trust Clinical Doctoral Fellowship (102176/B/ 13/ Z). Nithura Sivarajah (NS), a fellow trainee on the course, was a collaborator in the project, performing reliability checks.

Conflict of Interest Statement

The author(s) declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

Abstract

Aim: Access to timely treatment is key to early intervention in psychosis. Despite this, significant barriers to treatment remain. In this review we aimed to identify the structural barriers that patients and caregivers face in help-seeking for first-episode psychosis, and the recommendations provided to address these.

Methods: We conducted a systematic review (PROSPERO: CRD42021274609) of qualitative studies reporting structural barriers to help-seeking from the patient or caregiver perspective. Searches were performed in March 2023, restricted to studies published from 2001. Study quality was appraised using Critical Appraisal Skills Programme. Data were analysed using thematic synthesis.

Results: Nineteen papers from 11 countries were included. Across all papers, participants reported experiencing structural barriers to receiving healthcare. For many patients and caregivers, the process of accessing healthcare is complex. Access requires knowledge and resources from parents, caregivers, and healthcare providers, yet too often there is a misalignment between patients' needs and service resources. Expertise amongst healthcare providers vary, and some patients and caregivers experience negative encounters in healthcare. Participants highlighted earlier caregiver involvement and greater peer support are potential routes for improvement.

Conclusion: Patients and caregivers face multiple structural barriers, with legislative practices that discourage family involvement, and healthcare and transport costs found to be

particularly problematic. Understanding these barriers can facilitate the design of more accessible services for first-episode psychosis. Further research is needed focusing not only on the perspectives of patients and caregivers who have accessed professional help, but crucially on those who have not.

Keywords: schizophrenia, caregivers, systematic review, help-seeking behaviour, healthcare

Structural Barriers to Help-Seeking in First-Episode Psychosis: A Systematic Review and Thematic Synthesis

Introduction

It has been estimated that around 3% of the population will experience psychosis at some point in their lives (National Institute of Mental Health (NIMH), 2015). Whilst psychosis has the potential to lead to poor health and social functioning (Davies et al., 2018), early identification and treatment promotes better outcomes (Lally et al., 2017; O'Keeffe et al., 2022; Sicotte et al., 2021). These include increased quality of life, symptom remission, (Howes et al., 2021) and lower rates of mortality (de Pablo et al., 2021) when compared to those with a longer duration of untreated psychosis (DUP) (O'Keeffe et al., 2022; Watson et al., 2018). Therefore, the World Health Organisation (WHO) identify the appropriate and timely treatment of psychosis as a healthcare priority (for example: WHO: (Bertolote & Mcgorry, 2005)). In the UK, clinical guidelines state that assessment followed by evidence based treatment should occur within two weeks from referral to specialist psychosis services (National Institute for Health and Care Excellence, 2016). Despite this, many people with first episode psychosis (FEP) have long delays in seeking treatment, (Norman et al., 2004), or face barriers to accessing treatment due to factors such as service costs (James et al., 2019) and institutional racism (Davis et al., 2022).

Structural barriers to help-seeking in early psychosis is of particular interest given recent drives to improve healthcare structures (Fusar-Poli et al., 2017; Moe et al., 2018; National Institute for Health and Care Excellence, 2016). These barriers focus on problems

associated with the design of mental healthcare systems, including financial costs and service availability (Tomczyk et al., 2020), and enacted stigma, defined as the experience of unfair treatment from others such as healthcare providers (Gray, 2002). A recent systematic review from O'Connell et al., (2022) found structural barriers in the implementation of early intervention in psychosis services to include inadequate funding, lack of resources, and poorly adapted facilities. Their review included studies from several countries representing a wide range of demographics. However, understanding barriers to access specifically from the patient and caregiver (PAC) perspective is still needed.

The caregiver perspective is especially important given the typical onset of psychosis occurs in late adolescence-early adulthood when patients often live with families (Onwumere et al., 2021; Pope et al., 2019). Yet too often this perspective is missed (Eassom et al., 2014; Lavoie, 2018). This is problematic given this may result in a longer DUP, which can ultimately lead to greater impairments in quality of life (O'Keeffe et al., 2022; Watson et al., 2018) suicide attempts (Barrett et al., 2010), greater symptom severity (Penttilä et al., 2014), and a reduced chance of remission (Howes et al., 2021). Understanding what prevents and facilitates both PACs from seeking help and accessing treatment, is critical in discovering ways to reduce the DUP and mitigate its negative consequences. However, there have been no reviews focusing specifically on caregiver barriers to date.

In the current review we sought to systematically assess findings from qualitative studies investigating help-seeking for FEP. The primary aim was to understand the structural barriers to help-seeking for FEP as reported from the perspective of PACs. In addition, we aimed to identify the recommendations given by PACs on how to reduce or remove these structural barriers.

Methods

A systematic review was conducted following PRISMA guidelines (Page et al., 2021) and using thematic synthesis (Thomas & Harden, 2008). This was registered in PROSPERO (reg: CRD42021274609) on 31/08/2021.

Search Strategy

A comprehensive search strategy was developed (see Appendix B), including 4 key concepts: psychosis, help-seeking, barriers, and qualitative research. Scopus, Web of Science, CINAHL, PsycINFO, Medline, and EMBASE were first searched in January 2022, with the final search conducted in March 2023. Backwards reference searching and forwards citation searching was performed on included full text articles.

Inclusion and Exclusion Criteria

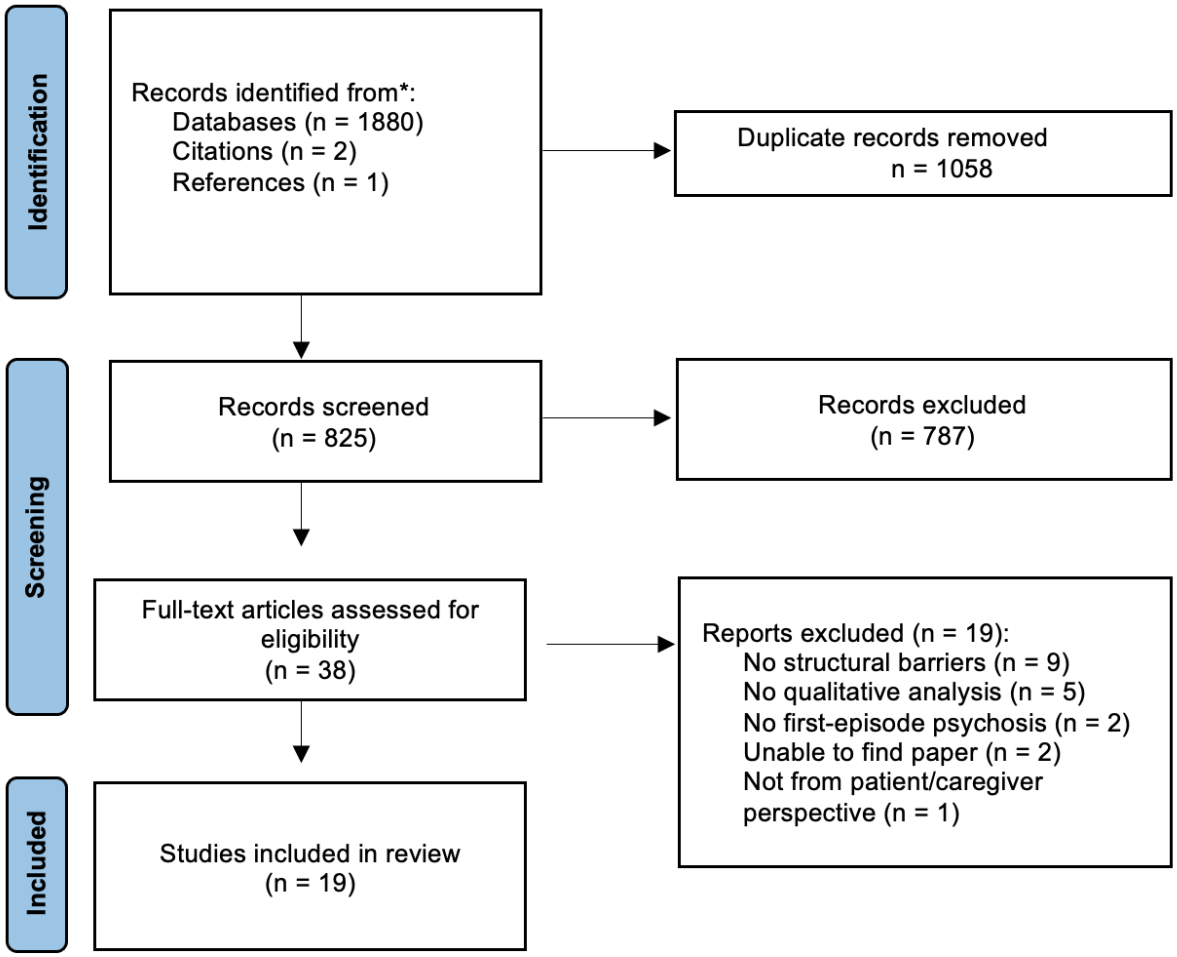
Studies were included if they 1) focused on the perspectives of patients or their caregivers, 2) discussed structural barriers, 3) used qualitative data collection and qualitative analysis methods, and 4) were English language papers. Existing review papers, individual case descriptions, and papers published prior to 2001 were not included. These criteria were chosen so that included studies provided in-depth first-person perspective accounts of barriers relevant to current healthcare provision.

Study Identification

In total, 1883 studies were identified. After removing duplicates 825 abstracts and 38 full texts were screened by CC. A second reviewer (NS) screened 20% of the abstracts and 25% of the full texts. Cohen's kappa (κ) of 1 was reached for both abstracts and full texts. Any disagreements were resolved by FW and MK. The complete process of study identification is shown in the PRISMA flowchart (Figure 1.1).

Figure 1.1.

PRISMA flowchart of study selection



Quality Appraisal Tool

Study quality was assessed using the Critical Appraisal Skills Programme (CASP) appraisal tool for qualitative research; a ten-item tool, with a rating scale of 0-20. For this study, a score of 16-20 was considered high quality, 11-15 was considered medium quality, and 10 or below was considered low quality. A sample of 25% of the texts were rated by two

authors (CC & NS) and any discrepancies were discussed between the authors. A Cohen's kappa (κ) of 0.85 was achieved.

Data Extraction

A data extraction form was developed and used to extract information about the study population, methodology and analysis. A sample of 50% of the data extraction was undertaken by two independent reviewers (CC & NS) and any disagreements were resolved by consulting the third and fourth reviewers.

Data Synthesis

Inductive thematic synthesis was conducted, as outlined by Thomas & Harden (2008), in order to collate and identify patterns within the data that encompassed the structural barriers and recommendations to these voiced by PACs. This followed three stages: (1) line-by-line and axial coding, (2) development of descriptive themes, and (3) generating analytical themes in relation to the research questions. For the purposes of this review, findings were classified as all text in the results/findings section of qualitative papers, and the findings resulting from qualitative data collection and analysis in mixed-methods papers. All papers were entered into QSR International's NVivo, Release 1.6.2 software. Two reviewers (CC & NS) independently conducted line-by-line coding of 25% of the papers and discussed discrepancies, with one reviewer (CC) coding the remainder of papers. All open codes were then discussed between two researchers (CC and MK), and axial coding was completed to refine these early codes. Codes were then grouped into descriptive themes, which were then organised into analytical themes through close discussion amongst CC, MK & FW of how the descriptive themes may fit together to answer the research questions. Our analysis was not restricted to themes highlighted by the authors of the original papers, but rather reflected themes that evolved from the synthesis of findings of multiple studies.

Positioning statement

CC identifies as a white female, with lived experience of mental health difficulties. MK identifies as a white male, with lived experience of ill health. FW identifies as a white female. All authors in this paper hold professional interests in psychological treatments for psychosis, minority perspectives, and improving access to healthcare.

Results

Characteristics of included studies

Nineteen papers were included. Of these, 18 were qualitative, and one was mixed methods. All 19 papers had medium methodological quality or above, with the majority of papers (*n*=14, 73.7%) rated as having high methodological quality. All studies had appropriate methodology and the majority had suitably rigorous analysis with results that provided valuable contributions to the literature. Common limitations were lack of adequate consideration of the relationship between participants and the researcher, and lack of description of the research designs used. Due to the relatively high quality of all studies, risk of bias was deemed low and therefore all studies were included in the analyses. Emphasis within the findings did not reflect methodological quality but rather how well they answered the research questions. Study characteristics are provided in Table 1.1.

Of the 19 studies, 47.4% of these focused on the views of caregivers only (*n*=9), and 10.5% of these focused on patients only (*n*=2), with the remainder of papers focused on both PACs (*n*=8). The majority of studies (*n*=16) were based in Western, educated, industrialised, rich and democratic (WEIRD) countries, though access to healthcare varied. Participants in all studies were recruited from mental health services, therefore, the identified themes are shaped by PACs who received professional help following help-seeking.

Table 1.1

Characteristics and quality rating of studies

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
Anderson et al., 2013	Canada	Patients only (*n*=16)	Patients (*n*=16)	20-24	4F, 12M (sex)	Visible minority (*n*=5), not a visible minority (*n*=11)	Graduated high school or less (*n*=8), Further education after high school (*n*=8)	Qualitative	Structured & semi-structured interviews, Content analysis	18
Bay et al., 2016	Norway	Patients only (*n*=8)	Patients (*n*=8)	17-44	4F, 4M (sex)	No information	No information	Qualitative	Semi-structured interview Combined IPA and Systematic Meaning Condensation	17
Bergner et al., 2008	USA	Caregivers only (*n*=12)	Caregivers (*n*=12) - Mothers (*n*=7) - Fathers (*n*=2) - Sisters (*n*=1) - Grandmothers (*n*=1) - Uncles (*n*=1)	32-62	9F, 3M†	African American (*n*=12)	Graduated high school & attended trade/ vocational school/college (*n*=10)	Qualitative	Interviews, Qualitative analysis	16
			Patients (*n*=10)	18-28	3F, 7M†	African American (*n*=10)	Not graduated from high school (*n*=6)			
Cabassa et	USA	Patients and	Patients (*n*=20)	M = 23.7	9F, 11M	Hispanic (*n*=11), African	No	Mixed	Semi-structured	15

† Unclear whether the demographic data collected referred to gender or sex.

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
al., 2018		Caregivers (*n*=30)			(gender)	American (*n*=5), Non-Hispanic White (*n*=2), Asian (*n*=2)	information	methods	interviews, Grounded theory & case	
			Caregivers (*n*=10) - Mothers (*n*=8) - Brothers (*n*=2)	No information	8F, 2M (gender)	No information	No information		study methodology	
Cadario et al., 2011	New Zealand	Patients and Caregivers (*n*=26)	Patients (*n*=12)	15-18	5F, 7M (gender)	NZ European (*n*=7), NZ Maori (*n*=4), NZ Maori/Cook Island Mauri (*n*=1)	No information	Qualitative	Semi-structured and unstructured interviews General inductive approach	17
			Caregivers (*n*=14) - Mothers (*n*=12) - Fathers (*n*=2)	No information	No information	No information	No information			
Connor et al., 2016	United Kingdom	Patients & Caregivers (*n*=28)	Patients (*n*=14)	*M* = 25.6	4F, 10M (gender)	Asian Pakistani (*n*=7), White British (*n*=4), Black African (*n*=2), Black Caribbean (*n*=1)	No information	Qualitative	Semi-structured interview, Framework analysis	16
			Caregivers (*n*=14) - Mothers (*n*=6) - Fathers (*n*=2) - Sisters (*n*=2) - Brothers (*n*=2) - Sister-in-laws (*n*=1) - Aunts (*n*=1)	No information	10F, 4M (gender)	No information	No information			

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
Dos Santos Martin et al., 2018	Brazil	Caregivers only (*n*=13)	Caregivers (*n*=13) - Mothers (*n*=9) - Fathers (*n*=3) - Husbands (*n*=1)	*M* = 47.5	9F, 4M†	No information	No information	Qualitative	Interviews, Thematic analysis	18
Dutta et al.	India	Caregivers	Caregivers (*n*=25)	No infor	7F, 18M	No Information	Illiterate	Qualitative	Semi-structured	15

† Unclear whether the demographic data collected referred to gender or sex.

			- Children (*n*=2) - Uncle/Aunt (*n*=1) - Grandparent (*n*=1)				High school (*n*=5), Intermediate (*n*=1), Graduate/post graduate (*n*=5)			
			Patients (*n*=25)	No information	9F, 16M (gender)	No information	Illiterate (*n*=1), Primary (*n*=1), Middle school (*n*=7), High school (*n*=8), Intermediate (*n*=5), Graduate/post graduate (*n*=3)			
Ferrari et al., 2015	Canada	Patients & Caregivers (*n*=34)	Patients (*n*=25)	No information	12F, 13M (sex)	European (*n*=16), Caribbean (*n*=4), African (*n*=5)	Completed high-school or less (*n*=17), completed more than high-school (*n*=8)	Qualitative	Focus groups & in-depth interviews, Thematic analysis	18

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
			Caregivers (*n*=9)	No information	No information	European (*n*=6), Caribbean (*n*=3)	No information			
Gerson et al., 2009	USA	Caregivers only (*n*=14)	Caregivers (*n*=14) - Mothers (*n*=9) - Fathers (*n*=3) - Brothers (*n*=1) - Aunts (*n*=1)	No information	10F, 4M†	No information	No information	Qualitative	Open-ended interviews Phenomenological approach	14
			Patients (*n*=13)	16-24	3F, 10M†	Caucasian (*n*=5), Hispanic (*n*=4), African American (*n*=3), East Asian (*n*=1)	No information			
Hasan & Musleh, 2017	Jordan	Caregivers only (*n*=27)	Caregivers (*n*=27) - Parents (*n*=13) - Siblings (*n*=5) - Spouses (*n*=7)	37-68	22F, 5M (gender)	No information	Primary or below (*n*=10), Secondary school (*n*=8), College or above (*n*=9)	Qualitative	Semi-structured interviews, Thematic analysis	17
Islam et al., 2015	United Kingdom	Patients and Caregivers (*n*=33)	Patients (*n*=22)	No information	11F, 11M (gender)	Asian/Asian British Pakistani (*n*=9), Asian/Asian British-Bengali (*n*=1), Black/Black British-African (*n*=3), Black/Black British-Caribbean (*n*=8), Other (*n*=1)	No information	Qualitative	Focus groups with interviews, Conceptual thematic framework	18
			Caregivers (*n*=11)	*M* = 42	8F, 3M (gender)	Asian/Asian British Pakistani (*n*=3), Black/Black British-	No information			

† Unclear whether the demographic data collected referred to gender or sex.

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
						African (*n*=2), Black/Black British-Caribbean (*n*=5), Other (*n*=1)				
Marthoenis et al., 2016	Indonesia	Caregivers only (*n*=16)	Caregivers (*n*=15) - Parents (*n*=9) - Siblings/cousins (*n*=5) - Sons (*n*=1) - Spouses (*n*=1)	27-68	8F, 7M (gender)	Acehnese (*n*=13), Gayonese (*n*=3)	Primary complete (*n*=6), Senior high complete (*n*=4), University attended (*n*=4), Graduated from junior high (*n*=1), No formal education (*n*=1)	Qualitative	In-depth interviews, Content analysis	16
			Patients (*n*=17)	14-74	3F, 14M (gender)	No information	no formal education (*n*=2), primary school complete (*n*=5), secondary school complete (*n*=4) attended university (*n*=2)			

References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
McCann et al., 2011	Australia	Caregivers only (*n*=20)	Caregivers (*n*=20) - Parents (*n*=17) - Unknown (*n*=3)	21-76	17F, 3M (gender)	No information	No information	Qualitative	Semi-structured interviews IPA	18
Oluwoye & Stokes, 2023	USA	Patients and Caregivers (*n*=14)	Patients (*n*=6)	19-28	2F, 4M (gender)	No information	No information	Qualitative	Semi-structured interviews, Qualitative content analysis	12
			Caregivers (*n*=8) - Mother (*n*=5) - Father (*n*=1) - Sibling (*n*=2)	31-57	6F, 2M (gender)	No information	No information	Qualitative		
Skubby et al., 2015	USA	Caregivers only (*n*=11)	Caregivers (*n*=11)	No information	No information	No information	No information	Qualitative	Semi-structured interviews, Issue-focused analysis	16
			Patients (*n*=11)	No information	8F, 3M†	White (*n*=7) Black (*n*=4)	No information			
Tanskanen et al., 2011	United Kingdom	Patients & Caregivers (*n*=30)	Patients (*n*=21)	*M* = 26.5	6F, 15M (gender)	White British (*n*=3), White Other (*n*=4), Black African (*n*=3), Black Caribbean (*n*=5), Asian Bangladeshi (*n*=4), Mixed race (*n*=2)	No information	Qualitative	Semi-structured interview, Thematic analysis	16
			Caregivers (*n*=9) - Mothers (*n*=6) - Sisters (*n*=1)	26-68	8F, 1M (gender)	White British (*n*=5), White other (*n*=2), Black Caribbean (*n*=1), Mixed race (*n*=1)	No information			

† Unclear whether the demographic data collected referred to gender or sex.

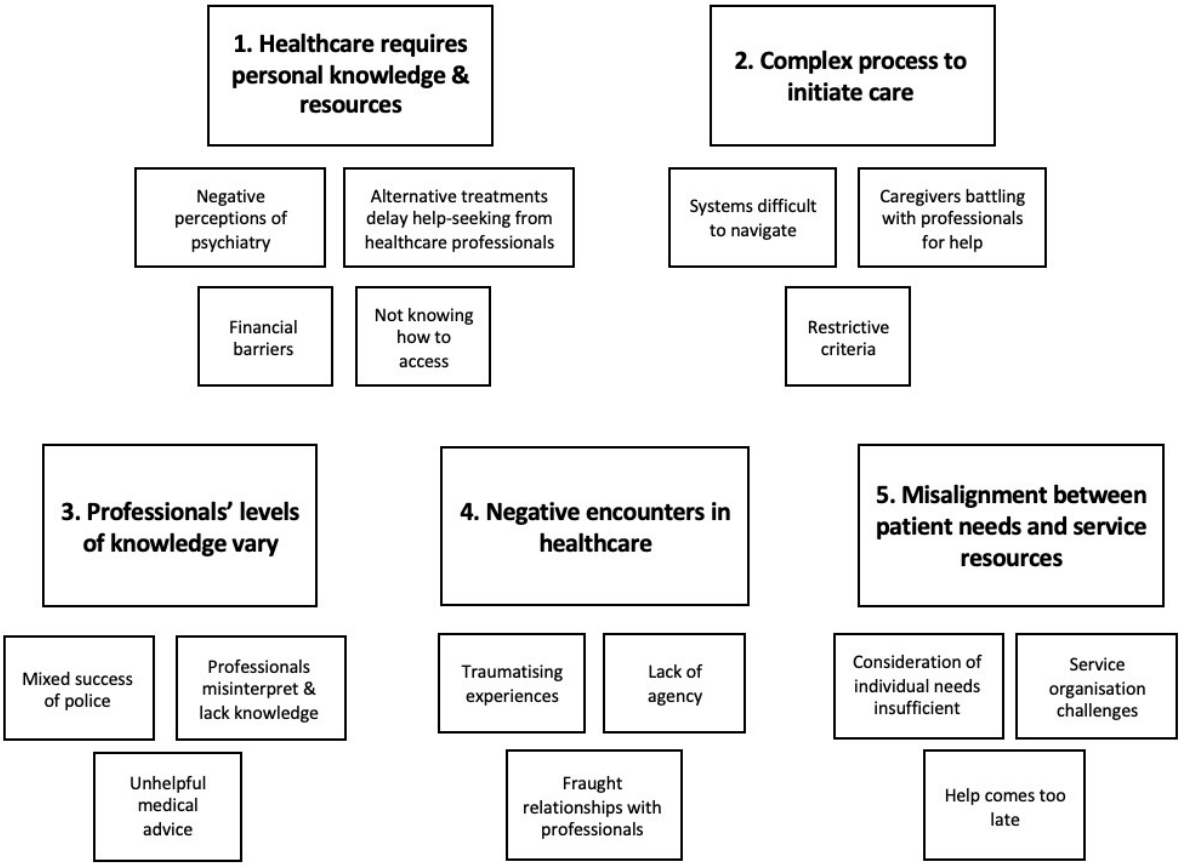
References	Country	Patients and/or Caregivers	Number of participants/ the people they care for	Age (range/ mean (*M*))	Gender/ Sex	Ethnicity	Education	Study type	Methodology and analysis	CASP Rating
			- Partners (*n*=1) - Mother-in-laws (*n*=1)							
Wong et al., 2020	Malaysia	Caregivers only (n=18)	Caregivers (n=18) - Mothers (n=6) - Fathers (n=5) - Sisters (n=4) - Husbands (n=2) - Brothers (n=1)	33-69	10F, 8M (gender)	No information	No information	Qualitative	Focus group, Thematic analysis	17
Yarborough et al., 2019	USA	Patients and Caregivers (n=32)	Patients (n=22)	*M* = 21.6	11F, 11M (gender)	White (n=14), Asian/Pacific Islander (n=3), Black (n=1), Hispanic (n=3)	No information	Qualitative	Interviews Inductive content analysis	15
			Caregivers (n=10) - Parents (n=8) - Grandparents (n=1) - Siblings (n=1)	No information	No information	No information	No information			

Findings

The findings from 19 papers were synthesised into 5 analytical themes, formed of 16 descriptive themes (Fig. 1.2). Quotes were included from across the papers to illustrate the themes. Further quotations can be found in Appendix C.

Figure 1.2.

Analytical and descriptive themes generated from the thematic synthesis



1. Healthcare requires personal knowledge and resources

Across all studies, there was an overarching theme that pre-existing resources and knowledge of services were required to successfully seek help. Knowledge informed by negative stereotypes, as well as limited financial resources, were shown to result in the avoidance of, or inability to attend, healthcare services. In some studies, this was shown to

lead to the use of alternative treatments that delayed healthcare access. For those who had the resources to attend services, not knowing where to go, who to see, and how to get there, created additional challenges to help-seeking.

1.1. Negative perceptions of psychiatry

Some PACs voiced negative views of psychiatric services that discouraged help-seeking. In a minority of cases, these were informed by media reports of psychiatric hospitals where patients were *"fighting… naked"* and *"hitting"* which contributed to beliefs *"that psychiatric treatment is bad*" (Wong et al., 2020, p. 8). A minority also worried about the effects of medication, and whether it *"might be habit forming"* (Dutta et al., 2019, sec. Effects of medication). These negative assumptions of psychiatric settings left some patients feeling *"petrified"* (Anderson et al., 2013, p. 389) that something bad would happen to them and that *"once [they were] in…(psychiatric settings), [they'd] never come out*" (Connor et al., 2016, p. 339).

1.2. Financial barriers

Finances were reported as a barrier to care by numerous families, but only in low-income countries and those lacking free healthcare. Some spoke of how healthcare costs created barriers due to *"antipsychotic medication [being] very expensive"* (Hasan & Musleh, 2017, p. 674), and that this alongside the often *"lengthy process of treatment seeking… caused [families] to suffer financially*" (Marthoenis et al., 2016, p. 3). Others described how they were unable to initiate help-seeking as they could not *"afford… to take [patients] to a doctor"* (Dutta et al., 2019, sec. Financial constraints). Even when free healthcare treatments existed, transport costs were highlighted as creating further financial barriers. For some, these financial restraints reduced "*the family's hope of getting recovery"* (Hasan & Musleh, 2017, p. 674), and left them feeling like *"there's… nothing [they] could do"* (Bergner et al., 2008, p. 533).

1.3. Alternative treatments delay help-seeking from healthcare professionals

In several studies, families described that informal healthcare services such as traditional healers, religious communities or spiritual leaders were often the initial help-seeking contact. These were said to initially *"[prevent] the families from taking the patient to a health professional"* (Marthoenis et al., 2016, p. 4) either due to beliefs surrounding treatment efficacy, or misinformation about healthcare treatments. It was only when these alternative treatments were attempted *"without any improvement"* (Wong et al., 2020, p. 5) that psychiatric care was sought, with this perceived as a *"last resort"* (Ferrari et al., 2015, p. 7). A minority of patients recommended that emphasising *'the non-medication aspects of early intervention'* (Anderson et al., 2013, p. 388) such as vocational services, may be of benefit in increasing help-seeking from healthcare professionals.

1.4. Not knowing how to access

A key theme across the studies was that most PACs lacked knowledge of how to access healthcare for FEP. Some patients described *"trouble finding the right words"* (Bay et al., 2016, p. 73) and not knowing what to say to receive help. Families spoke of not knowing *"which doctor deals with this (psychosis)"* (dos Santos Martin et al., 2018, p. 251) or even being aware that services could help them. In some cases, even when families knew where to go, they did not know how to get there, due to logistical issues such as transport. This 'not knowing' was described as *"one of the hardest things"* (Tanskanen et al., 2011, p. 6) by some caregivers, with the *"responsibility for help-seeking… without adequate knowledge… lay[ing] a heavy burden on [them]"* (Connor et al., 2016, p. 340).

2. Complex process to initiate care

This theme highlighted the complexity of healthcare systems as perceived by PACs attempting to help-seek for FEP. Restrictions posed by services and legal protections made it difficult for patients to find appropriate services, caused frustration, and often led to caregivers entering a perceived battle with professionals for care. Families spoke of a desire for more information, and for earlier caregiver involvement in the help-seeking process.

2.1. Systems difficult to navigate

Many help-seekers reported a "*long journey*" (Cadario et al., 2011, p. 87) to finding appropriate services, with multiple steps and "*complicated referral system[s]"* (Marthoenis et al., 2016, p. 6). When the correct services were found, caregivers spoke of how *"psychiatric clinics ha[d] to process official documents"* (Hasan & Musleh, 2017, p. 674) and obtain references in order to be seen, lengthening the DUP. For some, *"insurance… contributed to the delayed initiation of treatment"* (Oluwoye & Stokes, 2023, p. 57) with caregivers struggling to find *"anyone who would take [their] insurance*" (Gerson et al., 2009, p. 814). Accessible information was appreciated by families, yet sometimes lacking, with some families wishing for *'more information… available at school'* (Bay et al., 2016, p. 74) and increased *"visibility of early intervention services"* (Anderson et al., 2013, p. 388).

2.2. Restrictive criteria

Services were reported to operate with narrow access criteria by some PACs, predominantly by those in countries without access to free healthcare. Often, these criteria specified that patients needed to be *"convincingly unwell"* to receive care, often meaning that *"people [had] to get really sick"* (McCann et al., 2011, p. 159) and enter crisis before they were seen. For those attempting to help-seek through the police, some families were told *"if the patient is not aggressive… they also cannot do anything"* (Wong et al., 2020, p. 6) which often meant a deterioration in mental health before receiving help. Some services, however, showed restrictions in the opposite direction, with doctors refusing help to patients deemed

"*too sick"* (Gerson et al., 2009, p. 814), which families found frustrating. Some services also required GP involvement in the referral, which created further barriers to help-seeking.

2.3. Caregivers battling with professionals for help

Caregivers often described feeling excluded by healthcare professionals, due to "*never [being] brought into conversations*" (Skubby et al., 2015, p. 893), or *"ask[ed] for their input"* (Cabassa et al., 2018, p. 651). This could often be due to legal entitlements and privacy protections, that meant patients were "*legally required to call for [themselves]"* (Yarborough et al., 2019, p. 6) and had "*to be the one… to initiate [care]"* (Bergner et al., 2008, p. 533), yet some caregivers shared that their loved one lacked the insight to seek help. One mother spoke of how her son "*who thinks God wants him to go to Egypt may not make the best decisions"* and how she wished she would have known that after he turned eighteen, she would be unable to help-seek on her child's behalf as she *"may have been more forceful and said this kid really needs help. He really needs help"*(Yarborough et al., 2019, p. 13). Caregivers described fighting for loved ones through "*door-knocking*" (McCann et al., 2011, p. 159), assertiveness, and in one paper, even *"exaggerating symptoms"* (Islam et al., 2015, p. 744*)* in order to be heard by professionals. For many, it was only through persistence that they were given the information necessary to access care, with some reporting *"it [taking] years just to get someone to listen"*(McCann et al., 2011, p. 159). This exclusion delayed timely access to care for many, meaning hospitalisation was often required, and in some instances, led to service disengagement. Families asked for ways *"to be brought in sooner"* (Gerson et al., 2009) so that they could better support their loved ones.

3. Professionals' levels of expertise vary

Patients reported inconsistencies in the levels of professional expertise. Whilst some professionals were perceived as supportive and facilitating help-seeking, others misinterpreted symptoms and gave medical advice that was perceived as unhelpful and led to

psychosis being undiagnosed and untreated. Some patients suggested further training for healthcare professionals, and more consistent care.

3.1. Mixed success of police

Police involvement in help-seeking was found to vary across the studies. For many, police officers were linked to hospitalisation, with some directly *'involv[ed] in hospitalisation'* (Gerson et al., 2009, p. 813), and others involved indirectly through providing information regarding hospitalisation. For some, this was a positive experience where families found *"the police were nice"* (Ferrari et al., 2015, p. 7), and helped them gain awareness that psychosis *"can be treated"* (Wong et al., 2020, p. 8). Others, however, reported the police as forceful, *"overly aggressive"* (Oluwoye & Stokes, 2023, p. 56) and having a general *"lack of understanding"* (dos Santos Martin et al., 2018, p. 251) about psychosis.

3.2. Professionals misinterpret and lack knowledge

Those seeking help often found that symptoms were misinterpreted either as physical health problems such as *"asthma or something"* (Tanskanen et al., 2011, p. 7), other mental health problems such as *'depression and anxiety'* (Bay et al., 2016, p. 73), and in one case, even *"the effect of black magic"* (Dutta et al., 2019, sec. Supernatural causation). In many cases, healthcare professionals could not, or *"[would] not give [the patient] a diagnosis"* (Skubby et al., 2015, p. 892), frustrating families. These experiences led a minority of caregivers to question whether there was sufficient mental health training with one providing suggestions that *"GPs needed further training in detecting the symptoms of mental illness"* (Islam et al., 2015, p. 744). Others were less critical but spoke of how they felt that *"nobody had the overall perspective"* (Skubby et al., 2015, p. 892) which could lead to delayed care.

3.3. Unhelpful medical advice

Caregivers reported unfavourable medical advice from professionals, with many feeling that symptoms were minimised through advice such as *"ask[ing] [the patient] to relax"* (Wong et al., 2020, p. 5), reduce screen time, or even to just *"give it time and see"* . Another family spoke of how they were advised to *"get used to it"* as symptoms would be lifelong (Gerson et al., 2009, p. 814), rather than encouraging help-seeking. Some reported that symptoms were not recognised at all due to an overreliance on investigations such as brain scans which resulted in advisement that treatment was unnecessary.

4. Negative encounters in healthcare

Many patients described the process of help-seeking as traumatic due to experienced violence or restrictive care. PACs reported that professionals were experienced as stigmatising, dismissive, and unapproachable, and reported feeling like they had lost their agency. Patients requested better interprofessional communication, and for professionals to respond to PACs in ways that are more validating and empathetic, and that foster equality over coercion.

4.1. Traumatising experiences

PACs described facing distressing encounters during the help-seeking process, with caregivers describing their loved ones being *"traumatised by the system"* (Oluwoye & Stokes, 2023, p. 57). Involuntary hospitalisation was described as particularly traumatising, both for patients who felt it was "*just like jail"* (Cabassa et al., 2018, p. 653) and for the caregivers who had the *"horrible feeling"* of *"leav[ing] [them] in the… ward"* (Gerson et al., 2009, p. 813). Both verbal and physical abuse was described by some during these admissions, with patients recounting being *"beat[en] the **** out of"*, "*injected… in the back of neck"* and *"locked… in a jail cell"* (Ferrari et al., 2015, p. 8). Better communication between care providers was requested to minimise this and facilitate continuity of care.

4.2. Fraught relationships with professionals

Mixed relationships between PACs and healthcare professionals were described. Some professionals were described as empathetic, understanding and providing *"a good level of support" as they "rang patients frequently… [and] would visit [them] at work"* (Cadario et al., 2011, p. 89). Often, however, they were described, as dismissive, unapproachable, and stigmatising, which hindered the help-seeking process. Concerns provided by PACs were often dismissed as being nothing out of the ordinary, with some professionals reportedly going as far as to say that patients were attention-seeking or "*faking it*" (Ferrari et al., 2015, p. 8). These experiences understandably left help-seekers feeling *'unheard'* and as though "*no-one believes [them]"* (Connor et al., 2016, p. 339). There was a felt sense of power imbalance between professionals and patients, with doctors described as intimidating and at times patronising. Help-seekers described wishing for greater validation of their experiences, and to receive more empathetic responses from service providers.

4.3. Lack of agency

In a few papers, patients described experiencing a loss of control within their lives through help-seeking. They spoke of how professionals often did not speak directly to them, and felt decisions were being made *"about [them] not with [them]"* (Connor et al., 2016). This was also apparent in the involuntary hospitalisations that many patients experienced. A shared narrative as a result of these experiences was that patients felt invisible and dehumanised and felt *"like they were just doing what [they were] asked to do… like a young dog, being trained to pee outside"* (Anderson et al., 2013, p. 390). Patients spoke of the importance of being made to *"feel like an equal"* (Ferrari et al., 2015, p. 8) and of *'limiting the use of force or coercion'* (Anderson et al., 2013, p. 388) to improve the help-seeking experience.

5. Misalignment between patient needs and service resources

Patients felt at times there was insufficient consideration of their individual needs which made help less accessible. Further, time-restricted appointments and lack of continuity of care meant that care was often difficult to obtain. This resulted in a consensus that when help was received, it came too late. Some patients recommended more individualised treatments, more peer support, and a reduction in waiting times.

5.1. Consideration of individual needs insufficient

Some PACs reported a lack of matching of themselves to healthcare professionals based on their demographics. Cadario et al., (2011) for example, spoke of how language could be "*one of the main barriers"* (p. 159) to help-seeking, alongside a lack of consideration of ethnicity when allocating professionals. The latter was not always considered necessary, however, as long as "*professionals acknowledged [the patient's] culture and treated them with respect"* (Islam et al., 2015, p. 746). This was not always found, however, with some patients reporting professionals to be *"disrespecting [their] culture*" (Oluwoye & Stokes, 2023, p. 57) through administering drugs after they declined due to cultural beliefs. PACs highlighted that, *"peer support within the services"* (Cadario et al., 2011, p. 89) was highly valued, as it allowed shared understanding and support. Some families requested more peer support opportunities, as well as requests for more *"individualised treatments"* (Anderson et al., 2013, p. 388).

5.2. Service organisation challenges

Healthcare service design was noted as problematic for many PACs. Time constraints of services were one concern, with families frustrated at out of hours crisis services, and the short appointment times in which professionals are *"supposed to be able to figure out how [patients are] doing"* (Gerson et al., 2009, p. 814). Others spoke of how the lack of continuity of care made treatment-seeking challenging, and recommendations were given by patients to improve interprofessional communications so that *"patients aren't forced to*

continually recount their stories' (Anderson et al., 2013, p. 388). A minority of patients also reported design issues with *'crowded waiting rooms [being] challenging for those with paranoia'* (Anderson et al., 2013, p. 388).

5.3. Help comes too late

PACs commonly reported feeling that their attempts to help-seek were futile until the patient's wellbeing had deteriorated significantly. Families felt as though hospital *"could have been avoided"* with earlier treatment (Yarborough et al., 2019, p. 6) and that help *"was always too late and a lot of damage [was] already done"* (McCann et al., 2011, p. 159). Families were upset that "*early attempts to ask for help were dismissed"* (Ferrari et al., 2015, p. 7) and recommended that in order to provide better support for PACs, healthcare services should *"give more help from the beginning"* (Gerson et al., 2009, p. 814) and reduce waiting times.

Discussion

In this review, we aimed to identify the structural barriers to help-seeking for FEP reported by PACs, and recommendations they gave to address these. Centring on these aims, our thematic synthesis of 19 studies generated five analytical themes which predominantly focused on barriers to help-seeking from the perspectives of caregivers. These themes highlighted the complex process of accessing healthcare for many PACs, due to factors such as limited knowledge and resources of PACs, limited knowledge and differing expertise of healthcare providers, and negative encounters with professionals. Recommendations including greater peer support and earlier involvement of caregivers, were highlighted by PACs to address some of the barriers.

In this review we found structural barriers to be consistent across a wide range of demographics and geographical areas. All barriers were found to be present across both countries with and without free healthcare, with the exception of financial barriers and

restrictive criteria which were found to be restricted to studies in countries without free healthcare. One of the most commonly reported barriers related to the requirement for pre-existing knowledge and resources; tools commonly depleted in those from disadvantaged backgrounds. Whilst a large body of evidence supports a link between social disadvantage and psychosis (Anderson et al., 2013) and a negative association between social disadvantage and help-seeking (Sweeney et al., 2015), the reasons behind this are understudied. This review highlights a possible explanation for this, insofar that the resources necessary to access help, such as knowledge and transport, are commonly unavailable to these groups (Powers et al., 2016). These findings were most prominent in studies held in countries without access to free healthcare, as the majority of studies in this review were.

Police involvement was found in many patient's pathways to care to varying levels of success, with many encounters resulting in involuntary psychiatric admissions. Various programmes have been implemented to try and reduce this issue, including Crisis Intervention Training in the US (Ellis, 2014; Rogers et al., 2019). Whilst these programmes have shown improvements in police attitudes towards mental health (Rogers et al., 2019), reductions in hospitalisation and police violence have not been indicated, and it has been suggested that implementing crisis-specific teams with alternative professionals may be a preferable option (Marcus & Stergiopoulos, 2022). Currently, these exist in few countries.

Negative perceptions of healthcare professionals were reported frequently by PACs. The presence of provider stigma has previously been recognised in several studies (Hansson et al., 2013; Sivec et al., 2020), and has been influential in patient engagement in help-seeking. Qualitative interviews with patients have suggested a shifting of power balance is needed to enable better relationships with professionals (Laugharne et al., 2011). In the UK, the introduction of peer support workers (staff with lived-experience relevant to the people they are supporting) into services has facilitated this and their presence has been shown to

increase trust in healthcare professionals (White et al., 2017). Research into the benefits of peer support workers in other regions is required to better understand whether this method is effective in facilitating help-seeking for FEP.

This is the first systematic review to highlight structural barriers that may work against caregivers help-seeking on behalf of loved ones with FEP. This is a dilemma for services where the emphasis is on both early recognition and treatment of psychosis and respecting legislative practices that protect the rights of patients, such as the UK's Mental Health Act (*Mental Health Act*, 2007). In some countries, guardianship has been proposed as an alternative, to allow caregivers to make decisions in the best interests of patients (Sugiura et al., 2020). However, this has received criticism due to limitations on patient autonomy (Kohn et al., 2012). More recently, supported decision-making has become the preferred alternative whereby an 'associate' can legally assist in healthcare decisions without making the decision itself (Gooding, 2013; Shogren et al., 2017). Whilst this has previously been reserved for those lacking capacity, translating a similar concept to patients with FEP (particularly those lacking insight into their condition) may empower individuals to seek help, without excluding caregivers.

Implications

This review points to some clear recommendations provided by PACs to reduce the barriers to help-seeking for FEP. These were predominantly the earlier inclusion of caregivers in the help-seeking process and more peer support programmes. PACs also recommended creating environments where healthcare professionals are perceived as more validating of patient concerns. This may be facilitated through empathic validation training programmes which aim to encourage patients to feel as though they are heard and understood (Tietbohl, 2022). Further research focusing specifically on the recommendations of PACs on how to improve services for FEP, would be invaluable in developing person-centred, accessible care

for FEP, with preliminary research in Norway suggesting developing services alongside patient recommendations can lead to improved outreach and reduced barriers to early intervention services (Romm et al., 2019).

In addition to recommendations provided directly by PACs, further clinical implications were highlighted. Firstly, the streamlining of pathways and clearer information on how to navigate services for FEP would likely reduce demands on both services and help-seekers. This may be done through the implementation of triage systems for psychosis with clear pathways based on presenting symptoms (e.g., GPs having clear guidelines of symptoms that may indicate referrals to EISs vs at-risk mental state services vs other mental healthcare services), and psychosis-specific training of staff in primary care settings (e.g., for GPs, practice nurses, pharmacists), to ensure staff are better equipped to spot the symptoms and advise patients on how to access specialist services. This is supported by a recent systematic review by Radez et al., (2023) which highlighted the need for training in primary care to help identify the symptoms of emerging psychosis as early as possible to facilitate early help-seeking and treatment for improved outcomes. Clearer information campaigns for how to enter these services targeted at PACs could also facilitate help-seeking, as shown in Norway, where it has been found that targeted community education increased referrals and improved pathways to care in early psychosis (Hegelstad et al., 2012). Further facilitation of help-seeking may be achieved through diversification of the workforce to facilitate service understanding and consideration of patient needs. This may be assisted through more holistic admission processes that assess the unique experiences of applicants in addition to standard measures of achievement when employing staff (Conrad & Meyer-Ohle, 2019), and mentorship programmes that seek to promote diversity in leadership (Lee et al., 2021; Renninger et al., 2015). Finally, the study findings suggest that healthcare systems, particularly in lower income countries, would benefit from better transport links such as non-

emergency medical transportation to reduce financial barriers to accessing healthcare (Wallace et al., 2005).

Limitations

Limitations arose from the lack of clarity as to whether findings in the included papers in the review represented participants' views as opposed to the authors' interpretations. Although efforts were made to give an accurate representation of the findings across studies, it is unavoidable that some of the voice of PACs will have been lost through this process. Further, the development of themes was primarily conducted by a single researcher, which may have increased the likelihood of the themes being influenced by the individual biases gained from previous clinical work with people with psychosis who often faced many structural barriers to treatment access, particularly complex pathways, financial barriers, and fraught relationships with professionals. To mitigate this, an inductive approach rooted in critical realism was taken, and themes were regularly discussed and developed between two researchers.

Due to the limited demographic information in many studies included in this review, it was not possible to identify whether structural barriers differed based on demographics. Future research in this area would benefit from reporting on this information more clearly, to inform more individualised, patient-centred services that are also cost-effective, for example, funded services for specific populations from the point of care. Finally, as this review found papers solely where PACs had received care following help-seeking, it remains unclear what additional barriers may exist for those who have either not attempted help-seeking or have attempted and been unable to access care. Qualitative research specifically targeting these populations would maximise understanding of how to design more accessible services for all patients with FEP.

Conclusions

These findings highlight that PACs experience multiple structural barriers and that they have some clear ideas for how to improve access. PACs identified legislative practices that discourage family involvement, undesirable encounters with police, and complicated pathways that serve as barriers. They provided recommendations of how to minimise these such as greater family involvement and peer support in healthcare. Designing services informed by these accounts may lead to effective change in healthcare, but this would need developing and testing, taking into consideration the perspectives of both PACs who have attempted to access services, as well as those who have not.

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Service Improvement Project

Improving access to secondary mental health services for young Pakistani women: a qualitative study

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The Journal of Cross-Cultural Psychology is an international journal with an Impact Factor of 2.577, that provides the latest empirical research on the interrelations between culture and the thinking and behaviour of individuals and welcomes qualitative research. Author submission guidelines are presented in Appendix D.

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The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

Abstract

Background: Almost three quarters of mental health problems start by the age of 25, yet youth are often underrepresented in UK services. This is particularly true for those of ethnic minorities. In this service improvement project, we aimed to understand how young Pakistani women and their parents make decisions to seek help for mental health problems, and the barriers and facilitators that may exist to them accessing professional help.

Methods: Young Pakistani women with experience of severe mental health problems and their parents were recruited from a community sample. Semi-structured interviews were conducted with six young people and two parents. Data were analysed using reflexive thematic analysis.

Results: Pakistani culture and its interplay with British culture strongly influenced the decisions and ability of young Pakistani women and their parents to help-seek, largely through the role of stigma. External stigma, low mental health literacy, and lack of culturally informed services were identified as the most common barriers to accessing care. These barriers fed into the internalised stigma these young women experienced which, through fear of damaged reputation and personal prejudices, posed further barriers to seeking help. Participants highlighted recommendations for both individual-level (e.g., increased education

and awareness) and service-level change (e.g., greater choice over care) to facilitate accessibility of professional help.

Conclusions: Young Pakistani women face multiple challenges to accessing care for mental health difficulties, largely surrounding the cultural tensions and stigma they face. Addressing both individual and service-level challenges may facilitate the development of services that are more inclusive and accessible.

Keywords: youth mental health; help-seeking; diversity; ethnic minority; access

Improving access to secondary mental health services for young Pakistani women: a qualitative study

Introduction

Mental health problems (MHPs) are common in young people, with more than 50% of youth impacted by MHPs before 15 years of age (McGorry et al., 2022). Both the prevalence and complexity of MHPs increase during adolescence (Brimblecombe et al., 2015), with 62.5% of all MHPs, and 75% of serious MHPs such as psychosis, diagnosed by the age of 25 (Kim-Cohen et al., 2003; Solmi et al., 2021). When left untreated, symptoms of these serious MHPs can have major long-term adverse effects on physical health (Goodman et al., 2011), social relationships (Ford et al., 2013), and future employment (Clayborne et al., 2019), given the critical period for development from adolescence to young adulthood (Kessler et al., 1995). It is crucial, therefore, that timely mental health support is provided to young people to reduce the long-term negative outcomes associated with serious MHPs (McGorry & Mei, 2018; Patalay & Fitzsimons, 2018).

Despite high incidence rates, only around one-quarter of young people experiencing MHPs access professional help (Mental Health Foundation, 2018), with young people remaining underrepresented in services (Sheppard et al., 2018). This inequality is particularly prominent in those of ethnic minorities, with young people in the UK significantly less likely

to receive help if they are not Caucasian (Messent & Murrell, 2003; Radez et al., 2021; Yeh et al., 2004). Various reasons for this have been proposed, including low mental health literacy (MHL) (Begum et al., 2020), social stigma (Kapadia et al., 2017), and a lack of focus on ethnic diversity in both mental health services and research (Ali et al., 2016; Hussain-Gambles et al., 2004). Further, existing research has commonly aggregated multiple ethnic groups, such as Pakistani and Bangladeshi into 'South Asian', which does not consider the nuances arising from cultural differences (Stein et al., 2003).

Pakistani youth are commonly cited as underrepresented in mental health services, both in the UK and in Pakistan (Ahmad & Koncsol, 2022; Ali et al., 2016; Goodman et al., 2008). This underrepresentation may be due to stigmatising beliefs in the community (Shafiq, 2020; Shah et al., 2019), such as cultural beliefs that mental health symptoms indicate "badness" (Stern et al., 1990). The role of intersectionality in these stigmatising views may be important, with mental health stigma in young Pakistani women (YPW) particularly prominent. For example, in some parts of the Pakistani community, the expression of MHPs in YPW is thought to impinge upon family honour and self-respect ("izzat") (Gunasinghe et al., 2019), leading to family ostracism, reduced marriage prospects, and honour-based violence (Sangar & Howe, 2021; Tabassum et al., 2000). This gender inequality poses additional barriers to help-seeking for MHPs. There is also evidence suggesting that Pakistani parents are significantly less likely than White British parents to seek professional mental health support for their children (Shah et al., 2004; Stein et al., 2003). This may pose a significant barrier for this population given that young people are often reliant on caregivers to support help-seeking for MHPs (Gulliver et al., 2010). However, research in this area is limited and it is currently unknown what makes young people from these minoritised ethnic backgrounds more or less likely to seek help for MHPs.

In Oxfordshire, it is estimated that 6.6% of the population are Pakistani (Oxfordshire Insight, 2021), yet only 3% of the Oxfordshire Early Intervention Service (OEIS) caseload, where young people with symptoms of psychosis and other serious MHPs typically present, are Pakistani. In this service improvement project, OEIS identified young Pakistanis as a target for outreach due to their underrepresentation in the service. Given the role of intersectionality in health service inequality (Holman et al., 2021), and the influence of gender inequality on help-seeking in Pakistan (Childress, 2018), this study focused specifically on YPW. Through qualitative interviews with YPW and their parents, we aimed to explore how YPW made decisions about seeking professional help for serious MHPs and what the perceived barriers and facilitators were to seeking help from mental health services in Oxfordshire.

Methods

Design

A qualitative interview study using reflexive thematic analysis (Braun & Clarke, 2006, 2019) was conducted, which followed the COREQ Checklist (Tong et al., 2007) (Appendix E). Ethical approval was received from the University of Oxford Research Ethics Committee (R81751/RE001).

Position Statement

The study team consisted of clinicians with expertise in psychosis, all of whom were White British and had experience working with the target population. Data collection and analysis was conducted by CC (female trainee clinical psychologist) who also had lived experience of serious MHPs in adolescence. Given this position, regular reflection with the research team was carried out to minimise biases based on these prior experiences throughout data collection, analysis, and interpretation.

Public and Patient Involvement (PPI)

All study materials were developed by the research team, and interview guides, information sheets, and consent forms were also developed with three YPW and one parent. Consultation with one young Pakistani woman on the recruitment strategy, theme generation and write-up was also conducted.

Service Context

OEIS is a mental health service for 14–65-year-olds with a first episode of psychosis. This service aims to support recovery and wellbeing through providing NICE-recommended treatments. An audit of this service in 2021 found people of Pakistani backgrounds to be underrepresented, accounting for only 3% of referrals despite their representation of 6.6% within Oxfordshire (Oxfordshire Insight, 2021).

Participants

Participants were recruited from the general population in Oxfordshire through social media (Twitter, LinkedIn, Facebook), email outreach to charitable organisations (e.g., Oxfordshire Mind, Oxford Against Cutting), community outreach (e.g., community groups, mosques), and posters. Participants were included if they, or their child, were aged 18-25 years, identified as a woman, identified as Pakistani, lived in or had a GP in Oxfordshire, and had experienced a serious MHP (anxiety/low mood/psychosis that significantly interferes with everyday functioning). Exclusion criteria were insufficient English for interviews; lack of access to Microsoft Teams; and lack of capacity to consent. All participants were screened for eligibility using an online form on Qualtrics, and eligible participants were asked to provide their email address for the researcher to contact them for interview. Based on this, eight YPW and seven parents were screened as eligible. However, upon contact one young person did not live in Oxfordshire, and five parents and one young person were identified as

imposter participants (Ridge et al., 2023). No participants declined or dropped out. Therefore, six young women and two parents participated in the study.

Procedure

All eligible participants were emailed the information sheet and invited to a video call with the lead researcher. At the start of the call, participants were asked to provide verbal consent. A digital consent form was signed on each participant's behalf. Information was collected about their age, religion, generation, and help-seeking experiences.

Semi-structured interviews (24-74 minutes, *M*=49.9, *SD*=17.1) were conducted by CC. Six interviews were conducted in single sessions with only the researcher present, and one was spread across two sessions due to technical difficulties. The interview topic guide (Appendix F) included open-ended questions about their understanding and personal experience of their/their child's serious MHPs, experience of and attitudes to help-seeking, and perceived barriers and facilitators to help-seeking. At the start of all interviews, the researcher emphasised the research rationale, reasons for her interest in this area, and the importance of the participant's views to minimise power imbalances and promote engagement. All interviews were audio-recorded, anonymised, and transcribed verbatim by CC.

At the end of the interview, participants were given the chance to debrief with the lead researcher. Participants were compensated £15 for their time.

Analysis

Reflexive thematic analysis was used to analyse the transcripts. This approach was chosen given its theoretical flexibility and ability to identify patterns within and across data in relation to participants' lived experience, which aligns with the study aims (Nowell et al., 2017). An inductive approach was used to establish clear links between the research aims and raw data and was rooted in critical realism to reduce researcher bias. Given the small sample

size of parents, YPW and parents were treated as a single group for coding and theme generation. Any specific views of each group are reported within the write-up of the results, to highlight any differences.

Six phases of analysis were followed (Byrne, 2022) in an iterative process, which was led by CC. Data were familiarised through transcription, reading, and re-reading the data set. An initial set of codes was derived from the data using latent and semantic coding, and these codes were refined, grouped into themes, and further refined through regular discussion with the research team (LJ, FW), using NVivo 1.6.2 software (QSR International Pty Ltd., 2022). For example, the code “wider education and awareness” was initially amended to “wider awareness and raising education”, before being refined to “education on MHPs and services is powerful” (see Appendix G). As part of PPI, one YPW consulted on the final themes and write-up, and amendments were made accordingly to improve the appropriateness and accessibility of the findings for YPW.

A reflexive journal was kept by CC, to note ideas that arose from data familiarisation and coding for each participant. This helped create an awareness of initial patterns across interviews and minimise any biases CC had. For example, some codes were noticed to be influenced by a previous thematic analysis CC had conducted on barriers to healthcare, but through the reflexive process were discerned as less relevant to this population.

Results

Demographic Information

Six YPW (*M*=21.67 years old, range 18-25), and 2 mothers (*M*=53 years old, range 52-54) were recruited, all of whom identified as following Islam. Four YPW and one parent were first-generation Pakistani, with the remaining participants of second generation. The MHPs experienced were predominantly anxiety disorders and depression. All YPW had

sought help from mental health professionals, and one of the two parents had sought professional help on the child's behalf. All participants had experiences of seeking help in the UK either directly or through their child, predominantly through academic institutes or the NHS. For some, there were additional experiences of help-seeking privately in their home countries. Participant characteristics are presented in Table 1.

Table 1.

Participant characteristics

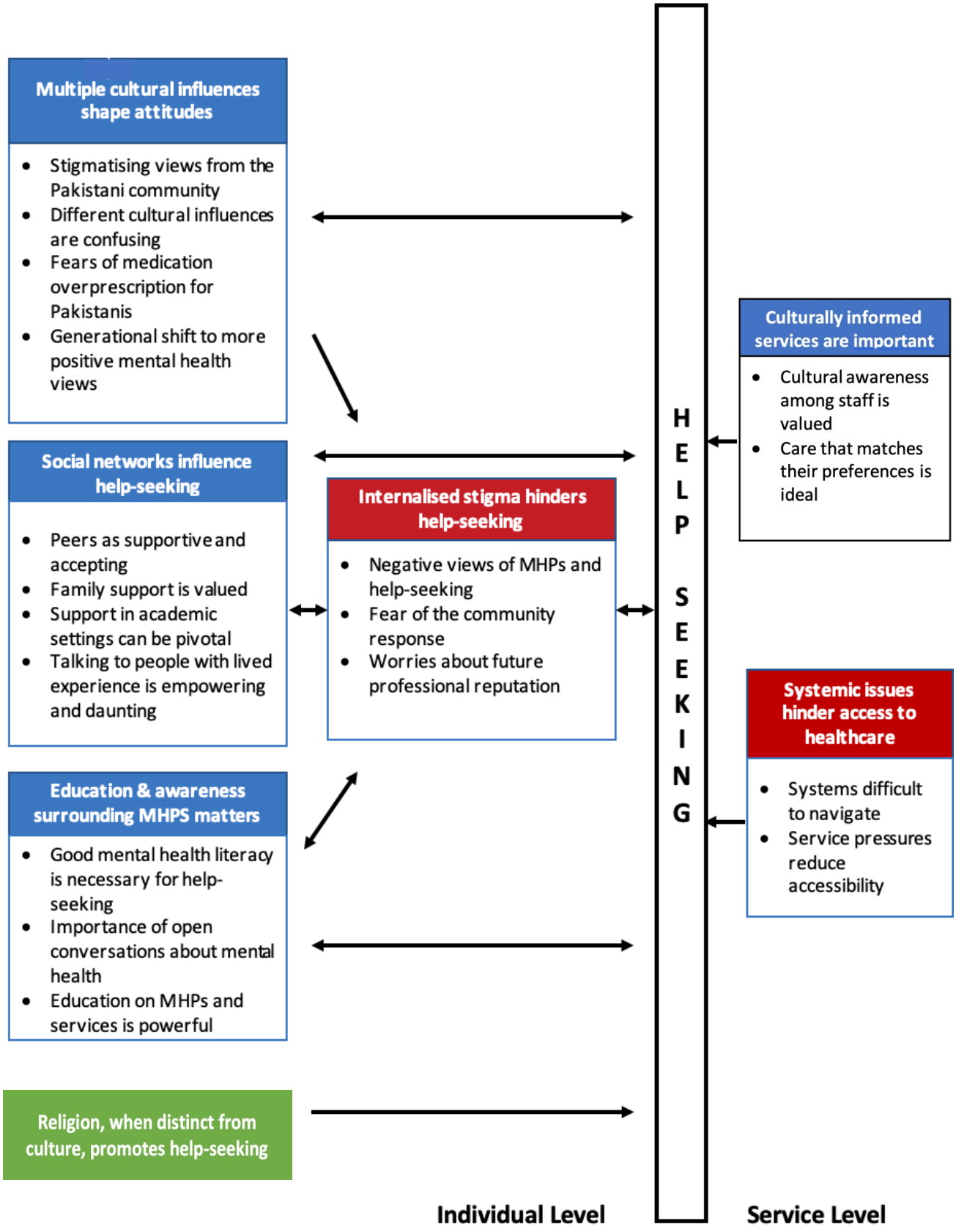
Participant	Lived experience of MHPs*	Help-seeking experiences
YP1	Social anxiety, generalised anxiety, low mood	School/university mental health services and healthcare services. All in the UK. Started around 14 years old.
YP2	Depression, anxiety	School/university mental health services and healthcare services. All in the UK. Started around 14/15 years old.
YP3	Low mood and anxiety related to physical health condition	Healthcare services. All in the UK. Started around 12/13 years old.
YP4	Generalised anxiety	Healthcare services in Pakistan. School/university mental health services in UK. Started around 13/14 years old.
YP5	Depression, anxiety	School/university mental health services. All in the UK. Started around 19/20 years old.
YP6	Anxiety, low moods	Private services. School/university mental health services. All in the UK. Started around 14/15 years old.
Parent1	Generalised anxiety, eating difficulties**	Supported young person accessing healthcare services in Pakistan, and school/university mental health services in the UK. Started when their child was around 13/14 years old.
Parent2	Low mood and anxiety related to physical health condition**	Directly contacted healthcare services. All in the UK. Started when their child was around 12/13 years old.

*****Participants' self-described experiences, not diagnosed by researchers
**Characteristics related to the child they supported to help-seek.

Overview of Themes

Seven themes were generated describing the experiences of help-seeking for MHPs. At the individual level, YPW and their parents described culture, social networks, and education and awareness as dominant influences in their decisions and ability to help-seek. For YPW these influences contributed to internalised stigma, which then hindered help-seeking. Religion, on the other hand, when distinct from culture, facilitated help-seeking. Participants (predominantly YPW) spoke of how, at the service level, service pressures could reduce accessibility, and spoke of the value of culturally informed services in facilitating help-seeking for MHPs. Themes with outlined quotes are presented below, with additional quotes available in Appendix H. The final thematic map is presented in Figure 1.

Figure 1 – Final Thematic Map



1. Individual level

1.1 Multiple cultural influences shape attitudes

YPW shared that **different cultural influences are confusing**, referring to differences between British and Pakistani cultures. Participants voiced that in Pakistan, *"mental health is [not] a priority"*, and that help-seeking often wasn't in *"the form of… therapy… [as] it is in the Western world"* (YP2). YPW spoke of feeling *"torn between different cultures"* due to having *"different influences and different expectations culturally"* (YP5). For example, the expectations in Pakistani culture not to *"admit to someone that you were suffering or even seeing a counsellor"* (Parent2), compared to the British culture of having more open conversations about MHPs.

Most participants discussed Pakistan to be a private society with a culture of *"keep[ing] [MHPs] behind closed doors"* (YP1), and that there is *"very much a sense of secrecy that you shouldn't tell people your weaknesses because there's such a big sense of community… they think it's dangerous"* (YP2). In line with this, participants shared concerns that disclosing MHPs would result in negative social and professional consequences, some of which were gendered: *"Their daughter gets labelled as somebody who's got mental issues then she's definitely not getting married"* (Parent1). As such, all participants spoke of hearing **stigmatising views from the Pakistani community.** Commonly these included narratives that MHPs are *"a weakness"* (YP1), *"a choice"* (YP5) or are a sign that someone is *"crazy"* (YP4).

Several participants also spoke of **fears of medication overprescription**, following experiences of healthcare in Pakistan where *"people who do get mental health support always end up on medication"* (YP6), which was perceived as unnecessary. Participants described witnessing the *"negative impacts [of medication] on people [they] really care for"* (YP4),

which further exacerbated fears. Participants worried about the same pattern in the UK, creating a reluctance to seek help in either place.

The strength of these cultural influences differed based on generation, with participants noting a **generational shift to more positive mental health views.** Participants spoke of how in older generations, MHPs are *"a taboo"* (YP3) but that younger generations were becoming *"more open to the reality of mental health (problems)"* (YP2). There was also a narrative surrounding the "*difference… around Pakistanis who are second, third generation"* (YP6) compared to first-generation Pakistanis who were perceived as less open, which may relate to the differing cultural influences in their upbringing.

1.2. Religion, when distinct from culture, promotes help-seeking

Participants discussed that **religion, when distinct from culture, promotes help-seeking** with narratives that Islam expressed *"a really positive message"* (YP2) with regards to MHPs. Many participants spoke of how "*Islam encourages you… to reach your full potential"* (Parent1) and was a source of support which facilitated help-seeking. Additionally, one young woman spoke of how it was largely through her "*detachment with religion*" which was *"internally… [her] biggest umm change"* that highlighted her MHPs and need to seek support. Despite this, participants voiced how "*religion and culture… [are] entwined in a way that they shouldn't be"* (YP1) and that this led to community views that they *"need to speak to God and pray more"* (YP6) if experiencing MHPs rather than seek professional help. Most participants spoke of a clear distinction between religion and culture, voicing that *"religion is not telling you not to access anything… it's the culture"* (Parent2), highlighting that when combined with culture, religion could instead become a barrier to seeking help.

1.3. Social networks influence help-seeking

All participants spoke of the influence of social networks in help-seeking for MHPs. Both parents and YPW described both Pakistani and British **peers as supportive and**

accepting, *"provid[ing] some understanding… [and] a bit of a safety net around [them]"* (YP1), which ultimately facilitated help-seeking. Many spoke of how peers *"shaped [their] attitude"* (YP5) and encouraged help-seeking. For some, peers directly initiated help and *"told the school [they] were struggling"* (YP2).

In contrast, the influence of family and academic settings was mixed. Whilst YPW shared that **family support is valued**, they described how it was sometimes missing. For some, family was described to be *"their support system"* (YP4), and to "*encourage [them] to go talk to somebody"* (Parent1). Others, however, described not *"feeling like [they] could talk to them"* (YP2), due to family *"minimis[ing] [MHPs] for a long time"* (YP5), stigmatising MHPs, or holding a strong sense that their child should have gratitude and *"not act like [they're] struggling when [their parents have] struggled more"* (YP6).

Similarly, participants spoke of how **support in academic settings can be pivotal** but often lacking. During school, most YPW spoke of positive experiences of staff, with staff encouraging help-seeking and providing counselling. These *"positive experience[s] of seeking help"* enabled YPW to *"learn that… [help-seeking] could have good consequences"* (YP1). This contrasted with the views of parents, however, with one describing school staff as *"clueless"* to the presence of MHPs (Parent1). Further, at university, YPW spoke of how *[academic staff] will not accommodate you if you are not doing well"* (YP4) with MHPs, resulting in YPW not sharing their difficulties with university staff due to concerns for their reputation.

Participants shared that **talking to people with lived experience is empowering and daunting**, depending on the narratives shared. Many YPW described hearing others speaking out as *"admirable… and empowering"* (YP1) in their own help-seeking journey. At times, however, participants noted that experiences that others shared, such as experiences of racial discrimination *"were not great, so that was a bit daunting"* (YP3). These negative

experiences could lead to YPW developing prejudices of help-seeking that were based on *"second-hand experience as opposed to [their] own"* (YP6).

1.4. Education and awareness surrounding MHPs matters

Both YPW and parents spoke of how **good MHL is necessary for help-seeking**. Most participants spoke of delays in realising they or their child were experiencing MHPs due to low MHL: *"I've had a lot of problems trying to deal with my anxiety from a young age, but I didn't really understand that that was what was the issue"* (YP5). For many YPW, MHPs were often misinterpreted which could result in self-stigma: *"I was just kind of low and I was like oh I'm just being really difficult and problematic"* (YP6).

Both YPW and parents spoke to the **importance of open conversations about mental health** to help gain perspective and encourage help-seeking: *"Talking about it, like making it seem normal, was a big umm like motivator for me to even start thinking about seeking therapy"* (YP5). One young person spoke about how *"there's a specific way that [these conversations] need to take place"*, however, due to concerns that MHPs may become trivialised amongst peers depending on their narrative.

Many participants flagged that **education about MHPs and services is powerful**. YPW spoke of the importance of additional, and earlier, education in schools and through social media. Both parents and YPW emphasised the importance of parental education and *"upskilling… actually preparing the parents from the South Asian families to have groups… where they discuss these issues"* (Parent2): **"***We also have to equip… the parents… who are stuck still in that point of view that mental health is not something we talk about"* (YP1).

1.5. Internalised stigma hinders help-seeking

The experiences of multiple cultural influences, social networks, and education and awareness (or lack thereof) could contribute to an internalisation of stigma in YPW, leading to **negative views of MHPs and help-seeking,** which discouraged sharing with social networks

and having open conversations about MHPs. Participants described how these views were largely determined by their upbringing, which in some cases could hinder help-seeking: *"I think I had a pretty negative view of umm help seeking. Umm and I probably still do to an extent. Just because it was never something that was supported culturally with my family." (YP5).* These views could result in *"never fully liv[ing] down the stigma, even in [their] own head" (*YP4).

YPW commonly shared **fears of the community response** if they were to disclose MHPs, with worries of what their friends and *"family might do or think if they find out."* (YP1). Some spoke of how this fear restricted disclosure even within mental health settings: *"I also couldn't speak about everything because I knew… if you're a danger to yourself we're going to have to tell your parents and I didn't want my parents to know"* (YP2). This demonstrates how beliefs about the self and others directly influenced help seeking.

Finally, YPW expressed **worries about future professional reputation** if they disclosed MHPs. Some YPW spoke of not wanting to share MHPs due to fears it would affect their academic work, their jobs, and how they were perceived professionally: *"If you go to the NHS and if they decide to put a label on you… that's always gonna be carried on you, and that can implicate you"* (YP6). *"It will impact how high performing they see me"* (YP4).

2. Service level

2.1. Systemic issues hinder access to healthcare

YPW spoke of finding **systems difficult to navigate** in the UK and requested greater outreach and information: *"I'm not sure… how I would find somebody that I would connect with or be able to understand the issues that I have"* (YP5). *"The outreach element is really important… getting it out into the community"* (YP1). Participants spoke of several different first contacts, and challenges in referrals from one service to the next. One participant spoke

of an additional *"barrier in Oxford where people (students) are quite kind of transitory in their [nature]"* (YP6), making it particularly challenging to access professional help.

YPW shared that **service pressures reduced accessibility** of healthcare, such as *"the waiting list to actually get someone [being] extremely long"* (YP3), inability to offer treatments, and limited sessions: *"I was constantly told during the session like that's beyond my remit, like we're here to talk about da da"* (YP6). One parent also highlighted that *"when you have a secure relationship with somebody (e.g., GPs), it's easier to speak"* but due to service pressures that's *"changed a lot and it makes it harder"* (Parent2).

2.2. Culturally informed services are important

YPW highlighted the need for culturally informed services, and how **greater cultural awareness among staff is valued.** For example, one participant spoke of a professional who asked, *"could you explain that a little bit?" or you know umm "what does that mean to you?"* and shared how "*those little things make you feel heard… so that… the cultural part of your experiences… isn't ignored."* (YP1). Many participants, however, described that staff lacked awareness, and at times, interest in their culture: *"I felt like she didn't even want to hear about those things."* (YP6). Participants were eager for greater cultural awareness amongst staff and suggested better assessment questions that included an *"awareness of the differences in British culture and Pakistani culture"* (YP5).

YPW also highlighted that **care that matches their preferences is ideal**, which was mirrored by parents**.** Participants highlighted feeling *"more comfortable speaking to a woman"* (YP4) and younger professionals due to *"associat[ing] somebody who is older with having patronising attitudes to mental health"* (YP5). Some YPW also highlighted a preference for staff of similar ethnicity. A choice in how care is received was emphasised, including *"a more anonymous experience"* (YP6) and options for peer support throughout the process. It was shared that *"having someone even in the referral process that you identify with*

that will… not just understand, but have… somewhat experienced what it's like to be in that situation" (YP2) would be particularly beneficial in fostering a more comforting journey to help-seeking where YPW could feel more understood.

Discussion

We set out to explore how YPW living in the UK, and their parents, make the decision to seek help for serious MHPs and their perceived barriers and facilitators to this. Help-seeking was informed by YPW's own beliefs and internalised stigma, which were shaped by the interplay between Pakistani and British culture, social networks, and mental health awareness. Religion was found to be distinct from culture and to facilitate help-seeking. Participants highlighted that both the structure and cultural context of services impacted access to professional help, and recommended both individual- (e.g., increased education and awareness) and service-level (e.g., greater choice over care) implementations to facilitate accessibility of services.

The results of this study highlight the challenges YPW face when navigating the relationships between Pakistani and British cultures in relation to help-seeking for serious MHPs. Both YPW and their parents spoke of stigmatising views towards MHPs within Pakistani culture, consistent with previous research (Bonanno et al., 2021; Sangar & Howe, 2021). Many participants discussed a generational shift to less stigmatising views towards MHPs, both in younger ages, but also in later generations of Pakistani immigrants. This may be explained by prior research suggesting that first-generation foreign-born children are more likely to relate to their country of origin, a country which participants spoke of as holding high mental health stigma (Phinney et al., 2000). Finally, participants discussed that religion was a source of support in help-seeking. This is in part consistent with prior qualitative research in Pakistanis that found religion to be an effective source of coping and a therapeutic resource, however, perceptions that MHPs were a result of 'black magic' and therefore

something to not seek mental health support for were described to directly relate to religion (Ali et al., 2016; Cinnirella & Loewenthal, 1999). This study highlights a need for greater understanding of the contributions of religion and culture as distinct when understanding processes for help-seeking for MHPs.

This study found that cultural influences were strongly linked to internalised stigma and worries about personal reputation, findings that have been previously demonstrated in Pakistani communities (Ali et al., 2016; Husain et al., 2020; Shefer et al., 2012). Feeding into this internalised stigma were the influences of social networks and education (or lack thereof). Notably, participants spoke of how other young people most often reduced this stigma, whilst experiences with family and academic settings were more mixed. This self-stigma was exacerbated by a lack of awareness and understanding of MHPs.

Many participants spoke of the power of education in facilitating help-seeking. This was raised as particularly important for parents, whose knowledge is often required to identify MHPs and access appropriate services (Tully et al., 2019) and may be especially reduced in this population where parents may not have been raised in UK culture. Previous research has highlighted a need for MHL education programmes for parents (Hurley et al., 2020). However, there is little evidence to suggest that current methods for this are effective (Peyton et al., 2022). In this study, parents suggested the use of community-based groups to improve MHL, highlighting the importance of PPI in these initiatives.

Alongside these individual barriers to help-seeking, participants spoke of several service level barriers such as difficulties when navigating services and limited remit. These findings are consistent with those of previous systematic reviews that explore barriers to help-seeking in young people in the UK (Radez et al., 2021; Salaheddin & Mason, 2016). Additionally, this study highlighted service-level barriers underpinned by their cultural values

such as lack of professionals whom they felt able to relate to, with most stating a preference for young, female professionals.

The findings of this study provide clear clinical implications. Almost all participants emphasised a need for greater focus on their cultural experiences in healthcare. Based on this, clinicians should endeavour to increase cultural competence in line with equality, diversity and inclusion initiatives in the NHS (NHS England, 2022). This may be achieved through allocated time to acquire knowledge and skills that fit the cultural context of clients (such as greater understanding of the nuances between religion and culture) and developing a greater awareness of their own cultures and biases these may create (Pumariega et al., 2005). Therapeutic alliance was also highlighted as crucial in this study. Clinicians can promote a culture of flexibility, respect, and interest to boost the therapeutic alliance (Ackerman & Hilsenroth, 2003), whilst paying attention to their communication, for example through avoiding labels, using first-person language (Healy et al., 2022), and providing detailed and balanced information about all treatment options, specifically medication, which may help to reduce clients' internalised stigma.

Wider systemic and service implications were also indicated. Participants voiced a desire for a choice of healthcare professionals, with most requesting younger, female professionals, in line with their cultural values and beliefs that younger generations would be less stigmatising. YPW also requested the support of someone who understood their cultural context throughout the referral process. Previous research in the Netherlands has found that the inclusion of young peer support workers (PSWs) in services can be effective in reducing disparities, promote hope, and facilitate engagement (de Beer et al., 2022). In the UK, PSWs have been introduced as a new NHS workforce (Lawton-Smith, 2013). However, to date this has solely focused on adult populations. Based on the findings of this study, the inclusion of young PSWs with cultural awareness may be an area for development. Finally, both mental

health services and educational institutions can improve help-seeking through raising awareness of MHPs and providing better understanding of how to access services. Participants suggested this may be particularly beneficial if done through social media and community outreach, and that this may be particularly important for parents of YPW.

Limitations

There are several limitations. Firstly, due to recruiting from an underrepresented community, accessing participants was challenging, contributing to a small number of participants, particularly parents. This meant that other views, such as those of fathers, were not heard. Further, all participants had sought mental health support. Therefore findings do not reflect the barriers of those who have not yet accessed professional help. These limitations may reflect the heightened stigma within this community in speaking about MHPs, in addition to accessibility issues of the research due to all researchers being White British, and exclusion criteria (e.g., insufficient English for interviews) that may have paralleled the barriers YPW and their parents face in accessing services. Future studies may wish to facilitate recruitment using community outreach from those in the Pakistani community, as well as using interpreters so that the voices of more YPW and parents can be heard. Additionally, whilst PPI was conducted when developing the interview schedule to ensure the use of appropriate and sensitive language, the language used when focusing on serious MHPs, and the questions asked surrounding these, may have resulted in community and cultural beliefs specifically about psychosis were not discussed. Finally, despite recruiting participants who had accessed multiple services, no participants in the study had lived experience of psychosis or unusual experiences, perhaps due to community-based recruitment. Future research may wish to recruit directly from Early Intervention Services to understand help-seeking specifically in this population.

Conclusions

This study highlights the complexities of help-seeking for MHPs for YPW. Pakistani culture and its interplay with British culture, and internalised stigma were found to be prominent in influencing the decision and ability to help-seek. Recommendations given by YPW and their parents largely focused on increased education and awareness through schools and community outreach, in addition to providing more culturally informed services with greater cultural awareness and choice over care. These findings highlight the need for research in specific populations to understand how best to design inclusive services. Further research would benefit on trialling some of the suggestions mentioned such as the integration of young PSWs into services, and focused cultural awareness training of staff, alongside further qualitative research focusing on YPW who have not yet been able or willing to seek help for their MHPs.

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Theory-Driven Research Project

Fighting OCD together: an experimental study of the effectiveness and acceptability of seeking and receiving emotional support for OCD

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The journal of *Behaviour Research and Therapy* is an international multi-disciplinary journal with a major focus on experimental approaches to understanding, preventing, and treating emotional and behavioural disorders using cognitive, behavioural, and psychophysiological models. This journal welcomes submissions with innovations in the implementation of evidence-based practice into clinical practice. Author submission guidelines are presented in Appendix J.

Acknowledgements

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Conflict of Interest Statement

The author(s) declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

Abstract

Excessive reassurance-seeking in OCD has been linked to the maintenance of OCD, functioning as a type of checking ritual. Current treatments recommend the imposition of the extinction of seeking and providing reassurance; however, this is not well tolerated. Although it has been suggested that the provision of support may provide a more helpful alternative, there is no empirical evidence for this. In the present study, 36 participants with OCD engaged with two personalised semi-idiographic scenarios in which they imagined seeking and receiving reassurance and seeking and receiving emotional support in counterbalanced order. The primary outcome measure was urge to seek reassurance, which was found to significantly decrease in the support condition relative to the reassurance condition regardless of order of presentation. Emotional support was perceived as significantly more acceptable when compared to imagining reassurance in terms of higher ratings of perceived helpfulness in managing emotions, feelings of calmness and closeness, and the sense that they were fighting OCD together. These findings provide preliminary evidence for the value of encouraging the seeking and giving of emotional support as an alternative to reassurance. Implications for clinical work and further research are discussed.

Fighting OCD together: an experimental study of the effectiveness and acceptability of seeking and receiving emotional support for OCD

Introduction

Obsessive-compulsive disorder (OCD) is a common and pervasive mental health disorder characterised by the presence of severe and disabling obsessions and compulsions, (American Psychological Association, 2023). Thought to have a lifetime prevalence of up to 1.5% (Fawcett et al., 2020), OCD is associated with increased autoimmune disorders (de la Cruz et al., 2022), long-term socioeconomic difficulties (Pérez-Vigil et al., 2018), significantly impaired quality of life (Eisen et al., 2006; Macy et al., 2013), and significant strains on peer and family relationships (Grover & Dutt, 2011; Walseth et al., 2017).

Cognitive theories of OCD focus on the threat of harm to self and/or others, and an inflated sense of responsibility for such harm, as the precipitating factors and motivators of the responses that maintain OCD (Rachman, 2002; Salkovskis & Warwick, 1985; Smith et al., 2022). Compulsive behaviours motivated by responsibility beliefs are considered key maintaining responses, functioning as safety-seeking behaviours (SSB) intended to achieve certainty that harm or responsibility for it is eliminated (Salkovskis, 1991). Like most SSBs, however, checking has the effect of preventing disconfirmation and maintaining pre-occupation (Osborne & Williams, 2013). For example, with each instance of checking the memory of previous checks is tarnished (Radomsky et al., 2006). As such, the level of certainty of safety tends to decrease, and checking is perpetuated (Rachman, 2002; Tolin et al., 2002). Recent work thus suggests that excessive reassurance-seeking (ERS) is a special type of checking, defined as the "*verbal and/or non-verbal interaction with someone who you perceive has access to potentially threat relieving information, with the intention of increasing your perceived sense of certainty from harm*" (Halldorsson & Salkovskis, 2023). Unlike most

other forms of checking, this interaction has the additional function of transferring responsibility onto others (Rachman, 2002; Salkovskis, 1999).

Unsurprisingly, the most common response to ERS is the provision of reassurance, with loved ones reporting they often do not know what else to do (Halldorsson et al., 2016; Lebowitz et al., 2016). Research indicates that *outside* the context of cognitive-behavioural therapy (CBT*),* providing reassurance is in fact an effective way of helping the sufferer, in the sense that in the short-term this helps all concerned to manage daily life and reduces the levels of distress for those involved (Champion & Grisham, 2022; Kobori & Salkovskis, 2013). However, as with other types of compulsions, once reassurance is sought and provided for a subjectively crucial negative outcome, it can lead to increasing levels of reassurance-seeking. As a result, reassurance unintentionally perpetuates the person's OCD (Albert et al., 2017; Halldorsson & Salkovskis, 2017b). Furthermore, ERS comes with a high social cost, with the repetitive seeking of reassurance ultimately leading to strained relationships with others (Boeding et al., 2013), and increased levels of distress in family members (Albert et al., 2017).

Currently, the principal strategy proposed for ERS advises that family members or peers withhold reassurance (Neal & Radomsky, 2020). Whilst it may be clinically effective in some instances, this method has been shown to further strain relationships rather than improve them (Halldorsson et al., 2016), and the withholding of reassurance has been shown to result in negative outcomes such as heightened levels of anger and discomfort, and increased distress for those with OCD (Marinchak, 2013; Salkovskis & Kobori, 2015). Kobori and Salkovskis (2013) found that asking loved ones to simply discontinue *giving* reassurance would be both counterproductive and difficult or even impossible to sustain. However, if reassurance is indeed a key maintaining factor in OCD, what is needed, is an alternative to the

seeking and offering of reassurance which does not have the negative impacts inherent to ERS and allows the person to discontinue *seeking* reassurance.

Halldorsson and Salkovskis (2023) propose that the development, adoption, and provision of emotional support for the person's efforts to confront their OCD would serve as an effective alternative to ERS. At the same time, it is possible that this may maintain or even enhance the interpersonal relationship, which has often been damaged by extensive and frustrating rounds of ERS. Emotional support-seeking has been defined as involving *"interpersonal behaviour, verbal or non-verbal, that is intended to get (or give someone) encouragement, confidence or assistance to cope with feelings of distress"* (Halldorsson & Salkovskis, 2023). It has therefore been proposed as an alternative to providing reassurance, with support-seeking understood theoretically as the opposite to an SSB with its intention of helping the person confront, and ultimately resolve their fears (Halldorsson & Salkovskis, 2023). ERS, therefore, represents a shift from a primary threat-focus of seeking to prevent the occurrence and responsibility of harm, to a more emotional-focus (Halldorsson et al., 2016). This alternative focus is distinctly on the recognition of the person's OCD, in terms of a shared understanding of how the person's obsessions cause both distress and safety-seeking responses, which can be overcome and extinguished.

At present, there is some evidence to suggest that when embedded in focussed CBT, the adoption of a support focus as an alternative to ERS and the provision of reassurance, is not only effective in reducing anxiety/discomfort and urges to seek reassurance, but also more acceptable than currently endorsed treatment methods (Halldorsson & Salkovskis, 2017a; Neal & Radomsky, 2020). Although there is some empirical grounding, what is needed is studies contrasting support-seeking and the provision of support in comparison to ERS and reassurance provision in clinical OCD populations.

In the present study, we aim to investigate whether the imagined seeking and provision of emotional support as opposed to the imagined seeking and provision of reassurance, in response to imagined situations that would normally evoke ERS, would produce better outcomes in terms of effectiveness and acceptability.

Hypotheses

Primary

- The imagined seeking and receiving of emotional support will result in an overall reduction in the anticipated urge to seek further reassurance, relative to the imagined seeking and receiving reassurance.

Secondary

- The imagined seeking and receiving of emotional support will result in a greater overall decrease in both anticipated anxiety and belief in intrusions, relative to the imagined seeking and receiving of reassurance.
- Imagined emotional support will be perceived to be at least as acceptable as imagined reassurance.

Methods

Design

A crossover design was used, whereby each participant, following completion of symptom measures and an overall baseline, undertook both imagined reassurance and support conditions in randomly counterbalanced order. This meant that the core design was a mixed model factorial design (within and between subject factors; that is, 2 (experimental condition: imagined reassurance vs imagined support) x 2 (vignette order: imagined reassurance first or imagined support first) x 3 (time point: rating of reassurance provoking situation (T1), rating immediately after reassurance or support is received (T2), rating 20 minutes later (T3)). The primary dependent variable was anticipated urge to seek reassurance, and secondary variables

were anticipated anxiety/discomfort and belief in intrusion. Tertiary variables were measures of acceptability of imagined support/reassurance (perceived helpfulness in emotion management, calmness, closeness, fighting OCD together).

An *a priori* power analysis was conducted using G*Power version 3.2 (Faul et al., 2007). Results indicated the required sample size to detect a small to medium effect (F=0.2) at 80% power and a significance of α =.05 was 34 participants.

Participants

Participants for the study were recruited via Twitter, OCD charities (OCD-UK, OCD Action, Orchard OCD), LinkedIn, Instagram, course recruitment databases, and word of mouth. For each participant recruited into the study, a payment of £2 was paid to OCD-UK for their support with recruitment.

Participants were asked to complete a screening form on Qualtrics and were invited to participate if they met the study criteria. This included being aged 18 or over, scoring 40 or above on the Obsessive-Compulsive Inventory, having sought support from others for OCD previously, and meeting cut-off scores on the Reassurance Seeking Questionnaire. Participants were excluded if they had diagnoses of a personality disorder, severe autism, or neurological conditions that may impair functioning. A full list of inclusion and exclusion criteria can be found in Appendix K.

Based on the screening criteria, 52 participants were invited to take part. Of these, 13 declined, leaving 39 people to complete the study. Prior to analysis, a further 3 people were excluded for not clearly meeting the criteria of having previously sought support. Of the 36 participants included in the analysis, 32 (88.9%) were female and 4 (11.1%) were male. Participant ages ranged from 20-56 years (M = 33.8, SD = 9.87) and they were predominantly of white ethnic backgrounds (91.7%). Seventeen participants (47.2%) were presented with the

emotional support vignette first, and nineteen participants (52.8%) were presented with the reassurance vignette first.

Measures

Obsessive Compulsive Inventory (OCI)

The OCI (Foa et al., 1998) is a 42-item self-report instrument that measures obsessive thoughts and behaviours in both clinical and non-clinical populations. It includes 7 subscales: washing, checking, doubting, ordering, obsessing, hoarding and mental neutralising. Items are scored on a 5-point Likert scale, with a score of 40 indicating clinically significant levels of obsessions and compulsions. The scale has been shown to have high internal consistency in previous studies (α =.86 to .95) and the current study (α = .92), good discriminative validity and satisfactory convergent validity (Foa et al., 1998).

Reassurance Seeking Questionnaire (ReSQ) Source

The ReSQ Source (Kobori & Salkovskis, 2013) is a 21-item self-report instrument that measures the places in which people seek reassurance from. Items are scored on a 5-point Likert scale. The scale has been shown to have good internal consistency in previous studies (α =.862), with the current sample suggesting satisfactory internal consistency (α =.675). Previous studies have found this scale to have good test-retest reliability (r = .527 to .918) and satisfactory criterion-related validity (Kobori & Salkovskis, 2013).

Reassurance Seeking Questionnaire (ReSQ) Intensity

The ReSQ Intensity (Kobori & Salkovskis, 2013) is a 21-item self-report instrument that measures the frequency in which people seek reassurance from particular places. Items are scored on a 5-point Likert scale. The scale has been shown to have good internal consistency both in previous studies (α = .82) and the current sample (α = .814). Previous studies have also shown good test-retest reliability (r =.700 to .926), and satisfactory criterion-related validity (Kobori & Salkovskis, 2013).

Patient Health Questionnaire-8 (PHQ-8)

The PHQ-8 (Kroenke & Spitzer, 2002) is an 8-item self-report instrument that measures symptoms of depression over the last 2 weeks, with the exclusion of a question about suicidal or self-injurious thoughts. Items are scored on a 4-point scale. Respondents are asked to rate based on the last 2 weeks. Research has shown scores from the PHQ-8 to be highly correlated to the PHQ-9 (Corson et al., 2004) which has been shown to have high levels of internal consistency (α = .86-,89), inter-rater reliability (0.84) construct validity, and criterion validity (Kroenke et al., 2001). In this study, the PHQ-8 was found to have good internal consistency (α = .817).

Generalised Anxiety Disorder Questionnaire-7 (GAD-7)

The GAD-7 (Spitzer et al., 2006) is a 7-item self-report instrument that measures symptoms of general anxiety over the last 2 weeks. Items are scored on a 4-point scale, with a total cut-off score of 8 and above suggesting significant general anxiety symptoms. This scale has been shown to have high inter-rater reliability (κ =.83), construct, and criterion validity (Spitzer et al., 2006). The scale has also been shown to have high internal consistency in previous research (α =.92), and in the current sample (α =.841).

Visual Analogue Scales

For the purposes of this study, 11 visual analogue scales were created to provide outcomes specific to the hypotheses. All scales were rated on a scale of 0-100 and measured: participants' urge to seek reassurance, anxiety/discomfort, how sure they were in their obsession, how helpful reassurance/support was in its ability to manage emotion, how calming reassurance/support was, how much closer they felt to their loved one after reassurance/support, and how much they felt they were fighting OCD together with their loved one when receiving reassurance/support.

Demographics

A demographics questionnaire was administered to participants to gather information on their age, gender, ethnicity, education levels, marital status, and living situation.

Materials

Two vignettes were created for the purposes of this study (see Appendix M) and were adapted for each participant. Both vignettes described a situation where the person was involved in an activity, most typically watching TV, when suddenly an intrusive thought popped into their mind. The participant was required to imagine that they were in that scenario for 10 minutes. In the support vignette, after a further imagined 5 minutes, the participant imagined requesting support and was being provided with this, and that this continued for 20 minutes. In the reassurance vignette, after a further imagined 5 minutes, the participant imagined requesting reassurance and being provided with this, before not receiving any more reassurance for 20 minutes. Both vignettes were adapted to contain a real intrusive thought the participant experienced, as well as real ways they sought and received reassurance and support. All scenarios and lengths of times were imagined, with participants not actively requesting or receiving any support or reassurance, and the total time spent imagining each vignette lasting around 5 minutes.

A choice of two guided grounding exercises were offered to participants after the presentation of each vignette. One of these was a beach visualisation exercise, and the other a five-senses grounding exercise (see Appendix N).

Piloting

Prior to the main study, the study was piloted with three people with lived experience of OCD. Two of these pilots did not include the acceptability questions, but these were developed in collaboration with the final pilot prior to piloting. Feedback was received from each of the pilots and based on this, changes were made including the addition of a screening question screening for previous support seeking, and rewording of the certainty scale.

Procedure

This study received full ethical approval from the University of Oxford Research Ethics Committee (R79097/RE001). Participants were emailed an information sheet and invited to a Microsoft Teams call with the lead researcher which lasted for 60-80 minutes. Each participant was randomised into receiving either emotional support or reassurance first prior to the call using an online block randomisation tool (Sealed Envelope 2022).

At the start of the Teams call, participants were given a brief description of the study and given the opportunity to ask questions, before providing informed consent. Rating scales were then practiced with participants. Participants were asked for their understanding of the difference between reassurance and emotional support before being given a standard description of emotional support and reassurance and the opportunity to ask questions. Following this, participants were asked about their obsessions, and a specific obsession was chosen, along with phrases of what they said when they sought reassurance and emotional support, and what others said back to them. This information was then inserted into the two standard vignettes. Examples of intrusions reported were varied, but included checking intrusions, contamination intrusions. harm-related intrusions and intrusions related to romantic relationships.

The first vignette was then read out to participants in 4 parts (before the thought popped into their mind (T0), after imagining the thought had been in their mind for 10 minutes (T1), after they had imagined asking for and receiving reassurance/support (T2), and 20 minutes later (T3)), asking participants to rate their anticipated urge to seek reassurance, level of anxiety/discomfort, and their belief in their intrusion after each part. Due to the imagined nature of the vignettes, the time between all time points was imagined, with around 2 minutes elapsing between each time point. The vignette and ratings were followed by one of the two grounding exercises. The second vignette was then presented which followed the

same procedure and ended with one of the two grounding exercises. Participants were then asked to answer the acceptability questions, before being presented with a written debrief form, which included routine signposting to support services, and having a verbal debrief with the researcher.

Analysis

Analyses were conducted using IBM SPSS Statistics 29, with alpha set at .05. *t*-tests and chi-squared tests were conducted amongst the demographic variables and questionnaire scores between groups. To test hypotheses 1 and 2, mixed model ANOVAs were used.

Results

2.1. Sample Characteristics

2.1.1. Demographics

A significant difference was found in education levels between the two groups ($t_{(34)}$ =2.05, p = .359). No other significant differences in demographics were found between the two groups (Table 3.1.).

Table 3.1.

Demographic variables compared between the experimental groups

	Reassurance-first, n (%) (*N*=19)	Support first, n (%) (*N*=17)	χ2	*t*	*df*	*p*
Gender			.892	.929	34	.359
Male	3 (15.8%)	1 (5.9%)				
Female	16 (84.2%)	16 (94.1%)				
Highest level of education			7.609	2.047	34	.048
High/Secondary School or equivalent	2 (10.5%)	1 (5.9%)				
Sixth form/college or equivalent	4 (21.1%)	0				
Higher education diploma	1 (5.3%)	0				
Undergraduate degree	6 (31.6%)	5 (29.4%)				
Postgraduate degree	3 (15.8%)	8 (47.1%)				
Doctorate degree	3 (15.8%)	3 (17.7%)				
Ethnicity			2.928	.291	34	.627
White (any background)	17 (89.5%)	16 (94.1%)				
Mixed or multiple ethnic groups	0	1 (5.9%)				
Asian (any background)	2 (10.5%)	0				
Marital status			2.368	.325	34	.747
Single (never married)	10 (52.6%)	8 (47.1%)				
Married or in a domestic partnership	7 (36.8%)	9 (52.9%)				
Divorced	1 (5.3%)	0				
Separated	1 (5.3%)	0				
Living Situation			1.536	.291	34	.773
Living alone	5 (26.3%)	3 (17.7%)				
Living in a house share	2 (10.5%)	2 (11.8%)				
Living with a partner	8 (42.1%)	8 (47.1%)				
Living with parents	4 (21.1%)	3 (17.7%)				
Other	0	1 (5.9%)				
Employment			2.396	.230	5	.820
Full-time employed	13 (68.4%)	11 (64.7%)				
Part-time employed	1 (5.3%)	2 (11.8%)				
Self-employed	1 (5.3%)	1 (5.9%)				
Unemployed	1 (5.3%)	1 (5.9%)				
Student	3 (15.8%)	1 (5.9%)				
Unable to work	0	1 (5.9%)				

2.1.2. Descriptive Psychopathology

No significant differences in descriptive psychopathology were found between the two groups (Table 3.2.).

Table 3.2.

Descriptive psychopathology variables between the experimental groups

Variable	Reassurance-first (*N*=19) *M (SD)*	Support first (*N*=17) *M (SD)*	*t*	*df*	*p*
Age	32.58 (9.67)	35.18 (10.19)	.784	34	.438
OCI total	88.00 (22.94)	82.65 (28.04)	.630	34	.533
OCI obsessions	20.84 (5.75)	18.29 (5.76)	1.326	34	.194
OCI washing	14.79 (9.25)	15.35 (10.57)	.171	34	.866
OCI checking	21.00 (8.01)	16.35 (7.56)	1.784	34	.083
OCI neutralising	8.84 (3.72)	11.53 (6.79)	1.449	24.174	.160
OCI hoarding	3.74 (2.83)	3.82 (3.38)	.084	34	.934
OCI ordering	10.16 (4.99)	9.65 (5.11)	.303	34	.763
OCI doubting	8.63 (2.17)	7.65 (3.16)	1.100	34	.279
ReSQ Source	49.21 (14.79)	50.12 (13.22)	.193	34	.848
ReSQ Intensity	28.67 (1.16)	34.80 (7.60)	1.346	6	.227
PHQ-8	10.74 (4.89)	9.24 (4.16)	.987	34	.331
GAD-7	13.00 (4.61)	10.76 (4.51)	1.468	34	.151
Urge VAS baseline	38.95 (29.33)	38.82 (28.48)	.013	34	.990
Anxiety VAS baseline	29.21 (26.05)	42.06 (28.49)	1.419	34	.165

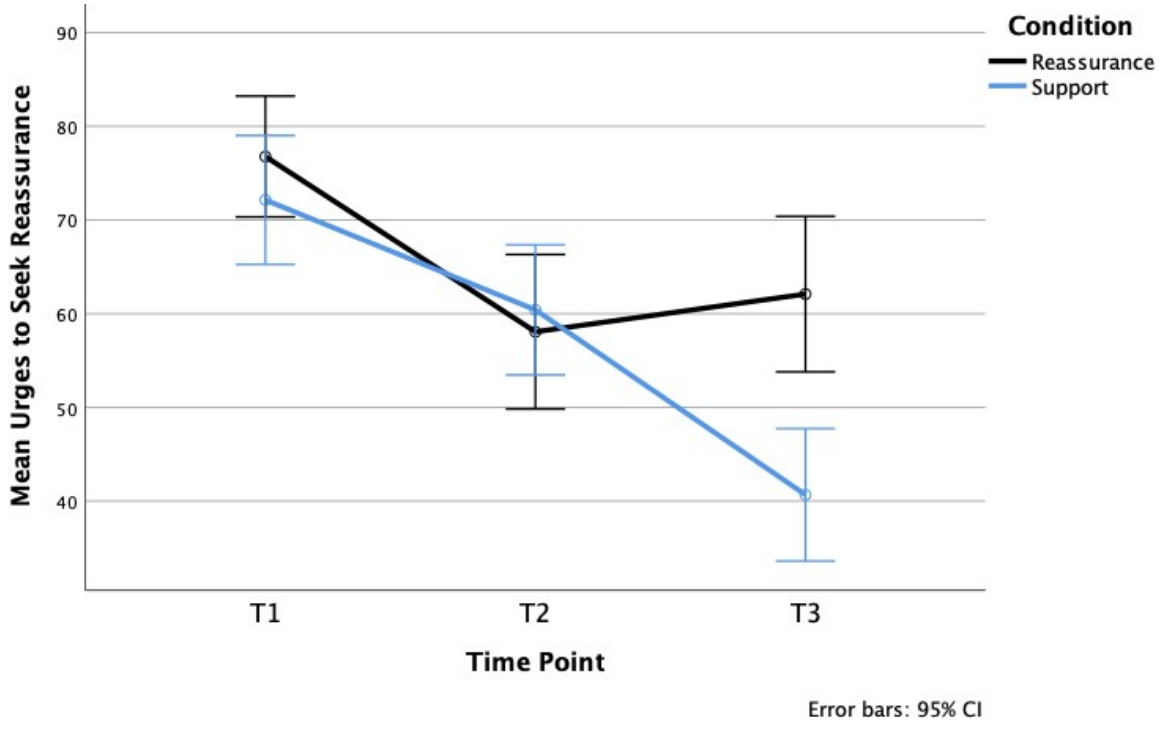
2.1 Primary Outcome Variable: Urges to seek reassurance

A 2 (group) x 2 (vignette order) x 3 (time point) factorial ANOVA was conducted with urges to seek reassurance as a dependent variable. There was a main effect of time point, $F_{(1.83, 62.2)} = 61.40$, $\eta_p^2 = .644$, $p < .001$ and of condition $F_{(1, 34)} = 7.741$ $\eta_p^2 = .185$, $p = .009$.

There was no main effect of group, $F_{(1, 34)} = .383$, $\eta_p^2 = .011$, $p = .540$. The main effects were modified by a significant group x time point interaction, $F_{(1.83, 62.2)} = 9.643$, $\eta_p^2 = .221$, $p < .001$, and a significant time point x condition interaction, $F_{(2, 68)} = 11.446$, $\eta_p^2 = .252$, $p < .001$. There was no group x condition interaction, $F_{(1, 34)} = .564$, $\eta_p^2 = .016$, $p = .458$, nor was there a significant third order interaction (group x condition x time point), $F_{(1.96, 66.7)} = 2.407$, $\eta^2 = .066$, $p = .099$. The crucial condition x time interaction is shown in Figure 3.1.

Figure 3.1.

Change in urge to seek reassurance by experimental condition



Multiple comparisons were used to decompose the significant interaction of condition x time point by carrying out paired *t*-tests between experimental conditions separately for each time point. There were no significant differences between groups for T1 ($t_{(35)} = 1.87$, $p = .069$) or T2 ($t_{(35)} = .57$, $p = .572$) . However, T3 showed a significant difference in urges to

seek reassurance between the reassurance and support condition ($t_{(35)}$= 4.58, p<.001). This difference is displayed in Table 3.3.

Table 3.3.

Primary and secondary outcomes between the experimental groups for each condition

			Urge to seek reassurance, *M (SD)*	**Anxiety, *M (SD)***	**Belief in intrusion, *M (SD)***
Reassurance	T1	Reassurance first	82.37 (16.19)	75.53 (13.73)	68.68 (22.96)
		Support first	71.18 (21.76)	74.12 (18.14)	66.56 (20.23)
		Overall	77.08 (19.58)	74.86 (15.74)	67.71 (21.47)
	T2	Reassurance first	49.37 (27.92)	51.84 (27.90)	54.21 (25.02)
		Support first	66.76 (19.44)	65.06 (16.60)	59.06 (21.47)
		Overall	57.58 (25.52)	58.08 (23.90)	56.43 (23.25)
	T3	Reassurance first	56.95 (28.66)	60.79 (27.85)	59.47 (26.45)
		Support first	67.24 (18.62)	68.53 (17.21)	62.06 (20.37)
		Overall	61.81 (24.66)	64.44 (23.45)	60.66 (23.56)
Support	T1	Reassurance first	73.68 (20.40)	68.16 (20.76)	67.89 (22.63)
		Support first	70.59 (20.15)	75.00 (15.51)	65.00 (17.89)
		Overall	72.22 (20.05)	71.39 (18.54)	66.57 (20.36)
	T2	Reassurance first	58.58 (24.59)	57.89 (22.19)	60.00 (26.67)
		Support first	62.24 (14.51)	62.94 (12.76)	58.44 (19.56)
		Overall	60.31 (20.26)	60.28 (18.28)	59.29 (23.36)
	T3	Reassurance first	39.11 (22.22)	36.42 (20.35)	45.79 (28.69)
		Support first	42.24 (19.17)	45.29 (16.72)	41.56 (20.06)
		Overall	40.58 (20.60)	40.61 (19.00)	43.86 (24.86)

2.1. Secondary Outcome Variables

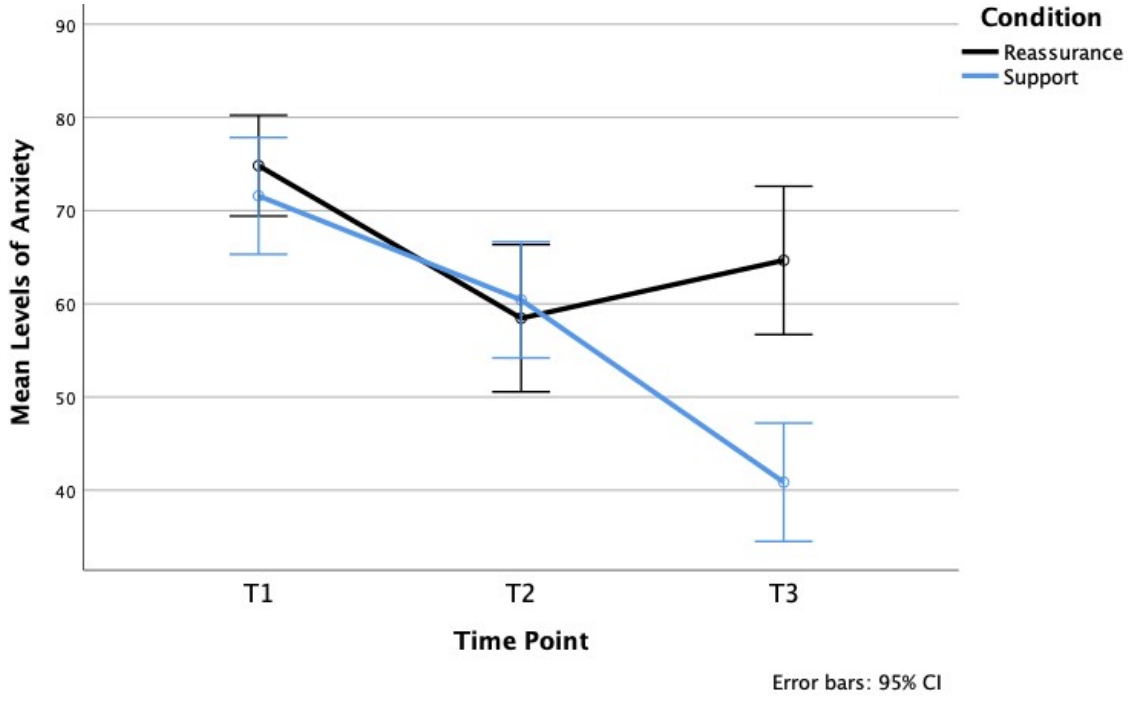
2.1.1. Anxiety/Discomfort

A further 2 x 2 x 3 ANOVA using the same independent variables was conducted with anxiety/discomfort as a dependent variable. There was a main effect of time point, $F_{(1.6, 55.1)}$ = 45.850, η_p^2 = .574, p < .001, and of condition, $F_{(1, 34)}$ = 11.157, η_p^2 = .247, p = .002. There was no main effect of group, $F_{(1, 34)}$ = 1.848, η_p^2 = .052, p =.183. The main effects were modified

by a significant time point x condition interaction, $F_{(2, 68)} = 17.361$, $\eta_p^2 = .338$, $p < .001$. There was no significant group x time point interaction, $F_{(1.6, 55.1)} = 1.285$, $\eta_p^2 = .036$ $p = .280$, group x condition interaction $F_{(1, 34)} = .007$, $\eta_p^2 = .000$, $p = .936$, nor significant third order interaction (group x condition x time point), $F_{(1.9, 64.8)} = 1.585$, $\eta_p^2 = .045$, $p = .214$. The crucial condition x time interaction is shown in Figure 3.2.

Figure 3.2.

Change in anxiety/discomfort by experimental condition.



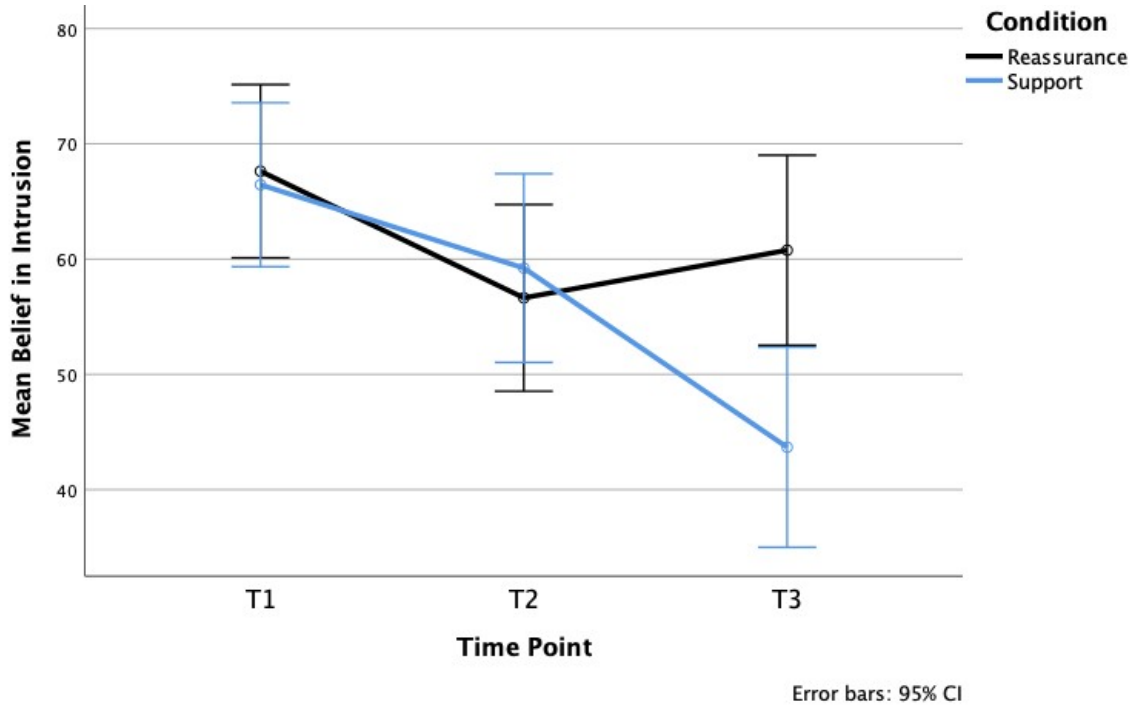
Multiple comparisons were used to decompose the significant interaction by carrying out paired *t*-tests between experimental conditions separately for each time point. There were no significant differences between conditions for T1 ($t_{(35)} = 1.28$ $p = .208$) or T2 ($t_{(35)} = .52$, $p = .607$) . However, T3 showed a significant difference in mean levels of anxiety between the reassurance and support condition ($t_{(35)} = 6.23$, $p < .001$). This difference is displayed in Table 3.3.

2.1.2. Belief in intrusion

A further 2 x 2 x 3 ANOVA using the same independent variables was conducted with belief in intrusion as a dependent variable. There was a main effect of time point, $F_{(1.22, 40.1)} = 20.80$, $\eta_p^2 = .387$, $p < .001$, and of condition, $F_{(1, 33)} = 5.31$, $\eta_p^2 = .139$, $p = .028$. There was no main effect of group, $F_{(1, 33)} = .007$, $\eta_p^2 = .000$, $p < .933$. These main effects were modified by a significant condition x time point interaction, $F_{(2, 66)} = 12.59$, $\eta_p^2 = .276$, $p < .001$. There was no significant group x time point interaction, $F_{(1.22, 40.1)} = .41$, $\eta_p^2 = .012$, $p = .567$, group x condition interaction $F_{(1, 33)} = 1.06$, $\eta_p^2 = .031$, $p = .311$, or third order interaction (group x condition x time point), $F_{(1.93, 63.7)} = .329$, $\eta_p^2 = .010$, $p = .713$. The crucial condition x timepoint interaction is shown in Figure 3.3.

Figure 3.3.

Change in belief in intrusion by experimental group.



Multiple comparisons were used to decompose the significant interaction by carrying out paired *t*-tests between experimental conditions separately for each time point. There were

no significant differences between conditions for T1 ($t_{(35)}$= .43, p=.668) or T2 ($t_{(35)}$= .84, p=.406). However, T3 showed a significant difference in belief in intrusion between the reassurance and support condition ($t_{(35)}$= 4.53, p=<.001). This difference is displayed in Table 3.3.

2.3. Further Analyses: Acceptability

2.3.1. Perceived helpfulness in emotion management

There was a statistically significant difference in helpfulness ratings, such that support was found to be significantly more helpful in managing emotions (M = 65.83, SD = 15.19) than reassurance (M = 42.44, SD = 26.22), $t_{(35)}$ = 4.274, d = .712, p <.001.

2.3.2. Calmness

There was a statistically significant difference in calmness ratings, such that support was found to be significantly more calming (M = 66.03, SD = 17.21) than reassurance (M = 43.33, SD = 25.16), $t_{(35)}$ = 4.720, d = .787, p <.001.

2.3.3. Closeness

There was a statistically significant difference in closeness ratings, such that support was found to significantly increase feelings of closeness (M = 65.22, SD = 25.12) compared to reassurance (M = 38.47, SD = 29.52), $t_{(35)}$ = 5.296, d = .883, p <.001.

2.3.4. Fighting together

There was a statistically significant difference in togetherness ratings, such that support was found to significantly increase feelings of fighting OCD together (M = 69.86, SD = 22.63) compared to reassurance (M = 27.03, SD = 29.20), $t_{(35)}$= 6.906, d = 1.151, p <.001.

Discussion

The study described here was designed to evaluate the way in which people with OCD react to imagining a situation where the need for reassurance is triggered, followed by imagining seeking and receiving either reassurance or emotional support. As predicted, the imagined emotional support scenario was associated with a greater reduction in anticipated longer-term urge to seek reassurance relative to the imagined reassurance scenario. Similar results were obtained for anticipated anxiety and belief in intrusion. Imagined emotional support was also perceived to be significantly more acceptable than imagined reassurance, in relation to feeling closer to their loved one, calmer, better able to manage emotions, and feeling as though they were fighting OCD with someone.

The results of this study are consistent with previous research that has shown emotional support to be perceived both as more effective (Halldorsson & Salkovskis, 2017a) and more acceptable than reassurance, both for people with OCD (Halldorsson & Salkovskis, 2017b), and those from non-clinical populations (Neal & Radomsky, 2019, 2020). Qualitative research has indicated that people with OCD recognise the seeking of reassurance to be compulsive, to come with a need for certainty that is not achieved, and to produce interpersonal strain, whereas they recognise that support is instead non-compulsive, makes them feel better with lasting effect, and strengthens their relationships (Halldorsson & Salkovskis, 2017b). Until now, however, these findings had not been demonstrated in an experimental study in people with OCD, with previous research relying on these qualitative accounts, single case studies, or non-clinical populations. The results of the current study provide novel experimental evidence for the narratives described, with this study being the first of its kind to compare the effectiveness and acceptability between both emotional support and reassurance using experimental paradigms in a population with OCD.

Limitations

The current study used semi-idiographic vignettes in which participants were asked to imagine the urge to seek reassurance followed by the seeking and receiving of support and reassurance. Whilst all vignettes were adapted to be idiosyncratic to the person's intrusions and communication styles, as the scenarios were imagined it remains unclear whether the vignettes realistically simulated the conditions of emotional support and reassurance. Further, due to the imagined nature of the time points, and lack of inclusion of T0 (vignette baseline) in the analysis, it is also unclear whether the outcomes accurately reflected how the participants may feel in real time, and whether 20 minutes of emotional support was enough to reduce anxiety, urges to seek reassurance and belief in intrusions back to baseline levels. Due to the nature of crossover designs, there was also a risk of aliasing in this study. As no significant third-order interactions were detected these risks appear minimal. Finally, there were some limitations with the population sampled in this study, due to its low proportion of males, and significant difference in education levels between the two order sequence groups (although the absence of detectable order effects helps). The sample was also not recruited from a clinical setting, although the majority of those participating came through OCD charities and most had been seen by clinical services. Future research may wish to recruit a larger population to avoid the need for a crossover design, and use stratified random sampling to ensure a more representative sample. Sampling from clinical settings would also be desirable.

Implications

The findings from this study support the long-standing proposition that reassurance can improve subjective outcomes in the short-term, but worsen them in the long-term (Salkovskis & Kobori, 2015; Salkovskis & Warwick, 1985). In contrast, emotional support was shown to improve outcomes slightly in the short-term, with even larger improvements in the long-term.

Whilst little is known of the exact mechanisms of emotional support, this finding supports current theories which propose that support acts in a contrasting way to reassurance, being an approach supporting behaviour, as opposed to an SSB (Halldorsson & Salkovskis, 2023). These findings also provide some preliminary evidence that some of the mechanisms underlying the benefits of support may be the strengthening of interpersonal connection, and through this an increased ability to tolerate distress, which is in line with previous qualitative evidence (Halldorsson & Salkovskis, 2017b). Further research may wish to understand the mechanisms underlying support in more detail, to better understand the core therapeutic mechanism such that therapy can be most effective. In particular, this research did not focus on the aspect of transfer of responsibility, a key theory of why people reassurance seek (Rachman, 2002). Future research may wish to understand whether responsibility is perceived to be transferred through the seeking and provision of emotional support.

The results of the current study suggest that the provision of support may provide a more acceptable alternative to the refusal of reassurance with nothing in its place. In current psychological treatments, this may be introduced via the “Theory A/Theory B” model (Salkovskis, 1999), whereby people with OCD and their loved ones are encouraged to shift from seeking and providing reassurance to seeking and providing emotional support. This differs from current clinical wisdom based on learning theories which would suggest that reassurance should not be provided by others due to its role as a safety behaviour that prevents full exposure to the feared stimulus (Craske et al., 2014; Foa & McLean, 2016). Withholding reassurance alone, however, has been found to be immensely upsetting, causing interpersonal conflict and further suffering for all concerned. It also proves difficult for caregivers, who see their response as a method of communicating care and concern (Halldorsson et al., 2016). This novel use of emotional support as an alternative is likely to lead to better engagement with therapy, as people are supported to tolerate their distress

within the context of a re-appraisal of how their OCD works (“Theory B”) and strengthen the interpersonal connection which is so important to their wellbeing.

The present findings have several implications for further research. Whilst this study focused solely on people with OCD, the interpersonal nature of ERS means it will be important to understand whether a replication of this study in caregivers would provide similar results in terms of effectiveness and acceptability. Further, as the results of the current study are limited using vignettes, it is recommended that future research uses *in-vivo* experiments, where the seeking and provision of reassurance and support is experimentally induced in live scenarios between people with OCD and their loved ones. In the longer term, it is suggested that research should aim to conduct single-case experimental designs, to investigate whether support remains effective and acceptable in clinical practice. The findings here related to OCD, but there is considerable evidence for the importance of reassurance across diagnoses, particularly anxiety disorders (Kobori & Salkovskis, 2013; Rector et al., 2019). Whilst it is recognised that the topography and motivations for reassurance-seeking may differ between populations with OCD and other anxiety disorders (Haciomeroglu & Inozu, 2019; Halldorsson & Salkovskis, 2023), future research may wish to investigate the effectiveness of support in populations with these other diagnoses.

Conclusion

The present study highlights the anticipated advantages of seeking and receiving emotional support as opposed to reassurance. People with OCD imagined support as not only more effective in the long-term, but also as more acceptable when compared to reassurance. Future research may benefit from assessing these outcomes in caregivers of those with OCD also, in addition to *in-vivo* experiments that can investigate the effectiveness and acceptability of reassurance in practice.

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Executive Summary

Fighting OCD together: an experimental study of the effectiveness and acceptability of seeking and receiving emotional support for OCD

Research has shown that excessive reassurance-seeking (ERS) is common in obsessive-compulsive disorder (OCD). ERS involves repeatedly asking someone questions to try to achieve certainty that threat will not occur with respect to a particular obsession or worry. Despite its intended function of reducing uncertainty about threat and alleviating anxiety, it has been described as a safety-seeking behaviour (SSB) that instead works to perpetuate OCD symptoms by enhancing both uncertainty and distress in the same way as checking does. Current treatment recommendations typically advise the external prevention of others giving reassurance. Whilst this may sometimes improve clinical outcomes in OCD, the acceptability of this form of treatment is low, often causing difficulties within family, peer, and partner relationships.

Emotional support-seeking (ESS) has been proposed as an effective alternative to ERS, defined as the interpersonal behaviour intended to get assistance to cope with distress rather than “danger”. Whilst it may look externally similar, it instead functions to build strategies that allows the person to tolerate the distress associated with the threat, such that the perception of the threat level is ultimately reduced. Essentially it represents a shift in terms of the perception of the problem; that it’s not that the feared things will happen, but rather that the person is experiencing fear of things happening. There is currently no evidence for the effectiveness and acceptability of ESS relative to ERS in OCD. The present study investigates whether the anticipation of provision of reassurance to reduce threat, or the provision of support to alleviate distress and thereby tolerate threat, could be a more effective and acceptable method of treatment for ERS.

An experimental study was conducted, where 38 participants identified as having OCD were presented with scenarios in which they imagined reassurance-seeking and provision, or support-seeking and provision. All participants received both scenarios in counterbalanced order. These scenarios were adapted to contain real-life ways each individual sought and received reassurance and support for their specific obsessions. During the presentation of these vignettes, participants were asked to rate their urge to seek reassurance, level of anxiety, and belief in intrusion at 4 different time-points. Participants were then asked to rate how acceptable they perceived the reassurance and support scenarios.

Statistical analysis demonstrated that when compared to the seeking and provision of reassurance, emotional support was found to significantly reduce urges to seek reassurance, levels of anxiety and belief in intrusion over time. Emotional support was also perceived as significantly more acceptable than reassurance with regards to increasing feelings of calmness, feelings of closeness, perceived helpfulness of emotional management, and feeling like they were fighting OCD together.

Overall, the seeking and provision of emotional support was found to be both more effective and more acceptable than reassurance in people with OCD. This supports the long-standing notion that reassurance can be of subjective benefit in the short-term but worsen outcomes in the long-term. The therapeutic shift to emotional support as an alternative to ERS in clinical treatments may lead to better engagement with therapy through an increased ability to tolerate distress, whilst also strengthening relationships with loved ones. Future research should aim to assess whether these findings can be replicated in caregivers of those with OCD and in real-life situations.

Connecting narrative

When starting training, I had a strong sense of my interests both having worked in a psychosis research team that used symptom specific approaches and had a clear ethos of improving access, as well as through my own lived experiences of OCD. The projects I developed and conducted encompass these interests, with the thread of improving help-seeking and patient-centred care interwoven throughout.

Focusing on my interests in psychosis, my SRL focused on structural barriers to help-seeking in first-episode psychosis, with a hope that these findings could provide clear implications for organisations that could facilitate patient-centred, accessible care. As my first systematic review, this project did not come without its challenges, particularly the struggle of inter-rater reliability and reliable quality ratings. From this, however, I have developed skills in defining research criteria in a way that is replicable, as well as developing awareness of what makes good qualitative research. Although present, these challenges were so clearly outweighed by the impact I felt this research could have when reading the many accounts of patients with first-episode psychosis and their caregivers who had struggled throughout their pathways to care. Having worked in psychosis services, I very wrongly assumed the results of the study would show nothing I hadn't seen already, but I learned so much through this project, not only about the innumerable hurdles along the way, but about the ways in which they can, and should be improved.

With regards to the service improvement project, my focus on improving access to mental health services continued, but this time specifically focusing on young Pakistani women. My interest in this area peaked following an assignment in first year in which I chose to write an extended essay on the reduced offering of psychological treatment for those of ethnic minority backgrounds, and I felt a sense of responsibility to do what I could to better understand and help bridge this gap. As a young, White British woman, recruiting from the

Pakistani population with very narrow inclusion criteria, I (and many others), had doubts about the feasibility of this project, and whether it was indeed possible. This was exacerbated by the influx of “imposter participants”, after which another avenue of recruitment was lost, an experience that was felt as personally challenging. I am so glad that with the encouragement of my supervisors that I did not alter or abandon this project, however, as I have learned so much about the importance of perseverance, hope, and drive to reach those that are so often termed “hard to reach”. I have also learned so much from these wonderful women about the Pakistani culture, and how I can be a better, more inclusive clinician. I feel truly honoured that they have entrusted me with their stories. I hope that I have done them justice, and that these findings can help more young Pakistani women seek and access the help they deserve.

My theory-driven research project focused on my interest in OCD and symptom-specific approaches and was a project I felt deep kinship with based on my personal experiences. As with the other projects, this was not without its challenges, having started out the size of a PhD itself, resulting in a re-focus, re-design, and resubmission of ethics. Whilst what remained was still time-intensive and ambitious given the many course deadlines and balancing of other projects, what became of this project, with the guidance and support of my supervisor and the wonderful Lucy, I am so incredibly proud of. I have learned how important it is to have a little faith, carefully manage my time, and to take the time to speak to participants about their experiences to help remind me why to persevere when things go a bit awry. I am so grateful for every single person who filled out the questionnaires, volunteered their time, and reminded me of my love of clinical research. Thanks to this, I will now be continuing this research in a PhD and look forward to the next chapter of translating this research into clinical practice.

Acknowledgements

To all the participants who kindly gave their time, shared their stories, and made this all possible. Thank you for reaffirming why I chose this path.

Thank you to my course tutor and supervisor, Paul Salkovskis for putting up with my relentless emails, panics, and chaos and for agreeing to do so for the next four years. Your *support* throughout all of this has been invaluable. Most of all, thank you for all you do for the OCD community, it is a true privilege to work alongside you.

A big thank you to my research supervisors Matthew Knight, Louise Johns, and Felicity Waite. I am so grateful for your guidance, patience, and much needed encouragement throughout this whole process. Thank you for keeping me going during the times I wanted to give up, for reading what felt like a million drafts, and for teaching me how to produce quality qualitative research. I'm incredibly proud of the work we've produced.

A special thank you to Lucy Clarkson, Jerica Radez, Hibah Hassan & Nithura Sivarajah for your input into the research design, recruitment, checking, and for all your encouragement and faith in this research. I couldn't have done this without you.

To my fellow Covid cohort trainees (and flatmates), Corah, Josh, Joe, and Bethan. I don't know where to begin. You have made this wild ride infinitely better with all the cups of tea, sofa lectures, voice note rants, many memes and most importantly so much love and laughter. I can't imagine better people to have been on this journey with. Forever grateful for you.

Thank you to my mum, for inspiring me to work in this field, and for always being at the end of the phone through the good and the bad. Thank you to Aunty Anna and Uncle Vince for always believing in me – it means the world. Finally, a big thank you to my friends and O-CAP family for all your support through the last three years, with special thanks to Nico. You have been my absolute rock, and the best friend and lockdown bubble a person could ask for. I cannot thank you enough.

Appendix A

SRL: Author guidelines for *Early Intervention in Psychiatry*

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Thank you for your interest in *Early Intervention in Psychiatry*. Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

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Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

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• The corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

Print copies of the article can now be ordered (instructions are sent at proofing stage).

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Measuring the Impact of an Article

Wiley also helps authors measure the impact of their research through specialist partnerships with **Kudos** and **Altmetric.**

Appendix B

SRL: Search Terms

	Ovid – Medline, Embase & PsycInfo	WebOfScience	Scopus	CINAHL
Psychosis	(psychosis OR psychotic* OR schizoaffect* OR schizophreni*)	AB (psychosis OR psychotic* OR schizoaffect* OR schizophreni*) TI (psychosis OR psychotic* OR schizoaffect* OR schizophreni*)	(TITLE-ABS (psychosis OR psychotic* OR schizoaffect* OR schizophreni*)	AB (psychosis OR psychotic* OR schizoaffect* OR schizophreni*) TI (psychosis OR psychotic* OR schizoaffect* OR schizophreni*)
	AND	**AND**	**AND**	**AND**
Barrier	(barrier* OR obstacle* OR delay*)	AB (barrier* OR obstacle* OR delay*) TI (barrier* OR obstacle* OR delay*)	TITLE-ABS (barrier* OR obstacle* OR delay*)	AB (barrier* OR obstacle* OR delay*) TI (barrier* OR obstacle* OR delay*)
	AND	**AND**	**AND**	**AND**
Help-seeking	(“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*)	AB (“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*) TI (“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*)	TITLE-ABS (“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*)	AB (“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*) TI (“help-seek”" OR seek* OR treatment* OR therap* OR intervention* OR service*)
	AND	**AND**	**AND**	**AND**
Qualitative	(qualitative OR interview* OR thematic* OR theme* OR "interpretative phenomenolog" OR	AB (qualitative OR interview* OR thematic* OR theme* OR "interpretative phenomenology" OR narrative*) TI (qualitative OR interview* OR thematic*	TITLE-ABS (qualitative OR interview* OR thematic* OR theme* OR "interpretative phenomenology" OR narrative*)	AB (qualitative OR interview* OR thematic* OR theme* OR "interpretative phenomenology" OR narrative*) TI (qualitative OR in

	narrative*)	OR theme* OR "interpretative phenomenology" OR narrative*)		terview* OR the matic* OR theme * OR "interpretative phenomenology" OR narrative*)
	NOT	**NOT**	**NOT**	**NOT**
Unrelated	(neuro* O R pharmac o* OR ani mal* OR b rain* OR a ntipsychoti c* OR med ication*)	AB (neuro* OR pharmac o* OR animal* OR b rain* OR antipsychot ic* OR medication*) TI (neuro* OR pharmac o* OR animal* OR b rain* OR antipsychot ic* OR medication*)	TITLE-ABS (neuro* OR ph armaco* OR a nimal* OR bra in* OR antipsy chotic* OR me dication*)	AB (neuro* OR phar maco* OR animal * OR brain* OR a ntipsychotic* OR medication*) TI (neuro* OR phar maco* OR animal * OR brain* OR a ntipsychotic* OR medication*)
	AND	**AND**	**AND**	**AND**
Limits	limit to abstracts, English language, human, yr = “2001-current”.	Refined by NOT Publication Years: 1992 or 1996 or 1998 or 1999 or 2000. Languages: English.	EXCLUDE (PUBYEAR, 1999) OR EX CLUDE PUB YEAR, 1998) OR EX CLUDE (PUB YEAR, 1996) OR EXCLUD E (PUBYEAR, 1 992) OR EXC LUDE (PUBYEAR, 1 967)) AND (LI MIT-TO (LAN GUAGE,“"En glis”"))	Limiters–- Published Date: 20010101-20221231 Expanders–- Apply equivalent subjects Narrow by Language: - abelleh

((psychosis OR psychotic* OR schizoaffect* OR schizophreni*) AND (barrier* OR obstacle* OR delay*) AND ("help-seek" OR seek* OR treatment* OR therap* OR intervention* OR service*) AND (qualitative OR interview* OR thematic* OR theme* OR "interpretative phenomenolog" OR narrative*) NOT (neuro* OR pharmaco* OR animal* OR brain* OR antipsychotic* OR medication*))

Appendix C

SRL: Additional Quotes

Theme number	Theme Heading	Example Quotes
1. Healthcare requires personal knowledge and resources		
1.1	Negative perceptions of psychiatry	*"I'm petrified of that place. Of going into the asylum"* (Anderson et al., 2013, p. 389) 'Stigma… in mental health services…seems to be more hurtful than when experienced outside the healthcare system' (Ferrari et al., 2015, p. 7) *"It's like sort of getting arrested but not quite. Like you're getting taken away to somewhere that you're not, you don't feel that you're in an environment that you want to be in"* Cadario et al., 2011, p. 99)
1.2	Financial barriers	*"I had to… bear all the expenses. It was difficult"* (Dutta et al., 2005, sec Financial constraints", para. 4) *"I have to pay… for transportation… even though the consultation fee is free"* (Hasan & Musleh, 2017, p. 674) *'This lengthy process of treatment seeking… caused the family to suffer financially"* (Marthoenis et al., 2016, p. 3)
1.3	Alternative treatments prevent service use	*"we went to see a dukun… he did not allow us to see a doctors… said doctor gives pills that block the nerves"* (Marthoenis et al., 2016, p. 4) *'treatment at psychiatric hospital seems to be the last option when treatment through traditional sectors has not improved the patient's condition'* (Marthoenis et al., 2016, p.3) "we have done it (referring to religious therapy) for 5 years…" (Wong et al., 2020, p. 5)
1.4	Not knowing how to access	*'We haven't lived in this system… don't necessarily know that there are people there… for this"* (Anderson et al., 2013, p. 389) *"There are about one or two fishing boats… if I miss that one, I will have to stay here"* (Marthoenis et al., 2016, p. 5) "*it's such a vague thing it's hard to know where to go and who to talk to"* (Tanskanen et al., 2011, p. 6)

		"I didn't know whether you just turn up… I didn't know about these services [EIS]" (Connor et al., 2016, p. 340)
2. Complex process to initiate care		
2.1	Systems difficult to navigate	*"You have to call over to their intake place. They give you an appointment, and then you have to come back. Then when you come back they do the paperwork."* (Bergner et al., 2008, p. 533) *"So then I couldn't get anyone who takes his insurance"* (Gerson et al., 2009, p. 814) *"this is too complicated for me…, we cannot understand this… [system]"* (Marthoenis et al., 2016, p. 6)
2.2	Restrictive criteria	*"It took me a long time to help as he didn't fit into any categories (for access to a specific service)"* (McCann et al., 2011, p. 159) "*I think I was afraid I might not be sick enough"* (Bay et al., 2016., p. 74) *'Young people need to be convincingly unwell when they present to clinicians, otherwise they may be denied access to a service.' (*McCann et al., 2011, p. 159)
2.3	Caregivers battling with professionals for help	*"After about 15 hours convincing them that I was not taking him home, they admitted him"* (Ferrari et al., 2015, p. 5) *"no-one responded. No one was there…"* Bergner et al., 2008 (p. 533) *'However, with persistence, they eventually become knowledge about the existence and location'* (McCann et al., 2011, p. 159) *"It's been very frustrating along the way but you get quite good at pushing your family member to get what they need"* – (McCann et al., 2011, p. 160) *"Even if I look for help for him, they (services) won't provide anything"* (Connor et al., 2016 p. 340) *"Even if he's got those services, they can't speak to me without his consent"* (Connor et al., 2016, p. 340) Without a caregiver to initiate care, however, some patients "*acknowledged that they would not have obtained help for their symptoms of psychosis"* (Anderson et al., 2013, p. 389). *"The hospital say they cannot force if patient refuses…"* (Wong et al., 2020, p. 652) *"I was told every time, 'you can't call on his behalf'* (Yarborough et al., 2019, p. 6) *"He never let me talk to him… the doctor… they didn't give me no chance to talk to him"* (Cabassa et al., 2018, p. 652)
3. Professionals' levels of expertise vary		
3.1	Mixed success of police	*"It looked like 100 police was here… broke the door down… handcuffed her…"* (Gerson et al., 2008, p. 813) *'Described how they were exposed to verbal and*

		physical violence as well as the trauma of experiencing psychotic episodes while in detention.' (Ferrari et al., 2015, p. 8)
3.2	Professionals misinterpret & lack knowledge	*"The doctor was telling me that he was autistic"* (Wong et al., 2020, p. 5) *"doctor…thought it was probably due to some depression and not having friends"* (Skubby et al., 2015, p. 891) *"The psychologist thought he had too much time and he needed to get a job"* (Skubby et al., 2015, p. 892) *"none of these people [university psychological service/ psychiatrist] told me about any other resources"* Ferrari et al., 2015, p. 7)
3.3	Ill-suited medical advice	*"his idea was to turn the TV off at a certain time"* (Skubby et al., 2015, p. 892). *"Congratulations, you don't have anything, there's nothing on the exams"* (Wong et al., 2020, p. 251) *"give him these (sleeping) tablets and he'll be fine"*. (Tanskanen et al., 2011, p. 7)
4. Negative encounters in healthcare		
4.1	Lack of agency	*"I think they treat you more like a number… you're not a person, anymore"* (Ferrari et al., 2015, p. 9) *"It was almost the release of any self-will"* (Anderson et al., 2013, p. 390) *"he spoke to my sister more than he spoke to me"* (Connor et al., 2016, p. 341) *"It's like sort of getting arrested but not quite. Like you're getting taken away to somewhere that you're not, you don't feel that you're in an environment that you want to be in"* (Cadario et al., 2011, p. 99)
4.2	Traumatising experiences	*"It really, made me not like being in the hospital. I did not want to go back there ever"* (Ferrari et al., 2015, p. 8) *'Admission of the young person to an adult psychiatric ward was highlighted as being particularly stressful. "It's scary I think"'* (Cadario et al., 2011, p. 90) *"The hospital just left me by myself"* (Cabassa et al., 2018, p. 654)
4.3	Fraught relationships with professionals	*"I was very, very unhappy with him [psychiatrist], and my son was very very unhappy with him"* (Skubby et al., 2015., p. 892) *"Oh you guys are just not getting along…it happens with adolescents and parents. You'll get past it."* (Skubby et al., 2015, p. 891) *"He [family doctor] turned me down flatly 'cause I was smoking weed"* (Ferrari et al., 2015, p. 8) *"She [social worker] said I should look at it as that I have three kids, two are good and one is not good"* (Gerson et al., 2009, p. 814)

		"Oh, I remember meeting with the doctor… it was a bad experience" (Cabassa et al., 2018, p. 652) *"he (GP) referred… (carer's son) to our local hospital… organised for them to accept"* (McCann et al., 2011, p. 158) *"I'm sorry about what's happened to you, but this is what you need to do"* (Skubby et al., 2015, p. 893) *"for the GP it sounded like, 'Oh my God', you know'… So I was then referred"* (Tanskanen et al., 2011, p. 4) *"Make an effort to validate the patien''s experiences and not be dismissive of delusions or hallucinations"* (Anderson et al., 2013, p .388)
5. Misalignment between patient needs and service resources		
5.1	Consideration of individual needs insufficient	*"Maori support worker and he was great, her was real… the first support worker… she wasn't real"* (Cadario et al., 2011, p. 90) *"It would have been good to talk to somebody who had a kid, a child with psychosis"* (Cadario et al., 2011, p. 100). *"There needs to be more services out there for young people… they don't fit into the adult mental health system"* (McCann et al., 2011., p. 159)
5.2	Service organisation challenges	*'An important complaint was about a lack of continuity of care'* (Cadario et al., 2011., p. 90) *"We kept on getting sick of telling our same story to different people. We probably saw about three different psychiatrists in the time we were there"* (Cadario et al., 2011, p. 100) *'inflexibility of appointments and inefficient scheduling processes'* (Bergner et al., 2008, p. 533)
5.3	Help comes too late	*"Finally, the doctor assessed my concerns… and I was admitted"* (Bay et al., 2014, p. 74) *'if treatment had begun sooner, it could have reduced the suffering of the young persons'* (dos Santos Martin et al., 2018, p. 251)

Appendix D

SIP: Author guidelines for *Journal of Cross-Cultural Psychology*

1. **Aims and scope**

***Journal of Cross-Cultural Psychology* publishes papers that focus on the interrelations between culture and psychological processes. Submitted manuscripts may report results**

from either cross-cultural comparative research or single culture studies.

Research that concerns the ways in which culture, and related concepts such as ethnicity, affects the thinking and behavior of individuals, as well as how individual thought and behavior define and reflect aspects of culture are appropriate for the *Journal of Cross-Cultural Psychology*.

Cultural Variables. Cultural variables that may be related to the behavior(s) of interest should be assessed rather than relying upon conjectures regarding assumed cultural differences that could be influencing behavior(s).

Empirical Research. Most papers published in the *Journal of Cross-Cultural Psychology* are reports of empirical research. Empirical studies must be described in sufficient detail to be potentially replicable.

- **NOTE:** The *Journal of Cross-Cultural Psychology* does not publish psychometric studies of test construction or validation. Studies that compare scale performance or factor structure among different cultural groups are also not considered by the *Journal of Cross-Cultural Psychology*.

Reviews and Theoretical Papers. Integrative reviews that synthesize empirical studies and innovative reformulations of cross-cultural theory will also be considered. These reviews are expected to reformulate or offer a novel perspective to an existing cross-cultural theory or research area.

Single Nation/Culture Research. Studies reporting data from within a single nation should focus on cultural factors and explore the theoretical or applied relevance of the findings from a broad cross-cultural perspective.

Methods. Psychology publishes studies using quantitative, qualitative, and mixed methods.

Authors who are uncertain about the appropriateness of particular manuscripts should contact the Editor, Senior Editor, or any of the Associate Editors for clarification and advice.

2. **Manuscript Submission Guidelines:**

Journal of Cross-Cultural Psychology (*JCCP*) publishes material in three categories: (1) regular, unsolicited manuscripts, (2) brief reports, and (3) special issues. We do not publish book reviews. Summary details of each category are as follows:

1.Regular, Unsolicited Manuscripts. This is *JCCP*'s main emphasis. See Aims and Scope for a detailed description of appropriate manuscripts.
Manuscripts should be submitted electronically to http://mc.manuscriptcentral.com/jccp. Authors will be required to set up an online account on the SageTrack system powered by ScholarOne. Manuscripts will be sent out anonymously for editorial evaluation. Obtaining permission for any quoted or reprinted material that requires permission is the responsibility of the author. Submission of a manuscript implies commitment to publish in the journal.

Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the Editor.
Manuscript length should normally be 15 to 35 double-spaced, typewritten pages. Longer papers will be considered and published if they meet the above criteria. Manuscripts should be prepared according to the most recent edition of the American Psychological Association Publication Manual. Manuscripts are reviewed by the Editorial Advisory Board. Allow up to 3 months for a publication decision and up to 1 year for publication.

- **L.** Brief Reports. Accepted Brief Reports should be no more than 10 double-spaced manuscript pages long, including title page, references and any tables.
- **L.** Special Issues. An important part of *JCCP*'s publication policy is the periodic publication of special issues or special sections of regular issues. Current needs, emerging trends, and readership interest guide the publication of material in this category. Ideas or suggestions for special issues or special sections should be discussed with Walter J. Lonner (Walter.Lonner@wwu.edu), Founding and Special Issues Editor, or other members of the Editorial Advisory Board, especially current Editor, Deborah L. Best (best@wfu.edu).

Orcid
As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized. The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.
If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.
English language editing services
Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using the services offered by SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information. Here is the link:
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If you or your funder wish your article to be freely available online to nonsubscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE Choice, subject to the payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Choice. To check journal eligibility and the publication fee, please visit SAGE Choice. For more information on open access options and compliance at SAGE, including self/author archiving deposits (green open access) visit SAGE Publishing Policies on our Journal Author Gateway.

Appendix E

SIP: COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	56
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	54
Occupation	3	What was their occupation at the time of the study?	54
Gender	4	Was the researcher male or female?	54
Experience and training	5	What experience or training did the researcher have?	54
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	56
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	56
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	54
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	54
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	55
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	55
Sample size	12	How many participants were in the study?	55
Non-participation	13	How many people refused to participate or dropped out? Reasons?	55
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	55
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	56
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	57 & 58
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	56
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	56
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	56
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	56
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	57
Description of the coding tree	25	Did authors provide a description of the coding tree?	57
Derivation of themes	26	Were themes identified in advance or derived from the data?	57, 60
Software	27	What software, if applicable, was used to manage the data?	57
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	61-67
Data and findings consistent	30	Was there consistency between the data presented and the findings?	61-67
Clarity of major themes	31	Were major themes clearly presented in the findings?	60-67
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	61-67

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix F

SIP: Interview Topic Guides

F.a. Young Pakistani Woman Topic Guide

Introduction: *Many young people experience mental health problems. However, they can often find it tricky to get help. In this interview, I will be interested to hear more about you, your experiences, and ideas for better helping young people like yourself when they experience mental health problems. Although I'm not part of the Pakistani community, I have friends and colleagues who are, and I'm passionate about improving access to mental health services for this community, which is why I am asking these questions.*
This interview will last up to one hour and there will be no right or wrong answers. I will only be interested in what you think. Before I begin, can I check that you're in a room alone and are comfortable to speak? Any other questions?

Understanding of SMHP (serious mental health problems)

1. Can you tell me about your understanding of mental health problems?
   - Probe: what does 'having a serious mental health problem' mean to you?

2. How do people in your community view mental health problems?
   - Probe: how do people in your immediate family see serious mental health problems?
   - Probe: how do people in your extended family see serious mental health problems?
   - Probe: how do your friends perceive serious mental health problems?
   - Probe: do you know what makes you/your family/friends about serious mental health problems in a certain way?

Personal experience of SMHP (serious mental health problems)

3. Can you tell me a bit about your experience with mental health problems?
   - Probe: how old were you when you realised you were experiencing a mental health problem?
   - Probe: how long did it take you to realise or accept that you were suffering from a mental health difficulty?
   - Probe: what changes did you notice within yourself?

4. What was it that prompted you to realise you were experiencing a mental health problem?
   - Probe: what role did your immediate family play in identifying symptoms of a serious mental health problem in you?
   - Probe: what role did your extended family play in identifying symptoms of a serious mental health problem in you?
   - Probe: what role did your friends play in identifying symptoms of a serious mental health problems in you?
   - Probe: what role did school/college/work/religious community play in identifying symptoms of a serious mental health problems in you?

- Probe: Who did you feel most comfortable expressing what you were going through to out of these people?

Personal experience of help-seeking

5. Have you sought *any* help for your symptoms of serious mental health problems?
   a) *If yes – can you describe this experience to me*?
   - Probe: where did you seek help? Who did you speak to?
   - Probe: what made you speak to that particular person?
   - Probe: were you successful in seeking help?
   - Probe: have you sought help with professionals (including schoolteacher or your GP)?
   - Probe: what role did your family/friends/religious community play in you speaking to a professional?

   b) If no – What stopped you from seeking help?
   - Probe: what stopped you from speaking with your family/friends?
   - Probe: what stopped you from speaking to a professional (including schoolteacher or your GP)?
   - Probe: what role did your family/friends/religious community play in you **not** speaking to a professional?
   - Probe: Did your personal beliefs/religion make you feel that you didn't need help?

Attitudes towards help-seeking

6. What do you think about speaking to other people about symptoms of serious mental health problems?
   - Probe: Who do you think plays the most important role in how you see help-seeking for serious mental health problems? School/friends/family/religious community? Why?
   - Probe: What would you think about someone else who speaks about their mental health problems to other people?
   - Would you have found it easier to seek help if you lived alone rather than with your family?

7. What are some of the common stereotypes you've heard about mental health?
   - Probe**:** Do you think there is a stigma attached to mental health problems, and if so, why?
   - Probe: Is mental health something that is commonly discussed within your family? Do you have any experiences of this in your family?

8. Do you think that you would think about help-seeking differently if you were living in Pakistan?
   - *If yes* – how do you think that living in Pakistan would affect your thoughts about help-seeking?
   - Do you think you would have thought differently about mental health problems if you were living in Pakistan?

Barriers to help-seeking

9. Now let's think about professional help only. What do you think are the main reasons that stop young people like yourself from seeking professional help for symptoms of serious mental health problems?
    - Probe: How easy/hard it is for young person like yourself to get professional help for symptoms of serious mental health problems?
    - Probe: Would your friends know where and how to seek and access professional help for symptoms of serious mental health problems?
    - Prob**e:** What role does a family/friend play in a young person seeking and accessing professional help for symptoms of serious mental health problems?
    - Have you heard of anyone else's bad experiences when help-seeking that have made you not want to seek professional help?
    - Probe: What role does someone's cultural/religious background/nationality play in young person seeking and accessing professional help for symptoms of serious mental health problems?
    - Prob**e:** Do you think the gender, ethnicity, or cultural background of the professional makes a difference when help-seeking?
    -

Facilitators to help seeking

10. In Oxfordshire, many people like yourself do not seek professional help for their serious mental health problems. What do you think are things that could make it easier for young people like yourself to seek or access professional help?
    - Probe: What kind of services do you think would be most interesting/attractive for young people like yourself?
    - Prob**e:** What kind of person would young people like yourself find it easiest to talk to? What role does the professional's nationality play in that?
    - Probe: How do you think that people around you could help you seek/access professional help?
    - Probe: what do you think that professionals can do to make the services more available and accessible for young people like yourself?
    - Prob**e:** Would you feel more comfortable going to a professional to seek help alone, or with someone else to support you?

F.b. Parent Topic Guide

Introduction: *Many young people experience mental health problems, but they can often find it tricky to get help. Often, it is the young person's parent/carer that instead is involved in seeking help. In this interview, I will be interested to hear more about your experiences of help-seeking how you felt about it, and ideas for better helping young people like your child when they experience mental health problems. Although I'm not part of the Pakistani community, I have friends and colleagues who are, and I'm passionate about improving access to mental health services for this community, which is why I am asking these questions. This interview will last up to one hour and there will be no right or wrong answers. I will only be interested in what you think. Before I begin, can I check that you're in a room alone and are comfortable to speak? Any other questions?*

Understanding of SMHP

1. Can you tell me about your understanding of mental health problems?
   - Probe: what does 'having a serious mental health problem' mean to you?
   - Probe: how can you tell if your child is struggling with serious mental health problems?

2. How do people in your community view mental health problems?
   - Probe: how do people in your family see serious mental health problems?
   - Probe: how do your friends perceive serious mental health problems?

Personal experience of SMHP

3. Can you tell me a bit about your experience with your child's mental health problem?
   - Probe: when did you realise your child was experiencing a mental health problem?
   - Probe: how long do you think this had been going on for before you realised?
   - Probe: what changes did you notice?
   - Probe: what role did your wider family play in identifying symptoms of a serious mental health problem in your child?
   - Probe: what role did school/college/work play in identifying symptoms of a serious mental health problems in your child?

Personal experience of help-seeking

4. Have you sought *any* help for your child's symptoms of serious mental health problems?
   c) *If yes – can you describe this experience and how you felt about it to me*?
   - Probe: where did you seek help? Who did you speak to?
   - Probe: what made you speak to that particular person?
   - Probe: were you successful in seeking help?
   - Probe: have you sought help with professionals (including schoolteacher or their GP)?
   - Probe: what role did your wider family/friends play in you speaking to a professional?
   - Probe: How did the mosque support help-seeking?

- Probe: did you ever seek help from your Imam?

d) If no – What stopped you from seeking help?

- Probe: what stopped you from speaking with your family/friends?
- Probe: what stopped you from speaking to a professional (including schoolteacher or your GP)?
- Probe: what role did your wider family/friends play in you **not** speaking to a professional?
- Probe: was there anyone else that played a role, like a religious leader or anyone else?

Attitudes towards help-seeking

5. Do you think that you would think about help-seeking differently if you were living in Pakistan? *If yes* – how do you think that living in Pakistan would affect your thoughts about help-seeking?

Barriers to help-seeking

6. Now let's think about professional help only. What do you think are the main reasons that stop parents/carers like yourself from seeking professional help for symptoms of serious mental health problems?

- Probe: How easy/hard it is for a parent like yourself to get professional help for your child's symptoms of serious mental health problems?
- Prob**e:** What role does a family/friend play in a parent/carer seeking and accessing professional help for their child's symptoms of serious mental health problems?
- Probe: What role does someone's cultural/religious background/nationality play in you seeking and accessing professional help for your child's symptoms of serious mental health problems?

7. And what do you think are the main reasons that stop young people like your child from seeking professional help for symptoms of serious mental health problems?

- Probe: How easy/hard it is for a young person like your child to get professional help for your child's symptoms of serious mental health problems?
- Prob**e:** What role does a family/friend play in a young person accessing professional help for their child's symptoms of serious mental health problems?

Facilitators to help seeking

8. In Oxfordshire, many people like yourself do not seek professional help for their child's serious mental health problems. What do you think are things that could make it easier for parents/carers like yourself to seek or access professional help?

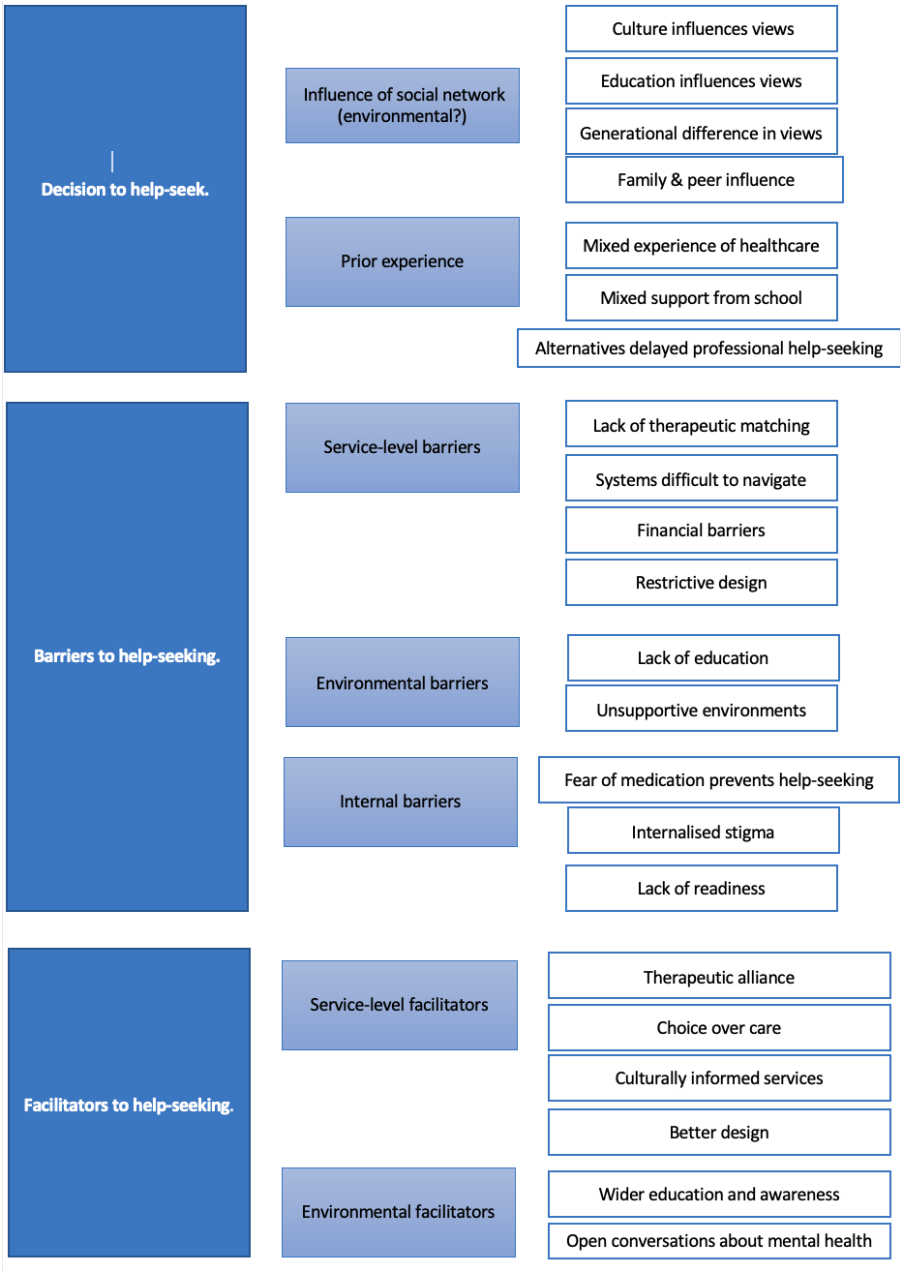
- Probe: What would you want the professional services to look like?
- Prob**e:** What kind of person would young people like your child find it easiest to talk to? What role does the professional's nationality play in that?

Probe: How do you think that people around you could help you seek/access professional help

Appendix G

SIP: Iterations of Theme Organisation

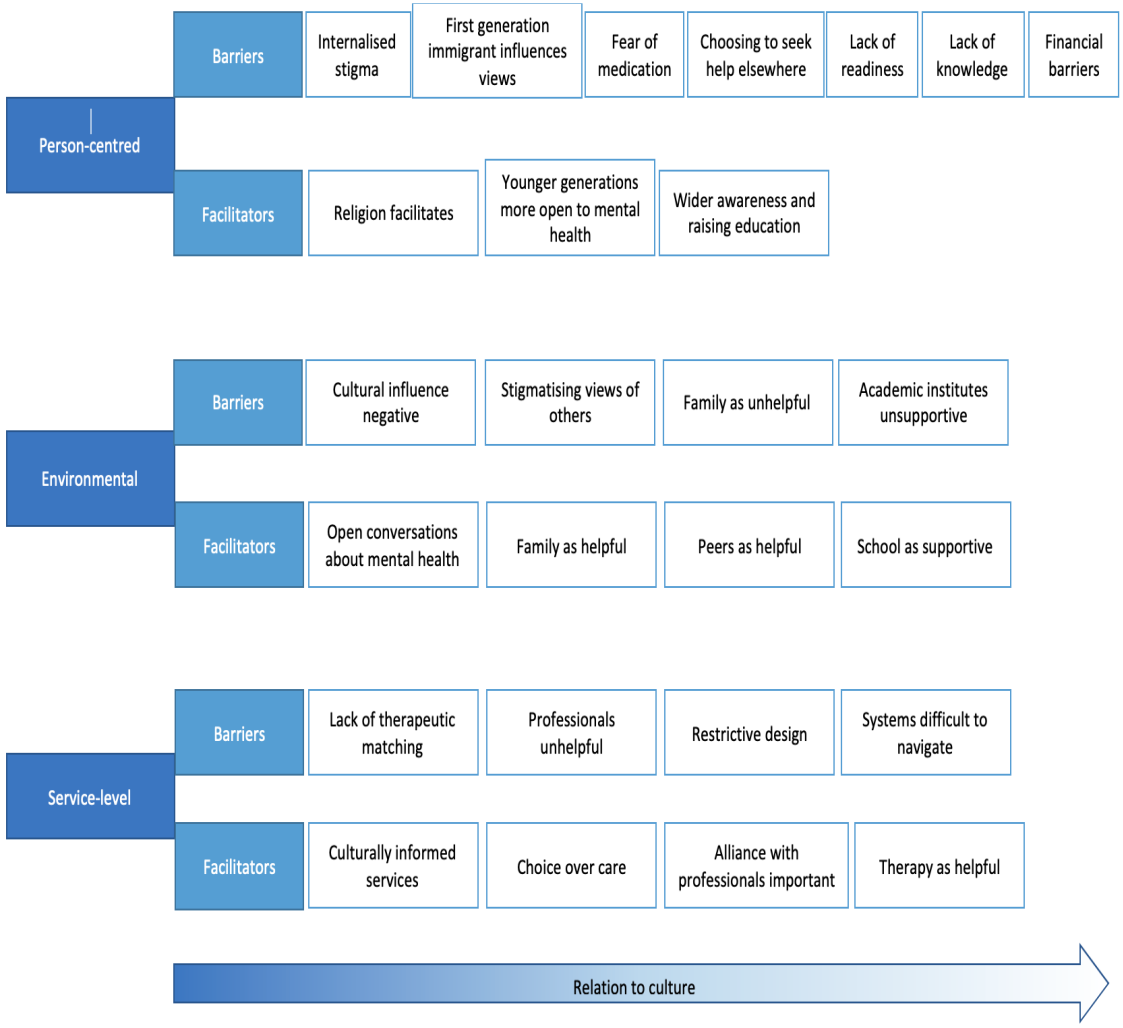
G.a. Iteration 1



This first iteration was developed by CC grouping the codes into subthemes and themes which initially appeared to fall into categories related to the study aims. It was noted that decisions to help-seek were based on influences of social networks such as families and peers, and the education system, and this differed dependent on education levels, culture, and generation. Prior experiences of help-seeking also influenced the decision to help-seek. Barriers consisted of internal, service-level and environmental barriers such as internalised stigma, systems difficult to navigate, and unsupportive environments. Participants also noted

however, that there could be environmental and service-level facilitators such as wider education and awareness, more choice over care, and culturally informed services.

G.b. Iteration 2



The second iteration was borne out of discussions with the research team about Iteration 1. It was felt that decisions to help-seek were difficult to separate from some of the barriers and facilitators, and that as some subthemes were similar, these were better grouped as main themes e.g., service-level, environmental. It was further discussed that there was an emphasis of culture throughout many of the themes to varying degrees, therefore it was decided to place themes based on how much the related to culture.

From this, the three main themes found were person-centred, environmental, and service level, each of which had their own barriers and facilitators. Participants discussed many personal barriers such as internalised stigma, lack of knowledge, and financial barriers that made it difficult to seek help. Being of a younger generation, having wider education and awareness and religion were noted to counteract some of these barriers. With regards to the environment, the influence of culture was found to be negative along with stigmatising views of others. Both family and academic institutes could active as both barriers and facilitators. Peers generally facilitated help-seeking. As for service-level barriers and facilitators, these remained much the same as before.

Upon further discussion with the research team, it was felt that many of the barriers and facilitators were paired, and lots of subthemes influenced one another, so it was decided to merge some of the subthemes and think about how they may link to help-seeking and one another. From this, the final iteration was borne.

Appendix H

SIP: Additional Quotes

Multiple cultural influences shape attitudes	
Stigmatising views from the Pakistani community	YP1: *"Umm… that it's a hoax. Umm… it's a punishment from God. I''s you know demonic possession. Umm it's just a weakness. Umm that you can choose. You can choose to to be mentally. Umm I think that you're an attention seeker. Yeah that that it just it doesn't exist really"* PARENT2: *"Umm, and I will say it's something that's not talked about really and is kind of frowned upon, frowned upon still. So people so I don't think I'm not sure what the word is in Urdu or Punjabi for mental health but there is something that people used a word like mad which sounds very extreme that the alternative of that.*
Different cultural influences are confusing	YP2: *"if you're not consciously thinking it's because I'm Pakistani it's because your family is bred into a certain mindset and that will really affect how easy it is for you to access mental health services and also be willing to talk about things like mental health"* YP4: *"Our experiences shape us. Our points of view shape us. Our belief system shape us. If you were raised to feel guilt about not being mentally well you are going to carry that forever."* YP5 *"I think I really am a product of the cultural experiences that I've had umm being both British and Pakistani*
Fear of medication overprescriptio n in Pakistanis	YP4: *"Umm there is a lot of stigma against the prescription of medicine. Umm, and in some ways I believe rightfully so, just because we have an issue in Pakistan and in the U S and around the world at the moment where we are being overprescribed* PARENT1 *"In Pakistan it's very difficult. As I said, they're very few people… in the previous generation I think there was just one or two that I knew about and they were totally robbing people and nobody knew any better. At that time, medicine was also really dangerous"*
Generational shift to more positive mental health views	YP2: *"I think slowly we're becoming more and more open to what the reality is of mental health and how getting help can make it better"* PARENT1: *"Yeah, so yeah, there's not much acceptance, there's not much acceptance still, but it's better than from the last generation, I would say."*
Social networks influence help-seeking	
Peers as supportive and accepting	YP1: *"always sort of verbally appreciated me sort of talking about how I'm feeling, and that's really influenced me because you know umm I know what a good sort of active listening relationship is… I can give that to other people as well umm because I know how it*

	feels." YP5: *"I think that umm he definitely shaped my attitude and was really supportive when I decided to contact the counselling services and… and definitely like was a big motivating factor in that too, because he pointed it out to me in the first place."*
Family support is valued	YP3: *"he was definitely she picked up on it and I think would mention it to my paediatric doctor when we went in for like appointments and she spoke to her and then my doctor referred me over to the psychologists."* YP4: *"my immediate family was my support system"* YP5: *think personally my family have not been able to support the mental health support that I need because they don't understand it and I don't feel comfortable talking to them about it because I felt that they minimised it for a long time"*
Support in academic settings can be pivotal	YP1: *"Umm but in terms of school yeah definitely a few teachers were umm… supporting me in umm… the school counsellor was the main person I think but then going into sixth form when these things were really getting in the way* YP4: *"At Oxford, I don't know if people have figured it out yet. I think we're just all running all the time so I don't know if we even have a second to take a breath and say like "can we get help?"."* PARENT1: *"But they were paying extra special attention to her, and so when X had some trouble, she went to one of her teachers. And he recommended a… a friend of his.*
Talking to people with lived experience is empowering and daunting	YP1: *"I would be quite admirable, you know I'd find that quite admirable… and empowering you know when other people talk about their mental health issues"* YP2: *"and then the other thing with my friends was that they were all like therapy's useless and it's kind of like so everyone's just in that mindset where they just don't want to go to therapy"* YP3 *"umm a lot of my friends have also gone and seeked help with like pression and stuff I think literally all my friends close friends have seeked help from like a psychologist"*
Education and awareness	
Good mental health literacy is necessary for help-seeking	YP1: *"I think I sort of did the classic sort of… umm… am I anxious umm… questionnaire on sort of BuzzFeed or something online or I umm… you know saw people in tv shows experiencing it and I was like ohh okay this is similar to what ''m experiencing so that's how I thought ok is it anxiety"* PARENT2: *"as a young person at first they've got to realise what the problem is and what they're suffering. Maybe they don't understand that. Umm and then where do they go?*
Importance of open conversations	YP1: *"sort of realising that umm I don't need to hide it, I don't need to hide my symptoms"* YP4: *"I think it is important to talk about it because also when you*

about mental health	*don't talk about it you make it worse in your head and then you do get stuck whereas when you talk about it and gaining perspective from someone else that helps so I think i''s a really positive thing"*
Education on MHPs and services is powerful	YP3: *"in schools like maybe having like groups and kind of discussing it would be a bit like I know it's spoke about in like PHSE but it's not as widely. And I think from a younger age as well"*
Internalised stigma	
Negative views of MHPs and help-seeking	YP1: *"I also had this kind of just internal voice this really self-critical voice that was always being like oh you're just making this up, oh you're diagnosing yourself, this is not, this is not true"* YP6: *"I go back and forth on the need for more kind of treatment or help or umm speaking about more about it, but then I also am very much someone who's very independent and I'm like let me just read online about things that can help and let me try that out first and let me see if a half an hour walk instead of a 15 minute walk will help"*
Fear of the community response	YP1: *"that can be really tough for some people to actually just process… umm especially if you're going through adolescence and you know you just want your peers to like you, you don't want to be different.* YP4: *"yeah a lot of their families will stigmatise them"*
Worries about their professional reputation	YP5: *"Umm, I wouldn't say so because in… in professional or academic environments, I wouldn't… I wouldn't try to make it umm known that I was dealing with these things."* YP6: *"I can speak from my own, like my own feelings and what I seem to perceive from other people is that there's a fear around the implications and the repercussions of of speaking to people. A) in terms of having a label put on you umm and even if not within society within the health service and your engagement with the health service."*
Religion promotes help-seeking	
Religion promotes help-seeking	YP2: *"I personally think that turning to religion is something 'hat's helped me in terms of like getting help and things like that"* PARENT1: *"Islam encouraged me to do what I'm doing now. And had I stayed with culture, I would be more restricted."* YP5: *"When I was a religious person, I haven't been deterred from seeking mental health support because of that, it's only been because of the umm cultural influences and the way that that's been like, been come to understand that has stopped me."*
Culturally-informed services important	

Cultural awareness among staff is valued .	YP1: *"she asked sort of meaningful questions about "okay you know I'm just trying to understand a little bit more about, about this could you explain that a little bit?" or you know umm "what does that mean to you?". I think those little things make you feel heard, make you feel seen as well, umm, so that your… the cultural part of your experiences which is part of all of our identity's'isn't ignored."* YP4: *"I think that would be useful for professionals like yourself to be able to skim the literature and be like okay these things might come up and these are sensitive points so we should like ask these questions"* YP5: *"so some of the advice I was given was to speak to my family about these problems and when I did, it was coming up against a brick wall because they don't understand where I'm coming from. So that wasn't a method that was really going to be helpful.*
Care that matches preferences is valued	YP2: *anonymous chat boxes or like being able to refer yourself things like that make a huge difference because it is harder in person I think to talk about it is easy when'you're hiding behind a screen"* YP5: *"I think in person because it just feels more human to be able to talk to somebody face to face."* YP6: *"You play a role and you have a… you get a say in kind of who speak to and who you engage with would definitely encourage people I think."*
Systemic issues hinder access to healthcare	
Systems difficult to navigate .	YP3: *"well for me it was quite simple because I went just to the hospital, but one of my friends she was like referred to like CAMHS for like children and they were like "sorry we can't help you" and she just kept getting referred back and forth and it was like no one was really like taking her. So I think that's a bit of an issue trying to find out where to go."* PARENT2: *"I think it's a nightmare." (navigating services)*
Service pressures reduce accessibility	YP1: *"he referred me to CAMHS to have an assessment umm and I did have an assessment but they couldn't offer me any treatment at the time."* YP3' *"I'm still on the list for another guy who's in adults and I think I've been in that list for nearly a year now."* YP4: *"like have you listened to this ebook and it cost 60 pounds was like first I'm not paying £60.00 for an ebook and secondly I don't want an e-book."*

Appendix I

SIP: CUREC University of Oxford Ethics Approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE

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

CONFIDENTIAL

Dr Louise Johns & Chiara Causier
20 September 2022
Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre
Warneford Hospital
Oxford

Dear Dr Johns and Chiara,

Research Ethics Appro–al - CUREC 2 Ethics Approval Reference: R81751/RE001

Study title: Improving access to secondary mental health services for young women of Pakistani backgrounds – a qualitative study

Short title: Improving access to mental health services for young Pakistani women

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

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing o^{n} **20th September 2022.**

You will be required to submit an annual progress report on each anniversary of study approval, until the study is completed, and your study may be selected for review during an annual audit.

Amendments

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

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for

Dr Helen Barnby-Porritt Research Ethics Manager

Appendix J

TDRP: Author Guidelines for *Behaviour, Research and Therapy*

Submission
Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail. Submit your article Please submit your article via https://www.editorialmanager.com/BRAT

Queries
For questions about the editorial process (including the status of manuscripts under review) or for technical support on submissions, please visit our Support Center.

Peer review
This journal operates a single anonymized review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor’s decision is final. Editors are not involved in decisions about papers which they have written themselves or have been written by family members or colleagues or which relate to products or services in which the editor has an interest. Any such submission is subject to all of the journal's usual procedures, with peer review handled independently of the relevant editor and their research groups. More information on types of peer review.

Preparation
While full-length articles have no explicit limits in terms of numbers of words, tables/figures, and references, an article’s length must be justified by its empirical strength and the significance of its contribution to the literature

Article structure
Subdivision - unnumbered sections
Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when crossreferencing text: refer to the subsection by heading as opposed to simply 'the’text'.

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

Essential title page information
• Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
• Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author’s name and in

front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
• Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.
• Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time‘, a 'Present address''(or 'Permanent address') may be indicated as a footnote to that author’s name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Highlights
Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please ‘use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract
A concise and factual abstract is required with a maximum length of 200 words. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Graphical abstract
Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Keywords
Immediately after the abstract, provide a maximum of 6 keywords, to be chosen from the APA list of index descriptors. These keywords will be used for indexing purposes.

Abbreviations
Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements
Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.). Formatting of funding sources List funding sources in this standard way to facilitate compliance to f’nder's requirements:

Funding:
This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Shorter communications
This option is designed to allow publication of research reports that are not suitable for publication as regular articles. Shorter Communications are appropriate for articles with a specialized focus or of particular didactic value. Manuscripts should be between 3000-5000 words, and must not exceed the upper word limit. This limit includes the abstract, text, and references, but not the title page, tables and figures.

Artwork
Electronic artwork
General points
• Make sure you use uniform lettering and sizing of your original artwork.
• Embed the used fonts if the application provides that option.
• Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
• Number the illustrations according to their sequence in the text.
• Use a logical naming convention for your artwork files.
• Provide captions to illustrations separately.
• Size the illustrations close to the desired dimensions of the published version.
• Submit each illustration as a separate file.
• Ensure that color images are accessible to all, including those with impaired color vision.
A detailed guide on electronic artwork is available. You are urged to visit this site; some excerpts from the detailed information are given here.

Formats
If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply ’’s is' in the native document format. Regardless of the application

used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below): EPS (or PDF): Vector drawings, embed all used fonts. TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi. TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi. TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

• Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
• Supply files that are too low in resolution;
• Submit graphics that are disproportionately large for the content.

Tables

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

References

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

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Preprint references Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

Reference management software

Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley. Using citation plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the ’journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes from different reference management software.

Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Seventh Edition, ISBN 978-1-4338-3215-4, copies of which may be ordered online.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letter‘ ’a'‘ ’b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. Journal of Scientific Communications, 163, 51–59. https://doi.org/10.1016/j.sc.2010.00372.

Reference to a journal publication with an article number:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2018). The art of writing a scientific article. Heliyon, 19, Article e00205. https://doi.org/10.1016/j.heliyon.2018.e00205. Reference to a book: Strunk, W., Jr., & White, E. B. (2000). The elements of style (4th ed.). Longman (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), Introduction to the electronic age (pp. 281–304). E-Publishing Inc.

Reference to a website: Powertech Systems. (2015). Lithium-ion vs lead-acid cost analysis. Retrieved from http://www.powertechsystems.eu/home/tech-corner/lithium-ion-vs-lead-acid-cost-analysis/. Accessed January 6, 2016

Reference to a dataset: [dataset] Oguro, M., Imahiro, S., Saito, S., & Nakashizuka, T. (2015). Mortality data for Japanese oak wilt disease and surrounding forest compositions. Mendeley Data, v1. https://doi.org/10.17632/ xwj98nb39r.1.

Reference to a conference paper or poster presentation: Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.

Reference to software: Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S. (2020, March 25). Advanced Terrestrial Simulator (ATS) v0.88 (Version 0.88). Zenodo. https:// doi.org/10.5281/zenodo.3727209.

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Appendix K

TDRP: Full list of Inclusion and Exclusion Criteria

Inclusion:

- A score of 40+ on the Obsessive-Compulsive Inventory (OCI)
- A score of 2 or more in 3 of Q1-Q10 or Q13 in the ReSQ-Intensity Scale
- Being a resident in the UK/ROI
- Being aged 18+
- Speaking and understanding fluent English
- Access to a technological device
- Asking others for support with obsessional thoughts

Exclusion:

- Diagnosis of psychosis, personality disorder, or moderate-severe autism
- Experiencing dementia, amnesia, delirium

Appendix L

TDRP: Reassurance Seeking Questionnaire (ReSQ); Kobori & Salkovskis, 2013

L.a. ReSQ Source Subscale

with permission from Professor Paul Salkovskis

1-1. "Who do you seek reassurance from?"

The questions below are about how you react when you are worried or anxious, and concern ways in which you might try to be reassured or to reassure yourself.

Please note that these questions are repeated 3 times with a different emphasis. **Firstly, please rate how you <u>USUALLY</u> react using the scale below.** Put a circle round the number at the right hand side of the question.

Never (0) Rarely (1) Sometimes (2) Often (3) Very often (4) Always (5)

(1)	I ask reassurance from my family	0 1 2 3 4 5
(2)	I ask reassurance from my partner	0 1 2 3 4 5
(3)	I ask reassurance from people close to me	0 1 2 3 4 5
(4)	I ask reassurance from people I know	0 1 2 3 4 5
(5)	I ask reassurance from mental health professionals	0 1 2 3 4 5
(6)	I ask reassurance from strangers	0 1 2 3 4 5
(7)	I ask reassurance from technical professionals (e.g., electrician, plumber etc.)	0 1 2 3 4 5
(8)	I ask reassurance from religious authority (e.g., clergy, priest, rabbi)	0 1 2 3 4 5
(9)	I ask reassurance from my therapist	0 1 2 3 4 5
(10)	I ask reassurance from my family doctor	0 1 2 3 4 5
(11)	I seek reassurance from websites	0 1 2 3 4 5
(12)	I seek reassurance from books	0 1 2 3 4 5
(13)	I seek reassurance from notes I have taken in the past	0 1 2 3 4 5
(14)	I rephrase the reassurance I already had in my mind	0 1 2 3 4 5
(15)	I keep telling myself that there is nothing to worry about	0 1 2 3 4 5
(16)	I try to reassure myself by thinking over what I've done in the past	0 1 2 3 4 5
(17)	I try to get someone to be with me when I worry about something	0 1 2 3 4 5
(18)	I get other people to watch me when I do things which worry me	0 1 2 3 4 5
(19)	When I have a worrying thought I feel reassured if I've said it out loud in front of others	0 1 2 3 4 5
(20)	I try to watch the way other people react when I do things which worry me	0 1 2 3 4 5
(21)	I ask others to do things as a way of reassuring me	0 1 2 3 4 5

L.b. ReSQ Intensity Subscale

1-3. "How much reassurance do you seek?"

Thirdly, when you are worried or anxious, how OFTEN do you respond in the way specified? In other words, **how many times do you seek the same reassurance until you stop?** Please now rate each item using the scale below.

For the item which you do NOT use as reassurance, put a circle round N/A

Never (0) Only Once (1) Twice or Three Times (2) Four to Six Times (3) Many Times (4)

(1)	I ask reassurance from my family	N/A 0 1 2 3 4
(2)	I ask reassurance from my partner	N/A 0 1 2 3 4
(3)	I ask reassurance from people close to me	N/A 0 1 2 3 4
(4)	I ask reassurance from people I know	N/A 0 1 2 3 4
(5)	I ask reassurance from mental health professionals	N/A 0 1 2 3 4
(6)	I ask reassurance from technical professionals (e.g., electrician, plumber etc.)	N/A 0 1 2 3 4
(7)	I ask reassurance from religious authority (e.g., clergy, priest, rabbi)	N/A 0 1 2 3 4
(8)	I ask reassurance from my therapist	N/A 0 1 2 3 4
(9)	I ask reassurance from my family doctor	N/A 0 1 2 3 4
(10)	I ask reassurance from people even if I know what they are likely to say when I ask them	N/A 0 1 2 3 4
(11)	I seek reassurance from websites	N/A 0 1 2 3 4
(12)	I seek reassurance from books	N/A 0 1 2 3 4
(13)	I seek reassurance by using my phone to call people	N/A 0 1 2 3 4
(14)	I keep telling myself that there is nothing to worry about	N/A 0 1 2 3 4
(15)	I try to reassure myself by thinking over what I've done in the past	N/A 0 1 2 3 4
(16)	I try to reassure myself by checking what I recall in my head	N/A 0 1 2 3 4

Appendix M

TDRP: Study Vignettes

Reassurance Vignette
You are at home, watching your favourite TV programme with [insert person]. It's beautiful and sunny outside and you have no plans for the weekend other than to relax and wind-down.

[T0 - ratings of effectiveness]

Suddenly, something triggers the intrusive thought that "[insert obsession]" and you begin to question things. You try to get this thought or doubt out of your head, but you cannot stop thinking about it. This continues for about 10 minutes as you try to carry on watching the TV with [insert person].

[T1 - ratings of effectiveness]

After a further 5 minutes, you feel like you are not able to get rid of the thought on your own, so ask [insert person] for reassurance by saying [insert question] and [insert person] then provides reassurance, saying [insert reassurance].

[T2 - ratings of effectiveness]

20 minutes have now passed since your [insert person] gave you this reassurance.

[T3 - ratings of effectiveness]

Support Vignette
You are at home, watching your favourite TV programme with [insert person]. It's beautiful and sunny outside and you have no plans for the weekend other than to relax and wind-down.

[T0 – ratings of effectiveness]

Suddenly, something triggers the intrusive thought that "[insert obsession]" and you begin to question things. You try to get this thought out of your head, but you cannot stop thinking about it. This continues for about 10 minutes as you try to carry on watching the TV with your [insert person].

[T1 – ratings of effectiveness]

After a further 5 minutes, you feel like you are not able to get rid of the thought on your own, so you ask [insert person] for emotional support to deal with the distress that this intrusive thought is causing you by saying "[insert request for emotional support]". ` [Insert person] then provides this, saying [insert support].

[T2 – ratings of effectiveness]

20 minutes have now passed since your loved one said this to you during which they've been [insert specific emotional support] and giving you emotional support.

[T3 – ratings of effectiveness]

Appendix N

TDRP: Visualisation/ Grounding Exercises

Option 1: Guided Beach Visualisation

Begin by finding a comfortable position either sitting or lying down in a location where you will not be interrupted.

Take a deep breath through your abdomen, hold for a few seconds, and exhale slowly. As you breathe, notice your stomach rising and your lungs filling with air.

Breathe in…and out

As you exhale, imagine the tension in your body being released and flowing away.

Inhale… exhale. Feel your body already relaxing.

As you go through each step, remember to keep breathing.

Inhale…exhale

Feel your body releasing all the tension, becoming relaxed, calm, peaceful. Feel the weight of your body, the limpness of your arms and legs. A wave of relaxation is flowing from your head, down to your neck, chest, back, arms, legs, and feet.

Now imagine yourself walking towards a quiet, inviting beach. You notice the white sand stretching along the shoreline as far as you can see.

You begin to feel the warmth of the sun across your face. You stand there a moment and just take in the warmth; you feel it flowing all through your body.

Breathe in…and out

As you walk in the sand, you feel its warmth on your feet, while at the same time feeling the coolness of the ocean breeze on your skin.

You gaze at the ocean and see a deep shade of blue with white crests of waves sweeping towards the shore.

You take a moment to watch the beauty of the ocean. You hear the calm breaking of the waves. The waves are washing up onto the sand and receding back towards the ocean… washing up…and flowing back…washing up…and flowing back.

You listen to the calming rhythm of the waves. You take a deep breath in and can smell the cleanness of the salty air…and exhale. You allow yourself to appreciate the soothing scent of ocean air. You begin to walk slowly towards the water.

As you step closer to the ocean, you can feel the firmness of the wet sand. The cool, soft ocean water sweeps across your feet, relieving you from the heat of the sun. With every touch of water to your skin, you feel more and more relaxed.

Breathe in…and out

You begin to leisurely walk along the shoreline.

All of your tension has melted away.

Breathe in…and out Pause for a few seconds

Breathe in…and out Pause for a few seconds

When you are ready to return from your vacation, do so slowly. Gently bring your attention back to the room, still feeling relaxed and comfortable. As you bring yourself back to a level of alertness, keep that relaxation in your mind and body. Open your eyes, stretch, and feel refreshed.

Option 2: 5, 4, 3, 2, 1 grounding

This technique will take you through your five senses to help remind you of the present. This is a calming technique that can help you get through tough or stressful situations.

Take a deep belly breath to begin.

5 - LOOK: Look around for 5 things that you can see and say them out loud. For example, you could say, I see the computer, I see the cup, I see the picture frame.
4 - FEEL: Pay attention to your body and think of 4 things that you can feel and say them out loud. For example, you could say, I feel my feet warm in my socks, I feel the hair on the back of my neck, or I feel the pillow I am sitting on.
3 - LISTEN: Listen for 3 sounds. It could be the sound of traffic outside, the sound of typing or the sound of your tummy rumbling. Say the three things out loud.
2 - SMELL: Say two things you can smell. If you're allowed to, it's okay to move to another spot and sniff something. If you can't smell anything at the moment or you can't move, then name your 2 favourite smells.
1 - TASTE: Say one thing you can taste. It may be the toothpaste from brushing your teeth, or a mint from after lunch. If you can't taste anything, then say your favourite thing to taste.
Take another deep belly breath to end.

Appendix O

TDRP: CUREC University of Oxford Ethics Approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE

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

CONFIDENTIAL

Professor Paul Salkovskis & Chiara Causier
Oxford Institute of Clinical Psychology Training & Research (OXICPTR)
Isis Education Centre
Warneford Hospital
Oxford

18 May 2022

Dear Professor Salkovskis and Chiara,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R79097/RE001

18 May 2022

Study title: The effectiveness and acceptability of receiving support vs reassurance in OCD: an experimental investigation

Short title: Understanding the consequences of support vs reassurance in OCD

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

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of 18 **months**, commencing on **18th May 2022.**

Amendments

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

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for

Dr Helen Barnby-Porritt Research Ethics Manager