

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

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A qualitative exploration of working with Panjabi speakers in Buckinghamshire Memory Clinic

Theoretically Driven Research Project (TDRP) 5, 058 words

Stigma and its Impact on Seeking Professional Psychological Help – Are there Cultural Differences?

Executive Summary 964 words

Connecting Narrative 995 words

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Abstracts

CRL

A systematic narrative review of the shared mechanisms in substance abuse and eating disorders

Objective: Eating disorders (ED) and substance use disorders (SUD) have high rates of comorbidity and the highest mortality rates of any mental health disorders. Several reasons for the comorbidity have been suggested. The aims of this review were to synthesise the research evidence for comorbid ED and SUD and evaluate the quality of the studies.

Methods: Six databases were searched, using terms related to ED, SUD, and psychological mechanisms. The search yielded 3,725 papers. 20 papers met inclusion criteria. Data on the measures used and mechanisms explored was extracted, and the quality of each paper was rated by two independent raters. Findings were synthesised in a narrative review.

Results: Of the 20 papers, five papers measured DSM-5 Axis II personality pathology and showed mixed results, with evidence for clusters A, B and C in both disorders. Twelve papers measured various personality temperaments or dispositions. Impulsivity and novelty seeking were two aspects of personality traits repeatedly linked to comorbid ED and SUD. Five papers explored emotional regulation and showed individuals with comorbidity are more likely to struggle with emotional regulation skills.

Conclusion: Papers focusing on personality pathology and traits failed to propose specific mechanisms for how ED-SUD comorbidity occurs. Personality traits are not considered modifiable and therefore do not readily lead to treatment targets. Emotional regulation-based factors used schema-based models and proposed several treatment options. Future research should focus on schema (and related cognitive) based models.

Keywords: Eating disorders; substance use disorders; comorbidity; impulsivity

SIP

A qualitative exploration of working with Panjabi speakers in Buckinghamshire Memory Clinic

Introduction: Government reports have highlighted the rising rates of dementia in Black, Asian and Ethnic Minority individuals. However, many ethnic minority groups face barriers in accessing memory services, and often feel services are not set up for them. South Buckinghamshire Memory Clinic aimed to explore the needs and views of non-English speaking Panjabi individuals, to consider how they might best work with this group.

Methods: Semi-structured interviews were carried out with eight Panjabi speaking members of the local community, aged between 55 and 76 years old. The authors also conducted focus groups and interviews with staff from the memory clinic to explore their experiences of working with Panjabi speaking service users.

Results: Thematic analysis of the data revealed four key themes for community members: wanting to be around “people like us”; negative views of memory difficulties; believing services “don’t have things for people like us”; and valuing professional help. Data from staff members revealed six key themes: A desire to be person-centred; staff don’t always feel confident; family members want to be helpful; having a choice in interpreters; difficult to keep tests reliable and valid; and using flexible approaches to gathering information.

Discussion: This study made several recommendations for South Buckinghamshire Memory clinic including use of second languages in the staff team to support assessments, using resources specifically made for Panjabi individuals, and being mindful that families may not want an interpreter, but service users may still benefit from being offered one.

TDRP

Stigma and its Impact on Seeking Professional Psychological Help – Are there Cultural Differences?

Introduction: Individuals from a South Asian background are thought to utilise mental health services less often than other individuals. Literature has suggested several barriers to accessing mental health support, one being stigma. Corrigan et al.'s *Why Try?* model is used to understand perceptions of stigma from others (public stigma) and stigma towards the self (self-stigma). This paper aims to explore whether a population of South Asian individuals has more negative views towards seeking professional psychological help, when compared to White British individuals, and whether stigma or acculturation play a role in this.

Methods: An online questionnaire was used to gather data on people's attitudes towards seeking professional psychological help, views on self-stigma, perceptions of public stigma and levels of acculturation.

Results: There were no differences in attitudes towards seeking professional help between the two groups. Public stigma was not associated with attitudes to seeking help, however greater self-stigma was associated with poorer attitudes to seeking help, regardless of culture. Acculturation impacted the relationship between public stigma and attitudes to seeking help only.

Conclusion: This paper adds a novel contribution in its recruitment of individuals who have experienced mental health difficulties. The paper highlights the importance of looking at other barriers outside of public or self-stigma to understand why South Asian individuals may be underrepresented in mental health services.

Critical review of the literature

A systematic narrative review of the shared mechanisms in substance abuse and eating disorders

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Proposed Journal: This report is intended for submission to the International Journal of Eating Disorders and has been written and formatted in accordance with this (Appendix 1A). This journal has been selected as it is recognised for publishing papers related to eating disorders and their comorbidities, and similar methodologies have been published by this journal.

Abstract

Objective: Eating disorders (ED) and Substance use disorders (SUD) have high rates of comorbidity and the highest mortality rates of any mental health disorders. Several reasons for the comorbidity have been suggested. The aims of this review were to synthesise the research evidence for comorbid ED and SUD and evaluate the quality of the studies.

Methods: Six databases were searched, using terms related to ED, SUD, and psychological mechanisms. The search yielded 3,725 papers. 20 papers met inclusion criteria. Data on the measures used and mechanisms explored was extracted, and the quality of each paper was rated by two independent raters. Findings were synthesised in a narrative review.

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Conclusion: Papers focusing on personality pathology and traits failed to propose specific mechanisms for how ED-SUD comorbidity occurs. Personality traits are not considered modifiable and therefore do not readily lead to treatment targets. Emotional regulation-based factors used schema-based models and proposed several treatment options. Future research should focus on schema (and related cognitive) based models.

Keywords: Eating disorders; substance use disorders; comorbidity; impulsivity

Introduction

Eating disorders (ED) and substance use disorders (SUD) have the highest mortality rates of any mental health disorder (Chesney et al., 2014; Franko et al., 2005). The overlap presents a serious challenge for clinicians, yet little is understood about the mechanisms that underlie their comorbidity.

EDs are estimated to affect 1% of the population in high-income countries (Zipfel et al., 2015). They occur most commonly in younger women, with peak onset between 16 and 20 years of age (Wood et al., 2019). Substance abuse, which encompasses alcohol abuse and legal and illegal substance abuse, is estimated to affect one in four individuals with an ED (Bahji et al., 2019). The lifetime prevalence of substance abuse in individuals with anorexia nervosa (AN) is estimated to be between 12 to 18%, and between 30 to 70% in bulimia nervosa (BN) (Devoe et al., 2021; Pearlstein, 2002). A national survey in America showed a significant association between all EDs, including AN, BN, binge eating disorder (BED) and sub-clinical binge eating, and all types of substance abuse including alcohol dependence and illicit substance dependence (Hudson et al., 2007).

When both an ED and substance abuse are present, outcomes are worse, with greater functional impairments and higher mortality rates (Glasner-Edwards et al., 2011; Pearlstein, 2002). Reviews of prevalence have suggested that the link between EDs and substance abuse is strongest in BN, and weakest in AN (Bahji et al., 2019; Calero-Elvira et al., 2009; Gadalla & Piran, 2007; Harrop & Marlatt, 2010). However, less is known about the mechanism(s) underlying this comorbidity.

Several models have been proposed, however, they have received significant criticism. For example, addiction models (Cooper, 1989) are considered out-dated, and rooted solely in addiction literature without accounting for mechanisms specific to EDs such as eating

disorder cognitions (Polivy & Herman, 2002; Schulte et al., 2016). Genetic models (e.g. (Peveler & Fairburn, 1990; Von Ranson et al., 2003) have not been able to show genetic factors with shared risk or vulnerability. Biological models (Murray et al., 2014) have mostly been conducted using animal studies and on the effects of starvation; such studies cannot be easily generalised to human beings and cannot explain the high rates of comorbidity with BN or BED (Shapiro, 1998).

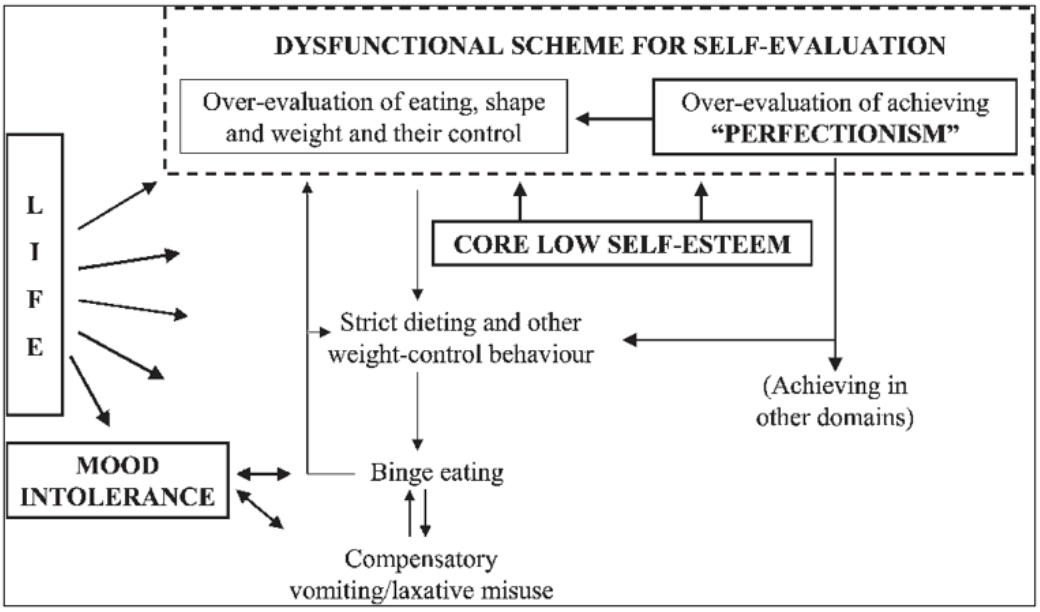
Psychological models have focused on differences in temperament and personality. One aspect of temperament that has been studied extensively in comorbid EDs and substance abuse is impulsivity (Calero-Elvira et al., 2009). Several definitions for impulsivity have been proposed, and various measures developed. However, an agreed definition or theory of how impulsivity might function is lacking (Bakhshani, 2014). It has been suggested it is a cognitive process, part of executive functioning, and manifests in an inability to inhibit behaviours or cognitions (Chudasama, 2011). Elsewhere, it has been suggested it is an innate personality characteristic to *make up one's mind quickly* (Eysenck, 2004). Impulsivity is higher in some subtypes of EDs than others (Dawe & Loxton, 2004). Comorbid SUDs also tend to be higher in subgroups found to be more impulsive on measures, for example, in BED (Bahji et al., 2019). This supports the idea that impulsivity may function as a shared mechanism in at least some EDs and substance abuse.

Other studies have suggested novelty-seeking (Del Pino-Gutiérrez et al., 2017), shared impulsivity or reward sensitisation (Calero-Elvira et al., 2009) or experiential avoidance (Elmquist et al., 2018) could all be important aspects of a shared temperament in EDs and substance abuse. However, overall there does not appear to be a single or comprehensive psychological model in the literature, and it is not clear how these proposed temperaments or characteristics might fit together as a shared mechanism.

The transdiagnostic cognitive theory of EDs (Fairburn et al., 2003) could provide a useful framework to explain substance abuse comorbid with EDs. Within the cognitive framework, (*Figure 1*), life stressors lead to changes in mood, and intolerance of mood states (as often seen in EDs) leads to binge or restrictive behaviours. Several studies have recently suggested substance abuse serves the same function - to manage difficult moods or emotions such as anger and to help regulate mood or affect (Crawford, 2014; Lavender et al., 2015; Wakeford et al., 2018). This explanation, which incorporates EDs more fully, has been less investigated but is arguably a more comprehensive explanation for the comorbidity of EDs and substance abuse.

Figure 1

A schematic representation of the extended cognitive behavioural theory of the maintenance of bulimia nervosa, from Fairburn et al., (2003).



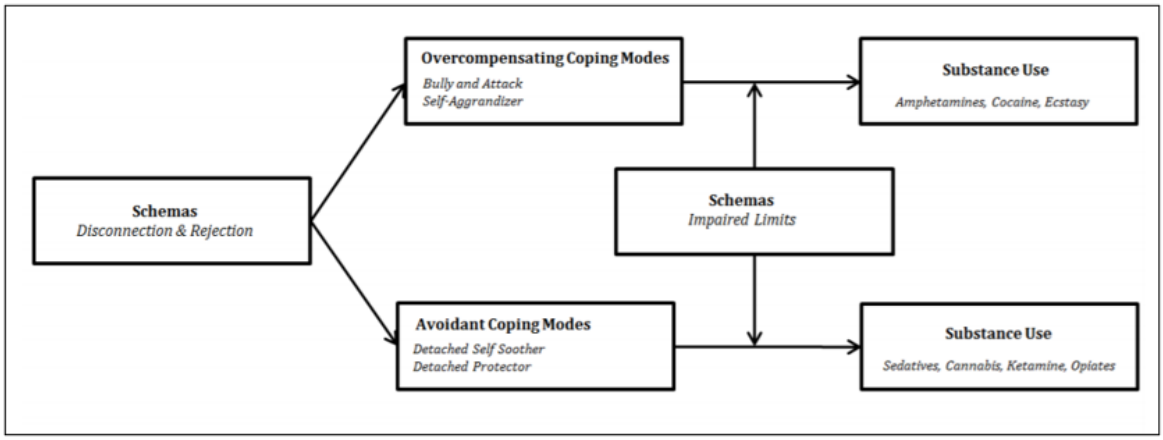
Note. Life is shorthand for interpersonal life.

Cognitive models have also been proposed for substance abuse. Tiffany (1990)'s model suggested that a combination of emotional states and drug urges or cravings lead to drug-use behaviours, however the concept of "urges" has been contested, and the role of emotional states is thought to be necessary but not sufficient.

Schema based models are more similar to the ED models proposed above; schema-based models for substance use suggest early maladaptive schemas lead to experiences of negative affect, and substance abuse serves as a coping strategy to avoid these emotional states (Straver, 2017) (Figure 2). There is some limited evidence that schema models can explain substance abuse (Knapík & Slancová, 2020). There is some support for this more recent hypothesis. In survivors of childhood trauma, affect dysregulation appears to be a key mechanism in the development of both substance abuse and BN (Crawford, 2014).

Figure 2

The moderated mediation model of schemas, coping modes and substance abuse (Straver, 2017).



Several reviews have attempted to synthesise the psychological literature thus far (Harrop & Marlatt, 2010; Wolfe & Maisto, 2000). These reviews have several limitations including the small number of databases searched, (only two in Wolfe & Maisto, 2000); the exclusion

of key papers, such as those looking at individuals with BED only, BN only or males only (Harrop & Marlatt, 2010); the lack of quality appraisal of the selected papers; and the fact that all the reviews are now more than 10 years old, and a number of relevant papers have been published in the intervening years. Another review focused on risk factors and associations, but did not explore mechanisms (Eskander et al., 2020). An updated, high-quality, comprehensive, and robust review of the literature on the psychological mechanisms underlying comorbid EDs and substance abuse is thus timely and needed. It is also important to critically evaluate the evidence for the proposed mechanisms and discuss its implications for the relevant theories.

The current review will aim to address the following questions:

I. What psychological mechanisms can explain the comorbidity between EDs and substance abuse?
II. What evidence supports the existence of these mechanisms and thus theories?
III. What is the quality of the evidence?

Through answering these questions, it is hoped this review will offer guidance for future research in terms of which mechanisms may be most relevant to consider, identify where more research is needed, and explore where psychological treatment might best be targeted when EDs and substance abuse are comorbid.

Methods

Search Strategy

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Based on the most recent systematic review of prevalence rates of comorbid substance abuse and eating disorders (Bahji et al., 2019), six electronic databases were searched: PubMed, MEDLINE, PsycINFO, CINAHL, Cochrane and EMBASE. The search terms used are listed in *Table 1* (Appendix 1B). The search was carried out in November 2020 (the search was updated in May 2022 and revealed no new relevant papers). This review was registered on the PROSPERO website (CRD42020200742).

Eligibility criteria

Papers were included if they:

I. were available in the English language
II. were peer-reviewed
III. used human participants only
IV. measured ED behaviours in either clinical or non-clinical samples using a validated ED symptom measure or diagnostic screening questionnaire/interview
V. measured substance abuse behaviours in either clinical or non-clinical samples using a validated substance use symptom measure or diagnostic screening questionnaire/interview
VI. measured or assessed a relevant psychological construct or potential mechanism.

Papers were excluded if they:

I. used animal models
II. included individuals under the age of 10 years
III. did not study psychological constructs (potential mechanisms)
IV. did not specify how eating disorder behaviours were conceptualised – e.g. "binge eating" was not assessed using a validated ED symptom or diagnostic measure
V. only looked at laxative use, diuretic use, or insulin abuse (these are considered used for the purpose of aiding weight loss and thus less likely to have a psychological function, and are also not psychoactive) (Bulik et al., 1990)
VI. did not look at comorbid substance abuse and ED symptoms or diagnoses
VII. purely qualitative studies.

Study selection

The systematic review process is summarised in the PRISMA flowchart (*Figure 3).* The combined search of all six databases retrieved 5,608 papers, yielding 3,725 papers following removal of duplicates. The first author searched all abstracts and titles to ensure they met eligibility criteria. A second rater screened a subset of the papers (20% of papers). At this stage, inter-rater reliability was deemed high (Cohen's $k = 0.99$, 95% CI 0.995 to 0.985, $p < 0.001$), therefore the remaining abstracts and titles were screened by the first rater only.

Full-texts of the 40 papers that met eligibility criteria were then hand-screened to further check suitability. *Figure 3* illustrates reasons for excluding papers at this stage. As a complement to this search, the author performed backward searches (i.e., examining reference lists of eligible studies) which retrieved two further papers. In total, 20 papers were used in this review.

Data extraction and quality assessment

A data extraction tool was created to ensure reliable and consistent data extraction from each study. Data on study setting, type of ED population, type of substance abuse population, and psychological mechanism measured were extracted by the first author. Full data extracted can be found in *Table 2*.

The quality of each paper was assessed using the Standard Quality Assessment Criteria (Kmet et al., 2004). This tool consists of 14 questions examining broad areas of research, including strength of design, adequate sampling and power, and appropriateness of conclusions. Three items (concerning randomisation, and blinding) were excluded as they were not relevant to any of the papers here. The remaining 11 items were rated as either yes (2 points); partially met (1 point); or no (0 points) giving each paper a score out of 22. This measure does not provide any cut offs to define the quality of the paper. Two independent reviewers (RB and CG) rated each paper using the quality tool. Initial inter-rater reliability was poor (k = 0.40) and therefore a third independent reviewer (MC) was consulted. Each reviewer explained the reasons for their scoring. A document was created listing the items which caused discrepancies, and each rater explained their interpretation. The three raters then discussed each item until a standardised way of interpreting the questions was agreed (Appendix 1D). This led to a final moderate reliability score (k=.61).

This systematic review examines papers with various methodologies, including case-control, longitudinal and correlational studies. Due to the different methodologies, findings were synthesised using a narrative synthesis and organised according to the following broad groups: (a) personality pathology e.g. Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) personality disorder clusters(American Psychiatric Association, 2013); (b) non-pathological personality traits and characteristics e.g. impulsivity or reward dependence (n = 12); (c) emotional regulation, such as anger rumination and negative schemas (n = 5). Some studies were double counted as they explored more than one area, and

therefore the total number of studies does not equal twenty. The quality ratings of each study were incorporated with the synthesis of findings to summarise the overall strength of research in each area.

Figure 3

PRISMA flow diagram (Moher et al. 2009).

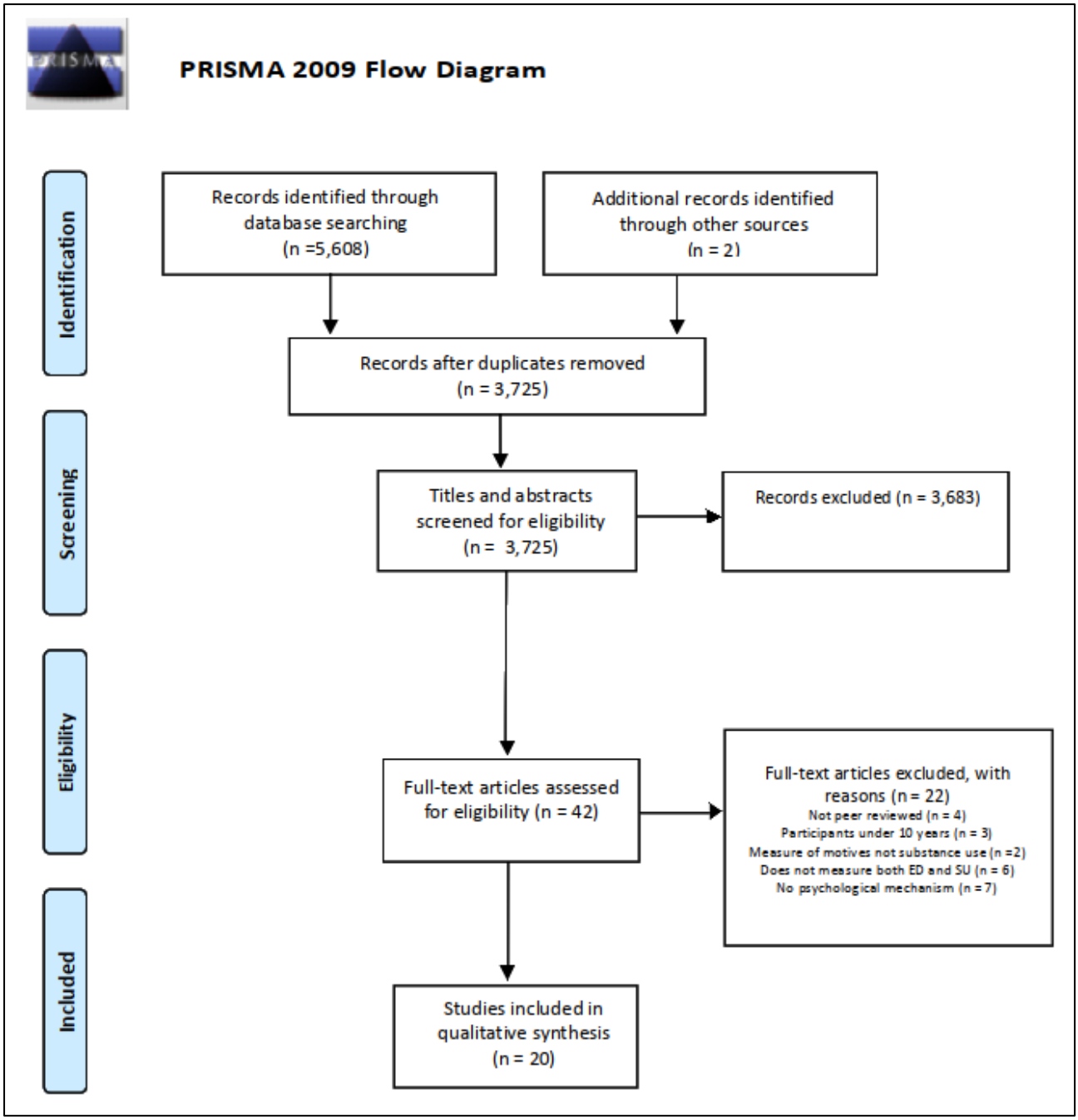


Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Baker et al. 2013	764 women with a lifetime diagnosis of AN; Mean age = 29.5 years (SD = 11.0; range 16–76)	AN	SCID-I; SIAB	Alcohol Use	SCID-I	Novelty Seeking, Harm Avoidance and Reward Dependence; Impulsivity; Anxiety	TCI-R; BIS; STAI-Y	Age; YBC-EDS; Y-BOCS
Becker & Grilo, 2015	347 patients, men (25%) and women (75%), Mean age = 44.7 years (SD = 9.2)	BED	SCID-I; EDE	SUD	SCID-I	Personality Disorders	DIPD-IV	BMI; EDE; BDI; RSES
Benjamin & Wulfert, 2005	335 female undergraduate students; Mean age = 19.6 years (SD = 1.8)	Binge eating symptoms	QEWP-R	Alcohol Use	CORE Alcohol and drug survey	Impulsivity; Tolerance of Deviance; Self-Esteem; Rejection Sensitivity; Extraversion–Introversion, Emotional Stability; Conscientiousness; Social Desirability	Eysenck Impulsiveness Questionnaire; HBQ; ISE; questionnaire by Downey and Feldman (1996); Goldberg's Mini-Markers Scale; Marlowe–Crowne Social Desirability—Short Form	-

Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Bulik et al., 1997	114 women who took part in a CBT-BN trial: age 17 to 45 years	BN	SCID	Alcohol Use	DSM-III criteria for alcohol dependence	Personality Characteristics; Personality Disorders	TCI-R; BIS; Defence style questionnaire; SCID-II	HDRS; GAF
Claudat et al., 2020	98 Patients. Mean age = 25.49 years (SD = 6.63)	AN; BN; EDNOS	SCID-5; EDE-Q	SUD	SCID-5	Emotional Regulation; Reward Sensitivity;	DERS; SPSRQ; BEST	Suicidality risk; STAI-T; BDI-II; Borderline personality disorder symptoms
Dir et al., 2003	430 Undergraduate students; (76.2% female); Mean age = 22.36 years (SD = 6.59)	ED Symptoms	EDE-Q		AUDIT	Negative Urgency	UPPS-P; Self Control Scale; Affective Lability Scale – Short-form	DSHI
Elmquist et al., 2015	519 patient records (387 men and 132 women); Mean age = 42.16 years (SD = 10.70)	Bulimia and binge-eating symptoms	ED subscale of the PDSQ	SUD	AUDIT; DUDIT	Early Maladaptive Schemas	YSQ-L3	Gender

Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Elmquist at al., 2018	108 Patient records from men receiving treatment for substance use disorders; Mean age = 34.5 years (SD = 10.1)	BN	ED subscale of the PDSQ	SUD	AUDIT; DUDIT	Experiential Avoidance; Psychological Inflexibility	AAQ-II	-
Fischer at al., 2012 (Study 1)	104 female patients (Mean age 21.97 years (SD = 4.37) in one group and 36.26 (SD = 9.86) in other)	Any ED diagnosis; ED symptoms	SCID-I; EDE	SUD	SCID-I	Impulsivity constructs including Negative Urgency; Alcohol Expectancy; Eating Expectancy	UPPS-R; AEQ; EEI; TREI	-
Kane et al., 2004	23 women with Dual diagnosis; 21 BN; 22 controls; Age range 18 to 34 years	BN	SCID-IV; EDI-2	Alcohol Use	AUDIT	Impulsivity	EIS; CARROT; BIS; BAS;	STAI

Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Krug et al., 2009	371 female Eating disorder outpatients, Mean age = 24.58 years (SD = 5.59)	AN-R, AN-B, or AN-B/P	DSM-IV-TR	Lifetime SUD	SCID-I	Novelty Seeking	TCI-R	ED Diagnosis; age of onset; BMI; education
Loxton & Dawe, 2001	232 high school girls (age range 16 to 18 years old)	Dysfunctional eating	EDI-2; Drive for thinness scale	Alcohol use	AUDIT	Behavioural Inhibition	BIS; BAS	-
Peterson et al., 2005	84 women with BED; Mean age = 40.9 years (SD = 10.9)	BED	SCID-P; BES	SUD	SCID-I	Self-Esteem; Personality	RSEQ; MPQ	HDRS;
Pino-Guiterraz et al., 2017	998 Patients; Mean age = 25.1 years (SD = 5.0)	BN	SCID-I; EDI-2	Substance abuse	SCID-I	Impulsivity related constructs	TCI-R	Gambling Disorder

Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Ralph-Nearman et al., 2020	183 Students; (71.6% female; 28.4% male), Mean age = 20.28 years (SD = 1.68)	Binge eating	BES	Alcohol Use	Alcohol Use Disorders Identification Test (AUDIT)	Negative Urgency	UPPS-P	Gender
Rosińska et al., 2020	67 Patients;	AN; BN; BED; EDNOS	DSM-5 Criteria	SUD	DSM-5 Criteria	Personality Characteristics; Impulsivity	TCI-R; BIS	BMI; BDI; STAI
Shapira & Courbasson, 2011	314 patients (86% female; 14% male); Mean age = 37.43 years (SD = 11.49)	BN; AN; BED; EDNOS	SCID-IV; EDE-Q	SUD	Addiction severity index; SCID-IV	Self-Esteem	RSES	BDI; BAI;
Shisslak et al., 1989	74 women; Mean age = 24.70 years (SD = 6.37).	BN; AN	EAT; EDQ	SUD	ADUQ	Personality Characteristics	MMPI	-
Thompson-Brenner et al., 2008	213 Females; all over 18 years old	BN; AN-R; AN-BP	LIFE-EAT II	SUD	Research Diagnosis Criteria for DUD and AUD	Personality Pathology	SIDP-R	-

Table 2

Data extraction table for the 20 studies included in the review.

Author(s)	Study Population	ED	ED Measure	SU	SU Measure	Mechanism of Interest	Mechanism measure(s)	Confounders/other variables
Wakeford et al., 2018	652 university students; (80% female; 20% male); Mean age -= 26.55 (SD = 10.08)	BN; BED (full or sub-threshold)	EDDS	Alcohol Use	AUDIT-C	Anger Rumination	ARS	DASS-21

SCID = Structured Clinical Interview for DSM-5; DUD = Drug Use Disorder; AUD = Alcohol Use Disorder; SIAB = Structured Interview for Anorexia Nervosa and Bulimia Nervosa Syndromes; TCI = Temperament and Characteristic Inventory; BIS = Behavioural Inhibition scale; BAS = Behavioural Approach scale; STAI-Y = State-Trait Anxiety Inventory Form Y; YBC-EDS =Yale–Brown–Cornell Eating Disorder Scale; YBOCS = Yale Brown Obsessive-Compulsive Scale; EDE = Eating Disorders Examination; HDRS = Hamilton Depression Rating Scale; BDI = Beck Depression Inventory; DIPD – IV = Diagnostic Interview for DSM-IV Personality Disorders; DERS = Difficulties in Emotion Regulation Scale; HBQ = Health Behaviour Questionnaire; RSES = Rosenberg Self-esteem Scale; QEWP-R = Questionnaire on Eating and Weight Patterns – revised; GAF = General Assessment of Functioning; SPSRQ = Sensitivity to Punishment and Reward Questionnaire; PDSQ = Psychiatric Diagnostic Screening Questionnaire; AUDIT = Alcohol Use Disorder Identification Test; DUDIT = Drug Use Disorders Identification Test; YSQ-L3 = Young Schema Questionnaire L3; AAQ = Acceptance and Action Questionnaire; BEST = Borderline Evaluation of Severity Over Time; AEQ = Alcohol Expectancy Questionnaire; EEI = Eating Expectancies Inventory; TREI = Thinness and Restricting Expectancy Inventory; CARROT = Card Arranging Reward Responsiveness Objective Test; BES = Binge Eating Scale; UPPS – P = Urgency, Premeditation (lack of), Perseverance (lack of), Sensation Seeking, Positive Urgency, Impulsive Behaviour Scale; EDDS = Eating Disorder Diagnostic Scale; MMPI = Minnesota Multiphasic Personality Inventory; EAT = Eating Attitudes Test; EDQ = Eating Disorder Questionnaire; SIDP-R = Structured Interview for DSM-IV Personality Disorders – Revised; LIFE-EAT-II = Longitudinal Interval Follow-up Evaluation for Eating Disorders; MPQ = Multidimensional Personality Questionnaire; DASS-21 = Depression Anxiety Stress Scales – 21; DSHI = Deliberate Self-Harm Inventory; ARS = Anger Rumination Scale

Results

Of the 20 studies included in this review, eight studies included individuals with a diagnosis of AN, 12 with a BN diagnosis or symptoms, and eight with a BED diagnosis or symptoms, with some overlap between studies. Three studies included a diagnosis of EDs not-otherwise specified (EDNOS), and two studies looked at ED symptomology without a diagnosis.

Within the literature, eight studies measured alcohol use or alcohol dependence only, and 12 studies measured substance abuse, which included alcohol and drug use. The majority of studies used clinical samples (n = 15). Five studies used non-clinical samples, such as university students, and employed correlation-based techniques.

Each paper was placed into a category based on the theoretical approach and mechanism measured. This review identified three main categories: personality pathology factors, non-pathological personality traits and emotional-regulation factors. Studies will be summarised below in these three categories. Attempts were made to discriminate between apparently similar mechanisms and link each one to one of these three categories. Where papers explored two or more different mechanisms, these papers appear in more than one category.

Personality Psychopathology

According to the *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (DSM-5) (American Psychiatric Association, 2013), there are three clusters of personality disorders, *odd/eccentric* (A), *dramatic/erratic* (B), *anxious/fearful* (C). Each cluster is thought to have common traits that predict behaviour patterns. Four papers used this framework.

Rosińska et al., (2020), Becker & Grilo (2015) and Bulik et al. (1997) examined the ED-SUD comorbidity using Axis II personality clusters from the DSM-5 (American Psychiatric Association, 2013). Rosińska et al., (2020) found that individuals with comorbid ED and substance abuse were more likely to have a cluster B personality disorder (*dramatic/erratic)*. They suggested borderline and histrionic presentations were more common in the comorbid group, and a common characteristic of both of these personality disorders is impulsivity – a construct which is further explored later in this review.

Becker & Grilo (2015) conducted their research on a mixed population of men and women with BED. They found that individuals with an avoidant personality subtype were most likely to experience ED-SUD comorbidity, followed by those with the obsessive-compulsive subtype. Clusters A (odd or eccentric) and C (anxious or fearful) were most represented in the comorbid group. They also measured mood, and individuals who struggled with all three (ED, SUD, and mood disorder) were more likely to have a borderline personality type.

Bulik at al. (1997) investigated lifetime comorbidity of alcohol abuse in BN. They found women with an ED-SUD comorbidity had higher rates of borderline and histrionic personality subtypes. Much like Becker & Grilo (2015) they also found higher rates of cluster A disorders, however, unlike Becker & Grilo (2015) they also found higher rates of cluster B disorders. They also assessed the retrospective impact of *childhood externalising disorders* (Campbell et al., 2000); individuals who had both BN and alcohol dependence were significantly more likely to have met criteria for a childhood externalising disorder. Finally, Bulik et al. (1997) also measured personality temperament (this will be discussed in the personality temperament section).

Thompson-Brenner et al. (2008a) used the DSM-5 Axis II categories to create novel personality clusters characteristic of those with EDs. In this paper, Thompson-Brenner et al. (2008b) used subtypes derived in a previous study (Thompson-Brenner et al., 2008a); high

functioning; emotionally dysregulated; behaviourally dysregulated; avoidant-insecure; and obsessional-sensitive. Individuals with obsessional-sensitive personality types were least likely to abuse substances, and those with behaviourally dysregulated personality types were most likely to abuse substances. This did not hold however when controlling for substance abuse history.

The final study to explore personality psychopathology was Shisslak et al. (1989). Individuals with bulimia alone, drug/alcohol use alone, or a combination scored higher on the Minnesota Multiphasic Personality Inventory (MMPI) (Dahlstrom & Welsh, 1960) – a measure of personality psychopathology - than normal controls, with individuals with both bulimia and substance abuse scoring higher than the other groups.

Quality of evidence. Becker & Grilo's paper (2015) had several strengths (quality score 18/22); it included a large sample of men and women, differentiated between substance and alcohol use, and considered the impact of comorbid mood disorders. However, the study is correlational in nature, as was Bulik et al. (1997), making it difficult to draw causal conclusions, and neither paper hypothesised about possible mechanisms underlying comorbidity. A lack of proposed mechanisms means the papers do not have straightforward clinical implications, and therefore it is hard to see what the implications for psychological therapy might be.

Bulik et al. (1997) (quality score 18/22) also measured childhood externalising disorders but there is no model or theory to link this experience to comorbid substance abuse and EDs. This study also included some participants who reported previous "alcohol abuse" in the non-alcohol dependent sample, which could be a potential limitation as the mechanisms that led to current alcohol dependence in the alcohol group may be similar to those who have

historically reported alcohol abuse, making it difficult to differentiate the comorbid from the BN only group.

Table 3

Quality rating per item and as a total out of 22 for each paper, according to the Standard Quality Assessment Criteria (Kmet et al., 2004).

	Item Score (0=No, 1=Partial, 2 = Yes)											
Author(s)	1	2	3	4	8	9	10	11	12	13	14	**Total (/22)**
Personality Pathology												
Becker 2015	2	1	1	2	2	2	2	1	1	2	2	**18**
Bulik 1997	1	2	2	2	2	2	2	1	1	2	1	**18**
Rosińska 2020	2	2	1	1	2	1	2	2	1	2	1	**17**
Shisslak 1989	2	2	1	1	1	1	2	1	0	2	1	**14**
Thompson-Brenner 2008	2	2	1	1	2	2	2	1	0	2	1	**16**
Average score												**16.6**
Temperament and Character												
Baker 2013	2	1	1	2	2	1	1	1	2	2	1	**16**
Bulik 1997	1	2	2	2	2	2	2	1	1	2	1	**18**
Del Pino-Guiterraz 2017	2	2	2	2	2	1	2	1	2	2	2	**20**
Krug 2009	2	1	2	2	1	2	2	1	2	2	2	**19**
Rosińska 2020	2	2	1	1	2	1	2	2	1	2	1	**17**
Average score												**18.0**
Dispositions												
Benjamin 2005	2	1	1	2	1	1	2	1	2	2	1	**16**
Average score												**16.0**
Impulsivity												
Baker 2013	2	1	1	2	2	1	1	1	2	2	1	**16**
Bulik 1997	1	2	2	2	2	2	2	1	1	2	1	**18**
Dir 2013	2	2	1	2	2	2	1	2	1	2	1	**18**
Fischer 2012 Study 1	2	2	1	1	2	2	2	1	1	2	2	**18**
Kane 2004	2	2	2	1	2	1	2	1	1	2	1	**17**
Loxton 2001	2	2	1	1	2	2	2	1	2	2	1	**18**
Peterson 2005	1	2	2	2	1	1	1	0	0	1	1	**12**
Ralph-Nearman 2020	2	2	1	2	2	2	2	1	1	2	1	**18**
Average score												**16.8**
Emotional Regulation												
Elmquist 2015	2	2	2	2	2	2	2	2	1	2	1	**20**
Elmquist 2018	2	2	2	2	2	1	2	1	2	2	2	**20**
Claudat 2020	2	1	1	2	2	1	2	1	1	2	1	**16**
Shapira 2011	2	2	1	2	2	2	2	2	1	2	1	**19**
Wakeford 2018	2	1	1	2	2	2	2	1	2	2	1	**18**
Average score												**18.6**

Note. (Items 5, 6 and 7 have been removed as they were not relevant here).
Papers may appear twice if discussed in more than one section.

Thompson-Brenner et al. (2008b), (quality score 16/22) re-conceptualised personality clusters in an attempt to make them more relevant to EDs. The study used longitudinal data (over six months), which was a strength as this methodology was rare amongst the papers reviewed here, and also made attempts to distinguish between behaviourally dysregulated impulsivity and emotionally dysregulated impulsivity. This is useful because the targets for interventions would be different depending on the type of dysregulation and therefore speaks to a more specific mechanism.

The quality of the studies varied from 14 to 18 out of 22 (see *Table 3)*, for example Shisslak et al. (1989) (quality score 14/22) did not fully describe their recruitment strategy, making it difficult to replicate the study; they used language that is now considered stigmatising (e.g. *bulimics*, *drug addicts*), and concluded that it may be inadvisable to treat EDs and substance abuse together.

Overall, the implications of research in this area suggest EDs and comorbid substance abuse occur due to "fixed" personality pathology, which suggests they cannot be changed and therefore does not lead to useful implications for psychological therapy.

Personality temperaments, characteristics, and dispositions

Personality temperaments are emotion-driven, automatic responses, often associated with neurotransmitters. They are considered relatively stable over time (Cloninger & Svrakic, 2014; Garcia et al., 2020). Disposition is a similar term used for characteristics that are stable over time and also unconscious (Lösel, 2001; Zuroff, 1986). Character on the other hand, is a conscious, cognitive process that relies on self-directedness, and introspection, and is changeable over time. Papers in this section have been divided by methodology and measures; studies which measure temperament according to the Cloninger et al. (1993)

model, studies which measure a range of dispositions not specific to a model, and studies which measure impulsivity.

Temperament and character

The psychobiological model of personality (Cloninger et al., 1993) focuses on four areas of temperament (harm avoidance, novelty seeking, reward dependence, persistence) which are thought to be unconscious and automatic, and three areas of character (self-directedness, cooperativeness, self-transcendence) which are considered to be conscious and self-aware. These seven personality traits have been associated with different subtypes of EDs (Harrop & Marlatt, 2010; Pearlstein, 2002) and also with SUDs (Grekin et al., 2006). Five studies examined the relationship between temperament and comorbid substance abuse-eating disorders, using the Temperament and Character Inventory - Revised (TCI-R) (Cloninger & Svrakic, 2014). Some studies have suggested the TCI-R may lack good reliability and construct validity (Farmer & Goldberg, 2008; Grucza & Goldberg, 2007) however, this has been contested (Cloninger, 2008).

All five papers found that the temperament of novelty seeking was higher in individuals with both substance/alcohol abuse and an ED, when compared to a group with one of those diagnoses only (Baker et al., 2013; Bulik et al., 1997; Del Pino-Gutiérrez et al., 2017; Krug et al., 2009; Rosińska et al., 2020). Novelty seeking is considered stable (i.e. not modifiable) (Garcia et al., 2020) and refers to trait differences in individual behaviours such as exploratory activity in response to novelty, impulsive decision making, extravagance in approaching reward signals, loss of temper and avoiding frustration.

Krug et al. (2009) expanded on this notion by exploring novelty seeking across different ED subtypes. They showed that novelty seeking was associated with substance abuse in individuals who had bulimic features, and those who had moved from anorexia to bulimia

presentations, but not those with an anorexia-restrictive subtype. Baker et al (2013) also showed women with a binge-purge subtype of anorexia were more likely to experience alcohol use disorder and also more likely to show higher scores in novelty seeking.

Rosińska et al. (2020) found that harm avoidance (how one copes with events which may be considered harmful) was lower in individuals with a dual diagnosis, when compared to individuals with only an ED.

Quality of evidence. Of the studies in this section, Baker et al. (2013) was the only study to also explore the temporal sequence of the comorbidity between EDs (quality score 16/22), specifically AN, and alcohol use disorder. This is useful for potential preventative interventions, but also to further the evidence-base beyond issues of bi-directional correlations to assess potential causality. However, there were some limitations. The sample included both ill and recovered individuals; those who have recovered may have scored lower on some measures than those who were still ill and grouping them together may have obscured any differences in potential mechanisms. The study excluded male participants which limits the generalisability to women only.

The biggest limitation of Rosińska et al.'s, (2020) study is the small sample size (quality score 17/22), which may have led to the study being under-powered and potential differences in temperament between the groups could have been missed. In addition, Krug et al. (2009)'s attempts to explain higher novelty seeking in those with binge-purge subtypes was related to animal models, which are considered to lack validity in human populations and can be difficult to generalise (Shapiro, 1998).

A limitation of all five studies was that they did not attempt to describe a potential linking, or common mechanism about how novelty seeking might lead to both EDs and substance abuse. The studies provided some good quality cross-sectional evidence that novelty seeking

is higher in those with both disorders however, a cross sectional correlation cannot be considered to provide evidence of causation. The reliability of the TCI-R has also been questioned, with some constructs such as harm avoidance, self-directedness and novelty seeking overlapping (Farmer & Goldberg, 2008).

With this in mind, there is a substantial amount of literature supporting the role of novelty seeking in both substance abuse and EDs, however the exact mechanism(s) has not been explored yet and the overlap with and between constructs such as impulsivity remains unclear.

Dispositions

One study looked at a broad range of personality "dispositions" that were not tied to any particular framework. Benjamin and Wulfert (2005) explored a range of personality dispositions in college women. Women who engaged in binge eating or binge drinking were described as impulsive, with a high *tolerance of deviance* and women who engaged in both binge eating and drinking were described as emotionally unstable. Low self-esteem was considered to be a predictor of binge eating but not of alcohol use.

Quality of evidence. This study was correlational and conducted on a group of college women (quality score 16/22). This means the study cannot determine causation and results may not be applicable to clinical populations. College women may also be unique in being at a stage of life which can lead to increased alcohol use, but this may not necessarily translate to clinical alcohol dependence. The authors looked at a wide range of relevant dispositions, e.g. impulsivity, however the paper lacked a framework or theory to situate these ideas within.

Impulsivity

There is no one unifying definition of impulsivity (Whiteside & Lynam, 2001), but it has been proposed to overlap with certain personality disorders and with some traits (e.g. with behavioural inhibition or novelty seeking) (Garcia et al., 2020; Rosińska et al., 2020).

Nine studies explored impulsivity, or a construct thought to be a part of impulsivity (Baker et al., 2013; Bulik et al., 1997; Claudat et al., 2020; Dir et al., 2013; S. Fischer et al., 2012; Kane et al., 2004; Loxton & Dawe, 2001; Peterson et al., 2005; Ralph-Nearman et al., 2020). Within these nine studies, several theories and measures of impulsivity were included. Claudat et al. (2020) explored impulsivity as an emotional regulation strategy and used a corresponding measure of emotional regulation difficulties; this will be in a later section.

The remaining eight studies have been grouped according to the conceptualisations of impulsivity and measures used. Two studies used the Barratt Impulsivity Scale (Patton et al., 1995) which measures three domains (cognitive, motor, and non-planning). Baker et al. (2013) showed that women with both AN and Alcohol use disorder showed higher impulsivity scores than women with AN only. Bulik et al. (1997) used this scale in a population of women with BN and showed similar results - higher scores were found in women with comorbid alcohol use disorder.

Two studies used the Behavioural Inhibition/Behavioural Activation Scales (BIS/BAS) (Carver & White, 1994) based on Gray's (1970) conceptualisation of impulsivity as sensitivity to rewards in the environment. Both studies showed higher behavioural approach (sensitivity to reward) and lower behavioural inhibition (sensitivity to punishment) in individuals with a SUD–ED comorbidity (Kane et al., 2004; Loxton & Dawe, 2001). Kane et al. (2004) also used Eysenck's Impulsiveness Scale (Eysenck & Eysenck, 1991) and the findings are in keeping with the general trend of higher impulsivity in the comorbid group.

One study, Peterson et al. (2005), measured the impact of impulsivity according to the Multidimensional Personality Questionnaire (Tellegen, 1982) which is a broad measure of personality traits. Again, Peterson et al. (2005) found impulsivity was higher in groups with comorbid EDs and SUDs.

Finally, three papers measured impulsivity according to the Urgency, Pre-meditation, Perseverance, Sensation Seeking and Positive urgency (UPPS-P) Scale (Smith et al., 2007; Whiteside et al., 2005). Fischer et al. (2012) and Ralph-Nearman et al. (2020) both focused on the negative urgency construct within impulsivity, and Dir et al. (2013) used all scales of the UPPS-P measure. All found higher negative urgency (the tendency to act rashly in the face of negative emotions) in those individuals with a comorbidity when compared to those with just one of the two diagnoses.

Quality of evidence. The literature on impulsivity is mixed (quality scores range from 12 to 18), however individual papers do have some strengths. For example, Kane et al. (2004) (quality score 17/22) introduced a novel card-based task approach to measuring impulsivity, alongside self-reported impulsivity. The card sorting task correlated well with self-reported score, providing good construct validity and evidence which did not rely on accurate self-report.

However, there were also some limitations. Loxton and Dawe (2001) (quality score 18/22) and Ralph-Nearman et al. (2020) (quality score 18/22) both used non-clinical populations, such as students, which could limit how generalisable the findings may be to clinical groups. Loxton and Dawe (2001) used arbitrary cut-offs to categorise individuals as high risk, and the rationale for this was not clearly explained.

Each study had a good sample size and explained their findings in terms of a model. The model suggested negative urgency leads to behaviours that distract an individual from

difficult feelings, therefore becoming an effective and self-reinforcing affect regulation strategy (S. Fischer et al., 2012). However, all these studies are cross-sectional in nature, and have limitations in terms of explaining causation.

Emotional regulation

Five studies explored emotional regulation. Claudat et al. (2020) attempted to bridge the gap between impulsivity as a trait and impulsivity as an emotional regulation strategy. They explored impulsivity from an emotional regulation perspective, i.e. impulsive tendencies manifest as alcohol use, drug use or ED behaviours when combined with an inability to regulate an emotion. They showed that individuals with an ED who also had a SUD were more likely to struggle with utilising emotional regulation strategies, were more impulsive, and less likely to engage in goal directed behaviours.

Shapira and Courbasson (2011) agree that ED behaviours and substance abuse contribute to methods of emotional regulation. In their sample of treatment seeking men and women, they explored "escape theory" which suggests low self-esteem leads to a higher drive to avoid the "self-awareness" of anxious or depressing feelings (Heatherton & Baumeister, 1991). Depression and anxiety were associated with severity of the ED, and anxiety and low self-esteem were associated with severity of substance abuse. Anxiety symptoms were an overlapping significant predictor of both disorders.

Wakeford et al. (2017) explored the experience of one particular emotion – anger, from a cognitive perspective i.e. impact of rumination. They found that students who showed higher binge eating symptomology and greater alcohol use also scored higher on experiences of angry afterthoughts and anger memories than individuals who only showed high alcohol use, or neither. Similarly to Shapira and Courbasson (2011), Wakeford et al. (2017) suggested ED

and substance abuse behaviours occur in an attempt to distract from self-awareness of negative *cognitions,* rather than just negative affect.

Elmquist et al. (2015) aimed to understand *why* some individuals aim to avoid negative affect this way, by exploring the root of emotional regulation difficulties using cognitive models of early maladaptive schemas. They explored the impact of early maladaptive schemas, caused by negative childhood experiences, on EDs and substance abuse. In a sample of men and women seeking treatment from a substance abuse facility, they found several maladaptive schemas were associated with both ED and SUD (abandonment, approval-seeking, enmeshment, insufficient self control, social isolation, subjugation, unrelenting standards, and vulnerability). Children who have experienced negative events may not have the skills to cope with such difficult schemas and therefore may develop maladaptive ways of coping, which Elmquist et al. (2015) suggest may explain the correlation with ED symptoms and substance abuse.

Elmquist et al. (2018) explored how individuals may attempt to evade such experiences or reduce the frequency of such experiences – termed experiential avoidance. In their study of men in treatment for substance abuse, they found experiential avoidance was higher in men with greater bulimic symptoms.

Quality of evidence. Elmquist et al. (2015) (quality score 20/22) based their hypotheses on schema theory which has frequently been used to understand the emergence and maintenance of several mental health difficulties (Young & Lindemann, 1992; Young et al., 2003). However, the study faces some methodological limitations; childhood experiences were not measured, nor was the study longitudinal, and therefore cannot provide evidence to argue childhood experiences caused the maladaptive schemas found.

Wakeford et al. (2017) (quality score 18/22) suggested binge eating may serve as a coping strategy for symptoms like anger rumination, however they used a non-clinical sample and so results may not generalise to those with a diagnosis. They also excluded individuals with AN from their study so we may not know how this relationship differs or indeed generalises to other EDs.

Overall, literature in this area was of good quality (average quality score 18.6/22). The majority was cross-sectional or correlational which again, leads to difficulties in understanding causation, however, each paper had clear implications regarding clinical treatment. Elmquist et al. (2015) suggested focusing on early schema, Claudat et al. (2020) suggested dialectical behaviour therapy (DBT) may be useful, Elmquist et al. (2018) suggested acceptance and commitment therapy. These papers proposed mechanisms which can be modified or adapted, for example, if substance abuse and comorbid ED occur due to an inability to manage difficult emotions, an individual can modify this, with support, in order to develop coping skills. This is in contrast to the previously discussed notions of personality disorders or dispositions, which were conceptualised as fixed and stable over time, therefore likely to be hard to modify with psychological therapy.

Discussion

This systematic narrative review aimed to synthesise and review the quality of literature looking at the shared psychological mechanisms in substance abuse and EDs. The review examined 20 papers in total to address the three aims of the paper.

The three aims were to summarise the psychological mechanisms that have been proposed, summarise the evidence for each mechanism and comment on the quality of the evidence. Mechanisms were explored according to three broad categories; personality pathology, non-pathological personality traits and emotion regulation related factors.

Personality psychopathology was approached from three different perspectives in the literature; according to DSM-5 clusters (American Psychiatric Association, 2013), the MMPI (Dahlstrom & Welsh, 1960) and a reconceptualization of DSM-5 personality clusters for EDs (Thompson-Brenner et al., 2008b). Overall, there was limited evidence supporting this hypothesis (i.e. five studies) and the quality of studies varied vastly. The majority of studies explored correlations between a personality disorder or cluster, and its relationship to comorbid EDs and substance abuse. Unfortunately, this does not further our understanding of *why* or how the comorbidity occurs and what can be done about it. Amongst these papers, some found higher rates of cluster A (Bulik et al., 1997), some of cluster B (Bulik et al., 1997; Rosińska et al., 2020) and others of cluster C (Becker & Grilo, 2015). Combining findings from these studies suggests EDs and comorbid substance abuse could be associated with any of the personality clusters, and therefore does not lead to a clear conclusion.

Thompson-Brenner at al. (2008b) used a longitudinal study of personality clusters that had been reconfigured specifically for ED phenotypes. This led to a proposal of *how* a personality type can lead to comorbidity between ED and SUD. The paper highlighted the role of a

"behaviourally dysregulated" personality subtype, which encompasses impulsiveness, risk taking and emotional dysregulation.

The majority of the literature fell into the second category of exploring personality temperament and characteristics. Literature using the TCI (Cloninger & Svrakic, 2014) found that novelty seeking was strongly predictive of comorbid substance abuse and EDs. Novelty seeking, also linked to sensation seeking elsewhere (Whiteside & Lynam, 2001), has a background in part in neurobiological theories of reward and dopamine. Novelty seeking is considered a type of behavioural dysregulation, which is consistent with the findings from Thompson-Brenner et al. (2008b) and has been used to support ideas of a dimensional view of mental health disorders. For example, Del Pino-Gutiérrez et al., (2017), suggest disorders like substance abuse, EDs and also gambling disorders share common features such as novelty seeking. However, this perspective should be viewed with caution as such theories align themselves with EDs as "addictions" which can be considered inaccurate and stigmatising (von Ranson & Cassin, 2007).

Negative urgency was another trait strongly associated with both substance abuse and EDs. Negative urgency is defined as the disposition to act rashly when faced with negative affect and has been closely linked to impulsivity (Cyders & Smith, 2008). This tendency to act rashly has been linked to alcohol consumption, drug use and binge eating. However, in its broadest sense, a disposition to act rashly in the face of negative affect could be conceptualised as a form of affect regulation and can therefore thicken the narrative that both substance abuse and EDs serve emotional regulation functions. However, this proposed mechanism may not be relevant to less impulsive EDs such as anorexia.

It is important to note that many of these constructs, impulsivity, negative urgency, behavioural inhibition etc., are overlapping when defined and complementary. They all draw from personality, and neurobiologically based theories. Without an agreed consensus on how

we understand impulsivity, it is also difficult to integrate the existing knowledge. Furthermore, personality, and neurobiologically based theories do not lend themselves readily to clinical implications as they often suggest these traits are innate or fixed. This is a limitation of the first two categories (personality pathology, and personality traits) and is perhaps better addressed by the third category, emotional regulation.

Literature on emotional regulation suggested early experiences lead to the development of maladaptive schemas, such as beliefs that you will always be vulnerable (Young et al., 2003). It was suggested that children who develop such schemas may also lack the ability to manage the difficult emotions that accompany such schemas as they have not had the nurturing environment needed to develop these skills. They may therefore use effective yet harmful methods of managing emotions such as restricting eating, binge eating or substance abuse. Considering substance abuse and EDs from a more psychologically grounded model may serve to generate treatment ideas and counteract the idea that there is little an individual can do. Models in Elmquist et al. (2015) and Claudat et al. (2020) are examples which can map more readily onto treatment targets, such as addressing schemas, or addressing the intolerance of negative emotional states.

Limitations of the literature

There were some reoccurring themes in the literature reviewed; several papers failed to locate the research within a particular field or area of research and did not adequately describe the theoretical background of the study. Future literature should aim to clearly describe which theoretical background they are approaching the topic from.

Several papers did not define the type of substance abuse that was included in their sample, how many individuals in the sample used drugs, how many used alcohol and which types of drugs. The majority of papers were cross-sectional or correlational. This means it

cannot be determined if the mechanism proposed *caused* an ED or substance dependence, or whether it was correlational.

In comparison to literature in other areas, e.g. EDs and self-harm behaviours, literature in this area can be criticised for focusing on broad distal factors, and not as much on proximal factors (Kiekens & Claes, 2020). Kiekens and Claes (2020) used the Conceptual Non-Suicidal Self-Injury and Eating Disordered Behaviors (NSSI-ED) risk factor model (Claes & Muehlenkamp, 2014) to explain how individual distal factors, such as personality and temperament, and social distal factors, such as family environment, culture and trauma, interact with proximal factors. Proximal factors in this model include peer influence, emotional regulation, and vulnerable cognitions. The model suggests this interaction can lead to the onset of eating disorders and comorbid self-harm. Future research would benefit from focusing on some of the proximal factors such as those presented in this model.

Limitations of this review

There were some limitations concerning the quality appraisal tool used, the Standard Quality Assessment Criteria. Whilst the tool has evidence of good inter-rater reliability (Kmet et al., 2004), the type of tool used can impact the findings of a systematic review (Jüni et al., 1999). The raters had difficulty with guidance on how to determine whether the sample size was sufficient; "Seems reasonable with respect to the outcome under study*"* involves subjective judgement, and whilst statistically significant results can be a good guide to sufficient power, this is not useful as a principle for studies with non-significant results.

There was also an overlap in mechanisms listed in the results section. For example, impulsivity has been explained as both a personality characteristic, and a means of emotional regulation. This overlap is caused by the aforementioned lack of clarity in definitions and

lack of positioning of concepts within broader frameworks and theories. This subsequently meant the subjective bias of the author had an impact on how studies were grouped.

Finally, psychological mechanisms may only provide a partial explanation of the comorbidity between substance abuse and ED; for example, neurotransmitters (Garcia et al., 2020) or familial risk factors such as history of drug or alcohol use (Krug et al., 2009) may all play a role. Thus a combined psychological and biological approach may be appropriate.

Conclusion

This systematic narrative review summarised the findings from 20 papers which explored different mechanisms and correlates of comorbid EDs and substance abuse. Literature looking at personality disorders and temperaments often did not propose a mechanism and often looked at a fixed construct that cannot be modified, such as personality temperament. A significant number of the papers explored impulsivity, however there is no one clear definition of impulsivity – in the papers reviewed here it has been discussed as both a personality trait and as a component of emotional regulation. The papers which spoke about emotional regulation used a cognitive schema-based model to understand the role of emotional regulation. As this leads to mechanisms which can be modified with psychological therapy, it would be beneficial for future research to explore the impact of schemas further and investigate potential treatment options for supporting emotional regulation.

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Service Improvement Project

A qualitative exploration of working with Panjabi speakers in Buckinghamshire Memory Clinic

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Proposed Journal: This report is intended and formatted for submission to Qualitative health research (Appendix 2A). This journal publishes qualitative papers exploring descriptions and analyses of the illness experience or help-seeking experiences and values a variety of perspectives which includes the cross-cultural perspective addressed in this paper. Papers covering similar topics and methodologies have been published in this journal and therefore it was deemed a suitable choice.

Abstract

Introduction: Government reports have highlighted the rising rates of dementia in Black, Asian and Ethnic Minority individuals. However, many ethnic minority groups face barriers in accessing memory services, and often feel services are not set up for them. South Buckinghamshire Memory Clinic aimed to explore the needs and views of non-English speaking Panjabi individuals, to consider how they might best work with this group.

Methods: Semi-structured interviews were carried out with eight Panjabi speaking members of the local community, aged between 55 and 76 years old. The authors also conducted focus groups and interviews with staff from the memory clinic to explore their experiences of working with Panjabi speaking service users.

Results: Thematic analysis of the data revealed four key themes for community members: wanting to be around “people like us”; negative views of memory difficulties; believing services “don’t have things for people like us”; and valuing professional help. Data from staff members revealed six key themes: A desire to be person-centred; staff don’t always feel confident; family members want to be helpful; having a choice in interpreters; difficult to keep tests reliable and valid; and using flexible approaches to gathering information.

Discussion: This study made several recommendations for South Buckinghamshire Memory clinic including use of second languages in the staff team to support assessments, using resources specifically made for Panjabi individuals, and being mindful that families may not want an interpreter, but service users may still benefit from being offered one.

Introduction

Dementia is a broad diagnostic term used to refer to degenerative conditions of the brain that impact multiple areas of cognition, such as memory, language, perception, and mood (Arvanitakis et al., 2019). Dementia is currently the leading cause of death in the UK (Office for National Statistics, 2018). The prevalence rate of dementia in those aged over 65 years is estimated to be 7.1% (Prince et al., 2014) and these rates are thought to be well below the true rate of dementia in the population (NHS Digital, 2022).

Government directives have highlighted the importance of early diagnosis in dementia to allow for potential treatments to slow disease progression, to allow individuals and families time to plan care, and to preserve an individual's level of functioning (Kmietowicz, 2012; Rasmussen & Langerman, 2019). Reliable early diagnosis is not easily achieved (Brayne & Kelly, 2019) and individuals from non-white ethnic minority groups are known to face greater delays and greater chances of a missed diagnosis overall (Lin et al., 2021), whilst facing a higher incidence of dementia globally in some minority groups (Novek & Menec, 2021).

Dementia and the South Asian community

The All-Party Parliamentary Group (2013) highlighted the rising level of dementia in Black, Asian and Minority Ethnicity (BAME) groups. In the next 30 years, it is anticipated there will be a seven-fold increase in the number of people with dementia in minority groups, compared to a two-fold increase expected in the whole population (Shiekh et al., 2021). One recent review of prevalence rates suggested there was no difference in prevalence rates of dementia in South Asian communities (ranging between 4 and 9%) and White British communities, however, sample sizes were relatively small and there was vast heterogeneity in

methods of assessment used (Blakemore et al., 2018). In other studies, the incidence of dementia diagnosis in Asian women was 18% lower than White women, and 12% lower in Asian men than White men (Pham et al., 2018). It remains unclear if this difference reflects actual lower incidence rates, or underdiagnosis, due to the barriers faced in accessing help and barriers to accurate diagnosis.

Accessing help in the South Asian community

Arblaster, (2021) summarises the various barriers faced by ethnic minority communities in accessing help for dementia. First, four out of five people in the South Asian community aged over 65 years do not read or write in English (Office for National Statistics, 2011). Secondly, South Asian people may be less likely to seek support for mental health difficulties (Hines et al., 2017) due to experiences of stigma (Arora et al., 2016) or views on dementia, for example, South Asian individuals may be more likely to view symptoms of dementia as a normal part of ageing (Purandare et al., 2007). Finally, South Asian individuals may not seek professional help due to having culturally preferred coping strategies, e.g. preferring care from family (Bowes & Wilkinson, 2003).

Dementia is considered a relatively new concept in Indian communities and there is not a direct translation for the word in many Indian languages, including Panjabi (Seabrooke & Milne, 2004). Therefore, Indian communities may have poorer understanding of the causes or symptoms of dementia (Giebel et al., 2015). When Indian individuals do access services, they may face further barriers such as a lack of culturally appropriate service provision, needing use of interpretation services and lack of culturally appropriate diagnostic tools (Arblaster, 2021).

Panjabi-Indians, from the Panjab province in India tend to face language barriers, stigma, and family views on keeping health difficulties within the family (Jarvis et al., 2011). Despite a growing body of research focusing on the needs of South Asian individuals, only a small number of papers has focused on the needs of the Panjabi community specifically (Gill, 2014; Jutlla & Moreland, 2009). This service improvement project focuses on supporting South Buckinghamshire Memory Service in working with local Panjabi speakers.

In South Buckinghamshire, 11.3% of the population are Asian and after White British, the largest ethnic groups are Pakistani (4.2%) and Indian (2.2%). Whilst there is no local data on languages spoken, both Indian and Pakistani populations are known to speak Panjabi, and Panjabi is the third most spoken language across the UK (Office for National Statistics, 2011). This is not reflected in referrals to the South Buckinghamshire memory clinic, with only five referrals being received across two years for Panjabi speakers. The memory clinic wanted to understand how they could improve the way they work with Panjabi speakers, particular in relation to cognitive screenings, given the emphasis on the need for culturally sensitive screening and assessment.

The need for Cross-cultural neuropsychology

Cross-cultural neuropsychology centres on the need to understand and ameliorate cultural differences in the accuracy of neuropsychological testing, to allow for reliable and valid measures across different groups of people. How to achieve this is a multi-faceted and complex issues because culture impacts several aspects of cognition (Fernández & Abe, 2018; Manly, 2008). NICE (2018) guidelines recommend dementia assessments should be provided in a culturally appropriate and sensitive manner, by understanding cultural and dialectal differences (Nguyen et al., 2021).

Adapting neuropsychological tests to match an individual's language proficiency (e.g. through an interpreter) leads to more comparable test results (Pedraza & Mungas, 2008) particularly when educational attainment is considered (Taussig et al., 2008). However using interpreters may lead to a biased increase in scores (Casas et al., 2012). This highlights the importance of using formal interpreters that are trained in neuropsychological testing (Franzen et al., 2021). Guidance on working with interpreters can be too vague or too focused on specific languages and does not cater for Panjabi or Indian populations. The idiosyncratic needs of the Panjabi community have not been fully understood and there is a need to explore the experiences of non-English speaking Panjabi service users in neuropsychological testing.

Aims

The South Buckinghamshire Memory service aims to better understand how to work with Panjabi speakers, in cognitive screenings, by understanding Panjabi speakers' views of seeking support for memory difficulties, and by understanding how staff currently work with Panjabi-speakers and what support they might need in order to provide culturally sensitive services.

The research questions are:

I. What are Panjabi-speaking community members' views on utilising memory services and specialist memory assessments when facing memory difficulties? (Primary)

II. What are South Buckinghamshire memory clinic staff members' experiences of working with Panjabi speaking service users?

Methods

Design

This study used focus groups with staff members to facilitate natural discussion (Stewart, 1999) and used semi-structured interviews with community members as these are thought to be better suited to sensitive issues such as those explored here (Harrell & Bradley, 2009). This study also planned to interview interpreters to gain an additional perspective, however, due to recruitment issues this was not possible.

Inclusion and exclusion criteria

Community members

All participants were aged over 50 years. This age limit was chosen because literature has emphasised the importance of early diagnosis and early help in dementia (Novek & Menec, 2021; van Vliet et al., 2013). All community members spoke Panjabi as a first language, and self-identified as not being fluent in speaking English. Participants were excluded if they were deemed as lacking capacity to consent to the research as assessed by the interviewer and if they were unable to understand and communicate in Indian-Panjabi[1].

Staff members

All memory clinic staff had previous experience of carrying out dementia screening assessments with a Panjabi speaker in either a lead or assistive role within South Buckinghamshire Memory Clinic. There were no exclusion criteria for staff.

[1] There are different dialects in Panjabi, including Indian-Panjabi and Pakistani-Panjabi. Both RB and RV both only speak and understand Indian-Panjabi and therefore this was an inclusion criterion.

Participants

Community members were recruited using opportunity sampling via a Sikh Gurdwara[2]. Eight participants were recruited over six interviews[3]. All participants met inclusion criteria, and there were no dropouts. There were five male and three female participants, aged between 55 and 76 years old (M = 64 years). Interview duration ranged from 7minutes to 20 minutes.

Staff who took part in the focus group were self-selecting volunteers who had heard about the research in team meetings. A total of six members of staff took part in the research, as summarised in Table 1. Interview and focus group duration ranged from 15 minutes to 24 minutes.

Table 1

Summary of focus groups and interviews conducted with staff and information on their level of experience.

Setting	No. of attendees	Professions	Years experience (Range)
Focus Group 1	3	Consultant Psychiatrist, Consultant Nurse, Administrator	6 months – 15 years
Focus Group 2	2	Clinical nurse lead, Assistant psychologist	4 months – 5 years
Individual interview	1	Mental health nurse	6 months

[2] Place of worship for members of the Sikh faith.
[3] Two male participants wished to take part with another person present and so this was facilitated.

Position of the researcher

RB being a Panjabi researcher may have aligned with some views of community members around accessing help, and this may have informed some of the decisions made in this study (Gray, 2002). The dual "identity" of the researcher is also important to consider in staff interviews, as RB was a Panjabi individual, interviewing staff about working with Panjabis. One of the research supervisors (RV), is also from an Indian-Panjabi background and the other supervisor, AC, is White British. It is important to consider the three varied perspectives that would inform the analysis of data. The researcher also employed a flexible view to data collection during field work and acknowledges this is also indicative of a certain stance around adapting qualitative methodologies for minority groups (Ngozwana, 2018).

Procedure

Community members

All participants were recruited through convenience sampling at the Gurdwara. The researcher attended the Gurdwara every Sunday (busiest day for Worship) for six weeks and approached individuals offering them information on the study in Panjabi and sought verbal consent. Interviews took place in a quiet area of the Gurdwara. Three participants expressed a desire to be interviewed over the phone.

Prior to all interviews, participants were reminded of anonymity, and were asked for consent to audio record the interview. The interview schedule (Appendix 2B) was designed following consultation with two individuals who acted as partners in experience (one Panjabi speaking female with previous experience of mental health services and working as an interpreter, and another Panjabi speaking male who had utilised memory services not in this area).

Key topics explored in the community member interview schedule were about:

1. Understanding of memory difficulties and what can be done
2. Experiences with memory difficulties (themselves or others) and what they did
3. Perceptions of seeing a GP or going for further cognitive screening
4. Views on using a screening tool (e.g. “pencil and paper test”)
5. Barriers and facilitators to seeking help in this way
6. Views and experiences of working with interpreters

Staff members

The researcher shared study posters with the team via email and also attended team meetings to garner interest in the study. Prior to the start of all focus groups, participants consented to audio-recording of the discussion and were reminded of their right to withdraw. The interview schedule (Appendix 2C) was designed following discussions with the research team (including AC who works in the South Buckinghamshire Memory Clinic), consulting with the memory clinic lead, and consulting relevant literature.

Key topics explored in the staff member interviews schedules were about:

1. Experiences of working with Panjabi speakers – considerations and adaptations staff may make
2. Experiences of working with Panjabi interpreters – things that worked well and not so well
3. Views on using different screening tools and how this is decided
4. Support that staff may want to help them to work with Panjabis speakers appropriately and effectively

Analysis

Reflexive thematic analytical methods are thought to be appropriate when there is no previous prediction of themes of findings, and themes are derived across data sets, from coding of the data itself (Braun & Clarke, 2021). This was thought to be the approach that best fit the researchers' epistemological stance and best suited to the aims of the study. RB's epistemic view is that there is some objective truth to be discovered, however this is influenced by language and culture, forming a somewhat socially constructed view to reality. Data analysis followed Braun and Clarke's (2022) guidance (Appendix 2D). RB completed initial coding and theme development according to this method. One section of transcripts from both staff and community members interviews was read by RV to review coding, and all three researchers met to review and refine final themes.

Results

A total of eight Panjabi speaking community members and six staff members from the memory service took part in this study. Reflexive thematic analysis was used to analyse data for the two groups separately; themes and subthemes for community members and staff members are described separately in Tables 2 and 3 respectively.

Community member themes

Table 2

Summary of themes and subthemes from community member interviews.

Themes	Subthemes
Wanting to be around "people like us"	
	People from Similar backgrounds
	Preferring familiar sources of support
"There is nothing": Negative views of memory difficulties and a lack of hope	
	"It's just forgetting" – "nothing you can do about it"
	Burden on the family
"They don't have things for people like us"	
	We are not the right fit
	It may not fit for Panjabi community
Valuing professional help	
	Faith in medical professionals
	Preference for interpreters

1. Wanting to be around "people like us"

People from similar backgrounds

Participants expressed feeling more connected to people from similar backgrounds, e.g. other Panjabis, people from similar countries (e.g. Pakistan) where they might have weather or diet in common; "*The best thing is having an Indian doctor, we always hope if we get an Indian doctor that would be best"* (P2).

Preferring familiar sources of support

Almost all participants referred to a preference for sources of support that are familiar to them, for example, listening to Indian-Panjabi doctors in the media, going to their families for support, or religious support; "*First you should go to your family. Speak to your children first. They would know best"* (P6). There was also a desire to keep things "inside the home" and worries about what would happen if they were to seek support from outside of the home.

2. "There is nothing": Negative views of memory difficulties and a lack of hope

"It's just forgetting" – "nothing you can do about it"

Six participants thought there was nothing that could be done about memory difficulties; "*I don't know. There is nothing. There is no medication for this thing either. Its just like that."* (P7). Five participants thought memory difficulties were just something that happened in old age and viewed it as a "necessary" part of old age; "*We get memory problems mostly in old people… There is no treatment"* (P3).

Burden on the family

Three participants said they worried about burdening their family; "*You have to look after them as if they are a child*" (P7). Experiences like this combined with the perception that there is nothing that could be done to help in terms of treatment left participants feeling like memory difficulties were particularly hard for families.

3. "They don't have things for people like us"

We are not the right fit

Participants spoke about not having the language or words needed to access services; *"It's hard to explain something to someone in another language"* (P2), and there was an impression that having some level of English meant they would not need an interpreter,

despite confidence/competence in spoken English; "*Oh it's fine I know a bit of English I will just go on my own – but it is broken English and so it won't be as good as if someone was able to help them"* (P6).

Participants also felt they would not be the right fit because they would be unfamiliar with the process; *"We don't really know what you mean by a test or a pencil and paper test"* (P2). Participants referenced how their familiarity with school might impact them during an assessment; "*For people like me, we never did stuff like that at school…"* (P8).

It may not fit for Panjabi community

Half of the participants felt the Panjabi community was a "*religious-minded*" community, likely to think about their religion, more than their own well-being. Where wellbeing was referenced, this was often from a biological perspective, referencing dietary deficits or excess alcohol as possible causes of memory difficulties. Two participants also spoke about the need for more awareness on memory issues; "*I think it is about re-educating people on it, … re-educate on what things can affect someone's memory so they can make the changes"* (P8).

4. Valuing professional help

Faith in medical professionals

All participants emphasised the importance of following the advice of medical professionals. They spoke about doctors being important in Indian culture and being seen as a figure of authority. The idea that you "should do" what the doctor says was present in all interviews; "*Anything the doctor says, we put all trust on them"* (P2).

Preference for interpreters

Participants valued the contribution of interpreters over a family member; "*Panjabi translation gives you peace of mind that everything you say will be understood correctly… It*

is better than family because family members sometimes only tell you half of what has been said" (P6). Participants said that having an interpreter also gave them more time to think whilst the clinician spoke. Two participants spoke about having to ask for interpreters themselves, rather than this being offered to them.

Staff member themes

Table 3

Summary of themes and subthemes from staff member focus groups and interview.

Themes	Subthemes
Desire to be person-centred	
	Wanting to get patient perspective
	Wanting the patient to be comfortable with the interpreter
	Considering which measure to use
Staff don't always feel confident when working with non-English speakers	
	Placing trust in interpreters
	Picking translated or English measures can be hard
	Feeling unsure about dialects
Family members want to be a helpful resource	
	Family members often want to help in the assessment
	Families are often concerned if they can't help
Having a choice in interpreters	
	Wanting interpreters with mental health skills
	Wanting familiar interpreters
Difficult to keep tests reliable and valid	
	Family impacting on validity of assessment
	Interpreters not always skilled in written language
Flexible approaches needed to gathering information	
	Adapting communication
	Needing to fit with clinic process

1. Desire to be person-centred

Wanting to get patient perspective

Five staff members expressed wanting to keep the assessment person-centred and found it harder to get the patients' perspective if they did not speak English; "*How am I going to get the… information from the patient, I guess about their thoughts on the referral, if they don't speak English.*" (S4). Triaging calls was described as particularly difficult as there is no telephone interpreter available so often, these calls were done through family relatives.

Wanting the patient to be comfortable with the interpreter

Staff wanted the patient to feel comfortable with the interpreter by having the interpreter introduce themselves to the patient beforehand and build rapport, and by clinicians being mindful of the need to facilitate three-way conversation; *"They spoke to me and then you know, they would come back and forth and build some sort of like a rapport with the patient"* (S6).

Considering which measure to use

Staff thought it was important to consider the needs of the person when choosing an assessment measure; "*I've considered which not just in terms of using the Panjabi versus English MoCA, but which is actually the most appropriate screening tool for the person"* (S2). One individual preferred to use the RUDAS (Rowland Universal Dementia Assessment Scale (Storey et al., 2004)) with non-English speakers, and another considered the education level of the individual when deciding between the Panjabi and English MoCA (Montreal Cognitive Assessment, (Nasreddine et al., 2005)).

2. Staff don't always feel confident when working with non-English speakers

Placing trust in interpreters

Staff described having to put a lot of trust into interpreters without knowing the accuracy of what was being said, *"I feel like the question I've asked is quite brief and structured, but then the translator seems to be talking for an awfully long time… I can't tell if that's just actually how the language is or if they've actually put their own spin on things"* (S2).

Picking translated or English measures can be hard

Senior staff often have to decide which measure to use and often experienced difficulties in choosing measures when working with Panjabi interpreters. Staff spoke about having had

less experience with the Panjabi MoCA and therefore preferred the English version, and two staff members expressed a preference for letting the interpreter decide; "*I normally let the translator make the decision. I tend to take both"* (S4).

Feeling unsure about dialects

Staff do not feel confident with the types of dialects they may encounter and spoke about finding it helpful to know how to ask about these, and then being able to book the relevant interpreter. *"I'm not always sure if that's the correct one or not. It's not always noted … if it's a specific dialect."* (S3)

3. Family members want to be a helpful resource

Family members often want to help in the assessment

Half of the staff felt family members were an important resource within assessments as they could help clinicians identify if the dialect of interpreters was incorrect, *"Oh well, they're not speaking the same dialect or it's not the same language"* (S4), they could help guide adaptation to questions so that individuals could answer to the best of their ability and occasionally could help to interpret if it was not possible to book an interpreter.

Families are often concerned if they can't help

Half of the staff said that when families could not be the ones interpreting for their relative, they would worry about their relative. "*It tends to come more from families they're not normally overly happy about having someone else there"*. (S4). This often led to staff having to reassure family members and re-explain the purpose of the interpreter.

4. Having a choice in interpreters

Staff said it was important to think about the experience of the interpreter and therefore would find it helpful to be able to have a choice of interpreter, which is not currently possible. Two staff also said the gender of the interpreter was important to consider, *"you don't speak about your health stuff with anyone in the family and certainly not the men"* (S2).

Wanting interpreters with mental health skills

Staff wanted interpreters who have knowledge of interpreting for mental health services; they felt there were some specific words that are harder to interpret into Panjabi. *"There's not exact interpretation for … certain words in mental health… that could be a barrier."* (S6)

Wanting familiar interpreters

Wanting to work with the same interpreters repeatedly was highlighted by four staff members who felt it was easier to work alongside an interpreter who had worked with the service before; *"Normally they're pretty clued up on what's going on"* (P1). New interpreters required more time commitments from staff as they would need to meet them prior to the session and explain the process to them.

5. Difficult to keep tests reliable and valid

Family impacting on validity of assessment

Half of the staff members worried about how family members may inadvertently impact the validity of the results by offering patients information that may improve their performance on the cognitive screening tests; *"They think that they can do the translation, which obviously isn't really protocol because of… the information they can feed them"* (P3). There was a preference to use interpreters over family members as they interpret in a more

standardised way.

Interpreters not always skilled in written language

Staff said interpreters could also impact validity as not all interpreters interpret verbatim and are not always familiar with cognitive assessments, which can make certain concepts harder to accurately interpret; "*I know in the past when I've been with people with a translator, they can't always translate the MoCA completely over into the language"* (S2).

6. Flexible approaches needed to gathering information

Adapting communication

Staff spoke about changing their communication style when working with Panjabi interpreters; *"I tried to make my sentences shorter and more concise."* (P2). Staff also felt unsure whether bilingual staff should or could use their additional languages in their clinical work.

Needing to fit with clinic process

Staff said any changes would need to fit practically with the clinics processes, for example, different clinicians have different ways of working and so would need to be able to maintain these differences. Staff also spoke about practical solutions such as administrative staff being given feedback on whether the dialect was correct, and splitting assessments up into sections; *"It gives everyone a break actually, because I'm sure it must be just as overwhelming for everyone else in the [assessment]"* (S5).

Interpreter Interview

Due to recruitment difficulties, only one Panjabi Interpreter was interviewed, and therefore

data from this interview was not analysed. The interpreter felt that families were not always aware there was going to be an interpreter. The interpreter also acknowledged that neuropsychological tests are difficult to interpret verbatim and spoke about phrasing questions in a way to help people understand, which could reflect staff concerns of “threat to validity”. Further information can be found in Appendix 2E.

Discussion

Thematic analysis showed that Panjabi speakers in the Buckinghamshire community expressed an initial preference for familiar help such as religious support, or family members. This idea of culturally preferred methods is supported by previous research suggesting South Asians utilise more familiar sources of support, which can be a strength of the community (Bowes & Wilkinson, 2003). Secondly, participants expressed feeling hopeless about whether anything could be done about memory difficulties, in particular, viewing it as a part of normal aging. This has been found to impact help-seeking (Mukadam et al., 2015; Purandare et al., 2007).

Participants also expressed worries about burdening the family. Research has shown that not seeking help early on in the dementia journey is thought to *increase* the burden on the individual, family and on services (Cooper et al., 2010; Mukadam et al., 2011) and therefore this is an important barrier to address.

Staff expressed a desire to be person-centred throughout their approach, however, staff do not always feel confident working with non-English speakers as they are less sure about *how* to pick measures and may rely on guidance from the interpreters. This was particularly pertinent for the staff that are leading assessments as often they are the ones choosing measures and there is no standardised way of doing so (Franzen et al., 2021). Literature suggests staff in memory screening clinics could benefit from training in working cross-culturally with neuropsychological measures (Barber, 2020) to address this. Staff did not always feel confident in being able to check the accuracy of speech with the interpreter which is in-keeping with previous findings (Brickman et al., 2006). Staff did find it helpful to work with family members as often they were a resource in areas that staff felt less confident in, such as knowledge on dialects. Dialect has been highlighted as an important aspect to

consider in cultural neuropsychology, as sometimes, individuals can try and "make do", but dialectal differences can increase the chances of miscommunication (Nguyen et al., 2021) and so it important to support staff to feel confident with this.

Given the recruitment difficulties faced in this study, there are also implications for future research including the importance of forming strong links with local community services, including interpretation services, and the importance of utilising partners in experience in future research exploring the needs of the Panjabi community.

Strengths and limitations

These findings represent the views of people who *may* need to access services at some point, but this limits representativeness as they were not selected for their experience of memory difficulties, and therefore we cannot assume intentions would translate to behaviours; future research could focus on understanding the views of those who are experiencing memory difficulties. This study also recruited a relatively small sample, and several of the community member interviews where shorter than would be usual for qualitative interviews of this nature (e.g. shortest being seven minutes) which may have limited the themes and findings. Finally, interpretation may not have been completely accurate due to the potential for different meanings (e.g. Panjabi wording for "you should go" could be interpreted as an obligation or a preference).

This study also had many strengths: triangulation was used to obtain perspectives from several different sources, interview schedules were designed in collaboration with relevant partners in experience, and qualitative analysis adhered to guidance on conducting thematic analyses in a robust and transparent way. This study makes a valuable contribution to the cross-cultural neuropsychology literature as it furthers our understanding of the needs of individuals who speak Panjabi, a population that has not been widely studied.

Service improvement recommendations

Recommendations made, and responses from staff are presented in Table 4. It is recommended the memory service could review their progress in relation to the recommendations presented here in 12 months time, to review what has been helpful and what has been difficult to implement.

Conclusion

It is hoped the themes discussed and recommendations made here will support the South Buckinghamshire memory clinic in working with Panjabi-speaking service users in the area, to increase engagement in memory clinic screening assessments and to support the validity of cognitive testing carried out cross-culturally.

Table 4

Key findings and corresponding recommendations for South Buckinghamshire Memory Clinic.

Finding	Recommendation	Feedback from memory clinic staff
To support service users and community members		
Participants valued familiar resources, and this often made it easier to seek help – for example, watching videos of Indian doctors. Participants also spoke about not seeking help as they believe nothing can be done to help their memory difficulties, and participants placed a lot of value on advice from a GP. Many participants in this study spoke about "memory difficulties" and said not many people in the community knew what dementia was.	Offer resources in a format that is familiar to the individual for example, videos made specifically for Panjabi speakers (as opposed to videos made for general population and then dubbed). Alzheimer's society has a range of useful leaflets and resources that could also be used. These leaflets might offer psychoeducation e.g. addressing the idea that "nothing can be done about it" and signposting individuals to groups that are tailored to Panjabi, or South Asian individuals. This may include adapting language to fit what service users are familiar with e.g. using "memory difficulties" instead of "Dementia".	Staff found this suggestion valuable and recognised that as a service, they may have more work to do in order to make valuable community links to take this forward.
Staff were unsure if it was recommended to use any additional languages they spoke to support service users, and one felt she should not use her second language as it is not standard practise. Given findings that community members really value being surrounded by familiarity and things they may connect with, our first recommendation would be that staff who speak an additional language are encouraged to use this where this may support engagement of service users. For example, Slough Memory Service utilise staff who speak Panjabi, and have designated posts for Panjabi-speaking assistant psychologists, in order to better serve the local community (Arblaster, 2021).	Encourage and support bilingual staff to use any additional languages they may speak; particularly when this would support the engagement of the service user, for example, at first contact or at triage, and particularly if the additional language spoken helps the assessment process because the staff member is able to check how much is being understood.	Staff expressed wanting to find out about what languages are spoken in the team

Table 4

Key findings and corresponding recommendations for South Buckinghamshire Memory Clinic.

Finding	Recommendation	Feedback from memory clinic staff
Community members said they often feel they do not meet the "threshold" for "needing" an interpreter – e.g. they felt having some level of English meant they could do without one and so would not ask for one. However, literature has suggested this can still impact the accuracy of neuropsychological assessment and so a trained interpreter should be offered where possible.	Consider encouraging the service user to use an interpreter if their English is not fluent. Service users may suggest they are fine without an interpreter, but it could be helpful for staff to explore this further with them as they may still perform better with an interpreter.	Staff observed that this is something they do as standard – all bilingual service users receive an interpreter.
To support staff members		
Staff felt unsure when to use an English MoCA and when to use a Panjabi MoCA or something else. One member of staff suggested taking both versions into an assessment and liaising with interpreter. However, it is important to consider that interpreters are not as confident with translating written language as they are with spoken language and therefore may default to the English MoCA, but this may not be the best solution for the service user. The Panjabi MoCA goes beyond a literal translation, but also adapts some questions to make them more culturally appropriate for the person and so may help the service user in their performance (Cova et al., 2021). Staff may also wish to consider the use of the RUDAS (Storey et al., 2004) which was specifically developed for cross-cultural use.	When deciding on which measures to use, at triage stage, consider the individual's language and culture and see if any views can be obtained from family members of which measure to use. This could then be discussed at multi-disciplinary meetings or memory clinic meetings so that the decision does not sit with just one staff member but becomes a team decision. Consider the use of the Panjabi MoCA and the RUDAS. Literature has supported the use of the RUDAS in measuring cognitive functioning cross-culturally (Nielsen et al., 2018)	One member of staff offered to find a copy of the Panjabi MoCA to add to team resources. The RUDAS is already part of the team resources. Staff do still have concerns over interpreters being able to work with translated measures. Staff would like further guidance on *how* to find out more from the family, e.g. whether to ask about when they went to school/if at all, to get an idea of cultural familiarity.
Staff said they were unsure of the different dialects and how to ask about this. The two types of Panjabi dialects	At triage, ask Panjabi speakers if they would like an Indian-Panjabi or Pakistani-Panjabi interpreter.	Staff generally agreed with this theme and set actions to find out more about dialects.

Table 4

Key findings and corresponding recommendations for South Buckinghamshire Memory Clinic.

Finding	Recommendation	Feedback from memory clinic staff
most commonly spoke in the UK are Indian and Pakistani Panjabi.		
Staff wondered about how to best explain to family members why an interpreter is being used to support the assessment. It may be helpful for staff to align with interpreters before seeing a family so that they are both able to explain together how having an interpreter may aid the relative they are there to support, and to highlight the importance of the family in giving collateral information so that family members are able to have their views heard and still feel involved, without impacting the validity of any tests.	Continue meeting with interpreters ahead of sessions as staff are currently doing – as part of this discussion, staff may want to think with the interpreter about how the interpreter could explain to the family why they are being used instead of a family member. NHS guidelines do not currently recommend the use of family members as interpreters, and this could be important to communicate with families.	Staff expressed a desire to develop a consistent process around how to use interpreters, and a desire to spend more time in assessments explaining why family members are not used – staff thought NHS guidelines would be helpful here.
Other recommendations		
Staff highlighted the importance of interpreters needing specialist knowledge on cognitive screening measures.	It may be beneficial for staff to work closely with their local interpretation service to become more familiar with the staff they may meet and to offer training to interpreters, for example, what sorts of adaptations are helpful in neuropsychological assessment, and which adaptations may threaten validity. Literature suggests interpreters should be trained in working in a neuropsychological context (Brown et al., 2021; Hernández-Cardenache et al., 2015) using neuropsychological terms or concepts specifically (Brickman et al., 2006). This could be helpful given the concerns staff expressed.	This felt particularly important to staff members, who were keen to ensure they had enough time at the start of sessions to show the measure to the interpreter, remind them not to coach, and to explain the question in more detail than is written in the screening measure itself. There were concerns that such training could be costly and may not be used by all interpreters.

Table 4

Key findings and corresponding recommendations for South Buckinghamshire Memory Clinic.

Finding	Recommendation	Feedback from memory clinic staff
Community members felt there was a need for more awareness within the Panjabi community, and many people did not seek help as they did not think there was much that could be done, or it would not fit for them. Clinical implications from the themes highlight the importance of GP services in supporting Panjabi speakers with getting support for memory difficulties as they are a valued source of help. It may be important to think about how awareness can be raised within local communities, perhaps via GPs, so that the community are aware of the support available.	The service could consider outreach into the local community, for example via mailshots to GP surgeries, so that GPs are aware of some of the beliefs held in Panjabi communities and so that the team can form strong links between the memory clinic team and local community members. Working closely with the community will allow services to understand what could be done differently to make the service more accessible.	Staff generally agreed with this theme, and felt this should be reciprocal i.e. GP's also reaching out to local memory services to find out more.

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Theoretically Driven Research Project

Stigma and its Impact on Seeking Professional Psychological Help – Are there Cultural Differences?

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Proposed Journal: This report is intended for submission to the Journal of Cross-Cultural Psychology (Appendix 3A) due to its focus on empirical research into cross-cultural differences such as ethnicity and their impact on behaviour. Studies with similar designs and focusing on similar topics have been published in this journal.

Abstract

Introduction: Individuals from a South Asian background are thought to utilise mental health services less often than other individuals. Literature has suggested several barriers to accessing mental health support, one being stigma. Corrigan et al.'s *Why Try?* model is used to understand perceptions of stigma from others (public stigma) and stigma towards the self (self-stigma). This paper aims to explore whether a population of South Asian individuals has more negative views towards seeking professional psychological help, when compared to White British individuals, and whether stigma or acculturation play a role in this.

Methods: An online questionnaire was used to gather data on people's attitudes towards seeking professional psychological help, views on self-stigma, perceptions of public stigma and levels of acculturation.

Results: There were no differences in attitudes towards seeking professional help between the two groups. Public stigma was not associated with attitudes to seeking help, however greater self-stigma was associated with poorer attitudes to seeking help, regardless of culture. Acculturation impacted the relationship between public stigma and attitudes to seeking help only.

Conclusion: This paper adds a novel contribution in its recruitment of individuals who have experienced mental health difficulties. The paper highlights the importance of looking at other barriers outside of public or self-stigma to understand why South Asian individuals may be underrepresented in mental health services.

Introduction

Individuals from a South Asian background are currently the largest non-white group in the UK, making up almost 7% of the population (Office of National Statistics, 2018). In the UK, the term South Asian refers to people from the Indian subcontinent including India, Pakistan, Bangladesh, and Sri Lanka (Minority Rights Group, 2021). In the US, the term *Asian* is often used in research and covers a broader group of people including East Asian and South Asian communities (U.S. Census Bureau, 2000).

Help-seeking in South Asian communities

South Asian individuals are 0.55 times less likely to utilise mental health services than White individuals (Hines et al., 2017). South Asian women are less likely to utilise services than other ethnic groups (C. Cooper et al., 2013; J. Cooper et al., 2010) and when they do, they are more likely to be compulsorily admitted to an inpatient service (Bhui et al., 2002).

It is important to understand the barriers to seeking help, in order to offer equal and early access to services. Individuals from a South Asian community can face several barriers to seeking mental health support. These include internal barriers, such as cognitive representations of mental health (e.g. if it is an issue for the individual or for their social group), shame or stigma (Leong et al., 2011). Notably, South Asian individuals express high rates of stigma towards seeking help for mental health difficulties (Arora et al., 2016; Loya et al., 2010; Robinson, 2005).

Individuals may also face external barriers such as economical factors, language barriers, or lack of diversity represented in the staff teams working in mental health services (Islam et al., 2017; Soorkia et al., 2011).

Impact of stigma on help-seeking

Masuda et al. (2009) identified mental health stigma as being particularly strong in people from a South Asian origin. Beliefs around mental illness being a punishment from God, or the result of bad deeds are thought to contribute to the public stigma seen in some South Asians communities (Arora et al., 2016).

Stigma has been defined as "an attribute that is deeply discrediting" (Goffman, 1963). Mental health illnesses are considered a heavily stigmatised attribute and often lead to the stigmatised individual being labelled, set apart from others, and discriminated against (Corrigan et al., 2012), and when internalised, this can prevent help-seeking (Corrigan et al., 2004). Therefore, stigma, whether perceived or actual, is thought to be an important barrier to seeking help from mental health professionals (Arora et al., 2016; Corrigan, 2004; Eisenberg et al., 2009; Loya et al., 2010).

Theoretical background of stigma and help-seeking

Corrigan et al. (2004, 2014) distinguishes between two types of stigmas that can prevent individuals from seeking help: perceptions of public stigma and self-stigma. Public stigma occurs where members of the public, or close others, endorse a negative stereotype of a characteristic and act in a discriminatory way towards people with that characteristic (Corrigan et al., 2012). Perceptions of public stigma will be referred to as public stigma.

Self-stigma involves four processes: being aware of the public stereotypes, agreeing with these, developing the stigmatised condition, and applying these stereotypes to oneself. This forms the basis of Corrigan et al.'s *Why Try?* Model (2009). According to the model, self-stigma is problematic because it can have a negative affect on self-esteem and in turn, this can lead to a person giving up on trying to achieve goals or participating in evidence-based practices such as seeking help for their problems (Choi & Miller, 2014). A longitudinal study

has provided further support for perceptions of public stigma leading to self-stigma (Vogel et al., 2013).

The current study is specifically focussed on the impact of self-stigma and perceptions of public stigma on attitudes to help-seeking, as summarised in Figure 1 (Corrigan et al., 2012). Research on stigma and help-seeking has shown that perceptions of public stigma lead to negative views towards seeking formal help and this is largely explained by the process of self-stigma (Vogel et al., 2007).

Perceptions of public stigma and self-stigma are thought to be affected by a range of factors such as gender, with men showing higher levels of self-stigma (Vogel et al., 2011) and culture, with ethnic minorities showing greater overall stigma and lower likelihood of seeking support for mental illness (Gary & Flan, 2006).

Stigma and its impact on help-seeking in South Asian communities

South Asian communities are thought to have higher levels of public stigma towards a range of mental health difficulties (including depression and psychosis) (Arora et al., 2016; Loya et al., 2010; Robinson, 2005), higher levels of self-stigma (Eisenberg et al., 2009), and more negative views of seeking professional help for mental health issues when compared to their White British counterparts (Han & Pong, 2015; Leong et al., 2011).

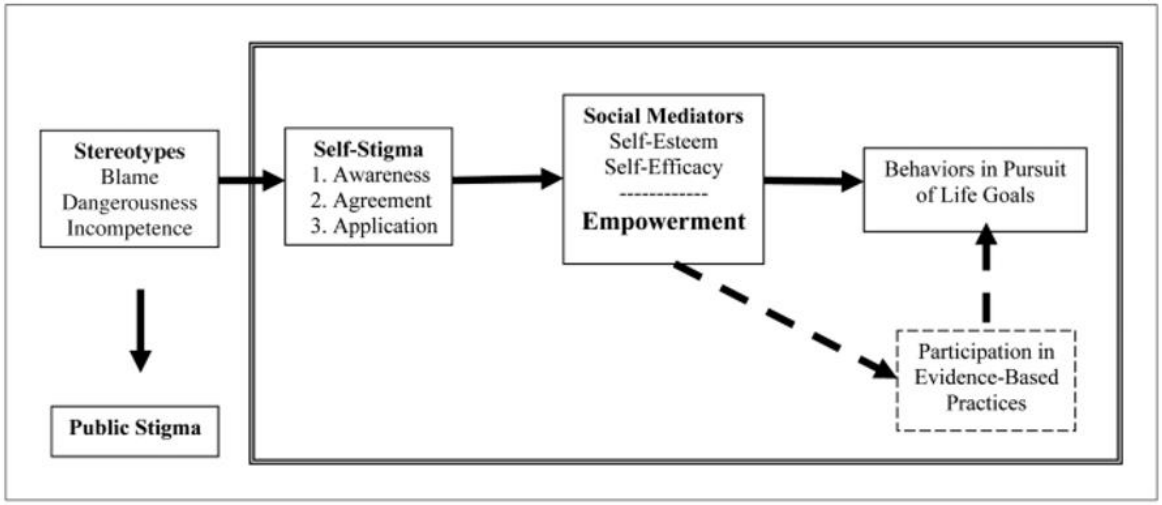
Ahmed et al. (2020) compared a group of South Asian individuals to White British individuals and found that those from a South Asian background endorsed greater prejudice and more negative stereotypes towards those with a mental health illness (public stigma). However, these studies often recruit through universities, leading to a relatively homogenous group of participants, which could limit the age, socio-economic and educational diversity and therefore generalisability of the findings.

Furthermore the role of acculturation has not been considered in these studies. Research has suggested the role of cultural differences in stigma and help-seeking may be influenced by levels of acculturation (Robinson, 2005). Acculturation refers to a person's position between maintaining their own cultural traditions and establishing or maintaining a relationship with the larger society (Postmes et al., 2013) resulting in a psychological and behavioural blend of two cultures. The concept consists of four hierarchical strategies: marginalisation, separation, assimilation, and integration. In Asian American college students, high levels of assimilation to American values led to more positive views of help-seeking for psychological distress, whereas the opposite was true for those identified as being closer to their Asian values (Elhai et al., 2007). In a group of South Asian university students in England, greater subscription to South Asian values was shown to be associated with negative attitudes towards seeking professional psychological help (Soorkia et al., 2011).

Whilst it is acknowledged that many people from a South Asian community may prefer informal methods of help seeking (Mahapatra & DiNitto, 2013), stigma is identified as a barrier for those who would otherwise wish to access formal support and leads to formal support being accessed primarily in crisis (Choudhury et al., 2009; Mukadam et al., 2015).

Figure 1

The "Why try?" Effect (Corrigan et al., 2009).



Present study

The present study aims to investigate whether British South Asians who identify as having mental health difficulties have more negative attitudes towards seeking professional psychological help than White British Individuals. This study also aims to explore whether individuals' perceptions of public stigma or individual self-stigma can explain differences in attitudes towards help-seeking. As an additional exploratory aim, this study will also look at the role of acculturation with respect to stigma and help-seeking.

It is recognised that "South Asian" encompasses several heterogeneous ethnicities and it is important to acknowledge the differences present in the communities that make up the South Asian diaspora. Research suggests there are similarities in the way Indian, Bangladeshi and Pakistani people are impacted by stigma (Yan et al., 2019), utilisation of mental health services in Pakistani and Bangladeshi women (Elhai et al., 2007), and referral to primary care mental health services. Given these similarities it felt useful and meaningful to explore help seeking across South Asian communities. In the absence of being able to explore each ethnicity individually, the grouping of South Asians will be used to explore the needs of a group that shares several main languages, religions, and cultural aspects.

The specific research questions to be addressed are:

I. Are there differences in the attitudes towards seeking professional psychological help between White British people and South Asian people, who self-identify as having a mental health difficulty?

II. Is the relationship between cultural group and attitude to seeking professional psychological help mediated by differences in self or perceived public stigma?

III. For South Asian participants, does acculturation moderate the relationship between self or perceived public stigma on attitudes to help seeking.

Hypotheses

I. (Primary hypothesis**)** South Asian participants who identify as having mental health difficulties will have more negative attitudes towards seeking professional psychological help than White British participants.

II. Higher self-stigma and higher levels of public stigma will explain any observed differences between the groups such that negative attitudes towards seeking professional help will be mediated by self-stigma and perceptions of public stigma consistent with the *Why Try?* model.

III. South Asians who are more closely aligned with their South Asian identity (measured using acculturation measure) will show higher levels of perceived public stigma and therefore higher levels of self-stigma and more negative attitudes towards seeking help than those South Asians who are less closely aligned with their South Asian identity.

Methods

Participants

Attrition

A total of 166 participants were recruited into the study. 140 went on to give consent and complete the required minimum data set. The attrition rate was therefore 15.7%.

All participants had to meet the following inclusion criteria: (I) UK residents; (II) Aged between 18 and 65 years; (III) Self-identify as belonging to either a White British or South Asian community (defined here as Indian, Pakistani, Sri Lankan or Bangladeshi (Aspinall, 2003)); (IV) Self-identify as having a (self-described) mental health difficulty currently or in the past; (V) Fluent in written English.

One participant identified as having mixed Pakistani and White British heritage and therefore did not meet inclusion criteria. This data set was excluded from analysis. 139 complete responses were used in the final analysis.

Power

An a priori power analysis (G*Power v. 3.0; (Erdfelder et al., 1996)) calculation where power = 0.80 and $\alpha = 0.05$ showed that a sample size of 128 participants was needed to detect a medium effect size of culture on attitudes to seeking professional psychological help (primary analysis).

Design

A cross-sectional design was employed to explore differences between two independent groups: White British and South Asian participants. The outcome variable

measured attitudes towards seeking help for mental health problems from professional sources. Self-stigma, public stigma and acculturation were measured as co-variables.

Measures

Demographics

Information on age, sex, mental health diagnosis (or self-identification with diagnosis), previous involvement with mental health services, and other sources of support (e.g. family, faith groups) was collected.

Perceptions of public stigma

Perceptions of public stigma were measured using the Perceptions of stigmatisation by others for seeking help scale (PSOSH) (Vogel et al., 2009). The PSOSH is a five item self-report questionnaire which measures an individual's views on how others would react to them if they were aware they were seeking help for a mental health difficulty. Each item is rated on a 1 to 5 scale, based on how much participants believe others would respond a certain way, with 1 = Not at all, and 5 = A great deal. A higher score indicates a higher perception that there will be negative public stigma. The PSOSH has good test-retest validity and good concurrent validity with measures of stigma towards help-seeking and self-stigma (Vogel et al., 2009). (Appendix 3B).

Self-stigma

Self-stigma was measured using the Self-stigma of seeking help scale (SSOSH). The SSOSH is a 10-item questionnaire which measures the extent to which an individual would hold stigmatising views towards themselves for seeking help for mental health difficulties. Items are rated from 1 = strongly disagree to 5 = strongly agree, with a higher score

indicating more negative views of self-stigma for seeking help. The SSOSH has good reliability and shows evidence of construct, criterion, and predictive validity (Vogel et al., 2006). (Appendix 3C).

Attitudes towards seeking help

This study used the Attitudes toward seeking professional psychological help scale – Short Form (ATSPPH-SF) (Fischer & Farina, 1995) to measure the extent to which an individual has positive or negative views towards seeking professional psychological help for a mental health difficulty. The questionnaire consists of 10-items which are rated on a 4-point Likert scale, with 0 = disagree and 3 = agree. A higher score indicates a more positive view towards seeking professional psychological help. The ATSPPH-SF has been shown to have good reliability, good construct validity and good criterion validity (Elhai et al., 2007). (Appendix 3D).

Acculturation

The Four Item Social Identity scale (FISI (Postmes et al., 2013)) was used to measure acculturation in those participants who identified as South Asian. This measures the felt sense of belonging to a particular social group. In this study, it was used to refer to the group defined as a South Asian Community. Each of the four items are rated on a seven-point scale, from 1 = Strongly disagree, to 7 = strongly agree. A higher score indicates greater identification with South Asian values and therefore less acculturation to the host culture, in this case, British culture. The FISI shows good reliability and validity in measuring social identification (Postmes et al., 2013). (Appendix 3E).

Procedure

Participants were recruited online, through volunteer sampling. Recruitment took place from May 2021 to August 2021. The study was advertised on social media pages and distributed through both general and South Asian mental health advocacy groups e.g. community support group *Taraki*. Posters were also placed in community buildings, although this was limited due to restrictions during the covid-19 pandemic.

Interested participants were asked to click on a link to Qualtrics – an online survey platform. Participants were presented with an information sheet and were asked to confirm they met inclusion criteria and consented to take part. Participants were then presented with the aforementioned measures. Upon completion or exiting the survey, participants were shown a debrief statement. The study was approved by the Ethics Committee of the University of Oxford, Approval Reference: R74111/RE001.

Statistical Analyses

All analyses were carried out using IBM SPSS Statistics version 27 for Windows 10. Descriptive statistics were used to summarise participant demographics; continuous variables were summarised using means and standard deviations; t-tests were used to compare between group differences. Categorical variables were summarised using percentages and Chi squared was used to compare between groups.

To address the primary hypothesis, a one-way ANOVA was used to examine the effect of culture on ATSPPH scores. Secondly, a mediation analysis according to Hayes method (Hayes, 2012) was used to explore if the relationship between culture and ATSPPH was mediated by self or public stigma. A moderation analysis was then used on scores from South Asian participants only, to explore if acculturation moderated the impact of stigma on ATSPPH.

Results

Demographics

Of the 139 participants, 58 participants (41.7%) were White British, and 81 participants (58.3%) identified as belonging to a South Asian community. Age, sex, and a breakdown of the ethnicities present in the South Asian group are presented in Table 1.

Pearson's Chi square tests showed there were no group differences in age (χ^2 (1, 3) = 3.140, p = .371), however there were significant group differences in sex (analysis conducted on Male and Female only to account for minimum required cell numbers) (χ^2 (1, 1) = 6.316, p = .012). The White British group had more males than expected, and fewer females, and the South Asian groups had fewer males than expected but more females.

Clinical Characteristics

Clinical characteristics are shown in Table 2. Some diagnoses given in the "Other" section included premenstrual dysphoric disorder (n = 2); complex post traumatic stress disorder (PTSD) (n = 2); attention deficit hyperactivity disorder (ADHD) (n=1) and several comorbidities. Statistical comparison was not completed on mental health difficulty due to the number of cells which did not meet minimum cell number requirements.

Previous Help-seeking

Ninety-two participants (66% of total sample) had sought previous support from mental health services. 22% of those 92 found services to be very effective, 43% found services to be somewhat effective, 20% found services to be somewhat ineffective and 15% found services to be very ineffective. There were no significant differences between the two groups in consulting a GP, receiving a formal diagnosis, and use of mental health services; there were

also no differences between the groups in how effective they rated mental health services to be.

Alternative places for help seeking included friends (57%), family (55%) and social media for individuals in the White British group and friends (60%), family (51%) and faith support (35%) for those in the South Asian group.

Table 1

Summary of demographics of participants according to group.

Group	White British (n = 58)		South Asian (n = 81)		Total (n = 139)	
	n	%	n	%	n	%
Age range (years)						
18 to 24	8	14%	21	26%	29	21%
25 to 30	25	43%	33	41%	58	42%
31 to 40	10	17%	14	17%	24	17%
41 to 50	3	5%	10	12%	13	9%
51 to 60	7	12%	3	4%	10	7%
61 to 65	3	5%	0	0%	3	2%
No response given	2	3%	0	0%	2	1%
Sex						
Male	17	29%	11	14%	28	20%
Female	37	64%	70	86%	107	77%
Other	2	3%	0	0%	2	1%
No response given	2	3%	0	0%	2	1%
Ethnicity						
White British	58	100%	-	-	58	42%
Indian	-	-	47	58%	47	34%
Pakistani	-	-	22	27%	22	16%
Bangladeshi	-	-	7	9%	7	5%
Sri Lankan	-	-	2	2%	2	1%
Other	-	-	3	4%	3	2%

Table 2

Summary of clinical characteristics across groups.

Group	White British (n = 58)		South Asian (n = 81)		Total (n = 139)	
	n	**%**	**n**	**%**	**n**	**%**
Mental health difficulty						
Anxiety	19	33%	30	37%	49	35%
OCD	0	0%	1	1%	1	1%
Depression	9	16%	24	30%	33	24%
ADHD	0	0%	2	2%	2	1%
Eating Disorder	3	5%	5	6%	8	6%
Bipolar disorder	3	5%	0	0%	3	2%
Psychosis	2	3%	0	0%	2	1%
EUPD	6	10%	0	0%	6	4%
PTSD	5	9%	2	2%	7	5%
Other	3	5%	9	11%	12	9%
No response given	8	14%	8	10%	16	12%
GP consulted	37	64%	48	59%	85	61%
Formal diagnosis	30	52%	31	38%	61	44%
Previous use of Mental health services	41	71%	51	63%	92	66%

Differences in attitudes to seeking help

The original data violated two assumptions of a One-Way ANOVA. Firstly, a Kolmogorov-Smirnov test for normality showed that the data for the South Asian group ($D(81) = .953$, $p = .044$) and the White British group ($D(58) = .907$, $p = .007$) were not normally distributed. The distribution for both groups had a slight but significant negative skew in the distribution. There were also significant outliers. The data was then transformed using a square root of the reflection of the data, which led to it fitting all assumptions for a one-way ANOVA. A second Kolmogorov-Smirnov test of normality revealed the data distributions for both South Asian ($D(81) = 0.988$, $p = .200$) and White British ($W(58) = 0.962$, $p = .197$) groups were normal following the transformation.

A one-way ANOVA was used to address the primary hypothesis of whether there are differences in attitudes towards seeking psychological support between the White British and South Asian groups. There were no statistically significant differences in attitudes to seeking professional psychological help between the two groups $F(1, 137) = 1.040$, $p = 0.310$. Mean attitudes towards seeking professional psychological help (ATSPPH scores) were similar in the White British group ($n = 58$, 19.759 ± 0.737), and South Asian group ($n = 81$, 20.556 ± 0.614).

Mediation effects of self-stigma and perceptions of public stigma

A secondary hypothesis was to explore the impact of self-stigma and perceptions of public stigma of seeking help on ATSPPH scores. As there were no group differences between South Asian participants and White British participants, the subsequent mediation and moderation analysis was not carried out. In its place, simple correlations were used to explore if either SSOSH or PSOSH were associated with attitudes to seeking help, separately for the two groups. Results are summarised in Table 3.

For participants in the White British group, both self-stigma and public stigma was negatively correlated with attitudes towards seeking help, whereby an increase in either self- or public-stigma led to a poorer attitude to seeking professional psychological help. In the South Asian group, only self-stigma appeared to be significantly negatively correlated with attitudes towards seeking help. Perceptions of public-stigma were also negatively correlated with attitudes towards seeking professional help, however this association did not appear to be significant.

Table 3

Pearson's correlation coefficients and p values for correlations between SSOSH and ATSPPH, and PSOSH and ATSPPH, presented separately for White British participants and South Asian participants

Correlation	White British (n = 58)		South Asian (n = 81)	
SSOSH*ATSPPH	-.515	<.001	-.481	<.001
PSOSH*ATSPPH	-.474	<.001	-.121	.281

Post-hoc analyses

Due to sex differences between the groups, a post-hoc analysis of covariance was conducted on ATSPPH, PSOSH and SSOSH with sex as a co-variate. Sex differences between groups did not account for any of the differences between groups in ATSPPH (p = .671), PSOSH (p = .157) or SSOSH (p = .932).

Discussion

This study aimed to understand whether there are differences in attitudes to seeking professional psychological help between a group of White British and South Asian participants. All participants identified as having a mental health difficulty.

Differences in attitudes to seeking help

There were no differences in attitudes towards seeking professional psychological help between the White British and South Asian groups. This is inconsistent with the findings from other literature (Choi & Miller, 2014; Eisenberg et al., 2009; Masuda et al., 2009) which have found a significant difference in help-seeking or attitudes to help seeking between Asian-American groups and European American groups. These studies recruited university students and were conducted in America. The present study recruited from the general population which could potentially improve the reliability of the data. Secondly, there may be key differences between British South Asians and Asian Americans, as the two groups are defined differently (Minority Rights Group, 2021).

In America, healthcare is privatised which means some individuals may face financial barriers that make it harder for them to seek psychological support, for example, minority groups (Lai & Surood, 2013). In the UK, healthcare is free at the point of delivery, it may be possible that attitudes to seeking professional psychological help are influenced by some of these financial and service-related barriers (for example, item 8 of ATSPPH addresses time and money commitments). Studies on the impact of healthcare insurance have shown increases in healthcare coverage leads to increased service utilisation and reduced disparities between ethnic groups (Card et al., 2008).

Mediation effects of self-stigma and perceptions of public stigma

The mediation and moderation analysis was not carried out, as there were no significant group differences in ATSPPH and therefore no relationship to explore a mediation or moderation of. In its place, basic correlations showed that regardless of group, higher self-stigma does lead to more negative attitudes to seeking professional psychological help, however higher perceptions of public-stigma only seemed to be correlated with more negative attitudes to seeking help in the White British group, not the South Asian group.

Previous papers recruited samples who did not experience a mental health difficulty. This study recruited participants who have specifically experienced a self-described mental health difficulty and would have had to consider whether to seek professional psychological support. The clinical characteristics of this sample suggests South Asian participants have similar attitudes to seeking help as White British participants, and were as likely to consult a GP or have a formal diagnosis as White British participants. This brings into question whether the under-representation of South Asians in mental health services is due to other barriers outside of stigma, as there appears to be evidence of equal "help-seeking" in this sample (Bhavsar et al., 2021).

This finding does not fit with Corrigan et al.'s *Why Try?* Model (2009). One possibility could be that the model is useful in describing how stigma could lead to individuals not engaging in evidence-based interventions such as seeking professional help, however if the sample used in this study did engage in such interventions, i.e., two thirds of the sample have accessed help, the model may not apply in the same way and so stigma may not be as relevant.

Moderation effects of acculturation in South Asian group

Acculturation did not moderate the relationship between self-stigma and ATSPPH. Acculturation was found to moderate the relationship between perceptions of public stigma and ATSPPH. This means those South Asians who did not identify with being South Asian as strongly, were more likely to experience the effect of high public stigma on attitudes to help seeking. Strong identification with a South Asian identity was protective against the impact of perceived stigma from others on attitude to seeking help. However, despite the significant impact of acculturation, public stigma was not significantly associated with ATSPPH.

It could be hypothesised that a strong sense of ingroup identity, as seen in acculturation scores here, can be protective against the impact of stigma in line with other literature. (Derks et al., 2006). This could be because a strong sense of group identity can lead to more positive perceptions of receiving help, and social solidarity can be protective against stigma (Reicher et al., 2006). As the population of this study was relatively young, the South Asian sample may have felt more able to have equal access to mental health services in England and may be less likely to consider their close community to stigmatise them for seeking help. Whilst research on stigma and help seeking in South Asian populations has grown over recent years, acknowledging the nuanced challenges faced by first- and second-generation South Asian people through the lens of acculturation and assimilation lags behind, and the understanding of this relationship remains unclear.

Clinical Implications

Harwood and colleagues (2021) highlighted the ongoing unequal access to services between White British individuals and individuals of other ethnicities; individuals who are Black African, Asian, or Mixed ethnic groups are less likely to self-refer to a mental health service, and less likely to receive an assessment or treatment. If these differences are not as a

result of self or public stigma or attitudes to help seeking, mental health providers and services should consider moving beyond thinking about barriers placed within the individual, to consider systemic barriers, or the role of stigma *from* services (Schulze, 2007).

Not all minority groups will face barriers in the same way; within the South Asian diaspora different groups may face different challenges – one size does not fit all. It is vital that services take the time to understand the communities they serve in their local area (Arafat, 2021) to understand what services could be doing to support engagement. Self-stigma may impact engagement regardless of cultural group and this should also be considered.

Implications for Future Research

These findings suggest further research exploring structural barriers in the mental health care system may be useful to better understand how people from Non-White British communities' experience mental health services in the UK. It is recommended that research should focus on qualitative methodologies, particularly with those who have experienced mental health difficulties, to better understand the experience of the British South Asian community. Future research could benefit from considering the role of acculturation as a possible strength as well as a potential challenge to better understand generational differences.

This study recruited a majority of participants with anxiety or depression. Future research could investigate the impact of other diagnoses, such as schizophrenia which may be more stigmatising (Pescosolido et al., 2010) and were less represented in this study.

Limitations

This study exceeded the minimum required sample number for a medium effect size. However, considering the conflicting finding with extant literature, it may be the case that the true effect size in this population was too small to detect using this sample size and therefore, a larger sample size may have been valuable.

There were significantly different amounts of males and females in the two groups. Males are thought to experience greater self-stigma than females (Vogel et al., 2011) and therefore if there were more males in the White British group than South Asian, this could have inflated stigma scores in the White British group. Furthermore, the PSOSH measure did not define who a "close community" was and so this would be left to interpretation of the participants in each group.

Online data collection could have biased the sample to favour those characteristics of internet users and may have restricted the representativeness of the sample (Andrade, 2020). Additionally, as the study population had high rates of depression (24%) and anxiety (35%), these difficulties may be considered less stigmatising than other difficulties such as psychosis (Chang et al., 2016), and therefore stigma rates in this sample may have been lower overall than a sample with higher proportions of highly stigmatised difficulties.

This study also relied on self-identified mental health difficulties; this relies on the accuracy of self-report and therefore is not verified.

Conclusion

This study suggests South Asian individuals have similar attitudes to seeking professional psychological help as those who are White British, and self and public stigma do not appear to impact this relationship. Furthermore, acculturation appeared to only be related to perceptions of public stigma and not self-stigma, but this cannot prove causality. Strong

identification with a south Asian identity was thought to be protective against the impact of public stigma on help-seeking. These findings indicate that the reasons that South Asians are under-represented in some mental health services may not be due to their own personal views on stigma, but rather other potential barriers that were not explored in this paper.

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Executive Summary

Study Background

Research and data from mental health services has shown that people who are White are more likely to use mental health services than people who are not White (often referred to as ethnic minorities in the U.K.). There are several possible reasons for this; people who are from an ethnic minority might experience more stigma. Stigma is a process where people make negative judgements about someone with a particular characteristic, like mental illness.

Ethnic minorities, particularly people from a South Asian community (e.g. Indian, Bangladeshi, Pakistani, Sri Lankan or another group) might be more likely to experience stigma and therefore might be less likely to use a mental health service, because the stigma makes them feel judged or criticised for seeking help.

A model called the "Why Try?" model suggests public stigma (where other people around you e.g. family, society, hold negative views about you) can make a person experience self-stigma (where the person internalises other people's views and actually feels negatively towards themselves too). The model suggests this may lead to some individuals thinking "Why try?" and therefore they choose not to go to mental health services for this reason. People from a South Asian community may experience higher levels of both public and self-stigma, and this is thought to be linked to why they are not using mental health services as much.

However, stigma isn't the only explanation. Sometimes even when ethnic minorities do try and seek help, mental health services might not be able to meet their needs, for example, they may not understand that person's language, or religion, or culture, or they may not have a diverse staff team so people from a minority group might not *want* to go to that service.

A lot of the research that has looked at public and self-stigma in South Asian communities used university students – these students didn't necessarily have a mental health difficulty and would have been in a specific age bracket, and been from a particular educational background, so their results might not be the same for everyone else. A lot of the studies were also carried out in America.

This study aimed to see if public stigma or self-stigma was linked to people's attitudes to seeking help or not. This study aimed to recruit people from all ages (over 18 years), who have all experienced mental health difficulties themselves, so would have a clear idea of what help they would consider pursuing. In order to be able to compare results, this study recruited people who identify as White British and people who identify as being from a South Asian community.

Finally, this study measured acculturation which measures how much a person from a different culture identifies as being a part of that culture, instead of the culture of where they live now. This was measured because acculturation may affect how much stigma impacts people from a South Asian background.

The research questions

This study had three research questions:

1. Do White British people have different attitudes towards seeking help for their mental health, compared to people from a South Asian community?
2. Does public stigma or self-stigma affect people's views of seeking help in each group?
3. For those people who are from a South Asian community, does acculturation matter in how much self- or public- stigma they experience and does this impact their view on seeking help?

Study Methods

The study was conducted online using a series of questionnaires. To find participants, the research was shared on social media to pages that talk about mental health in general or talk about mental health in the South Asian community.

Participants who clicked on the study were asked to confirm they were over 18 years old, self-identified as being White British or South Asian, and self-identified as having a mental health difficulty. They were then asked some further voluntary questions about which mental health difficulty they experience, whether they had ever been to a mental health service, and what other help they had sought. They were then shown three questionnaires on public stigma, self-stigma and attitudes to seeking professional psychological help. People who were from a South Asian community were given one extra questionnaire to measure acculturation.

Key Findings

This study recruited 139 participants, 58 participants who identified as White British, and 81 participants who identified as South Asian. There were 107 women, and 28 men (two participants identified as another sexuality, and two participants did not respond). The age range was 18 to 65 years old.

The main finding was that there was no difference in attitudes to seeking professional psychological help between the two groups, and there was no difference in perceptions of public stigma or self-stigma.

Higher self-stigma was associated with negative attitudes to seeking professional help, but this didn’t change across the two groups. Finally, acculturation did not affect the relationship between self-stigma and help-seeking for people in the South Asian group, but it did affect the relationship between public stigma and help-seeking, whereby high identification to the South Asian identity was protective against the impact of public stigma.

Conclusion

This study shows that stigma is not always the reason why ethnic minorities are less represented in mental health services. In this study, people from a South Asian background had the same views towards seeking help as White British people and had similar levels of stigma. In fact, identifying strongly with their South Asian identify seemed protective.

This suggests future research should focus on what some of the service-related barriers might be when people try to seek help. Research could also look at the role of acculturation further, particularly between first-generation and second-generation South Asians, as the population in this study was relatively young and this difference has not been fully understood yet.

Connecting Narrative

Overall reflections

Coming from a master's degree that taught me to be confident in my research skills, I was really looking forward to carrying out research to such a high quality as part of my doctorate. Having to choose my projects at such an early stage felt overwhelming at first; I had so many areas I could have been passionate about, it was difficult to think about a single area to research. This is why my projects cover such a diverse range of topics, however the theme that draws them all together is something close to my heart; the importance of understanding marginalised or stigmatised groups. I see my role as a clinician and an academic as being important in helping to understand those who are marginalised, whether that be in my clinical work or through the topics I choose to research.

Critical review of the literature

I have previously volunteered for eating disorder charities and worked in an adult eating disorder team pre-doctorate. As the mental health illness with the highest mortality, I have always been interested in furthering my understanding of eating disorders. However, I was also aware that this was a heavily researched area, and so to make my work valuable and important I wanted to focus on a topic that is covered less often. I recall having a conversation with a colleague about a patient who had been receiving therapy for her eating disorder for several months, and only then did it become apparent that she was also struggling with substance misuse issues. I became curious and began doing some reading, and was struck by how old, stigmatising, and disjointed the literature was. Nobody seemed to have a sufficient understanding of this comorbidity, and even fewer people seemed to be talking about it. This is what drew me to this topic. The literature was stigmatising in the sense that it often spoke about eating disorders as "addictive" and used dated terminology such as

"addicts". I hope my review helps others to get a good overview of psychological explanations for the comorbidity and helps to focus future research on possible mechanisms that are routed in theory and align well with possible interventions.

Service Improvement Project

This project is the one that sits closes to my heart. In 2015 my grandad was diagnosed with dementia. His reaction to the news was that he would "rather have a cancer". Just seven short months later, he passed away of throat cancer. Through this process, he was unable to access any help for his dementia and my family was left feeling terrified of this illness we knew nothing about.

The Panjabi community are struggling with rising rates of dementia, but this is not paralleled with rising levels of support, or rising levels of awareness. So when an opportunity came during a research fair for me to support South Buckinghamshire Memory Clinic in reviewing how they work with Panjabi speakers, it pulled on a big personal passion of mine; again, my desire to support those who are marginalised or may struggle to access support.

This was also the project that taught me the most; firstly, I faced several challenges in recruitment and had to learn new ways of engaging the local community. Being able to use my mother tongue to help me with this was a pleasure, and finding ways to engage with local services, third sector organisations and community groups taught me about how I can involve various stakeholders in the research process.

This project was also my first time completing qualitative data analysis. I found this disconcerting in the initial stages, as I was less familiar with the process I had chosen, thematic analysis. I realised how important it was to keep a track of all of my decisions throughout the research process, for example, why I asked the questions I did and why I grouped themes in the way I did. This process relied on my self-reflexivity skills, which I

greatly enjoyed as I was able to bring aspects of my "self" into research supervision meetings and I was able to also explore the thought processes of my supervisors to support the decisions I made.

Theory driven research project

As mentioned, my projects were driven by a theme of wanting to understand and support marginalised and stigmatised groups. Due to my own cultural background, I was drawn to researching the needs of the South Asian community.

I met with my Internal Supervisor, Lorna Hogg, and we began to have conversations of what this might look like. Lorna specialises in the area of stigma, and so she bought a particular interest in this to our meetings. I became curious about the link between culture, stigma and the impact on help-seeking and so chose this the topic for my research.

I consulted with several partners in experience along the journey. I recall one notable conversation with a Panjabi male from Canada with lived experience of mental health. He talked to me about an alternative perspective I had not previously considered; a lot of literature focuses on placing the "problem" within the individual that is under-represented in services. For example, *they* are experiencing stigma, or *their community* stigmatises them, or *their religion* impacts their beliefs. Whilst some of this may be true, this partner in experience alerted me to how this is only part of the picture, and in fact the problems are systemic, and that it is not always a case of individuals "not seeking help" but also a case of services not being set up to help them in a way that caters for everybody's needs.

In light of this conversation, I was able to understand the findings from my research within this context. The fact that my data shows there was no difference in stigma or attitudes to help seeking makes me keen to publish my findings, as non-significant findings are much less likely to be published but are perhaps just as important findings.

Acknowledgements

My first thank you is to all of my participants; to everyone who completed my online research study and was willing to share personal information about their experience of mental health, and to everyone who gave up their time so I could interview them in my slightly clumsy Panjabi, I would not have this thesis without any of you, so thank you.

To my research supervisors, Anna Crabtree, Reena Vohora, Lorna Hogg, Ryan Nah, and Myra Cooper, and my course tutor Matthew Knight – your thoughtfulness, your generosity with your time and the unique contributions you each brought to our meetings made the past three years enjoyable, and have shaped the researcher I can now confidently say I am.

To my family; my mum, dad, brother, sister, Bibi and baba, throughout all my achievements, you will always be in my heart and mind.

My biggest thank you goes to my two biggest supporters. Cathy, and Marcel. Cathy, our journey together through this doctorate was written in fate and you have been there through every single step of this journey; from moving houses in a pandemic, to drying my tears, to being my biggest cheerleader. I could not have achieved any of this without you by my side, and I know I have a sister for life in you.

Marcel, you inspire me every day and have kept me going through all of the evenings and weekends I have been busy typing away. Thank you for all the times you made my breakfast because I didn't have time to eat, all the times you've prompted me to go for a walk because you know before anyone else when I need some time out, and for being my sense of home. I'm excited to see what life with you will be like in our next chapter.

My final thank you is the most immeasurable. In the remembrance of God are knowledge, meditation and the essence of wisdom.

Appendices

Appendix 1A: CRL Author Guidelines

1. SUBMISSION AND PEER REVIEW PROCESS

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at: mc.manuscriptcentral.com/ijed.

For help with submissions, please contact: **ijed@wiley.com**.

This journal does not charge submission fees.

DETAILED MANUSCRIPT PREPARATION GUIDANCE

Title Page

The Title Page of the manuscript should comprise:

- A brief informative title containing the major keywords. The title should not contain abbreviations (see Wiley's best practice SEO tips).
- All co-author details, including affiliation and email address.
- Up to ten keywords.
- If published already as a preprint, a link to the preprint server.
- An author contributions statement that succinctly indicates how each author contributed to the piece of work, using the CRediT "Contributor Roles Taxonomy". Author contributions are also required within the submission form of both original and revised submissions.
- Any applicable statements relating to our ethics and integrity policies, such as:
  - data, materials and code availability statement
  - funding statement or other acknowledgements of support
  - conflict of interest disclosure
  - permission to reproduce material from other sources

Abstract

The Abstract provides a succinct summary of the article content. The recommended format and word limit vary by **article type**.

Structured abstracts have a recommended maximum of 250 words and should be organized into: **Objective**: state the primary purpose of the article, or major question addressed in the study. **Method**: indicate the sources of data, give brief overview of methodology, or, if it is a review article, how the literature was searched and articles were selected for discussion. For research-based articles, briefly note study design, how participants were selected, and major study measures. If your data are based on a preregistered study, provide the preregistration number or link. **Results**: summarize the key findings. **Discussion**: indicate main clinical, theoretical, or research applications/implications.

Main Text File

The main text file should be in MS Word and include the following content and recommended formatting:

- Main body, formatted as Introduction, Method, Results, and Discussion, as recommended by the International Committee of Medical Journal Editors (ICMJE) (**J. Pharmacol. Pharmacother. 2010, 1, 42–58**). Exceptions to these formatting recommendations include Commentaries, Forum articles, and Perspective articles.
- A Public Significance statement (< 70 words) that explains why this research is important and is written in plain English for a general, educated public.
- Figure titles should be supplied as a complete list in the text.

References

Please refer to **article types** regarding the number of permissible references.

This journal offers Free Format submission and authors may submit using their preferred referencing style, as long as consistency is applied throughout the manuscript.

The typesetter will apply the American Psychological Association reference style on manuscripts accepted for publication. If authors wish, they may review **reference style guidelines** prior to submission.

Tables

Tables should include a descriptive title and, if needed, footnotes defining abbreviations and any other information critical to interpreting the data shown.

Figures

Figures should have legends (and if needed, notes) that succinctly describe the information being displayed. Figures should be uploaded in the highest resolution possible.

Supporting Information

Supporting Information is information that is supplementary and not essential to the article but provides greater depth and background. Examples include more detailed descriptions of therapeutic protocols, results related to exploratory or post-hoc analyses, and elements otherwise not suitable for inclusion in the main article, such as video clips, large sections of tabular data, program code, or large graphical files. It is *not* appropriate to include in the Supporting Information any text that would normally go into a Discussion section; all discussion-related material should be presented in the main article.

Additional Guidance Regarding Manuscript Preparation

The IJED reaches a global audience. Authors are encouraged to consider the implications of their research for populations, settings, or policies beyond those applicable to their own local circumstances.

For studies involving human participants, to aid comprehensive and consistent reporting across regions/countries and cultures, the IJED provides **Demographic Characteristics Reporting Guidelines**.

Authors for whom English is not their first language are encouraged to seek assistance from a native or fluent English speaker to proofread the manuscript prior to submission.

Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

Terminology. Authors should refrain from using terms that are stigmatizing, discriminatory, or ambiguous. The journal rejects stand-alone nouns that refer to individuals by their diagnosis or condition (e.g., “anorexics," “obese,” “diabetics," etc.), race and ethnicity identification (e.g., “Whites,” “Hispanics,” etc.), or presumed disadvantaged status (“minorities”). “Participants” should be used in place of “subjects.” For further explanation and examples, see "*Speaking of that: Terms to avoid or reconsider in the eating disorders field*" (DOI: **10.1002/eat.22528**.)

Abbreviations: Only abbreviate terms if they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter, use the abbreviation only.

Units of measurement: Please use the International System of Units. Access **www.bipm.fr** for more information.

Numbers under 10 should be spelt out, except for: measurements with a unit (8 mmol/L); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Trade Names: Chemical substances or drugs should be referred to by the generic name only, not by trade names. For proprietary drugs, the proprietary name and the name and location of the manufacturer should be added in parentheses.

Reviews and Meta-Analyses – see checklist

These articles critically review the status of a given research area and propose new directions for research and/or practice. Both systematic and meta-analytic review papers are welcomed if they review a literature that is advanced and/or developed to the point of warranting a review and synthesis of existing studies. Reviews of topics with a limited number of studies are unlikely to be deemed as substantive enough for an IJED Review paper. The journal does not accept papers that merely describe or compile a list of previous studies without a critical synthesis of the literature that moves the field the forward.

All Review articles must follow the **PRISMA Guidelines**, summarized in Page et al. (2021) article entitled *"The PRISMA 2020 statement: an updated guideline for reporting systematic reviews"* (J. Clin. Epidemiol.). See **translations of PRISMA documents**. Authors who choose this contribution type must include the **2020 PRISMA Flow Diagram** and complete the **IJED Review Checklist** upon submission of the manuscript. This example is for informational purposes only. During the submission process, authors will be prompted to confirm they have followed the Review checklist in the submission form. The rationale for any unchecked items on the Review Checklist must be explicitly described in the accompanying Cover Letter.

In addition to the required PRISMA review paper components, all Review articles must also include a full description of the age, gender, race, ethnicity, and socioeconomic status of participants in the reviewed studies. This information will most often take the form of separate entries in tables describing the studies included in the review. If a paper included in the review does not report these demographic variables, then "NR" (Not Reported) should be indicated in the appropriate table cells. Review papers must also explicitly discuss (in the text) the diversity of the samples and the ways in which this diversity (or lack thereof) may impact the generalizability and representativeness of the study results and conclusions.

RESEARCH REPORTING GUIDELINES

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it.

At the time of submission, authors will be prompted to confirm whether they have completed a checklist that is specific to each of IJED's article types and designed to aid authors in ensuring that their article includes required and recommended information about study methods and procedures.

If the study sample lacks diversity in demographic characteristics, particularly with populations typically underrepresented in eating disorders research (e.g., male participants, minoritized populations, etc.), this should be explained (unless self-evident, e.g., a study of obstetric complication in patients with eating disorders would not include male participants) and noted as a study limitation and an area for future research.

Authors should apply study relevant research reporting standards. A list of the most well-known guidelines is given here:

- Consolidated Standards of Reporting Trials (CONSORT)
- Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT)
- Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)
- PRISMA Protocols (PRISMA-P)
- Strengthening the Reporting of Observational studies in Epidemiology (STROBE)
- Consolidated criteria for reporting qualitative research (COREQ)
- STARD 2015: An Updated List of Essential Items for Reporting Diagnostic Accuracy Studies
- TRIPOD: Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis
- Consolidated Health Economic Evaluation Reporting Standards (CHEERS)
- The EQUATOR Network: an author's one-stop-shop for writing and publishing high-impact health research

- FORCE11: Recommended reporting guidelines for life science resources
- ARRIVE (Animal Research: Reporting of In Vivo Experiments) guidelines
- Guidance for the Description of Animal Research in Scientific Publications
- The Gold Standard Publication Checklist
- Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals

Additional Guidelines for Cover Pictures, Visual Abstracts, and Table of Contents Graphics

- Concepts illustrated in graphical material must clearly fit with the research discussed in the accompanying text.
- Images featuring depictions or representations of people must not contain any form of objectification, sexualization, stereotyping, or discrimination. We also ask authors to consider community diversity in images containing multiple depictions or representations of people.
- Inappropriate use, representation, or depiction of religious figures or imagery, and iconography is prohibited.

- Use of elements of mythology, legends, and folklore might be acceptable and will be decided on a case-by-case basis. However, these images must comply with the guidelines on human participants.
- Generally, authors should consider any sensitivities when using images of objects that might have cultural significance or may be inappropriate in the context (for example, religious texts, historical events, and depictions of people).
- Legal requirements:
    - All necessary copyright permission for the reproduction of the graphical elements used in visuals must be obtained prior to publication.
    - Clearance must be obtained from identifiable people before using their image on the cover, table of contents or graphical abstract and such clearance must specify that it will be used on the cover, graphical abstract or table of contents. Use within text does not require such clearance, unless it discloses sensitive personal information, such as medical information. In all situations involving disclosure of such personal information, specific permission must be obtained. and images of individuals should not be used in a false manner.

Graphics that do not adhere to these guidelines will be recommended for revision or will not be accepted for publication.

Author Guidelines updated March 2022

Appendix 1B: CRL Search terms

Table 1

Terms searched across six electronic databases. Conducted November 2020 and updates in May 2022.

Combinations	Terms Searched
1	"eating problem*"[Title/Abstract] OR "binge eating*"[Title/Abstract] OR anorexi*[Title/Abstract] OR bulimi*[Title/Abstract] OR "eating disorder*"[Title/Abstract]
2	eating disorders [MeSH Terms]
3	1 or 2
4	Comorbid*[Title/Abstract] OR Predictor*[Title/Abstract] OR Mechanism*[Title/Abstract] OR Prevalence[Title/Abstract] OR impulsiv*[Title/Abstract] OR "affect regulation"[Title/Abstract] OR "affect dysregulation"[Title/Abstract] OR "emotion regulation"[Title/Abstract] OR "emotion dysregulation"[Title/Abstract] OR "self-esteem" "Self esteem"[Title/Abstract] OR "novelty-seeking"[Title/Abstract] OR "distress-tolerance"[Title/Abstract] OR personalit*[Title/Abstract] OR "anger rumination"[Title/Abstract] OR "experiential avoidance"[Title/Abstract] OR anger[Title/Abstract] OR association[Title/Abstract] OR Angry[Title/Abstract] OR "Dual Diagnosis"[Title/Abstract] OR "Self perception"[Title/Abstract] OR "Self Worth"[Title/Abstract]
5	comorbidity [MeSH Terms]
6	self esteem [MeSH Terms]
7	emotional regulation [MeSH Terms}
8	4 or 5 or 6 or 7
9	"Substance* Abuse"[Title/Abstract] OR "Substance Misuse"[Title/Abstract] OR "Drug Addict*"[Title/Abstract] OR "Drug Abuse"[Title/Abstract] OR "Drug Misuse"[Title/Abstract] OR Ecstasy[Title/Abstract] OR MDMA[Title/Abstract] OR Cannabis[Title/Abstract] OR Cocaine[Title/Abstract] OR Heroin[Title/Abstract] OR Opiate*[Title/Abstract] OR Addict*[Title/Abstract] OR "Alcohol* Abuse"[Title/Abstract] OR "Alcohol Misuse"[Title/Abstract] OR Alcoholism[Title/Abstract] OR Alcoholic*[Title/Abstract] OR "Problem Drinking"[Title/Abstract]
10	substance abuse [MeSH Terms]
11	8 or 9
12	3 and 8 and 11

Appendix 1C: Quality Assessment tool

STANDARD QUALITY ASSESSMENT CRITERIA FOR EVALUATING PRIMARY RESEARCH PAPERS

Manual for Quality Scoring of Quantitative Studies

Definitions and Instructions for Quality Assessment Scoring

How to calculate the summary score

Total sum = (number of "yes" * 2) + (number of "partials" * 1)

Total possible sum = 28 – (number of "N/A" * 2)

Summary score: total sum / total possible sum

1. Question or objective sufficiently described?

Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is not considered sufficiently described.

Partial: Vaguely/incompletely reported (e.g. "describe the effect of" or "examine the role of" or "assess opinion on many issues" or "explore the general attitudes"...); or some information has to be gathered from parts of the paper other than the introduction/background/objective section.

No: Question or objective is not reported, or is incomprehensible.

N/A: Should not be checked for this question.

2. Design evident and appropriate to answer study question? (If the study question is not given, infer from the conclusions).

Yes: Design is easily identified and is appropriate to address the study question /

objective.

Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question.

No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified.

N/A: Should not be checked for this question.

3. Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.

Yes: Described and appropriate. Selection strategy designed (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defi ned (e.g., "cancer" -- ICD code or equivalent should be provided). Studies of volunteers: methods and setting of recruitment reported. Surveys: sampling frame/strategy clearly described and appropriate.

Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as "volunteers" or "healthy volunteers". Surveys: target population mentioned but sampling strategy unclear.

No: No information provided. Or obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in

men). Or presence of selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study).

N/A: Descriptive case series/reports.

4. Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?

Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defi ned (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). Decision analyses: baseline estimates for input variables are clearly specified.

Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). Or incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). Decision analyses: incomplete reporting of baseline estimates for input variables.

No: No baseline / demographic information provided.

N/A: Should not be checked for this question.

5. If random allocation to treatment group was possible, is it described?

Yes: True randomization done - requires a description of the method used (e.g., use of random numbers).

Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).

No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys.

6. If interventional and blinding of investigators to intervention was possible, is it reported?

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys.

7. If interventional and blinding of subjects to intervention was possible, is it reported?

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys.

8. Outcome and (if applicable) exposure measure(s) well defi ned and robust to measurement / misclassification bias? Means of assessment reported?

Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, "objective" criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. Surveys: clear description (or reference to clear description) of questionnaire/interview content and response options. Decision analyses: sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, or not sure (i.e., not reported in detail, but probably acceptable). Or precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. Or instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). Surveys: description of

questionnaire/interview content incomplete; response options unclear. Decision analyses: sources of uncertainty are defi ned only for some input variables.

No: Measures not defi ned, or are inconsistent throughout the paper. Or measures employ only ill-defi ned, subjective assessments, e.g. “anxiety” or “pain.” Or obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). Surveys: no description of questionnaire/interview content or response options. Decision analyses: sources of uncertainty are not defi ned for input variables.

N/A: Descriptive case series / reports.

9. Sample size appropriate?

Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > ½ effect size) and/or problems with multiple testing are evident. Decision analyses: size of modelled cohort / number of iterations specified and justified.

Partial: Insufficient data to assess sample size (e.g., sample seems “small” and there is no mention of power/sample size/effect size of interest and/or variance estimates aren’t provided). Or some statistically significant results with standard errors > ½ effect size (i.e., imprecise results). Or some statistically significant results in the absence of variance estimates. Decision analyses: incomplete description or justification of size of modelled cohort / number of iterations.

No: Obviously inadequate (e.g., statistically non-significant results and standard errors > ½ effect size; or standard deviations > _ of effect size; or statistically non-significant results

with no variance estimates and obviously inadequate sample size). Decision analyses: size of modelled cohort / number of iterations not specified.

N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. Analysis described and appropriate?

Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”/“Kaplan-Meier with log rank tests”, etc.) and appropriate.

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. Or minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). Or multiple testing problems not addressed.

No: Analysis methods not described and cannot be determined. Or obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). Or a study with a descriptive goal / objective is over-analysed.

N/A: Descriptive case series / reports.

11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)?

Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model.

Partial: Undefined “+/-“ expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not

provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model.

No: No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis.

N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.

12. Controlled for confounding?

Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc). Decision analyses: dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. Or control of confounding reportedly done but not completely described. Or randomized study without report of comparability of baseline characteristics. Or confounding not considered, but not likely to have seriously distorted the results. Decision analyses: incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. Decision analyses: dependencies between variables not considered.

N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. Results reported in sufficient detail?

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. Or difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or "n" changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of "unknown" is not used where needed). Or results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as "more likely" without quantitative report of actual numbers).

N/A: Should not be checked for this question.

14. Do the results support the conclusions?

Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren't based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in addition to rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., "suggesting," "possibly").

Partial: Some of the major conclusions are supported by the data, some are not. Or speculative interpretations are not indicated as such. Or low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defi ned by the sampling frame/strategy).

No: None or a very small minority of the major conclusions are supported by the data. Or negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. Or conclusions are missing. Or extremely low response rates invalidate

generalizing the results to the target population of interest (i.e., the population defi ned by the sampling frame/strategy).

N/A: Should not be checked for this question

Appendix 1D: Inter-rater reliability guidance

Table 11

Details of items where discrepancies occurred between raters, and guidance on how this was interpreted to improve reliability and standardisation.

Item with discrepancy	Comment	Guideline to support reliability and accuracy
2. Design evident and appropriate to answer study question? (If the study question is not given, infer from the conclusions). **Yes:** Design is easily identified and is appropriate to address the study question / objective. **Partial:** Design and /or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question. **No:** Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified.	Some raters interpreted "easily identified" as being written in text "e.g. this study used… design", whereas others were looking to see if it could be determined through the text. "Appropriateness" to answer question was also subjective to the raters views on whether the design had significant limitations or not (e.g. correlational).	Following discussions with MC, RB and CG, it was decided appropriateness should be interpreted only in relation to the designs ability to answer the question, and not in terms of limitations. So if a correlational study can answer the question, it should still be given full marks, regardless of potential drawbacks of the design. Raters agreed that studies that explicitly describe their design should be awarded a 2, and studies which do not describe it explicitly, but it is deduced from text, should be awarded a 1.
9. Sample size appropriate? **Yes:** Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > ½ effect size) and/or problems with multiple testing are evident. Decision analyses: size of modelled cohort / number of iterations specified and justified. **Partial:** Insufficient data to assess sample size (e.g., sample seems "small" and there is no mention of power/sample size/effect size of interest and/or	It was difficult to objectively determine what "seems reasonable", particularly when the results were not statistically significant, and order standard errors were not reported.	It was agreed that significant results would be awarded a 2. Non-significant results would be awarded a 2 where power and sample size were addressed in the text (e.g. power calculation), a 1 where power **or** sample size were commented in discussion/results but no formal power analysis was shown, and a 0 where there was no mention of power or sample size.

variance estimates aren't provided). Or some statistically significant results with standard errors > ½ effect size (i.e., imprecise results). Or some statistically significant results in the absence of variance estimates. Decision analyses: incomplete description or justification of size of modelled cohort / number of iterations. **No:** Obviously inadequate (e.g., statistically non-significant results and standard errors > ½ effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). Decision analyses: size of modelled cohort / number of iterations not specified.		
11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)? **Yes:** Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model. **Partial:** Undefined "+/-" expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at "time 1"	Several of the older papers only used standard deviations as any measure of variance. Raters were unsure if this should be considered appropriate or not.	In discussion with MC, it was decided standard deviations alone should only be awarded a 1, as they are not considered a sufficient enough estimate of variance. Standard errors, confidence intervals or other measures can be awarded a 2.

or “time 2” but does not provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model. **No:** No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis.	

Appendix 2A: SIP Author Guidelines

What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Qualitative Health Research*, please ensure you have read the Aims & Scope.

1.2 Article Types

Each issue of Qualitative Health Research provides readers with a wealth of information —, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

Abstracts should be 250 words or less, and Original Research Articles should be 6,000 words or less excluding the abstract and references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

4. Preparing your manuscript for submission

4.1 Article Format (see previously published articles in QHR for style):

- Blinding: A version of the manuscript which has had any information that compromises the anonymity of the author(s) removed or anonymized. This version **will** be sent to peer reviewers.
- Title page: Title should be succinct; list all authors and their affiliation; keywords. Include any removed or anoymized material. Please upload the title page separately from the main document. This **will not** be sent to the peer reviewers.
- Blinding: Do not include any author identifying information in your manuscript. See https://sagepub.com/Manuscript-preparation-four-

double-blind-journal for detailed guidance on making an anonymous submission.

- Abstract: Maximum of 250 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: Original Research Articles should be 6,000 words or less excluding the abstract and references. Manuscripts should be as tight as possible.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Authors should not include qualitative research checklists, such as COREQ (COnsolidated criteria for REporting Qualtiative research), within their manuscripts. Based on the specific qualitative methodology and/or methods, it may be appropriate for authors to describe steps, activities, or concepts related to rigor. For additional, information on this policy, please read Why the *Qualitative Health Research* (QHR) Review Process Does Not Use Checklists
- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e. INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
    - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
    - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
    - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

https://journals.sagepub.com/author-instructions/qhr - top

Appendix 2B: Community member interview schedule

- Can you tell me your name Kī tusīṁ mainū āpaṇā nāma dasa sakadē hō

- What is your understanding of memory difficulties and what can be done about them?

- Have you or anyone you know ever struggled with memory difficulties? Who did you speak to about these difficulties? What impacted your decision of whether to get help or not?

- Imagine if you did start to experience memory difficulties, who would you speak to first and why?
    - Would you consider going to your GP? Why/why not?
    - Would you go to a mental health service specific (speak to nurse and doctor, have a brain scan) to memory difficulties?
    - Would you accept a memory assessment at a clinic?
    - Would you want to do an assessment e.g. pen and pencil?

- What would help you to go? What would support you?
  Kihaṛī cīza tuhāḍē la'ī jāṇā āsāna baṇāvēgī

- Have you had any experience of working with a translator in other medical appointments, was this helpful or unhelpful? Why?
    - Kī tuhānū hōr maiḍīkala appointment vica anuvādaka nāla kama karana piya hai aghe?

- If a translator could be provided, how would that make you feel? would this be helpful or unhelpful?
    - Jēkar kō'ī anuvādaka pradān kītā jā sakadā hai, tāṁ iha tuhānū kivēṁ mahisūsa karēgā? Kī iha madadagāra jāṁ lāhēvada hōvēgā?

- Is there anything else you would want a memory clinic to consider when assessing memory difficulties for Punjabi speakers?

Appendix 2C: Staff member interview schedule

- Can you tell me your name and a bit about your role in the memory clinic?

- Can you tell me about the experiences have you had of working with translators?
    - What experiences have you had of working with Punjabi Translators?

- Thinking back to some of the referrals you have received for Punjabi speakers, what are some of the issues you consider when you receive a referral for a Punjabi speaker?
    - Did you make any adaptations, if so, what were they?

- When assessing a Punjabi speaker, which memory screening tool do you use (English MoCA or Punjabi MoCA) and why do you choose this one? (perhaps provide a list of options)

- Can you tell me a bit about your experience of using interpreters with Punjabi speaking service users?
    - What, if any, difficulties have you experienced when using Punjabi interpreters in this service?
    - Can you think of things that have worked well when working with a Punjabi Interpreter?
    - How easy or difficult was it to interpret the responses when working with a Punjabi interpreter?

- What kinds of support do you need, if any, to feel confident when working with Punjabi speakers?

- Out of all the things we have spoken about today, which one thing feels most important for you?

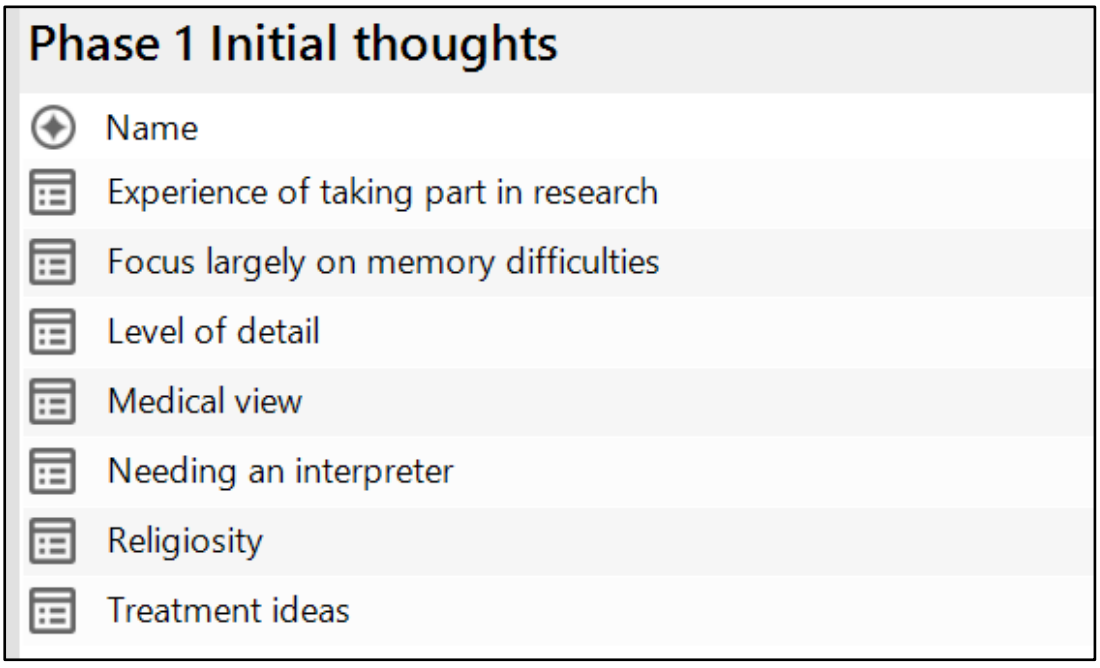
- We would like to improve the experience of Punjabi speakers in this service. We would like to think about how to improve it, and what types of things might make a difference to staff, translators and service users. Is there anything that you would like to mention that I haven't asked you about?

Appendix 2D: Reflexive Thematic Analysis

The thematic analysis was initially carried out using NVivo for Windows Desktop. Braun and Clarke's (2022) guidelines were used to code data and analyse themes. The process was carried out separately for community member data and staff member data. The process is summarised below.

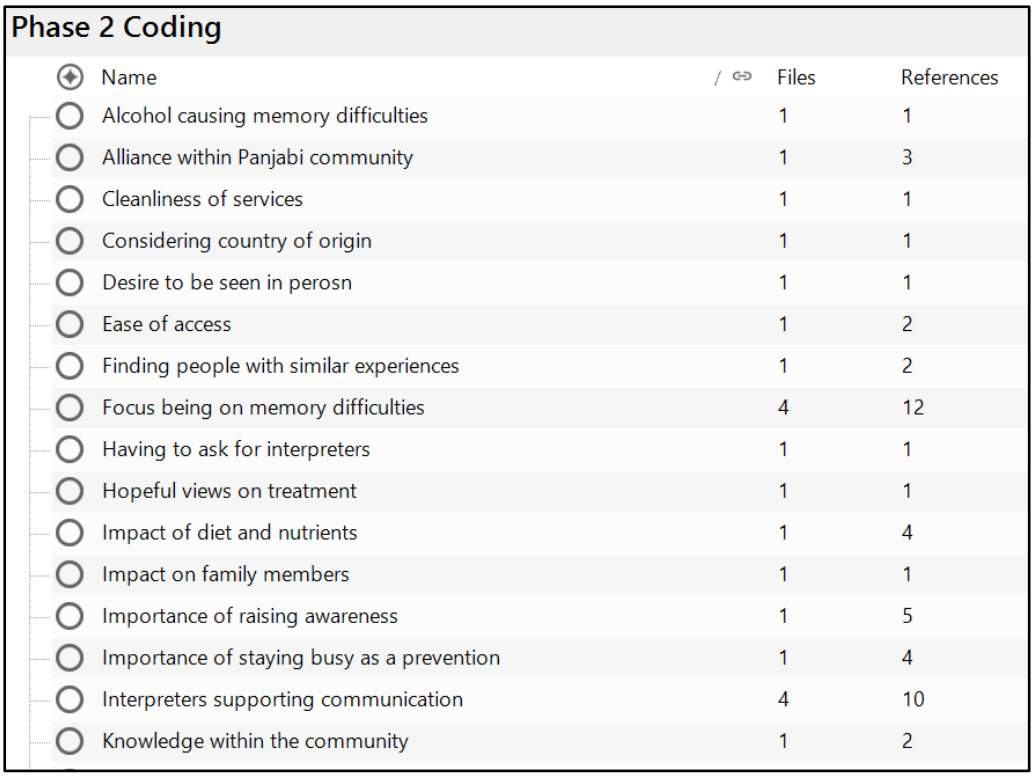
Phase 1: Data immersion and familiarisation

This was done at two stages: firstly at transcription. I manually transcribed all staff focus groups and interviews and interpreted and transcribed Panjabi interviews. This led me to already feel very familiar with the data. I then read through all of the transcripts and using the *Memo* feature on NVivo began to describe some of my thoughts. Examples of Memos are shown below. Memos were broader ideas pertaining to things I observed in interviews.



Phase 2: Systematic coding

I then began coding my data. Occasionally, one quote would be placed in multiple codes. Codes were a combination of descriptive and implicit. This is an example of my open code.



Phase 2 Coding

Name	Files	References
Alcohol causing memory difficulties	1	1
Alliance within Panjabi community	1	3
Cleanliness of services	1	1
Considering country of origin	1	1
Desire to be seen in perosn	1	1
Ease of access	1	2
Finding people with similar experiences	1	2
Focus being on memory difficulties	4	12
Having to ask for interpreters	1	1
Hopeful views on treatment	1	1
Impact of diet and nutrients	1	4
Impact on family members	1	1
Importance of raising awareness	1	5
Importance of staying busy as a prevention	1	4
Interpreters supporting communication	4	10
Knowledge within the community	1	2

Phase 3: Generating themes

I began to group some codes together. This stage was done using the *Maps* feature to support my visualisation of emerging themes.

Figure 4

Phase 3 from community member data.

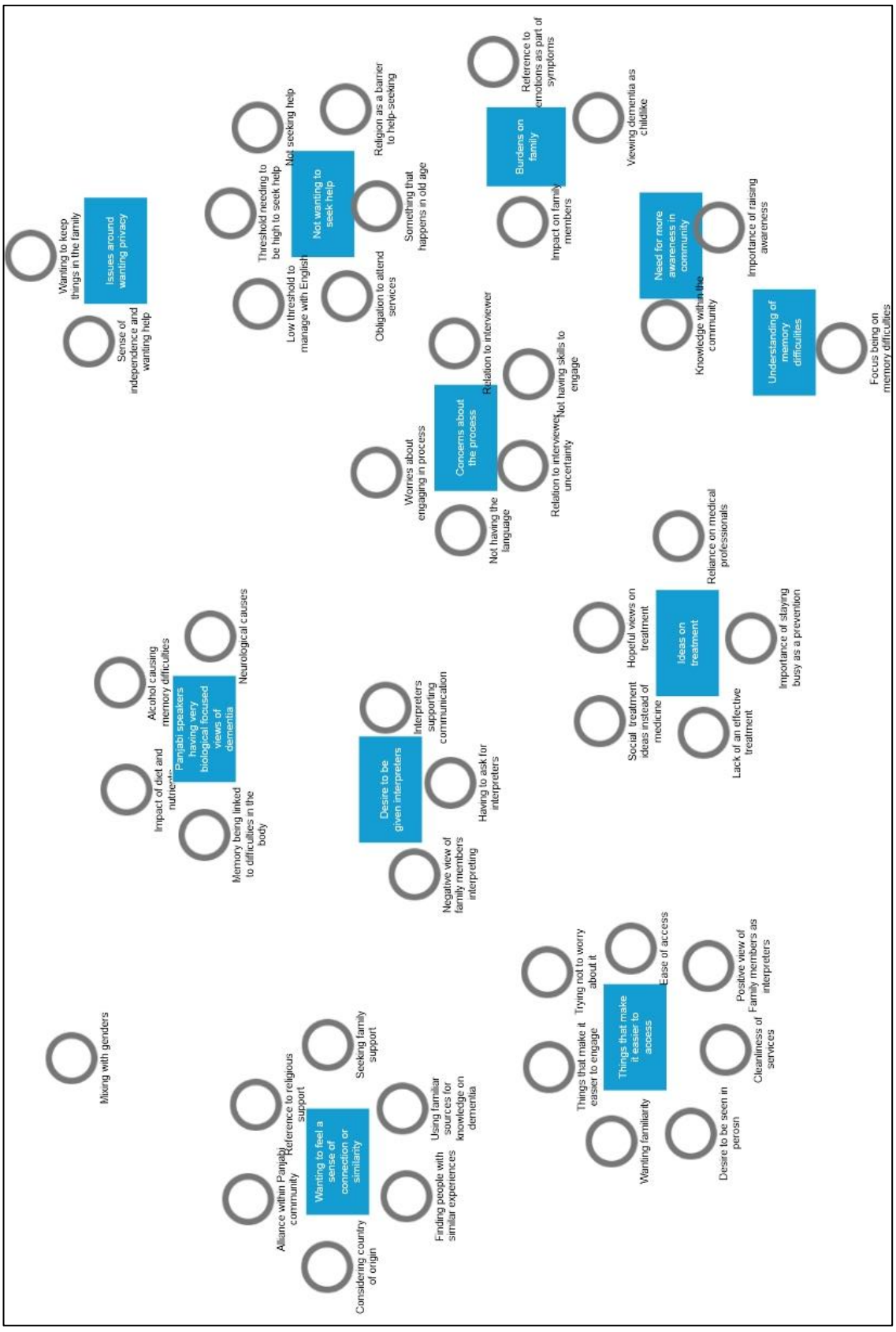
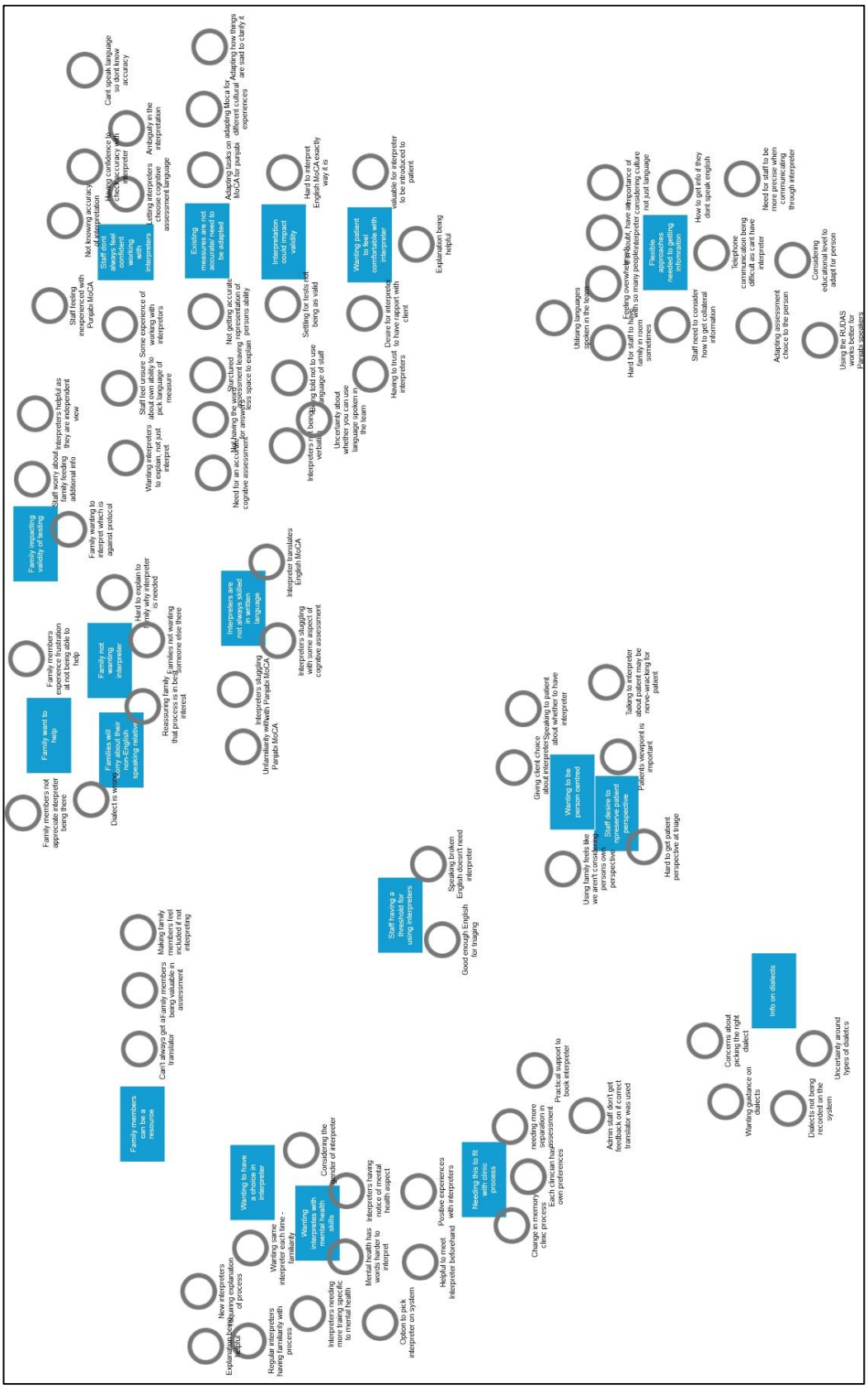


Figure 5

Phase 3 from staff member data.



Phase 4: Review themes

I then re-read my data with my themes in mind. This process involved renaming some code, merging codes and themes, clustering code around themes or getting rid or some themes. *Maps* and *Memo's* was used in this process.

Figure 7

Phase 4 from community member data.

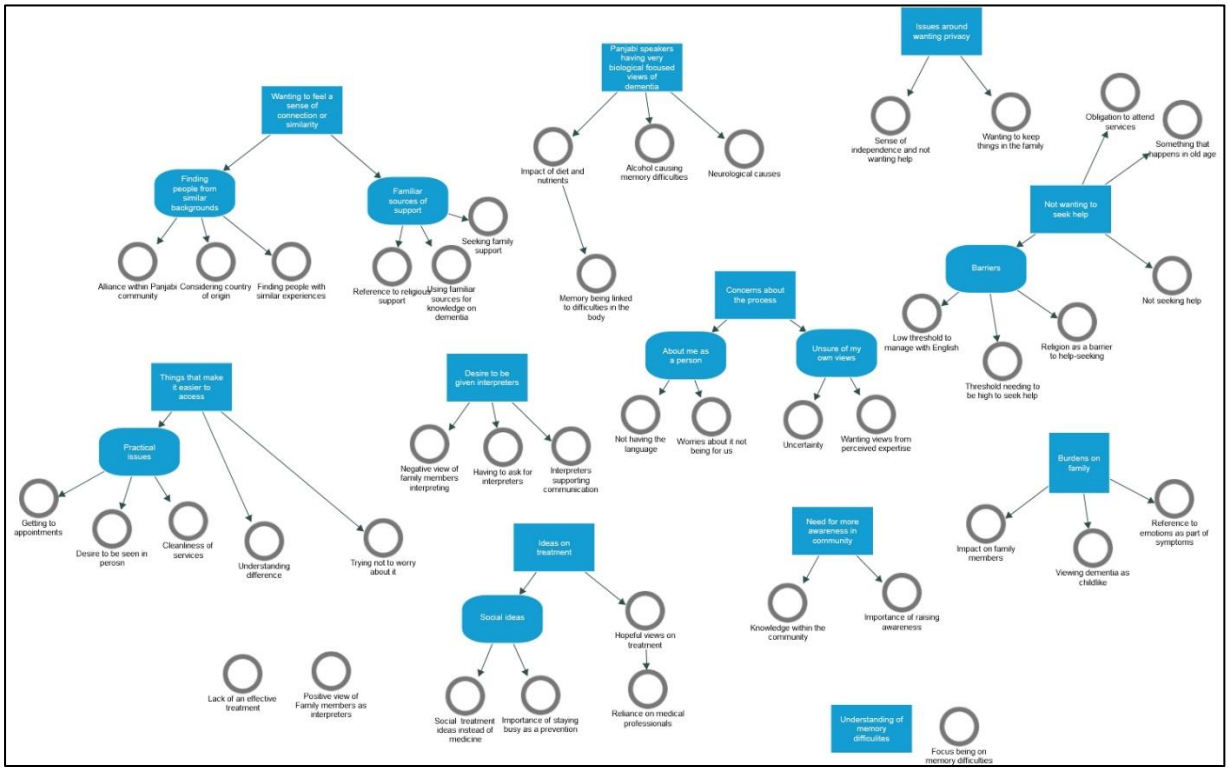
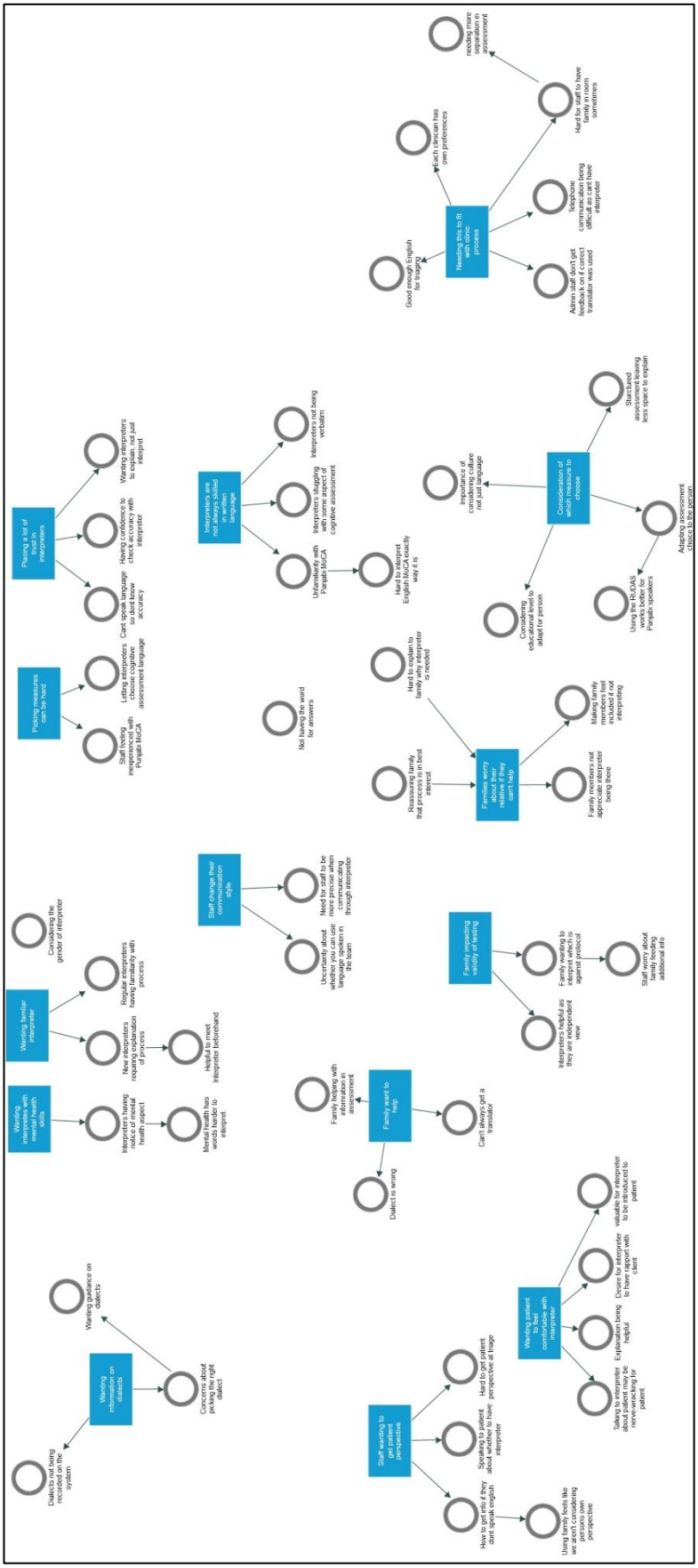


Figure 7

Phase 4 from staff member data.



At this stage, a section of transcript was shared with my supervisor to review my codes.

Phase 5: Refine, define and name themes

I then met with both RV and AC to review and refine themes. In speaking with my supervisors, I was able to share my definitions and reflect on boundaries of themes and subthemes.

An example of the codebook in process in shown below.

Table 6

Example of themes, subthemes and definitions developed during coding process according to reflexive thematic analysis.

THEME (SUBTHEME)	DEFINITION
Finding people with similar experiences	Things that help people to feel connected with others on various levels
Alliance within Panjabi community	Mentions of Panjabi community as being a positive thing they would seek out
Considering country of origin	Importance of whether someone is from the same country as you
Using familiar sources for knowledge on dementia	Seeking information or support from sources you are already familiar with
Reference to religious support	Mentions of God, worship, prayer, etc as a supportive aspect
Seeking family support	Ways people might use family members (excluding as interpreters) to help them with memory difficulties
Focus being on memory difficulties	
Hopeful views on treatment	Positive statements about what treatments could provide
Reliance on medical professionals	Reference to doctors being knowledge or following things said by doctor
Social treatment ideas instead of medicine	Ideas about what the individual could do to prevent or manage difficulties that are not biological
Importance of staying busy as a prevention	Reference to being busy as a preventative or coping strategy for memory difficulties
Impact on family members	Any mention on how difficulties with memory in interactions in the process may impact family negatively
Reference to emotions as part of symptoms	Mention of things beyond just forgetting where you are and where you have put something, reference to feelings, emotions.
Viewing dementia as childlike	Refence to symptoms being child-like or person being infantilised

THEME (SUBTHEME)	DEFINITION
Interpreters supporting communication	Positive connection with interpreters as having helped the communication in some way
Having to ask for interpreters	Not given interpreter and having to request one
Negative view of family members interpreting	Ways in which family members may not interpret in the way wanted of them
Knowledge within the community	How the Panjabi community views memory, or help-seeking, or causes. Any links to knowledge or lack of knowledge amongst community/society
Importance of raising awareness	Awareness in the Panjabi community on memory difficulties or seeking help
Lack of an effective treatment	Not knowing what can be done as treatment or comments about nothing being done/nothing being useful
Memory being linked to difficulties in the body	Biological or physical explanations for memory difficulties
Alcohol causing memory difficulties	References to alcohol
Impact of diet and nutrients	Mention of food, drink or nutrition
Neurological causes	References to memory difficulties being something to do with the brain
Not seeking help	Reasons or comments about not wanting to seek professional help or visit the doctor - different to not needing to
Low threshold to manage with English	Seeing the presence of “some” level of English as a reason to not have an interpreter regardless of confidence with the language
Obligation to attend services	Feeling as though they "have to" attend or "should attend" - not sounding like something they considered themselves.
Religion as a barrier to help-seeking	How religion may impede or negatively impact desire to seek professional support
Something that happens in old age	Normalising difficulties or mention of difficulties being understood in relation to normal aging
Threshold needing to be high to seek help	Where not seeking help is thought of in terms of symptoms not being “bad “enough, or needed to get worse before seeking help
Sense of independence and not wanting help	Not wanting to rely on others for help or wanting to do things by yourself
Wanting to keep things in the family	Text about not telling other people outside of the family
Things that make it easier to engage	Ideas or experiences where it has been easier to seek help for memory difficulties
Getting to appointments	Physical act of going to an appointment and process of getting it booked
Cleanliness of services	Comments about cleanliness of services
Desire to be seen in person	
Positive view of Family members as interpreters	Mentioning positives for using a family member to interpreter for you – benefits
Trying not to worry about it	References to ignoring worry

THEME (SUBTHEME)	DEFINITION
Understanding difference	Worries about how clinicians or professionals not understanding elements of how they are different e.g. language, school experience
Worries about it not being for us	Expressions of concern about anything that worries the individual in hypothetical or actual engagement in the process of seeking help for memory and/or interpreter involvement that may relate to their identity
Not having skills to engage	Individual suggesting they may not have knowledge or skills to do what it being requested of them
Not having the language	Speaking about translation, not having the words for things.
Uncertainty	Questions or queries to interviewer that suggest the person is unsure how to answer
Wanting views from perceived expertise	Directing questions back to interviewer

Phase 6: Reporting

It is important to note that phases 3 to 5 were not linear – the process took several iterations at each stage.

Charts and *Framework Matrices* were used to explore overlap between themes and participant demographics. Patterns were examined across themes, as well as within themes.

Figure 8

Final themes from community member data.

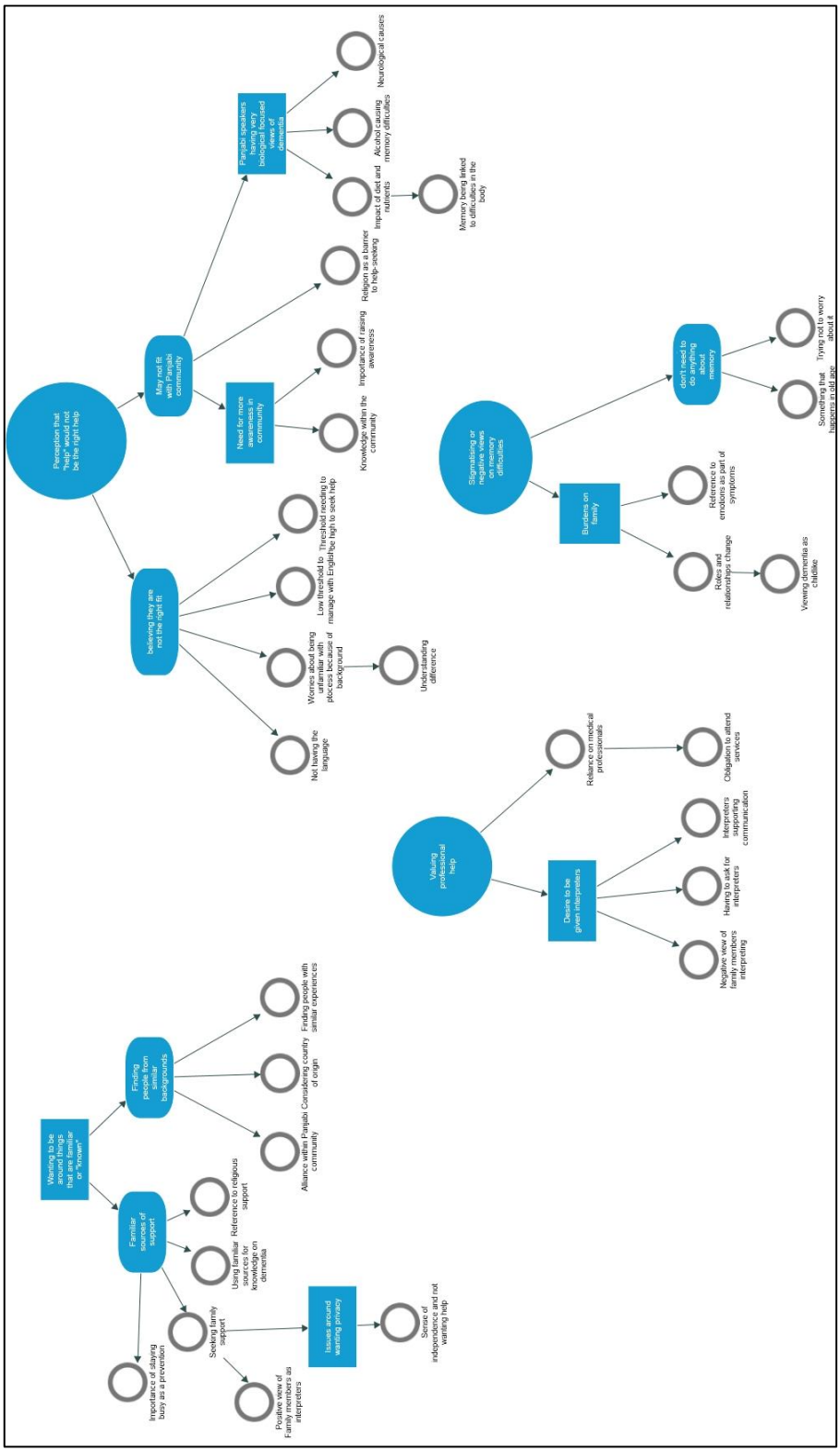
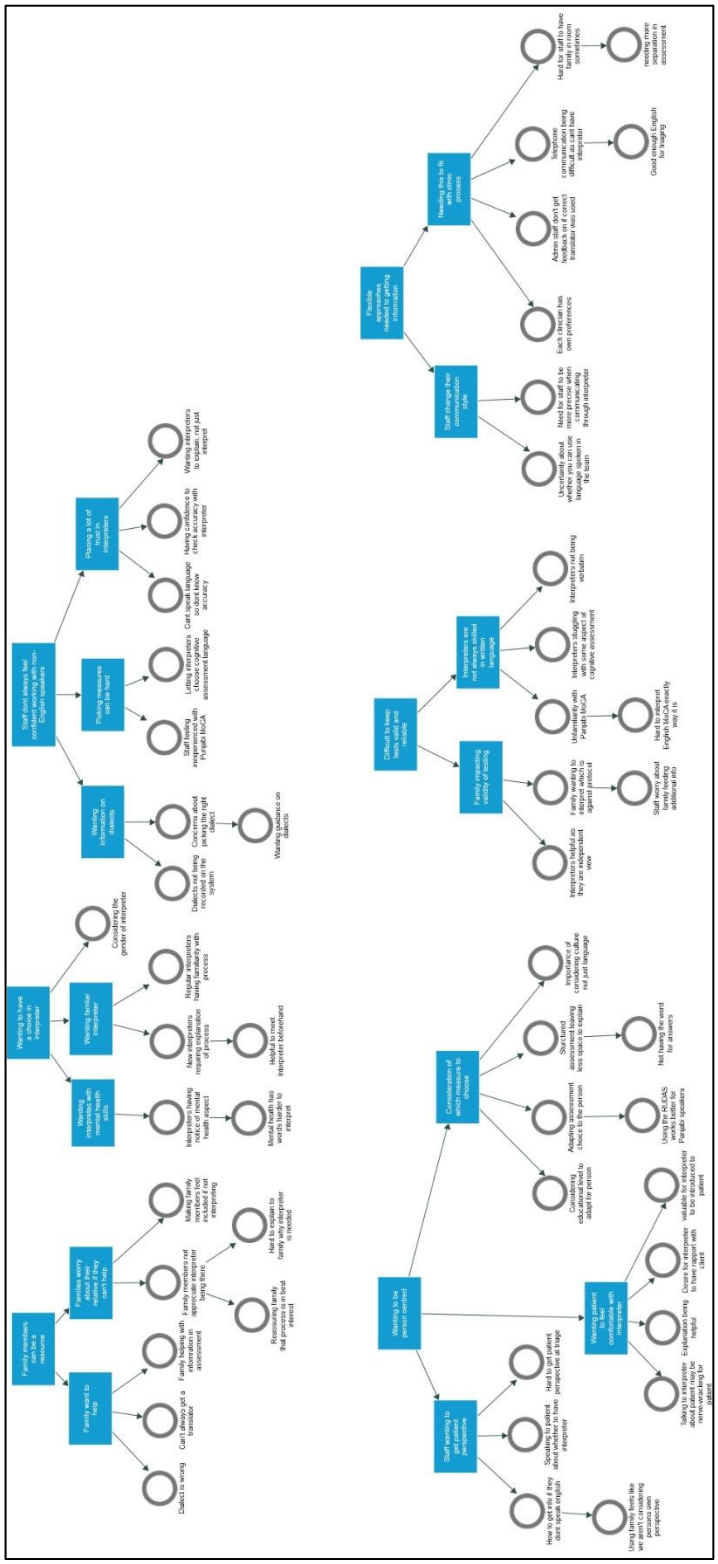


Figure 9

Final themes from staff member data.



Appendix 2E: Supplementary information from interpreter

This study initially aimed to recruit interpreters in addition to staff members and Panjabi speakers, in order to gather an additional perspective on the problem. One interpreter was recruited through opportunity sampling as I was able to share information on the study at South Buckinghamshire Memory clinic at an initial assessment I was observing. After contacting the associated interpreting service, however, I was told the interpreting services were unable to support any further recruitment as we were looking for volunteers and the service would need to charge for interpreter time.

Other surrounding interpreting services were also contacted, however similar problems were encountered. Snowballing or word-of-mouth was also explored from the one interpreted that had already been recruited, however, this interpreter was not aware of any other Panjabi interpreters. This means the findings may be missing the views of the third stakeholder involved.

Emerging themes from the interview with the one interpreter are presented below.

- Phrasing questions in a way to help people understand – the interpreter said often, people would feel confused by his questions so he would adapt his questions to help them to understand what was being asked, in a way that ensured the other party still got the information they were looking for.
    - This was in-keeping with staff saying they are not always sure how much is being interpreted verbatim. From this perspective, it appears it may not always be verbatim but when it is not, this is done carefully in service of helping the individual understand.

- Not being able to interpret verbatim – *"the English vocabulary is massive in respect to the Panjabi one"* and so often, this translator would have to change the wording of

the question. The interpreter spoke about being unable to translate scientific words or names of diseases.

  - This was also reflected in community member interviews as they also felt they don't always have the right words – a shared experience with this interpreter.

- Respecting the boundaries of culture – "You have to think twice of what you're going to say to the person in Panjabi because I don't know how he's going to see it or react … most of the time they avoid personal stuff, like family member or talking about a person. So you have to be very careful to not harm the person in front of you. Yeah, you have to be very sensitive with the words"
  - Community members echo this idea – they also said they prefer to "keep things in the family" and this makes them more likely to seek out familiar sources of support. An interpreter may be viewed as an "external" source of support and so patients may also feel sensitive with their words.

- Considering gender – this interpreter had experience of a female patient not feeling comfortable working with a male interpreter.
  - A similar concern was mentioned by staff in the focus groups.
- *"Most times happen that they don't know there will be an interpreter. You turn up and they don't know who you are. So just tell someone is coming to help them understand the situation so that they are informed".* The interpreter felt patients were not always aware he was coming.
  - Staff spoke about wanting interpreters to explain the purpose of them being there, however, here, the interpreter would like staff to do this. In our recommendations, we suggest this form part of the discussion staff and

interpreters have when they meet before the session. Staff will have the knowledge to explain why an interpreter has been chosen and interpreters will have the ability to relay this information, and therefore it important for the two to align prior to meeting the patient.

Appendix 2F: Codebooks

Table 7

Final codebook with definitions for themes and subthemes from community member interviews.

Themes	Subthemes	Definition
Wanting to be around "people like us"		A desire to seek support or be supported by people and places that are similar to or familiar to the person speaking.
	People from similar backgrounds	A desire to want to be around communities where there are similarities in language, migration or country of origin. This can include a desire for professionals to be from a similar background to them.
	Preferring familiar sources of support	Help-seeking from people, places or sources that are more familiar to the individual. For example, family members, familiar sources of media. Things they would have interacted with more frequently.
"There is nothing": Negative views of memory difficulties and a lack of hope		Negative statements associated with the treatment or prognosis of dementia or memory difficulties and the wider implications this could have.
	"It's just forgetting" – "nothing you can do about it"	Reference to a lack of treatment, or lack of effective treatment, or lack of support around memory difficulties.
	Burden on the family	Reference to the lack of support/changes in person with memory difficulties impact on the family negatively.
They don't have things for people like us		Different ways that services do not work for Panjabi speakers or people from Panjabi background.
	We are not the right fit	Attributions about themselves as a person or about their experiences that mean they are not suitable for services; phrased in a way where problem is placed within the person/community themselves.
	It may not fit for Panjabi Community	Aspects of the Panjabi community that may not fit the service, or expectations from the service which means characteristics of the community would not fit.
Valuing professional help		Positive perceptions of professional help offered through NHS services or equivalent, or comments pertaining to positives or strengths of going to see a medical or healthcare professional.
	Faith in medical professionals	Positive comments about GPs or placing trust in the advice of GPs or suggesting advice would be followed simply because it came from a GP or other medical professional.

Themes	Subthemes	Definition
	Preference for interpreters	Advantages or benefits of having an interpreter to interpret, and comments about ways in which interpreters would support differently to family.

Table 8

Final codebook with definitions for themes and subthemes from staff member focus groups and interview.

Themes	Subthemes	Definition
Desire to be person-centred		Various ways clinician may try to keep the patient and their needs/feelings at the centre of decisions they make.
	Wanting to get patient perspective	Considering ways the patients view/voice might get lost and thinking about adaptations that could help ensure their view is held in mind
	Wanting the patient to be comfortable with the interpreter	Considering how the patient and interpreter would work best together and whether the patient feels comfortable or not.
	Considering which measure to use	Person centred considerations for choice of measure – such as individual context, education etc. guided by centralising concept of what would work best for patient.
Staff don't always feel confident when working with non-English speakers		Uncertainty surrounding various aspects of working with a non-English speakers may make staff feel less confident and less sure in decision making.
	Placing trust in interpreters	Mentions of uncertainty when working with interpreters or references to needing to place trust in them, or "not knowing" or being sure.
	Picking translated or English measures can be hard	Uncertainty about which measure to pick pertaining to language choice, translation and skill of interpreter.
	Feeling unsure about dialects	Concerns or uncertainty about which dialect someone might speak and which to use in assessment.

Themes	Subthemes	Definition
Family members want to be a helpful resource		Ways in which family could be useful and quotes related to family members viewing themselves as useful.
	Family members often want to help in the assessment	Experience of family or relatives who have expressed a desire to help answer questions or support patient in an appointment, and ways in which clinicians have experienced family members as helpful.
	Families are often concerned if they can't help	Experiences of family reactions if they are not able to help/not asked to help/other help is available e.g. interpreter.
Having choice in interpreters		Clinicians value being able to have a choice in interpreter.
	Wanting interpreters with mental health skills	References to interpreting for mental health services, or neuropsychological contexts being different to, or more challenging than other contexts.
	Wanting familiar interpreters	Benefits of having the same interpreter more than once and disadvantages of having unfamiliar or new interpreters at each assessment.
Difficult to keep tests reliable and valid		Concerns about validity and reliability shaping the decisions clinicians make or threats to validity and reliability of assessments.
	Family impacting on validity	Threats to validity associated with family or relatives being involved in assessment.
	Interpreters not always skilled in written language	Threats to validity associated with how well interpreters can carry out their role.
Flexible approached needed to gathering information		Practical considerations when trying to adapt assessments for Panjabi speakers.
	Adapting communication	Clinicians thinking about how they talk or write during an assessment with a non-English speaker or any other communication with a non-English speaking patient.
	Changes need to fit clinic process	Clinicians thinking about broader service context and certain processes that would need to be considered if the service was to change aspects of their working.

Appendix 2G: Illustrative quotes

Table 9

Illustrative quotes for themes and subthemes from community member interviews.

Themes	Subthemes	Illustrative quote
Wanting to be around familiar support		
	People from similar backgrounds	*Pakistan is similar to India, so it helps. The weather is the same, so the illnesses are the same. India is a hot country, and our system for eating and drinking is different. Here, people prefer packed food*. (P1)
		You need to think about the environment, think about the country they are from. (P8)
	Preferring familiar sources of support	*Here in Baba Ji's [Gods] house, we keep busy, walking around, and with Baba Ji's grace, we are staying exactly fine. We come into the gurdwara, and we stay okay. (P3)*
		It is in God's hands. *(P4)*
		If I can have a family member, I would prefer that. (P5)
		We live in families, so my mother-in-law does not want someone else to come and help her and does not want to go to any groups. We were offered groups to go to where you sit and talk but she did not want to go. She was not convinced. She said she wants to stay at her home. So when she is at home, we just do things how she wants. For now, we are in control. Going forward, if it gets worse, we might need more help, but we are family orientated people so it more about family support, rather than going outside. (P7)

Themes	Subthemes	Illustrative quote
Negative views of memory difficulties and a lack of hope		
	"It's just forgetting" – "nothing you can do about it"	*We did nothing. It's just about people forgetting – what can you do about it.* (P1)
		I am not sure. You can tell me if there is, but I doubt it. It seems like there is not much treatment for it. (P3)
		I am not sure what I would do. I would tell the person not to worry about it. (P8)
		No there is nothing. My brother had dementia and he got worse but there was nothing the doctors could do. But there was nothing you could do, from what I saw, he was same age as me. (P4)
	Burden on the family	*They may keep asking the same questions over and over, or if you don't tell them something, they start to get angry or frustrated because they don't understand what's happening. It's happening to my mother-in-law, but it has only just started, like she will start arguments.* (P7)
		Yes, it does get hard for family too. (P6)
They don't have things for people like us		
	We are not the right fit	*I think people don't always know they can have an interpreter. They think "oh it's fine, I know a bit of English I will just go on my own", but it is broken English and so it won't be as good as if someone was able to help them.* (P6)
		But you need to understand how education has changed, for people like me, we never did stuff like that at school. 50 years ago, education was different, and people did not go to school in that time. So they would not be able to understand. (P8)
		We would only sometimes understand, and sometimes we wouldn't. (P3)

Themes	Subthemes	Illustrative quote
		With the groups, they are usually for White people. They don't have things for people like us. She was offered a group but the language in the groups is different. If you don't know the language, you would just sit there looking at people's faces, right? It would be much harder for you. (P7)
	It may not fit for Panjabi Community	*I have heard of dementia, but a lot of people are not aware. I have only heard of it in the family, like a distant relative, like, nobody near me has had this happen to them.* (P5)
		The Indian community is a religious minded community, they are very going around in circles with their religion. They think a lot about their religion and not about their health or well being. They think more about religion and less about their health. (P8)
Valuing professional help		
	Faith in medical professionals	*No you should go, if that's what they think is best at the medical centre we should go, what does it matter to us?* (P1)
		In India, people who have diabetes have to wake up and take tablets straight away and that was given to them by the doctor. Even if you forget things, you would go to the doctor and tell them. Indian people are very dependent on doctors. Whatever the doctor says goes. (P2)
		Yes, you should go. (P4)
		If I noticed I was forgetting stuff or my memory was decreasing, I would tell the doctor and they would tell me what I can do. And then with that, I would do it. (P5)
	Preference for interpreters	*It's hard to explain something to someone in another language. In Panjabi they would be able to be open and tell us in more detail and explain it to us our way. They would tell you what problems you have.* (P2)

Themes	Subthemes	Illustrative quote
		It was better than having a family member. If I go to the doctor and they give a translator, I take it. It is better than family because family members sometimes only tell you half of what has been said. The interpreter tells you fully everything that is said, and so I liked that. They take every word and translate every single word. I think a translator is better than family. (P6)

Table 10

Illustrative quotes for themes and subthemes from staff member focus groups and interview.

Themes	Subthemes	Illustrative quote
Desire to be person-centred		
	Wanting to get patient perspective	*And then I in a way, I guess I feel like I'm not always totally considering the patients point of view. As to whether or not they want to be referred, you are relying on the next of kin.* (S4)
		Well, for me my initial thought would be how am I going to get the collateral information if the, well, the information from the patient, I guess about their thoughts on the referral, if they don't speak English. Uh, because obviously we can't have it translator over the phone. So I guess it's more about. (S2)
	Wanting the patient to be comfortable with the interpreter	*Sometimes we will go through the procedure of the assessment and explain everything before. You know, for the assessment. Uh, so that that tends to sort of, you know, put everybody at ease.* (S1)
		So I've had some people come in and they are. They just spoke to the patient then they spoke to me and then you know, they would come back and forth and build some sort of like a rapport with the patient. (Mental health support worker)
	Considering which measure to use	*And she had not, like, she hadn't seen a rhino. So she kept calling it a hippo, which a lot like, it's kind of controversial because. Some people say you should allow that. Some people say you don't, but I think it should be allowed because she'd never actually seen a rhino. And she doesn't know what that was. So she was like, "I can see it's got a horn. I don't know what it's called".* (S6)
Staff don't always feel confident when working with non-English speakers		

Themes	Subthemes	Illustrative quote
	Placing trust in interpreters	*And again because, I don't understand it the, the language, I can't tell if that's just actually how the language is or if they've actually put their own spin on things. And so yeah. And so then I get like, a, a long answer back, abbreviated into a really short like translation, that sort of thing. I'm 'cause I again, I don't speak, for my sins I only speak English, so I just don't... know....* (S2)
	Picking translated or English measures can be hard	*And I had a patient at a previous job who I'm pretty sure she was Panjabi speaking, but we actually used the RUDAS, the different screening tool. Which is a lot easier to translate into different languages. Purely 'cause of the questions they ask. Its not like, you know, they don't ask for specific letters. So that I think worked well with the translator.* (S4)
		Screening people or assessing people who speak a different language is not always the language, it's the cultural differences that I find. I perhaps don't understand well enough to be able to. To kind of ascertain how that's going to affect the assessment. So it's not so much the language. Uh, that I've had challenges with. Oh yeah. Like, like I said, I think it's more the cultural differences. (S1)
	Feeling unsure about dialects	*The only thing I can think of is did we get the right dialect of Panjabi speaker? As I say there are different Uh, you know, dialects to choose from even on the when you're booking it.* (S3)
		I guess if there's different like dialects of it that that would be helpful to know the different ones, so it particularly if you're triaging and you can perhaps ask that question you know not just what language you speak, but if they say Panjabi can say what type of Panjabi might be helpful. (S5)
Family members want to be a helpful resource		
	Family members often want to help in the assessment	*I've only spoken like three or four patients who were specifically Panjabi speakers, and their families were luckily quite involved and were able to. Ask for support or*

Themes	Subthemes	Illustrative quote
		communicate their needs better, which was pretty handy but. Yeah, I've been lucky. I guess I've not had any active issues with itself. (Mental health support worker)
	Families are often concerned if they can't help	*Often when you speak to their relative on when you do the triage, they don't want an interpret or they want to do it themselves. … You can't always get an interpreter. So yeah, so that's the big thing on whether things can be translated.* (S2) *I've had things like, Oh well, they're not speaking the same dialect or it's not the same language. My mum's never going to be able to answer that or, you know, those sorts of things. I think it's trying to just sort of educate the family, isn't it? That it, you know, it is in their relatives' best interests that we have to do the assessment and find what we can, whatever we find out, what we can do to help and having a translator will help that. It's a bit smoother.* (S4) *Yeah, I think we've always sort of said at the time myself and consultant or whoever is with me, you know that it's just standard practice to have an interrupt. Oh, it's not because we don't trust you or we don't think that you want to do the best for your relative, but it's just it's protocol for us and then we have to do that.* (S2) *Uh, I think same saying about the family members can be quite frustrated that they're not being used. And can't really understand why they interpreters being booked. So that's kind of the issues that I've experienced come from.* (S5)
Having choice in interpreters		
	Wanting interpreters with mental health skills	*But I understand there could be some barriers to that and 'cause, like I said, there's not exact interpretation for certain things and certain words in mental health UM. So I think that could be a barrier.* (Mental health support worker)

Themes	Subthemes	Illustrative quote
		We choose them under the medical selection, and we specify mental health, so they do at least have some idea of what's going to be expected of them. You know, the terminology, that kind of thing. So they do have some advanced notice of what's going to be asked. (S3)
	Wanting familiar interpreters	*But from time to time I think, uh, most of our interpreters, sort of interpreter actually knows the process in terms of them coming in.* (S1)
		And, you know, check their paperwork and normally they're pretty clued up on what's going on, what what's going to be asked of them. (S4)
Difficult to keep tests reliable and valid		
	Family impacting on validity	*And the thing I have found is that if a family member comes with the patient, they don't always appreciate having the translator there because they think that they can do the translation, which obviously isn't really protocol because of, you know, the information they can feed them.* (S4)
	Interpreters not always skilled in written language	*Because we do have a MoCA as well in in in Panjabi, which we. Which I think we rarely use that. What we normally do, we use the normal sort of English MoCA and then the translator will translate as such. But sometimes when we don't do the MoCA, the direct translation from the English version to the Panjabi, sometimes it can be sort of a bit sort of ambiguous.* (S1)
		So I know in the past when we when I've been with people with a translator, they can't always translate the MoCA completely over into the language. I know there are copies of the MoCA in different languages, and I know that there have been translators who take who looked it and gone. I can't read that. I need the English version and then try and translate it. So yeah, like the. (S2)
Flexible approached needed to gathering information		

Themes	Subthemes	Illustrative quote
	Adapting communication	*I suppose if there was someone in the team who spoke the language, then I don't know if that's a resource that you can….* (S4) *Because the assessment in terms of being able to structure your questions, it's kind of almost like everybody knows that your questions and your answers need to be quiet.* *Not to the point where they you know, you exclude stuff, but then they're more concise than more brief. And I know when I'm working through a translator, I try to speak more clearly.* (S4)
	Changes need to fit clinic process	*But then I never I never hear back. If it was the wrong one or the right one or anything like that. So I just kind of have to hope for the best if I don't know.* (S3) *Uh, because obviously we can't have a translator over the phone. So I guess it's more about. Yeah, considering that that I would need to go to the next of kin.* (S4)

Appendix 2H: SIP Approval Letter

Bassi Ranjeet (RNU) Oxford Health

From: Khosla Vivek (RNU) Oxford Health
Sent: 20 December 2021 16:09
To: Bassi Ranjeet (RNU) Oxford Health
Subject: RE: Clinical Audit form

Hi Ranjeet

Ok happy to approve from service perspective. I will leave the issue around ethics etc with you as not my area of expertise.

Best wishes

Vivek
Vivek Khosla
Clinical Director | Buckinghamshire Mental Health Directorate
The Whiteleaf Centre, Bierton Road, Aylesbury, HP20 1EG | Tel: 01865 901337 (Emma Peachment)
Consultant Forensic Psychiatrist| Oxford Health NHS Foundation Trust
Oxford Clinic MSU, Littlemore Mental Health Centre, Sandford Road, Oxford, OX4 4XN
Tel: 01865 902907
Mobile: 07887791621 | vivek.khosla@oxfordhealth.nhs.uk |
www.oxfordhealth.nhs.uk

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From: Rhodes Katie (RNU) Oxford Health
Sent: 24 July 2020 15:29
To: Bassi Ranjeet (RNU) Oxford Health
Subject: FW: Clinical Audit Quality improvement proposal form

Hi Ranjeet,

Your audit proposal has now been approved.

Please see attached copy of an Audit Report Template in which will need to be completed and returned once the project is complete.

Kind Regards,
Katie Rhodes
Senior Team Administrator
Oxford Health NHS Foundation Trust
The Whiteleaf Centre
Bierton Road
Aylesbury
HP20 1EG

Appendix 2I: Recruitment Poster

Help us in our research!

We are interested in speaking to:

- Memory clinic staff
- Punjabi Translators
- Punjabi speakers who have had a memory clinic appointment

We would like to understand more about memory clinic assessments for those who speak Punjabi, to try and improve this process.

If you would like to find out more information, or to get involved please contact me!



Ranjeet Bassi
Trainee Clinical Psychologist
Ranjeet.bassi@oxfordhealth.nhs.uk



Dr Anna Crabtree
Clinical Psychologist
Anna.crabtree@oxfordhealth.nhs.uk

UNIVERSITY OF OXFORD

NHS
Oxford Health
NHS Foundation Trust



Appendix 3A: TDRP Author Guidelines

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. 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.

Appendix 3B: PSOSH Measure

INSTRUCTIONS: Imagine you had an emotional or personal issue that you could not solve on your own. If you sought counseling services for this issue, to what degree do you believe that the people you interact with would _____.

1 = Not at all 2 = A little 3 = Some 4 = A lot 5 = A great deal

1. React negatively to you
2. Think bad things of you
3. See you as seriously disturbed
4. Think of you in a less favorable way
5. Think you posed a risk to others

Scoring: add items 1-5.

Appendix 3C: SSOSH Measure

INSTRUCTIONS: People at times find that they face problems that they consider seeking help for. This can bring up reactions about what seeking help would mean. Please use the 5-point scale to rate the degree to which each item describes how you might react in this situation.

1 = Strongly Disagree 2 = Disagree 3 = Agree & Disagree Equally 4 = Agree 5 = Strongly Agree

1. I would feel inadequate if I went to a therapist for psychological help.
2. My self-confidence would NOT be threatened if I sought professional help.
3. Seeking psychological help would make me feel less intelligent.
4. My self-esteem would increase if I talked to a therapist.
5. My view of myself would not change just because I made the choice to see a therapist.
6. It would make me feel inferior to ask a therapist for help.
7. I would feel okay about myself if I made the choice to seek professional help.
8. If I went to a therapist, I would be less satisfied with myself.
9. My self-confidence would remain the same if I sought professional help for a problem I could not solve.
10. I would feel worse about myself if I could not solve my own problems.

Items 2, 4, 5, 7, and 9 are reverse scored.

Appendix 3D: ATSPPH-SF Measure

APPENDIX 1. REVISED ATSPPH-SF ITEMS

1. If I thought I was having a mental breakdown, my first thought would be to get professional attention.
2. Talking about problems with a psychologist seems to me as a poor way to get rid of emotional problems.
3. If I were experiencing a serious emotional crisis, I would be sure that psychotherapy would be useful.
4. I admire people who are willing to cope with their problems and fears without seeking professional help.
5. I would want to get psychological help if I were worried or upset for a long period of time.
6. I might want to have psychological counseling in the future.
7. A person with an emotional problem is not likely to solve it alone; he or she is more likely to solve it with professional help.
8. Given the amount of time and money involved in psychotherapy, I am not sure that it would benefit someone like me.
9. People should solve their own problems, therefore, getting psychological counseling would be their last resort.
10. Personal and emotional troubles, like most things in life, tend to work out by themselves.

Appendix 3E: FISI Measure

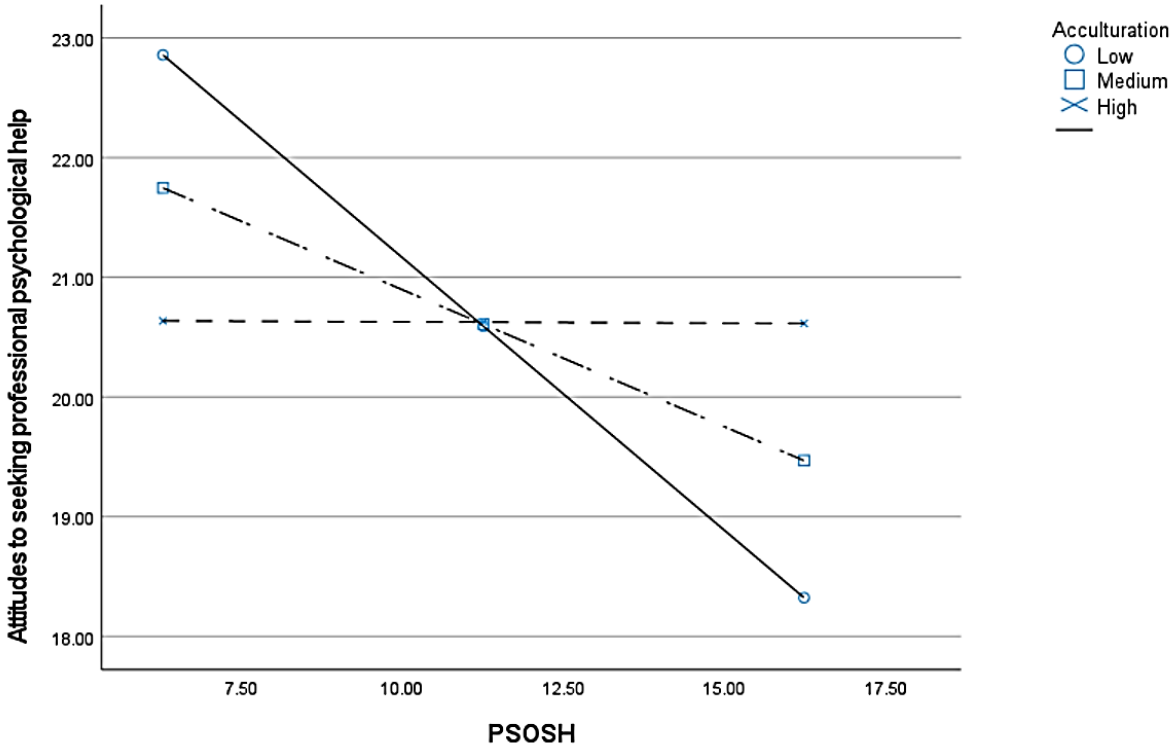
If you have less space *or* if you have no a-priori reasons to expect different effects on the individual components of self-investment, we recommend using a Four Item measure of Social Identification (FISI, see discussion section of Postmes, Haslam, & Jans, in press) on a scale from 1 (*strongly disagree*) to 7 (*strongly agree*):

1. **I identify with [In-group]** (SISI, Postmes et al., in press; adapted from Doosje et al., 1995)
2. **I feel committed to [In-group]** (Doosje et al., 1995; Leach et al., 2008, item 3)
3. **I am glad to be [In-group]** (Doosje et al., 1998; Leach et al., 2008, item 4)
4. **Being [In-group] is an important part of how I see myself** (Doosje et al., 1998; Leach et al., 2008, item 10)

Appendix 3F: Categories collapsed for Chi Square Test

Category	**Collapsed categories for analysis**	**Included responses**
Age	18 to 24 years old	18 to 24 years old
	25 to 30 years old	25 to 30 years old
	31 to 40 years old	31 to 40 years old
	41 to 65 yeas old	41 to 50 years old 51 to 60 years old 61 to 65 years old
	(excluded data)	Prefer not to say
Gender	Male	Male
	Female	Female
	(excluded data)	Other Prefer not to say

Appendix 3G: Moderation of acculturation on PSOSH



Appendix 3H: Research Ethics Approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Miss Ranjeet Bassi
Oxford Institute of Clinical Psychology Research and Training
Isis Education Centre
Warneford Hospital
Oxford

26 February 2021

Dear Ranjeet,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R74111/RE001

Study title: Cultural differences in attitudes to help-seeking and the role of self and public stigma

Short title: The role of stigma in seeking professional help for mental health difficulties

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University 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 **26th February 2021.**

Approval is **subject to:**

a) **you following the BPS guidelines for online research**
b) **the PI agreeing to comply with the requirements for administering any tests or questionnaires and, if in doubt, to contact the publisher of those tests or questionnaires**
c) **the PI ensuring that, where new research staff are engaged, they are suitably qualified by training and/or experience.**

I would like to remind you that your study may be selected for review for the purposes of monitoring and/or 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

H. Barnby-Porritt

Dr. Helen Barnby-Porritt
Research Ethics Manager, Medical Sciences

Appendix 3I: Participant Information sheet

The role of stigma in seeking professional help for mental health difficulties

Participant Information Sheet (Dated 15/02/2021)

Ethics approval Reference: R74111/RE001

Ranjeet Bassi, Trainee Clinical Psychologist
Ranjeet.bassi@hmc.ox.ac.uk

Lorna Hogg, Research Supervisor
Lorna.hogg@hmc.ox.ac.uk

Ryan Nah, Research Supervisor
Ryan.nah1@nhs.net

Why is this research being conducted?
The aim of this study is to understand the relationship between stigma in relation to mental health challenges (that is, the extent to which people perceive others to hold negative attitudes towards people who have mental health difficulties, and/or apply those attitudes to themselves i.e., internalised stigma) and seeking help from mental health services. We are particularly interested in whether there are differences in this between people from different cultural backgrounds. This is important as it could help mental health services to change the way they work with people.
Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

You may ask any questions before deciding to take part by contacting the researcher (details below).

The Principal Researcher is Lorna Hogg, who is attached to the Oxford Institute of Clinical Psychology Training and Research at the University of Oxford. This project is being completed under the supervision of Lorna Hogg and Ryan Nah.

Why am I being asked to take part?
We appreciate your interest in participating in this study. You have been invited to participate as you are:

- Are a UK Resident
- Are aged between 18 and 65 years
- identify as belonging from a White British background or a South Asian background (defined here as Indian, Pakistani, Sri Lankan, Bangladeshi, or Other South Asian Identity e.g., Punjabi)
- identify as having a mental health difficulty

We have defined **mental health difficulties** as:

A mental health difficulty is where you may notice your thoughts, feelings, or ways of reacting to situations become very severe, persistent, and so difficult to cope with that they seriously impact your quality of life (e.g., social relationships or work). It can feel as bad as having a physical illness. Common mental health problems are things like low mood and anxiety or worry, and rarer problems are things like unusual perceptual experiences such as seeing or hearing things others don't, distressing beliefs others find hard to understand or extreme mood swings.

You may have experienced a mental health problem without it being diagnosed. For example, you may have had a period of life where you felt one of these things:

- *Feeling very low in mood*
- *Worrying a lot about lots of different things or feeling very anxious – finding worry hard to control*
- *Feeling a lack of purpose in life for example you might find it hard to get out of bed*
- *Difficulties understanding or dealing with a new environment*
- *Physical impact of mental health illness such as not eating or sleeping properly, not feeling physically fit (stomach pain, headaches that are persistent and unexplained)*

What am I being asked to do? You are being invited to complete an online research study. The study will ask you to complete 3 questionnaires': one on your views of seeking professional psychological help for mental health problems, one questionnaire on your views of internalised-stigma, and one on your perception of stigma from others. You will be asked to give some basic demographic information about yourself. If you are South Asian, you will also be asked to complete an additional questionnaire about your relationship with culture. This should take about 15 minutes. No background knowledge is required.

Do I have to take part?

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button/ closing the browser or not returning the questionnaire if you are completing a hard copy.

To withdraw after you have participated, email the researcher with your unique identifier number (last 4 digits of your phone number), and ask to be withdrawn. Your data will then all be deleted.

What will happen to information collected about me in the study?

The data we will collect that could identify you will be age, sex, and ethnicity. This data will be kept on a separate password-protected file from your consent form or any other information (e.g. email address) that may be directly identifiable. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The responses you provide will be stored in a password-protected electronic file and may be used in academic publications. Identifiable information, such as email address, will be deleted as soon as it is no longer required for the research. Research data (including consent records) will be stored for three years after publication or public release.

Qualtrics is the data processor with respect to your personal data. Please see their privacy notice here https://www.qualtrics.com/privacy-statement/. Qualtrics will share only de-identified data with the University of Oxford, for the purposes of research. The University of Oxford is the data controller and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.

Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/

You will provide a unique ID number (last 4 digits of your phone number) and this will appear on all data. A report of the findings of the research will be sent to all interested participants who provide their email address for this purpose.
This project will be written up for a doctoral degree.

Who is organising and funding this study?
The study is funded by the University of Oxford. The study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Ref: R74111/RE001). The main researcher is Ranjeet Bassi, Trainee Clinical Psychologist at The University of Oxford and is employed by Oxford Health NHS Trust. The project is supervised by Lorna Hogg (Deputy Course Director & Consultant Clinical Psychologist) and Dr Ryan Nah (Lead & Clinical Psychologist PATH West).

Who do I contact if I have a concern about the study or I wish to complain?
If you have a concern about any aspect of this study, please contact Ranjeet Bassi, ranjeet.bassi@hmc.ox.ac.uk or Lorna Hogg, lorna.hogg@hmc.ox.ac.uk, and we will do our best to answer your query. I/we will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

Contact details
If you have any questions about any of this information, or would like to ask anything before you agree to take part, please contact either:

Ranjeet Bassi, Trainee Clinical Psychologist
Ranjeet.bassi@hmc.ox.ac.uk

Lorna Hogg, Research Supervisor
Lorna.hogg@hmc.ox.ac.uk

Ryan Nah, Research Supervisor
Ryan.nah1@nhs.net

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