

Understanding perceived expressed emotion in South Asians' experiencing a first episode of  
Psychosis

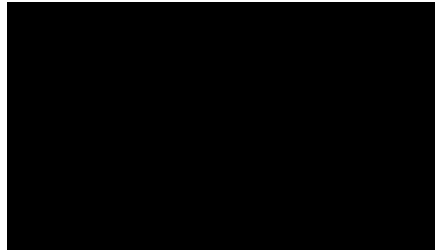
Amrita Ramanathan  
D.Clin.Psy. thesis (Volume 1), 2022  
University College London

**UCL Doctorate in Clinical Psychology**

**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



Name: Amrita Ramanathan

Date: 30<sup>th</sup> June 2022

## **Thesis Overview**

### **Part 1: A Systematic Review**

This review aims to understand the relationship between acculturation and psychosis. Findings from fourteen studies are presented through a narrative synthesis. Results indicated that the relationship between acculturation and psychosis appears to be inconsistent and that multiple confounding factors such as language, culture and ethnicity may be influencing the relationship. Clinical and research implications of findings are discussed.

### **Part 2: An Empirical Paper**

This paper aims to explore perceived EE in the South Asian context for individuals with a first episode of psychosis (FEP) understand the impact of perceived EE on clinical outcomes for individuals with a FEP. A mixed methods design was used to address these aims (i.e. thematic analysis and exploratory statistical analysis). Interviews were conducted with 24 individuals for the qualitative and/or the quantitative study. Results indicate four main categories: connection and support, understanding and awareness, boundaries and independence, and context and influence. These themes are understood in relation to acculturation, gender roles, generational differences, and stigma. For the second aim, significant correlations were found between perceived EE such as the LEE and clinical symptoms such as the HADS and PSYRATS. Limitations are discussed and recommendations are made for future research

### **Part 3: A Critical Appraisal**

This chapter offers a critical reflection on the process of research and follows the journey of clinical research from study design, recruitment, and interview through to analysis and writing.

### **Impact Statement**

Both the review and empirical paper have numerous potential impacts on future research and clinical practice:

1. *Individuals with a first episode of psychosis:* In current empirical paper, service users' perspectives of caregiving are limited but necessary as this can have implications for interventions. This research begins to highlight these important service user perspectives which can pave the way for future research in similar areas. It also empowers individuals with a FEP to reflect on their own experiences of care.
2. *Clinical Practice Implications:* Currently, there is limited research exploring the relationship between perceived expressed emotion and psychosis, particularly in South Asian communities. It is important to consider perspective of individual's perceived EE as this can influence individual's psychosis journey and possibly clinical outcomes. Furthermore, NICE (2014) highlight the need to research whether culturally-adapting family intervention for schizophrenia would facilitate engagement; thereby improving clinical care and reducing relapse/readmission rates for minority ethnic groups. The empirical paper seeks to understand how individuals with a FEP understand caregiving in South Asian communities residing in the UK. The unique perspectives of individuals with a FEP within South Asian community has not been studied. This can provide important considerations in clinical practice when engaging with South Asian families within EIP services. The project has important implications for understanding the need for cultural competence training to FI therapists and to raise awareness of culturally appropriate care in the workforce.

3. *Academics and researchers:* Part 1 of this thesis provides a systematic review on literature that highlights the relationship between acculturation and psychosis. The findings indicate numerous other factors that may further facilitate this relationship such as language, ethnicity, economic status. The review paper in this thesis examines in the relationship between acculturation and psychosis. The findings provide a range of tools that are used to currently measure acculturation. The recommendations on acculturation measurement may inform future research that attempts to capture acculturation. The findings from this study provide recommendation for future research and clinical practice. In terms of research the findings indicate the need for further exploration of constructs that facilitate the relationship between perceived expressed emotion and psychosis.

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## **Acknowledgements**

During this thesis journey there are a few people I wish to thank. Firstly, I am grateful to the participants who gave up their time to take part in this study. It was a privilege to have heard their experiences, without which this project would not have been possible.

My deepest thanks Dr Madiha Shaikh for being an amazing thesis supervisor. Her support, expertise, and guidance has carried me forward in this project. I found that Madiha's knowledge in the subject area enabled me to expand my own awareness. She believed in me in moments when I did not believe in myself; for this I am grateful.

An enormous thank you to Syed Miah, who I had the privilege of doing this joint thesis with. Thanks for being such a supportive friend and research partner in this project. I feel proud considering how much we have achieved and grown in the last three years. Thank you also to Hira Sharif and Lidushi Nagularaj for all your help with carrying out this study. Thank you to all the EIP services, specifically the research assistants Kelly, Katie, Leah, Gamze, Niamh, Rand, Jasmine and Louise for helping us coordinate with all the teams.

A sincere thank you to my friends near and far who showered me with encouragement through this process. A specific thank you to my UCL friends, on WhatsApp and in the library who I have laughed and cried with through this process. You made the time more memorable. Last but certainly not the least to my family, Ramya, Aswin, Anika, Amma, Appa, Aishu and Keshav for their encouragement, kind words, love and food, all which fuelled me through this journey.

## Part One: Systematic Review

What is the relationship between acculturation and psychosis?

## **Abstract**

### **Aims**

This review aimed to understand the relationship between acculturation and psychosis.

### **Method**

A systematic search of the literature was conducted to identify publications which studied the relationship between acculturation and psychosis/schizophrenia. The electronic databases EMBASE, OVID Medline, PsychINFO, and Web of knowledge were searched for articles.

### **Results**

Fourteen articles met the inclusion criteria. The relationship between acculturation and psychosis appears to be inconsistent across studies. Some studies found a significant relationship between the two, such that higher acculturation was associated with more psychosis symptom severity. However, other studies found no associations between psychosis and acculturation. Multiple confounding factors such as language, culture and ethnicity have been found to influence the relationship.

### **Conclusions**

The relationship between acculturation and psychosis is complex and involves multiple confounding factors. Tools used to measure acculturation are varied and inconsistent. Acculturation may be an important factor to consider within clinical practice in relation to other sociodemographic factors such as ethnicity, language, cultural values and family values.

## **Introduction**

Current literature suggests there is an association between mental health and migration. Studies have shown that forced migration increases the risk of depression, anxiety and other mental health concerns (Silove, Ventevogel, and Rees; 2017). There has been specific evidence of migration associated with psychosis (Morgan et. al., 2010). As the population of refugee migrants increase, studies investigate the role of culture as a risk or protective factor (Price & Cuellar, 1981; Madianos, 1984; Burnam et. al., 1987; Caetano, 1987; Kaplan & Marks, 1990, Berry, 1997; Ortega et. al., 2000; Bhugra, 2004; Lau et. al., 2005; Kim & Omizo, 2006; Madianos et. al, 2008). More specifically they investigate the role of acculturation in mental health (Balidemaj & Small, 2019; Mengistu & Manolova, 2019).

## ***Acculturation***

Acculturation is the process of cultural and psychological change that takes place as a result of contact between two or more cultural groups and their individual members (Redfield, Linton, & Herskovits, 1936, p. 146; Berry, 2006). There are numerous factors associated with acculturation such as language fluency (Berry, 2003; Yeh, 2003), social support (Bhugra, 2003) and the number of years living in a country (Oh, Koeske & Sales, 2002; Park et al., 2003). Over the years there has been a large attempt to measure acculturation (Thomson & Hoffman-Goetz; 2009) and examine its impact on mental health (Balidemaj & Small, 2019; Mengistu & Manolova, 2019).

Empirical findings have been mixed, as some studies link greater acculturation to poorer mental health, whereas others demonstrate a favourable relationship or no association at all

(Miranda & Umhoefer, 1998; Shen & Takeuchi, 2001; Koneru et. al., 2007). Some studies have identified that the process of migration and acculturation, introduces risks to mental health and psychosocial well-being (Bhugra, 2004a; Bhugra, 2004b; Bhugra & Minas, 2007). The impact of acculturation on mental health is a product of an individual's attempt to adapt or assimilate into a new society whilst reconciling their culture of origin (Phinney et. al., 2001). Acculturative stress is a result of immigrants' continuous and unsuccessful efforts for social integration and acceptance by the host population, leading to identity crises, feelings of frustration and subsequent aggression directed toward themselves or others (Ruesch et. al., 1948; Bhugra, 2004). Conversely, other studies have shown that acculturation can promote social interaction (Chun, Balls Organista & Marín, 2003) and increase awareness of treatment options (Rodriguez-Reimann et. al., 2004). Studies have shown that acculturation has close links with cultural identity and self-esteem (Berry et. al., 2006) because of the factors used to measure the construct i.e. language, education, and socio-economic status (Chun, Balls Organista & Marín, 2003).

### ***Types of Acculturation***

Berry's (1997) model of acculturation stipulates different kinds of acculturation strategies occur in conjunction with two dimensions. The first dimension is the rejection or retention of an individual's native culture and the second is the rejection or acceptance of an individual's host culture. Based on these dimensions four kinds of strategies can occur. Assimilation occurs when individuals adopt the cultural norms of a dominant or host culture, over their original culture. Separation occurs when individuals reject the dominant or host culture in favour of preserving their culture of origin. Separation is often facilitated by

immigration to ethnic enclaves. Integration occurs when individuals are able to adopt the cultural norms of the dominant or host culture while maintaining their culture of origin. Integration leads to and is often synonymous with biculturalism. Marginalization occurs when individuals reject both their culture of origin and the dominant host culture.

### ***Psychosis and Schizophrenia***

Schizophrenia is a severe long-term mental health condition affecting approximately 24 million people or 1 in 300 people worldwide (Institute of Health Metrics and Evaluation, 2022). Schizophrenia is defined as a disorder commonly identified by the presence of psychosis. Psychosis is when an individual perceives or interprets reality in a very different way from people around the individual; it is commonly identified by experiences of delusions and hallucinations (*Overview—Schizophrenia*; 2021). Delusions can be described as fixed beliefs that conflict with reality (Eterović & Kozarić-Kovačić, 2015). Hallucinations are understood as any sensory experiences (i.e. hear, see, smell, taste or feel) that appear to be real but only exist in the mind of the individual (Arciniegas, 2015). Although a large proportion of schizophrenia is associated with genetic and neurobiological factors, several environmental factors have been identified (Brown; 2011).

Immigrant status is a significant risk factor for schizophrenia (McDonald & Murray, 2000). A meta-analysis found that the risk of schizophrenia is higher amongst immigrants compared to that amongst natives; there have been associated factors differing between ethnic groups (Cantor-Graae & Selten, 2005). Especially prominent among the African Caribbean population in England (Harrison et. al., 1997), though the mechanism is unknown (Sharpley et. al., 2001). There is some understanding that acculturation impacts mental health more broadly

such that acculturative stress impacts the severity of mental health (Koneru et. al; 2007).

However, there is limited research looking explicitly at the relationship between acculturation and psychosis.

This review evaluated existing evidence with regard to acculturation and psychosis. Specifically, the following questions are addressed:

- 1) What is known about the relationship between acculturation and psychosis?

## **Method**

### ***Search Strategy***

The systematic search was conducted by searching EMBASE, OVID Medline, PsychINFO, and Web of knowledge. Keywords and terms used for the search included psychosis, schizophrenia, and acculturation (see Table 1 and/or Appendix B).

### ***Selection process***

Screening for articles was conducted in two rounds 1) articles relevant based on title and abstract, 2) full text. Articles were chosen based on inclusion and exclusion criteria by an initial researcher and then verified by a secondary researcher. Where discrepancy existed, a consensus approach was used. If the two reviewers were unable to reach a consensus, a third reviewer was consulted.

### ***Eligibility Criteria***

Inclusion Criteria

- Peer-reviewed journals that include data on psychosis or schizophrenia and acculturation. In regard to acculturation, all studies that explicitly identify migration status, language, race or other terms as a measurement of acculturation.
- Studies that included adults (age 18 and older) with psychosis and/or schizophrenia.
- Studies in which the main focus was not psychosis or acculturation were included if they reported or commented on the specific relationship between psychosis or schizophrenia and acculturation.
- Studies that were empirically based, using either qualitative or quantitative methodologies. With regard to quantitative methodology, all study designs were included i.e. cohort, epidemiological, cross-sectional, longitudinal, randomised, and case-controlled.
- Studies written in English.

#### Exclusion Criteria

- Studies that did not report on the results associated with psychosis or schizophrenia and acculturation.
- Review articles, case studies, conference presentations, thesis, letters, editorials, books or discussion papers.
- Studies that did not examine acculturation in adults with psychosis or schizophrenia such as adolescence, children, carers and practitioners.
- Studies where adults with psychosis-like experiences due to substance use and organic course.



**Table 1.** Literature review search terms.

Psychosis	Acculturation
Psychosis	Acculturative stress
Psychotic	Cultural assimilation
Schizophrenia <sup>a</sup>	Culturation integration
Schizo affective	Culturation adaptation
Schizo affective	Bicultural <sup>a</sup>
	Multicultural <sup>a</sup>
	Marginalisation <sup>a</sup>
	Marginalization <sup>a</sup>

<sup>a</sup> Truncated terms to allow for multiple endings of words.

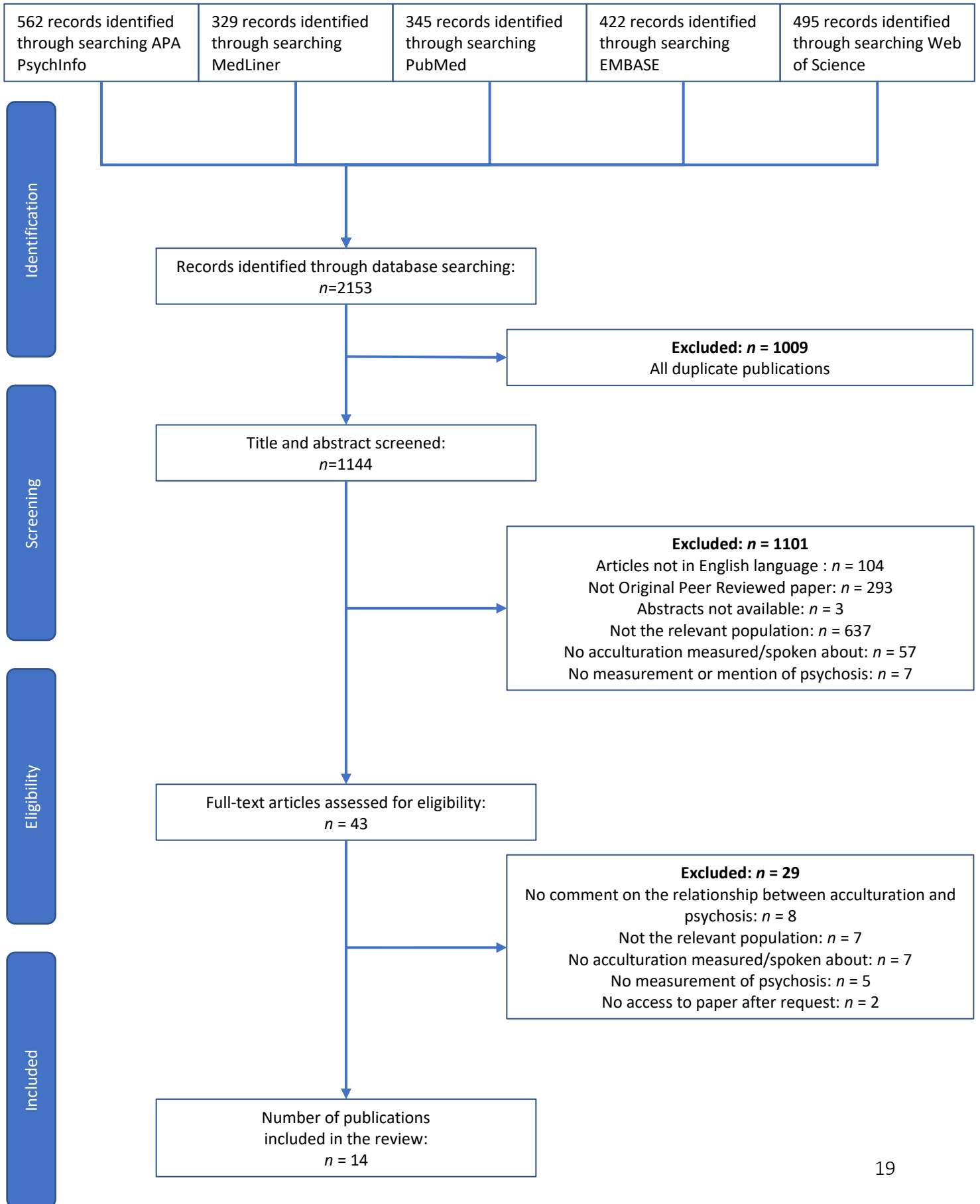
### ***Quality assessment***

A data spreadsheet was used for data extraction across the relevant fields including author, title, date of publication, country of study, sample size, population, ethnicity, design and method, acculturation measurements used, psychosis measures used and other measures/variables included (see Appendix C). Furthermore, the results, statistical analysis used, the significance of the statistics, findings of the study and limitations of the study were extracted.

The STrengthening the Reporting of OBservational Studies in Epidemiology (STROBE) checklist was used to evaluate the quality of all the studies (Bastuji-Garin et. al., 2013; Von Elm et. al.,2014). The 22-item checklist was used as it ensured a thorough, clearly defined and high-quality assessment that could be used for both cross-sectional and longitudinal cohort studies.

As there was a combination of cross-sectional and longitudinal cohort studies, Items 6, 12, 14, and 15 were answered when relevant to the study design. The STROBE score is defined as the number of the 22 STROBE items adequately reported divided by the number of applicable items, expressed as a percentage. The 13 STROBE items with several questions (2 to 15 questions per item, online supplement) were considered adequately reported when at least 50% of their questions had 'yes' answers (after exclusion of the 'not applicable' components) (Garin et.al, 2013; Langan et. al., 2010). There were no qualitative studies examined in the final review.

**Figure 1.** PRISMA Flow Chart of study selection.



## **Results**

The database search included at least one of the search terms from the first domain and one of the search terms from the second domain (table 1) and identified 2153 records. A PRISMA flowchart for the study selection is presented in Fig 1. Of these records, 46.86% (1009 records) were excluded as duplicate publications. 96.15% (1100 records) of the 1144 titles and abstracts that were screened were excluded based on language, non-peer-reviewed paper, abstract not accessible, not the relevant population, lack of acculturation measure and lack of psychosis measurement or mention. 61.36% (27 records) of 44 records were excluded due to the irrelevance of population, the lack of comment on the relationship between acculturation and psychosis, the lack of acculturation measurement or mention, not being an original peer-reviewed paper and the lack of access to paper after requested. Nineteen articles met the inclusion criteria.

### ***Study Methodology***

Table 2 outlines the study country of origin, sample population studied, the ethnicity of the population, design and methodology used for each study. These studies were conducted in five different countries, thirteen of which were conducted in the USA, two from Greece, and one each in Australia, UK, Germany and Netherlands. The sample size ranged from 32 to 2554 participants. 10 studies recruited specifically for populations with psychosis or schizophrenia, whilst the other four studies collected data from the general population via surveys or existing databases.

All 14 studies were quantitative in methodology, 11 used a cross-sectional design and three used a longitudinal design. Eight of the cross-sectional studies described the relationship

between psychosis, acculturation and other factors within one sample group. Five studies compared the variables between different ethnic groups. One of the cross-sectional studies had a comparison group with individuals with psychosis.

### ***Quality Assessment***

As shown in Table 5, 13 studies met more than 85% of the quality assessment criteria, and 11 studies met more than 90% of the quality assessment. Some studies did not meet the criteria due to funding sources, study size and other analyses.

### ***Study Measures***

Table 3 includes the questionnaires and variables used to measure acculturation, psychosis, and other variables. 12 studies used only validated measures to assess acculturation and two studies (Bae and Brekke, 2002; Lewis-Fernández et. al., 2009) used social demographic factors including place of birth, language used, educational background, years of living in the US, and English proficiency. The Acculturation Rating Scale for Mexican Americans (ARSMA; Cuellar, Harris & Jasso, 1980) and the Abbreviated Multidimensional Acculturation Scale (AMAS; Zea et. al., 2003) were the most commonly used measures. In the ARSMA measure, acculturation was defined by three factors; language, ethnic identity, and ethnic interaction. Whereas in the AMAS measure acculturation was defined by language, cultural competence, and cultural identity.

For the measurement of psychosis outcomes, 12 studies used a specific self-reported or interview-based validated measure, the Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993) and DSM-III checklist, whilst two studies (Lewis-Fernández et. al., 2009; Lim et. al., 2019) used clinical outcome data. Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993) is a tool

used by clinicians and researchers to assess symptom severity using 18 symptom constructs such as hostility, suspiciousness, hallucination, and grandiosity. Higher ratings for each construct indicate higher severity of symptoms. DSM-III was the most common diagnostic tool for studies whose main population was individuals with a diagnosis of psychosis. Other variables measured in the majority of the studies included key demographic information such as age, ethnicity, gender, level of education, primary language spoken, occupation, marital status, and medication adherence.

### ***Study Analysis and Findings***

As presented in table 4, the majority of studies ran statistical analyses to investigate the direct or indirect relationship between acculturation and psychosis, except for one study that provided descriptive data (Lim et. al., 2019). Six studies analysed both direct and indirect associations between acculturation and psychosis (Telles et. al.,1995; Koneru and de Mamani, 2006; Aguilera et. al., 2010; Gonidakis et. al., 2013; de Mamani et. al., 2017; Vinkers et. al.,2021), four studies analysed direct associations between psychosis, and acculturation (Dassori et. al., 1998; Lewis-Fernández et. al., 2009; Price et. al., 1981; van de Beek et. al., 2017), and three studies analysed the indirect associations between psychosis, and acculturation (Bae and Brekke, 2002; Bilanakis, Madianos, & Liakos, 1998; Randolph et. al., 1985).

### **Direct associations between acculturation and psychosis**

Five studies found significant associations directly between acculturation and psychosis such that high levels of acculturation are linked with high symptom severity (Aguilera et. al., 2010; Telles et. al., 1995; Gonidakis et. al.,2013; Lewis-Fernández et. al., 2009; Koneru and de

Mamani, 2006), whereas five studies did not find significant associations directly between acculturation and psychosis (Dassori et. al., 1998; van de Beek et. al., 2017; Vinkers et. al., 2021; de Mamani et. al., 2017; Price et. al., 1981).

*Positive symptoms, relapse rates and treatment outcome*

Aguilera et. al. (2010) study found significant correlates between relapse and U.S. acculturation such that higher acculturation, which was considered to be closer to American culture, correlated with higher relapse rates. Similarly, Koneru and de Mamani (2006) found that acculturation was a significant predictor of more severe symptoms of schizophrenia and that overall significant correlation between acculturation and BPRS scores. Telles et. al.(1995) identified statistically significant interactions of treatment with patient acculturation on several symptom severity scales including the BPRS and GAS. Furthermore, the level of patient acculturation appeared to be an important factor influencing treatment outcomes, which will be further discussed below in the indirect interaction summary. Gonidakis et. al.(2013) findings indicated that individuals with psychosis had statistically significant higher mean on the acculturation measure (Immigrant Acculturation Scale; Madianos et. al., 2008) score than the group without psychosis. Lewis-Fernández et. al. (2009) initially defined higher English proficiency as a part of their acculturation definition. Based on this, they found significant associations between current psychotic symptoms and higher English proficiency and seeking comfort for emotional problems through religious or spiritual means. Although the significance of this relationship is unclear due to the study's limited definition of acculturation as language proficiency.

### *Global Functioning*

Gonidakis et. al.(2013) study also found that total acculturation score, as well as the everyday life acculturation scores, were positively correlated with Global Assessment Function (GAF) scores, meaning that higher adaptation to Greek mainstream culture and everyday life rituals correlates with higher psychotic immigrant's general function as measured by GAF.

### *No significant relationship between psychosis and acculturation*

On the other hand, studies like Vinkers et. al. (2021) ran similar analyses between acculturation and psychotic symptoms and did not find significant associations. Both van de Beek et. al. (2017) and de Mamani et. al. (2017) studies stratified their participant sample into Berry's Model of acculturation styles and found that levels of depressive symptoms and psychotic experiences did not differ significantly between acculturation groups. In Price et. al. (1981) study level of acculturation was not found to be significantly correlated as there was no difference in psychopathology scores (DPD) between the two interview groups.

### *Negative symptoms*

Although the Gonidakis et. al.(2013) study found significance in the positive symptoms measures (i.e. GAF), there was no significant correlation found between the acculturation measure and the Positive and Negative Syndrome Scale (PANSS). Similarly, Dassori et. al. (1998) found no significant correlations between total Negative Symptoms Assessment scores or the cognition subscale score and level of acculturation. However, this population was moderately acculturated based on the initial measures. Furthermore, statistical analysis was not provided so it is unclear whether confounding factors had an effect on these findings.



## **Indirect associations between acculturation and psychosis**

### *Ethnicity, language and other demographics*

Many of the studies explored further relationships between acculturation and psychosis in relation to an additional factor. For example, Koneru and de Mamani (2006) further stratified their group by ethnicity to understand the associations between acculturation and severity of symptoms of schizophrenia in Florida, USA. The results indicated that the relationship between acculturation and symptom severity is complex and varies by ethnicity. The sample sizes for these correlations were too small to reach the level of significance when separated by ethnicity. However, statistical observations indicated that the greater White ethnic group acculturation appeared to be associated with greater schizophrenia symptoms whereas acculturation that was greater in the Latino ethnic group was associated with less severe schizophrenia symptoms. Lastly, there was no relationship between acculturation and symptom severity in the Black ethnic group.

On the contrary, Bae and Brekke (2002) study found no statistical differences when comparing acculturation and psychosis in the context of ethnicity. Bae and Brekke (2002) determined the Korean-American patients' group to be less acculturated than the other ethnicities based on socio-demographic factors related to language, number of years in the host country, and education. They found that there were no differences in symptomatology between the ethnic groups. Based on the classification of the Korean-American population as less acculturated than the other groups, the study stipulated that there is no relationship between acculturation and psychosis symptomatology. However, it should be noted that no

statistical analysis was conducted directly between acculturation factors and psychosis symptom severity measures. This raises concerns regarding the reliability of this conclusion.

Lim et. al. (2019) reported that about half of foreign-born participants experienced acculturative stress during the past 6 months. However, there were no specific statistical analyses used.

Randolph et. al. (1985) found that language facility or cultural bias may impact the scoring on the clinical outcome. However, it must be noted that Hispanics who scored below the average on the acculturation measure were deleted from the analysis to ensure consistency within the group.

Gonidakis et. al.(2013) found other demographics such as region of origin, marital status, and duration of stay in Athens were confounding factors for the higher mean acculturation of individuals with psychosis versus scores of individuals without psychosis. Price et. al. (1981) found verbal fluency, acculturation, and self-disclosure can collectively predict the effect of language on the expression of psychopathology in bilingual patients, and that acculturation and verbal fluency can each act as single predictors of this effect. Vinkers et. al. (2021) found direct and indirect effects of social defeat on psychotic symptoms that were mediated by acculturation.

### *Quality of Life*

Although in de Mamani et. al. (2017) study there was no difference in BRPS scores between acculturation groups they found that quality of life (QoL) regressed on assimilation scores, enculturation scores, and the interaction term, as well as ethnicity. There was a positive main effect of assimilation on QoL, with a large effect size, indicating that greater assimilation

scores were associated with greater QoL. Enculturation was also positively related to QOLI scores, with a medium effect size, such that greater enculturation was associated with greater QoL. Moreover, the interaction between assimilation and enculturation was significant, with a medium effect size, indicating that for individuals who were low on assimilation, QoLI scores became further reduced as enculturation scores declined (marginalization).

#### *Treatment groups, psychiatry and medication*

Aguilera et. al. (2010) study used a model to assess the interaction of expressed emotion (EE) and U.S. acculturation while controlling for medication adherence showed that higher levels of EE were related to a steeper positive symptom slope as U.S. acculturation increased. Telles et. al.(1995) found that level of patient acculturation proved to be a very important stratifying factor in treatment differences. Among patients who were below average in the level of acculturation, there were a number of very significant treatment differences in favour of individual case management over Behavioural Family Intervention (BFT). Low-acculturated patients who were treated with BFT had a significantly poorer course and one-year outcome than those who received case management.

Bilanakis, Madianos, & Liakos's (1998) study found high levels of acculturation were associated with an increased rate of psychiatric disorders or overall psychological impairment. Although the number of individuals with psychosis within the sample was too small to run any specific statistics between acculturation and symptoms specific to psychosis.

**Table 2.** Method of studies included in systematic review

Author(s) and Date	Country of origin	Sample Size	Population	Ethnicity/Group Comparisons	Design and Methodology
Aguilera et. al. (2010)	USA	60	Caregivers and their relatives with schizophrenia	Mexican Americans	Longitudinal study Questionnaire and clinical interview
Bae and Brekke (2002)	USA	223	People with schizophrenia	Korean-American (n= 40) Euro-American (n = 95) African-American (n = 60) Latino (n = 28)	Cross sectional Two different sources using an identical quantitative measurements baseline retrospective data set and baseline prospective study
Bilanakis, Madianos, & Liakos (1998)	Greece	198	Greek migrants in the Joannina province	Greek migrants in the Joannina province	Cross-sectional study Questionnaire and semi-structured interview
Dassori et. al. (1998)	USA	51	People with schizophrenia	Anglo American (n=25) Mexican American (n=26)	Longitudinal study Questionnaire and clinical interview
de Mamani et. al. (2017)	USA	128	People with schizophrenia	Hispanic (n= 66) Blacks (n= 62)	Cross sectional study Questionnaires
Gonidakis et. al.(2013)	Greece	382	Patients (n=65) Non-psychotic immigrants (n= 317)	Patients (n=65) Non-psychotic immigrants (n= 317)	Cross-sectional study Questionnaire and interview

Koneru and de Mamani (2006)	USA	47	People with Schizophrenia	White American (n=16) Latino-American (n=17) Blacks (n=14)	Cross sectional study Survey Questionnaire
Lewis-Fernández et. al. (2009)	USA	2554	Data from National Latino and Asian American Study (NLAAS) Non-institutionalized Household residents in USA	Latino population in the US	Cross sectional study Survey Questionnaire
Lim et. al. (2019)	USA	75	People with schizophrenia	Asian Americans	Cross sectional study Questionnaire and interview
Price et. al. (1981)	USA	32	People with schizophrenia	Mexican American patients	Cross sectional study Questionnaire and interview
Randolph et. al. (1985)	USA	81	People with schizophrenia	Hispanic (n=41) Anglo (n=40)	Cross Sectional Study Questionnaire and clinical interview
Telles et. al.(1995)	USA	40	People with schizophrenia and low income	Spanish speaking	Longitudinal study Questionnaire, Interviews
van de Beek et. al. (2017)	Netherlands	267	Young Moroccan-Dutch visiting the online website	Moroccan-Dutch population	Cross sectional study Online self-reported Questionnaires
Vinkers et. al. (2021)	Germany	53	Immigrants to Rotterdam	Caribbean immigrants to Rotterdam	Cross sectional study

**Table 3.** Measures and variables for studies in systematic review

<b>Author (s) and Date</b>	<b>Acculturation measured</b>	<b>Psychosis/Schizophrenia Measured</b>	<b>Other Measures/ Factors measured</b>
Aguilera et. al. (2010)	Bidimensional Acculturation Scale (BAS; Marin and Gamba; 1996)	Expanded Brief Psychiatric Rating Scale (BPRS; Ventura et. al. 1993) Relapse rates	Medication adherence from CFI interviews (Velligan et. al., 2006) Camberwell Family Interview (CFI, Vaughn & Leff, 1976)
Bae and Brekke (2002)	Socio-cultural variables: Place of Birth Language used Educational Background	Brief Symptom Inventory (BSI; Derogatis and Melisaratos 1983) Number of days in psychiatric hospitals Frequency of psychiatric hospital admissions Days on medications	Community Adjustment Form (CAF; Test et. al. 1991) Satisfaction With Life (SWL; Stein & Test, 1980) Index of Self-Esteem (ISE; Hudson 1982)
Bilanakis, Madianos, & Liakos (1998)	Greek Immigrants Acculturation Scale (GIAS) (Madianos; 1984)	Langner Scale (Langner, 1962) Structured Clinical Interview for D.S.M. III (SCID; Spitzer et. al. 1991)	Demographic and Social Variables: Age, Gender, Ethnicity
Dassori et. al. (1998)	LAFECA acculturation scale (Cuellar, Harris, & Jasso, 1980)	Brief Psychiatric Research Scale, (BPRS; Overall & Gorham 1962) Negative Symptoms Assessment (NSA; Alphas et. al., 1989) Structured Clinical Interview for DSM-IV [Diagnostic and Statistical Manual of Mental Disorders (4th edition)] CGI scale (Guy; 1976)	
de Mamani et. al. (2017)	Abbreviated Multidimensional Acculturation Scale (AMAS; Zea et. al., 2003)	Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993) DSM-III SCID-I/P (First et. al., 1997)	Quality of Life Inventory (QOLI; Frisch et. al., 1992)  Demographic variables: age, ethnicity, gender, length of time in the U.S, education, primary language
Gonidakis et. al.(2013)	Immigrant Acculturation Scale (IAS; Madianos et. al., 2008)	The Positive and Negative Syndrome Scale (PANSS; Kay, Opler, & Fiszbein, 1987) Calgary Depression Scale for Schizophrenia (CDSS; Addington, Addington, & Maticka-Tyndale, 1993) Global Assessment of Functioning (GAF; Endicott et. al., 1976)	Demographic variables: Gender, Religion, Marital status, Age, Education, Duration of stay in Greece
Koneru and de Mamani (2006)	Suinn-Lew Asian Self-Identity Scale (Suinn et. al., 1992)	Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993)	Structured demographic questionnaire measures including: Gender, Age, Ethnicity, Occupation, Caretaker occupation, Length of residence in U.S., Generation in U.S., Educational level, Primary language
Lewis-Fernández et. al. (2009)	Socio-cultural variables: Language Years of living in the US English proficiency	World Health Organization Composite International Diagnostic Interview (WMH-CIDI) (Kessler and Ustun, 2004) CIDI - Clinical measures included lifetime and current psychiatric disorders and presence of psychotic symptoms, medical conditions; self-rated mental and physical health; exposure to traumatic events, and measures of mental health service use, mental health-related disability, and suicidal ideation. Endorsement of psychotic experiences Clinical variables: Lifetime prevalence, Any depressive disorder,	Demographic measures included: Age, Gender, Education, Household income, Marital status

		substance use disorder, No, psychiatric disorders in the last 12 months, No, psychiatric disorders lifetime, No. chronic medical conditions, Self-rated mental health	
Lim et. al. (2019)	Mexican American Prevalence and Services Survey (Vega et. al. 1998)	Psychiatric information diagnosis from medical records Clinical history (age at onset of illness, length of illness) use of mental health services (duration of service use, medication adherence) Assessment of medication adherence was based on days of antipsychotic medication use during the previous 180 days, and then recoded as continuous, regular, low, or nonuse in accordance	Demographic and Social Variables: age, gender, race, marital status, primary language, English proficiency, educational level, employment status, religious affiliation, living arrangement, family stressors, frequency of family contact, immigration histories (nativity status, country of birth, age at time of immigration, and generational status) Trauma exposure questionnaire (Turner & Lloyd, 1995) Life Event List (Cohen et. al. 1993)
Price et. al. (1981)	Acculturation Rating Scale for Mexican Americans (ARSMA; Cuellar, Harris and Jasso, 1980)	Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993).  Mental Status Examination (Cohen, 1964)	Wechsler Adult Intelligence Scale (WAIS; Waschler, 1955) Escala de Inteligencia Wechsler Para Adultos (EIWA; Wechsler; 1968)
Randolph et. al. (1985)	Acculturation Rating Scale for Mexican Americans (ARSMA; Cuellar, Harris and Jasso, 1980)	Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993) Clinical Global Impressions (CGI; Busner, & Targum, 2007) Global Assessment Scale (GAS; Endicott et. al., 1976) Hopkins Symptom Checklist (SCL-90; Derogatis, 1974)	Drug abuse/dependence summary Number of DSM-III symptoms, positive diagnoses, diagnoses with symptoms reported to a physician, diagnosis present with 2 weeks until last year, Treatment history (number of weeks hospitalized during past year). Control variables: Ethnicity (Anglo or Hispanic), Level of acculturation (Hispanics only)
Telles et. al.(1995)	Acculturation Rating Scale for Mexican Americans (ARSMA; Cuellar, Harris,Jasso; 1980)	Brief Psychiatric Rating Scale (BPRS; Ventura et. al., 1993) Global Assessment Scale (GAS; Endicott et. al., 1976) Present State Examination (PSE; Wing et al, 1974) DSM-III	Camberwell Family Interview (CFI; Vaughn & Leff, 1976) Present State Examination (Wing et. al., 1974) Psychiatric and Social History Schedule developed by the UCLA MHCRC Medication Compliance
van de Beek et. al. (2017)	Acculturation Scale (Instituut voor Sociale Geneeskunde. Acculturatieschaal; 2004)	Pro- dromal Questionnaire-16 (PQ-16; Ising, 2012)	Kessler Psychological Distress Scale 10 (K10; Kessler et. al. , 2002) Every Day Discrimination Scale ( Ikram et. al. 1995, Williams DR et. al. 1997, Krieger et. al. 2005) Oslo Social Support Questionnaire (Meltzer et. al., 2003) Social Defeat Scale (Gilbert & Allan; 1998) Social Comparison Scale (Ilan and Gilbert; 1995)
Vinkers et. al. (2021)	Ethnic and National Identity questionnaire (12 items). (Berry et.al. 2006) Dutch and Antillean cultural acculturation scores - higher scores indicated higher degree of involvement in the Dutch or Antillean culture.	Community Assessment of Psychic Experiences (CAPE-42; Konings et. al., 2006)	Demographic items: age, gender, first/second generation migrant status, previous mental healthcare, highest completed level of education, All items were dichotomised International Comparative Study of Ethnocultural Youth (ICSEY Phinney et. al., 2001) Brief Core Schema Scales (BCSS; Fowler et. al., 2006) Delinquent behavior questionnaire ( Van der Laan et. al., 2006)

**Table 4.** Analysis and findings of studies in systematic review

Author (s) and Date	Statistical test?	Type of Stat	Associations between acculturation and psychosis? Direct, indirect, or both?	Statistical significance found?	Test Value	P-values
Aguilera et. al. (2010)	Yes	Correlation Regression	Both	Yes	r = .28 coef = 0.0012	p < .05 p < .05
Bae and Brekke (2002)	Yes	ANCOVA	Indirect	No	F = 0.25	not reported
Bilanakis, Madianos, & Liakos (1998)	Yes	Chi-Square Pearson's correlation Multiple Regression	Indirect	Yes	x <sup>2</sup> =21.45 r(38) = -0.26 Beta=1.880, SE=0.960, t2.30	p<0.05 p < 0.001 p<0.02
Dassori et. al. (1998)	Yes	Pearson's correlation ANOVA	Direct	No	r = 0.12 r= 0.09	
de Mamani et. al. (2017)	Yes	ANOVA Regression	Both	Partially	t(115) = 0.43, η <sup>2</sup> = 0.04 t(115) = -0.39, η <sup>2</sup> = 0.04) F(3115) = 0.23, η <sup>2</sup> = 0.01 (Integration M = 52.85, SD = 12.18; Assimilation M = 55.19, SD = 14.33; Separation M = 51.39, SD = 14.22; Marginalization M = 54.03, SD = 12.90). R <sup>2</sup> = 0.13, F(4, 119) = 4.46	p=0.67 p=0.70, p = 0.86 p = 0.002
Gonidakis et. al.(2013)	Yes	T-test Chi-square Pearson's correlation Regression	Both	Yes	t(380)=5.1, t(380)=4.5, t(380)=2.8 X <sup>2</sup> (380)= 24.1, X <sup>2</sup> (380)=13.7 OR= 1.4, OR = 1.1, OR = 1 r=0.3, r=0.1, r=-0.8	p=0.001, p=0.001, p=0.005 p=0.001, p=0.001 p = .001, p = .02, p = .001 p<0.05, p>0.05, p>0.05
Koneru and de Mamani (2006)	Yes	Regression Pearson's correlation	Both	Partially	R <sup>2</sup> = .084, B = 0.29 NA r=0.29, r=0.24, r=-0.13, r=0.07	p<.05 p>.05 p<0.05, p>0.05, p>0.05, p>0.07
Lewis-Fernández et. al. (2009)	Yes	Correlation	Direct	Yes	47.3% OR=2.86	p<0.00 CI = 1.30 – 6.29
Lim et. al. (2019)	No					
Price et. al. (1981)	Yes	Regression Correlations	Direct	Partially	r=0.20, R <sup>2</sup> =0.04, df(1/30), F=1.24 R <sup>2</sup> =0.06, df=2/29, F=1.01 R <sup>2</sup> =0.25, df=2/29, F=4.85 r = +.36, r = -.36 F(1, 27)= 6.52	Ns Ns p=0.05 p < .05, p< .03 p < .05
Randolph et. al. (1985)	Yes	Multivariate analysis	Indirect	No		NS
Telles et. al.(1995)	Yes	chi-square ANOVA	Both	Yes	x <sup>2</sup> =0.02, df =38 F=7.59, d.f. = 1,33 F= 5.20, F= 5.20 , F= 9.18, F= 15.79 F=10.22, F=4.13, F=11.75, F=20.8	p = 0.005 p=0.0095, P= 0.029, P= 0.029, P= 0.005, P= 0.0004 p=0.005, p=0.056, p=0.003, p=0.0002
van de Beek et. al. (2017)	Yes	Descriptive Regression	Direct	No		ns
Vinkers et. al. (2021)	Yes	Multiple Regression	Both	Partially	β = -0.13 β = -0.05 z = 3.52 z = -0.26	p = 0.280 p = 0.670 95% CI = 0.16–0.55 95% CI = -0.02–0.02



**Table 5.** STROBE Quality assessment and outcomes for studies

	Item No	Aguilera et. al. (2010)	Bae and Brekke (2002)	Bilanakis, Madianos, & Liakos (1998)	Dassori et. al. (1998)	de Mamani et. al. (2017)	Gonidakis et. al.(2013)	Koneru and de Mamani (2006)	Lewis-Fernández et. al. (2009)	Lim et. al. (2019)	Price et. al. (1981)	Randolph et. al. (1985)	Telles et. al.(1995)	van de Beek et. al. (2017)	Vinkers et. al. (2021)	N	(%)
<b>Title and abstract</b>																	
<b>Introduction</b>																	
Background/rationale	2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Objectives	3	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	13	92.86
<b>Methods</b>																	
Study design	4	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Setting	5	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Participants	6	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	13	92.86
Variables	7	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Data sources/ measurement	8*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Bias	9	Y	N	?	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	11	78.57
Study size	10	N	Y	Y	N	N	Y	Y	N	Y	Y	Y	Y	Y	N	9	64.29
Quantitative variables	11	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Statistical methods	12	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	13	92.86
<b>Results</b>																	
Participants	13*	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	12	85.71
Descriptive data	14*	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	12	85.71
Outcome data	15*	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	13	92.86
Main results	16	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Other analyses	17	Y	Y	Y	N	N	Y	Y	Y	Y	?	N	Y	Y	Y	10	71.43
<b>Discussion</b>																	
Key results	18	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Limitations	19	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Interpretation	20	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	14	100.00
Generalisability	21	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	13	92.86
<b>Other information</b>																	
Funding	22	Y	Y	N	N	Y	N	N	Y	N	N	N	Y	Y	N	6	42.86
<b>Overall Percentage</b>		95.45	95.45	86.36	59.09	90.91	95.45	95.45	95.45	95.45	86.36	90.91	90.91	100.00	90.91		

Items with a \* indicate that two or more questions were asked, responses were determined based on percentage. I.e. if one or more answer was Y then the item scored Y.

## **Discussion**

Prior literature indicates that acculturation may be an important factor in mental health (Phinney et. al., 2001) particularly among immigrant communities as immigration can cause increased stress leading to mental health concerns. Several meta-analyses have indicated that migration is associated with a risk of psychosis (Cantor-Graae & Selten, 2005; Bourque, van der Ven, & Malla, 2011; Castillejos, Martín-Pérez and & Moreno-Küstner, 2018; Henssler et. al., 2020), such that it is 1.8 more likely for first-generation and second-generation immigrants to have psychosis compared to native population (Henssler et. al., 2020). Studies have identified that the process of migration and acculturation, introduces risks to mental health and psychosocial well-being (Bhugra, 2004a; Bhugra, 2004b; Bhugra & Minas, 2007). However, there has been no review of the specific relationship between acculturation and psychosis. This is important as immigrant communities have higher rates of psychosis and acculturation may play an important role in this. Hence, this narrative systematic review set out to explore the relationship between acculturation and psychosis.

### ***Summary of main findings***

#### **Acculturation Measure**

The findings indicate that there is a complex relationship between acculturation and psychosis. More specifically it highlights the variability in the way in which acculturation is understood and measured by different countries and at different times. This brings into question whether utilizing a consistent measure of acculturation would further help clarify this relationship. The current review indicates that many acculturation measures are short and lack internal validity, as a result these measures only capture a small part of the acculturation

process (Celenk, 2011). Furthermore, measures tend to focus predominantly on behavioural adjustment outcomes which lack nuance and do not fully capture acculturation. The review suggests that to improve the measure of acculturation there should be measurements from multiple domains associated with acculturation both publicly and privately (i.e. language, ethnicity, family values) (Celenk, 2011). Studies found that demographic variables such as region of origin, verbal fluency, marital status, and years of and duration of stay in were confounding factors for the higher mean acculturation of individuals with psychosis versus scores of individuals without psychosis (Gonidakis et. al.,2013, Price et. al., 1981; Vinkers et. al., 2021). This may indicate the multiple domains associated with acculturation which requires further consideration as to what domains are used to measure acculturation.

### **Direct links between psychosis and acculturation**

Several studies found direct associations between acculturation and psychosis such that high acculturation was associated with high symptom severity (Aguilera et. al., 2010; Telles et. al., 1995; Gonidakis et. al.,2013; Lewis-Fernández et. al., 2009; Koneru and de Mamani, 2006). This may connect with some current literature that has identified high levels of acculturative stress associated with significant mental health concerns such as higher psychological distress and clinical depression (Hwang & Ting; 2008). However, some literature suggests that acculturation may be a protective factor related to mental health. For example, those who are aware of the customs of the new culture can adapt better and have better access to care which promotes better mental health (Bhugra; 2004).

### **Confounding factors linked with psychosis and acculturation**

Other studies found no direct association between the two factors (Dassori et. al., 1998; van de Beek et. al., 2017; Vinkers et. al., 2021; de Mamani et. al., 2017; Price et. al., 1981). This may be due to several confounding factors that influence this relationship such as language, years in the host country, education and ethnicity. Acculturation was identified as a mediator between the psychosis symptom severity and factors such as expressed emotion and social defeat. This relationship may be understood through studies that explain acculturation as a sociocultural process that has different impacts depending on cultural and familial context. Studies have found that cultural values of autonomy and interdependence shape how care is perceived or expressed (Hooley & Gotlib, 2000; Breitborde, López, & Nuechterlein, 2009). Depending on these ethnic or familial cultural values, acculturation may have a different impact on the relationship between symptom severity and other factors such as expressed emotion (de Mamani et. al., 2007).

Furthermore, Selten and Cantor Graae (2005) discuss the high prevalence of social defeat in patients with schizophrenia and point out that this is especially common in immigrants and minorities. Ethnic minority communities who experience difficulties in identifying with either the minority culture or the host culture may be faced with a sense of identity void, which may be likely to exacerbate their symptom severity.

### ***Overall completeness and applicability of the evidence***

Furthermore, the majority of study designs were cross-sectional (Bae and Brekke, 2002; Bilanakis, Madianos, & Liakos, 1998; Gonidakis et. al., 2013; Koneru and de Mamani, 2006; Lewis-Fernández et. al., 2009; Price et. al., 1981; Randolph et. al., 1985; van de Beek et. al.,

2017; Vinkers et. al., 2021; de Mamani et. al., 2017) which made it hard to stratify participant sample into Berry's Model of acculturation styles. Studies found that levels of depressive symptoms and psychotic experiences did not differ significantly between acculturation groups (van de Beek et. al., 2017; de Mamani et. al., 2017).

### ***Certainty of the evidence***

It is difficult to determine the certainty of evidence due to the variability of size sample, quality and study populations. Some of the study associations were done in larger cohorts where individuals with psychosis were a subset. Hence the significance of this relationship needs to be reviewed in larger cohorts. Furthermore, the use of various measures and definitions for acculturation may be a contributing factor in the contradicting findings of the relation between the acculturation process and mental health. Because of this complexity, it is hard to understand the direction relationship. Prior studies have found that acculturation more specifically acculturative stress is found to be high amongst immigrants but more specifically forced immigration which increases mental health concerns.

### ***Potential biases in the review process***

All studies have been conducted in the US and European countries which only account for specific acculturation processes and may not represent acculturation in other parts of the world. The countries included in this review tended to be Western and majority white countries which further limits the application of these findings to a specific kind of acculturation. It is important to consider the immigration history of the populations that are studied as this may limit the study findings to the specific communities that were part of the target population. Given that the study was limited to English this may further bias the kinds of studies that were

selected for the process. Furthermore, this review excluded studies from grey literature which may provide further insight into this topic.

### ***Limitations***

This study pertains several limitations. First due to the variability of how participants were recruited and the study populations difficult to ascertain the applicability of these studies specifically to individuals with psychosis. Additionally, the varied ways of measuring acculturation can be a contributing factor to the contradicting findings in the literature. The inconsistency of measures used in these studies may indicate a need to further solidify clear measurements and stringencies to ascertain the construct of acculturation. As identified by prior literature (Celenk, 2011) acculturation is a very broad construct which has negative aspects such as acculturative stress and positive aspects such as successful assimilation. Hence, this complexity adds to measurement issues. It is also important to highlight that the construct of Berry's model of acculturation is formed within a White Western context of immigration which at times lacks the necessary contextual understanding of how individuals or communities adapt in new environments.

Further, many of the studies collude with reductionist ethnic categories such as 'Latino Americans' which erases nuanced intersecting identities. More specifically, it is important not to make broad assumptions about acculturative strategies of specific ethnic groups as this lacks the nuance of individual context amongst each immigrant community i.e. history, geography, race and other sociocultural aspects. Further given the population needs, the majority of studies excluded individuals experiencing a current or active episode of psychosis, which may reduce our understanding of acculturation and psychosis in those experiencing severe or active

symptoms. Some of these studies varied in quality and did not have the appropriate power to run further analyses for the interactions, hence it may not be captured the extent and direction of associations between acculturation and psychosis.

### **Implications for practice and policy**

This review highlights the varying extent to which acculturation may impact psychosis severity and the relationship to clinical outcomes. When applying these findings in clinical practice, it is important to consider contextual factors such as culture, family engagement, language and ethnicity when working with people with psychosis who are assimilating to a new host culture. This is in line with what other studies suggest such that the adoption of an integrative mode of acculturation is linked with better psychological adjustment and mental health of the immigrant (Fabrega, 1969; Mavreas & Bebbington, 1990; Adamopoulou et. al., 1990; Sam & Berry, 1995; McLachlan et. al., 2004; Lau et. al., 2005).

### ***Conclusion***

The relationship between acculturation and psychosis is complex and involves multiple confounding factors. Tools used to measure acculturation are varied and inconsistent. The tools tend to capture different aspects of the construct. Furthermore, it may be that negative components such as acculturative stress are associated with psychopathology. Acculturation requires further consideration in clinical practice as it may shed light on important sociodemographic factors such as ethnicity, language, cultural values and family values.

### ***Future directions***

Future reviews should explore other factors that are linked with this association, particularly ethnicity and language. It may be important to also explore the dual identity of

psychosis and an immigrant and how these identities interact and impact mental health and well-being. Furthermore, it would be important to explore the relationship between acculturation and psychosis in terms of the direction of the effect and to continue investigating whether acculturation is a risk or a protective factor.



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## Part Two: Empirical Paper

Perceived expressed emotion and clinical outcomes of first episode psychosis in South Asian communities in the UK

## **Abstract**

### **Aims:**

- 1) To explore perceived EE in the South Asian context for individuals with a FEP (first episode of psychosis).
- 2) To understand the impact of perceived EE on clinical outcomes for individuals with a FEP.

**Methods:** A mixed methods design was used to address the two aims.

Qualitative data was collected to answer the first aim. Semi-structured interviews with service users (SU) were conducted. Thematic analysis was used to identify the themes that emerged from the interviews. A preliminary coding scheme was established and used in all interviews.

A quantitative analysis was conducted for the second aim. A cross-sectional design was used to explore the relationship between SU perceptions of EE and clinical outcomes. SU perceptions of EE were measured using self-reported measures about experiences of being cared for. Clinical outcomes were measured using self-reported questionnaires on well-being, symptom presentation, as well as routine clinical data including the number of relapses, hospital admissions and bed days.

### **Results**

For the first aim, four main categories were identified; connection and support, understanding and awareness, boundaries and independence, and context and influence. These themes are understood in relation to acculturation, gender roles, generational differences, and stigma. For the second aim, significant correlations were found between perceived EE such as the LEE measure and clinical symptoms such as the HADS and PSYRATS.

## **Conclusions**

Individuals with psychosis who identify as South Asian have a range of experiences with their carers such as practical and emotional support, love, care, intrusiveness, expectations, and awareness of mental health that are informed by culture, mental health, family narratives and structure. Acceptance, communication and negotiating their relationship with their carer are common.

## **Introduction**

### ***Expressed Emotion***

Expressed emotion (EE) can be defined as a set of attitudes, emotions and behaviours expressed by relatives about a family member. Families with higher levels of EE are understood to have high criticism, hostility, and emotional over-involvement (EOI) (Kavanagh, 1992). Studies have found that chance of someone who has previously experienced a mental illness having a relapse is understood to be greater if families are over-involved, critical and hostile (Finnegan et. al., 2014; Brown et. al., 1972; Vaughn & Leff, 1976; Vaughn et. al., 1984; Karno et. al., 1987). The common omission of warmth and positive regard components from analysis, means that little is known about the protective aspects of relationships (Bhugra & McKenzie, 2003). There have been repeated calls for a re-inclusion of these factors, based upon the hypothesis that they may interact with, and mitigate the impact of, negative aspects of EE in culturally variant ways (Bhugra & McKenzie, 2003; Singh et. al., 2013; Claxton, Onwumere, & Fornells-Ambrojo, 2017; López et. al., 2004; Bebbington & Kuipers, 1994). Indeed, warmth was shown to be protective against symptoms of psychosis for Mexican Americans, whilst not relating to the course of illness for Anglo American families (López et. al., 2004).

### ***Perceived Patient EE***

Perceived EE can be described as the perception of family care by the individual. Current literature suggests patient perceptions of caregiver EE indicates some level of impact on treatment outcome such that higher levels of perceived criticism is associated with lower levels of social functioning, higher levels of negative affect, and negative schematic beliefs in psychosis (Onwumere et. al., 2009). A recent longitudinal study has identified that higher levels

of perceived EE at 6 months was associated with higher transition to psychosis at 12 months (Izon et. al., 2021). Another study found that lower patient ratings of family cohesion and caregiver warmth were associated with greater symptom severity (Gurak & de Mamani, 2016). Although much of this research is limited to predominant Western frameworks, some research suggests that when examining family EE in ethnic minority groups, patient perspective may be a better predictor of clinical outcome than standard measures of EE making it an important factor to investigate (Tompson et. al., 1995).

### ***Culture and EE***

Given the original EE conceptualisation work took place within the UK, some cultural variation is unsurprising. A closer look at the cross-cultural literature demonstrates variation in EE, both in term of prevalence and in its relationship to patient outcomes (O’Driscoll et. al., 2019, Bhugra & McKenzie, 2003; Singh et. al., 2013; López et. al., 2009; Cheng, 2002; Jenkins & Karno, 1992). Behaviours would have been defined as pathological against UK norms, with emotional over-involvement, for example, being evidenced through over- protective and self-sacrificing actions, considered maladaptive in individualistic Western culture (Bhugra & McKenzie, 2003). Hence studies have also found that levels of EE can vary based on culture and ethnicity (Weisman, 1997). For example one study found the frequency of high EE in non-Latino white families was three times as high as those in Latino families (de Mamani, 2007). Other studies have not found a correlation between several EE constructs and clinical symptom severity. For instances, in a sample of African Americans, high levels of relative’s criticism and intrusive behaviours were associated with higher rates of relapse prevention (Rosenfarb, Bellack, & Aziz, 2006). Researchers hypothesise that African American communities may

perceived behaviours commonly associated argumentative or confrontational as a sign of care and communication (Kochman, 1986). Similarly, another study comparing EE between Mexican American families and non-Latino white families found that high levels of EE was not associated with relapse for schizophrenia among Mexican American, but in contrast high levels of EE was significantly correlated with relapse rates among non-Latino white sample (Kopelowicz et. al, 2002). Researchers suggest in contrast to certain Western cultures a lack of 'emotional over involvement' from family members may be understood as a lack of care (Akhtar et. al., 2013; Singh et. al., 2013). Furthermore, it may be that cultural differences in family involvement and support play a role in explaining mental health treatment disparities (Snowden, 2007). Most recent studies have continued to identify that within diverse cultural groups, 'the predictive links of high EE and poorer outcomes are not uniform' and therefore need further investigation (Onwumere & Kuipers, 2021). Such cultural variability points to the inherent complexity of this psychosocial risk factor and a need to critically examine the assumption that reducing EE within families is always appropriate and of clinical benefit for the patient.

### ***South Asian Context and EE***

There have been few studies exploring EE in South Asian groups living in a western context. There are strikingly variant results within South Asian populations such that British Pakistani families had higher level of EE compared to British Sikh and White families. However, none of the family EE predicted psychosis relapse. (Hashemi & Cochrane, 1999). Another study found baseline emotional overinvolvement was not associated with relapse at either 1- or 2-year follow-up amongst a North Indian community (Leff et. al., 1987; Leff et. al., 1990). Pakistani relatives showed higher levels of emotional over-involvement and hostility as

compared to many other cultures (Ikram et. al., 2011). In most studies South Asian SU perspective has been understood as part of a larger cohort group, hence it is difficult to capture specific narratives of South Asian community (Roach, 1992).

### ***Rationale***

In recognition that (i) EE may capture cultural constructs rather than pathogenic traits (ii) EE constructs may not translate across various cultures and (iii) there is limited understanding of perceived EE in relation to culture, there has been increasing call for studies to examine the cross-cultural variability of EE (Bhugra & McKenzie, 2003; Hashemi & Cochrane, 1999; Singh et. al., 2013). To the best of our knowledge, there have been no other studies exploring EE within South Asian families living within a Western setting. Furthermore, there have been no studies exploring the relationship between patient perceptions of caregiver EE and treatment outcome within South Asian families. This study aims to expand on the existing literature by (i) examining the facets of EE within cultural context by understanding how the EE impacts clinical outcomes in South Asian communities. This paper also aspires to deconstruct the concept of EE and explore beyond the original constructs by using a bottom-up methodological approach. Additionally with regards to patient perceived EE, this paper takes a targeted interest in the perspective of individuals with a FEP both within the EE constructs and beyond.

Assessing cross cultural variability in EE and understanding more about the relationship between the experience of caregiving and patient outcomes in South Asians in the UK would inform not only research but also clinical interventions. In particularly, NICE (2014) highlight the need to research whether culturally-adapting FI for schizophrenia would facilitate engagement;

thereby improving clinical care and reducing relapse/readmission rates for BAME groups. This study aims to respond to the need to further develop our understanding of patient perception of EE from a cross-cultural perspective and to better understand the complexity of the EE-relapse relationship in under-researched BAME groups most likely to utilise early intervention services.

### ***Study Aims***

The aims of the study are:

- 1) To explore perceived EE in the South Asian context for individuals with a FEP (first episode of psychosis).

As this is an exploratory aim, no specific hypothesis has been identified.

- 2) To understand the impact of perceived EE on clinical outcomes for individuals with a FEP.

Based on the literature, we hypothesised that patient perception of EE would impact clinical outcomes such that patients who perceive high EE will have poorer clinical outcomes. Below in table 1 is a detailed breakdown of the specific hypothesis for each EE measure and domain. The predicted direction of the relationship is also provided.



**Table 1.** Hypothesis for secondary aim

Hypothesis	EE Construct	Effect of Clinical Symptom	Predicted Correlation
I. Increased patient perception of overall EE would result in poorer patient outcome.	Overall EE	Poorer	Positive
II. Increased patient perception of intrusiveness would result in poorer patient outcomes.	intrusiveness	Poorer	Positive
III. Increased perception of negative attitude toward illness would result in poorer patient outcomes.	negative attitude toward illness	Poorer	Positive
IV. Increased perception of high emotional response would result in poorer patient outcomes.	high emotional response	Poorer	Positive
V. Increased perception of tolerance and expectation would result in better patient outcomes.	tolerance and expectation	Better	Negative
VI. Increased perception of critical comments would result in poorer patient outcomes.	critical comments	Poorer	Positive
VII. Increased perception of warmth would result in better patient outcomes.	warmth	Better	Negative

## **Methods**

### ***Joint Project***

This is a joint project with Syed Kausar Miah (Trainee Clinical Psychologist). Development of measures/questions, recruitment and data collection was done jointly for this project. Syed's thesis focuses on caregiver EE. (see Appendix D for a detailed summary of researcher involvement).

### ***Service User Consultation***

Prior to the start of this thesis, Patient and Public Involvement (PPI) had been actioned as part of the wider research study. In order to gain feedback on the initial research project, a panel was made up of members from a London trust patient experience service and a local grassroots SU led mental health organisation in London provided feedback which was then incorporated into subsequent revisions.

A summary of the study and proposal were by the carer forum (monthly carers support group for relatives of individuals that have experienced a first episode of psychosis within NELFT) and two SU from NELFT EIS from a South Asian background. Both groups provided positive feedback. Specifically they were pleased that a study explored issues specific to South Asians.

Furthermore, 3 SU from University College London Service User and Carer Reference Group piloted the questionnaires. The group provided feedback that the questionnaire took too long as it took an hour to complete for all 3 participants. Feedback was also given about the wordiness of the instructions and the size of the font in some questionnaires. Based on the

feedback, adaptations were made to the study such as reducing the measures, increasing font size and simplifying the instructions.

### ***Ethics***

This study received ethical approval by the Yorkshire and The Humber – South Yorkshire Research Ethics Committee (IRAS: 230098). Given that data collection was done during the COVID-19 pandemic, further amendments were made to the study to collect data remotely. Additionally, amendments were made to the study to add in a qualitative data collection.

### **Consent**

Informed consent was taken from all participants by members of the research team online or over the telephone. Participants were given a copy of an information sheet providing details of the study and given a minimum of 24 hours between reading the information sheet and signing the consent form to think about their decision to take part (Appendix E). They were also given a copy of the consent form and asked to read all content and sign it if they are happy to partake (Appendix F) and encouraged to ask any questions that they may have. Where participants lacked sufficient literacy skills for this process, the researcher would read the information sheet and consent form aloud to them. Participants were made aware of their right to withdraw from the study without needing to give a reason and told that their participation is completely voluntary.

### **Safety practices**

No harm was anticipated to come to participants as procedures are non-invasive. However, if participants were distressed when completing the questionnaires or interview they were told that they could choose to discontinue with the study without any repercussion to

their clinical care. Researchers ensured they have time to sit with SU and give them space to express any distress to them. Researchers reflected back to them what they have understood about their distress as a way of letting them know they have been heard/listened to and to also normalise difficulties. Where necessary, researchers would encourage the service user to make a plan to talk to their care coordinator and share with the care coordinator any ongoing distressing thoughts so that they can be supported as needed in an ongoing way. When appropriate researchers reminded SU of contact details of mental health support lines available to them to use (details of which they will already have been given as part of their routine care). Interviews were no longer than 90 minutes to prevent fatigue.

### **Compensation**

All participants were eligible to receive the £10 compensation for their time for each interview. If SU were distressed when completing the questionnaires and chose to discontinue with the study, they still receive the £10 compensation for their time.

### **Participant anonymity and Confidentiality**

All participants were told before taking part that if they disclose anything that leaves the researcher concerned that they could be at risk to themselves or others that the researcher would be duty bound to pass this information on to a member of their care team. This mirrors confidentiality agreements that they had been informed of as part of their care with the service.

## **Participants**

### **Sample Size**

As research in this area is scarce, two studies looking at perceptions of EE in psychosis (Onwumere et. al., 2009; Gurak & de Mamani, 2016), which reported effect sizes of 0.26 and 0.42, respectively informed the power analysis. G Power (Faul et. al., 2007) was used to conduct the power analysis and an estimated sample size ranging from 42 - 113 provides 80% power with an alpha of 0.05 to detect a medium (0.42) to small (0.26) effect size. Of these 42 participants 10 to 15 patients with FEP were aimed to be interviewed.

However, as this study sample is a hard-to-reach population our final sample size was 22 participants for the quantitative study and 16 participants for the qualitative study. Further information provided in the recruitment section below.

### **Recruitment**

Participants were recruited from several North London Early Intervention in Psychosis Teams between October 2020 to May 2022. Information about the study and a poster was given to the different services (Appendix G). Overall, 169 SU with a FEP were identified from 6 different Early Intervention for Psychosis Services (Figure 1). Patients were initially approached either at entry into the service or through a search of the current service caseload. In both cases, an initial identification of potential participants was carried out by clinical staff working in the service e.g. Assistant Psychologist, Clinical Psychologist or Care Coordinator. 48 SU were excluded as they did not have a care coordinator or their care coordinator was not contactable. 121 Service user capacity was assessed as part of routine clinical practice by treating clinicians. After consulting with treating clinician, 31 SU excluded due to being discharged (n=11), mental

health capacity (n = 7), English not being their first language (n = 6), not-eligible due to ethnicity (n = 3), moving service or country (n = 3), and a disability (n = 1). 90 SU were identified as being suitable for the study, of which 24 individuals participated in the study. Basic information about the study was then provided to the South Asian SU entering the service by the treating clinician or someone involved in their care (member of the clinical team). These potential participants were then asked if they were interested in hearing more about the study and were willing to be contacted by a member of the research team.

SU who verbally expressed an interest and agreed to be contacted were called by one of the thesis students and were given a more detailed explanation of the study. Information about GDPR regulations were provided. Following this, and at least 24 hours later, they were contact to answer questions they have and, if they are happy to go ahead, to arrange a meeting to take consent.

### ***Eligibility Criteria***

#### **Inclusion criteria**

- Under the care of the EIS service with a diagnosis of FEP
- Over the age of 18
- English Speaking
- Self-identified South Asian heritage including the following countries Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan, Sri Lanka

#### **Exclusion criteria**

- Unidentified and uncontactable care coordinator, in order to check for appropriateness for the study
- Unable to participate due to significant mental health as identified by the care coordinator/service i.e. currently in inpatient, experiencing significant cognitive difficulties
- Non-English Speaking

### ***Data Collection***

A mixed methods approach was used which included a survey about perceived EE and clinical outcome measures and a semi-structured interview which explored perceived EE within the cultural context. Both the survey and the interviews were conducted via Microsoft Teams. If participants were unable to access the internet, the interview was conducted via telephone. Participants were given the option to participate in either the survey, interview or both.

### **Qualitative Questionnaire**

The semi-structured interview consisted of 5 open-ended questions designed to capture perception of expressed emotion (Appendix H). These questions were informed by the Five-Minute Speech Sample (FMSS; Gottschalk & Gleser, 1969) and aimed to elicit open responses. Interviews were conducted by the research team which included 3 trainee clinical psychologists. Interviewers were trained to prompt participants with open-ended verbal cues, e.g. 'could you clarify information?' and 'could you expand on that?', 'could you give me an example of that?', 'what does that look like?', 'what does that mean to you?'. All qualitative interviews were recorded and transcribed using Microsoft teams automated transcription. Transcripts were then formatted and stripped of any identifiable information, such as mention of names or places.

## **Quantitative Measures**

A cross sectional design was used to explore service-user perception of expressed emotion and compare this with their clinical outcomes. The self-report questionnaires and clinical data used are explained below:

### *Demographic Information*

Self-reported demographic data and information asking for age, ethnicity, country of birth, gender, religion, education level, main language spoken, number of years living in the UK, relationship status, employment status, relationship to carer, weekly contact with carer and if they live with their carer.

### *IV SU EE perception*

*Level of Expressed Emotion Scale (LEE: Cole & Kazarian, 1988):* This scale assesses expressed emotion from the perspective of both caregiver and service user. It is a 60 item, self-report scale based upon the EE construct with four sub scales of Intrusiveness, Emotional Response, Attitude Toward Illness and Tolerance and Expectations. Items are rated as either true or false and the scale generates an overall continuous EE score in addition to a score for each subscale. The overall score can also be stratified into high EE and low EE using the median score as a cut off. The initial analysis indicated that the scale has sound psychometric properties of internal consistency; reliability; independence from sex, age, and amount of contacts; and construct validity.

*Perceived Criticism (PC: Hooley & Teasdale, 1989):* This scale assesses the EE component of criticism from caregiver and patient. It is a 4 item self-report scale which includes questions



about how critical each member of the dyad perceives the other. Items are rated on a 10-point Likert scale ranging from 'not critical [or upset] at all' to 'very critical [or upset]'. The research supports the concurrent and predictive validity of PC.

*Warmth Questionnaire:* This is a new five-item measure created based on current literature relating to warmth (Family attitudes scale, The Family Affective Attitude Rating Scale, Lindsay Smith Thesis Care-giving Relationships Questionnaire, CFI). The items are rated on a 4 point Likert (never/very rarely to very often) based on the Family Questionnaire (FQ). Higher scores indicated greater levels of warmth in relationships. The measure was pilot with a small public sample who self-identified as South Asian. Participants were asked what the measure was assessing; forty percent indicated warmth, and other answers including 'love', 'closeness' and 'compassion'. This indicated that the measure has face validity (see measure in Appendix I),

#### *Clinical Outcomes measures*

*Psychotic Symptom Rating Scales (PSYRATS; Haddock 1999):* This is a 17 item clinician rated scale to assess levels of psychotic symptoms; one part of the scale to assess auditory hallucinations and the other part to assess delusions. The scale measures different dimensions of symptoms including frequency, duration, location, conviction, amount of distress and intensity of distress. The two scales were found to have excellent inter-rater reliability. There was some validity when comparing the measure to the Psychiatric Assessment Scale (KGV; Krawiecka et al. 1977).

*Self-Evaluation of Negative Symptoms (SENS; Dollfus, Mach & Morello, 2016)*: The SENS is a self-assessment constituted of 20 sentences and based on 3-point Likert-scale (0-2). It indicated good convergent and discriminant validity, and excellent intrasubject reliability.

*Global Assessment of functioning scale (GAF; Hall, 1995)*: A clinician rated scale that considers psychological, social and occupational functioning. Study indicated high validity and maximum interrater reliability for the modified GAF due to the increased structure.

*Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)*: This scale assesses anxiety and depression in both hospital and community settings. It is a 14-item self-report questionnaire consisting of two subscales to measure both anxiety and depression. Measure was found to be a reliable instrument for identifying level of depression and anxiety in a hospital outpatient clinic. There was also found to be valid measures of severity of the emotional difficulties.

Other Clinical Indicators: Routine clinical data including relapses, number of hospital admissions, total bed days, involvement of acute services (including HTT Involvement) and number of sections.

### ***Analysis***

Qualitative data was analysed to answer the first aim which was to explore perceived EE in the South Asian context for individuals with a FEP. Quantitative data was analysed to answer the second aim which was to understand the impact of perceived EE on clinical outcomes for individuals with a FEP.

## **Qualitative Analysis**

Thematic analysis (Braun & Clarke, 2006, 2014; Clarke & Braun, 2018) was used to identify key themes. Thematic analysis is a commonly used research method that involves identifying, analysing and reporting recurring patterns (themes) within the data (Braun & Clarke, 2006) and allows for large sets of data to be analysed in a systematic way. This analysis helped researchers understand how patients perceive their carers as using a bottom-up approach (Mays & Pope, 2000). Transcripts were reviewed and core themes were identified by trainee clinical psychologist, and a clinical psychologist/research supervisor. Using the core themes, a dictionary coding sheet was established.

### *Researcher's reflexivity*

As a part of the thematic analysis procedure it is important for the researcher to examine biases and prejudices that may inform the way themes are categorised and understood (Braun & Clarke, 2006). Hence, the researcher met with an external researcher to consider the perspectives that may inform the qualitative questions and analysis. The researcher acknowledges her role as a Tamil speaking Indian, Singaporean, female trainee clinical psychologist, in her late twenties, having her own experiences of being part of a South Asian family and the potential this has to influence interpretation and analysis. Identifying as South Asian may bring cultural assumptions during the analytic process about how participants may feel towards their carer and what their expectations are of their carer. Hence, once key themes were established, thesis student and research supervisor reviewed the transcripts and further sharpened definitions of coding themes and consider how the researchers identities inform the analysis to encourage as much objectivity as possible . Once a consensus codes were

reached, final codes were established the codes were transferred to NVivo (QSR International Pty Ltd, 2008).

### **Quantitative Analysis**

JASP Team (2022). JASP (Version 0.16.1)[Computer software] was used to carry out statistical analyses. All variables were checked for assumptions of normality using skewness and kurtosis cut off 1/-1. Variables that did not meet the assumptions of normality were analysed using non-parametric correlation test. Descriptive statistics were used to describe the demographic data and to explore the range mean and standard deviation of the scores from all of the EE variables. Analysis was conducted to test each hypothesis indicated below in table 2. Correlations will be conducted for all hypothesis with individual EE measures and each of the clinical measures.

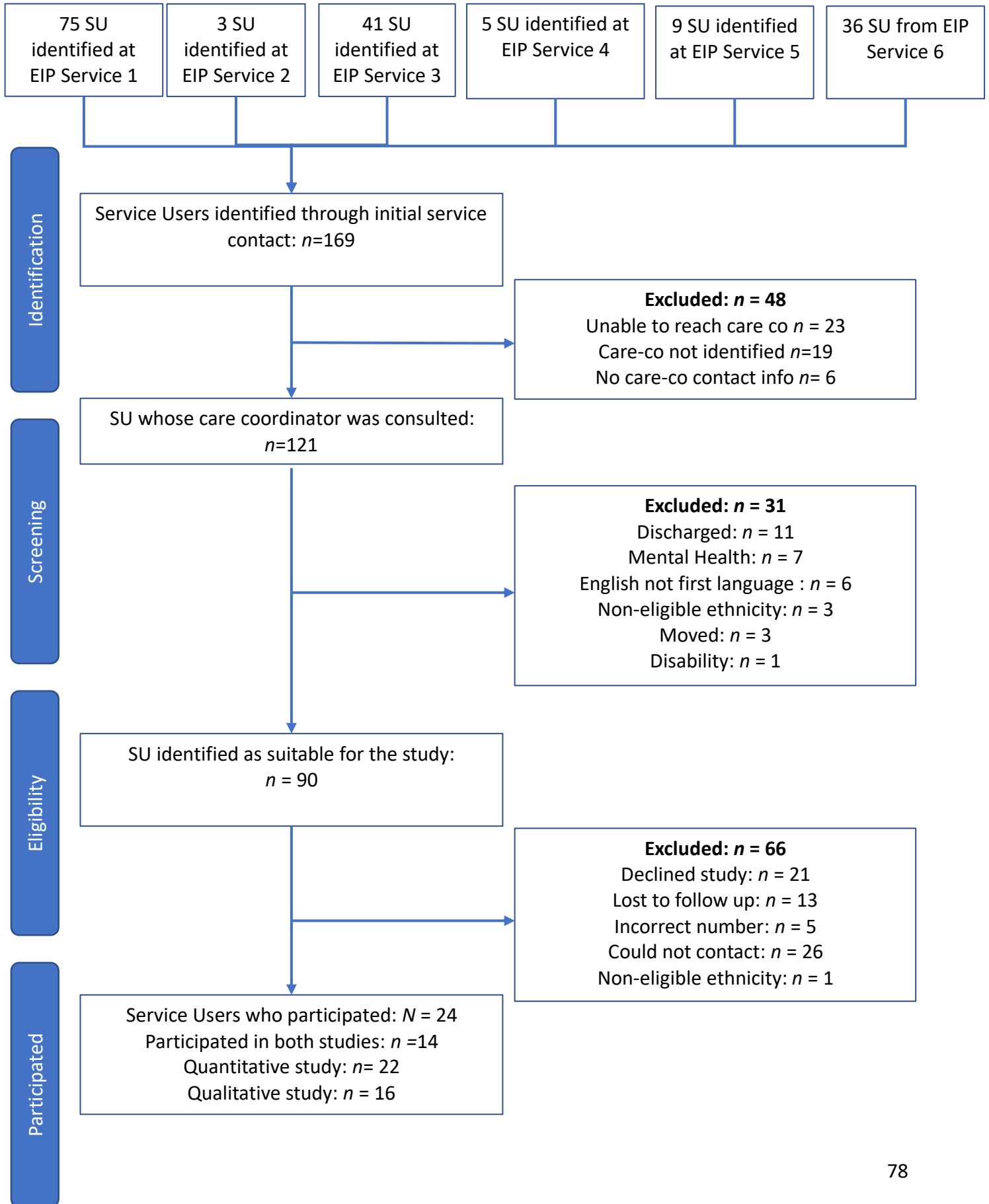
For further analysis, LEE total scores were stratified into high and low EE based on if scores were above or below the median score of 9. A parametric tests were conducted first to check for significance followed by a Mann-Whitney test between LEE high-low groups for each clinical measure. This similar method has been used in original measure (Cole & Kazarian, 1988). LEE domain level was not stratified due to limited power.

**Table 2.** Quantitative analysis for secondary aim

Hypothesis	EE Measure	Clinical Measure	Tests Run	Number of Tests
I. Increased patient perception of overall EE would result in poorer patient outcome.	LEE total score	All clinical measures and domains	Correlations Two sample t-tests	34
II. Increased patient perception of intrusiveness would result in poorer patient outcomes.	LEE intrusiveness domain	All clinical measures and domains	Correlations	17
III. Increased perception of negative attitude toward illness would result in poorer patient outcomes.	LEE negative attitude toward illness domain	All clinical measures and domains	Correlations	17
IV. Increased perception of high emotional response would result in poorer patient outcomes.	LEE high emotional response domain	All clinical measures and domains	Correlations	17
V. Increased perception of tolerance and expectation would result in better patient outcomes.	LEE tolerance and expectation domain	All clinical measures and domains	Correlations	17
VI. Increased perception of critical comments would result in poorer patient outcomes.	Perceived criticism scale	All clinical measures and domains	Correlations	17
VII. Increased perception of warmth would result in better patient outcomes.	Warmth measure	All clinical measures and domains	Correlations	17

Note all clinical measures refer to HADS, PSYRATS, SENS, GAF, number of hospital admissions, relapses, sections, total bed days and domain level for each measure hence correlation are 17.

**Figure 1.** Flow Chart for Recruitment



## Results

24 people, 14.2% of the originally identified SU participated. 22 SU participated in the quantitative study, and 16 participated in the qualitative study (Figure 1).

### *Demographics*

The means presented in the tables are divided between quantitative and qualitative study participants shown on table 3. Average age of the participants for the quantitative study was 29.5 (SD=9.5), and for qualitative study was 30.8 (SD=10.9).

Main ethnicities were Pakistani (Quant: n=8, 36.4%; Qual: n=4, 25.0%), Indian (Quant: n=7, 31.8%, Qual: n=5, 31.3%) and Sri Lankan (Quant: n=5, 22.7%, Qual: n=5, 31.3%), followed by Bangladeshi (Quant: n=1, 4.5%, Qual: n=2, 12.5%) and Nepali (n=1, Quant: 4.5%, Qual: n=0, 0.0%). Participants were split relatively equally between female (Quant: n = 10, 45.5%; Qual: n = 9, 56.3%) and male (Quant: n = 12, 54.5%; Qual: n = 7, 43.8%) participants. Majority of participants were born in the UK (Quant: n = 14, 63.6%; Qual: n = 10, 68.8%), single (Quant: n = 19, 86.4%; Qual: n = 13, 81.3%), and unemployed (Quant: n = 13, 59.1%; Qual: n = 10, 62.5%). Education level were mostly split between A-level/vocational level training (Quant: n = 9, 40.9%; Qual: n = 6, 37.5%) and higher education or professional/vocational equivalent (Quant: n = 9, 40.9%; Qual: n = 8, 50.5%).

As displayed on table 4, majority of participants spoke about a parent for the interview (Quant: n = 15, 68.2%; Qual: n = 13, 81.3%), a few spoke about a partner (Quant: n = 2, 9.1%; Qual: n = 2, 12.5%).

**Table 3.** Demographic information for the quantitative (n = 22) and qualitative group (n = 16)

Measures	Quantitative	Qualitative
Age mean (SD)	29.5 (9.5)	30.8 (10.9)
Range	21-59	21-59
<b>Ethnicity <i>n</i> (%)</b>		
Bangladesh	1 (4.5)	2 (12.5)
India	7 (31.8)	5 (31.3)
Nepal	1 (4.5)	0 (0.0)
Pakistan	8 (36.4)	4 (25.0)
Sri Lanka	5 (22.7)	5 (31.3)
<b>Country of Birth <i>n</i> (%)</b>		
Bangladesh	0 (0.0)	1 (6.3)
India	1 (4.5)	1 (6.3)
Nepal	1 (4.5)	0 (0.0)
Pakistan	3 (13.6)	0 (0.0)
Spain	1 (4.5)	1 (6.3)
Sri Lanka	2 (9.1)	2 (12.5)
UK	14 (63.6)	11 (68.8)
<b>Gender <i>n</i> (%)</b>		
Female	10 (45.5)	9 (56.3)
Male	12 (54.5)	7 (43.8)
<b>Religion <i>n</i> (%)</b>		
Buddhist	1 (4.5)	1 (6.3)
Christian/Catholic	3 (13.6)	4 (25.0)
Hindu	1 (4.5)	2 (12.5)
Muslim	11 (50.0)	6 (37.5)
None	2 (9.1)	1 (6.3)
Other	1 (4.5)	0 (0.0)
Sikh	3 (13.6)	2 (12.5)
<b>Relationship Status <i>n</i> (%)</b>		
In a relationship (not cohabiting)	2 (9.1)	1 (6.3)
Married	1 (4.5)	2 (12.5)
Single	19 (86.4)	13 (81.3)
<b>Education level <i>n</i> (%)</b>		
A Level, vocational level (e.g. NVQ) 3 or equivalent	9 (40.9)	6 (37.5)
GCSE (5 or more grades A*-C), vocational level (e.g. NVQ)	2 (9.1)	2 (12.5)
Higher education or professional/vocational equivalent	9 (40.9)	8 (50.0)
Other qualification not listed (e.g. certificate)	1 (4.5)	0 (0.0)
Post graduate education or professional/vocational equivalent	1 (4.5)	0 (0.0)
<b>Employment status <i>n</i> (%)</b>		
Apprenticeship	1 (4.5)	1 (6.3)
Employed full time	3 (13.6)	3 (18.8)
Employed part-time	3 (13.6)	2 (12.5)
Self-employed	1 (4.5)	0 (0.0)
Unemployed	13 (59.1)	10 (62.5)
Unknown	1 (4.5)	0 (0.0)

Note: M = Mean; SD = Standard Deviation, *n* = participant count



**Table 4.** Carer spoken about for quantitative (n = 22) and qualitative group (n = 16)

Which carer are they speaking about <i>n</i> (%):	Quantitative	Qualitative
Parent	15 (68.2)	13 (81.3)
Partner	2 (9.1)	2 (12.5)
Sibling	2 (9.1)	0 (0.0)
Child	1 (4.5)	1 (6.3)
Other (specify)	2 (9.1)	0 (0.0)

### ***Thematic Analysis findings***

Table 5 displays an overview of the themes and subthemes that were distinguished into four categories; (1) connect and support, (2) understanding and awareness, (3) boundaries and independence, and (4) context and influence. Throughout the results section participant number are indicated in brackets.

**Table 5.** Summary of Themes

<b>Categories</b>	<b>Themes and Subthemes</b>
<b>1. Connection and Support</b>	<b>Love and Expressions of Love</b>
	Physical Affection of care
	Humour and Playfulness
	Unconditional Love
	Kindness
	Safety
	<b>Support</b>
	Advice, wisdom and knowledge
	Bonding and spending time
	Caring
Financial and practical support	
Listening and being present	
<b>2. Understanding and Awareness</b>	<b>Mutual relationship</b>
	<b>Concern for carer's health</b>
	<b>Appreciation and gratitude for one another</b>
	<b>Awareness of Mental Health</b>
	Checking in - are you okay
	Not having to explain
	<b>Fear of being rejected</b>
	<b>Non-judgment and increased trust</b>
	<b>Open dialogues and communication</b>
	<b>Understanding and patient</b>
<b>Patient</b>	
<b>3. Boundaries and Independence</b>	<b>Acceptance about carer</b>
	<b>Controlling, Intrusiveness, Protectiveness</b>
	Controlling
	Expectations and demands
	Intrusiveness
	Protective
	<b>Hopes and worries</b>
	Wanting independence and increased trust
	Open conversations
	<b>Negotiating change in relationships and arguments</b>
Change in relationship	
'Something I need to work on my side'	
<b>Provides freedom and choice</b>	
'Doesn't ask too many questions'	
Gives freedom and space	
<b>4. Context and Influence</b>	<b>Cultural and Generational Differences</b>
	<b>Family Roles and Dynamics</b>
	<b>Mental Health</b>

## **Connection and Support**

Participants reported different kinds of connection and support that they valued or sought out from their carers. Some participants appreciated and were grateful for the support whilst others wished for there to be more understanding. Key themes that presented under this category included expressions of love, support, mutual relationship, concern for carer's health and appreciation and gratitude for one another.

### ***Love and Expressions of Love***

Participants described various forms of love expressed between them and their carers presented in table 6.

#### *Physical Affection of care*

The theme commonly presented in the context of women speaking about their relationship with their mother or daughter. For example participant 1157 describes that her mother 'like she helps her with cooking and shows her affection like giving hugs. This may be partly due cultures norms around women expressing more about the physical aspects of the relationship.

#### *Humour and Playfulness*

Some participants described humour and playfulness as a way being close and showing love. For example, as participant 1141 describes teasing one another as a way of showing their love for one another.

#### *Unconditional Love*

Several participants spoke about qualities of unconditional love that their carer had for them. This unconditional love seemed to be contextualised in the family roles and possible duties linked with culture. Participant 1084 described that that unconditional love was part of the

normal relationship between a son and mother and presented this a normal relationship.

Similarly, another participant described that his wife was unconditionally committed to the relationship and did not expect any money but just his love.

### *Kindness*

Kindness was a quality that carer's valued about the participants or participants valued about them. Participant 1023 described that her mother and her are extremely kind to each by expressing their desire to spend time with one another.

### *Safety*

Some participants described that the carer's love and affection provided them with a sense of safety and comfort. One participant described humour as one way they felt comfortable and safe with their carer.

**Table 6.** Quotes for theme Love and Expressions of love

Sub theme	Quote
Physical affection and care	“like she helped me with the cooking and she shows me affection like gives me hugs and tells me to be there for me that nothing's going to happen to you. I'm here for you and she always tries to see the positive things in life and she put. She pushes me up to do well and things like that.” (1157)
Play and humour	<p>“Yeah, I like to play kind of like jokes on my mum, Uhm, just like mucking about really, we just, um, a sort of just like pinch her, that kind of thing. (laughs) 'cause we, uh, but yeah, it's usually like I pincher on her cheeks or something like that or like arm. Yeah, I would say that that we are quite like playful in that sense like kids and so yeah and she just sort of reacts and I kind of like that reaction. So yeah ..... She's sort of reacts in like back in like a playful way as well. She would just be like go away or like, Sort of like in like Tamil, she would say that and so it's just like a way we, just like, I guess not communicating but just have fun really.” (1141)</p> <p>“I like being with her. She makes me laugh so I enjoy. I enjoy that she's quite funny. Right, so I kind of just kind of enjoy that..... She'll tell me jokes about her friends, or she'll say something or describes somebody funny, right? So she's quite nice. It's quite funny. That is, sometimes I laugh and say depends on what level my mood is in.” (1031)</p>
Unconditional love	<p>“I'd say we have an unconditional relationship, unconditional love relationship in the sense like normal mother would have for the son. Umm and normal relationship” (1084)</p> <p>“Uh I married in 2005 my marriage is arranged marriage. Uh is 2003 my mom and, uh, theirs family, they speak to the marriage. But that time my situation is, uh, you know, uh, I need to do something in my life. I'm very young that time I straight away, I tell to my wife's first meeting in the phone. I can't marry now I need another two years time. She say it's OK, I'm staying. After that until now she is one of the best. I never seen anything she's speaking about, uh, wrong. Any other people or, uh, you know I, she's behaviour everything, she is very nice. She's honestly ... honestly and she's don't like money or anything she like, uh, you know, the love only.” (1115)</p>
Closeness, Bonding, and Kindness	<p>“I don't know, I think it was more like. We were both like... don't know we were just being really kind to each other. And then even when we came home and I was like, I really like spending time with you movie shopping and she was like yeah she, she always says that about me anyway, She's always like, yeah, you're really good company and that when we go out she's like, yeah, you're really good company. But this time I felt like I just felt a lot closer to her. I'm not sure why, maybe because I started doing my wedding shopping as well so it kind of hit us both that OK yeah like it happened. It's all happening so. I bought a few things for my wedding and Yeah, like I think we kind of got a bit closer over that 'cause we were choosing other things together and stuff like that.” (1023)</p>
Safety	<p>“She'll tell me jokes about her friends, or she'll say something or describes somebody funny, right? So she's quite nice. It's quite funny. That is, sometimes I laugh and say depends on what level my mood is in... uh, there's a lot there. There's a lot of affection there, nice, I feel kind of quite safe with her.” (1031)</p>

## ***Support***

Majority participants spoke about different kinds of support they received from their loved one either when they were unwell or experiencing mental health difficulties and beyond the mental health difficulties. (Quotes on table 7)

### *Advice, wisdom and knowledge*

Some spoke about how they valued advice or knowledge about certain things from their loved one as it helped face their low mood. For others, the knowledge and advice helped them excel in their career and life.

### *Bonding and spending time*

Many participants described bonding and spending time together as a way of recognising the support they had. Participants who's carer was a parent or a child spoke about spending time through activities such as shopping, traveling, playing sport, going to the cinema and talking with one another.

### *Caring*

Several participants described the carer's supporting them with medications and coordinating care for their mental health needs. Participants found this practical support with medications and mental health to be helpful and supportive.

### *Financial and practical support*

Others spoke about the practical and financial support that their carer provided. Participants who had children appreciated that their carers supported them with childcare tasks like taking the kids to school. Participants who identified as children to their parents appreciated the commodities and education that their parent was able to buy them. One participant described

spending time together as “family time”(1157) and appreciated that the time they spent with their carer allowed them to bond.

*Listening and being present*

Participant described that they felt supported when they were listened to by their carers. When they were present and listening to their needs it showed some that they are valued.

**Table 7.** Quotes for theme Support

Sub theme	Quote
Advice, wisdom and knowledge	<p>“ Well, he's very supportive of me and um. Yeah, he's very supportive. Uh, he's very helpful is quite knowledgeable, so he always likes to share knowledge with me, UM, on different things. And knowledge does come in handy as well” (1050)</p>
Bonding and spending time	<p>“ I'm just because I said I I'm quite close to her. I had discussed like about things with her, but like my future, my past and the present and and I feel like we like bond a lot. So I think that's probably like a major reason why I feel like close to her.”(1057)</p>
	<p>“ We do things together, right? We kind of sit and we talk together we'll share things together. We'll have dinner together and like there's a lot of like the family things that I enjoy doing with her and she'll find out things to do right and and then she'll sort of like you know, say to me there's this happening in barking shall we go there? Shall we do this? Shall we do that? It makes a lot more that she makes a lot more effort with me and that I like that.” (1031)</p>
	<p>“We go for a walk together. Sometimes when we walk the dog or because we live together. So we do a lot of things together; we watch TV together and some... Yeah she does all the cooking and I help her with her computer stuff like.” (1068)</p>
Caring	<p>“Uhm, recently..uhm..uhm...I say he's looking out for me in terms of like my medication that I've been taking, so he's been calling up my care coordinator to help me get it changed because I've gained a lot of weight on it. So he's conscious that, about my health as well. So he's been looking out for my health. Hmm, yeah, he's been actively trying to get my medication changed as well, which I should be doing myself, but he's just taking a careful..taking care of it for me...” (1014)</p>
Financial and practical support	<p>“Uhm, I'll say he's very caring as well, like, he always looks out for me. He always buys my favourite food or gets me clothes and like always looks out for me and provides for me as well like and. Yeah, I think that's it.” (1014)</p>
	<p>“Yeah , he supports me a lot and I'm not able to do my things and all, so he does for me and especially my.. I was a good cooker, cooking food and so now I'm not able to do so. He's supports me with that so he's like he's looking after children, plus he's looking after me as well so it's a lot of hard work, hard job for him.” (1109)</p>
	<p>“it's compromising, UM, you know, in different aspects of, for example, like we share our duties like when I have a baby. So like when I look after the baby so we have one night when she look after them. Then one night I look after like that.” (1157)</p>
Listening and being present	<p>“ I think I've touched on everything, but she's a really good, UM. Really good listener. UM, like really good listener should always listen to me. She always, you know, make time for me when I need her. Uhm, like just after I got ill when I came back home she'd always make me spend time with her like in her bedroom like, uhm, just before I go sleep. And and she'd always call it. Like she'd be like yeah, we need to have a meeting in my room. She'd always call a little meeting. Little meeting in my room.” (1023)</p>



### ***Mutual relationship***

Participants spoke about how their relationship with their carer was a give and take such that not only is their carer present and supportive for them but they are present for their loves (quotes on table 8). For example participants 1023 and 1010 shared their experiences of helping their loved one as well. A few participants described hoping to reciprocate the support and love they received from their carers as highlighted by participant (1007)

### ***Concern for carer's health***

Participants who had carers of an older age described worrying about their carer's health and at times the longevity of their carer's life. Some hoped that their carer could take better of themselves whilst others worried about their responsibility in ensuring their loved ones had a long life. For example participant 1061 describes how they wished their parent would look after their health more.

### ***Appreciation and gratitude for one another***

In relation to the support and care participants received from their loved one, several participants described a sense of gratitude and appreciation for having their loved one present. The gratitude for the care they received made them feel that they could not ask for more as they were satisfied with the kind of care they received.

**Table 8.** Quotes from category Connection and Support

Themes and subthemes	Quote
<b>1.3. Mutual relationship</b>	<p>“Yeah, it's generally a good relationship and I'm just trying to think of aspects. Uhm? I think we're pretty understanding towards each other as well, because sometimes she goes through things and then I'm there for her too...” (1023)</p> <p>“there’s marital problems between her and my dad sometimes. And there's like arguments so like, the way like I have leant on her for support when I wasn't unwell, like she's kind of lent unlike me and my sister for support in that kind of thing, so it's like. Uhm, I like that we can talk about those things and just kind of like. Uhm, be that one over in that way, uhm, yeah yeah.” (1010)</p> <p>“Uhm... I would be more caring and more loving and supportive and being there for her rather than her always being there for me. I would um be able to reciprocate those um those conversations, and I I know she wants to talk to me about that stuff and I'm having to shut it down or leave the room and. So that makes the guilt difficult.” (1007)</p>
<b>1.4. Concern for carer's health</b>	<p>“I wish that she would look after her health... yeah ultimately I worry about her, you know, it's it's it is her.. health, uh.. well being, uh, you know, her life. So you know it would ultimately affect her.” (1061)</p>
<b>1.5. Appreciation and gratitude for one another</b>	<p>“No, not really. I mean, you know the fact that she's there is, you know, I'm grateful for grateful enough and, uh, I can't really ask for more. I wouldn't want my mother to do anymore that, you know, to do what she is doing, yeah.” (1061)</p> <p>“It's I think it's kind of rare to find someone that fully supports you and everything that you do come apart from your family, sometimes with certain families you don't even get that. So I'm just grateful that like we have like supportive parents and and someone there to care for us. So I guess in that sense, yeah. Yeah, that sense. It's just nice to have that person there just anchors us as people.” (1141)</p>

## **Understanding and Awareness**

Participants spoke about their loved ones understanding and awareness of their mental health and several factors that may have facilitated this understanding, including the involvement of early intervention services, open dialogues, patience and reassurance. Themes and quotes for the category highlighted on table 9.

### ***Awareness of Mental Health***

Participant described that as their carers had more engagement with the early intervention services they gained a better understanding and awareness of the participant's mental health needs. One participant shared that their carer learnt to be aware of their mental health signs and checking in with them by offering to go out for a walk. Others described this feeling of not having to explain their mental health to their loved one.

### ***Fear of being rejected***

Sometimes participants felt nervous about speaking with their loved ones about their mental health for fear of being rejected. One participant spoke about the fear of shame from the larger family for possibly being misunderstood.

### ***Non-judgmental and increased trust***

For some participants they noticed an increased trust and lack of judgement from their carers as the carer understood more about their mental health.

### ***Open dialogues and communication***

Many participants mentioned theme about open communication and dialogue. Some participants found that their communication had bettered since coming into contact with

mental health services. Others described they wish to communicate more openly about personal matters beyond logistical factors; hoping that participants would share more about what was going on for them. For example participant 1007 described noticing himself shying away from conversations with his mother due to his mental health even though he wished to be more open with her.

### ***Understanding***

Many participants described increased understanding and patience from their carers as their carers learnt more about what they were experiencing. Participants described initially finding it difficult to explain their mental health experiences. However, many reported noticing that over time with more support from the early intervention team and open dialogues with their carer the carer's understanding increased. Others found that beyond the engagement with early intervention teams there was open and honest conversation with their loved one which helped them explain their mental health.

**Table 9.** Quotes from category Understanding and Awareness

Themes and subthemes	Quote
<b>2.1. Awareness of Mental Health</b>	<p>“I think they kind of like speak to each other a lot more right there. I'm like I'm like I'm not a topic, but I can't find another word, but uhm, say you know when they when they meet with each other they talk about me. They will sort of like you know, say what's happening so they're getting bit more understanding and because I'm able to, right, put things in as well, right? When [care coordinator] says to me my appointments and so they are, they have checked. There are a lot more patient or a lot more understanding of me so they will listen to me more and they won't , they won't make me feel well, it's not bad, it's not happening.” (1031)</p>
Checking in - are you okay	<p>“ Participant 1123: Ohh yeah and just generally how I'm feeling or if I'm feeling a bit withdrawn he might ask are you ok? Something like that.            Interviewer: Yeah so maybe he's a bit aware of kind of            Participant 1123: - Yeah a bit more aware of the yeah it's like the symptoms of mental health problems            Interviewer: I see, yeah and I guess in what ways does he kind of um..in what ways is he attuned to that? It sounds like he's quite attuned to those the things that you might need help with, or like when things may feel kind of different. He's there to kind of notice those things. And I wonder what does that change look like for you? Like how? How do you feel about that?            Participant 1123: Yeah, I think it's quite, it's quite good, isn't it, just to be able to pick up on things. Like maybe sometimes I might be internalising some things and not thinking about it, even though I'm probably all right at the time. It's just good to have a like a check just in, just in case I'm not ok..which is quite nice.” (1023)</p>
Not having to explain	<p>“Uhm, at say it's a pretty good relationship like I talked to her a lot about my problems and when I'm like feeling upset or like feeling down. She can always usually tell without me even come telling her. So I think we have a pretty good relationship. Uhm, yeah, we spend a lot of time together. And UM. Yeah, like, I listen to her advice and she gives me a lot of advice as well, so. Yeah, I'd say we have a good relationship.” (1057)</p>
<b>2.2. Fear of being rejection and judgement</b>	<p>“I thought she would reject me or I would get kicked out of the house or you know things um I would be blamed for, but she understood it was a medical thing and it wasn't my fault. She was a caring mother in that sense.” (1007)</p> <p>“I think, I think in it right in the beginning and everything, right? Uhm. 'cause I didn't know what was happening with me and it's like I do want to speak about and I was too frightened to shamed. And, you know, didn't know what was going on in my head and I going mad, right? So I said to them, sort of like not to tell any relatives or anything except my brother. My brother knows, right? And I think the fact is that they I think they spoke to each other about it and then sort of like came with, you know and listen to that decision of mine, right? Not to tell the external family or anything, 'cause I don't like anybody knowing my business. Anyway, yeah</p>

and I don't want other people judging me. Or you know, there's enough when I'm on the tube or trains or buses. People looking at me and I just feel that they're constantly judging me.”

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**2.3. Non-judgment and increased trust**

“Uhm? I like that she listens. I like that she understands. I like that she went to the doctor to seek medical help. And even when I tell her about alternative therapies like acupuncture or herbal medicine, she's open to it. She understands, she takes me to my appointments, she gets medicine I need, so it's very calming and it's very reassuring that um she's there in like anytime I would say, You know, I'm gonna try this so this therapy or I need to talk to this doctor. She's very understanding, she's like straight away, Let's go to the doctor let's make the appointment the UM, Work around your work. She's. Yeah, she's very, very good at that.” (1007)

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**2.4. Open dialogues and communication**

“Uh I like that he's like..we're both understanding of each other and we communicate a lot better with each other, especially like we had like family psychology sessions. So after that, it's improved a lot. Like we understand each other, we don't, you know, get angry at each other or shout at each other. We do it in a civilised way and we communicate it.” (1014)

“ would like talk. Like to talk about more personal things instead of organization or the logical stuff. I would like to have, um a more personal conversation with her and it, because of the psychosis I'm not, I haven't been able to do for the past 2 1/2 years have a conversation so that's something I would want.....Uhm... I would be more caring and more loving and supportive and being there for her rather than her always being there for me. I would um be able to reciprocate those um those conversations, and I I know she wants to talk to me about that stuff and I'm having to shut it down or leave the room and. So that makes the guilt difficult.”(1007)

“r I wouldn't say the relationship's changed, but I say the conversations and things you talk about has changed because there's a..there's a bit more about, yeah bit more about mental health that we're talking about. or I think my dad was having some psychology sess - I don't know. It was a psychology..I don't know, he was talking to someone from the services. It might be the psychologist about some of the things that was going on and then we had some group psychology sessions as well with the family. So those kind of things fell into the conversations we were having. I don't think the relationship's changed so much. I think it's probably similar.” (1123)

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**2.5. Understanding**

“I think she was very lost at the beginning and didn't really uhm understand what was going on. Very nervous and scared me um. The treatment team really helped her calm down and they will have their phone heard. Have conversations about me just, you know, for her. And they were ask for family intervention therapy and family therapy. And they use to come to the house. My mom would cry and talk to them and they were very caring and. They helped her in ways I couldn't. I couldn't express. I couldn't talk to her because the voices were quite aggressive towards her. That intervention team and the Medical Centre they kind of did that for me and that really calmed her down and. Yeah, she trusted them. Yeah, she couldn't do that for me right now. They stepped in really well....I feel like she really stepped up. She took the time to get educated and um to know what was going on. And um, and I think the conversations she had behind the scenes with the medical teams and the therapist without really uhm. Helped her to leave me alone sometimes and helped her to deal with it, and which again made the relationship better, allowed us to communicate or personal things rather than the medical stuff.” (1007)

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Patient Uhm, I like the fact she's very caring, uhm? She's, uh, she's really like she's a kind hearted person, I'd say, and she's just not judgmental. And yeah, we get along really well... Uhm, well, I'd say like when I was not doing too great like a year or two ago and I think like she played like a really important role in helping me get better. Like to get help and she was like really patient with me and I think that really helped. Yeah, I think it could be and it can be quite difficult when someone is going through like a mental health problem. I think it can like put a strain on a relationship, but she was really good at, sort of like diffusing this strain. If you know what I mean. (1057)

“Uh, I say it's a fairly good one. We're pretty close. We do a lot of things together. Spend a lot of time together. Uhm, I talked to about everything that I need to, especially after I got ill. I kinda got. She's my first go to UM. And. Yeah, sometimes we disagree on things obviously, but I think that's normal and yeah, we, I say we've gotten a lot closer since I got ill. And I think she understands me a bit better as well, and she's a lot more patient with me. Uhm, I don't know if I can say the same about me being patient with that, but yeah, she's definitely more patient with me and she's... honestly, she's literally been my rock since I wasn't well. She gives me so much good advice now. And I think that probably comes from the fact that she knows more about what was going on with me. So she's definitely done heavy search and yeah, she's been there to support me through everything.” (1023)

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## **Boundaries and Independence**

The category of boundaries and independence was evidently present in the data (Quotes on table 10). In this category, participants raised themes around negotiating and hoping for changes in their relationship with their carer. At times when participants were not able to change the relationship or found it less problematic, some participants were willing to accept the pattern of their relationship. Participants also highlighted aspects of their relationship they found difficult or unhelpful such as being controlling, intrusive and protective. These constructs may be linked to aspects of EOI. While some participants accepted the current dynamic, others strived for change or reflected on the change in relationship between their carers and them since the beginning of their contact with services.

### ***Acceptance about carer***

When participants spoke about their carer's qualities, some described the sense of acceptance of the relationship style between their carer and them. For example, participant 1123 spoke felt that although she was not able to change the bickering between her and her parent, she did not distinguish it as significant enough to change; hence she was willing to accept that it was a part of the relationship. A common factor with acceptance was when participants felt that the unhelpful qualities in their relationship were not significant enough to want to change.

### ***Controlling, Intrusiveness, Protectiveness***

Certain qualities such as controlling, intrusiveness and protectiveness were found to be unhelpful by participants.



### *Controlling*

Controlling behaviours or schedule were some of the aspect's participants found to be unhelpful. The lack of autonomy felt by participants made some feel frustrated and less close with their loved ones. Although, some participants could understand the possible intent and worry that drove the controlling behaviours, they were not willing to accept this.

### *Expectations and demands*

Expectations and demands on academic performance and career can feel like an unsaid standard in South Asian communities. One participant spoke about how his mother did not have the same academic standardise as others would in the middle-class Bengali community he grew up in; this was spoken about as an unexpected trait.

### *Intrusiveness*

Some participants described an overbearing quality from their carer when they were unwell, which they did not find helpful. As one participant stated (1031) they understood their need to be alone was coming from the low mood but found that they did not wish to be with their carer who would not give them the space.

### *Protective*

In conjunction with intrusiveness some participants also described that their carer was protective of them when going out with friends or speaking people on the phone. Some participants described this as overprotective other described it as protective. For some participants this felt like there was a lack of trust from their carer.

### ***Hopes and worries***

#### *Wanting independence and increased trust*

At times as a result of their carer's control, intrusiveness or protectiveness participants described wanting a sense of independence and increased trust. Participants expressed a hard balance to strike between gaining a sense of independence and recognising that their carer's worry and questions came from an understandable place.

#### *Open conversations*

Other participants hoped share and talk about more personal matters to be able to further build the bond and mutual understanding.

#### ***Negotiating change in relationships and arguments***

Negotiating the independence and autonomy with their carer sometimes resulted in arguments and disagreements in the family. Many described this as a natural part of the relationship however others found this unhelpful and disruptive to the relationship (1014).

#### *Change in relationship*

Over time many had noticed that the negotiations in their relationship with the support of the EIP team helped facilitate better understanding and communication between them and their carer.

#### *Something I need to work on my side*

A few participants confessed that they had responsibility and things that they needed to change on their side such as participant 1023 spoke about how she wished to be more motivated to listen to her carer and do things around the house.

#### ***Provides freedom and choice***

#### *Doesn't ask too many questions*

Another person spoke about how the simplicity of the relationship in terms of his mother's awareness or understanding of mental health meant that she asked less questions which was helpful for him.

*Gives freedom and space*

Some participants spoke about how their carer provided with the space to come to their own decisions. For example participant 1115 spoke about how his partner would not stop him from drinking or smoking when they were initially married but told him that he should "look after" himself. He noticed that his habits changed slowly without her demanding those changes from him.

**Table 10.** Quotes from category Boundaries and Independence

Themes and Subthemes	Quote
<b>3.1. Acceptance about carer</b>	<p>‘Interviewer: Yeah, hmm, yeah, ok. Yeah and I guess, um, I guess thinking a little bit about, you know, is there anything that you would change about your relationship with your father? Or would you - would like to be different?’</p> <p>Participant 1123: Not really, no. I think we got a good relationship.</p> <p>Interviewer: Yeah, yeah, so everything- so I guess like the thing that maybe some of the stuff you talk about, about some of the bickering between your parents is that something that you find, that's fine?</p> <p>Participant 1123: Yeah, I'll probably change that if I could, yeah (laughs) but but you can't really change those things. It's not something, it's not something so significant that I'd say I want to change it. If it could happen less yeah’</p>
<b>3.2. Controlling, Intrusiveness, Protectiveness</b>	<p>Controlling</p> <p>Like even though she never pushed it there was there was expectation. Apart from that it was really toxic that she always had to contact me every day. I had to call her or she has to call me. Otherwise there was repercussion like people like she will let my father know and my father will contact his friend in London and they will find out where I am and what I'm doing. It was like, suffocating sometimes...Apart from that she has, she had to control my everything. Where I live, where I eat, even though she isn't close by. And I had to answer for every moment ,like whatever wherever I go, I have to answer for that.... I wouldn't say it's better this way, but, uh...the. I I could have enjoyed a little bit freedom, but it's not like that I don't wanna have any relationship with my mother ... I would love, I'll I'll. I will love her to be close but not the way I would suffocate. (1119)</p> <p>‘Uhh, I’ll try and speak like I’ll try to speak to him in a normal way like this..like you know, when we had arguments, I wouldn’t get angry or start shouting..I, I will try to explain my point of view clearly, but he would just kind of ignore my point of view and just carry on like rambling about what he, what his point of view is. He wouldn’t understand where I’m coming from before. Yeah, and it was pretty like it was to me and my brother as well, it was just his personality was just like that before. Well I’d say he’s improved a lot now.....Umm...particularly unhelpful...I’d say, just the limitations like I didn’t see as it as it has, it wasn’t helpful at all because I thought it was just too controlling and uh, it just made me angry and it just made me not want to do what he was telling me anyway. So for like, it wasn’t, you know, it wasn’t a win win for both of us, it was more like a lose lose like nobody is getting their way’ (1014)</p>
Expectations and demands	<p>‘I see like the expectations...um like before I had my psychotic episode, he used to pressure me a lot. I used to be like really stressed all the time because he’s always telling me to study and like get off the computer, stop playing games, you just..he said study, study and go to uni, make sure you pass your your years of uni and yeah..and he did this for sixth form as well, like throughout my whole childhood, pretty much like a lot of pressure. And I didn’t find that helpful at all because like I thought, if I was to do something, I’ll do it from my own will like I was</p>

very like you can't force me to do this or that so it just didn't work out, like those two personalities clashing.....Uhm...I'd say like, his intentions were always good like he, he always wanted me to like, you know, excel in life and because he used to talk to me about how hard it is for him to work like 'cause since he didn't get a university degree so he had to work long hours every day and said I don't want that for you. That's why I'm always pressuring you to do something so you can work, work an easier job like a skilled job which will pay more and you'd have to work less hours. You have more free time so he always have intentions like right. Like I understood that as well. But I'd say just the way of doing things when it came to it wasn't right, I just couldn't, you know, do it." (1014)

"like she like, I came from, uh, a good family, at the middleclass family where your cousins are doing really... doing someone is becoming engineer Doctor. So my mother had an expectation of me being an engineer as well, but when she felt that it wasn't going to happen, she never forced me to do anything. She never pressed me." (1119)

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Intrusiveness - I just feel like you know, just go away and leave me alone	'Sometimes when I'm feeling in a low mood right? She's there and I don't want her there. I don't want her to ask me anything. I don't want her to disturb my mind thinking right? And she there and it's like go away. Which comes in, and I'm sort of in that low mood, but I see only time that I, you know, I just feel like you know, just go away, leave me alone.... Yeah, yeah, that's the times that I kind of like almost you know just don't even want her there, 'cause my mind is so low at that time.' (1031)
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Protective - she worries more about me	'Even with this, even this conversation and doing this, she was kind of like asking questions like why is this? Why you had this in our therapy session? And I was like no. It's a questionnaire and to help them. Just explaining what this was, just for her ease. I think she's worried that I might get riled up or something might trigger the voices. So just letting her know that the last session we had, you know it was calming, it was normal, everything was fine and it allowed her to kind of be OK with it and have that trust again, like everything was fine. So just explain. Uhm, explaining things to her. Is very helpful for the relationship for us.' (1007)
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'uhm, I'd say she's always been overprotective. I'd say that's been there, UM, and when I think of the relationship, I'd say nothing much as well what what's? What would she use to do, UM? Uh. I'm sorry, I can't really think at the moment, uh, do apologize.

Interviewer: That's OK. I I had a question about what you said about she's always been overprotective before that how overprotective can look like? Kind of asking you loads of personal questions, you know we're friends and things, I was, does over protectiveness come out in any other ways, other than you know, does she overprotective in any other ways other than asking you like you know loads of question?

Participant 1084: Um like if- if I'm if I'm on the phone to someone she'll just come up and be like what's it about who my talking to? I get annoyed at sometimes because I don't want her to come up to me all the time and ask me what I'm doing wrong, or grow up or who am I talking to what's it about and stuff. Uh, what else, uh' (1084)

### 3.3. Hopes and worries

To come back into my normal self	'So actually, my aim is to come back into my normal self like. So I'm hoping when my things will come when I'm able to do. Cause I was... I was very active and very flexible and moveable and I don't know like all these things changed and now I'm just I just come kitchen, make mighty eat and sit and. So it's like it's changed. And I'm 41 now, so.... At the age of 41 in this situation so, I don't know whether I will grow older or, or still age there. So, we need to do it. So, my aim is to like to get support and get back in my self, that's that's the expect like from. Then he cannot support me all the time because he has to go back to work and look for. Like he has his futures then so all the time, but whatever I got is great at the moment.' (1109)
Wanting independence and increased trust	'Uhm, I think just what I said before, like about sort of the arguments and stuff in regards to like being independent. I think it's frustrating for me because when I was at uni I got used to like having like being by myself and being a bit more independent. And then when I became unwell, of course that wasn't like appropriate or like I should not, I, you know, I should have been home. I should have been looked after, but I think since kind of getting better and UM like I've got like a job as well, like I work part time now and like and it's sort of like the age or like in my head. I'm like kind of comparing what my friends are doing, 'cause they're all graduated and they're all like doing all these things that I'm just kind of at home. And like my mom wants know where I am at all the time. And that's the bit that I don't like, which is kind of makes me sound a bit ungrateful and stuff like she's done so much for me. But I'd be lying if I said that I was like I didn't get frustrated at times. Like that, yeah,' (1010)
Open conversation	"Uhm? I would like talk. Like to talk about more personal things instead of organization or the logical stuff. I would like to have, um a more personal conversation with her and it, because of the psychosis I'm not, I haven't been able to do for the past 2 1/2 years have a conversation so that's something I would want. Interviewer: And is there when you say, more personal conversation, what would that look like? How is that different to kind of the more organization or type of conversation? Participant 1007: Talking about family and relatives or You know just talking about. Yeah, just talk about family and you know asking about her work and her friends and talking about things on TV. Or you know, just normal things that I want to do in my life. I can't have those conversations with her. That brings... makes it difficult," (1007)
<b>3.4. Negotiating change in relationships and arguments</b>	<p>'Participant 1014: Uhh, I'll try and speak like I'll try to speak to him in a normal way like this..like you know, when we had arguments, I wouldn't get angry or start shouting..I, I will try to explain my point of view clearly, but he would just kind of ignore my point of view and just carry on like rambling about what he, what his point of view is. He wouldn't understand where I'm coming from before. Yeah, and it was pretty like it was to me and my brother as well, it was just his personality was just like that before. Well I'd say he's improved a lot now.</p> <p>Interviewer: Hmm, okay..and is there anything you know, any particular aspects about your relationship with your dad in the past I guess that was particularly unhelpful for you?</p> <p>Participant 1014: Umm...particularly unhelpful...I'd say, just the limitations like I didn't see as it as it has, it wasn't helpful at all because I thought it was just too controlling and uh, it just made me angry and it just made me not want to do what he was telling me anyway. So for like, it wasn't, you know, it wasn't a win win for both of us, it was more like a lose lose like nobody is getting their way'</p>

Something I need to work on my side	<p>'I think sometimes I can be quite like there's not my mom, 'cause my mom doesn't really do anything wrong. Uhm, I don't think that she does, but sometimes I can struggle with my motivation and sometimes that gets her a bit like impatient with me in a bit angry and it definitely say that I need to work on that on my side where I need to be a bit more motivated, do more like around just like general things that around the house and stuff, because sometimes that all that dampen our relationship. If I don't listen to her sometimes. And that's just something I need to work on my side' (1023)</p>
<b>3.5. Provides freedom and choice</b>	<p>'Participant 1115: Uh, you know, uh, she don't like, uh, you know, I as in case I'm not drinking, I'm give up some time I drink my mental health though I'm going to stress a couple of wine glasses. Before I smoke, sometime I use cannabis in my with friend. Uh, finally she is not hating, little by little she's speaking, uh. Finally I give up everything that's very important.  Interviewer: Ah, so she she didn't hate, didn't hate you for doing these things.  Participant 1115: Yeah, see, she's not pressure or anything.  Interviewer: Yeah  Participant 1115: She says you enjoy your life but look after yourself. You are not in here. We all getting problem. You know she and kids she's speaking like that. She giving big freedom for me. No arresting nothing.'</p>
Doesn't ask too many questions	<p>'The aspect that I like is that she's you know she, UM, doesn't really question me too much about about my life, about things she's not, too picky in terms of what I should be doing. What I shouldn't, and you know the fact that sometimes because she is simple, uh, you know, kind of, you know, kind of works for me because I'm at a stage in my life. Anyway, where I'm really sort of wouldn't want technicalities or anything to you know to complex, uh, things are kind of a complex, you know, and you know it's it works. You know it's she's always been like. And that that really. Uh, you know, helps in my in my recovery you know. It's helping in my recovery, you know, so.' (1061)</p>
gives freedom and space	<p>'Participant 1031: Yes yes she does- so she'll sort of find things that are like very short right? We go for walks over and then when I had enough right we will turn back and we will head home and once I know that I'm heading home and I and I and I get happy then she she relaxes as well. So she knows that.  Interviewer: So there's also something I'm hearing about her being in tune with what what you're comfortable with is also helpful.  Participant 1031: Yes  Interviewer: uh, and not maybe pushing you to go too far or do too much.  Participant 1031: No, no, she doesn't push me. And in the beginning in the beginning it used to be, but it's sort of change now. In the last year it has changed.' (1031)  'So yeah, there was expectation. But she never, uh, crushed me the, those expectations like I could have like, she always believed I mean, that, uh, if I do something just alright, it will be fine for her. She never wanted me to provide her. She always provided me and she never expected anything else.' (1119)</p>

## **Context and Influence**

It was important to consider how the dyad related with one another in the context and influences of different cultural background, generational background, other family members, the influence of roles in the family and mental health. (quotes in table 11).

### ***Cultural and Generational Differences***

Participants spoke about the cultural and generational differences that may cause conflict when trying to get their point of view across with their family member. This was particularly highlighted when participants spoke about parent who was from another generation. Within the cultural differences some participants highlighted class and educational differences that made their understanding and priorities of things different. This was not unnecessarily highlighted as a negative difference between the dyads, as many participants stated that this as the context for the difference but did not wish to change that.

### ***Family Roles and Dynamics***

Some participants mentioned how several other family members facilitated or impacted the dyad. For example participant 1031 spoke about her other daughters speaking to each other helped increase understanding and support for her daughter who lived with her as her carer. This in turn bettered the relationship.

Some also spoke about how the different roles in the family changed what was expected for one another. Participant 1119 highlighted the different expectations as the boy child in his family and that this parents were partial to him in comparison to his sister. Those who spoke about women carer described more household choices and support in terms of affection, love



and care. Those who spoke about men as carer's spoke about other kinds of bonding like financial support, sport and education.

***Mental Health and relationship with voices***

A few described how their mental health symptoms would impact their relationship with their carer, such that they were more likely to withdraw from them. For some, the voices they heard were actively creating mistrust or distance between them and their loved one. For others, like participant 1119, the voices were representation of the critical comments they received from their carer in regard to their sexual identity.

**Table 11.** Quotes from category Context and Influence

Themes and Subthemes	Quote
<b>4.1. Cultural and Generational Differences</b>  <b>Cultural</b>	<p>“UM, like recently I was kind of dating someone for the first time. That's the first time, like I've like ever done that and like told my parents and stuff. Uhm, but it was just like the views about like in in regards to like relationship and like sex and that kind of thing that was just like, I just I didn't really like necessarily agree with that. I couldn't really say anything because it's like, you know, that's my mom and like I can't kind of disagree with especially when like areas like that. But it was just like some some of the like judgmental like sort of tones and that kind of thing in regards to that area. Yeah” (1010)</p>
	<p>“Participant 1119: Yes, she had to answer lots of questions for that. Uh, maybe because it has to do with the security, because as a boy I had, I needed less security from society, while my sister had to be look out for her safety. Because there was much more like security issues uh among South Asian woman has to face in a daily basis. I believe that was the issue. Interviewer: I see. So there is a lot of kind of difference of of kind of roles in your family where you you had a lot of kind of you were saying a little bit that you felt like you're a bit spoiled in some ways, because whatever you ask for given. Participant 1119: Yes, I had the full freedom and my sister had less. If I'd be honest, to be honest, Interviewer: yeah, of course. Yeah no, I appreciate, appreciate your honesty and and your reflection. [inaudible] You know where your parents are aware? – Participant 1119: I believe that they know that they have discriminated. Interviewer: Sorry what I couldn't quite catch you. Participant 1119: I believe my parents are aware that they have discriminated, but, uh, maybe they think that they have done the right thing. That's because, uh. Interviewer: Right Participant 1119: you cannot. Like in that society in the Bengali society. Because I'm from a rural community. So I I think that they did not had any choice rather than that that you give like you gave my sister a less freedom.”</p>
<b>Generational</b>	<p>“I'd say like, his intentions were always good like he, he always wanted me to like, you know, excel in life and because he used to talk to me about how hard it is for him to work like 'cause since he didn't get a university degree so he had to work long hours every day and said I don't want that for you. That's why I'm always pressuring you to do something so you can work, work an easier job like a skilled job which will pay more and you'd have to work less hours. You have more free time so he always have intentions like right. Like I understood that as well. But I'd say just the way of doing things when it came to it wasn't right, I just couldn't, you know, do it.” (1014)</p> <p>“Uh, not really. I just think like this isn't this, doesn't have anything to do with my mental health. It might be like a generational thing, like she grew up in a different time, so she's much more traditional than I am, whereas I grew up in a different time in a more diverse society, so I think slightly differently to her so we clash on that a bit. But it's like I think we both understand that we have different views and that now that I've, you know, grown up, I've sort of developed my own views that are different to her. So I think I think that's normal. Like for every family, so.” (1057)</p>

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**4.2. Family Roles and Dynamics**

Participant 1031: I think over the years like she 'cause she's learned about my situation, right? So she's more easy for her to understand now. And plus the other siblings, right? They talk amongst themselves and this sort of like more, UM? When you talk about things and you kind of like understand it more or less at ease with you. Interviewer: Hmmm, Yeah Participant 1031: So they shared awful lot together and sometimes I'm included in that sometimes I'm not. Sometimes I choose not to be. Interviewer: OK. Right, so your daughters' sort of having conversations amongst themselves has been helpful Participant 1031: Yeah been helpful Interviewer: thing to your relationship. Participant 1031: Yeah it's been helpful to them, like cause it's only the one daughter lives with me. But the other two daughters they live in Stratford, which isn't that far from me, right? But they they're popping a lot so they give her, my elder daughter, the sort of like bump up that she needs as well. Interviewer: OK, so your your your daughter having support from your other daughters is helpful for your relationship with your daughter. Participant 1031: Yeah yeah. 'cause my eldest daughter we obviously live together as well. Interviewer: Hmmm That's quite interesting how other people are, also, you know in the in the background maintaining your relationship with your daughter by being there.

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**4.3. Mental Health and Relationship with Voices**

“Yeah, um maybe couple of days ago. Asking where I was going after work and asking how am a spending my money and what am I spending my money on... And like things like that can be quite intrusive. And not understanding, and I can't express it because of the voices. And yeah, you know, it seems quite psychotic. So she, yeah controlling my money, asking questions knowing it. But sometimes I give her the control, like I would hand her the money to take care of me because I know that the voices won't allow me to take care of myself sometimes, but the constant questioning makes you feel like. You know, you're not treated as an adult in this situation. Yeah, that's it. ” (1007)

“I think when I'm sort of like hearing voices and things right, UM? I like it that she's there sometimes, but I don't like it there because there's a part of me that you don't want to want her to believe that there are happening inside of me, right? I can't explain that. I just want her to sort of like leave me alone till the phase kind of ends. That's what I'd like to change and she's like there and that there's a part of me that knows and understands that she cares right? And wants to be there. And there's a part of me that thinks that you will be like an old grandmother to me. And being on top of my case all the time, leave me alone out of my head. I got enough people in my head. ”(1031)

“Yes. Because I was feeling like, uh, I didn't have any friend, I didn't have anything to talk about or talk to, so I was creating imaginary friends like it's..... At the beginning, that was like really good like I was enjoying the moment. And eventually that turned out to be very bad idea because they had nothing to add to any conversation conversation and they were just screaming back to me. The... what we call that... The misjudgment I did the wrong things I did. What could have been? What could have been different? So all the negative thoughts were now. Coming out through my imaginary friends. ----- Yeah, they were showing me another picture that what could in my life been if I if if I just hold on to my sexual urges and then went for other things I desire currently, that's it... Yes, they were being the moral police to be honest and they were just being a mirror to my mother to be honest like your life would be so much better if you just could hold on to yourself and don't be what you are right now.” (1119)

### ***Statistical Results***

Table 12 indicates the valid responses, missing responses, means, standard deviations, skewness, kurtosis, minimum and maximum values for all measures for the 22 participants. A Spearman's correlation was used for all data that had a kurtosis or skewness higher or lower than -1. Otherwise, a Pearson's correlation was used.

All correlational tests results can be found in table 13. Table 14 provides a breakdown of the correlation results based on hypothesis. The following results were all positively correlated such that high scores in one domain were significantly associated with high scores in the other domain. High scores of LEE total were significantly associated with high scores of PSYRATS total ( $r = 0.467, p < 0.05$ ), high scores of HADS total ( $r = 0.637, p < 0.01$ ), high scores of HADS Anxiety ( $r = 0.508, p < 0.01$ ), and high scores of HADS Depression ( $r = 0.534, p < 0.01$ ). High scores of LEE Emotional Response domain were significantly associated with high of HADS total score ( $r = 0.449, p < 0.05$ ). High scores of LEE Attitude Toward Illness domain were significantly associated with high scores of PSYRATS Delusion domain ( $r = 0.435, p < 0.05$ ), high scores of HADS total ( $r = 0.484, p < 0.05$ ) and high scores of HADS Anxiety domain ( $r = 0.573, p < 0.01$ ). High perceived criticism measure was significantly associated with high HADS anxiety score ( $r = 0.466, p < 0.01$ ). High warmth measure was significantly associated with low SENS Alogia domain scores ( $r = -0.552, p < 0.01$ ). There was no significant correlation between any of the EE measures and other routine clinical indicators.

Further analysis was conducted once LEE measure was stratified into high and low EE. Descriptive statistics from high low groups are presented on table 15. Assumption checks were conducted on all the clinical measures split by the high and low EE groups. All t-test scores

indicated on table 16. Mann Whitney tests found significant differences between the high and low EE groups such that the high EE group scored higher than the low EE group on the HADS total measure ( $U(N_{\text{higher}}=14, N_{\text{lower}}=8) = 99.00, z = 3.424, p < 0.05$ ), HADS depression scale ( $U(N_{\text{higher}}=14, N_{\text{lower}}=8) = 94.00, z = 3.366, p < 0.001$ ), PSYRATS total ( $U(N_{\text{higher}}=14, N_{\text{lower}}=8) = 87.50, z = 2.496, p < 0.05$ ) and the PSYRATS delusion total scores ( $U(N_{\text{higher}}=14, N_{\text{lower}}=8) = 92.50, z = 3.239, p < 0.05$ ). Furthermore, the higher EE group scored higher for the HADS anxiety on the parametric t-test however was not found significant for the non-parametric test.

Lastly, a Mann Whitney test indicated that a statistically significant difference between the GAF scores of the high EE group and the low EE group such that the lower EE group had significantly higher GAF scores than the higher EE.  $U(N_{\text{higher}}=14, N_{\text{lower}}=8) = 23.00, z = -32.224, p < 0.05$ . This indicates that the lower EE group had higher global functioning than the higher EE group. There were no significant differences found between the groups in relation with SENS scores (items 1-6) or any of the service utilisation data (items 14-17).

Table 12. Descriptive Statistics

	Valid	Missing	Median	Mean	Std. Deviation	Skewness	Std. Error of Skewness	Kurtosis	Std. Error of Kurtosis	Min	Max
1. LEE_Total	22	0	9	10.591	7.582	<b>2.659</b>	0.491	<b>9.331</b>	0.953	3	39
2. LEE_Intrusiveness	22	0	5	5.727	2.511	0.618	0.491	-0.624	0.953	2	11
3. LEE_Emoional Response	22	0	1.5	2.182	2.771	<b>3.012</b>	0.491	<b>11.415</b>	0.953	0	13
4. LEE_Attitude Toward Illness	22	0	0	0.727	1.077	<b>1.609</b>	0.491	<b>2.59</b>	0.953	0	4
5. LEE_Tolerance and Expectations	22	0	1	1.955	2.4	<b>2.719</b>	0.491	<b>9.542</b>	0.953	0	11
6. PC_Total	22	0	19	19.091	8.112	-0.062	0.491	-0.12	0.953	2	34
7. Warmth_Total	22	0	13	12.636	2.013	-0.45	0.491	<b>-1.017</b>	0.953	9	15
1. SENS_Total	22	0	10.5	14.182	9.354	<b>1.131</b>	0.491	0.723	0.953	3	38
2. SENS_Social withdrawal	22	0	2	2.591	2.343	0.985	0.491	0.435	0.953	0	8
3. SENS_Diminished emotional range	22	0	2.5	2.773	2.329	0.402	0.491	-0.997	0.953	0	7
4. SENS_Avolitation	22	0	2.5	3.227	2.448	0.61	0.491	-0.466	0.953	0	8
5. SENS_Anhedonia	22	0	3	3.5	2.521	0.314	0.491	<b>-1.245</b>	0.953	0	8
6. SENS_Alogia	22	0	2	2.091	1.9	<b>1.552</b>	0.491	<b>3.34</b>	0.953	0	8
7. PSYRATS_total	22	0	22.5	23.909	17.517	0.17	0.491	<b>-1.351</b>	0.953	1	50
8. Del Total	22	0	9.5	8.5	6.759	-0.018	0.491	<b>-1.773</b>	0.953	0	18
9. Hal Total	22	0	14	15.409	12.18	0.312	0.491	<b>-1.301</b>	0.953	0	34
10. HADS Total	22	0	14	13.955	7.26	0.586	0.491	-0.172	0.953	5	31
11. HADS_Anxiety	22	0	8	8.227	3.915	0.546	0.491	-0.537	0.953	2	16
12. HADS_Depression	22	0	5	5.727	4.474	0.419	0.491	<b>-1.052</b>	0.953	0	15
13. GAF	22	0	75	76.364	12.834	-0.872	0.491	0.499	0.953	45	95
14. Number of Hospital Admissions	22	7	0	0.591	0.854	<b>1.455</b>	0.491	<b>1.681</b>	0.953	0	3
15. Total Bed Days	22	7	0	20.5	47.833	<b>3.207</b>	0.491	<b>10.769</b>	0.953	0	203
16. Involvement of Acute Services	22	7	1	1.318	1.862	<b>1.679</b>	0.491	<b>2.07</b>	0.953	0	6
17. Sectioned	22	7	0	0.364	0.79	<b>2.412</b>	0.491	<b>5.7</b>	0.953	0	3

Number is split into two groups first group of 1-7 is the EE measures, and second 1-17 group are the clinical measures. Skewness and Kurtosis beyond -1 and 1 are in bold

**Table 13.** Correlations

Variable		1. LEE Total	2. LEE Intrusiveness	3. LEE Emotional Response	4. LEE Attitude Toward Illness	5. LEE Tolerance and Expectations	6. Warmth Total	7. Perceived Criticism Total
<b>1. SENS Total</b>	Pearson's r							
	p-value							
	Spearman's rho	0.252	0.101	0.287	0.214	0.12	-0.257	-0.075
<b>2. SENS Social withdrawal</b>	p-value	0.257	0.656	0.195	0.34	0.595	0.247	0.741
	Pearson's r		0.247					0.065
	p-value		0.267					0.775
<b>3. SENS Diminished emotional range</b>	Spearman's rho	0.332		0.151	0.154	0.232	-0.199	
	p-value	0.131		0.502	0.494	0.3	0.374	
	Pearson's r		-0.003					-0.125
<b>4. SENS Avolition</b>	p-value		0.99					0.58
	Spearman's rho	0.103		0.179	0.065	0.023	-0.351	
	p-value	0.647		0.425	0.773	0.919	0.11	
<b>5. SENS Anhedonia</b>	Pearson's r		-0.051					0.03
	p-value		0.82					0.894
	Spearman's rho	0.221		0.104	0.34	0.137	0.034	
<b>6. SENS Alogia</b>	p-value	0.324		0.646	0.122	0.543	0.88	
	Pearson's r		0.161	0.038	0.235	0.219	0.004	-0.055
	p-value		0.474	0.866	0.293	0.327	0.988	0.809
<b>7. PSYRATS Total</b>	Spearman's rho	0.153	0.04	0.265	0.117	0.315	<b>-0.552</b>	-0.089
	p-value	0.496	0.86	0.233	0.605	0.153	<b>0.008**</b>	0.692
	Pearson's r							
<b>8. Delusions Total</b>	p-value							
	Spearman's rho	<b>0.467</b>	0.347	0.124	0.412	0.146	0.061	-0.025
	p-value	<b>0.028*</b>	0.114	0.584	0.057	0.518	0.786	0.913
<b>9. Hallucinations Total</b>	Pearson's r							
	p-value							
	Spearman's rho	<b>0.492</b>	0.384	0.097	<b>0.435</b>	0.226	0.014	-0.185
	p-value	<b>0.02**</b>	0.078	0.669	<b>0.043**</b>	0.312	0.951	0.409

	p-value							
	Spearman's rho	0.39	0.255	0.197	0.35	0.086	0.122	0.043
	p-value	0.073	0.253	0.38	0.11	0.703	0.589	0.851
<b>10. HADS Total</b>	Pearson's r		0.284					0.289
	p-value		0.2					0.193
	Spearman's rho	<b>0.637</b>		<b>0.449</b>	<b>0.484</b>	0.356	-0.088	
	p-value	<b>0.001**</b>		<b>0.036**</b>	<b>0.023**</b>	0.104	0.698	
<b>11. HADS Anxiety</b>	Pearson's r		0.268					<b>0.466</b>
	p-value		0.227					<b>0.029**</b>
	Spearman's rho	<b>0.508</b>		0.345	<b>0.573</b>	0.322	-0.051	
	p-value	<b>0.016**</b>		0.115	<b>0.005**</b>	0.144	0.821	
<b>12. HADS Depression</b>	Pearson's r		0.226					0.061
	p-value		0.311					0.787
	Spearman's rho	<b>0.534</b>		0.409	0.307	0.296	-0.12	
	p-value	<b>0.01**</b>		0.059	0.164	0.181	0.593	
<b>13. GAF</b>	Pearson's r		-0.298					0.223
	p-value		0.178					0.319
	Spearman's rho	-0.386		-0.066	-0.111	0.101	-0.215	
	p-value	0.076		0.769	0.621	0.655	0.337	
<b>14. Number of Hospital Admissions</b>	Pearson's r							
	p-value							
	Spearman's rho	0.032	0.203	-0.137	-0.024	0.094	-0.021	-0.155
	p-value	0.887	0.366	0.543	0.916	0.679	0.926	0.49
<b>15. Total Bed Days</b>	Pearson's r							
	p-value							
	Spearman's rho	-0.042	0.165	-0.204	-0.123	0.057	0.009	-0.169
	p-value	0.852	0.464	0.362	0.585	0.801	0.967	0.452
<b>16. Involvement of Acute Services (including HTT Involvement)</b>	Pearson's r							
	p-value							
	Spearman's rho	-0.178	-0.035	-0.167	-0.209	-0.064	0.024	-0.212
	p-value	0.429	0.878	0.459	0.351	0.776	0.914	0.343
<b>17. Sectioned</b>	Pearson's r							
	p-value							
	Spearman's rho	-0.065	-0.008	-0.105	-0.105	0.198	0.117	-0.07
	p-value	0.773	0.972	0.643	0.641	0.378	0.604	0.759

p-values<0.05 are indicated with \*, p-values <0.01 are indicated with \*\*.



**Table 14.** Quantitative analysis for secondary aim

Hypothesis	Tests Run	EE Measure	Clinical Measure	Sign Correlation?	Significant T-test?
I. Increased patient perception of overall EE would result in poorer patient outcome.	Correlation	LEE total score	HADS	Yes	Yes
			PSYRATS	Yes	Yes
			SENS	No	No
			GAF	No	Yes
			admissions	No	No
			total bed days	No	No
			acute services sections	No	No
II. Increased patient perception of intrusiveness would result in poorer patient outcomes.	Correlation	LEE intrusiveness domain	HADS	No	-
			PSYRATS	No	-
			SENS	No	-
			GAF	No	-
			admissions	No	-
			total bed days	No	-
			acute services sections	No	-
III. Increased perception of negative attitude toward illness would result in poorer patient outcomes.	Correlation	LEE negative attitude toward illness domain	HADS	No	-
			PSYRATS	No	-
			SENS	No	-
			GAF	No	-
			admissions	No	-
			total bed days	No	-
			acute services sections	No	-
IV. Increased perception of high emotional response would result in poorer patient outcomes.	Correlation	LEE high emotional response domain	HADS	No	-
			PSYRATS	No	-
			SENS	No	-
			GAF	No	-
			admissions	No	-
			total bed days	No	-
			acute services sections	No	-
V. Increased perception of tolerance and expectation would result in better patient outcomes.	Correlation	LEE tolerance and expectation domain	HADS	No	-
			PSYRATS	No	-
			SENS	No	-
			GAF	No	-
			admissions	No	-
			total bed days	No	-
			acute services sections	No	-

VI.Increased perception of critical comments would result in poorer patient outcomes.	Correlation	Perceived criticism scale	HADS	No	-
			PSYRATS	No	
			SENS	No	
			GAF	No	
			admissions	No	
			total bed days	No	
			acute services sections	No	
VII.Increased perception of warmth would result in better patient outcomes.	Correlation	Warmth measure	HADS	No	-
			PSYRATS	No	
			SENS	Yes	
			GAF	No	
			admissions	No	
			total bed days	No	
			acute services sections	No	

**Table 15.** Descriptive statistics for High and Low LEE Groups

		Valid	Missing	Mean	SD	Skewness	Std. Error of Skewness	Kurtosis	Std. Error of Kurtosis	Min	Max
1. SENS_Total	High	14	0	16.286	10.194	0.887	0.597	0.051	1.154	3	38
	Low	8	0	10.5	6.719	1.528	0.752	3.255	1.481	3	25
2. SENS_Social withdrawal	High	14	0	3.143	2.627	0.651	0.597	-0.501	1.154	0	8
	Low	8	0	1.625	1.408	0.48	0.752	-0.564	1.481	0	4
3. SENS_Diminished emotional range	High	14	0	3.143	2.413	0.38	0.597	-1.082	1.154	0	7
	Low	8	0	2.125	2.167	0.349	0.752	-1.782	1.481	0	5
4. SENS_Avolitation	High	14	0	3.857	2.713	0.149	0.597	-1.034	1.154	0	8
	Low	8	0	2.125	1.458	0.824	0.752	2.002	1.481	0	5
5. SENS_Anhedonia	High	14	0	3.786	2.547	0.311	0.597	-1.461	1.154	1	8
	Low	8	0	3	2.563	0.407	0.752	-0.914	1.481	0	7
6. SENS_Alogia	High	14	0	2.357	2.061	1.591	0.597	3.627	1.154	0	8
	Low	8	0	1.625	1.598	1.378	0.752	2.674	1.481	0	5
7. PSYRATS_total	High	14	0	30.214	17.093	-0.327	0.597	-1.261	1.154	2	50
	Low	8	0	12.875	12.62	0.747	0.752	-0.72	1.481	1	35
8. Delusions Total	High	14	0	11.429	6.073	-0.957	0.597	-0.343	1.154	0	18
	Low	8	0	3.375	4.627	2.115	0.752	4.879	1.481	0	14
9. Hallucinations Total	High	14	0	18.786	12.831	-0.053	0.597	-1.687	1.154	0	34
	Low	8	0	9.5	8.751	0.269	0.752	-2.036	1.481	0	21
10. HADS_Total	High	14	0	17.214	6.682	0.347	0.597	0.221	1.154	6	31
	Low	8	0	8.25	4.097	1.29	0.752	0.522	1.481	5	16
11. HADS_Anxiety	High	14	0	9.5	3.878	0.388	0.597	-0.892	1.154	5	16
	Low	8	0	6	3.024	0.785	0.752	-0.159	1.481	2	11
12. HADS_Depression	High	14	0	7.714	4.358	-0.373	0.597	-0.575	1.154	0	15
	Low	8	0	2.25	1.753	1.407	0.752	3.319	1.481	0	6
13. GAF	High	14	0	72.143	13.26	-0.542	0.597	0.301	1.154	45	95
	Low	8	0	83.75	8.345	-1.69	0.752	4.97	1.481	65	95
14. Number of Hospital Admissions	High	14	0	0.5	0.65	0.978	0.597	0.176	1.154	0	2
	Low	8	0	0.75	1.165	1.355	0.752	0.62	1.481	0	3
15. Total Bed Days	High	14	0	8.929	14.409	1.928	0.597	3.85	1.154	0	49
	Low	8	0	40.75	75.776	1.858	0.752	2.695	1.481	0	203
16. Involvement Acute Services	High	14	0	0.929	1.639	2.578	0.597	7.518	1.154	0	6
	Low	8	0	2	2.138	1.052	0.752	0.153	1.481	0	6
17. Sectioned	High	14	0	0.214	0.426	1.566	0.597	0.501	1.154	0	1
	Low	8	0	0.625	1.188	1.652	0.752	1.355	1.481	0	3

**Table 16.** Secondary Analysis using Mann-Whitney

	Test	Statistic	df	p
1. SENS_Total	Student	1.43	20	0.168
	Mann-Whitney	73		0.258
2. SENS_Social withdrawal	Student	1.505	20	0.148
	Mann-Whitney	75		0.198
3. SENS_Diminished emotional range	Student	0.986	20	0.336
	Mann-Whitney	70		0.352
4. SENS_Avolitation	Student	1.662	20	0.112
	Mann-Whitney	77.5		0.146
5. SENS_Anhedonia	Student	0.694	20	0.495
	Mann-Whitney	65.5		0.536
6. SENS_Alogia	Student	0.864	20	0.398
	Mann-Whitney	69		0.381
7. PSYRATS_total	Student	2.496	20	0.021*
	Mann-Whitney	87.5		0.034*
8. Delusions Total	Student	3.239	20	0.004**
	Mann-Whitney	92.5		0.013*
9. Hallucinations Total	Student	1.811	20	0.085
	Mann-Whitney	78		0.141
10. HADS_Total	Student	3.424	20	0.003**
	Mann-Whitney	99		0.004**
11. HADS_Anxiety	Student	2.192	20	0.040*
	Mann-Whitney	84.5		0.052
12. HADS_Depression	Student	3.366	20	0.003**
	Mann-Whitney	94.5		0.009**
13. GAF	Student	-2.224	20	0.038*
	Mann-Whitney	23		0.021*
14. Number of Hospital Admissions	Student	-0.768	15	0.454
	Mann-Whitney	31		0.7
15. Total Bed Days	Student	-1.645	15	0.121
	Mann-Whitney	30		0.623
16. Involvement of Acute Services	Student	-1.22	15	0.241
	Mann-Whitney	20.5		0.153
17. Sectioned	Student	-1.217	15	0.242
	Mann-Whitney	30		0.555

p-values<0.05 are indicated with \*, p-values <0.01 are indicated with \*\*

## **Discussion**

This study aimed to explore how individuals with a FEP perceive EE. More specifically, the first aim of the study sought to explore how carer and patient relationships can be understood beyond the existing knowledge of EE constructs in a South Asian context. The secondary aim of this study was to understand the impact of perceived EE on clinical outcomes within a South Asian context.

For the first aim, a qualitative semi-structured interview was conducted with individuals with a FEP. There were four main categories identified when individuals were speaking about their carer; connection and support, understanding and awareness, boundaries and independence, and context and influence. For the second aim, a quantitative analysis found significant correlations between LEE total scores and the PSYRAT and HADS scores. Furthermore, there was a correlation found between the warmth measure and the SENS alogia domain. This discussion will consolidate the findings in relation to existing literature. Further, qualitative data will be used to provide meaning for the final quantitative results.

### ***Relationship between EE and clinical symptoms***

Exploring the relationships within the existing constructs of EE a quantitative analysis was used to explore the relationship between perceived EE measures and clinical outcomes. It is important to note that due to the variability and limited data it is difficult to determine concrete implications for these results. First, there was a significant correlation between the overall LEE score and the overall psychotic symptoms scale which meant that high levels of EE were associated with high scores on the psychotic symptoms. This may link with existing literature that has found that highly expressed emotion is linked with clinical symptom severity

(Izon et. al., 2021). Furthermore, there were also correlations between the LEE measure and the HADs anxiety and depression scale. This also aligns with prior literature that highlights the impact on EE of overall mental health presentation (Brown et. al., 1972; Vaughn & Leff, 1976; Vaughn et. al., 1984; Karno et. al., 1987). On the domain level correlations, there was a significant correlation between attitude towards illness and HADS scores such that increased negative attitudes towards illness were associated with high scores on the HADS measure. The explanation for this correlation may be connected with some of the themes identified in the qualitative interview around the impact of a carer's understanding and awareness of mental health further mentioned below. It may suggest that when participants perceive their carers as having negative attitudes towards their mental health this impacts their overall anxiety and depression.

Furthermore, a secondary analysis indicated a significant difference between the high and low EE groups for the global functioning scale scores. This differs from some of the existing literature as one study found no differences in GAF scores between high and low EE groups (Miura et. al., 2004). However, there are other study findings that indicate EE is associated with patient global functioning such that higher EE is associated with lower functioning. (Gómez-de-Regil, Kwapil & Barrantes-Vidal; 2013). These results may indicate that EE does impact patients' global functioning. However, it should be cautioned that GAF scores were determined by researchers after conducting a clinical interview with participants. Given the limited nature of the clinical interview (i.e. 20-30 minute single interview), it is hard to determine the ecological validity of the GAF scores.

### ***Possible mediating factors in the relationship between EE and clinical symptoms***

There was also a significant correlation between overall LEE scores and the delusions domain, whereas there was no observed correlation with hallucinatory experiences. A possible reason for this may be that the overall appropriateness for participation was determined by the care coordinator's judgement which may have biased the sample to have fewer positive symptoms and a better functional state. Additionally, given that the symptoms scale was solely based on participant self-report it may be that some participants may be weary of sharing the extent of their mental health symptoms for fear or paranoia. This makes it difficult to assess the extent to which these symptoms scales appropriately measure the psychosis.

The same was found for negative symptoms presentation and global assessment of function for the initial analysis where no significant relationship was found. It may be that participants who took part in the study were more likely to have a higher level of overall functioning. The lack of significance between EE measure and some domains such as service utilisation data may be explained by the limited data as there were several missing data points. It may also be an indication of the variability in the access to the service. Results from the qualitative study provide a number of possible mediators in the relationship between perceived EE and clinical symptoms. These factors are not captured in the current data; factors such as acceptance, communication, and acculturation will be further explored below. It would be important to further investigate this relationship in light of these possible external factors that influence this relationship.

### ***Different characterisation of warmth***

In the qualitative study, most participants expressed support and connectedness with their carers. More specifically, they described many types of expressions of love such as physical affection of care, kindness, safety, humour and playfulness. Existing literature mentions better social support as a factor associated with a higher quality of life and functional status in psychosis more generally (Howard et. al., 2000; Koivumaa-Honkanen et. al., 1999; Lam & Rosenheck, 2000). These themes could possibly link with studies that have identified warmth as a protective factor in relapse prevention (López et. al., 2004). Although participants did not use the word warmth to describe the carer's actions, many used the words related to warmth such as love, support and care.

In the quantitative results, there was a significant negative correlation between warmth and alogia domain such that high levels of warmth were associated with low levels of alogia. Alogia is described as poverty in speech. This significance suggests that increased perceived warmth from carers is related to decreased poverty in speech. It is possible that the relationship between warmth and speech is understood by constructs around communication and understanding as highlighted above. Prior study has found links between communication deviance, EE and cultural diversity in psychosis (Kymalainen & de Mamani, 2008), which may apply to these results as participants may perceive higher levels of warmth if their poverty of speech is low. However, it is hard to confirm this relationship without further evidence.

### ***Gender differences in the expression of love and support***

There was a subtle difference in expressions of love and support between female participants who spoke about their mothers and male participants when speaking about their



fathers. When female participants spoke about their mother's care they mentioned support in household chores and physical affection such as hugs and kisses. When male participants spoke about their fathers, they commonly mentioned practical financial support and material support such as buying clothes. These findings were similar to a study exploring fathering behaviours and experiences among UK Asian men. The study identified patterns of paternal versus maternal contributions and variations across families such that 'income-earning and material provision was consistently identified as an integral part of being a father across respondents from all four religious and ethnic groups' whereas it was more common for mothers to hold personal caregiving tasks like cooking for the child (Salway et. al., 2009). These gendered differences may have been some of mediating factors between expressed emotion and the clinical symptom measures in the quantitative findings. Due to the limited data, it is hard to ascertain the extent to which these factors impact the relationship.

### ***Involvement of EIP services in improving understanding and awareness***

'Understanding and awareness' was another prominent cluster of themes noted from the interviews. Many participants expressed their appreciation for their carer's increased understanding and awareness that was facilitated through the EIP services. A qualitative study similarly highlighted that carers in ethnic minority groups report an increased understanding and awareness of their loved one's mental health through the support of EIP services (Lavis et. al., 2015). When mentioning early intervention services, all participants spoke positively about the roles of services facilitating communication and understanding between their carers and them. It is important to note that as participants were recruited through services may have been more willing to participate in the study hence these results capture a subgroup of

perspectives about the EIP service. Additionally, these findings contradict some existing literature; for example one study highlighted that many South Asian SU find services were not adequately addressing their needs and involving support in their family system (Bowl, 2007). Yet it should be noted that since this study, EIP services have evolved in the last decade to incorporate support for caregivers and provide tailored interventions targeting psycho-education and well-being (Claxton, Onwumere, & Fornells-Ambrojo; 2017). One study found that carer groups facilitated by services enabled a sense of shared collective experiences and increased understanding of mental health which further enhanced skills in supporting individuals experiencing psychosis (Petrakis et. al., 2014).

### ***Stigma and rejection from the larger family***

Some participants described the fear of rejection not only from their carer but the larger community. This largely relates to the prominent stigma that many individuals with psychosis experience from wider family and services amongst British South Asians (Vyas, 2021). The study indicated different kinds of stigma associated with ‘individual experiences and intersecting stigmatised characteristics such as race, religion and socio-economic status’. Similar to acculturative stress which will be discussed further below, the pressure to assimilate and integrate into one’s community may result in significant stress which may impact mental health functioning (Rastogi et. al, 2014).

### ***Open dialogue and communication***

Many participants mentioned that open dialogues and communication with their carers had improved their relationship. Others were grateful that communication was something that was always present in the relationship. This may be linked to the literature exploring the

relationship between communication deviance, EE and cultural diversity in psychosis. Communication deviance is the degree to which a relative's communication lacks clarity and causes disruptions in the focus of attention (Singer & Wynne, 1965). The article found that cultural beliefs, values, and communication patterns may interact with EE and CD, and schizophrenia outcomes in different ethnic groups (Kymalainen & de Mamani, 2008). More specifically, this could indicate that the cognitive difficulties associated with psychosis (McCleery et. al; 2019) may require clear communication from carers to avoid misunderstanding. Perhaps this may be another factor influencing the relationship between EE and symptom severity for the quantitative findings.

### ***Acceptance and negotiation***

Prominent themes within the category of boundaries and independence included acceptance and negotiating the carers' involvement. Many participants described nuanced perspectives between being grateful for their carer's support and intentions. However, they also expressed frustration with a lack of boundaries or autonomy in the relationship. Some reported minimal intrusiveness or controlling behaviours from their loved ones, whilst others mentioned this was a regular part of the relationship. During the interviews, it was hard to identify what specific sociocultural factors contextualised carer involvement. Sometimes it was found that the carer's involvement was in response to the participant's mental health and psychosis, whilst other times participants mentioned that the carer has always been involved before participant's mental health concerns. This may be where South Asian family values and responsibility of care contextualise carers' behaviours. Existing literature has identified that in some cultures a lack of 'emotional over-involvement' from family members may be understood

as a lack of care (Akhtar et. al., 2013; Singh et. al., 2013). A study investigating South Asian carers of people with dementia identified South Asian carers held more 'traditional caregiving ideologies' compared to White carers; this ideology was seen as natural, expected and virtuous (Lawrence et. al., 2008). Although this study population is different, the values indicated by carers may hold a similar resemblance to the carer of individuals with psychosis. It may be important to further investigate the perspectives of carers in relation to these ideologies.

It is important to note that there was a large variation in how participants described carers' involvement and communicated the boundaries of the relationship. Some described their carer's involvement at times as controlling, intrusive and protective. It may be that the perception of these carer qualities vary depending on several possible factors (i.e. level of controlling, protective or intrusive behaviours, the individual's own mental health and level of acceptance). This is consistent with the idea that the intrusive elements of emotional overinvolvement are linked to relapse and worse clinical outcomes (Singh et. al., 2013) which appears to apply in the context of British South Asians experiencing a FEP. Others mentioned these qualities as minor characteristics in their relationship that they would not want to change.

### ***Acceptance as a part of family unity***

Acceptance can be a product of collectivist interest. For example, family cohesion may be particularly protective for ethnic minorities (Gurak & de Mamani; 2016), hence coming to acceptance of the carer's behaviours may be a result of not wanting to disturb the family system and maintain peace. Further studies suggest that Asian families often function as a unit, and 'parental obligation and family pressure can take precedence over autonomy with resultant

emotional conflict' (Tran et. al., 2005, Ekanayake et. al., 2012). Hence as a result young adults may have the stress of negotiating their 'dual identity' one at home and one outside which may impact their mental health (Rastogi et. al., 2014).

The varied perspectives on boundaries and independence can be attributed to a range of sociodemographic factors such as gender roles, language, economic mindset, family role, class, generation, roles associated with age, and religion (Robinson, 2005). This links with prior research that identified differences in EE levels between two cultural similar groups British Pakistani and British Sikhs (Hashemi & Cochrane, 1999). This study supports the notion that there are varied perspectives on caregiving constructs between communities that are considered culturally similar. It further emphasises the need for research and clinical practice to consider the nuanced intersectional identities that make subcultural experiences unique.

### ***Acculturation and Immigrant narratives***

It may be that acculturational differences play a large role in determining how participants and carers communicate and negotiate. For example, one study investigated the experiences of parents who immigrated from South Asian countries such as India, Bangladesh, and Pakistan to the United States. They found that acculturative stress experienced by immigrant parents leads to unrealistic expectations for their children in the hopes deter their children from the same financial or educational struggle that they faced (Bhattacharya & Schoppelrey, 2004). Acculturative stress and migration have been largely associated with high rates of mental health disorders among South Asian migrants (Karasz et. al., 2019). These studies relate to some of the experiences described by participants; for example one participant mentioned 'I'd say like, his intentions were always good like he, he always wanted

me to like, you know, excel in life and because he used to talk to me about how hard it is for him to work like, cause since he didn't get a university degree so he had to work long hours every day and said I don't want that for you, that's why I'm always pressuring you to do something so you can work, work an easier job like a skilled job which will pay more and you'd have to work less hours.' This might also fit the concept of intergenerational trauma and how adverse experiences or limited opportunities can impact parenting style which can lead to unrealistic expectations for children (Lang & Gartstein; 2018).

Another study found that when perceived external acculturation expectations contrasted with Muslim minority youth's personal acculturation preference this resulted in higher levels of stress and less adaptation (Kunst & Sam, 2013). The study also found that depending on the level of perceived external acculturation the types of acculturation strategies changed (i.e. integrate, assimilate or separate). This may connect with the findings of this study where when participants have different expectations for themselves around their cultural practices compared to their parents, pressure to acculturate results in frustration, annoyance and an attempt to negotiate an acculturation strategy.

### ***Limitations***

This study had a number of limitations in the design, recruitment, and analysis of the data. Recommendations for future studies are considered.

### **Design**

It is important to recognise that the nature of recruitment for the study may encourage recruitment bias as participants with internet or phone access were more contactable and engaged with the study. In addition, as participants were recruited through EIP services the

sample was biased to a certain level of cognitive and mental functioning. Alongside this, it is important to recognise that English language inclusion criteria is restricted in particular for a South Asian study but this was due to limited funding resources for the study to allow for translation. However, this hugely limits the perspectives that were explored in addressing the aims of the study. Furthermore, the lack of language diversity is a huge limitation as it lacks exploration of caregiving constructs characterised in non-English speaking communities; a community that is significantly underrepresented in research but a large part of the targeting population who may identify as South Asian. Although participants were told that their participation was voluntary and would not affect their clinical care, it is more likely that participants involved in research had more positive comments about the services and the role that the service played in facilitating communication with carers.

### **Recruitment**

The study was largely underpowered and had several recruitment issues including contacting care coordinators to discussing service user's appropriateness for the study, participant due to declining the study, loss to follow up, incorrect number and inability to contact. A possible reason for the barriers in contacting care coordinators could be the pressure and lack of time that many services face particularly during COVID-19. A possible reason for the recruitment difficulties with SU was the nature of the population meant that many services users may not have felt comfortable in participating due to mental health difficulties or lack of trust. These limitations are further discussed in part 3 with possible recommendations made.

### **Limited Sample Size**

Due to the limited sample size there was not enough scope to investigate the interaction or the mediating or moderating effect of warmth on other EE domains. Some current literature suggests warmth may be a protective factor when (Tsai et. al., 2015). Another study in China found that warmth in conjunction with criticism is not concerning as criticism is perceived as a sign of concern (Ran et. al., 2003). This relationship between warmth and the other EE constructs need to be further examined with a larger sample size.

### **Lack of Diversity**

The small sample size limited the scope of this study such that there was a lack of diverse representation within the South Asian diaspora such as people who identify as Maldivian, Afghani or Bhutanese. Further there was a lack of diversity in regard to other sociodemographic factors, such as religion, language, immigration status, generational differences and gender roles for which a large sample is required. Such factors provide a large amount of nuance in understanding the complex identities within South Asian Diaspora. There needs to be an increased investigation of specific kinds of patient-carer relationship such as husband and wife, child and parent.

### **Limited Data and Measures**

For the quantitative project a larger sample size would have provided opportunity to explore the effect size. There was a lack of follow up data which limits our understanding of the long-term impact of perceived EE on clinical symptoms. The warmth measure has been developed by the research team and has not been formally validated to determine whether it accurately measures warmth. The warmth measure could have included more items to capture



the nuances within the warmth construct. However, it could also be argued that the small number of items may contribute to the lack of variance in responses. However, it has been argued that when a construct is unambiguous or narrow in scope, that single or low-item measures should not be considered invalid and there has been a recent push for low-item measures in psychological science (Allen et. al., 2022).

Furthermore, majority of the measures used were self-report which may result in participants providing more socially acceptable answers about their mental health functioning rather than being truthful for fear of judgement or repercussion. A large flaw in the study was that LEE is the only measure that captures EE. One of the main reasons LEE was the only measures used was that it is one of the few measures that captures the dyad's experience. Moreover, the lack of language diversity is a huge limitation of the study as it limits the way in which caregiving constructs are characterised in non-English speaking communities. In addition, one study found that patient LEE measure is a good predictor of symptoms severity (Cole & Kazarian; 1993). However, Hooley and colleagues (2006) suggest a number of alternative measures that capture EE constructs such as Camberwell Family Interview (CFI; Leff & Vaughan; 1984) and the Five Minute Speech Sample (FMSS; Magaña et. al., 1986). However these two measures are interviews conducted with the carer so would not be suitable for perceived EE. The Family Attitude Scale (Kavanagh et. al 1997) appears to be a more promising measure of EE as it can be completed by both carer and SU and the constructs closely map on to the original CRI interviews (Hooley et. al., 2006).

## **Validity of Perceived Expressed Emotion**

It was difficult to ascertain the influence of symptoms of psychosis on participants perceived EE. For example, if participants found particular caregiving behaviours unhelpful, it was difficult to understand to what extent this was influenced by the voices or paranoid beliefs or if participants felt like this beyond the symptoms of psychosis. This is important to consider as externalising participant's perceived EE to the symptoms of psychosis avoids pathologizing the patient and carer relationship. A possible consideration would be to look at the dyads' perceptions to help understand the context of symptoms and insight in order to know whether the family is part of the delusion belief or not. However, the disadvantage of this may be that we value the perspectives of SU less due to their mental health.

## ***Implications***

### **Clinical implications**

This paper begins to highlight the perspectives of individuals experiencing psychosis, which has been minimally examined in the context of EE and South Asian communities. NICE (2014) highlight the need to research whether culturally-adapting family intervention for schizophrenia would facilitate engagement; thereby improving clinical care and reducing relapse/readmission rates for minority ethnic groups. The findings from this paper can be possibly used for clinical consideration when working with South Asian communities within EIP services. It highlights that there is a relationship between EE and clinical outcomes which can be explored in teams. Furthermore, this thesis can provide services with an opportunity to consider factors that may be facilitating the relationship between perceived EE and clinical

symptoms such as acceptance, acculturation, communication and family values. This thesis may guide services to retain curiosity towards the experiences of South Asian caregiving roles. It also serves as a reminder that South Asian caregiving experiences are not solely about the negative aspects of EE but also about warmth and connection which is a strength and resource. Lastly, it reminds services that South Asian caregiving experiences are complex and that multiple intersectional identities shape individual caregiving experiences.

### **Research implications**

This paper provides an initial attempt at understanding perceived EE in South Asian communities. It provides an opportunity for future research to further examine EE among South Asian communities, specifically to consider how to more accurately measure perceived EE. Initial themes from the qualitative findings can be further examined in future searches to investigate how this impacts clinical symptoms and relapse rates perhaps through measuring constructs that map to acceptance and examining how this interacts with perceived EE and clinical symptoms. The study can provide the basis for further development in the understanding of EE from a cross-cultural perspective. It could also be used to better understand the complexity of the EE-relapse relationship in under-researched BAME groups most likely to utilise early intervention services. It would be important for further research to explore the specific dyadic relationships in depth that this study has initially identified i.e. gender roles informing carer roles and generational differences in carer expectations.

### **Conclusion**

As an initial study exploring EE perception in South Asian communities in the UK, this study has identified numerous nuances factors contributing to relationship of EE and clinical

symptoms as well as provide a first account of perceived EE from the perspectives of those experiencing a FEP and not limited by known EE constructs. Future studies should further explore the impact on perceived EE on clinical symptoms and long-term clinical outcomes as well as the relationship between perceived EE and caregiver EE utilising dyads. Research should measure external factors such as acceptance, communication and acculturation and investigate the impact of these factors on the relationship between perceived EE and symptoms. Specific to South Asian diaspora, it is important to identify the varying social qualities that contextualise this relationship.

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### Part Three: Critical appraisal

## **Introduction**

This critical appraisal will attempt to provide reflections and improvements for different parts of the empirical study. I will first provide my reflections on the overall research process. I will discuss strengths of the study design and areas that could improve for better understanding. Furthermore, I will present reflections on the recruitment and data collection process. Finally, I will provide a conclusion summarising my reflections on the study.

## **Researcher's perspective and process**

As someone who identifies as South Asian, I was drawn to this research largely because the study felt personally and professionally important to me. Whilst conducting this research, I reflected on my own identities as a Hindu, Indian, Tamil, first-generation Singaporean, woman who is an immigrant to the UK (United Kingdom). Before the study data collection, I had an initial reflective interview with one of my colleagues about the reasons for being drawn to this study. I recognised from this exercise that my identity may not match the participants' experiences of being cared for in a South Asian community. It was important to revisit the intentions of the study and continue to be curious and to name participants' experiences. I noticed early in the study that intersectionality needs to be accounted for in research. Although everyone identifies as South Asian, the South Asian label is contextualised by various other identities like religion, generation, acculturation, language, subcultural frameworks, economic status, gender etc. Whilst we could not capture everything in this study, it is important to consider how experiences shift based on different identities. This was evident at times; for example, the experiences that daughters had with their mothers were different from sons who spoke about their fathers based on gender and generational identities. Religion, class and

stages of acculturation may play huge factors in the way in which South Asian families care for one another.

During the study, I wondered what are the benefits of a singular identity and what it means to be South Asian. In the historical context, South Asian identity was created to form unity to combat colonial division. In the ninetieth century, colonial rulers invested in the term 'communalism' which was used to manipulate religious and ethnic differences and incite strife between people who identify in different communities to gain political power. However, at the same time unification of identity may create a singular monolithic narrative which inevitable silences minority intersectional identities.

During this study, I have reflected on my similarities to the interviewees' experiences and tried to remain curious whilst asking questions that capture experiences that feel shared and unsaid. I have found certain moments during the interview process when participants laugh or provide body language cues whilst answering a Likert scale question difficult to further explore within the design of the study.

### **Design Process**

Using a mixed methods design has advantages and challenges. Research indicates two main advantages of mixed methods design; (i) the data for both methods can be used to mutually support and validate the findings and (ii) it provides a more holistic rich understanding as opposed to a monomethod research design (Kelle, 2006).

The results from the qualitative interviews provide possible explanations or factors that may be factors involved in the results of the quantitative data (Mays & Pop; 2000). In this study, there were several themes identified that were possible explanations for the correlations

between certain EE domains and clinical symptoms. However, at the same time, one of the disadvantages of qualitative design is applying findings beyond the scope of the interviewed sample (Devers & Frankel, 2000). The quantitative methods provide objective scales that can capture larger group data and trends. The results can allow for generalisations to be made across a large group of people (Babbie, 1989). However, the disadvantage of quantitative methods is the lack of nuance indicated by the statistical results. Due to the small sample size, it was difficult to explore further statistical results.

During the initial construction of the study, there were certain decisions we made to improve the clarity of the study design and the time for interviews. One of the measures I wished we could have added was a measure for acculturation. We decided to remove this measure from our study as the length of the questionnaire became too long and the number of exploratory variables was too vast given the limited sample size. Acculturation has some impact on the presentation of EE. One study found that lower acculturation was related to less criticism (López et. al., 2009). Given this literature, acculturation may have been an important factor in the relationship between perceived EE and clinical symptoms. Other future studies can explore this relationship further.

Furthermore, for the warmth measure, I wish we had included more items in the measure for the reliability of the measure. However, there is support for shorter item measures in current research to improve the accessibility of measures. Perhaps it would be important to include items related to warmth such as support, love and positive regard. A few alternative measures we could have considered were items from existing scales that measured warmth as a domain. For example, the Parenting Styles and Dimensions Questionnaire-Short Version

PSDQ; (Robinson et. al., 1995) identifies certain behaviours that can be attributed to warmth as 'they are responsive to me'.

For the qualitative study, I found it difficult to elicit how South Asian identity is directly presented in the data. Many participants situated how South Asian identity impacted EE but many times this was not explicitly linked. To further understand this context, it would be important to include this as a possible question related to South Asian identity and caregiving. Furthermore, it would have been helpful to

Considering the limitations on the inclusion and exclusion criteria, capacity was a large limiting factor in the study. Due to the questionnaire format of our study, we were not able to recruit participants who have reduced cognitive abilities to be able to engage in the study. As a result we interviewed people who are well enough to function and might hold a unique experience in carer relationships than of more unwell people. This may have significantly impacted the kinds of relationships and perspectives we have from service users about their experiences. In line with this, another bias of the study was the criteria for service involvement. Individuals eligible to participate are required to have experienced psychosis within the last three years. This wide timeline may have increased variability in the symptom severity, the carer involvement and understanding of the psychosis. A solution to this could be to ensure that service users are contacted within the first year of engaging with EIS so that there is less variability of symptom severity and an opportunity to collect data on the change in symptoms and carer relationships over time.

## Recruitment Barriers and Considerations

One of the biggest challenges for this project was the recruitment process. Only 14% of the service users originally identified for the study participated. A barrier in the recruitment process was contacting care coordinators to discuss service users' appropriateness for the study. Almost 28% (n=48) were excluded from the study as we were unable to contact the care coordinator. There may be several reasons why we were unable to contact care coordinators: (i) The time pressure that many of the EIP services were under due to the understaffing because of COVID and other service barriers. (ii) Fluctuating staff changes in services, which meant care coordinators who left had no one to take on their caseload in their absence (iii) The disconnect from the team as we introduced ourselves to the services via email and online zoom MDT meetings. If done differently, I would have liked to make a stronger presence with some of the services by visiting the teams and regularly speaking to the care coordinator individually. It may have also been beneficial to incentivise care coordinators to send appropriate referrals so that it was made a priority. Factors that helped the recruitment was building relationships with individual services and being in regular contact with the assistant psychologist, who urged their teams to provide service users suitable for the study.

Another part that was challenging about study recruitment was the participants' follow-through. 39% (n=66) of service users who were suitable for the study did not participate due to declining the study, lost to follow-up, incorrect number and inability to contact. This felt like the most time-consuming and demoralising part of the study particularly when we had participants who were lost to follow-up. There may be several reasons for this decline in participation: (i) I had no prior contact with participants before the call so perhaps reaching out to discuss the

study may have felt impersonal or irrelevant. (ii) Some participants may have been wary of talking about their experiences of psychosis and their relationship with their carers, which may have limited the success of recruitment. (iii) The £10 amount of compensation given for participation. The amount of compensation paired with the two-hour time commitment may have been less enticing to participate. (iv) the timings that participants were called were during office hours 9 to 5, (v) individuals may have felt weary about participating in a study that their carers were offered to participate in too despite informing them that the data was stored separately and not shared with carers. One factor that may have increased trust and familiarity with potential participants is informing them that we had spoken to their specific care coordinator before contacting them. Providing a brief rationale to emphasise the importance of the study was another element we highlighted on the phone call. We also informed them of the time and the incentive early in the call so that participants had essential information to make their decision.

Several viable options could have been taken to improve recruitment amongst participants. We could encourage EIP services to use opt-out participation. The 'opt-out' approach is when all patients have the right to be informed of relevant research opportunities. One study found that using the 'opt-out' approach is more beneficial and successful than the 'opt-in' as it increased access to information about current research and allowed for better equality of who gets to participate (Henshall et. al., 2021).

### **Interviewing and Data Collection Process**

During the interview, several challenges led to important opportunities to reflect. First, it was important to consider participants' capacity to participate due to language limitations.

Some of the participants who were interviewed for the study had limited English vocabulary but understood and spoke enough English to be appropriate for the study. Some of the terms that were used in the measures were difficult to understand for participants. Specifically, when interviewing Tamil-speaking individuals in English, I considered this enormous limitation in the study. It brought into question why and who are we doing this research for. More specifically I wondered whether I was adapting and neutralising my questioning to standardise how questions were asked. You could argue that so much rich information is lost in translation and interviews strictly sticking to English. This is a current problem in medical research. A systematic review found that to reach 'hard to reach' communities research team must implement 'extended timeframes, plan for higher resourcing costs and operate via community partnerships' (Bonevski et. al., 2014)

Challenges another engagement during interviews was something I faced. There were a few interviews that were shorter in length and had limited qualitative data. Reflecting on why this was the case, I noticed that this was early in recruitment and interviewing. At the time of the initial set-up of the study, I was sticking to the guidelines of study questions too rigidly which limited opportunities for data saturation. Reflecting on this I could have prompted more and asked more follow-up questions to further understand. Next time I would have been more curious about what specific words meant to the participant such as 'support'. Further, I would have asked how the relationship has changed over time, and if it had not changed what had stayed the same. I took these interviews to supervision to consider the value of including them in the final data and we decided that there was still vital information captured in these interviews.



In another specific interview, the interviewee opted to drop out of the study as they found the questions too personal. I recognised how difficult the topics may be for individuals to speak about. One reason why the interviewee disengaged was the nature of the questions formatted on a Likert scale which limited an opportunity to explore these themes.

Finally, ethical considerations regarding participant payment were something that I reflected on during this process. At times there were participants who were eager to participate in the study for compensation. It felt like this compensation was highly valuable to some participants, particularly participants who may have been struggling financially. I found the ethical considerations for this to be challenging as some participants who may not have felt comfortable disclosing their feelings in the interview may have felt financially obligated to do so. Although we had iterated to participants that they would still be compensated for their time if they wished to drop out of the study at any time, there may have still been pressure to participate and complete the interview.

## **Conclusion**

This critical appraisal offers my reflections and suggestions for the study through the format of a reflective log. I feel fortunate to have grown and learnt more about a topic area that is important to me. It has explored what it was like conducting this research as someone who identifies as South Asian. It has considered the complexities of South Asian identities and highlighted the importance of intersectional identity. The appraisal also highlights the design strengths and weaknesses in the study. For example, it explores the advantages of using a mixed methodological approach. It explores why certain design decisions were made and what could have been some alternative considerations. It addressed the recruitment barriers and

provided suggestions as to how to overcome them. It provides my reflections on the interviewing process and how we handled certain barriers as a team. I hope that the critical appraisal offers some insight into the journey of conducting this research project as well as provides context to the study.

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## Appendix

### Appendix A: List of terms used in Part 1 and Part 2

EE.....	Expressed Emotion
EIS.....	Early Intervention in Psychosis Service
EOI.....	Emotional Overinvolvement
FEP.....	First Episode of Psychosis
FI.....	Family Intervention
SU.....	Service User

## **Appendix B: Search Strategy**

*(psychosis OR psychotic OR schizophreni\* OR schizoaffective OR "schizo affective") AND  
(acculturat\* OR "acculturative stress" OR "cultural assimilation" OR "cultural integration" OR  
"cultural adaptation" OR bicultur\* OR multicultur\* OR marginaliz\* OR marginalis\*)*

## Appendix C: STROBE Checklist

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
<b>Introduction</b>		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
<b>Methods</b>		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants (b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses

Continued on next page

<b>Results</b>		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
<b>Discussion</b>		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
<b>Other information</b>		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).



## **Appendix D: Contributions to the Research Project**

This is a joint project with Syed Kausar Miah (Trainee Clinical Psychologist). Both Syed and I developed questions for the qualitative interview and warmth questionnaire. Participant recruitment and data collection was carried out jointly. Our project differed in terms of the aims and the data we analysed. Syed's project exclusively includes the carer data and hard data from service users, whereas I exclusively explored the service user perception of EE. The qualitative transcription and coding of the study data was conducted individually. Analysis of results, and the write-up of the theses were also carried out individually.

## Appendix E: Participant Information Sheet



Understanding Caregiving Processes in South Asian Families  
IRAS: 230098, R&D: 170916  
Version 6.0 (30.10.2019)

### **Information sheet for service users (this is a student study)**

#### **Project title: Understanding Caregiving Processes in South Asian families**

We would like to invite you to participate in this research study because you self-identify as South Asian and are accessing support from your Early Intervention Service. Before you decide whether to take part, it is important for you to understand why the research is being done and what participation will involve. Please take some time to read this information sheet carefully. We encourage you to ask questions if you find anything on this sheet unclear or feel unsure about any aspect of the research, or if you would like more information. Thank you for reading this.

This is a student study. Data collected will be used for work required as part of the doctorate in clinical psychology.

#### **What is the purpose of the study?**

The aim of the study is to better understand the relationship between an individual experiencing psychosis and their carer. A carer may be a parent, grandparent, partner, sibling or friend who is in close and regular contact with the service users. We are interested in understanding more about the relationship between service users and their carers in South Asian families specifically, because to date this is a group which has tended to be less included in research and yet we know that culture and ethnicity can influence the nature of family relationships.

We hope this research will help ensure that the Family Interventions offered by services, which can be useful for supporting families during this time, are designed in a way that is relevant to people from a range of cultural backgrounds.

#### **Why have I been invited to take part?**

We are inviting all service users and their carers who self-identify as South Asian and are accessing support from your Early Intervention Service (EIS) to participate in the study. We are hoping to recruit 42 service users and 42 carers, making 84 participants in total. Service users and carers who are not deemed to have capacity to consent to being involved in the study will not be approached.

#### **Do I have to take part?**

No. It is your choice whether or not you would like to participate. If you do decide to participate, you will be given this information sheet to keep, and you will later be asked to sign a consent form. If you do agree to take part, you are still free to leave the study at any point, without giving a reason. A decision to withdraw at any stage will not affect the standard of care or support you or your relative receives from the EIS.

#### **What will happen to me if I decide to take part?**

You will be contacted by a member of the research team who will invite you to meet with them to check you have understood this information sheet and, if you still wish to partake in the study, to

complete a consent form. Following this they will ask you to complete a range of questionnaires asking about your relationship with your carer, your mood, and how you have been feeling lately. The meeting should take approximately 1 hour and would take place either at the clinical service where you receive treatment, or in some circumstances upon request at your home. There are no right or wrong answers to the questions you will be asked. The researchers will also be interested to collect information from you about some of the symptoms you may have been experiencing. They may ask you questions about this directly, in which only written notes will be made of the answers you give. Alternatively, the researchers may request this information from the clinical team you have been receiving treatment from, if they have already collected this information from you.

With your permission you may be re-contacted after 6 months and then again after 1 year has passed and invited to complete the same questionnaire measures again. In each instance you would again meet with a member of the research team for approximately 1 hour, be given a copy of the information sheet, and asked to complete another consent form.

#### **What are the possible risks of taking part?**

We do not expect that participation in this study will cause any harm. However, if you find any of the questions upsetting and would like to talk about it, you are welcome to speak with a member of the research team (see end of this document for contact details). The researchers will also have information on local resources and support services you might find helpful.

#### **What are the possible benefits of taking part?**

Whilst there are no immediate benefits for participating in the study, we hope that this research will help ensure that the therapy we offer to service users and their families in future are culturally appropriate and therefore more effective.

#### **Will I be paid for taking part?**

Yes, to compensate you for your time and travel, we will offer you £10 upon completion of the questionnaires. The same reimbursement arrangement would apply for data collection at the six month and 1 year time points if the study continues to the point and you choose to participate.

#### **Who will know I am taking part?**

Your treating clinician at the EIS will know you are taking part in the study and the information you provide will be viewed by members of the University College London research team. The only time we would pass information on to anyone else would be if, during the course of the study it was suspected that you are at immediate risk of harm to yourself or others, in which case the researcher would take appropriate action, for example by letting your care co coordinator know or calling emergency services.

However, all of your answers to the questionnaires will be kept anonymously, which means that your name will not be written anywhere on the paperwork, instead we will use a participant ID number for you.

Your data will be stored in secured locations within University College London premises only. Your name and participant ID will be stored separately so that we can identify you in future should we need to (for example if you wanted us to withdraw your information from the study). The paper copies of the questionnaires will be kept securely in locked filing cabinets in a locked office. Any electronic files created will be password protected. Your details will be kept till the end of the study which is estimated to be 3 years and then be confidentially destroyed. We will keep an anonymised copy of the dataset, from which you will not be able to be identified at all.

### **What will happen to the results of the research study?**

The anonymised results of this study will be published within several doctoral theses. The results may also be published in academic journals and presented at conferences. There will be no way of identifying you or your relative in any reports or publications that result from this study. Upon completion of the study, a report of the study will be sent to you, should you wish to receive it.

### **Data Protection Privacy Notice**

In line with new General Data Protection Regulations (GDPR) we need to give you some information about how your data will be used. The data controller for this project will be University College London (UCL). The UCL Data Protection Office oversees UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk) if you have any questions regarding your data protection rights. [UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk.](#)

Your personal data will only be processed for the purposes of the research study. The legal basis for us using your personal data will be Article 6 (1) (e): '*public task*'. Under data protection law, the information that we will get from you is regarded as special category personal data. The legal basis for us collecting this type of data from you is Article 9 (2) j: '*processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes*'.

You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed until the research has been completed, which we estimate will be in about 3 years time. Your data will be anonymised, and a study ID code will be used instead of your name. We will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please refer to the attached document detailing your rights and how your personal data will be used. You can also contact UCL at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

**Who is organising and funding the research?**

The study is being funded by the UCL Doctorate in Clinical Psychology Departmental funding.

**Who has reviewed this study?**

All research conducted within the NHS is reviewed by an independent group to ensure protection and proper treatment of those who participate in the study. This study has been reviewed by the Yorkshire & The Humber – South Yorkshire Research Ethics Committee.

**What should I do if there is a problem?**

If you wish to complain or have any concerns about any aspect of the way you or relative have been approached or treated by members of staff during your participation in the study, National Health Service or UCL complaints mechanisms are available to you. This includes the option to contact the local NHS Patient Advice and Liaison Service (PALS) either by calling 0800 389 8324, or by emailing: [PALS@bhrhospitals.nhs.uk](mailto:PALS@bhrhospitals.nhs.uk). Please ask the researchers if you would like more information about this.

In the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr. Madiha Shaikh, who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

**Contact Details**

If you wish to contact the research team to discuss any of the information further or any concerns you have about the study, then please get in touch with the research team via the email below:

[southasianstudy@ucl.ac.uk](mailto:southasianstudy@ucl.ac.uk)

If you feel that we have not addressed your questions adequately or if you have any concerns about the conduct of the research team, then please contact the research supervisor:

Dr. Madiha Shaikh, email: [madiha.shaikh@ucl.ac.uk](mailto:madiha.shaikh@ucl.ac.uk) telephone: 07973626897

Address: Research Dept of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB

Thank you for reading this information sheet and for considering taking part in this research study.

## Appendix F: Participant Consent Form

1



Understanding Caregiving Processes in South Asian Families  
IRAS:230098,R&D:170916  
version 4.0 (05.06.2018)

### Consent form for service users

Project title:

**Understanding Caregiving Processes in South Asian families**

You will be given a copy of this Consent form to keep and refer to at any time.

**Please initial the statements below if you agree with them:**

I have read and understood the participant information sheet dated 30/10/19 (version 6) for the above study. I have been given the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.

I consent to participate in the study. I understand that personal information such as my relationship with my carer, my mood, and any symptoms that I may have been experiencing will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing my data.

I understand that my data gathered in this study will be stored anonymously and securely, and that all my personal details will be destroyed once the study is complete. Once the study is complete, only an anonymised copy of my data will be stored securely at UCL.

I understand that my participation is voluntary and that I am free to withdraw at any time. I do not have to give any reason for withdrawing from the research. If I decide to withdraw there will be no negative consequences for me, including no change in any ongoing care I receive from the service, or any change in the care that my carer might receive from the service.

I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.

I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.

I understand that besides being compensated £10 for my time in the study each time I complete the questionnaires, I will not benefit financially from this study or from any possible outcome it may result in in the future.



Understanding Caregiving Processes in South Asian Families  
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I agree to members of the research team accessing clinical information about me from the team I am receiving treatment from where it is directly relevant to the research study.

I understand that all information I give will be treated as strictly confidential in accordance with the Data Protection Act 2018 , and General Data Protection Regulations (GDPR).

I understand that the data collected during this study will be looked at by individuals from University College London or from the NHS Trust where it is relevant to my taking part in this research.

I understand that the information I give will be used for scientific publications and reports. Confidentiality and anonymity will be maintained and it will not be possible to identify me or my carer from any publications.

I agree to be re-contacted in the future by a member of the research team only. This would for the purpose of inviting me to provide data again to aid the research team to explore change over time.

I understand that should I lose the capacity to consent that I will be automatically withdrawn from the study but that any information I have already given will be kept and used for the purposes of the study

I agree that the information I give can be kept anonymously and securely, and my data may be used by others for the purpose of future research. No one will be able to identify me from the shared data.

I agree to take part in the above study

Signed: \_\_\_\_\_ Printed \_\_\_\_\_ Date: \_\_\_\_\_

Signed (Researcher): \_\_\_\_\_ Printed \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix G: Recruitment Poster



The quality of the family environment can contribute to the wellbeing of people experiencing psychosis and those who care for them. Specifically, how families communicate and express emotion can impact our mental well-being. This research aims to better understand how emotions are expressed and communicated in South Asian families.

### Participants will be asked to participate in:

- 1 Interview
  - Completing questionnaires
- There will be an option to participate in a second interview.

### Participants will receive:

- Paid £10 for participating
- Support throughout participation

### Location

The interview will take place virtually or over the phone depending on preference and safety.

### Are you eligible?

- 18 years or older
- Have experienced or care for somebody who has experienced a first episode of psychosis.
- Self-identify as South Asian

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### Contact Us:

If you would like to participate or have any questions about the study, please contact a member of the research team:

[southasianstudy@ucl.ac.uk](mailto:southasianstudy@ucl.ac.uk)



Reviewed by the Yorkshire & The Humber – South Yorkshire Research Ethics Committee (IRAS:230098)



## Appendix H: Qualitative Interview Questions

### ***Clinical: Pre-explanation for client of what the purpose of the qualitative interview:***

Think of a person you have a close relationship with. This person could be:

- a.) someone that you live with or have done in the recent past
- b.) a partner or relative (e.g. boyfriend/ girlfriend/ spouse/ child/ parent/ sibling/ niece/ nephew/ uncle/ aunt/ grandparent/ grandchild etc.)
- c.) someone who would take a significant role in caring for you

We would like you to keep this person in mind whilst you answer the following questions.

### ***Client Questions:***

#### **What's your relationship with X like?**

- Prompt: Is there a reason you feel this way?

#### **Has your relationship with X changed since contact with mental health services/early intervention team?**

- Prompt: In what way has it changed? Could you elaborate? Have you got a recent example of that? Can you think of something recently that happened?

#### **What kind of aspects do you like about your relationship with X?**

- Prompt: Have you got a recent example of that? Can you think of something recently that happened? Use the specific terms such as helpful and unhelpful to clarify.

#### **What kind of aspect do you not like about your relationship with X?**

- Prompt: Have you got a recent example of that? Can you think of something recently that happened? Use the specific terms such as helpful and unhelpful to clarify.

#### **Is there anything in your relationship with X that you would like to change/different?**

- Prompt: Refer to prior question – would you want to change anything you mentioned in the previous question e.g. \_\_\_\_\_

## Appendix I: Warmth Questionnaire

The following are a number of statements. For each statement indicate whether your carer has been doing the following never/very rarely, rarely, often or very often over the past month 1.

**1. They are warm towards me**

0 Never/Very rarely

1 Rarely

2 Often

3 Very Often

**2. They appreciate what I do for them**

0 Never/Very rarely

1 Rarely

2 Often

3 Very Often

**3. They really value me**

0 Never/Very rarely

1 Rarely

2 Often

3 Very Often

**4. They want to understand how I see things**

0 Never/Very rarely

1 Rarely

2 Often

3 Very Often

**5. They feel very close to me**

0 Never/Very rarely

1 Rarely

2 Often

3 Very Often