

**Understanding Caregiving Processes in South Asian Families:  
Relationship between caregiver EE and clinical outcomes in first episode  
psychosis**

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**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.

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## Overview

Chapter one is a conceptual introduction which reviews the literature on the expression of emotions, before critiquing the Expressed Emotion (EE) construct. EE is considered in the context of psychosis and the cross-cultural validity of the construct. Literature regarding the treatment implications of EE is also reviewed.

Chapter two presents a quantitative, empirical study on the relationship between caregiver EE and clinical outcomes in First Episode Psychosis (FEP) within South Asian families. Moreover, this study aims to explore the EE characteristics of this population. This study uses primary and secondary data from service users with FEP and their caregivers, collected from several Early Intervention in Psychosis Services.

Chapter three is a critical appraisal of the process and experience of undertaking this thesis. Reflections are offered on the salient aspects of chapter one and two, including the process of choosing methodologies, data collection, analyses and navigating the COVID-19 pandemic. This chapter concludes with a personal reflection, focusing on the importance of this study and its connection to the author.

This study was a joint project with fellow trainee clinical psychologist, Amrita Ramanathan. Their project was a mixed-methods study examining perceived expressed emotion and clinical outcomes of first episode psychosis in South Asian communities.

## Impact Statement

The current study presented in chapter two has several potential research and clinical implications. With regards to academic research, to the best of the author's knowledge, this study is the first to explore the relationship between EE and clinical outcomes in FEP between dyads of service users and caregivers within the South Asian population. This presents an opportunity to build on existing research that has examined and questioned the cross-cultural validity of EE. Furthermore, few studies have specifically focused on the relevance of EE in the South Asian population specifically, and thus this study offers an important contribution towards developing the field of EE. This study may inspire and warrant future studies to explore other cultural backgrounds beyond South Asian or replicate this study with a larger dataset to assess the reliability of the findings. Dissemination of this study's findings via publication in a journal may give rise to further academic implications.

Regarding clinical implications of the current study, results presented expand on recent literature that has questioned the universality of the clinical utility of EE. The lack of relationship found between caregiver EE and service user clinical outcomes suggest that the current conceptualisation of EE may not apply to the South Asian population, the same way it does for Western populations. This is important clinically, as current Family Intervention (FI) within Early Intervention for Psychosis Services (EIS) partly focuses on reducing high EE and this may not be beneficial for the South Asian population. Therefore, this study's findings could influence the adaptation of FI and other interventions so that they better consider the idiosyncrasies and meet the needs of differing cultural groups. Further studies that explore different cultural groups and establish the need for a culturally sensitive understanding of EE may lead to national changes in EIS interventions, whilst potentially influencing NICE guidelines. Conversely, findings from this study may influence EIS more

informally, by raising awareness among staff of the need to consider and exhibit cultural awareness. This could be achieved through training, that informs the practice of interventions such as FI. Dissemination of these results and their clinical implications will begin through presenting them to a multidisciplinary team at an EIS that the author is working in, as well as the services that took part in the study and discussing ways in which such results can inform practice.

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## **Chapter 1: Conceptual Introduction**

A Cultural Critique of the Concept of Expressed Emotion

## **Abstract**

This conceptual introduction aims to explore the broad research areas surrounding Expressed Emotion (EE) and psychosis, with a focus on the cultural critique of EE, whilst considering any possible implications for treatment. It begins by exploring emotional expression in a general sense, particularly the development and how it links to mental health and culture. The formal construct of EE is then introduced including how it links to broader mental and physical health. The relationship between EE and psychosis is then examined in detail. Cultural differences in the experience of psychosis are discussed before exploring the relationship between EE and culture. The conceptual introduction concludes by commenting on the role of Family Interventions and how they have been culturally adapted recently. Overall, the conceptual introduction builds towards the idea of developing a cultural understanding of EE in order to enable the tailoring of such interventions and thus improve clinical outcomes.

## **Development of Emotional Expressiveness**

Emotional expression is critical for communicating important social information including behavioural intentions, needs and emotional states (Andersen & Guerrero, 1998; Chervonsky & Hunt, 2017). Attachment theory (Bowlby, 1969) proposes that an individual's experience of receiving care from attachment figures in childhood, will shape their goals, working models and coping strategies with regards to future relationships (Ainsworth, 1989; Bowlby, 1980). Mikulincer and Shaver (2003) proposed that individuals belonging to the different categories of insecure attachment, would have differing strategies to deal with negative situations. For example, when avoidantly attached individuals feel threatened, they are likely to experience anxiety and psychological distress, and will try to inhibit emotions using avoidant coping strategies. Thus, working models formed in response to attachment histories would thus inform how individuals perceive, manage and express emotions in relationships (Kobak and Sceery, 1988).

Outside of attachment theory, it has been proposed that difficulties in "reading" the feelings of others as well as understanding the causes and consequences of emotional states can contribute to difficulties with relationships with peers during childhood (Cassidy et al., 1992; Dodge, 1986). The family context, especially children's relationships with members of their family i.e. parents, is at the heart of the development of emotional expressivity and understanding of emotions (Eisenberg et al., 1998). Moreover, parents' emotional expression is related to various children's socio-emotional outcomes such as emotion regulation (Eisenberg et al., 2010).

It is important to note that the idea that primary caregivers i.e. parents, contribute significantly towards the emotional climate of the home has been long established (Fonagy et al., 2002). Such theories also offer possible explanations on how emotional expression is developed. For example, the Meltzoff-Gopnik hypothesis (Meltzoff & Gopnik, 1993)

proposes that innate mechanisms facilitate the imitation of facial gestures of adults such as mouth opening. Thus, whilst the primary caregivers use of facial expressions is key, this theory proposes that the expression of emotions is an innate process that begins in infancy. Whilst this view of innate emotions has been embraced, there is a general acceptance of the biosocial theory of emotional development that proposes mother and infant develop a communication system in which the mother plays a crucial role in modulating the infant's emotions (Beebe et al., 2005; Bowlby 1969). Moreover, Fonagy et al. (2002) emphasise the role of parents in the development of emotion through parental affect mirroring which is likened to a natural social feedback training. Whilst it is beyond the scope of the review to explore these and other models in detail, it is clear that the role of parents in emotional development is well established and considered from multiple perspectives.

Given that so much attention has been directed towards understanding the how emotional understanding and expression develops, there is surprisingly very little inclusion of culture and how differences between cultures may influence such development. With research emphasising emotional mirroring and imitation, differences in cultural norms regarding emotional expression would likely impact how caregivers interact with their infants and thus influence development.

### ***Mental Health and Emotional Expression***

Along with influencing the expression of emotions, attachment theory (Bowlby, 1969) is also implicated in the development of mental health problems. Early research has identified insecure and disorganised attachment styles as risk factors for psychopathology in children (Greenberg, 1999; Warren et al., 1997). Similar associations have been shown for insecure adult attachments and different psychiatric disorders (Dozier et al., 1999). Moreover,

research has linked attachment avoidance to minimisation of affect, social isolation and interpersonal hostility (Mikulincer et al., 2003).

Another point of consideration regarding emotional development is emotional intelligence, which has been defined as the set of abilities linked to managing, expressing and perceiving emotional information (Salovey & Mayer, 1990). A similar construct is alexithymia (Nemiah et al., 1976) which includes the difficulties in describing and identifying subjective feelings, as well as impacting the ability to use emotions to cope with stressful situations. This is an important consideration which highlights the presence of individual differences in the way people understand and express emotions. This heterogeneity in emotional intelligence has also been linked to mental health. For example, one study explored Trait Emotional Intelligence (TEI), which refers to the process of understanding and using interpersonal and intrapersonal emotions (Sinclair & Feigenbaum, 2012). TEI was explored in terms of its relationship with symptom severity associated with Borderline Personality Disorder (BPD), difficulties with emotional regulation and ability to engage in mindfulness. Results showed TEI related to greater BPD symptom severity, difficulties in ER and lower mindfulness ability. Moreover, TEI scores predicted BPD diagnosis with 95% accuracy. This highlights the importance of considering how we understand and express emotions and further highlights the link between expression of emotions and mental health.

Research has long acknowledged the presence and significance of interpersonal difficulties (i.e. rejection from others) associated with people with mental health problems including eating disorders, depression and psychosis (Broberg et al., 2001; Huprich et al., 2016; Penn et al., 2004; Siegel & Alloy, 1990). Such disrupted personal relationships can include problems in family and marital relationships (Beach et al., 1990). For example, when comparing depressed and non-depressed couples, the former is more likely to exhibit a negative tone which tends to generate greater negative affect in each spouse (Gotlib &

Whiffen, 1989). Marital interaction where mental health problems are present have also been associated with poor communication and verbal aggressiveness (Basco et al., 1992; Segrin & Fitzpatrick, 1992). When considering people with depression, there have been differences in communicative behaviour compared to those without depression, including paralinguistic behaviour (i.e. speaking slower and less), speech content, gaze, facial expression, posture and gesture (Segrin, 1996). Thus, this illustrates a range of ways in which feelings can be expressed and the impact on mental health from the way in which this happens. Whilst the studies discussed above so far may differ in terms of their exact findings, many suggest the importance of the role of family, especially parents, in the development of emotional expression. It may then be implied that the cultural background of the family plays a role in social dynamics, particularly in terms of how emotions are expressed and the degree to which they are discussed.

### ***Culture and Emotional Expression in the Family***

Whilst the effects of parental emotional expression on children's development has been consistent across cultures (Chen et al., 2011; Eisenberg et al., 2001), the patterns of emotional expression may vary between parents from different cultural backgrounds (Camras et al., 2006; Ng et al., 2007; Parker et al., 2012). Individuals adapt emotional expression to align the expectations and norms of their culture (Ekman, 1971) and such norms are usually transmitted via the context of the family (Friedlmeier et al., 2011). Specifically, the language used by individuals to talk about emotions may influence the intensity or frequency of emotional expression (Chen et al., 2012).

One study found differences in emotional expressivity within a group of Chinese American immigrant parents, depending on their cultural orientation (Chen et al., 2015). Results showed higher American cultural orientations were typically related to higher levels



of self-reported emotional expressivity. In contrast, higher Chinese orientation was linked to lower emotional expressivity. Thus, demonstrating the influence of culture on emotional expressivity, whilst also suggesting differences within and between cultural groups.

### ***Measuring Emotional Expressiveness***

There are a variety of ways in which the expression of emotion can be measured due to the variation in which emotions are expressed by humans. A large area of study is facial expressions, particularly in terms of facial recognition of emotions (Wolf, 2015). Studies have explored how mental health problems affect the facial expression of emotions, suggesting that patients with psychosis display a paucity of facial expressions, with such limitations being correlated with the amount of negative symptoms (Pulkkinen et al., 2015). Moreover, patients with schizophrenia and depression have both shown less spontaneous facial expressions of emotion when compared to healthy individuals (Trémeau et al., 2005). Whilst the universality of emotional facial expressions has been proposed (Darwin, 1872; Ekman, 1999), the communication of emotions such as happiness and sadness varies significantly across cultures and contexts (Barrett et al., 2019).

There are various other measurements that attempt to capture the expression of emotions in different forms including the Emotional Expressivity Scale (Kring et al., 1994), a 17-item questionnaire that examines self-perceived verbal and non-verbal expressions of emotions. This measure was shown to have validity, with exploratory and factor analysis being conducted, showing all items significantly loading onto the single general expressivity factor and all error variances correlating (Dobbs et al., 2007). In addition, reliability was also strong with a coefficient of 0.93. The Distress Disclosure Index (Kahn & Hessling, 2001) focuses on tendencies to conceal or disclose negative feelings to others. This self-report measure showed strong internal consistency ( $r= 0.92$ ), test-retest reliability ( $r= 0.80$ ), and

construct validity, with strong correlations shown between a measure of expressive suppression ( $r= 0.69$ ) and typical emotional expressivity ( $r= 0.71$ ) (Kahn et al., 2012). Therefore, the depth and variability of emotional expression is illustrated by the range of different measures used to capture aspects of this critical form of communication. Such complexity suggests the difficulty in being able to capture the entirety of emotional expression in one measure.

The above two measures have not been assessed in terms of their cross-cultural validity and the degree to which the items for each measure consider the cross-cultural norms of emotional expression. Thus, there does not appear to be any indication of the applicability of these measures to the South Asian population. In addition, the use of self-report measures, which depend on a certain level of writing and reading proficiency, may not sufficiently capture emotional expression in its entirety. Rather, emotional expression may be better measured using self-report measures which capture the perspective of the person expressing emotion and somebody that receives the emotional expression, in addition to more objective observation. Any such measurement would likely benefit from the consideration of influencing factors such as culture, personality, emotional intelligence and other individual differences.

## **Expressed Emotion**

### ***Definition and Development***

Different to the general term of emotional expression, the term *Expressed Emotion* (EE) refers to the quality of family interactions, specifically, a caregiver's view of a person with a mental health condition, which is reflected by statement made about the person (Brown & Rutter, 1966). Whilst the measurement of EE is focused on the caregiver's attitude and communication style towards the care recipient, EE is considered a measurement of the

quality of social interaction in which *both* caregivers and patients are ‘involved in a system of mutual influence.’ (Hooley & Gotlib, 2000, p.136).

EE measures positive and negative statements made by a caregiver about their unwell relative, in terms of frequency and intensity of five specific domains (Hooley & Gotlib, 2000). Domains include emotional over-involvement (EOI), criticism, hostility, warmth and positive comments (Kuipers, 1979). EOI represents different behaviours related to an extreme overconcern with the caregiver (i.e., overprotectiveness and intrusive attempts to control patient’s behaviour). The number of statements that illustrate anger or frustration with the patient’s behaviour, along with changes in vocal qualities (i.e. tone) are used to rate the criticism scale. Hostility scale is measured as either expressed or not expressed and designed to capture caregiver displays of animosity and resentment towards the individual as opposed to their behaviours. Hostility is associated with criticism and seldom rated in its absence. Behaviours and comments demonstrating warmth (i.e. empathy) and positive comments about the patient’s behaviour and/or character are also coded (Kuipers, 1979). It is important to note that whilst this is the original conceptualisation of EE, EE has also been defined and measured with different domains as found in the Level of Expressed Emotion scale (LEE; Cole & Kazarian, 1988).

EE was conceptualised by research conducted in the UK by George Brown, Michael Rutter and colleagues in the late 1950s and 1960s whilst originally trying to determine whether emotions in regular family relationships could be accurately and objectively measured (Brown & Rutter, 1966; Hooley, 2007). Brown et al. (1958) found that male patients, of whom many had a diagnosis of schizophrenia, reported worse psychiatric outcomes after a one-year follow-up from discharge if they were living with partners or parents compared to supported accommodation or with siblings. However, this difference was not statistically significant. Nevertheless, results showed psychiatric outcomes were also

related to the amount of contact patients had with close relatives (Brown et al., 1958; Hooley, 1985). This suggests some degree of importance of familial relationships with regards to recovery from mental illness, particularly psychosis.

Following results from Brown et al. (1958), Brown et al. (1962) tested their semi-structured interview in a controlled, prospective experimental study of 128 male patients with schizophrenia that were being discharged from hospital. Results showed patient outcomes at follow-up were strongly associated with ratings of Hostility and Emotional Involvement expressed by a significant relative alone during the interview.

After patients were split into dichotomous groups characterising high and low emotional involvement, results showed individuals returning to live with relatives from the high group were significantly more likely to have relapsed by 1-year follow-up, compared to the low group (Brown et al., 1962). These preliminary results ultimately led to the development of the presently used and empirically derived construct of EE (Brown et al., 1972) and highlighted that higher levels of emotional involvement were negatively impacting on potential relapse.

The measurement of EE has typically involved the rating of responses given by caregivers during the semi-structured interview but has since been adapted and shortened to form the Camberwell Family Interview (CFI) (Vaughn & Leff 1976a; Wuerker, 2000). Further studies have examined EE in formal care contexts to measure the quality of patient-staff relationships (Berry et al., 2011; Endley & Berry, 2011), as well as modified and validated the CFI interview (Rutter & Brown, 1966; Vaughn & Leff, 1976a) and substantiated the relationship between relapse in schizophrenia and a high EE living environment (Brown et al., 1972; Vaughn & Leff, 1976a).

### ***EE and Broader Mental Health***

The impact of EE on patient outcomes across a broad range of mental health problems, outside of psychosis, has been explored. For example, Hooley et al., (1986) identified relapse rates (51%) for married inpatients with depression, which is similar to earlier research on depression and EE (Vaughn & Leff, 1976b). Moreover, there was a significant relationship identified between criticism and relapse, with spouses of relapsing patients making more critical remarks than spouses of those who did not relapse. Similar relationship was shown between EE and depression amongst children (Asarnow et al., 1993).

With regards to eating disorders, the relationship between EE and patient outcomes appears ambiguous. Early research found an association between patients with eating disorders treatment noncompliance and parental EE (Szmukler et al., 1985). Yet research has also shown little evidence for hostility, low EOI scores and low frequency of critical comments, with just 6% of parents classified as high EE (Le Grange et al., 1992).

A clinical trial examining imaginal exposure versus cognitive therapy for Post Traumatic Stress Disorder (PTSD) found significant differences between high and low EE rated relatives on measures of depression and anxiety (Tarrier et al., 1999). However, this relationship was in the opposite expected direction, as patients living with low EE rated relatives scored higher on anxiety and depression measures. This could relate to low EE representing an under-involvement from relatives that resulted in reduced support to patients. Yet, across the 14 outcome measures, there was greater improvement in patient outcomes for those living with low EE relatives.

There has been little exploration of EE in relation to borderline personality disorder. One study found hostility and criticism were not predictive of patient outcomes during a 1-year follow-up (Hooley & Hoffman, 1996). Moreover, contrary to expected patterns, higher EOI was related to better outcomes i.e. absence of re-hospitalisation. This finding could be

explained by emotional over-involvement being a sign that the family cares for the person with borderline personality disorder and is engaged with them.

### ***EE and Physical Health***

It is important to note that the relationship between EE and patient outcomes for physical health problems has also been an area of interest. Research into diabetes shows conflicting results with one study suggesting no association between EE domains and glucose control, with the exception of EOI, in which high levels are related to better glucose control (Stevenson et al., 1991). However, Koenigsberg et al. (1993) showed patients who experienced critical comments by relatives had poorer glucose control. In addition, strong associations between EE and patient outcomes have been noted for epilepsy (Jadresic, 1988) and obesity management (Flanagan & Wagner, 1991).

EE related research for many of these mental health and physical health conditions is too disparate and limited to draw general conclusions. The studies above demonstrate both strengths and limitations of the applicability of EE to various conditions, with studies showing high EE linked to worse clinical outcomes in one condition and better outcomes in another. An area in which the impact of EE on clinical outcomes has been explored in more depth, is psychosis.

### **EE and Psychosis**

Psychosis illness can be considered an umbrella term for disorders such as bipolar disorder and schizophrenia. The conceptualisation of psychosis began in the 19<sup>th</sup> century and remains a significant area of debate. Many clinicians and researchers debated and questioned the singular nature of the schizophrenia label due to the diverse clinical presentations (Dutta et al., 2007). As a result, subtypes of schizophrenia were identified to separate between

significantly different symptoms including catatonic schizophrenia and paranoid schizophrenia (McGlashan & Fenton, 1991). This was the beginning of the shift of schizophrenia as a singular mental illness to a syndrome with differing manifestations as well as phenomenological similarities (Van Os & Tamminga, 2007). However, many of these subtypes have since been removed from the revised Diagnostic and Statistical Manual of Mental Disorders (5th ed., DSM-V, American Psychiatric Association, 2013) due to issues with efficacy in distinguishing treatment and expected course of the disorder.

The conceptualisation of psychotic disorders has been scrutinised, especially as research continues to identify information about possible causes and mechanisms (Freeman et al., 2012). Many of the arguments against the current classification of psychosis are rooted in the idea of using a symptom-based approach (Bentall, 2003) and reducing the stigma of diagnostic labels in clinical practice (Silveira et al., 2012; Van Os, 2009).

Psychotic disorders are presently categorically defined and diagnosed based on the pattern, severity and duration of symptoms, with the aim of enabling predictions about course, prognosis and to inform treatments (Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-V), American Psychiatric Association, 2013; International Classification of Diseases-10 (ICD-10), World Health Organisation (WHO), 1992). The term psychosis can be described as a mental illness. This conceptualisation signifies both a deterioration in mental health and the possibility of recovery. There has been no single cause of psychosis identified in years of research, but rather a multitude of potential risk and protective factors, such as quality of family environment (Radua et al., 2018).

This illness is typically characterised by positive (i.e. hallucinations) and negative (i.e. flat emotion) symptoms, as well as thought/speech disorder (Howes & Murray, 2014). Symptoms of psychosis usually reveal themselves in late adolescence and early adulthood

(Eranti et al., 2013) and can be preceded by a prodromal phase which can include unusual experiences (Yung & McGorry, 1996).

The term “First episode of psychosis” (FEP) is used to describe individuals who have experienced frank psychotic symptoms, which may or may not have been preceded by an overt prodromal phase (McGorry et al., 2006). “Frank”, referring to experiences that can be clearly defined as psychotic symptoms mentioned above, with little or no uncertainty i.e., acute symptoms. The pattern and illness trajectory of individuals with FEP is variable with the majority of individuals likely to experience another episode within 3 years and one fifth likely to fully recover symptomatically (Jääskeläinen et al., 2012; Lang et al., 2012).

Psychotic disorders can be serious, disabling and considered one of the leading causes of total burden of disease worldwide (Salomon et al, 2012). Moreover, treatment costs an estimated 18 billion euros annually worldwide and ultimately consumes a significant proportion of healthcare budgets in European countries (Tajima-Pozo et al., 2015). Psychosis is currently ranked third globally with regards to societal costs related to mental illness (Collins et al., 2011). Additional costs come from families of individuals with psychosis in the form of private expenditure and loss of employment to meet care needs (Jin & Mosweu, 2017). Therefore, the overwhelming personal and economic impact of psychosis, stresses the need for research to prioritise the development of culturally appropriate prevention and intervention methods (Collins et al., 2011). To date, there has been an extensive amount of research exploring the relationship between EE and psychosis.

### ***Implications of High EE***

A rating above threshold in any of the three negative domains of EE (EOI, criticism and hostility) can result in a high EE rating. The relationship between high EE and relapse in schizophrenia has been well replicated since the development of EE and initial findings



(Kuipers, 1994). More recent studies have continued to demonstrate this association whilst focusing on particular nuances such as comorbidity (da Silva et al., 2021). This was also illustrated by a meta-analysis of 27 studies using CFI with a caregiver, to measure prediction of relapse over a 9-to-12-month period for people with FEP and those with medium-high illness chronicity (Butzlaff & Hooley, 1998). Results showed 24 of the studies affirmed the association between high EE and relapse, with individuals returning to a high EE environment twice as likely to relapse, compared to a low EE environment. On a domain level, criticism and EOI, which have been shown to predict relapse in psychosis (Alvarez-Jimenez et al., 2011), have demonstrated predictive utility for poorer treatment outcomes in different mental health conditions such as eating disorders and depression (Hooley, 2007).

### *Positive Domains of EE*

Despite research demonstrating high warmth as a critical feature of positive caregiving relationships (Kuipers et al., 2010), there has been significantly less consideration of the positive domains of EE compared to the negative, especially regarding their predictive utility (Bhugra & McKenzie, 2003; Michelson & Bhugra, 2012) and counteracting qualities in the presence of negative domains. This is despite Brown et al. (1972) indicating the protective function in the progression of illness.

Warmth has been suggested to serve as a mechanism that facilitates social bond and affiliation (Williams & Bartlett, 2015) and this has translated to research in the at-risk for developing psychosis population in which increased social functioning was linked to warmth (Schlosser et al., 2010). A more recent systematic review which explored the relationship between family warmth and positive remarks (Butler et al., 2018) found evidence for protective effects of warmth on psychosis relapse and a greater association between outcomes and EE warmth compared to EE positive remarks. Moreover, both warmth and positive

remarks predicted life satisfaction. This suggests clinical interventions should aim to foster warmth within families in the context of psychosis as well as reduce the negative aspects of EE.

The warmth domain of EE has also been considered from a cross-cultural perspective with variability in impact for different ethnic groups (Hoste et al., 2012). This was shown by high warmth buffering the negative effects of EOI related interactions among Mexican American populations (Breitborde et al., 2007; Singh et al., 2013). Cultural differences in the appraisal of EE domains have also been noted including the combination of criticism and warmth representing normative family relationships, as well as being an aspect of low EE (Subandi, 2011).

### ***EE and Patient Outcomes***

Whilst there have been questions on whether EE is causal in its relationship with patient outcomes, a large amount of research suggests EE does have an independent effect on patient outcomes. For example, studies assessing the impact of family interventions, which are partly designed to reduce high EE on relapse rates, suggest they may reduce likelihood of relapse compared to receiving medication alone (Lam, 1991). Confirmatory evidence in the form of randomised controlled trials (RCTs) demonstrates the efficacy of family interventions in reducing levels of EE, relapses and hospital readmission (Alvarez-Jimenez et al., 2011a; Bird et al., 2010; Lobban et al., 2013; Onwumere et al., 2011; Pharoah et al., 2010). Although this evidence is indicative of a causal role of high EE in triggering relapse in psychosis, this is not evidence that high EE is a risk factor for psychosis as there have not been any longitudinal studies looking at the predictive value of EE within the general population or even in the at risk mental state cohort.

As with emotional expression discussed earlier, the role of cultural differences in EE is prominent and this has been demonstrated by research. Before exploring this, it is important to acknowledge the cultural differences in the experience and epidemiology of psychosis itself.

### ***Cultural Differences in Psychosis***

There are a number of proposed definitions of culture that have changed over time (Lederach, 1995; Matsumoto & Juang, 2011). A common and accepted definition was proposed by the Center for Advanced Research on Language Acquisition (CARLA, 2013) as *“shared patterns of behaviours and interactions, cognitive constructs, and affective understanding that are learned through a process of socialisation. These shared patterns identify the members of a culture group while also distinguishing those of another group”*.

Cross-cultural differences in the experience of psychosis were identified from as early as the 1970s. In particular, the International Pilot Study of Schizophrenia (Sartorius et al., 1972) compared 9 countries that varied significantly in terms of their sociocultural characteristics. Results demonstrated that whilst people with schizophrenia had similar symptomology across countries which enabled comparisons, there were cultural differences in prognosis and outcome which suggested individuals from more developing countries (i.e. India) had better outcomes (Sartorius et al., 1977).

**Symptoms.** Cross-cultural differences in the experience of psychotic symptoms have been identified (Luhmann et al., 2015; Vega & Lewis-Fernandez, 2008), including higher frequency of hallucinations for non-European ethnicities in community and hospital settings in London (Johns et al., 2002; Ndeti & Vadher, 1984). Along with the experience of symptoms, one study has identified ethnic differences in the reporting of psychotic symptoms

with White British individuals less likely to report symptoms on a specific measure, compared to Pakistani and Caribbean individuals (Heuvelman et al., 2018).

**Epidemiology.** A robust body of evidence suggests there are variations in incidence rates across ethnic groups and countries and within regions (McGrath et al., 2008; McGrath et al., 2004). This includes a repeated finding of ethnic minorities having higher incidence rates of psychosis internationally as well as a relative risk ratio of 2.9 for developing schizophrenia among migrants, compared to native populations (Cantor-Graae & Selten, 2005; Fearon & Morgan, 2006; Kirkbride et al., 2012). In contrast, studies on native ethnic populations such as Caribbean people in Barbados have shown rates of psychosis that are not greater than the global average (Mahy et al., 1999; McGrath et al., 2004). This is suggestive of environmental factors, potentially having a strong influence on the development and clinical presentation of psychosis.

Whilst there are many cross-cultural differences in the experience of psychosis, that is not to say that culture alone explains such differences. Whilst it has been suggested that the proportion of the expression of psychosis that is culturally dependent is 15-30% (Stompe et al., 2006), there are many possible explanations for cultural and ethnic disparities, including migration, discrimination, access to healthcare, biological factors, low social support and syndemic effects (Coid et al., 2020; Gayer-Anderson & Morgan, 2013; Veling & Susser, 2011).

## **EE and Culture**

Early research has proposed the conceptualisation of EE as the way in which a family responds to an unwell relative and that transgressive behaviours are defined by culture (Jenkins & Karno, 1992). Jenkins (1991) also noted that the EE domain of criticism could be

culturally defined as negative responses to perceived cultural rule violations. This was supported by findings from methodologically similar studies demonstrating variations in high EE rates and prevalence of the domains of EE, among Mexican-American and Indian groups compared to North American and European groups (Jenkins et al., 1986; Karno et al., 1987; Leff et al., 1987; Vaughn & Leff, 1976b; Wig et al., 1987). Many years later, researchers attempted to explain how family and cultural factors (i.e., attitudes towards illness and role expectations) influence patient outcomes through EE (Bhugra & McKenzie, 2003).

### ***Variation in EE profiles between ethnic groups***

Multiple studies have identified variation in rates of EE profiles and domains across different ethnic groups. For example, one study found caregivers of people with schizophrenia and dementia from the UK reported greater levels of high EE compared to Japanese caregivers of people with the same conditions (Nomura et al., 2005). Moreover, results showed stark differences in the median number of critical comments across ethnic groups (UK= 6.5 and Japanese = 2).

Domain level differences across geographical regions have been highlighted by studies that showed Indian and Chinese samples having higher criticism and warmth compared to Danish and British samples (Ran et al., 2003; Wig et al., 1987). This may be because, unlike in Western cultures, in Chinese cultures, criticism is viewed as a symbol of concern (Ran et al., 2003).

A recent meta-analysis explored the distribution of EE and its domains across cultures, whilst also assessing the relationship between EE and psychotic relapse (O'Driscoll et al., 2019). Ninety-six studies using the CFI to measure EE were included in the study. Results showed that exposure to high familial EE increased the chance of a relapse by 95% compared to low EE and suggests this relationship is universal. However, there were no

significant differences in overall EE scores or domain level scores based on geographical regions. The authors note the categorisation of high and low EE may neglect normative family values and the complexity of culturally defining EE domains. In addition, multiple adjustments to scoring the CFI were made, based on cultural norms, especially for criticism, EOI and warmth. Thus, authors argue against a universal normative EE profile due to the presence of cultural variation in the scoring and interpretation of EE (O'Driscoll et al., 2019).

Whilst the cross-cultural adjustments in scoring in the CFI have been highlighted, the domains of EE (i.e. criticism, EOI and hostility) have been shown to strongly predict relapse in psychotic disorders cross-culturally and is inclusive of immigrant populations (Butzlaff & Hooley, 1998; Kopelowicz et al., 2002). However, cultural variations in the manifestation and degree of EE domains have been noted (Bhugra, 2003). Moreover, Akhtar et al. (2013) surmised that intrafamilial interactions differ cross-culturally and such differences may influence caregivers' emotional responses towards an unwell family member.

### ***Variation in EE Profiles Within-Ethnic Groups***

As mentioned above, a longstanding finding is the variation in rates of EE between ethnic groups and cultures. In addition, studies have also found differences in EE rates within the same ethnic groups. For example, an early study comparing high EE rates in families caring for someone with psychosis, found significantly lower rates of high EE in India compared to UK and Denmark (Wig et al., 1987). Moreover, when the Indian sample was separated into rural and urban inhabitants, high EE rates were considerably lower in rural families (8%) compared to urban (30%). Similar findings were highlighted by another study exploring EE in Chengdhu, China (Ran et al., 2003), which also noted that people living in the city displayed greater emotional expression than people living in rural areas. It is important to note that speculating on such studies should be done with caution as comparing

such methodologically differing studies can be difficult. Nevertheless, cultural variation in EE, whether between or within ethnic groups, has implications for the predictive utility of EE domains.

### ***Cultural Differences in the Predictive Validity of EE Domains***

With regards to exploring cross-cultural differences in predictive validity, research has primarily focused on the EE domain EOI. One study systematically reviewed 28 longitudinal studies to examine the predictive validity of EOI in relation to clinical outcomes across varying cultures (Singh et al., 2013). Results showed an inconsistent relationship between EOI and negative clinical outcomes across cultures, with over half of the studies using European samples and the majority of studies in Asia reporting no association between clinical outcomes and EOI.

When considering other EE domains, the combination of low warmth and high EOI has been noted to more strongly predict relapse than the domain of criticism among Mexican American groups (Aguilera et al., 2010). The role of high warmth remains unclear as authors have suggested it may act as a buffer against modest EOI levels (Breitborde et al., 2007). However, this does not align with studies in Europe showing an independent relationship between clinical outcomes and warmth (Bertrando et al., 1992; Ivanović et al., 1994).

Further cultural differences have been demonstrated by a study that showed more positive clinical outcomes associated with higher levels of critical comments and intrusive behaviours by caregivers in a group of black African American families (Rosenfarb et al., 2006). This differed from patterns identified for white American families. To explain this relationship, the authors propose that the experience of critical and intrusive behaviours by black African American service users may be positive and associated with being caring and supportive (Rosenfarb et al., 2006; Weisman et al., 2006) and therefore absence of EOI may

be interpreted as a lack of care (Akhtar et al., 2013). This explanation is linked to the claim that collectivist cultural contexts have a strong emphasis on family bonds (Singh et al., 2013), whereby caregiving is a tool for constructing family ties (Pyke & Bengtson, 1996). In contrast, in Western cultures, families minimise caregiving and personal independence is culturally emphasised (Pyke & Bengtson, 1996) and thus criticism may be more detrimental.

It is important to note that differences in EE profiles and predictive validity across countries, cultures and ethnicities may not entirely be a result of cultural differences but could also be a reflection of using a measurement instrument that inadequately captures EE in different cultural contexts (Lopez et al., 2009).

Another important consideration is acculturation, sometimes described as the process of cultural and psychological change that takes place due to contact between different cultures and its members (Berry, 2005). This is key among migrant populations in which assimilation, in the form of adopting aspects of a dominant new culture, can occur. Whilst the discussion of acculturation is beyond the scope of this chapter, it is important to note that whilst there is debate amongst terminology and measurement (Bhugra & Bhui, 2007; Ryder et al., 2000), acculturation may influence EE and thus require consideration when designing and applying interventions. Measurement of acculturation may inform treatment as second-generation migrant siblings from the same household could hold differing cultural orientations based on the degree to which they have assimilated.

Nevertheless, such stark differences in the appraisal of caregiving behaviours between individualistic and collectivist cultures suggests that the current conceptualisation of EE may not represent many collectivist cultures. This highlights the significance of understanding the unique cultural definitions and appraisals of EE domains in order to accurately assess their impact on clinical outcomes. Moreover, it may be that current interventions that target EE,



need to be examined and tailored to consider cultural variability and whether EE as it is currently conceptualised, needs to be targeted.

Whilst culturally distinguishing terms such as collectivist and individualistic have been used to highlight differences across cultures, it is important to consider the limitations of such concepts. Hofstede (1980) proposed cultural dimensions framework which now comprises six dimensions including power distance, indulgence, long-term orientation, uncertainty avoidance, masculinity and individualism. The latter, individualism, refers to the degree to which society emphasises and values the self-concept, different to collectivism, in which the emphasis is group wellbeing. Criticisms include the assumption of homogeneity within a particular country. However, labelling and generalising a given country as collectivist can be considered reductionist in that it ignores cultural differences and heterogeneity within countries. This has been particularly important with time as globalisation and rapid developing technology may have influenced the changing of cultures, thus challenging the assumption that culture remains stable over time. Another criticism is the lack of representative sample in the original conceptualisation, in which IBM staff were used, from which generalisations about countries were made (Shaiq et al., 2011). Therefore, whilst categorisation such as collectivist and individualistic cultures hold some utility, it is important to note that cultures are not necessarily so polarised and that variance may exist in each category.

In sum, there are cultural differences in EE across and within cultures. In addition, there are idiosyncrasies that exist across all families, including family subcultures, intergenerational effects and migratory trajectories. Thus, it is important to acknowledge that identifying clear cultural classification in terms of EE may be difficult, especially when distinguishing EE from other influencing factors. Whilst it may be possible to explore cultural differences within the individual domains of EE, this process also has its conceptual

and cultural limitations in the form of using a Western developed EE construct on non-Western populations. Rather, it may be more beneficial to explore what conceptual domains would be relevant for other cultures such as within the South Asian population.

### **Family Interventions**

Family interventions (FI) are used for a range of mental health difficulties, but for psychosis, they usually describe evidence-based talking therapy as strongly linked to the improvement of a range of patient clinical outcomes (Pharoah et al., 2010) and caregiver outcomes (Lobban et al., 2013). FI's are heterogenous in many ways (i.e. sessions in clinic or family home) but share a number of key aspects, including psychoeducation, emotional processing, problem-solving, communication and stress management (Addington and Burnett, 2004; Kuipers et al., 2002). These components aim to address different understanding of psychosis, the emotional effect on family relationships, coping behaviours and risk of relapse (Onwumere et al., 2011). Important aspects of FI's have been identified by qualitative studies which include psychoeducation, improving communication and problem-solving skills, developing a shared understanding of psychosis and having a safe place to discuss problems (Nilsen et al., 2016; Rapsey et al., 2015).

### ***Rationale for Family Interventions***

**Patients.** The clinical application of EE is primarily in the form of Family Intervention (FI) due to the longstanding finding that the way in which families respond to psychosis significantly influences the illness course (Butzlaff and Hooley, 1998; Cechnicki et al., 2013). With FEP typically occurring between late adolescence and early adulthood (Mueser and McGurk, 2004), support provided by family is especially important due to many individuals in this group still living at home during this period (Garety and Rigg, 2001;

Jansen et al., 2015). Family support has been linked to positive effects on patient outcomes, including improved mortality (Revier et al., 2015), significantly reduced relapse and re-hospitalisation rates, and increased treatment engagement (Norman et al., 2005; Stowkowy et al., 2012).

**Caregivers.** The adverse impact of psychosis on caregiver outcomes and the implications on patient outcomes has been covered in detail (Gupta et al., 2015; Kuipers et al., 2010; Poon et al., 2017). Higher levels of EE have been linked to negative effects on caregivers including higher burden of care and less adaptive coping strategies (Kuipers et al., 2006; Raune et al., 2004). High burden can include reports of financial hardship, fatigue, loss and trauma (Gupta et al., 2015; Kingston et al., 2016; Onwumere et al., 2018). Moreover, literature highlights that informal caregivers of individuals with psychosis (i.e. family members), report significantly greater incidences of mental health disorders and distress, compared to the general population (Gupta et al., 2015; Hayes et al., 2015).

The Cognitive Model of Caregiving (Kuipers et al., 2010) attempts to explain the development and maintenance of three proposed types of relationships between informal caregivers and patients with psychosis (positive, emotionally over-involved and critical/hostile). The model proposes that prior to psychosis, there is an initial relationship between caregiver and patient. Following psychosis, the caregiver's appraisals of the patient's behaviours and the psychosis itself, results in cognitive and affective changes in the caregiver. Such changes can influence caregiver behaviour exhibited towards patients, relationship with services and caregiver outcomes. This empirically based model is based on the integration of psychosis research, drawing on topics of EE, attributions and illness perceptions (Kuipers et al., 2010). This model provides potential targets for treatment, whether that be via caregiver or family interventions, such as appraisal of behaviours/illness

or behaviours such as avoidant coping. Moreover, the model places emphasis on caregiver perceptions of the patient and not just the expression of emotions. However, the role of culture is absent in this model and thus there is no consideration towards how culture may influence core processes in the model, such as appraisal of behaviours.

The sizeable body of evidence highlighting the adverse impact of psychosis on both patient and caregiver outcomes, along with FI's being shown to be cost-effective (Mihalopoulos et al., 2004) has contributed to them being placed within treatment guidelines across the globe. This includes America (Kreyenbuhl et al., 2010), Canada (Norman et al., 2017), Australia (Galletly et al., 2016) and Europe (National Institute for Health Care Excellence, 2014). The latter, linked to the UK, recommends family-based interventions for individuals with psychosis who are in regular contact with their families.

### ***Evidence-Base for FI***

Whilst many reviews have reported mixed results on the efficacy of FI in early psychosis (Askey et al., 2007; Penn et al., 2005; Sadath et al., 2015), an earlier systematic review of just 3 randomised controlled trials within Early Intervention for Psychosis Services (EIS) found more positive results (Bird et al., 2010). This study showed reduced likelihood of relapse and hospital admission for patients whose families engaged with FI compared to those who received standard care. A more recent systematic review and meta-analysis aimed to address the ambiguity regarding the efficacy of FIs identified in previous studies (Claxton et al., 2017). Results showed FI for psychosis improved patient functioning and reduced relapse rate by the end of treatment. Whilst psychosis symptoms did not improve by the end of treatment, they had significantly decreased by follow-up for those in the FI group. In terms of EE, caregivers receiving FI were more likely to move from high EE to low EE whilst also engaging in less conflict communication and reporting less criticism towards patients.

Moreover, those receiving FI displayed improved caregiver burden and well-being by the end of treatment. However, this was not sustained until follow-up and FI had no effect on caregiver emotional over-involvement.

### ***Culture and FI***

The involvement of family in the care of people with psychosis is generally present across most contexts (Del Vecchio et al., 2015) and in some countries, family involvement can be particularly high. For example, in some Asian countries such as India, it is usual for families to be involved in care with approximately 90% of patients with psychosis living with their families (Chakrabarti, 2011). It has therefore been proposed that FIs need to be adapted to suit different cultural contexts so that explanatory models of illness, cultural beliefs and socio-economic factors can be included in the design of these interventions (Degnan et al., 2018).

Whilst NICE guidelines recommend ten sessions of FI (FI; NICE, 2014) with the aim of developing the patient's and family's relationships and resilience by increasing understanding of psychosis, it also recommends considering culture and ethnicity in such interventions (NICE, 2014). It is unclear whether evidence informing NICE guideline recommendations (Pharoah et al. 2010; Wykes et al. 2008) generalises across different ethnicities and cultures, given the under-representation of minority groups in clinical trials of most interventions (Brown et al., 2014; Waheed et al., 2015).

Most psychosocial interventions, including FI are developed in Europe or USA and thus underpinned by Western culture, which could explain why such interventions are linked to poorer outcomes for minority groups compared to Caucasians (Bhugra et al., 1997; Chakrabarti, 2011). Moreover, despite being a recommended treatment for psychosis, FI engagement numbers are low across all groups but particularly low for the African-Caribbean

population (Berry & Haddock, 2008) which may be due to a culture and ethos conflict between services and service users. This could also be linked to interventions being primarily developed in Western countries (Bernal & Saez-Santiago, 2006).

A range of benefits linked to interventions that have been successfully culturally adapted include an increase in engagement and likelihood to accept psychiatric support (Husain et al., 2017). Moreover, culturally adapted interventions can enhance the efficacy of psychosis treatment with the degree of adaptation correlating with the degree of efficacy (Degnan et al., 2018). Efficacy has also shown to double for specific cultural groups when interventions are delivered in native languages compared to those that are not adapted in this way (Griner & Smith, 2006). Furthermore, cultural adaptations to interventions are critical in enabling the delivery and evidencing of psychosocial interventions in low and middle income countries (Feigin, 2016). Whilst there is a lack of evidence for culturally tailored interventions due to minimal research on ethnic minorities, the evidence base for culturally adapted family intervention for psychosis is growing.

### ***Evidence-Base for Culturally Adapted Interventions***

In an important systematic review and meta-analysis of 46 culturally adapted psychosocial interventions for psychosis (Degnan et al., 2018), results showed culturally adapted interventions were linked to greater improvement in symptom severity. Moreover, when considering a range of mental health problems beyond psychosis, a review of meta-analyses showed that culturally adapted interventions produce moderate to large effect sizes (Rathod et al., 2018). It is important to note that many systematic reviews have found comparable effect sizes for primary outcomes between culturally adapted and non-adapted interventions in Western populations (Chowdhary et al., 2014; Huey & Polo, 2008; Smith et al., 2011; Wykes et al., 2008). However, most reviews include mixed samples in terms of

diagnosis and ethnicity and thus it is difficult to isolate the influence of the cultural adaptation on outcomes.

With regards to FI, a recent study by Husain et al. (2020) assessed the feasibility and acceptability of a culturally adapted family intervention for schizophrenia in Pakistan. There were several rigorous cultural adaptations including adaptations of concepts, language and cultural-specific norms in case vignettes. The authors highlighted a number of factors that influenced low levels of access to psychiatric care i.e. limited trained staff and resources and differing explanatory models of illness. Yet, results were positive, demonstrating 90% participant attendance and retention, with over 85% of participants rating the quality of the intervention as good to excellent.

Another recent study examined the acceptability of a culturally adapted family intervention for African-Caribbean individuals with psychosis and their families (Jensen et al., 2021). This was based on the pilot and feasibility study by Edge et al. (2018) and showed both service users and caregivers found the intervention acceptable. This study (Jensen et al., 2021) shows from an experiential standpoint, that service users reported personal benefits (i.e. increased confidence), developing a greater knowledge and understanding of their diagnosis, better communication with family and professionals as well as other factors. Family members also noted improved communication with service users and improved coping strategies. Moreover, both caregivers and family members commented positively on the cultural appropriateness of the interventions. Whilst it is clear that research shows culturally adapting interventions, specifically FI as being beneficial, what remains to be determined is what types of adaptations are most efficacious (Degnan et al., 2018).

These findings highlight the importance of considering culture and applying culturally informed adaptations when designing interventions due to the positive impact they can have on outcomes. Current cultural adaptations are not EE specific but given that one of FI's

targets is EE, it could be suggested that a better understanding of EE from a cultural lens may help to further tailor FI's for families from different cultural backgrounds. For example, if what determines a caregiver as high EE is something that is perceived as a positive care characteristic in a given culture (i.e. criticism), FI could be tailored away from reducing EE and instead, towards something that fosters this interaction.

Therefore, exploring EE on a domain level may provide a better understanding of the construct and provide the opportunity to examine how caregiving processes may be perceived differently by different cultural groups. Any identified culture-specific variations in how emotions are expressed will update the current theoretical framework of EE and will inform how clinicians adapt their interventions to suit the needs of cultural groups. Moreover, improved understanding of EE through a cultural lens may inform the current cognitive model of caregiving (Kuipers et al., 2010) by moving from an ethnocentric view of relationship types and appraisals of behaviours, to one that is more person-centred.



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## **Chapter Two: Empirical Paper**

Understanding caregiving processes in South Asian families:  
Relationship between caregiver EE and clinical outcomes in first episode psychosis

## Abstract

**Background:** Expressed Emotion (EE) measures the quality of significant relationships in the family environment. High EE is considered to precipitate relapse in people with psychosis and thus is a target for intervention. However, research has questioned the cross-cultural validity of EE. Understanding EE within the South Asian population may lead to developments in interventions that better suit this population.

**Aims:** The current study aims to explore EE characteristics of South Asian families in the presence of a first episode of psychosis (FEP) and whether there is a relationship between caregiver EE and clinical outcomes.

**Methods:** Caregivers and individuals with FEP known to several Early Intervention in Psychosis Services were recruited. Clinical outcomes were collected for service users and caregiver EE was assessed using various measures of EE. The general profile of EE was examined using descriptive statistics. The relationship between caregiver EE and service user clinical outcomes was examined using correlation analyses and Mann-Whitney U tests.

**Results:** The EE profile of the sample was dependent on which measure of EE was used. The Level of Expressed Emotion showed a 50% split in terms of high and low EE, whereas the Family Questionnaire categorised 68% of the sample as low-EE and 32% as high-EE. There were no significant relationships found between caregiver EE on a domain level or broader (high/low) level and clinical outcomes.

**Conclusion:** This study adds to the existing argument that the current conceptualisation of EE may not be universally associated with poor outcomes for psychosis. The clinical and research implications for this are discussed, with consideration of the limitations of this study.

## Introduction

Psychosis can be considered an umbrella term for disorders such as bipolar disorder and schizophrenia. Typically, it is characterised by the presence of positive symptoms, referring to distortions of reality (i.e., delusions and hallucinations) and negative symptoms (i.e. blunted affect and poverty of speech) (Tibber et al., 2018). Psychotic disorders can be serious, disabling and considered one of the leading causes of total burden of disease worldwide (Charlson et al, 2018). Moreover, the economic impact of psychosis is significant worldwide, with treatment using a significant proportion of healthcare budgets (Jin & Mosweu, 2017; Tajima-Pozo et al., 2015). Research has demonstrated a link between Expressed Emotion (EE) and relapse in psychosis (Alvarez-Jimenez et al., 2011; Brown et al., 1972; Butzlaff & Hooley, 1998).

EE is the measurement used to assess the overall quality of the family environment, with a focus on the social interaction in a caregiving relationship. EE was originally designed to assess the domains of emotional over-involvement (EOI), criticism, hostility, warmth and positive comments (Kuipers, 1979). The relationship between high EE, often referring to the domains EOI, criticism and hostility, and increased likelihood of psychotic relapse has had implications for treatment with EE being a focus for some interventions.

The National Institute for Health and Care Excellence (NICE) guidelines for schizophrenia have consistently recommended Family Intervention (FI) as a first-line recommended intervention across all stages of the trajectory and care pathway (NICE, 2002; NICE, 2009; NICE, 2014). This recommendation is a result of some research showing potential positive effects of FI in terms of reducing relapse rates and hospital admissions, increasing medication compliance and improving general functioning (Bighelli et al., 2021; McFarlane et al., 2003; Pharoah et al., 2010).

FI is designed to target and reduce levels of EE within families and promote positive environments. FI is widely used in varying psychosis services across the UK, including those catering for the needs of multicultural populations (Bucci et al., 2016). The consideration of cultural differences is a salient point of discussion, given that the original conceptualisation of EE took place within the UK and thus individualistic Western culture may influence how EE is understood and interpreted. However, culture may impact the manifestation of EE, for example, what is considered ‘emotional over involvement’ from a Western perspective may not be perceived as negative or related to unfavourable outcomes in some cultures (Hashemi & Cochrane, 1999). With NICE (2014) guidelines recommending FIs for *all* families, care is needed to ensure interventions are relevant to *all* families. Moreover, NICE (2014) guidelines emphasise the importance of interventions being delivered in a culturally appropriate way.

## **Warmth**

Whilst warmth was included in the original conceptualisation of EE, as an expression of positive affect, it was largely dropped from consideration in research due to the complex nature of its relationship with other domains of EE and relapse in psychosis. Rather, for many years research focused on the domains of EOI, criticism and hostility as predictors of relapse. However, early research indicated a protective function when caregivers showed considerable warmth (Leff & Vaughn, 1985).

Multiple international studies have demonstrated the protective impact of family warmth on psychosis outcomes. For example, high warmth and moderate EOI have been shown to be predictors of good outcomes in psychosis among Mexican American families (Lopez et al., 2009). Moreover, in families from Barcelona, reduced patient symptoms correlated with high warmth (Medina-Pradas et al., 2013) and high parental warmth was

protective against psychiatric disorders in children in Puerto Rico (Santesteban-Echarri et al., 2017).

Cultural research has played a significant role in bringing focus back onto the importance of warmth as a predictor of good outcomes. However, measurement of warmth still lacks consideration of cultural variation in the expression of warmth (Lim, 2016) and display of affection (Ruby et al., 2012). Thus, a cross-cultural understanding of the interplay of warmth with other domains of EE in predicting relapse is important, as the expression may vary.

### **Cross-Cultural Validity of EE**

The cross-cultural validity of the concept of EE and its measurement (Cheng 2002; Jenkins & Karno, 1992; Kavanagh, 1992) has been an area of exploration for many years in research. This is supported by the lack of consistency in findings from studies exploring the relationship between EE and psychosis outcomes in different cultures, which questions the validity of using current FIs across cultures. It has been argued that theories and instruments need to be grounded within the culture they are applied in, to be considered culturally valid, which requires them to reflect local values and priorities and thus interpret outcomes within each culture's norms (Jadhav, 2009). This is particularly relevant to EE and the domains that it measures (i.e. emotional over-involvement). For example, emotive idioms from an Indian context such as "I slapped him with love" (Hindi: *Pyaar se chaata mara*) do not fit the neat domains of EE and are also likely to be missed when assessing for EE using current measures (Jadhav, 2009).

Findings from Western countries such as the UK, USA and Australia, demonstrate a link between high-EE and high relapse rates in psychosis when compared to household where low-EE was present (Bhugra & Mckenzie, 2003). However, both prevalence of high-EE and

its relationship to patient outcomes are inconsistent among non-Western countries such as India, Egypt, China and Japan (Bhugra & Mckenzie, 2003). Studies have also shown that cultural differences in EE are present across culturally varying groups living within the same country (Hashemi & Cochrane, 1999; Lopez et al., 2009).

Further discrepancies emerge between cultures when looking at EE domains (Heru. 2020). Research in many Asian countries have found criticism and hostility to be strong predictors of relapse in psychosis (Leff et al., 1987; Mino et al., 1997), suggesting these are stable domains universally. Yet, for many studies within Western countries, EOI has been the greatest predictor of relapse (Brown et al., 1972; Karno et al., 1987; Vaughn & Leff, 1976b), which has not been the case in many Asian studies (Leff et al., 1987; Mino et al., 1997; Sadiq et al., 2017).

Inconsistency in EE patterns have also been demonstrated when looking at African populations. Results from an early study suggested that high-EE may be associated with a better symptom course (Rosenfarb, et al., 2006). This was confirmed and replicated in a study that looked at caregiver EE and psychosis patient symptoms, in the African American population (Gurak & de Mamani, 2017). This pattern is typically opposite to what has been found in Western culture. The same study explored the reasons for this which included the importance of family interdependence and collectivism.

Therefore, the relationship between EOI and poor psychosis outcomes appears inconsistent across cultures (Singh et al., 2013). It has been proposed that this difference is due to variation in the appraisal of the EE domains. For example, in Western cultures, EOI is perceived as crossing boundaries, pathological and invasive, whereas in Asian countries where collectivist culture dominates, EOI is perceived as the norm (Bhugra & McKenzie, 2003).



## **South Asian**

It is recognised that studies assessing the efficacy of FI for First Episode Psychosis (FEP) currently lack representation of Black and Asian Minority Ethnic (BAME) groups, which has resulted in calls for more research focusing these underrepresented FEP groups (Claxton et al., 2017). There have been very few studies exploring EE in South Asian groups living in a western context.

EE and its relationship to patient outcomes has been explored in some South Asian countries such as Pakistan. One study (Sadiq et al., 2017), found greater relapse rates (72%) within high-EE households, compared to low-EE households (36%), thus, supporting the validity of EE predicting relapse within a Pakistani sample. Examining EE in terms of high/low in this way may reveal similar trends to that found in Western countries. However, examining EE on a deeper domain level often reveals cross-cultural variation. Furthermore, much of the research in this field indicates that the current conceptualisation of EE is not culturally sensitive. This is exemplified by the questions regarding the cultural validity of EE measurement (Cheng, 2002), which have led to the development of culture specific EOI and criticism scales in Pakistan (Akhtar et al., 2013).

In families where psychosis is present, there have been differences in high-EE rates across South Asian countries with one study in Pakistan finding 75% rate of high-EE (Ikram et al., 2011) whereas the earlier Chandigarh study in India (Wig et al., 1987), found much fewer households with high-EE (23%), despite sharing seemingly similar cultural settings. A similarly low proportion of high-EE families was found in another region of India, Assam (Gogoi, 2016). This inconsistency may suggest that nuances between cultures may be responsible for the variation in EE rates.

With regards to South Asian groups living in a western context, one study explored the relevance of EE for British South Asian families of patients with schizophrenia (Hashemi

& Cochrane, 1999). This study found much higher levels of EE in British Pakistani families compared to British Sikh and White families. Moreover, neither South Asian sample demonstrated a link between EE and relapse rates for schizophrenia. This study further demonstrates the cultural variability of EE and its relationship to psychosis outcomes, even when comparing seemingly similar cultural groups and suggests each culture differs in its response to relatives with a mental illness.

Evidence suggests there is no simple unidirectional relationship between EE and clinical outcomes in psychosis, which indicates EE profiles across cultures differ normatively. Furthermore, domain level cultural variability highlights the complexity of EE as a psychosocial risk factor. Researchers examining EE cross-culturally have emphasised the notion that domains such as EOI may not be intrinsically pathological but rather culture-specific and therefore may not be detrimental in all cultures (Singh et al., 2013). This has implications for treatment such as FI which typically aims to reduce EE. However, doing so, may inadvertently increase family stress by reducing aspects of family functioning that may in fact be protective within certain cultures. Thus, FI's in which EE reduction is a focus should consider a culturally sensitive approach when treating families from different ethno-cultural backgrounds.

### **Current Study**

Gaps in our understanding of the mechanisms underlying caregiver EE during the early stages of psychosis remain (Hinojosa-Marque's et al., 2020). Therefore, this study aims to respond to the need to further develop our understanding of EE from a cross-cultural perspective and to better understand the complexity of the EE-relapse relationship in under-researched BAME groups likely to utilise early intervention services in the UK. Variation in EE within British South Asian groups (Hashemi & Cochrane, 1999), suggest this population

is of interest, however, to the best of our knowledge, there have been no subsequent studies exploring EE within South Asian families living in the West. Moreover, to date, studies have not explored the relationship between EE and First Episode Psychosis (FEP) within South Asian families.

Assessing cross cultural variability in EE will lead to an increased understanding about the relationship between the experience of caregiving and clinical outcomes in South Asians in the UK which may inform clinical interventions. Authors of a recent study exploring the stigma experiences of British South Asian people using Early Intervention in Psychosis Services (EIS) emphasise the importance of considering people's cultural context when engaging people from this population (Vyas et al., 2021). Thus, this study has important implications for understanding the need for cultural competence training for FI therapists and to raise awareness of culturally appropriate care.

## **Research Aims**

The overall objective of the current study is to further understand the relationship between caregiving processes (i.e. EE) and clinical outcomes (e.g. indicators of relapse) in South Asian families where a family member has experienced a FEP.

In line with this objective, the current study aims to address the following questions:

- (a) What are the EE characteristics (i.e. overall EE rating and domain-level characteristics) of South Asian families where a member has FEP?
- (b) Is there a relationship between caregiver EE and service user clinical outcomes?
  - Hypothesis: Higher scores on caregiver EE domains will be associated with worse psychosis related clinical outcomes.

## **Method**

### **Joint Project**

This study was a joint project with a fellow trainee clinical psychologist. Their project was a mixed-methods study examining perceived expressed emotion and clinical outcomes of first episode psychosis in South Asian communities (Ramanathan, 2022). Please see Appendix 5 for a detailed summary of roles and researcher involvement.

### **Ethics**

This study is a sub study, part of a wider research project “Understanding caregiving processes in South Asian families”. The ethical approval for the wider research project was granted by NHS Health Yorkshire & The Humber, South Yorkshire Research Ethics Committee (Ref: 18/YH/0296). Substantial amendments (Ref: 17/0916) made in response to the COVID-19 pandemic were also ethically approved by the same Research Ethics Committee. Permission was obtained from the following NHS Trusts Research and Development Offices to enable the recruitment of participants via clinical teams: North East London Foundation Trust (NELFT) and West London NHS Trust.

### **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. Two service users of South Asian background from an EIS and the carer forum within NELFT reviewed a summary of the study proposal. Both parties gave positive feedback and approved the idea of research focusing on this population.

PPI also involved the ‘reader’ panel of the NELFT Patient Experience Services and a service user led mental health organisation in London. After the ideas about the study were

shared in these forums, feedback, including suggestions and constructive criticism were incorporated into subsequent revisions.

Utilisation of the University College London Service User and Carer Reference Group enabled the piloting of questionnaires with three service users. Constructive feedback raised awareness regarding the measures being overlong which was consistent feedback from all participants. Furthermore, written instructions were experienced as having too small font size and being extensive in words. Therefore, this feedback was used to make instructions more accessible and reduce the length of the procedure.

## **Design**

This study used a cross-sectional design, with participants completing several questionnaires. The current study employed primary and secondary data-analysis to explore the research aims mentioned above.

## **Participants**

### ***Inclusion/Exclusion Criteria***

The following inclusion and exclusion criteria (Table 1) for service users and caregivers were used to guide the selection of potential participants. Alongside those who declined, attrition in recruitment conversion rates may be partly explained by this screening process.

**Table 1****Inclusion and Exclusion Criteria**

	Caregiver	Service User
<b>Inclusion Criteria</b>		
Under the care of the EIS with a diagnosis of FEP	✗	✓
Over the age of 18	✓	✓
Self-identifying as of South Asian heritage	✓	✓
Self-identify as a caregiver	✓	✗
<b>Exclusion Criteria</b>		
Severe learning disability, those who are deemed to lack capacity and therefore unable to provide informed consent	✗	✓
Psychotic symptoms due to an organic disorder	✗	✓
Speak little or no English	✓	✓
A primary diagnosis of substance abuse, suffering from any known organic disorder or with a moderate-to-severe learning disability	✓	✗

Note: South Asian heritage refers to identifying as belonging to at least one of the following countries: Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan, Sri Lanka.

***Sample Size Determination***

A power analysis for the clinical study was informed by studies (Hamaie et al., 2016; Domínguez-Martínez et al., 2014) which have investigated the relationship between caregiving EE and FEP outcomes and reported small to medium effect sizes. ‘G\*Power 3’ software (Faul et al., 2007) was used for the calculation, specifying alpha = 5% and desired power = 80% and using an averaged effect size of 0.3. The estimated sample size was 84 or 42 dyads of caregivers and service users.

## **Consent and Data Security**

Participants were explained the purpose of the study verbally and in written form at least 24 hours prior to participation. Their right to withdraw and voluntary basis of the study was communicated. All participants received a copy of the information sheet (Appendix 1) and consent form (Appendix 2) prior to taking part in the study. Consent was taken with an investigator present who was available to answer further questions. Consent forms were signed and returned via email. Except where this was not possible, verbal consent was accepted.

All participants were assigned a research number for identification and personal contact information were kept separate from all data collected from the study. Any electronic files containing sensitive and identifiable information were secured with password protection and stored on a private and secure cloud drive.

## **Recruitment**

Clinical teams received a presentation about the study and posters (Appendix 3) to distribute to potential participants. After researchers presented and introduced the study to EIS within NELFT and West London NHS Trust, participants were recruited, on a paid volunteer basis, into the current study. This occurred during the period of April 2021 – February 2022 via several EIS across the two NHS trusts. This study was focused on South Asian populations and therefore people accessing support from the EIS who self-identify as South Asian (ethnicity from the following countries: Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan, Sri Lanka) were initially approached. Care co-ordinators and assistant psychologists identified potential participants to receive information about the study at entry into the service or through a search of the current service caseload. The research team consulted with Care coordinators prior to contact with service users or caregivers, to assess

suitability for study participation. After gaining consent, contact details of potential participants were securely given to researchers so that they could be invited to the study.

Participants formed two groups including service users (individuals experiencing an FEP and accessing an EIS) and caregivers (people who care for the service user in an unpaid capacity). This study aimed to collect data from pairs of service users and caregivers, referred to as dyads. It was essential for caregivers to take part in order to gather EE data and desirable for service users to take part. In the case where only a caregiver participated in the study, clinical outcome data collected routinely by EIS was used, if the service users had consented for this to be used for research purposes on the electronic patient record system. Due to an insufficient number of pairs of service users and caregivers (8) participating in the study, primary data was only collected and used for caregivers. Instead, for the corresponding service users, secondary data in the form of the routinely collected clinical outcomes by EIS, outlined below, were used in the analysis, independent of whether the service user took part in the study. In this way, pairing of service users and respective caregivers remained.

### ***Recruitment Figures***

A total of 281 service users and caregivers were referred for recruitment into the study by the six EIS teams (Table 2). Whilst there was a similar number of referrals made for service users (n=145) and caregivers (n=136), there were greater discrepancies between the number of referrals offered by individual EIS teams. This is in part due to staff turnover in which Assistant Psychologists responsible for recruitment left their EIS, which ultimately paused and delayed recruitment for multiple months. In addition, some EIS engaged with recruitment later in the study timeline. There was also a large discrepancy between the number of people who did not participate for various reasons (n=241) and those that did



(n=40), with a participation rate of approximately one in seven referrals. Overall, there was a similar number of service users (n=18) and caregivers (n=22) who participated in the study.

**Table 2**

Recruitment Figures

EIS	No response/declined/excluded		Participants		Total referred	
	Service user	Carer	Service user	Carer	Service User	Carer
EIS 1	2	1	1	0	3	1
EIS 2	68	59	7	10	75	69
EIS 3	13	20	4	6	17	26
EIS 4	30	21	6	5	36	26
EIS 5	5	5	0	0	5	5
EIS 6	9	8	0	1	9	9
Totals	127	114	18	22	145	136

## Procedure

Participants that consented to take part in the study, completed a series of self-report measures during a research interview that took an average of one hour to complete. This involved student researchers meeting with participants at a mutually convenient time with the aim of taking consent, reading the questions to participants and recording answers. Although self-report measure may have been completed independently, this “interview” format provided participants with an opportunity to ask questions and check understanding. Some of the measures differed depending on whether the participant was a service user or caregiver (see Table 3). As a result of COVID-19 related precautions and convenience, interviews were conducted over the telephone or online via Microsoft Teams. Interviews were recorded where consent was given to do so. Participants were reimbursed ten pounds sterling for their involvement.

## **Measures**

All measures were translated into digital versions using Microsoft Excel, which formed the database in which data was stored securely. Paper versions of measures were not used due to COVID-19 related precautions. Datasets were linked to anonymised participant numbers. There were several measures used to collect data from participants for the purpose of the wider research study. However, listed below are those measures relevant to this thesis (see Table 3).

### ***Demographic Information***

A standard form was used to collect information on participants' socio-demographic data. This included country of birth, ethnicity, age, gender, religion, relationship status, level of education, employment status, and relationship to caregiver/service user and whether the participant lives with caregiver/service user.

### ***Expressed Emotion***

**Family Questionnaire (FQ; Wiedemann et al., 2002).** The FQ uses 20 items equally distributed into two subscales (emotional over involvement (EOI) and criticism) to measure expressed emotion in caregivers. These are rated on a 4-point Likert scale ranging from 'never/very rarely' to 'very often' and totalled to form an emotional over-involvement and criticism score. Higher scores suggest higher expressed emotion.

Internal consistency was assessed via Cronbach's alpha and was acceptable for both criticism (0.92) and EOI (0.80) (Wiedemann et al, 2002). The FQ has good construct validity as it showed 74% agreement with the Camberwell Family Interview's (CFI; Vaughn & Leff, 1976a) classification of 155 relatives' EE. The test-retest reliability, which was conducted

over a two week interval, showed Pearson's correlation coefficients for criticism ( $r=0.84$ ,  $P<0.001$ ,  $N=35$ ) and EOI ( $r=0.91$ ,  $P<0.001$ ) (Wiedemann et al, 2002).

The original development of the FQ did not consider cultural validity and no validation has been conducted on the British South Asian population to date. However, there has been cultural adaptation made to the FQ for a Brazilian sample of relatives of people with schizophrenia (Zanetti et al., 2013). This Brazilian Portuguese version of the measure was shown to be comparable to the original version in terms of patterns of dimensionality. The measure demonstrated good reliability in the form of internal consistency (Cronbach's alpha; 0.863 (criticism) and 0.656 (EOI)) and test-retest over a two-to-four-week period (Pearson's correlation;  $r = 0.689$ ,  $p < 0.001$  (criticism) and  $r = 0.769$ ,  $p < 0.001$  (EOI)). The Sense of Coherence Scale (SOC; Antonovsky 1987) was used to test convergent validity which found negative and moderate correlations with criticism ( $r = -0.46$ ,  $p < 0.001$ ) and EOI ( $r = -0.35$ ,  $p < 0.001$ ) domains of FQ. This demonstrates that whilst this measure has not been validated on the British South Asian population, it may be possible for such adaptations to be made.

**Level of Expressed Emotion Scale (LEE; Cole & Kazarian, 1988).** The LEE is a 60-item measure used to evaluate the perception of expressed emotion of a person's most important relationship. Items are rated as either true or false. There are four subscales including attitude toward illness, emotional response, intrusiveness, and low tolerance/high expectations. The LEE generates an overall score and individual subscale scores. Two versions of the LEE were used, a service user version (asking service users to evaluate their significant caregiver) and a caregiver version (asking caregivers to evaluate the service user).

The LEE was shown to have good psychometric properties including internal consistency which determined using the Kuder-Richardson Formula 20 (KR-20). The KR-20 reliability coefficients were .985 for both subsamples and ranged from .932 to .962 for the

four subscales (Cole & Kazarian, 1988). Moreover, the test-retest correlation coefficients were  $r = .82$ ,  $p < .01$  for the overall scale,  $r = .76$ ,  $p < .01$  for intrusiveness,  $r = .67$ ,  $p < .05$  for emotional response;  $r = .74$ ,  $p < .01$  for attitude toward illness and  $r = .81$ ,  $p < .01$  for low tolerance/high expectations. With regards to construct validity, when compared with the Influential Relationships Questionnaire (IRQ), the overall LEE scale correlated ( $r(45) = .86$ ,  $p < 0.0001$ ). Correlation between IRQ subscales and LEE subscales ranged from .39 to .86 (Cole & Kazarian, 1988).

Similar to the FQ, cross-cultural validity was not considered during the time of development of this scale. Moreover, this measure has not been adapted and validated for the British South Asian population. This is important to consider as these measures are used in the present study on the British South Asian population and thus may not capture EE accurately whilst considering cultural norm. This emphasises the need for measures that are adapted and validated for this population (Akhter et al., 2013).

**Warmth.** The warmth measure is a new five-item measure introduced for this study, which aims to measure how warm a significant other is to the person completing the measure, in the context of EE. This 5-item measure is rated on a 4-point Likert scale, mirroring the options from the FQ (never/very rarely to very often), with the highest score being 20. Higher scores are assumed to represent greater levels of warmth in the relationship. This measure was designed and developed by the research team involved in this study. Literature searches on the subject area of warmth in relation to EE were followed by discussions by the research team which helped decide what items and format to select. This measure was developed using existing measures that consider the warmth domain of EE including the CFI (Vaughn & Leff, 1976a) and the Family Attitudes Scale (FAS; Kavanagh et al., 1997).

Items were initially thought of and decided by the research team, based on how the literature and measures above had described warmth. This measure was piloted and trialled with a small number of members of the general public that self-identify as South Asian. Participants were asked what they thought the measure was assessing. Forty percent answered “warmth”, with other answers including “love”, “closeness” and “compassion”.

Warmth in this measure, sits within the conceptualisation of EE, that is, in a relational context with someone in a significant relationship. However, warmth has never been considered in isolation, nor has there been any development of a specific measure of warmth. Moreover, the current conceptualisation of warmth may be limited to a Western cultural understanding, thus excluding how other cultures define expression of warmth. In terms of psychometric properties, testing the internal consistency through test-retest method would potentially demonstrate the measure’s reliability. The accuracy of the measure and the construct validity could be assessed using confirmatory factor analysis, whilst it could also be compared to other items of warmth on the FAS, to establish convergent validity.

### ***Service User Clinical Outcomes***

Due to only eight dyads of service users and caregivers completing interviews as part of the study, service user clinical outcome data was limited. For those service users that did take part in the study, psychotic symptoms were assessed using the Psychotic Symptom Rating Scales (PSYRATS; Haddock et al., 1999) and the Self-Evaluation of Negative Symptoms (SNS; Dollfus et al, 2016), whilst anxiety and depression levels were captured using Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). These measures were excluded from analyses due to insufficient data, with the study instead focusing on data relating to indicators of relapse, collected from EIS.

**Indicators of relapse.** Clinical factors indicative of relapse were captured. However, there is a lack of consensus regarding the operationalisation and definition of relapse.

Different factors that can be used to define and indicate relapse, include measures to assess psychiatric symptoms (i.e. PSYRATS), hospitalisation, change in treatment, physician assessment and the occurrence of risk related behaviour (Olivares et al., 2013).

For this study, relapse was defined by clinical outcomes relating to hospital admissions and involvement of acute services. After consenting service users participated in the study, the clinical teams from the relevant EIS provided information on the number of hospital admissions, total bed days, involvement of acute services and sections under the Mental Health Act (MHA; Mental Health Act, 2007), from the point of referral to the EIS, to the date they participated in the research study. This data was also collected for service users that did not take part in the study, but their caregivers did, using their caregiver’s research interview date as the end point.

**Table 3**

Distribution of Study Measures

Measurement Method	Caregiver	Service User
Demographic information	✓	✓
Family Questionnaire	✓	✗
Level of Expressed Emotion	✓	✓
Warmth	✓	✓
Psychotic Symptom Rating Scales	✗	✓
Self-Evaluation of Negative Symptoms	✗	✓
Hospital Anxiety and Depression Scale	✓	✓
Indicators of Relapse	✗	✓

## **Data Analyses**

### ***Software***

The data collected during interviews were initially scored and converted into a quantitative and meaningful format for analysis using Microsoft Excel (Microsoft Corporation, 2018). The data were then imported into SPSS version 28 (IBM Corp, 2021) and analysed.

### ***Data Screening***

Prior to any analyses being conducted, normality was checked for all the potential variables suitable for analysis. Normality was assessed using SPSS by calculating kurtosis and skewness, visually inspecting histograms, and Q-Q plots, and identifying any extreme outliers. These calculations and visual inspections showed variables to have non-normal distribution, with most showing positive skew, which was considered when selecting statistical tests for analysis. The small sample size may have contributed to the non-normal distribution. There were no missing data across all variables to address.

### ***Variable Transformation***

Data from FQ and LEE domains were used as continuous variables and converted into binary variables to represent “low” and “high” EE. Cut-offs outlined in the literature were used to mark high and low EE for the FQ measure. A score greater than 23 for the domain of criticism and/or a score greater than 27 for the domain of EOI indicated high EE (Wiedemann et al., 2002). For LEE, there was an unclear cut-off of 9 in the literature (Cole & Kazarian, 1988) so the total LEE score was split by the median (8.5) which was close to the cut-off in the literature.

### *Statistical Analyses*

Frequency tables were used to explore means and percentages of demographic characteristics across the sample. Due to the lack of service users taking part in the interviews in the study, demographic analysis is limited to age and gender for service users which was collected from EIS. All demographic variables are available for caregivers. Similarly, descriptive statistics were used to summarise the service user clinical outcomes.

Aim 1: To examine the EE characteristics of South Asian families where a member has FEP

Descriptive statistics were used to assess and explore the range, mean and standard deviation of scores for seven continuous EE domain variables. Moreover, the binary versions of the FQ and LEE, indicating high and low EE were examined using frequency tables.

Aim 2: To explore whether there is a relationship between caregiver EE and service user psychosis outcomes.

The main analyses were to assess any relationships between domains of caregiver EE (i.e. FQ criticism, FQ EOI, LEE intrusiveness, LEE emotional responsiveness, LEE attitude toward illness, LEE tolerance and expectations and warmth) and service user clinical outcome variables (i.e. number of hospital admissions, bed days, involvement of acute services and sections under MHA). Given that the variables were not normally distributed, the non-parametric test, Spearman's Rank-Order Correlation, was chosen (Field, 2017). A total of seven correlations were run in this way with each EE domain tested against the four clinical outcome variables.



The use of correlations enabled a process of variable selection, with any significant correlating EE domains being further tested through inclusion in a multiple linear regression model with relevant clinical outcome variables. Due to no significant relationships between EE at a domain level and clinical outcomes being identified from the Spearman's Rank-Order Correlations, an alternative second stage of analysis was conducted.

This further exploration of the data, in line with the research question, assessed whether there were relationships between caregiver EE categorised as high or low, and service user clinical outcomes. Mean differences between high and low EE groups for each dependent variable were tested using the non-parametric version of the independent samples T-test, the Mann–Whitney U test (Field, 2017). This test was used to identify any significant differences between EE groups and highlight any important relationships between clinical outcomes and EE on a broader level. In addition, the calculation of effect size (Cohen's d) allowed the determination of the strength of any significant relationships.

### **Caregiver Demographics**

A total of 22 caregivers self-identifying as South Asian participated in the study. An overview of sample demographics for caregivers is presented in Table 4. A significantly higher proportion of the caregivers were female (73%) and over half were the parent of the service user with FEP (55%), followed by siblings (27%). This is in line with previous research exploring caregivers of individuals with a FEP (Chien et al.,2016), as well as research looking at caregivers from a South Asian population (Sadiq et al., 2017). A large proportion of the caregivers were married (64%), compared to single (27%) and the majority were living with the service user (82%).

The mean age for the caregivers was 46 years old, ranging between 28 and 85 years old. All caregivers were educated to at least GCSE level or equivalent (27.3%) with slightly

higher proportions educated to A-Level (36.4%) and higher education level (36.4%) or equivalent. Moreover, 50% of the caregiver sample was employed to some capacity compared to 46% being unemployed. Only one participant was retired.

Regarding South Asian ethnicity distributions, 46% of the caregivers were Indian, with Pakistani (27%), Bangladeshi (18%) and Sri Lankan (19%) forming the remaining ethnicities in the sample. Half the sample of caregivers were born in the UK and classified as second-generation immigrants, whilst the other half of the sample were first-generation immigrants born in India (n=5), Bangladesh (n=3), Sri Lanka (n=2) and Tanzania (n=1). All caregivers identified as belonging to a religion with over half identifying as Muslim (59%), followed by Sikh (18%), Hindu (14%) and Christian (9%).

**Table 4**

Caregiver Demographic Characteristics

Demographic information		N=22
Gender, <i>n</i> (%)		
	Female	16 (72.7)
	Male	6 (27.3)
Age, mean (SD) [range, in years]		46 (13.38) [28-85]
Ethnicity, <i>n</i> (%)		
	Bangladesh	4 (18.2)
	India	10 (45.5)
	Pakistan	6 (27.3)
	Sri Lanka	2 (9.1)
Country of birth, <i>n</i> (%)		
	Bangladesh	3 (13.6)
	India	5 (22.7)
	Other	1 (4.5)
	Sri Lanka	2 (9.1)
	United Kingdom	11 (50)
Religion, <i>n</i> (%)		
	Christian	2 (9.1)
	Hindu	3 (13.6)

	Muslim	13 (59.1)
	Sikh	4 (18.2)
Relationship to service user, <i>n</i> (%)		
	Child	1 (4.5)
	Parent	12 (54.5)
	Partner	3 (13.6)
	Sibling	6 (27.3)
Living with service user, <i>n</i> (%)		
	No	4 (18.2)
	Yes	18 (81.8)
Relationship status, <i>n</i> (%)		
	In a relationship (cohabiting)	1 (4.5)
	Married	14 (63.6)
	Other	1 (4.5)
	Single	6 (27.3)
Education, <i>n</i> (%)		
	A-Level or equivalent	8 (36.4)
	GCSE or equivalent	6 (27.3)
	Higher education or equivalent	8 (36.4)
Employment status, <i>n</i> (%)		
	Employed full-time	6 (27.3)
	Employed part-time	5 (22.7)
	Retired	1 (4.5)
	Unemployed	10 (45.5)

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### Service User Demographics

Along with routinely collected clinical outcome data, gender and age information was available for the twenty-two service users linked to the twenty-two caregivers that took part in the study (see Table 5). Dissimilar to caregivers, there was a near even split of females (n=10) and males (n=12). Service user ages ( $M = 30.7$ ,  $SD = 10.3$ ) ranged from twenty-one to sixty-two years.

**Table 5**

## Service User Demographic Characteristics

Demographic information		N=22
Gender, <i>n</i> (%)		
	Female	10 (45.5)
	Male	12 (54.5)
Age, mean (SD) [range, in years]		30.7 (10.3) [21-62]

**Results**

The results are presented in two sections. The first of which addresses the research aim of outlining the caregiver EE characteristics in this sample using descriptive analyses. The second section focuses on the second research aim of exploring the relationship between caregiver EE and service user clinical outcomes relating to psychosis relapse.

**Research Aim One: What Are the EE Characteristics of South Asian Families Where a Member Has FEP?**

The FQ, LEE scale and the newly developed warmth measure introduced in this study were completed by all 22 caregivers that took part in the study. The FQ and LEE measures were assessed on a domain level and on a broader level focusing on classification of high and low EE.

***Domain Level***

The FQ measures two domains of EE (criticism and EOI). As shown in Table 6, both criticism (13-32) and EOI (14-31) showed a similar range of scores. However, EOI ( $M = 23.4$ ,  $SD = 4.7$ ) showed a higher mean score than criticism ( $M = 18.9$ ,  $SD = 6.1$ ). The mean

scores for both criticism and EOI are below the cut-off score indicating classification of high EE (23 and 27 respectively).

The LEE scale measures four domains of EE in which greater scores are associated with greater EE. As shown in Table 6, the domain measuring Intrusiveness recorded the greatest mean score ( $M = 4.6$ ,  $SD = 2.4$ ) of the four domains with Attitude Towards Illness having the lowest average score ( $M = 0.6$ ,  $SD = 0.8$ ). The warmth measure was designed to be a domain specific measure for warmth. Scores ranged from eleven to twenty ( $M = 17.8$ ,  $SD = 2.3$ ).

**Table 6**

Caregiver EE at Domain Level

N=22

Domain	Minimum	Maximum	Mean	Standard deviation
FQ Criticism	13	32	18.9	6.1
FQ EOI	14	31	23.4	4.7
LEE Intrusiveness	1	9	4.6	2.4
LEE Emotional Responsiveness	0	7	2.3	1.8
LEE Attitude Towards Illness	0	3	0.6	0.8
LEE Tolerance and Expectations	0	4	1.2	1.0
Warmth	11	20	17.8	2.3

***Broader EE Classification Level***

As mentioned above, the FQ domain scores were scored and transformed using predefined cut-off scores to categorise caregivers (n=22) as high or low EE. Table 7 shows more caregivers met criteria for low EE (n=15, 68%) compared to high EE (n=7, 32%), according to the FQ. With regards to the LEE, high and low EE classification was made using the total LEE score, which represented the sum of the four domains. In line with the literature, the cut-off was the median score (8.5). Results show an even split of high and low EE (n=11, 50%).

**Table 7**

Caregiver EE Classification		N=22
FQ, <i>n</i> (%)	High	7 (32)
	Low	15 (68)
LEE, <i>n</i> (%)	High	11 (50)
	Low	11 (50)

### **Research Aim Two: Is There a Relationship Between Caregiver EE and Service User Clinical Outcomes?**

#### *Overview of Service User Clinical Outcome Variables*

Descriptive analyses identified the minimum and maximum values and calculated the mean and standard deviation for each service user clinical outcome variable (Table 8).

Unsurprisingly, hospital admissions ( $M = 0.7$   $SD = 1.1$ ) and number of sections under the MHA ( $M = 0.6$ ,  $SD = 1.0$ ) have an identical range of frequencies (0-3). The total number of bed days ( $M = 27.3$ ,  $SD = 55.6$ ) shows a larger range (0-203), with the mean much closer to the minimum value. The number of acute service involvement ( $M = 1.9$ ,  $SD = 2.5$ ) had a greater range (0-10) than hospital admissions and sections (MHA), with the mean closer to the minimum.

**Table 8**

Service User Clinical Outcome Variables					N=22
Clinical outcome	Minimum	Maximum	Mean	Standard deviation	
Hospital admission	0	3	0.7	1.1	
Bed days	0	203	27.3	55.6	
Acute services involvement	0	10	1.9	2.5	
Sections (MHA)	0	3	0.6	1.0	

**Primary analyses: Spearman’s Rank-Order Correlations**

A total of seven correlation analyses were run, each testing a domain of EE against the clinical outcome variables. Results show no significant correlations between any of the caregiver domains of EE and the clinical outcome variables (Table 9). In general, the lack of any significant correlations suggests that these domains of EE may not be related to the clinical outcome variables. Moreover, Spearman’s Correlation ( $\rho$ ) ranges from  $-.001$  to  $.20$ , indicating low magnitude of effect.

**Table 9**

Correlation Matrix		N=22			
EE Domains		Hospital admissions	Bed days	Acute services involvement	Sections (MHA)
FQ Criticism	Spearman’s Correlation	.003	.041	.078	.154
	Significance (2-tailed)	.990	.857	.730	.493
FQ EOI	Spearman’s Correlation	.116	.090	.200	.149
	Significance (2-tailed)	.607	.691	.372	.481
LEE Intrusiveness	Spearman’s Correlation	-.022	-.056	.051	-.107
	Significance (2-tailed)	.924	.803	.820	.634
LEE Emotional Responsiveness	Spearman’s Correlation	.079	.043	.043	.018
	Significance (2-tailed)	.727	.850	.851	.936
LEE Attitude Towards Illness	Spearman’s Correlation	.091	.039	.069	.190
	Significance (2-tailed)	.688	.862	.761	.396
LEE Tolerance and Expectations	Spearman’s Correlation	-.001	-.004	.035	.094
	Significance (2-tailed)	.996	.984	.877	.677
Warmth	Spearman’s Correlation	-.100	-.062	-.108	-.074
	Significance (2-tailed)	.657	.785	.631	.742

**Further analyses: High and low EE**

Mann–Whitney U tests were conducted to assess whether there were statistically significant differences in the clinical outcome variables between high and low EE groups.

High and low EE groups were calculated according to both the FQ and the LEE scale. FQ and LEE binary variables were tested against the clinical outcomes.

**Table 10**

Mann–Whitney U Tests – Summary of Differences High and Low EE Groups (FQ)

Clinical Outcome	EE Classification		Z-value	Significance (2-tailed)
	Low (n=15)	High (n=7)		
Hospital admissions	11.00	12.57	-.615	.538
Bed days	11.00	12.57	-.613	.540
Acute services involvement	10.73	13.14	-.837	.403
Sections (MHA)	10.63	13.36	-1.068	.286

**Table 11**

Mann–Whitney U Tests – Summary of Differences High and Low EE Groups (LEE)

Clinical Outcome	EE Classification		Z-value	Significance (2-tailed)
	Low (n=11)	High (n=11)		
Hospital admissions	11.27	11.73	-.191	.848
Bed days	11.50	11.50	.000	1
Acute services involvement	10.50	12.50	-.746	.456
Sections (MHA)	11.50	11.50	.000	1

Results for the Mann–Whitney U tests for the FQ determined high and low EE groups are shown in Table 10, whilst Table 11 shows the results for the LEE determined high and low EE groups. The LEE and FQ results showed no significant differences between high and low EE and any clinical outcomes. Effect sizes were calculated using mean, standard deviations and sample sizes to assess if there were any potentially clinically meaningful relationships. Only acute services involvement for the FQ showed a medium effect size ( $d=0.5$ ), whilst small effect sizes were observed for all others across the FQ and LEE.



## Discussion

### **What are the EE Characteristics of South Asian Families Where a Member Has FEP?**

The first aim of the study was to identify what the EE characteristics were on a domain level and broader categorical level (high and low EE) of South Asian families where a member has FEP. With regards to domains of caregiver EE, it was difficult to make comparisons between measures due to differences in conceptualisation, scoring and interpretation. Within the FQ, the two domains of criticism and EOI were similar in range of scores and both means were below their respective cut-offs for high EE. This is in line with previous research which has suggested that criticism and over involvement may be connected (Okasha et al., 1994).

This uniformity contrasts with the LEE measure where there was a greater variation between domains. The two domains with the lowest averages (Attitude towards illness and Tolerance and expectations) also had the lowest ranges in score, thus suggesting little variation in the sample. This suggests that for this sample of South Asian families, caregivers had an attitude towards FEP that was considered closer to low EE. The same can be suggested for caregivers' expectations and tolerance towards service users with FEP. Conversely, the LEE domain of Intrusiveness had a higher mean (4.6) suggesting that caregivers were considered more intrusive, and this was closer to high EE. Both the FQ and the LEE measure excessive caring in the form of EOI and Intrusiveness, respectively, with means of both falling below cut-offs for high EE in this sample. However, Intrusiveness appears significant when compared to other LEE domains, which highlights the question of conceptualisation of intrusive and non-intrusive behaviours, specifically with the consideration of cultural norms and EOI.

The highest possible score on the newly created warmth measure was 20 and the mean was 17.8 which suggests that the items on this measure elicit similarly high scores in

relation to warmth. This may suggest that the caregivers in the study *do* exhibit warmth towards service users. This fits previous research that has found that South Asian families express criticism/EOI and high warmth at the same time (Ikram et al., 2011; Wig et al., 1987). It is possible that the strong presence of warmth may have a protective function against some of the negative domains of EE, as warmth has been suggested to mediate negative outcomes in psychosis (Lopez et al., 2009; Medina-Pradas et al., 2013). Thus, high levels of warmth in this study may have impacted other domains and high/low EE classification. Nonetheless, questions remain as to whether the items in the measure accurately pick up nuances and variances in warmth. Moreover, the question of whether items were designed to make it easy for caregivers to express low warmth is highlighted, given social desirability was likely to be a factor (Richman et al., 1999).

When looking at EE in terms of high and low categories based on the FQ and LEE, FQ identified a higher percentage of low EE families (68%) compared to high EE (32%), whilst LEE showed an even split between high and low EE families (50%). The latter is closer to previous research looking at caregiver EE in the South Asian population (Sadiq et al., 2017). Both measures identified the presence of high EE in South Asian families, whilst LEE showed a larger percentage of high EE which demonstrates the variance between measures of EE. Again, this can be explained by the measures assessing different domains of EE and using varying scoring systems. The inconsistency between the FQ and LEE is in line with previous research which has explored the several measures of EE that vary in conceptualisation and categorisation of EE (Hooley & Parker, 2006). As with the issue of measuring intrusive and non-intrusive behaviour mentioned above, this further raises a conceptual question about whether measures target entirely different aspects of family functioning that may or may not fall into the conceptualisation of EE and whether they are cross-culturally applicable.

The inconsistencies at a categorical level of caregiver EE may represent the wider conceptual issue of uncertainty about what exactly is being measured. However, it may also suggest that for South Asian families where FEP is present, current measures and conceptualisation of caregiver EE do not provide an accurate picture of EE, highlighting the need for cultural-specific measures to be established (Akhtar et al., 2013).

### **Is There a Relationship Between Caregiver EE and Service User Clinical Outcomes?**

The main aim of the study was to explore if there was a relationship between caregiver EE and service user clinical outcomes. This was first assessed using the different domains of EE across the FQ, LEE and warmth measure. No statistically significant correlations were found between the seven domains of EE and service user clinical outcomes. Therefore, the hypothesis that higher scores on caregiver EE domains will be associated with worse psychosis related clinical outcomes, was rejected. This hypothesis was based on previous research which showed a strong relationship between high EE and worse clinical outcomes in psychosis (Alvarez-Jimenez et al., 2011; Brown et al., 1972; Butzlaff & Hooley, 1998).

At face value, the results may indicate that for South Asian families where FEP is present, EE domains are not meaningfully related to clinical outcomes and therefore domains of EE may not be relevant in the South Asian population. However, it is important to note that the lack of significant correlations may be a product of low power due to the small sample size in this study (n=22).

Whilst the identification of high EE categories across measures suggests there is some relevance of the broader EE categories, this does not appear to translate to EE at domain level. This may further suggest issues at a conceptual level in terms of whether current understanding of EE, including at a domain level, is valid for the South Asian population.

This was explored previously (Hashemi & Cochrane, 1999) using a population-based normative study which found Pakistani families were more likely to be rated as high EE than white British families which suggests that domains such as EOI may be better ascribed to culture, rather than pathology.

Given that no significant relationships were found at domain level, further enquiry of the data was explored to assess if there were differences between high and low EE groups in terms of service user clinical outcomes. Mann–Whitney U Tests showed no significant differences between FQ and LEE determined high and low EE groups for each clinical outcome. This is in line with previous research by Hashemi & Cochrane (1999), who found that high EE did not predict psychosis relapse among British Pakistani and British Sikh groups. Whilst such results appear to confirm the lack of relationship between caregiver EE and service user clinical outcomes, at the broader categorical level, it is hard to draw any conclusions given the low sample size.

### **Strengths and Limitations**

To the author's knowledge, this was the first study to explore the relationship between caregiver EE and service user clinical outcomes, within South Asian families in the UK where a member had FEP. This research aimed to highlight patterns in the relationship between EE and clinical outcomes for the South Asian population. This study required establishing research links with several EIS in London which has developed the foundation for future research projects. Moreover, data collection occurred during the COVID-19 pandemic and thus navigation of potential obstacles opened new and safe opportunities for data collections including via digital platforms. Beginning the process of collecting data from a niche population, has granted face value understanding of how feasible data collection is in

the South Asian psychosis population in London. This study considered an oft-neglected domain of EE, warmth, by developing and including a novel and new measure of the domain.

There are several limitations to be discussed. The design of the study was cross-sectional and utilised retrospective service user outcome data (point of referral to EIS to date of carer's research interview), thus if any significant relationships were identified it would not be possible to conclude any predictive causality.

Another important limitation that obscures the interpretation of the results is the small sample size in the study (n=22). Quantitative analyses, particularly regression models, are impacted by small samples due to the lack of power that comes with them. Lack of power impacted the type of statistical tests that were chosen and the conclusions that could be drawn from results (VanVoorhis & Morgan, 2007). Underpowered tests are also less likely to find a true effect. Consequently, this ultimately means this study can tell us little about the British South Asian population, specifically in terms of the relationship between caregiver EE and clinical outcomes in psychosis. However, given that much of the focus during this study was recruitment and data collection, there is much learning to be discussed in this regard that may aid the facilitation of future research in this population.

There are several factors that may have contributed to the low sample size including difficulties in recruiting participants. Recruitment was dependent on EIS team members forwarding appropriate research candidates to be contacted. This process was regularly disrupted and delayed due to staff turnover and disrupted communication links between the EIS teams and research team. There were a limited number of dyads that participated in the study due to some service users and carers declining participation and repeated cancellations of appointments. There were also instances in which service users did not want their carer to take part in the study. Consequently, the lack of dyads that took part in the study, meant analyses were limited to using service user outcomes routinely collected by EIS. This

resulted in psychosis symptom measures and anxiety/depression scores being excluded from analyses. This demonstrated the difficulty in recruitment and data collection processes for this specific population. Such processes will require longer periods to attain sufficient data for analyses.

One of the greatest barriers to recruitment discussed is the reliance on the English language due to the lack of resources to accommodate interpreters during interviews and translation of resources, which were not readily available. This barrier is significantly impactful given the cultural focus of the study. This excluded many individuals, often caregivers that could not engage in English which ultimately resulted in selection bias of participants for the study whilst filtering out authentic and rich perspectives from first-generation migrants. Should resources become available in future studies, this design would likely benefit from interpreters that could attend research interviews and the translation of both outcome measures and study resources such as posters. This inclusive approach may help to encourage those with less fluent English skills to participate, whilst changing exclusion criteria.

Another issue to consider is service users and caregivers tended to participate if the service user was “well”, in that they were not experiencing significant psychotic symptoms and distress. Whilst this makes sense, it perhaps means that participants were of a particular type and having a longer period of time for recruitment where service users could be reinvited if they were to feel better may have also helped recruitment. Moreover, in the cases where service users declined to participate if their caregivers took part, more effort and emphasis could have been placed to explain confidentiality between pairs.

An important point to consider is the mixed use of first and second generation migrant populations in this study. This could have had influential effects on EE due to processes of acculturation and assimilation that happen in differing degrees. Moreover, it may be that first-

generation migrants are closer to their culture of origin, whilst second-generation migrants may have adopted British or other cultures. Therefore, this raises the question of whether conducting a study exploring South Asian culture in the UK is entirely valid. Whilst one way to mitigate the potential mixture of cultures may be to entirely study first-generation migrants, another method if resources allowed would be to use samples from South Asian countries themselves. A related issue is the heterogeneity of culture that exists within the umbrella of “South Asian”. Cross cultural variation exists within South Asia which is a diverse geographical area. Thus, looking at South Asian as a whole, whilst an important first step, can be considered over generalising and excluding of nuances and differences that exist within and across countries.

Efforts were made to involve service users in the design and conceptualisation of the study. Whilst consultation regarding the study proposal and piloting of the selected measures was useful in gaining feedback and constructive criticism which tailored the procedure, service users and caregivers could have been more heavily involved in the study. For example, all of the service user and caregiver involvement took place at the point in the study where the proposal had already been developed. Involvement in the form of consultation and joint decision making when developing the study conceptually may have resulted in approaches that would have helped to answer the research questions or formulate more pertinent questions. Furthermore, there was no further service user and caregiver involvement after the initial period. In this way, there was little sense of partnership or control given to service users and caregivers. Possible ways of increasing involvement could have included recruitment and data collection, especially potential problem solving in this regard. Moreover, involvement in discussions regarding the results and limitations could have resulted in unique insights that could not be attained through the lens of researchers.

The warmth measure which was developed and introduced in this study has not been formally validated to determine whether it accurately measures warmth. 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).

The final limitation is related to social desirability, in which participants may answer questions, particularly about how caregivers care for service users, in a more socially desirable direction. This can occur in face-to-face settings but also over digital platforms (Richman et al., 1999). Furthermore, social desirability may have been increased due to researchers also being from a South Asian ethnic background. Thus, whilst it is difficult to mitigate the effect of social desirability, it is important to acknowledge the potential impact on results.

## **Implications**

### ***Clinical***

It is important to note that any clinical implications at this stage would be tentative and subject to further research due to the limited nature of the results because of small sample size and subsequent lack of power.

When taken at face value, results suggest that for South Asian families, EE at both domain and broader high/low levels, is not related to clinical outcomes in service users. This supports previous research that has questioned the cross-cultural validity of the current conceptualisation of EE (Bhugra & McKenzie, 2003; Hashemi & Cochrane, 1999; Lopez et al., 2009; Sadiq et al., 2017). Clinically, this raises questions about interventions offered in EIS, such as FI which target the reduction of high EE to low EE. Yet, if high EE is not



significantly related to or predictive of poorer clinical outcomes, there may not be a need to reduce EE, especially as the current study identified that at least half of the families were already characterised as low EE.

Whilst the cross-cultural inconsistency of EE is well documented (Hashemi & Cochrane, 1999), the underlying mechanisms resulting in differences between Western and South Asian populations remain to be better understood. Research has suggested that domains such as EOI are not necessarily pathological universally but rather culture specific, nor is there a universal normative experience of EE (O’Driscoll et al., 2019; Singh et al., 2013). Thus, given the inconsistencies in the relationship between EE and outcomes, it is important for the training of clinicians to include increasing awareness of cross-cultural impact of EE and differences in norms relating to caregiving relationships. This is emphasised by research demonstrating service users perceiving EIS to be less culturally competent than service providers perceive themselves to be (Venkataraman et al., 2018). Moreover, this could inform potential adaptations to current interventions such as FI to enable flexibility when considering what to target in treatment, especially in multicultural settings.

When thinking about the South Asian culture beyond EE, there are broader suggestions for how EIS may best support this population clinically. A qualitative study exploring the experience of stigma among a sample of British South Asian people using EIS (Vyas et al., 2021) found a theme in which participants experienced an underappreciation placed upon their social environment, culture, religion and identity by EIS. This resulted in an increased negative experience of psychosis and feeling further stigmatised. This study also highlighted the socially isolative effect of stigma and the often-differing view of psychosis compared to caregivers and the South Asian community in general. Equally, having supportive relationships was a common protection against the experience of stigma.

Therefore, clinical psychologists could play a role in helping this population feel less stigmatised and more understood by engaging in person-centred treatment that specifically considers culture and how this may have impacted the experience of stigma and discrimination. Moreover, clinical psychologists could use a systemic approach to encourage the sharing and understanding of differing cultural perspectives of psychosis between service users and caregivers. On a more macro level, EIS could utilise its outreach ethos by connecting with meaningful places to British South Asian population including places of worship and community centres. This could help services and clinicians develop a cultural and shared understanding of psychosis. Such outreach, along with service level review and updates of social equality policies could increase engagement with EIS. Therefore, there are several ways in which EIS can improve the care provided to South Asian population with FEP and their families, beyond the focus of EE.

### ***Research***

Given that the current study's results are underpowered due to the small sample size, an extension of this study will allow the collection of more data and thus improve the statistical power of any analyses performed. Recruitment and data collection is continual as part of the larger study. Moreover, expanding recruitment and data collection to EIS beyond London would increase generalisability of results. Increasing recruitment numbers may also increase dyad counts and thus enable the inclusion of symptom measures in analysis, thus broadening the range of outcome measures for service users.

Future research could also continue to develop and validate the warmth measure introduced in this study. The sample in this study was not sufficient to assess the psychometric properties of this measure but this should be conducted in future research. This is important as research has acknowledged the potential of warmth as a protective factor in

the context of EE (Leff & Vaughn, 1985), yet there is no established measure to enable exploration of cross-cultural differences in warmth. Moreover, an exploration of other potential protective factors that could be targets for interventions could be explored.

With multiple studies, including this one, suggesting that the current conceptualisation of EE may not be cross-culturally valid, future research could aim to further explore and understand the underlying mechanisms of EE for different cultures. However, given the exploratory nature of this study, a qualitative approach to understanding caregiving in the South Asian population in the context of psychosis, could be utilised. In addition to potentially reducing the demand of a larger sample size associated with quantitative studies, there are several other advantages that could be accessed. For example, interviewing service users and caregivers on how they receive and express care, could allow for exploration of what is considered helpful and unhelpful caring within the South Asian population, that is independent of the Western concept of EE. Furthermore, this could highlight and contextualise cultural norms which may challenge the current conceptualisation of EE. Approaching the study in this bottom-up way would allow the identification of important themes and domains within this population without confining it to the already established EE construct, which may not be relevant. Moreover, this approach could challenge the currently established domains of EE such as emotional over involvement, by further clarifying and defining the term “over” in relation to cultural norms. Most importantly, a qualitative approach, in contrast to a quantitative approach that uses restrictive responses based on preconceived concepts and measures, would allow for the inclusion of unfiltered authentic perspectives and voices.

## **Conclusion**

Results were statistically underpowered due to the small sample size and therefore no meaningful conclusions can be derived from the data analysed. Nevertheless, this study facilitated valuable learning with regards to feasibility of recruitment of the FEP South Asian population in the UK. A range of difficulties and challenges were identified with regards to recruitment and data collection which were considered in terms of implications, solutions and alternative research designs. Future research should build on the foundations of this study by replicating it with a larger sample size to validate the results. Research should also aim to further explore EE within the South Asian population in a bottom-up approach to increase understanding of what aspects of caregiving and receiving are helpful in this population and consider how this may inform treatment.

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## **Chapter Three: Critical Appraisal**

## **Introduction**

This critical appraisal chapter addresses personally significant aspects of the research process. It begins with an outline of my interest in this research topic. This is followed by reflections on the Conceptual Introduction and the impact of COVID-19 on implementing the research project. The experience of recruitment, data collection and data analysis are then discussed before reflecting on research methodology in terms of quantitative and qualitative approaches. The chapter then closes with personal reflections, including the emotional impact of conducting the project and interviewing participants that spoke of personally relevant experiences.

## **Why I Chose This Project**

My exposure to psychosis as a mental illness began prior to clinical psychology training, in both professional and personal contexts. Professionally, I had some theoretical understanding of the illness from reading and gained clinical experience working in an older adult inpatient unit as a healthcare assistant. Whilst in this role, I cared for many individuals with chronic and severe psychosis. Whilst there were pockets of pleasant interactions with service users, there were many challenging moments, including those where recovery appeared unlikely, which made me feel powerless and upset. Some service users spoke to me about helpful and more often, unhelpful relationships they had with caregivers. In addition to service users, I was able to work with and interact with caregivers, who for each service user, played different roles and had varying levels of involvement. Here, I noticed the difference in helpfulness of some relationships between service users and caregivers.

Prior to any professional or educational exposure to psychosis, my first exposure to psychosis involved close family members experiencing it. This was one of the most difficult and upsetting experiences my family has experienced. Over a period of years, I not only

learnt about what psychosis was and how it affected individuals who experience it, but also how the effects of such an illness can ripple through and disrupt the entire social network around the person with psychosis. Here, without knowing it at the time, I gained my first experience of Expressed Emotion (EE), from the context of my own South Asian family. Moreover, I learnt the importance of caregiving relationships in terms of its impact on illness recovery and deterioration. Both my professional and personal experiences taught me about psychosis as an illness and a great deal about the importance of caregiving relationships and EE in the context of psychosis.

These experiences, whilst difficult and overwhelming, sparked an interest in learning more about psychosis and what helps recovery (i.e. treatment). I was fortunate enough to be able to complete a Master of Science (MSc) in Early Intervention in Psychosis at King's College London. This MSc further developed my understanding of psychosis, particularly Early Intervention Services and First Episode Psychosis (FEP). It was during this course that I learnt about the term EE, which was helpful in trying to make sense of my own personal experiences. Whilst I was able to match some of my family experiences with the EE theory, there were aspects that did not fit my experience. For example, EE conceptualised emotional over involvement as negative, whilst my own experience would suggest that high level of emotional involvement from family members was protective. It was during this course that both my interest in EE and my curiosity about cultural differences developed.

Being of Bangladeshi ethnic background, I identify as South Asian. Thus, I understand my family experiences with psychosis within the context of South Asian culture and recognise the importance this had on individual and collective experiences. It is important to recognise the generalisation of South Asian culture and that nuances exist between different ethnicities and subcultures. I felt a strong connection to this research topic and would attribute this primarily to the personal significance of having had psychosis



present in my family and belonging to the South Asian population. Furthermore, I was drawn to the potential clinical implications of this research, in helping tailor interventions, such as Family Intervention for psychosis (FI), to address the cultural differences and strengths of the South Asian population.

### **Conceptual Introduction**

I chose to do a conceptual introduction over a systematic review for several reasons. The main influencing factor was my desire to immerse myself in EE literature in order to expand my knowledge in this area. I also preferred the freedom of the conceptual introduction to explore broader aspects of EE before focusing on areas relevant to the empirical paper. Whilst organising and synthesising the vast domains of literature was challenging, I am pleased with my decision to do a conceptual introduction.

Conducting the literature review was helpful in grounding me in research on emotional expression separate to the EE construct. I was amazed at all the research that had looked at how humans express emotions and the importance of this in relation to development of expression styles, mental health, culture and how it is measured. It was clear to me from this early into my literature search that there was no one truth of how emotions are expressed but rather there is a degree of complexity and multiple nuances involved to consider (Barrett et al., 2019).

Although I was familiar with EE and some of the research regarding its development in the context of psychosis, I was pleasantly surprised to learn about the application of EE across a range of broad mental health conditions including eating disorders, as well as physical health conditions such as diabetes (Wearden et al., 2000). This gave me a further appreciation of the importance of the quality of caregiving relationships and considering this

in relation to clinical outcomes. In this way, the conceptual introduction helped develop and changed my understanding of EE and its clinical utility.

This conceptual introduction revealed the attention that exploring the cross-cultural validity of EE has received over recent years. Moreover, it highlighted the importance of further addressing this critique of EE due to the clinical implications it has on interventions focused on addressing EE such as FI.

### **Impact of COVID-19**

The COVID-19 pandemic had a disastrous impact on many people's lives in several different ways. Whilst it is essential to acknowledge that disruptions to a thesis is trivial in comparison to some of the more severe impacts of COVID-19, it is important to reflect on and consider the impact of the pandemic on various stages of this research project.

COVID-19 affected the experience of conducting this research in several ways. Due to government and organisational policies around social distancing and isolation, substantial amendments to the previously approved NHS ethics application were required. This was stressful as it not only required more work, but also delayed the commencement of the research project. These amendments included moving recruitment, data collection, payment and other aspects of the study to digital mediums. Furthermore, there was uncertainty over whether such amendments would be approved and thus whether this project would be able to proceed or whether I would need a whole new project which was an anxiety-inducing prospect. Whilst there was a delay in commencement of the study, fortunately the amendments were approved. Upon reflection, whilst I was aware of delays related to ethics and amendments (Barker et al., 2016), I believe the context of this being a doctoral thesis which has a deadline and assessment component contributed towards the anxiety experienced in relation to COVID-19 related delays. I am not sure if it would have had the same impact if

this was a standalone research project that did not have any bearing on my passing of clinical training.

The move to, and reliance on virtual interaction during the COVID-19 pandemic meant that there was no physical presence of the research team in EIS teams that were helping the recruitment of participants. This was a stressful experience, particularly as recruitment and participant numbers were low, as it was difficult to engage with EIS teams remotely and thus interactions were limited. Similarly, from the outset of the research project, all meetings with the research team, including my supervisor, were remote. On reflection, it feels strange that I have not met the people involved in a significant part of my training in person, throughout the entire two-to-three-year period. That being said, all parties involved did exceptionally well to adapt to unprecedented circumstances and engage in this research project.

### **Experience of Recruitment and Data Collection**

This research project was based on collecting and analysing primary data which placed emphasis on recruitment and data collection. These stages were some of the most important, yet challenging, due to the barriers to research participation associated with individuals with FEP. Such barriers included timing of the approach and perceptions that research may be harmful (Woodall et al., 2011). Difficulty in recruitment and data collection was hypothesised and anticipated due to the nature of FEP as an illness which impacts on functioning and engagement. Moreover, EIS teams would screen out any service users that were considered too unwell to participate. The focus on South Asian ethnicity naturally further reduced the pool of potential participants.

Recruitment was further hindered by logistics and practicalities of liaising with six different EIS teams. Even with the support of another trainee clinical psychologist, EIS staff

turnover and delays in communication ultimately delayed recruitment and data collection. This was a regular theme during the study which invoked a feeling of powerlessness due to not having any control over this domain of the study. The constant struggle of trying to gain data meant that participants not attending scheduled interviews as well as subsequent rescheduled interviews was particularly stressful and frustrating, especially due to the anxiety linked to thesis completion.

These factors also affected recruitment of dyads of service users and their caregivers. The lack of complete dyads that took part in the study resulted in significant variables being left out from analysis, including clinical outcomes such as psychosis symptoms. This was frustrating as the study was then based on outcome data collected routinely by EIS teams, which made it feel like valuable data was wasted. Whilst it was important to acknowledge and accept the reality of low numbers, an important discussion was had among the research team to reflect on how the specific issue in recruiting dyads could be addressed in the future. Ideas included emphasising confidentiality between service users and carers by ensuring different members of the research team interviewed each member of a dyad and finding ways to offer more than £10, which did not seem significant to many potential participants who offered to forgo payment.

During the early stages of data collection, I noticed feelings of anxiety and subsequent avoidance around contacting and interviewing service users, which was not the case for caregivers. This may be because I was concerned about asking service users about difficult experiences (i.e. symptoms) and this being experienced as intrusive and distressing. It was helpful to have some of the questions modelled by my supervisor and advice was given on how to sensitively ask such questions. I found that my anxiety quickly dissipated with each interview as they all turned out successful in this regard.

## **Experience of Data Analysis**

Given that this project was quantitative, I was aware of the expectation to have large data numbers, which made me concerned about the small sample size I had to work with. I recognised that any statistical analysis I conducted would be underpowered (VanVoorhis & Morgan, 2007) which left me feeling worried that my analysis would not be good enough for a doctoral thesis. However, after meeting with my supervisor and consulting with another member of staff with expertise in statistical analysis, I was able to develop a plan that optimised analysis of my dataset whilst accounting for the small sample size. Moreover, I recognised that for this research project, the main body of work and resources was concentrated in recruitment and data collection.

## **Reflections on Methodology**

Given that the wider study has both quantitative and qualitative components, I have reflected on my choice of methodology in regard to these two approaches. During the process of selecting a research project, I noticed myself prioritising a quantitative methodology, likely due to my previous undergraduate and MSc experience and thus familiarity with this approach. Whilst this research project was initially entirely quantitative, the research team and I recognised the value in adding a qualitative arm to collect rich data on the South Asian perspective of giving and receiving care. I remain curious about the qualitative data that my thesis has not addressed and although I would like to explore this data, I am aware of the time it would have taken to do this in addition to the recruitment and data collection linked to the quantitative arm of the study.

I am aware that quantitative methods generally align with positivism (Comte, 2009) in terms of epistemology, which attempts to describe an objective truth in the world. This is

contrary to my quantitative research project which partly aimed to explore whether there are differences in experiences of the world based on culture. Thus, whilst this research is quantitative in methodology, epistemologically, it could be considered closer to relativism (Jupp, 2006), which argues there is no absolute universal truth. Moreover, this research project is also aligned with social constructionism (Burr, 2015) which emphasises human experiences are influenced by context (i.e. culture, language and history). Whilst I find myself between the two philosophical points of positivism and relativism, I align closer towards relativism and more specifically, the social constructionism perspective in research.

### **Personal Reflections**

The process of conducting this thesis was both practically and emotionally demanding, as it provoked a constant feeling of anxiety which only reduced towards the end of the thesis when I had finished statistical analyses and towards the end of writing up. Upon reflection, the initial excitement of engaging in a project that was personally meaningful was overshadowed by worry linked to the uncertainty around COVID-19, time pressure of completing the thesis and other demands of the course. In addition, during the thesis process, I received news that my wife was pregnant. Whilst this news was most welcome, it added further stress and anxiety about moving ahead with the thesis so that aspects of life did not conflict in an overwhelming way. I feel an element of disappointment that I was not able to fully immerse myself in the research project due to focus being shared between other aspects of the course (i.e. placement) and personal life. However, I am aware that this experience is shared by many trainees and is an unintended consequence of balancing competing demands of clinical training and life. Nevertheless, although there are limitations in the data collected thus far, I am grateful to have been a part of building the foundation to this research project.

Furthermore, the long-term clinical implications for South Asian and potentially other cultural groups remains an exciting prospect.

Another emotionally significant element of conducting this thesis was during data collection, in which I interviewed service users and caregivers about their experiences. Being from a South Asian background, whilst also experiencing psychosis in my own family, I found it hard not to see and hear my own family members and personal experiences when listening to research participants. I was moved by the stories shared by participants, including the challenges faced, strengths and commitment towards recovery. This created an urge to help participants and I often had to reflect on and manage my roles of research and of psychologist, as it was tempting to move into therapist domain at times. Whilst this was challenging, it gave me clarity over my future career ambitions, as it strengthened my desire to work with psychosis both clinically and in research.

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## Appendices

## **Appendix 1 – Study Information Sheet for Service Users and Caregivers**

### **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-ordinator 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) I: '*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.

## **Information sheet for caregivers (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 your relative is accessing support from an Early Intervention Service. Before you decide whether to take part, please take some time to read this information sheet. We encourage you to ask questions if you find anything on this sheet unclear or feel unsure about any aspect of the research.

This is a student study. Data collection 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 relative. A carer may be a parent, grandparent, partner, sibling or friend who is in close and regular contact with the service user. 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/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 range of questionnaires asking about your relationship with the person you care for, 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.

With your permission you may will 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 roughly 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 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?**

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.

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

Your relative's 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 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 relative's 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 the 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 in 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.

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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 year's 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 do so by getting 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 2 – Consent Form for Service Users and Caregivers

### 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.

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 be 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:  
.....

## Consent form for caregivers

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 to the person I care for and my mood 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. 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 or support that either I, or the person I care for, 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.

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, nor the person I care for, 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 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:

.....

# Understanding Care Giving Processes in South Asian Families

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.

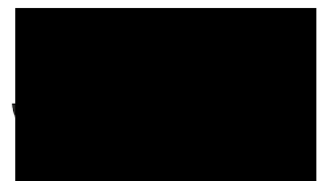
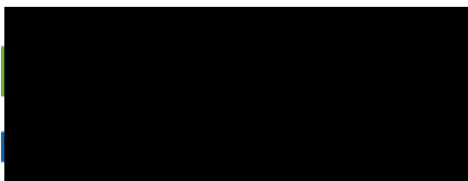
## Are you eligible?

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

## 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)



### Appendix 4 – Warmth Measure

	<b>Never / Very rarely</b>	<b>Rarely</b>	<b>Often</b>	<b>Very Often</b>
<b>1. I am warm towards them</b>				
<b>2. I appreciate what they do for me</b>				
<b>3. I really value them</b>				
<b>4. I want to understand how they see things</b>				
<b>5. I feel very close to them</b>				

## **Appendix 5 – Joint Thesis: Summary of Contributions**

This thesis is part of a joint project with fellow trainee clinical psychologist Amrita Ramanathan. Both Amrita and I jointly made substantial amendments to the study protocol to enable COVID-19 related flexibility in conducting the research and adding the qualitative arm of the larger study. Amrita and I jointly contributed to the development of the qualitative research interview and warmth measure. In addition, we both contributed towards the development and editing of study resources including posters, information sheets and consent forms. We allocated EIS equally between us and presented to and liaised with staff from our allocated services. However, we also worked across each other's EIS to support liaison with care coordinators. Amrita formatted and created spreadsheets to record data in. We both collected data from service users, caregivers. Hard data collection from EIS teams was largely collected by me. The analysis of data and write-up of the thesis was conducted separately. Amrita's project focused on service user perception of EE and clinical outcomes whereas my project focused on caregiver EE and clinical outcomes. Regular team meetings between Amrita and I were arranged to discuss thesis related queries and allocate tasks between us.