Flipping between cultural worlds: a qualitative exploration of stigma experiences of British Asian people using an Early Intervention in Psychosis Service

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Abstract

Background

Addressing stigma is a government priority in the United Kingdom (U.K.). It is recognised that people with a psychosis diagnosis experience higher levels of stigma compared to any other mental health diagnosis. Therefore their experiences of stigma are more likely to have detrimental personal consequences. Mental health stigma is also a pervasive issue within South Asian communities. It was recently found that second-generation minority groups are at increased risk of developing psychosis. Moreover, there is currently an under-representation of South-Asian people using mental health services in the UK. However, to date there are no qualitative studies specifically examining the experiences of stigma from the perspective of second-generation British-Asian people (those born in the U.K. rather than migrants to the U.K.) experiencing psychosis.

Aim

The current study aimed to explore the stigma experiences of second-generation British-Asian people using Early Intervention in Psychosis (EIP) services.

Method

The present study took a critical realist ontological position and a contextualist epistemological position. A qualitative research methodology was employed and semi-structured interviews were conducted with a total of 10 participants. Thematic Analysis was used to interpret findings. Recruitment took place in EIP services in an urban and diverse area using purposive sampling.

Findings

Four themes and twelve sub-themes were constructed. The main themes included 'the burden of silencing', 'the un-noticed aspects', 'experience as the other' and 'finding ways to cope and thrive'. Themes incorporated forms of internalised and public stigma. They describe how participants felt distressed and silenced by stigma. Themes also explored dual identities and how participants' straddled eastern and western frameworks of understanding. Additionally participants outlined ways in which EIP services had not noticed these aspects of them. Themes also captured 'othering' experiences faced by participants like discrimination and islamophobia which led to isolation and exclusion. The importance of supportive relationships and social inclusion was also described within the findings.

Discussion

This study was able to explore second-generation British-Asian peoples' experience of stigma. Findings were discussed and linked to theory and previous research. Multiple intersecting stigmas were overarching across the findings. The current study adds novel insights about an under-researched population who have experienced historic and present-day stigmatisation and marginalisation in society. Strengths and limitations, dissemination and the researchers' reflections are presented. Implications for clinical practice and future research are discussed based on specific study findings.

Chapter 1. Introduction

Chapter Overview

This chapter is an overview and understanding of psychosis, stigma and the South-Asian population in the U.K to provide background into the study. Firstly, the conceptualisation of psychosis will be considered including an overview of the biological, psychological and psychosocial models. Literature, theories and research about stigma will be summarised and reviewed. Next, the experiences of South-Asian people in relation to mental health, race, culture and stigma will be outlined. The introduction chapter concludes with a thematic synthesis of South-Asian peoples' experiences of stigma related to mental health. It includes an overview of research aims and questions.

Terminology

The term 'schizophrenia' is a psychiatric construct based on a medically developed diagnostic category. Its use has been increasingly challenged by service-users (British Psychological Society; BPS, 2014). Survivor movements believe that this language further pathologies and labels human experience and advocates for terms like 'hearing voices', 'seeing visions' and 'unusual experiences' to describe experiences of psychosis (Hearing Voices Network, 2018). Furthermore, disciplines like Psychology, Sociology and Anthropology consider alternative discourses to understand psychosis experiences. Consequently, medicalised terms like 'schizophrenia' and 'mental illness' have been avoided where possible. 'Psychosis' is a commonly preferred term by service-users (BPS, 2014). For the purposes of this thesis, 'psychosis' is used as an umbrella term for those who identify as hearing voices and holding culturally-unacceptable beliefs such as paranoia and delusions.

The use of terms like Black Asian Minority Ethnic (BAME) and Black Minority Ethnic (BME) has attracted differing opinions. Some believe that the term is imposed for political-correctness, used to group together people who are other than white, without accounting for significant differences and disadvantages of those labelled with the term (Eddo-Lodge, 2017; Phillips, 2015). Indeed, by its very nature, it will not be possible to find a term which represents a vast number of ethnicities which have been traditionally grouped together. Therefore terms such as BAME and BME will be avoided. Where possible the ethnicity identified by the individual will be used or the term 'People of Colour' (POC) which is considered to be a socially-acceptable term, in line with social justice movements (Adams, Bell & Griffin, 1997; Eddo-Lodge, 2017).

Definition of Psychosis

According to National Institute of Health and Care Excellence (NICE), approximately 1% of the population in the United Kingdom (U.K.) are thought to experience psychosis (NICE, 2014). Psychosis has been broadly understood as a disturbance in thought, emotion or behaviour which can impact an individual's capacity to make sense of reality (Bentall, 2003; NICE, 2014). The term "psychosis" refers to a mental state characterised by positive and negative symptoms (Mellor 1970). Positive symptoms are understood as the presence of certain, unexpected experiences (Fletcher & Frith, 2009). They are multidimensional and include delusional beliefs and hallucinatory experiences which are culturally inconsistent and sometimes referred to as 'unusual experiences' (BPS, 2017). Negative symptoms are understood as the absence of certain expected traits (Fletcher & Frith, 2009). These include low mood, social withdrawal, alogia and loss of motivation. The type and severity of psychosis

experience is variable. NICE (2014) describe psychosis as referring to "the group of psychotic disorders that includes schizophrenia, schizoaffective disorder, schizophreniform disorder and delusional disorder" (pg.5).

The Development and Biological Understanding of Psychosis

The study of psychosis dates back to the work by Emil Kraepelin, a German psychiatrist. He considered this condition as an ongoing deterioration and decline in a person's mental state and a disintegration of their cognitive functioning (Kraepelin, 1919). Kraepelin believed psychosis was a result of a brain disorder. Following Kraepelin's work, Eugen Bleuler (1911; 1950) introduced the term "schizophrenia" which translates in Greek as the "splitting of the mind". This categorisation is still reflected in the psychiatric diagnostic criteria such as the DSM-V (American Psychiatric Association, 2013). Biological understanding of psychosis being a long-term disease related to abnormalities in the brain (Deacon, 2013), genetics (Weinberger et al., 2001) and a chemical imbalance (Hess, Bracha, Kleinman, & Cresse, 1987) is still a dominant conceptualisation of psychosis. Consequently, guidance (NICE, 2014) still draws on a medical approach, recommending psychotropic treatment as a first-step for those experiencing psychosis.

However, the medical model has been criticised for the problems with diagnosis, such as its usefulness, reliability and validity (BPS, 2014). It has been suggested that it is not possible to define, ascertain and separate psychosis from normative developmental processes (Meissner, 1981) as it exists on a continuum (Keyes, 2002). It may not be meaningful to name experiences as 'psychosis' and understand them as an illness (Insel, 2013). Diagnosis may feel stigmatising for individuals who do not perceive their experiences negatively. It is argued that a biogenetic

understanding of distress increases the likelihood of the stigmatised individual being categorised as different and distanced from a 'normal population' in a separate social outgroup (Read & Harre, 2001). Thereby a medicalised framework of understanding permits society to distance from people experiencing distress (Link & Phelan, 2001). Consequently, a change in paradigm has been explored. It is argued that psychological and social conceptualisations to psychosis are a more helpful alternative to the medical model (BPS, 2011).

Psychological Understanding of Psychosis

Psychodynamic understanding of psychosis. The psychodynamic understanding of psychosis was historically influenced by the biological approach. According to the psychodynamic theory, psychosis is considered fragmentation of a person's reality stemming from past and present relationships and experiences (Bateman & Holmes, 1995; Freud, 1894; 1911). The psychodynamic approach views psychosis as a defence against unbearable parts of reality (Freud, 1894; Martindale & Summers, 2013). Freud believed distress is displayed through defence mechanisms (Hingley, 1997). Examples of these defences used during psychosis include denial, projection, projection identification, splitting, fragmentation, attacks on linking, disordered thinking and a manic defence (Martindale & Summers, 2013). Klein (1946) suggested 'splitting' is used to ward off extreme persecutory anxiety as a normative part of child development. However, if infants do not have supportive enough caregivers, splitting may develop into reality distorting defences (in some cases defences may form psychosis experiences). The psychodynamic approach attempts to understand why fragmentation occurs and integrates experiences into a coherent account (Bion, 1962; Klein 1946).

However, empirical evidence of psychoanalysis is very limited and there is no consensus between contemporary researchers on the nature and existence of the unconscious (Bargh & Morsella, 2008). Other difficulties of the model are that psychoanalysis is not falsifiable (Popper, 1986) and interpretations of the same phenomena may differ between psychoanalysts (Colby, 1960). Albeit, psychoanalysis does point towards the significance of interpersonal interactions based on attachment which have been widely acknowledged and will now be outlined.

Attachment theory. Attachment theory proposes the development of close attachments is essential (Bowlby, 1980). Attachment theory is helpful to understand a person's relationships, interpersonal functioning and coping with distress (Bowlby, 1980). During childhood, mental representations are established about the self in relation to others which form the basis of their internal working models (Danquah & Berry, 2013). Secure attachment involves infants feeling they can rely on their caregivers to attend to their needs. These include caregivers being in close proximity to the infant to provide emotional support and protection (Bowlby, 1980). Secure attachments allow children to feel safe from perceived threats and explore their surroundings (Ainsworth & Bell, 1970; Bowlby, 1980).

Insecure attachments develop when infants have not been able to rely sufficiently on caregivers to meet their needs (Bowlby, 1980). There is evidence that shows disrupted attachment has a key role in the development of psychosis (Berry, Wearden, Barrowclough & Liversidge, 2006; Bucci et al., 2014; Gumley et al. 2014). Insecure attachment can increase a person's vulnerability to a psychological distress and psychosis (Berry et al., 2007; Berry & Drake, 2010; Read, Van Os, Morrison, & Ross, 2005). Birchwood (2003) suggested that it is harder to integrate and explore psychosis experiences if individuals have had difficulties in

early attachment, which in turn affect their internal security. In particular those with attachment style like ‘avoidant’ or ‘dismissive’ have an increased likelihood of experiencing psychosis (Couture, Lecomte, & Leclerc, 2007; Dozier, 1990; Ponizovsky, Nechamkin, & Rosca, 2007).

It is important to consider family relationships when understanding psychosis, particularly ‘Expressed Emotion’ (EE) (Brown, 1985). It is thought that being raised in families with high negative EE such as hostility, criticism over-intrusiveness increases vulnerability of developing psychosis (Vaughn & Leff, 1976; Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). However, EE was found to not be indicative of relapse in Asian families, illustrating that EE is culture-specific (Hashemi & Cochrane, 1999).

Cognitive models of psychosis. Cognitive models offer a psychological framework to understand psychosis (Mander & Kingdon, 2015). Cognitive-Behavioural Therapy (CBT) suggests that the development of mental health problems is based on attachment difficulties and stressful life events which manifest as negative beliefs about themselves and others (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). CBT for psychosis (CBTp) focuses on the way people appraise their psychosis experiences to reduce distress and improve functioning (Garety et al., 2001; Morrison, Renton, Dunn, Williams, & Bentall, 2003). There are two main CBT models for psychosis which are summarised below.

Morrison (2001) developed an integrative cognitive model of delusions and hallucinations based on existing literature on anxiety and depression literature. He suggested psychosis is cognitively developed in a similar way. Morrison (2001) argues that psychosis is fundamentally misinterpreted intrusions causing distress. Morrison proposes that these misinterpretations are influenced by societal knowledge and a critical view of the self which

can have a negative impact on a person's cognitive, emotional, behavioural and physiological state. For example the negative misinterpretations can lead to selective attention (cognitive), fear and anxiety (emotional), safety behaviours (behavioural) and tension (physiological). Morrison (2001) suggested that factors such as biological, genetic, and cognitive disruptions increase biopsychosocial vulnerability. Furthermore Morrison (2001) emphasised that traumatic and adverse early life experiences lead to harmful beliefs about the self, others and the world increasing the likelihood of misinterpretations and ultimately psychosis experiences.

Garety et al., (2001) developed a positive symptoms cognitive model of psychosis. Their model uses a biopsychosocial understanding incorporating biological, psychological and social theories. Garety et al., (2001) argue that a person's biopsychosocial vulnerability can be influenced by events and pre-existing harmful beliefs about the self, others and the world can lead to psychosis experiences. Garety et al., (2001) highlight two types of cognitive disturbances which result in the occurrence of psychosis. The first cognitive disturbance is difficulties holding previous memories, which then lead to the inability to process and interpret information in the present. This then has an impact on sensory feedback. The second cognitive disturbance is the struggle to identify and differentiate the internal experience. Positive symptoms of psychosis manifest as a result of cognitive disturbances together with emotional changes, particularly low self-esteem.

CBTp has come under recent scrutiny for "overselling" its effectiveness (McKenna & Kingdon, 2014). Jauhar et al., (2014) conducted a systematic review and meta-analysis of the effectiveness of CBTp and identified that it has a small range therapeutic effect. Both models stress the importance of psychosocial factors; however it has been argued that CBT fundamentally propagates a particular western worldview, ignoring cultural factors (Kinouani,

2017). Furthermore, Kinderman (2017) puts forward that CBT negates significant social and political causes of distress by focusing on people's interpretations, thus locating blame inside individuals and ignoring socio-political factors.

Psychosocial Understanding of Psychosis

It is argued that psychosis occurs in response to stressful life experiences (Laing, 1960, 1964; Szasz, 1960). More recently, Romme and Escher (1989) and Bentall (2003), suggested hearing voices and paranoia were externalisations that serve as protective functions to help individuals manage real situational threats and were understandable responses to traumatic life experiences. Furthermore, following the development of the anti-psychiatry movement and the growth of human rights has strengthened a change in the way psychosis is conceptualised (Kings Fund, 2014). An alternative discourse has emerged which views psychosis by incorporating psychological and social influences.

Trauma, adversity and psychosis. There has been a significant increase in research into the association between the development of psychosis and trauma life events (Moskowitz, 2011). Research suggests that psychosis can be significantly influenced by adversity and trauma including violence, sexual abuse, neglect, bullying, migration, social deprivation and racism (Mander & Kingdon, 2015; Varese et al., 2012). Alsawy, Wood, Taylor, & Morrison, (2015) found a prevalence of 72% of people experiencing psychosis (ranging from across 50% to 98% research studies) had also experienced trauma and adversity. Studies have shown that 70% of people develop voice hearing after a traumatic event (Romme & Escher, 1989).

Social and environmental influences. Social and environmental factors have a considerable influence on the risk of developing psychosis and need further attention (Cantor-Graae, 2007; Harrison et al., 2001). There are a wide range of psychosocial factors which influence the development of psychosis (Read et al., 2014). Furthermore it has been established that social disadvantage and social isolation are associated with increased risk of psychosis (Dean & Murray, 2005). Poverty is consistently associated with psychosis and can even determine choice of treatment and diagnosis given to individuals (Read, 2010). Low socio-economic status is also associated with psychosis (Cantor-Graae, 2007; Dean & Murray, 2005). Norman et al., (2005) found that reduced positive symptoms of psychosis are associated with supportive social environments. Living in an urban area is often associated with increased risk of psychosis (Freeman, 1994; Kirkbride et al., 2017; Pedersen & Mortensen, 2001; Van Os et al., 2001).

It has been argued that considering a person's access to social and economic power is important to develop a better understanding of their distress (Johnstone & Dallos 2013; Smail, 2005). Wickham, Taylor, Shevlin and Bentall (2014) have found that social deprivation and social inequalities play a crucial role in the manifestation of psychosis. They suggest ameliorating economic injustice may promote the population's mental health. Ignoring these factors is associated with epistemic injustice (Fricker, 2007), which refers to the unfairness of having a shared, just and representative understanding of a person's experience.

Increased psychosocial factors can lead to psychosis, however further understanding is still needed (Bentall et al., 2012; Read et al., 2014). The Power Threat Meaning Framework (PTMF) was recently developed by Johnstone et al., (2018) as an alternative to a medical conceptualisation of mental health. PTMF emphases understanding distress as an

understandable response to threat and it endorses focus on narrative and context. It considers how discrimination and social power influence individual narratives. However, Scheherazade (2018) argues that PTMF is a product of the conflicting discourses between psychiatry and psychology, which detracts from individuals' lived experience. Consequently, Scheherazade (2018) suggests PTMF disempowers service-users by taking away their voice to define their own experiences. The prevalence and association between ethnic minorities and psychosis will be discussed later in the introduction chapter.

Service Provision for Early Psychosis

Research has shown the prevalence of psychosis vastly increases in those aged 14 and above, with peak incidence in adolescence and early twenties (Gillberg, Wahlström, Forsman, Hellgren, & Gillberg, 1986; Thomsen, 1996). The outcomes for young people experiencing first episode of psychosis (FEP) appear to be worse in comparison to adults with FEP (Hollis & Rapoport, 2011; Robinson et al., 1999a). Furthermore, delayed access to treatment during early-onset psychosis is associated with poorer future outcomes (Bottlender et al., 2003; Harrigan, McGorry & Krstev, 2003; Robinson et al., 1999). The first three to five years of psychosis are considered a critical period (Birchwood, Tood & Jackson, 1988).

The Early Intervention in Psychosis (EIP) model was first developed in Melbourne, Australia (McGorry, Edwards, Mihalopoulos, Harrigan & Jackson, 1996). Since, the EIP model has been adopted in the U.K. (McGorry, Killackey & Yung, 2008). EIP services have arisen as a result of more biopsychosocial approaches to understanding psychosis (McGorry et al., 1996). The approach focuses on identification and treatment during the formative years of psychosis. In 2001 the development of early psychosis teams was considered "a priority"

(Department of Health; DoH, 2001). Consequently, timely access to secondary mental health services for those experiencing FEP is recommended (NICE, 2009; 2013; 2014). Significantly, more recent guidance has recommended that service-users under the care of EIP should be offered psychological treatment within two weeks of joining the service (NICE, 2015; 2016). This includes CBTp and family intervention. Studies show that people referred to EIP services receiving specialist treatment, attain better engagement, improved symptomatology, recovery, social inclusion and reduced relapse rates (Bird et al., 2010; Petersen et al., 2005).

Summary of Understanding of Psychosis

The dominant understandings of psychosis have been presented. The medical conceptualisation of psychosis has dominated historically and continues to do so. This can unhelpfully lead to stigma for people experiencing psychosis (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Kvaale, Gottdiener, & Haslam, 2013). However, psychosocial theories challenge biological approaches and are now more widely acknowledged. This is demonstrated in psychosocial approaches being integrated into national treatment guidelines (NICE, 2014). This section explored understandings of psychosis to provide context within which stigma is considered in the following sections.

Stigma

Stigma is the distinguishing mark of a particular circumstance, quality or person which is perceived as undesirable. The word stigma is derived from the Greek language specifically the term “stizein” which indicates a person who is tarnished in some way (Arboleda-Florez, 2002; Goffman, 2009). Historically it was used to describe people from a low socio-economic status, slaves and criminals, signifying them as defective, bad, tainted, blemished and immoral within society (Arboleda-Florez, 2002; Goffman, 2009). It is thought that stigma still carries these negative connotations in modern society, particularly for people who are considered to be different to the majority of the population (Byrne, 2001). The phenomenon of stigma was originally explored by sociologist Emile Durkheim (1895) who wrote:

“Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviance, properly so-called, will there be unknown; but faults, which appear venial to the layman, will there create the same scandal that the ordinary offense does in ordinary consciousnesses. If then, this society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such” (p.68).

Durkheim (1895) distinguished stigma as a less desirable public perception resulting in deviation from social norms. Goffman (1963) was an influential sociologist who further developed the conceptualisation of stigma. He asserted that all individuals have a social identity exhibited through social interactions. He believed that stigma was the result of a person’s social identity being damaged. Goffman (1963) defined stigma as ‘‘an attribute that is deeply discrediting’’ and considered those who experience stigma as “spoiled”, “tainted” and “discounted” (p.13). Goffman explained that stigma occurred through the individual’s internalisation of negative societal beliefs. Goffman (1963) proposed three categories of stigma:

'abominations of the body' (i.e. physical deformities); 'blemishes of individual character' (i.e. tarnished character), and 'tribal stigma' or 'tribal identities' (i.e. race, religion, nationality). There has been criticism of Goffman's work for not acknowledging the impact of the environment and the interaction of societal ideas, but instead locating stigma within the person (Link & Phelan, 2001).

Theories of Stigma

There are two key overarching theoretical models of stigma (Link & Phelan, 2001; Corrigan & Watson, 2002). These models and related research are outlined below.

Link and Phelan's (2001) theoretical framework of stigma. Social psychologists Link and Phelan (2001) developed a five-part model of stigma related to mental health. They believed that stigma needed to be better conceptualised to include the complexity of relational and social influences. Link and Phelan (2001) proposed that consequential social rejection can lead to social withdrawal which can then influence self-esteem, shame and vulnerability. Their model of stigma is outlined with a description of each component below.

***Labelling*.** Labelling is considered socially constructed and a way of marking a clear difference. These differences are distinguished because they pose a social threat to the 'norms' of their respective society. For example, a label may be particularly given to those from a marginalised group. They suggested that labelling is culturally-bound due to different cultural interpretations and conceptualisations. Labelling is the first component of the model that links to next component 'stereotypes'.

Stereotypes. The linking of widely culturally held assumptions of an undesirable label may result in stereotypes. They assert that stereotypes develop as people are predisposed to categorise information to make sense of their world and that these categorisations are based on social interactions within their social worlds. Mental health is linked to negative generalised beliefs or stereotype such as unpredictability, volatility and dangerousness (Corrigan et al., 2012). Negative stereotypes leads to the public's separation to those who have been stereotyped.

Separation. The separation component places the individual who has been labelled into clear category. This allows for separating an 'us' and 'them' providing distance from the undesirable label and the associated negative stereotypes. In the worst cases, when the individual poses a social threat, they are considered to be so different, that they are not even human. This further permits people to emotionally detach and respond in a negative way without feeling guilt about their actions. Separation results in Link and Phelan's (2001) fourth component, 'status loss and discrimination'.

Status-loss and discrimination. The labelled, negatively-stereotyped and socially isolated person then experiences loss of the standing within different areas of their life because they are devalued and rejected. A stigmatised person is then further disadvantaged by experiencing discrimination. This includes prejudice and maltreatment by others, limited or no opportunities and less social, economic and political power. Personal responses and distress are a consequence of status loss and discrimination.

Personal Reactions. 'Personal reactions' are the fifth and final component of stigma (Link & Phelan, 2001). It is thought that following stigmatisation, a person will feel set apart from others and experience disapproval and excluded by others, leading to social withdrawal

and psychological distress (Link & Phelan, 2001; Link, Yang, Phelan, & Collins, 2004). Link and Phelan (2001) identified that "stigma is entirely dependent on social, economic, and political power" (p.375) which determines whether an individual can challenge stigma or become a victim of stigma.

Critique of Link and Phelan's (2001) theoretical framework of stigma. Link and Phelan's (2001) model describes the formation and maintenance of stigma. The model presents the relational, social and evolutionary nature of stigma. However the model has been criticised for not thoroughly examining personal responses to stigma and does not have a clear enough explanation for the role of society affecting stigma. It has been argued that a clear distinction and conceptualisation should be made between externalised (public) and internalised (self) stigma (Corrigan & Watson, 2002; Major & O'Brien, 2005; (Rusch, Corrigan, Powell, et al., 2009). Corrigan and Watson (2002) presented their model of stigma which aimed to address this.

Corrigan and Watson's (2002) theoretical framework of stigma. Corrigan and Watson (2002) outline stigma as the "negative reactions that the general population has to people with mental illness" (p.16). Corrigan and Watson (2002) developed a theoretical model which stresses two specific components: public stigma and internalised-stigma. They suggest that public and internalised stigma are interconnected and influence one another (Corrigan & Watson, 2002; Corrigan, Kerr & Knudsen, 2005).

Public-stigma. Public stigma is the negative social, behavioural, affective and cognitive responses towards someone with a perceived stigma (Corrigan & Watson, 2002). Corrigan and Watson's (2002) model interlink with concepts from Link and Phelan's (2001), in that they view public stigma through stereotypes, prejudice and discrimination. Negative stereotypes are culturally-bound and develop when people appraise them as 'negative' leading to prejudice. In turn this forms prejudicial attitudes (Thornicroft, Rose, Kassam, & Santorius, 2007). What is crucially different to Link and Phelan's (2001) model is that Corrigan and Watson (2002) suggest that an individual must be in agreement with the label and the negative stereotype, allowing negative emotional responses to prejudice. According to Corrigan and Watson (2002) discrimination is the negative action or response based on prejudice. Types of discrimination can include bullying, fear, avoidance and physical harm causing great concern. Discrimination can occur at different levels such as individual, social and structural (Corrigan & Watson, 2002; Corrigan, Kerr & Knudsen, 2005; Link & Phelan, 2001). Discrimination is thought to be the most detrimental and harmful aspect of public stigma.

Public stigma and media. There has been extensive research which shows media influences public stigma by depicting negative and misleading ideas about mental health (Baun, 2009; Tartakovsky, 2015). The Sun newspaper published a front page article titled "1,200 KILLED BY MENTAL PATIENTS". (The Sun front page, 7 October 2013). The article stated that: "disturbing failings in Britain's mental health system… have allowed high-risk patients to kill 1,200 people in a decade". This article was strongly criticised for being misinformed (Appleby et al., 2013). It also led to concerns that this kind of tabloid reporting might generate more negative public attitudes and further stigmatise individuals experiencing distress (Thornton and Wahl, 1996; Angermeyer and Matschinger, 1995; Torrey, 2011).

Internalised-stigma. Internalised-stigma (sometimes referred to as self-stigma) is the self-directed negative social, behavioural, affective and cognitive responses (Corrigan & Watson, 2002). Self-stigma stigmatisation is a psychological process which can be conscious or unconscious (Corrigan & Watson, 2002). It includes the identification and internalisation of elements of public stigma (i.e. negative stereotypes, prejudice and discrimination) (Corrigan & Watson, 2002; Pryor & Reeder, 2011). Internalised-stigma can have a harmful influence on a person, such as "diminished hope, self-esteem, and achievement," which further worsens their self-devaluation (Jones & Corrigan, 2014, p. 18). According to Corrigan and Watson's (2002) model, there are two main concerns about internalised-stigma depending on how a person makes sense of their experience: the harmful influence on self-esteem and 'righteous anger'. If internalised-stigma is egosyntonic (fits with how a person sees themselves) and internalised, they may develop low self-esteem (Corrigan & Watson, 2002). However, if internalised-stigma is egodystonic (does not fit with how a person sees themselves) and deemed unjust, they may develop 'righteous anger' (Corrigan & Watson, 2002). Moreover, social factors may impact the development of stigma such as social networks, family and social identity (Corrigan & Watson, 2002).

Process of stigmatisation. Watson, Corrigan, Larson and Sells (2007) have outlined a cognitive process which develops and maintains internalised-stigma. This includes stigma awareness, stigma agreement and self-concurrence. The process of stigmatisation is initiated when the individual who is stigmatised consciously becomes aware of public stigma, known as *stigma awareness* (Watson & River, 2005). Next, the person also advocates the associated unfavourable and harmful stereotype which is identified as *stigma agreement* (Corrigan, Watson & Barr, 2006). Lastly, the individual applies the associated unfavourable and harmful stereotype to themselves personally making them *self-concurren*t. This then solidifies the

process of self-stigmatisation. It is the presence of stigma agreement and self-concurrence following stigma awareness that establishes the process of stigmatisation.

Critique of Corrigan and Watson's (2002) theoretical framework of stigma. Corrigan and Watson's (2002) model has developed a more detailed psychological understanding of stigma. The model has informed therapeutic assessment, intervention and research (Corrigan & Shapiro, 2010; Mittal, Sullivan, Chekuri, Allee & Corrigan, 2014). However, although Corrigan and Watson (2002) suggest that self-stigma would not exist without public stigma, they identified stigma as "the person's problem" (p.71). Also they do not clearly explain why stigma can be internalised for some and not for others.

Psychological Models of Stigma.

Psychological models of stigma centre on the complexity of the internalisation of stigma and resulting emotional distress. The most salient psychological models of stigma are discussed below.

A cognitive approach to understanding internalised stigma. The cognitive-behavioural approach proposes that emotional distress is maintained by negative thoughts, beliefs and appraisals (Beck, 1976; Beck, Rush, Shaw, & Emery, 1979). Life experiences inform a person's beliefs about themselves, others and the world. Distressing or threatening experiences can then develop into more unhelpful (or dysfunctional) ways people respond to these beliefs. This can lead to triggering situations or a maintenance cycle of negative thoughts, emotions, physiological responses and behaviours (Salkovskis, 1991). Stigma could be thought of as a harmful, discriminatory experience resulting in a person internalising these beliefs about

themselves, others and the world, influencing thoughts, emotions, physiological responses and behaviours. A recent integrative cognitive model of stigma has been proposed (Wood, Byrne & Morrison, 2017). This CBT-based framework supports the development of idiosyncratic formulations of internalised stigma. Wood et al., (2017) recognise the social context causing and maintaining internalised stigma, thus establishing an integrative cognitive model of stigma.

Social mentality theory and stigma. Social mentality theory (SMT) proposes internalised stigma is a response to social threats (Gilbert, 2010). It is hypothesised that stigma poses a threat to social roles by influencing perceived social rank and incurring external and internal shame. External shame is the belief that others will perceive the individual in a rejecting, detrimental way. Internal shame is the belief that the individual will perceive themselves in a rejecting, detrimental way (Gilbert & Procter, 2006; Gilbert, 2010). Consequently, to protect their social role, individuals submit to social order to avoid shame (Matos, Pinto-Gouveia, & Gilbert, 2012). Birchwood et al., (2007) draw on SMT to conceptualise how social anxiety develops in those experiencing FEP. They propose an other-to-self process which develops from internalised cultural ideas of mental health related stigma. External shame such as fear of others' rejection or judgement results in internal shame and negative self-focus. This social focus can result in social anxiety (Clark, 2001). Birchwood et al. (2007) demonstrate how stigma and shame can cause distressing emotional responses.

Critical summary of psychological models of stigma. These models broadened understanding of the internalised experience of stigma. For example how shame can maintain internalised stigma. Additionally, the models provide clinicians direction on how they can work with those experiencing internalised stigma, by using CBT formulations (Wood et al., 2017). However, the models focus on individual aetiology rather than a social aetiology whereby the

'problem' is rooted in the individual, rather than dominant social discourses which perpetuate and maintain stigma and marginalisation (Read et al., 2014). As a result, structural inequality is maintained as well as positioning those stigmatised in sick role (Parsons, 1951) and judgements are made about whether people are legitimately unwell (Beresford, 2016). From a systemic perspective, this sets up the dynamic of those that are 'being helped' and those that are doing the 'helping' (Johnstone & Dallos 2013) which may further polarise those who are disadvantaged (Marmot, 2012; Hoggett, 2006). Significant factors like socio-economic status are ignored such as poverty and unemployment.

Mental Health Related Stigma

Stigma is a serious concern for those experiencing mental health problems. Research into mental health stigma has been growing over the last twenty years (Elaine Brohan, Slade, Clement, & Thornicroft, 2010). The World Health Organisation (2001) note the harm caused from stigma such as experiencing rejection by family, friends, community and employers resulting in damaging consequences. These include loneliness, social isolation, low mood, access to services and the form of treatment provided. Stigma is recognised as significantly distressing for people with mental health experiences (Dinos et al., 2004).

Psychosis and Stigma

The gravity of stigma for those experiencing psychosis is significant. A large body of research has shown that in comparison to people with other mental health problems, people who experience psychosis, also experience significant increased stigma (Arboleda-Florez, 2005; Caveleti, Rusch, & Vaulth, 2014; Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002; Karidi et al., 2015; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). A large survey

showed that for 87% of people experiencing psychosis, stigma was a major concern (Schizophrenia Commission, 2012). Crisp et al., (2005) explored attitudes to mental health in the U.K. They found those experiencing psychosis are the most discriminated compared to other marginalised groups. Those with psychosis were considered to be the most violent, unpredictable, dangerous and least likely to recover. A further follow-up survey based on the same attitudes measure found that this was an ongoing pattern in the U.K. (Wood, Birtel, Alsawy, Pyle, & Morrison, 2014). Belonging to a stigmatised group can exacerbate internalised stigma (Corrigan & Watson, 2002; Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). Harmful stereotypes of psychosis exist specifically related to unpredictability, volatility and dangerousness based on societal beliefs perpetuated by the media (Burke et al., 2016; Corrigan et al., 2012).

Corrigan and Watson (2002) identified that those experiencing psychosis had also experienced discrimination from their social system. Similarly, Pitt et al., (2009) found that those experiencing psychosis felt disempowered, labelled and experienced stigma and social exclusion. There is evidence that people experiencing psychosis are more likely to be the target of violent crimes (Hiroeh et al., 2001). In addition, individuals who are experiencing psychosis report more verbal and physical abuse, social marginalisation than people experiencing anxiety or depression (Dinos et al., 2004). Furthermore it felt safer to say they were experiencing anxiety, depression or physical health problems and hide their psychosis experiences (Burke et al., 2016; Dinos et al., 2004). As a result, stigma for those experiencing psychosis is believed to represent a barrier to psychological wellbeing and social functioning (Burke et al., 2016).

FEP and stigma. Evidence shows that diagnosis of FEP can led to fear of stigma and can initiate identification with stigma (Franz et al., 2010; Iqbal, Birchwood, Chadwick, & Trower, 2000). Pitt, et al., (2009) employed a service user-led study to explore how a psychosis diagnosis resulted in internalised stigma. Participants identified they felt "labelled" and socially excluded following their psychosis diagnosis, triggering stigmatisation. Birchwood et al. (2007) found that for those experiencing FEP social anxiety was related to greater internal shame, hopelessness and low self-esteem. Furthermore they found that psychosis led to feeling socially inferior, marginalisation and loss of social status.

To date there has been only one systematic review which explores mental health related stigma for those experiencing FEP. Gronholm, Thornicroft, Laurens and Evans-Lacko (2017) systematic review encompasses qualitative, quantitative and mix-methods research studies. Findings showed difference or standing out negatively led to judgement from others, individuals feeling shame, embarrassed and worried about upsetting others by talking about their experiences. This attributes to a limited understanding of mental health and deters individuals from services out of fear of being judged and labelled. Gronholm et al., (2017) emphasis how stigma repeatedly presented as a barrier to help-seeking, in line with existing research (Dockery et al. 2015; Ferrari et al. 2015).

Protective factors of stigma. A number of protective factors have been identified to cope with stigma. As previously discussed, secure attachments in the form of supportive relationships are significant, but also help to protect against stigma (Gumley et al., 2010). This is evidenced in qualitative study examining service-user perspectives (Pyle & Morrison, 2013; Wood et al., 2016) and in relevant stigma literature (Chronister, Chou, & Lao, 2013). Even if people have experienced stigmatisation on multiple levels, support from family and friends can

mitigate the impact of stigma on individual (Wood et al., 2015). Research suggests that peer-support and social-connectedness can moderate distress related to stigma (Leamy, Bird, Le Boutillier, Williams & Slade, 2011; Lim & Gleeson, 2014). Peer-support is argued to provide understanding, empathy and normalisation (Russinova et al., 2014). Repper (2013) suggested that peer-support can improve self-esteem and self-value, lessening the experience of internalised stigma. Furthermore, encouraging results have been found from treatments for internalised stigma which have involved peer-support (Corrigan et al., 2013; Russinova et al., 2014). Alongside social support, research has shown the value of individuals engaging in pleasurable activities and finding purpose in life to cope with psychosis (Pitt et al., 2007). Similarly, Lambri, Chakraborty, Leavey and King's (2012) suggest seeking fulfilment and quality of life are essential for those experiencing psychosis.

Critical View of Stigma

The most prominent protective factors were related to social-connectedness and supportive relationships (Gumley et al., 2010; Leamy, et al., 2011). Lack of social interaction and inclusion is argued to increase stigma (Longdon & Read, 2017). Limited social contact predicates stigma and alienation in local communities (Killaspy, 2007). This is a significant barrier given that social inclusion, connectedness and having a sense of identity is associated with more helpful outcomes for people experiencing psychosis (Leamy, et al., 2011). More focus on social rather than individual aetiology model would transcend medicalised perspectives to offer a post-colonial, critical perspective that sheds light on structural prejudice and discrimination which are often unchallenged (Harper & Vakili, 2008). It is thought this may lessen public stigma (Longdon & Read, 2017). Consequently, social change and a more dimensional approach to distress relative to a person's social world and environment have been

suggested as more meaningful (BPS, 2017; Harper & Vakili, 2008). Social systems of power and oppression need to be examined at how they interact and coincide at an individual, community and societal level (Cole, 2009; Link & Phelan, 2014). There are very few studies which have explored stigma in POC experiencing psychosis within the U.K. Chakraborty, McKenzie and King (2009) found African-Caribbean people in the U.K. experienced more social discrimination than White-British people with a diagnosis of psychosis. Their findings indicate how racial stigma, alongside mental health stigma may influence people. Thus highlighting the prominence of stigma multiple and intersectional stigma.

Multiple and intersectional stigma. Stigmatised identities may be multiplicative, interacting in a complicated manner to produce a given experience for individuals (Bauer, 2014; Panchankis et al., 2017; Turan et al., 2019). More recently, researchers have studied the effect of multiple stigmatised identities, within the paradigm of intersectionality. Crenshaw (1989) first coined the notion of 'intersectionality'. It examines how interlocking systems of power and inequality influence people who are most marginalized in society. Characteristics like gender, sexuality, ability, race and socio-economic status are thought to be intertwined and can simultaneously influence disadvantages at an individual (micro) level and societal (macro) level (Turan et al., 2019). The concept of 'intersectional stigma' has developed from the idea that multiple stigmatised identities converge (Bowleg, 2012). It is argued that stigma identities "do not exist in a vacuum" (Turan et al., 2019, p.2537); therefore it is not possible to tease part and explore individual stigma identities.

Critical summary of stigma. Stigma is considered to be a critical concern particularly for those experiencing psychosis. It is important to note that stigma is protected against through social connectedness (Gumley et al., 2010; Leamy, et al., 2011). It is argued that stigma is

rooted within a social, cultural, historical and political context (Harper & Vakili, 2008; Read et al., 2014; Beresford, 2016). Therefore going forward such factors need to not only be considered, but also integrated into the understanding, development and experience of stigma. This section aimed to provide context for the stigma related to mental health, specifically psychosis and an FEP population relevant to the current study. The following section will now explore the South-Asian population, incorporating the stigma related to race and religion to further contextualise this thesis.

South-Asian Population

The South-Asian population refers to people whose heritage originates from the South-Asian or Indian subcontinent, specifically India, Pakistan, Bangladesh or Sri Lanka. The end of British Empire involved partition, resulting in India, Pakistan and Sri Lanka being created as separate countries in 1947. Bangladesh formed later from what was East Pakistan. Increased numbers of South-Asian diasporic communities migrated to the U.K. in 1950s and 1960s due to the extended fallout from partition, for reasons such as expulsion, civil war and to pursue job opportunities. Since diversity is growing in the U.K., with South-Asian people (individuals whose cultural-heritage descends from India, Pakistan, Bangladesh and Sri Lanka) representing approximately 7.5% of the population in England and Wales (Office for National Statistics, 2011).

South-Asian population and mental health. Mental health problems are higher in minority groups in the U.K. (Rees et al., 2016; Williams & Earl, 2007). The DoH (2005) has stated the need to engage meaningfully with everyone regardless of their ethnicity. This five-year initiative aimed to reduce the inequalities in access to mental health services, develop

more cultural-awareness and improve equity in service provision. Despite this, there remains a low prevalence of South-Asian communities engaging and receiving treatment from mental health services (Bowl, 2007; Goodman, Patel & Leon, 2008; Ikram et al., 2014; Patel & Shaw, 2009; Williams & Mohammed, 2009).

South-Asian population and psychosis. It is important to note the disparities of psychosis between the South-Asian communities. Within the U.K., rates of psychosis are 2–4 times higher in individuals of Pakistani and Bangladeshi origin (Kirkbride et al., 2008). However the treated prevalence rates of the Pakistani and Bangladeshi population are less than half the white population (Cochrane 1977). Notably, research shows that Pakistani and Bangladeshi populations are significantly less well educated, more deprived and less "acculturated" than is the Indian population in the U.K. (Cochrane, 1983). Also, Gupta (1992) expressed concern that Asian service-users disengage with specialist mental health services and further information of the well-being of this population is not available. Birchwood et al., (1992) tentatively suggested that Asian people may have better rates of recovery from psychosis, if there is a higher level of family support. However, given this research is outdated and remains limited, firm conclusions cannot be made.

Second-generation South-Asian population and psychosis. To orientate the reader, second-generation South-Asian people are descendants from South-Asian people who were not born in the U.K. (i.e. first-generation or migrant South-Asian people). Descendants from migrant minority groups experience increased risk of psychosis in comparison to the majority population (Bourque, van der Ven, & Malla, 2011; Cantor-Graae & Selten, 2005; Harrison et al., 1988: McGovern & Cope, 1987; Littlewood & Lipsedge, 1988). Bhugra (2002) asserted that for ethnic minorities, the country of origin has lower rates of psychosis. It is the impact of

migration which produces high levels of stress and rates of psychosis. Bhugra (2002) identified rates of psychosis are even higher in the second-generation, thus suggesting that social factors such as cultural identity and racism may increase vulnerability to psychosis. Similarly, a recent study by Kirkbride et al., (2017) reviewed the FEP in relation to ethnicity and generational differences within minority groups in the U.K. Findings showed that rates of psychosis were raised for Black, Pakistani, and Bangladeshi groups in urban areas. In particular they found that second-generation minority groups were at increased risk of psychosis in comparison to the UK-born white British population**.** Kirkbride et al., (2017) suggested that social exposures, including socio-cultural adaptation, social isolation and discrimination experienced by minority groups were more prominent with the development of psychosis.

Critical summary of South-Asian population. From the research and literature outlined, psychosis appears to be a major issue for the South-Asian population. It is particularly problematic for the descendants of South-Asian people. However, very little is known about this population and their experience of psychosis given the low prevalence rates of engagement in mental health services (Goodman et al., 2008; Gupta, 1992). What is known is that government statistics show that a POC is more likely to be sectioned (Race Disparity Unit, 2019). It has been argued that psychosis and related diagnosis such as 'schizophrenia' are a result of racialisation (Fernando, 2018). Following the special hospital service authority inquiry, it was suggested that POC were associated as being more dangerous (Crichton, 1994). This may attract a psychosis diagnosis given that the diagnosis itself is associated with danger (Knifton, 2012). Therefore racism (racial stigma) is pertinent to the South-Asian population and will now be explored.

Racism

Racism (or racial stigma) occurs when a person is identified as belonging to a perceived inferior group by society. It can be based on social qualities like race, ethnicity or nationality. A common example of racism is where white people are considered civilised and superior and POC are considered primitive and inferior (Davids, 2011; Lowe, 2014). This is a longstanding concept. For example Fanon (1967) suggested POC who have been historically colonised face disadvantages to fit into the social, cultural and racial norms established by the wider white society. Sewell (2017) proposed that stigmatised and racialised groups can come to accept and internalise a 'damaged' identity. This is a form of internal oppresion (Pyke, 2010).

Those who are seen as inferior can become marginalised in society. An example of this is the othering and stigmatisation of South-Asian people and recent rise of Islamophobia in the U.K. (Tell Mama, 2018). Some people identifying as Asian fear being perceived as a threat, therefore denounce or distance themselves out of fear of discrimination attirbuted to being muslim (Hopkins, Botterill, Sanghera & Arshad, 2017). This leads to stigmatisation and marginalisation of people indentifying as muslim (Saeed, 2007) seen in the quote below.

"The fluidity of my own personal identity on any given day was further compounded by the changing labels assigned to Asians in general. As children in the 1980s, when my brother and I were stopped near our home by a skinhead who decided to put a knife to my brother's throat, we were black. A decade later, the knife to my throat was held by another "Paki", a label we wore with swagger in the Brit-Asian youth and gang culture of the 1990s. The next time I found myself as helplessly cornered, it was in a windowless room at Luton airport. My arm was in a painful wrist-lock and my collar pinned to the wall by British intelligence officers. It was "post 9/11", and I was now labelled a Muslim", Ahmed (2016, para 1-2).

Stuctural racism and mental health services. Structural racism is where racism is practiced within organisations (Stokeley & Hamilton, 1967). Psychological practitioners often remain silent about prejudice and discrimination based on inequality (Bhugra & Bhui, 1998; Lowe, 2006). Crehan and Rustin (2018) suggest clinicians' avoiding discussing difference and diversity as these issues can evoke anxiety, resulting in avoidance. Furthermore, Tjale and De Villiers (2004) assert that there is a miscommunication between euro-centric healthcare professionals and those from different cultures.

Summary of racism. This section explored racial stigma and how is exists within systems and society. Research shows that South-Asian people feel their racial and cultural difference excludes them from mental health services (Bowl, 2007; Greenwood et al., 2000; Hillier et al., 1994; Hussain & Cochrane, 2002; Islam et al., 2015; Penny et al., 2009). The significance of culture will now be outlined.

Culture

Culture can be conceptualised in different ways (Marsella & Yamada, 2007). It is thought to be rooted externally in social worlds, ideas and practices instead of being a fixed set of beliefs and values that exist within a person (Adams & Markus, 2004; Shweder, 2003). Markus and Kitayama (1991; 1994; 2010) suggest a person's experiences are informed by socio-culturally patterns that are reflective of how individuals implicitly and explicitly engage with the world.

Individualism and collectivism. It has been suggested that culture varies across two dimensions; individualism and collectivism (Hofstede, 2001). These dimensions relate to how

humans think, feel and navigate themselves within groups (e.g. families, friendships), (Arrindell, 2003). According to Hofstede (2001), individualistic cultures are thought to follow an independent self-schema, viewing the self as an autonomous, self-contained entity (typically western countries). In comparison, collectivistic cultures are thought to follow an interdependent self-schema, viewing the self as an entity related to others (typically non-western countries). However, these dimensions do not account for psychological differences between cultures (Kagitcibasi, 1997). Within interdependent, South-Asian culture, traditionally individual identity does not exist, instead people identify with a collective identity (Bhugra, 2004; Hofstede, 2001). Whereas, within western culture individual identity is considered an important part of adolescence and personality development (Waddell, 2002).

Western vs eastern models of understanding mental health and psychosis. It is widely noted that there are differences in the way mental health is understood in eastern and western cultures. Kleinman's (1980) developed the concept of 'Explanatory Models' (EM) of health. This denotes how people from different cultures understand and place meaning of different health conditions. EMs are "cultural interpretations of mental illness held by members of a social group strongly influence their response to persons who are ill and both directly and indirectly influence the course of the illness" (Good, 1997, p. 233). There are beliefs within South-Asian community that mental health is related to religion and spirituality (Charles, Manoranjitham & Jacob, 2007; Joel at al., 2006; Zafar et al., 2008).

EMs can differ in the understanding of psychosis. Western EMs often attribute psychosis to biological or medical causes, whereas eastern EMs attribute psychosis more supernatural and spiritual causes (Wahass & Kent, 1997; McCabe & Priebe, 2004). Arguably, it is more beneficial to consider religious, spiritual and cultural beliefs of mental health

experiences as part of a multi-faceted framework of understanding (Heffernan Neil, Thomas, & Weatherhead, 2016; Jablensky & Sartorius, 2008; May, 2012). Alongside this, researchers have proposed that frameworks of understanding are flexible depending on experiences (Good, 1997; Kleinman, 1980; Williams & Healy, 2001). However, when comparing the content of delusional beliefs in a Pakistani sample, Suhail and Cochrane (2002) found that the local culture of the country they inhabited identified more about the content of their beliefs than the culture of the country they were originally from.

Cultural identity. Although there may be fluidity between culture and EMs, positioning in-between cultural dimensions can be problematic (Hofstede, 2001). Cultural assimilation is a process whereby a minority group adapts themselves to resemble the dominant group so that they are seen as more 'socially-acceptable' to the dominant group (Berry, 1990; Boyer, 2001). Szapocznik, Kurtines, and Fernandez (1980) report immigrant populations may strive to adopt the customs of the host community in order to integrate and minimise their feelings of alienation. Degrees of acculturation fluctuate across generations (Persons, 1987). However, it is argued that minority groups should not have to 'culturally-adapt' to a dominant population (Krause, 2018). Arguably, post-colonialism in itself can lead to fragmentation of cultural identity (Hall, 1994). Historical context and expropriation informs identity; therefore cultural identity is a matter of the past, present and future. Furthermore, generational and cultural differences within families (Ennaji, 2005) can damage the internalised cultural identity. Stress may be caused by being stuck between two or more cultures. It involves splitting or disabling a person's sense of identity and cultural belonging (McKenzie-Mavinga, 2009).

Cultural belonging. Cultural identity conflict can influence belonging. Ontological insecurity refers to a person's sense of 'being' in the world. It was originally explored by Laing (1960) who identified the lack of stability in oneself to cope with life following his work with people experiencing psychosis. Giddens (1991) developed the concept to being unable to give meaning to the self, others, surroundings and reality, thus a person not knowing their identity and place in the world. Ontological insecurity is further compounded by migration, which is considered to impact both migrants and future generations' sense of home and belonging (Binaisa, 2015; Yuval-Davis, 2012). This highlights the difficulties of belonging to two cultures.

Summary of culture. This section explored the influence of culture in terms of understanding health, identity and belonging. Stigma related to mental health and race has already been discussed. Stigma within the South-Asian population will be focused on to lead to the systematic review.

Mental Health Stigma within South-Asian Culture

There is a taboo related to mental health within South-Asian culture (Kishore, Gupta, Jiloha, & Bantman, 2011). Given that South-Asian societies are interdependent and communal, social-status and image are considered paramount; anything that taints this image is seen as problematic within Asian communities (Triandis, 1995).

Al-Adawi et al. (2002) have asserted that attitudes to mental health in Asian communities are more devastating than the mental health experience itself. Similarly, Amri and Bemak (2012) found that those descending from Muslim countries like Pakistan and Bangladesh "believe that admitting to having a mental health problem is a form of loss of face

and shameful" (p. 50). Tabassum, Macaskill, and Ahmad (2000) identified South-Asian people were prepared to interact superficially with those who were stigmatised, but were significantly less likely to socialise with them or deem them suitable for marriage.

Gilbert et al. (2004) studied South-Asian women living in the U.K. and highlighted the relevance of mental health related stigma. They identified the term 'izzat' which has no literal translation to English but is a culturally-transmitted concept indicative of shame and honour which can be brought to others (i.e. family and friends) by one's behaviour. Given South-Asian communities descend historically from a collectivistic culture; research shows stigma is distressing for not only the individual person but also their entire family (Pirani, 2009).

South-Asian population, stigma and psychosis. There are high rates of internalised stigma and social exclusion for people experiencing psychosis in India (Koschorke et al., 2014). It has ramifications of negative feelings and fear of others finding out. However, it was proposed that better knowledge about psychosis is associated with lower level of stigma (Koschorke et al., 2017; Singh, Mattoo & Grover, 2016). Lauber and Rossler (2007) literature review found variations within and across countries and cultures in the intensity of stigma. However, overall stigma and discrimination are significantly problematic. In particular, dangerousness is a common belief and often leads to social exclusion. Families can both stigmatise the person with mental illness and in turn, themselves be stigmatised through association by the community (Lauber & Rossler, 2007).

Critical summary of stigma within South-Asian culture. Broadly the concept of stigma is understood across diverse cultures (Dovidio, Major, & Crocker, 2000). However given there are variations in the conceptualisation of mental health and psychosis in different cultures and sub-cultures, therefore the related associations of stigma may differ (Pescosolido, Olafsdottir, Martin, & Scott Long, 2008). There is limited research on stigma related to psychosis amongst the South-Asian population, within the U.K. (Bhugra 2002; Evans-Lacko et al., 2012; Kirkbride et al., 2017). However, these studies were conducted outside the U.K. where there may be different socio-political factors and cultural understandings of psychosis and stigma. Therefore, these studies may not be generalisable to South-Asian population in the U.K.

Summary of Research and Literature

The introduction chapter has sought to explore relevant research and literature. Psychosis greatly impacts psychological wellbeing, functioning and sense of reality. The associated public and internalised stigma further compounds a person's distress, alongside their psychosis. Furthermore, there are even more disadvantages and consequences for those with multiple stigma identities such as race. The South-Asian population was explored in relation to culture understandings and how pervasive stigma is within Asian communities. This chapter has contextualised stigma within a South-Asian and psychosis population. A systematic literature review will now be presented to synthesise how mental health related stigma is experienced by South-Asian populations in the U.K.

Systematic Literature Review

Rationale and Aim

Systematic reviews identify, summarise and evaluate data across multiple studies. They are considered the "gold standard" of reviewing literature (Clarke & Stewart, 1994). Whilst searching for systematic reviews that looked at mental health of South-Asian population, two reviews were found that incorporated aspects of South-Asian individuals' experiences of depression (Hussain & Cochrane, 2004; Trivedi, Mishra & Kendurkar, 2007). However both reviews focused solely on South-Asian women and were considered outdated. The aim of the current systematic literature review was to explore mental health related stigma experienced by South-Asian people in the U.K. The review question was:

What are South-Asian peoples' experiences of stigma related to mental health in the UK?

Method

The methodology of reviews should be reflective of their overall purpose (Dixon-Woods et al., 2006). Qualitative research allows for detailed exploration of experiences (Greenhalgh & Taylor, 1997). Given that the current review aimed to explore experiences of stigma, a qualitative systematic review was conducted. According to the PROSPERO database, the international register for systematic reviews (https://www.crd.york.ac.uk/PROSPERO/), there were no existing reviews or protocols of reviews underway exploring the stigma experiences of South-Asian people in the U.K. The current systematic review followed guidance using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Liberati et al., 2009).

Search strategy. As recommended by PRISMA, the search strategy was developed using Sample, Phenomenon of Interest, Design, Evaluation, Research (SPIDER; Cooke, Smith, Booth, 2012). The tool enables systematic retrieval of qualitative data for systematic reviews. A qualitative systematic search of existing, peer-reviewed literature was undertaken between May to June 2018. The electronic search of published literature was conducted using five journal databases: CINAHL Complete, Medline, PsycArticles, PsycInfo and E-journals. There were no date restrictions placed on year of publication of papers. The SPIDER criteria informed the search criteria and justifications for inclusion and exclusion criteria presented in Table 1 (Appendix A).

Quality control. The qualitative Critical Appraisal Skills Programme (CASP) tool was used to screen the quality and methodological strength of each paper (CASP, 2014). The tool is comprised of a sequence of questions within the domains of appropriateness of the research design, recruitment strategy, data collection, position of the researcher, ethics, methodological rigour, clarity of findings and value of the research.

Data analysis. Thomas and Harden's (2008) guidelines for thematic synthesis was followed to create a systematic synthesis of the relevant literature. It is argued that synthesising qualitative studies may de-contextualise findings (Sandelowski & Barroso, 2007). However, Thomas & Harden (2008) refute that qualitative syntheses are necessary to make data more accessible to a wider audience. Thematic synthesis was thought to be suitable for identifying data, interpreting rich material and synthesising data (Cruzes & Dyba, 2011). It advocates the interpretation of detailed subjective accounts which is in line with this study's epistemological and ontological positioning (i.e. contextualist-critical realism) further discussed in chapter two.

In accordance with the thematic synthesis process (Thomas & Harden, 2008), papers were read twice to have a thorough grasp of the studies. This ensured the researcher was fully immersed in the review process (Cruzes & Dyba, 2011). Data from study findings' was coded systemically line-by-line to develop initial descriptive themes. Only relevant data to the review was included. Comparisons were then made across the datasets and the researcher went 'beyond' the original data to develop main analytic themes, typifying thematic synthesis (Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004).

Participant quotes will be used to illustrate themes.

Results

Data extraction. The PRISMA diagram (Appendix A) outlines the search and screening process described. The titles and abstracts of the total 226 identified papers were screened to determine relevance. The papers were reduced to 160 papers following the removal of duplicates. After reading titles and abstracts, 140 papers were excluded as they did not meet the criteria. The remaining 20 full text papers were read in accordance with inclusion and exclusion criteria. One further paper was identified by citation searching by means of Scopus. In addition, two more papers were identified through a Google Scholar search. These additional papers were also screened and were included as they explicitly met the inclusion criteria. Therefore, 12 papers which explicitly met the criteria were selected and taken forward to review. Participants sampled in the included studies originated from within the Indian sub-continent (India, Pakistan, Bangladesh or Sri Lanka). There were two studies which included non-Asian ethnicities (Islam et al., 2015; Knifton, 2012). However, both studies distinguished the South Asian participants targeted in the current literature review when discussing emerging themes in the results section. Therefore these specific findings could be included. All included

studies were conducted between 2000 and 2017. Table 4 (Appendix C) shows summaries of the studies included in the review.

Methodical strengths and limitations. The included papers varied in terms of quality and methodological strength. They were assessed using CASP criteria (Appendix B). There were no papers rejected due to quality. Given the papers were peer-reviewed and provided relevant, rich and useful information in an under-researched area, it was felt important to include them in the current literature review.

All papers clearly stated their aims, methodology, data collection methods and findings adequately. Majority of studies discussed their recruitment process adequately and reported purposive sampling. The majority of studies were conducted in urban areas across the U.K. with a built-up South-Asian population. Consequently, findings may be comparable to similar areas with a large South-Asian population. Although the majority of studies commented adequately on the process of data analysis, some studies (Bowl, 2007; Hussain & Cochrane, 2003; Chew- Graham et al., 2002; Gilbert et al., 2004) would have benefited from clearer details about how this process was carried out.

Some studies did not specify the proportion sampled from individual South-Asian populations, for example Indian, Pakistani, Bangladeshi or Sri Lankan (Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Knifton, 2012). Studies by Penny et al., (2009) and Dogra et al., (2005) included young people and their families. They were the only studies that distinguished the different experiences between those born in the U.K. and those born outside of the U.K. All other studies did not account for this and reported South-Asian accounts as one homogeneous group (Bowl, 2007; Chew-Graham et al., 2002; Gask et al., 2011; Gilbert et al.,

2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015; Knifton, 2012; Wittkowski et al., 2011). As these studies did not report whether participants were migrants or non-migrants in their findings, they neglected generational differences within the South-Asian sample. Therefore, the application of the findings cannot be easily generalised to all South-Asian populations in the U.K.

Several papers did not discuss ethical approval (Bowl. 2007; Dogra et al., 2005; Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Knifton, 2012). Although some of the papers stated the researchers' ethnicity, there was no further discussion on researcher-reflexivity, researcher-participant relationship and potential researcher influences (Dogra et al., 2005; Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2s003; Knifton, 2012; Penny et al., 2009). Some studies questioned the reliability of their interpreters (Bowl, 2007; Chew-Graham et al., 2002; Gilbert et al., 2004; Greenwood et al., 2000; Islam et al., 2015; Knifton, 2012; Penny et al., 2009). There was an increased chance of data possibly being 'lost in translation'. Albeit without interpreters, these studies may not have been conducted in an under-researched area.

Themes. Themes include: 'how South-Asian communities tarnish mental health', 'shame and stuck-ness', 'cultural understanding of mental health related stigma' and 'difference and stigma leading to exclusion from services.' Perspectives of people identifying as South-Asian were synthesised to form the four themes presented below.

Theme one: how South-Asian communities tarnish mental health. South-Asian people were worried about how their mental health would be perceived by their community.

Many participants felt they experienced additional stigma and negative consequences specifically within Asian communities.

> "There is a huge stigma of being mentally ill in the public, but for us Asians there is a double disadvantage". (Wittkowski et al., 2011).

They had concerns around fear of judgement, blame, gossip within the Asian community and heritability of mental health experiences (Bowl, 2007; Chew-Graham et al., 2002; Dogra et al., 2005; Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015; Knifton, 2012; Wittkowski et al., 2011). There was an emphasis on striving to remain within social and cultural norms within the South-Asian community. It was damaging to be seen to have a mental health problem, demonstrated in the below quote.

> "I think for Asian people it's quite difficult having a mental health problem . . . Asian people aren't as accepting if you have a mental health problem and treat you very differently". (Penny et al., 2009).

Mental health problems were associated with loss of status in the community (Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015) and rejection of the individual by their families (Bowl, 2007; Gilbert et al., 2004). Mental health experiences were associated with stigma, specifically negative stereotypes, prejudice and discrimination within Asian communities. This theme captures how public stigma related to mental health tarnished individuals' standing within their family and in the wider Asian community.

Theme two: shame and stuck-ness. The internal distress related to stigma was present in all the studies included. Participants' had negative thoughts, ideas and experiences from their relationships, cultural community and wider community. Shame was frequently described in the included studies (Chew-Graham et al., 2002; Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015; Wittkowski et al., 2011). Shame was thought to not only affect the individual, but also other people such as family members (Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015). Bringing shame on family members was considered dishonourable and felt painful emotionally for individuals.

> "It could be if you talked to anyone else outside then it becomes a shame issue because it would be shameful if people find out". (Gilbert et al., 2004).

Several studies referred to stuck-ness and isolation (Chew-Graham et al., 2002; Gask et al., 2011; Wittkowski et al., 2011). Gilbert et al., (2004) identified that South-Asian women felt 'entrapped'. They suggested that this occurred as South-Asian women are disadvantaged in subordinate positions in relation to power due to cultural tradition, socio-economic adversity and oppression. This was associated with a loss of identity, self and control (Gilbert et al., 2004, Gask et al., 2011; Penny et al., 2009) and lead to despair and self-harm (Chew-Graham et al., 2002; Hussain & Cochrane, 2003).

> "I just got to the point where I couldn't take any more . . . I couldn't deal with him and the children and keeping it all going . . . I was too scared to say anything, so I just did this [cut wrists] to myself". (Hussain & Cochrane, 2003).

This theme epitomises distress related to internalised stigma of mental health problems. It describes how isolated how Asian individuals felt and how they perceived themselves as inferior because of wider beliefs held in Asian communities.

Theme three: cultural understanding of mental health and stigma. Within the current review, there was variation between participants understanding of mental health and stigma. Many papers identified that participants had an understanding of mental health based on South-Asian culture which impacted engagement with services that used a westernised understanding of mental health (Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015).

> "In Asian culture when they [people] are mentally depressed they don't feel very free in going to talk to people. In this country, if someone is English they will go and look for help and everything to make them better". (Dogra et al., 2005).

Religion, prayer and spiritual healing were very important and used to manage mental health and the associated stigmatisation (Islam et al., 2015; Knifton, 2012; Penny et al., 2009).

> "You see my religion is my spiritual food, if I don't eat it, I'll be ill". (Greenwood et al., 2000).

Furthermore, the current review found that culture and identity may have influenced how participants made sense of their mental health and stigma. In Chew-Graham et al.'s (2002) study, participants acknowledged differences across religious communities (i.e., Sikh, Hindu, Muslim) and locations in the U.K., but the experiences of Asian women across these communities were often similar. Bowl (2007) reported some participants identified more with western ideals. This raises questions about how individuals from a South-Asian background identify themselves and whether this shapes their experience of mental health and stigma.

Theme four: difference and stigma leading to exclusion from services. The consequences of differences in understanding mental health and public-stigma had an impact on wanting to seek help from services. South-Asian people preferred to manage mental health within the family, believing white mental health professionals would not understand them. This is highlighted in the quote below.

> "It's not just language and food . . . English people don't understand us, our world is completely different to theirs, it's the way we live, that's what they need to understand". (Hussain & Cochrane, 2002).

All of the papers made reference to a form of cultural exclusion. Language barrier issues shaped unhelpful experiences of services (Bowl, 2007; Greenwood et al., 2000; Hussain & Cochrane, 2002; Islam et al., 2015; Penny et al., 2009; Wittkowski et al., 2011). Studies reported that South-Asian people feared engaging with services that highlighted their 'differentness' and led to fear about being a burden and misunderstood by professionals (Greenwood et al., 2000; Hussain & Cochrane, 2002; Islam et al., 2015; Wittkowski et al., 2011).

This was compounded by a lack of awareness of religious beliefs and customs amongst professionals (Bowl, 2007; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; Islam et al., 2015; Knifton, 2012; Wittkowski et al., 2011). Moreover South-Asian people felt mistrustful of mental health services and had experience of prejudice, discrimination and racism within services (Chew-Graham et al., 2002; Greenwood et al., 2000; Islam et al., 2015; Wittkowski et al., 2011).

"Because you're Asian, they don't feel the need to bother", (Greenwood et al., 2000).

There were also fears of bias, being treated differently and pathologising of mental health experiences from services based on cultural identity (Chew-Graham et al., 2002; Hussain & Cochrane, 2002). Notably, some participants had different experiences of professionals. Studies conducted within EIP services reported staff as accommodating and considerate (Islam et al., 2015; Penny et al., 2009). However, participants who were in different services (Chew-Graham et al., 2002; Greenwood et al., 2000) felt discrimination by staff. This highlights how participants reported feeling excluded from mental health services.

Discussion

This review was the first to conduct a synthesis of South-Asian peoples' experiences of mental health stigma in the U.K. The review included a total of 12 peer-reviewed, qualitative studies. There were four main themes identified relevant to review question. These included 'how South-Asian communities tarnish mental health', 'shame and stuck-ness', 'cultural understanding of mental health and stigma' and 'difference and stigma leading to exclusion from services.'

The themes described the pervasive impact stigma had on South-Asian individuals. In particular, the process of internalised and public stigma related to mental health significantly affected South-Asian populations. These findings fit with established theoretical models outlining public and internalised stigma (Link & Phelan, 2001; Corrigan & Watson, 2002). However, what is different about the review findings is how pubic stigma was found to be particularly problematic in South-Asian populations. Similarly to Al-Adawi et al. (2002) who

asserted that attitudes within the community are more devastating than the mental health experience itself.

The theme 'cultural understanding of mental health and stigma' could be considered in the context of EMs and culture informing understanding of mental health (Kleinman, 1980; Markus & Kitayama, 2010). As previously discussed in the chapter, culture is highly influential in how people make sense and manage their experiences. Supporting this, Jablensky and Sartorius (2008) argue it is more beneficial for services to consider religious and cultural beliefs of mental health experiences as part of a multi-faceted framework of understanding.

The continued low prevalence of South-Asian populations engaging with services has been reported (Ikram et al., 2014). Therefore it is important to consider how factors such as language barriers and fears of being treated differently due to ethnicity influence exclusion from services. Notably, there were disparities between experiences of those using EIP services and those sampled in other settings. The EIP model attempts to engage service-users more flexibly, which might explain why participants in their studies reported more inclusion and better experiences with staff. Furthermore, the studies based in EIP services (Islam et al., 2015; Penny et al., 2009) were conducted following guidance to engage more minority groups (DoH, 2005). Nonetheless, participants from these studies also reported feeling culturally-excluded. Moreover, the review contains studies in which participants make reference to their difference leading to being excluded from services, following the government's directive (DoH, 2005)

A key limitation of the current review is that most studies included are dated and may not accurately represent how South-Asian people experience mental health stigma currently. The review needs to be interpreted tentatively as it consisted of a somewhat small number of

studies, which included small sample sizes. Nonetheless, the aim of synthesising qualitative research is to offer evaluation within the research area (Doyle, 2003). The current review analysed studies in an under-researched area. Also, arguably limited studies demonstrate the need for further research.

Due to limited studies, South-Asian perspectives were gleaned from different settings and mental health diagnoses in this review. In some studies, it was unclear whether participants had been given a mental health diagnosis, its complexity and the level of input by services. Psychosis is considered the most stigmatised mental health problem (Crisp et al., 2005; Wood et al., 2014). As it was not possible to focus on South-Asian people experiencing psychosis, the review findings may not accurately reflect those who experience the increased levels of stigma.

However, it was noted that South-Asian samples included migrants to the UK, first-generation and second-generation. Therefore the experiences of all three groups were not differentiated and instead amalgamated. There were no studies that solely captured people born and living in the U.K., whose heritage originates from Indian, Pakistan, Bangladesh or Sri Lanka. This is particularly pertinent given negative consequences are increased for the second-generation ethnic minorities (Bourque, van der Ven, & Malla, 2011; Cantor-Graae & Selten, 2005) outlined earlier in the chapter. Consequently, a marked limitation of the studies included and review is that significant generational differences between migrants and non-migrants were not separated.

Rationale for Current Study

The introduction chapter has explored how South-Asian people experience considerable stigma and exclusion in South-Asian communities and wider society, including mental health services (Chew-Graham et al., 2002; Greenwood et al., 2000; Hussain & Cochrane, 2002; Islam et al., 2015; Wittkowski et al., 2011). Despite the increasing diversity in the U.K. (Office for National Statistics, 2011), research on this population is dated and remains limited (Bhui et al., 2003; Goodman et al., 2008; Ikram et al., 2014; Kirkbride et al., 2017). Thus highlighting that more needs to be done to bridge the gap to ensure that all South-Asian service-users feel included within services and supported meaningfully.

Addressing stigma associated with psychosis is a priority to U.K. government (Her Majesty's Government, 2011). Psychosis is considered the most stigmatised mental health problem (Crisp et al., 2005; Wood et al., 2014). In particular, public stigma (Corrigan & Watson, 2002; Corrigan & Shapiro, 2010) and internalised stigma (Thornicroft et al., 2009) have been demonstrated to be a significant problem for those experiencing psychosis.

Furthermore, this chapter has demonstrated the negative impact of stigma, particularly on South-Asian people (Al-Adawi et al. (2002). The systematic review found how stigma significantly influences South-Asian people, in the form of internalised stigma, public stigma and exclusion from mental health services. Thus highlighting the importance of understanding how and why people can be stigmatised based on their background and experiences. A gap of the current review and existing research is the lack of research from perspectives of second-generation South-Asian people who have experienced psychosis (Bourque, van der Ven, & Malla, 2011; Cantor-Graae & Selten, 2005; Kirkbride et al., 2017). This leads the way for the focus of the current study.

Focus of current study. To orientate the reader, for the purpose of the introduction chapter and review, the umbrella term 'South-Asian' was used to capture a broader Asian population of which there is a relatively limited research. The term 'British-Asian' will hence forth be used to signify specifically second-generation South-Asian people born and living in the U.K., whose heritage originates from Indian, Pakistan, Bangladesh or Sri Lanka.

Aims and objectives. The present study aimed to enhance the existing literature by exploring British-Asian peoples' stigma experiences. The sample was targeted within EIP services, given they are designed for young people experiencing psychosis. The current study aimed to explore how internalised stigma and public stigma influence British-Asian people and how they perceive themselves and others.

Another aim was to explore British-Asian peoples' experience of EIP services. It was anticipated that the study could glean a better understanding of how EIP services could support British-Asian service-users experiencing stigma. It was hoped this study would promote engagement through developing more supportive mental health service provision.

Research Aim

How do British-Asian people using an EIP Service experience stigma?

Research questions:

How do British-Asian service-users experience public-stigma?

How do British-Asian service-users experience internalised stigma?

How do British-Asian service-users experience EIP services?

Chapter 2. Method

Chapter Overview

This chapter will provide an overview of the qualitative approach and the chosen methodology and analysis for this research thesis. It will discuss the philosophical underpinnings and the ontological and epistemological position of the current study. Other relevant factors such as participant selection, recruitment and ethical considerations will also be presented.

Rationale for Qualitative Approach

The aims and nature of research determines its methodology (Cresswell, 1998). Consequently it is important to choose a methodology which reflects the research question and what the research is trying to explore. Guba and Lincoln (1994) propose that methodology is a tool used by the researcher to discover what they believe can be known. Generally, quantitative research sets out to test specific hypotheses and manipulate variables, whereas qualitative research is concerned with exploring personal experiences and subjective meaning (Greenhalgh & Taylor, 1997). Traditionally quantitative methodologies have been given more superiority than qualitative methodologies. However, qualitative methodologies can attend to the minutiae of subjective experiences in ways that quantitative research methodologies cannot (Denzin & Lincoln, 2000).

Qualitative research is naturalistic as it endeavours to make sense of peoples' truth and reality as they are experienced in the world. It is recognised the researcher cannot fully know a person's lived experience. However it is thought by undertaking qualitative methodology;

the researcher can come alongside the participant's truth and reality. This notion is summarised well by Laing (1967), "I cannot experience your experience, you cannot experience my experience…I experience you as experiencing. I experience myself as experienced by you" (p.16).

The focus of the current study is to explore the stigma experiences of British-Asian people using an EIP service. A qualitative approach enables understanding of participants' experiences and their meaning in depth, which was felt to be paramount to the study aims. Furthermore, qualitative methodology is considered collaborative and empowering for people who are commonly marginalised in society (Willig, 2012; Beresford & Croft, 2016).

Research Paradigm

The research paradigm refers to the conceptual and philosophical context in which the current study was undertaken. This is rooted in how the researcher considers subjectivity, culture, co-creation, social processes and power within their research (Willig, 2012). The research paradigm is shaped by the beliefs the researcher holds about reality, truth and knowledge (Mills, Bonner & Francis, 2006). Underpinning assumptions of ontology shapes the epistemology of research, consequently affecting the overall research strategy and methodology (Silverman, 2013). It is important to be clear about the ontology and epistemology of the current research as they are fundamental to the choice of research methodology (Scotland, 2012). The following sections will outline ontological and epistemological assumptions, followed by the researcher's own position.

Ontology. Ontology is concerned with the nature of reality, existence and considers what is known (Creswell, 2013). Ponterotto (2005) proposes that a researcher's ontological position represents their perception of reality in relation to the study. There are different ontological positions, which are conceptualised along a continuum. This continuum has varying ontological positions which are separated by philosophical underpinnings. These positions include positivism/post-positivism, critical theory/emancipatory research, constructivism, pragmatism, postmodernism and realism (Denzin & Lincoln, 2005). Positivist and interpretivist approaches are on polar-opposite ends of the continuum. On one end, positivism and realism assume that an objective reality or 'truth' independently exists and needs to be discovered by robust methodological examination (Coghlan & Brannick, 2005; Giddens, 1974). On the other end of the continuum, interpretivism and relativism assume reality is subjective, suggesting that multiple realities exist based on individual experiences, meaning, context and social interactions (Crotty, 1998; Gergen, 1985; Hudson & Ozanne, 1988). A balance between these opposing ontological positions is that there are several layers and structures objectivity and subjectivity which concurrently interact.

With regards to the current study, the researcher assumes that there are individual beliefs and experiences co-occurring across multiple realities. It is thought these are partially, rather than fully shared by others. For example there may be similarities between people who share the same ethnicity, background, upbringing, etc., however there are also marked differences which need to be captured and understood. Furthermore, this research assumes these are based in an overarching objective reality influenced over time by social, political and economic factors (Guba & Lincoln, 1994; Pilgrim & Bentall, 1999; Burr, 2003). Consequently, the current study acknowledges a realist perspective which is shaped by peoples' experiences and attached meaning using a relativist perspective. This brings together a more balanced

ontological position, towards critical theory, considered to be a mid-point on the ontological continuum (Pilgrim and Bentall, 1999).

Critical theory. Critical theory assumes that ideas and knowledge are not value-free and bias should be recognised (Guba & Lincoln, 1994). It critiques science behind positivism and aims to understand how peoples' experiences were developed at a specific point in time, by integrating geography, economics, sociology, history, political science, anthropology, and psychology (Horkheimer, 1982). Critical theory views phenomena as transformative, in that when participants develop awareness of how they are oppressed, they can make changes to alter the world (Guba, 1990). In the context of critical theory, pertinent factors within the current research have been deliberated. These include the study's philosophical assumptions about the nature and accumulation of knowledge, which informs a critical, qualitative research inquiry. Furthermore, the current study developed the aims following critical appraisal of existing research and literature within the historic and current socio-political climate. Also, this study critically considers the role of ethics and position of researcher in bringing to light conscious understanding of participants' experiences, alongside explicit researcher-reflexivity throughout the research processes.

Epistemology. The ontological position influences the epistemological stance of research, regarding the nature of reality and how it impacts the relationship with what is being explored. Epistemology is understood as "the study of knowledge, the acquisition of knowledge, and the relationship between the knower [participant] and would-be knower [the researcher]" (Ponterotto, 2005, p. 127). It concerns how a person comes to obtain information and develop ideas and beliefs within the overarching nature of knowledge (Burr, 2003). Epistemology deciphers how knowledge is defined, what is considered 'trustworthy' and 'valid'

and the boundaries set around knowledge (Honderich, 1995). Correspondingly, the epistemological positioning shapes how the researcher understands and makes sense of the research (Harper, 2011). Like ontology, epistemological stances can be considered to be on a continuum from objective to subjective stances (Cohen & Crabtree, 2006; Condie, 2012). The contextualism–critical realist epistemological position will be outlined in relation to the current study.

Contextualism-critical realism. Contextualism is a balance between realism and relativism. This approach proposes that ideas are created inter-subjectively where knowledge is rooted in the meanings developed by people in a specific, concrete context. It was developed as a move away from traditional positivism approach, whilst also addressing the shortfalls of social constructivism in understanding how knowledge is created (Bhaskar, 2008). Rather than taking up either polar position, contextualism-critical realism assumes that people are material beings, for whom there is no one truth that can be defined. Instead, it is suggested that people are in constant transition within a social and historical context. Within this approach, it is contended that objective reality exists, but peoples' 'truths' are subjective and furthermore shaped and coloured by the observer's lens in making sense of them (Burge, 1993; Madill, Jordan, & Shirley, 2000). Therefore Bhaskar (2008; 2016) argues it is not possible to fully understand peoples' objective truth as it cannot be realistically examined with certainty and without bias (Willig, 2001). Bhaskar (2016) asserts that to obtain knowledge, the structures knowledge is based in, needs to be learned, understood and named (Bhaskar & Lawson 1998). These structures can be unconscious. It is argued that drawing out these unconscious structures into conscious awareness denotes contextualism-critical realism. Understanding the role of both the individual and the collective are central to contextualist-critical realism (Archer, 1998). Contextualism-critical realism recognises the value of relativism in making sense of subjective

experiences at a 'micro' level, as well as considering the occurrence of these experiences within wider social, political and historical context at a 'macro' level (Sayer, 2000).

Current research position. A contextualism–critical realist ontological and epistemological position has been assumed for the current study. This position acknowledges that participants' truth is influenced by their own subjective experience and understanding of that truth. Alongside this, contextualism-critical realism acknowledges there can be similarities and differences in the 'truth' or knowledge of participants. The researcher assumes that a person's objective truth exists, but that it is based on individual experiences, meaning, environment and transactional processes. The researcher believes that these factors and interactions shape how a person sees themselves, others and the world. Additionally, it is thought the relationship between the researcher and participant is key to the participant sharing their experiences. It is assumed that the dynamic between the researcher and participants' will yield a richer insight into the participants' experiences and the way they make sense of their experiences. Given the researcher's personal background, it is recognised that their position may explicitly and implicitly shape how the data is generated and analysed, in keeping with a contextualism–critical realist stance (Bhasker, 2008; 2016).

The concept of stigma was considered using a contextualist–critical realist stance. This position is often assumed within clinical psychology, in terms of measuring psychological constructs and concepts such as cognitions, affect and behaviours. Stigma is a concept which is fixed within the social environment in which it manifests (Goffman, 1963). The current study is interested in exploring internalised and externalised stigma, which are not reliably, measurable positivist concepts. Given the existing literature, the researcher perceives internalised and externalised stigma to be based on individual perceptions of stereotypes,

discrimination that occurs within a public, social and cultural context (Corrigan & Watson, 2002; Link & Phelan, 2001). Therefore a contextualist-critical realist position was thought to be best suited to the current study.

The contextualism component of the contextualism–critical realist position recognises that subjective experiences can only be comprehended within the social, historical, power and political context (Willig, 2012). Bhaskar and Collier (1998) argue that without contextualism, “false beliefs” can be acquired through research, leading to discrimination and inequality of marginalised groups. According to Bhaskar and Collier (1998) knowledge is gained through longstanding “context of a social structure” (p. 390). This could be applied to salient concepts within the current study such as stigma and marginalisation of British-Asian groups. Through gaining knowledge of such concepts and understanding these structures can bring about discovery and change. The contextualist–critical realist position aligns with providing opportunity to de-marginalise vulnerable groups (Archer, 1998). It is suggested that understanding unconscious social structures, social practices and relational interactions can only happen within a social, historical and political context (Archer, 1998). Therefore, a contextualist–critical realist position is adopted which informed the aims, methodology and analysis of the current study.

Thematic Analysis

Thematic Analysis (TA) was chosen in the current study. It will now be outlined, followed by justification for this study. TA was initially developed as an approach by Gerald Holton in the 1970s. In recent years TA has become a more acknowledged qualitative approach, following the guidelines established by Braun and Clarke (2006). It is now a commonly used qualitative method, despite often being poorly demarcated and recognised (Braun & Clarke,

2006). Braun and Clarke (2006) contend that TA is a credible qualitative method in its own right and should sit alongside other 'major' qualitative methods. It is based on a structured framework which synthesises and interprets large amounts of qualitative data in a coherent way (Polit & Beck, 2008). TA uses a systematic approach to data analysis, permitting the researcher to identify and understand material across the data and analysing participant accounts meaningfully (Alhojailan, 2012).

Different qualitative methods are employed in keeping with an explicit epistemological position. These positions are applied as a 'lens' in seeing data and making sense of it. TA is a distinctive approach as it is not constrained by advocating a particular theoretical positioning, data collection and ontological and epistemological stances (Boyatzis, 1998). Braun and Clarke (2006) suggest that it is a strength of TA to not identify with any particular position, as it can be applied more flexibly.

Braun and Clarke (2006) recognise the limitations of TA such as claims around language use (Guest, Namey & Mitchell, 2012). Also, TA has also been criticised for missing the individual's voice (Packer, 2011). However, it is contested that these limitations are more attributable to research questions lacking focus or poor analysis (Braun & Clark, 2006; Hayes, 2000). Moreover, Braun and Clarke (2006) have encouraged researchers using TA to employ a sequence of choices to clarify their theoretical position and to enable more transparency and rigor so that research may be replicated.

Justification of Thematic Analysis. The ontological and epistemological position of the current study was considered in choosing the form of analysis. It was thought TA could be used alongside the researcher's contextualism-critical realist stance in relation to the data

(Bhaskar, 1998). TA is considered to be the most commonly used method of qualitative data analysis (Guest et al., 2012). It allows for inductive or deductive, semantic or latent approaches to coding and developing themes. In doing so, TA lends itself well to creating detailed and complex descriptions and meanings of data (Cruzes & Dyba, 2011). Thus, it was felt that TA could successfully address the aims of the study.

What is more, TA recognises the role of the researcher and encourages reflexivity of what they bring to the research (Braun & Clarke, 2006). It is thought this allows the researcher to transparently and critically analyse the ways they have shaped the research, such as background, knowledge and theoretical underpinnings (Lawthom & Tindell, 2011). In essence, acknowledging the research findings are derived from an interactive process between researcher and the data. Through this process, a coherent exploration of the data is developed (Lyons & Coyle, 2016). Consequently, it was thought that TA could successfully address the aims of the study as well and highlight researcher-reflectivity which is pertinent to the current study.

Additionally, TA has also been used to explore experiences of psychosis and stigma (Buizza et al., 2007; Burke et al., 2016). Furthermore, TA has been highlighted as especially helpful when exploring an under-researched area (Braun & Clarke, 2006). With these outlined justifications in mind, Braun and Clarke's (2006) TA was the chosen qualitative approach undertaken to explore the aims of the current study.

Researcher Reflexivity

When undertaking qualitative research, it has been advocated that the researcher should fully immerse themselves in the data analysis (Willig, 2013). The researcher should pay attention to minutia and how experience is constructed in order to understand phenomena, meaning, truth and experience (Charmaz, 2004). Charmaz (2004) contended that "We can know about a world by describing it from the outside. Yet to understand what living in this world means, we need to learn from the inside" (p.980).

Qualitative studies acknowledge the influence the researcher has on participants' narratives. By undertaking qualitative research, the researcher is an active participant in the drawing out and analysis of data. Stiles (1993) summarises this as *permeability* where interactions between the researcher and participant can impact the data. For example qualitative researchers have highlighted that it is not only what the researcher asks, but also *how* they ask questions that can shape their experiences and understandings. This can lead to a circular dynamic in the process of qualitative research. Importantly, the researcher's truths and experiences need to be understood.

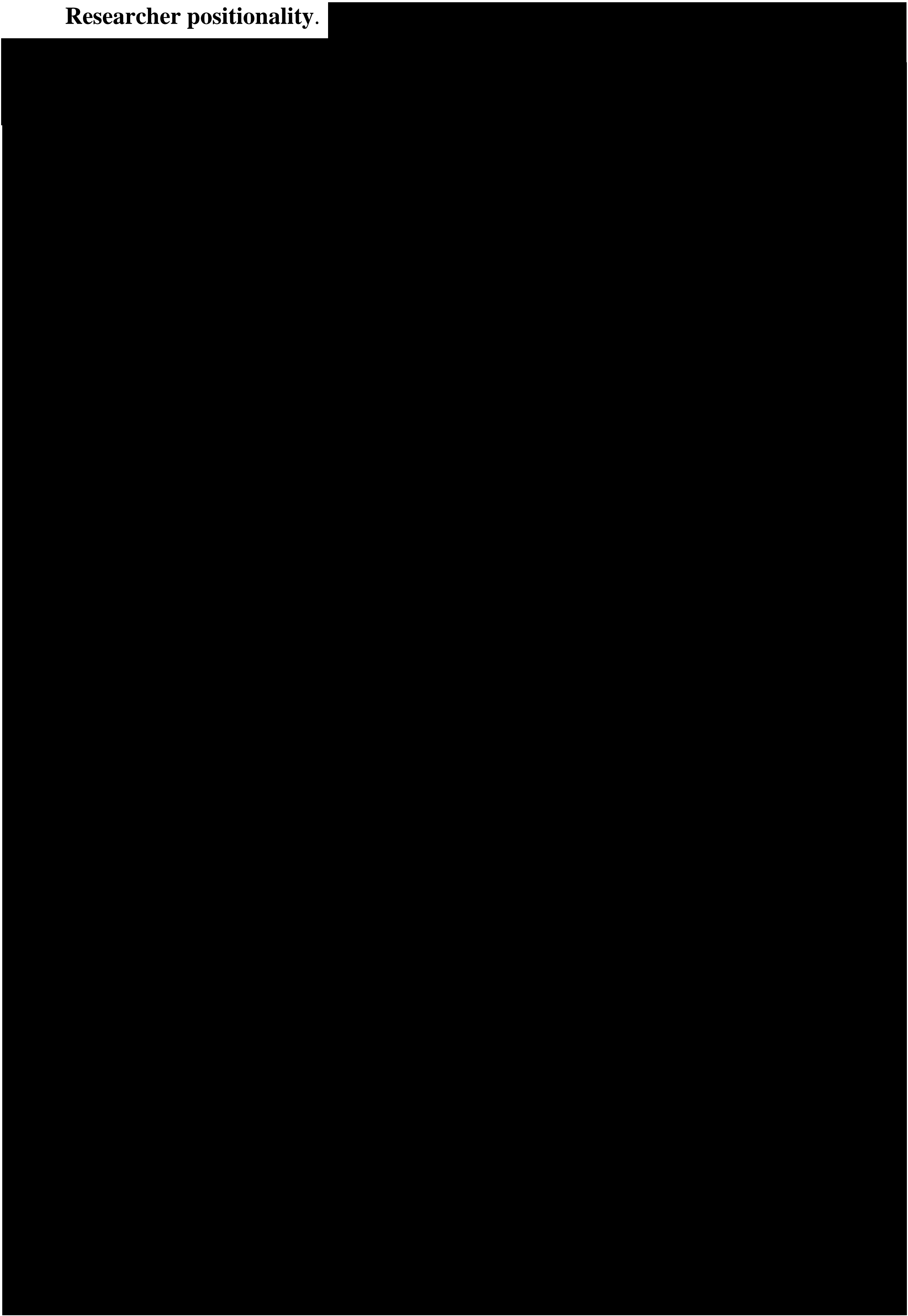
Personal-reflexivity. Finlay (2003) asserted, "our understanding of 'other-ness' arises through a process of making ourselves more transparent: without examining ourselves we run the risk of letting our un-elucidated prejudices dominate our research" (p. 108). Self-reflexive practice is considered essential in qualitative research (Shaw, 2010). *Personal-reflexivity* encompasses how the researcher's values, politics, beliefs, interests and experiences might influence their research (Primeau, 2003; Willig, 2013). Personal reflexivity is also based on how the researcher's social identity may have impacted on the research and equally how the

research may have fundamentally shaped the researcher's work and them as a person (Willig, 2013).

It was been proposed that shared ethnicity between the researcher and participants' lends itself well to explore experiences relating to culture (Grewal & Ritchie, 2006; Suwankhong & Liamputton, 2015). Although the researcher has endeavoured to consider their own background, experiences and assumptions in a balanced way during the research process, it is possible they may have implicitly influenced data interpretation and analysis. Indeed, Suwankhong and Liamputtong (2015) recommend researchers who share ethnic identity with participants to not be "insufficiently curious". They advocate researchers to momentarily suspend their subjective experiences and understandings of culture, in order to remain close to participants' subjective experiences. Similarly, Starks and Trinidad (2007) suggest that the researcher must "engage in the self-reflective process of 'bracketing', whereby they recognize and set aside (but do not abandon) their a priori knowledge and assumptions, with the analytic goal of attending to the participants' accounts with an open mind" (p. 1376). Therefore, the researcher endeavoured to remain open and inquisitive to participants' understandings and meanings. An example of this is asking participants to explain their understanding of key concepts within the research (i.e. stigma) and within Asian culture (i.e. black magic), rather than the researcher attributing their own understanding and meaning to these concepts.

Furthermore, given the close alignment of ethnicity between the researcher and participants, the researcher made use of a reflective research diary to think about their identification with participants, biases and blindspots. Furthermore, the researcher's background and experiences of the research process are also considered in the reflective sections. These reflective sections will be written in first person by the researcher.

Researcher positionality.



Participants

Sample size. A sample range of eight to twenty participants is generally considered optimal in qualitative research (Bird, 2005; Turpin et al., 1997). The current study adopts Braun and Clarke's (2013) TA which is a well-established and rigorous qualitative analysis. A power calculation of participants has been recently suggested for TA (Fugard & Potts, 2015). However, Braun and Clarke (2016) have argued such an approach is at odds with and lessens the richness of qualitative data. Braun and Clarke's (2013) recommend ten participants for studies using TA at doctoral thesis level. Furthermore, the researcher was mindful of recruiting a population which is often felt distrustful about participating in health-related research (Bowes & Dar, 2000) and under-represented in mental health services (Brubaker, Loveman, &

Stamatov, 2004). Accordingly, it was anticipated that eight to twelve participants would be recruited to participate in the current study.

Participants were specifically recruited from EIP services. These services are designed to identify and treat individuals experiencing psychosis in formative years in a timely manner. The ethos of EIP is to offer more flexibility, specialist support engagement and support than generic mental health services (Johannessen et al., 2001; Lal & Mala, 2015; McGorry et al., 2008). It is hoped that this ethos allows for a more personalised approach which encompasses the individual needs of the clients. Furthermore, participants were recruited across three EIP services within the same geographical region and within a diverse urban area. Consequently, it was thought mental health services targeted at young adults in a local area with a higher British-Asian population would match the aims of the current study.

Sampling method. Purposeful sampling was used rather than random sampling as the current study aimed to specifically explore the experiences of a specific cultural group. Purposeful sampling of British-Asian individuals using EIP services allowed the deliberate recruitment of participants based on their background and experience (Patton, 1990; 2002).

Inclusion criteria. The inclusion criteria reflected the aims of the current study. Participants were included in the study if they met criteria to access EIP services and were under the care of an EIP service at the time. Participants were included if they identified as originating from India, Pakistan, Bangladesh and Sri Lanka and were second-generation British-Asian (those born within the U.K. rather than migrants to the U.K.). Participants had to have been aged 18 or over.

Exclusion criteria. Participants were excluded from the study if they were unable to speak English due to the cost of an interpreter. Considering ethical issues, individuals were excluded if they were deemed to lack capacity to give informed consent. This decision was made by discussions within the respective multi-disciplinary EIP services. In accordance with the Mental Capacity Act (MCA, 2005) were assumed to have capacity unless proved otherwise. The researcher carefully communicated with individuals who expressed a wish to participate in the study, providing the participant information sheet to ensure they were able to make an informed choice. Those who had an acquired brain injury or experiencing a severe thought disorder at the time were excluded as they were deemed to not have capacity. Where substance-misuse was judged to be the acute cause of the psychosis experiences were also excluded. Individuals who had participated in another research study within the last six months.

Research Procedure

Patient and public involvement. In line with a contextualist-critical realist position, it has been argued that research should be informed by service-users who have experience of being within the context of the research (Beresford, 2016). NICE guidelines have indicated the importance of exploring first-hand perspectives of those experiencing psychosis in research (2014). Furthermore, the value of participatory action research has been documented (Bryant et al., 2010). Consequently, service-users were consulted whilst the researcher worked in a Psychosis Service under Patient and Public Involvement (PPI). Meetings were held with two service-users who identified as second-generation British-Asian to examine, develop and co-construct the topic guide, participant information sheet (PIS) and consent form used in the interviews. Their perspective and thoughtful contribution helped shape the research process. For example, service-users suggested starting the topic guide with subjects that felt easier to

discuss to allow participants to feel settled at the outset of the interview. Also, care was given to ensure the language within the materials was understandable and accessible. Neutral language and un-leading questions were posed to avoid assumptions of the participants' experiences (Ritchie & Lewis, 2003). Service-users recommended that the researcher should allow more time for participants if they wished. Also, service-users advocated that the researcher should maintain personal boundaries, but approach interviews with understanding and openness, such as disclosing their own ethnicity (i.e. being British-Asian) if asked by participants, given how Asian communities often feel mistrusting of professionals (Bowes & Dar, 2000). Additionally, consultation with research supervisors experienced in the subject area and analysis also informed the topic guide (McNamara, 1999).

Participant recruitment. The study background and rationale was presented to each EIP team. They were informed of the participant eligibility criteria and processes required to identify a potential participant for recruitment. Staff then discussed the study with potentially eligible participants that they were working with using the PIS (Appendix E). This ensured staff in EIP services were aware of clients that were possibly taking part in the study from the outset. If they were interested in participating in the study, individuals would complete a tear-off slip confirming they were happy for the researcher to contact them regarding the study and to obtain their informed consent to participate. This tear-off slip was returned to the researcher by posting it in allocated boxes at the EIP team base for the researcher to collect. The researcher then contacted the individuals to discuss the study using the PIS. Individuals were invited to be interviewed if they met the inclusion criteria and were able to provide written consent to participate. See Appendix N for recruitment flowchart.

The interviews were conducted in private clinic rooms at the EIP service site where participants were receiving care. It was hoped this reduced inconvenience for the participants and provided a safe and secure environment to interview participants. Each participant read

the PIS and informed consent was obtained. All interviews were audio recorded using a Dictaphone. Once all data has been collected and analysed, initial codes that were identified by the researcher were fed back to six of the participants to check for accuracy and credibility. This additional session took between 20 – 30 minutes.

Data Collection

Interviews. Interviews were chosen as the preferred data collection method as it was thought they would they allowed participants to talk more freely and elaborately than other methods may allow (Howitt, 2010). Within qualitative research, interviews are assumed to be an effective method of data collection to understand lived experience (Madill, 2007). It was anticipated that interviews would allow for depth and richness of data about stigma experiences and interviews were best placed to explore the aim of this study. There were 10 participants recruited who were eligible and consented to participating in the current study.

***Topic guide*.** A topic guide was developed for the purposes of the current study to facilitate a participant-led narrative and yield rich, idiosyncratic data. The term 'topic guide' is used rather than 'interview schedule' as it highlights topics instead of specific questions (Arthur & Nazroo, 2003). Whilst conducting semi-structured interviews the researcher pose the same questions in a similar way to each participant, with limited prompting for further exploration (Arthur & Nazroo, 2003). A topic guide approach permits the researcher to probe, explore and follow-up information connected to the study's aim in a way that fits and makes sense for the participant (Berry, 1999; Wenden, 1982). Three broad areas were included in the topic guide used in the current study (Appendix D). These included self-stigma, public stigma and how and if participants' wanted their experiences to be different. Further clarification and exploration questions were asked when required. The possible influence of the researcher was considered (Kvale, 1996); therefore open-ended prompts were asked in a neutral way. For example the researcher used phrases like: "Could you say more about that please?"

***Transcriptions*.** It has been advocated that researchers should transcribe interviews themselves in order to deepen their understanding of research data (Pope, Ziebland & Mays,

2000). The researcher sought to transcribe each interview as closely as possible to the interview. All of participants' verbal responses and pauses were included in the transcriptions, (i.e. sighing and laughing). Digital audio recordings were saved to a university computer, listened to on Windows Media Player software and transcribed onto password protected Microsoft Word documents. Transcription of interviews was based on the order they were carried out. Care was taken to ensure that participants' responses were not altered in some way by punctuation. Once all interviews had been transcribed, all interviews were listened to again on three occasions to ensure they were accurate and anonymous. This aided the process of the researcher becoming immersed and embedded in the data so that they were "intimately familiar with the content" (Ellsberg & Heise, 2005, p.204).

Demographic information. The demographics questionnaire collected information about participants' age, gender, marital status, religion, education, how they identified their own ethnicity and qualitative data about their psychosis experience (Appendix G). It was thought this information would be useful to consider once themes had been generated.

Data Analysis

The current study aimed to analyse rich data about the stigma experiences of British-Asian people using an EIP service using TA. Within TA, the researcher must think about whether the data will be examined at a semantic, descriptive level, or latent, interpretive level at the outset of research. Consequently, this influences whether the analysis will be inductive, rooted in data or deductive, informed by existing knowledge. Braun and Clarke (2012) recognise that "in reality, coding and analysis often uses a combination of both approaches. It is impossible to be purely inductive, as we always bring something to the data when we analyse

it" (p.38). As previously discussed, it is unlikely that the researcher's background, experience and knowledge will be truly separated from the research interviews and analysis. Therefore, datasets were examined both descriptively and interpretively. This form of analysis is in keeping with the current study's contextualist-critical realist stance, a balance between realism and relativism. It acknowledges participants' objective reality or truth (i.e. sematic and descriptive participants' accounts of stigma), alongside subjective experience and influences (i.e. latent meaning of stigma experiences). Therefore within the current study, surface level data is equally as important as the underlying assumptions of participants (Lyons & Coyle, 2016).

The current study followed Braun and Clarke's (2006) six-phase approach of TA. These phases are considered a recursive way of analysing data rather than a linear step-by-step procedure (Braun & Clarke, 2006). Analysis was undertaken using NVIVO (version 12), a qualitative data analysis software.

Phase one: Familiarisation with the data. The researcher began to absorb themselves the data whilst transcribing interviews (Bird, 2005). Each transcript was read multiple times so that the researcher could familiarise themselves with the content of data and develop initial ideas, which were documented.

Phase two: Producing initial codes. Interview transcripts were coded line-by-line (Appendix I) to identify key concepts. Codes were data-driven and derived systematically by going through each transcript one-by-one. It was not necessary for codes to be either semantic or latent, but needed to demark the diversity and range of multiple participants' perspectives. One transcript was also coded by one of the research supervisors to corroborate codes. To

ensure accuracy and credibility, initial identified codes were fed back to participants to check they were reflective of participants' experience of the interviews.

Phase three: Searching for themes. Codes were organised and clustered together to form possible thematic categories by the researcher. The researcher was aware of the possible links between codes, themes and between various levels of themes. A reflective log was kept of the researcher's thinking and decision-making processes.

Phase four: Reviewing themes. The stage included the fine-tuning and re-reading of themes. Care was taken to ensure themes were developed coherently and meaningfully (Patton, 1990). Themes and their sub-themes were identified if they shared and highlighted a fundamental organising concept. A key aspect of this included the researcher ensuring themes did not overlap, but appeared connected to one another. The validity of themes was considered in line with Buetow's (2010) saliency analysis. Therefore themes had to be represented by a number of participants and given importance (saliency). Miscellaneous codes that were not reflective across the data-sets were not integrated into themes and discarded. Themes and sub-themes were continually discussed with research supervisors to ensure the codes and categories were reliable and in keeping with the study aims and participants' accounts.

Phase five: Defining and labelling themes. The names and clear definition of themes and sub-themes were developed and fitted with the data captured. Themes had to be consistent across all interviews and at the individual, participant level. Furthermore, themes needed to be integrated into a 'story' evidenced by quotes to explain what each theme entailed.

Phase six: Producing the report. The last stage involved producing a coherent, narrative report of themes and sub-themes alongside data extracts establishing their occurrence within the dataset. The report considered the data in relation to the overall study aim and research questions. Furthermore the report also discussed commonalities, differences and possible explanations within the interviews in the context of existing research and literature discussed in the introduction, to further understanding in this under-researched area.

Ethical Consideration

Obtaining ethical approval to conduct the research. Ethical approval was obtained from the Health Research Authority (HRA) (Appendix J). The study was also approved by the Research and Development Department within the NHS Trust which is responsible for research conducted within the Trust (Appendix K) and the University of Essex Research Ethics Committee (Appendix L).

Informed consent. Eligible individuals that met the inclusion and exclusion criteria were approached by staff and given the PIS to explain the aims and nature of the study emphasising the anonymity and confidentiality of all data analysed for the study. The PIS stated that participation in the study was entirely voluntary and that participants may withdraw from the interview at any time without needing to give a reason. Participants were informed that withdrawing from the study would not impact on their care from the NHS. This right to withdraw was in accordance with standard 1.4 of the Code of Ethics and Conduct (BPS, 2009). Potential participants indicated their interest in taking part in the research by completing a tear-off slip and posting it in allocated boxes in the EIP service base for the researcher to collect. Once potential participants had the opportunity to discuss the research and were given enough

time to think about whether they wish to participate in the research, they were required to sign the consent form (Appendix F). This gave their explicit permission for the interview to be recorded, to show their agreement to participate and for their interview data to be used for the purpose of the study, as in accordance with ethical standard (BPS, 2009).

Anonymity and data storage. Only the researcher and participants were present during the interview. To preserve anonymity, pseudonyms were assigned to participants. Interviews were audio recorded using an encrypted Dictaphone. They were transcribed verbatim by the researcher for analysis. Interview transcripts were anonymised and only available and accessible to the researcher and the researcher's supervisors. The audio recordings were password protected and written transcripts of the interviews were stored securely and confidentially at the University of Essex in the School of Health and Human Sciences in a locked cabinet. These will be destroyed following completion of the study.

Risk of harm. It was explained to participants that whilst the information they provide is confidential, this confidentiality would need to be breached if the researcher felt that the participant or other were at risk of harm. The researcher ensured risk procedures were followed at all sites, in line with local policies and Trust procedures. For this research it was vital to provide a debriefing at the end of the interview to ensure the participants were not negatively affected by the interview. It was important to assess well-being after the interview by talking to the participant and asking how they felt and found the interview. It was also essential to liaise with EIP services if any concerns arose during the interview, as well as being familiar with each participant's risk assessment.

Power and ethical issues. It was recognised that some participants may find it difficult to talk about personal or sensitive information. The researcher was culturally-sensitive to the participant and used her clinical skills to ensure that the participant felt emotionally contained. The researcher endeavoured to remain neutral, whilst holding a therapeutic approach to facilitate a containing and safe interview environment.

Relationality is derived from equity and caring (Lincoln, 1995). It has been argued that researchers are obliged to address relationality and power imbalances with participants (Hall & Callery, 2001; Kvale, 1995). It was anticipated that participants might be interested in the researcher's ethnicity and background. It was also thought that some participants may feel more uncomfortable with a researcher of the same ethnicity (Hussain & Cochrane, 2002) fearing judgement or the sharing of personal information. It was hoped that by disclosing some aspects of the researcher's background if asked by participants (i.e. the researcher acknowledging their own ethnicity) and reinforcing confidentiality showed sincere curiosity and developed a more equal researcher-participant relationship.

Furthermore, it was recognised that alongside the researcher's ethnicity and background, participants may have still experienced a power difference. For example social factors and professional status may have impacted how participants shared their experiences. In addition, the researcher was aware of their status as a trainee clinical psychologist when interviewing participants and the potential power imbalance participants may have perceived as a result. It was hoped that by providing clear written and verbal communication of the study and the opportunity to ask questions helped to manage these potential issues. Also the researcher emphasised the importance and value of participants' experiences as proposed by

Henwood, Pideon, Sarre, Simmons and Smith (2008) to reduce the potential of the power difference.

Financial remuneration. Participants who attended the interview were given £10 as compensation for their time. It was felt that the sum of £10 was adequate to compensate participants, without being too coercive. The compensation was also used to recognise the contribution of those who participated in the study. A receipt of payment form was signed by each participant (Appendix H).

Rigor in Qualitative Research

The trustworthiness of research is integral to increasing confidence in interpretation and findings. Therefore Lincoln and Guba's (1985) evaluative criteria for qualitative research was considered in order to ensure the reliability, validity and overall rigor of the current study.

Credibility. Lincoln and Guba's (1985) suggest that the credibility criteria relate to depicting the participants' perspectives by staying true to the original data provided. The study's epistemological stance asserts that individual lived experiences are subjective truths which are partially shared by others. Therefore, it was acknowledged that participants' accounts would be varied. Plummer (2000) contended that it is not possible to obtain *the* truth, but one can look for truths and meanings. Consequently, a 'member checks' technique was used to ensure credibility, which involved testing that data collected accurately represented the participants of the study. If participants had consented to being contacted again, they were consulted with the initial codes generated by the researcher. It was hoped this allowed for variation and reduced misrepresentation of participant data. However this study acknowledged

the limits of 'member checks' in the context of there not being the same fixed truth or reality for all the participants. In light of this, the researcher employed other credibility checks. These included being immersed in the data by re-reading transcripts and having supervisors experienced in qualitative research checking transcripts against audio recordings.

Transferability. Transferability refers to the extent data can be generalised and transferred to other contexts. Transferability can be promoted by the researcher sensibly considering congruency between the context of how and where the study took place and the context where the findings are being applied (Lewis & Ritchie, 2003). Consequently the limits of the current study in terms of its context and application to other contexts (Shenton, 2004) and British-Asian populations in the U.K. are considered in the discussion chapter.

Dependability. Dependability relates to the reliability and consistency of research, with particular focus on whether research can be replicated and repeated (Lincoln & Guba, 1985). Therefore within the same context, if the same methods were employed, the findings would be comparable, providing the researcher undertook the study accurately and carefully (Carcary, 2009; Lincoln & Guba, 1985). Accordingly a detailed description of the design, procedure and methodical issues is presented to enhance reliability and consistency of the current study's findings.

Confirmability. The criteria of confirmability refer to the objectivity of the research. It is concerned with the extent to which the findings could be confirmed and corroborated. Therefore it is crucial to monitor the influences and beliefs of the researcher which might implicitly and explicitly shape the data collection and analysis (Lincoln & Guba, 1985; Shenton, 2004). One the research supervisors' coded a transcript to ensure identification of codes was

corroborated. Also steps were taken to ensure the confirmability by providing researcher transparency.

Transparency. The importance of transparency is often stressed in qualitative research so that it illuminates the decision-making process (Baxter & Eyles, 1997; Moravcsik, 2014). Given that TA values advocate reducing misrepresentations of data (Braun & Clark, 2006), it is imperative that analysis transparently and systematically develops themes. Furthermore, Yardley (2000) also recommends that there should be reflection of how the researcher's expectations might influence the data analysis. Therefore the researcher strived to consider how their own beliefs and motivations might have impacted research they were undertaking.

The researcher's preconceived belief was that participants would have had some experience of stigma, given its prevalence for those who have psychosis experiences (Burke et al., 2016; Wood, et al., 201; Wood, Byrne, Varese & Morrison, 2016). However, the researcher had no assumptions on the extent and how second-generation British-Asian participants might be affected by stigma. It was thought that the researcher's interests would be mediated and would not explicitly dictate the direction of the interview and data collection as current service-users were consulted in shaping the research and topic guide.

The researcher was mindful that data analysis was being informed by ongoing exposure to interviews. It has been argued that this gradual analysis is in some way unavoidable due to the researcher's seeing and hearing information from the ongoing interviews (Pope et al., 2000). Pope et al., (2000) suggest that is actually helpful in deepening the researcher's understanding of the data.

Impact

Most importantly, participants of the study were provided with a written summary of the results. This study aimed to enhance the existing literature by exploring British-Asian peoples' experiences of internalised self-stigma and public stigma within their communities. It is hoped this study will inform clinicians in EIP services how stigma impacts British-Asian individuals and the influence it has on engagement and being meaningfully supported. It is thought that the research will be of interest to commissioners in areas with a large British-Asian population. Therefore, the researcher will endeavour to disseminate the research findings by presenting at a relevant conference. Also the study will be written into an article for publication in a peer-reviewed journal such as Psychosis or the Journal of Cross-Cultural Psychology.

Chapter 3. Findings

Chapter Overview

The findings of this study will be presented in this chapter. Demographic information about the sample will be provided. Themes and sub-themes developed using thematic analysis will be explored and described in detail, alongside extracts from the interview transcriptions to situate the reader in participants' experiences.

Participant Demographics

There were a total of 10 participants interviewed for this study. The participants' ages ranged from 19 to 39 with a mean average age of 23.5. The sample included eight males and two females under the care of an EIP Service. All participants had a single marital status. All research participants were second-generation, British-Asian. The majority of participants were students. The interviews were all carried out face-to-face. Interviews lasted between 27 – 60 minutes, with a mean average interview length of 44.5 minutes.

Table 5 below provides the sample characteristics in the order of the research interviews conducted. To protect the confidentiality and anonymity of participants, demographic information and identifiable contextual information is omitted and pseudonyms have been assigned to all participants.

Table 5. Participant demographics.

Participant Pseudonyms	Age	Gender	Ethnicity	Religion	Education (highest achieved)	Employment Status
Udit	22	Male	British-Indian	Atheist	A-Level	Student
Tippu	39	Male	British-Bangladeshi	Islam	Primary School	Out of work and looking
Ethan	19	Male	British -Sri Lankan	Hindu	GCSE	Student
Hemisha	19	Female	British-Indian	Hindu	A-Level	Student
Aaliyah	21	Female	British-Bangladeshi	Agnostic	A-Level	Student
Zaair	20	Male	British-Pakistani	Islam	A-Level	Student
Fahad	27	Male	British-Pakistani	Islam	Irish Leaving Certificate	Student
Ali	20	Male	British-Pakistani	Christian	GCSE	Unable to work
Syed	27	Male	British-Pakistani	Islam	A-Level	Student
Anwar	21	Male	British-Bangladeshi	Agnostic	A-Level	Student

Analysis

As discussed in chapter two, a six-phase approach of thematic analysis was used (Braun and Clarke, 2006). Four themes and twelve sub-themes were developed using thematic analysis (Braun & Clarke, 2006). The themes integrate the complexity of participants' experiences. What is prominent about the findings is how the participants' experiences of different types of stigma intersected and the adverse consequences that followed. These included distress, internalised stigma and further marginalisation. Sub-themes have been named using direct quotes from participants to capture their voices in each theme. Table 6 illustrates the themes and subthemes which will be presented below in detail. Themes are presented in a way that reflects the participants' overall narrative across the dataset.

Table 6. Themes and sub-themes developed from research interviews.

Themes	**Sub-themes**
The burden of silencing	"It rips you from yourself"
	"It's a bad thing to tell people"
	"My family keeps it hush hush"
The un-noticed aspects	"Understanding all these parts of me"
	"It's a harsh environment"
	"Services don't really see me"
Experience as 'the other'	"It was safer to be alone"
	"It's contagious, it spreads"
	"I'm not associated with ISIS"
Finding ways to cope and thrive	"It's like sharing the load"
	"I feel like a social butterfly now"
	"I needed help to understand"

Theme one: the burden of silencing. This theme refers to how participants felt they were discouraged from speaking out. Being unable to externalise their experiences led to the need to stay silent and internalise their experiences. There were different ways participants felt unable to speak freely. Participants described several layers to their silencing, from internalised distress, worries about disclosing experiences due to fear of stigmatisation and how families avoided talking about psychosis due to stigma in Asian family culture. The need to be silent about psychosis was related to negative stereotypes and labelling within Asian families and more generally. Consequently, silencing was sustained by suppressing or trying to hide psychosis experiences due to internalised stigma and the social unacceptability of psychosis.

The first sub-theme "it rips you from yourself" explains how participants' experiences of stigma related to internalised stigma. Many participants felt that it was better to hide what they were experiencing out of fear that their social networks and wider community would see them as inferior. This resulted in the sub-theme "It's a bad thing to tell people". Participants' reluctance to speak linked in with their own experience of Asian family culture, which encouraged them to contain or minimise their psychosis experiences, fearing the responses and labelling by people in the wider Asian community outside the immediate family. This is illustrated in the final sub-theme of "My family keeps it very hush hush". The pervasive nature of stigma for people experiencing psychosis and disempowerment through silencing was highlighted in this theme.

1.1 "It rips you from yourself". All participants spoke about their internal psychological distress. They described the significant impact the stigma of psychosis had on their view of themselves. Distress transpired in different ways. For Syed, he discussed feeling upset that he had lost his identity prior to his psychosis and how he saw himself in a more inferior way.

> Syed: It rips you from yourself. You don’t have a self-image. You’re not the same after you’ve gone through it. You just see yourself differently, you know you’re a lesser person and the world knows it [...] I really hate who I am now.

What is notable about the participants’ accounts is the way they spoke critically about themselves following their psychosis. Anwar believed he must be a ‘bad person’ for developing psychosis. He discussed feelings of self-hate and thoughts about being defective, “Why else would I have this? […] I just thought ‘something is really wrong with me’ […] I just hated myself”. Participants’ spoke about struggling with feelings of despair. Tippu shared how he felt fed-up of his life and could not distance himself from relentless distress. He stated, “I’ve had enough of this life” and commented “this rubbish that’s going on inside of me and all around me all day and night”. Some participants believed they had hit a ‘low point’ which affected their self-esteem and self-worth. Ethan reflected, “I feel like I’ve hit rock bottom already, that’s why I don’t care anymore. I don’t think I can get any lower, that’s why I lost that care attitude”.

Similarly, Udit talked about his psychosis diagnosis generating a self-perception of being less abled and degraded. He became emotional in the interview as he expressed the significant negative consequences on his self-esteem and hope for the future.

> Udit: I mean I’m a schizophrenic now. I think the fact remains, you’re disabled. It can help you manage a little bit, but you’re still going to be disabled […] It’s tough when everything’s shit and all aspects of yourself are just degrading. I miss how I was. I miss how life used to be so easy […] I have much lower self-esteem now, much lower and what’s the word, less confidence in myself just because I have to live in reality and the reality is looking bleak (tearful, pause) yeah so that’s the difference with me.

Like Udit, Anwar also identified with stigma associated with psychosis. He believed that his life prospects had deteriorated. This seemed to significantly influence how Anwar perceived himself in a negative way.

> Anwar: What's the point now? I have schizophrenia. This is my life now. I don't know if I'll ever be normal again. It's gonna make my life 10 times harder. I struggle to do my work, I hate myself. I must be crazy! I don't know who I am anymore, I can't understand it.

This sub-theme shows how stigma related to psychosis impacted participants' mental health through internal processes. This made it harder for them to speak about themselves, which implies that the 'burden' was theirs alone to hold. Therefore reinforcing the feeling that they are alone with experiences and unable to share it with people around them.

1.2 "It's a bad thing to tell people". This second sub-theme demonstrates the influence of how people close to the participants and wider society perceives them. All participants spoke about feeling restricted and that they had to conceal their psychosis experiences. Many participants discussed negative stereotypes of psychosis and were scared that they would be labelled and considered inferior. For example when talking about wider society, Fahad said, "I'm classed as second, as if no one would take me seriously. It's a sign of weakness basically, that's how I feel about it".

Fearing judgement from social networks was a main concern for participants. When talking about his friendship group Zaair "I think people would judge me on my personality, the way I speak, how I react to things, what my views are like". These fears of judgement from friends and family were similarly expressed by Syed, which left him avoiding sharing his psychosis experiences.

> Syed: I think it's just too hard to convey what's going on and if I did try to tell them what's going on, I wouldn't be able to tell them everything. They would have a judgement on just a few words so I reserve from speaking […] it feels like if I do speak about all these issues, then straight away I'm under the light because I'm suffering. I don't think there's a way to speak about these issues to my family and friends without them tying it in with me. That's unhelpful to me.

Aaliyah also spoke about her reluctance to share her experiences. She thought she would be linked to damaging stereotypes of people experiencing psychosis. Aaliyah's fear that disclosure would lead to detrimental changes to her relationships and being treated differently. As a result, she concealed her experiences.

> Aaliyah: I think I was just really scared about telling people. I know when you're really scared about hearing voices, I just think automatically that everyone's going to think I'm crazy and like no one is going to talk to me. I just won't be treated the same. I just had all these negative thoughts. I just thought it's better not to tell anyone rather than go and tell. I just worried that relationships would change. I just thought it's a bad thing to tell people.

Tippu articulated that he felt people in wider society did not want to listen to him about his distress and how he censored his experiences.

> Tippu: You're not supposed to give too much details or talk about it in too much depth. People get fed up of it afterwards and think there's too much of it. It's better not to say anything, people won't say nothing to you then, they won't judge you then.

Hemisha spoke about her own stigmatising beliefs she held at a young age which she felt stemmed from a lack of understanding. She talked about her own negative stereotypes she had about people who experienced mental health problems and were detained. Hemisha

admitted the fear and judgement she held and how people in wider society might pass similar judgement. She noted this was a barrier to her sharing her psychosis experiences.

> Hemisha: When I was younger I used to think people were mad, that they belonged in those institutions, things like that. That was when I was quite young, but just before I got it, I started understanding that "oh people have this and its ok for people to have this. Like it's when someone breaks their leg or something, like it's not as bad as people make it out to be. To be fair when I was younger I used to be scared of them, but I think that's because I didn't really understand it. (Pause). But I guess, it's still not something you go round broadcasting. People might judge you.

Collectively these quotes relate to the broader theme of 'the burden of silencing', as the impact of negative stereotypes and fears of judgement from people influenced disclosure of psychosis. This sub-theme illustrates the impact of negative stereotypes and fears of judgement from the social networks and general society influences how participants choose not to disclose their psychosis diagnosis. This ties in with the broader theme as it shows how participants are further motivated to stay silent.

1.3 "My family keeps it very hush hush". This theme is specific to immediate family members. In addition to experiencing negative stereotypes and feared judgements from others, participants also specifically talked about how the unfavourable meaning families gave to psychosis played a significant role for them. Participants spoke about how it was better to remain silent and hide their psychosis experiences because of the perceived stigma within families. Udit and Aaliyah both used the phrase "hush hush" in relation to the way their families responded to psychosis experiences. Participants believed that negative perception of psychosis was generated from Asian family culture. They described how stigma not only impacted them, but also their family unit as a whole. Zaair noted that 'saving face' and protecting family reputation is important. He explained, "you're considered a disgrace to your family and reputation". The tarnishing of family reputation and consequential avoidance of discussing psychosis was also a factor for Anwar.

> Anwar: I feel like with my family in general there was always that need to make sure everything looked good that people were going to university, people were going to the mosque, people were getting married and stuff like that. If something came up about my mental health, my family wouldn't tell people which kind of made it worse. I feel like it's a competition between people and it's a lot about pride, family pride.

Similarly, Hemisha noted that her parents had negative ideas about mental health. She noted in Asian culture it can be controversial for young women to romantically date. Hemisha made a comparison of how psychosis was considered worse than talking about dating to emphasise the negative connotation of psychosis in Asian culture. She felt this was a barrier in her speaking about her experiences and seeking their support.

> Hemisha: I had just started sixth form and my parents were being so un-supportive. I literally felt I couldn't tell them anything, they were being really weird about it because I used to self-harm. They think people with mental health disorders are not as intelligent

> as other people. That we're basically lower down in society. That they were unable to do things. It's easier to talk about having a boyfriend, than my psychosis and that's saying something in Asian families!

Hemisha expressed a wish for her family to develop psychological understanding. This was particularly important to Hemisha, as she reported perceived stigma of psychosis in her family. She described feeling anger as her parents refused to get involved in her care with the EIP service.

> Hemisha: It made me really angry, like they weren't trying to understand how I felt […] this really, really, really angered me. Yeah it was hard. I just told my care coordinator to stop calling them that they'd just continue to say no. There's no point asking them. Even a few weeks ago they asked my parents to come in and they wouldn't.

Syed, Udit, and Tippu expressed not knowing how to approach the topics related to mental health with their families. They articulated how social stigma was an obstacle to discussing their experiences with immediate family members which made their experience of stigma worse.

> Syed: I'm still trying to figure out how to speak to people in my culture, in my community. I'm not really sure how to speak to my parents about it at times. I still need to process it. We don't talk enough about these things in our culture; we're just quiet about it all.

> Udit: For the majority of the time it wasn't very talked about openly. I think my grandmother was very loving […] but there was that like social stigma that someone is crazy… but we know not to talk about it in our family.

> Tippu: It's like don't let your parents know that you're going through a difficult time […] at home I don't have no one to talk about this basically […] We don't talk about it. I know that I don't want to stress my parents out.

This sub-theme captures the stigma and consequential avoidance of discussing psychosis in immediate families. Therefore, contributing to participants' experience of feeling alone with their distress and feeling silenced. It is possible that this avoidance is linked to a wider stigma around psychosis amongst broader Asian communities. These are further outlined in the sub-theme "it's contagious, it spreads".

Theme two: the un-noticed aspects. All participants discussed how several aspects of themselves remained unknown and hidden to others. Continued attempts to adapt to meet expectations of different cultures and environments placed added stress on participants. Participants were concerned that aspects of their identity were not 'acceptable' in particular situations, resulting in feeling further stigmatised. The first sub-theme "Understanding all these parts of me" describes the impact of having a dual identity of being British-Asian. Participants discussed how aspects of their identity can be conflicting. Participants clashed with the views and beliefs of people in their families who were from a different generation (first-generation migrant population). For example, differences between eastern and western understandings of psychosis and associated stigma.

Another aspect of participants' experiences that remained unnoticed were the influences of their socio-economic status. These included additional struggles and adversity within an urban environment (e.g. housing). This resulted in participants' feeling more stigmatised within society, characterised by the sub-theme "It's a harsh environment". The sub-theme "Services don't really see me" relates to participants' experiences of EIP services. The lack of consideration and recognition of different aspects of participants' identities shaped their

experiences of psychosis and stigma. The 'un-noticed aspects' theme captures how salient aspects of participants' identities were compartmentalised, which EIP services did not notice.

2.1 "Understanding all these parts of me". The influence of identity was stressed by many participants. The fragmentation and splitting of their identities, further compounded participants' psychosis and stigma. These identity conflicts lead to a process of having to adapt and assimilate as British-Asian people within society. Participants felt they had to homogenise to avoid perpetuating stigmatised stereotypes. The extent to which participants needed to homogenise was fluid and idiosyncratic to each participant depending on their particular situation. Anwar made reference to how his cultural identity and the stress of having to adapt to the majority group influenced his beliefs.

> Anwar: Being British-Asian, I think that we switch through things in a way that other people don't and we do it very quickly without even realising it. You flip between both worlds and you do that so quickly in different situations and I don't even know how much. I feel like there's a point with adaptability where it gets stressful, really stressful. Especially if you're trying to adapt to different cultures and you're doing it so much on the fly that you start to question your own beliefs, is this my belief or is this someone else's belief that I'm taking in.

Aaliyah also discussed having to adapt how she presented like Anwar. Aaliyah described different aspects of her identity which felt overwhelming to think about and manage. These parts of her identity could be thought about as multiple stigmas, for example the stigma of being Muslim.

> Aaliyah: I just change I just adapt to who I am with so if I'm with my friends I'll be relaxing and socialising or whatever. When I'm with my family I will be a bit more modest and I would be a bit more wary of whom I am around…When you break it down

like that, you just think, oh my god, that's just so much. That's a lot. I think a) I'm a female; b) I'm Muslim, c) my culture. When you think about it that way, it feels really overwhelming. How do you cope with all those at once?

Some participants like Aaliyah and Udit wanted to distance themselves from their culture as a way of integrating in society or managing conflict of their identity. This could be thought of as a psychological defence of splitting and assigning parts of their identity as good and bad. In this case, as denial of Asian culture.

Aaliyah: A lot of the time I just want to abandon my culture. I just think I'd rather not be a part of this. It makes me feel like I have got something to hide. There's a difference between keeping it to yourself and not having everyone know about it. There's that difference of feeling like there is something wrong with you and that you should hide it. I feel like I'm being shunned out sometimes.

Udit: I'm not very fond of culture, particularly Indian culture. As a kid I wasn't very fond of it. So as a kid I was very detached from that. I think if I was very into that, I think I would have very different attitudes towards all of these things. I'm quite detached […] to be fair I was brought up here in the U.K. and I've been quite distant with the culture. I'm not a good Indian. I'm not a very 'Indian', Indian.

Participants discussed identity conflict stemming from generational differences with their parents. Participants described their parents' coming from an eastern, collectivist, interdependent cultural background which influenced how they conceptualised identity, stigma and psychosis. Zaair outlined the significance of being part of two cultures in terms of education and understanding psychosis.

Zaair: British-Asians are part of two different cultures. From a young age I've surrounded myself with more westernised people, people who grew up here, people

> who are from here as well, most of my friends are Asian, but they are educated and understanding.

Zaair believed his father would draw on eastern, religious ideas and use black magic to make sense of psychosis, which to him felt stigmatising. Whereas being raised in the U.K., Zaair felt he identified with a western, individualist and independent cultural background to conceptualised identity, stigma and psychosis. Zaair explained he preferred to consider adverse and stressful life events to understand his experiences.

> Zaair: Background wise, he's more 'backwards' in terms of his generation. He's more closed-minded, and not as open to thinking about illness. He'll call it black magic, or say that I'm mad. He wouldn't be understanding of circumstances or situations that could cause mental health problems.

Hemisha and Aaliyah noted the different ways their parents would understand psychosis. They felt closer and more aligned with their brothers who were of the same generation than their parents. Both felt their brothers could understand their experiences better. Hemisha referred to the difference being based on her parents' upbringing in a different country, which she believed influenced them to be less open-minded.

> Hemisha: My parents, even though they didn't grow up here, they grew up in Africa then came here they still had that way of thinking. My brother was born here and raised here; he's more like open-minded and has more awareness.

Aaliyah articulated that her family think about religion to explain psychosis, whereas she did not. She felt less comfortable talking about psychosis to her parents than her brother who seemed to share her values.

> Aaliyah: I think me and my brother we're quite similar, we have similar experiences. I know it's just easier to communicate with him. Like our family are quite a religious family and my brother and I are the complete opposite of that […]. They think about religion and mental health as the same. Like you get voices because of black magic, that kind of thing […]. It's not something that we can talk about openly with parents, he just gets me though, we grew up in the same way, have the same values.

Additionally, participants spoke about how they believed in some aspects of their religion, but discounted other parts of their religion. Participants spoke about taking into account western approaches, alongside their parents' eastern approaches. Their beliefs were idiosyncratic and considered in a fluid way on a continuum, rather than concretely held like their parents' generation. For Fahad, this conflict between religion and a western scientific approach seemed to cause confusion and stuck-ness.

> Fahad: I believe a lot in science, but I can't believe everything about it, it's something we're restricted to do as Muslims. I do believe science has a lot of answers though, it can give a definition. It's just a clash between my culture and science. If you talk too much about science, people degrade you in Pakistan, its bad over there. I feel quite stuck.

Anwar talked about his fluctuation between seeing his experiences in a western way as psychosis, but also in an eastern, religious way as spirits and black magic.

> Anwar: I know I've got this psychosis now. But then I think of black magic and jihn, it's hard to completely get rid of that idea, because it's always going to be playing at the back of your mind. It might be a jihn, it might be black magic, and maybe I'm wrong. But then I remind myself that I have psychosis, something you have therapy for, change your thoughts. I have to just think of it that way.

Ethan held a religious belief of being "cursed". He expressed ambivalence about religious beliefs. His family believed he was cursed because he did not partake in a religious and superstitious practice of placing chilli oil on his forehead to stop others being jealous of him. Ethan later went on to perform the practice and expressed confusion as although he disagreed with parts of his religious culture like this specific practice, a part of him believed in the superstitious ideas advocated within his religious culture when thinking about his experiences.

> Ethan: That's why I don't like my culture that much, because it's absurd and I don't find it makes sense. Like the only reason I did that chilli stuff was to put my mum's mind at ease, she kind of forced me to do it. But, I guess there's a part of me that believes it too.

Anwar recognised the influence of his religious background on mental health, which impacted stigma and the way he coped with his experiences. He articulated how there was shame and secrecy around suicide. This layer of religious understanding increased the experience of stigma.

> Anwar: I think an important part about mental health is suicide and in Islamic communities suicide is really frowned upon. Attempting suicide means like you're damned to go to hell […] the Imams will tell you that. Some Imams might be a bit more empathetic and say that if you ask for forgiveness enough, God might forgive you. But I feel like there is a stigma around that as well.

Therefore, this sub-theme grapples with how the intersections of British-Asian identity and psychosis affect the experience of stigma. These include cultural understandings, religious understandings and generational differences all of which are fluid and intertwined in a complex manner.

2.2 "It's a harsh environment". Participants spoke about the hardship and disadvantages they faced in relation to the places they lived and environmental difficulties. These factors complicated the experience of stigma for participants. They discussed how coping with their living environment made them more vulnerable to feeling distressed and stigmatised in society. Tippu talked about the hardship he faced relating to homelessness. He described the pressure to attend appointments with the council, believing he would not have somewhere to sleep overnight if he missed them. Tippu felt the council did not care about his experiences. He made reference to the detrimental way people treated him and how this influenced his distress.

> Tippu: I've applied a few times for council housing, I've lived on the streets and I've been homeless and all that. We ended up on the streets, been living on the streets. We went to the council and we didn't get nowhere and we stayed in the homeless shelter for about 26 months. They were giving me these appointment dates every single week, not to miss any of them. If I did, they would kick me out from them shelters. It's so deep and nasty the things I've been through, the way people treat you. I was getting nowhere, I was stressed out and I was depressed […]. There's so much more information, but I don't want to get into it. It's so deep and nasty things that I've seen and been through as well; I've seen it […] no one wants to know about all this.

Ethan spoke about how the difficulties in his environment and lifestyle, negatively impacted his wellbeing and experience of voices. He noted the difference he experienced when visiting his relatives who live in a middle-class area; away from where he lives.

> Ethan: It's weird because when I was away I didn't hear any voices at all and didn't feel depressed whilst I was there. Then as soon as I got back here, that's when I started to hear voices again […] it's just the lifestyle here. That's why I was so eager to go

> away because I just felt so much happier there […] no one gets how much this place can get to you.

Like Ethan, Fahad also found his local, urban environment hard to bear. He felt this was something that was not acknowledged by services. Despite being brought up in the U.K., Fahad reported it was more difficult to live in the U.K. when comparing it to living in another country. Fahad described needing to hide his vulnerabilities. He felt he had to protect himself by being ‘tough’ and only showing strength in public situations to cope with his environment.

> Fahad: People don’t realise what it’s like here. I feel like the place where I live and the kind of mentalities around here are harsh, it’s a harsh environment. I feel like you have to be really strong and not show your weaknesses. That’s how it is. It’s made me the person I am. I probably wasn’t like this when I was living in Pakistan. Here, people don’t want to know about your worries, they don’t have time for them. You adapt to how society is – this is how *my* society is. It’s just how society is and what it demands from you. You need survival skills. I feel like not showing your weaknesses, showing you’re happy and you’re doing well is a survival skill here […]. It’s like a front […] that’s not something you talk about though with your counsellor, you just know, nothing’s going to change it.

Collectively, these quotes capture how these participants have been stigmatised by their living situation. Some participants reported that professionals within social systems have missed the influence of living in an urban environment. Participants’ felt their living situations were additional disadvantages that they faced in society. Hence, environmental factors are an aspect of participants within the overarching theme of ‘Understanding all these parts of me’.

2.3 “Services don’t really see me”. Many participants felt EIP services did not notice parts of their cultural identity that professionals were not familiar with. As a consequence, aspects of participants’ stigmatised identity were often unattended and unsupported by

professionals. Tippu commented he did not like seeing the EIP service as contact with professionals added to his stress rather than helping him feel supported. He said, “I’m getting hassle coming here. I don’t see my care coordinator. Every time I was coming she was stressing me out”.

Ali, Anwar and Aaliyah noted the interview was their first experience of a professional being interested in their cultural identity and how that related to their mental health. Particularly, there was a narrative around participants not feeling able to discuss their religious and cultural background, fearing they would be categorised by diagnoses. Aaliyah articulated that professionals used a western approach ignoring eastern influences on participants, such as focusing on thought processes and trauma. She expressed a wish for EIP services to consider and prioritise cultural factors more.

> Aaliyah: This is my first time talking about it all properly, about my background and my religion, I’ve only ever lightly touched on it with the person I spoke to when I contacted the service, but other than that it’s just this. I think it’s something that people don’t really pick up on in the service. That’s just from my experience. Or if they do it’s a much later on factor and less of significant factor…It’s kind of mainly focusing on what you’re hearing or what you’re feeling. I think other factors aren’t paid attention to. I think they’ll look to things like childhood trauma, things like bullying where I think that’s a very different experience to cultural experiences. I don’t think cultural experiences are off the bat, considered and therefore reinforced… I think I want them to try to understand a bit more that if you’re from an Asian background that you’re going to have a lot more of a different experience from patients who are white, or even black. It’s very different that they’ve got different stresses, different pressures to other patients. I’d like them to consider a bit more about the culture, to see what it’s like, just to learn about it a bit more. Just be a bit more careful in your approach.

Ali pointed out that he felt disappointed that the psychologists he saw provided generic treatment based on a westernised, medical approach. This contrasted with his outlook which was challenging for Ali as he felt services would not understand him.

Ali: I'm here in this team now, I don't think they understand it, but I don't think they ever could unless they experienced it themselves. They don't really understand it. They can't understand it because they think differently, they think much more differently to what it should be [...] I think when they come to work, they leave all their experiences at home and they just put on the medical hat and start doing diagnosis. So they become like the same person almost. If you listen to one psychologist and you listen to another psychologist, you'll probably see a lot of common things that they're saying. They don't base their thoughts on experiences, they base it on medical practice that they've had.

Anwar and Aaliyah spoke about the importance of professionals' ethnicity. They felt that clinicians' from a Black or Asian background would have more knowledge about cultural issues and be more comfortable talking about it. They felt these professionals would then be more open to thinking and talking about aspects of their cultural identity, ultimately having more understanding of their stigmatised identity.

> Anwar: I guess a lot of the religious aspects and beliefs and stuff like that I couldn't really touch on properly. I just didn't want to make her uncomfortable. If the psychologist was Asian then I guess there would be a lot more understanding.
>
> Aaliyah: I feel like maybe the staff come from a brown or black background they'll ask about it, because they know about cultures. I just feel like if you're from a white background, I don't think it's the first thing they consider.

A key frustration of EIP services expressed by participants' was a lack of understanding families had of psychosis, which perpetuated stigmatisation. Udit and Syed commented they were given little support or not offered any support for families by services. Udit pointed out

how services miss how mental health is understood in Asian culture. He described the lack of recognition of the different types of difficulties within his community and how mental health is generalised and stigmatised as a whole. Udit felt this part of his experience was lost by EIP services.

> Udit: My family, they don't know anything about mental illness and the team don't realise that. You know all the variations that we have, like there's this kind of disorder and that kind of disorder […] in my culture they don't know any of that. They know that some people are crazy and then 'there's the rest of us that are normal'.

Similarly, Syed was keen to have more information and education from services.

> Syed: There's just not enough information about psychosis. If I never suffered from it, I would have never known anything about it. It would be helpful if there was education based on mental health. I never found anything to read whilst I was going through it. I found out what depression was after I was going through it, so there's not enough education on the matter of mental health in my opinion, because if I had not suffered from any of this I wouldn't know anything about any of this.

In relation to EIP services failing to support families, Aaliyah discussed how her family cared for her uncle who experienced psychosis. She felt her family did not have enough information to meaningfully support her uncle.

> Aaliyah: Well for the longest time they didn't really know how to deal with it, but they knew he was unwell. They kept him in the house much longer than he should have been. I remember my mum and dad trying but it's just because they didn't understand *how* to help. I think that's the problem they have sometimes now. They want to help but they don't know what to do. They're not educated about it.

These quotes reinforce how participant's felt that services were not recognising different aspects of their identity, which contribute to the experience of psychosis and stigma.

Theme three: experience as 'the other'. The theme of 'experience as the other' explores the ways participants felt alienated and excluded from society. All the participants spoke about fear of being with other people within the Asian community and wider society. Participants felt targeted, persecuted and discriminated against, which led to isolation demonstrated in the first sub-theme "It was safer to be alone". The sub-theme "It's contagious, it spreads" relates to participants' experiences of 'otherness' specifically within the Asian communities and how these communities would distance themselves from participants. Othering was also a predominant feature of the sub-theme "I'm not associated with ISIS" which conveys participants' experiences of discrimination, islamophobia and dehumanisation within British society.

3.1 "It was safer to be alone". This theme relates to how participants isolated themselves due to public stigma. Isolation and fears about safety could be perceived as part of psychosis. However, given the context of participants' narrative, this theme is based on coping with a stigmatised identity. All participants were worried about how people in wider society would treat them. Consequently, fears about their safety influenced participants' decisions to hide or segregate themselves in society as well as social networks. Syed discussed isolating himself from his friends and community, "I kind of ostracised myself from people […] I don't want them to see me differently […] being by myself was easier". Equally, Tippu also wanted to be by himself, he commented, "I just don't feel comfortable around people anymore". In addition, Anwar spoke about avoiding people when he leaves his house as a way of protecting himself and keeping safe.

> Anwar: I tried to keep my head down a lot when I'm out so people don't notice me[...] It might just be me overthinking, but I try and avoid talking to different people so they don't judge me […] it's just safer that way.

Ethan described how he kept his social network small as it felt safer. He explained how this related to whether he could trust other people. He reflected, "I just prefer to be by myself so there's less chance of me being betrayed, so that's why I try and keep the circle real tight".

Anwar and Aaliyah both expressed fear of being in public, within their local areas. They were worried about being stigmatised in public, which increased their sense of vulnerability. This developed into a wish to isolate themselves from society, demonstrated in a quote below by Anwar.

> Anwar: It's mostly that fear of different communities and what do they think of me […]. It's hard to leave the house […]. My fear plays up on the fact that people are trying to out me or single me out. I don't want to be around big groups of people.

Aaliyah spoke about her concerns about being in public and how she was previously attacked for wearing a religious headscarf. She felt that if people also found out about her psychosis experiences, she would be further stigmatised and her vulnerability would be heightened. This captures multiple stigmatised identities that influenced Aaliyah's sense of wanting to be alone.

> Aaliyah: I know that certain places will trigger me like if I'm in a big public space or if I get on the train or things like that where I feel like I am probably open to being attacked again. I used to wear a headscarf and I got attacked. I don't want to give people another excuse. That's why I don't want to be around people. It just makes sense to be at home most of the time and if I have to go out, I go places with my mum or get a lift with my brother.

The role of media in relation to increasing public stigma was reported. Hemisha and Anwar talked about how the media perpetuates stigmatised beliefs about people experiencing psychosis. Thus, enabling a harmful narrative which stigmatises people experiencing psychosis. Hemisha had observed these messages in the media, which added to the wish to self-isolate and not attend school.

> Hemisha: […] like you know on TV and things like that. They basically exaggerate what a person's like with a mental health disorder. They think that people who hear voices or see things are automatically going to attack them like you see in films where they get sent to the hospitals with the wards and they get strapped down and things like that. I didn't want people at school to think that of me, it made me not want to go in.

Anwar also spoke about school. He reported having lessons encouraging pupils to think about mental health. However, he did not realise the impact media had on not only how he was perceived by others but wanting to isolate himself.

> Anwar: In the lesson they played a clip from EastEnders and in that clip someone had bipolar or something and the question was what do you think is wrong with this clip? […] I didn't understand how different that could be. How it could play on people's subconscious, it could play on people's fears and hopes and stuff like that […] it makes it hard. If people see that, will they be scared of me? I don't wanna have to deal with that. It made me just wanna be alone.

These quotes highlight how some participants felt more comfortable in self-isolating to feel protected from stigma perceived from members of the wider community.

3.2 "It's contagious, it spreads". Participants discussed how psychosis experiences were associated with harmful and stigmatising stereotypes within wider Asian communities. They explored how Asian communities distanced themselves from those individuals who are seen negatively and 'othered' within the community. Being part of an Asian community and experiencing stigma seemed to be intensified due to the closely – connected nature of a collectivist, interdependent culture. This perhaps explains why those around the stigmatised individuals were strongly associated with stigmatising attributes, illustrated in the quote below by Hemisha.

> Hemisha: Oh don't see her because she has a mental health disorder, you might get it as well". They think it's contagious, it spreads. I don't want to have to go to a family event and have all of them look at me like I'm dying or something you know.

It was emphasised how Asian communities would separate and distance from participants. Anwar talked about how people in his extended family looked and treated him differently at family event. He also noted how people physically distanced themselves from him which was upsetting.

> Anwar: So if I was to go to a family gathering or anything no one would make eye contact. You could tell by the way they talked they didn't really understand what was going on so they were a bit on edge. I remember when I was out of hospital I wasn't really in the right state of mind so when they saw me and the way I was acting and stuff like that, they wanted to keep their distance and stuff. I remember trying to sit next to my relatives and my relatives literally got up and moved a couple of spaces away from me. That was bad, I got quite numb after.

In the same way, Udit stressed how stigma is a community experience within Asian culture. He believed it is perpetuated through association with someone who is thought to have stigmatising qualities like psychosis.

> Udit: I could see other Asian people having that stigma. The stigma exists within the tribe and if you're Asian one of the tribe. I think that's why it extends. So within your tribe you have the stigma of whatever it is, you have the stigma of mental illness and then if you meet another Asian person it's like 'Oh no, it's a member of the tribe' and then you have that stigma and then you are less likely to (pause). They see through that lens and then I don't want to tell them about (pause) my mental illness.

Similarly Aaliyah discussed how people in the Asian community are closely connected. This significantly compounded her psychosis experiences. Furthermore, it stopped Aaliyah and her mother from disclosing anything about psychosis to her extended family and wider Asian community.

> Aaliyah: it is what people are saying but I know she's [mum] worried about me, being worried about people in the community talking about me, which is a massive thing for me being paranoid. And she would rather contain it just to people that should know, but I think she's also worried about it getting out, because everyone is connected, aren't they? I think even for myself I would rather almost not let any family know as I just feel like they won't get it either. But if anybody has noticed my mum would just pass it off as a migraine (laughs) it will be like "Oh she's just having a migraine and she just doesn't like talking, she's needs to stay at home".

This sub-theme is captured in accounts by Hemisha, Anwar, Udit and Aaliyah who all feared the gaze of others within their extended families and Asian communities. These concerns about judgement and stigmatisation within Asian communities were distressing.

3.3 "I'm not associated with ISIS". This sub-theme explores stigma related to race and religion. Participants spoke about their stigma experiences being related to racism, islamophobia and ultimately dehumanisation. Ethan attempted to justify his humanity by asserting "I'm not primitive, I'm human, but it is harder for my family to adjust to western stuff" (Ethan). This comment by Ethan was thought to relate to race and culture as he spoke in relation to members of his Asian family adjusting and assimilating from eastern to western society. The use of the word 'primitive' evokes a provocative racial stigma. The notion of 'primitive' relates to how people of colour are regarded as animal-like, inferior, unintelligent and savage within a racial hierarchy. Ethan's need to justify himself shows his attempt to distance himself from this damaging, racialized and stigmatised identity.

Some participants shared they felt alienated in society and portrayed feeling that they didn't belong in the U.K. Tippu made comparisons to not being a paedophile, which conveys how his experience goes a step further than stigma. He defends himself by acknowledging his human traits of caring for others, indicating dehumanisation.

> Tippu: I live in this place, people don't want me here, I got all these different problems in me…I'm not an evil person who doesn't care for someone; I do care for humans, any kind of life basically […] I'm not a paedophile or anything […] the neighbours are choosing who they want in, who to stay and who not to stay […] these people are White, English people. I'm the one that's always been targeted. I'm fed up of this country.

Within this quote, Tippu describes stigma in relation to where he lives and "problems" he perceives in him. It is difficult to tease out whether he is referring to stigma of psychosis or stigma of race and who exactly has implied he is evil. However, within the wider narrative of the interview, he talked about feeling socially-excluded by the White majority group in the U.K., Therefore it appears that Tippu is referring to stigma related to race. Given that Tippu

also previously described stigma related to psychosis, this demonstrates the multiple and intersecting stigmas that impact his lack of belonging in society. Similarly, Anwar described a lack of security and belonging in wider British society, highlighting a sense of exclusion. He reflected, “I just felt like you don’t really have a place to fit, I didn’t belong here and people wanted to take stuff from me, but it was worse than that”.

Islamophobia was described as another form of religious stigmatisation, discrimination and othering in British society by participants. Islamophobia was not only another layer of stigmatisation, but alongside stigma associated with psychosis, it also significantly impacted participants’ experience of psychosis. Aaliyah described experiencing islamophobia in the form of being physically assaulted on a train on two occasions. The impact of these assaults was significant for Aaliyah, “for me, being in a head scarf, I don’t feel safe in it anymore. When you’re dealing with voices, that’s a major factor and I don’t feel safe in it. I’d rather not wear it”. Following the attacks, Aaliyah began to hear voices and experience paranoia which led to her changing her appearance in public to feel safe. Thus demonstrating how distinguishing features of being Muslim resulted in discrimination and stigmatisation, feeding into psychosis experiences.

> Aaliyah: [voices] say “someone’s going to attack you” or I just get a paranoid feeling that I’m going to be attacked […] I feel it strips away a lot of my confidence. My main fear is being attacked; I have been that’s why it’s such a major thing for me. I rather not wear it, or I might chose to wear it again later, but for now, I chose not to.

Fahad also shared experiences of islamophobia. He described how anti-muslin posters were put through letterboxes in his local area, including his. These posters encouraged prejudice, discrimination and violence. They advocated verbal abuse, torture, pulling headscarves off women, acid attacks on Muslims and bombing mosques. Fahad reflected, “My

family even got this 'Punish a Muslim' flyer through the door telling people to attack Muslims, it really upset my sisters. You have to be strong, deal with the harsh".

Anwar shared his experience of islamophobia whilst being on an inpatient unit. He spoke about the detrimental impact it had on him and another Asian service-user on the ward. Alongside this, Anwar felt he needed to denounce any association with terrorism and extremism during the interview. This is a manifestation of internalised oppression and stigmatisation related to harmful social narratives of Islam being associated with terrorism.

> Anwar: In the hospital when I first came in, there were windows and a lot of patients would look out the window because it was relaxing when you're in an environment like that, we would look out the windows. There were a couple of patients that didn't like Muslims, they wrote on the windows things like "fuck ISIS", "fuck Islam" and stuff like that – they carved it out. At first I tried to not notice it but it did get to me, obviously like I'm not associated with ISIS or anything but it's kind of like the fact that people would associate Muslims with that as well. That played a role into it. There was another patient that came in and he took one look at the window and he had a mental breakdown. He was Asian.

This sub-theme epitomises the racial and religious stigma participants faced, in addition to mental health stigma.

Theme four: finding ways to cope and thrive. The final theme explores participants' attempts to find connection and meaning in their lives. This seemed to be something that helped them to cope with the impact of stigma, by bringing out a sense of understanding and fulfilment. Specifically, supportive relationships with people, finding meaning about their experiences and developing an understanding of themselves with support from services were paramount to participants. This theme epitomises supportive relationships and engaging in values protected

participants against stigma. The sub-theme "It's like sharing the load" navigates participants' sharing their psychosis experiences with friends and family members. It explores what participants gained by feeling heard, validated and cared for. The next sub-theme "I feel like a social butterfly now" explores participants' journeys in finding purpose and fulfilment, which were vital for participants to move forward from psychosis and stigma. The final sub-theme "I needed help to understand" illustrates the helpful support and therapy participants' received from EIP services. This was an important aspect of participants' journey, which helped them understand their experiences. The theme 'finding ways to cope and thrive' captures participants' engaging with values.

4.1 "It's like sharing the load". Participants placed significant value on having close relationships with people they could trust and share their experiences. Syed pointed out that "it helps if you have a friend or a family member that you can just open up to. It helps having someone with you that knows and understands". Furthermore, Ethan noted he felt more "connected to" family members who had also experienced mental health problems. However, cultural understanding highlighted in the sub-theme "Understanding all these parts of me" continued to play a role in conceptualisation and disclosure. Tippu reflected, "I feel more comfortable talking in my language, there's more ways of expressing yourself […] but here there's only one way to explain it so people don't always get it". It is important to note as Syed describes below that it was not just about the secrecy and shame of sharing, but physically not having the right words to describe things in a different language. This is really powerful representation of the practical and emotional barriers to sharing experiences of psychosis.

> Syed: It's not like the Asian culture demonises you for it, it's more just they don't understand. The best advice I could give would be to get someone you can speak to. It's hard speaking to your parents in their language, whatever the language may be, it's hard to express your emotions through a second language so find someone to speak

> your first language […] I know some bits get lost, but if it's English, find someone to speak English with and build a rapport with them, like a family member, if not a sister, brother, cousin. It's like sharing the load. They'll know what you're going through and you know there's someone there that knows. That would be a very big help.

Hemisha considered her friendships essential to her coping. In particular, she found it helpful in the way she saw herself and felt understood. Hemisha felt her friends were consistently supportive, which allowed her to share her experiences and feel less alone with her mental health, for instance when she felt increasingly distressed.

> Hemisha: I think honestly the support of my friends, because they were the only people who didn't change their opinion of me and were always there no matter what or how I felt. I used to lash out at them a lot because of myself and my parents and they used to understand that. But they still stood by me and really supported me, they really did a lot. They were all encouraging as well, because they are all technically a year above me, so they handed their experiences down to me. I'm really grateful to have them in my life [...] Yeah I told them everything. I used to feel quite suicidal and my friend used to come to stay at my house, like in the middle of the night she would come over.

The sub-theme "My family keeps it hush hush" illustrated how Asian family culture contributed to stigma. However, some participants spoke about the value of communication within families. Families that were emotionally-available open to hearing experiences; learning about psychosis and provided support was reportedly helpful to some participants. This willingness to understand and learn more about psychosis seemed to ease the participants' experiences, allowing them to feel less alone and reduced feelings of stigma. For example, Zaair felt he was able to share his feelings with his mother knowing she would be understanding rather than critical of him.

> Zaair: Yeah I've told my mum. I knew she wouldn't judge me or anything. She's the one I trust and confide in. She's the one that I trust because she's the one that's more open-minded out of my two parents, so she's the one who's more understanding. I felt I could confide in her and tell her how I felt […] she's more western, she thinks differently to my dad.

Similarly, Ali talked about how supportive his immediate family members were. The use of humour was important with his siblings. Through sharing his experiences with his father, Ali discussed looking up to his father as a model of how to cope. He learnt ways to express his feelings.

> Ali: I come from a family that's really supportive, like my brother laughs with me, he jokes around with me and stuff all the time and my sisters are alright. They're there for me if I need them about anything, it's really good. They haven't thrown me away or anything. When I talked to my Dad, he helped me. He said he just talks his feelings out and anything that's weighing him down. He lets it out, he doesn't keep it with him and he repairs himself. That's what I do now too.

Fahad felt his family were more engaged with what he was going through, following diagnosis and becoming aware of his experiences. He observed helpful differences in the way his family interacted with him and highlighted the benefit of feeling less isolated by feeling more connected to his family.

> Fahad: Just me being at home more has brought us more closer. When I was diagnosed, they did start caring for me more and were open to my doctors talking to them about how to help me. Then they started telling me that I didn't need to study as much, it took the pressure off. They did support me, I feel like they've listened to me more. They've taken a step back, asked me questions and allowed me to make my own decisions and that's made things easier […] sometimes you need people around you. Being alone can

affect your mood or your personality, you become lonely. I'm trying to make friends at university.

These quotes from some of the participants highlight the importance of being able to share their difficulties with others peers and family members who are more likely to understand their experiences of psychosis. However, notably some participants like Tippu and Anwar did not have relationships with people to share their experiences with.

4.2 "I feel like a social butterfly now". The search for purpose and fulfilment was discussed by participants. Stories of engaging in activities and values that allowed participants to thrive were explored. Although as previously presented, religion added to experiences of stigma (i.e. black magic) for Fahad, Ali, Ethan and Zaair, it still provided solace and meaning. Engaging in their respective religions was an important aspect of understanding themselves and their experiences. Ethan commented, "I still pray and it helps me". Likewise, Zaair said, "being a Muslim still helps me sometimes". Fahad pointed out religion helped him to cope with psychosis and stigma.

Fahad: As I'm growing up and getting more religious and getting more fascinated by my religion, I try to pray 5 times a day which is what I have to do for my religion. Every year we have Ramadan so I keep the fast even though I have exams through some of it. I am very inquisitive about my religion. It's helped me with the hardship I have faced and it's led me towards a more helpful path.

Ali went further to describe how his religion helped him to understand his psychosis as a blessing. He felt it developed his sense of self, strength and resilience.

> Ali: When I have the problem, I look at my religion and I look to my God and I can put all my problems on him and he can heal me […] I think of psychosis more as a blessing because it makes me stronger and it makes my belief stronger and it gives me something to exercise. Sometimes you battle with it, you know it says you're bad and you say you're good. You learn to speak your own voices and develop into a different person […] I've overcome stuff, I feel like I understand myself a lot more. I'm more aware of mental health, my environment around me. What things to put aside, what things to put my mind into, to not listen to. I'm more aware. I'm more sure of myself.

The importance of social activity and connectedness was highlighted. An aspect of this was the social networks that were opened up through education. Many of the participants were studying and had regular contact with people that way. Syed articulated, "I'm trying to make friends at university, put myself out there. You need that social support". Anwar discussed that although there was a hesitation to disclose psychosis in these settings, the value of social support and being with others through education was appreciated.

> Anwar: I don't want to offend them, they're really sweet people, they are nice people. I don't want to tell them something that might make them feel weird. But I do have friends now, people I hang out with, like spend time with and stuff.

Similarly, Aaliyah spoke about how it helped being in a group of friends at university. She also felt able to disclose her experiences to one friend and feel supported.

> Aaliyah: I've got quite a diverse group of friends at uni which I like. We gossip and go for meals, that kind of thing (laughs). I've told my one friend who I'm very close to […] I feel like I can tell her anything, we're very open about mental health which really helps me.

Hemisha also found meaning in social connectedness and felt able to thrive by engaging in social activities. She described a sense of achievement and confidence and noticed the difference in herself.

> Hemisha: I found the courage to join the dance class or to do activities with people I didn't know. Things like that. Before, I didn't want to go where people were that I didn't know. But now, like I'm even going clubbing in London, with my friends! I feel like a social butterfly now (smiles and laughs).

This sub-theme epitomises how social-connectedness, social functioning and quality of life help cope with psychosis and stigma.

4.3 "I needed help to understand". The shortcoming of EIP services missing part of participants' experiences was presented in a previous sub-theme. However, some participants praised the support they had been given by services. In particular, some participants found the psychological input meaningful in terms of understanding themselves, their experiences and identifying aspects of themselves they liked. Support from a psychologist developed Syed's sense of feeling understood and raised hope.

> Syed: I've had my second session with a psychologist, one on one. It's been refreshing that someone could follow my train of thought because it's so confusing my own mind, I thought it was impossible for someone to understand, but when the psychologist relayed the information back to me, it was actually better than what I could've actually said. So it's been very promising.

In the same way, Fahad drew comparisons of how he felt before and after therapy, emphasising how it had helped him.

> Fahad: I've got proper counselling here and it's been really, really good. It's been brilliant. Before therapy, I wasn't really aware of the kind of person I was. Going through therapy I'm able to see the kind of qualities I have. For example people tell me I work hard. I never knew that about me. I just used to get on with things. After therapy I realised there's a lot of good qualities that I do have.

Hemisha expressed how the care of the EIP service was very beneficial in terms of having direct contact whenever she needed it.

> Hemisha: I think it's really good that I was put under the care of here. I've had counselling sessions, I have a care-coordinator who calls me and checks up on me to see if I'm okay. I was able to call a direct line if I wasn't feeling good. They've helped me; it's been really good here!

In particular, Hemisha liked that she was able to develop and share a psychological formulation of relational difficulties with her family. This allowed her to connect her experiences and repair ruptures which had affected her.

> Hemisha: Me and my counsellor figured this out together and I told my dad. He never used to give me enough attention as a child, like as much I needed. He would always leave me alone. I remember I used to cry at the window […] I wanted my dad's attention and yeah I said that to him. I said this is what we spoke about and like now he'll feel really bad for it. He'll be like I'm sorry for like leaving you, he feels really bad.

Although these participant quotes described positive experiences of EIP services, Aaliyah, Tippu, Ali, Anwar and Udit reported that services failed to recognise and explore aspects of their identity that were stigmatised. Notably, those who felt missed by services (described in sub-theme "Services don't really see me"), expressed the most frequent and

severe forms of stigma across their accounts. This highlights how different types of stigma intersect, which may impact disclosure and accessing support.

Chapter 4. Discussion

Chapter Overview

The research findings will be summarised and discussed in this chapter. The findings will be considered in the context of psychological theory, existing research and relevant literature. Also, key limitations and strengths will be presented, alongside clinical practice implications and recommendations for future research. Finally, the chapter will conclude with the researcher's reflections on their journey throughout the study.

Findings Overview

The aim of the study was to explore how second-generation British-Asian people using EIP services experience stigma. The study explored participants' experiences of internalised stigma, external stigma and their experiences of mental health services. The study employed thematic analysis to integrate participants' experiences in order to identify and develop interconnecting themes. The current study identified that stigma is a prominent issue for British-Asian people experiencing psychosis. Four themes and twelve sub-themes emerged from participants interviews reflecting the aims of the study.

Findings in relation to Existing Theories, Research and Literature

Themes and subthemes in relation to the study aims are now presented and discussed. Findings will be considered in the context of relevant literature and research.

The burden of silencing. This theme conceptualised ways participants were unable to speak about their experiences. It encompassed the oppressive nature silencing related to stigma had on participants. Silencing was sustained by suppressing or trying to hide psychosis experiences due to the social unacceptability of psychosis which appeared to develop internalised stigma.

The first sub-theme “It rips you from yourself” reflected participants struggle with how they saw themselves. It emphasises their internalised psychological distress based on negative ideas of psychosis, (i.e. feeling of ‘hitting a low point’). It relates to silencing as self-directed prejudice and discrimination maintained distress which prevented them from externalising their experiences (i.e. speaking out). The internalisation of stigma was present in all participants, mirroring a large body of internalised stigma theories (Birchwood et al., 2007; Corrigan & Watson, 2002; Link & Phelan, 2001; Wood, et al., 2017). Participants accounts of self-denigration, despair and low self-esteem, fit with existing research identifying service user’s poor sense of self and the role of psychosis and internalised stigma in contributing to this (Birchwood et al., 2007; Corrigan & Watson, 2002; Link & Phelan, 2001; Wood, et al., 2017).

The sub-theme also connects to the literature on shame being related to psychosis, which is also evident in Asian populations (Chew-Graham et al., 2002; Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015; Wittkowski et al., 2011). Participants spoke about negatively identifying with a psychosis diagnosis, identified by previous service user literature (Pitt et al., 2009). This is important to consider in the current FEP population who are often in receipt of a new diagnosis (Gronholm et al., 2017; Iqbal et al., 2000). Furthermore, this theme is in line with how shame, hopelessness and low self-esteem are problematic for those experiencing FEP (Birchwood et al., 2007). Participants perceived themselves in a rejecting, detrimental way in line with internal shame

(Gilbert & Procter, 2006; Gilbert, 2010). This shaped their distress and negative affect related to internalised stigma, as suggested by Wood et al., (2017). Silencing is seen as behavioural response to shame, blame, hopelessness, which are all components of internalised stigma (Wood et al., 2017).

The second sub-theme “It’s a bad thing to tell people,” relates to stigma theories on labelling and stereotypes (Link & Phelan, 2001). Participants’ identified with stereotypical labels for those experiencing psychosis such as ‘weak’, ‘inferior’, ‘mad’ and ‘dangerous’. Consequently, they wished to conceal their psychosis as a result of negative generalised beliefs (Corrigan et al., 2012). This played a key role in participants’ reluctance to disclose experiences, as reported in existing research (Corrigan & Matthews, 2003; Ferrari et al., 2015). This sub-theme also potentially demonstrates a safety behaviour to cope with stigma (Garety et al., 2001; Morrison, 2001), given how participants were secretive and avoided sharing their experiences to protect themselves from feeling stigmatised. Safety behaviours are a common response to internalised stigma, where disclosure of psychosis is avoided within social networks (e.g. friends, family) (Corrigan et al., 2013).

The third sub-theme “My family keeps it hush hush” is indicative of the role families played in participants’ silencing and stigmatisation. Participants reported that their families also identified with stigma and shame associated with psychosis, resulting in an avoidance to discuss psychosis. This added to how participants felt silenced. It is identified that in Asian communities rooted in interdependent, collectivistic culture, shame affects the individual, but also people associated to the individual such as family members (Gask et al., 2011; Gilbert et al., 2004; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015; Killian, 1990; Pirani, 2009). Culturally, this is considered dishonourable and felt upsetting for

participants (Al-Dawi et al. (2002), thus being a barrier to them speaking out and seeking support.

Overall, the burden of silencing is congruent with majority populations who experience internalised stigma related to psychosis. It draws out the internal distress participants experienced, but also fear of disclosure. However, Asian family culture appears to have an additional layer of stigma that may not be applicable to non-Asian populations. Given how prominently shame affected individuals and their families in the context of a collectivist culture, this aspect of silencing was a distinction, specific to Asian culture. This is repeated, pertinent findings will be further expanded on within this chapter.

The un-noticed aspects. This theme captured how identity conflicts left participants feeling further stigmatised. These several aspects of participants were unseen and unknown to others, particularly EIP services. It shows how aspects of participants' identities were stigmatising and managed by using defences and compartmentalisation.

The first sub-theme "Understanding all these parts of me" explores the stress of navigating multiple identities for participants. This theme corresponded to research identifying that the difficulties minorities face in assimilation and adaptation to the White majority ethnic group. Goffman (1963) explicitly identified that stigma can occur within the context of race and religion. It is proposed that POC need to be closer to whiteness, in order to be considered acceptable (Fanon, 1967). It is also reflective of Link and Phelan's (2001) stigma model components 'separation' and 'status-loss and discrimination', given that adaption and assimilation to the white majority show a desire to not be separated and discriminated against. The attempt to adapt and assimilate may also demonstrate a race-related stigma awareness, stigma agreement and self-concurrence (Watson et al., 2007). Participants' distanced

themselves from their culture as a way of integrating in society or managing conflict of their racial and religious identity. This appeared to be a psychological defence of splitting and assigning parts of their identity as good and bad (Klein, 1946).

Identity conflict was imbued by straddling conflicting eastern and western 'Explanatory Models' (EMs; Kleinman, 1980) of conceptualising psychosis. Some participants' beliefs fluctuated, sometimes drawing on an eastern understanding. Cultural and religious concepts within Asian culture such as black magic and curses further compounded stigma, alongside the stigma associated with psychosis in wider society. For example one participant described suicide as religiously unacceptable. This was an additional layer of distress and stigma, which was experienced to different extents for each participant. Religious conceptualisation fits with studies which found British-Asian people using EIP services will use religion and culture to understand and cope with their experiences (Islam et al., 2015; Penny et al., 2009).

Contrastingly, fluctuating beliefs rather than strongly held beliefs is thought to relate to cultural and generational differences (Berry, 1990; Markus & Kitayama, 2010). Generational differences of EMs between first and second-generation British-Asians were thought to exacerbate participants' feelings of difference. There is existing research based on migrant and first-generation South Asians, but there is very limited research which examines specifically experiences of second-generation British-Asian (Bhugra, 2002; Bourque, van der Ven, & Malla, 2011; Cantor-Graae & Selten, 2005; Kirkbride et al., 2017). Generalisations of research findings of South Asian populations are problematic as they do not account for generational differences specifically, experiences of second-generation British-Asian people which can be markedly different. This difference is demonstrated in rates of psychosis being even higher in the second-generation, than first-generation British-Asian people (Bhugra, 2002).

Ignoring these details would lose the nuances and complex experiences of second-generation British-Asian individuals. The issue of cultural identity is pertinent for this population for many reasons. Firstly, psychosis is the fragmentation of reality and identity (Bateman & Holmes, 1995; Freud, 1894; Martindale & Summers, 2013), which has significant negative cognitive, emotional, behavioural and physiological consequences (Garety et al., 2001; Morrison, 2001). Cultural assimilation to the dominant group to be more 'socially-acceptable' (Berry, 1990; Boyer, 2001) is an additional stress. Together, participants may have experienced increased fragmenting of reality and identity, which is psychologically damaging (Laing, 1960). Through a conscious and unconscious process, internalised stigma described earlier, could be an inadequate reflection of participants' cultural identity (Corrigan, 2012).

Secondly, participants' reported fluctuating cultural beliefs about psychosis and stigma. In Asian culture, collective identity exists (Bhugra*,* 2004*;* Hofstede, 2001*)*. Contrastingly, in western culture, more value is placed on developing individual identity (Klein, 1946; Waddell, 2002). Furthermore, through a post-colonial lens, identity development is problematic for those who move between two cultures (Ennaji, 2005; McKenzie-Mavinga, 2009). Fanon (1967) described this as, "individuals without an anchor, without horizon, colorless, stateless, rootless" (p.218). Together all these aspects were significantly overwhelming for participants. They negotiated and navigated their simultaneous identities at a micro (personal distress) and macro level (social-acceptability), (Turan et al., 2019). This sub-theme grapples how stigma was multi-faceted and intersected in a complex and distressing way for participants (Bowleg, 2012). These multiple stigmas were not noticed by others.

The next sub-theme "It's a harsh environment" relates to how adverse psycho-social factors influence psychosis. Participants reported how lifestyle in their local, urban environment impacted their psychosis, making them more vulnerable and stigmatised in

society. This is congruent with research that shows urbanicity is associated with increased risk of psychosis (Freeman, 1994; Kirkbride et al., 2017; Pedersen & Mortensen, 2001). Furthermore, a lower socio-economic status in the context of less social, economic and political power is associated with stigma (Link & Phelan, 2001). Goffman's (1963) concept of tribal stigma explains how groups can be stigmatised based on social and cultural differences. Expanding on this, the social and economic influence on psychosis can be underestimated, missed and neglected (Johnstone & Dallos, 2013; Smail, 2005). Participants experiencing increased adversity and social deprivation (e.g. homelessness) faced more stigmatisation. The current sub-theme also fits with critical, psycho-social approaches of the development of psychosis (Mander & Kingdon, 2015; Varese et al., 2012) and associated stigma (Read et al., 2014). Consequently, highlighting how important it is to understand the intersecting factors that affected participants' experiences of stigma. It is important to this theme in the context of British-Asian people being more likely to face multiple social disadvantages compared to other groups (e.g. White-British population) (Cochrane, 1983; Saeed, 2007).

The sub-theme “Services don't see really me” pertains to mental health professionals' lack of exploration and thinking about participants' cultural background and families' understanding. Participants experiences of EIP services mirrored how mental health stigma and racism are repeatedly ignored in wider society (Eddo-Lodge, 2017). This sub-theme corresponds to a miscommunication between Eurocentric healthcare professionals and those from a differing cultural background can influence despondent attitudes in professionals (Tjale & De Villiers, 2004). Additionally, this perception reflects literature which has identified that practitioners often remain silent about prejudice and discrimination based on inequality (Bhugra & Bhui, 1998; Lowe, 2006). Crehan and Rustin (2018) suggest clinicians' anxiety about not knowing how to discuss intersectional differences may go some way to explain the current study findings. Nevertheless, it is imperative for services to consider these findings

given that British-Asian people have less equal access to mental health services (Brubaker et al., 2004) despite explicit equity-driven health policy in the NHS (DoH, 2005). Participants' experienced epistemic injustice as they felt un-heard by professionals (Fricker, 2007).

Participants indicated that they felt more comfortable with professionals who shared their ethnicity, matching research indicating POC prefer to be seen by professionals of the same ethnicity (Hussain & Cochrane, 2002). Arguably, POC find it more comfortable seeing professionals who are POC as there is an assumed shared solidarity, understanding and attention to cultural factors (Goode-Cross & Grim, 2014). Research shows that professionals' are more willing to discuss discrimination if they have also shared this experience, comparatively to those who have not (Lowe, 2014; Wilson & Francis, 1997). Participants raised frustrations that treatments and approaches felt impersonal, ignoring salient factors culture. This was key given the importance of integrating spirituality, religion and non-medical alternatives making sense of psychosis (May, 2012). Particularly relevant for participants was the lack of exploration of how Asian culture attributes religion, superstition and spirituality to psychosis (Charles et al., 2007; Joel at al., 2006; McCabe & Priebe, 2004; Zafar et al., 2008).

Experience as ‘the other’. The theme describes how participants sense of otherness and being treated differently. This includes social isolation, being treated negatively within the Asian community and Islamophobia. The theme reflects participants’ experience of being alienated and excluded both in Asian communities and in wider society. Participants’ were preoccupied with how they were perceived in society and spoke about socially isolating themselves out of fear of being discriminated against. Collectively, this theme described the reciprocal isolating experience which occurred between the participant, their Asian community and wider society as a whole. This was a common experience for participants as a result of both discrimination and racism, thus affecting participants’ sense of being in the world (Giddens, 1991). This theme is congruent with Wood et al.’s (2016) qualitative study which highlights how social networks and the stigmatised person mutually-withdraw, maintaining otherness.

The first sub-theme “It was safer to be alone” is reflective of how participants isolated themselves due to public stigma. They were living in fear of how people in wider society would treat them because of their differences and concerned about their safety. These worries about stigmatising stereotypes, prejudice and discrimination are congruent with Link, Wells, Phelan and Yang’s (2015) concept of perceived stigma. This concept describes how people believe they may be stigmatised based on negative stereotypes. Participants were understandably worried about both mental health and race related discrimination. For example, following mental health stigma and islamophobia, participants’ ostracised and segregated themselves from society. It is possible that intersections of difference like race and mental health increased participants’ experience of ‘otherness’, sense of danger and isolation (Crenshaw, 1995; Yuval-Davis, 2012). This sub-theme speaks to existing literature about othering within racialised social hierarchies. Those who are seen as ‘different’ on the basis of their race are stigmatised in society (Crenshaw, 1995; Fanon, 1967).

The second sub-theme “It’s contagious, it spreads” corresponds to how Asian communities distanced themselves from participants. This was because Asian communities had negative attitudes towards psychosis and did not want to be associated with stigmatised individuals. Link and Phelan’s (2001) theoretical framework of stigma identifies separation and distancing as a significant component, which places the person who has been labelled into a category, allowing an ‘us’ and ‘them’, creating a social outgroup (Read & Harre, 2001). In doing so, this provides society distance from the unwanted label and the associated negative stereotypes. Given the impact of culture on stigmatisation (Markus & Kitayama, 2010), it is important to consider that participants’ families come from Asian communities which are interdependent where social status and image are crucial (Triandis, 1995). Participants’ spoke about wanting to hide their experiences from others within the community, fearing the consequences of sharing would be more devastating than psychosis, such as people within the Asian community being less likely to associate themselves with them and being considered an ‘outcast’. This is notably similar to existing research illustrating how mental health is considered ‘taboo’ and more devastating than the mental health problem, due to the likelihood of being socially-rejected (Al-Dawi et al., 2002; Amri & Bemak, 2012; Tabassum, et al., 2000).

The third sub-theme “I’m not associated with ISIS” concerns stigma related to race and religion. Participants spoke about their stigma experiences being related to racism, islamophobia. Participants’ described prejudice, discrimination and racism such as physical attacks and threatening anti-Muslim posters sent to their homes. This sub-theme draws on research showing that in extreme cases, where individuals are considered a social threat or too different based on their race and religion, they are not counted as human, permitting people to emotional detach and negating guilt to their harmful actions (Link & Phelan, 2001; Saeed,

2007). This links to how social distancing from those who are considered different in some way (or 'the other'), facilitates prejudice, stigmatisation and discrimination (Baunmann, 2007).

It was difficult to tease out stigma related to race, religion and psychosis. However, participants' accounts in this sub-theme were deemed to be based on race and religion given the context of the narratives. For example one participant asserted how he was not inferior or "primitive" when talking about his Asian family adjusting and assimilating to white, western culture. The participant believed he was less human, as he was from an eastern culture and had to acculturate to the white dominant group. This is construed as a racial stigma relating to how POC are considered inferior to white people within western society (Fanon, 1967; Lowe, 2014). Furthermore, it is based on a longstanding history of colonialism and slavery where white people are considered more powerful and superior to POC (Hall, 1994).

Notably, the participants of a Muslim background most strongly reported stigma and discrimination through experiencing islamophobia. This is a significant problem currently in the U.K., particularly in relation to the rise in hate-crimes (Tell Mama, 2018). Participants' accounts of islamophobia are examples of primitive state of mind within society (Davids, 2011), whereby fear and anxiety associated with threat were projected onto participants of a Muslim background. One participant identified with this projection, indicating internalised stigma (Corrigan & Watson, 2002) and internalised racism (Fanon, 1967) by anxiously denouncing any association to a terrorist group. Given that he had less social power due to his religion and ethnicity (Hagan & Smail, 1997), he may have internalised prejudicial ideas about British Muslims to give such a response (Dalal, 2002; Moss, 2003). This further demonstartes feelings of alientation and the marginalisation of participants indentifying as muslim in British society (Saeed, 2007).

Multiple stigmas were indicated within this sub-theme (Bowleg, 2012; Turan et al., 2019). Participants expressed concerns about how these differences would compound the difficulties they faced from psychosis. Thus illustrating how their differences increased 'otherness'. In light of multiple stigma relating to race, ethncity, religion and psychosis, participants expericned increased ontological insecurity (Giddens, 1991). They did not feel a sense of belonging in the U.K. further exacerbating their distress, psychosis and feeling of safety.

Findings ways to cope and thrive. The last theme discussed the ways in which participants sought out connection and meaning in relation to manage psychosis and experienced stigma. Importantly, fewer participants endorsed this theme, but it was an important part of understanding participants' experiences. This theme relates to the value of connectedness with others within family, friendship circles and wider community. It also highlights the importance participants engaging in their values for fulfilment and the benefit of support from EIP services. All sub-themes are indicative of how supportive relationships can protect individuals from stigma (Gumley et al., 2010). They can be considered within the context of how better outcomes for those experiencing psychosis are associated with social-inclusion and social-connectedness (Leamy, et al., 2011). This is widely established in the stigma literature (Chronister, Chou, & Lao, 2013), specifically from service-user perspectives (Pyle & Morrison, 2013). Close social networks can protect against stigma, even if stigma is multiple (Wood et al., 2015).

Within the first sub-theme "It's like sharing the load", describe how supportive relationships helped participants share their experiences of psychosis and stigma. This finding sits with established research suggesting that the reciprocity within peer-support and social connectedness moderates distress related to psychosis and stigma (Leamy, et al., 2011; Lim &

Gleeson, 2014). Notably, the use of different language was thought to be a barrier to sharing with different levels of complexity. Participants pointed out they use different languages and ways to explain their experiences and solely using one did not entirely capture the way they saw themselves. This finding is in line with Gilbert et al. (2004) study, which depicted that some South-Asian terms do not have a literal English translation. For example, the term 'izzat' which has no literal English translation but is a culturally-transmitted concept indicative of shame. Research shows that despite people being bilingual, data might be 'lost in translation' (Bowl, 2007; Greenwood et al., 2000; Hussain & Cochrane, 2002; 2003; Islam et al., 2015). These findings need to be understood through eastern and western EMs (Good, 1997; Kleinman, 1980; Williams & Healy, 2001). These are powerful examples of how participants' experiences were stuck in-between ways of understanding and expressing themselves.

The next sub-theme "I feel like a social butterfly now" encompasses the significance of fulfilment and thriving for participants to cope with psychosis and stigma. This sub-theme is notably similar with Lambri, et al.'s (2012) study which suggests seeking fulfilment and quality of life are essential for those experiencing psychosis. Participants described finding meaning in religion and engaging in fulfilling activities were valuable in managing the hardship they faced related to stigma and psychosis, comparable to existing research (Islam et al., 2015; Knifton, 2012; Penny et al., 2009). Furthermore, these finding are in keeping with systematic reviews suggesting that social-connectedness is important in alleviating distress related to psychosis and stigma (Leamy, et al., 2011). This sub-theme fits with how improvement in social functioning is extremely important to the needs of those experiencing psychosis (Pitt et al, 2007).

The last sub-theme "I needed help to understand" highlighted the ways in which participants' valued EIP services in aiding them to make sense of themselves. The accounts of

some participants' about EIP staff is congruent with other research which found that British-Asian people using EIP services reported staff as accommodating and considerate (Islam et al., 2015; Penny et al., 2009). Perhaps this relates to the ethos of EIP to offer more flexible, specialist support (Johannessen et al., 2001; Lal & Mala, 2015; McGorry, Killackey & Yung 2008) to improve recovery and social inclusion (Bird et al., 2010; Thorup et al., 2005).

Positive experiences of psychological treatment capture how psychological therapies can be helpful for people experiencing psychosis (Freeman & Garety, 2003; Mander & Kingdon, 2015). Some participants' found psychological therapy helped to understand parts of themselves, their experiences and relational difficulties (Lewis et al., 2002). For some participants therapy enabled social connectedness. This corresponds to findings from a qualitative systematic review of CBTp which identified similar benefits such increased understanding of their experiences within the context of a supportive therapeutic relationship (Wood, Burke & Morrison, 2013). This is important in the context of the DOH's recommendation to offer psychological therapy to service-users within two weeks of joining EIP services (NICE, 2015; 2016).

Summary of Key Ideas

The contextualist-critical realist epistemological position helped to identify the pluralisms (e.g. dual identities) and nuances within the data. Throughout participants' accounts it became apparent that intersectionality is a key consideration of this study. The current study found it was not possible to understand individual types of stigmatisation in isolation. Stigmatised identities were complex and fluid depending on individuals' background as this often seemed to shape their experience of stigma (i.e. psychosis, racism, cultural identity, socio-economic status).

Stigmatised identities may be multiplicative, interacting in a complicated manner to produce a given experience for individuals (Bauer, 2014; Panchankis et al., 2017; Turan et al., 2019). This was reflected in the current study. There was difficulty to differentiate whether stigma experiences were related to psychosis or being British-Asian, or the intersecting nature of both. Participants described how they experienced psychosis stigma within Asian communities and in wider society. Alongside this, participants also perceived racial stigma within wider society. Furthermore, some participants felt stigmatised living in an urban environment. All of these types of stigma are individually problematic, but simultaneously-enacted were significantly distressing for participants. This mirrors participants' confusing and fragmented psychosis experiences such as paranoia and hearing voices. Attempts were made to differentiate types of stigma, which could have easily been conflated with one another. For example, narratives and context of the participants' accounts was relied upon to distinguish the type of stigma participants were referring to where possible. However, it is important to also note that different types of stigma may not be understood as separate to each other by the participants. Therefore various types of stigma experiences may have been conflated together.

Multiple stigmas were thought to be intertwined influencing disadvantages at an individual (micro) level and societal (macro) level (Turan et al., 2019). Individually, participants identified with harmful stereotypes which shaped a negative and inferior view of themselves. This presented as shame and attempting to hide experiences, epitomising internalised stigma (Corrigan & Watson, 2002). At a societal level, prejudice, discrimination and racism (i.e. Islamophbia) significantly impacted participants, illustrating public stigma (Corrigan & Watson, 2002). Notably, participants did not all feel stigmatised to the same extent. Arguably, those who faced more disadvantages reported more stigmas. What is salient is how different forms of stigma were missed by EIP services. Although some participants had

positive experiences of therapy, this was not a dominant perspective. Multiple stigmas were not explored and integrated into treatment by EIP services.

The current study is novel in that it explored what it means for second-generation British-Asian people to straddle eastern and western cultural understandings of themselves and their experiences. A consequence of multiple stigmas was cultural identity conflict. Participants felt they did not have a sense of belonging in the U.K, meaning their position in society was precarious. Interestingly, the Home Office Citizenship Survey (2004) found South-Asian people abroad were more strongly-attached to the U.K. than British-Asian people. Therefore, this sense of not belonging is specific to British-Asian people. This was confusing and distressing for participants and further compounded their experience of stigma. It is argued that structures based on social hierarchies produce conditions for belonging (Ahmed, 2017). Therefore, for those who are 'different' in any way become accustomed to not belonging. In other words, social structures create conditions for stigmatisation.

The focus of the study was internalised-stigma, public stigma and experience of EIP services. It was surprising the extent to which multiple stigmas affected participants. The gravity of multiple intersecting stigmas did not become apparent until the analysis. Therefore further research is warranted to explore intersecting identities which may increase experience of stigma. This will be further discussed later in this section.

Methodological Critique

The study's methodological and theoretical strengths and limitations will now be outlined, along with ethical consideration of the research. Drawing from this, clinical practice implications and future research will be considered. The consolidated criteria for reporting

qualitative studies (COREQ; Tong, Sainsbury & Craig, 2007) checklist has been considered to critique the current study. This framework has been used to underpin the strengths and limitations of this section.

Strengths

Novelty. This current study added to the existing research and knowledge on the stigma experiences of British-Asian people using EIP services. The study explored the experiences of an under-researched population and thus adds novel insights into their experiences. There are no qualitative studies to date solely on the experiences of second-generation British-Asian people and specifically the stigma experiences of second-generation British-Asian people using an EIP service. The current study was able to give a voice to the subjugated knowledge of the population and harness an understanding of the populations' experiences (Smart, 2010). Therefore, the current study is felt to be novel and a useful starting point to learn more about a population that has been historically stigmatised, oppressed and marginalised in British society.

Approach. A clear definition of the research paradigm and the researcher's attempt to hold a contextualist-critical realist epistemology was pertinent. This allowed a critical exploration of the social surroundings (i.e. multiple stigmas), whilst also attempting to understand the intricacies of their subjective experience (internalised experiences). Together, this provided scope for exploring the transactional processes between participants' internal and external worlds. Drawing on different models and theories facilitated a multi-faceted and nuanced understanding of participants' experiences.

A qualitative exploration was deemed most appropriate to explore the research aims. It permitted rich, detailed participant accounts to be gleaned and cope to integrate diversity and

difference (Baggini, 2016). Efforts were made to ensure the study employed the methodology in a rigorous, systematic and transparent way. This is demonstrated with the consideration given to the study's credibility, transferability, confirmability and dependability outlined in the methods chapter (Lincoln & Guba, 1985). The rationale of methodology and analysis used is explicitly defined to increase accountability and replication of the study (Johnson & Waterfield, 2004).

Methodology. A combined inductive and deductive approach of TA (Braun & Clarke, 2013) was taken. This acknowledged the reality of what the researcher brought to the study to ensure transparency and improve overall quality. A reflective diary was completed throughout data collection and analysis process. The reflective diary highlighted times the researcher identified with participants, their biases and blind-spots providing transparency of how the researcher has used themselves as an 'instrument' in the analysis, and credibility in terms of critiquing the robustness of the analysis. Also, the researcher self-reflexivity was thought to usefully provide context to their relationship to the topic and their interpretation of the analysis. For example the researcher is second-generation British Indian and shares a family history of immigration to the U.K. However, the researcher is not of a Muslim background, therefore is less likely to experience concerns about Islamophobia like some of the participants from a Muslim background.

Researcher-reflexivity. It is felt that the researcher's ethnicity in terms of being a second-generation, British-Asian helped participants to express themselves and shine light on unexplored areas. This is aligned with research suggesting that shared ethnicity between researcher and participants' enables a stronger relationship to explore experiences relating to culture (Grewal & Ritchie, 2006; (Hussain & Cochrane, 2002) Suwankhong & Liamputton, 2015). It is possible that researchers who are not second-generation, British-Asian may not

have explored and elicited similar data. However, Suwankhong and Liamputtong (2015) advise caution to researchers who share ethnic identity with participants in being "insufficiently curious". They suggest researchers should momentarily suspend their subjective experiences and understandings of culture, in order to remain true to participants' perspectives and stories. Therefore the researcher attempted to stay curious, to allow intricacies of participants' account to come to light. For example the researcher was aware of concepts like black magic. However, participants were asked to explain their meaning to ensure the researcher remained curious. This captured participants' subjective identification with eastern and western culture, recognising their conceptualisations of psychosis and stigma were idiosyncratic, influenced by intersectionality. The assumption participants' had of the researcher understanding their experiences as the researcher shared their ethnicity and might relate to them is further discussed in the personal reflections.

Sampling. Sampling and recruitment transparency aimed to strengthen the credibility and applicability of the current research (Johnson & Waterfield, 2004). The sample size of 10 participants was obtained. On balance, this size is considered within acceptable parameters (Flick, 2008; Morse, 1994; Creswell, 1998). It has been suggested that a power calculation of participants is needed for TA (Fugard & Potts, 2015). The current study adopts Braun and Clarke's (2013) TA which is established and considered a robust qualitative analysis. They have argued that Fugard and Potts' (2015) sample size recommendations based on power calculations are an attempt to get closer to quantitative research paradigm, which inherently undermines qualitative data as is at odds with the richness and subjectivity of gathering qualitative research (Braun & Clarke, 2016). Furthermore, the number of participants was felt to be appropriate and within the guidelines for using Braun and Clarke's (2013) TA which recommends 10 participants at doctoral thesis level. This is further compounded by a sample population for which there is limited research (Kirkbride et al., 2017).

Recruitment took place within three EIP services. This increased homogeneity between participants, as all three services were in urban areas, in close vicinity to each other, within the same geographical region. Thus enabling a more rigorous analysis of psychological variability and is congruent with the contextualist-critical realist position of the current study. Regarding validity, initial codes were checked with six participants so that their experiences were accurately and fairly represented (Leininger, 1994). In terms of reliability, coding was cross-checked with an experienced qualitative research supervisor to ensure inter-rater reliability. Data was systematically analysed and identifying themes and sub-themes in accordance with the six phases of TA (Braun & Clarke, 2006).

Limitations

The study findings' should be interpreted cautiously given there is theoretical and methodological limitations to the current study.

Sample. Purposive sampling was used. It effectively addressed the study aims; however, the study did not solely focus on one particular British-Asian population, which limits sample homogeneity. Although, most participants originated from Pakistan or Bangladesh, two identified as British-Indian and one as British Sri Lankan. Pertinently, rates of psychosis are 2–4 times higher in individuals of Pakistani and Bangladeshi origin in the U.K. (Kirkbride et al., 2008). Therefore experience of psychosis markedly differs within British-Asian populations. Furthermore, within the current study, those identifying as British-Pakistani and British-Bangladeshi reported discrimination in the form of islamophobia, whereas those identifying as British-Indian and British-Sri Lankan did not. Therefore, the transferability and generalisability of findings is complex. It is important to ensure the study findings do not mis-

represent the experience of all British-Asian people using an EIP service. Again, this emphasises the need to examine the idiosyncratic intersections British-Asian people experience. Furthermore, there may have been bias based on the recruitment by staff. The participants that were engaging in services and viewed as individuals who may make 'good' participants by staff, may have been approached about the study. Those not engaging and with poor relationships with staff (e.g. may be due to stigma) may not be included in the current study.

Demographics. With regards to the sample demographics, presented findings are an amalgamation of data obtained across British-Asian backgrounds. There are significant differences within British-Asian backgrounds, ethnicities and experiences, such as religion. Also the current study found that participants experiences were idiosyncratic, based on their background, identity and particular situation. Therefore, care needs to be taken not to conflate the experiences of all British-Asians when extrapolating and generalising the findings.

Notably, the majority of the sample was men, with only two women recruited. Although both female participants spoke in relation to being Asian women, limited data was gleaned due to a small sample of women recruited. Asian women experience distress differently to Asian men (Patel et al., 2005). British-Asian women have higher rates of suicide and self-harm than British-Asian men (Husian, Waheed & Husain, 2006). Furthermore, through a lens of intersectionality (Crenshaw, 1989), women are deemed to face more social disadvantages than men. In light of this, the current study has shortcomings of not further exploring and representing the experiences of British-Asian women.

Additionally, it would have been helpful to identify how representative the sample of participants used in the current study was in relation to the wider service they were recruited from. Demographic information was requested from all three EIP teams that were used for recruitment. Unfortunately, this data was not able to be obtained.

Recruitment. Participants may have taken part with preconceived ideas expectations of what to discuss in the interview. There is a short description of stigma and the areas the study aimed to explore in the PIS (Appendix F). This was to ensure participants had an informed understanding of what the study involved. However, the short description may have shaped participants what they discussed in the study. Similarly the discussions with EIP staff may have influenced participants responses in the interviews. It is not possible to know to what extent the short description and conversations with staff in EIP services impacted participants.

Mirroring the sub-theme "it's contagious, it spreads" in terms of stigma within Asian communities, there may have been some potential participants who were deterred in participating in the research as they felt uncomfortable with a researcher of the same ethnicity. Bowes and Dar (2000) found South Asian communities often felt distrustful about taking part in health-related research. Participants may have felt concerned that they might be judged or identifiable information from their interviews might be relayed to others (Hussain & Cochrane, 2002). Therefore it is possible that the current study neglected to include these perspectives, due to fear of judgement and mistrust, manifesting as resistance to participate.

The study was conducted across three neighbouring EIP services, in an urban area in the U.K. where a British-Asian population is the largest ethnic group in the local area. As the study used a contextualist-critical realist epistemology, participants accounts were explored in relation to the context they were in (i.e. an urban area). The themes draw on the multiple

stigmas participants faced in their specific environment. British-Asian perspectives of those living in different areas in the U.K. (e.g. rural areas and other cities) may further differ due to environmental factors. This means that findings from the study may not be generalisable to all British-Asian people using EIP services.

Furthermore, British-Asian people have less equal access to mental health services (Brubaker et al., 2004) and a low prevalence of engagement with mental health services (Goodman, et al., 2008; Ikram et al., 2014; Patel & Shaw, 2009). Therefore, the current study may have failed to capture the experiences of individuals who did not access or dis-engaged with EIP services. There is research which shows Asian people prefer seeking support outside of mental health services (Dogra et al., 2005), like places of worship (Zafar et al., 2008). If this study was conducted within a place of worship, there may have been more focus on religious conceptualisations of psychosis (e.g. black magic and jihns) and associated stigma.

Analysis. The themes identified are predominantly the interpretation of the researcher. As previously discussed, the researcher being British-Asian was considered to be an advantage (Grewal & Ritchie, 2006; (Hussain & Cochrane, 2002) Suwankhong & Liamputton, 2015). However, it is possible that researchers of a different ethnicity, professional background and theoretical position may have analysed the data differently, thus producing different findings.

Ethical Considerations

It is possible for dilemmas and risks to occur when undertaking qualitative research therefore issues of power and coercion need to be considered. It is thought direct contact between the researcher and participant may increase the participant's likelihood to disclose sensitive information during the interview (Rice & Ezzy, 1999). However, participants may

feel it is increasing difficult to withdraw from the research (Mishna, Antle, & Regehr, 2004). Grzyb & Chandler (2008) noted that participants might feel unable to assert themselves, similar to a person feeling unable to assert themselves in an uncomfortable social situation. In the current study, space was allowed for participants to ask questions at the outset and the start and end of their interviews to reduce possible coercion. Participants were reminded the research was voluntary and that their withdrawal would have no negative impact on their care.

Resistance is also a consequence of unequal power relations (Beaunae, Wu, & Koro-Ljungberg, 2011; J. Butler, 1990). Participants can experience the researcher to be in a position of power over them (Bourdieu & Wacquant, 1992; Richards & Schwartz, 2002). In the current study, this was often demonstrated by participants' lack of response after agreeing to be interviewed at the outset. Therefore initial contact was followed-up only once to ensure participants were not coerced.

Specifically in a British-Asian population, some participants may have felt more uncomfortable with a researcher of the same ethnicity fearing judgement or the sharing of personal information (Hussain & Cochrane, 2002). It was hoped that reinforcing confidentiality and disclosing some aspects of the researcher's background developed a more equal researcher-participant relationship. Also, the researcher emphasised a wish to learn from participants' experiences as that may influence power imbalance (Birks & Mills, 2015).

Furthermore, most participants were adolescent and young people. The complexity of the unequal power imbalance between adults and young people should be carefully considered (Kirk, 2007). Duncan, Drew, Hodgson & Sawyer (2009) argue that young people might struggle with having the confidence to assert themselves in asking questions and withdrawing

from research due to their lack of life experience. The researcher expressed placing value on participants' experiences as suggested by Henwood et al. (2008) to lessen the power dynamics.

Additionally, Visweswaran (1994) suggested that allowing participants to be actively involved in the research places them in a more equal position of power to the researcher, which is helpful in addressing the implicit power imbalance. Participants voiced how a lack of information affected their and their families' understanding of psychosis and help-seeking. Therefore a leaflet for service users and families was created by the researcher and participants who wished to be involved in creating and developing materials to be distributed to EIP services within the Trust (Appendix M).

Study Implications

Firstly, wider study implications will be discussed. Next, clinical practice implications of the findings in relation to EIP services and clinical psychology will be presented. Lastly, future research and dissemination will be outlined.

Wider public discourse. The government has made efforts to address stigma using anti-stigma campaigns, for example 'Time to Change' (2013; 2014; 2016). However, this is based upon the medical model which arguably roots the 'problem' within the individual (Longdon & Read, 2017). They do not recognise dominant social discourses which perpetuate stigma and marginalisation. For example, the Time to Change campaign potentially perpetuates a narrative of separating 'us' and 'them' in relation to those who are different due to their mental health. Within this, significant factors like poverty and racism are ignored. A more dimensional approach to distress relative to a person's social world and environment would be more meaningful (BPS, 2017). Consequently, addressing social power-imbalances and social

threats is imperative (Johnstone et al., 2018). This study promotes the 'Only Us' (2015) anti-stigma campaign in the U.K. This advocates not to distinguish 'one in four', but to see all as human and capable of becoming distressed in the context of disadvantaged circumstances. It has been argued that if public perception of psychosis was based on a psychosocial conceptualisation, it would lessen public stigma (Longdon & Read, 2017).

EIP services. Despite a recognised need for support dealing with stigma, engaging British-Asian people in EIP services is a challenge. EIP services in multi-ethnic contexts would benefit from information about stigma-related issues that may impact disparities in service uptake. The current findings demonstrate that professionals in EIP services did not explore and acknowledge different types of stigmatising experiences. This was perceived as barrier to British-Asian service-users engaging in EIP services meaningfully.

At an organisational level, social equalities policies could be regularly reviewed and updated, identifying how to improve engagement with British-Asian service-users. On a front-line level, staff need to understand intersecting stigmas affecting British-Asian people. This could be in the form of training and workshops. Part of this training could include understanding racial prejudices, cultural conceptualisations of psychosis and ways to explore these with service-users. Issues around racial differences can provoke shame, prejudice and avoidance in staff, preventing them from fully engaging with service-users, ultimately being complicit in marginalisation (Bhugra & Bhui, 1998; Fernando, 2018). Training may help staff address difficulties staff face and build confidence and skills to sensitively explore intersecting stigmas with service-users.

The significance of negative attitudes towards psychosis in the Asian community was stressed by participants. Given the ethos of EIP services of being flexible, outreach work in

Asian communities is recommended, particularly in places of worship and local Asian community centres. This would enable clinicians to familiarise themselves with present-day socio-political issues relating to British-Asian people (i.e. Islamophobia) that may prevent service-users accessing and using EIP services. This could be facilitated using Patient and Public Involvement (PPI) in delivery of EIP services specifically with British-Asian service-users and families from local communities.

Alongside this, participants reported that their families also identified with stigma and shame associated with psychosis, resulting in participants hiding their experiences. Birchwood et al., (1992) suggested that Asian people may have better rates of recovery from psychosis, if there is a higher level of family support. Therefore, systemic work with British-Asian service-users and family intervention is recommended, which is indicated in existing national guidance for psychosis (NICE, 2009). Furthermore, participants described of lack of information and education for families about psychosis and the approach taken in EIP services. It is recommended that educative materials are developed and disseminated to British-Asian service-users and their families, such as customised leaflets (Appendix M).

Clinical psychology. When working with British-Asian EIP service-users, clinical psychologists should consider cultural and social issues. This is essential to inform idiosyncratic assessment, formulation and interventions. Stigma was prominently experienced by participants; therefore it should be incorporated at assessment. This could be in the form of semi-structured interview measure of stigma (SIMS; Wood, Burke, Byrne, Enache & Morrison, 2016) in psychosis. Additionally, there is an existing integrative model of stigma for psychosis (Wood et al. 2017) outlining a CBT-based framework to create idiosyncratic formulations of internalised stigma related to psychosis. However, the SIMS (Wood et al., 2016) and CBT model for stigma (Wood et al., 2017) were not developed specifically with Asian communities.

Given the significance of culture within the findings, interventions need to be integrative, drawing on systemic approaches which encompass culture.

A key finding of this study is the difference of cultural understanding participants had compared to their parents. This prohibited them from sharing their experiences. Therefore, a systemic approach is advocated to facilitate understanding about service-users' and their families' understanding of psychosis and consequential stigma. It is important to attend to religious, spiritual and wider beliefs about psychosis within Asian communities to identify possible stigmatisation. Using a systemic approach, it is helpful to understand relational exchanges between family members that maintain cultural misunderstanding (Dallos & Draper, 2010). Also psychologists should explore shared family-beliefs and family-narratives (Johnstone & Dallos 2013). This could be achieved using family intervention, genograms and timelines. Additionally, participants' cultural identity was paramount to individual experiences of stigma. Therefore, narrative identity (McAdam, 2001) work is recommended. Connecting life experiences into an internalised story would provide service-users a more integrated sense of identity, unity and purpose. This intervention is shown to provide a more coherent narrative for those experiencing psychosis (Lysaker, Davis, Hunter, Nees & Wickett, 2005).

Notably, participants experienced multiple stigmatised identities, which were commonly missed by professionals. It was challenging to tease out different forms of stigmas within interviews, which may not have even been separated out by participants. Consequently, it would be helpful to adopt an integrative approach, to enable British-Asian EIP service-users to explore parts of their social identity that they may feel stigmatised in wider society. It is important to develop shared idiosyncratic psychological formulations with service-users, considering intersectionality. Psychological tools like power maps (Hagan & Smail, 1997) could be used at a direct level. These visually illustrate how power structures impact individuals.

It is thought this may explore how British-Asian service-users may be disempowered by aspects of their social identity such as race, class and gender. In turn this may shape formulations of how stigmatisation influences the way British-Asian service-users understand themselves. Additionally, the PTMF (Johnstone & Boyle, 2018) is a systemic approach which can be used to inform multi-faceted psychological formulations. This would identify social structures and individual narratives, that affect British-Asian service-users' sense of security and belonging in society.

Clinical psychologists are uniquely trained to integrate models to meet service-user needs. Integrating an understanding of internalised stigma, culture and multiple identities is recommended for British-Asian service-users. A shared dialogue of these issues should be facilitated on a case-by-case basis given the idiosyncratic presentations of stigma experienced by British-Asian people. It is hoped that the findings from this study add to their knowledge and can be integrated into their clinical practice to meaningfully engage with British-Asian service-users.

Furthermore, the current findings indicate the need for psychologists from minority backgrounds. In 2016, 450 applicants successfully gained places on clinical psychology training courses, out of which 2% were from Black backgrounds and 4% were from Asian backgrounds (Leeds Clearing House, 2019). These statistics demonstrate the lack of diversity in clinical psychology. Given participants reported feeling more comfortable with psychologists from a similar background, more equal representation of ethnicities within psychology is needed. Furthermore, clinical training courses could integrate and recognise the significance of culture and diversity. This would help psychologists to feel able to culturally-engage with marginalised groups.

Further Research

This study is the only current research solely focused on second-generation British-Asian people. It was conducted in a specific part of the U.K.; therefore it may be beneficial to repeat the study in other areas of the U.K. to construct a broader picture of stigma experiences of British-Asian people using EIP services. This is important given that British-Asian people have less equal access to mental health services (Brubaker et al., 2004) despite explicit equity-driven health policy in the NHS (DoH, 2005).

Future research may also benefit from including views of professionals working in EIP services. Given participants' felt services did not explore different aspects of their identity, it may be useful to understand the barriers clinicians may face in discussing stigma experiences with British-Asian service-users. This would provide triangulation of perspectives and a fuller picture of the potential difficulties' professionals in EIP services have in exploring and integrating stigma within care.

The current study provided a rich understanding of participants' experiences using a qualitative methodological approach. However, difficult it was to tease out and differentiate multiple stigmas influencing participants within the study. Therefore, it may be beneficial for future research to focus on this. Studies using a quantitative methodological approach could distinguish the different intersecting stigmas experienced by British-Asian people more objectively. Quantitative approaches could also examine the magnitude of the effect of stigma and make comparisons between ethnicities (i.e. British-Pakistani vs British-Indian). This could un-pack more clearly multiple, intersecting stigmas, and enable services to better address and explore the different stigmas impacting British-Asian service-users.

Furthermore, the current study highlighted how participants from Muslim backgrounds faced more disadvantages. Further exploration could focus on separating different British-Asian ethnicities, specifically British-Pakistani and British-Bangladeshi. This may shed light on why stigma was more problematic for these individuals from these backgrounds. Similarly, there was limited representation of British-Asian female perspectives in the current study. More understanding is needed given British-Asian women report more suicidality and self-harm than British-Asian men (Hussain et al., 2006).

These suggestions outlined for future research would deepen knowledge on how stigma impacts various marginalised minority groups and inform more targeted understanding and treatment.

Dissemination. The researcher will provide a study summary to each participant of the study. In addition, the researcher will meet with the respective EIP services to relay the study findings. The current study will also be considered for a relevant, peer-reviewed journal and research conference presentation.

Conclusion

The findings indicate that public and internalised stigma significantly impacted British-Asian participants. The extent of this was largely not recognised by EIP services. Supportive relationships are protective of stigma. However, participants felt unable to share with their families due to cultural understanding differences and stigma within Asian community. Cultural identity was important to participants. The current study is novel in that it explored what it means for British-Asian people to straddle eastern and western cultural understandings of themselves and their experiences. This is a distinction of the targeted second-generation

population of the study. Furthermore, stigma relating to participants' religious background, race and social environment, marginalised them further in wider society. Stigma would not exist without negative public attitudes and social discourses. A focus on the internalised experience does not account for social and cultural factors. These appeared to be salient within the study. Equally, if social and cultural factors are only considered, peoples' individual different relationship to stigma would not be recognised. Stigma manifests differently based on intersectionality. Multiple intersecting stigmas are pervasive causing significant distress and social disadvantages. EIP services in a multi-ethnic context should support British-Asian service-users with stigma, to ensure equitable access and engagement. In light of the findings, EIP services must be pluralistic, integrative and socially-conscious. Research in this area is still limited and warrants further exploration.

Key Points:

- Public and internalised stigma significantly impacted British-Asian participants
- The extent of stigma experienced by participants was unknown to EIP services
- Cultural understanding of stigma impacted participants experience of stigma and psychosis
- Multiple, intersecting stigmas (i.e. religion, social environment) had a pervasive impact on participants

Personal Reflections

It has been hard to ignore the backlash of Brexit during the process of this research. There has been a rising disenfranchisement in the U.K., and it has been trying to re-establish its place in the world since. There has been a striking increase of 475% of Islamophobic street attacks following the EU referendum (Tell Mama, 2018). It was saddening to hear how

participants were affected by Islamophobia. It was hard to hear how participants and their families were living in fear and I felt angry that these experiences were missed by services. I felt a great sense of responsibility to raise awareness of participants' experiences which they reported to not have shared before. This was further confounded by hearing stories of homelessness and social deprivation. There were aspects of participants' stories I could relate to. However, I reflected on my own privilege and social advantages I hold as a result of my education and profession. I felt uncomfortable that these participants had faced social disadvantages and hardship in ways I have not.

I considered what makes it hard for services to engage with British-Asian service-users. Crehan and Rustin (2018) suggest there is anxiety in not knowing how to talk about difference. Perhaps in this case it relates to professionals not knowing the extent of how history and social discourses impact British-Asians in the U.K. today. There is also anxiety about how to begin conversations about difference without saying something 'wrong', often leading people to avoid, deny or retreat.

The analysis has felt like a hard task given the fragmented nature of psychosis. In attempting to construct an understanding, I felt a pull to make sense of participants' experiences through one 'lens' in order to provide some fixed-certainty (Mason, 1993). This wish for certainty is understandably common in anxiously organised mental health systems (Menzies-Lyth, 1960). I also noticed the desire to draw on euro-centric models (e.g. CBT) and research, perhaps reflective of my learning and own internalised ideas of what is considered more favourable approaches in research. However, I thought about how this mirrored the stress of adaptability participants faced and how parts of their experiences needed to be highlighted, considered and integrated into a whole (Berry, 1990; Klein, 1946). I have attempted to do the participants' justice by integrating and reflecting their experiences. I drew on the scope

provided by my epistemological position, being British-Asian and a trainee clinical psychologist to integrate ways of thinking. I think this enabled me to be transparent, whilst being aware of my shortcomings.

I have become increasingly mindful of being part of a predominantly White-British profession. Mirroring participants' sentiments about the importance of seeing professionals who are POC, I have found myself looking up to senior colleagues who are POC. Such individuals are unfortunately rare in clinical psychology. It is meaningful for POC to see themselves reflected in senior positions. I valued that my thesis supervisor is from a minority background. I felt this helped me in being able to seek support related to participants' stories of racism, feel understood and speak honestly about the research. I have found it important to engage in a dialogue with colleagues about how difference can be recognised more meaningfully, but also embraced and celebrated.

I consider myself fortunate to train as a clinical psychologist and undertake this study. What I take away from it is there will be systems and social hierarchies which have the power to oppress people seen as 'different'. However, my clinical training reminds me the value of giving people with less power a voice, so that their experiences can be heard and understood. I feel hopeful that this can also enable inclusivity, both socially and structurally in society.

"We realise the importance of our voices only when we are silenced" – Malala Yousafzai.

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Appendices

Appendix A: Systematic Review: Search Strategy, Criteria and Prisma Diagram

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Appendix A: Systematic Review: Search Strategy, Criteria and Prisma Diagram

Table 1. Systematic search strategy of databases and results.

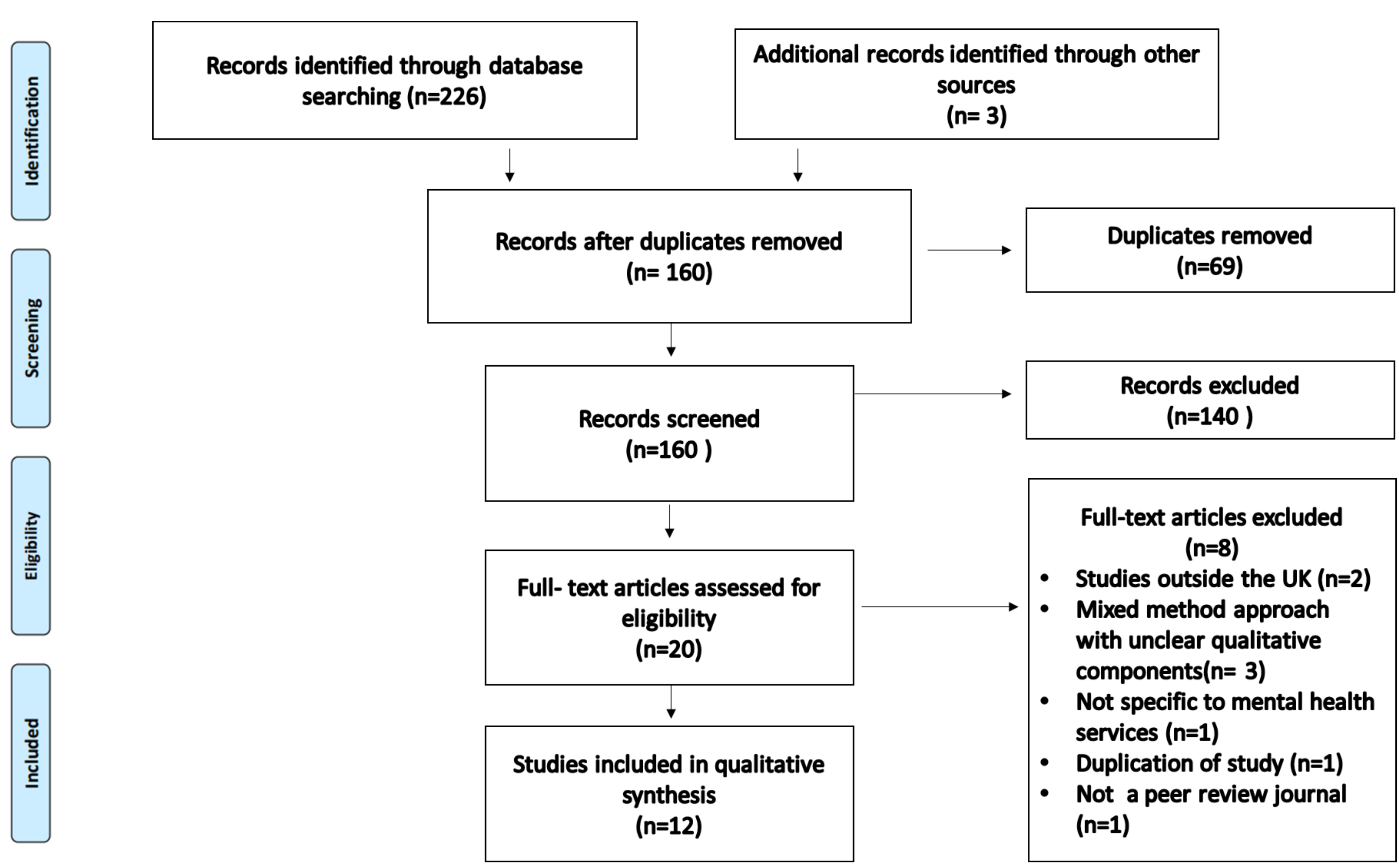
Search	Search terms	Results
1	South Asian* OR Indian OR Pakistani OR Bangladeshi OR Sri Lankan OR Gujarati OR Punjabi OR Panjabi OR Hindu OR Sikh OR Muslim OR British Pakistani OR British Indian OR British Asian* OR Tamil OR Bengal*	478,817
2	experienc* OR narrative* OR belief* OR view* OR opinion* OR perce* OR perspective* OR attitude* OR barrier* OR problem* OR facilitat* OR challeng* OR issue* OR difficult*	16,339,110
3	Mental health* OR psycholog* OR distress* OR emotion* OR mental health service* OR mental health team* OR mental health care OR mental health provision OR mental health secondary care OR psycholog* service* OR psychiatr* service* OR mental healthcare OR mental health-care OR psychiatr* care OR secondary care OR IAPT OR improving access to psychological therapies	6,062,228
4	Stigma* OR prejudic* OR discriminat* OR racism OR social exclusion OR shame OR izzat OR sharam OR besharam OR dishonour OR disgrace OR isolation	2,145,801
5	UK OR United Kingdom OR England OR Britain OR Great Britain OR GB OR Wales OR Scotland OR Wales OR Ireland	3,187,457
6	qualitative OR interview* OR focus group*	1,816,078
7	#1 AND #2 AND #3 AND #4 AND #5 AND #6	226

Table 2. Inclusion and exclusion criteria

	Inclusion criteria	Justification using SPIDER criteria
1.	South Asian experiences of mental health related stigma in the U.K.	Focus on sample and phenomenon Focus of review
2.	Service-users, carers and families in the U.K. whose heritage originates from South Asia, specifically India, Pakistan, Sri Lanka or Bangladesh.	Focus on sample (service-user experience) Obtain rich accounts and experience Focus of review
3.	Mental health experiences of adults, older adults and families including young people being interviewed alongside parents.	Focus on sample (service-user experience) Focus on phenomenon Focus of review
4.	Qualitative methodology including mixed-methods approaches which have clear and distinguished qualitative component, separately analysed and reported.	Obtain rich accounts and experience Focus of review
5.	Studies using a mix-sample of participants where results for a specifically South Asian demographic were clearly identifiable to extract for the literature review.	Focus on sample (service-user experience) Obtain rich accounts and experience Focus of review
6.	Studies within NHS mental health services and non-NHS mental health services (e.g. tertiary organisations, community groups and support groups.	Focus on sample (service-user experience) Obtain rich accounts and experience

	Exclusion criteria	Justification using SPIDER criteria
1.	Non-English language	Translation unavailable
2.	Papers not from peer-reviewed journals	Accessible empirical evidence wanted
3.	Search not within full-text	Identify full range of available research
4.	Studies outside of the U.K.	Not focus of review
5.	Perspectives of mental health professionals	Not focus of review
6.	Studies focusing on Dementia, Parkinson's, Learning Disabilities or Autism	Viewed differently to mental health problems by South Asian populations (Turner, Christie & Haworth, 2005). Not focus of review

Figure 1. PRISMA Diagram.



Appendix B: Systematic Review: CASP Appraisal of Reviewed Studies

Table 3. CASP quality appraisal of reviewed articles (N= 12)

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Wittkowski, Zumla, Glendenning & Fox (2011).	2	2	2	2	2	2	2	2	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are explicitly discussed. Further research areas are discussed, though rather limited.

Reviewed Article	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Appropriate research design?	4. Appropriate recruitment strategy?	5. Appropriate data collection?	6. Relationship between researcher and participant considered?	7. Ethical issues considered?	8. Rigorous data analysis?	9. Clear statement of findings?	10. How valuable is the research?*
										Clinical implications are discussed.
Islam, Raibee and Singh (2015).	2	2	2	2	2	1	2	2	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are explicitly discussed. Further research areas are not discussed. Clinical implications

Reviewed Article	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Appropriate research design?	4. Appropriate recruitment strategy?	5. Appropriate data collection?	6. Relationship between researcher and participant considered?	7. Ethical issues considered?	8. Rigorous data analysis?	9. Clear statement of findings?	10. How valuable is the research?*
										are discussed but limited.
Hussain and Cochrane (2002).	2	2	2	2	2	1	1	2	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are explicitly discussed. Further research areas are not discussed. Clinical implications are discussed.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Dogra, Vostanis, Abuateya and Jewson (2005).	2	2	2	2	2	1	1	2	2	Findings were discussed in relation to previous research, but not in relation to policy or theory and practice. Limitations are discussed, though limited. Further research areas are not discussed. Clinical implications are discussed but limited.

Reviewed Article	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Appropriate research design?	4. Appropriate recruitment strategy?	5. Appropriate data collection?	6. Relationship between researcher and participant considered?	7. Ethical issues considered?	8. Rigorous data analysis?	9. Clear statement of findings?	10. How valuable is the research?*
Hussain and Cochrane (2003).	2	2	2	2	2	1	1	1	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are explicitly discussed. Further research areas are discussed. Clinical implications are discussed.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Penny, Newton and Larkin (2009).	2	2	2	1	2	1	2	2	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are not discussed. Further research areas are not discussed. Clinical implications are discussed.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Greenwood, Hussain, Burns and Raphael (2000).	2	2	2	2	2	1	1	2	2	Findings were discussed in relation to previous research, policy, theory and practice, though limited. Limitations are not discussed. Further research areas are not discussed. Clinical implications are discussed though limited.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Knifton (2012).	2	2	2	2	2	1	1	2	2	Findings were discussed in relation to previous research, policy, theory and practice, though limited. Limitations are not discussed. Further research areas are not discussed. Clinical implications are discussed.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Gilbert, Gilbert and Sanghera (2004).	2	2	2	2	2	1	1	1	2	Findings were discussed in relation to previous research, policy, theory and practice, though limited. Limitations are explicitly discussed. Further research areas are discussed, though rather limited. Clinical implications are not discussed.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Chew-Graham, Bashir, Chantler, Burman & Batsleer (2002).	2	2	2	1	2	1	2	1	2	Findings were not discussed in relation to previous research, policy, theory and practice. Limitations are discussed, though limited. Further research areas are not discussed. Clinical implications are discussed.

Reviewed Article	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Appropriate research design?	4. Appropriate recruitment strategy?	5. Appropriate data collection?	6. Relationship between researcher and participant considered?	7. Ethical issues considered?	8. Rigorous data analysis?	9. Clear statement of findings?	10. How valuable is the research?*
Gask, Aseem, Waquas and Waheed (2011).	2	2	1	2	2	1	1	2	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are discussed but not explicitly. Further research areas are not discussed, Clinical implications are discussed, though rather limited.

Reviewed Article	**1. Clear statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Appropriate research design?**	**4. Appropriate recruitment strategy?**	**5. Appropriate data collection?**	**6. Relationship between researcher and participant considered?**	**7. Ethical issues considered?**	**8. Rigorous data analysis?**	**9. Clear statement of findings?**	**10. How valuable is the research?***
Bowl (2007).	2	2	1	2	2	1	1	2	1	Findings were discussed in relation to previous research and theories though limited, but were discussed in relation to policy and practice. Limitations are not discussed. Further research areas are not discussed. Clinical implications are discussed, though rather limited.

* contribution of the study to existing knowledge, consideration of findings in relation to current practice, policy, or literature base, areas identified for further research, transferability of findings discussed; 2 = yes; 1 = can't tell; 0 = no.

Appendix C: Systematic Review: Reviewed Studies

Table 4. Information on studies included in the current literature review.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
The experience of postnatal depression in South Asian mothers living in Great Britain: a qualitative study. Wittkowski, Zumla, Glendenning & Fox (2011).	N = 10 Participants identified as Asian Indian (n = 5) Asian Pakistani (n = 4), and Asian Bangladeshi (n = 1). Greater Manchester.	To understand the experience of postnatal depression in South Asian mothers.	Qualitative: semi-structured interviews were analysed using Grounded Theory Approach.	"Internalised misery", fear of judgement from others, isolation, lack of understanding from health professionals.
The need for change in U.K. mental health services: South Asian service users' views. Bowl (2007).	N= 26 Pakistani and Indian service-users participated. U.K. Metropolitan borough.	To investigate the views of South Asian service users experiences of mental health services and how they might be improved.	Qualitative: focus groups were examined using thematic analysis.	Socio-economic exclusion, cultural exclusion, institutional exclusion, feeling unsafe to share, the need for culturally appropriate services and training for staff.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
Depression in South Asian women: Asian women's beliefs on causes and cures. Hussain and Cochrane (2002).	N=13 South Asian service-users (n=10) and carers (n=3) participated. Birmingham.	To explore the thoughts, feelings and beliefs of Asian women on the causes and cures of their depression.	Qualitative: semi-structured interviews were analysed using Grounded Theory Approach.	Conflicting cultural expectations, distinctions between psychological, physical and spiritual problems, general and culture-specific communication problems
Whispering on the Water British Pakistani Families' Experiences of Support from an Early Intervention Service for First-Episode Psychosis. Penny, Newton and Larkin (2009).	N=11 Pakistani family members participated. Birmingham.	To explore families' experiences of support from an EIS.	Qualitative: semi-structured interviews were examined using Interpretative Phenomenological Analysis.	Loss of self, relational, cultural and social understanding of psychosis, possible solutions and cultural resources.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
Black and Minority Ethnic Groups' Perception and Experience of Early Intervention in Psychosis Services in the United Kingdom. Islam, Raibee and Singh (2015).	N=56 Participants included Black and South Asian service-users, carers, community and voluntary sector organisations, service commissioners, professionals and spiritual care representatives*. Birmingham.	To understand How easily reached and suitable are Early Intervention Services for the ethnic and cultural needs of BME communities in Birmingham and how can these be improved.	Qualitative: focus group interviews analysed using a thematic approach and framework analysis.	Barriers to help-seeking relating to mistrust of services, contrasting explanatory models of illness, social stigma and shame, improving BAME access and experiences of services.
Asian in-patient and carer views of mental health care. Asian views of mental health care. Greenwood, Hussain, Burns and Raphael (2000).	N=24 South Asian service-users (N=14) and carers (N=10) participated. London.	To gain an understanding of Asian individuals' experiences of mental illness and treatment.	Qualitative: semi-structured interviews were analysed using Grounded Theory Approach.	Cultural identity, value of religion, communication barriers, stigma and understanding of mental health, being treated differently to others within the service.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
Living with depression: Coping strategies used by South Asian women, living in the U.K., suffering from depression. Hussain and Cochrane (2003).	N=10 South Asian service-users (n=7) and carers (n=3) participated. Birmingham.	To explore the coping strategies used by Asian women suffering from depression.	Qualitative: semi-structured interviews were analysed using Grounded Theory Approach.	Main coping strategies were religion, prayer, crying and self-harm. Strategies were mediated by perception of problem.
Isolation, feeling 'stuck' and loss of control: Understanding persistence of depression in British Pakistani women. Gask, Aseem, Waquas and Waheed (2011).	N=15 South Asian service-users participated. North-west and north-east of England and London.	To explore the experience of persistent depression in British Pakistani women.	Qualitative: semi-structured interviews were studied using thematic analysis.	Stuck-ness related to family conflict, isolation externally determined by social and cultural factors, loss of a sense of control.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
Understanding and addressing the stigma of mental illness with ethnic minority communities. Knifton (2012).	N = 87 Participants from Chinese, Pakistani and Indian community groups were recruited. Scotland.	To explore commonly held beliefs about mental illness, patterns of stigma and discrimination and perceptions about the current national anti-stigma campaign.	Qualitative: focus groups were analysed using Grounded Theory approach.	High-level of stigmatisation experienced within communities, shame reduced help-seeking, anti-stigma failing to reach or engage south Asian communities due to westernised delivery.
South Asian women, psychological distress and self-harm: lessons for primary care trusts. Chew-Graham, Bashir, Chantler, Burman & Batsleer (2002).	N=31 South Asian women were recruited through local women's community groups. Manchester.	To conduct a qualitative study of suicide and self-harm services in relation to South Asian women.	Qualitative: focus groups were studied using framework analysis.	Social, political and economic pressures, racism, stigma and stereotyping resulting in distress and self-harm, mistrust of services being a barrier.

Title of study, author and date	Sample and location	Aims	Design, method and analysis	Main themes
Understanding of mental health and mental illness by Gujarati young people and their parents. Dogra, Vostanis, Abuateya and Jewson (2005).	N=30 South Asian parents (n=15) and South Asian young people (n=15) participated. Leicester	To explore Gujarati young people's and their parents' understanding of the terms 'mental health' and 'mental illness'	Qualitative: semi-structured interviews were studied using thematic analysis.	Understanding the terms mental health and mental illness, causes of mental health experiences; and socio-cultural factors and stigma.
A focus group exploration of the impact of izzat, shame, subordination and entrapment on mental health and service use in South Asian women living in Derby Gilbert, Gilbert and Sanghera (2004)	The number of participants was unspecified. Participants were South Asian women recruited from a local women's project. Derby.	To explore participants meanings of izzat, shame, subordination and entrapment on mental health and service use.	Qualitative: focus groups were analysed using Interpretative Phenomenological Analysis.	Powerful role of family shame, fear of bringing shame on others, social and cultural rules of honour, loss of status, entrapment linked with mental health experiences, lack of cultural understanding within services.

Appendix D: Topic Guide

Interview Topic Guide

Introduction

Hi, my name is Anisha Vyas. Thank you for agreeing to be interviewed today. I will be asking about your experiences of stigma.

[Prompts for researcher]

- Discuss information sheet and ensure participant understand the extent of their involvement in the research
- Discuss consent form and allow time for participant to ask questions
- Sign consent form

Introduction to interview

Many people who have used mental health services may have experienced stigma. I am interested in finding out whether this has had an impact on you and if so, in what ways this might have affected you.

Draft topic guide

Beginning interview

- Explore how participant understands mental health stigma following information sheet definition

Views and reactions of other people

Reactions of other people to participant's mental health experiences

Perspectives of other people on participant's mental health experiences

Changes in relationships with others

Participant's views on other British Asian people's mental health experiences

Experiences of talking to others about mental health

Participant's views of themselves

Participant's understanding of their mental health experiences

Changes in perception of themselves following mental health experiences

Participant's belief about how other people see them

Influence of culture on participant's beliefs

Mental health services

Attitudes of mental health services

Participant's experience of support from services with how they see themselves

Participant's experience of support from services with how others see themselves

How services could be helpful

Ending interview

- Anything further participant would like to add
- Check how participant is feeling following interview – ensure participant is not left distressed
- Close the interview and thank the interviewee for their participation.

    - Prompts will be use to glean further understanding and clarification.

De-briefing

Thank you for participating in this study. I am grateful for your time and discussing your experiences. I am hoping that this research will benefit clinicians and service users. I would also appreciate it if you would refrain from discussing any part of the study with anyone else who is participating or might be participating in this study. Please let me know if any part of the discussion upset you in any way. I will send you a summary of the findings once the research study is complete. Please do not hesitate to contact me if you have any further questions about this study.

Appendix E: Participant Information Sheet

INFORMATION FOR PARTICIPANTS

Title of Study

An exploration of stigma in British Asian people who have experienced a first episode of psychosis.

Invitation and brief summary

- You have been invited to take part in a research study. Taking part in this study is entirely up to you. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you.
- This information sheet will help you to decide whether or not you would like to take part and you can ask any questions that you may have about the research. Please feel free to talk to others about the study if you wish.
- This study has been reviewed by an NHS ethics committee (IRAS ID: 228534) to ensure that the rights, safety, dignity and well-being of everyone that takes part in this study are protected.

Chief Investigator

Anisha Vyas – Trainee Clinical Psychologist, School of Health and Human Sciences, University of Essex, Colchester, CO4 3SQ. Tel: XXXXX. Email: XXXXX

Supervised by:

- Dr XXXXX – Lecturer in Clinical Psychology, School of Health and Human Sciences, University of Essex, Colchester, CO4 3SQ. Email: XXXXX
- Dr XXXXX – Senior Lecturer in Clinical Psychology, School of Health and Human Sciences, University of Essex, Colchester, CO4 3SQ. Email: smcpher@essex.ac.uk

Purpose of the Study

You have been invited to participate in a research study which is being undertaken as part of a professional Doctorate in Clinical Psychology. Stigma and discrimination are when people are treated negatively or unfairly depending on their particular situation. Research shows that people who experience psychosis can often be treated differently by others and experience stigma. This can have a negative impact on a person. Stigmatising beliefs can be internalised, making people feel bad about themselves. For example some people might experience shame, guilt or fear because of stigma. For this reason, experiencing stigma can be extremely upsetting

and distressing for people. There is a lack of understanding of how mental health stigma impacts people originating from South Asian countries like India, Pakistan, Bangladesh and Sri Lanka who experience psychosis. As there are not many people from South Asian communities engaging with mental health services in the U.K., it is important to understand more about this so that services can engage and support service users more meaningfully.

This exploratory research involves interviews discussing how stigma impacts the way that you see yourself and influences your relationships in your community. You have been invited to participate as I am looking to find out about experiences of stigma in South Asian people over the age of 18. It is hoped that you consider this interview as a space to express your honest opinions.

Study Procedures

If you agree to participate, you will be invited to a one-to-one interview regarding your experiences of stigma with the chief investigator. The length of the interview will be an hour approximately and will take place at the base of the mental health service where you are receiving support. At the end of the interview there will be 10 minute debriefing to discuss the study more in detail. Every interview will be audio recorded and transcribed by the researcher. All participants will be provided with feedback on the themes of the study and offered the opportunity to talk about the findings.

Potential Risks and Benefits

There are minimal risks in taking part in this study as it does not involve any treatments. Your responses from this interview will develop a further understanding of the South Asian community which may be key to future clinical implications. There is the possibility that some participants may find the material covered in the interview sensitive, as you will be asked about your personal experiences and views regarding psychosis and stigma. Please note that if you disclose information which leads to concerns about your safety or the safety of others including criminal disclosures, this will be reported as necessary. The interview will also involve talking about stigma which might bring up a variety of emotions for people. This is why some time is allowed at the end of the interview for the chief investigator and yourself to discuss how you felt about the interview and to address any concerns. There will be £10 compensation for your time in participating in this research study.

Voluntary Participation

Your participation in this study is entirely on a voluntary basis, you can choose not to participate. You may also change your mind and stop participating in this study at any time. Your decision not to take part in this study, or to stop participation, will not affect your care in any way. If you choose to stop taking part in this study, please inform the researcher of your decision as soon as possible. All information collected before your withdrawal will be destroyed. The researcher may also stop your participation in this study at any time if they decide there are concerns with safety or if it is felt that you are experiencing any psychological distress.

Confidentiality

Other people involved in your care such as your Consultant Psychiatrist, Care Coordinator and GP (if consented) will be informed of your participation in the interview. Your contact details that you provide on the tear-off slip below will be stored on a password protected computer at the University of Essex. Only the chief investigator will have access to your personal identifiable details. It will not be shared with anyone else and your contact details will be destroyed once you have been contacted with the findings of the study. The recordings, transcripts and participant information from this study will be treated with strict confidentiality, anonymised and stored securely. They will not be made publicly available and only people involved in this research will have access to your anonymous information. If there are any publications from this study, information relating to you will be anonymous. If you consent, any of your quotes included in a publication will be anonymised.

What if there is a problem?

Please do not hesitate to contact the researcher if you have any questions about your participation in this study at any point. Please contact Anisha Vyas, Trainee Clinical Psychologist, University of Essex, Colchester, CO4 3SQ. Email: XXXXX. If you are still concerned or you think your complaint has not been addressed to your satisfaction, please contact the supervisor, Dr XXXXX – Lecturer in Clinical Psychology, University of Essex, Colchester, CO4 3SQ. Email: XXXXX If you remain unhappy and wish to complain formally, you can do this by contacting XXXXX, Research Governance and Planning Manager, Research Office, University of Essex, Colchester, CO4 3SQ, by emailing: XXXXX

If you would like independent advice about taking part in research please contact:

Patient Advice and Liaison Service (PALS), XXXXX

Tear-off Slip

I agree for my name and contact number to be provided to the chief investigator so they can contact me directly to answer any questions I have about this study.

Name………………………………………………… Signed……………………………..

Telephone Contact Number……………………………………………

Date……………………

Appendix F: Consent Form

CONSENT FORM

Participant Identification Number for this study: ……….

Project Title:

AN EXPLORATION OF STIGMA IN SOUTH ASIAN PEOPLE WHO HAVE EXPERIENCED A FIRST EPISODE OF PSYCHOSIS.

Name of Researcher: Anisha Vyas

Name of Participant: **Please initial box**

1. I confirm I have read and understand the participant information sheet (Version 2 01.02.2018) for the above study, have been given a copy to keep and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to my service-user interview of stigma being audio recorded (optional) ☐
4. I consent to anonymised direct quotations from my interview to be used in write up and publications (optional). ☐
5. I consent to being contacted about the results of the study (optional). ☐
6. I consent to my GP being informed about my participation in this research study (optional) ☐
7. I consent to a copy of this consent form being kept with my medical notes (optional). ☐
8. I consent to being contacted to discuss the themes and findings of the interviews (optional). ☐

________________	________________	________________
Name of Participant	Date	Signature
________________	________________	________________
Researcher	Date	Signature

Appendix G: Demographic Information Sheet

Demographic Information Questionnaire

1. Age:

2. Gender: Female Male

3. Ethnicity: ____

4. Education – circle highest level achieved:
   No schooling
   Nursery School
   Primary school
   Secondary School
   O-Levels / GCSEs
   A-Levels
   Undergraduate degree
   Masters Degree
   Doctorate / PhD
   Other ………………………………………………………..

5. Marital status
   Single Married / domestic partnership Widowed Divorced Separated

6. Professional / employment status (circle appropriate)
   Employed Self-employed A student
   A homemaker Military Retired
   Out of work and looking Out of work, not looking
   Unable to work

7. Which religion do you identify with?

Islam Hinduism Buddhism Jainism Sikhism Christianity Judaism
Atheist Agnostic Other (please specify below)

……………………………………………………………………………………………

8. In relation to your ethnicity, which country do you originate from?

India Pakistan Sri Lanka Bangladesh Other (please specify below)

……………………………………………………………………………………………

Appendix H: Receipt of Payment

SCHOOL OF HEALTH AND SOCIAL CARE

Subject Payments

Study title: an exploration of stigma in South Asian people who have experienced a first episode of psychosis.

I acknowledge that I have received £10 as inconvenience fee for taking part in the research study above.

I have not received any other payments from the University in the current tax year (i.e. since 5 April 2016).

Signed ……………………………………………Date………………………………………

Appendix I: Transcript Excerpt

more vigilant

more stigma related to psychosis ↓ they are distinct labels.

Interviewer: is there a difference talking about depression or talking about psychosis?

P4: Umm, yeah. Psychosis, obviously hearing voices, people are more scared, they're like "oooh what's going on", they're more wary. With depression it's more like "ooh they want to kill themselves" type of thing you know. That's the difference. When I hear a conversation about both, they're more scared of people that hear voices.

sounded dangerous

Interviewer: what do you think that fear is about?

P4: Maybe they're going to attack them or something, like something like that. They probably think that.

negative stereotypes and assumptions

Interviewer: I wonder what that's based on?

negative portrayal

P4: Probably like you know on TV and things like that. They basically exaggerate what a person's like with a mental health disorder. They think that people who hear voices or see things are automatically going to attack them like you see in films where they get sent to the hospitals with the wards and they get strapped down and things like that. I didn't want people at school to think that of me, it made me not want to go in.

Influence of media

out of control

assumptions + beliefs in society

Interviewer: what was that like?

wish for support + understanding

P4: I just wanted someone to understand. Like honestly I just wanted one of my parents to just sit down with me and to listen to what I was saying without making any side comments or anything.

feeling alone?

anticipating negative response / criticism

Interviewer: what kind of side comments have they made in the past?

P4: Like "oh it's just all in your head, none of it is real, I don't know why you keep talking about it" or it'd be like "oh it's because you've been eating junk food". Like just because I had a pizza yesterday doesn't mean I hear voices. There no correlation at all. Or its "it's because your always on your phone" or "you never spend any time at home, you're always out with your friends". Like they just find things that generally annoys them and they just put that into the situation and blame it on that. It's really, really annoying.

experience not heard!

not believed

irritated, frustrated

difference in sense-making of voices.

Interviewer: and that still happens?

P4: Um barely, my mum just says "oh it's all in your head". But they don't blame it on anything else now. My dad doesn't say anything, but my mum thinks it's all in my head.

expressed annoyance at mum

change in perspective

difference between parents response ↓ mum does not share perspective.

Interviewer: what would it mean if your mum said that you had a mental health problem?

P4: She'd think that she was like a bad parent. Like she's said that to me before. Like in conversation and I said something like "oh you're such a good person mum" and she said "if I was such a good person or parent then why do have this hearing voices thing". I'm like "it has nothing to do with you, it's like myself you know". It's the past experiences from when I was younger have affected the way I think and like the reasons why I did get the psychosis.

shame?

parents blaming themselves

psychological understanding of psychosis

Interviewer: could your parents make sense of it in that way?

P4: Me and my counsellor figured this out together and I told my dad. He never used to give me enough attention as a child, like as much I needed. He would always leave me alone. I remember I used to cry at the window (pause) like you know, it's just that I wanted my dad's attention and yeah I said that to him. I said this is what we spoke about in therapy and like now he'll feel really bad for it. He'll be like I'm sorry for like leaving you, like he feels really bad.

therapy process

therapy helped understand experiences and communication with dad. → developed shared understanding.

Interviewer: does he understand now?

P4: Yeah.

Interviewer: can your mum?

P4: No! (laughs). Like my dad's side of the family and my mum's side of the family, like you know both sides are very traditional, but my mum is more traditional, more orthodox, more closed-minded when it comes to mental health compared to my dad's side. So my auntie, the nurse, she's from my dad's side. It's very complicated then because even if my parents are Gujarati, the culture within the families is very different. But there was a time like in-between where both my parents were completely unsupportive. When I first got put on medication and I told my parents, they confiscated my medication from me. They hid it from me. I told them the doctor told me to take it, but they wouldn't let me. They think its spirits.

assumption 'I know' as researcher (being Asian)

hard to tease apart alone

western understanding

differences within Gujarati culture

Parents intervened/stopped prescribed treatment due to different (eastern?) understanding

Interviewer: could you say more?

P4: Yeah my dad's side of the family are really superstitious. Like there was a glass table in a room upstairs and suddenly out of nowhere is smashed into tiny little pieces and my dad was like "there's something in the house" and I was like "what you on about, there's nothing here". He thought that some sort of spirit was in the house and that's what broke the glass. I think it just broke because there was things on it.

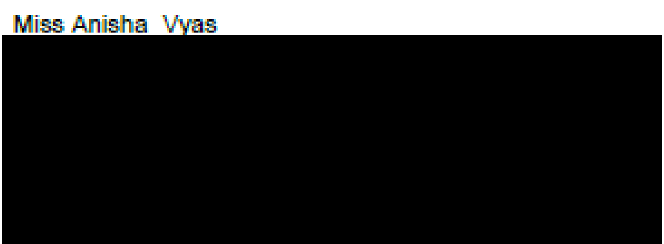
Is it culture, or religion or both?

spirits

different understanding to parents.

Appendix J: HRA Approval Letter

Miss Anisha Vyas



Email: hra.approval@nhs.net

06 March 2018

Dear Miss Vyas

Letter of HRA Approval

Study title:	**An exploration of stigma in south asian people who have experienced a first episode of psychosis.**
IRAS project ID:	**228534**
REC reference:	**18/EE/0004**
Sponsor	**University of Essex**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	228534

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the HRA website.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	228534

procedure. If you wish to make your views known please use the feedback form available on the HRA website.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the HRA website.

Your IRAS project ID is **228534**. Please quote this on all correspondence.

Yours sincerely

Assessor

Email: hra.approval@nhs.net

Copy to: *University of Essex, Sponsor Contact*
North East London NHS Foundation Trust, R&D Contact

Appendix K: Trust Research Governance Approval Letter

26/04/2018

Dear Miss Anisha Vyas,

Letter of access for research

As the holder of an existing NHS honorary clinical contract you do not require an additional honorary research contract with the NHS Foundation Trust. We are satisfied that such checks as are necessary have been carried out by your employer. This letter confirms your right of access to conduct research through the NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 26/04/2018 and ends on 08/09/2019 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct activities associated with such projects as you have received authorisation confirmed in writing from the Research and Development Director of the NHS Foundation Trust. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to the NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this Trust, in particular that of an employee.

While undertaking research through the NHS Foundation Trust, you will remain accountable to your employer NHS Foundation Trust but you are required to follow the reasonable instructions of your nominated manager in this Trust or those given on her behalf in relation to the terms of this right of access.

You must act in accordance with the NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer NHS Foundation Trust is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

You are required to co-operate with the NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998.

Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the NHS Foundation Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Please also ensure that while on the premises you wear your NHS ID badge at all times, or are able to prove your identity if challenged. Please note that this Trust accepts no responsibility for damage to or loss of personal property.

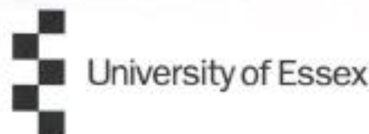
If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform the Research and Development Department and your nominated manager in NHS Foundation Trust.

Yours sincerely

Deputy Director of Research and Development,

NHS Foundation Trust

Appendix L: University of Essex Ethics Application and Approval Letter



10 April 2018

MISS ANISHA VYAS

Dear Anisha,

Re: Ethical Approval Application (Ref 17028)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

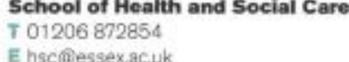
Yours sincerely,

Ethics Administrator
School of Health and Social Care

cc. Research Governance and Planning Manager, REO
Supervisor

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

School of Health and Social Care
T 01206 872854
E hsc@essex.ac.uk



Appendix M: Leaflet for Service–Users and Families

Understanding Psychosis

for

Asian Communities

Information Leaflet for Service-Users and Families

What is Psychosis?

We all have mental health needs. It is just a part of our general health and wellbeing. It doesn't always stay the same, is can change depending on life circumstances. Psychosis is a normal response to stressful events and difficulties a person faces. The word 'psychosis' (sometimes referred to as schizophrenia) is used to describe a number of experiences including:

- **Hearing voices**—sometimes referred to as hallucinations
- **Seeing things other people cannot see**—sometimes referred to as hallucinations
- **Unusual beliefs** that are not shared by others, such as paranoia, and feeling controlled. These are sometimes referred to as delusions

People can find psychosis very distressing, worrying and can influence their sense of identity and relationships. It can be hard to open up about psychosis because of stigma and discrimination. Sometimes Asian people experiencing psychosis worry about generational differences, language barriers and not sharing the same cultural and religious beliefs as their families. Therefore they might struggle to find the words and hold back sharing their experiences fearing they will be misunderstood and labelled. It is important to find people to trust and talk to about psychosis such as family members, friends and mental health professionals.

Talking about mental health & psychosis

Problems with mental health is something that can affect us all. Often people with psychosis will have experienced hardship, trauma and social disadvantages.

Mental health can be particularly difficult to talk about in Asian communities. There can be worries about how a person and their family will be seen by their community. There is fear around gossip, loss of status, people looking down on them and discrimination. There are harmful ideas and negative stereotypes in Asian communities about mental health being related to bad parenting, faulty genes passing down generations impacting marriage prospects, a punishment for something bad in a previous life and black magic or God's will. Sometimes it can also be difficult to know the difference between religious beliefs and unhelpful ideas and beliefs about mental health. As a result, psychosis is often 'unspoken' in Asian families.

Understandably, this be hard for those who are already trying to cope with psychosis. This can lead them to feel further depressed, anxious, shame, different, isolated, disconnected from others and alienated in society.

What can I expect from the team?

Psychosis is more likely to be diagnosed in people with from a Black and Asian minority background. However, research shows that people from these backgrounds are not accessing mental health services for support. People have found it helpful to get information, seek support and understanding from those close to them and talking to mental health professionals. Services can help people to :

- Understand themselves and their experiences
- Talk to family and friends
- Find ways to cope
- Help families understand psychosis
- Provide medication

Important things to remember

- **Any of us** could experience a mental health problem
- Mental health problems are **common** and psychosis is more common than people think
- Psychosis happens as **a normal reaction** to difficult life events
- **Understanding** and **support** are key to help people feel better

Further information

- Further information and support can be found from charities such as Mind and Rethink :

  https://www.mind.org.uk
  https://www.rethink.org

- There is no 'them and us', there is 'only us'. Whatever the diagnosis, we are all humans, and mental health affects us all.

  https://twitter.com/OnlyUsCampaign

Other formats and languages

- On request we can provide this information in another language or in other formats like large print or an electronic copy.
- An interpreter can be provided if needed.

Appendix N: Recruitment Flowchart