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First Episode Psychosis in British South Asians: Exploring the sibling's lived experience.

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This Portfolio has been submitted in partial
fulfilment of the requirements for the Professional
Doctorate in Counselling Psychology (DPsych).

City, University of London
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Preface

This portfolio captures my journey in counselling psychology and consists of three parts that represent my development and competence as a scientist-practitioner: a doctoral research study; a combined case study and process report; and a publishable paper. The portfolio commences with Section A, a doctoral research study, which aims to explore the experience of having a sibling with a first episode of psychosis within the British South Asian population. Section B illustrates a piece of clinical work that I undertook during my doctoral training and represents my ability to work with a client within a cognitive analytic framework. Section C consists of a publishable paper, which draws on one of the main findings from the larger empirical research study (Section A).

A central theme that connects these three parts is the experience of positive psychological growth after adversity, which has also been referred to as post-traumatic growth (Tedeschi & Calhoun, 2004). This is a transformative experience that occurs in response to highly distressing, life-altering events, which can provide a new impetus for growth as individuals can find strength and meaning in life. This experience of post-traumatic growth occurs concomitantly to the residual anguish of trauma (Morton, White & Young, 2015). Individuals may develop a greater sense of self-awareness and self-worth, changes in self-perception, resilience and improved interpersonal relationships (Higginson & Mansell, 2008; O'Leary, Alday & Ickovics, 1998; Tedeschi & Calhoun, 2004).

Acknowledging the ability to experience positive growth following highly traumatic experiences is central to the counselling psychology ethos. The fundamental humanistic values of this practice consider that human beings strive to develop and grow, even in the most unfavourable and adverse circumstances. Woolfe and Dryden (1996) suggested that the field of counselling psychology emerged from the scrutiny of therapeutic practice which overlooked attainment of one's potential and instead, primarily attended to pathology and dysfunctional characteristics of human behaviour. Rogers (1959) referred to the term 'actualising tendency' to describe a single motivational drive that leads to a strong sense of realisation and growth in all human beings.

This portfolio foregrounds the deeply profound experience of psychological survival and positive growth following adversity. The portfolio also represents my own experience of personal growth throughout this arduous doctoral journey. As I look back on the entire process, I am aware that I have encountered many challenges in relation to the research process and my clinical training. There have been moments of self-doubt throughout the last four years, where I have experienced myself as not being a ‘good enough’ researcher or clinician. Encountering challenges with recruitment difficulties when conducting the research study, writing the thesis during a pandemic, and experiencing ruptures in therapy with clients are just some of the hurdles I have faced. However, I believe that these experiences have ultimately contributed to my personal development and shaped me as a practitioner, a researcher and a human being.

Section A: Doctoral Research Study

My identity as a British South Asian inspired me to pursue an avenue of doctoral research which could give voice to ethnic minority communities and marginalised groups. Moreover, I have always been fascinated with the phenomenon of psychosis and how it can impact both the individual diagnosed and their loved ones. Growing up, I was aware of the many differences between Western and Asian cultural beliefs about severe mental illness, such as psychosis, which often left me feeling conflicted with my own position. These differing perspectives and cultural nuances ultimately contributed to my curiosity about the human mind. This was one of my motivations for venturing into counselling psychology and conducting the doctoral research study depicted in Section A.

The empirical research study sought to explore how British South Asians experience having a sibling with a first episode of psychosis. By using semi-structured interviews and conducting Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009), three novel overarching themes emerged which depicted a journey of struggle and survival. The first theme captured a complex entanglement of emotions that were expressed in response to the sibling, family members, mental health professionals and individuals in the wider cultural community. The second theme depicted the many ways that the participants attempted to minimise the impact of their emotionally complex experience and resolve feelings of overwhelm.

Paradoxically, the final theme reflected positive psychological shifts, as participants expressed having a new understanding of themselves, others and the world. These attributes were affiliated with a desire to live more purposefully. Their experiences of growth and resilience had surprised and delighted me, as I had anticipated that the participants would primarily describe significant challenges and reflect on the negative impact of their lived experience. Developing an awareness of the interconnectedness between psychological growth and adversity through this research project enabled me to consider the important role that counselling psychologists also have in empowering individuals, which is part of the mandate. This is discussed further in Section A, where I outline the clinical implications of the research.

Throughout the research process, my own emotions were perhaps somewhat parallel to the participants' experiences of struggle and survival. The doctoral journey itself was challenging, with many hurdles to overcome. Conducting the analysis and writing up the findings was a painstaking, demanding process and evoked an array of mixed emotions within me, including frustration, worry, disbelief, helplessness, hope, and eventual relief and pride. The support I received from my supervisor, family, and friends helped to reignite my sense of passion and ambition in moments of difficulty and enabled me to persevere.

Section B: Combined Case Study and Process Report

This segment of the portfolio provides an example of my clinical work with a client whom I saw in my final year of training within a secondary care mental health service. I present both a case study and process report to demonstrate my ability to apply the theoretical principles of Cognitive Analytic Therapy ([CAT], Ryle, 1985). Working within this framework was deemed to be suitable based on the client's diagnosis, presentation and therapeutic goals. The client presented with longstanding difficulties in interpersonal relationships, low mood and low self-esteem, which led to the development of maladaptive coping strategies, such as self-harming behaviours. In some ways, this client shared some similar experiences to those described by the research participants. She identified as a second-generation British-African who had experienced interpersonal tensions with her family members due to a cultural conflict in values and beliefs. These experiences are partly what led her to access therapy; thus, it was important to understand the impact of her sociocultural context, which CAT acknowledges.

A central theme of the work with this client was working relationally and avoiding collusions with her reciprocal roles, in order to establish an alliance. In addition, supporting the client to connect with and tolerate painful emotions and increase her capacities for self-reflection was also important. This ultimately led to a sense of personal growth and positive psychological change after 24 sessions, as she had developed exit strategies. The case study provides an overview of the client's therapeutic journey as she began to create meaning and develop a greater sense of self-awareness of her internal experiences, which ultimately resulted in a more valued way of living and strengthened her interpersonal and intrapersonal relationships.

Through working with this client, I was required to monitor and attend to my own cognitive and emotional responses. Reflecting on my own inner world was challenging at times and there were moments where I had not realised myself colluding with the client's relational patterns and was instead being drawn into them. These were often moments where I was confronted with my own anxieties of not being a 'good enough' therapist. However, this experience was also transformative as this process of introspection enhanced my own personal and professional development and has contributed to my evolving identity as a counselling psychologist. Acknowledging the value of the therapeutic relationship as being the vehicle for change highlighted the important role of counselling psychologists in facilitating a collaborative process of exploration and meaning-making of adverse experiences, to help clients reach their potential.

Section C: Publishable Journal Article

The final part of this portfolio consists of a publishable journal article which draws on the findings from the doctoral research study but focuses on one novel, overarching theme. This paper attends to the experience of post-traumatic growth, following the experience of having a sibling with first episode of psychosis. This theme was selected as this phenomenon appears to have been under-researched within the existing literature base, particularly within the British South Asian population. Although this research provides valuable insights, it is hoped that the findings will inspire further research in this field.

The Psychosis journal was chosen as a suitable publication due to the diverse, multidisciplinary readership, including a wide range of mental health professionals who may support or engage with siblings, such as psychiatrists, psychologists, family therapists, mental health nurses and social workers. It is hoped that disseminating these findings can be beneficial within the mental health field, including counselling psychology. Allowing siblings to tell their story in therapy can be psychologically restorative, as therapists can work collaboratively with clients to explore and create meanings in relation to their difficult experiences. This can create a space which fosters psychological change and positive growth.

To summarise, this portfolio strives to enhance understandings on the experience of growth following adversity. Engaging with the research and clinical work has allowed me to appreciate the important role of counselling psychologists in recognising potential and positive aspects of human functioning amidst distress. Alongside the research participants and the client who I worked with, I believe that I too have been on a journey of growth and development. This process of compiling the portfolio has deepened the relationship that I have with myself.

Section A:
Doctoral Research

First Episode Psychosis in British South Asians: Exploring the sibling's lived experience

Supervised by Dr Aylish O'Driscoll

Abstract

Psychosis has been characterised as the experience of a loss of contact with reality and severe changes in self-experience. Research has illustrated that a first episode of psychosis (FEP) is a distressing experience, not only for the individual but also their loved ones. Siblings play a crucial role in supporting their loved one during an onset of psychosis; however, they are emotionally impacted by this experience and have their own needs. A critical literature review on sibling experiences of having a brother or sister with a FEP revealed an apparent gap in the existing knowledge base, as this phenomenon appears to be under-researched within the United Kingdom. In particular, the experiential realities of siblings have not been explored at all within the British South Asian community. This is surprising, considering that the prevalence of psychosis appears to be higher within this population when compared to the indigenous community. It is therefore crucial to deepen our understanding of how siblings who identify as British South Asian make sense of their experiences and what impact this has on them.

By adopting a phenomenological approach, the current study has attempted to expand on the literature base by answering the following research question: How do second-generation British South Asians experience having a sibling with a first episode of psychosis?

Six participants were recruited through volunteer sampling and participated in semi-structured interviews. These interviews were audiotaped, transcribed and analysed using Interpretative Phenomenological Analysis. The analysis rendered novel findings which are depicted through three superordinate themes: ‘An Emotional Storm: conflicting feelings leading to a sense of overwhelm’; ‘Avoidance vs. Approach’; and ‘“*It’s shown me who I am”*: awareness of growth and transformation’.

This research hopes to provide further insight and increase knowledge in a relatively under-researched field and give voice to a marginalised group.

Literature Review

1.1 Overview

This chapter will outline a solid rationale to highlight the importance of conducting research which explores the experience of having a sibling with a first episode of psychosis (FEP) within the British South Asian (SA) population. The term ‘psychosis’ is first introduced and defined, before a historical overview is presented to illustrate how our understanding of this phenomenon has evolved over time. This is followed by a summary of the British SA demographic and a discussion of the nature, prevalence and impact of a FEP within this population.

Thereafter, a thorough literature review highlighting the existing research on caring for a relative with psychosis is examined. Within the literature, family members have frequently been referred to as informal carers or family caregivers, although there appears to be an ongoing debate relating to the functionality of these terms. An ‘informal caregiver’ is broadly defined as an individual who is not paid to support and help another human being who requires ongoing assistance, for example, due to having a physical disability, a neurocognitive disorder, or a mental illness. Parents of individuals experiencing a FEP have often been referred to as informal carers within the literature. However, this has the potential to overlook other individuals who still remain in close contact with their relative and experience themselves as playing an active role in their care, for example, siblings. Irrespective of whether the term family member or informal caregiver is used, the findings across these studies encapsulate many similarities in experiences. Hence, research on both family members and informal caregivers of individuals with psychosis is explored in this review. The cognitive model of caregiving in psychosis is also outlined to provide a theoretical understanding of these experiences.

Research on the impact of having a sibling experiencing psychosis has received growing attention over the last two decades. A significant portion of this chapter examines qualitative and quantitative research studies on sibling experiences that have been conducted within countries in the Western world, such as the United Kingdom (UK), Canada, the United States, Norway and Sweden. These countries adopt individualistic cultures and appear to share similarities in their approach to conceptualising psychosis and in their treatment interventions. The literature will be critically appraised to illustrate what is currently known and where gaps may exist in the knowledge base. As will become evident, research in this field appears to lack methodological rigour due to sample characteristics and a focus on particular attributes of the sibling experience, rather than exploring unique aspects of this phenomenon. Moreover, there appears to be a dearth of literature on sibling experiences of a FEP within the UK, with no studies having explored this phenomenon within the British SA community.

Finally, the chapter will conclude by outlining the aims and research question for the current study and discuss the potential implications within the field of counselling psychology.

1.2 Literature Search

A comprehensive literature search was undertaken in order to obtain relevant existing research. Literature published within the last 20 years was prioritised, although research conducted prior to this was also explored. Databases including CityLibrary Search, Wiley Online Library and PsychINFO were utilised to conduct these searches as they contain a variety of journals, newspaper articles, books, published dissertations and review articles. In addition, browsing in journals including *The Journal of Family Therapy, Psychosis, Journal of Mental Health (UK)* and *Journal of Cross-cultural Psychology* was also undertaken. Examples of keywords which were in searched in various combinations included: ‘British South Asians’, ‘Psychosis’, ‘Family Caregivers’, ‘Siblings’, ‘First Episode Psychosis’, ‘Caregiving Experiences’, and ‘Second-generation South Asians’. Overall, the database searches yielded around 10,000 articles, which were systematically reviewed and either included or excluded for the purpose of this literature review.

1.3 Psychosis

Psychosis has been characterised as the experience of losing contact with reality and severe changes in self-experience (Schwannauer & Gumley, 2013). When an individual experiences psychosis, their cognitions, perceptions, emotions and behaviour are perceived as deviating from societal norms. Moreover, their interpersonal relationships and functionality are often severely impacted, resulting in significant emotional distress (Schwannauer & Gumley, 2013).

Within the field of psychiatry, the term psychosis is used to describe an array of mental health disorders including schizophrenia, delusional disorder and schizophreniform disorder. These are considered to be amongst the most severe mental health conditions and those which have the most unfavourable outcomes (The Schizophrenia Commission, 2012). The range of symptoms is complex and diverse for the individuals who are diagnosed with a psychotic disorder (National Institute for Health and Care Excellence, [NICE], 2014). Hearing voices, expressing unusual beliefs and experiencing disturbing thoughts are symptoms most commonly associated with psychosis. In addition, a sense of being in imminent danger, often due to interpersonal threat, is frequently experienced, which impinges on a state of vulnerability (Schwannauer & Gumley, 2013). Marcsisin, Rosenstock and Gannon (2016) indicate that there has been much debate around the origins of psychosis, despite this phenomenon seemingly existing in some form since ancient times.

1.3.1 History of Psychosis

Historical accounts illustrate that our understanding of psychosis has evolved over the years. For example, religious scripts such as the Hindu Vedas and the Bible, and primeval medical texts from China and Egypt capture accounts of insanity and madness, often associating these experiences with disturbances in the spiritual realm, such as possession by an evil entity (Marcsisin et al., 2016). These early descriptions of madness can be found to share many similarities with modern-day mental health disorders. However, as Foucault (1965) recognised, it was not until the late 19th century that the term ‘madness’ was reconceptualised to ‘mental illness’ due to the evolution of medical science and a diminishing interest in the religious domain. Hence, rather than being understood within the supernatural realm to depict an alternate reality, it became recognised as a lack of reality (Davidson, 2003).

Emil Kraepelin, a German psychiatrist who is often perceived as a pioneer of contemporary nosology of psychiatric illnesses, was the first individual to distinguish between what we now call schizophrenia and other serious mental health disorders. In the late 19th century, Kraepelin coined the term ‘dementia praecox’ to depict a persistent illness which emerged during adolescence and resulted in an imminent worsening in the individual’s functioning and behaviour. It was thought that individuals with this condition had no prospect of recovery. From his many thorough clinical observations, Kraepelin was able to differentiate between presentations of dementia praecox with ‘affective psychoses’ which we now refer to as bipolar disorder, due to differences in prognosis and outcome (Marcsisin et al., 2016).

Eugen Bleuler, a Swiss psychiatrist, acknowledged the value of Kraepelin’s work but perceived that dementia praecox was more diverse and therefore required revision and development. In 1908, he conceived the term ‘schizophrenia’ to replace Kraepelin’s terminology. Bleuler perceived that there was a group of schizophrenias which shared key symptoms but were more changeable in their course and outcome. This understanding prevailed throughout much of the 20th century as practitioners identified and diagnosed schizophrenia from the basic and fundamental symptoms that Bleuler had initially recognised (Weinberger & Harrison, 2010).

The concept of schizophrenia was later expanded upon by Schneider (1959) who further identified essential features that he believed were of considerable importance for a clinical diagnosis. These became recognised as ‘Schneiderian first-rank’ symptoms and were instrumental in the development of contemporary classification systems including the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition ([DSM-IV], American Psychiatric Association [APA], 1994) and the International Classification of Diseases 10th Edition ([ICD-10], World Health Organisation, 1993). These classification systems comprise clusters of related symptoms to represent schizophrenia and other related disorders and have been updated over time. The most recently revised system, the DSM-5 (APA, 2013) identifies the diagnostic categories for schizophrenia and other psychotic disorders. The DSM-5 distinguishes between ‘positive symptoms’ and ‘negative symptoms’ of psychosis – the former is thought to include the experience of hallucinations, disorganised cognition, abnormal motor functioning and delusional thinking, whilst the latter refers to a diminishing ability to function in daily life, for example, due to social withdrawal, a lack of motivation or an incongruence in affective responses (APA, 2013). These positive and negative symptoms were initially derived by Bleuler but have been revised over time.

In order to meet the diagnostic criteria for a psychotic disorder, an individual must experience a range of particular symptoms over a given time-period; however, diagnoses may vary slightly depending on the classification system being used. Today, different countries utilise different diagnostic criteria, however the classification systems which exist still appear to share similar features in terms of description, prognosis and outcome. Therefore, psychosis is now widely acknowledged as an objective and naturalistic phenomenon which exists in the world. This aligns with the assumption that mental illness and abnormality exists, with an inherent pathology, and can be identified and established through a process of observation (Pilgrim, 2008).

Nevertheless, research has identified that individuals who do not meet the threshold for a clinical diagnosis of psychosis can still experience psychotic-like symptoms. Based on their systematic review and meta-analysis, van Os, Linscott, Myin-Germeys, Delespaul and Krabbendam (2009) claimed that only one in 50 individuals who experience these symptoms actually meet the diagnostic criteria. For example, hearing voices, having a telepathic experience and expressing beliefs in the paranormal such as being in the presence of ghosts are very common within the general population (British Psychological Society [BPS], 2014). Hence, the divide between sanity and mental illness appears less distinct and it has instead been suggested that psychosis lies along a continuum between these two presentations. Positive and negative symptoms of psychosis lie on this spectrum with nonpsychotic symptoms, and it is assumed that all human beings variably move along this continuum between good and poor mental wellbeing during the lifespan (BPS, 2017).

1.3.2 The Biopsychosocial Model of Psychosis

During the early 20th century, psychosis was primarily understood to be a physical disease resulting from organic neurological deficiencies and genetic abnormalities, corresponding with Kraepelin and Bleuler's theories (Bentall, 2004). This perspective aligned with a biomedical model of mental illness and aided practitioners in treating individuals with psychosis through medical interventions, such as brain surgery, which was the most conventional approach at the time. Pharmacological treatment was subsequently introduced during the mid-20th century. However, contemporary research refuted the notion of causation, arguing instead that there is a lack of concrete evidence demonstrating that genes and neurobiological dysfunction directly induce the experience of psychosis. The biomedical model has been heavily criticised for lacking credibility due to these limitations. Instead, as Cooke (2014) acknowledges, recent research introduced the role of psychological, social and environmental factors alongside biological theories of psychosis. Thus, the biopsychosocial model emerged. This approach posits that there is no sole determinant causing psychosis, rather, a combination and interaction of these risk factors may contribute to the onset of this experience. Hence, the role of biology is still apparent, though it is not assumed to be the only risk factor for psychosis. The different factors will now be briefly discussed.

Family studies were one of the earliest and most prevalent forms of research which explored the role of genetics in psychosis. Gottesman (1991) conducted a prominent study on 40 family members and concluded that the more genetically related family members were to one another, the greater the probability of experiencing schizophrenia if a relative had already been diagnosed. Hence, the concordance rates for schizophrenia were found to be highest for twins, illustrating the role of genetics. However, this research overlooked any additional factors which may have influenced the onset of schizophrenia, such as socio-psychological adversities. A study conducted in Finland by Wahlberg and colleagues (2004) examined schizophrenia spectrum disorders in sets of adopted twins who had been reared separately. Their results indicated that environmental attributes interact with genetic factors to predict the onset of schizophrenia. These findings further refute a hereditary hypothesis which considers genetics to be the sole determinant for causing psychosis.

Additional research has explored neurochemical imbalances in the brain which are thought to be implicated in the experience of psychosis. For example, the dopamine hypothesis refers to the theory that differing levels of activity of the neurotransmitter dopamine in particular brain regions are involved. Da Silva Alves and colleagues (2008) reviewed brain imaging studies and concluded that hypoactivity of dopamine within the prefrontal cortex was associated with symptoms of schizophrenia, whilst Brisch et al. (2014) report that hyperactivity of dopamine in the mesolimbic brain regions have also been implicated in psychosis. However, Pruessner, Champagne, Meaney and Dagher (2004) observed that adverse life events and psychosocial stressors resulted in an excess release of dopamine in certain areas of the brain. Hence, while it appears that dopamine plays a role in the experience of psychosis, the role of environmental factors in influencing the activity of this neurotransmitter once again appears to indicate that neurobiological deficiencies alone do not induce this phenomenon.

In recent years, greater attention has been paid to the role of stressful life events on an individual's wellbeing, particularly trauma and deprivation. Traumatic life experiences such as abuse in early life are considered to be risk factors to experiencing psychosis as an adult. Varese, Barkus and Bentall (2012) determined that there is significant evidence to suggest associations between sexual abuse in childhood and the experience of hallucinations in later life. Research has also explored the association between trauma, neurochemical imbalances and changes in brain structure and findings have further refuted a solely biomedical model of psychosis. For example, Hoy and colleagues (2012) examined associations between the experience of trauma in childhood and changes to the amygdala and hippocampal brain regions in a sample of individuals who had experienced a first episode of psychosis. They concluded that the experience of childhood trauma significantly predicted abnormal amygdala and hippocampal volumes, characteristics which have been observed in individuals experiencing psychosis. Read, Fosse, Moskowitz and Perry (2014) identified that interpersonal trauma from early life is associated with neurodevelopmental changes, which result in a greater sensitivity to stress, emotion dysregulation and poor interpersonal functioning. These attributes are often observed in individuals with psychosis. This has been termed the traumagenic neurodevelopmental model of psychosis and underlines the role of attachment styles on biology and later psychological functioning.

Bowlby's (1969) attachment theory has also been highly influential in understanding what factors may result in a vulnerability to developing psychosis. This lifespan theory posits that an individual's early caregiving experiences contribute to the development of internal representations of the self, others and the world (Berry, Bucci & Danquah, 2020), which subsequently influences our relational patterns in later life. When a child perceives their caregiver as attentive and nurturing, they experience a felt sense of security and safety.

They feel protected in threatening situations as they can seek comfort from the caregiver. The child therefore develops a secure attachment style which, as Bowlby (1969) asserted, is essential for healthy psychological development and better social functioning. On the contrary, empirical research over the past two decades has suggested that an insecure attachment style is associated with the experience of psychosis (Berry, Barrowclough & Wearden, 2008; Gumley, Taylor, Schwannauer & Macbeth, 2014; Berry et al., 2020). This is characterised by inconsistently responsive, overly intrusive, abusive or neglecting caregiving experiences, where the child develops a negative self-image and a negative perception of interpersonal relationships. These individuals later experience cognitive deficits and difficulties in social functioning, attributes which are commonly observed in individuals experiencing psychosis (Berry et al., 2020). Nevertheless, we cannot conclude that adversities in an individual's early attachment experiences will inevitably result in psychosis. Psychologists believe that this inability to infer causation reduces a sense of blame that family members often have when their relative has been clinically diagnosed (BPS, 2017).

Psychosocial factors including race, migration and social status have also been attributed to the experience of psychosis. It is thought that individuals from ethnic minority backgrounds experience greater social adversity and prejudice due to their differences, which may negatively impact their mental health (Veling, Hoek, Wiersma & Mackenbach, 2010). Living in urban environments has also been identified as a risk factor for developing a psychotic disorder, as has low socio-economic status (Kirkbride, Jones, Ulrich & Coid, 2012).

As a result of this complex web of interacting factors within the biopsychosocial model, psychological interventions gained recognition and were introduced alongside psychotropic medication as a recommended treatment for psychosis.

1.3.3 The Stress-vulnerability Model

The stress-vulnerability model (Zubin & Spring, 1977) emerged alongside the biopsychosocial approach and amalgamates existing theories on the aetiology of psychosis, such as environmental, developmental and biological theories. This model considers that individuals have a biological vulnerability or other predisposition to developing psychosis. This vulnerability is determined by a combination of pre-existing factors such as genetics, chemical imbalance in the brain, complications during birth and adverse childhood experiences, such as neglect and abuse. Yet, it is an interaction between vulnerability and psychosocial stressors (such as substance abuse and challenging interpersonal relationships) which is thought to result in an increased susceptibility to experiencing psychosis.

An individual’s home environment may have a negative emotional climate which could also precipitate a first episode of psychosis or subsequent relapses (Amaresha & Venkatasubramanian, 2012; Barrowclough, 2004). This adversity has been referred to as ‘expressed emotion’ which is a construct consisting of three unfavourable interpersonal patterns: critical, hostile and emotional overinvolvement. Expressed emotion is considered to be an environmental stressor which may trigger an onset or relapse of psychosis for individuals who have an underlying vulnerability (Butzlaff & Hooley, 1998).

Nevertheless, biological vulnerabilities are not ubiquitous in all individuals who experience psychosis. Moreover, as Romme and Escher (2012) convey, simply acknowledging any psychosocial adversities as triggers diminishes the impact of these experiences and results in overlooking the subjective meaning that these events have for the individual.

1.4 First Episode Psychosis

A FEP usually transpires between late adolescence and early adulthood, often between the ages of 16 and 35 years (Kessler et al., 2007). Breitborde, Srihari and Woods (2009) characterise a FEP as having three key features. Firstly, the individual must not already have a clinical diagnosis relating to a psychotic disorder or have previously encountered professional support within a clinical mental health setting for psychosis. Second, they must not have previously received any pharmacological or psychological treatment interventions for psychosis. Thirdly, the individual must have been experiencing psychotic symptoms for a particular time period and meet the relevant diagnostic criteria. This initial experience of psychosis is thought to last between two and five years, with clinical diagnosis and interventions being offered during this time. The point at which diagnosis and intervention occurs is, however, dependent upon when the individual presents to mental health services. Although the onset of psychosis is often sudden and unpleasant, there appears to be an initial prodromal phase which can be observed by the progressive development of wide-ranging, indistinct symptoms such as changes in mood and sleeping patterns, and impaired social functioning (APA, 2013).

A FEP can be a highly distressing experience, not only for the individual but also their family members. The impact of a FEP differs from the experience of chronic or relapsing psychosis as the challenges facing both the individual and their family members are somewhat dissimilar. During a FEP, greater ambiguity and ambivalence is often experienced by the individual, their family members and even clinicians who are contemplating clinical diagnosis (Addington, Collins, McCleery & Addington, 2005).

1.4.1 Treatment for First Episode Psychosis

In the UK, the National Institute for Clinical Excellence ([NICE], 2014) provides standardised guidance on how to support individuals experiencing a FEP. They recommend appropriate psychological interventions alongside or as an alternative to psychotropic medication. Moreover, they suggest that individuals experiencing a FEP should be treated through Early Intervention for Psychosis Services (EIPS), which were established by the British Department of Health and are now included within mainstream mental health care pathways in the UK. These services strive to identify and treat psychosis at the earliest opportunity during first onset and provide ongoing support throughout the critical period of this initial episode, which is thought to last up to five years (Birchwood, Fowler & Jackson, 2000). EIPS offer effective evidence-based medical, social and psychological interventions, which are intended to promote and improve access and engagement during an onset of psychosis (Islam, Rabiee & Singh, 2015). Individuals receive comprehensive care from a multidisciplinary team of professionals.

The psychological interventions offered in EIPS include individual therapies such as Cognitive Behavioural Therapy for Psychosis (Fowler, Garety & Kuipers, 1995), and systemic interventions such as family therapy or family psychoeducation informed by the stress-vulnerability model (Burbach, 2016). To establish suitability for family interventions, psychologists engage with family members and the individual experiencing psychosis, through initial individual or collective meetings (Burbach & Ekdawi, 2021). EIPS promote inclusion of relatives and caregivers and strive to encourage their active involvement, as many individuals experiencing FEP are often still living with their family members (Addington & Burnett, 2004). Systemic interventions are critical to minimising distress within the home environment and improving family functioning, for example, by ensuring that there is a shared understanding about the nature of psychosis and the individual's difficulties within the social context (Bebbington & Kuipers, 2010). Enhancing the support system of the individual experiencing a FEP can also have great importance for recovery (NICE, 2014).

In addition to interventions provided by EIPS, there are other services in the UK which are tailored to support individuals experiencing psychosis and their family members. These are predominately non-governmental organisations, such as Rethink Mental Illness, who offer support groups for individuals who share similar experiences, such as those caring for a relative with psychosis. Individuals are able to meet with one another in an informal setting and reflect on their thoughts, emotions and needs.

Around one in every hundred individuals in the UK is thought to experience a FEP and receive a clinical diagnosis (BPS, 2017). Currently, it is estimated that there are half a million individuals within this population living with this mental illness, although it appears that individuals from ethnic minority communities are at a higher risk of experiencing psychosis. McManus, Bebbington, Jenkins and Brugha (2016) reported that the prevalence of psychosis within the British SA population appears to be higher than in the indigenous community. Moreover, Kirkbride and colleagues (2008) claim that SA women in the UK are deemed to be at a particularly high risk of developing a psychotic disorder. Although psychosis appears to be prevalent within this population, Agius, Talwar, Murphy and Zaman (2010) claim that this group underutilizes mental health services and are unlikely to adhere to treatment that is offered.

1.5 British South Asians

The term South Asian (SA) can be used to describe individuals belonging to an ethnic group whose familial heritage and culture originates from Bangladesh, India, Pakistan or Sri Lanka (Moller, Burgess & Jogiyat, 2016). Although there are different religions and languages between these groups, Quraishi and Evangeli (2007) claim that they share many common cultural customs, ideologies and values. The SA culture is collectivist and places importance on conformity, self-sacrifice and co-dependence, where the needs of the family and the wider community are considered to be of utmost importance (Soorkia, Snelgar & Swami, 2011). Individuals are expected to be subservient and respectful towards older relatives, maintain emotional self-control and ensure they live in a manner which aligns with the goals of the entire family system, which often requires abandoning personal desires (Pandya & Herlihy, 2009). This differs greatly from Westernised societies, such as the UK, which promote independence, introspection, affective expression, and prioritisation of the self over the group. Soorkia and colleagues (2011) convey that the collectivistic expectations held within the SA culture may give rise to elevated levels of mental distress in this population, as each family member is heavily impacted by the suffering of another.

In the years after World War II ended, SAs began emigrating to the UK (Robinson, 2005). Many of these individuals initially came from India and Pakistan, in search of a more prosperous life. Today, the British SA population makes up the largest ethnic minority group in England and Wales, comprising 5.3% of the total population (Office for National Statistics, 2012). Moreover, British SA's are now also comprised of second-generation and third-generation immigrants, who were born in the UK.

The extent to which immigrants adopt the attitudes, beliefs and values of their host culture is known as acculturation (Kohatsu, 2005). Rather than acculturate, Dasgupta (1998) conveyed that first-generation SA immigrants are more inclined to pursue their native cultural practices. For second-generation SA migrants, there appears to be greater ease in adapting to the host culture whilst maintaining strong ties with their SA roots (Dey, Balmer, Pandit, Saren & Binsardi, 2017). These differences have been defined as the ‘acculturation gap’ and appears to be associated with intergenerational conflict as well as greater psychological distress in second-generation migrants who may struggle to accommodate opposing attitudes from their two cultures (Farver, Narang & Bhadha, 2002).

1.5.1 Psychosis in the British South Asian Community

Tahira and Agius (2012) highlighted that second-generation migrants living in Britain have the highest risk of developing psychosis when compared to the Native British population and even first-generation immigrants. Challenges with acculturation may contribute to internal identity conflicts and therefore precipitate distress. Moreover, younger individuals from ethnic minority backgrounds, such as British SAs, are especially vulnerable to developing psychosis (Mirza, Birtel, Pyle & Morrison, 2019), as onset typically occurs during adolescence (Kessler et al., 2007) and prevalence rates are high within the ethnic minority population (McManus et al., 2016). Hence, more research is needed in this field to ascertain why ethnicity-based disparities may exist and explore the impact of a FEP within the British SA community, due to the sizable population and the continuing increase in social diversity across the UK. Research could also consider intergenerational differences and further explore the attitudes, beliefs and experiences of psychosis in second-generation SAs in the UK.

Experiencing a FEP as a British SA would place the individual in two minority groups, which could present a layered challenge. The concept of intersectionality could explain this further. Intersectionality refers to the complex overlapping nature of identity markers such as race and gender (Crenshaw, 1989), which can create disadvantage as certain markers have been associated with the experience of stigma. Stigma is defined as a negative perception towards an individual due to distinguishing characteristics and attributes which depreciate their social identity (Goffman, 1963). SA’s living in the UK experience discrimination and stigma due to their ethnic minority identity (Major & O’Brien, 2005). Moreover, psychosis is one of the most stigmatised mental health conditions in Britain (Wood, Birtel, Alsawy, Pyle & Morrison, 2014). Agius and colleagues (2010) suggest that stigma of psychosis appears to be particularly prevalent within the SA community. Within the SA culture, there appears to be a taboo of mental illness as it is perceived as shameful and a sign of weakness for both the individual and their family members (Kishore, Gupta, Jiloha & Bantman, 2011). Hence, British SA's experiencing psychosis, or those who have a family member with psychosis, may experience shame and dishonour due to the intersecting nature of their stigmatised characteristics.

1.6 The Impact of First Episode Psychosis on Family Members

Researchers have explored the impact of a FEP on both the individual who has been diagnosed and their family members. Though this research is copious, studies have primarily focused on the viewpoints of parents or spouses, overlooking other family members such as siblings, despite all relatives being affected by this experience (Smith, Fadden & Taylor, 2010). Moreover, there is a very small body of literature that has focused primarily on the experiences of family members within the British SA population.

As the onset of psychosis typically occurs at a relatively early age, individuals who experience this are often still living with their family members such as parents and siblings, or at least remain in close contact with them (Lobban & Barrowclough, 2009). This proportion appears to be even higher within ethnic minority communities, such as the British SA population (Commander, Odell, Surtees & Sashidharan, 2003). Family members are often involved in their relatives care and treatment process, even if they are not residing in the same home.

Research has extended beyond focusing just on the individual with psychosis due to the importance of social support and the value of family interventions in enhancing the individual's quality of life, improving prognosis and ensuring better service provision (Onwumere, Smith & Kuipers, 2010; Pharoah, Mari, Rathbone & Wong, 2010). In addition, supporting family members alongside the individual and including them within the treatment process has also been attributed to a reduction in their own distress and an increase in positive caregiving appraisals (Sin, Murrells, Spain, Norman & Henderson, 2016). This, in turn, enhances the prospect of recovery from a FEP and reduces the chances of relapse (NICE, 2014).

Nevertheless, literature which has been conducted within the Western world, such as the UK, continues to find that experiencing a family member with a FEP is demanding, distressing and burdensome, with significant personal costs. This is not surprising given the debilitating impact of a FEP on the individual's functioning, which can adversely impact those within their support system and precipitate conflict, even in close family units (Onwumere, Jansen & Kuipers, 2018). High levels of burden have been observed in family caregivers (Barrowclough, 2004). Caregiver burden has also been associated with high levels of expressed emotion and a greater risk of relapse in psychosis (Kuipers, Onwumere & Bebbington, 2010).

Many family members express feelings of grief and anger as they find it incredibly difficult to accept the considerable changes that are observed in their relative (The Schizophrenia Commission, 2012). Fear and uncertainty are also experienced as family members are often initially unaware of their relative's diagnosis and prognosis, finding it difficult to make sense of their behaviours and feeling ill-equipped to cope. Moreover, some family members may feel unsupported by mental health services which may precipitate greater emotional distress, particularly feelings of frustration (Burbach, 2016; The Schizophrenia Commission, 2012). Kuipers (2010) contended that family caregivers may also experience a worsening of their own physical health and even develop symptoms associated with post-traumatic stress disorder or other common mental health disorders such as depression and anxiety. These findings emphasise the need to support family members from the earliest opportunity.

Increased levels of carer burnout have also been reported in family carers during the early stages of psychosis. Emotional exhaustion, depersonalisation and feelings of inadequacy can all be experienced during burnout and appear to be associated with negative appraisals of caregiving (Onwumere et al., 2018). An abundance of research has recognised that the appraisals of caregivers can engender a multitude of responses and behaviours towards a family member with psychosis. This has contributed towards the development of theoretical models of caregiving in psychosis.

1.6.1 The Cognitive Model of Caregiving in Psychosis

The cognitive model of caregiving in psychosis is an experientially informed model which was developed by Kuipers and colleagues (2010). It provides a theoretical understanding of informal caregiving relationships and builds on the concept of expressed emotion, which acknowledges the impact of a negative family environment and unhealthy interpersonal patterns. The model encompasses three relationship styles which are attributed to the caregiving experience: critical/hostile, emotionally over-involved and positive relationships.

The authors claim that critical and hostile attitudes are frequently experienced by most informal caregivers, including parents, spouses, siblings and children. These negative appraisals usually involve attributing blame towards the individual with psychosis. Moreover, the model proposes that family carers may hold expectations that their relative should take personal responsibility in their recovery journey. Hence, they often manage emotional distress through avoidance strategies, waiting to observe any improvements in their family member's presentation. It could be postulated that these relational styles may be less apparent within British SA families due to the collectivistic culture which prioritises the needs of others. Moreover, as British SAs are likely to attribute psychosis to supernatural causes (Bhika, Farooq, Chaudhry, Naeem & Hussain, 2015; Furnham, Raja & Khan, 2008; Mirza et al., 2019), this may reduce feelings of blame that they experience towards their family member.

Emotional over-involvement is more frequently observed in caregivers who identify as parents of individuals with psychosis. High levels of emotional overinvolvement in these family members have been associated with poor physical and psychological wellbeing. Feelings of guilt, self-blame and loss are often experienced (Patterson, Birchwood & Cochrane, 2005; Peterson & Docherty, 2004) and family members feel compelled to protect their loved one from further distress and harm. Attributes such as self-sacrifice and overprotectiveness are commonly observed in caregivers who are emotionally overinvolved. However, these behaviours are regarded as socially acceptable in more collectivistic cultures, including the SA culture (Bhugra & McKenzie, 2003). Hence, one may expect this interpersonal style to be evident in British SA caregivers.

The cognitive model of caregiving also acknowledges positive relationship styles between carers and their loved one. Research has identified that these patterns have been associated with better recovery rates after a FEP (O'Brien et al., 2006).

1.6.2 Experiences of Psychosis in British South Asian Families

Contemporary cross-cultural research has slowly begun to explore the experience of having a family member with psychosis in the British SA community, although as previously mentioned, the literature in this field is still scarce. The findings that are reported in this segment of the chapter represent the small body of research that has been conducted within this population.

Lloyd and colleagues (2011) examined levels of burden and emotional distress in a sample of 23 British SA parents who were caring for a child with a diagnosis of schizophrenia or schizoaffective disorder. The authors conducted a cross-cultural cohort study and compared findings with a sample of 16 White British parents. The SA parents were first-generation North Indians who had migrated to the UK. All parents were approached to participate in the study through their son or daughter, who were themselves initially selected by a mental health professional responsible for their care. This method of recruitment raises concerns due to the potential of selective bias, particularly as the children were required to select only one primary caregiver with whom they were in regular contact with. Hence, parents who were selected to participate could have been in a more harmonious relationship with their child experiencing psychosis. Parents completed well-established self-reports measuring levels of general health and perceived burden. However, many of the North Indian participants were not fluent in English; therefore, an interpreter was required to translate questionnaires into Hindi. This raises questions regarding how effectively the interpreters were able to translate psychological constructs and obtain accurate findings, particularly as the validity and reliability of the self-report measuring perceived burden in Hindi had not been established.

Findings from the quantitative measures indicated that there was no significant difference in levels of burden between the two groups of parents overall. However, Indian parents did experience higher levels of burden and distress when their child displayed positive psychotic symptoms or verbally aggressive behaviours. These findings provide a welcome addition to the existing research and are useful to practitioners working with British SA parents who care for a child with psychosis. It could be useful to further explore the experiences and needs of British SA parents who care for their child through qualitative research in order to enhance the richness of the data and better understand the experiential realities of parents. Moreover, understanding whether experiences of distress and burden differ between SA parents of children with chronic psychosis and FEP could also be useful to mental health practitioners working with this population.

Penny, Newton and Larkin (2009) explored the experiences of British Pakistani family members who had a relative experiencing psychosis and receiving treatment within an EIPS. Rather than acquiring objective knowledge, the researchers adopted a qualitative, exploratory approach and aspired to develop a better understanding on the nature of the participants experiences, including their beliefs about psychosis and perceptions on the treatment and support from services. This was achieved through conducting semi-structured interviews and examining the data using Interpretative Phenomenological Analysis. This methodology is valuable as it illuminates meaning-making processes, enables researchers to study the complexities of human experiences and provides novel insights into a particular group being studied (Barker, Pistrang & Elliott, 2015). Eleven British Pakistani's from six different families were recruited to participate in this study. The majority of the sample consisted of first-generation migrants who were either parents or grandparents of the individual who was experiencing a FEP. Three other participants in their study were siblings who identified as second-generation British SAs.

Three of the participants who identified as first-generation utilised an interpreter during the interview as they were not fluent in the English language, whilst one participant requested to use their family member as a translator for the same reason. The use of an interpreter can be empowering and give voice to individuals who are underrepresented in research, offering them a space to talk about sensitive and emotive subjects. However, the use of interpreters in phenomenological research has been criticised, as Squires (2009) asserts that this approach requires an accurate attentiveness towards participants language which is used to describe their experiential realities. Using an interpreter and subsequently translating data can impede the analytic process. Within their study, Penny et al. (2009) acknowledge that there were some discrepancies in how questions were translated.

Nevertheless, three superordinate themes arose as a result of the phenomenological analysis. These themes represented the impact of a family member's FEP, beliefs and perceptions of psychosis and utilisation of different cultural resources. A strong sense of loss was described, predominately by parents, due to the changing nature of family life and a need to re-evaluate thoughts about the future. All participants referred to spiritual or social factors in conceptualising psychosis, which concurs with existing literature that has examined culture-specific beliefs and causal explanations (e.g., Bhika et al., 2015; Furnham et al., 2008; Mirza et al., 2019). Many older participants also described the importance of turning to religion and spirituality to cope. When they perceived their relative's behaviour as deviating from socio-cultural norms, family members experienced feelings of apprehension and self-blame. They also felt overlooked by EIPS services who failed to provide adequate information. Interestingly, younger participants expressed a stronger desire for their voices to be heard by professionals and perceived themselves as playing an important role in their relatives' recovery, whilst older participants (parents and grandparents) viewed mental health practitioners as the experts. These generational differences continue to highlight a need for future research to further explore these experiences in more homogenous samples. Expanding this research to address a particular sub-group, such as second-generation British SA caregivers may provide greater insight into the experiential realities of these individuals. Moreover, focusing solely on either grandparents, parents or siblings rather than amalgamating their experiences could provide more valuable and nuanced insights.

1.7 Siblings: The Forgotten Family Members

Having explored the existing literature on the experiences and impact of a FEP in British SA families, it is evident that this population has been under-represented. Sibling experiences in particular have been neglected, as existing research has predominately focused on parents within this cultural group.

The longest relationship that an individual will encounter over the lifespan is a sibling relationship, with approximately 90% of the entire population having at least one brother or sister (Buist, Deković & Prinzie, 2013). As with all human relationships, sibling relationships are complex and multifaceted. The reciprocal nature of this attachment relationship is variable, with different levels of intimacy and commitment over the lifespan (Whiteman, McHale & Soli, 2011). Despite the enduring nature of this relationship, research on individuals who have a brother or sister experiencing a FEP appears to be limited, although there has been growing interest in this topic over the past decade, particularly in the Western world.

Nonetheless, siblings have often been described as the invisible family members who have been largely neglected and forgotten in clinical practice and research (Bowman, Alvarez-Jimenez, Wade, Howie & McGorry, 2017; Griffiths & Sin, 2013). This is striking given the high probability that most individuals would still be living with their sibling during an onset of psychosis which suggests that the sibling would encounter similar events and experiences as their parents (Lobban & Barrowclough, 2009). Moreover, researchers and clinicians still acknowledge the role of genetics as a risk factor in developing psychosis, which therefore casts doubt as to why this group of individuals has been generally overlooked (Smith, Fadden & Taylor, 2010).

There appears to be some debate in the literature in attributing the term caregiver to siblings. Some researchers describe siblings as secondary caregivers who support their parents in the recovery process (Birchwood, 2003). However, other research has disregarded using this term. In some studies, individuals have referred to themselves as siblings rather than caregivers in an attempt to normalise their roles and responsibilities as a family member during onset of their brother or sister's psychosis (Sin, Moone, Harris, Scully & Wellman, 2012).

As with all family members, siblings can play a pivotal role in supporting their loved one during a FEP. The sibling relationship could be considered to be a protective factor in the onset, occurrence and recovery of a FEP as well as subsequent relapses. During the early stages, particularly the prodromal phase, siblings may provide emotional and practical support, comfort and companionship (Goetting, 1986). Moreover, siblings often have a positive impact on their brother's or sister's recovery as they impede social isolation, which appears to be a risk factor for psychosis (Bowman, Alvarez-Jimenez, Howie, McGorry & Wade, 2015; Norman et al., 2005; Selten & Cantor-Graee, 2005). Smith, Fadden and O'Shea (2009) also recognise that a FEP could also result in a significant change and adversely impact the sibling relationship, with the potential for increased conflict and ambivalence. Siblings are often required to adapt and find ways to cope with changes in their loved one, which creates another dimension to the relationship.

Research has also demonstrated that siblings themselves are significantly impacted by their brother's or sister's condition and they may experience high levels of emotional distress. This existing literature will now be reviewed.

1.7.1 Sibling Experiences of Chronic Psychosis

Research has predominately focused on the experiences of having a sibling with long-term psychosis. Whilst these studies provide valuable contributions to the knowledgebase and support mental health clinicians in their practice, there are still some gaps which could be addressed through future research.

Findings from research studies that have explored the impact of psychosis on siblings have determined that there are similarities with parental experiences. Mixed emotions including guilt, shame, sorrow, loss, anxiety, uncertainty, anger, compassion, love and hope have been frequently reported in the literature (Barnable, Gaudine, Bennett & Meadus, 2006; Kristoffersen & Mustard, 2000; Schmid, Schielein, Binder, Hajak & Spiessl, 2009; Stålberg, Ekerwald & Hultman, 2004).

Sin (2013) used the term 'survival guilt' which refers to the notion that siblings often feel guilty for being well whilst their loved one is suffering. This appears to induce a sense of pressure in siblings who try to then overcompensate. One of the earliest qualitative studies on sibling experiences identified that guilt was experienced differently between younger and older siblings of individuals with psychosis (Samuels & Chase, 1979). This retrospective study conveyed that younger siblings felt guilty for being psychologically healthy, whilst older siblings reflected on earlier memories of sibling conflict and rivalry, which precipitated their feelings of guilt. Taking responsibility for their brother or sister appeared to be a coping strategy to manage feelings of helplessness, although the level of active involvement varied over time.

Guilt was also expressed by siblings in a more recent qualitative study, conducted by Barnable et al. (2006). The researchers endeavoured to explore the impact of having a sibling with schizophrenia in a sample of six adults (one male, five female) living in Canada. Participants were interviewed and data was analysed using hermeneutic phenomenological methodology. A sense of self-blame emerged in the findings, as participants felt somewhat responsible for their brother or sister's illness. They also struggled with the system due to challenges with obtaining help and support from professionals which precipitated feelings of helplessness and frustration. The researchers also identified a sense of personal growth and better insight as a result of these experiences. This contradicts findings reported by Samuel and Chase (1979), who observed that participant's experienced personal growth only after a period of separation from their sibling and the family unit during early adulthood. The study could be expanded on, by further exploring these experiences in male siblings and gaining a richer insight into their perspectives, given that this study sample predominately consisted of females.

Experience of grief is another prevalent theme within the literature. Siblings struggle to adapt to the changes they observe in their brother or sister and experience feelings of loss (Lively, Friedrich & Buckwater, 1994). These feelings are also precipitated by changes in wider family dynamics (Lukens, Thorning & Lohrer, 2004). Kristoffersen and Mustard (2000) explored the emotional impact of having a sibling with schizophrenia. They also utilised a hermeneutic methodology to interpret and analyse data which had been collected through research interviews. The sample consisted of 16 adult siblings from Norway. Grief was central to four interconnected themes which emerged in the findings. The first theme depicted a sense of 'ambiguous loss'. This is a paradoxical experience which refers to feeling the loss of a person who is still physically present. An internal 'prohibition' was also experienced in relation to grief. Participants felt unable to grieve despite experiencing the loss of their sibling. Mixed emotions were expressed as a result of the 'fluctuating nature' of the sibling's psychosis. Participant's reported shock and despair when their sibling was unwell but felt more hopeful when their sibling's condition improved. The final theme reflected the experience of 'invalidation' from the wider community in response to feelings of grief and loss. Hence, these findings illustrate the overwhelming and complex internal experiences in response to having a sibling with chronic psychosis and as such may provide a better understanding of their needs.

The impact of having a sibling experiencing chronic schizophrenia has also been systematically examined by Lively, Friedrich and Rubenstein (2004). This American study utilised several well-established and comprehensive questionnaires which were adapted to measure the sibling relationship, levels of stress and the impact of illness behaviours. A large sample of 752 adults participated, although most of these individuals were female and

Caucasian. The lack of gender and ethnic diversity within this sample limits the findings, which may not be representative of all siblings of individuals with psychosis across America. Nonetheless, the researchers concluded that psychological distress and conflict in family relationships was associated with observing more disturbing psychotic behaviours in siblings. The findings also illustrated that both the sibling relationship and the relationship between the participant and their parents were adversely impacted.

Some researchers explored the coping strategies that are utilised by individuals who have a sibling experiencing chronic psychosis. For example, Gerace, Camilleri and Ayers (1993) conducted a thematic analysis on interview data from 14 individuals living in America who had a sibling with schizophrenia. They identified three patterns of coping from the interview data: collaborative and active coping, crisis-oriented coping and detached avoidant coping strategies. However, the study has limitations with recruitment and sampling which impacts the generalisability of these findings. As with other studies on sibling experiences of chronic psychosis (Barnable et al., 2006; Lively et al., 2004), most of the participants in this study were white females. Moreover, they were recruited through support groups and it could be assumed that the nature of these groups may have influenced their coping behaviours. As this study was conducted almost three decades ago, it could be useful to replicate today with a more diverse sample.

Nevertheless, similar coping strategies have been reported in a Swedish study by Stålberg et al. (2004). The researchers conducted a Grounded Theory study in a sample of 16 individuals who had a sibling with schizophrenia and explored their perceptions of the sibling role and the sibling relationship. Their findings echoed the coping patterns that were identified by Gerace et al. (1993) as some participants conveyed their active involvement whilst others reported isolation or avoidance. However, two additional coping strategies were identified: normalisation and grieving. Moreover, fear of the future and acquiring the illness due to the hereditary nature of psychosis was a key theme, with many siblings worrying that their own children could develop psychosis in the future.

Challenging behaviour such as physical violence has also been reported in the sibling literature and is one of the most difficult illness-related variables to manage. From their systematic review, Large and Neilssen (2011) concluded that almost two-thirds of siblings have observed violent behaviours during onset of their brother or sister’s psychosis. Solomon, Cavanaugh and Gelles (2005) claim that after parents, siblings are the next most likely family members to be targets of physical violence.

Burden has also been extensively reported within the literature. Schmid and colleagues (2009) conducted a content analysis using narrative interviews in a sample of 37 adults living in Germany. All participants had a sibling with psychosis who was receiving treatment in an inpatient service. The findings indicated that participants experienced heavy emotional burden due to feelings of powerlessness, helplessness, fear of the future, fear of developing the illness themselves and concerns regarding the wellbeing of parents. Anger towards the sibling was prevalent, although participants also felt guilty for not being supportive enough. Yet, they also reported positive experiences, including a stronger bond with their sibling and feelings of importance due to their sibling duty. The authors acknowledge that they did not identify all sociodemographic variables, such as birth order. It is possible that these factors may be associated with experiences of burden. These features have been explored in more recent studies with siblings of individuals with FEP (Bowman et al., 2017).

The studies discussed so far have been conducted in the Western world and focus on siblings who have a brother or sister with long-term psychosis. Many of these studies utilise qualitative methodologies which result in rich findings, highlighting the value of the research design. Alongside these pockets of qualitative research, it could be useful to conduct more quantitative research in this field to observe whether patterns exist in certain populations and draw overall conclusions about human behaviour. This could enable researchers to establish generalisability of findings to wider contexts. The research has also failed to explore sibling experiences of psychosis within migrant or ethnic minority populations. It is possible that culture and ethnicity could result in differences in the experience of having a sibling with psychosis. This could inform the basis of future research.

1.7.2 Sibling Experiences of First Episode Psychosis

Research on siblings of individuals with a FEP have identified similar findings with existing literature on sibling experiences of chronic psychosis. Nevertheless, there are also some disparities and there appears to be a wider range of experiences which have been reported in this group. For example, Fisher, Bordass and Steele (2004) conveyed that self-neglect, impaired social relationships and poorer academic performance were experienced by siblings of individuals with a FEP, as many siblings were still in education during onset of their brother or sister's illness. These findings have seldom been reported in the literature on chronic psychosis. However, Fisher et al. (2004) also identified that siblings reported feelings of frustration due to being largely ignored by professionals, despite their desire to be more involved in their brother's or sister's care. This concurs with the findings reported by Barnable and colleagues (2006), demonstrating that siblings continue to feel neglected and forgotten if their loved one later relapses.

More recently, quantitative research has attended to particular features and specific issues concerning sibling experiences of FEP, such as quality of life (QoL). Bowman, Alvarez-Jimenez, Wade, Howie and McGorry (2014) conducted a survey methodology to assess QoL in 157 siblings of young adults with FEP in Australia. The researchers not only sought to measure QoL but also wanted to ascertain whether this was associated with birth order or the sibling's illness-related behaviours. All siblings with psychosis had been receiving treatment in the same service where the age range of patients was 15 to 29 years. The same age range was set for participants as the researchers wanted them to be in same stage of development as their brother or sister. As siblings were receiving treatment from one service, the findings may not be generalisable to other populations. Nonetheless, the results from a regression analysis provided interesting findings. Low levels of satisfaction in the social QoL domain were identified when participants were living with their siblings, indicating that participants' social relationships had been negatively impacted. Low satisfaction was also experienced across all QoL domains when the sibling with psychosis had been physically aggressive or had attempted suicide. This adds to existing literature on the challenges and impact of coping with a sibling's violence. Gender and age differences were also apparent, with the lowest satisfaction in QoL being reported by participants who were younger sisters. In contrast, older brothers reported the highest satisfaction. This study could benefit from replication through qualitative research to enrich these findings and develop a deeper understanding of the impact of a siblings FEP on QoL. However, this research still provides an important contribution to the literature and enables professionals to consider how to best support different subgroups of siblings of individuals with FEP.

Bowman and colleagues (2015) further conducted quantitative research on the same group of participants to examine how the sibling relationship may be impacted by illness-related variables during a FEP. The Adult Sibling Relationship Questionnaire (Stocker, Lanthier & Furman, 1997) was administered to examine the impact of the sibling's FEP on three facets within the sibling relationship: conflict, rivalry and warmth. A lack of warmth within the relationship was associated with hospital admissions, persistent psychotic symptoms, physical aggression, use of illicit substances and a long initial period of untreated psychosis. Conflict and rivalry within the sibling relationship were associated with residing with the sibling with psychosis, hospital admissions, refusal to engage with treatment and physical violence.

Hence, living with a sibling appears to significantly impact the sibling relationship during a FEP. The three relational dimensions could be comparable to research that has explored the concept of expressed emotion in families, which has been shown to precipitate distress in all family members and increase the risk of relapse. However, it is important that causation should not be inferred within this study. These findings instigated further research by the same authors who quantitatively explored the relationship between illness-related behaviours, experiences of caregiving and burden within the same population (Bowman et al., 2017). Younger sisters scored highest on questions relating to negative experiences of caregiving and burden, which resulted in less warmth in the sibling relationship and a poorer QoL. Interestingly, these participants also scored highest on questions relating to concealing their sibling's psychosis from others. Hence, gender appears to be a significant factor that explains how illness related variables are associated with caregiving appraisals, caregiving experiences and coping strategies. Although these findings are valuable in demonstrating an association between gender, birth order and sibling burden during FEP, the researchers did not identify other sociodemographic variables such as ethnicity.

As these three studies were conducted in Australia, generalisability of the findings may be limited, despite cultural similarities in service provision within the Western world. All participants were selected by their sibling with psychosis to partake in these studies; therefore, the findings may be influenced by selection bias and may not be truly representative. Moreover, all three studies used a quantitative approach to explore the impact of a sibling's FEP. Although this is helpful for understanding different determinants which are impacted by having a sibling experiencing FEP, a qualitative approach would allow further exploration and generate deeper insights into these experiences, providing siblings with a voice.

In the UK, a handful of qualitative research studies have explored the experiences of having a sibling with a FEP. The findings from these studies have echoed research conducted into sibling experiences of chronic psychosis. Sin, Moone and Harris (2008) explored the lived experiences and needs of 10 young adults who had a brother or sister experiencing a FEP. The siblings with FEP were receiving support from EIPS in South East England. Due to the standardised practice of these services across the UK, the findings from this study could be useful for clinicians working with family members in these settings. The researchers conducted semi-structured interviews with each participant in their own homes and intended to explore their subjective experiences. Once transcribed, data was analysed using a descriptive phenomenological approach. Five key themes emerged: the emotional impact of the sibling's psychosis; the impact on family relationships; coping strategies; resilience; and needs. Participants described an array of emotions in response to their sibling's FEP, leading to a sense of overwhelm. Emotions such as guilt, loss, blame and shame due to stigma were reported, which concurs with the existing qualitative literature on siblings of individuals with chronic psychosis (e.g., Barnable et al., 2006; Schmid et al., 2009) as well as other family caregivers. Participants also struggled with conflicting emotions as they described feeling resentful towards their sibling but also guilty and helpless from being unable to support them. This paradox was also highlighted by Ståhlberg and colleagues (2004), indicating that ambivalence persists when a sibling experiences chronic psychosis. Many participants were concerned about the impact of their brother or sister's psychosis on other family members, particularly parents. In order to manage these anxieties, they shared the caregiving role with their parents. However, others found the experience incredibly distressing and instead distanced themselves from their sibling to cope. Some of the participants described a sense of personal growth and resilience, reflecting on an increased sense of empathy and an ability to provide better practical support to the sibling. This improved the sibling relationship and resulted in a more cohesive family system. However, most participants still expressed a need for psychoeducation and more accessible support services that could be tailored to siblings and other family members. Having a space to reflect on their own personal experiences was also strongly desired.

Newman, Simonds and Billings (2011) conducted a qualitative study in the UK to explore the impact of having a sibling with a FEP on self-identity and roles within the family. Two male and two female White British participants who had a sibling receiving support from an EIPS in London were recruited. The researchers employed a narrative methodology and provided a thorough outline of the analytic strategy. The findings were comprehensive and compelling, as the authors were able to give voice to each individual participant whilst identifying similarities and distinctions across accounts due to the homogeneous sample. The analysis revealed gender differences in identity and roles within the family. Male participants reflected a more pragmatic tone as they were focused on responsibilities of being a caregiver for the sibling and developing more positive relationships with parents. Conversely, female accounts depicted a personal journey of finding meaning from their difficult experiences, which resulted in a new perspective on their lives. There were some similarities across all narrative accounts, including feelings of disbelief at the onset of the sibling's psychosis and a sense of ambivalence overall. Feelings of distress and loss were experienced alongside a sense of growth and personal development. All participants also expressed a need for more support and information from services due to their caregiving responsibilities. Many of these findings concur with Sin et al. (2008) and highlight the importance of supporting siblings. Although the research findings cannot be generalised due to the small sample size, they provide some value when being shared in other similar contexts. The researchers advocate that future research would benefit from exploring these experiences in individuals from different ethnic backgrounds due to the influence of culture on meaning-making.

Sin and colleagues (2012) qualitatively explored the experiences of having a sibling with a FEP in a more diverse sample. A total of 31 participants aged between 11 and 35 years were selected through EIPS services in South East England, where their siblings had been receiving treatment. Five of these participants identified as SA. Researchers conducted semi-structured interviews and thematically analysed data which resulted in six key themes. The first theme reflected siblings' roles. Participants reported actively engaging with their brother or sister in many ways, including supporting with medication, providing emotional support and liaising with mental health professionals. However, participants younger than 16 years were not as actively involved due to family conflict and tension within the home. Instead, they remained unobtrusive. The second theme encompassed an array of complex and conflicting emotions that have been consistently identified in the existing literature. Differences in age were observed once again as younger participants were more likely to conceal their experiences from others due to fear of stigma and embarrassment. This concurs with findings depicted by Bowman et al. (2017). However, some of these younger participants did reach out to friends or teachers for emotional support. In addition, SA participants were more likely to be living in the family household and reported greater feelings of burden and stress due to providing practical support in the home and supporting their parents with the caregiving role. This echoes existing literature on psychosis in British SA families where burden is often prevalent due to the close familial relationships (Lloyd et al., 2011).

A range of coping strategies were also identified, with differences between older and younger participants. Withdrawal and avoidance were common in younger participants, who were more reluctant to get involved in their sibling's treatment process due to a lack of knowledge. Conversely, older participants used active coping strategies, including seeking out information from professionals and raising awareness of psychosis in the wider community to reduce stigma. The final three themes depicted changes in family relationships, a greater sense of resilience, and an identification of sibling needs from services. These themes reiterated earlier research findings in studies by Sin et al. (2008) and Newman et al. (2011) as well as existing research on sibling experiences of chronic psychosis. However, the researchers did not disclose whether any sociodemographic variables, such as ethnicity, were associated with these themes. Nevertheless, this qualitative research provided rich insights into the phenomenon of having a sibling with a FEP and from a markedly sizeable sample.

As with the quantitative research studies on sibling experiences of FEP (Bowman et al., 2014, 2015, 2017), participants in this study were self-selected by their brother or sister who was unwell. In some cases, parents were also required to give consent if the participants were under 16 years of age. This may have resulted in a selection bias, leading to omission of significant experiences. In addition, the sample was predominately female. Male siblings appear to be largely underrepresented in the sibling literature. Nevertheless, this study was one of the first to recruit a more ethnically diverse sample and the researchers acknowledged some differences in sibling experiences as attributable to this sociodemographic factor. It could be helpful to explore this further by replicating this research and recruiting a larger sample of individuals from ethnic minority populations, such as the British SA community.

Overall, the literature suggests that the experience of having a sibling with a FEP is highly distressing and burdensome. Existing research on this phenomenon provides valuable knowledge and conveys similarities and differences in experiences and needs between younger and older siblings. However, it is evident that there is only a small volume of research that has explored this phenomenon, particularly within the UK. These existing studies have predominately recruited Caucasians and neglected ethnic minority populations. Hence, it is not known whether cultural factors impact the lived experience of having a sibling with a FEP.

1.8 Rationale for this Doctoral Research Study

Given that existing research findings have identified that individuals can be significantly impacted when their brother or sister experiences a FEP, it would be important for counselling psychologists and other mental health practitioners working with these individuals to deepen their understanding of how siblings make sense of their experiences, in order to meet their needs and provide appropriate support. As has become evident in this literature review, few studies have explored sibling experiences of FEP within the UK, despite researchers acknowledging that siblings are important sources of support (Goetting, 1986; Norman et al., 2005) who are often still living with, or close by to their relative during the onset of the illness (Lobban & Barrowclough, 2009). Until now, no research has exclusively explored this phenomenon within ethnic minority populations in the UK. As the risks and prevalence of a FEP may be higher in second-generation minority communities in the UK (Tahira and Agius, 2012), such as the British SA population (McManus et al., 2016), it seems crucial to deepen our understanding of how individuals belonging to this population experience having a sibling with a FEP.

To add to the existing knowledgebase and address the aforementioned gaps, this research study endeavours to explore and understand the experiential realities of second-generation British SA's who have had a brother or sister experience a FEP. By adopting a phenomenological perspective, this study has attempted to answer the following research question: *How do second-generation British South Asians experience having a sibling with a first episode of psychosis?*

This research study hopes to contribute to the existing literature by providing insight and knowledge to a relatively under-researched field. Moreover, this research aims to give voice to individuals within a marginalised group by exploring the impact of culture and ethnicity on their experiences. Human beings are inextricably embedded within their socio-cultural context. Counselling psychologists have a duty to be culturally competent which requires respect, understanding and the ability to communicate with individuals from different cultures who may hold different beliefs to their own (BPS, 2017). Being able to appreciate and understand how society and culture impact an individual's meaning making processes enables psychologists to foster greater cultural sensitivity in therapeutic practice. This, in turn, enhances the cultural applicability of services which is especially important within a multicultural society, such as the UK. Hence, the findings from this research study may have important implications for clinical practice.

Methodology

2.1 Overview

This chapter intends to demonstrate my rationale for adopting a qualitative perspective to answer my research question. I present my epistemological position, which is based on my underlying philosophical beliefs, before outlining the methodological framework. Ethical considerations have been outlined in order to demonstrate how this research has adhered to established ethical guidelines. This chapter ends with a focus on reflexivity whereby I examine how my judgments, belief systems, presuppositions and practices may have impacted the research process. However, my relationship to the research is also explored throughout the chapter.

2.2 Rationale for a Qualitative Approach

Qualitative research seeks to describe and interpret human experience through an inductive and exploratory process, whereby individuals are given a platform to voice their perspectives (Willig, 2012). A qualitative approach has the potential to produce rich, novel and poly-dimensional insights into aspects of an individual's lifeworld. Moreover, it has the ability to examine subtle nuances and is therefore favourable when exploring personal meanings of a given phenomenon (Pistrang & Barker, 2012). In addition, Willig (2012) contends that this approach enables researchers to investigate phenomena in naturalistic contexts, where participants have the freedom to describe their experiences in their own words, which can alter the power dynamics between a researcher and participant.

This stands in contrast to a deductive approach, which examines causal relationships by making predictions based upon existing theories and testing hypotheses in controlled environments. Hence, this alludes to the existence of a universal truth which can be measured objectively (Willig, 2012). Langdridge and Hagger-Johnson (2009) assert that these differences do not reflect a lack of precision within the qualitative approach, but instead suggest that the two research paradigms have a different lens of focus.

As discussed in the previous chapter, my intention for conducting this research is to explore, understand and capture the texture and quality of the lived experience of having a sibling with a FEP. Hence, a qualitative approach was deemed suitable as my research seeks to unearth how individuals make sense of this phenomenon and what it means to them, rather than quantifying this experience.

A variety of qualitative methods exist and in order to select the most appropriate research design, awareness of one’s philosophical perspective and research aims are important (McLeod, 2015). It is imperative that the choice of methodology aligns with the researcher’s worldview in order for valid knowledge to be acquired (Smith & Osborn, 2015). This is discussed in the following sections of this chapter.

2.3 Choice of Methodology and Philosophical Positions

2.3.1 Epistemological Position

Ontology refers to the nature of reality and theories of being, whereas epistemology refers to theories of knowledge, including our beliefs about how we come to understand this knowledge (Ponterotto, 2005). As previously mentioned, the method and methodology of a research study must correspond with the researcher’s ontological and epistemological position. Willig (2013) contends that ontological beliefs exist on a continuum, with realism at one end and relativism at the other, whilst epistemological perspectives can be identified as realist, phenomenological or social constructivist. There are other ways of conceptualising these different positions; however, I intend to use the terms adopted by Willig (2013).

A realist ontology presumes the existence of a real world containing social, psychological and material processes or objects that have causal relationships to one another. It assumes that these structures and mechanisms are separate from the knowledge we may have about them (Denzin & Lincoln, 2011). A research study which adopts this position would be expected to produce knowledge which accurately represents a phenomenon in the world. In contrast, a relativist ontology rejects the notion of a world that is independent from perception and instead argues that there are multiple realities which are equally credible and constructed from our perspectives (Maxwell, 2012). The type of research that is carried out from this position often explores the impact of language, culture and politics in constructing multiple versions of an experience. Hence, it is highly sensitive to the diversity of interpretations and tensions that arise when analysing linguistic data.

I reject the notion of a relativist ontology, which states that there is no such thing as a real world and advocates that reality is primarily constructed through language. My beliefs about reality are more aligned with a realist ontology, which explains that a real world exists independently of our conceptualisations, constructions and theories. However, whilst I believe that there is a real world out there, I do not think that there is any possible way of accurately understanding this reality and measuring it objectively, as our understanding is inevitably influenced by our individual subjective perceptions. Thus, I find myself holding beliefs bound between realism and relativism due to the scope and limitations in acquiring knowledge.

I position myself within a critical realist epistemological framework, which combines a realist ontology with a constructivist epistemology (Maxwell, 2012). A critical realist perspective proposes that whilst there is a physical reality that exists autonomously from human perspective, it can only be understood partially due to the inevitable influence of our interpretations when engaging with phenomena within the world (Guba & Lincoln, 1994). The meaning that we impose on structures in the world is inextricably linked with subjective interpretation. Therefore, the nature of reality – in this case a realist ontology – cannot be reduced to epistemology, as there is no direct access to the real world (Fletcher, 2017). This has been termed '*the epistemic fallacy*' (Bhaskar, 1978, p. 27), and implies that research being conducted in a controlled environment which adopts a positivist approach is fruitless as we cannot ascertain an objective truth. Reality can only be understood from our view of it, and this perspective is influenced by cultural, social and historical contexts as well as our physiology (Willig, 2013). Hence, although this position refutes the existence of socially constructed multiple realities, it acknowledges that there are diverse valid perspectives on a single extant reality (Maxwell, 2012).

Thus, this research study aims to generate critical realist knowledge and attempts to gain an insight into the meaning-making process of individuals who have experienced a sibling recover from a first episode of psychosis (FEP). I assume that psychosis is a real phenomenon which exists in the world, although it can only be observed and understood partially through the filter of human interpretation. Moreover, as reflected within my literature review, psychosis is not experienced and understood universally across the world. As a critical realist, I believe that there are many ways in which individuals can identify and understand this phenomenon, due to the influence of our subjective interpretations in acquiring knowledge. However, within this research study, psychosis is framed as an organic disease with inherent properties, which can be observed and understood at an empirical level through utilising clinical diagnostic criteria and in accordance with the biopsychosocial model. This perspective represents my own interpretation, which has been informed by my own professional experience of working with individuals with a diagnosis of psychosis.

In relation to recovery of psychosis, I concur with the term 'clinical recovery', which is defined as an improvement and reduction in symptoms of psychosis, based on the judgment of an external observer (Slade, 2009). Within this research study, the external observer is the sibling of the individual who had been diagnosed with FEP. In accordance with my philosophical position, I believe that experiencing a sibling recover from psychosis cannot be perceived in a universal manner due to differences in how individuals encounter material in the world, which shape their perspectives. Rather than obtaining an accurate reflection, this research study attempts to explore how participants make sense of having a sibling who has recovered from a FEP and aims to provide an insight into their processes of meaning-making. Moreover, this study instead attempts to capture a glimpse into the profound and vast reality of this experience, as the knowledge produced is considered to be partial (Maxwell, 2012).

Whilst it is possible that the data obtained within a research study will reflect aspects of a participant's reality in an un-mediated fashion, it will nevertheless be impacted by the researcher's values and beliefs, which are inherently tied to the research process (Ponterotto, 2005). Hence, the knowledge acquired within the present research study will be influenced by my own perspective as well as the perspective of the participants. Nevertheless, I believe that if this has been acknowledged and evaluated by the researcher, it is still possible to acquire insight into how participants make sense of a lived experience.

To align with my research question, epistemological framework and perspective on the researcher's relationship to the data, Interpretative Phenomenological Analysis ([IPA]; Smith, 1996) was selected as the most suitable qualitative methodology for the present study.

2.3.2 Theoretical Framework of IPA

IPA is a qualitative approach concerned with exploring an individual's lived experience and how they make sense of this experience (Smith, Flowers & Larkin, 2009). It was developed as an experiential research methodology and is designed to capture how experiences are perceived and interpreted, by examining the claims that are made about a phenomenon. The approach is informed by three philosophical traditions: phenomenology, hermeneutics and idiography (Smith & Shinebourne, 2012).

Phenomenology

Phenomenology is defined as the philosophical study of human existence and experience (Larkin & Thompson, 2012). The concept of phenomenology was established by Edmund Husserl, whose primary interest was in exploring phenomena which present themselves in the lifeworld (Willig, 2013). The lifeworld refers to the world in which human beings exist, a world which contains phenomena such as objects, emotions and events that emerge in our conscious everyday experience (Langdridge, 2007). Husserl described the lifeworld as pre-reflective and was interested in examining how phenomena are perceived in the world rather than solely focusing on what is perceived (Brooks, 2015). He suggested that our knowledge of structures and processes within the world can only be acquired when they are rooted in concrete experience (Husserl, 1929). However, he concurred with the notion that an objective reality is not directly accessible and instead implied that we can develop knowledge of phenomena by exploring human subjective experience.

Moreover, Husserl proposed that phenomenological researchers should attain what is knowable by going '*back to the things themselves*' in order to capture the core essence of personal lived experience (Smith et al., 2009, p. 12). His approach to phenomenological inquiry is concerned with transcending everyday assumptions about a phenomenon in order to discover how it presents itself in human consciousness. In order to do this, a process of phenomenological reduction should be employed, whereby one must abandon their natural attitude and 'bracket' any judgments and preconceptions in order to allow the essential features of the phenomenon to arise (Husserl, 1929). This gives rise to the emergence of a clear, boundless attitude towards the lifeworld, known as the *epoché* (Brooks, 2015). Husserl's work has been influential for qualitative research methodologies, particularly descriptive phenomenology which aims to acquire transcendental knowledge. His ideas have also contributed to IPA, which places emphasis on taking a reflective stance in order to understand human experience (Smith et al., 2009).

However, Husserl's assumptions regarding the need for phenomenological reduction in order to describe a phenomenon in its totality received much criticism from subsequent phenomenological philosophers, who described his ideas as idealistic and unattainable (Smith et al., 2009). Martin Heidegger, a student of Husserl's, proclaimed that acquiring direct access to the pure essence of phenomena by bracketing presuppositions is unachievable, as individuals are inseparable from their preconceptions. He introduced the concept of *Dasein*, or 'Being-in-the-world' to illustrate how human beings are already invariably placed into a world containing structures and processes from which we cannot isolate ourselves (Heidegger, 1962).

In addition, Heidegger expanded on Husserl's ideas and proposed the concept of intersubjectivity, which refers to the continuous and complex relationship between human beings in the world (Heidegger, 1962). This relatedness enables us to communicate with and understand one another, as well as objects we encounter, due to the shared, intersecting nature of our engagement in the world (van Deurzen & Kenward, 2005). Thus, to some extent, human beings influence and are influenced by others when making sense of phenomena. The current study acknowledges the influence of intersubjectivity, for example, between participants and their family members and also between researcher and participant in understanding the participant's meaning-making processes.

IPA embraces Heidegger's perspective by acknowledging the influence of our historical and socio-cultural contexts. When considering his ontological position, Heidegger viewed human beings as a part of reality, and proposed that it is our relationship to, and interpretation of, aspects within the world that enable us to experience it as meaningful (Rennie, 1999). His ideas diverged from Husserl's focus on generating transcendental knowledge in accordance with descriptive phenomenological approaches. Instead, Heidegger's existential view of human nature led to an affiliation between phenomenology and hermeneutics (Moran, 2000). Thus, hermeneutic phenomenology was established.

Hermeneutics

Hermeneutics refers to the theory of interpretation (Finlay, 2009). Hermeneutic phenomenologists contend that interpretation is inevitable when acquiring knowledge and making sense of phenomena, due to the inability to evade presuppositions (Larkin, Watts & Clifton, 2006). IPA heavily resonates with hermeneutic phenomenology, as the approach strives to understand the texture and quality of human experience and recognises the influence of interpretation in this process (Smith & Osborn, 2015).

When developing his approach to hermeneutic phenomenology, Heidegger (1962) contended that the appearance of a phenomenon has a dual quality. He explained that appearances hold manifest (visible) and latent (concealed) meanings and suggested that it is possible for phenomenologists to explore the hidden concepts through an interpretative process, to better understand the significance that an experience has for an individual. Nevertheless, Heidegger identified that the presence of the interpreter's preconceptions, which he termed 'fore-structures', would influence this process and suggested that these assumptions should be 'bracketed' (Smith et al., 2009). However, this process could be hindered by a struggle to identify fore-structures when encountering new material. Placing precedence on new objects and engaging with this material instead of attending to presuppositions can enable the interpreter to overcome this challenge. Therefore, although this process of bracketing is used in IPA, Smith et al. (2009) contend that it can only be partially achieved due to the dynamic and complex nature of fore-structures.

In addition to Heidegger, IPA is also influenced by the work of Schleiermacher (1998) and Gadamer (1975) whose ideas contributed to the theory of hermeneutic phenomenology. Schleiermacher (1998) introduced grammatical and psychological interpretation as essential facets of the interpretative process. He suggested that attending to both of these aspects creates a more holistic understanding of the individual and the meaning of their experience. IPA embraces this perspective and acknowledges how we interpret and understand structures in the world through language. IPA researchers consider the meaning behind the claims that are made by an individual, including their emotional responses relating to an experience (Larkin, Watts & Clifton, 2006). Schleiermacher's approach to interpretation involves intuition on the interpreter's behalf as well as detailed, systematic engagement with the data. He believes that the interpretative analyst can provide further value if they are able to examine data in this manner and claimed that this could result in '*an understanding of the utterer better than he understands himself*' (Schleiermacher, 1998, p. 266). However, Gadamer (1990) was hesitant in concurring with this notion and argued that it is more important to understand the meaning of an individual's words than to understand the individual themselves.

Whilst Schleiermacher was concerned with what interpretation illuminates about an individual and their intent, Gadamer's contribution to hermeneutic phenomenology was focused on how structures and processes could be understood within a historical context (Eatough & Smith, 2017). Gadamer also echoed Heidegger's beliefs and acknowledged that it may not always be possible to identify preconceptions prior to engaging in interpretation. Instead, this awareness may develop after interpretation has begun, particularly when encountering new material. Nevertheless, Gadamer (1990) suggested that biases may be avoided during interpretation if a reflexive stance is achieved.

IPA researchers consider that interpretations enable us to understand our place in the world and the experiences that we have encountered (Eatough & Smith, 2017). Preconceptions and biases must be acknowledged when carrying out research. Through a reflexive process, the researcher becomes aware of how their own assumptions have influenced the research. Thus, a reflexive attitude suggested by Gadamer is embraced, which enables the data to '*present itself in all its otherness, and thus assert its own truth against one's own fore-understandings*' (Gadamer, 1990, p. 269).

IPA researchers play an active role when exploring the lived experience of a phenomenon, whereby a dual interpretation occurs. This is referred to as 'double-hermeneutics' (Smith & Osborn, 2003), and is a dynamic process which entails the researcher making sense of the participant's sense-making. In one respect, the researcher is akin to the participant as both human beings utilise everyday resources to create meaning within the world. However, the researcher differs from the participant as they have indirect access to the participant's experience which they approach from an experientially informed perspective. Therefore, the researcher's sense-making is considered to be second-order (Smith et al., 2009). Moreover, IPA adopts two interpretative standpoints which produce different types of knowledge: hermeneutics of empathy and hermeneutics of suspicion (Ricoeur, 1970). Empathic interpretation elucidates implicit meaning by attempting to get as close as possible to the participant's experience in order to develop a greater understanding of what presents itself in the text. Suspicious interpretation aims to access latent meaning by looking beyond the data, and often incorporating theoretical concepts to make sense of the participant's language. These two positions align with Heidegger's theory on appearances which have manifest and latent meanings. An essential facet of IPA is the researcher's responsibility to construct interpretations that are grounded in the participants accounts; therefore, a synthesis of empathic and suspicious interpretation is required to obtain rich and meaningful insights about an individual's experience (Willig, 2013).The researcher attempts to comprehend the experience from the participant's perspective as an 'insider' (Conrad, 1987), whilst also remaining curious by approaching the data from a different perspective and asking questions.

In addition, IPA requires the researcher to engage in an iterative and dynamic process where they must focus on both the individual parts of the participant's experience as well as the experience in its entirety. This immersion in the data is referred to as the 'hermeneutic circle' (Polkinghorne, 1983) and enables the researcher to obtain a more holistic view of the individual and their experience. The researcher is required to adopt an open, curious stance in order to interpret the data at different levels, which reveals striking and prominent aspects of experience (Smith et al., 2009). In IPA, the concept of double-hermeneutics and the hermeneutic circle are inter-related, as the researcher is aware of using preconceptions to make sense of the data whilst moving back and forth between self and other as well as parts and the whole of the text in order to acquire an understanding.

Idiography

As IPA is concerned with exploring how individuals make sense of an experience, it requires a deep level of interaction with the data which occurs through individual case-by-case analysis. IPA is therefore idiographic and focuses on convergences and divergences between the participants' experiences (Smith et al., 2009). This commitment to understand the particular indicates that the approach is not concerned with making assertions about a large population. In contrast, IPA seeks to understand how a particular experience is perceived by particular individuals within a specific context (Smith, Harré & van Langenhove, 1995). The approach refrains from making generalisations, although the focus on unique individual experience can enable the researcher to tentatively provide general claims which may contribute to the wider literature about the phenomenon. In addition, the researcher is able to make connections between their research findings and their professional and personal experience. Hence, IPA aligns with theoretical generalisability, rather than statistical generalisability (Smith & Osborn, 2015).

2.3.3 Rationale for IPA

IPA was considered to be the most suitable methodology in answering my research question for several reasons. Smith et al. (2009) suggest that it is useful when investigating the subjective experience of novel and multidimensional topics which are considered to be meaningful for a particular group of individuals. My research study seeks to capture and understand the experiences of second-generation British SAs who have experienced a sibling with a diagnosis of FEP. Using IPA will enable me to explore how this particular group of individuals make sense of this particular experience, by offering them a platform to voice their stories (Larkin, Watts & Clifton, 2006), which further aligns with my research aims.

Despite its '*epistemological openness*' (Larkin et al., 2006, p. 114), IPA was further deemed to be a suitable approach as it corresponds with my critical realist epistemology, due to recognition of both a lifeworld and the role of subjective interpretation in exploring human experience. It does not seek to provide an objectively accurate representation of a phenomenon or generate probabilistic findings in accordance with nomothetic approaches (Smith, 2004). In the present research study, I intend to explore the phenomenon of having a sibling with a FEP. Nevertheless, I do not strive to accurately access the core essence of this lived experience, as I do not believe this is possible. IPA does not claim to understand an experience in its entirety, as this is not attainable (Willig, 2013). Rather, IPA acknowledges that individuals experience the same objective reality in diverse ways.

IPA also acknowledges how the researcher's assumptions influence their understanding of the phenomenon. However, these preconceptions are not viewed as biases as they are inherent to understanding another individual's experience (Smith et al., 2009). Direct access to a participant's reality is unattainable in IPA as the exploration of experience is mediated by their own preconceptions as well as the researcher's interpretation. Hence, IPA views interpretation as necessary for acquiring knowledge and revealing insights into an individual's process of meaning-making (Smith et al., 2009). I felt this was pertinent when considering the choice of research methodology, particularly when distinguishing between descriptive and interpretative phenomenological approaches. As a British SA who has worked with individuals with psychosis, I believe that it is important to reflect upon my own presuppositions and biases in order to avoid overlooking significant and meaningful aspects of the participants' experiences. Acknowledging my own assumptions would allow me to look more deeply at the data to access hidden meanings. Moreover, the interpretative stance of the approach could generate unique insights into the participants' sense-making which they may have been unaware of themselves. Hence, the reflexive attitude which IPA researchers adopt was appealing to me.

Other qualitative approaches were considered for the present research study yet deemed to be unsuitable, due to an incongruence with my research aims and epistemological position. Discourse Analysis (DA) is a research methodology which focuses on the importance of language in mediating and constructing an individual's sense of reality (Starks & Trinidad, 2007). It is based on a relativist ontology and social constructivist epistemology, as it refutes the possibility of a single reality (Georgaca & Avdi, 2012), which differs from my own philosophical position. Functional and rhetorical components of speech are examined across accounts in this approach, in order to identify how individuals construct their experiences. Whilst DA and IPA acknowledge the importance of linguistic features in exploring phenomena, the approaches differ in their attitude towards the status of cognition (Potter & Wetherell, 1987). DA is influenced by aspects of social psychology and is dubious of reducing language to cognitive processes. In contrast, IPA attempts to understand the thoughts and emotions that an individual may experience about a phenomenon through their use of language (Eatough & Smith, 2008). These internal experiences and perhaps more hidden meanings are not explored in DA. IPA has been criticised for disregarding how individuals use language to construct themselves and others (Eatough & Smith, 2008). However, as this research study sought to explore the intricacies of subjective experience and meaning-making, rather than identifying linguistic or social processes, IPA was considered to be more appropriate than DA. Exclusively focusing on language creates a potential to overlook other important features of an individual's lived experience. This further enticed me to IPA, as the approach could enable me to capture the quality and nuances of the participants experience of having a sibling with a FEP, in a manner that DA could not.

A Grounded Theory (GT) approach was also considered for this research study, but it was deemed to be unsuitable for several reasons. GT was developed by Glaser and Strauss (1967) and emanates from symbolic interactionism. This approach aims to explain how meaning is constructed and seeks to develop theories that illuminate the social processes behind a given phenomenon. In contrast to IPA, participants' internal experiences tend to be overlooked in GT, which does not strive to explore personal meaning (Langdridge & Hagger-Johnson, 2009). Rather than exploring what something is like, GT questions how and why an experience (such as psychosis) occurs and attempts to develop explanatory models, which IPA is unable to do (McLeod, 2011). Moreover, GT attempts to create macro-level claims by observing data from an outsider's perspective (Charmaz, 1995). Hence, GT was not chosen for the present research study as it did not align with my aim of exploring the inner world of individuals who have experienced a sibling with a FEP. IPA was favoured due to its micro-level analysis of personal lived experience and detailed exploration of meaning-making. In addition, I believe that IPA was more suitable as its bottom-up approach to acquiring knowledge could still enhance or contribute towards the construction of macro-level claims. Thus, exploring the internal world of individuals who have had a sibling experience a FEP was deemed to be essential for acquiring understanding which could subsequently result in significant clinical implications.

2.3.4 Limitations of IPA

Willig (2013) contends that it is important to be mindful of the constraints of a chosen research methodology. IPA seeks to explore how individuals make sense of a lived experience which requires the researcher to rely on exploring reflective accounts. These are predominately drawn from interview transcripts or diary extracts. Acquiring knowledge of a phenomenon is therefore dependent upon what a participant shares which creates some concern around the credibility of language. Individuals may experience difficulties in communicating their experiences if they are unaccustomed to expressing their perceptions, thoughts and emotions. This has become a criticism of IPA, as researchers have claimed that the approach is only appropriate to individuals who are highly articulate. Willig (2013) contends that insight, resilience and competence are needed to generate suitable accounts for IPA research. However, my own view is that this predicament is not unique to IPA and applies to all qualitative methodological approaches. Within this research study, participants were able to communicate their experiences through descriptive words, metaphor and body language, and I was struck by their vivid and emotive descriptions.

Despite recognising that language is only one feature that represents human experience, phenomenologists have been further criticised for neglecting to acknowledge and evaluate the importance of its use (Langdridge & Hagger-Johnson, 2009). Human beings express and make sense of most of their experiences through language. IPA suggests that experience precedes language, which is then used to describe a phenomenon in different ways by different individuals. However, language does not accurately reflect reality as it is contingent upon factors such as an individual's socio-cultural context. Thus, IPA researchers must be culturally competent in order to understand the experiential words of their participants (Smith et al., 2009). Within this research study, I have attempted to demonstrate my own cultural awareness, for example, by illustrating my understanding of cultural perceptions and experiences of psychosis within the British SA community in the Literature Review.

A final critique of IPA concerns the role of cognition within phenomenology. It has been argued that cognition should not be explored within phenomenological research, which primarily attends to pre-reflective aspects of experience (Langdridge & Hagger-Johnson, 2009). However, IPA recognises cognition as being inextricably linked to the world, subscribing to Heidegger's notion of 'being-in-the-world' (Eatough & Smith, 2008). Therefore, the approach considers that cognitions can augment our understanding of an individual's meaning-making processes.

2.3.5 IPA and Counselling Psychology

Counselling Psychology places great importance on the complexities of human subjective experience which it strives to understand, rather than seeking to obtain a universal truth (Rafalin, 2010). As a therapist, I seek to understand the subjective psychological world of my clients by adhering to the core conditions of the person-centred approach whilst viewing them as the expert.

Research has always been integral to the field of Counselling Psychology and tends to subscribe to qualitative and idiographic approaches, due to an appreciation for individuality (Orlans & van Scoyoc, 2008). Mearns and McLeod (1984) recognise similarities which exist between therapists and phenomenological researchers, including a desire to explore and understand human experience, an appreciation of the values and beliefs of others, and a recognition of interpersonal factors. In addition, Willig (2008) acknowledges that CoP's and IPA researchers strive to see through another's eyes, which requires a reflexive attitude in both cases. This congruence between qualitative approaches and the narrative features of therapy is what attracted me to adopt this style of research inquiry.

My doctoral training experience has enabled me to recognise the profound impact of interpretation within the therapeutic encounter, which enhances understanding and meaning. Moreover, whilst adopting a stance of unknowing with my clients, I concede with Cooper's (2010) assertion that my own assumptions will enable me to acquire some form of knowledge and illuminate aspects of meaning with my clients. Therefore, my professional experience undoubtedly influenced the construction of the research aims in the present study and enticed me to adopt an interpretative phenomenological approach, as I felt it was coherent with the values and beliefs that I hold as a CoP.

2.4 Procedural Aspects

2.4.1 Sampling

As IPA research studies seek to explore an individual's subjective perspective of a phenomenon, it requires researchers to obtain rich data from participants, which is then analysed in great depth (Smith & Osborn, 2015). This can be time-consuming; hence, IPA studies tend to be comprised of fairly small and homogenous sample sizes of participants who experience the research question as meaningful (Smith & Shinebourne, 2012). However, the scope of homogeneity varies between research studies, depending on the particular phenomenon being explored.

Smith et al. (2009) contend that a sample size between four and ten participants is appropriate for a doctoral research study. This sample size enables each individual account to be analysed in great depth, adhering to the idiographic principles of IPA (Smith & Osborn, 2015), as convergences and divergences can be examined. On this basis, I felt that a sample size of six to eight participants was pragmatic for the present research study, although I eventually obtained six participants. As this sample size is relatively small, it is not representative of a population. However, IPA does not seek to acquire findings which are representative, irrespective of sample size. Instead, the research participants represent a perspective of a lived experience.

2.4.2 Participant Criteria

To achieve homogeneity in relation to participant experiences, it was important to first identify inclusion and exclusion criteria, which would facilitate the recruitment process. Determining these criteria required me to go back to research question and aims.

Firstly, it was concluded that individuals partaking in the research study must have identified with being a second-generation British SA, meaning that they must have either been born in, or moved to the United Kingdom before the age of 5. In addition, their cultural heritage must have originated from Bangladesh, India, Nepal, Pakistan or Sri Lanka.

The inclusion criteria also specified individuals who identified with having a brother or sister who had experienced a FEP and received a clinical diagnosis relating to a psychotic disorder. The sibling of the potential participant must have recovered from their FEP no less than one year ago, and no more than ten years ago. Initially, this range depicting the sibling's recovery from a FEP was between one and five years. However, due to some challenges in the recruitment process (which I describe in the following section), the time constraints were adapted. A lower limit of one year was selected in order to minimise the impact of distress for participants when describing their experiences. A maximum limit of ten years was selected due to my desire to obtain rich accounts of participants' experiences, which I believe is partly based on accuracy of memory of past events. As mentioned earlier within this chapter, recovery from FEP was based on the judgement of each potential participant, in accordance with Slade's (2009) definition of 'clinical recovery'.

In addition, participants were required to be at least 16 years of age when their sibling experienced a FEP, as it was deemed that the experience of this phenomenon would differ greatly for children (under 16 years of age). At the time of data collection, participants were required to be at least 21 years of age. This minimum age requirement was determined as previous research suggests that adults are more likely to provide coherent and reflective accounts of an experience involving a sibling relationship in comparison to adolescents (Scharf, Shulman & Avigad-Spitz, 2005).

Individuals who identified with having a complex or severe mental illness were also excluded from participating in the study in order to minimise the risk of distress and safeguard their wellbeing, due to the sensitive nature of the phenomenon being explored.

Furthermore, as this research study only sought to explore the participants' lived experiences of having a brother or sister with a FEP, understanding whether or not their siblings had experienced subsequent episodes of psychosis was not considered within the inclusion or exclusion criteria.

Ascertaining whether individuals met the inclusion criteria was completed via a screening telephone call which took place prior to conducting any research interviews. During this screening procedure, I asked questions relating to the inclusion and exclusion criteria which informed my decision regarding their participation. Due to the sensitive nature of the research topic, it was important to explore whether participants met the criteria by asking questions in a respectful and compassionate manner, whilst assuring that this encounter did not evolve into a research interview or therapeutic encounter. I also assessed risk, by exploring the individuals' current mental state and asking whether they had any mental health conditions. Assessing these criteria depended on my own personal and professional judgement.

2.4.3 Recruitment Strategy

Convenience sampling and purposive sampling strategies are considered to be the most conventional methods used to recruit participants in IPA research studies (Smith & Osborn, 2015). Convenience sampling was used in order to recruit one participant for a pilot interview and purposive sampling was subsequently carried out to obtain six participants for the research study.

A variety of organisations were approached through different communicative methods including telephone, email correspondence and face-to-face contact. Prior to disseminating a recruitment flyer (Appendix A), I ensured that consent had been obtained from these establishments, which were located in many regions across the UK. Examples of these organisations included various MIND and Rethink Mental Illness services. These establishments were deemed appropriate to contact as they offered support to family members of individuals with psychosis. Additional organisations offering other support services such as personal therapy for individuals in the SA community were contacted. Appendix B outlines a complete list of services approached.

Many organisations were forthcoming in sharing information about my research study and disseminated my recruitment flyer by advertising across their services and social media platforms. One organisation invited me to attend a support group for individuals who had a sibling with psychosis to discuss the purpose of my research. I agreed to attend once the group session had ended in order to respect the confidentiality of the group members. Discussing the purpose of my research felt like a daunting process due to my position as an ‘outsider’ (see Reflexivity section), which left me wondering how forthcoming individuals would be. However, positive feedback was obtained from the group members who suggested that the research felt valuable. Nevertheless, they did not meet the inclusion criteria as none of the individuals identified as British SA.

Social media platforms were also used to advertise my recruitment flyer. These internet-based applications are advantageous as they enable researchers to connect with a larger population of individuals who may otherwise be difficult to access (Gelinas et al., 2017).

Mental health services providing supported accommodation to individuals with psychosis were also contacted, including a service which I had previously worked within. These organisations agreed to display my recruitment flyer across their services and advertise within their newsletters.

Finally, I circulated my research flyer amongst friends and family members within my own cultural community, who subsequently utilised their own personal and professional social networks to share information regarding my research.

Individuals had the opportunity to respond to the recruitment flyer by contacting me or my supervisor via email if they were interested in partaking or wanted to receive further information. As a show of gratitude, individuals were informed that they would receive a £10 voucher for participating in the research study. This was stated on the recruitment flyer (Appendix A). The value of this incentive was decided upon due to the rigorous and time-consuming nature of the data collection method – a research interview. I believe that the amount was sufficient to remunerate individuals who invested their time to participate.

I anticipated that I could encounter some challenges when recruiting participants. As mentioned in the Literature Review, psychosis can be viewed negatively within SA communities (Kishore et al., 2011), which can result in a reluctance to access mental health support services (Mirza et al., 2019). My own affiliation with the British SA community also engendered feelings of apprehension in individuals' willingness to participate, as I was aware of a taboo of mental distress within the culture. Acquiring participants did appear to be an initial difficulty, as there was a lack of responses, which left me feeling despondent. After discussing this in supervision, it was determined that this challenge could be managed by widening the inclusion criteria. Thus, the range depicting a sibling's recovery from a FEP was changed from 1-5 years to 1-10 years in order to broaden the target population. This resulted in a higher response rate from individuals wishing to partake in the research.

Nine individuals expressed a wish to participate in the study and of these, six met the inclusion criteria. Utilising my own personal network was valuable as three participants were recruited through this approach, although I did not personally know these individuals. My own identity as a British SA therefore felt advantageous in gaining access to individuals within the cultural community who had experienced a sibling with FEP. Two other participants were recruited after responding to my recruitment flyer placed in a mental health support service at which I had previously worked. The final participant was selected through Helpfulpeeps, a social media platform.

2.4.4 Data Collection – Semi-structured Interviews

Smith and Osborn (2003) contend that semi-structured interviews are considered to be the most suitable and popular method of data collection for IPA studies. Marks and Yardley (2004) suggest that it is possible to also obtain rich and meaningful data through analysing diaries and conducting focus groups; however, a one-to-one semi-structured interview was deemed to be more appropriate for my research, due to the flexibility that it provides a researcher to probe into particular areas of interest that may arise, as well as any ambiguities in the participants' accounts (Kvale & Brinkmann, 2009). Moreover, engaging in a conversation with the participants in real time generates rich accounts containing novel insights into the phenomenon being explored. I chose to conduct one-off interviews for each participant due to the prospect of generating detailed coherent accounts whilst retaining a simplistic design (Flowers, 2008).

Conducting semi-structured interviews enabled me to facilitate rather than dictate the interview process, as the use of open-ended questions allowed a more natural dialogue to emerge (Marks & Yardley, 2004). Finding the right balance between facilitating and being led is essential to acquiring high-quality data (Willig, 2013). The participants were able to take the lead and were considered to be the expert in telling their story, which enabled them to feel heard.

Hart and Crawford-Wright (1999) explain that the usefulness of a research method is partly contingent upon the researcher's ability to facilitate participant disclosure relating to the phenomenon being explored. This requires a positive alliance between researcher and participant. Semi-structured interviews are considered to be advantageous in phenomenological research as the intersubjectivity enables a rapport to be established (Kvale & Brinkmann, 2009). This collaborative process is similar to that which is observed in a therapeutic setting between client and therapist, where the therapist is often required to facilitate the session whilst promoting the client's agency. I believe my role as a CoP equipped me with the skills necessary to conduct a research interview and develop a rapport with the participants. The practical skills of therapists are favourable when conducting a research interview, as there is an understanding of the importance of trust, empathy and active listening in facilitating disclosure (Haverkamp, 2005).

Nevertheless, ethical issues pervade research that uses interviews. I was conscious that I should not step into the role of being a therapist, although Hart and Crawford-Wright (1999) acknowledge that this can sometimes be difficult. The nature of the research study meant that there was potential for participants to become highly emotive during the interview. Therefore, it was important to consider ways of managing distress should this arise. In addition, the research interview is a professional dialogue which consists of an asymmetrical power dynamic. The researcher has a responsibility to guide the conversation according to their research aims and has ownership of subsequent interpretations (Kvale & Brinkmann, 2009). I reflect on these dilemmas further and discuss how they were played out and managed within the Ethical Considerations section of this chapter.

2.4.5 The Interview Schedule

As Smith and Osborn (2003) suggest, I developed an interview schedule prior to the research interviews taking place, as this enabled me to consider potential difficulties that could have been encountered. I devised an interview schedule (Appendix C) following the guidelines outlined by Smith et al. (2009). This schedule adopted a semi-structured interview format as it contained a brief set of questions along with prompts which could be used to explore the phenomenon. Smith and Osborn (2003) suggest that the questions from the schedule do not need to be adhered to in terms of their ordering. However, they advocate that the interview schedule should be memorised prior to the interview taking place. This flexibility enabled me to remain curious, attentive and attuned to what the participants were sharing, whilst ensuring that I did not lose track of the research aims.

I began each interview with a broad question relating to the participants' understanding of psychosis, before asking more detailed questions that aimed to elicit their thoughts and feelings to capture their meaning-making. Smith et al. (2009) advise that the opening questions of an interview schedule should be descriptive in order to reduce potential anxieties and enable participants to feel at ease with talking. Starting with a more generic question enables the parameters of the interview to be set by the participant (Hefferon & Gil-Rodriguez, 2011). Following on from this, more structural and evaluative questions were asked to encourage reflection and deeper exploration of the phenomenon in question (Spradley, 1979).

In accordance with Smith (1995), I intended to use open questions and avoided any jargon. In addition, I ensured that there was no value-laden terminology, although this was initially a challenge due to my knowledge from the existing literature, my professional experience as a trainee CoP and my identity as a British SA. For example, avoiding questions such as the following was important: 'Did you experience yourself becoming critical or overprotective towards your brother/sister and if so, how did you manage this?'. Questions such as these relate to my knowledge of Expressed Emotion, which has been identified in literature conducted on British SA family members of individuals diagnosed with psychosis (Bhugra & McKenzie, 2003).

Discussing my interview schedule with my supervisor enabled me to reframe particular questions in a way that adhered to my epistemological framework and research methodology. For example, I acknowledged the influence of the participants' socio-cultural context in relation to the phenomenon by asking questions in an open and sensitive manner: 'How did you experience reactions from others in your cultural community towards yourself?'

To conclude each interview, participants were asked if they had any further reflections or comments that they felt were relevant to the research. McLeod (2015) suggests that this invitation to the participant is valuable in recognising the credibility of information and the significance of the interview for the participant.

2.4.6 Pilot Study

Prior to conducting the research interviews, I conducted a pilot study to examine whether the interview schedule met the requirements for an interpretative phenomenological research study. This interview was completed with a female colleague who offered to provide honest and frank feedback about how they experienced the interview process. Feedback was obtained on different aspects of the interview including the use of language, appropriateness of questions and ease of engagement. Moreover, the pilot study enabled me to evaluate whether I had been able to obtain rich meaningful data about the phenomenon in question within a suitable timeframe. McLeod (2015) contends that reflecting on whether the data generated from a pilot interview corresponds with the researcher’s aims is imperative.

Smith and Osborn (2003) suggest that a pilot study may be conducted on an individual who may not exclusively fit the inclusion criteria but who should have some connection with the phenomenon in question; therefore, I agreed to interview my colleague as she had experienced a sibling with a FEP but did not identify as a British SA. Hence, all of the questions on the interview schedule were applicable to her, including those exploring the responses of those in the cultural community, as there was no specific reference to the SA culture. However, her data was not analysed as part of the full-scale research study.

The pilot interview was conducted in the same manner as the subsequent research interviews (see below), as written information about the research was provided, consent was obtained and a debrief process took place once the interview had ended. The pilot interview was conducted in a private room at City, University of London and lasted just under 90 minutes.

The feedback was positive as my colleague reported that it was an enlightening experience, stating that the manner in which questions were asked made it easier to tell her story in a coherent, meaningful and holistic way. She reported feeling comfortable with sharing her experiences throughout the interview, although wondered whether subsequent participants would be as forthcoming in their responses if they tended to be more reserved. After reviewing this feedback with my supervisor, the interview schedule was modified slightly with more prompt questions added, to ensure that I could achieve the same depth of data reflecting the participants' experiences.

I had not entirely memorised the interview schedule for the pilot interview and therefore returned to it at multiple points to identify which questions had not been asked. This enabled me to recognise the value of learning the questions in advance in order to create a more natural dialogue and prevent the participant from becoming distracted. Smith et al. (2009) suggest that memorising the schedule also enables the researcher to more easily bracket their theoretical assumptions and preconceptions so that they can focus closely on the participants' words and illuminate particular aspects of experience.

2.4.7 Conducting Interviews

The full-scale research study was conducted after the pilot interview. As previously mentioned, nine individuals contacted me to express an interest to participate. Through email correspondence, these individuals were subsequently invited to partake in a screening telephone call which was arranged according to a time which suited them. Six individuals met the inclusion criteria and were subsequently emailed a Participant Information Sheet ([PIS]; Appendix D) which outlined further information about the nature and purpose of the research. I agreed to call them seven days after sending this information to ascertain whether they still wanted to participate or withdraw from the research study, as this felt like ample time. All six individuals agreed to participate during the second telephone interaction and were subsequently invited to attend a research interview. The location, date and time of the interview was primarily determined by the participant in order to suit their needs, and confirmation of these details was emailed to them. Marks and Yardley (2004) advise that it may be more beneficial to conduct interviews in the participant's home as this environment is familiar and comfortable and can aid the interview process. However, a Lone Working Risk Assessment (Appendix E) was first carried out in order to consider the safety and suitability of the environment for both parties.

Five interviews took place in the participant's own home, whilst one interview was conducted in a mental health support service providing accommodation in which the participant's sibling was residing. This was a service within which I had previously worked, although the participant and their sibling were not known to me. A private and quiet room had been booked for the interview and I had pre-arranged this with staff members in the service.

Prior to the research interviews commencing, participants were given a hardcopy of the PIS along with a Consent Form (Appendix F), which they were required to sign if agreeing to partake in the study. They were then given the opportunity to ask any questions about the research and informed of their right to withdraw. The consent form acknowledged that the interview would be digitally audio-recorded using a Dictaphone, in addition to other procedures involving data protection, confidentiality and research publication.

Once written consent was obtained, the Dictaphone was switched on with the participant's permission. I then provided a brief introduction in which I repeated the aims of the research study, reminding the participants that I was interested in understanding their lived experience and that there were no right or wrong answers to questions. I informed the participants that they could take a break at any point or terminate the interview. I then continued by asking the opening question from the interview schedule (Appendix C).

Throughout the interviews, I continually remained aware of the key skills outlined by Marks and Yardley (2004) that are required to elicit data, including listening, eye contact, pacing and asking clarifying questions. As these skills are also key to Counselling Psychology practice, I felt more confident in using them across all the research interviews to allow an exploration of thoughts, emotions and meaning to emerge. The interview process initially felt somewhat unnatural as I attempted to establish a rapport and obtain a large amount of information in just one encounter, which differs greatly from the process of therapy. Nonetheless, gathering data within one sitting also felt achievable, as the presence of an interview schedule enabled me to guide the discussion in a manner which elicited rich and meaningful insights into the participants' sense-making.

Interviews lasted between 60 and 90 minutes, which corresponded with the timeframes that Smith and Osborn (2003) suggest for IPA researchers. I believe that the participants felt comfortable through the interview process in openly sharing their experiences as they offered rich descriptions in response to my questions. I also wondered whether they perceived me as a trusted professional with whom they could connect, due to my cultural identity. One participant even used the phrase *'oh you know how it is'* when reflecting on the impact of how others in the cultural community responded towards him.

Once the interviews ended, participants received a Debrief Information Sheet (Appendix G) which outlined a summary of the research and a list of contact details for a variety of support services, should they have felt the need to access them. They were also given the opportunity to ask further questions, although most participants instead shared further reflections. I explore these responses further within the Discussion chapter. Participants were also emailed the £10 voucher on the day following their interview.

2.4.8 Transcription

Prior to analysing the data, each audio recording was first transcribed verbatim, as recommended with IPA guidelines. When transcribing, I included non-verbal communication, fragmented speech and phonic utterances in order to develop a script which reflected the participant's experiences of meaning-making as accurately as possible. Although Smith et al. (2009) suggest that these prosodic features are not necessary due to the goal of interpreting meaning, they were nevertheless included as I deemed them important to enable a psychological and linguistic analysis to be conducted. In addition, Kvale and Brinkmann (2009) suggest that transcription is a form of interpretation, hence the researcher should aim to explicitly report what is heard from the recordings. Whilst this was time-consuming and demanding, it enabled me to become immersed in the data, which complemented the analytic process.

2.4.9 Analytic Strategy

Transcriptions were analysed using IPA guidelines outlined by Smith and colleagues (2009). In accordance with my epistemological framework, this analysis was selected in order to explore how participants make sense of their individual experiences, rather than trying to discover one real truth.

Each transcript was studied individually in accordance with the idiographic principles of IPA. The first step of analysis involved familiarising myself with the data by reading and re-reading a transcript several times, as well as listening to the audio recording alongside this. The reason for this immersion in the data is that each encounter with the text may reveal new insights (Smith & Osborn, 2003). Moreover, hearing the participant's voice is favourable for the researcher when completing the subsequent stages of analysis (Smith et al., 2009).

I was apprehensive about analysing the data and doing justice to my participants' narratives by illuminating their lived experiences and meaning-making as congruently as possible. I also felt overwhelmed by the voluminous data and the many ideas that I had already formed from noticing potential connections. After listening to the first audio recording and reading the transcript, I ensured that I bracketed my observations and preconceptions and wrote my thoughts, feelings, perceptions and additional curiosities in my reflexive journal. For example, I noted feelings of confusion from observing the participants' reluctance to support their sibling when they became unwell.

Following this familiarisation with the text, the next stage of analysis required engaging with the transcript line-by-line and identifying descriptive, linguistic and conceptual statements. As explained by Smith et al. (2009), descriptive comments refer to keywords and phrases stated by the participant which demonstrate the structures that contribute to their experience; linguistic comments refer to the way in which verbal and non-verbal language is meaningfully presented to represent content and meaning; and conceptual comments consist of more abstract interpretative statements which are interrogative of the data. My own personal and professional knowledge inevitably influenced the interpretations that were generated to form conceptual comments. However, it was important to ensure that these comments remained rooted in the participant's account. A comprehensive set of comments were made in the right-hand column of a word document in which the transcript was presented. An example of this can be observed in Appendix H. Descriptive comments were typed in blue, linguistic comments in green and conceptual comments in red. Certain keywords and phrases were also de-contextualised during this stage, and these comments were typed in purple. De-contextualisation is a process in which the researcher endeavours to get closer to the participant's words and attend to context which illuminates connections between their processes of meaning-making. These comments are often obtained by reading a line in reverse or exploring unique units of language. Overall, this stage of the analysis was labour intensive, although it enabled me to develop a greater sense of familiarity with the data. It was helpful to often remind myself of Smith et al.'s (2009) explanation that a researcher does not need to follow a strict set of guidelines to generate comments on the data, nor do they need to comment on each unit or segment of text.

At times, I found myself viewing the data through the lens of a CoP who has worked in a secondary care psychosis service, particularly when my participants spoke of their experiences of obtaining professional help for their siblings. In addition, I also found myself perceiving the data through the lens of a British SA and was aware of my own assumptions relating to the stigma and taboo of mental illness within the cultural community when the participants discussed their experience of judgement from others. These sections of the transcript enriched the data but also precipitated obstacles due to my strong emotional responses. I was aware that these judgements and reactions could skew the analytic process, hence, in order to remain attentive to the data, I continued to make use of my reflexive journal by noting down my internal experiences.

The next stage of analysis was an iterative process that required developing emergent themes. This tentatively balanced my own psychological interpretation with the participant's description to capture concise and meaningful phrases representing their lived experience.

This demonstrated engagement in the hermeneutic circle, whereby the whole (themes) could be identified by the parts (the transcript extracts), and the parts being defined by the whole. Emergent themes were constructed where relevant throughout the entire transcript and written in the left-hand column. An example of this can be observed in Appendix H.

I experienced this stage of analysis as challenging and felt uncertain about my ability to represent my participants' experiential realities by appropriately balancing description with interpretation. I questioned whether I was actually giving my participant a voice and shedding light on their lived experience, or whether I had simply been presenting my own interpretations, which initially raised ethical dilemmas relating to power and ownership of research. I found it helpful to constantly return to the transcript and question how the experience was for the participant, what they had been communicating, and what sense they made, whilst reminding myself of the impossibility of accurately representing their reality. In addition, continually acknowledging my research question and discussing a tentative list of themes with my supervisor was valuable. Subsequently, I went back to the data and modified my themes by attempting to balance 'hermeneutics of empathy' with 'hermeneutics of suspicion' (Ricoeur, 1970) to capture both the participants' language and the psychological essence of the text.

The following stage involved exploring whether there were any connections among the emergent themes. This included a process of organising themes into clusters to display overarching patterns across the transcript. I completed this stage electronically. A variety of techniques suggested by Smith et al. (2009) were used to search for these connections, including abstraction (placing corresponding themes together), subsumption (where an emergent theme was elevated to become a higher-level theme), numeration (forming a cluster based on the frequency of emergent themes) and polarisation (focusing on divergences by combining oppositional emergent themes). This stage of the analysis involved an iterative process where I referred back to the transcript to see whether the clusters of themes were meaningfully representative of the data. During this process, some emergent themes were discarded as it was decided that this would not influence the representation of the participant's meaning-making. An example of the theme clusters, their corresponding emergent themes and discarded themes for one participant can be observed in Appendix I.

The stages above were repeated for each individual transcript, generating six tables of theme clusters representing the lived experiences of each participant. Smith et al. (2009) contend that it is important to acknowledge each transcript individually in order to uphold their individuality by bracketing reflections after analysing each account. Nevertheless, as Heidegger (1962) implied, the researcher's understanding is influenced after reading each transcript, thus changing their fore-structures.

The final process of analysis involved searching for convergence and divergence across the individual cases in order to construct a master table depicting superordinate themes consisting of higher-order concepts. The cluster themes from all six transcripts were first handwritten onto a piece of paper (along with their underlying emergent themes), cut up, placed on the floor and arranged spatially. I then searched for similarities and distinctions and examined the themes in relation to one another to form groupings. Although recognising the frequency of themes can enhance credibility of findings (Smith et al., 2009), it was not the only method used to form superordinate themes, as I also used techniques of abstraction, subsumption and polarisation. As with the previous stages, I continued to refer back to the original transcripts to ensure that the superordinate themes were grounded in the participants' narratives. As I immersed myself in this process, I was left feeling surprised as I developed new unexpected insights into the data, such as the theme 'Seeing the sibling', which appeared to be a significant and novel experience. Appendix J depicts an initial table of all the cluster themes generated for each participant, whilst Appendix K shows a more finalised table of superordinate themes with subordinate themes (sub-themes) to demonstrate how the cluster themes were reconfigured and relabelled.

2.5 Ethical Considerations

Research ethics are defined as the moral principles that influence and guide scientific inquiry (Thompson & Russo, 2012). This research study was granted ethical approval from two academic staff members within the Psychology Department Ethics Committee at City, University of London. The research adhered to the guidelines within the British Psychological Society (BPS) Code of Human Research (2014), and relevant measures were put in place to address potential ethical implications.

To avoid any deception, participants were made aware through the PIS (Appendix D) of the nature and rationale of the research, in addition to what would be expected of them in the interview. The PIS explained their right to withdraw from the research study without offering any reason, which I hoped would reduce potential power differentials in the researcher-participant relationship. Participants could withdraw at any point up until the data analysis stage. The PIS also indicated that participants could abstain from disclosing any personal information or answering any questions should they wish to. Moreover, the PIS stated that participants would receive a £10 voucher after the interview had been completed. If they chose to subsequently withdraw, it would have no impact on this incentive.

Informed consent is an essential requirement prior to participation in any research study (Haverkamp, 2005). Written consent was therefore required from all participants prior to conducting the research interviews, although they were also verbally asked whether they would like to participate.

Furthermore, participants received a Debrief Information Sheet (Appendix G) at the end of the interview when a thorough debrief session took place in which participants were invited to provide feedback and ask any questions. I also explored whether they had experienced any unanticipated emotional responses in order to minimise potential distress once the interview had ended.

Due to the sensitive nature of the research topic and the exploratory method of data collection, there was a possibility for participants to experience psychological distress and become highly emotive in the interviews. Therefore, a Distress Protocol (Appendix L) was created so that I had a clear understanding of the actions that were required should participants become distressed. I intended to remain attentive to their verbal and non-verbal responses throughout the interviews as well as being mindful of the appropriateness of my own questions and responses, ensuring that I was not overly intrusive. My professional experience and psychological knowledge enabled me to better assess for signs of distress. The measures from the Distress Protocol were also put in place to prevent the interaction evolving into a therapeutic encounter. Nevertheless, across all six interviews, participants did not appear to display any psychological distress, although some noted feelings of sadness at the end of the interview due the all-encompassing nature of the questions, which prompted them to explore all aspects of the lived experience, including memories they had attempted to avoid. At the same time, they reported that the interview process was cathartic and reflected on feelings of hope for the future, which connects with one of the superordinate themes that emerged. Their responses reminded me of a key dilemma that exists within qualitative research, which requires individuals to reflect on highly emotive experiences in order to acquire knowledge of their experiential realities.

Principles of confidentiality and anonymity were also followed in relation to the BPS (2014) ethical guidelines. I attempted to ensure that screening telephone calls took place when both parties were in a private environment so that personal information could be discussed. Furthermore, any electronic data including audio recordings and interview transcripts were stored on password-protected computer files and encrypted hard drives. During the process of transcription, personal information such as names and addresses were all replaced with de-identifiable codes or pseudonyms, in order to further preserve anonymity. Paper documents were also stored in a locked filling cabinet within my home and will be archived for 10 years in accordance with statutory requirements. Participants were also informed of the limits of confidentiality, including the need to breach confidentiality and approach relevant services in the event of any risk of harm to the researcher, participant or others in the community. This was discussed verbally as well as written on the PIS. However, no risk emerged across all six interviews.

As previously mentioned, five interviews were conducted in the participant’s home and therefore, to ensure safety of both parties, a Lone Working Risk Assessment was first conducted in order to establish the relevant actions that needed to be followed. A full list of control measures can be observed in Appendix E.

Kvale and Brinkmann (2017) explain that whilst it is important to acknowledge potential ethical issues that arise throughout the research process – which they refer to as ‘micro ethics’ – researchers should also consider the impact of a research study within the wider community, which they define as ‘macro ethics’. This will be explored within the Discussion chapter.

2.6 Dissemination

The PIS (Appendix D) explained that participants could request a summary of the findings once the doctoral thesis had been written up. To request this summary, they were required to sign an additional section of the Consent Form (Appendix F) and provide their preferred email address. In addition, the PIS informed participants that they would also have access to the full doctoral thesis upon completion via City, University of London’s website.

I decided that I would not share the findings of my analysis with the participants prior to writing up the results of the thesis. Willig (2013) explores the concept of participant validation in qualitative research, although suggests that this creates a challenge for critical realists. Participant validation refers to involving the participants in the analysis process by showing them the findings to obtain their perspective, prior to writing the entire research study. A critical realist position would take the view that individuals may be unaware of the existence of latent aspects of meaning-making. Therefore, participant validation was not conducted as it was deemed to be incongruent with my epistemological position and methodology.

Two participants expressed an interest in receiving a summary of the findings, hence a document (Appendix M) has been created which I intend to email to them. This document could also be disseminated across services supporting individuals with psychosis, such as community mental health teams.

2.7 Reflexivity

Reflexivity is defined as a process of conscious self-awareness about how our values, judgements, beliefs and practices can influence our research. From a critical realist perspective, it is important for a researcher to engage in self-reflection as they cannot conduct a research study holding a neutral perspective. To maintain an introspective stance, I frequently wrote in a reflexive journal throughout each stage of the research process, where I examined my assumptions, experiences, motivations, beliefs, hopes and fears. As a CoP, engaging in reflection is something which I often do, hence, continuing this as a researcher felt attainable. I share some of my insights in section 2.7.1 below.

Researchers often consider three types of reflexivity when engaging in a research study. Methodological reflexivity refers to the researcher's self-awareness of their process of conducting a research study (Kasket, 2013). Willig (2013) acknowledges two other forms of reflexivity – epistemological reflexivity and personal reflexivity. The former refers to a process of reflecting upon one's perspective of the world and one's assumptions of acquiring knowledge. The researcher considers how these assumptions may influence the research process, including the outcomes. The latter refers to the way in which a researcher's beliefs, values, interests, experiences and social identity influence how a research study is shaped and how the researcher is subsequently changed by the findings. Therefore, reflexivity enables a researcher to explore personal and intersubjective processes which, as Finlay (2002) contends, contributes to the integrity of the research study.

Throughout this chapter, I have attempted to demonstrate both epistemological and methodological reflexivity. Hence, this final part of the chapter will focus on my personal reflexivity.

2.7.1 Personal Reflexivity

Kasket (2013) suggests that CoPs develop an awareness of research needs through their prior experiences. I have come to realise that various experiences I have encountered throughout my life, along with parts of my identity, have influenced my motivations for conducting this research study.

Firstly, I identify myself as a second-generation British SA, like my research participants. Growing up, I became aware that mental illness is conceptualised very differently between the two cultures that I am affiliated with. Within my own family, mental illness was rarely, if ever, spoken of, although when it was, there appeared to be great stigma attached to it as it was viewed negatively, particularly with members of the older generation. However, I have also been exposed to a very different perspective on mental health through the British culture in which mental illness is discussed more openly and viewed through a medical or psychological lens. My sensitivity to the differences between Western and Asian cultural norms has often left me feeling conflicted with my own position. I often find myself holding beliefs that align with a more Westernised understanding of mental health, although I believe that my awareness and experience of the differing perspectives has ultimately contributed to a curiosity about the human mind and how people make sense of it. This was one of my motivations for both becoming a CoP and conducting the present research study.

I believe that my interest in exploring psychosis within the British SA community stemmed from my previous experience of working with individuals with psychosis in different healthcare settings. After working withing a supported housing setting for individuals with psychosis and complex needs, I noticed that there appeared to be minimal engagement with or support for the families of service users, who were often overlooked. I witnessed the struggles that families encountered, particularly those within the SA population, who found it difficult to leave their relative in the care of others for an extended time period, as this felt unnatural. When some service users became increasingly unwell, I often wondered how it was for their family members, as they were rarely asked, yet very much present and would frequently visit their loved one.

During my doctoral training, I was on a clinical placement in a secondary care psychosis service within a community largely comprised of an ethnic minority population. At this service, I implemented both individual and family interventions, which provided me with a greater insight into the recovery process for family members of individuals who experience psychosis. I was surrounded by discourses relating to the importance of attending to the needs of relatives as well as the individual with psychosis in order to promote personal recovery. For example, I witnessed the value of family psychoeducation. These professional experiences further inspired me to conduct the present research study and explore what it was like for the siblings of an individual experiencing psychosis.

Being a British SA, I felt responsible for giving a voice to individuals within my cultural community who I felt were largely underrepresented due to being a minority. I felt passionate about raising awareness of their experiences of having a sibling with a FEP and I believe that this could better inform my own practice when working with this population in a therapeutic setting. Moreover, I felt that my ethnicity was advantageous as it enabled me to obtain a sample of participants from a hard-to-reach population due to my ‘insider’ status as a British SA. Dwyer and Buckle (2009) explain that insider research is where a researcher belongs to the population of research participants that they are investigating, due to shared language, identity or experience. This familiarity may enable participants to feel more comfortable in sharing their lived experiences, therefore strengthening rapport between research and participant and resulting in rich, meaningful data (Moore, 2015). However, becoming over-familiar with a group due to insider status has some limitations. Participants may describe their experiences in less detail if they assume that the researcher has similarities to themselves (Dwyer & Buckle, 2009). In addition, there is the potential for the researcher to be less objective when attempting to approach the data through the lens of the participant. This can result in the research being shaped by the researcher’s assumptions rather than the participant’s experiences. To maintain a stance of curiosity, it was important to recognise my prior assumptions, psychological knowledge and responses to the data through a process of bracketing. Although I identity as a British SA, I recognised my ‘outsider’ status as I do not have a sibling who has experienced psychosis. This further enabled me to remain as open and inquisitive as possible throughout the research process.

Prior to conducting my research, I anticipated that I would obtain data reflecting feelings of anger and shame due to the struggles in supporting a sibling with psychosis. I assumed that the participants would have encountered judgements from others in the SA community including extended family members. Throughout the data collection and analysis stages, I experienced an array of emotions. I felt both disheartened to hear that the participants felt let down by healthcare services, and also angry as they reflected on the responses of others in the SA community. At the same time, I was also in awe of their ability to flout their cultural norms in order to support their sibling and experienced them as resilient. I believe that I have been changed from the findings in my research and I intend to reflect on this further within the Discussion chapter.

2.8 The Research Participants

Before presenting my analysis, I shall first introduce the six participants. Table 1 presents the participants’ pseudonyms along with their age ranges at the time of the research interview and at the time when their sibling experienced a FEP. Half of the participant group identified as male and the other half identified as female. Three participants were British Pakistani, two were British Indian and one was British Bangladeshi.

Table 1: Participant Demographics

Participant Pseudonym	Participant Gender (M/F)	Participant Age Range during research interview	Participant Age Range at the time of sibling's FEP
Aisha	F	20-25	20-25
Sara	F	35-40	25-30
Akshay	M	30-35	25-30
Yusuf	M	20-25	20-25
Sonia	F	25-30	20-25
Vikash	M	35-40	25-30

Analysis

3.1 Overview

In this chapter, I have endeavoured to thoughtfully illuminate the experiential content of my participants' narratives. Following a comprehensive analysis of transcripts both individually and collectively, an abundance of rich data was obtained; however, it is impossible to discuss the entirety of the material within this chapter. Thus, careful consideration was taken to prune the data by selecting a number of interconnecting themes that reflect on the core experiences pertinent to the research question. The themes I have discussed in this analysis chapter aim to provide a glimpse into the intricacy of the participants' experiences of having a sibling with a FEP.

I have attempted to uphold integrity by reflecting on the perceptual content of each individual experience along with the associations between them, in order to provide a voice for every participant within the group. To further demonstrate this, a selection of extracts from the participants' transcripts has been used to illustrate the themes being discussed. This has enabled me to stay grounded in the data and provides a greater insight into the phenomenon being explored.

The quotations used in this analysis chapter reflect un-edited extracts from the interview transcripts, which, as previously stated, have been transcribed verbatim. The quotations are all followed by the participants' pseudonym and the page number and line number(s) from that transcript, respectively (e.g., *Aisha, 11, 259-260*). Pauses in the text due to silences or breaks in speech are depicted by an ellipsis: … whilst text that has been omitted is reflected by parenthesis: [ ]. Non-verbal gestures are shown in brackets: ( ) and words which were accentuated by participants have been rendered in bold.

When composing themes, I sought to manage the tension between the participants' processes of meaning-making and my own interpretations of their lived experiences, which, as previously mentioned, is referred to as 'double hermeneutics' in IPA research (Smith & Osborn, 2003). Hence, the themes are encapsulated by meaningful phrases that largely comprise of the participants' language, to capture their experiential realities, along with some psychological terminology. This reflects a co-construction of meaning-making between the participant and researcher (Smith et al., 2009) and highlights the complex interconnected nature of understanding phenomena in the lifeworld. A decision was made to omit theoretical literature within this chapter in order to stay grounded in the participants' accounts and as close to their lived experiences as possible. Instead, the Discussion chapter will strive to examine the relationship between the analytical material and the existing research literature.

The analysis is depicted by three superordinate themes which follow a chronological account of the participants' journeys. This narrative stance adheres to the philosophical position of IPA, as Smith et al. (2009) denote that the development of a narrative reflects a manner in which meaning is constructed. The overarching superordinate themes reflect compelling and meaningful facets of the participants' lived experiences but are not mutually exclusive; connections within and between them will be discussed within this chapter. These constituent themes further consist of sub-themes to reflect the range of different experiences related to the research question; however, the sub-themes are not all applicable to the entirety of the participant group. Table 2 depicts the superordinate themes and their respective sub-themes, whilst a visual diagrammatic representation of the inter-relations between themes can be seen in Figure 1.

Table 2: Superordinate themes and subordinate themes.

An Emotional Storm: conflicting feelings leading to a sense of overwhelm	**Avoidance vs. Approach**	***'It's shown me who I am'*: awareness of growth and transformation**
Feeling overwhelmed in response to the sibling's changing identity	*'A case of ostrich syndrome'*	
'What do I ***do***?': An internal conflict	Going *'against the grain'*	
'You can lead the horse to water but you can't make it drink': feeling helpless	Sharing experiences for validation and affiliation	
Frustration towards family members and the wider South Asian community due to a conflict in values	Separation for self-preservation	
'It's sad but it's a blessing': ambivalence towards the sibling's treatment	Seeing the sibling	

As illustrated in Table 2 (above) the final superordinate theme does not contain any sub-themes, as there were few cluster themes that were collated across the six participant transcripts (see in Appendix K). Hence, they were instead grouped into a higher order superordinate theme.

Figure 1 (below) demonstrates the relationship between the three overarching themes. ‘An Emotional Storm’ describes how the participants made sense of their experience of having a sibling with FEP and focuses largely on their affective responses, whilst ‘Avoidance vs. Approach’ explores how they coped. Conversely, the third superordinate theme refers to a process of personal development and psychological growth which has arisen as a result of their lived experience. Hence, this theme inextricably linked with the first two superordinate themes but reflects how the participants live in the present and how they have been changed.

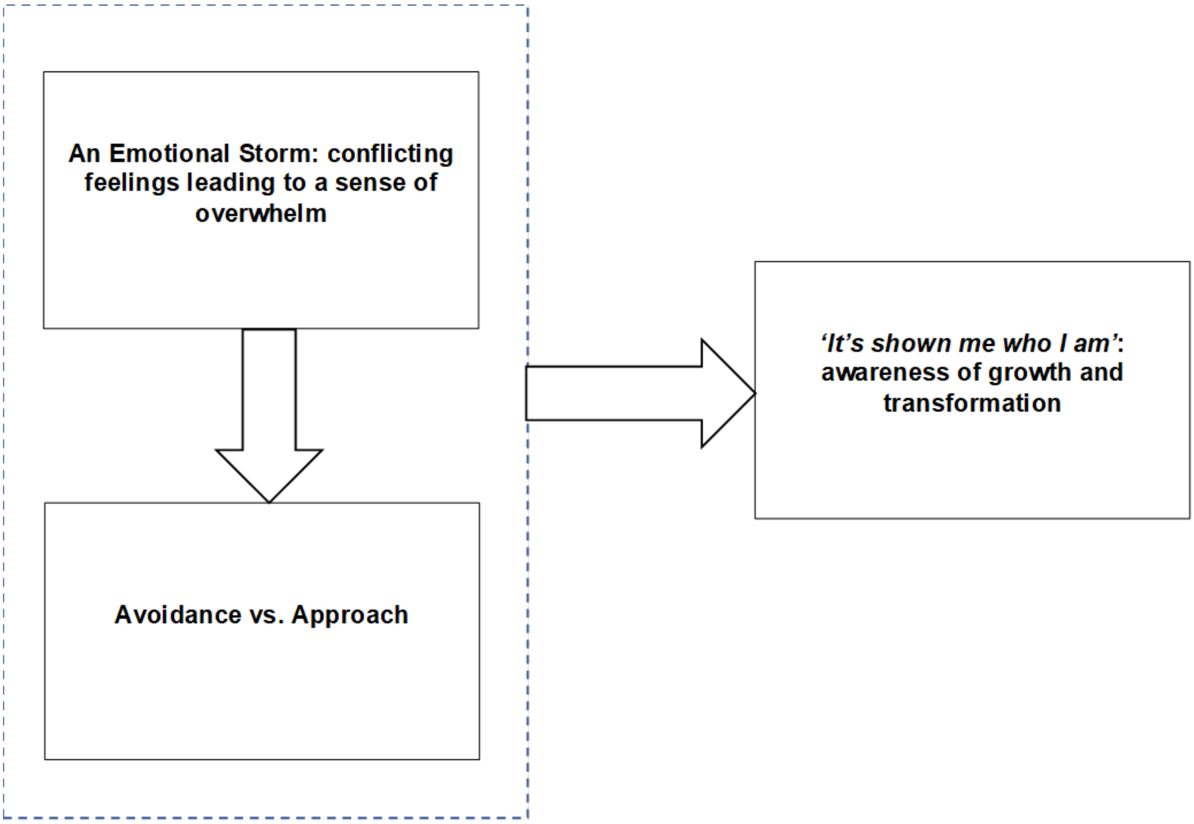

Figure 1: Diagrammatical representation of superordinate themes.

3.2 An Emotional Storm: conflicting feelings leading to a sense of overwhelm

This first superordinate theme encapsulates the powerful subjective experience of ambivalence and overwhelm, which I have attempted to capture through symbolism. The imagery of an emotional storm intends to represent the embodied experience of co-existing and conflicting thoughts and emotions which are difficult to manage, creating an overwhelming internal experience. This theme elucidates participants’ intrapsychic processes in relation to extrinsic factors. Across all interviews, the participants convey multiple contradictory expressions relating to how they experience their sibling, their sibling’s treatment process, their family and the wider community. A dissonance arises from this ambivalence which appears to perpetuate a state of uncertainty and self-doubt. This is comparable to being amidst a physical storm where one may be left feeling out of control and unstable on one's feet, with a poor sense of direction due to the unpredictability of the storm's course. Five subordinate themes emerged within this overarching superordinate theme, which I will now explore in turn.

3.2.1 Feeling overwhelmed in response to the sibling's changing identity

This sub-theme captures a complex web of emotions which the participants experienced in response to witnessing a change in their sibling's demeanour. A state of overwhelm appears to transpire from dominant and powerful feelings including fear, anger, sadness and sympathy. Throughout all of the accounts, there is also a palpable sense of uncertainty, as the participants express a struggle to comprehend the changes in their sibling. For example, Aisha continually questioned the identity of her brother when returning home from university:

'…I just thought, what's happened to you? Like what what has you know is this really you or, are you, are you putting on an act like, you know do you, do you want attention or is there actually something wrong with you…' (Aisha, 11, 218-221)

This excerpt illustrates the many questions that Aisha was grappling with in relation to her brother's disposition. There appears to be a difficulty in meaning-making due to the multiple possible perspectives she held, leaving her feeling conflicted towards him. Moreover, Aisha's repetition of several words in this extract illustrates a struggle to articulate her thoughts during the interview, and this may reflect the uncertainty that she experienced. Her confusion appears to be linked to a profound state of anxiety, perhaps due to a fear of the unknown:

'…I was a bit confused, and also really worried, erm it made me quite anxious, like it brought out more emotions in me than I really have ever thought about or felt before' (Aisha, 11, 221-223)

Here, Aisha describes a significant cognitive and emotional transition. Her use of words such as *'more'* and '*quite'* are ambiguous yet emphasise the increasing intensity of her affect. This unfamiliar and uncomfortable internal experience alludes to a sense of overwhelm as she describes a multitude of emotions associated with fear.

Like Aisha, Vikash also describes feeling *'confused' (5, 116)* as a result of a change in his sister's demeanour. He explains that his sister: *'…started developing very extreme behaviour, er, towards myself and other siblings…and it started to become violent, throwing things and screaming at people' (5, 113-114)*. It seems that his uncertainty could be connected to a deeper layer of emotions, including fear of his sister due to the severity of her aggressive behaviours, which impacted him and those around him.

Echoing Aisha and Vikash, Sara expresses fear as an integral part of her affective experience. This was apparent when she described what it was like to converse with her brother:

'…the thing's they're saying it's just fucked up, you know (laughs)…' (Sara, 42, 896-897).

Sara's use of profanity may reflect her attempt to express unpleasant and intense emotions in a more tolerable way. Thus, she seems to convey an overwhelming sense of trepidation due to a struggle to comprehend her brother's narrative. She then began to laugh, and I felt that this reaction was not congruent to what she was describing and the reality of her affective experience. My understanding is that Sara's laugh and use of profanity served the same purpose – they enabled her to express feelings of anxiety relating to her brother's behaviour in a way that trivialised the intensity and discomfort associated with it. She then continues:

'…it's a scary and eerie thing, it's scary for me as a sister who has grown up with him to see somebody go through that you know, I feel like there is someone else in the room…I've felt like that and it's a bit scary, its eerie' (Sara, 42, 900-901).

An overwhelming sense of fear is evident from Sara's repeated expression of the words '*scary*' and '*eerie*'. Instead of perceiving her brother, it appears that she sensed an unknown, unfamiliar presence which created a profound state of angst. In this excerpt, Sara also recognises her role as a sister and appears to illustrate a strong sibling bond with her brother as she describes how they were raised together during childhood. To perceive a sudden change in him may have left Sara feeling vulnerable in his presence.

Sonia also depicts an unsettling experience of being unable to identify her brother. In her account, these emotions are depicted through vivid descriptions of her brother's non-verbal communication:

'…when he looks at you just, his eyes are just ***dead*** *like there's nobody there' (Sonia, 5, 112-113).*

Sonia's emphasis on the word '***dead***' suggests a profound and perplexing experience of loss. Although she refers to a deceased other, this appears to be a more spiritual and poetic expression that illustrates the absence of a psyche, rather than a literal description. My understanding is that Sonia felt unable to connect with her brother due to perceiving him as emotionless. She elaborates on this experience by referring to him as '*nobody'*, which also indicates that being in the presence of an unrecognisable entity that once felt familiar was now incredibly frightening. She continues to describe this experience by introducing a metaphor:

'…it was Aaron but it just was just the shell of Aaron, it wasn't the Aaron that we know' (Sonia, 6, 119-120).

Using the imagery of a shell to portray her brother is compelling as it reflects an individual whose exterior remains strong and sturdy, whilst the inner self is one of hollow emptiness. Despite his physical appearance being discernible, Sonia could no longer perceive the characteristics and internal qualities that her brother had once possessed, resulting in a state of bewilderment. It seems that this discrepancy arising from the physical presence and psychological absence of her brother contributed to an unresolved sense of loss. Sonia's uncertainty appears to be a shared experience, as she expresses herself using the first-person plural '*we*', which serves to amplify and validate the anxiety that she appears to describe.

Like Sonia, Akshay too reflects on a shared experience of anxiety within the family. He acknowledges that his brother became more violent and unpredictable and describes what it was like to be in his presence during this time. However, Akshay also associates his anxiety with intense feelings of anger:

'…we all got very anxious, we didn't know what to do. I had to keep strong, try to erm, I used to get quite nervous whenever I used to go there, and also cos I used to have a build-up of adrenaline, because I wanted to beat the shit out of him in my head' (Akshay, 43, 1132-1134).

Here, Akshay demonstrates feeling under threat and expresses an impulse to physically harm his brother, possibly to protect himself. His feelings of resentment are evident, although it seems that Akshay did not act on his angry thoughts as they remained in his '*head*'. There is a sense that this created an overwhelming internal experience due to the build-up of emotion which was not released. Akshay also expresses a need to be perceived as someone of great strength, and although holding back on his impulses illustrates some self-control, it suggests that there was a struggle to be emotionally vulnerable. Nevertheless, towards the end of his interview, Akshay acknowledges and lists an array of emotions which emphasise the overwhelming and distressing nature of his experience:

'it's exhausting, erm it's er it's erm…experiencing a sibling is exhausting, it's, it's feeling of anxiousness, it's feeling of helplessness, of er er…yeah it's a feeling of, of not fitting in, it's a feeling of erm…er…craziness, madness…' (Akshay, 60, 1575-1577).

It seems that these negative emotions were difficult to manage, leaving Akshay feeling depleted and utterly devastated. His narrative of feeling like an outsider as a result of his brother's erratic and peculiar disposition perpetuates his feelings of alienation. In addition, his feelings of helplessness could be connected with a deeper layer of emotions, including self-doubt in his own abilities. His experience of helplessness will be explored in greater detail later in this chapter. Akshay appears to shift from expressing his own emotions to then in the last line describing how he made sense of his brother's presentation. One wonders whether this shift suggests a struggle to convey just how overwhelming and peculiar the overall experience was for him. There is a great deal of hesitation seen in the many utterances and pauses in this excerpt, which may further indicate such a struggle. He continues:

'it's such an altered state of mind, it's erm…it's a boy crying out for help…' (Akshay, 60, 1579)

Akshay portrays his brother as a *'boy'* despite him being an adult. This may reflect feelings of sympathy due to perceiving his brother to be in a vulnerable child-like state. Strong feelings of compassion towards the sibling and their experiences of suffering were expressed in all the interviews. For example, Yusuf describes intense unpleasant feelings by expressing that he felt '*horrible*' (37, 1203) as his brother '*didn't deserve it' (37,1204),* whilst Sara acknowledges immense feelings of sympathy alongside a state of uncertainty: *'…I was very sympathetic, er but I was also very unaware of what it meant for him…' (3, 44-45).*

To summarise, this theme reflects a range of intense emotional experiences described by the participants which appear to be contingent upon their sibling's behaviour. Furthermore, there appears to be a yearning to resolve an ongoing state of uncertainty along with a wish for their sibling to return to their old self.

3.2.2 'What do I do?': An internal conflict

This sub-theme depicts an internal conflict arising from feeling torn between polarised emotions and competing needs within the sibling relationship. A sense of personal struggle is evident across three of the interviews, as the participants reflect on the numerous dilemmas they encountered, which appears to evoke a process of questioning on how they should respond to their sibling's changing demeanour. '*What do I* ***do***?' is a quote taken from Aisha's account, which I feel best captures this state of disarray, as it demonstrates a longing to obtain answers.

Aisha recognises her influential role in the family by describing herself as *'the rock of the house' (11, 235-236).* There is a sense that she feels valued due to her dominant presence within the household. Her metaphor indicates that she perhaps experiences herself as someone of great strength, who is able to support and emotionally hold her family members' distress and pain due to having a reliable and attuned presence. Despite acknowledging her position within the family system, Aisha expresses a resistance towards adopting this role due to experiencing multiple demands in other areas of her life. She explains that she was living away from home at university at the time and describes how this distance created a strain on her family, as her mother would frequently say to her, '*you're not here, you don't understand what it's like*' *(19, 407)*. It seems that her identity as the dependable sibling and daughter was challenged due to her being away from the family. This appears to have left Aisha feeling under pressure, perpetuating a state of self-doubt:

'…I felt oh god like you know, what do I **do***? You know like I don't know what like I can or can't do like I'm at uni, if I come all the way home and you know give up my education…' (Aisha, 19, 409-410).*

A conflict between Aisha's own needs and the needs of her family is evident within this extract. Sacrificing her own needs by abandoning her education appears to have been less desirable than remaining at university. However, it is possible that Aisha also felt guilty for being away from her family due to this unresolved state of confusion that she expresses. Her exclamation of '*oh god'* appears to accentuate feelings of exasperation due to an abundance of thoughts and emotions, which seem to pull her in different directions. Feelings of frustration are also indicated by the lexical stress that she places on the word '***do***'.

Sara echoes Aisha's struggle as she too depicts herself as feeling caught between two choices. She expresses self-assurance in her ability to communicate with her brother, which she attributes to her gender and identity as a sister. Sara holds a belief that women are better able to communicate than men: '*I feel women in general are more able to talk…' (23, 498-499)*. These perceived differences result in her experiencing a power dynamic in the sibling relationship, as she describes feeling *'responsible' (23, 504)* for her brother. She continues to then express that: '*it empowered me to do stuff for him because I was his sister' (23, 505-506).*

Nevertheless, Sara also reports that she felt increasingly conflicted about her actions due to possessing other roles such as a wife and an expectant mother. She describes *'being conflicted by my partner' (33, 721).* There is a sense that a conflict arose from the interpersonal demands that she encountered, relating to the differing parts of her identity. This appears to have left her feeling overwhelmed with responsibility, leading to a prolonged unpleasant experience of intense psychological and physiological distress:

'…for months I remember feeling anxiety and, erm, you know feeling like a heavy burden, here (points to chest), erm' (Sara, 33, 714-715).

Here, Sara uses gestures as well as words, which serves to amplify the connection between her emotional and physical experience of anxiety. She continues:

'…maybe I couldn't be part of it and maybe I could have er, you know I should help him more, what could I do…[ ]… it was a lot of conflict and a heavy feeling of burden, I do remember that feeling and it wasn't a nice feeling' (Sara, 33, 720-724).

Sara's internal dialogue demonstrates that she felt confounded by the many possibilities she considered, along with the many questions that were raised. The emotional strain that she experienced is emphasised through her repetition of *'heavy burden'*, and her use of the adjective '*heavy*' conveys a sense of experiencing heartfelt and overwhelming emotions which were difficult to manage. I wonder whether Sara's uncertainty about how to proceed could be associated with a fear of not fulfilling certain expectations and succeeding as a *'responsible'* other.

Vikash also experienced doubt in his role as a sibling as he described feeling caught between two opposing emotional states:

‘we were close erm, but again I think I was confused about my obligation to her as a brother and my resentment towards her for arguing all the time and causing problems’ (Vikash, 10, 195-196).

A conflict arises for Vikash due to experiencing ambivalence towards his sister, yet he tentatively conveys this by stating ‘*I think’*. He acknowledges that the relationship with his sister has remained ‘*close*’, yet his subsequent utterance ‘*erm*’ indicates some hesitation with this statement. It seems that he harboured some resentment and blame towards his sister, which created a struggle in fulfilling his sibling duty; however, I wonder if this could be associated with underlying feelings of guilt or shame. There is a sense that being in the midst of this unresolved process felt exhausting, perhaps creating a sense of frustration towards the self, due to an inability to reach a decision. Achieving a resolution may have been increasingly challenging due to the emergence of this critical inner voice.

In summary, this sub-theme has captured a disconcerted internal experience described by Aisha, Sara and Vikash, who express conflicting thoughts and emotions regarding their needs and desires. All three of these participants identify their sibling duty, yet there is a reluctance to fulfil this responsibility. Aisha and Sara both convey a struggle to balance their own needs and assume other roles alongside that of being a sibling, whilst Vikash expresses ambivalence towards his sister which evoked feelings of uncertainty. Overall, the conflict and confusion explored in this theme alludes to a sense of a lack of mastery for these participants.

3.2.3 *‘You can lead the horse to water but you can’t make it drink’:* Feeling helpless

This sub-theme captures the challenging encounters that participants experienced in trying and subsequently failing to alleviate their sibling’s distress, which resulted in a profound state of helplessness and evoked additional feelings of insecurity and self-doubt. Moreover, this theme will illustrate the arduous process of attempting to obtain professional help for the sibling, along with the frustrations that arose from this. Throughout all the interviews, there is a sense of emotional turmoil due to an absence of resolution.

The quotation used to encapsulate feelings of helplessness within this sub-theme heading was expressed by Vikash. Throughout his interview, Vikash continually reflected on a struggle to influence his sister's behaviour. He uses powerful imagery which appears to hold contradictory expressions to convey a sense of both helplessness and control:

'…I've accepted you know, you can't change, you can lead the horse to water but you can't make it drink…' (Vikash, 18, 385-386).

This proverb indicates that Vikash recognised his ability to guide his sister and offer suggestions, yet there was no guarantee how she would respond. He uses the image of a horse to demonstrate how he felt he had some level of control, similar to how one can hold the reigns of a horse to communicate with it and steer its direction. Yet, a horse ultimately makes its own decisions regarding its behaviours, much like human beings. Despite conveying feelings of acceptance, his statement alludes to a sense of frustration and insecurity, along with feelings of exhaustion due to multiple attempts which did not end in success.

Across Vikash's account, there is also a palpable sense of fear as he describes how his sister *'would bring out a knife and try and kill people' (13, 260)*. However, there appears to be a struggle for Vikash and his family to feel heard when subsequently reporting these concerns to professionals, as he seems to experience his sister as being able to deceive others by controlling these behaviours. He compares sudden changes in her behaviour to that of a switch:

'…when we, when my brother-in-law and family reported all of that she would switch, it was like a switch and she was like perfectly normal and we were like no no no trust me, she was like really bad (laughs)…' (Vikash, 13, 261-263).

The repetition of *'switch'* further amplifies the immediacy of the changes that Vikash observed in his sister. He characterises her as akin to someone *'perfectly normal'* during moments when she would switch, which appears to have left him feeling powerless as it became increasingly difficult to defend any concerns that were reported. His account reflects a profound state of desperation, as it became impossible to perceive any form of aggression. This is also conveyed through his imploring nature and repeated expression of *'no'*. His laugh at the end of this extract may serve to help him disconnect from and manage the discomfort associated with acknowledging feelings of helplessness.

Sonia and Aisha convey similar expressions of helplessness by also considering the limitations in their own abilities to influence the behaviour of their respective siblings:

'…what was challenging…again just feeling like there's nothing I can do. There's literally nothing. I tried, but there's not a lot you can do. You can't force them to eat…' (Sonia, 19, 413-414).

'…that's the hard part, like trying to, you know you can't force an adult to do anything…' (Aisha, 5, 105-106).

Despite conveying a sense of acceptance in acknowledging their inabilities, there again is an underlying tone of frustration and discomfort that appears to be related to a conviction that nothing can be achieved. Sonia's repeated expression of *'nothing'* emphasises a sense of despair and perhaps also guilt due to an inability to find a solution. Like Vikash, her story reflects a struggle due to many failed attempts in eliciting change in her brother's behaviour. Food is one of the basic human needs to ensuring survival in the world, yet it seems that Sonia was unable to ensure that her brother consumed any sustenance, which perhaps evoked feelings of inadequacy in her role as a sister.

Aisha's excerpt also reflects an inability to exert power and authority over her brother. She uses the term *'adult',* which conveys a struggle to influence a fully developed and mature individual. This lack of control may have further depleted any sense of hope. She reflects on her feelings of helplessness as the *'hard part'* of the experience which foregrounds the immense struggle.

Echoing Vikash, Sonia and Aisha, Yusuf also expressed strong feelings of powerlessness but associates this with his youth, as he was a teenager at the time:

'I felt quite powerless, because I felt like I couldn't change anything…in terms of what was going on, because I was too young to change anything…' (Yusuf, 15, 468-469).

Here, Yusuf describes feeling submissive in the presence of his brother, due to his age. There appears to be a desire to help yet also a sense of hopelessness which results in Yusuf refraining from attempting to enforce any action. The term *'anything'* is repeated, which amplifies this negative self-perception of impotence. Aisha reiterates this by expressing that she felt *'useless' (22, 465)*, however, she expresses some self-doubt regarding her abilities to create change: '…*I was like I don't think there is anything that I can do about it' (Aisha, 22, 465-466).* Sara similarly conveys a sense of helplessness as well as feelings of inadequacy as she felt unable to manage the situation independently:

‘I couldn’t support him by myself so I needed proper, you know guidance’ (Sara, 9, 177).

As the eldest sibling, Akshay portrays an image of an assertive rather than submissive individual by referring to himself as *‘dominant’ (15, 382)*, stating that he could voice *‘quite strong views and opinions’ (29, 763)* with his brother and other family members in the household. Nevertheless, he too expresses anxieties by depicting the struggles he encountered in influencing his brother’s behaviour:

‘…how do you, get a doctor to see him if he doesn’t wanna see the doctor?’ (Akshay, 28, 737-738).

Akshay recognises his brother’s reluctance to seek help which seems to leave him feeling frustrated due to a struggle to find solutions. This rhetorical question reflects a lack of ability to problem-solve and conveys feelings of helplessness, which, in turn may have altered his beliefs regarding his capabilities. He later associates this struggle with wider systemic challenges to seeking professional help:

‘…I think what we need is a system that can enable, a system that people can access where they have these services at their fingertips, it shouldn’t feel like to be, it shouldn’t feel like a place where people can’t get help…’ (Akshay, 48, 1248-1250).

Akshay expresses strong feelings of disapproval and frustration towards the existing pathway to accessing mental health support services. There is a sense that he experienced these services as undesirable and unwelcoming when reflecting on what they *‘shouldn’t’* feel like. The phrase *‘at their fingertips’* reflects his wish to have better ease of access into these services, which further emphasises the barriers he encountered. A stronger tone of anger is reflected in Sonia’s account, as she too identifies barriers in accessing professional support for her brother:

‘…I just found it useless, even for them to come to the home and visit him, they wouldn’t do it because they didn’t know like what kind of situation they would walk into, so it’s really hard to get someone help when they’re like that, it’s just ridiculous’ (Sonia, 24, 525-528).

The terms *‘useless’* and *‘ridiculous’* which are reflected at the beginning and end of this excerpt amplify feelings of dissatisfaction and even disgust from Sonia towards services. She describes them as having restrictive boundaries and perhaps felt let down by their disregard. It seems as though she felt unable to challenge their approach, which indicates a strong sense of powerlessness and despondency. This is further emphasised by her describing the process as *'really hard'*.

Therefore, a common experience of impotency is reflected across the participants' stories. Whilst they express a desire to support their sibling, this feels impossible due to the confines of human ability, the perceived barriers in help-seeking and an unresolved state of uncertainty.

3.2.4 Frustration towards family members and the wider South Asian community due to a conflict in values

This sub-theme explores a tension that participants experience within their culture, which is illustrated across most of the interviews. There appears to be a discord with prevailing South Asian (SA) cultural narratives, resulting in the participants experiencing a conflict in values with their family members and those in the wider SA community. It seems that these divergent beliefs evoked strong feelings of frustration and resentment as most of the participants acknowledged how cultural narratives influence the behaviours of said others towards themselves and their respective sibling experiencing psychosis. However, they also report feelings of sympathy and convey a sense of understanding towards the responses of these individuals, which further reflects their ongoing state of ambivalence.

In his account, Yusuf shares his knowledge of apparent contradictions between existing cultural beliefs of mental illness:

'…I I feel like in the Asian culture it's more like when when someone has a mental issue they they see it as like, the person can be possessed or something, they don't they don't view these erm these like err issues as clinical' (Yusuf, 23, 726-727).

His repetition of several words in this excerpt illustrates a struggle to articulate and some hesitance in expressing his perception of differing cultural narratives, which indicates a state of uncertainty. Using the ambiguous term *'something'* to reflect on Asian cultural beliefs strengthens this notion of doubt, along with the utterances *'erm'* and *'err'* which are expressed when Yusuf seems to be describing a Westernised approach to mental illness. Despite this uncertainty, a sense of fear is palpable when he acknowledges beliefs of *'possession'* within the Asian culture, as this indicates the existence of an evil entity within the spiritual realm. This anxiety, coupled with his apparent confusion, suggests a lack of affiliation with these cultural norms. Yusuf later continues to express how these cultural narratives influenced the responses of his extended family members when his brother became unwell:

'…*I feel like no one was really supporting it, like the issue, I feel like no one really understood, no one understood what was going on' (Yusuf, 35, 1131-1133).*

He continues:

'…I don't know if it's something with the Asian, with Asian families…' (Yusuf, 35, 1135).

Feelings of isolation appear to be conveyed here and perhaps arose as a result of experiencing everyone as unsupportive. Although he depicts a connection between the behaviours of his family members and their cultural beliefs, Yusuf's tentativeness in expressing his assumptions is once again evident. His uncertainties indicate the existence of other possibilities he may have considered regarding the dismissive nature of his family members. Despite this generality in stating that *'no one'* was supportive, Yusuf later conveys a different experience and reflects on more positive interactions with certain family members:

'…I had some family members that did give me support you know, made sure I was ok, I I just realised it now that they kind of took my mind of things and, you know, they, when when he was going through that they actually understood…' (Yusuf, 36, 1154-1156).

This extract conveys an appreciation for others due to their empathy and care towards Yusuf and his brother. It is apparent that his memory of this experience emerged during the process of the interview, perhaps as a result of the exploratory nature of questioning. It seems that Yusuf felt contained by the presence of certain others who not only provided emotional support but also averted his attention from the circumstances with his brother at the time.

Aisha echoes Yusuf's ambivalent feelings towards family members. In particular, she depicts conflicting emotions which she experienced towards her mother:

'…I just resented her a little bit so I just felt like, I felt like she needed support, but, I also felt like, I don't she was, like I said she was playing victim, and then I didn't, I didn't quite like that…' (Aisha, 25, 537-539).

Despite expressing feelings of resentment, she uses the phrase *'a little bit'* to convey that this was not an intense emotional experience. Aisha then reflects on her mother's struggle to cope as she acknowledges her need for support, which possibly indicates feelings of sympathy. However, there appears to be an underlying sense of frustration towards her mother's submissive behaviours as she continues to describe her mother as *'playing victim'*, which implies a fabrication and dramatisation of a helpless individual who has experienced adversity. Hence, this use of terminology perpetuates a sense of resentment and animosity harboured by Aisha. Nevertheless, the disjointed and incoherent phrases that are expressed in this excerpt indicate a sense of discomfort in expressing these judgements.

A complex narrative is also depicted in Akshay's account, due to the seemingly ambivalent statements that are expressed when referring to his mother:

'…what my mum's been through, my mums biggest advocate of my brother, like, never wanted to admit anything was wrong…erm just sort of followed him blind…' (Akshay, 24, 639-641).

Akshay considers that his mother has endured some hardship by reflecting on what she has *'been through'*, which possibly indicates feelings of sympathy. By referring to his mother as an advocate, he conveys his mother's caring and supportive nature. However, feelings of frustration are also discernible, due to his mother's avoidance of acknowledging apparent concerns. Akshay's disapproval of her oversight suggests that he took on a blaming stance towards his mother's actions. Aisha also attributes blame towards her mother, which is connected with feelings of frustration:

'…I don't know if its cos, I'm Pakistani and in our culture, erm you know sometimes boys are mollycoddled as they're growing up and you know you don't know if if they're just, stuck in that erm mindset whereas if mum's gonna look after you or whatever…' (Aisha, 6, 118-121).

Aisha's relationship with her Pakistani identity appears to be convoluted due to a dissonance with some of the cultural customs. Like Yusuf, she expresses feeling uncertain about the relationship between her Pakistani culture and the behaviours of others. She tentatively explains that boys are *'mollycoddled'* as a result of these cultural norms, which indicates an over-protective nature of Pakistani parents towards their sons. Aisha describes her brother being *'stuck'* in a *'mindset',* implying that his innate qualities, such as his dependent nature, are predominately fixed as a result of her mother's unduly attentive nature. This appears to evoke strong feelings of frustration experienced by Aisha towards her mother, due to adherence to cultural customs.

Contrary to the other narratives, Vikash almost entirely conveys feelings of resentment towards the responses of his family members and others in the SA community. In his account, there is an absence of mixed emotions as he conveys a negative perception of others. Like Aisha, Vikash attributes blame towards his parents for precipitating his sister's experience of psychosis, and associates this with their powerful role in decision-making. He experiences strong feelings of animosity towards them:

'…the arranged marriage, this probably was the trigger and who arranged it? My parents. They didn't listen to my uncle, everyone was against it, they still went ahead through fear of whatever, insecurities that they had, and then that led to resentment towards my parents…' (Vikash, 20-21, 428-430).

Vikash also expresses some uncertainty about the causes of his sister's psychosis by explaining that her arranged marriage *'probably was the trigger'.* Despite attempting to provide some reasoning for his parents' actions by acknowledging their *'insecurities'*, there is a clear conflict in values due to his condemnation of their behaviours. In addition, it seems that Vikash experienced sympathy towards his sister's powerlessness due to the controlling nature of his parents, and I wonder if he also felt powerless, due to being unable to voice his concerns and challenge them. This further amplifies his feelings of helplessness which were explored in the previous sub-theme.

Sonia experienced an intergenerational conflict as she felt angry towards individuals in the SA community of her grandmother's generation:

'I was angry at them cos they just, their minds are so closed off, especially older generations they don't really understand mental health, their just like 'oh just get up and pull yourself together and carry on'…' (Sonia, 21, 466-469).

I wonder whether the differences in knowledge and age that Sonia perceived could also be connected with cultural differences and her identity as a second-generation British SA. By describing the older generation as *'so closed off'*, it seems that Sonia experienced these individuals as holding an incredibly rigid and restrictive set of beliefs regarding her brother's psychosis. At the end of this extract, Sonia raises her pitch and changes her tone of voice to convey the responses of others and illustrates how they expressed an indifference towards her brother. Experiencing others as ignorant therefore evoked strong feelings of anger. However, as with most of the accounts, Sonia also expresses ambivalence in her responses towards others:

'…and because ***we*** *didn't understand at the time, if we don't understand it they can't understand it either…' (Sonia, 28, 631-632).*

Thus, although Sonia experiences animosity to others, this quotation also reflects a measure of sympathy and acceptance, due to a shared experience of uncertainty. She places lexical stress on the term *'**we**'*, which perhaps indicates a sense of disbelief and exasperation when acknowledging her own bewilderment towards her brother's behaviour. Moreover, feeling uncertain alongside her family members may validate this affective experience.

In contrast to the other participants, Sara expresses how growing up, there was a collective disregarded towards some cultural norms within her family:

'…I know our culture is, the Asian culture is very much about don't talk or what have you but I think my family and I were very vocal with, if we had a problem, we discuss…' (Sara, 11,231-233).

Here, Sara explains that concealing experiences of distress is a general expectation within the Asian culture. It appears that she experiences a disdain towards this cultural norm. Recognising the differences in communication between her own family and the wider SA community illustrates a distancing from her Asian identity. My understanding here is that Sara feels empowered by disregarding these cultural norms and competent in her ability to be transparent. However, this detachment from her cultural ancestry through communicating about difficulties seems to result in an additional experience of feeling criticised by others in the SA community, including her partner at the time:

'so my ex used that, saying that all your families a bit erm loopy, so I had that thrown back at me and that made me realise why people don't talk up about it, cos they assume if you've got family history then you are also prone to it…' (Sara, 12, 255-257).

Again, Sara expresses feelings of frustration in response to the negative judgements she and her family received. Being referred to as *'loopy'* perhaps alludes to a sense of alienation, as the term reflects individuals who are perceived to deviate from societal standards and norms. The utterance *'erm'* perhaps represents an interjection which carries some emotional discomfort as Sara expresses the comments made by her ex-partner. Having these remarks *'thrown back'* at her suggests that Sara perhaps felt saddened as a result of being negatively judged and felt unable to escape these comments.

To conclude, the participants report an array of emotions which are experienced towards their family members and others in their cultural community, ranging from strong feelings of resentment to sympathy. However, a general undertone of frustration is conveyed across all but one of the accounts, due to a conflict in values between self and other. Yusuf appears to be the only participant who did not describe feelings of frustration towards others, although he expresses some uncertainty in response to their behaviours.

Continually engaging in a reflexive process felt pertinent when writing up this sub-theme, due to my identity as a British SA. When immersing myself in the analytic process, I had a strong affective response to the cultural and interpersonal experiences that were expressed by the participants. Thus, it has been important for me to remain aware of my own beliefs and experiences as a British SA and bracket these in order to do justice to conveying my participant's experiences. I have used the Methodology chapter to share my own reflections which were written in my reflexive journal and continue to explore this further in the Discussion chapter.

3.2.5 'It's sad but it's a blessing': Ambivalence towards the sibling's treatment

The final sub-theme encapsulated within the first superordinate theme reflects a cyclical experience of optimism, relief and despondency towards the sibling's treatment process and their recovery from their FEP. However, a sense of loss pervades this entire segment and appears to be at the centre of this recurring affective experience. The quotation used to embody this theme was captured within Sonia's account. She expresses mixed emotions with regards to the outcome of her brother's treatment:

'…it's sad but it's a blessing at the same time when I see him now, he was just ***so*** *lost before' (Sonia, 32, 720-721).*

There appears to be a process of change over time, as Sonia reflects on the differences between her perception *'now'* and *'before'*. This results in an overall sense of relief in the eventual outcome, which in this case seems to be the reappearance of her brother. She describes previously experiencing him as *'lost'*, which conveys strong feelings of sadness. Sonia emphasises the initial magnitude of this loss due to the lexical stress she places on the term *'**so**'*. The co-existence of her feelings of sadness and gratitude perhaps suggests that this sense of loss still remains, but to a lesser extent. She elaborates on her conflicting emotions by describing how parts of her brother's identity remained hidden as a result of his medication:

'…he was Aaron, like 20% Aaron but at least he was walking and eating, that was enough…' (Sonia, 23, 500-501).

Using a percentage to quantitatively describe her brother serves to provide more clarity in understanding her perception of him. The numerical value *'20%'* suggests that a large part of her brother's identity remained unrecognisable, which could be connected with feelings of despondency and perhaps even fear. It seems as though her expectations for his recovery were not met; however, there is still a sense of appreciation for the relatively small degree of change. The phrase *'at least'* indicates Sonia's need to attend to the positive outcomes within this process, which she denotes as an increase in her brother's physical behaviours. Nevertheless, it appears that she experienced this process as merely satisfactory. Vikash also conveys a struggle to accept the outcome of his sister's treatment process, by expressing conflicting emotions:

'…she's still wasn't well but just wasn't as bad, so it's amazing but at the same time I have these enormous feelings of loss' (Vikash, 17, 352-353).

Like Sonia, he too appears to convey a deep sense of anguish as he grieves the loss of the sister that he once knew. Despite expressing relief in how his sister's presentation had improved, Vikash also conveys a strong sense of disappointment and diminished hope due to a recognition that his sister remained partly unwell.

Yusuf expresses uncertainty alongside feelings of frustration towards his brother's treatment and, in particular, the use of medication:

'…I feel like sometimes it's just erm…it's just making someone like like a tranquilised effect, but I don't feel like it actually tackles like the actual root issue' (Yusuf, 29, 919-921).

Yusuf describes his brother's medication as having a *'tranquilised effect'*, which suggests that it had a calming impact and relieved any mental distress that his brother was experiencing. Whilst this may have evoked feelings of comfort, it seems that this was momentary, as the treatment did not address the underlying causes of his brother's psychosis, which Yusuf refers to as the *'root issue'*. Thus, feelings of frustration arose due to these perceived limitations, along with a sense of disappointment due to the inauthentic nature of the treatment.

Echoing the accounts above, Akshay expresses feelings of relief; nevertheless, he also conveys a sense of curiosity towards a change in his brother's disposition following his recovery from his FEP:

'…he's recovered and now he's been discharged but who is this boy now…and now we see a guy who's kind of middle, in-between, who's *got the characteristics of, of his younger self but also some of the creative spark that he's retained now…' (Akshay, 60, 1557-1559).*

Once again, Akshay uses the terms *'boy'* to depict his brother, although later in this extract refers to him as a *'guy'*. It seems that even after his brother's recovery, Akshay continues to experience him as a dependent and innocent individual and therefore uses this term in an endearing manner. However, the impersonal and objective term *'guy'* is subsequently expressed, which conveys a sense of uncertainty and a struggle to fully discern and understand his brother. Acknowledging the *'creative spark'* in his brother appears to reflect a new characteristic which has emerged as a result of his psychosis. This relates to an ebullient persona and vivid imagination. I wonder if this evoked feelings of anxiety for Akshay as these traits are connected to his brother's initial experience of becoming unwell. Thus, it seems that he feels caught between two presentations that he observes, one of which is familiar and one which feels obscure. This results in an overall sense of doubt about the true identity of the person standing before him.

Aisha also expresses doubt; however, this appears to be related to an inability to be in the presence of her brother whilst he received treatment from professional healthcare services:

"…we trusted them I had, our hearts in their hands, so our hearts and hands so it was erm, you don't really know it's like putting an old person in a home like you don't really know like what's gonna happen like you hear horror stories so we weren't sure so we trusted the system…" (Aisha, 37, 803-806).

Aisha's uncertainty is palpable within this excerpt, due to her repetition of '*don't really know'*, which appears to be associated with opposing feelings of fear and hope. The phrase *'heart in hands'* is a symbolic expression which refers to putting oneself in a vulnerable position by willingly expressing aversive emotions. This powerful imagery reflects how Aisha perhaps conveyed both her fears and hopes to the professionals caring for her brother and dubiously placed her trust in them. Her feelings of worry which pervade this passage seem to be associated with the possibility that her brother could be mistreated by the staff as she anticipates how his treatment could compare to the unpleasant experience of a horror story. Nevertheless, it seems that Aisha continues to embrace a sense of optimism by having faith in the ability of professionals.

In contrast to the other accounts, Sara almost entirely expresses adverse emotions in response to her brother's treatment. She conveys a strong sense of despondency due to the lack of support that she received from healthcare professionals:

'…I just thought that it wasn't enough help on that side, helping the person who's helping the person, the guidance…' (Sara, 27, 576-577).

It seems that Sara felt isolated and burdened by her sibling responsibility, which was difficult to manage. An absence of *'guidance'* left her feeling neglected and perhaps even frustrated towards the professionals supporting her brother. The disregard from professionals appears to be an integral part of her experience and there is a desire for more practical and emotional support. The responses from these services compelled Sara to seek additional support from a spiritualist, as she *'wasn't getting the answers' (27, 584)*. However, her encounter with a spiritual healer appears to have been a frightening experience:

'…that that world is all about spirits and possession and being you know and that that did scare me cos I didn't even think about those things…' (Sara, 9, 190-191).

Here, Sara expresses her need to consider alternative sources of support which she would have not otherwise considered had she felt acknowledged by healthcare services. Her encounter with a spiritualist was a new and unfamiliar experience which felt unnerving. However, her need to seek support from this alternative source conveys feelings of desperation to find a solution and obtain a greater sense of clarity.

To conclude, this sub-theme depicts an array of emotions which were experienced in response to the sibling's treatment process which the participants oscillate between. Painful feelings of loss were experienced despite recognising some value in the outcome of the treatment. In addition, many participants express a frustration towards the impact of medication, which perhaps results in some distrust towards the mental healthcare system. Sara expresses additional dissatisfaction due to experiencing a lack of warmth from professionals. Aisha's distrust of professionals appears to be associated with her inability to oversee their actions, which amplifies her existing feelings of anxiety. Nevertheless, she retains a sense of hope which could reflect a self-protective mechanism in dealing with these unpleasant emotions. This will be discussed further in the next superordinate theme which explores how the participants managed their conflicting and overwhelming emotions.

3.3 Avoidance vs. Approach

This second overarching theme captures a polarised set of experiences relating to the different ways in which the participants attempted to resolve their ambivalence and emotional overwhelm. Hence, the processes encapsulated here ensue from the affective experiences described in the first superordinate theme. Some strategies involved disengaging and escaping from emotional turmoil, whereas others involved acknowledging and directly confronting their internal conflict through various means. Both approaches reflect an endeavour to break an existing cycle of emotions which preserves their pain, and thus, tackle the emotional storm. Moreover, the methods which were employed by participants to alleviate their distress were inextricably linked to their perception of, and relational stance towards others, including their sibling with psychosis and family members. Therefore, there is a focus on the connection between the participants' intrapsychic and interpersonal processes within this theme. This superordinate theme comprises five sub-themes which capture avoidance or approach styles of coping; however, these underlying themes are not all pertinent to each of the participant's experiences. Therefore, many differences in the participants' behaviours can be observed between the sub-themes as well as within, and these will be discussed below.

3.3.1 *'A case of ostrich syndrome'*

Three of the participants describe how they refused to acknowledge their sibling's psychosis, due to feelings of guilt and shame that arose from this experience. This denial included concealing their experiences from others, which seems to have resulted in a profound sense of loneliness. The term *'ostrich syndrome'* is an idiom which represents this psychological avoidance in a compelling manner and was expressed by Vikash:

'…I also was embarrassed about it, erm guilt, I felt very guilty, erm I think it's a case of erm Ostrich syndrome I just put my head in the sand…it hurt so much that I thought the only way to deal with it, it's out of my control, therefore I'll take myself out of the situation' (Vikash, 15, 316-319).

There is a need to escape from a multitude of distressing emotions which seemed to overwhelm Vikash. Like an ostrich which buries its head in the sand, Vikash conveys that he engaged in similar behaviours by hiding away from others and completely enshrouding unpleasant internal experiences which became too difficult to bear. It is as though he could no longer concede the existence of his sister's psychosis due to the intolerable level of anguish that this created. Feelings of embarrassment are expressed when Vikash reflects on his experience of being in the presence of others during this time, which in some ways could be associated with a sense of shame. He also reports feeling *'guilty'* and *'out of control'*, which further conveys a sense of helplessness. My understanding here is that his inability to find a resolution serves to amplify a negative self-perception, which therefore resulted in the need to escape. This, in turn, perpetuated his feelings of inadequacy.

Yusuf echoes Vikash's need for avoidance and describes a process of becoming reticent:

'…*I became very much closed up, and I just didn't wanna speak about anything I just kind of, became very like a, upset and everything you know, about what was going on' (Yusuf, 12, 360-362).*

This excerpt conveys Yusuf's conscious decision to disconnect with the reality of his experience by concealing his thoughts and emotions from others, perhaps because acknowledging and naming his brother's psychosis felt too distressing. The latter part of this excerpt further conveys a struggle for Yusuf to name the experience within the interview, as he instead uses the ambiguous term *'what'*. However, it seems as though these defensive mechanisms were futile, as he acknowledges feeling increasingly *'upset'*. Nevertheless, a tone of assurance is conveyed throughout this excerpt due to the repeated expression of the word *'just'*, which indicates that suppressing his thoughts and emotions was deemed to be the only adequate solution for him. Yusuf later expresses that concealing his brother's psychosis and refraining from sharing his emotions with others was due to a fear of their responses:

'…*the reason why I was so closed up is because I was scared that people would like judge and stuff…' (Yusuf, 11, 329-330).*

Yusuf anticipates that others could ridicule his brother and perhaps him too, due to not meeting certain expectations. I wonder if this could be associated with his perception of the cultural beliefs that others held, which I have already discussed within this chapter. Thus, the fear and uncertainty that arise from holding these assumptions could reflect deeper feelings of shame. It seems as though Yusuf experiences a discomfort due to these insecurities and conveys a desire to be accepted by others. I wonder whether this seemingly introspective and avoidant process resulted in a sense of isolation due to his lack of communication with others.

Sara's account also depicts a process of psychological avoidance as she describes how she refrained from expressing her emotions with her *'ex and his family's community' (26, 552)* due to their negative judgements. However, this process of evading emotional transparency left Sara experiencing an incongruence:

'…if I am upset and affected by something then I am gonna not be myself in front of them, they won't know the full picture about me, but equally, I'd rather do that than hear their comments because I don't wanna hear negative comments' (Sara, 13, 268-270).

Sara expresses a reluctance to expose herself by keeping others in the dark and concealing her emotional distress. Yet, this seems to create a conflict, as she also has a desire to express her emotional vulnerability with others. Her decision to present with a façade demonstrates a strong desire to avoid receiving criticism, which seems to carry greater consequences than constraining her own affect. It is as though she feels fearful of letting others see her authentic self. Thus, her avoidance appears to be a self-protective mechanism.

To summarise, Vikash, Yusuf and Sara describe their attempts to manage uncomfortable feelings such as shame and guilt, through avoiding the reality of their sibling's psychosis by suppressing their thoughts and emotions from others. This appears to have been a protective mechanism whereby they attempted to attain some control amidst their tumultuous experience. Nevertheless, there were occasions where these participants openly expressed their emotions and discussed what was happening in the family home. This will be explored in some of the following sub-themes.

3.3.2 Going '*against the grain*'

This sub-theme is represented by an idiom which conveys a process of defying cultural norms and expectations. Some participants took a stand and intentionally disclosed their experience of having a sibling with psychosis, despite acknowledging that this would be frowned upon within the SA community. Their need for support was more significant than their allegiance to their cultural ancestry. In addition, distancing themselves from their cultural community was connected to a conflict in values and feelings of frustration. Thus, going against the grain captures an active process of opposing cultural norms as these did not align with the participant's beliefs. Vikash uses this term to describe how he disclosed his sister's behaviours to healthcare professionals, despite his parent's objection:

'…its kind of, you know like brush it under the carpet like everything else… but yes I felt obligated to tell people, I felt er, I had to be very honest… erm, and I felt I had to go against the grain' (Vikash, 8-9, 147-151).

Feelings of frustration are evident as Vikash acknowledges his parent's denial. The phrase *'brush it under the carpet'* refers to a process of concealing and ignoring information from others as it may harm one's reputation. In contrast, Vikash recognises his duty to reveal the truth, perhaps as secrecy fostered a sense of angst and guilt. It appears as though he was left in a position where he had no other choice as a solution had not been reached, therefore he felt inclined to expose the reality of what had been happening in the family home. This process of being authentic perhaps felt empowering. Nevertheless, the pauses and utterances conveyed in his quote perhaps reflect a struggle to articulate this opposing stance. Vikash's use of imagery at the beginning and end of this excerpt perhaps assisted him in articulating these complex experiences as they transcend non-figurative meaning. Sara also illustrates her non-conformity to cultural expectations by using the same idiom:

'… I go against the grain anyway you know so for me it didn't have an impact cos those people who are very cultural and don't talk about this stuff weren't really part of my life' (Sara, 25, 537-539).

Here, Sara reports that disclosing her brother's psychosis was limited to individuals who were not strongly affiliated with the SA community. Thus, it appears that her defiance of cultural norms had no significant impact, as she distanced herself from these individuals. Her dissimilarity with this in-group further demonstrates the fragile connection to her SA identity. She continues to recognise her ability to challenge norms by discussing what is often considered to be forbidden, which perhaps enhances feelings of pride: *"…I think for me I've always been, the ability to talk openly about things that are taboo" (11, 237-238).*

Whilst acknowledging her family's desire for secrecy, Aisha sought emotional support from friends by informing them of her brother's psychosis:

'…I spoke to my friends more than I spoke to my family cos I couldn't speak to my family about anything, it was always, like "oh don't tell Aisha cos it will slip out of her mouth" you

know…whatever, so, I don't know I've always like I've, for me, I don't really hide anything…' (Aisha, 32, 691-694).

Aisha appears to express contempt for keeping secrets, which contradicts with her family norms. Like Sara, she too appears to pride herself on her ability to be entirely transparent and share *'anything'*. However, her inability to openly communicate with her family members perhaps felt frustrating and created a conflict within herself and with others. The expression *'slip out of her mouth'* indicates that she was experienced by her family members as untrustworthy and liable to unintentionally disclose information. Thus, there is a sense that she believed that her family members kept secrets from her, which may have left her feeling like an outsider, as she was overlooked within the family system. After acknowledging their judgemental attitudes, Aisha pauses and then continues to say *'whatever'*, which conveys an unwillingness to continue to dwell on their actions, perhaps as she felt hurt. Nevertheless, she disregards her family's reluctance to share information and communicates with her friends, which perhaps evoked a sense of relief.

To conclude, this subordinate theme elucidates on the growing distance between the participants and their SA identity as they express a need to challenge these cultural norms through actively disclosing and sharing their experiences with others. For Vikash, Sara and Aisha, transparency perhaps felt fulfilling and enabled them to experience containment from others.

3.3.3 Sharing experiences for validation

This sub-theme explores the value of communication and connection. Across many of the accounts, participants illustrate how they sought to alleviate distress through sharing their experiences in order to feel less alone. They turned to many different sources, including friends, family members and healthcare professionals in order to unburden themselves. Both verbal and non-verbal forms of interpersonal communication proved to be valuable coping strategies. Akshay acknowledges how he reached out to his brother's psychiatrist in order to better understand his psychosis:

'…erm, well I think what I coped then was, I think inadvertently my getting psychiatrist on board was quite good because talking out at a practitioner meant it made it all real and showed me that I wasn't going mad myself…' (Akshay, 63, 1632-1634).

Akshay acknowledges how he unintentionally sought support from the psychiatrist, who he felt appreciative towards. The expression *'on board'* refers to a process whereby an individual – in this case the psychiatrist – willingly engages in a process due to their acceptance. Hence, it appears that Akshay experienced this professional as supportive and validating. Engaging in a verbal dialogue with him perhaps felt reassuring. This is further conveyed when Akshay expresses a sense of relief from the realisation that he was not *'going mad'*, which suggests that there was an initial sense of emotional distress building inside him which felt uncontrollable. This appears to have dissipated following his interaction with the psychiatrist.

As previously mentioned, Aisha turned to her friends in order to seek emotional support, as she greatly valued these interpersonal relationships. Thus, her restrain of emotional display was limited to being in the presence of family members. An inherent desire to relieve herself from her inner turmoil felt possible in the presence of non-judgemental others:

'…they were always whenever I needed like you know to cry with somebody, to laugh with somebody or you know to keep my mind occupied or to vent to someone about something or they, they were like my rocks through everything…' (Aisha, 35,764-767).

Aisha recognises that she herself was in need of support when her brother became unwell and appears to stress the importance of human connection. The consistent presence of her friends perhaps enhanced a sense of belonging. Moreover, it appears as though she experienced others as validating in response to her sharing a range of verbal and non-verbal emotive expressions. In keeping her *'mind occupied'*, Aisha demonstrates how her friends had the ability to distract her from distressing thoughts and emotions, which perhaps evoked feelings of relief. In addition, she seemed to benefit from expressing some of the intense emotion as she describes her ability to *'vent'*, which indicates the attentive nature of others. Moreover, Aisha's use of metaphor in which she compares her friends to *'rocks'* implies that she experienced them as reliable and supportive, and valued their emotional strength.

In contrast to most of the other participants, Yusuf talks positively of the relationship with his mother as he acknowledges their ability to share emotions with one another. He appears to feel comforted by her empathy, which fostered a sense of containment: *"…she would give me a lot of emotional support so, I felt like I could speak to my mum" (32, 1015).* The ability to reach out and share experiences was reciprocated: *"I could talk talk to my mum and I could understand what like she was going through" (32, 1020-1021).* This affiliation perhaps further evoked a sense of emotional security as he recognised that his affective experiences were not aberrant, which perhaps reduced the intensity of emotional discomfort. However, I wonder if his ability to express his emotions was limited to this particular interpersonal relationship as other individuals did not endure the same experience as Yusuf and his mother.

Sara describes a unique process in which she intended to share her emotions through letter writing. She explains how her parents attributed her brother's psychosis to the moment when she moved out of the family home. This experience of being blamed appeared to evoke feelings of resentment as Sara described feeling wrongly accused:

'…so that was like oh I don't need this, you know I just thought you can't blame that on me now' (Sara, 18, 375-376)

It appears that Sara felt frustrated and unwilling to tolerate these accusations through her words *'I don't need this'*. Being blamed therefore perpetuated existing emotional distress and perhaps evoked feelings of self-doubt. This resulted in a need to unburden herself from a state of conflict by writing a letter to her mother:

'…it helped me unload and get things into perspective because you're being accused or you know what have you you have to tell yourself did I?...' (Sara, 19, 407-408).

Telling her story through written words appears to have alleviated Sara's emotional distress. Moreover, the idiom *'put things into perspective'* reflects a process of comparing different ideas, perhaps by gathering evidence, in order to ascertain the truth. Thus, it appears that letter writing offered Sara a greater sense of clarity in understanding what precipitated her brother's psychosis, as well as enabling her to express her emotions. However, she mentions that she did not actually send the letter as initially intended:

'…without sending it it was very therapeutic it helped me get over because that burden…' (Sara, 19, 415).

This term *'therapeutic'* further represents a process of healing, and there is a sense of relief as Sara acknowledges her ability cope with discomfort. Thus, despite seeking external validation from her mother, writing a letter appears to have fostered a sense of self-validation.

In summary, the participants reflected on the many ways in which they attempted to reach out and share their experiences. What is common across all of these accounts is the desire to feel heard and accepted whilst confronting an emotionally demanding experience. Experiencing validation evoked a sense of emotional security and, for some, a sense of belonging.

3.3.4 Separation for self-preservation

This sub-theme explores active and avoidant strategies which were employed by many of the participants, as they expressed a need to physically distance from their sibling in order to manage existing feelings of helplessness. It seems that this form of escape evoked a sense of relief as it diminished emotional distress and enabled the participants to prioritise their own needs. For example, Aisha acknowledges how she coped through a process of separation and self-enrichment:

'…I couldn't even deal with it anymore, I just thought, this is really tough like you know I, I've gotta go back to uni I kind of don't wanna be in this house cos it's taking a toll on my education' (Aisha, 9, 193-195).

Here, Aisha reveals that she reached a moment in time where her emotions became too overwhelming and intolerable. There was a need to step away and focus on more personal aspects within her life, education being the predominant concern. Prior to this shift, it appears as though she had been investing much of her time in supporting her brother. However, the phrase *'taking a toll'* suggests that this was beginning to feel unattainable due to the emotional strain that Aisha was experiencing. This arduous process perhaps left her feeling helpless and hopeless due to a lack of resolution, hence, her only option was to leave the family home and divert her attention elsewhere, in order to escape from the turmoil. Yet, Aisha appears to be reluctant to disclose her need for physical distance in her interview. This can be understood from the tentative phrase *'kind of'*. I wonder if this could be connected with feelings of guilt for leaving her family to manage without her. Akshay conveys a very similar experience to Aisha as he expresses a need to separate from the family and focus on his own education:

'…after a while, I then kind of you know got involved in my own stuff so my law school, I was tryna carve out a career, so I left them to it…' (Akshay, 16, 417-418).

This excerpt reflects Akshay's process of taking some space from his brother and other family members *'after a while'*. The ambiguous timeframe illustrates that a shift took place and Akshay began to focus on his own needs rather than attending to his brother. The colloquial term *'tryna'* conveys a sense of determination to fulfil his aspirations which perhaps is connected with a desire to achieve a sense of agency. Moreover, diminishing his sibling responsibility may have enabled Akshay to compartmentalise unpleasant emotions, such as feeling helpless when attempting to have more of an active role in his brother's treatment. These experiences have been described earlier in this chapter.

Sonia also describes a process of decision-making which resulted in distancing herself from her brother; however, her need for separation appears to be connected to her role as a mother:

'…when he got really really bad I couldn't stay over anymore with my kids I was like no I can't sleep in that house, and then as soon as Aaron left, I was like OK I'll come back in now…' (Sonia, 14, 302-304).

There is a palpable sense of fear throughout this excerpt as Sonia acknowledges her brother's increasingly unpleasant behaviour which she describes as *'really really bad'.* This became unbearable and ultimately resulted in her leaving the family home along with her children. The choices that she made demonstrate a prioritisation of children over her brother. Being in the presence of her brother became seemingly impossible and it seems that she felt highly concerned for her children's safety as well as her own, which further amplified a sense of fear and helplessness. Thus, it is likely that she experienced feelings of relief and safety from this separation. However, despite the discomfort she experienced in her brother's presence, she did not entirely avoid the family home:

'…I avoided it, I would only go for like the day visit, not not a sleepover or anything' (Sonia, 14, 308).

Here, Sonia conveys a need to maintain contact with her brother by occasionally visiting the family home, although she expresses a reluctance to spend great lengths of time with him. Her unwillingness to *'sleepover'* further amplifies a sense of fear as this conveys that temporarily she could not spend the night in her brother's presence. Thus, maintaining a distance perhaps enabled Sonia to feel more in control and at ease.

Sara associates her need to detach from her brother with his intrusive behaviour. She describes a process of removing him from her home and placing him in alternative accommodation, following a host of false accusations that he declared against her:

'…I had to detach myself from it cos I was pregnant, I was starting a new life I was about to have a child, there was already so much unrest in me, why would I take on the burden of this?' (Sara, 8, 172-174).

Sara reflects on personal life transitions that were taking place at the time, including her pregnancy. Like Sonia, she appears to prioritise motherhood over her sibling relationship and expresses a need to protect not only herself but her unborn child. It is interesting to see that she associates her pregnancy with *'starting a new life'*, which conveys the beginning of a new journey and entering into unfamiliar terrain. However, in order to reach this destination, it seems as though Sara felt the need to let go of old relationships and patterns which were hindering her from making progress. This included separating from her brother in order to manage her emotional distress. Sara's use of rhetorical questioning emphasises the importance of upholding this decision, as there is no expectation for an answer.

Thus, four of the participants took action by physically distancing themselves from their respective siblings as a self-protective mechanism. This separation served to minimise unpleasant emotions, which perhaps enabled them to function more effectively in everyday life. Aisha and Akshay diverted their attention towards career aspirations, whilst Sonia and Sara acknowledged the importance of their parental responsibility which took precedence over their sibling. The self-preservatory actions reflected across each of these accounts convey an underlying sense of self-worth.

3.3.5 Seeing the sibling

Despite distancing themselves, Sonia, Aisha and Sara also expressed a need to physically 'see' their sibling in order to resolve a state of uncertainty. Hence, this subordinate theme explores a method of reassurance-seeking, whereby they attempted to search for clues and gather information to ascertain answers regarding their sibling's welfare. A process of reality testing is conveyed in Sonia's account as she describes how she managed her anxieties:

'…I know it didn't help him but it helped me just to see, like I know it's bad that he's on the floor but he's still alive on the floor' (Sonia, 15, 318-320).

This excerpt reflects how Sonia sought to observe and confirm her brother's existence. It seems that sight dominated her entire perception, and an inability to see her brother evoked intense feelings of fear as she considered the possibility that he may no longer be alive. Feelings of relief are apparent as she reports that her visual recognition of her brother *'helped'*.

Echoing Sonia, Aisha expresses how her anxieties were maintained by a lack of visual evidence:

'… I I like to see everything so I like to someone getting fed and put to bed, the medication they're getting…and because I'm, I dunno a bit of a control freak…' (Aisha, 38, 815-817).

Here, Aisha describes her wish to regain a sense of control. She expresses a need to not only see her brother, but also to observe the actions of others who were supporting him whilst he was receiving treatment. This seems to be associated with the doubts she held regarding her brother's treatment process. She defines herself as a *'control freak'*, which implies an overly obsessive need to exert control in all situations in order to manage her uncertainties. A discomfort appears to arise as Aisha acknowledges these personal attributes, and this can be depicted from the hesitance and tentative language that precedes her use of the colloquial term that she uses to define herself. Nevertheless, obtaining clarity through routinely visiting her brother in hospital diminished her fears, enabling her to feel more in control:

'…you know I went like once a fortnight, erm, and that helped just seeing him and having a conversation with him…' (Aisha, 39, 835-836).

The importance of visibility is highlighted here as Aisha reflects on the frequency of encounters that would take place. She also acknowledges the importance of verbal communication alongside seeing her brother and both of these methods of interpersonal communication allude to a sense of relief.

Although she had removed her brother from her home, Sara expresses her need to maintain proximity to him and a keep a vigilant eye on him in order to manage her uncertainties:

'…and I didn't, I didn't completely detach I kept an eye on him, and used to go to his room and then I'd find him not being there and then the discovery of oh my god he's got a gambling habit as well…' (Sara, 30, 650-652),

By stating that she *'didn't completely detach'* from her brother, Sara describes her attempts to hold the tension between wanting to separate from her brother whilst also needing to see him, which is connected to the internal conflict that she experiences. Visiting him frequently indicates that she remained cautious yet concerned about his actions. Thus, her disbelief in uncovering information about his addictive behaviours may transcend initial feelings of uncertainty.

In summary, Sonia, Aisha and Sara engaged in a process of reassurance seeking to manage their fears. It appears that their doubts resulted in a drive to obtain a sense of clarity through visually observing the behaviours of their siblings. This evidence either concurred with or disproved their existing worries, resulting in a greater sense of emotional control. However, the act of visually perceiving another individual reflects a passiveness and I wonder if this could have perpetuated their feelings of helplessness.

3.4 *'It's Shown Me Who I Am':* awareness of growth and transformation

This final superordinate theme explores a significant shift in perspective which occurred for almost all of the participants as a result of their sibling's FEP. Surviving this adverse experience has shaped their sense of self and the choices they make. They reflect on a higher level of awareness of their inner world and a greater sense of self-assurance, including a recognition of personal strengths, an increasing sense of compassion towards others and greater knowledge of psychosis. These attributes are affiliated with a desire to live more purposefully, which suggests that this overall experience was bittersweet. Thus, this theme explores their awareness of this personal transition and is encapsulated by a quote from Aisha's account: *'it's shown me who I am' (48, 1034).* She appears to see some value when acknowledging her brother's FEP and describes it as a personal learning experience. She continues:

'…so, I think it's defined my friendship circle, my like my future partner…my, whatever it may be…' (Aisha, 48, 1040).

Despite her initial tentativeness, Aisha indicates that her experience of having a sibling with a FEP has enabled her to clearly understand what she values from interpersonal relationships. This excerpt suggests that she obtained a new perspective which has assisted her in seeking out friendships and intimate relationships. Moreover, it appears that she has greater agency and feels more confident in connecting with others due to this sense of clarity. The ambiguous term *'whatever'* further emphasises the profound impact that this experience has had in shaping many parts of her life. This transformative experience appears to be irrevocable.

Sara echoes Aisha's experience of personal growth by stating that: *"I feel that I'm able to use that experience for my own personal development as a person" (35, 758-759).* As a result of her brother's FEP, it appears as though Sara feels more confident in being able to reach her potential by improving her own quality of life. For example, she identifies that an increase in knowledge has prompted her to engage in more self-care:

'…erm obviously I know it can run in families, and I do believe it can, um, I protect my emotional health more so, because I know that if my brother had it then there's a high chance that something could trigger that off in me as well…' (Sara, 35, 751-753).

A sense of fear arises from the possibility that she too could develop psychosis, which in turn evokes an increase in attentiveness to her psychological wellbeing. Thus, it seems that Sara also experiences a greater sense of agency due to taking more caution. However, she expresses some doubt in understanding what could precipitate an onset of psychosis as she uses the ambiguous word *'something'*. Hence, it is possible that Sara continues to experience worry regarding her future, despite her self-protective endeavours. This is also depicted in Yusuf's account:

'…it makes you very cautious about what like road that you take that path that you take it makes you it makes when when you see someone that's going through such an issue it makes you very cautious about your own mental health…' (Yusuf, 38, 1230-1232).

Fear of the future is pertinent within this extract as Yusuf emphasises a high degree of caution which has arisen from his experience. My understanding here is that Yusuf desperately wishes to protect himself to avoid facing the same experiences as his brother. His use of imagery *('the road you take'*) symbolises the importance of one's actions in fostering progress and change. The journey through each road is different, as is the destination. Hence, choosing which road to take is important. There is a sense of pressure building as Yusuf recognises his need to exercise good judgement in different areas of his life, as this can ultimately impact his emotional wellbeing in different ways. Like Sara, he acknowledges being at risk of developing psychosis. However, he also recognises his ability to cope with potential adversity in future and experiences himself as more resilient after having survived his brother's FEP:

'I feel like when you go through stuff like this then when you get another hardship it makes you more like stronger against it' (Yusuf, 18, 572-573).

Here, Yusuf implies that he feels more equipped to manage challenges that may arise in future, which seems to be inevitable. By referring to himself as *'stronger'* he identifies a personal shift which appears to be connected with a greater ability to tolerate distress. He continues to reflect on a process of development as he recognises that these personal attributes will continue to flourish over time. Thus, like Aisha and Sara, he too conveys a sense of self-assurance and perhaps even pride when recognising these strengths. Akshay reiterates this growth in confidence within his interview by stating that he feels *'very much in control now' (66, 1723)* in managing potential adversity in future, including his brother potentially becoming unwell once again. The term *'now'* further demonstrates his awareness that a shift has taken place over time.

Vikash acknowledges a newfound sense of purpose and describes how he strives to now share the knowledge he has gained about psychosis from his personal experience:

'…now it's totally different, I volunteer to speak about it, I've even been back to Bangladesh to speak about it and raise awareness…' (Vikash, 19, 424-425).

The phrase *'totally different'* implies a significant shift has taken place, whereby he no longer puts his *'head in the sand' (15, 317)*. Instead, Vikash willingly discloses his experiences with others and conveys a need to be transparent and open, with the hope of inspiring change. There appears to be a desire to influence the beliefs and attitudes of others. Going to Bangladesh where his ancestral roots lie demonstrates his determination to educate others in the wider SA community, which perhaps leaves him feeling fulfilled and empowered. He associates these aspirations with feelings of frustration towards current challenges in the cultural community that need to be addressed, particularly the act of reticence:

'…people ought to be talking about it, the reason why there are so many problems within our communities is because nobody talks about it' (Vikash, 19, 428-429).

Hence, Vikash also seeks to make others conscious of the importance of communicating about psychosis. Thus, his experience of having a sister with FEP has undeniably changed him.

Contrary to what was expressed within the other accounts, Sonia describes herself as being unchanged by this experience:

'I don't think it's had any impact on how I am towards myself, I don't know why it hasn't really actually (laughs), I think I am more aware and more understanding, say if one of my family members suffered from this I would be more sympathetic and I would understand it completely' (Sonia, 30, 664-667).

A discord arises in the first line of this excerpt, as Sonia conveys a sense of self-doubt when expressing that she remains untarnished. Her uncertainty is depicted by the expression *'I don't know'*; however, I wonder if there is a deeper layer of meaning beneath this. It is possible that Sonia's uncertainty could be connected to feelings of anxiety which arise when she is confronted with the possibility that a transformative process has occurred. Moreover, I wonder if her expression of humour enables her to safely express this uncomfortable realisation. Despite experiencing her intrapersonal processes as almost invariable, Sonia acknowledges a change in her interpersonal relationships which she attributes to a greater sense of knowledge. It appears that her brother's FEP was a powerful learning experience which subsequently fostered feelings of care and compassion towards others who may encounter the same experience. A similar experience is reflected in Aisha's account:

'…I'm able to analyse and understand er behaviours a little bit more, so if someone has some sort of mental health or whatever I can, I can kind of feel it or sense it when I'm talking to someone by their body language the way they are…' (Aisha, 44, 952-954).

An increase in knowledge appears to have augmented her ability to empathise with others who may experience mental illness. This, in turn, evoked a new sense of purpose. She continues:

'…I feel like I can have the conversations I had with my brother with someone else and try and make an impact to their life…' (Aisha, 44, 955-956).

Thus, it seems that Aisha's experience of having a sibling with FEP has enabled her to reconsider what is meaningful within her life. Almost all of the participants convey a similar transition. Hence, experiencing a sibling with a first episode of psychosis appears to have shaped their identities.

Discussion

4.1 Overview

The analytic journey depicted in the previous chapter reflects a co-construction between researcher and participants, although there is perhaps a greater emphasis on the participants meaning-making, as the interpretations have remained grounded in their experiences. This discussion chapter, however, will transcend the analytic data by exploring how it links with existing theory and research. This final chapter begins with a summary and discussion of significant findings that emerged from the analysis, which are contextualised within the wider literature, by drawing on similarities and differences with existing research studies. Notably, novel findings that arose will be examined, which draw upon many of the themes. However, it could be assumed that all of the findings, to some degree, are unique, due to this research study being the first to explore sibling experiences of FEP within the British SA population. Clinical implications of this research study and its significance to the field of counselling psychology, mental health services and the wider societal context will then be explored. In addition, this chapter will illustrate the measures that were taken to ensure that a high-quality research study has been conducted. Credibility will be evaluated by assessing the strengths and limitations of the research design and analytic strategy. Opportunities for future research will also be considered and recommended, to improve and build on the current knowledge base. This chapter ends with a reflexive discussion where I share my subjective thoughts and emotions on the entire research process.

4.2 Key Findings

The key findings from this research study have been presented under four areas which are thought to have significance for practitioners considering delivering or improving interventions for British SA siblings.

4.2.1 Psychological Distress

This doctoral research study has attempted to address the shortcomings in the literature by attempting to answer the following research question, which was posed in the initial chapter of the thesis: *How do second-generation British South Asians experience having a sibling with a first episode of psychosis?*

What is evident from the analysis is the significant impact of this lived experience on the participants' intrapsychic and interpersonal processes. All of the participants expressed a complex entanglement of emotions in response to interactions with, and perceptions of, their sibling, their family members, the wider SA community and mental health services. Feelings including fear, uncertainty, disbelief, anger, helplessness, ambiguous loss, compassion, sympathy and relief are depicted across their accounts. These diverse emotional responses are echoed in previous research studies with individuals following their brother or sister experiencing a FEP (e.g., Newman et al., 2011; Fisher et al., 2004; Sin et al., 2008, 2012). Similarly, studies exploring experiences of having a sibling with longer-term psychosis have also conveyed a wide range of contradictory emotions (e.g., Barnable et al., 2006; Kristoffersen & Mustard, 2000; Schmid et al., 2009; Stålberg et al., 2004).

In addition, the experience of frustration towards mental health services was prevalent in this study, as participants identified challenges with initially obtaining professional support for their siblings. They also described feeling relieved and grateful when services eventually became involved in their sibling's care. However, one participant described feeling overburdened with responsibility and felt her own needs were overlooked by mental health professionals. These experiences amplified a sense of helplessness and disempowerment and concur with findings from other research studies conducted by Newman et al. (2011) and Sin et al. (2012). Within these studies, some siblings reported feeling frustrated due to being disregarded by professionals. They also expressed a desire for more information from support services. Similar findings were reported by Penny et al. (2009). Although their study did not exclusively explore sibling experiences, participants who identified as British Pakistani and were of a younger generation expressed a strong desire to feel noticed and heard by professionals who were involved in caring for their relative with a FEP. Hence, the findings from the present study add to the existing literature and demonstrate that this discontent can also be experienced by second-generation British SA siblings.

During the debriefing stage of the current research study, all participants expressed their gratitude in having received further information on specialist services offering a range of interventions for family members of individuals experiencing psychosis (Appendix G). They reported that they were not aware of many of the agencies that were listed and stated that it was a valuable resource they could utilise, which further illustrated their desire to receive more guidance and support. Although this was not included in the analysis, one participant expressed feeling '*disappointed'* that services hadn't provided him with such information. These findings are surprising, given that professionals within EIPS should follow recommended guidelines which suggest engaging with family members and caregivers and offering support programmes and carer-focused psychoeducation during the early stages of psychosis (NICE, 2016). However, despite national policies and guidelines, Allen and Livingstone (2021) argue that service provision often fails to meet recommendations, which may perhaps explain these findings. Eassom, Giacco, Dirik and Priebe (2014) suggest that this may occur for several reasons, including insufficient planning, supervision and execution within services.

Overall, the overwhelming and conflicting emotions described by the participants in this study reflect a state of emotional ambivalence due to the co-existence of both positive and painful emotions. This often arises in response to significant life experiences that are deemed to be emotionally intricate (Rees, Rothman, Lehavy & Sanchez-Burks, 2013). Finding ways to support individuals to cope with these difficult unresolved emotions is therefore important. Nevertheless, some researchers, including Larsen, Hemenover, Norris and Cacioppo (2003) suggest that experiencing positive and negative emotions alongside one another may actually enable the individual to cope better when faced with adversity, as they can hold numerous understandings and meanings of an experience. The ability to embrace and accept these opposing and contradictory emotions is also a strong predictor of resilience (Larsen et al., 2003). However, the participants in this study described a number of ways in which they attempted to manage this emotionally distressing and all-encompassing experience, which perhaps also reflects their resilience.

4.2.2 Coping

Griffiths and Sin (2013) convey that the coping mechanisms employed by siblings of individuals experiencing mental illness are pivotal to their psychological well-being. Thus, understanding these mechanisms is important for practitioners working with these individuals. Coping is characterised as a change in one's thoughts and behaviours in order to manage discomforting situations (Folkman & Lazarus, 1985). As depicted in the Analysis chapter, participants adopted a variety of active and avoidant strategies to minimise the impact of their emotionally complex experience. Roth and Cohen (1986) suggest that utilising both avoidant and active strategies may be the best approach when faced with distress, although resolution is ultimately based on individual differences and contextual factors. Avoidance may provisionally minimise intolerable emotions, whilst active and proactive problem-solving strategies engender a sense of control and mastery. These processes are akin to those described by Lazarus and Folkman (1984) who examine two types of coping strategies: problem-focused and emotion-focused. The former refers to methods which attempt to solve a problem and put an end to the stressor, whilst the latter reflects processes which strive to diminish emotional distress associated with the stressor. All participants within this study seemed to engage in a variety of both approaches.

Participants engaged in different forms of avoidance in an attempt to diminish their psychological distress. Some strategies were behavioural whilst others were cognitive. For example, three participants intentionally suppressed their unpleasant internal experiences, which is comparable to cognitive avoidance, a term used by Folkman and Lazarus (1985). Similar findings are echoed by Stålberg et al. (2004) who identified that siblings of individuals with chronic psychosis also cope through avoidance. Psychological avoidance has also been associated with increased burden and feelings of overwhelm within additional literature which explored the coping strategies of young carers of individuals with FEP (Cotton, McCann, Gleeson, Crisp, Murphy & Lubman, 2013). Kuipers et al. (2010) suggest that cognitive avoidance may be helpful when addressing problems that ultimately resolve. However, they assert that this coping strategy may create adverse consequences, should problems intensify and become prolonged.

Some participants distanced themselves physically from their sibling in order to escape their emotional turmoil, although this did not involve completely detaching as they still remained present in their sibling's lives. There was a need to escape from their environment and create personal space by moving out of the family home or moving the sibling out. Bowman and colleagues (2015) also identified that siblings of individuals experiencing FEP engaged in distance coping strategies when things became too overwhelming. Interestingly, Sin and colleagues (2012) noticed that only younger siblings were more likely to distance from their brother or sister experiencing FEP as well as other family members. By contrast, older siblings in their study were more proactive in their approach as they were more inclined to research information about psychosis and raise awareness within the family and wider community. In addition, Sin et al. (2012) identified that older siblings of ethnic minority backgrounds were more likely to share caregiving roles with other family members. These findings were not observed within the current study. An association between birth order and coping style was not apparent, as all the participants engaged in both active and avoidant strategies. For example, one female participant described her need to physically distance from her brother and disengage with certain family members in order to cope with her emotional pain. Yet, she also reflected on her ability to openly talk about her experiences with others in order to spread awareness within the community. Furthermore, none of the participants in this study described themselves as secondary caregivers. It is not possible to ascertain why these findings deviate from those found by Sin et al. (2012). However, notable differences in the samples could be considered. Siblings in the current study all identified as British SA whereas siblings of ethnic minority backgrounds in Sin et al.'s (2012) study identified as Asian, Mixed Race or Black African. Exploring the degree to which coping strategies of siblings are associated with particular cultural or ethnic groups could be considered for future research.

One noteworthy and unique coping behaviour that emerged from the analysis highlighted gender differences in participant experiences. Only female participants expressed a need to physically see their sibling in order to resolve an unbearable state of uncertainty. This coping style has not been previously reported within the literature on sibling experiences of FEP. Reassurance-seeking has been defined as a safety behaviour (Borkovec, Alcaine & Behar, 2004) in which an individual attempts to diminish doubt and anxiety. Carleton (2016) explains that family members may particularly struggle to manage uncertainty when concerned for their loved one. This results in a need to gather information to reduce a sense of ambiguity. Female participants within this study seemed to engage in a process of reality testing due to experiencing a profound and intolerable state of uncertainty and fear in relation to the welfare of their sibling. This subsequently appeared to engender a sense of relief. However, seeking reassurance only temporarily reduces distress (Helbig-Lang & Petermann, 2010), hence, it is possible that the female participants continued to experience a prolonged state of anxiety, despite seeing their sibling.

Many participants also reflected on their attempts to acquire support for their sibling from mental health services, which could be deemed as a problem-focused coping strategy (Lazarus & Folkman, 1984). Researchers have suggested that the negative perception of psychosis within collectivistic cultures such as the SA community may adversely impact help-seeking behaviours, as individuals feel more inclined to maintain a socially acceptable family image (Gilbert, Gilbert & Sanghera, 2004; Penny et al., 2009). However, participants in this study reflected on their struggles to acquire support, indicating their active intentions to access mental health services for their siblings. This perhaps illustrates a distancing from their SA identity and will be explored further in the following section. It is difficult to ascertain the extent to which culture and ethnicity influence these help-seeking behaviours. It would also be important to consider whether other factors are associated, such as age or level of educational attainment, which could be explored in future research.

Additional active coping strategies involved turning to and confiding in others in order to receive support and raise awareness. Some participants sought comfort from friends whilst others turned to certain family members. One male participant also experienced emotional validation when seeking reassurance from a psychiatrist and valued this source of support. For some participants, this intentional disclosure to others represented an act of defying cultural norms and expectations, which felt empowering. These coping behaviours seemed to arise in response to feelings of frustration towards the attitudes and behaviours of parents and others in the cultural community, which will be explored next.

4.2.2 Intergenerational Conflict

A significant finding which emerged reflects a tension between participants and family members or other individuals from the British SA community who were of an older generation. This could be associated with the concept of ‘intergenerational conflict’ (Abouguendia & Noels, 2001), which is often most intense between first- and second-generation immigrants who have been brought up in different cultural environments. Generational differences can create strong interpersonal conflict due to a clash in values and beliefs. This may create challenges when supporting a loved one with psychosis, as research has shown that a family environment which has a negative emotional climate comprising of conflict, criticism and confusion can adversely impact recovery and precipitate relapse in psychosis (Raune, Kuipers & Bebbington, 2004).

Participants associated their parents’ attitudes and behaviours with SA cultural norms, which they strongly opposed. Four participants expressed feelings of anger towards their parents when evaluating their caregiving abilities and attitudes. For example, one participant blamed his parents for arranging his sister’s marriage as he felt this could have triggered the onset of her psychosis. Another participant resented her mother’s overprotective nature and felt this behaviour adversely impacted her brother. Some participants also disagreed with their parents’ concealment of their sibling’s condition from others. These individuals were also told to keep it a secret but expressed a strong sense of indignation in relation to these expectations. Instead, they reflected on the importance and value of sharing their experiences with others.

The current research study builds on existing literature and demonstrates that individuals of a younger generation tend to hold ideologies that are antithetical to those held by older family members in relation to psychosis. Similar findings have been reported by Newman et al. (2011). In their qualitative study, one female participant expressed feelings of frustration towards her mother’s behaviours when evaluating how she had supported her sibling with psychosis. Moreover, in a Swedish study exploring sibling experiences of chronic psychosis (Ewertzon, Cronqvist, Lützén & Andershed, 2012), participants expressed a willingness to accept their brother’s or sister’s diagnosis, whilst their parents were more reluctant to acknowledge and disclose the illness to others due to a fear that this may bring shame and disgrace upon the family. Their findings perhaps suggest that a generational shift in attitudes towards psychosis has occurred over time. Moreover, the findings from both of these studies suggest that interpersonal tensions and the experience of intergenerational conflict are not exclusive to immigrants or ethnic minority communities such as the British SA population. However, whilst the authors above acknowledged tensions between siblings and parents, the participants in their studies did not reflect on their interpersonal tensions arising from a cultural conflict. By contrast, siblings in the present study describe intergenerational tensions in relation to their frustration towards the cultural values, beliefs and attitudes of older individuals within the SA community. Thus, this research study also offers unique insights by reflecting on how interpersonal conflict could be associated with the participant's bicultural identity.

Some participants in this study described other older individuals from the SA community as judgemental and rejecting towards their sibling with psychosis, which evoked strong feelings of anger. They perceived these individuals as ignorant of their sibling's condition and associated their attitudes and behaviours with a taboo and stigma of mental illness, which is prevalent within SA communities (Agius et al., 2010; Kishore et al., 2011). As mentioned in the introduction, within a collectivistic culture such as the SA community, mental illness is more likely to bring disgrace and dishonour on the entire family and tarnish reputation (Lauber & Rössler, 2007). Hence, for British SAs, having a relative with psychosis can be highly stigmatising, with a devastating social impact on all relatives. Some participants in the current study experienced stigma from others. For example, one female participant explained that she and her family were called '*loopy*'. Derogatory remarks such as these resulted in a sense of alienation and rejection from extended family members in the cultural community.

Stigma has also been reported in research studies exploring experiences of second-generation British SAs with FEP. Vyas, Wood and McPherson (2021) found that individuals with FEP felt pressured to conceal their mental distress due to the shame and dishonour this would bring to their family. Participants in their study experienced a tension from being positioned between different cultures. Many felt they were not affiliated with their SA cultural identity and attempted to distance themselves from the SA culture by sharing their experiences with close others who they perceived as trustworthy and understanding. Similarly, most participants in the current study actively sought practical and emotional support from others whom they regarded as compassionate and non-judgemental. Rather than concealing their sibling's psychosis, participants coped with interpersonal tensions by going *'against the grain'*. This is striking, given that obedience and loyalty towards elders in the family are paramount within the SA culture (Shariff, 2009). However, their defiance against cultural collectivistic norms enabled the participants to cope with their emotional strain. It is possible that the participants were influenced by Western individualistic cultural values, including affective expression, prioritisation of the self and autonomy (Soorkia et al., 2011). Given that the SA culture places importance on conforming to cultural norms, participants who defied these ingrained values may have experienced further disapproval from family members and others in the cultural community. This may have augmented the experience of intergenerational conflict.

Thus, many participants identified a need to cope with interpersonal tensions that arose between themselves and individuals from the older generation due to a conflict in values. They expressed a desire to confront and challenge existing cultural norms tied to their SA heritage, due to a distancing from their SA identity. Overall, these findings add to the existing literature on intergenerational conflict and demonstrate that this tension can arise within the British SA families where an individual is experiencing FEP.

4.2.3 Post-traumatic Growth

Although the experience of having a sibling with a FEP was highly distressing, it subsequently fostered a sense of personal growth and shaped the participants view of themselves and their world. Participants described having more resilience, greater self-assurance, increased knowledge, self-efficacy, a new sense of meaning and purpose in the world, and greater compassion and empathy. These thought-provoking findings demonstrate that positive psychological change can arise following the adverse experience of having a sibling with a FEP, which is akin to the transformative experience of post-traumatic growth ([PTG], Tedeschi & Calhoun, 2004).

PTG occurs in response to a major life crisis, whereby the underlying facets of one’s assumptive world are threatened. Psychological distress is heightened as predictability and controllability are challenged and the individual is confronted with a sense of uncertainty regarding sense of safety, self-identity and the future (Janoff-Bulman, 2004), all of which are reflected in the participants accounts in this research study. As demonstrated within this study, having a sibling with a FEP is a highly distressing, life-altering experience. Coping resources may become overwhelmed and individuals may indirectly experience additional consequences from their sibling’s condition, including interpersonal tensions with others. Morton, White and Young (2015) suggest that highly challenging experiences, such as these, provide a new impetus for positive growth, which can occur concomitantly to the residual anguish of the trauma. Thus, PTG arises. Following a traumatic event, internal cognitive schemas are modified to become more resistant to the impact of future life events which have the potential to shatter one's internal world (Tedeschi & Calhoun, 2004). This sense of change following adversity can be a deeply profound experience, as individuals surpass the levels of adaptation they had prior to the stressful event.

Tedeschi and Calhoun (2004) propose that PTG consists of five domains: increased resilience, new opportunities and priorities, greater admiration for life, spiritual development and stronger interpersonal relationships. Many of these concepts are reflected throughout the participants accounts within the current research study. For example, one participant reflected on his resilience in being able to cope with, and overcome, the emotional distress that arose in response to his sibling's presentation. This individual also expressed an increase in personal strengths following his experience of adversity, as he described feeling more self-assured in coping with potential hardships that may arise in the future. Experiences such as this lie at the core of PTG, as individuals can find strength and meaning from their negative experiences (Kaufman, 2020). Positive growth and resilience have also emerged in previous empirical research on sibling experiences of FEP. Although they did not acknowledge or define PTG, Sin and colleagues (2012) reported that participants in their study felt emotionally stronger and expressed self-improvement following their experience of having a sibling with FEP.

Participants in this study also reflected on a clearer sense of life purpose, which is considered to be an important facet of PTG (Tedeschi & Calhoun, 2004). Many expressed how their experience had shaped their goals, opened up new opportunities and provided a new sense of direction in their life. For example, one participant expressed his newfound desire to raise awareness about psychosis within the cultural community by spreading the knowledge he had developed from his experience. These findings are perhaps comparable to those identified by Newman and colleagues (2011). In their study, female participants reflected on a new sense of personal meaning, whilst male participants emphasised a change in priorities, following their sibling's FEP. The authors associated these findings with the concept of PTG. Similarly, Barnable and colleagues (2006) noted that siblings of individuals with chronic psychosis reported that their experience had uncovered a new sense of meaning and purpose.

Some participants also described a significant shift in attitudes and perspectives towards their sibling and other individuals. They described becoming more empathic, compassionate and insightful towards others experiencing mental illness and associated this change with having increased knowledge. Similar findings have been depicted in previous studies, where siblings of individuals with FEP expressed that they felt more considerate, supportive, understanding and better able to communicate with others (Bowman et al., 2015; Sin et al., 2008; Sin et al., 2012). In these studies, participants also described a stronger sibling bond as well as a more cohesive family system. Participants in the current research study did not reflect on such changes. However, one participant conveyed that her experience has ultimately informed her future relationships as she has become more insightful as to what she values from interpersonal connections.

To date, there appear to be no studies which solely examine the experience of PTG in siblings of individuals with psychosis. Sanders and Szymanski (2013) quantitatively examined whether siblings of individuals with mental illness experience PTG. Using the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), the researchers concluded that siblings experienced significantly higher levels of positive growth when compared to a control group. The authors postulated that coping strategies adopted by the siblings such as distancing may have contributed to new meanings and enhanced PTG. Exploring the connection between coping strategies and PTG in relation to sibling experiences of FEP could be a fruitful avenue for future research.

Overall, the findings from the current research study imply that the participants not only survived but were ultimately changed by their experience. The PTG framework could be useful to further our understanding of the positive changes that arise as a result of experiencing a sibling with a FEP. This would be important, given that Smith, Greenberg and Mailick Seltzer (2007) suggest that individuals who experience more personal growth from coping with their sibling's psychosis are more likely to better support their brother or sister in future.

4.3 <u>Implications for Counselling Psychology and other contexts</u>

Outlining the research findings from the current study and situating them within the existing literature, will hopefully enable CoP's to translate these new insights and understandings into professional practice. The research findings may have various implications which are not only applicable to CoPs, but also other mental health clinicians, politicians and legislators involved in service development, as well as funding bodies and community leaders working closely with the British SA population. These implications could create social and systemic changes at local and national levels which might impact siblings of individuals with FEP. In this section, I intend to demonstrate the value of my research study by exploring the impact and importance that the research findings could have within the field of CoP and the wider socio-political context.

Due to sibling experiences of FEP being largely neglected in the literature, there has been a lack of clear guidance as to how mental health providers can best respond to their needs (Sin, Jordan, Barley, Henderson & Norman, 2015). Rather than specifically addressing siblings, national guidelines instead recommend that family interventions should be offered for all significant carers and relatives of an individual experiencing FEP (NICE, 2014). However, research has identified that siblings seldom utilise these services (Sin, Henderson, Spain, Gamble & Norman, 2017). Moreover, Eassom et al. (2014) suggest that services often consider family support as secondary to support required by the service user experiencing psychosis and fail to recognise the importance of attending to the needs of caregivers and relatives. They further assert that family work is generally overlooked in services due to a lack of funding and resources. Participants within the current study did not discuss family interventions, hence it is not known whether these were offered and whether siblings would have wanted to engage, given the interpersonal tensions that arose.

Service providers and policy makers should review the effectiveness and comprehensiveness of existing treatment interventions for family members. CoPs and other practitioners offering therapeutic interventions within EIPS may want to consider how to ensure that interventions are inclusive towards siblings who may not be the primary caregivers, so that they do not feel neglected or overburdened. Given that EIPS may be stretched in terms of resources (Eassom et al., 2014), mental health professionals and policy makers should be pragmatic in considering what other support could be provided to siblings. Services could consider whether they could provide appropriate and accessible individual therapy to siblings. Where this is not possible, services could consider whether they have the scope to offer group interventions targeted at specific sub-groups of relatives, such as parents or siblings. This may be valuable, given the intergenerational tensions that can arise within the family. However, it is important to consider that funding may be required for this.

Moreover, as individual therapy for siblings may not be practically possible, EIPS could perhaps consider providing one-off support sessions delivered face-to-face, via telephone or remotely, where siblings have their own space to ask questions, express their own needs and feel listened to. These one-off interactions would differ from psychological therapy and therefore could take place between siblings and a variety of clinicians working within the multidisciplinary team. However, CoPs could perhaps provide training to staff with regard to developing basic therapeutic skills so that they feel equipped to engage with and respond to the needs of this population, given the level of psychological distress that siblings may experience.

Mental health professionals working with siblings may also benefit from receiving training focused on enhancing awareness of how sibling experiences and family dynamics are situated within a socio-cultural, political and historical context. CoPs may be well positioned to offer such training or supervision, by encouraging a reflexive attitude towards culturally normative beliefs about siblings and other family members. This can cultivate greater cultural sensitivity and respect towards individual differences, which may enable professionals to feel better equipped with understanding and responding to siblings' and other family members' needs within the British SA population. This could subsequently lead to more positive treatment experiences for siblings.

Given that the participants within this study expressed gratitude in having received information on support services (Appendix G), services may also want to consider developing suitable resources such as information leaflets that are specifically tailored to siblings, so that they are aware of the many external agencies that provide appropriate support. Such resources could be distributed within mental health services or through other platforms such as social media (for example, culturally relevant groups such as 'southasiantherapists' on Instagram).

CoPs could also extend their role beyond their workplace and collaborate with non-governmental organisations in the community, such as mental health charities in the UK (for example, Rethink Mental Illness), or organisations specifically offering support for individuals within the British SA community (for example, Sharing Voices Bradford). CoPs could support these services in developing or improving existing sibling support interventions, which could be delivered in person or virtually. Whilst sibling support groups do currently exist, it seems that individuals within the British SA population do not tend to utilise such services, as discussed in the Methodology chapter. Thus, service providers and researchers may first want to explore why British SA siblings may not access these groups.

CoPs and other professionals may have the opportunity to work therapeutically with British SA siblings in a one-to-one setting, for example, within the private sector. Therapists should recognise and validate the internal experiences and actions of siblings through the core conditions of congruence, empathy and unconditional positive regard as this can be a healing experience (Greenberg, 2007). Allowing siblings to tell their story and reflect on their intra-psychic distress, coping mechanisms and interpersonal tensions can enhance flexibility and awareness of the complexities of their emotional repertoires, which is crucial for managing ambivalence (Harrist, 2006). Moreover, exploring ambivalence and emotional overwhelm through therapy can be psychologically restorative, as siblings are able to use the space to make sense of their painful experiences through problem-solving and positive reinterpretation (Sanders & Szymanski, 2013), which can subsequently enhance PTG through schematic change (Tedeschi & Calhoun, 1996).

In response to the Covid-19 pandemic, therapists and other mental health professionals have adapted to new ways of working, primarily through engaging with and delivering interventions to service users remotely. Cronin and colleagues (2021) explored the effectiveness of using technology to deliver family interventions. Their research indicated that there was an increase in engagement and receptiveness for some relatives as they experienced less emotional overwhelm from social pressures. Although we cannot draw conclusions about the effectiveness of such interventions for siblings, future research could explore this further and consider whether siblings may benefit from, or be open to, receiving support from professionals through this form of communication.

4.4 Evaluation of Research

4.4.1 Quality, Validity and Theoretical Generalisability

Evaluating a research study requires adhering to a set of specific criteria that is consistent with the epistemological framework which has been adopted (Willig, 2012). Often, the concepts of validity, reliability and generalisability are assessed in quantitative research. However, this can be problematic when conducting qualitative research due to the lack of standardised measures and small sample sizes (Yardley, 2008). These criteria do not fit with a critical realist perspective, which has been identified as my epistemological position. Rather than aspiring to obtain a factual truth, this research study has focused on generating novel insights and nuanced understandings. Moreover, as IPA aspires to offer one of several interpretations, assessing the reliability of the methodology has been challenged by Yardley (2008), who suggests that this is not relevant or possible.

As previously mentioned in the Methodology chapter, this qualitative research study has aspired to achieve theoretical generalisability. This implies that the findings are not expected to be duplicated in another sample, but instead they aim to provide some value when being shared in other similar contexts (Yardley, 2008). In this chapter, I have attempted to contextualise the rich and meaningful data generated from the analysis within the wider literature. It is hoped that this will enable the reader to evaluate and assess transferability of the findings to other settings and populations. For example, the research findings may provide valuable insights for mental health professionals working with siblings from minority groups. Thus, the findings may be theoretically assimilated into clinical practice. Moreover, dissemination of the research findings and clinical applications through various means including a journal article and a leaflet for relevant mental health services (Appendix M) may further facilitate transferability. Therefore, theoretical generalisability appears to be broad and have flexibility within the qualitative approach.

Validity refers to the extent to which a research study corresponds with its aims and philosophical framework. Yardley (2008) proposes four generic principles which she believes are important in demonstrating the quality and validity of qualitative research. She contends that they should be appropriately adapted to the chosen research methodology. These principles are sensitivity to context, commitment and rigour, coherency and transparency, and impact and importance.

In order to demonstrate sensitivity to context, I familiarised myself with the existing literature to develop a coherent rationale for carrying out my research. This is demonstrated in the Introduction chapter, where I outlined how existing research shaped the research question and aims of this study. This process involved extensive reading both within and beyond the field of psychology. In accordance with my critical realist perspective, I believe that socio-cultural contexts partly shape our perspective of phenomena in the world. Thus, I explored historical and socio-cultural influences to demonstrate cultural sensitivity to the research topic, which is also depicted within the Introduction chapter. In addition, I have attempted to thoughtfully position the research findings within the wider socio-cultural and temporal context in this chapter. Moreover, I have also demonstrated sensitivity to my participants by remaining attuned to the social context and power differentials within the researcher-participant relationship. In the Methodology chapter, I outlined the steps that were taken during the data collection stage to avoid positioning myself in an expert role. This included enabling participants to choose a suitable location for interviews, as well as asking open-ended questions during the interviews to allow participants to freely express their thoughts and emotions.

Commitment can be identified by acknowledging the researcher's dedication to conduct a high-quality research study, whereas rigour refers to the thoroughness of the research process. During my doctoral training, I participated in research groups where I could discuss the procedural aspects of my research (such as sampling criteria and interview schedule) and practise coding as part of analysis. This enhanced my proficiency in conducting IPA research. In addition, completing a pilot interview was beneficial, as it provided me with an opportunity to attend to my interviewing skills to ensure that I could obtain rich and meaningful accounts that could be sufficiently analysed. Within the analytic process, continually returning to the interview transcripts when constructing higher-level themes enabled me to stay grounded within the participants' stories.

Coherence and transparency refers to the ability to demonstrate clarity and logic within the research process, which I have attempted to illustrate throughout this entire research study. In the Methodology chapter, I comprehensively outlined each facet of the data collection process and stages of analysis that I adhered to, as well as explicitly describing how I followed ethical guidelines. In the Analysis chapter, I provided quotations in verbatim from the participants transcripts, to enable the reader to evaluate the credibility and aptness of my interpretations. To support this, I have provided further evidence of the materials and resources that were used within various stages of the research process, which are shown within the Appendices. Yardley (2008) suggests that keeping a paper trail enables readers to retrace the steps that were taken by the researcher.

Finally, the impact, importance and implications of the research findings for CoP and the wider sociocultural community have been explored elsewhere within this chapter.

4.4.2 Strengths

There are many additional strengths of the current study. Firstly, the research is unique in that it is the first study to explore the experience of having a sibling with a FEP in an under-researched population – the British SA community. Although there has been an abundance of empirical attention directed towards caregiving in FEP, less recognition has been paid to sibling experiences. Devoting attention solely to siblings rather than other sub-groups of relatives has allowed their perspectives to be foregrounded and their needs to be conveyed.

As previously mentioned, the existing literature on sibling experiences of FEP in the UK has generally overlooked socio-cultural influences such as ethnicity. Thus, it is hoped that the current research study has deepened our understanding around the impact of culture on meaning-making processes for siblings within the British SA community who are of second-generation. The findings provide a useful contribution to the current literature, affording clinicians and other readers novel insights into the experiential realities of these individuals and enhancing the cultural applicability of wider services.

Further strengths of this study relate to the data-collection and analytic process. Adopting a phenomenological approach was valuable as the findings were not shaped by existing theoretical pre-conceptions and instead faithfully depicted the participants' subjective experiences. Moreover, the semi-structured interviews offered participants a platform to share their experiences in a safe space, which appeared to be advantageous. Individuals described the interview process as cathartic due to the nature of the questions which focused on their experiences as opposed to their sibling's experience. For many of them, this was the first opportunity they had to reflect on their inner world. Participants also expressed a sense of gratitude and pride from having had the opportunity to contribute to what they perceived to be a meaningful area of research. Thus, giving a voice to each participant further highlighted the value of exploring subjective experiences through IPA. Recognising and engaging with diverse perspectives through first-hand accounts also adheres to the values of CoP, which seeks to understand an individual's particular context and lifeworld (Rafalin, 2010). This further aligns with my critical realist epistemological position, which posits that experiences cannot be perceived in a universal manner. Furthermore, understanding subjective experiences can engender transformative change at both a micro- and macro-level. For example, research interviews can enhance individual meaning and empower research participants (Kasket, 2011). Insights into their experiential realities can also inform clinical practice. This has been addressed elsewhere in this chapter.

4.2.1 Limitations

Despite the aforementioned strengths and the compelling findings which have provided insights into the participants experiential realities, this study is not without its limitations. Firstly, as mentioned in the Introduction chapter, the concept of psychosis can be understood differently in various cultures. Clinical diagnosis and treatment approaches can also vary. Thus, as this research study was conducted in the UK, the findings and clinical implications may not be applicable to other countries.

In addition, the British SA population is composed of a variety of sub-groups of individuals whose cultural roots have differences in language and religion. This variability is also often depicted by geographical origin as South Asia is subdivided into different countries. In this study, sub-group differences were not considered, therefore, the sample may not necessarily reflect a homogenous group. Three participants identified as British Indian, two as British Pakistani and one as British Bangladeshi. However, Shariff (2009) argues that SAs do have a shared system of cultural customs and values regardless of nationality, language and religion. Nevertheless, it could be interesting to explore sibling experiences of FEP in British SA sub-groups in future to ascertain whether subtle distinctions arise.

Although there were some challenges with recruitment, all six participants expressed a willingness to partake in the research study and were selected through purposive sampling. However, all participants were from London, which is the most ethnically diverse city in the UK. It is possible that the experience of having a sibling with a FEP may have differed for British SAs residing in other parts of the UK.

Moreover, the research findings are based on retrospective recollection which raises concerns in relation to the accuracy of the participants' memory of their lived experience. Issues concerning memory may have arisen due to different time scales of each individual's experience. Participants were required to have a sibling who had been diagnosed with and recovered from a FEP within the last 10 years. Variability in recall periods may have impinged on the participants' ability to describe and reflect on their experiences. It has also been contended that IPA explores memory of a lived experience instead of the experience itself. Thus, obtaining retrospective accounts could be considered to be a limitation of this study and raises questions with regards to the validity of the findings. However, as previously discussed, the phenomenological approach does not seek to obtain a true reality of events. Instead, it strives to understand how an individual makes sense of a phenomenon which presents itself in the lifeworld. Hence, exploring the experience of having a sibling with a FEP retrospectively, without making assumptions about truth and reality, is not deemed to be a limitation within this research study.

4.3 Recommendations for Future Research

It is hoped that the research findings generated from this study can inspire future researchers to build on existing literature. The insights acquired can be building blocks which motivate further exploration. With the limitations above also in mind, this section of the chapter will provide recommendations for researchers to avoid potential obstacles when expanding on this research topic in future.

There are many opportunities for the current research study to be expanded. Firstly, the experience of interpersonal tensions and conflict in cultural values seemed to be a significant novel finding in this study and future research could perhaps expand on this by focusing more explicitly on the relational patterns between second-generation British SAs, their sibling with FEP and their other family members. This would be important to understand, given that interpersonal conflict and a challenging family environment can negatively impact all family members and precipitate future relapse for the individual experiencing psychosis. Attending to this in future research could enhance cultural awareness and competence of mental health practitioners working with British SA families.

Secondly, it could be interesting to explore intergroup differences by examining sibling experiences of FEP with various British SA subgroups. This would be valuable for observing any subtle distinctions and enhancing knowledge of researchers and practitioners working with these populations. Enhancing knowledge of unique group experiences related to culture aligns with the philosophical underpinnings of counselling psychology, which asserts that subjective experiences should be understood in connection with the socio-cultural context within which an individual is situated (Rogers, 1961). In addition, counselling psychology's dedication to multiculturalism highlights that clinicians should continuously be attempting to enhance their cultural awareness and cultural competence through exploring how concepts such as religion impact an individual's meaning-making and shape their sense of self (Cornish, Wade, Tucker & Post, 2014). This further indicates the importance of examining intergroup differences in British SAs' siblings.

The current study also yielded interesting findings relating to how British SA siblings cope with the impact of having a sibling with a FEP. The complexities of responding to this experience could be explored further in order to enhance understanding on whether the avoidant or problem-focused coping mechanisms employed had additional consequences. Research could also explore whether the coping strategies utilised by siblings are associated with particular appraisals or affective experiences. Lazarus and Folkman's (1984) transactional model provides a theoretical framework which explains that an individual's appraisal of a situation and their evaluative judgements about their coping abilities subsequently mediate their behaviour. Barrowclough and Parle (1997) noted that this theory is applicable to caregivers of individuals experiencing psychosis. It could be interesting to explore these potential connections with siblings of individuals with FEP.

Researchers could also utilise different methodologies to explore sibling experiences of FEP in the British SA population. For example, researchers could conduct large-scale quantitative studies and recruit siblings from different regions of the UK in order to attain a more representative sample of second-generation British SA siblings of individuals with FEP. This would enhance the applicability of the findings and could establish generalisability. Such research may also be better positioned to influence policy and systemic change. By conducting studies in a more experimentally controlled manner and perhaps employing standardised questionnaires, researchers may be able to identify whether there are differences according to gender, birth order, coping mechanisms and PTG in this population.

Within Australian literature, caregiving appraisals and interpersonal relationships have been quantitatively explored in siblings of individuals with FEP (Bowman et al., 2015, 2017). The authors used standardised measures such as the Experience of Caregiving Inventory (Szmukler et al., 1996) and the Adult Sibling Relationship Questionnaire (Stocker, Lanthier & Furman, 1997) to measure such concepts. Questionnaires such as these could be employed in future research being conducted in the UK, where researchers may be interested in focusing on more specific attributes of the sibling's experience.

As mentioned earlier, the concept of PTG also warrants further research in association with sibling experiences of FEP. It could be useful to conduct quantitative or mixed methodology research on a larger scale to further investigate positive and negative outcomes for British SA siblings, following their brother or sister recovering from a FEP. Extending this research to see whether siblings of individuals experiencing chronic psychosis also experience PTG could also provide valuable insights for clinicians.

4.4 Overall Reflections

Starting out this research journey was incredibly daunting, and I find myself now experiencing a sense of achievement as I come to the end of this process. Although the research findings reflected a co-construction of meaning between myself and the participants, this study has essentially explored and foregrounded the participants' experiential realities of having a sibling with a FEP. Nevertheless, I have inevitably had my own journey alongside that of the participants, which has been enlightening and inspiring. I believe that the research process has challenged my fore-understandings and shaped me, both as a human being and as a CoP.

Undertaking this research study has impacted me in a number of ways. I had moments of pause and reflection when the participants described their different ways of coping with the emotional turmoil they had experienced. I was struck by the polarity of their coping behaviours, some of which went against ingrained cultural values and others which appeared to conform to them. Moreover, gaining an awareness of the positive growth that was experienced by the participants was eye-opening and evoked feelings of hope and delight. My surprise in developing these new insights suggested that I had been able to step into the participants shoes and bracket my own assumptions. As a result, this study enabled me to feel more appreciative of the subjective and emotional intricacies of second-generation British SA siblings.

One of the main challenges that I experienced when conducting this project was recruitment. I had approached many third sector charities providing support groups for siblings but was often met with disappointment, as I had been informed that the British SA demographic rarely accessed said services. Nevertheless, engaging with organisations such as Rethink Mental Illness enabled me to develop positive relationships with professionals in the community. Many of these individuals wanted to remain in contact and expressed an interest in receiving a summary of the findings through dissemination, to enhance their knowledge and practice. This inspired me and led me to consider the positive influence of community psychology in invoking transformational change. Moreover, it has activated a desire to work more with other community leaders in the British SA population and use my platform as a CoP to generate conversations and educate others about the impact of psychosis in different socio-cultural contexts.

Writing up this thesis through a pandemic has been a challenging process as I often found myself plagued by feelings of isolation and self-doubt. Having a supportive supervisor and utilising personal therapy throughout this process was invaluable, as I was able to express these emotions in a safe space and feel validated. Moreover, when composing and bringing together each chapter, I was reminded about the value of this research, which enabled me to persevere. Using a reflexive journal has also been helpful, as this enabled me to bracket particular thoughts and emotions and fully attend to the participants' experiences. For example, noticing my own feelings of frustration towards the SA cultural community and connecting with my own experiences of having gone 'against the grain' were noted down in my journal. As a result, I felt more confident with interpreting the data from the participants' perspectives by continually asking myself, *'how is it for them?'* and *'what are they communicating?'*. This enabled me to eschew developing a piece of work which reflected similarities between the participants experiences and my own. Overall, I believe that this project encouraged me to become more reflexive and introspective as a researcher.

To conclude, I would like to end this doctoral study by devoting my final words to the six research participants, for whom I have utmost admiration. I feel privileged that they were willing to share their insights with me and believe they have been valiant and brave, given the emotional intricacies of their lived experience and the challenges of talking about mental illness in the cultural community. Their irrevocable experience of having a sibling with a FEP appears to have engendered a new understanding of themselves, of others, and of their world. I hope that their voices have been meaningfully and respectfully conveyed within this research study.

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Appendix A: Recruitment Flyer

Department of Psychology
City, University of London

Do you identify as a second generation British South Asian?

Do you have a brother or sister who has experienced psychosis?

Do you remember what it was like for you the first time they became unwell? If so, we would like to hear more from you.

We are looking for volunteers to take part in a research study to explore their experiences of having a brother or sister who has experienced and recovered from a first episode of psychosis.

As a participant in this study, you would be asked to take part in a face to face research interview, in a confidential setting, lasting approximately 60 to 90 minutes.

In appreciation for your time, you will receive a £10 Amazon voucher.

For more information about this study, or to volunteer for this study, please contact:

Ritu Sethi (Trainee Counselling Psychologist, Researcher)
[redacted]

or

Dr Aylish O'Driscoll (Counselling Psychologist, Research Supervisor)
Email: aylish.odriscoll.2@city.ac.uk

This study has been reviewed by, and received ethics clearance through the City, University of London Psychology Research Ethics committee.

If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on [redacted] or via email: [redacted]

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk.

Appendix B: Use of Services During Recruitment Process

NAME OF ORGANISATION/SERVICE	ACTION	RESPONSE
[redacted]	[redacted]	[redacted]
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Appendix C: Interview Schedule

INTERVIEW SCHEDULE

Opening Dialogue

As you have read from the Participant Information Sheet, my research topic is based on your experience of having a brother/sister who has had a first episode of psychosis. I am specifically interested in exploring what it was like for you as a sibling, as previous research has been limited on this, so the questions I will ask during this interview are intended to focus on how it was for you and to explore what this experience was like for you.

Opening Questions

- What is your understanding of psychosis based on your experiences? (*Inform participant "There is no correct answer as this term is understood differently by different individuals i.e. professionals [psychologists, doctors, nurses], those who are diagnosed, etc. however I am interested to explore what it means to you*)

Experiences of Sibling FEP

- Could you describe what it was like for you when your brother first became unwell? *(Note: could also use terminology used by participant from previous question)*
- *Prompts:*
    - How did you feel when this happened? (Physically, emotionally)
    - What thoughts did you experience about what was happening?
    - What impact (if any) did it have for you when your brother/sister became unwell? (i.e. did this have an impact on your social life, family life, psychological well-being, relationship with sibling?)
    - How did you view yourself in the relationship with your sibling during this time?
    - In what ways did this change?
    - Can you describe any positive/negative aspects this experience had for you?
    - What things did you find challenging about being a brother/sister to your sibling during this time?
    - What things did you value about being a brother/sister to your sibling during this time?
    - Can you tell me about a particular time when ___? *(relate to something they have described)*

- What was your experience of how others were responding to your brother/sister becoming unwell?
- Prompts:
    - How did people in your culture/community respond to what was happening?
    - How did you experience reactions from others towards yourself?
    - What was this like for you?

- What was your experience of your sibling receiving treatment?
- Prompts:
    - What thoughts/feelings did you have about your brother/sister's treatment?
    - Were you involved in the treatment approach in any way?

- What was it like for you to see your brother/sister become well after experiencing this first episode of psychosis?
    - What are your thoughts on your sibling's recovery?

- Can you tell me a bit about what helped you cope during this time?
- *Prompts:*
    - Did you talk to anyone about what was happening during the time?
    - What was this like for you?

Ending

- Looking back on this experience of your brother/sister's first episode of psychosis, how do you make sense of it now?
- Prompts:
    - Has this experience impacted your feelings and beliefs about psychosis?
    - Has this experience had any impact on how you think about your own mental health?

- What is your understanding of psychosis based on your experiences that you have shared with me today?

- What does the future look like for you as a sibling of someone with psychosis in the context of what happened?

- Are there any other comments/thoughts/ideas which you want to add?
    - Is there anything we have not discussed that you think is important or that you would like to add before we finish?

Appendix D: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Title of study First Episode Psychosis in British South Asians: Exploring the sibling's lived experience.

Name of principal investigator Ritu Sethi (Research Investigator); Dr Aylish O'Driscoll (Research Supervisor)

We would like to invite you to take part in a research study. 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. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Psychosis is a term used to define a range of mental health conditions, such as schizophrenia and is often described as a loss of touch from reality. The British Psychological Society identify that an individual who has been diagnosed with psychosis may experience hallucinations (such as hearing voices), delusions (unrealistic beliefs) and thought disturbances, along with withdrawal, lack of motivation and possible difficulties in expressing emotion. A first episode of psychosis often has an impact on the family members as well as the individual who is experiencing it. Sibling relationships are often one of the longest relationships that an individual will possess in their lifetime; therefore, it is important to explore their experiences. Until recently, there have been few studies exploring the experience of a first episode psychosis in an individual from the sibling's perspective. In addition, there is little research which has explored this experience within the British South Asian culture.

This research study aims to explore the experiences of second-generation British South Asian individuals who have a sibling that has experienced a first episode of psychosis. Moreover, the sibling must have experienced and recovered from their first episode of psychosis within the last ten years.

Recovery from a first episode of psychosis will be based on your perception of whether you believe there has been an improvement or reduction in the symptoms of psychosis which your sibling initially experienced. Understanding whether there have been subsequent episodes or relapse after this first episode of psychosis will not be discussed within this research study.

The research study will be conducted as part of a Professional Doctoral programme at City, University of London. You will be required to take part in an interview with the researcher, lasting approximately 60 to 90 minutes.

Explicit Consent

As this research is intending to focus specifically on the experience of British South Asians, you must consent to allowing the identity of your ethnic origin to be discussed in this study. All other personal information such as names and ages will be kept confidential and anonymous.

Why have I been invited?

You have been invited to take part in this research study as you have identified yourself as a second-generation British South Asian who was born in, or moved to, the United Kingdom before the age of 5 years. You also have a brother or sister who has experienced and recovered from a *first* episode of psychosis within the last 10 years. You must currently be at least 21 years of age and must have been no younger than 16 years of age when your sibling experienced their first episode of psychosis. In addition to you, there will be approximately 7 other individuals who will be taking part in this research study.

Do I have to take part?

Participation in this research study is optional and voluntary. If you do decide to take part, you will be asked to sign a consent form. You have the option to withdraw from the study at any stage up until data analysis begins to take place and you do not need to give a reason as to why you would like to withdraw. Data analysis will begin 3 months after the interview has taken place. However, once the data analysis begins, there will no longer be an option to withdraw your data from the study. In addition, once the research study has been written up and if it is published, there will not be an option to withdraw your data from the study.

It is not compulsory to answer all questions as part of the interview if you feel uncomfortable in doing so, and you will not be penalized or disadvantaged in any way.

What will happen if I take part?

If you agree to take part in this research study, you will set an interview date with the researcher. The research interview will take place in a private one-to-one room in City, University of London. However, there is also the option of having the interview completed in your own home if this is more suitable for you.

The research interview will last approximately 60 to 90 minutes and the session will be recorded. During the interview, you will be asked questions about your own experiences of having a brother or sister who has experienced a first episode of psychosis and how you made sense of this experience. You will not be required to complete any questionnaires.

Voucher for Participation

You will be offered a £10 Amazon voucher as a show of appreciation and gratitude for taking the time to take part in this study. This voucher will be given to you by the researcher once the research interview has taken place.

What do I have to do?

If you are interested in taking part in this study, you will need to confirm by signing a Participant Consent Form once reading this information sheet. You must then agree with the researcher, a suitable time and location in which the interview will take place. The interview must take place in a relatively quiet environment due to the nature of the discussion which will take place and the importance of obtaining a clear recording.

What are the possible disadvantages and risks of taking part?

As this interview is interested in your experiences of having a sibling who has experienced a first episode of psychosis, it is possible that some questions or topics may be difficult to discuss and may cause some level of emotional upset. For this reason, you will be able to stop the interview to take a break or terminate at any point.

What are the possible benefits of taking part?

The research may inform professionals of the needs of siblings who have a brother or sister with psychosis, which is often overlooked. This research would enable them to develop a better understanding of the impact of culture and ethnicity on psychosis within a British South Asian family and better inform practitioners of the needs of siblings. It may enable mental health professionals to develop more supportive and positive relationships with siblings of individuals with psychosis, which can therefore have an important role in the recovery process.

What will happen when the research study stops?

Once the research study, stops, the results will be written up as part of a doctoral thesis. Any data relating to this research, other than the digital audio recordings, will be stored securely on encrypted documentation for 10 years at City, University of London. The audio recordings from the interviews will be destroyed immediately once they have been transcribed. You will have the opportunity to be sent a summary of the research study should you wish, by providing your email address on the Consent Form.

Will my taking part in the study be kept confidential?

- Only the primary researcher (Ritu Sethi) and research supervisor (Dr Aylish O'Driscoll) will have access to the research data.
- All interview recordings will be deleted once they have been transcribed
- Any names of individuals, including yourself, will be kept anonymous
- Any data stored on hard-drives will be kept on encrypted documents
- If you choose to withdraw your data in future, you must contact the researcher
- No data will be shared with other outside organisations
- If information relating to risk to you or other individuals is reported during the interview, confidentiality may need to be breached. If this is the case, the

researcher will first discuss this with you and may then need to inform other parties in order to protect individuals who may be at risk of harm.

- The interview data will be archived for 10 years in line with statutory requirements at City, University of London. After 10 years, this data will be destroyed.

What should I do if I want to take part?

If you are interested in taking part in this study, please inform the researcher (Ritu Sethi) once you have finished reading this Participant Information Sheet. You will then need to provide consent to take part in the research by signing a Consent Form. This does not mean that you are unable to withdraw from the study, as withdrawal will be possible until the commencement of data analysis, which will take place 3 months after the research interview.

What will happen to results of the research study?

Once the interview transcriptions have been analysed and the results are written up, you may request for summary of the findings of the research study. It is possible that this research study could be published in future. However, any personal details which you have provided regarding yourself and others will remain anonymous.

What will happen if I do not want to carry on with the study?

You can withdraw from research study at any point up until the data analysis begins. You do not need to provide any explanation for this and will not be penalized. Please inform the researcher (Ritu Sethi) if you decide that you do not want to continue participating in the research study.

Who has reviewed the study?

This study has been approved by City, University of London Psychology Research Ethics Committee.

Further information and contact details

For further information, please note the following contact details:

Ritu Sethi (Principal Researcher): [redacted]
Dr Aylish O'Driscoll (Research Supervisor): Aylish.ODriscoll.2@city.ac.uk

What are my rights under the data protection legislation?

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this information sheet. The legal basis for processing your personal data will be that this research is a task in the public interest. City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

Further, City considers the processing of special category personal data (such as ethnic origin) will fall under Article 9(2)(g) of the GDPR as the processing of this data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects.

The rights you have under the data protection legislation are listed below, but not all of the rights will be apply to the personal data collected in each research project.

- right to be informed
- right of access
- right to rectification
- right to erasure
- right to restrict processing
- right to object to data processing
- right to data portability
- right to object
- rights in relation to automated decision making and profiling

For more information, please visit www.city.ac.uk/about/city-information/legal

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at [redacted] or phone [redacted], who will liaise with City's Data Protection Officer [redacted] to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *First Episode Psychosis in British South Asians: Exploring the sibling's lived experience.*

You could also write to the Secretary at:
[redacted]
Research Integrity Manager

Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: [redacted]

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

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

Date: 11.12.19
Version: 5.0

Appendix E: Lone Working Risk Assessment

LONE WORKING RISK ASSESSMENT

The primary objective of this document is to ensure safety of the researcher during the data collection process.

The Lone Working risk assessment considers the following:

- Is there a risk due to the environment, location, contents or unfamiliarity? (If yes, the interview cannot be conducted in the participant's home)
- Is there safe entry and exit from the location? (If no, the interview cannot be conducted in the participant's home)
- Are there any risks of harm – based on known history of person being visited; family circumstances; living arrangements; personal security and safety; communication availability? (If yes, the interview cannot be conducted in the participant's home)

If a research interview is deemed appropriate to take place in the participant's home, pending on the above, the following control measures must be put in place. The researcher must always adhere to these guidelines:

- Informing the supervisor/safety contact before entering the participant's home, providing a rough estimate of length of time that will be spent there.
- Informing the supervisor/safety contact after leaving the participant's home.
- Informing the supervisor/safety contact of a particular code word that will be used in the event of any risk of harm or danger.
- Having the safety contact and emergency contacts on speed dial
- Taking a personal alarm
- Arranging the layout of interviews where there is easy access to exits i.e. close to the front of the house or near a door

Appendix F: Consent Form

CONSENT FORM

Research Study: *First Episode Psychosis in British South Asians: Exploring the sibling's lived experience*.

I confirm that I have had the research project explained to me and I have read the Participant Information Sheet, which I may keep for my records.

I understand that this will involve: Please Initial Box

Being interviewed by the researcher (Ritu Sethi)	
Allowing the interview to be digitally audio recorded	
Having the interview written up and stored securely and electronically on encrypted documents on a hard-drive	
This information will be held by City as data controller and processed for the following purpose(s): Public Task: The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees. I understand that the following special category data will be collected and retained as part of this research study: ethnic origin City considers the processing of special category personal data will fall under: Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects and also under Article 9(2)(a) of the GDPR as the provision of these personal data is completely voluntary.	
I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any point up until the researcher begins to analyse the data. I will not be penalised or disadvantaged in any way for withdrawal.	
I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
I agree to the arrangements for data storage, archiving, sharing	
I agree to the use of anonymised quotes in publication.	
I agree to take part in the above study.	

____________________ ____________________________ _____________
Name of Participant Signature Date

____________________ ____________________________ _____________
Name of Researcher Signature Date

If you would like a summary of the results of the study once it has been completed, please provide your email address below:

………………………………………………………………………………………………………

Alternatively, if you would prefer a summary of the results to be sent to you via the post, please provide details of your address below:

………………………………………………………………………………………………………

Appendix G: Debrief Information Sheet

DEBRIEF INFORMATION SHEET

Research Title: *First Episode Psychosis in British South Asians: Exploring the sibling's lived experience.*

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

This research was conducted in order to gain an insight into your experiences of having a sibling who has experienced and recovered from a first episode of psychosis. The data from the interviews will be analysed using Interpretative Phenomenological Analysis which seeks to explore how you make sense of these experiences and what they mean to you.

The experience of psychosis in South Asian families can be challenging due to the prospect of facing stigma within the wider South Asian community. The role of the family is important in South Asian communities, and mental illness can therefore be a distressing experience for the family members. Sibling relationships are one of the longest relationships and individual will encounter in their lifetime, hence the onset of a first episode of psychosis may impact both the individual with psychosis and their sibling. It is therefore important to explore this experience from the perspective of the individual who has a sibling with psychosis.

Until recently, there have been few studies exploring the experience of first episode psychosis in an individual from the sibling's perspective. Prior to this, much of the literature was limited to other family members' experiences, particularly parents. Research on the experience of individuals who have a brother or sister who has experienced first episode psychosis is scarce within the British South Asian population.

Exploring the lived experiences of individuals with a sibling who has experienced first episode psychosis could benefit mental health professionals and counselling psychologists, who are required to work in culturally competent ways to benefit the needs of both service users and their family members. Within the mental health field, there has been a greater move towards promoting psychological interventions involving the family which focuses on the dynamics of family relationships as part of the recovery process. Developing supportive relationships with family members, such as siblings, can play a pivotal role in the recovery process for individuals with psychosis.

The research question explored throughout the interview was: What are the lived experiences of second-generation British South Asians who have experienced a sibling recover from First Episode of Psychosis?

If you have any concerns about this research or about what has been discussed, please inform the researcher (Ritu Sethi). In addition, if you would like any support after what has been discussed in the interview today, please feel free to contact the following agencies:

Mind (Mind Infoline):

- Tel: 0300 123 3393
- Website: https://www.mind.org.uk/information-support/your-stories/joining-a-support-group/#.W_X5nU1prIU
- *Providing information on support groups for family members of individuals with a mental illness*

Rethink Mental Illness:

- Tel: 0300 5000 927
- Website: https://www.rethink.org/services-groups
- *Providing support groups for siblings of individuals with psychosis in various locations across the UK i.e. Croydon Siblings Support Group*

Hearing Voices Network

- Email: info@hearing-voices.org
- Website: http://www.hearing-voices.org/hearing-voices-groups/find-a-group/
- *Providing various support groups and therapy groups in different locations across the UK*

Intervoice (The International Hearing Voices Network):

- Website: http://www.intervoiceonline.org/support-recovery
- *Providing information about psychosis as well as having the opportunity to participate in online discussion forums and attend a variety of groups in different locations.*

Voice Collective (Mind, Camden):

- Tel: 020 7911 0822.
- Website: http://www.voicecollective.co.uk/support/about-groups/
- *Providing peer support groups and information for family members and carers' of individuals who hear voices.*

SANEline:

- Tel: 0300 304 7000
- Website: http://www.sane.org.uk/
- *Providing emotional support through texts, telephone helplines and face to face communication for individuals experiencing difficulty due to a family member being unwell, as well as an online peer support forum*

If you wish to find out more information on counselling and therapy services across the UK, please feel free to explore the following organisations, all of which provide information about qualified practitioners:

British Association for Counselling and Psychotherapy (BACP):

- Website: https://www.bacp.co.uk/search/Therapists

United Kingdom Council for Psychotherapy (UKCP):

- Website: https://www.psychotherapy.org.uk/find-a-therapist/

British Psychological Society (BPS):

- Website: https://www.bps.org.uk/public/find-psychologist

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Ritu Sethi (Research Student)
[redacted]

Aylish O'Driscoll (Research Supervisor)
Aylish.ODriscoll.2@city.ac.uk

Ethics approval code: ETH1920-0648*

Appendix H: Example of Coding and Emerging Themes

TRANSCRIPT EXTRACT FROM PARTICIPANT "SONIA"

(Extract taken from pages 25-28 of original transcript)

Emerging Themes	Transcript	Coding
Sonia's frustration from failing to be heard when trying to help Aaron	R: mm, mm, and how was that for you during those times, to be around him?	
	S: I was the same as I am around him now I didn't change, I didn't change, I'd be like "Aaron come on", I'd try and talk to him but it was like talking to a brick wall	D: self as unchanged L: repetition 'I didn't change' – confirmation that her attitudes behaviours towards her brother remained the same; emphasis that she remained constant in her approach C: a need to be the same/importance of consistency in order to cope/manage the situation – perhaps to help her brother; sense of determination? D: attempting to motivate and engage her brother and enforce change C: frustration towards her brother, feeling ignored and dismissed by her brother, sense of helplessness due to this struggle Dx: talking to a brick wall' – talking to someone who does not listen/respond
	R: mmm	
	S: he would never be aggressive or anything but I would try and talk talk talk but it would just, not go in, it was	L: never – affirming her brother's lack of violence – not violent/angry/hostile/confrontational at all C: perhaps she did not feel threatened/intimidated by him or experience him as dangerous L: or anything – general reference to things considered to be similar to aggression; perhaps wanting to re-affirm that he was not a threat L: talk talk talk – emphasis to show her behaviour in trying to continuously communicate with her brother D: attempting to communicate with her brother

Creating distance from her brother to cope with discomfort	falling on deaf ears he just wasn't listening he just wasn't there at that point	C: desperation to get brother to listen and respond, sense of responsibility and determination Dx: 'falling on deaf ears' – recipient does not listen/ignores C: feeling dismissed and ignored by her brother, sense of frustration and helplessness D: lack of presence of her brother, had completely withdrawn C: loss of brother, sadness and confusion in being unable to connect with him
	R: mmm, yeah,	
	S: when he got really really bad I couldn't stay over anymore with my kids I was like no I can't sleep in that house, and then as soon as Aaron left, I was like OK I'll come back in now	L: really repetition – emphasis on the challenging situation, became increasingly unpleasant C: sense of this being distressing and coping through separation; the need to protect her children; role of mother was more important than role of sister at this point, self as protector, unable to manage, feeling overwhelmed by the situation D: being in the home with her brother and children was not an option L: internal dialogue with the self, process of figuring out how to manage the difficult situation C: sense of worry and fear of safety when in the home, for others i.e. children? Feeling insecure around her brother; hypervigilance D: the need for distance from her brother, inability to spend lengths of time in the home C: relief in leaving the family home, feeling more confident in returning once her brother had left
	R: yeah	
	S: but I avoided it, I would only go for like the day visit, not not a sleepover or anything	D: avoidance of the family home, needing to reduce her time there – intentionally keeping her distance, conscious decision making C: coping through avoidance, keeping distance but not complete separation, form of protection and coping mechanism L: would not stay overnight temporarily – sleepover – providing this to demonstrate that she would not stay for extended length of time C: feeling uncomfortable to stay in the home, didn't want to remain, perhaps not associating the space with a positive experience

Seeking reassurance by observing her brother	R: mmm yeah, I wonder if there was anything else that helped you to cope during that time?	
	S: I don’t think so, I think the main thing was just seeing him, even though it didn’t help him it helped me cos I was like “oh ok he’s still alive like he hasn’t tried to kill mum”	L: uncertainty L: main thing – most important part of coping was seeing (“seeing is believing”) D: importance of visually observing her brother which was a useful coping strategy C: coping through seeing; importance of physical proximity/observation as a containing experience as it brings certainty – demonstrating that perhaps her uncertainty was associated with fear/anxiety due to the unknown? C: sense of relief and reassurance in seeing her brother and having physical exposure to the situation that her mother is safe L: hes still alive, he hasn’t tried to kill mum – possibility of death: expectation of the worst happening to others C: constant worry for the worst, fear for safety of others L: internal self-dialogue – process of reassurance seeking for herself
	R: yeah	
	S: and then my mum would tell me things that he had done too, I know it didn’t help him but it helped me just to see, like I know it’s bad that he’s on the floor but he’s still alive on the floor	D: learning about her brothers actions/behaviours from others; gathering information through hearing/communication to gain certainty/enhance understanding C: process of reassurance and seeking some certainty – another form of coping, C: reassurance and relief/comfort in seeing her brother alive, coping mechanism perhaps indicate prior anxiety, reality testing, knowing through seeing; L: ‘I know its bad’ – appears certain that her thoughts are inappropriate therefore needing to provide a justification C: self as investigator

	R: yeah yeah and how did you view yourself in your relationship with him during the time when he first became unwell?	
Feeling helpless when experiencing her brother as detached	S: mmm…I don't know. There's not really much I could do, like you can't really say anything that's gonna change it, like I tried to help my mum and get him to eat and drink but he just wasn't…there	L: mmm, I don't know- hesitation and pause followed by uncertainty in knowing where she stood in the relationship with him – perhaps the pause indicates a sense of discomfort in not knowing C: sense of helplessness and powerlessness, feeling defeated, recognizing and accepting her limitations D: acknowledging her limits/capacity to influence the situation C: sense of obligation as sister to support other family members, sympathy towards her mums helplessness D: her words have no power, recognising her limitations D: experiencing her brother as withdrawn; lack of absence L: pause at the end – difficulty to articulate her brothers presentation, perhaps discomfort in reflecting on this struggle C: sense of loss, frustration, feeling ignored ? continuous failure and inability to help/ influence change led to frustration
	R: mmm	
Sonia's frustration from failing to be heard when trying to help Aaron	S: so even if I wanted to there's nothing I could physically do or say to make it better or change it, like I tried, everybody tried, talk talk talk talk talk but it doesn't make a difference	D: acknowledging restrictions and limitations; difficulty in influencing change despite her desperation and desire to; physical limitations C: feeling frustrated and helpless, defeat, powerless in her actions and words L: nothing – certain & absolute, affirming statement to emphasize limitations, C: striving to help/influence positive change L: everybody – shared experience, perhaps emphasising the great sense of struggle in enforcing change D: her words had no power L: talk repetition – emphasising how her words had no impact; also to represent a sense of exhaustion and that she tried many times (desperation/determination) C: frustration that nothing was changing despite the effort she put in, perhaps feeling inadequate due to this?

Appendix I: Creating Cluster Themes From Emergent Themes

USING EMERGENT THEMES TO CREATE CLUSTER THEMES – "SONIA"

CLUSTER THEME (Superordinate themes for Sonia)	EMERGENT THEME	EXAMPLE TRANSCRIPT EXTRACT
Feeling helpless when experiencing her brother as detached	Sonia's frustration from failing to be heard when trying to help Aaron	*" so even if I wanted to there's nothing I could physically do or say to make it better or change it, like I tried, everybody tried, talk talk talk talk talk but it doesn't make a difference" (15, 331-333)*
	Feeling helpless when experiencing her brother as detached	*"mmm…what was challenging…again just feeling like there's nothing I can do. There's literally nothing. I tried, but there's not a lot you can do. You can't force them to eat. I mean I remember there would be piles of food and sometimes if we got lucky he would eat something that was there the day before if we were lucky, but even then it would be something little…you can't force feed someone" (19, 413-417)*
Sonia's fear when witnessing a change in her brother's identity	Sonia's fear from being unable to recognise her brother	*"…he would um, I remember when I was at my mums one time and he came downstairs and he was looking at my mum like "who are you? Why are you here? I don't know who you are", like he was just out of it, just not even, it was Aaron but it just was just the shell of Aaron, it wasn't the Aaron that we know" (6, 117-120)*
	Feeling frightened when witnessing Aaron's peculiar behaviours	*"I remember seeing loads of things like a book and it had all random writing on it like "oh you're useless 10%, 90% that doesn't make sense but the way he wrote it, it was 3 people talking and he was writing it down so it's like a conversation with 3 people just written down and then Aaron was in there somewhere…it was just random it was just really scary" (7, 131-138)*

Feeling conflicted towards her brother's treatment process	Feeling conflicted towards Aaron's changes during the treatment process	*"…but because he had his medicine, he was just, he was Aaron, like 20% Aaron but at least he was walking and eating, that was enough I was like oh my god finally, thank god… (23, 500-501)*
	A conflict between feeling guilty and appreciative of the treatment process	*"I mean I felt sad for him because every time I'd go he was locked behind a door, so I was like oh my god this is so sad and when it came to saying bye I was like I'm going into the world and Aaron is like locked behind a door…[ ]…but I was also like this is the best place for you, like this is where you have to be unfortunately until you're better…" (24-25, 538-546)*
	Feeling vulnerable amidst the unpredictable behaviours of others when visiting Aaron in hospital	*"…but I mean it was uncomfortable being in the hospital, cos you can't go in their rooms either so you have to go into the common room and that's where all the other patients would come and they would come and sit next to you and start talking and then the staff would try and tell them to leave politely but then they would start hitting the walls and screaming" (25, 563-567)*
	Sonia's awe when witnessing unexpected progress in Aaron	*"I would always visit him on a Sunday, cos my husband's off so he looked after the kids, and I went in and Aaron was up and about and he'd be walking which I hadn't seen him do in about 6 months and he had a biscuit and I was like oh my god (laughs) and the staff said they were trying to feed him up so then one time I brought him McDonald's when I went to visit and he sat and ate it all and I was like "what the hell?!" (22, 491-496)*
	Feeling frustrated when encountering restrictions in acquiring knowledge about the treatment process	*"…if he stops taking the medication I don't know if he would start hearing voices again or what, I mean I don't really know anything about all that stuff. Sometimes we couldn't be told things because Aaron is an adult so for data protection we weren't able to speak to staff about certain things, so in that sense the family was left out, unless Aaron tells us, which he didn't really, so I felt a bit lost in a way, we had no idea…" (27, 596-601)*
	Sonia's relief in observing Aaron's progress	*"…lovely, I was like oh thank god he's alright, because it could have gone so bad because he was at such a low point… he was either gonna hurt someone or hurt*

		himself, so it was a relief, I mean I think he's doing so much better now, he's still lazy but that's just the Aaron we know anyway…" (26-27, 586-591)
Sonia's sympathy towards her brother's experiences of hardship	Sonia's sympathy towards her brother's difficulties being disregarded	*"yeah cos he, I remember he did try and voice it and say that he was hearing voices but he was just told that he was just um, a child acting out or just doesn't wanna follow rules" (3, 65-67)*
	Sonia's sympathy towards her brother's struggle to cope with hearing voices	*"…he really just, he just went so underweight, I have tried to talk to Aaron about that, I was like "why didn't you eat?" and he said cos the voices were telling me not to" (9, 193-194)*
Experiencing sympathy towards the responses of others	*Experiencing sympathy towards the responses of others*	*it's hard because you would get a reaction like "oh just tell him to get a job" or, they don't understand they just, and because* **we** *didn't understand at the time, if we don't understand it they can't understand it either… so it was just like, erm, you're tryna talk to someone and explain something but you don't fully understand what you're explaining…" (28-29, 630-63)*
Avoidance of family members in the older generation due to their misconceptions	Sonia's frustration towards others' judgements of Aaron	*"…they don't get the severity of it they just think oh Aaron is lying in his room, he can't be bothered to do anything, he's just being lazy, and that's what he's been like always anyway, so these people are just assuming he's just been himself, so yeah" (29 , 641-643)*
	Feeling resentful towards family members in the older generation due to their ignorance	*"I was angry, so it affected my relationship with other people because I was angry at them cos they just, their minds are so closed off, especially older generations they don't really understand mental health, their just like "oh just get up and pull yourself together and carry on" (21, 466-469)*

	Coping with feelings of resentment towards extended family by distancing the self	*"…they don't understand like how it can really hold someone back and, make them sink really low, they don't understand their just like oh just get on, pull yourself together, do a hobby, so then I didn't talk to these people" (21, 473-475)*
Seeing value in her brother's psychosis as a learning experience	Feeling appreciative of her increasing knowledge of psychosis through time	*"mmm…I don't think so actually, I don't think it's had any impact on how I am towards myself, I don't know why it hasn't really actually (laughs), I think I am more aware and more understanding, say if one of my family members suffered from this I would be more sympathetic and I would understand it completely, so yeah" (30, 664-667)*
Experiencing frustration in help-seeking	Sonia's frustration from the barriers in initially accessing professional help	*"getting someone help is just so hard, unless they've been in the system already and their on record, for new people coming in it's really hard, luckily as well Aaron had written that book of conversations down, cos we took that into the GP and that made everything go much faster, without that they just weren't listening and wanted to see him when he wouldn't come in, I just found it useless, even for them to come to the home and visit him, they wouldn't do it because they didn't know like what kind of situation they would walk into, so it's really hard to get someone help when they're like that, it's just ridiculous" (23-24, 521-528)*
Sonia's fear for the safety of her loved one's	Sonia's fear for the safety of her loved ones in the presence of her brother	*"I, I felt so, because I've got two kids so when, say I would go upstairs to go to the toilet I would say to my mum stay with them don't let them go upstairs, because I just don't know what he's, what he's thinking what he's doing…" (6, 131-133)* *"mmm just very stressful, I remember feeling very stressed and until he actually went into hospital I was stressed out because I was worrying about my mum every night… if he's gonna do something, my mum was saying she would hide the knives and everything, so she was hiding it in like the house just in case… so I was just very stressed out, worrying what's happening to him" (12, 252-258)*
Seeking reassurance by		*"I don't think so, I think the main thing was just seeing him, even though it didn't help him it helped me cos I was like "oh ok he's still alive like he hasn't tried to kill*

observing her brother to manage anxieties	Seeking reassurance by observing her brother	*mum"… and then my mum would tell me things that he had done too, I know it didn't help him but it helped me just to see, like I know it's bad that he's on the floor but he's still alive on the floor" (14-15, 313-320)*
Sonia's relief from the support of healthcare professionals	Sonia's relief from support of healthcare professionals	*"mmm, Aaron has got help, that's the only thing, and also because he stayed in hospital for so long he was then passed over to social services, because if he had gone back to my mum, he, I think he would have erm, just gone back in his room and got back into his old routine of just sitting there and then it would have happened all over again…" (17-18, 385-388)*
Creating distance from her brother to cope with discomfort	Creating distance from her brother to cope with discomfort	*"…when he got really really bad I couldn't stay over anymore with my kids I was like no I can't sleep in that house, and then as soon as Aaron left, I was like OK I'll come back in now… but I avoided it, I would only go for like the day visit, not not a sleepover or anything" (14, 304-308)*
EXAMPLES OF DISCARDED THEMES	Experiencing frustration towards her brother's dishonesty (DISCARDED: relating to her brother's personal characteristics and not specifically the research question)	*"…it's hard because Aaron, when Aaron tells a story he adds a bit extra into it and he changes it… I don't know why he does that, so you never get the full story from him, but you can't always get the full story from other people either because sometimes they cant talk about things, so it feels like there's a gap sometimes" (27-28, 610-617)*
	Feeling comforted by the continued physical presence of healthcare professionals around Aaron (DISCARDED: relating to the support her brother receives now in the present)	*"now he's in a setting where he's supported, there's somebody there to check on him and ask him if he wants to do activities, but at my mums he wouldn't have that, he would just be in his room sitting, so I feel OK because I know that there are people there to keep an eye on him every day…" (18, 393-396)*

Appendix J: Table of Cluster Themes across all six accounts

TABLE OF CLUSTER THEMES FOR ALL SIX PARTICIPANTS

Sonia	Yusuf	Akshay	Aisha	Vikash	Sara
Feeling helpless when experiencing her brother as detached Sonia’s fear when witnessing a change in her brother’s identity Sonia’s fear for the safety of her loved one’s Creating distance from her brother to cope with anxiety Feeling conflicted towards her brother’s treatment process Sonia’s sympathy towards her brother’s experiences of hardship Avoidance of family members in the older generation due to their misconceptions	Yusuf’s anxiety arising from the uncertainty of his brother’s presentation Yusuf’s frustration towards the lack of empathy from others due to their judgemental attitudes Experiencing emotional containment from his mother Fear for the safety of his loved ones in the presence of his brother Feeling helpless due to his vulnerabilities as the younger sibling Coping with vulnerability through avoidance Feeling conflicted towards his brother’s treatment process	Feeling self-assured from his influential role within the family system Feeling overwhelmed with anxiety due to his brother’s unpredictability Akshay’s fear for the safety of his loved one’s in the presence of his brother’s aggressive behaviour Akshay’s frustration in response to his brother’s intrusive behaviours Feeling helpless in acquiring support for his brother due to his uncertainties Akshay’s frustration from the barriers in accessing professional help for his brother	Feeling overwhelmed from the uncertainties relating to her brother’s presentation Feeling conflicted between personal needs and the needs of her brother Coping with emotional distress through separation and self-enrichment Losing hope due to experiencing helplessness Being the ‘rock of the house’: feeling valued when recognising her influential role as the older sibling with others Seeking comfort through transparency with others	Feeling overwhelmed from his sister’s changing identity throughout time Vikash’s sympathy towards his sister’s powerlessness The prevalence of helplessness throughout time Vikash’s anger towards his parents for their overbearing control An inner conflict due to uncertainty of his role Vikash’s resentment towards Asian cultural norms Going ‘against the grain’ – Vikash’s defiance against Asian cultural norms	Sara’s overwhelming fear from witnessing changes in her brother Feeling angry towards the societal challenges relating to mental illness Sara’s self-sufficiency in managing uncertainty: expressing the self through writing Sara’s desperation to seek help for her brother The influence of personal life transitions in deflecting from her brother’s psychosis Going ‘against the grain’: Sara’s need for congruence through disregarding Asian cultural norms

Seeing value in her brother’s psychosis as a learning experience Experiencing frustration in help-seeking Seeking reassurance by observing her brother to manage anxieties Experiencing sympathy towards the responses of others Sonia’s relief from acknowledging the support her brother received from healthcare professionals	Awareness of the impact of his brother’s psychosis on identity development Recognising a personal growth in resilience and self-awareness as a result of his brother’s psychosis Yusuf’s idealisation of his brother prior to his psychosis Yusuf’s sympathy towards his brother’s experiences of adverse life events Feeling betrayed by his brother	Feeling conflicted towards the attitudes and responses of his family members Ambivalence towards Asian cultural norms The importance of interpersonal communication to manage uncertainties Akshay’s sympathy towards his brother’s experiences of hardship The need for separation and self-investment as a means of self-preservation Akshay’s desperation to acquire help Feeling hopeful due to the relief in seeing parts of his brother’s identity re-emerge Ambivalence towards the treatment of psychosis: fear, sadness, acceptance	Feeling empowered when defying cultural norms Aisha’s frustration towards Asian cultural norms Attributing blame towards others to manage her uncertainties Feeling conflicted towards her mother’s reactions Seeing the sibling to gain reassurance Feeling hopeful when receiving professional support for her brother Aisha’s fear of the potential for her brother to become unwell in future Awareness of a transformative self	Coping with vulnerability: a case of ‘Ostrich Syndrome’ Ambivalence towards the treatment process Awareness of resilience from coping with personal trauma(s)	Sara’s internal conflict arising from multiple demands Sara’s guilt when engaging in counterfactual thinking Feeling lonely in response to neglecting and unsupportive others Sara’s ambivalence towards her brother Maintaining proximity and a vigilant eye Sara’s resentment towards family members for their critical judgements Experiencing incongruence when avoiding transparency to cope with criticism Resentment towards the concept of perfectionism as an Asian cultural norm Separating from her brother for self-preservation

		Awareness of personal strengths arising from his experience			Experiencing greater self-worth through transparency with others The powerful self: Sara’s self-efficacy due to her identity as an older sister Sara’s awareness of personal growth from her experiences

Appendix K: Generating Superordinate and Subordinate Themes

TABLE OF SUPERORDINATE THEMES AND SUBORDINATE THEMES GENERATED FROM CLUSTER THEMES

OVERARCHING SUPERORDINATE THEME	**An Emotional Storm: conflicting feelings leading to a sense of overwhelm**	**Avoidance vs. Approach**	**'*It's Shown me Who I Am*': awareness of growth and transformation**
SUBORDINATE THEMES (AND UNDERLYING CLUSTER THEMES)	**Feeling overwhelmed in response to the sibling's changing identity** Sonia's fear when witnessing a change in her brother's identity Sonia's fear for the safety of her loved one's Yusuf's sympathy towards his brother's experiences of adverse life events Feeling betrayed by his brother (Yusuf) Yusuf's anxiety arising from the uncertainty of his brother's presentation Fear for the safety of his loved ones in the presence of his brother (Yusuf) Feeling overwhelmed with anxiety due to his brother's unpredictability (Akshay) Akshay's fear for the safety of his loved one's in the presence of his brother's aggressive behaviour Akshay's frustration in response to his brother's intrusive behaviours	***'A case of Ostrich syndrome'*** Coping with vulnerability through avoidance (Yusuf) Coping with vulnerability: a case of 'Ostrich Syndrome' (Vikash) Experiencing incongruence when avoiding emotional transparency to cope with criticism (Sara) **Separation for self-preservation** Creating distance from her brother to cope with anxiety (Sonia) The need for separation and self-investment as a means of self-preservation (Akshay) Coping with emotional distress through separation and self-enrichment (Aisha) **Going 'against the grain'** Feeling empowered when defying cultural norms (Aisha)	**NO SUBORDINATE THEME** Seeing value in her brother's psychosis as a learning experience (Sonia) Awareness of the impact of his brother's psychosis on identity development (Yusuf) Recognising a personal growth in resilience and self-awareness as a result of his brother's psychosis (Yusuf) Awareness of personal strengths arising from his experience (Akshay) Awareness of a transformative self (Aisha) Experiencing greater self-worth through transparency with others (Sara) Sara's awareness of personal growth from her experiences

	Akshay’s sympathy towards his brother’s experiences of hardship Feeling overwhelmed from the uncertainties relating to her brother’s presentation (Aisha) Sara’s overwhelming fear from witnessing changes in her brother (Sara) Feeling overwhelmed from his sister’s changing identity throughout time (Vikash) Vikash’s sympathy towards his sister’s powerlessness Sara’s ambivalence towards her brother **‘What do I do?’: An internal conflict** Feeling conflicted between personal needs and the needs of her brother (Aisha) Being the ‘rock of the house’: feeling valued when recognising her influential role as the older sibling with others (Aisha) Sara’s internal conflict arising from multiple demands The powerful self: Sara’s self-efficacy due to her identity as an older sister	Going ‘against the grain’: Sara’s need for congruence through disregarding Asian cultural norms Going ‘against the grain’ – Vikash’s defiance against Asian cultural norms **Sharing experiences for validation and affiliation** The importance of interpersonal communication to manage uncertainties (Akshay) Seeking comfort through transparency with others (Aisha) Experiencing emotional containment from his mother (Yusuf) Sara’s self-sufficiency in managing uncertainty: expressing the self through writing **Seeing the sibling** Seeking reassurance by observing her brother to manage anxieties (Sonia) Seeing the sibling to gain reassurance (Aisha) Maintaining proximity and a vigilant eye (Sara)	

	An inner conflict due to uncertainty of his role (Vikash) **<u>‘you can lead the horse to water but you can’t make it drink’: feeling helpless</u>** Feeling helpless when experiencing her brother as detached (Sonia) Experiencing frustration in help-seeking (Sonia) Feeling helpless due to his vulnerabilities as the younger sibling (Yusuf) Feeling helpless in acquiring support for his brother due to his uncertainties (Akshay) Akshay’s frustration from the barriers in accessing professional help for his brother Akshay’s desperation to acquire help Feeling self-assured from his influential role within the family system (Akshay) Losing hope due to experiencing helplessness (Aisha) Sara’s desperation to seek help for her brother		

	The prevalence of helplessness throughout time (Vikash) Feeling lonely in response to neglecting and unsupportive others (Sara) **Frustration towards family members and the wider South Asian community due to a conflict in values** Avoidance of family members in the older generation due to their misconceptions (Sonia) Experiencing sympathy towards the responses of others (Sonia) Aisha’s frustration towards Asian cultural norms (Aisha) Feeling conflicted towards her mother’s reactions (Aisha) Yusuf’s frustration towards the lack of empathy from others due to their judgemental attitudes Experiencing emotional containment from his mother Ambivalence towards Asian cultural norms (Akshay) Feeling conflicted towards the attitudes and responses of his family members (Akshay)		

	Vikash’s anger towards his parents for their overbearing control (Vikash) Vikash’s resentment towards Asian cultural norms Sara’s resentment towards family members for their critical judgements Resentment towards the concept of perfectionism as an Asian cultural norm (Sara) **‘it’s sad but it’s a blessing’: ambivalence towards the sibling’s treatment** Feeling conflicted towards her brother’s treatment process (Sonia) Sonia’s relief from acknowledging the support her brother received from healthcare professionals Feeling conflicted towards his brother’s treatment process (Yusuf) Feeling hopeful due to the relief in seeing parts of his brother’s identity re-emerge (Akshay) Ambivalence towards the treatment of psychosis: fear, sadness, acceptance (Akshay)		

	Aisha’s fear of the potential for her brother to become unwell in future Feeling hopeful when receiving professional support for her brother (Aisha) Ambivalence towards the treatment process (Vikash)		
DISCARDED CLUSTER THEMES	Sonia’s sympathy towards her brother’s experiences of hardship Yusuf’s idealisation of his brother prior to his psychosis Attributing blame towards others to manage her uncertainties (Aisha) Awareness of resilience from coping with personal trauma(s) (Vikash) Feeling angry towards the societal challenges relating to mental illness (Sara) Sara’s process of investigation to manage uncertainty The influence of personal life transitions in deflecting from her brother’s psychosis (Sara) Sara’s guilt when engaging in counterfactual thinking		

Appendix L: Distress Protocol

DISTRESS PROTOCOL FOR RESEARCH INTERVIEWS

Stages to manage potential distress in the research interview (requiring researcher judgment):

1. Continue to observe participant’s responses and body language throughout the interview. If they appear to show low levels of distress, consider changing the line of questioning or reminding them that they do not need to answer the question if it feels too difficult

2. If the distress appears to be mild, ask the participant if they would like to take a break, get some fresh air or have some water

3. If the distress appears high, this may require the termination of the interview, and asking the participant if they would like to continue on another day (without coercing them by also reminding them of their right to withdraw)

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Section B:

Combined Case Study and Process Report

The use of Cognitive Analytic Therapy in working with a client to increase capacities for self-reflection

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[1] All names used within this report are pseudonyms which have been changed to maintain confidentiality and protect the identity of the client and other individuals.

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Section C:

Publishable Journal Article

Formatted according to author guidelines for the *Psychosis Journal* (Appendix B)

First Episode Psychosis in British South Asians: The experience of post-traumatic growth in siblings

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