The Understanding and Help-Seeking of Psychotic Disorders amongst Service Users, Family Carer’s and Laypeople: A Sikh Perspective

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Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Health Sciences

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July 2022
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Acknowledgements

Firstly, I would like to express my upmost gratitude to my first supervisor – Professor Swaran Singh. Without Prof., I would have not been offered this amazing PhD opportunity. I also greatly thank Prof., for the time he has taken to provide me with invaluable guidance throughout my doctoral studies.

I would also like to give a huge thanks to my second supervisor – Dr Helena Tuomainen. I am truly appreciative for her dedicated advice, support and encouragement that she has provided me with throughout this process.

My sincerest gratitude to everyone that participated in my research, as well as all the individuals who spread the word about my study and encouraged people to take part. All of you really helped me get participants, which made this research possible!

Last but not least, thank you to my family and friends who have always made me believe I can achieve a PhD. Especially, my parents who have always provided me with endless love and have had constant faith in me, from the very beginning.
Dedication

To my remarkable grandparents – Gurmit & Rajinder - of whom I have always wanted to make proud.
Declaration

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where states otherwise by reference or acknowledgment, the work presented is entirely my own.
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Abstract

**Background:** Sikhism is the fifth largest major world religion across the globe. Despite forming a significant proportion of the minority ethnic population in Britain it has been overlooked in mental health research. Psychotic disorders are disproportionately higher across minority ethnic groups and there exists no research on how the Sikh community understand and seek help for psychosis. The way in which a community perceives psychosis can impact their duration of untreated psychosis, treatment pathways, diagnosis, experience and engagement of mental health services, and treatment outcomes.

**Aims:** To explore the understandings of psychotic disorders and associated help-seeking amongst adult Sikhs in England, and how family, religion, culture, and lived experience of psychotic disorders, influence these.

**Method:** An exploratory qualitative design was employed, utilising purposive and snowball sampling techniques to recruit Sikh service users in recovery of psychosis, their family members, and laypeople across England. The total sample size was 43, with semi-structured interviews conducted on 30 laypeople, 9 family members, and 4 service users.

**Results:** Each study had numerous superordinate themes and sub-themes. The common themes amongst all participant groups included: a lack of awareness and knowledge of psychosis; negative perceptions towards psychosis and general mental illness; professional help-seeking encouraged; the importance of family in help-seeking and support; and the religion and culture divide.

**Conclusion:** Based on these research findings, strives should be made to educate the Punjabi, Sikh community on different mental illnesses and this should be executed at both an individual and family level. Through increasing the awareness of psychosis and other specific mental illnesses, two essential benefits can be achieved: help-seeking for psychosis and other mental illnesses could be sought at an earlier stage which would positively impact clinical, social and functional outcomes and the negative perceptions around mental illness would be reduced.
Definitions of Key Terminology

South Asian
South Asian typically describes those whose origins are from the Indian subcontinent. It includes the countries of Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan, and Sri Lanka. However, for the purpose of this study, South Asian will be used to describe those of Bangladeshi, Indian and Pakistani origin.

Punjabi
The term Punjabi is used to describe people whose origins are from the Punjab region of North India. The majority of Sikhs in the UK are Punjabi, in most instances this includes those that have migrated from East Africa.

Indian
The term Indian is used to describe people whose origins are from India.

Sikh
The term Sikh is used to describe people who follow the Sikh religion founded in the 15th Century by Guru Nanak Dev Ji.

Religion
The term religion refers to a collection of beliefs and practices which a group of people follow regarding the cause, nature, and purpose of life.

Culture
The term culture refers to the learned beliefs, norms, characteristics, and social behaviour of a particular group of people.

Ethnicity
The term ethnicity can be linked to nationality and relates to people who identify with each other on similarities such as a common ancestry, religion, language, and cultural traditions.

First Generation
The term first generation in this study refers to those who immigrated from another country to the UK and are now a resident in the UK.

**Second Generation**
The term second generation refers to an individual who was born in the UK to one or more parents who were born in another country.

**Third Generation**
The term third generation refers to an individual’s parents born in the UK, but at least one grandparent born in another country.

**BAME**
The term BAME is an abbreviation for Black and Minority Ethnic individuals. In the UK it refers to those of non-White descent.

**Mental Health**
Mental health refers to a functional state of mind and body, feeling protected and the ability to cope with life, with a sense of connection with friends, family, and the wider community and environment. In this study, participants would use the term mental health as synonymous with mental illness (see definition below).

**Mental Illness**
The term mental illness is interchangeably used with mental health disorders or mental ill health throughout this study. It refers to disorders that impact an individual’s mood, thinking, and behaviour.

**Psychotic Disorders**
The term psychotic disorders in this study are used interchangeably with psychosis. It refers to severe mental disorders that causes abnormal thinking and perceptions, characterised by symptoms such as hallucinations and delusions.
Thesis Outline and Structure

The overall aim of this research study was to explore how the Punjabi, Sikh community in England understood and would seek help for a psychotic illness, and how family, religious and cultural belief and practice, and lived experience of psychotic disorders may influence this.

This thesis has seven chapters:

Chapter One begins with a background on psychosis and its relationship with ethnic minority groups. The sociodemographic profile and acculturation of the South Asian population in the UK is discussed which leads to the rationale for why Sikhs are the focus of this research. A comprehensive background on Sikhs, including their history and origins, principal beliefs, diaspora and the associated culture is outlined.

Chapter Two provides a comprehensive literature review on mental illness within the Sikh community, with an emphasis on research that focuses on how the Sikh community understand and seek help for mental illness. The review includes the religious and cultural view taken towards mental illness. The risk factors, causes, and help-seeking behaviours of mental illness are also discussed from academic and grey literature. The chapter closes with the rationale for the current research.

Chapter Three outlines the current study’s research aims and objectives followed by the rationale for adopting a qualitative methodology and the epistemological and ontological underpinnings. Details of the recruitment, data collection and analysis procedure are described, in addition to ethical considerations, researcher reflexivity, and the quality and credibility of the research.

Chapters Four to Six present the findings from the laypeople, family member, and service user study, respectively.

Chapter Seven comprises the discussion, implications and conclusions of the current research. This includes summarising the overall findings of the thesis and how these are in
line with the existing literature. The strengths and limitations of my methods are delineated. Recommendations are also provided for researchers, service providers and policy makers.
1. Background

This chapter provides a succinct background of the relationship between psychotic disorders and ethnic minorities and why the Sikh community is the chosen population for this study.

1.1. Psychotic Disorders

Psychotic disorders are a cluster of chronic and severe mental disorders that are conceptualised by abnormal thinking and perceptions. Individuals lose touch with reality, are unable to think rationally, and exhibit improper emotional reactions. This leads to daily life being difficult to carry out alone (Public Health England, 2016).

Psychotic disorders are correlated to chronic medical conditions, premature mortality, and are a significant burden to families and society (World Health Organization, 2019). This illness also accounts for a great proportion of the UK National Health Services (NHS) budget (Mangalore & Knapp, 2007; Ride et al., 2020). Thus, effectively treating psychosis is acknowledged as a national and international priority.

1.1.1. Symptoms

There are a variety of symptoms that present during a psychotic episode. The type and severity of symptoms can vary between individuals. The two core categories of psychotic symptoms are classified as positive and negative (World Health Organisation, 2019).

The primary characteristics of a psychotic episode include hallucinations and delusions. These are also known as positive symptoms. Hallucinations are usually auditory (hearing voices), but can also impact other senses, such as seeing, smelling, or feeling things that do not exist. Delusions refer to forming fixed false beliefs with conviction, despite them being bizarre or improbable.

The negative symptoms of psychosis refer to a decline in normal functioning and include: a decrease in speaking (alogia); appearing withdrawn; lack of motivation; reduced emotional expressiveness; poor speech; and the inability to enjoy things (World Health Organisation, 2019).
1.1.2. Types of Psychotic Disorders
There are a range of psychotic disorders which are recognised in two key diagnostic manuals: the International Classification of Diseases, Tenth Edition (ICD-10) (World Health Organisation, 2019), and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013).

The most common psychotic disorder is schizophrenia. This is considered the most severe, whereby the individual experiences many of the aforementioned symptoms. Other psychotic disorders are schizoaffective disorder (a mixture of psychotic symptoms and mood disorder symptoms), brief psychotic disorder (short-term display of psychosis typically resultant of stressful life events), schizotypal disorder (milder form of schizophrenia), and delusional disorder (experience only delusions, and no other features of psychosis).

Psychosis can also exist in other mental health disorders. These include bipolar disorder with psychotic features and major depression with psychotic features (NHS, 2019).

1.1.3. Prevalence
Globally, psychotic disorders affect up to 20 million people (Charlson et al, 2018). In the UK, psychosis is estimated to impact less than one adult in a hundred (0.7%) (McManus et al., 2016).

The first episode of psychosis generally arises between adolescence and early adulthood (Kessler et al., 2007). Men are at an increased risk of all psychotic disorders in comparison to women (Jongsma et al., 2019; NICE, 2016). Ethnic minorities are also at an increased risk of developing psychosis (Jongsma et al., 2019; NICE, 2016).

1.1.4. Aetiology
The causes of psychotic disorders are complex and not fully understood (Calabrese & Al Khalili, 2022).

Biomedical considerations for the causation of psychosis have been dominant in western psychiatry (Gilmore, 2010; NICE, 2016). Evidence for the hereditary nature of psychosis and
the role of genetics has been well documented (Gejman, Sanders & Duan, 2010; Avramopoulos, 2018; Pepper & Cardno, 2014).

The lifetime prevalence of psychosis in those with a first degree relative with schizophrenia is significantly higher than in the general population (Chou et al, 2017; LE et al., 2020). However, genetic risks alone are not adequate to justify the development of psychosis, as most of those who do acquire the illness do not have an affected relative (NICE, 2016).

Thus, psychosis has also been noted as a manifestation of social and environmental factors. These include childhood trauma (e.g., abuse, neglect, bullying), stressful life events (e.g., death, domestic violence, physical and sexual assault), substance abuse (e.g., early alcohol abuse, use of cannabis, ketamine and amphetamines), and socioeconomic deprivation (Public Health England, 2016; Read et al., 2005; Stilo & Murray, 2019; Schlosser et al., 2012; Varese et al., 2012; Longden & Read, 2016).

Research has also associated the function of epigenetics in the development of psychosis, by which related genes can be triggered as an outcome of social or environmental factors (Roth et al., 2010; Read, Bentall, & Fosse, 2009). Thus, the development of psychotic phenomena may arise as a result of a dynamic interplay of biological, social and psychological factors (Calabrese & Al Khalili, 2020; Zwicker, Denovan-Wright & Uher, 2018; Read et al., 2014).

1.1.5. Treatment and Management

In line with the medical model of psychosis, antipsychotic drugs are the most common treatment method (Calabrese & Khalili, 2022; NICE, 2016). Antipsychotics have a proven ability in both the treatment and relapse prevention for psychosis (Horst et al., 2005). However, they do not cure the illness and pose certain challenges for patients (Haddad & Correll, 2018). This includes a proportion of service users displaying a poor response to conventional antipsychotics (Sacco et al., 2009), in addition to experiencing undesirable side effects such as weight gain, sedation, and sexual dysfunction (NICE, 2016).

Antipsychotic medication can also be used in conjunction with psychological and psychosocial interventions. These include Cognitive Behavioural Therapy for psychosis
(CBTp) and Family Intervention for Psychosis (Flp) which are both NICE recommended (Sivec & Montesano, 2012; Claxton, Onwumere & Fornells-Ambrojo, 2017, NICE, 2014).

CBTp is based on a cognitive model of psychosis which proposes that the way an individual interprets an event can impact how they think, feel and behave (Wood, Burke & Morrison, 2013; Kuipers & Bebbington, 2006).

Research has found CBTp is significantly associated with an improved mental state, reduction in positive and negative symptoms, low social anxiety, improved mood and functioning, high satisfaction ratings and low disengagement (Lewis et al., 2002; Pilling et al., 2002; Wykes et al., 2008).

The family and caregiver are also considered a significant factor in the management of a psychotic illness (Pilling et al., 2002, NICE, 2014; McFarlane, 2016). Specifically, Flp is grounded on the principle that the individual with psychosis exists within a wider context. Thus, successful interventions must examine the close relations to the service user. Flp has been associated with reduction in relapses and less likelihood of hospital readmission (Bird et al., 2010; Pilling et al., 2002).

1.1.5.1. Duration of Untreated Psychosis

An early diagnosis of psychosis has been recognised to improve long-term outcomes of the illness (McGorry, Killackey & Yung, 2008). However, this may not be possible as the illness can go years undetected and undiagnosed by medical professionals. This period of untreated psychosis is referred to as duration of untreated psychosis (DUP) (Anderson, Fuhrer & Malla, 2010).

A large evidence-based has found that a longer DUP can lead to dire consequences (Marshall et al., 2005; Perkins et al., 2005; Norman & Malla, 2001). These include poor clinical, social and functional outcomes for the individual (Kirkbride, 2008; Drake et al., 2020). Shorter DUP leads to more effective treatment outcomes, improvements in symptoms and functioning, and better quality of life post-treatment (NHS England, 2020).
1.1.6. BAME Communities and Psychotic Disorders in the UK

The UK is an ethnically diverse society. According to the latest census results that are available, 86% of England and Wales total population is White. The remaining 14% accounted for ethnic minorities (Office for National Statistics, 2011).

A growing body of research has established ethnic variations in prevalence, prognosis and experiences of psychotic illness (Public Health England, 2016). The following sections discuss these topics in further detail.

1.1.6.1. Incidence of Psychosis in BAME Communities

Systematic reviews and meta-analyses have identified variations in psychosis prevalence by ethnic group (McGrath et al., 2004; Cantor-Graae & Selten, 2005; Bourque, van der Ven & Malla, 2011; Castillejos et al., 2018; Jongsma et al., 2019; Selten, van der Ven & Termoshuizen, 2020; Tortelli et al., 2015; Kirkbride et al., 2012).

According to these reviews the prevalence of psychotic disorders in all minority ethnic populations pooled is approximately 1.5 to 3.0 times the prevalence in majority populations (Morgan, Knowles & Hutchinson, 2019).

Regarding UK specific data, the Adult Psychiatric Morbidity Survey provided prevalence data of both treated and untreated psychiatric disorder in the English adult population. The latest version found that psychotic disorders were significantly associated with ethnic groups (McManus et al., 2016). Black African-Caribbean males experienced the highest prevalence rates of psychosis in the past year (3.2%), followed by Asian men (1.3%), and White men (0.3%)

This is in line with a systematic review and meta-analyses on the incidence of psychotic disorders in England from 1950-2009 (Kirkbride et al., 2012). Different forms of psychoses were significantly elevated amongst Black Caribbean, Black African, and South Asian groups in England.
1.1.6.2. Explanations for Increased Incidence in BAME Communities

The increased incidence of psychosis amongst BAME groups has been attributed to several factors pertaining to the social disadvantage of ethnic minorities (Das-Munshjl et al., 2010; Kirkbride et al., 2007; 2008; Morgan et al., 2007; 2008; Schofield et al., 2019; Karlsen and Nazroo, 2002).

These include socio-economic deprivation (Kirkbride et al., 2008; Kirkbride et al., 2017); unemployment (Boydell et al., 2013), consistent exposure to discrimination and racism (Pearce et al., 2019); limited social networks and social isolation (Kirkbride et al., 2014).

Additionally, ethnic minorities are reported to have an increased risk of adverse life experiences during childhood which could exacerbate the likelihood of developing psychosis (Morgan et al, 2007; Morgan & Gayer-Anderson, 2016). This includes increased incidence of single-parent families, separation from parents, increased negative childhood experiences, and lower academic attainment (Morgan et al, 2007).

Highest rates of psychosis within the UK have also been found in socially deprived areas and urban inner-city areas (Public Health England, 2016). Deprived neighbourhoods are largely inhabited by ethnic minorities, apart from those of Indian, Chinese, White-Other, or White-Irish origin (Office for National Statistics, 2020).

Misdiagnosis of psychosis has also been proposed to occur amongst BAME groups (Singh et al., 2007; Schofield et al., 2019). This has been attributed to clinicians not being sensitive to the cultural background of service users (Schofield et al., 2019), or due to racist assumptions (Singh et al., 2007).

1.1.6.3. Pathways to Care for BAME Communities

BAME groups have an elevated risk of adverse pathways to care for serious mental illness. These include compulsory admission, detainment, emergency department referrals, and criminal justice involvement (Weich et al., 2017; Bhui et al., 2003; Singh et al., 2013; Anderson, Fuhrer & Malla, 2010; Mann et al., 2014; GOV UK, 2018; Barnett et al., 2019; Halvorsud et al., 2018; 2019).
A recent systematic review explored ethnic variations in compulsory detention under the Mental Health Act in both UK and international data (Barnett et al., 2019). Black and South Asian ethnic groups were significantly more likely to be compulsory admitted in comparison to White ethnic groups (Barnett et al., 2019).

Similar findings were reported in a further systematic review on ethnic inequalities in pathways to care for adults with psychosis across England and Wales (Halvorsud et al., 2018). In comparison to British White, increased rates of civil detentions were found highest in Black Caribbean, followed by Black African, and South Asian. Additionally, Black African-Caribbean individuals were significantly more likely to have more police contact, and have criminal justice system involvement (Halvorsud et al., 2018).

Comparatively, South Asians had no significant difference in police or criminal justice involvement when compared to British White. This was a novel finding when compared to previous research which reported higher odds for civil detention amongst South Asians (Singh et al., 2013; Singh et al., 2007). However, South Asians had significantly higher rates of repeat admission and GP involvement (Halvorsud et al., 2018).

Numerous explanations have been proposed to account for the disparities in the pathways to care for BAME groups. This includes: the increased incidence of psychosis in ethnic minority groups, as previously outlined (Bourque et al., 2011); inadequate awareness of psychotic illness (Singh et al., 2007); recurrent negative experiences with mental health services (Morgan, Knowles & Hutchinson, 2019; Lawrence et al., 2021); institutional racism and discrimination (McKenzie & Bhui, 2007; Paradies, Truong & Priest, 2014); stigma towards psychosis (Mirza et al., 2019); and different illness expressions in ethnic minorities or disparity in explanatory models of illness (Carter et al., 2017).

Despite these existing explanations, it is still a government priority to tackle the disproportionate detentions for BAME groups. The recent review of the Mental Health Act (GOV UK, 2018), also known as the Mental Health Act White Paper, proposes that it must become a priority to reduce detentions for BAME service users and address their barriers for accessing services.
1.1.6.4. Religious and Cultural Needs of BAME Communities

Whilst religion and culture are two distinct concepts, they are often used interchangeably, with both having an influence on an individual’s understanding and experience of serious mental illness (Koenig, 2009; Mohr et al., 2006). However, the degree to which an individual’s religious and cultural needs are met is rarely acknowledged in mental health care (Dorwick et al., 2009; Mermon et al., 2016).

Mainstream mental health services are based on the ‘bio-medical model’ and have been described as ‘eurocentric’ (Race Equality Foundation, 2015). The practice of clinicians is ‘one size fits all’, with the view that all care and treatment is suitable for every ethnic community (Joint Commissioning Panel for Mental Health, 2014).

The UK Government has previously advocated cultural competency training be delivered to mental health services staff in England (Department of Health, 2005). However, subsequent research has proven that a lack of culturally appropriate care is still an ongoing issue (Islam, Rabiee, & Singh, 2015; Kang & Moran, 2020).

Mental health professionals have conveyed a lack of understanding and training to recognise and meet the religious and cultural needs of BAME patients (Islam, Rabiee, & Singh, 2015; Kang & Moran, 2020). Concerns were raised about healthcare professionals’ inability to distinguish whether unfamiliar views and practices were expressions of religiosity or delusions (Kang & Moran, 2020). This could lead to a lack of engagement and poor treatment outcomes reported in BAME groups.

In some cases, patients’ perceptions of clinicians lacking knowledge of cultural and religious needs has led to a lack of disclosure of their cultural and religious practices (Heffernan et al., 2014). Heffernan et al. (2014) found this was due to fear that these practices would be erroneously construed as a symptom of their mental illness. Service users have also expressed they desired to discuss their religious and cultural beliefs with their clinicians in an open manner without judgement (Singh et al., 2013).

Culture and religion should be integrated into mental health assessments (McSherry and Ross, 2002; Kang & Moren, 2020). However, training in religious and cultural competency alone will not wholly meet the needs of service users (GOV UK, 2018). It has been suggested
that collaborating with faith and community leaders would also be beneficial (Bhui et al., 2007; Department of Health, 2014).

Being considerate of the significance of religion and culture in mental disorders could lead to important developments in service provision. This includes timely access to care and the development of culturally accessible and appropriate service provision for minority ethnic groups (Fulford & Woodbridge, 2007). This is particularly important for psychotic disorders, whereby being left untreated leads to damaging consequences to the individual (Norman & Malla, 2001).

1.2. South Asians in the UK

South Asians are the largest and fastest growing minority ethnic group in the UK. They account for a total 7.5% of the population, equating to over 3 million people (Office for National Statistics, 2011).

The ethnic sub-category ‘Indian’ accounts for 1.4 million of the population (2.5%) and is the largest ethnic group in the UK, after White. Indians are generally those of Hindu or Sikh religious affiliation. In the UK, Sikhs make up 0.8% of the population, whilst Hindus’ make up 1.5% (Office for National Statistics, 2011).

South Asians remain poorly represented in mental health research, especially in comparison to Black African-Caribbean groups (Bowl, 2007). South Asian samples that have been used in mental health and psychosis-specific research have either lacked specificity, by grouping South Asians together, or have been largely comprised of Pakistani and Bangladeshi participants, who are of Islamic faith (Kings Fund, 2016).

Studies that group South Asian as one group suggest that the South Asian community is the same, sharing more similarities than differences. However, British South Asians are a heterogeneous group where great ethnic, cultural, and religious differences exist (Nazroo, 1997; Ineichen, 2008). Thus, it is pivotal that the subgroups from within the South Asian umbrella are explored individually. This will produce accurate data that can successfully address the challenges of misdiagnosis, underdiagnosis, and contribute to the development of culturally competent services.
1.2.1. Acculturation of the South Asians

Acculturation is a procedure in which a person embraces, acquires and transforms to fit into a new cultural environment (Robinson, 2005). There exist multiple models of acculturation. These models can aid in the understanding of how South Asians have endeavoured to accept and embrace their new British identity.

A popular model is Berry’s Model of Acculturation (1997). This is a bilinear model that classifies acculturation approaches into four tenets: assimilation, integration, separation, and marginalisation.

Assimilation refers to someone from a different culture, choosing the new culture and adopting the new cultural norms. Integration refers to combining both their original and new culture, adopting them simultaneously. Separation exists when the new dominant culture is rejected, and their inherent culture is retained. This often happens when the person moves to a region where there already exist large numbers of a similar ethnic community. Lastly, marginalisation is when an individual rejects both their original and new dominant culture.

Muslims have been found to prefer a separation strategy, with an inclination to emphasise their distinct religious identity (Ghuman, 1999; Robinson, 2003). Comparatively, Indians born in Britain, of both Hindu and Sikh faith, have been found to adopt an integration acculturation strategy (Ghuman, 1999; Robinson, 2003). This can be supported by findings from the British Sikh Report (2013), whereby Sikhs revealed they are proud of their ‘Britishness’ and have a preference to be identified as ‘British Sikh.’

Berry’s (1997) model theorises those individuals who implement an integration strategy will exhibit better psychological adaption than those favouring the other acculturation processes. Therefore, Sikhs may be less susceptible to psychological health issues than other minority ethnic groups, due to their better adjustment into the British society.

The acculturation literature has highlighted the important differences within the different ethnic and religious subgroups of the South Asian community which re-emphasises the significance of exploring research topics within these subgroups independently.
1.3. Sikhs

1.3.1. Why Sikhs?
Despite being one of the youngest religions, Sikhism is the fifth-largest major world religion. There are approximately 27 million Sikh followers worldwide. Most Sikhs remain in North India, where the religion originated, however there exists a strong Sikh presence across Europe and America, particularly Canada and the UK (Ember, Ember, & Skoggard, 2005).

There are over 432,429 Sikhs throughout the United Kingdom, with the majority residing in England alone (Office for National Statistics, 2011). This is a 28% increase from the previous UK Census in 2001 which reported 336,149 Sikhs (Office for National Statistics, 2001). 56.6% of this figure are British born.

Despite the Sikh community being a significant minority community in the UK, they have seldom been the focus of research. If researched at all, they are frequently integrated into the larger South Asian category. However, it is evident from the research outlined above that the Sikh community has key differences to other South Asian sub-groups that are generally used within mental health research.

1.3.2. An Overview of Sikhism
Sikhism originated in the 15th Century in the Punjab region of Northern India. Thus, most Sikhs identify with the Punjabi culture. The Sikh faith was founded by Guru Nanak Dev Ji\(^1\), the first of ten gurus\(^1\) (Singh, 2011; Nesbitt, 2015). The term Guru\(^2\) means teacher or mentor, and the term Sikh\(^3\) means learner.

The traditions, principles and philosophies of Sikhism is based on the teachings of all ten Guru’s between the period of 1469 to 1708. Each Guru supplemented and reinforced the message imparted by the previous Guru (Grewal, 1990).

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1 The founder of the Sikh religion
2 Teacher or Mentor
3 Student or Learner
The sacred Sikh scripture is the *Guru Granth Sahib*\(^4\), which is considered a living *Guru* and an everlasting guide to Sikhism by its compilation of teachings from the *Guru*’s (Singh 2011; Cole, 2010; Nesbitt, 2015).

Sikhism is distinctive to other major world religions, by condemning idolatry and discarding the oppressive caste systems. These are key tenants within the Hindu religion. Additionally, it does not promote fasting, circumcision and pilgrimages, which are pivotal principles of Islam. Instead, Sikhism is considered monotheistic, and endorses equality, believing all individuals are equal despite socioeconomic status or gender (Singh, 2011; Nesbitt, 2015).

The essence of Sikh teachings is that there is only one God *‘Waheguru’*\(^5\) who is considered shapeless *‘Nirankar’*, timeless *‘Akal’*, and invisible *‘Niranjan’*. The ultimate purpose of life for Sikhs is to concentrate on loving God and eventually uniting with God. This is reachable through acts of prayer, meditation and selfless service *‘seva’*\(^6\).

Sikhs engage in a form of meditation known as *Naam Simran*\(^7\). Prayer and meditation are thought to help peace of mind and enable the individual to get closer to God. A further unique tenet of Sikhism is *seva*, which consists of being of service to others without expecting any reward (Cole, 2010; Singh, 2011; Nesbitt, 2015).

In 1699, the tenth *guru*, *Guru Gobind Singh Ji*\(^8\), established the *Khalsa*\(^9\) which is one’s commitment and dedication to Sikhism. The *Khalsa* honours five volunteers who were willing to offer their lives for God. After they offered their lives to *Guru Gobind Singh Ji*, they were doused in *Amrit*, which consists of sugar and water mixed by a double-edged sword, known as a *khanda*. This ceremony, which is still used today, is known as the *Amrit Sanskar ceremony* and it signifies becoming a *Amritdhari*\(^10\) who is part of the *Khalsa*. Sikhs who are not baptised are known as *Sehajdhari*.

\(^4\) Religious scripture of Sikhism  
\(^5\) The Sikh name for God  
\(^6\) Selfless service and dedication to others  
\(^7\) Spiritual meditation on God’s name  
\(^8\) The last living guru  
\(^9\) The Pure One’s  
\(^10\) Baptised Sikh, initiated into the Khalsa
Both men and women can become *Khalsa* Sikhs, and they must dress in accordance to the *Five K’s*, which is their visible display of commitment to their faith. The *Five Ks* are as follows: *Kesh* (uncut hair); *Kangha* (wooden comb); *Kara* (steel bracelet); *Kaccha* (cotton undergarment/shorts); and *Kirpan* (steel sword). Additionally, *Khalsa* males are required to wear a turban, whilst females can just cover their hair with a scarf but can wear a turban if they choose.

Sikhs also have a distinctive individuality in having the surnames ‘*Singh*’¹¹ for men and ‘*Kaur*’¹² for women. The use of *Singh* and *Kaur* as an individual’s surname is to eradicate indication of status or caste and symbolises equality, as traditional surnames would reveal the caste of which the individual belongs.

Sikhs congregate together in a *Gurdwara*¹³, which is their place of worship. Within the *Gurdwara* is where Sikhs can practice *seva*¹⁴, through preparing and serving food for those who come to the *Gurdwara*. The meal served within the *Gurdwara* is known as *Langar*. The *Gurdwara* serves other purposes such as being a place for religious services, such as name giving, marriage and funeral ceremonies. Additionally, it is a place where individuals can study the Sikh faith and traditions, learn Punjabi and traditional musical instruments. It is also a community centre which offers food, sanctuary and companionship for those in need, particularly for the elderly.

With the principal of equality being pivotal to Sikhs, there is traditionally no official clergy. Although, within each *Gurdwara* there exists a *Granthi* who is a guardian and reader of the *Guru Granth Sahib*¹⁵, and may also have obligations such as care-taking the *Gurdwara*, leading services and ceremonies. There is also a *Gyani*, who is a person of comprehensive spiritual understanding and divine knowledge (Cole, 2010; Nesbitt, 2015; Singh, 2011).

¹¹ Lion  
¹² Princess  
¹³ Door to the Guru / A Sikh Place of Worship  
¹⁴ Selfless service and dedication to others  
¹⁵ Religious scripture of Sikhism
1.3.3. The British Sikh Diaspora

The first recorded Sikh in Britain is Maharaja Duleep Singh in 1854, who settled in Elveden, Suffolk. Maharaja Duleep Singh was the last King of the Sikh empire before he was exiled. This is generally accepted as the starting point of the Sikh diaspora (Singh & Tatla, 2006; Singh, 2011).

Whilst some Sikhs began migrating to the UK from the early 20th Century, the first major migration occurred in the 1950s, primarily due to the greatest mass migration in human history – the partition of India in 1947. India was divided into two independent territory states – India and Pakistan. Muslims settled in Pakistan, whilst closely half of the Sikh population in that region were required to desert their homes and settle in the Punjab.

Succeeding this phase of political unrest, the Indian economy depreciated and went into crisis (Chatterji, 2007). During this period, the prosperity within Britain and opportunities available for migrant workers led many Sikhs to leave their homeland in the Punjab, and work in manual labourer jobs in the UK (British Sikh Report, 2013; Singh & Tatla, 2006; Singh, 2011).

Thus, migrant Sikhs generally resided in traditionally manufacturing regions such as the Midlands, Yorkshire, Lancashire, and certain areas of London such as Southall and Ealing (Bance, 2007).

Whilst the vast number of Sikhs in the UK are from the Punjab region of India, many also migrated from their adopted home of East Africa in the 1960s and 1970s. This was due to the growing desire to ‘Africanise’ countries like Uganda and Kenya, which led to many Sikhs losing their jobs. Their migration story differed to those from Punjab, as Sikhs who had first migrated to East Africa were deemed ‘experienced migrants’ who were more skilled and educated, thus had more employment opportunities. Additionally, they were familiar with living outside their indigenous country of India (Robinson, 2005). As they lacked a strong connection to a native country, they were able to settle into Britain with more ease. Sikhs who migrated from East Africa initially settled in Leicester and London.

Whilst the UK Sikh community comprises largely of those who migrated from the Punjab and East Africa, other groups of Sikhs have also migrated to the UK over the years. This
includes Sikhs from Afghanistan who largely migrated in the 1990s to West London, due to oppression by the Taliban (Nesbitt, 2011).

The first built *Gurdwara*\(^{16}\) in the UK (also the first *Gurdwara* in Europe) was established in 1908 in Shepherds Bush. As the UK Sikh community has expanded, there are approximately 300 *Gurdwara*’s across Britain. Some of these are the largest outside of India (British Sikh Report, 2013).

1.3.4. *The Religion and Culture Divide*

Key principles of Sikhism are gender equality, abolishment of a caste system, and the prohibition of alcohol consumption. However, many aspects of Punjabi culture conflict with these. The following sections will delve into this discord between the Sikh religion and Punjabi culture.

1.3.4.1. *Gender Equality*

Whilst the teachings of the Sikh faith strongly promote gender equality, the Punjabi culture instead is prejudiced and patriarchal against women. The Punjabi culture is renowned for a strong gender imbalance, with women frequently being treated inferior to men.

This is evident within the family structure, whereby sons are favoured over daughters within a Punjabi, Sikh household. This is a phenomenon known as ‘son preference’ which exists in both subtle and overt ways (Sabherwal, 2014). The British Sikh Report (2013) reporting that 71% of British Sikh women have experienced gender discrimination from within their extended family, and 43% from within their immediate family.

There are several cultural practices that contradict the religious teachings of gender equality. This includes the celebrations of *rakri* and *lohri* (Kaur-Aujla, Shain & Lillie, 2019). *Rakri* is a celebration between brothers and sisters. A sister will tie a thread around her brother’s wrist which symbolises a brother’s protection over her. In return, the brother will give his sister a gift. The idea that a sister needs protection, posits that Sikh women need a man to be

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\(^{16}\) Door to the Guru / A Sikh Place of Worship
dependent on (Kaur-Aujla, Shain & Lillie, 2019). Additionally, the festival of lohri is to celebrate a birth of a boy. No such celebration exists for the birth of a girl.

Based on religious teachings, Sikh women should be equally allowed to act in religion roles such as Gyani\(^{17}\) or Granthi\(^{18}\), and serve in the community the same way as a Sikh man. However, females are rarely visible within Gurdwara\(^{19}\) committees. 55% of women experienced discrimination at the Gurdwara and 44% from within the local community (British Sikh Report, 2013).

1.3.4.2. Castes

Traditionally, Sikhs were taught to promote equality for all, and the abolishment of a caste system was sanctioned by Guru Gobind Singh\(^{20}\) in 1699. Nevertheless, the cultural Punjabi norms have led many Sikhs to still identify with the socially constructed caste system. A person’s caste is based on the occupation of their ancestors.

In 2013, the British Sikh Report found that only 30% of 650 Sikhs identified with a caste, and 69% of this group were those who identified with the caste ‘Jatt’\(^{21}\). This is considered a high caste. A very limited number of participants (3%) stated caste to be very significant (British Sikh Report, 2013). This could insinuate that, whilst still operating strongly in some parts of Punjab, the caste system in the UK has diluted over the years, as Sikhs are becoming well integrated in the British society. However, 20% of 757 Sikh respondents stated they would not be comfortable with their family member marrying into a different caste (British Sikh Report, 2014).

1.3.4.3. Alcohol Use

Intoxicants such as alcohol are forbidden in the Sikh faith. The gurus teach that "Drink makes one forget God and renders one liable to punishment in the other world." Additionally, “Do not drink this liquor, if you wish to swim across the ocean of life” and "Never should a Sikh take wine" (Sikh Wiki, 2016).

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\(^{17}\) Person of comprehensive spiritual understanding and divine knowledge
\(^{18}\) Guardian and reader of the Guru Granth Sahib
\(^{19}\) Door to the Guru / A Sikh Place of Worship
\(^{20}\) The last living guru
\(^{21}\) Farmers / Land owners
Despite these religious teachings, the Punjabi culture often encourages conflicting outlooks through community gatherings, media and entertainment. Thus, alcohol use and alcoholism as an addiction are very prevalent amongst the Punjabi, Sikh community (Aquis et al., 2008; Ahuja et al., 2003; Cochrane and Bal, 1989; Cochrane and Bal., 1990; Orford, Johnson & Purser, 2009; Taak, Brown & Perski, 2021).

Sikh men have a higher incidence of alcohol-related disorders (Cochrane & Bal., 1989). Developing liver cirrhosis leading to early mortality is also twice as high in Punjabi, Sikhs, in comparison to the general population (Balarajan et al., 1984). The British Sikh Report (2013) revealed that 27.5% of a large pool of Sikh participants found that alcoholism was an issue that affected families.

On a sample of over 2,500 respondents, 3% consumed alcohol daily, and 22% drank up to several times a week. 21% found that they had a family member within their household that drank alcohol to the point where it was a detriment to their health, and 24% stated that a household members alcohol use seriously impact the other household members adversely (British Sikh Report, 2019).

In a South Asian subgroup comparison, Sikh men drank more regularly and in higher quantities than Hindu and Muslim men (Cochrane & Bal, 1990). This finding reiterates the differences that exist within the South Asian subgroups.

Cochrane & Bal (1990) found that Sikhs who were more religious were less likely to drink alcohol. However, the British Sikh Report (2013) revealed a highly unanticipated result, whereby 13% Amritdhari²² Sikhs reported consuming alcohol, with up to 4% of this figure drinking at least several times a week.

Alcohol abuse within the Punjabi, Sikh community has dated back since the first migration in the 1950s (British Sikh Report, 2018). This was attributed to the need to quickly adapt to their new ‘home’ without the support of their family who remained in India. They were also pressured to earn a good income to send back to India. Additionally, they experienced racism,

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²² Baptised Sikh, initiated into the Khalsa
discrimination and segregation as a result of language barriers. For these reasons, many Sikh men coped through alcohol use (Kumar et al., 2018).

1.4. Chapter Conclusion
Psychosis is the severest form of mental disorder and ethnic minority communities have higher susceptibility and experience adverse pathways to care in relation to this illness.

South Asians are the largest minority ethnic group within the UK, however research pertaining to psychosis and South Asians is explored at a broad level. There are notable sub-group differences between South Asians, thus caution must be taken when making assumptions of South Asians generally.

Particularly, the Sikh community are more acculturated and assimilated into British society than other South Asian sub-groups. Additionally, they hold distinct spiritual traditions, customs, and cultural behaviour patterns. Nonetheless, they are rarely the focus of research.

The following chapter provides a literature review on mental illness in the Sikh community, with a focus on how they understand and seek help for mental illnesses.

2. Chapter Two: Literature Review
This chapter presents findings of a scoping literature review on the perceptions and help-seeking of mental illnesses within the Sikh community and the rationale for the current research.

2.1. Aim of the literature review
The overarching aim of this review was to summarise the current research evidence on how the Punjabi, Sikh community understand and seek help for mental illnesses. Due to the limited literature in this area, the review also included research that explored mental and psychological wellbeing.

There are several key focuses of the review:
1. To explore the understanding, beliefs and attitudes towards mental illness and mental wellbeing amongst Punjabi, Sikhs

2. To investigate the help-seeking behaviours of mental illnesses and barriers to accessing services amongst Punjabi, Sikhs

3. To investigate the role of the Punjabi culture and Sikh religion in the understanding help-seeking, and coping of mental illness and mental wellbeing

2.2. Search Strategy

2.2.1. Sikhs and Mental Health
An electronic search of academic literature was undertaken from inception to date (3rd March 2022) across six databases: PubMed, PsychInfo, ASSIA, Web of Science, and CINAHL. Searches were conducted at several time-points to ensure any new articles could be included (20th June 2020, 9th February 2021, 3rd March 2022).

Search terms included: (Sikh OR Sikhism) AND (Mental Health OR Mental Disorder* OR Psychiatr* OR Mental Illness OR Psychological Wellbeing OR Emotional Wellbeing OR Psychological Distress OR Distress)

The search was not limited to psychotic disorders and included studies on general mental health, psychological distress, psychological/mental wellbeing. Only studies in the English language were included.

Based off the latest search (3rd March 2022), there was a total of 404 papers retrieved across the databases, with 334 remaining after duplicate removal. After title and abstract screening there remained 40 relevant results. Of these, 22 were deemed applicable after full text review.

Papers were excluded from this search if they did not refer to mental illness, psychological distress, or psychological/mental wellbeing. They were also excluded if they did not clearly detail the inclusion of Sikhs as part of their sample.

Appendix 1A contains the full electronic database search strategy results.
2.2.2. South Asians and Mental Health

Due to the limited number of results retrieved from the Sikh mental health literature search, a second database search was also performed on South Asian mental health. This was to identify papers which may have included Sikhs as part of their sample but could have been missed in the initial search.

This search was conducted from inception to 9th February 2021 across PubMed and PsycINFO.

**Search terms included:** (Punjabi OR Panjabi OR South Asian) AND (Mental Health OR Mental Disorder* OR Psychiatr* OR Mental Illness OR Psychological Wellbeing OR Emotional Wellbeing OR Psychological Distress OR Distress OR psychosis OR psychotic OR schizo*) AND (knowledge OR understanding* OR belief* OR attiud* OR percept* OR concept* OR help seek* OR pathways to care OR treatment* OR service* OR explanatory model* OR prevalence OR incidence)

A total of papers 2467 were retrieved across the two databases, with 2347 remaining after duplicate removal. After title and abstract screening there were 372 papers deemed potentially relevant. 12 articles were already included based on the Sikh mental health electronic database search, thus were removed from this pool. Of the remaining 359 papers, 25 were included after full text review.

Papers were excluded for the same reasons as detailed above in Section 2.2.1.

**Appendix 1B** contains the full database electronic search strategy results.

2.2.3. Additional Searches

Backward chaining of the reference lists of relevant studies was also carried out. Titles were initially screened from the reference lists, and for those broadly deemed relevant, abstracts were scanned. This included titles that referred to Sikh, Punjabi, South Asian, Asian or Indian.
Additionally, Google’s search engine was utilized to retrieve other material, such as grey literature including Master’s or Doctoral Dissertations and national governmental documents. Search terms across these two searches included: ‘Sikh Mental Health’.

It is important to note that in addition to the studies included which have Sikh participants, papers will also be cited which report the heterogenous group of South Asian with no specified inclusion of Sikhs for either context, comparison, or further support within the review.

2.2.4. Data Synthesis
Using the data from the articles which met the inclusion criteria, a narrative synthesis was performed whereby themes were identified across the studies. A description of the findings is reported below.

2.3. The Sikh Religious View of Mental Illness
There is no clear mention or definition of mental illness within the Guru Granth Sahib\(^{23}\). However, Sikhs may attempt to understand mental illness through interpreting the teachings and scripture within the Guru Granth Sahib (Karla et al., 2012; 2013).

The Sikh religion teaches that life is a cycle of birth, death and rebirth. This is also known as reincarnation (Cole, 2010; Nesbitt, 2005). Sikhs go through this cycle 8.4 million times, and the human or animal body they rebirth into is based on their previous life’s karma\(^{24}\). Physical and mental illness can be considered a consequence of your past actions (Cole, 2010; Nesbitt, 2005; Gilbert et al., 2011).

The goal of life is to permit the atma\(^{25}\) to exist on earth as a human. Being a human is considered the last life form and is an opportunity to finally liberate themselves from the reincarnation cycle and reach their goal which is to reunite with Waheguru\(^{26}\) in muki\(^{27}\).

\(^{23}\) Religious scripture of Sikhism
\(^{24}\) The consequences of a person's actions and words
\(^{25}\) Soul
\(^{26}\) Sikh name for God
\(^{27}\) The freeing of the soul from rebirth/reincarnation
Sikhs are taught that there are essential characteristics within them that will enable them to reunite with Waheguru. These attributes are known as the Five Virtues\(^{28}\), and are ‘Sat’ (truth), ‘Daya’ (compassion), ‘Santokh’ (contentment), ‘Nimrata’ (humility), and ‘Pyaar’ (love).

There also exists negative characteristics within everyone, which prevents them from reaching mukti. These are known as the Five Vice\(^{29}\) (also known as the Five Evils). These are ‘kama’ (lust), ‘krodh’ (rage), ‘lobh’ (greed), ‘moh’ (attachment) and ‘ahankar’ (conceit) (Karla et al., 2012; 2013; Sandhu, 2005).

Sikhs must also remove additional barriers including having a selfish ego (haumai), being self-centred (manmukh) and the impression that impermanent and insignificant things in life (such as material goods) are permanent and valued. This is known as ‘maya’ (British Sikh Report, 2018; Singh, 2008; Pirta, 2013).

When the haumai\(^{30}\) and five thieves become dominant, they may govern to the point that the mind and body become separated from their soul (Pirta, 2013). Subsequently, the haumai and five thieves prevent individuals from recognising and appreciating Waheguru. This prevents release from the reincarnation cycle.

Mental distress may also occur when these negative attributes become dominant. The five thieves can cause numerous adverse situations for an individual. They can cause immoral and dishonest behaviour, undesirably impact relationships, promote stress levels and destructive thoughts, decrease self-esteem, and lead to feelings of melancholy. These ‘symptoms’ appear congruous with the conventional Western view of mental illness, specifically depression (British Sikh Report, 2018; Jhutti-Johal, 2017; McLeod, 1989; Karla et al., 2012; 2013).

The Guru’s taught that by conquering the five thieves\(^{31}\) and haumai\(^{32}\), positive psychological wellbeing can be achieved. Surmounting these negative attributes can be achieved by Sikh

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\(^{28}\) Five qualities that are essential for a Sikh
\(^{29}\) Five attributes that can consume an individual, and lead them to actions with negative consequences
\(^{30}\) Selfish ego
\(^{31}\) (also known as the five evils) Five attributes that can consume an individual, and lead them to actions with negative consequences
\(^{32}\) Selfish ego
practices, including seva\textsuperscript{33} and nam simran\textsuperscript{34}. These practices are pivotal to calm the mind (British Sikh Report, 2018).

Nam simran has been considered the ultimate and highest action a Sikh can do. It enables the individual to silence the mind and focus, which leads to a peaceful state, eradicating negative thoughts and overcoming mental distress. The Guru Granth Sahib\textsuperscript{35} teaches that when Waheguru\textsuperscript{36} is chanted continuously it acts as a shielding and therapeutic measure for emotional suffering (Singh, 1993; Karla, 2012; 2013).

The significance of incorporating Sikh practices in daily life has also been supported in research on mental distress and adverse life experiences (Lawrence et al., 2006; Acharya & Northcott, 2007). Devoting time to Sikh religious practices, such as attending the Gurdwara\textsuperscript{37}, prayer, and belief in God, was described as more effective than medication for physical and mental illness (Acharya & Northcott, 2007). Some members of the Sikh community have also stated that through embracing the values and practices of their religion, such as reciting prayers, they had the strength to conquer adversity (Miller, 2005). Furthermore, Gilbert et al. (2011) found prayer formed an integral part of mental health treatment.

Sohi, Singh & Bopanna (2018) also found that engaging in the Sikh religious practice of seva\textsuperscript{38} provided several benefits to wellbeing. Those practicing seva exhibited higher levels of social wellbeing. This association was mediated by the sense of community. Through the community relationships and social bonds that were created, Sikhs felt they developed a strong support system. Being actively involved in a religious community was associated with more resilience to mental health conditions (Koenig, McCullough & Larson, 2001). This finding has been credited to numerous factors: trust in God (a sense of security); social benefits (a sense of belonging); and internal levels of control (God and/or moral purpose within me supports me to apply my own will and do better) (Parkes & Gilbert, 2010).

\textsuperscript{33} Selfless service and dedication to others  
\textsuperscript{34} Spiritual meditation on God’s name  
\textsuperscript{35} Religious scripture of Sikhism  
\textsuperscript{36} Sikh name for God  
\textsuperscript{37} Door to the Guru / A Sikh Place of Worship  
\textsuperscript{38} Selfless service and dedication to others
*Chardi Kala* is another concept in Sikhism which describes a mind frame Sikhs should accept and practice (Majhail, 2010; Cole, 2010; Karla, 2012; 2013). It consists of having a positive, optimistic and joyful attitude towards life, and can be achieved through *nam simran* and *seva* (Majhail, 2010). Practising these acts on a daily basis are considered to provide protection and immunity to mental illness (Ruprai, 2016). The practices adopted by Sikhs to maintain psychological wellbeing echoed the techniques that are applied in Cognitive Behavioural Therapy.

**2.3.1. Sikh Value of Heroism**

The value of heroism is core to the Sikh religion and culture. This concept derives from the historical narrative of Sikh bravery. In the early years of Sikhism, Sikhs battled for their beliefs and traditions.

Adopting the value of heroism could act as a potential coping strategy for Sikhs when faced with adversity or mental distress, particularly for Sikh men (Ahluwalia & Alimchandani, 2013). Silencing their psychological distress could be a result of trying to uphold the religious narrative of heroism. Sikhs express their need to control feelings of being a victim, take charge and transform their circumstances (Sandhu, 2004).

Ruprai (2016) provided a novel mental health help-seeking narrative from the Sikh perspective. In this study that explored how psychological wellbeing is constructed in the Sikh community, participants conveyed the importance of being a ‘warrior’, with a need to be a ‘fighter’, remain ‘tough’ and have ‘resilience’ in times of hardship. This was because of the challenging beginnings of their religious heritage. Identifying as Sikh acted as a much greater role than just a religious affiliation. Instead, it was an identity they adopted to confront difficulties. This identity leads them to tackle adverse life situations alone, without seeking the support of others.

This connected to another finding whereby Sikhs deemed self-help to be crucial for coping with mental health problems (Lawrence et al., 2006a). This could be achieved by adjusting your outlook on life. External support either formal or informal were a secondary option.
2.4. The Cultural View of Mental Illness

Whilst the religious view of mental illness is based on interpretations from the *Guru Granth Sahib*[^39], cultural attitudes and beliefs can influence the way in which mental illness is understood. For Sikhs, there are some cultural concepts that they share with other South Asian communities which may conflict with their religious teachings (British Sikh Report, 2018; Gilbert et al., 2011).

The *Guru Granth Sahib* teaches Sikhs not to believe in sorcery or spirit possession (British Sikh Report, 2018). However, it is well documented amongst South Asian mental health research that mental illness can be a result of religious or supernatural causes such as *jadu tona* (black magic), *nazaar* (evil eye) and *jinn* (spirit possession) (Bhika et al., 2015; McCabe & Priebe, 2004; Charles, Manoranjitham, & Jacob, 2007; Kulhara, Avasthi, & Sharma, 2000; Mirza et al., 2019; Carter et al., 2017; Knifton, 2012).

Sikhs have also been known to attribute mental illness to supernatural factors (British Sikh Report, 2018; Sheikh & Furnham, 2000; Bhui, Bhugra & Goldberg, 2002; Chui et al., 2005; Gilbert et al., 2011). This is antagonistic of their religious beliefs.

These beliefs in supernatural and religious explanations for mental illness leads to help-seeking to be sought from religious sources. Sikhs have been reported to visit healers of different faiths such as a *Pandit*[^40] or *Pir*[^41] for treatments for mental health conditions (British Sikh Report, 2018). This is discussed further in Section 2.8.2.

This further indicates the divide between culture and religion which has been described in Section 1.3.6.

### 2.4.1. The Importance of Family

Family is very important to Sikhs and living as part of an extended family is common for the Sikh community. The extended family usually consists of parents, grandparents, children, and aunts/uncles living in one household or nearby (Sidhu et al., 2016).

[^39]: Religious scripture of Sikhism
[^40]: Brahmin scholar or a teacher of any field of knowledge in Hinduism
[^41]: Sufi (form of Islam) master or spiritual guide
Research has reported that Sikhs prefer to deal with adversity alone. However, in instances where this is not achievable, family is considered a significant source of support. Receiving help from family has been deemed equally effective as receiving professional care from psychological services (Ruprai, 2016). Furthermore, being surrounded by family provides a support system that can help with both physical and mental health issues (Labun & Emblen, 2007; Sidhu et al., 2016; Ruprai, 2016).

A belief embedded through the generations is that an individual problem is a problem which concerns the whole family (Ruprai, 2016). Sikhs take a holistic approach to health decisions, whereby the role of the individual, family, and religion are considered (Ebrahim, Bance, & Bowman, 2011). This contrasts with the western culture, whereby decisions are generally focused on the individual alone.

Specifically related to psychosis research, for South Asians, family members have been found to be key in detecting symptoms of the illness before the patient does (Judge et al., 2005). Furthermore, South Asians are more likely to agree to family therapy for the treatment for schizophrenia and schizoaffective disorder, in comparison to other BAME groups (Das-Munshi, Bhugra, & Crawford, 2018).

South Asians have also been reported to have the best treatment outcomes when compared with other ethnic groups at a three-year follow up at an early intervention service. Many of these patients lived with their family (Agius et al., 2008). The authors reported that improved treatment outcomes could be caused by the traditional values held by the South Asian patient and their families.

Another study which explored parental carer burden in family caregivers of schizophrenia in British White and British Sikh parents, reported a lack of relationship between burden and psychiatric service use for British Sikhs but not British White (Lloyd et al., 2013). This was attributed to burden being shared among Sikh family members and the wider community, largely due to the British Sikh participants living in extended households (Lloyd et al., 2011). British White parents had fewer people with whom they could share the responsibility of caring for their ill child, thus being more reliant on psychiatric services (Lloyd et al., 2013).
2.5. Defining Mental Illness

Literal translations of western mental illnesses do not exist in the Punjabi language or Sikh scripture.

A definition of mental health from the Sikh perspective was collected in a research study investigating outlooks on mental health from minority ethnic groups (Simich et al., 2009). Sikh participants stated that ‘good mental health’ was related to cultural values of the community. These included ideas linked to functioning in social gatherings, decision making ability, handling stress, sustaining financial security, helping the community, and meeting employment and family responsibilities. Having a balanced and well-rounded life was also related to positive mental health (Islam et al., 2017).

‘Poor mental health’ was characterised by a failure to meet obligations. For example, one participant said that a mental illness is when a person is unable to fulfil social and family responsibilities and incapable of distinguishing between wrong and right. These attributes can lead to a person’s mental stability deteriorating.

Across the Sikh literature, mental health has frequently been defined in terms of stress, hopelessness, low mood, depression, insecurity, avoidance of social interactions, and straying from religion (Simich et al., 2009; Ruprai, 2016; British Sikh Report, 2018).

Punjabi Sikhs have been found to characterise mental or emotional distress using metaphors and proverbs such as ‘sinking heart’ and ‘my heart is heavy’. This is further discussed in Section 2.8.4.

No definition or description of severe mental illnesses has yet been documented for the Sikh community.

2.6. Risk Factors and Causes of Mental Illness

The causal attributions and explanatory models’ individuals hold towards a mental illness considerably effect help-seeking decisions and treatment pathways (Gupta & Bhugra, 2009).
There is an established evidence base which has found that members of the South Asian community commonly attribute the cause of mental illness to religious or supernatural causes (Bhika et al., 2015; McCabe & Priebe, 2004; Charles, Manoranjitham, & Jacob, 2007; Kulhara, Avasthi, & Sharma, 2000; Mirza et al., 2019; Carter et al., 2017; Knifton, 2012).

These include evil eye, spirit possession and black magic, which is a prevalent finding in studies involving those identifying as Muslim (Furnham, Raja, & Khan, 2008; Mullick, Khalifa, Nahar, & Walker, 2013; Dein & Samad-Illaee, 2013; Penny et al., 2009).

These causes have also been used to explain psychotic disorders such as schizophrenia within South Asian samples (Bhika et al., 2015; McCabe & Priebe, 2004; Charles, Manoranjitham, & Jacob, 2007; Kulhara, Avasthi, & Sharma, 2000; Mirza et al., 2019; Carter et al., 2017).

Some literature has proposed that Sikhs also endorse religious and supernatural attributions for mental illness (Queensland Health, 2011; British Sikh Report, 2018; Sheikh & Furnham, 2000; Bhui, Bhugra & Goldberg, 2002; Chui et al., 2005; Gilbert et al., 2011).

Sheikh & Furnham (2000) found that Sikhs preferred supernatural attributions for mental illness over western physiological causes and non-western physiological causes. Additionally, Bhui, Bhugra, & Goldberg (2002) found that religious explanations were attributed to an individual’s psychological distress. This was in addition to medical/somatic explanations (Bhui, Bhugra, & Goldberg, 2002). In a further study, one Sikh female participant described mental illness to be ‘a bad spirit residing in me’ (Chui et al., 2005).

However, endorsing such beliefs is incompatible with Sikh teachings, whereby Sikh scripture outlines that witchcraft and possession are not beliefs that should be held by a practicing Sikh (British Sikh Report, 2018; Gilbert et al., 2011).

A recent study found that Punjabi Sikh participants acknowledged that religious and supernatural causes were endorsed by the wider community (Ruprai, 2016). However, the participants did not support these causes. Instead, they prescribed biological and social causes towards mental health. These included anomalies in the brain, dietary related causes, bereavement or stressful life events (Ruprai, 2016). This is in line with Gilbert et al. (2011) who also found similar social causes to be used as explanations for mental illness. These
included trauma, life events, drugs, and alcohol use. However, several Sikh participants also endorsed evil eye and black magic as a cause of mental illness. These participants stated that this was due to cultural belief rather than Sikh teachings, as Sikhism teaches that there is only one spirit – God.

Additionally, karma and God’s will were important religious understandings towards health and mental illness amongst all nine Sikh participants (Gilbert et al., 2011). Thus, participants held dual explanatory models towards mental illness. This has been further supported by Bhika et al. (2015) who explored psychotic illness perceptions in South Asians and participants expressed a preference for holding a dual explanatory model. DUP was also significantly related to the explanatory model held (Bhika et al., 2015).

Across the Sikh mental health literature, stress was cited as the most common causal factor (Greenwood et al., 2000; Sheikh & Furnham, 2000; Chui et al., 2005; Taylor, Brown & Weinman, 2013). Particularly, the stress of gender-role expectations have been noted as a precipitating or exacerbator factor for Sikh women’s severe mental illness (Chui et al., 2005). After immigrating from India, women in Canada have expressed feeling extreme stress with the increased household workload in addition to outside employment. When taking time away from the ‘Canadian lifestyle’ and returning to India they have expressed no longer needing their psychiatric medication (Chui et al., 2005). Similarly, immigrant Sikh women have been found to experience substantial pressures and mental health challenges because of their bicultural lives (Mann, Roberts & Montgomery, 2017).

Additionally, in another study the lack of respect experienced as a woman from their husband and/or in-laws led to emotional suppression increasing feelings of stress and isolation (Chui et al., 2005). This was further supported in a study which found amongst older generations that depression was perceived to be caused by marriage troubles, including being in an incompatible relationship (Lawrence et al., 2006b).

Specific personality attributes such as ‘oversensitive’ and ‘weak nerves’ have been also acknowledged risk factors for depression (Lawrence et al., 2006b).

Biological causes for mental illness have also commonly been endorsed, whereby Sikh participants viewed mental illness as hereditary (Bradby et al., 2007; Knifton, 2012; Gilbert
et al., 2011). For example, one participant in Bradby’s study stated that ‘madness’ ‘comes in the blood’ (Bradby et al., 2007).

These causes are congruent with Western explanations for mental illness. This could be related to the acculturation strategy of integration which is generally adopted by Sikhs (Robinson, 2005). Sikhs are reportedly better integrated into British society, suggesting that Sikhs have a more western approach to mental health than other subgroups of the South Asian umbrella. Additionally, Indian women born in the UK were found to hold more western illness models towards mental illness than those who immigrated (Taylor, Brown & Weinman, 2013).

Ruprai (2016) and Gilbert et al. (2011) were the only studies to qualitatively explore causal explanations towards mental illness from a sole Sikh sample. However, in both instances mental illness was investigated broadly. Thus, not distinguishing between different mental illnesses which differ in symptoms, causes, treatments, and severity. Consequently, we cannot ascertain which mental illness participants might be referring to when providing their causal explanations.

Furthermore, participants in Ruprai’s (2016) research stated that severe mental illnesses such as schizophrenia do not impact the Sikh community. This would indicate that they were not providing causal explanations for severe mental illness as they believe Sikh’s are not vulnerable to them.

2.7. The Help-Seeking Behaviours for Mental Illness
Mental health services are underutilised by the South Asian community (Goodman, Patel, & Leon, 2008; Bhui et al., 2003; Cooper et al., 2013). This could be due to a number of reasons, including a lack of culturally appropriate care, seeking help from untraditional sources, stigma and shame, low mental health literacy, somatising symptoms, and other religious and cultural influences. These are elaborated on below.

2.7.1. Lack of Culturally Appropriate Care
Mental illness is primarily treated based on western models, with a disregard to cultural and religious factors which are integral to the service user (Islam et al., 2017). This has been
found in research focusing on South Asians (Chew-Graham et al, 2002; Moller, Burgess & Jogiyat, 2016). Subsequently, this can lead to misdiagnosis and ineffective support.

Considering religion and culture within mental health assessments was reported to be important to South Asian service users, of which Sikhs were part of the sample. However, these factors are seldom acknowledged by clinicians (Bhui, Chandran, & Sathyamoorthy, 2002; Greenwood et al. 2000; Lai & Surood, 2013).

Seeking help for mental health issues from someone who shares the same religion or culture has been well documented by Sikh participants (Simich, Maiter & Ochocka, 2009; Bhui, Chandran, & Sathyamoorthy, 2002; British Sikh Report, 2019).

A further study found that South Asian mental health service users stated that having a clinician of the same culture or religion was deemed useful and easier for the assessment procedure (Bhui, Chandran, & Sathyamoorthy, 2002). However, this opportunity was not provided to service users. Asian men in this study reported that their appeared to be a lack of understanding regarding the nature of their diagnosis and justification for treatment. On reflection of the mental health assessment, it was reported that the process was impolite and authoritative.

In another study, a further Punjabi, Sikh mental health service user reported experiencing marginalisation from the mental health system (Simich, Maiter & Ochocka, 2009). This participant emphasised that mental healthcare professionals must understand their patients’ culture in order to provide appropriate care. This participant stressed the importance of seeking help from someone of your own culture.

Cultural incompatibility, with reference to language barriers, has also been reported as a significant service barrier to mental health care (Lai & Surood, 2013; Chui et al, 2005; Greenwood et al., 2000). Male service users who were reflecting on their mental health assessment stated no efforts had been made to establish the English language proficiency of service users, and whether an interpreter would be required (Bhui, Chandran, & Sathyamoorthy, 2002). Additionally, several studies have reported challenges in having interpreters or translators on site (Chew-Graham et al, 2002; Chui et al., 2005; Greenwood et al., 2000).
A mistrust in services and fears of clinician’s breaching confidentiality has also been cited amongst Sikhs (Ruprai, 2016; Simich et al. 2009; Chew-Graham et al. 2002; Bhugra, Baldwin & Desai, 1997). Participants have expressed fears that if their clinician was South Asian, they might be associated with someone in their social network which could lead to gossiping amongst the community (Chew-Graham et al., 2002; Moller, Burgess & Jogiyan, 2016; Bradby et al., 2007). This latter finding is associated to the increased stigma that is linked to mental illness which is further discussed in Section 2.8.3. However, these participants still advocated help-seeking from South Asian clinicians as they would acknowledge cultural and religious issues (Moller, Burgess & Jogiyan, 2016).

A recent study had found that that only recently had mental health staff become familiar with baptised Sikhs wearing a Kirpan42 (Kang & Moran, 2020). Thus, those who are unfamiliar with the religious significance of the item may identify it as a threat to staff or the patient themselves.

2.7.2. Traditional and Religious Healers

Seeking help from traditional and religious healers for mental illness has been a well-cited source of care for South Asians, including the Sikh community (Greenwood et al., 2000; Knifton, 2012; Sembhi & Dein, 1998, Dein & Sembhi, 2001; Hussain & Cochrane, 2003; Chui et al., 2005; Taylor, Brown & Weinman, 2013; Cinnirella & Loewenthal, 1999; Gilbert et al., 2011).

Traditional and religious healers have been documented as a means of getting treatment for psychosis in India (Joel et al., 2003). Furthermore, an increased delay in receiving professional care from Early Intervention Services for psychosis in the UK has been reported in South Asians whose first point of help was from a religious source (Islam, Rabiee, & Singh, 2015).

In cases where religious or supernatural explanations are attributed as the cause of an illness, individuals will seek out support from alternative sources (Pirani et al., 2000; Greenwood et al., 2000; Knifton, 2012; Hussain & Cochrane, 2003). For example, a Sikh female participant

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42 One of the Five K’s – A steel sword
in Canada attributed her mental illness to a bad spirit inside of her which directed her to traditional healing practices which would ‘take the bad spirit out’ (Chui et al. 2005).

The language barrier that might affect recent migrants to the UK could also influence their use of traditional or religious healers as an alternative to accessing professional care (Knifton, 2012). For example, seeking mental health treatment from religious sources was found amongst first-generation South Asians in the UK (Cinnirella & Loewenthal, 1999).

A discussion of the use of spiritual healers for mental illness amongst Sikhs was reported by Gilbert et al. (2011). With specific reference to healers who provide treatments in exchange for payment, two participants in their study endorsed this, whilst several participants condemned it. This was due to the belief that you should not have to pay for healing, and instead seeking prayer and support from the local *Gurdwara* should be sought.

In a pilot study, Sembhi & Dein (1998) found that from a sample of fourteen South Asian psychiatric patients in the UK, five had used a traditional healer during the course of their illness. A further five had consulted a traditional healer for other difficulties. A case study was also presented of a 70-year-old Sikh woman who had a diagnosis of depression (Sembhi & Dein, 1998). This case study reported a desire to seek help from a traditional healer for her depression but was unable to do so as they were too costly. Instead, she created her own traditional medicine at home to help with her illness. This has been echoed in other research which have found South Asian’s wanting to consult traditional healers for their psychiatric illness but due to expense or lack of knowledge on how to find one they were unable to do so (Dein & Sembhi, 2001; Chui et al., 2005).

Help-seeking from such sources has not always been reported as a method of preference (Chui et al., 2005). One participant in Chui’s study expressed that Ayurvedic medicine for psychiatric illness could be effective, but treatment efficacy would take longer in duration in comparison to psychiatric medicine.

This is further supported by Bhui et al. (2001) who found no significant cultural differences in the mental health help-seeking pathways amongst Punjabi and English individuals. Less

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43 A gurdwara is a place of assembly and worship for Sikhs
than half of each ethnic group did not seek help (English 40%, Punjabi 46%). Religious, traditional and alternative treatments were sought in 3.9% of Punjabi cases and 3.2% of English cases. Similarly, Commander et al. (2004) reported no participants used a traditional healer or other unconventional forms of support for their psychiatric illness.

2.7.3. Stigma and Shame
Stigma and shame has been extensively cited as a factor for not disclosing a mental illness and help-seeking avoidance within the Sikh community (Knifton, 2010; 2012; Bradby et al., 2007; Time to Change, 2010; Chew-Graham et al., 2002; Gale & Thalitaya, 2017; Chui et al., 2005; Lawrence et al., 2006a; Taak, Brown & Perski, 2021; Moller, Burgess & Jogiyat, 2016; Islam et al., 2017; Ahmed et al, 2020; Ruprai, 2016; Gilbert et al., 2011).

Mental illness is rarely openly discussed within Sikh households, and hiding a mental illness is encouraged (UK Sikh Healthcare Chaplaincy, n.d). A diagnosis of mental illness should be kept secret, and revelation of a diagnosis to the extended family and social network of the individual is considered tarnishing for the family’s name and reputation (Time to Change, 2010; Bradby et al., 2007; Lawrence et al., 2006). An individual would lose respect in the Sikh community if they were labelled with a mental illness (Ruprai, 2016; Bradby et al., 2007).

Core attitudes towards mental health problems include fear, secrecy and sharam44 (Time to Change, 2010). The concept of shame impedes an individual’s access to any kind of support, including professional care as well as support from the family and the community (Bradby et al., 2007).

Negative perceptions around seeking professional treatment for mental illness is frequently mentioned (Gilbert et al., 2011; Ruprai, 2016; Moller, Burgess & Jogiyat, 2016). Sikh participants stated that seeking professional support would make them appear weak and it would be considered a betrayal to their family (Ruprai, 2016). They only enter services if they were forced to (Ruprai, 2016). Similarly, regarding counselling, participants stated that it was not only perceived as abnormal but also shameful and stigmatising to the entire family (Moller, Burgess & Jogiyat, 2016).

44 Shame
A diagnosis of a mental illness was characterised as a ‘family problem’ (Bradby et al., 2007). This finding was associated to the cultural value and belief that an individual’s personal shame reflects upon the wider family, and impacts that family’s izzat\(^{45}\) (Moller, Burgess & Jogiyat, 2016; Bradby et al., 2007).

The cultural concept of izzat has been cited in further studies as an influencing factor on an individual’s decision to seek help (Chew-Graham et al, 2002). All participants in Chew-Graham’s study spoke of the importance of izzat influencing them and their family’s life. izzat is given superiority and preference over the wellbeing and contentment of members within the family. izzat was perceived to pressure women into staying silent about their issues. Women accessed services and received appropriate care only at the point of crisis (Chew-Graham et al., 2002). These women collectively emphasised the importance of forced silence within their culture in relation to mental health.

The pressure of marriage within families increases the impact of stigma and the insistence to keep it hidden (Knifton, 2012; Time to Change, 2010; Ruprai, 2016; Bradby et al., 2007; Gale & Thalitaya, 2017). Sikhs deemed mental illness to be a terminal illness that would have a ‘grave effect’ on prospects of marriage (Ruprai, 2016). This issue is particularly prevalent in Sikh women (British Sikh Report, 2018). There is less desirability in marrying someone with a mental illness due to the perceived risk of mental illness being hereditary and subsequently passing to future generations (British Sikh Report, 2018; Time to Change, 2010; Bradby et al., 2007; Knifton, 2012). Marrying someone with a mental illness was considered shameful (Knifton et al., 2010). Furthermore, it is assumed that a woman with a mental illness will not be able to fulfil the stereotypical gender-role responsibilities that are expected of her.

The Sikh community has also been found to hold a negative and judgemental attitude towards mental health service users (Ruprai, 2016). These views have been unconsciously fostered due to their parent’s views. In one study, 31% of Indian service users received medium to high levels of discrimination by members of their own community (Time to Change, 2010b).

\(^{45}\) Honour, reputation or prestige
Another study presented a vignette of psychosis to South Asians and found that participants held increased affective prejudice and negative stereotypes (Ahmed et al., 2019). This included avoiding someone with psychosis and isolating them away from the rest of the community. In another psychosis-specific study, Burnett et al. (1999) found that many South Asian patients with psychosis lived with their families, who tried to handle the illness at home which caused the symptoms to progress and intensify.

2.7.4. Somatising Symptoms

Somatisation refers to manifesting symptoms of mental illness or psychological distress through physical health complaints (Kawanishi, 1992). Consequently, this can cause a misdiagnosis, lack of referral, and not receiving the appropriate care they require (Husain, Creed, & Tomenson, 1997; Jacob, Bhugra, & Lloyd, 1998).

Somatisation has been well documented within the South Asian community (Gaw 1993; Ineichen, 1990; Kawanishi, 1992; Patel, & Oomman., 1999; Bhui, 1999).

Brewin (1980) suggested that people may express their mental illness in culturally appropriate behaviours that GPs may not be familiar with. This could cause GPs to incorrectly diagnose the condition as a physical health problem. In a study whereby South Asian women presented symptoms of depression to their GP, in only 1 out of 5 instances was depression noted (Husain, Creed, and Tomenson, 1997).

Whilst there is no definition of mental illness within the Sikh religion and Punjabi language, members of this community have been known to express distress with terms such as ‘my heart is heavy’. This is the concept of ‘the sinking heart’ which was first explored by Krause (1989). The ‘sinking heart’ was described as a physical feeling of the heart losing strength and moving downwards. This feeling may be accompanied by a fatigue, headache, mouth dryness, and shortness of breath.

The ‘sinking heart’ is understood to be caused by numerous factors, including social failure, worry, bereavement, absent family members, or excessive heat. Thus, the ‘sinking heart’ is focused on a culturally specific view that social, physical and emotional symptoms are
intertwined (Krause, 1989). The term can be used to describe the existence of somatic symptoms in mental distress. The concept was explored amongst Punjabi Sikhs and Hindus, however Krause (1989) specified that both religious groups are influenced by Sikhism. Terms and teachings from the Guru Granth Sahib \(^\text{46}\) were constantly used in connection to the ‘sinking heart’.

This concept has received empirical support (Fenton & Sadiq-Sangster, 1996; Bhugra et al., 1997). One study found Punjabi women expressed their feelings of their mental distress by phrases whereby the heart was the focus (Fenton & Sadiq-Sangster, 1996). For example, ‘my heart kept falling’ and ‘feeling as if something heavy was resting on my heart’. A further study on Punjabi women found that although they are familiar with the word depression, they preferred using terms such as ‘weight on my heart/mind’ or ‘pressure in the mind’ to describe a low mood state (Bhugra et al., 1997).

Thus, the ‘sinking heart’ concept could clarify why research has found that Punjabis present with significant somatic symptoms when experiencing depression (Bhui et al., 2001; Bhui et al., 2004). Amongst a South Asian female sample, with 11 Sikhs participating, physical symptoms were expressed in the experience of depression (Burr & Chapman, 2004). This led to participants presenting to the GP for these physical complaints rather than their psychological distress.

These findings pertaining to somatisation could be associated with the belief posited by South Asians that depression is not considered a medical illness which requires medical treatment (Burr & Chapman, 2004, Jacob, Bhugra, & Lloyd, 1998; Greenwood et al., 2001; Lawrence et al., 2006b; Knifton, 2012). This is in part due to the idea that an illness must be physical (Burr & Chapman, 2004). This has led to people not divulging all their psychological difficulties to their GP (Jacob, Bhugra, & Lloyd, 1998).

\[ 2.7.5.\text{Mental Health Literacy} \]

Mental health literacy refers to the recognition, knowledge, and attitudes an individual has towards mental illnesses (Jorm, 2000). Several studies have found Sikh participants do not consider depression as an illness which could insinuate a lack of mental health knowledge.

\(^{46}\) Religious scripture of Sikhism
(Knifton, 2012; Burrs & Chapman, 2004; Greenwood et al., 2000; Lawrence et al., 2006b). For example, Greenwood et al. (2001) found participants described mental illness as ‘being mad’ and associated it with violence. Those with depression were deemed to not be violent or ‘psychotic’, thus depression was not considered a mental illness. In another study, when presented with a case vignette of depression, participants expressed little understanding of the character’s difficulties, implying a further lack of mental health knowledge (Taylor, Brown & Weinman, 2013). Additionally, Sikh participants have stated that they are not susceptible to severe forms of mental illness such as schizophrenia (Ruprai, 2016). This emphasises a particularly low level of knowledge for severe mental illnesses.

Sikhs have displayed an unawareness of local services available for mental health (Ruprai, 2016; Simich et al. 2009; Greenwood et al., 2000). They hold little knowledge regarding mental health treatments, to the extent of being oblivious to the existence of talking therapies (Ruprai, 2016). In a study by Ruprai (2016), these findings applied also for those who have direct access to a friend or family member who have accessed services.

Generational differences were reported in the lack of education and awareness of mental health issues, and this influences the help-seeking behaviours amongst the generations (Taak, Brown & Perski, 2021).

In one study, a participant stated that the Sikh community’s comprehension about mental health would ‘fall at one or even zero’ if they were to rate their level of knowledge in this area (Simich et al., 2009). In a further study which asked participants to rate their level of knowledge on mental health services, the majority expressed a lack of confidence in their knowledge (Islam et al., 2017). This was despite the majority of participants being users of mental health services.

Research has also found a key barrier to care for South Asians with psychosis is the individual’s (Etheridge et al., 2004) and families’ (Judge et al., 2005) inability to acknowledge the illness as a psychotic disorder and their lack of awareness of where to seek help (Etheridge et al., 2004) or detecting symptoms, but not seeking help (Addington et al., 2002).
2.8. Summary and Rationale for Current Research

This chapter has reviewed the literature conducted on the Sikh community regarding their understanding and help-seeking pathways for mental illnesses. It was evident from initial literature searches that there is a lack of mental health research on the Sikh community alone. More importantly, very few studies focusing on Sikh participants have exclusively explored psychotic disorders (Ahmed et al., 2019; Lloyd et al., 2011; Lloyd et al., 2013; Bhugra et al., 1999). None of these have consisted of a qualitative exploration.

The following sub-sections highlight four key areas that provide a justification for the current research. The purpose and importance of research will then be outlined.

2.8.1. Sikhs: A Distinctive Community

Sikhism is the fourth largest religion within the UK. However, there is a dearth of mental health research in this community alone. Sikhs are generally integrated into the umbrella group ‘South Asian’, which neglects their distinctive identity.

Thus far, the established evidence base on the understanding and help-seeking behaviours of mental illness are focused on South Asians broadly. Thus, sub-groups are not identified. In other instances, participants are primarily of Pakistani or Bangladeshi ethnic origin and/or identify as Muslim (Anand & Cochrane, 2005; Bhika et al., 2015; Bowl, 2007; Cinnirella & Loewenthal, 1999; Ekanayake, Ahmad & McKenzie, 2012; Gilbert, Gilbert, & Sanghera, 2004; Hussaine & Cochrane, 2002; Karasz et al., 2019; Kumar & Nevid, 2010; McCabe & Priebe, 2004; Mirza et al., 2019; Randhawa & Stein, 2007; Rao et al., 2011; Rastogi et al., 2014; Soorkia, Snelgar & Swami, 2011; Wales et al., 2017; Weng & Spaulding-givens, 2017).

These studies are not representative of members of the Sikh community, as it is evident that there are vast ethnic, cultural, religious, and sociodemographic differences within the subgroups of the South Asian umbrella. For example, the acculturation literature highlights that Sikhs are more integrated into British society than other South Asian sub-groups. Sikhs embrace a unified identity whilst Muslim participants prefer a separation strategy from the British society (Ghuman, 1999; Robinson, 2003).
Cultural variation with response to mental illness between Pakistani Muslims and Indian Sikhs has also been identified (Hashemi & Cochrane, 1999). In a review on expressed emotion in schizophrenia across cultures, the authors stated that to European researchers Pakistani Muslim and Indian Sikh cultures may appear very similar, however they are two distinct religions and cultures (Hashemi & Cochrane, 1999).

Generalising South Asians has also been noted as an issue within healthcare settings (The UK Sikh Healthcare Chaplaincy Group, 2011). Sikhs have reported that some healthcare professionals are unable to distinguish between Sikh, Hindu or Muslim patients. This could lead to the religious needs of each group not being met. For example, Sikh patients have been given halal meat which is prohibited by their faith (The UK Sikh Healthcare Chaplaincy Group, 2011). Thus, it is important to research Sikhs separately from other South Asian subgroups, for clinicians to be able to respond to their specific cultural and religious needs.

In conclusion, it is evident that grouping ethnic groups together is problematic as it obscures significant differences that arise within the individual subgroups (Nazroo, 1997). Conducting research at a granular level by selecting specific communities such as Punjabi Sikhs can support us in accounting for the variety of ethnic groups that exist.

2.8.2. Mental Illness as a Broad Concept
There appears to be a focus on more common forms of mental illness across the Sikh literature. Research is commonly associated with depression, depressive symptoms, distress or stress (Karla et al., 2012; 2013; Lawrence et al., 2006a; Ruprai, 2016).

In most instances, the type of mental illness has not been made explicit. Instead, mental illness has been explored as a general concept (Gilbert et al., 2011; Simich, Maiter & Ochocka, 2009; Simich et al., 2009; Knifton, 2012; Sheikh & Furnham, 2000). Severe mental illness has rarely been acknowledged across the literature.

Such research negates the fact that there exist various mental illnesses which have very different causes, symptoms, treatments and severity. It is important to develop an accurate representation of how the Sikh community understands these illnesses.
2.8.3. Absence of Psychosis within the Sikh Literature

Ethnicity is predictive of diagnoses of psychosis (McManus et al., 2016). The existing BAME psychosis literature has been heavily dominated by Black African-Caribbean communities or broadly South Asians (The Kings Fund, 2016). There remains very little research concerning the understanding, help-seeking and experience of psychosis amongst the sub-groups of the Asian population.

Very few studies exploring psychotic disorders have included Sikhs as part of the sample (Ahmed et al., 2020; Lloyd et al., 2011; Lloyd et al., 2013; Bhugra et al., 1999). All of these were quantitative studies which predominately explored emotional expression (Lloyd et al., 2011; Lloyd et al., 2013). Other studies have also involved Sikh service users with psychosis and/or their carer’s, however these studies have also included participants with other mental illnesses such as major depression, anxiety and bipolar, with results not been reported according to diagnosis (Bhui, Chandran & Sathyamoorthy, 2002; Bradby et al., 2007; Chui et al., 2005; Dein & Sembhi, 2001; Greenwood et al., 2000). No study to date has carried out a qualitative exploration of psychosis within the Sikh community.

Research has revealed that culturally specific concepts of illness can define how people perceive their symptoms, help-seeking pathways and engagement with mental health services (Lauber & Rössler, 2007; Carter et al., 2017). Thus, it is essential to be informed how specific ethnic communities understand an illness and their preferred care pathways in order to be aware of potential barriers when accessing appropriate care.

2.8.4. Community Shift in Perceptions

Mental illness exists within the Sikh community; however, it is rarely openly talked about. This is due to the associated stigma and social taboo (Knifton et al., 2010; Knifton, 2012; Time to Change, 2010). However, there has been a recent shift in the openness to address and discuss mental illness within this community. This is in part due to younger Sikh generations being acculturated into the mainstream society and privy to mental health issues. Dialogue surrounding mental illness had become prominent on social media where younger Sikhs have an active presence.
Evidence of this change is reflected in the various initiatives that have been developed over recent years which target mental illness specifically for the Punjabi and Sikh community. This includes ‘Taraki’\textsuperscript{47}, which was founded in 2017 by Shuranjeet Singh who has lived experience of mental illness. The ‘Taraki’ team work on various projects across the UK. They aim to reshape approaches to mental health within the Punjabi community. They work within universities, faith centres, and social spaces to achieve this goal. Particularly, they have worked to break the stigma around male mental health.

‘Sikh Your Mind’\textsuperscript{48} is a further organisation which aims to increase awareness of mental health difficulties in the Punjabi Sikh community. They host events across the UK. Events include mental health drop-ins in Gurdwaras and delivering talks on the topic within universities. There are a number of other charities, groups and representative bodies that have focused on mental health and wellbeing within the Punjabi, Sikh community. This includes The Heera Foundation\textsuperscript{49}, SOCH\textsuperscript{50}, and Sikh Forgiveness\textsuperscript{51}

Additionally, recently books such as ‘My Father & The Lost Legend of Pear Tree’ by Kalwinder Singh Dhindsa (2018) have been published. This is a true story of a Sikh boy who loses his father due to suicide. ‘The Boy with the Topknot: A Memoir of Love, Secrets and Lies in Wolverhampton’ by Sathnam Sanghera (2008) is a further memoir of how mental illness affected the author’s family due to their ignorance about it. This memoir was also produced into a BBC series in 2017.

In addition, ‘Sikh Help Line’\textsuperscript{52} is a free counselling service, where people can call to discuss any issue, including depression, substance abuse, and other mental health issues. Thus, it is evident that there is a growing community effort to open up about mental illnesses and raise awareness. Hence, this is a crucial time to explore severe mental illnesses such as psychosis within the Sikh community to complement other ongoing projects.

\textsuperscript{47} https://www.taraki.co.uk
\textsuperscript{48} http://sikhyourmind.com
\textsuperscript{49} https://www.theheerafoundation.org.uk/home
\textsuperscript{50} https://www.sochmentalhealth.com/
\textsuperscript{51} https://sikhforgiveness.com/
\textsuperscript{52} https://www.sikhhelpline.com
2.8.5. Purpose of Research

Considering all the above, it is unclear how the Sikh community perceive and understand psychotic disorders and subsequently seek help for this illness.

Sikhs have emphasised the importance of the Sikh identity and its distinction from Western culture (Ebrahim, Bance, & Bowman, 2011). Sikhs take into consideration the individual, family, and religion, as an interconnected unit when making health decisions (Ebrahim, Bance, & Bowman, 2011). This holistic approach is considered in the current research.

Additionally, there is an evident religion and culture divide for Sikhs. Cultural concepts may take precedence over religious teachings when attempting to understand psychosis. Thus, both religion and culture must be examined to truly grasp how the Sikh community understand psychosis.

Hence, the current research aims to explore the Sikh community’s understanding and associated help-seeking behaviours towards psychotic disorders. Additionally, this research will investigate how family, religious and cultural beliefs and practices, and lived experience of psychotic disorders, influence these.

The study will focus on the following groups of adult Sikhs in England: current service users in recovery of psychosis, family members of those with psychosis, and laypeople. The rationale for obtaining data from these three participant groups is to gather a comprehensive understanding of this community’s perspectives and experiences.

Sikh mental health service users have rarely been the point of focus in research. Thus, it will be important to understand their lived experience. Additionally, the importance of family has been well documented across the Sikh mental health literature and South Asian psychosis literature (Labun & Emblen, 2007; Sidhu et al., 2016; Ruprai, 2016; Kathamna., et al., 2004). Thus, immediate family members of those with psychosis will be a vital source of information for the current study. Finally, lay members of the Sikh community are important to explore due to their possible inexperience with psychotic disorders.

A lived experience of mental illness is known to change one’s views towards the illness (O’Brien & Major, 2005). Thus, service users and their family members may have adopted an
altered approach to mental illness due to their direct experience. The way in which participants with lived experience interpret psychosis could reflect their developed familiarity and understanding of the disorder unknowingly. In comparison, lay people may have little to no direct experience with psychosis and be more inclined to understand psychosis in line with their cultural and religious beliefs. This is supported by Mirza et al (2019) who found that South Asians with lower to moderate levels of psychotic experience had stronger beliefs in supernatural causes.

2.8.6. Importance of Research

The current research is of importance for several reasons. Primarily, it will be the first to explore severe mental illness within the Sikh community. Specifically, by investigating their perceptions and understanding of psychotic disorders, potential reasons for a longer DUP could be derived. This information could be utilised by healthcare providers who aim to reduce DUP due to poor clinical, functional and social outcomes that arise due to delayed access to care (Kirkbride, 2008; Drake et al., 2020).

Furthermore, this research will be one of few whereby Sikh mental health service users and their family members are involved as participants. The Sikh mental health literature has largely been dominated by lay members of the community. The lived experiences of Sikh mental health service users, particularly those with a severe mental illness, has been seldom documented.

Healthcare professionals may also not have sufficient knowledge on the Sikh population. This could lead to inability to appropriately manage mental illnesses within this group. Thus, this research will offer clinicians fundamental information on how Sikhs understand and explain psychosis and their views on seeking professional help. Additionally, from the service user and family member perspective, their experiences of seeking medical care can provide useful feedback for clinicians in order to provide culturally appropriate care for this group.
3. Research Aims and Methodology

This chapter outlines the research aims and objectives of the current study, followed by the underlying epistemological approach, methodology and methods employed with justification for choices. Details of the recruitment, data collection and analysis procedure are delineated, in addition to ethical considerations, researcher position, and the scientific rigor of this research.

3.1. Research Aims & Objectives

The overarching aim of the current study is to explore the perceptions and understandings of psychotic disorders and associated help-seeking amongst adult Sikhs in England, and how family, religious and cultural belief and practice, and lived experience of psychotic disorders, influence these.

The main research aims, and associated objectives are the following:

Research Aim 1: To explore the understanding and beliefs towards psychotic disorders, amongst adult Sikhs in England with and without lived experience of psychotic disorders

1. Explore how mental health service users, their family members and laypeople perceive and explain psychotic disorders and its symptoms
2. Ascertain how the extended family influence both service user’s and their immediate family members views and understanding of psychotic illness
3. Investigate whether (and how) their religious and/or cultural beliefs and practices influence their understanding of psychotic disorders

Research Aim 2: To investigate the help-seeking behaviours and experiences with psychotic disorders, amongst adult Sikhs in England with and without lived experience of psychotic disorders

1. Investigate actual/potential help-seeking pathways among service users, their family members and laypeople when experiencing psychosis,
2. Ascertain whether their religious and/or cultural beliefs influence where they seek help from.
3. Explore their attitudes towards (and experiences with) mental health services and seeking professional help for psychotic disorders
4. Examine the role of the wider family in detecting psychotic illness and help-seeking

3.2. Epistemological and Ontological Considerations
Philosophical foundations must be considered prior to determining and choosing the applicable research paradigm for a study (Creswell, 2013; Morrow, 2007).

Ontology refers to the nature of reality and focuses on addressing the question ‘What is reality?’ (Creswell, 2013; Fletcher, 2017; Rehman & Alharthi, 2016). Thus, it is concerned with the way in which reality is created (Creswell, 2013; Willig, 2013). Ontological beliefs dictate epistemological assumptions (Guba & Lincoln, 1994; Rehman & Alharthi, 2016).

Epistemology refers to the examination of reality and addresses the question ‘How can I know reality?’ (Carter & Little, 2007). It focuses on the theory and study of knowledge, rationalisation and justification of belief, and concerns the way a researcher can go about gaining this valid knowledge (Barker, Pistrang, & Elliott, 2012).

Epistemology can be explained as an understanding of how we know what we know whereas ontology is the way we explain things and the interactions that occur between them. The association between the two is the focus on perceptions of knowledge and what can be known about reality (Willig, 2013). The combination of an oncological and epistemological position provides a holistic view on how a researcher can understand reality, and subsequently defines the research paradigm (Guba & Lincoln, 1994).

The current study subscribed to the critical realist paradigm, which is considerate of both positivist and interpretivist views. The two major paradigms of positivism and interpretivist will first be described, followed by an outline of critical realism and the rationale for this philosophical framework.
3.2.1. Positivism

The basic notion of the positivist paradigm is that the world is perceived as external and objective (Creswell, 2013). The purpose of research which has an underlying positivism paradigm is to reveal the laws that govern human behaviour. This paradigm posits that people are a product of their environment, and people behave in certain ways dependent on what they have been exposed to through their socialisation, thus society has shaped the individual (Ryan, 2018). Reality is said to occur on cause-and-effect principles and that this reality can be calculated. It poses an objective way of conducting research, generally through quantitative means using precise methods that can be statistically analysed to produce valid and reliable results (Ernest, 1994). This leads to the researcher being independent and detached from the topic of study and its participants, with no provision for human interest (Carter & Little, 2007). It has been contended that this paradigm fails to represent the convolution of human behaviour and social interaction (Jensen, 1989).

3.2.2. Interpretivist

The interpretivist paradigm is also known as constructivism. In contrast to positivism, it suggests that the world is perceived to be socially created and subjective (Mack, 2010). Individuals are thought of as elaborate and complex, who have consciousness, and are not simply a product of their social environment. People will not experience reality in the same way, and they can hold different experiences and understanding of the same phenomenon in diverse ways. Their interpretation and construction of knowledge and reality is based on past experiences and cultural factors.

The purpose of research is to obtain an in-depth understanding of the selected participants in order to derive meaning as to why they behave the way they do (Ernest, 1994). Whilst positivists focus on facts and adopt a deductive approach, constructivists focus on meaning, and they aim to derive meaning of a phenomenon using qualitative methods through an inductive approach (Ryan, 2018).

3.2.3. Critical Realism

The current study has adopted a critical realist approach, which is considerate of both positivist and interpretivist views (Mack, 2010). Harmonious with positivism, critical realists agree that objective realities exist and can be directly observed. However, critical realists
contend that we cannot understand the world solely from a positivist stance (Fletcher, 2017). This is because we must accept that people’s knowledge of the world is always comparative to who individuals are and what they are doing to obtain knowledge. Critical realism has been described as a less naïve expression of positivism because it accepts the part of subjectivity in the development of knowledge about the world.

In line with interpretivism, critical realists believe that knowledge and reality is concept-dependent and requires interpretive understanding. However, distinct from interpretivism, it does not eliminate causal justification (Sayer 2000).

Critical realism embraces that knowledge or ‘truth’ can occur and be reciprocated by many different people (Willig, 2013). Nonetheless, an individual’s understanding of truth will be subjective to their own personal creation of that truth. If an individual has substantial evidence for that truth, then the truth will effectually gain prominence (Ernest, 1994).

3.2.3.1. Rationale for Critical Realism

The current study aimed to understand how the Punjabi Sikh community perceive and understand psychotic disorders. For this reason, the critical realistic approach deemed the most fitting, as it posits that there is an objective reality, but people’s knowledge of this reality is formed through their exchanges with the world, which can impact their views, beliefs and cultural contexts (Fletcher, 2017). Utilising a critical realist perspective allows for individual’s experiences to be understood as influenced by social, personal, and historical contexts, suggesting an interpretation instead of a direct manifestation of ‘reality’.

The significance of the critical realistic approach on the current study is that it accepts that a physical reality exists, but individuals accounts will be created and recollected in a way which epitomises their own personal perceptions and interpretations of the world (Lawani, 2020). This stance enables the researcher to recognise that there are socially created cultural discourses. These are influenced by personal, social, cultural, religious and historical factors, which might impact the participants’ understanding and help-seeking behaviours towards psychotic disorders.
Furthermore, the current study does not intend to examine whether the accounts participants provide are either true or false. This is harmonious with a critical realist approach whereby the aim is to understand a person’s experience, and what they remember of the experience and how they view it is what is meaningful (Willig, 2013).

3.3. Qualitative Approach

Together, ontology and epistemology form a research paradigm, which establishes the methodological approach that is best suited to examine the knowledge of interest (Silverman, 2016). Based on the critical realist position of the current study, a qualitative methodological approach was most appropriate to answer the research questions.

There exists a multitude of approaches within qualitative research, but the mutual underpinning of each is that they are focused on how an individual makes sense of the world, and they act to review and enhance our existing understanding of a particular phenomenon (Ashworth, 2003). This allows for a much richer and deeper understanding of a phenomenon, as well as embracing the individuality of human experience.

On the other hand, quantitative research is focused on testing for causal relationships in order to support and/or reject hypotheses, and to enable data to be representative of the general population (Balnaves & Caputi, 2001). In quantitative methodology, human behaviour is diminished to a set of measurable variables and does not expose the complexity of individual’s meanings and experiences, which is preserved in qualitative data (Strauss and Corbin, 1990). The conduct of quantitative research in this instance would not allow for subjective exploration of human experience and depict the way it influences the perception of mental health.

Utilising qualitative methods in research can develop researchers’ insight of how subjective, social, and cultural viewpoints influence a person's psychological experiences (Silverman, 2016). This can help to enhance consideration of varying viewpoints held by different people, in addition to increasing knowledge of the aspects in which people comprehend their experience, and the methods employed to structure meaning from their experience (Charmaz, 2006). Furthermore, the contribution of participants as partners in the research process can be
empowering for them, as well as potentially being the only authentic way to precisely explore their experiences (Davidson, 2003).

The implementation of qualitative methodologies within mental health research has been increasingly highlighted, with a particular consideration of this methodology being especially fitting for vulnerable groups within mental health (Peters, 2010). Peters (2010) stated that qualitative methods offer a way of providing a voice for participants within mental health research. This is especially significant for this project, as the voice of Punjabi Sikhs has been scarcely heard in mental health research.

Moreover, qualitative methods are often encouraged for research with minority ethnic groups; they have the capacity to empower ostracised groups (Oakley, 2000). Researchers in this area suggest that individuals must be acknowledged through their individual and cultural belief system, which can be achieved through qualitative methodology (Patel, 1999).

Additionally, the use of a qualitative research design to explore the experiences of psychosis amongst service users and carers has been documented in a number of studies. These include a study which explored service user and carer experiences of seeking help for a first episode of psychosis (Tanskanen et al., 2011), as well as studies exploring the experiences of psychosis in service users and/or carers (Pitt et al., 2009; Wood et al., 2010; Sin et al., 2012; Sin et al., 2021).

Based off these points, adopting a qualitative methodology to explore how the Sikh community understand and seek help for psychosis was deemed most appropriate.

3.3.1. Comparing Qualitative Approaches

Within the qualitative paradigm, there are numerous methodological approaches and methods of analysis which can be employed by researchers (Yardley, 2000).

There are five traditional qualitative methodological approaches to research: case studies, narrative research, phenomenology, ethnography, and grounded theory (Silverman, 2016). Additionally, there has emerged further approaches which have becoming increasingly
popular in the field, including interpretative phenomenological analysis (IPA) and thematic analysis (Smith & Shinebourne, 2012; Braun & Clarke, 2006; 2013).

When considering the most appropriate methodology for this research, each approach was reviewed. Based on the research paradigm and research question the method of thematic analysis was chosen. Below is a description of each approach and their unsuitability for the current study and the rationale for selecting thematic analysis.

3.3.1.1. Case Studies and Discourse and Narrative Analysis
Both discourse and narrative analyses were not suitable for the current study, as they do not focus on the experience and reality of a person, but instead how people create and use language and stories to interpret the social world (Starks & Trinidad, 2007; Silverman, 2016). Additionally, case studies were not appropriate as they focus on an intensive inquiry usually confined to a single individual, but can also look at a group of people, or an event, and data collection is gained from a variety of sources (Heale & Twycross, 2018). As the current study aimed to develop a more comprehensive understanding from several participant groups, the case study approach was deemed unsuitable.

3.3.1.2. Ethnography
Ethnography focuses on immersing yourself within the culture of your target population, in order to develop a rich understanding of their interactions, behaviours, motivations, practices, etc. (Reeves, Kuper & Hodges, 2008; Silverman, 2016). Thus, the researcher tends to act as a ‘participant observer’ in the target sample’s real-life environment. This was not deemed appropriate for the current study, as the focus was not on the community’s behaviours, but their knowledge, perceptions and understanding of psychosis with broad topics already established for discussion.

3.3.1.3. Grounded Theory
Grounded theory is a research method concerned with systematically collecting data from a variety of sources in order to develop a theory for a phenomenon (Willig, 2013). It is primarily used to discover social relationships and behaviours of groups, known as social processes (Noble & Mitchell, 2016).
There exists numerous varieties and versions of grounded theory, which have differing theoretical foundations and methodical procedures (Birks & Mills, 2011). In general, grounded theory offers an exploratory framework for interpreting the phenomenon which is being explored. Typically, it is based on theoretical sampling.

Avoiding predetermined theories and conceptualisations on the topic of interest has been a traditional endorsement of grounded theory (Noble & Mitchell, 2016). Data collection methods involve interviews, focus groups, observations and studying texts or artefacts, or a combination of these (Strauss & Corbin, 1990). The collection of data and conducting analysis occurs simultaneously. Categories are recognised and combined from the data, which leads to the generation of a theory. Establishing links between categories and constructing associations between them is of principal significance (Willig, 2008).

Despite grounded theory’s ability to address inquiries concerning an individual’s personal experience, theory building remains an essential element, which was not applicable to the current study. The current research did not aim to develop a new theory, and was more exploratory in nature, thus grounded theory was not suited.

3.3.1.4. IPA

IPA aims to provide detailed information of an individual’s lived experience of a situation or event, how they make sense of these experiences and the meaning they give to these experiences (Smith & Osborn, 2015). IPA assumes that individuals strive to understand their experiences into some form that is plausible to them.

It is both a phenomenological and interpretative approach as it focuses on how individuals make sense and discuss a phenomenon and involves the researcher undertaking interpretative work to elucidate the participants’ descriptions of their lived experiences (Smith, Flowers, & Larkin, 2009).

There are several key features of IPA. Firstly, it is vigorously idiographic as it focused on a meticulous analysis on a case-by-case basis (Smith, Flowers, & Larkin, 2009). Furthermore, this approach is inductive throughout data collection and analysis as it adopts flexible methods to enable unanticipated themes and thoughts to arise. Thus, it is not an approach that
aims to validate existing theories or research but instead intends to gather rich and in-depth data. The final key characteristic of IPA is that it is viewed as interrogative whereby the goal of the research findings is to add to the current evidence-base, through interrogating the current inquiry (Smith, Flowers, & Larkin, 2009).

IPA was a consideration for the current research, particularly as it is generally underpinned by a critical realist paradigm and focuses on the lived experiences of a particular phenomenon (Larkin, Watts & Clifton, 2006). However, there were several factors as to why it was deemed unsuitable for this study.

Firstly, due to detailed and in-depth nature of IPA studies, data collection is primarily through in-depth interviews and with the need to do case-by-case analysis, sample sizes are relatively low, with participant numbers ranging from 1-15 of a homogenous group (Alase, 2017; Larkin, Watts, & Clifton, 2006). IPA would have therefore been an appropriate approach if the current study aimed for a deep exploration of the lived experience and narratives of a small number of service users. However, this research aimed to develop a comprehensive overview of the perceptions and help-seeking behaviours of psychosis from several participant groups, resulting in a larger sample size.

It has been recommended that thematic analysis should be used instead of IPA if the research targets a larger sample and the researcher’s focus is concerned with more patterned meaning across the dataset (University of Auckland., n.d). This view is also endorsed for research that asks experiential questions within a phenomenological framework (Braun & Clarke, 2019).

Furthermore, in IPA, themes are not identified across the dataset and instead are picked out according to each unique transcript (Smith & Shinebourne, 2012). The decision to have several participant groups in the current study was to compare the themes between them; this would not be in line with an IPA approach.

3.3.1.5. Thematic Analysis
Thematic analysis is an umbrella term for approaches which focus on examining themes within data. It relates to the method of recognising, analysing and recording patterns in
datasets that are associated to a particular phenomenon (Braun & Clarke, 2006; 2013; Clarke et al., 2019).

Over the past decade, thematic analysis has become a widely embraced method in health and social sciences qualitative research (Clarke et al., 2019). Braun and Clarke (2006; 2013; 2019) have delivered clear and structured recommendations on the theoretical and methodological use of thematic analysis. Their approach to coding and theme development can be deemed systemic and accessible.

Thematic analysis is considered theoretically flexible, with the ability to be utilised with a choice of theoretical, ontological and epistemological positions (Braun & Clarke, 2006). Thus, the researcher will decide on the theoretical beliefs directing the research, the form of data to be collected, and how the analysis will be employed. The approach’s flexibility is also apparent in that it can be used to investigate a broad spectrum of research questions and can be used to analyse various forms of qualitative data which could be collected via interviews, interviews, focus groups, documents, diaries, etc.

There are several approaches in thematic analysis: coding reliability, codebook, and reflexive analysis (Braun & Clarke, 2019; Clarke et al., 2019). In brief, a coding reliability approach shares similarities with a quantitative approach and positivist stance, placing importance on the reliability and replicability of data. The themes derived from a coding reliability approach are regularly conceptualized as domain summaries, whereby data collection questions and a codebook/coding frame drive the coding process. Data is sorted into the pre-established themes by multiple coders and accuracy of coding is established by calculating Cohen kappa which signifies the degree of agreement between coders. This is considered a partially qualitative approach.

**Codebook approaches such as framework analysis share similarities with the coding reliability approach, in that themes are pre-defined in advance to the full analysis, and this can be driven by the data collection questions (Gale & Heath, 2013). Thus, themes are created which are considered domain summaries. Unlike the coding reliability approach, codebook approaches does not usually use coding reliability measures.**
Reflexive thematic analysis is the most popular approach to thematic analysis and includes the most employed form in research by Braun & Clarke (2006). This approach is deemed a very valuable way to represent the complexities of meaning within data. The researcher will take time to study and develop an in-depth understanding of the dataset, extracting rich, detailed and significant patterns (themes) from the data, applicable to addressing the research questions (Braun & Clark, 2019). No use of a codebook or coding frame is required. Instead, the coding process is natural, flexible, and iterative, allowing for a logical and compelling analysis which is based off the data. There is a level of subjectivity in reflexive thematic analysis, whereby the interpretation of the data and generation of themes is cultivated by the researcher’s scholarly knowledge, theoretical beliefs, and social and cultural influences. However, Braun & Clarke (2019) considered researcher subjectivity to be an advantage to the method instead of a possible peril. Furthermore, the strong thematic description which can be derived from this form of analysis is particularly valuable when investigating new or under-researched topics.

3.3.1.5.1. Rationale for Thematic Analysis

Having critically compared a range of qualitative methodologies and methods, reflexive thematic analysis was selected for the current project.

The aforementioned approaches, excluding thematic analysis, are methodologies, which have a particular framework with predetermined ontological and epistemological assumptions, advocating the use of particular data collection methods and analysis techniques. In comparison thematic analysis is not bound to an explicit theoretical framework, nor is it considered a methodology, instead it is defined as a method. The lack of specificity regarding the epistemological stance of thematic analysis has been considered an advantage (Braun & Clark, 2006).

Furthermore, after reviewing the several schools of thematic analysis, the reflexive approach was more in line with the ontological and epistemological position of the current research (Braun & Clark, 2019). The coding reliability approach is considered incompletely qualitative and is in-keeping with a positivist framework. Reflexive thematic analysis supports the critical realist paradigm by going outside of discernible material to more
embedded themes recognising the structures, interests, and relations that influence the meanings co-produced by the researcher and participants (Kiger & Varpio, 2020).

In particular, the codebook approach of framework analysis was considered for the current study as it involves following a step-by-step process which guides the identification of recurrent and significant themes within a dataset which is harmonious with reflexive thematic analysis (Smith & Firth, 2011). Furthermore, adopting a framework analysis would allow for the analysis of a large and complex qualitative dataset as well as enabling me to identify variations that may exist within the population of study which were analytic factors I wanted to undertake (Goldsmith, 2021). However, employing a defined framework and establishing themes prior to full analysis, based off only data familiarisation, restricts the level of engagement and flexibility which is crucial to qualitative research practice. Thus, both the coding reliability and codebook approaches were not deemed appropriate for this research.

As there is a dearth of literature existing regarding Punjabi Sikhs and their understanding and help-seeking of psychosis and general severe mental illnesses, this research will be highly exploratory in nature, which is best matched with the flexible approach of reflexive thematic analysis. Reflexive thematic analysis permits adaptability in how much exploration can be applied. This permits researchers to make choices through the analysis process, contingent on what is considered applicable for the specific data set. This degree of flexibility lets researchers alter the method to the requirements of their study (Braun & Clarke, 2006; Willig, 2013).

Reflexive thematic analysis was also deemed the most appropriate qualitative analytic method for the current study as it enables the analysis of a large quantity of data from various participants (Braun & Clarke, 2019; Clarke et al., 2019). The current study set out to explore the research aims and objectives amongst three participant groups, leading to a relatively large sample size. A large sample size does not suit methodologies such as IPA, which would have been considered a good fit if the focus had been on obtaining an in-depth understanding of the experiences of psychotic disorders in one small participant group.

Furthermore, the aim of the current research was to develop an understanding of how the Punjabi Sikh community understand and seek help for psychosis, and how factors such as family, religion, and culture influence these. An aim was also to explore how these narratives are similar or distinctive across three participant groups. The emphasis of this research was
thus broader than that of an individual experience. For that reason, the adaptable nature of reflexive thematic analysis would allow for the development of unexpected outcomes and comprehension of individuals within a broader context, including their family systems.

The same research paradigm (critical realism), data collection method (semi-structured interviews) and analytic procedure (thematic analysis) has been documented in several comparable studies that have explored the understanding, help-seeking, and treatment of mental health problems amongst British South Asians, including the distinctive subgroups. This includes the study of general mental health in Gujarati Hindus (Patel, 2016) and Pakistani Muslims (Ahmed, 2019), psychological distress in Punjabi Sikhs (Ruprai, 2016), and eating disorders in South Asians (Nazir, 2015). This reinforced the decision in selecting thematic analysis as the most appropriate method for this study.

The detailed process of the reflexive thematic analysis utilised in this research is detailed in Section 3.4

3.4. Data Collection

3.4.1. Semi-Structured Interviews

Qualitative research can be conducted in a multitude of ways (Silverman, 2016). The most common methods are interviews and focus groups, which were two options I explored (Gill et al., 2008). After consideration, semi-structured interviews were chosen as the method to address all research aims and objectives amongst all three participant groups.

When comparing interviews and focus groups, it was considered that focus groups have an advantage over interviews in that they can provide a richer and broader range of information, and in some instances decrease angsts and potential stresses that one-to-one interviews may create for participants (Silverman, 2016). Furthermore, focus groups enable participants to debate, dispute and discuss their experiences (Bryman, 2012). However, a focus group approach may not allow for less confident or quieter participants to be heard. Thus, not everyone’s views would have an equal opportunity of being showcased, which could lessen the depth of accounts, more easily achieved from individual interviews.
More importantly, interviews are the most appropriate method and preferred technique when exploring sensitive topics (Alsaawi, 2014). The literature review made it evident that mental illness is highly stigmatised and viewed negatively in South Asian communities. Thus, discussing mental illness in a focus group setting would likely cause a reluctance to participate (Leask, Hawe, & Chapman, 2001).

Interviews allow for participants to express themselves as openly as possible, free from fear of judgement from other members of the community. This is particularly important for the service user and family member participants, whereby discussing one’s personal experience with mental illness would be a greatly sensitive matter (Elmir et al., 2011). Additionally, previous research has made it evident that a diagnosis of a mental illness is kept hidden and stays within immediate family circles (Time to Change, 2010; Bradby et al., 2007; Lawrence et al., 2006b). It would be highly unlikely that service users and family members would be open to discuss a personal mental health matter to other members of the community. Thus, the use of semi-structured interviews in comparison to focus groups is preferred due to issues around confidentiality of personal matters.

Other advantages of semi-structured interviews include the high validity of data that are captured (Silverman, 2016). Semi-structured interviews allow participants to delve deep into their experiences, sharing stories that they are unlikely to disclose in a group setting. Semi-structured interviewing also permits me to develop a structured guide to address research questions, but also the freedom to explore topics that may arise (Kvale & Brinkmann, 2009). I can probe participants to elaborate further on certain points and clarify any ambiguities or contradictions. This might not be feasible in a focus group setting, whereby expansion of points by each participant could lead to a lengthy focus group duration. Thus, semi-structured interviews hold the benefit of providing a comprehensive and thorough account from the participants, based on their understandings and beliefs in a timely manner. This method of data collection has also been carried out in similar studies which have qualitatively explored the experience of psychosis amongst service users and carers (Tanskanen et al., 2011; Pitt et al., 2009; Wood et al., 2010; Sin et al., 2012; Sin et al., 2005).

Exploring these studies helped inform the interview guides. Additionally, the McGill Illness Narrative Interview (MINI) helped inform some questions in the interview guides (Groleau, Young & Kirmayer, 2006), as well as considering key points from the literature review. All
questions were open-ended to prompt the experiences and views held by participants. The interview guides were developed in collaboration with my supervisors and revised until all research members felt the questions were appropriate and supportive to the overall research goal. Please see Appendix 6 for the interview guides used.

3.4.1.1. Semi-Structured Interviews with Laypeople

The lay people topic guide was influenced by a recent study that explored minority ethnic groups’ understanding and perceptions of schizophrenia (Cadge, Connor & Greenfield, 2019). The interview guide for the laypeople interviews was detailed and comprehensive. However, this was intended to be suggestive and not prescriptive in order to ensure that certain points get touched upon. Appendix 6A contains the full topic guide used in this study.

Based off the literature review, it was evident that severe mental illnesses such as psychosis and schizophrenia may be unfamiliar to some members of the Punjabi Sikh community. As these interviews were not based off personal experience with psychosis, there was a possibility that due to the lack of knowledge and awareness this community may hold towards these illnesses that the interviews might be short in duration and derive limited data. Thus, various probing resources were in place in order influence a detailed discussion and capture a thorough understanding of the topic.

This was firstly achieved by beginning the interview with the presentation of a case vignette of psychosis. Utilising a case-vignette to derive how individuals understand and would seek help for an illness has widely been used in mental health research. The case-vignette used in this research was developed and used in a previous study which explored explanatory models of psychosis amongst British South Asians (Bhika et al., 2015) (see Appendix 7A). For the purpose of this study, the original name in the vignette was replaced with a Punjabi, Sikh name ‘Manjit’ to allow participants to resonate with the character. After participants read the case-vignette, specific questions were asked relating to the presentation. The questions asked were inspired by those that are used in the Short Explanatory Model Interview (SEMI) (Lloyd et al., 1998). These included: what they believe ‘Manjit’ is experiencing, what may have caused it, and help-seeking pathways. Following this, participants were told that the case-vignette presentation was experiencing psychosis. Questions were then focused on the participant’s familiarity, awareness and knowledge of psychosis and schizophrenia.
Participants were then presented with a document which highlighted the early signs of psychosis (Appendix 7B). They were asked if someone within their immediate family presented with these symptoms – how would they perceive this and whether they would offer support and/or seek informal or professional help. Participants were then presented with the core symptoms that arise during a full psychotic episode – hallucinations and delusions (Appendix 7C). I asked the same questions regarding illness perceptions and help-seeking pathways at this ‘later’ stage of illness presentation.

The remainder of the interview explored general help-seeking behaviours for psychosis; attitudes towards seeking professional help; recommended coping strategies; knowledge of mental health treatments and services; perceived reactions from family and wider community towards psychosis; attitudes and beliefs around psychosis; and causal explanations for psychosis. After participants were asked about their causal attributions towards psychosis, a probing sheet was presented to discuss potential causes for psychosis. These included social, biological, religious, and supernatural causes (Appendix 7D).

For many questions, participants were asked to speak from their own perspective, but also give their view on the perspective of their family and wider Punjabi Sikh community.

3.4.1.2. Semi-Structured Interviews with Service Users

The interviews conducted with service users were intended to be more narrative in nature. Appendix 6B contains the service user topic guide.

The categories addressed in the service user interviews included: their experience during the onset of illness; what symptoms presented; their understanding of and reactions to initial changes in behaviour; beliefs and attitudes towards disorder; initial help-seeking behaviours (when was help sought and who from); other coping strategies utilised; causes of delays in help-seeking (if applicable); family and wider social circle reactions; and experiences of professional mental healthcare.
3.4.1.3. Semi-Structured Interviews with Family Members

The family member interviews followed a similar process to the service user interviews. Appendix 6C contains the family member topic guide.

The categories of interview discussion included: noticing a change in the service user’s behaviour; what changes were noticed; their understanding of and reactions to symptoms; beliefs and attitudes towards disorder; initial help-seeking behaviours advised (when was help sought and who from); other coping strategies recommended; feelings towards family and wider social circle reactions; and experience of professional mental healthcare.

3.4.1.4. Sample Size in Interviews

There are no concrete guidelines concerning the correct sample size for interview-based studies. Sample size generally relies on the concept of ‘saturation’, which is when the same themes keep repeating themselves, and no new data is being observed in data collection (Guest, Bunce & Johnson, 2006; Braun & Clarke, 2019).

When experimentally testing when saturation is likely to occur, Guest, et al (2006) found that saturation occurs within the first 12 interviews, whilst a similar study found it occurred within 16 interviews (Hagaman & Wutich, 2016). In research that uses thematic analysis, data saturation can be achieved in as few as 6-12 interviews (Ando et al. 2014).

Due to the in-depth nature of these interviews, and interviews being conducted in three participant groups, more than 20 participants per group could compromise analysis, in that in-depth analysis would be difficult to perform on the transcripts if the sample size is too large. Thus, it was intended to have 12-15 participants per group. However, due to recruitment challenges because of the COVID-19 pandemic, this figure was not met. This is discussed in more detail below.

3.4.2. Participants and Recruitment

Recruitment took place between February 2020 until September 2021. It is essential to note that recruitment and data collection coincided with the COVID-19 pandemic. This meant that significant changes had to be made to the original research plan, including ceasing all in-
person recruitment and conducting all data collection online. The recruitment process, sample size, and inclusion and exclusion criteria for each participant group will be discussed in turn.

3.4.2.1. Laypeople

The recruitment of those from minority ethnic religious groups has been found to be difficult (Mohammed, Jones & Evans, 2008). Thus, lay participants were recruited through multiple methods, utilising a purposive and snowball sampling technique.

The criterion for recruiting laypeople is outlined in Table 1.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Inclusion and Exclusion Criteria for Laypeople Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusion Criteria</strong></td>
<td><strong>Exclusion Criteria</strong></td>
</tr>
<tr>
<td>Age 18+</td>
<td>No previous clinical diagnosis of a serious mental illness</td>
</tr>
<tr>
<td>Identify as Sikh</td>
<td></td>
</tr>
<tr>
<td>Fluent in spoken English</td>
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</tbody>
</table>

Prior to the pandemic, it was anticipated that recruitment would primarily take place in-person. Recruitment for the laypeople study began in February 2020, which was just before the COVID-19 lockdown.

Recruiting within the West Midlands was chosen due to the practicality of being the location where I reside. Furthermore, statistics released by The Census Ward Data (ONS, 2011) specified that the largest quantity of Sikhs live in the West Midlands (31.57%). Birmingham is also the second largest city in the UK, with Indian being the second largest ethnic minority group within this city (Islam, Rabiee, & Singh, 2015). Additionally, Coventry has been found to have higher percentages of individuals from BAME groups, compared to the national average. The second largest ethnic group, accounting for 16.3% of Coventry’s population, is Asian/Asian British (Office for National Statistics, 2011).

Established groups and organisations which were Punjabi and/or Sikh based and situated in the West Midlands were identified and contacted by me. These included: university societies
such as Sikh Societies and Bhangra societies; community centres which host groups and events such as Punjabi language classes, Bhangra lessons, etc; and Punjabi focused mental health organisations.

_Gurdwara’s_53 were also a key place for recruitment for this community. I pursued _Gurdwara’s_ across the West Midlands which had the largest congregations. This information was made known to me by key informants in the community. I identified key individuals who had close links with these _Gurdwara’s_ and/or sat on the committee panel of these _Gurdwara’s_. Specific groups and events that take place in these _Gurdwara’s_ were also made note of.

Recruitment with these various organisations and/or groups was two-fold. Firstly, I would engage with the leaders of these organisations and/or groups and have them circulate the recruitment poster (Appendix 2A) amongst the attendees. This was achieved by having the posters printed and advertised within the organisations, in addition to having an electronic version of the recruitment poster circulated to the organisations mailing lists and/or WhatsApp groups. Secondly, I would visit these organisations and/or groups at a date and time recommended by the organisation leader and actively recruit onsite. It was also encouraged by me that the recruitment poster should be snowballed onto other relevant groups and individuals, in order to maximise recruitment for this study.

By March 2020, the COVID-19 lockdown was in place, thus recruitment could no longer be in-person and follow these routes. Utilising the contacts, I made with these cultural and religious based organisations pre-pandemic, these organisations were contacted again to advertise a modified form of the recruitment poster (Appendix 2B) across their social media pages, mailing lists, and relevant WhatsApp groups.

Participation no longer needed to be limited to the West Midlands region. Thus, an extensive search of key Sikh organisations across England was conducted, primarily through identifying social media pages with large Sikh followings. Instagram was a particularly useful platform in recruitment and a multitude of relevant accounts were contacted and advertised the study. Some of the prominent Punjabi Sikh based organisations that assisted in

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53 A gurdwara is a place of assembly and worship for Sikhs.
promoting the research included Taraki\textsuperscript{54}, Sikh Forgiveness\textsuperscript{55}, Sikh Your Mind\textsuperscript{56}, The Sikh Press Association\textsuperscript{57}, and SWAN (Sikh Women’s Action Network)\textsuperscript{58}. Additionally, my supervisors forwarded the study information and recruitment posters across the Sikh Doctors Association\textsuperscript{59} mailing list and to a health and wellbeing charity\textsuperscript{60} catering for Sikhs in the West Midlands area. With my primary supervisor also being Punjabi Sikh, they also had many personal Sikh contacts of whom my study information was shared with.

Due to the depth and variety of data derived from these interviews and people’s expressed interest to take part, it was decided to conduct more laypeople interviews than initially intended. The laypeople sample size was increased to ensure different age ranges were included. Thus, a total of thirty participants took part in the laypeople interviews. Of these, 11 were male and 19 females. The age range of participants was 19-69, with a mean age of 37. All participants identified as Sikh, with a census rated ethnicity of Asian/Asian-British Indian, apart from one participant who identified their census rated ethnicity as Asian/Asian British Other. Most participants were 2nd generation migrants, whereby their parents were born abroad, and they were born in the UK (n = 21), followed by 3rd generation migrants (n = 5), and 1st generation migrants (n = 4). All but two participants had some form of experience of mental health issues/problems, including personal experience (n = 18), having a close family member experience mental health problem (n = 16), or someone within their wider social network (n = 10). Table 2 contains full participant characteristics for the laypeople study.

\textsuperscript{54} https://www.taraki.co.uk
\textsuperscript{55} https://sikhforgiveness.com
\textsuperscript{56} https://sikhyourmind.com
\textsuperscript{57} https://www.sikhp.com
\textsuperscript{58} https://swanempower.co.uk
\textsuperscript{59} https://sdda.org.uk
\textsuperscript{60} https://www.safscare.org/
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<th>Country of Birth</th>
<th>Marital Status</th>
<th>Living Status</th>
<th>Education Level</th>
<th>Employment Status</th>
<th>Practice Religion</th>
<th>Experience with Mental Health</th>
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<td>LI1</td>
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<td>25</td>
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<td>UK</td>
<td>Single</td>
<td>Alone</td>
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<td>Yes</td>
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<td>Student</td>
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<td>P, CFM, WSN</td>
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<td>UK</td>
<td>Cohabitating</td>
<td>With Partner &amp; Children</td>
<td>First Degree (or equivalent)</td>
<td>Student</td>
<td>Yes</td>
<td>P</td>
</tr>
<tr>
<td>LI4</td>
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<td>2nd</td>
<td>UK</td>
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<td>With Partner</td>
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<td>With Parents /Guardians</td>
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<td>Employed Part-Time</td>
<td>Yes</td>
<td>P, CFM, WSN</td>
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</table>

61 Participants were asked if they had experience with mental health, either through personal (P), close family member (CFM), or their wider social network (WSN).
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<td>Yes</td>
</tr>
<tr>
<td>LI16</td>
<td>F</td>
<td>22</td>
<td>3rd</td>
<td>UK</td>
<td>Single</td>
<td>With Parents /Guardians</td>
<td>First Degree (or equivalent)</td>
<td>Yes</td>
</tr>
<tr>
<td>LI17</td>
<td>F</td>
<td>Not Stated</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Extended Family</td>
<td>First Degree (or equivalent)</td>
<td>Self-Employed</td>
</tr>
<tr>
<td>LI18</td>
<td>F</td>
<td>33</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Parents/Guardians</td>
<td>Postgraduate Degree</td>
<td>Yes</td>
</tr>
<tr>
<td>LI19</td>
<td>M</td>
<td>39</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>Postgraduate Degree</td>
<td>Yes</td>
</tr>
<tr>
<td>LI20</td>
<td>F</td>
<td>23</td>
<td>3rd</td>
<td>UK</td>
<td>Single</td>
<td>With Parents/Guardians</td>
<td>First Degree (or equivalent)</td>
<td>Student</td>
</tr>
<tr>
<td>------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>------</td>
<td>--------</td>
<td>------------------------</td>
<td>-------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>LI21</td>
<td>F</td>
<td>25</td>
<td>2nd</td>
<td>UK</td>
<td>Single</td>
<td>With Parents/Guardians</td>
<td>First Degree (or equivalent)</td>
<td>Employed Full-Time</td>
</tr>
<tr>
<td>LI22</td>
<td>F</td>
<td>36</td>
<td>2nd</td>
<td>UK</td>
<td>Other – In Relationship</td>
<td>Alone</td>
<td>Postgraduate Degree</td>
<td>Employed Full-Time</td>
</tr>
<tr>
<td>LI23</td>
<td>F</td>
<td>54</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>GCSE (or equivalent)</td>
<td>Employed Full-Time</td>
</tr>
<tr>
<td>LI24</td>
<td>F</td>
<td>53</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>First Degree (or equivalent)</td>
<td>Employed Part-Time</td>
</tr>
<tr>
<td>LI25</td>
<td>M</td>
<td>19</td>
<td>3rd</td>
<td>UK</td>
<td>Single</td>
<td>With Parents/Guardians</td>
<td>A Level (or equivalent)</td>
<td>Student</td>
</tr>
<tr>
<td>LI26</td>
<td>F</td>
<td>26</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner</td>
<td>Postgraduate Degree</td>
<td>Student &amp; Employed Part-Time</td>
</tr>
<tr>
<td>LI27</td>
<td>F</td>
<td>58</td>
<td>2nd</td>
<td>UK</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner</td>
<td>Postgraduate Degree</td>
<td>Employed Part-Time</td>
</tr>
<tr>
<td>LI28</td>
<td>M</td>
<td>58</td>
<td>1st</td>
<td>India</td>
<td>Widowed</td>
<td>Alone with Children</td>
<td>A Level (or equivalent)</td>
<td>Self-Employed</td>
</tr>
<tr>
<td>------</td>
<td>----</td>
<td>----</td>
<td>-----</td>
<td>-------</td>
<td>---------</td>
<td>---------------------</td>
<td>------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>LI29</td>
<td>F</td>
<td>60</td>
<td>2nd</td>
<td>UK</td>
<td>Divorced</td>
<td>Alone</td>
<td>Postgraduate Degree</td>
<td>Employed Part-Time</td>
</tr>
<tr>
<td>LI30</td>
<td>F</td>
<td>69</td>
<td>1st</td>
<td>Africa</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>Postgraduate Degree</td>
<td>Employed Part-Time</td>
</tr>
</tbody>
</table>
3.4.2.2. Service Users with Psychosis

Service users were recruited from mental health trusts within the West Midlands. The choice of this location was not only due to practicality as it was where I was located, but also the West Midlands has been reported as one of the areas where increased numbers of new cases of psychosis occur (Public Health England, 2016).

Several mental health trusts within this county were identified, including Coventry and Warwickshire NHS Partnership Trust (CWPT), Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT), Dudley and Walsall Mental Health Partnership NHS Trust (DWMH) and Black Country Partnership NHS Foundation Trust.

Prior to deciding which trusts would be involved in the enrolment for this study, team managers of the community mental health teams (CMHTs) at these trusts were contacted to discuss the prevalence of Sikhs using these services and the feasibility and practicality of recruiting from these trusts. Freedom of Information requests at these trusts were completed to identify how many Sikh service users there were within the trust with a diagnosis of psychosis (excluding those with drug induced psychosis).

CWPT and BSMHFT were deemed the most viable options for recruitment of Sikh service users. This decision was also made as my supervisor had worked at both trusts, thus assisting me in connecting with specific consultants of whom might treat Sikh service users.

The criteria for recruiting service users are outlined in Table 3. After receiving NHS/HRA ethical clearance (see Appendix 8C), the recruitment process for service users began in July 2020. I worked with CWPT and BSMHFT to begin identifying and recruiting eligible service users. There were several main strategies of recruitment. Firstly, I would contact team managers of CMHTs, who would then connect me with key members of staff who were able to aid in recruitment. Secondly, I attended CMHT team meetings via MS Teams to present the research and identify consultants who treat Sikh service users with psychosis. Thirdly, my primary supervisor provided numerous key contacts of consultants at both trusts who might treat the target population.
Table 3

Inclusion and Exclusion Criteria for Service User Study

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 18-65</td>
<td>Lack of Capacity to Consent</td>
</tr>
<tr>
<td>Diagnosis of a psychotic disorder</td>
<td>Primary diagnosis of learning disability or substance abuse (substance-induced psychosis)</td>
</tr>
<tr>
<td>Identify as Sikh</td>
<td></td>
</tr>
<tr>
<td>Fluent in spoken English</td>
<td></td>
</tr>
</tbody>
</table>

From these strategies, if a consultant expressed that they did have an eligible service user who was well enough to take part, it was on the part of the consultant or care co-ordinator to provide the eligible service user with a recruitment poster (Appendix 2C) and participant invitation letter (Appendix 2D). If the eligible service user expressed an interest in taking part, the staff member would obtain initial consent for their details to be passed onto the me. I would then contact them via email or telephone in due course to arrange a time and date to complete the interview.

Due to the impact of the COVID-19 pandemic, recruitment of service users was greatly affected. I was no longer able to visit these trusts to aid in the recruitment of participants. Additionally, mental healthcare staff stated that they had difficulty contacting service users during this period. This was due to many service users not having access to internet or a computer for online video consultations. Furthermore, many service users were not answering or returning telephone calls regarding their regular psychiatric consultations. These impediments are discussed in detail in Section 7.3.1.

Due to these challenges, four participants took part in the service user study, all of whom were male. The age range of participants was 22 – 40 years, with a mean of age of 34 years. All participants identified as Sikh and selected their census rated ethnicity of Asian/Asian-British Indian. For self-ascribed ethnicity, one participant put ‘British Sikh’, and another wrote ‘British Indian’. Table 4 contains full participant characteristics for the service user study.
Table 4
Service User Study – Sample Characteristics

<table>
<thead>
<tr>
<th>ID</th>
<th>Sex</th>
<th>Age</th>
<th>Migrant Generation</th>
<th>Country of Birth</th>
<th>Education Level</th>
<th>Marital Status</th>
<th>Living Situation</th>
<th>Practice Religion</th>
<th>Illness Described</th>
</tr>
</thead>
<tbody>
<tr>
<td>SU1</td>
<td>M</td>
<td>40</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>Prefer Not to State</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>No</td>
<td>Psychosis</td>
</tr>
<tr>
<td>SU2</td>
<td>M</td>
<td>39</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>First Degree (or equivalent)</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>Yes</td>
<td>Affective Bipolar</td>
</tr>
<tr>
<td>SU3</td>
<td>M</td>
<td>22</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>Postgraduate Degree</td>
<td>Single</td>
<td>With Parents</td>
<td>No</td>
<td>Non-Organic Psychosis</td>
</tr>
<tr>
<td>SU4</td>
<td>M</td>
<td>34</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>India</td>
<td>Postgraduate Degree</td>
<td>Married &amp; Cohabiting</td>
<td>With Partner &amp; Children</td>
<td>Yes</td>
<td>Psychosis</td>
</tr>
</tbody>
</table>
3.4.2.3. Family Members of those with Psychosis

Recruitment of those who had an immediate family member with a diagnosis of psychosis commenced in July 2020, alongside the service user recruitment. Following on from the service user study, if service users consented for one of their family members to also take part, I would provide a recruitment poster (Appendix 2C) and participant information sheet (Appendix 3C) to the service user to pass onto a relevant family member. If the family member wished to take part, they could contact me directly. Two service users declined for their family member to take part (SU1 and SU4), the remaining two had a family member participate (SU2-C4 and SU3-C6).

Due to the limited number of service users recruited through mental health trusts, family members with a lived experience of psychosis were also recruited through the same avenues used to recruit laypeople. These methods have been discussed in detail in Section 3.3.2.1. The recruitment poster was amended to be more concise and suitable for social media platforms (Appendix 2E), and this method of recruitment commenced in September 2020. The criteria for recruiting family members are outlined in Table 5.

Table 5

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 18+</td>
<td>No previous clinical diagnosis of a serious mental illness</td>
</tr>
<tr>
<td>Immediate family member of someone with a diagnosis of psychosis</td>
<td></td>
</tr>
<tr>
<td>Identify as Sikh</td>
<td></td>
</tr>
<tr>
<td>Fluent in spoken English</td>
<td></td>
</tr>
</tbody>
</table>

Nine participants took part in the family member interviews. Of these, 3 were male and 6 females. The age range of participants was 20 – 66 years, with a mean age of 41. All participants identified as Sikh. Six participants selected their census rated ethnicity of Asian/Asian-British Indian, apart from three participants. Two participants identified their census rated ethnicity as Asian/Asian British Other, and one participant put ‘Sikh’ next to
this. Another selected ‘Any other ethnic group’ under the census ratings, and self-ascribed their ethnicity as ‘Sikh’. Most participants were 2nd Generation migrants, whereby their parents were born abroad, and they were born in the UK (n = 6), followed by 1st Generation migrants (n = 2) and 3rd Generation migrants (n = 1). The participant who selected their migrant status as 3rd Generation did state within the interview that their mother is from India, whilst her father is from UK. Please see Table 6 for full participant characteristics for the family member study.
<table>
<thead>
<tr>
<th>ID</th>
<th>Sex</th>
<th>Age</th>
<th>Migrant Generation</th>
<th>Country of Birth</th>
<th>Education Level</th>
<th>Practice Religion</th>
<th>Relation Of Participant</th>
<th>Family Member Who is Ill</th>
<th>Diagnosis of Ill Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>M</td>
<td>-</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Son</td>
<td>Mother</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>C2</td>
<td>F</td>
<td>20</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>First Degree (or equivalent)</td>
<td>No</td>
<td>Daughter</td>
<td>Mother</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>C3</td>
<td>M</td>
<td>41</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt;</td>
<td>UK</td>
<td>First Degree (or equivalent)</td>
<td>Yes</td>
<td>Brother</td>
<td>Brother</td>
<td>Mild Schizophrenia</td>
</tr>
<tr>
<td>C4</td>
<td>F</td>
<td>66</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>India</td>
<td>GCSE (or equivalent)</td>
<td>Yes</td>
<td>Mother</td>
<td>Son</td>
<td>Affective Bipolar Disorder</td>
</tr>
<tr>
<td>C5</td>
<td>F</td>
<td>50</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
<td>Kenya</td>
<td>Postgraduate Degree</td>
<td>Prefer Not to State</td>
<td>Sister</td>
<td>Brother</td>
<td>Psychosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>C6</td>
<td>F</td>
<td>23</td>
<td>3rd</td>
<td>UK</td>
<td>Postgraduate Degree</td>
<td>Prefer Not to State</td>
<td>Sister</td>
<td>Brother</td>
<td>Brief Psychotic Disorder</td>
</tr>
<tr>
<td>C7</td>
<td>M</td>
<td>42</td>
<td>2nd</td>
<td>UK</td>
<td>Postgraduate Degree</td>
<td>Yes</td>
<td>Brother</td>
<td>Brother</td>
<td>Psychosis as a result of Hypoxic Brain Injury</td>
</tr>
<tr>
<td>C8</td>
<td>F</td>
<td>37</td>
<td>2nd</td>
<td>UK</td>
<td>Postgraduate Degree</td>
<td>Yes</td>
<td>Daughter</td>
<td>Mother</td>
<td>Paranoid Schizophrenia</td>
</tr>
<tr>
<td>C9</td>
<td>F</td>
<td>47</td>
<td>2nd</td>
<td>UK</td>
<td>First Degree (or equivalent)</td>
<td>Yes</td>
<td>Mother</td>
<td>Son</td>
<td>Paranoid Schizophrenia</td>
</tr>
</tbody>
</table>
3.4.3. Ethical Considerations

Ethics committee approval was obtained by University of Warwick Biomedical & Scientific Research Ethics Committee (BSREC) (Reference: BSREC 13/19-20 AM03) and NHS HRA (Reference: SOC.08/19-20 AM02) (Appendix 8). Several amendments were made to the original ethics application throughout the research process to address the changes made to the original research plan due to the COVID-19 pandemic. The following were considered key ethical issues to be addressed:

3.4.3.1. Informed Consent

Informed consent was initially established through providing all participants with a participant information sheet (see Appendix 3) prior to taking part in the study. This sheet detailed the research aims, what participation would entail, the risks and benefits of taking part, and information on data protection, data storage, and protecting participant confidentiality.

Participants were encouraged to ask any questions regarding the information they were given prior to completing a consent form. Consent forms (see Appendix 4) were then sent via email in most instances. For service users who did not have an email access, a verbal script which detailed the information in the participant information sheet and consent form (see Appendix 4C) was read out loud by me. The consent form detailed the participant’s agreement to have their interview audio-recorded and for their data to pseudonymised and used in dissemination outputs. It was also highlighted that participants had the right to withdraw their participation up to any point before the interview without consequence. They also had the right to withdraw their interview within 72 hours of taking part. After this point, I would begin transcribing and analysing the data. Once consent forms were signed, one copy was retained by participants and the other by me. All consent forms held by me were stored electronically on an encrypted computer.

On the date of the interview, prior to the interview commencing, information regarding the study and consent was revisited between myself and the participant. Participants were again invited to ask any questions regarding their participation. Participants were then asked to confirm that they consented to me beginning the audio recording for the interview.
3.4.3.2. Confidentiality and Anonymity

Data was collected and managed according to the UK’s latest Data Protection Act (2018).

All participants were attached with an appropriate pseudonym, and these pseudonyms were labelled on the sociodemographic surveys, audio recordings and transcripts. These files were all stored within an encrypted computer hard drive which only I had access to. Audio recordings were permanently deleted from the computer hard drive and back-ups once the data was accurately transcribed.

The pseudonymised transcripts were accessed by the me, my supervisors, and a second reviewer for thematic analysis. Any identifiable data that may have been within the transcript’s contents had been redacted before other members of the research team had access. Participants were made aware that their pseudonymised transcripts could be read by the other research team members. Identifiable data that were in the contents of consent forms or email correspondence was kept independently and securely away from the research data.

Participants were notified about the parameters of confidentiality as defined in the consent form and actions for safeguarding data as highlighted in the participant information sheet.

3.4.3.3. Right to Withdraw

If participants had agreed to take part, they could withdraw at any point until the interview date without negative affect. If participants took part in the interview, they had the right to withdraw their data within 72 hours of taking part in the study with no consequence. They were made aware that after this point I would begin the transcription and analysis process.

3.4.3.4. Minimising Psychological Harm

Specific consideration was given to reducing possible harm caused by the conversation of sensitive issues in the interview. Particularly for those with lived experience of psychosis, there was a possibility that reliving the experiences surrounding the psychotic break could cause distress for both service users and family members. To mitigate this risk, both service users and family members were made fully aware of the nature of topics that were to be discussed, particularly that I wanted to hear the ‘story’ from when changes in behaviour began to occur to the point where help was sought.
All participants across the groups had the right to refuse to answer any question. Furthermore, they had the opportunity to terminate the interview at any point, request breaks, or ask for re-scheduling the interview at another time-point to continue. No consequence would come about for participants if they made any of these requests.

Due to the restricted verbal and social cues in a video and telephone interview, I took mindful actions to pause regularly and permit participants to process and reply to the questions. If I deemed a participant to appear slightly distressed, I would 'check-in', offer to pause the audio recording and take a break, and confirm whether they wished to continue the interview.

At the end of the interview, participants were debriefed and encouraged to discuss any additional questions or worries regarding the study. This was to ensure the participant left the interview in the same psychological state as they entered. Local mental health support information was detailed in the participant information sheet, and participants were reminded of this at the end of the debrief.

3.4.4. Data Collection Procedure

The research procedure is outlined in Figure 1. Across the participant groups, all participants who expressed a willingness to take part could telephone or email me. Their eligibility was assessed against the inclusion criteria and if eligible they would be sent a participant information sheet via email (Appendix 3).

For those that still wished to partake after reading the participant information sheet, a date and time convenient for both myself and the participant was arranged. An email calendar invite would be sent, alongside an attached consent form (Appendix 4) and sociodemographic survey (Appendix 5) to complete prior to the interview date.

Due to the COVID-19 pandemic, all interviews were conducted either via online video or telephone, at the participants choice. For those who selected the option of a Microsoft Teams online video call, an encrypted auto-generated link for the interview was sent with the email calendar invite. Those who chose a telephone interview were contacted on their preferred contact number on the date and time of arranged interview.
Prior to these interviews, I confirmed that participants had read the participant information sheet and if they had any questions regarding their participation. They were reassured that all data would be kept confidential, and they are able to skip any questions that they are not comfortable answering. Guidelines around the withdrawal process and if they wished to no longer have their data used in the study was also discussed prior to the interview starting. Full ethical considerations are detailed previously in Section 3.3.3.

For service users who did not have access to email, I read out a verbal script version of the participant information sheet and consent form (Appendix 3C & 4C). Participants could then verbally consent to understanding what their participation entailed and their consent to take part. The sociodemographic survey would also be completed verbally in these instances where I asked the service users the contents of the survey and the options, they had available as answers.

After these formalities, participants would be made aware that the audio recording of the interview via encrypted Dictaphone would start, and the topic guide was followed to direct the discussion with a level of flexibility in reply to the subjects raised by the participants.

The duration of interviews varied, with laypeople interviews lasting on average between 40-60 minutes, family member interviews lasting between 20-40 minutes, and service users interviews lasting between 10-30 minutes.

At the end of the interviews, participants were verbally debriefed. In the instance of laypeople interviews, the actual study’s purpose was made clear, as the study was advertised as being regarding mental health in the Sikh community with no specific reference to psychosis. This was to mitigate participants educating themselves on psychosis prior to the interview. Mental health support lines were provided on the participant information sheet, and participants were made aware of this at the end of interviews, should they wish to contact support.

The audio recordings of interviews were uploaded onto an encrypted computer immediately after the interview had ended and permanently deleted from the encrypted Dictaphone. These audio recordings were labelled with the date of interview and participant pseudonym. For
example, ‘LI1’ would refer to the first layperson interview. Audio recordings were then transcribed by me within 14 days of the interview date. Full details of the transcription process are detailed in Section 3.4.1. Once the transcripts were checked for accuracy alongside the audio recordings, the audio recordings were permanently deleted from my computer and computer back-ups, following the process approved by the ethics committee.

Sociodemographic surveys were also stored on an encrypted computer, with the relevant pseudonym and date of interview attached to these document titles. Consent forms, which contained identifiable data, were stored in a separate encrypted folder.

Transcripts were imported into NVivo 12 and analysed using reflexive thematic analysis, as detailed below in Section 3.4.
Figure 1

Procedure Flowchart

Potential participants contact researcher via email or telephone if interested in taking part.

Researcher assesses participants eligibility to take part and provides participant information sheet.

Date, time, and choice of online video or telephone call is confirmed.

Interview call takes place - Consent is revisited; Interview then follows topic guide; Audio recorded.

Researcher receives consent form and sociodemographic survey before scheduled interview.

Participant sent an email calendar invite, with attached consent form and sociodemographic survey to complete.

Participants debrified. Mental health support information is provided.

Audio Recordings, Sociodemographic Survey, and Consent Form all stored on encrypted computer, labelled with pseudonyms.

Audio recordings transcribed within 14 days of interview date, and permanently deleted from computer following accurate transcription.

Transcripts imported within NVivo 12 and analysed using reflexive thematic analysis.
3.5. Data Analysis
The chosen analysis for this research was reflexive thematic analysis (Braun & Clarke, 2019), and the rationale for this has been described in Section 3.2.1.5. Braun and Clarke (2006; 2019) defined a six-step framework for completing thematic analysis, which can be employed flexibly to suit the research question and data. The process of the phases employed are displayed in Figure 2. Each participant group was analysed separately, in order to compare the narratives between service users, family members and laypeople.

Thematic analysis can take two approaches: an inductive “bottom-up” form or a deductive “top down” form. A deductive approach links themes to pre-existing theoretical theories and hypotheses (Braun & Clarke, 2006). An inductive approach generates themes independent of existing theory and knowledge and is driven by the raw data (Clarke et al., 2019).

The novel nature of this research and limited research conducted on the Punjabi Sikh community would classify for an inductive approach to be most appropriate when analysing the data, as there is no existing framework or theoretical model to lead the analysis. Furthermore, inductively analysing data has generally recommended as most applicable for exploratory research.

An inductive approach will allow innovative and flexible understanding of the data and development of themes with marginal presumptions. However, my engagement with the literature carried out prior to data collection may have affected how the data was construed. Nevertheless, due to my position as a Punjabi, Sikh it is impossible to escape the influence of prior knowledge and personal and epistemological commitments which undeniably shaped the relationship I had with the research process.

Thematic coding can also take place at a semantic (explicit) or latent (interpretative) level, which relates to the depth of analysis. Semantic codes and themes can be considered descriptive. Only the surface meaning of the data is identified, without a researcher going outside what the participant has said (Braun & Clarke, 2006). Contrariwise, latent codes or themes are considered interpretative. They require a researcher to go beyond the data and deliver a deeper level of understanding, with codes to portraying inherent concepts, patterns, and assumptions.
The analytic process of this research began at a semantic level, whereby themes were anticipated to be obvious within the data. This would circumvent incorrect interpretation in an area where there has been limited research conducted. The analysis progressed to an interpretative level, as an explanation of findings in relation to the previous literature and broader context essential for the discussion, as recommended by Braun and Clarke (2013).

An external reviewer was also involved in the analytic process. The second reviewer was provided with a proportion of uncoded transcripts from each participant group and was asked to familiarise themselves with the data and then perform initial coding. These transcripts were then returned to the me and were merged into the master NVivo file for each participant group, where coding was then compared. The external reviewer and I met and discussed the initial codes constructed, their impressions of the data, and potential candidate themes. Once I had developed a refined list of candidate themes, these were discussed with both the external reviewer and supervisory team for validation. Regular supervision throughout each phase of the analytic process was also undertaken for support and to discuss the various ideas and themes that were prevailing.

3.5.1. Transcription

An encrypted Dictaphone provided by the University was used to audio record all interviews. Transcription of all data was performed which allowed me to be fully immersed and familiarised with the data, which is a key component of thematic analysis (Braun & Clarke, 2006). All data was also transcribed within 14 days of the interview data to ensure successful and meaningful engagement with each data set.

Transcription was performed at a high-quality level, ensuring accuracy. This was achieved by listening to the original audio recordings a multitude of times, and consistently checking the audio recordings against the transcripts.

Following this, I edited the audio files on Audacity software, slowing down the pace and using various functions to improve voice quality. These edited versions were also listened to and checked against the transcripts to ensure accuracy of transcribed data.
Audio was transcribed verbatim, which meant that the verbal pauses, utterances and non-semantic sounds made by both parties were captured. This allowed for the transcripts to be as near to the original audio as possible and to ensure that the spoken data depicted the way the individuals communicated themselves (Braun & Clarke, 2006; 2013).

The classification of each speaker was distinctly marked using ‘Researcher’ and the pseudonym assigned to the participant, e.g., LI1, SU1, C1. Any identifying details within the transcript were redacted to aid anonymity and protect confidentiality.

Whilst the inclusion criteria for all participant groups was a fluency in spoken English, many participants did state a few Punjabi words or phrases. As I am Punjabi Sikh, I was familiar with the words and phrases used and thus was able to translate these. For the write-up of analyses, if Punjabi language was spoken within a data extract, this was included in italics and the translation was included as a footnote.

Furthermore, to aid readability, the data extracts that have been included in the final write-up have been presented in an intelligent verbatim style. This allows for the extracts to be cleaned up slightly, through the insertion of punctuation and removing distracting fillers.
Figure 2
Process Of Data Analysis Based on the Six Phases of Thematic Analysis (Braun & Clarke, 2006; 2019)

Phase One - Familiarisation with Data
Audio recordings thoroughly reviewed and transcribed. Transcripts read systematically and numerously to increase familiarisation with data, allowing researcher to become immersed in the data. Meaning, patternings, and initial reflections towards data began to be formed, and a reflective diary was kept.

Phase Two - Generating Initial Codes
Themes and patterns across the whole data set were coded systematically and inductively within NVivo 12. The same extracts could have different codes attached to them. Initial codes revised, with some codes merged, rejected, or replaced. A portion of transcripts were sent to an external reviewer and supervisor for validation.

Phase Three - Searching for Themes
Initial codes were organised and aggregated into 'canditate' themes relevant to the research question. The process was exploratory and iterative, with some themes being repudiated or combined, and others were retained and stated as sub-themes. The relationship between the different themes were considered.

Phase Four - Reviewing and Refining Themes
The 'canditate' themes were reviewed by the supervisory team and external reviewer. Transcripts were re-read, and each theme was inspected and examined for consistency to make sure it represented the actuality of the participants' narratives and the corpus of data.

Phase Five - Defining and Finalising Themes
Acquiring names that correctly consider the data excepts at code level and assembly of codes at theme level. The essence of each theme is refined and clarified, ensuring that it addresses the research questions and encapsulates the complete picture.

Phase Six - Constructing the Report
The analysis report was constructed. Representative and strong extracts that supported the essence of each theme were selected and embedded amongst an analytic narrative that related back to the research question. Key extracts that indicated commonalities and deviations from the themes were also included.
3.6. Quality and Credibility

One of the central critiques of qualitative research is the lack of rigour and objectivity (Yardley, 2000). Thus, standards for conducting good qualitative research were applied, to ensure the data is trustworthy and credible (Elliott et al., 1999; Nowell et al., 2017).

Firstly, regular supervision was sought throughout the research process by my PhD supervisors, of whom are experts in the research topic and/or methodology applied in the current project. For example, my primary supervisor is a Professor in Social and Community Psychiatry who has extensively researched in the area of BAME mental illness and works with psychosis service users. My secondary supervisor is an Assistant Professor in Youth Mental Health, who is well-experienced in qualitative research methodologies and sensitive research topics. The expertise of both were valuable in shaping my approach towards the project, ensuring each phase of the research was completed to a high degree of quality.

Specific examples of ensuring credibility included the development of an appropriate topic guide for each participant group which was created in collaboration with both supervisors who are experts in the field.

Credibility can also be improved through supportive engagement (Lincoln & Guba, 1985). Supportive engagement was employed in this research through allowing participants to select a time and date which was convenient for them to take part, in addition to allowing them to have a telephone interview instead of a video interview if they did not feel comfortable with an online face-to-face discussion. These approaches, along with exercising rapport-building strategies, allowed for a safe research environment to be fostered. This permits participants to feel comfortable to share comprehensive details of their experiences.

Providing credibility checks throughout the analytic process from an additional researcher who is equally a specialist in the field and proficient in supervising research is also recommended (Elliot et al., 1999). This was achieved through regular supervision with both supervisors through the analytic process. This allowed for researcher triangulation and constant credibility and validity checks on the themes as they arose.

An external reviewer was also sought to validate the themes and findings from the data collected. The external reviewer is a Core Psychiatry Trainee and Academic Clinical Fellow,
who has worked in the area of psychiatry for several years and commonly worked with psychosis service users. As specified in Section 3.4., the external reviewer coded a proportion of transcripts from each participant group which I then checked to determine the consistency of initial codes and themes emerging. The external reviewed and I also met to discuss how we both viewed the data and discussed potential candidate themes. Once the final themes were developed, feedback and corroboration were sought from the external reviewer. The external reviewer was also sent the write-up of the analysis for their opinion.

A clear audit trail was also kept throughout the analysis process. This was achieved using NVivo 12 qualitative software, which permitted for each step of the reflexive thematic analysis to be recorded, from initial coding (see Appendix 9B) to final themes. Annotations of data could also be stored within the NVivo project file, which display my thoughts about the data and/or analysis.

A research diary (Appendix 9D) was also kept throughout the data collection and analysis phases. The diary included field notes and emerging thoughts and themes, as well any issues or challenges. Time was spent after each interview to reflect on the discussion, which also helped to notice if data saturation was reached. The use of a research diary also allowed for data triangulation, as data could be corroborated from several sources: interviews, field notes taken at time of data collection, and my impressions at the time of data analysis.

Delivering evidence of themes through adequate examples from the data is another instance of good practice in qualitative research, which has been completed in this project and demonstrated in the write-up of findings in Chapters 4-6. Finally, it is advised that the theoretical orientations of research are clearly indicated by me in order to ensure the credibility of research (Elliot et al., 1999). This has been indicated in Section 3.1.3.1.

3.7. Researcher Reflexivity
Qualitative research is subjective and reflexive, whereby a researcher is not considered an observer of the research process, but rather an “instrument” within the process (Pyett, 2003). A researcher is actively engaged in and has an impact on the collection, choice and analysis of data. Thus, it is imperative that I must be clear about my position in this research and
participate in critical self-reflection of how my social background, subjective perspectives, and behaviour could impact the research (Finlay & Gough, 2008).

Through being reflexive, transparency is achieved, errors are reduced by ensuring sufficient interpretation of findings, and subjective bias is reduced (Berger, 2013). In order to foster reflexivity and to ensure trustworthiness, I kept a research diary through the data collection and analysis phases. This enabled me to record personal reflections on the research process, and to note any implicit views I may hold which could impact the data. This diary was also used to record rationales for research decisions, the logistics of the research, and considerations of what is happening in relation to my values and interests, ensuring that the research stayed in harmony to my own beliefs and assumptions (Nowell et al., 2017). Reflexive discussions were also completed throughout research supervision, which allowed me to consider my position within the construction of all aspects of the research.

It could be claimed that I am an ‘insider’ because I share the same religious and cultural identity as the participant sample. I am a 28-year-old, third-generation, Punjabi Sikh female, who currently resides in Coventry, West Midlands in the United Kingdom. I have grown up in a multi-cultural community, where there have been many Punjabi Sikhs throughout my primary, secondary and higher education. For this reason, I do not personally feel like an ‘ethnic minority’.

My first-generation grandparents immigrated to the United Kingdom in the 1960’s, from Kenya, East Africa. My immediate and extended family are all fluent in English, including my grandparents, and for this reason I have not learnt to speak or understand much of the Punjabi language. My limited Punjabi language skills were used to an advantage during data collection, whereby participants were made aware of my language position and thus were encouraged to unpack the meanings of any Punjabi terms used. Having participants explain their personal definitions of collective cultural or spiritual expressions was beneficial as these terms could carry distinct connotations for each participant.

I also consider myself to hold a very basic understanding on Sikh practices and do not have an in-depth knowledge of the religion. Again, I used this to my benefit, as participants were encouraged to elaborate on religious concepts that they brought up, which is imperative as religious scripture and concepts are open to interpretation. Thus, if I was well-acquainted in
the Sikh faith, I may not have asked for further clarification on certain beliefs and may have applied my own subjective meanings to the data collected.

Asselin (2003) recommended for ‘insider’ researchers to collect data as if they know nothing about the topic being studied. My limited knowledge of the Sikh faith, in addition to there being no research existing on psychosis within the Punjabi Sikh community, allowed this to be achieved. It was also an integral part of the interview for participants to provide their own meanings to terms such as ‘psychosis’, ‘schizophrenia’ and ‘severe mental illness,’ rather than me imposing my own meaning of these illnesses onto participants.

Culturally, I had an awareness of beliefs and superstitions that exist within the community. I believed this to be useful as it allowed me to facilitate and probe discussion on this topic if it did not arise organically. Participants may also feel more comfortable speaking about cultural beliefs and superstitions with someone of matched heritage in comparison to an ‘outsider.’ Furthermore, participants may generally feel more of a willingness to talk to a researcher of the same heritage as they may feel they are able to relate to them and understand basic cultural concepts. The less differences between research and participant have been considered to enhance rapport, which provides more rich and in-depth data (Andrade, 2000).

Another advantage of sharing the same religious and cultural identity with participants included my ability to easily attain access to the community. I have a substantial network of family and friends who are of Punjabi Sikh heritage. Some of these individuals connected me to key members of the community and/or potential participants. Additionally, they promoted the study on my behalf which allowed for a much greater outreach for recruitment.

Prior to the pandemic, the Gurdwara62 was a key place for recruitment for the laypeople study. Being a member of the community also allowed for me to be aware and adhere to the cultural and religious behaviours in a Gurdwara.

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62 A gurdwara is a place of assembly and worship for Sikhs.
4. Laypeople Perceptions and Understanding of Psychosis

This chapter presents the findings from the study which explored how a lay sample of Sikh participants understood and would hypothetically seek help for a psychotic illness. Using the principles of thematic analysis, six main themes and numerous sub-themes were identified (See Table 7). Each theme is discussed in turn. The chapter concludes with a summary and discussion of findings.

Table 7

*Overview of Main Themes and Sub-Themes from Laypeople Study Analysis*

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Awareness, Knowledge &amp; Understanding of Psychosis (&amp; Other Mental Illnesses)</td>
<td>1.1. Lack of Awareness, Knowledge &amp; Understanding of Psychosis and Schizophrenia 1.2. Lack of Use and Knowledge of Mental Health Terms 1.3. Increased Awareness of Common Mental Illnesses</td>
</tr>
<tr>
<td>3. Help-seeking and Support for Psychosis (&amp; Other Mental Illnesses)</td>
<td>3.1. Professional Help-Seeking 3.2. Religious Coping and/or Help-Seeking 3.3. Informal Support 3.4. Views towards Culturally Appropriate Care 3.5. Supernatural Beliefs and Associated Help-Seeking</td>
</tr>
</tbody>
</table>
4. Negative Attitudes towards Psychosis & Other Mental Illnesses

4.1. Stigma
4.2. Denial & Ignorance
4.3. Secrecy
4.4. Fear & Judgement

5. The Role of Family & Community in Psychosis & Other Mental Illnesses

5.1. Family Not Supportive of Mental Health Struggles
5.2. No Open Discussion around Mental Illness Amongst Family and Community
5.3. The Role of the Gurdwara

6. Religion Vs. Culture

6.1. The Role of the Sikh Religion in Psychosis & Other Mental Illnesses
6.2. The Role of Culture in Psychosis & Other Mental Illnesses

4.1. Awareness, Knowledge & Understanding of Psychosis (& Other Mental Illnesses)
There was a strong lack of knowledge and awareness of psychosis and schizophrenia described by participants. Participants stated that this limited understanding would be greater amongst some of their family members, the wider Sikh community, and those from an older generation. However, there is a growing awareness of more common forms of mental illness, such as depression, amongst the participants and wider community. Nevertheless, the limited education around mental illnesses in general leads to the Sikh community not distinguishing between different mental illnesses, with there being inadequate use of actual diagnostic terms and most mental illness presentations being perceived as “paagal63,” “mad,” or depression.

4.1.1. Lack of Awareness, Knowledge & Understanding of Psychosis and Schizophrenia
Participants were asked about their awareness of the term psychosis. Many were personally unfamiliar with the term and expressed both lack of understanding and knowledge about the illness. This finding was true across genders and age ranges interviewed.

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63 Punjabi Term for Crazy/Mad
For example, LI16 [F, 22] stated, “Um, okay so I have heard of it, but I'm not actually like, like I wouldn't be able to tell you what it is exactly because I'd be lying to you... But even I was a bit like, I know, that's bad, but I don't actually know what it is, like, I'd have to read.”

Similarly, when LI25 [M, 19] was asked, he responded “No... So psychotic yeah. So, it’s just a bit... um yeah, I am not really sure.”

LI30 [F, 69] who has worked as a doctor for decades, also stated that they lacked knowledge of psychosis. “I don't understand, I mean I never did, Psychiatry at all, you know, mental health or anything in my training. And I, you know, I'm the first one to raise my hand that I am very green with mental health.

Lack of knowledge towards the term psychosis was even true for some of those who had studied a discipline covering mental illnesses, as well as those who had a personal interest in mental health. For example, LI13 [F, 24] who had studied Psychology said “Honestly, I don't know. Like I don't know. Because I'm like, I'm trying to go back to what I studied.”

Comparably, LI18 [F, 33] who expressed a “really big interest in this subject matter” and researches into mental health in their own time, admitted that they “don't fully understand it not in a meaningful way. I wouldn't throw that word around, because I don't actually know what it means”.

The few that were familiar with the term and were able to share their understanding of the illness (namely typical symptoms) were those that had studied in a relevant subject area, such as a first degree in Psychology. For example, LI14 [F, 29] specified, “I've got a background in psychology and mental health... Erm, from my understanding it would mean, like not... erm thinking like you're hearing voices or you're not being yourself. Like you're living in the world, but erm... you don't really feel part of that, your sort of dissociated from the world.”

One participant (LI15 – M, 34) went onto to say that before they worked in mental health law, they knew very little about mental health, but now were familiar with the symptoms of psychosis. A further participant [LI9 – M, 39] stated their own experiences with mental
health had led them to research into deeper forms and undertake mental health training. This had led to their familiarity with illnesses such as psychosis.

Some participants had experience with the illness through other family members or friends, and stated they only became familiar with psychosis and/or schizophrenia as a result of this experience. For example, LI22 [F, 36] said, “I had a close friend last year, suffer a psychotic break,” but prior to this experience they, “Never knew what it was ever.”

Other participants with family or friend experience with psychosis and/or schizophrenia were familiar with the term, but they still held limited knowledge of what the illness entails. For example, LI7 [M, 43] spoke of their friend who had a psychotic episode “for the first time” and was “detained”, which allowed them to hear “a little about her experience.” However, LI7 went on to say “but I don't really know what they are [referring to psychosis]. I would say that, you know, it's it's a mental health term, but if you ask me to describe exactly what symptoms of it are, or what the, erm what the what, how would you describe it, I wouldn't know how to do that really.”

All participants were asked about the typical characteristics they would expect in someone with a psychotic illness. Across ages, gender, and those with and without experience with mental illnesses, responses were similar. Seeing or hearing things that are not there was most often mentioned, and in half of these cases the correct term of “hallucinations” was used. The other most common ones were withdrawal, paranoia, delusions and self-neglect.

Schizophrenia was more widely recognised as a term than psychosis for participants, for example LI21 [F, 25] said “I think probably because schizophrenia is like a term more like... I think more commonly used than psychosis.” Another participant (LI10 – F, 43) stated that schizophrenia is more familiar because it is, “mentioned even in like, programs, and films and things.”

Whilst schizophrenia was a more acquainted term, a parallel limited amount of knowledge was held towards the illness by participants. LI17 [F] described schizophrenia as, “I think from what I've heard is, it's, is it like a sharper way of being, having depression, and dementia? Where there erm... I can't describe it.” Another participant (LI18 – F, 33) expressed not knowing schizophrenia was a “a subset of psychosis.”
Paranoia was the most cited characteristic of schizophrenia, in addition to hallucinations, schizophrenia being “two extremes of emotion”, and schizophrenia being like a personality disorder.

Some participants awareness of psychosis/schizophrenia was displayed when they correctly identified that the case vignette presentation was this illness. For example, LI6 [F, 31] stated that “schizophrenia, psychosis” was “the first thing I was thinking” due to the vignette presenting with hearing voices and being convinced others will harm her.

As participants were not that familiar with psychosis and schizophrenia, they were also asked about their understanding of severe mental illnesses. Severe mental illness was most described as having a significant impact on your life. Specific characteristics included self-neglect and harming yourself.

Most participants expressed familiarity with the term severe mental illness and offered their interpretations of the terms meaning. For example LI8 [F, 49] explained it as, “so, anxiety, to an extent, might not be classed as severe mental illness. But if it was debilitating, it would be severe mental illness. So, I would see it as a spectrum. Most mental, mental illnesses are a spectrum. And I guess when we say severe mental illness, it is at, right at that other end, where it is debilitating.”

Another participant (LI28 – M, 58) described severe mental illness to be where, “somebody is, is dependent on somebody now, they shouldn't be on their own.”

A smaller few were unaware of the term severe mental illness or misinterpreted it, for example LI17 [F] believed severe mental illness to not be “bipolar” but “something like dementia (...) someone's got like severe dementia.”

4.1.1.1. Wider Community’s Perceived Knowledge and Awareness of Psychosis and Schizophrenia

When participants discussed the knowledge and awareness their family and/or the wider Sikh community may have towards psychosis, they proposed there would have a much greater
lack of awareness. This was a prevalent finding. For example, LI17 [F] said, “I don't think it's the the norm to know. I think they will just think like the English words are paranoid or dementia.”

LI9 [M, 39] said that if these terms (psychosis and schizophrenia) were used, “you’d see people with blank faces”, and LI18 [F, 33] said in response to if the wider community is knowledgeable of psychosis, “the answer is absolutely not, absolutely not. It's not understood.”

The same was reported for the wider Sikh community’s perceived familiarity and understanding towards schizophrenia. For example, LI1 [M, 25] said “It [schizophrenia] is badly understood, like as a as a, like a, like a medical condition, you know, that needs like treatment.”

LI13 [F, 24] said that whilst her “extended family and the Sikh community in general” may know about schizophrenia “loosely”, she didn’t think “they will ever talk about it if they see someone experiencing it or ever really understand it properly, unless they do research which they probably won't do.”

4.1.1.2. Generational Differences in the Knowledge and Awareness of Psychosis and Schizophrenia

A greater lack of awareness and understanding of terms such as psychosis and schizophrenia was described amongst older generations.

For example, LI9 [M, 39] said, “if I was looking at say my my parents’ generation from India, absolutely not, no. Like if I mentioned that to like you know a Punjabi background person, schizophrenia, they wouldn't have a clue. But within, within our, someone of my generation that are born and bred here, yes, I would have thought that the term schizophrenia is used a bit more.”

Similarly, LI16 [F, 22] stated that if she were to say the term schizophrenia to her grandmother, “she literally wouldn’t know what that is. She would be like what’s that. And
then I would have to explain to her in Punjabi, like oh it’s like Nani it’s this. I would do this
in the most like, watered down version possible."

4.1.1.3. Lack of Knowledge of Mental Health Services & Treatments for Psychosis

With regard to knowledge on services and treatments available for psychosis and general severe mental illnesses, participants held limited knowledge. This included some participants that studied and/or worked in the area of mental health. For example, LI12 [M, 38] said “to be honest I am not quite sure. I know there is talking services like counselling or like, but otherwise I'm not aware of treatments actually no.”

Regarding knowledge of treatments for psychosis, medications were most mentioned, followed by talking therapies such as CBT and counselling. With regard to specific services for psychosis, participants gave varied responses, including seeing mental health case workers, mental health nurses, crisis teams for severe mental illness, and community mental health teams for psychosis. Healthcare providers were said to provide a diagnosis, but participants had mixed responses on which healthcare provider could provide a diagnosis, including counsellors or therapist and mental health specialists.

Some participants recognised hospital admission and sectioning as a part of the service pathway for psychosis or other severe mental illness, largely in cases where they had personal experience. For example, LI21’s [F, 25] sister presented with “hallucinations,” “significant delusions,” and “paranoia,” and described the care pathway experience as, “it’s got to the point where like, I've had to call an ambulance, for example, so the person can go to hospital, because I just didn't know what was going on.”

4.1.2. Lack of Use and Knowledge of Mental Health Terms

It was widely reported that actual mental illness diagnostic terms are rarely used amongst the participants, their family and wider Sikh community.

Mostly the term “mental health” is used as a catch all term, or terms such as “mad”, “mental”, or “paagal” are used.

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64 Punjabi Term for Crazy/Mad
LI4 [M, 31] stated that due to the ignorance towards mental illnesses, the community, “will just say 'paagal hogiya'⁶⁵, and they've gone mad. And it's a shame because if you call somebody 'paagal' in the Punjabi community especially, you think that they're gone, pretty much.”

Not distinguishing between mental illnesses was also a common reutterance by participants, with depression being a catch-all term for any mental illness. For example, LI7 [M, 43] said, “I think people would probably just wrap it all up as something called depression in the Sikh community. Because they wouldn't, they wouldn't know the differences.” LI7 stated that mental health terms would especially not be recognised by those who are of an older generation, less educated, and those of whose first language is not English, “which is why they would just probably use something like depression as a catch all term, because it's probably easy.”

LI18 [F, 33] stated that due to a “language issue” and not having “words to describe it in the first place”, is why words such as “sad” or “paagal” are used by the Punjabi community to describe behaviour which is “not considered normal.” Thus, the lack of use of professional mental health terms could be attributed to there being no literal translation in the Punjabi language for these western illnesses.

This was suggested by several other participants, for example LI4 [M, 31] said, “if you're looking at a Punjabi Sikh communities, specifically, there's no sort of words that translate you either have two don't you, you have (inaudible) or paagal. And that's pretty much as wide as the mental health terminology goes.”

Similarly, LI17 [F] stated mental health terms are not used by the Punjabi community, “because you wouldn't be able to translate them (...) So, they would just say 'orna tha depression hoiya'⁶⁶ or 'orh paagal hoiya', they've gone mental. Mental being this... As 'paagal', as mental, just in one box, mental.”

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⁶⁵ Punjabi to English Translation: “They’ve gone crazy/mad”
⁶⁶ Punjabi to English Translation: “They’ve got depression.”
With specific regard to psychosis and how it would be described by either the participants family members or the wider community, findings were similar to that of general mental illness. In that, terms such as “mad”, “paagal”\(^{67}\) and “crazy” would be used.

LI19 [M, 39] said that if his family were to see someone talking to themselves, a large proportion of them would, “still say somebodies mad” or “oh phagal hogiyah\(^{68}\) (...) It would just be so blasé to say.” Equally, LI22 [F, 36] said “hearing voices is oh they've gone paagal.”

Some participants also described those terms related to psychosis or schizophrenia are used in a context to insult another person. For example, LI12 [M, 28] stated that the term “psycho” is used when someone has done “something strange” or “something weird”. The term can also be used in two ways – “a banterous way” or “a bullying negative way,” with the meaning of the word not being considered. Another participant (LI30 – F, 69) discussed the term “schizo” being “bantered around.”

### 4.1.3. Increased Awareness of Common Mental Illnesses

Participants expressed they had more awareness of depression over severer forms of mental illness such as psychosis.

This was evident from some participants responses to the case vignette presentation. In most cases, participants perceived the vignette presentation to be depression. As indicated by LI10 [F, 43], “Erm... well this is some kind of mental health issue, but it depends. Erm, obviously, where it says, hearing voices of strange people. Erm, it sounds it, to me, it sounds like depression. Erm, especially looking at her background.” Another participant LI18 [F, 33] said the vignette was, “suffering from depression. I think clinical, clinical depression.”

Similarly, when participants were presented with the early symptoms of psychosis later in the interview, the majority stated that they would not perceive this to be indicative of psychosis and instead would think an individual displaying these symptoms would be going through depression. For example, LI13 [F, 24] said, “I reckon if they were displaying those early

\(^{67}\) Punjabi Term for Crazy/Mad

\(^{68}\) Punjabi to English Translation: “They’ve gone crazy/mad”
symptoms, everyone usually would jump to depression. And even me without knowing that they can be the early symptoms of psychosis also, would probably also look at, yeah, depression in terms of when I look at that, and that's what I would perceive them having rather than psychosis.”

Likewise, LI16 [F, 22] assumed, “If it was just early ones, I would think that they are depressed. I would look at those because I feel like a few of those are like symptoms of depression, like spending more time alone, and a lack of motivation to the drop in study, the trouble with thinking clearly because they're so like isolated in their own thoughts. I would think it would be depression.”

LI11 [M, 34] said that depression and anxiety might be more familiar terms to the wider Sikh community because they are easier to explain and impact us all on some level. Psychosis causes “behaviours, which are a bit more confusing to the average person or a bit more bizarre,” thus take “a lot more detail” to explain, “whereas something like depression and anxiety, these are things which I think everyone goes through in some form. So those are, they just more familiar, they're just more commonly used and addressed.”

Likewise, LI20 [F, 23] said that there is more awareness of these illnesses “because almost everywhere you look, somebody has got it or somebody knows somebody that's struggled from depression, anxiety.”

Other factors to account for the increased awareness of common mental illnesses included mental health being more openly addressed on television, across social media platforms, in schools and Universities. Individuals are now opening up to share their own mental health struggles on such platforms. This is particularly true for those who have had battles with depression and those of a younger generation.

For example, LI20 [F, 23] said mental health has “become such a conversation of topic”, namely depression and anxiety disorders, which are now commonly discussed in schools and universities.

Furthermore, LI10 [M, 43] described the increased understanding in mental health to be a result of people being “more vocal now”, and “you hear it all the time now on TV (...) it's all
over the internet. Erm, there's a lot of help now out there. And I think that's where the knowledge is coming from."

One participant (LI14 – F, 29) stated that illnesses such as depression are now even addressed on Sikh television channels, “but I still think that there's sort of a lack of awareness about like psychotic symptoms or that sort of area of mental health.”

Online platforms, particularly social media channels such as Instagram were widely cited as a way of obtaining mental health knowledge and/or hearing about people’s mental health experiences. LI13 [F, 24] described those online platforms are a “great space” allowing people to speak out about their experiences with mental health and allows for online users to become “aware of different types of like mental health conditions and different mental illnesses.”

Importantly, there has been significant recent movements and initiatives created to better understand and tackle mental health specifically within the Sikh, Punjabi, and/or wider South Asian community. Organisations such as SOCH Mental Health69, Taraki70, and Sikh Your Mind71 were commonly cited organisations.

Participants praised these organisations for allowing conversations around mental health to open up within the community. LI19 [M, 39] stated that he is “really pleased to see the momentum in our own South Asian community, people come forward and organisations talking about the stuff.”

However, none of the participants mentioned any open discussions on severer forms of mental illness across these organisations and platforms. Several participants who work closely within the community mentioned that psychosis has not been touched on yet.

LI2 [M, 21] stated that this is because the Sikh community is “at its very infancy” with regard to mental illnesses, “within such an infancy stage, it's, you know, starting to look at the more minor form before we do get to the, to the major forms.”

69 https://www.sochmentalhealth.com/
70 https://www.taraki.co.uk/
71 https://sikhyourmind.com/
4.2. Causal Beliefs of Psychosis

Without probing, social factors were the most cited attributions for psychosis, with most participants stating a traumatic incident would likely trigger the illness. When participants were presented with a probe sheet that stated social, biological, religious, and supernatural causes for psychosis, participants tended to endorse multiple causal factors. Social factors still gained precedence as the primary factor, but some participants recognised an interconnection between social factors triggering a biological response or endorsed both social and religious factors. Very few participants personally endorsed supernatural causes for psychosis but emphasised that these are beliefs held by either members of their family and/or the wider Sikh community.

4.2.1. Social Causes

Social attributions were the most cited causal factor for psychosis.

A traumatic event happening previously in someone’s life was most mentioned. For example, LI25 [M, 19] said “a trauma in previous... in their life or something. So maybe they... where it says someone has smells, tastes or feels things. Maybe that’s what they’ve experienced them beforehand in their life.”

LI11 [M, 34] also stated that psychosis was likely the result of a traumatic incident that may have been “suppressed” or dealt with in a “dysfunctional” or “different” way. LI11 stated that his answer was “partly influenced by what you see on TVs and movies and stuff.”

Similarly, LI16 [F, 22] said psychosis could be caused by dealing with a traumatic event such as “rape” by themselves, “because they’re scared to like, talk about it. So, they just kind of like isolate themselves, like hearing voices and things like that might be hearing voices from that night or when it happened.”

Other trauma’s which could provoke a psychotic illness included childhood trauma and/or abuse. As described by LI9 [M, 39], “it could just be trauma from the childhood that I see got flared up, then later on later on in life, which can contribute to it,” and LI3 [F, 28] “but overall, the thing that sticks out the most would be... um... like something traumatic or abuse.”
Some participants went onto attribute trauma as a cause for general mental illnesses. LI13 [F, 23] said “I know that in depression that is the case and in like a lot of mental health that is the case as well and then something can trigger it so either that's like this this socioeconomic status or it's like trauma coming up, or it's like the impact of stress and that can perhaps cause like an episode as well.”

This was true for a participant (LI20 – F, 23) who has experienced poor mental health, “But I think for me, it was kind of the trauma of my parents separation and my mom's condition that I kind of knew that was that was what was causing, causing me to feel the way I was.”

Other social factors mentioned by various participants included substance abuse such as cannabis and/or alcohol abuse. For example, LI11 [M, 34] stated that they live in an area where there is a longstanding drug problem and said, “you do see people that are long-time users, whether it be alcohol or anything else, go down a route that looks like there's some psychosis.”

Furthermore, LI16 [F, 22] stated that they believe substance abuse to be a cause, “I do think because there's some drugs that actually can make you hallucinate and things like that. So maybe the like, the come down after a drug possibly, or if you've used that drug quite a lot possibly.”

Stress was another quoted cause as described by LI15 [M, 34]. “if you're not taking time out for yourself, pressures could become too much. Stress is known to induce things like psychosis. If you have too much going on, work related, family related, lack of support.”

Participants believed it was unlikely that older generations would recognise how social factors could play a role in the development of psychosis. For example, LI18 [F, 33] said that they, “definitely think that there's a lack of understanding that things like trauma, or the list under this, the social category, and I don't think people realise that those things can trigger mental health conditions. But yeah, I think they'd be very likely to go down the whole religious and supernatural path sadly.”
4.2.2. Supernatural Causes

Supernatural factors being attributed to the cause of psychosis and other mental illnesses was discussed largely by participants.

Very few endorsed such beliefs themselves, but it was deemed prevalent either amongst participants family members and/or the wider Sikh community. For example, LI30 [F, 69] stated that with regard to black magic, evil eye, and nazar22 – “No, I don't believe in that. I think with emotion with mental burden is has got nothing to do with that. It's biological or social that's what I would go for,” and described the Sikh community as “so so behind with the mental health.”

Another participant [LI9 - M, 39] said “things like spirit, black magic all day long you hear things like that as soon as somebody gets any form of mental health illness, they'll say 'hah, kisseh neh kosh keeta’73, somebody must have done something.”

This phrase of “somebody has done something” was extensively mentioned across participants when referring to someone presenting with a mental illness or behaviours that deviated from the norm. It was often associated with someone having done black magic on another. For example, LI10 [F, 43] when asked what the wider community may perceive the cause of psychosis to be, she said “It's more related to like they said, you know, someone's done black magic on you, and jadoo74, and all that, that's, that's the road, they would actually, they wouldn't associate it with erm mental health. So, yeah, they would think that someone else has done something.”

Similarly, LI26 [F, 26] said that “somebody's done something or yeah black magic and all that,” are explanations she would expect to be put forward by her extended family. Whilst, LI12 [M, 28] stated that an explanation such as “someone has done magic on you,” is also something that may be proposed by the younger generations but not “in a serious sense (...) I think my age people say like black magic, like as a banterous term, oh someone has done some black magic on you, oh, but we don't mean it, we kind of humour it a little bit to lighten it.”

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72 Punjabi Term for Evil Eye
73 Punjabi to English Translation: “Yes, somebody must have done something.”
74 Punjabi Term for Magic/Sorcery
Evil eye was also commonly mentioned by participants as an explanation put forward for mental illness. As described by LI20 [F, 23] “I don’t personally believe that it can be the evil eye, but I think that can be quite a big belief, that somebody’s done something to them in order to get to where they are... You try to explain to them, what she’s got, they would completely deny it and probably, and probably say no it’s the evil eye, somebody’s has done something to her.”

The concept of psychosis appearing as someone being possessed was also put forward in some instances, for example LI12 [M, 28] said the term “phoot chardga” may be used, which means “there is a ghost in you.” LI12 went onto say “because obviously, the fact that you talk... like some things like talking to yourself, and when someone’s telling you to do something, they’d be like someone’s in... someone’s inside your body.”

Similarly, LI13 [F, 24] stated that she knows of people that have had “experienced episodes like that” referring to psychotic symptoms, and words such as “atma75” and “phoot76” are used, “they always say oh something’s possessed them.”

Someone putting a curse on you and witchcraft were also mentioned by participants as a potential supernatural cause of psychosis from either their family and/or wider Sikh community perspective.

Some participants even spoke of personal family experience of attributing mental illness or physical illness to supernatural causes. For example, LI19 [M, 39] spoke of his cousin who experienced hallucinations and delusions and was hospitalised. He described the family response as “the typical thing, oh my god, how did this happen, what's happened, oh must be possessed. There must be some spiritual thing you know. They had, they had like spiritual people involved, from India, and conversations and all sorts of weird and wonderful things.” LI19 attributed this response as a “knee jerk reaction” for something they didn’t understand and had never experienced before.

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75 Punjabi Term for Soul
76 Punjabi Term for Ghost
Likewise, LI5 [F, 21] spoke of how she is aware her family “do believe in that kind of concept of black magic” because when her aunt became ill and “somebody else was blamed (...) I think there was somebody in a distant family who has that reputation of being capable of doing black magic.”

LI9 [M, 39] stated that they have had experiences of individuals believing that they were possessed but later were diagnosed with psychosis, “I have experiences where people they've, they've been convinced that they're possessed by spirits that are giving them a message and guiding them or whatever, but later on, years down the line, and they've come to know that it's actually they were suffering from psychosis.”

Endorsing supernatural explanations were described to be generally driven by culture than religion. For example, LI6 [F, 31] said that these beliefs are endorsed more by those who are “culturally Punjabi than they are practicing Sikh.”

Furthermore, LI19 [M, 39] stated that supernatural explanations are not “a Sikh thing, I think it's a Punjabi thing, it's a cultural thing. I think it's the South Asian thing, you go to India. You know, I've been to my village as well. And there's different, there's a whole vast majority of different people from Hindu, Muslim to Sikhs. But the one common factor I found was they, they believed in all of this supernatural stuff, regardless of whatever the religious teachings were.”

Similarly, LI10 [F, 43] agreed that supernatural beliefs are a “cultural thing, because obviously, they don't have anything like that, you know, within the Sikh religion.” LI10 said that this exists particularly in India, whereby “people tend not to go to the Gurdwara” and tend to go to this this Baba, there's that person, there's this person, you know. Erm, and that is why there's so much of it around.”

LI6 [F, 31] proposed that such explanations were put forward by “past generations” because they could not explain the presentation of mental illness “scientifically, medically, or even socially.”

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77 A gurdwara is a place of assembly and worship for Sikhs.
Likewise, LI19 [M, 39] stated that people “entertain things like black magic, and spiritual, spirit possession all of these things, because they don't see another logical reason (...) This is why I think people ignore biological, social, religious and go straight to supernatural, as an extreme extenuation of what the community think to explain things that they don't understand.”

Older generations placing greater validation on supernatural (and religious) explanations for psychosis and general mental illness was reiterated by other participants. LI14 [F, 29] stated that there a “generational difference in how you look at mental health and then how you support someone through it,” with the older generation edging towards “more supernatural or the religious reasons for being mentally ill,” including “naazar\textsuperscript{78} or somebody has done some sort of evil spell on the family.”

Another participant (LI3 – F, 28) echoed that older generations would support religious and supernatural causes and would be “more likely to stick with their beliefs and not really be open to looking at other reasons.” LI4 [M, 31] also stated that “it's very few and far between” within the older generations to not believe in supernatural causes for mental illness.

### 4.2.3. Religious Causes

After seeing the probe sheet, participants tended to discuss religious causal beliefs around psychosis. Unlike supernatural causes, many participants did agree with these causes. Often using them in conjunction with social factors.

God’s will was most discussed, and was often synonymous with “divine will”, “written in our destiny”, and the Sikh concept of “Hukam\textsuperscript{79}”.

LI15 [M, 34] stated that supernatural and superstitious explanations are “unlikely” and mental illness is “just in fact, God's will.”

\textsuperscript{78} Punjabi Term for Evil Eye

\textsuperscript{79} Punjabi Term for "command" or "divine order." In Sikhism, Hukam represents the goal of becoming in harmony with the will of God.
Furthermore, LI6 [F, 31] whilst karma may be a cause of mental illness, “god’s will” which is synonymous with “Hukam” plays a “huge” role – “we kind of throw that word around all the time. It's Hukam. It's Hukam, and then I think in a way I think that is self-soothing as well. To know that actually what's happening is not your fault. It's not in your control. It's divine order. It comes from the divine.”

One participant (LI1 - M, 25) described how the Sikh concept of Hukam helped them through their depression, “believing in sort of religion gave me gave me at least something, you know, when I basically didn't have anything, and, for example, like, it helped with my acceptance of the situation, because, you know, for example, I personally would like to use a mantra, 'Hukam kapoorh', like I accept it. You know, my situation. I accept what's happening.”

LI11 [M, 34] stated that the concept of God’s will is not a separate factor in itself but interlinked with social and biological factors, “God's will for example, to me, that's the you're saying the same thing as you know, that this is biological. This is just you know, within your DNA.”

In line with LI11’s thought, LI17 [F] stated that mental illness can be a result of biological, social, and “even supernatural” causes, but ultimately these factors are all a result of a person’s “karma.”

Similarly, LI27 [F, 58] endorsed karma as a cause for psychosis, by stating that if “they've done something bad, and now they're having to pay the consequences of that. And it's kind of fate, not fate, yeah karma that's it, karma.”

LI14 [F, 29] echoed how the community may interpret psychosis to be a result of karma, “Another way people could look at it is in a religious aspect, like what the what your karma is, so, what your, what your past deeds are based on your current deeds and all of that plays into it.”

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80 Punjabi Term for "command" or "divine order." In Sikhism, Hukam represents the goal of becoming in harmony with the will of God.
Two participants also mentioned the Sikh concept of *The Five Evils* contributing to psychosis and/or general mental illness. For example, **LI25** [M, 19] said if we were to view mental illness from what is written within the Guru Granth Sahib, “it would be about, there are five demons inside the body. So, these five demons can also cause mental health as well. They can cause things like depression; they can cause things like anxiety. Then it's like, it's like a battle every day between the five demons and the mind.”

**4.2.4. Biological Causes**

Biological causes received the least amount of discussion. Some participants endorsed biological causes before probing, others after, and some not at all.

In most instances, biological causes were mentioned in conjunction with social factors, whereby psychosis could be caused by an interplay between both factors. For example, **LI6** [F, 31] said psychosis was a result of a “chemical imbalance in the brain” which is “caused through various things, societal factors, environmental factors, even genetics.”

Comparably, **LI22** [F, 36] stated that she thought “a social element can actually trigger something biologically.” Furthermore, **LI12** [M, 28] believed psychosis was a result of something traumatic which then “triggered something in there like neurological system”

Genetic predisposition was also commonly cited, followed by psychosis being hereditary. For example **LI15** [M, 34] said that psychosis is “known to pass through genes.” Furthermore, **LI18** [F, 33] said “I think I have heard that, like, if your parent suffers from that, you are more likely to, to, to suffer from it as well (...) I think it can be genetic.”

Additionally, several participants spoke of personal family experience where they believe mental illness to be genetic and/or hereditary. **LI21** [F, 25] stated that she believes psychosis is a result of “genes to some extent, just because they're like people with bipolar in my family. So, like, from more than one like household. So, I would think maybe genes could potentially have something to do with it.”
Similarly, LI26 [F, 26] said that she has a family history of mental health, which is why she believes psychosis to be “maybe genetic,” and is more “mindful” of the genetic predisposition to mental illness “because I've seen the pattern.”

In a similar manner to the endorsement of social factors as a cause for psychosis, some participants stated that it would be unlikely for older generations to acknowledge biological factors in relation to a psychotic illness. For example, LI18 [F, 33] stated that older generations would not realise “how much a part genetic, genetics play.”

4.3. Help-seeking and Support for Psychosis (& Other Mental Illnesses)
Seeking professional medical help for psychosis was considered the most important pathway, with GP involvement being most cited. Religious practices such as prayer and meditation were considered an important coping mechanism for individuals experiencing psychosis and other mental illnesses and being most useful when combined with professional medical care. Religious practices were not considered a treatment. Cultural beliefs around supernatural causes for a mental illness presentation may lead to a family’s seeking help from alternative sources such as traditional healers. Other forms of support were considered useful for mental illnesses, including contacting Sikh/South-Asian-specific mental health organisations or generic mental health charities. Participants also considered the importance of the role they would play if someone they know was experiencing a psychotic illness or other illness. Finally, having a clinician matched on a patient’s heritage received mixed views.

4.3.1. Professional Help-Seeking
Professional help for psychosis was the primary help-seeking pathways mentioned by participants. This pathway was endorsed for the case vignette presentation, early symptoms, and later symptoms of psychosis.

4.3.1.1. GP Help-Seeking
In nearly all instances, the GP was the first port of call. For example, LI23 [F, 54] said that they would “get that person to go and visit a GP first. And if the GPs can refer them to the service, to the correct service, they need.”
Many participants recognised that the GP would then make an appropriate referral. As described by LI7 [M, 43] “So my first point of call would be the doctor. And then hopefully, they would, her GP would then sign post from there.”

Likewise, LI6 [F, 31] stated that the “first place would be a GP” for help. Whilst recognising that there exists mental health helplines and support groups, LI6 said that “it's harder to pick up the phone or reach out to a for support group that is kind of for a specific mental health issue, than is to go to your GP, and not label it, or label yourself and just say, you know what, Doctor, this is how I’m feeling. And for the doctor to kind of steer the conversation towards what needs to happen.”

The GP route was also recommended at the later stage of the illness, whereby symptoms such as hallucinations and delusions are presenting. As explained by LI19 [M, 39], “if you see at the later stage, I think that was definitely when you need to refer to sort of professional help and erm sort of NHS GP route. And get support.”

Seeking help from a GP as a first port of call for psychotic symptoms was also true for participants who also worked within a mental health field or had some form mental health background through studies. For example, LI24 [F, 53] stated that her “first suggestion would be that they go and see their GP so that they can be referred on to appropriate services and offered immediate support.”

Additionally, LI12 [M, 28] said “I'd say obviously, kind of with my previous experience, obviously being in this industry a little bit, I'd say go to the GP initially, and the GP would obviously be able to advise better.” LI12 went onto say that “go and see the doctor” is a “standard thing to say”, and doctors “seem to have all the answers for all kind of like anything crazy.”

The GP route was also advocated as the primary pathway for psychosis by those who have personally experienced mental illness, namely depression, and sought help for it. For example, LI2 [M, 21] stated that if the symptoms of psychosis worsen to the later stages, “I would maybe tell that person, you know, if you are, you know, going through the mental health problems, there are plenty of avenues that you can go down. You know, probably one of the best is to go to your GP.”
Participants with family experience with mental illness also shared that the GP was the first professional help-seeking pathway in their cases, whereby individuals were experiencing depressive and/or anxiety symptoms. However, participants shared negative experiences with the GP, including the GP not acknowledging or detecting symptoms of mental illness.

**LI22** [F, 36] shared that when her mother was “behaving erratically” which was “not normal for her”, they sought help from the GP to “offer her some sort of support (...) and the GP laughed me out of the office, out of the surgery. Yeah. He’s like, she’s fine, there’s nothing wrong with her, she seems fine to me. And I was like, but you don’t live with her day in day out. You’re just seeing her right now where she’s quiet. And she’s not talking to you because she doesn’t want to be here.”

Similarly, **LI9** [M, 39] stated that whilst someone presenting with the symptoms of psychosis would require a “professional in that field” from their own “actual life experiences, I probably wouldn't go through GP and if finance wasn't an issue, then I will directly get the next available appointment to get an actual diagnosis from a psychiatrist and then start looking at therapy.”

One participant (**LI1** – M, 25) spoke of their depressive symptoms not being acknowledged by their GP. However, this participant still recommended the GP route as the first professional help-seeking pathway for psychosis symptoms. Another participant (**LI16** – F, 22) spoke of a GP’s inability to detect their sibling’s anxiety, and thus sought out a second GP’s opinion who detected the individual may be experiencing anxiety.

4.3.1.2. Importance of Talking Therapies

Whilst participants discussed the importance of seeking out a GP when the early and/or later symptoms of psychosis arise, many participants also heavily cited seeking talking therapies such as counselling for psychosis. For example, **LI23** [F, 54] said that “first of all, I probably would make things a bit clearly by saying to them, maybe they need counselling, maybe talk to somebody who won’t judge them. Just somebody who will listen... Yeah that's it, like I say, who I mean, I would say to them get some counselling... Because it will help.”
Talking therapy and counselling appeared to be a preferred treatment option over medication, but participants did endorse the combination of both for psychosis. For example, **LI22 [F, 36]** said that “this isn't just about medication alone, this is about understanding the root cause of what has led them to this scenario, right. There has got to be something that has kind of like attributed to this and it might be the most smallest thing that has been planted within them that has then you know, caused this ripple effect. So, I think talking is one.”

Similarly, **LI10 [F, 43]** stated that “everyone is different. And erm one size doesn't fit all. You know, somebody might, might benefit from medication, but it's not just the medication that's going to work, you know, they, you know, they might need some other therapy.”

### 4.3.1.3. Medical Intervention at Later Stage of Illness

Regarding later symptoms of psychosis, participants recognised the severity of these symptoms in comparison to the early symptoms. Proposing that whilst in the early stage’s participants can offer recommendations of different avenues of support, whether formal or informal, at the later stage this is no longer an option, and “definitely help is required” - (**LI17**, F).

Medical intervention was considered essential during the later stage of illness presentation, whereby hallucinations and/or delusions are existent. The professional medical interventions suggested at this later stage of illness were varied amongst participants, but included: GP, mental health professionals, contacting 999 and visiting A&E.

**LI18 [F, 33]** perceived “hearing voices” as “quite serious,” and they would have “no strategies to recommend” because the presentation appears to have gone “too far (...) they really need proper help at that point, like professional medical professional help.”

The safety of the person and those around them at this stage was considered, which further warranted the need for medical intervention. For example, **LI24 [F, 53]** said “this is the point where you have to worry about their erm sort of general safety possibly (...) you have to worry about what the voices are telling them to do.” She said that if the voices are suggesting harm to themselves, then a “serious intervention” would be required, “even if it's potentially against the individual's wishes.”
4.3.1.4. Negative Attitudes towards Professional Help-Seeking

Whilst all participants did personally recommend seeking professional help for psychosis, they stated that there does exist negative attitudes and perceptions of seeking professional help either within their families and/or wider Sikh community.

LI16 [F, 22] stated that “getting professional help” is not “accepted,” and if professional help were to be sought it would be kept “very secret (...) we don't tell anybody. I think it's one of those that there's this kind of taboo about getting seek professional help.”

Another participant (LI24 - F, 53) who works in within mental health stated that, “the Sikh community is just not coming forward in accessing the help. They're very reluctant to do it, because they feel that it can be and should be contained at home and dealt with at home.”

Not accessing help is for numerous reasons including the stigma and secrecy around mental illness (further discussed in Section 4.4.1.).

4.3.2. Religious Coping and/or Help-Seeking

Professional help-seeking was personally endorsed by participants for psychosis, and participants expressed that professional treatment trumped any form of religious help-seeking. However, religion was discussed as a major form of coping and support for someone experiencing psychosis and other common mental illnesses such as depression and anxiety.

Particularly prayer and meditation were deemed the most useful, in addition to visiting religious healers or attending the *Gurdwara*\(^81\). In much fewer cases were religious support deemed a treatment for psychosis, with many participants not endorsing religious help-seeking as a sole pathway. Instead, combining professional medical help-seeking alongside religious coping mechanisms was deemed useful for someone with psychosis.

Other methods of religious help-seeking including visiting a specific person, often described as a “baba”, but also as a saint, astrologer, or religious person. This form of pathway often

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\(^81\) A gurdwara is a place of assembly and worship for Sikhs.
overlapped with the supernatural beliefs held towards mental illness, emphasising the blurred line between religious and cultural beliefs. These specific people were largely based in India; thus, people would visit India to see them. People would then be told to recite prayers or practice rituals. This pathway is further discussed with examples in Section 4.3.5.

Other religious support and help-seeking included mantra’s, looking to the Guru Granth Sahib\textsuperscript{82} for help, and seva\textsuperscript{83} – however these were mentioned either by much fewer participants, in some cases just one.

No religious help-seeking or support was considered when participants viewed the vignette presentation of psychosis.

4.3.2.1. Prayer and Meditation

Prayer to help cope with the symptoms of psychosis and other mental illnesses was most discussed. Prayer was thought to bring comfort and peace to an individual, which in turn acts as a support mechanism. This finding was prevalent across all age ranges. Particularly, listening to prayers was thought to be helpful during the severe symptom expressions of psychosis, whereby participants recognised the individual might not be able to pray themselves.

\textbf{L120 [F, 23]} said that keeping \textit{“paath\textsuperscript{84} on in the background”} may be helpful in making the individual feel that they are not alone. Similarly, \textbf{L126 [F, 26]} said this is something that is common within her family, \textit{“they'll have the radio on that's running prayers all day every day. And it's just running in the background because it's a comfort thing. It brings comfort.”}

\textbf{L18 [F, 49]} who has experienced bouts of mental illness, particularly depression, said that even at her \textit{“lowest point”}, she has \textit{“put the Kirtan\textsuperscript{85} and Paath on, and that's what's made me probably saved myself.”}

\textsuperscript{82} Holy religious scripture of Sikhism  
\textsuperscript{83} Selfless service  
\textsuperscript{84} Punjabi Term for Prayers  
\textsuperscript{85} Kirtan refers to devotional singing in Sikhism
Some participants mentioned there being Bani’s\(^{86}\) that can be useful to listen to or read when you are in a low mental state. For example, LI6 [F, 31] said that if you are not feeling happy, “people always say listen to Sukhmani Sahib\(^{87}\), the song of happiness.”

This was reiterated by another participant (LI17, F) who said, “you would always hear the saying, if someone's in a dark place, or a place where they're not, they need help, they would read like Sukhmani sahib paath\(^{88}\), to get Sukh\(^{89}\), and then they read Dukh bhanjani\(^{90}\) paath as well to get Sukh.”

The benefits of meditation were also prominently discussed by participants, with the vast majority recommending meditation (in some instances described as Naam Simran\(^{91}\)) as a powerful coping mechanism for psychosis and other mental illnesses.

LI10 [F, 43] stated that meditation “is a big part of the Sikh religion,” and helps with general mental wellbeing. Another participant (LI23 - F, 54) said that they would recommend someone with psychosis to do Naam Simran, because it is “soothing” and can take your mind off negative things.

Some participants discussed personal experiences of meditation helping depression and anxiety. For example, LI25 [M, 19] had a family member experience a mental illness and said “with their depression and anxiety, they were taught to meditate for like this many days, this many times a day. So do their Simran, and they did it... the thing is the more, the more meditation you do, probably, the more you feel comfortable with yourself, the more you probably want to talk to somebody as well.”

Another participant (LI11 - M, 34) stated that they knew “for a fact that depression and anxiety” have been helped by being within “Sikh environments” and through “Sikh practices.” They were interested to see if this could also be applied for someone with psychosis.

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86 Short for Gurbani – which is various compositions by the Sikh Gurus
87 Sukhmani Sahib is translated to mean Prayer of Peace
88 Translated to mean Prayer of Peace
89 Punjabi Term for Peace
90 Translated to mean somethings that cuts or destroys sorrows or ailments
91 Meditation or contemplation of the various Names of God
One participant (LI9 - M, 39) stated that they sought support from their religion for their own mental health struggles before seeking professional help, which was at the point of crisis, “I think it's not that I didn't want to seek help, I just didn't, I just, nobody kind of understood what's happening. And then it was, it was multiple different things of, of others thinking that this could be sorted out religiously, you know, go to this person, go to that person, do this paath92, do that.”

Whilst participants did support prayer and meditation to help cope with psychosis (less severe symptoms) and other mental illnesses, they also expressed that such religious practices would only be beneficial depending on how close an individual is to their religion.

For example, LI13 [F, 24] said that “there's no point in forcing that upon someone, if they don't feel connected, and they don't feel close, if they're just born into a Sikh family rather than actually practising it.”

Moreover, LI8 [F, 49] agreed that it is dependent on “how strong their faith is” and that it would not be useful recommending turning to religion, “if their faith isn’t there (…) like my kids would say, well, we don't really go to the Gurdwara93 much. We don't do any prayers, ourselves. So that, what's that going to do.”

LI4 [M, 31] participant did note that engaging in Sikh practices with focus such as Naam Simran94, reading Gurbani95, and praying has been known to cure physical ailments. However, “if you're not in the right frame of mind, mentally” then such practices might not beneficial “because your focus isn't going to be there.”

4.3.2.2. Combining Professional Help-Seeking with Religious Practices

Ultimately, combining professional help-seeking with religious coping strategies such as prayer and meditation was deemed the best treatment and support for an individual experiencing psychosis and other mental illnesses.

92 Punjabi Term for Prayer
93 A gurdwara is a place of assembly and worship for Sikhs.
94 Meditation or contemplation of the various Names of God
95 The various compositions by the Sikh Gurus
LI2 [M, 21] recognised that with psychosis “being a serious illness” religious and spiritual support might “help a lot” but cannot provide the formal diagnosis and medical help which is required.

This was echoed by LI24 [F, 53] who said practicing religion was considered “something that can help them alongside any medical intervention, but sometimes prayers on their own just don’t work.”

LI7 [M, 43] also stated medical help would be required first to get the individual “functioning normally” and “once they can get to the point where they're functioning normally, then yes, I would say that if there are things such as meditation, obviously, reciting, listening, reciting, or listening to hymns, that sort of stuff, if that helps them mentally, then that's a good thing. But I wouldn't say that you should do that over medical treatment.”

Likewise, LI17 [F] said that once an individual has started treatment and become “a bit more better, then that's when you can go back and say well, you know, maybe what would help us is a little bit of Japji Sahib96 or a little bit of Mool Muntar97. But I wouldn't say straight away to somebody pray, why ain't you praying?”

4.3.3. Informal and Non-Medical Support

In addition to the professional help-seeking pathways that were endorsed by participants for psychosis, participants discussed an array of other recommendations for someone with a psychotic illness.

4.3.3.1. Be Supportive and Talk

The most prominent was being supportive and personally providing talking support to a person experiencing psychosis or another form of mental illness.

96 Japji Sahib is the Sikh thesis, that appears at the beginning of the Guru Granth Sahib
97 The phrase "Mool mantar" means "Main chant" and as such is an important verse which most Sikhs are very familiar with and which they chant
For example, LI27 [F, 58] said, “it's just about reminding them that they've got people around them to help them that, you know, family, friends, myself.” Engaging in other activities that may “distract” the individual, or “something they normally would enjoy” or something they would find “calming” was also recommended.

Additionally, LI15 [M, 34] said that in addition to “try and support them, try to be there for them, try to remain positive around them,” engaging in activities that is “helpful to our general mental health on a daily basis,” should also be tried. This includes, “exercise, eating well, and kind of being around other people and trying to be social.” LI15 recognised that these forms of support would be more likely recommended during the early symptom presentation.

Reassuring an individual that they can speak about what they are experiencing and opening up about their mental health was also suggested. As described by LI20 [F, 23] “reassurance from the people around them is really important. To not make them feel like there's something wrong with them and just kind of reassuring them that it's okay to talk about whatever they're seeing what they're hearing or what they're feeling,”

Approaching an individual displaying the early symptoms of psychosis and talking to them personally was generally mentioned before any form of professional route was recommended. For example, LI12 [M, 28] said “I would lean to sort of wanting to check in with them without maybe not triggering anything but just checking in with them and just being like, like, do you know what's going on kind of thing? Are you okay? That kind of thing. That's how I would do it.”

Moreover, LI14 [F, 29] said that validating what the person is feeling or experiencing is important, rather than denying their experience of hearing voices, “not just going to them and saying, oh, you know, that's not true, you can't hear.” Instead, LI14 said you should “hear them out,” thank them for sharing their experience, and by going about it this way and validating their feelings, “I think they're more likely to seek support.”

Offering talking support was also recommended for the case vignette presentation. Many participants said it would be important for the vignette character to talk with her husband first. If the character did not feel comfortable speaking with her husband, they should seek
out other trusted family members, friends, or those within their support network. From this, the character should then seek out professional support from either GP or other medical professional.

4.3.3.2. Mental Health Organisations and Helplines

Participants also discussed seeking advice from Sikh mental health organisations or charities regarding a family or friends mental health or recommending such an avenue to someone they know who might be experiencing mental ill health. Common community-led organisations mentioned included SOCH Mental Health\(^98\), Sikh Your Mind\(^99\), and Taraki\(^100\).

One participant (LI1 - M, 25) who has been previously diagnosed with depression, stated they sought support from a South Asian based mental health charity based where they lived, which they “highly recommend.”

Non-Sikh specific mental health charities and hotlines were also recommended, with a particular point of seeking somewhere where the individual can talk to someone. These included mental health charities such as Mind, Samaritans, and SANE.

Mental health charities were also recommended by several participants in response to the case vignette of psychosis. For example, LI21 [F, 25] said the vignette character should “maybe call like a charity, like mind mental health, and because that's free to call and just, I think speak to someone about how she's feeling so she can get help.”

LI6 [F, 31] made the point that there may be a generational difference in accessing helplines or organisations. She said that within the Punjabi, Sikh community “we look to medical professions, and specifically doctors, a lot more than we do to kind of all these amazing help lines and organisations that have been set up. And I think that because mostly, they're been set up by the youth and erm the generation... you know, kids that are born in this country, and their parents aren't. And I think that people are therefore reluctant to approach them.”

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\(^98\) https://www.sochmentalhealth.com
\(^99\) https://sikhyourmind.com
\(^100\) https://www.taraki.co.uk
4.3.3.3. Researching the Illness

A number of participants also discussed personally researching into what an individual displaying symptom of psychosis may be experiencing, in order to determine what help and support they require.

For example, LI11 [M, 34] said that “It would just be about doing my research, speaking to somebody more experienced, medical professionals, and seeing what help would be out there.”

Another participant (LI16 - F, 22) said “I'm really bad when it comes to like when something comes up in the family, I Google, I'm like, oh, how can how can you help like people going through psychosis? So, I would be... so I would kind of like search what, what helps psychosis.”

4.3.4. Views towards Culturally Appropriate Care

When asked whether it would be beneficial to seek help from someone of same culture and/or faith, generally South Asian, the majority discussed the benefits of this and recommended it, particularly for older generations.

The benefits of seeking help from someone of the same religion and/or culture included: an understanding of cultural issues that other clinicians wouldn’t be able to provide and a feeling of trust and comfortability of someone from same faith/culture background.

Clinicians and/or other support offered does not have to be matched on religion alone, generally someone from South Asian background would be useful, or even just someone from a minority background. For example, LI2 [M, 21] who has personal experience of mental health care said from “speaking to counsellors or mental health experts, from a different community, especially, you know, white British community, there is only so much that they're able to understand about the context of my mental health problem.” LI2 said that by having professionals even just from the South Asian community, “not necessarily being a Sikh themselves,” this would “definitely promote a lot of people to actually talk about these things. And coming forward to talk about these things.”
Another participant (LI18 - F, 49) speaking from personal experience of counselling said that it was when she eventually received an Asian counsellor that “she was the one who really helped me the most,” and that it made a “big difference” in comparison to her previous counselling sessions. LI18 said the Asian counsellor “could understand how, you know, the family, how it all works. How it’s all brainwashed into us and everything. And, you know, girls are like this and boys and, and she could understand (...) she knows the culture and can understand the culture. And... we’re, and how we're brought up.”

If the clinician isn’t of same culture-faith, then it is important for clinician to be aware of the role culture and religion plays for patient. For example, LI14 [F, 29] who also has accessed mental health services stated that from her experience, “I think it's really important for a therapist or any clinicians to be aware of like the role that faith and culture plays in accessing them services. Because I had a few therapists and it wasn't until I got to the third one, it was someone of South Asian culture who got the faith aspect, got the culture aspect, sorry (...) I think it's always important to understand, how like faith and culture can develop someone's psyche in a way and how that can affect them, one accessing services.”

A few participants discussed the limitations of seeking support from someone of same faith-culture – this was due to fear of gossip or stigma. For example, LI3 [F, 28] stated that she would “actually rather not have someone of the same culture purely because there's that worry that they're going to have certain, erm, stigmatising beliefs.”

This was reinforced by LI22 [F, 36] who stated that whilst her parents and grandparents generation would not want to “share it with somebody who's not Sikh, or the same culture,” they would also have the fear that “they're going to go talk about me,” if they did confide in a health professional of same heritage, “they'll be very reluctant as to how much they share it just because this person will go off and talk to somebody.”

One participant (LI10 - F, 43) shared their negative experience of seeking help for mental illness from someone of the same culture. Speaking on her first therapist, “she wasn’t Sikh, but she was Indian,” she said that “with some of this stuff, you know, I did say to her, and she was, oh, yeah, but that happens. And oh, yeah. but, you know, that happens. So they've got this. You know, it's almost like, they know how our culture our religion works, and they're accepting that and they, and they think that's okay.”
4.3.5. Supernatural Beliefs and Associated Help-Seeking

As previously discussed in Section 4.2.2., whilst many participants did not personally endorse supernatural causes for psychosis, they did specify that this is something that prevails either within their own families and/or the wider Sikh community. Such beliefs can lead to alternative help-seeking being sought for mental illness.

This pathway would be endorsed particularly by older generations and would be fuelled by the belief that a mental health presentation is associated with the “somebody has done something”, which alludes to black magic. This help-seeking pathway tended to involve visiting healers (which were commonly cited as “baba”) which could be of any South Asian faith, often visiting India to do so, and individuals engaging in certain rituals that were advised by the healers.

LI27 [F, 58] said, “from my own personal experience, erm this is going back generations maybe as well, but there's a tendency to think that it might be something else other than mental health. Then people sometimes seek out faith healers or some religious maybe erm leaders that might offer advice rather than going straight to mental health or GP, but I think it's slowly changing.”

However, participants of younger generations stated that this standpoint still exists, for example LI26 [F, 26] stated that her family would likely assume “somebody's done something, or it’s like, you know all these old tales, or they need to go and see this saint, or that person or this prayer, or they need to be doing that... And then they'll be like you need to speak to this baba or that saint.”

Similarly, speaking from family experience, LI10 [F, 43] who has had depression stated that it is unlikely for families to “class it as depression,” and changes in behaviour would be addressed “they would go and seek some Baba and ask, oh, you know, there's always fighting in our house, our daughter-in-law, or our sister-in-law, or whoever it is (...) it would be oh, someone's done something to her or they would give me some of this, you know, silly erm remedy or something to do.”

LI22 [F, 36] stated that you can seek this form of help in “difference places in the UK”, but it is more “extreme” in India, which is commonplace where you would go seek these routes.
Whilst LI22 has not personally witnessed seeking help this way, she said that “your parents will unnecessarily or your grandparents will unnecessarily will take you, or other elders.” Visiting these healers is based off “hearsay (...) oh, we heal this person from their voices, and then they turned to God, and now they do all the seva (...) they would rather believe the hearsay, than believe the actual scientific kind of elements.”

The popularity of these alternative routes in India was also mentioned by LI18 [F, 33] who that from her visits she has seen the “whole industry” of these alternative healers, such as astrologers, “it's literally their business, like they charge for it.”

Some participants offered personal examples of such avenues being sought in a case of mental illness within a family member. LI25 [M, 19] gave an example of his father who had depression, “a lot of people thought it was black magic, a lot of people started doing rituals, which didn't work.”

Another participant (LI27 - F, 58) spoke of her cousin who had bipolar, but at the time (1970s), the family were unaware, and “took her to India, because they thought she needed to be exorcised.”

These routes were also noted for physical ailments. LI22 [F, 36], whose sister has epilepsy, stated that she had family members who “instigated the whole oh it's black magic and you don’t need to be taking medication and you should take her to India, she should go see this person, that person.”

Seeking out healers was also reported by another participant (LI19 - M, 39) who had a family member experience hallucinations and delusions. He stated that the initial family reaction was “the typical thing, oh my god, how did this happen, what's happened, oh must be possessed. There must be some spiritual thing,” and thus, “they had like spiritual people involved, from India.” LI19 stated it was because of his families lack of understand towards mental illness, and no one having “experienced it before,” which led to thoughts that “it must be possession.”

No mention of supernatural pathways of help-seeking or support was mentioned in the case of the vignette presentation of psychosis.
4.4. Negative Attitudes towards Psychosis (& Other Mental Illnesses)

All participants spoke of the negative attitudes that are held towards psychosis and other mental illnesses. Participants did not personally endorse these attitudes but described them to be prominent in the Sikh and wider South Asian community.

4.4.1. Stigma

Stigma was most cited. Particularly a stigma around psychosis and schizophrenia. For example, LI1 [M, 25] said that an illness like psychosis would “definitely not talked about” because it is “very heavily stigmatised.” Similarly, LI23 [F, 24] said that whilst there might be more awareness of depression and anxiety, “people might not know as much about psychosis because of the stigma that may come with it.”

This was followed by a discussion on general mental health stigma. For example, LI26 [F, 26] emphasised mental health having a “massive stigma attached to it (...) especially in the Sikh community.”

Moreover, LI4 [M, 31] said that “just the word mental is a bit taboo (...) when you call someone mental, again it goes down to that word 'paagal' doesn't it, a bit crazy, especially when I was growing up”

LI24 [F, 53] who works within the mental health field stated that whilst there “definitely” is a “stigma in the Sikh community” around mental health, this “huge stigma” exists for all communities.

One participant [LI7 - M, 43] spoke of the specific stigma and negative perceptions attached to depression, “people have always talked about it, but it's always talked about a negative connotation. It's not talked about in a, with an acceptance that actually everybody can suffer from a level of depression (...) when you hear about it within the Sikh community, it's often spoken about in the stigmatising way, it's not talked about in a supportive way... [Depression is spoken about in a] probably quite derogatory way I think, as well, quite a lot.”

101 Punjabi Term for Crazy/Mad
Another participant [LI4 - M, 31] spoke of gender roles and the stigma around mental illness, causing Punjabi, Sikh men to especially keep quiet about mental health struggles they might be experiencing, “for the men, it's like, there's absolutely no room no space for South Asian men to actually talk about mental health. Because it's just not something that happens to us. You know, we're meant to be the soldiers, go hunting, etc. We look after the house, and we can't show any sort of weakness (...) it's embarrassing when somebody is going through it. So if you're the man of the house is going through, let's say, a mild depression, or bit of stress, etc, then other households will look like 'haw, eh bundah ah'\(^\text{102}\) like is he even a man.”

Such stigma leads to mental illness not being openly spoken about within families and as a community. One participant (LI25 - M, 19) stated this was due to the impact it would have on reputation, “Not many people in the Sikh community will open up about if they've got certain issues or if they've got certain illnesses, not many people open up about it. Just because there's a stigma around reputation.”

Another participant (LI2 - M, 21) described the “unwillingness to tell people within the community” of a mental health issue is due to feeling an “overbearing taboo” attached to it.

Whilst one participant (LI21 - F, 25) recognised that mental health within the Punjabi culture is now “definitely something that we're like getting better at talking about,” she stated that it is “definitely still a taboo topic and there's still a stigma around it.” LI21 attributed this to the cultural expectations surrounding aspirations that “Indian parents might have for their children.” Such aspirations included completing education through to university, followed by marriage and starting a family, “but like life doesn't... it's not as simple as that, like things happen.”

Several participants also stated that there is also a stigma around taking medication. One participant [LI7 - M, 43] said this could be due to people being “scared of things like addiction and lifelong life, the lifelong, need to continue taking medication.” LI7 acknowledged that for a physical ailment, people would take medication “for life” is

\(^{102}\) Punjabi to English Translation: “Is he a man?”
required, thus “the brain is another part of your body that sometimes might need some medication to help it function.”

4.4.2. Denial & Ignorance

Psychosis and other mental illnesses were described to be dismissed and ignored by the Sikh community. The common consensus was the lack of understanding and education around mental illness for the Sikh community leads to their fear, ignorance and denial of the issue.

With specific regard to psychosis, two participants who worked within the mental health field discussed this. For example, LI15 [M, 34] stated that if the term psychosis was used, “I think it'd be immediately dismissed... Erm you know, despite even if you're a professional, you know what you're going on about. I don't think they would accept it. They might not initially accept, well, no, sorry, immediately, yes, I think it would be dismissed, I think they will dismiss any claim that it’s psychosis.”

Similarly, LI24 [F, 53] said that psychosis is considered “an uncomfortable term and most people would try and ignore it. If they don't like the sound of it, they kind of hope that it will just go away.”

More so, participants discussed the heavy ignorance and denial of mental ill health generally, with phrases such as “get on with it” and “brush it under the carpet” commonly used by participants to describe the family and/or community response to a mental illness. For example, LI6 [F, 31] said “I think there might be kind of the level of, if I just don't talk about it, or if I push it to the side, it's not happening, and I think that's really very common and apparent in the in the Sikh Punjabi community.” LI6 went onto say that she feels “some people are ignorant because they want to be ignorant, and they want to stay ignorant. And they and they want to live in the world where these things don't exist. And they don't happen, and they don't happen to us. And they don't happen to our children and our siblings and our parents and our grandparents. And therefore, if we, if we don't see it, and if we don't speak about it, it's not happening.”

Another participant [LI4 - M, 31] stated that the denial of mental health issues within the Sikh community could be due to the importance “in the Punjabi tradition, that we would
always talk about positive things. So if somebody is going through depression historically, you would always try to say positive things to them, boost them up, etc.”

The concept of staying positive can be associated to the Sikh concept of *Chardi Kala*\(^{103}\), which was explicitly mentioned by several other participants. For example, **LI5 [F, 21]** stated that from reading Sikh narratives they could be potentially be “detrimental to the cause if you misinterpret them (...) some of the terms like Chardi Kala, which means like, you know, we're always happy so like, you know, that, that image of Sikhs kind of, they always want to be seen as the, the warrior race (...) it's about being brave, but it's not about necessarily always being tough on yourself. And I also think that most Sikhs happen to be Punjabi’s and that does feed into the narrative, because the Punjabi’s are seen as very extraverted, happy people. So, then it's almost like you have to kind of respect the status quo.”

### 4.4.2.1. Generational Differences in Mental Health Dismissal

The dismissal and lack of acknowledgement of mental illnesses was described as greater amongst older generations. For example, **LI12 [M, 28]** stated that both his parents and grandparents’ generation would have “an unwillingness to see as what it is (...) I would say that there is something of an unwillingness to address it, especially say, within close family members or personal mental health problems.”

This was reiterated by **LI14 [F, 29]** who said, “I think the older generations and generally like mental health isn't really spoken about, though it's like is sort of in some ways for them it's not really acknowledged.”

This increased ignorance and dismissal of mental illness towards mental illnesses was associated with the older generations increased experiences with adversity and hardships. **LI11 [M, 34]** described the impact of the partition of India, which left the country “completely lawless.” The experience of this for older generations led to them adopting a “survival mindset,” and all they know is “how to be functional (...) all they're thinking about is you know, make money, get food and protect the next generation or raise the next

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\(^{103}\) Punjabi Term for aspiring to maintain a mental state of eternal optimism and joy.
generation.” This “very different mindset” leads to them not being as “empathetic to like how much trauma can affect someone.”

This was echoed by LI8 [F, 49] who speaks as a second-generation migrant, describing her parents as having “often had quite a hard life. And I think they can sometimes become a bit insensitive, and think you've got everything, you've got, you don’t even have to think about heating, because they were literally functioning at a completely different, you know, level of hardship. So, they see our issues as, oh, it's first world problems. And that's somehow minimizes the issues.”

Similarly, LI12 [M, 28] who said that due to the older community going through “so many hardships,” consequently “they don’t want to have another problem, they avoid problems at all costs... so, anything that they can kind of... bypass that's not too imminently serious in their life. They'll just ignore... until things get worse.

4.4.2.2. Personal Experiences of Mental Health Dismissal

Many participants spoke of personal experiences where they witnessed mental illness being dismissed. LI8 [F, 49] had a relative commit suicide in India, however many family members were in denial that she executed this act, “they were like, she wouldn't do something like that. She wouldn't do anything like that. No. Nonsense. No, she wasn’t well, that’s all she wasn’t well, she didn't kill herself though... And even her children, no say she killed herself, she was really depressed.”

Similarly, LI2 [M, 21] said that from his experience “there is a case to just ignore (...) even to the extent where someone commits suicide, the cause of the suicide is, you know, completely overlooked.” LI2 went onto state that “people do within the Sikh community do realise that someone is depressed, but they wouldn't say that is a mental illness,” and would be “quite dismissive of it.”

Another participant [LI20 - F, 23] spoke of her mother who had been diagnosed with psychosis, stating that her family’s response when her mother became unwell as “instead of looking into it and seeing what is going on what's happening, how can we help? It's just kind of, well, let's just push her to the side, because she's kind of lost the plot and let's just carry
on with life. And I think they were very much in doubt. “It's okay. She'll wake up tomorrow, she'll be fine. She'll be back to normal. We can carry on as normal again”, but obviously, that wasn't the case. You try to explain to them, what she's got, they would completely deny it and probably, and probably say no it’s the evil eye, somebody’s has done something to her.”

**LI22 [F, 36]** spoke of how the ignorance of mental illness led to help-seeking avoidance by her family in the case of her uncle who “became extremely paranoid” as a result of a mental illness. She stated that she approached his wife and children to get him some help, but “it just lands on deaf ears. Or they go yeah, yeah, we will, we will. And then there’s nothing done. And they just allow the behaviour to continue to the point where it’s actually really bad. And you’re like, this isn't normal that I don’t understand why you guys don’t get this.”

Delayed help-seeking was also reported by **LI1 [M, 25]** who had experienced depression. Due to not understanding depression “at all (...) I didn’t really get help when I initially had it.” **LI1** described himself as being in “heavy denial, you know, I was like, I can’t I can’t have, you know, this medical condition. I couldn’t accept that at all.”

4.4.2.1. Accept Physical Illness, Not Mental Illness

Recurring amongst the dataset was the community’s acceptance of physical illness but not mental illness. Mental illness was not considered a medical illness. This is due to not being able to see a physical decline, as you would with a physical illness.

**LI3 [F, 28]** said that physical illnesses seem to be taken seriously, whilst mental health “it seems very dismissed.” **LI23 [F, 54]** attributed this to the inability to “see anything” with regard to mental illness, “it is not happening, because it's like a hidden disability. Because it's easier for them because it's they'll probably be in denial, they don't understand that this actually is a condition, that's what it is.”

Furthermore, **LI14 [F, 29]** stated that in comparison to physical illness, mental illness is “harder for them to accept it as a problem,” with some families “probably don't even acknowledge that you can get ill mental health.”
4.4.3. Secrecy

Participants expressed that if someone were to have a mental illness, the family would urge it to be kept within the immediate family.

For example, LI6 [F, 31] said with regard to a mental illness “we don't talk about it to anyone. And if we do talk about it to anyone, it's certain family members like an uncle and aunty. We don't discuss it outside of the family. And if anyone asks, you've just erm you've developed a food allergy or you're really low in vitamin D or something like that.”

LI13 [F, 24] stated that the preference to “keep it within the family and not talk about it at all” leads to “no help and support” being sought for the individual with mental ill health.

Some participants spoke of their personal experience in hiding their own mental health troubles. For example, LI1 [M, 25] who was diagnosed with depression said he “definitely hid it” from his family. He attributed this to not wanting to worry his mother.

Furthermore, LI2 [M, 21] who was also diagnosed with depression said he “definitely kept my family in the dark about that.” He said this was for mixed reasons, “half because of family politics (...) and second of all, because of the sort of reaction that they may have.”

Another participant (LI3 – F, 28) whose family eventually found about her mental ill health described their response as “it wasn't really like okay, we need to get her help. We have to keep this quiet’. That was that was definitely a big thing. But still it was the whole like, 'we have to keep this quiet' and that lack of understanding. It was just kept between us, like they didn't want to tell anybody. And they told me specifically not to tell anybody I'm seeing someone about this.”

Similarly, some participants shared experiences of having a family members mental illness kept hidden from others. LI21 [F, 25] whose sister was experiencing a mental illness and was eventually diagnosed with depression and anxiety said that her “family's attitude was just like to keep them in the house like and not let them go anywhere (...) if you had like visitors come to the house like don’t let them in (...) just keep it like private and like deal with it internally.”
Another participant (LI5 – F, 21) had a family member who committed suicide, and she described the family as “ever so miserably were trying, they were literally trying to have her funeral and trying not to disclose that she killed herself (...) they tried to really suppress it.”

LI12 [M, 28] spoke of how a member of his wife’s family has schizophrenia, “but the family don’t talk about it”. He described becoming aware of the diagnosis after the individual disclosed to “one of my cousins that I’m schizophrenic. but she was like don’t tell anybody because my family don’t want anybody to know.” Whilst this individual is being supported by her family and receiving relevant professional treatment, LI12 said that her family won’t talk about it, and he assumes it is because “the family are embarrassed.”

4.4.4. Fear & Judgement

Fear appeared as a recurring theme which connected to numerous factors. For example, participants discussed people’s fear of psychosis as an illness. This included “keep your distance from them”, being scared to approach someone with psychosis, and being scared they might do something to you.

For example, LI4 [M, 31] said that people within the community perceived mental illnesses such as psychosis to be “contagious.” This was echoed by LI21 [F, 25] who said that the cultural beliefs around an individual presenting with psychosis would be “you shouldn't really go near them, like, don't touch them, you might catch it like that kind of thing.”

Other participants spoke of the perception that someone with an illness like psychosis may “do something to you.” For example, LI17 [F] said that “you would hear from a young age or don't go speak to that person, because they might do something to you, or might have nazaar\textsuperscript{104} on you or that type of thing?”

Similarly, LI12 [M, 28] said looking at the Sikh community and in his family, “we would be scared to approach that person directly (...) If they're showing signs that oh they could be mental, or there’s something going on, they would be like okay keep your distance away from them (...) because you know, they might do something to you.”

\textsuperscript{104} Punjabi Term for Evil Eye
Additionally, there was a fear of gossip around mental health issues, particularly around what others would say. For example, LI17 [F] said that “the same typical thing that we have in our Punjab society, ‘Lōka kī karanagā’\textsuperscript{105}, what will people say? You know, so even if you have it within the house of a friend or family member, you tend not to talk about it because you don’t want to be judged.”

This was emphasised by many other participants, including LI26 [F, 26] who said, “the biggest thing is, what will people say is the biggest phrase, is if somebody finds out what they’re going to say (...) it’s huge in the Sikh community - what would people say.”

This fear around gossip was linked to the community being described as judgemental, particularly towards those with mental health issues. For example, LI16 [F, 22] said that “there definitely be like a few looks and like a few different stares,” if a diagnosis of psychosis was to be revealed to the wider Sikh community. She described the response of the community would “be very much looking down” and “quite judgemental.”

4.5. The Role of Family & Community in Psychosis (& Other Mental Illnesses)
Family especially played a very important role when participants answered questions. Particularly when considering help-seeking for psychosis and other mental illnesses, the attitudes, beliefs, and awareness of mental illness the family held would determine when someone seeks help and where they seek help from. Additionally, participants who had personal experience with mental illness stated that their family influenced whether they would disclose their mental health struggles to others.

4.5.1. Family Not Supportive of Mental Health Struggles
Family members were considered not to be supportive to another family members mental health struggles. This was largely due to their family’s lack of awareness and education around mental illness. For this reason, family members are not able to detect mental illness and are unable to provide the right support and guidance regarding help-seeking pathways.

\textsuperscript{105} Punjabi to English Translation: “What will people say?”
LI17 [F] stated that regardless of the mental illness being experienced, your family would simply perceive it as “you're mental and you've got something wrong with you, and then that's all your labelled as. They wouldn't actually look into why, or how or how can we fix this? It'd just be that's your issue, that's you.”

In the case of the vignette presentation, several participants also perceived the character’s family to not be able to provide the relevant support the character would need. For example, LI10 [F, 43] said “they probably don't think that there is anything wrong. You know, it's like, come on, you know, get on with it and, you know, go 'kaam karda'\footnote{Punjabi to English Translation: “Do some work.”}, and, you know, that kind of.... I mean, It's not, it's not entirely their fault. Because they haven’t, they haven’t. They haven’t been exposed to it. They probably haven't got the knowledge.”

More participants also spoke of personal experiences where their family were unsupportive towards mental health struggles. For example, LI20 [F, 23] whose mother experienced psychosis, stated that her family's response to when her symptoms intensified was to “just push her aside because she's kind of lost the plot and let's just carry on with life (...) everyone in the family had no idea what was going on, no idea what to do.”

Another participant (LI18 - F, 33) whose mental health struggles became known to some of her family members, stated that they “literally just didn't know how to handle it (...) they'd say, to my face, I don't want to say anything to you in case I say the wrong thing.” She described this being said “quite aggressively,” and some family members “actually feeling quite frustrated with me and my behaviours”

Furthermore, LI8 [F, 49] who has experienced depressive episodes described her family and community response to her illness as unsupportive, including her husband. Describing their reaction, she said they would question “what have you got to be depressed about? (...) you've got three children. you've got a house, you've got car, you've got everything.” LI8 state that there was “no support at all,” even when she was “on the verge of suicide,” describing her mother and uncle’s response as “my mom, my uncle just said, well, it's a sin you know, if you do that. And it's seen as a sin in the Guru Granth Sahib\footnote{Holy religious scripture of Sikhism}, and that's it you know.”
Some participants did express family members becoming more supportive and/or understanding towards mental illness once they had direct experience with mental illness. For example, LI16 [F, 22] said that her sister’s diagnosis of anxiety has allowed her and her family to become a lot more educated in mental illness, “it’s one of those that like, if it doesn’t affect you, then, you don’t know about it.”

Similarly, LI18 [F, 33] described that after her sister suffered depression “a long time ago” that a “shift took place in my immediate family, including myself, where we had to, we’ve been forced to understand it more, you know. And all of that has meant that I we are now more open about it.”

Furthermore, in the case of LI21 [F, 25] whose family’s response to her sisters mental ill health was to keep it hidden, “once that like official diagnosis came through it was like, oh no, like really need to, like be careful and like a lot more of a caring kind of attitude rather than locking away (…) It was less like keeping it behind closed doors and more like let's try and help them get better.”

Despite participants stating that families are likely to be unsupportive during mental health struggles, when presented with the case vignette presentation, many participants still endorsed seeking support and guidance from the family network as an initial form of help. Furthermore, when participants were presented with the early symptoms of psychosis some participants did state that there may be issues around seeking support from your family and family involvement would be dependent on the families perceived understanding and acceptance of mental illnesses. When the later symptoms of psychosis were presented, family involvement was further endorsed due to the severity of symptoms. The involvement of family members was more so advocated if the individual was refusing help.

4.5.2. No Open Discussion around Mental Illness Amongst Family and Community

There has historically been no open discussion around mental illness within the Punjabi, Sikh family unit and wider community. This is interlinked with the negative perceptions around mental illness which have previously been discussed and the lack of understanding and knowledge around mental illness.
LI29 [F, 60] said that mental illness is a field “that people want to address it, they’re fearful addressing it.” Furthermore, LI30 [F, 69] who works as a doctor and stated that there are “so many medical people in our family,” said mental illnesses are “never been spoken about in the family (...) we talk about medical things all the time (...) but mentally, I don’t think anybody does talk about mental illness... we don’t talk about mental illness at all. And I don’t know why.”

Another participant (LI6 – F, 31) shared how this lack of discussion around mental illness has led to some people never seeking help for their illness, “I just heard so many stories of children that are going, you know, and even young adults, or even, you know, not even young adults, you know, men and women in their 40s 50s and 60s that don’t talk to their families and live in one room and just stare at a TV screen because they have a mental health problem, and it’s so obvious, and nobody wants to talk about it.”

Participants provided examples of no open discussion around mental illness occurring within their own family members. For example, LI26 [F, 26] said that she had grown up being around mental illness from a young age, as her mother has had severe depression, “she's been clinically depressed as long as I could remember (...) but it's never really it was never really spoken about growing up.” LI26 went onto say that “especially from the Sikh community (...) whatever happens behind closed doors should stay behind closed doors. She attributed this lack of open dialogue to the fear of being judged negatively.

Due to the lack of openness around mental illness, participants spoke of not disclosing their own mental health struggles to their family members. One participant (LI1 - M, 25) spoke of disclosing their diagnosis of depression only after they visited the GP. Another participant (LI3 - F, 28) described their school recognising their changes in behaviour regarding mental health, however their family was still not openly discussing the mental illness the participant was experiencing.

In the instances where mental illness is disclosed within the immediate family unit, it then must be kept within this circle and not openly discussed outside of this unit, which was previously addressed in Section 4.4.3.
Some participants mentioned that an openness to discussing mental illness is determined by family dynamics and education level. For example, LI18 [F, 33] stated that “in our community, generally, your family is your first support network.” However, she stated that if your family are not “well educated or forward thinking or fluent in English, they might not understand” mental illness. Thus, the expectation would be “just get on with it.”

However, family members not being supportive or open to mental health struggles was even indicated in situations where immediate family members were educated professionals in medical, sciences, and social services backgrounds. One participant (LI6 – F, 31) spoke of their parents being in medical and sciences background, and a history of mental illness existing within their immediate and extended family. When this participant was asked if the families background in the medical profession allows them to be more open to psychotic illness and severe mental illness, the participant stated “No, absolutely not.” She attributed this is to the “typical” Punjabi, Sikh mentality of “push through it, you can get through it. We are all strong. You know, the constant reminder of living in chardi kala.” LI6 also attributed her family’s lack of openness towards mental illness to be the belief in karma, “as Sikhs we believe in karma, and whatever, whatever is happening is a consequence of your actions, you know, from this life or previous life, and you've you've got to bear it,” as well as an embarrassment feature of having a mental illness.

4.5.3. The Role of Gurdwara

The Gurdwara is the Sikh place of worship, yet it has been described as an ineffective place to obtain mental health support. This is largely because they are not well equipped with mental health knowledge.

As LI11 [M, 34] described, “unfortunately, very few, if any Gurdwareh are equipped at dealing with these things on an ongoing long-term basis. And to be fair, even on a short-term basis, even as in the immediate. (...) sadly, I’m not aware of any Gurdwareh that are running specific mental health programmes that could help treat somebody who's actually in the middle of erm something.”

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108 A gurdwara is a place of assembly and worship for Sikhs.
Another participant (LI19 - M, 39) spoke of a discussion he had with a Sikh mental health charity regarding this issue, “the Gurdwara at the moment if I walk in there, I don't have much confidence that they will give me the support I need or be able to signpost me to the right services.” Whilst LI2 [M, 21] said some Gurdwara’s have a “flat-out kind of refusal or denial of these kinds of things.”

Other participants spoke of reasons they would personally not take someone that was experiencing a mental health issue to the Gurdwara if they were experiencing mental health struggles, such as psychosis. For example, LI26 [F, 26] said she would feel “very guarded about taking them out to the Gurdwara, just because of how judgmental people are,” with that experience potentially affecting them negatively, “It could make them withdraw again.” LI26 continued by saying, “I would probably say, yeah, please don’t speak to anybody at the Gurdwara, they're probably going to make you feel 10 times worse.”

Other participants spoke of not going to the Gurdwara for mental health struggles due to who they are run by. For example, LI6 [F, 31] whose response to being asked whether they would seek support from the Gurdwara was “no way.” She attributed this to the Gurdwara being run mostly by men who are of an older generation, where a language barrier is also an issue. She perceived that they would “likely to kind of have stereotype, stereotypes of the emotional woman, she's probably just on her period or, you know, she's, she's just a silly emotional woman.” LI6 said the Gurdwara would be equally unhelpful for a Punjabi, Sikh man to seek support from. The fear of community gossip was also a perceived issue in seeking help from the Gurdwara from this participant, “and then there's the whole, like, everyone knows everyone in the community. And people talk, you know. Erm, I wouldn’t recommend it.”

Moreover, LI9 [M, 39] spoke of how general Gurdwara’s are run by “Gyani’s and the Granthi’s” of whom “have no knowledge of these things, and very ignorant to these (...) they haven't got the knowledge for kind of taking care of anything of this, on this level.”

Others mentioned the usefulness of going to the Gurdwara for mental illness being context dependent. Contingent on the committee panel, with younger generations running Gurdwara’s deemed more beneficial in promoting mental health education in a Gurdwara.

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109 A gurdwara is a place of assembly and worship for Sikhs.
setting. For example, LI23 [F, 54] said whilst there are still some Gurdwara’s “that are stuck in their in their ways,” there are now more “modern” and “younger” run Gurdwara’s that “are a bit more open.”

Comparably, LI13 [F, 24] said that it depends on how “modern” the Gurdwara is, acknowledging that some Gurdwara’s are trying to get “more talks in from different like mental health organisations. And they are putting that on, and they are the more supportive, but it depends on whether they live in that sort of area or not.”

Participants stated that promoting mental health awareness and mental health signposting within Gurdwara’s would be valuable. LI19 [M, 39] said a financial budget should be in place for Gurdwara’s to have a mental health representative, as well as educational talks, which “can be used to really help people with mental health and other aspects of life really.” Agreeably, LI22 [F, 36] said if “every Gurdwara had an affiliated mental health liaison… Honestly, that would be really great.”

One participant (LI10 - F, 43) spoke of how their local Gurdwara spoke about mental health, which is provided older generations with “a little bit of education” on an area they don’t have much understanding on, “and because it's because it's come from the Gurdwara, they would actually take it more seriously. Rather than coming even if it came from a medical professional, they probably wouldn't take it as serious, but because it's coming from that kind of platform.”

The benefits of going to the Gurdwara if experiencing mental health struggles were less so about speaking to someone to confide in, but more so about the calming and peaceful environment the Gurdwara offers. LI13 [F, 24] described the Gurdwara as “a really, really safe space for me,” whilst LI22 [F, 36] described “going to the Gurdwara is a very peaceful experience” which can provide “solitude.”

LI26 [F, 26] also mentioned the benefits of the social aspect the Gurdwara can provide, and being involved in acts of seva110, “getting involved in the community and speaking to people, it is probably a good thing, it’s building a sense of community, you’re not on your own.”

110 Selfless service
4.7. Religion Vs. Culture

The association between the Sikh religion and Punjabi culture was described as “diluted” and being “so separate”. By participants, the Sikh faith was described as one of peace and compassion, with Sikh scripture offering ways to maintain good mental health and wellbeing. Contrastingly, the Punjabi culture was deemed toxic and judgemental, fuelling the negative perceptions around mental illness, navigating individuals to supernatural beliefs and help-seeking pathways for psychosis and other mental illnesses, as previously discussed in Section 4.2.2. and 4.3.5.

4.7.1. The Role of the Sikh Religion in Interpreting Psychosis (& Other Mental Illnesses)

The Sikh faith was characterised as that of peace, brave, resilience, warriors, who would have empathy and compassion towards someone with psychosis or mental illness. When participants were asked if they know if psychosis, severe mental illness, or other mental illnesses are mentioned within the Guru Granth Sahib111 and how the religion may explain psychosis, findings were mixed. The majority said psychosis or severe mental illness had no reference in Sikh scripture. Others were unsure and some said it is mentioned but were unable to recall the passage from scripture. Several participants offered explanations of psychosis based on their interpretation of Sikh teachings.

For example, LI14 [F, 29] said that mental illnesses such as psychosis, which we “might perceive to be negative is actually come into our life to lead us towards God, and remember God, and through that there's a concept of ‘Dukh Daroo’ 112. So, like the pain actually being the medicine. So, in terms of some things that you go through, maybe that had to become the pain in your life to actually become the medicine of what helps you get to peace.”

This idea of God speaking to you being connected to hearing voices was mentioned by one participant. LI9 [M, 39] stated that “there’s a lot of mention of you having that connection and communicating with, with God within you. That speaks so they could be, they could very much be a lot of confusion. Thinking that God speaking to you, but where you’re actually

111 Holy book of Sikh scripture
112 A concept in Sikhism - dukh as daroo – translated as “pain as medicine.”
experiencing the mental health illness. And so there’s that really fine line and how do you know.”

Similarly, LI6 [F, 31] mentioned there being specific Sikh pastures that “speak about the person that sees things and hears things, and the whole world is laughing at the person that sees things and hears things, but who are you to laugh at the person whose boat is out to see, because your boat is yet to go up to see and people might laugh at you. And, you know, you laugh at the person that speaks out loud, but how do you know that that speech is not coming from God… But there's the opposite as well, like the person that speaks to themselves is out of their mind, because they're not speaking to God.” These conflicting messages within scripture was attributed to Sikh scriptures being “written by different people at different times from different backgrounds, from different religious points, different language, that has an effect on what they experience.”

Another participant, LI26 [F, 26] related the symptoms of psychosis such as hallucinations and delusions being associated to the “idea of transcending in Sikhi.” She described this as through Simran\textsuperscript{113} and meditation “you can transcend to your higher self. So, I'm not sure if it's something like that could explain it.” She also mentioned “ego” being a big part of Sikhi, and mental health and psychosis could be related to our ego, “how ego can be a big part and a root of a lot of problems that we experience in the world today.”

LI4 [M, 31] also explained psychosis from a “religious point of view,” stating that “it's always a battle with the mind. So there's, there's several in Gurbani\textsuperscript{114} that I should talk about, you're battling the mind and the way that it works is that the mind is like a fortress, you're trying to invade that fortress to try to get in, but you've got all these gods here, you know, stopping you from actually conquering the mind. So from that it's more of a more of a sort of spiritual battle. If that makes sense, in the sense by you're just trying to conquer the mind and get complete control over it. But then you've got all these things that are forcing you astray such as attachment and greed and what not.”

\textsuperscript{113} Meditating on the name of God
\textsuperscript{114} Various compositions by the Sikh Gurus
More references to mental illnesses such as depression and/or anxiety were said to be within Sikh scripture. For example, LI14 [F, 29] said “there's a lot of sort of talk about mood and anxiety, and things like that. So, I think mental health is touched upon, and I think that in our scriptures, but because and maybe the way that society portrays it, especially in culture, it is not really acknowledged.” LI14 said from their own mental health struggles they turned to Sikh scripture and found “a lot about anxiety and trying to control the mind, and stuff like that. But what I came across so far it doesn't really lean towards psychosis or severe mental health.”

Comparably, LI11 [M, 34] said there was “definitely depression and anxiety more” mentioned within Sikh scripture, and “it does mention that these things will cause you anxiety, that cause you depression.” LI11 stated that the familiarity with concepts such as depression, which he said is sometimes called tension “tension horgi”\textsuperscript{115} by the community, and anxiety within Gurbani\textsuperscript{116} could explain why there is more awareness of such illnesses in comparison to psychosis.

Each participant that did have Sikh scripture knowledge described how they believed the Sikh religion would explain psychosis or other mental illnesses in a different way. This could lend to the subjective nature of interpreting scripture. For example, one participant described that a general concept of illness is mentioned, known as “rokh”, which could be attributed to both physical and mental illness. LI18 [F, 33] said “where in the Sikh scriptures does it talk about what causes diabetes? It doesn't does it, so why does it have, why does, why are we looking for, why are we looking for something? It talks about illness; it uses the word 'rokh' a lot. 'Rokh' just means illness. So, the Sikh faith has never, if you want to talk about religious texts, the religious texts has never said that whether it's talking about physical illness or mental. So, if I would, if I were to read it, I would say when it talks about illness in general, I would go with the assumption that it's covering all illnesses. It doesn't, it's not discriminating and specific specifying, and only talking about physical illnesses. And thereby, someone might be able to draw the conclusion that it completely eliminates mental health. It's not, it's not making specific reference, it talks about 'rokh' and 'rokh' is just illness or ailment.”

\textsuperscript{115} Punjabi to English Translation: “I've/You've got tension.”

\textsuperscript{116} Various compositions by the Sikh Gurus
Participants themselves agreed that interpretation of scripture varies. For example, LI26 [F, 26] said “I think the one thing about Sikhi and what we forget about the Gurbani is the way it’s written, it’s very poetic, it’s poetry. So, it’s open to interpretation. Everybody will understand it slightly differently because although we have very similar life experiences, we also have very different life experiences. But I think it’s is taking the time to understand that and what it means to you.”

Whilst Sikh scripture may not specifically mention mental illness, it was described to contain a lot of reference to the mind and maintaining good mental health.

LI15 [M, 34] who works in mental health law described an association between Sikh philosophies and CBT, “I think the Sikh religion and its true ingrained meaning is significantly helpful to the practice of mental health today (...) the more I understand about mental health, the more I understand about therapy such as CBT and BT. And the support that is available for mental health. Indeed, it comes through the teachings of Sikhi... And I think, you know, when I read, when I read books, or when I speak to psychologist’s, it’s, you know, well hold on my religions told me this for 300 odd years (...) the spin on it is if you do what the Sikh religion entrenches in what you should be doing, generally that is a practice of what psychologists will want you to do to maintain good mental health.”

Another participant (LI19 - M, 39) said that coping mechanisms can be found within Gurbani which are “really powerful.” LI19 stated that Gurbani uses metaphors and “put life in perspective (...) the teachings are there to give you a real deeper perspective of the world and the bigger picture (...) I think the Sikh faith almost gave a framework for society to cope with life.”

4.7.2. The Role of Culture in Psychosis (& Other Mental Illnesses)

The Punjabi culture was described to fuel the negative perceptions surrounding mental illnesses.

The cultural view of psychosis was associated with being “crazy” and not normal. This was described by LI26 [F, 26] who said mental illness would just viewed as “they've gone
paagal\textsuperscript{117}, they've gone crazy. And you know, thinking, oh my God, what is wrong with them? They're absolutely crazy. Culturally, I think people would just be oh, he's gone mad, he's completely lost it, he's paagal.”

One participant described how their grandparents would perceive someone displaying the symptoms of psychosis, and reinforced this interpretation of the person is crazy, and this is driven by cultural beliefs. \textbf{LI16 [F, 22]} said “I think if this was like my grandparents, and they saw someone talking to themselves, they would be like, oh, she's a bit crazy,” and that is driven by culture, “I think it's things that weren't even taught by our gurus, like it wasn't taught, this is stuff we've just taken from Western culture, Eastern culture and kind of brought it together. And I think it's that stigma that's attached to the culture as well.”

Another participant (\textbf{LI17 – F}) agreed that these negative perceptions are not based on religion but “maybe culture. Society has portrayed this as just a label we just stick this on that person. Religious, if it was a religious person, they would probably want to pray for you. As opposed to just erm label you.”

Additionally, it is the Punjabi culture which fuels the supernatural superstitions around mental illness, rather than religion. As stated by \textbf{LI19 [M, 39]} who said “I think it's a Punjabi thing, it's a cultural thing... I think it's the South Asian thing, you go to India. You know, I've been to my village as well. And there's different, there's a whole vast majority of different people from Hindu, Muslim to Sikhs. But the one common factor I found was they, they believed in all of this supernatural stuff, regardless of whatever the religious teachings were.” Comparably, \textbf{LI25 [M, 19]} said “I think if you're more towards the Punjabi culture, I think you'll think people will be able to do black magic on other people.”

Several participants discussed supernatural beliefs and help-seeking towards mental illness is not in line with the teachings of the Sikh faith. For example, \textbf{LI25 [M, 19]} said “even in Sikhism, there's no such thing about black magic or rituals or anything like that. But I think because this day and age we're in I think it's getting more... I think cultural is becoming more of a thing and the religions going down more. People are stemming more towards a Punjabi culture and less towards the actual religion and what the religion says about mental health

\textsuperscript{117} Punjabi Term for Mad/Crazy
and all these things.” In harmony with this, LI18 [F, 33] said regarding supernatural beliefs, “in Sikh religion, we don’t believe in those things.”

The Punjabi culture was characterised as toxic, judgemental, macho, extraverted. Culturally, people would be less empathetic towards someone with a mental illness. LI26 [F, 26] described the Punjabi culture as “very macho,” “very loud and brash,” and “you have to put on the act.” LI26 went onto say that she deems to qualities of the Punjabi culture as “quite dangerous, because I think you put on this persona, but you're taught not to talk about anything. So, nobody will ever talk about anything. Nobody will address anything; nobody will share experiences... It’s that toxic, is that toxic culture of putting a strong front and keep going and if he's struggling with something, have a drink and that will fix it which is completely in opposite to the Sikh faith.”

4.8. Chapter Summary and Discussion

In summary, there was a considerable lack of awareness and knowledge towards psychosis. Participants that had awareness of the illness were those that have either studied in the field, worked in the area, or personally knew someone who has had psychosis. Schizophrenia was a more recognised term than psychosis by participants. Yet, there was still a lack of understanding and knowledge of what schizophrenia entails. This reinforces previous evidence that has demonstrated low mental health literacy in Sikhs (Simich et al., 2009).

Participants perceived their family and wider Sikh community to hold an even greater lack of awareness towards psychosis and schizophrenia, with this being greatest amongst older generation Sikhs.

Actual mental illness diagnostic terms are rarely used amongst the participants, their family and wider Sikh community. In most cases the term ‘mental health’ is used as a catch all term, or terms such as ‘mad’, ‘mental’, or ‘paagal’\(^{118}\) are used. This echoes Greenwood et al. (2000) who found participants describing mental illness as simply ‘being mad.’ There also exists no translation of western mental illnesses in the Punjabi language – which is why professional mental health terms are not used by the community. In most cases, hearing someone has psychosis or schizophrenia or seeing someone with the typical symptoms of a

\(^{118}\) Punjabi Term for Mad/Crazy
psychotic illness such as hallucinations and delusions would be perceived as ‘mad’, ‘crazy’, and ‘paagal’ and described negatively. Some participants described those terms related to psychosis or schizophrenia are used in a context to insult another person – ‘schizo’, ‘you’re such a psycho’.

Whilst the current research focused on psychosis, the vast proportion of participants mentioned common mental illnesses, particularly depression and occasionally anxiety. Participants expressed they had more awareness of depression, and that this is likely the case for the wider Sikh community as well. This conflicts with earlier research, whereby even mental illnesses such as depression were not well known by the Sikh community, and in some cases, depression was not even considered a mental illness (Knifton, 2012; Burrs & Chapman, 2004; Greenwood et al., 2000; Lawrence et al., 2006b; Taylor, Brown & Weinman, 2013).

The rising awareness of common mental illnesses was attributed to the increasing recognition and discussion around mental illness in modern society, with common mental illnesses (mainly depression) being spoken about across television and online media platforms, particularly social media. People are now also openly sharing their own mental health experiences and mental health talks within schools and Universities are increasingly prevalent. There is now also significant initiatives and organisations specifically within the Sikh, Punjabi, and/or South Asian community to target mental health challenges.

A great lack of awareness and understanding even for common mental illnesses was reported for older generations. The generational differences in the understanding of psychosis and other mental illnesses were described to be resultant of numerous factors, including: no mental health education in previous generations; no open discussion of mental illness in previous generations; younger generations increased accessibility to gaining mental health information online and through social media; and younger generations increased interest in learning and addressing mental illness. This is in line with Taak, Brown & Perski (2021) who reported generational differences in the lack of education and awareness of mental health issues, with this influencing the help-seeking behaviours amongst the generations.

119 Punjabi Term for Mad/Crazy
When looking at the causes of psychosis, social causes were the most cited causal attribution. Particularly trauma acting as a trigger. Popular examples of trauma that participants thought could be attributed to the development of psychosis included childhood trauma and/or abuse (including domestic violence). Other common social causes mentioned included general life triggers and stressors and substance abuse. This is congruent with Gilbert et al. (2011), who found Sikhs to report similar social causes for mental illness. However, it conflicts with Bhika et al. (2015) who found social explanatory models for a psychotic illness were only endorsed by 18% of her British South Asian sample.

Supernatural causes around psychosis were also widely discussed. Whilst the majority of participants did not endorse these factors, they stated that these are prevalent beliefs within their families and/or wider Sikh community, particularly older generations. This echoes Ruprai’s (2016) research, whereby Sikh participants did not personally endorse supernatural causes for psychological distress but acknowledged the prevalence of religious and supernatural causes being endorsed by the wider community.

A common belief discussed was “somebody has done something” which alluded to black magic, in addition to evil eye (nazaar), and spirit possession. These causes have been reported as explaining psychotic disorders such as schizophrenia within South Asian samples (Bhika et al., 2015; McCabe & Priebe, 2004; Charles, Manoranjitham, & Jacob, 2007; Kulhara, Avasthi, & Sharma, 2000; Mirza et al., 2019; Carter et al., 2017). Such beliefs are fuelled by culture rather than religion, as well as a lack of mental health education. This is in line with Gilbert et al. (2011), whereby Sikh’s stated the endorsement of evil eye and black magic as a cause of mental illness. was due to cultural belief, rather than Sikh teachings, as Sikhism teaches that there is only one spirit – God.

If supernatural causal beliefs are endorsed, it was stated that it would be likely that help-seeking pathways that align with these beliefs would be sought. These included seeking treatment from a ‘baba’, which would likely be based in India, and undertake various rituals or alternative treatment that such a healer might recommend. The religious affiliation of these healers can be of any South Asian religion such as Hindu or Muslim. This was also reported
in the British Sikh Report (2018), whereby Sikhs visit healers of different faiths such as a *Pandit*¹²⁰ or *Pir*¹²¹ for treatments for mental health conditions.

Without probing, religious beliefs around the causes of psychosis were not mentioned as much. When probed, many participants personally endorsed religious factors such as “*God’s will*” and “*Karma*” being a contributory factor to psychosis and other mental illnesses. This echoes research by Gilbert et al. (2011) who found concepts such as karma and God’s will were important religious understandings towards health and mental illness amongst Sikh’s. Often, social and religious factors were combined and most cited together, which also supports research which found that for South Asians, a dual explanatory model for psychosis is preferred (Bhika et al., 2015).

Biological causes were given the least amount attention when discussing causal factors for psychosis. In most instances, biological causes were mentioned in conjunction with social factors, with an interlink seen between the two. Similar to social causes, it was thought that biological causes would not be acknowledged by older generations as a causal factor for a psychotic illness. The limited acknowledgment of biological causes for a psychotic illness by a South Asian sample was also reported by Bhika et al. (2015), whereby only 4% of the sample endorsed it.

Various help-seeking pathways were discussed by participants, with professional help-seeking being most recommended for someone experiencing the early and/or later symptoms of psychosis. Visiting a GP was seen as the first port of call, which would lead on to relevant referrals. This was in line with research which has found higher levels of GP involvement for South Asians with psychosis (Halvorsud et al., 2018; Mann et al., 2014).

Seeking talking therapy and counselling was widely recommended by participants, which contradicts previous research which found Sikhs to perceive counselling as abnormal, and shameful and stigmatising to the entire family (Moller, Burgess & Jogiyat, 2016).

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¹²⁰ A Pandit is a man with specialised knowledge or a teacher of any field of knowledge in Hinduism.
¹²¹ A Pir is a title for an Islamic Sufi spiritual guide.
Whilst talking therapies appeared to be a preferred treatment option over medication, participants did recognise that severer forms of mental illness such as psychosis require medication. Hospital admission was also recognised as a common route for severer forms of mental illness such as psychosis.

Religious support such as prayer and meditation were largely mentioned as a coping and support mechanism for psychosis and other mental illnesses. This is in line with research which has shown for Sikhs, prayer to be an integral part of mental health treatment (Gilbert et al., 2011). Combining both professional medical treatment and religious support was particularly advocated, which is harmonious with previous research (Dein & Sembhi, 2001; Bhika et al., 2015).

Whilst participants personally advocated for professional support and treatment as a primary help-seeking pathway for psychosis, the negative attitudes and perceptions surrounding seeking professional help was discussed from their families or wider Sikh communities’ viewpoint. These negative views lead to help not being sought until the point of crisis. This supports previous research, where seeking professional treatment was viewed very negatively by Sikh’s (Gilbert et al., 2011; Ruprai, 2016; Moller, Burgess & Jogiyat, 2016).

In supplement to the professional help-seeking pathways that were recommended by participants for psychosis, other forms of support were discussed. This included being personally supportive and talking to someone who is experiencing mental struggles. Seeking advice and talking support from mental health charities, both Sikh/South Asian specific and general was also suggested.

All participants spoke of the negative attitudes that are held towards psychosis and other mental illnesses, which is also supported by a wealth of previous evidence (Knifton, 2010; 2012; Bradby et al., 2007; Time to Change, 2010; Chew-Graham et al., 2002; Gale & Thalitaya, 2017; Lawrence et al., 2006a; Moller, Burgess & Jogiyyat, 2016; Islam et al., 2017; Ahmed et al, 2020; Ruprai, 2016; Gilbert et al., 2011). Participants did not personally endorse these attitudes but described them to be prominent in the Sikh and wider South Asian community. This included the stigma around psychosis and schizophrenia, general mental health stigma, mental health being ‘taboo’, and ‘sharam’ (shame) around mental health. Additionally, there exists a denial and ignorance around mental illness amongst the
community, and secrecy around having a mental illness which is fuelled by the fear of gossip and judgement amongst family and wider community.

Family played a key role when participants answered questions. Many participants stated that it was unlikely that family would be supportive of mental health struggles, and for this reason mental illness would go undisclosed, with no help sought. Lack of family support was largely due to their lack of awareness and education around mental illnesses and the negative perceptions surrounding mental illness. Several participants provided personal examples of this. Nonetheless, seeking initial support from family was still considered as a primary pathway by participants when presented with the case vignette presentation, early symptoms, and later symptoms of psychosis.

The role of the Gurdwara was also deemed an ineffective source of help for mental health struggles. Many participants stated they would not recommend seeking help and support for psychosis within a Gurdwara setting, for similar reasons as relating to lack of family support – lack of mental health awareness and education and negative perceptions around mental illnesses. Several participants stated that some Gurdwara’s are starting to provide mental health education, and that they should be used as a hub for providing mental health support. Whilst Gurdwara’s may not provide guidance and appropriate professional signposting for mental illness, the calming and peaceful environment of the Gurdwara setting was thought to be beneficial for mental health.

The final theme to emerge was the distinction and confliction between religion and culture, and how they both influence how individuals understand and address mental illnesses. With regard to the Sikh religion, findings were mixed as to whether severe mental illnesses such as psychosis as well as other mental illnesses were mentioned within Sikh scripture or could be explained by the religion. Participants who did provide an explanation as to how the Sikh religion might explain psychosis did so in different ways, which may indicate the subjective nature when interpreting religious scripture. The Punjabi culture appeared to have a greater influence on perceptions, attitudes and help-seeking of psychosis and other mental illnesses. Particularly, culture fuelled the negative perceptions and attitudes towards psychosis and other mental illnesses, in addition to driving supernatural causal beliefs and either delaying help-seeking or seeking help from alternative sources.
5. A Family Members Lived Experience of Psychosis

This chapter presents the findings from the study which explored the accounts of family members who had an immediate family member experience psychosis. Using the principles of thematic analysis, five main themes were identified, in addition to numerous sub-themes (See Table 8). Each theme is discussed in turn. The chapter concludes with a summary of findings.

Table 8

Overview of Main Themes and Sub-Themes from Family Member Study Analysis

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5. Personal Experience Improving Attitudes and Education of Mental Illness

5.1. Researching the Illness
5.2. Mental Illness Should Be Accepted Like Physical Illness
5.3. Positive Impact on Family

6. The Role of Religion
6.1. Having Faith Helps
6.2. Promoting Mental Health in the Gurdwara

5.1. Help-Seeking at Crisis Point

5.1.1. Dismissing Behavioural Changes

Participants were asked to recount the story around when they first began noticing changes in their family member’s behaviour to the point of diagnosis. Each story varied in nature, whereby some participants noticed “unusual” behaviours for years before diagnosis, whilst others stated that they witnessed changes in the person’s presentation in a few weeks. These behaviours tended to start with symptoms such as emotional withdrawal, responsibility withdrawal, such as suddenly leaving their employment, and as the illness worsened the common behaviours were paranoia, delusions, and hallucinations.

C1 [M], who was a child at the time, stated that he began noticing changes in his mother’s behaviour at the age ten. Because of C1’s young age at the time, they recognised that what their mother was saying was unusual but believed it to be true as they were only a child: “She always used to say some really weird stuff. That she could hear things in the walls, or she heard something, knocking noise somewhere or there's people outside listening to conversations, that kind of stuff.”

Eventually, as the symptoms persisted over the course of several years and C1 and his sibling increased in age, they realised that these statements that their mother was saying were untrue. However, C1’s father and the remainder of the immediate family were dismissive to the behaviour. When specifically asked about his father’s reaction to the behaviour, C1 stated that he was “completely dismissive and typical Indian bloke. Urm, just rather, bury his head in the sand and go to work.” C1 went onto say with regards to the rest of their family and
their reaction to his mother’s behaviour pre-diagnosis, “families back then were totally unsupportive, I think. Yeah, yeah. Nobody wants to know really (...) I do harbour some resentment to them, really.”

Another participant (C2 – F, 20) stated that her mother was diagnosed with schizophrenia shortly after her mother’s arranged marriage with C2’s father, and before C2 was born. In C2’s retelling of events, she explained that just after her mother and father got married in India, which was where her mother was from, she experienced, “a really bad episode, obviously I wasn’t there, but from what I’ve heard (...) family members, I don’t know who, but they were saying, you don’t want to ruin your son’s life. Like, don’t bring her back to England, pretend that the wedding didn't happen. Pretend it got called off or whatever reason. Get your son married to someone else. You don’t want to get yourself into this mess. Which sounds awful, but that's the truth.”.

When C2’s mother experienced another episode shortly after arriving in the UK was when she was admitted into a psychiatric facility and received a diagnosis of schizophrenia. When asked whether anyone was aware of the illness prior to marriage, C2 stated that her mother was not diagnosed in India, and her mother’s paternal family said, “we actually don’t know what’s going on, kind of thing.”

In some instances, behaviours that were considered ‘not normal’ were dismissed as mental illness because they were attributed to other problems. For example, C5 [F, 50] spoke of her older brother who was always labelled with “behavioural difficulties” by their parents since childhood, “From when he was a child, I remember the kind of behaviour, my parents found him very disruptive, and he used to get punished a lot (...) he was marked as a troublemaker, or something as a problem”.

C5 stated that as she got older, she suspected her brother might have psychosis but did not share this with any other family members because, “I didn't think I had anyone too (...) I think if you something, tell somebody something like that [participant laughs], would you tell them, I don't think my family was going to be very supportive, you know, so I didn’t tell anyone.”
Even when C5’s brother presented with a mental health crisis many years later in mid-adulthood by expressing suicidal ideation to his mother, when social services were contacted by C5, she described the parents held a dismissive attitude towards the situation, “It was quite as if they, you know, heard all of this before, kind of thing.” C5 also expressed that her parents felt “annoyed” and “very angry” at the person, even post-diagnosis, due to his “difficult” behaviours over the years. This is also true for C5’s other older brother, who “doesn't, you know, want to have any kind of role in it, in whatever's happening to him”, with regards to their brother with psychosis.

C9’s [F, 47] son has paranoid schizophrenia and began presenting with changed behaviour during his GCSE’s such as “becoming very disengaged from the family”, “staying in his room a lot,” “obsessed with lots of things,” and “being paranoid”. These behaviours were initially attributed to the “stressful time” of the GCSE period, as well as just being the typical behaviours of a teenager, “teenagers, you know, to go through stages where they’re just a bit reclusive”. Eventually C9’s son stopped wanting to go into school and had to sit the examinations in a room by himself, which C9 said “should really brought up red flag to us”, but at this point it went overlooked as a serious issue by them and the family.

In another account, C3 [M, 41] spoke of his younger brother who is now diagnosed with a mild form of Schizophrenia. C3 described his brothers “cognitive thinking” since early teenage years to be “impaired a little bit.” Thus, the negative symptoms of psychosis such as inexpressive emotions, monotone speech, and low motivation that the person was displaying for many years were not perceived as a “diagnosable mental illness.”

Furthermore, C6 [F, 23] described that their brother who recently had a brief psychotic episode, previously experienced a depressive episode two-years prior for which he received talking therapy referred by a mental health early intervention team. C6 described her brother’s behaviour to present initially as “low mood and kind of lashing out on us, like being angry. Things getting to him easily. And when we asked him what’s up and him not really wanting to talk about it.”. Due to the familiarity of his previous depressive episode, C6 stated that herself and her parents thought, “that’s just him being him, and he’s going through something, but we didn’t think it was that serious.”
5.1.2. Medical Help at Crisis Point

Due to the changes in the person’s presentation being dismissed or attributed to another cause, it was primarily at the peak of a psychotic episode that medical help was sought.

At the point of crisis, many participants described the person to be acting aggressive in addition to the hallucinations and delusions which were “confusing” and “frightening” to participants, which fuelled their decision to seek medical help.

C1 [M] described the point of breakdown as a “standout moment from childhood” whereby his mother was experiencing heightened hallucinations and delusions. This was several years since the participant first started noticing changes in his mother’s behaviour. “She goes, I’ve had enough. They’re coming to get me. I need to go. I was like urm nobody’s coming to get you (...) The Russians are coming. Urm, somebody is trying to get me, your uncle, your dad’s uncles are coming for me. I need to get out. Somebody’s help me,” as well as exhibiting “frightening” behaviour, “and then all of a sudden, she screamed her head off. She was just screaming and screaming.”

C1 stated that his father tried to diffuse the situation by suggesting a walk in the park, which she refused. It was then C1 whose first port of call was to contact their GP, “he couldn’t calm down her down. And she just started throwing water at him (...) My dad, urm I am sure my dad’s started crying at this point, in fear, and shock. Er, and I was just like Dad we got to call, call erm, a doctor. Get on the phone and call him.” C1 stated that they took their mother to the GP surgery shortly after, where the doctor stated that she was experiencing a “breakdown” and was referred to the local psychiatric hospital, where she was subsequently sectioned and hospitalised for several months.

Similarly, C3 [M, 41] described his younger brother’s route of care to be firstly the GP which led to local psychiatric hospital referral where the participant then stayed for a period of time. However, in this instance a full-blown episode of psychosis did not occur for help to be sought. Rather a progressive lead up of negative psychotic symptoms in addition to “irritation” and the person being “overly aggressive on certain situations.”
The GP was also the first thought for help-seeking for C6 [F, 23]. This was due to the family’s familiarity with the person’s depressive episode which occurred two-years prior, and GP help was successfully sought during that period. However, due to the breakdown occurring in the evening, the surgery was closed and C6 and her parents contacted 111. This service was deemed “unhelpful” as they did not recognise the situation as “immediate”, and the family were told to contact their GP in the morning.

As the person’s behaviour became more “scary” by “losing control and being aggressive”, C6 and her parents contacted the ambulance, who again did not perceive the situation as “urgent”, thus arriving an hour after the call was made. When the ambulance service arrived, C6 stated that her brother was “more calm, like seeing a stranger in the room and not really communicating with them (...) He was calm in front of them so they were like, urm we wouldn’t take him to the hospital, the Mental Hospital, it’s not really a nice environment, so you should probably wait to see your doctor and see what they say can be done further. They didn’t see it like how we would have seen it before they came because he was completely different in front of them.”

C6 and her parents made a final attempt at crisis point for help that evening by contacting the police as the person continued to exhibit “aggressive” behaviours, was consuming alcohol, and stated they were going to leave the house. C6 described the police’s response as similar but slightly more helpful than the ambulance service, “they said there’s not much we can do, it’s more of a medical thing. You need to be in touch with your GP again. They, they I would say they were more helpful than the ambulance, they were like we will wait outside if you walk, because we was scared that he’s gonna leave the house and they were like we will wait outside if he acts out or tries to leave.”

The police were contacted again the following morning as C6’s brothers presentation continued to deteriorate, “he was being very paranoid and those a lot on the news about Coronavirus at the time. So a lot of factors were just scaring him. And then he was I think I’ve got the Coronavirus, don’t come near me, so you know, just paranoid thoughts. And then he was like don’t come near me, and then he, the door was locked, he ran outside the house. Urm, he ran from his bedroom, so it wasn’t really, he was only wearing his pants, I think. So he ran outside, and I don’t know why he was just refusing to come back in. And then I urm, I called the police, urm 999 saying my brother has like been having a mental health crisis
Police were the first port of help in another male case who was exhibiting aggressive behaviours. C4 [F, 66] initially got a phone call that her son was displaying aggressive behaviours such as “breaking up things, he’s fighting, he wants his passport, he wants to go to India or something, and he’s lashing out”, from his partner. C4 stated that the partner should contact the police. After he was arrested and assessed by a psychologist, C4 and her husband, went to collect him. C4 stated that her son, “looked all fine. And we thought oh he is well, but they said that he just had a breakdown, a mental breakdown.”

C4 continued her account of events, where her son’s behaviour deteriorated after being released from police custody: “so what we then did was to bring him home and, in that journey, in the car you know, he's talking normally. And we thought okay he's fine now, you know, and my brother said something against religion. And he completely shut down. And you know he started looking outside the window. And he just glared outside which was very scary. And then we brought him home and urm it was like urm just like, I really just not understanding, it was the scariest thing, he would get up in the middle of the night and he’d have a hoodie on because he said his ears were ringing, urm and then he started chanting and cleaning. He started cleaning the walls of the house with the urm, with the towel, and chanting. And I was looking at him and I thought you know, I was completely, completely confused. Completely confused.”

As the night progressed, his behaviour became more erratic and aggressive that C4 had to contact the police again, “And then he went, erm, and then there was a period where he started lashing and getting angry. And we had to call the police in again. And they took him in. And again I cried whether I was doing the right thing.” After the police arrived, he was then sectioned and hospitalised.

C8 [F, 47] also described her mother’s behaviour as “quite violent” preceding an ambulance being contacted, and her mother being sectioned and hospitalised: “she became very aggressive towards my dad. And she'd had a knife and they'd have, they'd called 999. I was in halls in Aston and urm was on the phone to my mum trying to convince her to go with the
paramedics because she needed help. And they had to physically restrain mum to take her and then put her on a whole load of sedative medicines to to keep, to calm her down, I don’t know, to sedate her, to keep her calm until they could take her to the hospital and and then she stayed there for six months, I think, five or six months.”

Another case where help was sought at a point where the person’s behaviour was considerably deteriorated was told by C9 [F, 47]. Whilst C9 recognised changes in her son’s behaviour during his GCSEs, it was one-year later that C9’s son’s behaviour “went downhill” and she suspected it was “definitely a mental health issue” as “his paranoia increased, he stopped spending time at home, he started staying nights at the local Sikh temple. And then, I don’t think he was sleeping much at all (...) we’d go back, we’d go to the temple, pick him up, bring him home, and literally, he’d stay home ten minutes and go back out again. And when I say go back out again, his reasoning totally went. Because if we lock the door, he goes through the window. He just physically couldn't stay at home anymore.”

At this stage, C9 stated she made an appointment with a private psychiatrist; however her son asked another family member for tell her to cancel the appointment “because there's nothing wrong with me, I was just feeling a bit strange, but I'm feeling better now.” C9 did as her son requested, but said “looking back on it, I shouldn't have done” and that her recognition that this was a mental health issue was “probably too late.”

As her son’s presentation declined within the year, “He wasn't sleeping, his self-care was nothing. He wasn't combing his hair. He wasn't brushing his teeth. He wasn't changing his clothes,” that “an emergency appointment with a private psychiatrist to get him some medication” was booked and a referral to the Early Intervention Team was made and appropriate treatment was sought.

C9 was the only participant who directly went to a psychiatrist for her son’s behaviour, stating that she did not seek GP help because “because I have no, no faith in the NHS system. And because for me, it was urgent. I was not going to wait around for an appointment. I wasn't going to wait around while my GP to refer me to someone that I didn't, that I hadn't researched. So I wanted the best basically. And I wanted it quickly. So I did my own research, find a psychiatrist.”
A similar case of the ill person’s refusal to allow his parents to seek help was told by C5 [F, 50]. C5 stated that whilst her parents deemed her brother’s behaviour to be a result of behavioural difficulties, her mother “suspected something” and tried to seek help from a doctor when her brother was approximately sixteen, “she took him to the doctor’s, and, to try you know, to see because, I think she suspected something was wrong, but didn’t know what. But he wouldn’t cooperate. So I guess to all [inaudible] for, to the outside world, he just seemed like a normal albeit a bit you know quirky, or whatever person.” It was only many years later during adulthood, when C5’s brother stated he “wanted to kill himself” that C5 then contacted social services as a first point of contact.

5.1.3. Emotional Reactions by Family

When recounting the breakdown of their family member with psychosis, many participants reported strong emotional reactions towards the situation. The main emotions that participants described were confusion, shock, and fear/feeling frightened. The feeling of relief once the person had been diagnosed and received help was another common emotion expressed.

C1 [M] experienced a range of feelings and emotions at the point of his mother’s breakdown. Initially C1 stated that he felt “a bit angry” when his mother continued to persist in delusional thoughts, “She goes, I've had enough. They're coming to get me. I need to go. I was like urm nobody's coming to get you.” As the episode reached its peak that day, C1 predominantly felt fear and shock, “And it was just a shock. I thought what… It was really frightening (…) I was probably more shocked than anything,” whilst he described his sister and father as crying, “then my sister came down. She just took one look at her and burst into tears (…) My sister’s there crying. My dad, urm I am sure my dad's started crying at this point, in fear, and shock.”

Similarly, C4 [F, 66] spoke of the spectrum of emotions she felt as she watched her son’s breakdown. From feeling scared of his behaviours, to feeling “completely confused”, and “trembling”. C4 stated she “had emotions that I had never felt before. I thought I had lost my son. Tears were coming down my, I was putting oil in his hair trying to, you know, it was like he was going on and off.” It appeared many of these emotions were fuelled by C4’s lack of understanding of mental illness, and in this specific case – bipolar, “I was like, erm, scared
for my own, you know, what is this? It was completely new (…) we were distraught as a family. We did not have any understanding. Because we we've never ever seen it before. Never seen it before (…) And we were just lost. Because his behaviours was becoming, urm we were scared by him basically.”

C3 [M, 41] stated that he felt shocked, but this was regarding his brother’s diagnosis, “it was shock and disbelief, I think. I think sometimes when you hear something, you know, what is this? You know, how did this happen? You know, what does this mean? So different questions”.

In comparison, some participants stated they felt relief at the diagnosis. For example, C1 stated that once his mother was hospitalised, “There was relief, there was relief, because she's getting some help now.” Similarly, C4 stated that she felt relief when the psychologist told her that her son was going to be okay.

Another participant (C2 – F, 20) expressed the relief they felt when they found out their mother’s diagnosis was schizophrenia. C2 had been told by her family growing up that her mother had depression, which she suspected was not the case. Eventually at age 18 she found out her mother in fact had schizophrenia, she described the situation as, “for me the initial reaction was it’s a big relief because it all makes sense, in a strange way in my head, I was like, I wasn't going crazy all these years knowing that this can’t depression. Urm, so in my head it was a big relief of that makes sense now.”

5.2. Lack of Understanding towards Psychosis and General Mental Illness

One of the primary factors as to why help was not sought until the point of crisis was due to a lack of understanding of psychosis and general mental ill health.

C3 [M, 41] described his brother’s behaviour as having always been different, but as the negative symptoms of schizophrenia began presenting more throughout his teenage years, they were unsure of what the issue was but believed it required some form of help, “I think it was just, just continuous sort of erm lead up in terms of his symptoms, and it was like we need to sort of get him some help. There’s something going on, we don't quite know what it is, why is he acting the way he is.” C3 further discussed his limited knowledge of schizophrenia,
“I didn't know it was different varying forms of schizophrenia. But I did think it would be sort of a challenge for that person to get through it. It would need a lot of focus. But I didn't have any idea what it might involve.”

Similarly, C1 [M] expressed that despite his mother presenting the symptoms of psychosis for several years prior to diagnosis, including paranoia and delusions, nobody suspected that it was a mental illness she was experiencing. When asked if this was due to an unawareness of mental illness, C1 responded, “Exactly, exactly yeah. Nobody in our family ever had it. Well, they had. They just weren't aware of it. And it wasn't ever talked of like that.”

C1 spoke of his relative’s lack of understanding of mental illness towards the treatment his mum would receive when hospitalised, “I had one relative saying, why have you taken her there? They're gonna fry her brain or something. You need to get her out of there.” Their lack of understanding also led to limited support offered by relatives to his mother post-diagnosis, “but I think nobody really in the Asian community really knows too much about what it is, you know mental health, so they guess they did as much as they could.

Also speaking on the community, C6 [F, 23] stated that not many people were informed of her brother’s illness due to their limited understanding of mental illness, “It's not, it's not like a normal illness, in the sense its mental health, and I think not many people understand what it is, like you know how Asians are, like you’ll just think oh they’ve gone paagal122 or mental.”

5.2.1. Generational Differences

Whilst many of the participant held limited to no knowledge of psychosis and/or mental illness generally, it was commonly expressed that those of an older generation were likely to have even less of an awareness and understanding of mental ill health.

C4 [F, 66] admitted that she had no understanding of mental illness prior to her son’s diagnosis which he received in adulthood, “You know what, I had absolutely no idea about mental illness, absolutely none. And then we brought him home and urm it was like urm just like, I really just not understanding, it was the scariest thing (...) You know. Blaming myself,

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122 Punjabi Term for Crazy/Mad
more questions than answers. I really had no idea about bipolar (...) I really had no idea. I still had no idea. I thought, oh my god has my son gone mad? Has he gone mad? Is he gone? Will I see the real [participant’s name] again? I was completely, we were distraught as a family. We did not have any understanding. Because we we've never ever seen it before.”

Furthermore, whilst C3 [M, 41] acknowledged having limited knowledge of schizophrenia, he stated that he did not believe his parents were even aware of what psychosis or schizophrenia was, “To be honest, their like, first generation born in India, and then they didn't really have an understanding as such of mental illness and the difficulties that people can face and what it means to live with that. As, as some most of us, I think we didn't really understand it that much. So their reaction is like you know, he’s got a problem, lets sort of try and get him help, but let's not talk about it too much. As it’s a taboo subject, you know they don’t want to talk about it with family, with other families, other people.”

Similarly, C5 [F, 50] stated that whilst she had an awareness of psychosis from “media” and “hearing about it”, after her brother received his diagnosis of psychosis. Regarding her parents’ reaction she stated, “I don’t think they fully understood it to be honest with you.”

C7 [M, 42], whose brother experiences episodes of psychosis because of a hypoxic brain injury, also stated that his “understanding [of psychosis] of it was a lot better than what my families was”, because him and his wife work in the healthcare field. However, his parents nor his brother’s wife had an awareness of the term psychosis, and just perceived his brother as “paagal.”

C8 [F, 37] stated that she did not believe that her mother’s generation would know what schizophrenia was. Likewise, when asked about the wider Sikh community’s familiarity with terms such as psychosis, C2 [F, 20] stated “I don’t want to speak for everyone, but when I go to the Gurdwara, from like older generations, not my age kids, but older generations I do not think they do, no.”

C2 went onto speak of how her grandmother refers to her mother’s illness of schizophrenia as “tension,” and “pressure on her head.” Not using the official diagnostic term to describe the

123 Punjabi Term for Crazy/Mad
person’s illness is a common theme that was conveyed by numerous participants and is
further discussed below in Section 5.2.2. Using these alternative terms for the illness is
fuelled by the lack of understanding towards psychosis, “I shouldn’t be really advocating
here, but I’m like, she’s 80 years old, I don’t know how to explain schizophrenia to my
grandma, who doesn’t even know English, how is she going to understand neurotransmitters,
I think it’s a very much more complex condition.”

Comparably, C6 [F, 23] spoke of her mother being from India and her English “is not that
great.” Thus, when she tried to explain her brother’s episode of psychosis, in Punjabi she
described it as, “that its stress related, you know, all these bad thoughts have brought on this
pressure on his brain and caused him to act this way. And that’s really.” C6 also went onto
state that her father, who is born in the UK and works as a teacher also did not know what
psychosis was.

5.2.2. Supernatural Beliefs and Alternative Help-Seeking

Lack of understanding towards mental illness was also demonstrated by participants who
spoke of how either themselves or other members of their family at some points believed
something supernatural might be causing the behaviour of the ill person.

When asked about this, C1 [M] stated, “Oh yeah yeah. It all came out. (...) somebodies done
some black magic or something, you know (...) It was suggested by a lot of family members,
because they don’t understand really. Or maybe they do understand then there might be an
alternative treatment. I don’t know. But yeah, it was suggested about going see this person or
do do this bit of nonsense. I don’t believe in any of that sort of stuff (...) I think I might have
even done it just to please them.”

C7 [M, 42] also stated that whilst he does not believe in these methods as help, his mother
and his brother’s wife turned to alternative help-seeking for his brother’s condition by trying
different prayers and speaking to “babeh124” in India. C7 attributed seeking help this way to
be down to a matter of education, “my sister-in-law is from India as well. As is my mom. So,
there’s that [inaudible] with them, where they believe in Babeh and believe that if you eat a

124 Term used for Alternative Healer

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certain vegetable, do this paath\textsuperscript{125} this many times, it will take the problem away, which isn’t really the reality of it (...) when my Aunty came from India she brought some stuff for him, I don’t know, some, and they started rubbing it in his head and it’s supposed to work on the brain because one person said, and I was just like oh you won’t take the medication the Doctor said but you will believe in this.”

Similarly, C\textsuperscript{5} [F, 50] recalled her mother turning to alternative help-seeking whilst growing up, “Oh gosh, yeah, I remember a faith healer, like the Sufi, a Sufi healer that came. But he didn’t get very far, he came to see me as well [participant laughs], it totally creepes me out. But erm, that didn’t have any effect yeah. Because yeah, faith healers, er whatever, I don’t what the other terms are, yeah faith healers, a Sufi, a Hindu saint, a Hindu faith healer, yeah, she went down those routes (...) the Hindu faith healer it was all about making offerings and prayer, and finding out whose done whatever, black magic to your family, or something like that.” This was prior to her brother’s diagnosis and during the period where her brother’s behaviour was deemed “difficult.”

C\textsuperscript{2} [F, 20] also stated that some family members believed that her mother’s illness was a result of someone doing black magic on her. However, no alternative help-seeking was sought. Likewise, C\textsuperscript{8} [F, 37] stated that her aunty believed C\textsuperscript{8}’s mother’s behaviour prior to diagnosis could be a result of “jadoo\textsuperscript{126}”. C\textsuperscript{6} [F, 23] also stated that believing that such things are a result of “black magic” is “common” for Asians, “I think it's, it can be quite normal for our culture to just put it off and think, you know, bad evil eye and someone's done something.”

C\textsuperscript{4} [F, 66] admitted that when first observing her son’s behaviour when he was experiencing a breakdown, she stated, “I thought somebody's done something to him. I didn't want to go along them lines.” C\textsuperscript{4} believed that a particular person who has been teaching her son about Sikhism may be to blame and that he may be “controlling” her son or done “voodoo” on him. This belief of “somebody’s done something to him” was also shared by some other family members. At one stage, C\textsuperscript{4} stated that she did go to the Gurdwara to try and help her.

\textsuperscript{125} Punjabi Term for Prayer
\textsuperscript{126} Term for Magic/Sorcery
son by giving offerings, “just go and give some food like milk and rice and we did that” but did not do anything else “extreme” in pertaining to other alternative healing routes.

She continued to say that she also informed the doctors of how she believed this man had done something to her son but received little acknowledgement. Eventually, the participant recognised that her initial causal beliefs were incorrect, “I really didn’t understand it. I thought they [the health professionals] got it- they were giving him- I thought oh what, why are they are talking, why aren’t they telling him not to, you know to stop following that man, why aren’t they, why are they just listening to him. I don’t, you know, urmm so he was having these tablets. So I was living with my own thoughts, you know, and through that process slowly slowly, you know, it was it was so basically, we didn’t learn from the outside, we learnt from our own journey. You know, the journey that my son took took us on."

Despite discussing supernatural beliefs, all participants acknowledged that social factors (substance abuse, childhood, life stressors) are predominantly the cause for psychosis. Most participants also recognised biological factors playing a role in the cause of psychosis, with personal examples of mental illness existing in multiple family members alluding to a genetic predisposition and the hereditary nature of mental illness.

5.2.3. Official Diagnostic Term Not Used

All participants stated that the official diagnostic term for their family member tended not to be used either within the immediate family, wider family, or wider community. This was due to a lack of understanding of mental illnesses as well as negative perceptions around mental illness which are discussed further in Section 5.3.

C3 [M, 41] stated that his mother does not use the term schizophrenia regarding his brother’s diagnosis due her lack of understanding, “well, my mom always sort of says, like, his mind or his brain is not quite right. So she doesn't fully understand schizophrenia as such.”

As described in 5.2.1., C6 [F, 23] stated that she had to describe her brother’s psychosis to her mother as “stress related” and a “pressure on his brain”, due to her mother’s lack of proficiency in English. Similarly, C2 [F, 20] said that her grandmother refers to her mother’s condition of schizophrenia as “tension” or “pressure on her head.”
C2 went onto state that her mother’s paternal family also refer to the illness as “tension.” C2 spoke of her confusion as to why they refer to it as this, “I don’t know if they’re trying to protect me, or they feel uncomfortable with the word or if they genuinely don’t know the word.” Not using the term schizophrenia is also the case amongst her wider family, “Urm, they just say, no, they just say my mom gets ill. So it’s very much like, I don’t even think we ment- like we don’t say the word mental health. Which is weird. And yeah, they just say when your mom gets ill.”

Another point of interest from C2’s case, was that her family had told her that her mother’s illness was depression, since C2 witnessed her mother’s first schizophrenic relapse at age twelve. C2 described the relapse as, “it was very, very odd for me to see because it's not a nice experience, because my mom just went like, blank faced, urm didn't recognise me didn't want to talk to anyone. She was doing things that weren’t normal in a way, things you would not see an average human being do.” When she asked her family “what’s going on? Is she okay?”, her father said that her mother had depression.

In parallel, C8 [F, 37] stated that whilst her mother’s diagnosis of schizophrenia is not shared with anyone outside of the immediate family, when people ask it is described as either “not well” or “depressed.” Later, the participant speaks of depression within the community being more accepted as a term, “I think as a community, we’ve gotten much better at... like depression, I think depression is used as, as a as a catch all term for any kind of; that’s the accepted term now I think for any kind of mental illness. Oh depression hoiya\textsuperscript{127}. You know it’s that kind of it could be anything, it could be a multitude of things, but that's the accepted face of it.” C8 also said not disclosing the official diagnosis was due to “the judgement, the gossip” from others and the specific judgement towards severe mental illnesses by the community, “I don't think when it comes to severe psychosis, schizophrenia, paranoia, you know, I don't think, we're not we're not at that level yet to take those issues on and talk about them in a judgement free zone.”

\textsuperscript{127} Punjabi to English Translation: “Oh, they have depression.”
C1 [M] also stated that his using the actual diagnosis of schizophrenia was never used by anyone, “It was never used by anybody (...) Well, I mean, it's basically mental hogay128 (...) so they would just say mental. That was the word used commonly. Quite abrupt isn’t it.” C1 attributed this to shame, stating that he was made to feel “shame” around his mother’s condition, and people perceived it as, “it was almost a shame on the family that this has happened.” C1 states that he now openly uses the term schizophrenia, recognising that it is just like any other health condition.

5.3. Limited Discussion and Secrecy around Mental Illness
Discussing the person’s mental illness was found to be a limited discussion within the immediate family and often kept hidden from the wider family and community. This was not only due to their being a general lack of understanding towards mental illnesses by the family and community but also the negative perceptions around mental illnesses. Mental illness is considered a “taboo” and stigmatised topic, which results in feelings of shame and embarrassment for the family and fear of gossip and judgement.

5.3.1. Mental Illness Not Spoken About Within Family
Many participants stated that the condition of the person diagnosed with psychosis is not an open topic of discussion. For example, C2 [F, 20] referred to her family as “very traditional”, which is the reason she has never openly discussed her mother’s diagnosis of schizophrenia with her immediate family once she became aware of it. This was also the case for her wider family, “in terms of my wider family... I just think, we don't talk, we don't talk about, and I don't know why. We just don’t.”

C2 also stated that in general, within her family the term mental health is not said. C2 went onto give two other examples whereby mental illness is not spoken or addressed within her family. She stated that her cousin suffers from anxiety and wanted to leave her university studies, but her family dismissed the anxiety and would repeatedly tell her to “just get on with it.” Additionally, C2 stated her grandmother suffers from health anxiety, with a fear of going to the hospital. C2 said that whilst she recognises the issue her grandmother experiences, the remainder of the family just “brush it off.”

128 Punjabi to English Translation: “They are mental.”
In a similar manner, whilst the majority of C8’s [F, 37] family and the wider community are aware that her mother is “not well”, they do not openly address it as a mental illness. C8 spoke of how her mother’s paternal family who live in Delhi do not ask about her mother’s wellbeing, but instead ask about her functioning as a mother and wife. She described a conversation with her grandmother, where she asked “does your, does your mom cook? Does your mom clean? Does your mom look after the house? It wasn’t, it wasn’t about her – is she well? How is she doing? It was more questions about is she doing her perceived duties in the house if that makes sense. Not about her as a person, it was more about her behaviours, is she functioning. It was almost, is she functioning as a housewife.”

Not openly discussing things was also stated by C5 [F, 50]. C5 expressed that she suspected her brother might be experiencing psychosis, however felt she could not speak to anybody in her family regarding this. She said she thinks her sister also suspected the same, “but nobody spoke about it. We didn’t have the language, we didn’t speak about anything to be honest, anything that’s personal.”

After her brother was diagnosed with psychosis, C5 said that her brother’s illness was still not openly discussed and that she thought her parents did not understand the illness that was diagnosed. She went onto say, “my family we don’t actually talk about things. So it’s not about you know, how do you feel, nobody like says how they feel or how they think. There there’s more of a not saying anything, urm, because I, I don’t know actually I don’t know, but it’s not a, they are not in a culture of discussing things openly.”

C7 [M, 42] also states that his father does not speak about C7’s brothers’ psychosis, “my dad doesn’t talk about it, he won’t talk about it.” C7 attributes this to a generational ‘male’ typical behaviour rather than something associated with the Sikh community, “he’s like old school, my dad is like 80 years old. Men are men. You know. And I don’t think that’s a Sikh thing, I think that’s an older generation thing. You see that in all different communities and ethnicities.”
5.3.2. Keep Mental Illness Hidden from Wider Family and Community

Due to the “taboo” nature of mental illness, C3 [M, 41] stated that once his brother was diagnosed with mild schizophrenia, his parents’ reaction was, “he’s got a problem, let’s sort of try and get him help, but let’s not talk about it too much. As it’s a taboo subject, you know they don’t want to talk about it with family, with other families, other people (...) I think my mom and dad wanted to sort of keep it within the sort of you know close family, so immediate family, so we didn’t really talk about it as much.” In addition to this decision being fuelled by the taboo nature of the illness, C3 stated that his parents did not want other people to think or talk negatively of them or their son.

C8’s [F, 37] mother has been unwell for many years, and she recalls the wider community, particularly her mother’s friends, constantly questioning what was happening, “There was, there was a lot of inquisition and inquiry, from a gossip perspective and judgement. But it was never around genuine care for how she is.” C8 continues to keep her mother’s actual diagnosis hidden from the wider community as she believes they are only asking out of judgement and to subsequently gossip, “If someone had asked from a position of care, I think I would have been happy to at this point in time to say (...) But I am not able to do that because you know that it’s coming from a place of judgement and gossip and and tittle tattle, why would you put your mom out like that to be someone else's fulfilment or fix of gossip.”

In another case, where the diagnosis was revealed to the wider family, C1 [M] also recalled family members were not supportive following the diagnosis of his mother, and would often call for the purpose of gossip, “I just remember getting phone calls from relatives, saying, what's happened? More interested in what's going on. Not willing to help or anything, just wanted to know what's happening. Not, can we do anything, can we help you. Just wanting a bit of gossip really (...) some of them kind of made fun of it almost.”

Keeping the diagnosis hidden from others was also expressed by C5 [F, 50] who said there is “a lot of shame” surrounding mental illness, and it is looked at as, “More of an embarrassment I guess for when I was growing up, it's seen as a weakness, it's seen, it's a vulnerability, so therefore you're weak. And also it means there's something wrong with your family, so you know, so you you know become isolated.”
C5 stated that due to shame, her family’s lack of trust in the community, and the impact revealing such a diagnosis can have on family reputation such as marriage prospects of her siblings and “the social capital that comes with not being ‘normal’ in quotes,” the illness has not been disclosed to others outside of the immediate family.

Disclosing issues such as mental illness influencing marriage prospects and “honour” was also mentioned by C7 [M, 42]. Similarly, C7 stated his family have not revealed his psychosis to others as they consider it taboo, “they won’t tell other people and that sort of thing, try to keep it in-house, which doesn’t help.” Additionally, that due to the unpredictable episodes of psychosis his brother experiences they do not bring him to wider family events such as weddings, because there is an “embarrassment feature” to his behaviours, “they wouldn’t put him in that situation. I said it’s an embarrassment thing for them. But people are going to talk and that”

C7 also stated that it is due to the lack of understanding of his brother’s illness, that his family perceive it more as embarrassing, “They see it more as an embarrassment to themselves, that he’s suffering these episodes not the fact that he is mentally is.”

Comparably, C3 [M, 41] said that he believes the stigmatising beliefs held towards his brother’s condition is more so a result of people’s lack of knowledge, “but sometimes you don’t know how to react or it’s probably not that person’s fault but it’s just knowledge that should be made available to a lot more people.”

C9 [F, 47] wants to speak about her son’s diagnosis, but said “the thing I didn't like is, after that people treat you a little bit like a leper.” She said that people seem to be “afraid” of the discussion, “I don't think it's accepted or talked about or communicated about as it should be, to make that patient or that family feel comfortable. Because then everyone's sort of stepping on eggshells, but I actually like talking about it openly (...) Everyone seems afraid of it (...) So I would definitely like it to be more out there, more open.”
5.4. Weaknesses of Professional Care Experience

Some participants spoke of the limitations they faced when their family member was experiencing a psychotic episode.

C6 spoke of the unhelpful experience of contacting a variety of emergency services professionals at the point of her brother’s breakdown. Described previously in Section 5.1.2., C6 had reached out to various emergency services pathways whilst her brother was experiencing the peak of his psychotic episodes, with ambulance services and police responding with “there's not much we can do, it's more of a medical thing.” Appropriate action was eventually taken by emergency services the following morning after C6 contacted the police again, and her brother was then sectioned.

C6 said “there needs to be more like with mental health, like what helplines you can call in crisis and how quickly you can get the help, because it's so easy for that one thing to escalate to the another and before you know, damage has been done to oneself.” It was only when the situation got “really serious” that professionals took appropriate action, “it didn't really have to get that bad.”

Comparably, C8 [F, 37] spoke of her mother’s poor experience with healthcare professionals during years of misdiagnosis of her condition. Since C8 was a child, her mother was incorrectly diagnosed with clinical depression and prescribed antidepressants. C8 recognised that her mother’s behaviour did not make sense in relation to her diagnosis, “at the time as a child I couldn’t make sense of it, but I knew it wasn't quite right” but “the GP didn't really make another referral to get mum fully assessed. It was oh you know she, she's depressed and she has anti-depressants, and it was like that for a long time.”

C8’s mother was then then misdiagnosed with bipolar depression throughout C8’s teenage years, which C8 still suspected was not right after researching the condition, “I just thought this, this is the surface of it. A lot of this stuff didn't, it didn't, they didn't capture the conversations she was having in her head, the laughter to herself.” However, C8 accepted the diagnosis given and described her mother to be strongly medicated during this period, “the medicine that she was on from, I would say, from seven through to eighteen pacified her, it made her sleep a lot. That's what it did. It made it bearable for us to have a life that wasn’t
as turbulent as it could have been, because she was pretty much sedated for most of that time.”

Eventually, a severe episode of psychosis occurred when C8 went to university, which was when her mother was sectioned and received a diagnosis of schizophrenia, “it took a team of paramedics and ambulance and mum being sectioned for her to be diagnosed with schizophrenia.” C8 stated she felt “resentful to the system” for the misdiagnoses and length of time it took to receive the correct diagnosis, despite multiple visits to the GP and psychiatrist over the course of years.

Whilst C8’s mother has finally received the correct diagnosis, C8 states that the care she receives is still not adequate, due to issues such as “a really high turnover of the psychiatrist that you're seeing each time and you are having to start again, explain the backstory” and a focus on medicating the individual rather than understanding them, which is discussed below further.

5.4.1. Focus on Medication

From the point of receiving professional care all participants spoke of the primary method of treatment being medication and spoke of the limitations of this.

When C7’s [M, 42] brother was hospitalised for his psychotic episodes, he spoke of the treatment facilities effort on solely medicating his brother, “Every time he would suffer an episode they would just give medicine and sedate him (...) which wasn’t helping with his condition, urm it just tried to escape him seeing things really (...) they tried to sedate him with medication which wasn't the right answer for what he needed at the time.”

Eventually, C7’s brother returned home where he receives full time support by his family. C7 said he saw a “massive improvement” in his brother’s presentation when comparing him to being within the hospital environment, attributing this to, “I think had he stayed in that place he would have got worse and worse, because their simple answer was just to medicate and not deal with the problem.”
**C8 [F, 37]** also described that the focus on all her mother’s diagnoses, including the incorrect diagnoses of depression and bipolar depression, were solely treated by medication and healthcare professionals never looked to explore the underlying reasons further, “initially in terms of what mom’s access, it was she had, she went to the GP, and she was given antidepressants for a really long period. There were some trigger points, but they were never really explored further.” When the diagnosis switched to bipolar depression, **C8** continued, “even when I'd go with mom to the appointment, and they would say it was very medicinal. It was, this is what she needs, this is what, you know, you just need to make sure she has this medicine.”

Even now with a diagnosis of schizophrenia, **C8** stated that her mother has never been offered talking therapies for any of her diagnoses, but **C8** considers these vital in order to understand the patient’s condition. **C8** feels professionals need to explore “what's happened to you to get you to this place (...) I feel like they don’t take enough time to understand the person, it's almost like they're trying to break it down into purely the medicine.” **C8** said her mother had a degree in English, thus language was not a barrier for talking therapy.

**C8** believed that it was because her mother was “brown” that “there's an acceptance that if a brown woman isn't talking about, if a Sikh woman isn't talking about her experiences, or there’s just an oh yeah well, she's not going to talk about it. Rather than trying to help someone to get to that point in time (...) I think if my mum was white, that she wouldn't have been just pushed down.”

Recognising the importance of talking therapy in the treatment for psychosis, but not being offered it was also mentioned by **C6 [F, 23]**, “Also, mental health teams, I think in his case, he could have better, erm, they mentioned something about him getting CBT, but he never got that after being discharged from the hospital. He just goes for his monthly depo injection. But I don't think that's enough, because he still, it's very easy for him to get distressed thinking about the past and he doesn't get good sleep.”

Furthermore, **C9 [F, 47]** spoke in detail of the medications her son was on, and when asked about talking therapy she stated that this is where the service had “probably fallen down” because “all the early intervention teams are just doing a prescription service.” Whilst for
the first year the team were “amazing”, but now “it’s like here’s your blood test, here’s your clozapine, sort of thing.”

C2 [F, 20] also stated that her mother has never had CBT, and only ever had “straight meds.”

5.4.2. Limited Information of Condition Provided by Professionals

Not being well informed of the condition post-diagnosis was mentioned by several participants. For example, C4 [F, 66] spoke positively of the care her son received from healthcare professionals following his sectioning and hospitalisation. However, C4 stated that it would have been “helpful had they told us look, you know, it can be caused by stress (...) I think that would have helped me if they said nobodies done anything to him. Full stop. Like this is your son, coping, and he’s coped with so much stress.”

Similarly, C3 [M, 41] also stated that it would have been beneficial to “know exactly what your condition involves, and where you can get support (...) an information guide would be great,” after his brother received his diagnosis, “because it's difficult to suddenly not have experience of this and it certainly hits your family and you’re sort of thinking, oh what is going to happen here, what we're going to do.”

In the case of C8 [F, 27], this participant felt they had to spend a “lifetime to try and figure out for ourselves”, regarding understanding their mother’s condition and the poor experience of care they have received over the years by professionals. When speaking on finally understanding the causes of her mother’s triggers, C8 said “we found out from you know no, insight from my cousin [who is a Clinical Psychologist] and me putting it together that maybe there's a reason behind this. It didn't... that wasn't surfaced through six months of a residential stay in a mental health unit.”

Whilst C7’s [M, 42] brothers’ primary condition was hypoxic brain injury, experiencing recurrent psychotic episodes was a result of this injury. C7, who works in pharmaceuticals and thus had familiarity with medication used in psychosis, stated that the family were not initially made aware of the psychosis element of his brother’s condition, “a lot of the medications that were being prescribed to him, because obviously he had a heart condition,
so on one side of the medications, they were psychosis medications being prescribed, so we were like well why are these being prescribed, so that’s when they started to tell us like well we think it’s this and this. We thought well you’ve decided to put him on medicines X, Y, and Z, without any consultation.”

C7 also stated that the healthcare professionals attempted to section his brother without informing the family, and when they were made aware of the psychosis element to the condition they received little information, “they didn’t really have any support with regards to that, or, or literature or, it was all in regard to hypoxic brain.”

5.4.3. The Need for Culturally Appropriate Care

After reviewing their experience with professional care for their family member with psychosis, many participants put forward improvements that they feel could be made to allow mental health services cater better for the Punjabi, Sikh community.

Having a translator within services was proposed by C1 [M], who stated that his mother’s English whilst “pretty good”, there still sometimes is a communication breakdown between patient and professional, “I need to jump in and do some translating here and there on certain words. Her English is decent. She can 90%. She gets the odd thing here with times and dates. That could probably improve a little bit.” Other than this improvement for professional care, C1 stated the care his mother has received has been “fantastic.”

C3 [M, 41] also proposed having a translator in services would be beneficial, in addition to health professionals training to become more culturally sensitive of the Sikh faith, “maybe when seeing doctors and stuff, they, they, they understand what Sikhism is, first and foremost, and what our beliefs are, how we can be culturally sensitive.”

C7 [M, 42] proposed that matching a doctor “from the same cultural background” would be beneficial for care, “when you are trying to explain something to an English, white doctor, as opposed to saying it to an apnah129 or a Hindu or whatever, who will understand the cultural aspects is slightly different. Why this would work and why, you know, stuff like that. Because I think stuff like that needs to be looked at.”

129 Punjabi Term for “One of our own.”
Having mental health literature in the Punjabi language was advocated by C3, describing this as “definitely” needed to “know exactly what your condition involves, and where you can get support. So that's important”. C3 said this information should also be provided in setting such as Gurdwara’s and community centres.

5.5. Personal Experience Improving Attitudes and Education of Mental Illness

Many participants spoke of the experience of their family member being diagnosed with psychosis having either had a positive impact on them by enabling them to become more educated and accepting of mental illness. Some also spoke of the positive impact the experience had on family dynamics.

5.5.1. Researching the Illness

Due to the limited knowledge held towards psychosis, many participants stated that they and other family members researched the illness to garner a better understanding.

C3 [M, 41] spoke of how his other brothers suicide led him to begin researching into mental health conditions, and once his other brother was diagnosed with mild schizophrenia, him and his parents looked into the condition due to having little understanding, “I didn't know, know. Like, you know, this is what [inaudible] symptoms, this is what happens, this is what you know it means to live with it, this is what you have to do to support a person living with it, I didn’t know any of that, so not much detailed knowledge. But obviously, we read up a little bit about it. And we thought this doesn't look too good”.

As previously discussed in 5.2.2., C4 [F, 66] initially held incorrect beliefs regarding her son’s presentation. C4 expressed that gradually she has spent time, “trying to understand mental illness, and how it affects people differently.”

Additionally, C9 [F, 47] stated that before she booked an appointment with the psychiatrist because of her son’s decline in health, she “definitely” researched the illness online, and completed an online survey which revealed what her son may be experiencing, “There's surveys online, isn't it, you can put the symptoms in it comes up with various things, whether it's depression, psychosis, urm you know manic depressive, or some other things. So I sort of
had an inkling, I didn't want to admit it to myself, but pretty much knew what it was gonna be.”

In the case of C8 [F, 37], her mother was incorrectly diagnosed with depression and then bipolar depression by medical professionals. C8 spoke of how her, her sister and father researched into bipolar depression and felt that some of the behaviours her mother exhibited did not match the diagnostic criteria of bipolar depression: “We looked into bipolar, and it, a lot of it made sense, but the bits that didn’t make sense were we could see how sometimes she was almost having a conversation in her own mind or reacting to a conversation in her own mind (...) I don't think it was the right diagnosis.”

Similarly, C2 [F, 20] was initially told by her family that her mother had depression rather than her actual diagnosis of schizophrenia. C2 spoke of researching into depression and the diagnostic criteria not matching her mother’s presentation, “I started looking up depression on like NHS, [inaudible], oh you encourage them to move, oh you encourage them to go out, [inaudible]. And I was like when I talk it’s literally me talking to a blank wall. So I was like, how am I, this doesn’t make any sense, I would sit there and say is this depression.”

When C2 found out the actual diagnosis, she further researched into it, as well as expressing her father had also researched the illness, “I kind of did my research on it (...) I know, my dad's done research. I think my dad knows like, obviously he I think he knows more than me at this point. He’s been through it from the beginning.”

5.5.2. Mental Illness Should Be Accepted Like a Physical Illness

C1 [M] said that when his mother was initially diagnosed with her condition during his early teenage years, he felt there was a lot of “shame” around what had happened. As he has got older, he is more open about his mother’s diagnosis and spreading the awareness of mental illness, acknowledging that mental illness should be treated like any other health condition, “But now it's just like a condition. It’s a problem in the mind, you know people have problems with their backs don’t they, and they get treatment, they is just a problem of the mind. And, but yeah I'm open and I like to spread the word actually”.

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A similar statement regarding mental illness being treated like physical health was mentioned by C4 [F, 66], “mental illness you know is like say if somebody has got a broken neck, and you knew that, you wouldn't allow that person to walk on that broken neck. And, you know, mental, mental illness is like that, when your brain is sad, and it's upset and it's hurting, it shouldn't be stigmatised. It's just the same as having a broken neck, it's just that we can't see it and we need to be aware of it.”

As also described by C9 [F, 47] who stated that she wanted conversations around psychosis and her son’s illness to be “more out there, more open” because “it’s a part of life isn’t it. People break their legs, people break their bones, well actually people’s minds can go as well.”

C7 [M, 42] also stated that Sikh television channels will focus on physical ailments such as diabetes and high blood pressure, but “I don’t see any programs about mental health issues (...) I think the awareness does need to be raised.”

5.5.3. Positive Impact on Family

C4 [F, 66] expressed that the experience of her son’s condition has had a positive experience on the family, stating that the “experience has changed us in many ways,” and has made her and her husband “better parents.” Whilst confessing to previously being judgemental, “you know, as Indians do, you know ‘you don’t know nothing’ or just judging, we used to judge quite a lot,” C4 said the family are “more understanding” and she personally has “a huge compassion with people who are mentally ill, I just really feel for them, you know. I suppose I have empathy with them.”

Whilst C4 was unaware of her son’s triggers whilst he was initially hospitalised following his breakdown, “I would say the wrongs things. I didn’t know that my, my language was urm... triggering,” she has learnt to be more aware of these triggers and when she notices her son becoming “unwell” she encourages the rest of the family to “just to stay calm around him.”

Correspondingly, C3 [M, 41] stated that him and his family are a lot more “sensitive to his needs” pertaining to his brother’s triggers and “empathetic” since researching the condition after diagnosis. C3 also stated that he personally tries to provide “positive encouragement”
for his brother, as well as regularly visiting him, checking in on his feelings, and staying “in contact with his care coordinator.”

Exploring and understanding a person’s triggers was also important to C8 [F, 37], who alongside other family members such as her cousin who is a Clinical Psychologist, and her sister, spent many years trying to understand the underlying triggers of her mother’s schizophrenic episodes. C8 also stated that her mother’s illness is accepted by the immediate family, “There was an acceptance that this is the cards that we’ve been dealt. This is our Hukam¹³⁰, this is what we’re working through, we will deal with it.”

The experience having a positive effect on the family was too described by C6 [F, 23] who expressed that following the hospitalisation of her brother, despite it being a “stressful time” it did not have a “bad effect” on the family. Instead, “it brought us closer, like going through that as a family it was more of like, a teamwork thing (...) I always see like the positive, so it's definitely brought us closer with him and he's not as distant.”

5.6. The Role of Religion

5.6.1. Having Faith Helps

Regardless of whether participants practised their religion or not, many said that having faith helped them and their family through this journey.

For example, C9 [F, 47] who is a baptised Sikh, as is her son who has paranoid schizophrenia, stated that whilst this experience has “changed out life hugely” their faith has helped them as a family get through the illness, “It made us stronger and more able to cope. Sikhism always teaches life isn't always going to be easy. It's going to be ups and downs. So you just got to say, stay steadfast in your faith”.

C3 [M, 41] who is also a baptised Sikh stated that his faith has “helped me keep straight and narrow,” and in turn this has allowed him to help his brother, “I'm, I'm quite, you know, stable, grounded and I can come from a point of empowering him.”

¹³⁰ Punjabi word meaning “command” or “divine order.” In Sikhism, Hukam represents the goal of becoming in harmony with the will of God.
Furthermore, C8 [F, 37] stated that although her mother has schizophrenia, as a baptised Sikh she has always kept her devotion to her faith, “always throughout her illness, throughout her whole life, she's always continued with her, her nitnem\textsuperscript{131}. She's always done her paath\textsuperscript{132} in the morning, the evening, the night, that's always been something that she's done. She's always does her ardas\textsuperscript{133}.”

Some participants admitted to not being “very religious” or practising the religion, but faith has played a role in helping them through the experience. For example, when C4 [F, 66] was asked if the Sikh religion has helped her and her family through this difficult period, she responded “Faith is always been there with me. Faith has always been, it’s been a huge part. And, but I don’t, I don’t practice it, but it’s always been there.”

Similarly, C6 [F, 23] stated that whilst her family is not “very religious”, every Sunday her mother makes “prashad\textsuperscript{134}” and “and then we'll do like a small prayer every Sunday.” C6 went onto say, “when bad stuff happens, we think of God anyway, naturally, we start doing more things and praying. So yeah, my mum would get my Nani to go in India and pray.” Likewise, C7 [M, 42] stated that his mother and sister-in-law do various prayers for his brother.

5.6.2. Promoting Mental Health in the Gurdwara

Many participants advocated for the Gurdwara\textsuperscript{135} setting to be a valuable place to increase the awareness and education around mental illness. For example, C3 [M, 41] stated that mental health literature should be made available in the Punjabi language within Gurdwara’s and community centres.

Similarly, C6 [F, 23] stated that “posters in Gurdwara and religious places would definitely help,” as well promoting discussion around mental health in educational classes that occur within Gurdwara’s, “whilst you're teaching them about the Sikh and Guru Granth Sahib,

\textsuperscript{131} Nitnem is a collection of Sikh hymns to be read minimally 3 different times of the day. These are mandatory and to be read by every Amritdhari Sikh.
\textsuperscript{132} Punjabi Term for Prayers
\textsuperscript{133} The Ardās is a set prayer in Sikhism.
\textsuperscript{134} A sacred sweet offering in Sikhism.
\textsuperscript{135} A gurdwara is a place of assembly and worship for Sikhs.
you could also teach them mental health and therapy classes. It’s just well-being at the end of the day.”

**C7** [M, 42] stated that prior to the COVID-19 pandemic, discussions sessions covering health topics were in place at his local *Gurdwara*. **C7** encourages the *Gurdwara* to be a place for open discussion for people to discuss health matters. When thinking of his mother and sister-in-law who primarily deal with his brother’s illness, he said “some of these people, they need to have an open forum for people like my mom and my sister-in-law to go and share experiences, because it’s not something they talk with anyone, like some random Indian person. But if there was an environment where they go for an hour and its people in same boat as you, and you can learn and you can talk (...) you know it’s that sharing of best practice as they say.”

The importance of encouraging mental health education within the *Gurdwara* was made clear by the account told by **C9** [F, 47], whose son spent a lot of time, in the *Gurdwara* during the period his behaviour began deteriorating, including sleeping there.

**C9** stated that she had a close relationship to the head of this *Gurdwara*, “the Baba Ji there”, and they were “accommodating” to her son, allowing him to stay there because they too were “worried.” She went onto say, “they were thinking that staying at the temple was gonna give him sort of some peace of mind and sanctuary to be able to sort of work through his thoughts. But I think actually, the thinking overthinking and sleep deprivation just sort of broke him even more.”

When asked if anyone in the *Gurdwara* proposed that her son could be suffering from mental illness, **C9** responded, “Yes, one person did. And they said he needs medication as soon as possible, because if you don’t give him medication, it's gonna get worse (...) But, like I said, for us, for me, personally, medication was completely the last resort. But when he couldn't, because we waited so long it was there was no other option. I couldn't see any other option.”

Medication was also not advocated by the *Baba Ji* at this *Gurdwara*, “because they didn't initially, they didn’t want medication for him, they wanted to sort of fix him, you know, internally” through prayer and meditation.
This account demonstrates that the people within the Gurdwara currently are not well equipped with mental health knowledge, and thus appropriate help-seeking was evidently delayed in this instance.

5.7. Chapter Summary and Discussion

This study of family members experiences and views re-emphasises the lack of awareness and understanding the Punjabi, Sikh community hold towards mental illnesses. Thus, when an immediate family member displayed an altered behavioural presentation because of a psychotic illness, behaviours were initially dismissed by family members. Some participants described immediate family members holding an unreservedly dismissive attitude towards the persons changed behaviours, whilst others stated that the changes were attributed to other causes rather than a mental illness. Being dismissive, in denial, or ignorant to a presenting mental illness was also strongly cited in the layperson’s study.

Generally, it was at a point of crisis where behaviours such as paranoia, hallucinations, delusions, and aggression had intensified, that medical help was sought. The main pathways of care were contacting the GP or emergency services through 999. In most instances where medical help was sought at the peak of a psychotic episode, individuals were sectioned and hospitalised.

Family members spoke of the strong emotions they felt at the point of this breakdown. Common emotions and feelings being confused, frightened, and shocked. Such emotions such as confusion, reiterate the lack of awareness and understanding the family members held towards psychosis. A feeling of relief once a diagnosis and treatment was provided for their family member was expressed by some participants.

In line with the findings from the layperson’s study, lack of awareness and understanding of mental illness was conveyed by all participants, regardless of age, gender, and education status. However, participants did suggest that this would be greater amongst older generations. One example of a lack of mental health understanding, particularly amongst older generations, was the endorsement of supernatural beliefs (black magic, jadoo\textsuperscript{136}, evil

\textsuperscript{136} Magic / Sorcery
eye) that are said to be commonly held by the Asian community, with other research also supporting this (Bhika et al., 2015; Mirza et al., 2019; Carter et al., 2017; Knifton, 2012).

This sometimes lends to alternative help-seeking being sought with some participants recalling themselves or their family reaching out to faith healers and “babeh”\(^{137}\). In most of the accounts that described the use of these, they were either used in conjunction with professional help or sought prior to professional help when the person's symptoms were not at their worst. In other cases, it was not sought at all, despite other members of the family or community alluding to a supernatural cause behind the person's changed presentation. Nevertheless, professional medical help was always the primary method of care and treatment for the ill persons. This was in accordance with the findings from the layperson’s study, whereby even if supernatural or religious beliefs were endorsed as a cause for a person’s ill presentation, professional help-seeking eclipsed any form of alternative help-seeking.

Additionally, all participants acknowledged that social factors are more likely the cause of a psychotic illness, which is harmonious with the layperson’s study. Genetics was also discussed as a cause, as some participants spoke of the hereditary nature of mental illness existing within their family.

Another generational difference was the total lack of awareness and/or understanding of the term schizophrenia and psychosis, which was also presented in the laypeople study. Many participants spoke of their parents who would be first-generation migrants from India, not knowing these terms. This is because there is no literal translation in Punjabi for these western mental illnesses.

This lends to another sub-theme, whereby the official diagnostic term given to the person would often not be used within family discussions or within the wider community. The reason for this was two-fold. Firstly, there is no Punjabi term for such illnesses. Thus, participants said their families would describe the illness as "stress," "pressure," "tension," "not well." This is associated to existing research, which has found Punjabi women to prefer

\(^{137}\) A term used for an alternative healer.
statements such as “weight on my heart/mind” or “pressure in the mind” to describe a low mood state (Bhugra et al., 1997).

In two cases, participants spoke of their family member's illness also being termed "depression." For one participant, this was because depression was considered the more accepted term by the community. This was a prominent finding in the layperson’s study, whereby, the community referred to any mental illness as depression. This also connects to research which has found Sikh individuals considered the definition of mental illness as “depressive symptoms” and/or “stress” (British Sikh Report, 2018; Simich et al., 2009).

Another reason for the diagnostic term to not be said amongst the family and community was for the negative attitudes and beliefs surrounding mental illness. Mental illness is considered a "taboo," with stigma, shame and embarrassment attached to it. Disclosing a mental illness lends to a fear of judgement of gossip and can impact a family’s "honour" and "social capital." This is in line with current literature on South Asians (Time to Change, 2010; Bradby et al., 2007; Lawrence et al., 2006a). Therefore, many participants stated that the person's illness was kept within the immediate family and/or shared only with a few trusted family members. These were all prevalent themes that existed in the layperson’s study.

Not only is mental illness seldomly shared to the family's wider network but it is also scarcely discussed within the immediate family unit. This is not specific to psychosis, but any mental health issue or discussions around feelings and emotions are to a minimal. This limited discussion is for numerous reasons which were explained in detailed extracts from the layperson’s study, including the lack of understanding and negative perceptions around mental illness.

When reviewing the professional care received, some negative experiences and limitations of the care were discussed. Many spoke on the emphasis professionals have on medicating the ill individual. Talking therapies were not provided to any of the participants, despite participants recognising the benefits it could have had for their family member. This is in line with the layperson’s study, whereby talking therapy was advocated as beneficial and preferred in the treatment of mental illnesses.
Whilst some spoke positively of the care received, professionals seemed to not provide much information about the condition and the best ways the family could support the ill individual. This was suggested as an improvement. Having this literature available in Punjabi was also encouraged. Several other improvements for professional care were also put forward which were in line with the existing literature. This included having translators at appointments if needed (Chew-Graham et al., 2002; Chui et al., 2005; Greenwood et al., 2000); having more consideration and understanding of a person’s religious faith (Bhui, Chandran, & Sathyamoorthy, 2002; Greenwood et al. 2001; Lai & Surood, 2013); and assigning doctors of the same culture-faith (Bhui, Chandran, & Sathyamoorthy, 2002).

The experience of having a family member with a psychotic illness was seen to have a positive impact on the participants personally, as well as the family unit. Many participants educated themselves on the illness, allowing them to provide better support for their unwell family member and become more attentive to their triggers. Other participants stated that the experience improved family dynamics.

The Sikh faith was also deemed as beneficial in helping families through this experience, regardless of whether they were a practising or non-practising Sikh. Whilst the layperson’s study revealed that the Gurdwara is an ineffectual place to currently seek mental health support, many participants from this study spoke that raising awareness in a Gurdwara setting would be valuable.
6. Service User Lived Experience of Psychosis

This chapter presents the findings from the service user study, of whom have experienced a psychotic illness. Using the principles of thematic analysis, five main themes and six sub-themes were identified (See Table 9). A brief case study of each service user is first presented, followed by the themes derived from the analysis. The chapter concludes with a summary of findings.

6.1. Case Studies

Service User 1 (SU1)
SU1 was a 40-year-old male who has experienced two psychotic episodes. His symptom presentation consisted of auditory hallucinations and paranoia for approximately one month prior to GP help being sought, which was encouraged by his spouse. He expressed prior to his diagnosis, having no awareness of psychosis. SU1 attributed the illness to stress and believed excessive alcohol consumption exacerbated the onset of his illness.

Service User 2 (SU2)
SU2 was a 39-year-old male who experienced his first manic episode at the age of 24-years. Early symptom presentation including thoughts of religious grandeur, which he experienced for a long time before help was sought. His pathway to care was through police involvement at the point of crisis, which led to being sectioned and hospitalised, and received a diagnosis of affective bipolar disorder. SU2 attributed his illness onset to stress relating to family problems and employment workload.

Service User 3 (SU3)
SU3 was a 22-year-old male, who was diagnosed with non-organic psychosis, one-year prior to the interview. His symptom presentation began as over-working, eating and sleeping less, and withdrawal, which led to paranoia. These symptoms occurred over a two-week period before professional help was sought, and SU3 was sectioned and hospitalised. SU3 attributed his illness the stress of not finding relevant employment after he graduated University.
Service User 4 (SU4)

SU4 was a 34-year-old male who described his condition as psychosis and experienced his first episode 6-months prior to the interview. His symptom presentation consisted of having visual hallucinations which were religious in nature. He was unaware of his pathway to help-seeking, but stated his family were involved in him seeking treatment. SU4 did not wish to state what he believed to have caused his illness.

Table 9

Overview of Main Themes and Sub-Themes from Service User Study Analysis

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6.2. The Importance of Family in Help-Seeking and Support

6.2.1. Family Involvement in Help-Seeking

All participants had professional help sought at the point where hallucinations and/or delusions were presenting. In these cases, family members were integral in facilitating help-seeking on behalf of the service user.

In two instances (SU2 and SU3), it was at the peak of a manic/psychotic break that help was sought, with family members needing to intervene and contact professionals. In both instances there was police involvement which led to the individual being sectioned under the Mental Health Act.

SU2 stated he was exhibiting aggressive behaviours within his household, which led to the involvement of the police which was recommended by his mother, “the police came around, and they took me into the police station, and they gave me a once-over with the nurse and the psychologist.” His family, of whom he does not live with, collected him and brought him back to their home when he experienced the peak of his manic episode through aggressive and “argumentative” behaviour with his family members. This prompted them to contact the police again. He stated that the “police knew I wasn’t right,” which led to a doctor referral, and the participant to subsequently be sectioned, hospitalised and receiving a diagnosis of affective bipolar disorder.

Family was also crucial in seeking help for SU3 as he experienced the peak of a psychotic episode. The events leading to SU3’s psychotic break included feeling stressed due to overworking and failing a job interview. His emotions and behaviours following this included being “really upset”, “wasn’t really speaking to anyone,” “arguing with my family a lot.” He stated that his family noticed that he was different, but initially thought his changed presentation was a result of the stress he was experiencing at this time and not doing well in his job interview.

These behaviours intensified to paranoia, thinking extended family members were following him and trying to get into his house, which SU3 expressed to his family. This led them to “trying to ring up support” through doctors and ambulance services due to his mental state.
In the initial interview conducted with SU3, his recollection of events was as follows: he stated that after his family told him the ambulance were coming, he experienced a seizure which led him to be hospitalised. After a medical examination he was referred to the psychiatric ward. SU3 said that when he initially woke up in the hospital, he was “confused,” and rang his family to ask what had happened. They told him he “wasn’t well,” and following this he received a diagnosis of psychosis by doctors during his six-week inpatient stay.

SU3 got in touch after this interview because he said he remembered more events and wanted to discuss them; this included an altered version of help-seeking events. He recalled the seizure happened whilst he was hospitalised, not before. It was when he was experiencing “delusions” at home, his father contacted the ambulance, but they were not able to help, stating they need to contact the GP instead. Additionally, SU3 stated that his father wanted to involve another family member “to help out in this situation,” but his mother refused and said, “no we don’t need to do that, we can just ring up ambulance or pray.” The following morning his family contacted the “local mental health team” because his presentation was “quite bad (...) I was trying to leave the house,” which led to referral of the assessment centre “to be assessed for mental health” and he was sectioned under the Mental Health Act.

Neither of SU3’s help-seeking accounts corroborate entirely with his sister’s account who was also interviewed as part of the family member study (C6). Thus, SU3’s recall of events at the point of his psychotic break is distorted, and this is supported by his sister stating that “He still doesn't remember all of it, like he really wants to know what happened and we are, we don't hesitate to tell him but urm it really upsets him.” Additionally, SU3 is aware at the time he wasn’t “entirely aware of what was happening.”

In a similar manner, SU4 acknowledged that he does not have a clear recollection of how professional help was sought during his psychotic episode. He believed there to be nothing wrong with him, and instead he “personally felt like I was in the connection with God.” It was his wife and his brother who sought professional help on his behalf as they thought he was not “mentally right (...) especially my brother thought that” and they “got scared. Especially my wife.” SU4 thinks “they might have rung a mental health team,” as first point of help.
In another case, family encouraged help-seeking via a GP. SU1 stated that for one month prior to seeking help from their doctor, he was hearing voices that were "just saying stuff like, bad things." After confiding in his wife about what he was experiencing, professional help was sought, “I told my wife and everything (...) She sort of helped me go to the doctors (...) I was going crazy at the time (...) I was like getting paranoid and stuff like that.”

6.2.2. Lack of Awareness of Psychosis

Family intervention at the point of crisis was due to families exhibiting no prior knowledge and awareness of a psychotic illness.

For example, SU2 stated that prior to receiving his diagnosis of bipolar, his family had no awareness of this illness, “Nah, they were, they were very, they didn’t have much of a clue what bipolar was, or mental health, but they've really learned a lot over the journey now.” At the point where he was presenting aggressive behaviours during his manic episode, he described his family just thinking he was “under a lot of stress from not talking to the family, getting married and having a baby as well.”

Similarly, SU3 spoke of his family attributing his changed behavioural presentation to the stress he was experiencing in finding a job post-graduation. It was as his behaviour intensified with delusions, of which he expressed to his family, that they began suspecting it was something mental-health related. SU3 mentioned that he thought he might be experiencing the early signs of depression. Likewise, his sister (C6) also thought he may be depressed as it was something he experienced two-years prior which he sought help for.

SU3 stated that his father is from England and is a teacher, whilst his mother is from India and does not speak English. Whilst his father had slightly more understanding of what psychosis was post-diagnosis, with there being no translation of psychosis in the Punjabi language, the illness had to be explained by his sister to his mother in some form. SU3 was not sure how the illness was explained to his mother, but from the interview with C6, she described it as being “stress related, you know, all these bad thoughts have brought on this pressure on his brain and caused him to act this way.”
Regarding mental illnesses generally, SU3 stated he thinks his mother knows what mental illness is, “but words in Punjabi get loosely thrown about (...) which might explain mental illness, but are never really taken seriously (...) like when you say someone is paagal\textsuperscript{138}.”

SU3 also stated that his grandparents in India were informed of his illness, but he does not think they would have known what psychosis was, “especially when they are India it is a bit more difficult to communicate.” Instead, they might have thought he had depression, “because obviously I was upset in those days as well.”

Comparably, SU4 stated that his family had limited understanding of what psychosis was post-diagnosis, particularly his parents who are based in India. He said he thinks his family don’t “really understand what it is (...) they are trying to be as supportive as they can be, erm but I don’t think they really understand, and I don’t think it’s helped by the fact that my parents are in India, and they don’t understand it.”

All participants expressed that they were also were unaware of the illness they were diagnosed with. For example, SU1 stated after hearing voices for a month, he knew he needed to seek medical help, “I knew I needed medication,” and he “just knew I weren’t well.” However, he was uncertain of the nature of the problem he was experiencing. SU1 stated he had not heard of the term psychosis prior to his diagnosis, nor had he seen psychosis within television or other media.

\textit{6.2.3. Supportive Family Post-Diagnosis}

All participants expressed that their family had been supportive since their illness was diagnosed. For example, SU1 particularly highlighted the support of his wife through this period, and that his general “family lot are supportive.”

SU3 also described his family as being “supportive” during his hospitalisation, by visiting him every day. After being released from hospital, he said he spent a lot more time with his family, and regarding his recovery, “I think family has helped quite a bit,” and they

\textsuperscript{138} Punjabi Term for Crazy/Mad
encourage him to open up and talk to them about what he is feeling and to “share what is happening.”

Several of SU3’s family members were made aware of the illness post-diagnosis but never openly discussed it with him. Instead, there focus was on acknowledging that he was “upset” and talking about “more happy things (...) things I enjoy.” He said that not talking about the incident is “understandable” because his family may have thought it would distress him.

Being understanding aware of the individual’s triggers was also noted by SU3, as well as SU4, “they are just being mindful of what to say to me and what not to say to me I guess.”

Family supportive was particularly emphasised by SU2, who said he received a lot of positive support and care from his family post-diagnosis. This includes his parents adopting a “very open minded” attitude and taking the time to learn and understand bipolar, “they've been very supportive. very caring, very loving (...) they didn’t have much of a clue what bipolar was, or mental health, but they've really learned a lot over the journey now.”

In comparison to the other accounts whereby the individual’s diagnosis was kept limited to the immediate family (see Section 6.3), SU2 spoke of how many of his friends and family are aware of his illness and they all have been “very supportive,” with many of his family members visiting him after he was sectioned. SU2 said that he “was given so much love,” which made him feel “like being a young boy again.”

6.3. Limited Disclosure of Diagnosis to Others Due to Stigma

Those informed of the service user’s illness was largely limited to immediate family members (spouse, parents and siblings), and in some instances selected few extended family members. This decision was generally made by the service user and was associated to the stigma attached to mental illness.

SU1 expressed that “not many people know” about his illness, and that it has been “kept in-house.” Whilst some extended family have been made aware of his diagnosis, he has not informed any of his friends, “Friends – I am staying away from them until I am better (...) I haven’t shared this with my friends with, the more I am keeping to myself, the more quicker I
will get better. The more I explain it to everybody, people just feel sorry for you and make you feel down. Or it could go the other way and try to ruin your life.”

SU1 went onto state that his main concern around revealing his diagnosis to friends and wider family was because “people look at you different.” Despite this, SU1 said that he has not experienced this from those who have been made aware of his illness, and he has been treated “quite nice”.

Likewise, SU4 stated that other than his immediate family, he only shared his illness with one of his best friends. He credited this to stigma, stating that, “in Asian families it’s definitely, it’s probably not, very well, erm very well received if someone has got a mental health issue, I don’t think they would really understand.”

SU4 also spoke of stigma being a concern when accessing mental health services, “there is a stigma around mental health, mental health treatments and er if you are getting treated by mental health, I think people think that you are a nutcase.”

In another case, SU3 stated that he chose for his family not to disclose his illness to the rest of the family and his friends. When he was initially hospitalised, family members visiting his home were told he was at work by his mother. After weeks passed, the family went onto say that SU3 was in hospital for a chest infection. Eventually, some members of his mother’s paternal family were made aware of his actual diagnosis after approximately six-weeks of him still being in the hospital. SU3 states that although he is aware some family members know, “they have never had an open discussion with me about it... as of yet.” He also stated due to the COVID-19 lockdown, the opportunity had not arisen to have that sit-down open discussion with other family about his illness.

Regarding his friends, SU3 said that many of his friends attempted to contact him whilst he was in hospital as they were “worried,” but he would ignore their calls. One-week prior to the research interview, which would be one-year since his diagnosis, SU3 had informed two of his friends of his illness. Their reaction was understanding, but he found it difficult not being able to see his friends after disclosing his illness, due to the pandemic lockdown.
Non-disclosure of SU3’s diagnosis was again attributed to stigma, with him particularly emphasising the stigma of mental illness amongst Punjabi men, “Men in Punjabi culture are seen as sheer, like lion” and cultural expectations, “especially for men, it does not allow for mental ill health (...) The whole concept of being a lion is quite important, being strong, being able to fight these kinds of things.”

Contrastingly, SU2 said he felt “fine” about revealing his diagnosis to his family and friends “because I’ve got a lot of love and support from my family.” SU2 also stated that with mental illness being more openly spoken about on the television, “it’s made people open up towards mental health disorders.” The openness to mental health that is becoming widespread across society has made SU2 feel less stereotyped than when he was initially diagnosed over ten-years prior, “I first was a bit stereotyped as like being mental and whatever.”

6.4. Experiences of Professional Care

Several participants expressed a positive experience with accessing professional care and receiving treatment from mental health services. For example, SU2 expressed that mental health services have provided him “a lot of support”, with an assigned community psychiatric nurse (CPN), doctor, and psychologist, and medication plan that has allowed him to become stable and no longer hear voices.

A similar experience of a “really supportive” mental health team and successful medication plan, “my medication has helped, significantly,” which has allowed the participant to feel “stable” was also described by SU3. SU3 also has sought support post-diagnosis through other avenues, such as his university disability advisory service, where he has been assigned a mentor who offers support regarding his academic studies.

Participants also expressed that the services they accessed catered to the Sikh religion. For example, SU2 stated that there was a Gyani139 present when he initially entered services at the time of sectioning and hospitalisation, “there was a Gyani that was there. And I had a chat with him. And that was quite good.” Similarly, SU3 said due to his mother only speaking Punjabi, an interpreter was offered.

139 An honorific Sikh title used by someone learned in the Sikh religion.
In another example, SU1 expressed his comfortability with seeking professional help and having experienced a psychotic episode twice, both times the services have been “good.”

6.4.1. Improvements to Care

When probed, participants proposed some improvements for mental health services, particularly targeting faith and cultural aspects of care. For example, SU1 stated that health professionals should be taught more about the Sikh religion, “because people are falsely told that the religion is er messing with your mind. Where your just mind is gone unstable and er needs medication to balance itself out.”

Additionally, SU3 recommended that Punjabi versions of leaflets should be provided, which would be particularly useful for someone like his mother who is unable to speak English and has a considerable lack of awareness of different mental illnesses.

SU4 also expressed his preference of a care co-ordinator being of the same heritage, “if there was a choice given, if they can, because I think I was only given [name of care co-ordinator], but [name of care co-ordinator] is really good, but doesn’t understand Sikh heritage, Sikh background. If there was a choice, I would have probably chosen a Sikh, a Sikh carer. Male or female probably wouldn’t have mattered, but as long as they understood where I was coming from.”

SU4 was also the only participant who described his experience as “okay, but it could be a lot better” in comparison to the more positive attitudes held by the other three service users. In particularly, he described services as being “far too stretched,” related this to his request for a psychologist 9-10 weeks prior but had not heard anything further on the matter since.

Moreover, despite SU2 expressing, “the system has been good” to him and that he “can’t really fault the system,” SU2 did acknowledge that the quality of services varies across the country, “my friend told me, he’s closer to the one in York, and it was really bad. He had bipolar as well.”
6.5. Impact of Illness on Service Users’ Life

Many participants spoke of how this experience and living with their diagnosis has had a positive impact on their life.

For example, SU2 expressed that his lifestyle has improved post-diagnosis. Having battled addiction issues with gambling and drugs, SU2 is now celebrating fourteen months of sobriety, and attending rehab for these issues. This had a constructive impact on his wellbeing as well as increased his faith in God. He described his mental health to have got a “a lot better over time (...) I’ve been through a long journey, and I’ve come out better on the other side.”

Whilst SU2’s illness caused the participant to temporarily lose his driving license which he described as, “I lost a bit of freedom without driving the car,” SU2 looked to the positive side of this, “I walk more now, which is good, it’s good for the mental health. But I try to keep positive I'm trying to keep focus.” SU2’s positive approach to his diagnosis was associated with his “very supportive family.”

Similarly, SU3 said that one-year on from his diagnosis he is “more happier,” and says the experience has “made me a stronger person.” When comparing himself to the person he was prior to his episode, he describes himself as “not doing much, in retail, didn’t have a proper job... felt low all the time,” but now he has returned to academic studies through the encouragement of his father and feels he has a “motivation to live (...) motivation to do stuff (...) so it's all looking up now.” Reflecting on his journey, SU3 optimistically said, “when you look back to see how far you have come from a year ago, it’s quite reassuring that recovery is really possible.”

Furthermore, SU3 has also stated that he is now more open to discuss his illness with his wider family, “Now that it has been a year since it happened, I will be able to be more open about it.”

Both SU2 and SU3 also said that they engage in non-medical forms of coping which improves their mental wellbeing. For example, SU2 stated that post-diagnosis he stays active, does breathing exercises and takes multi-vitamins. Additionally, SU3 said that four factors
are pivotal to his mental wellbeing: exercise, music, diet, and environment. Particularly, SU3 said that playing football matches with his friends is not only beneficial for the fitness aspect, but for the social facet as well.

Only one participant spoke of the negative impact this illness has had on both his home and work life. SU4 stated that his wife no longer lives with him, which is partially a result of his illness. Additionally, he has not been able to return to work yet, after experiencing his episode six-months prior.

SU4 indicated that since his diagnosis, “I find myself a little bit depressed now but I never was depressed before (...) So I find myself on a low mood, in the low mood quite a bit (...) I used to be more upbeat, I used to have targets, I used to have things to do, and I used to be enthusiastic about stuff like that, but now I don’t care.” When asked if there has been anything that has helped the participant through this period of their life, SU4 responded, “Nothing so far,” as well as not knowing what could help them.

6.6. The Role of Religion

Religion was touched upon in two modes by participants, either through the practice of religion after being diagnosed, or the presentation of religious hallucinations and/or delusions prior to diagnosis.

6.6.1. Religious Delusions

Two participants (SU2 and SU4) experienced religious delusions as part of their illness presentation.

In the case of SU4, prior to help being sought, he thought he “was in connection with God,” rather than recognising he was experiencing a deteriorated mental state. The basis of his delusions included “seeing pictures in my head whilst I was having a break, erm of er wartime, like Guru Sahib had fought (...) I saw my baba fighting a war er whilst I was awake.” Due to the religious nature of his delusions, he became “quite religious at the time,” stating that he would meditate at home “pretty much 24/7, 24 hours I was awake. With various 10/15 hours, 10/15 minutes small breaks.”
Similarly, SU2 said he began learning a lot about Sikhism through a friend who was “very religious” prior to his manic episode. Leading up to the episode, he “started to go to the Sikh temple very early in the morning,” as well as “reading a lot of Bani,\textsuperscript{140}” “doing a lot of chanting,” and taking “cold showers.”

SU2 said that “everything started to have this greater purpose, greater meaning in life,” and that he was “having thoughts of religious grandeur” and “I thought I was becoming a saint (...) I thought I was becoming enlightened (...) I used to go to the temple, and I thought the gurus were there.” These thoughts persisted until he “spiralled out of control.”

The “very spiritual” nature of SU2’s presentation and his newly formed close friendship with his religious friend led to his family to think that his behaviour might be a result of his friend “manipulating him (...) they thought I was joining a cult.” This is supported by his mother’s account who was also interviewed as part of the family member study (C4).

\textbf{6.6.2. Religious Support}

Following on from the above, religion “has helped a lot really” for SU2. Specific religious practices include listening to Naam Simran\textsuperscript{141} as he goes to sleep and listening to Bani “now and then.” SU2 has also been to addictions rehab post-diagnosis and stated that “the belief in God in rehab is a lot (...) they talk about God a lot,” which is a further reason for his strong faith.

The role of religion was not specific to the SU2’s Sikh faith, stating that religion has helped even through turning to his wife’s faith in Buddhism, “It’s helped, it’s helped (...) my wife is Buddhist, so I go to the Buddhist church, the Buddhist temple as well.”

In contrast, despite SU4 also experiencing religious delusions as part of his illness presentation, he stated that he has disengaged from religious practices post-diagnosis, because he “just don’t feel like it anymore.”

\begin{footnotes}
\item[140] Short for Gurbani – which is various compositions by the Sikh Gurus
\item[141] Meditation or contemplation of the various Names of God
\end{footnotes}
Religion played an important role in SU3’s recovery process. During his time at the hospital, he thought his illness might have been a result of karma, “at the time I was thinking this is for any bad things I’ve done, this is a punishment.” When he returned home, he researched around Sikhism and mental health post-diagnosis, and found helpful quotes such as “Naam is the medicine for all diseases (...) so like taking God’s name regularly, all the time, every day, helps a lot.”

Another quote from Gurbani, he found, “Conquer your own mind, and conquer the world,” which the participant said, “if you think about that every day (...) I think that’s really true in my case, because moving a year on, I started uni again, I am studying, and generally getting on with hardships of life.”

Combining medication and religion was useful for SU3, “when you start believing in God again, alongside taking medication, all difficulties are gone I’d say.” He spoke of a side effect of his medication included having vivid dreams, and through listening to “Gurbani” before bed, which he considers a “mindfulness technique”, it aids him falling asleep.

SU3 also found Sikh social media based organisations which target mental health and wellbeing helpful and “supportive.”

Family members recommending seeking support from religious sources was noted in two cases. For example, SU1 said his family encouraged him to seek help from religious bases, “people telling me to go to er to a Guru. But erm, I did go and get prashad the first time.” He did this simultaneously as receiving professional treatment. However, SU1 said they were “not bothered” to seek out religious help for their last relapse, “this time I just took the medication.”

Moreover, SU3 stated that post-diagnosis, “the first thing my mum did want to do is go to the Gurdwara and pray,” and that she “just thanks God for getting us through this period... of psychosis.” He also said that his grandparents in India when made aware of the illness said to “just pray (...) and keep in good spirits.”

142 Various compositions by the Sikh Gurus.
143 A sacred sweet offering in Sikhism.
6.7. Chapter Summary and Discussion

The themes that have derived from this analysis are harmonious with what has been found in the previous two chapters on laypersons and family members. This includes help-seeking not being sought until the point of crisis, largely due to an individual-and-family-level lack of awareness and knowledge of psychotic illnesses, as well as general mental illness. This supports research which has shown BAME groups are more likely to be compulsory admitted to psychiatric hospitals (Barnett et al., 2019), with one explanation for this being due to inadequate awareness of psychotic illness (Singh et al., 2007).

A key finding from this analysis was the importance immediate family members play in the role of help-seeking for the individual. As discussed in the literature review, family is very important to Sikhs, with many living as part of an extended family within the household. Due to the illness often progressing to a full psychotic and/or manic episode, family members were required to intervene as the individual did not have the mental capacity at this stage to recognise there is a problem. This echoes research by Judge et al. (2005), who indicated the significant role family play in identifying behavioural changes in an individual with psychosis prior to seeking help.

Help-seeking routes family members sought were primarily through medical professionals and varied from GP to emergency services. This is in line with the family member study, whereby these two routes were the leading pathways to care.

Immediate family members were described as very supportive post-diagnosis, which was considered pivotal for the recovery of the service user. This reinforces research which has highlighted the family to be significant source of support for Sikhs experiencing psychological distress (Ruprai, 2016).

Akin to the laypeople and family member study, the disclosure of a mental illness diagnosis was kept limited to other family members and friends. This was due to the stigma that is attached to mental illness, particularly within the Punjabi community (Knifton et al., 2010; Knifton, 2012; Bradby et al., 2007; Time to Change, 2010; Ruprai, 2016; Gilbert et al., 2011).
Most participants described the positive experience of care they have received from mental health services. This contrasts from the family member study, whereby numerous weaknesses of professional care were outlined.

The impact the illness has had on an individual’s life varied, with most describing a more positive outlook on life.

Religion was deemed helpful in the recovery of some service user’s illness. Particularly, listening to Gurbani¹⁴⁴ before sleep. This supports the religious coping mechanisms suggested in the layperson study, whereby participants endorsed listening to prayers for an individual experiencing psychosis. Religion also played an involvement in the nature of delusions experienced by two participants.

¹⁴⁴ Various compositions by the Sikh Gurus.
7. Discussion

This chapter provides a summary of the research aims and objectives and the key findings across all three studies. This will be followed by a discussion of the findings against existing literature, a consideration of the strengths and limitations, and recommendations for future research.

7.1. Summary of Research

The purpose of this study was to explore the perceptions and understandings of psychotic disorders and associated help-seeking amongst adult Sikhs in England, and how family, religious and cultural belief and practice, and lived experience of psychotic disorders, influence these.

With an exploratory qualitative design, utilising a critical realist approach, in-depth semi structured interviews were conducted with service users with psychosis, family members with lived experience of psychosis, and a lay sample of adult Sikhs. The forty-three interviews conducted were audio-recorded, transcribed, and analysed through reflexive thematic analysis. This approach was an applicable method for this study; it permitted for the Punjabi Sikh community’s understandings and experiences to be considered and allowed for comparison between participant groups to be made. Extracts of the interviews within the analysis have also presented a richer insight of the themes displayed in this study.

7.2. Comparison of Findings with Literature

There are five core themes that prevailed across all participant groups:

1. Limited Awareness, Knowledge & Understanding Of Psychosis
2. Negative Perceptions Around Psychosis And General Mental Illness
3. Professional Help-Seeking Is Encouraged
4. The Importance Of Family In Help-Seeking
5. The Punjabi Culture Vs. The Sikh Religion

These themes will be discussed in relation to the existing literature.
7.2.1. Limited Awareness, Knowledge & Understanding of Psychosis

Across the participant groups, it was evident that there was a lack of awareness and knowledge of psychosis. This finding was true across genders and age ranges.

In the case of the laypeople study, those that had studied or worked in areas such as Psychology or mental health or had a family member or friend experience the illness expressed a slightly increased familiarity with psychosis. However, no participant voiced confidence in holding a good understanding of the illness apart from some specifying the key symptoms such as hallucinations, ‘hearing voices’, and delusions.

Schizophrenia was more widely recognised as a term than psychosis for lay participants. However, a comparable limited amount of knowledge was held towards the illness. Lay participants proposed that their family and/or wider Sikh community’s awareness and knowledge of psychosis and schizophrenia would be more limited than their own. This was attributed to numerous factors, including there being no education around mental illness in previous generations. Thus, if an individual was to exhibit behaviours of a mental illness, they would be perceived negatively. This is further discussed in Section 7.2.2.

Furthermore, many lay participants spoke of their family and/or wider community not perceiving mental illness as a medical illness, due to not being able to see a physical decline as you would with a physical illness. This is in line with previous studies whereby Sikhs did not consider depression as an illness (Knifton, 2012; Burrs & Chapman, 2004; Greenwood et al., 2000; Lawrence et al., 2006b).

This lack of awareness of psychosis was made evident also by lived experience groups, where in most instances, help-seeking for psychosis was sought at the point of crisis due to the family members stating they had not heard of the term psychosis prior to diagnosis.

Previous literature has found that understandings and beliefs regarding mental illness significantly impact help-seeking and mental health service use (Kleinman, 1978; Helman, 1994). Particularly, studies have found a key barrier to care for South Asians with psychosis being the individuals (Etheridge et al., 2004) and their families (Judge et al., 2005) inability to acknowledge the illness as a psychotic disorder and their lack of awareness of where to
seek help (Etheridge et al., 2004). Many family members discussed taking the time to improve their education of psychosis post-diagnosis through researching the illness.

From the service user perspective, all participants stated that they had not heard of psychosis prior to their diagnosis. They also stated that their immediate family members had no awareness of psychosis. Thus, family members attributed the service user’s initial behavioural changes to being under stress rather than them experiencing a mental illness.

Particularly in the lay study, participants proposed that those of an older generation were highly unlikely to be familiar with the term psychosis and understand what the illness was. This is in line with Taak, Brown & Perski (2021) who reported generational differences in the lack of education and awareness of mental health issues for Sikhs, which then influences the help-seeking behaviours amongst the generations. This is also supported from the family member and service user study, whereby participants stated that to parents or grandparents of whom are from India and/or have limited English speaking ability, they would not use the word psychosis to describe their illness. This is due to their being no translation of psychosis in the Punjabi language. This is discussed further in Section 7.2.1.2.

Regarding knowledge of services and treatments available for psychosis and general severe mental illnesses, lay participants held limited knowledge. This included some participants that studied and/or worked in the area of mental illness. This is like Ruprai (2016) who found Sikhs to have inadequate knowledge of mental health treatment and services, including several participants who had accessed services.

Lay participants understood psychosis required medication but highly recommended talking therapy. Similarly, family members discussed that medication was the sole treatment for the service user, however wanted them to receive talking therapy. Many participants across groups spoke of the benefits of therapy and/or having personal experience with therapy. This contrasts with prior research which found Sikhs to be unaware of the existence of talking therapies (Ruprai, 2016). Moller, Burgess & Jogiyat (2016) also found Sikhs to perceive seeking therapy as abnormal, shameful, and stigmatising to the family. An explanation for this disparity in these findings is discussed in the following section (7.2.1.1.).
7.2.1.1. Increased Awareness of Depression

There did exist an increased awareness and education around common mental illnesses, particularly depression. This was made evident by members of the lay sample who explicitly stated they held more awareness of depression over severer forms of mental illness. Furthermore, when lay participants were presented with the case vignette of psychosis, all participants proposed it could be depression, with a small few mentioning psychosis or schizophrenia. Similarly, when presented with the early signs of psychosis, many lay participants said they would not perceive these symptoms as indicative of a psychotic episode, but rather depression.

Similarly, family members with lived experience of psychosis expressed that they attributed the initial behavioural changes of the service user to either be stress or depression. Thus, it reached the point of crisis where they sought emergency medical help.

This increased awareness and knowledge of depression contrasts with previous literature whereby low levels of literacy of depression have been found. For example, several studies found Sikh participants to not consider depression as an illness (Knifton, 2012; Burrs & Chapman, 2004; Greenwood et al., 2000; Lawrence et al., 2006b). Furthermore, when presented with a case vignette of depression, Taylor, Brown & Weinman (2013) found participants expressed little understanding of the character’s difficulties.

The difference in findings between the current research and previous could be attributed to all these studies, excluding Ruprai (2016) and Moller, Burgess & Jogiyat (2016), having been conducted over a decade ago, when mental illness was less openly addressed. This can be supported by participants who spoke of mental health awareness now being raised across many different platforms, including school and university talks, social media, and television, including News channels. Furthermore, many people are opening up about their own mental health struggles and holding mental health conversations, but this tends to be more focused on depression and anxiety disorders. Thus, this could account for the increased familiarity with common mental illnesses.

Furthermore, there now exists Punjabi, Sikh and South Asian specific charities and organisations which are targeting mental health. Most of whom have been founded within the
last decade, including SOCH\textsuperscript{145} (2015), Sikh Your Mind\textsuperscript{146} (2015), Taraki\textsuperscript{147} (2017), and Sikh Forgiveness\textsuperscript{148} (2018). It could also be argued that whilst Ruprai’s and Moller, Burgess & Jogiyat’s work was published in 2016, it would have been conducted possibly a year or more prior to this, which would be before these Punjabi and Sikh based mental health charities were established. Thus, the participants account from these studies would still be at a time when mental illness is not as explicitly addressed within such communities.

Within the last decade there has also been significant mental health campaigns established by prominent members of the British society. This includes ‘Heads Together’\textsuperscript{149} which is led by the Duke and Duchess of Cambridge. Founded in 2016, this campaign inspires millions of people to have valuable conversations about mental health. ‘Heads Together’ have also partnered with the English Football Association to create the ‘Heads Up’\textsuperscript{150} campaign, which specifically targets the discussion around male mental health, and has been supported by many England football players.

Mental Health Awareness Week\textsuperscript{151} which takes place in May each year, although founded in 2001, has also gained popularity over recent years. It is the UK’s national week to raise awareness of mental health, introduced by the Mental Health Foundation\textsuperscript{152}. Each year it touches on a different theme within mental health, with many organisations and media platforms partaking in this week by hosting certain events or encouraging people to share their stories.

These important campaigns address general mental health, particularly depression and suicide. Thus, it is likely that the positive strives made by these campaigns to normalise mental health conversation for everyone can account for why the participants in the current study are more familiarised with depression.

\textsuperscript{145} https://www.sochmentalhealth.com/
\textsuperscript{146} https://sikhyourmind.com/
\textsuperscript{147} https://www.taraki.co.uk/
\textsuperscript{148} https://sikhforgiveness.com/
\textsuperscript{149} https://www.headstogether.org.uk/
\textsuperscript{150} https://www.headstogether.org.uk/heads-up/
\textsuperscript{151} https://www.mentalhealth.org.uk/campaigns/mental-health-awareness-week/
\textsuperscript{152} https://www.mentalhealth.org.uk/
Participants did state that discussions or content on severer forms of mental illness do not seem to exist within the Punjabi, Sikh community yet, and several lay participants who work closely within the community mentioned that psychosis has not been touched on yet.

7.2.1.2. Mental Health Terminology
The use of professional diagnostic terms for mental illnesses seemed to be limited across participant groups. For example, in the family member study it was reported that the diagnosis of the service user would rarely be said within the immediate family, wider family, and social circle. Some family members stated that the service users would just be described as ‘unwell’ or ‘depressed.’ They attributed not using the actual diagnosis either due to people’s lack of understanding of psychosis and/or the negative attitudes and beliefs towards mental illness.

Participants across all groups stated that they would unlikely use the term psychosis to someone of an older generation, as they would not know what it is. Two family members stated that to their parents or grandparents, who speak limited English, they would describe the illness as ‘tension’ or ‘pressure on her head’. This echoes early research by Bhugra et al. (1997), who found older Punjabi women would describe low mood state in terms such as ‘weight on my heart/mind’ or ‘pressure in the mind.’

Another study found that in place of depression or other psychiatric terms, South Asian women use terms which highlight worry and anxiety related to life situations, such as ‘tension’ or ‘tension rog’ (Karasz, 2005). A systematic review of ‘tension’ and distress in the South Asian population also found that ‘tension’ is commonly used as a verbal expression for many sub-groups of the South Asian community to talk about stress and distress (Weaver & Karasz, 2022). Many of the studies in this review noted similarities with the term ‘tension’ and psychiatric categories, with ‘tension’ symptoms being akin to the symptoms of common mental disorders.

The term ‘paagal’ was commonly mentioned across all participant groups. It is a Punjabi term used to describe someone who is mad or crazy. Many participants stated that if someone was to display psychotic behaviours or behaviours not considered ‘normal’, they would just

153 Punjabi to English Translation: “Tension Sickness”
be called ‘paagal,’ ‘mad’, or ‘mental’. Again, participants attributed this to the community’s lack of awareness of mental illnesses and there being no Punjabi translation for any specific mental illness. This term has negative connotations and is associated with the adverse perceptions that are held towards mental illnesses, which is discussed in Section 7.2.2.

A study on the experiences of Pakistani women in the UK who have been hospitalised for mental illness also found that the term ‘paagal’ is the only word used for someone with a mental illness, particularly those that have been hospitalised for it (Wheeler, 1998). ‘Paagal’ would be used regardless of whether the individual had depression or schizophrenia and the term is considered unidimensional and highly stigmatised.

Wheeler (1998) found that once a family member was branded with the term ‘paagal’ they were considered ‘always out of their mind’ and ‘total nutters’. This led to the individual being marginalised within the family and their identity negated. The current study did not report such a negative response by family members post-diagnosis of the service user. Instead, the immediate family members in the current study were supportive of their loved one, with encouragement to help them get back to some level of ‘normality’. This was also supported by the service user accounts. However, family members did state that the reason the diagnosis of their loved one was kept within the immediate family was due to the likelihood of wider family and community considering the individual ‘paagal’ and viewing them negatively. Furthermore, it is probable that the family members that took part in the current study are those that are more accepting and supportive of their loved ones psychotic illness. Thus, these accounts may not be representative of a portion of the Punjabi, Sikh community, of whom might hold similar feelings to those reported in Wheeler’s study.

In keeping with findings from the literature, there also appeared to be no distinction between mental illnesses. Particularly in the lay study, whilst questions were psychosis specific, in many instances participants digressed onto discussing illnesses such as depression or discussed mental illness as a singular illness. Participants agreed that this lack of distinction across mental illnesses is prominent across the Sikh community. This reinforces the need have more education on specific mental illnesses. However, as described with the use of the term ‘paagal’ for any mental illness, it could be that the community’s attitudes and beliefs would not differ regardless of the severity of the mental illness.
7.2.2. Negative Perceptions around Psychosis and General Mental Illness

Psychosis and general mental illness being viewed negatively by the Sikh community was voiced by all participants. Participants stated that the negative perceptions around mental illness are culturally driven and fuelled by the lack of mental health awareness and education the Sikh community has.

Typically, participants spoke of stigma and shame being attached to any mental illness, which is also supported by a large Sikh and South Asian evidence base (Knifton et al., 2010; Knifton, 2012; Bradby et al., 2007; Time to Change, 2010; Chew-Graham et al., 2002; Gale & Thalitaya, 2017; Chui et al., 2005; Lawrence et al., 2006a; Taak, Brown & Perski, 2021; Moller, Burgess & Jogiyyat, 2016; Islam et al., 2017; Ahmed et al, 2020; Ruprai, 2016; Gilbert et al., 2011).

This stigma then leads to participants stating that a revelation of a mental health diagnosis to the wider family, their friends, or social network would be unlikely, which is in tune with previous findings (Time to Change, 2010; Bradby et al., 2007; Lawrence et al., 2006a; Knifton, 2012; Ruprai, 2016; Gale & Thalitaya, 2017).

Several of the service users in the current study stated those informed of their illness is limited to immediate family members (spouse, parents and siblings), and in some instances selected few extended family members. This decision was generally made by the service user and was associated to the stigma attached to mental illness.

Family members also stated that they would not be comfortable revealing the diagnosis of their loved one, due to the negative attitudes attached to mental illness by the wider community. Participants reinforced the idea that mental illness is a taboo topic within the community, which results in feelings of shame and embarrassment for the family and fear of gossip and judgement.

Previous literature has also reported that a revelation of a mental illness would have a negative impact on the family’s honour and reputation (Time to Change, 2010; Bradby et al., 2007; Lawrence et al., 2006; Ruprai, 2016). This was mentioned by numerous participants in the current study, with a common phrase reiterated by participants being “what will people say?”.
A study by Wheeler (1998) found that in Pakistani women who were hospitalised for mental illness and had the label ‘paagal’ attached to them, led to the label being also attached to their children. Their children would be considered tainted, stigmatised, and their children’s in-laws would lack respect for their spouses family and the family. Similarly, Ruprai (2016) found that the reluctance to access mental health services for Punjabi, Sikhs was due to the impact it could have on marriage prospects.

Mental illness having a negative impact on a family’s honour and reputation is linked to the cultural concept of izzat. Izzat was a prominent term in previous literature, pertaining to a cultural value and belief that an individual’s personal shame reflects upon the wider family, and impacts that family’s izzat (Moller, Burgess & Jogiyat, 2016; Bradby et al., 2007). Izzat has been shown to influence an individual’s likelihood to seek help, with many giving superiority of their family’s izzat over the wellbeing of themselves, thus not getting the help they need (Chew-Graham et al, 2002). The concept of izzat was not mentioned by any participant in the current study, however words that could be considered synonymous with this term such as ‘shame’, ‘reputation’, and ‘honour’ were stated.

7.2.3. Professional Help-Seeking is Encouraged

Despite the negative perceptions around mental illness held by the Punjabi Sikh community and the lack of knowledge around mental illnesses and treatments and services, professional help-seeking was endorsed by all participants. Professional help-seeking gained superiority over any other form of help-seeking for psychosis, particularly at the later stage of symptom presentation.

Across all participants groups, contacting the GP was the most frequent help-seeking pathway recommended. For example, within the lay study, participants recommended seeking support from the GP when presented with the case vignette, early signs of psychosis document, and at the later stage of illness presentation. This is in line with a large-scale systematic review which found South Asians had significantly higher rates of GP involvement in the pathways to care for psychosis when compared with other ethnic groups (Halvorsud et al., 2018). Moreover, a qualitative study exploring British Pakistani experiences of seeking help for first-episode psychosis found the GP was the first port of call for many families (Penny et al., 2009).
Particularly, medical intervention was deemed critical during the later stage of illness presentation, whereby hallucinations and/or delusions were present. The professional medical interventions proposed by the lay sample at this later stage of illness differed between participants, but included: GP, mental health professionals, contacting 999 and visiting A&E. This is in line with the family member accounts, where at the point of crisis, the main help-seeking avenues contacted were the GP and emergency services such as ambulance service or police.

The encouragement of professional help-seeking for a mental illness contrasts with the existing literature, which posits that such help-seeking is viewed negatively and not actioned (Gilbert et al., 2011; Ruprai, 2016; Moller, Burgess & Jogiyat, 2016). Islam, Rabiee, & Singh (2015) reported that the fear of social stigma from members of the South Asian community is a significant barrier for them to not seek professional help for psychosis. Specifically for Sikhs, Ruprai (2016) reported that they would appear weak if they sought professional mental health support and it would be a betrayal to their family.

The disparity in findings regarding seeking professional help for mental illness could be explained two-fold. Firstly, many previous studies have explored mental illness broadly or focused on milder forms of mental illness such as psychological distress and depression. The symptoms that present in these illnesses may be considered less severe than a full psychotic episode. For example, when lay people were presented with the early signs of psychosis, whilst many participants did recommend possibly seeing a GP, they also contended that an individual could seek help in a plethora of non-medical ways, with one of the most cited being talking support to the person experiencing these symptoms. It was mainly when hallucinations and delusions presented that urgent medical intervention was proposed. Secondly, as previously mentioned in Section 7.2.1.1., mental health awareness has gained huge prominence over recent years, with seeking help for mental health being highly encouraged. Thus, the stigma that was once attached to accessing services could be reducing.

The previous literature surrounding the barriers of professional help-seeking for South Asians have also posited that current mental health services are not culturally appropriate (Bhui, Chandran, & Sathyamoorthy, 2002; Greenwood et al. 2001; Lai & Surood, 2013; Islam, Rabiee, & Singh, 2015). Factors such as culture and religion are not acknowledged by
clinicians and cultural incompatibility due to language barriers have been well cited (Bhui, Chandran, & Sathyamoorthy, 2002; Greenwood et al. 2000; Lai & Surood, 2013). However, the current research found mixed views from participants regarding this. All but one service user stated that they had positive experiences with the service they received, with services offering translators, as well as *Gyani’s*\(^{154}\) being present at services to speak to the service users.

Limitations of mental health services were generally posited by family members rather than service users. Some limitations of care included: clinicians providing a lack of information regarding what the person was experiencing when they accessed care; a focus on medication with no talking therapies offered; not having mental health literature in the Punjabi language; and not offering a culturally matched clinician.

The latter point has been well-documented in the literature, with Sikhs wanting to seek help from someone who shares the same religion or culture as themselves (Simich, Maiter & Ochocka, 2009; Bhui, Chandran, & Sathyamoorthy, 2002; British Sikh Report, 2019). Whilst this was a point put forward from some family members, it received mixed opinions from the other participant groups. For example, some lay participants stated that seeking help from someone of matched heritage can be beneficial as it can provide a feeling of trust and comfortability. Others stated they would prefer not to have a culturally matched clinician due to the fear of stigma and gossip. This is line with previous research which found participants voicing fears that if their clinician was South Asian, they may be linked with someone in their social network, which could lead to gossiping amongst the community (Chew-Graham et al., 2002; Moller, Burgess & Jogiyyat, 2016; Bradby et al., 2007). Thus, culturally matching clinician to service user could be considered on a case-by-case basis.

Furthermore, whilst professional help-seeking was strongly advocated, it was not uncommon for participants to state that their family would likely explore other help-seeking avenues that are related to their faith or culture. Particularly in the lay sample, participants stated that it is common for family to seek help from healers (which were often cited as “*baba*”) which could be of any South Asian faith. This decision was driven by cultural beliefs and encouraged by the older generations. These healers may do certain rituals, ask the individual and/or their

\(^{154}\) An honorific Sikh title used by someone learned in the Sikh religion
family to partake in a ritual, and/or provide some form of traditional medicine for the individual to take. These healers are primarily from India, and in some cases the family must travel to India to receive this healing.

Similarly, some family members stated that they have either engaged in such practices or have been advised by other members of their family to seek such help. This is harmonious with previous research which has shown the use of alternative healers in the treatment of mental illness for Sikhs and the wider South Asian population (Greenwood et al., 2000; Knifton, 2012; Sembhi & Dein, 1998, Dein & Sembhi, 2001; Hussain & Cochrane, 2003; Chui et al., 2005; Taylor, Brown & Weinman, 2013; Cinnirella & Loewenthal, 1999; Gilbert et al., 2011).

However, this form of help-seeking was often reported as being in conjunction with professional medical help-seeking, which is in line with the previous literature (Penny et al., 2009; Bhika, 2015; Dein & Sembhi, 2001). For example, Bhika (2015) found that regarding South Asians and psychosis, a favoured treatment option would be to visit a religious healer in addition to receiving medical treatment. Similarly, Dein & Sembhi (2001) reported that traditional healing was used in conjunction with psychiatric services in instances where people experienced mental illness.

Comparably, from a religious perspective, many participants in the current study endorsed the practice of meditating and either listening to or reciting prayers as a coping mechanism for those with psychosis and other mental illnesses, yet stated that this would not trump professional medical help-seeking. The combination of both religious coping strategies with medical care was considered the best treatment.

7.2.4. The Importance of Family in Help-Seeking

Punjabi Sikhs are known to have strong family networks and to be very close knit (Singh, 2009). This was evident in the current study. For the lay sample, all participants considered their family when addressing topics without being probed to do so. Particularly when considering help-seeking for psychosis and other mental illnesses, the attitudes, beliefs, and awareness of mental illness the family held would determine when someone seeks help and where they seek help from. This is in line with the family member and service user study,
whereby the family’s lack of awareness of psychosis led to the individual seeking help at the point of crisis.

Previous research has found that Punjabi Sikhs and/or South Asians seek help from within the family first. For example, Ruprai (2016) found that for Punjabi Sikhs, their first point of contact when needing support would be their family. They would also not seek help professionally for psychological problems. Instead, they could share their burdens with their family members as this was considered comparable to accessing psychological services. This study also found that the extended family would care for those with a mental health problem before seeking any professional care.

The findings from Ruprai’s (2016) research are both similar and dissimilar to the current research. One interpretation from Ruprai’s findings could suggest that the individual experiencing mental health struggles would come forward and openly discuss their struggles, which is not in line with this research. Whilst the family member and service user study detailed the family to be pivotal in seeking help for the service user, it was not because the service user had openly discussed what they were experiencing, but rather the illness had progressed to crisis point where urgent medical intervention was required. However, the family could theoretically be considered the first point of help-seeking in these instances and supportive in attempting to get the appropriate treatment for their loved one.

Furthermore, most of the lay sample specified that openly divulging their mental health struggles to their family would be highly unlikely. If they were to address what they were experiencing with their family, the family were deemed as unsupportive, posing their negative attitudes and beliefs towards mental illness onto the individual. They would not provide the right support and guidance regarding help-seeking pathways. On the other hand, despite participants stating that families are likely to be unsupportive during mental health struggles, when presented with the case vignette presentation, many participants still encouraged seeking guidance from the family network as an initial form of help. Lay participants stated that seeking help from the family within the early phases of a psychotic illness would be dependent on the families’ perceived understanding and acceptance of mental illnesses. However, when hallucinations and delusions are presented, family involvement was advocated due to the severity of symptoms.
A common issue relating to the reluctance for individuals to open up to their families about their mental health struggles was due to the families’ perceived response to ‘get on with it’. For the struggles the individual might be experiencing the expected response would be to ‘brush them under the carpet.’ These were recurring phrases within the lay study which were associated with the heavy ignorance and denial of mental illnesses.

This can be further supported by the family member study, whereby many reported that whilst they and other immediate family members noticed changes in the individual’s behavioural presentation for some time, it went ignored and dismissed until crisis point. Again, this was attributed to the limited mental health knowledge Punjabi Sikh families hold towards mental illness. This also links to research which found a key barrier to care for South Asians with psychosis was the individuals and families detecting symptoms, but not seeking help (Addington et al., 2002). By ‘brushing it under the carpet’ and telling someone to ‘get on with it,’ the family may believe the issue will go away and professional help would not have to be required, which is believed to impact the family honour and reputation.

The phrase ‘get on with it’ could also be related to the Sikh value of heroism, a concept which originates from the historical narrative of Sikh bravery whereby during the foundational years of the Sikh religion, Sikhs had to fight for their beliefs and traditions. Ahluwalia & Alimchandani (2013) found that embracing this value of heroism may take effect as a coping strategy for Sikhs when faced with adversity or mental distress. Furthermore, Sandhu (2004) found that Sikhs expressed their need to control feelings of being a victim, take charge and transform their circumstances. Importantly, Ruprai (2016) presented a novel mental health help-seeking narrative for Punjabi Sikhs which relates to the value of heroism. By adopting a ‘warrior’ and ‘fighter’ identity, participants in this study stated that they could deal with difficult and adverse life situations by themselves, and this identity was fuelled by the challenging beginnings of the Sikh faith.

Such themes did not prevail in the current research. Participants did not discuss much about their religious heritage and how it may have influenced the ways in which they might address mental health struggles. However, several participants did discuss the concept of Chardi Kala which could be related to the prevalence of response of ‘get on with it’. Chardi Kala refers to a mental state of eternal optimism and joy which Sikhs are taught to practice on a daily basis, even through the times of adversity (Majhail, 2010; Cole, 2010; Karla, 2012; 2013). To be in
this frame, you must hold no negative emotions such as anxiety, jealousy, or anger. It could be that the expectation to sustain the state of Chardi Kala is why mental illness is dismissed by the individual and/or their family.

The support of family is evidently essential whether a person seeks professional help for a mental illness. Given, the closeness that symbolises Indian families (Medora et al., 2000), even if younger generations are more aware and understanding of mental illnesses, it would still be the prevalent cultural and family values that would influence help-seeking decisions. Judge at al. (2005) found South Asian family members were crucial in detecting symptoms of a psychotic illness before the patient does. Thus, it is integral that families become educated on mental illnesses and early signs of psychosis, and for mental health conversations to be normalised within the Punjabi Sikh household.

Nevertheless, all family members, several service users, and many of the lay participants of whom had personal experiences with mental illness, stated that once professional help was sought, the family became a lot more supportive towards the individuals struggles. Particularly family members, of whom stated they had the drive to educate themselves on psychosis and the triggers of their loved one. Service users also expressed that their immediate family members were considered very supportive post-diagnosis and pivotal in their recovery. This is in line with previous research which has found family to be considered the most important structure when caring for those with mental health problems (Lawrence et al., 2006a). Similarly, Lloyd et al. (2013) found that Punjabi Sikh families insist on caring for a family member with a mental illness. Many of the family members in the current research also expressed their desire to increase mental health awareness since going through this experience.

7.2.5. The Punjabi Culture Vs. The Sikh Religion

The current study found the Punjabi culture and Sikh religion appear to be contrasting constructs. The Sikh faith was depicted as one of peace and compassion, with Sikh scripture recommending ways to maintain good mental health and wellbeing. Contrastingly, the Punjabi culture was regarded toxic and judgemental, stimulating the negative opinions around mental illness, navigating individuals to supernatural beliefs and alternative help-seeking pathways for psychosis and other mental illnesses.
This study found that the Punjabi culture held a superior influence over the attitudes, beliefs, and treatment of psychosis and other mental illnesses, in comparison to religion.

Furthermore, there was a lot more agreement in participants’ discussions around cultural interpretation of mental illness with nearly all participants considering similar cultural beliefs regarding mental illness such as stigma, shame, and supernatural attributions. On the other hand, religious explanations for psychosis and general mental illness differed by participants, which could owe to the subjective nature of interpreting religious scripture.

The most prominent themes regarding culture and religion are discussed below.

7.2.5.1. Supernatural Explanations for Mental Illness and Associated Help-Seeking

Whilst social causal attributions were most endorsed for psychosis across all participant groups (Greenwood et al., 2000; Sheikh & Furnham, 2000; Chui et al., 2005; Taylor, Brown & Weinman, 2013), as well as the belief that mental illness is a result of religious concepts such as ‘God’s will’ and/or karma (Gilbert et al., 2011), many participants spoke of the prevalence of supernatural beliefs which are used in connection to mental illness.

This included concepts such as black magic, which was used synonymously with the phrase “somebody has done something”, naazar (evil eye), and in some cases spirit possession. These findings are in line with the broader South Asian literature, whereby mental illness is attributed to supernatural factors (British Sikh Report, 2018; Sheikh & Furnham, 2000; Bhui, Bhugra & Goldberg, 2002; Chui et al., 2005; Gilbert et al., 2011). However, supporting supernatural beliefs is antagonistic of Sikh teachings, whereby Sikh scripture outlines that witchcraft and possession are not beliefs that should be held by a practicing Sikh (British Sikh Report, 2018; Gilbert et al., 2011).

In line with Ruprai (2016), the majority of participants in the current study did not personally endorse these factors, but stated it is a prevalent belief within their family and/or wider Punjabi Sikh community, which has commonly been passed down through the generations. Specifically, it would be those of an older generation that would support supernatural causes for psychosis and other mental illnesses. Some participants alluded to these cultural beliefs
being informed by past generations who were not able to explain the presentation of psychotic symptoms.

The participants not directly supporting supernatural beliefs could be attributed to acculturation. Research has shown that acculturation has a substantial impact on the way individuals make-sense of mental health issues (Hammid et al., 2009). As discussed in the literature review, the Sikh community are well integrated into British society (Ghuman, 1999; Robinson, 2003). Thus, they could have been more subjected to Western beliefs which have affected the way they perceive mental illness. This can be supported by a study which found South Asian’s who were British born held beliefs about causes and treatments for mental illness that were in keeping with Western views of mental illness (Sheikh & Furnham, 2000). The authors proposed that although British South Asian’s are shaped by beliefs from their home culture, it is their dominant new culture which may have a superior effect on how they understand mental illness.

Furthermore, English language proficiency and education could account for the generational difference in this finding. A previous study has found that the conceptualisations of mental illness considerably contrasted for South Asian women who spent most of their life in their home country, had low English-speaking ability, and received non-western schooling compared to British born South Asian women (Furnham & Malik, 1994). In this study, participants also attributed the generational difference in understanding mental illness to education and language, in that there are no Punjabi words for western mental illnesses.

Endorsing supernatural beliefs can lead to individuals seeking help from alternative sources such as faith/traditional healers, and this has been well cited for the Sikh community (Greenwood et al., 2000; Knifton, 2012; Sembhi & Dein, 1998, Dein & Sembhi, 2001; Hussain & Cochrane, 2003; Chui et al., 2005; Taylor, Brown & Weinman, 2013; Cinnirella & Loewenthal, 1999; Gilbert et al., 2011). The prevalence and nature of this occurring amongst this research sample has previously been discussed in Section 7.2.3. Thus, despite many of the participants not supporting supernatural explanations for mental illness, given the importance and closeness of the Punjabi Sikh family network, these avenues could still be sought if it is a dominant cultural belief within the family.
Interestingly, participants in the current study never specified that the ‘healer’ that they or their family had visited was of Sikh faith. Instead, the ‘healer’ was often described as a ‘baba,’ with several participants stating that they would either be Hindu or Muslim. This is congruent with research that reported Sikhs to visit healers of different faiths such as a Hindu Pandit or Islamic Pir for the treatment of a mental health condition (British Sikh Report, 2018).

7.2.5.2. The Importance of Religious Practices in Improving Mental Health

This study did not uncover a concrete explanation as to how the Sikh faith might explain psychosis, but the Sikh scripture was thought to contain a lot of reference to the mind and maintaining good mental health.

Whilst participants were not able to provide much insight into how the Sikh community might interpret an illness like psychosis, there was agreement amongst participants regarding the importance of religious practice in promoting an improved mental state.

The significance of incorporating Sikh practices in daily life has also been supported in research on mental distress and adverse life experiences (Lawrence et al., 2006; Acharya & Northcott, 2007).

Engaging in prayer and meditation (sometimes referred to as Naam Simran or Simran) as a major form of coping and support for someone experiencing psychosis and other common mental illnesses, such as depression and anxiety, was discussed by all participant groups.

Naam Simran is deemed the essential and highest action a Sikh can do. It empowers the individual to quiet their mind and focus, which leads to a peaceful state, eradicating negative thoughts and overcoming mental distress. The Guru Granth Sahib also teaches that when Waheguru is recited continuously it can act as a protective and therapeutic measure for emotional suffering and allows you to obtain power over ‘evil’ thoughts (Singh, 1993; Karla, 2012; 2013).

155 A man with specialised knowledge or a teacher of any field of knowledge in Hinduism
156 Sufi spiritual guide
157 Holy Scripture of Sikhism
158 Word used in Sikhism to refer to God
Many lay participants supported these statements, by reporting that they personally turn to meditation, listening to and/or reciting prayers when they have experienced mental health struggles. Similarly, two service users discussed the importance of listening to Bani\textsuperscript{159} in their recovery of psychosis. Family members also mentioned they had turned to their faith during and after their lived experience.

Turning to meditation to help with your psychological wellbeing was also reported by Ruprai (2016), whereby participants stated that Sikhism already promotes psychological wellbeing through practices such as meditation which helps an individual achieve inner peace.

Prayer was believed to bring calm and peace to an individual, which in succession acts as a support mechanism. This result was widespread across all age ranges. Particularly, lay participants suggested that for those with psychosis, listening to prayers might be more useful as they might not have the capacity to read the prayers themselves. This is in line with the service user study, whereby they stated they listen to prayers rather than reciting them. This also supports Miller (2005) who found for Sikhs who recited prayers they felt they had the strength to conquer adversity.

Many participants also stated the combination of professional care and religious coping strategies is the ideal combination for dealing with psychosis and general mental illness. This is in line with Gilbert et al. (2011) who found prayer formed an integral part of mental health treatment.

7.3. Methodological Considerations

7.3.1. Testing Times and an Untested Community

It is well-established that engaging minority ethnic groups in research is challenging (Darko, 2022). My literature review further revealed that Punjabi, Sikhs are even more scarcely represented in both mental health and general health research compared with other minority ethnic groups such as Black British and Black African/Caribbean and Pakistani communities. Thus, with the unexpected outbreak of the COVID-19 pandemic, my research faced many

\textsuperscript{159} Short for Gurbani, the term used by Sikhs to refer to various sections of the Holy Scripture
challenges and sudden changes to the original research plan which need to be considered in relation to the final output.

Recruitment and data collection for this study commenced simultaneous to the COVID-19 UK Lockdown, which was March 2020. Significant adjustments had to be made to account for no in-person recruitment or data collection which considerably affected the recruitment of service users which in turn impacted family member recruitment.

Originally, recruitment for the service user study would have involved me being active at the relevant Trust sites and being referred eligible participants by consultants or CPN’s. In most instances, I planned to meet with an eligible participant after their in-person consultation with their psychiatrist to explain the study and ask whether they were interested in taking part. This would have firstly allowed me to establish an effective rapport with Trust staff which may have allowed them to be more willing to offer their time and collaborate in recruiting. Moreover, by approaching potential participants personally I could create a better rapport and promote the importance of the research which may have encouraged more service users to partake.

Due to no in-person contact being permitted during this period, I had to rely on Trust staff to pass on the study information to eligible participants at their next appointment which would have either been an online video call or via telephone. This connects to a further limitation, whereby Trust staff had emphasised to me their difficulties in obtaining contact with service users during the pandemic. This was either due to service users not having access to the relevant technology, including not having internet or email access, or service users not responding to telephone calls. For ethical reasons, I would have not been able to obtain the contact details of any eligible participant and contact them without their consent.

I made the decision to widen the scope of service user recruitment by potentially setting up another Trust. Thus, I contacted West London NHS Trust, which covers areas highly populated by Sikhs, including Southall, Slough, and Hounslow. After discussing the feasibility of recruiting Sikh service users with the Trust’s Research Lead, I was advised that due to the lack of engagement I had received with the West Midlands sites and a similar difficulty in West London’s Trust staff contacting service users during the pandemic, it would not be practical to set-up this study site.
I exerted my best efforts in attempting to recruit service users from the sites that were already set-up, through consistently contacting consultants and care co-ordinators over a fourteen-month period. However, there were limited number of Sikh service users and of those that were informed of the study, most declined to take part and the others were too unwell to take part.

These unforeseen challenges led to a small sample size of four service users and nine family members with lived experience. Thus, the reflections of these small samples may not be generalised to all Sikhs who have lived experience with psychosis. However, qualitative methods do not strive to attain generalisation of results; they concentrate on understanding complex phenomena (Willig, 2008). Thus, the final sample size could be considered a foundation in developing an understanding of the experiences of Sikh with lived experience of psychosis and can provide a basis for future research to be conducted.

Furthermore, I explored multiple avenues and utilised a plethora of methods for the recruitment of each participant group during these challenging times, with my total recruitment duration spanning nineteen-months. The combined findings across the participant groups where many similarities were found can still offer valuable insights into the Punjabi, Sikh community’s understanding and experiences of psychosis and general mental illness.

7.3.1.1. Further Limitations

Regarding sample characteristics, various points should be considered. In the case of the service user sample, all four service users were male which indicates the findings are not representative of Sikh females who have experienced psychosis. The reflections of these four service users may also not be generalised to all Sikhs who have experienced psychosis.

Furthermore, whilst there is strength in the lay sample, in that the sample varied in gender, age, education level, and migrant generation, it comes with some weakness. For example, all participants were fluent in the English language and in most instances had spent their formative years in the UK. Thus, they could be considered more acculturated to Western views which has shaped their outlook on mental illnesses.
Also, with only those who could speak English allowed to partake, it is probable that this study has not captured the voices of all the Punjabi, Sikh community, particularly older generations or recent migrants. To account for this drawback, participants were encouraged to address questions from their own perspective but also how the wider community or older generations may deliver on the topics raised.

Another consideration from the lay sample was that all but one participant had some form of experience with mental illness. This varied between a personal, family member, or wider social network level. Whilst this sample still had very little experience and knowledge of psychosis, they would have had more knowledge than someone that did not have a personal connection with mental illness. Many of these participants also stated that they took part because they had an interest in mental health and/or raising awareness of it within the Punjabi, Sikh community. Consequently, the outcomes from this study may signify a particular perspective.

This latter limitation could also be applied to the family member study. This study might have attracted those who are more accepting of their family member’s psychotic illness and/or want to share their story and spread awareness. Many of the family members stated this within their interview, stressing that mental health awareness needs to be increased and mental illness must be destigmatised in the Punjabi Sikh community. It is likely that those families who have not well-understood or accepted their family member’s psychotic illness would not take part in this study. However, these are unavoidable drawbacks of a self-selected sample.

Furthermore, with the strong issues around stigma of mental illness and the shame it brings on one’s family and reputation, and the community’s fear of gossip and judgement, many family members and service users may have had a reluctance to partake, at the risk of others finding out. This is supported by Brown et al’s (2014) review paper which found that there is a stigma associated with participating in mental health research amongst minority ethnic groups. This was due to numerous factors including the fear of being labelled as mentally ill (Chen et al., 2005) and the impact it could subsequently have on their family's reputation (Arean et al., 2003).
As this research embraced a critical realist position, inter-rater reliability could also be deemed a methodological constraint, as all elements of the research process were primarily completed by the myself. However, as specified in Section 3.5., I took many avenues to ensure the quality and credibility of the research was to a high standard. This was primarily achieved with regular supervision sessions with my supervisors who were experts in the field, as well as having the analysis and theme development process reviewed by an external reviewer and supervisors.

7.3.2. Strengths
This qualitative interview study has many strengths. Firstly, it provides a new contribution to the literature by being the first study to explore a severe mental illness in an exclusive Punjabi Sikh sample, and one of few that has explored a service user sample of Punjabi Sikhs.

To the best of my knowledge, it is also the largest sample of Punjabi Sikhs in a qualitative mental health study, with a total of forty-three participants. Whilst there were challenges with the service user recruitment, which is detailed above in Section 7.3.1., it is also well documented that recruiting individuals from minority communities to partake in research is exceptionally challenging (Brown et al., 2014, Waheed et al., 2015). Thus, the sample size for this qualitative study can be considered a strength.

Furthermore, the lay sample had a diversity of characteristics, with a fairly equal representation of gender, migrant status, and education level. Also, a good proportion of participants from different age groups took part. Whilst the other participant groups were smaller in size, there were clear themes that prevailed across all participant groups, suggesting that overall, the findings from this study can be representative of the Punjabi Sikh community.

A further strength was obtaining data from different participant groups of service users, family members, and lay people, which allowed for a triangulation of data. This allowed me to depict the parallels in knowledge and experience and explore this through various lenses (Peters, 2010).
Moreover, lay and family member participants were not constrained to a geographical location. Due to the online nature of recruitment and data collection, participants represented various areas of the UK, permitting for findings from these groups to be representative of Punjabi Sikhs based across the UK. Prior to the COVID-19 pandemic, it would be unlikely that a similar research study could achieve such a geographical scope.

Another strength was the flexibility I put forward concerning the times and mode of conducting the interview. Whilst data collection commenced during the COVID-19 lockdown, interviews could only be conducted via telephone or online video call. However, this was advantageous as it removed any time and location constraints that participants may have had prior to the lockdown. For example, a challenge considered in the original research plan was assessing a convenient location for both myself and the participant to conduct the interview. As there were no incentives or reimbursements of travel expenses for participants, this may have considerably reduced the number of individuals willing to take part. With the interviews being conducted remotely, it allowed for people to take part at a time and mode which was most suitable for them.

Online video calls during this period had also become the norm, with many people connecting with family, friends, and employees through online video communication platforms such as Zoom and Microsoft Teams. Thus, participants may have considered this another video call where they can discuss a topic and/or experience at their leisure.

The familiarity of the participants home surrounding when taking part in the interviews potentially also allowed for the conversation to flow without disturbance or fear of judgement. I have considered that some participants may have been limited to how much they could share in fear of other individuals in the home over-hearing them. Furthermore, in-person interviews may yield better rapport the ability to engage in informalities before and after the interview starts where useful nuggets of information may be provided. However, I attempted to alleviate this by employing many rapport building strategies such as making casual conversation before and after the interview, minimising complex questions and jargon, being empathic and an active and attentive listener.

Another potential challenge of the current study could have also been participants’ reluctance to openly discuss mental illness and/or their experience with it, due to the topic being highly
sensitive and stigmatised. To my advantage, all participants were open about their knowledge and experience with psychosis or any other mental illness, which allowed for substantial and rich data to be gathered.

Furthermore, I had the advantage of being a member of the Punjabi Sikh community. This may have enabled me to access groups which might not have been easily accessible to those not of the same background. The ethnic matching of researcher and participant has been considered important when conducting research, as it is thought to produce higher quality of data, as the researcher has a better possibility to appreciate and empathise with the participants culture and experiences (Elam & Fenton, 2003). This is further discussed in Section 3.6 and 7.3.3.

7.3.3. Reflexivity

As highlighted in the methodology chapter, utilising a qualitative approach in research moves the attention of research from objectivity to subjectivity (Parker, 2005). In Section 3.6., I detailed how I fostered reflexivity throughout the research process, through a combination of keeping a reflexive diary, holding reflexive discussions with supervisors, and consistently making note of how my knowledge and experience may have influenced the interpretation of interviews and how the analysis of data was executed. All these methods allowed me to sustain rigour throughout the research process (Etherington, 2004).

Researchers have emphasised the advantages of conducting research within the community they belong too (Serrant-Green, 2002; Dwyer & Buckle, 2009). I also felt that my similarities in culture and faith provided me with several advantages through the research process.

Firstly, by being an ‘insider’ it allowed for me to get easier access for a very hard-to-reach community who scarcely take part in research. Prior to the pandemic, I visited numerous Gurdwara’s for the recruitment of the layperson study, where I had an awareness of the appropriate religious behaviours permitted and thus adhered to them. Furthermore, I had contacted many Sikh organisations and/or established groups and was invited to attend events that they were putting on to promote my study. I feel if I were an ‘outsider’, it could be a daunting experience to attend large cultural or faith-based events to promote a research study targeted on a community to which you do not belong to. Whilst I did have apprehensions about attending certain events as although I am able to understand some Punjabi, I am limited
in speaking the language. However, I had the benefit of taking a close friend or family member along who could ease the language barrier. This also proved not to be much of a drawback as many of those I interacted with spoke fluent English.

Furthermore, my substantial family and social network of Punjabi Sikhs enabled me to attain a greater outreach for recruitment. This was made superior by having my primary supervisor also be Punjabi Sikh with a large network of people who were either eligible for my study or could promote the study to appropriate people/groups. This was especially helpful when my main sources of recruitment were online, as many friends, family, and gatekeepers circulated my poster across their Facebook, Instagram, and Twitter pages, as well as on WhatsApp groups.

I feel I would have not achieved such a substantial lay sample had it not been for the pandemic. Prior to the pandemic, online recruitment and data collection was not common research practice and was not a consideration for this study originally. In future research, employing similar online recruitment methods and offering people the option to participate in an interview through online video platforms or telephone is something I will consider as I have seen the great advantages it has had for my study.

Furthermore, many of the participants who took part had an interest in mental illness and a desire to promote mental health awareness. I felt that many of those who took part saw this as an opportunity for being part of something that is going to make a difference for the Punjabi Sikh community. As I belonged to the Punjabi Sikh community, participants may have felt more inclined to take part by seeing this as a chance to share their views and experiences with a like-minded individual trying to make a difference for their own community. Many participants across the groups expressed positivity to the research I was doing, reiterating that more needs to be done to tackle mental health challenges in the Punjabi Sikh community. However, their accounts are unlikely to be reflective of a portion of the Sikh community who do not acknowledge mental illnesses.

Despite the similarities in culture and faith affording me some advantages, limitations still existed. For example, on certain occasions participants would say certain phrases in the Punjabi language or assumed I knew the same things about the culture or faith as they did. However, I ensured from the beginning of the interview to inform participants that I
understood little Punjabi and would always ask participants to either translate something they have said or elaborate on a particular cultural or religious concept. Personally, I think that my limited proficiency in the Punjabi language offered the advantage for participants to define the meanings of any Punjabi terms used. Shared religious or cultural terms could hold distinct connotations for individuals, as proven in this study whereby religious scripture was interpreted differently by some participants. If I was well-acquainted with the Punjabi language, I may not have asked for further elaboration on certain terms and concepts, instead unconsciously imposing my own subjective meanings to these terms.

Despite the great challenges experienced due to the COVID-19 pandemic, I have found the whole research process to be interesting and educative. I have seen the benefits of conducting research online which I would have not been privy to if the pandemic did not occur, and I feel this has altered the way I will conduct future research studies. Whilst I would have wished for more service users to take part, I know that I did the best I could during this testing period. Now that I have reached the end, I feel more knowledgeable in my own culture and faith, and I hope it will inspire more research on mental illness in the Punjabi Sikh community. More importantly, I feel proud to have completed this insightful research despite the unanticipated challenges I was faced with.

7.5. Recommendations

The current research has uncovered some valuable areas that would warrant further investigation. The following sub-sections will discuss recommendations for clinicians, researchers, policy makers, and community-based organisations.

7.5.1. Service Providers and Policy Makers

At a clinical level, mental health service providers serving multicultural populations should ensure their all staff and clinicians receive relevant training in the Punjabi culture and Sikh faith. Particularly, cultural barriers such as stigma, shame, and confidentiality need to be considered, as this may impede this community’s access to services and/or treatment engagement.

The fear of gossip and the importance of reputation need to be respected and could potentially be addressed by reminding service users and their families of any ethnicity that
confidentiality is guaranteed when accessing services. Clinicians could consider providing online consultations for service users and/or their family members who may not want to attend mental health clinics due to their fears surrounding judgement and gossip.

Given that family is significantly important to Sikhs and are integral when seeking help for mental illness, especially in the case of psychosis, clinicians need to also be mindful of this. It is often due to the families’ poor mental health literacy that illnesses such as psychosis are not managed until the point of crisis. Thus, clinicians need to take the time to provide psychoeducation on psychosis.

Furthermore, as family are integral in the care of the service user post-diagnosis, clinicians should provide guidance on how the family can best support the service user. Thus, by safeguarding confidentiality and creating a strong therapeutic relationship with the service user and their family, clinicians may be able to provide more efficient care when working with this community.

Some participants also spoke of a stigma around taking medication in the Punjabi Sikh community, thus it may be useful for clinicians to detail exactly how medication will benefit the patient and any potential side effects that may arise. Essentially, clinicians need to consider it vital to engage family members with the care and treatment of the service users.

Furthermore, taking on board that supernatural explanations for psychosis are prevalent, particularly those from an older generation or a recently migrated family, it is essential for clinicians to be aware and open to these explanations that the family may relay. This would allow for mental health services to be considered more accessible and culturally sensitive.

These recommendations are particularly relevant for GP’s, who were reported to be the first port of call in most health crises, including the presentation of a psychotic episode. For those who are presenting with early symptoms of psychosis, GPs should be considerate of all the above and avoid misdiagnoses.

Especially, as the term psychosis is unfamiliar to many members of the community, it is important for GPs to consider cultural expressions of psychosis and other mental illness. The term ‘tension’ was commonly used by Punjabi, Sikhs, who spoke limited English, to describe
symptoms sometimes synonymous with a psychiatric illness. GPs should be mindful to look beyond the term ‘tension’ and consider an individual might be experiencing something psychiatric in nature.

In the case of this sample, family interventions may also be substantially more effective in the recovery of the service user given the prominent role families have in the care for the service user post-diagnosis. FLP has been related with a decrease in relapses and less possibility of hospital readmission (Bird et al., 2010; Pilling et al., 2002). These are two core aims of the reformed Mental Health Act (2022), whereby the UK government are aiming to reduce repeat sectioning, particularly for BAME groups. South Asians are also known to prefer family therapy for the treatment for schizophrenia and schizoaffective disorder, in comparison to other BAME groups (Das-Munshi., Bhugra, & Crawford, 2018).

Talking therapies were also highly recommended by most participants, but in the case of the family member and service user study, it is not something that has been offered. Thus, mental health services need to consider implementing a talking therapy as part of the treatment plan.

7.5.1.1. Collaborating with Faith-Based Organisations

As addressed in the White Paper regarding Reforming the Mental Health Act (Department of Health and Social Care, 2021), it is a current government priority to address disparities faced by people from BAME backgrounds in access, experience and outcomes of mental healthcare. This paper posits that those from BAME backgrounds are more likely to be detained and experience repeat detention, which is in line with my research which found that compulsory admission was the primary pathway to care for the majority of lived experience participants. This was due to the lack of awareness and education the Punjabi Sikh community hold towards psychosis. Thus, one important implication could be for statutory health-care organisations to work directly with community-based mental health charities to improve pathways to care for this group.

Working collaboratively with health-care organisations, Punjabi Sikh based mental health charities could create culturally sensitive factsheets and deliver information on specific mental illnesses, in both English and Punjabi. These factsheets should consider the recognition and treatment of different mental disorders, available services and interventions,
and pathways to mental health care. They could be distributed in various places such as Gurdwara’s, schools, universities, as well as GP surgeries as this was found to be the primary contact for any health-related concern.

The Gurdwara was noted as a place that individuals, particularly those of older generations, could become more educated in mental illness. However, this study has found that currently the Gurdwara was deemed a futile place to obtain mental health support due to them not being equipped with mental health knowledge and because of fear of judgement and community gossip. In order to tackle this, community-based charities and Punjabi, Sikh healthcare professionals could host regular engagement projects and mental illness informational talks and workshops within the Gurdwara.

By raising mental health discussion within a Gurdwara, this could help reduce the cultural stigma and shame connected with mental illness and seeking help for it. Particularly, if such information is disseminated by a religious leader or well-respected individual of the community, individuals may be more inclined to increase their awareness of psychosis and other mental illnesses. Additionally, hearing the information in a safe public forum allows for anonymity to a community whereby confidentiality is critical. Delivering mental health awareness programmes to increase awareness and decrease mental health stigma has also been advised by the WHO (World Health Organization, 2001). Whilst mental health awareness programs have been implemented in Gurdwara’s by some Sikh mental health charities over the past several years, it is important for these talks to briefly go over the range of mental illnesses that an individual may experience.

Punjabi, Sikh and South Asian based mental health charities and organisations that are knowledgeable in different mental illnesses could also join forces with popular media platforms. This includes hosting talks on community radio stations such as BBC Asian Network or making an appearance on television channels such as ‘Sikh Channel.’

Furthermore, given that the findings suggested that there was a considerable reliance on social media to acquire mental health knowledge, the heavy utilisation of social media should be considered a primary platform to distribute knowledge on psychosis and other specific

160 https://sikhchannel.tv/
mental illnesses. Punjabi, Sikh based mental health charities could develop and circulate ‘Psychosis Factsheets’ or ‘Schizophrenia Factsheets’, which detail the early warning signs of the illness, how and where to seek help, across pages which have a large Sikh following should be carried out. The anonymity of these forms of communication allows for individuals to become educated on mental illness whilst evading cultural stigma. This is supported by evidence which has found using mass media to spread mental health awareness has showed significant change in decreasing mental health stigma (Brinn, Carson, Esterman, Chang, & Smith, 2010). Furthermore, promoting mental health awareness on social media could offer a means to share knowledge and normalise ‘unusual’ experiences (Donovan, 2003).

It also essential that this education occurs at a family level. The current study stressed the importance family has on acknowledgement, understanding and help-seeking of psychosis and other mental illnesses. It is well evidenced that early intervention for psychosis has many benefits, this includes: a change in the trajectory of illness; ameliorating long-term prognosis; promotion of psychosocial recovery; reduction in treatment resistance; limits negative effects of psychotic symptoms; facilitates a rapid recovery; and has a reduction in the care burden and negative impact psychosis can have on the family (Marshall & Rathbone, 2011; Reading & Birchwood, 2005). Thus, it is integral for the family as a unit to be educated on different mental illnesses, particularly illnesses which can progress to a severe stage.

7.5.2. Researchers
The literature review revealed that there are few mental health studies carried out on an exclusive Punjabi Sikh sample. Of these studies, mental illness is explored at a broad level. Thus, future research should look to explore the Punjabi Sikh community’s understandings and help-seeking behaviours towards various mental illnesses, such as generalised anxiety disorder, health anxiety, bipolar disorder, obsessive compulsive disorder, etc.

The findings from the current study found that most attitudes and beliefs held toward general mental illness were no different to psychosis specifically. Thus, it would be interesting to find out whether these general attitudes, beliefs and behaviours are the same across different mental illnesses. For these future studies, it is also recommended that service users are a pivotal participant group to target, as there are few studies completed on Sikh mental health service users.
Following on from this research, due to the limited sample size of family members and service users, it is essential for further research to be conducted on these groups in order to determine whether the themes derived from both the family member and service user study are an accurate reflection of the Punjabi Sikh lived experience of psychosis. Furthermore, the current study did not have a female service user. Thus, future research could look to explore the experience of psychosis from a Sikh female perspective. These recommended studies could also employ an IPA approach, in order to capture a rich and detailed account of the individuals lived experience of psychosis and how they made sense of this experience. An ethnographic approach to exploring the experiences of mental illness in this community would also be insightful, particularly a researcher who is fluent in the Punjabi language of whom could target members of the community which I could have not.

As previously specified, despite the diversity of participant characteristics regarding age, gender, education and migrant status, all participants were fluent in the English language and had spent their formative years in the UK. Thus, their accounts may not be reflective of those who are recent migrants and/or those who are not fluent in English. Thus, similar research should be conducted in samples whereby participants are recent migrants and/or have limited English speaking ability. This would allow for a more comprehensive picture of how Punjabi Sikhs make-sense and seek help for a psychotic illness, as well as seeing whether there are differences in their views.

Future researchers could also explore similar research questions from focus groups which occur in natural settings. This could include approaching specific Punjabi, Sikh social groups such as those that attend Punjabi language classes, Bhangra classes, and other social groups that congregate in the Gurdwara. This will aid in identifying views from individuals who may not have a specific interest in mental health issues.

To further assess the generalisability of this study’s findings, a questionnaire could also be developed based off the key themes drawn from this study and distributed to a much larger sample of Sikhs.
7.6. Conclusion

This research provides a significant contribution to the literature, by being the first study to explore the understandings, help-seeking, and experiences of psychosis in an exclusive Punjabi Sikh sample, providing a distinct insight into an under-researched community who has tended to be submerged within the broader South Asian community.

Despite this research focusing on psychosis, it was evident that whilst many mental illnesses exist, this community largely perceive the term ‘mental illness’ as a universal term for any behaviour that deviates from the ‘norm’.

There was a significant lack of awareness and knowledge of different mental illnesses, and very limited awareness and understanding of psychosis. This results in negative perceptions to be held towards psychosis and other mental illnesses and mental health help-seeking not being sought until the point of crisis.

This study also identified that the Punjabi Sikh community shared many commonalities with the wider South Asian community, largely the cultural perceptions of mental illness such as endorsing supernatural explanations for mental illness and mental illness being viewed adversely. Whilst the Sikh faith was deemed helpful in coping with mental health struggles, through the practices of prayer and meditation, culture had a superior influence over the understandings and help-seeking of psychosis and general mental illness.

These cultural values are entrenched within the close family unit and particularly endorsed by older generations. Given, the close-knit nature that represents Punjabi Sikh families, even if younger generations are more becoming aware of mental illnesses, it could still be the dominant cultural family values that influence help-seeking decisions. Thus, significant strives should be made in order to educate the Punjabi Sikh community on different mental illnesses and this should be executed at both an individual and family level.

Through increasing the awareness of psychosis and other different mental illnesses, two core benefits can be achieved: help-seeking for psychosis and other mental illnesses can be sought at an earlier stage which would positively impact clinical, social and functional outcomes; and the negative perceptions around mental illness would be reduced.
This research has offered prospects to inform the clinical practice of GP’s and healthcare professionals who work with Punjabi Sikhs in the mental health arena. Furthermore, it has provided recommendations for the collaboration of mental health service providers and Punjabi Sikh based organisations to provide vital psychoeducation to this community.
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Appendices

Appendix 1: Literature Review – Electronic Database Search Results

Appendix 1A: Sikhs and Mental Health – Electronic Database Search

Date of Final Searches: 03/03/2022

Search Terms: (Sikh OR Sikhism) AND (Mental Health OR Mental Disorder* OR Psychiatr* OR Mental Illness OR Psychological Wellbeing OR Emotional Wellbeing OR Psychological Distress OR Distress)

PsycINFO
Search Results: 42

PubMed
Search Results: 38

Web of Science
Search Results: 37

CINAHL
Search Results: 17

ASSIA
Search Results: 273

Total: 407 Results
After Duplicate Removal: 337 Results (70 Duplicates)
After Title and Abstract Screening: 49 Results
After Full Text Review: 22 Papers
Appendix IB: South Asians and Mental Health – Electronic Database Search

**Search Terms:** (Punjabi OR Panjabi OR South Asian) AND (Mental Health OR Mental Disorder* OR Psychiatr* OR Mental Illness OR Psychological Wellbeing OR Emotional Wellbeing OR Psychological Distress OR Distress OR psychosis OR psychotic OR schizo*) AND (knowledge OR understanding* OR belief* OR attiud* OR percept* OR concept* OR help seek* OR pathways to care OR treatment* OR service* OR explanatory model* OR prevalence OR incidence)

**Final Date of Searches:** 03/03/2022

**PubMed**
Search Results: 2090

**PsycINFO**
Search Results: 716

**Total** – 2806 Results
**After Duplicate Removal** – 2686 (120 Duplicates)
**After Title & Abstract Review** – 374
**After Full Text Review** – 35 (12 of these were also retrieved from the Sikh mental health database search)
Appendix 2: Recruitment Posters and Invitations

Appendix 2A: Laypeople Study Recruitment Poster (pre-pandemic)

Mental Health

What are your thoughts?

Very little is known about the mental health views and needs of the Sikh community.

A better understanding of these can improve access to care for those in need.

What does this study involve?

We invite you to join a group discussion here at the (ENTER LOCATION) with 6-8 other members of the Sikh community about mental health. Your views are extremely valuable!

Can I take part?

This study is open to those over the age of 18, with good English speaking language ability. You do not need to have experience with mental health in order to take part.

Time and date TBC.

Want to know more?

Please contact Ariana Kular for further information:
Call or text "Sikh Mental Health" to 0********
or Email: ariana.kular@warwick.ac.uk
Appendix 2B: Laypeople Study Recruitment Poster (modified for social media)

Sikh Mental Health & Wellbeing

What are your thoughts?

You are invited to join a one-to-one interview, to discuss mental health and wellbeing within the Sikh community!

You have the option to take part via video interview or an in-person interview, at a time, date, and location convenient for you.

Your views are extremely valuable!

Please Contact Ariana for Further Info:
E: ariana.kular@warwick.ac.uk
T: 07710611469

Date: Laypeople Interview Consent Recruitment Poster V1.23 5/6/2020
Short Study Title: Views of Mental Health and Wellbeing within the Sikh Community
Appendix 2C: Service User Study Recruitment Poster

MENTAL HEALTH

WHAT ARE YOUR THOUGHTS?

ARE YOU A SIKH MENTAL HEALTH SERVICE USER OR CARER?

If you are a service user with a diagnosis of psychosis, we would like to hear from you and your carer.

We invite you to join a confidential interview, to discuss your thoughts on psychosis, and your personal experience with the condition.

You have the option take part via Microsoft Teams Video Interview or Telephone Interview at a time and date convenient for you.

Interviews with service user and carer will be held separately.

CAN I TAKE PART?

This study is open to those who:
• Are a Service User diagnosed with a psychotic disorder (and your carer)
• Aged between 18-65
• Good English Speaking Language Ability

WANT TO KNOW MORE?

Please contact Ariana Kular for further information:
Call or Text “Sikh Mental Health” to 07710611469
or Email: ariana.kular@warwick.ac.uk
Dear Service User,

The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

We are inviting you and your carer to take part in a study which is being conducted as part of a PhD project at the University of Warwick. The study aims to explore the perceptions, understanding and help-seeking behaviours for mental illness amongst Sikhs who reside in England. This study would particularly like to explore your personal experience of having a diagnosis of psychosis, and the experience and views of your carer.

The study will involve interview with yourself and your carer separately, and can take up to 1 - 1.5 hours to complete. The date and time of the interview will be one that is convenient for you. Due to the current COVID-19 pandemic, the interview will take place either via Microsoft Teams video interview or telephone interview, and will consist of a one-to-one interview with the PhD researcher.

In accordance to UK Government guidelines regarding social distancing, you may have the option to take part in an in-person interview in the future. In this instance, the interview will take place in a private room within the mental health trust you currently receive care from. If you wish for the interview to take place in another setting, please discuss this with the researcher to discuss the possibility of this. Another researcher from the University of Warwick will also be present for in-person interviews, to assist the PhD research in taking notes.

Please note the separate interviews for yourself and your carer do not need to be on the same date. Not taking part in the study, or a later change of mind will not affect the quality of care you receive.

It is hoped that by gaining this valuable information will help improve the Sikh community’s knowledge of severe mental illness, and enable individuals to recognise mental illnesses, which in turn could lead to more effective and timely help-seeking of services. Additionally, it could provide healthcare professionals with a Sikh view towards mental illness, which
could lead to the development of culturally appropriate and improved mental health care for the Sikh community.

Enclosed is an information sheet for yourself and your carer which will provide more details regarding the study. Please both read the enclosed information sheet carefully and take time to think about whether or not you would like to take part.

If you and your carer are interested in participating or if you would like to find out more about the study, please provide the contact details for yourself and your carer on the reply slip below, and attach this back to your consultant via email. Your consultant will then pass on your contact information to the researcher, who will be in touch. Alternatively, you can contact the researcher directly through the contact information stated below.

Yours Sincerely,

Ms. Ariana Kular  
PhD Student (Health Sciences)  
Warwick Medical School  
University of Warwick  
Gibbet Hill Campus  
Coventry  
CV4 7AL  
Telephone: 0**********  
Email: ariana.kular@warwick.ac.uk
Reply Slip – Service User

I am interested in taking part in this study [ ] (please tick if appropriate)

Please indicate the best time and day for the researcher to contact you:

Name: ________________________
Contact Telephone Number: _______________________

Reply Slip – Carer

I am interested in taking part in this study [ ] (please tick if appropriate)

Please indicate the best time and day for the researcher to contact you:

Name: ________________________
Contact Telephone Number: _______________________
Sikh Family Member Views on Psychosis & Schizophrenia

Do you have a family member who has experienced psychosis/schizophrenia?

We would like to hear from you!

You are invited to join a confidential one-to-one interview to discuss your thoughts, views and experiences with the condition.

The Interview will take place via Video Interview at a time and date convenient for you.

Please contact Ariana:
E: ariana.kular@warwick.ac.uk
T: 07710611469
Appendix 3: Participant Information Sheets

Appendix 3A: Laypeople Study Participant Information Sheet

Participant Information Leaflet for Laypeople Interview

Study Title: The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Investigator(s): Ms Ariana Kular, Professor Swaran Singh, Dr Helena Tuomainen

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

This research is part of PhD study being carried out at the University of Warwick and is funded by the Warwick Medical School.

What is the study about?

The aim of this study is to explore the perceptions, understanding and help-seeking behaviours for mental illness amongst Sikhs who reside in England.

It is hoped that gaining this valuable information will help improve the community’s knowledge of mental illness, and enable individuals to recognise mental illnesses, which in turn could lead to more effective and timely help-seeking of services. Additionally, it could provide healthcare professionals with a Sikh view towards mental illness, which could lead to the development of culturally appropriate and improved mental health care for the Sikh community.

What would taking part involve?
This study will involve you taking part in an interview with one researcher, and you have the option for it to be a video interview via Microsoft Teams or an in-person interview.

Prior to participation, the researcher will contact you separately to arrange a suitable time, date and location for the interview. The interview should typically last 45-60 minutes, but you are able to leave any time you wish.

If you opt for a video interview, the researcher will send you a Microsoft Teams email invite to join a private video interview. You will be first asked to electronically sign a consent form to take part. You will then be asked to electronically complete a sociodemographics form which will not collect any identifiable data such as your name or contact details. Once these forms are completed, the interview will commence where you will then be asked a number of questions regarding your understanding, knowledge and beliefs towards mental illness.

If you opt for an in-person interview, a location which is convenient for yourself and the researcher will be agreed upon, and you will be asked to complete a consent form and sociodemographics survey in paper format. The interview will then commence once these have been completed. The in-person interview will be conducted in accordance with the UK Governments latest social distancing guidelines. Hand sanitiser will be available. Refreshments will also be provided.

Both the video interviews and in-person interviews will be audio recorded via an encrypted Dictaphone, which only the researcher will have access to, so that the researcher is able to transcribe all the information provided. The video interviews will not be video recorded.

You will have the opportunity to ask any questions both before and after the interview.

For further information on the process of recruitment, please see Appendix A on page 7.

Do I have to take part?

No. Participation in this study is completely voluntary and choosing not to take part will not affect your circumstances in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

You can also choose to withdraw your participation at any time before the interview date, without giving a reason by contacting one of the research team. If you attend the interview, you can leave at any point, and you have up to 72 hours to withdraw your data. After that point, the researcher will begin transcribing and analysing your data.

Further details about withdrawing from the study are provided later on in this document.

What are the possible benefits of taking part in this study?

Very little is known about how members of the Sikh community within the UK understand and deal with mental health disorders. This information is vital as it can help people experiencing mental illnesses receive the appropriate care they require in a timely manner. Furthermore, the valuable information you provide could be used in the future by mental health services in order to provide culturally appropriate and accessible care for the Sikh community.

What are the possible disadvantages, side effects or risks, of taking part in this study?
The likelihood of a participant being at any risk is unlikely. Although, some people may find discussing mental illnesses difficult or distressing. If you feel uncomfortable to answer certain questions you are able to decline to answer. If you find that you are feeling distressed discussing certain topics you can ask for the interview to be paused or terminated, and can speak with the researcher at any point.

The researcher will also be able to offer information about suitable services and support that you will be able to access following this research if needed.

Please see the section ‘Useful Contacts and Helplines’ on Page 5 of this Participant Information Sheet for mental health and psychological support helplines which provide free confidential support for those in need.

The researcher is aware that the time taken to complete the interview can be lengthy, and this may be deemed as a disadvantage. This length of time is required to explore the different areas of mental health and obtain valuable and meaningful data.

**Expenses and payments**

Participation for this study is voluntary. Participants will not receive any payment for participation or reimbursement of travel expenses.

**Will my taking part be kept confidential?**

All information which is collected during this study will be kept strictly confidential, and will be securely stored and managed in accordance with the Data Protection Act 2018.

For interviews that are taking place via Microsoft Teams video call, participants are able to sign in to the meeting using a pseudo-name. This allows the participant to protect their identity if they choose.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. Your name and your chosen contact method (email address, mobile number) will be only be required up until the interview date, for the purpose of the researcher setting up the interview. Once the interview has ended, the researcher will permanently remove both the key to identification and your name and contact details from their computer. For participants who wish to receive the final study results, you are able to provide your email address to the researcher, and the researcher will securely retain these details until the final results are published. If you no longer wish to receive the final results, you can contact the researcher and inform them of this, and the researcher will permanently delete your name and contact details.

The current study will require key sociodemographic data such as age, gender, education level, etc. to be collected in paper or electronic format. Paper forms will be kept in a locked cabinet in the researcher’s office, and electronic forms will be stored on a password-protected desktop computer, in a password-protected folder.

If any names are stated within the interviews, they will be removed during transcription. The researcher will use some direct verbatim quotes from the interviews to be used in journal article publications and the PhD thesis. These quotes will not be identifiable to the participant, and only the gender of the participant will be associated to the quote.
The interview will be audio-recorded using an encrypted Dictaphone, which means that only the researcher will have access to the original audio recording and it will be shared with no other individual. Once the interview has been completed, the researcher will transfer the audio recording from the Dictaphone onto their secure password-protected computer, and will be permanently removed from the audio recording device. Once the audio recorded has been transferred to the researchers computer, it will be stored in a password-protected folder, to ensure the audio recordings are securely stored, and would not be accessible to anyone other than the researcher.

Once the study is complete, and the results from the study are published as a PhD thesis and journal articles, all data will be permanently removed from the password protected computer.

In some instances there may be limits to maintaining confidentiality, for example if a participant were to disclose that they, and/or others, may be at risk of harm, there is a duty of care for the researcher to report this to the relevant authorities.

What will happen to the data collected about me?

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep your identifiable data (name and contact details) until the end of the focus group, at which point the researcher will permanently delete this information from their encrypted computer device. All other unidentifiable data will be stored securely until it has been published as a PhD thesis and as journal articles.

Research data will be pseudonymised as quickly as possible after data collection and it will not be possible to withdraw your data after 72 hours of participation, as the researcher will begin transcribing and analysing your data.

Data Sharing

Data will not be shared outside the University for this study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice or by contacting the Information and Data Compliance Team at GDPR@warwick.ac.uk.

What will happen if I don't want to carry on being part of the study?
Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. If you decide not to participate in this research it will not affect any healthcare that you receive now or in the future.

If you agree to participate but decide you no longer wish to, you are able to contact the researcher directly and withdraw your participation from the study without giving a reason. You are also free to leave the interview at any point. You are also able to withdraw your data up to 72 hours of participation, after that point the researcher will begin transcribing and analysing your data.

To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University’s Information and Data Compliance policies.

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

Results of this study may be disseminated in a variety of ways, including publications within scientific journals, conference posters and as a PhD thesis. Any verbatim quotations that may be used in the final report will not be identifiable to the participant, with only the gender of the participant being associated to the quote.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the Biomedical & Scientific Research Ethics Committee (BSREC 13-19/20 AM02).

**Who should I contact if I want further information?**

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Ms. Ariana Kular  
T: 0********  
E: ariana.kular@warwick.ac.uk

**Who should I contact if I wish to make a complaint?**

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

**Head of Research Governance**

Research & Impact Services  
University House  
University of Warwick  
Coventry  
CV4 8UW  
Email: researchgovernance@warwick.ac.uk  
Tel: 024 76 522746

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer, Anjeli Bajaj, Information and Data Director who will investigate the matter: DPO@warwick.ac.uk.
If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

**Useful Contacts and Helplines**

**Samaritans**
Confidential support for people experiencing feelings of distress or despair.
Telephone: 116 123 (free 24-hour helpline)
Website: [www.samaritans.org.uk](http://www.samaritans.org.uk)

**SANE**
Emotional support, information and guidance for people affected by mental illness, their families and carers.
Telephone: 0300 304 7000 (daily, 4.30pm to 10.30pm)
Textcare: comfort and care via text message, sent when the person needs it most:
[www.sane.org.uk/textcare](http://www.sane.org.uk/textcare)
Website: [www.sane.org.uk/support](http://www.sane.org.uk/support)

Please find further useful mental health and psychological support helplines on the NHS Website: [https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/](https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/)

Thank you for taking the time to read this Participant Information Leaflet
Participant Information Leaflet for Service User’s

Study Title: The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Investigator(s): Ms Ariana Kular

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

This research is part of PhD study being carried out at the University of Warwick, and is funded by the Warwick Medical School.

What is the study about?

The aim of this study is to explore the perceptions, understanding and help-seeking behaviours for mental illness amongst Sikhs who reside in England. The study would also like to explore your personal experience of caring for someone with this condition.

It is hoped that gaining this valuable information will help improve the community’s knowledge of mental illness, and enable individuals to recognise mental illnesses, which in turn could lead to more effective and timely help-seeking of services. Additionally, it could provide healthcare professionals with a Sikh view towards mental illness, which could lead to the development of culturally appropriate and improved mental health care for the Sikh community.

What would taking part involve?

If you agree to take part, you will be asked to sign a consent form.
This study will involve service user’s and carer’s of those diagnosed with a psychotic disorder to be interviewed by one researcher, in order to gather information regarding your personal experience with the disorder, as well as general questions regarding your understanding, knowledge and beliefs towards psychotic disorders.

Service users and carer’s will be interviewed separately, and the researcher will contact both parties separately to arrange a suitable time and date. Carer’s will only be contacted to participate in this research once the service user has provided permission that they are allowing their carer to discuss their experience of psychosis.

You will have the option for it to be a video interview via Microsoft Teams, telephone interview, or an in-person interview. In-person interviews will take place in accordance to UK Government guidelines regard COVID-19 and social distancing.

The interview should typically last 90-120 minutes, but due to the in-depth nature of the interviews, they could possibly last longer. You are able to stop the interview at any time if you wish, and could also arrange to continue the interview at another time point if you are unable to complete the interview in one sitting. If you require a break at any point during the interview, this will be facilitated.

If you opt for a video interview, the researcher will send you a Microsoft Teams email invite to join a private video interview. You will be first asked to electronically sign a consent form to take part. You will then be asked to electronically complete a sociodemographics form which will not collect any identifiable data such as your name or contact details. Once these forms are completed, the interview will commence where you will then be asked a series of questions on the topic matter. This will be a one-to-one interview with yourself and the PhD researcher.

If you opt for a telephone interview, the researcher will set up a time and date convenient for you, for the telephone call to take place. This will be a one-to-one interview with yourself and the PhD researcher. To take part, you will have the option to either read and sign an electronic consent form, or provide verbal telephone consent. Verbal telephone consent will involve the researcher providing key information about the study, and you agreeing to take part. The procedure of verbal telephone consent will approximately take between 5-7 minutes. Additionally, you will have to complete a sociodemographics form, which will not collect any identifiable data such as your name or contact details. This can either be completed electronically by yourself, or can be conducted before the telephone interview questions begin, and will involve the researcher reading out the questions and inputting your answers into an electronic form. Once consent is provided, and the sociodemographics is complete, the interview will commence where you will then be asked a series of questions on the topic matter.

If you opt for an in-person interview, the interview will take place within the mental health trust that the service user currently receives care, unless alternative arrangements are agreed upon between yourself and the researcher. You will be asked to complete a consent form and sociodemographics survey in paper format. The interview will then commence once these have been completed. For in-person interviews, the PhD researcher will be accompanied by another researcher from the University of Warwick to assist in taking field notes.

Video interviews, telephone interviews, and in-person interviews will be audio recorded via an encrypted Dictaphone, which only the researcher will have access to, so that the researcher is able to transcribe all the information provided. The video interviews will not be video recorded. If you opt for a telephone interview, whereby verbal telephone consent is being obtained, the audio recording will begin at the point of the researcher reading out the consent form, in order to have evidence of your consent.
You will have the opportunity to ask any questions both before and after the interview.

For further information regarding the recruitment process, please see Appendix A, on page 7.

**Do I have to take part?**

No. Participation in this study is completely voluntary and choosing not to take part will not affect your medical care or any other circumstances in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

You can also choose to withdraw your participation at any time before the interview date, without giving a reason by contacting one of the research team. If you attend the interview, you may withdraw your data within 72 hours of participation. After this point, the researcher will begin to transcribe and analyse your data.

Further details about withdrawing from the study are provided later on in this document.

**What are the possible benefits of taking part in this study?**

Very little is known about how members of the Sikh community within the UK understand and deal with mental health disorders. This information is vital as it can help people experiencing mental illnesses receive the appropriate care they require in a timely manner. Furthermore, the valuable information you provide could be used in the future by mental health services in order to provide culturally appropriate and accessible care for the Sikh community.

**What are the possible disadvantages, side effects or risks, of taking part in this study?**

The likelihood of a participant being at any risk is unlikely. Although, some people may find discussing mental illnesses difficult or distressing. If you feel uncomfortable to answer certain questions you are able to decline to answer. If you find that you are feeling distressed discussing certain topics you can be excused, and can speak with the researcher at any point. The researcher will also be able to offer information about suitable services and support that you will be able to access following this research if needed.

Please see the section ‘Useful Contacts and Helplines’ on Page 5 of this Participant Information Sheet for mental health and psychological support helplines which provide free confidential support for those in need.

The researcher is aware that the time taken to complete the interview is lengthy, and this may be deemed as a disadvantage. This length of time is required to explore your personal experience with psychosis, in addition to your general understanding and perceptions of the disorder, to obtain valuable and meaningful data. Participants will be provided refreshments during the interview, and will be offered breaks at regular intervals, or when the participant feels they would like a break.

**Expenses and payments**

Participation for this study is voluntary. Participants will not receive any payment for participation or reimbursement of travel expenses, if necessary.

**Will my taking part be kept confidential?**
All information which is collected during this study will be kept strictly confidential, and will be securely stored and managed in accordance with the Data Protection Act 2018.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. Your name and your chosen contact method (email address, mobile number) will be only be required up until the interview date, for the purpose of the researcher setting up the interview. Once the interview has ended, the researcher will permanently remove both the key to identification and your name and contact details from their computer.

For participants who wish to receive the final study results, you are able to provide your email address to the researcher, and the researcher will securely retain these details until the final results are published. If you no longer wish to receive the final results, you can contact the researcher and inform them of this, and the researcher will permanently delete your name and contact details.

The current study will require key sociodemographic data such as age, gender, education level, etc. to be collected in paper or electronic format. Paper forms will be kept in a locked cabinet in the researcher’s office, and electronic forms will be stored on a password-protected desktop computer, in a password-protected folder.

If any names are stated within the interviews, they will be removed during transcription. The researcher will use some direct verbatim quotes from the interviews to be used in journal article publications and the PhD thesis. These quotes will not be identifiable to the participant, and only the gender of the participant will be associated to the quote.

The interview will be audio-recorded using an encrypted Dictaphone, which means that only the researcher will have access to the original audio recording and it will be shared with no other individual. Once the interview has been completed, the researcher will transfer the audio recording from the Dictaphone onto their secure password-protected computer, and will be permanently removed from the audio recording device. Once the audio recorded has been transferred to the researchers computer, it will be stored in a password-protected folder, to ensure the audio recordings are securely stored, and would not be accessible to anyone other than the researcher. Verbal telephone consent will be a separate audio recording to the interview. The same data recording, transfer and management process will be followed for cases whereby verbal telephone consent is obtained.

Once the study is complete, and the results from the study are published as a PhD thesis and journal articles, all data will be permanently removed from the password protected computer.

In some instances there may be limits to maintaining confidentiality, for example if a participant were to disclose that they, and/or others, may be at risk of harm, there is a duty of care for the researcher to report this to the relevant authorities.

**What will happen to the data collected about me?**

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.
We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep your identifiable data (name and contact details) until the end of the interview, at which point the researcher will permanently delete this information from their encrypted computer device. All other unidentifiable data will be stored securely until it has been published as a PhD thesis and as journal articles.

Research data will be pseudonymised as quickly as possible after data collection and it will not be possible to withdraw your data after 72 hours of participation, as the researcher will begin transcribing and analysing your data.

Data Sharing

Data will not be shared outside the University for this study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice or by contacting the Information and Data Compliance Team at GDPR@warwick.ac.uk.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. If you decide not to participate in this research it will not affect any healthcare that you receive now or in the future.

If you agree to participate but decide you no longer wish to, you are able to contact the researcher directly and withdraw your participation from the study without giving a reason. If you attend the interview, you may withdraw your data within 72 hours of participation. After this point, your data will be pseudonymised and the researcher will begin to transcribe and analyse your data.

To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University’s Information and Data Compliance policies.

What will happen to the results of the study?

Results of this study may be disseminated in a variety of ways, including publications within scientific journals, conference posters and as a PhD thesis. Any verbatim quotations that may be used in the final report will not be identifiable the participant, with only age and gender of the participant being associated to the quote.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the NHS Research Ethics
Committee (NHS REC) and the Health Research Authority (HRA) (will insert reference number upon approval).

Who should I contact if I want further information?
If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Ms. Ariana Kular
T: 0********
E: ariana.kular@warwick.ac.uk

Who should I contact if I wish to make a complaint?
Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer, Anjeli Bajaj, Information and Data Director who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

You can also contact your local Patient Advice and Liaison Service (PALS) based at your local NHS Trust, which is a service introduced to ensure that the NHS listens to patients, their relatives, carers and friends, and answers their questions and resolves their concerns as quickly as possible.

Coventry and Warwickshire NHS Partnership Trust
Patient Advice and Liaison Service
Coventry and Warwickshire Partnership NHS Trust
Wayside House
Wilson Lane
Coventry
CV6 6NY

Telephone: 0800 212 445 (Freephone) / 024 7653 6804
Email: pals.complaints@covwarkpt.nhs.uk

Birmingham and Solihull Mental Health Foundation Trust
Customer Relations - PALS service
Birmingham and Solihull Mental Health NHS Foundation Trust
Useful Contacts and Helplines

Samaritans
Confidential support for people experiencing feelings of distress or despair.
Telephone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

SANE
Emotional support, information and guidance for people affected by mental illness, their families and carers.
Telephone: 0300 304 7000 (daily, 4.30pm to 10.30pm)
Textcare: comfort and care via text message, sent when the person needs it most:
www.sane.org.uk/textcare
Website: www.sane.org.uk/support

Please find further useful mental health and psychological support helplines on the NHS
Website: https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

Thank you for taking the time to read this Participant Information Leaflet
Appendix 3C: Family Member Study Participant Information Sheet

Participant Information Leaflet

Study Title: The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Investigator(s): Ms Ariana Kular

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

This research is part of PhD study being carried out at the University of Warwick and is funded by the Warwick Medical School.

What is the study about?

The aim of this study is to explore the perceptions, understanding and help-seeking behaviours for psychotic disorders amongst Sikhs who reside in England.

The most common form of psychosis is schizophrenia, but there are also additional types of psychotic disorders including: schizoaffective disorders, brief psychotic disorder, psychotic depression, and delusional disorders.

If you have had an immediate family member who has personally experienced any of these conditions, we would like to hear from you.

It is hoped that gaining this valuable information will help improve the community’s knowledge of severe mental illness, and enable individuals to recognise signs and symptoms of severe mental illnesses, which in turn could lead to more effective and timely help-seeking of services. Additionally, it could provide healthcare professionals with a Sikh view towards mental illness, which could lead to the development of culturally appropriate...
and improved mental health care for the Sikh community.

**What would taking part involve?**

This study will involve a one-to-one confidential interview with a researcher, which will look to explore family member perspectives and experiences with psychosis.

Questions will also be asked regarding your understanding, attitudes and beliefs towards psychotic disorders.

The interview will take place via Microsoft Teams as a Video Interview. The researcher will contact you to arrange a convenient time and date for the interview.

The interview should typically last 30 – 60 minutes. You are able to stop the interview at any time if you wish, and could also arrange to continue the interview at another time point if you are unable to complete the interview in one sitting. If you require a break at any point during the interview, this will be facilitated.

You will be first asked to electronically sign a consent form to take part. You will then be asked to electronically complete a sociodemographics form which will not collect any identifiable data such as your name or contact details. Once these forms are completed, you will be sent Microsoft Teams email invite to join a private video interview.

You will have the opportunity to ask any questions both before and after the interview.

**Do I have to take part?**

No. Participation in this study is completely voluntary and choosing not to take part will not affect your medical care or any other circumstances in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

You can also choose to withdraw your participation at any time before the interview date, without giving a reason by contacting one of the research team. If you attend the interview, you may withdraw your data within 72 hours of participation. After this point, the researcher will begin to transcribe and analyse your data.

Further details about withdrawing from the study are provided later on in this document.

**What are the possible benefits of taking part in this study?**

Very little is known about how members of the Sikh community within the UK understand and deal with mental health disorders. This information is vital as it can help people experiencing mental illnesses receive the appropriate care they require in a timely manner. Furthermore, the valuable information you provide could be used in the future by mental health services in order to provide culturally appropriate and accessible care for the Sikh community.

**What are the possible disadvantages, side effects or risks, of taking part in this study?**

The likelihood of a participant being at any risk is unlikely. Although, some people may find discussing mental illnesses difficult or distressing. If you feel uncomfortable to answer certain questions you are able to decline to answer. If you find that you are feeling distressed discussing certain topics you can be excused, and can speak with the researcher at any point. The researcher will also be able to offer information about suitable services and support that you will be able to access following this research if needed.
Please see the section ‘Useful Contacts and Helplines’ on Page 5 of this Participant Information Sheet for mental health and psychological support helplines which provide free confidential support for those in need.

The researcher is aware that the time taken to complete the interview is lengthy, and this may be deemed as a disadvantage. This length of time is required to explore your personal experience with psychosis, in addition to your general understanding and perceptions of the disorder, to obtain valuable and meaningful data. Participants will be will be offered breaks at regular intervals, or when the participant feels they would like a break.

Expenses and payments

Participation for this study is voluntary. Participants will not receive any payment for participation or reimbursement of travel expenses, if necessary.

Will my taking part be kept confidential?

All information which is collected during this study will be kept strictly confidential, and will be securely stored and managed in accordance with the Data Protection Act 2018.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. Your name and your chosen contact method (email address, mobile number) will be only be required up until the interview date, for the purpose of the researcher setting up the interview. Once the interview has ended, the researcher will permanently remove both the key to identification and your name and contact details from their computer.

For participants who wish to receive the final study results, you are able to provide your email address to the researcher, and the researcher will securely retain these details until the final results are published. If you no longer wish to receive the final results, you can contact the researcher and inform them of this, and the researcher will permanently delete your name and contact details.

The current study will require key sociodemographic data such as age, gender, education level, etc. to be collected in paper or electronic format. Paper forms will be kept in a locked cabinet in the researcher’s office, and electronic forms will be stored on a password-protected desktop computer, in a password-protected folder.

If any names are stated within the interviews, they will be removed during transcription. The researcher will use some direct verbatim quotes from the interviews to be used in journal article publications and the PhD thesis. These quotes will not be identifiable to the participant, and only the gender of the participant will be associated to the quote.

The interview will be audio-recorded using an encrypted Dictaphone, which means that only the researcher will have access to the original audio recording and it will be shared with no other individual. Once the interview has been completed, the researcher will transfer the audio recording from the Dictaphone onto their secure password-protected computer, and will be permanently removed from the audio recording device. Once the audio recorded has been transferred to the researchers computer, it will be stored in a password-protected folder, to ensure the audio recordings are securely stored, and would not be accessible to
anyone other than the researcher.

Once the study is complete, and the results from the study are published as a PhD thesis and journal articles, all data will be permanently removed from the password protected computer.

In some instances there may be limits to maintaining confidentiality, for example if a participant were to disclose that they, and/or others, may be at risk of harm, there is a duty of care for the researcher to report this to the relevant authorities.

**What will happen to the data collected about me?**

As a publicly-funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep your identifiable data (name and contact details) until the end of the interview, at which point the researcher will permanently delete this information from their encrypted computer device. All other unidentifiable data will be stored securely until it has been published as a PhD thesis and as journal articles.

Research data will be pseudonymised as quickly as possible after data collection and it will not be possible to withdraw your data after 72 hours of participation, as the researcher will begin transcribing and analysing your data.

**Data Sharing**

Data will not be shared outside the University for this study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: [https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice](https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice) or by contacting the Information and Data Compliance Team at [GDPR@warwick.ac.uk](mailto:GDPR@warwick.ac.uk).

**What will happen if I don’t want to carry on being part of the study?**

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. If you decide not to participate in this research it will not affect any healthcare that you receive now or in the future.
If you agree to participate but decide you no longer wish to, you are able to contact the researcher directly and withdraw your participation from the study without giving a reason. If you attend the interview, you may withdraw your data within 72 hours of participation. After this point, your data will be pseudonymised and the researcher will begin to transcribe and analyse your data.

To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University’s Information and Data Compliance policies.

What will happen to the results of the study?

Results of this study may be disseminated in a variety of ways, including publications within scientific journals, conference posters and as a PhD thesis. Any verbatim quotations that may be used in the final report will be not be identifiable to the participant, and only the age and gender of participant will be associated to the quote.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the Biomedical & Scientific Research Ethics Committee (BSREC 13/19-20 AM03).

Who should I contact if I want further information?
If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Ms. Ariana Kular  
T: 0*******  
E: ariana.kular@warwick.ac.uk

Who should I contact if I wish to make a complaint?
Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance  
Research & Impact Services  
University House  
University of Warwick  
Coventry  
CV4 8UW  
Email: researchgovernance@warwick.ac.uk  
Tel: 024 76 522746

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer, Anjeli Bajaj, Information and Data Director who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Useful Contacts and Helplines
Samaritans
Confidential support for people experiencing feelings of distress or despair.
Telephone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

SANE
Emotional support, information and guidance for people affected by mental illness, their families and carers.
Telephone: 0300 304 7000 (daily, 4.30pm to 10.30pm)
Textcare: comfort and care via text message, sent when the person needs it most:
www.sane.org.uk/textcare
Website: www.sane.org.uk/support

Please find further useful mental health and psychological support helplines on the NHS Website: https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

Thank you for taking the time to read this Participant Information Leaflet
Appendix 4: Consent Forms

Appendix 4A: Laypeople Study Consent Form

Laypeople Consent Form for Interview

Participant Identification Number for this study:

Title of Project: The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Name of Researcher(s): Ms. Ariana Kular, Prof. Swaran Singh & Dr Helena Tuomainen

Please initial all boxes

1. I confirm that I have read and understand the information sheet (V2.23.06.2020) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw participation up until the interview date, and leave the interview at any given point, without giving any reason and without any consequences of any kind.

3. I understand that I am able to withdraw my data within 72 hours from the participation date.

4. I understand that I have the option to participate via a video interview or in-person interview.

5. I understand that data collected during the study, may be looked at by individuals from The University of Warwick, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my data.

6. I agree to the interview being audio-recorded via an encrypted Dictaphone, with pseudonymised verbatim quotations possibly being included in the PhD thesis, journal publications, and conference presentations.

7. I agree to keep what I hear from other participants strictly confidential.
8. I am happy for my data to be used in future research.

9. I agree to take part in the above study.

Please Print and Sign your name on the next page.

________________________  ______________________  ______________________
Name of Participant        Date                        Signature

________________________  ______________________  ______________________
Name of Person             Date                        Signature
taking consent
Appendix 4B: Service User Study Consent Form

Service User Consent Form for Interviews

Participant Identification Number for this study:

Title of Project:  The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Name of Researcher(s): Ms. Ariana Kular, Prof. Swaran Singh & Dr Helena Tuomainen

Please initial all boxes

I confirm that I have read and understand the information sheet (V5.03.11.2020) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. □

I understand that my participation is voluntary and that I am free to withdraw participation up until the interview date, and withdraw my data within 72 hours after the interview has finished, without giving any reason and without any consequences of any kind. □

I understand that I have the option to participate via Microsoft Teams Video Interview, telephone interview, or an in-person interview, in accordance to the UK Government guidelines concerning COVID-19. □

I understand that data collected during the study, may be looked at by individuals from The University of Warwick, from regulatory authorities, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my data. □

I agree to my interview being audio-recorded via an encrypted Dictaphone, with pseudonymised verbatim quotations possibly being included in the PhD thesis, journal publications, and conference presentations. □

I am happy for my data to be used in future research. □

I agree to take part in the above study. □
Please Print and Sign your name on the next page.

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<th>Name of Participant</th>
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Verbal Telephone Consent Script and Form for Service Users

Hello, my name is Ariana Kular. I’m working on my PhD study which explores the perceptions, understanding and help-seeking behaviours towards a psychotic disorder.

You are being contacted by telephone today as you have expressed your interest in taking part, and have opted for a telephone interview.

In order to take part, you will need to provide your verbal consent over the telephone. Before I proceed with further information about the study and consent procedure, do you consent to me beginning the audio recording from this point, in order to have a record that you have heard all key information about the study, and are making the decision whether you would like to consent and take part: *(If participant says yes, proceed with the script; if the participant says no, explain that you cannot proceed with the call without consent being audio recorded.)*

*If participant says provides consent to audio recording:*

Thank you. Before you decide, you need to understand why the research is being done and what it would involve for you. I will read out the following key information about the study. Once I have finished you can make the decision as to whether you are happy to participate. Please ask if there is anything that is not clear or if you would like more information.

This research is being carried out at the University of Warwick, and is funded by the Warwick Medical School.

The aim of this study is to explore the perceptions, understanding and help-seeking behaviours towards psychotic disorders amongst Sikhs who reside in England. The study would also like to explore your personal experience and journey with psychosis.

It is hoped that gaining this valuable information will help improve the community’s knowledge of severe mental illness, and enable individuals to recognise psychotic disorders, which in turn could lead to more effective and timely help-seeking of services. Additionally, it could provide healthcare professionals with a Sikh view towards mental illness, which could lead to the development of culturally appropriate and improved mental health care for the Sikh community.

This study will involve you, as a service user, and your carer to be interviewed by one researcher, in order to gather information regarding your personal experience with the...
disorder, as well as general questions regarding your understanding, knowledge and beliefs towards psychotic disorders.

The interview with your carer will be held at a separate time and date. This will be arranged separately between myself and them. Your carer will only be contacted to participate in this research once you have provided permission that you allow them to.

The interview should typically last between an hour and an hour and a half. Due to the in-depth nature of the interviews, they could possibly last longer. You are able to stop the interview at any time if you wish, and could also arrange to continue the interview at another time point if you are unable to complete the interview in one sitting. If you require a break at any point during the interview, this will be facilitated, just ask me.

Participation in this study is completely voluntary and choosing not to take part will not affect your medical care or any other circumstances in any way.

You can also choose to withdraw your participation at any time before the interview date, without giving a reason by contacting one of the research team. If you attend the interview, you may withdraw your data within 72 hours of participation. After this point, the researcher will begin to transcribe and analyse your data.

The likelihood of you being at any risk is unlikely. Although, some people may find discussing mental illnesses difficult or distressing. If you feel uncomfortable to answer certain questions you are able to decline to answer. If you find that you are feeling distressed discussing certain topics you can be excused, and can speak with the researcher at any point. The researcher will also be able to offer information about suitable services and support that you will be able to access following this research if needed.

You will not receive any payment or incentive for participation.

All information which is collected during this study will be kept strictly confidential, and will be securely stored and managed in accordance with the Data Protection Act 2018.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and will be replaced with a participant number. The key to identification will be stored separately and securely to the research data to safeguard your identity. Your name and your chosen contact method (email address, mobile number) will be only be required up until the interview date, for the purpose of the researcher setting up the interview. Once the interview has ended, the researcher will permanently remove both the key to identification and your name and contact details from their computer and telephone.

If you wish to receive the final study results, you are able to provide your contact details to the researcher, and the researcher will securely retain these details until the final results are published. If you no longer wish to receive the final results, you can contact the researcher and inform them of this, and the researcher will permanently delete your name and contact details.

The current study will require key sociodemographic data such as age, gender, education level, etc. which will be collected after you agree to consent via telephone. I will ask you
these questions and I will input the data you provide onto an electronic form. These electronic forms will be stored on a password-protected desktop computer, in a password-protected folder. You can decline to answer any of the questions on the sociodemographic survey.

If any names are stated within the interviews, they will be removed during transcription. The researcher will use some direct verbatim quotes from the interviews to be used in journal article publications and the PhD thesis. These quotes will not be identifiable to the participant, and only the gender of the participant will be associated to the quote.

The interview will be audio-recorded using an encrypted Dictaphone, which means that only the researcher will have access to the original audio recording and it will be shared with no other individual. Once the interview has been completed, the researcher will transfer the audio recording from the Dictaphone onto their secure password-protected computer, and will be permanently removed from the audio recording device. Once the audio recorded has been transferred to the researchers computer, it will be stored in a password-protected folder, to ensure the audio recordings are securely stored, and would not be accessible to anyone other than the researcher.

Once the study is complete, and the results from the study are published as a PhD thesis and journal articles, all data will be permanently removed from the password protected computer.

In some instances there may be limits to maintaining confidentiality, for example if a participant were to disclose that they, and/or others, may be at risk of harm, there is a duty of care for the researcher to report this to the relevant authorities.

Data will not be shared outside the University for this study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

Results of this study may be disseminated in a variety of ways, including publications within scientific journals, conference posters and as a PhD thesis. Any verbatim quotations that may be used in the final report will not be identifiable the participant, with only age and gender of the participant being associated to the quote.

This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee and the Health Research Authority.

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study. The contact telephone number for this individual is 024 76 522746.

That is the end of the key information that I needed to provide.
Do you have any questions?

Do you agree to participate in this study?

[ ] Yes: Document oral consent below and continue with the interview.

[ ] No: Thank them for their time.

Name of Subject:

--------------------------------------------------------------------------------------------------

**Person Obtaining Consent**
I have read this form to the subject. An explanation of the research was given and questions from the subject were solicited and answered to the subject’s satisfaction. In my judgment, the subject has demonstrated comprehension of the information. The subject has provided oral consent to participate in this study.

--------------------------------------------------------------------------------------------------

Name and Title (Print)

--------------------------------------------------------------------------------------------------

Signature of Person Obtaining Consent    Date
Appendix 4E: Family Member Study Consent Form

Consent Form for Interviews

Participant Identification Number for this study:

Title of Project: The Perceptions, Understanding and Help-Seeking of Mental Illness within the Sikh Community

Name of Researcher(s): Ms. Ariana Kular, Prof. Swaran Singh & Dr Helena Tuomainen

Please initial all boxes

1. I confirm that I have read and understand the information sheet (V1.27.01.2021) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw participation up until the interview date, and withdraw my data within 72 hours after the interview has finished, without giving any reason and without any consequences of any kind.

3. I understand that I will participate via a Microsoft Teams Video Interview.

4. I understand that data collected during the study, may be looked at by individuals from The University of Warwick, from regulatory authorities, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my data.

5. I agree to my interview being audio-recorded via an encrypted Dictaphone, with pseudonymised verbatim quotations possibly being included in the PhD thesis, journal publications, and conference presentations.

6. I am happy for my data to be used in future research.
7. I agree to take part in the above study.

Please Print and Sign Your Name on the Next Page:

_________________________  ________________________  _______________________
Name of Participant          Date                       Signature

g_____________  ________________________  _______________________
Name of Person taking consent Date                       Signature
Appendix 5: Sociodemographic Surveys

Appendix 5A: Laypeople Study Sociodemographic Survey

Participant Identification Number for this study:______________ (For Researcher to Complete)

Sociodemographics Survey

Age:

_________________
Prefer not to state [ ]

Gender:

Male
Female
Other (Please Specify) 
Prefer not to state

Self-Ascribed Ethnicity (How would you define your ethnicity?)

Prefer not to state [ ]

Ethnicity (Census):

Not Known
White British
White Irish
White Other
Black/Black British – Caribbean
Black/Black British – African
Black/Black British – Other
Asian/Asian British – Caribbean
Asian/Asian British – Indian
Asian/Asian British – Pakistani
Asian/Asian British – Bangladeshi
Asian/Asian British – Other
Any Other Ethnic Group
Chinese
Welsh
Not Stated
Other
Prefer not to state [ ]

Migrant Generation

1st Generation (Born Abroad)
2nd Generation (Born in the UK, Parents born abroad)
3rd Generation (Parents born in the UK, Grandparents born abroad)
> 3rd Generation
N/A
Prefer not to state [ ]

**Country of Birth (Please Specify)**

Prefer not to state [ ]

**Fluency in English:**

<table>
<thead>
<tr>
<th>Not Fluent</th>
<th>Fluent – Spoken and Fluently Spoken and Written Fluent – Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluent – Spoken</td>
<td>Written</td>
</tr>
<tr>
<td>Prefer not to state [ ]</td>
<td></td>
</tr>
</tbody>
</table>

**Religion**

*Identified Religion:*

<table>
<thead>
<tr>
<th>Christian</th>
<th>Sikh</th>
<th>Catholic</th>
<th>Muslim</th>
<th>Hindu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atheism</td>
<td>Agnostic</td>
<td>Spiritual</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Other (Please Specify)</td>
<td>Prefer not to state [ ]</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Do you practice this religion?**

Yes
No
Prefer not to state [ ]

**Current Marital Status**

<table>
<thead>
<tr>
<th>Married and Cohabiting</th>
<th>Married, but separated</th>
<th>Cohabiting</th>
<th>Single</th>
<th>Widowed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divorced</td>
<td>Civil Partnership</td>
<td>Other (Please Specify)</td>
<td>Prefer not to state</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Housing Situation: Living Status**

<table>
<thead>
<tr>
<th>Alone</th>
<th>Alone with Children</th>
<th>With Partner</th>
<th>With Partner and Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>With Parents/Guardians</td>
<td>With Extended Family (Grandparents Living in Same Household)</td>
<td>Other (Please Specify)</td>
<td>Prefer not to state [ ]</td>
</tr>
</tbody>
</table>
Education:
No Qualifications
CSE/GCSE/NVQ Level 1 or 2/O-Levels
A-Level/GNVQ/BTEC/NVQ Level 3
Degree/HND/NVQ Level 4 or above
Postgraduate Degree
Prefer not to state [ ]

Current Job:
Employed full-time
Employed part-time
Unemployed and currently looking for work
Unemployed and not currently looking for work
Student
Retired
Self-employed
Homemaker
Unable to work
Prefer not to state

Do you have personal or family experience of mental ill health?
Yes
No
Prefer not to state

If yes, please tick/highlight which box applies:
Personal
Close Family Member
Wider Social Network
Prefer not to state
Appendix 5B: Service User Sociodemographic Survey

Participant Identification Number for this study: _________

Sociodemographics Survey

Are you a:
Service User [ ] Carer [ ]
Please Tick the Box that Applies

Age:
____________________
Prefer not to state [ ]

Gender:
Male Other (Please Specify) Prefer not to state
Female ______ [ ]

Self-Ascribed Ethnicity (How would you define your ethnicity?)
Prefer not to state [ ]

Ethnicity (Census):
Not Known Mixed White and Black Asian/Asian British –
African Other
White British Mixed White and Asian Other
White Irish Mixed Other Chinese
White Other Mixed White and Black
Caribbean Any Other Ethnic Group
Black/Black British –
Caribbean Asian/Asian British –
Indian Welsh
Black/Black British –
African Asian/Asian British –
Pakistani Not Stated
Black/Black British –
Other Asian/Asian British –
Bangladeshi Other
Prefer not to state [ ]

Migrant Generation
1st Generation (Born Abroad)
Country of Birth (Please Specify)
Prefer not to state [ ]

Fluency in English:
Not Fluent
Fluent – Spoken
Fluent – Spoken and Written
Fluent – Other
Prefer not to state [ ]

Religion
Identified Religion:
Christian
Sikh
Catholic
Muslim
Hindu
Atheism
Agnostic
Spiritual
None
Other (Please Specify)
Prefer not to state [ ]

Do you practice this religion?
Yes
No
Prefer not to state [ ]

Current Marital Status
Married and Cohabiting
Married, but separated
Cohabiting
Single
Widowed
Divorced
Civil Partnership
Other (Please Specify) ___________
Prefer not to state

Housing Situation: Living Status
Alone
Alone with Children
With Parents/Guardians
With Extended Family (Grandparents Living in Same Household)
Other (please specify) _____________________________________________
Prefer not to state [ ]

**Education:**
No Qualifications
CSE/GCSE/NVQ Level 1 or 2/O-Levels
A-Level/GNVQ/BTEC/NVQ Level 3
Degree/HND/NVQ Level 4 or above
Postgraduate Degree
Prefer not to state [ ]

**Current Job:**
Employed full-time
Employed part-time
Unemployed and currently looking for work
Unemployed and not currently looking for work
Student
Retired
Self-employed
Homemaker
Unable to work
Prefer not to state
Appendix 5C: Family Member Study Sociodemographic Survey

Participant Identification Number for this study: _________

Sociodemographics Survey

Age: 
______________
Prefer not to state [ ]

Gender: 

<table>
<thead>
<tr>
<th>Male</th>
<th>Other (Please Specify)</th>
<th>Prefer not to state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>______</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Self-Ascribed Ethnicity (How would you define your ethnicity?)

Prefer not to state [ ]

Ethnicity (Census):

<table>
<thead>
<tr>
<th>Not Known</th>
<th>Mixed White and Black</th>
<th>Asian/Asian British – Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>Mixed White and Asian</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td>Mixed Other</td>
<td></td>
</tr>
<tr>
<td>White Other</td>
<td>Mixed White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Black/Black British – Caribbean</td>
<td>Asian/Asian British – Indian</td>
<td>Welsh</td>
</tr>
<tr>
<td>Black/Black British – African</td>
<td>Asian/Asian British – Pakistani</td>
<td>Not Stated</td>
</tr>
<tr>
<td>Black/Black British – Other</td>
<td>Asian/Asian British – Bangladeshi</td>
<td>Other</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>Prefer not to state [ ]</td>
</tr>
</tbody>
</table>

Migrant Generation

1st Generation (Born Abroad)
2nd Generation (Born in the UK, Parents born abroad)
3rd Generation (Parents born in the UK, Grandparents born abroad)
> 3rd Generation
N/A
Prefer not to state [ ]
Country of Birth (Please Specify)

Prefer not to state [ ]

Fluency in English:

Not Fluent
Fluent – Spoken
Fluent – Spoken and Written
Fluent – Other

Religion

Identified Religion:

Christian
Sikh
Catholic
Muslim
Hindu
Atheism
Agnostic
Spiritual
None
Other (Please Specify)

Do you practice this religion?

Yes
No
Prefer not to state [ ]

Current Marital Status

Married and Cohabiting
Married, but separated
Cohabiting
Single
Widowed
Divorced
Civil Partnership
Other (Please Specify)
Prefer not to state

Housing Situation: Living Status

Alone
Alone with Children
With Parents/Guardians
With Extended Family (Grandparents Living in Same Household)
Other (please specify)
Prefer not to state [ ]

Education:

No Qualifications
CSE/GCSE/NVQ Level 1 or 2/O-Levels
A-Level/GNVQ/BTEC/NVQ Level 3
Degree/HND/NVQ Level 4 or above
Postgraduate Degree  Prefer not to state [ ]

**Current Job:**
Employed full-time
Employed part-time
Unemployed and currently looking for work
Unemployed and not currently looking for work
Student
Retired
Self-employed
Homemaker
Unable to work
Prefer not to state
Appendix 6: Interview Topic Guides

Appendix 6A: Laypeople Study Interview Topic Guides

Laypeople Interview Topic Guide

Participants will be presented with the following psychosis vignette. After the vignette they will be asked questions specific to the vignette:

*Manjit is a 30-year-old housewife with three small children. Her husband is a manual labourer. For the past 6 months she has stopped doing household work. She does not interact with the children or look after their needs. Her personal care is poor. She has been socially withdrawn and prefers to be alone. Her family has noticed that she smiles to herself and admits to hearing voices of strange people speaking to her. She is convinced that others will harm her. Her sleep is disturbed and her appetite is poor. Her in-laws live next door but are not supportive.*

Perceptions and Understanding of Illness of Vignette

- What do you think is happening to Manjit?
  - Why do you think that?
- Why do you think this could be happening to Manjit?
  - What may be the cause/causes of her problem?

Help-Seeking and Coping of Vignette

- What might Manjit do about what she is experiencing?
  - What might Manjit’s family do about this situation?
- Where could they seek support from? (And why?)

After specific questions are addressed concerning the vignette, the interview will explore broader questions concerning psychotic illness and help-seeking for this illness. The researcher will explain that the vignette was of an individual experiencing psychosis:

Personal Perspective - Awareness, Familiarity & Knowledge of Psychosis

The condition psychosis or having a psychotic disorder – are you familiar with this term?
- What does the term ‘psychotic disorders’ mean to you?
- What about the term ‘severe mental illness’ – what does this term mean to you?
- What characteristics might you expect in an individual with psychotic disorders
- If someone had a severe mental illness, what characteristics would you expect in them?
- Is there anything else you know about psychotic disorders?
- Is there anything else you know about severe mental illnesses?
**Wider Community Perspective - Awareness, Familiarity & Knowledge of Psychosis**

Now looking at the Sikh community generally, is having a psychotic disorder or psychosis something that is known to the community?

- If no, why do you think that this is?
- Experiencing psychosis, although it may not be prevalent as other mental illnesses such as depression or anxiety, it still can have an impact upon anyone, it is still a prevalent mental illness across the world – so why do you think this illness has been not really been spoken about by the Sikh community?

**Personal Perspective - Awareness, Familiarity & Knowledge of Schizophrenia**

“Psychotic disorders are severe mental illnesses, the most common being Schizophrenia.”

- Are you familiar with the illness Schizophrenia?
- If yes, what do you know about them?
- What characteristics would you expect in someone with schizophrenia?
- Is the illness schizophrenia something that is spoken about within the Sikh community?
- If no, why do you think that is?
- Is it something that people are aware of, but they prefer not to speak about it, or is it that there is no awareness that this illness exists?
- How does the awareness of psychotic disorders or schizophrenia differ among generations, for example would your parents/grandparents be familiar with the term – would they know what it is?

**Early Indicators of Psychosis**

“The early symptoms that are prevalent in psychotic disorders include trouble with thinking clearly and concentrating, a decline in self-care and personal hygiene, spending more time alone, a drop in study or job performance.”

[DISPLAY EARLY INDICATORS OF PSYCHOSIS SHEET]

If you saw someone within your immediate family with these symptoms, what would you think they are going through?

- Would you think it’s possible a mental illness?
- How would you go about addressing the issue?
- Would you approach them personally or their family?
- What support would you suggest they seek?
- Would you recommend any professional care?

**Later Presentation of Psychosis**

“As the illness progresses, symptoms such as hallucinations and delusions prevail. Similar to what I asked before, if the early symptoms went unnoticed, but someone within your immediate family started showing signs of paranoia, talking to themselves, hearing voices, believing things are happening that are not actually happening.”
[DISPLAY SIGNS OF FULL PSYCHOTIC EPISODE DOCUMENT]

• How would you address this?
• Would you go to them personally or approach someone in their family first?
• What help and support would you recommend for them?
  o Probe: medication / psychological therapies / religious support / family/social support
• Why have you chosen this option?
• What other coping strategies would you recommend for them to cope with their symptoms?
  o Are there any religious practices that might help them?
    ▪ If yes, why would these help them?
  o Would you recommend they look for support from members of the Sangat at the Gurdwara?

Awareness and Knowledge of Treatments and Services for Psychosis

• What is your awareness of the treatments or services that are available for severe mental illnesses such as psychosis?
• Would you recommend these treatments/services to someone close to you who might be experience mental illness?
• How do you think professional services would help?
• What is your awareness of the treatments or services that are available for other common mental illnesses such as depression or anxiety?

Causes of Psychosis

• What do you think causes this psychotic illness to come about?
• Why do you think this is the cause?
• Do you think there could be any other causes?
• Do you think that the causes you have stated would be the something that older generations would also believe in? (parents’ generation, grandparent’s generation)
  o If no, why?

[SHOW THE CAUSES PROBE SHEET]
Of these causes, we have biological, social, supernatural and religious:

• Are there any factors on here that you think might be a cause for psychosis?
• Which do you believe is the most likely cause? (and why?)
• Which do you believe is the least likely? (and why?)

Attitudes and Beliefs around Psychosis

• What attitudes and beliefs do you hold around psychosis?
• Are there any particular attitudes and beliefs that the general Sikh community may hold towards psychotic disorders (or severe mental illnesses)?
• Has your religious beliefs influenced yours (as well as wider communities) attitudes and beliefs towards severe mental illnesses?
• Has your culture influenced your (as well as wider communities) attitudes and beliefs around severe mental illnesses?

Religious and Cultural Explanations for Psychosis
• Taken into account everything we have spoken about regarding psychosis today, the symptoms etc. How do you think psychosis could be explained by the Sikh religion?
• Is there anything within the Sikh teachings about psychosis or severe mental illness?
• What about milder forms of mental illness such as depression – what does the Sikh religion teach about that?
• What about your culture – are there any cultural beliefs around severe mental illnesses such as psychosis?

Sikh Coping Strategies for Psychosis
• How could someone’s belief and practice of Sikhi help them through a psychotic illness?

Thank you for answering all the specific questions I had. Now is an opportunity for you to bring up any key issues regarding general mental health in the Sikh community – anything you think is important.
Appendix 6B: Service User Study Interview Topic Guides

Service User Interview Guide

What was your diagnosis?

The Onset of Difficulties
- Could you start by talking about when your illness began to manifest, what initial symptoms were you experiencing?
- What did you initially believe may be wrong with you?
  - How did you make sense of what you were experiencing?
- What reactions from your family or friends did you receive in response to your symptoms (the onset of your illness)?
  - What did they think initially was wrong with you?
- Have you ever seen, read or heard on television, radio, in a magazine, a book or on the Internet of a person who had the same health problem as you?
  - In what ways was that person’s problem like or different from yours?

Explanatory Model
- According to you, what did you initially believed caused your health problem?
  - Are there any other causes that you think played a role?
  - Since being diagnosed and living with the illness, do you still believe in these same causes?
- Did you consider that you might have a psychotic illness [and specify the actual diagnosis they received once known]?
- Before you were diagnosed, were you familiar with the term psychosis?
  - If yes, what did you know about it?
  - What did you believe usually happens to people with a psychotic illness?
  - How do people usually react to someone who has a psychotic illness?

Coping and Help-Seeking
- How did you initially deal with the symptoms you were experiencing? This is more so regarding the start when you first experienced changes with your behaviour.
- Where did you initially look to for support with what you were experiencing? (Online, family, friend, etc.)
  - How were you supported in this instance?
- What other sources of help did you seek out before accessing mental health services?
  - How were you supported in these instances?
- When did you decide to seek professional help?
  - (Whose decision, yourself, family member)
- How did you feel about seeking help professionally?
- How did you initially feel about mental health services?
- What were your main concerns about accessing services?
- What was your family’s reactions and feelings towards you accessing mental health services?

Experience of Diagnosis
- How did you feel when you were diagnosed by a mental health professional?
- What were your concerns regarding receiving a diagnosis of mental illness?
- How did you feel about revealing your diagnosis to your family and friends?
• How did your family and friends react to your diagnosis?

Experiences of Services
• What has your experience of mental health services been like?
• How your initial views about mental health have services-seeking help professional changed since you have accessed services?
• How do you think mental health services could be improved to cater better for members of the Sikh community?

Impact on Life
• How has your condition changed the way you live?
• How has your condition changed the way you feel or think about yourself?
• How has your condition changed the way you look at life in general?
• How has your condition changed the way others look at you?
• What has helped you through this period in your life?
• How have your family or friends helped you through this difficult period of your life?
• How has your religion helped you go through this difficult period of your life?
  o Is there anything else you would like to add?
Appendix 6C: Family Member Study Interview Topic Guide

Family Member Perspective of Psychosis Interview Guide

The Onset of Difficulties
- When did you first start noticing changes in your family member’s behaviour?
- What changes were these? What initial symptoms were they displaying?
- What did you initially believe may be wrong with them?
- What was your understanding and responses to their symptoms?

Explanatory Model
- According to you, what did you initially believed caused their health problem?
  - Prompt: did your religious beliefs influence you at all?
  - Are there any other causes that you think played a role?
  - Now that the service user has accessed services, do you still believe in these same causes?
- Did you consider that they might have a psychotic illness [and specify the actual diagnosis they received once known]?
- Before they were diagnosed, what did having a psychotic illness mean to you?
  - What did you believe usually happens to people with a psychotic illness?
  - How do people usually react to someone who has a psychotic illness?

Help-Seeking and Coping
- Who did they initially go to for support, and what were your views on this?
- At the time, who did you recommend they go to for support?
- Prior to accessing professional services, what other support did they seek, and what were your views on this?
- When did they decide to seek professional help? (Who’s decision, you, or service user, etc.?)
- How did you feel about them seeking help professionally?
- What attitudes and beliefs did you initially hold towards mental health services?
- What were your main concerns about them accessing services?
- What were the reactions of other family members regarding them accessing services?

Experience of Diagnosis
- How did you feel when they were diagnosed by a mental health professional?
- What were your concerns regarding them receiving a diagnosis of mental illness?
- How did other family members, or their wider social circle respond to their diagnosis?

Experiences of Services
- How do you feel the service your family member has received has been like?
- How have your initial attitudes and beliefs that you held towards mental health services/seeking help professional changed since your family member has accessed services?
How do you think mental health services could be improved to cater better for members of the Sikh community?

**Impact on Life**
- How do you think their diagnosis has impacted or changed their life?
- How has it impacted and/or changed your family’s life?
- How has your religion helped you go through this difficult period of your life?
  - Is there anything else you would like to add?
Appendix 7: Other Laypeople Study Interview Materials

Appendix 7A: Psychosis Case Vignette

Manjit is a 30-year-old housewife with three small children. Her husband is a manual labourer. For the past 6 months she has stopped doing household work. She does not interact with the children or look after their needs. Her personal care is poor. She has been socially withdrawn and prefers to be alone. Her family has noticed that she smiles to herself and admits to hearing voices of strange people speaking to her. She is convinced that others will harm her. Her sleep is disturbed, and her appetite is poor. Her in-laws live next door but are not supportive.
Early Signs of Psychosis

- Trouble with thinking clearly and concentrating
- A decline in self-care and personal hygiene
- Spending more time alone
- A drop in study or job performance
- Strong, inappropriate emotions or having no feelings at all.
Later Symptoms of Psychosis

Hallucinations
- Hallucinations are where someone sees, hears, smells, tastes or feels things that don't exist outside their mind.
- e.g. hearing a voice that no one else can hear.

Delusions
- A delusion is where a person has an unshakeable belief in something untrue.
- e.g. believing that someone is after them / believing that they are famous etc.
What Do You Think Causes Psychosis?

Biological
- Genes
- Brain abnormality

Social
- Traumatic event (e.g. death of a loved one)
- Emotional / Physical / Sexual abuse
- Childhood trauma (neglect, abuse)
- Substance abuse
- Stress
- Socioeconomic status (living in poverty)

Religious
- God’s Will
- God’s Punishment
- Karma
- Karmic Punishment

Supernatural
- Spirit Possession
- Black Magic
- Evil Eye (Nazaar)
Appendix 8: Ethical Approvals

Appendix 8A: BSREC Full Approval

Dear Mira Kular,

WM5
University of Warwick
Coventry
CV4 7AL

Ethical Application Reference: BSREC 13/13-00
Title: Perceptions, Understanding and Help-Seeking regarding Psychotic Disorders amongst Services Users, Carers and Laypeople: A Qualitative Study of the Sikh Perspective

Thank you for submitting your revisions to the Biomedical and Scientific Research Ethics Committee (BSREC) for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted.

Before conducting your research it is strongly recommended that you complete the on-line Research Integrity training:

www.warwick.ac.uk/training. Support is available from the BSREC Secretary.

In undertaking your study, you are required to comply with the University of Warwick’s Research Code of Practice:

http://warwick.ac.uk/services/ris/research_integrity/code_of_practice_and_policies/research_code_of_practice/

You are also required to familiarise yourself with the University of Warwick’s Code of Practice for the Investigation of Research Misconduct:

http://warwick.ac.uk/services/ris/research_integrity/research_misconduct/codeofpractice_research_misconduct/

You must ensure that you are compliant with all necessary data protection regulations:

http://warwick.ac.uk/services/it/dk

Please ensure that evidence of all necessary local permissions is provided to BSREC prior to commencing your study.

Yours sincerely,

[Signature]

Professor James Covington
Deputy Chair, Biomedical and Scientific Research Ethics Committee
Appendix 8B(i): BSREC Amendment Approvals

Please also be aware that BSREC grants ethical approval for studies. The seeking and obtaining of all other necessary approvals is the responsibility of the investigator.

Any further substantial changes to any aspect of the project will require further review by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes. The BSREC Secretary should be notified of any minor amendments to the study.

May I take this opportunity to wish you the very best of luck with your study.

Yours sincerely,

Dr David Ward
Chair, Biomedical and Scientific Research Ethics Committee

---

Appendix 8B(ii): BSREC Amendment Approvals

Please also be aware that BSREC grants ethical approval for studies. The seeking and obtaining of all other necessary approvals is the responsibility of the investigator.

Any further substantial changes to any aspect of the project will require further review by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes. The BSREC Secretary should be notified of any minor amendments to the study.

May I take this opportunity to wish you the very best of luck with your study.

Yours sincerely,

Dr David Ward
Chair, Biomedical and Scientific Research Ethics Committee
Appendix 8B(ii): BSREC Amendment Approvals

Thursday, 11 February 2021

Miss Ariana Kilar
Warwick Medical School
University of Warwick
Coventry
CV4 7AL

Dear Miss Kilar,

Ethical Application Reference: BSREC 13/19-20 AM03
Amendment Number: 3
Title: Perceptions, Understanding and Help-Seeking regarding Psychotic Disorders amongst Service Users, Carer's and Laypeople: A Qualitative Study of the 5th Perspective

Thank you for submitting your substantial amendment application to the Biomedical and Scientific Research Ethics Committee (BSREC) for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full ethical approval for your project is hereby granted, subject to the conditions outlined in Appendix 1.

Any further substantial changes to any aspect of the project will require further review by BSREC and the PI is required to notify the BSREC as early as possible should they wish to make any such changes. The BSREC Secretary should be notified of any minor amendments to the study.

Should issues arise during the course of the project that present risks to the safety and wellbeing of participants, these must be reported to BSREC. In such an event, recruitment and research activity must be halted until the appropriate actions have been taken, as agreed in consultation with BSREC.

I would like to take this opportunity to wish you all the best with your study.

Yours sincerely,

Dr David Ellard
Chair, Biomedical and Scientific Research Ethics Committee

Appendix 1

Please also be aware that BSREC grants ethical approval for studies. The seeking and obtaining of all other necessary approvals are the responsibility of the Principal/Chief Investigator. For advice on what additional approvals may be required, please visit the following BSREC Other Approvals page.

Please ensure that evidence of all necessary local permissions is provided to BSREC prior to commencing your study.

Before conducting your research it is strongly recommended that you complete the online Research Integrity training.

You must ensure that you are compliant with all necessary data protection legislation. Legal and Compliance guidance can be accessed on their GOPE information pages.

In undertaking your study, you are required to comply with the University of Warwick's Research Code of Practice.

You are also required to familiarise yourself with the University of Warwick's Code of Practice for the Investigation of Research Misconduct.

Further advice and support is available from the BSREC Secretary via BSREC@warwick.ac.uk.
Appendix 8C: NHS HRA Full Approval

Dear Prof Singh,

Study title: Perceptions, Understanding and Help-Seeking regarding Psychotic Disorders amongst Service Users, Carer’s and Laypeople: A Qualitative Study of the Sikh Perspective

IRAS project ID: 272921
Protocol number: SOC.08/19-20
REC reference: 20/NW/0092
Sponsor: University of Warwick

I am pleased to confirm that the HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the ‘Information to support study set up’ section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The standard conditions document ‘After Ethical Review – guidance for sponsors and investigators’, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Yours sincerely,
Rekha Keshwa
Approval Manager
Email: approvals@hra.nhs.uk
Copy to: Miss Aruna Kulur
Appendix 8D(i): NHS HRA Amendment Approvals

IRAS Project ID 272921. HRA and HCRW Approval for the Amendment
solihull.rec@hra.nhs.uk <noreply@harp.org.uk>
Thu 24/09/2020 11:35
To: Singh, Swaran <S.P.Singh@warwick.ac.uk>; KULAR, ARIANA (PGR) <Ariana.Kular@warwick.ac.uk>

Dear Ariana,

<table>
<thead>
<tr>
<th>IRAS Project ID:</th>
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<tr>
<td>Short Study Title:</td>
<td>Views of Mental Illness and help-seeking within the Sikh Community</td>
</tr>
<tr>
<td>Amendment No./Sponsor Ref:</td>
<td>SOC.08/19-20 AM01</td>
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<tr>
<td>Amendment Date:</td>
<td>27 August 2020</td>
</tr>
<tr>
<td>Amendment Type:</td>
<td>Non Substantial Non-CTIMP</td>
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I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/](http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/).

Please contact [amendments@hra.nhs.uk]amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Andrea Bell  
Approvals Specialist  
Health Research Authority  
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH  
E: amendments@hra.nhs.uk  
W: [www.hra.nhs.uk](http://www.hra.nhs.uk)

Sign up to receive our newsletter [HRA Latest](http://www.hra.nhs.uk).
Appendix 8D(ii): NHS HRA Amendment Approvals

24 November 2020
Miss Arora Kumar
129 Wantyge Avenue South
Coventry
CV3 6BY

Dear Miss Kumar,

Study title: Perceptions, Understanding and Help-Seeking regarding Psychotic Disorders amongst Service Users, Carers and Laypeople: A Qualitative Study of the Sikh Perspective

REC reference: 26/AM/0062
Protocol number: SOC/08/19-20
Amendment number: SOC/08/19-20 AM02
Amendment date: 03 November 2020
IRAS project ID: 272921

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee made the following recommendation which is not a condition of the favourable opinion.

The Sub-Committee noted a typographical error on the consent form which should be updated, the phrases "participant says provides consent", "needs altering to", "participant provides consent", "This change does not need submitting to the REC for review".

Approved documents
The documents reviewed and approved at the meeting were:

A Research Ethics Committee established by the Health Research Authority.

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<td>Copies of materials calling attention of potential participants to the research [Service Users and Carer Recruitment Poster]</td>
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<tr>
<td>Letters of invitation to participant [Participant Invitation Letter]</td>
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<td>03 November 2020</td>
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<td>Participant consent form [Service User's Consent Form (Face to Face Interviews)]</td>
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<td>03 November 2020</td>
</tr>
<tr>
<td>Participant consent form [Carer's Consent Form (Face to Face Interviews)]</td>
<td>6</td>
<td>03 November 2020</td>
</tr>
<tr>
<td>Participant consent form [Verbal Telephone Consent Script for Service Users]</td>
<td>2</td>
<td>20 November 2020</td>
</tr>
<tr>
<td>Participant consent form [Verbal Telephone Consent Script for Carers]</td>
<td>2</td>
<td>20 November 2020</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [Carer Participant Information Sheet]</td>
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<td>20 November 2020</td>
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<td>Participant information sheet (PIS) [Service Users Participant Information Sheet]</td>
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<td>20 November 2020</td>
</tr>
<tr>
<td>Research protocol or project proposal [HRA Protocol]</td>
<td>5</td>
<td>03 November 2020</td>
</tr>
</tbody>
</table>

Membership of the Committee
The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations
Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of the amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19
We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify any relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning
We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities—see details at: https://www.hra.nhs.uk/staffinfo-and-learning-research-learning/
Appendix 9: Data Analysis

Appendix 9A: Excerpt from Transcripts

---

Laypeople Interview
Participant 15

Date: 10/07/2020
Duration: 24:29

Researcher
Yeah. Okay. So, what do you think Manjit might be experiencing?

L15
I'm early signs and symptoms of depression, erm potential psychosis but with an affective element to her presentation.

Researcher
Okay

L15
Erm, there are also appear to be some negative symptoms, potentially. Yeah, that's kind of... what, I think she's on the early onset of that.

Researcher
Okay

L15
Okay, what specific symptoms kind of related to what you just said like what's jumping out at you to say that?

Researcher
L15
Okay, so she stopped doing her household work, which doesn't appear to be common. It's an uncommon practice, of the daily kind of routine. So there's early warning signs there. Erm, she doesn't interact with her children. So her social interaction erm with others is lacking. So much so that she's not even looking after herself. And when you take pride if I can dare say that word with oneself, and yeah, she's kind of lost that touch I mean. It also says she's socially withdrawn. Erm her family have noticed that objectively, there appears to be some response to external stimuli. And yeah, that idea that she's admitting to hearing voices of strange people speaking to her, would suggest auditory hallucinations.

---

Carer Interview
Participant 6

Date: 20/02/2021
Duration: 30:07

Researcher
Okay, so when did you first start noticing like changes in your brother's behaviour?

C6
Um, so he got ill this time last year. So around about a few weeks, a week before he went into hospital, and got admitted into the ward. It was just like things like low mood and kind of looking out on us, like being angry, things getting to him, you know. And when we asked him what's up and him not really wanting to talk about it, and we thought, you know, that's just him being him, and he's going through something, but we didn't think it was that serious.

Researcher
Okay, so then.

C6
Okay.

C6
Offactually, two years before that he had got really depressed during undergrad. So he was seeing someone at that time. But we didn't think it would come back, a lot worse. So that's all there.

Researcher
Okay.

C6
Okay.

C6
Like, we had been through it before, so I was kind of telling my parents that maybe he needs to see someone. But then within a week, it got really bad, where he was getting paranoid, and stuff and hearing things. And you know, and needed urgent attention.

Researcher
Okay.

---
# Appendix 9B: Example of Initial Codes from NVivo Codebook (Laypeople)

<table>
<thead>
<tr>
<th>Name</th>
<th>Files</th>
<th>References</th>
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<tbody>
<tr>
<td>#Age for later symptoms of psychosis</td>
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<tr>
<td>ability to understand anxiety dependent upon if they have anxiety</td>
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</tr>
<tr>
<td>Accept MH as a concept, but not it being attached to a family member</td>
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<td>1</td>
</tr>
<tr>
<td>Accept physical illnesses, but not mental illnesses</td>
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<td>18</td>
</tr>
<tr>
<td>accept physical illness requires medical treatment, but not mental illness</td>
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<td>3</td>
</tr>
<tr>
<td>Mental illness not considered a medical illness</td>
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<td>5</td>
</tr>
<tr>
<td>physical illness more understood than mental</td>
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<tr>
<td>Address early symptoms of psychosis with parents first</td>
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<td>3</td>
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<tr>
<th>Name</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address psychosis with parents first</td>
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<td>1</td>
</tr>
<tr>
<td>alcohol is a coping mechanism for punjabi's</td>
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<td>12</td>
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<tr>
<td>Alcoholism Common in Punjabis - Linked to Depression, hence depression more familiar</td>
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<td>1</td>
</tr>
<tr>
<td>All mental illnesses should be made familiar and discussed - not just milder ones</td>
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<td>1</td>
</tr>
<tr>
<td>Antidepressants</td>
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<td>antidepressant to treat psychosis</td>
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<td>antidepressants made symptoms of depression and anxiety worse</td>
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<td>2</td>
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<td>Anxiety</td>
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<td>57</td>
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<td>anxiety - coping techniques</td>
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<td>anxiety - GP positive experience</td>
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<tr>
<td>anxiety - GP visit and feedback positive</td>
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<table>
<thead>
<tr>
<th>Name</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>understanding of psychosis based on TV portrayal</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Understanding of schizophrenia obtained through novel</td>
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<tr>
<td>Awareness of various MH terms, but not psychosis</td>
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<tr>
<td>awareness or knowledge of mental health if family member works in the area</td>
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<tr>
<td>Background in MH enabled detection of MH symptoms</td>
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<tr>
<td>barrier to awareness</td>
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<tr>
<td>be open minded when addressing early symptoms of psychosis</td>
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<tr>
<td>Be supportive of other people's mental health</td>
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<td>become aware of mental health due to personal family experience</td>
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<td>being open about mental health experiences to reduce stigma</td>
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<th>References</th>
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</thead>
<tbody>
<tr>
<td>Fear of Psychosis</td>
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<td>10</td>
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<tr>
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<tr>
<td>Fear that someone with psychosis will do something to you</td>
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<tr>
<td>reluctance to approach person experiencing psychosis</td>
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<td>Fear of the unknown</td>
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<tr>
<td>fear to use mental health terms</td>
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<tr>
<td>scared of diagnosis of anxiety</td>
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<tr>
<td>worried about how the person with MH might behave in front of others</td>
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<td>Fear of Psychosis</td>
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<tr>
<td>fear of approaching individual experiencing psychosis</td>
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<tr>
<td>Fear that someone with psychosis will do something to you</td>
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**Appendix 9C: Example of NVivo Project File Coding (Family Member Study)**

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<th>Name of Transcript</th>
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<th>Total number of text references assigned a code</th>
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<tr>
<td>C2</td>
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<td>C5</td>
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<td>320</td>
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<td>C6</td>
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<td>C7</td>
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<td>186</td>
</tr>
<tr>
<td>C8</td>
<td>83</td>
<td>312</td>
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</table>

- **Name of Code**: Involvement of police - description of episode
- **Name of Transcript Code is Located in**: Files
- **How many times code appears in each transcript**:
  - C4: 6, Coverage: 8.05%
  - C6: 10, Coverage: 8.72%
Appendix 9D: Extracts from Reflexive Analysis Diary (Laypeople Study)

Analysis – Diary of Reflexivity

22/01/2021 – Pre-Analysis Thoughts:
- Reflexive Thematic Analysis is the confirmed analysis of codes.
- Met with supervisor Helena to discuss analysis and all discuss general themes that emerged from doing the interviews alone.
  - The interview has provided various perspectives, for example participants have responded to a case vignette or a hypothetical character with psychosis which addresses what they think the illness is and help-seeking behaviours. Their mid-way through the interview, the early and later symptoms of psychosis are discussed, and the researcher asks ‘If someone close to you, let’s say immediate family member is experiencing these symptoms what would you think is wrong, and how do you go about this issues?’ – i.e. asking about their understanding and help-seeking again this time through a hypothetical situation but with someone who is a real person in their life. It would be interesting to compare the two responses to these – do they differ?
  - Also, participants provide their own personal understanding, attitudes, beliefs, perception and help-seeking behaviours towards psychosis but also speak on behalf of the wider Sikh community. These two views differ, and there is a general consensus amongst most of the laypeople interviews that the participants themselves express more understanding and more westernised views towards mental illness (i.e. social and biological causes, seeking help from GP, etc.) but when they talk on behalf of the wider community they all deny to the negative attitudes and beliefs there are towards psychosis and mental health more generally.
  - They also speak about religious and supernatural causes being a belief within the Punjabi, Sikh community with is considered more of a culturally driven belief rather than religious, however, the views between the two are blurred. However, this answer is generally mentioned only when the researcher has probed, and reflects the views of the wider Sikh community, and is generally not endorsed by the participant themselves, but they express these views as prevalent in the Sikh community, as it is in other South Asian groups such as Pakistani Muslim community.
  - Mental health as a catch all term – participants also would use the terms psychosis and mental health interchangeably – possibly reinforcing the idea that was apparent in the literature that mental health is just seen as a broad illness, with little distinction between the illnesses. Another viewpoint could be that the belief towards psychosis would be no different than the views of other forms of mental illness – and that is that the Sikh community perceive mental health the same way, and their attitudes and beliefs will not differ depending on the type, i.e., having a mental illness is just having any mental illness, and it’s looked at negative regardless.

26/01/2020 – Initial Coding

Transcripts that were coded today: L14 & L14
A separate node will be created for ‘Case vignette’ – I will separate all the data derived from case vignette portion of interview under this node. This is so that I might possibly do a separate analysis for this. I have still done coding on this portion as well along with the rest of the transcripts for this.

Initial Thoughts

Despite questions being psychosis specific, it is evident that participants answer most questions also related to general mental health (mainly when it pertains to questions on attitudes and beliefs). Reinforces the lack of distinction between different mental illnesses and thinking of mental health as one singular illness.

27/01/2020 – Initial Coding

Transcripts that were coded today: L18 & L14
Regarding vignette presentation, I have noticed thus far people say depression, but then recognize the voices as something distinct from depression. Some people also have voices meaning schizophrenia. Important to note though, that the first three interviews transcribed L12, L14, and L14 all have a background in mental health – Two have done psychology (L13 and L14) and L14 has said they have worked in the area of mental health.

Participants don’t generally allude to religious and supernatural beliefs, attitudes and causes on their own, but when probed they do agree it is a prevalent thing within the Sikh community. L13 is an example of this.

03/02/2021 – Initial Coding

Transcripts that were coded today: L13 & L21

Some thoughts from L12:
- Cultural explanations and religious explanations differ
- Cultural explanations are closely linked to the supernatural attributions such as evil and 郭非

Stage 1: Familiarisation

As I collected the data myself, I had that initial familiisation with data. Following this, I transcribed the data myself, and undertook three rounds of transcription which involved listening to the audio recordings simultaneously. This, supplemented my familiarisation with the data. Once these final transcripts were imported into NVivo I read through the transcripts several times, prior to initial coding. I would read the transcripts that I was analysing that day, due to the volume of data I had I made any annotations within NVivo where necessary. I also had a separate Analysis Diary, where I made any key notes or thoughts from the data I realised that day.

Stage 2: Initial Codes

12 Transcripts

The first 12 transcripts that were coded were:
- L13 (94 Codes)
- L15 (110 Codes)
- L15 (144 Codes)
- L15 (159 Codes)
- L16 (191 Codes)
- L16 (191 Codes)
- L17 (91 Codes)
- L14 (197 Codes)
- L13 (191 Codes)
- L12 (105 Codes)
- L14 (125 Codes)
- L13 (85 Codes)

Initial coding was done predominantly as line-by-line coding, but where necessary some codes spanned 2-4 lines. Also, multiple codes may have been used for the same highlighted passages.

After the first 12 transcripts were initially coded, there was a total of 886 codes.

The large number of codes was largely due to the researcher coding ideas using words that could be used interchangeable, i.e. (knowledge of psychosis, awareness of psychosis, familiarity of psychosis, understanding of psychosis, perceptions of psychosis, etc.). These terms all allude to the same overall concept.

Additionally, there were several codes that were referring to the same concept but were worded differently.

Also, the researcher used abbreviations such as SM or MH for some codes but stayed out the severe mental illness and mental health for other codes, which led to an overlap of similar codes.

Finally, initial coding was carried out very detailed and specific, which also accounts for the large number of codes.

04/02/2021 – Initial Coding

Transcripts that were coded today: L04 & L20

- People are starting to understand more about depression
- Anxiety is still not as known
- SM would be the least known
- Early symptoms of psychosis being perceived as depression - a dominant theme
- Therapy and counseling seem to be commonly mentioned in all transcripts
- Wider community and other generations perceiving psychosis just as ‘normal’ and not looking into it any further, or not understanding it any further, nor willing to understand it.
- Rarely thinking that the person will just get better, that they don’t have to get help, they will eventually just get better by themselves
- External blame on mental illness, including psychosis
- Culture can influence mental health attitudes, beliefs, understanding more religion.

05/02/2021 – Initial Coding

Transcripts that were coded today: L04 & L21

- Education impacts racial beliefs. Skills that are less educated are more likely to endorse religious and supernatural causes, whereas those who are educated would endorse biological and social
- Important when researching themes that establish that participants are talking about the wider Sikh community
- Another common theme is that those with a mental illness like psychosis won’t get better
- Another common theme is that religion and culture divide. It is in fact culture that influences most people perceptions towards psychosis and mental illness, but there is a blurred line, there appear to be little influence of the actual Sikh religion on understanding and perceiving mental illness

06/02/2021 – Initial Coding

Transcripts that were coded today: L13 & L21

Some thoughts from L12:
- Cultural explanations and religious explanations differ
- Cultural explanations are closely linked to the supernatural attributions such as evil and 郭非