Experiences of Caring for a Child with Mental Health Difficulties: An Interpretative Phenomenological Analysis of South Asian Familial Caregivers in the UK

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Declaration

I confirm that this thesis is an original piece of work conducted by the author. It was competed and submitted as a requirement for the author's Clinical Psychology Doctorate at the University of Essex. This thesis has not been submitted for any other academic award.

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Abstract

Background: Despite an awareness of significant mental health difficulties (MHD) seen amongst the British South Asian (SA) population, there remains large ethnic disparities in mental health treatment and service utilisation. This may lead to South Asians (SAs) being more likely to support MHD within the family. Despite this, limited research has investigated the experiences of these familial caregivers within a British SA context.

Aims: This study explored the experiences of caring for a child with mental health difficulties amongst SA caregivers in the UK. It aimed to understand their views on help-seeking and how they may use aspects of their culture and religion in the way they understand mental health and support their child.

Methodology: Semi-structured interviews were conducted with 10 SA primary caregivers who were currently caring for at least one child aged 5-19 with MHD. Participants were recruited through social media and word-of-mouth. Interpretative Phenomenological Analysis (IPA) was conducted to explore the in-depth meaning of participants' experiences.

Results: The analysis revealed three Group Experiential Themes (GETs). GET one, "Leaving the Past in the Dust and Paving a New Path", described participants difficulties with cultural pressures, the cultural silence around mental health, and their efforts to break away from these norms. GET two, "Navigating the Never-Ending Tunnel of Distress" detailed participants' efforts to support the child's mental health and the impacts of doing so. GET three, "Caught in the Tug of War of Support", portrays the conflicting relationship caregivers experienced with religious and cultural support, as well as their resistance to culturally-inappropriate statutory services.

Discussion: The findings suggest the SA experience of making sense of and caring for MHD is complex. The findings emphasise an urgency for culturally sensitive policies and interventions that recognise the various religio-cultural values and needs of SAs with MHD. The findings are discussed in the context of the strengths and limitations of the study and have significant implications for policy, communities, clinical practice, and future research.

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Abbreviations

SA	South Asian
SAs	South Asians
MHD	Mental Health Difficulties
MHS	Mental Health Services
IPA	Interpretative Phenomenological Analysis
PETs	Personal Experiential Themes
GETs	Group Experiential Themes
UK	United Kingdom
GP	General Practitioner
NHS	National Health Service
CASP	Critical Appraisal Programme Tool

Chapter 1: Introduction

1.1 Chapter Overview

This chapter will contextualise the present research by aiming to set the context for the South Asian mental health experience in the UK. It will provide an overview of the historical background of South Asian (SA) migration to the United Kingdom (UK), the prevalence of mental health problems in South Asians (SAs), factors influencing this prevalence, the barriers and enablers to accessing mental health support, the experiences of familial caregiving for mental health, and the role of family in SA culture. A systematic literature review will follow this, summarising the current research in the field of familial caregiving for mental health within a SA context. Thus, this chapter will provide an understanding of the importance of carrying out the present research and justify the research question of the empirical study.

1.2 The British South Asian Diaspora

Historically in the UK, the term 'South Asian' has often referred to individuals from the Indian subcontinent. However, the term 'Indian subcontinent' is problematic as it is inextricably linked with the region's colonial heritage and is thus seen as offensive by many from this part of the world. This term also positions India within a dominant position, leading to the historical neglect of Pakistanis, Bangladeshis and Sri Lankans as SA people (Chapman, 2009). Thus, this research will refer to the geographical region that includes the countries of India, Pakistan, Bangladesh and Sri Lanka as 'South Asia'. The Office for National Statistics (ONS) (2021) does not differentiate South Asia from other parts of Asia, utilising the ethnic group of 'Asian or Asian British', which includes Indian, Pakistani, Bangladeshi, Chinese, and Any other Asian Background. In doing this, it does not take into account the cultural differences between SAs and East Asians, for example. The present research defines 'South Asian' as Indian, Pakistani, Bangladeshi, or Sri Lankan, or any other SA background, such as

Punjabi, individuals from mixed SA parentage, or third-generation Asians. This ethnic definition goes further than the historically used geographical definition. This ethnic category is utilised throughout current literature as it refers to people who share time, place, similar cultural traditions, and socio-political histories (Hamer et al., 2020). Nonetheless, there will undoubtedly be significant differences between and within various SA communities, in terms of origin, caste, religion and language (Sangar & Howe, 2021).

SAs were present in the UK from as early as the 17th century, with the first large groups arriving being *lascars* (sailors), recruited by the British East India Company, and soldiers working for the British Army. A surge of emigration of SAs to the UK occurred in the post-World War II period, with the largest group of settlers arriving in the 1950s (Peach, 2006). The Partition of India in 1947, following the end of the British Raj, led to the establishment of the Dominion of India and the Dominion of Pakistan. Following the Bangladesh War of Independence in 1971, the regions of East Pakistan and West Pakistan split to become what is now known as Bangladesh and Pakistan respectively. Many individuals from the Sylhet region of Bangladesh migrated to Britain during this time, to avoid civil unrest (Peach, 2006). The impact of the British rule and Partition left many parts of India, Pakistan and Bangladesh unsettled (Kalayil, 2019). This, alongside the British post-war labour shortages, led to many moving across to Britain in seek of a better life (Arnold, 2012). Migrants found work in the manufacturing, textile, and service industries, as well as jobs in factories. Sri Lankans have settled in the UK since the 19th Century, during the British Ceylon period, although the majority of Sri Lankan migration occurred in the 1980s, during the Sri Lankan Civil War (Jones, 2014).

Understanding the widespread migration of SAs to the UK is a complex task that requires an exploration of the impact of British colonialism on SAs. The British rule from the 1800s to the mid-1900s caused intense human tragedy across South Asia. Those under British rule experienced exploitation of their industries and resource extraction, all whilst India was reduced to poverty and famine (Bose & Jalal, 2022). The creation of arbitrary divides across the region created internalised conflict and fuelled political unrest (Mishra, 2016). Despite the Partition being publicly viewed as freedom and liberation, it tore families apart and led to widespread displacement (Leaning & Bhadada, 2022). Colonialism left the two new nations of India and Pakistan in turmoil; with instability and few job prospects, many were forced to relocate to Britain (Leaning & Bhadada, 2022). This journey was rife with challenges, with those migrating required to uproot all they've known, often leave their families behind, and adjust to a new world and way of living (Chawla, 2014). Despite the end of the British Raj, the impact of British rule is ongoing and the trauma experienced by those under imperialism has been inadvertently passed through to younger generations (Qureshi et al., 2023). The feelings of sadness, anger and not belonging experienced by younger generations of SAs in the UK have been exacerbated by overt racism in Britain, mirroring the experiences of their parents and grandparents.

Population estimates in 2019 show that 6.1% of the population in England and Wales identified as being Indian, Pakistani, or Bangladeshi. (ONS, 2021). Several religions[1] are practised among SAs, with Islam[2] being the most prominent religion followed by Pakistanis and Bangladeshis, and the fastest-growing religion in the UK (Halkon, 2015; ONS, 2018). Amongst Indians, Hinduism and Sikhism are followed as well as Islam.

1.3 Mental Health in British South Asians

Many terms and phrases have been used over the years to describe an individual's problems with their emotional wellbeing. Terms such as 'mental disorder' are now outdated,

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[1] Religion refers to a particular system of faith and worship, relating to the service and worship of a higher power (e.g., God or multiple Gods) and behaviour and practices that align with such beliefs (e.g., prayer).

[2] Islam is an Abrahamic religion wherein followers believe in one God, (*Allah* (SWT[1])), and that Prophet Muhammad (SAW[2]) was his final messenger. The word *Islam* is Arabic for *submission* or *surrender*, indicating followers' faithful surrender to the will of Allah. Islam is the second-largest religion in the world, after Christianity (Hughes, 2021).

given the understanding of mental health existing on a continuum and the issue of mental health stigma (Keyes, 2002; Sickel et al., 2014). For this thesis the term mental health difficulties (MHD) will be utilised, as it appears to move away from a stigmatising view and an enduring nature of mental health. MHD was preferred over ‘mental health problems’ as the latter use of ‘problem’ may insinuate there is a single, correct solution, whereas ‘difficulties’ lends to the idea that MHD are barriers that can be overcome by working through them, creating a more empowering image for individuals experiencing MHD. When referring to MHD in this thesis it will refer to periods where individuals may struggle with their thoughts, emotions, or behaviours which become persistent and difficult to manage that they impact various aspects of their day-to-day life (e.g., learning, occupation, or family relationships). These difficult experiences might fluctuate and may also be in response to stressful life events.

Given SAs’ history of oppression, over the last 20 years research has begun to increasingly focus on exploring mental health difficulties (MHD) in SA populations in Britain (Karasz et al., 2019). There appear to be significant ethnic differences in the prevalence of MHD. An epidemiological study found higher rates of common mental disorders (CMDs) in all categories of SA men aged 35 and under, and significantly higher rates of CMDs among Indian and Pakistani females (24% and 26% respectively) compared to White counterparts (19%) (Weich et al., 2004). Ethnic differences in the manifestation of common mental disorders have also emerged. For example, in a sample of Punjabi and English people based in London, general practitioners (GPs) were more likely to identify Punjabis with CMDs as having somatic symptoms than English subjects (Bhui et al., 2001).

Similar patterns of ethnic differences in psychological distress are seen in SA youth. Research has found that SA children (Indian, Pakistani, and Bangladeshi) showed significantly higher levels of MHD than White children (Bains & Gutman, 2021; Platt, 2012).

More specifically, Pakistani and Bangladeshi children have been shown to exhibit more internalising difficulties than their White counterparts (Midouhas, 2017; Zilanawala et al., 2015). These results suggest worse mental health is not limited to SA adults, indicating a need for understanding the causes at play and appropriate intervention. Several factors have been implicated in the proliferation of MHD in SA communities, which will now be discussed in turn.

1.3.1 Racism and Discrimination

Racism is an experience that is not uncommon for many SAs in Britain. Racism refers to discrimination or prejudice towards an individual or group of people based on their race, ethnicity, or skin colour. This can occur at an intra-personal, individual, institutional or policy level. Historically it has centred around the idea that one race (i.e., White) is more superior than others (Blum, 2020). Racism does not just relate to overt acts of discrimination (e.g., verbal aggression) but also more covert, day-to-day microaggressions (e.g., mispronunciation of someone's name because it is perceived as too difficult to say). Since SAs began settling in the UK, they have been the target of discrimination, through both overt verbal and physical abuse and also microaggressions, where there is often no direct incident but an awareness of being treated unfairly because of race (Sue et al., 2007). The fear instilled in victims of racism can lead to pessimism, hopelessness, and low self-confidence. Psychological distress is an understandable reaction to threats to an individual's identity, with the possibility of post-traumatic stress occurring from explicit hurtful comments and physical attacks (Bhui et al., 2018). An increasing body of evidence is shedding light on the link between racism and mental health, wherein psychological disorders such as psychosis and depression are more likely to occur in those who have experienced racism (Karlsen & Nazroo, 2014; Williams & Etkins, 2021).

Following a series of terrorist attacks in the 21st century, including 9/11 and 7/7, the religion of Islam has become inextricably associated with violence and the instigation of fear (Ghumkhor & Younis, 2021). As many British SAs are Muslims[3], this link has regrettably been extrapolated to most SAs based on skin colour (Allen, 2004). This fear of terror attacks has exacerbated existing racism towards SA Muslims with increasing negative depiction in the media, alienation, and perpetuation of violence (Ciftci, 2012). The UK Government's commencement of the 'war on terror' led to enhanced monitoring of extremist activity in an attempt to combat terrorism (Younis, 2021). This has led to a focus on Muslim communities, where individuals have become the target of racial and religious profiling as a result of policies such as Prevent, which allow organisations to report individuals they fear are at risk of radicalisation (Cohen & Tufail, 2017). These actions of the UK Government have encouraged and perpetuated Islamophobia within Britain. Islamophobia is complex and multi-faceted. It generally refers to racism, discrimination, and prejudice towards and against Muslims. This may take the form of religious or racial slurs, protests, and/or physical violence to deny Muslims "dignities, liberties and rights across a range of political, economic, social and cultural institutions" (Beydoun, 2016; Elahi & Khan, 2017, p.7). The effects of terror attacks and Islamophobia have impacted Muslims' faith, feelings of marginalisation, and confusion regarding their identity as British citizens, which leaves them at higher risk of psychological distress (Dadabhoy, 2018).

1.3.2 Acculturation

A discussion around the theory of acculturation initially requires a firm understanding on what is meant by culture. There is no one definitive definition of culture and as such this thesis takes the understanding that culture is the customs, beliefs, values, behaviours, and

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[3] The terms Muslim and Muslims are used interchangeably to refer to the name given to those who follow the religion of Islam. The term *Muslim* may also be used as an adjective (e.g., Muslim country to describe a country where Islam is the predominant religion).

norms shared by a particular group of people or community (Fernando, 2010). Culture may not only consist of material objects, but also spiritual components, social processes, and internal psychic processes (Mironenko & Sorokin, 2018). It is important to note that culture is an ever-evolving and complex idea and its definition may differ depending on the context in which it is described. Within Western countries understandings of culture have historically been situated within the context of ethnicity, particularly being related to racially minoritised individuals (Spencer-Oatey, 2012). This view is overly simplistic as the view of culture as the aggregation of aspects of a particular social group does not negate the existence of White majority groups exhibiting their own cultural practices (Grossman & Charmaraman, 2009). Perhaps the historical positioning of culture as solely situated within minoritised communities perpetuates the idea of difference-ness and thus marginalisation of the global majority.

As culture forms an integral part of this thesis, it is important to delineate what is specifically meant by SA culture and British culture within the context of this research. SA cultures have been described as predominantly collectivist, where an individual is seen as wholly embedded within the social group's identity and the idea of autonomy is generally discouraged. These norms encourage emotional dependence, fulfilling duties, and maintaining familial integrity, which may lead to the sharing of care within the in-group (Triandis, 2018). On the other hand, Western societies are seen as individualistic, where independence and autonomy are valued and the rights of individuals take priority (Otto & Keller, 2014).

Sam and Berry (2006) describe the term *acculturation* as "the process of cultural and psychological change that results from the continuing contact between people of different cultural backgrounds". This model of acculturaton discusses the balancing act between, generally, two different cultures. The culture from which a person is from is termed the 'origin culture' and the culture to which a person migrates to is termed the 'host culture'

(Sam & Berry, 2006). The term *host culture* may be perceived as outdated as it may insinuate the new country welcomes migrants, which is not always the case, and that the migrants are temporary guests to the new country when in fact many perceive it as their long-term home (Schwartz et al., 2010). Instead, the term 'receiving culture' will be used which may reflect the acculturation process more accurately. Berry (1992) posits there are four outcomes to acculturation: *assimilation*, where cultural values are abandoned and the receiving culture's norms are completely adopted, *separation*, where there is complete identification with the origin culture and rejection of the receiving culture, *integration*, where aspects of the new culture are merged with the original culture identity, and *marginalisation*, where the individual renounces both the heritage and dominant cultures. Research has identified differences in acculturation strategies between first-generation migrant parents and their second-generation children that were born and brought up in a different culture to their origin country; SA caregivers tend to favour separation, whereas adolescents lean more towards integration (Birman, 2006).

The challenges that occur during acculturation are known as acculturative stress (Berry, 2006). Although Western values may posit adolescence as a developmental period of independence, it is recognised more as a continuation of childhood within SA households (Masood et al., 2009). The differences in approaches to acculturation between parents and adolescents often lead to conflict at home, as SA youth attempt to navigate the increasing influence of Western ideologies which may generate acculturation gaps (Abouguendia & Noels, 2001; Masood et al., 2009; Tonsing, 2014).

. Difficulties in acculturation may be intensified due to the balancing act required to maintain the origin cultural values in the family home and the adoption of ideals from the new culture's wider society. These attempts to coalesce two cultures impact various aspects of an individual's life, including language fluency, dress, and mannerisms (Rudmin, 2009;

Safdar et al., 2020). Understandably, acculturative stress can lead to individuals constantly negotiating their identity (Sekhon & Szmigin, 2011). This may explain the preference of SA adolescents for friendships with individuals of a similar ethnic background, as a way of maintaining their cultural beliefs in a Eurocentric country (Bhui et al., 2005; Shams, 2001). As well as conflict between those who migrated and those who were born and brought up in the new country, acculturative stress also encompasses discrimination which, combined with factors such as material deprivation, can create high levels of distress and poor mental health. For example, SA adolescents who had more culturally integrated friendships, that is friends from both their own and different cultures, had fewer MHD than those who only had friends from their own or other cultures (Bhui et al., 2005). Acculturative difficulties with ingroups and outgroups have been associated with greater levels of depression, eating disorders, and low self-esteem (Abouguendia & Noels, 2001; Kunst & Sam, 2013; Lesser et al., 2014). SA adolescents born and brought up in the West describe having a dual sense of self and experience stress that this duality cannot be expressed openly (Tummala-Narra et al., 2016).

1.3.3 Structural Disadvantage

SAs are often disadvantaged by systemic socioeconomic inequalities that are embedded within Western society via policies that favour White, middle-class communities (Barling, 2022). Of all Pakistani and Bangladeshi households in the UK, 35% live on a low income, compared to 14% of White households, and SAs are more likely to live in the most deprived areas (Toleikyte & Salway, 2018). In terms of education, SAs are generally less likely to receive adequate schooling and inadequate education has been associated with negative effects on mental health, such as feeling depressed (Jiang et al., 2020; Midouhas, 2017). Employment can have positive impacts on individuals, due to the financial stability and sense of fulfilment it can provide. Despite this, employment can be a major source of stress for SAs. Those who do achieve academic success and complete a university degree are less likely to find permanent jobs and their lifetime earnings are significantly less than their White counterparts (Bhui et al., 2018). Pakistanis and Bangladeshis are 9% more likely to be unemployed than White individuals (Toleikyte & Salway, 2018). In-depth interviews with SA male service users revealed that many felt worries about employment and earnings were factors in the precipitation of their MHD (Bowl, 2007). Poor education, poor housing, unstable employment, and poverty have been consistently linked with psychological distress, to which SAs are more susceptible (Karlsen & Nazroo, 2002; Nazroo, 2003).

1.4 Mental Health Service Utilisation Amongst South Asians

The term ‘help-seeking’ is one that has become inextricably linked particularly to the sphere of mental health. It refers to the action of an individual actively seeking help for MHD, either for their self or someone they know. Within research it is often referenced when specifically discussing seeking help from professional MHS, such as those within the NHS. However, this focus tends to negate that accessing help for MHD may occur through other avenues, such as through friends and family (Rickwood & Thomas, 2012). The term ‘help-seeking’ may be difficult for some to accept, due to values of independence and ‘getting on with it’ (Ishikawa et al., 2023). There must also be mention of the fact that seeking help does not always equate to the receiving of help. Despite concerns with the use of this term, it will be utilised in this thesis as it reflects the language used in the majority of published research, which will be important during dissemination for the research to reach the appropriate audiences.

Despite evidence that MHD are prevalent amongst British SA communities, there is a lack of representation of these individuals within traditional mental health services (MHS)[4].

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[4] Mental health services refer to formal, professional services that provide healthcare for those experiencing mental health difficulties. This includes statutory services (e.g., NHS), third-sector/voluntary organisations, and state-funded services that are run privately. Such services often consist of multi-disciplinary professionals including, but not limited to, psychiatrists, mental health nurses, social workers, psychologists, therapists, and support workers.

Between 2021 and 2022, Asian and Asian British individuals were 8% less likely to be in contact with professional MHS than White individuals (Baker & Kirk-Wade, 2023). Research on British youth found that 65% of participants who stated they would not reach out to professional MHS were SA by background (Randhawa & Stein, 2007). This underutilisation of services has been attributed to variation in help-seeking practices, in that SA people are less likely to seek support for psychological difficulties.

1.5 Cultural Barriers to Help-seeking

1.5.1 Stigma

Several cultural factors have been highlighted as possibly affecting the likelihood of help-seeking, one of which is stigma. Early conceptualisations of stigma by Erving Goffman describe stigma as the rejection of an individual from society due to an attribute they possess which is discrediting (Goffman, 1963). In doing so, the difference between a *normal* person and a *stigmatised* person is not something of reality but perception (i.e., "stigma is in the eye of the beholder") (Byrne, 2000). As a result of discriminatory practices, those who experience stigma deal with shame and secrecy. Negative stereotypes, such as dangerousness, weakness, and attention-seeking, are often associated with mental illness and can have harmful consequences for those suffering with MHD. A significant amount of evidence has arisen supporting stigma and negative stereotypes of mental illness (Corrigan et al., 2015; Sadler et al., 2012). In comparison to White British individuals, SAs viewed mental health problems as more dangerous and attributed more anger and avoidance to people with MHD (Ahmed et al., 2020; Mirza et al., 2019). SA girls constructed mental health issues as being 'abnormal' and 'a disease', likely reducing help-seeking behaviour to ensure family honour is not impaired (Sangar & Howe, 2021).

1.5.2 Honour and Shame

There is also a role of honour (*izzat*) and fear of shame (*sharam*) in help-seeking. Within SA cultures there is an emphasis on individuals maintaining the reputation and *izzat* of the family, and the belief that disclosing private matters to the outside leads to *sharam* being brought onto the family. Gossip, which brings familial matters into public knowledge, violates *izzat* (Bradby et al., 2007. Discussing MHD with anyone outside the immediate family, such as medical professionals, is perceived as threatening *izzat* and may bring *sharam* to the family if members of the SA community became aware (Hussain, 2006). Thus, the image that is depicted to 'outgroups' is of the utmost significance, often resulting in the secrecy of MHD. This may explain why research in British SAs has found that cultural values such as preserving family honour affect the uptake of services, and shame predicts reluctance to access professional mental health support (Gilbert et al., 2004; Pilkington et al., 2012).

1.5.3 Beliefs about Psychological Distress

The somatisation of symptoms is often part of an explanatory model used amongst South Asians to explain psychological distress (Tabassum et al., 2000). Research has shown Pakistanis tend to show high rates of somatic symptoms and this may be related to their higher likelihood to believe in a biological or medical cause for their mental distress than other racially minoritised groups (Tabassum et al., 2000). If this is the case, there may be a greater reliance on psychotropic medication to alleviate distress and thus help-seeking behaviours will differ compared to individuals who align with more psychological models of distress. In fact, research has found a link between a belief in a biological explanatory model of distress and a lesser likelihood to attempt to access psychological services (Pilkington et al., 2012)

Religion may also play a role in attitudes towards help-seeking. MHD may be attributed to the possession of a spirit (*Jinn*), as a result of the individual engaging in sinful activities (Shah & Carlsson, 2016). Qualitative studies in SA have identified supernatural forces, such as *Jinn* influence, as common explanations for the emergence of disturbances in the mind (Ali et al., 2017; Dein et al., 2008; Khalifa et al., 2012; Tabassum et al., 2000). As such, individuals may be more likely to look towards religious healing opportunities rather than statutory services (Nizam and Ali, 2021).

The belief of psychological distress being part of an individual's *kismet* (fate/destiny) is one that is held by many South Asians, particularly those with a religious affiliation. Thus, psychological distress is often viewed as something given by God, either as a punishment or a test of an individual's faith (Aggarwal, 2012). Distress may be viewed as part of an individual's *kismet* and thus also cannot be alleviated unless dictated by their destiny. In this case, reaching out to a health professional is seen as an attempt to control or change one's *kismet*, which may be viewed as a sin (Hussain, 2006). Any treatments for psychological distress, such as medication, are only seen to be effective if willed by God and hence, for some, statutory services are seen as redundant (Hussain, 2006). Instead, individuals are more likely to practice *sabr* (patience), having faith that God will ameliorate the distress in time, as well as leaning into religious observance (Hussain, 2006).

1.6 Structural Barriers to Help-seeking

1.6.1 Language Barriers

For SAs who were not born and brought up in the UK, English is likely to be a second language, which may lead to language barriers. For example, there are often not direct translations into SA languages for a number of terms used in MHS, such as mental health, depression, and anxiety (Hussain & Cochrane, 2004). This may make it difficult for individuals to understand the purpose of a service and if they could support them. Furthermore, those who do not understand or speak English to a conversational level may be completely ostracised from such services that don't offer interpreters (Tabassum et al., 2000).

Even when interpreters are available evidence suggests these encounters are not ideal, with service users often reporting the information they shared was misinterpreted and not translated appropriately (Munoz, 2014). Being monolingual in a SA language is likely to increase an individual's feelings of isolation due to it being linked to a lack of knowledge of MHS and available support (Chew-Graham et al., 2002).

1.6.2 Systemic Racism

Healthcare providers may perpetuate the lack of representation of SAs in services by neglecting to resolve persistent ethnic inequalities that are ingrained in the UK healthcare system. For instance, UK GPs are significantly less likely to identify MHD in SAs than White individuals, particularly when individuals show depressive symptoms (Bhui et al., 2001). This systemic racism weaved into the British healthcare system sustains the harmful idea of lesser importance of and prioritisation towards those from SA backgrounds. Similar patterns are seen within psychological therapy services, where SAs are less likely to be given an assessment and treatment (Harwood et al., 2023). In general, SAs are less likely to be referred to specialist services following recognition than all other ethnic groups (Bhui et al., 2003). This evidence suggests there are discriminatory practices ingrained within the healthcare system that may exclude SAs that do seek help from receiving appropriate care.

1.6.3 Mistrust of Services

The lack of trust towards services is often placed specifically towards White professionals, with SAs fearing being misjudged by them (Prajapati & Liebling, 2021). Some research suggests SA individuals view White therapists as "culturally ignorant", unable to understand SA culture (Moller et al., 2016). Individuals have shown concern regarding professionals giving inappropriate advice (e.g., cut ties with your family) that does not take into account the intricacies of a situation, leaning into stereotypes about a 'typical SA' person, and making racist comments (Gilbert et al., 2004; Patel 2016). This discordance between SA cultural values and the perceived ignorance of White professionals may lead to a resistance to engage with services.

It has been suggested improvements in help-seeking amongst minoritised communities may occur through mental health workforces that are diverse and reflect the communities they are attempting to serve (Kyere & Fukui, 2023). In alignment with this, SAs have consistently shared their preference for a professional that shares ethnic and/or religious identity with their selves (Chew-Graham et al., 2002; Gilbert et al., 2004; Moller et al., 2016). SA professionals are perceived as sharing cultural understanding and values, such that they would better understand an individual's challenges and the context in which they're situated, allowing them to open up with more freedom (Prajapati & Liebling, 2021). Having SA professionals present and visible in a service's workforce may signal a sense of safety to individuals from a similar cultural background.

However, working with a SA professional may be a double-edged sword and not always the preferred approach. Although there is a consensus that SA professionals would be more understanding of cultural issues, individuals were concerned about seeking help from them. In relation to themes of stigma and upholding *izzat* as described earlier, SA communities may resist accessing services out of fear of confidentiality not being maintained. Worries regarding confidentiality appear to be a particular concern in instances where mental health professionals may share cultural identity with the individual seeking help, with a fear that information shared would be fed back to the wider SA community (Cinnirella & Loewenthal, 1999; Moller et al., 2016). For some this concern is based on real experiences where confidentiality was breached, leading to individuals being placed in dangerous situations (Chew-Graham et al., 2002). Research suggests these concerns are also more generalised, with samples of Pakistanis and Indians sharing narratives of professionals as a whole being untrustworthy and a source of gossip (Hussain, 2006; Thompson, 2010). These experiences may understandably lead to the development of mistrust towards all services, making SA individuals unlikely to feel able to trust professionals again.

1.6.4 Lack of Cultural Sensitivity

A significant barrier to accessing services is the perceived dissonance between the cultural and religious needs of SAs and what is offered in services. Firstly, MHS in the UK primarily work within a diagnostic framework. However, SAs may view psychological distress differently, as a normal reaction to stressful situations and hence may not align with being labelled as "unwell" or with a diagnosis (Hussain & Cochrane, 2003). Psychotropic medication is often the first line of treatment in services. This approach may be opposed by SAs due to concerns about side effects and becoming dependent (Prajapati & Liebling, 2001). The lack of understanding of the needs of racially minoritised service users seems apparent from the outset of entering services, with some SAs reporting that their culture or religion was not taking into account during the initial assessment phase (Bowl, 2007). This took the form of not involving an individual's family in decisions about their care and not acknowledging religious needs by not providing an appropriate place to pray (Bowl, 2007; Patel, 2016). In fact, for some individuals, engaging in religious observance over and above what is seen as 'the standard' may be viewed as obsessional and pathologised, furthering feelings of cultural exclusion (Bowl, 2007).

Whiteness (i.e., the unspoken norms that perpetuate the power of those who are White and maintain the oppression of the racially minoritised[5]) is deep-rooted in the delivery of MHS in the UK (Lindner, 2018). Whiteness is perpetuated through the offering of

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[5] The terms 'racially minoritised/ethnically minoritised' are used interchangeably in replace of the terms 'Black, Asian and minority ethnic (BAME)' and 'ethnic minority/minorities' which have historically been used in research and academia. Recent discussions have highlighted the use of these terms as unhelpful in that they lack specificity and imply those from a non-White background are inherently a minority based on their skin colour (Saeed et al., 2019). The term 'minoritised', coined by Gunaratnum (2003), provides the understanding that people are actively minoritised by others and thus the act of minoritisation is a social constructionist process fuelled by power (Predelli et al., 2012).

psychological therapies that are often culturally inappropriate, unable to make sense of cultural manifestations of distress. For example, Cognitive Behavioural Therapy (CBT) is currently the most recommended psychological therapy by the National Institute of Health and Care Excellence (NICE) across various client groups (NICE, 2022). However, therapies such as CBT were developed from a Western, Educated, Industrialised, Rich, and Democratic (WEIRD) perspective and thus geared towards those from individualistic cultures, disregarding the different needs of those from collectivist cultures such as SAs (Hays, 2018; Pantalone et al., 2010). Of those who do attempt to access services, they are often faced with professionals who lack cultural competence, which may re-traumatise them and impact their resistance to further treatment (Rehman, 2016, as cited in Karasz et al., 2019). Further, inadequate recognition of, and insensitivity and discrimination towards, the mental health needs of SAs may actively push such individuals away from accessing services (Memon et al., 2016; Weatherhead & Daiches, 2010). These experiences may lead to SA individuals and groups developing mistrust towards MHS, which is understandable given their history of colonisation (Soorkia et al., 2011)

1.7 Attempts to Address Racial Disparities in Mental Health Services

Inside Outside is a policy document which aimed to improve mental health support access for those from racially minoritised backgrounds in England (National Institute for Mental Health in England (NIMHE), 2003). The focus of *Inside Outside* emphasises that change should occur both at the service level and within the communities wherein racially minoritised individuals reside. It set out three main objectives: to decrease and eradicate ethnic differences in the experience and clinical outcomes of MHS, to develop a workforce in mental health that is culturally competent to deliver appropriate services to an ethnically diverse population, and to develop capability within racially minoritised communities to manage MHD (Sashidharan, 2003). Little movement and progress were seen from this policy.

It is possible that due to the policy being written and produced by professionals working in the field and stakeholders, the limited influence from racially minoritised service users may have resulted in aims of the policy that may not have accurately aligned with those of the communities it sought out to help (Nazroo et al., 2020). It

The *Delivering Race Equality in Mental Health Care* (DRE) report built upon Sashidharan's (2003) work, aiming to set out the process of implementation of the strategies highlighted in *Inside Outside* (Department of Health, 2005). The emphasis shifted to institutional change rather than specific outcomes and received backing from service users, community groups, third-sector organisations, and health and social care services (McKenzie & Bhui, 2007). DRE consisted of a five-year plan where three building blocks are outlined to address deeply ingrained race-related problems within mental health systems: more appropriate and responsive services, community engagement, and better information. By 2010, DRE envisioned that racially minoritised communities would be less fearful of and more satisfied with MHS, there would be a reduction in racially minoritised admissions to inpatient units and use of the Mental Health Act (1983), and a range of culturally appropriate and effective treatments and therapies (Department of Health, 2005). However, racially minoritised individuals were still underrepresented in services and persistent inequalities in rates of detention and length of inpatient stays remained following the end of the DRE programme in 2010, highlighting its ineffectiveness (Dyer, 2019). The language used in the name of the policy itself may be perceived as unhelpful, particularly the term *'equality'*. Equality suggests the policy strives to provide the same resources or opportunities to all, which may not accurately support minoritised groups like SAs who have historically been dismissed within services. This disadvantaged position means they may require additional assistance and thus a more equitable approach (Culyer & Wagstaff, 1993).

Inside Out and *DRE* are not the only policies that have been introduced to try and mitigate ethnic inequalities in the treatment and experiences of minoritized individuals. Ashe (2021) found that 589 recommendations were put forward across thirteen race equality policies between 1981 and 2017. The inability of these policies to enact lasting change suffers from the healthcare sector's imperviousness to positive reform, likely as a result of institutional racism (Fernando & Keating, 2008). The lack of transition from policy to practice contributes to the maintenance of MHS within a Eurocentric context, perpetuating the marginalisation of racially minoritised communities. The combination of historical deprivation, discrimination and governmental unwillingness to shift directly impacts the experiences of SA people.

1.8 Childhood, Mental Health, and the Role of Parents

It is clear that British SAs experience fluctuations in their mental well-being with limited support from wider society, which can be understood within a complex system of socio-political factors. This signifies a need to identify the life stage within which these difficulties most often arise, which may guide the use of early interventions. The significance of the first few years of life on later psychological well-being has been discussed extensively within the world of psychology and psychiatry for decades (Skovgaard, 2010). Research has highlighted that some MHD may emerge as early as age four and can last throughout life (Kessler et al., 2007). A recent survey by National Health Service (NHS) England (2022) suggests that over 20% of children aged 8-16 had a probable, diagnosable mental health difficulty. Adolescence is marked by the transition between childhood and adulthood, which comes with physical changes in the body, changes in social environments, and psychological changes, which generate vulnerability for the development of MHD. An epidemiological study found that 75% of MHD emerge before the age of 24 (Kessler et al., 2005). This evidence highlights the significance of the childhood and adolescent periods for healthy psychological development.

The development of MHD early in life can be understood within the context of attachment theory. Attachment theory suggests that infants are born with an innate desire to seek closeness with significant others, known as an attachment figure (Holmes, 2014). It posits that the type of attachment, or lack of attachment, formed with the primary caregiver influences the child’s later ability to feel secure in adulthood relationships (Holmes, 2014). A secure attachment is marked by the caregiver’s sensitive responsiveness to their child’s needs and provision of a safe base for the child to leave and explore their surroundings and foster independence but also to return to in times of distress. It is believed this attachment style develops adults who hold positive views of themselves and others, are independent, and have strong, positive relationships with others (Mikulincer & Shaver, 2010). On the other hand, those with an insecure attachment are thought to struggle with developing stable long-term relationships with others into adulthood. Also, according to attachment theory, interactions with inconsistent, insensitive caregivers predispose individuals to poorer mental health (Mikulincer & Shaver, 2012). This has been evidenced through meta-analyses, where greater levels of attachment anxiety and avoidance have been related to greater levels of depression and anxiety (Spruit et al., 2020; Zhang et al., 2022). However, like many models in psychology, attachment theory is steeped in Whiteness through its development within Western patterns of relatedness. Attachment theory’s claims of universality disregard caregiving practices in non-Western parts of the world. The mere notion of attachment implies the importance of autonomy and independence, whereas this view does not align with non-Western, collectivist cultures, such as SA culture, where relatedness and interdependence are valued (Otto & Keller, 2014). As a result, those from collectivist cultures are often deemed as being insecurely attached due to an overly close caregiver-child attachment

(Agishtein & Brumbaugh, 2013). However, research in Asia has shown that close bonds between the mother and child are adaptive and protective for children, rather than dysfunctional as positioned by Western attachment pioneers (Rothbaum et al., 2002). Thus, care must be taken when extrapolating concepts from attachment theory to SA culture, due to its bias towards Western ways of thinking.

Nonetheless, the role of parents, in general, has a large influence during childhood and is integral to psychological health, with research finding that parental warmth, lesser parental conflict, and lower maternal stress were associated with fewer emotional and behavioural difficulties in SA children (Iqbal & Golombok, 2018). Poorer mental health is seen in SAs where parental control is high (Maynard & Harding, 2010a). Further, the influence on children and adolescents is not limited to caregivers but also the family system as a whole. Depressive symptoms are significantly lower in early adolescence for those who experience greater family cohesion (Chen & Harris, 2019). These influences of family connectedness last far beyond childhood. For example, in a sample of SA American adults, those with a lack of family support and greater conflict with family experienced greater levels of psychological distress (Masood et al., 2009). These influences are not limited to mental health; those who are raised with positive family relationships are more likely to experience fewer chronic health difficulties, better physical health, and higher levels of cognitive functioning in adulthood and older adulthood (Andersson, 2016; Ferraro et al., 2016; Lee & Schafer, 2021). Parents' perceptions of problems are critical to whether their children are identified and referred to MHS; parents' perceived need for and expectations of professional support predict barriers to treatment and their child's engagement (Kazdin et al., 1997; Nock & Kazdin, 2001). Thus, despite the increased independence of children throughout adolescence, the role of parents is not to be dismissed.

1.9 The South Asian Family System

The role of parents, and other family members, may have more specific importance within SA families, where various family members tend to hold specific responsibilities. Understanding this structure of SA families is essential in comprehending why SAs may be more likely to look towards social systems for support (Klineberg et al., 2006). It is important to note, however, that the organisation of SA settlements in the UK are not homogenous, as values and actions may differ depending on religion, language, and individual differences. Thus, the following description gives a brief overview of the key features and values of the majority of SA households. The collectivist nature of SA culture prioritises the well-being and success of the family, over and above individual needs. These values also cultivate an environment wherein interdependence is encouraged, such that children may rely on their parents into adulthood, and vice versa. For example, it is uncommon for a child to move out of the family home until they are married (Bhopal, 2019). Structural Family Therapy (SFT) may describe such close involvement between family members as enmeshment, where the boundaries between familial roles are blurred which assumes a lack of independence (D'Astice & Russell, 2019). This idea of a 'strong' family system positioned around independence is that of a Western, European, individualistic concept, whereas the definition of a family is wholly dependent on its construction within the context of culture (Lau, 2018). In adopting this view of enmeshment, SA families may be dismissed as dysfunctional and their difficulties viewed as unchangeable and non-intervenable by those in authority with the power to provide support.

The influence of parents as authority figures is paramount in all aspects of a SA child's life, and elders are viewed as wise, knowledgeable, and powerful individuals to be respected and listened to. The practice of cultural values such as collectivism becomes complicated for migrant SA families who must adjust to the values and norms of their receiving country. This challenge is reflected in the conflict seen between parents and children when adolescents born and socialised in the West adopt Western ways of living that clash with their parents' expectations (Robinson, 2005).

Within SA families there appears to be certain roles held by various family members. Women, particularly mothers, hold a pivotal position in the family hierarchical structure. Historically in SA culture, personal caregiving, quality time, and discipline have been the primary responsibility of mothers, leading to many being homemakers (Bhopal, 1998). This traditional view of the role of SA women is somewhat reductionist in the modern-day, with this role having changed over time and things like paid employment becoming more common (Ahmad et al., 2007). Still, those who do work must juggle this alongside their caring responsibilities, which may lead to guilt when they are not with their children. Often, wives move in with their husbands and their families following marriage, which adds further complexities to the familial structure (Mehrotra & Calasanti, 2010). Despite the extreme pressures and responsibility placed on mothers within a patriarchal society, for SA women mothering can foster a sense of empowerment and her relationship with her children plays a significant role in developing her own identity as a SA woman (Sangha, 2014; Tsai et al., 2011).

Fatherhood in SAs is linked to a great sense of responsibility and commitment. An integral part of their role revolves around earning income to provide for their family (Gill, 2020. Raising children to have respectful moral values, a good education, and to be linked with their religious and ethnic community is thought to establish successful children (Salway et al., 2009). This is achieved by paying attention to their academics, introducing cultural and religious resources, and integrating them into wider society (Yeung, 2013). The image of a typical authoritarian Asian father figure is one that many contemporary SA fathers disassociate from, with a healthy father-child bond being of utmost importance (Salway et al., 2009).

The distinctive roles of the mother and father within a SA family can be thought about within the context of family systems theory (FST). FST posits that a family can best be understood by viewing the family as a complex, dynamic system of different parts wherein each individual member holds a particular purpose (Broderick, 1993). In this way, it is thought that difficulties in individuals are a result of a dysfunctional family system. Part of Bowen's (1993) theory focusses on the idea of a nuclear family (i.e., two parents and their children) and the development of problems through difficulties within the various relationship patterns in this nuclear family. With this way of thinking, FST may not be appropriate to understand SA families. Many SA families do not purely consist of parents and children, rather their households may include grandparents, aunts, uncles and cousins. This wider, extended familial living can provide additional support in the child-rearing process. For example, the paternal grandmother, aunts, and older siblings can have a great influence on tending to the children and the children's development (Crozier & Davis, 2006). This lack of consideration of diverse cultural differences amongst psychological theories aimed at understanding family set-ups may perpetuate feelings of being misunderstood in racially minoritised communities, furthering their distance from services.

1.10 Caregiving and Familial Support in the Context of Mental Health

As a result of the institutional barriers to services, cultural values, and influential role of family in SA communities, SAs may be more likely to receive support for MHD from within their immediate circle (Klineberg et al., 2006). This lends to a need to understand the experiences of those who might be providing this support. MHD are accepted as being incredibly challenging to live with, given their wide-reaching impacts on all aspects of an individual's life (Connell et al., 2012; Walton-Moss et al., 2005). It becomes an effortful task for those around an individual to support them through the process of managing the mental health difficulty. Caring for a mental health difficulty is arguably inherently unique in comparison to other caring contexts; mental health symptoms tend to fluctuate, which may lead to a caring role that is fuelled with uncertainty and unpredictability (Dam & Hall, 2016).

As mental health policies have failed to deliver systemic change in services and look to diverge from the historical way of supporting mental health through institutionalisation, the consequence is a shift of the burden of care away from services and towards informal carers (Broady & Stone, 2015). Family involvement does appear to be protective in SA youth, with greater parental involvement and more family activities predicting lower levels of depression (Maynard & Harding, 2010b; Murshid, 2017). Nonetheless, there are particular issues that SA teenagers would not feel comfortable discussing with their parents, such as difficulties in romantic relationships, due to fear of judgment (Ali et al., 2017). During adolescence, the influence of friendships tends to take precedence over parental authority, and this is no different in SA youth. Peer support has been linked to emotional distress, with data from a sample of Pakistani adolescents finding satisfaction in friendships was negatively associated with depressive symptoms (Aftab & Sakiz, 2021). Lower levels of peer social support are related to lower well-being scores in Bangladeshi adolescents in East London (Smith et al., 2015). However, adolescence can be a turbulent time for peer companionship, thus the family environment is thought to be a more consistent source of support (Khatib et al., 2013).

Whilst the positive impact of familial involvement on young people has been recognised, this experience of providing care does not come without its challenges. The negative impacts of caregiving across different contexts have been well-documented. One such impact is that on a caregiver's physical health. Research on caregivers of family members with a severe mental illness found higher rates of sleep difficulties, insomnia, and pain compared to other caregivers (e.g., of individuals with dementia) (Gupta et al., 2015). As well as the physical impacts, the emotional and psychological toll of providing care can have drastic impacts on a carer's mental wellbeing (Awad & Voruganti, 2008). Caring for an individual's mental health can lead to economic strain as well as restrictions on a caregiver's social and professional life (Moudatsou et al., 2021). Understandably, these added stressors and sacrifices may precipitate and perpetuate anxiety, depression, and even poor self-esteem if caregivers perceive their efforts are not fruitful (Cabral et al., 2014; Cheng et al., 2022; Kim, 2017). Despite the capacity for caregivers to endure adverse consequences from caring for a family member, this experience may also encompass some positives. Through the caregiving role individuals can experience an immense level of satisfaction, especially when seeing the happiness in the person they're caring for (Bauer et al., 2013). They may also experience personal growth, improved interpersonal relationships, social support, and a sense of fulfilment (McCann et al., 2015; Savage & Bailey, 2004; Veltman et al., 2002).

Despite there being a plethora of evidence on experiences of caregiving, much of this research is situated within White, Eurocentric contexts. As discussed earlier, a number of factors may make this evidence inapplicable to the South Asian population. With collectivism there is a larger focus on togetherness than in individualistic, Western cultures, such that the family's perceived needs often become prioritised over an individual's (Triandis, 2018). Also, values of *izzat* (honour) and *sharam* (shame) may lead to extra effort to conceal MHD from the outside community, which may lead to added pressures for caregivers (Mustafa et al, 2017). The SA value of solving problems within the family may lead to SA parents holding much of the responsibility for supporting their child's mental health. This added responsibility leads to the intensification of parenting, whereby the whole process of child-rearing becomes time-consuming and labour-intensive (Faircloth, 2023). The ideal of being a 'good parent' may be exacerbated for migrant parents, such as SAs, who must also navigate the challenges that come with migration and acculturation in their child-rearing efforts (Faircloth, 2013). Although intensive parenting comes with a rewarding and fulfilling feeling, the burden of being a ‘good parent’ may weigh heavily on individuals and produce feelings of stress and overwhelm, particularly for those from marginalised backgrounds (Nomaguchi & Mikie, 2020). Hence, these cultural differences may lead to wholly different experiences of caregiving in SAs than what has been described above.

1.11 Conclusions from Previous Literature

The literature presented here highlights that MHD are not absent in SAs, rather they may be more susceptible to them than their White counterparts. Due to structural barriers to services and the collectivist nature of SA families, MHD may be primarily managed within the family. This may be especially true for children with MHD, wherein parents generally hold primary responsibility for caregiving anyhow. Despite a large body of evidence on the experiences of caregivers of MHD, there appears to be a lack of a coherent understanding of how the SA population experience caregiving in this context. Understanding the current literature on these experiences will allow gaps in the literature base to emerge, which may serve to be critical in developing an awareness of how services can better serve the needs of SA service users. The following systematic literature review explores this.

Systematic Literature Review

A systematic literature review (SLR) relevant to the present study’s aims is presented in this section. This thesis has so far presented a comprehensive background to the experience of SA mental health in the UK. It has demonstrated the influence of social, economic, cultural, and political context on SA mental health and help-seeking. Despite acknowledging the need for mental health support in SAs, services continue to be culturally insular. This may lead to MHD being primarily managed within the home, with the support of family members. Despite recognition of the importance of family within SA communities, a comprehensive understanding of how SA familial caregivers experience supporting a family member with MHD is lacking within existing literature. The present SLR aims to provide a comprehensive summary of the main findings from the qualitative literature on the mental health caregiving experiences of SA familial caregivers. Therefore, this systematic review aims to answer the following question: “What are South Asian caregivers’ experiences of caring for a family member with mental health difficulties?”. The findings from the SLR will provide justification for the empirical study that follows, which addresses a gap in the knowledge base.

1.12 Methods

1.12.1 Search Strategy

Initial scoping of the literature revealed very little research in the UK and on caregivers of children pertaining to the review question. Thus, the inclusion criteria were widened to include data from any familial caregivers and from anywhere in the world, including both countries with and without majority SA populations. An electronic search was conducted using the databases PsycINFO, CINAHL Ultimate, MEDLINE Ultimate, Scopus, and Web of Science, in December 2023. These multidisciplinary databases include literature from various areas of research such as psychology, education, and nursing, and therefore were thought to be appropriate for this review. The strategy involved searching for journal articles using the options ‘Title’ and ‘Abstract’. Databases were searched using terms that were collated through reviewing previous literature and were linked to SA people, mental health, and caregiving (see Table 1). Search terms were truncated where appropriate to ensure all pertinent results were obtained (e.g., parent* = parents, parental). Search terms were combined using the Boolean operators ‘OR’ and ‘AND’ (see Table 1).

Table 1

Database Search Strategy

1. South Asia* OR Bangladesh* OR Pakistan* OR India* OR Sri Lanka*
2. Parent* OR caregive* OR mother OR father OR guardian OR carer
3. Support* OR caring* OR look* after
4. Child* OR adolescen* OR teenage* OR family member
5. Mental health OR mental illness* OR emotional distress OR distress* OR stress* OR wellbeing OR well-being
6. #1 AND #2 AND #3 AND #4 AND #5

1.12.2 Selection Criteria for Studies

The initial search identified 5136 papers. Following the removal of duplicate records, the titles of reports were screened for relevancy to the review topic. Abstracts were then reviewed against the inclusion and exclusion criteria to decide if the research was suitable (see Table 2). Following this, the full texts of the remaining 47 papers were reviewed using the inclusion and exclusion criteria. The literature review only included studies with qualitative data as qualitative research aims to gather an in-depth understanding of how people understand the world and make sense of experiences, which quantitative research may struggle to capture (Willig, 2013). Due to the complex and multi-faceted setup of SA families, data from any familial caregiver were included (Yeung et al., 2018). Research on caregivers of people with autism/an intellectual disability was excluded as it was deemed there would be nuances that would differentiate these experiences from those of caregiving for a mental health condition. Studies written in a non-English language were excluded due to time constraints. Non-peer-reviewed research was excluded, including grey literature. Following eligibility checking, nine studies were included in the analysis. The citations and reference lists of the included articles were then reviewed to identify any further relevant research. Through this process, a further two suitable articles were identified. A total of eleven articles were included in the analysis. This process is outlined in Figure 1.

Table 2

Literature Search Inclusion and Exclusion Criteria

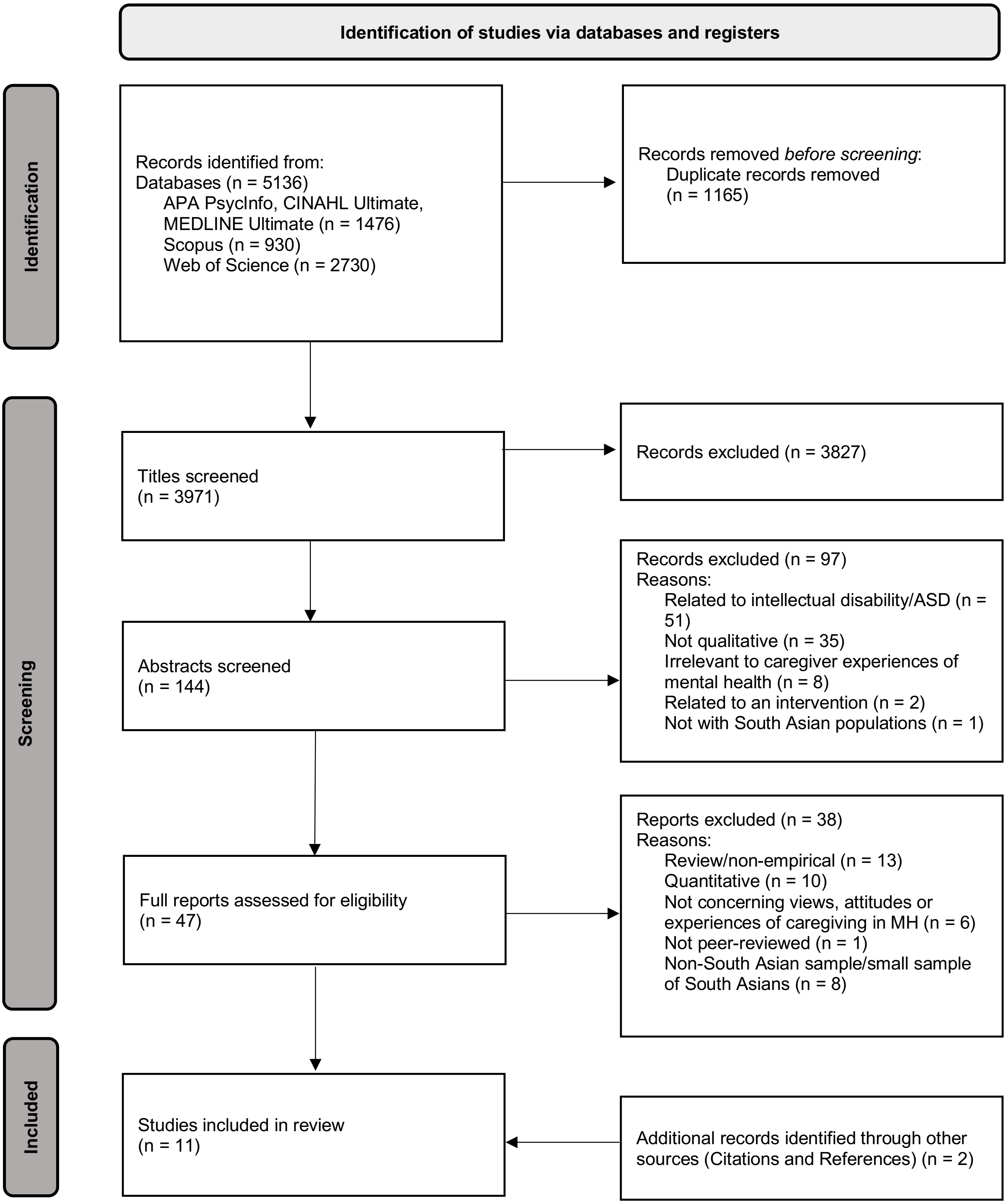
Inclusion Criteria	Exclusion Criteria
• The study must include data about views, attitudes, or experiences of caregiving • The study must contain a reference to mental health • The study must include data from SA caregivers • The study must be peer-reviewed • The study must contain qualitative data • The study must be written or translated into English • The study must be empirically based (i.e., not a review of previous literature)	• The study is quantitative • The study focusses on participants caring for an individual with autism spectrum disorders, an intellectual disability, or a physical health condition • The study contains a small number of SAs (i.e., less than 50% of the sample) • The study only contains data from non-familial caregivers (i.e., mental health professionals)

1.13 Results of Search

This literature review features eleven papers. Ten of these studies utilised a purely qualitative methodology, with one study using a mixed-methods design. Nine studies were based in India, with the other two having been conducted in the UK. Most of the studies explored purely the caregiver's views and experiences (n=8), with the others investigating both the experiences of caregivers and the person being cared for (n=3). One study did not directly investigate the caregiving experiences of people with MHD, rather they explored their experiences of accessing an Early Intervention Service (Penny et al., 2009). However, on viewing the full text, the findings showed relevance to themes of their experience of caregiving and therefore the paper was included in the review. Upon searching citations and references two additional studies were identified but ultimately excluded as the results firmly

Figure 1.

PRISMA Flow Diagram of Study Selection Process



related more to experiences of MHS/mental health needs from services rather than personal experiences of caregiving (Bradby et al., 2007; Dogra et al. 2007). See Appendix A for a full summary of the characteristics, findings, strengths and limitations of each study.

1.14 Quality Appraisal of Studies

1.14.1 Approach to Critical Appraisal

Critical appraisal involves the systematic and careful investigation of empirical research to examine its credibility, value and pertinence in a particular context (Burls, 2015). Well-established appraisal criteria exist to determine the validity, reliability, and objectivity of studies, though these are more relevant to quantitative studies (Porritt et al., 2014). Critical appraisal within qualitative research may be more prone to subjective bias, as instruments may differ in the criteria they cover and varying criteria may be used depending on the theoretical stance taken by the researchers (Hannes, 2011). The Critical Appraisal Programme Tool (CASP) qualitative studies checklist was used for the present literature review (CASP, 2018). It consists of 10 questions which each focus on a specific aspect of the research's methodology. It requires the examiner to assess the study in three broad categories: rigour, credibility, and relevance (Masood et al., 2011). The CASP tool is thought to be a user-friendly option for novice researchers and has backing within health and social care-related research, wherein it is the most commonly used quality appraisal tool (Long et al., 2020). The quality assessment of each of the papers is shown in Table 3.

1.14.2 Assessing Study Quality

Aims. All studies provided clear aims and rationale for the research. Five studies explored the roles and experiences of family caregivers of people with MHD (Issac et al., 2023; Joshi et al., 2008; Littlewood & Dein, 2016; Mathias et al., 2019; Meheli 2023), three studies explored caregivers' specific experiences of stigma and discrimination (Banerjee & Dixit, 2021; Dijkxhoorn 2023; Koschorke et al., 2014), one study focussed on the needs of caregivers (Jagannathan et al., 2011), one study focussed on caregivers' use of religion and spirituality in their caregiving (Raghavan et al., 2022), and one study investigated caregivers' experience with a mental health service (Penny et al., 2009).

Sample. Sample sizes ranged from eight to eighty participants for qualitative, family caregiver parts of studies. Most studies provided sufficient information about the sample, including characteristics such as age, gender, relationship to family member with the mental health difficulty, education level and occupation. One study did not provide a summary of the characteristics of their sample (Raghavan et al., 2022). One study only provided information regarding gender and age (Joshi et al., 2008). Mathias et al. (2019) did not provide a summary of participant characteristics, rather providing the gender, age, family relationship and household responsibilities of individual participants. Purposive sampling was the most commonly used recruitment strategy, which fit well with the aim of recruiting a homogenous sample. Most samples had more females than males, except for Meheli (2023) who had slightly more males than females (i.e., 14 and 13 respectively). This is not surprising given the traditional gender roles amongst many SA families, wherein caregiving is primarily the role of women (Hossain et al., 2020; Sharma et al., 2016). All samples were recruited through either an inpatient mental health setting or a community mental health service. This may limit the representativeness of the findings as the experiences of caregiving are unlikely to represent the perspective of those caregivers whose family members have not accessed professional mental health support.

Country. Two studies were conducted in the UK, with each of these conducting their study with participants of one particular SA ethnicity, Bangladeshis and Pakistanis respectively. (Littlewood & Dein, 2016; Penny et al., 2009). The other nine studies were conducted in India and thus, although ethnicity data was not reported in these studies, it is assumed all participants were of Indian ethnicity. The original scope of this review was to only include studies in the UK, as the country's socioeconomic make-up, understanding of mental health, and mental health treatment access substantially differ between Western countries, such as the UK, and SA countries. With a focus on UK research, the results of the present review would be more applicable to the context of this research project. Nonetheless, there will likely be aspects of caregivers' experiences that translate across the world.

Ethics. Most studies provided a statement regarding receiving ethical approval and informed consent, however, few showed evidence of consideration taken with respect to ethical issues such as anonymity and confidentiality of data, safeguarding, and de-briefing.

Data Collection. The methodological approach appeared appropriate in most studies, with respect to the aims and objectives. The majority utilised semi-structured interviews to collect data. Meheli (2023) utilised questionnaires to collect data which may have limited the extent of participants' responses due to the inability to prompt for elaboration of answers. Two studies used only focus groups which was appropriate for the larger sample sizes (Jagannathan et al., 2011; Joshi et al., 2008). However, in utilising focus groups researchers may have forfeited the depth of individual participant experiences.

Data Analysis and Findings. Studies varied significantly regarding the detail provided about the data analysis process**.** The majority of studies utilised thematic analysis to analyse the data, which was appropriate given their sample sizes. One study utilised Interpretative Phenomenological Analysis (IPA) which was appropriate given the smaller sample size of eleven (Penny et al., 2009). One study utilised the Constant Comparative Method, which is more suited to grounded theory research rather than the exploration of experiences unrelated to developing hypotheses/theories (Banerjee & Dixit, 2021). Content analysis was used by Meheli (2003) which was appropriate given their use of questionnaires to collect data. Three studies did not mention utilising a specific analytical approach and the process by which themes were generated is unclear, which presented difficulties in assessing the trustworthiness of the findings and ultimately reduces the studies' quality (Jagannathan et al., 2011; Joshi et al., 2008; Littlewood & Dein, 2016). All studies provided clear statements of findings and linked these to their research aims. Most studies also utilised participants' quotes to illustrate their findings. Most studies provided clear directions for future research or clinical implications. Few studies utilised credibility checks to ensure the trustworthiness of findings, such as multiple researchers involved in the analysis (Koschorke et al., 2014).

Reflexivity. Three studies discuss the impact of shared and different characteristics (e.g., ethnicity and gender) between the researchers/interviewers and participants on participant responses and the data analysis (Banerjee & Dixit, 2021; Littlewood & Dein, 2016; Mathias et al., 2019). One study's researchers additionally acknowledged their 'outsider' position as non-SAs and therefore employed members of the participants' community to aid with interviewing (Littlewood & Dein, 2016). This was especially helpful for participants whose first language was not English, allowing individuals who may usually be excluded to participate. This was a particular strength of this study. Banerjee & Dixit (2021) showed additional thought regarding reflexivity by maintaining a reflexive journal throughout the research process, wherein the researcher reflected upon her own beliefs and understandings about mental illness and stigma. No other researchers shared personal reflexivity through discussion about the relationship between themselves and the participants, hindering the credibility of these studies.

1.14.3 Conclusion of Appraisal

Based on the CASP tool, a minority of studies were poorer in quality than others (Joshi et al., 2008; Meheli et al., 2023). The decision was made not to exclude these studies from the synthesis due to the limited nature of research in this field and to ensure there was sufficient breadth and depth of study results to produce a robust review. Despite the poorer quality design of these studies, the findings still make an important contribution to the field of SA mental health.

1.15 Synthesis Strategy

The researcher employed thematic synthesis to synthesise the qualitative findings of the included studies. Thematic synthesis was chosen over other qualitative synthesis techniques (e.g., meta-ethnography) as it can synthesise both ‘thin’ (descriptive themes) and ‘thick’ data (in-depth, analytical themes), which suited the nature of the included studies (Flemming et al., 2019). The included studies ranged from those with richer data (e.g., theme of *‘bleak to bright horizons’* in Mathias et al., 2019) and those with less rich data that would not sustain contextual interpretation required by a meta-ethnographic approach (e.g., theme of *‘coping strategies’* in Issac, 2023). Furthermore, aims varied across the included studies and thus thematic synthesis was deemed suitable as it offers a clear, systematic, and structured approach to the construction of themes despite differing study aims.

The present review follows thematic synthesis guidelines outlined by Thomas & Harden (2008), involving three stages. The first stage pertained to open line-by-line coding of each primary study. This process was inductive such that the list of codes increased as additional studies were coded. The final set consisted of 248 codes. For studies that did not have a sample solely comprised of caregivers, codes were not created for statements that specifically related to the views and experiences of non-caregivers (e.g., service users). Therefore, all codes related to the experiences of familial caregivers; example codes included ‘mental illness is something to be hidden from society’ and ‘sacrificing of personal life to provide care’. In stage two, all codes were examined and those that were related were grouped together and labelled, constructing descriptive themes. During this stage, the researcher frequently compared emerging themes to the original papers to ensure themes were grounded in participants’ accounts. Finally, the third stage involved interpreting

Table 3

Quality Appraisal of Included Articles using Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist

Criteria	1. Was there a clear statement of aims?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is this research?
Banerjee & Dixit (2021)	Yes	Yes	Yes	Yes	Yes	Yes	No (but statement regarding ethical approval)	Yes	Yes	Provided unique insights into the experience of stigma for not just caregivers but also professionals
Dijkxhoorn, (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Linked to creation of a novel framework to understand the phases of caregiving experiences
Issac et al. (2023)	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Provided insights on positive aspects of caregiving for mental health

Jagannathan et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Novel research on Indian caregivers’ needs
Joshi et al. (2008)	Yes	Yes	Yes	No	No	No	No	No	Yes	Added ideas about the strength of family bonds that prevent leaving the person with mental illness.
Koschorke et al. (2014)	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	Valuable contribution to the knowledge base on ‘what matters most’ to people with schizophrenia and their carers.
Littlewood & Dein (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Provided insights into the explanatory models of mental health and caring in a generally underrepresented group in research.

Mathias et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Provided unique insights on caregiving in mental health from a gendered perspective
Meheli (2023)	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Novel insights regarding ‘lost ideal’ for the caregiver
Penny et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Adds to the specific understanding of British Pakistanis’ experience of mental health
Raghavan et al. (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Provided unique insight with regard to the use of religion in managing caregiving experiences

descriptive themes and relating them to the review question, creating deeper, analytical themes. This comprised making links between themes that ultimately made sense of family members' experiences of caregiving in the context of mental health. Through this process, five main themes were identified. An overview of each study's contribution to each theme is provided in Table 4.

1.16 Synthesis of Findings

1.16.1 Theme 1: A Stigmatising Experience

Overall, the studies consistently explored the experiences of caregivers from a stigma point of view. In many of the studies, participants spoke about the presence of mental health being stigmatised within their communities (Banerjee & Dixit, 2021; Dijkxhoorn, 2023; Issac et al., 2023; Joshi et al., 2008; Koschorke et al., 2014; Mathias et al., 2019; Meheli, 2023, & Raghavan et al., 2022). It is important to note that all studies where stigma was a theme were conducted in India.

Having a mental health difficulty was often synonymous with the idea of being 'crazy' or 'mad' and thus participants were reluctant to be open about mental health in their family to the community due to being judged or discriminated against. Participants often felt that mental illness should be hidden and thus made attempts to hide the mental illness of their family member from the wider community:

> *It (mental illness) must be concealed, because, it feels bad. Everyone would think that my husband is mad … they would directly say her husband is mad. That's why I do not share these things with others…I try not to reveal it…till date I didn't.* (Banerjee & Dixit, 2021 p. 12)

Table 4

Contribution of Each Study Towards Themes

Study	A stigmatising experience	An emotionally turbulent journey	A tale of loss and sacrifice	The silver lining of caregiving	Searching for a path through the stress
Banerjee & Dixit (2021)	✓	✓	✓		✓
Dijkxhoorn, (2023)	✓	✓	✓	✓	✓
Issac et al. (2023)	✓	✓	✓	✓	✓
Jagannathan et al. (2011)		✓	✓		✓
Joshi et al. (2008)	✓	✓	✓	✓	✓
Koschorke et al. (2014)	✓	✓			
Littlewood & Dein (2016)			✓		✓
Mathias et al. (2019)	✓	✓	✓		✓
Meheli (2023)	✓	✓	✓		
Penny et al. (2009)		✓	✓	✓	
Raghavan et al. (2022)	✓		✓	✓	
Total	8	9	10	5	7

Hiding mental illness was often not sufficient enough to remove the fear of others finding out about the illness, especially for those whose family member's symptoms included non-normative behaviour that was challenging to conceal (Dijkxhoorn, 2023; Koschorke et al., 2017). There was consistent fear of others finding out, which seemed to be related to wanting to fit in and maintaining their family's honour: caregivers worried about being perceived as abnormal, being treated differently, and the effect on their family's status in the community if the MHD were disclosed:

> *My friends would look at me with disgrace. They would not respect me. Even my relatives would 'not respect me. I may not get respect in my old workplace. (...) When there is a tribunal in our area, I could not go and talk there. I would feel very embarrassed and I would stay at home.* (Koschorke et al., 2017 p. 6)

Some participants also spoke about isolating their selves and family member out of the desire to protect their family member from harm:

> *When my son was in school I would talk to everyone and I went out often to sit with my neighbours. . . Now I don't send my son outside because people tease him and make fun of him. I also don't like talking much and unnecessarily with neighbours and people.* (Mathias et al., 2019 p. 13)

A common concern around stigma was the impact on marital prospects. Getting married was considered an important societal and cultural role expectation to be met when an individual is at the appropriate life stage (Koschorke et al., 2017). Participants spoke about the fear that they would be unable to find a suitable spouse, for themselves and the service user, due to the stigma others may hold about a family where mental illness is present:

> *Sometimes, I am worried that the family I am about to get married to will reject me because of her (*Meheli, 2023 p. 8)

Most participants spoke about their fears and expectations around stigma. Few spoke about their direct experience of being stigmatised as a result of their family member's mental illness:

> *Ma (mother) is sick. I mean, she is a mental patient. So, people talk about it at neighbourhood and at my in-law's place. But they (in-laws) assume that Ma had this problem from the beginning and its genetic, and we concealed it from them at the time of marriage. Often, I have to listen to such accusations. I feel bad. Listening to those allegations. After all, she is my mother!* (Banerjee & Dixit, 2021 p. 14)

Another related aspect of stigma that was discussed was the community's limited understanding of MHD. This impacted society's attributions of the cause of the illness, which commonly were placed on the caregiver or the family as a whole, leading to feelings of blame and shame amongst caregivers:

> *Some say that it's my fault that my husband is mentally-ill ... I didn't give him proper care, because of which he has fallen ill ... After I do whatever is possible, people still blaming me for all the misfortune is heartbreaking ...* (Issac et al., 2023 p. 3)

1.16.2 Theme 2: An Emotionally Turbulent Journey

The efforts involved in caregiving for an unwell family member are well-documented and, unsurprisingly, providing care can be stressful. Alongside this, a significant theme discussed across studies was the emotional aspects of caregiving for a family member with

MHD (Banerjee & Dixit, 2021; Dijkxhoorn, 2023; Issac et al., 2023; Jagannathan et al., 2011; Joshi et al., 2008; Koschorke et al., 2014; Mathias et al., 2019; Meheli, 2023; & Penny et al., 2009). Caregivers struggled with managing a variety of different feelings and emotions.

Worry was a major aspect of caregivers' daily lives. As caregivers would often hold sole responsibility for their family member's care and routine, this would put a strain on individuals to 'get it right'. This pressure naturally allowed the development of worry. Most participants identified the worry as an unnatural, uncomfortable feeling, although, one study's participants explained that due to the pervasive and constant concern they experienced, worry had become the natural state for the family (Penny et al., 2009). Participants discussed anxiety in the context of keeping their family member safe and the family member's care when leaving them:

> *We have to leave one person at home for him, when we are away, we think about him for the whole day.* (Joshi et al., 2008 p. 4)

Worry also manifested in the form of uncertainty. With the nature of many MHD often being 'uncurable' (i.e., the difficulties are lifelong but can be managed), caregivers naturally worried about the uncertainty of the progression of the illness (Dijkxhoorn, 2023 & Meheli, 2023). Participants also expressed uncertainty regarding their family member's future and the future caregiving of the family member when the caregiver is no longer able to provide care:

> *After me, I don't know who will take care of my wife. My son and future daughter-in-law may not take care of her. Because we are not able to say how people will change in the future* (Dijkxhoorn et al., 2023 p.7)

Frustration and anger were emotions heavily present in participant's accounts. Many participants spoke about the fact that they had no choice in becoming a caregiver, rather it was an expected responsibility that they had to take on due to their duty to their family (Dijkxhoorn et al., 2023; Issac et al., 2023; Penny et al., 2009). Frustration was also directed towards the person being cared for, due to their non-normative behaviour (e.g., aggression), non-engagement in social norms, and inability to meet societal role expectations:

> *My son is always in the home. He never goes out. He does not mix even with our relatives or workers… he finds it difficult to get out of the room.* (Jagannathan et al., 2010 p. 6)

Some participants experience shame in response to their felt anger towards their family member, as they understood their family member did not choose to be mentally unwell and the cultural need to show respect to their loved ones:

> *At times I feel very angry with her, and then I feel very angry at myself too, that being her child I could feel that way for my mother. I feel bad because I yell at my mother and say many things to her. Sometimes I want to hit her but until now I have not lifted my hand against her. My parents raised me with such love and affection (bade pyaar se), and yet see how I am behaving with them.* (Mathias et al., 2019 p.12)

Sadness was a prominent theme in caregivers' experiences, concerning the challenges of providing consistent care and the expectation of a bleak future for their family member and themselves (Jagannathan et al., 2011; Joshi et al., 2008;

Koschorke et al., 2014; & Mathias et al., 2019). This despair often led to feelings of hopelessness which, in some extreme cases, gave rise to suicidal thoughts:

> *It is very difficult [sobbing]. There are so many wrong thoughts (galat khayal) that come to my mind. I think about what a waste it is to be alive without happiness. . .. These problems are continuing for years now. It would be better if I were dead.* (Mathias et al., 2019 p.11)

1.16.3 Theme 3: A Tale of Loss and Sacrifice

Providing care for those with MHD, especially those who are seriously unwell, can be burdensome (Banerjee & Dixit, 2021; Dijkxhoorn, 2023; Issac et al., 2023; Jagannathan et al., 2011; Joshi et al., 2008; Littlewood & Dein, 2016; Mathias et al., 2019; Meheli, 2023; Penny et al., 2009; & Raghavan et al., 2022). As many caregivers held sole responsibility for caring for their family member, alongside managing their own home and personal life, it is understandable themes of caregiver burden emerged from participants' accounts. As a result, caregivers often had to endure personal sacrifices, such as giving up further education or their careers (Issac et al., 2023; Meheli, 2023). One further sacrifice was the ensuing isolation from being unable to attend social events:

> *I don't get to spend time with friends, as I used to spend earlier …* (Issac et al., 2023 p. 3)

Loneliness was not purely a result of the time burden of caregiving, but also due to the repercussions of stigma which made participants fearful of social situations in case of negative reactions:

> *My relatives do invite me to celebrations. But if we go there, they might talk about mother, so I do not go to such programmes.* (Dijkxhoorn, 2023 p. 7)

Accounts were permeated with themes of loss. Participants grieved the loss of an ideal future for themselves, which they had lost hope for as a result of the caregiving responsibility they had undertaken. Generally, the duty of caring for their family member took precedence over their own wants and needs. Many young, female caregivers spoke about their desire to marry to fulfil their cultural duty but that being a caregiver was a barrier to achieving this:

> *I think about my marriage and the need for a companion in my life who would take care of me. But people say that it is not possible in my life. In that case I feel constantly upset and depressed.* (Dijkxhoorn, 2023 p. 10)

Along the same vein, caregivers also spoke over the lost ideal for their family member, mentioning the loss of who they could have been and what they could have done if it wasn't for the mental health difficulty they were facing:

> *He was the main person. He was my eldest son. He was intelligent, clever. Now he is 'shurboshantho' (very calm). He has become the youngest. Nothing is left. He doesn't have work, his mind/temperament is not the same. No laughter, smile, happiness. He has got nothing. When the younger siblings look at him, they would see their eldest brother just sitting. He has got nothing.* (Littlewood & Dein, 2016 p.13)

Traditionally, in SA culture, when an individual ages and thus requires caretaking, the children will generally take over this responsibility. Parent caregivers spoke about how they had hoped their child would look after them as they grew older but with the mental health difficulty came a reversal of these role expectations which was a further loss:

> *When I used to get worried about him, he'd reassure me by saying, "Mum, I'll take care of you when I am older," but now, he doesn't do anything [...] When I went for Hajj, he came with me, and we saw a lady there whose son was helping her to perform Hajj. I just thought that if I was in the same situation, would my son do the same? [...] The poor thing, it's not his fault at all, not at all.* (Penny et al., 2009 p.8)

Caregiving involved supporting family members with every aspect of their daily routine, including activities such as cooking meals, administering medication, organising appointments, and attending to their personal hygiene. The impact of this took a toll on caregivers' bodies and physical health:

> *I have difficulty sleeping and lie awake most of the night. . . I have headaches and body ache. I used to be a very healthy and jovial kind of person but since his illness everything has changed.* (Mathias et al., 2019 p. 12)

The effects of caring for the mental illness were not limited to the person being cared for and the caregiver but also extended to other family members and the family as a whole.

> *Earlier, we all used to have some family time … But after my mother fell ill, we hardly share good times… Family interactions have reduced…* (Issac et al., 2023 p. 3)

In studies conducted in India, where mental health care is not free at the point of access as it is in the UK, themes of financial stress were present in participants' accounts of burden (Issac et al., 2023; Joshi et al., 2008; Mathias et al., 2019; & Meheli, 2003). The family member's treatment was often expensive, leading to sacrifices in other areas of life and general stress about how to gather an income:

> *Because we have a lot of debt for my mother's medical expenses, my children could not study after 12th standard, and they had to start working* (Dijxhoorn, 2023 p. 10)

1.16.4 Theme 4: The Silver Lining of Caregiving

Participants perceived an immense amount of personal growth through the care they provided. Caregivers often felt that they were personally stronger and had more confidence to deal with trials and tribulations the future may bring due to the challenges they had already faced and overcome (Dijkxhoorn et al., 2023 & Issac et al., 2023). Reflection on their efforts and ability to meet their family member's needs produced positive feelings in caregivers, such as pride, which helped develop a sense of self-efficacy (Dijkxhoorn et al., 2023; Issac et al., 2023; & Mathias et al., 2019). For one caregiver, these positive feelings weren't specific to the direct caregiving but externalised to the taking on of the breadwinner role that isn't traditionally taken on by women in India:

> *My day starts with care and cooking. My children also help with housework so I can go to earn. Then I have to go to work at someone's place for money. Or else I go to the fields to work as a daily labourer. . .. Some days if there is no labouring work then I go to collect wood in the forest to sell.*
> (Mathias et al., 2019 p. 16)

These positive feelings were heightened when the caregiver's endeavours to support their unwell relative were acknowledged by those outside the immediate family:

> *Many relatives praised me at a recent family celebration for the way I take care of my mother. They said she looked much better than before and that it is admirable that I am able to handle her. That made me very happy.*
> (Dijkxhoorn et al., 2023 p. 10)

These aspects of personal growth in response to adverse life experiences make way for the building of resilience amongst some caregivers. Resilience was seen as essential to be able to withstand the difficulties associated with being the main caregiver for their family member (Dijkxhoorn et al., 2023). For many caregivers, their family member's mental health problem was their first experience with mental health and thus the process of caregiving led to increased knowledge about various mental illnesses and their treatment options (Banerjee & Dixit, 2021). For one caregiver this increased knowledge allowed for a newfound passion and career:

> *I have learnt a lot about mental stability and psychiatric problems by observing my mother. Now I work as a nursing assistant with people with mental illness. The personal experiences with my mother helped me in this job* (Dijkxhoorn et al., 2023 p. 11).

Personal growth also took the form of the development of other characteristics, such as compassion. Participants felt that they had become more compassionate, as the management of their unwell family member's non-normative behaviour and symptoms required empathy (Dijxhoorn et al., 2023 & Joshi et al., 2008). This newfound compassion was often directed towards other families who may be going through similar difficulties:

> *While we are waiting at the clinic, I talk to new families and try to answer their questions. I like to help others, because we all had so many questions when we first came to the clinic* (Dijkxhoorn 2023 p. 11)

One study identified gender differences regarding how self-affirming caregivers were about their efficacy as caregivers (Mathias et al., 2019). Male participants were more likely to describe their efforts in the first person, amplifying their personal role in producing change in their relative, whereas females were more likely to diminish their active role in caregiving:

> *I took my wife to so many doctors in Moradabad and other places. . . I don't know how many lives my wife must have prayed and meditated to get a husband like me and a family like ours. . . It is no easy thing to get treatment and provide good care for a patient. It takes a very strong heart (bahut majboot dil).* (Mathias et al., 2019 p. 12)

The positive effects of caregiving were not limited to the individual caregiver themselves; participants spoke about the connectedness it created between their self and their family members (Dijkxhoorn et al., 2023; Joshi et al., 2008; & Mathias et al., 2019). Caregivers felt that the relationship with their unwell family member improved through providing care. This enhanced caregivers' drive to persist in looking after their family member, alongside feelings of love, affection, and a sense of responsibility (Dijkxhoorn et al., 2023). Caregivers also felt a sense of unity with their whole family system, with family members coming together to manage difficulties:

> *Whatever money we generate is from our own efforts. I sell the buffaloes' milk, my two daughters are teaching in a school, and through togetherness we can do it 'sab milkr is karya ko kar sakte hai'. My son... is also joining some factory to earn money. . .. All my children are trying their best to earn for the family.* (Mathias et al., 2019 p. 15)

1.16.5 Theme 5: Searching for a Path Through the Stress

Given the challenging nature of caring for a family member with mental health problems, efforts to cope with the difficulties were mentioned. The most prevalent coping strategy discussed was related to religion and faith. This was particularly pertinent in Raghavan et al. (2022), whose focus was on Muslims using their faith to address challenges. The use of religion and faith were used in differing ways to cope. Some made sense of the mental health difficulty by seeing it as a challenge given by God (Raghavan et al., 2022). Some participants had unwavering faith in God that He would relive their relative's illness, as He was the all-powerful:

> *Insha'Allah, he will get better, I have dreams that I am at Mecca, and that Allah is saying, "Don't worry, he will get better." Allah will help.* (Penny et al., 2009 p.10)

This staunch belief in God's power often led participants to spend time in prayer, with the hopes that connecting with God would lead to a stronger connection and a greater likelihood of God answering their prayers (Raghavan et al., 2022). Prayer was also used in a different way, to ask God for strength and courage to manage the challenges that were associated with being a caregiver for their relative:

> *Only prayer is trustworthy. The main thing is prayer and nothing else. Other than prayer there's nothing else. That I have experienced. For whatever reason, we pray to God sincerely, we will feel better soon. That is true 100%.* (Raghavan et al., 2022 p. 10)

Other coping strategies were used to cope with the experiences of providing care. Participants spoke about being hopeful for the future, and that things would get better, which alleviated worries about day-to-day challenges in the present (Joshi et al., 2008; Mathias et al., 2019). Some participants spoke about struggling with their relative's initial mental health diagnosis, due to unfamiliarity and uncertainty about what caused the problem (Dijkxhoorn et al., 2023; Koschorke et al., 2014; & Littlewood & Dein, 2016). Over time some caregivers found peace with no longer resisting the fact that their family member was mentally unwell, and thus acceptance was a powerful technique to provide relief:

> *Initially, I couldn't accept that my husband is mentally-ill… I started to understand that there is no point in worrying about the future…* (Issac et al., 2023 p. 3)

Although only one study focussed purely on the needs of familial caregivers (Jagannathan et al., 2011), themes around participants' ongoing needs to efficiently support their family member and their selves were present in other studies (Issac et al., 2023; Mathias et al., 2019). Linked to the topic of stigma discussed in theme one, participants felt that society did not understand mental illness. Caregivers, and their unwell family members, wanted to feel accepted within society and accurate education for the community about mental illness would allow for this, by reducing stigma and the resulting sense of isolation:

> *There is a lot of stigma about this illness… a lot of misconceptions about mentally ill patients. They do not understand what type of illness this is, what is the problem. So educating society is important.* (Jagannathan et al., 2010 p. 7)

This lack of understanding was not only a difficulty present in wider society but also amongst caregivers' wider family. This had a direct impact on caregivers' abilities to rely on support from extended family members:

> *All our relatives, especially my in-laws side, have broken all contacts with us. They haven't given us any money or share in the property. Everyone feels that because of my husband's condition we will be a burden for them,*

> *so no-one keeps in touch with my family except my mother-in-law…*
> (Mathias et al., 2019 p. 14)

Alongside the need for direct support from family, participants expressed the things they needed from systems such as the state/government and the mental health care services providing care to their family member. This included increased knowledge regarding mental illness, its treatment options other than medication, management of the day-to-day symptoms, and available support for caregivers, as well as adaptations to caregivers' occupations to ease the stress of caregiving (Jagannathan et al., 2011; Littlewood & Dein, 2016). One caregiver provided a specific example of what support they may find helpful for themselves:

> *Development of local support groups in city/hometowns like palliative care groups for cancer patients will be a great relief to all people, wherever we are.* (Jagannathan et al., 2010 p. 8)

1.17 Discussion of Findings

Overall, the themes from this systematic literature review have identified the challenges of SAs caregiving for MHD, including experiences of stigma, negative emotions, and loss, but also the positives to come out of this role, and how they find ways to cope with the difficulties they experience. Themes of stigma, negative emotions, loss, and coping have been well-documented in the wider research sphere around caregiving for MHD (Leith et al., 2018; Slaunwhite et al., 2017; Venkatesh et al., 2016; Walke et al., 2018). However, the personal growth described by caregivers is a theme scarcely focussed on in previous research and provides a unique insight into the complexity of the caregiving experience. Comparing the Indian and UK studies, the studies from India were more likely to contain 'thin' data consisting of simple, descriptive themes. Interestingly, the studies from the UK contained in-depth mention of experiences of MHS, whereas this was less likely to form a major part of the findings in the Indian studies. This divergence may reflect differences in the setup of statutory mental health support in these different countries, where the pathways and available support are clearer in the UK (World Health Organization, 2021).

1.18 Conclusions of the Systematic Literature Review

This review is the first to examine published literature exploring SA caregivers' experiences of caregiving in the context of mental health. The findings provide an important and necessary addition to the field's understanding of SA mental health, highlighting specifically the impact of MHD on an individual's family. SA familial caregivers often take primary responsibility for supporting their unwell relative, which can have effects on their own emotional and physical well-being. The burden of caring for their family member often leads caregivers to find ways to cope with the associated challenges, wherein religion and acceptance are most commonly used. Caregivers recognise a need for increased understanding and support from their community and MHS, to support the work they do in caring for their relative.

This review highlights the challenges associated with caregiving for a mental health difficulty, and how this may be exacerbated by cultural responsibilities within SA culture. However, it also sheds light on the positive aspects of caregiving, such as personal growth, that may not be immediately obvious from narratives of caregiving. The review provides context to the importance of carrying out the present research, as will be described below.

1.19 Literature Gap

Despite this review summarising the current themes in narratives of caregiving for mental health difficulties amongst SA carers, it also highlights several gaps in the literature. Despite the increasing amount of evidence of SA caregivers' experiences of caring for a mentally unwell family member in SA countries, this is still limited in the UK. The majority of studies included in this review were conducted in India. The experiences of SAs with MHD and their families in India versus those in Western countries, such as the UK, are likely to be vastly different for several reasons. Firstly, there are disparities in the setup of mental health care between developed and developing countries; developed countries' governments provide 50 times more funding towards mental health treatment and there are almost 20 times more beds available to treat mental health inpatients (World Health Organization, 2021). Secondly, stigma towards mental illness is generally higher in Eastern versus Western countries, which may impact how MHD are managed (Loya et al., 2010; Mirza et al., 2019). Finally, SAs in the UK are racially minoritised, versus being part of the majority in SA countries. Therefore, it is unlikely that findings from SA countries can be directly extrapolated to Western countries such as the UK.

Of the two British studies presented in this literature review, they both consist of samples of only one SA ethnicity, Bangladeshis and Pakistanis respectively (Littlewood & Dein, 2016; Penny et al., 2009). Furthermore, these samples consisted of caregivers of individuals who had accessed or were currently accessing external, professional mental health support either through mental health day centres, social services, or community mental health teams (Littlewood & Dein, 2016; Penny et al., 2009). The caregivers in these samples also all cared for an adult family member above the age of 18. Therefore, there still exists a gap in the literature regarding the experiences of British SA caregivers of children with mental health struggles, as the experiences of caring for an adult versus a child will undoubtedly have nuances. This is especially important given the development of the majority of MHD occur within childhood, as discussed earlier in this thesis. More specifically, there exists a gap in the experiences of caregivers of those not accessing statutory MHS as, again, these experiences will differ substantially from those of caregivers of family members who have accessed formal mental health support.

1.20 Rationale for Current Study, Aims, and Research Questions

As present literature on SA caregivers of mental health are limited in the UK, on children with MHD, and on families not under professional services, the present research strived to elucidate these experiences and start to fill in these literature gaps. As such, this research study aimed to explore the experiences of caring for a child with mental health difficulties amongst SA caregivers in the UK. The main aim was to contribute to the limited body of literature on the topic by gathering direct evidence from SA caregivers themselves. This overarching aim encompasses a more specific sub-aim to investigate how caregivers may use aspects of their culture and religion in the way they support the child in question. As a result, the work will offer clinical implications for policymakers and service providers to improve the accessibility to and support of MHS for SAs and strengthen relationships between services and SA service users. For the current study, the following research question and sub-questions were developed to explore these aims:

1) **How do South Asian caregivers experience caring for a child with mental health difficulties?**
    a) **How does culture and/or religion influence South Asian caregivers' views and experiences of supporting a child with mental health difficulties?**
    b) **How do South Asian caregivers view help-seeking for mental health difficulties?**

Chapter 2: Methodology

2.1 Chapter Overview

This chapter discusses the methodology used to answer the research question. It details the researcher's theoretical and philosophical position in relation to the research, the qualitative research method chosen, and the rationales for doing so. It provides a step-by-step process of how each element of the study was conducted, from the planning of the study, to data collection, to data analysis. Areas where the research method was adapted to ensure the research was culturally sensitive are highlighted. Reflections from the researcher about various aspects of the research process are dispersed throughout this chapter.

2.2 Reflexivity

It is well known that researchers, particularly qualitative researchers, are often drawn towards populations and topics they feel passionately about (Burnham et al., 2008). In this respect, it is therefore important that I reflect on how I am implicated in the current research. This approach aligns with Interpretative Phenomenological Analysis (IPA), wherein the identity and position of the researcher is something to be reflected on throughout the research process (Smith et al., 2022). I will provide my personal reflections throughout this thesis, which will be highlighted by the use of first-person terminology and sub-headings where appropriate.

The choice of this research project was based on several different reasons. First, my own identity as a SA woman had an impact. Experiences of growing up and living in the UK often led to feelings of marginalisation. From living in a small, ethnically similar town, to attending a majority White private school, to postgraduate jobs where I was often the only person of colour in a team, my identity as a Brown woman was not something I could hide from. The subsequent feelings of not fitting in regularly led to a longing to connect with others from a similar racial background, likely impacting my pursuit of this thesis topic in an academic institution where I was the only SA Muslim woman in my Doctorate in Clinical Psychology cohort. I wondered who else would pursue research in underrepresented groups, in racially minoritised communities if not someone who has a lived connection to the topic?

My interest specifically in the management of MHD in children came from my own experience with mental health. I experienced difficulties with depression in my teenage years, during which the role of my family was vital, particularly my mother's. Upon reflection, I wondered how my mother was able to provide me with emotional support whilst trying to understand the phenomenon of depression that was entirely novel to her, given the lack of the term in her mother tongue of Bangla. The divide between my parents' understanding of mental health compared to my own widened once I started to pursue a career in psychology. When explaining my role as a trainee clinical psychologist to family members in Bangladesh my parents would often use the term *manēr ḍāktār*, which translates to 'doctor of the mind'. Amongst many SAs that migrated to the UK, a career in psychology is often not considered a stable job nor is it held in high regard, partly due to unfamiliarity with the field. My experience with this unfamiliarity of mental health in SAs spurred me to research this topic, given mental health remains somewhat of a taboo in these communities. Furthermore, from my own experiences of my mother supporting me through my own MHD, I, perhaps self-indulgently, wanted to understand these narratives of caregiving.

Dwyer and Buckle (2009) describe how researchers may hold dual roles as both an insider and outsider when conducting qualitative research with particular groups of people. In the present research, I am an insider in the way that I share SA identity with my participants. This sharing of ethnicity and culture allows me to connect with my participants around the experiences and challenges they face day-to-day as racially minoritised individuals. I reflected on the impact this similarity would have on the fostering of trust and openness between the participant and myself. Alongside this, I am also an outsider in that I am not a parent or primary caregiver for a child and therefore have no experience of what it means to care for and raise children in today's day and age. I was an outsider also in terms of my identity as a researcher and clinician, and reflected on the possible perception of myself by participants as an ‘expert’. Throughout this project I was conscious of occupying these multiple roles; not only was I a researcher but also an interviewer, an analyst, a student, a clinician, South Asian, and Muslim. Juggling these roles throughout the research process was challenging; although I was encouraged to purely hold the position of researcher this felt impossible as being human is inherently intersectional. Whilst participants shared sensitive experiences, I felt compelled to respond compassionately as I would in my clinical role as a psychologist but felt restricted in my capacity as a researcher to do so.

2.3 Developing a Phenomenological Consciousness

A phenomenological approach to my research, that is understanding experiences in their true essence, was deemed integral to conducting the present research (Husserl, 2014). My own experiences of societal marginalisation and that of fellow SAs meant the accurate understanding of participants’ experiences was integral to fostering a sense of valuing SA voices in research. In this sense, traditional approaches towards qualitative research, which arbitrarily group individual narratives together using descriptive labels, felt inadequate to reflect the uniqueness of individual lived experiences. From the outset of pursuing this research, readings on hermeneutic phenomenology stood out to me.

Hermeneutic phenomenology seeks to uncover the life world or human experience as it is lived (Suddick et al., 2020). Heidegger’s ‘being-in-the-world’ suggests the world is fundamental to the essence of what it means to be human, it is part and parcel of the being (Malpas, 2008). This concept felt crucial to the understanding of SA caregiver experiences, due to the existence of their minoritised position living in a Western society, which would undoubtedly impact their caregiving experiences. Importantly, this phenomenological position also utilises the idea of the hermeneutic circle, which suggests an understanding of true human experience requires interpretative effort, where understanding the whole is dependent on understanding each individual part and this process, in turn, leads to the identification and revision of preconceptions (Suddick et al., 2020) Again, this felt fitting with this research, which planned to investigate individual topics such as culture and religion and their impact on the wider issue of caregiving for mental health. Overall, this development of a hermeneutic phenomenological consciousness influenced the whole research process and determined the choice of analytic method, IPA. Although IPA shares similarities with hermeneutic phenomenology with their bases in hermeneutics and phenomenology, IPA differs in its focus on specific individual experiences, whereas hermeneutic phenomenology tends to interpret collective meaning (Godden & Kutsyuruba, 2023).

A hermeneutic phenomenological approach suggests that phenomena should be understood "as they show themselves in themselves" (Heidegger, 1999, p.58). However, those who are attempting to do the interpreting, such as researchers, are also independent beings and thus have their own knowledge about the phenomenon at hand (Farrell, 2020). According to Heidegger, this is not necessarily an issue but requires researchers to "step away from the subject matter initially given and back to that on which it is based" (Heidegger, 1999, p.58). Some in the world of phenomenological research argue that it is important for researchers to explicitly explain their forestructures of understanding, that is the preconceptions and prior knowledge that are held about the phenomenon, and put them to one side to limit the impact on the interpretative process (Farrell, 2020). Heidegger described the term *Dasein*, or Being-in-the-world, to refer to the mode of Being that is unique to human existence (Stapleton, 2009). He suggested that the day-to-day world in which we live in, and our relationship to it, are fundamental to what it means to be human (Stapleton, 2009). In this way, we cannot detach ourselves from the world around us. Hence, bracketing out preconceptions may be something that can never be truly achieved. Instead, prior knowledge may be used as a resource to better understand the phenomena under study. In line with this, I aimed to complete a reflective journal throughout the research process to reflect upon how my identity as South Asian, a woman, a psychologist, and a researcher impacted upon the data analysis. This also ensured a phenomenological consciousness was present within every aspect of the study.

2.4 Philosophical Positioning

2.4.1 Ontological Position

Ontology is concerned with the nature of being, existence, and reality (Willig, 2013). Researchers who align with the idea that there is a singular reality that exists irrespective of human consciousness or experience may fit within a *realist* ontology. On the other end of the spectrum, *relativism* assumes that human consciousness and experience create reality, such that there is no singular reality but rather multiple realities created by individuals based on the social and cultural contexts they are situated (Willig & Rogers, 2017). My ontological view as a researcher fits somewhere close to *relativism* as I believe there does exist a 'reality' beyond what may be socially constructed, though the meaning and nature of this reality are dependent upon our perspective on it and engagement with it. This fits with a hermeneutic phenomenological approach, which assumes that there is a 'reality' out there, and it searches to get as close to that 'reality' as possible, but that this 'reality' differs between individuals. This fits with the current research also, wherein the experience of MHD is 'real' but the experience of this reality will differ from participant to participant due to the contexts within which they live. However, as part of an IPA approach, it is important to bracket out ontological assumptions to suspend judgment that may act as a screen for understanding the true phenomena under study (Smith et al., 2022).

2.4.2 Epistemological Position

Epistemology is concerned with the theory of knowledge; how we know what we know and whether what we know is reliable and valid (Willig, 2013). Historically, epistemology has been thought of using two opposing stances, *positivism* and *interpretivism.*

Positivism posits that knowledge can only be gained through objective, measurable, scientific methods. This stance has been taken in natural sciences research, where empirical observation and analysis of quantitative measurements have been utilised in the development of generalisable theories and models (Blaikie, 2007). In such paradigms context and interpretation are deemed unimportant to the process of gathering knowledge and thus the researcher and the setting within which the research is conducted are considered separate from the phenomena under study (Fox, 2008). *Interpretivism* is based on critique of positivism, stating that subjective perspective is integral to what constitutes acceptable knowledge. It denies that the individual can be separated from their knowledge, rather that truth and knowledge are subjective and affected by historical and social context. Interpretivist researchers aim to understand reality as it is perceived by individuals and recognise this perception of 'reality' may differ from that of another person based on historical and cultural factors.

The development of *constructivism* shares historical roots with *interpretivism*, with both holding the goal of understanding the lived experience from the viewpoint of the participants, refuting the idea that there is one true reality (Lee, 2012). *Constructivism* differs in that it posits knowledge is actively constructed by individuals using their experience and social discourse, and that this construction is mediated by culture and politics (Lee, 2012). Thus, individual perceptions are a product of construction rather than a direct reflection of the world, lending to the idea of there not being a singular 'knowledge' to be studied but rather multiple 'knowledges' (Willig, 2013). Constructivist research attempts to understand these 'knowledges' by focusing on how the participant and researcher interpret their experience, within which language takes a pivotal role (Mills et al., 2003). Importantly, this approach acknowledges the researcher's presence and role in the research process, wherein the researcher is also constructing their own reality. *Contextual constructivism* takes this concept further and takes the position that all knowledge is situation-dependent (Madill et al., 2000). It posits that results will differ depending on the context in which the data was collected so that data collected during an interview with a specific researcher at a specific location and time will generate a distinctive narrative that would change if any of these factors differed (Madill et al., 2000). Contextual constructivism prompts the investigation of views and experiences within a cultural context that gives significance to those views and experiences (Cobern, 2007).

In line with a relativist ontology, this research attempted to get as close to each SA caregiver's reality through individual qualitative interviews with an IPA approach. IPA attempts to understand individuals' lived experiences through their own and the researcher's interpretation of their narrative, which fits within a contextual constructivist stance. The weight this paradigm puts on context further supports the aim to situate SA parents' experiences of supporting their child's MHD within wider societal, cultural, and political factors. The contextual constructivist position emphasises the importance of researchers positioning the research within the context of their own characteristics (e.g., gender, ethnicity, age), highlighting to the reader the effect of these on the data and analysis (Madill et al., 2000). Thus, this position allows me to reflect on my own identity as a SA woman and as a trainee clinical psychologist, which will undoubtedly alter the knowledge of participants' accounts. This research therefore sits within the contextual constructivist epistemological realm.

2.5 Rationale for Qualitative Methodology

Given the lack of research regarding the experiences of caregiving for mental health in SAs, utilising a methodology that allows for direct communication with SA caregivers was integral to developing the body of research in this field. Qualitative research approaches enable the exploration of human experiences to answer questions around the '*how*' and '*why*'

(Willig & Rogers, 2017). In this way, qualitative research allows for the building of knowledge through the collection of subjective experience, something which quantitative approaches struggle to achieve with their focus on numerical and statistical data (Hennink et al., 2020). I was conscious of SAs' history of marginalisation within the UK and society's diminishment of their views and believed utilising a quantitative approach would have reduced my participants' voices to numbers rather than the complex narratives they exist as. A qualitative approach also allowed me to continuously reflect on the context within which this project sits and the lens I use to view this research, which aligns well with my epistemological position described above.

2.6 Interpretative Phenomenological Analysis

2.6.1 Development and Historical Roots of IPA

IPA is a relatively new qualitative analysis approach, utilising existing theoretical and philosophical principles. Developed by Smith (1996) with the aim to develop a qualitative method specifically for the field of psychology, it has since been applied to various psychology domains (e.g., health, clinical, occupation) as well as other disciplines (e.g., allied health professions, music, education, fashion). IPA focuses on understanding how individuals make sense of their experiences and identifying overarching themes across accounts (Pietkiewicz & Smith, 2014). IPA as a methodological approach follows three principles, as described below.

2.6.2 Phenomenology

Phenomenology is deemed the study of human experience. IPA is concerned specifically with the meaning of an individual's experience. A phenomenological approach aims to allow the expression of this experience in its own terms, by encouraging participants to share details of their experience in their own words rather than limiting them to restricting categories. This is appropriate for this research as the study aims to allow individuals to reflect upon their own subjective, personal experiences in their own words. IPA holds the view that the descriptions provided by people will demonstrate how the individual has made sense of their experience (Smith et al., 2022). Researchers are encouraged to set aside their thoughts, beliefs and judgements so that the phenomenon in question is seen in its essence and wholly understood (Smith et al., 2022).

2.6.3 Interpretation

IPA is also underpinned by hermeneutics (i.e., the theory of interpretation), although it could be argued that phenomenology is inherently interpretative in itself. IPA specifically employs a double hermeneutic, where the participant attempts to make sense of their experience and the researcher attempts to make sense of the participant's experience (Smith & Osborn, 2003). IPA recognises that, although it pursues to get to the true meaning of individual experience, this is not fully possible and thus it becomes an interpretative effort for both the participant and researcher (Smith et al., 2022). Results from the data are thus dependent upon the participant's ability to detail their experience and the researcher's ability to comprehend their narrative. IPA also acknowledges that the researcher's biases and preconceptions will shape the interpretations made, despite efforts to mitigate their impact (Smith et al., 2022).

2.6.4 Idiography

Idiography, concern with the particular, also heavily influences the IPA approach, where the focus is on understanding the particular experiences of a particular group of people in a specific context. As a result, IPA tends to favour smaller sample sizes to allow for the collection of in-depth data. Thus, IPA is appropriate for this research, which aims to gather detail and depth of individual caregiver experiences and examine congruity and dissimilarities across a small number of cases. IPA lends itself towards the concept of 'thick description', which aims to move away from the generation of great detail and the simple description of phenomena. Rather, it goes further to interpret behaviour within a wider context and attributes purpose and intentionality to these actions, whilst also grasping participants' emotions and cognitions (Ponterotto, 2006). In achieving 'thick description', the findings of such research are likely to have rich meaning, allowing readers to situate themselves within the research context and thus enhancing credibility.

2.7 Consideration of Alternative Methodologies

Grounded Theory is specifically concerned with investigating phenomena and constructing new theories based on systematically collected data (Glaser & Strauss, 2017). In this way, it provides a way of generating explanatory frameworks for topic areas that are novel within the research sphere (Birks & Mills, 2004). This was not appropriate for the current study, which aimed to gather the meaning of participant experiences, rather than the processes behind their experiences. Thematic Analysis was also considered; however, this approach focuses purely on themes that emerge across different individual accounts, which would have resulted in broader, rather than in-depth, descriptions of individual experiences (Braun & Clarke, 2006). Thus, IPA was considered most suitable as it allows for a detailed exploration of sense-making in each individual.

2.8 Design

2.8.1 Cultural Considerations

'Whiteness' refers to the social construct that depicts the invisible norms, rules, privileges, and dialogue that perpetuates the power of those racialised as White and maintains the systemic oppression of ethnically minoritised individuals, such as SAs. As a result of the extensive history of marginalisation SAs in the UK have experienced, several aspects of the study were reviewed to limit the impact of Whiteness on the research and ensure the research was culturally sensitive.

Although I am from a SA background, I represent an academic institution and a career which have both been historically dominated by those from White, middle-class backgrounds. Given the history of marginalisation of minorities in the UK, I was conscious of the possibility of potential participants feeling used and uncomfortable to participate in the research due to cultural differences, which may partly explain the known difficulties of recruiting racially minoritised communities into research (Mason et al., 2014; Sheikh et al., 2009). Thus, it was of utmost importance to create a research space which fostered containment and safety to allow participants to bring their experiences. Aiming to achieve this, I conducted telephone calls with interested participants, so individuals became familiar with me and I could start to build a rapport. At the beginning of the interview, I spent time warming the context by reflecting to the participants why I was pursuing this research. I also felt it was crucial that participants also gained something from participating, to account for the burden of taking time out of their lives to take part (Hussain-Gambles, 2004). Each participant was given a £20 Amazon voucher for participating in the interview, although this was a small gesture in comparison to the time and effort participants gave to share their personal, intimate experiences. These vouchers were funded through a research fund offered by the University of Essex.

2.8.2 Participant Consultants

With the history of SA communities being marginalised within society, I aimed to ensure my research was collaborative in that I would work *with* participants, rather than *on* them. This felt particularly necessary with a SA participant population, who have historically gained knowledge and wisdom from familial elders, community leaders, and religious figures, rather than from research that is often presented as the *'expert'* view in the Western world (Babu et al., 2017; Bano, 2013). I felt that SA parents themselves, who had been supporting their children with MHD, would be the *'experts'* and best placed to identify topics most relevant to them and to be able to identify the challenges they faced. Therefore, a consultant group was created to achieve this collaborative aim. The group consisted of two SA mothers who had supported/were supporting their child with MHD. They did not meet the inclusion criteria for the study as both had children who were over 19 years of age. Consultants were reimbursed for their time with a £20 voucher for each meeting.

I met together with the consultants twice throughout the study. The first meeting was during the study planning phase, intending to gather their views on various aspects of the study such as the inclusion criteria and draft advertisement flyer. With regards to the inclusion criteria, initially only parents were included but the consultants correctly pointed out that SA families are often not structured in the same way as that of White British families so the main caregiver may not necessarily be a parent. Furthermore, I had concerns about the language and terms I should use to describe mental health difficulties, especially as SAs are less likely to have received a mental health diagnosis and many SA languages do not have terms to describe mental health, anxiety or depression. The consultants provided helpful insights around language use and felt that most individuals would understand the term ‘mental health difficulties’ but to provide non-pathologising examples for those that may not. This feedback was taken on board and examples of mental health struggles that felt relevant to the SA community, such as somatic symptoms, were included in the participant information sheet (PIS) (see Appendix B).

The interview schedule and recruitment were the focus of the second meeting. The consultants suggested that some questions around the experience of caring for their child implied there were inherent challenges of doing so and thus suggested there should also be the allowance of space to discuss the positives of caring for their child, resulting in the addition of a question around this. The consultants also felt that, as discussing mental health and their child’s experience would be a sensitive topic for many, the setting up of the interview and initial questions were important to build a rapport with each participant. This discussion led to the inclusion of an introductory question regarding why they decided to take part in the study and a plan for how I would set up a warm, safe space. They provided helpful avenues for recruitment that had not initially been thought about, such as attending groups of SA mental health organisations and handing out flyers at religious institutions, as this would allow direct contact between myself and potential participants which may help in building rapport.

2.9 Participants

At the starting point of recruitment, this thesis strived to conduct interviews with parents and primary caregivers from different SA ethnicities and religions, to reflect the British SA diaspora. However, the final sample consisted mostly of Pakistanis and Muslims. As such, the recruitment strategy outlined below pertains to the original target population. It is important to acknowledge that if the sample of this research included other SA ethnicities and religions, the resulting data, analysis procedure, and findings would likely have been different to what is stated in the remaining chapters of this thesis.

2.9.1 Inclusion and Exclusion Criteria

Clear inclusion criteria were created for the study (see Table 5). Participants were parents or primary caregivers of South Asian background and had a child aged between 5-19 that was experiencing a mental health difficulty. ‘South Asian’ constituted any individual with an ethnic background from India, Pakistan, Bangladesh, or Sri Lanka, including those of mixed SA heritage. It was important to ensure primary caregivers were included as within SA communities the primary caregiver is not always the child’s biological parent (Babu et al., 2017). This study stipulates the child with MHD must be between the ages of 5 and 19, as MHD have been identified in children as young as five and the World Health Organisation defines the end of adolescence as 19 years of age (Sayal & Taylor, 2004; WHO et al., 2016;

Xue et al., 2005). The study further stipulates that the child in question does not necessarily have to have been diagnosed with a specific mental health disorder as barriers described earlier in this thesis, such as culturally inappropriate services, may make SA individuals less likely to access and receive professional mental health support, but this does not negate the fact that these individuals may still be experiencing MHD. Participants were required to understand and speak English. Utilising translators and associated transcription resources would require additional costs and time expenditure that were beyond the scope of this thesis. It is crucial to note this may have excluded many participants, especially migrants, whose experiences are valuable and may reflect aspects of being marginalised.

2.9.2 Recruitment

Initially, purposive sampling was used. Purposive sampling is a sampling technique that deliberately selects participants from the target population (e.g., SA caregivers) based on characteristics they possess and practical criteria (e.g., availability and willingness to

Table 5

Inclusion Criteria for Participant Recruitment

Inclusion Criteria
• Parent or primary caregiver • South Asian ethnicity (Indian, Pakistani, Bangladeshi, Sri Lankan, or mixed South Asian) • Has/caring for a child aged 5-19 with current mental health difficulties • UK resident • Over the age of 18 • Understands and speaks English

participate) (Etikan et al., 2016). This technique aims to recruit participants who are knowledgeable or experienced in the phenomenon of interest and thus able to provide well-informed and versed accounts of their experience (Palinkas et al., 2015). This strategy was used to identify individuals through known acquaintances that may meet the inclusion criteria. One participant was recruited through the researcher's known acquaintances.

Recruitment also took place through several different avenues, including social media and independent organisations. A recruitment flyer (see Appendix C) was shared through social media (Twitter, Instagram, Facebook, LinkedIn, and WhatsApp). The flyer was posted on the social media profiles of the named researcher and her known acquaintances, as well as in South Asian, parenting, and mental health groups on Facebook. A recruitment poster was shared amongst faith-based networks and organisations (e.g., Inspirited Minds, Muslim Women's Organisation) and distributed in Islamic, Sikh, and Hindu places of worship (e.g., mosques, gurdwaras, mandirs). The recruitment poster was shared with SA and mental health charities (e.g., Asian Single Parents Network, South Asian Health Foundation, Taraki, Mind) and independent organisations working with SA communities (e.g., The Black, African & Asian Therapy Network). The majority of participants were recruited through social media. Snowball sampling was also utilised, whereby participants who had taken part in the research were asked to recruit other potential participants from among their contacts who meet the inclusion criteria (Parker et al., 2019). One participant was recruited through snowball sampling.

Reflections from the Recruitment Process. Due to my own experience of mental health within my SA culture, I was acutely aware of the unfamiliarity and stigma of mental health within SA communities. Thus, I was expecting and not surprised by the difficulty in recruiting participants for my project. In the early stages of recruitment, I had a conversation with a potential participant who described their distrust of MHS and their lack of hope for this research to make any meaningful change and explained that this was the reason they would not participate in the research. I remember feeling disheartened following this conversation whilst also understanding the individual’s position completely. I reflected upon the discordance between my expectation for participants to open up about their own and their child’s struggles, and possibly difficulties with accessing services, and there being no guarantee that what they would share would make a real-life impact. However, I understood that wide-reaching, systemic change is often a long process and this change must start somewhere, which spurred me on with my research. I was initially hopeful that snowball sampling would be the key to recruitment. I was therefore taken aback when many of my participants stated they did not know anyone else who might fit the inclusion criteria. On reflection, I wondered whether this was true or whether it was the case that participants were not aware of acquaintances’ children having MHD due to the tendency in SA culture to not share familial difficulties with others outside the family.

From October 2023, I noticed significant difficulty in recruiting for my research, which coincided with the conflict between Israel and Palestine. For many SAs, the injustices inflicted on Palestinians by the colonial state of Israel may have reflected their history of colonialism, possibly triggering deeply held intergenerational trauma. As many Palestinians are of Muslim faith, this conflict may have particularly affected SA Muslims, who were witnessing the deaths of their fellow Muslims. The impact of this conflict likely had negative effects on SAs’ physical and mental well-being. Speaking to a psychological professional who worked within SA communities, they described service users were significantly disengaging from services during this time. It appeared that SAs were not in the right mindset to engage in research that did not support their agenda at the time for gaining justice for Palestinians. This also significantly impacted my willingness to push for recruitment, as it felt counter-productive for me to do so when it was clear it was not a priority for my participants.

Situating the present research within the geopolitical context of the time is crucial given the inescapable nature of such crises and the acknowledged negative impacts of them, including on mental health (Ventriglio et al., 2024). Doing so also aligns with the hermeneutic phenomenological approach of this study, which stipulates an individual's experience cannot be wholly understood without sense-making of the world in which they live in (Malpas, 2008).

2.9.3 Sample Size

Data saturation, the point at which no new information, themes or codes are attained from the data, is often seen as the "flagship of validity in qualitative research" (Constantinou et al., 2017, p. 585). However, there has been considerable critique of the use of data saturation to determine sample sizes, focusing on the lack of a standard procedure to reach data saturation and limited discussion regarding why data saturation is the gold standard (Braun & Clarke, 2021). Low (2019) further described the problematic use of data saturation, stating that it 'is a logical fallacy, as there are always new theoretical insights to be made as long as data continues to be collected and analysed' (p. 131). This idea aligns with IPA, where data analysis and findings are dependent on the researcher's interpretation. Thus, the concept of data saturation does not appear appropriate for the present study.

Many researchers have suggested the depth of data gained from interviews is more important than the size of the sample (Fusch & Ness, 2015). Specifically, IPA studies aim to gather in-depth data and thus tend to have smaller sample sizes, as the focus is on gathering a detailed account of individual experience (Smith et al, 2022). In this way, IPA is unique compared to other qualitative approaches, as it focuses on the quality of the data gathered rather than the quantity, positing that a richer analytic process occurs from a focused honing in on a small number of cases (Smith et al, 2022). A larger number of interviews may lead to less time to develop in-depth interpretations and engage in reflection, which may not allow for justice to be served to participant narratives and the development of a strong analysis. In addition, for clinical psychology doctoral theses, it has been suggested that 6-8 participants are sufficient, as it provides enough data to investigate patterns and distinctness, without the volume of discourses becoming too difficult to manage (Turpin et al., 1997). Taking all these factors into consideration, the present study aimed to recruit 8-10 participants.

2.9.4 Final Sample

In total, 10 caregivers participated in this research. The sample include female (n=9) and male (n=1) participants, aged between 18-49. All participants identified as British South Asians and were in a primary caregiving role for the child they were caring for. The majority of the sample was Pakistani (n=8), with others identifying as Indian (n=1) and mixed South Asian (n=1). Table 6 provides demographic information for the participants. Due to the sensitive nature of this research and participant concerns regarding anonymity, demographics have been provided more generally rather than linking them to any one participant.

2.10 Data Collection Procedure

2.10.1 Initial Screening

Participants who responded to the recruitment advertisement were initially contacted via telephone call. The purpose of the telephone call was to provide participants with information, ensure they met the inclusion criteria and also encourage the building of rapport between myself and the participant. Participants were also given the opportunity to ask any questions they may have. Those that met the criteria were sent the PIS, consent form, and a link to the demographics form. Once the consent form was returned a date and time for the interview was arranged.

Table 6

Participant Demographic Information (n=10)

Demographic		Frequency
Age	18–24 years	1
	24–34 years	2
	35–44 years	5
	45–54 years	2
Gender	Female	9
	Male	1
Ethnicity	Pakistani	8
	Indian	1
	Mixed South Asian	1
Religion	Islam	9
	Sikhism	1
Level of Education	School	3
	Bachelor’s degree	2
	Master’s degree/postgraduate diploma	2
	Doctorate degree	2
Occupation	Employed	7
	Homemaker	2
	Student	1
Migrant status	Born outside of the UK	1
	Born and brought up in the UK, with at least one foreign-born parent	8
	Born and brought up in the UK, with at least one foreign-born grandparent	1

2.10.2 Materials

The demographic form collected information about age, gender, ethnicity, migrant status, education level, employment status, age of child, gender of child, and child’s MHD (see Appendix D). Here, ‘migrant status’ refers to immigrant generation i.e., those who are foreign-born and migrated to the UK, those who were born, brought up, and socialised in the UK with at least one foreign-born parent, and those who were born, brought up, and socialised in the UK with at least one foreign-born grandparent. The demographics form was created using Google Forms. The PIS included information about the purpose of the study, inclusion criteria, what taking part would entail, advantages and disadvantages of taking part, data management, and researcher contact details. The consent form requested participants' consent regarding the recording of the interview, confidentiality, anonymisation, right to withdraw data, and dissemination of the findings (see Appendix E).

The interview schedule was initially created by the researcher, by brainstorming topics of interest and referring to similar past research in the field of interest (Azman et al, 2017; Sharif et al., 2020; Zegwaard et al., 2020). Initial questions were based around themes that were prevalent in the literature (e.g., challenges with the caregiving role) and also those that were not prevalent but appeared to be an important area of discussion for SAs (e.g., culture and religion in the caregiving role). It is important to note that published research evidence is only a small section of a larger valuable knowledge base. It was thus crucial to ensure knowledge from people in the community were also utilised when creating the interview schedule. Hence, the initial draft schedule was then shared with the participant consultant group, to discuss the questions' relevance to the project aims and the target population. Following changes as discussed with consultants, the final schedule consisted of nine questions in total (see Appendix F). An introductory question regarding participants' motivations for taking part was asked to not only build rapport with participants but also gather information about their position on the research topic as a whole. The rest of the main questions were split into three sections covering the four following areas: caregivers' understanding of mental health, caregivers' experiences of caring for their child with MHD, the impact of caregiving on participants, and caregivers' perception of and engagement with professional MHS. This order was thought to provide a natural flow to the interview and build comfortability up to the perhaps more difficult and sensitive questions later in the schedule. Within each section, questions were asked about participants' culture and religion to ensure these aspects were considered within every part of their caregiving experiences. Ending questions were included to ensure participants had space to discuss any topics that were important to them but not mentioned earlier in the interview.

2.10.3 Interview Procedure

Individual semi-structured interviews were utilised for data collection as this was deemed the most appropriate method to capture SA caregivers' experiences. Focus groups were also considered, due to their ability to foster the co-creation of knowledge that is common in SA communities. However, focus groups were ultimately deemed unsuitable due to the sensitive nature of the research topic and the tendency to keep issues private in SA culture, such that focus groups may have prevented participants from sharing their true experiences out of fear of judgment.

Semi-structured interviews are interviews in which the researcher has an aim for what knowledge they want to gain from the interview and therefore has a set of questions to ask, but the questioning is open and the conversation can fluctuate (Fylan, 2005). This format of interviewing allows variation in how the interview schedule is administered, providing flexibility for interviewees to expand on their responses and freedom for the interviewer to prompt and probe specific areas of interest. This approach provides a unique path to explore the lived world of the subject and is therefore deemed suitable for the present research, which aims to explore the richness and depth of caregivers' experiences (Brinkmann & Kvale, 2018). Similar research investigating the experiences of SA families (Heer et al., 2015; Lakhanpaul et al., 2017) and SA perceptions of mental health (Ekanayake et al., 2012; Naeem et al., 2015) have also utilised semi-structured interviews.

Due to the ongoing COVID-19 pandemic, ethical approval was granted to conduct interviews both face-to-face and remotely. The option to provide remote interviews was crucial to encourage engagement with a historically minoritised group, such as SAs, and combat the influence of Whiteness as much as possible. Face-to-face interviews would require participants to travel, which may have inadvertently excluded those from the study who were financially unable to do so and/or had fixed caregiving responsibilities. Participants were able to choose whether they would like to be interviewed face-to-face or virtually; all participants chose remote interviews. Providing an option may have also afforded participants a sense of control over their involvement, in contrast to their voice not being heard as some SAs have experienced within the culture of Whiteness in the UK. Remote interviewing can be further advantageous as it allows participants to conduct the interview from their own homes, where they may feel more comfortable and therefore more able to provide honest, in-depth responses. Nonetheless, utilising a virtual interviewing format comes with some weaknesses. Most individuals call into remote interviews from their homes, and for some, this may have not been a confidential and safe space to discuss sensitive issues, such as experiences of supporting MHD. Remote interviews were conducted over Zoom using a laptop and recorded through Zoom's recording function.

Prior to the beginning of the interview, participants were informed of what to do in the case of disconnection and were given signposting information. Before all interviews, the researcher reminded participants of the limits of confidentiality. The interviews lasted between 60 and 90 minutes. Throughout the interview, the researcher provided prompts for participants to elaborate on their answers. Interviews will be audio-recorded. At the end of each interview, the researcher encouraged participants to further talk about topics that were relevant to the interview that had not been discussed. Participants were debriefed following the interview, informing them of how their data would be processed, and were also sent a debrief form which highlighted sources of further support (see Appendix G). Immediately following each interview, I documented my reflections, particularly focussing on her thoughts, feelings, and moments that stood out to her.

2.10.4 Reflections from the Interview Process

Throughout some of the interviews I found myself experiencing feelings of surprise. Firstly, I was taken aback by the participants' openness and vulnerability in describing such personal, challenging experiences of caring for their child/family member. On reflection, I wondered why I felt this bewilderment, given those who come forward for qualitative research interviews often hold the characteristic of openness. I believe my own prejudices about the stigma of mental health in SA communities played a part. Perhaps it was because of this taboo that participants were so open, perhaps they were grateful for having a space to talk about their sensitive experiences. This feeling of shock was also present when participants spoke about aspects of their culture being helpful in the support they provide. These feelings were likely precipitated by my own experiences of struggling with mental health, during which aspects of my Bengali culture often hindered my recovery. Keeping a journal wherein I reflected on thoughts and feelings following each interview allowed me to recognise my own biases and prejudices.

2.10.5 Data Recording and Transcription

The interviews were recorded via the recording function on Zoom. These audio recordings were transferred to the researcher's password-protected laptop. The researcher verbatim transcribed all interviews from the audio recordings, by initially listening and transcribing and then ensuring accuracy by listening for a second time to identify any mistakes. Transcripts included all words and utterances, including pauses, hesitations, or stumbling in speech (e.g., 'umm', laughter).

2.11 Data Analysis

Guidance for conducting IPA data analyses is flexible rather than prescriptive. IPA researchers have described an iterative and inductive process for analysing data. The following outlined process for the present study is primarily obtained from Smith et al. (2022). The first stage of analysis is focussed on the researcher reading and re-reading the transcript several times, to immerse their selves in the dataset. This stage requires researchers to approach the data with openness and willingness, whilst all the time holding in mind the participant at the centre of the analysis.

The second phase involves making exploratory notes (ENs). The researcher aims to conduct a line-by-line review of the whole transcript, making annotations to the transcript of points of interest. Smith et al. (2022) and Smith and Nizza (2021) have suggested these notes may cover three areas: 1) descriptive comments about *what* the participant is talking about; 2) linguistic comments about *how* the participant uses language and linguistic devices; and 3) conceptual comments about the *why* something had been said, starting the more interpretative part of the analysis by trying to understand the underlying meaning behind the participant's account. Throughout this process the researcher aims to identify what is important to the participant (e.g., beliefs, relationships), the meaning of these for the participant, and their position in relation to these things (Larkin & Thompson, 2012; Motta & Larkin, 2023). This stage of analysis is the most labour-intensive and complex part of IPA analysis and thus the use of strategies such as underlining and reading sections of transcripts backwards may aid in ensuring the researcher remains focussed on what the participant is saying. Whilst making the exploratory notes, the researcher is encouraged to notice how they may be responding to the text, reflecting upon how and why it is generating such reactions. ENs were noted on the right-hand side of the transcript (see Appendix H).

The next stage of analysis shifts from working from the transcript itself to using the ENs. At this point, ENs with connections or patterns are transformed into experiential statements (ESs), which aim to capture an understanding of the meaning of an experience for the participant. As the ESs should clearly stem from the EN, the frequency of an ES in a single transcript is dependent upon how often the participant has spoken about a theme in the interview. Although ESs should be grounded in the data, they should also capture higher-order concepts so the researcher's interpretation of their understanding of the participant's experience becomes important in this stage. Crucially, in line with IPA as an iterative process, the ESs are not final at this point and may change later in analysis (e.g., during clustering). During the analysis, ESs were noted on the left-hand side of the transcript (see Appendix H).

The fourth stage of analysis consists of searching for connections across ESs, mapping out how they fit together to form clusters. Again, this process is not prescriptive and therefore what clusters may be based on can differ; groupings may form around objects of concern or experiential claims. Clusters may not only be formed of similar ESs but also themes that may be in opposition to one another. The aim is to present the key features of the participant's experience and their sense-making (Smith & Nizza, 2021). Once clusters have been formed each is named to form personal experiential themes (PETs). The names of PETs should relate directly to the participant's experiences or their experience of sense-making and should reflect themes in the whole transcript, rather than being bound to distinct instances in the transcript. Each PET may also have subthemes that come under them. Throughout this process, the researcher is encouraged to continually examine the clusters and PETs to ensure they reflect the participant's experiences and life-world.

The fifth stage involves moving to the rest of the transcripts, where stages one to four above are repeated for each case in turn. Researchers are encouraged to analyse each case individually, so that each participant's account is treated in its own terms, given the idiographic nature of IPA. This requires analysers to not be fixed to themes that have emerged from previous cases. Nonetheless, researchers will inevitably be influenced by what has already been found, demanding effort to ensure the allowance of new analytic material to emerge (Smith et al., 2022).

The sixth and final stage of analysis occurs once PETs of each transcript have been finalised. Researchers then compare PETs across participants, looking for both convergences and divergences, to create a set of group experiential themes (GETs). A table is generally created at this point to map out how each PET maps onto the GETs, whilst also noting whether the shared quality is between subthemes or ESs. The final GETs should reflect similarities across cases whilst also indicating how each participant's account is distinctively showing this commonality (Smith et al., 2022).

2.11.1 Reflections from Data Analysis

When analysing some interviews, I found myself experiencing frustration when I perceived that some of what participants had shared did not speak to the topic at hand. I wondered whether this reflected a felt inability amongst participants to share sensitive stories in other spaces in their lives, whereas this research space afforded some comfortability for them to do so. Still, during the analysis, I felt a tendency to focus less on these perceived 'irrelevant' parts, likely due to time pressures and my own preconceived ideas about what is meant by relevant. Nonetheless, I stayed with the process and recognised how some of these conversations, initially discerned as trivial, had underlying meanings and were powerful additions to the findings.

Sometimes thoughts about a previous interview emerged during the analysis of the present interview. I found my mind would automatically make connections between themes that may have emerged from another participant's account. This required me to document such thoughts separately, putting these preconceptions to one side, and return to the present transcript with a clearer focus.

At times it felt difficult to move from experiential statements to creating PETs and then eventually GETs. Although I regularly vetted my interpretations by comparing them back to the participant's initial quote, in an attempt to manoeuvre from particular parts to the whole in a circular hermeneutic manner, I often questioned whether I was moving too far away from the text. This hesitation may reflect a wider tension of polarity that exists in the use of IPA as an analytic method. In one respect, focus should be placed on maintaining idiography through a dedicated process of understanding individual sense-making. However, in the same breath, researchers are also expected to relate participant narratives together and create overarching themes.

2.12 Ethical Considerations

2.12.1 Ethical Approval

Ethical approval was granted by the University of Essex Ethics Committee on 15th August 2022 (Ethics reference number: ETH2122-1296) (see Appendix I). Non-substantial amendments regarding participant reimbursement were made to the ethics application in December 2022 (Ethics reference number: ETH2223-0318). Further substantial amendments related to the target participant population were granted on 14th July 2023 (Ethics reference number: ETH2223-2006).

2.12.2 Informed Consent

All participants were required to complete and sign a consent form before the interview took place. Following participants showing interest in the study, the PIS was sent to each individual via e-mail. Participants were given one day to read through the PIS and decide if they wanted to take part in the study and to ask any questions they may have, after which they were sent the consent form. The consent form required participants to confirm they had read and understood the PIS. Once the consent form had been returned a date for the interview was arranged.

2.12.3 Right to Withdraw

All participants were informed of their right to withdraw from the study before data analysis began in November 2023. This information was provided on both the PIS and consent, and participants were also reminded of this at the start of the interview. They were informed withdrawing their data would not affect the reimbursement they received for participation.

2.12.4 Risk and Protection from Harm

A risk assessment was submitted alongside the ethics application, which highlighted potential risks to the participant and researcher, the likelihood of the occurrence of these risks, and measures to minimise these risks. The nature of this study, requiring participants to share personal experiences about caregiving, mental health, and possible themes of racism and marginalisation, meant that there was a risk of participants becoming distressed as a result. To mitigate this, participants were told that if they did experience psychological distress during the interview, the researcher would take an understanding approach, allow moments of recess, and end the interview if needed. Participants were also given a space to debrief following the interview, to discuss how they found the interview and if it had brought up any difficult feelings for them. Alongside this, participants were given a 'Debrief and Further Information Sheet' both before and after the interview, which detailed sources of further support should they wish to access them.

As this research is exploring a sensitive topic, the accounts provided by participants were likely to be emotionally charged. Thus, it was important to consider the effects this may have on me as a lone researcher. I kept a reflective journal of my interviews, allocating time after each interview to reflect on my experience of interviewing and any difficult thoughts or feelings that may have arisen (see Appendix J). I also utilised external support via my course personal tutor and personal advisor mentor when required.

2.12.5 Anonymity and Confidentiality

Participants were informed of the aim to ensure confidentiality where possible during the research. They were informed of the bounds of confidentiality, in that disclosure of risk of harm to self or others and other safeguarding concerns would require me to inform the relevant services.

Due to the nature of qualitative research gathering participants' narratives, there runs the risk of participants becoming identifiable through the information they share. Anonymisation of data can minimise this risk (Wiles et al., 2008). Each participant was given a participant number and pseudonym. These pseudonyms and participant numbers were used to identify which interview notes, demographic forms, transcripts, and spreadsheets related to which participant. In the write-up, the demographic information was not connected to any one participant and only pseudonyms were used. Any other identifiable information that was shared during the interview (e.g., workplace, area of living) was removed during transcription.

2.12.6 Data Management

The demographic information collected was extracted from the demographics form and stored in a password-protected folder on the researcher's personal laptop. All interviews were audio-recorded and this audio file was transferred to the researcher's laptop and stored in a secure, password-protected folder. All interviews were transcribed by myself. The original digital transcripts, subsequent annotated transcripts, and Excel spreadsheets used for analysis were all stored digitally in a secure, password-protected folder. All handwritten and physical sheets containing data were subsequently destroyed.

2.12.7 Other Ethical Issues

A further consideration is that many of the participants may be caring for a child who has not been officially diagnosed with MHD or who is not receiving professional help. Thus, it was important to ensure participants were aware that the role of the research was not to diagnose their child with a specific mental health problem but rather to explore their experiences of caring for a child who may be experiencing struggles with their mental health, which was reflected to participants at the start of the interview. During the debrief, participants were given details of services whom they may wish to contact for support for their child.

Another aspect to take into consideration, due to the COVID-19 pandemic, is the use of remote interviewing. Although this can be a convenient approach to conducting interviews, it introduces a potential issue regarding confidentiality. Most individuals who agree to remote interviews will call into them from their homes, and for some, this may not be a confidential and safe space to discuss sensitive issues, such as experiences of supporting MHD. Participants were asked at the beginning of the interview if they were in a safe space to continue the interview.

Chapter 3: Results

3.1 Chapter Overview

This chapter presents the findings from the IPA of ten interviews. Three GETs emerged from the analysis relating to the experiences of SA caregivers of children with MHD: *Leaving the Past in the Dust and Paving a New Path*; *Navigating the Never-Ending Tunnel of Distress;* and *Caught in the Tug of War of Support.* Each GET comprised a number of subthemes that together provide a holistic view of the complexity of the caregivers' experiences. Each theme is discussed in detail, supported by participant quotes and the researcher's interpretations. Convergences and divergences within and between individual transcripts are highlighted where appropriate, providing the ability to follow particular narratives.

3.2 Sample Characteristics

The final sample consisted of 10 caregivers. To maintain the confidentiality of participants, the majority of participant demographics have not been linked with individual participants. Table 7 shows participant pseudonyms, basic child demographics, and caregivers' relationships to the child they are caring for. These demographics were chosen to be linked to individual participants as they provide important context to participants' accounts and were deemed to not compromise their anonymity.

Table 7

Participant Details (n=10)

Participant pseudonym	Age of child	Gender of child	Relationship to child
Saanya	19 and 11	Males	Mother
Alia	15	Male	Sister
Harpreet	6	Male	Mother
Saima	10 and 7	Males	Step-mother
Farid	16	Male	Father
Aisha	11	Female	Mother
Nadia	8	Male	Mother
Rani	10	Female	Mother
Amina	14	Male	Mother
Nafisah	16	Female	Mother

The analysis revealed eight subthemes, nestled within three separate Group Experiential Themes (GETs) (see Table 8). The following section of this thesis aims to provide a comprehensive overview of each theme in turn, through my interpretations along with participant quotes to evidence my sense-making, whilst also noting convergences and divergences across and within participants' narratives. It is integral to note that my attempts to make sense of participants' sense-making are somewhat rooted in my own views and experiences. In this way, the findings are likely to differ if participants were interviewed within a different context and if the researcher was different, aligning with the contextual constructivist epistemological position this research sits within. Still, I have endeavoured to ensure the analysis has remained grounded within participants' accounts through a reflective and iterative analytic process.

Table 8

Group Experiential Themes, Subthemes, and Theme Prevalence (n=10)

Group Experiential Theme	Subtheme	No. of Participants Representing Each Theme
Leaving the Past in the Dust and Paving a New Path	Coping with Unhelpful Cultural Expectations and Breaking Away from Cultural Norms	8
	Taking the Skeleton of Mental Health Out of the Closet	10
Navigating the Never-Ending Tunnel of Distress	Traversing the Labyrinth of the Mental Health Difficulty	8
	Grappling with the Cost of Caregiving	8
	Looking Past the Distress Towards the Bright Side	6
Caught in the Tug of War of Support	The Double-Edged Sword of Religious Guidance	9
	The Push-and-Pull of the South Asian Community	8
	Resisting a Mental Health System Impervious to Change and Taking Matters into Own Hands	8

3.3 Group Experiential Theme 1: Leaving the Past in the Dust and Paving a New Path

This theme reflects the weight of expectations and pressures placed on individuals by the wider SA culture, the normality of silence around the concept of mental health, and their efforts to move away from these norms and foster new cultural values.

3.3.1 Subtheme One: Coping with Unhelpful Cultural Expectations and Breaking Away from Cultural Norms

Participants spoke about the inherent pressures that are part and parcel of the nature of being SA. One such pressure is that of educational and occupational achievement, which begins from a young age. Harpreet and Saima both spoke about the influence of the SA generation above them on their own children's desire to attain academic success:

> *"I suppose there's a narrative associated with South Asian people where your kids have to be these high-flying, super-achieving, academic bunnies… my parents say he should be reading now and it's like he's four, do you want to let him enjoy his childhood before he gets into the rat race and has to read every single day?"* (Saima).

> *"That is interesting that the first thing he said when he comes home is 'I was the first boy to get 100 stars', like why is that inbred into him that you've got to compete and be the first for everything? That's not me that's his grandmother."* (Harpreet).

Saima's use of language such as *'bunnies'* and *'high-flying'* provides a vision of young people having to always be 'on' and acting like superheroes, which appears unachievable. Both women's use of phrases such as *'rat race'* and *'first boy to get 100 stars'* suggest the pressure of achievement is not just one placed onto children by wider family members, but one that becomes internalised and leads to comparison with peers, furthering the feeling of pressure.

This academic pressure may have direct impacts on the development or exacerbation of MHD in children, which may add an additional consideration for parents and caregivers to keep in mind in the caregiving process.

For some, the pressures of achieving continue throughout life, in the form of expectation of marriage and material possessions, which are reflective of success in traditional SA culture:

> *"And then the next context is about are you suitable to get married? Why are you not getting a million marriage proposals? Why have you not found the one yet? Why are you still 28 years old and sat on the shelf?"* (Saima).

The use of the phrase *'sat on the shelf'* by Saima is suggestive of marriage as an integral milestone in the life of a SA, without which individuals are not deemed as valuable. This requirement to reach important milestones, and the possible fear of being perceived as less worthy if unable to meet them in a timely manner, may exacerbate the pressure felt by individuals.

Participants described that it is not just the pressure of individual achievements that perpetuates a feeling of pressure, but also the added responsibility of putting the family's and community's needs at a priority. This prioritisation of others' needs is likely born out of the collectivist nature of SA culture, where the well-being of the whole community often takes precedence over that of the individual. In this way, the successes of the individual are often perceived as reflecting the success of the wider family: *"I haven't achieved all those expectations so my parents haven't been happy for years and years with me… I've always been trying to please them or trying to please the community"* (Farid). Others also spoke about this responsibility and its impact on their life and children:

> *"My dad was unwell recently so I was there for a few days and so my husband was on his own with the kids and I think for the kids it's just it's really chaotic, it's like 'oh where are they?' they rarely have all of us together"* (Harpreet).

Harpreet's comments highlight how the responsibility for caring for wider family members may place burden on the ability to be there for her children consistently, and thus effectively support their mental health. Nonetheless, despite the difficulties that these additional responsibilities produce, some participants felt that this was part of their living duty. For example, Rani spoke about how she would not hesitate to provide non-stop care again to her parents who recently passed away, highlighting her selflessness and the value of connectedness in SA families:

> *"I didn't take anything from the system to care for my parents, but I had a duty towards them and if I could do it, run that thing again I'll do it again my parents can come back again I'll redo it again no regrets"* (Rani)

The high expectations of the SA community often led participants to experience a barrage of judgment towards themselves and their child. Harpreet and Saanya both described how their children's non-normative behaviour as a result of MHD was seen as a reflection of poorer parenting, but Saanya felt this judgment was particularly geared towards women/mothers:

> *"As a mother you're always blamed so whatever it is there's always this blame 'you're not doing something right there must be something that you're doing'… I found in my experiences with both my children it's always 'oh you need to spend more time with them'"* (Saanya).

This comment by Saanya highlights the traditional gender roles held by those in SA culture, wherein a mother is often presumed to be the main individual who holds responsibility for the care and behaviour of her children. This norm, again, may add to the pressure to be a 'good' parent and be a source of constant stress, especially when a child's behaviour is perceived as unacceptable within the community.

Gender norms were further discussed in relation to what positions women/mothers versus men/fathers hold in the family. Farid felt it was his responsibility to hold power in the household by "*taking action on what is right and wrong*". Farid also spoke about how his migrant parents would hold the idea that "*women shouldn't go to work, women should look after the house, do the cooking, do the cleaning*". However, this was not the approach that second-generation Harpreet wanted for herself, wanting more independence than was offered:

> *"My husband even said it to me when I had my second [child] 'why don't you stay at home for a little bit and focus on the kids' and I was so offended I was like 'why don't you stay at home I'm going to work I'm going to be different to all the other women'"* (Harpreet).

The word '*even*' highlights the deep-rootedness of gender roles in SA culture, where Harpreet was surprised such views were being spoken from her husband, suggesting that cultural norms transcend generations and the influence of British culture. Alia spoke about how the norm for SA boys to be 'tough' would hinder the ability for her younger brother to get the support he may need at school:

> *"He's kind of adopted characteristics of South Asian guys in his school so he wouldn't show [emotions] in front of the teacher and it's a really difficult situation because he has to be vulnerable for the teacher for them to know that something is wrong but he won't do it"* (Alia).

Despite the longstanding and normalised nature of the expectations and norms discussed above, participants did not shy away from sharing their disagreement with the unhelpfulness of some of these norms. In doing so, many had committed to not passing down the ways they were parented to the parenting of their own children, in the hopes of providing a better childhood for the children than they had experienced. For Aisha and Saima, this was their main aim when approaching the supporting role of caregiving:

> *"My experience as a child motivated me to be different and not be like my family that didn't take mental health seriously."* (Aisha).

Nafisah specifically outlined how she had been breaking generational patterns by providing her children with more privileges than she had encountered.

> *"I tried to allow more freedom with my daughters like what I wanted, that's what I feel like I'm giving them, they go to college they go to university"* (Nafisah).

Despite some participants being able to challenge these cultural norms, others felt incapable of breaking away and doing what they deemed best for their child due to the influential seat upon which elder SAs sit and their demand for respect:

> *"There has to be a line where you know you can no longer argue with the community or your family and you just have to say 'yes I've heard it' but I speak less"* (Farid).

> *"Despite being an adult, I do find myself being like the child again in my relationships with my parents. When they're telling me how to raise my son and my daughter I find it hard to sort of push forward my own authority"* (Harpreet).

The use of language such as *'I speak less'* and *'being like the child'* suggests a sense of powerlessness and being inadvertently silenced, possibly perpetuating a feeling of lack of ability to produce long-term change in maladaptive cultural norms.

3.3.2 Subtheme Two: Taking the Skeleton of Mental Health Out of the Closet

Participants reported growing up with a lack of open conversation about mental health. This was specifically rooted in a scarcity of vulnerability in relation to speaking about emotions. This perpetuated a feeling of being silenced and thus feeling isolated. Farid spoke about the presence of this:

> *"I never talked to anyone about myself my own struggles my own problems because you couldn't, coming from a South Asian family or community"* (Farid).

Their reference to '*family*' and '*community*' suggests the issue of silence is not specific to their families but is a deep-rooted issue that is assumed by the larger SA community as a whole. The certainty of '*you couldn't*' and '*that's what happens*' brings light to the fixed nature of this silence, possibly sustaining a feeling of powerlessness. This concept of cultural silence was more complex for third-generation Alia, who recognised the dissonance between this suppression and the opposing encouragement within her school setting:

> *"It feels like you're living in two worlds almost because you learn about mental health in school and about the signs of mental health and how you should treat mental health and who you should go to to speak about it and then you go home and it's completely the opposite where it's don't talk to people don't tell anybody how you're feeling"* (Alia).

I wondered whether this experience would lead to Alia feeling as if she had to present as two different people in these two contexts and whether this would further add to the battle between British culture and SA culture that is present for many British SAs.

Many participants made attempts to make sense of this silence, as a way of understanding why this unhelpful way of living had become normalised. One way of sensemaking was through positioning it within the busyness of SA lives. Saima felt that "*there's always so much on in South Asian families… I think the peripheries for the generations are dismissed sometimes*". Amina shared a similar sentiment in understanding how the busyness had impacted the generation before her: *"My parents, when they came to this country, they didn't have time to talk about mental health they were too busy at work and they were too busy raising children".*

Narratives of emotions and mental health being minimised were highly prevalent in participants' accounts. Farid shared how his family would outright deny the existence of MHD:

> *"My mum would've said now if we had a conversation 'There are no problems there are no issues there are no worries you're making these worries these problems'"* (Farid).

For Nafisah, minimisation occurred in the context of others explaining away and downplaying what may be perceived as an abnormal presentation, as she stated that *"even if it is talked about in families… they'll make fun of it or [say] they're not feeling well"* (Nafisah). Farid's and Nafisah's narratives provide examples of how the minimising of mental health may have led to the invalidation of participants' and their children's feelings, possibly furthering views of being unsupported and isolated, which may explain the aforementioned struggles for Farid to speak to members of his community about his difficulties.

The concept of stigma was the main way in which participants pursued to comprehend the silence around mental health in the SA community. Farid shared how traditional views of mental health in SA culture were based on an extreme idea of being mentally unwell:

> *"My mum, she would come out with like 'mad case' and she would use this term 'pagal' which means a mad person, deranged... growing up I heard it always."* (Farid).

This extract highlights the naturalness of labelling. This labelling suggests an inherent nature of being *'mad'*, possibly signalling to the community's perception of the permanent nature of having MHD and the inability to recover. The ease within which this labelling of others happens may allow those from the SA community to differentiate and distance themselves away from what is perceived as '*bad'*, under which category MHD may fall under. This distancing may perpetuate a sense of superiority, which may be a similar reason why academic and financial success is valued so highly. In this way, MHD may be perceived as a *"sign of weakness"*, as described by Nadia.

Later, Nadia further delved into the impact of stigma on how an individual is perceived in the community. SA individuals may often strive to be shone in a positive light by those in the community. In Nadia's narrative, it is not just the community's direct perception of MHD as negative that is present, but also the adverse snowball impact on other cultural expectations, which may further the desire to hide MHD from others:

> *"I think people worry about uh marriage and how if the word gets out that someone has mental health [difficulties], their eligibility in terms of partners might be affected"* (Nadia).

Nadia's comment highlights that the image portrayed to the outside community takes precedence over the needs and care of the individual, wherein the individual may get forgotten about by the community and their selves. Furthermore, the likening of MHD with the idea of 'madness' may go even deeper, wherein those with MHD aren't perceived as human. This concept suggests a specific ideal of what a 'healthy' human should look like, within which MHD do not fit:

> *"I think people still have that fear that if they talk openly about it that people will think that, in a way, they're not human anymore"* (Nadia).

All participants attempted to position themselves away from this stigmatising view of mental health, hoping to turn a corner and move away from the cultural norm of silence. For many, this required a conscious and active effort to notice when such patterns were playing out and to challenge them. Alia recognised the need to escape the confusion of the *'two worlds'*, mentioned earlier, by not playing a passive role in the way she supports her sibling:

> *"We've made the decision to not continue the mistakes of our grandparents and we have communication, we're open and honest… we've chosen to go down the opposite route."* (Alia).

Some provided specific ways in which they endeavoured to change the currents of silence by providing a validating and containing space for conversation about emotions and mental health. Farid reflected on how his current parenting behaviour was in complete contradiction to how he was parented by his mother:

> *"I've listened to him I've given him support but I think I've adapted my own strategy where my mum would have never given a supportive family environment… whereas now I, as a father, and my wife, we're more open you can speak to us we can have a conversation"* (Farid).

Farid's tone suggests he revels in pride in his ability to recognise and move away from the hindering nature of his parent's generation's normalcy of denying and labelling MHD to produce a nurturing environment for his son. This was shared by participants Nadia and Harpreet also. This highlights their awareness of the need to break the vicious cycle of silence to do what they deem is best for their children, prioritising their child's well-being over the maintenance of the status quo of the SA community.

3.3.3 Summary of GET 1

This theme delved into the vast nature of cultural expectations that are placed on individuals and the pressurising effect this has on individuals' mental health and participants' ability to be there for the children they are caring for. Participants battled with cultural silence around mental health, putting in effort to do the opposite and be open about MHD, to be the best they could for their child. Although caregivers made efforts to break away from these expectations and cultural norms around mental health, many struggled to see deep-seated change in this area.

3.4 Group Experiential Theme 2: Navigating the Never-Ending Tunnel of Distress

This over-arching theme describes the process of supporting their child/sibling with their MHD. It details the efforts and techniques utilised by caregivers to support the various difficulties generated by the child's mental health difficulty, the trials and tribulations the caregiver encounters through the process of caregiving, and their search for the positives out of this difficult situation.

3.4.1 Subtheme One: Traversing the Labyrinth of the Mental Health Difficulty

Participants described that they attempted to distract their child from their distress through a variety of different avenues. For Amina, she encouraged her son to engage in acts of service to distract from his distress:

> *"I'll say to him 'just go outside and pick up all the litter on the street or brush the garden or go next door to Grandad's and see if he needs you to do anything'"* (Amina).

This extract highlights Amina's attempt to instil a sense of responsibility in her son, whilst also trying to divert his attention away from his inner issues, thus killing two birds with one stone. This was an important theme throughout participants' narratives, that is the multiple purposes and outcomes of strategies to manage the child's distress. Inadvertently, this also reflects the cultural value of helping others and the wider community, as previously discussed in GET one. However, here the responsibility of helping others is positioned as positive and helpful towards mental health. Nonetheless, perhaps the tendency to use distraction techniques reflects cultural, generational coping patterns of ignoring issues as it is easier to do so rather than tackling the difficulty head-on. Others employed distraction through escaping the stress and distress of everyday life:

> *"I try to mask it by like taking him on holidays… thinking that will make it better, surely we'll just go away and he'll splash around in a pool and go to the beach… but the sadness is still there, it follows him"* (Harpreet).

Here, Harpreet recognises that these diversions only provide temporary relief rather than long-lasting change for her son. The description of the sadness *'following him'* brings to mind an image of a dark shadow. Positioning the mental health difficulty in this way may represent the unrelenting nature of mental health distress, undeterred by efforts of resolve from loved ones.

The use of distraction and other techniques employed by caregivers was often based on participants' own experiences of what had helped their selves when experiencing emotional difficulties. For example, Nafisah encouraged her daughter to spend time outside:

> *"It's good just to get out, because I'm a bit of a recluse as well, I don't like people I don't like being around crowds and things like that, but I force myself out because I know it will help me so that's what I try to do with her"* (Nafisah).

This delving into her own knowledge and experience suggests a sense of resourcefulness, a characteristic arguably necessary to manage the unpredictability and uncertainty associated with MHD. The words *'I force myself out'* bring light to the effortful nature of making progress in relieving mental health symptoms, which requires individuals to become comfortable with the feeling of being uncomfortable.

Some participants strived to provide order to the child's life, amongst the disarray caused by the emotional difficulties. This was put in place by Saima through a reminder to her son about the role of a child. This movement to position her child as a child may reflect her belief in the adult-like nature of MHD, wherein emotional distress is considered a mature experience that should not be experienced by the innocence of a child. Further, her strategy of administering chores may indicate a desire to develop a sense of holding responsibility for her son, similar to Amina's earlier extract:

> *"We line them all up together and say okay this is your treat you will get like a Freddo or something on a Friday… I'm putting him back in that position where actually you are the child and you can be a kid and have those good things"* (Saima).

Others aimed to provide order through the implementation of routine. Similar to her earlier extract, Amina's encouragement for her son to spend time with extended family members formed an integral part of this regimen:

> *"We've got him in a routine where he'll do things like that with his grandad and I'll encourage it as well… so things like that, very natural day-to-day things"* (Amina).

In this way, parental guidance towards maintaining familial bonds is perceived as crucial in cultivating positive mental health, again, reflecting the importance of the value placed on family in SA culture. Through sustaining a routine, this also reflected a desire to maintain a state of normality, combatting the distress caused by the instability of emotional struggles.

Amina's discussion around the importance of familial togetherness for her child reflected a wider theme for participants, that is, the importance of providing avenues for building connection. The lack of long-lasting change from strategies such as distraction may have led to participants searching for other ideas of support. Harpreet attempted to move away from the tendency to escape and looked for connection closer to home:

> *"This morning he said 'Mama make sure you make daal chawal when I come back' so I made him rice and curry that's waiting for him downstairs so it's little things… maybe I'm biased there's something very healing about Asian food… Arjun also loves that he's part of something, that there is such a deep history and he loves hearing stories about it all so 'tell me about the partition tell me about when this happened'… those sort of conversations help his mental health"* (Harpreet).

It appears that the sheer nature of being SA is inherently supportive towards MH. Here, Harpreet seems to position SA culture as holding a unique quality, that envelops those in the community with a warmness. The importance of the caregiver's role in supporting the child's developing affection and connection to their background and culture is apparent, with a possible hope for this connection to provide enduring support for the child's well-being in the future. The mere act of talking about SA history and culture may hold the dual function of building the bond between caregiver and child, as well as that with SA culture.

The hope to provide ongoing support for the child in the future was an account shared by many participants. This emerged through a push to build the child's self-efficacy to manage their own emotional difficulties:

> *"You have to be strong, you need to talk more, you need to be open… I'm not saying you shouldn't cry or you shouldn't feel a lack of energy to do stuff, but you need to face up to the problems"* (Farid).

The tone in this excerpt suggests a sense of desperation towards the child to develop characteristics such as strength and openness to deal with the mental health difficulty, which may reflect a feeling of powerlessness to make change from the caregiver's perspective and a transfer of responsibility to the child. The repetition of *'you'* in this excerpt further lends to the idea of the child needing to take individual accountability, which appears to be in direct contradiction to the collective nature of SA culture, possibly suggesting the internalisation of individualist beliefs from British culture. Through this statement, Farid is walking the fine line between empowering his son and ensuring he is not invalidating his son's experiences at the same time.

For others, this building of self-efficacy was positioned in contrast to the typical ways of supporting mental health through medical intervention. Amina longed to support her child to be mindful and look inward, rather than outwards and relying on external sources of support. In this way, she appears to be situating *'popping pills'* as a temporary relief from emotional distress rather than getting down to the route of the problem:

> *"It's so important to have your balance in life, to make sure that you are seeing to your mental health needs, and I don't mean just by taking medicines and popping pills, I mean by really being in tune with what your body needs and what your mind needs"* (Amina).

The experience of supporting children's MHD often led to caregivers feeling powerless in their ability to cultivate long-lasting positive effects, due to the mental health difficulty's unpredictability, as Amina stated *"I always feel that each day I have to start again"*, and resistance to change, as described by Nafisah: *"I try and get through to her um I just feel she's constantly negative"*. This may have led to participants relinquishing their sense of power and control and putting the child in the driver's seat, to truly understand and put the child's needs first:

> *"We're letting it all be led by him with what he's comfortable with… we use the half hour before bed just to talk about things, we did it where he was leading the conversation… when we find something that was an interest with him… he would talk"* (Saima).

> *"You want to just give an instruction… that doesn't work, you can't go on this leadership thing of 'I'm your mum and you need to listen to me', it doesn't work"* (Amina).

In this way, Saima appears to be releasing herself from the pressure of using particular, structured techniques to support her stepson, instead, attempting to build a trusting relationship. The impact of focusing on the child's interests suggests the lack of need for specialist approaches that require the caregiver to go above and beyond. Amina's recognition of the lack of helpfulness of an authoritative approach suggests supporting MHD is a process of trial and error. This change in approach may reduce the sense of hierarchy and power difference between parent and child, allowing the building of a sense of empowerment in the child and a feeling of having been validated.

3.4.2 Subtheme Two: Grappling with the Cost of Caregiving

Themes of the emotional toll of caregiving for a child with MHD were highly prevalent in most participants' accounts. Caregivers navigated a rollercoaster of different emotions throughout the supporting process. One such emotion was sadness, which was experienced intensely by Amina and Saima, especially when they were managing their child's distress in the immediate moment:

> *"I'm just summarising it for you but it's really emotional at the time, there's lots of high voices, lots of shouting, lots of emotional tears"* (Amina).

This quote signifies the lack of control participants have over their own emotions when dealing with their child's mental anguish. Amina's clarification that she was *'summarising'* suggests that the intensity of her distress is so complex and severe that it was impossible to condense and simplify within the constraints of the interview. It appears that the sheer nature of witnessing their child's distress is painful for the caregivers, without the added stress of the challenges that come with trying to manage their child's distress.

Several parents shared the feeling of living in a constant state of uncertainty and anxiety. Some participants worried about how their child's difficulties may worsen in the future: *"Today it's toothpaste he's worrying about, at age 14 what's it going to turn into?"* (Harpreet). Others' worries consisted of the fear of relapse. Despite making significant progress with her son's mental state, Saanya could not shake the worry that the difficult past they had experienced may return:

> *"It's improved a lot but then I always worry what if he hears a loud sound and he thinks he's being attacked again… that worry's always there… even*

> *now when he goes to work or uni[versity], I'm always worried one little trigger and he'll probably be back to where he was… I think that worry doesn't leave you"* (Saanya).

In this way, participants appeared unable to escape the all-encompassing nature of MHD. This is evident in Saanya's narrative, where it appears she is incapable of revelling in the improvement of her child's mental health difficulty due to the perpetuating anxiety. This fear may also reflect a wider fear around the reduced influence of parents, and subsequent ability to support their children, as they grow up and develop independence.

The MHD, and the challenges of managing them, had significant impacts on participants' perception of their abilities and selves as a whole. This often came to light through themes of self-doubt. Participants found themselves questioning if they were taking the right approach with the child they were supporting. This was an uncomfortable position to be in and led participants to wonder if they were able to provide the care that the child needed:

> *"I'm saying things over and over again and it feels like it isn't working… sometimes I do not know what to do… it makes me feel like there's something I'm missing and there's something I'm not doing well"* (Aisha).

This feeling of doing something wrong was echoed by Nafisah, whose account appears to reflect how the feeling of being *'useless'* had unfortunately become part of her identity, extrapolated to other parts of and roles in her life:

> *"I just feel… I don't feel very good at it I feel useless, that's how I feel… I feel like I'm doing everything wrong, I'm a bad mum, I'm a bad wife, I'm a bad daughter, I'm a bad work colleague. I'm just not doing anything right* (Nafisah).

The challenges of managing the MHD were compounded by the supporting role being a constant role. Unlike a broken leg, which may heal in a few months, MHD are unlikely to be completely 'cured' and its impact on an individual's life is ever-changing. This, combined with the cultural value of helping others, often meant participants had no time for reprieve from their role of supporting mental health. For Rani, she felt she had to go above and beyond for her daughter, leading to exhaustion but, still, she persevered with her continuous role of supporting her daughter:

> *"I sometimes feel that to save her I have to go a lot of extra miles to do things, to keep her afloat and there would be days when I'm just so tired to do anything, but I still have to pull myself together and get out and do it"* (Rani).

The role of supporting the children with their MHD was further complicated by the various cultural responsibilities that form a fundamental part of the nature of being SA. This pressure primarily came from the strain of providing time and effort to care for extended family members:

> *"He's so anxious about being away from me, if I'm not here because I'm looking after my dad it's like double whammy, is grandad Nannu going to die and where's Mama gone… but being an only child who else will look after them if it's not me?"* (Harpreet).

Here, Harpreet describes how illness of wider family members not only exacerbates the child's mental distress but also weakens her own ability to manage her child's distress. The mentioning of *'who else will look after them if not me?'* indicates her inherent responsibility to provide care for her parents and the lack of choice in the matter. This question may also reflect her desire for more support for herself to manage the juggling of these various responsibilities, the longing for someone else to help her carry the burden.

Unfortunately, it is not just the caregivers themselves who are negatively affected by the child's mental health struggles; the impacts are more far-reaching. Despite the general lack of visibility of MHD, resulting changes in behaviour are often recognised by loved ones. This inability to hide MHD may be especially difficult in SA families, where closeness between family members is encouraged. In this way, wider family members may become entangled within the distress of the mental health difficulty, regardless of not being directly involved in the caregiving:

> *"Everyone's walking on eggshells… you don't want to upset her, or you don't want to say the wrong thing to her… obviously there's a tension then in the family when someone's not feeling well… it's like a rut that the whole family then falls into"* (Nafisah).

The comment of *'walking on eggshells'* reflects the complex considerations wider family members take to ensure their words or actions do not exacerbate the child's emotional difficulties. This appears to be a delicate and time-consuming task that requires individuals to be continuously monitoring their behaviour. The shared familial experience of falling into a *'rut'* may indicate the togetherness and bond of the SA family, where one person's mental state directly impacts upon others'.

The constant, non-stop act of caring for a child with MHD highlights the time-consuming and effortful nature of this role. This pervasiveness of MHD often led to participants having to sacrifice their own needs and desires, to ensure the child is provided with the best possible care. For Rani and Harpreet, this materialised in their having to let go of their jobs to do what they perceived to be best for their child, which was to be present with them more often:

> *"When I used to work in the city he's like 'Mama but you're not going to come back are you'... so, then I left that job and looked for a job working from home, it's better… I loved that job in the city but nothing's more important than being at home with your kids, nothing so, I've got a bit of a boring job"* (Harpreet).

Harpreet's recognition of the negative impact the job was having on her son's mental health required her to make the difficult decision to change jobs to one that fit better for her child. However, Rani felt she had to completely let go of her career to be there for her daughter and wider family: *"It's just not going to work for me at this moment in time so, I ended up giving up my job"*. This choice both caregivers made suggests they had positioned their children's needs as more important than their own. This may reflect a wider cultural value of caring for others and putting the needs of others and the community as a whole ahead of their selves as an individual. It appears Harpreet specifically is coming to terms with what this change means for her feeling of fulfilment.

3.4.3 Subtheme Three: Looking Past the Distress Towards the Bright Side

Despite the unrelenting nature of MHD and the challenges that come with managing them, some participants were able to notice where progress had been made in their child's recovery:

> *"The only positive I take away is that sometimes my child really believes that everything is going to be okay and they kind of cooperate with me… it feels like I've achieved a really big feat"* (Aisha).

Here, Aisha's child's internalisation of her efforts to reduce their distress allows for a sense of accomplishment for Aisha to revel in. However, the fact that this occurs only *'sometimes'*, and is in direct contrast to Aisha's earlier sentiment of *'I do not know what to do'*, reminds us that the progress of MHD is not a linear process, rather it is a wave with peaks and troughs. This may make appreciating the 'good' moments even more integral. For some, the recognition of having made progress was intensified when the child they were caring for also acknowledged their efforts to support them:

> *"He'll come up to me and he'll just be so thankful… he'll say 'mummy thank you for doing that' or 'mummy it's really good that you've done that"* (Amina).

This appreciation from her child may allow the development of confidence in Amina's abilities to support her child. Knowing that her efforts are fruitful not only in producing change in the mental health struggles but also in developing a grateful stance in her child may make the time, effort, and adversities worthwhile, and motivate her to spur on in the role. Further, it could allow for the calming of feelings of self-doubt caregivers may experience, as discussed in the previous subtheme.

This evolution in caregivers' self-esteem may be further perpetuated by others' observation of the positive changes. For Amina, it wasn't just the child with the MHD that perceived these benefits, but also the wider family and SA community:

> *"My other children will notice as well… they'll say things like 'oh you've done a good job there mum' so that is priceless uh when you get that information from people around you and even the wider community as well will observe how my son handles situations"* (Amina).

The observations of those somewhat at a distance from the family provide a sense of just how widespread the impacts are of the parent's efforts on the child's mental health. Amina's endeavours appear to have manifested into changes that have generalised beyond the four walls of the home in which she supports his mental health. As a family's image in the community is often of most importance in SA communities, the positive comments from community members provide a source of comfort from this stress.

Growth for some participants did not cease with improvements in their self-esteem; caregivers also noticed development in their personal characteristics. Alia, Nafisah, and Farid all spoke about how they are now able to hold a more understanding and compassionate position with others going through MHD. This links to subtheme two in GET one, where participants spoke about breaking out of the mould to take a more accepting approach to mental health. Here, participants appear to appreciate their ability to challenge the status quo:

> *"[I'm] a lot more understanding of how others feel, I don't think I would know this much about other people's mental health problems and how people react to things if it wasn't for Mustafa… it definitely has a positive impact with how I treat other relationships like with my friends and family"* (Alia).

Alia recognises that her role in supporting the management of her brother's MHD was the main driver for this increased tolerance. This excerpt may highlight that the capacity to possess an accurate awareness of mental health is wholly dependent on having had a direct experience with mental health where the challenges are visible to your own eyes. Nonetheless, Alia appears able to look past the suffering that came with taking on this stressful role and use it to her advantage to support her connections with others, thus generalising her learnings.

It is not just the primary caregiver who is experiencing positive personal effects of supporting a child with MHD, these influences seem to have externalised to others in the family system, helping flourish the caregiver's relationship with said person:

> *"I think it has strengthened my husband's relationship with myself… just that psychological value, that emotional mindedness, it's pulling things out of him*

> *that are new and he's seen the value of it… he's thinking about things in that way that he probably wouldn't have considered before"* (Saima).

Saima's husband appears to have developed a fresh mindset towards mental health. Still, *'pulling things out'* suggests this perspective was always something he had capacity for, perhaps he needed an experience, such as supporting his son with mental health, for it to be brought to the surface and into the individual's awareness. This excerpt highlights the importance of caregivers holding an aligned approach towards caregiving with their partner to nurture a supportive romantic relationship, which in itself is integral to not feeling isolated within the caring role. I wonder if Saima felt that she had a significant role in shifting her husband's attitude, which may in turn further strengthen her self-esteem.

3.4.4 Summary of GET 2

This master theme depicted the process of caregivers using both direct and indirect strategies to support the child they were caring for with their MHD. It appears this non-stop role of caregiving comes with various challenges, including loss, sacrifice, and a rollercoaster of emotions. Despite the struggle that caregivers experienced, they were able to see the silver lining of the improved self-esteem and positive qualities that were welcomed by-products of this role.

3.5 Group Experiential Theme 3: Caught in the Tug of War of Support

This over-arching theme describes the process of supporting their child/sibling with their MHD. It details the efforts and techniques utilised by caregivers to support the various difficulties generated by the child's mental health difficulty, the trials and tribulations the caregiver encounters through the process of caregiving, and their search for the positives out of this difficult situation.

3.5.1 Subtheme One: The Double-Edged Sword of Religious Guidance

For many, religion was positioned as valuable in supporting their child's mental health. This occurred in two contrasting ways. Individuals were required to be resourceful and extrapolate teachings from their religion and religious scriptures to support their child. Amina spoke about her use of stories of the prophets to help build a sense of strength in her child: *"If you read those there's always lessons and there's always things that you can draw from that can build character"*. This was echoed by Saima. Alternatively, Amina and Saima also talked about the more direct influence of religion. Their quotes provide a sense of how religious practices integral to Islam are inherently therapeutic and thus remedial for mental health:

> *"They really encourage yoga as a way of calming and connecting with yourselves but for me I see lots of similarities that have been happening centuries ago which is the prayer and how we pray five times a day and we're supposed to take it slowly and the movements are supposed to be really slow"* (Amina).

Amina appears to be positioning Islam as similar to more modern-day mental health techniques, hinting at a multipurpose nature of religion. It may be that she is putting her religion on a pedestal as it has been supporting emotional well-being since *'centuries ago'*, whilst modern-day techniques are just catching up with this idea of mindfulness in recent years, suggesting a sense of pride towards being a Muslim.

Religion was also deemed as supportive towards caregivers' own well-being. The challenges of caring for a child with MHD, as documented in GET two, may cause participants to search for ways of managing the distress that is inevitable with this caring role. Moving towards their religion was one way in which participants strived to achieve this. Having an unwavering faith in God allowed participants to be reminded of their resilience:

> *"Allah won't burden you with more than you can bear, so He knows that this test you can deal with it, he wouldn't have given it to me if I couldn't deal with it… those things, you know, help with my mental health, because I think I can overcome this"* (Nafisah).

Nafisah's excerpt highlights her battle with her anxieties regarding her ability to manage the caregiving role and the contradicting trust imparted in her by God. Nonetheless, it appears that she is able to push through conflict through the strength provided by her religion, giving her the confidence to keep going in her caregiving role. This theme was reflected in Nadia's interview also. Harpreet's discussion around the influence of religion was focussed more on her faith providing her with a sense of peace, a needed quality through the hectic nature of the caregiving role:

> *"I did turn my mind more towards religious scriptures and there was so much solace to be found, there was so much, it was so soothing it was so healing… so that really did help"* (Harpreet).

Harpreet's tone appears to convey a sense of surprise at how beneficial she had found religious scriptures. Farid and Nafisah searched the Quran for direct passages around supporting mental health but were disappointed. Harpreet's and Nafisah's earlier extracts seem to indicate a more indirect effect of religion and religious scriptures on building characteristics and qualities to cope with the challenges that come with this caregiving role. Importantly, this realisation may require introspection and reflection.

Despite the positive impact of a relationship with God and religious scriptures, this sentiment was not mirrored in participant's accounts of support from religious leaders and institutions. Saima experienced a rigidity in Muslim faith leaders' ability to comprehend mental health and provide individualised support:

> *"Within masjids that we frequent there is a lack of understanding of what happens when people fall into depressive states and what happens when they show these symptoms and what causes it and what can help it… I spoke to a few Imams… and their response felt quite rehearsed, things like have Sabr, pray, and read Quran… remember Allah and Allah will remember you and that's good that's great but I think my kids need a little bit more"* (Saima).

Saima appears to recognise that there are aspects of her religion that are helpful but was hoping for additional advice and new avenues of support. It seems that she feels let down by these institutions, possibly perpetuating a feeling of loneliness in the caregiving role. I wonder if also the prescription given to her about following religious practices may inadvertently make her feel like she and her children's faiths were not strong enough. This theme may have also been shared by Harpreet, who appeared to avoid the support of highly religious community members due to fear of judgment: *"I cut my hair I wear nail varnish got my ears pierced, that's not really allowed so I feel like if I go to an older generation it would be like 'well sort that stuff out first and then come for spiritual guidance'"*.

3.5.2 Subtheme Two: The Push-and-Pull of the South Asian Community

Participants found aspects of their SA culture and community beneficial in supporting their child. An important value shared across SA cultures is that of being family-oriented, the pressures of which were exemplified in GETs one and two. Here, however, family-centredness was also described by some participants as invaluable in supporting their child. Harpreet spoke about the influence of the generation above her:

> *"I encourage him to spend time with his grandparents because I think that they are really experienced and very knowledgeable people, very loving people, which will give him a lot of life lessons"* (Amina).

> *"It's just a way of being that's so different it's a calmness about that generation… there's no urgency they're not like 'right next okay we've ticked off soft play now we're going to need to tick off Pizza Hut and now we're going to do the next thing' for them it's just like 'no let's just sit at home let's just play'"* (Harpreet).

This *'calmness'* of Harpreet's parents appears to be positioned as an inherent characteristic of this generation. It appears to be in direct contrast with her child's difficulties with anxiety, possibly providing a breath of fresh air to the turbulent nature of the mental health difficulty. Like the support found through religion, culture seems to be inadvertently beneficial towards mental health through wider characteristics, rather than through direct means. This was visible through Amina's interview also, where she described her encouragement for her son to spend time with his grandparents was so that he could learn *"life lessons"*.

For caregivers' coping, participants reflected on the qualities needed by others around them to be able to develop a trusting relationship and share personal experiences. Shared ethnic identity, religious identity, and life experience were all deemed integral to this. Harpreet's account signifies that shared identity reflects a deeper shared understanding of what it means to be SA and the strengths and challenges that come with this, something that those not directly in the system would not understand. In this way, these close relationships provide a safe, containing space to delve into the sensitive intricacies of life, including the nature of caring for a child with MHD:

> *"My cousin, she's Punjabi and Sikh and she gets it… she's in a similar life stage to where I am… she's grappling with how do we navigate intergenerational tensions, how do we navigate feeling distant from God*

> *but equally holding on to that… I think her being in a similar position, a similar age really helps"* (Harpreet).

For Saima, however, she was surprised by an experience where shared life experience took precedence over shared cultural identity in feeling supported at work:

> *"My line manager, weirdly, is Gujarati Indian and I felt like I didn't get a lot of support from her… when I actually sat down with the clinical lead, she was so sympathetic. She's actually the mother of an adopted child with learning disabilities, so she knows all about the complexities that come with taking care of the mental health of kids that aren't necessarily yours"* (Saima).

Saima attempts to make sense of her manager's lack of assistance appeared futile, with her concluding *"I just found it really strange"*. This suggests she experienced a range of emotions, from shock to disgust. Perhaps these feelings represented facing the undermining of the SA cultural expectation of togetherness. Nonetheless, this experience led her to search for support through other means, finding the validation she needed through someone who 'gets her', similarly to Harpreet.

Despite Harpreet finding comfort in a similar family member, participants described the long-standing issue of a lack of understanding around MH in the wider SA community, as initially described in GET one, and the impact of this on their feelings of being supported. Nadia described a lack of curiosity towards children with MHD and rather a jump straight to judgment:

> *"I'll look at a child and if I see a child having a meltdown I think what's making them do that, I wonder what's triggered them and I wish that was the reaction of everybody as opposed to the judgmental 'this kid's naughty and*

> *there's something wrong with his parents' … it just makes you not want to talk to them about anything"* (Nadia).

The immediate connection made between a child's unconventional behaviour and their parents' rearing techniques may negatively impact parents' self-esteem. This may inadvertently lead to caregivers avoiding approaching community members for support, due to the expectation of judgment, possibly furthering feelings of isolation. Following on from GET one, Nadia's extract again signifies her ability to show a different response to non-normative behaviour than her community. The wish for some more patience and consideration from the community was echoed by many participants.

3.5.3 Subtheme Three: Resisting a Mental Health System Impervious to Change and Taking Matters into Own Hands

Most participants were aware of the various avenues for mental health support available through the state, such as the GP and Child and Adolescent Mental Health Services (CAMHS). However, caregivers were resistant to attempting to access such services and described several barriers to doing so. The main barrier was the length of waiting lists, which would mean caregivers and their children would be waiting a long period of time between seeking help and receiving the support they needed:

> *"I think going to your GP for any sort of mental health help is just a very arduous process for an adult at least. I think going through that as a kid I can't imagine what it's like. I think it's already a kind of testing time as you're trying to grow up and navigate yourself and your own identity"* (Saima).

Saima appears to be fearful of her child's distress worsening through the long process of accessing support, on top of the already challenging period that is adolescence. Saima also described the pursuit of the medical model in GP services as a further barrier, feeling that offering medication was not in line with the help they wanted and needed for their child: *"It's not psychologically minded it's not considering the person's emotions… it's just numbers on a page… it's not the approach that people that have been through trauma need"* (Saima). It appears clear that Saima recognises a lack of individualisation in traditional MHS, with instead a larger focus on just getting people through the system without consideration of whether an individual is receiving the help they need to improve their mental health.

This lack of individualisation appeared to be a theme for others, such as Farid, who felt that MHS were not individualised to the SA community as a whole:

> *"There is a lack of services that are geared to meet the community's needs… being a minority individual accessing services in Britain you would think things would have changed, okay they have people from diverse backgrounds in these positions… but the services are very white-orientated"* (Farid).

Farid recognises that although services consist of a more ethnically diverse staff team than previously was the case when he had accessed these same services as a child, this has not amounted to ingrained, systemic change to make MHS more culturally appropriate. Thus, it appears recruitment of people from diverse backgrounds may be tokenistic. Farid's expressions that '*you think things would have changed'* may reflect his frustration with the stagnant nature of these services. This excerpt seems to position the SA community as a forgotten, abandoned people within the context of MHS. This lack of understanding was echoed by Harpreet (*"the Western norms, they don't fit, they don't easily apply… they just wouldn't get it")* and Rani *("I feel these services are not for us"*).

For others it was less about the services themselves that were leading to avoidance but rather the stigma around mental health. Similar to what was described in GET one regarding the stigma around being open about mental health in the SA community, participants were also anxious about the community finding out about individuals accessing MHS. This was the primary reason why Alia felt like her brother would not engage in talking therapy:

> *"I don't know if Mustafa would be comfortable with the idea of going through to a therapist… I don't think he would respond well to being like 'oh you're going to a therapy session today', I think he would find that really insulting and almost embarrassing… if he thought that anybody in our community or in his school found out about that he'd be embarrassed definitely"* (Alia).

Alia's excerpt provides an insight into the narrative around what accessing traditional mental health support would mean for an individual. The words *'insulting'* and *'embarrassing'* suggest a negative perception towards this support; perhaps therapy signifies an inability to be independent, to sort problems out by yourself, and even weakness for Mustafa. Thus, it seems the stigma around mental health becomes internalised by those experiencing MHD and may impact their willingness to access organisations that may be helpful, although, as described above, they may be equally as unhelpful. This internalised stigma was also present for caregivers themselves who were considering how to access support for their own mental health. For Nafisah, her experience of someone close to her being directly judged based on their utilisation of psychotropic medication has a direct influence on her desire for similar support:

> *"I don't know whether to go to the GP myself because I don't really want to take medication because of what people think about people who are on medication… my family say like 'loopy loo' or something like that about someone being erratic… my sister gets it a lot like, everyone thinks she's crazy because she's been on medication"* (Nafisah).

Due to this discomfort with the notion of accessing statutory services for themselves, and the lack of reliable support from their community, as described in subtheme two, caregivers were required to lean on other forms of support to help them manage the everyday distress of caring for MHD. This took the shape of practising self-care. For most caregivers, this was about taking time to their selves, away from the tempestuous nature of MHD:

> *"I make sure I get up before the children even if it's an hour so I can shower get ready make sure that I've prayed make sure that I've had my breakfast and have had a quiet morning even if it's an hour before"* (Amina).
>
> *"Now I work part-time because at least I can have a couple of days where Hassan is at school and I'm not at work and it gives me some breathing space, to do chores or to do things that I like or just sometimes doing nothing, just to sit and think"* (Nadia).

This suggests forward planning is necessary to allow for a temporary escape from the constant role of caregiving; for Amina and Nadia, it appears that there is no such thing as a spontaneous self-care activity. Importantly, this self-care does not appear to be anything special or out of the ordinary, rather it consists of small, simple, everyday actions which allow for the ease of including them within their busy lives. Unfortunately, for Nadia this time away from her child may be used to fulfil other responsibilities, which begs the question of whether caregivers can truly have time for themselves.

For participants, the rationale for supporting their selves often consisted of a hidden motive of supporting their child in turn. In this way, it appears actions to support the self are never completely self-focused, with caregivers always keeping the needs and interests of the family in mind. This further shines a spotlight on the importance of familial responsibility and the caring nature of SAs, which Amina's interview exemplified:

> *"Tending to my needs through my Salah or even other things like my diet, my health… these things that I do bring balance into my life so that I can then be productive in helping his mental health"* (Amina).

For some, self-care also took the form of releasing their self from the pressure of taking care of the home and the child with MHD:

> *"I give myself a bit more leeway after a day with him… maybe I should be going downstairs and putting the dishwasher on, but it's okay I'm in bed and that's okay I'll do it in the morning it'll wait"* (Nadia).

Nadia appears to be permitting herself to not be constantly 'on the go'. It may have been the challenging nature of her child's MHD that pushed her to be able to do this. This excerpt seems to signify an internal battle with herself where she is questioning herself and her expectations. Nonetheless, she seems to be able to win this battle and allow herself room for reprieve. However, for other caregivers, they felt unable to fully let go of the sole responsibility of caregiving and put their trust in others. This was evident in Rani's interview in relation to getting support from her child's school. Her excerpt below highlights her frustration towards the lack of offering of support. It appears she is unable to release herself from holding the sole responsibility of her child's progress; without the possession of this burden the child wouldn't get the assistance required and thus is an adaptive characteristic:

> *"Still, I had to be doing the leg work to get that help rather than them approaching us as a family, I had to be doing that footwork… I don't think there was enough support on bereavement areas in the school, and then I had to be chasing around to make sure she was given the support that she needed"* (Rani).

3.5.4 Summary of GET 3

This theme detailed caregivers' multi-faceted, conflictual relationships with their religion and SA culture in regard to getting support for the child and their selves. Participants recognised both the positive impacts of their community and faith but also where they were more disappointed and wishful for change. This hope for reform was also expressed towards statutory mental health support, which participants felt was not set up to support the SA community. This led participants to look inward and find support within themselves.

Chapter 4: Discussion

4.1 Chapter Overview

This chapter discusses the findings from this research study, providing a summary of each main theme and relating the findings to previous literature and psychological theories. This is followed by a consideration of the clinical implications of the research, as well as a discussion around the strengths and limitations of the study, to be taken into account when extrapolating the findings. Lastly, suggestions are made for the future direction of research in this field, concluding with personal reflections from myself.

4.2 Summary of Findings

This thesis aimed to explore the experiences of caring for a child with mental health difficulties amongst SA familial caregivers in the UK. The main aim was to contribute to the limited body of literature on the topic by gathering direct evidence from SA caregivers themselves. The following section will relate the findings with the relevant literature and psychological theories and describe how the findings answer the research questions, which were:

1) **How do South Asian caregivers experience caring for a child with mental health difficulties?**

a) **How do South Asian caregivers view help-seeking for mental health difficulties?**

b) **How does culture and/or religion influence South Asian caregivers' views and experiences of supporting a child with mental health difficulties?**

4.2.1 GET 1: Leaving the Past in the Dust and Paving a New Path

In this theme, caregivers spoke about the vast nature of cultural expectations that are placed on them as individuals throughout their lives. This included pressures relating to academic success, financial success, material possessions, and caring for the wider family. These pressures differed between participants due to the differential gender roles held by SA culture. This supports previous research that has identified clear, distinct responsibilities between SA men and women (Hickey, 2008). This could be understood through systemic theory, where these pressures seem to stem from long-held familial and cultural scripts regarding success (Byng-Hall, 1995). Moreover, systemic theory posits individuals in a family system take up certain roles, such as the rigid gender roles described by participants. Importantly, participants recognised how the pressures described impacted their own and the child's mental health. As discussed in chapter 1, previous research had identified cultural correlates with MHD in SAs (e.g., family conflict) (Masood et al., 2009). However, this previous research was quantitative in nature, identifying how these cultural values may increase or decrease the likelihood of MHD. The present research contributes to the literature base by evidencing the complex process by which certain aspects of SA culture may play a part in the development and maintenance of poor mental health through first-hand, qualitative accounts.

Caregivers reflected on how the pressures placed on them through their culture may impact their ability to provide consistent, loving care to their children which, again, is a unique insight into the impact of gender roles and cultural pressures on providing care within a mental health context. Caregivers were determined to break the vicious cycle by not putting the same expectations on their own children, to provide a less pressurising child-rearing environment. In this way, caregivers were breaking old scripts and putting in place a new, more adaptive script, in which they are attempting to change their behaviour based on past observations of their own parents' child-rearing practices (Dallos & Vetere, 2021). In this way, they were actively choosing not to repeat certain things from their own childhood that they perceived as unhelpful (Dallos & Vetere, 2021). This idea of challenging cultural norms is not completely novel, with similar themes having been found in other samples of SA people (e.g., couples, youth) (Shariff, 2008; Singh & Bhavana, 2015). The present study, however appears to take this concept further by describing specifically how norms are being challenged through changes in behaviour and how these changes are following through to the next generation of SAs. Chapter 1 described the concept of acculturation and it appears through the challenging of norms participants may be exhibiting strategies reflective of *integration.* Nonetheless, for some, this departing from cultural norms was easier said than done due to the cultural importance of elders and respecting family (Babu et al., 2017).

This theme of breaking away from cultural scripts was also seen in participants' experiences with mental health. Overwhelmingly, participants spoke about the normalisation of silence regarding mental health in their communities. Some made attempts to make sense of the silence. The impact of the silence on their abilities to express their emotions was clear. This experience of silencing appeared to form part of a wider theme of mental health stigma, a relationship that has been studied in the past within various contexts (Austin et al., 2024; Moll et al., 2013). Stigma was a highly prevalent topic discussed, where the view of MHD was highly negative in participants' communities and often took the form of labelling. This commonality of stigma towards mental health aligns with previous research in both South Asia, as discussed in this paper's earlier systematic literature review, and amongst British SAs

(Ahmed et al., 2020; Banerjee & Dixit, 2021; Dijkxhoorn et al., 2023; Koschorke et al., 2017; Mirza et al., 2019; Sangar & Howe, 2021). This highlights the transcultural nature of mental health stigma and its endurance in the SA community despite the wider influence of a social context within Great Britain where disclosure may be more openly accepted within society (Evans-Lacko et al., 2013). Nonetheless, the current study does elaborate on this topic compared to previous research, with participants not merely describing how mental health stigma presents in communities but going further to share how they were battling with the normalisation of stigma (e.g., through having open discussion with others).

Different to previous research in South Asia, the present study's participants' active efforts to move away from silence around mental health and provide a more open experience for the children they were caring for offer a novel insight into the experiences of SA caregivers. Previous qualitative research on SA caregivers in South Asia, as outlined in this thesis' earlier SLR, does not appear to mention this challenging of cultural silence (Dijkxhoorn et al., 2023; Issac et al., 2023; Joshi et al., 2008; Mathias et al., 2019; Meheli, 2023). Perhaps this strength exhibited by the caregivers of this study to confront these longstanding scripts reflects acculturation to Western norms, where outspokenness and voicing of critical opinions are valued (Arpaci et al., 2018; Durkin, 2011). However, these values also reflect individualisation, which carries the consequence of Western societies being less collective and more isolating, consequences SAs appear to resist (Zaidi et al., 2016). An alternative explanation is that much of the previous research focussed on the direct experiences of caregiving, rather than the wider, cultural influences on caregiving within which challenging cultural norms of silence may sit.

This theme pertains directly to the research question as it highlights how culture plays an integral role in the day-to-day of SA individuals. Cultural scripts inform SAs how to think and behave, and the pressures of following these expectations strictly can impact how available caregivers are to provide attention to the child they are caring for. These cultural expectations extend to views around mental health, directly impacting how MHD are perceived and managed in SA families.

4.2.2 GET 2: Navigating the Never-Ending Tunnel of Distress

SA caregivers discussed their use of both direct and indirect strategies to support the child they were caring for with their mental health. This included distraction, connecting with nature, reaffirming the role of the child, providing routine, and connecting with family. Through these strategies, it appears caregivers are attempting to bring the unbalanced state of the family back into equilibrium, wherein the child's good mental health is a core tenet to returning homeostasis to the family system (Guttman, 2014). What appeared to be integral to all of these strategies was the desire to foster the caregiver-child bond, which is consistent with attachment theory, in that a secure attachment relationship between caregiver and child is crucial for healthy emotional functioning in the child, in childhood and beyond (Howe, 2012). Chapter 1 described the effects of acculturation on British SAs, with previous research finding a conflictual relationship between SA children and their migrant parents due to differences in acculturation (Abouguendia & Noels, 2001; Tonsing, 2014). Conversely, the current research appears to contradict this idea, instead positioning SA caregivers as prioritising their relationship with the child they are caring for, over and above cultural pressures. Still, this may be explained by the majority of the caregivers in the present study identifying as a second-generation immigrant. Alongside active strategies, caregivers also attempted to develop their child's self-efficacy to manage their mental distress independently, through developing characteristics such as introspectiveness. This encouragement of independence and developing resourcefulness seems to contradict traditional SA cultural values of collectivism (Shariff, 2009). Perhaps this reflects a shift towards the adoption of neoliberal views and values of the UK by minoritised parents. Importantly, caregivers felt they had to put the child in a position of control to most effectively support the child. This approach of relinquishing parental control seems to go against a perception of a hierarchical nature of SA families that is dominant in current literature, instead aligning more with a client-centred approach that is highly prevalent amongst current recommendations for mental health treatment (Becher, 2008; Chatterjee, 2004; Smith & Williams, 2016).

Unsurprisingly, the various challenges that came with supporting a child with MHD formed a significant part of participants' accounts. Caregivers experienced sadness witnessing the child's distress and anxiety in response to the uncertainty of the future state of the MHD. These findings are consistent with previous qualitative research in SA caregivers supporting adult family members with MHD, as presented in the earlier SLR (Banerjee & Dixit, 2021; Dijkxhoorn, 2023; Issac et al., 2023; Jagannathan et al., 2011; Joshi et al., 2008; Koschorke et al., 2014; Mathias et al., 2019; Meheli, 2023; & Penny et al., 2009). Much of this previous research was conducted in South Asia rather than the UK, which is suggestive of a universal experience of caregiving for MHD that is permeated with emotions that transcends distance and culture. The unrelenting nature of the MHD had significant impacts on the caregiver's self-esteem, with many questioning their ability to support the child they were caring for. This finding contributes to previous quantitative literature on poor self-esteem in caregivers of those caring for people with disabilities and MHD, highlighted in Chapter 1, by specifically describing how self-esteem is directly impacted by the caring role and situating this amongst SA caregivers (Cheng et al., 2022; Kim, 2017). Not only was the role of supporting the mental health difficulty a constant one but this was compounded by caregivers' other cultural responsibilities, which was an exhausting juggling act for many. As a result of the pressures, caregivers made many sacrifices to be the best support for their child, including forfeiting an ideal career. These findings of the necessity for personal sacrifices align with previous findings that found similar amongst SA familial caregivers of adults with MHD (Dijkxhoorn, 2023; Issac et al., 2023; Meheli, 2023). The child's MHD did not only have an impact on the caregivers themselves but also on the wider family which, again, has similarities with themes found in previous qualitative research on SA caregivers of MHD (Issac et al., 2023).

Despite the diverse difficulties that came with the experience of caring for a child with MHD, caregivers were able to find an element of hope. Some were able to recognise the positive impact of their efforts on their child's mental health, which in turn developed caregivers' self-esteem and confidence in this role, and this was intensified when the positive changes were observed by others in the community. Some caregivers saw growth in the form of the development of their personal characteristics, such as becoming more understanding and compassionate. All of these findings are consistent with previous research on SA caregivers of adults with MHD, who found similar positive effects on self-esteem and personal growth (Dijkxhoorn et al., 2023; Issac et al., 2023; Joshi et al., 2008; & Mathias et al., 2019). This theme regarding positive impacts did, however, produce a novel finding in that the impacts on personal growth were not only experienced by the caregivers themselves but sometimes also extended to other family members and the process of providing care often improved familial relationships as a whole. This extends previous research by highlighting the far-reaching beneficial effects of the caregiving process.

This theme relates to the research question as it highlights the complexities of the experience of caring for a child with MHD, that not only are there the challenges of the MHD itself, but also the knock-on, negative impact on the caregiver and wider family. This theme also signifies how culture can play contradicting roles in both supporting their child's MHD and worsening the caregiver's ability to manage the MHD.

4.2.3 GET 3: Caught in the Tug of War of Support

Religion was generally viewed as supportive for caregivers in their efforts to support the children they were caring for. Although some were disappointed by the lack of direct guidance from religious scriptures on how to support MHD, others found the scriptures useful through the extrapolation of teachings to fit within the context of mental health. Caregivers also recognised the inherent characteristics of their religion and how this aligned with current treatment practices for mental health. These appear to be novel findings within this area of research, that is, how SA caregivers use religion to directly support a family member with MHD. Previous research on caregivers have focussed on how religion may be used as a coping strategy for the caregivers themselves whereas the present research highlights how faith may also be used to support the person being cared for, indicating towards multiple functions of religion and their resourcefulness (Malhotra & Thapa, 2015; Pearce et al., 2016; Walke et al., 2018). Still, religion was also helpful for caregivers themselves, by providing them with resilience and a sense of peace to manage the challenging role of caregiver. This aligns with previous qualitative research on SA caregivers which positions the relationship with God as integral to the coping process (Malhotra & Thapa, 2015; Raghavan et al., 2022). The positive effects of religion were not mirrored for those who had contact with religious leaders; caregivers felt advice from religious leaders lacked depth and personalisation. This was a complex relationship in which their somewhat rigid views often isolated caregivers from accessing support for their selves also. This finding adds to previous research which has found conflicting views in caregivers towards the role of religious leaders in providing effective healing to unwell family members, highlighting how this confliction also extrapolates towards caregivers' own desires for help (Littlewood & Dein, 2016; Penny et al., 2009; Raghavan et al., 2022). These conflicting views towards religious leaders appear to be present amongst those living within both majority and non-majority SA cultures, suggesting that they transcend cultural influences. Overall, the findings go further to show the relationship with religion more generally is complex, with participants able to hold the fact that it can be both helpful and unhelpful towards mental health at the same time.

There were similar conflicting attitudes towards cultural support for caregivers and the way they support the children they were caring for. Aspects that were perceived as beneficial were the nature of being family-oriented, which supported connection for the children and allowed them to benefit from the calmness and wisdom of their grandparents. This is an original finding in the field of how culture is used as a positive coping strategy in experiences of caregiving, given much previous research has focussed on how culture impacts the general caregiving experience (Pharr et al., 2014; Sun et al., 2012). For caregivers, connecting with others in the community who shared cultural and religious identity or life experience was supportive in feeling less alone. This theme of the importance of shared identity in interpersonal relationships has previously been shown as integral in the strength of and positive effect garnered from such relationships amongst different racially minoritised groups, and thus this appears to be no different for SAs (Kiang & Fuligni, 2009; Leszczensky & Pink, 2017). Despite the positives of culture, the lack of understanding around MH and the tendency for judgment in the SA community as a whole would prevent caregivers from truly connecting with wider community members and accessing their support, maintaining feelings of isolation. This, again, highlights the complexities of the influence of culture in its ability to both positively and negatively impact the caregiving experience. Participants shared a desire for more understanding and compassion from the SA community. This adds to the literature on SA caregivers' needs, which have historically focussed on their needs from state and statutory services; this research extends previous findings by highlighting the need for change within communities in the effort to support caregivers.

In terms of statutory support, most participants were aware of the avenues to receive such support for the child they were caring for. However, several barriers prevented them from doing so, such as long waiting lists, a lack of individualisation in services, and a lack of cultural understanding in services. This is consistent with previous research on barriers to help-seeking for SAs experiencing MHD, where lack of consistency and cultural sensitivity are significant barriers (Moller et al., 2016; Penny et al., 2009; Rehman, 2016). The present research is dissimilar to much of this previous research, which have been conducted with service users or the general SA population, not caregivers (Prajapati & Liebling, 2021). This suggests the views around MHS being inappropriate are widely and deeply held within various groups of SAs. This interplay of services being insensitive to both ethnic and religious differences lends to the model of intersectionality, which explains how multiple disadvantages compound to create unique experiences of discrimination and oppression (Collins & Bilge, 2020). This could explain why some participants were avoidant of services due to fear of both their religious practices and cultural values being misunderstood. Understandably, caregivers did not want their child to experience these aspects of services out of fear of it making their difficulties worse and hoped for systemic change towards culturally appropriate services.

Barriers to accessing traditional mental health support were also influenced by stigma, with caregivers' avoidance of services, for both their selves and the child being cared for, being spurred on by concern over the community perceptions of them. This finding is unsurprising given the extensive amount of previous research on the impact of stigma on help-seeking in the SA community (Arora et al., 2016; Gilbert et al., 2004; Goel et al., 2023; Loya et al., 2010; Pilkington et al., 2012). The unsuitability of MHS led caregivers to find other ways to support themselves through self-care, which took the form of taking time for themselves, doing activities of value, and letting go of the sole responsibility of care. This furthers previous research identifying the importance of self-care as a coping strategy for familial caregivers, by situating it within a specific context of caregiving for mental health among SA caregivers (Machado et al., 2018; Sabo & Chin, 2021; Waligora et al., 2019).

This theme answers the research question, specifically sub-question b), as it highlights the conflicting relationship caregivers have with help-seeking, in that they both recognise the need for more explicit support than they can offer to their child but are resistant to many forms of support due to past negative experiences. Not only is this conflicting relationship present for the support for their child but also for the support for themselves regarding the challenges associated with caregiving. This understandable avoidance of statutory services leads caregivers to seek support elsewhere, often internally and through religion.

4.3 Implications of the Research

4.3.1 Policy

Participants' narratives suggest there remains institutional racism in services which prevents SAs from receiving timely and appropriate care. This is somewhat expected given recent efforts to provide equitable care to those from ethnically minoritised backgrounds, such as the policies *Inside Outside* (NIMHE, 2003) and *Delivering Race Equality in Mental Health Care* (Department of Health, 2005), have been unsuccessful in creating systemic change in service user outcomes and experiences (Dyer, 2019). Perhaps this fruitlessness could be explained by these policies' negligent grouping of 'BAME' individuals which does not reflect the unique experiences of SA individuals that undoubtedly differ from those experiences of their Black counterparts, for example. Policymakers may use the present findings to produce policies that recognise the particular mental health needs of SA communities.

A lack of funding for statutory services has been an ongoing issue in the UK for several years due to austerity policies (Cummins, 2018). This concern was highlighted by some participants through their recognition of long waiting lists and offers of short-term support. This points to a need for increased funding into MHS as a whole, to reduce waiting lists and increase therapeutic capacity. Most NHS services currently offer up to 12 sessions of therapy (Pybis et al., 2017), which may not be sufficient for SA clients due to historical mistrust of services, demanding a longer period of time to build therapeutic rapport (Prajapati & Liebling, 2021). Recent years have seen an increase in training places for clinical psychologists following a recognition of a need for improved MHS (Health Education England, 2020). Whilst this is a welcome advancement, the availability of additional funding for different aspects of MHS will be crucial in bringing innovation and creating a welcoming environment for SA service users.

4.3.2 Communities

The present findings highlight caregivers' conflicting attitudes toward the available support, or lack of it, from their cultural and religious communities. Some participants explicitly expressed their desire for an understanding community and a space where they could share their struggles with like-minded others which is non-pathologising, unlike statutory services. This lends towards the idea of setting up support groups within institutions that the community frequents (e.g., in religious establishments), which may allow caregivers to feel less alone in their caregiving journey and the sharing of ideas of support and coping. This aligns with ideas from community psychology, which focuses on working collaboratively with communities, and the expertise they come with, to support systemic change through social connection and solidarity (Kagan et al., 2019). This in-group approach may be particularly empowering for SAs who have faced oppression and social injustice from external influences such as colonialism. A community-led approach may allow caregivers to use the valuable knowledge and experience they have developed to support and empower others in their community towards collective healing. However, this is dependent on the willingness and bravery of individual members of the community to lead this initiative, which may feel difficult given themes around the continued presence of stigma in regard to mental health. Still, the creation of such support groups may help make strides in the longer-term goal of challenging the deeply-held stigmatised response towards mental health in the SA community.

Although some caregivers shared a positive experience of support from their children's schools, this was not a shared experience across the group. For those who did receive support, this was an arduous process requiring caregivers to highlight to the school their children's difficulties. This additional responsibility appeared to add pressure to caregivers' already full plates. This finding has several implications for schools in how they may be able to support SA children's well-being and their families. Schools should develop clearer pathways to initially identify those young people who may be particularly struggling with their mental health. This requires an individualised approach where staff will need to understand each student's personality to recognise changes in their behaviour that may be indicative of changes in mental well-being. This is especially important for racially minoritised students, such as SAs, who may be more likely to mask such changes (Anyon et al., 2014; Patel & Kull, 2011). The improved recognition of those with mental health struggles is highly dependent on the provision of mental health training to school staff. This may consist of, for example, the recognition of unique early warning signs amongst SA youth (e.g., an increased likelihood of internalisation but a lesser likelihood of engaging in externalising behaviour or deliberate self-harm) (Goodman et al., 2008). Appropriate training will allow teachers to feel more confident in supporting their students' mental health within the school environment. Throughout this process, parents and other caregivers/family members should be kept informed about the child's well-being and involved in the support provided by the school. This approach of involving family seems to be in place for those students who have been diagnosed with a specific mental health diagnosis or are accessing statutory MHS (e.g., Team Around the Family meetings (North Yorkshire Safeguarding Children Partnership, 2011)). However, this may inadvertently lead to the neglect of those without such diagnoses, which is more likely among SAs as evidenced by this thesis and previous research (Goodman et al., 2008). A whole family approach is needed in this respect, to reflect the non-nuclear nature of SA families.

4.3.3 Statutory Mental Health System

The nature of statutory MHS, such as CAMHS, has historically catered towards a White, secular demographic, leading to the overlooking of racially minoritised groups. Before we can consider what overt changes are required of these services to develop SAs willingness to engage with them, the culture within services requires thought. Participants shared they feel services don't understand the essence of what it means to be SA. This includes language, family structure, and cuisine, as well as cultural expectations and values such as respect and togetherness. Understanding how all these aspects combine to create SA culture is integral to creating an environment in which SA service users feel heard and respected. This could occur through reading about SA history and culture but also by going out into such communities and engaging with SA individuals to gain first-hand knowledge of their experiences. Services must question their selves and their practices to bring to awareness how whiteness may be operating and replicating systemic racism. It is not enough for only certain individual professionals to engage with this; systemic change to create a culture of openness and understanding requires a whole-system approach.

It is clear that SAs are generally not being identified as in need of mental health support and are falling through the cracks between different service levels (Bhui et al., 2001; Patel et al., 2023). This leads to the requirement for a better understanding of how mental health difficulties may present in this population, especially as there are considerable differences compared to that of the White majority (Bhui et al., 2001). This may be achieved by reaching out to the SA community themselves to understand what emotional difficulties may look like. An overwhelmingly powerful theme emerging from the findings is that of the feeling that services are not for SAs. Thus, the creation of services, or pathway to improving services, would benefit from co-production with SA service users themselves, as they would be best placed to reflect the needs of their own community and support the development of culturally appropriate services. To ensure this would lead to deeply ingrained change, rather than surface-level, tokenistic change, this approach must be positioned as an ongoing process of trial-and-error that may be reflected through service user development group meetings that hold the service to account, for example. This systemic resolution would be especially important in areas in which there is a high proportion of SAs residing and may lead to changes in SAs' views towards services, where they now feel seen and heard.

Although creating culturally sensitive services is important, there still exists the difficulty of mental health stigma that was positioned as a significant barrier towards accessing traditional MHS by participants in the current study. Much of this stigma appears to be perpetuated by a lack of an accurate understanding of mental health. Services may be able to challenge this stigma through outreach to the SA community and the provision of education regarding the normalcy of struggles with thoughts and emotions. They must also develop a better understanding of racial trauma and how social inequalities may give rise to many of the MHD seen in racialised communities. This could be achieved through joint working with third sector organisations that may already have strong links with the community, but also religious institutions, as it appears religious leaders and establishments are well-respected amongst the SA diaspora.

4.3.4 Clinical Psychology and Therapeutic Practice

The findings suggest the first resort mental health treatment of psychotropic medication common across the UK is not one that aligns with caregivers' views about what support is needed for the child they are caring for. This then lends to a shift of focus towards other forms of support, such as psychological input. Over recent years guidelines have been produced to support clinical psychologists in working with diverse groups of clients (British Psychological Society, 2017; UK Council for Psychotherapy, 2019). These guidelines have unfortunately tended to group communities that are ‘different’ from the British norm and thus don’t take into consideration the uniqueness of different groups of minoritised peoples and faith communities, which may partly explain mental health professionals’ hesitancy and lack of skills towards working with culture and religion in therapy (Joseph, 2014). This finding is unsurprising given the lack of consideration of such factors in clinical psychology training, with research finding UK clinical doctorate programmes providing between zero to three days of teaching on psycho-spiritual issues throughout the three-year course (Mills, 2010). This highlights a need for the provision of specific training and guidance in the area of working with culture, religion, and spirituality in therapy across all psychological professions. It could be argued that the clinical psychology profession is inadvertently neglecting SAs by not providing clear guidance on these topics, given that religiosity, interdependence, and experiences of prejudice are core concepts that distinguish those from minoritised backgrounds from the advantaged majority (Hall, 2001).

There exists a religiosity gap between the religious affiliation of clinical psychologists and the wider population, with those who are religious being underrepresented in the mental health profession (Delaney et al., 2007; Smiley, 2001). Suggestions have been made that the psychological workforce needs to better reflect the communities they serve, in the hopes this will improve minoritised communities’ engagement with traditional MHS. In line with this, schemes have been developed to improve access to psychological professions for those from disadvantaged backgrounds, such as those from ethnically minoritised communities (Health Education England, 2021). Whilst the implementation of such programmes may have good intentions, it may not have the desired impact; the current and previous research suggest that, although clients may initially show a preference for a therapist from a similar background, shared ethnic and religious identity between the therapist and client is not the most important factor in determining the strength of the therapeutic relationship or mental health outcomes (Cabral & Smith, 2011; Mayers et al., 2007). Instead, it seems the crucial factor underlying this preference is for an individual's culture or religiosity to be respected and accepted, reflected through the therapist's openness to discuss the client's beliefs and values (Mayers et al., 2007). Therefore, rather than a focus purely on visual representation, attention should be placed on therapists providing a safe space where permission is provided from the outset for culture and religion to be part of the therapeutic process.

Psychological formulation is a collaborative process occurring at the beginning stages of therapy which conceptualises the development and maintenance of a client's difficulties (Johnstone & Dallos, 2013). In this process a therapist can ask the client about how their culture and/or religion may have impacted their difficulties but also how they may be supportive towards their mental health. It is important for clinicians to not make assumptions about a client's religious practice (Crossley & Salter, 2005). Thus, spirituality and religiosity could be explored more generically by asking questions such as 'what gives you strength and purpose in life?', 'what do you rely on when you feel hopeless?'. In the current study, caregivers shared their frustration at the lack of control they often feel concerning the support of their child. Holding this in mind, therapists should encourage the empowering of SA youth by ensuring the provision of choice and opportunities to exert control (e.g., in the choosing of therapeutic modality). Family therapy may be considered given the interdependent nature of SA families, although the desire of the young person should always be prioritised. Systemic ideas should be taken into consideration throughout the therapeutic process if systemic therapy is deemed not suitable and caregivers kept in the know as much as possible.

Alongside the work therapists must do inside the therapy room with clients, there also appears a need for therapists to engage in individual reflective work when working with SA clients, especially considering the mistrust and fear of secular services described by caregivers. This work may consist of using supervision and peer reflective spaces to consider their attitudes and biases towards religion and non-British cultures and reflect upon their influence on the therapeutic process. A tool to help facilitate such discussions is the 'social GGRRAAACCEEESSS', an acronym that describes different aspects of social and personal identity, which include culture, ethnicity, religion, and spirituality, that afford people different levels of privilege (Burnham, 2012). By reflecting on identity, therapists may recognise points of difference between their selves and their client which may otherwise go unnoticed and negatively impact the therapeutic relationship.

Although psychologists and therapists must strive to improve upon their practice, training and reflection may only go so far as individual cases often are more complex than what is taught in teaching sessions, especially where culture and religion intersect and may be both detrimental and supportive towards mental health. Therapists should be encouraged to accept the limits of their skills and expertise and approach others who may be more knowledgeable in aspects of culture and religion (Breuninger et al., 2014). Therapists may wish to co-work with faith groups and services in the community and, if the religious content is an important part of the work, consider bringing in an appropriate faith leader into some sessions. This wider networking may inadvertently strengthen the therapeutic relationship as SA clients observe their therapist going above and beyond to best support them, something they may not have experienced in the past.

4.4 Strengths and Limitations

A particular strength of the current research is its novel investigation of a stigmatised topic with a marginalised, minoritised population. Although some researchers may raise concern regarding the relatively small sample of this study, recruiting 10 participants from this population group is an achievement given the historical labelling of SAs as a 'hard to reach’ population. Responsibility has often been placed on SAs and their culture for their perceived lack of engagement in services (Kapadia et al., 2017; Kirmayer & Bhugra, 2009). The present research challenges this notion of SAs being a ‘hard to engage’ group, instead providing context to their observed disconnection and presenting them as a community ready and willing for change. This was achieved with the small participant group which allowed rich information to be gathered, evident through participants’ detailed accounts. This will hopefully impact the perception of SAs within the research sphere and encourage more researchers to pursue research with SAs as a participant group. Changing the narrative from SAs being ‘hard to engage’ to ‘easy to ignore’ may allow services and researchers to reflect on the influence of the socio-political system on lack of engagement.

Recruiting participant consultants, those that had direct experience with the research topic and fit the criteria for the study, into the study to support the development of the research proved to be integral in facilitating a supportive research environment. This was a significant strengthening aspect of the research. Given the history of marginalisation SAs in the UK have experienced, the inclusion of these consultants felt particularly important to create a research space that was relevant and tailored to the community themselves, rather than the researcher’s perception of the community (Aldridge, 2016). This enhances the credibility of the research.

The study is not, however, without its limitations. One unfortunate weakness of the study is the majority female sample, leaving the voice of fathers and other male family members something to be desired. It was acknowledged during the planning stage of the study that, generally, it is difficult to recruit fathers for research about parental involvement (Mitchell et al., 2007). This may be further impacted in SA communities, where SA fathers tend to be less involved as personal caregivers and view mothers as having closer relationships with their children (Salway et al., 2009). This realisation led to pursuing specific avenues of recruitment (e.g., asking participants if they knew any fathers who would fit the inclusion criteria and advertising within specific fathers' parenting groups), with the hopes of recruiting a larger sample of male caregivers. Unfortunately, this approach was unsuccessful, with the only male participant, Farid, expressing interest in the study through social media. Farid's account detailed his specific experiences with the pressure of being a father in SA culture, which was wholly different to that of the female participants. Importantly, he described his direct involvement in supporting his child with his mental health, in contrast to the notion that SA fathers do not hold a significant role in this regard. Still, due to only one male participant, caution should be taken when extrapolating the present findings to male SA caregivers as a whole, as GETs and subthemes drawn from interviews are likely to be different if more males were represented in the sample.

Along the same vein, the sample was also not fully representative of the wide array of ethnicities and religions encompassed within SA communities. The sample consisted mostly of Pakistanis (8 participants) and Muslims (9 participants). Thus, the narratives of Bangladeshis, Indians, and Sri Lankans and those that follow Hinduism and Sikhism were generally not heard. The lack of Bangladeshis, for example, could be understood by migration patterns. For example, the main migration of Indians and Pakistanis to the UK occurred earlier than the migration of Bangladeshis, thus, the majority of Bangladeshis in the UK in the age range of having adolescent children are more likely to be have been born and brought up in Bangladesh rather than the UK (Peach, 2006). Those who are second-generation (i.e., born and brought up in the UK) are likely to be more accustomed to British culture, where mental health is generally less stigmatised than in South Asian communities (Lauber & Rössler, 2007; Robinson, 2009). Therefore, they may be more aware and understanding of mental health and possibly more likely to participate in research on the topic (Woodall et al., 2010). Despite similarities between different religions and SA ethnicities, some differences do exist. For example, Hinduism has henotheistic and pantheistic inclinations whereas Islam is purely monotheistic (Wani, 2013). Thus, the present research may not be generalisable to the whole SA community but rather a specific subset of this wider community.

One major tenet of IPA research is the requirement for a homogenous sample (Alase, 2017). The sample was homogenous in the sense all participants shared the experience of caring for a child with MHD and SA ethnic identity. However, to ensure a sufficient sample could be gained to gather detailed caregiver accounts, less focus was placed on the heterogeneity of the children being cared and thus they were a wide range of ages and had different MHD. This is reflective of the present study being the first of its kind and therefore aiming to take an all-encompassing, exploratory approach. Nonetheless, it is important to note caring for children of different ages and different difficulties will undoubtedly come with diverse challenges. Taking a spotlight on particular contexts of caregiving within this wider ethnic group (e.g., only with caregivers of children experiencing symptoms of anxiety) will be important to identify these differences.

A limitation of the applicability of the present study is the choice of a non-clinical sample. All children that were being cared for had not received an official diagnosis of a mental health difficulty. This was a deliberate choice for this study, given the historical unlikeliness for SAs to present to services, and thus receive a diagnosis, and the focus of previous research on the experiences of those under MHS (Baker & Kirk-Wade, 2023; Prajapati & Liebling, 2021). Although this choice allowed the voices of SA caregivers, which may have been historically neglected, to shine, it is likely the narratives shared would be vastly different if the children had received a diagnosis. Having received a diagnosis and any follow-up support may have impacted the way caregivers felt they could provide care to the child and also their perspectives towards MHS, which would change the findings produced.

This relates to a limitation within the field of practice, as psychologists and other mental health professionals often only work with issues that have been diagnosed, particularly within the public sector. Thus, caution should be taken when considering sharing these findings within clinical settings.

4.5 Future Research

Future research may wish to build upon the present research by continuing the research with a more representative sample of the SA community. This would include more participants from varied ethnicities (i.e., Bangladeshi, Indian, and Sri Lankan) and religions (Hinduism, Sikhism, Christianity, and those that are non-religious). This would allow clear identification of not only convergences but also divergences between different accounts and possibly place these within the context of ethnicity and/or religion.

The present study focussed on caregiver experiences, as past research has primarily investigated the direct experiences of those with MHD themselves. It would be interesting for further studies to explore the perspectives of SA children with MHD, and the impact of culture and religion on their MHD, alongside their caregivers'. This may allow a comparison between their experiences to identify whether there is consistency or if their views differ, especially where different immigrant generations may signify different levels of acculturation. This information would prove vital in the consideration of the offering of support; would the children wish to be supported differently from how their caregivers were supporting them? Similarly, exploring the experiences of mental health professionals working with SA families would be crucial to identify where a common pathway could be established and what support may be missing, not only for the SA families themselves but for the mental health system supporting them. These findings would be particularly interesting given differences in participants' preference for support from someone with a shared cultural/religious identity vs someone with lived experience of caring for MHD.

This research has particularly identified the struggles of SA caregivers supporting a child with MHD. A particular finding is subtheme 3 of GET 3, *'Resisting a Mental Health System Impervious to Change and Taking Matters into Own Hands'*, which details how participants feel MHS are "*not for us*". Future research should focus on understanding how SA caregivers would like their selves and the children they are caring for to be supported by statutory services. Participants in this study began to shed light on what ideal services may look like but this requires further exploration to build a clearer picture and take this forward into visible action.

Due to the theme of SAs often feeling unheard amongst the majority, especially concerning decisions about their own or their child's care, future research should aim to include SAs in the creation of research as much as possible. One way of achieving this is through Participatory Action Research (PAR). PAR aims to privilege the knowledge production of the participant group, moving away from the pedestal upon which researchers are positioned as the 'outside expert' (Baum et al., 2006). This method allows participants ownership of the research they partake in, providing them with power and control over what narrative is told and how it is shared (Noorani, 2013). In this way, the historical marginalisation of SAs can be combatted and instead foster a sense of feeling heard amongst the SA community.

4.6 Final Reflections

Being of Bangladeshi ethnicity, I felt a sense of importance to be able to do justice to the stories of my participants. This was especially crucial given their history of oppression and being misunderstood. I feel I have designed and conducted this research in a way that aligns with my values and, I hope, those of the wider SA community. I am proud of what I have achieved with this research despite my inability to fully utilise a participatory research design given the constraints of a Doctorate in Clinical Psychology. I have brought my whole, authentic self to this research whilst also recognising my position of power, and believe this has allowed for participants' narratives to shine.

I consider my insider status immensely valuable in facilitating openness from participants. However, I feel my insider position may have also impacted my ability to be fully curious, stopping me from questioning further at points, possibly due to an assumption I knew the reasoning behind certain descriptions. I often felt a deep conflict between my insider status and outsider position, as I was also a clinician who was part of the MH system participants had such negative experiences of. I sometimes felt quite hopeless, as I shared much of the caregivers' frustration regarding the inflexibility of MHS. Still, I believe I hold a unique position where I not only reflect services but also the group that has been so frequently marginalised. Perhaps transformation may need to start with small changes on the inside, slowly working out towards the wider system.

Although this research has been incredibly fruitful in delivering new knowledge to an under-researched area, I am left with more questions than answers. Although participants' narratives were open, exposing their truth, I'm still wondering what is still left unsaid. For example, how were participants able to break generational patterns? Perhaps these unanswered questions may reflect what is still too difficult to talk about within a Whiteness setting or what may be so ingrained in the unconscious that is yet to enter awareness. I am hopeful for future research to further uncover the truth that is yet to be unveiled.

Being SA and having had my own past experiences of MHD, I felt overwhelmed at points, hearing about participants' experiences of marginalisation and oppression, given these mirrored my own reality of racism in the UK. The fine balance of juggling both British and SA culture whilst maintaining a religious identity was one I completely resonated with. This battle was something I wrestled with throughout the write-up process, where I felt the pressure to write the thesis within the sphere of Whiteness. This pressuring influence created a need in me to pander to the relentless gaze of Western academia and express the caregivers' experiences in a way that would be palatable to a non-SA, non-religious reader. My supervisors, research consultants, and independent mentor encouraged me to stay with my unique position and produce a write-up that was consistent with the SA cause.

I have learnt so much from this process and deeply appreciate how participants have been able to challenge my preconceptions and biases. At the end of interviews participants consistently shared how beneficial it was to speak to a fellow SA who understood their position. I take away from this the importance of visible representation but also providing non-judgmental, safe spaces to have such sensitive conversations, which may be integral to breaking down the barrier of stigma. I am left contemplating how I can continue to create such welcoming spaces for these discussions going forward in my day-to-day work. I conclude this research with the voice of a participant, Nafisah, enduring in my mind, *"Don't let this die, you must keep it going"*. I endeavour to maintain the momentum of being a voice for the less heard and am hopeful for the possibilities we can create in the future.

4.7 Conclusion

This research aimed to explore SA caregivers' experiences of caring for a child with MHD and the influence of culture and religion on these experiences. IPA with 10 participant interviews revealed a detailed sense-making process. The analysis revealed a complex journey in understanding and managing MHD, starting from their own experiences in childhood and which is still an ongoing process. This study did a deep dive into the impact of cultural expectations and pressures on mental health awareness and management, the negative and positive impacts of caregiving, and the push-and-pull of different types of support systems. From what is known, this appears to be the first research to take an in-depth, individualistic approach to exploring the experiences of SA caregivers of MHD and the first to explicitly explore the influences of culture and religion. The findings add to the body of research by providing unique insights into the sphere of SA mental health, specifically into how MHD may be managed within the family and the impacts of doing so.

Above all, this research provided space to magnify the stories and experiences of SAs', whose voices have historically been ignored. Future research should continue to amplify the voices of SAs by providing non-judgmental, safe spaces to share their truth. The findings have important implications for policymakers, communities, and MHS regarding ensuring they are meeting the mental health needs of SAs by giving specific attention to their experiences of marginalisation and cultural sensitivities. To achieve this, researchers and clinicians must not overlook this group and instead see the value of working *with* SA communities and their knowledge, not *on* them.

If we carry intergenerational trauma (and we do) then we also carry intergenerational wisdom. It is in our genes and in our DNA. — Kazu Haga

References

Abouguendia, M., & Noels, K. A. (2001). General and acculturation-related daily hassles and psychological adjustment in first-and second-generation South Asian immigrants to Canada. *International Journal of Psychology, 36*(3), 163-173. https://doi.org/10.1080/741930008

Aggarwal, E. (2012). *South Asian women's attitudes toward help-seeking behaviors*. [Unpublished masters dissertation]. California State University.

Agishtein, P., & Brumbaugh, C. (2013). Cultural variation in adult attachment: The impact of ethnicity, collectivism, and country of origin. *Journal of Social, Evolutionary, and Cultural Psychology, 7*(4), 384. https://doi.org/10.1037/h0099181

Ahmad, F., Lissenburgh, S., & Modood, T. (2007). South Asian Women and Employment in Britain. In E. Spaan, F. Hillmann, & T. Van Naerssen (Eds.), *Asian migrants and European labour markets: Patterns and processes of immigrant labour market insertion in Europe* (pp. 115-137). Routledge.

Ahmed, S., Birtel, M. D., Pyle, M., & Morrison, A. P. (2020). Stigma towards psychosis: cross-cultural differences in prejudice, stereotypes, and discrimination in White British and South Asians. *Journal of Community & Applied Social Psychology*, *30*(2), 199-213. https://doi.org/10.1002/casp.2437

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies*, *5*(2), 9-19. http://dx.doi.org/10.7575/aiac.ijels.v.5n.2p.9

Aldridge, J. (2016). *Participatory research: Working with vulnerable groups in research and practice.* Policy Press.

Ali, N., McLachlan, N., Kanwar, S., & Randhawa, G. (2017). Pakistani young people's views on barriers to accessing mental health services. *International Journal of Culture and Mental Health, 10*(1), 33-43. https://doi.org/10.1080/17542863.2016.1248456

Allen, C. (2004). Justifying Islamophobia: A post-9/11 consideration of the European Union and British contexts. *American Journal of Islam and Society, 21*(3), 1-25. https://doi.org/10.35632/ajis.v21i3.505

Andersson, M. A. (2016). Chronic disease at midlife: do parent-child bonds modify the effect of childhood SES?. *Journal of Health and Social Behavior, 57*(3), 373-389. https://doi.org/10.1177/0022146516661596

Anyon, Y., Ong, S. L., & Whitaker, K. (2014). School-based mental health prevention for Asian American adolescents: Risk behaviors, protective factors, and service use. *Asian American Journal of Psychology*, *5*(2), 134-144. https://doi.org/10.1037/a0035300

Arnold, G. (2012). *Migration: Changing the world.* Pluto Press.

Arora, P. G., Metz, K., & Carlson, C. I. (2016). Attitudes toward professional psychological help seeking in South Asian students: Role of stigma and gender. *Journal of Multicultural Counselling and Development*, *44*(4), 263-284. https://doi.org/10.1002/jmcd.12053

Arpaci, I., Baloğlu, M., & Kesici, Ş. (2018). The relationship among individual differences in individualism-collectivism, extraversion, and self-presentation. *Personality and Individual Differences*, *121*, 89-92. https://doi.org/10.1016/j.paid.2017.09.034

Ashe, S. D. (2021). *SHF Race Report: 40 years of tackling racial inequality in Britain.* Stuart Hall Foundation. https://www.stuarthallfoundation.org/wp-content/uploads/2021/01/SHF-Race-Report-2021.pdf

Austin, L. J., Browne, R. K., Carreiro, M., Larson, A. G., Khreizat, I., DeJonckheere, M., & Schwartz, S. E. (2024). "It Makes Them Want to Suffer in Silence Rather Than Risk Facing Ridicule": Youth Perspectives on Mental Health Stigma. *Youth & Society* https://doi.org/10.1177/0044118X241237236

Awad, A. G., & Voruganti, L. N. (2008). The burden of schizophrenia on caregivers: a review. *PharmacoEconomics*, *26*, 149-162. https://doi.org/10.2165/00019053-200826020-00005

Azman, A., Jamir Singh, P. S., & Sulaiman, J. (2017). Caregiver coping with the mentally ill: a qualitative study. *Journal of Mental Health*, *26*(2), 98-103. https://doi.org/10.3109/09638237.2015.1124395

Babu, N., Hossain, Z., Morales, J. E., & Vij, S. (2017). Grandparents in Bangladesh, India, and Pakistan: A way forward with traditions and changes in South Asia. In S. W. Shwalb & Z. Hossain (Eds.), *Grandparents in Cultural Context*, (pp. 159-186). Routledge.

Bains, S., & Gutman, L. M. (2021). Mental health in ethnic minority populations in the UK: Developmental trajectories from early childhood to mid adolescence. *Journal of Youth and Adolescence, 50*(11), 2151-2165. https://doi.org/10.1007/s10964-021-01481-5

Baker, C., & Kirk-Wade, E. (2023). *Mental health statistics: prevalence, services and funding in England (CBP-06988).* House of Commons Library. https://researchbriefings.files.parliament.uk/documents/SN06988/SN06988.pdf

Banerjee, B., & Dixit, S. (2021). Perceived Stigma among family members of persons suffering from mental illness: A narrative exploration from West Bengal, India. *The Qualitative Report*, *26*(4), 1309-1330. https://doi.org/10.46743/2160-3715/2021.4648

Bano, M. (2013). Madrasas as partners in education provision: the South Asian experience. In P. Rose (Eds.), *Achieving Education for All through Public–Private Partnerships?* (pp. 82-94). Routledge.

Barling, K. (2022). Racial economic inequality: The visible tip of an inequality iceberg?. In S. Schifferes & S. Knowles (Eds.), *The Media and Inequality* (pp. 54-67). Routledge. https://doi.org/10.4324/9781003104476

Bauer, R., Sterzinger, L., Koepke, F., & Spiessl, H. (2013). Rewards of caregiving and coping strategies of caregivers of patients with mental illness. *Psychiatric Services*, *64*(2), 185-188. https://doi.org/10.1176/appi.ps.001212012

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health, 60*(10), 854. https://doi.org/10.1136%2Fjech.2004.028662

Becher, H. (2008). *Family practices in South Asian Muslim families: parenting in a multi-faith Britain*. Springer.

Berry, J. W. (1992). Acculturation and adaptation in a new society. *International Migration, 30*, 69-69. https://doi.org/10.1111/j.1468-2435.1992.tb00776.x

Berry, J. W. (2006). Acculturative stress. In P. T. Wong & L. C. Wong (Eds.), *Handbook of multicultural perspectives on stress and coping* (pp. 287-298). Springer.

Beydoun, K. A. (2016). Islamophobia: Toward a legal definition and framework. *Columbia Law Review Online, 116*(7), 108-125. https://columbialawreview.org/wp-content/uploads/2016/11/November-2016-11-Beydoun.pdf

Bhopal, K. (1998). South Asian women in East London: Motherhood and social support. *Women's Studies International Forum, 21*(5), 485-492. https://doi.org/10.1016/S0277-5395(98)00067-3

Bhopal, K. (2019). *Gender, 'race' and patriarchy: a study of South Asian women.* Routledge.

Bhui, K., Bhugra, D., Goldberg, D., Dunn, G., & Desai, M. (2001). Cultural influences on the prevalence of common mental disorder, general practitioners' assessments and help-seeking among Punjabi and English people visiting their general practitioner. *Psychological Medicine, 31*(5), 815-825. https://doi.org/10.1017/S0033291701003853

Bhui, K., Nazroo, J., Francis, J., Halvorsrud, K., & Rhodes, J. (2018). *The impact of racism on mental health.* The Synergi Collaborative Centre. https://legacy.synergicollaborativecentre.co.uk/wp-content/uploads/2017/11/The-impact-of-racism-on-mental-health-briefing-paper-1.pdf

Bhui, K., Stansfeld, S., Head, J., Haines, M., Hillier, S., Taylor, S., Viner, R., & Booy, R. (2005). Cultural identity, acculturation, and mental health among adolescents in east London's multiethnic community. *Journal of Epidemiology & Community Health, 59*(4), 296-302. http://dx.doi.org/10.1136/jech.2003.014456

Bhui, K., Stansfeld, S., Hull, S., Priebe, S., Mole, F., & Feder, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK: systematic review. *The British Journal of Psychiatry, 182*(2), 105-116. https://doi.org/10.1192/bjp.182.2.105

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide.* Sage.

Birman, D. (2006). Measurement of the "Acculturation Gap" in Immigrant Families and Implications for Parent-Child Relationships. In M. H. Bornstein & L. R. Cote (Eds.), *Acculturation and parent-child relationships: Measurement and development* (pp. 113–134). Lawrence Erlbaum Associates Publishers.

Blaikie, N. (2007). *Approaches to social enquiry: Advancing knowledge*. Polity.

Blum, L. (2020). "Cultural racism": biology and culture in racist thought. *Journal of Social Philosophy, 54*(3), 350-369. https://doi.org/10.1111/josp.12370

Bose, S., & Jalal, A. (2022). *Modern South Asia: history, culture, political economy*. Routledge.

Bowen, M. (1993). *Family therapy in clinical practice*. Jason Aronson.

Bowl, R. (2007). The need for change in UK mental health services: South Asian service users' views. *Ethnicity and Health, 12*(1), 1-19. https://doi.org/10.1080/13557850601002239

Bradby, H., Varyani, M., Oglethorpe, R., Raine, W., White, I., & Helen, M. (2007). British Asian families and the use of child and adolescent mental health services: a qualitative study of a hard to reach group. *Social Science & Medicine, 65*(12), 2413-2424. https://doi.org/10.1016/j.socscimed.2007.07.025

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health, 13*(2), 201-216. https://doi.org/10.1080/2159676X.2019.1704846

Breuninger, M., Dolan, S. L., Padilla, J. I., & Stanford, M. S. (2014). Psychologists and Clergy Working Together: A Collaborative Treatment Approach for Religious Clients. *Journal of Spirituality in Mental Health*, *16*(3), 149–170. https://doi.org/10.1080/19349637.2014.925359

British Psychological Society. (2017). *BPS Practice Guidelines.* 3rd edition. https://explore.bps.org.uk/binary/bpsworks/7cd81b0048d10fff/b33867dfe47ba494c80dca795cc203acdf4a426630d6ab2b1835429144a575aa/inf115_2017_english.pdf

Broady, T. R., & Stone, K. (2015). “How can I take a break?” Coping strategies and support needs of mental health carers. *Social Work in Mental Health*, *13*(4), 318-335. https://doi.org/10.1080/15332985.2014.955941

Broderick, C. B. (1993). *Understanding family process: Basics of family systems theory.* Sage.

Burls, A. (2015). What is critical appraisal? *International Journal of Evidence-Based Practice for Dental Hygienist, 1*(2), 80-85. https://doi.org/10.11607/ebh.001516

Burnham, J. (2012). Developments in Social GRRRAAACCEEESSS: visible–invisible and voiced–unvoiced. In I. Krause (Eds.), *Culture and reflexivity in systemic psychotherapy: Mutual perspectives* (pp. 139-160). Routledge.

Burnham, J., Alvis Palma, D., & Whitehouse, L. (2008). Learning as a context for differences and differences as a context for learning. *Journal of Family Therapy*, *30*(4), 529-542. https://doi.org/10.1111/j.1467-6427.2008.00436.x

Byng-Hall, J. (1995). Creating a secure family base: Some implications of attachment theory for family therapy. *Family Process, 34*(1), 45-58. https://doi.org/10.1111/j.1545-5300.1995.00045.x

Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment*, *6*(1), 65-72. https://doi.org/10.1192/apt.6.1.65

Cabral, L., Duarte, J., Ferreira, M., & dos Santos, C. (2014). Anxiety, stress and depression in family caregivers of the mentally ill. *Atención Primaria*, *46*, 176-179. https://doi.org/10.1016/S0212-6567(14)70087-3

Cabral, R. R., & Smith, T. B. (2011). Racial/ethnic matching of clients and therapists in mental health services: a meta-analytic review of preferences, perceptions, and outcomes. *Journal of Counselling Psychology, 58*(4), 537-554. https://psycnet.apa.org/doi/10.1037/a0025266

Chapman, G. (2009). *The Geopolitics of South Asia: From Early Empires to India, Pakistan and Bangladesh* (1st ed.). Routledge.

Chatterjee, I. (Ed.). (2004). *Unfamiliar relations: Family and history in South Asia*. Rutgers University Press.

Chawla, D. (2014). *Home, uprooted: Oral histories of India's partition*. Fordham University Press.

Chen, P., & Harris, K. M. (2019). Association of positive family relationships with mental health trajectories from adolescence to midlife. *Jama Pediatrics, 173*(12), e193336-e193336. https://doi.org/10.1001%2Fjamapediatrics.2019.3336

Cheng, W. L., Chang, C. C., Griffiths, M. D., Yen, C. F., Liu, J. H., Su, J. A., ... & Pakpour, A. H. (2022). Quality of life and care burden among family caregivers of people with severe mental illness: mediating effects of self-esteem and psychological distress. *BMC Psychiatry*, *22*(1), 672. https://doi.org/10.1186/s12888-022-04289-0

Chew-Graham, C., Bashir, C., Chantler, K., Burman, E., & Batsleer, J. (2002). South Asian women, psychological distress and self-harm: lessons for primary care trusts. *Health & Social Care in the Community*, *10*(5), 339-347. https://doi.org/10.1046/j.1365-2524.2002.00382.x

Ciftci, S. (2012). Islamophobia and threat perceptions: Explaining anti-Muslim sentiment in the West. *Journal of Muslim Minority Affairs, 32*(3), 293-309. https://doi.org/10.1080/13602004.2012.727291

Cinnirella, M., & Loewenthal, K. M. (1999). Religious and ethnic group influences on beliefs about mental illness: A qualitative interview study. *British Journal of Medical Psychology*, *72*(4), 505-524. https://doi.org/10.1348/000711299160202

Cohen, B., & Tufail, W. (2017). Prevent and the normalization of Islamophobia. In F. Elahi, & O. Khan (Eds.), *Islamophobia: Still a Challenge for Us All.* (pp. 41–45).

Runnymede Trust. https://eprints.leedsbeckett.ac.uk/id/eprint/5462/1/PreventandtheNormalizationofIslamophobiaPV-TUFAILpdf.pdf

Collins, P. H., & Bilge, S. (2020). *Intersectionality*. John Wiley & Sons.

Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M., & Paisley, S. (2012). Quality of life of people with mental health problems: a synthesis of qualitative research. *Health and Quality of Life Outcomes*, *10*, 1-16. https://doi.org/10.1186/1477-7525-10-138

Constantinou, C. S., Georgiou, M., & Perdikogianni, M. (2017). A comparative method for themes saturation (CoMeTS) in qualitative interviews. *Qualitative Research, 17*(5), 571-588. https://doi.org/10.1177/1468794116686650

Corrigan, P. W., Bink, A. B., Fokuo, J. K., & Schmidt, A. (2015). The public stigma of mental illness means a difference between you and me. *Psychiatry Research*, *226*(1), 186-191. https://doi.org/10.1016/j.psychres.2014.12.047

Critical Skills Appraisal Programme (2018). CASP qualitative checklist. *Critical Skills Appraisal Programme.*

Crossley, J. P., & Salter, D. P. (2005). A question of finding harmony: A grounded theory study of clinical psychologists' experience of addressing spiritual beliefs in therapy. *Psychology and Psychotherapy: Theory, Research and Practice*, *78*(3), 295-313. https://doi.org/10.1348/147608305X26783

Crozier, G., & Davies, J. (2006). Family matters: a discussion of the Bangladeshi and Pakistani extended family and community in supporting the children's education. *The Sociological Review, 54*(4), 678-695. https://doi.org/10.1111/j.1467-954X.2006.00666.x

Culyer, A. J., & Wagstaff, A. (1993). Equity and equality in health and health care. *Journal of Health Economics*, *12*(4), 431-457. https://doi.org/10.1016/0167-6296(93)90004-X

Cummins, I. (2018). The impact of austerity on mental health service provision: a UK perspective. *International Journal of Environmental Research and Public Health, 15*(6), 1145. https://doi.org/10.3390/ijerph15061145

Dadabhoy, H. (2018). *Islamophobia: Psychological Correlates and Impact on Young Muslim Identity Development.* [Unpublished doctoral dissertation]. University College London. https://discovery.ucl.ac.uk/id/eprint/10057163/8/Dadabhoy_10057163_thesis_sig_removed.pdf

Dallos, R., & Vetere, A. (2021). *Systemic therapy and attachment narratives: Applications in a range of clinical settings*. Routledge.

Dam, K., & Hall, E. O. (2016). Navigating in an unpredictable daily life: a metasynthesis on children's experiences living with a parent with severe mental illness. *Scandinavian Journal of Caring Sciences*, *30*(3), 442-457. https://doi.org/10.1111/scs.12285

D'Astice, T., Russell, W.P. (2019). Enmeshment in Couples and Families. In J. L. Lebow, A. L. Chambers, & D. C. Breunlin, D.C. (Eds.), *Encyclopedia of Couple and Family Therapy* (pp. 911-915). Springer.

Dein, S., Alexander, M., & Napier, A. D. (2008). Jinn, psychiatry and contested notions of misfortune among east London Bangladeshis. *Transcultural Psychiatry, 45*(1), 31-55. http://dx.doi.org/10.1177/1363461507087997

Delaney, H. D., Miller, W. R., & Bisonó, A. M. (2007). Religiosity and spirituality among psychologists: A survey of clinician members of the American Psychological Association. *Professional Psychology: Research and Practice*, *38*(5), 538-546. https://psycnet.apa.org/doi/10.1037/0735-7028.38.5.538

Department of Health. (2005). *Delivering race equality in mental health care: An action plan for reform inside and outside services.* https://documents.manchester.ac.uk/display.aspx?DocID=54691

Dijkxhoorn, M. A., Padmakar, A., Bunders, J. F., & Regeer, B. J. (2023). Stigma, lost opportunities, and growth: Understanding experiences of caregivers of persons with mental illness in Tamil Nadu, India. *Transcultural Psychiatry*, *60*(2), 255-271. https://doi.org/10.1177/13634615211059692

Dogra, N., Vostanis, P., Abuateya, H., & Jewson, N. (2007). Children's mental health services and ethnic diversity: Gujarati families' perspectives of service provision for mental health problems. *Transcultural Psychiatry, 44*(2), 275-291. https://doi.org/10.1177/1363461507077727

Durkin, K. (2011). Adapting to western norms of critical argumentation and debate. In L. Jin & M. Cortazzi (Eds.), *Researching Chinese learners: Skills, perceptions and intercultural adaptations* (pp. 274-291). Palgrave Macmillan UK.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods, 8*(1), 54-63. https://doi.org/10.1177/160940690900800105

Dyer, J. (2019, July 12). How can we have the same outcomes when we’re not having the same experiences? *NHS England*. https://www.england.nhs.uk/blog/how-can-we-have-the-same-outcomes-when-were-not-having-the-same-experiences/

Elahi, F., & Khan, O. (2017). Islamophobia: Still a challenge for us all. London: Runnymede Trust. https://assets-global.website-files.com/61488f992b58e687f1108c7c/61bcd30e26cca7688f7a5808_Islamophobia%20Report%202018%20FINAL.pdf

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1), 1-4. http://dx.doi.org/10.11648/j.ajtas.20160501.11

Evans-Lacko, S., Henderson, C., & Thornicroft, G. (2013). Public knowledge, attitudes and behaviour regarding people with mental illness in England 2009-2012. *The British Journal of Psychiatry*, *202*(s55), 51-57. https://doi.org/10.1192/bjp.bp.112.112979

Faircloth, C., Hoffman, D., & Layne, L. (Eds.). (2013). *Parenting in global perspective: Negotiating ideologies of kinship, self and politics.* Routledge.

Faircloth, C. (2023). Intensive parenting and the expansion of parenting. In E. Lee, J. Bristow, C. Faircloth, & J. Macvarish (Eds.), *Parenting Culture Studies* (2nd ed., pp. 33-68). Palgrave Macmillan.

Farrell, E. (2020). Researching Lived Experience in Education: Misunderstood or Missed Opportunity?. *International Journal of Qualitative Methods*, *19*. https://doi.org/10.1177/1609406920942066

Fernando, S. (2010). *Mental health, race and culture* (3rd ed.). Bloomsbury Publishing.

Fernando, S., & Keating, F. (Eds.). (2008). *Mental health in a multi-ethnic society: A multidisciplinary handbook.* Routledge.

Ferraro, K. F., Schafer, M. H., & Wilkinson, L. R. (2016). Childhood disadvantage and health problems in middle and later life: Early imprints on physical health?. *American Sociological Review, 81*(1), 107-133. https://doi.org/10.1177/0003122415619617

Flemming, K., Booth, A., Garside, R., Tunçalp, Ö., & Noyes, J. (2019). Qualitative evidence synthesis for complex interventions and guideline development: clarification of the purpose, designs and relevant methods. *BMJ global health*, *4*(Suppl 1), e000882. https://doi.org/10.1136/bmjgh-2018-000882

Fox, N. J. (2008). Post-positivism. In L.M. Given (Eds.), *The SAGE Encyclopaedia of Qualitative Research Methods* (pp. 659-664). Sage. https://www.academia.edu/download/32932785/postpositivism_with_citation.pdf

Fusch, P. I., & Ness, L. R. (2015). Are We There Yet? Data Saturation in Qualitative Research. *The Qualitative Report, 20*(9), 1408-1416. https://doi.org/10.46743/2160-3715/2015.2281

Ghumkhor, S., & Younis, T. (2021). Naming the injury: War on terror and the legibility of trauma. In Bridge Initiative Team, *The Terror Trap: The Impact of the War on Terror on Muslim Communities since 9/11* (pp. 160-166). Georgetown University. https://bridge.georgetown.edu/wp-content/uploads/2021/10/THE-TERROR-TRAP-FINAL.pdf#page=160

Gilbert, P., Gilbert, J., & Sanghera, J. (2004). A focus group exploration of the impact of izzat, shame, subordination and entrapment on mental health and service use in South Asian women living in Derby. *Mental Health, Religion & Culture, 7*(2), 109-130. https://doi.org/10.1080/13674670310001602418

Gill, S. S. (2020). ‘I need to be there’: British South Asian men’s experiences of care and caring. *Community, Work & Family, 23*(3), 270-285. https://doi.org/10.1080/13668803.2018.1531827

Glaser, B. G., & Strauss, A. L. (2017). *Discovery of grounded theory: Strategies for qualitative research.* Routledge.

Godden, L., & Kutsyuruba, B. (2023). Hermeneutic Phenomenology. In J.M. Okoko, S. Tunison, & K.D. Walker (Eds.), *Varieties of Qualitative Research Methods* (pp. 225-230). Springer.

Goel, N. J., Thomas, B., Boutté, R. L., Kaur, B., & Mazzeo, S. E. (2023). “What will people say?”: Mental health stigmatization as a barrier to eating disorder treatment-seeking for South Asian American women. *Asian American Journal of Psychology*, *14*(1), 96. https://doi.org/10.1037/aap0000271

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Simon and Schuster.

Goodman, A., Patel, V., & Leon, D. A. (2008). Child mental health differences amongst ethnic groups in Britain: a systematic review. *BMC Public Health*, *8*, 1-11. https://doi.org/10.1186/1471-2458-8-258

Grossman, J. M., & Charmaraman, L. (2009). Race, context, and privilege: White adolescents' explanations of racial-ethnic centrality. *Journal of Youth and Adolescence, 38*, 139-152. https://doi.org/10.1007/s10964-008-9330-7

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82. https://doi.org/10.1177/1525822X05279903

Gunaratnam, Y. (2003). *Researching 'Race' and Ethnicity. Methods, knowledge and power.* Sage.

Gupta, S., Isherwood, G., Jones, K., & Van Impe, K. (2015). Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC psychiatry*, *15*, 1-11. https://doi.org/10.1186/s12888-015-0547-1

Guttman, H. A. (2014). Systems theory, cybernetics, and epistemology. In A. S. Gurman, & D. P. Kniskern (Eds.), *Handbook of Family Therapy* (pp. 41-62). Routledge.

Hall, G. C. N. (2001). Psychotherapy research with ethnic minorities: empirical, ethical, and conceptual issues. *Journal of Consulting and Clinical Psychology*, *69*(3), 502-510. https://psycnet.apa.org/doi/10.1037/0022-006X.69.3.502

Hamer, K., McFarland, S., Czarnecka, B., Golińska, A., Cadena, L. M., Łużniak-Piecha, M., & Jułkowski, T. (2020). What is an "ethnic group" in ordinary people's eyes? different ways of understanding it among American, British, Mexican, and Polish respondents. *Cross-Cultural Research*, *54*(1), 28-72. https://doi.org/10.1177/1069397118816939

Hannes, K. (2011). Critical appraisal of qualitative research. In J. Noyes, A. Booth, K. Hannes, A. Harden, J. Harris, S. Lewin, & C. Lockwood (Eds.), *Supplementary guidance for inclusion of qualitative research in Cochrane systematic reviews of interventions.* Cochrane Collaboration Qualitative Methods Group. https://lirias.kuleuven.be/retrieve/564342

Harwood, H., Rhead, R., Chui, Z., Bakolis, I., Connor, L., Gazard, B., Hall, J., MacCrimmon, S., Rimes, K. A., Woodhead, C., & Hatch, S. L. (2023). Variations by ethnicity in referral and treatment pathways for IAPT service users in South London. *Psychological Medicine, 53*(3), 1084-1095. https://doi.org/10.1017/S0033291721002518

Hays, P. A. (2018). Introduction. In G. Y. Iwamasa & P. A. Hays (Eds.), *Culturally Responsive Cognitive Behavior Therapy: Practice and Supervision* (2nd ed., pp. 3-24). American Psychological Association.

Health Education England. (2020). *Psychological professions | Health Education England.* https://www.hee.nhs.uk/our-work/mental-health/new-roles-mental-health/psychological-professions

Health Education England. (2021). *Psychological professions workforce plan for England.* NHS. https://www.hee.nhs.uk/sites/default/files/documents/Psychological%20Professions%20Workforce%20Plan%20for%20England%20-%20Final.pdf

Heer, K., Rose, J., & Larkin, M. (2012). Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: an experiential–contextual framework. *Disability & Society*, *27*(7), 949-963. https://doi.org/10.1080/09687599.2012.699276

Heidegger, M. (1999). Ontology: Hermeneutics of facticity (J. van Buren, Trans.). Indiana University Press. (Original work published 1928).

Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. Sage.

Hickey, M. G. (2008). New worlds, old values: Cultural maintenance in Asian Indian women immigrants' narratives. In Z. Bekerman & E. Kopelowitz (Eds.), *Cultural Education-Cultural Sustainability: Minority, Diaspora, Indigenous and Ethno-Religious Groups in Multicultural Societies*, (pp. 375-394). Routledge.

Holmes, J. (2014). *John Bowlby and attachment theory*. Routledge.

Hossain, M. Z., Stores, R., Hakak, Y., & Dewey, A. (2020). Traditional gender roles and effects of dementia caregiving within a South Asian ethnic group in England. *Dementia and Geriatric Cognitive Disorders*, *48*(5-6), 330-336. https://doi.org/10.1159/000506363

Howe, D. (2012). Attachment Theory. In M. Gray, & S. Webb (Eds.), *Social Work Theories and Methods*, (pp. 75-110). Sage Publications.

Hughes, A. W. (2021). Islam and its history. Handbook of Contemporary Islam and Muslim Lives, 3-18. In M. Woodward, & R. Lukens-Bull (Eds.), *Handbook of contemporary Islam and Muslim lives* (pp. 3-18). Springer. https://doi.org/10.1007/978-3-319-73653-2_4-2

Hussain, N. (2006). Culturally determined care goals and the efficacy of statutory services. *International Journal of Qualitative Studies on Health and Well-Being*, *1*(3), 149-158. https://doi.org/10.1080/17482620600756080

Hussain-Gambles, M. (2004). South Asian patients' views and experiences of clinical trial participation. *Family Practice*, *21*(6), 636-642. https://doi.org/10.1093/fampra/cmh611

Husserl, E. (2014). *Ideas for a pure phenomenology and phenomenological philosophy: First book: General introduction to pure phenomenology*. Hackett Publishing.

Iqbal, H., & Golombok, S. (2018). The generation game: Parenting and child outcomes in second-generation South Asian immigrant families in Britain. *Journal of Cross-Cultural Psychology, 49*(1), 25-43. https://doi.org/10.1177/0022022117736039

Ishikawa, A., Rickwood, D., Bariola, E., & Bhullar, N. (2023). Autonomy versus support: self-reliance and help-seeking for mental health problems in young people. *Social Psychiatry and Psychiatric Epidemiology*, *58*(3), 489-499. https://doi.org/10.1007%2Fs00127-022-02361-4

Issac, A., Yesodharan, R., & Sequira, L. (2023). Primary caregiver's experiences in caring paranoid schizophrenia patients: A qualitative study. *Clinical Epidemiology and Global Health*, *24*, 101413. https://doi.org/10.1016/j.cegh.2023.101413

Jagannathan, A., Thirthalli, J., Hamza, A., Hariprasad, V. R., Nagendra, H. R., & Gangadhar, B. N. (2011). A qualitative study on the needs of caregivers of inpatients with schizophrenia in India. *International Journal of Social Psychiatry, 57*(2), 180-194. https://doi.org/10.1177/0020764009347334

Jiang, W., Lu, Y., & Xie, H. (2020). Education and mental health: Evidence and mechanisms. *Journal of Economic Behavior & Organization, 180*, 407-437. https://doi.org/10.1016/j.jebo.2020.09.032

Johnstone, L., & Dallos, R. (2013). *Introduction to formulation*. In L. Johnstone and R. Dallos (Eds.), *Formulation in Psychology and Psychotherapy* (pp. 1-17). Routledge.

Jones, D. (2014). Diaspora identification and long-distance nationalism among Tamil migrants of diverse state origins in the UK. *Ethnic and Racial Studies, 37*(14), 2547-2563. https://doi.org/10.1080/01419870.2013.835852

Joseph, N. E. (2014). *The scared, supernatural and spiritual: Views and experiences of Faith Leaders and Clinical Psychologists concerning religion, spirituality and mental health* [Unpublished doctoral dissertation]. University of East London. https://repository.uel.ac.uk/download/14eae2240f1a5736096a21627ee5d6706dc6f8e9da3ae3a52ab5431450eb8581/1651245/U0619517_Thesis_Final.pdf

Joshi, H. L., Yadav, A., & Bangia, H. (2008). Sharing experiences of care giving: A qualitative study on caregivers of patients with severe mental disorders. *SIS Journal of Projective Psychology & Mental Health, 15*(1), 58.

Kagan, C., Burton, M., Duckett, P., Lawthom, R., & Siddiquee, A. (2019). *Critical community psychology: Critical action and social change.* Routledge.

Kalayil, S. (2019). *Second-generation South Asian Britons: Multilingualism, heritage languages, and diasporic identity*. Rowman & Littlefield.

Kapadia, D., Brooks, H. L., Nazroo, J., & Tranmer, M. (2017). Pakistani women's use of mental health services and the role of social networks: a systematic review of quantitative and qualitative research. *Health & Social Care in the Community, 25*(4), 1304-1317. https://doi.org/10.1111/hsc.12305

Karasz, A., Gany, F., Escobar, J., Flores, C., Prasad, L., Inman, A., Kalasapudi, V., Kosi, R., Murthy, M., Leng, J., & Diwan, S. (2019). Mental health and stress among South Asians. *Journal of Immigrant and Minority Health, 21*(1), 7-14. https://doi.org/10.1007/s10903-016-0501-4

Karlsen, S., & Nazroo, J. Y. (2002). Relation between racial discrimination, social class, and health among ethnic minority groups. *American Journal of Public Health, 92*(4), 624-631. https://doi.org/10.2105%2Fajph.92.4.624

Karlsen, S., & Nazroo, J. Y. (2014). Ethnic and religious variations in the reporting of racist victimization in Britain: 2000 and 2008/2009. *Patterns of Prejudice, 48*(4), 370-397. https://doi.org/10.1080/0031322X.2014.951160

Kazdin, A. E., Holland, L., & Crowley, M. (1997). Family experience of barriers to treatment and premature termination from child therapy. *Journal of consulting and clinical psychology, 65*(3), 453. https://doi.org/10.1037/0022-006X.65.3.453

Kessler, R. C., Amminger, G. P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Üstün, T. B. (2007). Age of onset of mental disorders: a review of recent literature. *Current Opinion in Psychiatry, 20*(4), 359-364. https://doi.org/10.1097%2FYCO.0b013e32816ebc8c

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry, 62*(6), 593-602. https://doi.org/10.1001/archpsyc.62.6.593

Keyes, C. L. (2002). The mental health continuum: From languishing to flourishing in life. *Journal of Health and Social Behavior*, *43*(2), 207-222. https://doi.org/10.2307/3090197

Khalifa, N., Hardie, T., & Mullick, M. S. (2012). Jinn and psychiatry: comparison of beliefs among Muslims in Dhaka and Leicester. *Publications Archive: Royal College of Psychiatrists' Spirituality and Psychiatry Special Interest Group*. https://www.rcpsych.ac.uk/docs/default-source/members/sigs/spiritualityspsig/spirituality-special-interest-group-publications-jinn-and-psychiatry-comparison-of-beliefs-najat-khalifa-tim-hardie-mohammad-s-i-mullick.pdf

Kiang, L., & Fuligni, A. J. (2009). Ethnic identity in context: Variations in ethnic exploration and belonging within parent, same-ethnic peer, and different-ethnic peer relationships. *Journal of Youth and Adolescence*, *38*, 732-743. https://doi.org/10.1007/s10964-008-9278-7

Kim, D. (2017). Relationships between caregiving stress, depression, and self-esteem in family caregivers of adults with a disability. *Occupational Therapy International*, *2017*. https://doi.org/10.1155%2F2017%2F1686143

Kirmayer, L. J., & Bhugra, D. (2009). Culture and mental illness: social context and explanatory models. In M. Ihsan & J.E. Mezzich (Eds.), *Psychiatric Diagnosis: Challenges and Prospects*, (pp. 29-40). World Psychiatric Association.

Klineberg, E., Clark, C., Bhui, K. S., Haines, M. M., Viner, R. M., Head, J., Woodley-Jones, D., & Stansfeld, S. A. (2006). Social support, ethnicity and mental health in adolescents. *Social Psychiatry and Psychiatric Epidemiology, 41*, 755-760. https://doi.org/10.1007/s00127-006-0093-8

Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H. A., Chatterjee, S., Pereira, J., Naik, S., John, S., Dabholkar, H., Balaji, M., Chavan, A., Varghese, M., Thara, R., Thornicroft, G., & Patel, V. (2014). Experiences of stigma and discrimination of people with schizophrenia in India. *Social Science & Medicine, 123*, 149-159. https://doi.org/10.1016/j.socscimed.2014.10.035

Kunst, J. R., & Sam, D. L. (2013). Relationship between perceived acculturation expectations and Muslim minority youth's acculturation and adaptation. International Journal of *Intercultural Relations, 37*(4), 477-490. https://doi.org/10.1016/j.ijintrel.2013.04.007

Kyere, E., & Fukui, S. (2023). Structural racism, workforce diversity, and mental health disparities: A critical review. *Journal of Racial and Ethnic Health Disparities*, *10*(4), 1985-1996. https://doi.org/10.1007/s40615-022-01380-w

Larkin, M., & Thompson, A.R. (2012). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper and A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 101-116). Wiley-Blackwell.

Lau, A. (2018). Family therapy across cultures. In J. L. Cox (Eds.), *Transcultural Psychiatry* (pp. 234-252). Routledge.

Lauber, C., & Rössler, W. (2007). Stigma towards people with mental illness in developing countries in Asia. *International Review of Psychiatry*, *19*(2), 157-178. https://doi.org/10.1080/09540260701278903

Leaning, J., & Bhadada, S. (Eds.). (2022). *The 1947 partition of British India: Forced migration and its reverberations.* SAGE Publishing India.

Lee, C. J. G. (2012). Reconsidering constructivism in qualitative research. *Educational Philosophy and Theory, 44*(4), 403-412. https://doi.org/10.1111/j.1469-5812.2010.00720.x

Lee, H., & Schafer, M. (2021). Are positive childhood experiences linked to better cognitive functioning in later life?: Examining the role of life course pathways. *Journal of Aging and Health, 33*(3-4), 217-226. https://doi.org/10.1177/0898264320972547

Leith, J. E., Jewell, T. C., & Stein, C. H. (2018). Caregiving attitudes, personal loss, and stress-related growth among siblings of adults with mental illness. *Journal of Child and Family Studies*, *27*, 1193-1206. https://doi.org/10.1007/s10826-017-0965-4

Lesser, I. A., Gasevic, D., & Lear, S. A. (2014). The association between acculturation and dietary patterns of South Asian immigrants. *PloS one, 9*(2), e88495. https://doi.org/10.1371/journal.pone.0088495

Leszczensky, L., & Pink, S. (2017). Intra-and inter-group friendship choices of Christian, Muslim, and non-religious youth in Germany. *European Sociological Review*, *33*(1), 72-83. https://doi.org/10.1093/esr/jcw049

Lindner, A. (2018). Defining whiteness: Perspectives on privilege. *Gnovis Journal, 18*(2), 43-58. http://hdl.handle.net/10822/1050459

Littlewood, R., & Dein, S. (2016). Carers and families: life and suffering among Bangladeshi psychiatric patients and their families in London–an interview study 3. *Anthropology & Medicine, 23*(1), 54-70. https://doi.org/10.1080/13648470.2015.1049120

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1), 31-42. https://doi.org/10.1177/2632084320947559

Low, J. (2019). A pragmatic definition of the concept of theoretical saturation. *Sociological Focus, 52*(2), 131-139. https://doi.org/10.1080/00380237.2018.1544514

Loya, F., Reddy, R., & Hinshaw, S. P. (2010). Mental illness stigma as a mediator of differences in Caucasian and South Asian college students' attitudes toward psychological counseling. *Journal of Counseling Psychology, 57*(4), 484. https://psycnet.apa.org/doi/10.1037/a0021113

Machado, B. M., Dahdah, D. F., & Kebbe, L. M. (2018). Caregivers of family members with chronic diseases: coping strategies used in everyday life. *Cadernos Brasileiros de Terapia Ocupacional*, *26*, 299-313. https://doi.org/10.4322/2526-8910.ctoAO1188

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*(1), 1-20. https://doi.org/10.1348/000712600161646

Malhotra, M., & Thapa, K. (2015). Religion and coping with caregiving stress. *International Journal of Multidisciplinary and Current Research*, *3*, 613-619. http://ijmcr.com/wp-content/uploads/2015/07/Paper36613-619.pdf

Malpas, J. (2008). *Heidegger's topology: Being, place, world*. MIT press.

Mason, S., Hussain-Gambles, M., Leese, B., Atkin, K., & Brown, J. (2003). Representation of South Asian people in randomised clinical trials: analysis of trials' data. *BMJ, 326*(7401), 1244-1245. https://doi.org/10.1136/bmj.326.7401.1244

Masood, N., Okazaki, S., & Takeuchi, D. T. (2009). Gender, family, and community correlates of mental health in South Asian Americans. *Cultural Diversity and Ethnic Minority Psychology, 15*(3), 265. https://doi.org/10.1037/a0014301

Masood, M., Thaliath, E. T., Bower, E. J., & Newton, J. T. (2011). An appraisal of the quality of published qualitative dental research. *Community Dentistry and Oral Epidemiology, 39*(3), 193-203. https://doi.org/10.1111/j.1600-0528.2010.00584.x

Mathias, K., Kermode, M., San Sebastian, M., Davar, B., & Goicolea, I. (2019). An asymmetric burden: Experiences of men and women as caregivers of people with psycho-social disabilities in rural North India. *Transcultural Psychiatry*, *56*(1), 76-102. https://doi.org/10.1177/1363461518792728

Mayers, C., Leavey, G., Vallianatou, C., & Barker, C. (2007). How clients with religious or spiritual beliefs experience psychological help-seeking and therapy: A qualitative study. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice, 14*(4), 317-327. https://doi.org/10.1002/cpp.542

Maynard, M. J., & Harding, S. (2010a). Perceived parenting and psychological well-being in UK ethnic minority adolescents. *Child: Care, Health and Development, 36*(5), 630-638. https://doi.org/10.1111/j.1365-2214.2010.01115.x

Maynard, M. J., & Harding, S. (2010b). Ethnic differences in psychological well-being in adolescence in the context of time spent in family activities. *Social Psychiatry and Psychiatric Epidemiology, 45*, 115-123. https://doi.org/10.1007/s00127-009-0047-z

McCann, T. V., Bamberg, J., & McCann, F. (2015). Family carers' experience of caring for an older parent with severe and persistent mental illness. *International Journal of Mental Health Nursing*, *24*(3), 203-212.

McKenzie, K., & Bhui, K. (2007). Better mental healthcare for minority ethnic groups–moving away from the blame game and putting patients first: Commentary on… Institutional racism in psychiatry. *Psychiatric Bulletin, 31*(10), 368-369. https://doi.org/10.1192/pb.bp.107.017145

Meheli, S. (2023). Experiences of Family Caregivers of Patients with Schizophrenia: A Qualitative Study in India. *Journal of Psychosocial Rehabilitation and Mental Health*, 1-12. https://doi.org/10.1007/s40737-023-00355-2

Mehrotra, M., & Calasanti, T. M. (2010). The family as a site for gendered ethnic identity work among Asian Indian immigrants. *Journal of Family Issues, 31*(6), 778-807. https://doi.org/10.1177/0192513X09357557

Memon, A., Taylor, K., Mohebati, L. M., Sundin, J., Cooper, M., Scanlon, T., & De Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *BMJ open, 6*(11), e012337. http://dx.doi.org/10.1136/bmjopen-2016-012337

Midouhas, E. (2017). School poverty effects on trajectories of child behaviour: Do they depend on gender and ethnicity?. *Health & Place, 46*, 281-292. https://doi.org/10.1016/j.healthplace.2017.06.009

Mikulincer, M., & Shaver, P. R. (2010). *Attachment in adulthood: Structure, dynamics, and change*. Guilford Publications.

Mikulincer, M., & Shaver, P. R. (2012). An attachment perspective on psychopathology. *World Psychiatry, 11*(1), 11-15. https://doi.org/10.1016/j.wpsyc.2012.01.003

Mills, J. (2010). *An exploration of trainee clinical psychologists' experiences of engaging with psycho spiritual issues in clinical practice* [Unpublished doctoral dissertation]. University of Leicester. https://figshare.le.ac.uk/articles/thesis/An_exploration_of_trainee_clinical_psychologists_experiences_of_engaging_with_psycho_spiritual_issues_in_clinical_practice/10098806

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5*(1), 25-35. https://doi.org/10.1177/160940690600500103

Mironenko, I. A., & Sorokin, P. S. (2018). Seeking for the definition of "culture": Current concerns and their implications. A comment on Gustav Jahoda's article "Critical Reflections on some Recent Definitions of "Culture"". *Integrative Psychological and Behavioral Science, 52*, 331-340. https://doi.org/10.1007/s12124-018-9425-y

Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural differences in psychosis: The role of causal beliefs and stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, *50*(3), 441-459. https://doi.org/10.1177/0022022118820168

Mishra, S. K. (2016). The Colonial Origins of Territorial Disputes in South Asia. *Journal of Territorial & Maritime Studies, 3*(5), 5-23. https://www.jstor.org/stable/26664123

Mitchell, S. J., See, H. M., Tarkow, A. K., Cabrera, N., McFadden, K. E., & Shannon, J. D. (2007). Conducting studies with fathers: Challenges and opportunities. *Applied Development Science, 11*(4), 239-244. https://doi.org/10.1080/10888690701762159

Mitra, S., De, R., Basu, M., & Sardar, J. C. (2023). Quality of life of caregivers of children with psychiatric illnesses: a comparative study in a tertiary care hospital, Kolkata. *Asian Journal of Medical Sciences*, *14*(11), 155-161. https://doi.org/10.3126/ajms.v14i11.56712

Moll, S., Eakin, J. M., Franche, R. L., & Strike, C. (2013). When health care workers experience mental ill health: institutional practices of silence. *Qualitative Health Research*, *23*(2), 167-179. https://doi.org/10.1177/1049732312466296

Moller, N., Burgess, V., & Jogiyat, Z. (2016). Barriers to counselling experienced by British South Asian women: A thematic analysis exploration. *Counselling and Psychotherapy Research*, *16*(3), 201-210. https://doi.org/10.1002/capr.12076

Motta, V., & Larkin, M. (2023). Absence of other and disruption of self: an interpretative phenomenological analysis of the meaning of loneliness in the context of life in a religious community. *Phenomenology and the Cognitive Sciences, 22*(1), 55-80. https://doi.org/10.1007/s11097-022-09832-8

Moudatsou, M., Koukouli, S., Palioka, E., Pattakou, G., Teleme, P., Fasoi, G., ... & Stavropoulou, A. (2021). Caring for patients with psychosis: mental health professionals' views on informal caregivers' needs. *International Journal of Environmental Research and Public Health*, *18*(6), 2964. https://doi.org/10.3390/ijerph18062964

Munoz, A. (2014). *Lost in Translation: A Qualitative Study Exploring Clients Experiences of Utilizing a Language Interpreter to Receive Mental Health Services* [Unpublished doctoral dissertation]. The Chicago School of Professional Psychology. https://www.proquest.com/openview/6f33d8eab1a84f73cd0b9d689d539634/1?pq-origsite=gscholar&cbl=18750

Murshid, N. S. (2017). Parents, friends, and depression: A multi-country study of adolescents in South Asia. *Children and Youth Services Review, 79*, 160-165. https://doi.org/10.1016/j.childyouth.2017.06.018

Mustafa, N., Zaidi, A. U., & Weaver, R. R. (2017). Conspiracy of silence: cultural conflict as a risk factor for the development of eating disorders among second-generation Canadian South Asian women. *South Asian Diaspora*, *9*(1), 33-49. https://doi.org/10.1080/19438192.2016.1199421

National Institute for Mental Health in England. (2003). *Inside outside: improving mental health services for black and minority ethnic communities in England*. Department of Health. https://www.nimhe.org.uk/downloads/inside_outside.pdf

National Institute of Clinical Excellence. (2009). *Depression in adults: treatment and management of depression in adults: Guidance* (NICE Guideline NG222). NICE. https://www.nice.org.uk/guidance/ng222

Nazroo, J. Y. (2003). The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. *American Journal of Public Health, 93*(2), 277-284. https://doi.org/10.2105/AJPH.93.2.277

Nazroo, J. Y., Bhui, K. S., & Rhodes, J. (2020). Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of Health & Illness, 42*(2), 262-276. https://doi.org/10.1111/1467-9566.13001

NHS England. (2022). *Mental Health of Children and Young People in England 2022 - wave 3 follow up to the 2017 survey*. NHS. https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2022-follow-up-to-the-2017-survey

Nizam, H., & Ali, S. M. (2021). Perceived barriers and Facilitators to access mental health services among Pakistani adolescents. *Biosight*, *2*, 4-12. https://doi.org/10.46568/bios.v2i2.46

Nock, M. K., & Kazdin, A. E. (2001). Parent expectancies for child therapy: Assessment and relation to participation in treatment. *Journal of Child and Family Studies, 10*, 155-180. http://dx.doi.org/10.1023%2FA%3A1016699424731

Nomaguchi, K., & Milkie, M. A. (2020). Parenthood and well-being: A decade in review. *Journal of Marriage and Family, 82*(1), 198-223. https://doi.org/10.1111/jomf.12646

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power, 6*(1), 49-68. https://doi.org/10.1080/2158379x.2013.774979

North Yorkshire Safeguarding Children Partnership (2011). *Team Around the Family*. https://www.safeguardingchildren.co.uk/wp-content/uploads/2019/11/79301-TAF-Guidance-4-Nov.pdf

Office for National Statistics. (2021). *Ethnic group, England and Wales: Census 2021*. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021

Otto, H., & Keller, H. (Eds.). (2014). *Different faces of attachment: Cultural variations on a universal human need*. Cambridge University Press.

Oyserman, D., Coon, H. M., & Kemmelmeier, M. (2002). Rethinking individualism and collectivism: evaluation of theoretical assumptions and meta-analyses. *Psychological Bulletin*, *128*(1), 3. https://doi.org/10.1037/0033-2909.128.1.3

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533-544. https://doi.org/10.1007/s10488-013-0528-y

Pantalone, D. W., Iwamasa, G. Y., & Martell, C. R. (2010). Cognitive-behavioral therapy with diverse populations. In K. S. Dobson (Ed.), *Handbook of cognitive-behavioral therapies* (3rd ed., pp. 445–464). Guilford Press. https://www.researchgate.net/profile/Windy-Dryden/publication/227153297_Rational_Emotive_Behavior_Therapy/links/563200b808ae3de9381d893e/Rational-Emotive-Behavior-Therapy.pdf#page=460

Parker, C., Scott, S., & Geddes, A. (2019). Snowball sampling. *SAGE research methods foundations*. https://dx.doi.org/10.4135/9781526421036831710

Patel, K., Cardno, A., & Isherwood, T. (2023). 'Like I said about culture. You don't talk about mental health': An interpretative phenomenological analysis of the experience of first-episode psychosis in South Asian individuals. *Early Intervention in Psychiatry*, *17*(8), 771-783. https://doi.org/10.1111/eip.13368

Patel, S. G., & Kull, M. A. (2011). Assessing psychological symptoms in recent immigrant adolescents. *Journal of Immigrant and Minority Health*, *13*, 616-619. https://doi.org/10.1007/s10903-010-9382-0

Peach, C. (2006). South Asian migration and settlement in Great Britain, 1951–2001. *Contemporary South Asia, 15*(2), 133-146. https://doi.org/10.1080/09584930600955234

Pearce, M. J., Medoff, D., Lawrence, R. E., & Dixon, L. (2016). Religious coping among adults caring for family members with serious mental illness. *Community Mental Health Journal*, *52*, 194-202. https://doi.org/10.1007/s10597-015-9875-3

Penny, E., Newton, E., & Larkin, M. (2009). Whispering on the water: British Pakistani families' experiences of support from an early intervention service for first-episode psychosis. *Journal of Cross-Cultural Psychology*, *40*(6), 969-987. https://doi.org/10.1177/0022022109347967

Pharr, J. R., Dodge Francis, C., Terry, C., & Clark, M. C. (2014). Culture, caregiving, and health: exploring the influence of culture on family caregiver experiences. *ISRN Public Health*, *2014*, 1-8. https://doi.org/10.1155/2014/689826

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal, 20*(1), 7-14. https://doi.org/10.14691/CPPJ.20.1.7

Pilkington, A., Msetfi, R. M., & Watson, R. (2012). Factors affecting intention to access psychological services amongst British Muslims of South Asian origin. *Mental Health, Religion & Culture, 15*(1), 1-22. https://doi.org/10.1080/13674676.2010.545947

Platt, L. (2012). How do children of mixed partnerships fare in the United Kingdom? Understanding the implications for children of parental ethnic homogamy and heterogamy. *The Annals of the American Academy of Political and Social Science, 643*(1), 239-266. https://doi.org/10.1177/0002716212444853

Porritt, K., Gomersall, J., & Lockwood, C. (2014). JBI's systematic reviews: study selection and critical appraisal. *The American Journal of Nursing, 114*(6), 47-52. https://doi.org/10.1097/01.naj.0000450430.97383.64

Prajapati, R., & Liebling, H. (2021). Accessing mental health services: a systematic review and meta-ethnography of the experiences of South Asian Service users in the UK. *Journal of Racial and Ethnic Health Disparities*, *9*, 598-619. https://doi.org/10.1007/s40615-021-00993-x

Predelli, L., Halsaa, B., Sandu, A., Thun, C., & Nyhagen, L. (2012). *Majority-minority relations in contemporary women's movements: strategic sisterhood.* Springer.

Pybis, J., Saxon, D., Hill, A., & Barkham, M. (2017). The comparative effectiveness and efficiency of cognitive behaviour therapy and generic counselling in the treatment of depression: evidence from the 2nd UK National Audit of psychological therapies. *BMC psychiatry*, *17*, 1-13. https://doi.org/10.1186/s12888-017-1370-7

Qureshi, F., Misra, S., & Poshni, A. (2023). The partition of India through the lens of historical trauma: Intergenerational effects on immigrant health in the South Asian diaspora. *SSM-Mental Health, 4*, 100246. https://doi.org/10.1016/j.ssmmh.2023.100246

Raghavan, R., Brown, B., Hussain, S., Kumar, S., Wilson, A., Svirydzenka, N., ... & Wilson, M. (2022). How do Muslim service users, caregivers, and community members in Malappuram, Kerala, use their faith to address the challenges associated with mental ill health? *Mental Health, Religion & Culture*, *25*(10), 1012-1025. https://doi.org/10.1080/13674676.2023.2169268

Raghavan, V., Mohan, G., & Gopal, S. (2017). Felt needs of primary caregivers of individuals with schizophrenia: A study from South India. *Asian Journal of Psychiatry*, *29*, 1-2. https://doi.org/10.1016/j.ajp.2017.04.007

Randhawa, G., & Stein, S. (2007). An exploratory study examining attitudes toward mental health and mental health services among young South Asians in the United Kingdom. *Journal of Muslim Mental Health, 2*(1), 21-37. https://doi.org/10.1080/15564900701238518

Rickwood, D., & Thomas, K. (2012). Conceptual measurement framework for help-seeking for mental health problems. *Psychology Research and Behavior Management*, 173-183. https://doi.org/10.2147/PRBM.S38707

Robinson, L. (2005). South Asians in Britain: Acculturation, identity and perceived discrimination. *Psychology and Developing Societies, 17*(2), 181-194. https://doi.org/10.1177/097133360501700206

Rothbaum, F., Rosen, K., Ujiie, T., & Uchida, N. (2002). Family systems theory, attachment theory, and culture. *Family Process, 41*(3), 328-350. https://doi.org/10.1111/j.1545-5300.2002.41305.x

Rudmin, F. (2009). Constructs, measurements and models of acculturation and acculturative stress. *International Journal of Intercultural Relations*, *33*(2), 106-123. https://doi.org/10.1016/j.ijintrel.2008.12.001

Sabo, K., & Chin, E. (2021). Self-care needs and practices for the older adult caregiver: An integrative review. *Geriatric Nursing*, *42*(2), 570-581. https://doi.org/10.1016/j.gerinurse.2020.10.013

Sadler, M. S., Meagor, E. L., & Kaye, K. E. (2012). Stereotypes of mental disorders differ in competence and warmth. *Social Science & Medicine, 74*(6), 915-922. https://doi.org/10.1016/j.socscimed.2011.12.019

Saeed, A., Rae, E., Neil, R., Connell-Hall, V., & Munro, F. (2019, October 4). To BAME or not to BAME: the problem with racial terminology in the civil service. *Civil Service*

World. https://www.civilserviceworld.com/news/article/to-bame-or-not-to-bame-the-problem-with-racial-terminology-in-the-civil-service

Safdar, S., Goh, K., & Choubak, M. (2020). Clothing, identity, and acculturation: The significance of immigrants' clothing choices. *Canadian Journal of Behavioural Science*, *52*(1), 36-47. https://doi.org/10.1037/cbs0000160

Salway, S., Chowbey, P., and Clarke, L. (2009). Parenting in modern Britain: understanding the experiences of Asians fathers. *Joseph Rowntree Foundation & York Publishing: York.* https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/Asian-fathers-Britain-full.pdf

Sam, D. L., & Berry, J. W. (Eds.). (2006). *The Cambridge handbook of acculturation psychology.* Cambridge University Press.

Sangar, M., & Howe, J. (2021). How discourses of sharam (shame) and mental health influence the help-seeking behaviours of British born girls of South Asian heritage. *Educational Psychology in Practice, 37*(4), 343-361. https://doi.org/10.1080/02667363.2021.1951676

Sangha, J. K. (2014). Contextualising South Asian Motherhood. In A. O'Reilly (Eds.), *Mothers, Mothering and Motherhood Across Cultural Differences – A Reader* (pp. 413-428). Demeter Press.

Sashidharan, S. P. (2003). *Inside Outside: Improving mental health services for Black and minority ethnic communities in England.* National Institute for Mental Health in England. https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4019452.pdf

Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review*, *27*(1). https://doi.org/10.1071/ah042710111

Sayal, K., & Taylor, E. (2004). Detection of child mental health disorders by general practitioners. *British Journal of General Practice, 54*(502), 348-352. https://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC1266168&blobtype=pdf

Schwartz, S. J., Unger, J. B., Zamboanga, B. L., & Szapocznik, J. (2010). Rethinking the concept of acculturation: implications for theory and research. *American Psychologist*, *65*(4), 237. https://doi.org/10.1037/a0019330

Sekhon, Y. K., & Szmigin, I. (2011). Acculturation and identity: Insights from second-generation Indian Punjabis. *Consumption, Markets and Culture*, *14*(1), 79-98. https://doi.org/10.1080/10253860903562171

Shah, A., & Carlsson, J. (2016). Jinn possession as an explanation of mental illness influences the treatment-seeking behaviour. *Ugeskrift for laeger, 178*(27). https://content.ugeskriftet.dk/sites/default/files/scientific_article_files/2016-09//V03160194_3.pdf

Shams, M. (2001). Social support, loneliness and friendship preference among British Asian and non-Asian adolescents. *Social Behavior and Personality, 29*(4), 399-404. https://doi.org/10.2224/sbp.2001.29.4.399

Shariff, F. (2008). Straddling the cultural divide: second-generation South Asian identity and the namesake. *Changing English*, *15*(4), 457-466. https://doi.org/10.1080/13586840802493100

Shariff, A. (2009). Ethnic identity and parenting stress in South Asian families: Implications for culturally sensitive counselling. *Canadian Journal of Counselling and Psychotherapy*, *43*(1).

https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=94cfe96253489bb6947dc7dea5ef47f268ce11b3

Sickel, A. E., Seacat, J. D., & Nabors, N. A. (2014). Mental health stigma update: A review of consequences. *Advances in Mental Health*, *12*(3), 202-215. https://doi.org/10.1080/18374905.2014.11081898

Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to do a systematic review: A best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual Review of Psychology, 70*, 747-770. https://doi.org/10.1146/annurev-psych-010418-102803

Sharif, L., Basri, S., Alsahafi, F., Altaylouni, M., Albugumi, S., Banakhar, M., ... & Wright, R. J. (2020). An exploration of family caregiver experiences of burden and coping while caring for people with mental disorders in Saudi Arabia—A qualitative study. *International Journal of Environmental Research and Public Health*, *17*(17), 6405. https://doi.org/10.3390/ijerph17176405

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7. https://doi.org/10.5498%2Fwjp.v6.i1.7

Sheikh, A., Halani, L., Bhopal, R., Netuveli, G., Partridge, M. R., Car, J., ... & Levy, M. (2009). Facilitating the recruitment of minority ethnic people into research: qualitative case study of South Asians and asthma. *PLoS Medicine, 6*(10), e1000148. https://doi.org/10.1371/journal.pmed.1000148

Singh, M. D., & Bhayana, R. M. (2015). Straddling three worlds: Stress, culture and adaptation in South Asian couples. *Contemporary Family Therapy, 37*, 45-57. https://doi.org/10.1007/s10591-014-9319-1

Skovgaard, A. M. (2010). Mental health problems and psychopathology in infancy and early childhood. *Danish Medical Bulletin, 57*(10), B4193. https://www.researchgate.net/profile/Anne-Skovgaard/publication/47643987_Mental_health_problems_and_psychopathology_in_infancy_and_early_childhood_An_epidemiological_study/links/58628c0608aebf17d39556d6/Mental-health-problems-and-psychopathology-in-infancy-and-early-childhood-An-epidemiological-study.pdf

Slaunwhite, A. K., Ronis, S. T., Sun, Y., & Peters, P. A. (2017). The emotional health and well-being of Canadians who care for persons with mental health or addictions problems. *Health & Social Care in the Community*, *25*(3), 840-847. https://doi.org/10.1111/hsc.12366

Smiley, T. (2001). *Clinical psychology and religion: A survey of the attitudes and practices of clinical psychologists in South East England* [Unpublished doctoral dissertation]. University of Surrey.

Smith, N. R., Clark, C., Smuk, M., Cummins, S., & Stansfeld, S. A. (2015). The influence of social support on ethnic differences in well-being and depression in adolescents: findings from the prospective Olympic Regeneration in East London (ORiEL) study. *Social Psychiatry and Psychiatric Epidemiology, 50*, 1701-1711. https://doi.org/10.1007/s00127-015-1098-y

Smith, J. A., Flowers, P., and Larkin, M. (2022). *Interpretative Phenomenological Analysis: Theory, Method and Research* (2nd ed.). Sage Publications Inc.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Method* (pp. 218-239). Sage.

Smith, J. A., & Nizza, I. E. (2021). *Essentials of interpretative phenomenological analysis*. American Psychological Association.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications, Inc.

Smith, G. P., & Williams, T. M. (2016). From providing a service to being of service: advances in person-centred care in mental health. *Current Opinion in Psychiatry*, *29*(5), 292-297. https://doi.org/10.1097/YCO.0000000000000264

Soorkia, R., Snelgar, R., & Swami, V. (2011). Factors influencing attitudes towards seeking professional psychological help among South Asian students in Britain. *Mental Health, Religion & Culture, 14*(6), 613-623. https://doi.org/10.1080/13674676.2010.494176

Spencer-Oatey, H. (2012). What is culture. A compilation of quotations. *GlobalPAD Core Concepts, 1*(22), 1-21.

Spruit, A., Goos, L., Weenink, N., Rodenburg, R., Niemeyer, H., Stams, G. J., & Colonnesi, C. (2020). The relation between attachment and depression in children and adolescents: A multilevel meta-analysis. *Clinical Child and Family Psychology Review, 23*(1), 54-69. https://psycnet.apa.org/doi/10.1007/s10567-019-00299-9

Stapleton, T. (2009). Dasein as being-in-the-world. In B. W. Davis (Eds.), *Martin Heidegger: key concepts* (pp. 44-56). Acumen Publishing.

Suddick, K. M., Cross, V., Vuoskoski, P., Galvin, K. T., & Stew, G. (2020). The work of hermeneutic phenomenology. *International Journal of Qualitative Methods*, *19*. https://doi.org/10.1177/1609406920947600

Sue, D. W., Capodilupo, C. M., Torino, G. C., Bucceri, J. M., Holder, A., Nadal, K. L., & Esquilin, M. (2007). Racial microaggressions in everyday life: implications for clinical practice. *American Psychologist, 62*(4), 271. https://doi.org/10.1037/0003-066x.62.4.271

Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. *American Journal of Alzheimer's Disease & Other Dementias*, *27*(1), 13-22. https://doi.org/10.1177/1533317512438224

Tabassum, R., Macaskill, A., & Ahmad, I. (2000). Attitudes towards mental health in an urban Pakistani community in the United Kingdom. *International Journal of Social Psychiatry, 46*(3), 170-181. https://doi.org/10.1177/002076400004600303

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, *8*(1), 1-10. https://doi.org/10.1186%2F1471-2288-8-45

Thompson, M. (2010). *Engaging Asian faith communities and counselling psychology perspectives in the development of older adult services* [Unpublished doctoral dissertation]. University of Wolverhampton.

Toleikyte, L., & Salway, S. (2018). *Local action on health inequalities: Understanding and reducing ethnic inequalities in health.* Public Health England. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/730917/local_action_on_health_inequalities.pdf

Tonsing, K. N. (2014). Acculturation and adaptation of first-and second-generation South Asians in Hong Kong. *International Journal of Social Welfare*, *23*(4), 410-420. https://doi.org/10.1111/ijsw.12079

Triandis, H. C. (2018). *Individualism and collectivism*. Routledge.

Tsai, T. I., Chen, I. J., & Huang, S. L. (2011, March). Motherhood journey through the eyes of immigrant women. In *Women's Studies International Forum* (Vol. 34, No. 2, pp. 91-100). Pergamon. https://doi.org/10.1016/j.wsif.2010.12.002

Tummala-Narra, P., Deshpande, A., & Kaur, J. (2016). South Asian adolescents' experiences of acculturative stress and coping. *American Journal of Orthopsychiatry, 86*(2), 194. https://doi.org/10.1037/ort0000147

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A., & Walsh, S. (1997). Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology Forum, The British Psychological Society, 108*, 3-7. https://eprints.bbk.ac.uk/id/eprint/31224

UK Council for Psychotherapy. (2019). *Code of ethics and professional practice. https://www.psychotherapy.org.uk/media/bkjdm33f/ukcp-code-of-ethics-and-professional-practice-2019.pdf*

Veltman, A., Cameron, J. I., & Stewart, D. E. (2002). The experience of providing care to relatives with chronic mental illness. *The Journal of Nervous and Mental Disease*, *190*(2), 108-114. https://doi.org/10.1097/00005053-200202000-00008

Venkatesh, B. T., Andrews, T., Parsekar, S. S., Singh, M. M., & Menon, N. (2016). Stigma and mental health-caregivers' perspective: A qualitative analysis. *Clinical Epidemiology and Global Health*, *4*(1), 23-27. https://doi.org/10.1016/j.cegh.2015.06.003

Ventriglio, A., Ricci, F., Torales, J., Castaldelli-Maia, J. M., Bener, A., Smith, A., & Liebrenz, M. (2024). Navigating a world in conflict: The mental health implications of contemporary geopolitical crises. *Industrial Psychiatry Journal*. https://doi.org/10.4103/ipj.ipj_46_24

Waligora, K. J., Bahouth, M. N., & Han, H. R. (2019). The self-care needs and behaviors of dementia informal caregivers: A systematic review. *The Gerontologist*, *59*(5), 565-583. https://doi.org/10.1093/geront/gny076

Walke, S. C., Chandrasekaran, V., & Mayya, S. S. (2018). Caregiver burden among caregivers of mentally ill individuals and their coping mechanisms. *Journal of Neurosciences in Rural Practice*, *9*(2), 180-185. https://doi.org/10.4103%2Fjnrp.jnrp_312_17

Walton-Moss, B., Gerson, L., & Rose, L. (2005). Effects of mental illness on family quality of life. *Issues in Mental Health Nursing*, *26*(6), 627-642. https://doi.org/10.1080/01612840590959506

Wani, A. M. (2013). A comparative study of the concept of God in Hinduism and Islam. *International Journal of Scientific and Research Publications*, *3*(2), 1-5. https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=39526751903fc163aa0e6009a3bd4334bda9511d

Weich, S., Nazroo, J., Sproston, K., McManus, S., Blanchard, M., Erens, B., Karlsen, S., King, M., Lloyd, K., Stansfeld, S., & Tyrer, P. (2004). Common mental disorders and ethnicity in England: the EMPIRIC study. *Psychological medicine, 34*(8), 1543-1551. https://doi.org/10.1017/S0033291704002715

Wiles, R., Crow, G., Heath, S., & Charles, V. (2008). The management of confidentiality and anonymity in social research. *International Journal of Social Research Methodology, 11*(5), 417-428. https://doi.org/10.1080/13645570701622231

Williams, D. R., & Etkins, O. S. (2021). Racism and mental health. *World Psychiatry, 20*(2), 194. https://doi.org/10.1002%2Fwps.20845

Willig, C. (2013). *Introducing Qualitative Research in Psychology.* McGraw-Hill Education.

Willig, C., & Rogers, W. S. (Eds.). (2017). *The SAGE handbook of qualitative research in psychology*. Sage.

Wilstrand, C., Lindgren, B. M., Gilje, F., & Olofsson, B. (2007). Being burdened and balancing boundaries: a qualitative study of nurses' experiences caring for patients who self-harm. *Journal of Psychiatric and Mental Health Nursing*, *14*(1), 72-78. https://doi.org/10.1111/j.1365-2850.2007.01045.x

Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?. *BMC Psychiatry*, *10*, 1-10. https://doi.org/10.1186%2F1471-244X-10-103

World Health Organisation (2021). *Mental Health Atlas 2020.* https://iris.who.int/bitstream/handle/10665/345946/9789240036703-eng.pdf?sequence=1

World Health Organisation, UNICEF., & Mathers, C. (2016). Global strategy for women's, children's and adolescents' health (2016-2030). *Organization, 201*, 4-103.

Xiao, Y., & Watson, M. (2019). Guidance on conducting a systematic literature review. *Journal of Planning Education and Research, 39*(1), 93-112. https://doi.org/10.1177/0739456X17723971

Xue, Y., Leventhal, T., Brooks-Gunn, J., & Earls, F. J. (2005). Neighborhood residence and mental health problems of 5-to 11-year-olds. *Archives of General Psychiatry, 62*(5), 554-563. https://doi.org/10.1001/archpsyc.62.5.554

Yeung, W. J. J. (2013). Asian fatherhood. *Journal of Family Issues, 34*(2), 141-158. https://doi.org/10.1177/0192513X12461133

Yeung, W. J. J., Desai, S., & Jones, G. W. (2018). Families in southeast and South Asia. *Annual Review of Sociology*, *44*, 469-495. https://doi.org/10.1146/annurev-soc-073117-041124

Younis, T. (2021). The psychologisation of counter-extremism: unpacking PREVENT. *Race & Class, 62*(3), 37-60. https://doi.org/10.1177/0306396820951055

Zaidi, A. U., Couture-Carron, A., & Maticka-Tyndale, E. (2016). 'Should I or Should I Not'?: an exploration of South Asian youth's resistance to cultural deviancy. *International Journal of Adolescence and Youth*, *21*(2), 232-251. https://doi.org/10.1080/02673843.2013.836978

Zegwaard, M. I., Aartsen, M. J., Grypdonck, M. H., & Cuijpers, P. (2013). Differences in impact of long term caregiving for mentally ill older adults on the daily life of informal caregivers: a qualitative study. *BMC Psychiatry*, *13*, 1-9. https://doi.org/10.1186/1471-244x-13-103

Zilanawala, A., Sacker, A., Nazroo, J., & Kelly, Y. (2015). Ethnic differences in children's socioemotional difficulties: Findings from the Millennium Cohort Study. *Social Science & Medicine, 134*, 95-106. https://doi.org/10.1016/j.socscimed.2015.04.012

Zhang, X., Li, J., Xie, F., Chen, X., Xu, W., & Hudson, N. W. (2022). The relationship between adult attachment and mental health: A meta-analysis. *Journal of Personality and Social Psychology*, *123*(5), 1089. https://doi.org/10.1037/pspp0000437

Appendices

Appendix A: Systematic Literature Review – Characteristics of Included Studies

Study Characteristics of Included Studies (n = 11)

Author, year Title	Aims	Location, Participants and Sample	Data Collection	Data Analysis	Summary of Key Findings	Strengths and Limitations
Banerjee & Dixit, 2021 Perceived Stigma among Family Members of Persons Suffering from Mental Illness: A Narrative Exploration from West Bengal, India	To understand the experiences of family members of people with a mental illness in regards to stigma	Kolkata, India Purposive sampling 85 family members from 68 families (46 female, 39 male). Included parents, spouses, siblings, adult children, and other relatives.	Semi-structured, in-depth interviews	Constant Comparative Method	Family members had experienced direct and perceived stigma. Within the perceived stigma category, family members were concerned of the reaction of the community upon disclosure of the illness, the community's understanding and interpretation of the illness, and the impact of the disclosure on the family and their future.	+ Wider study gathered data also from mental health professionals to gain holistic understanding of caregiving + Carried out pilot study, from which participants' responses were incorporated into the development of the interview guides – Some interview questions could be perceived as

							leading, aiming to get a certain type of answer from the participant
Dijkxhoorn, 2023 Stigma, lost opportunities, and growth: Understanding experiences of caregivers of persons with mental illness in Tamil Nadu, India	To understand the lived experiences of caregivers of people with a mental illness in a low-income country	Tamil Nadu, India Purposive sample 50 caregivers (31 female, 19 male). Included parents, spouses, siblings, and adult children. Mean age: 50.6 years	Semi-structured interviews with 29 caregivers Focus group discussions with 21 caregivers	Thematic analysis	Four themes emerged from the findings: embarrassment and loss of honour in regards to ill family member's non-normative behaviour; fear in regards to uncertainty of the future; stigma, awareness and social exclusion; reduced social interaction and loneliness as a result of stigma, self-stigma, and caregiving responsibilities; and lost opportunities for caregivers as a result of providing care	+ + –	Data gathered from different types of family caregivers Utilised both individual interviews and focus groups to gather data and get an in-depth understanding Situated findings within Banyan model of caregiver experiences framework, a new framework which had been developed by the same researchers and therefore had not been tested for accuracy/replicability

Issac et al., 2023 Primary caregiver’s experiences in caring paranoid schizophrenia patients: A qualitative study	To investigate the lived experiences of primary caregivers of patients diagnosed with paranoid schizophrenia	Odisha, India Purposive sample 20 primary caregivers (18 female, 2 male). Included parents, spouses, and adult child. Age range: 23-64	Semi-structured interviews	Thematic analysis	Six main themes emerged: encountering gloom (negative feelings about the future, stigma, and criticism from others); challenges associated with caregiving; positive and negative impacts on the caregiver; managing the expense of the family member’s treatment; expectations from family members, health professionals, and society that have and haven’t been met; and caregiver’s use of coping strategies	+ Use of language experts during transcription to ensure the validity and accuracy of the translations – Interviews took place on the inpatient ward which may have affected the participant’s responses – Few males in sample – limits generalisability of findings to male caregivers
Jagannathan et al., 2011 A Qualitative Study On the	To investigate the felt needs of caregivers of people with schizophrenia in	Bangalore, India Purposive sampling	Five focus group discussions (6 caregivers in each group)	Unclear. Participants were involved in ranking importance of	Six main themes of needs emerged: support with managing the service user’s psychosis-related behaviour, managing the service user’s	+ Participants were involved in the data making process – Use of focus groups may have limited gathering of

Needs of Caregivers of Inpatients With Schizophrenia in India	an inpatient setting in India	30 caregivers (17 female, 13 male). Included parents, siblings, spouses, and other family relations. Mean age: 50.6 years		themes during the focus group. Researcher then grouped overlapping themes together in the second level of data analysis.	socio-vocational problems, the caregiver’s own physical and emotional health needs, the caregiver’s education needs regarding the illness, the caregiver’s rehabilitation needs, and managing the sexual and marital issues of the service user.	in-depth, personal experiences of each participant – No clear, validated, and reliable data analysis approach was taken
Joshi et al., 2008 Sharing Experiences of Care Giving: A Qualitative Study on Caregivers of Patients with Severe Mental Disorders	To gain a greater knowledge of the experiences of primary caregivers of people with schizophrenia and/or bipolar affective disorder	Delhi, India Purposive sample 60 primary caregivers (45 female, 15 male). Included parents, spouses, siblings, and daughters. Age range: 21-70	Focus group discussions	Unclear	The themes that were the most resonant within the groups of care givers were social stigma of mental illness, coping strategies, patient’s problems, and financial problems, effect on caregiver’s health, social isolation, and thoughts regarding leaving the patient.	+ Large sample so more likely to be representative – Type of analysis and the process to developing themes is unclear – Use of focus groups may lead to lesser likelihood of participants sharing their accurate views – No discussion regarding limitations, clinical

						implications or areas of future research
Koschorke et al., 2014 Experiences of stigma and discrimination of people with schizophrenia in India	To describe the experiences of stigma and discrimination of people living with schizophrenia and their caregivers and to identify factors influencing negative discrimination	Tamil Nadu, Goa, and Maharashtra, India. Purposive sample Sub-set of large quantitative sample (n=282) sampled for qualitative aspect of research: 36 people with schizophrenia and 36 caregivers	Mixed methods Semi-structured interview guide for qualitative interviews	Thematic analysis	Qualitative findings illustrate the major impact of stigma on ‘what matters most’ in the lives of PLS and highlight three key domains influencing the themes of 'negative reactions' and ‘negative views and feelings about the self’, i.e., ‘others finding out’, ‘behaviours and manifestations of the illness’ and ‘reduced ability to meet role expectations’.	+ Utilisation of mixed methods allowed exploration into areas with complex interactions + Transcriptions, codes, and themes were discussed and cross-checked amongst all researchers and interviewers, increasing inter-rater reliability – Participants that had experienced negative discrimination were purposefully overrepresented in the qualitative sample, which may make the results less generalisable

Littlewood & Dein, 2016 Carers and families: life and suffering among Bangladeshi psychiatric patients and their families in London – an interview study 3	To explore the role of family members in UK Bangladeshis with a mental illness. Specifically, looking to understand how families support those with mental health difficulties, the burden that is placed on them, and how family conflicts play a role in the causation of mental illness.	London, UK Convenience sample 25 people (16 male, 9 female) with a mental illness and 19 family carers (16 female, 3 male) Age range: carers 18-73; people with mental illness 27-65	Semi-structured individual interviews	Unclear	Family members were the primary source of support for those with mental health difficulties. Family carers experience emotional and physical burden as a result of the care they provide. Family conflict, between carers and the person being cared for, can sometimes lead to accusations of sorcery as an explanation for the mental illness.	+ Discussion about the ethnicity of interviewers and how this may have affected what was shared by participants + Inclusion of participants with a physical illness, as mental illness can often present somatically in SAs – Only a subsection of the SA community in London, so the sample may not be representative – Limited detail about the process of data analysis and generation of themes

Mathias et al., 2019 An asymmetric burden: Experiences of men and women as caregivers of people with psycho-social disabilities in rural North India	To explore the emotional, physical, and socio-economic experiences of caregivers of people with psycho-social disabilities and situate these in a gendered context	Uttar Pradesh, India Purposive sample 18 caregivers (11 female, 7 male). Included parents, spouses, siblings, and daughters. Age range: 22-55	In-depth, semi-structured interviews	Thematic analysis	9 sub-themes emerged, grouped under 3 meta-themes: intra-personal, inter-personal, and institutional. All caregivers experienced high levels of tension, with women generally feeling negative and hopeless about their individual future, whereas male carers were positive and hopeful of their future. Inter-personally, men had more opportunity for social connection and support than women. Under the institutional theme, both men and women described strength in unity.	+ + –	Compared themes across different gendered caregivers, providing important information about gender differences in caregiving experiences Discussion about the gender of interviewers and how this may have affected the participants' responses Conducted in rural villages in India and thus results may not be generalisable to other parts of India (e.g., urban cities)
Meheli, 2023 Experiences of Family	To understand caregiving experiences and caregiver's needs	India Purposive sampling	Questionnaires with 10 open-ended questions	Content analysis	Caregivers experienced caregiving in a temporal sequence, with themes situated in three domains of *past,*	+	Discusses the strengths, limitations and clinical implications of the findings

Caregivers of Patients with Schizophrenia: A Qualitative Study in India	in the context of life cycle stage disruption	27 caregivers (13 female, 14 male). Included parents, children, siblings, and spouses. Mean age: 38.9 years			*present, and future*. The *past* focussed on the changing roles of the ill person and the caregiver. The *present* focussed on the emotional and physical challenges of caregiving, the loss of an idealised life, and reflections about the reality of caregiving. The *future* focussed on caregiver's worries about the future, which felt uncertain.	– –	Lacks depth of participant's experience due to use of questionnaires Excluded participants who could not read or write in English and thus excluding responses that may reflect lower educational experience, limiting the generalisability of the findings
Penny et al., 2009 Whispering on the Water: British Pakistani Families' Experiences of	To investigate the experiences of British Pakistanis use of a mental health treatment service and their beliefs about	Birmingham, UK Convenience sample 11 caregivers from six families (8 female, 3	Semi-structured interviews	Interpretative Phenomenological Analysis	Three main themes emerged. Accounts focussed on loss: loss of hope for recovery, a change in their family and loss of future expectations for their family member. Caregivers understood the psychosis as a social problem, with the	+ +	Included data from more than one member of the family, allowing for a broader perspective from different familial roles Used interpreters/family members for participants who preferred the

Support From an Early Intervention Service for First-Episode Psychosis	psychosis and treatment	male). Included parents, older siblings, and grandmother.			development seen as a result of social stressors and it manifesting in social contexts as a failure to function within the family and community as was expected of them. The third theme focussed on ideas for recovery, with a combination of approaches being deemed as the best path.	 –	interview to be in their mother tongue, allowing inclusion of their participation in the study who may have otherwise been excluded Conducted in an area of the UK in which there is a large Pakistani and SA population. Thus, findings may not be generalisable to other areas of the UK
Raghavan et al., 2022 How do Muslim service users, caregivers, and community members in	To investigate the role of religion and spirituality in managing the challenges related to mental ill health in Muslim Indians	Kerala, India Purposive sampling 8 familial caregivers, as well as community	Interviews	Thematic analysis	Four key themes emerged. Participants made sense of the illness, attributing the cause to supernatural factors. Participants spoke about relying on the “will of God”, attributing the illness and the healing process to a part of	+	Caregivers were caring for family members with a wide range of diagnoses (psychosis, bipolar, depression, and anxiety). Thus, results may be more generalisable to

Malappuram, Kerala, use their faith to address the challenges associated with mental ill health?	members (n=6) and service users (n=10).		God’s plan. Prayer was the third theme, in which participants expressed the importance of asking God to heal any illnesses. Traditional healing methods were explored by participants, with faith seen as a prerequisite for any treatment.	caregivers of mental illness as a whole + Developed interview schedule with community members, thus the interview questions were likely to feel relevant to participants – Accounts from service users, caregivers, and community members analysed together so unable to differentiate between their views

Appendix B: Participant Information Sheet

Exploring the Experiences of South Asian Caregivers Caring for a Child with Mental Health Difficulties

My name is Sadia Riya and I am a Trainee Clinical Psychologist in the Department of Health and Social Care at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. It aims to answer any questions that you may have about the research. However, if you have any further questions, please feel free to contact Sadia (the main researcher).

What is the purpose of the study?

This study will be conducted as part of the requirements for Sadia Riya's Doctoral degree in Clinical Psychology. The research aims to find out about the experiences that South Asian caregivers have when supporting a child with mental health difficulties, how a south Asian caregiver perceives the idea of seeking help for mental health difficulties, and how religion and culture influences South Asian caregivers' views of mental health. I have both personal and professional interest in this area. Being from a Bangladeshi background, I have seen first-hand the importance of family in South Asian communities. I have also worked in areas with a high percentage of South Asian people, which has allowed me to witness how family members' involvement, culture, and religion can impact how mental health difficulties are perceived and managed.

Can I take part in this study?

To participate in this study you must meet the following criteria:

- A parent or primary caregiver
- South Asian (Indian, Pakistani, Bangladeshi, Sri Lankan, or any other South Asian background)
- Understand and speak English
- Caring for at least one child aged between 5 and 19 that is experiencing mental health difficulties

What is a mental health difficulty?

Below we explain what we mean by mental health difficulty. Your child may not experience the specific symptoms described below and they do not need to have experienced them for you to engage in this research. You may just find yourself struggling to manage your child's feelings and behaviours and we would like to hear about this.

We define a mental health difficulty as:

A period of time where your child may struggle with their thoughts, emotions, or behaviours which become so serious, persistent, and difficult to manage that they affect various aspects of their quality of life (e.g., school or family relationships). These difficult experiences might fluctuate so there may be times when your child is feeling better.
Some common mental health problems are depression and anxiety, but other problems exist, such as difficulties with eating or seeing/hearing things that other people don't.

Your child may experience a mental health difficulty without it having been diagnosed by a professional. They may be experiencing the following:

- Feeling low in mood, tearful
- Worrying about lots of different things
- Lacking energy/motivation to do day-to-day tasks
- Not doing activities that normally enjoy
- Problems with their sleep or appetite
- Physical signs (e.g., unexplained headaches, stomach aches, back pain)

This research study is aiming to recruit 6-8 participants who meet the above criteria to complete interviews.

Do I have to take part?

It is completely up to you to decide whether or not you wish to take part in this research study. If you do decide to take part you will be asked to provide written consent. You are free to withdraw at any time before the data is analysed in February 2024, without giving a reason. Any data provided will not be used in the results if you do withdraw before the analysis takes place and will be destroyed.

What will happen to me if I take part?

If you do agree to take part, you will be asked to give your consent to provide some information about yourself and complete an interview. There will be a short 15-minute telephone call to discuss the eligibility criteria. If eligible and still interested, you will be sent a demographics form to complete which gathers information about yourself and some information about your child. We will arrange a time for an interview (either online or in-person) that will last between 60-90 minutes. You will have the option to choose whether you would like to conduct the interview in-person or online. The interview will be conducted by the main researcher, Sadia, and will be audio recorded.

What are the possible disadvantages and risks of taking part?

This study will require you to give up over 90 minutes of your time. If you choose to conduct the interview face-to-face, this may require the interviewer to attend your home. If you are attending the interview from your home, either remotely or face-to-face, it is important to be aware that some topics of discussion in the interview will be sensitive and you may not want others to overhear.

During the interview you may be asked some sensitive questions about the support you provide your child, aspects about your culture/religion, and how this may impact you. If participating in this research causes you any distress or discomfort, you may wish to contact sources of support such as your family or friends. The researcher will also provide information on organisations and services that you can contact that may also be helpful.

What are the possible benefits of taking part?

By participating in this study you will be furthering our understanding of how South Asian families understand mental health, and specifically how South Asian parents use aspects of their culture and religion to support their child with mental health difficulties. We hope that by furthering our understanding in this area, this can impact how South Asian families with an individual with mental health difficulties can be supported. You will also be given a £20 Amazon voucher for your time.

What information will be collected?

The demographics form will collect information about your age, gender, ethnicity, generation, education level, employment status, age of the child, gender of the child, and the child's mental health difficulty. The interview will collect information about your views and understanding of mental health difficulties, your experience of supporting your child, and how religion and culture influence your views and how you support your child. At the point of transcribing the interview, any identifiable information (e.g., names) will be removed (e.g., pseudonyms used instead) and no identifying information will be published.

Will my information be kept confidential?

Yes, all information you provide in this study will be kept confidential and only used for the research study. The only instance where confidentiality can't be maintained is if you disclose information that indicates you or someone else is at risk of harm. In this case the researcher has a legal obligation to inform the appropriate authorities. The audio recording of the interview and any other data files will be encrypted and stored on a password-protected computer. The main researcher will be the only person with access to un-anonymised data, and the research supervisors will have access to anonymised data. The anonymised data will be stored in the University's data repository for 10 years.

What is the legal basis for using the data and who is the Data Controller?

The legal basis for using the data you provide will be your consent. A consent form will be sent to you to complete if you agree to participate in this study. Your data will be processed and stored in accordance with the Data Protection Act 2018 and GDPR.

The Data Controller is the University of Essex and the contact is the University Information Assurance Manager (e-mail dpo@essex.ac.uk).

What should I do if I want to take part?

Please contact the main researcher, Sadia, if you would like to take part. Contact details are below.

What will happen to the results of the research study?

The data collected during the study will be used as a part of a Doctoral Clinical Psychology research project at the University of Essex. The findings of the study will be submitted as part of a doctoral thesis. The thesis will be deposited in the University of Essex Research Repository as a PDF file. The research may also be later published as a journal article and presented at research conferences. Again, no participant will be identifiable in the results. If you would like a copy of the results of the study, please contact Sadia (the main researcher).

Who has reviewed the study?

Ethical approval for this study has been obtained from the University of Essex Ethics Committee.

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, Sadia, using the contact details below. If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, Susan McPherson (e-mail smcpher@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (e-mail sarahm@essex.ac.uk). Please include the ERAMS reference which can be found at the foot of this page.

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Appendix C: Recruitment Advertisement

University of Essex

INVITATION TO TAKE PART IN RESEARCH

Are you a South Asian parent or primary caregiver caring for a child aged 5-19 who is experiencing mental health difficulties?

If yes, you may be interested in taking part in this research study.

Who am I?

My name is Sadia. I am a Bangladeshi Trainee Clinical Psychologist interested in understanding the experiences of parents/caregivers of children who are struggling with their mental health. I am particularly interested in understanding your experiences of using aspects of your culture and/or religion when caring for your child.

We hope that sharing your experiences will help us understand how best to work with South Asian families regarding mental health.

Can I take part?

To take part you need to:

- **Bangladeshi, Pakistani, Indian, Sri Lankan, OR any other South Asian background**
- **Be a parent or primary caregiver**
- **Understand and speak English**
- **Care for a child aged 5-19 who is experiencing mental health difficulties**

What do I have to do?

Take part in a 60–90-minute interview.

You can choose if you would like to conduct the interview in-person or via video call.

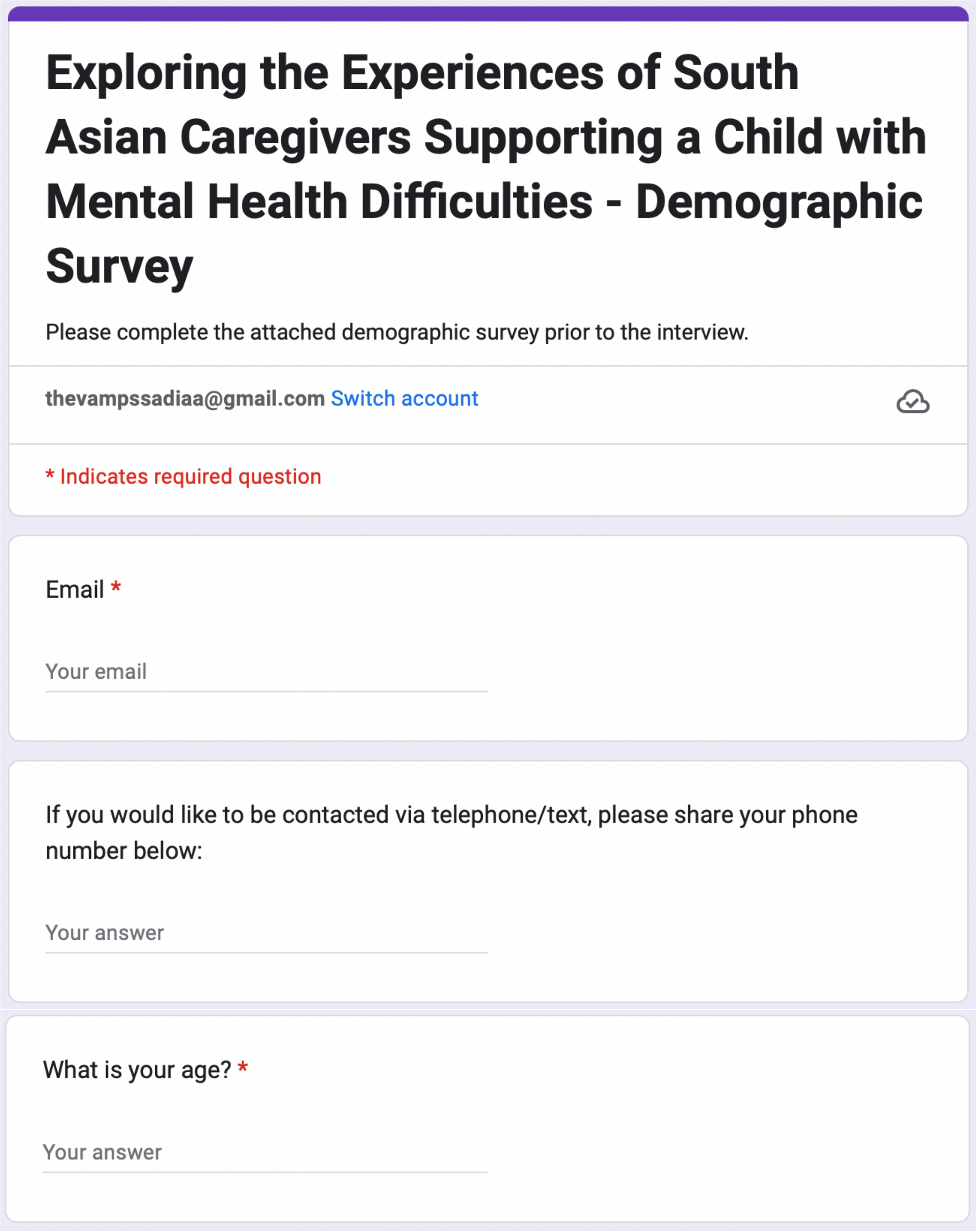
If you are interested in taking part or would like to know more information, please contact the Main Researcher using the contact details are below.

This study has received ethical approval from the University of Essex.
Code: ETH2122-1296

Main Researcher
Sadia Riya
sr21392@essex.ac.uk
07593971177

Please share this flyer with others who may be interested in taking part

Appendix D: Participant Demographics Form



Exploring the Experiences of South Asian Caregivers Supporting a Child with Mental Health Difficulties - Demographic Survey

Please complete the attached demographic survey prior to the interview.

thevampssadiaa@gmail.com Switch account

* Indicates required question

Email *

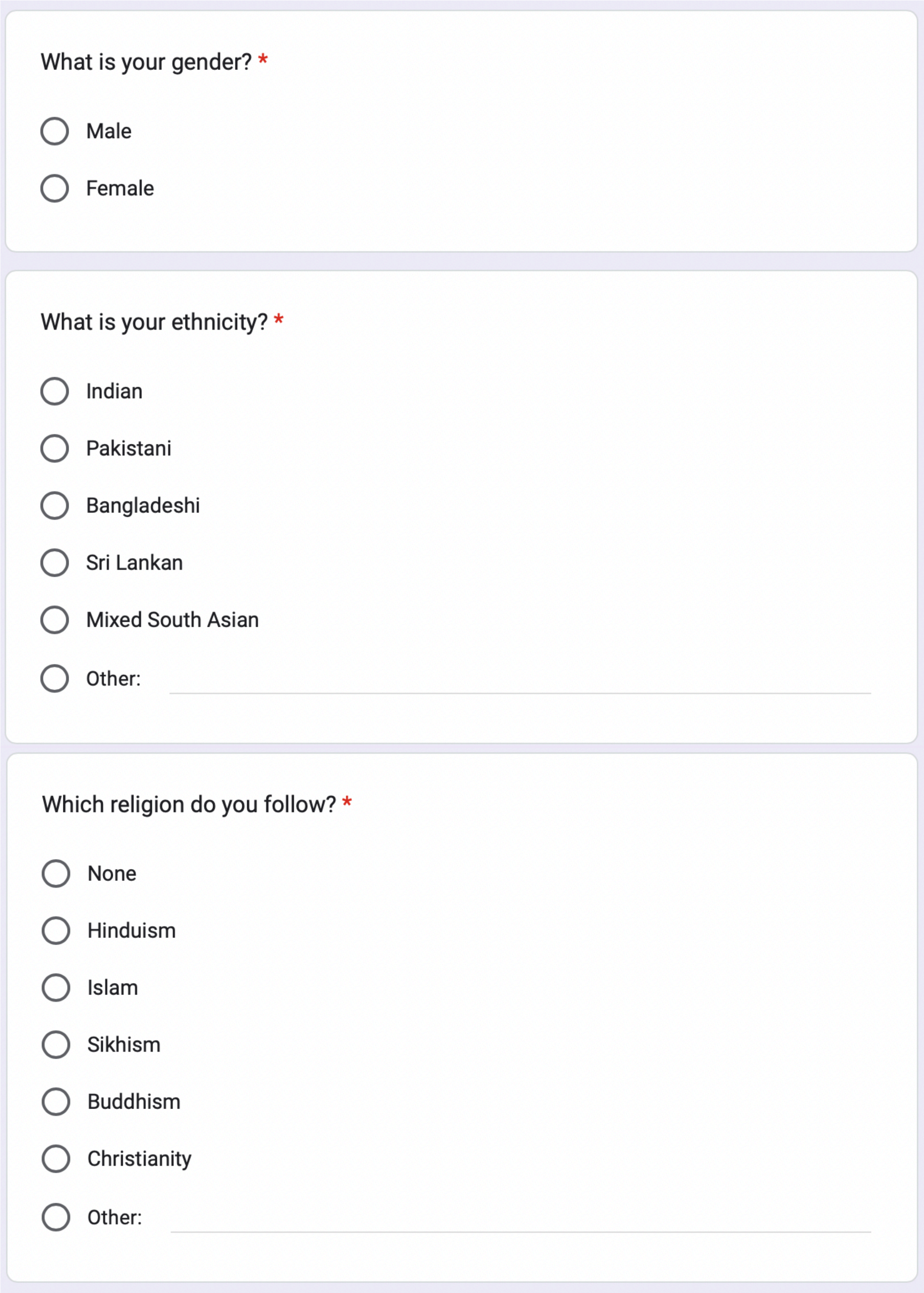
Your email

If you would like to be contacted via telephone/text, please share your phone number below:

Your answer

What is your age? *

Your answer



What is your gender? *

○ Male

○ Female

What is your ethnicity? *

○ Indian

○ Pakistani

○ Bangladeshi

○ Sri Lankan

○ Mixed South Asian

○ Other: ____________________

Which religion do you follow? *

○ None

○ Hinduism

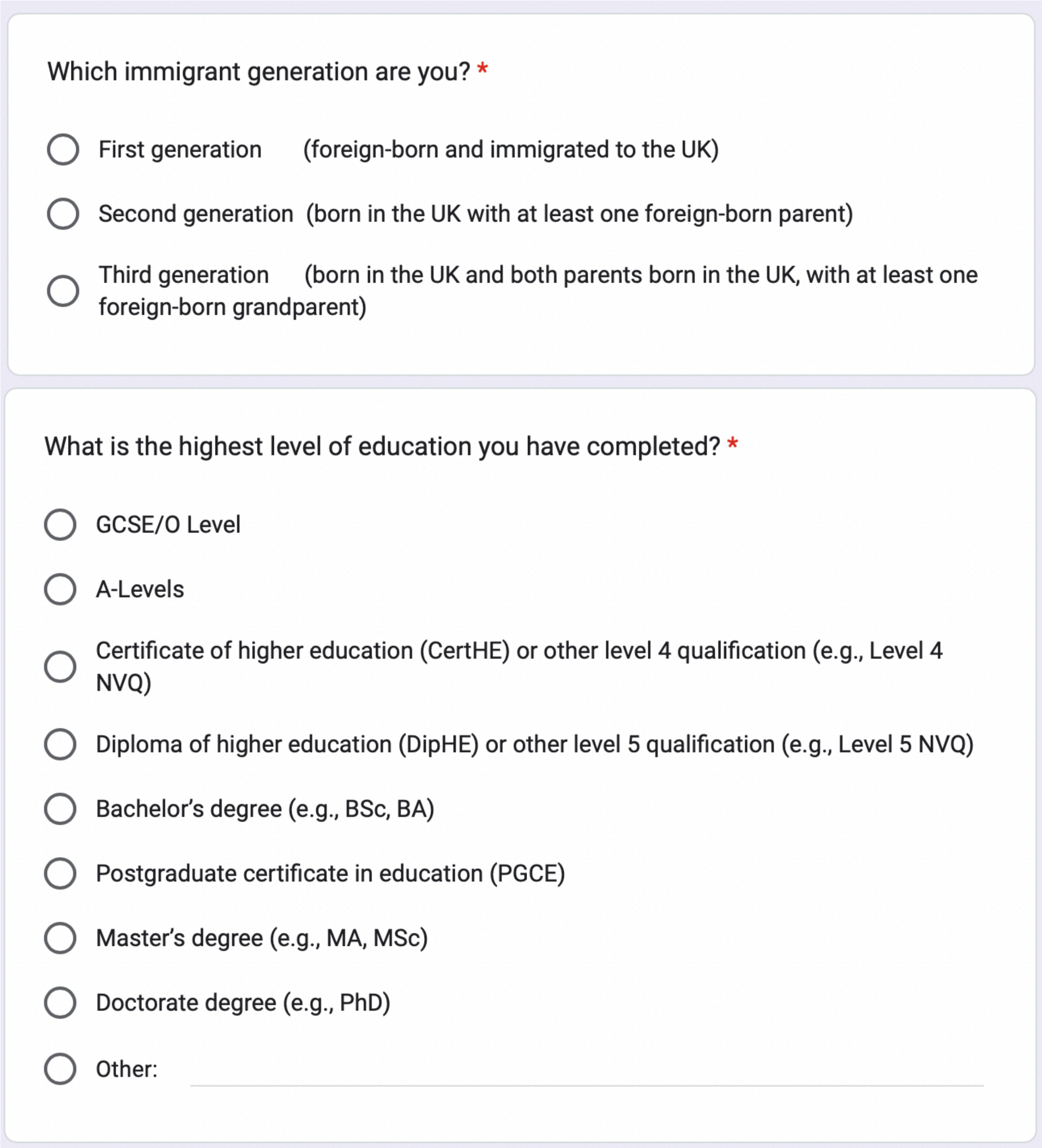
○ Islam

○ Sikhism

○ Buddhism

○ Christianity

○ Other: ____________________



Which immigrant generation are you? *

○ First generation (foreign-born and immigrated to the UK)

○ Second generation (born in the UK with at least one foreign-born parent)

○ Third generation (born in the UK and both parents born in the UK, with at least one foreign-born grandparent)

What is the highest level of education you have completed? *

○ GCSE/O Level

○ A-Levels

○ Certificate of higher education (CertHE) or other level 4 qualification (e.g., Level 4 NVQ)

○ Diploma of higher education (DipHE) or other level 5 qualification (e.g., Level 5 NVQ)

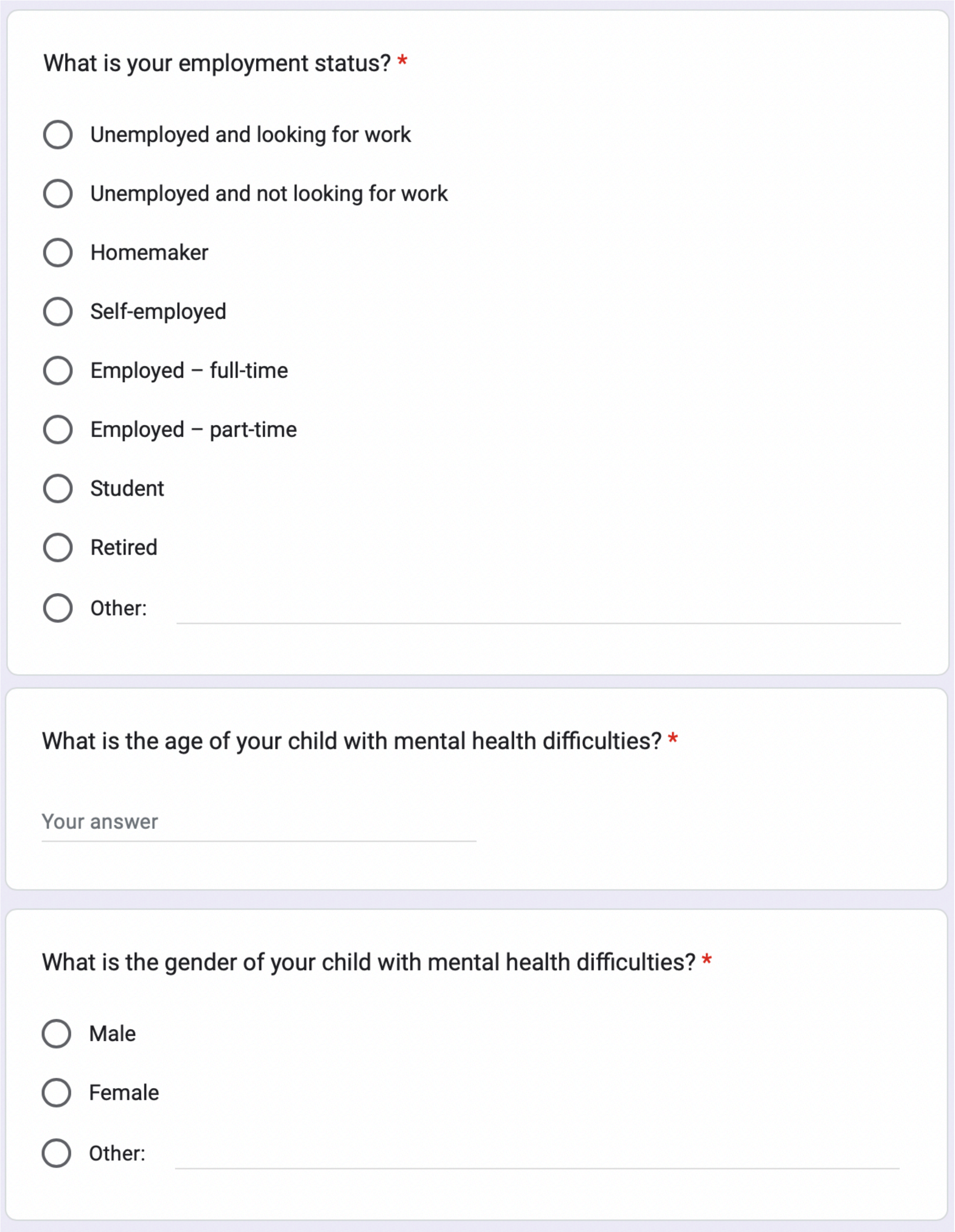
○ Bachelor's degree (e.g., BSc, BA)

○ Postgraduate certificate in education (PGCE)

○ Master's degree (e.g., MA, MSc)

○ Doctorate degree (e.g., PhD)

○ Other: ____________________



What is your employment status? *

○ Unemployed and looking for work

○ Unemployed and not looking for work

○ Homemaker

○ Self-employed

○ Employed – full-time

○ Employed – part-time

○ Student

○ Retired

○ Other: ____________________

What is the age of your child with mental health difficulties? *

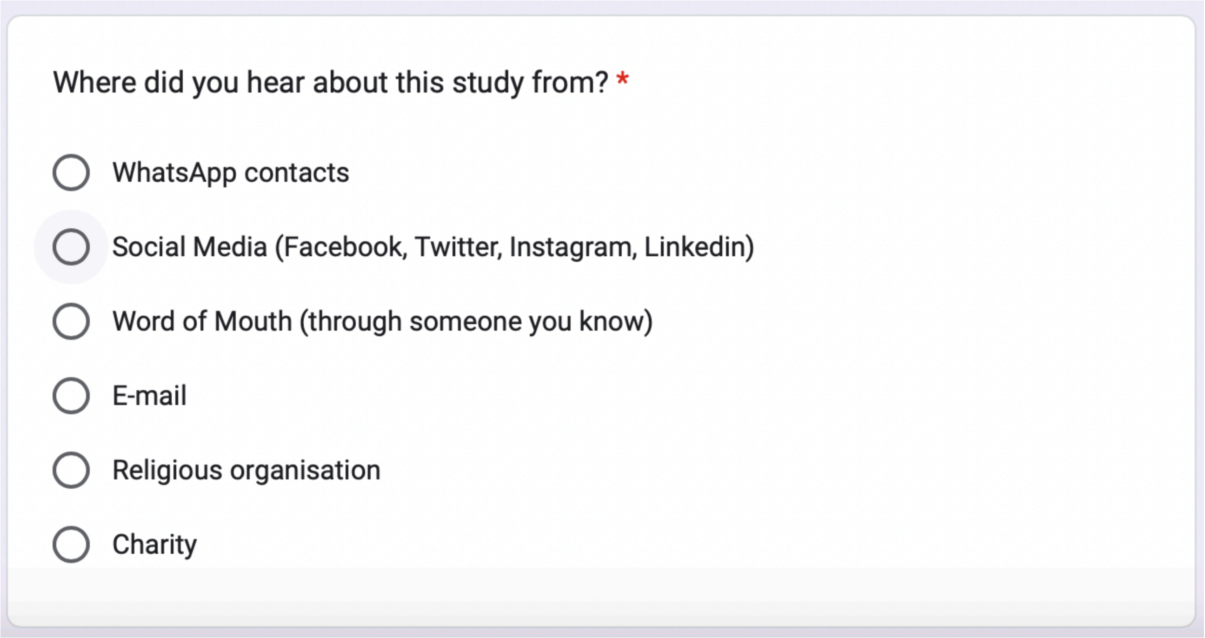
Your answer ____________________

What is the gender of your child with mental health difficulties? *

○ Male

○ Female

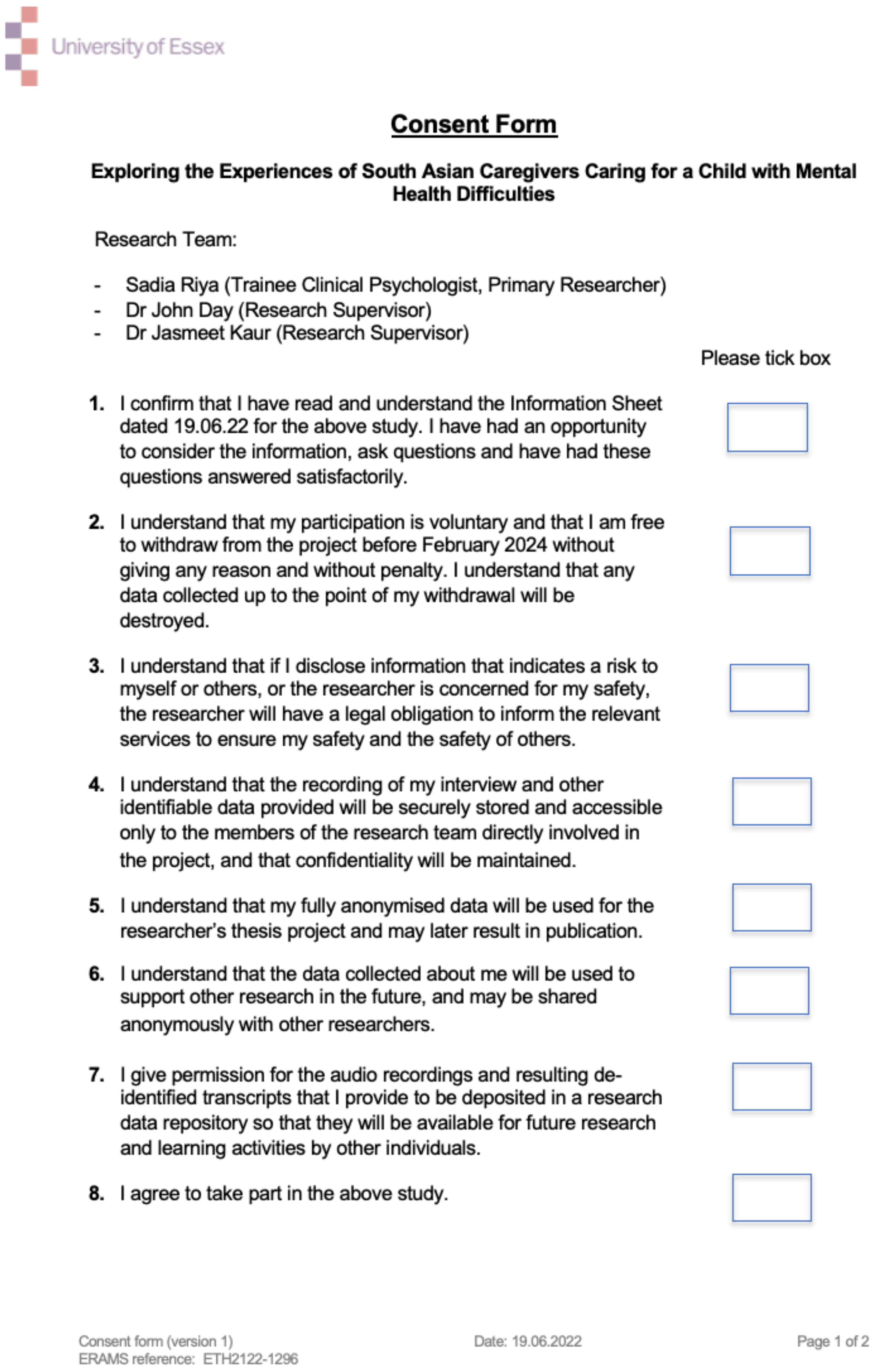
○ Other: ____________________



Where did you hear about this study from? *

○ WhatsApp contacts
○ Social Media (Facebook, Twitter, Instagram, Linkedin)
○ Word of Mouth (through someone you know)
○ E-mail
○ Religious organisation
○ Charity

Appendix E: Participant Consent Form



University of Essex

Consent Form

Exploring the Experiences of South Asian Caregivers Caring for a Child with Mental Health Difficulties

Research Team:

- Sadia Riya (Trainee Clinical Psychologist, Primary Researcher)
- Dr John Day (Research Supervisor)
- Dr Jasmeet Kaur (Research Supervisor)

Please tick box

1. I confirm that I have read and understand the Information Sheet dated 19.06.22 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the project before February 2024 without giving any reason and without penalty. I understand that any data collected up to the point of my withdrawal will be destroyed. ☐

3. I understand that if I disclose information that indicates a risk to myself or others, or the researcher is concerned for my safety, the researcher will have a legal obligation to inform the relevant services to ensure my safety and the safety of others. ☐

4. I understand that the recording of my interview and other identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐

5. I understand that my fully anonymised data will be used for the researcher's thesis project and may later result in publication. ☐

6. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I give permission for the audio recordings and resulting de-identified transcripts that I provide to be deposited in a research data repository so that they will be available for future research and learning activities by other individuals. ☐

8. I agree to take part in the above study. ☐

ERAMS reference: ETH2122-1296

University of Essex

Participant Name	Date	Participant Signature
__________________________	___________	__________________________
Researcher Name	Date	Researcher Signature
__________________________	___________	__________________________

Appendix F: Interview Schedule

Interview Schedule

Introductory questions

1. What motivated you to participate in this research?

Questions about Understanding Mental Health

2. Can you tell me what mental health means to you?
    - Has your culture influenced how you view mental health?
    - How does this fit with your religious beliefs? (If applicable)

Questions about supporting Child's Mental Health

3. Can you tell me about your child's mental health?
    - Could you describe a situation where your child struggled with their mental health?
    - What do you make of their difficulties?
    - How do you feel the current societal context e.g. Racism and Islamophobia influence their difficulties?
4. How do you support your child with their mental health?
    - What knowledge, if any, do you take from your culture that influences the way you support your child?
    - What knowledge, if any, do you take from your religion/religious scriptures to help you support your child?
    - Does your social circle/community influence how you support your child? If so, how?

Questions about Impact on Parents

5. What is it like for you to support your child’s mental health?
    - Could you please describe any challenges you face when supporting your child’s wellbeing
    - Could you describe any positives you have taken away from supporting your child’s wellbeing
6. How is your own wellbeing in relation to supporting your child?
    - How do you try to manage/cope with this?
    - How does it impact the family?
7. Do you receive external/professional support for your child’s mental health?

    If yes:

    - Describe your experience of the support you have received
    - What are some of the challenges you have faced with accessing support?
    - How do you feel the current societal context e.g. Racism and Islamophobia influence these challenges?
    - What are some of the positives you have found with accessing support?

    If no:

    - What avenues are you aware of to receive support?
    - What barriers, if any, have you faced with reaching out for/accessing support?

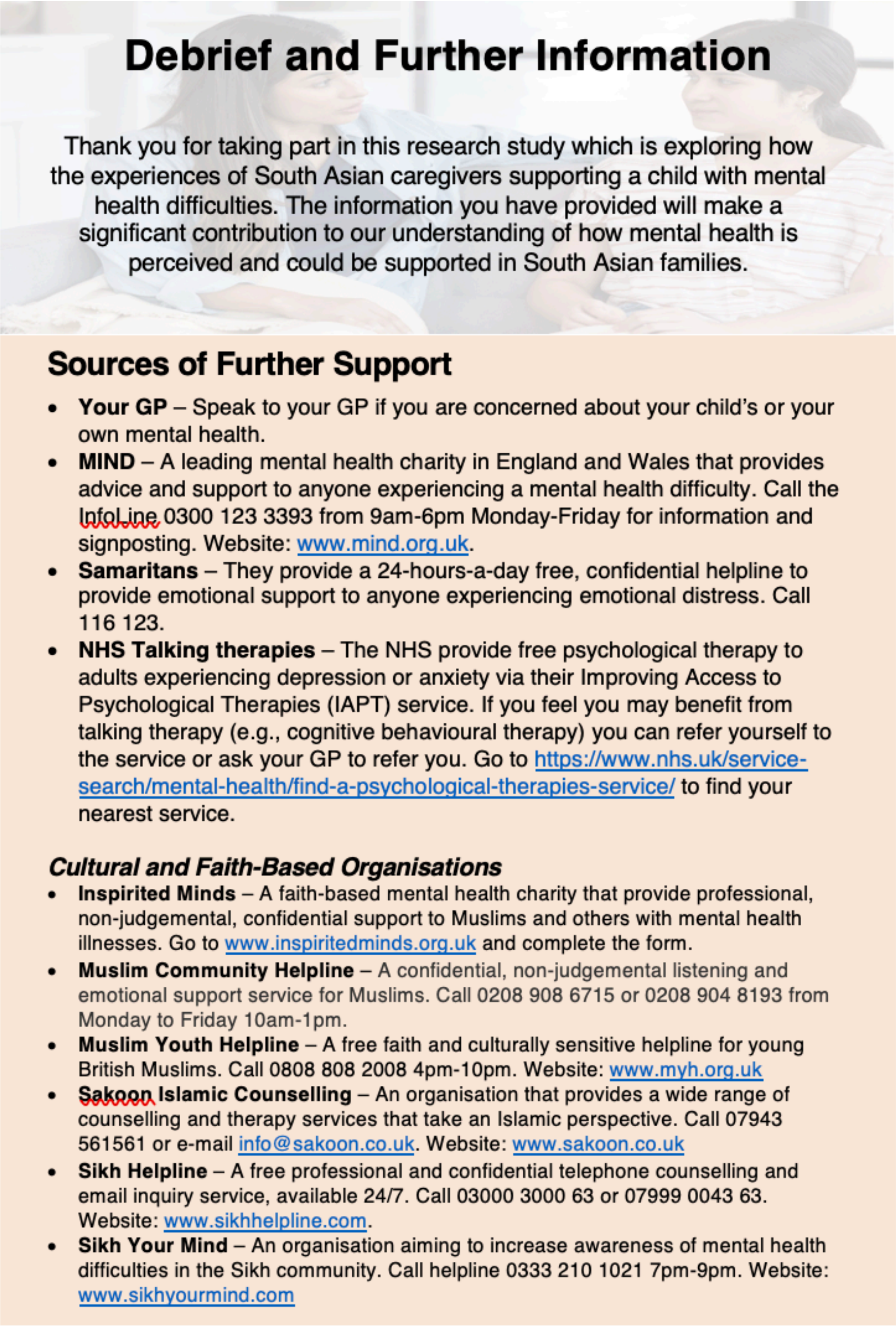
Ending questions

8. How has it felt participating in this research interview today?
9. Is there anything important you think we need to discuss that hasn’t been mentioned?
    - Did what we talk about meet your expectations?

General Prompts:

- Can you tell me more about that?
- Can you give me a specific example of that?
- How do you make sense of that?
- How did that make you feel?
- What did that mean for you?
- What did you think about that?

Appendix G: Debrief Information for Participants



Debrief and Further Information

Thank you for taking part in this research study which is exploring how the experiences of South Asian caregivers supporting a child with mental health difficulties. The information you have provided will make a significant contribution to our understanding of how mental health is perceived and could be supported in South Asian families.

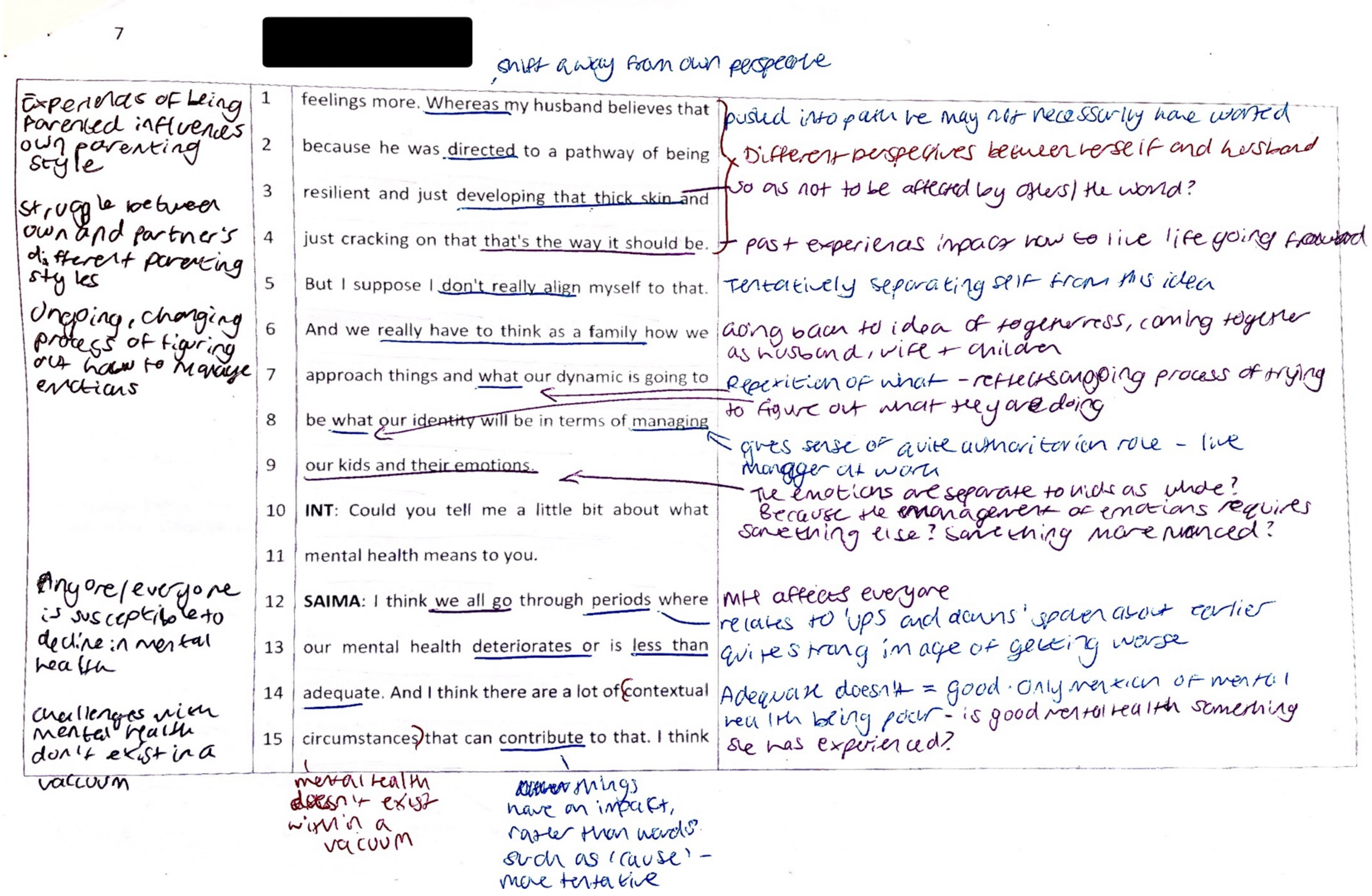
Sources of Further Support

- **Your GP** – Speak to your GP if you are concerned about your child's or your own mental health.
- **MIND** – A leading mental health charity in England and Wales that provides advice and support to anyone experiencing a mental health difficulty. Call the InfoLine 0300 123 3393 from 9am-6pm Monday-Friday for information and signposting. Website: www.mind.org.uk.
- **Samaritans** – They provide a 24-hours-a-day free, confidential helpline to provide emotional support to anyone experiencing emotional distress. Call 116 123.
- **NHS Talking therapies** – The NHS provide free psychological therapy to adults experiencing depression or anxiety via their Improving Access to Psychological Therapies (IAPT) service. If you feel you may benefit from talking therapy (e.g., cognitive behavioural therapy) you can refer yourself to the service or ask your GP to refer you. Go to https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/ to find your nearest service.

Cultural and Faith-Based Organisations

- **Inspirited Minds** – A faith-based mental health charity that provide professional, non-judgemental, confidential support to Muslims and others with mental health illnesses. Go to www.inspiritedminds.org.uk and complete the form.
- **Muslim Community Helpline** – A confidential, non-judgemental listening and emotional support service for Muslims. Call 0208 908 6715 or 0208 904 8193 from Monday to Friday 10am-1pm.
- **Muslim Youth Helpline** – A free faith and culturally sensitive helpline for young British Muslims. Call 0808 808 2008 4pm-10pm. Website: www.myh.org.uk
- **Sakoon Islamic Counselling** – An organisation that provides a wide range of counselling and therapy services that take an Islamic perspective. Call 07943 561561 or e-mail info@sakoon.co.uk. Website: www.sakoon.co.uk
- **Sikh Helpline** – A free professional and confidential telephone counselling and email inquiry service, available 24/7. Call 03000 3000 63 or 07999 0043 63. Website: www.sikhhelpline.com.
- **Sikh Your Mind** – An organisation aiming to increase awareness of mental health difficulties in the Sikh community. Call helpline 0333 210 1021 7pm-9pm. Website: www.sikhyourmind.com

Appendix H: Example of Analysed Interview Transcript



7 [redacted]

shift away from own perspective

Experiences of being parented influences own parenting style	1	feelings more. Whereas my husband believes that	pushed into path he may not necessarily have wanted
	2	because he was directed to a pathway of being	Different perspectives between herself and husband
Struggle between own and partner's different parenting styles	3	resilient and just developing that thick skin and	so as not to be affected by others/ the world?
	4	just cracking on that that's the way it should be.	past experiences impacts how to live life going forward
	5	But I suppose I don't really align myself to that.	Tentatively separating self from this idea
Ongoing, changing process of figuring out how to manage emotions	6	And we really have to think as a family how we	going back to idea of togetherness, coming together as husband, wife + children
	7	approach things and what our dynamic is going to	Repetition of what – reflects ongoing process of trying to figure out what they are doing
	8	be what our identity will be in terms of managing	gives sense of quite authoritarian role – like manager at work
	9	our kids and their emotions.	The emotions are separate to kids as whole? Because the management of emotions requires something else? Something more nuanced?
	10	**INT**: Could you tell me a little bit about what	
	11	mental health means to you.	
Anyone/everyone is susceptible to decline in mental health	12	**SAIMA**: I think we all go through periods where	MH affects everyone
	13	our mental health deteriorates or is less than	relates to 'ups and downs' spoken about earlier quite strong image of getting worse
challenges with mental health don't exist in a vacuum	14	adequate. And I think there are a lot of contextual	Adequate doesn't = good. Only mention of mental health being poor – is good mental health something she has experienced?
	15	circumstances that can contribute to that. I think	

mental health doesn't exist within a vacuum

things have an impact, rather than words such as 'cause' – more tentative

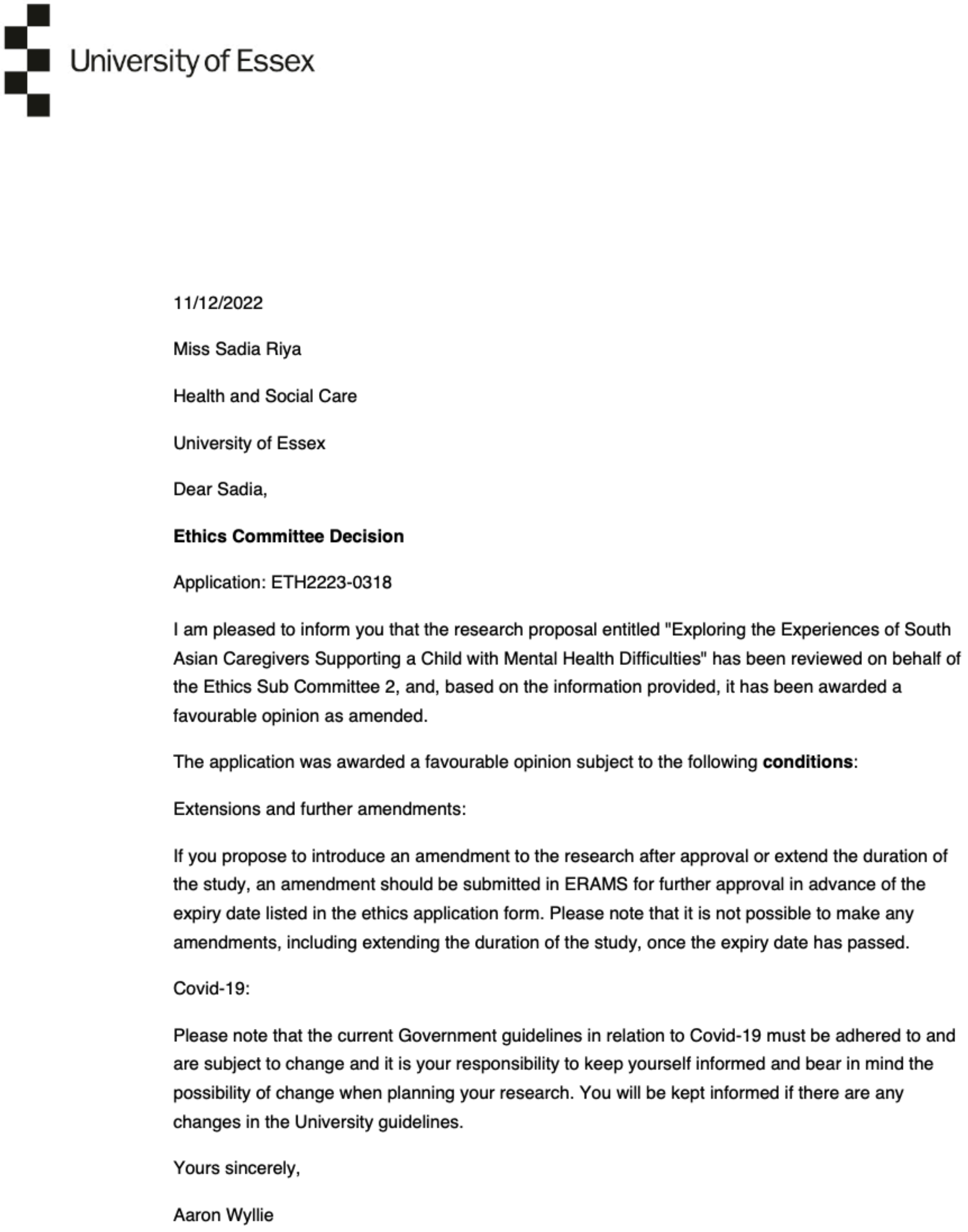
Key

🟥 Descriptive comments

🟦 Linguistic comments

🟪 Conceptual comments

Appendix I: Ethical Approval



University of Essex

11/12/2022

Miss Sadia Riya

Health and Social Care

University of Essex

Dear Sadia,

Ethics Committee Decision

Application: ETH2223-0318

I am pleased to inform you that the research proposal entitled "Exploring the Experiences of South Asian Caregivers Supporting a Child with Mental Health Difficulties" has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion as amended.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and further amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

Aaron Wyllie

Appendix J: Reflective Journal Excerpt

Reflective Journal Entry – Participant Interview 2 (08.04.2023)

I found, at times, [participant]'s lengthy narratives quite frustrating. In the moment I felt they were going off topic in their discussion and found it quite difficult to intervene and redirect the focus. However, I believe this urge of mine reflected a predefined sense of what I believed to be important and relevant. Being reflexive, I parked these preconceptions to the side and became open to truly hearing his narrative. Prompts revealed significant links between [participant]'s anecdotes and the experiences of caring for their child, which may have been missed if I had successfully redirected earlier in the interview.

I found myself surprised by the openness from the participant about some difficult past experiences. I wondered if this vulnerability from the participant was due to this interview space being one of the first spaces they have felt comfortable to share their story. From their narrative it appeared they had experienced frequent invalidation. If this was the case, I feel a sense of pride to have provided a safe space for the participant to be relieved from the pressure of having been silenced.

[Participant] shared some traumatic experiences that occurred throughout their life. At the time I felt quite overwhelmed with the heaviness of it all, experiencing a tightness in my chest and a coldness in my body. I felt a deep urge to respond compassionately, as I would in my psychologist role, but was stopped by the reminder of my position as a researcher. I felt I was still able to respond in a reassuring and validating way during the debrief, which felt essential for [participant] to feel valued.

Appendix K: List of Experiential Statements for Harpreet

1. Distancing self from the pathologising, hopeless societal understanding of mental health
2. Opening her eyes to the ubiquitous nature of mental health difficulties
3. Coping with the self-blame associated with making sense of the mental health difficulty
4. The visibility of mental health difficulties prevents ability to hide the reality of it
5. The barrage of judgment and wishing for more compassion from South Asian community
6. Experiencing dissonance between professional stance as a mental health professional and behaviours in personal life
7. Minimising child's mental health difficulty due to cultural stigma
8. Combatting cultural pressures around academic success that increase susceptibility to mental health difficulties
9. Living in a constant state of hyperawareness and worry
10. Doubting own methods and approaches to managing the mental health difficulty
11. Distracting child from distress acts as temporary solution
12. Internalisation of the South Asian community's attribution of blame in making sense of the mental health difficulty
13. Breaking away from the vicious cycle of cultural gender role norms
14. Splintering the pedestal fuelled by toxic masculinity upon which South Asian boys are placed
15. Riding the turbulent wave of guilt
16. The supportive nature of religion and the constant of God
17. Sitting with the static adverse influence of racism on child's feelings of safety
18. Battling with the cultural norm of silence
19. Using own experiences of being parented to inform own parenting behaviour
20. Trying to maintain a sense of calmness and joy amidst the chaos of South Asian culture
21. Meeting the child's needs for control
22. The complex nature of fear as a barrier to accessing traditional mental health services
23. Longing for a release from the cultural expectations of others to allow for an idealised life
24. The need for respite from the constant, exhausting role of caregiving
25. Feeling powerless in the struggle of challenging authority figures in South Asian culture
26. Developing child's sense of belonging
27. The restriction and barriers to support caused by fear of judgment from the South Asian community
28. The lack of cultural sensitivity in Western approaches to mental health
29. Shared identity and experience integral to building of trust and connection
30. Juggling the various responsibilities of a South Asian mother
31. Feeling isolated in the caregiving role and the desire for support
32. The damaging impact of different approaches to supporting child on her relationships
33. Prioritising child's needs and sacrificing her own desires
34. Looking past traditional mental health services to support self through own community resources

Appendix L: Personal Experiential Themes for Harpreet

PET 1: Breaking Away from the Chains of Cultural Norms and Responsibilities to do Best by Child

Experiential statements 8, 13, 14, 19, 23, 25, 30

PET 2: Battling with the Judgment and Stigma, Borne Out of the SA Community's Lack of Understanding of Mental Health

Experiential statements 5, 7, 12, 18, 27

PET 3: Coming to Terms with the Harsh Reality of MHD and Providing Order and Calm Within the Storm

Experiential statements 2, 4, 11, 17, 20, 21, 26, 29

PET 4: Relinquishing Own Needs and Finding Serenity Within Religion

Experiential statements 16, 24, 32, 33

PET 5: Riding the Turbulent Waves of Blame, Guilt, and Uncertainty

Experiential statements 3, 6, 9, 10, 15

PET 6: Avoiding a Culturally-insensitive System of Support and Finding Comfort Closer to Home

Experiential statements 1, 22, 28, 31, 34