Adult Autism in the Sylheti Family:

A Qualitative Exploration of Sibling and Parent Experiences over Time

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Abstract

This thesis reports on a practitioner research project examining the experiences of Bengali, specifically Sylheti, families living in the UK who have an adult family member with autism spectrum disorder (ASD). While there is extensive research exploring the experiences of parents and siblings of children diagnosed with autism, there is a lack of research concerned with the experiences of South Asian families, and specifically, the experiences of Sylheti families with an adult autistic family member. The study reported in this thesis was qualitative and interview-based. Four families were involved, including the parents (three mothers, one father) and the siblings of the autistic adults (two brothers and three sisters), with sixteen interviews completed in total. A narrative-based interview methodology was used, and the interview accounts were analysed thematically. Six main themes were identified regarding the experience of living with an autistic family member over time. These related to accepting autism, family cultures and the role of culture in the family, sibling identity and relationships, the experience of different forms of adversity, the emotional reality of life with an autistic family member and navigating external support. This thesis contributes to the broader professional field in helping to deepen understanding of the experiences of Sylheti families with autistic family members and how these families make sense of their experiences in a specific sociocultural context. This has practice and policy implications regarding how members of the Sylheti community can engage with local authority support for autistic persons and how the process of engagement with help can be articulated on their terms.

Keywords: adversity, autism, Bengali, caregiving, family resilience, intergenerational relationships, language, narrative, parenting, psychosocial research, qualitative research, religion, sibling relationships, stigma, Sylheti cultural identity

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Chapter 1: Introduction

Introduction

This thesis reports on research examining the experiences of Bengali, specifically Sylheti, families living in the UK who have an adult family member with autism spectrum disorder (ASD). While there is an extensive body of research which explores the experiences of parents of children diagnosed with autism (see, e.g., Legg *et al*., 2023), there is a lack of research concerned with the experiences of South Asian families living in the UK. Furthermore, very little has been documented about the experiences of Sylheti families with an adult family member with autism. The study reported in this thesis helps to address this gap. While the term ‘Bengali’ is typically used to describe people from Bangladesh, this study focuses specifically on Sylheti families — an Indo-Aryan ethno-cultural group from the Sylhet region of Bangladesh, who speak the Sylheti dialect and maintain distinct cultural practices. The choice to focus on Sylheti families reflects both the demographic concentration of this group in London and the absence of research that recognises their unique cultural and linguistic identity in autism care.

This qualitative and interview-based research involves a sample of four families and both the parents and siblings of autistic adults. The study is based on sixteen interviews, and an interview and analytic approach based on principles drawn from Hollway and Jefferson’s (2000, 2013) “Free Association Narrative Interview Method” (FANIM). Via an in-depth psychosocial exploration, the study focuses on family perceptions of autism and the place of autism in Sylheti culture. It does so by exploring family dynamics, relationships between siblings and the autistic family member, the language barrier, and extended family members’ perceptions of autism and its influence on the family, alongside other related matters of culture and religion.

Research background

Autism spectrum disorder is characterised by enduring difficulties in social communication and interaction, along with a pattern of restricted, repetitive behaviours and interests (American Psychiatric Association, 2013). While it is a lifelong condition, the specific presentation and level of impairment in functioning are recognised as varying considerably between individuals (ibid.).

A lack of understanding of autism remains a challenge amongst many Bengali and Sylheti families, meaning that children from this community may miss out on a diagnosis or receive a diagnosis later during their childhood or as an adult because family members do not recognise differences in their development that are attributable to autism (Perepa and Corbett, 2019). A recent literature review concerning Bangladesh located only six articles about autism which met predefined inclusion criteria for a meta-analysis (Hossain *et al.*, 2017). The authors of the review concluded that while the South Asia region represents over 20% of the global population, the prevalence of autism in the region remains largely unknown. There is also a challenge in helping parents from this community understand the nature of autism when there is no word to describe autism in the Sylheti language. It may be said that first-generation Sylheti parents can only go by their experience of raising an autistic child to learn and understand what autism means. There is also a lack of understanding of the Sylheti community through external services in culture, religion, and perception of autism where English is not the parent's first language.

The neglect of these families as a minority ethnic group by researchers, professionals, and service providers has been highlighted (Perepa and Corbett, 2019) and is echoed in the National Autistic Society's (2014) *Diverse Perspectives* report, which highlights the "limited evidence of the lived experiences of families from BAME communities in the UK who have been affected by autism", emphasising that the absence of such evidence further complicates the ability of autistic individuals within these communities to access the necessary support. The *Diverse Perspectives* report also references findings from the earlier *Make School Make Sense* research, which concluded that services were failing to address the cultural needs of individuals and there was limited awareness of rights and available services within specific communities. (National Autistic Society, 2007).

While some research exists that addresses the experiences of parents of adult family members recently diagnosed with autism in adulthood, as well as South Asian families' experiences of raising a child with autism (Legg *et al*., 2023; Raymond-Barker *et al*., 2016), enquiry in this area remains limited. Specifically, there is a scarcity of research that seeks to understand the lived experiences of South Asian families with autistic offspring, and the challenges faced by these families, particularly within culturally specific dynamics, remain under-explored. There is an emerging interest in this field as researchers increasingly recognise the need for culturally sensitive studies that address the unique contexts of South Asian families. Studies such as those by Habib *et al*. (2017) and Theara and Abbott (2015) highlight the significant challenges faced by South Asian families. Still, they typically focus on the experiences with children rather than adults. This focus on younger children leaves a considerable gap in understanding how South Asian families cope with having an adult family member with autism over time and across a lifespan. Recent studies, such as Legg *et al*. (2023), are beginning to address these gaps by examining the experiences of South Asian families and adults diagnosed later in life. The specific experiences of Sylheti families, though, remain unexplored. Understanding these families' journeys, particularly as they navigate the complexities of autism from childhood through adulthood, is crucial for developing effective support systems that are culturally responsive and comprehensive.

The Sylheti community in the UK

A brief account of the Sylheti community in the UK can provide some context to support the reader's understanding.

Bangladesh, located in Southern Asia and bordered by Indian states, has a predominantly Muslim population, comprising 91% of its citizens (CIA World Factbook, 2023). The capital city is Dhaka, and the native language is Bangla. Despite its history as one of the poorest countries in the world following its independence in December 1971, Bangladesh has emerged as the second-largest economy in South Asia after India (International Monetary Fund, 2023). Bangladesh's independence, previously known as East Pakistan, was hard-won after a nine-month war that brought significant sacrifices and extensive damage to an already struggling economy—this period of turmoil led to mass migration out of the country as people sought better opportunities elsewhere (Ahmed, 2022; Mir, 2020).

In 1962, the British government enacted the first Commonwealth Immigrants Act, which categorised migration through a voucher system into three groups: a) individuals with a specific job offer in Britain; b) those with special skills or qualifications for roles that could not be filled domestically, such as doctors and nurses for the National Health Service; and c) unskilled workers, with priority given to those who had served in the British forces during World War II (Alexander *et al*., 2009). Under the third category, individuals from Bangladesh were allowed to apply for visas to work in small factories, the textile industry, or other unskilled jobs in the UK. These migrants often sought to earn a living and support their families back home by sending remittances to Bangladesh. Subsequently, chain migration became prevalent, with existing migrants striving to bring over friends and relatives (Alexander *et al*., 2009). Through this process, individuals from Bangladesh, notably from Sylhet, established one of the largest immigrant communities in Britain. As the Sylheti community grew, small pockets of families started building their lives across the country. Most Sylheti families settled where extended family members lived and worked. In the 2021 Census, the Bangladeshi population in England and Wales was recorded as 644,881. London’s Bangladeshi population in 2021 was 322,054, with 34.6% of its population in Tower Hamlets, alongside Newham (15.9%), Redbridge (10.3%), Barking and Dagenham (10.2%) and Camden (6.8%).

The first generation of Sylheti families who migrated to Britain encountered significant challenges adapting to their new environment. These included acclimating to the colder climate, facing racism, overcoming language barriers, and navigating an unfamiliar education system. The challenges of navigating a new language and education system were particularly acute for the children of these immigrants, many of whom faced bullying and discrimination in schools, further complicating their integration into British society (Mir, 2020). Additionally, many families lived in poverty and endured overcrowded housing conditions. Fathers often shouldered the economic pressures of establishing a stable home while supporting extended family members who remained in Bangladesh. Despite these difficulties, Sylheti families began to see pockets of success within the community. Some first-generation migrants established and grew successful businesses, particularly in the restaurant and trade sectors (Gardner, 1995).

These enterprises often remained within the families, with sons inheriting and continuing the businesses, contributing to the community’s gradual economic advancement. The second-generation children of the Bangladeshi migrant community are often portrayed as aspiring to professional careers in fields such as medicine, engineering, information technology, management, teaching, and business (Karim, 2007). According to recent data, although there has been an increase in higher education attainment among British Bangladeshis, particularly among women, the community still faces considerable barriers in the labour market. As of 2024, a significant proportion of second-generation Bangladeshi men continue to be employed in low-skill sectors, with ongoing issues of underemployment and wage disparity compared to other ethnic groups (Office of National Statistic, 2023; Social Mobility Commission, 2022). Many Sylheti families in London boroughs live in social housing and come from low-income households, reflecting the community's ongoing socioeconomic challenges (Phillips, 2010).

The families involved in this research originate from the Sylhet region, northeast of Bengal, and speak the Sylheti dialect. Sylheti is an Indo-Aryan ethno-cultural group (Wang, 2012), and its culture is influenced by Hinduism, Sufism, and Turco-Persian ideas. This research adds to a broader understanding of not only first-generation parents who are immigrants who came to England but also second-generation siblings who are Western and understand Sylheti culture. This study seeks to help extend what is known about Sylheti families' lived experiences, raising and living with an autistic person. Anxieties about the future, the fear, and uncertainty surrounding what will happen when parents pass away, siblings' responsibilities, and support from extended family members are all essential factors that help shape Sylheti families' understanding of their situations. These are addressed as part of the research.

The study achieves this by examining the biographical experiences of both adult siblings and parents using an in-depth and narrative interview approach based on the principles of FANIM (Hollway and Jefferson, 2000, 2013). This method seeks to generate experience-based accounts which involve storytelling, thus allowing emotionally significant material to emerge as participants form associations with the questions asked (Archard, 2020; Archard and O'Reilly, 2022b, 2023).

The role of a practitioner or practice-near research project

The work reported in the thesis can also be aligned with the traditions of practitioner research, especially practice-near research, in education, health and social care and social work (Lunt and Shaw, 2017; Archard and O'Reilly, 2024). As acknowledged below, the ideas for the project developed from my own experience as an education professional, and I have sought to remain close to practice in completing the research, i.e., to take seriously the interface between the research and the act of helping the communities that education and social care professionals serve (Cooper, 2009). As a report of this type of practice-near practitioner research, this thesis does exhibit some variation from what might be considered a more conventional or "orthodox" academic writing style, specifically with a more active researcher voice being displayed, which aligns with how other practitioner researchers report their work (Lunt and Shaw, 2017).

Reflexive statement

This study originates in both my personal and professional experiences, each significantly shaping my interest in the subject over time. My journey into this research is rooted in a passion for being of service to others and a strong desire to help those in need. This commitment to service has driven me to explore the challenges faced by Sylheti families living with autism, as I have witnessed firsthand the struggles and resilience shown within these communities. My professional experiences further fuelled my determination to contribute meaningfully to this field, as I recognised the gap in understanding and support available to these families.

Professional experience

I have worked in education for over 15 years, holding various roles, including teaching positions in both secondary mainstream and specialist schools. My work in specialist schools for children initiated a keen interest in special educational needs, particularly in supporting children with social-emotional and behavioural difficulties. This interest led me to pursue a master’s course in Emotional Factors in Teaching and Learning, focusing on counselling.

During the third year of the course, I started the role of Head of Inclusion at a mainstream secondary school in South London. The student population was predominantly comprised of students from African and African Caribbean backgrounds, many of whom came from low-income households. In this role, I encountered challenges, including apparent parental reluctance to have their child assessed for special needs, notably autism, and the difficulties schools face in providing support without additional funding from the local authority.

After I completed my master’s degree, I started my current role in 2016 as a specialist teacher working for an inner London borough. In this role, I navigate a complex array of responsibilities across both primary and secondary schools, providing guidance and support that impacts the educational journey of students with special needs. In 2017, I trained to become a Special Needs Coordinator, earning the National Award in Special Education Needs Coordinator in line with the new 2014 Special Education Needs and Disability Code of Practice. This work involves collaborating with social workers, head teachers, and senior leaders to ensure students receive the best possible support. My work was underpinned by a postgraduate qualification in traumatology, which deepened my expertise in attachment and psychological trauma—areas that are central to my daily responsibilities.

I also oversaw complex admissions cases for the borough, managing the intricacies of individual cases that typically involved new arrivals with autism or students transitioning between schools or reintegrating after short stays at alternative provisions. While working on these cases, I often served as the first point of contact from the local authority, assessing children’s needs. A significant part of this assessment involved listening to parents, understanding their challenges and their grasp of the education and healthcare systems, and helping them make sense of their child’s needs, particularly in cases involving autism. This direct experience profoundly influenced my decision to pursue this research. It highlighted the importance of not just understanding autism from a clinical or educational perspective but also appreciating the experiences of parents, especially those with adult children on the autism spectrum, to give voice to their stories through my research.

I began the (Tavistock/University of Essex) Professional Doctorate in Advanced Practice and Research (Social Work and Social Care) part-time while in my role as a specialist teacher. Much of my work involved reflective practice and collaborating with families rather than direct teaching and the course played an integral part in my capacity to reflect on my professional practice whilst working on complex cases. My professional journey has provided me with extensive experience working with Sylheti families to complete Education Health Care Plans requests for various needs, particularly concerning autism and Early Help Assessment to identify and assess the needs of children and families who may benefit from additional support.

I have first-hand experience engaging with these families, listening to their challenges and daily difficulties in raising a child with autism, often complicated by language barriers and the gap between accessible support and support families feel they need. This experience inspired me to delve deeper into the challenges faced by Sylheti families with an autistic family member and how they coped with this adjustment to Western culture and their understanding of autism. My experience was that these experiences were overlooked or poorly understood by professionals, and I found there was insufficient representation of the Sylheti family’s experiences in the research literature and practice guidance related to autism.

Personal experience

Alongside this professional background, at a personal level, I am the daughter of a freedom fighter stationed as a platoon commander in the Bangladeshi army. My father fought for the independence of Bangladesh in 1971. He was one of ten men who came to Britain in 1981 as part of the Commonwealth Youth Ministry representing Bangladesh. My father continued to be heavily involved with the Bangladeshi community in England and published many books in Bangla. He also set up a charity organisation in 1998 in the heart of East London in Brick Lane, providing education and training for Sylheti men and women to access. From the 1990s onwards, my father also played a vital role in the Bangladeshi community, working closely with MPs across different London boroughs to create opportunities for the Sylheti community.

My mother was also centrally involved in this community in a less prominent but quietly influential way, providing day-to-day support on a voluntary and professional basis, especially to children and women, and supporting my father in his endeavours. For over 15 years, she worked in various helping roles, in teaching and learning support in primary schools, as an interpreter in maternity care, and volunteering for local charities. She also acted as an informal "social worker" for the Sylheti community, working out of the family living room in the evenings and helping community members with limited English literacy to fill out forms and applications whilst liaising with local government representatives.

Sylheti cultural influences were very much present in my childhood. Partly because of this, I wanted to research a subject that might help the community. I was also aware of the reported increase in diagnoses of autism in the Bangladeshi community in England – the majority of whom are from Sylhet. The London borough in which I grew up, Tower Hamlets, is densely populated with the Sylheti community.

According to the Tower Hamlets Local Authority SEND Sufficiency Review published in 2023, Tower Hamlets is 25% higher than national average for EHCPs in autism and Autism spectrum disorders assessment services (ASDAS) pathways. Pupils with SEN in Tower

Hamlets is 18.3% higher than national average of 17.3% in England. There is accessible support for children with autism and their families in Tower Hamlets, including services from the Parent Advice Centre, the SEND Information Advice and Support Service (SENDIASS), the Child and Adolescent Mental Health Service (CAMHS), and general support from the schools. All boroughs have "local offer" websites that provide links to services, charity organisations, and adult autism services specific to each borough. These services can be accessed by individuals aged 18 and over on a self-referral basis for assessments and relevant interventions. In Tower Hamlets, the local offer includes downloadable tools like worksheets and online video tutorials on employment and personal budgets. There are, however, no resources specifically tailored to the needs of Sylheti families, and only a limited number of charities provide direct support to these families.

In undertaking this research, I aimed to explore the experiences of Sylheti families with an autistic member to understand their broader needs. This included examining the accessibility of services and support for both families and the autistic adult, the cultural dimensions of experiencing autism within the family, and how first-generation parents comprehend, cope with, and support their autistic family members at different times in their lives.

Thesis structure

The thesis is divided into eight chapters. This first chapter has introduced the research study. The second chapter reviews relevant literature, contextualises the study in related research, and considers the virtues of a psychosocial theoretical framework to address the study question and aims. The third chapter details the study methodology and introduces the families involved in the research, and Chapters Four and Five report the study findings. Chapter Six considers the study's implications for policy, professional practice, and further research. Some reflections are also provided on the experience of undertaking the study and matters relating to research methodology. Chapter Seven concludes the thesis by providing some closing reflections on my experience undertaking the research.

Chapter 2: Literature Review

Introduction

This chapter contextualises the empirical research reported in this thesis within the existing literature. The chapter begins by considering definitions of autism, providing a brief historical account of how the condition is understood. This includes tracing shifts in conceptual understanding over time, as well as epidemiological data concerning autism prevalence within both the UK and the South Asian community. A brief review is then provided of research focusing on the experiences of parents and siblings in families with a member diagnosed with autism, including linked effects on social and emotional functioning. After this, the chapter examines prior research focusing on the experiences of South Asian families in the UK and their experiences with autism are considered. Lastly, a brief rationale for adopting a psychosocial perspective is that this study is put forward to capture the social and emotional complexity of experiences of living with autism in diverse familial and cultural contexts.

Literature search strategy

The literature reviewed in this chapter and used in the thesis was generally gathered via various means, but most notably through comprehensive searches of various academic databases and journals. Electronic resources ensured access to a wide range of peer-reviewed scholarly literature and the identification of relevant studies. The databases searched included PubMed, ProQuest, and Google Scholar. More granular searches of a group of interdisciplinary academic journals in the fields of education, health and psychology supplemented these searches of databases.

Understanding autism over time

According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (American Psychiatric Association, 2013), individuals with autism frequently experience challenges in communication and social interaction and often exhibit limited interests and repetitive behaviours, impacting their daily lives significantly.

This contemporary definition represents an evolved version of previous iterations of classifying the condition. Introduced by Swiss psychiatrist Bleuler in 1911, the term “autism” (from the Greek “autos”, as in “self”) was used to describe withdrawal into an inner world that others were unable to understand – a phenomenon Bleuler observed in individuals with schizophrenia (Nadesan, 2005). Bleuler’s understanding focused primarily on social withdrawal as a cardinal feature of autism. In 1943, Kanner expanded this by considering the presence of “infantile autism” in a particular group of children who exhibited restricted sociality, appeared to be fixated on material objects, and were resistant to changes in routine and environment (Baron-Cohen, 2015). Kanner’s work represented a significant advance in the understanding of autism in that it served to spotlight specific behavioural patterns and cognitive features associated with the condition. At around the same time, Bettelheim’s ideas regarding the psychogenesis of autism became particularly influential, attributing the condition in children to a cold, emotionally remote “refrigerator mother”. Although widely accepted at the time, this theory was later debunked by subsequent research and caused significant harm to families by placing undue blame on parents (van Rosmalen *et al.*, 2020). Indeed, both Kanner (1943) and Asperger (1944) developed views of autism as an innate inability to form reciprocal social relationships. This perspective laid the groundwork for later conceptualisations of autism as a neurodevelopmental condition (van Rosmalen *et al.*, 2020).

The 1980s were a period of significant advancements in understanding autism, notably with the idea of it being characterised by a “triad of impairments” (Wing and Gould, 1979), which identified difficulties in social interaction, communication, and restricted repetitive behaviours as characteristics of the condition. This conceptualisation was instrumental in shaping diagnostic criteria for autism and raising awareness of the varied presentations that could occur within the spectrum. 1980, the third edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1980) included a standalone diagnostic category for autism, marking its official recognition in psychiatric jargon. Subsequently, Asperger’s syndrome, characterised by challenges in social interaction and nonverbal communication along with restricted and repetitive behaviours and interests, was added to the fourth edition, further broadening the understanding of autism as a spectrum condition (American Psychiatric Association, 1994). Against this background, Wing and Gould’s (1979) work was particularly influential in increasing public awareness and acceptance of autism, highlighting the diversity of presentations within the autism spectrum and challenges associated with the condition, as well as the extent to which individuals with autism can lead fulfilling lives with appropriate support.

The last two decades have seen a shift towards understanding autism as a neurodevelopmental condition, with valid diagnostic tools and broader recognition in education, health and social care settings of the condition and spectrum of associated behaviours (Lord *et al*., 2018). This shift has been supported by extensive research into the genetic and neuropsychological underpinnings of autism and the development of more nuanced diagnostic criteria that capture wide variability in symptom presentation (Lord *et al*., 2020). Alongside these scientific advances, the neurodiversity movement has played an essential role in promoting wider acceptance of the autistic community, advocating for societal changes to better accommodate their needs and non-neurotypical ways of thinking and behaving.

Research into autism prevalence and epidemiological evidence has been conducted across various regions globally and nationally, providing insights into the prevalence of the condition and the variation across different populations. According to the National Autistic Society (2024), approximately one in 100 people in the UK are autistic, equating to over 700,000 individuals. Yet, this estimation belies an exponential growth in diagnoses of autism in the UK over the past three decades, as evidenced in Russell *et al*.'s (2021) comprehensive study using data from primary care settings. Russell *et al*. identified a 787% increase in autism diagnoses from 1998 to 2018, a rise attributed to enhanced identification, assessment and diagnostic practices rather than an actual increase in the prevalence of autism. This work develops from earlier research, highlighting how the condition can be reliably identified in school-aged children, as in Scott *et al*.'s (2002) analysis of the prevalence of autism among children aged 5–11 in schools in Cambridgeshire, finding that nearly 0.6% could be considered as being on the autism spectrum.

Beyond the UK, in South Asian contexts, there remains a need for more comprehensive data and robust epidemiological studies to understand the true prevalence of autism and the cultural and socioeconomic variation that may exist (Hossain *et al*., 2017). Systematic appraisal of available empirical evidence in South Asia indicates regional variation with, for example, estimates of prevalence rates ranging from 0.09% in India, 1.07% in Sri Lanka, and up to 3% in Bangladesh (Hossain *et al*., 2017). More recently, Akhter *et al*. (2018) conducted a cross-sectional study in rural Bangladesh, finding a prevalence of 0.75 per 1,000 children aged 18–36 months by way of the Modified Checklist for Autism in Toddlers screening tool (Robins *et al*., 2001), with confirmed diagnoses through health camps. The study found that while autism prevalence may be lower in some rural settings, likely due to underdiagnosis and lack of resources, the condition still significantly affected many children.

In this way, regional factors, such as the healthcare infrastructure, especially the availability of resources for specialist assessment, and cultural attitudes can play a crucial role in shaping how autism is identified and understood within communities and involved professional groups. For migrant communities in the UK, recognition of the condition and seeking support will be shaped by different “local” contexts, i.e., the community in which one resides and one’s “home” community/country of origin.

In addition to the UK and South Asia, research has highlighted the importance of considering geographical variation in prevalence rates globally. Zeidan *et al*. (2022), in their systematic review updating global prevalence rates of autism, found considerable variation across different countries. A systemic search of multiple databases was carried out by the authors, including PubMed, Embase and Web of Science, to help identify studies on autism prevalence published between 2012 and 2021. Studies using validated diagnostic tools and standardised criteria, as provisioned in the DSM and ICD systems were included, helping to ensure consistency across the data collected. Data was reviewed from over 150 studies across various geographical regions, looking at high-income as well as low to middle-income countries. The authors conducted meta-analyses to synthesise the prevalence rates and, assess the impact of cultural diagnostic, and healthcare factors on the reported prevalence. Their work underscores the significant variation in autism prevalence across different countries and highlights the critical need for culturally sensitive approaches in both diagnosis and care.

Experiences of families living with autism

Living with an autistic family member is recognised as having considerable impact on family relationships, siblings and parents, as well as parental mental and physical health. Parents need to adapt their parenting styles, develop new coping strategies, and manage heightened stress levels. Across a variety of family structures, the emotional and practical challenges faced by these families can be significant, requiring substantial resilience and support from a more comprehensive network (Zablotsky *et al*., 2012).

Research consistently shows that parents of autistic children are more likely to experience significant levels of stress and depression compared to parents of typically developing children, with a higher prevalence of active avoidance coping strategies, even among parents of high-functioning autistic children (Hayes and Watson, 2012; Lai *et al.*, 2015; Rao and Beidel, 2009). These parents often face poorer health outcomes and higher mortality rates due to severe conditions such as cancer and cardiovascular disease (Fairthorne *et al.*, 2015). There can be differences depending on parental role, and the interplay between various factors relating to family relationships, parental psychological functioning, and parental resources can significantly influence outcomes. For instance, research by Hastings *et al.* (2005), involving a cross-sectional design and self-report questionnaires from a sample of 120 parents (60 mothers and 60 fathers) of children with autism, indicates that mothers of autistic children tend to report higher levels of depression, but also more positive perceptions of their parenting role compared to fathers. High levels of parental psychological distress are also often associated with children displaying significant physical and communication challenges, further complicating the caregiving experience (Sloper and Turner, 1993). Parental coping strategies have been found to mediate and moderate the relationship between stress and quality of life among parents of children with autism (Dardas and Ahmad, 2013). In particular, the acceptance of responsibility has been identified as a key coping strategy mediating this relationship, while the seeking of social support and avoidance of escape are significant moderators.

The significance of wider environmental influences on families can also be considered. For example, qualitative evidence from interviews with parents about their experiences during the COVID-19 pandemic indicated that the pandemic exacerbated existing challenges for autistic children, particularly in relation to their experiences at school and with friendships during this period (Fox *et al.*, 2022). Fox *et al.*'s (2022) study employed semi-structured interviews to collect in-depth data from a diverse group of parents, allowing them to explore how the sudden shift to remote learning and social distancing measures impacted their children. The findings revealed that many autistic children struggled with the lack of routine and structure usually provided by in-person schooling, leading to increased anxiety and behavioural difficulties. Additionally, the disruption of social interactions contributed to feelings of isolation and hindered the development of peer relationships, further exacerbating the challenges these children faced.

For siblings, the presence of an autistic sibling is known to affect their psychosocial and emotional adjustment in various ways. Siblings of autistic children are often exposed to more significant challenges compared to siblings of neurotypical children, with research indicating they experience higher levels of internalising behaviour problems, depressive symptoms, and other psychological issues, as well as social difficulties (Lovell and Wetherell, 2016; Shivers *et al*., 2018). Lovell and Wetherell (2016) for example, conducted a study with a sample of 54 siblings of children with autism, using self-report questionnaires to assess psychological functioning, including measures of anxiety, depression, and social difficulties. The findings indicated that these siblings had higher levels of internalising problems compared to normative data. Similarly, Shivers *et al*. (2018) used a sample of 93 siblings, employing a combination of questionnaires and behavioural assessments to explore psychological and social outcomes. Their results supported the notion that siblings of children with autism are at greater risk for internalising behaviours and social challenges.

It has also been observed that having a sibling with autism can enhance the psychosocial and emotional development of typically developing siblings when demographic risk factors are limited. Macks and Reeve (2006) conducted a study involving 78 typically developing siblings of children with autism. They used a combination of parent and self-report questionnaires to measure psychosocial functioning and emotional development. The study found that in low-risk environments, these siblings often demonstrated greater empathy and emotional resilience.

As demographic risk factors—such as socioeconomic status, family stress, and limited access to support services—increase, the presence of a child with autism appears to have an increasingly unfavourable impact on these siblings’ development.

Experiences of South Asian families

Over the past decade and a half, a growing corpus of research has illuminated the experiences of South Asian families navigating the complexities of autism. These studies offer an in-depth and nuanced understanding of how cultural, social, and contextual factors interplay to shape these families’ journeys, both within and beyond the UK (Begum, 2023; Doig, 2012; Ehsan *et al*., 2018; Seach, 2021)

Hatton *et al*. (2003) conducted research in the UK, using in-depth interviews with 27 South Asian families to explore their support needs for children with severe disabilities, including autism. The study found that these families often struggled with balancing cultural expectations and the practical demands of caregiving, particularly when navigating healthcare and support services. The findings underscore the need for culturally sensitive support systems that can better accommodate the specific challenges faced by South Asian families.

Outside the UK, in urban Bangladesh, Ehsan *et al*. (2018) examined infrastructural and cultural challenges regarding care for the autistic community, focusing on the views of care professionals and parents. The study involved 46 participants (comprised of 18 parents and 28 care professionals) using a combination of interviews and focus group discussions. The findings highlighted the importance of attending to caregiver perspectives in planning care provision, noting a lack of reliable information regarding the condition, as well as other barriers impacting on the development of responsive care. These barriers include time constraints, issues with digital connectivity—especially for older generations—and pervasive stigma and stress associated with autism. The study underscores the need for culturally sensitive approaches to care that consider the specific challenges faced by South Asian families.

For a large-scale study, Jegatheesan *et al*. (2010) explored parental beliefs regarding autism in South Asian Muslim immigrant families living in the United States, revealing the significant influence of religious and cultural contexts on child-rearing practices. This study, which involved 17 months of fieldwork, including over 700 hours of participant observation in the home and community environments of three families, found that parents often view their children as a test or gift from Allah. This perspective frames their parenting roles as protectors and moral guides, leading them to take proactive actions to support their children's full inclusion in everyday life, both within and outside the home environment. The study spotlights how religious and cultural beliefs can shape parental responses to autism, highlighting the importance of considering these factors in both research and practice.

More in-depth studies of family experiences address a range of matters relating to parenting and family life (Begum, 2023; Doig, 2012; Seach, 2021). Begum (2023) explored the subjective experiences of Bangladeshi mothers using an exploratory design and narrative methodology. Although the study was based on the accounts of only five participants, the approach enabled the researchers to capture rich, detailed personal stories that highlighted several key themes. These included the emotional impact of living with and caring for an autistic child, the dynamics in relationships with extended family members, and the cultural identity of the participants.

One prominent theme in the findings was the profound sense of isolation felt by many of the mothers. This isolation was often compounded by cultural misunderstandings and a lack of support from extended family, particularly from the older generations, who sometimes held traditional beliefs that conflicted with modern understandings of autism. For instance, some participants reported that older family members viewed autism as a consequence of divine retribution, which not only added to the mothers' emotional strain but also hindered their ability to seek support and understanding within their family networks. The study also highlighted the resilience and adaptability of these mothers. Despite facing considerable challenges, many of the participants developed strong coping strategies and found ways to advocate for their children, both within their families and in broader social contexts.

Doig (2012) conducted an interview-based study in the United Kingdom involving nine Bangladeshi parents (two fathers and seven mothers) to explore their experiences with the assessment, diagnosis, and intervention processes related to autism. Using interpretative phenomenological analysis, the study revealed that parental intuition played a crucial role in early recognition of their children's difficulties, with many parents sensing something was different about their child well before a formal diagnosis. The study highlighted the emotional challenges parents faced in adjusting to their caregiving role after diagnosis, including feelings of grief, frustration, and helplessness. These emotions were often exacerbated by perceived inadequate support from healthcare services and the stigma associated with autism within their communities. Cultural beliefs and values were found to significantly influence how parents understood autism and developed coping strategies. For some, cultural and religious beliefs framed autism as a divine test, shaping their acceptance of the condition and their caregiving approach. The study emphasised the adaptive strategies these parents employed, often balancing traditional beliefs with modern medical understanding to navigate the complex demands of caregiving.

Seach (2021) conducted her research in the UK, where she used a nondirective narrative approach for in-depth interviews with eleven parents from nine families with different migration backgrounds to examine how families draw on multiple cultural influences in caring for an autistic child. Complementing this, Sabharwal (2022) explored the experiences of mothers in Indian and Bangladeshi intergenerational families, highlighting how cultural beliefs and intergenerational differences shape caregiving practices. Her study, though based in the US, revealed similar tensions between traditional caregiving expectations and modern approaches to autism, emphasising the role of extended family in either supporting or complicating the caregiving experience. A key theme was the role of personal idioms—unique ways of interpreting experiences—in shaping how parents understood their child's autism and their caregiving responsibilities. For some, these idioms were rooted in religious beliefs, framing caregiving as a spiritual duty, while for others, they were influenced by previous migration experiences, which had fostered resilience.

Further research such as that by Habib *et al*. (2017) and Theara and Abbott (2015), delves deeper into the experiences of South Asian parents with autistic children. Habib *et al*. (2017) explored the experiences of Pakistani mothers in Ireland, revealing that cultural expectations and a lack of extended family support significantly impacted their caregiving role. These mothers often felt isolated, both within their families, where autism was sometimes misunderstood or stigmatised, and in the broader community, where culturally sensitive resources were scarce. This isolation heightened their stress and made managing their child's condition more difficult.

Theara and Abbott (2015) focused on South Asian parents in the UK, identifying the tensions between cultural expectations and the realities of caring for an autistic child. The parents who took part often struggled to balance traditional caregiving roles with the demands of navigating a healthcare and educational system that did not always respect or accommodate their cultural beliefs, indeed could be experienced as alienating and unresponsive.

This work can be considered in relation to what is known about the experience of families with adult autistic family members. For example, Legg *et al*. (2023) conducted a mixed-methods study that combined quantitative surveys with qualitative interviews to examine the experiences of individuals with autism and their families. The study involved 150 participants, including both autistic individuals and their family members. The quantitative data, gathered through standardised questionnaires, revealed widespread difficulties in social inclusion, access to services, and mental health support. The qualitative interviews with a subset of 30 participants provided deeper insights into the personal struggles and perceptions of autistic individuals and their caregivers. The findings emphasised the need for more tailored support services that address the specific needs of the autistic community, as well as the importance of increasing societal awareness to reduce stigma and improve social integration.

Raymond-Barker *et al.* (2016) focused on the experiences of nine mothers whose adult children were undergoing assessments for autism spectrum disorder through a qualitative study employing semi-structured interviews. The research highlighted how these mothers experienced biographical disruption, as their life narratives were interrupted by the late autism assessments of their children. The findings included challenges in communication with healthcare professionals, emotional stress due to delays in diagnosis, and a general lack of support services. The mothers also reported feeling isolated and overwhelmed by these challenges, which intensified the difficulties of caring for an adult child with autism.

Taken together, the findings of these studies highlight the critical role of culture and contextual factors as they influence the experiences of South Asian families with autistic members. This includes the role of cultural and religious beliefs in shaping family perceptions and coping mechanisms in response to having an autistic family member. It also encompasses how these families are responded to in a wider community social stigma. Relationships with extended family are also highly significant, as something to be managed and navigated, but also in providing emotional support, practical assistance, and a sense of belonging, all of which contribute to resilience in response to the challenges of living with autism.

In terms of limitations, the generally small sample sizes in studies with South Asian families limits the generalisability of the findings and transferability to other settings. While there is some triangulation of sources, in-depth, semi-structured and narrative interview approaches rely on participant reports. These may not be focused on narrating experience directly relevant to the research objectives. Equally, though, where interviews are conducted in English, a non-native language for some participants, data quality may be compromised, as participants potentially may have struggled to express their experiences fully, leading to possible misinterpretation. In both focus groups and individual interviews, certain stories or accounts are more vulnerable to be overlooked, or not fully attended to. Focus group discussions may lack depth compared to individual interviews, and participants may feel less comfortable sharing sensitive information in a group setting. Parents and family members may also only provide certain information regarding their experiences in an interview for fear of judgement from the researcher.

Highlighting these limitations points to the value of future research that aims to include larger, more diverse samples to capture a broader range of experiences and perspectives. A greater range of qualitative methodologies and triangulation of data from multiple sources should be prioritised as part of this endeavour. Additionally, conducting interviews in participants' native languages should help enable accurate and rich data collection, ensuring participants feel comfortable and that their privacy is respected throughout the research process.

These issues notwithstanding, there is a risk of rehearsing more general debates regarding the merits and demerits of specific methods in qualitative research for studying cross-cultural phenomena, and qualitative research more generally (see, for example, Bhopal, 2001). Indeed, what the extant research does indicate is the value of qualitative methodologies in exploring, in-depth, how South Asian and, in particular, Sylheti families navigate the complexities of autism. While there is a need for more substantial research on their experiences, there are also areas which are underexplored, notably research on experiences with adults with autism within these communities and a life course perspective in relation to this. Adults with autism face ongoing challenges as they transition from the education system into adulthood, including issues related to employment, independent living, and social integration (Anderson *et al.*, 2018). These challenges are further amplified in culturally diverse families where adult children may remain more dependent on their families due to cultural expectations.

Virtues of a psychosocial approach

Qualitative research, with its focus on meaning and situated understanding, is a natural partner for forms of psychosocial understanding in social science. Broadly stated, a psychosocial approach focuses on the interplay between individual, inner experiences and social environments, i.e., seeking to transcend a dualism between the psychological and the social (Frost 2008, 2015). Whilst this can be conceptualised in a range of different ways, according to a researcher's discipline (see Redman, 2016), the idea has a lot in common with influential ideas regarding "person-in-environment" or "person-in situation", prevalent in developmental and educational psychology, and child welfare (see, for example, Walker, 2003). These frameworks emphasise the importance of considering the broader social context in which individuals operate, recognising that human behaviour is shaped not only by internal psychological processes but also by external social forces. It has also been described by Clarke (2006) as a "best of both worlds" attempt at combining aspects of psychodynamic psychology with social theory.

For the purposes of this study, a psychosocial lens and the use of principles from psychological and social theories affords a means for holistic understanding. This approach allows for the integration of personal and familial histories, experiences, individual and relational narratives (including unconscious conflicts and motivations), and family dynamics with a concern for meso- or macro-structures, i.e., prevailing discourses and social processes, the role of culture and religion, and the intersection of these elements. As Walker (2003) emphasises in his work on child mental health, applying psychosocial principles in community practice is crucial for addressing both the psychological and social dimensions of a child's mental health. This perspective is particularly relevant in understanding the complex dynamics within families with autistic children, where social contexts significantly influence mental health outcomes. There are questions about how concepts and practices derived from the clinical practice of psychoanalytic therapy can be utilised for research endeavours (see, for example, Archard, 2021; Archard and O'Reilly, 2023). The approach employed in this study is primarily concerned with conscious experience. A psychosocial approach was used to develop insights into the complex dynamics of relationships of families with autistic members, which, in turn, may be used to inform relationship-based forms of practice that are culturally sensitive and contextually appropriate (Cooper, 2009). By integrating psychological and social perspectives, the psychosocial approach offers a comprehensive framework for understanding the lived experiences of families with autistic members, providing valuable insights that might inform both research and practice.

Conclusion

This chapter sought to contextualise the empirical research reported in the thesis using available literature regarding other related research. After briefly addressing changing definitions of autism over time, and epidemiological data concerning autism prevalence within the UK and South Asian communities, findings from research focusing on the experiences of parents and siblings were outlined. This was followed by prior research focused on the experiences of South Asian families with autism being reviewed, with consideration of the multifaceted challenges they face, after which a brief rationale was made regarding the virtues of a psychosocial approach for this qualitative study to enable insight into the social and emotional complexity of experiences of living with autism. In covering these different areas, the need for research regarding the experiences of families with autistic family members with diverse backgrounds was reinforced, particularly migrant South Asian families residing in the UK. Chapter Three takes these concerns forward by detailing the methodology and research design adopted for this study.

Chapter 3: Methodology

Introduction

This chapter outlines the methodology and design of the research study, including the sampling strategy, interview approach, data analysis, and participant characteristics. It also addresses the related matters of research epistemology and ontology, researcher reflexivity and ethical considerations.

This study employed reflexive thematic analysis as outlined by Braun and Clarke (2022), which is well-suited for capturing the nuanced experiences of participants and the broader social contexts that shape these experiences. As previously noted, the study utilised an interview-based psychosocial methodology, incorporating ideas from psychoanalysis and informed by Hollway and Jefferson's (2000, 2013) FANIM (briefly introduced in the first chapter). FANIM offers several advantages as a method, drawing on techniques and understandings derived from psychoanalytic therapy (Archard, 2020, 2021; Archard and O'Reilly, 2023). However, it is important to reflect carefully on how the principles of this method translate to specific research contexts, such as conducting interviews in a second language and undertaking empirical enquiry with populations who may be less familiar with research and psychotherapy.

This chapter details how different methodological issues were navigated during the completion of the study. As in the thesis as a whole, I write in the first person to position myself in the arguments made. The material provided in the chapter is also supported by supplementary information provided in the Appendices (comprising the Institutional Ethical Review Form for the study (Appendix A), Participant Information Sheet in English (Appendix B) and Bengali (Appendix C), Participant Consent Form (Appendix D) and Interview Schedule (Appendix E).

Study sample and participant recruitment

A purposive sampling strategy was used. Purposive sampling is a non-probability method of sampling used with populations that can be directly accessed (Campbell *et al.*, 2020). This type of sampling strategy is often used when barriers exist to access a research population, as is the case with Sylheti families living in England, and where an enquiry aims not to build a reliably representative analysis but rather to provide in-depth insight into particular phenomena. Purposive sampling also tends to be used when the available resources for research are limited, as is the case for a study completed for a practitioner doctorate.

My intention was to interview individuals from four families, recruiting five families in total as contingency. Although I achieved this objective, doing so was not straightforward. First, there was a delay in recruiting families through services within the identified locality, specifically Parent Advice Centres and Adult Autism Services, via promotional materials (i.e. a flyer they could distribute and display). One of the challenges of recruiting families through these services is the general reluctance to participate and the lack of understanding of the research based solely on the material I made available (in English and Bengali versions). Staff in the services appeared to have limited time to support the research, despite my prompts and encouragement, and this may have hindered access to the families who considered participating.

A few weeks after sharing these flyers with the services, the study had attracted no interest, and I reflected that families accessing these services may have been circumspect about or unaware of the research. I therefore sought to identify suitable individual families through my own professional and personal contacts, including work colleagues and relationships in the wider community, in accord with the original study protocol.

Prior to the research, I had never met any of the families involved in the study, in a personal or a professional capacity. As such, although I was a stranger to these families, they were familiar with the person who introduced us, and this likely felt safer to them.

The process for contacting these families was as follows. Once I received the contact details for a family, I sent out participation information sheets – both Bengali and English versions. I then arranged telephone calls to introduce myself and explain the study further. This was challenging at times, especially having to speak with the parents in Sylheti and having to take the time to introduce myself and provide appropriate information about my background. I sought to put prospective participants at ease by finding cues of something we had in common - often the individual who introduced us – and this helped to break the ice and build familiarity.

After we had progressed through this "common ground" phase, I would introduce the research study. Care was taken with the use of the term autism in these initial conversations. Uncertain how family members, especially the parents, would respond, sometimes I would first say that I was interested in speaking about their son or daughter before using this term. On other occasions, I used the term earlier in the conversation and responded accordingly. Most of the time, usually after a short pause, the participant would speak comfortably. The first conversations with the parent participants could overall seem more awkward than those with sibling participants.

At times, with the parent participants, I felt discomfort when explaining the research and I took a short pause to hear them reply with a simple phrase to show that they acknowledged what I had said. I wondered how much I was being judged based on how I performed during the telephone conversation. Once any awkward silence ended, I would feel relieved that they were comfortable to continue with the telephone conversation.

In general, contact with prospective sibling participants was more straightforward. This appeared to be partly because I could communicate in English and because they were more familiar with the idea of research. From the first contact, most sibling participants I spoke to seemed enthusiastic about participating. The telephone call with these participants tended to be brief and involved me outlining the interview process.

This was the case for the sibling participants with whom I had direct contact, but it bears noting that all siblings within a family did not participate despite it being actively encouraged. In families, there were other siblings who declined to participate. During the initial telephone call, I enquired whether other siblings would be interested in taking part. The reasons given for an unwillingness to participate were the time commitment, absence from the family and lack of interest in the research.

Despite my best efforts, I could not secure interviews with the fathers from two of the families involved in the research. In the case of one family, the mother advised me that she was responsible for the daily care of her autistic daughter, as her husband worked outside London and was only at the family home for one weekend each month. Similarly, in the case of another family, the mother reported that her husband would potentially be offended and refuse to participate as he did not like to speak about his son's autism. Although I had an initial conversation with the mother from the fifth family (contingency family), she later declined to participate in the research as, she said, she felt taking part might lead to her becoming upset when talking about her son.

In total, nine individual participants were recruited to the study and 18 interviews were completed, comprising nine initial interviews and nine follow-up interviews, but only 16 interviews were used. The participants were drawn from five families, with three mothers, one father, three sisters and two brothers of autistic individuals represented. One family with the brother was interviewed twice as a contingency and not used as part of the study analysis due to no other family members being involved.

With respect to socioeconomic status, the families involved in the study could be considered working class, although distinctions may be made between the two generations represented in the sample (i.e. between parent and sibling participants). None of the mothers of the autistic adults who took part had undergone any formal schooling in Bangladesh or completed any education since coming to England. The one father had completed some schooling in Bangladesh and was able to communicate in English, but during the interview preferred to speak in Sylheti. By comparison, of the five sibling participants (aged 20–43), all had undergone formal schooling and, aside from one, completed university studies, with three possessing undergraduate degrees and one a postgraduate degree. Of the nine participants, two of the sibling participants did not live with the autistic family member. One parent participant was a widow and lived at home with her adult autistic son, who was in his mid-forties, and younger son, in his thirties, alongside his wife, and four young grandchildren. Another parent participant was a widower and lived at home with his eldest autistic son.

At the end of this chapter, "pen portraits" of the participants and participating families are provided. This accords with the way in studies are reported using a FANIM-informed approach (Hollway and Jefferson 2000, 2013).

Data collection

To gather data for the study, in-depth narrative interviews were used. The interview approach was developed using principles drawn from FANIM (Hollway and Jefferson 2000, 2013). This method seeks to prompt narrative accounts using open questions to prompt the participant to remember specific events and speak about their experience using storytelling (Hollway and Jefferson, 2008).

As an approach to the generation and analysis of data, FANIM had various advantages for the study. The type of more loosely structured interview protocol it involves can generate rich empirical material, enabling participants to have autonomy and to speak freely about their experiences in the order that suits them. In turn, FANIM supports the researcher in capturing the emotional meanings inherent to the complex responses of how the participant communicates.

With FANIM, the interview schedule (please see Appendix E) is flexible depending on what the participant speaks about; that is, the focus resides with following what they say (Hollway and Jefferson, 2008). The areas I sought to cover in interviews concerned: cultural experiences, the perceptions and experiences of extended family members, family responsibilities, plans for the future, and access to support from local authority. I also sought to encourage participants to speak about the emotional experience and lived reality of being a parent or sibling to an autistic person, including memories they had and their perspective on the impact this had on their lives.

While individual abilities for storytelling can vary considerably, using these prompts allowed participants to speak about specific memories, thoughts, or feelings from any point in their lives. Formulating questions and probing whilst listening to a participant was challenging at times as I had to listen and think simultaneously. For interviews in Sylheti, the focus on how to phrase a follow-up question or prompt was more demanding. I used probes depending on what the participant spoke about, reflecting back the phrasing they used or recalling things that were said. In completing the interviews, I became wary about using long silences and sometimes changed topic. Consequently, while silences in interviews are meaningful data and sometimes afford participants more control in the direction of the interview dialogue, they can have other functions (i.e. the silence being more about the interviewer's lack of understanding and or discomfort) and can create an unhelpful level of anxiety for the participant. On occasion, some of the parent participants would look sad when speaking and would pause, staring into space. As an interviewer, it is essential to navigate these moments with sensitivity, understanding that silence can be a powerful part of the narrative process. According to Roulston (2010), interviewers must be comfortable with the ambiguity of silence, recognising that it can signal a participant's deep reflection or emotional processing. In these moments, I sometimes found it challenging to discern whether they were engaged in silent self-reflection or awaiting a prompt or response from me. I believed it was important that the participant knew they were in control. As such, I would struggle to sit with this silence but refrain from asking a question to avoid losing valuable parts of the participants' narratives.

This often led to a significant discomfort for me. The silence could feel heavy and filled with unspoken emotions, making me anxious about missing cues or not providing enough support. I constantly battled with the urge to fill the silence with questions or reassurances, which could potentially disrupt the participant's thought process or narrative flow. This internal conflict was challenging, as I wanted to maintain a delicate balance between being empathetic and not intruding.

Reflecting on my questions during the interview added another layer of difficulty. I had to be mindful of how my probes might affect the participants, often refraining from asking certain questions to avoid causing unnecessary discomfort. This self-regulation was mentally taxing and required a high level of self-awareness and sensitivity to the participants' emotional states. These moments of discomfort underscored the complexities of conducting narrative interviews and highlighted the importance of creating a safe and supportive environment for participants to share their stories. The narrative interviewer needs to be comfortable dealing with complex and painful emotions (Long and Eagle, 2009). At times, though, I also found that it was challenging to reflect on my questions during the interview and I had to refrain from asking certain questions or probes to avoid creating unnecessary discomfort.

Another challenge when phrasing questions to parents was that there could be difficulties in explaining words such as “culture”, “anxiety” or “future”. I would first say the word in English and then explain the meaning in Sylheti. When prompting the participants, I attempted to use Hollway and Jefferson’s advice on how to ask questions. My first initial question was open-ended, allowing the participant to speak freely. I could sometimes stick to open-ended questions with the sibling participants partly because I could speak in English and confidently ask questions. At some points during the interviews, both with parents and siblings, I would become engrossed in their narratives and use a more structured interviewing style to help anchor their narratives in their experience.

Nine of the interviews conducted were at the families’ homes as this was convenient for the participants due to caring responsibilities for the autistic family member. Each participant was interviewed alone, usually in the lounge or living room, and I would ensure the autistic adult was not present or nearby. On most occasions, the autistic family member was either preoccupied in their room or outside the home, for example, out in the community with their carer. Interviews in person or online via video conferencing (Zoom) lasted between 45 minutes and an hour. Eight interviews were completed via video conferencing due to participant availability. The interview schedule was discussed with participants prior to the interview starting.

Both the initial and follow-up online interview were undertaken during the sibling participant’s working day (while they were on a break from their work) as, when they were at home, they shared a room with the autistic sibling. For one participant, the first interview and follow-up interview were both completed online in the late evening. This was after she had returned home after caring for her autistic brother, had completed housework and put her son to bed. Two online interviews were completed during the evening, with the participant sitting in their home office. All online interviews were conducted with just me and the participant alone in their respective rooms.

Data analysis

Data analysis involved several stages, and each of these stages involved sub-stages. The analytic approach was based on recommendations made by Hollway and Jefferson (2000, 2013) regarding FANIM, as well as Braun and Clarke’s (2022) framework for reflexive thematic analysis.

First, the interviews were transcribed as the data collection was ongoing. All the interviews were fully transcribed. For the parent interviews, I repeatedly listened to the audio recordings and then translated and transcribed the interviews from Sylheti to English. Transcribing and translating the interviews was a slow and time-consuming process as I would have to listen for a few seconds and then pause the audio to type. I would then rewind the audio to check if I had translated correctly. An ongoing challenge with this was the dialect of Sylheti spoken, which made it difficult to comprehend due to regional variations. To navigate dilemmas in translation and ascertain the intended meaning of words and phrasing used by participants, I consulted online sources and native Sylheti speakers. I also spent some time researching the Arabic spellings in English for certain religious phrases used, noting the definitions in brackets beside the Arabic word in the transcript.

The interview transcripts were also supplemented by field or “process” notes I kept after each interview. I recorded these after each interview, noting the overall atmosphere of the interview, my experience and anything that would not be picked up via the audio recording alone. I stored these notes alongside the other data.

Once all the interviews were transcribed, I read the transcripts and re-listened to the recordings multiple times. At this stage, I used Woodcock's (2016) approach to listening to the data four times from different perspectives: (1) the story and the researcher's reflexive responses; (2) how the participants speak about themselves; (3) how the participants place themselves within the social and relationship networks; and (4) dominant ideologies and power relations.

Using this approach, spending significant time with the interview recordings, notes, and transcriptions afforded me a deep familiarity with the data. My position as a Sylheti-speaking researcher was central to how I understood and interpreted the data. The ability to conduct interviews in Sylheti not only helped build trust but enabled participants to share emotionally complex and culturally situated narratives that might have remained inaccessible in English. This linguistic alignment allowed for the capture of subtleties in tone, emotion, and expression. I was also mindful of the power dynamics present in the interview setting, particularly the potential for participants to feel persuaded to participate, or to say more than they felt comfortable sharing due to cultural expectations around deference or familiarity, and how this may influence what was disclosed.

Following this process of familiarization with and immersion in the interview material, I coded all the interview transcripts using the MAXQDA 2022 (VERBI Software, 2021), coding tool on a line-by-line basis. While I had the option to code the sentence in vivo, I chose to highlight and use the keywords from individual statements to determine the appropriate code for the text. The process of coding and theme development was iterative and reflexive, consistent with the approach advocated by Braun and Clarke (2022). This method allows for flexibility in interpreting the data, accommodating the evolving understanding of the research context.

As I initially created four codes relating to cultural experience, family, religion, and fear/worry, I was familiar with how frequently these topics appeared during the interviews and while reading the transcripts. As I analysed the transcripts line by line, I developed additional codes through a reflexive engagement with the data such as “uncertainty”, participants seeming “unsure what to say”, memories of “happy moments”, and apparent feelings of “guilt”. Upon completing the coding process, I considered the relationships between the codes. For example, I grouped codes relating to “family” (for example, “family expectations” and “family support”) and began to map themes corresponding to the research questions.

Once these themes were constructed and refined through ongoing analysis, I revisited the subthemes, placing them within the relevant overarching themes. After categorising the themes, I analysed each one, noting that some quotes overlapped with multiple themes. This necessitated compressing and amalgamating the subthemes. Finally, I merged all the themes and the quotes from each of the participants into one document. This consolidation made it easier to access the quotes and themes for use in my findings.

I also used the “notes” feature in the MAXQDA tool, documenting observations, reflections on why I noticed certain aspects, and the robustness of my interpretations (Hollway and Jefferson, 2000). These notes were prompts to reflect on the interviews, helping me understand potential links to unspoken elements. Additionally, I used the field notes I recorded alongside the interview recordings and transcripts. These comprehensive notes allowed for a deeper analysis and interpretation of the data, ensuring a thorough understanding of participant experiences. As part of the analytic process, I developed pen portraits for each participant after the interviews were completed. These were not simply descriptive summaries but reflective tools that allowed me to hold onto the emotional tone, cultural nuance, and relational context embedded within each participant’s story. By writing these portraits, I was able to stay connected to the individuality of participants while identifying commonalities across the narratives. The pen portraits helped maintain a sense of the person within the thematic analysis process, preventing over-reliance on fragmented quotes alone.

Alongside the pen portraits, I kept a reflexive diary throughout the research process, which captured emotional reactions, reflections, and questions arising during and after interviews. These diary notes enabled me to notice patterns in my responses, areas of discomfort, and moments of emotional resonance, which in turn shaped my coding and theme development. Both the portraits and diary notes supported a more holistic and layered engagement with the data, contributing to a deeper interpretative process consistent with Woodcock's (2016) four-part listening model.

Epistemology and ontology

Epistemology is concerned with theories of knowledge (Ejnavarzala, 2019), specifically questions relating to what knowledge is, how knowledge claims are justified, and the nature of explanation, as well as subject-object relations and fact-value relations. Ontology is, by comparison, concerned with the nature of material, social, cultural, and political reality.

Hollway and Jefferson (2000) position their method in the philosophical tradition of critical realism – a tradition with which certain epistemological and ontological assumptions are associated. They also place an emphasis on the socially constructed nature of interview dialogue. Allied with this tradition, this research is based on a view that families who participated construct new understandings and knowledge through their experience of having an autistic family member, and they do so by integrating new information with what they already know. Each individual participant's experience is influenced by their personal feelings, perspectives, and values that shape how they experience themselves and others.

There is debate on the use of psychoanalytic ideas in research and Hollway and Jefferson's work regarding FANIM has been criticised for positioning the researcher as an "expert" regarding the meanings of what participants report, or do not say, in interviews (Archard, 2020, 2021). Although I have not undertaken formal clinical training in psychoanalytic therapy, prior to undertaking this research, I completed a master's degree which was heavily based on psychoanalytic perspectives. The knowledge I obtained with that training provided me with a foundation from which to use a psychoanalytic lens, alongside other ideas, to examine the research data.

Reflexivity

Broadly defined, researcher reflexivity denotes the part the researcher plays in the enquiry, the role of their identity and biography and how they shape the study (Creswell and Laughton, 2003). Throughout the research process, reflexivity is an essential part of the researcher's role, especially for considering the contribution they make to constructing meanings in the research. A reflexive researcher is not one who is detached from the subject of study during the research process (Nightingale and Cromby, 1999). The idea of reflexivity prompts the researcher to reflect on how their values, beliefs, experiences, interests, and political commitments have shaped the research, and linked to this, the notion of positionality represents a space in which objectivism and subjectivism meet (Bourke, 2014). Gair (2011) notes that the notion of insider/outsider status is understood to mean the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group.

In my professional experience working with Sylheti families with children with educational needs, I was already aware of the challenges accompanying parenting and living with these children and the associated cultural experiences. I approached this research as something of an insider researcher. I am also Sylheti and, so could relate to the parent and the sibling participants interviewed as we shared the same culture.

These commonalities of shared religion, culture and language notwithstanding, I still felt, in different ways, like an outsider looking in and listening to the participants' experiences. As Rose (1997) discusses, an outsider perspective often leads to a heightened awareness of boundaries between the researcher and participants, shaped by differing lived experiences and power dynamics. I am not a parent, nor do I have siblings or extended family members with autism; therefore, I was never directly impacted by autism in this way. My experience of being a daughter to first-generation Sylheti parents was also markedly different from the sibling participants I interviewed. While I grew up in a family that adhered to certain Sylheti cultural norms, there was no expectation for me to care for my siblings or other family members. This allowed me a greater degree of freedom compared to the caregiving responsibilities faced by many of my participants.

In this way, in this research, I occupied a dual position as both an insider and an outsider. Culturally, I share Sylheti's heritage with my participants, which may have helped foster a sense of trust and rapport during our conversations. This shared background could have encouraged participants to speak more openly about cultural expectations and family dynamics. As someone who has not experienced caregiving within my family, particularly in the context of autism, I was also an outsider to their lived experiences. This dual positionality may have shaped the way participants communicated their stories and the way I interpreted them.

Culturally, growing up with Sylheti norms and values instilled in me a strong awareness of family obligations, even though I personally did not have to navigate these expectations in the same way my participants did. This background likely sensitised me to themes around duty, responsibility, and the balance between individual freedom and family loyalty, which surfaced during the interviews. As a result, I was particularly attuned to how participants described negotiating these cultural pressures in their caregiving roles.

The use of field notes and research supervision

A valuable means of practising reflexivity in a psycho-social way is by using field notes (Hollway and Jefferson, 2000). As touched on above, after conducting interviews, particularly those at the family home, I would return to my car and self-record notes on how the interview went, capturing my thoughts, feelings, and any challenges encountered. For online interviews, I similarly recorded voice memos on my laptop.

Supervision meetings with my research supervisors also provided a crucial space for reflection on the research process and an opportunity to discuss the feelings and challenges I encountered. These sessions were essential for me, as they allowed me to better understand my emotions and gain clarity, effectively separating my feelings from those of the participants (Hollway and Jefferson, 2000, 2013). By acknowledging and processing my affective experience with the support of my supervisors, I was able to review my data with fresh eyes. This renewed perspective allowed me to engage more objectively with the participants' narratives, ensuring that my interpretations were not clouded by my own emotional responses. Understanding my emotions better also helped me to identify presuppositions I held, making it easier to approach the data analysis with a balanced and critical mindset. These reflective practices ultimately strengthened the rigour of my research, as I was able to maintain a clearer boundary between my own experiences and those of the participants.

Ethical considerations

Ethical approval for the research study was gained via the ethical review process of the study sponsor: The Tavistock and Portman NHS Foundation Trust Department of Education and Training (see Appendix A for Institutional Ethical Review Form).

Once families agreed to participate, written information sheets and consent forms were sent to them (ee Appendix B and Appendix C for the Participant Information Sheets (English and Bengali) and Appendix D for the Participant Consent Form). During the initial telephone contact, participants were given the opportunity to ask further questions and were all reminded that they could withdraw at any time and their involvement in the research was purely voluntary. Consent forms were signed and provided to me on the day of the interview, either in hard copy or via email attachment. By signing the consent form, participants gave consent to the interview being audio recorded, consent to original audio recordings being kept in separate locked filing cabinets, transcribed and saved as a password-protected document only accessible to me. They also provided consent to the anonymised transcripts being retained for between six to ten years, then destroyed.

During the initial telephone contact participants were told that the data collected during the study would be stored anonymously without any identifying information. All information gathered via audio recording during the time of the interview was stored in a secure place until transcribed. The participants were reassured that all transcribed data would be assigned a code for each participant for the purposes of anonymity. Only the researcher and supervisors had access to the transcribed material, and data was password-protected. Furthermore, in the reporting of the findings, pseudonyms have been used for participants and some information has been altered, as appropriate, to protect participants' identities. With this, I followed conventions that other researchers use to move beyond a simple "find and replace approach" of altering specific words in the transcripts, and rather considered the totality of the account, and the potential for participant identities to be deduced by others reading the research (Saunders *et al.*, 2015). Detail was needed for the in-depth analysis. However, care was taken to avoid the disclosure of information that could lead to the identification of participants by others. As such, removing some specific information or examples served as a "context sensitive" strategy to preserve participant anonymity whilst respecting the integrity of the data overall (Sanders *et al.*, 2015).

Participants were reminded that although the content of the interview was confidential, if they did disclose information which I deemed a concern or a safeguarding issue, I would discuss with my supervisors and refer to the appropriate services. I also had access to a list of free counselling services based in the borough the families were from. In none of the interviews was it necessary to share this information.

Given the sensitive nature of the research, informed consent was also treated as an ongoing process, revisited before and after interviews, and participants were consistently reminded of their right to withdraw or skip questions without consequence.

Pen portraits

This next section concludes the methodology chapter by introducing four families who were involved in the study and aspects of my observations when undertaking the interviews. Brief summaries are provided of the families, including the family structure, and living arrangements, as well as comment on relationships between family members and the autistic family member over time, socioeconomic circumstances, and the family relationship with Islam. In this way, the chapter provides an orientation for the reader to the themes presented as part of the two findings chapters (Chapters Four and Five) that follow. As noted earlier in this chapter, descriptions of the families have been anonymised by using pseudonyms and altering some identifying details.

There were clear commonalities amongst the families. Notably, the parents were highly aspirational for their children, working hard to provide opportunities, although these were embraced in variable ways. The families generally maintained close-knit relationships, albeit the degree of involvement differed both within and between the family members. For example, some sibling participants were much more actively engaged with their parents on a day-to-day basis than others. Additionally, all the families shared a strong reliance on religion and Islamic traditions. All the parent participants reported engaging in daily prayers, and each of the four sibling participants acknowledged the importance of religious faith within their families, even though their own lifestyles and daily routines did not always include such practices.

The Raza family

The Raza family is comprised of Sanjidah, the mother, and her seven adult children (two male and five female): Rani, Rupa, Tanim (the autistic adult), Sanja, Sultana, Salma, and Yusuf, aged between their early thirties and early fifties. Sanjidah and her youngest daughter, Salma participated in the study.

Sanjidah, in her early seventies, hailed from Bangladesh, but has lived in London for most of her life. I found her to be a devoted mother. She married in her adolescence before emigrating to England with her two eldest daughters and Tanim, her eldest son, who latency aged at the time. For the interviews, Sanjidah wore her traditional attire of saree and headscarf. She is slim and tall, and the years of care she’s provided seem to have etched worry lines onto her face – worries she spoke about during the interviews. Physical pain, in part due to the weight of responsibility in caring for Tanim, has, it appears, taken a significant toll on her.

As the youngest of the five daughters, Salma stands out in the family. In her thirties, and a university graduate, she works in finance. Unlike her mother and four elder sisters, she does not wear the hijab. She is tall like her mother, and during her interviews exuded energy and confidence, engaging openly about various aspects of her life, including challenges she has faced. Salma is a mother herself with a latency aged son. Living close to the family home where Tanim resides with his younger brother and his wife, and four nephews and nieces, Salma takes an active role in the family.

The family has faced considerable hardship in the loss of a father when Tanim was in his twenties, and challenges that resulted from this. Both Sanjidah and Salma had to mourn a husband and father while supporting Tanim, who has severe autism and epilepsy. Sanjidah, in particular, grappled with familial misunderstandings regarding Tanim’s autism, opting to keep her son at home to avoid judgements and labelling of him. Salma, on the other hand, faced challenges in the early loss of her father during her adolescence and combining responsibilities of motherhood and a career during early adulthood.

Despite the challenges, the Raza family remains close and supportive of each other. Sanjidah finds solace in her relationship with her daughters and appreciates the support her sons-in-laws provide in helping to care for Tanim. Salma forged strong bonds with her sisters and has taken on something of a caregiving role for both Tanim and Sanjidah. Islam and Sylheti culture are also integral aspects of the family’s everyday life. Sanjidah and her daughters observe daily prayers, and Tanim is in receipt of a bespoke care package provided via the local authority, which the family view as helpful and a recognition of his high level of need.

The most significant concern for the family is the future, and, specifically, how Tanim will be supported after Sanjidah is unable to care for him any longer. There is a consensus among the siblings to take turns caring for Tanim, but also a sense of sadness about this obligation. Salma has expressed her willingness to be his primary carer, seemingly taking ownership of the responsibility for the family.

The interviews with Sanjidah and Salma were contrasting experiences. Initiating the first interview with Sanjidah proved challenging. At the beginning, there was a prolonged silence, suggesting that she required time to make some sense of her experiences with Tanim's autism. Seated at the edge of a three-seat sofa, she did not directly face me, and her head turned intermittently during the conversation. There was a sense of hopelessness, which was particularly apparent when she spoke about her late husband, and I found myself worrying about causing her distress. It seemed that discussing her experiences was unfamiliar terrain; she had, until her husband's passing, prioritised maintaining family unity. Speaking about her own experience and desires was not something that was comfortable or acceptable to her. The pauses, coupled with Sanjidah's seemingly despondent gaze, also elicited discomfort in me and I wondered, at times, about the need to bring things to a close. Yet, she spoke at length and seemed motivated to give her account of her experience with Tanim.

By comparison, Salma's interviews were informative, and she appeared to use it as an opportunity to reflect on her experience, which provided insights into her experience and that of other family members. The phrase, "it was hard" punctuated her discourse, underscoring the challenges she has faced, with Tanim and in other parts of her life. Despite this, Salma was eloquent and seemed very confident, maintaining direct eye contact throughout the interview. It was hard not to feel admiration for the courage she has had in her life, as well as her frankness in discussing her personal circumstances and how choices she had made as a Muslim woman had been judged within the wider community.

The Alam family

The Alam family is comprised of father, Yunis, a widower and retired businessman in his early seventies, and his three sons, Ahmed, the eldest and in his mid-forties, who is autistic, Ali and Adam. Yunis and Ali participated in the interviews. Yunis, living with Ahmed, experiences daily struggles as Ahmed mourns for his mother. Carers provide support to Ahmed, which also appears to comfort Yunis in knowing Ahmed’s needs are attended to. Ali is much more involved with Yunis and Ahmed than Adam. Working in an academic position that allows him to work from home, he divides his time between his wife and two children and his father and brother. Ali’s wife also shares the responsibility of caring for her father-in-law and brother-in-law. Adam, by comparison, as the youngest son in his thirties, has moved away, living in the city, and seeing his family much more seldomly, seeming to create something of a disconnect within the family. The loss of a mother and wife was significant for all the family and appeared to have prompted Ali to rely increasingly on his Muslim faith and family.

Yunis and Ali are both quite formal in their dispositions, but personable in the way they related to me. When interviewed, Ali came across as confident and educated, speaking about a greater level of religious commitment and introspection following the loss of his mother. Yunis has limited mobility and uses a walking aid, and appeared to carry a weight of sadness in his eyes, as he reflected on the toll of caring for Ahmed amidst this loss. He prays five times a day at home. Conducting the interview with him required careful coordination to align with the presence of the carers at the family home.

My impression of Yunis was of a man who takes pride in his appearance (resembling my own father), with his neatly tucked-in shirt and smart trousers. Sitting in the conservatory with a view of the garden (while Ahmed was occupied by his carers upstairs), Yunis welcomed the conversation, and spoke of the journey he had taken following the loss of his wife and acknowledged the loss of faith he grappled with in accepting Ahmed’s autism. He reported that it took him several years to come to terms with the diagnosis, eventually finding peace and viewing it as Allah’s will. The weight of the conversation was palpable, especially when Yunis spoke about his late wife, and I found this emotional intensity to be considerable, having to look away at times, anxious, myself, about his well-being. I sensed that certain questions would be off limits, especially regarding how he felt about Ahmed’s autism, and I found I avoided these, with the fantasy in my own mind that our discussion might trigger distress that would have a detrimental impact on his health.

The Akhtar family

The Akhtar family is comprised of mother, Bina, father, Adnan, and their three children Hazera (in her twenties), Salim (an autistic adult slightly younger than Hazera) and Khalid (who is considerably younger). Bina and Hazera participated in the interviews.

Bina and Adnan migrated from Bangladesh with Hazera and Salim, when Salim was a young child. They faced considerable challenges in settling in England, with limited command of the English language and a lack of formal education. The family are of modest means, with Adnan working in service work.

Dressed in traditional salwar kameez and a headscarf, Bina’s demeanour is lively. She was playful when interviewed and giggled a lot. Yet, beneath this exterior joviality, more seemed to be at play. She spoke of the stress there was with supporting Salim when he was younger but noted that this has lessened as he has become more independent. Her account depicted a struggle: fighting against school bureaucracy and expressing regret that Salim’s autism diagnosis came late due to what she perceived as insufficient support from his school. She detailed how she took matters into her own hands to ensure he received the necessary support and continues to try to support him. For example, she encourages him to do basic shopping to foster independence.

Bina’s reflections highlighted the ongoing challenges and fears she faces, even as Salim’s independence grows. She described moments of feeling overwhelmed by the lack of resources and understanding from educational institutions. The late diagnosis of Salim’s autism added to her frustration and sense of battling a system that did not meet their needs. Despite these obstacles, Bina’s proactive approach has been crucial in navigating these difficulties and ensuring that Salim continues to develop life skills, illustrating her resilience and commitment to her son’s welfare. Her playful exterior during the interview contrasted sharply with the underlying narrative of struggle and perseverance, showing the complex layers of her experience as a mother supporting an autistic child.

Hazera, in her late twenties, also dressed modestly in a long dress and headscarf. When interviewed, she reflected on the importance of family support and a shared understanding of Salim’s needs. Hazera emphasised the difficulty of growing up amidst her parents’ arguments over Salim’s condition. Bina, despite sensing something was amiss, struggled to articulate it, an experience which, according to Hazera was compounded by their father, Adnan’s initial difficulty in accepting or acknowledging Salim’s condition.. She also spoke about the challenges Bina faced, particularly in managing Salim’s behaviour in front of extended family. Indeed, this pressure and feelings of inadequacy appeared to haunt Bina and were exacerbated by, what she described as, her husband’s differing perspective on Salim’s needs, which put a strain on the relationship.

Bina did, though, seem to be able to make use of this, eliciting support from members of the extended family and actively engaging in advocacy within her community. Following Salim’s diagnosis, Bina seemed to find a sense of purpose as a resource for other families facing similar challenges, including within her family, as a younger nephew was diagnosed with autism after Salim. A significant milestone for the family has been Salim obtaining a place at university. Despite ongoing challenges in communicating with others, Salim successfully integrated into university life, finding satisfaction in the work and participating in joint projects with other students – a point of pride for both Bina and Hazera.

For Bina, professionals involved with Salim during his time at secondary school played a vital role, particularly a psychologist who first identified autism but also guided Bina to access parenting classes specific to autism. Hazera expressed gratitude for the support that her husband and his family have provided for Salim, and ensures Salim has regular visits with them to spend time with her and her baby. This success and support notwithstanding, a sticking point was described as Adnan’s pressuring of Salim to seek and hold down paid employment, and tendency to uphold stereotypical expectations of what Salim should be and do, as a male.

Bina spoke of a strong connection to her Islamic faith and a gratitude towards Allah for what she has been given, including Salim, evident in her regular prayers. In particular, she said, her prayers focus on Salim’s welfare and future and hope that he finds a “good” wife who will take care of him. The worries about Salim’s future weigh on her mind, prompting her to seek divine intervention through her prayers.

Conducting the interviews with Bina and Hazera were straightforward and they were very accommodating of my involvement with them. Bina, in particular, appeared eager to share her experiences, which she related in a chronological order, detailing the extensive efforts she had undertaken to support her son. She related this without pauses, leading me to feel bewildered and, at times, frustrated as I navigated the rapid flow of information. I was struck by how there was a strong desire and urgency to be heard and convey the frustrations that had accumulated over the years in dealing with schools and colleges that fell short of meeting her son’s needs.

The Islam family

The Islam family is comprised of mother, Nahima, in her mid-fifties, father, Tarek, and sons Ali and Mohammad and daughters, Shahida and Sara – all of whom are in their early or mid-twenties. Sara is autistic. Nahima and Shahida took part in interviews.

Sara, who has also struggled with mental health since adolescence with a history of self-harm, stays at home with Nahima, who is a housewife with limited proficiency in English, no formal education, or work experience. Tarek works outside London and visits the family home once a month.

Shahida, the youngest sibling, is a full-time student and works part-time, aspiring to help her brothers buy a house for their mother. The family resides in a three-bedroom flat and works together to support Nahima. Nahima spoke about the challenges of running the household, especially shopping with Sara, and her gratitude for Ali driving her.

Nahima is petite, used the end of her saree to cover her head and spoke about the physical strain she has experienced caring for Sara, and the sleepless nights she has had filled with worries about Sara's future. Shahida has a discernible vitality about her but also appears sad about the lack of a connection she had hoped for with her sister, embracing her role as a support to her from a sense of duty and love. Despite residing in a densely populated area surrounded by other Sylheti families, the family is quite isolated, which Nahima seems to feel in caring for Sara. The daily pressure of ensuring Sara's safety and engaging her in activities is a struggle that is faced anew each day. This was described in terms of the challenge of coaxing her out of bed for essential tasks. Sara then spends much of her day in isolation, either in her room or gazing out of the window. Members of the extended family visit and acknowledge Sara's differences, but their understanding of autism is still limited. Her tendency to isolate herself is viewed by them as an indication that she is "mad" or unhappy. Religion is of paramount importance in the family, with Shahida and Nahima strictly observing the five daily prayers in Islam.

Nahima recounted challenges attending meetings for Sara, especially following occasions she has harmed herself. Limited local authority support, apart from transport for education, appeared to aggravate their difficulties. Tarek’s infrequent presence also appeared to create tension, with clashes arising when he visits. Nahima appeared, I thought, to feel accused of spoiling Sara, as Tarek was unwilling to acknowledge the diagnosis of autism (according to Nahima). Shahida must also balance managing her studies, part-time work, and caregiving duties alongside her mother. While Shahida understands that Sara may not marry and will likely remain with her mother, she grapples with concerns about what this might mean for Nahima’s health. The anticipation of additional support needed for Sara in the future is something she thinks about a lot, including contemplating the possibility of having Sara live with her, depending on her own marital circumstances and the support her future partner may offer.

Interviewing Nahima was a smooth process as we arranged to meet at her house. Sara was occupied in her room with Shahida, and Nahima’s friendliness shone through during our initial phone call, and I felt at ease in her presence. Sitting beside me, she extended a warm welcome, but, when we started talking, she occasionally became muddled, with pauses and lost trains of thought. When she spoke about the future and the challenges ahead, her emotions surfaced, leading to her becoming tearful. I found her to be quite graceful in the way she had managed the challenges she had faced. It was, all the same, clear that there were feelings of anger, frustration, and powerlessness in relation to Tarek and the lack of support he has provided. Nahima also shared the physical toll on her body, demonstrating wrapped feet due to swelling and complaining about pains within her body. I felt a sense of admiration for how resilient she seemed to be.

Interviewing Shahida was a gratifying experience. She was the youngest of all the participants and coordinating a suitable time for the interview proved challenging, requiring several attempts to set a date and time to visit with her at the family home. We availed of the opportunity to complete an interview when Sara and her mother were out shopping. Initially shy and uncertain, Shahida became more open and candid as she was interviewed. As with Nahima, I felt a sense of admiration as she spoke about the responsibilities she holds for her sister, something she seemed very dedicated to despite her relative youth. She also exhibited a mature understanding of culture, religion, and life, and presented as older than her age. I found myself reflecting on the differences between our lives, comparing my own experiences in my twenties with hers. I wondered how she felt deprived in not having an older sister she could rely on, and her gentle and polite tone evoked in me a strong desire to commend her for the seemingly selfless contributions she had made to her family and to find some way to shield her from any further sadness or pain.

Conclusion

This chapter set out the study methodology in advance of the presentation of the findings, addressing a range of matters in doing so. Some of these issues addressed will be returned to later in the thesis when comment is made on how this type of method might be used in similar research in future.

Via a series of pen portraits, the chapter also introduced the four families who were involved in the study, providing summative accounts of the participants and their families to orientate the reader in reading the themes presented as part of the two findings chapters that follow. It bears acknowledging that, due to the constraints of the research as an exploratory qualitative study, each family is represented by a single sibling due to logistical challenges in arranging interviews, a lack of desire from other family members to be involved in the research, and the inability or lack of capacity to allocate time to take part. It can also be acknowledged that fathers from two families expressed no interest in participating. The issue of participant recruitment for this type of research project is further commented on in the discussion chapter, following the two findings chapters.

Chapter 4: Findings I

Introduction

This chapter and the next chapter report the findings of the analysis undertaken for the study, detailing the themes that were identified through the analysis of the interview accounts. Throughout the two chapters, excerpts from the interview material are presented.

The overarching research question guiding the study concerned how Sylheti families experience the challenges through time of having an autistic adult family member, and, from the interview material, six overarching themes were identified. This chapter focuses on three of these themes. These themes are: *autism accepted – autism embraced*, which concerns how autism is acknowledged and embraced within the family; *family culture – culture in the family*, which concerns the role of culture within the family context, including how cultural factors influence perceptions and responses to autism; and *the sibling bond and sibling identity*, which is concerned with the nature of the sibling relationship and its impact on individual identities within the family. Each theme is comprised of between two and three subthemes (see Table 1).

Table 1: Initial themes and subthemes

Theme	***Subthemes***
Autism accepted – autism embraced	Accepting autism
	Representations of (understanding) autism
	Intuiting the issue/s
Family cultures – culture in the family	Family unity, responsibility and support networks
	Religion
	Espousals (re)considered
The sibling bond and the sibling identity	Sibling experiences in and outside the family
	Switching family roles

Autism accepted – autism embraced

Accepting autism

The narratives from all four parent participants illuminated unique paths to accepting having a child diagnosed with autism, and the development of means of coping and tolerating this fact. Yunis and Nahima both went through a process whereby they compared other children's "typical" development to their autistic child, gradually recognising differences in their child with autism. This process of comparison was represented as serving as a catalyst for acceptance over time, as they acknowledged and understood the uniqueness of their child's development better. This process seemed to mirror, in different ways, a process of grieving the loss of a hoped-for identity for the child, not unlike that described by Kubler-Ross (1969) regarding the physical death of loved ones, with denial and anger subsiding to acceptance. For Yunis for example:

> Before… I kept thinking he will get better or that things will change. But, by the time he was 10 years old, I had accepted it because I was seeing my other sons grow and the difference it had. It took time to accept what was wrong with him. (Yunis, Interview 1)

Yunis also described a process of spiritual reflection where he held onto hope, believing that Ahmed would improve or that circumstances would change. As he described it, this involved "hurt and pain" followed by "anger" towards Allah. It wasn't until Ahmed reached the age of 10 and Yunis witnessed the more minor milestones Ahmed met in his development, that he began to accept the reality of the situation.

Nahima, by comparison, spoke about the sense of sadness, as the difference between her daughter, Sara and her siblings became more apparent. "When I found out about her having this, I was sad. I looked at my other children and they were normal. None of them had any problems. They were fine" (Nahima, Interview 2). Nahima said she found she had no choice but to accept Sara’s autism out of a sense of maternal responsibility for her daughter, something which subsequently appeared to contribute to Nahima sacrificing her own needs to provide care to Sara, even when there was an impact on her own health. “I don’t know... All I know is that I have this daughter that needs a lot of help. She just can’t live like everyone else” (Nahima, Interview 1).

Bina, similarly, spoke about the painful feelings that accompanied the recognition that her son, Salim, was autistic, but how, eventually – over time, she was able to accept that their child was from Allah – a belief that she sought some solace in, in supporting Salim during his childhood and adolescence. Bina’s acceptance of Salim’s autism was shaped by her immediate family support, community attitudes, and cultural beliefs. She expressed concerns about the Sylheti community and the (lack of) acceptance of autism. However, what she said about this suggested that, paradoxically, this contributed to her being more supportive of Salim as an autistic person:

> Sometimes in our community if people know that child has this problem, they will treat them differently. But my point is outside people don’t need to know but family should so they can encourage the child more. Because he is supported by the family and he can improve. (Bina, Interview 1)

Salma, as a sibling, displayed resilience in her acceptance of her brother Tanim being autistic emphasising the need to adapt as a family to accommodate his needs. For Salma, what was important in this process was acknowledging the (painful) reality and adapting, as a family, to accommodate his needs.

> Or just been, it’s been, it’s been, I think you just get used to it, you adjust, you adapt to, you accept as well. I think it’s a big part of his acceptance of, accepting that this is my

> brother; this is how he is. This is what we have to deal with. This is, this is it. (Salma, Interview 1)

The other three sibling participants, Ali, Hazera, and Shahida, also spoke about a journey of intertwined adaption and acceptance in having a sibling with autism, which could occur at different times depending on when the diagnosis was formally made. The diagnosis of autism was represented as helping to prompt and promote a greater level of acceptance of the autistic family member as autistic with specific needs and behaviours that wouldn't be considered "normal" or "usual". Hazera said that her brother Salim was seen as "different" from when he was a teenager – something which created pressure for the family and mother, in particular, due to the perceptions of others.

> We didn't know my brother had autism when he was younger, so it was always this question of like when relatives will come round and be like, 'Oh what is wrong with him?'. My mum would always address his behaviour as she never wanted to look bad in front of people, so she did not want to show that she doesn't discipline him. At times she felt a lot of pressure having to explain herself a lot more. (Hazera, Interview 1)

Shahida, on the other hand, made more of a connection with the responsibility borne by her mother (which she didn't question as a child) and the sense of loss for herself in accepting her sister Sara as different.

> I have always seen my mum look after my sister. I just thought it was normal… but the older I got – like secondary school age – I learned that it's not the same. I went to a different school and my sister went to another school that was far. I think it all made sense to me when a bus used to come and take my sister... uhm... I think before that it was always different anyway like she wouldn't speak to me much and we never played together. (Shahida, Interview 1)

Representations of (understanding) autism

All four of the parent participants spoke about difficulties they experienced in understanding autism. In different ways, when it was spoken about as a "problem" or "illness", this seemed to refer as much to their experience as parents as it did their child, and a neurodevelopmental condition the child possessed, and often involved a profound sense of confusion and frustration. For Bina, for example, "They [health professionals] told me about his problem: if you have an illness and you don't know what the problem is and you don't know what the illness is, the illness will give you turmoil" (Bina, Interview 1). This statement reflects how distress or "turmoil" is associated with not properly comprehending the condition – something which would apply to both Bina as a parent and Salim as a child with autism.

Nahima spoke about how she did not entirely understand autism and linked this to not being helped by a perceived lack of support from local authority services. "I was confused because I did not clearly understand it. I never really understood her illness and so many times I called the council for help" (Nahima, Interview 1). Sanjidah spoke about how she was only really able to accept the explanation of what autism is when she was informed of it by her eldest daughter. "My older daughter explained it to me and when I kind of understood it my heart broke. I cried because I did not know how I can help him or how I could be a good mother to him" (Sanjidah, Interview 1). For Sanjidah, what could be described as her son Tanim's "spoiled identity" (Goffman, 1963) as autistic appeared to be directly linked to worries relating to her being (not) "good enough" as a mother and an (unsaid) hope that (good) mothering may resolve (or "cure") Tanim's autism. "I just thought this illness will go with time as any illness does, but it never went" (Sanjedah, Interview 1).

Yunis spoke about how his understanding of autism was impeded by a conscious wish to avoid speaking about it, and linked feelings of shame. "It took some time to understand what was wrong with him. I avoided everyone" (Yunis, Interview 1). Initially, when struggling with understanding Ahmed's condition, he avoided sharing this aspect of the family's life with extended family members. "There was a time where I avoided them out of guilt or shame; I just did not know how to explain it." Over time, "slowly I accepted and started telling people about it" (Yunis, Interview 1). In this way, as Yunis changed personally, he came to understand autism and Ahmed differently.

As Ahmed's brother, Ali's awareness or acknowledgement of Ahmed's autism also seemed to have been something that was consciously or unconsciously avoided for a long time. Seeking this understanding was prompted by curiosity, and then, when confronted by it, in black and white, in the form of official diagnostic reports, he did not appear to want to dwell on it (in life and the interviews).

> The first time I actually stopped and wondered about his autism was in my 20s when I took an interest to read all his paperwork. It did make me a little upset but there's not much you can do apart from move forward (Ali, Interview 1)

Moreover,

> Growing up, I just thought he was always needy, which made me more independent; I just went on doing my own thing, but when I took him to read all his paperwork, I reflected and realised what autism really was and how it's like to live with someone with it. (Ali, Interview 1)

Ali also spoke about how younger parents were, in his view, better equipped to understand and navigate autism, giving the example of a relative of a similar age to Ali whose son is a teenager and diagnosed with autism. Ali commented on younger parents having access to the internet as significant – a comment which appeared to be connected to both the availability of information and networked communities increasing the visibility of autistic persons. “Before internet was a luxury and no one really knew where to go and search things up, but now parents are more aware of this either from social media or using the internet” (Ali, Interview 1)

Hazera recounted her understanding of autism as growing whilst studying at university. There, she learned about learning disabilities, and speaking about her brother helped her “piece things” together. “I suppose the older I got I... was a bit more sympathetic with my brother. I started opening up about him at university and my degree helped me understand him more” (Hazera, Interview 1). Salma contrasted this understanding with the ways in which others did not seem to understand Tanim when he was younger, which appeared to affect her view of him also amidst an experience of growing up that “wasn’t easy”. Strikingly, in her account, after these comments, she proceeded to share a memory of violent misunderstanding and victimisation: Tanim had come home as an adolescent with “lots of blood” all over his head. Tanim had been violently assaulted by boys in the park because, she said, they thought he was “mad”. Indeed, a latent aspect of the interview accounts was the recollection of memories in which the autistic family member was excluded, victimised or, in some way, lost, or estranged, which were not uncommon across the interview accounts.

Nahima, Sanjidah and Bina all represented autism as an “invisible” illness, i.e., as something that could not be seen and hence was difficult to understand. Bina used phrases like “this kind of children” and “problem”, Nahima described autism as an “illness” that “never goes away” and Sanjidah spoke of children with autism as “mad kind of children”. In these descriptions, there was sometimes a sense of confusion about how autism could be an “illness” but also be permanent. “This....this um autism, yes, the autism I don’t know how else to see this; if this is not an illness what can it be?” (Sanjidah, Interview 1). At the same time, all three participants, as mothers, spoke about a lack of knowledge or awareness about autism or being ashamed to speak about it, despite their actions indicating that they had sought to develop this.

The three participants who were mothers also, to differing degrees, reflected on how their perception of autism was shaped by the family and cultural influences. Their comments illuminated how they had navigated certain understandings of autism, resisting some, whilst accepting others, and the internal and external barriers that developed in this process, which did not necessarily sit comfortably with traditional gender roles in the families. Nahima, for example, spoke about the limited knowledge of autism in her extended family limiting what can be said about Sara, who she is and what she does. Nahima commented on how extended family would always ask after Sara, but she finds she is unable to find the right words to express herself, instead replying that it is just “hard” anticipating that the family will always see Sara as a “mentally unwell” child.

Sanjidah received additional support from the local authority due to Tanim’s severe autism which appeared to have eased the pressure she was under so she could fully grasp Tanim’s needs and understand autism more fully. Yet, in Bina and Nahima’s accounts, their understanding of autism seemed to be derived primarily from their everyday experiences with the autistic family member, as a child and an adult.

Bina also spoke about her experience with her neighbours when Salim was 8 years old. She described feeling uncomfortable around her neighbours when they would see her, and how she found she was unable to be “open” and “genuine” in her relationships with her neighbours when speaking about Salim. She represented this feeling as changing, in quite a profound way, when she attended a six-week class for parents with autistic children, which shaped her attitude significantly, and left her feeling much less isolated and able to articulate Salim’s needs more adeptly. “I felt happy as it gave me comfort and not to worry that children like this still have some sort of a future and that mine can become someone too” (Bina, Interview 1). For Bina, the support of family was vital in supporting Salim. However, she said she also worried about stigma in the wider community if others were aware of the diagnosis – something that, she said, could be addressed by educative initiatives and increased awareness (as with her own experience of the parenting group).

As a father, Yunis spoke on how (culturally shaped) perceptions regarding the role of the eldest son and his own sense of "sadness" and shame compounded his own ability to understand autism. In this way, the acceptance and understanding of autism were very much intertwined.

> How can you accept something you have never heard of or explain to others properly? Back then people would just think people like him were mad. They had no explanation why and that's how I felt about him at first. But slowly I started to understand it and there was the fear if my other boys end up with it, but they did not. I was a little worried if all my sons would not speak at the right time and all these things caused me a lot of stress (Yunis, Interview 2)

Contrasting how Nahima, Sanjidah and Bina's understanding of autism was shaped by their everyday experiences as mothers, Yunis commented that, as he gradually accepted Ahmed's autism, he began spending more time at home with him. This prompted him to change his views and, he said, understand Ahmed better.

Salma's view of autism appeared to be very much shaped by the extent of Tanim's needs. She described him as having a level of intellectual understanding equivalent to that of an 8-year-old, which was coupled with the additional challenges of epilepsy and weak coordination. Despite greater awareness, for her, the level of disability was what was most significant. "I think when I was a lot younger as well, autism was such a rare thing. I feel like now it's become so common. I still think my brother, the spectrum of autism is the worst I've ever seen" (Salma, Interview 1). In this way, autism was sometimes defined in accounts in relation to a lack of some aspect of social, cultural or familial identity; for example, for Shahida, with Sara, that, “I would never be able to have a proper sister” (Shahida, Interview 1).

The sibling participants spoke about autism in terms of specific interests, a lack of sociability and a need for routine and sameness, as in this statement of Ali’s about his brother’s particularity with clothes, bed, food, and orderliness. “He is very particular about how his clothes are put away in the cupboard, how they are washed, how his bed is done and also his food; he did not like getting his clothes dirty” (Ali, Interview 1). After this statement, Ali commented that his brother does not socialise much and prefers to spend time alone in his room.

Similarly, Hazera spoke about Salim’s specific preferences when playing games, often playing with toys or engaging in activities that are typically associated with younger age groups. “He’s quite childish, like he’ll just enjoy watching CBeebies or watch like memes or stuff on YouTube that little children watch, and he enjoys it” (Hazera, Interview 2).

Issues with hygiene were also mentioned, notably by Hazera and Salma, especially in terms of a need to remind the autistic family member to wash and bathe on a regular basis, and the extent to which there seemed to be a limited concern for what others may think or feel about their behaviour. For example, the Raza family commented on Tanim’s inclination to collect tree branches and leaflets, which he would store in his room. This behaviour created stress for the family, as he would not allow anyone to enter his room to clean or dispose of the branches.

In some descriptions of the autistic family member’s behaviour, the sense of confusion and frustration was readily apparent. Nahima, for instance, spoke about Sara as tending to isolate herself and stay in her room, either looking out of the window or staring at the wall, which she linked to what she observed in Sara as a young child.

> My daughter has always been so different – even as a child she never cried. I remember some days she would just like to look out of the window and see people. Never goes

> out. All her life she has been quiet. Even now she just looks out of the window and stares. Sits and just looks into space. I don’t know how else I can help her. She hardly speaks. You have to push her to talk. It’s like she just does not understand anything at all; she just sits there quietly, and she does not speak to anyone. She has no understanding of how to keep clean. (Nahima, Interview 1)

Intuiting the issue/s

While the extent to which the emotional experience of the autistic family member was often opaque, the accounts given of early development evidenced degrees of recognising something was different, amiss or, in Nahima’s words, “not right”. Nahima, Bina, and Yunis all spoke about noticing how the autistic child began to seem different in their development from the age of one, including delays in speech, and gross motor skill milestones, as well as challenges they faced in managing them as toddlers. These judgements were made in relation to the “normality” of the child’s sibling’s or siblings’ behaviour. “I have a daughter who was normal so I could tell the difference” (Nahima, Interview 1). Likewise, for Yunis, “When he was five, my second son was like three years old, we started to notice things...like the younger one was walking making noises trying saying abba...but he was still not talking.” (Yunis, Interview 1).

Parent participants’ comments suggested that they often faced challenges in confirming whether their perceptions as parents were “correct” and they needed some degree of validation from a professional. This dynamic interplay between the family’s understanding and that of the educational institutions and professionals was particularly evident. Bina, for example, said she compared Salim’s development to his sister, Hazera’s, but when she reached out to the school and her impressions were not confirmed, she expressed her frustrations. “I wanted the school to support him with his learning, but all they said was his work was okay. But I knew inside myself since he was a child something was not right” (Bina, Interview 1).

Sanjidah described how she initially attributed Tanim’s challenging behaviour to him being a “difficult” infant, after he was born in Bangladesh. As a young mother with two older daughters, she said she lacked the experience of raising a boy and understanding the development of boys (compared to girls); it was not until she moved to England and experienced a different cultural context and different societal norms that she re-evaluated what she had previously assumed.

> When he was naughty growing up or being loud in the village, I just did not know he had this illness...I just thought that’s how boys are. Just naughty. I only had girls, so I had that experience. You know girls are easier to look after. (Sanjidah, Interview 2)

For the four sibling participants, latency and adolescence were represented as the time at which they began noticing their autistic sibling’s behaviours as “different”. Furthermore, this appeared to also stem from an awareness that their parents’ time was, disproportionately, dedicated to their sibling, and they did not get as much attention – or indeed spend as much time with them. For Shahida for instance: “I have always seen my mother look after my sister. I just thought it was normal but the older I got, like secondary age, I noticed she was not the same as others” (Shahida, Interview 1). Ali similarly observed that Ahmed required a significant amount of their parents’ attention while growing up, and by the end of primary school, his instinct was that his brother was different from other boys his age. “I just felt he was different from others; we just never really spoke or hung out like brothers” (Ali, Interview 1)

Family cultures – culture in the family

Family unity, responsibility and support networks

Participants from across the four families all spoke about a profound sense of responsibility towards their families, particularly the family member with autism, and duties this entailed, i.e., to provide care, love and support, and, at times, advocate on their behalf. With this responsibility, the importance of family unity was emphasised (although not always realised). Awareness and the embracement of the responsibility, though, appeared to change over time, depending on one's age and role within the family. Ali for example, as the middle son, with an older autistic brother, in Ahmed, recounted his responsibility in his family as an adult and how he had willingly taken charge of various aspects of Ahmed's care. He and his wife both engage in daily visits to ensure the well-being of his brother. There was, he said, a pressure with this, in terms of maintaining his health and avoiding disruptions.

> Then there's the pressure of making sure you are okay to be present for him…like, if we fall ill, it impacts the day schedule or when I am able to visit. So, there is this pressure of making sure my home is in check and also my parent's house. (Ali, Interview 1)

Nahima spoke about providing round-the-clock care for Sara, in bathing, assisting with toileting, and feeding, and the vigilance necessary regarding potential dangers, especially given Sara could seem impervious to these ministrations.

> I look after her, bathe her and sometimes I need to feed her with my hands. I don't let her in the kitchen because she just ends up burning herself like she is not scared of danger. I don't leave her alone at home in case because it is too dangerous, I take her with me always. (Nahima, Interview 1)

While the weight of responsibility was evident in the sibling and parent participant accounts, there were also comments on the strength found in family support, especially when extended family was involved. To some degree, this was viewed as what it means to be a family. For Salma, for example: “Among us, we take responsibility”. In a similar vein, for Hazera, in relation to her brother Salim (and, it seems, herself):

> I think having a family gives you support. And when you have support, you just feel like you know you’re able to get through things better; with my brother like I want him to always feel supported, like in terms of my family. (Hazera, Interview 1)

In Sanjidah and Salma’s accounts, a support network, involving all the siblings and two caregivers from the local authority, was represented as important in sharing the responsibility for Tanim’s care. Likewise, in the Alam family, Ali and his wife seemed, to some degree, to take it upon themselves to ensure daily contact with Yunis and Ahmed. “Although both my father and brother have carers coming to the property, we pop over daily to make sure everything is okay.” (Ali, Interview 1)

Religion

As with family support, in all the accounts gathered, religion and, specifically the role of Islam, was foregrounded. Religious beliefs appeared to play a significant role in shaping the values, social mores and decisions of the families. During the interviews, all the participants, at some point, used Arabic phrases, for example, “Alhamdulillah” (Praise be to God) and “Inshallah” (If God wills). Bina consistently praised Allah, Nahima, Yunis and Sanjidah used Arabic phrases when mentioning something they viewed as positive, and this could be for seemingly inconsequential events. “Nowadays if he’s [Salim] late from university he texts me now, Alhamdulillah (Praise be to God) and then I don’t worry” (Bina, Interview 1)

All four of the parents talked of their faith as Muslims as a source of strength and solace during their lives as parents. “I thank Allah for giving me the strength to get this far” (Bina, Interview 1). Bearing and raising a child with autism was also spoken of as part of Allah’s divine plan – a test that they needed to face, and their faith holding a meaning that helped them understand and accept their situation (see, for example, Pargament, 1997). “I just did not understand why she was like this and maybe Allah was testing me” (Nahima, Interview 1). Bina, Sanjidah and Nahima made comments about making “dua” (prayer) to Allah as a means of supporting the autistic family member’s development.

What this development would resemble tended to be unclear, although, simply stated, it seemed to be less about a desire for a “cure” and more a wish for the autistic family member to have a good quality of life. Gratitude was expressed to Allah for any progress witnessed in the family member’s life, which was attributed to being part of Allah’s plan and protection. “But Mashallah [God has willed it], Allah, I give thousands and thousands of shukur [thanks] my son has improved a lot” (Bina, Interview 1). Yunis spoke about the role of hope with this in the difficulties of coming to terms with Ahmed’s autism, and others their faith as being connected to hopes for the future. Sanjidah said that she prays for Tanim’s future and worries what will happen when her own health deteriorates as she gets older. She also stated that Allah can only help ease her quality of life and prays that Allah gives her a “healthy life”.

For the sibling participants, who, growing up in England, were more exposed to secular, Western culture, there were views comparable to their parents on the role of Islamic faith, but also differences, and these views seemed to be elaborated based on their experience. Ali spoke about his faith being of profound personal importance, a source of solace and “what has helped me get through the years” (Ali, Interview 1). Islam was something, he said, he (re-)discovered as an adult, after he engaged in “researching” it during a difficult period in his life.

Speaking on the role of Islam and her sister, Sara, Shahida recalled a time in Bangladesh where her parents had an Iman perform a traditional Islamic healing ceremony or “ruqiya”.

> I remember when I was young in Bangladesh my parents…. had someone come round to see her and read Quran to her and my mum had to feed her this water for some days. But it made no difference… to her and maybe they had hope that she would change (Shahida, Interview 1)

Yet, despite the traditional healing ceremony making no difference, she spoke a lot about her faith in Allah and prayer habits, including her uncle’s instruction that it would help Sara. “They know she is different, and they always say to pray, and she will get better” (Shahida, Interview 1).

Salma spoke about the differences between herself and her sisters who wore the hijab and prayed daily, positioning herself as a liberal Muslim. However, despite her different approach to religious practices, she maintained that she held a strong faith in her religion, and that being Muslim was an “integral part” of who she is. This was, primarily, manifest in the way she acted and supported her family and her brother, to help her mother in particular. “Islamically as well, you know, they say heaven lies under the feet of your mother. And my mother’s happiness is ensuring her biggest worry – her son – is looked after. So yeah” (Salma, Interview 1). For Hazera, religion held great significance in her life, marriage, and future aspirations. She believed that following Islamic practices was essential in raising her own child and described her faith as nourishing her with strength while supporting her mother and brother. There could be a severeness to the way this was practised in her family, but it is something that anchored her in her life “We were all raised in a strict household, but I feel it gave me some grounding and to accept when Allah tests us” (Hazera, Interview 1).

Espousals (re)considered

The title of this subtheme plays with the term espousal as an archaic way of referring to a marriage/partnership and a way of referring to a commitment to a belief. It speaks to the ways in which prior (arguably, traditional) beliefs about marriage were reappraised due to the experience of living with an autistic family member and changing conceptions of what was the moral or "right" thing to do regarding marriage.

Members of all four of the participating families appeared to share a view that there needed to be acceptance from the family married into, regarding the autistic family member, whether the autistic family member was the one entering marriage or not. This was an important part in deciding who the family create ties with. How possible it was to anticipate or manage this appeared to be variable. Shahida appeared more circumspect, speaking about her sadness that there would be possible regret, and a lack of understanding of her responsibility to her sister. Resembling what can be described, using Kleinian psychoanalytic terminology (see Klein, 1946), as functioning in the depressive position, Shahida grappled with the realistic acceptance of her responsibilities and the potential emotional pressure of finding a partner who understands her commitment.

> You know one day I will have to get married and sometimes that does make me sad because I don't know if I will meet someone who will understand my family. That's important to me because that person will need to know that I need to help my sister (Shahida, Interview 1)

Salma, conversely, considered a lack of acceptance as a reason not to marry or continue a relationship with someone. As she put it: "If they didn't understand it, that would be a big no from me. Yeah. You know, if they did, you know any ill behaviour towards my brother, that would be a massive turnoff for me" (Salma, Interview 1). Indeed, for the three female sibling participants, the importance of potential in-laws accepting their sibling’s autism, as well as their family, was underscored. After marriage, they very much intended to continue to fulfil their responsibilities towards their siblings (in a sense, to return to Kleinian ideas, navigating between the paranoid schizoid position of defensive splitting and the depressive position of tolerating the demands of integrating their sibling’s needs into their future lives).

Amongst the parent participants, there were expressed disappointments, hopes and realisations regarding the prospects for the autistic family member becoming married and fulfilled in marriage. Yunis described contending with the reality of his son’s limitations and his own unfulfilled desires by openly expressing his sadness that Ahmed, as the eldest son, would not be able to fulfil the traditional role of getting married, starting a family, looking after the house and him, as his father. Bina spoke about how she hoped that Salim would be able to find a wife who can take care of him and get married but also worried about how he might be treated.

> It’s all in God’s hands. He is my eldest son of course and naturally I would want him to have a future. This is important to me. But I worry if the wife’s family treat him differently because of his illness. (Nahima, Interview 1)

Nahima and Sanjidah said that they recognised Sara and Tanim would, most likely, not be able to get married, and worried about how Tanim and Sara may be supported because of this.

> I don’t know if she will be able to get married and look after her husband. Even if both of my sons get married, I don’t know how it will be if they both live with me and their wives. My daughter will never move out. She will always have to live with me because of the help she needs. (Nahima, Interview 1)

Sanjidah, said, more resolutely, that she accepted that, for the rest of her life, she would be caring for Tanim, whose needs are “hard and difficult” and too much of a “burden” to pass on to someone else by marriage.

Future anxieties and anticipated loss

The extent to which interconnections between different systems (family, community, societal influences) shape the experiences of individuals, as articulated by Bronfenbrenner (1979), was evident in anxieties about the future apparent as a significant aspect of all four of the families’ lives. Uncertainty surrounding the death of parents, the future of the autistic adult, and potential challenges related to future relationships, living situations, partners for the siblings created a sense of unease for all families involved. The parent participants spoke about experiencing anxiety and worry when thinking about the future, their mortality and the daunting prospect of their adult child being left alone after their passing –a responsibility that seemed to weigh heavily on their minds.

For Yunis, for example: “I don’t know how long I will live for, and my only worry is that my son will be alone after I am gone” (Yunis, Interview 1). Likewise, for Nahima, in considering the future for Sara (and her siblings): “They all have grown and then I look at her and there is no changes and I worry what will happen if I die and who will look after her?” (Nahima, Interview 1). All four of the parents reported grappling with the reality of their own mortality and the well-being of their loved ones. Sanjidah, Bina, Nahima and Yunis reported praying about concerns for the future during their daily routines, with Sanjidah stating that thoughts of her passing “consumes” her, occupying her mind throughout the day.

The four sibling participants also spoke about what they understood and saw as their responsibilities in caring for their sibling in the future, including the reality of assuming guardianship once their parents were no longer able or had died. Salma said that, whilst it had not been explicitly discussed within the family, she had personally made the decision that her brother would live with her. The responsibility of looking after him would, all the same, very much rest with her and her siblings. "None of us will leave my brother to let go into the system. No one's going to do that. But right now, its anxiety and the fear of losing mum in the future and who is going to look after him. It's big. It's a big, big, big, big responsibility" (Salma, Interview 1). Shahida anticipated that she will eventually get married, and whilst the future was uncertain, she was certain that she would continue to play an active role in Sara's care:

> Her [Sara's] future is still a huge concern for us, but we know that whoever she marries her husband will need to look after her. Like bathe her, feed her and look after her….no one can do that like how my mum does…and my sister does not think or talk about marriage. It's something we all kinda accepted that she won't be able to [do]. Like my mum is her full-time carer and also me and then us siblings we will never be comfortable with anyone else. I will always have to be there for her. (Shahida, Interview 2).

The sibling bond and the sibling identity

Sibling experiences in and outside the family

A close, albeit often conflictual, bond between a sibling and the autistic family member was described in the accounts of all four of the sibling participants. This relationship was positioned as important in terms of the sibling's identity within the wider family and family hierarchies of responsibility. This relationship seemed to intensify over time when the sibling was prompted to take on a greater level of responsibility for the autistic family member, when their parents were less able. For Ali, for example:

> I never really took interest. You know, you just get busy with your life and mum mostly looked after him. In my twenties I was busy with my own life to notice how needy he was and before I knew it was in his mid-forties. (Ali, Interview 1)

All four sibling participants commented on how their mother's attention was focused on the autistic sibling during their childhood, which impacted on their own experiences. The sibling participants witnessed their mother's constant care for their sibling, which they initially did not perceive to be unusual, but they appeared to re-evaluate this as they grew older. There were recollections of a sense of their sibling being different from them. As Shahida described it: "From when I was young, umm I think it was always different anyway: like, she would not speak to me much and my mum would always have to do things for her" (Shahida, Interview 2). Ali reported that what he recollected most about his brother, as a young child, was how difficult he was, and how this sapped his parents' attention, but he saw this as a demonstration of their love for him.

> So, we are like three years apart so growing up I remember him just being difficult. Always crying, crying over almost anything and everything… even when I was young, I remember he would just take all of my parents' attention. I suppose he was the first-born son and they adored him so much. (Ali, Interview 1)

All four of the siblings described feeling a sense of obligation to their autistic sibling, often taking on a caregiving role, at home or when going out or spending time with family. This additional responsibility affected social interactions and, it appeared, the way they conceived their relationship with their sibling, and themselves, with all four sibling participants reporting feeling lonely at times. For example, Shahida recounted outings with her cousins, where she would take on the responsibility of looking after Sara, seeking to ensure her well-being was prioritised and needing to keep physically close and hold her sister to prevent her from wandering off and coming to harm. “If we go out to places or go out with cousins I have to look after her – I have to make sure she’s okay. I have to hold her when we walk and it’s just how it is” (Shahida, Interview 1). Part of Shahida seemed to long for something else, a more “typical” sibling relationship, going out together, taking photos, and enjoying shared experiences, rather than being the “older” more responsible sister and minder, despite being younger. This imagined relationship would, she said, be comparable to what her friends experienced without an autistic sibling.

> So, I, I don't know; like, it is hard because I can’t explain it, like, I when I speak to my friends and they have older sisters. It’s nice to hear how you know they have a good relationship; they will go out to eat or go for dessert though, like you know take photos together. You know like it is… it’s different and it’s nice but for me like sometimes it feels like I have to be the older sister. (Shahida, Interview 1)

Shahida also conveyed feelings of loneliness and spoke about difficulties she had encountered in trying to connect with Sara. Indeed, with an absence of a reciprocal relationship and sisterly bond, it could, she candidly said, sometimes be hard to view Sara as a sister. “I have my family but obviously with my sister doesn’t sometimes doesn’t feel like I have a sister she just feels like she’s just there” (Shahida, Interview 2). Shahida reflected that she had felt angry when she was younger and this stemmed from a perception that her mother devoted all her time to Sara, which occasionally manifested in her starting fights with Sara.

> I think I was a bit angrier with her – I’d always feel mad that my mum would spend all her time with her. She took she would always be with my sister. Sometimes I would just try start fights with her when I was at school and hurt her because I used to get angry with her. (Shahida, Interview 2)

Friends were represented as playing an important role in understanding and accepting their relationship with their autistic sibling, and the sibling participants reported that they viewed acceptance of this, amongst their friends, as necessary for the relationship to be sustained. Salma spoke about this being supported by being, herself, more open about her brother, Tanim, having autism. “But like now like it’s different like my I’m older now and my friends even my work friends they understand it” (Salma, Interview 1). Moreover, Salma expressed the importance of her friends understanding the significance of Tanim, and Tanim being autistic, in her life. She sought friends who could empathise with her experience and acknowledge the impact of Tanim’s autism on her family.

Ali, by comparison, spoke about how he was reticent to share much about his personal life with his friends at school and university, for which there was a notable absence of reflection, indicating it was, potentially, a source of pain he (consciously or unconsciously) avoided. “Yeah, we went to the same school but after that no one really knew my brother. I just kept it like that even at uni... it just never occurred to me to share that with anyone (Ali, Interview 1). Indeed, Hazera and Shahida described a different experience at secondary school, where they were wary of speaking about their sibling’s autism and struggled to find the words to explain it to their friends. For Shahida, this linked to her confidence in her understanding of autism and Sara.

> They [current friends] get it but maybe like when I was in secondary school it was more different like I’ll not talk about it… or I didn’t know what to say or how to explain it. It was just like, oh, I have this sister and my mum has to help her… but slowly like obviously now I’ve gotten older I understand it better. (Shahida, Interview 1)

Hazera, similarly, reflected on her own lack of understanding as playing a role in not speaking about her brother, as well as a “fear of judgment” from her friends, but how “a deeper understanding" of autism as she has grown up contributed to her ability and confidence in communicating with others about Salim.

Switching family roles

The sense of responsibility experienced by the siblings in caring for their autistic sibling was multifaceted and, typically, involved a painful renegotiation of traditional identities associated with birth order – a movement between lateral and horizontal family relationships (see Mitchell, 2003). These roles differed according to the family set-up and genders of the autistic family member and siblings. For the female sibling participants, this could involve more traditionally maternal qualities. Shahida, for example, integrates the reality of her responsibilities with her affection for her sister, leading to a mature and realistic acceptance of her role. She commented on how, despite referring to Sara as "afa" (older sister), her felt experience was of being the older sister in terms of the practical tasks she undertakes in caring for Sara to support her mother. The extent to which one ended up taking on responsibilities that typically fell under the purview of an older sibling was commented on across all the sibling participants' accounts. It seemed to be prompted by both a perceived need to offer support to one's parents, but also, in some way, to interact with the wider community, where their parents were unable to, or were ineffectual in navigating the responsibility. Hazera for example, spoke about making phone calls to the local authority, dealing with financial matters, as well as handling various practical tasks.

> "But even then, growing up, I was still the person that made the phone calls to the council to get things sorted, or I'll be the one that deals with the money to be fair. So I've always been in that kind of position" (Hazera, Interview 2).

In the Raza family, the loss of a father meant family roles rapidly changed, prompting the children to take more responsibility. As Salma put it, “Mum losing my dad at such young age; you know, it’s been 17 and 18 years. So that must have been… I think we, as siblings, had to step up” (Salma, Interview 1). Salma emphasised the difficulties her mother, Sanjidah experienced as the primary caregiver for Tanim, especially now she was in her seventies and her lack of proficiency in English limited her engagement with the community, hindering communication with agencies that provided help. Salma also linked this to her experience when Tanim was younger, and these difficulties were further compounded by the discrimination Tanim faced.

> So, my mum’s his primary carer – mum is now elderly. So, it’s basically me that looks after my older brother and my mum, and it’s been really, really challenging. I’d say it’s not easy at all and I think growing up [and] when I was younger, I found it really hard because people used to think he was mad. (Salma, Interview 1)

All four sibling participants referenced culturally shaped expectations and the way these influenced family relationships, shaping and defining their roles and responsibilities. Salma, for instance, referred to the expectation around looking after her parents and how this could also be seen to extend to Tanim, who would become the family responsibility, for her and her siblings.

> But, um, our culture is that we look after our parents. So, for me, my brother is like my parent. I lost my dad at 16 and he’s my older brother. And although I look after him, he’s always going to be my older brother, and there’s a duty for me to look after him, you know. So that will always be in my mind. (Salma, Interview 1)

For Ali, like Salma, the loss of a parent intensified an expectation that he would take on a greater level of responsibility and reinforced in him a commitment to this role.

The practical tasks these responsibilities involved were discussed, with some emphasis on administrative tasks, for which formal education was helpful, i.e., in phone calls with professionals, correspondence, or managing financial matters, which the autistic sibling and their parents would struggle or fail to manage without considerable support. They also touched on the trade-off this commitment entailed, in terms of how it affected their personal aspirations, social lives, and emotional well-being. However, the impression their accounts gave was that the sibling and family were important to prioritise.

Conclusion

This chapter, as the first of the two chapters dedicated to the study findings, detailed the first three themes identified as part of the analysis undertaken. These themes illuminate a range of challenges and experiences faced by families with autistic members, providing further insights into the role of acceptance, support networks, navigation of caregiving responsibilities, and the emotional struggles associated with having a family member with autism, with links made between immediate environments and broader societal influences (as in Bronfenbrenner’s (1979) ecological systems theory). The themes also illuminate aspects of the experience of having an autistic family member that may be considered particular to Sylheti families in England, in terms of intergenerational differences in understanding autism.

What is particularly striking (and was difficult for me to make sense of as a Sylheti woman and education professional working with neurodiverse students) was how apparently outmoded views of autism, that is, as an illness or “madness”, could coexist with a deep commitment to, empathy for, and acceptance of an autistic person in the families involved in the study. This paradox can be explored in how societal stigma is managed alongside a deep familial commitment and empathy for “spoiled identities” (Goffman, 1963). In different ways, the parent and sibling participants came across as sensitive to the needs of the autistic family member from a young age, although they would not necessarily be able to articulate this in a way that could be readily shared with and understood by professionals.

Also notable was the way in which roles and responsibilities within the family were influenced by the presence of an autistic family member and how this involved a seemingly often painful renegotiation of traditional roles, based on birth order and gender, where individuals integrate the reality of their caregiving responsibilities with their affection for their family members, ensuring family unity. Islamic faith was a significant source of direction and solace in grappling with the challenges of family life, as well as maintaining a sense of purpose and sense that one was living a “good” life.

For the families, the future loomed large in their thoughts, especially anxieties relating to how the autistic family member could be cared for, as the parental capacity for this diminished – a source of discomfort and apprehension. The question of who would fulfil this role was significant, though it was viewed as a responsibility that could not be avoided. In a similar vein, future partners (whether for the autistic family member or not) and the (other) family/families with whom the family would be linked was an important consideration, in terms of the capacity to accept autism and be a supportive presence.

Lastly, there is the issue of having an autistic sibling in a Sylheti family, which was found to be a multifaceted experience, varying on an individual basis, with some commonalities based on assumed roles as a female or male sibling, and the autistic family members’ identity as brother or sister. Siblings appeared to have varied roles in their autistic siblings’ lives, ranging from being a friend/companion through to an advocate and caregiver, providing emotional and practical assistance. These relationships and roles could be challenging and disappointing, but also afford a sense of obligation and fulfilment, in developing understanding and patience, in tolerating frustration and confusion. For the sibling participants, there was a strong sense of responsibility in relation to their autistic siblings, with them taking on caregiving and supportive roles, both in the present and in planning for the future.

The next chapter extends the analysis further. It does so by reporting on the three other themes identified from the analysis of the interview accounts.

Chapter 5: Findings II

Introduction

Following on from Chapter 5, this chapter continues to report the findings of the analysis undertaken for the study, detailing the themes identified through the analysis of the interview accounts. This chapter focuses on the remaining three main themes of the six identified overall.

These themes are: *confronting adversity*, which concerns the resilience and strength displayed in the journeys of the families facing the unique challenges that an autistic family member brought to their lives; *affective realities of life with an autistic family member*, which addresses emotional experiences within the families; and *navigating support*, which addresses the strategies and resources families employed to seek assistance and guidance in supporting the autistic family member, at home and in the community. Each theme is comprised of between two and four subthemes (see Table 2).

Table 2: Further themes and subthemes

Theme	***Subthemes***
Confronting adversity	Challenges
	Shame
	Death and loss
	Parental discord
Affective realities of life with an autistic family member	Fear and worry
	Sadness
	Coping
	Feelings of fulfilment/holding a sense of purpose
Navigating support	Local authority and school support
	The role of carers

Confronting adversity

Challenges

Participants from each of the four families discussed persistent challenges faced in the family household because of the presence of a family member with autism. These difficulties encompassed the responsibilities of caring for these family members, the events they encountered, and challenges associated with supporting autistic adults, at home and in the wider community.

Ali spoke about the internal conflicts and anxieties that arise from dual roles of caregiving. He commented on the difficulty of caring for both his father and Ahmed, recognising the added responsibility placed on the family, and him and his wife. “It’s just harder for us to look after two members of the family who depend on us. We both do our best that we can” (Ali, Interview 1). Ali and Salma discussed how a lack of awareness and understanding of autism within the Sylheti community has had an impact on their families, often resulting in feelings of isolation and a sense of abandonment and anxiety. This seemed to be more pronounced at difficult times, as in the context of Tanim having an episode of going missing as a teenager, as described by Salma, and more pervasive, as in Ali’s comment regarding the lifelong challenge of caring for Ahmed: “Having a brother with autism has been a challenge most of my life” (Salma, Interview 2).

Nahima described the struggles of raising her children, particularly Sara, who engaged more in self-injurious acts and self-harm as a teenager. She emphasised the difficulty of seeking help from medical professionals and accentuated the emotional and physical strain she experiences as a caregiver, describing the constant pain in her body and her worries about Sara’s future and well-being. “Is this my daughter’s life now? Will she ever be normal and have a happy life?” (Nahima, Interview 2).

Bina shared what she described as an ordeal when she attended numerous meetings at Salim's secondary school and spoke of the "hardship" she faced when she asked for support and assessments regarding Salim's needs, regretting what she viewed as a lack of support, wearing her down in the process. "The number of shoes that wore down from my walking and going to appointments I can't even tell you. I had a lot of hardship. A lot of it" (Bina, Interview 1).

Another common challenge among the families, as highlighted by Nahima and Shahida, was the time-consuming nature of providing care to the autistic family member. Nahima and Shahida described the need to encourage Sara to perform daily activities and the difficulties they faced in doing so. The constant need for supervision and assistance left them with limited time for personal activities and self-care, adding to the burden they reported experiencing . "We kinda have to force her to get up and have breakfast...and even when she gets up, she will refuse to go toilet and brush her teeth" (Shahida, Interview 1).

Hazera and Salma's recollections of family life and childhood experiences similarly revealed the challenges they encountered while attempting to supervise and support their autistic siblings, a responsibility which seemed to take a toll on their own well-being and was something which part of them wanted to opt out of. "... It has been quite draining and quite like you just want a…You just want that draining to stop" (Salma, Interview 2).

Salma and Hazera emphasised the emotional and physical exhaustion associated with this caregiving role, and the necessity of (some form of) respite. They highlighted their personal reliance on both their immediate and extended family for support when seeking a break.

Salma also discussed the financial constraints that her family faced while trying to address Tanim's changing needs. She emphasised the challenges of affording "expensive" items like Nintendo and other electronic devices, which Tanim was viewed as having something of an obsessional interest in. For Salma, this served to compound the financial strain already placed on her single mother, who was reliant on state benefits for income.

> [Tanim] is getting more expensive things and it’s hard because you can’t keep buying. He doesn’t look after it. So, obviously, my mum’s a single mother now. She’s on benefits. She doesn’t work. She’s been a housewife all her life, so she can't really afford to keep buying him these expensive things (Salma, interview 2)

Salma also spoke about the challenges of supporting her brother in taking care of himself and maintaining good personal hygiene, recounting a specific incident where the family had to take extraordinary measures to prompt him to shower. In different ways, the combination of this need for close care and trying to prompt him to do particular tasks could be a relentless imposed challenge. As she put it:

> My brother has the worst of it. Like, I’m not saying that there are no other people too, but like all challenging behaviours and it’s such hard work. It’s hard. You can’t leave him by himself, you know? Yeah. He’s under constant supervision. You got to feed him. He can’t cook. You know, he can’t pour himself a drink. So, you got to do everything for him. (Salma, interview 1)

Shame

Shame was a prevalent aspect of the experiences shared by these families in having a family member who was autistic and appeared to be bound up with a sense of perceived stigma related to this, reflective of internalised negative feelings from significant others and cultural expectations. Members of the Alam family expressed the shame they felt in not sharing the fact that Ahmed was autistic with their extended family. This shame appeared to be rooted in a sense of cultural disconnection, which contributed to a hesitancy about disclosing this fact. As Ali put it: “I think it’s where Bengali people don’t understand it, so shut off from accepting it, and then there’s the shame of having a child like that” (Ali, Interview 1). Similarly, for Yunis, speaking about his initial disappointment when his first-born son was diagnosed with autism: “This was many years ago and things were different and there was a bit of shame to tell others that my first-born was like this” (Yunis, Interview 1).

Hazera’s recounted experience involved comment on the difficulty she faced in talking about her brother Salim’s autism during her secondary school years. She spoke of both a sense of “shame and a lack of understanding” regarding autism, which hindered her in discussing it with others. In a not dissimilar manner to Yunis, as a parent, Hazera found that as she gained a better understanding of autism, it became easier to open up and speak to others about her brother’s needs. This process led to her sense of shame lessening, and a shift in her embracing aspects of a stigmatised identity to educate others through better understanding. “I think also like opening up and telling people it become a bit easier because I understood it better. Where...yeah...I did not feel as, I suppose, ashamed of it” (Hazera, Interview 1).

Comparing accounts, across parent and sibling participants, there were ways in which the experience of shame appeared to be gendered – family members could be placed in situations that were uncomfortable in terms of expectations of honour and act in ways that subverted traditional expectations of gender or family roles. Salma, for example, recounted a distressing memory of discovering Tanim experiencing an epileptic fit in the toilet, which left her very embarrassed. Etched on her mind, this incident not only tested her respect for her older brother but also brought about shame. “You know when you have that respect for your older brother but seeing him in that state, naked, yeah, and so, I found that really, really hard. I’ll never forget that never, never forget that” (Salma, Interview 1).

Nahima articulated her experience of shame in caring for Sara in terms of the nature of the acts of care, particularly tasks related to personal hygiene such as bathing and changing sanitary pads, which, she said, became even more challenging due to the taboo regarding open discussions about menstruation in the household, where she has adult sons. “It is so hard, it’s the shame of it and seeing her in that way. When she’s on her period it’s always hard” (Nahima, Interview 1). Shahida added support to this account, acknowledging the discomfort her brothers experienced in handling such issues, deeming it her responsibility as the only daughter with an understanding of Sara’s needs – and something that shouldn’t be spoken of openly. “Because I understand girly things... like you know period and stuff. Because my brothers will find that sort of stuff embarrassing” (Shahida, Interview 1).

Bina spoke about the pain of persistent questioning from her husband’s extended family regarding her ability to handle Salim’s behaviour during his younger years. These inquiries indirectly cast doubt on her capacity to parent, causing her to feel, she said, like a “bad mother”. In the presence of the extended family, she found herself compelled to plead with Salim to behave, further intensifying a sense of inadequacy.

Death and loss

The families’ experiences with loss, particularly the death of loved ones, was identified as a noteworthy subtheme in their narratives, illuminating the psychological and practical complexity of caring for autistic family members whilst also coping with bereavement. All four of the families involved in the research shared the common experience of losing a loved one, and this loss appeared to have had a profound impact on both parents and the autistic adult children in particular. Salma, for example, spoke about losing her father when she was in her mid-teens. Members of the Akhtar and Islam families spoke about the loss of paternal grandmothers, which deeply affected Salim and Sara who were both adolescents. In the Alam family, there was the loss of Ali and Ahmed’s mother and Yunis’ wife.

Yunis and Sanjidah, who lost their respective spouses, spoke about the sense of obligation to their autistic offspring whilst grieving and losing part of oneself and appreciating one would also die. Yunis expressed how he felt his survival was mainly for the sake of Ahmed; but this was complicated by his own ill-health. “My wife dying took a part of me away, and I only survive for my son, but I can’t help him properly because I am also unwell” (Yunis, Interview 1). He stated that the loss not only left a void in his life but also made him worry about Ahmed’s future. Sanjidah spoke about Tanim’s prolonged mourning for his father as “heart-wrenching”, witnessing him clinging to his father’s belongings as though it would somehow bring him back.

In the case of the Islam and Akhtar families, the loss of paternal grandmothers was described as having a significant impact on Sara and Salim, who were close to them. Nahima spoke about Sara’s grief as intense, with her crying throughout the day and isolating herself more in her room. The sight of her grandmother’s body and the realisation of her passing had a profound effect, she said.

> There was a time when her dadi [grandmother] passed away and she cried for so long. My child was fifteen then and I could not comfort her. We went to see the body and she saw her and kept crying; she never stopped crying for days. I had never seen her like that. She somehow understood that her dadi had died. (Nahima, Interview 2)

Salim, on the other hand, was described by Hazera as more expressive in his grief, asking questions and only slowly coming to terms with the concept of death. As Hazera described it, his growing maturity allowed him to better understand and cope with the loss, even comforting his mother as he did.

All four sibling participants described the process of loss in terms of temporal dimensions and how the experience of their autistic sibling affected them, including in providing comfort and support to them. Ali, for example, spoke about how Ahmed's daily cries for his mother served as a painful reminder of her absence, making it difficult for the family to move on. "I suppose he misses her. We all do. But when he cries it's even harder to cope because it's like a daily reminder" (Ali, Interview 1). Similarly, Salma spoke about how, for her, losing her father at a young age was a challenge compounded by Tanim's emotional struggles, his difficulty in comprehending the loss extending the time the family spent mourning the loss.

Language difficulties

Language, and challenges with language, were spoken about on several occasions in interviews, particularly in relation to interactions between family members and healthcare and educational systems. Barriers with language were spoken about in terms of an impact on the ability to effectively communicate, advocate for autistic family members, and access support.

Bina's account illuminated challenges she faced during Salim's secondary school years linked to her limited proficiency in English. She recalled the stress of attending meetings and attempting to convey her concerns to the school. While interpreters were occasionally present, their language capabilities did not align with her dialect, leaving her feeling unable to trust them to effectively communicate her message to school staff – a source of frustration and distress.

> I used to feel hurt and upset; some days I used to come home and cry. I used to get so angry and think to myself, today I don't know how to speak English, and this is why they do this to me. That's how I always felt. (Bina, Interview 1)

Similarly, Nahima made reference to language-related struggles when attending school meetings, CAMHS, and GP appointments for Sara. She described the professionals as holding Sara's well-being in their hands because she did not comprehend the processes and found interpreters unhelpful. Both Nahima and Bina shared feelings of helplessness due to limited English proficiency, which could lead to self-antipathy. "Sometimes after meetings, I would come home and cry... I used to get so angry with myself because I could not speak English, and if I did, these people would not have treated me like that" (Nahima, Interview 1). Over time, Nahima's older children could attend meetings and interpret for her.

Sanjidah's experience, while different, also involved issues with the navigation of language use with professionals. She did not speak fluent English, but her husband was able to communicate with professionals regarding Tanim. Additionally, they were supported by a carer who could act as something of a mediator, in handling administrative aspects of Tanim's care, despite not speaking Sylheti. This seemed to be disempowering for Sanjidah. "I did not really do much, just stay at home when my husband would look after everything to do with Tanim" (Sanjidah, Interview 1). Following her husband's passing, Salma tended to attend meetings with Sanjidah and act as an interpreter as local authority-provided interpreters were not always able to speak her dialect, something Salma, herself, highlighted. "The language barrier for my mum has been a massive issue" (Salma, Interview 1).

Parental discord

Discord between parents was addressed in both parent and sibling participant accounts, and this subtheme captures the nature of comments on this issue, particularly in relation to the absence of fathers within the family and decision-making regarding autism, which could be attributed to gender norms.

Bina’s account, for example, not only highlighted difficulties she encountered in raising Salim but also in her marriage. While she attended meetings and parent workshops to better understand autism and support Salim, she said her husband displayed “no interest” in these efforts and held a very different perspective, doubting Salim’s diagnosis whilst dismissing Bina’s persistent efforts to help him. “My husband still felt he was okay and said I should not have done all this – he is a man, they understand things differently” (Bina, Interview 1). His dismissive attitude left Bina feeling unheard and frustrated, with her recalling him telling her to “stay quiet”, asserting that she didn’t understand anything.

Nahima described challenges she faced in her marriage due to her husband’s limited presence at home, with him working outside London, visiting only once a month. During his infrequent visits, she said, he would reprimand her for what he perceived as spoiling Sara, without adequately comprehending the complexities of her daily care.

> You know men are difficult anyway. He has no idea how hard it is living with her. Sometimes he shouts at her, and I tell him not to but then he says it’s my fault that I spoil her and don’t let her do anything. (Nahima, Interview 1)

Occasional verbal outbursts directed at Sara led to conflicts with Nahima, who defended her care of Sara. Nahima described these situations as heated discussions, which, in turn, led to “tensions”.

As a sibling participant, Hazera shared her experiences of growing up in a household where her parents held diverging views on the best way to parent her autistic brother. She recalled her father adopting a stricter, more punitive approach, often shouting at Salim, while she represented her mother as more nurturing and understanding. Hazera said she sometimes felt compelled to intervene diplomatically and speak to her father about his treatment of Salim, which sometimes resulted in family conflicts and an atmosphere at home that could be “depressing” for her and her younger brother, and which impacted on her experience at school. The stress of navigating these opposing relationships within her family may have contributed to feelings of sadness and depression, as the conflicting approaches to parenting her autistic brother created a fragmented emotional environment.

Indeed, both Hazera and Shahida’s accounts acknowledged the strain placed on their parents’ marriage due to their different ways of handling their autistic sibling. Both expressed sadness and frustration regarding parental disagreement concerning their autistic sibling’s care. They recalled their respective parents frequently arguing about attending meetings and the lack of understanding on the part of their fathers. For Hazera, for example:

> Growing up, my mum and dad will fight a lot about Salim. They’ll always argue over why my mum’s going to these meetings and my dad would never understand it. I think my dad is quite, you know... typical kind of Bangladeshi man. So, I think yeah, they used to argue and used to get me quite sad because I’d always wonder like what is wrong with them. (Hazera, Interview 1)

In contrast, the accounts of Salma and Ali suggested there was not a comparable experience of parental differences in handling their autistic siblings, but rather their parents were able to navigate and find common ground in managing them, even though, in the case of Ali, his father Yunis was occasionally occupied with the family business. Sanjidah also spoke about being able to adjust in parenting Tanim with the support of her late husband, and their unity as a parental couple allowed for a more cohesive approach to parenting.

Affective realities of life with an autistic family member

Fear and worry

All four parent participants shared a common experience of fear and anxiety regarding the well-being of their autistic adult children, and concerns about their adult children's health and overall welfare which appeared to have had an impact on their own physical and emotional health. The common thread among the parents was a deep-seated fear and apprehension they experience concerning the welfare of their autistic adult children.

Nahima, in particular, described a state of ongoing worry and distress in relation to her daughter Sara, describing it as "heartbreaking" to witness her child's suffering. She reported having had certain expectations for Sara's future, but the challenges posed by Sara's condition had made it difficult to fulfil those expectations, intensifying her worries. Nahima spoke about her daily anxieties, which would heighten when they left their autistic offspring unattended, even for brief periods. Nahima said she felt a constant pressure to ensure Sara's welfare.

> She is my daughter and I know how hard I have to look after her – like I can't have a rest or fall ill. If I fall ill everything in the house falls apart. Like during the time we all had that illness...oh yes that COVID we were so ill. (Nahima, Interview 1)

Bina, too, reported grappling with pervasive worry, especially during Salim's teenage years when he remained undiagnosed. "No one caught this for 16 years and still till this day I feel sorry about it and at the beginning I used to cry a lot over this" (Bina, Interview 1). While Salim's eventual diagnosis brought some relief, it also came with a blend of sorrow and uncertainty regarding Salim's future. The concerns for his safety and overall welfare, such as his travels to and from school, had weighed heavily on her mind. "Another worry was if people pick on him what will he do and not do? Everything was a worry for me" (Bina, Interview 1).

For the sibling participants, parents' fears and worries could seem almost contagious in nature, affecting them in turn. As a sibling, Hazera characterised her experience of worry as rooted in observing her mother's perpetual anxiety about her brother, Salim, throughout her childhood. This ongoing concern appeared to have made a lasting impression on Hazera, and one of her most significant worries revolved around Salim's adjustment to her being married, so, she said, she maintains a routine of weekly visits to her parents, often hosting Salim at her marital home.

Shahida, too, spoke about having been influenced by her mother's seemingly constant anxiety regarding her sister Sara. She had taken on the role of comforting her mother, reassuring her not to excessively worry about Sara's well-being. Growing up, Shahida said, she had witnessed her mother's ongoing concerns, and now her worries extend to the family's living arrangements, particularly as her older brothers consider marriage. Her hope is to see her siblings collectively work toward purchasing a house that can accommodate the entire family, easing anxieties related to living space.

> My brother can't move out because my mum needs him around because he helps her a lot taking her shopping and everything. So, we are not sure we want to save money and buy a house so my mum will have enough space even after my brother gets married. (Shahida, Interview 1)

Sadness

All four parents expressed sadness in relation to their autistic adult children, as did the sibling participants, albeit in quite unique ways, that is, in being connected and disconnected to this emotion, both for themselves and the autistic family member. Ali, for example, described how he is constantly in a "default position" of caring for his brother, Ahmed. He admitted that allowing himself to stop and feel the emotions linked to this could seem almost overwhelming.

"I suppose you never stop and think how you feel about it. You are in this default position helping him daily. I suppose if you do stop and think or feel it makes you sad" (Ali, Interview 1).

In a similar vein, Bina acknowledged that sometimes it seemed easier to "keep busy" with daily chores rather than pause and contemplate Salim's life. When she does allow herself to reflect on his situation, she said, it fills her with sadness regarding the challenges he faces. "It used to be sad because you feel sad thinking… Oh why is he like this? Will he ever get married? How will he live his life?" (Bina, Interview 1).

Nahima considered her own persistent sadness stemmed from anger then disappointment in relation to caring for Sara with her husband and his apparent lack of willingness to accept she was autistic.

> It's sad and hard because I start getting angry with him, but I can't say or do anything. Because he is my husband, and I don't want to make him angry. I just pray to Allah that one day he understands. (Nahima, Interview 1)

For Hazera and Salma, as siblings, sadness seemed to be connected to both self-questioning why their sibling was "different" from the siblings of peers and that their sibling could be often misunderstood and judged by others, leading to a sense of isolation, as with Shahida who seemed to mourn not having a typical "sisterly" relationship.

Coping

The four families appeared to have developed individual ways for coping with the challenges they faced in having an autistic family member and the changes in relationships that this brought about. Strikingly, a commonality amongst the participants' accounts was them positioning themselves as responsible, or taking on more responsibility, for caring for or supporting the autistic family member. This may, one can imagine, have been different for those family members who did not volunteer to take part. Religion and prayer appeared to figure in this, but also other forms of support, that is from colleagues and professional support, in the form of psychological therapy.

Ali, in particular, spoke in detail about taking on more responsibility following the loss of his mother, adjusting his work arrangements to provide care for his father and brother. He said he sought therapy to support his own well-being, but as a means of not "burdening" others, especially his wife.

> As a family we all find ways to cope like spending time with him and then kind of making sure we are emotionally okay. My wife and I speak to each other, and I have a therapist I speak to which helps because sometimes I don't want to burden my wife as she's already got a lot to deal with. (Ali, Interview 2)

Salma described significant adjustments she had made in her personal life and work schedule to support her mother, Sanjidah, and brother, Tanim, including the use of annual leave to accompany them to appointments. She commented on how the network of support for Sanjidah and Tanim had changed over time. First, she received it through the bond with her siblings, but as they established their own families, she was prompted to seek further emotional support from friends and colleagues. "Being open and speaking to my friends and work colleagues about him makes it a lot easier and there's a lot of support from my managers" (Salma, Interview 1).

Along similar lines, Shahida said she was sustained by speaking about Sara with friends as she grew older and started to work herself. Shahida credited her workplace with playing a crucial role in helping her cope and feel accepted herself.

> I get it better because at work like they talk about it sometimes not just a disability and you know it's it's...important that you know everyone has to look after and respect everyone. But I think its [that] autism is one of those like it can always be different with anyone. (Shahida, Interview 1)

Hazera reported that she began disclosing more about her experience at home to her friends during university, finding relief in sharing her experiences. She said she had previously managed by "compartmentalising" her emotions as a means of getting by. Her paid work, working with vulnerable adults, served to enhance her empathy and understanding.

For the parent participants, an integral means of coping was the support of their non-autistic offspring, which was not necessarily referenced directly but referred to in terms of a "gift" from Allah, as well as prayer and their faith in Allah to help them cope. Sanjidah for example, said she had not stopped praying since her husband's passing and praised Allah for giving her five daughters.

> Allah gave me an ill child but blessed me with five daughters who are my backbone – may Allah bless them all for all they do for me. When they got married, I was worried I would be on my own, but Allah gave me five sons. (Sanjidah, Interview 1)

Sanjidah and Bina spoke about finding comfort in their daughters' visits, as well as an enduring hope that Allah will make their lives easier and gratitude for the blessings they saw themselves as having. "Sometimes when Hazera comes and visits us, and I see my grandchild I feel so happy. I feel grateful to Allah for blessing me with family no matter what hardship it brings" (Bina, Interview 1).

Yunis said that, as a father, he initially coped with his son's autism and needs by focusing on his business, which kept him busy and away from home, and that it took him several years to come to terms with Ahmed's condition. Learning to surrender to, what he described as, Allah's plans enabled him to spend more time at home and provide support to his immediate family, if not Ahmed directly.

> One day my heart just opened. I don't know what happened, but I just knew that I needed to love my son more he was. I cried to Allah to make it easier for him and after some years Allah answered my prayer. (Yunis, Interview 1)

Feelings of fulfilment/holding a sense of purpose

Participants from all four families spoke of occasions of happiness that they witnessed for their autistic adult child. Across these, a central aspect was the autistic family member's growth and development.

For Bina, for example, witnessing Salim's growth and increasing independence has been gratifying for her to observe when she recalls the anxiety she used to feel when Salim returned from school late, which prompted her to take small steps toward fostering his independence. Encouraging him to run errands, such as going to the shops with a shopping list, had, she said, enabled him to develop a greater degree of self-reliance. This transformation in Salim brought her a sense of relief, allowing her to shift her focus more towards her younger son as he became more independent.

> Now my mind is at ease these days. He goes to university and if he's late he will WhatsApp me. So, I don't worry as much as before. He has grown more and can travel alone. Before I used to worry so much if he was a little late from school. (Bina, Interview 1)

Hazera reflected on the pressure she felt as the firstborn in her family and the first to attend university. Despite these challenges, she found happiness in witnessing her brother's growth and development, cherishing the positive changes she has observed in him. "That was nice, and it's nice to see that he, he's been, he's grown, he's grown in his just in little ways, you know. And that's quite nice" (Hazera, Interview 2).

Salma spoke about improvements she'd witnessed in Tanim's social interactions, whilst recalling the earlier challenges he faced previously. Tanim enjoying spending time with his nieces and nephews was represented as a significant step forward, leading to a happier atmosphere within the family.

> You know... they used to call him mad the area kids so he never played with anyone. But these days he understands so much – yeah, he's still, has a mental age of a child but he really gets along with all the kids in the family. They love him, they all call him mama (uncle) and love to just play with him. It's just crazy how all the children are obsessed with him (Salma, Interview 1).

The sense of happiness was not always related to the autistic family member, but in the interconnected support as the children grew up and could become more responsible and, in quite practical ways, provide support to each other and their parents. Nahima, for example, described finding happiness in witnessing her children grow and reach significant milestones. Her eldest son having a car was a source of pride and happiness, as it eased the family's ability to go out, particularly with Sara.

Navigating support

Local authority and school support

Participants from all four families described experiences of accessing local authority support, which appeared to be a variable experience in terms of what was made available and the extent to which it was considered helpful or not, with some differences between the impressions held by different family members.

Nahima's experience with local authority support was, for example, limited. She said that she attempted to contact them for help but did not receive any support. When Sara was in secondary school, they were able to arrange transportation for her to and from school. Yet, now that Sara is an adult and not in education, the council no longer provides any assistance, which left Nahima feeling unsupported.

Bina, on the other hand, spoke about beneficial support she had received from a parent advice centre. She described this support as instrumental in helping her pursue an assessment and found the caseworker allocated to them to be understanding and effective. After Salim received an autism diagnosis, the caseworker was able to mediate access to transport training and after-school cooking clubs through the local authority, which helped Salim in developing skills for a greater level of independence.

> After they told me about the autism, the psychologist was able to arrange for transport training and sign him to after school cooking clubs which helped him become independent. One day he said to me 'let me peel and cut the onion for you' when I was in the kitchen, and I said 'How do you know that?' He said he learned from his class. This made me so happy that all these things was helping him. (Bina, Interview 1)

Hazera described this quite differently, recounting the family's struggles to obtain local authority support, particularly in getting Salim's diagnosis and the assistance he needed. Her view was that the family, particularly her mother, did not receive substantial help from the local authority.

> I know for my family like my mom, you know. She, she struggled a lot. She struggled a lot to get his diagnosis to help him help him achieve what he can. But, you know, in terms of local authority support really and truly we, we didn't get nothing. (Hazera, interview 1)

In contrast, the Reza family appeared to have had a much more positive experience with local authority support. Sanjidah spoke about how much she has appreciated the support provided by carers, and how this allows her to rest when they take Tanim out. Salma described the authority as "generous", providing the family with a comprehensive support package, including respite holidays and daily visits from carers. This support has been invaluable for the family. Similarly, the Alam family had access to carers and support from the local authority, and Ali emphasised the invaluable nature of this support for the family.

In the same way that local authority support was experienced, school support for the autistic family member was viewed as variable by the participants. As mothers, Bina and Nahima both spoke about how they found support from their children's schools to be unhelpful. Bina recounted attending several meetings to discuss Salim's progress, which she initiated herself, yet found these meetings did not lead to any solutions. She said she had to wait until her son was in Year 11 for him to receive a diagnosis, at which time he was at the end of his formal schooling. Bina placed a lot of blame on the school for a lack of support, and what she viewed as lost opportunities.

Nahima described reaching out to Sara's school when she was concerned about her self-harm. The school referred Sara to CAMHS in response, but Bina felt that there was no follow-up or ongoing support from the school, and she felt they did not adequately accommodate

Sara's needs, which led to her losing hope in the school's ability to provide meaningful assistance. In the account Nahima gave, Sara seemed to fall into a gap between the two, the school assuming CAMHS would take care of treating the self-harm, yet she still struggled with day-to-day support.

One example of an autistic family member who attended specialist provision during their secondary school years was Tanim. Salma explained that there was a period when the family struggled with Tanim's behaviour, and as a result, he was sent to a residential school. However, Sanjidah did not want him to be away from her, so the arrangement was eventually discontinued.

The role of carers

Two of the families had received or were at the time of the interviews receiving support from local authority carers. They indicated that having Muslim care staff made the process of being helped more straightforward and beneficial, along with having continuity within relationships with specific care staff.

For the Alam family, having carers provide frequent visits was viewed as a significant help and relief, especially, for Ali, in freeing him of some responsibility for day-to-day practical support. For Ali, "It is really helpful. It really takes the burden off me. They really do take care of him well" (Ali, Interview 1). Yunis also spoke about the fact that the carer, a young Muslim man, was respectful and appreciative of the family's values, making it easier for them to relate to, which brought with it a sense of ease. "It's sometimes nice because we have people in the house in the daytime. They chat to us" (Yunis, Interview 1).

For the Raza family, Salma recounted her family's long-standing involvement with a male carer, who became a cherished part of their lives and dedicated himself to supporting the family; as she put it he was a "strong pillar" in their lives. When this carer left after 15 years of service, it was challenging for the family to find a suitable replacement, the family feeling keenly his absence, particularly her brother. “We were a lot older, so we took a little more of a lead... after 15 years, but my brother found it extremely difficult to find that connection with another carer” (Salma, Interview1). They were subsequently supported by a female Muslim carer named Hamida, who they came to hold in very high regard. “We found someone that after so long after [name of previous carer], I’d say Hamida has been the next dearest thing to him” (Salma, Interview 1). Salma described this carer as “great”, and both Sanjidah and Salma appreciated that she is Muslim, which, they said, helps them relate to her. Her presence was viewed as having made a positive impact on the family unit, in part due to the fact that, prior to her arrival, they had two English male carers that Tanim did not respond well to.

Conclusion

This chapter, as the second of two chapters dedicated to the study findings, detailed the remaining three of six themes identified as part of the study analysis. These themes illuminate a range of aspects of the multifaceted experiences of the family members in having an autistic family member. These include the way in which shame is experienced, as an individual but also a socially produced emotion that is related to social and cultural norms and misunderstanding of autism, as well as the profound effect that death and loss had within families and the way in which autistic family members’ grieving changed the nature of the grieving and mourning process for the family.

Also illuminated was the impact of parental discord in response to, or brought into relief by, disagreements about the autistic family member’s condition, difficulties and needs, which served, in different ways, to destabilise traditional gender roles, and leave mothers shouldering a greater share of the emotional and practical demands as a consequence. As well as this, significant challenges were evidenced in families navigating support systems for their autistic family members, including the barriers posed by language and a lack of shared understanding about the nature of difficulties between a family and education and health professionals, and perceived lack of continuity and responsive practical support. At the same time, the value of continuity in relationships with professionals providing everyday support was readily apparent, and the added worth of care staff with a shared cultural understanding to the family.

In the next chapter, the findings of the analysis will be summarised and discussed, and their implications for future research, as well as policy and practice, will be considered.

Chapter 6: Discussion

Introduction

This chapter considers the implications of the study findings, reflecting on how the research question has been addressed and what the findings mean for practice in supporting Sylheti families with autistic family members in health, education, and social care settings. The study limitations are also considered, and comment is provided on the methodology utilised for the research.

Considering Sylheti family experiences with autistic adult family members over time

As specified at the beginning of the thesis, the aim of this research was to gain an in-depth insight into the emotional, psychological, and cultural experiences of Sylheti families with an adult family member diagnosed with autism, and, importantly, to consider what the family narratives illuminate about experiences with an autistic adult family member over time. Via sixteen interviews, involving four families and nine participants (one father, four mothers, one brother and three sisters), the accounts of different family members were considered on an individual basis (i.e., as personal accounts) and as related to family relationships and experiences in the wider community and society. Themes were identified in relation to these narratives, addressing both everyday lived experience and temporal dimensions of the family experience. These themes concerned accepting and embracing autism, relationships and bonds between the autistic family member and siblings, and the role of Sylheti culture in influencing relationships within a family. They also concerned confronting and navigating adversity, affective experience of life with an autistic family member, and accessing and navigating external support, i.e., via health, education and social care services.

The analysis of this study reveals that the Sylheti families who participated experienced having an autistic family member in unique and varied ways. The analysis underscores the need for a nuanced understanding of the relationships between different family members and the autistic individual to avoid premature judgments about how they are cared for or supported within the family. For instance, while family members may use outdated or seemingly prejudicial language when discussing autism, this can coexist with deep compassion and a strong commitment to the autistic family member. This aligns with the principles of the ethic of care, which emphasises the importance of relationships, context, and the moral significance of caring practices. Tronto (1993) argues that care encompasses all activities necessary to maintain, continue, and repair our world.

The parent participants displayed an understanding of autism that drew upon medical, religious, and secular understandings. They often viewed autism as an "ailment" involving severe difficulties and impairments, but also something that might, in some way, be overcome. Particularly, the parent participants appeared to struggle reconciling a medicalised understanding of autism with their religious beliefs, leading to a reconfiguration of their expectations and dreams for their child. This struggle also involved concerns about how the child would develop and integrate with the rest of the family and extended family. The process of raising an autistic child and observing their development was described as challenging and painful, especially in the context of wider culturally sanctioned expectations and gendered norms. The extent to which autism was construed as an "illness" or "madness" by parents, rather than a lifelong condition or identity, often reflected the significant strain experienced by these families, particularly by the mothers.

For the sibling participants, the experience of having an autistic sibling involved a profound sense of loss, which appeared to be more acutely experienced by a younger sibling, who finds him or herself unexpectedly taking on a role within the family that they did not previously anticipate. This transition induces both sadness and a lingering sense of guilt, which is then directed into activities within the family, and strategies to adapt and overcome challenges, influenced by prior experiences. In this way, tolerating or coping with disappointment was a central aspect of the family experience, and while the tight-knit nature of family could serve to fortify support, it could also be experienced as a burden, leading to strained relationships within a confined space – physical and emotional.

Gendered expectations appeared to exert a powerful influence on the experiences of siblings within families, whether in the sibling aligning with or resisting these expectations. In Sylheti culture, traditional expectations regarding gender roles are upended by the presence of an autistic family member who is unable to function in a way that would be considered independent by the family and wider community. Traditions which dictate that the eldest son continue the family lineage, and daughters marry to fulfil their roles as wives are overridden, placing these responsibilities on younger siblings instead. For daughters, leaving their own families to reside with their families in law evoked feelings of apprehension and worry. These worries particularly concerned the acceptance and support of their adult autistic sibling by the new family and whether they would accommodate their sibling's need for continued involvement in their own family, particularly in caring for the autistic sibling.

For male siblings, the hierarchical influence that would have been held by the eldest autistic male sibling is often bypassed, with the responsibilities falling to the next in line. Consequently, the younger brother assumes the duties traditionally associated with the eldest son by default and is placed in an uneasy position of navigating the challenges and expectations that come with this role reversal. In this way, longevity and shared values in relationships with external professionals become critical for sustaining support for siblings.

With these findings, the study helps develop an existing body of knowledge regarding the experiences of South Asian families with autistic family members, as with Doig's (2012) and Begum's (2023) UK-based studies which considered the experiences of Bangladeshi parents of autistic children, and Begum's (2023) exploration of parents' experiences in the context of Bangladesh. The findings of these studies foreground the role of religion as a coping mechanism, challenges in understanding and accessing support, the import of parental (particularly maternal) experience in shaping the understanding of autism and the impact of culture on family experiences. Yet, while research has concentrated on families with children affected by autism, there is a lack of research focusing on Sylheti families of adults with autism – a gap this study has helped to address. There, nonetheless, remains a need for further research in this area, which explores family relationships longitudinally but also examines the nature of beneficial interventions and support for the Sylheti community.

Building on these studies, this research focuses specifically on Sylheti families and helps extend the work of previous studies (e.g., Begum, 2023; Doig, 2012; Ehsan et al., 2018) which have explored the impact of cultural values, religious beliefs, and caregiving burdens in South Asian families, but have typically examined parenting in early childhood or middle childhood stages. In contrast, the present study offers insight into how Sylheti families experience and negotiate autism across the life course, particularly during adulthood, and how caregiving responsibilities shift and reconfigure within sibling relationships over time. This emphasis on sibling roles and anticipated loss in adulthood has not been a prominent focus in prior studies, which often centre the parental perspective. Moreover, this research captures how religion and familial loyalty can function both as protective and constraining forces — a dynamic not elaborated on in prior research in this area.

Limitations

This study was designed to involve four families with at least one adult autistic family member each. Gaining access to and involving a group that can be considered “hard to reach”, like Sylheti families with autistic adults, meant that considerable effort needed to be made to ensure inclusive research practices, and to establish meaningful connections within communities that may traditionally be less accessible. This being so, and notwithstanding the fact that the aim of the study was to develop in-depth understanding, a sample of four families can be considered limited, particularly as fathers from two of the participating families and other siblings declined to participate. Participants were those individuals who volunteered to take part and were recruited through my own personal and professional contacts after attempts to recruit via charity networks and local authority adult autism services proved unsuccessful. The recruitment process is, in this way, not free from selection bias. It was premised on the inclusion of individuals who were more accessible and more willing to participate and should not be considered reliably representative of other Sylheti families’ experiences.

The approach to gathering material for analysis also relied heavily on participants sharing their personal experiences. Follow-up interviews were used to establish further insight into the participants’ recollections of specific stories. However, given the fallibility of recalled memories over time, participants can be assumed to have selectively emphasised certain aspects of their past experiences, which will have differing degrees of resemblance to how the same events were experienced by others at that time, and subsequently. The research did seek to gather diverse perspectives to gain a more comprehensive understanding of the experiences. However, the accounts given in interviews were not triangulated by way of material gathered via ethnographic observation of family relationships over time. Future research in this area may wish to make use of such methods.

Methodological considerations

As has been recognised by other researchers (Archard, 2020, 2021; Frosh and Saville-Young, 2017), the narrative interview approach (which was based on principles drawn from Hollway and Jefferson's (2000, 2013) FANIM approach) served to yield rich narrative material. This method was valuable in affording in-depth insight into individual and familial experiences. But the sheer volume of data collected from 18 interviews had implications for accomplishing the analysis in a timely way, and the additional task of translating eight interviews before transcribing was time-consuming. As such, other researchers attempting to use this type of method for this research topic should be mindful that it constitutes a labour-intensive approach, requiring substantial time and effort. As interviews did not follow a predetermined order, in contrast to structured or semi-structured interviews, transcripts exhibited varied material without clear consistency, necessitating ongoing examination of the data to identify commonalities, and time spent refining a multitude of codes generated during the initial stages of data analysis.

If the research were to be conducted again, narrowing the focus may be beneficial by selecting a smaller number of families and focusing on specific aspects of the experience, for example of accessing external support or the dynamics of sibling relationships. While the overall approach would remain consistent, a shift towards a more narrative-based and conversational style could still be adopted in interviews. Even in the case of exploring sibling relationships, the approach could remain to interview the entire family and capture a comprehensive understanding of the dynamics and experiences within the familial context to provide a more focused understanding of sibling relationships.

The approach to the interviews involved a recognition that certain questions were responded to in a congruent, honest way by participants due to my identity as a Sylheti woman, and that some level of self-disclosure on my part not only aided this but was essential. Without this, participants might have felt uneasy with a "neutral" therapeutic stance, which is, to a greater degree, proposed by Hollway and Jefferson (2000, 2013). Establishing rapport and building relationships with participants was essential, and I found my professional background afforded me a helpful sensibility for interviews, which seemed to support some level of research beneficence, i.e. participants found it a helpful, reflective conversation (see, for example, Birch and Miller, 2000; Ruch, 2014: Archard and O'Reilly, 2022a). I wondered, at times, whether a greater degree of structure would have been advantageous in interviews, but the flexibility and empathetic approach aligned well with the research focus on a sensitive topic and my own professional identity as a practitioner-researcher. Moreover, the ability to conduct interviews in Sylheti was also crucial, enabling deeper trust and access to meanings that may have remained concealed had English been used.

To protect the anonymity of participants, pen portraits were carefully written to remove or alter potentially identifying details and composite descriptions were used in places to further protect identities. These steps were taken to ensure participants' privacy and confidentiality, particularly given the sensitive nature of the topics shared. These considerations should be taken into account when interpreting the findings and their wider transferability. Also, my experience undertaking the research has been that these considerations are highly important for ethical integrity in reporting this type of psychosocial research study.

Implications for practice

This study does not only aim to understand the lived experiences of Sylheti families with autistic adult members, but was undertaken with a view to generate insights that may support systemic change in how services engage in providing support to this community. Culturally unresponsive or procedurally rigid practices risk further marginalising communities whose voices are already underrepresented. Indeed, it can be said that a relational and culturally informed approach is a fundamental requirement in effective social work and social care.

Building on this, the study findings have a range of implications for practice, in health, welfare and education settings. First, the study findings attest to the significant challenges faced by Sylheti families with adult autistic family members. Although resilience and a daily need to endure and "get on" were apparent among family members, they also grapple with considerable difficulties, including the loss of close family members, the changing nature of relationships following the marriage of a sibling, and anxieties surrounding the acceptance of the autistic family member and their future. What is more, aspirations and dreams for the autistic adult can differ from those held by parents for other siblings. The families appeared to navigate between discerning achievable or realistic dreams and acknowledging dreams that may no longer be viable for the autistic adult, such as pursuing an independent life or marriage. The caregiving relationships for the autistic family members appeared to carry a distinctly gendered and generational nature, with fathers tending to be absent. It appeared that fathers could find the challenges too emotionally difficult to confront or they believed that dedicating themselves to hard work and expressing anger externally was the solution. This coping mechanism appeared to result in fathers distancing themselves from the family, as a means of not placing additional pressure on others, especially their wives. The implications of parental loss in this context could be profound, in terms of the effect on the dynamics of family relationships and the weight on the mother to shoulder responsibilities.

Second, the study highlights barriers to accessing support for Sylheti families and autistic adults from local authorities. While local authorities offer education for adults with an EHCP until the age of 25, there is a noticeable gap in supporting adults and families with autism who are aged 25 and above without an EHCP. Accessing support from charitable organisations like the National Autistic Society becomes crucial in this context. Although daily caregiver support is accessible for complex cases with sufficient evidence, families with autistic adults who function but are not entirely independent or complex can miss out on such assistance. Beneficial interventions, including therapeutic support for families, appear, in this vein, vital, particularly tailored therapy by way of counsellors fluent in languages such as Sylheti, as well as parent groups specifically tailored for Sylheti women, which can offer assistance and, conceivably, help lessen feelings of isolation. By participating in these groups, mothers would have the opportunity to share their stories, challenges, and experiences with others who can meaningfully relate to their unique cultural and linguistic context, which should serve to foster a sense of community and solidarity among Sylheti women.

Third, more comprehensive interventions for autistic adults to live independently appear important, as does collaboration between different agencies, such as education and social care services and employment support. While these agencies offer support to clients with special needs through access to work programmes, disability employment advisers, work capability assessments, and specialist disability employment programmes, they may tend to be more responsive to the immediate goal of securing employment. As such, there is a need to enhance these programmes by incorporating mentoring and emotional support to address the holistic needs of individuals with autism.

Fourth, the significance of language differences in relationships between families and the health, education, and care professionals involved with them also appear highly important. While services may provide interpreters, challenges arise due to variations in dialects and the apprehension of sharing personal information with the interpreter. The interpreter serves as the anchor for both parties and may take on the role of therapeutic agents, proactively checking in with family members throughout meetings and striving to establish a safe space (Leanza *et al*., 2015; Rousseau *et al*., 2011). Moreover, professionals without a shared cultural background may encounter increased challenges and should seek to recognise the (possible) significance of extended family and sibling relationships in supporting autistic adults and parents. Allocating time to address these relationships contributes to a more comprehensive understanding of family needs.

Fifth, and linked to this point, Sylheti families should be involved as stakeholders in shaping service provision, and this should be on their terms. The accounts in the research highlighted the potential for a young white mental health professional to inadvertently make a faux pas, such as asking a mother about her feelings towards her marriage. In navigating such sensitive situations, interpreters and other support personnel may play a key role, acting as cultural mediators to ensure effective communication and understanding, as well as having Sylheti professionals engaged in working with Sylheti families, at least periodically to acknowledge the significance of shared cultural backgrounds and language proficiency in fostering trust and effective collaboration. Consideration of a transcultural consultation model may also be, in this vein, beneficial, enabling the integration of diverse perspectives and expertise to enhance the cultural competence of mental health and therapeutic services for Bengali and Sylheti families (Carballeira Carrera *et al*., 2020).

Lastly, and collectively, the findings support a more culturally responsive approach within social work and social care practice. Families in this study, particularly siblings and mothers, shared experiences marked by grief, shame, and anticipated loss. These emotions were often hidden beneath resilience and daily caregiving. Such emotional realities require practitioners to avoid rigid adherence to “procedural” responses and take time to understand the cultural and religious frameworks that shape how Sylheti families view autism. Supporting these families means engaging with them in ways that recognise language, gendered roles, and religious beliefs as central to their lived experiences. This includes working with interpreters trained in cultural mediation, collaborating with community faith leaders where appropriate, and providing therapeutic and advocacy spaces for siblings and carers. Practitioners must also develop an awareness of how decisions around care are influenced by family hierarchy, duty, and emotional obligation. These factors may be overlooked in service assessments but, as the findings of the study suggest, can deeply affect how support is received and sustained.

Conclusion

This chapter discussed the implications of the findings of the study, particularly in terms of their significance for understanding support for autistic adults in Sylheti families, whilst underscoring the importance of ongoing efforts to improve support systems and enhance the quality of life for autistic individuals and their families. The next chapter brings the thesis to a close by providing some final reflections on my experience undertaking the research.

Chapter 7: Conclusion

Introduction

This chapter brings the thesis to a close by providing some closing reflections on undertaking this research, specifically on the nature of this experience based on my identity as a practitioner researcher, completing the study while working in an inner-city local authority as a specialist teacher. As Cooper (2009) has observed, undertaking this type of practice-near research, as a professional with a passion for the subject studied, invariably involves some form of personal change on the part of the researcher.

In this chapter, I provide some brief reflections on my professional development while engaged in the research. I comment on learning from the experience of undertaking the research and consider next steps in moving forward from the project.

Learning from (research) experience

As I embarked on this research, my intention was to "give voice" to – or provide a platform for – the experiences of the parents and siblings of autistic adults within my community, that is, the Sylheti community. My hope was to capture the experiences of parents and siblings and illuminate the complexities of living with an autistic family member over time, as a Sylheti family in England. Initially, I believed that these experiences would be primarily shaped by cultural, religious and knowledge-based influences. And yet, through the process of conducting this research, I realised that the matter is far more multifaceted than I had anticipated. The intricate interplay of emotional, social, and familial dynamics, alongside cultural and religious factors, presented a much more complex picture. This journey has deepened my understanding of the diverse experiences of these families, highlighting the importance of approaching such research with an open mind and a readiness to embrace its complexity. Ultimately, this study not only provided a platform for these voices but also challenged my own assumptions, leading to a more profound appreciation of the multifaceted nature of the experience of living with autism in a Sylheti family.

The objective of my research was to approach the perspectives of siblings and parents, as intertwined, to consider individual experiences but also delve into generational experiences. However, this endeavour necessitated a deeper understanding of the complexities inherent in each relationship and between generations. Initially, again naively, I was confident that my background and experience, having worked extensively in a borough predominantly populated by Sylheti families, would serve as a significant advantage in navigating the research. But, as I learned over time, while this background and experience served me well in accessing the families involved, immersing myself in the process of doing research, as a researcher, was more challenging. It required me to engage carefully with each participant and family and their accounts, to build relationships with them which made the process possible. Furthermore, in doing so, I was prompted to confront uncomfortable emotions and reflect on my own experiences. I would say that this served to be a profound lesson in patience and the need to acknowledge my own vulnerabilities, and embrace empathy and understanding, not just towards the participants, but also towards myself. I found that my own emotional experience was not something that could be set aside for the research, but rather was part and parcel of doing research.

I sought to be fully present throughout each stage of the research journey, recognising it as more than just a process of gathering data or analysing narratives, but immersing myself in the participants’ lived experiences, listening attentively to their stories, and honouring the trust they placed in me. I found myself deeply invested in ensuring they had the necessary mental space during our contact by creating an environment where their concerns about autistic family members could be explored openly, without judgement. And yet, while I sought to foster an environment of trust and safety that would allow for richer, more “live” accounts of experience within families, there were also moments when I felt uncomfortable.

Addressing the often-overlooked needs of the participants while simultaneously respecting the autonomy and dignity of the autistic adults posed a delicate balance. And it was precisely within this discomfort that I recognised the importance of my research. It was a reminder of the complexity and sensitivity inherent to having access to and representing the experience of the community involved and attempting to advocate on their behalf.

Alongside this, I have also learned that the process of self-understanding that is a (by)product of undertaking this type of practice-near, qualitative research extends beyond simply recognising the importance of patience and acknowledging vulnerability as a researcher (Cooper, 2009; Archard and O’Reilly, 2024). It also profoundly affects how one listens to others—not just in research, but as a practitioner. The process required not just patience in tolerating the burdens of conducting research, but also the resilience to navigate the normal ebbs and flows of a substantive research project. This included grappling with unexpected challenges, revising the methodology, embracing the iterative nature of academic enquiry, and understanding that human experience, especially when unconscious processes are involved, does not follow a linear trajectory.

I have found that this experience has profoundly influenced how I work as a professional, giving me greater confidence to take on more independent responsibilities. The process has also made me more inquisitive, encouraging me to consider the complexities of my work from a different perspective and to appreciate the tremendous effort required to complete research projects. My ability to recognise and understand unconscious processes has developed, especially when working with families, young children, and senior leadership teams in schools. This enhanced understanding has made me more attuned to the subtle dynamics at play in these interactions. Alongside this, I have noticed that I embrace a greater degree of creativity when devising strategies to support children and families, and I am more focused on the nuances in the information gathered during assessment practices. This research-minded approach has enriched the way I formulate the nature of difficulties and propose solutions in my work, allowing me to approach challenges with a different, i.e., more nuanced, thoughtful, and effective, mindset.

Next steps

While there is some sense of relief to be writing up and reporting the findings of the research, I find I am also enthused about the opportunities that lie ahead in making use of these findings and disseminating them through various channels. In the short term, I plan to present these findings at relevant professional conferences. To date, I have had the opportunity to present preliminary findings to managers of departments in education and children's services, which has prompted valuable dialogue around service development and training to ensure Sylheti families with autistic members are better supported by the local authority in which I work. Moving forward, I aim to develop this impact further by presentations, as well as academic publications.

Moreover, as touched on above, the lessons I have learned from undertaking this project have already been integrated into my day-to-day work, such as refining intervention strategies for children and adults with autism, advocating for policy changes to better support families, and engaging in reflective conversations regarding practice with colleagues. Conducting this research has not only reinforced my commitment to making a difference but has also deepened my passion for helping individuals with autism and their families. I am dedicated to ensuring that the insights gained from this study translate into meaningful change, both in my professional practice and in the broader community. My hope is to continue being a compassionate and effective advocate for those who may not always have a voice. In this respect, I look forward to continuing to translate the lessons from the research—both in terms of what I found and what I learned about myself and my work—into meaningful action that truly makes a difference.

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Appendix A: Institutional ethical review form

Tavistock and Portman Trust Research Ethics Committee (TREC)

APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact Paru Jeram (academicquality@tavi-port.nhs.uk)

Section a: Project Details

Project title	What are the emotional, psychological and cultural experiences among Bangladeshi families with an adult family member diagnosed with autism?		
Proposed project start date	September 2020	Anticipated project end date	September 2022

Section b: Applicant Details

Name of Researcher	Fahima Nita Khan
Email address	Nitakhan23@gmail.com
Contact telephone number	07491052411

Section c: CONFLICTS OF INTEREST

Will any of the researchers or their institutions receive any other benefits or incentives for participating in this research over and above their normal salary package or the costs of undertaking the research? YES NO If YES, please detail below:
Is there any further possibility for a conflict of interest? YES NO If YES, please detail below:

FOR ALL APPLICANTS

Is your research being commissioned by and or carried out on behalf of a body external* to the trust? (for example, commissioned by a local authority, school, care home, other NHS Trust or other organisation). *Please note that '"external" is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)	**YES NO NA**
If **YES**, please supply details below:	
Has external* ethics approval been sought for this research? (i.e. submission via Integrated Research Application System (IRAS) to the Health Research Authority (HRA) or other external research ethics committee) *Please note that "external" is defined as an organisation/body which is external to the Tavistock and Portman Trust Research Ethics Committee (TREC) If **YES**, please supply details of the ethical approval bodies below **AND** include any letters of approval from the ethical approval bodies:	**YES NO**
If your research is being undertaken externally to the Trust, please provide details of the sponsor of your research.	

Do you have local approval (this includes R&D approval)?	**YES** **NO** **NA**

SECTION D: SIGNATURES AND DECLARATIONS

APPLICANT DECLARATION I confirm that: The information contained in this application is, to the best of my knowledge, correct and up to date. I have attempted to identify all risks related to the research. I acknowledge my obligations and commitment to upholding our University's Code of Practice for ethical research and observing the rights of the participants. I am aware that cases of proven misconduct, in line with our University's policies, may result in formal disciplinary proceedings and/or the cancellation of the proposed research.	
Applicant (print name)	Fahima Nita Khan
Signed	F.khan
Date	24/03/2021

FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY

Name of Supervisor	**Andrew Cooper and Dr Vimala Uttarkar**

Qualification for which research is being undertaken	Professional Doctorate

SECTION E: Details of the proposed research

Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)
This research idea began from my role as a Specialist teacher at a London local authority. One aspect of this role is to assess children and young people with special education needs who have no Education Health Care Plan (EHCP). To apply for an EHCP, I complete an assessment based on the child's development, early years history and needs. During the assessment, parents share stories about their sadness and the helplessness the families have experienced. Access to education and specialist services reduce depending on the gravity of the autism, which impacts the families' experiences. In this research, I want to understand how the families cope with the cultural experiences, emotional and psychological challenges as the young autistic person develops and transitions into an adult. The primary question of this research is:

How do Bangladeshi families experience the challenges through time of having an autistic adult family member?

The subsidiary areas of my research will be:

How does the Bangladeshi culture impact the families’ experiences and their perceptions of autism?

Does the perception of autism alter between different ages?

How have these challenges changed and developed through time?

How have families negotiated the difficulties of having a child with needs who continues to need help?

What are the families’ experiences of education/services and communities?

What anxieties do the families experience when making plans for the future?

These areas will help me to understand the attitudes and beliefs about autism within the Bangladeshi community. By interviewing siblings and parents, this will give me an insight into common grounds and differences the two generations have of autism. What the families' emotional experiences are when they think about the future — such as marriage, moving homes, and bereavement? I will also need to be aware that a completely different area may also come up during the data analysis stage.

Provide a statement on the aims and significance of the proposed research, Including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. **(Do not exceed 700 words)**

In this research, I will recruit one family with level three autism and the rest of the families with levels one and two. I will focus on adults with levels one and two autism as access to relevant support programmes for these adults and families is limited. I also believe that interviewing a family with level three autism will help me compare their experiences to those on level one and level two.

A typical profile of a level one autistic adult would be able (to some degree) to be capable of living independently. There is no ongoing support to deal with changes for adults and families. Job opportunities and access to support from job coaches can be restricted. Level two and three do have some crossovers, but level two adults may not have access to the support that is provided for families at level three.

Adult autism services [redacted] Adults with level three autism receive continuous support from adult social care, respite and other interventions. Only two organisations offer support to families and the adult with autism across the borough. This support includes interventions training on independent living and advocacy support. There are no services that provide emotional support to families catering to the Bangladeshi community. This research will give first-hand narratives of experiences from two generations (parents and siblings) to understand what factors are needed to create an effective and impactful programme for the Bangladeshi adult and the family to access.

The research will open a broader discussion within the community to allow families to be more open about their experiences. By sharing their stories, it can be a method to ease the cultural pressures and stress that may hinder the family units. The stories shared by the participants will help parents with young children diagnosed with autism. Families will be able to relate to the experiences and learn about how to prepare for adulthood.

The potential impact of the research:

- Outcomes of the research can help local authorities working with the families to have an in-depth understanding.
- Local authorities and other external services to create engaging interventions to support the family.
- Make adult services for autism more accessible with workshops/interventions to enable the adult with autism to live independently to some degree.

Provide an outline of the methodology for the proposed research, including proposed method of data collection, tasks assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)

This research is based on a narrative approach, as this enables the participants to have a voice to share their lived experiences. The research design is a qualitative method involving free association narrative interviews (FANI). The FANI method is a great tool to gather complex information of the participants' cultural and emotional experiences. It gives the participants a platform to express their experiences in the order that suits them. I will take a flexible approach with siblings by offering a focus group or individual interviews using the FANI method.

Interview process

Stage one: – Initial question to parents

> *Take as long as you like, and I will not interrupt. Please tell me your experience of having a child with autism who is now an adult. In particular, the cultural perceptions and the challenges of planning for the future.*

I will repeat the question twice at the beginning in Bengali and English.

Stage two: Returning interview to probe and explore the responses to particular and unexplored areas related to my subsidiary areas.

Same stages and questions will be followed with siblings who will be interviewed individually or in groups.

I have changed parts of my data collection method due to Covid-19. The participants will have a choice of:

Interview at the property by following social distancing guidelines if London is not in lockdown.

Zoom interviews (*I will need to ensure parents have access to a laptop and headsets. One sibling will also have to be available in case there are technical difficulties).*

Access to a local community hall so the parents can come and meet with me.

I will use an audiotape to record and transcribe the interviews in person. I will use the recording facility on Zoom providing the participants agree. I have selected “video recording” in section 9 as the Zoom facility recording will be video. I will take notes as a contingency if the recorder stops working or there are some technical difficulties. The duration of each interview will vary depending on responses from participants, although I have a cut-off point of 120 minutes.

Data analysis

I am interested in psychoanalysis this research is not based on the psychoanalytic work on autism itself. Instead, I am interested in understanding the interview processes and the participant's anxiety that may surface by their responses. I will use Braun and Carke’s thematic analysis method to analyse relevant themes during the interview process.

I will use Woodcock's (2016) approach to listening to the data four times from a different perspective:

The story and the researcher’s reflexive responses.

How the respondents speak about themselves.

How the respondents place themselves within the social and relationship networks.

Dominant ideologies and power relations.

Data analysis

I will first translate the data from the parent’s interviews from Bengali to English by listening and typing up the response. I will then use the six-stage structure in thematic analysis to analyse my data.

The six stages include:

Data familiarity and transcribing

Initial coding

Searching for themes

Reviewing

Defining themes

Final report

After the interview I will give myself two weeks to transcribe the interview. Once I have transcribed the interview, I will delete the recording and save the transcription on a password-protected document.

I will require five months to recruit, complete the interviews and analyse the data.

SECTION F: Participant details

Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why this criteria is in place. (Do not exceed 500 words)

Recruitment process

I have liaised with [redacted]

I also have access to this community through my charity work and community networks. I have approached two suitable families who have indicated their willingness to participate in my research once I have received the ethics approval.

Initial contact with families

Once I have received interest via email or telephone, I will contact the families to have a conversation about the study and to determine if the family are best suited for the research – against the criteria. I will explain my research to ensure that I recruit willing and interested families in my study.

After I have recruited the four families, I will have an initial meet and greet via Zoom with each family. This will allow the participants to ask questions and become familiar with me. I will email or post information packs about the research and a contract to the families. Both documents will be in English and Bengali, so the parents will be able to understand everything. The contract will be clear, and it will explain that the information used will not identify the family. I will also state that if the families no longer wish to participate, they can withdraw.

Requirements for the participant:

Bangladeshi origin and must speak Sylheti dialect.

I am focusing on Sylheti speakers as I will be able to understand and interpret the parents' experiences. There is no age limit for the parents to participate in the research.

The families will need to have siblings aged 18 years old and above.

I have decided to interview siblings aged 18 years and over so they can understand and be in the position to explain their views. I am interested in exploring if there are differences in the perceptions and experiences of the parent group in comparison to those of the sibling groups.

The family must have an autistic adult aged 18 years and above.

The family must live in London.

The family must have access to a laptop, internet and a Zoom account.

The above criteria will be stated on the research flyer along with my email address to contact me. Once families contact me via email, I will arrange a telephone call to speak with the families that have expressed an interest and ask the following questions:

- How many siblings are there in the family?
- How old are the siblings?
- Do they have access to a laptop or internet?
- Describe the level of need the autistic adult has.

Once the participants are recruited, I will send via post and email the following documents:

Consent form – I will write this in Bengali and English

Participant information sheet – I will also write this in Bengali and English

The contract will explain that the information used will not identify the family. The information collected from the interview will be transcribed and the recording of the interview will be destroyed. The transcription will be kept for six to ten years. If families wish to withdraw from the research, they will have the time before and during the interview and up to two weeks after the interview to withdraw.

Will the participants be from any of the following groups?*(Tick as appropriate)*

☐ Students or staff of the Trust or the University.

☒ Adults (over the age of 18 years with mental capacity to give consent to participate in the research).

☐ Children or legal minors (anyone under the age of 16 years)[1]

☐ Adults who are unconscious, severely ill or have a terminal illness.

☐ Adults who may lose mental capacity to consent during the course of the research.

☐ Adults in emergency situations.

☐ Adults[2] with mental illness – particularly those detained under the Mental Health Act (1983 and 2007).

☐ Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).

☐ Prisoners, where ethical approval may be required from the **National Offender Management Service (NOMS).**

☐ Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).

☐ Healthy volunteers (in high-risk intervention studies).

☐ Participants who may be considered to have a pre-existing and potentially dependent[3] relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).

☐ Other vulnerable groups (see Question 6).

☐ Adults who are in custody, custodial care, or for whom a court has assumed responsibility.

☐ Participants who are members of the Armed Forces.

[1] *If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability*[3]*, any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.*

[2] *"Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home, or receiving hospital or social care services." (Police Act, 1997)*

[3] *Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.*

Will the study involve participants who are vulnerable? NO

For the purposes of research, "vulnerable" participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from the participant's personal characteristics (e.g. mental or physical impairment) or from their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness). Where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable.

Adults lacking mental capacity to consent to participate in research and children are automatically presumed to be vulnerable. Studies involving adults (over the age of 16) who lack mental capacity to consent in research must be submitted to a REC approved for that purpose. Please consult Health Research Authority (HRA) for guidance: https://www.hra.nhs.uk/

6.1. If YES, what special arrangements are in place to protect vulnerable participants' interests?

If YES, the research activity proposed will require a DBS check. *(NOTE: information concerning activities which require DBS checks can be found via https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance)*

Do you propose to make any form of payment or incentive available to participants of the research? NO

If YES, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in

English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)

My research participants will only be adults with capacity. The parents may not be comfortable in English so I have translated both the consent form and the participant information sheet into Bengali.

I will also meet with every family member and explain the research in both Bengali and English.

SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT

Does the proposed research involve any of the following? *(Tick as appropriate)*

☐ use of a questionnaire, self-completion survey or data-collection instrument (attach copy)

☐ use of emails or the internet as a means of data collection

☐ use of written or computerised tests

☒ interviews (attach interview questions)

☐ diaries (attach diary record form)

☐ participant observation

☐ participant observation (in a non-public place) without their knowledge / covert research

☒ audio-recording interviewees or events

☒ video-recording interviewees or events

☐ access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes

☐ administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process ☐ performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction ☐ investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs) ☐ procedures that involve the deception of participants ☐ administration of any substance or agent ☐ use of non-treatment of placebo control conditions ☐ participation in a clinical trial ☐ research undertaken at an off-campus location (risk assessment attached) ☐ research overseas (copy of VCG overseas travel approval attached)
Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life? NO If YES, please describe below including details of precautionary measures.

Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.
My experience of interviewing families with Special Educational Needs comes from my current role. In the last six years, I have worked with families to assess the child/young persons' needs on a weekly basis. The assessments are carried out during home visits or at a children's centre or school. Due to lockdown, I have had to adapt and carry out the assessments via Zoom or telephone call as some families do not have access to a laptop. When completing the assessments, I ensure the following are in place as I am not physically at the property: - Parents are not distracted and are in a quiet space. - Parents have enough time to engage in the assessment. - Internet access is working. - Families can have a break if needed. - Mobile phones or laptops are fully charged and there is access to a headset. During my first contact with the parents, I am clear that it will take up to 120 minutes to complete the assessment. Therefore, the parents will need to ensure they do not have any commitment elsewhere. During these assessments (at home, online or telephone) parents share at length their experiences, hardships and happy moments. When experiences are shared, sometimes a family member can get upset. In this instance, I stop the assessment by offering them a break or an opportunity to share their feelings. I have a Masters in Psychoanalytical perspective in teaching and learning, which helps me understand concepts such as projections, transference,

and countertransference. I also work as a school counsellor two days a week, and within my team, I specialise in attachment and how this impacts on the pupils' learning.

My education and experience will help me understand the families' emotional responses during the research.

Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)

NOTE: Where the proposed research involves students of our University, they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

From my experience many Bangladeshi families with an autistic family member feel isolated. Families with an autistic adult do not always attend events and if they do, only some of the members attend. The mother stays behind to care for the adult on the basis of feeling ashamed of the adult's behaviour/hygiene or lack of social skills. On occasions if the whole family attend, parents and siblings feel responsible for the autistic adult's behaviour and this has an impact on the family's experience of the social event.

The participants of this research will be able to share their experience and feel valued when their struggles are given a voice. Participants will be able to speak about what they felt was shameful and hurtful in having a sibling or a child with autism. It will allow participants during their interviews to reflect and be proud of their achievements as a family unit. By sharing their experiences, it will give the families a chance to feel part of a project which can have a positive impact for other families and in understanding what interventions are needed to better support families and the adult with autism.

Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)

Covid 19

Interviews and contact with the families might be delayed if the families are self-isolating or recovering from the virus. Therefore, I will need to be mindful of my own timescale.

I am an experienced professional who can provide a helpful response if difficult experiences and emotions surface for parents and siblings during the interview.

I have the following in place as contingency:

- Offer a break if the participant feels emotional.
- Offer access to counselling by a trained counsellor.
- Participant will be offered the opportunity to terminate the interview.

Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants. Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the

research, the participant’s performance and/or the results of the research. (Do not exceed 500 words)
After the interview, the families will have an opportunity to meet with me via Zoom informally. I will give some feedback on the interview process so far and allow the participants to reflect on the interview process, how they felt and if they would like to share their experiences with me. I can offer to refer them for counselling to colleagues in my organisations, and Step Forward with whom I have discussed and who have agreed to take on small numbers if I want to refer. Once the research has been completed, I intend to share the findings with the community and the families.

For Research undertaken away from the trust or outside the UK

15. Does any part of your research take place in premises outside the Trust?

YES, and I have included evidence of permissions from the managers or others legally responsible for the premises. This permission also clearly states the extent to which the participating institution will indemnify the researchers against the consequences of any untoward event.

16. Does the proposed research involve travel outside of the UK? No

YES, I have consulted the Foreign and Commonwealth Office website for guidance/travel advice http://www.fco.gov.uk/en/travel-and-living-abroad/

YES, I am a non-UK national and I have sought travel advice/guidance from the Foreign Office (or equivalent body) of my country of origin

YES, I have completed the overseas travel approval process and enclosed a copy of the document with this application

For details on university study abroad policies, please contact academicquality@tavi-port.nhs.uk

IF YES:

17. Is the research covered by the Trust's insurance and indemnity provision? NA

YES NO

18. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place.

NOTE:

For students conducting research where the Trust is the sponsor, the Dean of the Department of Education and Training (DET) has overall responsibility for risk assessment regarding their health and safety. If you are proposing to undertake research outside the UK, please ensure that permission from the Dean has been granted before the research commences (please attach written confirmation).

SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL

18. **Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials. YES**

If **NO**, please indicate what alternative arrangements are in place below:

19. **Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES

If **NO**, please indicate what alternative arrangements are in place below:

20. The following is a <u>participant information sheet</u> checklist covering the various points that should be included in this document.

☒ Clear identification of the Trust as the sponsor for the research, the project title, the Researcher or Principal Investigator and other researchers along with relevant contact details.

☒ Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.

☒ A statement confirming that the research has received formal approval from TREC.

☒ If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.

☐ A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.

☒ Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.

☒ Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.

☒ A statement that the data generated in the course of the research will be retained in accordance with the University's Data Protection Policy.

☒ Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

21. The following is a consent form checklist covering the various points that should be included in this document.

☒ Trust letterhead or logo.

☒ Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.

☒ Confirmation that the project is research.

☒ Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.

☒ Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.

☒ If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.

☒ The proposed method of publication or dissemination of the research findings.

☐ Details of any external contractors or partner institutions involved in the research.

☐ Details of any funding bodies or research councils supporting the research.

☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

SECTION H: CONFIDENTIALITY AND ANONYMITY

Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.

☐ Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?

☒ The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).

☐ The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).

☐ Participants have the option of being identified in a publication that will arise from the research.

☐ Participants will be pseudo-anonymised in a publication that will arise from the research. (i.e. the researcher will endeavour to remove or alter details that would identify the participant.)

☐ The proposed research will make use of personal sensitive data.

☐ Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations. YES

If NO, please indicate why this is the case below:

If there are legal requirements such as Freedom of Information request, I will be required to share it.

I am going to anonymise all the data gathered.

NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.

SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT

24. **Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES**

If **NO**, please indicate what alternative arrangements are in place below:

25. In line with the 5th principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.

☐ 1-2 years ☐ 3-5 years ☒ 6-10 years ☐ 10> years

NOTE: Research Councils UK (RCUK) guidance currently states that data should normally be preserved and accessible for 10 years, but for projects of clinical or major social, environmental or heritage importance, for 20 years or longer. (http://www.rcuk.ac.uk/documents/reviews/grc/grcpoldraft.pdf)

26. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.

☒ Research data, codes and all identifying information to be kept in separate locked filing cabinets.

☒ Access to computer files to be available to research team by password only.

☐ Access to computer files to be available to individuals outside the research team by password only (See **23.1**).

☐ Research data will be encrypted and transferred electronically within the European Economic Area (EEA).

☐ Research data will be encrypted and transferred electronically outside of the European Economic Area (EEA). (See **28**).

NOTE: Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

☐ Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.

☐ Use of personal data in the form of audio or video recordings.

☐ Primary data gathered on encrypted mobile devices (i.e. laptops). **NOTE:** This should be transferred to secure UEL servers at the first opportunity.

☐ All electronic data will undergo secure disposal.

NOTE: For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard “secure empty trash” option; an alternative is Permanent eraser software.

☐ All hardcopy data will undergo secure disposal.

NOTE: For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

27. **Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.**
N/A
28. **Please provide details on the regions and territories where research data will be electronically transferred that are external to the European Economic Area (EEA).**
N/A
29. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs? NO ☒
If **YES** please provide details:

SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS

30.* How will the results of the research be reported and disseminated? *(Select all that apply)

☒ Peer reviewed journal

☐ Non-peer reviewed journal

☒ Peer reviewed books

☒ Publication in media, social media or website (including Podcasts and online videos)

☒ Conference presentation

☐ Internal report

☐ Promotional report and materials

☐ Reports compiled for or on behalf of external organisations ☐ Dissertation/Thesis

☐ Other publication

☐ Written feedback to research participants

☒ Presentation to participants or relevant community groups

☐ Other (Please specify below)

SECTION K: OTHER ETHICAL ISSUES

31. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?

NA

SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS

32. Please check that the following documents are attached to your application.

☐ Letters of approval from any external ethical approval bodies (where relevant)

☐ Recruitment advertisement

☒ Participant information sheets (including easy-read where relevant)

☒ Consent forms (including easy-read where relevant)

☐ Assent form for children (where relevant)

☐ Evidence of any external approvals needed

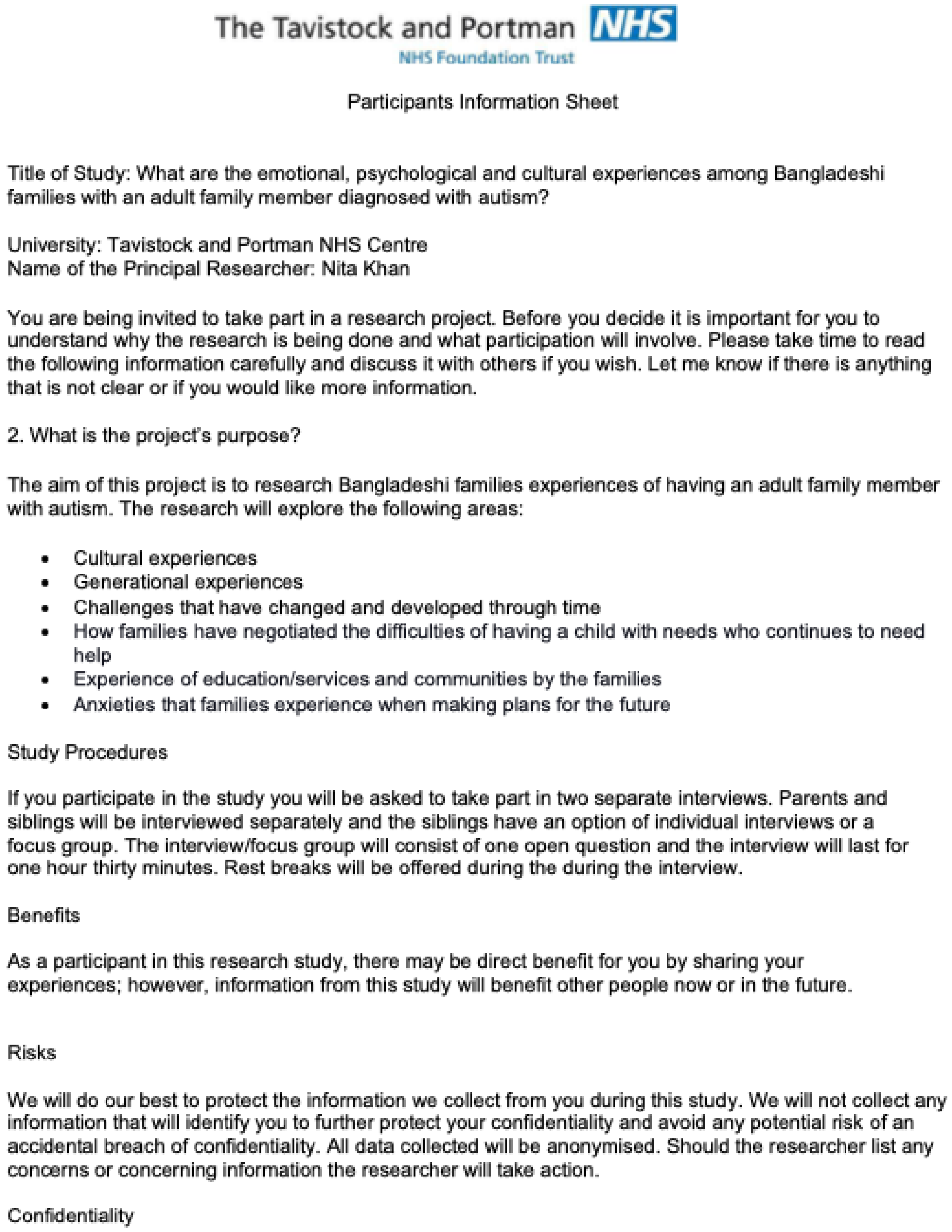
☐ Questionnaire

☐ Interview Schedule or topic guide

☐ Risk Assessment (where applicable)

☐ Overseas travel approval (where applicabl

Appendix B: Participant information sheet



The Tavistock and Portman NHS
NHS Foundation Trust

Participants Information Sheet

Title of Study: What are the emotional, psychological and cultural experiences among Bangladeshi families with an adult family member diagnosed with autism?

University: Tavistock and Portman NHS Centre
Name of the Principal Researcher: Nita Khan

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Let me know if there is anything that is not clear or if you would like more information.

2. What is the project's purpose?

The aim of this project is to research Bangladeshi families experiences of having an adult family member with autism. The research will explore the following areas:

- Cultural experiences
- Generational experiences
- Challenges that have changed and developed through time
- How families have negotiated the difficulties of having a child with needs who continues to need help
- Experience of education/services and communities by the families
- Anxieties that families experience when making plans for the future

Study Procedures

If you participate in the study you will be asked to take part in two separate interviews. Parents and siblings will be interviewed separately and the siblings have an option of individual interviews or a focus group. The interview/focus group will consist of one open question and the interview will last for one hour thirty minutes. Rest breaks will be offered during the during the interview.

Benefits

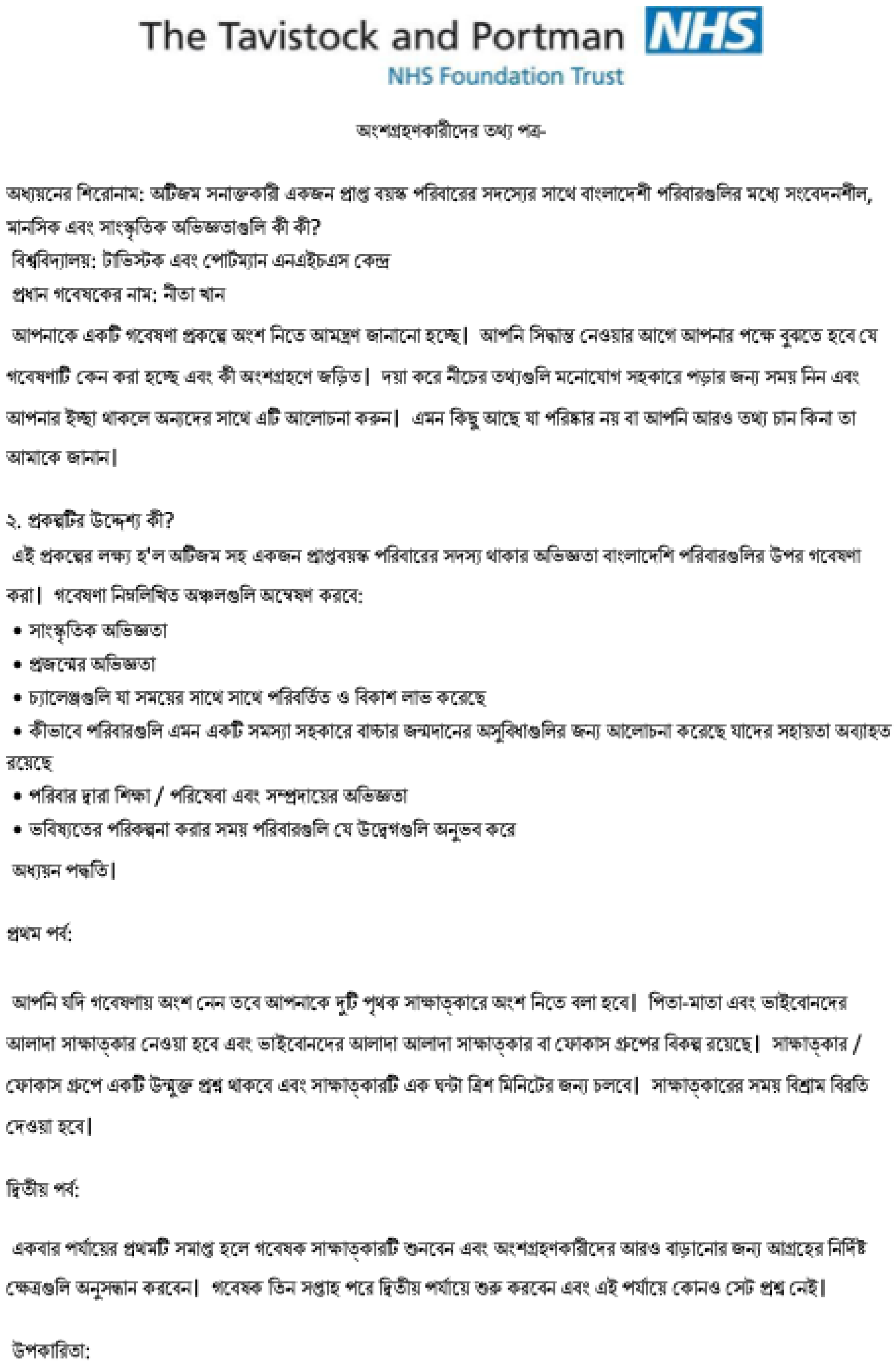
As a participant in this research study, there may be direct benefit for you by sharing your experiences; however, information from this study will benefit other people now or in the future.

Risks

We will do our best to protect the information we collect from you during this study. We will not collect any information that will identify you to further protect your confidentiality and avoid any potential risk of an accidental breach of confidentiality. All data collected will be anonymised. Should the researcher list any concerns or concerning information the researcher will take action.

Confidentiality

Appendix C: Participant information sheet (Bengali version)



The Tavistock and Portman NHS
NHS Foundation Trust

অংশগ্রহণকারীদের তথ্য পত্র-

অধ্যয়নের শিরোনাম: অটিজম সনাক্তকারী একজন প্রাপ্ত বয়স্ক পরিবারের সদস্যের সাথে বাংলাদেশী পরিবারগুলির মধ্যে সংবেদনশীল, মানসিক এবং সাংস্কৃতিক অভিজ্ঞতাগুলি কী কী?
বিশ্ববিদ্যালয়: টাভিস্টক এবং পোর্টম্যান এনএইচএস কেন্দ্র
প্রধান গবেষকের নাম: নীতা খান

আপনাকে একটি গবেষণা প্রকল্পে অংশ নিতে আমন্ত্রণ জানানো হচ্ছে। আপনি সিদ্ধান্ত নেওয়ার আগে আপনার পক্ষে বুঝতে হবে যে গবেষণাটি কেন করা হচ্ছে এবং কী অংশগ্রহণে জড়িত। দয়া করে নীচের তথ্যগুলি মনোযোগ সহকারে পড়ার জন্য সময় নিন এবং আপনার ইচ্ছা থাকলে অন্যদের সাথে এটি আলোচনা করুন। এমন কিছু আছে যা পরিষ্কার নয় বা আপনি আরও তথ্য চান কিনা তা আমাকে জানান।

২. প্রকল্পটির উদ্দেশ্য কী?

এই প্রকল্পের লক্ষ্য হ'ল অটিজম সহ একজন প্রাপ্তবয়স্ক পরিবারের সদস্য থাকার অভিজ্ঞতা বাংলাদেশি পরিবারগুলির উপর গবেষণা করা। গবেষণা নিম্নলিখিত অঞ্চলগুলি অন্বেষণ করবে:

- সাংস্কৃতিক অভিজ্ঞতা
- প্রজন্মের অভিজ্ঞতা
- চ্যালেঞ্জগুলি যা সময়ের সাথে সাথে পরিবর্তিত ও বিকাশ লাভ করেছে
- কীভাবে পরিবারগুলি এমন একটি সমস্যা সহকারে বাচ্চার জন্মদানের অসুবিধাগুলির জন্য আলোচনা করেছে যাদের সহায়তা অব্যাহত রয়েছে
- পরিবার দ্বারা শিক্ষা / পরিষেবা এবং সম্প্রদায়ের অভিজ্ঞতা
- ভবিষ্যতের পরিকল্পনা করার সময় পরিবারগুলি যে উদ্বেগগুলি অনুভব করে

অধ্যয়ন পদ্ধতি।

প্রথম পর্ব:

আপনি যদি গবেষণায় অংশ নেন তবে আপনাকে দুটি পৃথক সাক্ষাত্কারে অংশ নিতে বলা হবে। পিতা-মাতা এবং ভাইবোনদের আলাদা সাক্ষাত্কার নেওয়া হবে এবং ভাইবোনদের আলাদা আলাদা সাক্ষাত্কার বা ফোকাস গ্রুপের বিকল্প রয়েছে। সাক্ষাত্কার / ফোকাস গ্রুপে একটি উন্মুক্ত প্রশ্ন থাকবে এবং সাক্ষাত্কারটি এক ঘন্টা ত্রিশ মিনিটের জন্য চলবে। সাক্ষাত্কারের সময় বিশ্রাম বিরতি দেওয়া হবে।

দ্বিতীয় পর্ব:

একবার পর্যায়ের প্রথমটি সমাপ্ত হলে গবেষক সাক্ষাত্কারটি শুনবেন এবং অংশগ্রহণকরীদের আরও বাড়ানোর জন্য আগ্রহের নির্দিষ্ট ক্ষেত্রগুলি অনুসন্ধান করবেন। গবেষক তিন সপ্তাহ পরে দ্বিতীয় পর্যায়ে শুরু করবেন এবং এই পর্যায়ে কোনও সেট প্রশ্ন নেই।

উপকারিতা:

Appendix D: Participant consent form

The Tavistock and Portman NHS
NHS Foundation Trust

Consent to take part in research

Project Title: What are the emotional, psychological and cultural experiences among Bangladeshi families with an adult family member diagnosed with autism?

Principle researcher: Fahima Nita Khan

I... voluntarily agree to participate in this research study.

- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequence of any kind.

- I understand that I can withdraw permission to use data from my interview within two weeks after the interview has taken place, in which case the material will be deleted.

- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

- I understand that participation involves two interviews involving focus group with siblings/individual interviews. The first interview will consist of one question and the second interview will focus on areas that I covered in my first interview. I understand that for the second interview there are no set questions.

- I understand that I will not benefit directly from participating in this research.

- I agree to my interview being audio-recorded.

- I understand that all information I provide for this study will be treated confidentially.

- I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.

- I understand that disguised extracts from my interview may be quoted in the researcher’s thesis, conference presentation and published papers or journals.

- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities – they will discuss this with me first but may be required to report with or without my permission.

- I understand that signed consent forms and original audio recordings will be retained in and kept in separate locked filing cabinets and verbatim from the interview will be saved with password only access for the researcher.

- I understand that a transcript of my interview in which all identifying information has been removed will be retained for six years.

- I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.

- I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

Signature of research participant

--- Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

-- Signature of researcher Date

Appendix E: Interview schedule

Introduction
Thank you for agreeing to participate in this study. Confirm consent and the confidential nature of the interview.
The goal of this interview is to hear about your experiences of having an adult family member with autism. Please take your time and answer at your own ease.
Primary narrative question:
Take as long as you like, and I will not interrupt. Please tell me your experience of having a child with autism who is now an adult. In particular, I’m interested in how cultural perceptions have influenced your experience and the challenges you face in planning for the future.
Probing questions:
Can you tell me more about that?
How did that make you feel?
What do you think influenced that experience?
Reflective phase:
Looking back at what you’ve shared…
What do you think these experiences say about the support systems available to you and your family?
How have cultural perceptions shaped your journey?
Closing question:
Is there anything else you would like to share that we haven’t covered?
Debrief:
Thank you for sharing your story with me today. Your insights are invaluable. If you have any questions or thoughts afterward, feel free to reach out.