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The Experiences of Adult-Children from an Indian Heritage whose Parents have Lived with Mental Health Difficulties

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Contents

Table of Contents

List of Tables and Figures

Abstract

Research suggests that in the United Kingdom (UK), there are over two million children living with a parent experiencing mental health difficulties (MHD). There is a growing body of literature focusing on the experiences and impact on these children, finding that the majority can often experience troubling emotions, and psycho-social difficulties which go unnoticed by health and social care services, leading to difficulties remaining with individuals into adulthood.

To date, studies have neglected to explore the impact culture can have on family members, and therefore the aim of this study was to gain a richer understanding of the lived experiences from adult-children identifying as being from an Indian heritage, and who have grown up around parental MHD. Semi-structured interviews were conducted with seven individuals (four females, and three males) living in the UK, aged 34 to 54 years old, who had grown up with a parent with MHD. Transcripts were analysed using Interpretative Phenomenological Analysis where five master themes were co-constructed describing participants' experiences; 'Making sense with a lack of knowledge', 'Managing stigmatised silence', 'Recognising the internal and external void', 'Feeling distant yet accountable', and 'Gaining positives from parental mental health difficulties'. The data is discussed in consideration of theory and literature, finding similarities with existing research, and also factors unique to this population.

Given the findings from this study, clinical implications are explored, notably, emphasising the need for a whole family approach to interventions, and for services to be more culturally sensitive and relevant to the needs of populations underrepresented in service utilisation. Suggestions for further research are made, in a hope to add to the paucity of literature in the field of parental mental health and culture, and create change.

Chapter 1 - Introduction

This research sits in the field of parental mental health, focusing on the adult-child's perspective of growing up with a parent with MHD, where the family identify as originating from Indian heritage. Research illustrates a relationship between poor parental mental health, and challenging outcomes for their children (Rutter & Quinton 1984), however, there are studies suggesting parents who experience MHD can continue to parent well, without their child incurring problems later in life (Beardslee & Podorefsky, 1988).

This chapter starts by orientating the reader to the researcher's position in relation to the research, proceeding to define key terminology used in this study. The known prevalence of children affected by parental MHD will be introduced, followed by discussing themes highlighted in research exploring children's narratives of their childhood. Policies and legislation related to this field will be covered, moving on to consider contributing factors to a child's experience, namely theories of child development, and the role of culture. Lastly, existing literature exploring an adult-child's perspective of growing up with a parent experiencing MHD is systematically reviewed, gaps in the research are highlighted, leading on to the current study and its objectives.

1.1 Considering Reflexivity

'Experts contend that through reflection, researchers may be aware of what allows them to see as well as what inhibits their seeing' (Russell & Kelly, 2002 as cited in Watt, 2007 p.82). Becoming reflexive involves being considerate with the phenomena researched, recognising the researcher's impact of their thoughts, biases, and values on the work. I will endeavour to adopt an openness and transparency about this research at every stage. To introduce how I came to explore this topic, I have chosen to write in the first person allowing for a more personal stance.

1.2 The Researchers Position

As an Indian female, family has always been central in shaping my values, instilling culture, and helping in the development of my sense of self. I consider myself fortunate for my life experiences, and learnings that have been afforded to me along the way. My interest in this area stems from challenging situations that have arisen in my family, and those continuing to arise in the culture.

Whilst conducting this research, I found myself in awe of those individuals who came forward to share their stories, speaking with strength and humility. At times my feelings were coupled with sadness upon hearing about difficult childhoods, and for some participants ongoing challenges in adulthood. All participants reported wanting to participate in this study so at the very least, their experiences could be shared and perhaps resonate with others who grew up in similar situations. By adopting a qualitative approach, I was able to ensure participants' voices and stories were heard. Whilst I recognise my bias in interpretation and closeness to the topic, my intention in writing this study is to reinforce findings in this area, highlighting the role of culture, specifically Indian culture. It is hoped that when health and social care professionals engage with families affected by parental MHD, they remain curious, exploring the impact on children, and fulfilling needs that are often unmet (Knutsson-Medin, et al. 2007; Slack & Webber, 2008).

1.3 Theoretical Position of Researcher

Discovering my epistemological position has developed through doctoral training where I have been provided the opportunity to reflect on my values, understanding the lenses through which I view the world, starting to make sense of the type of Clinical Psychologist I wish to be. I entered Clinical Psychology with a strong foundation in positivist thinking, however, also recognising that the use of objectivity and neutrality could not account for the meaning individuals gave to certain experiences, as they experienced different parts of reality. I found taking a critical realist approach (Bhaskar et al., 1998) allowed me to account for the existence of reality, and the impact of culture and context on one's acquisition of knowledge, including how one viewed themselves, others, and the world. In this study, I will attempt to use the multiple experiences from participants to capture their lived experience of growing up with parental MHD, and the impact culture may have.

1.4 Use of Language

The following section outlines key terminology used throughout this thesis. It is known that language is a powerful tool that can be used to share knowledge, and empower individuals. In the field of mental health, language can also be used to dehumanise, stigmatise, and create difference. Terms used within this study, may not be the terms chosen by others, however, they are borne from the researcher's professional and personal experiences.

1.4.1 Adult-Child

Within the context of this study, the term adult-child refers to a person who is a child of a parent that experienced, or is experiencing MHD, and who is above the age of 18.

1.4.2 Indian Heritage

Indian heritage has been used to denote any person identifying as being from an Indian background, including all castes, religions, and creeds that reside in India. This includes but is not limited to individuals who identify as Sikh, Gujarati, Jain, Muslim, and Christian.

1.4.3 Mental Health Difficulties (MHD)

MHD as a term, can encompass a range of difficulties including those given diagnostic labels such as depression, anxiety, bi-polar disorder and schizophrenia (MIND, 2020). In this thesis, the term MHD has been chosen as it represents challenges and distress that can be faced with mental health, without the assumption of 'illness'. It was also important that the language used was familiar to participants.

1.5 Parental mental health and children

1.5.1 Prevalence

Studies estimate that one in four adults may experience MHD in their lifetime, with more than 50% of those individuals identifying as being parents (Royal College of Psychiatrists, 2011). The Children's Commissioner's Report on Vulnerable Children (2019) reported that 3.7 million children live with a parent experiencing MHD in the UK; just over half of these children (n=17,000) are below the age of 18 years old (The Royal College of Psychiatrists, 2011).

Through widening the research to include young carers, Abraham and Aldridge (2010) suggest 170,000 children care for a parent experiencing physical and /or MHD. It is understood that figures are an approximation, as it is argued that adult mental health services still fail to notice, and therefore support children's needs (Cooklin, 2009). The figures cited relate only to individuals who come forward and access support from services. This may exclude individuals from some cultural groups who may conceptualise distress differently, therefore seeking support via other avenues. Additionally, research exploring those who use services, report an inequitable variation of those from a Black Asian and Minority Ethnic (BAME) heritage, suggesting families are left without help and the support needed (Scheppers et al., 2006).

Research focusing on the experiences of children who live with a parent experiencing MHD is steadily growing, with the majority of studies suggesting children are significantly affected, often attending to their parent's needs instead of their own (Grove et al., 2015). Studies also find children are more vulnerable to developing their own MHD (Afzelius et al., 2017), showing a higher rate of behavioural and developmental difficulties, compared to their peers who live without the presence of parental MHD (Beardslee et al., 1988). Children can be affected regardless of whether the parent experiencing difficulties are mothers or fathers, however, there exists much less research on paternal mental health (Smith, 2004). Impact on the child(ren) depends on the severity and chronicity of difficulties experienced, and whether or not support is available to them. In their seminal work, Rutter (1966, as cited in Smith, 2004) suggested direct exposure to difficulties described as delusions, or unpredictable behaviour, can become very confusing for a child (Rutter 1966 as cited in Smith, 2004). Another pertinent factor in the experience for the child is their age and stage of development, as this determines the sense making, vulnerability, as well as the child's capacity to be resilient (Smith, 2004). For babies and young children, parental MHD can threaten their attachment with their main caregiver, resulting in their basic needs not being met (Murray, 1992; Smith, 2004). As children age, they can become accepting of the relational disruptions caused with their parent, however, if managing their parent's unpredictable behaviour, resentment and anger can develop (Smith, 2004). Overall, narratives from adult-children speak of a lowered self-esteem, and increased psycho-social problems (Abraham & Stein, 2010), and for some, an increased suicidal risk (Murphy et al., 2015). In many cases children may be acting as carers for their parents, without receiving the emotional or financial support they are due (Jenkins & Wingate, 1994). These understandings have led to a growing interest in exploring the experiences and needs of children.

1.5.2 Experiences as a child

Research conducted by Murphy and colleagues (2015, 2017) exploring the impact of parental MHD on children, reported the following themes: 'the difficulty of living with stigma and secrecy', 'the loss of identity and their parent', 'finding themselves' and 'living with fear and mistrust'. Narratives of childhood have also contained themes such as, feeling responsible for their parents, and concerns on how to support them (Dam & Joensen, 2017). Stallard et al., (2004) reported that children's confusion about their parent's behaviours, frequently led them to question family members to learn more. Their curiosity was often silenced by family not wanting to discuss or acknowledge it (Stallard et al., 2004). This can leave children harbouring worries, and feeling alone (Murphy et al., 2015). Moreover, recognising differences between themselves and their peers, may lead children to feel more isolated (Murphy et al., 2017). Other commonly reported risks factors for children include an unstable and unpredictable home life (Dam & Joensen, 2017), stigma from others around them, and the increased risk of being bullied (Lereya et al., 2015). Research exploring the longer-term effects of parental MHD have found that as children age into adulthood, they can experience difficulty in trusting others (Smith, 2004).

Howard (2000) suggested that professionals working in adult mental health, seldom acknowledged and explored the wellbeing of dependents, of parents with MHD. This, coupled with the finding that children may appear to be well and resilient while actually in need of support (Infant, Australian, Adolescent Child, and Family Mental Health Association, 2004), means children can often be overlooked. For some parents, MHD can be all-consuming, affecting parenting ability, resulting in the most extreme cases of having the child removed from home, or with the parent being hospitalised (Smith, 2004). On the occasions when these situations are not explained to a child, feelings of confusion can be further fuelled.

1.5.3 Children known as carers

As a child ages, their awareness and understanding of mental health may increase, and some children take on carer roles; the 2011 census reported 244,000 children in the UK, under the age of 19, were performing caring duties, with 23,000 children being under the age of nine years old (Office for National Statistics, 2013). Increasingly in the UK, third sector organisations working with young people, extend their age limit to 21 or 25 years old, bridging the gap between child and adolescent mental health services, and adult services. However, the distinction of ‘up to the age of 18 years old’ is important to recognise, as legally, individuals below the age of 18 are considered to be children, and require a level of responsibility and duty of care (Aldridge, 2018). This is important for children that do access services, to receive the benefits and support due to them.

There will also be children fulfilling a caring role, who are never identified. Within literature, these children are known as 'hidden' young carers (Aldridge, 2018). Gaining an accurate figure of the number of under 18 year olds fulfilling a caring role is problematic, in part due to societal stigma, prejudice, and discrimination connected to mental health, leading to familial secrecy and shame (Dearden & Becker, 2004; Tanner 2000). Another barrier to young carers being identified is due to beliefs that family, and their culture hold. There may be an expectation of helping family members when a person is unwell, thus not regarding a child as a carer, and rejecting the term all together (Aldridge, 2018). There can also be negative connotations associated with the term carer, and whilst some children as adults can reflect on their experiences of feeling a sense of burden (Wahl et al., 2017), others report experiencing a high sense of reward for caring for their parent (Hinrichsen et al., 1992). Studies have reported narratives from children, reflecting on how caring for parents was seen as a way of gaining greater control over their situation, hence managing better (Drost et al., 2016). Due to experiences and stories shared, some cultures can hold a mistrust for services, and these beliefs can filter down through generations, impacting engagement with services. Further research is needed to highlight the role of caring in different cultural contexts, as well as understanding from a child's and adult-child's perspective. It must be remembered that young carers are children first. Despite there being key policies in place recognising the needs of children, barriers remain to accessing support.

1.5.4 Policies supporting children growing up with a parent with mental health difficulties

No Health Without Mental Health (DoH, 2011) is a key strategy setting out objectives to improve health and wellbeing for individuals experiencing MHD. With respect to children and families, this strategy identified an increase in funding to expand workforces, and review the approaches used in services. Importantly it focused on early intervention and preventative approaches for children and their families, leading to the formation of services such as the Targeted Mental Health in Schools Initiative (DoE, 2011). No Health Without Mental Health spoke of the role of carers, and committed to enabling children to identify themselves as carers, gaining access to support from an early age (DoH, 2011).

The recognition and needs of young carers were first acknowledged in 1995 with the development of the Carers (Recognition & Services) Act, providing the ability to request an assessment from the local authority. Supporting this, in 1999, the DoH published Caring about Carers: A National Strategy for Carers, which holds a specific chapter dedicated to young carers and local resources. The importance of children's mental health and wellbeing was further highlighted by the discussion paper 'Closing the Gap' (DoH, 2014), which was written to bridge longer term goals, and develop shorter term actions. Specifically, the role of carers is mentioned, in making carer assessments simplified for use by children, involving them more in the care of their parent's mental health. Furthermore, the introduction of the Care Act (2014) and the Children and Families Act (2014) required professionals to identify and support carers and their families 'on the appearance of need', regardless of a request being made. Additionally, the NHS Long Term Plan (2019) builds on existing strategies, aiming to ensure more than 70,000 children and young people can access treatment each year by 2020/21. The hope is for 345,000 children and young people to be able to access NHS funded mental health services, and school or colleagues based services, for mental health support by 2023 /24 (NHS, 2019).

Policies are intended to protect and regulate the care of children, working towards better health and wellbeing, however in reality this does not occur consistently. It is important that those working with families who are affected by MHD are aware of the context of family members, as this can impact the understanding one makes in relation to their experiences. Common factors impacting a child's sense making will now be explored.

1.5.5 Child Development - Theoretical models

Well known theories of child development include Piaget's Cognitive-Developmental Theory (1971), and Vygotsky's Sociocultural Theory (1978). Piaget's theory centres on understanding how a child constructs their mental model of the world, suggesting that intelligence changes as children develop. The theory proposes that child development occurs over four stages which are, sensorimotor, preoperational, concrete operations, and formal operations (Woolfolk, 2004), with the last stage starting at approximately eleven years old, continuing into adulthood. This theory assumes that cognitive development is a result of independent exploration, however, it suggests the stages of development need to be approached in order, dependent upon the 'readiness of the child'. In contrast, Vygotsky saw development as continuous rather than staged. Vygotsky's Sociocultural Theory of Development (1978) comments on the culture in which a child resides, having an impact on their development. Development is seen as a socially mediated process, emphasising the role of social interaction in the process of meaning making. Vygotsky's theory places importance on socio-cultural contexts for learning, requiring the need for a skilled person to model behaviour and provide instruction. However, this theory has been criticised for its emphasis on scaffolding, which may not be culturally generalisable (Rogoff, 1990).

Considering parental mental health, Piaget's theory reminds us to consider the importance of the chronological and developmental age of the child, in terms of their understanding, sense making, and therefore resilience (Bromley et al., 2012). Much research has stated that the age and developmental stage of a child will determine the extent to which they understand mental health, which in turn determines how much they are affected by it (Beardslee & Poderefsky, 1988). Research has found that when children are able to classify unusual behaviours, understand the reasons behind them, and have knowledge about treatment options, their development can be normative. In contrast, younger children, who are unable to understand these concepts can experience more difficulties (Cogan et al., 2005).

Vygotsky's theory highlights the importance of discourses around mental health, as well as being supported by an individual modelling behaviours, for skills to be acquired (Vygotsky, 1978). Parents experiencing MHD may find it challenging attending to their child's needs, and without extra social support, this theory suggests a child's learning can be impacted. Cogan and colleagues (2005) explored the understanding and experiences of children (aged 12-17 years old), whose parents had experienced MHD. They found children who had been in the 'affected' group, spoke of their parent having 'problems', or 'bad days', or feeling depressed. Their language was less stigmatizing, and more medicalised phrases were used to understand parental MHD. In comparison, the children of 'well' parents adopted descriptive phrases such as 'not normal', and 'odd', demonstrating how stigma can be perpetuated where there is less understanding, or learning in their immediate family culture. Murphy and colleagues (2016) reported that for children who are unaware of what is happening for their parent, feelings of anxiety and concern can continue into adulthood, impacting on subsequent parenting styles. This study illustrates the potential adverse consequences, and long-term impact when difficulties are left unaddressed.

1.5.6 Attachment

Attachment is another important aspect of this research, as early relationships with parents (care givers) can form the template for future relationships (Bowlby, 1969). Depression, anxiety, and low self-esteem have been found to have a positive correlation with insecure attachment styles (Hazan & Shaver, 1990), and it is suggested that insecure attachments can occur when a primary care giver is unavailable, or unpredictable. If a parent experiences difficulties such as alcoholism, the adverse effects on children can intensify (Riebschleger, 2004), as some children can feel there is little room for their experiences to be voiced (Van Parys et al., 2015). Dam and Joensen, (2017) reported that children who have a stable childhood, therefore only carrying the emotional weight of caring for their parent, experience less emotional difficulties themselves, in comparison to those whose childhood is complex with adverse social factors, sibling problems, or simply having parents who cannot care for them.

It has been argued that there is a fine balance between giving a child enough information about their parent's difficulties, allowing them to feel knowledgeable, and providing too much information, burdening a child; this has been shown to be a challenge faced by many families (Stallard et al., 2004). If a child has a better awareness of their parent's difficulties, there is more chance of seeing the difficulties as separate to their parent, and therefore attachment may be unaffected. Children with little knowledge of their parent's MHD, have trouble making sense of their parent's lack of availability, and consequently adopt their own coping mechanisms believing their needs will not be met.

One of the main criticisms of Bowlby's theory of attachment is that it is not considered cross culturally acceptable or useful (Keller & Bard, 2017). Margaret Mead (1954) stated 'the character formation of the child, represents the child's total environmental situation as it is responded to, and introcepted by that child in terms of its constitution and individual life history' (Mead, 1954, p. 474). This speaks to the cultural nature of parenting, and asserts that children can adjust with parental absence when they are cared for by many people, which may be the case in more collectivist cultures. This has not been fully considered or researched within the parental mental health literature.

1.5.7 The role of culture

The term culture was first defined by Edward Taylor in 1871, describing it as '*the complex whole which includes knowledge, belief, art, law, morals, customs, and any other capabilities and habits acquired by man as a member of society' (*Eshun & Gurung, 2009, p.3). When exploring parental behaviour, cultural differences, beliefs, and social norms must be considered (Tahmouresi et al., 2017). There can be vast differences between collectivist cultures, such as in India and Eastern countries, and individualist cultures such as in England and Western countries, as for example argued above in relation to attachment relationships within families. These differences also exist in areas such as emotional expression which can affect both parent and child. Furthermore, within certain cultures, MHD is considered a taboo, therefore difficulties within the family can be hidden to avoid stigma (Fernando, 2010). However, secrecy can perpetuate feelings of shame, and self-blame, therefore exacerbating one's MHD (Dam & Joensen, 2017). With respect to individuals from an Indian heritage, due to factors such as stigma and shame associated with MHD (Bradby et al., 2007), individuals can be reluctant to access services that offer early or preventative interventions, allowing difficulties to perpetuate (Bowl, 2007).

When considering culture and parental relationships, especially within the Indian population in the UK, the impact of migration can be a strong factor in predicting parental distress (Taylor et al., 2013). There have been many peaks of migration in the UK, notably in the 1970's with South Asians moving from East Africa (Bhugra & Jones, 2001). When immigrating, individuals can acculturate to the new culture's beliefs and behaviours of the host country, whilst at times also retaining those from their culture of origin; a process termed enculturation (Berry, 2003). Research has found that individuals who have migrated, have a higher vulnerability to experiencing MHD due to the move, the breaking of family ties, and attempts to acculturate in a new culture (Bhugra, 2004). Racism has also been cited a contributing factor to MHD within Indian communities (Fenton & Sadiq, 1990; Fernando, 2010; Patel & Shaw, 2009). It has been reported that racial harassment and discrimination affects one in five people from a BAME background in the UK, impacting people personally in terms of their sense of worth, and socially with regards to interacting with others, including their families (Modood et al., 1997)

Despite policies such as the Race Relations Act (1965) which should protect individuals against receiving poor services on the grounds of race and ethnicity, there is an ingrained sense of mistrust in services. This is informed by experiences of inequitable responses, where individuals from a BAME heritage report being more likely to be maintained under the Mental Health Act (1983), rather than referred on for talking therapies when distress has been expressed to healthcare professionals (Howard et al., 2000; Sashidharan, 2003). Consequently, inequalities seen in accessing services have worsened over time (Grey et al., 2013). The Delivering Race Equality in Mental Health programme (DoH, 2009), was a five-year plan, launched in 2005 with the aim of bettering mental health services in the UK and meeting the needs of diverse communities. A review of the programme addressed 'key successes', yet failed to comment on what the programme had not achieved, and attributed a success to recognising a 'higher rate of mental illness in some BAME groups' (DoH, 2009 p.22); unfortunately, potential causes of these 'higher rates', was not considered. Wider contextual factors can also play a role, for example a mistrust of statutory services within cultures. Jones et al., (2002) explored the strengths and needs of black families where children of parents with MHD had assumed caring roles. It was noted that families were resistant to approach mental health services for support, due to a fear that their child would be taken into care. This fear is not unrealistic as research reports individuals from minoritized backgrounds are more likely to have their children taken into care (Barn, 2006; Chand and Thoburn, 2005).

Before introducing the rationale for the current study, it is necessary to understand preferences and potential barriers individuals from an Indian heritage can face when seeking guidance and support. The barriers identified below impact on every level from the individual to societal, exacerbating difficulties which are already present, in addition, creating new stressors.

1.6 Being Indian in the UK

1.6.1 External barriers

The 2011 census of England and Wales (www.gov.uk) reported there being 1,412,958 people who identify as originating from an Indian ethnic group, resulting in 2.5% of the total population. Despite this percentage, this population are constantly underrepresented in mental health services (Sheikh & Furnham, 2000). Findings from studies researching ethnicity, often show a higher level of unmet health need among ethnic minority clients, which may reflect differential access, referral pathways, service utilization as well as lack of cultural validity or sensitivity in services (Dogra & Karim, 2005).

Family is seen to play a significant role in one's wellbeing. The closeness and assistance within the family can help physically and mentally. It is thought that when difficulties arise, support is sought from within the family, reducing the need for external help (Sonuga-Barke et al., 2000). In contrast, other studies have reported that difficult situations within the home can lead to an increased risk of MHD for Indian women (Hicks & Bhugra, 2003). Additionally, Hackett et al., (1991) noted that parents within Gujarati communities demonstrated a pattern of parenting which placed a greater emphasis on obedience, and intolerance of temper tantrums and aggression, with their children, compared to English parents. These expectations, coupled with the stigma attached to mental health, and the impact of having a parent with MHD, may lead children feeling unable to show distress, and suffering quietly. Also, the misperception held by health professionals that Indian people all live within large supportive families, may lead to an assumption that services are not needed. A similar assumption is made when considering Indian communities. Typically, Indian communities are 'close knit', and can act as a source of support reducing the risk of MHD (Raleigh & Almond, 1995; Sproston & Nazroo, 2002). However, they can also be a source of distress; though community assistance can be invaluable, if the problems causing stress are stigmatised, a barrier will be formed to receiving and providing help (Patel & Shaw, 2009).

When individuals already face prejudice and discrimination, having to manage MHD can act as a ‘double stigma’ (Gary, 2005, p.4). Within Indian communities, stigma and shame appear to be more evident in comparison to other ethnic minority groups (Bradby et al., 2007), which can hinder individuals seeking help when needed (Bowl, 2007). It is argued that those who adhere to traditional cultural values, such as family honour, are also those who believe in the stigma and shame associated with MHD, therefore are less likely to seek help (Soorkia et al., 2011). Family honour is highlighted as a factor that is held in high regard within Indian communities, and research suggests people will go to great lengths to protect their family name, and avoid bringing shame upon themselves or their family (Gilbert et al., 2004; Pilkington et al., 2012). Shame is perceived to be evoked in situations ranging from an unmarried couple living together, to a member of a family experiencing MHD. Due to believing important life events (such as marriage) would be jeopardised if others knew of these situations, they are not disclosed (Mackenzie et al., 2006); in the case of MHD, pressure may be felt to avoid seeking help, allowing one’s mental health to deteriorate further.

1.6.2 Internal barriers

An individual’s behaviour can be the result of cultural and societal scripts, as these can influence the way emotions are understood, processed, and expressed (Maitra, 2006). When considering how distress is conceptualised, there can be stark differences between the Western and Eastern way of conceptualising. Western views separate the body from the mind, and when the mind is experiencing difficulties, the causal factors seen to be responsible, relate to individuals in terms of their thoughts, feelings, genetics, or behaviours (Gold, 1985). Fernando and Keating (2008), comment on the Eastern view and the unity between the mind, body, and spirt. Contentment is achieved when there is balance within an individual, their family, and their community (Fernando & Keating, 2008). Within the Indian population, emotional difficulties can often be somatised (Davar, 1995). Therefore if children are experiencing difficulties emotionally, they may be missed. The

Western perception of mental health informs practice in mainstream services, meaning therapy and the Eurocentric models used, can often feel foreign and inapplicable to BAME individuals' experiences (Nazroo et al., 2003). This can hinder individuals from coming forward to seek help, and also prevent mental health and social care practitioners accurately identifying MHD for those from BAME backgrounds (Mumford, 1992). This highlights the need for health and social care professions to develop a greater sensitivity in recognition of differing conceptualisations of distress, improving rates of utilisation from an under-served community.

Spiritual or religious ways of understanding distress can be de-legitimised through exclusively offering medicalised, individualised approaches (Soorkia et al., 2011). In Hinduism, there is a belief in Karma meaning 'what one sows they shall reap', and MHD can be seen as a result of Karma (Whitman, 2007). Research conducted in India found MHD are also attributed to the belief in the 'evil eye', or in Black magic; a belief that someone has put a curse on you (Charles et al., 2007; Joel et al., 2003). Assistance is therefore sought through religious and spiritual avenues, rather than through mental health services. Epidemiological studies do not include the prevalence of MHD in individuals who do not seek help from statutory services, or who seek help from community organisations such as spiritual institutions, which implies that the current figures regarding the prevalence of MHD in under-served communities could be skewed (Patel & Shaw, 2009).

Taking into account the factors outlined above, one may hypothesise that there is a need for this population to access services, and more research is needed to develop culturally informed and relevant mental health services aligned with the needs and wants of the Indian community. Research has found that a mutual understanding between professionals and those they see, can enhance cultural awareness, and improve clinical practice (Bhui & Bhugra, 2002), leading to greater client satisfaction (Callan & Littlewood, 1998), and therefore greater support seeking behaviour.

A review of the current literature seeking to understand adult-children's experiences growing up with parental MHD will now be considered.

1.7 Systematic Review of the literature

The discussion thus far has highlighted the challenges that can present themselves to children of parents who experience MHD. These challenges affect children socially, financially, as well as with their health both physically, and mentally. There are also children, who as adults, can reflect on their experience, and comment of their development of resilience and strength as a result of their childhood. When services are accessed, they have been found to be helpful. However as stated in the introduction, there can be various barriers facing individuals when seeking help, which can result in needs going unmet for both parents, and their families.

To further understand the perception and sense making of children who have a parent with MHD, a systematic review of peer-reviewed, primary research was conducted to explore and analyse the current knowledge base, in order to answer the question: *What is currently known about the experiences of adult-children growing up with parents with mental health difficulties?*

1.8 Search Strategy

Searches were run to find peer reviewed papers investigating an adult-child's perspective, exploring their experiences of growing up with a parent with MHD. The search omitted papers exclusively researching parenting styles of adult-children, and focussed more on retrospective studies looking to understand childhood experiences. As noted above the current research is heavily weighted towards negative aspects of children's experiences, therefore this review will also look at coping mechanisms, and positive aspects to gain a more balanced perspective.

The table below (Table 1) provides the terms used to conduct the literature search. These terms were then combined (Table 2) and used across three databases (Scopus, PubMed, and CINAL +). Further articles were identified through reference lists from relevant papers, and a Google Scholar supplementary search.

Table 1

Primary literature search terms

And	Not
Adult-child* or adult-offspring or child* or adult-daughter or adult-son	Physical Health or Disability
Parent* or mother or father or single parent	
Parental Mental Health or Parental Mental Illness or Psychiatric Disorders or parent* mental health difficult or mental health or mood disorder or mental disorder*	ADHD or ASD
Experience or Coping or Resilience	

Table 2

Combined search terms

And	Not
Adult-child* or adult-offspring or young adult	Physical Health or Disability or ADHD or ASD or cancer
Parent* or Parental* Mental or psychiatric* or depression or mental-ill* or parental mental illness or depress*	
Experience or Coping or Resilience or Reward and make sense	
Qualitative	

Findings obtained in search results from databases were first screened, removing duplicates. Abstracts of relevant studies were then read, further filtering out papers, and lastly full text papers meeting the inclusion and exclusion criteria (Table 3) were read. A PRISMA flow chart (Figure 1) demonstrates the process of identifying the papers used in this review.

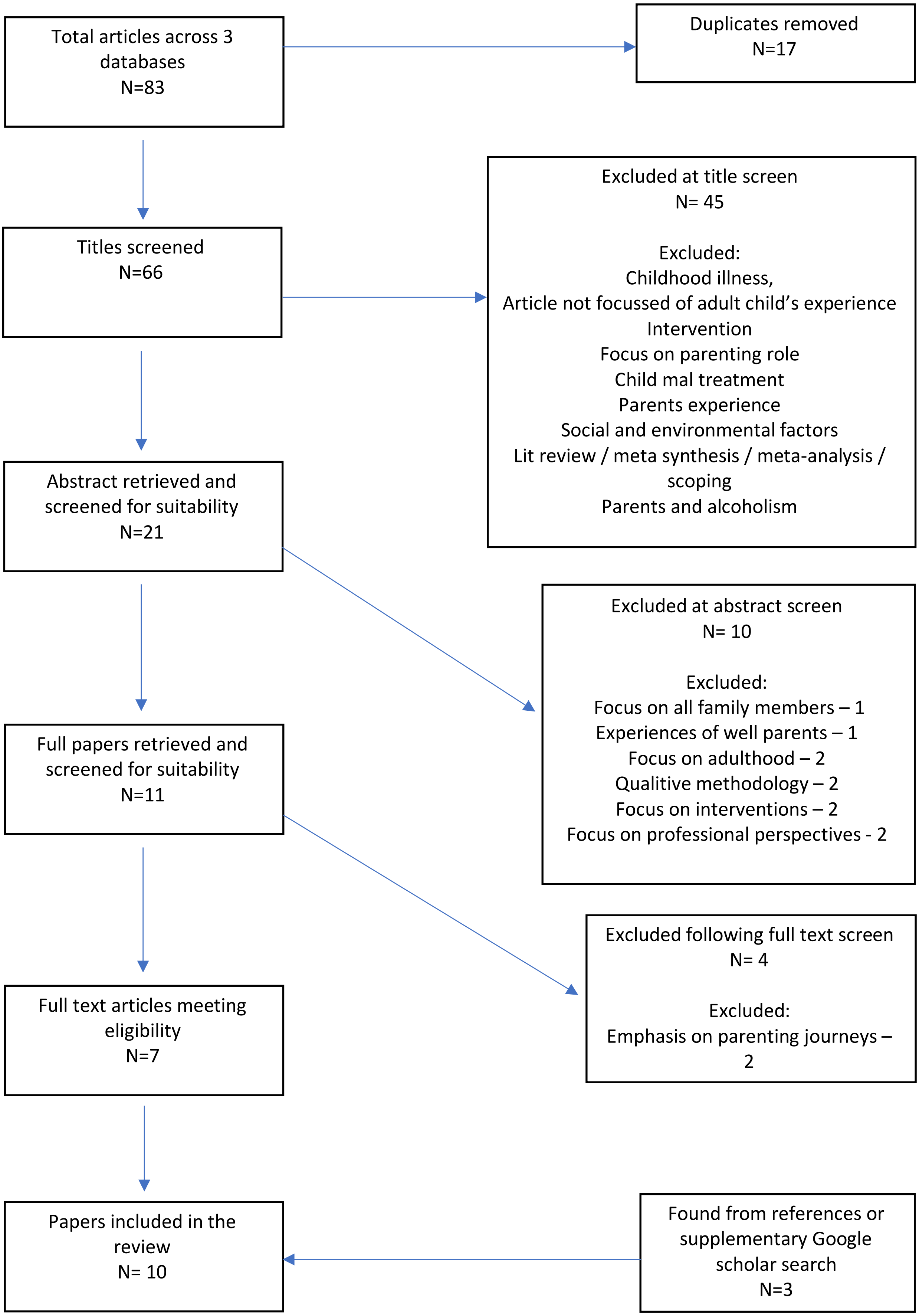
Table 3

Inclusion and exclusion criteria for systematic literature review

Inclusion	**Exclusion**
Focuses on adult children of a parent who has experienced mental health difficulties	Research exploring the experiences of all family members when a member of the family has mental health problems, where experiences of adult-children cannot be easily distinguished
Gathers information about adult-child's experiences and impact or adjustment of having lived with a parent with mental health difficulties	Intervention evaluations or epidemiological research (e.g. prevalence, causes of parental mental health)
Study available in English	Not primary research; not peer-reviewed; not available in English
Retrospective account	Parenting journeys

Figure 1

Flowchart illustrating the process of inclusion/exclusion of articles



1.9 Quality assessment

The studies within this review all adopt qualitative methods, however these differ in specific approaches, epistemological, and ontological ideas, presenting a challenge in choosing a quality assessment tool which can be applied universally (Lincoln & Guba, 1985). The use of an assessment framework is invaluable in assessing qualitative research, and Tracy's Eight 'Big-Tent' criteria (2010) provides an expansive framework, which is flexible enough to fit to differing goals of research, yet specific enough to access their quality (Tracy, 2010).

Table 4 below visually demonstrates how each paper met the eight criteria (see Appendix 1 for a textual representation).

Table 4

Comparative summary table showing the extent to which papers included in the systematic review met Tracy's (2010) Eight 'Big-Tent' quality assessment criteria

PAPER	Worthy Topic	Rich Rigor	Sincerity	Credibility	Resonance	Significant contribution	Ethical	Meaningful Coherence
A fractured journey of growth: making meaning of a ‘Broken’ childhood and parental mental ill-health	✓✓	✓✓	✓✓	✓✓	✓	✓✓	✓✓	✓✓
Five women’s recollections and reflections on being raised by a mother with psychosis	✓✓	✓	✓✓	✓	✓	✓✓	✓✓	✓✓
You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness.	✓✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Growing up with a mother with depression: an interpretive phenomenological analysis	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Childhood parental mental illness: Living with fear and mistrust	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Toward understanding the child’s experience in the process of parentification: young adult’s reflections on growing up with a depressed parent	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Experiences of adults who as children lived with a parent experiencing mental illness in a small scale society : A qualitative study	✓✓	✓	✓✓	✓✓	✓	✓✓	✓✓	✓✓
Adult children of parents with mental illness: dehumanization of a parent – ‘she wasn’t the wreck in those years that she was to become later	✓✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Adult children of parents with mental illness: navigating stigma	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Adult children of parents with mental illness: losing oneself. Who am I?	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓

Key: ✓✓ = Criteria well met ✓ = Criteria partially met X = Criteria not met

1.10 Method followed to synthesise the findings

This review aimed to identify, critically evaluate, and summarise findings from relevant research, acknowledging and advancing the current knowledge base of adult-children's perspectives on growing up around parental MHD.

This review followed the process described by Siddaway et al., (2019) of how to 'plan, conduct, and organise research findings'. To arrive at the seven main themes outlined below, attention was first given to the methods and results section of the full articles read, extracting and tabulating relevant themes and information. Reoccurring themes across different papers were noted, compared, and synthesised, returning back to original papers, to ensure the synthesis was representative of the original findings.

1.11 Summary of reviewed literature

A total number of 10 studies have been included in this literature review. Key findings have been described below, along with clinical implications and areas for further research. Quantitative and mixed methods design studies were assessed, however the final set of studies are all qualitative, due to the focus of the review being to understand the sense making of their experiences, from adult-children. The studies included, were conducted in four countries, with the majority of papers conducted in Australia (n=6). Sample sizes ranged from 5 to 30 participants, all with a higher female to male ratio. All studies had recruited participants above the age of 18 years old, who identified as having grown up with a parent with MHD. The type of MHD experienced by the parent were not restricted in the eligibility criteria for this review, and among the studies used, mothers were more often reported as the parent experiencing difficulties, in comparison to the number of fathers reported. The majority of studies used semi-structured interviews to gather data, however one study (Van Parys, et al., 2015) used a focus group (Appendix 2 provides a summary of all the papers included in this review).

Seven main themes were constructed across the reviewed papers; ‘the parent-child relationship’, ‘parental roles’, ‘the relationship between lack of trust, secrecy, and stigma’, ‘familial and extra familial support’, ‘sense of self’, ‘positives gained’ and ‘adult-children as parents’. These will now be analysed and synthesised, concluding in an evaluation of the literature.

1.11.1 The parent-child relationship

A key theme within all the papers was of the relationship participants had with their parent who experienced MHD, which was often reported to be marked with inconsistencies. For example, McCormack et al., (2017) conducted an IPA analysis finding a theme termed ‘who cares, nobody cares’. Participants reported experiencing a lack of parental nurturing, which left them feeling alone and isolated as children. It was felt that their feelings were less important than those of their parent, leaving participants with a sense of ‘their existence being inconsequential’ (p.335). Where participants reported having a parent that was well, they spoke of how that parent often felt confused and helpless when faced with their spouse’s MHD. For some children this resulted in going into foster care, reinforcing feelings of invisibility, and a sense of betrayal.

Within the majority of studies participants reported that they acknowledged from a young age that their parent exhibited behaviours which were different, and at times erratic. With little knowledge or awareness of mental health, some participants had difficulty separating out MHD from their parent; the parent’s identity was seen as the diagnosis (Foster, 2010; Murphy et al., 2017). Murphy et al. (2018) thematically analysed the narratives of 13 adult-children, and reported a theme of ‘dehumanisation’ of the parent with MHD; this term referred to someone being less of a person, or offering less value to society. Participants stopped noticing the humanness of their parent, and instead positioned them within an illness context. One participant commented *‘I remember thinking as a child, shame if she wasn’t ill, I think she would have been such a wonderful mother’* (Murphy et al., 2018, p3). Furthermore, participants who were physically abused by their parent experiencing

MHD, described feelings of fear, where they developed a vigilant attitude creating distance between them and their parent, in an attempt to protect themselves (Kadish, 2015). Murphy et al., (2015) reported how participants' use of language describing their parent with MHD was derogatory. There was a sense that in using certain terms and adjectives (for example, *'nutcase'* and *'strange'*), the person hearing these words would have a shared understanding of their meaning. This highlights the power behind language, and a recognition that the dominant negative social construction of MHD in most societies, may have led children and adult-children, to feel more negatively towards their parent, impacting their relationship and attachment.

Relationships were further distanced between child and parent through periods of hospitalisation, or children being sent to foster care. Murphy and colleagues (2016) reported that participants as children, would make up stories of parental death if their parent was hospitalised, conveying feelings of loss for their parental absence. Van Parys et al., (2014), noted that participants recalled the lack of love and affection they received as children from their mothers, evoking a feeling of sadness and isolation. To guard against the emotions experienced as children, as adults, participants created firm boundaries allowing them to be present for their parent, yet maintaining a distance protecting themselves from further hurt. Foster (2010) reported similar findings, noting that a turning point occurred when participants had their own children.

1.11.2 Parental Roles

Due to experiencing MHD, four studies (Dam, & Joensen, 2017; Kadish, 2015; McCormack et al., 2017; Van Parys et al., 2014;) reported that parents found it difficult to perform their parental roles, causing emotional distance between them and their child. Van Parys et al., (2015) noted that where participants felt they could speak to their parent about their feelings, they censored the information they disclosed, to prevent triggering a depressive episode in their parent. Many participants reflected on how from a young age they tried to care for their parent, providing emotional support, assuming the responsibilities of the house, as well as caring for younger siblings (Dam & Joensen, 2017; McCormack et al., 2017; Van Parys et al., 2014). Not only did this serve to protect their parent, participants explained how growing into a caring role kept them standing (Van Parys et al., 2014). For others, reflections illustrated how as a child they felt forced to grow up quickly, and found this responsibility burdensome; a burden and sense of frustration which continued into adulthood (Foster, 2010, Kadish, 2015).

1.11.3 The relationship between lack of trust, secrecy and stigma

A common theme in eight of the ten studies within this review, reported how participants felt a sense of mistrust for others, which was reinforced by secrecy and stigma. McCormack et al., (2017) found that participants experienced betrayal as children, as they were often provided with a lack of, or inaccurate information about what their parent was experiencing. Many participants tried finding out more about their parent's difficulties, however reported being told not to discuss their parental MHD with outsiders (Murphy et al., 2015). Whilst literature has described the protective nature of not involving children with details about their parent with MHD within a professional arena (Gladstone et al, 2011), participants explained this reinforced mistrust in others, self-blame for the problems at home, and a sense of confusion. With little knowledge about their parent's difficulties and how to, or who could help, children carried great concerns for their parent's wellbeing, which continued into their adulthood (Murphy et al., 2015). One participant's narrative demonstrated how familial secrecy was being maintained within the family, *'she said that she asked her family about mum and they said – that's just the way she is. She couldn't get any answers either. So everyone just locked it down and no discussion….I asked Dad at 21 and he wouldn't tell me, and we just had to accept that'* (Murphy et al., 2015 p.6).

Murphy and colleagues (2015), reported how participants described an uncertain and unpredictable home life, when thinking about their parent with MHD. This caused an increase in their anxiety levels, with concerns about being in public where individuals could witness behaviours which sat outside the social norm from their parents. Participants recalled periods of being bullied, and recognised sharing parts of their home life, such as parent hospitalisation for mental health reasons, may evoke social stigma, and further bullying. Moreover, if shared, participants felt their experiences may be misunderstood, seen as shameful, or not believed. This resulted in their stories and feelings remaining hidden, promoting the idea that there was something wrong with their parent, or something shameful about their experience, highlighting difference (Van Parys et al., 2014).

Participants reported being acutely aware that speaking about parental MHD was prohibited, however they also reflected on being unable to share their worries and anxieties with close family members, as they feared the impact of adding more of an emotional burden on to others (Van Parys et al., 2015). Foster (2010) found that participants who resisted asking for help or support from family or health professionals, related this to being independent. This finding is significant and is reported in other research (Kinsella & Anderson, 1996), where participants report caregiving to have enabled the development of skills that would otherwise not have been cultivated. Murphy and colleagues (2015) reported that the fear of stigma and consequence of further ridicule, was reported to be far greater than the consequence of keeping secrets. Additionally, children held a belief that seeking help from health professionals, could lead them to be viewed as unwell like their parents; it was thought that if people cared, they would offer help, one shouldn't need to ask for it (Foster, 2010). One participant stated *'I have to make a conscious effort to reach out for help…When I finally do ask for help, I am usually at crisis point' (Foster, 2010, p.3148)*. Dam and Joensen (2017) conducted their study specifically looking at parental MHD within a small-scale society. A theme termed 'everybody knowing everybody', referred to the lack of anonymity children felt, with everyone in the community knowing about the difficulties their parent experienced. In addition, participants reported often being ignored by others when outside, and hearing their parents being spoken about in a derogatory manner.

The idea of keeping parental MHD secret, was strengthened by the fact family members did not speak of it (Kadish, 2015). Van Parys and colleagues (2015) reported that children learnt to silence their worries, protecting their family, and not adding to the challenging situations at home. Upon reflection participants as adults, noted that having limited awareness perpetuated and intensified feelings of confusion (Murphy et al. 2015). As adults, receiving clarity on their parent's mental health brought about a sense of ease for some, but for others, their anxiety increased. Van Parys and colleagues (2014) found as participants had not felt able to share their childhood experiences when younger, they had grown up being fearful of trusting others and confiding in people about problems they may face. For other participants, with time they had learnt how to confide, though a lengthy process was reported to get to that point. Van Parys and colleagues (2015) reported how participants as adults had continued to seek understanding from family members about their parent's difficulties, however were repeatedly met with the long standing 'culture of familial secrecy' (Murphy et al., 2015, p.1).

1.11.4 Familial and extra familial support

Many participants reflected on their childhood as having a of lack of social support, and no one to turn to, conjuring a feeling of vulnerability and helplessness (McCormack et al., 2017). A theme within the focus group carried out by Van Parys and colleagues (2015) was 'finding little response outside of the family', which related to participants feeling lonely and let down by health care professionals, for not detecting and intervening in difficult family situations. In the examples given by participants where familial support had been offered during critical periods, the support was thought to be indispensable.

Participants were resourceful in seeking nurturing care, whether it was from their ‘well’ parent, or domestic workers who lived with families (Kadish, 2015). Having an available parent or adult, was thought to lessen adverse effects on children, and often compensated for any parental absence (Foster, 2010; Van Parys et al, 2014, 2015). For children who had access to familial support, the help was invaluable, and those with siblings reported how helpful they were in normalising their experiences, and being there to confide in. Not all children were supported, and instead were left with additional chores and responsibilities, such as caring for their siblings (Van Parys et al., 2015), whilst also ‘suffering and feeling lonely’ (Dam & Joensen, 2017, p.84).

1.11.5 Sense of self

Murphy and colleagues (2016) reported children felt a sense of confusion growing up with respect to their identity. Participants noted how they felt ‘less worthy’ in comparison to others in the family, and felt their needs were undervalued. With an ongoing sense of isolation from family members, and others outside the home, and continually trying to navigate the relationship with their parent, participants reported feeling emotionally and psychologically overwhelmed. This left little room for exploration of their identity, and as adults, participants noted feeling lost and encountering difficulties in relationships.

Foster (2010) also found that participants reported difficulties with relationships whether it was with peers, family members, or friends. Participants reflected on their experiences as children, describing how they felt different to their peers, and were therefore unsure how they fit in to the social world. Some participants explained that they were bullied or ostracised because of their parent’s MHD, where others stated that they simply found it difficult to relate to their peers; both situations left participants feelings lonely. Those who lacked social support, kept their feelings to themselves, and did not pay much attention to their own experiences, allowing them to overcome difficulties at home (Van Parys et al., 2014). It was more difficult to think of their family life being abnormal, and easier to adopt the idea of ‘this is my world’. Participants described growing into their role as a care-giver, getting used to life being this way, and recognising with age they could do more at home.

Kadish (2015) found that having a mother with MHD, affected participants’ psychological development. Participants had adopted coping mechanisms to become independent and self-reliant, and though these helped grow their resilience, these strategies remained into adulthood, leaving participants feeling emotionally drained, and having difficulty with depending on others. In this study participants also spoke of their own MHD, believing this was inherited from their mother. However, despite their anxieties, participants reported having become mothers, and having a good experience.

1.11.6 Positives gained

Fewer papers explored the benefits participants may have gained by growing up with a parent experiencing MHD. Through living with a parent with MHD, participants reported being compassionate, empathetic, and strong (McCormack et al., 2017; Van Parys et al., 2015). Murphy and colleagues (2016) noted that though home life could be a confusing and lonely world, when participants reported being outside the family home, they could create a sense of normality, and an external persona that was socially acceptable. Participants explained having a greater understanding and awareness of mental health, and with time, their capacity to reflect on their experiences, allowed them to make sense of their childhood. Education and employment was valued as they acted as a distraction away from home life, and provided the possibility of one day being able to leave home (to attend university, or become financially independent), and therefore creating distance between them and their childhood experiences. Foster (2010) found that participants developed strategies to help themselves feel in control such as escaping the house, reading, or self-soothing. These strategies had carried on into adulthood and had mostly been beneficial, however some had become problematic such as excessive alcohol use.

1.11.7 Adult-children as parents

Three studies spoke of the effects participants' childhood experiences had on them as parents. Van Parys et al., (2014) found that as parents, participants reported not wanting their children to experience what they had. One participant stated *'I would never ever let my children down. Not one of the four. This is what they [my parents] did to me'* (Van Parys et al., 2014 p.12). Another participant who described struggling with depression, reported letting their child know how they were feeling, appropriately. Participants were conscious to strengthen and develop their relationships with their children, and sought to explore their children's feelings, as this was something they felt they had missed. For some participants this came easily, however for others they reported feeling detached from their own children, needing to put great effort into developing an emotional connection with them (Foster, 2010).

1.12 Limitations

It should be noted that this review only identified ten studies meeting the inclusion and exclusion criteria, suggesting that the research into childhood experiences of living with a parent with MHD, using adult-children as participants is a growing topic, yet currently remains in its infancy. Interestingly, the research studies included in this review were conducted in four different countries, however not one study explored the impact culture may have on parenting, mental health, or the experiences of adult-children. Dam and Joensen (2017), specifically explored children's experiences within a 'small-scale society', learning the impact gossiping and lack of anonymity may have on children, and how they respond to others, themselves, and their parent. Although findings from the available research have provided an insight into difficulties experienced, and possible ways for early intervention, there appears to be little research exploring the relationship between parental mental health and culture, reinforcing the salience of the current study.

Cumulatively, the research studies included in this review had a higher representation of females in comparison to males (90 females and 21 males). This may limit the generalisability of findings, as males may interpret their experiences differently to females, and therefore their narratives may have provided different themes. Due to the nature of the research, participants were all recruited as volunteers; the voices of those who did not come forward, may have uncovered currently unknown themes. All the studies are retrospective in nature, and therefore it can be argued that participants' recall of their experiences may not be accurate. Murphy et al., (2016) commented on how participants in their study had not received any diagnoses relating to mental health, and therefore they had not experienced any therapeutic help, meaning participants' conceptualisation of self-worth, and feelings of grief may have grown over time, biasing findings. This, however, is also true of those participants who did experience MHD, and received help, therefore were able to rationalise their experiences, perhaps limiting the feelings they once held. Only three studies gathered positive qualities that participants felt they had gained from living with their parent, and overall, there was an emphasis on negative effects experienced.

Regarding the systematic review, a decision was made to use qualitative studies only, as existing quantitative research did not capture the narratives of adult-children recalling their experiences in childhood. This, along with the small number of studies included in this review, reduced generalisability of the findings. There can be a contention in using qualitative research for systematic reviews, and synthesising individualised findings (Dixon-Woods et al. 2006), however the aim of this systematic review was to find papers capturing themes from the rich experience of participants, in exploring a specific phenomenon. In developing the inclusion and exclusion criteria, choosing relevant papers, and in appraising them using Tracy's Eight 'Big Tent' criteria (Tracy, 2010), there was invariably a degree of subjective bias and interpretation. All the findings from the papers used may not be comprehensively discussed due to the inevitable process of reduction when conducting a systematic review, therefore readers are encouraged to consult original papers. Furthermore, many studies did not report on researcher reflexivity (n=6), understanding how the researchers may have influenced the study. This was particularly relevant in the study by Foster (2010), where the researcher was also a participant, or the work by Kadish (2015) where four participants were known to the researcher.

1.13 Evaluation and clinical implication

The studies chosen for this systematic review, highlight the emotional burden and responsibility, children of parents with MHD can carry. In most cases, the relationship with their parent experiencing MHD changed, where parents were unable to fulfil their parental role practically and emotionally, leaving children feeling alone. In the cases where children received support from their other parent or from those within the wider family, the potential adverse effects on children were reduced. Not all participants within the studies had extra support, and reported taking on a parental role, caring for their parent and younger siblings.

A strong theme through the papers related to stigma and mistrust. Participants reported being unaware of what their parent was experiencing, and though some tried to learn more about mental health, they were given inaccurate information, or it simply was not discussed within the family. Mental health stigma involves exclusion and difference for the person experiencing the difficulties and their family. The fear of being ostracised by others often led to family fears, concerns, and worries being hidden. For children, this led to being unable to share their concerns with anyone including health professionals, and a deep sense of fear, and mistrust for others. Participants reported lasting effects of mistrust where as adults, they had difficulty in intimate relationships, with some participants explaining that they had difficulty committing to relationships

(Foster, 2010). Experiencing feeling overwhelmed emotionally and psychologically left some participants with a loss of identity. These feelings are reported to be alike to the loss one experiences when they are bereaved (Murphy et al., 2016).

The findings from this review call for health professionals to be more aware of the impact of parental MHD on the whole family, and for a whole family approach to be taken. Health and social care professionals should be mindful of the support available to family members, especially children, exploring the individual impact on their health and social wellbeing. Specifically, professionals should be open and transparent with children sharing information as age appropriate, and being mindful of the language used, so as not to emphasise difference or stigmatise MHD further. By taking a whole family approach, and intervening as early as possible, the distress experienced by all family members could be limited and reduced.

1.14 Areas for further research and rationale for current study

Current policies within the UK regarding care in the community, state that children of parents with MHD require support (Ducan & Reder, 2000). In consideration of existing research, and the findings above, it seems studies have often lacked a cultural lens, neglecting to understand the impact culture may have on families.

This study will explore the experiences of adult-children who have grown up with a parent experiencing MHD, and who identify as originating from an Indian heritage. Research using the perspectives of younger children suggest that they do not portray a clear concept of MHD, and they can confuse MHD with learning disabilities and physical health problems (Wahl, 2002). As children's understanding increases with age, within the present study, the lived experiences of adult-children will be considered.

The study will ask the following questions:

- What are the experiences for children who have lived with a parent with MHD from the perspective of an adult child?

- What is the impact of culture, specifically in Indian families, on these experiences?

Chapter 2 – Methodology

This chapter will detail the method chosen for this research, as well as methodological considerations. The qualitative approach of Interpretative Phenomenological Analysis (IPA) will be introduced, following a rationale for its use within this study. The study design, ethical considerations, and expert by experience consultation will be reported, and finally the research will be assessed through the use of a quality assessment criteria.

2.1 A Qualitative Approach

The current research aimed to address the omission of the impact of culture within existing parental mental health literature, by exploring the experiences of adult-children from an Indian heritage who have lived with a parent who is experiencing, or has experienced MHD. As the literature demonstrates, there are no studies looking into the experiences of this population directly. Qualitative research exploring the experiences of adult-children surrounded by parental MHD, have found similar themes notably around 'stigma and secrecy', the identity loss of themselves and their parent, 'living with fear and mistrust', as well children gaining a sense of self (Murphy et al, 2015; 2017). Experiences of children, and adult-children in particular, can be complex, and with the additional lens of culture, a qualitative approach was deemed suitable to gather rich detailed information on the lived experience from participants, and understand their sense making.

This research used IPA to answer the following question: *What are the experiences of adult-children from an Indian heritage who have grown up with a parent with MHD?*

2.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) is a qualitative approach that draws on three methodological influences; phenomenology, hermeneutics and ideography.

2.2.1 Phenomenology

Phenomenology is a philosophical concept interested in understanding experiences, especially those that make up our lived world (Smith et al., 2009). Phenomenology takes into account societal influences, as well as individual interpretations of occurred phenomena. In contrast to a positivist approach which seeks to find the 'truth', phenomenology emphasises the interpretative nature of meaning making (Smith et al., 2009). Therefore, phenomenological epistemology states by interpreting an individual's experience, IPA can access "people's understanding of their experiences" (Smith et al., 2009, p.47).

2.2.2 Hermeneutics

Hermeneutics is the theory of interpretation (Finlay, 2014), which includes both grammatical interpretation, looking at textual meaning, and psychological interpretation understanding the role of the researcher and participant (Schleiermacher, 1998). This is reinforced by the work of Heidegger (2005), who stated that it is impossible to interpret the world of another without recognising the biases, and preconceptions the interpreter may carry. When using IPA the researcher is said to engage in 'double hermeneutics', meaning the researcher is making sense of the participants' stories, who are also trying to make sense of their experiences. IPA therefore becomes an iterative process where the researcher is going back and forth through the data. This also requires the researcher to continually engage in the process of reflexivity, understanding their contribution to the interpretations being made.

2.2.3 Ideography

Ideography is concerned with a thorough, systematic depth of analysis, and with understanding the particulars occurring within a phenomena, for particular people, within a certain context. It therefore requires a small homogenous number of participants, who have been purposively selected. Rather than hoping to gain information that can be generalised, ideography locates the generalisations in the particular; Smith and colleagues (2009) argue the particular and the general are not so different, implying much can be learnt from findings using this approach.

2.3 Strengths and weaknesses of IPA

One strength to IPA is the emphasis placed on understanding one's lived experiences. The analysis is interested in exploring the uniqueness of a person's experience, understanding how one makes sense of their experiences and the meanings attributed to it, at the individual level, as well as within their cultural roles (Shaw, 2001). IPA ensures themes remain close to an individual's narrative, and can therefore reveal accurate and nuanced accounts from those who have experienced the phenomena being explored (Smith et al. 2009). Furthermore, this methodology allows people's voices to be heard, who might otherwise have been silenced, unheard, or missing (Smith et al. 2009). As IPA uses open questions, the information gathered can be unexpected, leading to valuable material (Smith et al., 2009). Lastly, as a method of analysis, IPA is easily accessible, and there is guidance on how to conduct the steps of the analysis in a comprehendible way.

Due to the nature of IPA, it requires one to have the necessary language to be able to capture and share experiences (Willig, 2013). This can reduce the number of individuals who may be able to partake in a study which uses IPA, and therefore may limit the learning from findings. This is also true of using young children as participants, as their language skills may not be fully developed. Another challenge that can arise with IPA is the aspect of dualism. The researcher is committed to the ideography of the research, however, is also expected to search for connections across cases. Tuffour (2017) commented that each theme should include quotes from at least three participants to hold on to the individual's experience. The small sample sizes do limit generalisability, however, the aim of IPA is to gain depth and an appreciation of another's lived experience. Through an accumulation of similar studies, links, connections, and more general claims can be made (Smith et al, 2009).

2.4 The choice of IPA

In consideration of the research question, the methodology chosen would have to value and respect the individual's experience, and take into account the meaning they made from it, as well as understanding the cultural contexts of the participants' inner worlds. Therefore, IPA was identified to be the most suited approach.

2.4.1 Consideration of other qualitative methods

I was drawn to the principals of ethnographic research (Geertz, 1983), such as adopting a holistic approach, and viewing all aspects of a phenomena as an interrelated whole. I appreciated the perspective of cultural relativism within ethnographic research, where cultures are understood in their own terms, and not through the beliefs and influences of more dominant lenses. However, the time commitment required for direct observations would have proved challenging for this study and given time frame. Also, gaining access to Indian families where a parent is experiencing MHD might have proved challenging for all the reasons outlined in the introduction and literature review, such as the stigma attached to MHD within the culture. Furthermore, observation would not have provided accounts of meaning-making in the same way.

When considering discourse analysis (Willig, 2003), the emphasis on language, how it is used by participants, and the construction of knowledge interested me. I was keen to understand how language is used to understand mental health in Indian families, and recognise its impact. However, I would have lost the focus of meaning making participants gave to their experiences, which would have changed the focus of the research, therefore this approach was deemed unsuitable for this study.

Lastly, a narrative analysis approach (Riessman, 1993) was considered. Though there can be an overlap with narrative approaches and phenomenological research, a narrative approach is more concerned with the chain of experiences across time and how they are weaved into the stories people tell. The current research was interested in the lived experiences of individuals once they reached adulthood, and the meaning they made from it, therefore IPA seemed to fit best with these aims.

2.4.2 Position of the Researcher

In considering my epistemological stance as a researcher, my position of critical realist complemented the philosophical underpinnings of IPA. By using IPA, I was seeking to gain an understanding of individuals' lived experiences, whilst also recognising my role as researcher being the primary analytic, and interpretive instrument. I am aware that my assumptions would have influenced the construction of the findings, and I endeavored to make my thinking as transparent as possible through the use of reflective logs (Appendix 3) and through ensuring my raw data was accessible.

In addition, being an insider-researcher (Dwyer & Buckle, 2009), I was conscious of the need to remain reflective about my personal biases, and the impact on the research process and findings. I was mindful that the perceived 'sameness' between participants and myself may have hindered participants being explicit and elaborating on their points, with an assumption I knew what they meant. It is suggested that insider-researchers should gather data being very aware of their position (Asselin, 2003), however I also acknowledged I held a position as an outsider-researcher, being a trainee Clinical Psychologist. Literature suggests researchers may experience conflict and a competing pull when adopting two roles (Brannick & Coghlan, 2007). Transparency and the use of my supervisory team was invaluable in addressing these points. I also took part in a bracketing interview which was agreed with a colleague at University. Moreover, I was given the opportunity to have an extract of my work coded with other members of my IPA peer group, allowing me to check my codes and themes against what they had noticed. Similarly, my field and university supervisors independently coded a transcript, allowing us to compare interpretations, again recognising my potential influence on the findings. It is believed that being an insider-researcher does bring a number of advantages, that I hope enhanced this study (Dwyer & Buckle, 2009).

2.5 Participants

Once participants made contact via the portals available on the advert, a time was arranged for an informal discussion. This conversation allowed for introductions, providing further information on the study, setting expectations for participation, and gaining a brief understanding of the parent's MHD. Time was also created to answer any questions or concerns.

2.5.1 Recruitment

At the time of recruitment, unfortunately the world, England included, experienced a global pandemic – COVID-19. The country gradually went into national lockdown, consisting of no face-to-face contact with others, apart from with those one lived with. This meant that the initial phase of recruitment consisted of obtaining participants via social media. Social media profiles were created on Facebook and Instagram for the purpose of the study, and closed on completion of recruitment. These platforms were chosen due to their ability to have considerable reach, allowing individuals to contact me anonymously, whilst being cost effective for the researcher (Bender et al., 2017).

For Instagram, popular Indian influencers were contacted via their Instagram profiles, and informed about the study, alongside sharing the study's advert. It is known that individuals speaking about mental health on the internet can encourage others to find in-group support (Horgan & Sweeney, 2010), therefore approaching influencers was used as a way of overcoming the potential stigma and secrecy surrounding mental health in Indian culture. Influencers were approached from a variety of fields, such as those working in comedy and music, as well as within the wedding and beauty industry, advertising the study to a wide audience, including both males and females; it is already known that recruiting males as participants in the field of parental mental health is particularly challenging (Nolte & Wren, 2016). The thesis advert (Appendix 4) was shared with the influencers that responded to an initial private introduction message, and they kindly shared it on their social media pages. For Facebook, the study's advert was posted in a group called 'RecommendAsian' via the project specific profile. Details of how to directly contact the researcher were included, and consequently messages from interested individuals were received. These recruitment strategies produced seven participants.

2.5.2 Inclusion and Exclusion Criteria

Table 5

Inclusion and exclusion criteria for participant recruitment

Inclusion	Exclusion
Above the age of 18 years old	Individuals who are currently experiencing MHD
Identify as being from an Indian heritage	
To have grown up with a parent experiencing MHD	
MHD can be self-defined by participant	
Participants must speak fluent English	

MHD experienced by the parent were defined by the impact it had on the parent's functioning; parents did not require a formal diagnosis or to have used mental health services. This decision was made to include individuals whose parents had / were experiencing difficulties, but who may not have sought out professional help, as this was seen as likely to be common across the population.

Participants were excluded from the study if they were currently experiencing difficulties with their own mental health, as this may have impacted on their account and would also raise ethical concerns about participant wellbeing. Participants were also required to speak English for a number of reasons, including the reliance on language and meaning-making in the IPA method (Smith et al., 2009); financial constraints of the project made payment of interpreters or translators beyond the scope of the study; as well as managing researcher wellbeing, conducting the interviews in English was seen as a way to enable the researcher to create boundaries, and keep some emotional distance from the participants and their accounts during research interviews (Dickson-Swift et al., 2006).

2.5.3 The Sample

IPA is committed to the principal of ideography, and 'invites participants to offer a rich detailed first-person account of their experiences' (Smith et al., 2009, p. 56), and therefore smaller sample sizes are preferred. In consideration of the scope of the thesis and the guidance and aims of IPA (Smith et al., 2009), five to eight participants are seen as suitable for an IPA study.

Of the seven participants recruited, four were females, and three were males, aged 34 to 54 years old. All participants identified themselves as having an Indian heritage, with five participants describing their religion as Hindu, and two describing themselves as Sikh. None of the participants were currently living with their parent, and six of the seven participants, reported being parents.

Table 6

Participant Demographic Information

Participant Pseudonym	**Age Range**	**Religion**	**Gender**	**Education**	**Parent affected**	**Description of parent's difficulties**
Arpana	35-44	Hindu	F	Bachelor's degree	Mum	Paranoid Schizophrenia
Priya	25-34	Hindu	F	Bachelor's degree	Dad	Depression / alcoholism
Sukhi	35-44	Sikh	F	Bachelor's degree	Dad	Depression / alcoholism
Pankaj	35-44	Sikh	M	Bachelor's degree	Dad	Bi-Polar Disorder
Dinesh	45-54	Hindu	M	Post Graduate degree	Dad	Depression / alcoholism
Kalpesh	35-44	Hindu	M	Post Graduate degree	Dad	Depression
Nisha	25-34	Hindu	F	Bachelor's degree	Mum	Depression Bi-Polar Disorder?

2.5.4.Challenges in recruitment

Informal conversations about this research were held with individuals who were appropriate for this study, however, they did not want to partake. I realised the power of stigma, and how it can act as a barrier preventing individuals from coming forward. This is especially true of individuals who may have confronted prejudice and discrimination because of their racial identity (Gary, 2005). I was told that participants did not want to participate as they had moved on from the emotions they carried in their past, and did not wish to discuss them. Others spoke of respect for their family and how speaking about their parents' MHD would go against family wishes. The reluctance for people to come forward was further reinforced by the low numbers of individuals who responded to the adverts posted by the influencers on Instagram. Factors such as timing of these adverts would have played a role in who saw them, as well as biasing who came forward for the study. Limitations will be further explored in the discussion chapter, however, these recruitment challenges in itself began to shed interesting light on the research question.

2.6 Expert by experience consultation

'Experts by experience (EbE) are people who have recent personal experience (within the last five years) of using or caring for someone who uses health, mental health and/or social care services that we regulate' (CQC, 2020). Individuals with experiences relevant to research studies are invaluable in improving research design, and therefore outcomes (Trivedi & Wykes, 2002). With this study, through an Indian community group, the researcher was fortunate to be put in touch with an individual who met the criteria for participants in the study. This individual was willing and wanted to be a part of the study, and agreed to be an EbE consultant. It was important to ensure the role of consultant did not feel tokenistic, and payment was offered for their time in the study; NHS England, state the rate of pay for an EbE is usually £20 an hour. This was offered to the consultant, however, they did not want payment, instead commenting on how being part of the study was a privilege, and if their contribution could help, that was enough. Working with the consultant reinforced the importance of this work.

The EbE consultant agreed to take part in a pilot interview, which assisted in refining questions, ensuring they were comprehendible. This interview helped to gage the time needed to conduct future interviews, and think about questions that may evoke potential distress for participants. Conducting the pilot interview brought the study to life, where the researcher gained experience of listening to another's lived experience, and noticing their own emotions with hearing it. The researcher was able to reflect on how they were feeling through use of a reflective diary, and in regular sessions with their supervisory team.

2.7 Ethical Considerations

Ethical approval was sought and gained from the University of Hertfordshire Health and Human Sciences Ethics Committee, with the following protocol number - LMS/PGT/UH/04171 (Appendix 5).

2.7.1 Informed Consent and confidentiality

Prior to commencing the study, all participants were contacted for an informal discussion where it was ensured they met inclusion criteria. Individuals were briefed on the study, including their involvement if they chose to participate, and how their information would be stored confidentially and safely. Pietkiewicz and Smith (2014), speak of the importance of building a rapport with participants and starting to gain trust; there was hope that in having a conversation with participants, this process would begin.

All information provided was reiterated in written form and provided to each participant (Appendix 6). If participants were happy to proceed, they were asked to sign a consent form; given the current pandemic, and therefore virtual working, participants had the option of emailing or scanning their consent forms back to the researcher. Participants were made aware that should they want to withdraw from the study after their interview, the researcher should be informed within one calendar month post interview, to allow more participants to be sought. Following the interview, all participants were debriefed, and again sent a debrief sheet (Appendix 7).

In terms of confidentiality, the interviews were held online with only the researcher and participant being present, and recorded via an encrypted dictaphone which was solely available to the researcher. All participants were given pseudonyms, ensuring no data was personally identifiable. Electronic data was held on an encrypted external hard drive, only accessible to the researcher. The data shared with the researcher's supervisory team was non identifiable. Participants were made aware that the anonymised data collected would be stored electronically in a password-protected environment, for up to five years in line with the BPS guidelines, after which, it will be destroyed under secure conditions.

2.7.2 Potential distress and risk

During informal discussions before interviews started, and prior to participants signing the consent form, they were made aware that confidentiality would be breached if there were concerns about participants' safety or the safety of others. Considering the potential emotional impact the study may have had on participants, steps were taken to limit the potential distress that could be caused by the questions posed, through conducting a pilot interview with the EbE consultant. With all interviews, participants became emotional at different points; three participants became tearful, but stated they expected to, and were able to self-soothe and look after themselves. All participants were given the option to take a break, or resume the interview at a later time, but they opted to continue. A resource pack of support agencies was sent to participants along with the debrief form, and time was left at the end of each interview to answer any questions or concerns participants may have had.

In consideration of the impact this research may have had on the researcher, the use of consultation with the supervisory team was made by scheduling in frequent meetings, making time to discuss the researcher's wellbeing. Self-care strategies already in place were also available to the researcher.

As interviews were held online, there was no physical risk to the researcher in terms of travelling to unknown locations, and meeting unknown participants.

2.8 Data Collection

2.8.1 Pilot Interview

As discussed above, a pilot interview was held with an EbE consultant. Conducting a pilot interview allowed review of the suitability of the questions being asked, as well as gaging the time frame of interviews. The interview took place face-to-face, and was treated as the researcher had planned to do all interviews. Feedback from the consultant led to a change in the researcher's interviewing style, where the importance of asking open questions was highlighted, whilst also allowing time and space for participants to process the question, before prompting. The feedback received was positive, with the consultant reporting that the questions should allow participants to freely talk about their experience, without being overly leading.

2.8.2 Interviews

Questions for the interviews were first collated after assessing the available literature around the research question. These were then shared and refined with the help from the supervisory team, and the study's consultant, resulting in a semi-structured interview schedule (Appendix 8). Interviews are seen to help the researcher and participant engage in a conversation (Pietkiewicz & Smith, 2014), and therefore open questions were used to allow participants to answer freely, with prompts being used if participants found the questions too abstract. The schedule aimed to explore the experiences for participants in childhood, including how they made meaning of those now as an adult. Rather than being fixed, the schedule was used as a guideline, helping participants to speak freely about their experiences.

All interviews took place virtually using Zoom, allowing participants and the researcher to see each other. This was particularly important as non-verbal communication was observed which may have been lost conducting interviews via a phone call (Archibald et al., 2019). Conducting real-time interviews also allowed the researcher to prompt participants for any further information, or understanding required. In the initial informal discussion with participants, potential disturbances were problem solved. These included a conversation about childcare, ensuring participants were able to create time and a private space for the interview. To meet the needs of participants, the researcher remained flexible, agreeing to interviews on a day and time chosen by the participant.

Interviews lasted between 60 – 90 minutes, with each interview being recorded, and transcribed by the researcher. Post interview, the researcher made use of a reflective diary (see Appendix 3 for extracts), noting any main themes they felt were prominent in the interview, as well as how they were left feeling, and the rapport with the participant. It was interesting to refer back to and notice the similarities when the researcher came to analyse transcripts.

2.9 Data Analysis

Guidelines for IPA recommended by Smith and colleagues (2009) were followed, and the key stages are outlined below:

2.9.1 Stage 1 – Reading, re-reading and listening and re-listening

The researcher immersed themselves in the data by reading, and re-reading as well as listening and re-listening to each interview. Whilst engaging in the process, notes were made on a line by line basis of the interview, relating to initial thoughts or insights, noticing the language being used, initial interpretations, content or context. Discussion with the supervisory team, and personal insights allowed for new perspectives to be gathered. Notes were detailed enough to reflect the material in the interview. The qualitative data analysis software NVIVO was used to develop initial codes, and link to quotes and material in the interview (Appendix 10).

2.9.2 Stage 2 – Turning notes into emergent themes

At this stage, the researcher worked with their notes and codes made in stage one, transforming them into emerging themes. The themes remained close to the interview, demonstrating the hermeneutic cycle where '*the part is interpreted in relation to the whole, and the whole is interpreted in relation to the part*' (Pietkiewicz, & Smith, 2014 p.7).

2.9.3 Stage 3 – Seeking relationships and clustering themes

Lastly, connections between themes were explored, and themes were grouped based on similarities. If themes did not carry enough evidence behind them, or no longer fit with the overall structure of the interview, they were left out. Each cluster was given a descriptive label, and the ending table covered subordinate themes, and superordinate themes.

Stage 1-3 was repeated for all seven interviews, at which point connections across all interviews were explored, resulting in a master and sub-theme table (Table 7). Quotes from interviews were gathered to illustrate the evidence behind the themes.

2.10 Assessment of Quality of Current Study

The work of Yardley (2000) is frequently cited in IPA studies to measure the quality of qualitative research, and therefore the current research will also be assessed via this framework. Within this framework, there are four criteria which are, sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2000).

2.10.1 Sensitivity to Context

This criterium is concerned with demonstrating '*an endeavour to link the particular to the abstract and to the work of others*' (Yardley, 2000, p7). This was considered at every stage during the process of this study. Firstly, a thorough literature search was conducted considering the context of the current research within parental mental health. Developing a systematic review, recognised and appreciated the available research on this topic, as well as highlighted the gaps in knowledge, for example the impact of culture, which this study sought to explore. The knowledge gained from reading current literature on parental mental health, helped to identify and phrase the questions in the interview schedule. Yardley (2000) emphasises that the research should be sensitive to the socio-cultural context of participants, and this was definitely considered in conducting the pilot interview, and reviewing the interview schedule with the study's EbE consultant, as well as the supervisory team. Informal discussions with participants prior to interviews allowed the start of a relationship to be developed between the researcher and participants. As stated above, this conversation provided the time and space for participants to pose any questions about the study or the researcher; the researcher endeavoured to be transparent in their answers. The researcher was particularly aware of their influence on the research and the actions of participants, and they chose to bracket any assumptions they had before conducting interviews (Ahern, 1999), including keeping a reflective diary throughout the process. In terms of addressing the power between the researcher and participants, the researcher ensured questions were open enough to allow participants to answer them in a way they felt comfortable, disclosing as much, or as little as they wanted within the interview. The researcher strived to make the participants comfortable in the interviews, whilst listening, and showing an appreciation for them being experts in their experiences.

2.10.2 Commitment and Rigour

Commitment to the study was demonstrated by the researcher immersing themselves in the data, and transcribing and analysing the interviews themselves. The researcher's skills in analysis were supervised by their supervisory team, who are experts in IPA. An interview was independently coded by the researcher and supervisor, and the results were compared. Extracts of a transcript were shared with the IPA peer group at the University of Hertfordshire, comparing interpretations made. Examples of transcript and coding can also be seen in the appendices (Appendix 9, 10, 11, 12), where the reader is able to follow the researcher's method of analysis from what was said in interviews, the interpretations made, and consequently the themes developed. This provides 'checks of credibility' (Elliott et al., 1999), and though the researcher is confident in their interpretations of the transcripts, they are aware that the findings reflect their perspective, and therefore another individual viewing the transcripts may interpret them differently.

With respect to rigour, a homogenous sample was chosen who were appropriate to answer the research question. This was ensured by an informal discussion with potential participants prior to the interview taking place. As noted above, the questions within the interview schedule were consulted on by the expert by experience, and supervisory team.

2.10.3 Transparency and Coherence

When referring to transparency, Yardley (2000) stated that the researcher should inform the reader of how the research was conducted, and the rationale behind it. The researcher attempted to be as transparent as possible within this study, detailing each stage of the analysis, and providing comprehensive examples within the appendices. Furthermore, within the analysis, quotes from transcripts have been used to illustrate the themes generated. Lastly, the criteria of transparency were met through keeping a reflective diary during the research, demonstrating the use of reflexivity by the researcher in understanding their influence on the study.

'The quality of the narrative is an integral part of its productive value' (Yardley, 2000, p. 9). A coherent argument was made for this research through the introduction and then the systematic review identifying gaps in the literature. Overall, the coherence of the study will be judged by the reader, however the choice of methodology and analysis to answer the research question has been made explicit.

2.10.4 Impact and Importance

There is a growing body of literature looking into the experiences of adult-children and parental mental health, however currently, there is no research exploring the impact of culture. It is hoped that this research accurately captures the voices of those who participated in the study, and it resonates with those who feel alone and unable to share their stories. It is hoped the findings from this research inform practice by health and social care workers, to explore the impact and needs of all family members, when individuals within a family are experiencing MHD. The facts and figures discussed in the introduction portray a need for children, that is not currently being met by services, therefore, there is little doubt in this research being important and having an impact.

Chapter 3 - Results

This chapter will present the findings from the seven interviews conducted with adult-children who have grown up with a parent with MHD from an Indian heritage. Interviews have been analysed using IPA. Master and subordinate themes are presented below, with quotes and examples from participants' transcripts to ground the work in participants' lived experiences.

Five master themes were co-constructed through the analysis of the seven interviews:

- Making sense with a lack of knowledge
- Managing stigmatised silence
- Recognising the internal and external void
- Feeling distant yet accountable
- Gaining positives from parental MHD

The table below summarises the master themes alongside subordinate themes. The themes aim to capture participants' experiences and understanding during their childhood, as well as long standing effects into adulthood.

Table 7

A table illustrating master and subordinate themes, and the number of participants represented in each one

Master Themes	Superordinate	Priya	Dinesh	Arpana	Nisha	Sukhi	Kalpesh	Pankaj
Making sense with a lack of knowledge	Trying to make sense without understanding	x	x	x	x	x	x	x
	Feelings of regret and guilt for not knowing more, and feeling unable to help	x	x			x		x
	Sadness for the impact of not receiving help early enough	x	x		x	x		x
Managing stigmatised silence	Feeling undesirable to the Indian community and disappointed by lack of support	x	x	x	x	x		
	No one felt able or allowed to talk so no one really understood home life, to be able to help us	x	x	x	x	x	x	x
	The Asian community do not acknowledge mental health problems, and ostracized us	x	x	x	x	x		
Recognising the internal and external void	Navigating troubling emotions	x	x	x	x	x	x	x
	Missing a childhood; knowing the ugliness of life from a young age		x	x	x	x	x	
	Living with uncertainty and unpredictability	x	x		x	x	x	x
Feeling distant yet accountable	Experiencing the loss of a parent figure	x	x	x	x		x	
	Carrying burdensome cultural expectations	x	x	x	x	x	x	x
Gaining positives from parental MHD	Developing strategies to help me and others manage our mental health	x	x	x	x	x	x	x
	Growing in strength and awareness of mental health	x	x	x	x	x	x	x

3.1 Making sense with a lack of knowledge

The first master theme relates to the confusion, and later frustration, all seven participants felt as children, with having little access to information about their parent's MHD. Limited knowledge left participants with a feeling of helplessness, being unable to assist in gaining the support their parent, and family required. With age greater information was sought, and whilst this was helpful in shaping one's understanding of MHD, expressions of sadness were made for not receiving help at the right time, recalling how different life could have been for both the participant and their parent. Three superordinate themes were developed, namely 'Trying to make sense without understanding', 'Feelings of regret and guilt for not knowing more, yet feeling unable to help', and 'Sadness for not receiving help early enough'.

3.1.1 Trying to make sense without understanding

All seven participants spoke of trying to conceptualise and understand their parent's experiences. However, with limited knowledge about mental health, at times erroneous conclusions were made as to the cause of the difficulties, with nobody to correct them. This was particularly poignant in Pankaj's interview, where he attributed the cause of his father's *'consistent sadness'* to himself.

> *'I think if I tried to summarise it, it would be that why is Dad always feeling down and negative, even though we're doing our best. I guess part of that was, we would take it personally, because we always assumed that he was feeling that way because of us.'*
>
> *(Pankaj)*

Pankaj explained that he never wanted to discuss his father's mental health with him, as he feared it would cause upset. Pankaj reported constantly trying to *'be good'* and lift his father's mood, however was left feeling that his best was never enough, as he would witness his father being *‘sad’*. Similarly, Nisha commented on avoiding discussing her mother’s MHD with her for fear of ending the *‘good times’*, starting arguments, triggering further challenging situations. A cycle was described by participants where they would first be exposed to ‘*unusual’* or ‘*erratic’* parental behaviours, evoking feelings of anxiety and fear in them as children. If participants sought reassurance and information from family members, a response of *‘well that’s just the way it is’ (Nisha)* was received. Without new information being provided, children remained anxious and underinformed. It is possible that family members did not have the language to explain the difficulties being experienced, however, without an explanation, a sense of confusion continued to be felt.

> *‘As he hadn't opened up to us in terms of any issues at work or anything like that. So it was just like what’s happened here?’ (Kalpesh)*

Arpana recalled when younger, her father’s family would use phrases such as *‘she’s mad’*, *‘she will hurt you’* or *‘she’s dangerous’*, when referring to her mother. Unsurprisingly, Arpana remembered being frightened of her mother as a child, and as an adult reflected on how valuable age-appropriate information about mental health would have been for her and her family.

Some participants attempted to hold conversations with their parent wanting to learn more about their MHD, however their efforts were met with silence. Dinesh described feeling frustrated and angry with receiving a lack of answers from his father. For Kalpesh there was a sense of his father’s difficulties having been experienced for so long, that his feelings toward his father had changed. At 18 years old, Kalpesh described being *‘shocked’* when he learnt his father had tried to take his own life. He stated that at the time he was revising for his A-Levels, and had not noticed a change in his father’s wellbeing. With age, Kalpesh reported his responsibilities had increased, and though he still does not understand his father's feelings and behaviours, in the interview Kalpesh seemed exasperated with paying attention to, and managing his father's MHD.

> *'So I think I was probably more tolerant before than I am now. Like I said, now I think because there are different work pressures, I am in more senior roles at work so more going on there, I have family pressures, I have house pressures. There are so many different things going on. It doesn't help I will more easily talk back or argue back now straight away, because I can.' (Kalpesh)*

Gaining more information occurred for participants in adulthood, and mostly from speaking to trusted friends. The majority of participants reported the benefits of acquiring this knowledge in helping them understand their parent more, therefore enabling a different approach to be taken. This was true for Priya who explained that by being more aware of her father's difficulties, she was able to be more compassionate towards him, forming a better relationship.

> *'Instead of looking at my dad and thinking he is kicking off, I was understanding what was triggering him. I was trying to understand what would make my dad flip. So, I became more sensitive to him. I was never insensitive but like I looked at dad more differently, like knowing when he is having an episode and so needing to behave differently. So, speak to him differently, speak more softer, be more understanding towards him and show him compassion.' (Priya)*

Conversely for Pankaj, he explained that as an adult, learning more about what his father experienced with his mental health, led him to worry more about him and his well-being. At the time of the interview, most participants had a better awareness of the difficulties their parent was experiencing, but were still unsure how to categorise them.

> *'So whether it was mental health issues, depression, bi polar, was he manic depressive, there was something in him that made him feel inadequate and insecure.' (Dinesh)*

This superordinate theme highlights participants' meaning-making as adults, of the emotional impact of having and receiving little information about mental health as children. It seems that even when participants attempted to learn more, they were faced with barriers, resulting in either self-blame for the causation of difficulties being experienced, feelings of confusion, concern about their own mental health, and for some participants turbulent relationships with their parent. In adulthood, as understanding increased for some, compassion and empathy was fostered. However for others, due to the pressures of their life they seemed less tolerant of their parents MHD.

3.1.2 Feelings of regret and guilt for not knowing more, yet feeling unable to help

This superordinate theme expresses the feelings of guilt four participants reported for not knowing more about their parents' MHD during childhood, and for some participants, feelings of disappointment for not approaching the conversation with their parent. Priya's father passed away eight years ago, and she spoke of many regrets she still carries for not speaking to her father about his MHD and alcohol use. There was a sense that the guilt she felt was exacerbated as she did not live at home, and therefore was not always physically present.

> *'In my mid 20s when I came back to (town of origin), I didn't move back home, so for me, I didn't see the full scale of it, everything that was happening so I think there is a level of regret that I didn't have those conversations in my mid 20s, because I think I realised too late to have that conversation.' (Priya)*

Priya and Pankaj described their fathers as very private men, and with their fathers not discussing their mental health, they did not feel able to broach the subject. Priya and Pankaj felt unable to question their fathers; with Pankaj there was an added sense of sadness as he witnessed his younger brother take control of organising care for their father, however Pankaj stated that he was always conscious of respect, and never wanting to upset his father.

> *'I think because he's not really been so open about it, and he's a private person, how do I say, 'hey Dad check this out, have a look at this.' (Pankaj)*

Participants commented on being unaware of where to seek help, and how to phrase what was happening. There was a sense that opening up would make matters worse, or that services may not be able to help.

> *'Where do they go for help and advice. Or what could you do, and what should you say. You don't want to make the situation worse, and you don't want to give that hope.' (Arpana)*

This superordinate theme portrays the challenge participants experienced in balancing the want to help and respecting their parent's wishes. Again, participants' accounts illustrated that they did not know where to seek help, leaving the situation stagnant.

3.1.3 Sadness for not receiving help early enough

Due to experiencing barriers to receiving help, five participants reflected upon how their parents did not receive therapeutic help until a much later time. Nisha seemed despondent for her mother not accessing support earlier in life, as in her opinion, life could have been very different for her. In Nisha's account, responsibility not only lay with her mother, but also with services for not being available or easily accessible, and therefore not intervening at a critical period. Nisha explained how their relationship had improved since her mother had received counselling and medication, therefore had she received this earlier, perhaps Nisha may not have experienced such challenges in her childhood.

> *'You know, I wish there was more support available to her at the times that she needed it because she has missed out on so much of her life, you know, she's in her 50s now. She got married when she was 20, but you know, three fifths of her life have been taken away. So, I just wish she could have had more support, I wish she was open to having more support available to her. I wish she didn't feel like she couldn't go anywhere to talk to people about it. I wish she could have opened up to people, so many wishes of how it should have been.' (Nisha)*

Conversely Sukhi spoke of trying to access help for her father, however, she was told by the service she accessed, that they could only intervene with her father contacting them. This experience made her feel *'dismissed'*, giving her a negative perception of services, and feeling at a loss of where to turn to.

> *'He said, you know, there is nothing I can do, unless your dad calls me, and unless your dad wants help. There's nothing I can do. You know, it's really dismissive. It's like, my dad will never in a million years, A - wants to stop drinking or B - ask for help or, you know, acknowledge anything is wrong. So, it just felt like we had nowhere to turn at all.' (Sukhi)*

For Kalpesh, his experience of services intervening occurred at the point of crisis, where his father had tried to take his own life. Prior to this, to his knowledge little support was sought or offered to his father.

> *'So initially, when the episode kicked off that 15 or 20 odd years ago, I think it was followed through with hospital and their processes. Once you're already there, you go down certain routes such as mental health wards and all of that. It's always been through that.' (Kalpesh)*

Some participants also expressed concern about the cultural appropriateness and sensitivity of services. Dinesh reported that had his family recognised the MHD his father was experiencing, perhaps they could have sought help, however he remained '*sceptical*' about services existing for '*Asian communities*'.

> *'I think if there was the acknowledgement, we could have potentially sought help, we could have potentially got services and so on. However, I am hugely sceptical about that, I mean knowing now, and having worked in social care NHS, which I have been out of for about 15 years, and in the field, I am in, I still don't know that services for Asian communities exist. It is still a taboo to seek help, still the services are unknown, and if they are there, they are not tailored.' (Dinesh)*

This superordinate theme highlights the challenges individuals can experience when trying to access services. In all cases where input from services had been received, albeit at a later stage, a beneficial effect was reported for both the parent and the relationship with their child.

3.2 Managing stigmatised silence

The narratives from all seven participants told a story of the challenges faced, when considering the influence of the Indian culture. The power of secrecy and shame associated with MHD resulted in family members, including children, being fearful of sharing their experiences with anyone, and consequently lacking social support. Though participants commented on awareness within the Indian culture slowly changing, there was an emphasis on the prejudice and discrimination people still experienced where MHD was concerned. Three superordinate themes were constructed, namely, 'Feeling undesirable to the Indian community and disappointed by lack of support', '*No one felt able or allowed to talk so no one really understood home life, to be able to help us*', and '*The Asian community do not understand mental health problems, and ostracized us*'

3.2.1 Feeling undesirable to the Indian community and disappointed by lack of support

Five participants described feeling disappointed with the lack of support from family members, and the wider community. Priya spoke of feeling as though she was too dissimilar from the cultural expectations she perceived to be important to the Indian community, denoting how an Indian woman should behave, and how her values appeared to contrast those the community thought to be acceptable.

> *'When I look at what's important to Indian people like marriage and money, I can't comprehend that. Women want their sons to marry good Indian daughters that can cook, and are very academic and don't speak back.' (Priya)*

This feeling of difference created a distance between her and the Indian community, as she did not feel welcome or accepted, and therefore felt she had lost their support. Dinesh also commented on how he became more vocal as he aged, which was not seen as culturally desirable. He explained that due to experiencing his father's alcoholism, violence, and aggressiveness during his childhood, he became less tolerant towards his father's behaviours and started to '*talk back*', which was frowned upon by his grandparents, again causing distance in their relationship. From Dinesh's experience, the Indian community were uninterested in mental health. As an adult, Dinesh shared with his family that he was struggling with his own mental health and seeking support, however this was dismissed, and he reported being '*belittled*' by his brother.

> *'It would be a form of weakness to say, I have seen the doctor I am getting counselling, and medication. Their view when I said I have been to get counselling was, what are you wasting money for? Why are you wasting time talking to people? Why can't you pull yourself together?' (Dinesh)*

Arpana reported feeling disappointed with people's ignorance when they learnt about her mother's MHD, commenting on how they would '*run a mile'*. This surprised her, and the only sense she could make from it, was that others thought she might ask for their help. Arpana reported that all she was seeking was support.

Many participants described the impact on them personally, and on how they were perceived in the Indian community due to their parent's MHD.

> *'I think that people saw what was going on, and you just saw pity in their eyes, and that's not what you need. You don't need people feeling sorry for you because you're already feeling sorry for yourself.' (Nisha)*

Sukhi explained that due to her father's MHD, her appeal to suitors and their families for marriage, reduced. People within the community knew of her father's depression and alcoholism, and she explained '*nobody would want to get the genes of the crazy shit we have'*, limiting her options for an arranged marriage. The idea of '*bad genes*', also related to families not wanting grand children who carried the risk of inheriting MHD. She explained receiving offers for marriage from India, at the age of 15 years old when her father had passed away, as people thought they could '*exploit'* a vulnerability when the family was grieving, and gain a British passport.

This superordinate theme encapsulates participants' feelings of being different, as well as the consequences of parental MHD for children. These experiences depict how the Indian community often responds to mental health, leading families and individuals to conceal information about any difficulties that may be experienced, due to the impact it can have on all members of the family, as well as the family's reputation and therefore social standing.

3.2.2 'No one felt able or allowed to talk so no one really understood home life, to be able to help us'

This superordinate theme relates to participants feeling unable to talk about their parent's MHD, therefore internalising the anxiety and concerns they carried for their parents. All participants explained that they feared the outcome of sharing the difficulties occurring at home, with many of them worrying they would be separated from their parent. Sukhi reported experiencing physical sensations of anxiety as a child which manifested itself in stomach pains. At the time, she was unaware of what the pains were, and consulted her GP. When she realised the GP thought her pain may be connected to situations at home, she disengaged. Sukhi feared and mistrusted others, which included services, increasing her anxiety.

> *'He was trying to get me to keep a diary of when I had my stomach pains, and you know, if my mum and dad were fighting. I just shut down. I was like, I'm not going get taken into care, everything's fine, and I never saw him ever again.' (Sukhi)*

Most participants reported how their family never spoke about MHD, yet everyone knew about it. Dinesh reported '*It was the drunken Indian elephant in the room*'. However, there was a sense that even if parental MHD and the effects on the family were spoken of, no one would understand, so there was no point in talking. Sukhi explained that the idea of not talking to those outside of the family was instilled in her from a young age, with the explanation that it served to keep the family safe.

> *'Whatever is the fire that's going on behind closed doors, it needs to stay there, and you know, it's our mess, but we'll get through it.' (Sukhi)*

In contrast to Sukhi, Pankaj stated that his family thought the difficulties his father was experiencing was a '*short term thing'*, and the feelings would pass.

In summary, this superordinate theme describes participants' fear with sharing what was happening at home. Either they feared parental separation, or thought no one would understand, and with time the difficulties would pass.

3.2.3 'The Asian community do not understand mental health problems, and ostracised us'

Five participants spoke about the Indian community not understanding MHD, and wanting to distance themselves from it.

> *'The Indian community didn't understand my dad's erratic behaviour and I think that was really hard and I think, when they distanced themselves from him, it made his depression worse.' (Priya)*

Many participants also described the differences between how they saw the Indian community responding to their parent's distress, and how they now view MHD. During the interviews, participants commented on language used to describe individuals with MHD, such as '*weak'*, illustrating the prejudice held by some members in the community; these negative perceptions encouraged families to hide MHD. Dinesh described MHD within the community as '*it's that taboo thing'*, and stated if deemed to have MHD you were either *'the village idiot'*, or '*crazy'*. He reported that it was easier to use words such as '*ganda'* (meaning mad) to describe individuals with MHD, as there were no words to explain the conditions one may have been experiencing. Arpana also explained how her mum was referred to as *'Ganda Santa'*, as though that was her name, and slowly she became known as that in her family; participants reported individuals with MHD were dehumanised, and seen as different, creating an 'us and them' divide.

Moreover, within the Indian community participants explained that it was almost acceptable to be physically unwell, but not mentally, despite both difficulties being equally debilitating. This was reflected in Kalpesh's interview where he understood there to be different requirements when an individual is experiencing physical difficulties in comparison to MHD.

> *'No because I guess this is different to a physical disability, I guess, right? It's not the case you are in a wheelchair or need feeding kind of thing.' (Kalpesh)*

To be physically unwell requires care, whereas Pankaj explained being mentally unwell could be seen as a sign of weakness, particularly so for Indian males, thought to be head of the family.

> *'It's a taboo subject, and it may make you look weak in some way. I'm not saying that I am like that, but if you are brought up in a certain way like Dad, then you don't show signs of weakness. I guess that's the natural Indian guy mentality.' (Pankaj)*

These beliefs perpetuate within the Indian community, leaving the topic of mental health unaddressed until recently. Only two out of seven participants spoke of an increased awareness in the community.

> *'From the messages I have seen, advertisements on TV and the radio sort of things, they do push this a lot, and make it a well-known fact that it does affect the community pretty bad. It does hit us.' (Kalpesh)*

In this superordinate theme, participants spoke of the prejudice and stigma ingrained within the Asian community towards individuals with MHD, and the influence it can have on one's identity. Though awareness of MHD seems to be growing in the community, it is a very recent phenomena.

3.3 Recognising the internal and external void

This master theme captures the internal emotions all seven participants experienced as a result of parental MHD, as well as the impact of the lack of connectedness they experienced socially. It portrays how MHD experienced by an individual, affects all members of the family. Three superordinate themes were constructed, which are 'Navigating troubling emotions', 'Missing a childhood; knowing the ugliness of life from a young age' and 'Living with uncertainty and unpredictability'

3.3.1 Navigating troubling emotions

All seven participants spoke of the emotions they felt during their childhood, and the lasting effects into adulthood. Dinesh explained that he felt so angry and frustrated with his father much of the time, that it hindered him forming the relationship he would have liked. As already stated, participants did not always have social support to turn to, and so for Dinesh he carried feelings of anger, describing himself as a '*ticking timebomb'*. He recalled these feelings made concentration in education difficult, and as an adult, reflected on how feeling angry towards his father superseded happy memories with him.

> *‘My anger and frustration with him meant that I felt I wasn't as close or I didn't love him as much, or I didn't want to care for him as much, and what I was also doing in that, is maybe forgetting all the good things and the good times and all the good things that happened as a child and growing up and so on. Kids remember, sadly, kids remember pain and things that go wrong more often than you know.’(Dinesh)*

With a constant feeling of pressure and anger, Dinesh explained as an adult that his relationships were affected, notably he found interpersonal relationships challenging.

> ‘*There was always that tension around, and I just took that away with me into all my relationships, and it did affect my relationships as well growing up and so on.’ (Dinesh)*

Some participants spoke of the impact of their childhood experiences leaving them feeling low in self-confidence. Arpana explained due to attending to the needs of her mother and the rest of the family, there had been little time to worry and care for herself, and as an adult she had learnt to prioritise others over herself. Arpana’s worries and anxiety built up over time, and manifested itself in chronic pain.

> *‘I started getting like a lot of kind of chronic pain, I started not being able to eat, I had digestive issues like reflux, everything was going wrong. So, I went to speak to this nutritionist thinking she's going to tell me you need to stop eating this, and everything will be fine. So, I kind of told her my story and she just said, you've just got a lot going on and you need to just deal with some of this other stuff.’ (Arpana)*

Sukhi also described feeling inferior to her colleagues, which had continued to those she was now surrounded by such as family, leading her to withdraw in social situations, hindering her ability to form new relationships. Nisha reported her childhood experiences impacted on her self-worth which led her to struggle with low mood when she was younger, and now as an adult.

> *'You know there were times when I thought I can't do this, like, I don't want to be here. There were so many times when I felt like, it would just be easier if I wasn't around anymore. Being a teenager, and having those thoughts go through your mind is quite difficult to sort of explain to anyone how you feel, because nobody, unless they're going through that, kind of understands.' (Nisha)*

Nisha stated that now she is older and has a family of her own, she worried more about how low her mood can be, and becoming like her mother.

This superordinate theme speaks of the challenging emotions experienced in childhood, which did not always resolve themselves. Most participants spoke of experiencing MHD such as depression and anxiety, and seeking therapy as an adult.

3.3.2 Missing a childhood; knowing the ugliness of life from a young age.

Five participants spoke of the exposure they had had to unpleasant situations in their childhood.

> *'I didn't feel I had much of a childhood. My grand-ma and grand-dad were at home but I would have to do things like make the tea and toast in the morning before we went to school. When they [his siblings] came home, take care of them, almost being a father figure to my siblings because dad wasn't able to do it.' (Dinesh)*

Dinesh spoke of the responsibility he was expected to take on due to his father experiencing MHD, and with being the oldest son. Culturally it would be anticipated that Dinesh would have assumed the role of 'man of the house', and though he was young, he was also resuming care for his siblings. Throughout Dinesh's narrative, there was a sense of resentment he carried for having to be the one looking after everybody, without anyone caring for him.

Nisha spoke of a challenging relationship between her and her mum when she was younger, feeling as though she was being controlled.

> *'She was there from the outside, she did everything right. We went to school with a roof over our heads, we were fed, we were clothed, she did everything right. From the outside, everything looked perfect. But on the inside, there was so much wrong.' (Nisha)*

Nisha explained she wasn't allowed to have friends over and be a child, and on reflection, she reported feeling very lonely, and as though she had missed out on a childhood. It was common for participants to explain that there was little value telling others how they felt; to them if you hadn't experienced the '*hatred'* and feeling '*unwanted'*, then you would not understand the difficulties they were experiencing.

For Sukhi the impact of her father not being able to work because of his MHD, and the family living in poverty, had adverse consequences on her childhood.

> *'Everybody used to say I smelt because my clothes must have smelt of damp or 'tarka' [Indian cooking], or whatever. So, I was really badly bullied.' (Sukhi)*

Coupled with people knowing about her father's alcoholism and depression, Sukhi experienced bullying, reinforcing a sense of mistrust in others. Her father had already instilled this belief, which resulted in a difficulty forming and maintaining relationships as an adult.

In this superordinate theme participants remembered the weight of responsibilities and the emotional impact their experiences of childhood had on them. In most cases participants reported missing out on a childhood.

3.3.3 Living with uncertainty and unpredictability

This superordinate theme related to how participants described their environments. Six participants explained that that there was a sense of tension at home, describing it as a *'war zone'*, portraying conflict. Again, this superordinate theme highlights the impact upon the whole family when MHD are being experienced. When their parent was having a good day, participants would want to enjoy time together, however there would be a sense of anticipation for when this period would change, perpetuating feelings of anxiety. Dinesh explained that due to the uncertainty of the atmosphere at home, he would try and avoid being there. Unfortunately, not all participants were able to escape home, and Nisha explained that when her mother was feeling low, her mood would decrease quickly, which would escalate into arguments and conflict between them.

> *'When Mum was on a really, really, really low point, we would have been going through weeks and weeks of arguing over stupid little things, which would lead on to something massive, which would then result in her saying, she's going to leave the house and never come back, she's going to go and kill herself, she's going to go commit suicide.' (Nisha)*

For some participants, they reflected on how as children, though home life may have seemed turbulent and described as '*the worst of circumstances'*, they did not always know any different. Some participants considered their life to be normal until they were exposed to, or learnt about the childhood their friends had.

This superordinate theme summarises the constant sense of anxiety and stress participants described, which was fuelled by the tense atmosphere at home. These feelings lasted into adulthood with participants having difficulty in relaxing and feeling at peace as they had become accustomed to feeling on edge.

3.4 Feeling distant yet accountable

This master theme captures the impact MHD had on the parent-child relationship. All seven participants reported a distance created, as well as retrospectively describing the loss of a parent figure. The impact of an absent parent figure was determined by the availability and presence of another parent, however the majority of participants spoke of supporting their parent, whether due to duty and cultural expectations, or love. Two superordinate themes will be discussed, namely ‘Experiencing the loss of a parent figure’ and ‘Carrying burdensome cultural expectations’.

3.4.1 Experiencing the loss of a parent figure

Five participants reflected on witnessing the relationships between their friends and their parents.

> *‘Essentially when I look at other people’s parents, and kind of think well actually that’s what I wanted, and what I didn’t get.’ (Priya)*

For some participants there seemed to be a sense of regret for not getting the relationship they wanted. Arpana explained that she was kept away from her mother by her father’s family to protect her, as the family had little understanding of MHD. She spoke of missing a ‘mother figure’ growing up, and though she later built a good relationship with her mother, it appeared different to the relationship she had envisaged having. This was true of participants who recalled the parent experiencing MHD, being unable to provide a safe sense of home, and engage in activities they saw parents doing with their children. However, where the responsibility and care was taken over by another parent being present, the amount of absence felt was reduced.

> *'I missed having that father figure there physically. I can't say I struggled, my mum was my father and my mother, as opposed to my dad.' (Dinesh)*

Though Dinesh spoke of missing a father figure in his life, he commented on how his mother was there to support him, his siblings, and the whole family.

Distance in the relationship between parent and child was further created through participants feeling emotions such as embarrassment, when witnessing their parent's behaviours. Participants explained being worried that their parent may exhibit behaviours which were outside the social norm, in front of others such as their friends, and therefore they avoided inviting friends over to their house. Dinesh explained his father managed his depression through alcoholism, however drinking alcohol in public would lead to his father *'making a fool of himself'*, needing to be carried home, or getting so drunk and saying '*stupid things'*. Dinesh stated he couldn't feel the love he wanted to feel for his father, because he was always so angry with him. Kalpesh described that over years, he feels his tolerance for the difficulties his father experiences has decreased. He explained with age, life has brought other pressures such as work, and his own family, and therefore he has had to distance himself emotionally, to help him manage his life day to day.

> *'So, I think we've all grown up to just accept it and help where we can, because there has been a number since then, where he does it [suicidal attempts] quite regularly now. He has*

> *spent time in and out of hospital. He has been given help, but hasn't really made a difference to be honest. So, if you want to change, you got to change. If you're not, that's pretty much it, right.' (Kalpesh)*

Conversely, though Sukhi described childhood as being '*tough'*, with the family being '*ostracised'* from the Indian community, and with her and her mother supporting her father, she explained she was still very close to her father. In some cases, the ability to parent was unaffected for the person experiencing MHD. On reflection, Pankaj also commented on the resilience and strength of his father being present and engaging in activities with him and his brother, despite the low mood, and challenges he may have been internally facing.

> *'Dad was very private, but as a father he was always there for us. You know, we would never question where Dad was. He would never come home late unless he was working overseas somewhere. He was always there for us, and whether, again, that's a positive to him having mental health problems, and maybe there was something he was doing that we don't know about, but I don't know how he managed to raise three kids.' (Pankaj)*

Again, it appeared that the influence of a supportive spouse, lessened the impact and loss on children, and maintained the overall family wellbeing.

In summary, this superordinate theme describes the loss some participants reflected on as adults, for having a parent who did not fulfil their ideal. Importantly one participant reported his father as present, despite the difficulties he may have experienced.

3.4.2 Carrying burdensome cultural expectations

Though participants reported varying relationships with the parent who experienced MHD, all seven participants felt a responsibility towards them.

> *'So, whatever the problems were, my parents came from India and Africa, where you took care of your family. You know, if there's somebody who wasn't well, you'd earn extra money to feed them. If they had a disability, you push them around. So it was that kind of ethos.' (Dinesh)*

Many participants reported assuming a caring role, and for some, they were happy to take on these responsibilities. For others there seemed to be an expectation that as the eldest, or only child it was their duty to look after their parent. Dinesh reported feeling aggrieved for always being asked to go looking for his father whenever he was drinking alcohol. Dinesh was the eldest son, and he commented on it being unfair that his brothers were never sent to the pub to look for their father. Similarly for Kalpesh, he was expected to become 'head of the family'.

> *'Being Indian, and the male of the house, feels like a burden as I have to take on head of the family.' (Kalpesh)*

These responsibilities were described as 'burdensome', yet participants were unable to break free from them. Arpana was an only child, and as her father's family stated they could not care for her mother, she became her carer at the age of 16. Arpana described herself as *'literally still a child'*, with great responsibility.

> *'So, the real turning point for me, I think was when my Nanima (grand-mother) passed away and I was 16, almost 17, I think. It was almost from that moment; I was her sole carer.*

> *Although she lived in [city of residence], and I was in [city of residence], I was the only one who kind of had anything to do with her care. I mean, I had seen lots before that and she'd had hospital visits and all that kind of stuff, but it was at that point where my life just became about making sure she was okay, and taking care of her.' (Arpana)*

As participants aged, they spoke of university as an escape from home life, however they also reported that due to the responsibility they had towards their parents, no participant chose to live far away from home. There were implicit cultural expectations participants were presumed to uphold.

> *'[Within our culture]…the other is loyalty to your parents, it doesn't matter how good or bad your parent is, you will die for your parents. That's such a massive burden as well.' (Sukhi)*

All participants knew what was expected of them, and escaping situations at home long term was not an option. Sukhi explained *'If I was white, I would have just left, it would have been easier just to go'.*

This superordinate theme reflects the lack of choice participants perceived themselves to have in supporting their family. Many of them felt this was due to the implicit rules, values, and beliefs, instilled within the Indian culture.

3.5 Gaining positives from parental mental health

This master theme relates to the positive attributes all seven participants were able to reflect on, obtained through their childhood experiences. Many participants spoke of learning more about MHD for themselves, as well as the experiences their parent was living. For some participants this new understanding allowed them to recognise their parent as being separate from the difficulties being experienced. Two superordinate themes were constructed, namely, ‘Developing strategies to help me and others manage our mental health’, and ‘Growing in strength and awareness of mental health’

3.5.1 Developing strategies to help me and others manage our mental health.

All seven participants reflected on feelings they experienced in their childhood such as anxiousness and sadness, enabling them to develop strategies to manage their emotions, such as Arpana, who explained how helpful journaling became. As children, participants were fearful of speaking about situations at home to outsiders, however those that had someone they could turn to found the support invaluable.

> *‘Like I said, I used to use ChildLine, and the other person I had was my cousin.’ (Sukhi)*

Dinesh explained that he used to avoid being at home, as he found his father’s behaviour too unpredictable and therefore as soon as he could, him and his brothers would stay away from home as much as possible, to avoid conflict. Dinesh explained he engaged in lots of sport to help him release the anger he felt internally. Adopting hobbies acted as a distraction, and relief from any negative emotions participants may have been experiencing.

> *‘Mostly I did it through sport. I love playing football and cricket, and the hustle and bustle. I joined the army cadets; I did lots of physical things where I could release my own stresses and tensions and pressures along the way.’ (Dinesh)*

Many participants also spoke of investing time and energy into education, as they were aware that doing well and going to university could help them *‘escape’* the situation at home.

Marriage was also another factor that provided a new life, however as explained above, the stigma of having MHD in the family, hindered marriageability.

> *'I knew that I would have to sort out my wedding for myself, I knew that my mum and my brother wouldn't be able to do that. So I wouldn't be having an arranged marriage because of my family's history. I knew that would be a real problem.' (Sukhi)*

As adults, participants described the value of seeking therapeutic input, helping them to explore difficult emotions they had carried through their childhood, and think about a way forward.

> *'I started seeing this therapist who just really helped me, and she they basically just said to me that this is all just your body trying to tell you, you need to think about yourself, you need to put yourself first, you need to figure this out.'(Arpana)*

In summary, participants developed coping mechanisms and learnt education and marriage could act as an escape from their home life. Social contact was seen to be important in bettering one's mental health. For those who felt able to be open with others and develop relationships, benefitted from it, including for many participants, accessing talking therapy in adulthood. The act of sharing stories with other people who resonated with their experience was important, as participants believed through their experience, they could help others, and heal themselves.

3.5.2 Growing in strength and awareness of mental health

This superordinate theme relates to the feeling of strength and resilience all seven participants spoke of when thinking about the positives gained from their parent experiencing MHD. With age, more information about MHD was sought, which increased their awareness, and helped them to make sense of the MHD their parent may have been experiencing. Arpana explained her learning also occurred naturally over time.

> *'Over the years, I've met lots of other people through my mum, who've had their own kind of stuff going on, and I've supported and helped a lot of other people as well.'(Arpana)*

Arpana spoke of the people she would meet at appointments with her mum, and through conversing with them, in addition to her experiences with her mum, that too added to her learning. Being able to reflect on their experiences allowed participants to see how far they had come since being a child, and speak of their strength, and ability to help others in similar circumstances.

> *'I always thought I was debilitated in some kind of way, but the amount of mental strength I have now is solely because of that, and because of my childhood, and how much I have got through.' (Sukhi).*

Increasing awareness of mental health allowed many participants to better understand their own mental health, learning *' it's okay, not to be ok' (Priya)*. This new knowledge also allowed participants to better understand the reality their parents experienced, which cultivated empathy, and compassion.

> *'I wouldn't change her for anything. With everything that she has had going on, she's just one of the nicest, kindest souls I know. She's quirky and I just wouldn't change anything about her.' (Arpana)*

These statements were in contrast to the sense making participants described as children, when they felt confused, scared, and unaware of what was happening for their parent, or assumed the difficulties being experienced was their fault. When describing their parent, participants spoke in a way which humanised them, and separated out the symptoms and behaviours from the person.

In summary there appeared to be a positive impact of acquiring more information about the difficulties experienced, allowing participants to see their parent as a person, as well as recognising their parents' positive attributes.

3.6 Overall Summary

The findings revealed the difficult emotions participants experienced as children, without the understanding of the challenges their parent was experiencing. Though they were limited in access to accurate knowledge, they tried to make sense of the situations occurring, which for some, heightened their negative emotions. A retrospective account allowed participants to reflect on feelings of guilt for not accessing services, and supporting their parent and family as much as they could. However, as children, some were contending with feeling the loss of a parent figure in their lives, as well as a lack of support from the Indian community. There was a sense that nobody would understand the daily uncertainty and unpredictability children faced, and therefore there would be no point in talking.

Importantly services were either unknown, or participants were mistrusting of them, fearing consequences such as parental separation if they disclosed the situations occurring at home. Moreover, those that were aware of potential sources of support, reported feeling discouraged from engagement, as they were unsure if services were culturally tailored to the needs of Indian individuals. Alongside this, participants spoke of the prejudice, discrimination, and stigma, related to mental health within the Indian culture, causing further social isolation for them and their family. Due to the impact of gossip within communities, participants and their families were motivated to conceal difficulties.

Despite the troubling emotions participants experienced in childhood, they were able to report their coping strategies. In addition, assuming responsibility whether out of choice or cultural expectation, helped participants to perceive themselves as strong, from a situation that once made them feel helpless.

The following discussion will review the findings in detail, whilst also considering existing theory and literature.

Chapter 4 – Discussion

The following chapter will review the findings as described within the results section, considering the research aims, theory, and available literature. The use of IPA has enabled the exploration of lived experiences (Smith et al., 2009) which are held at the heart of this chapter. Clinical implications of the work will be explored, and a critique of the methodology will be provided. Lastly suggestions of future research will be made, with a conclusion and final reflections.

This study sought to understand the experiences of adult-children who identify as being from an Indian heritage, having grown up with parents experiencing MHD. Through using IPA, five master themes were co-constructed:

- Making sense with a lack of knowledge
- Managing stigmatised silence
- Recognising internal and external void
- Feeling distant yet accountable
- Gaining positives from parental mental health difficulties

Reviewing these findings in the context of the systematic review presented earlier, will show how participants from an Indian heritage shared many experiences, and faced similar challenges as have been described in the literature, by adult children who have grown up with parents experiencing MHD. However, it will also be highlighted how navigating these challenges and experiences within the context of Indian culture exacerbated troubling emotions for participants, with their needs being unrecognised and unmet.

When reviewing the data as a whole, the reader becomes aware of a story told from participants' childhoods, to reflections about their experiences as an adult. At first participants speak of being children, attempting to make sense of a situation that confuses them. They report feeling isolated, and being unable to share the troubling emotions they are experiencing, for fear of facing prejudice and further discrimination from individuals who also do not understand the situation. Participants as children felt anxious, with many reporting an unpredictable and unstable home life. Though participants spoke of wanting to escape their home life, they recognised and adhered to the cultural expectations and responsibility to care for others placed on them. As adults, participants reflected on their strength and resilience, which had been borne from their challenging childhoods.

4.1 Making sense with a lack of knowledge

The first theme relates to participants' reflections of being a child, trying to make sense of the MHD their parent was experiencing, without accurate, or any, information. As children, participants witnessed situations that they found confusing and at times frightening. Participants, in line with existing literature, commented on knowing there was something different about their parent's behaviour (Gladstone *et al.*, 2011), seeking to understand and make sense of it. As highlighted in the introduction, theories related to child development speak of the importance of a child's parents and culture, in forming and shaping how they interpret their world (Vygotsky, 1978). Whilst a child's interpretations can be powerful, their understanding is also related to their age and developmental stage (Cooklin, 2010). Research has found younger children tend to identify parental MHD as a sense of confusion, whereas older children may account for social influences, or use self-blame as explanations for their parent's MHD (Stallard et al., 2004).

As discussed in the systematic review, adult-children consistently report misinterpretations in relation to MHD in childhood (e.g., Baik & Bowers, 2006; Foster, 2010; Murphy et al., 2016), leading to them, for example, to form a negative perception of their parent, when unable to comprehend MHD, and therefore not being able to separate their parent from the challenges they experience. This was also apparent in the current study, including some participants reporting times where their parent ‘disappeared’, later learning this was due to periods of hospitalisation; or witnessing frightening or erratic behaviours, and feeling scared as a child. However, the current study showed how being from an Indian culture could exacerbate such lack of understanding. In this study, misperceptions were often compounded by language used by family members to describe the child’s parent. Within Indian languages, there are no direct words to translate diagnoses of MHD that can be labelled in English (Acharya et al., 2017). When coupled with the stigma attached to MHD within the Indian community, descriptions and phrases used can further dehumanise a person, fuelling feelings of misperception, and distress, highlighting the consequence of a lack of awareness, and stigma of MHD within the Indian culture (Shrivastava et al., 2012).

Literature has discussed the dilemma of whether parents and professionals should disclose details of parental MHD to children, citing reasons such as protection and not burdening children (Gammage & Nolte, 2020; Nolte & Wren, 2016; Stallard et al. 2004). Though most participants reflected on how invaluable gaining knowledge of MHD had been for them as adults, this study shows that for parents from an Indian background, there may be particular factors that further inhibit talking to children about parental MHD. Keen to learn more, participants within the current study described attempts to speak to their parent about their ‘unusual behaviours’, however reported feeling that their parent did not want to share their feelings and experiences. It can be tentatively speculated that this may have been a result of experiencing stigma, prejudice, and discrimination through their lifetime. Narratives from participants, told stories of the difficult social and cultural factors their parents had encountered. This included moving from their country of origin, assimilating and acculturating to the UK, and living in large joint families, where parents of participants carried a lot of responsibility, leaving little time to address one’s MHD. Research exploring the relationship between stigma and mental health within Indian populations, found individuals who reported a higher experience of stigmatisation, had tried to conceal the difficulties they faced with their mental health (Shrivastava et al., 2012). Within these studies, individuals reported overhearing negative attitudes related to MHD from others around them, explaining they did not want to be seen as unfavourable, or face discrimination (Shrivastava et al., 2012; Time to Change, 2011). This could be one reason why parents may not have felt comfortable discussing their MHD with their children.

Feelings of guilt is a reoccurring theme in existing research, with children reporting they did not know how to make their parent feel better (Kadish 2015; Murphy et al. 2016; Wagenblass 2001). Within this study, participants explained as children they felt helpless, unable to access services and receive support their parent and family required. This finding could be attributed to the age of participants as children, and being unaware of health services, as well as services perhaps not seeming accessible, or responsive to family needs. As adults, the feeling of helplessness transformed into guilt, with participants believing they could have done more to help. With age, participants developed a greater understanding of MHD, cultivating empathy and compassion towards their parent's experiences. New information was obtained through being exposed to other people and their families as participants grew older, however, they were still left with a sense of not fully knowing how best to help; this finding was echoed by the work of Van Parys and colleagues (2014).

An important finding of the current study was that, in considering participants' conceptualisations of MHD, it appeared that being second generation, and British born, Western ideology of MHD had been adopted, with participants using diagnostic terms such as 'depression' or 'anxiety' to describe MHD, and viewing talking therapy as a helpful response. It therefore raises the question of whether there may have been a difference in understanding distress between participants and their parents. Hashmi et al., (2011) found first generation South Asians, typically entered psychiatric care at a later age than second generation South Asians. One hypothesis for this difference was second generation British born individuals, may have stronger orientations to the UK, having English as their first language, learning about Western ways of living, and facing less cultural stigmatisation in terms of seeking therapeutic input. It is also possible that participants' parents held on to more Eastern-informed conceptualisations of distress, and might not have viewed health care services as the most beneficial response to their difficulties, or that they might have had less trust that their difficulties would have been fully understood and appropriately responded to by mental health services. This demonstrates the potential for an 'acculturation gap' that can emerge between generations over time, possibly leading to differing cultural values, and expectations (Farver et al., 2002). It also raises the question of how these inter-generational differences contributed to the difficulties in meaning-making described by participants. This is an area that deserves further investigation.

Research suggests that health and illness are conceptualised differently across cultures (Galanti, 2014), therefore one approach will not meet the needs of everyone. Figures demonstrate that mental health services implementing early interventions are underutilised by the Indian population (Schouler-Ocak, 2015). Reasons cited for these phenomena often relate to individuals not seeking help, however participants within this study were unaware of the services available. This highlights a need for services to promote themselves to communities who are underserved, ensuring they build relationships, developing services that are culturally relevant. Research supports the idea that cultural insensitivity acts as a significant barrier to seeking help (Incayawar et al.,2009), and it is the responsibility of services to ensure what they offer attends to issues of culture and inclusion (Shah & Beinecke, 2009), challenging the ever-present stigma, and mistrust of services within Indian society.

4.2 Managing stigmatised silence

A lack of support from outside one's family is a common finding in research of parental mental health, where children report feeling socially isolated (Duncan & Browning, 2009; Knutsson-Medin et al., 2007; O'Connell, 2008), which was also present in the current study, despite living in extended families, which might have been hypothesised as potentially mediating such experiences. Participants spoke of this challenge in relation to the cultural impact of stigma, reporting feelings of disappointment for the distance created between them and the Indian community. For some, this was an active choice as they felt that the difference between who they were, and the cultural expectations of who they 'should be', was too great.

For others, it seemed the community distanced themselves from the participants and their families, due to the negative attitudes towards those with MHD, echoing the work of Murphy et al., (2017). Typically, Indian societies are considered to be collectivist, promoting social cohesion and interdependence (Chadda & Deb, 2013). They can act as a great source of support, however, within this study where participants were not embedded within their community, it became a source of distress. It has been argued in the literature that the larger the acculturation gap between individuals, the more acculturation stress is thought to be evoked (Mehta, 1998). It has been suggested that open communication can lessen the effects felt by this gap (Koneru et al., 2007), however with mental health being considered a taboo, participants experienced little opportunity for such openness.

Participants' accounts highlighted the stigma the Indian community can often hold about MHD, and the types of messages passed down in families, such as 'MHD do not exist', and one should 'pull themselves together'. Some participants stated that MHD are seen as a form of weakness, or madness within the community. The shame evoked by these beliefs can prevent individuals from seeking help, until difficulties reach a crisis point where immediate crisis intervention is needed (Gopalkrishnan, 2018). This was reflected within the current study where participants felt they had nobody to talk to. Findings report silence can impact a child's sense making of their current situation, as well as inhibit their ability to express their emotions effectively (Harstone, 2010; Mordoch & Hall, 2002), yet participants, similarly to reports in existing literature, were hindered from sharing their experiences with anyone outside their house, for reasons such as fear of being separated from their parent. The risk of separation may stem from the dominant discourse of poor parenting being associated with parental MHD, evoking a fear strong enough to reinforce the need for secrecy. The literature shows that for parents with MHD this can be a fear based in reality, especially for racially minoritised families, who have been found to be disproportionately likely to have their children taken into care (Barn, 2006).

Another factor related to Indian families concealing MHD, is the importance of maintaining a family's reputation (Knifton et al., 2010). The subject of MHD often continues to be considered a taboo and highly stigmatised, leading to social exclusion at an individual, familial, and societal level; the topic of MHD can often be thought to bring shame on families. By not sharing the challenges faced at home, wider family members and the community, may have been unaware of the situations children were finding themselves in, and the reasons behind them. Individuals within the community may form their own misperceptions of the MHD being experienced, leading to increased stigma, and a lack of understanding, further motivating families to remain quiet. This finding was especially powerful where participants reported living in areas, where members of a close-knit community were familiar with one another. There was a fear of gossip within communities, as the consequences could impact a family's reputation, jeopardising life events such as marriageability; similar findings were reported by MacKenzie (2006).

Within the current study, stories told about marriage explained participants' experiences of a belief that families did not want to inherit genes thought to cause MHD. The typical Eastern view of mental health is more aligned with spirituality (Fernando & Keating, 2008), viewing difficulties as caused by influences such as the evil eye (Spiro, 2005), or connections with God, which have been given to individuals by God to test their faith, therefore should not be seen as alien, but there to cleanse and purify (Ciftci et al., 2013). Paradoxically the idea of inheriting 'ill genes' is more in line with a Western, medicalised conceptualisation of MHD, as noted earlier. This dominant view of MHD was held by some participants where they described a distinction between physical and mental health, alluding to physical health being more debilitating. One explanation for this finding may be due to the influence of acculturation, where the exposure and influence of Western ideas shape beliefs around MHD, therefore guiding where one will seek support (Hamid et al., 2009). Tabassum and colleagues (2000) conducted a study with first- and second-generation South Asians, exploring their attitude towards mental health. One of the main findings was that in comparison to British born, second generation individuals, the first-generation migrant community held onto cultural beliefs about MHD from their home country. Moreover, Sheikh and Furnham's (2000) study reported second generation British-Asian communities, would also hold explanations from their country of origin however, with the UK being their host country, the ideas of Western medicine carried more influence on how MHD were understood. These studies demonstrate a shift in thinking across generations, and emphasise the importance of services recognising the diverse populations in the areas they are located, ensuring they avoid homogenising cultures, and are knowledgeable on the impact and differing ways mental health may be conceptualised. This would align with existing initiatives designed to tackle ethnic inequalities in the provision of health services, such as the Health and Social Care Act, 2012 (www.gov.uk), and as set out in the NHS Long Term Plan (2019).

Within the participant narratives, only two participants spoke of the Western concept of MHD becoming more recognised within the Asian community, due to the recent suicides of Bollywood actors. This illustrates that open discussions about MHD are still in their infancy within Indian culture, and the act of keeping silent remains.

4.3 Recognising the internal and external void

Participants described the emotional impact of growing up with their parents experiencing MHD. Internally, feelings of anger were recalled, which impacted participants' ability to form relationships with others. The concept of relational difficulties is a long-standing finding from research (Camden-Pratt, 2006; Duncan & Browning 2009; Knutsson-Medin et al., 2007; Mowbray & Mowbray, 2006; Nathiel, 2007; O'Connell 2008). Specifically, this revolves around a lack of emotional affect, hypervigilance, and mistrust towards others. It was interesting to note that participants spoke of the interpersonal difficulties they experienced as a child, ranging from being bullied, to friends distancing themselves. This left participants with a sense of isolation and feeling different in comparison to their peers, which continued into adulthood. One lens through which these phenomena can be viewed is Erikson's stages of psychosocial development (Erikson, 1982). This theory highlights the importance of social experience, suggesting at eight stages of an individual's lifespan, conflict is experienced which may impact one's development. Successful management of conflict results in personality strengths, however if conflict remains, Erikson suggested the difficulties would continue into adulthood (Erikson, 1982). For example, some participants in this study spoke of the difficulties they experienced at school age with social interactions, and other children distancing themselves, or not performing academically due to their parental MHD. This led some participants to feel inferior to others in childhood, through to adulthood.

Despite mistrust of others being ingrained within their belief system, participants who were also parents did not want their children to have the same beliefs. Duncan and Browning (2009) reported that adult-children often struggled to have functional relationships. Perhaps this was due to learning as children, when they felt vulnerable, their needs went unmet. McCormack et al., (2017) explained that adult-children held memories of parents who were unavailable, failing to provide safety, love, and nurture. Other participants within this study described being so emotionally and psychologically overwhelmed with their parent, that little attention was paid to their needs. Murphy et al., (2016), found participants reported growing up questioning their identity and lacking self-confidence; experiences echoed by some participants in this study. Moreover, findings from the present study suggest participants' beliefs about themselves were formed by their experiences of growing up surrounded by parental MHD, rather than explorations of one's identity, and engaging in developmentally appropriate self-defining activities; findings consistent with existing research (Knutsson-Medin et al., 2007; Marsh et al, 1996;) emphasising the need for support for this population.

Many participants reported a turbulent home life, witnessing on-going arguments at home, with one participant describing it as a 'war zone'. All participants reported a constant 'feeling on edge', and reported never knowing the mood of the house, indicating how MHD affected all members of the household. A hostile atmosphere, and a sense of never-ending negativity has been described by many participants in research, leaving participants as children, feeling frightened, hyper-aroused, and constantly anxious; experiences similar to traumatised individuals (McCormack et al., 2017), and a suggested key determinant in understanding the severity of long-term negative outcomes for children (Rutter & Quinton, 1984).

An important finding from the current study relates to children distancing themselves from their parent, as they approached adulthood. In consideration of identity theory, Arnett (2000) defined a period termed 'emerging adulthood', whereby individuals reflect on their past and desired changes wanted for their future. This process usually occurs at a time where individuals enter a new life stage, providing opportunities to re-create their identities. Though participants within the current study reported knowing life events such as getting married, or engaging in further education, could help them leave home and begin a new stage of life, due to their sense of duty to their family, in line with Indian cultural values, participants made choices maintaining a strong connection to home and family life. These included choosing to attend universities which allowed participants to move away, yet remain close enough to return home frequently. Traditionally Indian families follow a patriarchal ideology, where they are patrilocal and patrilineal (Medora, 2007; Shangle 1995). Today, families are changing, yet there are still lines of hierarchy which can be clearly delineated, with males carrying power and authority (Chadda & Deb, 2013). Implicit expectations are placed upon members of a family such as frequent family visits, engaging in house chores, and support with childcare (Medora, 2007). This was true for participants in this study with siblings, who adopted the responsibility of looking after others from a young age. This finding is consistent in research on parental mental health, where participants have described the expectations placed on them as burdensome. In this study, participants spoke of living in extended families, thus the responsibilities felt greater with more people to care for.

4.4 Feeling distant yet accountable

In this study, similar to the work of Foster (2010), participants described difficulties bonding with their parent as they would have wanted. Physical distance was caused in the relationship due to periods of hospitalisation, or with children being removed from home. Emotional distance was caused by children experiencing their parent as inconsistent, and at times unavailable. Some participants grew up to regret having missed out on a relationship with their parent, and attempted in their adult life to compensate by becoming more closely involved, again at the cost of self-care. One participant reported that with time, though they still cared for their parent, their tolerance towards their parent’s behaviour was limited. This learning occurred on reflection; as children, participants did not know a different way of being until they were exposed to their friends’ families, witnessing the relationships family members had with each other. Foster (2010) found that children reported never knowing which ‘version’ of their parent they were going to encounter; sometimes children saw the kind welcoming parent, and at other times, they saw the sad or angry parent. Participants within this study reported being worried that their parent would exhibit unusual behaviours in front of others, therefore avoided inviting friends home or being out publicly with their parent. They also recalled fearing for the life of their parent, which for a child feeling isolated, increased their sense of apprehension and stress.

Some participants managed their emotions through caring for their parent, which brought a sense of feeling worthwhile. Many assumed a caring role for their parents, and the family. These findings align with the theory of ‘parentification’ (Boszormenyi-Nagy & Spark, 1973). It must be emphasised that parentification suggests there is a ‘right way’ to parent, however, parenting and care considered normative for one culture, may not be the same for all cultures (Engelhardt,2012), as the following illustrates. Though participants lived in extended families, which is common within Indian families (Chadda & Deb, 2013), they believed it was their place to engage in the caring role. Participants described themselves as children with an increased sense of responsibility, making reference to cultural expectations feeling burdensome. One participant explained that caring for their parent at a young age, formed their identity within the family, and later shaped their career path. Literature reports similar findings, discussing the emotional impact a caring role can have. Byng–Hall (2008) stated that whilst children may appear competent, they can feel overstretched, developing a negative self-perception. Similarly, some participants in the current study recall their education suffering due to demands at home, lowering self-confidence, and as adults, negatively impacted their career paths; similar findings to Becker and Becker (2008). Despite participants obtaining university level education, often exams needed to be retaken or grades obtained were below expected, limiting participants’ options of courses and universities. Paradoxically, whilst there was an expectation for the child to adopt more responsibilities, some participants reported feeling a sense of competence (Pölkki et al. 2004).

Within Indian families, the idea of ‘dharma’ (translated as moral duty) places expectations on children to care for members of a family who require it. It is important to note that the burden one experiences from caregiving is thought to be a result of how one perceives the role (Awad & Voruganti, 2008). Burden of care is perceived differently between cultures, taking into account family support, cultural values, and coping strategies (Talwar & Matheiken, 2010). Chakrabarti (2016) conducted research exploring caregiving related to mental health in India, and reported that providing care for family members caused distress and burden to caregivers, however, Indian families chose to deliver this care due to the familial obligations, belief in non-medical reasoning for MHD, and the role of families in decision-making. Participants within the present study were aware of the implicit expectations placed on them, whether it was assuming the role as head of the family, or returning home every weekend from university to provide care. There was a sense that escaping from the ongoing situation at home was not an option, due to the values and beliefs instilled in the culture. This highlights the potential ongoing impact for adult-children of parents who experience MHD, even after the children have left home, and shows how for Indian adult-children, this impact can be interwoven with the cultural sense of duty.

All but one participant was a parent, and within their narratives, they spoke of wanting their children to have a relationship with their parents, but of also needing to protect themselves. Similarly, Van Parys et al., (2014) reported as parents, adult-children felt that it was a constant balancing act maintaining relationships with their parents, yet retaining the strengths developed as an adult, and protecting themselves, and their children.

4.5 Positives from parental mental health difficulties

Within the current study, and existing research in the field of parental mental health, participants speak of strength, resilience, and self-development. Some participants spoke of their parent's resilience for experiencing challenges with their mental health, yet still being an available parent. Other research reported growing up around parental MHD was said to be a 'blessing in disguise' (McCormack et al., 2017, p.338). When considering relationships and parental mental health, attachment theory has been widely cited, emphasising Bowlby's theory that developing intimate emotional bonds to others, is a core element of human nature, and during childhood the working model of self, and that of the attachment figure are central to the functioning of personality through life (Bowlby, 1969). It should be noted that Bowlby's theory was developed using 'childhood trauma', alluding to a positive correlation between parental MHD and childhood trauma (Murphy et al., 2011). This was not the case for participants within this study, who spoke of their parent's presence and care, despite the challenges they may have been experiencing. Furthermore, this theory has been criticised for its emphasis on the mother-child bond, which does not always resonate with collective family living; indeed, whilst growing up, many participants within the current study did live in extended families.

Participants stated that with age they became more aware of MHD, which augmented the understanding of their parent's experiences. Learning more about mental health also allowed participants to reflect on their feelings and emotions, something not typically understood when they were younger. They learned resourcefulness, adopting skills such as journaling and engaging in hobbies, providing a distraction away from home. For some participants, carrying difficult emotions into adulthood resulted in accessing therapy, learning it is 'okay not to be okay', illustrating the long-lasting impact their childhood experiences had on them. Participants reflected on the changing of times, and how in their parent's generation, the idea of seeking therapeutic help in the form of counselling, or psychotherapy, would not have been considered. This reinforces the notion that with time, albeit slowly, more avenues for managing MHD are being explored.

As highlighted above, the majority of the participants in this study were parents, and they commented on being aware of their behaviour towards their children. Due to their childhood, participants paid careful consideration to their attitudes and behaviours around their children, and more so if they worried that they had adopted 'ill- traits'. Similarly, Van Parys et al (2014) reported participants wanted to parent very differently to their experience of being parented. Here participants were able to reflect on their changing identity, from being a dependent child, to now being a parent themselves. Self-categorisation theory (Turner & Reynolds, 2011) suggests one's identity is constantly evolving, which provides a useful lens when considering participants speaking of the various roles they adopted over time. Importantly this theory provides hope for the individual who has experienced negative emotions growing up with parental MHD, that reinventing oneself is possible.

For some participants, relational difficulties remained through their life stages, and Foster (2010) reported that as parents, adult-children faced challenges forming relationships with their children. In the present study, though participants reported good relationships with their children, for some, they had to continually work at connecting with their child and developing trust between them. Murphy and colleagues (2018) explored adult-children's parenting journeys, and found participants questioned their ability to parent, commenting they did not always have a healthy parenting framework to work with, however managed through the use of literature and books. In this study, participants also relied on help from their spouse.

Many participants spoke of how their experiences as a child had shaped who they are as adults. Due to the retrospective nature of this study, participants spoke of childhoods that were full of unhappy memories, however as adults, similar to the work of Kinsella and Anderson (1996), participants spoke of knowing who they were, feeling motivated to build a life for themselves and their family that was different to their childhood. By reflecting on their experiences, participants recognised their development and strength. They spoke of having helped others who had experienced similar situations; a driver reported for participating in this study. Participants were aware of the 'double stigma' (Gary, 2005) they experienced through life, and explained by sharing their story, they could help normalise another's experience, and challenge the cultural stigma held in the Indian community, thus highlighting a desire to now offer the support they never had (Marsh et al. 1996, O'Connell 2008).

4.6 Clinical Implications

This research adds to the field of parental mental health, as it is the first study to bring a cultural lens, specifically researching the Indian culture, to the lived experiences of adult children who have grown up with a parent with MHD. Where families are experiencing parental distress, the findings not only highlight the importance for health and social care professionals to hold culture in mind when working with families, but also point to a number of specific clinical implications for clinicians working with families from an Indian background. Firstly, a novel finding from this research was participants reporting how the role of culture exacerbated the challenging emotions experienced by children from an Indian heritage. The differing conceptualisations of MHD, and therefore the shame and stigma associated with it, left participants and their families feeling isolated. Some participants reported being 'ostracised' by the Indian community when they knew MHD were being experienced in the home. Moreover, families were motivated to conceal the challenges being experienced at home due to the impact on the family's name, and therefore affecting factors such as social standing and marriageability. Consequently, it appeared that keeping quiet was a helpful tactic, however participants spoke of carrying unresolved emotions into adulthood again affecting themselves personally, as well as impacting relationships with others. Furthermore, where participants spoke of considering or accessing services, they lacked trust in how welcoming services would be, if services would be culturally aware, and if the support provided would be culturally appropriate. It is therefore essential for professionals to hold this in mind when starting therapeutic work with families, for example by addressing stigma, cultural suitability and trust. These matters are considered below in the clinical implications.

Interestingly, as participants grew to an age where they could create distance between them and their home life, all participants chose to continue to adhere to cultural expectations, remaining in or near home, adopting the role that was expected of them. This again reduced the opportunity for participants to address how they felt. Again, it would therefore be essential for practitioners to be culturally aware and consider how western assumptions, for example 'boundaries' or 'separating' from family, might be unhelpful to young people from an Indian heritage. These matters are important when considering the clinical implications below.

Clinical implications will now be discussed with reference to the individual, family, and community level.

4.6.1 Individual level

A reoccurring theme in participants' narratives, was the need for information and support. Participants described growing up in a hostile environment, resulting in troubling emotions, and difficulties interpersonally, as well as in other areas such as education. This study and existing research suggest when ongoing adverse emotions are experienced by children, there is a greater risk for the development of MHD in adulthood (Hovens et al. 2015), yet as children, participants were silenced, with their needs often going unmet.

Current literature cites shame and stigma act as barriers to individuals from Indian communities seeking help (Bowl, 2007; Bradby et al., 2007; Soorkia et al., 2011). People from an Indian heritage have also reported not being able to seek help from their GP due to a lack of a trusting relationship, or feeling as though their GP did not understand cultural conceptualisations of distress (Pilkington et al., 2012). For these reasons, services within the voluntary sector specialising in working with various cultures, often remain best placed to educate other health and social care professionals in working in a culturally relevant and competent way, in line with the NHS Long Term plan (2019). It may also be important for health professionals involved with parenting journeys, such as midwives, or those running antenatal services such as National Childbirth Trust groups, to be aware of the potential anxieties expectant, or new parents, may hold in consideration of their childhood history of parental MHD. Having conversations sensitively about parents' own experiences of being parented, may open up conversation where fears can be safely disclosed (Reupert & Maybery, 2007). Professionals should feel knowledgeable and equipped to offer brief interventions, such as anxiety management techniques, or referral to services where appropriate.

In this study the majority of participants shared they had each engaged in differing forms of talking therapy, to help resolve some of their difficult emotions from childhood; reinforcing the importance of this study, and in requiring more available and accessible support early on. There is clearly a role for therapeutic input with adult-children, and Narrative therapy (White & Morgan, 2006) may be one beneficial option. The approach values cultural humility, allowing individuals to be the experts in their experiences, and valuing their unique cultural narratives, whilst also encouraging the therapist to engage in reflexivity and self-critique, challenging their own biases and assumptions. Participants within the current study spoke of the adverse situations they experienced in their childhood, and how these had helped shape their sense of self. Through the technique of externalisation, Narrative therapy may help individuals separate from the difficulties experienced, helping them to 'thicken' their stories, and view their narratives from a more critical and balanced perspective. A question participants struggled to answer, related to positives from their childhood experiences; there is hope that therapy such as a narrative approach would help participants develop greater self-compassion, in a non-pathologizing way, whilst framing the difficulties within a socio-cultural framework, and thickening the tentative narratives in the findings, related to resourcefulness, contribution, and skills development.

4.6.2 Family Level

The role of secrecy, stigma, and shame, coupled with characteristics of Indian families spoken of by participants, such as their hierarchical structure, and the emphasis on kinship obligations, affected relationships, causing distance between family members for participants in the current study. Similar findings have been reported in studies exploring parental MHD in India (Chadda & Deb, 2013; Chakrabarti, 2016). This study clearly demonstrates that when an individual experiences MHD within the family, all members are affected in their own way, and one coping mechanism might be to disconnect from one another (Kadish, 2010). The value of whole family interventions, including family meetings, or support groups for parent and child, has been found to be effective in enhancing a family perspective in relation to parental MHD, improving family relationships (MacFarlane, 2011), and for children reporting a sense of relief for being able to talk about their experiences (Pihkala et al., 2012). Developing genograms with the family, could sensitively open up conversations about closeness and distance in relationships, as well as explore the family's culture, and generational beliefs. Family sessions could be helpful in externalising difficulties experienced, and helping to join members of a family, enabling all to understand their relationship with the difficulty, and highlighting a family's strengths. A study by Power and colleagues (2015) found that greater understanding about mental health, reduced the overall feelings of stress within the family, and widened their support structure. This allowed family members to better support each other, combatting the sense of loneliness and isolation often spoken of by participants. Furthermore, having better insight into the challenges, families were able to identify early warning signs of mental health deterioration, implement early intervention, preventing the risk of relapse (Power et al., 2015).

Existing interventions focus on parents, supporting them with parenting skills (Fraser & Pakenham, 2008), psycho-education, and skills training (Kaplan et al., 2014). 'Let's Talk about Children', is a programme developed to help parents understand situations from their child's perspective, and empower parents to discuss the challenges they are experiencing with MHD with their children, in a developmentally and scaffolded way (Solantaus et al., 2010). Stigma may prevent parents engaging in these groups, however, home-based and community interventions may be helpful, especially where services have linked in with liaison and advocacy services, allowing families to feel supported (Brunette et al., 2004; Wansink et al., 2016). These interventions could also benefit from consideration through a cultural lens, improving cultural relevance of what is offered and encouraged.

Mental health services in the UK often operate at an individual level, if parental MHD affects many family members, they are typically only detected by services at an acute or crisis stage (Ackerson 2003). Reviews exploring the effectiveness of preventative interventions with families from an Indian heritage, found a positive effect on children's mental and physical health. This was especially the case for interventions that worked with both family and children (Thanhäuser et al., 2017), however ongoing and more rigorous research is needed.

4.6.3 Community Level

Participants spoke of services not being tailored to their needs, or understanding cultural conceptualisations of distress. It is paramount for services to ensure they are culturally sensitive to the needs of the community they are situated in (NHS, 2019). Sharing expertise in mental health, and allowing members of the community to educate professionals in how it may present, could help foster trusting relationships between cultures and services. Moreover, there has been a consistent push by the UK government for adult and children's services to move to a specialised 'whole family' engagement (Beardslee et al., 2011), addressing the needs of families affected by parental MHD, and the current study speaks once again to the importance of moving from intentions to actions.

Literature suggests services are needed which are family sensitive with on-going training for the workforce (Maybery & Reupert, 2009). It is thought if processes were implemented which routinely assess the children of parents with MHD, and their parenting ability, difficulties presenting themselves would be caught early. Programmes such as ‘Think Family’, have been developed for training and intervention, delivered over eight sessions, aiming to raise awareness of parental MHD with families (Toikka & Solantaus, 2006). After engaging with the programme, professionals reported their practice improving, reporting more confidence in working with families. Professionals had previously reported being worried to discuss sensitive topics with families, therefore neglecting them, however, training increased their confidence of knowing how to raise topics sensitively. Professionals recognised that a good rapport and trust was required first before these topics could be broached (Gatsou et al., 2017).

Considering children accessing help, perhaps schools could be a non-stigmatising place to assess children requiring support, as it is thought that teachers know children and their families well (Allen et al., 2020). In this study, school became a distraction from home life, indicating children may have become good at hiding their emotions, and would not want their place of escape to be filled with home life. Relationships already developed between teachers, children, and their families, could be a good place to recognise difficulties and support the system.

If parents have been hospitalised, and children are visiting, professionals could engage in conversation with them, exploring their wellbeing, and potential fears (Ballal & Navaneetham, 2018). Information about their parent should be shared appropriately, with consent from, or in collaboration with their parent, allowing children to have a better knowledge base of their parent’s experiences. Moreover, if families and children are willing to partake in family therapy, children could be invited to regular sessions where appropriate, or referred to specialist child services (Maybery & Reupert, 2009).

Additionally, the value of spiritual and religious systems was emphasised when considering conceptualisations of distress within an Indian community. Typically, when faced with perceived emotional difficulties, Indian families will seek support from traditional healers, or places of worship (Dein & Sembhi, 2001). In the UK, help may be sought from health services, yet despite the hegemony of Western biomedicine, additional advice is often sought indicating a strong belief in the socio-cultural explanations for distress. Advantages in seeking support via a healer include the lack of a language barrier, having more time to discuss their difficulties, and a more holistic family approach (Dein & Sembhi, 2001). It may be helpful for better interagency links to be made with third sector organisations, as well as spiritual leaders, allowing for mutual learning and collaboration, so that early interventions can be accessed by populations currently underrepresented in health services, and these services can be culturally informed and suitable.

The suggestions made above may sound idealistic, and studies exploring professionals' views often report a barrier to developing the rapport needed to engage with effective interventions, due to a lack of resources, skills, and confidence. With ever increasing demands placed on professions, with limited resources, support is required from the head of services, at a more policy and service structure level (Gatsou et al., 2017; Maybery & Reupert, 2009).

4.6.4 Key messages to health and social care professionals

The key messages for health and social care professionals are to be aware that children from diverse communities, who live with a parent experiencing MHD, may experience difficulties and require help; however their needs are currently unmet. More work is required by professionals to understand the communities within which services are located, and how distress may present. Importantly, the support offered needs to fit for those receiving it, and professionals are encouraged to develop their knowledge and be open to understand of the particular challenges faced by family members from minority backgrounds where parents experience MHD and to be creative with their practice, including offering therapies that value and respect cultural diversity, and delivering home or community-based sessions. Forging relationships with community leaders, such as faith leaders, may help foster better and more trusting relationships, between services and underserved communities. This may encourage help seeking behaviour, or at least create an awareness of services, which seem currently less known to BAME communities. Based on the findings of the current study, attending to the implications of stigma and secrecy, and discussing MHD openly seems particularly important when offering help to children of parents with MHD from an Indian heritage.

4.7 Suggestions for further research

While our understanding of the impact of parental mental health on parents, children, and the wider family is growing, cultural awareness has remained absent from this body of literature. This study is novel, and more are required to explore the role of culture, Indian culture in particular, on children's experiences of parental MHD. We have learnt that the way children make sense of their experiences can shape their interpretations of situations, leading to beliefs about themselves, others, and the world, and these are powerfully embedded in culture. This study gathered perspectives from adult-children, therefore reflections were from a position of having made sense of their experiences. Knowing participants were experiencing difficult emotions at a young age, there is merit in conducting similar research with samples of children from an Indian heritage across the life span, or conducting a longitudinal study furthering the current knowledge base, developing interventions which may prevent troubling emotions being carried into adulthood. Furthermore, the findings speak to the urgency for studies exploring the cultural relevance of interventions, currently offered to ethnically diverse communities.

Lastly, research exploring the impact of the adult-child's parenting from a cultural perspective would be helpful to understand the longevity of impact, as well as the relationship between culture, parental mental health, and parenting outcomes.

4.8 A critique of the methodology

Small sample sizes within IPA allow rich data to be gathered, with a focus on the individual's lived experience. Considering qualitative methodology, the aim of the research was not for generalisability. Instead, in line with the aims of the study, this research privileged hearing the voices of participants, understanding their meaning-making, and exploring the role of culture in the field of parental mental health. This offers a valuable new perspective, with potential for meaningful clinical implications. The methodology chosen was in line with the research question, and the researcher's epistemological stance, however due to the retrospective nature of the study, the results risked being socially desirable, with participants forgetting important aspects, or being biased by negative emotions (Earley & Cushway, 2002). Rather than seeing the narratives as biased, they were appreciated and considered to add valuable perspectives. IPA has also been used to good effect with other studies using retrospective accounts (e.g. Van Parys et al., 2014).

As stated in the method chapter, it is impossible (and in consideration of qualitative methodology, undesirable) to prevent the researcher having an influence on the findings and interpretations made within this study (Ahern, 1999). Being an insider researcher, and sharing many commonalities with participants within the study, assumptions of cultural knowledge and understanding may have been implied and unsaid between participants and the researcher. The researcher managed this through supervision, and demonstrating transparency, and reflexivity throughout this process, as well as providing their thoughts and reflections through the body of the work, inserting excerpts from their reflective diary in the appendices (Appendix 3).

Due to the global pandemic and restrictions in place, data collection was conducted virtually. This may have influenced those that volunteered to participant in this study; it is important to consider the experiences of those who met the inclusion criteria, but who did not have access to social media (Archibald et al., 2019). Furthermore, it was interesting to note that the majority of participants had accessed personal therapy, and therefore may have already reflected on their experiences of parental MHD. Having therapy implies a certain way of understanding and addressing MHD, which might not have been the case for individuals who are less accustomed to the medical construction of MHD, or for those who feel shame. Participants recruited through traditional methods, such as paper advertisements in local community centres, may have added greater understanding to the experiences being explored. Participants who volunteered for this study all held a relatively high level of education, which might have impacted on their meaning making, and having acculturated to Western ideas; perhaps those without this level of education may have shared different experiences, such as not being able to 'escape' their situations by attending university. It must be noted that IPA does seek to recruit a homogenous sample, and is interested in the meaning making of an individual's experience; it is less concerned with obtaining findings that are generalisable.

4.9 Conclusion

The aim of this research was to gain an understanding of the experiences from adult-children who had grown up with a parent experiencing MHD, and identified as being from an Indian heritage. In this study, participants generously shared their lived experiences from their childhood, and spoke of long-lasting effects they had carried into their adulthood. Some of the findings were similar to themes already cited within the literature, and as with many children with parents experiencing MHD, stigma influenced the amount of support available, and sought by family members. Participants spoke of their Indian heritage, and the importance placed on meeting socio-cultural expectations. There appeared to a be a strong stigmatised societal discourse around MHD, which led families to conceal any difficulties experienced. Further reinforcing feelings of isolation and difference, especially from the community whose strength in numbers was always thought to be a support system, not a shaming one. Despite the disconnect experienced with their community, participants were still abiding by cultural expectations, and maintained a sense of duty towards their parents and families, demonstrating the power of culture. For some, this felt burdensome, however, upon reflection all participants spoke of their growth in resilience, due to their childhood experiences. There was a sense that participants had an awareness of the impact of added cultural pressures, to the challenges already experienced with parental MHD, therefore wanting to share their story, helping others in similar situations.

This study and existing literature (O'Connell 2008), found participants experienced MHD themselves. This highlights a concern, as it is already known there are many barriers to individuals seeking help from mental health services, especially those from an Indian heritage. Despite the many policies and strategies in place highlighting the need for professionals and services to be more culturally sensitive (Aldridge & Becker, 2003), challenges were still described within participants' narratives. Participants spoke of mental health from a Westernised paradigm, illustrating that there has been an adoption of other perspectives in one's knowledge base, and there is evidence that individuals are able to mitigate the impact of adverse experiences, through positive relationships or engaging with a therapeutic intervention (Rutter, 2011). As such, efforts in understanding and reaching populations whose needs are currently unmet, must be a priority for health and social care professionals and services.

4.10 Final Reflections

The field of parental mental health and culture is a topic of great importance to myself, increasing the pressure to do this work justice. I was moved by participants' narratives, having held on to their stories, keeping them central within this study. Throughout this research process, I have endeavoured to be reflexive, considering my biases and the influence I have over the findings. Notably, one area where I may have shaped the narrative would be in developing the interview schedule. Though I checked the questions posed with the study's EbE, undoubtedly participants' answers to questions may have encouraged them to tell some stories, and leave others out. Despite participants being asked to share anything they felt they had not been asked about, I remained conscious of the experiences untold.

One challenge I have grappled with throughout this research is reporting the additional difficulties the Indian culture and community had on participants; in many accounts the community became a source of distress. I can resonate with the stories of participants and understand that for fear of intrusive intervention, and further stigmatisation, participants actively portrayed an image of managing, and appearing content to those around them. Reflecting back over all interviews, a feeling that remains is the sense of confusion and isolation felt by participants as children. Connection and support seemed to be what was desired; a fundamental desire we all have.

Not only am I mindful of the constant development required of services, this study has reminded me of the importance of understanding and considering all the systems surrounding an individual who may be experiencing difficulties with their mental health, and the stigmatising discourses reinforcing certain behaviours, and increasing distress. I will continue to raise awareness of these both professionally and personally, with the hope of challenging stigma and misperceptions existing not just in my community, but in all society.

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APPENDICES

Appendix 1: A textual representation demonstrating how each paper met Tracey's Eight 'Big-Tent' criteria (2010)

PAPER	NOTES
A fractured journey of growth: making meaning of a 'Broken' childhood and parental mental ill-health	• Both authors independently analysed the data and debated findings • The study explored positive and negative interpretations from adult children on their experience of growing up with parental mental health. • Authors biases and presuppositions were acknowledged increasing credibility of study. • Participants are all Caucasian with the majority being female, and therefore findings are not culturally or gender inclusive.
Five women's recollections and reflections on being raised by a mother with psychosis	• Four of the participants were known to the researcher which may have biased the results. • The mother-daughter relationship used to explore impact on adult child. • Ethical considerations well explored. • The sample is quite specific, and its acknowledged that further research is needed to generalise findings.
You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness.	• Transcripts were checked with participants to improve quality. • Throughout paper the term 'serious mental illness' was used instead of diagnosis specific terms. • There is an emphasis on negative effects on adult children, and no mention of any positives gained. • The impact of the researcher being a participant was not discussed – perhaps bias in results. • Only 10 voices were heard, and therefore more and possibly differing perspectives not heard.
Growing up with a mother with depression: an interpretive phenomenological analysis	• Authors acknowledge the sample being women for homogeneity in line with IPA, however the exclusion of males may have led to richer findings. • Rigorous application and transparency of IPA • Due to this study being retrospective it can suffer from accuracy in the stories told, and potential social desirability. • Authors discussed their reflexive practice • Due to the sample being female, and specific to the mother being diagnosed with depression, generalisability of findings are somewhat limited. • Research clear and comprehendible

Childhood parental mental illness: Living with fear and mistrust	• A partnership model for reflexive narrative for participant and researcher was used, for example the recruitment stage of the study invited participants to 'share time, space, and human experience'. • Method and analysis clearly stated • Great use of excerpts from participants narratives, which resonate with the reader • The study lacked gender neutrality • The recruitment strategy may not have been understood by differing cultural backgrounds, biasing those who volunteered for the study
Toward understanding the child's experience in the process of parentification: young adult's reflections on growing up with a depressed parent	• Worthy study looking at the role of parentification • Transparency and rigour was described through a detailed methodology • Good use of excerpts to support themes • Data was retrospective and therefore may have been skewed by the young adults developmental phase The sample consisted of volunteers therefore those who did not volunteer may have reported different narratives. • Due to the data being collected in a focus group, there is a risk that participants construct their narratives together.
Experiences of adults who as children lived with a parent experiencing mental illness in a small scale society : A qualitative study	• This study is novel in terms of thinking about participants who reside in a small scale society and noticing similarities and differences with existing research. • This study adds the current knowledge base with the factor of gossiping and its impact occurring in a small scale society. • The study used retrospective accounts which may have been affected by the current developmental phase and life events of participants. • The majority reported experiences related to their mothers mental health, and fathers were poorly represented; data may look different if mothers and fathers were more evenly represented • Ethical considerations made towards participants • Consistency between research question, method, analysis and findings • Findings consider the culture of individual living in the Faroe Islands, and therefore may be less generalisable. • Authors discussed and reflected on the meaning of preconceptions through the study demonstrating reflexivity
Adult children of parents with mental illness: dehumanization of a parent – 'she wasn't the wreck in those years that she was to become later	• Findings showed individuals who lived with a parent with mental illness, dehumanised them • Good use of participant quotes • Study explains clearly use of language and meaning • Participants in the study had not had any therapeutic input, and therefore parental dehumanization might have been a dominant feature

	• The authors position is not spoken about
Adult children of parents with mental illness: navigating stigma	• Highlights an awareness of stigma for children who have lived with a parent of mental illness • Narrative design facilitated a voice for participants • The design of the study considers the ethical obligation to ensure participants are heard, seen as individuals, and treated respectfully • Good use of quotes • The study was transparent in thinking about limitations • Highlights an important point of affording people a suitable language to discuss mental health.
Adult children of parents with mental illness: losing oneself. Who am I?	• Explores exclusively the finding of 'loss of self' adult children of parents with mental health difficulties can experience • Triangulation of findings was conducted with other members of the reach team • Continual discussions and reflections in research team noted, increasing trust worthiness of the study, methodology and findings. • There was a higher ratio of female to male in sample; there may be gender differences in how one experiences grief, and with few males, the study findings are less generalisable. • Authors are very transparent about the methodology and findings. • Author uses many quotes through work • Extends knowledge base of adult-children's perspective on being parented. • Good ethical considerations

Appendix 2: a summary of all the papers included in the literature search.

What is the current knowledge base of adult children growing up with parents with mental health difficulties?

	Title	Author & Date	Where the study was conducted	Sample Details	Parent experiencing the difficulty	Study Design	Findings	Key Implications	Critique
1	A fractured journey of growth: making meaning of a 'Broken' childhood and parental mental ill-health	McCormack, L., White, S., & Cuenca, J. (2017)	Australia	6 female and 1 male, aged 20-45 years old Inclusion: participant grew up with a biological parent affected by mental health	4 mothers with major depressive disorder 2 fathers alcohol dependence 1 mother with schizo affective disorder	Semi structured interview, with an IPA analysis	An overarching superordinate theme was found : A fractured journey of growth to adulthood which captures how life was unpredictable with insecure relationships due to parental mental illness. There were 6 subordinate themes : who cares-nobody cares, trauma and betrayal, transferring the distress, ducking, weaving and staying safe, growing up myself, and transforming a broken childhood.	Participants recalled unmet needs due to parental mental illness. They always experiences a betrayal, and inaccurate information was provided regarding their parents mental health. Assisting children to make sense of their parents difficulty is needed	It is possible that the authors subjective biases have unintentionally impacted on the findings. Participants are all Caucasian with the majority being female, and therefore findings are not culturally inclusive
2	Five women's recollections and reflections on being raised by a mother with psychosis	Kadish, Y. (2015)	South Africa	5 women aged 28-53 years old. Purposive and snowball sample Inclusion: above the age of 18, raised by mothers who had experienced psychotic illness	4 mothers psychotic illness (bi=polar 1 disorder, schizoaffective disorder, and schizophrenia) 1 mother did not disclose diagnosis	a semi-structured, open-ended interview schedule. The data was analysed using thematic content analysis	Nine themes and two sub-themes emerged from the interview data; these were (1) resilience and survival (with two sub-themes: (1.1) extreme self-sufficiency and (1.2) low self-esteem and the need for approval); (2) memories of maternal psychotic episodes; (3) mother–daughter bond; (4) importance of father; (5) sibling sounding boards and responsibilities; (6) silent family storms; (7) significant others; (8) stigma, shame, and	All participants stated their childhood and adulthood had been hugely affected by their mothers mental illness despite being from a financially secure background, and being high functioning as individuals. This study highlights the need for more research on socioeconomically disadvantaged individuals. Early interventions with this population, including familial, individual, group therapeutic, and educational interventions are exceedingly valuable for prevention.	Four of the participants were known to the researcher which may have biased the results. All participants were white, and from relatively high socio economic backgrounds. Other studies could explore diverse ethnicities, and socio economic groups

							secrecy; and (9) maternal psychosis, motherhood, and feminine identity. All participants believe that maternal psychosis had affected them profoundly, both in childhood and adulthood.		
3	You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness.	Foster, K. (2010)	Australia	8 women and 2 men (including the researcher) recruited aged 25- 27 years old Inclusion: Over 18, English speaking and spent time with at least one parent who they understood to have serious mental illness. No exclusion criteria evident.	4 mothers diagnosed with schizophrenia 1 mother diagnosed with bipolar disorder 1 mother diagnosed with bipolar and alcohol abuse 1 mother diagnosed with bipolar and substance abuse 1 mother with severe depression 1 mother schizoaffective disorder 2 fathers severe depression	Interpretive qualitative approach, purposive sampling and used ethnography to include researcher as participant. Unstructured interviews asking only one question. Retrospective design.	Themes: Being uncertain; struggling to connect; being responsible and seeking balance	Being an adult child to a parent who has mental health difficulty, can mean they take on a care giving role, and relationships between child and parent can become strained. Family focused care can support the whole family	Only 10 voices were heard, and therefore more and possibly differing perspectives not heard. There is an emphasis on negative effects on adult children, and no mention of any positives gained. The impact of the researcher being a participant was not discussed – perhaps bias in results.
4	Growing up with a mother with depression: an interpretive	Van Parys, H., Smith, J., and Rober, P. (2014)	Belgium	5 white European women aged between 39 and 47 years old	5 mothers diagnosed with depression	Semi structured interview, with an IPA analysis	Participants reported on feeling of desolation with a lack of support, and not paying attention to their own experience or the	The study helps us to understand families context where there is parental mental health, and a child's silences in family therapy.	Due to this study being retrospective it can suffer from accuracy in the stories told, and potential social desirability.

	phenomenological analysis			Inclusion: women whose mother had been diagnosed with depression			situations at home. However participants explained that they grew into a caring role to help them remain standing. Participants also reflected on now being adults, their understanding of the situation they were in as a child, manging their vulnerabilities, and creating different in their own family now.	The research also supports the need for support groups to be developed for children of parents who experience mental health difficulties.	Due to the sample being female, and specific to the mother being diagnosed with depression, generalisability of findings are somewhat limited.
5	Childhood parental mental illness: Living with fear and mistrust	Murphy, G., Peters, K., Wilkes, L., & Jackson, D. (2015)	Australia	3 men, 10 women aged 30-late 70's. Inclusion: participants who are English speaking, and had experienced parental mental illness. It was required that participants parents had been hospitalised for mental illness, and participants were now adult children who were parents themselves, who did not have mental health difficulties.	Participants reported their parent had been hospitalised with either schizophrenia, psychosis, or a mood disorder The gender of the parents was not cited)	Narrative enquiry approach. Two main questions were asked.	One main theme: Living with fear and mistrust. Included: lack of understanding about parent’s illness, worry about possible parental self-harming, threat of aggression, parental wellbeing, and participants own safety. The felt fear, generated ongoing hypervigilance.	Longitudinal nature of fear from child to adulthood. Participants noted a hypervigilance of others, which impacted on participants ability to trust and open up to others, contributing to feelings of fear and isolation. Health and social care professionals have a role in exploring social integration, and additional support for the whole family.	Lack of gender neutrality; there were more females than males. Recruitment posters used the term ‘mental illness, this may not have been understood by people from differing cultural backgrounds Large age range of participants meaning health and social care provision would have been different for each person relative to their experiences
6	Toward understanding the child’s experience in the process of parentification: young adult’s reflections on	Van Parys, H., Bonnewyn, A., Hooghe, A., De Mol, J., & Rober, P. (2015)	Belgium	18 women and 3 men aged 18-29 years old. Inclusion: no children of their own. No exclusion criteria evident	15 mothers diagnosed with depression	Focus groups were used to collect data, and then a ground theory approach was adopted	Three general domains were found. ‘Perceiving little room for own experiences’ reflects a retrospective view on their childhood	In therapy, therapists should not push a child who is quiet, as it may push the child closer to experiences that are difficult to process in the family context. Whilst prevention programmes for families is useful, there may be more value in children	The study used retrospective accounts which may have been affected by the current developmental phase of participants

	growing up with a depressed parent				6 fathers diagnosed with depression		experiences, resulting in consequences for their inner experiences, and not being in touch with own feelings at the time. The other two domains ‘toward s reflective stance’, and ‘ongoing processes of repositioning in the family’ were interrelated and evolved from on-going meaning making processes such as expressing one’s self, and growing awareness of parental depression and own emotions.	receiving support when they are adolescents as they are able to reflect more, and put their vulnerabilities and strengths side by side.	The sample consisted of volunteers therefore those who did not volunteer may have reported different narratives. Due to the data being collected in a focus group, there is a risk that participants construct their narratives together.
7	Experiences of adults who as children lived with a parent experiencing mental illness in a small scale society : A qualitative study	Dam, K., & Joensen, D.G. (2017)	Faroe Islands	8 women and 3 me, aged 18 to 49 years old. Inclusion: adult children above the ages of 18 who were brought up in the Faroe Islands, and as children lived with at least one parent experiencing severe mental illness. No exclusion criteria evident.	10 mothers and 1 father 5 parents were diagnosed with bipolar disorder and 6 parents were diagnosed with schizophrenia - the split of parent and exact diagnosis in unknown	Individual interviews were held, and these were transcribed and content analysis was used.	An overarching there of ‘living in a paradox’ was identified; the childhood of the participants was filled with contradictions. They reported a close and loving family, but also lacking awareness and insight in to what was happening, as well as burdensome caring and coping. Within the small scale society, it was found that ‘everybody knows everybody’, and children experienced a lack of anonymity, gossiping and social prejudice.	The needs of children and families should be considered when planning nursing care interventions, children need to be listened to and heard when care is being provided to a parent with mental illness, so early intervention can take place.	The study used retrospective accounts which may have been affected by the current developmental phase and life events of participants. The majority reported experiences related to their mothers mental health, and fathers were poorly represented; data may look different if mothers and fathers were more evenly represented
8	Adult children of parents with mental illness: dehumanization of a parent – ‘she wasn’t the wreck in those years that she was to become later	Murphy, G., Peters, K., Wilkes, L., & Jackson, D. (2017)		10 women and 3 men aged between 30 and 78 years old. Inclusion: participants to be over the age of 18, English speaking,	Participants reported their parent had been hospitalised with either schizophrenia, psychosis, or a mood disorder	Narratives were thematically analysed arriving at themes	Five themes were generated from narratives: living with fear and mistrust, navigating stigma, loss of self, dehumanisation of parent, and parenting journeys. For this paper,	All health services should adopt a whole family approach. Mental health services need to look at polices that may dehumanise parents, which further reinforces familial dehumanisation	Parental diagnosis was determined from participants knowledge – sometimes diagnoses can be inaccurate or misunderstood by others in the family Participants had not had therapeutic input in to the problems they disclosed, and therefore parental dehumanisation

			Australia	have lived with a parent with mental illness (schizophrenia, psychosis, or mood disorder)during childhood, the parent to have been hospitalised for their mental health, and for participants to be parents themselves	The gender of the parents was not cited)		dehumanisation of parent was focussed on. Individuals who have lived with parents experiencing mental health problems dehumanise their parent.		may have been a dominant feature, and participants may not had have the chance to reconceptualise their experience.
9	Adult children of parents with mental illness: navigating stigma	Murphy, G., Peters, K., Wilkes, L., & Jackson, D. (2015)	Australia	10 women and 3 men aged between 30 and 78 years old. Inclusion: participants to be over the age of 18, English speaking, have lived with a parent with mental illness (schizophrenia, psychosis, or mood disorder)during childhood, the parent to have been hospitalised for their mental health, and for participants to be parents themselves	Participants reported their parent had been hospitalised with either schizophrenia, psychosis, or a mood disorder The gender of the parents was not cited)	Narratives were thematically analysed arriving at themes	Participants narratives demonstrated a pervasive presence of stigma. The overarching theme of 'living with stigma', had two sub themes 'awareness of difference', and 'needing to maintain secrets'. Participants noted they were aware of social stigmas associated with mental illness which hindered them from talking to others about their experiences, and fuelled a culture of familial secrecy, reinforcing a sense of difference for children	Participants used value laden and stigmatizing language with regards to mental health; new constructs of mental health should be developed to provide people a suitable language to speak about mental health in a non stigmatising way, and safe in the knowledge that they and their family will not be discredited. A new language may evoke a positive societal response to mental health, and promote recovery for the persona with mental health difficulties and their family.	Parental diagnosis was determined from participants knowledge – sometimes diagnoses can be inaccurate or misunderstood by others in the family Given the large age range of participants, their experience of stigma may have changed over time.
10	Adult children of parents with mental illness: losing oneself. Who am I?	Murphy, G., Peters, K., Wilkes, L., & Jackson, D. (2016)	Australia	10 women and 3 men aged between 30 and 78 years old. Inclusion: participants to be over the age of 18, English speaking,	Participants reported their parent had been hospitalised with either schizophrenia,	Narratives were thematically analysed arriving at themes	This paper presents a main theme of 'a loss of self'. The narratives also founds a loss of social connectivity, a loss of social integration, and perceived loss of opportunity. Participants	The loss children from parents with mental health difficulties experience is alike to bereavement, and reconceptualising the children's experiences would support health and social staff to better cater for their and their family's needs. Seeing their experiences as loss and grief may also	Adult children within the study had not received therapeutic help, and therefore the loss described may have grown over time, as they had not had an opportunity to reconceptualise this.

				have lived with a parent with mental illness (schizophrenia, psychosis, or mood disorder)during childhood, the parent to have been hospitalised for their mental health, and for participants to be parents themselves	psychosis, or a mood disorder The gender of the parents was not cited)		positioned their own needs second to those of their parents and felt as though they had lost their sense of self, alongside a reduced emotional literacy.	reframe the child's perception of losing themselves	

Appendix 3: Extracts from reflective diary

Reflective Extracts

Reflections related to interviews

I have just completed my first interview, which was so moving and reminded me of the importance of this work. Until this point, I had been reading available literature and absorbing theory, however hearing another's experience, has really brought this thesis to life.

I noticed each person told their story differently. Some spoke really quickly without taking a breath, and I wonder if this was the first time they had spoken about their experiences in depth, as if by speaking about it quickly made it easier to 'get it out there', a bit like 'ripping off the band-aid'. Conversely one participant gave very short answers, seeming as though they did not want to disclose information that was too personal. Perhaps this was protecting themselves from the hurt they had once felt, or knowing that the difficulties were still present in their everyday live, perhaps troubling experiences were very live and they did not feel able to detail their experiences and feelings.

With some participants I found it difficult to end the interviews, and on reflection I wonder if a part of me thought it would be rude or invalidating to thank them and say we have finished. Though over zoom, these interviews seem so personal and intimate, and after each one I felt I had developed a relationship with each participant – this feels important as I worried I would lose the connection with participants, working over zoom.

I feel privileged to hear other's stories, and I can really connect with what some participants are saying, however I also feel the weight of responsibility to now ensure I capture accurately and respectfully their experiences.

Reflections on being Indian doing this research

I remember ending the interview with Kalpesh, and it was briefer than the others and I worried it was less rich than the others. However having looked through it again, perhaps as an Indian male, the stigma related to mental health difficulties, and the act of secrecy was making it difficult for him to speak. I wonder what the impact of being an Indian female had on his interaction, and if he might have felt more comfortable with a male, perhaps a non-Indian male? Some participants commented on it being easier to talk to me about their experiences because I was Indian, and there being an ‘understanding’ there. This made me wonder about mental health services, and the workforce. Having worked in many different services across my career, I have been struck by the ‘whiteness’ of services, and how that may deter people from seeking support.

Reflections on on-going challenges

I am reminded of the time when I completed a cultural genogram and had to describe the pride and shame connected to the culture I identify with. I love the Indian culture, yet again I am saddened by the reality of the stigma attached to mental health in the community. I can picture participants as children feeling alone, without knowing who to turn to, and as a soon to be Clinical Psychologist, I feel frustrated with services not seeming culturally sensitive, or accessible to underserved communities. Perhaps studies like this one can make ripples, and create change.

Reflections on recruitment

Having now completed seven interviews, though each story is different, there are strands that connect them. The data is rich, and I am unsure how I am going to do it justice and condense the data into themes which speak to participant’s experience. Transcribing each interview myself was time consuming, however with each interview, I could hear the participants speaking to me again, and I felt really immersed in the material.

Given the stigma and shame surrounding mental health difficulties in the Indian culture, I am pleased I have managed to obtain seven participants, with males and females. I am surprised that more people did not come forward to participate, however this may show the presence of stigma which is present is all generations. I have enough participants and data for the study, and given the time restraints I am going to stop recruitment, and start the analysis process.

Appendix 4: Advert for thesis

The experiences of adult children from an Indian heritage whose parents have lived with mental health difficulties

This study is exploring the experiences of adult children, who have lived with parents with mental health difficulties, and who identify as being from an Indian heritage. Though there is a lack of literature on this topic. This research will aim to add to the growing body of work, by gaining a rich understanding of what each participant's experience has been like, and exploring how this may have influenced them to date.

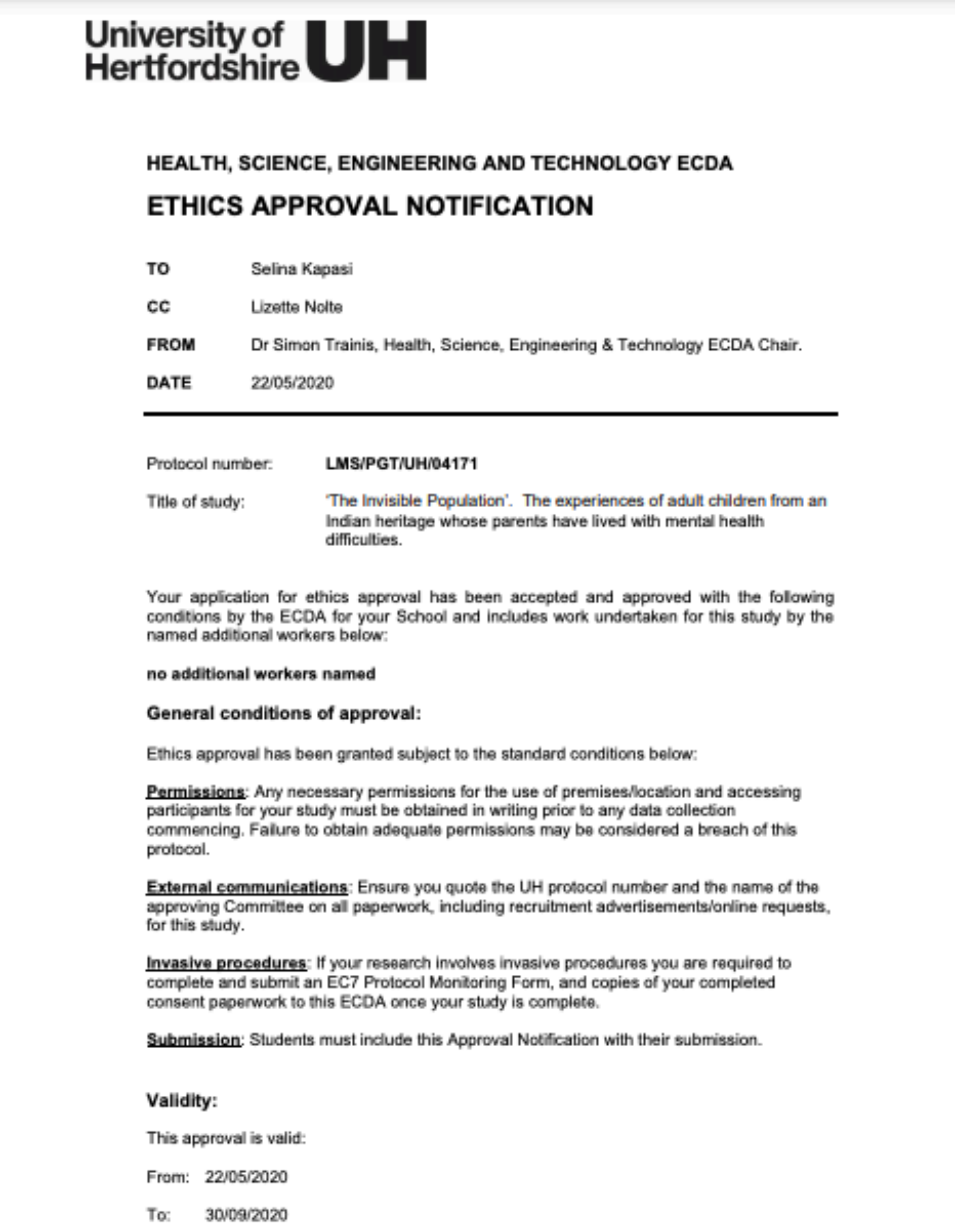
There is hope that this study will help address stigma attached to mental health difficulties, and lead on to recommendations for interventive strategies for the family as a whole.

Participation

- To participate in the study, you will need to be over the age of 18 years old. You will also need to be able to speak English fluently, be living in the UK.
- In addition, participants are expected to have lived experience of having a parent with mental health difficulties, and be from an Indian heritage.
- Participants will be interviewed on their experiences; the duration of the interview will be 1-1.5 hours – you have the right to withdraw at any time.
- The information collected will be held securely, and all the data will be non-identifiable. Confidentiality will be maintained throughout, and once the data is no longer needed, it will be destroyed.

If you would like to participate in this study, or would like to discuss it further, please email me at ThesisUH@gmail.com .

Appendix 5: Ethical Approval for study



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Selina Kapasi

CC Lizette Nolte

FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair.

DATE 22/05/2020

Protocol number: **LMS/PGT/UH/04171**

Title of study: 'The Invisible Population'. The experiences of adult children from an Indian heritage whose parents have lived with mental health difficulties.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 22/05/2020

To: 30/09/2020

Appendix 6: Written information about the study and consent form

PARTICIPANT INFORMATION SHEET

1 Title of study

The experiences of adult children from an Indian heritage whose parents have lived with mental health difficulties

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link:

http://sitem.herts.ac.uk/secreg/upr/RE01.htm

Thank you for reading this.

3 What is the purpose of this study?

The purpose of this study is to explore the experience of individuals from an Indian heritage who have experience of living with a parent who experiences mental health difficulties. The aim is to gain a rich understanding of what each participant's experience has been like, and to explore how this may have influenced them to date.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

5 Are there any age or other restrictions that may prevent me from participating?

To participate in the study, you will need to be over the age of 18 years old. You will also need to be able to speak English fluently, be living in the UK.

In addition, participants are expected to have lived experience of having a parent with mental health difficulties, and be from an Indian heritage.

6 How long will my part in the study take?

The study should take 1-1.5 hours, which will be the duration of the interview.

7 What will happen to me if I take part?

The first thing to happen will be arranging a time for the interview. Next we will meet to conduct the interview, at a location which is convenient for you, but private enough to allow you space to speak. Before the interview takes place, you will be briefed on the study, and asked to sign a consent form to take part. The interviews will be recorded for later accurate transcription. Once the interview is complete, I will debrief you, and provide you with a chance to share any question, or concerns you may have.

8 What are the possible disadvantages, risks or side effects of taking part?

The only identifiable risk, is that through recounting your experiences you may experience emotional distress. This response is normal, and I will check on you in terms of how you are feeling throughout. You will not be expected to disclose any information you do not want to, and once we have completed the interview, I will provide you with some information regarding relevant support services if appropriate.

9 What are the possible benefits of taking part?

There are numerous benefits to taking part in this study such as the time to reflect upon your experiences, in a safe, non-judgmental and safe place which may not have been available to you previously. There is hope that this study along with the growing body of research in this area will help address stigma attached to mental health difficulties, and lead on to recommendations for interventive strategies for the family as a whole.

10 How will my taking part in this study be kept confidential?

The interviews will take part in a location which can maintain your privacy, with only the researcher and participant being present. To keep your data confidential, you will be given a participation identification number which will be used to identify you instead of your name. Any forms where you are identifiable will be kept in a locked filing cabinet. Electronic data will be held on an encrypted external hard drive which will also be kept in a locked filing cabinet. These will only be accessible by the researcher. Access to viewing the data will only be available to the researcher and the researcher’s supervisory team. After completion and write up of the study, the data will be destroyed.

11 Audio-visual material

- The interviews will be recorded on an encrypted dictaphone, which only the researcher and the supervisory team can access.

- Participants will be given the option of completing the interview over skype thereby allowing a more flexible approach in terms of time and place the interviews take place.

12 What will happen to the data collected within this study?

- The data collected will be stored electronically, in a password-protected environment, for up to five years in line with the BPS guidelines, after which time it will be destroyed under secure conditions;

- The data collected will be stored in hard copy by the researcher, Selina Kapasi at the University of Hertfordshire in a locked cupboard until completion of the study, after which time it will be destroyed under secure conditions;

- The data will be anonymised prior to storage.

13 **Will the data be required for use in further studies?**

- The data will not be used in any further studies.

14 **Who has reviewed this study?**

This study has been reviewed by:

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is LMS/PGT/UH/04171

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email:

Selina Kapasi
thesisUH@gmail.com

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study

CONSENT FORM

'THE INVISIBLE POPULATION'
The experiences of adult children from an Indian heritage whose parents have lived with mental health difficulties

I, the undersigned *[please give your name here*, *in BLOCK CAPITALS]*

…….…
of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]*

…..……
hereby freely agree to take part in the study entitled *[insert name of stu*dy *here]*

………..

(UH Protocol number LMS/PGT/UH/04171)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself. In signing this consent form I accept that medical attention might be sought for me, should circumstances require this.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that my participation in this study may reveal findings that could indicate that I might require medical advice. In that event, I will be informed and advised to consult my GP. If, during the study, evidence comes to light that I may have a pre-existing medical condition that may put others at risk, I understand that the University will refer me to the appropriate authorities and that I will not be allowed to take any further part in the study.

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

8 I have been told that I may at some time in the future be contacted again in connection with this or another study.

Signature of participant………………………….…………..…Date………….………………

Signature of (principal)
investigator…………………………………………….………Date…………………………

Name of (principal) investigator *[in BLOCK CAPITALS please]*

Selina Kapasi

Appendix 7: Debrief Sheet

PARTICIPANT DEBRIEF SHEET

Thank you for participating in this research.

The aim of the study was to understand the experiences of living with a parent who has faced / is facing mental health difficulties, from the perspective of the adult child, from an Indian heritage. By taking part in this study, you have contributed to furthering the knowledge base and helping to identify factors which may be influential in one's experience. The hope is that there will be greater recognition in the needs of children of parents with mental health difficulties, and help will be more readily available.

If you would like to withdraw from the study, please contact me within three months of your interview. I can be contacted by email at sk08abu@herts.ac.uk.

I hope that participating in this study has proven to be a positive experience for you. However, if you feel that difficult emotions have been brought up, and would like further support there are a number of organisations you can seek support from.

Below is a list of organisations, alternatively you can seek support and access to psychological services via your GP.

Carers UK	www.carersuk.org
MIND	www.mind.org.uk
Samaritans	www.samaritans.org

Lastly, I would like to thank you for your time.

Thank you,

Selina

Appendix 8: Interview Schedule

UNDERSTANDING the experience of having a parent with mental health difficulties

- Could you tell me about your understanding of the difficulties your parent was experiencing?
    - What age do you first remember learning about the difficulties?
    - Was there a particular situation you can recall?
    - What sense do you remember making at the time about what was going on?

- Who else knew about your parent's 'illness'?
    - What did family members think?
    - What did your friends think?
    - What sense did the wider community make of the difficulties?

- How was it spoken about in the family?

- How are mental health difficulties perceived in your wider community?

IMPACT of having a parent with mental health difficulties

- Could you describe the impact of having a parent with mental health difficulties has had on you?
    - What impact did it have on your childhood (friendships, education, people coming over etc) ?
    - What about your adolescence (friendships, education, people coming over etc) ?
    - And now?

- In what way would you describe your relationship changed with your parent, if at all?

- What help did your parent access for the mental health difficulties they were experiencing?

- Did you ever care / look after your parent?
    - Did you gain support from others (family / friends / support agencies)?

- Did others help care for the parent? (family / friends / support agencies)?

ADULTHOOD – how have things changed for you

- How do you feel about having a parent with mental health difficulties?
    - Have you ever worried about the 'illness' being passed on to you?

- Has having a parent with mental health difficulties changed your view of difficulties?

- Do you feel as though your parent’s difficulties have impacted the way others see you?
    - If so has this impacted on other prospects such as marriage?

- What positive did you gain from having a parent with mental health difficulties?

Appendix 9: Transcript excerpt (Priya)

What do you mean by dads behaviour? What do you remember?

He was very erratic, so kind of incredibly erratic, so like he would have very little sleep My dad would sleep between 4 to 6 hours, and was always on edge, but I think that was because of his mental health because he was constantly, like I don't know if it was his psychosis of something like that, or the medication my dad was on was conflicting with each other, but you would have incredible great days and then you would have an erratic sort of experience that was completely off the scale, but I suppose most people are kind of right in the middle but then you would have the extreme sides of it. Ummm and I think my dad's social side was very good like he was incredibly social like, so you wouldn't see that side, but you would see that at home, so yeah.

And who was at home?

So it was me, my sister, my mum and that was it

Is that an older or younger sister?

Younger

OK, and what sense did you make of Dads erracticness and being on edge and not sleeping. You were saying that later on in life he had multi difficulties and alcoholism was a way to manage for him. But what sense did you make prior to knowing about his mental health difficulties?

I think it was acknowledging the… I would come home from uni or hang out in the evening and I would acknowledge that my dad's medication was just. My Dad would take some many medications and I think that's started the conversation, because my Dad, we didn't really have, I don't know how common this is amongst general parents and parenting and stuff like that, you are really open with your parents or the other end of the spectrum. We just didn't have that kind of conversation.

My dad was incredibly respectful, and incredibly proud, we just didn't have that next layer of conversation kind of thing, and I think that was something that was..he was never really available because my Dad used to like work in a pub, like I have grown up in a pub industry, so my dad would leave at 6, and by the time he had come back in the morning, he would drop us to school, then his day would be literally at the pub until 7, and it was just constant, so he just worked and worked and worked. So we never really got to that point, and I think in my mid 20s when I came back to Birmingham, I didn't move back home, so for me, I didn't see the full scale of it, everything that was happening so I think there is a level of regret that I didn't have those conversations in my mid 20s because I think I realised too late to have that conversation, so yeah I think that was kind of it.

Who knew about Dad's illness?

My mum knew but didn't understand enough the detail of it. You know as parents, and as husband and wife they would argue and stuff like that but, trying to explain to my mum now what I think, I think she acknowledged that my dad was under quite strong medication and she didn't realise that the medication and alcohol combined just wasn't working. So my mum knew about it, I don't know, so the thing is like, when I say my kind of had a split personality the person you would see outside, everyone knew my dad. He was incredibly sociable, so the people outside wouldn't know that my dad had just severe mental health. I don't even think my dad's brothers and sister knew about it. If they did, they acknowledged it but didn't understand the scale of it. Immediate family knew, my sister probably knew more and she stayed in the house until 26/27 and then she got married, and then my brother in law moved in here so they had already experienced at a later life , and I was really pragmatic when I was coming home to kind of explain it, so my mum had already known for a very long time, and she had probably known since mid to late 90s so it was a long time, but yeah that's who knew.

So it sounds like there are people who knew or might have known but nobody really spoke about it.

Yes it was kind of like no one spoke. Even in the community people just wouldn't speak about it. We knew it exists and we know it has always existed but no body addressed it and that was the thing. My dad never participated at anything related to the community. That's probably another reason, he was quite detached from that side, so we just never spoke about it, and the only way I came across mental health per-se was kind of like when I got to university, and started to speaking to other people, and those experiences that I shared, and it started then, sort of like, my experiences from studying started to shape my view of the world, so I think it wasn't spoken about in a wider context but I knew my dad used to go to a centre in Birmingham city, just outside Birmingham city centre and it was for people with quite severe mental health problems but it was only until my dad passed away, my mum requested his medical file, we didn't realise how often he was going. He would just leave the house and just go. Mum would just go to work, we would assume Dad was going to work, and because my dad worked part time, he was also going to this centre but we don't know what the conversations were because of confidentiality, and patient care and stuff like that, so we never really understood. Even to this day, I drive past that centre and I'm like do you know what , I want to go there and kind of like understand

Sure

So yeah

How would you describe the impact it had on you, having a parent with mental health difficulties?

I think it changes how you look at things, you become a little bit more, because since my dad has passed away, I have had quite bad mental health problems or experienced mental health (feeling emotional). I think it changes you mind set a little bit because me and my sister are probably the softest so for me in particular it's made me acknowledge that I didn't help at the time when I think I could have or stepped in. I think I feel regret, so yeah my personal experiences, and having my dad go through it, has made me realise the triggers my dad had, I don't think I would ever want to go down that path. So my relationship with alcohol has changed.

So it sounds like from what you are saying in childhood dad was dad, he worked, he could be erratic, would snap, but it was dad. You didn't know any difference, but when you left home, went to university and started speaking to other people, making friends, and perhaps doing your own research, that's when you realised things were a little bit different, is that right ?

Yeah, I think when you live in own little community, social friends and people you meet at college, I guess you've known them for a very long time. I knew my friends from the age of 9/10, so it wasn't until the point I got to university that my friendship circle changed drastically, and it was their experiences, and just having that conversation. I think in the Indian culture you just don't talk about it at all. It is just supressed, whereas in a lot of the communities in the friends that I had, predominately white middle class, they would speak and be open about it. I had friend who would say my parents are going through a difficult time or my dad's going through depression . It was only until those trigger points that you realise actually it's not just you and you are not just living in these sheltered experience there are other people, and understanding their experiences because as a south Asian I couldn't communicate with somebody who was in my group from school.

What do you mean by that?

So because of the friendship circles I had, you would have very deep friendships with people from Punjabi backgrounds, Guajarati backgrounds, and generally the natural group I was hanging out, but we never spoke about our experiences of our parents. Or you would hide it.

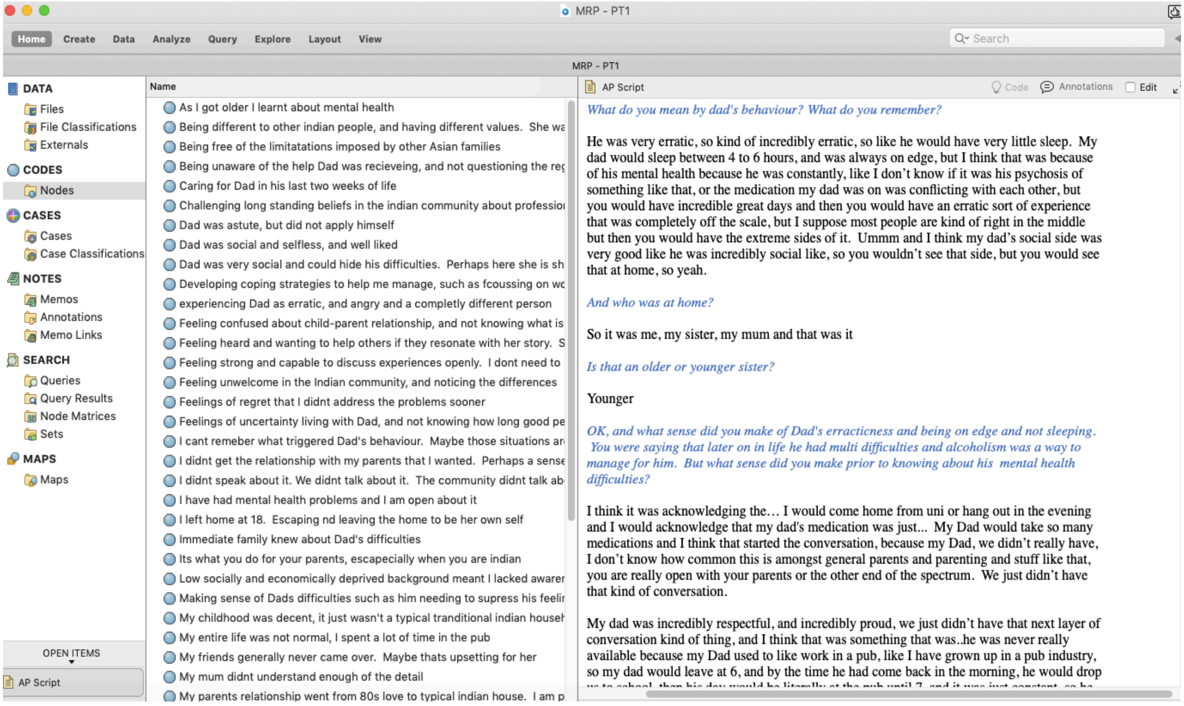
So with friendships in childhood, did your friends come over, was it ok?

Essentially, my friends very rarely came to this side of the city. I lived the furthest out of all my friends, so they would know who my dad was, they would have met him, they would come over to my house, but I more often than not I would go to their house. It was the done thing. A lot of my friends lived on the same street, or the same area so they would come to birthdays and Diwali celebrations and occasions where we know there would be groups of us together but generally they wouldn't come here. Even if we did meet nearer, my dad would be incredibly polite, and I know we have had friends over and ironically my dad would be like give them a drink or make sure they eat and that's the side they would see, so I would be comfortable having them over here but it was just never a done thing. As I got older it became less of a thing because I didn't live at home at that point.

So in term of coming over it was fine and you were comfortable. I am wondering about your relationship with dad and how it changed. It sounds like you become more aware as you got older, and I'm wondering how your relationship changed?

Instead of looking at my dad and thinking he is kicking off, I was understanding what was triggering him. I was trying to understand what would make my dad flip. So I became more sensitive to him. I was never insensitive but like I looked at dad more differently, like knowing when he is having an episode and so needing to behave differently. So speak to him differently, speak more softer, be more understanding towards him and show him compassion. I think that's what my dad had been missing for a very long time. (becoming tearful) and the Indian community didn't understand my dad's erratic behaviour and I think that was really hard and I think, I lost my dad when I was 28 so that conversation happened too late for me to change. My dad would have bouts of drinking excessively, he never drank spirits, he would just drink beer, but I didn't realise how bad my dad's drink problem was because he was able to hide it by working in a pub environment. The regret I have is not having that conversation with my dad. My dad would have stages when he didn’t drink for 2-3 weeks and he would be an incredibly different person.

Appendix 10: Example of Transcript coding (NVIVO) - Priya



- As I got older I learnt about mental health
- Being different to other indian people, and having different values. She wa
- Being free of the limitatations imposed by other Asian families
- Being unaware of the help Dad was recieveing, and not questioning the re
- Caring for Dad in his last two weeks of life
- Challenging long standing beliefs in the indian community about professio
- Dad was astute, but did not apply himself
- Dad was social and selfless, and well liked
- Dad was very social and could hide his difficulties. Perhaps here she is sh
- Developing coping strategies to help me manage, such as fcoussing on wc
- experiencing Dad as erratic, and angry and a completly different person
- Feeling confused about child-parent relationship, and not knowing what is
- Feeling heard and wanting to help others if they resonate with her story. S
- Feeling strong and capable to discuss experiences openly. I dont need to
- Feeling unwelcome in the Indian community, and noticing the differences
- Feelings of regret that I didnt address the problems sooner
- Feelings of uncertainty living with Dad, and not knowing how long good pe
- I cant remeber what triggered Dad's behaviour. Maybe those situations ar
- I didnt get the relationship with my parents that I wanted. Perhaps a sense
- I didnt speak about it. We didnt talk about it. The community didnt talk ab
- I have had mental health problems and I am open about it
- I left home at 18. Escaping nd leaving the home to be her own self
- Immediate family knew about Dad's difficulties
- Its what you do for your parents, escapecially when you are indian
- Low socially and economically deprived background meant I lacked awarer
- Making sense of Dads difficulties such as him needing to supress his feelir
- My childhood was decent, it just wasn't a typical tranditional indian househ
- My entire life was not normal, I spent a lot of time in the pub
- My friends generally never came over. Maybe thats upsetting for her
- My mum didnt understand enough of the detail
- My parents relationship went from 80s love to typical indian house. I am p

What do you mean by dad's behaviour? What do you remember?

He was very erratic, so kind of incredibly erratic, so like he would have very little sleep. My dad would sleep between 4 to 6 hours, and was always on edge, but I think that was because of his mental health because he was constantly, like I don't know if it was his psychosis of something like that, or the medication my dad was on was conflicting with each other, but you would have incredible great days and then you would have an erratic sort of experience that was completely off the scale, but I suppose most people are kind of right in the middle but then you would have the extreme sides of it. Ummm and I think my dad's social side was very good like he was incredibly social like, so you wouldn't see that side, but you would see that at home, so yeah.

And who was at home?

So it was me, my sister, my mum and that was it

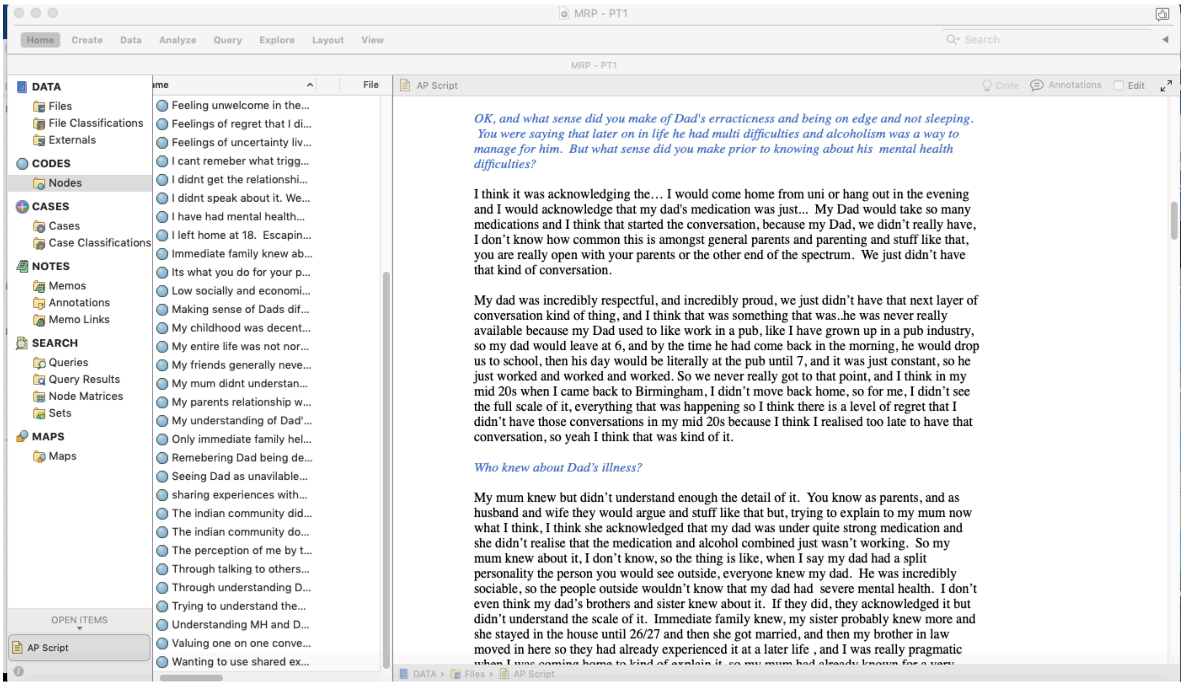
Is that an older or younger sister?

Younger

OK, and what sense did you make of Dad's erracticness and being on edge and not sleeping. You were saying that later on in life he had multi difficulties and alcoholism was a way to manage for him. But what sense did you make prior to knowing about his mental health difficulties?

I think it was acknowledging the… I would come home from uni or hang out in the evening and I would acknowledge that my dad's medication was just... My Dad would take so many medications and I think that started the conversation, because my Dad, we didn't really have, I don't know how common this is amongst general parents and parenting and stuff like that, you are really open with your parents or the other end of the spectrum. We just didn't have that kind of conversation.

My dad was incredibly respectful, and incredibly proud, we just didn't have that next layer of conversation kind of thing, and I think that was something that was..he was never really available because my Dad used to like work in a pub, like I have grown up in a pub industry, so my dad would leave at 6, and by the time he had come back in the morning, he would drop



- Feeling unwelcome in the...
- Feelings of regret that I di...
- Feelings of uncertainty liv...
- I cant remeber what trigg...
- I didnt get the relationshi...
- I didnt speak about it. We...
- I have had mental health...
- I left home at 18. Escapin...
- Immediate family knew ab...
- Its what you do for your p...
- Low socially and economi...
- Making sense of Dads dif...
- My childhood was decent...
- My entire life was not nor...
- My friends generally neve...
- My mum didnt understan...
- My parents relationship w...
- My understanding of Dad'...
- Only immediate family hel...
- Remebering Dad being de...
- Seeing Dad as unavilable...
- sharing experiences with...
- The indian community did...
- The indian community do...
- The perception of me by t...
- Through talking to others...
- Through understanding D...
- Trying to understand the...
- Understanding MH and D...
- Valuing one on one conve...
- Wanting to use shared ex...

OK, and what sense did you make of Dad's erracticness and being on edge and not sleeping. You were saying that later on in life he had multi difficulties and alcoholism was a way to manage for him. But what sense did you make prior to knowing about his mental health difficulties?

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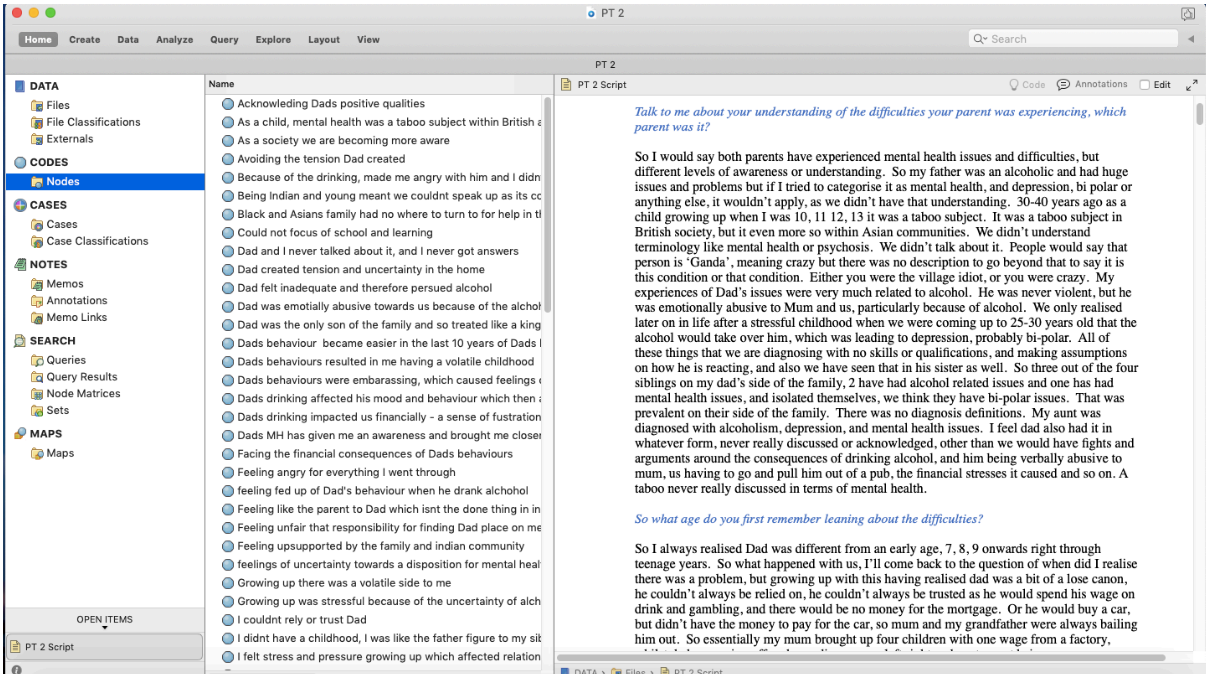
My dad was incredibly respectful, and incredibly proud, we just didn't have that next layer of conversation kind of thing, and I think that was something that was..he was never really available because my Dad used to like work in a pub, like I have grown up in a pub industry, so my dad would leave at 6, and by the time he had come back in the morning, he would drop us to school, then his day would be literally at the pub until 7, and it was just constant, so he just worked and worked and worked. So we never really got to that point, and I think in my mid 20s when I came back to Birmingham, I didn't move back home, so for me, I didn't see the full scale of it, everything that was happening so I think there is a level of regret that I didn't have those conversations in my mid 20s because I think I realised too late to have that conversation, so yeah I think that was kind of it.

Who knew about Dad's illness?

My mum knew but didn't understand enough the detail of it. You know as parents, and as husband and wife they would argue and stuff like that but, trying to explain to my mum now what I think, I think she acknowledged that my dad was under quite strong medication and she didn't realise that the medication and alcohol combined just wasn't working. So my mum knew about it, I don't know, so the thing is like, when I say my dad had a split personality the person you would see outside, everyone knew my dad. He was incredibly sociable, so the people outside wouldn't know that my dad had severe mental health. I don't even think my dad's brothers and sister knew about it. If they did, they acknowledged it but didn't understand the scale of it. Immediate family knew, my sister probably knew more and she stayed in the house until 26/27 and then she got married, and then my brother in law moved in here so they had already experienced it at a later life , and I was really pragmatic

Appendix 11: Example of Transcript coding (NVIVO) – Dinesh



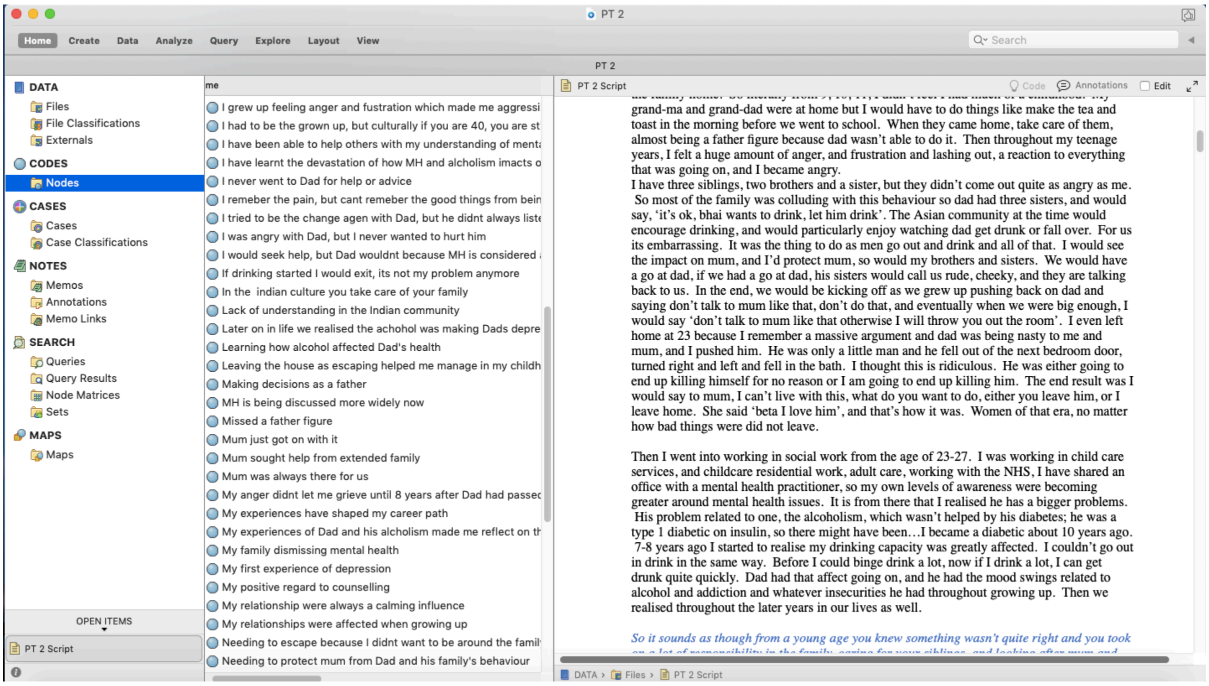
- Acknowleding Dads positive qualities
- As a child, mental health was a taboo subject within British a
- As a society we are becoming more aware
- Avoiding the tension Dad created
- Because of the drinking, made me angry with him and I didn
- Being Indian and young meant we couldnt speak up as its cc
- Black and Asians family had no where to turn to for help in tl
- Could not focus of school and learning
- Dad and I never talked about it, and I never got answers
- Dad created tension and uncertainty in the home
- Dad felt inadequate and therefore persued alcohol
- Dad was emotially abusive towards us because of the alchol
- Dad was the only son of the family and so treated like a king
- Dads behaviour became easier in the last 10 years of Dads l
- Dads behaviours resulted in me having a volatile childhood
- Dads behaviours were embarassing, which caused feelings c
- Dads drinking affected his mood and behaviour which then a
- Dads drinking impacted us financially - a sense of fustration
- Dads MH has given me an awareness and brought me closer
- Facing the financial consequences of Dads behaviours
- Feeling angry for everything I went through
- feeling fed up of Dad's behaviour when he drank alchohol
- Feeling like the parent to Dad which isnt the done thing in in
- Feeling unfair that responsibility for finding Dad place on me
- Feeling upsupported by the family and indian community
- feelings of uncertainty towards a disposition for mental healt
- Growing up there was a volatile side to me
- Growing up was stressful because of the uncertainty of alch
- I couldnt rely or trust Dad
- I didnt have a childhood, I was like the father figure to my sib
- I felt stress and pressure growing up which affected relation

Talk to me about your understanding of the difficulties your parent was experiencing, which parent was it?

So I would say both parents have experienced mental health issues and difficulties, but different levels of awareness or understanding. So my father was an alcoholic and had huge issues and problems but if I tried to categorise it as mental health, and depression, bi polar or anything else, it wouldn't apply, as we didn't have that understanding. 30-40 years ago as a child growing up when I was 10, 11 12, 13 it was a taboo subject. It was a taboo subject in British society, but it even more so within Asian communities. We didn't understand terminology like mental health or psychosis. We didn't talk about it. People would say that person is 'Ganda', meaning crazy but there was no description to go beyond that to say it is this condition or that condition. Either you were the village idiot, or you were crazy. My experiences of Dad's issues were very much related to alcohol. He was never violent, but he was emotionally abusive to Mum and us, particularly because of alcohol. We only realised later on in life after a stressful childhood when we were coming up to 25-30 years old that the alcohol would take over him, which was leading to depression, probably bi-polar. All of these things that we are diagnosing with no skills or qualifications, and making assumptions on how he is reacting, and also we have seen that in his sister as well. So three out of the four siblings on my dad's side of the family, 2 have had alcohol related issues and one has had mental health issues, and isolated themselves, we think they have bi-polar issues. That was prevalent on their side of the family. There was no diagnosis definitions. My aunt was diagnosed with alcoholism, depression, and mental health issues. I feel dad also had it in whatever form, never really discussed or acknowledged, other than we would have fights and arguments around the consequences of drinking alcohol, and him being verbally abusive to mum, us having to go and pull him out of a pub, the financial stresses it caused and so on. A taboo never really discussed in terms of mental health.

So what age do you first remember leaning about the difficulties?

So I always realised Dad was different from an early age, 7, 8, 9 onwards right through teenage years. So what happened with us, I'll come back to the question of when did I realise there was a problem, but growing up with this having realised dad was a bit of a lose canon, he couldn't always be relied on, he couldn't always be trusted as he would spend his wage on drink and gambling, and there would be no money for the mortgage. Or he would buy a car, but didn't have the money to pay for the car, so mum and my grandfather were always bailing him out. So essentially my mum brought up four children with one wage from a factory,



- I grew up feeling anger and fustration which made me aggressi
- I had to be the grown up, but culturally if you are 40, you are st
- I have been able to help others with my understanding of menta
- I have learnt the devastation of how MH and alcholism imacts o
- I never went to Dad for help or advice
- I remeber the pain, but cant remeber the good things from bein
- I tried to be the change agen with Dad, but he didnt always liste
- I was angry with Dad, but I never wanted to hurt him
- I would seek help, but Dad wouldnt because MH is considered a
- If drinking started I would exit, its not my problem anymore
- In the indian culture you take care of your family
- Lack of understanding in the Indian community
- Later on in life we realised the achohol was making Dads depre
- Learning how alcohol affected Dad's health
- Leaving the house as escaping helped me manage in my childh
- Making decisions as a father
- MH is being discussed more widely now
- Missed a father figure
- Mum just got on with it
- Mum sought help from extended family
- Mum was always there for us
- My anger didnt let me grieve until 8 years after Dad had passed
- My experiences have shaped my career path
- My experiences of Dad and his alcholism made me reflect on th
- My family dismissing mental health
- My first experience of depression
- My positive regard to counselling
- My relationship were always a calming influence
- My relationships were affected when growing up
- Needing to escape because I didnt want to be around the famil
- Needing to protect mum from Dad and his family's behaviour

grand-ma and grand-dad were at home but I would have to do things like make the tea and toast in the morning before we went to school. When they came home, take care of them, almost being a father figure because dad wasn't able to do it. Then throughout my teenage years, I felt a huge amount of anger, and frustration and lashing out, a reaction to everything that was going on, and I became angry.

I have three siblings, two brothers and a sister, but they didn't come out quite as angry as me. So most of the family was colluding with this behaviour so dad had three sisters, and would say, 'it's ok, bhai wants to drink, let him drink'. The Asian community at the time would encourage drinking, and would particularly enjoy watching dad get drunk or fall over. For us its embarrassing. It was the thing to do as men go out and drink and all of that. I would see the impact on mum, and I'd protect mum, so would my brothers and sisters. We would have a go at dad, if we had a go at dad, his sisters would call us rude, cheeky, and they are talking back to us. In the end, we would be kicking off as we grew up pushing back on dad and saying don't talk to mum like that, don't do that, and eventually when we were big enough, I would say 'don't talk to mum like that otherwise I will throw you out the room'. I even left home at 23 because I remember a massive argument and dad was being nasty to me and mum, and I pushed him. He was only a little man and he fell out of the next bedroom door, turned right and left and fell in the bath. I thought this is ridiculous. He was either going to end up killing himself for no reason or I am going to end up killing him. The end result was I would say to mum, I can't live with this, what do you want to do, either you leave him, or I leave home. She said 'beta I love him', and that's how it was. Women of that era, no matter how bad things were did not leave.

Then I went into working in social work from the age of 23-27. I was working in child care services, and childcare residential work, adult care, working with the NHS, I have shared an office with a mental health practitioner, so my own levels of awareness were becoming greater around mental health issues. It is from there that I realised he has a bigger problems. His problem related to one, the alcoholism, which wasn't helped by his diabetes; he was a type 1 diabetic on insulin, so there might have been…I became a diabetic about 10 years ago. 7-8 years ago I started to realise my drinking capacity was greatly affected. I couldn't go out in drink in the same way. Before I could binge drink a lot, now if I drink a lot, I can get drunk quite quickly. Dad had that affect going on, and he had the mood swings related to alcohol and addiction and whatever insecurities he had throughout growing up. Then we realised throughout the later years in our lives as well.

So it sounds as though from a young age you knew something wasn't quite right and you took

Appendix 12: Example of grouping codes into themes - Priya

Stage 1

Exploratory Comments	Emergent Themes
My mum didn't understand enough of the detail Low socially and economically deprived background meant I lacked awareness of mental health difficulties – context Trying to understand the triggers and causes to Dads mental health to try and make sense of it As I got older I learnt about mental health Making sense of Dads difficulties such as him needing to supress his feelings, and being erratic My understanding of Dad's mental health problems, and his behaviours	When younger I didn't understand Dad's mental health difficulties. With age I have learnt more about mental health Searching and investigating – searching for understanding
Being different to other Indian people, and having different values. She wants to empower others not compete Being free of the limitations imposed by other Asian families Challenging long standing beliefs in the Indian community about professions Feeling unwelcome in the Indian community. Noticing the differences between her and those that went to the temple. The perception of me by the Indian community is that I am loud. This is not desirable As a south Asian I couldn't communicate with somebody who was in my group from school.	Recognising personal values and community values do not align. Feeling unwelcome in the Indian community. I am not desirable in the Indian community Taking for granted that culture prevents talking
Dad was astute, but did not apply himself Dad was social and selfless, and well liked	Dad was very social, and knew how to hide his difficulties. As an Indian man you don't talk about your feeling, and Dad didn't. Remembering living with uncertainty and unpredictability

Dad was very social and could hide his difficulties. *Perhaps here she is showing that it's not her fault she didn't see it, but she does state that the problems showed themselves at home* My Dad Didn't talk about it experiencing Dad as erratic, and angry and a completely different person Feelings of uncertainty living with Dad, and not knowing how long good periods would last	

Stage 2

Subordinate Themes	**Superordinate Themes**
When younger I didn't understand Dad's mental health difficulties. With age I have learnt more about mental health. Searching and investigating – searching for understanding Dad was very social, and knew how to hide his difficulties. Only immediate family knew and helped with Dads problem *A sense that more help or options for support would have been appreciated?*	Lacking the understanding of mental health difficulties when younger, yet with age searching for explanations
Recognising personal values and community values do not align. Feeling unwelcome in the Indian community. The Indian community didn't want to understand Dads difficulty.	Feeling undesirable to the Indian community – Seeing culture as an obstacle to talking

Mental health is still a taboo subject in the Indian culture; it's not spoken about. As an Indian man you don't talk about your feeling, and Dad didn't. I am not desirable in the Indian community	
I managed by talking to others, moving out of home, exercising and focussing on my work. Wanting to share my story to help others I want to channel my energies positively It's okay not to be okay	Developing strategies to help me and others manage our mental health.