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**THE EXPERIENCES OF IMMIGRANT PARENTS WITH A CHILD WITH A
DEVELOPMENTAL DISORDER**

Section A: The experiences of South Asian and African immigrant families with a child with an intellectual and/or developmental disability: A literature review.

Word Count: 7,994 (55)

Section B: The experiences of African immigrant mothers in the UK with a child with an Autism Spectrum Disorder:

An Interpretative Phenomenological Analysis

Word Count: 8,000 (40)

Overall Word Count: 15,994 (95)

(excluding abstract, references, tables and figures)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of doctor of Clinical Psychology

June 2015

Salomons

Canterbury Christ Church University

Acknowledgements

I would like to dedicate this project to the eight parents who generously gave up their time to share their experiences with me. Their strength and determination was an inspiration to me throughout the process. Additionally, all the wonderful families and children I have worked with over the years, both in the UK and Africa, who inspired my interest in this topic.

Thank you to my research supervisors, Susanna Cole and Linda Hammond, for their support and enthusiasm. Thank you also to Paul Camic for his guidance during the analysis.

Finally, I could not have done this without the support of my husband, family and friends.

Summary

Section A provides a review of the literature relating to the experiences of South Asian and African immigrant parents, living in western cultures, with a child with an intellectual and/or developmental disorder. The literature is summarised with reference to the two research questions 1) how do the families make sense of their child's difficulties and diagnosis? 2) what are their experiences of accessing services? Empirical and conceptual literature is discussed and critiqued, followed by recommendations for clinical practice and future research.

Section B is a qualitative, interview-based study investigating the experiences of African immigrant mothers in the UK with a child with an Autism Spectrum Disorder. Six mothers participated and the results were analysed using Interpretative Phenomenological Analysis. Five super-ordinate themes emerged: caring for a child we didn't expect, the pain of stigma and rejection, making sense of our child's difficulties and diagnosis, managing conflicting values and beliefs, and faith in God as "key". These are discussed with reference to extant theory and literature. Limitations, implications for clinical practice and policy, and suggestions for future research are outlined.

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Section A

The experiences of South Asian and African immigrant families with a child with an intellectual and/or developmental disability: A literature review.

Word Count: 7,994 (55)

(excluding abstract, references, tables and figures)

Abstract

This review aimed to provide a systematic search, thematic analysis and critique of the relevant literature pertaining to the experiences of South Asian and African immigrant parents living in western societies with a child with an intellectual and/or developmental disorder. Specifically, the review aimed to investigate the way in which parents made sense of their child's disability, and their interactions with services. Two conceptual papers and thirteen qualitative empirical papers were identified. All papers pertained to the experiences of South Asian families, indicating they drew upon a combination of religious, traditional/cultural and biomedical explanations when making sense of their child's disability. Stigma and blame from within their minority communities appeared to influence some parents to adopt biomedical beliefs. Identified barriers to service uptake included language, a lack of knowledge of services, low confidence when interacting with professionals, perceptions of discrimination and feeling blamed. Many parents described feeling dissatisfied with services and had a high level of unmet need. Three papers included African parents in the sample; only one of these reported separate findings for this group. Clinical implications and areas for further research are identified, most notably the clear need for research focussing on the experiences of African immigrant families.

Key terms: Intellectual Disabilities, Child Developmental Disabilities, Culture, Immigrant Parents, South Asian, African

Introduction

The UK is an increasingly multi-cultural society, with the 2011 England and Wales census indicating that 13% of the resident population were born abroad (Office of National Statistics, 2011). In large cities such as London, this figure was considerably higher (37%), and estimates indicate it has risen further since 2011 (Oxford Migration Observatory, 2015). It is important that health, education and social care services are adapted to meet the needs of, and improve access for, families from diverse cultural backgrounds, as outlined in the Equality Act, 2010. Department of Health (DOH) papers such as “Learning Difficulties and Ethnicity: Updating a Framework for Action” (2012), “Valuing People Now” (2009) and “Delivering Race Equality in Mental Health Care” (2005) emphasise the importance of building the capacity of learning disability and mental health services to meet the needs of ethnic minority and immigrant communities. These documents state clinicians must demonstrate “cultural competence”. This involves being mindful of, and curious regarding, the potential impact of cultural factors on a family’s experience, and incorporating this information into assessments and treatment plans. Research into the specific needs and lived experiences of these groups is therefore a priority. The following review will discuss the literature pertaining to the experiences of South Asian and African immigrant parents living in western cultures, caring for a child with an intellectual and/or developmental disability, in order to inform clinical practice and policy for supporting these families.

Culture and child development

Culture is the term used to refer to a group of people's collective beliefs, goals and attitudes, which shape their view of themselves, others and the world (Matsumoto, 2001). In this sense, culture encompasses both internal (e.g. norms, social rules, values, beliefs) and external components (e.g. laws, customs, traditions, behaviours), which are learned by individuals within a group and are transmitted between generations (Linton, 1945). Individuals from different cultural groups are likely to perceive the world in distinct ways and to hold different norms and expectations of human behaviour (Skinner and Weisner, 2007). Culture is therefore likely to affect concepts of illness, disorder and disability, which are based on the premise of individuals being different in some way when compared to cultural norms. Consequently, behaviours perceived as a symptom of illness or disability in one culture, might be perceived very differently in another. For example, whilst eye contact is considered an important element of social behaviour in western cultures, with its absence being a cause for concern, it is considered disrespectful and therefore discouraged in some African and Asian cultures (Perepa, 2014; Zhang, Wheeler & Richey, 2006).

In Western societies such as the UK, the medical model is dominant in shaping the way in which these concepts are conventionally understood. Human differences are measured and categorised into discrete illnesses and disorders, which are attributed to the individual and are considered to require treatment in an attempt to rectify them (World Health Organisation, 1992). Such an understanding may conflict with the views of immigrant families (Welterlin &

LaRue, 2007). Literature indicates considerable cultural variation in frameworks of child development (Skinner & Weisner, 2007). Daley (2004), for example, found that Indian parents believed speech delays in boys were considered part of normal development, although these would indicate a cause for concern in western cultures. This can be illustrated by exploring attitudes towards children who are considered in western societies to have intellectual and/or developmental disabilities. These conditions affect an individual's cognitive ability, general adaptive functioning and/or social skills (Carr, 2011). They are considered present at birth, to manifest during childhood and to persist throughout the lifespan.

Literature suggests culture influences families on multiple levels when caring for a child with an developmental disability; from noticing and making sense of differences, to selecting treatment approaches, interactions with healthcare systems and expectations for the future (for literature reviews, see: Ennis-Cole, Durodoye & Harris, 2013; Ravindran & Myers, 2012; Mandel & Novak, 2005). However, existing research tends to emanate from the USA, focussing on cultural groups less prominent in the UK demographic (e.g. Dyches et al, 2004), or involves families who remain living in their country of origin (e.g Daley, 2002). Such research is of limited application to immigrant families in the UK, whose experiences will differ from those of British families, and from their cultural counterparts who have not migrated. Heer, Rose and Larkin (2012b) argue that an understanding of "minority experience" can highlight the distinct needs and experiences of immigrant families, which are influenced by a combination of social, biological and cultural factors.

Aims of this review:

The current review aims to provide a systematic search and critique of the extant published literature pertaining to the experiences of South Asian and African immigrant families with a child with an intellectual and/or developmental disability, living in a western society. Limited research exists to date pertaining specifically to the UK, therefore the decision was made to broaden the search to include literature from other countries with a similar socio-economic status, healthcare model and culture to the UK, specifically countries in Europe¹, North America, Australia and New Zealand. Whilst it is acknowledged that there are cultural differences and variations in migration patterns between these regions (Ghosh and Magana, 2009), it is believed that there is sufficient similarity in order for the results to have implications for the development of “culturally competent” (DoH, 2012) services in the UK.

The purpose of the review is to assist professionals in the UK to understand the experiences and needs of immigrant families, and to identify gaps in the empirical literature, suggesting areas for future research. The 2011 England and Wales census indicates the majority of foreign-born, non-European, residents are from South Asia (2.9%; 7.7% in London) and Africa (2.3%; 7.6% in London) (ONS, 2011). Therefore these two groups were selected. The term “South Asian” is generally used in the UK to refer to individuals from the “South Asian Subcontinent”, namely India, Pakistan, Bangladesh, Kashmir and Sri Lanka (Heer et al, 2012b). This group are of interest given their high rate of immigration to the UK, low service uptake and potential higher prevalence of

¹ If these papers were available in English

intellectual and developmental disabilities compared to the general UK population (Emerson, 1997). Furthermore, migration to the UK from countries within Africa has increased over the past decade (ONS, 2011) and there are indications these families are overrepresented in some child development services (Slade, 2014; Lindsay, Dockrell & Roulstone, 2012). Understanding the experiences and needs of these groups is therefore a priority. It is acknowledged that there is considerable cultural diversity within and between South Asia and Africa, and these terms are not intended to define distinct cultural groups. The review will focus on the shared “minority experience” (Heer et al, 2012b) of immigrants from these two large geographic regions.

Definition of terms

The term “children with an intellectual and/or developmental disability” will be used to refer to children who do not follow the typical developmental paths expected within the western medical model, and who would be described in the UK as having a “developmental disability/disorder”, “learning disability”, “intellectual disability”, or, in the USA, as “mentally retarded”. The International Classification of Disorders-10th Edition (World Health organisation, 1992) refers to intellectual disabilities as characterised by “a reduced level of intellectual functioning resulting in diminished ability to adapt to the daily demands of the normal social environment”. Children diagnosed with a “Pervasive development disorder” or “autism spectrum disorder/condition” will also be included in this review. These terms refer to a spectrum of conditions characterised by deficits in three main areas: social communication (affecting receptive and expressive language and communication skills), social interaction (difficulties initiating and

maintaining reciprocal interactions) and social imagination/flexibility of thought (restricted, repetitive patterns of activities and interests) (Carr, 2006; Volkmar, Lord, Bailey, Schultz & Kiln, 2004; Wing, 1981). Estimates suggest at least 50% of individuals with ASD also have a recognised intellectual disability (Charman et al, 2011).

In many cases, these differences will emerge during a specific stage in a child's development, at which point they do not develop the skills expected for their age (Carr, 2006). This is likely to present distinct challenges for parents when making sense of their child's differences, and often relies on the parent recognising a difference and seeking support from services (Skinner & Weisner, 2007). For this reason, childhood disabilities that are likely to be detected prenatally or at birth, such as Down's Syndrome, are not included in this review.

Review questions

The review seeks to address the following questions:

1. How do South Asian and African immigrant parents, living in a western society, make sense of having a child with an intellectual and/or developmental disability?
2. What are their experiences of accessing mainstream services?

Methodology

The databases PsychInfo, Medline, PubMed, ASSIA and CINAHL were electronically searched using the terms listed in table 1. Google Scholar was checked for additional papers, as were the websites of relevant third sector and Government organisations. With reference to the criteria in table 2, titles were initially screened, abstracts of potentially relevant papers were reviewed, and full texts read as necessary. Reference lists and citing articles were hand-searched, until no further relevant papers were identified. A flowchart showing the number of references encountered and excluded at each stage can be found in Appendix 1. No papers were excluded based on methodology and no date parameters were set, given an absence of previous reviews in this area.

Table 1.

Search Terms

<u>Search Terms</u>
["learning disabilit*" / OR "intellectual* disabilit*" / OR "intellectual development* dis*" / OR "develop* dis*" / OR pervasive dev* dis*" / OR neurodev* dis*" / OR autis* / OR asperger* / OR "autis* spectrum disorder" / OR "autis* spectrum condition/ OR "development* delay" / OR "cognitive impairment" / OR "mental retardation"]
AND [parent* / OR caregiver* / OR family / OR mother* / OR father* / OR "parent* perceptions" / OR "parent* attitudes" / OR "parent* beliefs"]
[cultur* / OR acculturat* / OR immigra* / OR "migra*" / OR "minority group*" / OR
AND "racial and ethnic group*" / OR "South Asia*" / OR Pakistan* / OR Bangladesh* / OR
India* / OR Africa* ²]

² Specific search terms relating to individual countries within Africa and South Asia yielded no additional papers.

Table 2.

Inclusion and exclusion criteria

<u>Inclusion Criteria</u>	<u>Exclusion Criteria</u>
<ul style="list-style-type: none"> • Literature investigating the views and/or experiences of parents of a child under 21 years of age with an intellectual and/or developmental disorder, and the parent was an immigrant from Africa or South Asia, living in Europe, North America, Australia or New Zealand • The paper presented a theoretical or conceptual framework for understanding the experiences of families meeting the above criteria • The paper was published in English, in a peer-reviewed, academic journal or by a third-sector or Government organisation • Available in English 	<ul style="list-style-type: none"> • Focus of the paper not relevant to the review questions • Papers which did not specify whether the parents were first generation immigrants (e.g. referred only to ethnicity and not immigration, including terms such as “African-American” without further clarification) • Papers evaluating parent training programmes • Papers focusing solely on children whose disabilities were detected prenatally or at birth (e.g. Down’s Syndrome)³.

³ Studies with mixed samples were included (e.g. some disabilities detected at birth and others later in childhood). Unfortunately, separate analysis was rarely conducted, meaning in these papers it was not possible to determine differences between these groups.

These methods resulted in the identification of 15 papers. Of these, 2 presented a theoretical, conceptual framework and 13 were empirical research papers, relating to 9 distinct studies. Three studies had multiple papers relating to the same sample; as these papers each addressed distinct research questions, all were included in the present review. Of the empirical studies, 7 were conducted in the UK and 2 in the USA.

Scope

Whilst the intention had been to separately review papers relating to the experiences of South Asian and African parents, only one empirical paper conducted separate analysis for African immigrant families (Perepa, 2014). The main focus of the review is, therefore, on the experiences of South Asian families.

Four studies investigated ASD and five investigated intellectual/learning disabilities. Whilst it is acknowledged that these different conditions can involve distinct patterns of strength and weakness, descriptive information in the papers indicated many of the children with ASD also had intellectual/learning disabilities. The papers have, therefore, been discussed together, as it is likely the parents experienced similar challenges.

The two conceptual papers are first presented individually. The empirical literature is then discussed and evaluated with reference to the review questions and main themes to emerge from the findings. Details of the study methodologies

can be found in table 3. Methodological limitations, clinical implications and suggestions for future research are outlined.

Quality evaluation

All papers employed a qualitative design and are evaluated with reference to quality criteria presented by Elliott, Fisher and Rennie (1999; appendix 2). Elliott et al present a set of guidelines with seven points relevant to both qualitative and quantitative studies, and a further seven points especially pertinent to qualitative approaches. A table evaluating each paper with reference to these items is located in Appendix 3.

Literature review

Conceptual literature

Two conceptual papers were identified. Heer et al, (2012b) present an “experiential-contextual framework for understanding the experiences and needs of South Asian families in the UK caring for a child with a learning disability” (see figure 1). Welterlin and LaRue (2007) present a conceptual framework for considering the role of social, economic and cultural barriers in determining access to healthcare services among USA immigrant families with a child with ASD.

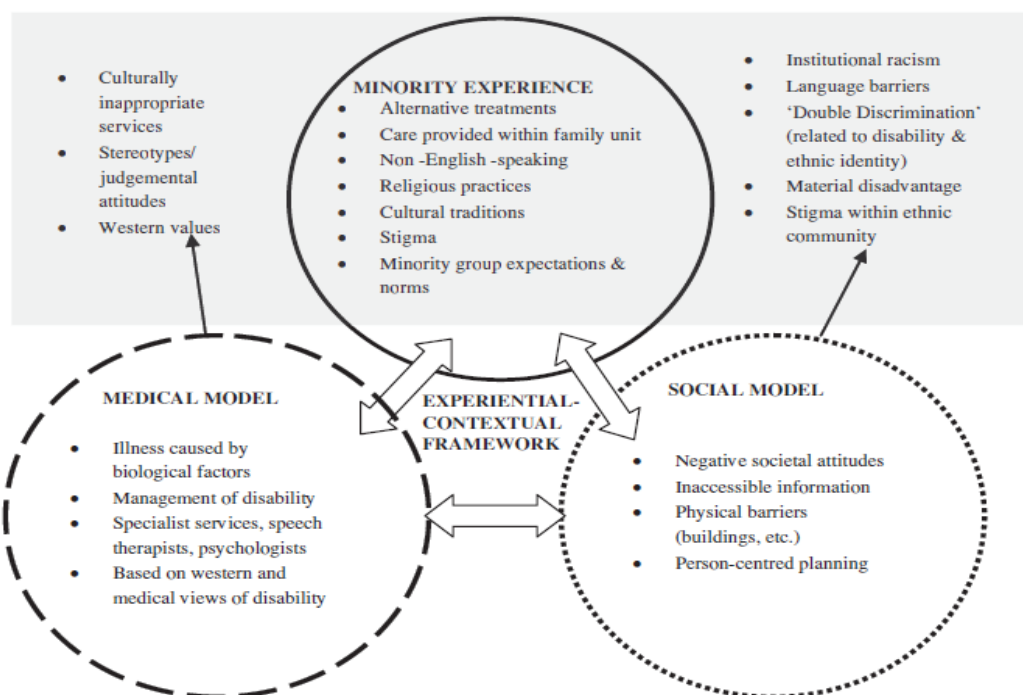


Figure 1. An experiential-contextual framework for understanding the experiences and needs of South Asian families caring for a child with a learning disability in the UK (Heer & Larkin, 2012).

Heer et al’s framework considers the relative influence of three conceptually distinct, although overlapping, models of disability: the medical

model, the social model and “minority experience”. The medical model, referred to above, considers biological factors as central to the development of disability. In this respect, disability is considered a universal concept. Advocates of the social model argue against the medicalisation of disability, particularly in reference to intellectual disability (Oliver, 1990; Goodley, 2001). They suggest instead that disability is a product of societies, their social norms and environment. Consequently, they argue environmental adaptations and changes to societal attitudes are needed in order to improve the lives of people considered to have a disability.

Heer et al (2012b) propose that aspects of both models impact upon the experiences of South Asian families in the UK caring for a child with a learning disability. They outline a number of social factors impacting on families’ experiences, including material disadvantage, employment, discrimination, language barriers and inaccessible information. They suggest that the social and medical models of disability fail to take into account the lived experiences of immigrant families, which are influenced by their “minority experience”. This includes factors such as culture and religion, social support networks, knowledge of services, aspects of the migration and acculturation process, discrimination and stigma. Heer et al suggest that a family’s cultural and religious background, and the people, practices and institutions of their minority community, shape their beliefs, values and assumptions regarding disability and difference. These resources are drawn upon by parents when making sense of their child’s development, shaping their treatment decisions and interactions with healthcare

systems, and may conflict with the host healthcare systems' attempts to support them.

Furthermore, the acculturation strategy a family adopts and the associated level of "acculturative stress" (Berry, 2005, p707), will determine the degree of conflict between their own views and those of the host society. Berry describes acculturation as the cultural and psychological change resulting from interactions between two cultures. Acculturation strategies are based upon two underlying dimensions: own cultural maintenance and integration with a new culture.

In summary, although the framework is presented in relation to South Asian families, its conceptual basis appears equally applicable to the needs and experiences of a diverse range of immigrant families caring for children with a disability.

Welterlin & LaRue (2007) consider the experiences of parents with a child with ASD, without focusing on a single cultural group. They argue that the challenges for these parents are intensified by the "psychological, social and economic costs of immigration" (p.748). The authors draw upon "ecocultural theory" (p749) to consider the meaning of an ASD diagnosis for immigrant families, and how this impacts upon treatment planning. The social and economic barriers outlined are similar to those discussed by Heer et al (2012b). However, Welterlin and LaRue expand the concept of cultural barriers, to include the views and perceptions of professionals, whose own culture may influence

their interactions with immigrant families, the diagnosis given and the treatments advised. Furthermore, they discuss the potential for conflicts in cultural values in greater detail. They provide the example of “normalisation”, a value underpinning many mainstream treatments for ASD in western societies, which aims to increase independence, ensure equal opportunities and maintain “quality of life” (p752). The authors argue that immigrant families may not share these values and goals. This conflict may prevent them from accessing services and adhering to treatment recommendations, and as a result they may turn to traditional approaches and meaning systems from their culture of origin. Linked to this, they discuss “cultural interpretations”, which influence perceptions and recognition of difference, attributions (i.e. whether the difference is viewed as positive or negative) and views of aetiology. Welterlin and LaRue helpfully include a list of recommendations for service providers and families, to improve the support provided to and accessed by immigrant families. This paper originates from the USA, where access to healthcare systems differs significantly from the National Health Service (NHS) model in the UK; therefore, aspects relating to interactions with services may be less relevant to UK practice. Additionally, immigrant demographics are likely to differ considerably to the UK, both in terms of migration patterns and socioeconomic status.

Collectively, these two conceptual papers contribute towards an understanding of the multi-faceted experiences of immigrant families caring for a child with ASD and are directly relevant to the review questions. Whilst the authors provide some empirical support for the conceptual frameworks they present, this research is not discussed or critiqued in detail. Additionally, further

relevant research has been conducted since these papers were published. The remainder of the review will discuss the 13 empirical papers thematically, with reference to the two review questions. For ease of synthesis, a discussion of the overall methodological limitations will follow in a separate section.

Table 3.

Table of studies.

<u>Study</u>	<u>Aim</u>	<u>Study design</u>	<u>Sample details</u>	<u>Recruitment method</u>	<u>Description of disability</u>	<u>Analysis method</u>	<u>Main findings</u>
Slade, G. (2014) UK	To explore the barriers faced by parents and carers of children with ASD from black, Asian minority ethnic (BAME) communities, when accessing services. To provide recommendations for commissioners and future policy.	Qualitative focus groups (structured discussion guide used)	130 participants 71 Asian (Indian, Pakistani, Bangladeshi, Chinese & Vietnamese) 56 black 2 white 1 Middle Eastern (Parents, siblings and carers) 106 female 24 male	Not stated – some through Black Asian Minority Ethnic (BAME) support groups.	ASD	Not stated	Themes and case studies provided. Some themes appear similar to experiences of White-British families; however participants appeared to face additional challenges linked to their BAME position. Themes: <ul style="list-style-type: none"> • Challenges getting a diagnosis • Awareness and understanding of ASD in people's communities (shame and blame) • The impact on families (denial, isolation, siblings, shame and blame within family) • Barriers to accessing support services (language & communication, accessing support) • Communication with professionals

Perepa, P. (2014) UK	To investigate parents' perceptions of ASD and the importance given to various social skills	Qualitative Semi-structured interviews (one-off)	63 parents Of which: 29 White-British 16 Afro-Caribbean 12 South Asian 6 Somali	Through ASD support groups	ASD	Thematic analysis	Evidence for cultural variations in interpretations of ASD and the importance attributed to different social skills, and which of these should be taught to children. White-British and South Asian parents were similar in terms of the behaviours they felt should be taught to their child (fitting with a social model of disability). South Asian and African parents were more likely to select eye contact as an important skill to teach, despite this conflicting with their cultural norms.
Raghavan, R., Pawson, N. & Small, N. (2013) UK	To explore family carers' views and experiences of transition from school to college or adult life, with special reference to ethnicity.	Qualitative interviews at two time points, a year apart (to observe any changes during transition)	43 parents Of which: 16 White-British 24 Pakistani 2 Bangladeshi 1 Black-African	Through day centres and transition services	Intellectual disabilities	Framework analysis	Some similar themes emerged across the White-British and south Asian groups. However, there did appear to be unique challenges facing the South Asian group in relation to language barriers, a lack of information about services and confusion about the transition process and the options available. Low levels of formal and informal support were reported by both groups; for the South Asian group this appeared linked to cultural values of duty and responsibility, and to experiences of stigma.

<p>Heer, K., Larkin, M., Burchess, I. & Rose, J. (2012) UK</p>	<p>To investigate the “cultural context of care-giving” for South Asian Sikh and Muslim parents of a child with an intellectual disability.</p>	<p>Qualitative Focus groups (one-off) 2 groups: 1 with Muslim parents, 1 with Sikh parents</p>	<p>9 parents (5 mothers, 4 fathers) Of which: 4 Indian (Sikh) 5 Pakistani (Muslim)</p>	<p>Through pre- existing NHS carer support groups</p>	<p>6 “Severe” Intellectual disability 3 intellectual disability</p>	<p>Interpretative Phenomenol ogical Analysis</p>	<p>Religion emerged as an important source of support and meaning. Expectations for the future differed between the two groups; with South Asian families appearing to have a different attitude to their child’s independence, which did not include them moving out of the family home.</p> <p>3 major themes: 1) Making sense of the disability All participants referred to theological beliefs, which varied in content between the Sikh and Muslim parents. The other sub themes were: a focus on “bad” behaviour, a problem with expression, struggling to get a diagnosis and medical negligence. 2) Feeling let down by services Muslim parents reported greater dissatisfaction with services and in particular their GPs. They described feeling blamed by services. Both groups reported negative interactions with “Asian” practitioners. 3) Looking to the future The Sikh parents expressed concerns about their child’s future. The Muslim parents felt services</p>
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Ravindran, N. & Myers, B. (2012) USA	To explore beliefs and practices regarding autism in Indian parents settled abroad	Qualitative Internet survey	24 parents All Indian 21 living in USA 2 in Canada 1 in Kuwait	Advertisements on online support websites	ASD	Content analysis – primary and secondary coder. Then ppts were classified into one of 3 categories	need to improve. Parents were categorised into three groups dependant on their beliefs about the causes of their child’s ASD and their chosen treatment approaches: Primarily Indian (4) Primarily Western (14) Combination (4) unable to classify (2)
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Croot, E., Grant, G., Mathers, N. & Cooper, C. (2012) UK	To explore the coping strategies used by Pakistani parents, and the factors influencing their choice or ability to use the different strategies identified.	Qualitative "in depth" interviews	12 participants from 9 families (8 mothers, 3 fathers, 1 grandfather) All Pakistani Four participants were interviewed more than once, with a total of 16 interviews	Recruited through: -clinicians and educational staff in 3 special schools for children with LD -a local parent support group -a child development centre -personal contacts of the interviewers	"Severe" Learning Disability	"Qualitative methods" (not specified)	The findings suggest use of the following coping strategies: <ul style="list-style-type: none"> • Sharing care with partner • Accepting support from extended family • Use of external support (e.g. school) • Taking a proactive approach • Reframing disability • Inner conviction (ability to care for child independently) • Recognition and enjoyment of care giving rewards • Maintaining interests outside the home
Croot, E. (2012) UK	To identify the factors that Pakistani parents felt were important components of their care.					"Qualitative methods" (not specified)	The findings indicate a number of factors Pakistani parents value in their interactions with professionals. <ul style="list-style-type: none"> • Feeling listened to and respected • Having control over their child's care • A relationship of trust and mutual respect • Honesty • Non-judgemental attitudes

<p>Croot, E., Grant, G., Cooper, C. & Mathers, N. (2008) UK</p>	<p>To provide a detailed account of the ways that Pakistani parents account for and understand their child's disability.</p>	<p>“Qualitative methods” (not specified)</p>	<ul style="list-style-type: none"> • from professionals • Professionals demonstrating genuine concern for their child's welfare • Relevant treatment goals <p>The author concludes by suggesting the care needs of Pakistani parents caring for a child with a learning disability are no different from those of White-British families. Furthermore, she states this provides evidence for the universality of care needs for families of children with learning disabilities.</p> <p>The results indicate parents drew upon a range of belief systems to understand the causes of their child's disability.</p> <ul style="list-style-type: none"> • All parents referred to theological beliefs (including child being a gift from God, a test from God, a punishment and a curse). These beliefs varied in nature both between participants and for individual participants at different points in the interview.
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- Parents appeared to hold a combination of beliefs simultaneously. In addition to theological beliefs, they also stated biomedical beliefs, beliefs they might be responsible due to their behaviour during pregnancy.
 - Parents appeared to use biological explanations for disability to discount the stigmatising beliefs held by others in their community.
 - All parents who referred to traditional Asian beliefs regarding disability were critical of these and spoke about the impact others' stigma had on them.

<p>Jegatheesan, B., Miller, P. & Fowler, S. (2010a) USA</p>	<p>To investigate how South Asian Muslim immigrant families make sense of having a child with autism, and their goals for their child's future.</p>	<p>Ethnographic Interviews with parents, supplemented by 17 months of participant-observation in homes and community (700 hours)</p>	<p>6 parents (3 couples) Of which: 3 Pakistani 3 Bangladeshi</p>	<p>2 through early intervention and special education teachers. 2 through snowball sampling (1 family did not complete the study)</p>	<p>ASD (with a learning disability)</p>	<p>Ethnography - thematic</p>	<p>The parents drew upon their Islamic beliefs to make sense of their child's difficulties, believing their son had been sent by Allah. This appeared to strengthen their resiliency and ability to cope. They described feeling upset by professionals' deficit-focussed views of their child. Their goals included for their son to be able to participate fully in social, linguistic and religious practices at home and in the community.</p>
		<p>Each mother interviewed at least 8 times (in informal settings), yielding at least 15 hours per mother.</p>					
		<p>Fathers - phone interviews minimum of 5 interviews per father, yielding at least 8 hours per father.</p>	<p>Same study as above</p>	<p>Same study as above</p>	<p>Same study as above</p>	<p>Same study as above</p>	<p>Narrative</p>

<p>Jegatheesan, B., Fowler, S., Miller, P. (2010b) USA</p>	<p>To develop an in-depth understanding of the experiences of three South Asian Muslim immigrant families who have a young child with autism. Specifically: the early period of their child's disability, their cultural conceptualisations of their child's disability and relationship with services.</p>						<p>The results are presented as a narrative for each family, under the theme of "identifying autism". The following sub themes are discussed:</p> <ul style="list-style-type: none"> • Recognising early signs • Seeking diagnosis • Reacting to diagnosis • Seeking information and formal support • Multilingual communication and family contact <p>The families descriptions of first noticing symptoms appear consistent with research involving western families; however they reported holding a belief that boys learn to speak later than girls. Families reported more positive interactions with traditional Asian professionals, who they felt were more compassionate and listened their concerns.</p>
<p>Bywaters, P. Ali, Z., Fazil, Q., Wallace, L. & Singh, G. (2003)</p>	<p>Part of a wider evaluation project of an advocacy service. The families' understanding of the causes of their child's impairment,</p>	<p>Qualitative Semi-structured interviews at 4 time-points -prior to support</p>	<p>19 families Same participants as study below, although one family did not continue</p>		<p>Thematic content analysis</p>	<p>A minority stated they drew upon religious beliefs to make sense of their child's disability. Parents described experiencing shame and stigma, and a range of barriers to accessing services.</p> <p>There was little evidence that</p>	

UK	feelings of shame, stigma and the influence of these on service uptake and expectations of their child's future were reported and role of religion.	-after 10 weeks of support -after 9 months of support -when support ceased.	Selected from referrals to an advocacy service (35 referrals, 20 families with greatest level of need selected)	"Severe" impairment	Not specified due to theoretical stance of research – likely to include both intellectual and physical disabilities	religious beliefs and associated attitudes, rather than institutional racism, had resulted in the low levels of service provision which the families experienced.
Fazil, Q., Bywaters, P., Ali, Z., Wallace, L., Singh, G. (2002)	To develop an understanding of the lives of ethnic minority families caring for a disabled child, the barriers they face in accessing services and the consequences for their wellbeing.	Mixed design Interviews: Semi structured questionnaire and 3 standardised outcome measures : for psychological wellbeing, social support and self-esteem.	39 participants from 20 families (20 mothers, 16 fathers 1 sister 2grandmothers) Of which: 15 Pakistani 5 Bangladeshi	Does not specify qualitative method.	Descriptive account of data from outcome measures.	The living circumstances of the families interviewed were characterised by disadvantage in terms of employment, socio-economic status and housing. Additionally, families had low levels of support from family members and professionals. Families described difficulties understanding and accessing services due to a range of factors (e.g. language barriers, uncertain who to contact), and reported a high level of unmet need. Severe depression scores among parents correlated with levels of satisfaction with social support. Mothers reported taking on the majority of caring responsibilities.

<p>Hatton, C., Akram, Y., Robertson, J., Shah, R. & Emerson, E. (2003)</p> <p>UK</p>	<p>Mixed design</p> <p>Phase 1: semi structured interviews to guide development of a structured interview measure.</p> <p>Phase 2: Structured interviews with 136 parents (to obtain quantitative data)</p> <p>Phase 3: Semi-structured interviews with 20 of the parents who took part in previous 2 phases to check analysis and gain</p>	<p>Phase 1: 26</p> <p>Phase 2: 136</p> <p>Phase 3: 20</p> <p>(Parents who took part in phase one were invited to participate in the other phases; 4 families declined as the child had died, 2 families had moved away)</p>	<p>Recruited through local authority services for children with learning disabilities: 9 special schools 1 assessment centre 1 community based service 1 independent support service for ethnic minority families 1 database of children receiving special education</p>	<p>“severe” intellect</p>	<p>Phase 1 & 3: IPA</p> <p>Phase 2: Structured outcome measures to describe the disclosure process</p>	<p>The findings indicate that under half of participants had been satisfied with the disclosure process for their child’s disability. The disclosure process appeared to impact upon parents’ long-term acceptance, support and wellbeing. They felt that a positive disclosure with adequate information, led to a better understanding of their child’s condition, allowing them to accept it. The factors participants felt were crucial to a positive disclosure are similar to those described by White-British families, with the exception of language. Whilst most participants said they would have preferred the disclosure to be conducted in their own first language, this happened for only 33% of families. Additionally, written information was often not provided, and when it was, this tended to be in English.</p>
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additional
information

Empirical literature

A basic thematic analysis of the 13 empirical papers was conducted in order to identify the main themes relating to the two review questions. Table 4 shows the themes identified.

Table 4.

Table of studies.

<u>Super-ordinate themes</u>	<u>Sub-themes</u>
Making sense of their child's difficulties and diagnosis	Religious beliefs
	Negotiating multiple beliefs
	Perceptions of their child's behaviour
Interactions with services	Beliefs held in the wider minority community
	Barriers to service access
	Interactions with professionals
	Feeling let down by services
	The journey to diagnosis

Making sense of their child's difficulties and diagnosis. Six studies investigated parents' beliefs about the causes of their child's difficulties (Slade, 2014; Raghavan et al, 2013; Bywaters et al, 2003; Croot et al, 2008; Heer et al, 2012; Ravindran & Myers, 2012; Jegatheesan et al, 2010a, 2010b). Overall the studies showed considerable diversity in beliefs and many parents appeared to hold a combination of biomedical and traditional/religious beliefs. Some parents described changing their beliefs over time, as they gained insight into biomedical explanations for disability (Croot et al, 2008). The studies found that a lack of

prior knowledge about child developmental disorders meant parents often felt uncertain about the causes of their child's condition (Slade, 2014; Croot et al, 2008). It appeared this confusion was, in part, due to language barriers. Some mothers reported believing that their husbands, who translated for them, had not passed on all relevant information, leaving them feeling confused (Bywaters et al, 2003). Furthermore, parents discussed stigmatising beliefs held by others in their communities, including that disability might be contagious and that the parents were to blame.

Religious beliefs. Croot et al (2008) interviewed 11 Pakistani Muslim parents and 1 grandfather of children with a "severe learning disability", using thematic analysis to identify themes. They found all parents referred to theological explanations. They described a range of beliefs including the child being a blessing or gift from God, which may bring future rewards, a test of their parenting abilities, or a punishment for past wrongdoings. Two parents believed they had been specifically chosen by God to parent their child, which provided meaning to their situation and helped them to cope. In contrast, Bywaters et al (2003), who interviewed 39 family members (mostly parents) of children with "severe impairments", from Pakistan and Bangladesh, found only "a minority" drew on theological explanations (p505). This appeared to be in the absence of a medical explanation. The authors acknowledge that interviews took place at a time when racial tensions towards Muslim families were high, meaning families may have felt reluctant to discuss their religious beliefs for fear of judgement.

An ethnographic study was conducted with three South Asian Muslim families with a child with ASD in the USA (Jegatheesan, Miler & Fowler, 2010a; Jegatheesan, Fowler and Miller, 2010b). The findings indicate parents made sense of their child's ASD primarily in religious terms. They described believing they had been "*chosen by Allah to raise His special child*" (p101), due to personal qualities such as strength, resiliency, patience and loyalty. They believed that caring for their child was a "*test*" and they must protect them, in order to prove themselves to God. The parents referred to Islamic teaching regarding human diversity, which shaped their positive views of their child. Two of the families referred to beliefs about fate and destiny, which had helped them to accept their child's difference. One family believed the mother had been chosen due to her relationship with her son in a previous life. The ethnographic methodology of this study is likely to have allowed the researcher to develop a more detailed and nuanced understanding of the families' experiences, compared with one-off interviews. Similar themes were reported by the 24 Pakistani families interviewed by Raghavan et al (2013) about their child's post school transition.

Religion appears to be an important source of meaning for the parents in these four studies. However, they all investigate the experiences of Pakistani and/or Bangladeshi Muslim families. Heer et al (2012) was the only study to compare and contrast the views of Indian Sikh and Pakistani Muslim parents. Parents (n=9) were recruited through existing support groups to take part in semi-structured focus groups, which were analysed using Interpretative Phenomenological Analysis (IPA). IPA (Smith, Flowers & Larkin, 2009) is an interpretive analytic method, which focuses on participants' attempts to make

sense of the world, and the researcher's interpretations of this. The findings suggest subtle differences in the content of these theological beliefs. Muslim parents viewed their child's disability as a *"test from God"*, similarly to those in studies cited above. Whilst Sikh parents also attributed their child's disability to God, they appeared less clear of the reasons for this, saying, *"it is up to God why he did this"* (p183). Unlike the Muslim families, who described feeling happy with their *"fate"*, Sikh parents said they *"pray to God that this type of thing doesn't happen to anyone"* (p183). Religious explanations were only voiced by the mothers in the study, which the authors suggest may indicate a gender difference in the use of religion as a resource for making sense of parenting a child with a disability. Given the small sample size, and particularly low number of fathers (n=4), further research is required to explore this potential finding and further investigate differences in meaning systems across religions.

Negotiating multiple beliefs. Croot et al (2008) found that although all parents cited theological explanations, they appeared to hold additional explanations simultaneously, including biomedical (oxygen starvation at birth, brain abnormalities) and individual responsibility (mothers blamed themselves for their behaviour during pregnancy). It appears parents drew upon theological beliefs in the first instance, but resorted to biomedical explanations when faced with stigma and negative attitudes. Some traditional beliefs, however, appeared incompatible with a biomedical understanding, leading the parents to discount these (e.g. *"curses"* and advice from *"herbalists"*; p610). Individual parents appeared to vary within the space of their interview as to which beliefs they endorsed.

Bywaters et al (2003) suggest parents tended to hold one framework of meaning, rather than integrating beliefs, and rejected theological/cultural beliefs in favour of a medical understanding. They provide examples of parents' attempts to integrate beliefs: "*We had blood tests done during pregnancy and they were negative. It is from God*" (p506). Other explanations included illness during pregnancy, child's illness during early life, medication side-effects, consanguineous marriages (between blood-relations) and doctors' failure to diagnose the condition earlier. Croot proposes that the contrasting findings between these two studies may link to the migratory patterns of the families, who were from different regions of Pakistan. Furthermore, the two theoretical papers (Heer et al, 2012b; Welterlin & LaRue, 2007) suggest acculturation is likely to influence the meaning frameworks drawn upon. Parents interviewed by Croot et al (2008) were all in marriages in which one parent was a first generation immigrant and the other was born in the UK to Pakistani parents. This is likely to have shaped the shared belief systems families developed.

Heer et al (2012a) found parents held beliefs about "medical negligence". This included that their children's difficulties had been caused by factors such as high doses of medication and oxygen starvation at birth, and fits with Croot et al's findings. One father described feeling "*70 percent sure*" that his sons' difficulties were caused by "*suspicious activity*" by a service provider (p184). This allowed him to make sense of having two sons without difficulties, both born in Pakistan, and two sons with difficulties born in the UK. Although some parents acknowledged being in a consanguineous marriage, in contrast to Bywaters et

al's (2003) findings, they did not feel this was the reason for their child's difficulties. Heer et al (2012a) did not discuss parents' attempts to integrate beliefs; the processes used by individuals were perhaps difficult to identify in a focus group setting.

Ravindran and Myers (2012) used an alternative qualitative methodology of internet questionnaire, consisting of semi-structured, open-ended questions and Likert rating scales. Twenty-four Indian Hindu parents of children with autism participated, most of whom lived in the USA. Taking into account their overall responses, parents were placed into one of three categories describing their beliefs about their child's difficulties: primarily Western (n=4, 17%), primarily Indian (n=4, 17%) and mixed (n=14, 58%). Six parents felt "*vaccine injury*" was to blame. This belief, although controversial and disproven, is held by some parents in Western societies, and is specific to ASD (Gerber & Offit, 2009). Nine participants (38%) believed a combination of genetic and environmental factors had caused their child's difficulties; again, this is in keeping with western medical views of ASD. Seven parents said they did not know how to explain the causes of their child's difficulties, and a further two cited solely genetic causes and food allergies. When asked to rate their agreement with various explanations on a Likert scale, parents agreed more strongly with western explanations. Whilst half of the participants endorsed traditional Indian beliefs ("*Karma*", "*destiny/fate*" and "*parental mistakes in present/past life*"; p47) when these were presented, very few parents recorded these beliefs in their responses to the earlier, open-ended questions. This suggests parents may not volunteer such information unless asked directly, which has obvious implications for

clinical practice and research. Although over half of parents in this study appeared to hold a combination of traditional and western beliefs, the questionnaire methodology limited the responses provided, meaning the manner in which these beliefs were integrated could not be established. A strength of the methodology is that it overcomes some limitations of previous studies, namely interviewer bias, social desirability of responses and low participant numbers. Parents could take part anonymously, at their own convenience. Heer et al, (2012a) stated recruitment difficulties due to concerns about confidentiality; Ravindran and Myers' methodology may have, therefore, increased participation. However, it did not allow for in-depth responses, further questioning, or clarification. Furthermore, the recruitment method of English language advertisements on online support forums resulted in a biased sample of high-earning, professional parents.

Perceptions of their child's behaviour. One study specifically investigated the meaning parents attached to their child's behaviours, rather than the disability as a whole. Perepa (2014) aimed to investigate and compare perceptions of behaviours characteristic of ASD among White-British (n=29), "Afro-Caribbean" (n=16), South Asian (n=12) and Somali (n=6) parents. An episodic interview approach was employed, in which parents were asked to provide narrative accounts of specific situations involving their child, and their interpretations of these. The results indicate cultural variations in interpretations of ASD and the importance attributed to various social skills. South Asian and White-British families appeared generally similar, placing most importance upon following rules and respecting personal space. Afro-Caribbean

and Somali families placed greatest importance on giving eye contact. All three immigrant groups rated “facial expressions” higher than the White-British families did. Perepa infers differences in the models of disability drawn upon by parents when deciding which skills to teach to their child. Parents from the three immigrant groups stated they would teach their children eye contact, even though this conflicted with their own cultural norms, due to this being a common deficit of ASD. Perepa suggests this fits with a “deficit model” of disability. The White-British parents were more likely to draw upon the social model (e.g. saying society should make allowances for their child’s behaviours). However, Perepa infers this may link to a perceived pressure for their children to fit British cultural norms, rather than a cultural difference in perceptions of disability.

Heer et al (2012) found that both Sikh and Muslim parents believed their children’s disabilities related to a difficulty with expressive, rather than receptive, communication. Whilst this may have been true for some children, many were likely to have had difficulties with both forms of communication. The authors suggest this manner of viewing their children’s difficulties may have provided parents with “relief and hopes for improvement in the future, thus allowing easier adjustment and less stress” (p.187).

Beliefs held by the wider minority community. The majority of studies suggest parents experienced high levels of stigma and blame from the wider South Asian community, which linked to cultural beliefs (Slade, 2014; Raghavan, Pawson & Small, 2013; Heer, 2012; Croot et al, date; Bywaters et al, 2003; Jegatheesan et al, 2010a, 2010b). Some mothers in the Slade (2014) study

described experiencing blame from their husbands, who accused them of having had an affair for which their child was a punishment. Additionally, they perceived that their child's disability reflected badly upon their extended family. This appeared to lead to social isolation, as parents kept their children hidden. Many parents in the Bywaters et al (2003) study reported that they avoided socialising and going out in public. Although some parents of physically disabled children cited practical reasons (e.g. transport difficulties), the authors felt negative community and family attitudes were equally to blame. Parents described experiencing judgements from others, including "*disgust*", "*nasty comments*" and their child being viewed as "*an outcast*" (p506).

Croot et al (2018) found parents avoided attending community events (e.g. weddings and funerals) due to negative reactions towards their child. Parents described feeling judged and blamed by their wider families. Jegatheesan et al (2010a, 2010b) found parents experienced a range of negative reactions from wider family, which tended to blame the mothers for causing the child's difficulties (e.g. behaviour during pregnancy and lack of adherence to religious practices).

Interactions with services. Seven studies investigated parents' views and experiences of services (Slade, 2014; Raghavan et al, 2013; Heer, 2012; Croot, 2012; Fazil et al, 2002; Bywaters et al, 2003; Hatton et al, 2003). The findings suggest parents were generally dissatisfied with services and many would have preferred a higher level of service support. Overall, parents described a range of perceived barriers to accessing services, and reported a

high level of unmet need. Fazil et al (2002) found low satisfaction with formal and informal support was associated with severe depression scores for parents.

Barriers to service access. All studies suggest, perhaps unsurprisingly, that parents who spoke English had a greater awareness of local services and professionals, and reported feeling clearer about their child's condition and the treatment options available. A reliance on informal interpreters (e.g. family members) led mothers in particular to feel alienated from services. Raghavan et al (2013) found that even when formal interpreters were used, some medical terms were difficult to translate. This sometimes led to the use of words with negative connotations (e.g. "disease"), which had not been intended by professionals. Hatton et al (1998) and Slade (2014) found that even when parents did speak English, they felt uncomfortable communicating with and expressing themselves to professionals, who often used medical language with which they were unfamiliar. Only 30% of the families in Hatton et al's study reported having received written information about their child's condition, the majority of which was in English. Whilst this study was conducted quite some time ago, Slade (2014) suggests families continue to have similar experiences.

Families described difficulties understanding the role of different services and professionals. Many described feeling uncertain regarding who to contact for different issues, and had been directed between services without receiving support (Slade, 2014). Of the 36 parents interviewed by Bywaters et al (2003), only 1 had been in contact with a social worker, and 13 with the child's schoolteacher, in the previous 6 months. Parents in this study described feeling

“scared” of visiting their child’s school and the majority did not attend scheduled meetings.

Findings regarding the role of religious beliefs in influencing service uptake are mixed. Jegatheesan et al (2010b) and Raghavan et al (2013) both found parents expressed a reluctance to accept support, due to concerns about the impact this may have on their religious practices. For example, parents appeared reluctant for their children to attend day centres due to concerns about the food provided and the potential their child may be “*led astray*” by their peers (Raghavan et al, 2013, p941). Bywaters et al (2003), on the other hand, specifically state they found no evidence for a link between low service uptake and religious beliefs, which was one of the stated aims of their study.

Interactions with professionals. The findings suggest some instances of positive interactions with professionals, but generally many parents felt dissatisfied. Slade (2014) found that parents reported lacking in confidence and self-esteem when meeting professionals. He infers this may be related to prior experiences of discrimination, difficulties expressing themselves in English and cultural values concerning authority figures. One parent said, “*White families meet white professionals and seem to be on professional terms. We were made to feel like outsiders*” (p18). Parents in other studies also felt professionals held discriminatory cultural stereotypes (Heer et al, 2012; Bywaters, 2003).

All parents in the Jegatheesan et al study initially sought support from “native-language physicians”, with whom they built up trust and felt able to

speaking openly with about a range of cultural issues. In contrast, they described mainstream, non-Asian practitioners as *“straight forward and time conscious”* (p804), which further contributed to their distress. As a result, they often opted to visit Asian doctors instead, even when they felt these doctors had less understanding of autism. This study was conducted in the USA, where parents may have more choice over which clinicians they see.

In contrast, a number of parents in the UK studies reported difficult interactions with Asian/ethnic minority professionals (Slade, 2015; Heer et al, 2012a; Hatton et al, 1998). Parents in the Heer et al study expressed a preference for *“white”* professionals, whom they perceived as being more helpful and *“better than our people”* (p185). The authors suggest this distrust of Asian professionals may stem from the stigma experienced from the Asian community. Slade (2014) suggests parents felt professionals from a similar ethnic background judged them based on their own cultural experience, rather than taking time to explore the family’s individual situation. Alternatively, others felt a more ethnically diverse workforce would be beneficial, and felt negatively judged by British professionals. A small number of parents in the Fazil et al (2002) study also stated they would rather have contact with an Asian professional.

Jegatheesan et al (2010b) found parents felt their views of their child conflicted with those of with medical professionals, who tended to emphasise their child’s deficits, rather than strengths. One mother said, *“they are talking about a child... I am his mother. I feel a lot of pain inside”* (p805). This appeared particularly offensive in light of their belief that their child was a gift from God.

Croot (2012) published a separate paper regarding the care needs of the families in her original study (Croot et al, 2008). The paper concludes by stating the findings indicate the needs of Pakistani parents caring for a child with a disability are no different to those of mainstream families, suggesting care needs of parents of children with disabilities are “universal”. This appears contradictory to the findings of the other two linked papers and is a somewhat general claim, considering the findings discussed above.

Feeling let down by services. Heer et al (2012) described the theme of families feeling let down by services. All parents in the Muslim group described feeling anger and frustration towards their GPs, who they felt were unresponsive to their child’s needs. This theme related both to the diagnostic process (or lack thereof) and the recommendations for supporting their children, which they felt were mismatched to their needs (e.g. medication as a “*quick fix*”, p185). Parents also described feeling blamed, particularly in relation to the issue of consanguineous marriages, which they felt was a way for professionals to “*side track the issue*” (p.185). Parents also described feeling blamed for contributing to their child’s health problems (e.g. obesity) through poor diet. Parents described feelings of helplessness and beliefs that services needed to change in order to effectively meet their children’s needs.

Slade (2014) found parents felt let down by their child’s schools for not identifying their behaviours as signs of ASD, instead labelling them as badly behaved. Some parents felt this was linked to negative racial stereotypes.

Diagnosis. The earliest of the identified studies (Hatton et al, 1998) conducted semi-structured interviews with 26 South Asian parents, followed by structured interviews with a further 110, to specifically investigate their experiences and views of the disclosure/diagnosis process. Under half of families reported satisfaction with the process, which appeared predominantly related to language barriers. They found that the manner in which the disclosure was delivered impacted upon parents' long-term acceptance of their child's condition, level of support they accessed and their family wellbeing. Parents who felt confused and uncertain about their child's condition understandably found it difficult to accept it and move on with supporting their child. Whilst the results provide important information regarding families' experiences of disclosure, the sample included parents of children with a wide range of disabilities, who had received the disclosure at different stages. A small number were told prenatally, the majority found out in the first four year of their child's life, and others as late as age 12. Experiences are likely to be significantly different depending on the child's age and condition.

The three sets of parents in the Jegatheesan (2010a,b) study described a "*long and traumatic*" journey to diagnosis, which took between 6 and 24 months (804). Heer et al (2012a) found parents felt that GPs were quick to minimise their concerns about their children's development, offering reassurance they would catch-up as they grew older. One parent described feeling "*distressed and furious*" that their child could have received an earlier diagnosis, which may have allowed for earlier treatment and a better outcome (p184). Parents who received an early diagnosis often did so after a crisis. Overall, parents appeared to have

experienced uncertainty and helplessness regarding their child's diagnosis and its meaning. The paper describes that, in the absence of a clear diagnosis, parents appeared to draw on alternative explanations, such as medical negligence.

Methodological limitations

In order to consider the findings of the 13 studies, it is important to evaluate their methodological strengths and limitations. See appendices 2 and 3 for an overview of the studies with reference to Elliott et al's (1999) guidelines. All but one study met the first seven points. The three papers by Croot, which pertain to the same study, are limited due to a lack of transparency regarding the analytic process. The papers state only that "qualitative methods" were used, without providing detail of these. In the Croot et al (2012) paper, it is difficult for the reader to assess validity as many of the themes do not appear adequately grounded in the quotes provided and the conclusions appear overly generalised. The majority of papers provide adequate quotations, which are clearly linked to the points made.

The remainder of this section will focus on part b of Elliott et al's guidelines. On the whole, the papers were of an acceptable quality, with some appearing of very good quality (e.g. Ravindran & Myers, 2012b; Jegatheesan et al, 2010a, 2010b). Slade (2014) was a report published by a third sector organisation. It lacks many important elements, such as a detailed description of the analysis and sample; however, these would not be expected in a publication of its type. Most studies provide sufficient detail to situate the sample. However, greater detail regarding children's disabilities and parents' time in the UK would allow a more nuanced understanding of the specific impact of these factors. Generally, the papers appear limited in two main areas: owning one's perspective and providing credibility checks. These are important elements to ensure reflexivity and transparency. Yardley (2000) suggests that reflexivity is

an important component of qualitative research, ensuring researchers are mindful of the influence of their own motivations, preconceptions, experiences and external pressures on the research process. For example, it appears from the languages spoken that many researchers were of a similar cultural background to the participants (e.g. Heer et al, 2012a). Reflection on the potential impact of this on the findings, and a description of the steps taken to ensure reflexivity, would be important to reduce bias, particularly where there is a lack of transparency regarding the method and analysis. Furthermore, Bywaters et al (2003) discuss their aim to investigate perceived cultural stereotypes towards Pakistani families, without outlining their own position in relation to these. Considering their findings differ to some of the other studies, an understanding of how they reflected upon their own positions would have been a valuable addition. These omissions may stem from the constraints of writing up for a journal; however, they do limit the quality of the papers, as the validity of findings cannot be established. Jegatheesan et al (2010a,2010b) were the only authors to reflect upon the researcher's position.

A strength of some papers is the involvement of a steering group including individuals with a range of diverse perspectives relevant to the research (Croot, 2012; Croot et al, 2012; 2008; Bywaters et al, 2003; Fazil et al, 2002). Discussion of how this group influenced the research process would have been beneficial.

Discussion

The present review aimed to investigate the experiences of South Asian and African immigrant parents of a child with an intellectual and/or developmental disability. A basic thematic analysis of the 13 studies identified 8 sub-themes relevant to these review questions. Given only three studies included African parents, only one of which conducted separate analysis for this group (Perepa, 2013), the main focus of the review was on South Asian families. The papers relate to children with intellectual/learning disabilities, and those with ASD. However, many studies were not specific about the children's disabilities, and included a wide range. The themes will now be discussed with reference to the two conceptual models (Heer et al, 2012b; Welterlin & LaRue, 2007) and the clinical implications.

Beliefs about the causes of disability

The findings suggest families draw upon complex systems of meaning when making sense of their child's disability. Religious beliefs appear to be highly influential for many South Asian families. However, western, medical beliefs are also drawn upon, particularly in response to negative attitudes and stigma from within families' minority communities. The diversity in beliefs across and within these studies is likely to relate to a number of factors, including individual differences, levels of acculturation and the heterogeneity of the South Asian sub-continent, within which there are numerous cultural groups, religions, languages and migration histories. The findings suggest clinicians should neither assume the beliefs of these families are similar or different to those of Western families, or other South Asian families. These findings provide

support for Heer et al's (2012b) model, which indicates parents' belief systems are likely to stem from a number of interlinking factors (e.g. culture, religion, education, views of their minority community and the acculturation process), and will be unique to each individual family. Furthermore, unless asked directly, parents may not share aspects of their cultural background relating to the care of their child. Professionals must therefore foster open conversations regarding families' belief systems, cultural and religious background, and their minority experience.

Interactions with services

Parents appeared generally dissatisfied with services and reported a high level of unmet need. Heer et al (2012b) and Welterlin and LaRue (2007) suggest social factors limit families when accessing services. The review findings support this, suggesting language barriers, a lack of knowledge regarding services, conflicting values, perceived discrimination and stereotypes by professionals, and low confidence when dealing with professionals, were all influential.

Most studies cited language barriers and informal translation arrangements (e.g. family members) as contributing towards parents' uncertainty about their child's difficulties. As is outlined in the Equality Act (2010), parents should be provided with accessible information and interpreter arrangements during all contacts with healthcare systems. This is particularly important when complex and sensitive information is being explained, such as a diagnosis or treatment options. Slade (2014) provides a number of useful successful examples of trained interpreters and advocates in practice.

Parents described feeling upset by professionals' deficit-focused descriptions of their children, which, for some, conflicted with their religious beliefs about their child. This finding supports the two conceptual models. Professionals must be sensitive to this when meeting with parents from ethnic minority and immigrant groups, whose cultural background may mean they are less familiar with the medical model of disability and deficit.

Parents described negative interactions with professionals, in which they felt blamed, judged and discriminated against. It is important for services to develop cultural competence in order to work with families in a sensitive and curious manner, supporting them to feel listened to, valued and respected. Mixed experiences were reported with regards to interactions with professionals from families' own cultural backgrounds. It should, therefore, not be assumed that a more diverse workforce would improve service uptake for immigrant families. Instead, a focus on raising awareness of disability within ethnic minority communities, and supporting families to access services with the aid of advocates may be more effective.

Research Gaps

The findings suggest parents draw upon religious beliefs to provide meaning to their experiences. It appears individual religions may provide subtly different frameworks of meaning. Given the majority of previous studies have involved Muslim parents, further research involving parents of other religions would be beneficial in order to investigate this further.

Whilst the review aimed to examine the experiences of parents of children whose developmental disabilities manifested during childhood, in reality many studies also included disabilities detected prenatally or at birth, such as Spina Bifida. Family impact is likely to vary considerably depending on the nature and course of the child's difficulties, perhaps leading parents to draw upon different systems of meaning. Further research focusing specifically on developmental disorders such as ASD, would allow exploration of the unique impact of these.

Additionally, many of the papers made no distinction between first and second-generation immigrants. Given the likely role of acculturation in influencing the meaning systems families draw upon (Heer et al, 2012b), further research focussing specifically on first generation immigrant families may allow the processes involved in this to be investigated, along with the potential impact of having a child with an intellectual and/or developmental disability on acculturation. Further research exploring the ways families integrate conflicting belief systems would be important in understanding their experiences.

Perhaps the most striking gap in the research to date is an absence of exploration of the experiences of African families. This is likely to be due to a change in immigration patterns, with South Asian families previously being more prominent in the UK demographic. However, the 2011 England and Wales census indicates immigration from Africa is increasing (ONS, 2011). Currently, clinicians have very limited empirical or theoretical literature to draw upon when supporting such families. Whilst Slade (2014) included a significant proportion of African families in his study, no separate analysis was run for this group, meaning the lived experiences of African parents could not be determined. Research involving this group is, therefore, clearly an important priority. Given the lack of prior research, individual interviews using IPA would be an appropriate method for investigating African parents' lived experiences.

Conclusion

The review has summarised literature relating to the experiences of South Asian and African immigrant parents of a child with an intellectual and/or developmental disability. Previous literature and theory had indicated the existence of cross-cultural differences in models of child development and disability. Understanding the experiences of this group is clearly important in order for services to provide appropriate care to meet their needs. The review indicates that South Asian parents drew upon a combination of religious, traditional/ cultural and biomedical beliefs when making sense of their child's disability. Additionally, experiences of stigma and blame appeared to stem from cultural beliefs held within the minority community. Generally negative experiences of services were reported, and parents described a range of barriers, including language, a limited knowledge of services and negative encounters with professionals. Suggestions for future research are presented, including a clear need for the experiences of African parents to be individually explored.

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Section B

The experiences of African immigrant mothers living in the UK with a child
diagnosed with Autism Spectrum Disorder (ASD): An Interpretative
Phenomenological Analysis

Word Count: 8,000 (40)

(excluding abstract, references, tables and figures)

For submission to Disability and Society

Abstract

The present study used Interpretative Phenomenological Analysis to investigate the experiences of African immigrant mothers living in the UK with a child diagnosed with an Autism Spectrum Disorder (ASD). Six mothers took part in one off semi-structured interviews. The results indicated five themes: caring for a child we didn't expect, the pain of stigma and rejection, making sense of our child's difficulties and diagnosis, negotiating conflicting belief systems and faith as "key". Many aspects of the mothers' experiences appear related to their position as immigrants from cultures with very different belief systems regarding child development and disability. Stigma, blame and social isolation appeared to compound the difficulties they experienced. Conflicts between African cultural beliefs and a western, medical understanding of ASD, appeared to create a feeling of cognitive dissonance for the mothers. The strategies they used to negotiate this appear to map onto Berry's (2005) acculturation strategies, suggesting the experience of having a child with ASD impacts upon the acculturation process. Implications for clinical practice and policy are discussed, including the importance of raising awareness of ASD among immigrant communities, supporting parents to integrate conflicting belief systems and facilitating the development of peer-support groups within minority communities.

Key words: Autism Spectrum Disorders, Immigrant families, Mothers, Culture,

Acculturation

Introduction

The majority of research pertaining to Autism Spectrum Disorders (ASDs) has been conducted in western countries, involving predominantly western participants (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). However, models of disability and child development vary cross-culturally (Skinner & Weisner, 2007). Therefore, the experiences of immigrant parents living in the United Kingdom (UK) with a child diagnosed with ASD, may vary significantly from the experiences of British families. To date, limited research has been conducted in this area. The present study uses a qualitative methodology to investigate the experiences of African immigrant mothers in the UK. Specifically, it aims to investigate their experiences of caring for their child and how they make sense of their difficulties and diagnosis.

Autistic Spectrum Disorders

ASDs are classified as "Pervasive Developmental Disorders" (PDD) in the International Classification of Diseases-10th-Edition (World Health Organisation, 1994) and the Diagnostic and Statistical Manual of Mental Disorders-5th Edition (American Psychiatric Association, 2013). They are considered present at birth, to manifest during childhood and to persist throughout the lifespan. ASD refers to a spectrum of conditions characterised by deficits in three main areas: social communication (affecting receptive and expressive language), social interaction (difficulties initiating and maintaining reciprocal interactions) and social imagination/flexibility of thought (restricted, repetitive patterns of activities and interests) (Carr, 2006; Volkmar, Lord, Bailey, Schultz & Kiln, 2004; Wing, 1981). Estimates suggest at least 50% of people with ASD have a recognised intellectual

impairment⁴ (Charman et al, 2011). Research suggests parents of children with ASD experience increased stress and emotional difficulties, compared to other developmental disorders (e.g. Hayes & Watson, 2013).

In the UK, a childhood ASD diagnosis is made using a combination of observation, parental report and clinical judgement. Whilst genetic factors are believed to contribute to the development of ASD, to date there is no agreed-upon aetiology (Chaste & Leboyer, 2012). Furthermore, it has been suggested that, rather than representing a discrete disorder, a diagnosis of ASD marks the extreme on a continuum of “autistic traits” distributed throughout the general population (Baron-Cohen et al, 2009, p500).

Prevalence

Estimates suggest the prevalence of PDD/ASD in western countries such as the UK and USA has increased considerably over recent decades (e.g. Fombonne, 2009). It is unclear whether this represents a true increase, or a combination of greater awareness and widened diagnostic criteria. The current estimated UK prevalence rate is approximately 1% (Baird et al, 2006; Baron-Cohen et al, 2009). Whilst presentations fitting the ASD phenotype are likely to exist worldwide, diagnostic rates differ considerably between countries (e.g. Kim, 2012) and between different ethnic groups within the UK (Lindsay, Dockrell, Law & Roulstone, 2012). These disparities are likely to reflect differences in methodology and a lack of evidence (Elsabbagh et al, 2012), in addition to cultural differences in models of child development and disability.

⁴ Indicated by an IQ level of below 70

Daley (2004), for example, found that Indian parents noticed developmental differences indicative of ASD 6-12 months later than US parents.

Cultural considerations

Culture refers to a group of people's collective beliefs, goals and attitudes, which shape their view of themselves, others and the world (Matsumoto, 2001). Literature suggests culture influences families on multiple levels when caring for a child with a developmental disability; from noticing and making sense of differences, to selecting treatment approaches, interactions with healthcare systems and future expectations (Ennis-Cole, Durodoye & Harris, 2013; Ravindran & Myers, 2012a; Norbury & Sparks, 2013; Mandel & Novak, 2005).

Research investigating cross-cultural perceptions of ASD tends to emanate from the USA, focussing on cultural groups less prominent in the UK demographic (e.g. Dyches et al, 2004), or involves families who remain living in their country of origin (e.g Daley, 2002). Such research is of limited application to immigrant families in the UK, whose experiences will differ from those of British families, and from their cultural counterparts who have not migrated. Heer, Rose and Larkin (2012b) argue that an understanding of "minority experience" (p951) can highlight the distinct needs and experiences of immigrant families. A family's cultural and religious background, and the people, practices and institutions of their minority community, shape the way they make sense of their child's difficulties and diagnosis, which may conflict with the dominant medical model of the host healthcare systems' attempts to support them. They argue factors influencing "minority experience" include: language,

material disadvantage, discrimination, social support, minority group pressures, stigma, and aspects of the migration and acculturation process.

Berry (2005) described acculturation as cultural and psychological change resulting from interactions between two cultures. Berry presents eight acculturation strategies, based upon two underlying dimensions: own cultural maintenance and integration with a new culture (see Figure 1). These strategies are likely to influence the extent to which individuals draw upon their cultural belief systems when making sense of their child's development. Berry suggests significant life events and interactions with majority culture systems influence levels of "cultural conflict" and "acculturative stress" (p707). Therefore, having a child with ASD, and the resulting contact with services, may influence the manner in which an immigrant family acculturates.

Whilst Heer et al's (2012b) model was developed in relation to intellectual disability, it is likely that immigrant families of children with ASD face a similar "minority experience". Two US studies investigated how South Asian immigrant parents made sense of their child's ASD diagnosis (Ravindran and Myers, 2012b; Jegatheesan, Miler & Fowler, 2010; Jegatheesan, Fowler & Miller, 2010). The findings suggest parents drew on a combination of bio-medical, traditional-Asian and religious beliefs. Welterlin and LaRue (2007) argue immigrant families may not share the values underpinning western treatment approaches, which focus on promoting independence and ensuring equal opportunities, with the aim of meeting "specific standards of social and academic functioning" (p.754).

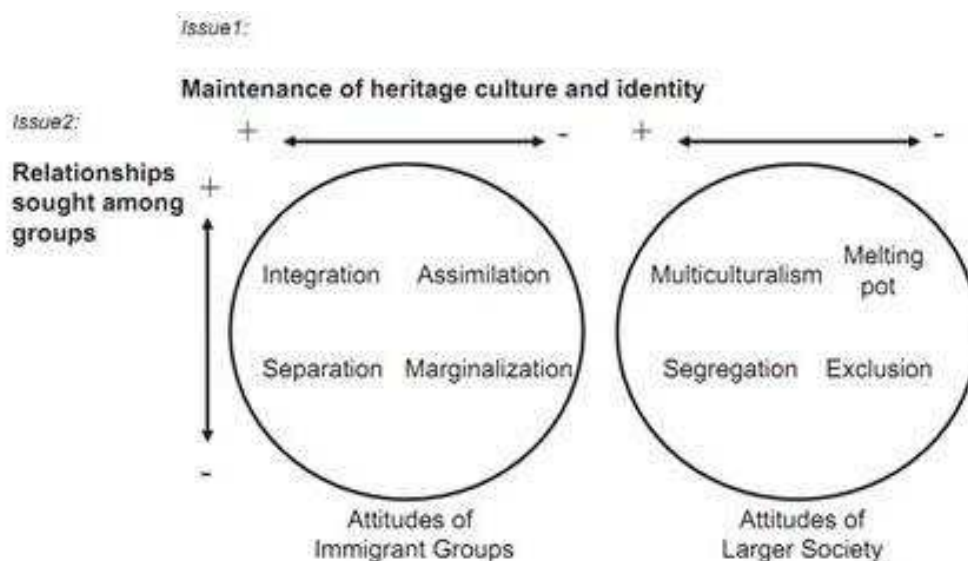


Figure 1. Acculturation strategies (Berry, 2005).

Extant research

To date two UK studies have investigated experiences of immigrant parents of a child with ASD. Perepa (2014) conducted interviews with African, South Asian and White-British parents. The findings indicate cultural variations in interpretations of ASD and the importance attributed to various social skills. Somali parents, who were the most recent immigrants, appeared to feel under pressure for their children to fit British cultural norms, even when these conflicted with their African culture (e.g. eye contact).

A recent report by the National Autistic Society (Slade, 2014) indicated limited awareness of ASD among ethnic minority and immigrant communities. Parents experienced stigma and blame, which appeared linked to cultural beliefs. This impacted upon the support families received and led to social isolation. Furthermore, parents reported difficulties accessing mainstream services due to

language barriers, limited knowledge of services, and negative attitudes from and towards professionals. The report does not conduct separate analysis for different cultural groups, recommending further research in this area.

Clinical implications

The 2010 Equality Act and Department of Health (DoH) papers such as “Learning Difficulties and Ethnicity: Updating a Framework for Action” (2012), “Valuing People Now” (2009) and “Delivering Race Equality in Mental Health Care” (2005), emphasise the importance of tailoring services to meet the needs of immigrant and ethnic minority groups, thereby reducing barriers to access. They state clinicians must demonstrate “cultural competence”. This involves being mindful of, and curious regarding, the potential impact of cultural factors on a family’s experience, and incorporating this information into assessments and treatment plans. Falk, Norris and Quinn (2014) state that effective services must reflect families’ lived experiences. Research investigating the experiences of immigrant families is of clear importance.

The 2011 England and Wales census indicates 13% of the resident population were born abroad (Office of National Statistics, 2011). The largest non-European immigrant groups were from South Asia⁵ (2.9% of the general population; 7.7% in London) and Africa (2.3%; 7.6%). Research pertaining to the experiences of these two groups is, therefore, a priority. Previous research has investigated the experiences of South Asian families of children with a range of disabilities (Heer, Larkin, Burchess & Rose, 2012a; Croot, Grant, Cooper &

⁵ including India, Bangladesh, Pakistan, Kashmir and Sri Lanka

Mathers, 2008; Bywaters, Ali, Fazil, Wallace & Singh, 2003). However, very limited research has involved African immigrant families.

Aims and objectives

The present study investigated the lived experiences of African immigrant parents in the UK caring for a child with ASD. Such information could helpfully inform clinical practice and policy concerning the provision of culturally-sensitive support. It is acknowledged that there is considerable cultural diversity within the continent of Africa; however, given the lack of previous research in this area, this study chose not to specify a region within Africa, instead focusing on immigrant African parents' shared "minority experience" (Heer et al, 2012).

Specifically, the research questions were:

- How do African immigrant parents living in the UK make sense of having a child diagnosed with Autism Spectrum Disorder?
- What are their experiences of caring for their child?

Method

Design

The present study employed a qualitative, interview-based design, using interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) to obtain rich and detailed accounts, providing a unique insight into these mothers' experiences. IPA is appropriate in areas with limited previous research, where the lived experience of participants is the phenomenon of primary interest. IPA explores the "double hermeneutic", considering both the meaning participants give to their experiences and the researcher's interpretations.

Participants

Participants were recruited through four Child and Adolescent Mental Health Services (CAMHS) within one NHS Trust in a UK city. This Trust was chosen due to a high local immigrant population. A purposive sampling method was used (see Table 1 for selection criteria).

Participants (n=6) were all mothers of a son diagnosed with ASD and a Learning Disability (see Table 2 and Table 3 for participant characteristics). The boys were all born in the UK. Three mothers were separated from their child's father; all fathers were from the same country as the mother. All mothers had completed higher education; three were professionals or students in health disciplines. The mothers described themselves as Christian (n=4), Jehovah Witness (n=1), and Muslim (n=1).

Table 1.

*Selection Criteria*Selection Criteria

- Parents of a child diagnosed with ASD, aged between 5 and 13 years.
- Parents who were of African ethnicity and were born in Africa
- Parents who had lived in Africa until they moved to the UK as an adult, in the past 25 years.
- Participants who had sufficient spoken English in order to participate without an interpreter. It was felt that the presence of an interpreter, who was likely to be from the same cultural/ethnic background as the participant, may affect the information parents shared, due to concerns about privacy (Norbury & Sparks, 2013).

Table 2.

Pseudonyms and Characteristics⁶

<u>Mother's name</u>	<u>Child's name</u>	<u>Child's age</u>	<u>Number of children</u>	<u>Mother's country of origin</u>
Mabinti	Adam	7	4	Sierra Leone
Ayana	Dembe	13	1	Ethiopia
Fumni	Chidike	7	1	Nigeria
Ife	Olu	8	1	Nigeria
Sanaa	Kasim	8	3	Uganda
Nyah	John	13	3	Uganda

⁶ Names have been changed and characteristics split across two tables to protect confidentiality.

Table 3.

Participant Characteristics

<u>Characteristic</u>	<u>Range in years</u>	<u>Number of participants</u>
Mothers' age	30-40	3
	40-50	3
Mothers' time in UK	<10	1
	10-15	2
	15-20	2
	>20	1
Child's age at ASD diagnosis	3	5
	>3	1

Materials

Individual semi-structured interviews were conducted. The schedule was developed following discussion with CAMHS clinicians, two IPA researchers and with reference to extant literature. The schedule consisted of eight open-ended questions, with prompts (Appendix 7). These related to parents' experiences of caring for their child, of receiving and making sense of their diagnosis, their contact with services and their cultural background. Questions were designed to encourage participants to tell "their own story, in their own words" (Smith et al, 2009, p40). The semi-structured format allowed the interviewer to follow the participant's lead. The first interview acted as a pilot, after which the schedule was adapted.

Ethics

Ethical approval was obtained from the NHS Research Ethics Committee and from the Trust Research and Development department. The British Psychological Society Code of Human Research Ethics (2010) was adhered to throughout. Consideration was given to ensuring informed consent; it was made clear participation was voluntary and would not affect their child's care. To show appreciation, a £10 voucher was given. This was felt necessary to encourage participation and compete with funded research projects recruiting in the teams. As this incentive was low in value and for a specified children's shop, it was felt it would not unduly influence participation.

Procedure

Figure 2 details the research procedure. Recruitment took place over ten-months. To facilitate, the researcher attended team meetings, emailed reminders and provided leaflets for clinicians. Due to significant recruitment difficulties, the initial selection criteria was expanded to include parents who had been in the UK for a longer duration. Interviews lasted between 50 and 110 minutes (mean=78). Participants reported finding the interview "supportive" and "non-judgemental".

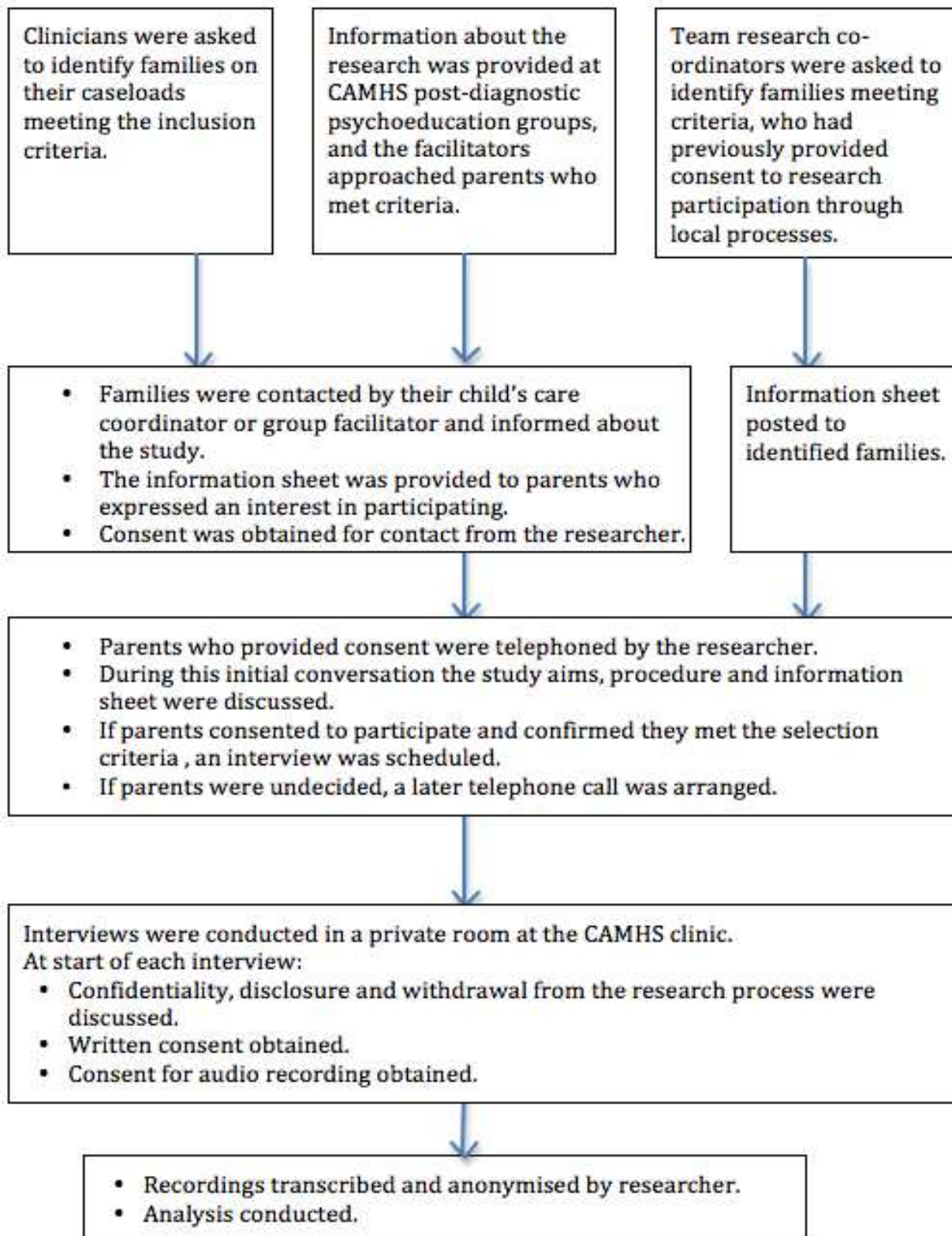


Figure 2. Diagram showing research procedure.

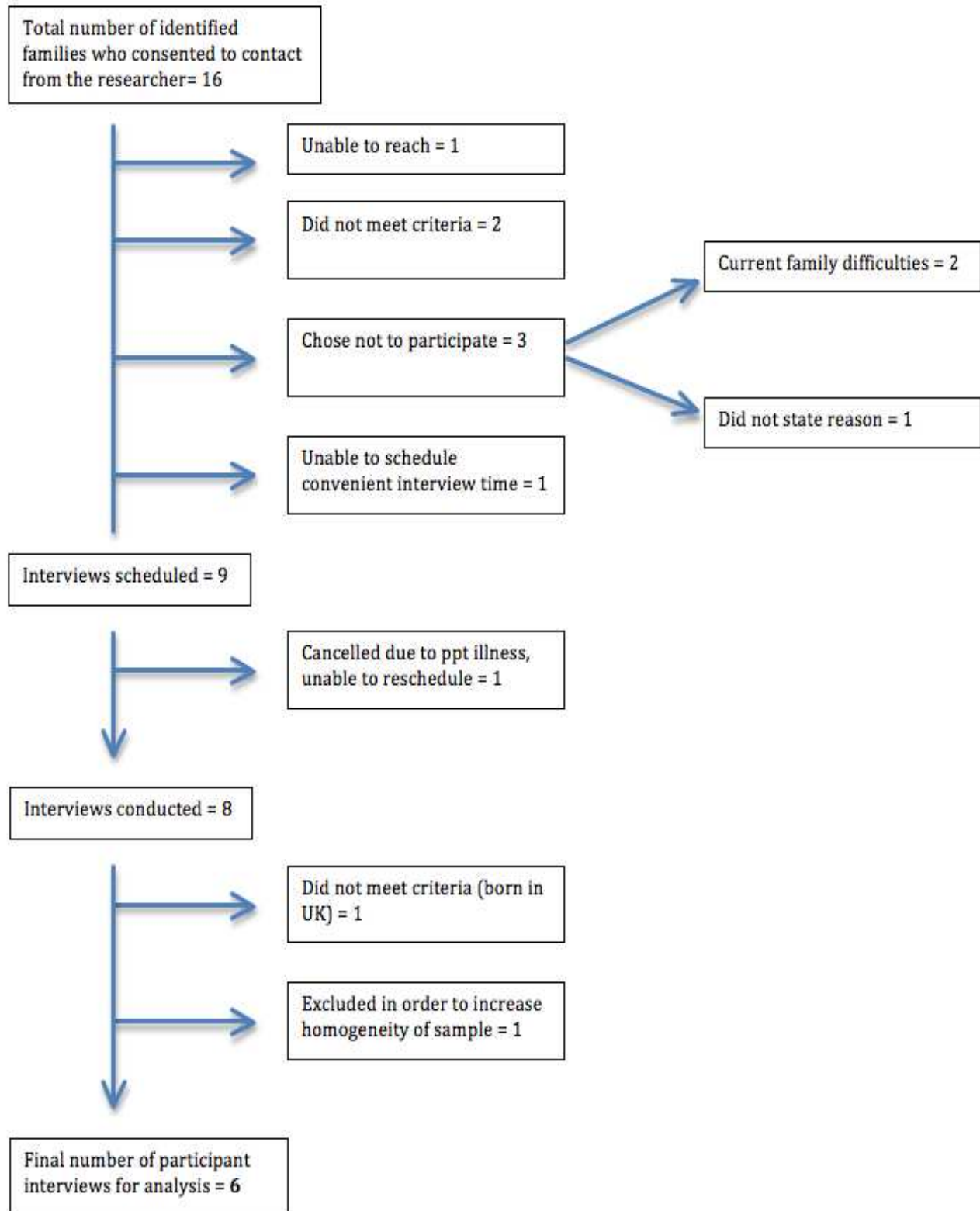


Figure 3. Flow chart illustrating the recruitment process.

Figure 3 details the recruitment process. Clinicians indicated very few participants declined researcher contact. Data from two participants was excluded following interview. One did not meet selection criteria. The other was excluded to maintain maximum sample homogeneity, as recommended for IPA studies (Smith et al, 2009). This participant was the only father, was of Arabic descent and had the only child without a learning disability. Although the exclusion of these participants' data did raise ethical concerns, given they had taken part on the condition of contributing to the study, this decision was made in order to maintain the quality and validity of the research data.

This resulted in six participants, which Smith et al (2009) state is a desirable sample size for IPA, providing "sufficient cases for the development of meaningful points of similarity and difference between participants, but not so many that one is in danger of being overwhelmed by the amount of data generated" (p.51).

Analysis

IPA is "a systematic, flexible, multi-directional analytic process" (Finlay, 2014, p125). Whilst there is no prescribed method, information presented by Smith et al (2009) was consulted for guidance. Transcripts were analysed on a case-by-case basis, in order for the researcher to become absorbed in each participant's account. Transcripts were read several times and descriptive, linguistic and conceptual comments noted. Emergent themes were identified and considered in relation to the researcher's interpretations. Following analysis of

individual transcripts, thematic patterns across the six participants were identified and super-ordinate themes compiled.

Quality assurance

Guidelines were consulted to ensure quality and validity (Yardley, 2000). Each stage of data collection and analysis was fully documented via a paper-trail. One transcript was independently analysed by a colleague, and the research supervisors audited a selection of transcripts and initial codes. Emergent themes were discussed with the supervisors, to ensure these were grounded in the data. "Reflexivity" was facilitated through use of bracketing interviews, a research diary (Appendix 15) and reflective conversations with colleagues, facilitating reflection on the impact of personal motivations and assumptions. These measures allowed me to maintain an awareness of my position in the research process and the influence of external pressures and constraints.

Results

The analysis indicated five super-ordinate themes (see Table 4). These will be discussed with example quotations⁷ (see appendix 17 for additional quotations).

Table 4.

Table of super-ordinate themes and sub-themes

<u>Superordinate theme</u>	<u>Sub-theme</u>
Caring for a child we didn't expect	All consuming A balancing act Maintaining privacy vs. seeking support Loss Denial
The pain of stigma and rejection	Others' judgements Conforming to perceived societal pressures Impact on maternal identity
Making sense of our child's difficulties and diagnosis	Shock and confusion Frameworks of meaning: Diagnosis Frameworks of meaning: Religion Cultural beliefs
Negotiating conflicting cultural beliefs	Shifting cultural allegiances Impact on cultural identity
Faith as "key"	Consistent and accepting Finding faith through hardship

⁷ ... indicates a significant pause

(...) indicates words removed for clarity/confidentiality

information in (brackets) has been inserted to provide context

words underlined indicate an emphasis by the participant

Caring for a child we didn't expect

This super-ordinate theme discusses the mothers' experiences of caring for their sons. Whilst some aspects might be common to all parents of children with autism⁸ (e.g. loss and denial), others relate to their minority experience. They described the task of parenting their sons as physically and emotionally exhausting, which appeared linked to balancing multiple demands, and a lack of support.

All-consuming. Whilst parenting is in itself all-consuming, there were increased demands on these mothers, leaving little time to focus on other aspects of life.

"It's very difficult to have a child who's got special needs, because ummm, they need 24 hour attention...they need your input all the time (...) I'm exhausted" (Fumni).

"We have no life, me and my husband and the other kids, it's always about Adam, Adam, Adam" (Mabinti).

Meeting their sons' needs and keeping them safe required hypervigilance and carried a high level of responsibility. This had an emotional impact on the mothers, who described constant worry and stress.

"You have to be keeping an eye on him constantly, constantly, you don't rest your mind, you rest your mind probably when you go to bed at night" (Nyah).

⁸ The mothers all used the term autism, rather than ASD

A balancing act. The difficulty of balancing multiple demands seemed a particular source of stress, as the mothers had no option but to prioritise their sons' needs. For Sanaa, Mabinti and Nyah, this appeared particularly painful, as they struggled with the guilt of trying to be a good mother to all their children.

"I just feel like my little ones they miss out (...) before I pick an activity I have to make sure that it's going to cater for all of them, which is hard 'cause (services) will say, 'oh we don't have the special kids service', so then they can't go to any activity, they can't have their friends come over, they can't go to other people's houses" (Sanaa).

Mabinti described the painful dilemma of her other children's reaction when Adam returned from respite care.

"Even (daughter) will just cry and say 'no, no Adam go', like if the carers take him out, when he's coming in all of them start crying, 'oh no go, go, go'."

Ife described the difficulty of balancing her own and her son's needs.

"I'm asthmatic, when he does that (challenging behaviour) it really affects me badly, and I'm the main carer so I really have to look after him well."

For Nyah, this balancing act impacted upon her marriage. She arranged opposite working hours to her husband, so one was always available to care for John; as a result they spent little time together. When discussing cultural celebrations Nyah said:

"Either my husband will go by himself, with the two girls, I will stay with (John), or I go."

Nyah appeared to have normalised this, saying she felt *"kind of used to it"*.

Maintaining privacy vs. seeking support. This balancing act appeared particularly difficult, as the mothers felt reluctant to seek support, due to privacy concerns.

"At the end all my business will be on the streets because they'll go and tell people" (Mabinti).

This perceived need to keep their situation *"private"* appeared linked to feelings of shame and embarrassment.

"With the behaviour and everything I was so embarrassed" (Ife).

Fumni and Ayana appeared upset by advice from professionals regarding Disability Living Allowance (DLA). This perhaps linked to cultural attitudes concerning the receipt of state support, as well as this being a confirmation of their sons' disability.

"She told me about DLA and I lost it (...) I don't want DLA, you know that's like (laughs) I'm not in this for...DLA, whatever it is" (Fumni).

Mabinti's reluctance to share her personal situation with her employer, led to her feeling unsupported and as though she was failing in her career.

"I wasn't talking about it so I didn't tell my workplace or my manager, they didn't know (...) I will just call for carers leave continuously (...) my manager was not happy."

"The pressure with work and them, it was too much. It made me feel... I was always forgetting".

All mothers felt they would have increased support had they remained in Africa, suggesting the social isolation intensifying this difficult balancing act was a product of migration.

"They help a lot when I go home (Africa), because I get a rest as well, I can go and visit friends because they will look after him. So it's not like here, like two of us all the time" (Nyah).

As a result, they appeared to feel alone and unsupported in the UK.

"We have to support ourselves, but...it's very difficult, financial, umm, everywhere is so difficult" (Ayana).

Loss. Receiving the autism diagnosis appeared a significant and upsetting event for all mothers.

"Oh I don't want to think about it again, I just, oh my world is just like something (...)I never forget that day" (Ayana).

They appeared to be mourning their "normal" babies (Mabinti, Fumni, Sanaa). This began when they first noticed differences compared to other children, and was compounded by the diagnosis. The following quotations from Fumni demonstrate this; in the first she described the pain of comparing her son to other children, and in the second she described her emotions upon receiving the diagnosis.

"It's quite difficult, really really difficult, really tough, ummm, because you know you look at other children and, his age, and you see the way that they are behaving and the way that they are interacting with their parents, you know questions back and forth and understanding and you just feel, ummm, sad really."

"Devastation, it was basically like a bereavement (...) it was a nightmare, like a life sentence."

They also appeared to be mourning the lives they had envisioned.

"Autism is the most difficult for all your life, my life I give up, that's it, everything" (Ayana).

Mabinti described reading a poem, which highlighted these losses. The realisation that other parents would be able to live the life she had expected, although for her it was no longer a possibility, appeared particularly painful.

"There was a part that I read that said...like you are going to, all of you, you and your friends planned to go somewhere, like China or France, then everybody went to France and you ended up half way through, that is how, you know that is what made me to understand it a little bit more how it is...its like all of you have kids, you know, but your own child is not going to be like the other kids, so it was a bit hard for me when I read that."

Denial. For Fumni, Sanaa and Nyah, an attitude of denial appeared to protect them from facing the difficult reality of their situation, helping them to cope.

"When the child is that young, it is so hard to even say there is something wrong with your child (laughs), it is so hard, and if someone had the nerve to come and say maybe your child (had difficulties), you would really hate them" (Sanaa).

"First when I got the diagnosis I was in denial and I was doing all the things I would usually do (...) in my mind there was nothing wrong" (Fumni).

It appeared that, over time, Fumni and Sanaa realised they must accept their sons' difficulties in order to appropriately support them.

"(support worker) said, oh you know what, the fact he can do this and he can do that, doesn't mean he doesn't need support, and that hit home" (Fumni).

The pain of stigma and rejection

This super-ordinate theme encompasses painful experiences of being judged and rejected. Sanaa described rejection from her family, Fumni from her church, Mabinti from the local African community, and all mothers, except Nyah, described feeling unwelcome in public places. The implication the mothers were to blame appeared to be at the root of many judgements and made these particularly difficult to bear, impacting upon their identities. Furthermore, they felt under pressure for their sons to meet others' expectations.

Whilst they described experiencing stigma from all groups in society, this appeared to occur to a greater degree from the African community, both within the UK and in Africa.

Others' judgements. For Mabinti, Ayana, Ife, Fumni and Sanaa, others' judgements appeared to be their greatest source of stress.

"The most difficult thing is dealing with other mums (...) even if they don't talk to you, you can see how judgemental they are, how they're like, they're so uncomfortable" (Sanaa).

"They laugh at me, they laugh at my kids, 'oh look at the type of kids she's got'" (Mabinti).

Whilst Sanaa appeared able, in some ways, to understand this reaction from parents at her son's school, she found it difficult to accept judgements from

the public and, most painfully, from her family. She described feeling *"tired of being judged and not accepted."*

The disparities between the mothers' own views of their sons, and those of others in the African community, appeared particularly painful.

"When you see my child, he's a normal child, he's a very lovely, beautiful son, and just the way he acts (...) they will show you he's not welcome."

Conforming to perceived societal pressures. In order to avoid judgements, the mothers appeared to feel a pressure to minimise their child's impact on others; however, this often conflicted with how they wished to parent.

"Parents feel this pressure it's (...) innate, you just feel the pressure to tell your child to stop, you just feel the pressure to make somebody's life...easier than yours (...) you tell him to stop even if you know very well this is him being happy". (Sanaa).

To manage these difficult feelings, the mothers isolated themselves, leading them to feel alienated and alone.

"You tend to limit your activities as well, either consciously or subconsciously, because it's just hard to really, to go out and to get all these comments (...) and to be judged" (Fumni).

"I just kept it to myself (...) I wasn't going out, not allowing anybody to come to my house" (Mabinti).

This appeared to create a further internal conflict, as the mothers felt guilty for limiting their sons' experiences.

"So he just stays at home and to me I feel like, that is not, it's not very healthy for him" (Sanaa).

In contrast, Ife appeared to pre-empt others' judgements.

"That is why you have to let people around you know what is happening, otherwise they give you stigma, and I don't want them to stigmatise him that maybe he's a bad boy or something, so I let them know that he has this problem."

Impact on maternal identity. The mothers appeared to internalise others' judgments, which impacted upon their sense of identity, leading to feelings of guilt and shame.

"People will start tagging you (touches chest) that maybe you are a bad parent" (Ife).

"Well the parent blames themselves sometimes, maybe I am a bad mum because other people point it out" (Sanaa).

Sadly, Mabinti experienced similar blame from her husband.

"If we had small arguments he would say, 'oh look at the type of kids you've got, look at your friends they gave birth to nice, good kids, oh look what you gave birth to, look at the boy, which type of child is this?'"

In order to counterbalance this imposed identity of being a "bad parent", Sanaa, Fumni, Ayana and Ife appeared to fight back by creating a new, positive, identity as strong, loyal and dedicated mothers to children with autism.

"I look after myself for him, not for me, I have to, I have a long term plan with him, he always is going to be with me (...) I don't want to get old, I don't want to get something illness, because I have to be very strong, it's not for me, it's for him" (Ayana).

"If you accept what the family are saying about your child, then your child is going to have nobody...so you sort of stand with your child and stay by yourself and that's it" (Sanaa).

For Nyah, an identity as a strong mother who was "coping" in the face of adversity, perhaps helped her to regulate the underlying pain she experienced.

"I felt frustrated, because I had the attitude, why mine...but eventually I got used to it and I started coping very well with it".

For Ayana, this identity appeared to underpin her decision not to have additional children.

"I have to concentrate on him, I don't need any other child, that's why I decided".

Alternatively, Mabinti described her attempts to have a "normal" child, which she perhaps felt would alleviate the blame she experienced and prove herself as a "good" mother.

"This one (youngest child) is now talking and I was so happy, I said look, I can have this one who is good, he is okay, for me I was so relieved."

Making sense of our child's difficulties and diagnosis

This super-ordinate theme relates to how the mothers made sense of their child and their diagnosis. Mabinti, Ayana, Ife, Sanaa and Nyah had never heard of autism prior to receiving the diagnosis. They began a search for information, drawing on the Internet, religion and their African culture.

Shock and confusion. They described feeling shocked and confused by the diagnosis and its meaning.

"I'd never ever heard anything like autism. So when he was diagnosed we started looking on the internet, what is autism (...) and then they said there is no cure, so umm, it was quite a difficult moment when he was diagnosed" (Nyah).

Additionally, they felt uncertain and apprehensive about the future and their ability to cope.

"For the first time when they say it, autism you have a child, you, just like a mountain... what's, what do I have to do? What is this? (...) how do I deal with these things? Can I manage this? Can I make this alone?" (Ayana).

Frameworks of meaning: Diagnosis. Whilst receiving the diagnosis was a painful moment, it appeared to offer a framework of meaning for understanding their child.

“For me when they said autism it was like (...) I can’t say relief, no, it’s not relief, it’s like, ummm, when you hear somebody tell you that your son might have that you (...) sort of see things clear, like, at least you know, you know what your son has and then you can see how to help him” (Sanaa).

“So I looked at it and I said ‘oh is this what it means’ then I went on the internet, yeah for me to get to know more about it, to know the symptoms, what to expect out of them, what they do” (Ife).

For Ife and Ayana, acceptance of a medical view appeared to protect them from feeling helpless, giving them power over their situation.

“You can’t say no when it is supposed to be yes...so it is not going to help the child is it (...) once they say that the child has got this, all you have to do is accept it and just look for solutions” (Ife).

All said they were in agreement with the diagnosis; however, they questioned whether it was sufficient to account for the entirety of their experience.

“Sometimes I feel like maybe they’ve misdiagnosed him...there might be more” (Mabinti).

Frameworks of meaning: Religion. The mothers drew upon their religious beliefs to make sense of their situation. Whilst this did not necessarily change their views of the causes, it appeared to offer meaning and comfort.

"Sometimes I still ask God why, you know, it wouldn't have cost you anything to give me a child without autism, but then people tell me 'oh well he saw something in you, you know maybe he felt that you could cope, you had particular strengths and he felt that you are the best guardian" (Fumni).

"We call them special people you know, they are specially made by God" (Ife).

Cultural beliefs. African cultural beliefs were also drawn upon, although the mothers appeared to disagree with the majority of these. All described the stigma stemming from these views, which appeared to form a dichotomy between people with visible and hidden disabilities.

"That's the problem with autism, you don't see it (...) people want to see a disability that's why, in my country in Africa, because they see someone in a wheelchair, that's disability, you cannot convince them that this person is able, this person can work (...) if they don't see it, this person is mad" (Sanaa).

Mabinti appeared to draw upon cultural beliefs more so than the other mothers; perhaps because she had migrated most recently and had lived in

Africa with Adam. She described the belief in a curse and sent money to Africa for “*sacrifices*” to stop it.

“Your husband’s family, they did not want you to have a child, then they sent something on you when you were pregnant”.

“I sent money, £100 (...) then they prayed and they give charity out, like to people working in the church (...) that was then, after that (daughter) started talking”.

Whilst these beliefs appeared to provide hope, they additionally increased the stigma and blame Mabinti experienced.

Negotiating conflicting cultural beliefs

The mothers perceived their sons were viewed by the African community as “*mad*”, “*possessed*” or “*naughty*”. These positions appeared equally painful, as they could not bear to view their sons as “*mad*” or “*possessed*”, however, the alternative labelled them as “*bad*” mothers. Additionally, they had learnt a new explanation: autism. Holding these sets of conflicting beliefs appeared to create a sense of cultural dissonance for the mothers, leading them to re-evaluate their previous beliefs and assumptions. This super-ordinate theme discusses the resulting shift in belief systems and its impact on the mothers’ identities.

Shifting cultural allegiances. African cultural beliefs about disability appeared unbearable for the mothers when applied to their sons.

"I took him somewhere and the woman told me he was possessed (...) I felt bad about it, that is a really bad word you know, especially saying someone is demonic" (Ife).

"Me and my husband decided to take him to Africa...but I was a bit scared to take him there (...) in Africa when a child behaves like that and they don't see a disability on you, well they will not understand, so they will beat him on the street, and I told my husband, I said I can't imagine myself to go for holiday and see Adam with sore all over his body (...) I said this is my child, I don't think I would be able to do that" (Mabinti).

Ife and Ayana described *"equipping"* (Ife) themselves with medical information regarding autism, replacing their prior beliefs.

"We have to enlighten ourselves you know, enlightenment is very important" (Ife).

Fumni and Ife distanced themselves from traditional African beliefs; Fumni felt her education had protected her, whereas Ife believed she had now learnt the *"truth"*.

"I mean you hear of all these horrible things, but not within my own circles (...) amongst maybe people who are not so educated (...) but luckily, you know, my own mum, she's a teacher" (Fumni).

"Now I know their mentality back home is nonsense number one...that one has opened my eyes" (Ife).

Sanaa described the discomfort she experienced when she realised she continued to discriminate against visibly disabled children, whilst viewing her own son as *"special"*.

"So when you are the one who is saying oh I don't want my child to go to the classroom with the child who is epileptic or who is disabled, properly disabled, you feel like you are doing the same thing to these children like what others did to you".

In order to manage this, Sanaa seemed to maintain her prior beliefs and assumptions about disability and *"madness"*, but considered autism an exception.

"For me when I come here and I see people like my son, I start to see a difference like, coz I wouldn't say that an autistic person is mad (...) because his mental state is not (...) completely gone, some of it is functioning".

Impact on cultural identity. The mothers' cultural identities appeared impacted by the experience of having a child with autism, and the resulting shift in belief systems.

Ife appeared to reject her African culture. She separated herself from "African women" and emphasised her allegiance with British culture. This appeared to allow her to discount the negative appraisals of her son.

"The mentality here has really exposed me (...) that is why I don't mix up with, you know, because my way of life is different from my country's culture, whatever, I know I can say I dress like them, but most of the things they do, I can't even bear it" (Ife).

For Fummi, her religious and cultural identities appeared intertwined. She described feeling betrayed and rejected by her church, as the values that she had believed were central to the church had been proved false. This led her to feel disconnected from her culture.

"Church is the worst place and that came as a shock to me, for Afro-Caribbean families church is very important, and it's always been an important part of my life, but to find out that church people are the most judgemental people I've come across because they want to be sanctimonious and they want to be holier than thou and they want to go to church and everything has to be perfect, not knowing that church is for people who need help".

"We stopped going and maybe pray at home (...) because it's just soul destroying".

This suggests a profound erosion of a core aspect of her sense of self. In response, Funmi described a sense of agency to change her situation and form new cultural and religious connections.

“My faith is very important to me, so my dream is, you know, to start a small ministry or a prayer meeting where (...) special needs children are welcome”.

Throughout the interview Mabinti switches between describing her African culture very positively, and very negatively. Although she appears to wish to remain connected to her African culture and maintains some of her prior belief system, she describes feeling alienated from the community in Africa.

“In Africa when (my children) behave like that (...) they think that is because they are from (UK), in (UK) they don't beat kids so that is why they are like that”.

However, she additionally experienced rejection by the UK African community.

“When I'm going outside they were saying, oh my kids are dogs, 'look at the dogs you've been bad'”.

Mabinti appeared to feel marginalised from both cultures, leading to her feeling overwhelmed and unable to cope.

"I went to the social services and I told them, Adam is here now so I'm not taking him back because I can't cope at all".

Ayana appeared to strongly connect to her African culture, whilst being in full agreement with the medical understanding of Dembe's difficulties. She appeared to manage this conflict by selectively drawing out certain aspects of her culture, and minimising those that conflicted with her new, medical knowledge. For example, although she refers to a range of African beliefs regarding disability, she most frequently cites the belief Dembe is a "blessing", and the value of "acceptance", which she feels stem from her cultural background.

"You should accept something, blessed, and believe and positive, it's really key, that's what I've found is really good benefit for me".

Nyah described a strong connection to her African culture; however, she chose to highlight 'safe' aspects, unrelated to values or beliefs about disability, thereby minimising this potential conflict.

"I kind of do same thing as we do back home, cook cultural food, dressing up, we kind of, it's not so different, and then when we're together we speak our language, it's not different to back home".

Faith as “key”

This final super-ordinate theme relates to religious faith as a protective factor. Whilst the mothers varied in religion, they all described their faith as a source of reliable support.

Consistent and accepting. It appeared that their faith was the only support upon which the mothers could rely consistently. Fumni described that whilst support from family fluctuated, God was always there.

“People can only help so much and then they go to their homes (...) so really only God, yeah, you need supernatural help” (Fumni).

Additionally, it appeared faith offered a place to which they could retreat from the demands of their lives.

“(faith offers) inner rest, peace of mind” (Ife).

It appeared to offer acceptance, in a world where others frequently rejected them.

“God doesn’t judge them, God is not judgemental, God loves them the way they are” (Fumni).

Finding faith through hardship. The difficulties the mothers experienced perhaps led to a strengthening of their religious faith.

"Some parts of Africa can be very difficult and hard, so it's only relying on God that you can get support and get what you want (...) you know us humans it is only when you have difficulties that you come to know God" (Ife).

It appeared they relied on God to improve their situations and offer hope for the future.

"Everything you give it to God because God created (...) we pray for him everyday, that one day God will help him" (Nyah).

Discussion

The research aims were to explore the experiences of African immigrant mothers with a child with ASD, and the meaning they attribute to this. The findings are now discussed with reference to extant research and theory. Implications for clinical practice, methodological limitations and suggestions for future research are outlined.

Many aspects of the mothers' experiences are, perhaps, common to all parents of children with disabilities. Descriptions of stress, grief, denial and a search for meaning, fit with findings from previous studies involving western (e.g. DePape & Lindsay, 2015; Hayes & Watson, 2013) and South Asian immigrant families (Jegatheesan et al, 2010b). Additionally, the impact of having a child with a disability on maternal identity has been previously reported (Landsman, 1998). However, the current findings suggest these mothers faced additional challenges, relating to their "minority experience" (Heer et al, 2012b).

The difficulties they described appeared compounded by an absence of formal and informal support, and significant social isolation. Most had not heard of ASD prior to the diagnosis, suggesting low awareness among the African immigrant community. Embarrassment and shame appeared to stem from negative attitudes and stigmatising beliefs held by others in the African community, which blamed the mothers. This led them to feel rejected by, and disconnected from, their potential support networks, and perhaps led to feeling under pressure to fit into British society. These themes support previous

findings (Slade, 2014; Perepa, 2014). However, the IPA methodology used in the present study allowed a more in-depth and interpretive understanding of the mothers' lived experiences and their psychological and cultural dimensions.

Whilst conceptual literature discusses the potential for parents' beliefs about their child to conflict with those of western healthcare systems (Heer, Rose & Larkin, 2012b; Welterlin & LaRue, 2007), there is little discussion of intrapsychic conflicts. Previous research suggests parents tend not to reject one belief system in favour of another, instead combining medical, traditional and religious beliefs (Heer et al, 2012a; Croot et al, 2008). The present study, however, suggests traditional African beliefs were incompatible with the medical information the mothers learnt. The current findings suggest the experience of having a child with ASD, and the resulting exposure to western, medical explanations, resulted in a feeling of significant cultural dissonance for the mothers, for whom traditional African beliefs were unbearable when applied to their child. Acceptance of a medical understanding offered a framework of meaning, absolving the blame they experienced and protecting their maternal identities. This fits with Tajfel's Social Identity Theory (1986), which states that individuals are motivated to achieve positive social identities. However, this led to conflict within their cultural identities.

It appears the mothers had all, at some point, felt marginalised from both cultures, resulting in feelings of shame and alienation. In order to cope with and minimise these feelings, they applied different strategies. These appear to map onto Berry's acculturation strategies (2005; Figure 1). Fummi and Ife appeared to

discount African beliefs, arguing education had either protected or enlightened them. In this sense, they were using the 'assimilation' strategy. However, Fumni appeared to wish to reconnect with her African culture by forming new connections, thereby adopting a strategy of 'integration'. Sanaa and Ayana appeared to selectively integrate belief systems, choosing aspects from each culture that protected them from stigma, without contradicting their new, medical knowledge. For example, Sanaa rejected traditional African beliefs about disability when applied to autism, but continued to hold these in relation to other disabilities. Nyah perhaps used the strategy of 'separation'; however, she chose to highlight non-contentious cultural aspects (e.g. food), thereby minimising dissonance. Mabinti appeared stuck in a position of 'marginalisation'. She appeared unable to discount her African beliefs or to selectively integrate these with a medical view, despite the stigma and shame she experienced.

Berry argues the 'integration' strategy is associated with minimal acculturative stress and improved psychological wellbeing, whereas 'marginalisation' results in poorest outcomes. The present study supports this. All mothers described the unbearable position of marginalisation. Mabinti, who appeared to remain in this position, felt overwhelmed and unable to cope, resulting in Adam going into care. Supporting families to integrate their cultural beliefs and maintain a sense of cultural identity should, therefore, be a priority for services.

Religious faith emerged as a significant protective factor, linking with research involving South Asian immigrant families (Croot, Grant, Mathers &

Cooper, 2012; Heer et al, 2012a). Whilst religion has featured in the accounts of western families (e.g. Marshall & Long, 2010), it appears to represent a more central element for immigrant families.

Clinical implications

The present findings have important implications for clinical practice and policy. Clinicians should ensure relevant, accessible and culturally-sensitive information is provided to families following diagnosis. Given the initial shock and confusion reported, follow-up appointments would clearly be appropriate. Interpreters, whilst essential to reduce language barriers, may increase privacy concerns. Confidentiality should be clearly outlined and interpreters appropriately trained.

Psycho-education is important. A group setting may be particularly beneficial. Gilligan (2013) found that peer-led psycho-education groups for South Asian parents of children with ASD were well received, providing a space to openly discuss cultural beliefs. Supporting African families to develop similar groups within their communities may reduce social isolation and facilitate new cultural connections.

Clinicians should foster open conversations regarding parents' minority experience, culture and wellbeing. Interagency working and appropriate signposting is essential. Tailored training and reflective practice to increase cultural competence should be further developed, with consultation from community members.

At a policy level, these findings suggest the DoH should continue to prioritise increasing ASD awareness within diverse communities. Such initiatives may reduce the stigma and blame parents experience. Heer et al (2012b) suggest this could be achieved through a “multidisciplinary approach, consisting of healthcare staff, outreach workers, religious leaders, as well as advocates from within the community” (p.958). Culturally sanctioned systemic change emanating from these sources is likely to be particularly effective in promoting education and attitudinal change (Campbell et al, 2007). Slade (2014) provides examples of successful service-user led initiatives targeting minority groups. Additionally, families should be consulted during the development and commissioning of services, regarding their specific needs and barriers to access.

Such recommendations would hopefully have a positive impact on parental wellbeing, and help minimise experiences of rejection and cultural conflict, leading to healthier acculturation experiences, increased support and reduced shame.

Limitations

The sampling method resulted in a specific subset of African mothers. All spoke English, had a high education level (three were healthcare professionals) and were known to CAMHS. Their experiences, therefore, are unlikely to be representative of the wider African immigrant population. Furthermore, participants potentially had different views to those who declined. Generalisability of findings, however, has never been an aim of IPA. Whilst the

sample size is small in comparison to qualitative studies using other methodologies, IPA aims for rich and detailed analysis, which can be inhibited by larger samples (Smith et al, 2009).

The decision not to use interpreters is perhaps a limitation; however, given the privacy concerns expressed, interpreters may have resulted in less personal accounts being provided.

My position as a White-British trainee psychologist, and the location of the research within CAMHS, will have influenced the accounts provided and my interpretations. IPA uses the researcher as a tool, whose personal experiences, beliefs and knowledge are brought into the analysis through interpretations. Whilst this is a valuable strength, it was important to monitor the use of reflexivity. Bracketing my assumptions, motivations and values allowed me to revisit these at later points and illuminate potential subjective biases, which could then be reflected upon and discussed with supervisors (Appendix 15).

Suggestions for future research

Research indicates immigrant families are less likely to have contact with services (Slade, 2014). Therefore, hearing the views of families unknown to CAMHS and/or who have different demographic characteristics (e.g. educational level) would be an important next step in order to investigate barriers to service uptake.

The findings elucidated key elements of the impact of having a child with ASD on the process of acculturation. Research involving parents who have lived in the UK for varying time periods, and inclusion of formal acculturation measures, may allow further investigation of this.

The mothers were from different African countries, cultural backgrounds and religions. Research focussing on specific African regions, and religions, would further contribute to understanding the experiences of immigrant families from this diverse continent. Furthermore, obtaining accounts from fathers would contribute to a more nuanced and rounded understanding of parental experience.

Conclusion

The present study indicates that whilst some aspects of these mothers' experiences are similar to those of White-British families, others are unique to their minority experience. They described experiencing stigma, blame and social isolation, linked to traditional cultural beliefs held within the African community. Whilst acceptance of a western, medical perspective absolved this blame to some extent, it appeared to create a state of cognitive dissonance for the mothers, impacting upon their cultural identity. The strategies they used to navigate these conflicting belief systems appear to map onto Berry's (2005) "acculturation strategies". These findings have implications for clinical practice and policy, including the importance of developing culturally competent services, raising awareness of ASD among immigrant communities and the development of peer-support groups.

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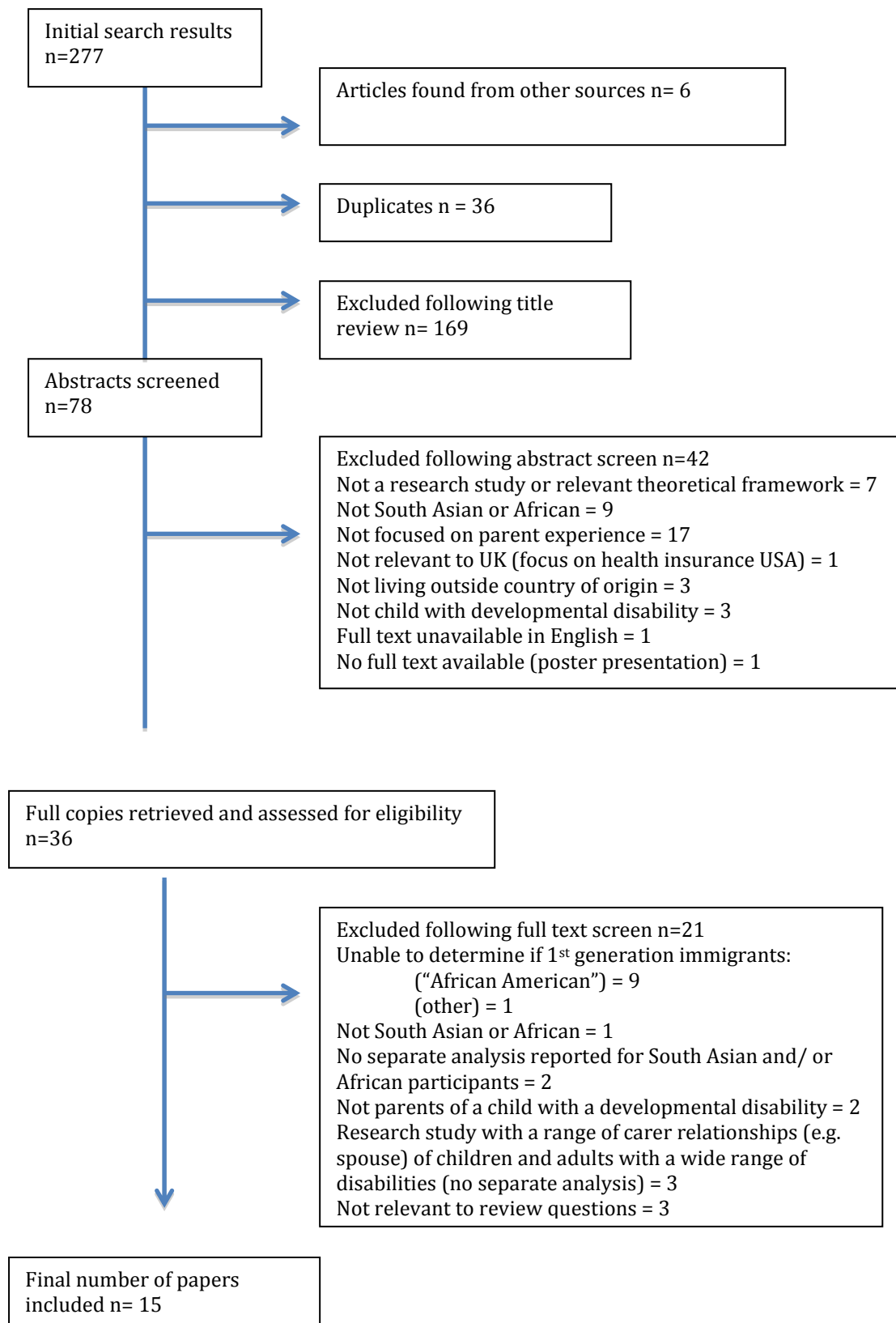
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Section C

Appendices and Supporting Material

Appendix 1: Flow chart showing search process



Appendix 2: Guidelines for Qualitative Research

Elliott, Fischer and Rennie (1999)

A. Publishability Guidelines Shared by Both Qualitative and Quantitative Approaches

1. Explicit scientific context and purpose
2. Appropriate methods
3. Respect for participants
4. Specification of methods
5. Appropriate discussion
6. Clarity of presentation
7. Contribution to knowledge

B. Publishability Guidelines Especially Pertinent to Qualitative Research

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs. specific research tasks
7. Resonating with readers

Appendix 3: Evaluation of papers with reference to Elliott et al (1999)

<u>Study</u>	<u>Aim</u>	<u>Owning one's perspective</u>	<u>Situating the sample</u>	<u>Grounding in examples</u>	<u>Providing credibility checks</u>	<u>Coherence</u>	<u>General vs specific</u>	<u>Resonating with readers</u>	<u>Comments</u>
Slade, G. (2014) UK This is a policy report, so full academic standards not expected	To explore the barriers faced by parents and carers of children with ASD from black, Asian minority ethnic communities, when accessing services. To provide recommendations for commissioners and future policy.	Yes – perspective of NAS	Part – ethnicity, gender, relationship to child. No info about: country of birth, number of years in UK	Part – Yes, but considering very large sample size, only limited examples and quotes were given	No	Yes	Yes General – no separate analysis done for different groups, but this is a recognised limitation	Yes	This is a policy report, so full academic standards not expected No separate analysis for different ethnic groups and for immigrants vs those who were born in the UK
Perepa, P. (2014) UK	To investigate parents' perceptions of ASD and the importance given to various social skills	No	Yes Years in the UK and age of children not stated	Yes	No	Yes	Yes	Yes	
Raghavan, R., Pawson, N. & Small,	To explore family carers' views and experiences of	No	Yes	Yes	No	Yes	Yes	Yes	

N. (2013) UK	transition from school to college or adult life, with special reference to ethnicity.								
Heer, K., Larkin, M., Burchess, I. & Rose, J. (2012) UK	To investigate the “cultural context of care-giving” for South Asian Sikh and Muslim parents of a child with an intellectual disability.	Part States first author could speak and understand both languages, indicating ethnic background	Yes	Yes	No	Yes	Yes	Yes	
Ravindran, N. & Myers, B. (2012) USA	To explore beliefs and practices regarding autism in Indian parents settled abroad	No	Yes Extensive information provided	Yes	Yes Two analysts	Yes	Yes Limitations of specific sample acknowledged	Yes	
Croot, E., Grant, G., Mathers, N. & Cooper, C. (2012)	To explore the coping strategies used by Pakistani parents, and the factors influencing their choice or ability to use the	Part Mentions profession and advisory group perspective	Yes	Yes But example quotes do not always appear to	No And does not state which qualitative method was	Part Themes are organised into categories	Part Quite general claims made in the discussion	Part	These 3 papers relate to one study. It includes parents of children with

UK	different strategies identified.			be making the point stated	used	but these do not always make sense – e.g. theme headings not matched to content			a wide range of disabilities (e.g. spina bifida and developmental delay) but does not acknowledge these are likely to be experienced v differently by parents.
Croot, E. (2012)	To identify the factors that Pakistani parents felt were important components of their care.	Yes	Part	Yes	No	Yes	No	Part	
UK					Other, linked paper, provides info on this		Very general claims made in discussion (e.g. “needs of families are universal”)	Very limited breadth	
Croot, E., Grant, G., Cooper, C. & Mathers, N. (2008)	To provide a detained account of the ways that Pakistani parents account for and understand their child’s disability.	Part	Yes	Yes	Yes	Yes	Yes	Yes	
UK					Project advisors commented on analysis				
Jegatheesan, B., Miller, P. & Fowler, S. (2010)	To investigate how South Asian Muslim immigrant families make sense of having a child with autism,	Part	Yes	Yes	Yes	Yes	Yes	Yes	Ethnographic approach has strengths compared to one off interviews
					“indefinite triangulation” Multiple analysts				

USA	and their goals for their child's future.	experience is presented, but limited reflection on the potential impact of this								(e.g. more detailed data, able to become immersed in participants' experiences and gain their trust), however potential for bias was not reflected upon
Jegatheesan, B., Fowler, S., Miller, P. (2010)	To develop an in-depth understanding of the experiences of three South Asian Muslim immigrant families who have a young child with autism. Specifically: the early period of their child's disability, their cultural conceptualisations of their child's disability and relationship with services.		Yes	Yes	Yes	Yes	Yes	Yes	As above	
USA										
Bywaters, P. Ali, Z., Fazil, Q., Wallace, L. & Singh, G. (2003)	Part of a wider evaluation project of an advocacy service. The families' understanding of the causes of their child's	Part Acknowledges context of research and steering group, but not researchers'	Yes	Yes	Part	Yes	Yes	Yes	Reference to steering group and multiple researchers but unclear	Nature of children's' disabilities not specified

UK	impairment, feelings of shame, stigma and the influence of these on service uptake and expectations of their child's future were reported and role of religion.	own perspectives	about the sample.						if they were involved in analysis
Fazil, Q., Bywaters, P., Ali, Z., Wallace, L., Singh, G. (2002)	To develop an understanding of the lives of ethnic minority families caring for a disabled child, the barriers they face in accessing services and the consequences for their wellbeing.		Details about the children's disability not provide; authors state this is due to the theoretical stance of the research.						
UK									
Hatton, C., Akram, Y., Robertson, J., Shah, R. & Emerson, E. (2003)		No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
UK			Doesn't state number of years in UK or if all immigrants						Multiple analysts and member checking

Appendix 4: Information sheet for parents

Ethics Reference number: 14/LO/0062
15/08/14

Version 4

Date

Information about the research

Project Title: The experiences of African parents who have had a child diagnosed with Autism Spectrum disorder in the UK: An exploratory study focusing on the role of culture.

Hello. My name is Kathryn Munroe and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. You can talk to others about the study if you wish. If you decide not to take part in the study, this will not affect the care you or child receives from the CAMHS team.

The research is being sponsored by Canterbury Christ Church University and is being supervised by Dr XXXXX (XXXXX Child and Adolescent Mental Health Service) and Linda Hammond (Canterbury Christ Church university). The research forms part of my doctoral studies in Clinical Psychology.

Project Summary

The purpose of the study is to develop an understanding of the experiences of parents from Africa, who have received a diagnosis of autism/autism spectrum disorder/asperger's for their child.

Why have I been invited?

You have been invited to take part in the study because you have a child with a diagnosis of autism/autism spectrum disorder/asperger's, and you have moved to the UK from Africa in the past 25 years.

What will I be asked to do?

Participation involves taking part in an interview with me. The interview would last approximately one hour (maybe a bit longer). You would only need to meet with me once. The interview would take place at the clinic where your child has been seen. If you would be unable to come to the clinic, we could discuss whether it would be possible for the interview to take place elsewhere.

During the interview, I will ask you some questions about your child and how it has felt for you and your family to receive this diagnosis for your child. I will need to audio record the interview so that I can remember what we talked about and so that I can type it up afterwards. When I do this, I will take out any information that would identify you or your child, such as names, places and dates. If you would like to see a copy of these notes to confirm I understood you correctly, this can be provided, or I can meet with you to discuss it.

Taking part in the interviews will not affect your child's care from the CAMHS team; this will continue as usual.

Expenses and payments

You will be paid expenses for your travel to the interview, up to a value of £10. As a thank you, we would also like to give you a £10 voucher for Early Learning Centre, for you to spend on your child.

What are the possible disadvantages and risks of taking part?

Although there are no identified 'risks' of taking part in this research, please think about whether you would feel comfortable talking to me about your child's diagnosis. Please also consider whether you feel you would have the time available to attend the interview.

What are the possible benefits of taking part?

You may find it helpful to talk to me about your child and the experience of receiving their diagnosis. I will not be able to offer you advice during the interview, but if you have any questions following the interview, I will ask your child's care coordinator to contact you. We cannot promise the study will help you but we hope that the information we get from this study will help us to develop a better understanding of the experiences of parents from your cultural background which may in turn lead to service improvements

What if there is a problem?

If you have a concern about any aspect of this study, please contact me on the number below and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, please contact Professor Paul Camic at Canterbury Christ Church University, on 03330117114, or e-mail paul.camic@canterbury.ac.uk.

Will my information be kept confidential?

Yes, all your information will be kept confidential. I will not have access to your child's care records during the research. I will only share information from the interview with a member of your child's care team if I have a concern your child's (or anyone else's) safety. Usually, I would discuss this with you first.

All information from your interview will be made anonymous – this means that I will take out any information that would identify you or your child, such as names, places and dates. Anonymous transcripts of the interviews will be stored on an encrypted memory stick and then kept in a locked cabinet at the university for 10 years after the research is finished. After this point, it will be destroyed. The information will not be used for any other research projects.

What will happen if I don't want to carry on with the study?

You can decide at any point before or during the interview that you no longer wish to take part in the study. If you decide you no longer wish to take part, all information collected from you so far will be removed from the research. You are not required to have any further involvement in the research after the interview.

What will happen to the results of the research study?

The results of the study will be written up into a research project, which will be available to clinicians working with families. We intend to publish the results of this study in an academic journal. Quotes might be used in the write up, but these would be made anonymous, so that you could not be identified from them.

You will be given the option of seeing the results and/ or a transcript of the interview before the project is completed and giving your comments. If you would rather, a summary of the results can be sent to you after the project is complete.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by XXXX Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or ask any questions, you can phone me on **XXXXX**. Please leave a message if I do not answer.

If you would like advice as to whether you participate in the research, you can talk to me, or to your child's care-coordinator.

Appendix 5: Consent form

Ethics reference number: 14/LO/0062

Version 1

Date 10/12/13

Consent Form

Title of research: *"The experiences of black African parents who have had a child diagnosed with Autism Spectrum disorder in the UK: An exploratory study focusing on the role of culture"*

Please circle as appropriate:

I confirm that I have read and understood the information sheet for this study, dated _____. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

Yes

No

I understand that my participation is voluntary and that I am free to withdraw at any time without needing to give a reason. This will not affect mine or my child's medical care or legal rights.

Yes

No

I agree to take part in the study, which will involve a one off interview approximately 60-90 minutes in duration, with a researcher from Canterbury Christchurch University. During the interview I will be asked about the experience of receiving a diagnosis of ASD for my child. I will also be asked to talk about my cultural background. I agree to this interview being audio recorded.

Yes

No

I understand that the information I give will remain anonymous and will not be shared with the CAMHS team, unless I say anything which suggests myself, my child or another person is at risk of harm.

Yes

No

I agree for anonymous quotes from the interview to be written up and published. My name and other identifying information will not be included.

Yes

No

Name of parent:

Parent signature:

Date:

Appendix 6: Leaflet for clinicians

The experiences of African parents who have had a child diagnosed with Autism Spectrum disorder in the UK: An exploratory study focusing on the role of culture

Inclusion Criteria:

- Parents of a child diagnosed with ASD (diagnosed in UK)
- Parent is of a black-African ethnicity and has moved to the UK from Africa in the past 25 years
- Child is of school age (5 – 16 years)
- Parent must speak English and not require an interpreter

Participation will involve:

- Parents taking part in a one-off, one hour interview to be held at CAMHS
- Parents will receive travel expenses plus a £10 voucher to spend on their child

If you have any children on your caseload whose parents meet this criteria:

- Please inform parents about the study and ask if they give consent to be contacted by the researcher.
- Please speak to (supervisor) or contact Kathryn via e-mail to discuss and to pass on details of any consenting parents.

XXXX@CANTERBURY.AC.UK

If parents consent, I will phone them to discuss the research further and answer any questions they may have. Alternatively, they can contact me on (number). They will need to leave a voicemail or send a text message.

Appendix 7: Semi-structured interview schedule

Points to cover before commencing interview:

- Thank you for coming today and for agreeing to take part in this interview. As you know, I will be asking you about your child, their diagnosis and about how this has felt for you. Do you have any questions before we start?
- As I explained on the phone, I would like to record today's interview so that I can remember everything we talked about. I will then type up our conversation, and I will remove any information that might identify you, such as names, places and dates.
- Go through consent form with participant and sign – explain information about withdrawing, confidentiality etc
- The interview will last approximately one hour to 90 minutes. If at any point you would like to take a break, just let me know. If there are any questions you don't understand, or that you would rather not answer, we can discuss these together. If at any point during the interview you want to stop, just tell me and we can end the interview.

- 1) I want to begin by asking you some questions about your child. Tell me about (name)?

Prompts:

- a. What are some of the things that your child likes? What are they good at?
 - b. What things they don't like? What do they find difficult?
 - c. Are there any ways in which they are similar to or different to other children their age?
- 2) I understand your child has been given a diagnosis of (ASD/autism etc). I'd like you to think back to before the diagnosis was given. Tell me about when you first noticed something was different?
 - a. Who first noticed they had (difficulties/insert word they have used)?
 - b. What were your views/feelings at this time?
 - c. How did you explain this at the time?
 - d. Views/feelings of wider family/ friends/ the other parent?
- 3) I'd like to now ask you about the assessment process. Can you tell me about this?
 - a. What was your understanding of what was happening?
 - b. What were your views/feelings during the assessment?
- 4) How did you feel when your child was first given the diagnosis?
 - a. What was your understanding of what it meant?
 - b. Is there another way you might have explained/thought about your child and their difficulties at this point?
 - c. How did others react (e.g. family, friends, the other parent)

- 5) And how do you feel about the diagnosis now?
 - a. Has anything changed?
 - b. Do you agree with the diagnosis?
 - c. What about (the other people you mentioned – family, friends, other parent)?

- 6) If and when they mention views of their child within the African community, ask them to say more about this.

If they do not raise this themselves, ask:
How might your child be viewed in Africa?
Prompts:
Or by the African community here?

- 7) I'd like you to now think about your own culture. By culture I mean the values, beliefs, customs and social behaviour that a group of people share. (check they understand this concept)
 - a. In what ways do you feel connected to the culture you grew up in?
 - b. And in what ways, if at all, do you feel connected to British culture?

- 8) Is there anything else you would like to say in relation to anything we've talked about today?
 - a. (Check understanding if there are any points I am not sure about/ want to clarify)

General prompts:

- You mentioned X, can you tell me more about that?
- How did that feel for you, as his mother?
- What was your response to that?
- What do you mean by X?
- What was your experience of that?

If not covered during interview, check:

- Details of the child's diagnosis
- Details of siblings
- Whether child attends a special or mainstream school
- Mothers age and education level
- Mothers country of origin and number of years in the UK

Appendix 8: NHS research ethics committee approval

This has been removed from the electronic copy

Appendix 9: NHS research ethics committee approval of amendment

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Appendix 10: Research and development Team approval

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Appendix 11: Research and development Team approval of amendment

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Appendix 12: Example coded transcript

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Appendix 13: Table of theme progression

<u>Master theme</u>	<u>Sub theme</u>	<u>Emergent theme related to sub theme</u>	<u>Participants within emergent theme</u>	<u>Total number contributing to theme</u>
Caring for a child we didn't expect	All consuming	Emotionally exhausting	All	All
		Physically exhausting	All	All
		Increased Responsibility	All	All
		Hypervigilance	All	All
		Stress and worry	All	All
		Meeting the needs of all my children	1, 5, 6	3
	A balancing act	Balancing own needs. i.e. child's needs	2, 3, 4	3
		Impact on work	1, 6	2
		Impact on marriage	1, 6	2
		Financial impact	1, 2, 3, 4	4
		Grief of child	All	All
		Loss of life expected	All	All
	Denial	Focusing on positives in order to cope	2, 3, 4, 5, 6	5
		Carrying on as normal	2, 3, 4, 5, 6	5
		Letting go of denial in order to meet child's needs	3, 5	2
		Stigma and rejection	Others' judgement	Feeling misunderstood
		Others' judgements leading to self-blame	1, 2, 3, 4, 5,	5
		Rejected (Mother and	1, 2, 3, 4, 5	5

		Child)			
		Stigma in African community	All		
	Conforming to perceived societal pressures	Social isolation in order to cope	1, 2, 3, 4, 5,	5	
		Minimising impact on others	All	All	
		Hyper-vigilant regarding impact on others	All	All	
		Conflict between meeting others' expectations and meeting sons' needs (Protecting him from rejection)	3, 4, 5	3	
	Impact on identity	Bad mother – internalised blame	1, 2, 3, 4, 5,	5	
		Prove herself as a good mother	2, 3, 4, 5, 6	5	
Making sense of child's difficulties and diagnosis	Shock and confusion	What is autism?	1, 2, 4, 5, 6	5	
		Shock	1, 2, 4, 5, 6	5	
		Confusion	1, 2, 4, 5, 6	5	
	Frameworks of meaning: Diagnosis	Searching for meaning	All		
		Diagnosis alleviates self-blame	1, 2, 3, 4, 5	5	
		Provides a framework for understanding behaviour	All		All

		Allows them to discount stigmatising beliefs in culture	2, 3, 4, 5,	4
	Frameworks of meaning: Religion	From God (blessed)	2, 3, 4, 6	4
		Why did God do this to me?!	2, 3, 4	3
		Chosen to raise this child	2, 3, 4	3
	Cultural beliefs	Faith provides comfort	2, 3, 4, 5, 6	5
		Visible vs hidden disability creates stigma	All	All
		Mad	All	All
		Naughty	All	All
Managing conflicting values and beliefs	Shifting cultural allegiances	Pain of conflicting beliefs	1, 2, 3, 4, 5	5
		Turning away from African cultural belief in order to protect maternal identity	3, 4, 5,	3
		Education as protection	3, 4	2
		Selecting 'safe' aspects of culture	2, 6	2
		Medical information protects them from stigma	2, 4, 5	3
	Impact on cultural identity	Identifying with British culture	3, 4	2

		Identifying in African culture	1, 2, 3, 5, 6	5
		Sense of agency to form new cultural connections	3	1
		Marginalisation	1, 3, 5	3
		Integration	2, 3, 4	3
Faith as 'key'	Consistent and accepting	Consistent and reliable support	All	All
		Only place of acceptance	2, 3, 4	3
	Finding faith through hardship	Faith strengthened by difficult experiences	4	1
		Offers hope for future	2, 3, 4, 6	4

Appendix 14: Table of themes for one participant

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Appendix 15: Abridged Research Diary

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Appendix 16: Characteristics of good qualitative research (Yardley, 2000)

Sensitivity to context

Theoretical, relevant literature, empirical data, sociocultural setting, participants' perspectives, ethical issues.

Commitment and rigour

In-depth engagement with topic, methodological competence/skill, thorough data collection, dept/breadth of analysis

Transparency and coherence

Clarity and power of description/argument, transparent methods and data presentation, fit between theory and method, reflexivity

Impact and importance

Theoretical (enriching understanding), socio-cultural, practical (for community, policy makers, health workers).

Appendix 17: Themes with example quotes

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Appendix 18: Publication guidelines for chosen journal

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Appendix 19: NRES end of study form

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Appendix 20: Summary Report to Research Ethics Committee

The experiences of African immigrant mothers living in the UK with a child diagnosed with Autism Spectrum Disorder (ASD): An Interpretative Phenomenological Analysis

The present study used Interpretative Phenomenological Analysis to investigate the experiences of African immigrant mothers living in the UK with a child diagnosed with an Autism Spectrum Disorder (ASD). Six mothers were recruited from four Child and Adolescent Mental Health Services (CAMHS) to take part in one off semi-structured interviews. The results indicated five themes: caring for a child we didn't expect, the pain of stigma and rejection, making sense of our child's difficulties and diagnosis, negotiating conflicting belief systems and faith as "key". Many aspects of the mothers' experiences appear related to their position as immigrants from cultures with very different belief systems regarding child development and disability. Stigma, blame and social isolation appeared to compound the difficulties they experienced. Conflicts between African cultural beliefs and a western, medical understanding of ASD appeared to create an internal conflict of beliefs for the mothers, leading to feelings of marginalisation. The strategies they used to negotiate this appear to map onto Berry's (2005) acculturation strategies, suggesting the experience of having a child with ASD impacts upon the acculturation process. The study met its objectives and the findings have important implications for clinical practice and policy, including:

- The provision of relevant, accessible and culturally-sensitive information is provided to families following diagnosis. Given the initial shock and

confusion reported, follow-up appointments would clearly be appropriate.

- Group psycho-education sessions specifically for African immigrant mothers.
- Open conversations between clinicians and families regarding their minority experience and wellbeing should be fostered. Interagency working and appropriate signposting to support services is essential. Tailored training to increase clinicians' cultural competence should be further developed, with consultation from community members.
- The importance of raising awareness of ASD among immigrant communities.

The research has been written up and submitted to Canterbury Christ Church University for the degree of Doctorate in Clinical Psychology. It will also be submitted for publication in a peer reviewed academic journal.