The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis

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Introduction

The majority of research pertaining to Autism Spectrum Disorders/ Conditions (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, there is limited research in this area. The present study used a qualitative methodology to investigate the experiences of African immigrant mothers in the UK. Specifically, it aimed to investigate their experiences of caring for their child and how they made sense of their difficulties and diagnosis.

The Autism Spectrum

ASDs are classified as 'Pervasive Developmental Disorders' (PDDs) 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 to be present at birth, to manifest during childhood, and to persist throughout the lifespan. These diagnostic manuals refer 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). Being a spectrum, individuals who meet the diagnostic criteria will have different patterns of strengths and difficulties.

In the UK, a childhood ASD diagnosis is made using a combination of behavioural observation, parental report, and clinical judgement. Whilst the general consensus is that genetic factors influence the development of ASD, to date there is no agreed-upon aetiology (Chaste & Leboyer, 2012). Therefore, the existence of ASD is dependent upon cultural norms regarding child development and behaviour. It has been suggested that, rather than representing a discrete condition, a diagnosis of ASD perhaps marks the 'extreme' on a continuum of 'autistic traits' distributed throughout the general population (Baron-Cohen et al, 2009, p500). An increasing body of literature has focussed on the concept of 'neurodiversity', which indicates many people diagnosed with ASD consider themselves as neurologically 'different', as opposed to having a disorder or a condition in need of treatment (Ortega, 2009). Indeed, many people with this pattern of strengths and difference achieve successful careers in which these behavioural 'traits' are advantageous.

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 limited evidence (Elsabbagh et al, 2012), in addition to cultural diversity in models of child development and disability. Daley (2004), for example, found that Indian parents first noticed developmental differences indicative of ASD 6-12 months later than parents in the USA.

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 that 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'. 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). Jegatheesan et al (Jegatheesan, Miler & Fowler, 2010; Jegatheesan, Fowler & Miller, 2010) conducted an ethnographic study involving three Pakistani Muslim families living in the USA with a child with ASD. These families appeared to make

sense of their child's difficulties primarily in religious terms, which appeared to impact on their uptake of services. Ravindran and Myers (2012b) conducted an internet survey with Indian parents living in the USA and elsewhere. They found that the majority of families who participated drew on a combination of bio-medical, traditional Asian and religious beliefs.

Extant research

To date two UK studies have investigated experiences of immigrant parents of a child diagnosed with ASD. Perepa (2014) conducted interviews with White-British (n=29), "Afro-Caribbean" (n=16), South Asian (n=12) and Somali (n=6) parents, in order to investigate interpretations of ASD and the importance attributed to various social skills. An episodic interview approach was employed, in which parents were asked to provide narrative accounts of situations involving their child, and their interpretations of these. The results indicate cultural variations which the author infers relate to differences in the models of disability drawn upon by parents when deciding which skills to teach to their child. South Asian and White-British families placed most importance upon following rules and respecting personal space, whereas Afro-Caribbean and Somali families placed greatest importance on eye-contact. Parents from the three immigrant groups stated they would teach their children eye-contact, despite this conflicting with their own cultural norms, due to this being a common deficit of ASD. This appears to fit with the 'deficit model' of disability. Alternatively, White-British parents were more likely to say that society should make allowances for their child's behaviours, fitting with the 'social model'. Perepa infers this may link to a

perceived pressure among immigrant parents for their children to fit British cultural norms, rather than a cultural difference in perceptions of disability.

A recent report by the National Autistic Society (Slade, 2014) employed structured focus groups to explore the barriers to accessing services faced by parents and carers of children with ASD from black and Asian minority ethnic communities. The findings indicate a limited awareness of ASD among ethnic minority and immigrant communities. Parents reported experiencing stigma and blame, which appeared linked to cultural beliefs and impacted upon the support families received, leading to social isolation. Furthermore, parents reported difficulties accessing mainstream services due to language barriers, a limited knowledge of services, and negative attitudes from and towards professionals. Data from the 130 participants is analysed and discussed as a whole, meaning a nuanced understanding of the impact of specific factors (e.g. whether the parents themselves were first generation immigrants, the country from which they migrated, and their education level) is not possible. The report concludes that further research in this area is needed.

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 Asia (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 & 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. An understanding of their experiences 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 and between different African immigrant groups, who will have varied cultural backgrounds, experiences and motivations for moving to the UK. Given the lack of previous research in this area, this study chose not to specify a region within Africa, instead focusing on African immigrant parents' shared experiences of integrating into a new culture whilst parenting a child who has received a diagnosis of ASD. Specifically, the research questions were:

- How do African immigrant parents living in the UK make sense of having a child diagnosed with ASD?

- What are their experiences of caring for their child?

Method

Design

The present study employed a qualitative, interview-based design, using Interpretive 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 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, the criteria being: African immigrant parents who had been in the UK for less than 25 years and had a child under 13 years old who had been diagnosed with ASD in the UK. Additionally, parents needed to have sufficient command of English in order to participate without an interpreter, the presence of whom may have affected the information they provided (Norbury & Sparks, 2013).

Participants (n=6) were all mothers of a son diagnosed with ASD and a 'Learning Disability'. The boys were all born in the UK. Five of the six boys received their ASD diagnosis at the age of three or younger. The mothers were aged

between 30 and 45 years and had lived in the UK for between 9 and 22 years. All 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). The mothers were from Sierra Leone (n=1), Ethiopia (n=1), Nigeria (n=2) and Uganda (n=2). See table 1 for participant pseudonyms and their children's ages.

Materials

Individual semi-structured interviews were conducted. The schedule was developed following discussion with CAMHS clinicians, IPA researchers and with reference to extant literature. The schedule consisted of eight open-ended questions, with prompts (see figure 2). 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. 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. Consideration was given to ensuring informed consent; it was made clear that participation was voluntary and would not affect their child's care.

Procedure

The research procedure is outlined in figure 3. Recruitment took place over ten months. Interviews lasted between 50 and 110 minutes (mean=78). Participants reported finding the interview 'supportive' and 'non-judgemental'.

Sixteen parents were identified and contacted regarding the study, of which eight participated. In order to maintain sample homogeneity, data from two participants was not included in the analysis for this paper. It transpired during interview that one participant had been born in the UK and lived in Africa only as a teenager; the other participant was the only father and his son did not have a learning disability, resulting in significantly different needs in comparison with the other children. This resulted in six participants, which Smith et al (2009) state is a desirable sample size for IPA. Although there were ethical concerns about excluding this data, given the parents had participated in order to contribute to the study, this decision was made in order to maintain the quality and validity of the research data. As agreed, all eight participants' experiences were fed back to the participating CAMHS teams.

Analysis

IPA is 'a systematic, flexible, multi-directional analytic process' (Finlay, 2014, p125). As outlined by Smith et al (2009), transcripts were analysed on a case-by-case basis and read several times, in order for the researcher to become absorbed in each participant's account. Whilst reading, descriptive, linguistic and conceptual comments were noted within the margins. Emergent themes were then identified and considered in relation to the researcher's own psychological interpretations regarding the mothers' experiences (i.e. how the researcher understood, from a psychological perspective, the mothers' attempts to make sense of their situation). Following analysis of individual transcripts, thematic patterns across the six participants were identified and overarching ('super-ordinate') themes were compiled, with example quotes to ensure they remained closely grounded in the data.

Quality assurance

Yardley's (2002) qualitative research guidelines were consulted to ensure quality and validity throughout the research design, procedure, analysis and write-up. 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' (Yardley, 2002) was facilitated through use of bracketing interviews, a research diary, and conversations with colleagues, facilitating reflection on my own motivations, prior assumptions and position in the research process, as well as the influence of external pressures and constraints.

Results

The analysis indicated four super-ordinate themes (table 3).

Caring for a child we didn't expect

This super-ordinate theme discusses the mothers' experiences of caring for their sons. They described this as all consuming, which appeared linked to physical and emotional exhaustion, balancing multiple demands, and a lack of social support. Whilst many aspects of this theme might be common to all parents of children with autism[1], the difficulties appear compounded for these mothers,

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[1] The mothers all used the term autism

who are distanced from their social support systems through migration and/or the stigma of their child's difficulties.

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. This had an emotional impact on the mothers, who described constant worry and stress.

'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).

'You don't rest your mind, you rest your mind probably when you go to bed at night' (Nyah).

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).

Maintaining privacy vs. seeking support. This balancing act appeared particularly difficult, as the mothers appeared reluctant to seek support due to privacy concerns. When discussing the reasons she decided against asking for help from a neighbour, who was also from Sierra Leone, Mabinti said:

'At the end all my business will be on the streets (...) they'll go and discuss it, tell the next person, "oh look at that child, look at Mabinti's child, he doesn't know anything, look at how he behaves"'

Additionally, her reluctance to share her personal situation with her employer, led to Mabinti 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 (...) the pressure with work and them, it was too much. It made me feel... I was always forgetting, my manager was not happy.'

The mothers' perceived need to keep their situations *'private'* appeared linked to feelings of shame, embarrassment and perceived stigma (see following theme).

'With the behaviour and everything I was so embarrassed...people were always looking at me strangely' (Ife).

Many of the mothers felt they would have increased support had they remained in Africa, as their close family would have been more tolerant of their

child's difficulties compared with the African communities in the UK. This suggests the social isolation intensifying this difficult balancing act was a product of migration.

'They help a lot when I go home (Uganda), 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).

Loss. The mothers appeared to be mourning their *'normal'* babies. 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.'

The mothers 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…it's 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.'

For Fumni, Sanaa and Nyah, an initial attitude of denial appeared to protect them from facing the difficult reality of this loss, 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, they realised they must accept their sons' difficulties in order to appropriately support them.

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, 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 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.'

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).

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).

'By the time the parent accepts that it is not their fault...this mum will have gone through a lot of stress and guilt' (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).

Whilst for Ayana this identity appeared to underpin her decision not to have another child, 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.

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

'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' (Mabinti).

Frameworks of meaning

This super-ordinate theme relates to how the mothers made sense of their child and their diagnosis. Only one mother (Fumni) had heard of autism prior to

receiving the diagnosis; the others therefore began a search for information, drawing on the Internet, religion and their African culture.

Diagnosis. Receiving the autism diagnosis appeared a significant and upsetting event for the mothers, who described feeling shocked, confused and overwhelmed.

'Oh I don't want to think about it again, I just, oh my world is just like …. I never forget that day (…) the first time when they say it, autism, 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).

'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 it was quite a difficult moment' (Nyah).

Once the mothers had *'equipped'* themselves with information about autism, through the internet and talking to professionals, all said they were in agreement with the diagnosis, which appeared to offer a framework for understanding their child.

'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).

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).

Religious beliefs. Whilst the mothers varied in terms of the religion they identified with, all appeared to draw upon their religious beliefs to make sense of their situation. Whilst this did not necessarily change their views of the cause of their child's difficulties, 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, they are specially made by God' (Ife).

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, and offered acceptance in a world where they felt rejected.

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

"God doesn't judge them, God is not judgemental, God loves them the way they are" (Fumni).

The difficulties the mothers experienced perhaps led to a strengthening of their religious faith, which in turn offered hope for the future

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

"We pray for him everyday, that one day God will help him" (Nyah).

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 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…after that he started talking'.

Whilst these beliefs appeared to provide hope, they additionally increased the stigma and blame Mabinti experienced, which can be seen in her comments about trying to prove she can have a *'normal'* child (see above theme).

Negotiating conflicting cultural beliefs

The mothers perceived that their sons were viewed by the African community as either *'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 and to find ways of integrating these sets of apparently conflicting information. 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).

In order to regulate this internal conflict, Ife and Ayana described *'equipping'* themselves with medical information regarding autism, in order to *'enlighten'* themselves. Throughout the interviews, the mothers 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'*. When describing her decision not to send Kasim to a school for children with a range of disabilities, Sanaa said:

'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'.

Sanaa appeared to manage these opposing positions and feelings of discomfort by maintaining her prior beliefs and assumptions about disability and 'madness', but considered autism as 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 (African people) 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 Fumni, 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 alternated between describing her African culture very positively, and very negatively. Although she appeared to wish to remain connected to her African culture and maintained some of her prior belief system, she described feeling alienated from the community in Africa.

'In Africa when (my children) behave like that (…) they think that is because they are from (England), in (England) 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 <u>at all</u>'.

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. Although she refers to a range of African beliefs regarding disability, some of which she does not agree with, 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 (...) it's not so different, and then when we're together we speak our language, it's not different to back home'.

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 many 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 internal and emotional 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 and emotional 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. However, this led to a painful 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). Fumni 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 painful 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 refers to the process of educating and empowering families to understand the individual needs of their child, and to support them appropriately. Delivering such sessions in a group setting may be particularly beneficial for immigrant families. Gilligan (2013) found that peer-led psycho-education groups for South Asian parents of children with ASD were well received and provided a space to openly discuss cultural beliefs. Supporting African families to develop similar groups may help to reduce social isolation and facilitate new cultural connections.

Clinicians should foster open conversations regarding parents' minority experience, culture and wellbeing, providing parents with a space to discuss these difficult emotions and internal conflicts. 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), were known to CAMHS, and had been in the UK for at least 10 years. 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.

Identifying and reflecting upon (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.

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'. The mothers 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 painful 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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