

**Understanding and awareness of autism amongst Somali parents living in the United
Kingdom**

Amal M Hussein¹, Elizabeth Pellicano² and Laura Crane¹

¹ Centre for Research in Autism and Education, UCL Institute of Education, London, UK

² Department of Educational Studies, Macquarie University, Sydney, Australia

Correspondence to:

Dr Laura Crane

Centre for Research in Autism and Education (CRAE)

UCL Institute of Education

University College London

London, WC1H 0NU, UK

Tel: +44 (0) 20 7331 5141

E-mail: L.Crane@ucl.ac.uk

Running Head: AUTISM AND THE SOMALI COMMUNITY

Abstract

Using vignettes and interviews, this study examined understanding and awareness of autism, and (a)typical development more broadly, among 32 Somali parents living in the United Kingdom (UK). Results demonstrated that parents of both autistic (n=16) and non-autistic (n=16) children were just as likely to identify vignettes of typically developing children, yet parents of autistic children appeared more astute to signs of atypical development. Across the whole sample, parents commonly identified and labelled vignettes of autistic children, but experienced more difficulty labelling vignettes that described children with other forms of atypical development, sometimes mislabeling these children as autistic. This suggests that there is a need for greater support in recognising and identifying different types of atypical development in the Somali community (to mitigate the risk that the term 'autism' may take on its own meaning within the Somali community, becoming a euphemism for a range of developmental conditions). Analysis of interview data identified key sociocultural factors that either helped or hindered the inclusion of families with autistic children within the community, including the Somali community's: (1) perceptions of disability; (2) beliefs about the causes of autism in the Western world; and (3) strong reliance on religious beliefs in understanding and accepting an autism diagnosis.

Understanding and awareness of autism amongst Somali parents living in the United Kingdom

In the United Kingdom (UK), one in every 100 children, young people and adults are estimated to lie on the autism spectrum (Baird et al. 2006; Brugha et al. 2009), with worldwide autism prevalence thought to be approximately one in 160 (Elsabbagh et al., 2012). Yet there are mixed views regarding the prevalence of autism in the Somali community. Hewitt et al. (2016) found that Somali and White children in Minneapolis, USA, were just as likely to be identified as autistic¹ (relative to Black and Hispanic children). In contrast, high rates of autism diagnoses have been reported in other communities. Barnevik-Olsson et al. (2008) found that, in Sweden, the prevalence of autism was three to four times higher in Somali children compared to all other ethnic groups. Elevated, but lower, prevalence rates have been reported in the UK, with Hassan (2012) finding that Somali, Black Caribbean and Black African children were twice as likely to receive an autism diagnosis relative to children from other ethnic groups.

While research is beginning to clarify the numbers of autistic children within the Somali community, there has been limited research on the views and experiences of Somali parents of autistic children. Fox et al. (2016) used semi-structured interviews to examine the experiences of 15 Somali parents of autistic children in Bristol, UK. This research highlighted how ‘navigating the system’ was a major challenge for Somali parents, as English tended not to be their first language. Even parents who were proficient in English struggled, as there is no word for autism in the Somali language. Parents added that they would have benefited from having an interpreter present, or a Somali individual who had

¹ We largely use identity-first (i.e., autistic child), opposed to person-first (i.e., child with autism) language, in view of this being the preferred term of the autistic community (Kenny et al., 2016; Sinclair, 1999) and less associated with stigma (Gernsbacher, 2017).

knowledge and awareness of autism, to support and enhance their understanding of the autism diagnostic and assessment process.

Reports of poor comprehension of autism, and a lack of appropriate language and vocabulary to explain autism, have been linked to stigma within the Somali community. Reporting on the same sample as Fox et al. (2016), Selman et al. (2017) outlined how parents experienced prejudice regarding 'invisible' disabilities within the Somali community, with parenting often being 'blamed' for their children's autism diagnosis. This led to parents feeling discriminated against (both overtly and subtly). Religion was, however, found to play a crucial role in supporting the parents through these circumstances.

Outside the UK, Miller-Gairy and Moyfa (2015) examined the roles of culture and tradition in relation to autism amongst eight Somali mothers of autistic children and six service providers (all involved in an inclusive summer camp for refugees in the USA). They reported that autism was thought to be a new condition caused by vaccinations, environmental factors (e.g., a lack of sunlight leading to vitamin D deficiencies), Western food, and traditional beliefs (e.g., Islamic concepts such as 'jinn'²). Mothers reported their families to be supportive about their children's autism diagnosis, but less than half felt that they received support from their community. Difficulties accessing healthcare services were reported due to language barriers and cultural/religious norms (e.g., not feeling comfortable interacting with male healthcare professionals). Service providers acknowledged that working with Somali families was a challenge, due to language barriers, but also a lack of family and community support that placed families under stress. Miller-Gairy and Moyfa (2015) concluded that there was a need for care providers to develop strong relationships

² A supernatural spirit thought to cause diseases, health problems, unwillingness to talk, accidents, fainting and mental illness (Boddy, 1989; Lewis, 1998). Many Muslims believe that these symptoms can be healed by a sheikh who recites the Quran to rid the body (and mind) of the jinn.

with families, and for professionals to work in partnership with the Somali community, to promote autism awareness (also see Selman et al., 2017).

To our knowledge, there is only one published study that focuses exclusively on the experiences of Somali parents of autistic children in the UK (Fox et al., 2016; Selman et al., 2017), with limited work on this topic outside the UK (e.g., Miller-Gairy & Moyfa, 2015). Extending these findings with a different sample of Somali parents in a different part of the UK is an important endeavour, given that we know so little about knowledge and understanding of autism in the Somali community (in the UK, or internationally). The current research sought to extend preliminary work in this area in three novel ways: (1) by examining knowledge and awareness of autism amongst Somali parents of both autistic and non-autistic children; (2) by ascertaining parental understanding and awareness of not only autism, but also typical and atypical development more broadly; and (3) by replicating (and broadening the generalizability of) existing research, by sampling another Somali community in the UK (London, as opposed to Bristol).

Method

Participants

Somali parents of autistic children were recruited via word-of-mouth, social media, and Somali organisations in London. Participants were included if they were: (1) a Somali parent (to an autistic or non-autistic child); (2) a member of the London Somali migrant community; and (3) able to speak an adequate level of English. All parents who met these criteria were invited to take part in the research. A total of 32 parents (30 mothers, 2 fathers; all from separate families) participated, including 16 parents of autistic children and 16 parents of non-autistic children. Most were first-generation Somali born, largely from South London. As can be seen in Table 1, the characteristics of the parent groups were broadly

similar, except parents of autistic children were significantly more likely to be divorced, whereas parents of non-autistic children were more likely to be married³.

Information was also collected about the autistic children (15 boys, 1 girl) of the parents. These children were, on average, 10.56 years of age ($SD = 2.13$, range = 6 – 15 years); parents first reported concerns about their children's development when they were, on average, 2.19 years of age ($SD = .94$, range = 7 months – 4 years); and their mean age at diagnosis was 5.94 years ($SD = 1.34$, range = 4 – 9 years).

[insert Table 1 about here]

Materials

Parents' knowledge and awareness of typical and atypical development (with a focus on autism) was elicited using a three-part interview methodology developed by Heys et al. (2016). Section One asked how children develop with age (e.g., "how does their behaviour change as they grow up?", "when children are developing, what might make you worry?"). Section Two involved discussion about seven vignettes (each accompanied by bespoke, culturally-appropriate images) (see Figure 1 for examples). Vignettes included descriptions of a typically developing boy (vignette 1), a boy with possible autism (vignettes 2, 3 and 6), a boy with possible developmental delay (DD) (vignette 4), a boy with possible attention deficit hyperactivity disorder (ADHD) (vignette 5) and a girl with possible autism (vignette 7). For each vignette, participants were asked, for example, "is this like other children of this age?" and "do you have any idea what might have caused this?". In Section Three, parents were asked: "What will be of help to the children when they grow old?", "How would the

³ Note that the current sample is small and this pattern is not present in other studies of parents of autistic children (e.g., Freedman Kalb et al., 2012; Hartley et al., 2010; Mandell, 2013).

community perceive or see these children?”, “Can these children go to school? How?”, “Do you think that a family with a child like this needs any particular help?” and “What kind of help would they need?”. Parents of autistic children were also asked specific questions about their children, including: “when did you first start noticing that your child might have difficulties?”, “At what age was your child diagnosed?”, “What does autism mean to you?”, “What do you think autism does?”, “What difference has it made to your family life?”, and “How do you explain to family members or members of the community about your child’s autism?”. The vignettes were always presented in the same order and, importantly, participants were never told whether the behaviours described were typical or atypical.

[insert Figure 1 about here]

Procedure

Ethical approval was granted via the Department of Psychology and Human Development at UCL Institute of Education.

Interviews were conducted by a researcher from the Somali community (to build trust and confidence in parents’ willingness to engage with the research). These took place face-to-face (in community centres or in parents’ homes) and in English. All interviews were recorded and transcribed verbatim⁴.

Quantitative data (regarding whether participants could correctly identify and label the typically and atypically developing children described in the vignettes) were analysed non-parametrically, using chi-square tests. Qualitative data (generated from discussions about

⁴ Note that the interviews of parents of autistic children ($M=41.41$, $SD= 6.63$) were significantly longer than those of parents of non-autistic children ($M=31.99$, $SD=2.40$), $t(30) = 5.34$, $p < .001$. This difference is likely due to the autistic parents having greater knowledge and experience of autism (and therefore talking about their own experiences of parenting an autistic child during the interviews), as well as the additional questions asked of parents of autistic children about their own children.

the vignettes and from responses to the interview questions) were analysed using thematic analysis, as outlined by Braun and Clarke (2006). For the latter analyses, an essentialist framework was used (to report the experiences, meaning and reality of participants, without attempting to fit the data to pre-existing coding schemes or assumptions of the researchers) and a semantic, data-driven approach was employed (without theorising beyond what participants had actually said). The process itself involved the authors independently familiarising themselves with the data (by reading and reviewing transcripts) before generating initial codes and themes. Regular meetings were scheduled to discuss and decide on final themes and sub-themes, as well as to resolve any discrepancies. During this process, the coding structure was reworked and refined to establish themes and sub-themes, which were agreed by the entire research team. Quotes below are attributed according to group: ‘P-AUT’ denotes quotes from parents of autistic children and ‘P-NT’ from parents of neurotypical children.

Results

Interviews began by asking parents to consider what they perceived to be signs of ‘typical’ and ‘atypical’ development in childhood. Parents (with and without autistic children) identified key milestones relating to physical development (e.g., crawling), language development (e.g., babbling) and the development of social interaction (e.g., knowing how to behave around others). They reported that “if they haven’t hit their targets, not at the exact age but six months down the line, I would be worried” (P-AUT). Parents in both groups also consistently identified speech and language delays as key indicators of atypical development: “it is so important that the child is able to speak and express himself. If he can’t then there is a problem and it could be an illness” (P-NT).

As can be seen in Table 2, when presented with the vignettes, parents of autistic children were as likely as parents of non-autistic children to correctly identify the vignette of

a typically developing child. Regarding the six vignettes of atypically developing children, parents of autistic children were, generally, more likely to correctly identify and label the vignettes, particularly those that featured children with possible autism. Yet parents from both groups could identify many behaviours indicative of possible autism, often referring to it by name: “I don’t have a name for it, but in Somali, we had children who were like this, we called them ‘loners’. But here they would most likely say the child has autism” (P-NT). This was not always the case for the autistic girl, however. Here, parents either minimised the level of autistic behaviours: “She sounds like she just doesn’t know how to talk to other people, which in comparison to all the things that could be wrong with her as a girl - is not the worst thing in the world” (P-AUT); or felt that they were not associated with autism: “Some of the children are just shy but, to me, it’s normal, she’s a girl – she’s meant to be this way” (P-NT).

All parents of autistic children could identify the vignette of a child with possible ADHD as being a child who was developing atypically, but only six of the 16 participants were able to use the term ‘ADHD’ to describe these behaviours. Likewise, just three of the 16 parents of non-autistic children, used the label ‘ADHD’. The parents tended to differentiate the child with possible ADHD from the other children presented in the vignettes, using language such as “he is full of kibir (rudeness)” (P-NT), or “he is just full of energy” (P-AUT).

Four out 16 parents of autistic children could identify the child with possible DD. Of the 12 that were unable to correctly label the child in this vignette, ten thought the child was on the autism spectrum. A similar (albeit weaker) pattern emerged amongst the 16 parents of non-autistic children (none of whom labelled the child as having DD), with five labelling the child as autistic. The other parents of non-autistic children either reported that they did not

know/have a term for this behaviour or referred to the child as being mentally ill or slow:

“Maybe, this child has mental health problems, because it is not normal” (P-NT).

[insert Table 2 about here]

Further analyses of the vignette and interview data yielded four key themes: (1) “Somali people don’t understand”, (2) differences between Somalia and the UK, (3) strong reliance on faith, and (4) ways to support Somali autism families in the UK (see Figure 2 for themes and sub-themes).

[insert Figure 2 about here]

Theme 1: “Somali people don’t understand”

Perceived lack of knowledge and understanding of autism. Parents of autistic and non-autistic children felt there was a lack of understanding and awareness of autism in the Somali community due to there being “no word for autism in the Somali language” (P-AUT); as one parent explained: “I never heard of autism before I came to this country” (P-NT). Parents believed that, “[Somali people] don’t know what autism is because we don’t have autism in Somalia” (P-AUT). The absence of overt physical characteristics among autistic children was felt to add to the community’s lack of understanding, and blame was often placed on the parents: “My son looks normal, so when people see how he behaves, they think it’s just bad parenting... I swear it would be easier to explain autism if the child looked disabled, but when a child looks normal and can speak – automatically it’s the parents’ fault” (P-AUT). Parents of autistic children reported how the hidden nature of autism, coupled with the fact that there is no ‘cure’ for autism, made it difficult for them to understand or accept

their child's diagnosis: "I just don't understand how it doesn't have a medication. If you are diabetic there is medication, if you have liver failure there [is] medication or transplant for that. I just don't understand *Subhanallah* [Allah is free from all evil]" (P-AUT).

Prejudice and discrimination. Perceived negative attitudes towards autism in the Somali community meant that many families experienced prejudice and discrimination: "Some people laugh at me, I know that they talk behind my back about my son and call him names... my own family" (P-AUT). Parents explained how these attitudes reinforced families' tendencies to hide their children: "why do I have to open the door for everyone so they can see what is wrong with my child. So, what? They can tell their children and my child is bullied tomorrow? No" (P-AUT). These incidents were attributed to the stigma attached to disability, especially cognitive (opposed to physical) disability, in the Somali community: "Somali people don't understand, your very own sister and brother insult you, because you have an autistic child. Your neighbours and community are no different" (P-AUT). Despite this, some parents reported that they were not ashamed of their child's autism diagnosis and did not want to hide their child from the community: "we do not hide our children and we take our children out and we say it 'my child is autistic' we have no shame and we do not care if we are being judged" (P-AUT).

"Quick to label" in the Somali community. Parents with and without autistic children spoke about labelling people who are 'different' within the Somali community: "we are so quick to label children as being mentally ill or disabled from very small behaviours that we see in them" (P-NT). Parents noted that Somali people, in particular, are inadvertent givers of nicknames and labels: "much of the Somali nicknames are literal like if you're missing an ear, you would be called 'one ear girl', that's just normal" (P-AUT); and parents often used negative labels when asked to describe how the Somali community might refer to the children presented in the vignettes: "these children are often referred to as crazy or sick or

ill” (P-AUT). Parents explained how the lack of appropriate descriptors for autism, coupled with a lack of recognition of autism mean that autism is often seen as a mental illness in Somali culture.

(Not) disclosing their child’s autism. The extent to which parents of autistic children were open about their children’s diagnoses varied. Whilst many openly discussed their children’s diagnoses: “I explain to them what autism is in a simple way” (P-AUT); some chose not to disclose: “I made the choice not to tell people, I don’t want people to pity my son” (P-AUT). Of the parents that were open to disclosing their children’s diagnosis, religious beliefs played a crucial role in their decision: “I have nothing to be ashamed of because *Allah* [God] has made them this way” (P-AUT). Many parents of non-autistic children commented that they felt they were being judged by *Allah*, as *Allah* treats those based on how you treat others: “*Allah* has made them this way and we are being tested on how we treat and look after these children. If we don’t treat them with kindness and look after them then *Allah* won’t be pleased” (P-NT).

Theme 2: Autism is not recognised in Somalia

“In my country autism doesn’t exist”. Many parents felt that autism was only found in the UK, not in Somalia: “In my country autism doesn’t exist, we don’t have autism” (P-AUT). Parents highlighted differences between the two countries as a way of explaining the causes of atypical behaviour: “we don’t have MMR back home and none of our children have autism” (P-AUT). Other parents identified the lack of sun and vitamin D in the UK compared to Somalia as a potential cause of autism: “Somali people, we come from a hot country, we’re exposed to the sun all day and all year around... we come to countries like England, where it is mainly always cold or dark, it could be possible that the change in weather and the lack of vitamin we’re getting could be the cause” (P-AUT).

Lack of provision for autistic children in Somalia. Parents believed that atypically developing children should attend school, but felt this was only possible “if they live[d] in the UK” (P-AUT). As one parent explained: “in the UK, there are special schools designed for children just like them. The children that are unable to speak can go to units, children with autism can go to autistic schools where the teachers are specialist in autism” (P-AUT). In Somalia, however, “these children wouldn’t go to schools because these illness and disabilities are not understood, so the parents would just keep them in the house” (P-NT). Many parents attributed the limited support and provision in Somalia to the lack of understanding and awareness of atypical development. Parents of autistic children specifically commented on the need for special schools, early intervention and one-to-one support: “They need that one-to-one because this will help them, develop the areas in which they are delayed. They need speech and language support, they need professionals who are knowledgeable in autism. They need continuous educational and psychological support” (P-AUT). This was echoed by parents of non-autistic children: “These children need tailored programs that help them build on their skills that they are missing” (P-NT).

Theme 3: Strong reliance on faith

Faith enables parents to accept their child’s diagnosis. Parents’ reported that their reliance on their faith played a crucial role in the acceptance of their child’s autism diagnosis: “Everything happens for a reason and *Allah* intend for it to be this way. My faith tells me that *Allah* has written everything for us, the fact that my children were going to be autistic is already written. My path and my children’s path are written already” (P-AUT). Many parents saw their child’s autism as a test and felt that they would, ultimately, be rewarded. “*Allah* says what I give you, you must be happy with. I truly believe everything I do for my son is good deeds for me in the hereafter. I will be rewarded for the difficulties, so how can I now complain when I know that I will be rewarded” (P-AUT).

“Jinn” as a cause of autism. Parents of autistic and non-autistic children reported on the Somali community’s commonly held belief that autism is result of a *jinn* entering the child’s body: “if the child is making strange noises you don’t understand it’s the *jinn* inside the child. But in this country, they just call it mental health” (P-NT). Other parents described the need to protect themselves from *jinns*: “I tell my boys everyday it is important to keep your *salahs* [prayers] and protect yourself from *jinn*” (P-AUT). Many parents did not believe that *jinns* cause autism: “Some people believe that a *jinn* is inside the child, and that’s why he or she has autism, but this is not true” (P-AUT). Yet one parent, despite stating that *jinns* do not cause autism, still linked the two: “When my son was about eight, his autism got worse [and] he started to get aggressive, hitting and biting. And at night I could hear really strange noises that I couldn’t understand, and I could hear voices that didn’t belong to my son. I called the *sheik* to the house and told him what I heard, and he said, and I believe him, a *jinn* was inside my son. I am not saying that autism is caused by *jinn* but the strange noises, voices that don’t belong to him, that can be explained by the presence of a *jinn*” (P-AUT).

Faith as a source of intervention for autistic children. Parents of autistic children spoke about turning to Islamic scholars and prayers in response to their child’s autism: “I call several *sheiks* and the men in my family, and they all came and read the *Quran* on him” (P-AUT). Parents of non-autistic children also said that they would turn to prayers and Islamic scholars if they discovered their child was developing atypically: “I would call the *sheik* and read the *Quran* on them” (P-NT). However, while prayers were a common practice by all parents, there was a clear move towards combining prayers with seeking more formal advice from healthcare professionals: “I think there has to be a balance, prayers are important but so is medical help” (P-AUT).

Theme four: Ways to support Somali families in the UK

Promoting awareness of autism in the community. Parents called for a need to promote awareness of atypical development, particularly autism, within the Somali community: “We need help understanding these illnesses. Before my son’s autism, I never knew about autism but now my whole life is autism. It is important that parents are taught about these illnesses” (P-AUT). Parents of non-autistic children, in particular, expressed a need for greater understanding of atypical development: “Conditions like autism and ADHD are all very new to the Somali community... the Somali people don’t really understand these conditions [which] means that they can’t seek help within each other to support each other... I don’t know even know what causes autism and I considered myself to be well informed” (P-NT). Encouragingly, some parents of autistic children felt there was growing awareness of autism in the Somali community, but added that there was still a long way to go: “I hope in the near future this will change, but already I think because autism is more common and more mainstream than a lot of disorders, it is causing more Somali people to come out and not be ashamed” (P-AUT).

Building capacity within the Somali community. Language was identified as a barrier to support by both groups of parents: “The sad thing is, some of these families are unaware of the services and schools available for their children simply because they don’t speak the language. This would mean that the families would lose out on crucial support that could have been available to them. Having an interpreter or having a support worker that speaks Somali is very crucial” (P-AUT). Parents of autistic children, in particular, called for professionals who understood their culture to deliver training: “Any training offered to families would have to be culturally sensitive to ensure that it’s appropriate for them and meets their needs” (P-AUT). Likewise, another parent commented: “It is so important that we educate and train parents on how to cope with having children with disability. It would be

great if there were someone who spoke English and Somali, who understood autism that could provide support to these families” (P-AUT).

Discussion

The current study investigated knowledge and awareness of autism, and typical and atypical development more broadly, amongst Somali parents with and without autistic children. A particularly novel aspect of the current study was the focus on Somali parents’ knowledge and awareness of autism but also typical and atypical development more broadly. Without a comparison group of non-Somali parents, it is difficult to make firm conclusions from these data. Nevertheless, it appears that Somali parents of autistic and non-autistic children could, generally, identify behaviours indicative of possible autism (especially in autistic boys), often referring to it by name. Whilst this was not the case for all parents (even those with autistic children, perhaps reflecting the diversity of the autism spectrum), it does suggest growing awareness and recognition of autism amongst the UK-based Somali community. This was not, however, the case when parents were asked to identify and label the children with other forms of atypical development (e.g., ADHD, DD). Here, parents often used alternative descriptions of the children’s behaviour (e.g., being full of energy, being rude) or even mislabelled the children as autistic. This finding highlights the need for greater efforts to raise awareness of all forms of atypical development amongst the Somali community. Otherwise, there is a risk that the term ‘autism’ may take on its own meaning within the community, such that autism becomes a euphemism for a range of developmental problems.

Interviewing Somali parents about typical and atypical child development also highlighted three key sociocultural factors that either helped or hindered the inclusion of families of autistic children within the community, including: (1) the Somali community’s perceptions of disability; (2) their beliefs about the causes of autism in the Western world;

and (3) their strong reliance on religious beliefs in understanding and accepting their child's autism diagnosis.

This study is not the first to highlight the Somali community's (perhaps negative) perceptions of disability (also see Arboleda et al., 2014; Fox et al., 2016; Miller-Gairy & Mofya, 2015), nor are such perceptions of disability unique to the Somali community (e.g., Daley, 2004; Grinker & Cho, 2013). Yet, parents in the current study felt that the Somali community's perception of atypical development could be particularly negative. Selman et al. (2017) discussed how this can result in stigma for both the child and the family (*courtesy stigma*), as well as the families themselves, who internalise this stigma and can lead to them not disclosing their child's autism diagnosis (*affiliate stigma*). Yet it is difficult to reduce the prejudice and discrimination experienced by Somali parents of autistic children to stigma alone, given that it is the norm to use nicknames and labels in this community. Whilst using nicknames and labels is found in other cultures and communities, parents in the current study reported that they felt this was particularly common amongst Somali people. The consequences of this also extend beyond autism: Loewenthal et al. (2012), for example, found that the Somali community's negative perceptions of mental health problems led to people concealing mental health problems that they experience. This may be due to feelings of shame or stigma, or fear of health professionals (Palmer, 2007; Whittaker et al. 2005).

The second sociocultural factor highlighted in this study regarded Somali parents' belief about Western causes of autism. Our sample of Somali parents emphasised that autism appears to exist in the UK and not in Somalia (also see Fox et al. 2016). This extends beyond the UK, with studies conducted in Minnesota reporting that the Somali community refer to autism as the "Minnesota Disease" (Arboleda et al. 2014) and in Sweden as the "Swedish

Disease” (Barnevik-Olsson et al. 2008)⁵. Indeed, BAME communities are more likely to see autism as a “white-only condition” (The National Autistic Society, 2013) and are less likely to associate autism with their native country. It is not possible to confirm whether this is based on a lack of knowledge of autism in Somalia or if there is a genuine difference in prevalence rates in the UK and Somalia. As such, there is a clear need to better understand the presentation of autism and the support of autistic children, young people and adults in this culture. Indeed, Decoteua (2017) recently proposed that race and nationality are integral to the way in which the Somali community conceptualise and explain the etiology and ontology of autism.

In the current sample, parents highlighted differences between Somalia and the UK as a way of explaining the causes of autism, especially regarding vaccinations. They spoke in detail about their own children, or children they knew, who ‘became autistic’ after receiving the MMR vaccination. They also noted how the MMR vaccination was not given to children in Somalia and could therefore be a cause of autism (since the MMR vaccination is routinely given in the UK). These findings are consistent with data highlighting how Somali parents have significant suspicions about the MMR vaccination and its links to autism (Tomlinson & Redwood, 2013), and are more likely to refuse the MMR vaccination than non-Somali parents (Wolff & Madlon-Kay, 2011). This is despite overwhelming evidence that there is no link between the MMR vaccine and autism (e.g., Taylor et al., 2014). The same applies to Vitamin D deficiency, which was commonly highlighted by our sample of parents as being causally related to autism, despite more research being needed to validate such suggestions (Fennell et al. 2015).

⁵ The authors do not condone the use of the term ‘disease’ in relation to autism, but are reporting this term verbatim, for scientific accuracy.

The Somali community's distrust of Western explanations of autism extends to healthcare more broadly. Raymond et al. (2014), for example, found that the Somali community were less likely to engage with cancer screening services due to beliefs that radiation from mammograms could cause cancer. Indeed, this disconnect between parents' and professionals' beliefs about the causes of autism exists beyond the Somali community (e.g., Fischbach et al., 2016). Previous studies have highlighted the significant influence of friends and family (i.e., local communities) on parents' decision making about healthcare issues (e.g., Brown et al., 2012; Brownlie & Howson, 2005). Appropriate information that explicitly addresses the fears of the Somali community surrounding Western explanations of autism, as well as a closer relationship between the local Somali community and healthcare professionals, are essential to ensure that the Somali community is well informed in this regard.

The third sociocultural factor identified in the current study was parents' strong reliance on religious beliefs in understanding and accepting their child's autism diagnosis (also see Fox et al., 2016; Selman et al., 2017). This interpretation is consistent with studies in South Asian Muslim communities (e.g., Jegatheesan et al., 2010), as well as those with other religious faiths (e.g., Gabel, 2004; Skinner et al. 2001). In such studies, parents of autistic children felt that their strong faith allowed them to uphold a positive attitude, accept their child's disability, and thus help their child (also see Jegatheesan et al., 2010; Morad et al., 2010). Religious beliefs appear to promote psychological wellbeing more broadly within the Somali community (see Whittaker et al., 2005). Ellis et al. (2010), for example, found that while mental health expertise was not valued by the Somali community, religion was a highly-valued source of healing. In addition, Hill et al. (2012) found that Somali women had more faith in God than science with regards to pregnancy and childbearing. However, the parents in the current study expressed a willingness to ensure that religious beliefs went

hand-in-hand with seeking help from healthcare professionals with regards to their autistic children.

The sociocultural factors identified in the current study are remarkably concordant with the results of previously published research on this group in another region of the UK (Fox et al., 2016; Selman et al., 2017) and in the US (Miller-Gairy & Moyfa, 2015). Such concordance is perhaps unusual in small qualitative studies across geographical areas, highlighting the robustness of the results. This is encouraging, since this sample represents a group whose views are rarely included in autism research (Corbett & Perepa, 2004; Slade, 2014). Nevertheless, this research is not without its limitations. First, the sample was small and therefore results of the group comparisons should be considered exploratory. The sample also focused heavily on mothers, with only two fathers involved in the study. This pattern is a reflection of research on parents of autistic children in general (e.g., Crane et al., 2016) but particularly of the limited research within the Somali community (e.g., Fox et al., 2016; Miller-Gairy & Mofya, 2015; Selman et al., 2017). Experiences of motherhood and fatherhood can be very different (Burrell et al., 2017), and it is important to investigate this more fully in future research on autism in the Somali community. Second, parents were recruited via convenience sampling from just one region in the UK, and were interviewed in English and not in Somali. Previous studies on autism in the Somali community have used an interpreter to elicit greater detail from participants (e.g., Arboleda et al., 2014; Fox et al., 2016; Selman et al., 2017), yet, due to resource constraints, this was not possible in the current study. Somali parents that do not speak an adequate level of spoken English may have different views and beliefs around atypical development (including autism), and particularly services (since they may be even more excluded from support available to parents of children on the autism spectrum). Although future research would benefit from ensuring that parents who do not speak English are not excluded from research, and that a larger, more

representative sample of parents was recruited, it is encouraging that our results so strongly echo those of previous studies on Somali parents of autistic children living in a different location in the UK (e.g., Fox et al., 2016; Selman et al., 2017) and in the US (Miller-Gairy & Moyfa, 2015). Finally, all participants in this study were parents of autistic or non-autistic children. Researchers should, in future, adopt a multi-informant approach whereby all key stakeholders (including professionals working with the Somali community, and autistic individuals from a Somali background) can contribute to the discussion (also see Miller-Gairy & Moyfa, 2015). This approach is crucial, as the views and experiences of different informants may not always align (e.g., Calder et al., 2013).

In conclusion, the Somali parents of autistic children in this study highlighted key socio-cultural difficulties they experienced in relation to autism, as well as barriers in accessing appropriate help and support. Some of the challenges highlighted (i.e., lack of available services, prejudice and discrimination) are not unique to the Somali community and have been reported by other ethnic groups (Sen & Sabire, 2007; The National Autistic Society, 2013). Yet, Somali parents in this study emphasised challenges that are specific to their culture, such as cultural beliefs about the causes of autism, as well as an emphasis on nicknaming and labelling. To ensure that Somali parents with an autistic child can access necessary support and services, professionals should (ideally) be from, or at least familiar with, the needs of the specific community. Somali parents with autistic children should also be included in the design of local services that will, ultimately, affect them and their family. By involving these individuals, and listening to the challenges and barriers they face, services can more successfully support and meet the needs of Somali families with autistic children in the UK.

References

- Arboleda, M., Call, K., Chang, X.G.S., Egal, M., McAlpine, D., Novillo, W., Pergament, S., & Yang, M.K. (2014). *A Qualitative Study of Families of Children with Autism in the Somali Community: Comparing the Experiences of Immigrant Groups*. Minnesota Department of Health. Report to the Minnesota Legislature.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, *368(9531)*, 201-215. doi: 10.1016/S0140-6736(06)69041-7
- Barnevik-Olsson, M., Gillberg, C., & Fernell, E. (2008). Prevalence of autism in children born to Somali parents living in Sweden: A brief report. *Developmental Medicine and Child Neurology*, *50(8)*, 598–601. doi: 10.1111/j.1469-8749.2008.03036.x
- Boddy, J. (1989). *Wombs and alien spirit: Women, men, and the zar cult in Northern Sudan*. Madison: University of Wisconsin Press.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3(2)*, 77-101. doi: 10.1191/1478088706qp063oa
- Brown, F, K., Long, J, S., Ramsay, M., Hudson, J, M., Green, J., Vincent, A, C., Kroll, S., Fraser, G., & Sevdalis, N. (2012). UK parents' decision-making about measles–mumps–rubella (MMR) vaccine 10 years after the MMR-autism controversy: A qualitative analysis. *Vaccine*, *30(10)*, 1855-1864. doi: 10.1016/j.vaccine.2011.12.127
- Brownlie, J., & Howson, A. (2005) A Leaps of faith and MMR: an empirical study of trust. *Sociology*, *39*, 221- 39. doi: 10.1177/0038038505050536
- Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F.J., Purdons, S., Harris, J., & Bankart, J. (2009). Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007. The

- Health & Social Care Information Centre, Social Care Statistics. Retrieved from <https://www.scribd.com/document/157134286/Autism-Spectrum-Disorders-in-Adults-Living-in-Households-Throughout-England>.
- Burrell, A., Ives, J., & Unwin, G. (2017). The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(4), 1135-1147. doi: 10.1007/s10803-017-3035-2
- Calder, L., Hill, V., & Pellicano, E. (2013). Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism*, 17(3), 296-316. doi: 10.1177/1362361312467866
- Corbett, C., & Perepa, P. (2007). *Missing Out? Autism, Education and Ethnicity: The Reality for Families Today*. London: National Autistic Society.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153-162. doi: 10.1177/1362361315573636
- Daley, T. C. (2004). From symptoms recognition to diagnosis: Children with autism in urban India. *Social Science and Medicine*, 58, 1323-1335. doi: 10.1023/A: 101794922349
- Decoteau, L. C. (2017). The “Western disease”: Autism and Somali parents' embodied health movements. *Social Science and Medicine*, 177, 169-176.
doi:10.1016/j.socscimed.2017.01.064
- Ellis, H., Lincoln, K, A., Charney, E, M., Ford-Paz, R., Benson, M., & Strunin. L. (2010). Mental Health Service Utilization of Somali Adolescents: Religion, Community and School as Gateways to Healing. *Journal of Transcultural Psychiatry*, 47(5), 789-811.
doi: 10.1177/1363461510379933

- Elsabbagh, M. , Divan, G. , Koh, Y. , Kim, Y. S., Kauchali, S. , Marcín, C. , Montiel-Nava, C. , Patel, V., Paula, C. S., Wang, C. , Yasamy, M. T., & Fombonne, E. (2012), Global epidemiology of autism. *Autism Research*, 5, 160-179. doi:10.1002/aur.239
- Fernell, E., Bejerot, S., Westerlund, J., Miniscalco, C., Simila, H., Eyles, D., Gillberg, C., & Humble, M.B. (2015). Autism spectrum disorder and low vitamin D at birth: a sibling control study. *Molecular Autism*, 6: 3. doi: 10.1186/2040-2392-6-3
- Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2016). “It was like walking without knowing where I was going” A qualitative study of Autism in a UK Somali Migrant Community. *Journal Autism Developmental Disorders*, 47(2), 305- 315. doi: 10.1007/s10803-016-2952-9
- Freedman, B, H., Kalb, L, G., Zablotzky, B., & Stuart, E, A. (2012) Relationship status among parents of children with autism spectrum disorders: a population-based study. *Journal of Autism and Developmental Disorders* 42(4), 539–548. doi: 10.1007/s10803-011-1269-y
- Gabel, S. (2004). South Asian Indian Cultural orientation toward mental retardation. *Mental Retardation*, 42, 12-25. doi: 10.1352/0047-6765(2004)42<12:SAICOT>2.0.CO;2
- Gernsbacher, M.A. (2017). The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861. doi: 10.1111/jcpp.12706
- Grinker, R.R., & Cho, K. (2013). Border Children: Interpreting Autism Spectrum Disorder in South Korea. *Ethos*, 41(1), 46-74. doi: 10.1111/etho.12002
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology* 24(4), 449–457. doi: 10.1037/a0019847

Hassan, M. (2012). Predicting the prevalence of Autism among ethnic groups. *Archives in Disease in Childhood, 97*, 95–96.

Hewitt, A., Hall-Lande, J., Hamre, K., Esler, N., Punyko, J., Reichle., & Gulaid, A, A. (2016). Autism Spectrum Disorder (ASD) Prevalence in Somali and Non-Somali Children. *Journal of Autism and Developmental Disorders, 46* (8), 2599-2609. doi: 10.1007/s10803-016-2793-6.

Heys, M., Alexander, A., Medeiros, E., Tumbahangphe, K, M., Gibbons, F., Sherstha, R., Mangala, M., Wickenden, M., Shrestha, M., Costello, A., Manadhar, D., & Pellicano, E. (2016). Understanding parents' and professionals' knowledge and awareness of autism in Nepal. *Autism, 21*(4), 1-14. doi: 10.1177/1362361316646558

Hill, N., Hunt, E & Hyrkas, K. (2012). Somali immigrant women's health care experiences and beliefs regarding pregnancy and birth in the United States. *Journal of Transcultural Nursing, 23*(1), 72-81. doi: 10.1177/1043659611423828

Jegatheesan, B., Miller, J, P., & Fowler, A, S. (2010). Autism from a Religious Perspective: A study of Parental beliefs in South Asian Muslim Immigrant Families. *Focus on Autism and Other Developmental Disabilities, 25*(2), 98-109. doi: 10.1177/1088357610361344

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. doi: 10.1177/1362361315588200

Lewis, I. M. (1998). *Saints and Somalis: Popular in a clan-based society*. London: Haan Associates.

Loewenthal, D., Mohammed, A., Mukhopadhyay, S., Ganesh, K., & Thomas, R. (2012). Reducing the barriers accessing psychological therapies for Bengali, Urdu, Tamil and Somali communities in the UK: some implications for training, policy and practice.

- British Journal of Guidance and Counselling*, 40(1), 43-66. doi:
10.1080/03069885.2011.621519
- Mandell, D.S. (2013). Divorce among parents of children with autism: dispelling urban legends. *Autism*, 17(6), 643-644. doi: 10.1177/1362361313509528
- Miller-Gairy, S. & Mofya, S. (2015). Elements of culture and traditions that shape the perception and expectation of Somali refugee mothers about autism. *International Journal of Child and Adolescent Health*, 8(3), 335-349. doi: 10.1007/s10803-016-2952-9
- Morad, M., Nasri, Y., & Merrick, J. (2001). Islam and the person with intellectual disability. *Journal of Religion, Disability and Health*, 5, 65-71. doi:
10.1080/02673843.2011.649565
- Palmer, D. (2007). Caught between inequality and stigma: the impact of psychosocial factors and stigma on the mental health of Somali forced migrants in the London Borough of Camden. *Diversity in Health and Social Care*, 4, 177-191.
- Raymond, N.C., Osman, W., O'Brien, J.M., Ali, N., Kia, F., Mohamed, F., Mohamed, A., Goldade, K.B., Pratt, R., & Okuyemi, K. (2014). Culturally informed views on cancer screening: a qualitative research study of the differences between older and younger Somali immigrant women. *BMC Public Health*, 14: 1188. doi: 10.1186/1471-2458-14-1188
- Selman, L., Fox, F., Aabe, N., Turner, K., Rai, D., & Redwood, S. (2017). 'You are labelled by your children's disability': A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom. *Ethnicity and Health*. doi: 10.1080/13557858.2017.1294663.

- Sen, E & Sabire, Y. (2007) Difficulties experienced by families with disabled children. *Journal for specialists in Paediatric Nursing*, 12 (4), 238-252. doi: 10.1111/j.1744-6155.2007.00119.x
- Sinclair, J. (1999). Why I dislike 'person-first' language. Retrieved from: http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm (accessed 21 January 2018)
- Skinner, D., Correa, V., Skinner, M., & Bailey, D. (2001). Role of religion in the lives of Latino families of young Children with developmental delays. *American Journal on Mental Retardation*, 106, 297-313.
- Slade, G. (2014). *Diverse Perspectives: The Challenges for Families Affected by Autism from Black, Asian and Minority Ethnic Communities*. London: The National Autistic Society.
- Taylor, E, L., Swerdfeger, L, A., & Guy, D, E. (2014). Vaccines are not associated with autism: An evidence based meta-analysis of case control and cohort studies. *Vaccines*, 32(29), 3623-3629
- The National Autistic Society (2013). *Push for Action: We need to turn the Autism Act into action*. London: The National Autistic Society
- Tomlinson, N., & Redwood, S. (2013). Health beliefs about preschool immunisations: an exploration of the views of Somali women resident in the UK. *Diversity & Equality in Health and Care*, 10, 101-113
- Whittaker, S., Hardy, G., Lewis, K & Buchan, L. (2005). An exploration of Psychological well-being with young Somali refugee and asylum-seeker women. *Jjournal of Clinical Child Psychology and Psychiatry*, 10(2), 177-196. doi: 10.1177/1359104505051210

Wolff, E.R., & Madlon-Kay, D.J. (2014). Childhood vaccine beliefs reported by Somali and non-Somali parents. *Journal of the American Board of Family Medicine*, 27(4), 458-464. doi: 10.3122/jabfm.2014.04.130275

Table 1. *Participant characteristics.*

		Parents of autistic children (n=16)	Parents of non-autistic children (n=16)	Statistics
Age		M=39.56 (SD=6.51) Range = 27 – 50 years	M=39.50 (SD=7.27) Range = 27 – 50 years	$t(30) = .03, p=.98$
Gender	Male	1 (6.25%)	1 (6.25%)	$\chi^2(1) = .00, p=1.00$
	Female	15 (93.75%)	15 (93.75%)	
Years in the UK		M=18.06 (SD=5.43) Range = 8 – 28 years	M=19.25 (SD=5.01) Range = 9 – 25 years	$t(30) = .64, p=.53$
Relationship status	Married	6 (37.5%)	13 (81.25%)	$\chi^2(2) = 8.02, p=.02$
	Divorced	8 (50.00%)	1 (6.25%)	
	Single	2 (12.5%)	2 (12.5%)	
Education level^a		M=2.87 (SD=1.02) Range = 1 – 4	M=2.67 (SD=1.01) Range = 1 – 4	$t(30) = .52, p=.61$

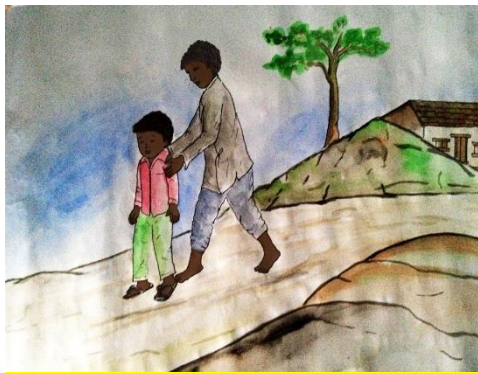
^a Parental education level was scored on a scale from 1 (no formal qualifications), 2 (school level), 3 (college level), 4 (university level).

Table 2. *Parents of autistic and non-autistic children who correctly identified and labelled the vignettes of typically and atypically developing children.*

Vignette		Parents of autistic children (max = 16)	Parents of non-autistic children (max = 16)	Statistics (two-tailed significance)
1) Boy with typical development	Correctly identified?	8 (50%)	10 (62.5%)	$\chi^2(1) = .51, p = .48$
	Correctly labelled?	8 (50%)	10 (62.5%)	$\chi^2(1) = .51, p = .48$
2) Boy with possible autism	Correctly identified?	16 (100%)	13 (81.2%)	$\chi^2(1) = 3.31, p = .07$
	Correctly labelled?	14 (87.5%)	8 (50%)	$\chi^2(1) = 5.24, p = .02$
3) Boy with possible autism	Correctly identified?	16 (100%)	11 (68.7%)	$\chi^2(1) = 5.93, p = .01$
	Correctly labelled?	16 (100%)	7 (43.7%)	$\chi^2(1) = 12.52, p < .001$
4) Boy with possible DD	Correctly identified?	16 (100%)	14 (87.5%)	$\chi^2(1) = 2.13, p = .14$
	Correctly labelled?	3 (18.7%)	1 (6.25%)	$\chi^2(1) = 1.14, p = .28$
5) Boy with possible ADHD	Correctly identified?	14 (87.5%)	6 (36.5%)	$\chi^2(1) = 8.53, p = .003$
	Correctly labelled?	7 (43.7%)	3 (18.7%)	$\chi^2(1) = 2.33, p = .13$
6) Boy with possible autism	Correctly identified?	16 (100%)	16 (100%)	n.s.
	Correctly labelled?	13 (81.2%)	7 (43.7%)	$\chi^2(1) = 4.80, p = .03$
7) Girl with possible autism	Correctly identified?	14 (87.5%)	5 (31.2%)	$\chi^2(1) = 10.49, p = .001$
	Correctly labelled?	11 (68.7%)	1 (6.25%)	$\chi^2(1) = 13.33, p < .001$



Vignette 1: Let's think about Mohammed. He is a 2-year-old boy who can make a sentence using two to four words. He likes playing 'pretend' using toys with his parents. When parents call his name, he almost always responds with a smile. He looks at his parents' eyes when they are talking to him. He points at things that he likes in order to attract attention from his parents and grandparents.



Vignette 6: Let's think about Hussein, he is an 8 year old boy who isn't going to school because the teachers said he was difficult in class. He talks to himself and makes strange noises all the time. He is very good at counting, but then is not good at looking after himself, e.g. getting himself dressed, feeding himself or going to the toilet. He opens and shuts doors all the time. He seems to watch what other children do but finds it hard to join in with their games. He likes to sit with one of his uncles and gets upset and anxious if he has to stay with other adults.

Figure 1. Examples of vignettes with corresponding illustrations, used in the current study.

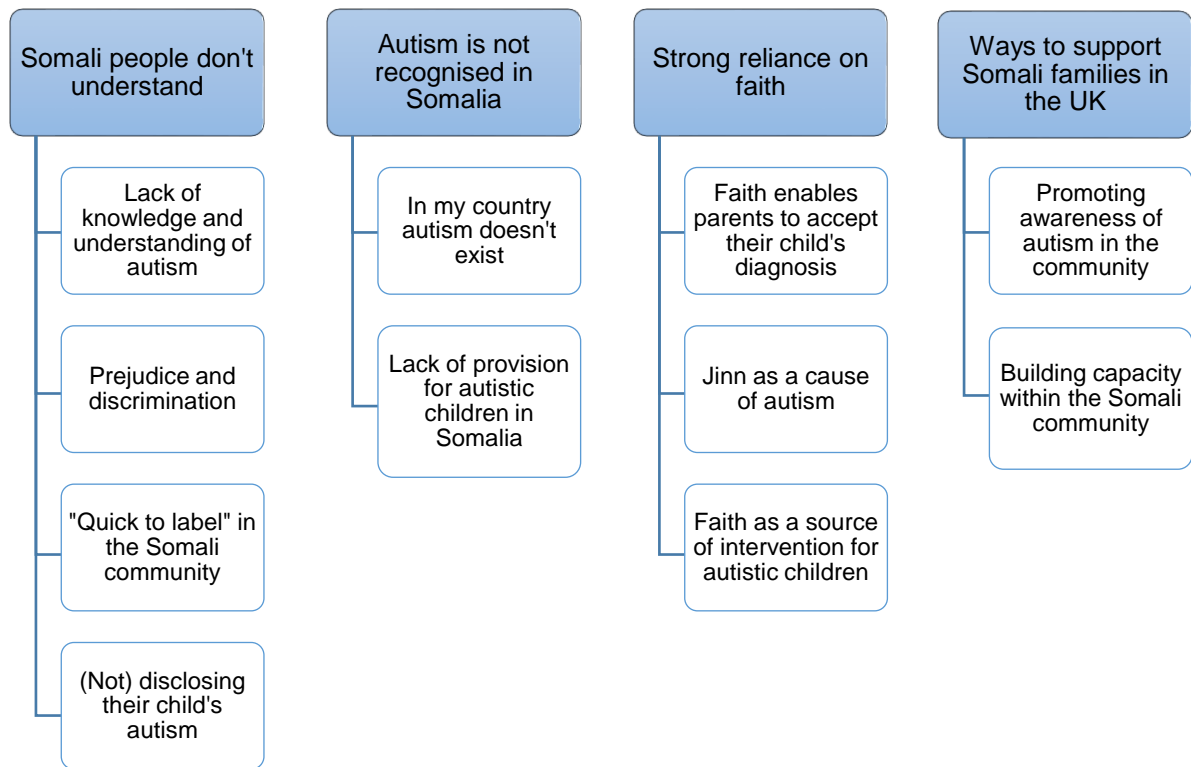


Figure 2. Somali parents' understanding and awareness of autism: themes and subthemes.