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Perceptions of autism spectrum disorder among the Swahili community on the Kenyan coast

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ABSTRACT

Background: In high-income and Western societies there is great understanding and awareness of autism spectrum disorder (ASD); however, for many low-middle income countries, research and knowledge is notably lacking. In Africa, there is a growing prevalence of ASD due to increased diagnosis, yet it is still a poorly understood condition.

Aims: Emerging literature has emphasised how cultural and societal beliefs underpin the level of understanding of ASD, and which typically results in lack of awareness and acceptance. As such it is important to investigate the cultural perceptions towards ASD within low-middle income communities of African culture, to further understand the challenges and barriers individuals with ASD face. The aim of the current study was to probe participants from the Swahili community, on the coast of Kenya, of their cultural views towards ASD.

Method: Semi-structured interviews were conducted with seven participants, and the data analysed using thematic analysis.

Results: Three key themes developed from the data; stigma, lack of awareness, and Government responsibility.

Conclusion: Cultural perceptions negatively impacted awareness and are exacerbated by lack of directive from the Government in providing appropriate diagnostic and educational support.

What this paper adds?

While in high-income and Western societies general perceptions about autism spectrum disorder (ASD) are broadly understood, the knowledge of perceptions of ASD in low-middle income counties is limited. The current research expands on this by investigating how ASD is perceived within the Swahili community, an under-researched populace located on the Kenyan coast of Africa. Through the three themes which emerged from the data, this study begins to develop a clearer understanding of the community's views about ASD. Similar to many low-middle income countries, where societal customs and social norms are particularly important, the Swahili culture is rooted in religion and tradition; therefore, neurodevelopmental conditions such as ASD are not widely accepted due to the associated societal stigma and linked somewhat to superstitious beliefs. This builds upon the past research with similar populations in Africa, where lack of awareness and acceptance regarding neurodiversity is bi-directional. The study has emphasised how much greater input from the Kenyan Government is required to both educate this community and provide adequate resources to support individuals with

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ASD and their families, as well as professional services and teachers. In all, opinions and understanding of ASD within the Swahili community are better understood because of this research. In turn, this work may act as a stepping-stone for further research and awareness campaigns within the Swahili community in Kenya and similar African populations.

1. Introduction

Autism spectrum disorder (ASD) is a developmental disorder, with diagnosis typically based on a triad of impairments including social and communication skills, along with rigid and repetitive patterns of behaviour and interests (American Psychiatric Association, 2013). The cause of ASD is unknown, though genetic, biological, and environmental explanations have been suggested (see Fakhoury, 2015). ASD is frequently comorbid with a range of conditions, such as epilepsy, attention problems, gastrointestinal problems, feeding disorders, oppositional behaviour, anxiety, depression, and sleep disorders (Hodgetts et al., 2015). In high-income and Western societies, there is awareness of ASD in the context as a developmental disorder. This is inconsistent worldwide, as understanding of ASD and information about it are broadly lacking in some low-middle income countries, including many in Africa (Bakare & Munir, 2011; Chambers et al., 2017). However, it is predicted that the prevalence of ASD in Africa is greater than it is currently known (Bakare et al., 2014). A recent study of over 1 million children, attending school in the Western Cape Province of South Africa, found that ~1% had a diagnosis of ASD (Pillay et al., 2021); this rate is similar to prevalence estimates of ~1.5% reported in other developing countries (Lyall et al., 2017).

ASD-focussed research in Africa is notably lacking, however a growing body of evidence demonstrates that many communities do not recognise ASD as a neurodevelopmental disorder. Rather, cultural attitudes play an important role on both professional and familial perceptions about causes of ASD and treatment options for autistic people (Bunning et al., 2017; Gona et al., 2015). One notable population is the Swahili community, located on the coastal strip of Kenya in East Africa. Swahilis are predominantly Muslim, with societal beliefs firmly rooted in religion, culture, and tradition (Eastman, 1994; Swartz, 1988). Central within Swahili culture is the avoidance of bringing shame to the family, accordingly societal issues are not openly discussed for fear of stigma and ridicule (Bakare et al., 2014). As such, the culture itself promotes the idea of secrecy, and Swahilis go to considerable lengths to achieve “*siri*” (secret) and avoid “*aziri*” (exposure) (Swartz, 1988). This cultural approach results in a lack of awareness of, and misunderstood attitudes towards ASD.

The Swahili way of life is conservative, priding themselves on passing their culture between generations. For instance, traditional gender roles are embedded into children from a young age (Gearhart, 2013) along with primary caregiving being the mother’s responsibility (Kawarazuka et al., 2019). A child with ASD, therefore, negatively reflects upon the mother’s style of parenting (Cloete & Obaigwa, 2019) and any associated shame is attributed to the mother’s nurturing, rather than due to neurodiversity (Dehnavi et al., 2011; Gona et al., 2016). The characteristics associated with ASD are also believed to be the result of a child receiving preferential parental treatment and, as such, that they will outgrow such behaviours (also see Fox et al., 2017). Many Kenyan communities attribute disability to preternatural causes such as witchcraft and evil spirits (Bunning et al., 2017), thus these superstitious cultural beliefs negatively influence attitudes towards individuals with ASD and their families (Ricci, 2011). This results in emotional distress, feelings of guilt, financial difficulties, and disrupted family relationships (Gona et al., 2010). Furthermore, these cultural attitudes embed both spiritual and societal expectations. For example, Cloete and Obaigwa (2019) interviewed parents of children with ASD and reported overarching emotional burden, with the disorder blamed on inter-tribe marriages and possession of evil spirits, predominantly due to the mother’s actions; a pattern which is mirrored within other African communities (Bakare et al., 2009; Cohen, 2012).

Within professional services in Africa, there are many barriers to support individuals with ASD and their families, including a lack of awareness regarding symptoms, prognosis, and treatment by healthcare workers (Bakare et al., 2009; Igwe et al., 2011). These problems are magnified due to large rural populations with differing languages and dialects (Franz et al., 2017; Ruparelia et al., 2016), and because resources to translate and validate established diagnostic materials is lacking (Abubakar et al., 2016). Thus, despite parents raising developmental concerns, reduced access to appropriate screening and diagnostic resources can delay diagnosis (Bakare et al., 2022; Franz et al., 2017) and intervention (Oswald et al., 2017). In low-middle income countries in Africa, formal diagnosis of ASD often occurs relatively late compared to high-income countries outside of Africa (Bakare et al., 2009). A recent study found the average age for diagnosis of children with ASD in Nigeria was 9 years of age, taking around 7 years from parents raising concerns to receiving pre-diagnostic support, and a further 6 months to diagnosis (Bello-Mojeed et al., 2017). This is exacerbated by a shortage of facilities and qualified personnel which results in a lack of support for both the child and their families (Paget et al., 2016; Sengupta et al., 2017). However, even when specialist educational provisions are accessible, the delivery of the curriculum does not factor in the needs of individuals with ASD and other disabilities (Ekene & Oluoch-Suleh, 2017), and does not consider the specific needs to enable inclusivity (Ileri et al., 2021; Ressa, 2021). A similar pattern is observed in other low-middle income countries, such as India, where parents have voiced concerns regarding appropriate educational facilities and lack of professional expertise (Minhas et al., 2015).

Although emerging literature is helping to increase awareness of ASD in Sub-Saharan countries, it is still a poorly understood condition in Africa. Culture is important within the Swahili community, but there is limited research investigating the influence of their cultural perceptions towards ASD, and how this may impact on awareness and support for these individuals and their families. The aim of the current study was to expand on the literature by investigating perceptions and understanding of ASD among the Swahili community from a closer perspective. Using qualitative methods, semi-structured interviews allowed the researchers to explore the opinions and experiences of Swahili community members, and to probe a more detailed understanding on the perspectives of ASD from this community. This enabled the participants to give a voice to the issues surrounding cultural perception and awareness of ASD within their community, along with identifying barriers faced when trying to support individuals with ASD.

2. Method

2.1. Design

The research used a qualitative approach and employed inductive thematic analysis. Participants engaged in semi-structured interviews and gave their own perspective of what they felt was important. Participants were able to provide information based on their lived experiences. The process allowed the researcher to have a clearer understanding as to how ASD was perceived.

2.2. Participants

Participants were recruited through social media and personal contacts. Purposive sampling was used, focusing on potential participants who live at the Kenyan coast and have some awareness of ASD, or had an ASD diagnosis themselves. Seven participants were interviewed, including two males; participant ages ranged from 38 to 60 years. Six participants were from the Swahili community in Mombasa and one originally from the Swahili community in Kilifi, a coastal community north of Mombasa. All participants were living in Mombasa at the time of interviewing. All had some basic knowledge or understanding of ASD, and one participant has an autistic cousin. All participants were well-educated with all having a minimum of an undergraduate (UG) degree or equivalent. Their employment statuses were an accountant, a businessman, two clinical and counselling professionals, a lawyer, a medical laboratory technologist, and an engineering and military intelligence employee. Participants' names were replaced with pseudonyms to maintain anonymity.

2.3. Procedure

Ethical approval for the study was provided by the authors' institutional Department of Psychology ethics committee (ethics number: 32958). The participants were emailed an information sheet and consent form, and the interviews took place with author 2 via Zoom, the online video-calling platform. The interviewer was fluent in both Swahili and English, and whilst all interviews were conducted predominantly in English, small amounts were carried out in Swahili which were then translated to English in the transcription. Interviews lasted approximately 30–40 minutes.

A semi structured interview format was used to establish what the participants knew of, or understand about, ASD (e.g. *How do you think people get autism?*), their personal opinions towards individuals with ASD (e.g. *What are the factors inhibiting the increase in awareness of ASD in your community?*), and whether their cultures and communities recognise and support individuals with ASD (e.g. *How do you think the community perceives autism?*). In all, the interview schedule comprised 21 questions with additional follow-up points across the three key areas. The interview schedule is available in the [Supplementary Materials](#). The interviews were audio recorded and transcribed verbatim using the online transcription service Otter, before re-listening and checking the transcripts for accuracy. The interview with the first participant was treated as a pilot. After this interview the recording was listened to and the transcript read closely, making notes of any changes that may be required to the interview schedule. However, as no major changes were deemed necessary, that participant's data is included in the analysis.

2.4. Data analysis

Thematic analysis was used to analyse the data, using six steps of analysis (Braun & Clarke, 2006, 2019).

Phase 1: Dataset familiarisation

Author 2 conducted the interviews and transcribed the data, including translations where appropriate. All researchers then familiarised themselves with the data by reading and re-reading the transcripts.

Phase 2: Data coding

Using NVivo, author 2 highlighted the transcripts and arranged highlights into initial codes. These codes were given code labels to summarise their meaning. Codes were predominantly inductive, deriving directly from the data rather than from theory and past research.

Phase 3: Initial theme development

Author 2 clustered the codes and code labels, essentially creating the earliest set of provisional themes resembling something closer to topics; these proto themes were then reviewed by author 3 through a series of meetings. Within these meetings author 2 would present the codes, topics, and the proto themes, and discussions then took place between the two authors about how these fit together and the underlying ideas and themes that connect them. Author 2 then refined the proto themes and a follow-up meeting would take place to discuss the changes made, as well as discuss any further changes to make. Once the proto themes were developed, author 1 was brought into these meetings for the later provisional theme development. As a group, these were then arranged into a rough hierarchy through identifying overarching themes.

Phase 4: Theme development and review

These provisional themes were developed further, they were reviewed by the research team to create richer and more detailed

themes. Careful consideration was taken to ensure clear boundaries between the core themes, whilst still allowing for nuance and discussion within the theme that resembled the range of views expressed at interview. This was done by reviewing the content of each theme and sub-theme, looking at areas which may relate to other themes. Based upon this the decision was made to move and merge parts of the themes, to create themes that were more distinct from one and other. Through this process the themes became deeper and had more nuanced connections between the ideas contained within, compared to when these ideas were split across multiple themes and subthemes. Through this stage it became clear that the subthemes only detracted from the content of the theme and did not add to the narrative within the data. A decision was made to remove the breaking down of the data into subthemes, to bring out the nuance and connections between the points made by participants.

Through this stage the underlying aspects (e.g. the language used by participants) were brought out, which had a major influence on the final themes. At the end of this stage, these themes were compared to the interview transcripts to ensure that the themes resembled what the participants had discussed and still gave them a strong voice. These changes were discussed in meetings and agreed upon by all authors.

Phase 5: Theme refining, defining, and naming

A theme definition for each theme was written, including an overview of the theme and the ideas contained within, and some key quotes for that theme. This was first done by author 2 and then a wider discussion was had around how to refine these further as a research team. This led to some minor refinements between theme boundaries, with minor changes between themes and the moving of content which would have previously been in different subthemes to help with the narrative within the data. At this point each theme was named, with the intention to summarise the range of ideas contained within. Further quotes were added to illustrate the minor points made in each theme.

Phase 6: Writing up

Throughout the writing phase, analysis continued through refining and tweaking of the themes; this was done to build a clear narrative through the data and ultimately present clear findings to the reader. This was led by author 1 but discussions were had between all authors about these changes. All authors agreed with the final set of findings presented here.

All authors took a social constructionist epistemological approach. The view held here is that the research process produces the themes and findings, rather than uncovering evidence of them within the data. Further, language is of particular importance, as what is expressed with the language itself is not viewed as a reality but a tool which channels meaning. This is pertinent here, as most of the built environment comprises social constructs, which are important when considering the topic at hand. It should also be noted that the research team bring with them their own biases which undoubtedly affected the analysis in various ways. Author 2 is from the Swahili community and with this comes prior insights into the perceptions of ASD. However, they have lived outside this community in the UK since 2020, which has given some distance from the subject matter. This has likely changed their views of ASD through both work and education. Authors 1 and 3 are from and live in the UK, and whilst author 3 has worked with the Swahili community briefly, both approached this research as non-natives of the Swahili community and viewed through a Western European lens. In addition, they both take a neurodiversity approach toward ASD which likely biases some readings of the language used by participants.

3. Results and discussion

Analysis developed three key themes: stigma, lack of awareness, and Government responsibility. These are summarised in [Table 1](#).

3.1. Stigma

The Swahili society is embedded in its culture. The impact of culture's influence regarding the community's attitude towards ASD was evident in the participants' views.

"Culture plays a very big role in each and every perspective and in every angle. Culture affects almost, it has a wider range of affection regarding our lives" - Fatuma.

In part, this culture has led to people closing off, for fear of social stigma *"our society that doesn't open up to its problems for the fear that they would be stigmatized, or for the fear that they will be laughed at"* – Kazunga. This view is consistent with the cultural attitude of promoting secrecy (Swartz, 1988), indicative of the negative attitudes towards ASD (Bunning et al., 2017; Kinnear et al., 2016), and

Table 1

Titles and brief summaries of each theme.

Theme	Description
Stigma	An exploration of Swahili culture and the impact it has on the attitudes towards people with ASD. Often this leads to stigmatising views of people with ASD.
Lack of awareness	This looks at the impact of awareness and how this can lead to some of those views explored in the 'Stigma' theme. The role of diagnosis comes into this theme, as does public awareness, and the language used to describe ASD.
Government responsibility	The role of Government and funding is discussed here. This impacts inclusivity and support offered to people.

feeds into the stigma-based challenges families with children, diagnosed with ASD, face (Bakare et al., 2014). This was echoed by Fatuma “*There is a lot of stigmatizations in Mombasa in almost everything. So, I think that is why people will withhold,*” and highlights the importance of avoiding familial shame within Swahili culture (Gona et al., 2016; Swartz, 1988). Within the community more widely, most participants specifically referred to the lack of acceptance “*...society has not accepted them...has not assisted them, [and] is probably ashamed*” – Kazungu, and parents often deny that their child may be neurodiverse “*they deny it’s like they’re in denial*” – Fatuma. This lack of acceptance can result in isolation for children with ASD, as parents may hide their children from the community to protect both themselves and their child (Cloete & Obaigwa, 2019; Gona et al., 2016). The shame and subsequent challenge this brings may also lead to family breakdown, as highlighted in Rehema’s account of a family who had a child with ASD and Attention Deficit Hyperactivity Disorder (ADHD):

“the husband had abandoned [the mother] because he could not handle the child at all. And he says that, ‘I don’t know where you got this child from this cannot come be coming from me’ and his extended family also, they just couldn’t manage it. So that is the only that is one family that totally rejected her” - Rehema.

A similar pattern was observed in a recent study undertaken in Nairobi with parents and primary caregivers of children with ASD. Cloete and Obaigwa (2019) reported maternal blame, extra marital affairs, as well as strained and broken marriages due to a child having ASD. This is evident in other low-middle income countries outside Africa; in India, Minhas et al. (2015) found stigma was one of the biggest challenges faced by parents of a child with ASD, and that it negatively impacted family functioning.

3.2. Lack of awareness

The issue of stigmatization results from a lack of awareness, as articulated by Mwanakombo “*there is a lot of knowledge that this society is not aware of*”. Similar attitudes are reported in other Kenyan communities. In Kisumu, Western Kenya, despite an organization attempting to support community care for children with disabilities, they saw it as result of the child receiving preferential parental treatment and something that they will outgrow (Cohen, 2012). This was emphasised by Fatuma “*But people tend to think that maybe this happens to the kids who are spoiled,*” echoing the opinions reported within the Somali community (Fox et al., 2017). This lack of awareness extends also to healthcare workers:

“Even when a professional has a child who is autistic... in the Swahili community it becomes difficult. You will see a whole professional child wearing and what is it called amulets to protect their child, why? Wearing different amulets, and then this person is a doctor who really should understand what autism is. So, it tells you a lot, it tells you a lot” - Mary.

This has been previously observed, with ASD awareness lacking in both healthcare workers and parents with autistic children (Bakare et al., 2009).

Whilst none of the participants in the current study believed in the association between witchcraft and ASD, they did articulate how these misconceptions were upheld in the Swahili community:

“...witchcraft that is the perception, you know, by the way, when (hemu muangalie huyu sije ikawa anfanganyiwa) have a look at this one maybe he has a spell on him, you know, just take care, concentrate, go and find out maybe this person has been witchcrafted or something like that, that is how they perceive it” - Fatuma.

This is consistent with spiritual beliefs that black magic and spirits cause ASD (Ruparelia et al., 2016), particularly within rural communities in Kenya (Bunning et al., 2017; Riccio, 2011). However, even when individuals are educated about such misbeliefs, other inaccuracies are evident. Referring to the now widely discredited link between the MMR vaccine and ASD (Editors of The Lancet, 2010), Rehema said: “*I met a Somali family [who believed] that there was a study in the UK that was done, that people who are autistic or that there is a vaccine [MMR] kids receive that give them autism*”. Such misbeliefs can persist even when relocating to Western countries. Hussein et al. (2019) found Somalis, now living in the UK, still believed that children developed ASD after receiving the MMR vaccine.

Most participants were aware that ASD is a neurodevelopmental disorder, yet six also referred to ASD in the context of mental health: “*...neuro general, degenerative diseases linked to mental health and autism spectrum is part of um mental disorders that are in that diagnosis statistical manual. Yeah. So yes, it is. Yes, it is linked*” - Mary. In contrast, only one participant dissociated ASD from mental health “*...autism is a developmental would you say a disease... It’s got nothing to do with mental illness*” – Mwanasiti. The language used here to describe individuals with ASD, being more focused on mental health rather than neurodiversity, is consistent with past research (Khamis et al., 2018). Interestingly, one participant indicated that associating ASD with mental health acted as a buffer and protected them from negative cultural attitudes towards such conditions:

“So that is where the mental health comes in, in allaying the fears of somebody who has a parent who has a child who’s autistic. It also helps the parents deal with the stigma from other people” - Rehema.

One participant, Kasungu, emphasised the importance of meeting children with ASD’s needs to help them thrive: “*...society should start looking for training centres to push these, these children so that they can grow up and be part...of the society*”. However, Mwanakombo pointed out that there is a lack of Special Educational Needs (SEN) provisions within the Swahili community, “*we don’t have these special facilities for such children*”. Some participants mentioned schools that were available for autistic children but were unaware of the support offered, whilst others had no awareness of any specialist provisions. Another stated she had visited a special school in Mombasa but found no children from the Swahili community went there, wondering whether it “*could...be that our people are not sending their autistic kids to special schools?*” – Rehema. A family member of one participant attended a SEN school but highlighted that

the staff there lacked awareness and the appropriate training to support children with ASD “*Most of the challenges that my mom used to complain about the teachers, they don't have the patience to deal with [my autistic cousin]*” – Katana. The aforementioned challenges, faced by educational professionals, are exacerbated by geographical differences between urban and rural educational settings. Odunsi et al. (2017) compared knowledge and understanding of ASD between primary school teachers working in urban and rural mainstream schools in Lagos State, Nigeria. There was a clear geographical divide with 46 % of urban teachers reported relatively accurate professional knowledge and understanding of ASD. In contrast, 69 % of teachers from urban schools had very little comprehension of the disorder. A similar challenge has also been seen in other low-middle income countries, such as India, whereby parents of children with ASD who attended mainstream education were concerned that teachers had limited knowledge and did not understand their child's needs (Minhas et al., 2015).

Participants also stated that diagnosis were broadly inaccessible “*Where can I diagnose my kid here really? ... do we have a centre that provides the diagnosis? Do we have it?*” – Mwanasiti. Similarly, there is lack of awareness as to which professionals provide diagnostic support:

“I think that the biggest challenge would be even for a parent to take that child to get assessed for autism. And I'm not even sure whether I don't I okay, the thing is even who would even assess at that child. It has it has to be would it be a psychiatrist? Would it be a neurologist? I'm even wondering” - Rehema.

Formal diagnoses of ASD occurs relatively late in low-middle income countries in Africa, compared to high-income countries outside of Africa (Bakare et al., 2009). This is exacerbated by a delay of over 7 years from initial parental concerns being raised, to pre-diagnostic support and subsequent diagnosis (Bello-Mojeed et al., 2017). One participant offered an explanation as to why diagnosis may take so long, observing that members of the Swahili community would often take a traditional route before seeking medical advice “*And you will try all the traditional treatments when they don't work. It's when you realize, oh, let me go to the hospital and take my child for check-up*” - Mary. Bakare et al. (2009) also found that the most common diagnostic pathway for children with neurodevelopmental disorders was to seek guidance from a traditional healer and then to mainstream medical assistance (also see Gona et al., 2016; Ruparelia et al., 2016). However, even when families seek out medical assistance many medical professionals do not have appropriate training unless they chose to specialise in a field like neurology (Ricchio, 2011), which can result in children with ASD being misdiagnosed.

It was clear that greater publicity is needed to support awareness of ASD in the participants' communities. Mwanakombo said “*they should just I mean publish in the media, they should also mention the, the characteristics of that condition for people to accept that the child is having that condition*”. In particular, Katana voiced that the Swahili community lacked someone to spearhead the promotion of ASD awareness to the same extent as mental health; “*We have all these other issues being championed, especially around mental issues of the ones in the asylum. But we don't have that anyone pushing that agenda [ASD]*”. Furthermore, the studies and campaigns aiming to create awareness of ASD rarely incorporates the different cultures in the accessibility to information. Language barriers, literacy levels, and socio-economic status can all act as barriers to awareness (Durkin et al., 2015). In Mombasa, whilst Swahili is the dominant language, there is little information educating people about neurodevelopmental disabilities available in the local dialect (also see Maulik & Darmstadt, 2007).

3.3. Government responsibility

All participants stressed the importance of the government funding SEN assistance in mainstream schools: “*They [the government] should also provide centers like clinics or schools for such children*” - Mwanakombo. However, they also voiced that the Kenyan government has done little to assist in creating spaces for children with disabilities, specifically ASD, because it is an “*invisible disability*” (Cohen, 2012). This lack of Government priority was evident in the views of the participants:

“...even in Kenya we have a mental Mental Health Act. I was going through it some other day, and I didn't see anywhere they had any engagement for autistic people. Even in the health act they're not there. For [the Government], I don't think it's a problem that needs any attention” - Katana.

This echoes other issues around inclusivity, particularly that no specific legislation on inclusive education for children with ASD exists in Kenya (Mwendo, 2011). This then feeds into the problem of financial constraints, and accessing appropriate schooling was clearly a major issue, with five participants referring to the socio-economic divide in the context of SEN education, for instance:

“Those who come from a rich family, they are capable of handling the condition well. But the ones who come from poor family, they just have to struggle with it. Because we don't have I mean, special schools for such children and those that are available are private expensive, more people cannot afford” - Mwanakombo.

Fatuma pointed out the expense of schools is a major barrier “*the one in Nyali is damn expensive. So, majority of the of the people cannot afford majority of the Mombasa community cannot afford*”. A recent study demonstrated that private schools in the area have fees which are beyond the reach of those who need this support (Chabeda-Barthe et al., 2019), and even then the support may not be adequate. Furthermore, Ekene and Oluoch-Suleh (2017) found that, even when children with ASD were in some form of specialist provision, these settings had only basic teaching materials. These were not sufficient to meet the standards set out to enable inclusive education and must be addressed at governmental level (also see Obasi, 2019). Accessing medical and educational facilities for those with disabilities is a constant struggle, and the predominant challenge in identifying children with ASD in Africa lies in the lack of inadequate standard of available educational and medical infrastructures (Mung'ala-Odera & Newton, 2007; Wannenburg & van Niekerk,

2018). Kazungu articulately summed up the importance of the Government's role in the overall care and support for individuals with ASD, along with how it needs to be responsible for driving ASD awareness to the wider Swahili community:

“The government has a big part to play, especially in providing the necessary infrastructure to support them, like, most of most of these people, especially when their parents are out on the field. They really suffer, they really suffer. So if the government would provide for them, a system where they could they can learn, they can learn soft skills, they can support themselves, and also teach the community on how to deal with them. Because the government has a bigger reach than those the community people that I've talked about. Provide spaces for them to learn, interact with other people, interact with doctors who can make their parents understand what's going on with them, and help them have a better life.”

4. Conclusions and limitations

The study investigated the awareness of and attitude towards ASD, of individuals living in the Swahili community in Kenya, a much under researched population. Despite most of participants being from urban communities they raised both cultural and political issues regarding awareness and management of ASD in the wider Swahili community. Central were the issues of stigma and lack of acceptance in having a child with ASD. Both were dominated by the lack of awareness, however the participants voiced that the ongoing cultural perspective was also due to lack of directive and funding from the government. This is consistent with other research in low-middle income countries whereby the narrative is driven by lack of awareness, acceptance, and appropriate education and support for individuals with developmental disorders, their families, and the wider community. This emphasises that the issues raised in this study, particularly the vulnerabilities of people with ASD, may apply to other communities more widely across Africa, as well as low-middle income countries elsewhere. A notable limitation of the current study is the sample as most were from the larger, more urbanised community of Mombasa. Furthermore, they were all educated to a high standard which is not representative of the education status typical of the community overall. The non-representative sample reflects the difficulty in recruiting participants from the rural coastal areas, and who were reluctant to openly discuss ASD. This silence from the rural community further emphasises the extent to which cultural attitudes towards ASD are embedded within this population.

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CRediT authorship contribution statement

S.S.M. Sood: Conceptualization, Data curation, Formal analysis, Writing – original draft. **D.R. Metcalfe:** Supervision, Validation, Writing – review & editing. **J.M.H. Greer:** Visualization, Validation, Writing – review & editing.

Ethical approval

Approval was obtained from the institutional Department of Psychology ethics committee, ethics reference number 32958, May 2021. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Data Availability

The transcripts of the interviews are obtainable from the corresponding author.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.ridd.2022.104370](https://doi.org/10.1016/j.ridd.2022.104370).

References

- Abubakar, A., Ssewanyana, D., de Vries, P. J., & Newton, C. R. (2016). Autism spectrum disorders in sub-Saharan Africa. *Lancet Psychiatry*, 3(9), 800–802.
- American Psychiatric Association, 2013. Diagnostic and statistical manual of mental disorders (5th ed.). <https://doi-org.ezproxy.frederick.edu/10.1176/appi.books.9780890425596>.
- Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, 14(3), 208–210.
- Bakare, M. O., Munir, K. M., & Bello-Mojeed, M. A. (2014). Public health and research funding for childhood neurodevelopmental disorders in sub-Saharan Africa: A time to balance priorities. *Healthcare in Low Resource Settings*, 2(1), 1–9.
- Bakare, M. O., Onu, J. U., Bello-Mojeed, M. A., Okidegbe, N., Onu, N. N., & Munir, K. M. (2022). Picture of Autism Spectrum Disorder (ASD) research in West Africa - A scoping review. *Research in Autism Spectrum Disorders*, 90, Article 101888. <https://doi.org/10.1016/j.rasd.2021.101888>
- Bakare, M. O., Agomoh, A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe, J. U., & Onyema, G. M. (2009). Etiological explanation, treatability and preventability of childhood autism: A survey of Nigerian healthcare workers' opinion. *Annals of General Psychiatry*, 8(6), 1–8.
- Bello-Mojeed, M. A., Omigbodun, O. O., Bakare, M. O., & Adewuya, A. O. (2017). Pattern of impairments and late diagnosis of autism spectrum disorder among a sub-Saharan African clinical population of children in Nigeria. *Global Mental Health*, 21(4), Article e5, 10.1017/gmh.2016.30.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), Article 589597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS One*, 12(8), Article e0182214. <https://doi.org/10.1371/journal.pone.0182214>
- Chabeda-Barthe, J., Wambua, T., Chege, W. L., Hwaga, D., Gakuo, T., & Rotich, G. C. (2019). Child developmental disabilities, caregivers' role in Kenya and its implications on global migration. *International Journal of Environmental Research and Public Health*, 16(6), 1–20.
- Chambers, N. J., Wetherby, A. M., Stronach, S. T., Njongwe, N., Kauchali, S., & Grinker, R. R. (2017). Early detection of autism spectrum disorder in young isiZulu-speaking children in South Africa. *Autism*, 21(5), 518–526.
- Cloete, L. G., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *African Journal of Disability*, 8, a435. <https://doi.org/10.4102/ajod.v8i0.435>
- Cohen, T., 2012. "The Invisible Disability:" Perceptions and Potential of Children with Autism in Kisumu, Kenya". Independent Study Project (ISP) Collection. 1245. (https://digitalcollections.sit.edu/isp_collection/1245).
- Dehnavi, S. R., Malekpour, M., Faramarzi, S., & Talebi, H. (2011). The share of internalized stigma and autism quotient in predicting the mental health of mothers with autism children in Iran. *International Journal of Business and Social Science*, 2(20), Article 251259.
- Durkin, M. S., Elsabbagh, M., Barbaro, J., Gladstone, M., Happé, F., Hoekstra, R. A., Shih, A., Lee, L. C., Rattazzi, A., Stapel-Wax, J., Stone, W. L., Tager-Flusberg, H., Thurm, A., & Tomlinson, M. (2015). Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. *Autism Research*, 8, 473–476.
- Eastman, C. E. (1994). Service, slavery ('utumwa') and Swahili reality. *Afrikanische Arbeitspapiere*, 37, 87–107.
- Editors of the Lancet. (2010). Retraction—ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet*, 375(9713), 445. [https://doi.org/10.1016/S0140-6736\(10\)60175-4](https://doi.org/10.1016/S0140-6736(10)60175-4)
- Ekene, O. G., & Oluoch-Suleh, E. (2017). Implementation of inclusive education for learners with disabilities in primary schools in Nairobi county. *Kenya Journal of Education and Practice*, 8(34), 22–32.
- Fakhoury, M. (2015). Autistic spectrum disorders: A review of clinical features, theories and diagnosis. *International Journal of Developmental Neuroscience*, 43, 70–77.
- Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). "It was like walking without knowing where I was going": A Qualitative Study of Autism in a UK Somali Migrant Community. *Journal of Autism and Developmental Disorders*, 47(2), 305–315.
- Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in Sub-Saharan Africa: a comprehensive scoping review. *Autism Research*, 10(5), 723–749.
- Gearhart, R. (2013). Seeing life through the eyes of Swahili children of Lamu, Kenya: A visual anthropology approach. *AnthropoChildren*, 3, 1–22.
- Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: What is the caregiver's experience? *Child: Care, Health and Development*, 37(2), 175–183.
- Gona, J. K., Newton, C. R., Rimba, K., Mapezi, R., Kihara, M., Van de Vijver, F. J., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for autism spectrum disorders (ASD) in a multicultural context on the Kenyan coast. *PLoS One*, 10(8), Article e0132729.
- Gona, J. K., Newton, C. R., Rimba, K. K., Mapezi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and Remote Health*, 16(2), 3517.
- Hodgetts, S., Zwaigenbaum, L., & Nicholas, D. (2015). Profile and predictors of service needs for families of children with autism spectrum disorders. *Autism*, 19(6), 673–683.
- Hussein, A. M., Pellicano, E., & Crane, L. (2019). Understanding and awareness of autism among Somali parents living in the United Kingdom. *Autism*, 23(6), 1408–1418.
- Igwe, M. N., Ahanotu, A. C., Bakare, M. O., Achor, J. U., & Igwe, C. (2011). Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi state, Nigeria. *Child and Adolescent Psychiatry and Mental Health*, 5(1). <https://doi.org/10.1186/1753-2000-5-1>
- Ireru, N. W., Mbwayo, A., & Ayaa, D. (2021). Assessing the impact of autism spectrum disorder on school going children in Nairobi County: A review of literature. *African Journal of Education, Science and Technology*, 6(2), 255–266.
- Kwarazuka, N., Locke, C., & Seeley, J. (2019). Women bargaining with patriarchy in coastal Kenya: contradictions, creative agency and food provisioning. *Gender, Place & Culture*, 26(3), 384–404. <https://doi.org/10.1080/0966369X.2018.1552559>
- Khamis, M. S., Kimani, J. M., & Ndambuki, P. (2018). The Swahilis traditional approach to mental health issues: a case of Swahilis of Mombasa. *IOSR Journal of Humanities and Social Science*, 23(6:7), 60–63.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953.
- Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., Lee, B. K., ... Newschaffer, C. (2017). The changing epidemiology of autism spectrum disorders. *Annual Review of Public Health*, 38, 81–102.
- Maulik, P. K., & Darmstadt, G. L. (2007). Childhood disability in low- and middle-income countries: Overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics*, 120(Suppl 1), S1–S55.
- Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S. U., Leadbitter, K., Taylor, C., ... Rahman, A. (2015). Parents' perspectives on care of children with autistic spectrum disorder in South Asia—Views from Pakistan and India. *International Review of Psychiatry*, 27(3), 247–256.
- Mung'ala-Odera, V., & Newton, C. R. J. C. (2007). Identifying children with neurological impairment and disability in resource-poor countries. *Child: Care, Health and Development*, 33(3), 249–256.
- Mwendo, M. C. (2011). Inclusive education for children with autism; Challenges facing teachers at city primary school, Nairobi Province, Kenya. Kenyatta University, Kenya, Africa. (Unpublished Master's Thesis). Retrieved 2 March 2022 from <https://ir-library.ku.ac.ke/bitstream/handle/123456789/4139/Matasio%20Christine%20Mwendo.pdf?sequence=3>.
- Obasi, K. K. (2019). Autistic learners' inclusion in the universal basic education programme in Nigeria. *International Journal of Innovative Research and Advanced Studies*, 6(4), 25–30.
- Oduksi, R., Preece, D., & Garner, P. (2017). Nigerian Teachers' Understanding of autism spectrum disorder: A comparative study of teachers from urban and rural areas of Lagos State. *Disability, CBR & Inclusive Development*, 29(3). <https://doi.org/10.5463/DCID.v29i3.637>

- Oswald, D. P., Haworth, S. M., Mackenzie, B. K., & Willis, J. H. (2017). Parental report of the diagnostic process and outcome: ASD compared with other developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, *32*(2), 152–160. <https://doi.org/10.1177/1088357615587500>
- Paget, A., Mallewa, M., Chinguo, D., Mahebere-Chirambo, C., & Gladstone, M. (2016). “It means you are grounded” – caregivers’ perspectives on the rehabilitation of children with neurodisability in Malawi. *Disability and Rehabilitation*, *38*, 223–234.
- Pillay, S., Duncan, M., & de Vries, P. J. (2021). Autism in the Western Cape province of South Africa: Rates, socio-demographics, disability and educational characteristics in one million school children. *Autism*, *25*(4), 1076–1089. <https://doi.org/10.1177/1362361320978042>
- Ressa, T. (2021). (Mis)schooling of children with disabilities in post-independent Kenya. *International Journal of Progressive Education*, *17*(2), 124–138. <https://doi.org/10.29329/ijpe.2020.332.8>
- Riccio, A., 2011. Autism in Kenya: A social, educational and political perspective. Independent study project (ISP) Collection. Paper - 1203.
- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., ... Newton, C. R. (2016). Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment: a report on the International Child Neurology Association Meeting on ASD in Africa, Ghana, April 3-5, 2014. *Journal of Child Neurology*, *31*(8), 1018–1026.
- Sengupta, K., Lobo, L., & Krishnamurthy, V. (2017). Educational and behavioral interventions in management of autism spectrum disorder. *The Indian Journal of Pediatrics*, *84*(1), 61–67.
- Swartz, M. J. (1988). Shame, culture, and status among the Swahili of Mombasa. *Ethos*, *16*(1), 21–51.
- Wannenburg, N., & van Niekerk, R. (2018). Early diagnosis and intervention for autism spectrum disorder in Africa: insights from a case study. *Health Science*, *18*(1), 137–146. <https://doi.org/10.4314/ahs.v18i1.18>