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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.

Key words: ASD, Swahili community, stigma, lack of awareness, Government responsibility

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25

26 What this paper adds?

27 While in high-income and Western societies general perceptions about autism
28 spectrum disorder (ASD) are broadly understood, the knowledge of perceptions of ASD in
29 low-middle income countries is limited. The current research expands on this by investigating
30 how ASD is perceived within the Swahili community, an under-researched populace located
31 on the Kenyan coast of Africa. Through the three themes which emerged from the data, this
32 study begins to develop a clearer understanding of the community's views about ASD.
33 Similar to many low-middle income countries, where societal customs and social norms are
34 particularly important, the Swahili culture is rooted in religion and tradition; therefore,
35 neurodevelopmental conditions such as ASD are not widely accepted due to the associated
36 societal stigma and linked somewhat to superstitious beliefs. This builds upon the past
37 research with similar populations in Africa, where lack of awareness and acceptance
38 regarding neurodiversity is bi-directional. The study has emphasised how much greater input
39 from the Kenyan Government is required to both educate this community and provide
40 adequate resources to support individuals with ASD and their families, as well as professional
41 services and teachers. In all, opinions and understanding of ASD within the Swahili
42 community are better understood because of this research. In turn, this work may act as a
43 stepping-stone for further research and awareness campaigns within the Swahili community
44 in Kenya and similar African populations.

1 PERCEPTIONS OF AUTISM SPECTRUM DISORDER AMONG THE SWAHILI
2 COMMUNITY ON THE KENYAN COAST

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5

1: INTRODUCTION

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

21 ASD-focussed research in Africa is notably lacking, however a growing body of
22 evidence demonstrates that many communities do not recognise ASD as a
23 neurodevelopmental disorder. Rather, cultural attitudes play an important role on both
24 professional and familial perceptions, about causes of ASD and treatment options for autistic

25 people (Bunning et al., 2017; Gona et al., 2015). One notable population is the Swahili
26 community, located on the coastal strip of Kenya in East Africa. Swahilis are predominantly
27 Muslim, with societal beliefs firmly rooted in religion, culture, and tradition (Eastman, 1994;
28 Swartz, 1988). Central within Swahili culture is the avoidance of bringing shame to the
29 family, accordingly, societal issues are not openly discussed for fear of stigma and ridicule
30 (Bakare et al., 2014). As such, the culture itself promotes the idea of secrecy, and Swahilis go
31 to considerable lengths to achieve “*siri*” (secret) and avoid “*aziri*” (exposure) (Swartz, 1988).
32 This cultural approach results in a lack of awareness of, and misunderstood attitudes towards
33 ASD.

34 The Swahili way of life is conservative, priding themselves on passing their culture
35 between generations. For instance, traditional gender roles are embedded into children from a
36 young age (Gearhart, 2013) along with primary caregiving being the mother’s responsibility
37 (Gona et al., 2014). A child with ASD, therefore, negatively reflects upon the mother’s style
38 of parenting (Cloete & Obaigwa, 2019) and any associated shame is attributed to the mother’s
39 nurturing, rather than due to neurodiversity (Dehnavi et al, 2011; Gona et al., 2016). The
40 characteristics associated with ASD are also believed to be the result of a child receiving
41 preferential parental treatment and, as such, that they will outgrow such behaviours (also see
42 Fox et al., 2017). Many Kenyan communities attribute disability to preternatural causes such
43 as witchcraft and evil spirits (Bunning et al., 2017), thus these superstitious cultural beliefs
44 negatively influence attitudes towards individuals with ASD and their families (Ricco, 2011).
45 This results in emotional distress, feelings of guilt, financial difficulties, and disrupted family
46 relationships (Gona et al., 2010). Furthermore, these cultural attitudes embed both spiritual
47 and societal expectations. For example, Cloete and Obaigwa (2016) interviewed parents of
48 children with ASD and reported overarching emotional burden, with the disorder blamed on
49 inter-tribe marriages and possession of evil spirits, predominantly due to the mother’s actions;

50 a pattern which is mirrored within other African communities (Bakare et al., 2009; Cohen,
51 2012).

52 Within professional services in Africa, there are many barriers to support individuals
53 with ASD and their families, including a lack of awareness regarding symptoms, prognosis,
54 and treatment by healthcare workers (Bakare et al., 2009; Igwe et al., 2011). These problems
55 are magnified due to large rural populations with differing languages and dialects (Franz et
56 al., 2017; Ruparelia et al., 2016), and because resources to translate and validate established
57 diagnostic materials is lacking (Abubakar et al., 2016). Thus, despite parents raising
58 developmental concerns, reduced access to appropriate screening and diagnostic resources
59 can delay diagnosis (Bakare et al., 2022; Franz et al., 2017) and intervention (Oswald et al.,
60 2017). In low-middle income countries in Africa, formal diagnosis of ASD often occurs
61 relatively late compared to high-income countries outside of Africa (Bakare et al., 2009). A
62 recent study found the average age for diagnosis of children with ASD in Nigeria was 9 years
63 of age, taking around 7 years from parents raising concerns to receiving pre-diagnostic
64 support, and a further 6 months to diagnosis (Bello-Mojeed et al., 2017). This is exacerbated
65 by a shortage of facilities and qualified personnel which results in a lack of support for both
66 the child and their families (Paget et al., 2016; Sengupta et al., 2017). However, even when
67 specialist educational provisions are accessible, the delivery of the curriculum does not factor
68 in the needs of individuals with ASD and other disabilities (Ekene & Oluch-Suleh, 2017), and
69 does not consider the specific needs to enable inclusivity (Ireru et al., 2021; Ressa, 2021). A
70 similar pattern is observed in other low-middle income countries, such as India, where
71 parents have voiced concerns regarding appropriate educational facilities and lack of
72 professional expertise (Minhas et al., 2015).

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

85

86

87

2: METHOD

88 2.1 Design

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

94

95 2.2 Participants

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

108

109

110 Procedure

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

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

131

132 2.3 Data Analysis

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

135 Phase 1: Dataset familiarisation

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

139 Phase 2: Data coding

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

143 Phase 3: Initial theme development

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

154 Phase 4: Theme development and review

155 These provisional themes were developed further, they were reviewed by the research team to
156 create richer and more detailed themes. Careful consideration was taken to ensure clear
157 boundaries between the core themes, whilst still allowing for nuance and discussion within
158 the theme that resembled the range of views expressed at interview. This was done by
159 reviewing the content of each theme and sub-theme, looking at areas which may relate to
160 other themes. Based upon this the decision was made to move and merge parts of the themes,
161 to create themes that were more distinct from one and other. Through this process the themes
162 became deeper and had more nuanced connections between the ideas contained within,
163 compared to when these ideas were split across multiple themes and subthemes. Through this

164 stage it became clear that the subthemes only detracted from the content of the theme and did
165 not add to the narrative within the data. A decision was made to remove the breaking down of
166 the data into subthemes, to bring out the nuance and connections between the points made by
167 participants.

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

173 Phase 5: Theme refining, defining, and naming

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

182 Phase 6: Writing up

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

187

188 All authors took a social constructionist epistemological approach. The view held here
189 is that the research process produces the themes and findings, rather than uncovering
190 evidence of them within the data. Further, language is of particular importance, as what is
191 expressed with the language itself is not viewed as a reality but a tool which channels
192 meaning. This is pertinent here, as most of the built environment comprises social constructs,
193 which are important when considering the topic at hand. It should also be noted that the
194 research team bring with them their own biases which undoubtedly affected the analysis in
195 various ways. Author 2 is from the Swahili community and with this comes prior insights into
196 the perceptions of ASD. However, they have lived outside this community in the UK since
197 2020, which has given some distance from the subject matter. This has likely changed their
198 views of ASD through both work and education. Authors 1 and 3 are from and live in the
199 UK, and whilst author 3 has worked with the Swahili community briefly, both approached
200 this research as non-natives of the Swahili community and viewed through a Western
201 European lens. In addition, they both take a neurodiversity approach toward ASD which
202 likely biases some readings of the language used by participants.

203

204

205

3: RESULTS AND DISCUSSION

206 Analysis developed three key themes: stigma, lack of awareness, and Government
207 responsibility. These are summarised in Table 1.

208

209 Table 1: Titles and brief summaries of each theme.

<u>Theme</u>	<u>Description</u>
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.

210

211

3.1 Stigma

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

214

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

217

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

222 et al., 2017; Kinnear et al., 2016), and feeds into the stigma-based challenges families with
223 children, diagnosed with ASD, face (Bakare et al., 2014). This was echoed by Fatuma “*There*
224 *is a lot of stigmatizations in Mombasa in almost everything. So, I think that is why people will*
225 *withhold,*” and highlights the importance of avoiding familial shame within Swahili culture
226 (Gona et al., 2016; Swartz, 1988). Within the community more widely, most participants
227 specifically referred to the lack of acceptance “*...society has not accepted them...has not*
228 *assisted them, [and] is probably ashamed*” – Kazungu, and parents often deny that their child
229 may be neurodiverse “*they deny it's like they're in denial*” – Fatuma. This lack of acceptance
230 can result in isolation for children with ASD, as parents may hide their children from the
231 community to protect both themselves and their child (Cloete & Obaigwa, 2019; Gona et al.,
232 2016). The shame and subsequent challenge this brings may also lead to family breakdown,
233 as highlighted in Rehema’s account of a family who had a child with ASD and Attention
234 Deficit Hyperactivity Disorder (ADHD):

235

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

240

241 A similar pattern was observed in a recent study undertaken in Nairobi with parents
242 and primary caregivers of children with ASD. Cloete and Obaigwa (2019) reported maternal
243 blame, extra marital affairs, as well as strained and broken marriages due to a child having
244 ASD. This is evident in other low-middle income countries outside Africa; in India, Minhas

245 et al. (2015) found stigma was one of the biggest challenges faced by parents of a child with
246 ASD, and that it negatively impacted family functioning.

247

248 3.2 Lack of awareness

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

258

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

263

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

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

269

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

274

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

284 Most participants were aware that ASD is a neurodevelopmental disorder, yet six also
285 referred to ASD in the context of mental health: “...*neuro general, degenerative diseases*
286 *linked to mental health and autism spectrum is part of um mental disorders that are in that*
287 *diagnosis statistical manual. Yeah. So yes, it is. Yes, it is linked*” - Mary. In contrast, only one
288 participant dissociated ASD from mental health “...*autism is a developmental would you*
289 *say a disease... It's got nothing to do with mental illness*” – Mwanasiti. The language used

290 here to describe individuals with ASD, being more focused on mental health rather than
291 neurodiversity, is consistent with past research (Khamis et al., 2018). Interestingly, one
292 participant indicated that associating ASD with mental health acted as a buffer and protected
293 them from negative cultural attitudes towards such conditions:

294

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

298

299 One participant, Kasungu, emphasised the importance of meeting children with
300 ASD’s needs to help them thrive: *“...society should start looking for training centres to push*
301 *these, these children so that they can grow up and be part...of the society”*. However,
302 Mwanakombo pointed out that there is a lack of Special Educational Needs (SEN) provisions
303 within the Swahili community, *“we don't have these special facilities for such children”*.
304 Some participants mentioned schools that were available for autistic children but were
305 unaware of the support offered, whilst others had no awareness of any specialist provisions.
306 Another stated she had visited a special school in Mombasa but found no children from the
307 Swahili community went there, wondering whether it *“could...be that our people are not*
308 *sending their autistic kids to special schools?” – Rehema*. A family member of one
309 participant attended a SEN school but highlighted that the staff there lacked awareness and
310 the appropriate training to support children with ASD *“Most of the challenges that my mom*
311 *used to complain about the teachers, they don't have the patience to deal with [my autistic*
312 *cousin]” – Katana*. The aforementioned challenges, faced by educational professionals, are
313 exacerbated by geographical differences between urban and rural educational settings. Odunsi

314 et al. (2017) compared knowledge and understanding of ASD between primary school
315 teachers working in urban and rural mainstream schools in Lagos State, Nigeria. There was a
316 clear geographical divide with 46% of urban teachers reported relatively accurate
317 professional knowledge and understanding of ASD. In contrast, 69% of teachers from urban
318 schools had very little comprehension of the disorder. A similar challenge has also been seen
319 in other low-middle income countries, such as India, whereby parents of children with ASD
320 who attended mainstream education were concerned that teachers had limited knowledge and
321 did not understand their child's needs (Minhas et al., 2015).

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

326

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

331

332 Formal diagnoses of ASD occurs relatively late in low-middle income countries in
333 Africa, compared to high-income countries outside of Africa (Bakare et al., 2009). This is
334 exacerbated by a delay of over 7 years from initial parental concerns being raised, to pre-
335 diagnostic support and subsequent diagnosis (Bello-Mojeed et al., 2017). One participant
336 offered an explanation as to why diagnosis may take so long, observing that members of the
337 Swahili community would often take a traditional route before seeking medical advice "*And*

338 *you will try all the traditional treatments when they don't work. It's when you realize, oh, let*
339 *me go to the hospital and take my child for check-up” - Mary. Bakare et al. (2009) also found*
340 *that the most common diagnostic pathway for children with neurodevelopmental disorders*
341 *was to seek guidance from a traditional healer and then to mainstream medical assistance*
342 *(also see Gona et al., 2016; Ruparelia et al., 2016). However, even when families seek out*
343 *medical assistance many medical professionals do not have appropriate training unless they*
344 *chose to specialise in a field like neurology (Riccio, 2011), which can result in children with*
345 *ASD being misdiagnosed.*

346 It was clear that greater publicity is needed to support awareness of ASD in the
347 participants' communities. Mwanakombo said *“they should just I mean publish in the*
348 *media...they should also mention the, the characteristics of that condition for people to accept*
349 *that the child is having that condition”*. In particular, Katana voiced that the Swahili
350 community lacked someone to spearhead the promotion of ASD awareness to the same extent
351 as mental health; *“We have all these other issues being championed, especially around*
352 *mental issues of the ones in the asylum. But we don't have that anyone pushing that agenda*
353 *[ASD]”*. Furthermore, the studies and campaigns aiming to create awareness of ASD rarely
354 incorporates the different cultures in the accessibility to information. Language barriers,
355 literacy levels, and socio-economic status can all act as barriers to awareness (Durkin et al.,
356 2015). In Mombasa, whilst Swahili is the dominant language, there is little information
357 educating people about neurodevelopmental disabilities available in the local dialect (also see
358 Maulik & Darmstadt, 2007).

359

360 3.3 Government responsibility

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

367

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

372

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

378

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

383

384 Fatuma pointed out the expense of schools is a major barrier “*the one in Nyali is damn*
385 *expensive. So, majority of the of the people cannot afford majority of the Mombasa*
386 *community cannot afford*”. A recent study demonstrated that private schools in the area have
387 fees which are beyond the reach of those who need this support (Chabeda-Barthe et al.,
388 2019), and even then the support may not be adequate. Furthermore, Ekene and Oluchi-Suleh
389 (2017) found that, even when children with ASD were in some form of specialist provision,
390 these settings had only basic teaching materials. These were not sufficient to meet the
391 standards set out to enable inclusive education and must be addressed at governmental level
392 (also see Obasi, 2019). Accessing medical and educational facilities for those with disabilities
393 is a constant struggle, and the predominant challenge in identifying children with ASD in
394 Africa lies in the lack of inadequate standard of available educational and medical
395 infrastructures (Mung’ala-Odera & Newton, 2007; Wannenberg & Niekerk, 2018). Kazungu
396 articulately summed up the importance of the Government’s role in the overall care and
397 support for individuals with ASD, along with how it needs to be responsible for driving ASD
398 awareness to the wider Swahili community:

399

400 “*The government has a big part to play, especially in providing the necessary infrastructure*
401 *to support them, like, most of most of these people, especially when their parents are out on*
402 *the field. They really suffer, they really suffer. So if the government would provide for them, a*
403 *system where they could they can learn, they can learn soft skills, they can support*
404 *themselves, and also teach the community on how to deal with them. Because the government*
405 *has a bigger reach than those the community people that I’ve talked about. Provide spaces*

406 *for them to learn, interact with other people, interact with doctors who can make their*
407 *parents understand what's going on with them, and help them have a better life.”*

408

409

4: CONCLUSIONS AND LIMITATIONS

410

411 The study investigated the awareness of and attitude towards ASD, of individuals

412 living in the Swahili community in Kenya, a much under researched population. Despite most

413 of participants being from urban communities they raised both cultural and political issues

414 regarding awareness and management of ASD in the wider Swahili community. Central were

415 the issues of stigma and lack of acceptance in having a child with ASD. Both were dominated

416 by the lack of awareness, however the participants voiced that the ongoing cultural

417 perspective was also due to lack of directive and funding from the government. This is

418 consistent with other research in low-income countries whereby the narrative is driven by

419 lack of awareness, acceptance, and appropriate education and support for individuals with

420 developmental disorders, their families, and the wider community. This emphasises that the

421 issues raised in this study, particularly the vulnerabilities of people with ASD, may apply to

422 other communities more widely across Africa, as well as low-middle income countries

423 elsewhere. A notable limitation of the current study is the sample as most were from the

424 larger, more urbanised, community of Mombasa. Furthermore, they were all educated to a

425 high standard which is not representative of the education status typical of the community

426 overall. The non-representative sample reflects the difficulty in recruiting participants from

427 the rural coastal areas, and who were reluctant to openly discuss ASD. This silence from the

428 rural community further emphasises the extent to which cultural attitudes towards ASD are

429

430 DECLARATIONS

431 Declaration of interests: none.

432

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435

436

437 AUTHOR CONTRIBUTIONS

438 SS: Conceptualization; Data curation; Formal analysis; Writing - original draft; DM:

439 Supervision; Validation; JG: Visualization; Validation; Writing - review & editing. All

440 authors read and approved the final manuscript.

441

442 DATA AVAILABILITY

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

444

445 ETHICAL APPROVAL

446 Approval was obtained from the institutional Department of Psychology ethics committee,

447 ethics reference number 32958, May 2021. The procedures used in this study adhere to the

448 tenets of the Declaration of Helsinki.

449

450 CONSENT TO PARTICIPATE

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

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