

ISSN Online: 2161-7333 ISSN Print: 2161-7325

A Review of Autism Spectrum Disorder among the Somali Diaspora: Implications for Autism Care in Somalia

Zakaria Ahmed Mohamed¹, Erick Thokerunga², Chunjiao Tang¹, Ali Omar Jimale¹, Jingyi Fan¹

¹Department of Pediatrics, Zhongnan Hospital of Wuhan University, Wuhan, China

²Department of Clinical Laboratory Medicine, Center for Gene Diagnosis, Zhongnan Hospital of Wuhan University, Wuhan, China

Email: *jfan@whu.edu.cn

How to cite this paper: Mohamed, Z.A., Thokerunga, E., Tang, C.J., Jimale, A.O. and Fan, J.Y. (2022) A Review of Autism Spectrum Disorder among the Somali Diaspora: Implications for Autism Care in Somalia. *Open Journal of Psychiatry*, **12**, 269-284.

https://doi.org/10.4236/ojpsych.2022.123020

Received: June 26, 2022 **Accepted:** July 25, 2022 **Published:** July 28, 2022

Copyright © 2022 by author(s) and Scientific Research Publishing Inc. This work is licensed under the Creative Commons Attribution International License (CC BY 4.0).

http://creativecommons.org/licenses/by/4.0/





Abstract

Despite the dramatic increase in autism spectrum disorders (ASD) globally, no research has been conducted in Somalia regarding ASD. However, research studies from Somali immigrants (diaspora) living in Sweden, the US, the UK, etc., have been major contributors to the subject of ASD among people of Somali descent. In this review, we aimed to examine ASD among the Somali diaspora community in terms of its prevalence, possible causes, knowledge of the diseases among the diaspora community, and the challenges faced in raising ASD-affected children in a foreign country. These findings create a general picture of the magnitude of the burden of ASD diagnosis and management and the coping mechanisms adopted by the Somali diaspora community, which are vital lessons for policymakers, child health non-governmental organizations, and the professional medical bodies aiming to tackle ASD back home in Somalia. The study found that ASD is three to five times more prevalent among children of Somali descent than their peers from other backgrounds and that Somali children were generally diagnosed much later than their peers and often presented with lower intellectual abilities than their peers. Furthermore, Somali immigrants were found to have low levels of knowledge about autism, faced stigma and discrimination and often resorted to religion and a small tight circle of friends and family for social support. They faced a huge challenge of seeking access to healthcare and schools for their autistic children and have a mistrust of social services for fear of the government taking away their children. These findings raise the possibility that neglected ASD cases may be prevalent in Somalia and thus makes recommendations for future research, social policy development, and early intervention services for individuals with autism in Somalia.

269

Keywords

Autism, ASD, Somali, Immigrants, Diaspora

1. Introduction

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder characterized by deficits in social interaction and communication and restricted repetitive or stereotypic patterns of behavior, interests, and activities. It is a complex group of neurodevelopmental disorders that include; autistic disorder, Asperger syndrome, and pervasive developmental disorder—not otherwise specified (PDD-NOS) [1]. To definitively diagnose ASD, the child must present with difficulties in two major areas of development: social communication and restricted, repetitive, or sensory behaviors. In addition, he/she must demonstrate difficulties in both areas, and the symptoms should have emerged before the age of three [2]. Although the definitive cause is not yet known, ASD is linked to a number of factors such as vitamin D deficiency, environmental factors, genetic and chromosomal variations, etc. Possible environmental factors include advanced parental age, prenatal exposure to air pollution, maternal diabetes, immune system disorders, infection, and immigration [3] [4]. Global prevalence estimates of ASD vary widely due to lack of awareness and diagnostic challenges, especially in developing countries. In the US, the most recent estimates indicate that 1 in every 44 children has autism [5]. Data from the world population review [6] indicate that western European countries have some of the lowest prevalence, while data from most developing countries are missing.

Globally, extensive research on ASD has significantly enhanced knowledge about the condition and led to more diagnoses and treatments for children in need. In Sub-Saharan Africa, however, the paucity of research continues to hider progress on ASD diagnosis and management. A recent global prevalence study conducted by Zeidan and colleagues [6] extensively curated studies on ASD from across the globe, and notably, most Sub-Saharan African countries, including Somalia did not have data on ASD. The federal republic of Somalia is located in the horn of Africa, bordered by Ethiopia to the west, Djibouti to the northwest, the Gulf of Aden to the north, the Indian Ocean to the east, and Kenya to the southwest. The country consists of 18 Regions and five federal states, with an estimated population of 16 million people [7]. Due to political instability, about 2 million Somalis (diaspora) live outside the country according a 2015 UN report [8]. A peculiar trend has emerged in studies done on Somalis in the diaspora. Results of studies conducted in Sweden [9], the UK [10], and the US [11], show that the incidence of ASD appeared to be higher among children of Somali origin compared to other children. Similar studies later on revealed that the differences in incidence between Somali and white children were not statistically significant. However, significant differences were observed among the Somali children and their black American and Latino counterparts [12].

The above findings of increased incidence and prevalence of ASD among Somali diaspora children raise a pertinent concern about the possibility of a masked prevalence of ASD in Somalia. To corroborate or refute these findings, hard data from Somalia is required. However, ASD data from Somalia is extremely scarce. An extensive survey of related data from PubMed and Embase databases showed zero studies on the prevalence of ASD conducted in the country relative to studies on the same topic in the neighboring East African countries. Figure 1 and Table 1 [13]-[19]. Autism remains a mysterious illness in Somalia, whose name too doesn't exist in the Somali dialect, as communicable diseases, such as Human Immunodeficiency Virus, Tuberculosis, Malaria, Measles, and Malnutrition take center stage on government priority diseases [20]. In this review, we assess the prevalence and factors associated with ASD among the Somali diaspora community, aiming to identify misconceptions and knowledge gaps among parents and caregivers of ASD children, their coping

Table 1. Details of studies assessing prevalence of ASD in the East African sub region.

Author Id	Study design	Participant characteristics	Outcome	References
Uganda				
Arinda, 2021	Cross-sectional survey	318 children, Aged 3 - 9 years.	The prevalence of significant ASD symptoms was found to be 45%.	[13]
Bonney, 2022	Retrospective descriptive study	237 children, Mean age 6.9 ± 4.0	The results confirm delays in access to ASD diagnosis and suggest that females are more likely to receive a ASD diagnosis later than males within the Ugandan context	[14]
Mwesigye, 2014	Cross-sectional survey	1169 children, aged 2 - 9 years	Prevalence of ASD was 120/100,000 children screened.	[15]
Wamulugwa, 2017	Analytical cross-sectional study	332 children, aged 4 - 18 years	The estimated prevalence of DSM-IV ADHD symptoms was 11%. Children aged less than 10 years were four times likely to have ADHD (OR 4.1, 95% CI 1.7 - 9.6, $p < 0.001$).	[16].
Kenya				
Samia, 2020	Retrospective descriptive study	116 children, aged 1 - 23 years	Prevalence of ADHD was 21%	[17]
Mamah, 2022	Cross sectional Survey	8918 youths, aged 15 - 25 years.	Across all participants, 0.63% were estimated as having High autistic traits, while 14.9% had Borderline autistic traits. Amongst community youth, prevalence of high autistic traits was 0.98%. Compared to those with low and borderline traits.	[19]
Tanzania, Rwanda, Burundi, Eritrea, Djibouti, Ethiopia and Somalia.	-	-	-	-

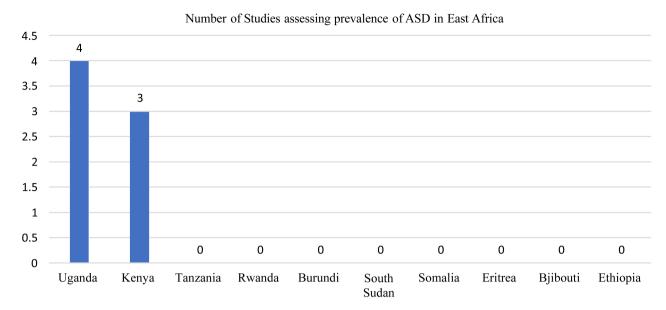


Figure 1. Studies assessing the prevalence of ASD in East Africa.

mechanisms, and other critical factors that influence ASD diagnosis and management that can guide future management, clinical research and policy needs concerning ASD in Somalia.

2. Prevalence of Autism among the Somali Diaspora Community

The prevalence of ASD among the Somali diaspora community has been estimated in the US, UK and Sweden (Table 2. [5] [9] [10] [12] [21]). The US hosts the majority of the Somali diaspora, both refugees and non-refugees. According to the 2020 US census bureau survey [22], there are approximately 170,192 Americans of Somali ancestry in the US. About 78,846 of them live in Minnesota, the largest Somali diaspora community in the US. In this population, the incidence of ASD is 1 in 32, not statistically different from that of white children; 1 in 36, but significantly higher than among black American and Latino children which were 1 in 62 and 1 in 80 respectively [11] [23]. Further studies have revealed that compared to their counterparts of other races, ASD children of Somali origin tend to have lower intellectual capabilities and were generally diagnosed much later than white children [11] [24].

Similar studies in Sweden by Barnevik-Olsson and colleagues also revealed that the prevalence of autism among Somali children living in Sweden was three to four times higher than in non-Somali children (0.7% vs. 0.19%). Furthermore, all the Somali children in the study (n=17) had been diagnosed with co-occurring intellectual disabilities [22]. These findings were also confirmed by Esler *et al.*, who found out that Somali children had a greater likelihood of ASD with intellectual disability than children from all other racial/ethnic groups [25]. Two years later, in 2010, Barnevik-Olsson repeated the same study in Stockholm, this time with a larger sample size (n=113,391), and the results was still similar

Table 2. Studies on prevalence of autism among Somali diaspora community.

Author ID	Country	Study design	Participant characteristics	Outcome	Reference
Maenner 2018	US	Retrospective descriptive study	234 children, aged 7 - 9 years, male to female ratio; 4.6:1.0	Results indicated that children of immigrants and refugees, and Somali children in particular, are being identified more frequently with ASD with intellectual disability than are other groups.	[5]
Barnevik-Olsson, 2010	Sweden	Retrospective analysis	113,391 children, aged 6 - 10 years,	The increased prevalence remained and was now between four and five times higher in children of Somali background.	[9]
Hassan, 2012	UK	Retrospective descriptive analysis	61,773 children, aged 0 - 19 years,	The analysis shows a higher prevalence of autism in Somali, Black African and Black Caribbean children which is at least twice the prevalence in all other ethnic groups in our borough	[10]
Hewwit, 2016	US	Retrospective descriptive study	12,329 children, aged 7 - 9 years	Results indicated that Somali (1 in 32) and White (1 in 36) children were about equally likely to be identified with ASD, but more likely to be identified with ASD than Black and Hispanic children	[12]
Barnevik-Olsson, 2010	Sweden	Retrospective analysis	113,391 children, aged 6 - 10 years,	The increased prevalence remained and was now between four and five times higher in children of Somali background.	[21]

to the previous one. ASD prevalence among Somali children was four to five times higher than in non-Somali children (0.98% vs. 0.21%) (3). Similar results were seen in the UK by Hassan and colleagues, who concluded that Somalis, Black Caribbean, and Black African children were twice more likely to get an autism diagnosis compared with children from other ethnic groups [10].

In short, the above studies all point to a much wider problem, which is the lack of information and awareness about ASD in Somalia. The diaspora children were diagnosed because they immigrated to countries where ASD facilities are available. Back home, however, autism is an unknown disease with no name in the local Somali dialect and is often referred to as "The western disease". It is highly likely that the disease is prevalent in Somalia, yet not being diagnosed due to the total lack of awareness, expertise and resources to manage it. These studies present an opportunity for the policy makers in Somalia, the healthcare non-governmental organizations and professional medical bodies to pay attention to ASD in the country as it may be a neglected neurodevelopmental time bomb.

3. Possible Causes of Autism among the Somali Diaspora Community

ASD is a diverse group of neurodevelopmental disorders whose exact cause is

not yet known. Factors such as genetics, vitamin D deficiency and environmental toxins are some of the proposed causes [3]. Among the Somali diaspora, the Swedish researchers assessed the hypothesis of lack of vitamin D as a cause. They found out that mothers of ASD children of Somali origin had significantly lower levels of 25-hydroxyvitamin D than Swedish mothers who had the same children with autism, with 18.7 and 68.2 nmol*L levels, respectively. On the other hand, the difference in 25-hydroxyvitamin D between mothers of Somali origin with and without an autistic child was not statistically significant (p < 0.001). [26]. Similarly, it was found that most of these babies are born in the winter and spring (The highest rate in March) when the sun is little to nonexistent hence suggesting that lower vitamin D levels during pregnancy may pose a risk for ASD [27] [28] [29] [30]. These remarkable findings are supported by the results of a recent sibling's control study which examined the vitamin D levels of 47 Gothenburg siblings with mixed ethnicities and 11 Stockholm siblings with Somali backgrounds, and found that Somali children with autism had lower levels of vitamin D than their non-ASD siblings [31]. Moreover, European studies have revealed that dark-skinned immigrants including Somali- immigrants who because of religion and culture, consistently wear concealing clothes, and have lower 25-hydroxyvitamin D (25(OH)D) levels than pale-skinned indigenous people [32] [33]. Although Somalia's climate is tropical, hot, and sunny all the year, this hypothesis needs to be explored further among the Somalis in Somalia to assess their vitamin D levels and its links to ASD.

Kanan et al. [34] and DeSoto et al. [35] meanwhile assessed the genetic relationships between ASD and Somali children. Kanan and colleagues examined a mentally retarded four-year-old Somali boy with autism and a history of seizures and found that the child had an increased urinary excretion of 2-methylbutyryl glycine due to a 2-methylbutyryl-CoA dehydrogenase deficiency, also known as short branched-chain acyl-CoA dehydrogenase deficiency (SBCADD). The disease is an autosomal recessive disorder caused by a defect in the amino acid L-degradation isoleucine's pathway. The child possessed homozygosity for the A > G substitution in intron 3 (c.303 + 3A > G) of the SBCAD gene. On the other hand, DeSoto and colleagues looked at a gene that encodes for Vitamin K epoxide reductase complex (VKORC1) in a sample of severely autistic children of Somali descent living in Minneapolis USA. They found an abnormally high number of substitutions that result in a reduction in the efficiency of the Vitamin K cycle. They concluded that it could be possible that this genetic difference is responsible for the development of autism in Somali children. Genetic factors are strongly linked to ASD. It is estimated that 40% - 80% of ASD cases are inheritable [36]. Some of the gene mutations associated with ASD include; ARID1B, ASH1L, CHD2, CHD8, DYRK1A, POGZ, SHANK3, and SYNGAP1. Most of these genes are directly involved in brain development, including processes like production, growth, and organization of neurons, modulating the number of neurons produced and regulating synaptic connections where cell-to-cell communication occurs [37]. It would be interesting to find out if some of these mutations occur in children of Somali origin.

4. Knowledge of ASD among the Somali Diaspora Community

Over the past few years, an enormous amount of research has been conducted among Somali diaspora parents to assess their awareness and understanding of autism [38]-[47]. The findings of these studies consistently revealed that Somali parents had low levels of knowledge about autism spectrum disorder. It is important to know and understand ASD in order to engage in help-seeking behaviors. For instance, when the main cause of ASD is attributed to spiritual causes as indicated by study findings among the Somali diaspora, it is clear that their first point of contact would be a traditional or religious healer - a practice common among children with ASD whose parents are Somali [45] [47]. Because Somali parents relied heavily on their Islamic faith to cope with their child's autism, it strengthened parents' resolve to avoid blame, discover acceptance, and keep hope for the future. They often expressed the idea that events are predestined and take precedence over human volition or free will and "always it is what Allah has already written" [38]. This practice, although it enables the parents to cope with the immense challenges of raising an autistic child, prevents them from seeking professional help, hence perpetuating their misery.

Secondly, the myth that the MMR vaccine causes ASD was a popular understanding among Somali parents [39]-[44]. This myth led to a sustained MMR vaccine hesitancy among the Somali community, especially in the US state of Minnesota, which hosts the largest Somali diaspora community [48] [49]. As a result, in 2019, there was a resurgence of measles outbreaks in the US, with clear clusters among the Somali communities in Minnesota. This is a clear example of how cultural myths promote vaccine hesitancy leading to the resurgence of once eradicated communicable diseases like measles. Despite years of living in the developed world with better education, science and technology, the myths about vaccines are still persistent among the Somali diaspora, therefore, tackling autism in Somalia is as vital as ensuring that the myths around it do not embolden vaccine hesitancy in the country and cause resurgence of vaccine preventable communicable diseases. Studies have shown that Somali parents simply do not believe that autism exists in Somalia or that Somalis living in western countries are particularly susceptible to severe forms of autism. They assume that the disorder is caused by environmental factors rather than genetics and that no one in their family in Somalia has ever witnessed such behaviors—Possibly because of a lack of awareness and diagnostic facilities in Somalia—As a result, many of them choose to return Somalia to cope with the diseases despite the severe lack of facilities to cater for ASD children in the country [46].

5. Challenges of Raising Autistic Children in the Diaspora

Raising an autistic child in itself is challenging; however, doing so in a foreign

country with little family support is far more difficult. Studies conducted on the challenges faced by Somali parents of autistic children describe a number of day-to-day problems that these parents face in raising the kids. As stated previously, the lack of knowledge on ASD among the Somalis in the diaspora and the myths surrounding it create a severe stigma for the affected children and their families. It's not uncommon to hear derogatory remarks from neighbors, or even family and friends towards these children, which stokes the fear of seeking early interventions, and impacts negatively on the child's prognosis. In one study, parents complained that they are often labeled by the condition of their children, creating a painful sense of social rejection and isolation. They have thus resorted to religious faith and a small circle of supportive friends to cope with the problem [38]. Back in Somalia, the stigma associated with mental health in general is worse. It is thus advisable that any future interventions to tackle ASD in Somalia will need to focus heavily on bursting disinformation and ensuring that the community gets the right message to morally support ASD patients and their families.

In the UK, researchers unearthed a number of social challenges faced by ASD affected parents ranging from difficulty in understanding the diagnosis to rejection by spouses. In one study, many of the respondents stated that when they were told of autism as their child's diagnosis, they were left confused as the word was unfamiliar to them. This is a diagnosis not recognized in Somalia. A clash between the Somali cultural beliefs about mental health and the western medical understanding of ASD created a state of cognitive dissonance among the parents of the children. [50]. Others explained that sometimes when playing in the park their child may suddenly hit another child leading to altercations with other parents and calling of the police; so, they simply avoid public places and keep the children at home, while the rest explained that community attitudes towards autism were negative, and this in combination with a lack of vocabulary for describing and explaining the disease made acceptance of the condition more difficult. This in turn prevented most parents from seeking early interventions as they couldn't explain what was exactly wrong with the child [51].

In terms of social services, access to healthcare and education services is the most challenging after a diagnosis of autism, given the unfamiliarity with foreign systems in the host country and the language barrier, especially for those who can't speak the mainstream language in the host countries. Choosing where to take the child to school is a challenge, too; while some parents have strong preferences for mainstream schools where their kids will study alongside their normal peers, others preferred special needs school designed specifically for those having communication disorders. Lastly, there is a mistrust of social services which prevents parents from participating in them. Parents fear that if the government sees that they are having difficulties in raising the child, then the child will be taken away from them [38] [50]. These challenges paint a picture of the magnitude of work that needs to be done to tackle autism in Somalia, and should be individually paid attention to.

6. Current State of ASD Diagnosis and Management in Somalia

Despite the high prevalence of ASD in the developed world like the US, little is known about the disorder in low-income regions including Africa. The lack of data regarding autism prevalence in Africa is striking, despite having a population of over 1 billion people, 40% of whom are children under fourteen years [52]. The public health focus in sub-Saharan Africa in the last few years has been on communicable diseases like HIV, malaria, and tuberculosis. However, with the decline in childhood mortality rates over the last two decades, noncommunicable diseases such as neurodevelopmental disorders should be getting the attention of policy makers. There has been some speculation that autism could be a culturally bound condition, and that autism spectrum disorder might be rare in places like sub-Saharan Africa. This, however, is proving to be inaccurate. In the 1970s, Psychiatrist Lotter et al. confirmed nine cases of autism in hospitals in six African countries [53]. Soon after, numerous cases of autism were documented in Nigeria, Ghana, Zimbabwe, Tunisia, Uganda, and Somalia's neighboring countries, Kenya and Ethiopia. Studies have shown that African children, on average, are diagnosed with autism around the age of eight, about four years later than their American counterparts. About half of these children were also diagnosed with a learning disability, compared to about a third of American children [54] [55]. As a result, recent research on autism in Africa has increased dramatically. There has also been an increase in the number of government-funded autism research projects, autism support centers, and specialized child mental health clinics operating in these countries, but none of these initiatives has been accomplished in Somalia.

Although Somalia's federal government adopted the Child Rights Convention (CRC) in October 2015, which outlines the fundamental human rights that all children should have regardless of where they live, such as the right to optimal development; the right to an education; and the right to be secured from exploitation [56], many children with autism as well as other neurodevelopmental problems who didn't get appropriate diagnoses continue to be locked up or kept hidden in their homes, with desperate parents and relatives preventing them from getting any sort of intervention. This is in large part due to the common derogatory comments and stigma associated with such children, which parents often have to live with on a daily basis, without any advocacy. Despite these alarming observations in the community, the country lacks governmental research programs for autism, pediatric neurologists, child development centers, or psychiatric centers for children and adolescents. In the capital Mogadishu, one private center for children with special needs was built to serve both local children with ASD and Somali diaspora families with ASD children, after returning home. The cost of raising an autistic child is enormous. In the US, it is estimated to be around \$17,000 annually [57]. The GDP per capita of Somalia is just about \$276.88 [58]. Without government support, an average Somali family cannot manage the task of raising an autistic child; therefore, government interventions, NGO partnerships, religious organizations and philanthropic initiatives are needed to fill this financing gap and save ASD affected families from financial ruin.

In terms of healthcare experts and diagnostic facilities, Somalia faces a difficult shortage of health workers across the board. The situation is particularly severe for pediatric and mental health practitioners. A 2019 survey [59] found about 6913 doctors, nurses and midwives on government payroll serving close to 12 million people. The exact overall number is unknown. This figure represents about 0.4 health workers per 1000 population, way below the WHO recommended 4.45 health workers per 1000 population [60]. Data on how many pediatricians or pediatric psychiatrists are present in the country does not exist, and with no study conducted on ASD in the country, information on ASD diagnosis and management is hard to find. This article should present a challenge to government policy makers, pediatrics and child health NGOs, in Somalia to consider with urgency the glaring needs of ASD children in the country.

7. The Future of Autism in Somalia: Directions and Recommendations

- 1) To tackle ASD in Somalia, a holistic approach is needed. Government, child health non-governmental organizations and professional medical bodies in the country will have to sit down and formulate enabling policies and recruit pediatricians and pediatric psychiatrists with ample knowledge of ASD, and develop or adapt diagnostic tools for the disease. In addition, budgetary allocations for health should include special considerations for ASD as a resource intensive disease, and ASD should be integrated into routine primary health care.
- 2) Secondly, the lack of information and disinformation among the masses that create stigma for ASD affected families and prevent them from seeking care must be tackled. Targeted mass media campaigns, the use of faith-based organizations, religious leaders and other influential persons in society to spread correct information can be explored. Cultural connotations about autism being a spiritual disease should be stopped. Parents of ASD patients should be informed that their children too can be treated and helped to live productively with the condition, especially if they seek help early.
- 3) Collaboration with the diaspora community, both ASD affected and those not affected should be explored. To our knowledge, there is only one facility in Mogadishu built to serve both local children with ASD and those returning from the diaspora. This is a sign that the diaspora citizens have both the right knowledge and resources that can be taped to create awareness and build tangible facilities to cater to ASD children at home.
- 4) Lastly, research into ASD must be supported. Studies conducted outside the country already show that children of Somali origin have a higher incidence of ASD than other children, and tend to have lower intellectual capacity than their

counterparts. Research into the factors responsible for these observations needs to be ascertained and characterized.

8. Conclusion

In summary, Somali immigrants around the globe, especially in the UK, US and Sweden, continue to experience increasing incidences of autism spectrum disorder among their children, implicating Somalia as a country where ASD prevalence could be high yet unknown. Our findings also show that Somali immigrants (diaspora) lack sufficient knowledge about autism spectrum disorder and are still skeptical about seeking treatment despite the exposure to first-world ASD facilities, raising the concern that the situation could be worse back home in Somalia. Autism care and research facilities in sub-Saharan African countries are very low and almost nonexistent in Somalia. To successfully tackle ASD therefore, a holistic approach involving government, child health NGOs, faith-based organizations, cultural leaders and professional medical bodies is needed to ensure policies are in place, resources mobilized, research encouraged and the masses sensitized about ASD care in the country.

Conflicts of Interest

The authors have no relevant financial and or non-financial interest to disclose.

Funding

This work was supported by the Scientific and Technological Innovation Nurturing Grant of Zhongnan Hospital of Wuhan University. Grant number: zn-py201805.

Authors' Contribution

The authors Z.A.M and E.T conducted the literature search, data extraction, data analysis and manuscript drafting. A.O.J and C.T reviewed the manuscript. J.F conceived the study and supervised the entire process of the study. All authors have read and agreed to the published version of the manuscript.

References

- [1] Rosen, N.E., Lord, C. and Volkmar, F.R. (2021) The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond. *Journal of Autism and Developmental Disorders*, **51**, 4253-4270. https://doi.org/10.1007/s10803-021-04904-1
- [2] American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Disorders. 5th Edition, American Psychiatric Association, Washington DC. https://doi.org/10.1176/appi.books.9780890425596
- [3] Karimi, P., Kamali, E., Mousavi, S.M. and Karahmadi, M. (2017) Environmental Factors Influencing the Risk of Autism. *Journal of Research in Medical Sciences*, 22, 27. https://doi.org/10.4103/1735-1995.200272
- [4] Magnusson, C., Rai, D., Goodman, A., Lundberg, M., Idring, S., Svensson, A., *et al.* (2012) Migration and Autism Spectrum Disorder: Population-Based Study. *The*

- British Journal of Psychiatry: The Journal of Mental Science, **201**, 109-115. https://doi.org/10.1192/bjp.bp.111.095125
- [5] Maenner, M.J. (2021) Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveillance Summaries, 70, 1-16. https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm?s_cid=ss7011a1_w
- [6] Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M.S., Saxena, S., et al. (2022) Global Prevalence of Autism: A Systematic Review Update. Autism Research, 15, 778-790. https://doi.org/10.1002/aur.2696
- [7] Somalia Population (2022) Live—Countrymeters. https://countrymeters.info/en/Somalia
- [8] Trends in International Migrant Stock: The 2015 Revision.

 https://MigrationStockDocumentation_2015.pdf

 https://www.un.org/en/development/desa/population/migration/data/estimates2/docs/MigrationStockDocumentation_2015.pdf
- [9] Barnevik-Olsson, M., Gillberg, C. and Fernell, E. (2010) Prevalence of Autism in Children of Somali Origin Living in Stockholm: Brief Report of an At-Risk Population. *Developmental Medicine & Child Neurology*, 52, 1167-1168. https://doi.org/10.1111/j.1469-8749.2010.03812.x
- [10] Hassan, M. (2012) Predicting the Prevalence of Autism among Ethnic Groups. Archives of Disease in Childhood, 97, A95-A96.
 https://doi.org/10.1136/archdischild-2012-301885.227
- [11] Minneapolis Somali Autism Spectrum Disorder Prevalence Project: Community Report 2013. https://ici.umn.edu/products/583
- [12] Hewitt, A., Hall-Lande, J., Hamre, K., Esler, A.N., Punyko, J., Reichle, J., et al. (2016) Autism Spectrum Disorder (ASD) Prevalence in Somali and Non-Somali Children. Journal of Autism and Developmental Disorders, 46, 2599-2608. https://doi.org/10.1007/s10803-016-2793-6
- [13] Arinda, A., Nakasujja, N. and Odokonyero, R. (2021) Prevalence of Autism Spectrum Disorder Symptoms in a Paediatric Neurology Clinic at a Tertiary Hospital in Uganda. *South African Journal of Psychiatry*, **27**, 1548. https://doi.org/10.4102/sajpsychiatry.v27i0.1548
- [14] Bonney, E., et al. (2022) Sex Differences in Age of Diagnosis of Autism Spectrum Disorder: Preliminary Evidence from Uganda. Autism Research, 15, 183-191. https://pubmed.ncbi.nlm.nih.gov/34826197 https://doi.org/10.1002/aur.2645
- [15] Kakooza-Mwesige, A., Ssebyala, K., Karamagi, C., Kiguli, S., Smith, K., Anderson, M.C., et al. (2014) Adaptation of the "Ten Questions" to Screen for Autism and Other Neurodevelopmental Disorders in Uganda. Autism: The International Journal of Research and Practice, 18, 447-457. https://doi.org/10.1177/1362361313475848
- [16] Wamulugwa, J., Kakooza, A., Kitaka, S.B., Nalugya, J., Kaddumukasa, M., Moore, S., et al. (2017) Prevalence and Associated Factors of Attention Deficit Hyperactivity Disorder (ADHD) among Ugandan Children; a Cross-Sectional Study. Child and Adolescent Psychiatry and Mental Health, 11, Article No. 18. https://doi.org/10.1186/s13034-017-0155-6
- [17] Samia, P., Kanana, M., King, J., Donald, K.A., Newton, C.R. and Denckla, C. (2020) Childhood Autism Spectrum Disorder: Insights from a Tertiary Hospital Cohort in Kenya. *African Journal of Health Sciences*, **33**, 12-21.

- [18] Ireri, N.W., White, S.W. and Mbwayo, A.W. (2019) Treating Anxiety and Social Deficits in Children with Autism Spectrum Disorder in Two Schools in Nairobi, Kenya. *Journal of Autism and Developmental Disorders*, 49, 3309-3315. https://doi.org/10.1007/s10803-019-04045-6
- [19] Mamah, D., Mutiso, V., Gitonga, I., Tele, A. and Ndetei, D.M. (2022) A Population-Based Survey of Autistic Traits in Kenyan Adolescents and Young Adults. South African Journal of Psychiatry, 28, 1694. https://doi.org/10.4102/sajpsychiatry.v28i0.1694
- [20] Liu, L., Johnson, H.L., Cousens, S., Perin, J., Scott, S., Lawn, J.E., et al. (2012) Global, Regional, and National Causes of Child Mortality: An Updated Systematic Analysis for 2010 with Time Trends since 2000. The Lancet (London, England), 379, 2151-2161. https://doi.org/10.1016/S0140-6736(12)60560-1
- [21] Barnevik-Olsson, M., Gillberg, C. and Fernell, E. (2008) Prevalence of Autism in Children Born to Somali Parents Living in Sweden: A Brief Report. *Developmental Medicine & Child Neurology*, 50, 598-601. https://doi.org/10.1111/j.1469-8749.2008.03036.x
- [22] US Census Bureau. U.S. Census Bureau (2016-2020). People Reporting Single Ancestry American Community Survey 5-Year Estimates.

 https://censusreporter.org/data/table/?table=B04004&geo_ids=01000US&primary_g
 eo id=01000US#valueType
- [23] Minneapolis Somali Autism Spectrum Disorder Prevalence Project. https://rtc.umn.edu/autism
- [24] Hall-Lande, J., Esler, A.N., Hewitt, A. and Gunty, A.L. (2021) Age of Initial Identification of Autism Spectrum Disorder in a Diverse Urban Sample. *Journal of Autism and Developmental Disorders*, 51, 798-803. https://doi.org/10.1007/s10803-018-3763-y
- [25] Esler, A.N., Hall-Lande, J. and Hewitt, A. (2017) Phenotypic Characteristics of Autism Spectrum Disorder in a Diverse Sample of Somali and Other Children. *Journal of Autism and Developmental Disorders*, 47, 3150-3165. https://doi.org/10.1007/s10803-017-3232-z
- [26] Fernell, E., Barnevik-Olsson, M., Bågenholm, G., Gillberg, C., Gustafsson, S. and Sääf, M. (2010) Serum Levels of 25-Hydroxyvitamin D in Mothers of Swedish and of Somali Origin Who Have Children with and without Autism. *Acta Paediatrica* (*Oslo, Norway*: 1992), **99**, 743-747. https://doi.org/10.1111/j.1651-2227.2010.01755.x
- [27] Maimburg, R.D., Bech, B.H., Vaeth, M., Møller-Madsen, B. and Olsen, J. (2010) Neonatal Jaundice, Autism, and Other Disorders of Psychological Development. *Pediatrics*, **126**, 872-878. https://doi.org/10.1542/peds.2010-0052
- [28] Stevens, M.C., Fein, D.H. and Waterhouse, L.H. (2000) Season of Birth Effects in Autism. *Journal of Clinical and Experimental Neuropsychology*, 22, 399-407. https://doi.org/10.1076/1380-3395(200006)22:3;1-V;FT399
- [29] Gillberg, C. (1990) Do Children with Autism Have March Birthdays? *Acta Psychiatrica Scandinavica*, **82**, 152-156. https://doi.org/10.1111/j.1600-0447.1990.tb01373.x
- [30] Kočovská, E. andorsdóttir, G., Weihe, P., Halling, J., Fernell, E., Stóra, T., et al. (2014) Vitamin D in the General Population of Young Adults with Autism in the Faroe Islands. *Journal of Autism and Developmental Disorders*, 44, 2996-3005. https://doi.org/10.1007/s10803-014-2155-1
- [31] Fernell, E., Bejerot, S., Westerlund, J., Miniscalco, C., Simila, H., Eyles, D., *et al.* (2015) Autism Spectrum Disorder and Low Vitamin D at Birth: A Sibling Control

- Study. Molecular Autism, 6, Article No. 3. https://doi.org/10.1186/2040-2392-6-3
- [32] Dijkstra, S.H., van Beek, A., Janssen, J.W., de Vleeschouwer, L.H.M., Huysman, W.A. and van den Akker, E.L.T. (2007) High Prevalence of Vitamin D Deficiency in Newborn Infants of High-Risk Mothers. *Archives of Disease in Childhood*, 92, 750-753.
- [33] Sääf, M., Fernell, E., Kristiansson, F., Barnevik Olsson, M., Gustafsson, S.A. and Bågenholm, G. (2011) Severe Vitamin D Deficiency in Pregnant Women of Somali Origin Living in Sweden. *Acta Paediatrica* (*Oslo*, *Norway*: 1992), **100**, 612-614. https://doi.org/10.1111/j.1651-2227.2011.02134.x
- [34] Kanavin, O.J., Woldseth, B., Jellum, E., Tvedt, B. andresen, B.S. and Stromme, P. (2007) 2-methylbutyryl-CoA Dehydrogenase Deficiency Associated with Autism and Mental Retardation: A Case Report. *Journal of Medical Case Reports*, 1, Article No. 98. https://doi.org/10.1186/1752-1947-1-98
- [35] DeSoto, M.C. (2016) Speculations on Vitamin K, VKORC1 Genotype and Autism. *Medical Hypotheses*, **96**, 30-33. https://doi.org/10.1016/j.mehy.2016.09.013
- [36] Chaste, P. and Leboyer, M. (2012) Autism Risk Factors: Genes, Environment, and Gene-Environment Interactions. *Dialogues in Clinical Neuroscience*, 14, 281-292. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3513682 https://doi.org/10.31887/DCNS.2012.14.3/pchaste
- [37] Rylaarsdam, L. and Guemez-Gamboa, A. (2019) Genetic Causes and Modifiers of Autism Spectrum Disorder. Frontiers in Cellular Neuroscience, 13, Article No. 385. https://www.frontiersin.org/article/10.3389/fncel.2019.00385 https://doi.org/10.3389/fncel.2019.00385
- [38] Ellen, S.L., Fox, F., Aabe, N., Turner, K., Rai, D. and Redwood, S. (2018) 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 & Health, 23, 781-796. https://doi.org/10.1080/13557858.2017.1294663
- [39] Jama, A., Lindstrand, A., Ali, M., Butler, R. and Kulane, A. (2019) Nurses' Perceptions of MMR Vaccine Hesitancy in an Area with Low Vaccination Coverage. *Pediatric Health, Medicine and Therapeutics*, 10, 177-182. https://doi.org/10.2147/PHMT.S212921
- [40] Bahta, L. and Ashkir, A. (2015) Addressing MMR Vaccine Resistance in Minnesota's Somali Community. *Minnesota Medicine*, **98**, 33-36.
- [41] Madlon-Kay, D.J. and Smith, E.R. (2020) Interpreters' Knowledge and Perceptions of Childhood Vaccines: Effect of an Educational Session. *Vaccine*, 38, 1216-1219. https://doi.org/10.1016/j.vaccine.2019.11.010
- [42] Wolff, E.R. and Madlon-Kay, D.J. (2014) Childhood Vaccine Beliefs Reported by Somali and Non-Somali Parents. *The Journal of the American Board of Family Medicine*, 27, 458-464. https://doi.org/10.3122/jabfm.2014.04.130275
- [43] Jama, A., Ali, M., Lindstrand, A., Butler, R. and Kulane, A. (2018) Perspectives on the Measles, Mumps and Rubella Vaccination among Somali Mothers in Stockholm. *International Journal of Environmental Research and Public Health*, 15, E2428. https://doi.org/10.3390/ijerph15112428
- [44] Christianson, B., Sharif-Mohamed, F., Heath, J., Roddy, M., Bahta, L., Omar, H., *et al.* (2020) Parental Attitudes and Decisions Regarding MMR Vaccination during an Outbreak of Measles among an Undervaccinated Somali Community in Minnesota. *Vaccine*, **38**, 6979-6984. https://doi.org/10.1016/j.vaccine.2020.09.022
- [45] Decoteau, C.L. (2017) The "Western Disease": Autism and Somali Parents' Embo-

- died Health Movements. *Social Science & Medicine*, **177**, 169-176. https://doi.org/10.1016/j.socscimed.2017.01.064
- [46] Hussein, A.M., Pellicano, E. and Crane, L. (2019) Understanding and Awareness of Autism among Somali Parents Living in the United Kingdom. *Autism*, 23, 1408-1418. https://doi.org/10.1177/1362361318813996
- [47] Aabe, N.O., Fox, F., Rai, D. and Redwood, S. (2019) Inside, Outside and In-Between: The Process and Impact of Co-Producing Knowledge about Autism in a UK Somali Community. *Health Expectations*, **22**, 752-760. https://doi.org/10.1111/hex.12939
- [48] Patel, M. (2019) Increase in Measles Cases—United States, January 1-April 26, 2019.
 Morbidity and Mortality Weekly Report, 68, 402-404.
 https://www.cdc.gov/mmwr/volumes/68/wr/mm6817e1.htm
 https://doi.org/10.15585/mmwr.mm6817e1
- [49] Belluz, J. (2017) Minnesota's Measles Outbreak Is What Happens When Anti-Vaxxers Target Immigrants. Vox.
 https://www.vox.com/science-and-health/2017/10/26/16552864/minnesotas-measles-outbreak-immigrants-anti-vaxxers
- [50] Fox, F., Aabe, N., Turner, K., Redwood, S. and 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, 305-315. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5309314 https://doi.org/10.1007/s10803-016-2952-9
- [51] Munroe, K., Hammond, L. and Cole, S. (2016) The Experiences of African Immigrant Mothers Living in the United Kingdom with a Child Diagnosed with an Autism Spectrum Disorder: An Interpretive Phenomenological Analysis. *Disability & Society*, **31**, 798-819. https://doi.org/10.1080/09687599.2016.1200015
- [52] Eze, U.A. (2018) Autism in Africa: The Critical Need for Life Saving Awareness. *Journal of Educational Leadership and Policy Studies*, 34-38. https://eric.ed.gov/?id=EJ1227555
- [53] Lotter, V. (1978) Childhood Autism in Africa. *Journal of Child Psychology and Psychiatry*, **19**, 231-244. https://doi.org/10.1111/j.1469-7610.1978.tb00466.x
- [54] Bakare, M.O. and Munir, K.M. (2011) Excess of Non-Verbal Cases of Autism Spectrum Disorders Presenting to Orthodox Clinical Practice in Africa—A Trend Possibly Resulting from Late Diagnosis and Intervention. South African Journal of Psychiatry, 17, 118-120. https://doi.org/10.4102/sajpsychiatry.v17i4.295
- [55] Belhadj, A., Mrad, R. and Halayem, M.B. (2006) A Clinic and a Paraclinic Study of Tunisian Population of Children with Autism. About 63 Cases. *Tunisie Medicale*, 84, 763-767.
- [56] UN News (2015) UN Lauds Somalia as Country Ratifies Landmark Children's Rights Treaty.
 https://news.un.org/en/story/2015/01/488692-un-lauds-somalia-country-ratifies-landmark-childrens-rights-treaty
- [57] The Elemy Learning Studio (2020) Guide to Estimating the Cost of Autism on a Family. https://www.elemy.com/studio/autism-treatment/estimate-the-cost
- [58] Somalia GDP per Capita—2021 Data—2022 Forecast—2013-2020 Historical-Chart. https://tradingeconomics.com/somalia/gdp-per-capita
- [59] Danish Immigration Service. Somalia Health System. 2020. https://www.justice.gov/eoir/page/file/1339226/download
- [60] World Health Organization (2016) Health Workforce Requirements for Universal

Health Coverage and the Sustainable Development Goals. Human Resources for Health Observer, 17. World Health Organization, Geneva, 40 p. https://apps.who.int/iris/handle/10665/250330

Abbreviations

ASD: Autism spectrum disorder

PDD-NOS: Pervasive developmental disorder – not otherwise specified **SBCADD**: Short branched-chain acyl-CoA dehydrogenase deficiency

25(OH)D): 25-hydroxyvitamin D

SBCAD: Short/branched chain acyl-CoA dehydrogenase

VKORC1: Vitamin K epoxide reductase complex

ARID1B: AT-rich interaction domain 1B

ASH1L: ASH1 Like Histone Lysine Methyltransferase **CHD2:** Chromodomain-helicase-DNA-binding protein 2 **CHD8:** Chromodomain-helicase-DNA-binding protein 8

DYRK1A: Dual Specificity Tyrosine Phosphorylation Regulated Kinase 1A

POGZ: Pogo Transposable Element Derived with ZNF Domain

SHANK3: SH3 and multiple ankyrin repeat domains 3 **SYNGAP1:** Synaptic Ras GTPase-activating protein 1

MMR: Measles-mumps-rubella

HIV: Human immunodeficiency virus

GDP: Gross domestic product **CRC:** Child Rights Convention