Parental Perceptions Upon Receiving Diagnosis of Autism Spectrum Disorder and/or Intellectual Developmental Disability for their Child in Nigeria

Chinomso Ihenagwam[1], Jennifer Hamrick[1], Katherine Wheeler[1],
Ugochi Iwuji[1], Henry Duru[1], Devender Banda[1]

[1] Texas Tech University, US.

HOW TO CITE:
Ihenagwam, C., Hamrick, J., Wheeler, K., Iwuji, U., Duru, H., & Banda, D. (2024). Parental Perceptions Upon Receiving Diagnosis of Autism Spectrum Disorder and/or Intellectual Developmental Disability for their Child in Nigeria. *International Journal of Special Education, 39*(1), 73-87.

CORRESPONDING AUTHOR:
Devender Banda;
devender.banda@ttu.edu

DOI:
https://doi.org/10.52291/ijse.2024.39.8

COPYRIGHT STATEMENT:
Copyright: © 2022 Authors. Open access publication under the terms and conditions of the Creative Commons Attribution (CC BY) license (http://creativecommons.org/licenses/by/4.0/).

ABSTRACT:

This study examined Nigerian parents' perceptions upon receiving an Autism Spectrum Disorder (ASD) and/or an Intellectual/Developmental Disability (IDD) diagnosis for their child. Using a cross-sectional design, this study surveyed Nigerian parents via a questionnaire containing a modified version of the Family Interview Schedule (*n* = 247) to examine how parents experienced stigma, their knowledge about ASD/IDD, and their perceived cause of ASD/IDD. Descriptive statistics indicated that the majority of surveyed parents experienced stigma and believed that autism could be cured. Furthermore, results from a stepwise linear regression demonstrated that parents' level of education significantly influenced their experiences of stigma, their choice of institutions for seeking initial help, their perception of the seriousness of the disorder, and the impact of others' belief in the transmissibility of their child's condition on child's condition could be transmitted significantly affected their experiences of stigma. Results are discussed, and implications for policy, research, and practice are provided.

Keywords: Autism Spectrum Disorder, Diagnosis, Intellectual Developmental Disability, Stigma, Nigeria, Parental Perceptions, Knowledge

INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disorder characterized by difficulties in social communication and social interactions, restricted and repetitive patterns in behaviors, interests, and activities challenges in moderating everyday functional tasks (American Psychiatric Association, 2013). ASD is a global disorder that affects individuals of different races and ethnicities and is found across all continents (Maenner et al., 2021; Paula et al., 2020; Salari et al., 2022; Zeidan et al., 2022). According to Adebowale (2022, April 2), ASD is one of the conditions that is ignored, rarely discussed and lacks adequate provision and management in Nigeria. There is limited knowledge and awareness about ASD, its symptoms, and the diagnostic process among people of Nigeria, including professionals (e.g., doctors, educators, and therapists), making it difficult for them to differentiate ASD from other developmental disabilities (Bakare et al., 2009). Esther (2019) noted that unhelpful, false beliefs are prevalent in the Nigerian community and described that some Nigerians label ASD as a “White man’s disorder,” meaning that ASD is a disorder that is associated only with Caucasians and countries from the advanced world. Esther (2019) further explained that although there is not much awareness of ASD in Nigeria, ASD is prevalent in Nigeria and not limited to any race, societal status, or religion.

Regarding the prevalence rate of individuals with ASD or Intellectual/Developmental Disabilities (I/DD) in African countries, the literature is still nascent. A global ASD prevalence study reported that the prevalence rates of autism in Africa are extremely limited (Zeidan et al., 2022). This is further compounded by the common co-morbidity of autism and I/DD within African countries (Bakare et al., 2012). Results of this global prevalence study indicated that the median prevalence rate per 10,000 was 205 in Africa (Zeidan et al., 2022). ASD was first identified in the 1970s in sub-Saharan Africa, including Nigeria, making it difficult to differentiate ASD from other intellectual developmental disabilities (IDD) due to the relatively recent recognition of ASD within Nigeria (Bakare et al., 2019; Bakare & Ikegwuonu, 2008; Bakare & Munir, 2011; Franz et al., 2017; Onuora, 1993).

Results from various studies conducted in Nigeria have provided varying prevalence rates of ASD across Nigeria. For instance, in a study conducted with 1,312 children with IDD, 30 of those children had symptoms of autism, with 9 meeting the criteria for ASD at the time of the study (Lotter, 1978). Another study conducted in the southeastern part of Nigeria within a space of one year reported the prevalence rate of ASD as 0.8% among 393 children in a hospital clinic setting (Bakare et al., 2011). Another study recorded a 2.3% prevalence rate of ASD among 2,320 new cases of children at child neurology and psychiatric clinics over a 6-year period (Lagunju et al., 2014). Yet another study recorded a prevalence rate of 11.4% among children with intellectual disabilities or neurodevelopmental concerns (Bakare et al., 2012). Bakare et al. (2012) reported a 14.8% prevalence rate of ASD among those with neurodevelopmental disabilities. Also, Chinawa with coauthors (2016) conducted a study in elementary and secondary schools in the southern part of Nigeria, and among children aged 3 to 18 years, a prevalence rate of 2.9% was recorded. Another study conducted in the western part of Nigeria indicated a prevalence rate of 34.5% in a community-based sample of 85 children with developmental disabilities (Oshodi et al., 2016). In addition, Adebowale (2022) stated that a study conducted in Nigeria indicated that 54 of the observed sample of 2,320 children in Nigeria had autism. Therefore, the true prevalence of ASD in Nigeria is still largely uncertain, given prevalence rates in the extent literature range from 0.8% to 34.5% depending on the studied sample and setting (e.g., within the neurodevelopmental disability population, school-based population, etc.; Bakare et al., 2019).

Diagnosis of ASD in Nigeria is often delayed due to factors such as ignorance, lack of experienced medical personnel, non-functional health facilities, lack of financial resources, shame, discrimination, as well as stigmatization among the family members (Adebowale, 2022, April 2); Bakare & Munir 2011a; 2011b; Onyenucheya, 2018). A high rate of discrimination has prevented a number of parents from seeking help for their children with autism, and some of these children are rejected, abused, and stigmatized within the family circles and society at large (Adebowale, 2022; Onyenucheya, 2018). According to Bakare et al. (2009), stigma and negative comments can contribute to late diagnosis. Children with ASD are reported as being locked up in their homes by their parents, thereby depriving them of the early intervention needed (Bakare et al., 2009). Further, parents reported that there is a delay in the diagnostic process of their children with ASD (Franz et al., 2017). This is due to a lack of knowledge about ASD, especially in low-income countries. Overall, the process of communicating with professionals during the ASD diagnostic process can be challenging for parents globally, and parents report that the diagnostic process is challenging as it is often perceived as slow, chaotic, and poorly handled (Gray, 1993; Mansell & Morris, 2004).

Studies have explicitly stated that children with ASD or IDD may often experience social behavioral challenges such as difficulties in caring, helping, and comforting, which prevents them from establishing close relationships with others and subsequently creating frustrations for parents (Grenier-Martin et al., 2022; McStay et al., 2014; Penner et al., 2005). For children with autism who may be experiencing challenges such as communication, self-stimulatory behaviors, and other behaviors of concern could be perceived as threatening by other children which could increase stress and difficulty for the individual with autism together with their parents (Hou et al., 2018; Lecavelier et al., 2005). Negative and poor acceptance of children with ASD by their peers and others creates a feeling of exclusion and social isolation for the parents (Alnazly & Abojedi, 2019; Benson, 2010). Parents of children with disabilities, in general, feel a sense of shame, guilt, and stigma (Corrigan et al., 2009). All of these may lead to parents feeling isolated, which can result in greater stress in caring for a child with ASD.

Obasi et al. (2019) noted that a diagnosis of ASD can cause stress for parents and that the burden of care falls on the caregivers. In fact, parents of children with ASD experience multiple challenges, especially with the fact that ASD does not manifest as a physical disability (Neely-Barnes et al., 2011), making it difficult for others to understand the child and parents' challenges towards their disabilities. When further considering the absence of a physical disability or physical manifestation of ASD, the result culminates in people blaming parents for their children's poor behavior which, in turn, results in increased family isolation. A study by Tekola et al. (2020) stated that parents of children with disabilities experience stigma directed toward their children, making them isolate themselves and their children with disabilities. Additionally, the extent literature also confirms that stigma is a continued barrier to individuals with IDD across cultures (Jansen-van Vuuren & Aldersey, 2020).

Further, Lesi et al. (2014) identified emotional burdens as one of the challenges faced by parents of children with autism. Similarly, studies conducted with families of children with autism in the United States report that parents face financial burdens, depression, stress, and anxiety (Hoefman et al., 2014; Kuhlthau et al., 2014; Mulder & Tudor, 2013; Zablotsky et al., 2013). Furthermore, research indicates that parents of children with autism experience feelings of shame, guilt, and stigma (Dababnah & Bulson, 2015; Dababnah & Parish, 2013; Hall & Graff, 2010; Kuhlthau et al., 2014; Nealy et al., 2012; Neely-Barnes et al., 2011). Conversely, studies demonstrate that psychoeducation on autism has yielded reductions in parent stress, increased parental knowledge of autism, increased child skill, and increased parental perceptions of their ability to care for their child with ASD (Kumari et al., 2020; Roughan et al., 2019). For example, Roughan et al. (2019) conducted parent psychoeducation groups for parents of children with ASD across two years and found that 82% of participants reported feeling more confident in managing their child's behaviors as well as feeling more confident in their ability to parent their child with ASD. Additionally, Kumari et al. (2020) implemented a psychoeducation module with 30 parents of children with ASD or IDD to explore the relationship between psychoeducation and child skill. Results demonstrated significant improvements in relationships and reciprocity, reduced behaviors of concern, enhanced communication, and increased emotional responsiveness. These results implicate the importance of understanding a disorder on parental experiences as well as child outcomes.

There has been an increasing number of studies about parents' perception of children with disabilities in different parts of the world, including Africa (Aldersey, 2012; Gobrial, 2018; Masulani-Mwale et al., 2016; Oti-Boadi, 2017; Tekola et al., 2020), however, there is a limited understanding of the perceptions of parents of children with autism and/or IDD, particularly in Nigeria. Parental perceptions of autism and their experiences of stigma have been studied in different countries but, none has been investigated in Nigeria. This study attempted to fill the gap in the literature concerning parental perceptions and experiences of stigma in Nigeria. Understanding parents' perceptions and experiences towards receiving Autism/IDD diagnoses can contribute to the development of meaningful support for parents and caregivers of children with autism. Specifically, this study sought to answer the following questions:

1. What are the experiences of stigma in Nigerian parents with children with neurodevelopmental disabilities?
2. Do demographic factors, explanatory models, and/or service provision and utilization predict feelings of stigma?
3. What are some perceived causes of neurodevelopmental disabilities among parents in Nigeria, and what intervention options do parents seek?

METHODS

Research for this project was approved by the university's Institutional Review Board. Prior to participation, all participants, including potential participants, were presented with an informed consent form embedded in the survey. Participants who voluntarily agreed to take part had the freedom to discontinue the survey at any point by exiting the online survey or closing the browser. No identifiable data was collected.

Participants

The inclusion criteria for this study were parents/caregivers with children that are reported to have ASD/IDD and lived in any area or region within Nigeria. Participants were recruited through social media groups for autism in Nigeria (i.e., Facebook, Instagram, and WhatsApp groups). Also, survey links were sent to school administrators, teachers, hospital administrators, and religious leaders in Nigeria, who then forwarded the survey link to parents of children with disabilities. Participants who completed the survey met the criteria of having at least one child with ASD/IDD. Exclusionary criteria included participants who did not have a child with ASD/IDD, parents living outside Nigeria, and parents below the age of 16. Overall, 318 surveys were completed online. However, 71 were excluded from data analysis due to the exclusionary criteria mentioned above, resulting in a final sample of 247 survey respondents (see Table 1).

Table 1. **Demographic and clinical characteristics of the respondents and association with score on the adapted Family Interview Schedule (FIS) stigma scale**

	Characteristic	*N*	*%*	*Mean FIS score*	*Unstandardized B coefficient*	*t*	*p*
Age	Mean age 36-55						
	16-25	13	5.3	21.69			
	26-35	85	34.4	21.96			
	36-55	133	54.1	20.41			
	56+	15	6.1	14.69			
Gender	female	184	74.5	21.13			
	male	44	17.8	16.86			
	non-binary	3	1.2	20.33			
Religion	Christianity	141	57.1				
	Islam	97	39.3				
	Traditional	7	2.8				
Parent Level of Education	Primary	16	6	24.31	-1.365	-2.735	0.007
	Secondary	71	28.7	23.49			
	4-Year University	108	43.7	20.48			
	Masters	34	13.8	16.85			
	Doctoral	5	2	9			
Region	City	219	88.7	21.19			
	Rural	27	10.9	18.42			
Number of children with ASD/IDD							0.013
	1	207	83.8	20.83			
	2	26	10.5	21.85			
	3	0	0	NA			
	4+	7	2.8	15.64			

	Characteristic	*N*	*%*	*Mean FIS score*	*Unstandardized B coefficient*	*t*	*p*
First seek help location							0.007
	Traditional (native medicine)	67	27				
	Biomedical (hospital)	135	54				
	place of worship	24	10				
	school	17	7				
Religious intervention tried							
	Prayer	209	85				
	Anointing oil	41	17				
	Holy water	31	13				
	Ashes	6	2				
	Handkerchief	10	4				
	Candles/incense	11	4				
	Fasting	98	40				
	Deliverance	30	12				
Religious informed knowledge							
	God's will	79	32				
	Possession	10	4				
	Evil eye	16	6				
	Witchcraft	11	4				
	Supernatural curse	30	12				
	Ancestral curse	18	7				

Measures

The survey used for this study included the following four sections: 1) parent/caregiver demographics, 2) child demographics, 3) beliefs and values, and 4) perception and stigma. The demographic section collected information on the age, religion, educational level, and region of the parents. The belief and values section comprised six questions which were modified from Tilahun et al. (2016) and included single select questions regarding explanatory models of illness, the perceived severity and prognosis of their child's disability, and interventions tried. Questions included examples such as "Where did you first seek help for your child?" and "Do you believe autism/IDD can be cured?"

Perception and stigma were measured using questions adapted from the Tilahun et al. (2016) study which included 14 questions inquiring about the family's experience of stigma. Tilahun et al. (2016) modified their stigma questions from the Family Interview Schedule (FIS), which was originally developed for families of people with schizophrenia, and Tilahun et al. (2016) modified the FIS for families of individuals with developmental disabilities. The internal consistency for the adapted FIS was good (stepwise Bach's Alpha = 0.92), and the content validity index of the stigma section of the FIS was 0.96. These questions were rated on a four-point scale, representing the feelings of stigma: *a lot* was given a score of 3, *often* a score of 2, *sometimes* a score of 1, and *not at all* a score of 0.

Study Design and Data Collection

A cross-sectional survey design was used to survey Nigerian parents. The questions were administered in the English language, as it is the official language of Nigeria (Britannica, 2019; Mann, 1990). The survey was integrity-checked across three iterations by the research team. The survey was then launched via electronic means (Qualtrics) for participant completion and was open for a period of three months.

Data Analysis

The data were analyzed using SPSS$^{(R)}$ (2020). Categorical variables were dummy-coded prior to importing data to SPSS. The frequency distribution of the survey variables was then examined to check for any outliers to determine the overall distribution. The adapted Family Interview Schedule (FIS) from Tilahun et al. (2016) was found to be normally distributed, allowing for further parametric analysis. A stepwise multiple linear regression was conducted, in replication of Tilahun et al.'s (2016) methodology, to test whether the demographic factors, explanatory models, and/or service provision and utilization predicted total FIS scores. Results were considered significant at the $p < .05$ level.

RESULTS

This study sought to address research questions regarding parental perceptions and experiences upon their children being diagnosed with ASD/IDD in Nigeria. Specifically, this study sought to explore parental experiences of stigma, perceptions of the causes of these disorders, and the interventions sought or tried after diagnosis. A total of 247 parents completed the survey. Table 1 outlines the demographic characteristics of the participants, and Table 2 describes the demographics of their children. The majority of the respondents were female (n = 184; 74%) between the age of 26-35 (*n* = 133; 54%) who lived in an urban/city setting (*n* = 219; 89%). Respondents primarily indicated having a four-year university education (*n* = 108; 44%). Thirty-three parents (13%) reported having more than one child with ASD, IDD, or both. Respondents reported having at least one child with ASD/IDD (*n*=207*;* 84%), and at least two children with ASD/IDD (*n*=26; 10.5%). Among the cases reported, most respondents identified their child as having an ASD diagnosis or IDD (*n* = 171; 69%), followed by an IDD diagnosis (*n* = 66; 27%), and only 10 reported children to have cooccurring ASD and IDD (4%). The majority of the children that were reported to have developmental disorders were between the ages of 4 to 12 years old (*n* = 196; 79%).

Table 2. **Demographic and clinical characteristics of the respondent's child**

	Characteristic	N	%	Mean FIS score
Age of child with developmental disorder	Mean age			
	0-3	8	3.2	18.29
	4-6years	79	32	20.33
	7-9years	61	24.7	22.13
	10-12years	56	22.7	22.94
	13-15years	20	8	23
	16-17years	14	5.7	13.07
	18+	6	2.4	13.4
Child's gender				
	female	76	31	20.87
	male	164	66	20.99
	non-binary	14	0.8	14
Siblings with developmental disabilities				
	No	207	84	20.99
	Yes	33	13	20.33
Type of Disability				
	Autism spectrum disorder (ASD)	171	69.2	21.2
	Intellectual/developmental disability (IDD)	66	26.7	20.42
	Both ASD/IDD	10	4	26.3

Experiences of Stigma

Parents reported having experienced stigma on many items of the adapted FIS. For example, out of the 247 respondents, 232 (94%) indicated that they *sometimes, often,* or *a lot* worry about being treated differently. Additionally, parents do feel, or have felt, ashamed or embarrassed of their child's condition (*n* = 221; 89%); have worried about being avoided by others because of their child's disability (*n* = 219; 89%); and have worried that people would blame them for their child's behavioral challenges (*n* = 207; 84%).

Parents also reported experiencing stigma related to the visibility of their child's disability within the community. About 85% expressed a need to hide the problem from others, and 81% of respondents have tried to keep their child's condition a secret. Further, 86% of parents have worried about other people finding out about their child's condition. Concerns about their child's future prospects were prevalent, with 87% of respondents worry and/or have worried that their child may not marry, and 92% worry and/or have worried about taking their child out to the community. Parents also felt grief and depression (*n*=232; 94%) and some felt that their child's condition might be somehow their fault (*n* = 221; 89%). On a positive note, parents reported seeking support from other parents who have children with similar conditions (*n* = 227; 92%). Moreover, 92% of parents expressed that they have helped other people to understand what it is like to have a child with delayed development and have explained to others that their child may not fit the stereotypical image of a "typical" child (see Table 3).

Perceived Causes of ASD/IDD

Parents reported a mixture of biological (*n* = 138; 56%), religious (*n* = 33 13%), and medical misperception (*n* = 96; 39%) factors as causes of their child's condition (see Table 4). Examples of medical misperceptions included head injury, maternal alcohol drinking during pregnancy, vaccines, and birth complications. Examples of biological factors included genetic or family history, and examples of religious causes included ancestral curses, sinful acts, and belief in God's will. Despite perceiving their child's developmental problems to be *very* or *quite* severe (*n* = 217; 88%), most of the respondents (*n* = 131; 53%) believed that the child's condition could be cured. Some parents held the belief that their child's condition could be transmitted to others (*n* = 51; 20%) or believed that others thought their child's disability could be transmitted (*n* = 118; 48%) (see Table 4).

Table 3. **FIS of the parents endorsing any level of stigma – the sum of "sometimes," "often," and "a lot"**

FIS Breakdown	Items	Number	Percentage
	Worried about taking him or her out	227	92
	Felt ashamed or embarrassed about it	221	89
	Sought out people who also have a child with similar problems with developing slowly	227	92
	Felt grief or depression because of it	232	94
	Felt that somehow it might be your fault	221	89
	Felt the need to hide this disability from people (i.e. that your child has challenges)	210	85
	Worried about being treated differently	232	94
	Worried other people would find out about it	212	86
	Helping other people to understand what it is like to have a child with slow development	226	92
	Worried about being avoided	219	89
	I have tried to keep the disability a secret	201	81
	Explaining to others that your child isn't like their picture of a "not typical" child	228	92
	Worried that people would blame you for his or her challenges	207	84
	Worried that a person looking to marry would be reluctant to marry into your family	215	87

Table 4. **Parent perceptions about the child with ASD/IDD, perceived causes of developmental disorder, and places help was first sought**

Variable		***Number***	***Percentage***
Believe that child's condition can be cured?			
	Yes, can be cured	131	53
	No cure but can be improved	113	45.7
	No cure nor Improvement	1	0.4
How severe do you think your child's condition is			
	Very serious	89	36
	Quite serious	128	51.8
	Not too serious	22	8.9
	Not serious at all	2	97.6
Do you think your child's condition can be transmitted?			
	Yes	51	20.6
	No	157	63.6
	Not sure	35	14.2
Do you think others think your child's condition can be transmitted?			
	Yes	118	47.8
	No	78	31.6
	Not sure	48	19.4
Perceived causes of child ASD/IDD*			
	Spirit possession	11	4.5
	Sinful Act	5	2
	Punishment from God	16	605
	Evil eye	4	1.6
	Curse	8	3.2
	Head injury	14	5.7
	Birth complication	59	23.9
	Infection	16	6.5
	Family history	37	15
	Genetic factors	41	16.6
	Environmental factors	18	7.3
	Drinking alcohol during pregnancy	10	4
	Vaccine	13	5.3
	No known cause	73	29.6
	Other	3	1.2
Places help first sought			
	Traditional (native medicine)	67	27.1
	Biomedical (hospital)	135	54.7
	Place of worship	24	9.7
	School	17	6.9

** Respondents could select multiple answers*

Types of Interventions Sought or Tried

When asked about the sources of help they sought for their child with ASD/IDD, many parents reported that they first sought help from medical institutions (*n* = 133; 54 %). Some parents first sought help from traditional/native medicine (*n* = 67; 27 %), religious entities/places of worship (*n* = 24; 10%), or schools (*n* =17; 7%; see Table 3).

Parents reported utilizing various approaches for the treatment of their child with ASD/IDD. These included medical treatments provided by hospitals (*n* = 133; 54%), as well as religious interventions such as prayers (*n* = 209; 85%), fasting (*n* = 98; 40%), deliverance (*n* = 30; 12%), anointing oil (*n* = 41; 17%), holy water (*n* =31; 13%), ashes (*n* = 6; 2%), handkerchief (handkerchief is a form of religious tool/instrument used by many church members in Nigeria for prayers and miracle with the belief it would provide solution to their problem), (*n* = 10; 4%), flogging (*n* = 6; 2%), and/or candles/incense (*n* =11; 4%). Parents also reported using traditional or native medicines as treatment interventions, such as herbs (*n* = 104; 42%), incantation (*n* = 23; 9%), massages (*n* = 10; 4%), and/or dietary restrictions (*n* = 27; 11%, see Table 1).

Parents Experience of Stigma

Parents of children with both ASD and IDD reported different feelings and experiences of stigma based on their report from the FIS score. Having a child with ASD and or IDD does not make any difference in the parent's experiences of stigma, however, the patents level of education had effect on their experiences of stigma as shown on Table 1. For example, the results indicate a negative relationship between education level and the experience of stigma. The higher the education the parents obtain the less they experience stigma about their child's condition. Responses such as "a lot, often, sometimes", are grouped together and are counted as one response. Results show that the parents are worried about taking their child out (*n* = 227; 92%), felt ashamed or embarrassed about their child condition (*n* = 221; 89%). Parents sought out people who also have a child with similar problems with developing slowly (*n* = 227; 92%), felt grief or depression because of it (*n* = 232; 94), felt that somehow it might be your fault (*n* = 221; 89%). Parents also responded to the following questions, felt the need to hide the child's disability from people (*n* = 210; 85%), worried about being treated differently (*n* = 232; 94%), worried other people would find out about it (*n* = 121; 86%), helping other people to understand what it is like to have a child with slow development (*n* = 226; 92%), worried about being avoided (*n* = 219; 89%), have tried to keep the disability a secret (*n* = 201; 81%), explaining to others that your child isn't like their picture of a "not typical" child (*n* = 228; 92%), worried that people would blame you for his or her challenges (*n* = 207; 84%), and worried that a person looking to marry would be reluctant to marry into your family (*n* = 215: 87%, see Table 3).

Regression Analysis Results

A forward stepwise linear regression was used to identify possible predictors of the FIS total score out of the surveyed demographic, clinical, or explanatory model and service use related variables (see Tables 1, 2, and 3). These variables were reduced to five variables: parent education level, total number of children, perceived seriousness of the condition, the place parents first sought help, and children with co-occurring ASD and IDD. These possible predictors are meaningful when considering them from an exploratory lens that may speak to future policy and parent education opportunities for the autistic community. By understanding which variables are associated with increased stigma, the potential for tailored parent psychoeducation becomes an option.

Table 1 further summarizes the results from the stepwise multiple regression analysis, examining the association between demographic and clinical variables with the total FIS score. The analysis revealed significant relationships between the FIS score and the following demographic variables: parent education level (β = -.17, $p < .05$), and the total number of children in the family (β = -1.35, $p < .05$). However, no significant relationships were found between the FIS score and the following demographic variables: parent age (β = .084, $p = .96$), parent gender (β = .70, $p = .10$), region (β = -1.68, $p = .35$, religion (β = 1.39, $p = .12$), and the total number of children with special needs (β = .68, $p = .56$).

Additionally, several explanatory variables showed significant associations with the experience of stigma, as indicated by the FIS sum score. These variables included the level of perceived seriousness of the disorder (β = -.14, $p < .05$), the location where parents first sought help (β = .183, $p < .05$), the presence of children with both ASD/IDD (β = 7.202, $p < .05$), the belief in the curability of ASD (β =-3.203, $p < .05$), and if others believe that their child condition is transmissible (β =-2.158, $p < .05$).

DISCUSSION

This study investigated Nigerian parental perceptions of autism diagnosis, causes, stigma, and knowledge. Some respondents reported having experienced a high level of stigma on the items of the adapted FIS. This is depicted in the result which shows a negative relationship between education level and the experience of stigma. The higher the education the parents obtain the less they experience stigma about their child's condition. This finding can be attributed to a lack of education and knowledge about ASD in Nigeria. A study by Tekola et al. (2020) explained that stigma could be associated with lack of knowledge, and discrimination. Some parents reported feeling ashamed or embarrassed about their child's disabilities. In addition, they reported that their child's disabilities were caused by their sins, and some stated that they were a result of punishment from God, indicating their misperception about ASD. Consistent with previous studies by Gona et al. (2015) and Oti-Boadi (2017), ASD/ IDD are often ascribed to supernatural causes which include curses, possession by evil spirits, and punishment from God for the sins that the child's family may have committed. Some parents reported seeking diagnoses from various entities such as native medicine, schools, hospitals, and religious leaders. These parents also sought intervention from churches, hospitals, schools, and traditional/native medicines, and have also tried risky or unproven treatments such as flogging, deliverance, ashes, and numerous other types of intervention for their child.

The majority of parents (88%) in this study believed their child's condition to be *very* or *quite* serious. Most of the data were obtained from schools, therefore, most parents that responded to the survey may have some level of education. This educational background may have influenced the level of stigma experienced by the parents. For example, the results indicate a negative relationship between education level and the experience of stigma. The higher the education the parents obtain the less they experience stigma about their child's condition.

The surveyed parents reported that the perceived causes of their child's condition are a mixture of religious/supernatural (e.g., spirit possession, punishment from God, sinful act, evil eye, curse), medical misperception (e.g., infection, alcohol use during pregnancy, head injury, birth complications, vaccine), and medical (e.g., genetic factors) factors. This finding is consistent with other studies which mention the coexistence of both medical and supernatural belief systems (Shyu et al., 2010). Also, most parents believed that their child's condition could be curable (53%). Results of the stepwise multiple regression indicate a negative relationship between the belief in the curability of autism and stigma, indicating that parents who are more convinced that autism is curable experience lower levels of stigma. This finding shows that most parents may have some unrealistic expectations of what can be achieved with treatment, hence hoping that any form of treatment and/or intervention given to their child could cure their neurodevelopmental disability. Another factor to consider when explaining why most parents feel that ASD/IDD could be cured is the parents' religious beliefs. This is evident through the number of respondents who have tried different religious interventions, such as prayer ($n = 209$; 85%). This study was conducted in Nigeria, a country with a high number of churches and mosques. The Nigerian society is deeply religious and most of the surveyed participants were religious (96.4%) and identified as Christian or Muslim. This could also be considered a coping strategy for these parents. For example, most of the respondents, as seen in the result section, reported seeking intervention from their religious leaders, and they have tried different religious interventions such as fasting, deliverance, and so on, suggesting that religious belief and faith in God serve as coping strategies for parents dealing with the stress of raising a child with a disability (Dababnah & Parish, 2013; Dardas & Ahmad, 2014; Kheir et al., 2012). Similarly, several other studies conducted in the United States also acknowledge that religious beliefs and spirituality served as a coping mechanism for parents of children with autism (Khanna et al., 2011; Kuhaneck et al., 2010). Some studies even suggest that raising a child with autism has strengthened parents' religious faith (Hutton & Caron, 2005).

The study results indicate that parental experiences of stigma include worrying about being treated differently, feeling ashamed or embarrassed about their child's condition, making efforts to keep their child's condition a secret, and explaining to others that their child does not fit stereotypical conceptions of mental illness. A study by Tekola et al. (2020) explained that some parents isolate themselves and their children due to the stereotypes associated with having a child with disabilities. Nigerian parents commonly report other experiences, such as feeling depressed, seeking support from others caring for a child with similar problems, and blaming themselves for the problem. These findings are consistent with studies conducted in both low-income countries and high-income countries that demonstrated that parents and caregivers of children with ASD and/or IDD encounter stigma and often experience emotions such as embarrassment, shame, and guilt (Ambikile & Outwater, 2012; Corcoran et al., 2015; Divan et al., 2012; Gray 1993; Heiman 2002; Shyu et al., 2010; Tilahun et al., 2016).

Other studies have explained that parents/caregivers responsible for their children with disabilities feel tired, exhausted, depressed, and worried about their child's future in society (Ambikile & Outwater, 2012; Divan et al., 2012; Wang et al., 2011). The findings of this study suggest that parents/caregivers who first seek help from traditional sources experienced higher levels of stigma. According to the results of the stepwise regression analysis, those who sought help from traditional sources experienced significantly higher levels of stigma. However, due to the cross-sectional approach of this study, it is not possible to determine the directionality between traditional support and stigma; that is, it remains unclear whether engaging in traditional approaches increases stigma or whether those who experience high levels of stigma are more likely to seek traditional support.

Parents reported a mixture of biological, religious and medical misperception factors as potential causes of their child's condition. Examples of medical misperceptions included head injury, alcohol drinking during pregnancy, vaccines, and birth complications. Biological factors mentioned by parents included genetic or family history, while religious causes included ancestral curses, sinful acts, and the God's will. Although most participants believed their child's developmental problems to be *very* or *quite* severe, some parents believed that their child's condition could be transmitted to others or thought that others held that belief. Parents who were more convinced their child's condition was transmissible reported experiencing significantly lower levels of stigma. The theoretical relationship behind this result is unclear and should be considered for further investigation in future research.

Many caregivers reported using a combination of traditional (e.g., herbs, incantation, massages), religious (e.g., prayers, anointing oil, holy water, ashes, handkerchief, candle/incense, fasting, and or deliverance, flogging), and medical (e.g., dietary restrictions) interventions to help their child. This is comparable to studies that were done in countries. For example, Heiman (2002) and Shyu et al. (2010) reported that caregivers used multiple services and treatment strategies to help their children with developmental disabilities, including psychological, medical, therapeutic, and paramedical services (Heiman, 2002), as well as special diets and traditional treatments (Ravindran & Myers, 2013; Shyu et al., 2010). Another study conducted in Nigeria confirmed that many parents initially sought help from traditional and religious healers, due to a lack of knowledge about ASD (Bakare et al., 2009). The wide range of interventions tried by parents may reflect a lack of awareness about evidence-based interventions for autism as they desperately search for treatments to help their child. These few studies conducted in Africa also confirmed a lack of awareness and a high level of stigma experienced by parents (Tekola et al., 2020; Tilahun et al., 2016; Zeleke et al., 2018).

IMPLICATIONS

This study has many implications for professionals working with parents/caregivers and children with developmental disabilities in Nigeria. Due to a clear implication surrounding parents' experiences with the diagnostic and post-diagnostic process, there is a need for a system-wide intervention that aims at improving public awareness about ASD/IDD in response to the high levels of stigma reported by parents/caregivers of children with ASD/IDD. This study's findings have implications for policies to increase awareness about ASD/IDD, reduce stigma, and address perceptions of parents with children with ASD/IDD. In response to the findings of many parents seeking help traditionally and religiously, professionals working with these individuals should be multi-culturally competent in understanding their patients' traditional and religious backgrounds and should provide psychoeducational interventions that that are sensitive to their beliefs. This approach would encourage openness from parents/caregivers while carefully discouraging harmful practices, such as chaining and flogging.

In response to the findings that neurodevelopmental disabilities can be cured, there is a need for professionals working in this field to develop culturally sensitive, evidence-based psychoeducational interventions. These interventions should aim to educate people about the lifelong management of ASD or I/DD, rather than perpetuating the misconception and unrealistic expectation of a complete "cure" for the condition. It is crucial for professionals to address these issues with sensitivity taking into account the religious and traditional beliefs held by individuals and families.

Family involvement is vital to support the success of children in inclusive settings. One manner in which to consider for increased access for families is increasing their access to the internet and mobile technologies (Hill et al., 2024). Hill et al. (2024) specifically recommends a three-prong approach in Nigeria to increase awareness and early intervention for children with neurodevelopmental disorders. This approach includes access to low tech interventions, psychoeducation on skill acquisition, and systemic changes in Nigeria to support access and inclusion for families. The inclusion of community-based organizations (e.g., churches, schools, etc.) in the psychoeducation of specific autism and I/DD characteristics as well as appropriate skill acquisition can provide a wraparound support for families as well that may reduce future stigma.

LIMITATIONS

Study results should be interpreted with caution due to some limitations. One of the limitations of this study is the lack of cell phones and/or internet to complete the survey. Only participants with smartphones were able to take part, which limits the generalization of this study findings. Costs associated with phone data use may have prevented some potential participants from completing the survey. Parents who are less than 16 years of age were excluded from this study limiting the generalization of results. A lack of funds was also identified as there were no incentives for the parents, which limits the number of participants willing to respond. Future research should consider these barriers to accessing responses.

CONCLUSION

Parents of children with ASD/IDD in Nigeria face many challenges including stigma, lack of adequate services and access to services, and lack of support from the community. Higher-level stigma was reported in parents/caregivers who sought help from traditional institutions, had lower levels of education, or believed others might think that their child's condition could be transmitted. Interventions to improve awareness about developmental disabilities, decrease stigma, and improve access to knowledge and support for parents are needed. Future researchers should replicate the study with a broader population of parents. Also, future research should specifically focus on evidence-based interventions and how these interventions impact parental perceptions and knowledge of ASD/IDD.

ACKNOWLEDGEMENTS

The data that support the findings of this study are available from the first author upon reasonable request.

DECLARATION OF INTEREST STATEMENT

No potential conflict of interest was reported by the authors.

FUNDING

None

REFERENCES

Adebowale, N. (2022). Premium Times. *For families of people with autism in Nigeria, treatment, and therapy cost a nightmare.* https://www.premiumtimesng.com/news/headlines/521399-for-families-of-people-with-autism-in-nigeria-treatment-therapy-cost-a-nightmare.html#:~:text=Autism%20is%20a%20condition%20rarely,management%20of%20the%20neurodevelopmental%20disorder

Aldersey, H. M. (2012). Family perceptions of intellectual disability: understanding and support in Dar es Salaam. *African Journal of Disability 1*(1). 1-12. https://doi:10.4102/ ajod.v1i1.32.

Alnazly, E. K., & Abojedi, A. (2019). Psychological distress and perceived burden in caregivers of persons with an autism spectrum disorder. *Perspectives in Psychiatric Care*, *55,* 501-508.

Ambikile, J. S., and Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. *Child and Adolescent Psychiatry and Mental Health*, *6*(1), 1-11.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA.

Bakare, M. O., & Ikegwuonu, N. N. (2008). Childhood autism in a 13 year old boy with oculocutaneous albinism: A case report. *Journal of Medical Case Reports*, *2*, 1-4.

Bakare, M. O., & Munir, K. (2011). Autism Spectrum Disorders in Africa. In Mohammad-Reza Mohammadi (Ed.), *A Comprehensive Book on Autism Spectrum Disorders,* (pp 183-194). https://www.intechopen.com/books/463

Bakare, M. O., & Munir, K. M. (2011a). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, *14*(3), 208-210.

Bakare, M. O., & Munir, K. M. (2011b). 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*(4), 118-120.

Bakare, M. O., Agomoh, A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe, J. U., & Onyeama, G. M. (2009). Etiological explanation, treatability and preventability of childhood autism: a survey of Nigerian healthcare workers' opinion. *Annals of General Psychiatry*, *8*(1), 1-8.

Bakare, M. O., Ebigbo, P. O., & Ubochi, V. N. (2012). Prevalence of autism spectrum disorder among Nigerian children with intellectual disability: A stopgap assessment. *Journal of Health Care for the Poor and Underserved*, *23*(2), 513-518.

Bakare, M. O., Ebigbo, P. O., Agomoh, A. O., Eaton, J., Onyeama, G. M., Okonkwo, K. O., ... & Aguocha, C. M. (2009). Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatrics*, *9*(1), 1-13.

Bakare, M. O., Igwe, M. N., Odinka, P. C., & Iteke, O. (2011). Neuropsychiatric diagnosis and psychotropic medication prescription patterns in a mental hospital-based child and adolescent psychiatric service in Nigeria. *Journal of Health Care for the Poor and Underserved*, *22*(3), 751-755.

Bakare, M. O., Munir, K. M., & Kinney, D. K. (2011). Association of hypomelanotic skin disorders with autism: links to possible etiologic role of vitamin-D levels in autism? *Hypothesis (University of Toronto. Dept. of Medical Biophysics)*, *9*(1), 1-12.

Bakare, M. O., Taiwo, O. G., Bello-Mojeed, M. A., & Munir, K. M. (2019). Autism spectrum disorders in Nigeria: A scoping review of literature and opinion on future research and social policy directions. *Journal of health care for the poor and underserved*, *30*(3), 899.

Benson, R. P. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders, 4*(2), 217-228

Britannica, (2019). *Languages of Nigeria*. Encyclopædia Britannica. https://www.britannica.com/place/Nigeria/Languages

Chinawa, J. M., Manyike, P. C., Aniwada, E. C., Chinawa, A. T., Obu, H. A., Odetunde, O. I., ... & Ibekwe, R. R. (2016). Prevalence and socioeconomic correlates of autism among children attending primary and secondary schools in southeast Nigeria. *African Health Sciences*, *16*(4), 936-942.

Corcoran, J., Berry, A., and Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, *19*(4), 356-366.

Corrigan, P. W., Larson, J. E., & Ruesch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry*, *8*(2), 75-81.

Dababnah S., & Bulson, K. (2015). "On the sidelines": Access to autism-related services in the West Bank. *Journal of Autism and Developmental Disorders, 45*(12), 4124–4134.

Dababnah, S., & Parish, S. J. (2013). "At a moment, you could collapse": Raising children with autism in the West Bank. *Children and Youth Services Review, 35*(10), 1670–1678.

Dardas, L. A., & Ahmad, M. M. (2014). Quality of life among parents of children with autistic disorder: A sample from the Arab world. *Research in Developmental Disabilities, 35*(2), 278–287.

Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. *Autism Research*, *5*(3), 190-200.

Esther, C. U. (2019). Counselling needs of pupils with autism in Enugu East local government area of Enugu State, Nigeria. *IAA Journal of Education, 5*(1), 53-70.

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.

Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social Sciences, 7,* 133, 1-11.

Gona, J.K., Newton, C.R., Rimba, K., Mapenzi, 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), 1-13. https://doi.org/10.1371/journal.pone.0132729

Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, *15*(1), 102-120.

Hall, H. R., and Graff, J. C. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing, 33*, 187–204.

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, *14*(2), 159-171.

Hill, J., Accrombessi, M., Briand, V., Dhabangi, A., Hoyt, J., Idro, R., Khairallah, C., Kariuki, S., ter Kuile, F. O., Kwambai, T., Luty, A. J. F., Manda-Taylor, L., Massougbodji, A., Otieno, J., Phiri, K. S., Rosu, L., Rujumba, J., Seddon, T., Tangara, B., Vincent, J. P., & Worrall, E. (2024) Implementation of post-discharge malaria chemoprevention (PDMC) in Benin, Kenya, Malawi, and Uganda: Stakeholder engagement meeting report. *Malaria Journal*, *23*(1), e89.

Hoefman, R., Payakachat, N., Van Exel, J., Kuhlthau, K., Kovacs, E., Pyne, J., & Tilford, J. M. (2014). Caring for a child with autism spectrum disorder and parents' quality of life: Application of the Carer Qol. *Journal of Autism and Developmental Disorders, 44,* 1933–1945.

Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities, 20,* 180–189.

Kakooza-Mwesige, A., Ssebyala, K., Karamagi, C., Kiguli, S., Smith, K., Anderson, M. C., Croen, L. A., Trevathan, E., Hansen, R., Smith, D., & Grether, J. K. (2014). Adaptation of the "ten questions" to screen for autism and other neurodevelopmental disorders in Uganda. *Autism*, *18*(4), 447-457.

Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41*, 1214–1227.

Kheir, N., Ghoneim, O., Sandridge, A., Al-Ismail, M., Hayder, S., & Al-Rawi, F. (2012). Quality of life of caregivers of children with autism in Qatar. *Autism, 16*(3), 293–308.

Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical and Occupational Therapy in Pediatrics, 30*, 340–350

Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8,* 1339–1350.

Kumari, N., Bhatia, T., Chakraborty, S., Balsavar, A., & Deshpande, S. N. (2020). A Pilot Trial of a Manualized Psychoeducation Module for Parents of Children with Autism with Intellectual Disability and Intellectual Disability Alone. *Indian journal of social Psychiatry*, *36*(3), 243–253.

Lagunju, I. A., Bella-Awusah, T. T., & Omigbodun, O. O. (2014). Autistic disorder in Nigeria: profile and challenges to management. *Epilepsy and Behavior*, *39*, 126-129.

Lecavelier, L., Leone, S., & Wiltz, J. (2005). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172-183.

Lotter, V. (1978). Childhood autism in Africa. *Child Psychology and Psychiatry and Allied Disciplines*, *19*(3), 231–244.

Maenner, M. J., Shaw, K. A., Bakian, A. V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A., Shenouda, J., Vehorn, A., Warren, Z., Constantino, J. N., … & Cogswell, M. E. (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 Surveillence,70* (No. SS-11), 1–16.

Mann, C. (1990). Choosing an Indigenous Official Language for Nigeria. https://api.semanticscholar.org/CorpusID:150426445

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of services. *Autism: The International Journal Of Research And Practice*, *8*(4), 387–407. https://doi.org/10.1177/1362361304045213

Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F., & Gladstone, M. (2016). Parenting children with intellectual disabilities in Malawi: The impact that reaches beyond coping? *Child Care Health Development, 42* (6), 871–880.

McStay, L. R., Trembath, D., and Dissanayake, C. (2014). Maternal stress and family quality of life in response to raising a child with autism: From preschool to adolescence. *Research in Developmental Disabilities, 35*(5), 3119–3130.

Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The impact of autism spectrum disorders on the family: A qualitative study of mother's perspectives. *Journal of Family Social Work, 15,* 187–201.

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14,* 208–225.

Onuora, A. B. (1993). Infantile autism: A case report. *Nigerian Journal of Psychiatry*, *1*(3), 169-171.

Onyenucheya, A. (2018). *Improving autism in Nigeria*. The Guardian. https://guardian.ng/features/improving-autism-management-in-nigeria/

Oshodi, Y. O., Olagunju, A. T., Oyelohunnu, M. A., Campbell, E. A., Umeh, C. S., Aina, O. F., ... & Adeyemi, J. D. (2016). Autism spectrum disorder in a community-based sample with neurodevelopmental problems in Lagos, Nigeria. *Journal of Public Health in Africa*, *7*(2), 76-80

Oti-Boadi, M. (2017). Exploring the lived experiences of mothers of children with intellectual disability in Ghana. *SAGE Open* 7 (4), 1–12.

Paula, C.S., Cukier, S., Cunha, G.R., Irarrázaval, M., Montiel-Nava, C., Garcia, R., Rosoli, A., Valdez, D., Bordini, D., Shih, A., & Garrido, G. (2020). Challenges, priorities, barriers to care, and stigma in families of people with autism: Similarities and differences among six Latin American countries. *Autism*, *24*(8), 2228-2242.

Penner, L. A., Dovidio, J. F., Piliavin, J. A., & Schroeder, D. A. (2005). Prosocial behavior: Multilevel perspectives. *Annual Review of Psychology*, *56,* 365–392.

Ravindran, N., & Myers, B. J. (2013). Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey. *Focus on Autism and other Developmental Disabilities*, *28*(1), 44-53.

Roughan, L. A., Parker, J. R., & Mercer, L. (2019). Improving interventions for parents of children and young people with autism spectrum disorder (ASD) in CAMHS. *BMJ Open Quality*, *8*(2), e000261. 1-6.

Salari, N., Rasoulpoor, S., Rasoulpoor, S., Shohaimi, S., Jafarpour, S., Abdoli, N., Khaledi-Paveh, B., & Mohammadi, M. (2022). The global prevalence of autism spectrum disorder: A comprehensive systematic review and meta-analysis. *Italian Journal of Pediatrics*, *48*(1), 1-16.

Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., Badr, H., Moussa, S., Essali, A. & Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry*, *20*(3), 281-289.

Shyu, Y. I. L., Tsai, J. L., & Tsai, W. C. (2010). Explaining and selecting treatments for autism: Parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*, *40*(11), 1323-1331.

Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science and Medicine*, *256*, 113034, 1-9.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC health services research*, *16*(1), 1-12.

Wang, P., Michaels, C. A., & Day, M. S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal Of Autism And Developmental Disorders*, *41*, 783-795.

Zablotsky, B., Anderson, C., & Law, P. (2013). The association between child autism symptomatology, maternal quality of life, and risk for depression. *Journal of Autism and Developmental Disorders, 43*, 1946–1955.

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M.S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778-790.

Zeleke, W.A., Hughes, T., & Chitiyo, M. (2018). The path to an autism spectrum disorders diagnosis in Ethiopia: parent perspective*. American Journal of Orthopsychiatry, 88*(3), 316–327.