

## Family Perspectives of Autism Spectrum Disorder in Urban Ghana

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### ABSTRACT

**Background:** Limited research is available on Autism Spectrum Disorder (ASD) in Africa. The purpose of this study is to increase understanding of the diagnosis, treatment and education of children and adults with ASD.

**Methods:** Questionnaires and a structured interview were used to gather information from families of children and young adults (n=25, 19 male, 6 female, age range 3-30 years) with ASD. Descriptive statistics and frequencies were used to describe demographic background information, parent concerns prior to diagnosis, medical and developmental history, associated symptoms, education and treatment history, and perceived treatment needs. Demographic, medical, school, and treatment characteristics are presented alongside case reports to illustrate common themes.

**Results:** Symptom severity measured using the Autism Spectrum Rating Scales revealed that the majority of the sample had ASD severity scores in the "elevated" or "very elevated" ranges. Participants were identified in early childhood, due to concerns about developmental delays. Few sleeping and eating difficulties were reported. While externalizing behaviors were cited as a primary concern, few participants utilized medications for the treatment of hyperactivity or aggression.

**Conclusions:** Caregivers in this sample cite significant concerns about managing behavior, highlighting the need for additional parent training.

**Keywords:** Autism, Ghana, West Africa

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### BACKGROUND

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder manifesting in early childhood that is characterized by deficits in social-communication functioning and the presence of repetitive behaviors and/or restricted interests [1]. A recent review of epidemiological surveys of ASD worldwide suggests prevalence estimates of 62/10,000. The results of this review do not support systematic differences in ASD by geographical region or ethnic group [2]. However, prevalence estimates of autism spectrum disorder (ASD) for African countries are not available and limited research is available on ASD in Africa [3,4]. Since Lotter's [5] documentation of the presence of ASD in Africa, subsequent studies have described the clinical characteristics children with ASD in case reports, revealing clinical characteristics similar to those seen in Western societies [6,7,8,9]. Bakare & Munir's [4] review of available studies on ASD in Africa indicated that the majority of children studied had intellectual disability (ID), severe speech delay, and were diagnosed after age 8 years. For example, in a case series study of children from Tanzania, Mankoski and colleagues noted concern that ASD is rarely diagnosed among children without ID, which implies that the full spectrum of ASD, specifically higher functioning children, may be underdiagnosed [9].

Bakare and Munir [4] propose that stigma and a lack of awareness about ASD among parents and professionals

combine to result in late diagnosis, which results in delayed intervention and thus low speech and cognitive functioning. This supposition is supported by the works of Igwe and colleagues, who contributed a series of articles concerning the training of healthcare workers in Nigeria [10,11,12]. Their research found that health care professionals and students in the health care professions were in need of education and training in the identification and care of ASD.

Few published studies provide information about ASD in Ghana though several unpublished documents, most prepared by non-governmental organizations, describe the education and treatment of children with disabilities in Ghana, including ASD. Owusu conducted a needs assessment by interviewing professionals and parents regarding the treatment of communication disorders, including ASD, in Ghana (*A needs assessment in speech and language therapy provision for children with communication disabilities in Ghana, unpublished observations*, Owusu, 2006). Her research revealed that assessment and treatment resources are available, albeit limited, but parents have difficulty gaining access to these resources due to distance from facilities, time-limited programs, and lack of information. Anthony conducted a study of access to education for students with autism in Ghana (*Access to education for students with autism in Ghana, unpublished observations*, Anthony, 2009). In Ghana, the

majority of children with disabilities are schooled in general education classrooms rather than self contained special education classrooms composed solely of children with disabilities. Anthony's results suggested that children with ASD did not have access to needed special education services and experienced ostracism and discrimination resulting from the social stigma of having an ASD. Denkyirah & Agbeke have provided the only quantitative study on ASD in a Ghanaian classroom [13]. In this study, teachers were asked to rank the importance of different types of services for preschool children with autism transitioning to kindergarten. The majority of teachers ranked early planning and preparation and collaboration with families as most important, while parent training and assistive technology were ranked as the least important components of transition planning. The nongovernmental organization, Inclusion Ghana, produced a report on the stigmatization and discrimination experienced by persons with ID in Ghana, including autism (*Report on the level of stigmatization, discrimination and exclusion of persons with intellectual disability and their families in Ghana*, unpublished observations, 2011). This report, which echoed many of the results from Owusu's and Anthony's papers, added that a primary factor in the identification of children with ID is lack of health professional's knowledge of ID, particularly in rural areas.

The developing literature on ASD in Africa has:

1. established the presence of ASD in Africa;
2. described possible trends among a small sample of case reports, and
3. illustrated the need for increased awareness of ASD symptoms among healthcare workers and the general population.

However, more research is needed to inform screening, diagnostic, educational, and intervention efforts. The symptoms commonly associated with autism (e.g. tantrums, sleeping and eating difficulties), have not been described in the literature on ASD in Africa. The current study includes the largest sample to date describing the clinical characteristics of ASD in Africa. The purpose of this study is to increase understanding of the diagnosis, treatment and education of children and adults with ASD. Specifically, the study objectives are:

1. to describe the demographic, medical and developmental characteristics of an urban sample of children with ASD;
2. to describe the educational and therapeutic interventions received by the sample;
3. to describe caregivers' primary concerns about their children with ASD, and
4. to document treatment needs.

Utilizing questionnaires and a structured interview, the current study gathered information from families of children and young adults with ASD. A summary of demographic, medical, school, and treatment characteristics is presented alongside case reports to illustrate common themes.

## METHODS

### Recruitment

The data was collected in July 2012. A convenience sample of children and young adults (n=25, 19 male, 6 female, age range 3-30 years) diagnosed with autism was recruited from three facilities (AwaaWaa2, Autism Awareness Care and Training Center (AACT) and the Restore, Inform, Maintain,

Advance (RIMA) Center, all located in Accra, the capital city of Ghana. These facilities were chosen as recruitment sites in an effort to gain access to children with established diagnoses of ASD. All participants had previously received a formal autism assessment and diagnosis, the majority from the neurology clinic of the Department of Child Health of the University of Ghana Medical School. The sample consisted primarily of children, including (n=10 ages 3-5 years and n=13 ages 7-13), but included 2 adults (ages 19 and 30) as they were receiving services at one of the facilities.

AwaaWaa2 is a Center offering speech therapy services to approximately 35 children under the age of 6 years with autism and other communication disorders. Weekly individual and group speech therapy sessions are provided to children under the age of 6. AwaaWaa2 also provides training for facilitators, who attend school with children to help them access school activities, in an effort to integrate children with autism and other disabilities into general education classrooms. The Autism Awareness Care and Training Center (AACT) is a private school providing instruction and speech therapy treatment for approximately 26 children with autism ages 5 to 19. RIMA is a multidisciplinary private clinic serving children and adults with a variety of medical conditions.

The study was approved by the Wayne State University Institutional Review Board and the ethical and protocol review committee of the University of Ghana Medical School. Written informed consent of parents was obtained for a 1 hour individual interview and administration of a symptom severity measure.

### Measures

A semi-structured interview was utilized to gather demographic background information, information about parent concerns prior to diagnosis, medical and developmental history, associated symptoms, education and treatment history, and perceived treatment needs.

The DSM-IV TR subscale of the Autism Spectrum Rating Scales (ASRS) was utilized as a measure of ASD symptom severity [14]. The ASRS is appropriate for rating the behavior of children ages 2-18 years, and has separate forms for children ages 2-5 and 6-18.

Participants elected to complete the 34-35 item scale in written or oral format. Completion of the ASRS requires a sixth grade reading level. Raters are asked to consider behavior observed during the past four weeks and rate each behavior using a Likert scale ranging from never (0) to very frequently (4). The ASRS has acceptable psychometric properties for United States and Canadian samples. For the DSM-IV-TR subscale reliability coefficients ranged from .91 to .98 and test-retest correlations range from .78 to .91. The ASRS was determined to have strong criterion, construct and content validity. In the absence of diagnostic measures that include African samples, the DSM-IV TR subscale was chosen because the content of the questions refers to the diagnostic criteria for ASD as outlined in the DSM-IV TR and ICD-9. These diagnostic criteria are used by the Department of Child Health of the University of Ghana Medical School in diagnosing children with ASD.

### Statistical Analysis

Basic descriptive statistics and frequencies were used to describe demographic background information, information about parent concerns prior to diagnosis, medical and developmental history, associated symptoms, education and

**Table 1: Family Characteristics**

	n (percentage)
<b>Respondents</b>	
Mother	16 (64%)
Father	4 (16%)
Both parents	3 (12%)
Aunt	2 (8%)
Parent marital status (married)	23 (92%)
<b>Number of adults in home</b>	
2	9 (36%)
3-4	15 (60%)
5-6	1 (4%)
<b>Birth order</b>	
1st	10 (44%)
2nd	7 (28%)
3rd-4th	5 (20%)
5th and up	2 (8%)
<b>Highest Father education</b>	
PhD/JD	4 (16.7%)
MA	8 (33%)
BA	10 (46%)
Vocational	2 (8%)
High school	0 (0%)
<b>Highest mother education</b>	
PhD/JD	0 (0%)
MA	5 (20%)
BA	11 (44%)
Vocational	5 (20%)
High school	4 (16%)

treatment history, and perceived treatment needs. All analyses were conducted with the Statistical Package for the Social Sciences Version 20 [15].

## RESULTS

Parent and family characteristics are presented in Table 1. The majority of interviewees were mothers of children with autism (64%). Parent marital status was reported to be primarily "married" (92%). The majority of households (64%) contain more than two adults in the home, including extended family members and live-in house help. The median number of siblings was reported to be 2, with the child with au-

tism most likely to be the first (44%) or second (28%) born. The majority of parents were educated beyond high school, with 64% of mothers and 96% of fathers having at least a bachelor's degree. The mean no of siblings in the family was 2 (SD=1.96).

Parents reported being concerned about their children early in their development (age range 0-41 months), and the average age of diagnosis was 37 months. Table 2 provides the basic demographic characteristics of the children with ASD in the study. All parents in the sample sought medical advice once they became concerned about their child's behavior or development. The most common reasons for concern were reported to be speech delay (40%) or delays in other areas of development (24%). Medical concerns were the presenting problems in 12% of cases (i.e. seizures, hydrocephalus) and regression was the presenting concern in 8% of the cases. The current median age of children was 9 years. Current symptom severity measured using the ASRS revealed that the majority of children had ASD severity scores in the "elevated" or "very elevated" ranges, with percentile ranks ranging from 73 to 99%.

While all pregnancies were reported to be full term, approximately one-fourth experienced maternal complications during pregnancy (e.g. gestational diabetes, high blood pressure). About one-third of the sample reported maternal or child complications during delivery (e.g. malaria, asphyxia). Table 3 contains medical history information, as reported by caregivers. Few participants had a history of seizure disorder (16%), allergies (8%), or hearing impairment (5%). Prescription medications are used by 24% of the children in the sample (e.g. carbamazepine, lamotrigine, risperdone, albuteral, clobazam). Sleeping and eating difficulties were reported in approximately one-fourth of the sample.

School and treatment history are presented in Table 4. Those children attending school (86%) were in private school settings, the majority at AACT. Children at AACT receive group instruction, speech therapy, behavioral therapy, and recreation. The majority of children at AACT have an assigned paraprofessional "carer" who works with them throughout the day on individual goals. About half of children experienced changes in their schooling as a result of their autism diagnosis, including changing schools (48%) or missing school due to expulsions or while parents searched for more appropriate placements (40%). Few (16%) parents reported seeking assistance from traditional healers regarding their child's autism diagnosis or symptoms. The majority of the sample (92%) is reported to receive speech therapy through their school or center.

Interviewees were asked to list the services that are needed to help their children with autism. The most frequently reported service needs were speech therapy (36%), teacher education (36%), parent/family training (32%), and behavior management (28%). Similarly, interviewees were asked to list the most challenging behaviors that they encounter in their children with ASD. The most challenging behaviors were hyperactivity (40%), tantruming (36%), lack of communication (28%), and difficulty managing children in public places (28%).

**Table 2: Demographic Characteristics**

<i>N</i> =25	<b>n (percentage)</b>	<b>Mean</b>	<b>Median</b>	<b>SD</b>
<b>Males</b>	19 (76%)			
<b>Current age (years)</b>		9.24	9 (years)	5.47
<b>Age at diagnosis (months)</b>		37.42	36 (months)	15.68
<b>Reasons for concern at dx</b>				
<b>Delayed speech</b>	10 (40%)			
<b>Delayed development</b>	6 (24%)			
<b>Medical concerns</b>	3 (12%)			
<b>Regression</b>	2 (8%)			
<b>Lack of responsiveness</b>	2 (8%)			
<b>Solitary play</b>	1 (4%)			
<b>Fussy baby</b>	1 (4%)			
<b>ASD severity</b>		92.57		7.90
<b>Very elevated</b>	8 (38%)			
<b>Elevated</b>	8 (38%)			
<b>Slightly elevated</b>	3 (14%)			
<b>Average</b>	2 (10%)			

**Table 3: Medical/developmental characteristics**

	<b>n (percentage)</b>
<b>Complications during pregnancy</b>	6 (24%)
<b>Complications during delivery</b>	8 (32%)
<b>Prescription medications (child)</b>	6 (24%)
<b>Seizure history</b>	4 (16%)
<b>Allergies</b>	2 (8%)
<b>Hearing impairment</b>	1 (5%)
<b>Visual impairment</b>	0 (0%)
<b>Sleeping difficulties</b>	
<b>Onset</b>	6 (24%)
<b>Maintenance</b>	7 (28%)
<b>Feeding difficulties</b>	6 (27%)

**Table 4: School/treatment history and needs**

	<b>n (percentage)</b>
Attending school	19 (86.4%)
Change in school after diagnosis	12 (48%)
School absence	10 (40%)
Seeking traditional healers	4 (16%)
Current speech therapy	22 (92%)
<b>Service needs</b>	
Speech therapy	8 (36%)
Teacher education	9 (36%)
Parent training	8 (32%)
Behavior management (home)	6 (28%)
Community education	4 (24%)
Caregiver training	2 (0.08%)
Evaluation	2 (0.08%)
Behavior management (school)	2 (0.08%)
Support groups	1 (0.04%)
Health worker education	1 (0.04%)
<b>Challenging behaviors</b>	
Hyperactivity/inattention	10 (40%)
Tantrums	9 (36%)
Lack of communication	7 (25%)
Public behaviors	7 (25%)
Toileting	6 (24%)
Aggression	5 (20%)
Sleep	2 (0.08%)
Repetitive behaviors	2 (0.08%)
Property destruction	2 (0.08%)
Elopement	1 (0.04%)

**Case Summaries**

The following case summaries are provided to highlight common themes described by the parents in the study. Cases were chosen that illustrate caregivers' experiences with attaining diagnosis, associated symptoms (e.g. eating difficulties, elopement, toileting), current treatment, and to provide context to the quantitative results.

Case 1

AJ is a 6 year old boy with ASD who lives at home with his parents, siblings, and a live-in house keeper. AJ's early developmental milestones occurred on time, including first words at 12 months and walking at 15 months. At age 18 months, his parents consulted a pediatrician due to their concern that he stopped using language. The pediatrician recommended a "wait and see" approach and advised them to return for another consultation at age 24 months. They were then referred to an Ear Nose and Throat specialist who informed them that he had concerns about autism and was recommending a consultation with a Child Neurologist. The Child Neurologist diagnosed him with autism and recommended speech therapy. The staff at AJ's nursery school expressed concern about his hyperactivity and asked his parents to find a different school. AJ received private speech

therapy at AwaaWaa2 until transitioning to his current school (AACT), where he receives speech therapy in a group format.

Case 2

RO is a 5 year old boy with ASD who was first diagnosed at age 3. He lives at home with his grandparents and siblings. His parents work in the United Kingdom. RO's family's primary concerns are that he is not yet toilet trained, does not communicate using speech, and has difficulty waiting. In public places such as markets and church, he has tantrums, screams, and attempts to elope. RO's medical history includes asthma and seizure disorder, for which he has not taken medications. He eats a restricted diet of rice and plantain. RO's family consulted a traditional leader for the treatment of his language delay, but discontinued as he refused to take the prescribed medication. He attended a nursery school but was asked to leave due to his hyperactivity. He receives group speech therapy at AwaaWaa2 but does not currently attend school.

Case 3

TS is a 12 year old girl with ASD who lives with her parents, grandparents and siblings. Her family became concerned about her development in her first year, as her early motor milestones were delayed. She was taken to a child neurologist for consultation regarding developmental delays and was diagnosed with autism at age 18 months old. TS walked at 24 months, began using single words at age 8 and phrases at age 12 years.

She is not yet toilet trained but assists with several chores around the house. Her family's primary concerns are toileting and language development. She is occasionally aggressive when asked to do a non-preferred activity. TS has attended AACT for 6 years, where she receives speech therapy in a group format.

**DISCUSSION**

The children and young adults that were the focus of this study were primarily male with severe symptoms of ASD. Participants were identified in early childhood, due to parent concerns about developmental delays, primarily lack of speech. They resided in an urban setting, Accra, the capital city of Ghana, in homes with well-educated parents. As a result, the results of this study are not likely representative of the majority of parents' experiences. This is similar to Ametepee & Chitiyo's [6] observation that within the literature on ASD in Africa there is an overrepresentation of parents with high socioeconomic status. The results of the current study depart from those of previous studies wherein the age of diagnosis tended to be in middle childhood. The average age of diagnosis (37 months) is comparable to epidemiological studies of US and UK populations, which suggests that parent education and socioeconomic status are strong predictors of age at diagnosis [16]. Educated parents are more likely to have access to resources that can lead to earlier diagnosis, such as information available via the internet on common signs and symptoms of autism, ready transportation to clinics, and financial resources to pay for private clinic services. The Child Neurology service that provided the diagnostic evaluations for the children in the study is well known to professionals and parents, which also likely facilitated the early presentation of children. Additionally, an obstacle to seeking help is often disability-related stigma. It is possible that the stigma often associated with disabil-

ity may be less severe for parents in the sample who may view autism as a biogenetic disorder, which can result in less perceived blame for the disorder [17]. These results have implications for the identification of ASD in children from rural areas and those whose parents have less knowledge of child development, and who thus may not seek consultation in early childhood. Similar to previous studies, the majority of children in the current study had a history of speech and language impairment. Health conditions and difficulties commonly associated with ASD, such as restricted eating patterns and problems with sleep onset or maintenance, were found in approximately one quarter of the sample compared to other studies that have reported sleep problems in about half of study samples of children with ASD [18,19]. Few participants received medications commonly prescribed to treat the associated symptoms of ASD. Further, seizures were not treated with medications. Many parents reported being discouraged to attempt suggested medications by family members or school personnel. Reported rates of current or past seizure disorder are consistent with other studies [20,21]. As the majority of the sample was recruited from institutions serving children with ASD, the majority received speech therapy services and attended private schools. While education in Ghana is compulsory, children who are not able to function independently in the regular classroom setting are not guaranteed accommodations, and are often asked to seek alternative settings. This finding corroborates Owusu's finding that many school-aged children are schooled at home because parents cannot find schools that would admit or maintain them. The absence of special education services in public schools has created the need for private, specialized settings, such as those sites who recruited participants for this study.

With regard to the type of services parents desire, a variety of service needs were reported, including those specifically for parents/families, (e.g. parent training, assistance with behavior management at home, support groups) and for the professionals serving their children (e.g. teacher education and healthcare worker education at ASD). Parents report the most difficulty with externalizing behaviors (e.g. hyperactivity, tantruming). Behavior management in public places was cited as a particular concern, particularly with regard to difficulties with public transportation and negotiating busy open markets. In summary, the findings from this study expand upon what is known about autism in Africa, particularly with regard to the influence of parent education and perceived need for services.

## CONCLUSIONS

Future research should be conducted with larger sample sizes to allow the statistical power to detect differences among sub-groups and explore relationships among variables. Future studies will need to include participants from less educated families and rural settings in an effort to understand unique challenges of parenting children with ASD in environments with fewer resources. The current sample may not represent the experiences of urban families who are not receiving services; it was largely taken from schools or centers providing services. Despite being highly educated and having sufficient resources to provide access to treatment, the caregivers in this sample cite significant concerns about managing behavior, highlighting the need for additional parent training.

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## Competing interests

The authors have declared that no competing interests exist.

## Author contributions

All authors made substantial contributions to the conception and design of the study, have been involved in the writing or revision of intellectual content and have given final approval of the submitted version.

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