



A Brief Survey of Medical Practitioner Knowledge and Attitudes Regarding Autism Spectrum Disorder in Bahir Dar, Ethiopia

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Summary

BACKGROUND

Autism spectrum disorder (ASD) continues to climb in prevalence worldwide. Developed nations have focused on aligning their medical and research communities in order to investigate the mechanisms of pathogenesis, diagnosis, and societal impact of this disorder. A simultaneous rise of ASD has impacted developing nations, such as Ethiopia, without a commensurate ability to research the knowledge, beliefs, resources, and training regarding this condition in the country.

MATERIALS AND METHODS

We administered a brief survey during a medical conference in Bahir Dar, Ethiopia, to investigate some of the education, information, and experiences with ASD within a small sample of medical and mental health providers in Ethiopia.

RESULTS

The data provided insight into the following areas pertaining to ASD in Ethiopia: perceived causes, knowledge, training, and areas of need.

CONCLUSIONS

Understanding local beliefs for causes and cures, as well as gaining indigenous opinions regarding what is needed for ASD education and resources in their nation, is the first step towards understanding the impact of this disorder and the approach to its treatment in Ethiopia.

Keywords: Autism Spectrum Disorder, Autism, Ethiopia, Africa, Medical Anthropology

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Introduction

With roots in both medical and mental health domains, autism spectrum disorder (ASD) suffers from a lack of understanding of its origin(s) as well as the stigma that surrounds mental and behavioral health conditions [1]. While the number of patients with ASD is increasing worldwide [2], the majority of the research on this condition is in developed nations and may produce results lacking external validity. Furthermore, attempts to gain information on the struggles of immigrant or minority groups within the context of developed nations have revealed the stigma these families face abroad, but reveal little about their experience in their native countries or environments [3].

Investigations examining the quantity and quality of ASD research in Sub-Saharan Africa has revealed a dearth of dedicated material and made calls to action for further efforts at examining ASD in these nations [4]. With the incredible genetic, ethnic, and cultural diversity displayed across the continent and even within nations such as Ethiopia [5, 6], it is integral that attempts at studying both the origins and impact of this condition begin with asking questions of the local practitioners and healthcare providers. By approaching the evaluation of this complicated disorder with an anthropologic lens [7], it reminds us that unique concerns and conditions will be illuminated in different populations and environments. It is by embracing these different needs that we can begin to understand, not only how the disorder exists, but its real-world impact on patients and families as well as the best approach to diagnosis, treatment, and counseling regarding this condition in various cultures and communities.

During the 2019 Bahir Dar Outreach for Neurology Education (BORNE) Symposium, we were invited to present material regarding the genetics of ASD as well as its diagnosis and treatment. This provided an important opportunity to travel to the Amhara region of Ethiopia and discover this disorder through the eyes of the citizens there. Our objective was to use a brief survey to gain better anthropological knowledge regarding the participants' own perceptions of the causes, diagnosis, treatments, and needs of families and medical institutions regarding ASD in Ethiopia. The goal was to use this information to improve our understanding and educational efforts for future conference presentations at this symposium. Furthermore, the broader implication of the gained indigenous insight has applicability for impacting tailored approaches to the care of complex medical and behavioral conditions worldwide.

Materials and Methods

Survey and Data Analysis

We administered a ten question, pen and paper, multiple selection survey to voluntary medical staff participants during a conference in Bahir Dar, Ethiopia in the summer of 2019. The surveys were collected anonymously.

Demographics were collected from respondents regarding their gender, career, and time in training. The majority of participants were in fields regarding mental health or neurology at the largest teaching hospital in Bahir Dar, with a smaller number of practitioners from the capital city of Addis Ababa. Their opinions reflected a random sample of practitioners involved and/or interested in the identification and/or treatment of ASD in Ethiopia, as evident by their attendance at the conference. There was no other formal means of sample selection. The ten questions in the survey are presented in Table



S1. Answers were extracted from the completed surveys and tabulated and analyzed in excel. The original purpose of our survey was to guide future education and discussions regarding knowledge about ASD at repeat conferences, but the data provided interesting insights into the knowledge and opinions of attendees that could direct education and treatment emphasis for Ethiopia at large.

Results

A total of 30 participants completed the survey (Table 1). A few participants omitted answers to questions, but their selections for completed questions were included. Given the content and location of the conference, the majority of our participants were in physical or mental health related careers including midwives, nurses, and medical doctors. The majority of respondents were males (80%), and

89% of them worked in Bahir Dar, the capital of the Amhara regional state in Ethiopia and one known for its newly built hospital and medical school. The group skewed towards a newly trained demographic, with the majority either still undergoing training for their profession or with less than 10 years of practice. This allowed us to interpret their answers as the opinions and information being currently experienced by a newer generation of health professionals.

A question pertaining to the perceived causes of ASD demonstrated that while the majority of respondents felt that genetics and environmental exposures accounted for the disorder (93% and 86%, respectively), there was still a substantial number that marked diet (24%) and witchcraft or bad spirits (14%) as possible causes of ASD (Table 2).

Table 1: Demographics of Survey Respondents at the 2019 Bahir Dar Outreach for Neurology Education (BORNE) symposium. NP: Gender information not provided.

	Total (N)	Male	Female	NP	Unanswered
Participants	30	24	5		1
Profession:	26	21	5		4
Psychiatry/Mental Health	2	1	1		
Physical/Physiotherapy	3	1	2		
Midwife	3	3	0		
Neurologist	6	5	1		
Nurse	6	5	1		
Physician	5	5	0		
Student	1	1	0		
Place of Work:	27	23	4		3
Bahir Dar University	24	22	2		
Addis Ababa	2	1	1		
Gondor University	1	0	1		
Years in Training:	23	18	4	1	7
<5 years	10	9	1		
5-10 y	10	7	2	1	
>10y	3	2	1		
Years in Practice:	18	13	4	1	12
<5 years	11	9	2		
5-10 y	6	4	2		
>10y	1	--	--	1	



About a third of participants indicated that there were also aspects of ASD causes that were unknown and two volunteered alternative answers for the cause such as “maternal problems during pregnancy” and “trauma (birth)”. The middle portion of the survey dealt with training and practice for participants

involved with ASD patients. The majority of participants (69%) felt that they had gained most of their information about ASD from medical school or other career training. On the job experience with patients and reading text or online material were other contributing education sources (59% each).

Table 2: Knowledge and Perception of ASD through the Lens of Survey Respondents at Bahir Dar University in Ethiopia

	Total (N)	Percentage (%)	"Other" Submissions
Perceived causes of ASD:	29		
Genetics	27	93	
Environmental exposure	25	86	
Diet	7	24	
Witchcraft or bad spirits	4	14	
Unknown	11	38	
Other: please specify	2	7	Maternal problems during pregnancy Trauma during birth
ASD treatments:	29		
Nothing	4	14	
Vitamins and minerals	7	24	
Confinement at home	6	21	
The help of a spiritual healer	4	14	
Behavioral therapy	27	93	
Prescription medications	14	48	
Other: please specify	6	21	Consultation with the parents Treat other comorbidities Psychotherapy and medication based on patient's presentation Treat co-morbid conditions It may help to treat the comorbid associated symptoms Parental training how to handle their children
Source of learning about ASD:	29		
Personal experience	4	14	
Work experience	17	59	
Medical school or medical training	20	69	
Reading	17	59	
Government issued information	2	7	
Other: please specify	0	0	

** Indicates that a participant selected two answers when only one was required.*



In regards to the confidence of participants in diagnosing ASD, the majority of participants selected that they were “somewhat confident” as described by “I would want to check my diagnosis with someone else but feel that I know some of the signs and symptoms.” This could, perhaps, be reflective of the training status of many of the participants or the simple lack of exposure to patients with ASD as more than half of respondents (57%) noted that they see less than 5 patients per year with ASD, and a provided answer to this question noted that this was likely “because of a low level of community awareness”.

Regarding treatment for ASD, the majority of participants (93%) selected that behavioral therapy was effective as well as prescription medication (48%). Interestingly, some participants also felt that “vitamins and minerals” (24%) or “confinement at home” (21%) were effective treatments. Additional written-in comments on this question appropriately raised the importance of treating comorbid conditions as well as parental training. Two questions on the survey were dedicated to the role of co-morbid conditions with ASD.

Table 2: Knowledge and Perception of ASD through the Lens of Survey Respondents at Bahir Dar University in Ethiopia Continued

	Total (N)	Percentage (%)	"Other" Submissions
Diagnostic confidence:	29		
Not confident at all	4	14	
Somewhat confident	14 *	48	
Fairly confident	6 *	21	
Confident	7	24	
ASD co-morbid conditions:	29		
Cerebral Palsy (CP)	13	45	
Intellectual Disability or Mental Retardation	24	83	
Mood Disorder: Anxiety/Depression	17	59	
Specific Learning Disorder	15	52	
Infectious Disease	7	24	
Other: please specify	4	14	ADHD predominate with inattention and behavior disturbances Seizures/epilepsy ADHD Down syndrome
ASD co-morbid condition diagnostic confidence:	28		
Not confident at all	4	14	
Somewhat confident	14	50	
Fairly confident	3 *	11	
Confident	8	29	

** Indicates that a participant selected two answers when only one was required.*



Table 2: Knowledge and Perception of ASD through the Lens of Survey Respondents at Bahir Dar University in Ethiopia Continued

	Total (N)	Percentage (%)	"Other" Submissions
ASD needs in Ethiopia:	29		
Medical professionals need more training on recognition and treatment	24	83	
The general public needs more information to de-stigmatize the condition	24	83	
There need to be more clinics available for diagnosis	17	59	
There need to be more clinics or people available for treatment	16	55	
Other: please specify	5	17	Schools with proper behavior therapy Community mobilization and regular screening at household level Research to compare the similarities and discrepancies with international geo-social and biological factors
ASD needs for Ethiopian families:	29		
A safe place to keep a child with Autism	15	52	
Better access to school for the child with Autism	21	72	
Better access to medical care or treatment	21	72	
Better social support and help de-stigmatizing the condition	24	83	
Other: please specify	1	3	Training on how to handle and care for children with autism spectrum disorder
Number of ASD patients per year:	28		
0	6	21	Because of a low level of community awareness
<5	16	57	
5-10	5	18	
11-16	0	0	
17 or more	1	4	

** Indicates that a participant selected two answers when only one was required.*



The majority of participants selected commonly co-occurring conditions as intellectual disability (83%), mood disorders (59%), specific learning disorders (52%), cerebral palsy (45%), and infectious disease (24%). This list was of course not exhaustive, and insightful written-in contributions included attention deficit and hyperactivity disorders (ADHD), seizures, and Down syndrome. When asked about their confidence in diagnosing the co-morbid disorders with ASD, the majority of respondents selected that they were “somewhat confident” as described by “I could likely tell something else was going on, but not necessarily what it was”.

The last two questions of the survey were dedicated to gaining information on what the participants felt was most needed in Ethiopia for patients and families dealing with ASD, as well as what specific endeavors or programs might best assist Ethiopian families with a child or relative with ASD.

Most participants (83%) felt that Ethiopian medical professionals needed more training on recognition and treatment of ASD and that the general public needed more information to de-stigmatize the condition. This was followed closely by the thought that there need to be more clinics available for diagnosis (59%) and treatment (55%). Submitted answers were astute, including suggestions for “community mobilization and regular screening at the household level” as well as the need for “research to compare the similarities and discrepancies with international geo-social and biological factors”. The highest-ranking family need was better social support and help de-stigmatizing the condition (83%), followed closely by better access to school and medical treatment for children with ASD (72% each).

Discussion and Implications

ASD and other behavioral and mental health conditions that continue to rise in prevalence, offer us an unprecedented opportunity to thoughtfully examine both the impact of the disorders themselves, as well as the impact of the cultural and socio-economic environment in which they occur. Perhaps unlike other purely physical conditions, disorders with a behavioral component must consider local beliefs, medical and community resources [8, 9], and communication campaigns in order to truly discover a therapeutic path forward.

This brief survey assessed the knowledge and needs regarding ASD in Bahir Dar, Ethiopia. With the responses we were able to both witness the participants’ knowledge of ASD and its treatment, as well as to discover that other origin explanations and therapeutic strategies may persist in this culture. Only by working within this framework and partnering with the local community and healthcare providers [10, 11] in nations such as Ethiopia, will we be able to create appropriate and tailored approaches that have any chance of success in these unique landscapes.

Information gained from this study revealed that care aspects such as community education campaigns, schools or other safe spaces for children with ASD, and access to diagnosis are the main needs for Ethiopian communities. Such understanding creates an informed starting point for future studies investigating the prevalence, causes, and therapeutic strategies for ASD in Ethiopia. Further expansion of this anthropologic approach to understanding ASD within the urban and rural pockets of Ethiopia is needed to continue to tailor efforts by and for their citizens.



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Conflicting interests

The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Supplementary tables

Table S1. Survey questions administered to participants at the 2019 Bahir Dar Outreach for Neurology Education (BORNE) symposium.

1. Please write in your answers to the following:

- a. Profession:
- b. Where do you work? (city, type of practice)
- c. Total number of years in training (please include everything past high school)
- d. Years in practice (or time since training)
- e. Male or Female

2. Based on what you know or have learned, what causes Autism Spectrum Disorder (Circle all that apply):

- a. Genetics
- b. Environmental exposure
- c. Diet (what you eat)
- d. Witchcraft or bad spirits
- e. Unknown
- f. Other: please specify _____

3. Based on what you know or have learned, what can help treat Autism Spectrum Disorder? (Circle all that apply):

- a. Nothing; there are no known treatments
- b. Vitamins and minerals
- c. Confinement at home
- d. The help of a spiritual healer
- e. Behavioral therapy
- f. Prescription medications
- g. Other: please specify _____

4. From where have you learned about Autism Spectrum Disorder? (Circle all that apply):

- a. Personal experience (a friend or family member with Autism)
- b. Work experience (encounters with patients diagnosed with Autism)
- c. Medical school or medical training
- d. Reading (books or online)
- e. Government issued information
- f. Other: please specify _____

5. How confident are you in your ability to diagnose a child with Autism Spectrum Disorder (Circle one):

- a. Not confident at all. I am very unfamiliar with Autism and its diagnosis
- b. Somewhat confident. I would want to check my diagnosis with someone else but feel that I know some of the signs and symptoms
- c. Fairly confident. I have had some exposure to Autism and know what to look for
- d. Confident. I feel I have accurately diagnosed Autism before and could do it again

6. Which conditions do you think are most co-morbid (frequently occur with) Autism? (Circle all that apply):

- a. Cerebral Palsy (CP)
 - b. Intellectual Disability or Mental Retardation
 - c. Mood Disorder: Anxiety/Depression
-



-
- d. Specific Learning Disorder
 - e. Infectious Disease
 - f. Other: please specify _____

7. How confident are you in recognizing the co-morbid conditions that tend to go along with Autism? (Circle one):

- a. Not confident at all. I don't think I could tell them apart
- b. Somewhat confident. I could likely tell something else was going on, but not necessarily what
- c. Fairly confident. I've had some exposure to multiple diagnoses in Autism and could do ok
- d. Confident. I have seen and diagnosed Autism with co-morbid conditions accurately before and could do it again

8. What do you think are the most pressing needs regarding Autism Spectrum Disorder in Ethiopia? (Circle all that apply):

- a. Medical professionals need more training on recognition and treatment
- b. The general public needs more information to de-stigmatize the condition
- c. There need to be more clinics available for diagnosis
- d. There need to be more clinics or people available for treatment
- e. Other: please specify _____

9. What do you think are the most pressing needs of a family who has a child with Autism? (Circle all that apply):

- a. A safe place to keep a child with Autism
- b. Better access to school for the child with Autism
- c. Better access to medical care or treatment
- d. Better social support and help de-stigmatizing the condition
- e. Other: please specify _____

10. How many children, per year, do you think you see with Autism?

- a. 0
 - b. <5
 - c. 5-10
 - d. 11-16
 - e. 17 or more
-