Knowledge Gaps about Autism Spectrum Disorders and its Clinical Management among Child and Adolescent Health Care Workers in Uganda: A Cross-Sectional Study

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Abstract

Background: There is limited literature on the knowledge about Autism Spectrum Disorder (ASD) among child and adolescent health professionals from resource limited settings.

Methods: 40 child and adolescent health professionals were purposively sampled from the two national referral hospitals in Uganda. Participants completed a standardized questionnaire that collected data on socio-demographic characteristics, the Knowledge about Childhood Autism among Health Workers (KCAHW) and the challenges related to diagnosing and managing ASD. General linear model with the Poisson regression was used to evaluate bivariate and multivariate factors associated with limited knowledge about ASD.

Results: The study participation rate was 90% with the majority being females (N = 21, 58%). Also, most (N = 20, 55.6%) were mental health professionals working at the Butabika pediatric out-patient clinic while (N = 16, 44.4%) were pediatric health professionals working at the Mulago mental and neurological pediatric clinics. The mean score on KCAHW was 11.8 (SD = 3.75). The participants (36.1%) who scored below the mean score were regarded as having limited knowledge about ASD. Health workers with limited knowledge about ASD (KCAHW score < 11.8) were less likely to have a degree [adjusted Prevalence rate ratio (aPRR) = 0.26, 95%CI = 0.08 to 0.78, p-value = 0.018. Mental health and Non-mental health workers had comparable KCAHW mean scores. Clinical Psychologists, Psychiatrists, psychiatry residents and pediatric nurses had the highest KCAHW scores while psychiatric nurses and medical social workers had the lowest scores.

Conclusion: The proportion of child and adolescent health professionals with limited knowledge about ASD is substantial. There is urgent need to increase focus on training in autism spectrum disorders especially among non-specialist health workers.

Keywords: Knowledge; Childhood Autism; Child and Adolescent; Health Workers

Abbreviations

ASD: Autism Spectrum Disorders; KCAHW: The Knowledge about Childhood Autism among Health Workers; GBD: Global Burden of Disease; WHO: World Health Organization; LMIC: Low-and-Middle-Income Countries; SD: Standard Deviation; PRR: Prevalence Rate Ratio; (aPRR): Adjusted Prevalence Rate Ratio

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Introduction

Autism spectrum disorders (ASD) are ranked among the top five developmental disabilities among children younger than 5 years in 195 countries and territories [1]. The World Health Organization (WHO) recognizes ASD as a significant public health problem yet there is limited research data on ASD from low- and middle-income countries [2].

Indeed, a recent scooping review on ASD in Sub-Saharan Africa found only 53 publications of which eight publications focused on assessing the knowledge of health workers about ASD [3]. All these studies were performed in either Nigeria or Ghana. Generally, these studies found substantial levels of limited knowledge about ASD. For example, Bakare and colleagues [4] found that 27% of nurses believed the aetiology of ASD to be supernatural, for example, lineage curses, actions of the devil, and cursed ancestral spirits.This state of affairs creates knowledge gaps in this part of the world which in turn affects the quality of health care for children living with ASD.

Uganda has large human resource challenges but in recent years there have been efforts to improve the assessment for ASD. This has involved a lot of task shifting and non-specialized staff are now involved in ASD management. It is therefore important for researchers to determine what relevant professional groups currently know about ASD and develop strategies to improve their knowledge, skills and attitudes.

Aim of the Study

The goal of this study is to document the levels and nature of knowledge gaps about ASD among child and adolescent health care workers to provide information that can guide policy-makers to improve existing training curricula in Uganda.

Methods

Study design and setting

A hospital-based cross-sectional study was conducted in pediatric mental and neurological out-patient units of Butabika and Mulago National Referral hospitals from February to March 2018. Mulago is situated in the outskirts of Kampala city-the capital of Uganda. Its pediatric mental and neurological clinics are open three days a week and on average attend to 60 children and adolescents weekly. Butabika hospital is located 12 km East of Kampala, near the shores of Lake Victoria. It is the only gazetted mental hospital in Uganda. Its pediatric mental out-patient clinic is open five days a week and receives 250 children and adolescents on average per week. Ethical clearance was obtained from Mulago and Butabika hospital research ethical committees, as the study was part of the training for fulfilment for the award of Advanced diploma in Child and adolescent mental health, and also approved by Institutional review board of MHREC. Written informed consent was obtained from all participants. Confidentiality was assured during the data collection process.

Inclusion and exclusion criteria

To be recruited in the study, participants had to be health professionals working either in the pediatric mental out-patient clinic in Butabika national referral hospital or the mental and neurology pediatric clinics in Mulago national referral hospital and had to provide informed consent. Child and Adolescent psychiatrics, Pediatric neurologists and any other health professional who had attended a child and adolescent mental health training course in the past one year were excluded from the study.

Sampling and data collection procedures

Participants were recruited purposively until a sample of 40 was attained. Data were collected through self-administered structured questionnaires. The questionnaire was delivered to each participant by a research assistant who requested the participant to complete

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the questionnaire in their presence and then immediately collected after completion. This was done to prevent participants from consulting any study material or discussing responses with their colleagues. The questionnaire had three parts; the first part was socio-demographic characteristics, the second part was the Knowledge about Childhood Autism among Health Workers (KCAHW) and the third part focused on challenges related to diagnosing and managing children with ASD.

Study measures

Socio-demographic variables

The questionnaire asked about descriptive information including age, gender, marital status, nature of health profession, and education status. Age was treated as a continuous variable. Education status was categorized into "degree level versus diploma/certificate level". Marital status was categorized into "single versus married". Nature of health profession was categorized as mental health related (psychiatrists, psychologists, resident psychiatrist, psychiatric clinical officer, psychiatric nurse) versus non-mental health (paediatrician, paediatric nurse, and medical social worker).

The knowledge about childhood autism among health workers (KCAHW)

The Knowledge about Childhood Autism among Health Workers (KCAHW) tool designed by Bakare., *et al*. 2008 [5] was used in assessing knowledge of ASD among the participants. It is a self-administered questionnaire which comprises of 19 items across the four domains. Domain 1 assesses social interaction. Domain 2 assesses impairment in communication and language development. Domain 3 assesses obsessive and repetitive behavior. Domain 4 assesses characteristics of autism as a disorder and its comorbidities. The cumulative score is 19 with higher scores indicating adequate/good knowledge. In this study it demonstrated high reliability (Cronbach's alpha = 0.97). The mean total score on KCAHW questionnaire among a particular sample population or community is identified as the benchmark of knowledge about childhood autism among that particular sample population or community.

Challenges related to diagnosis and management of ASD

The questionnaire included questions asking whether or not participants had been involved in ASD management in the past (yes coded 1 and no coded 0), whether or not they experienced challenges in making a diagnosis of ASD (yes coded 1 and no coded 0) and whether or not they experienced challenges in biological and psychosocial management of ASD (yes coded 1 and no coded 0). A description of challenges was also requested.

Statistical analysis

Statistical analyses were performed using STATA statistical software version 15. Descriptive statistics were used to describe the demographic characteristics and challenges experienced by the study population. Differences in KCAHW scores between 1) mental health and non-mental health workers; 2) degree and non-degree health workers were assessed using t-tests. Due to violations of normality in the dependent variable, we opted to use general linear model with the Poisson regression to evaluate bivariate and multivariate associations between limited knowledge (KCAHW < 11.8) and other study variables. Statistical significance was considered at two-tailed P ≤ .05.

Results

A total of 40 questionnaires were distributed and 36 (90%) were returned. The participants age ranged from 28 to 59 with a mean of 36.75 (SD = 6.16). There was a female preponderance (21, 58%) among the participants. Most (20, 55.56%) of the participants were mental health workers working in the Butabika pediatric mental out-patient clinic.

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Diagnostic challenges described by study participants included difficulties in making a diagnosis, misconceptions about ASD presentation, un known etiology which makes it difficult to explain to the care takers, poor understanding and confusion in symptoms, Failure to communicate with a child with autism, Autism occurring with comorbidities like seizures makes diagnosis complicated. Treatment challenges described included late diagnosis, few child psychiatrist, scanty speech and behavioral therapists, few affordable special needs schools, having limited information on how to handle a child with ASD, limited centers for referral, poor attitudes of care givers once a diagnosis is communicated, poor adherence to therapies and scarcity of psychiatric drugs. Table 1 shows a detailed description of the study population.

Characteristics	Frequency	Percentage (%)
Gender		
Male	21	58.33
Female	15	41.67
Education level		
Certificate/Diploma	12	33.33
Degree	24	66.67
Marital status		
Single	09	25.00
Married	27	75.00
Religion		
Christians	32	88.89
Non-Christians	04	11.11
Area of specialization		
Psychiatrist	05	13.89
Pediatrician	06	16.67
Pediatric nurse	05	13.89
Clinical psychologist	04	11.11
Psychiatry residents	03	08.33
Psychiatric nurse	06	16.67
Medical social worker	02	05.55
Psychiatric clinical officer	05	13.89
History of autism case management		
Yes	27	75.00
No	09	25.00
Reports diagnostic challenges		
Yes	18	50.00
No	18	50.00
Reports treatment challenges		
Yes	14	38.89
No	22	61.11

Table 1: *Characteristics of study participants (N = 36).*

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The KCAHW scores ranged from 3 to 16 with a median of 12 and a mean of 11.83 (SD = 3.75). The prevalence of limited knowledge (KCAHW mean score < 11.83) was 36.1%.

Degree level health workers had higher KCAHW mean scores in domain 1, domain 3 and domain 4 than non-degree health workers and this was statistically significant, while the mean scores in both groups were comparable in domain 2.

Mental health and Non-mental health workers had comparable KCAHW mean scores across all the four domains. The main item in each of the domains where most participants demonstrated knowledge gap (got it wrong or do not know response warranting a score of 0) were; domain 1 question on Absence of social smile in a child with autism (16;44%), domain 3; Association of autism with abnormal eating habit (16;44%) and domain 4; On set of autism (28;778%) and Association of autism with comorbidities; mental retardation and/ or epilepsy (19;52.8%).

Differences in KCAHW domain scores between 1) mental health and non-mental health workers; and 2) degree and non-degree health workers are shown in table 2a and 2b. Table 3 shows the factors associated with limited knowledge using bivariate Poisson regression models.

KCAHW Domain scores	Mental health workers Mean (SD)	Non-Mental health workers Mean (SD)	Mean difference (95%CI)	P-value
Domain 1	4.26 (1.86)	4.30 (1.88)	0.04 (-1.27 - 1.36)	0.943
Domain 2	0.95 (0.20)	1.00 (0)	0.04 (-0.07 - 0.16)	0.460
Domain 3	2.86 (1.42)	2.92 (1.03)	0.05 (-0.86 - 0.97)	0.906
Domain 4	3.82 (1.40)	3.46 (1.50)	-0.36 (-1.38 - 0.65)	0.471

Table 2a: *A comparison of KCAHW Domain scores between Mental health and Non-Mental health workers).*

KCAHW Domain scores	Degree health workers Mean (SD)	Certificate/Diploma health workers Mean (SD)	Mean difference (95%CI)	P-value
Domain 1	4.75 (1.64)	3.33 (1.92)	-1.41 (-2.66 - -0.16)	0.027
Domain 2	0.95 (0.20)	1.00 (0)	0.04 (-0.07 - 0.16)	0.487
Domain 3	3.37 (0.87)	1.91 (1.44)	-1.45 (-2.24 - -0.67)	0.001
Domain 4	4.08 (1.38)	2.91 (1.24)	-1.16 (-2.12 - -0.20)	0.018

Table 2b: *A comparison of KCAHW domain scores between degree and non-degree health workers.*

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Characteristics	KCAHW scores < 11.8 N (%)	KCAHW scores ≥ 11.8 N (%)	Prevalence rate ratio (PRR) (95%CI)	P-value
Gender				
Male	5 (38.46)	10 (43.48)	0.87 (0.35_2.21)	0.778
Female	8 (61.54)	13 (56.52)		
Age (Mean/SD)[a]	40.00 (7.34)[a]	34.91 (4.60)[a]	Mean diff (95%CI) -5.09 (-9.12 - -1.05)	0.015*
Marital status				
Single	4 (30.77)	5 (21.74)	0.75 (0.29 - 1.93)	0.551
Married	9 (69.23)	18 (78.26)		
Religion				
Christians	11 (84.62)	21 (91.3)	0.69 (0.2 - 2.35)	0.551
Non-Christians	2 (15.38)	2 (8.70)		
Education				
Certificate/diploma	8 (61.54)	4 (17.39)	0.31 (0.12 - 0.76)	0.011*
Degree	5 (38.46)	19 (82.61)		
Area of specialization				
Non-Mental health	5 (38.46)	8 (34.78)	0.90 (0.36 - 2.26)	0.830
Mental health	8 (61.54)	15 (65.22)		
Managed case of Autism				
Yes	10 (76.92)	17 (73.91)	1.111 (0.37 - 3.34)	0.851
No	3 (23.08)	6 (26.09)		
Diagnostic challenges				
Yes	10 (76.92)	8 (34.78)	3.333 (1.06_10.7)	0.039*
No	3 (23.08)	15 (65.22)		
Treatment challenges				
Yes	1 (7.69)	13 (56.52)	0.131 (0.02 - 0.97)	0.046*
No	12 (92.31)	10 (43.48)		

Table 3: *Factors associated with limited knowledge of ASD at bivariate analysis.*

Note: a = Mean/SD.

*: Significant Values.

During multivariate analyses, only one factor was found to be independently associated with limited knowledge about ASD. Participants with limited knowledge were significantly less likely to have a degree level of education [adjusted Prevalence rate ratio (aPRR) = 0.26, 95%CI = 0.08 to 0.78, p-value = 0.018].

Pattern of distribution of the KCAHW mean scores among the child and adolescent health care professionals

Psychiatry resident doctors, Clinical Psychologists, Psychiatrists and Pediatric nurses had scores above the study mean score of 11.8; SD = 3.75 on the KCAHW tool; (15; SD = 1.0), (15; SD = 0.81), (14.2; SD = 1.8), (13.4; SD = 1.9) respectively and therefore had good knowledge.

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The category of health workers who had limited knowledge about ASD and scored below the study mean score of 11.8 on the KCAHW tool included; medical social workers (9; SD = 2.8) psychiatric nurses (6.8; SD = 3.9) Psychiatric clinical officers (11.4; SD = 2.3) and pediatricians (11.2; SD = 3.9) as detailed in figure 1 above.
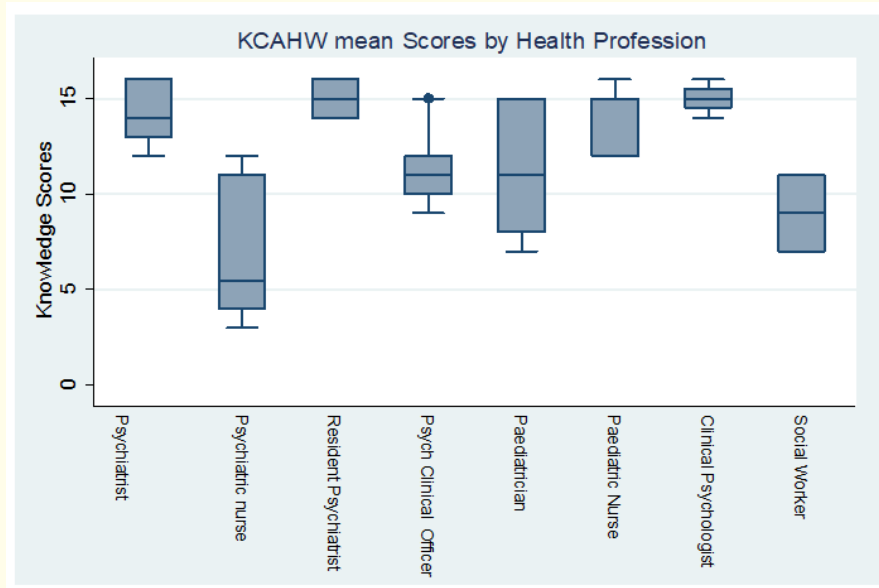

Figure 1: *A box plot of the KCAHW mean scores by health profession.*

Factors associated with limited knowledge about ASD.

Health workers with limited knowledge about ASD were more likely to be older than those with good knowledge with an age Mean difference of -5.09, 95%CI = -9.12 to -1.05, p -value = 0.015, though age lost its significance at multivariate analysis.

Health workers with limited knowledge about ASD were less likely to have a degree Prevalence rate ratio (PRR) = 0.31, 95%CI = 0.12 to 0.78, p-value = 0.011 and this maintained its significance at multivariate analysis [adjusted Prevalence rate ratio (aPRR) = 0.26, 95%CI = 0.08 to 0.78, p-value = 0.018].

Health workers with limited knowledge about ASD were more likely to report diagnostic challenges Prevalence rate ratio (PRR) = 3.33, 95%CI = 1.06 to 10.7, p-value = 0.039 and those with good knowledge more likely to report treatment challenges Prevalence rate ratio (PRR) = 0.13, 95%CI = 0.02 to 0.97, p-value = 0.049 although these associations were not maintained at multivariate analysis.

Discussion

Our main findings were 1) ASD is managed by both specialized and non-specialized mental health staff. 2) Younger health care providers had better knowledge than their older counterparts 3) Knowledge was dependent of the level of training. 4) Higher diagnostic knowledge did not equate to better management knowledge.

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Knowledge across the various health workers: The low total mean score in this study highlights a deficit in knowledge, education and awareness of childhood ASD. This limited knowledge is both in mental health and non-mental health professionals. This is consistent with the low level of knowledge and awareness among health workers in other studies conducted in sub-Saharan Africa and other parts of the world [6-8]. Overall mental health and non-mental health workers had comparable knowledge in this study which is contrary to previous studies that have found mental health specialists to be better than non-mental health specialist [7,8]. Nonetheless a better knowledge of autism has been associated with specialization in psychiatry and pediatrics, place of work, and age of practice [7,9].

Age and knowledge of ASD: Younger health workers having greater knowledge of ASD may be due to the fact that the diagnosis of ASD is not more than 60 years old. Also, greater understanding of the biological underpinnings of the disease have only been made in the last 50 years. As such health workers who got the training earlier may not have been introduced to the illness. It highlights the need for greater training on ASD especially for older clinicians.

Training of ASD: Health workers with limited knowledge about ASD were significantly less likely to have a degree level of education, however previous studies conducted elsewhere in Nigeria or India did not report on the relationship between education level and knowledge about childhood ASD. It is important to be cognizant of the fact that there are gross human resource limitations for mental health services in LMIC. This is even more pronounced in child an adolescent mental health care yet most severe mental illnesses develop in this age group. It is crucial that programs that improve training of health workers are promoted. Programs like The East London-Butabika link Mental health Trust [10] have shown that it is possible to improve mental health literacy for cadre staff at different levels

Diagnosis and management of ASD: Even those staff who were able to diagnose ASD noted difficulties in managing the illness. This is similar to an Indian study by Shah K., *et al.* 2001 [11] that assessed diagnostic practices for autism among healthcare professionals that included psychiatrists, psychologists and pediatricians. 80% of respondents noted that diagnosis of autism is difficult. Future programs may need to specifically tackle this problem. In this study for example there were no respondents from speech and language therapists and occupational therapist who are very few in the country [12].

Given that ASD management is primarily behavioural management with occasional pharmacotherapy, strengthening the behavioural management training is recommended. Inappropriate treatment may be the reason for use of alternative therapies in low resource settings [13].

Different health cadres and knowledge: Although difference in scores were not statistically significant, there were variations in raw test scores among the different cadres.

There were lower scores in non-mental health cadres like pediatricians and social workers as well as low cadre mental health workers like Psychiatric clinical officers, and Psychiatric nurses. The pattern of knowledge distribution among the participants is consistent with previous findings that indicate a better knowledge of autism among those in the specialties and practice of pediatrics and psychiatry [7,8]. The high scores in the psychiatrist and clinical psychologists could be due to pathways of care were children with neuro-developmental disorders initially present with behavioral problems, delayed milestones, learning difficulties and feeding problems to either a pediatrician or psychiatrist who many times later refer the child to a clinical psychologist to manage the behavioral symptoms; hence this group of specialists have expertise to be knowledgeable about neuro-developmental disorders, including autism, which could present with these symptoms. However in this study the pediatric nurses performed better than the pediatricians, this could be explained by the fact that in Uganda for many years autism has been managed in neurology clinics and it was expected for pediatricians to have better knowledge since they are involved in diagnosis and treatment of children, however probably because on rare occasions; is medication required for children with autism, pediatricians may not give more time to take keen interest to know other behavioral symptoms associated with it. While nurses tend to have more interaction with these children in the clinic, and hence were able to pick up more detailed symptomatol-

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ogy. The other reason in this this study could be the fact that three of the pediatric nurses working in the pediatric neurology clinic had biological children with autism, this made them have better knowledge on the disorder.

On the contrary the Psychiatric nurses in this study had limited knowledge than pediatric nurses. This was different from a study done by Monday N Igwe., *et al.* 2011 [8] which found that psychiatric nurses had more knowledge than pediatrics nurses. The Psychiatric nurses majority having limited knowledge in this study could have been due to their educational training curriculum which does not include child and adolescent mental health, this they learn through practice on different psychiatric wards in the country, and also the fact that a separate child and adolescent mental health clinic has just been started about 7 years in Uganda, made them have less experience.

Specific gaps in knowledge: The widest knowledge gap was regarding the period of onset of the disorder in childhood, three quarters of the participants, were wrong and gave answers depending on their specialty. Those in pediatrics thought it was neonatal, while their counterparts in psychiatry and related fields thought it was infancy, and others were unsure. Likewise, a Pakistan study found that 43.6% of physicians did not think that onset before 36 months (a diagnostic hallmark of autism) was necessary for a diagnosis of autism [9].

Conclusion

The proportion of child and adolescent health professionals with limited knowledge about ASD is substantial and this was significantly associated with non-degree level of education. There is urgent need to increase focus on training in autism spectrum disorders especially among non-specialist health workers. We recommend that ASD needs a task sharing rather than a task shifting approach in this setting. A multidisciplinary approach, therefore both mental health and non-mental health workers, together with non-degree health workers training curricular should include training on ASD.

Limitation of the Study

The limited sample size was due to the limited human resources for mental health in Uganda. We were not able to assess knowledge of autism among the child and adolescent health workers at the lower levels of our health care systems like the district, and sub- county health care facilities, therefore our findings may not be generalizable. The study however provided useful insight into the knowledge gaps about child hood ASD among the child and adolescent health workers.

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Competing Interests

The authors declare that they have no competing interests.

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