Evaluating the impact of an educational intervention on knowledge, perception, cultural beliefs and associated social stigma of autism spectrum disorder (ASD) in Uganda.

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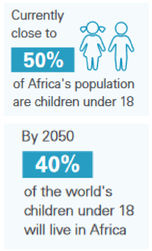
BACKGROUND

ASD[1] is recognized by the World Health Organization as a growing global public health concern and **may represent some of the greatest burden of disease in children and adolescents**[2]. Yet, although 90% of the world's children and adolescents live in low- and middle-income countries, **only 10% of ASD research** is performed there **("90-10" divide)**[3]



Infographic (left): The UN predicts that, by 2050, 40% of the world's children will live in Africa[4].

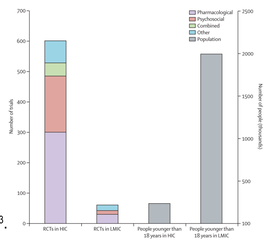


Table (right): "90-10" divide[3].

Almost all clinical interventions, service developments, research and policy work for children and adolescents in East Africa have focused on communicable diseases (e.g., HIV), Tuberculosis (TB), and Malaria, and on reducing infant mortality [United Nations, 2015], **with almost no focus on neurodevelopmental disorders such as ASD**[6]**.**

UGANDA AND CHILDREN WITH ASD

In Uganda, children with ASD and other neurodevelopmental disabilities are among the most neglected groups in the policy domain as well as in the private sphere[5]**.** There is lack of research, education, and limited access to specialized care. Children with disabilities are at high risk to be subjected to physical, sexual, or emotional abuse, or may be neglected by their caregivers [3-5].

Infographics (above): Uganda violence against children survey findings from a national survey [2015, United Nations].

UGANDA DEMOGRAPHIC AND HEALTHCARE

Figure 1: Uganda is wedged between Kenya, Sudan, the Democratic Republic of Congo, Rwanda and Tanzania. It has an important role as source of political stability in sub-Saharan Africa.

- **Population 47 million; doubling every 16 years**
- **50% of country's population is under age 15 years**
- **61% of Ugandans are living on less than $2 a day.**

Figures 2 (above): Left: Luo people in rural Uganda. Right: >80% of population live in rural areas with poor access to medical facilities.

- **13 % of Ugandan children live with a disability (=2.5 million children)**[6]

Uganda Healthcare Facts:

- **Extreme shortage of health care workers**
- **Poor quality of health care services, lack of trust in them, a lack of needed treatments, high costs, and long distances to facilities**
- **Health expenditure 32.41$ per capita (vs. 10,317.57$/ capita in U.S.)**
- **1:7,272 Physician/per Ugandans (2.64 /1000 ratio in U.S.)**
- **~N=5 child neurologists in entire Uganda**
- **No formal child neurology training**

OBJECTIVES

To **evaluate the impact of an educational intervention** on knowledge, perception, cultural of autism spectrum disorder in Uganda.

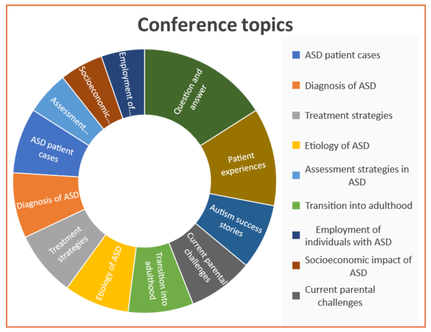
SPECIFIC AIMS

1) To assess whether an educational intervention improves **knowledge and understanding** of ASD in Uganda.
2) To **evaluate current perception, misconceptions, cultural beliefs, and social stigma** associated with ASD in Uganda.
3) To assess whether an educational intervention may have the **potential to change** cultural beliefs, misperceptions and social stigma associated with ASD in Uganda.

METHODS

1. An educational intervention program was delivered through a 2-day conference workshop targeting **teachers, parents, and community leaders**. The workshop covered topics related to the characteristics of ASD, its diagnosis, and management.
2. A single **cross sectional pre-and post- conference survey** collected quantitative and qualitative data on acquisition of knowledge about autism, cultural beliefs, perception and associated social stigma in conference attendees.
3. A single **cross-sectional post conference survey** collected quantitative and qualitative data on educational satisfaction of the educational intervention.

The survey instrument was adapted from published educational assessments on ASD and cross culturally adjusted[7].

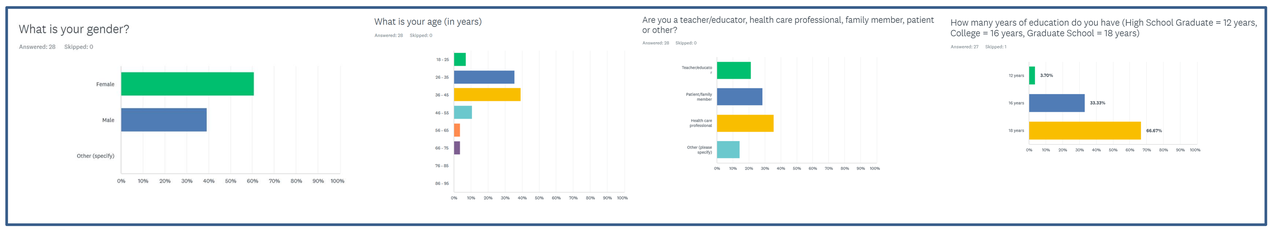


Figures 3 (above): Autism conference topics.

Figures 4 (above): Conference attendants during lectures, Q&A sessions, painting event, patient testimonies, and history and physical exam of selected patients.

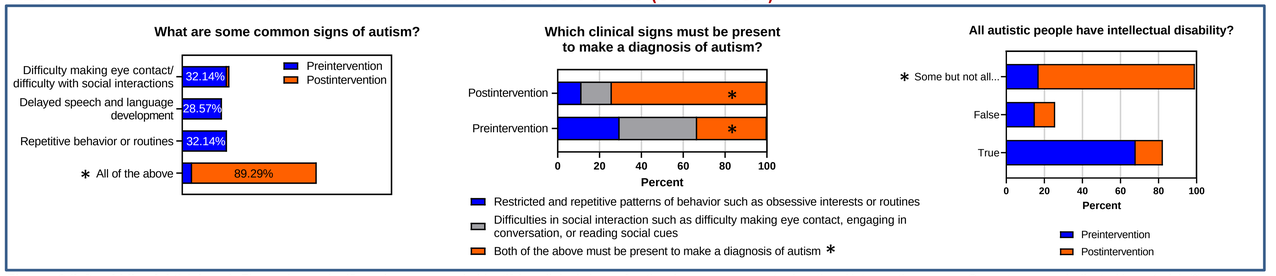
PARTICIPANTS - DEMOGRAPHICS

N=94 participants attended the educational conference. N=28 participants completed both parts of the pre-and post-intervention survey. N=11 participants completed the post-conference satisfaction survey.



Figures 5 (above): Participant demographics.

RESULTS I – PRE/POST EDUCATIONAL INTERVENTION OUTCOMES (SELECTION)



Figures 6 (left, middle, right) (above): Figure shows significant improvement in identifying clinical signs of autism in pre versus post educational intervention survey. Correct answers indicated by asterisk (*).

RESULTS II – INDIVIDUAL INTERVIEWS

Interview with Jill (Mother to patient S., Male, 11 years old)

"I knew something was not right when he was 6 months old. He did not make eye contact while nursing. Doctors told us to send him to school so that his behaviors could be corrected with strictness. There were no speech language or occupational therapists familiar with his condition. He was restrained [chained to the wall] when he had a tantrum and was beaten. He did not learn to speak until we started therapies at the therapy center (…). My family told me to hide my child from the public eye as they believed he was cursed (…). I was shamed for conceiving a child who was not able to cook or clean and was viewed as a financial burden."

RESULTS III – QUALITATIVE SURVEY DATA:

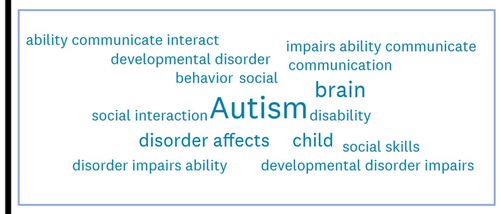
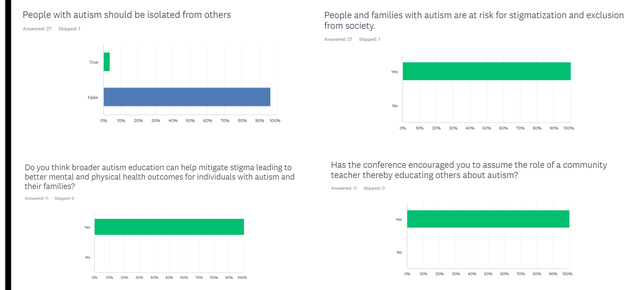


Figure 7 (left): Survey question "What is autism?". Before educational intervention: 85% of participants answered e.g., congenital birth defect, maternal bloodline, maternal infidelity, caused by evil spirits, curse, etc. **Word cloud after educational intervention**: 95% answered: 'a type of neurodevelopmental disability'.

RESULTS IV– PERCEPTION AND STIGMA:



Figures 8 (above): Survey results on perception, attitudes and social stigma related to autism spectrum disorder.

DISCUSSION

- **Post-intervention survey revealed increase in knowledge** about ASD.
- The survey **identified factors contributing to stigma**, such as misconceptions, lack of awareness, cultural beliefs, financial strain, lack of access to medical care and physical abuse and neglect.
- Caretakers reported that their children were publicly shunned, were believed to be cursed or possessed by evil spirits, which led to isolation, denial of medical care, and even physical harm.
- **Participants felt empowered to become local community educators** to decrease stigma on a rural community level.

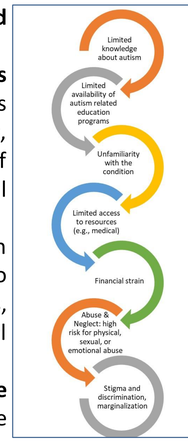


Figure 9 (above): Factors contributing to stigma, discrimination and marginalization of children with autism in Uganda.

CONCLUSIONS

An educational intervention program can improve knowledge about ASD and attitudes of educators, parents, and community leaders. It encourages and empowers community leaders to become patient advocates. Education has been proven to directly combat stigmatization against people living with disabilities by disproving misconceptions associated with disabilities.

We propose that education at the community level crucial to combat autism stigma in Uganda and other developing countries. Learners can educate others, expanding the program's reach. Further research is needed to determine if education and stigma reduction improves health outcomes for those with autism and their families.

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