

Community Engagement to Impact Epilepsy Health Literacy in Uganda

Pratamesh Ramasubramanian, Isha Shah, Langley Barnes, Paula Njeru, Izzy Andrews, Neil Prose, Deborah Koltai

BACKGROUND

Epilepsy is a chronic, non-communicable neurological illness characterized by recurrent seizures caused by abnormal electrical activity in the brain. Epilepsy affects nearly 70 million people globally, at least 10 million of which live in Sub-Saharan Africa where the treatment gap exceeds 95%. Use of effective and relatively inexpensive antiepileptic drugs (AEDs) yields a substantial reduction or elimination of seizures in about three out of four patients. Barriers to reaching care include poor uptake of available resources due to social stigma and misconceptions.

OBJECTIVES

We seek to understand the experiences of adolescents with epilepsy (AWE) in relation to community stigma and discrimination and its impact. This knowledge will facilitate development of partnerships with local experts and community stakeholders to determine effective intervention approaches.

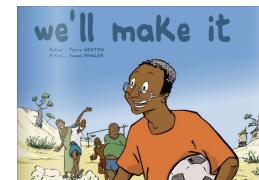
METHODOLOGY

1. We conducted a systematic review of all epilepsy community engagement studies conducted in Africa to consider successful approaches
2. We developed a qualitative, cross-sectional study targeting adolescents aged 12-18 years living with epilepsy.
 - We will recruit small focus groups of four to six individuals, up to 32 total participants, until we reach thematic saturation.
 - We will utilize a semi-structured questionnaire to collect data to help create a culturally relevant community engagement program that impacts epilepsy health literacy in the community. The questionnaire queries:
 - i. Lived experience
 - ii. Audiences most needing intervention
 - iii. Methods of learning amongst those audiences (eg, social media, community leaders, written material, plays).
 - iv. Ideas about types of intervention approaches.

NEXT STEPS

- Conduct focus groups to further understand AWEs' experiences and to inform the development of an epilepsy education intervention.
- Coordinate with local professionals and experts to implement the intervention.

This comic book (utilized by Tekle) is an example of educational material that could be implemented in the community to impact epilepsy health literacy.



TEAM PRIORITIES

- Respect AWE and learn from their perspectives and stated needs
- Respect the culture and recognize the critical value of expert collaboration and community partnerships to execute effective work.

REFERENCES

- Tekle-Haimanot, Redda & Preux, Pierre-Marie & Gerard, Daniel & Worlu, Dawit & Demissie, Hanna & Awraris, Meron. (2016). Impact of an educational comic book on epilepsy-related knowledge, awareness, and attitudes among school children in Ethiopia. *Epilepsy & behavior* 148: 61-218-221. [10.1016/j.yebeh.2016.05.002](https://doi.org/10.1016/j.yebeh.2016.05.002).
- Kaddumukasa, M., Nalubwama, H., Kaddumukasa, M. N., Lhatoo, S., Sewankambo, N., Katabira, E., Sajkovic, M., & Blieden, C. (2019). Barriers to epilepsy care in Central Uganda, a qualitative interview and focus group study involving PLWE and their caregivers. *BMC neurology*, 19(1), 161. <https://doi.org/10.1186/s12883-019-1398-z>