Barriers to Biomedical Care, Beliefs about Epilepsy, and Care Seeking in Uganda: A Quantitative Approach

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Objective: The purpose of this study was to survey patients with epilepsy (PWE) and their caregivers to understand their beliefs about epilepsy, healt care seeking patterns, and the barriers to reaching biomedical care.

BACKGROUND

In sub-Saharan Africa, the epilepsy treatment gap is immense, with estimates suggesting that less than 70% of PWE reach care. In Uganda, biomedical resources are scarce, whereas there are far greater numbers of traditional healers (TH). Provider to population ratio estimates are:
-- physician 1:20,000
--psychiatrist 1:900,000
--neurologist 1:2,800,000)
--traditional healers 1:290
In addition to access, culturally based beliefs, health care utilization pathways, and specific barriers impact the treatment gap. We sought to better understand these factors.

METHODS

Recruiting from biomedical clinics at Mulago and Butabika National Referral and Mbarara Regional Referral Hospitals and affiliated clinics, we surveyed 626 PWE and caregivers of PWE.

RESULTS

Seizure frequency was 2.78 (SD 3.7) initially, and 1.2 (SD 1.5) currently. Seizure severity was considerable, with 92.3% reporting loss of consciousness with seizures and 55% endorsing substantial lag in intellectual or learning ability.

Beliefs about Epilepsy

- 7.8% believed that epilepsy was an infectious disease
- 27.5% thought burns indicated the epilepsy would worsen
- Of those that thought epilepsy could cause other illnesses, concern was raised most frequently for mental illness (n=97) and madness (n=43).
- While 97% recognized the brain as the organ involved in epilepsy, 39% believed that the soul was involved

Barriers to Biomedical Care

We explored barriers related to practical factors, cost and payment process, doctors, and medicine efficacy and availability. Six of 27 barriers were endorsed by at least 20% of the sample as mattering some, a lot, or very much in how difficult it was to get biomedical treatment:

- Anti-Epileptic Drugs given at the facility run out (66%)
- Cost of medicine (65%), cost of travel (51%), cost of tests (29%)
- Distance to the medical facility (50%), having to take time from work (32%), and limited number of family members who can assist those who need help (21%)

37% of the sample had consulted a TH first, 7.5% consulted a pastoral healer (PH) first, and 56% went to biomedical care first. *Seeing a TH first delayed arrival at biomedical care by 16.8 months. Note however, that medical pluralism was common-- not the exception.

	TH first	PH first	Biomedical first
Time to consultation	3.2 mo.	2.4 mo.	6.7 months*
Seizure Outcomes:			
Szs stopped (%)	4.3	2.2	12.3
Frequency ↓ (%)	10.8	10.9	42.1
Severity ↓ (%)	1.7	6.5	12.3
No change (%)	83.1	80.4	31.8
Strongly Agree factor can cause epilepsy:			
Witchcraft	23.8	23.9	16.9
Spirits	22.5	30.4	16.6
Brain illness	29.4	47.8	33.5
Brain injury	29.9	45.7	37.8

CONCLUSIONS & PLANNED ANALYSES

- These data, together with the qualitative arm of this BASS Barrier project (Sanchez et al, 2018), illustrate factors related to epilepsy beliefs and barriers to care, that influence health care use
- Beliefs about etiology, and perceived barriers of drug stock outs, cost of medicine, studies, and travel, and distance all warrant attention in planning outreach and interventions
- Planned analysis will prioritize capacity building and access interventions by utilizing multivariate regression modeling to explore the predictors of health care utilization patterns. We will explore demographics, illness related variables, beliefs, and perceived barriers to better understand care pathways in their social, cultural context.