



Understanding the Barriers and Potential Solutions to Epilepsy Care in Uganda: A Qualitative Study



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OBJECTIVE

Many people with epilepsy in Uganda do not seek treatment from biomedical providers. The objective of this study was to determine the barriers to getting to biomedical care and what are the proposed solutions to overcoming these barriers from different vantage points. This will be the first study to consider perspectives of multiple stakeholder groups involved in epilepsy treatment in Uganda.

METHODOLOGY

Qualitative methods consisting of interviews and focus group discussions (FGDs) with (n=83), with participants from four groups of stakeholders:



- Patients and Families
- Neurologists and Psychiatrists
- Pastoral Healers
- Traditional Healers

Provider participants were recruited from Kampala and rural areas outside of Kampala. Patients and families were recruited from neurological facilities (Mulago National Referral Hospital and Kiruddu Hospital) and psychiatric facilities (Mulago National Referral Hospital and Butabika National Referral Hospital).

Patients/ Families	Neurologists/ Psychiatrists	Traditional Healers	Pastoral Healers
5 interviews at Mulago Hospital	1 neurologist interview	3 FGDs (n= 9, 9, 7)	6 interviews
3 interviews at Kiruddu Hospital	1 neurologist FGD (n=4)	2 "Townhall" groups (n= 15, 15)	
5 interviews at Butabika	1 psychiatrist FGD (n=6)		
2 FGDs at Butabika (n=5, 6)			

Table 1- Description of Dataset

Returning from fieldwork, the BASS connections team transcribed all FGDs and interviews, searched for themes in a subset of transcripts until saturation was reached, and developed a codebook using thematic analysis. Two bass team members then coded the data set using NVivo 11 software and conducted an IRR.

RESULTS

Beliefs about the cause of epilepsy is related to the perceived barriers to care and the proposed solutions.

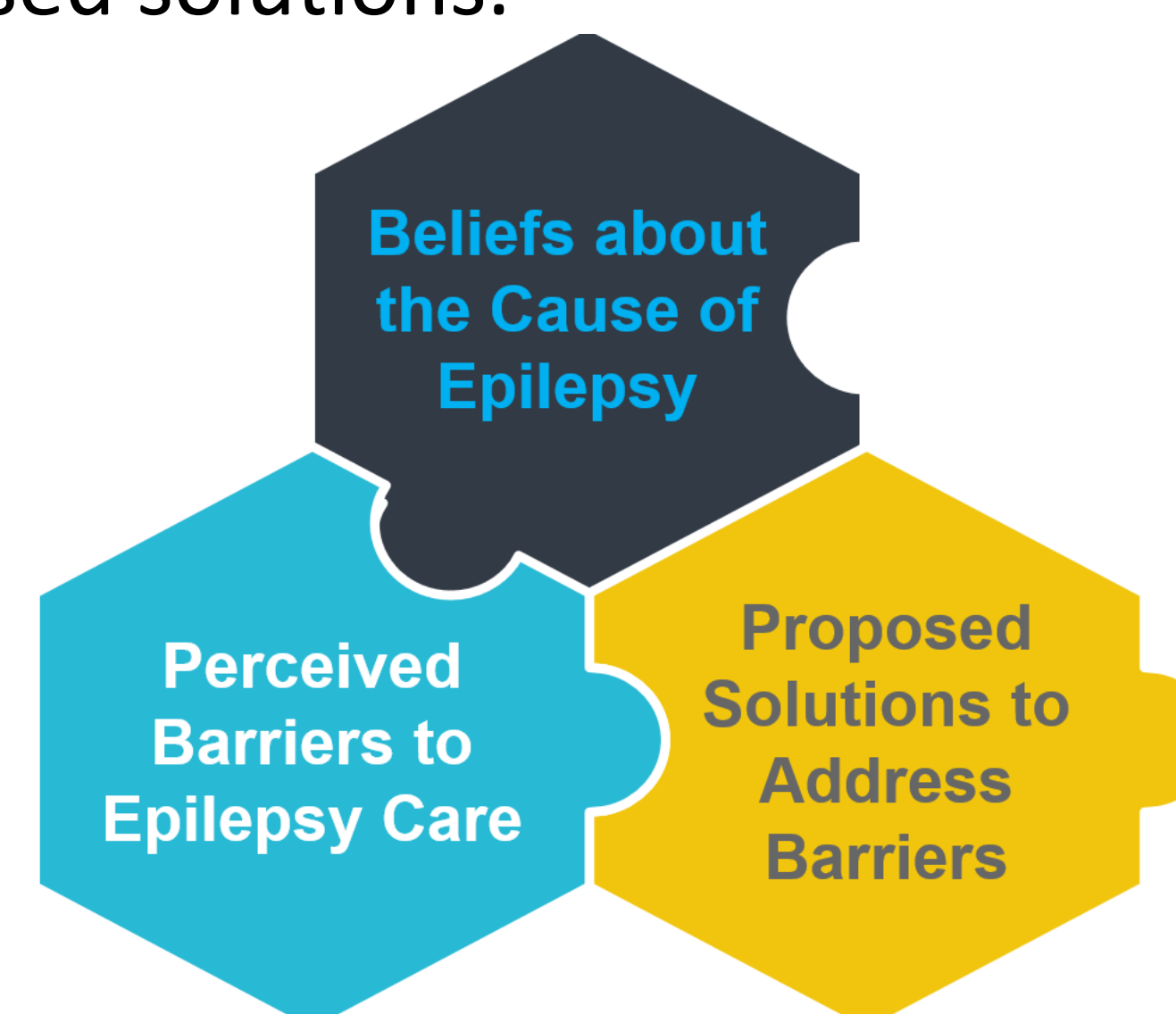


Figure 1- Major Interrelated Themes from the Dataset

Beliefs about the cause of epilepsy varied from spiritual to biological, and participants often endorsed a combination of both.

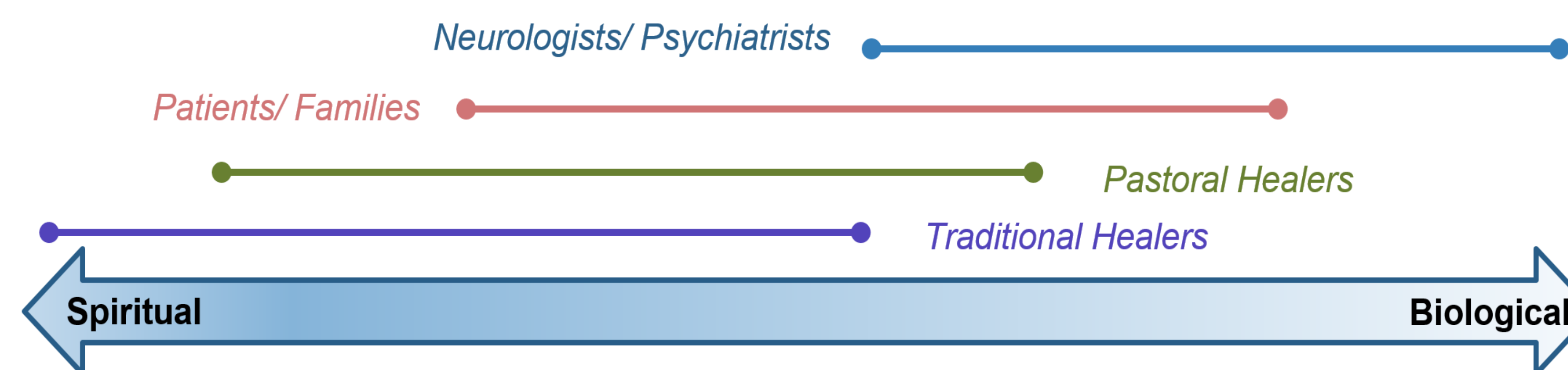


Figure 2- General representation of the beliefs about the cause of epilepsy by participant group

RESULTS (cont.)

Theme	Subtheme	Quote
Barriers to Care	Stigma	"So even today, I told her not to get out, because you might fall, and people will see you." Caretaker
Barriers to Care	Medical Infrastructure> Stockouts	"Can you describe what the challenges are for patients to get biomedical care for their epilepsy in Uganda?" "There is no medicine." Caretaker
Solutions	Building Infrastructure> Epilepsy Clinic	"What do you think is the most important issue for us to focus on in our research and helping people?" "actually having an exclusive place, a place made for people with epilepsy" Pastoral Healer
Solutions	Collaboration between Biomedical Providers and Traditional Healers	"Look, these people go to the traditional healers, and we've got to bring them on board if we want to try and solve this issue." Neurologist

Table 2- Quotes describing major themes from data

CONCLUSIONS

When designing future interventions, the following should be taken into consideration:

- Patients and families heavily addressed **medication stockouts** as the biggest barrier to epilepsy care.
- Many stakeholders identified having an **epilepsy clinic** as a next step for improving care.
- All four stakeholder groups identified **stigma** as being a significant barrier to care.
- Different providers revealed **differing willingness to collaborate** with one another, and collaboration looks different for different stakeholders.

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