



# Barriers to access to education for young people with epilepsy in Northern Tanzania: A qualitative interview and focus group study involving teachers, parents and young people with epilepsy



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## ABSTRACT

**Objective:** Educational outcomes for young people with epilepsy (YPE) in Hai District, Tanzania, are poor, as is commonly observed elsewhere in Sub-Saharan Africa. The reasons for this finding are not well understood, though stigma arising from supernatural concepts of epilepsy is frequently cited as a barrier to YPE accessing education. In this study, we aimed to explore the reasons why many YPE in Tanzania experience poor access to education, and elicit ways in which education could be improved for YPE according to teachers, parents and YPE. **Methods:** Ten focus group discussions with teachers were organized in Hai schools between March and May 2016. The themes arising from these discussions were identified, coded, analyzed and tested in semi-structured interviews with 19 YPE and 17 parents identified from a prevalent cohort of YPE identified in 2009.

**Results:** Behavioral problems and learning difficulties were cited as the main barriers to education for YPE. Other barriers included parental stigmatization, teachers' inadequate seizure management, and limited access to specialist schools. Teachers perceived that parents and YPE believe in spiritual etiology and traditional management for epilepsy. However, the majority of teachers, parents, and YPE cited biological etiology and management options, although understanding of epilepsy etiology and management could be improved amongst all groups. **Significance:** A multidimensional approach is needed to improve educational access, and hence outcomes, for YPE. Widespread community education is needed to improve knowledge of epilepsy etiology and management. Teachers require seizure management training, and parents need help to recognize YPE's right to education. Educational needs assessments would help to identify YPE requiring specialist schooling, and access to this could be improved. These interventions will likely reduce stigma, ensure appropriate academic and pastoral care at school, and thus enable YPE to attend, and succeed, in education.

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## 1. Introduction

Approximately 80% of the world's 50 million people with epilepsy (PWE) live in low- or middle-income countries, where they are often subjected to prejudice borne of ignorance about the condition's etiology,

physical presentation, and treatment [1]. Stigma around epilepsy is often blamed for children with epilepsy's (CWE) exclusion from education.

In Sub-Saharan Africa (SSA) educational outcomes are often poor for CWE, who may be refused registration by teachers or removed from classes by their parents [2,3]. The belief that epilepsy has a spiritual etiology is commonly cited as a reason for CWE's exclusion by either teachers or parents, alongside teachers not feeling adequately trained in seizure management [4–6].

One hundred and twelve CWE aged six to fifteen years were identified in a demographic surveillance site (DSS) in Hai District, Northern Tanzania during a prevalence study in 2009 [7]. Unadjusted prevalence was 2.91 per 1000 (95% confidence interval 2.4–3.5). Prior to the research team diagnosing and prescribing medication to these CWE,

**Abbreviations:** PWE, people with epilepsy; CWE, children with epilepsy; YPE, young people with epilepsy; SSA, Sub-Saharan Africa; DSS, demographic surveillance site; FGD, focus group discussion; SSI, semi-structured interviews.

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the treatment gap was estimated to be 69% [8]. Half of the CWE in this cohort did not attend school regularly, for reasons including seizure activity, learning difficulties, behavioral disturbance and poor access [9]. It is difficult to ascertain from this whether epilepsy is the excluding factor for education, as the association of the condition with learning difficulties means for many CWE mainstream schooling would be inappropriate, and little is known about access to specialist schooling.

The prevalence of disordered behavior was 66% in CWE compared to 19% of aged-matched controls. Despite this, only 12% of the half of CWE not in school were excluded due to a behavioral disorder, and one parent's view that, "*teachers in our schools do not have skills to educate or take care of epileptic children*", implied teachers were a barrier to CWE accessing education [8]. At follow-up in 2015, behavioral disorder for CWE in this cohort had decreased to 48% (14% in controls,  $p < 0.001$ ), and improved behavior was associated with better seizure control [10]. Despite these improvements, only 26.2% of the now adolescent cohort of CWE were still in education or had completed secondary school, compared to 73.4% of controls (personal communication).

We explored, through qualitative methods, teachers', parents' and young peoples' perceptions of educational access for young people with epilepsy (YPE). We examined knowledge, attitudes and practices of school teachers towards YPE through focus group discussions, reasons given by parents and YPE (semi-structured interviews) for poor access to education and factors which teachers, parents and YPE believe need to change in order to improve access to education for YPE.

We wanted to determine to what extent stigma, teachers' poor seizure management, or other emerging factors act as barriers for YPE to access education.

## 2. Material and methods

### 2.1. Ethical approval and consent

Ethical approval was obtained from the Tanzanian National Institute of Medical Research. Local permission to work in schools was granted from the District Education Officer. All teachers, parents and YPE who took part in this study provided written consent for participation. The consent form was provided in English but was verbally translated to Swahili (the local language), where necessary. For any YPE who may have lacked capacity to consent, a parental signature was obtained on their behalf. Additionally, where participants were illiterate, a thumb print was obtained in place of a signature.

### 2.2. Focus group discussions (FGD) with teachers

A conceptual framework was created and then used to develop a question guide. Questions were kept as open as possible to allow participants to bring in other ideas. A senior Tanzanian teacher (AS) provided introductions in order to access teachers in five primary and five secondary government-funded schools in Hai. FGDs lasted 30–60 min and included between three and six teachers at each school.

### 2.3. Semi-structured interviews (SSI)

SSI with YPE and parents allowed for certain themes to be discussed in every interview, but also individual stories and experiences to be shared. A similar question guide was developed for FGD from the same conceptual framework. This was later adapted following the completion of FGD in order to incorporate different discussion themes raised by teachers.

YPE identified in the original prevalence study and known to still be alive and resident in the district in 2015 were identified and selected according to logistical possibilities for travel during the study period. Within Hai DSS, each village uses enumerators to collect demographic information for each village member. Enumerators from each selected village located individual YPE for interview. YPE and their parents

were invited to their village health center for a discussion about epilepsy and access to schooling. Translation and interpretation was done by a Tanzanian field worker who had been familiarized with the research question and conceptual framework. A total of 19 YPE and 17 parents were interviewed in seven villages.

### 2.4. Analysis

Verbatim translation for FGDs and SSIs happened real-time and was conducted by AS and ES respectively. No Swahili transcription was made, but where translation had occurred the transcripts were checked against original video recordings for translational accuracy by Tanzanian medical students. Transcripts were produced directly from video recordings which enabled the primary investigator (CQ) to become familiar with the dataset. An iterative approach was taken with each FGD transcribed immediately. This permitted an evolving analysis with incorporation of newly emerging ideas into subsequent FGDs, in keeping with the constant comparative analysis technique developed by Glaser and Strauss [11]. Transcripts were then coded line-by-line, with similar codes organized into themes, in-keeping with practice described by Barbour [12] and guided through supervision by HS. The resulting FGD themes were then used to adapt the question framework for interviews with YPE and parents, enabling comparisons of views and perceptions on certain aspects of epilepsy between teachers, parents and YPE. The interview transcripts were subjected to the same process of coding and thematic analysis. Throughout the writing process, themes were adapted and important concepts were further developed.

## 3. Results

### 3.1. Demographics

The demographics of the teachers interviewed are shown in Table 1.

The 19 YPE interviewed were aged 13–21, eight were male, six were currently enrolled in or had completed secondary school, and ten had been previously diagnosed with cognitive impairment [10]. Eleven mothers and six fathers were interviewed. During FGDs and SSIs three key themes emerged: causes and management of epilepsy, school life for YPE, and teachers' approaches to seizure management and teachers' support needs.

### 3.2. Causes and management of epilepsy

The views on causes and management of epilepsy are shown in Table 2.

Teachers perceived that parents and YPE believed in a spiritual etiology, and sought help from traditional healers or through prayer. The stigma associated with a spiritual cause was suggested as a reason

**Table 1**  
The demographics for teachers partaking in FGD.

Characteristic	Number of teachers, (% total)			
Total teachers	35			
Age	<b>20–30</b>	<b>31–40</b>	<b>41–50</b>	<b>51–60</b>
	10 (29%)	10 (29%)	9 (25%)	6 (17%)
Sex	<b>Male</b>		<b>Female</b>	
	13 (37%)		22 (63%)	
Tribes	<b>Chagga</b>		<b>Other</b>	
	19 (54%)		16 (46%)	
Religion	<b>Christian</b>		<b>Muslim</b>	
	32 (91%)		3 (9%)	
Teaching level	<b>Primary</b>		<b>Secondary</b>	
	16 (46%)		19 (54%)	
Witnessed a seizure at school	<b>Yes</b>		<b>No</b>	
	29 (83%)		6 (17%)	

Bold values indicate significance at  $p < 0.05$  level.

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