



Myths, perceptions, and incorrect knowledge surrounding epilepsy in rural Zimbabwe: A study of the villagers in Buhera District

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ABSTRACT

The aim of this study was to assess the myths, perceptions, and incorrect knowledge that people in Buhera Rural District harbor about epilepsy. The study was conducted among people living with epilepsy ($n = 100$) using a standardized questionnaire that was developed after two focus group discussions with the village health workers ($n = 20$) and interviews with the key informants. Each respondent was interviewed during their monthly visit to Murambinda Mission Hospital. Focus group discussions and interviews identified 32 types of myths, perceptions, and incorrect knowledge relating to the causes, prevention, treatment, and effects of epilepsy. Most of the respondents agreed that epilepsy is a misunderstood condition that has stigmatizing myths, perceptions, and incorrect knowledge surrounding it. The study concludes that these myths, perceptions, and incorrect knowledge are a hindrance to the aim of reducing the treatment gap in epilepsy in Buhera, Zimbabwe and that desired quality of life for people with epilepsy can only be achieved after imparting accurate understanding of epilepsy in rural communities.

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1. Introduction

Epilepsy is a seizure disorder that affects more than 50 million people globally. The World Health Organization (WHO) estimates that this neurological disorder affects 1% of any given population. In Zimbabwe, the Epilepsy Support Foundation (ESF) estimates that over 1% of the population are living with epilepsy [1] although a previous study by Levy showed a prevalence of less than 1% [2]. The ESF argues that because of myths and stigma, most people with epilepsy are either prohibited from disclosing their diagnosis or are afraid to do so. This may result in underestimates of disease prevalence.

Epilepsy results in physical, intellectual, psychological, and social limitations for people with epilepsy [3]. In severe cases, it results in disability and death due to burns, drowning, and even depression-induced suicide [5]. In their cross sectional study of people living with epilepsy in Zambia, Atadzhanov showed that people with epilepsy had limited education, employment, and healthcare opportunities compared with the rest of the Zambian population [6]. These findings were confirmed in other studies in other parts of sub-Saharan Africa [7], India [8], and Taiwan [9].

A myth is a widely held false belief, while a perception is the manner of how beliefs are viewed and understood by others [1]. In the context of epilepsy, myth and perceptions together with incorrect knowledge contribute to stigma [3] and promote the discrimination of people with epilepsy. Communities hold myths, perceptions, and incorrect knowledge

about how people get epilepsy, how it can be managed, and how people with epilepsy should be treated [10,11]. In the Kilimanjaro Region of Tanzania, myths have attributed epilepsy to witchcraft [10,12]. Myths, perceptions, and incorrect knowledge have shaped names for epilepsy with the resulting effect being names that may cause society to discriminate against people with epilepsy [13]. For example in Zimbabwe, having epilepsy named as *zvifaiifa*, which means dying several times, may make a person with epilepsy unemployable on the misunderstanding that they will disrupt work and may not be productive.

In Zimbabwe, myths, perceptions, and incorrect knowledge regarding epilepsy have been reported in various studies including a study by Saburi, Mapanga, and Mapanga [1] and Mielke, Adamolekun, and Mundanda [2]. These studies focused on community awareness programs in urban areas as a way of reducing the treatment gap in epilepsy. Our study is unique, first, because it focuses on a non-urban Zimbabwean population, and second, because it attempts to assess felt stigma (stigma experienced by the affected person) and its origin in local epilepsy-associated myths, perceptions, and incorrect knowledge. We hope that by identifying these myths and by showing their direct link to felt stigma, interventions to reduce stigma through community education may be developed.

2. Methods

2.1. Study population

The study targeted people living with epilepsy in Buhera District, which has an estimated total population of 200,000 people. Buhera

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is a rural area in Eastern Zimbabwe. The targeted people were all members of a support group run by the Epilepsy Support Foundation, an association of people with epilepsy which is affiliated with the International Bureau for Epilepsy (IBE). The support group was based at Murambinda Mission Hospital, which is the central hospital in the district. The support group had a total of 202 members as of December 2012. Of these, 100 consenting members took part in this study. These included 60 females and 40 males. The samples were selected using stratified random sampling according to gender (40 males and 60 females) which had a ratio of 2:3 (males:females) based on the support group registry. Availability sampling was then applied to select 100 consenting participants.

It was justifiable to use 100 participants based on the researcher's available time and resources. Since availability sampling was used, 100 respondents who fitted the inclusion criteria were interviewed, giving a 100% response rate.

Before a questionnaire was developed for this population, preliminary data were gathered from the village health workers and the key informants. The village health workers are members selected from villages and trained to address community health-related issues including epilepsy. The key informants for this study included a leader of an epilepsy support group, a counselor from the Department of Social Welfare, a medical doctor, and a community health nurse. The outcome of the preliminary data gathering was used as the research tool which then was pretested on 10 people with epilepsy for suitability (especially language) and comprehensiveness. However, results from the pretest were not included in the analysis since the research questions were slightly changed in line with the improvements made to make the questionnaire relevant to the study group.

2.2. Data collection

This study was approved by the Research Board and informed consent was obtained from all participants before their participation in this study.

The study adopted a qualitative and a quantitative design and started with focus group discussions (FGD) that involved two groups of 10 village health workers each. This was done to establish the possible forms of myths, perceptions, and incorrect knowledge available in the District. A list of such myths, perceptions, and incorrect knowledge was then established. This process was followed by interviews with the key informants. This part of the data collection improved the list. The list was then transformed into a questionnaire which was pretested on 10 people with epilepsy. The last part of the data collection involved interviewing 100 people with epilepsy to find out if they experienced any of the listed myths, perceptions, and incorrect knowledge and if they had new ones to add.

All 100 respondents could express themselves well in their vernacular language but a communication problem was encountered by Mushi et al. with two of their respondents [10]. It was difficult to finish the interview with the first one, and responses from the second one had numerous gaps. These were replaced with two other respondents since the data were screened on the same day as the interviews were done.

The duration of the interviews with the individuals ranged from 25 min to 55 min, and the average time was 36 min. Each key informant took 45 min to complete the interview. Focus group discussions took 2 h each. Each FGD had 10 participants and the interviews used English as the main language but Shona was also used. The FGD involved village health workers who did not take part during the pre-testing of the research instrument.

The questionnaire for individual interviews was divided into three sections. The first section recorded respondents' details like age, sex, village, years with epilepsy, medical condition, etc. It also had a section on date of interview and place and time when the interview was taken. The second section was in table format with the first column

containing forms of myths and the second containing responses 'Yes' and 'No'. The last section of the questionnaire had an adequate space for the interviewer to record observations and any other issues.

Since interviews were not recorded by audio means, the two researchers took notes concurrently (to ensure consensus) and these notes were compared during data cleaning.

2.3. Data analysis

Interviews with the village health workers and the key informants were analyzed using thematic content analysis. After the themes were developed, forms of myths, perceptions, and incorrect knowledge were classified according to the themes. The two researchers sat down and compared notes for each respondent in the process of identifying major themes which were noted down. The themes for the day were developed by analyzing the most recurring themes on the responses.

The forms of myths, perceptions, and incorrect knowledge were then presented to the respondents who confirmed their existence or not. The authors read these out to a respondent and asked the respondent to express it in their own understanding. If their understanding matched with the interview's requirement, then the respondent was asked to answer 'Yes' if the form of myth was available in their village or 'No' if it was not available. In the event that the understanding of the interviewee mismatched with that of interviewer, the interviewer offered an explanation.

This quantitative aspect of the study was analyzed using basic computer tools mainly to get sum totals. A feedback session comprising the village health workers and the key informants was arranged after analysis of data as a way to report and collect further data to feed into the final report.

Respondents were invited to attend a feedback session which fell on the 4th day after all the interviews. The day selected for the session was the same day most of the respondents attended a support group meeting. On that day, 40 respondents managed to attend the meeting. Twenty participants could not attend since they had to quickly go back to their respective homes when they could still secure transport to their rural homes. Forty did not turn up for various and some unknown reasons.

3. Results

Results are presented in six sections. The first section concerns demographic details of respondents. The other five sections focus on myths, perceptions, and incorrect knowledge as they relate to causes of epilepsy, prevention of epilepsy or seizures, treatment and control of epilepsy, and effects of epilepsy.

3.1. Demographic details

A total of 100 people with epilepsy participated in the study. Generalized seizures were recorded on 80 patients, while 20 patients had absence seizures. Of these, 60 were females and 40 were males. The mean age of the respondents was 37.7 years. Their age ranged from 22 years to 65 years, indicating an all adult target group. Respondents were all on epilepsy treatment. In terms of delay in treatment, 90% started medical treatment after the 5th year of having seizures. In terms of stopping therapy, 80% had done so more than once since they initiated treatment. Full seizure control was confirmed in only 30% of the respondents. In terms of marital status, 40% of males and 39% of females were in marital relationships. Educational status reflected that 30% of females and 47% of males had acquired secondary education.

3.2. Categories and forms

The categories and forms of myths, perceptions, and incorrect knowledge were initially developed with the village health workers

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