

Epilepsy Treatment Adherence Complexities Among Caregivers Of Children With Epilepsy In Zimbabwe: An Exploratory Study

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Abstract

Background: Epilepsy continues to ravage health institutions worldwide causing untold psychological, physical and social consequences. WHO estimates that only 80% of the 10 million people who live with epilepsy in Africa have access to modern medicine. Failure to access epilepsy medication is attributed to grave stigma attached to this disorder and African views about epilepsy. Health authorities at hospitals in Zimbabwe regularly run intensive workshops aimed at increasing caregiver knowledge about epilepsy and its medical treatment. Although caregiver views about treatment of epilepsy have been studied elsewhere in the world, this has not been the care in Zimbabwe. Therefore, this study investigated the views of caregivers of children living with epilepsy based at a hospital in Zimbabwe about factors which hamper patient adherence to epilepsy treatment. Participants were twelve caregivers, two medical doctors and one psychologist. Purposive sampling strategy was used to identify and recruit the participants. Data for the study was collected using in-depth interviews focus group discussions. Content analysis was used to make sense of the data collected for the purpose of the study. Findings indicate that adherence to epilepsy treatment is hampered by beliefs that witchcraft, a curse from God, having extra marital affair, conflict with in-laws, modern family planning, stigma and discrimination are causes of epilepsy. In the African cultural context more workshops are necessary to change views of caregivers of children with epilepsy.

Materials and Methods: The study utilised a qualitative approach to explore the views of caregivers of children with epilepsy about factors that hamper patient adherence to epilepsy treatment. Specifically, an interpretive phenomenological approach was adopted to explore the perceptions of these caregivers. The approach is appropriate for studies to identify phenomena as they are perceived by the actors (Polite & Hungler, 1999).

Results: Findings Indicated that witchcraft, a curse from God, having extra marital affair, conflict with in-laws, modern family planning are some of the believed causes of epilepsy by some caregivers.

Conclusions: The study revealed that caregivers' beliefs that epilepsy is caused by witchcraft, a curse from God, having extra marital affair, conflict with in-laws, modern family planning methods, stigma and discrimination hamper epilepsy treatment adherence among epilepsy patients.

Key Words: Views, epilepsy, caregivers, epilepsy treatment, hospital

Date of Submission: 06-09-2023

Date of Acceptance: 16-09-2023

I. Introduction

Epilepsy is a prevalent brain disorder worldwide including Zimbabwe (Gibb et al., 2003). The signs and symptoms of epilepsy are significantly different from those of other illnesses. This condition is characterised by repeated seizures or fits which range from short lapses of attention to severe and frequent convulsions (Okonkwo, 2011). Research has revealed that views of caregivers about epilepsy treatment vary from country to country (Bassili, 2002; Bradlely, 1992). For example, Japanese caregivers believe that epilepsy should be treated by traditional healers or religious doctors. According to these caregivers, hospitals should not be visited as often as the traditional treatment institutions (Andermann, 2005). Obot (2012) notes that the view that epilepsy is spiritual and should be treated using traditional methods is prevalent among Nigerian caregivers of children with epilepsy. A study conducted in Zimbabwe by UNICEF in 2011 revealed that ultra-conservative apostolic caregivers were confident that epilepsy is easily treated through prayers and consulting other traditional healers. It is evident that most native caregivers of African origin hold traditional spiritual views about treatment of epilepsy. This is so because in their view epilepsy is a divine punishment. Caregivers from these environments strongly believe that a state of health exists when a person lives in total harmony with

nature. Illness is viewed as an imbalance between ill person and supernatural forces. In contrast, Bassili (2002) notes that Western caregivers of children with epilepsy view epilepsy as a natural scientific phenomenon and advocate for medical treatment that combats microorganisms or use sophisticated technology to diagnose and treat epilepsy. This attitude motivates Western caregivers to seek epilepsy treatment in hospitals. To respond effectively to epilepsy, it is important to investigate and document caregiver views about epilepsy treatment.

II. Materials and Methods

Research design:

The study utilised an Explanatory Sequential Mixed Methodology design to investigate the impact of institutionalisation on the well-being of orphans. In this design quantitative results are presented and elaborated ahead of qualitative results. The approach is appropriate for studies that collect both numerical and verbal data and use descriptive statistics and qualitative strategies to analyse the data (Borg & Gall, 1989).

Procedure methodology

Permission for the study was sought from the hospital administrators. Each participant signed a consent form. The interviews were scheduled for a time when the participants felt comfortable to talk to the researchers. Focus group discussions were conducted in room provided by the hospital administrators. Before the study commenced, participants received information about the research. The information provided explained in detail the research purpose, procedures, risks and benefits including the rights of the participant and contact information of the researchers.

Data analysis

Content analysis (Elo&Kyngas, 2008) was used to analyse and draw themes from the data. The aim was to attain a condensed and broad description of views of caregivers about epilepsy treatment. This involved reading out each in-depth interview and group discussion flipchart responses to identify potential codes and creating a coding system and assigning codes to relevant texts.

III. Result

The themes reported by participants included witchcraft, a curse from God, having extra marital affair, conflict with in-laws, modern family planning affects pregnancy, stigma and discrimination. Participants' responses on each theme are presented and discussed in the sections that follow.

Epilepsy Is Caused By Witchcraft

Five participants were convinced that epilepsy is caused by witchcraft and seeking help from hospitals worsened the sickness. One of the participants dejectedly disclosed that her child did not improve despite receiving modern medication for epilepsy. Other participants acknowledged visiting the hospital here and there which is inconsistent with modern the requirements of treatment of epilepsy. Their typical words were: *We go hospital here and there, simply because our family members force us to do so otherwise, we believe that traditional medication is the right treatment for epilepsy.*

Epilepsy is a curse from God.

Caregivers A13, A14 and A15 believed that epilepsy is a curse from God. According to these caregivers, epileptic patients or their parents should ask for forgiveness from God for the wrong things they did. Tablets from the hospitals are useless as they do not cleanse transgressions. It was also established that caregivers only used hospital medication to manage convulsions. One participant said: *I will only use it when the child convulses.* It is evident that due to misconceptions regarding the cause of epilepsy, caregivers do not administer medication for epilepsy as prescribed by medical doctors (Vermeire et al., 2000). Among people of African origin adherence epilepsy treatment regime is a problematic issue.

Extra-Marital Affairs Cause Epilepsy

Caregiver A8, A9 and A11 believed that epilepsy is caused by extra marital affairs. Therefore, epilepsy should be treated by performing a ritual not by taking tablets. This view is illustrated by the following typical statements captured from the participants during focus group discussion: *As long as the husband is promiscuous, he has to perform the ritual. Such a process cannot be replaced by tablets to heal epilepsy or any disease.* Such attitude undermines adherence to hospital treatment for epilepsy.

Conflict with the In-Laws Causes Epilepsy

According to participants A1 and A2 conflict with the in-laws causes of Epilepsy. For example, A1 had this to say: *My wife was not loyal enough to my culture which I believe is the source of healing for our child.*

Consequently, she went on to give my child tablets for treating epilepsy and the illness worsened. Similarly, participant A2 reported that epilepsy treatment adherence for his child is hampered by conflicting beliefs about causes of epilepsy among him and other family members. His actual words were; *My wife and in-laws believe that epilepsy is an illness that can be treated at the hospital, and I am a traditionalist who believes that traditional medicine is the best treatment option.* As indicated earlier in this paper, divergent views about what causes epilepsy and how it should be treated affect the administration of epilepsy medication.

Modern Family Planning Causes Epilepsy

Participant A3 and A4 agreed that modern methods of family planning can cause epilepsy. A3 argued that pregnant women should take traditional medicines in order to protect their babies from diseases such as epilepsy. The participant's typical words were: *A pregnant woman should chew traditional herbs to avoid birth complications and diseases which may affect the baby's health.* It is apparent that people with such traditional beliefs about health and treatment of diseases would not consider modern epilepsy treatment as an option should they have a child with epilepsy.

People with Epilepsy are Stigmatized and Discriminated

All participants lamented that they are living in a world where stigmatization and discrimination are prevalent. Children with epilepsy are liable to be stigmatised and discriminated by members of the community. Visiting hospitals for routine epilepsy medication will be greatly resisted by adolescent and adult patients for fear of victimisation and discrimination. Comments from the members of that: *Epilepsy is pure witchcraft and spiritual. Go to a traditional healer for epilepsy treatment* will negatively affect patient adherence to modern epilepsy treatment.

IV. DISCUSSION

Hindrances to adherence to Epilepsy treatment reported by the caregivers of children with epilepsy are in line with studies by Gibbs (2003) who found that epilepsy is a disease that traditionally has been wrapped in magic beliefs. Inevitably, these beliefs hamper modern treatment options as they discourage patients from adhering to hospital medication for epilepsy. Unless something drastic is done people of African origin will continue to value spiritual and religious treatment options for epilepsy. Issues to do with the hospital may be considered far-fetched and useless (Andermann, 2005). These sentiments are rooted in the African culture and tradition that has been practiced for decades, and as such caregivers of children with epilepsy may find it difficult to adhere to epilepsy treatment because they were socialized to understand that traditional medicines are the best for any illness. To effect adherence to epilepsy treatment the health practitioners should be guided by cross cultural (Andermann, 2013). This model should emphasise that the need to understand patients' culture, perception of their illness then acknowledge and discuss the difference and similarities in terms of treatment. In other words, Andermann notes that adherence to epilepsy treatment can be positive and successful if health practitioners develop interest in the traditional beliefs and culture of the patient with epilepsy.

V. CONCLUSION

The study revealed that caregivers' beliefs that epilepsy is caused by witchcraft, a curse from God, having extra marital affair, conflict with in-laws, modern family planning methods, stigma and discrimination hamper epilepsy treatment adherence among epilepsy patients.

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