

**EXPERIENCES OF PATIENTS WITH EPILEPSY SEEN AT
GOOD SHEPHERD HOSPITAL, TSHIKAJI, WESTERN KASAI PROVINCE,
DRC ABOUT THEIR ILLNESS**

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DECLARATION

I, Dr Blaise NDANDU MAYIMONA, hereby declare that the work on which this dissertation is based, is original (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or shall be submitted for another degree at this or any other university, institution for tertiary education or examining body.

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Signature:

Date:

DEDICATION

To my mother Nzonza Landu Marie and my late father Mfulu Zowa Antoine for their affection and all boundless sacrifices towards me. To my wife Ntumba Kabeya Noëlla for her love and support throughout the writing of this work.

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ABSTRACT

BACKGROUND

Epilepsy is a neurological disorder which affects many aspects of personal health including psychological and sociological dimensions. Patients seen at Good Shepherd Hospital reported late for care since they perceived themselves victims of stigma, or discrimination.

METHODOLOGY

This study sought to explore experiences of patients with epilepsy seen at Good Shepherd Hospital of Tshikaji about their illness; the objectives were to explore experiences of stigmatization and discrimination of patients suffering from epilepsy, and their experiences resulting in them reporting late for care at the hospital. The setting was Good Shepherd Hospital, a private hospital in a rural area in the Province of Western Kasai, Democratic Republic of the Congo. An exploratory descriptive qualitative study was designed with free attitude interviews as a data collection technique. The study population was patients with epilepsy and who were attending at Good Shepherd Hospital. Purposeful sampling was the method used in the selection of the sample. A total of 8 epileptic patients attending at the hospital agreed to participate out of a total of 12 who were recruited initially. The free attitude interviews were conducted from October 2008 to April 2009. All interviews were tape-recorded and transcribed; and the transcripts were analyzed using thematic analysis.

RESULTS

The seven themes emerging from this study are as follows: experience of seizures, knowledge, stigma, family relationships, alternative treatment, unhealthy lifestyle, and unemployment. The study showed that patients' experience were associated with the experience of seizures as a phenomenon which characterized their life. The participants, their families and the community had poor knowledge on epilepsy. The stigma resulted from the community members' negative beliefs on the illness. The relationship of family members with the epileptic patient varied according to the family members' opinion about the disease. The participants resorted to alternative treatment according to their belief of being victims of bad fate. Unhealthy lifestyle and unemployment were part of patients' experience as expressed by the participants in the study.

CONCLUSION

Epilepsy has physical and psychosocial impacts which require a holistic approach for an appropriate management, but this remains a dream in the DRC. The patients' experiences were marked by the existence of seizures (which affected their lives negatively resulting in physical injuries), poor knowledge on the condition and the perception of being victims of stigmatization and discrimination.

The role of the health care provider is to educate the patients and the community on the disease and encourage the patients to attend and adhere to their medication for adequate control.

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