

# Perceptions of Parkinson's disease and epilepsy in rural Tanzania



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Parkinson's disease

## Introduction

Parkinson's disease (PD) is a debilitating neurological disorder that results in a reduced quality of life for people with Parkinson's disease (PWP) and their carers. It is the second most common neurodegenerative disease globally and is associated with a host of motor and non-motor complications. There is poor a knowledge and understanding of chronic disease in SSA as a result of research being focussed on infectious disease in the region. This lack of understanding is associated with limited availability and access to appropriate health care services and treatment.

## Aim + Objective

To explore the experiences of people with Parkinson's disease in a Tanzanian cohort in regards to their PD treatment and further explore how the social and cultural context in which people with Parkinson's disease live shapes their understanding of treatment.

## Results

The main findings of this study include the emotional strain of PD for PWP and carers, including depression, hopelessness, social isolation and dependence. Coping mechanisms for PWP and carers included family support networks and religion. Various cultural beliefs about cause of disease were identified, faith healers were seen by all PWP. All participants thought their disease was God given and so prayers and spiritual healing were crucial in treatment.

## Conclusion

Religion, prayers and family support networks are crucial in the management of PD in Hai. It is apparent that biomedical treatment practices need to be integrated into traditional aspects of life in SSA in order to be completely effective

## References

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 Hunter, E et al (2016) The epilepsy treatment gap in rural Tanzania: A community based study in adults. *Seizure*. 36, pp49-56.  
 Mshana, G et al (2011) "We call it the shaking illness": perceptions and experiences of Parkinson's disease in rural Northern Tanzania. *BMC Public Health* 11, pp219

Superordinate themes	Themes
Experiences of people with Parkinson's disease	1. Deterioration of sufferers condition over time 2. Improvement in well-being with medication • Emotional strain of PD on sufferers
Experiences of carers of PWP	1. Emotional strain of the role of a full time carer • Physical strain of caring for someone with PD 2. Financial strain associated with PD
Coping mechanisms for PWP and carers	
Perceived causes of disease and cultural belief systems	
Treatment seeking behaviours of PWP	

## Methods

Two convenience samples, one of TH and another of PWP and their carers, were identified through the use of local census enumerators. Semi-structured interviews were carried out in Swahili, in conjunction with a local interpreter, with 3 people with Parkinson's disease and 6 carers and 8 traditional healers. Thematic analysis was used to analyse transcripts of interviews with PWP and their carers. Interpretative phenomenological analysis was used to analyse transcripts of interviews with TH.

Superordinate themes	Themes
Being a healer	1. Becoming a healer 2. Dreaming and connection to the spiritual world 3. Recognition of biomedicine
Healers perceptions of seizures	1. Symptoms of <i>degedege and kifafa</i> 2. Biomedical and spiritual causes of disease
Treatment of seizures	1. Administration of medicines 2. Spiritual power of the healer 3. The power of prayer

## Introduction

Epilepsy is a common disease in sub-Saharan Africa. Qualitative research suggests that traditional healers (TH) may influence medication compliance by competing with biomedical healthcare services and encouraging explanations of spiritual causes of epilepsy within communities. TH have also been suggested to have an important role mediating epilepsy-related stigma within communities by providing explanations of disease aetiology which either blame or absolve the patient and family.

## Aim

To explore traditional healers' understanding of and approaches to the management of seizures in the Hai district of Tanzania

## Objectives

1. To elicit the explanatory models used by traditional healers regarding seizures
2. To gather information on interactions between traditional healers and biomedicine

## Research questions

1. What does it mean to be a traditional healer?
2. What are traditional healers' understandings of seizures?
3. How do traditional healers manage seizures?

Epilepsy

## Results

This study found that TH had a strong connection to the spiritual world, typically mediated through dreams. They identified natural and spiritual causes of epilepsy, which only TH could treat. Spiritual causes of disease could be divided into Islamic beliefs (Jinn) and traditional African beliefs (witchcraft). Healers relied on local herbs, their own spiritual powers and prayers to cure their patients.

## Conclusion

The appeal of traditional healers to people with epilepsy may be due to their broad explanatory models of disease, which are more likely to overlap with those of people with epilepsy than the explanatory models of biomedical healthcare professionals.