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Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations

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ABSTRACT

Purpose: Most studies conducted on the diagnosis and treatment of psychogenic nonepileptic seizures (PNES) have been performed in developed countries with developing countries, such as Namibia, receiving less attention. This study aimed to contribute to the aims of The International League against Epilepsy Psychogenic Nonepileptic Seizure Task Force by investigating the perceptions and frustrations of healthcare providers (HCPs) in Namibia regarding the diagnosis and treatment of psychogenic nonepileptic seizures.
Methods: Semi-structured interviews were conducted with fifteen HCPs from the private healthcare sector in Namibia. Thematic analysis was used to analyse the semi-structured interviews in order to identify themes and subthemes within the data.
Results: Main themes centred on the areas of diagnosis, treatment, patients and awareness. It was found that HCPs' perceptions and frustrations were often related to the lack of knowledge and awareness regarding the disorder. Furthermore, the lack of access to specialized services and equipment contributed to HCPs' frustrations. Delays in the diagnosis of PNES added to HCPs' concerns regarding ineffective referral practices and the subsequent increase in healthcare costs. Although HCPs expressed the need for adequate training opportunities and increased awareness concerning the disorder, the lack of such opportunities and awareness campaigns were identified as possible problem areas.
Conclusions: It was evident from the findings that there are several gaps in how PNES are diagnosed and treated in Namibia. The unique challenges faced by a developing country such as Namibia were evident in some of the subthemes that highlighted the cultural differences in how PNES are conceptualized and treated.

1. Introduction

Psychogenic nonepileptic seizures (PNES), resemble or mimics epileptic seizures (ES), but are in reality episodes of altered experience, sensation and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors [1–3]. PNES is categorized as a conversion disorder, convulsion/seizure type by the Diagnostic and Statistical Manual of Mental Disorders [4]. At present, most of the studies conducted on the diagnosis and treatment of psychogenic nonepileptic seizures have been performed in developed countries with developing countries, such as Namibia, receiving less attention [5–8]. No official statistics or diagnostic and treatment guidelines on PNES or epilepsy are currently available in Namibia (H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016).

Namibia is a country in South-western Africa, bordering on South Africa with a surface area of 824 116 square kilometres. It is a former German protectorate and mandate of South Africa from 1922 until 1966, after which it gained its independence in 1990.

The World Health Organization estimated the Namibian population at 2 459 000 in 2015 with a population density of 2.2 persons per square kilometre [9]. Despite its relatively low population and density, Namibia is culturally diverse with nine defined ethnic groups [10]. Thirteen national languages are recognized in Namibia with 87.8% of the population speaking ten indigenous languages and 11.2% speaking 3 Indo-European languages [10]. English is the official language of Namibia despite its status as a minority language [10].

The country is divided into 14 administrative regions, with the Khomas Region as the most central. The capital, Windhoek, is located in this region and acts as the judicial and administrative centre of the country. Windhoek is home to most of Namibia's

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manufacturing industries as well as business, educational, healthcare and transport sectors [11]. Poverty levels are estimated at 29% of the population, the unemployment rate is 27.4% and HIV/AIDS prevalence is at 18.2% [12]. Neurological disease/disorders were rated as one of the top ten causes of death in outpatients in 2012 [12].

The general government expenditure on health as a percentage of total health expenditure is 60.4%, while 18.65% of the total health expenditure is covered by private health insurance and the remainder is out-of-pocket [9]. According to the World Health Organization, Namibia has 0.374 physicians per 1000 people, 12 psychiatric beds per 100 000 people, 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people [9]. No video-EEG monitors, which are known as the gold standard for diagnosing PNES, are available in the country.

The misdiagnosis of PNES as ES is common due to a lack of access to specialized equipment and expertise. Prolonged treatment with anti-epileptic drugs (AED) [7], associated stigma and loss of quality of life are compound consequences of misdiagnoses [13]. Patients who claim disability compensation on the basis of being declared medically unfit are costly both to the economy and the healthcare infrastructure. Improved understanding of the disorder by both patients and physicians may be achieved through accurate diagnosis and psychoeducation, which can potentially decrease the economic impact by between 69% and 97% [14].

In an attempt to raise awareness regarding PNES, the International League against Epilepsy (ILAE) PNES Task Force, initiated a worldwide campaign to collect information on the diagnosis and treatment of PNES. The aim of the current study was to identify the perceptions and frustrations of Namibian HCPs regarding the diagnosis and treatment of patients suffering from PNES. This study may not only contribute towards the goals of the ILAE PNES Task Force, but can also pave the way for future research on PNES in Namibia and other developing countries.

2. Methods

2.1. Participants

According to the Ministry of Health and Social Services Essential Indicators Database 2006–07 as reported in the WHO Regional Office for Africa Country Cooperation Strategy [15], Namibia has 557 medical practitioners which include dentists, psychologists and pharmacists. Namibia currently has two psychiatric wards, one in Windhoek and another in Oshakati with facilities that cater for approximately 200 patients in total [12]. The unit in Oshakati has access to one psychiatrist and one neurologist who is in private practice. There are seven psychiatrists in Namibia in total, of which four are in private practice in Windhoek, two are employed by government and one is in private practice in Swakopmund. Namibia is being served by three neurologists, two of which are situated in Windhoek and the other in Oshakati in the far north of the country. Approximately 30 clinical psychologists practice privately in Windhoek and roughly the same number in the rest of the country, mainly situated in the coastal region. Mental Healthcare Services are predominantly provided in and around Windhoek for patients with access to medical aid funds [15].

Governing bodies for healthcare providers are limited to the Ministry of Health and Social Services (MoHSS), the Health Providers Council of Namibia (HPCNA), Namibia Medical Aid Fund Administrators (NAMAF) and other private bodies. No organizations or societies exist for neurologists or psychiatrists specifically.

Purposeful sampling was used to identify potential participants from the available healthcare service providers' pool in Namibia. Recruitment took place between September 2015 and June 2016. The Health Research Ethics Committee at Stellenbosch University granted ethical approval for this study (protocol number: REC-050411-032). Eligibility for participation in the study was based on the speciality of the healthcare provider and excluded participants under the age of 21. HCPs were sourced from the private healthcare sector, taking into consideration that few specialists are employed by the public sector. Involving psychiatrists and neurologists in the study was vital considering the limited availability of specialists. General practitioners (GPs) were identified based on experience in treating epilepsy and PNES patients, years in practice and special interest in neurology and psychology.

2.2. Data collection

The Namibian telephone directory lists approximately 180 GP entries, of which the majority includes e-mail addresses and was used to identify potential participants. Telephone directory listings for GPs indicated specific specialization areas such as family practitioner, occupational health, avionics, obstetrics and psychiatry. Obtaining information on specialists such as psychiatrists and neurologists proved much simpler due to their limited numbers. A list of possible service providers was compiled while preference was given to specialists such as psychiatrists and neurologists. The remainder of the list comprised of GP's with specializations and finally psychologists with a special interest in neuropsychology.

Twenty-eight HCPs were invited to participate in the study. This included 2 neurologists, 5 psychiatrists, 10 psychologists and 11 GPs. An e-mail including a short description of the purpose and relevance of the study and an invitation to participate was sent out.

Table 1
Questions that were used to guide the interviews.

Number	Questions
1	Tell me about your work with patients with PNES.
2	What procedures do you use to diagnose PNES? What about your confidence in making a diagnosis of PNES?
3	What are the complexities involved in making a diagnosis of PNES?
4	How is the diagnosis communicated to the patient?
5	What are your thoughts on the role of stigma in PNES?
6	How do patients understand/accept the diagnosis of PNES?
7	What are in your experience the main causes of PNES?
8	What role does secondary gain play in the diagnosis?
9	What is your opinion regarding referral of patients with PNES?
10	What would you consider the most effective treatment for PNES?
11	What are in your opinion the main challenges that healthcare professionals face when dealing with patients with PNES?
12	What will make it easier for you as a healthcare professional to deal with patients with PNES?
13	What is in your opinion the main challenges faced by patients with PNES?
14	What do you think can make it easier for patients with PNES?