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Professional nurses' experiences of managing epilepsy at limited resource rural facilities in Limpopo and Mpumalanga Provinces, South Africa

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ABSTRACT

Background: Epilepsy is a neurological disorder affecting approximately 50 million individuals globally, contributing significantly to the global disease burden. Professional nurses play a crucial role in the care and treatment of people living with epilepsy, ensuring their safety and well-being. Professional nurses frequently encounter challenges, such as restricted access to drugs, specialised equipment, and epilepsy treatment training. Despite these obstacles, professional nurses are essential to providing high-quality care to patients with epilepsy in remote locations.

Methods: A qualitative design using explorative, descriptive, and contextual design was employed to achieve the objectives of the study. The sample comprised 20 professional nurses working in selected rural communities in Limpopo and Mpumalanga. Data was collected through in-depth individual interviews and analysed using Tesch's eight steps of data analysis.

Results: Four themes emerged from the data: experiences of professional nurses during management of epilepsy; inadequate training in management of epilepsy; insufficient supply of antiepileptic drugs and late presentation to local clinics.

Conclusion: The study found that professional nurses experienced several challenges hindering the effective management of epilepsy. Cultural beliefs in supernatural causes of epilepsy significantly influence treatment preferences, consequently delaying diagnosis and treatment. Despite limited resources and cultural barriers experienced by professional nurses, they strive to provide appropriate care to minimise seizures. Ongoing education and training on epilepsy management is vital to enable professional nurses to keep up-to-date with current methods and new developments.

1. Introduction

Professional nurses play an essential role in managing epilepsy globally, including in Sub-Saharan Africa and South Africa, ensuring their safety and well-being (Huchinson et al., 2023). Lack of resources and specialized training is one of the key challenges encountered by professional nurses in managing epilepsy in many regions of the world (Huchinson et al., 2023). In America, there are limited neurology specialists to provide guidance on treatment options [1]. Consequently, the professional nurses only rely on their clinical judgements and experience to make decisions on care and treatment of people living with epilepsy (PLWE).

In Sub-Saharan Africa, professional nurses experience unique challenges in care and treatment due to limited resources and access to healthcare services [2]. Many PLWE in this region do not have access to appropriate diagnosis and treatment, leading to uncontrolled seizures and increased risk of complications.

In South Africa, professional nurses also face significant challenges in managing epilepsy due to factors such as socioeconomic discrepancies, limited resources, poverty and cultural beliefs [3]. Moreover, access to healthcare services and medications may be limited, leading to delays in diagnosis and treatment.

Epilepsy is associated with superstitious beliefs about its cause and treatment [4]. Communities in rural villages are from diverse cultures and consult traditional healers and faith-based healers as they perceive them to have the ability to treat the condition [5,6]. Traditional and faith-based healers provide complementary therapies, which may seem contradictory to nurses' medical procedures. Some of the concerns

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raised included the potential for adverse interactions between prescription drugs and herbal medicines or spiritual practices recommended by traditional or religious healers [6].

People living with epilepsy, like individuals with other chronic illnesses, are treated and cared for by the public health system, which provides care to the majority of people from low socioeconomic backgrounds [3] However, the situation with epilepsy might be worse compared to other chronic illnesses. Despite the fact that access to quality healthcare is guaranteed by the Constitution, unfair resource distribution remains a major concern [3]. Therefore, the protection and advancement of human rights, in addition to the delivery of community-based care that supports cultural preservation, accommodation, and reintegration, should be prioritised for this population. Failure to address these could negatively impact their mental health and wellbeing of PLWE [3].

The management of epilepsy is perceived to be inadequate in primary health care settings. This view was corroborated by Deloitte et al. (2020) and Welton et al. (2020) in Australia, on dealing with the difficulty of an epilepsy diagnosis, particularly in the context of fragmented health and social care systems and unequal access to care in rural areas. Among the issues raised were: insufficient knowledge and understanding of epilepsy among community and primary care providers, which delayed specialist referrals; regional differences in treatment and services; poor communication; and an excessive dependence on tertiary expert services (Hutchinson et al., 2020; [7]). These barriers may exacerbate poor health, psychosocial consequences, and hospitalisations for individuals living with epilepsy.

It is further documented that in sub-Saharan Africa, the scarcity of trained health employees, limited diagnostic equipment, limited antiepileptic drug (AED) supplies, cultural beliefs, and social stigma contribute to the massive treatment gap for epilepsy [2,8]. In Uganda, the epilepsy treatment gap was estimated to be as high as 95 %, meaning that most people with epilepsy do not receive treatment for their conditions [9]. In low- and middle-income countries, cultural beliefs regarding the cause of seizures, the use of traditional medicine, a lack of experienced healthcare workers, the high cost of AEDs, inadequate medical supplies, and restricted access to health facilities are common obstacles to epilepsy care [2,10].

In rural communities, the management of epilepsy is difficult because of limited access to healthcare resources and a lack of awareness about the condition [11]. Professional nurses' experiences with managing epilepsy in remote regions have highlighted several difficulties [2]. These included a lack of adequate epilepsy education and training, restricted access to AEDs, and societal attitudes that stigmatise PLWE. These obstacles notwithstanding, professional nurses have persevered in trying to give patients with epilepsy in rural areas high-quality care [2].

The management of epilepsy has been a topic of concern for healthcare professionals and traditional healers alike [12,13]. Recent years have witnessed an increasing interest in collaboration between these two groups to provide comprehensive care for patients with epilepsy (Lambert et al., 2022). They acknowledge that practitioners may offer cultural insights into care that can enhance treatment outcomes. By working together as a team, healthcare providers from different backgrounds can provide holistic care that addresses both the physical symptoms and spiritual needs of PLWE. Professional nurses are an integral part of the healthcare team, and their experiences in managing epilepsy can provide valuable insights into the challenges and successes of treating this condition (Hutchinson et al., 2021). This paper aimed to explore the experiences of professional nurses in managing epilepsy in the selected rural communities of Limpopo and Mpumalanga.

2. Materials and methods

2.1. Study setting

This study was conducted in the rural communities of Limpopo and Mpumalanga, South Africa. The selected rural communities in Limpopo were Malavuwe, Mtititi, and Bochum, while the selected rural communities in Mpumalanga were Clara, Acornhoek, and Jerusalem. Different cultures with diverse beliefs, values and practices are represented among the community members. The management of epilepsy and cultural beliefs were taken into consideration when selecting the communities.

2.2. Design

This study adopted a qualitative approach using explorative, descriptive and contextual designs to attain the objectives (De Vos, Strydom, Fouché, and Delport, 2015; [14]). The researcher had direct interactions with the individuals to collect detailed data.

2.3. Population and sampling

The study population included professional nurses working in local clinics in the selected rural communities in Limpopo and Mpumalanga. Purposive sampling was used to sample the villages. Purposive sampling was also used to select the participants. The researcher visited the local clinics on treatment review days and identified relevant Professional Nurses. Those who granted consent for participation were recruited. Only those who managed epilepsy in the selected rural communities in Limpopo and Mpumalanga were included in the study.

2.4. Measures to ensure trustworthiness

The criteria of credibility, transferability, dependability, and confirmability were employed to ensure trustworthiness.

Credibility was ensured through prolonged engagement, persistent observation and member checking. Biographical data was gathered to ensure transferability, and a thorough explanation of the study approach and results was given. (De Vos, Strydom, Fouché, and Delport (2015); [14]). Furthermore, transferability was ensured by comprehensively describing the participants' background information. To address dependability more directly, the research design, data collection and analysis methods of this study were reported in detail to allow future researchers to repeat or scrutinise the work. A detailed description of the methodology was provided to facilitate a rigorous examination of the research findings and to ensure their integrity.

2.5. Pilot study

Before the actual data collection process, the researcher selected participants from rural communities in Limpopo and Mpumalanga to conduct a pilot study (Brink, van der Walt & Van Rensburg, 2017). Six participants were interviewed to determine their understanding of the interview question. The participants who were interviewed during pilot study were not part of the study. The duration of the pre-test was 25 to 30 min.

2.6. Data collection

Data was collected through in-depth individual interviews at the clinics in the selected rural communities in Limpopo and Mpumalanga. The duration of the interviews was 30 to 45 min and the interviews were conducted in Sepedi, XiTsonga, and TshiVenda. After obtaining consent from the participants, a voice recorder was used to record the discussion. The interviews were guided by the following central questions:

- *Kindly share with me your experiences of management of people living with epilepsy at your health facility?*

Based on the participants' initial responses, probing questions were posed to participants to elicit more detailed information and gain deeper

insights. This process entailed employing techniques such as listening, clarifying, reflecting, focusing, and paraphrasing. Subtle vocal cues, like nodding the head, saying "mm", "Yes", and "continue", allowed the conversation to flow naturally and prompted people to share their thoughts. Consequently, participants felt more at ease and were open to talking about their experiences.

2.7. Data analysis

In line with Creswell's [15] guidelines on qualitative research, the open coding data analysis guide developed by Tesch was adopted in this study. Tesch provides eight steps that should be considered when analysing qualitative data. The researcher listened to recordings repeatedly and transcribed the data verbatim. After that, to get a clear sense of what participants said, the researcher read through each transcript thoroughly, one at a time. Similar responses were noted down and grouped into categories.

As sub-themes emerged, they were arranged into columns. Thereafter, the researcher generated a list of themes for every topic. Related topics were grouped together into columns. Different colored pens were used to facilitate the process. Next, the researcher revisited the data, abbreviating the topics as codes and annotating the appropriate segments with these codes. The researcher used tables to display the findings that emerged. The researcher's theme, categories, and subcategories were used to arrange the tables. The data analysis process was done manually, no computer programme was used.

2.8. Ethical considerations

The ethical considerations of this study included the principle of respect for persons, informed consent, privacy, confidentiality and anonymity. To avoid ethical dilemmas, ethical considerations were strictly adhered to. Ethical clearance was obtained from the University of Venda Human and Clinical Trial Research Ethics Committee (SHS/19/pH/37/2101). Permission to access the clinics was obtained from the Department of Health.

3. Results

Table 1 presents the demographic profile of professional nurses. The population comprised 20 participants and included males ($n = 5$) and females ($n = 15$). The participants' ages ranged between 25 and 55 years. Most participants ($n = 12$) were from Limpopo, with the remainder ($n = 8$) from Mpumalanga. All participants were qualified professional nurses. The lowest qualification was a diploma and the highest was a master's degree. TshiVenda was the most commonly spoken language, followed by XiTsonga and Sepedi.

Table 1
Demographic profile of professional nurses ($n = 20$).

Criterion	Characteristics	Frequency	Percentage
Age	20–30	3	15 %
	31–40	7	35 %
	41–50	5	25 %
	51–60	5	25 %
Gender	Female	15	80 %
	Male	5	25 %
Marital status	Married	14	75 %
	Single	6	30 %
Ethnicity	TshiVenda	9	45 %
	XiTsonga	6	30 %
	SePedi	5	25 %
Qualifications	Diploma in Nursing	7	35 %
	Degree in Nursing	8	40 %
	Master's degree in nursing	5	25 %
Years of experience working experience as a professional nurse	02–05	3	15 %
	06–10	5	25 %
	11–15	4	20 %
	16–20	3	15 %
	21–25	5	25 %
Advanced training in epilepsy management	Yes	0	00 %
	No	20	100 %

The findings revealed that the professional nurses experienced several challenges while managing epilepsy (Fig. 1). These challenges include a lack of training in the management of epilepsy, an insufficient supply of AEDs and late presentation to local clinics.

The findings further revealed the perceptions of professional nurses regarding collaboration with traditional healers and faith-based healers as discussed below.

Theme 1: Experiences with managing clients who present with epilepsy

This study revealed that professional nurses rely on guidelines for managing epilepsy as provided by the Department of Health. Because the majority of PLWE give first preference to traditional healers and faith-based healers, they only consult at clinics after several episodes of seizures. The comments below represent some of the professional nurses' experiences with epilepsy management:

A 38-year-old female explained:

"During seizures, we make sure that all harmful objects are removed next to the patient to prevent injuries, then identify the type of seizures and record the frequency. We don't give any treatment orally during seizures. However, diazepam is administered on the rectum if the seizures are persistent."

A 43-year-old female stated:

"Sometimes the management of seizures is difficult because patients consult at a later stage. Some of them disclose that they consult traditional healers and use traditional remedies as preferred and supported by their families. When the seizures are not controlled or become persistent, that is when they consult at the clinic and it only delays them from receiving appropriate treatment."

A 29-year-old female noted:

"We refer to the guidelines of seizure management. For first episode, we do history taking, assess the severity and frequency, then refer to hospital for an antiepileptic drug prescription. For known epileptic patients, we monitor progress and side effects, then we provide health education to promote treatment adherence and support from family. The regularly prescribed drugs are Tegretol, Epilim and diazepam, though they are out of stock sometimes."

A 33-year-old male commented:

"Health education is also necessary for both patients and family members to promote care and support. We educate them about the risk factors, warning signs such as headaches, unusual tastes, confusion, and aura. We also educate about management at home so that the patient must be safe before, during, and after seizure episodes. Family members are not supposed to give anything to the patient through the mouth during seizures to prevent choking. They can only assist to remove dangerous objects and observe the patient."

Theme 2: Inadequate training on management of epilepsy

The findings of this study revealed that professional nurses had received basic nursing training in epilepsy but not in the advanced management of epilepsy. Participants further indicated no workshops were conducted or in-service training on diagnosis and management of epilepsy provided. However, guidelines and protocols, such as the Essential Medicines List facilitated the management of epilepsy. These findings were elaborated on in the following quotes:

A 35-year-old female noted:

"I have never attended any workshop on epilepsy management since I was employed in this clinic. I usually refer the patient to the nearest

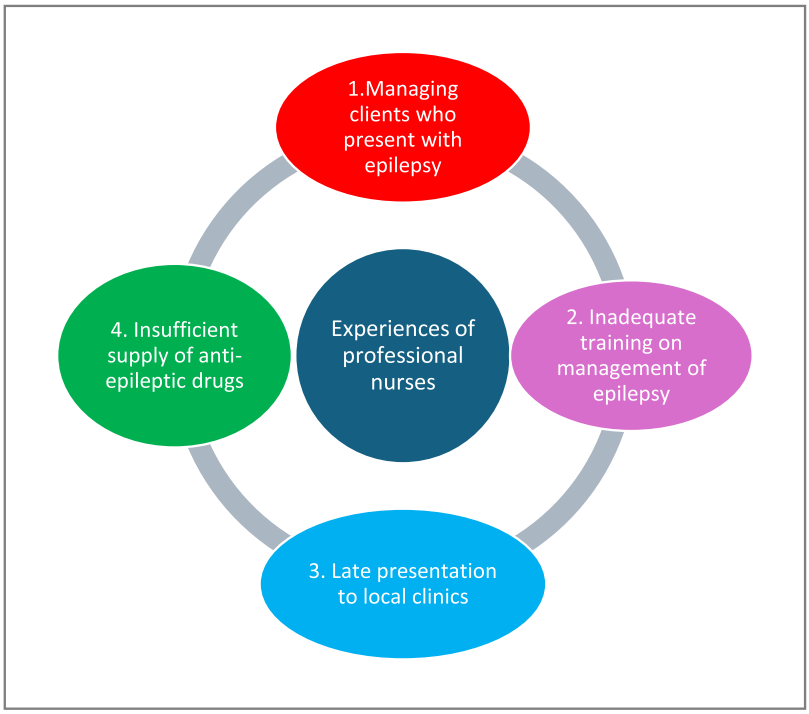

Fig. 1. Experiences of professional nurses.

hospital if it is the first episode of seizures. However, I first do history taking on frequency and severity of seizures."

A 41-year-old female explained:

"I really don't know much about epilepsy management as I refer to EDL (Essential Drugs List) for management. The patients are usually diagnosed by doctors at the hospital. Then we administer the prescribed medication monthly. I haven't received any training on epilepsy management at work; I only learned about it at university many years ago."

A 32-year-old female commented:

"The government doesn't organise any workshop or training on management of epilepsy. I just refer to the guidelines if I need information. Workshops for other chronic conditions like HIV are conducted continuously but there are none conducted for epilepsy."

A 35-year-old female noted:

"I do need training for epilepsy management but there are no opportunities provided. I have never attended or heard about any training related to epilepsy management. Only doctors diagnose and prescribe treatment."

Theme 3: Insufficient supply of antiepileptic drugs

This study found that professional nurses face a significant challenge due to inadequate AED supply, which hinders both management and treatment adherence. This was elaborated on in the following quotes:

A 34-year-old female reported:

"The drugs that are available at the clinics are carbamazepine, Tegretol and Epilim. However, there are times there is insufficient supply and patients must buy. Only those who can afford will continue with treatment. Those who cannot usually afford default."

A 29-year-old elaborated:

"It is not easy because the drugs can be out of stock for a while and there is nothing we can do except refer them to pharmacies for purchase which is really unfair for the PLWE."

A 36-years-old noted:

"The antiepileptic drugs are not always available. Tegretol is the most prescribed treatment. Phenobarbital is usually very scarce."

Theme 4: Late presentation to local clinics

Late presentation to local clinics was one of the major challenges experienced by professional nurses. It contributed to unnecessary delays in the diagnosis and treatment of epilepsy. This was supported by the following quotes:

A 50-year-old reported:

"Most of PLWE present themselves at local clinics at a later stage and it makes it so hard to manage the condition because the seizures become uncontrollable. We are forced to refer the PLWE to hospital for further management. On history taking, some reveal that they were admitted by a traditional healer for treatment. It means that they take traditional remedies instead of antiepileptic drugs."

A 36-year-old explained:

"Some PLWE have their own cultural beliefs of which some are just myths associated with epilepsy. They explain that epilepsy is caused by witchcraft, demonic spirits, or any other supernatural causes. This led them to seek treatment from traditional healers or faith-based healers. They only come for consultation after trying all those other alternatives, which delays them to initiate treatment."

A 28-year-old elaborated:

"Working with PLWE from rural communities is a challenge because most of them are not well informed about their illness. Traditional healers are usually preferred for treatment over health professionals. They are greatly immersed in cultural beliefs of which some of them are so misleading. For instance, they believe that epilepsy is caused by witchcraft. They go up and down seeking treatment from churches and traditional healers. Clinics are considered as a last resort."

4. Discussion

As noted by Toledo, Figuredo, Lara and del Busto (2014), seizures due to epilepsy can happen anytime, anywhere, and for any duration of time. Both people with existing epilepsy and those experiencing their first seizure almost invariably experience sudden, unprovoked seizures. In the event of an epileptic seizure, medical professionals should know what to do because making the incorrect decision could have permanent consequences (Toledo et al., 2014). Moreover, the management of seizures includes recording the duration and frequency of the seizure, identifying the type of seizure, and assessing the level of consciousness. In addition, recording vital signs such as blood pressure, heart rate and oxygen saturation is crucial to make appropriate interventions [16,17].

According to the findings of this study, professional nurses refer to guidelines provided by the Department of Health for the management of epilepsy. They experience challenges with individuals who consult the clinic at a later stage due to treatment preferences influenced by cultural beliefs, values, and practices. For instance, some PLWE believe in supernatural causes such as witchcraft, and prefer treatment from spiritual healers. They argue that spiritual epilepsy cannot be treated by modern medical or Western treatments.

Notably, Tirikulem et al. (2021) and Pechillo [18] also found that many cultures believe that epilepsy is a result of divine retribution or demonic possession. As a result, rather than going to local clinics for treatment, PLWE consult traditional healers or faith-based healers. These beliefs in supernatural explanations not only stigmatised epilepsy but also hindered access to appropriate medical treatment. The true nature of epilepsy is not well understood, which causes undue suffering for individuals afflicted by delayed diagnosis and insufficient treatment (Tirikulem et al., 2021; [18]).

The management of epilepsy during seizures includes removing dangerous objects, assessing the severity and frequency of seizures and administration of diazepam (an antiepileptic drug) in case of persistent seizures. Furthermore, health education is provided to family members and PLWE to promote support and equip them with seizure management skills at home.

Contrary to the above findings, in developed countries such as the United Kingdom, epilepsy specialist nurses (ESNs) play an important role in psychosocial support, education, treatment, and risk management, as well as providing solutions to the challenges faced by PLWE. They facilitate greater coordination of care and act as a communication conduit with other health and social care providers within and across systems [1]. The role of the ESN is underpinned by the principle of holistic care. ESNs consider all aspects of the patient's life as part of a comprehensive assessment and care process, incorporating lifestyle and psychosocial issues, and aiding diagnosis and treatment [19]. They offer information, education, and support regarding clinical, social, and safety aspects. These contributions provide patients and carers with the tools to cope successfully with epilepsy

In developed countries such as the United States, training in epilepsy management is advanced, and they have all the necessary resources to make appropriate interventions. For instance, the Epilepsy Foundation of America provides training programmes for school nurses and other community-based providers. Clinical practice guidelines for nurses have recently been developed by the American Association of Neuroscience Nurses for the care of children and adults with epilepsy.

In contrast, the findings of this study indicate that professional nurses who work in rural communities do not receive any training in epilepsy management, which is crucial to provide maximum care to PLWE. However, they rely on guidelines for the required information. One major challenge faced by professional nurses is the struggle in diagnosing and treating epilepsy without appropriate medication. At some point, they are forced to refer PLWE to local pharmacies to purchase the AEDs. Consequently, those who cannot afford these drugs experience significant challenges such as increased seizure frequency. These findings were also supported by Al-Aqeel. (2020), who indicated that limited access to AEDS hinders the effective control of seizures, leading to increased morbidity and mortality rates. This not only places the PLWE at risk but also puts a heavy burden on healthcare providers who observe the suffering of PLWE without being able to provide appropriate interventions.

In Uganda, where specialty epilepsy providers are rare, health centres with shortages of trained providers and essential drugs must manage to care for PLWE [2]. However, limited data is available on the specific knowledge and needs of such health staff from various provider settings [2]. Moreover, inadequate AED supply hampers the ability of nurses to provide consistent and comprehensive education to patients with epilepsy [20]. People living with epilepsy require ongoing counselling and guidance on medication adherence, potential side effects, and lifestyle modifications [21]. However, without a reliable supply of AEDs, offering accurate information or monitoring treatment progress effectively becomes challenging.

5. Conclusion

Professional nurses working in rural clinics face several challenges due to insufficient supplies of AEDs and inadequate training in the management of epilepsy. These challenges include the late presentation of PLWE causing delays in diagnosis and treatment, a lack of education and training about epilepsy, as well as ethical dilemmas related to limited resources.

This study highlighted the importance of a multifaceted strategy to address these issues, including better education programmes for both communities and healthcare providers, more funding for rural healthcare infrastructure, and improved coordination between healthcare facilities and suppliers to guarantee a sufficient supply of antiepileptic medications.

Declaration of competing interest

The authors declare that they had no financial or personal relationship(s) which may have inappropriately influenced them in writing this manuscript.

Data sharing statement

The corresponding author will provide the data used in this study upon reasonable request.

Ethics approval and consent to participate

All authors declare that all processes contributing to this work fulfil the ethical standards of the University of Venda. The University of Venda Human and Clinical Trial Research Ethics Committee reviewed and approved this study. Informed consent for all participants was approved before commencement of the study. Confidentiality and anonymity were ensured throughout data collection and analysis.

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Authors' contributions

All the authors contributed to the study's conceptualisation and design, the analysis and interpretation of the data, and the drafting and revising of the paper. They have reviewed and approved the final manuscript.

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