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Research Paper

Health workers' perceptions of epilepsy and its treatment implications: A survey of nurses and other healthcare workers' in Addis Ababa, Ethiopia

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ABSTRACT

In Ethiopia, the epilepsy knowledge gap among healthcare workers remains high. In this study, we conducted a survey among health care workers in Addis Ababa, Ethiopia, exploring their knowledge, attitudes, beliefs, and perceptions about social inclusion and exclusion regarding epilepsy. Furthermore, we analysed if and how these factors influence the management and quality of care provided. During a training workshop, 50 participants completed the survey. Nurses made up 22% of the participants, midwives comprised 11%, health officers constituted 16%, and medical officers represented 4%. Of the respondents, 69% were male, and 59% had experience in treating patients with epilepsy. This study showed that while 51% of respondents correctly identified epilepsy as being diagnosed after two seizures, many were uncertain about the criteria. Although 90% believed epilepsy is treatable, some were unsure or held misconceptions. Regarding its contagiousness, 82% correctly stated it is not contagious, but some held incorrect beliefs. Treatment options varied, with most recognizing clinical medicines, but some still believed in alternative methods like spiritual or herbal healing. Additionally, understanding of person-centered care was lacking, with several respondents admitting they were unfamiliar with the concept. The factors contributing to the epilepsy treatment gap in Ethiopia were a lack of comprehensive knowledge among healthcare workers about epilepsy, misconceptions such as the belief that epilepsy is contagious, inadequate management practices, challenges in accessing and securing medications due to shortages, and limited community awareness about the condition. Additionally, the study exposed a concerning gap in understanding of person-centered care among some healthcare workers. This study underscores the urgent need for targeted training programs, healthcare policies, and community awareness initiatives to enhance the quality of care for individuals with epilepsy in Ethiopia and similar settings.

1. Introduction

Epilepsy, a chronic neurological disorder characterized by recurrent seizures, poses a significant health challenge globally [1,2]. It affects individuals of diverse backgrounds and socioeconomic status, with highest prevalence in low-income countries [3]. In these regions, limited access to healthcare, a shortage of qualified medical professionals able to manage epilepsy, and widespread societal misconceptions contribute to a considerable treatment gap, leading to a reduced quality of life for those living with epilepsy [1–3]. These challenges are especially greater in resource-limited settings like Africa, further underscoring the urgent need for targeted interventions [4–11].

Ethiopia, like many sub-Saharan African countries, faces profound challenges in addressing epilepsy care [12–22]. In Ethiopia, epilepsy management is integrated into a tiered healthcare system, from primary care to specialized hospitals. Health extension workers at the community level identify and refer patients to primary healthcare centers, where nurses play a key role in initial management and ongoing care.

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Nurses typically first assess patients and refer them to physicians or specialists at higher levels of care. The health system is organized hierarchically, starting with health posts, followed by health centers and district hospitals, and culminating in regional and specialized hospitals for complex cases, ensuring accessible and escalated care. In a study evaluating the perception of epilepsy among the general population of Ethiopia, the most cited 'causes' of epilepsy were stress (91 %), substance abuse (61 %) and spiritual factors 49.8 % [22]. Alarmingly, societal stigma is pervasive, with 94.2 % of respondents unwilling to employ a person with epilepsy and only 6.7 % willing to allow a family member to marry someone with epilepsy. Furthermore, research indicates that stigma worsens with the duration and frequency of seizures [13].

The knowledge gap in epilepsy is alarmingly wide within low-income countries, not only among the general population but also among healthcare professionals [1]. This gap severely compromises the quality of care provided, resulting in poor health outcomes for people with epilepsy [2–4]. This knowledge gap and negative perception was found among health care workers as well (15) and medical students (17). Some health workers suggested holy water treatment and Church healing sessions as epilepsy remedies. This agrees with considerable percentage of Ethiopians viewing epilepsy through the lens of evil spirit and insanity rather than a neurological condition, leading to misguided recommendations of religious interventions over medical treatments and perpetuating stigma and negative perceptions [21]. Yet, amidst these negative perceptions, there is a glimmer of hope, as evidenced by a study on community attitudes reporting a 60.8 % rate of positive attitudes towards epilepsy, especially among those with prior awareness or firsthand experience of seizures [14].

Numerous studies have recommended education, training and awareness initiatives [13,14,15,17,20,21]. For example, training of primary healthcare workers yielded promising results, with a notable increase in epilepsy knowledge by 19.25 %, positive attitude shifts by 36.17 % and an increased case identification rate by 21.35 % [15].

This study is centered on Ethiopia, where nurses and healthcare workers are often at the forefront of delivering healthcare services, due to a shortage of physicians. Primary care nurses, for example, are most likely the first health workers to meet a person with epilepsy and provide a diagnosis. The primary aim of this study is to understand how the perceptions of health care workers influences the quality of care and outcomes for individuals with epilepsy. The larger aim is to bridge this knowledge gap by exploring how these factors affect the care provided to individuals with epilepsy in Ethiopia, addressing a crucial gap in the existing literature. While prior research has delved into knowledge and perceptions of epilepsy, this study uniquely examines the direct correlation between healthcare workers' understanding and their management of epilepsy [1]. By identifying areas for intervention and improvement in their knowledge and attitudes, we seek to generate lessons useful to enhance the quality of care and outcomes for those with epilepsy in Ethiopia in particular, and in low-income countries in general. While some research addressed this issue [5,6], to our knowledge this is the first study that correlates this knowledge gap with epilepsy management gap. In this study, we surveyed Ethiopian health workers' knowledge, attitudes, beliefs and perceptions of epilepsy. Furthermore, we sought to correlate these results with the quality of patient care by comparing the results with their actual management practices.

2. Methodology

A survey questionnaire was administered to nurses and healthcare workers at a training workshop organised by the Ethiopia Epilepsy Care (EAA) in Addis Ababa, Ethiopia. A standard questionnaire developed by the Epilepsy Alliance Africa (EAA) and previously used in Rwanda, was adapted for this study, with permission. The survey questionnaire was distributed in person during a training workshop organised by Care-Epilepsy Ethiopia (CEE). The objectives of the workshop were to identify gaps in the practice of healthcare workers through a pre-training survey and then address these gaps during the training sessions. The survey assessed participants' knowledge, attitudes, beliefs and perceptions and management of epilepsy while also exploring the intersection of Africa-centered and person-centered care, emphasizing the need for culturally relevant and individually tailored healthcare that respects the unique needs and contexts of the African community. The questionnaire was distributed to 55 participants at a training workshop and 50 participants responded.

Table 1*: Demographic details of participants.*

Participants were mostly between the ages of 25 and 32 years. Regarding educational background, seventy-five (75 %) percent had a diploma, 8 % had a degree and 14 % possessed a post-graduate degree. The professional composition constituted 22 % nurses, 11 % midwives, 16 % health officers, and 4 % medical officers. Males constituted 69 % of the respondents, while the remainder being female. Fifty-nine percent (59 %) had experience treating patients with epilepsy. The questionnaire was created in Google Forms, printed and distributed manually. Challenges with access to internet and language barriers led to the survey being distributed in person instead of online. Quantitative responses were analysed using Google Forms software. Qualitative responses were analysed manually through repeated readings by two investigators to identify recurring themes. The two investigators developed themes separately then came together combine and determine final themes.

3. Results

3.1. Knowledge of epilepsy

Participants were asked a series of questions to determine their knowledge about epilepsy focusing on diagnosis, treatability and infectability. Responses are shown in Table 1.

3.1.1. Diagnosis

The survey revealed that 51 % of respondents correctly identified that epilepsy is diagnosed after two seizures, while others were less certain, with 23 % believing it requires three seizures, 8 % saying four, 6 % after one, and 12 % unsure.

3.1.2. Treatability

Additionally, 90 % believed epilepsy is treatable, 8 % thought it is sometimes treatable, and 2 % were uncertain. When asked about the contagiousness of epilepsy, 82 % correctly stated it is not contagious, but 8 % believed it is, another 8 % thought it sometimes is, and 2 % were unsure.

Asked to select the different ways of treating epilepsy, 86 % said clinical medicines, 54 % said counselling or social healing, 26 % said spiritual healing by God or healers, 20 % said dietary treatment and 8 % said herbal medicine. There was an option to add other interventions, but none was added. The questionnaire did not include surgery.

Table 1
Knowledge of diagnosis, treatability and infectability of epilepsy.

Question	*Responses (n-50)*				
A person with epilepsy is diagnosed after how many seizures?	2 seizures 51 %	3 seizures 23 %	4 seizures 8 %	1 seizure 6 %	Don't know 12 %
Do you think epilepsy is treatable?	Yes 90 %	Sometimes 8 %	Don't know 2 %	– –	– –
Is epilepsy contagious or infectious?	No 82 %	Yes 8 %	Sometimes 8 %	Don't know 2 %	– –

Participants were asked to rate the effectiveness of medical treatment with anti-epilepsy drugs. Only 8 % thought that all (100 %) people diagnosed with epilepsy can be treated, 14 % though only 50 % of people diagnosed with epilepsy can be treated and 78 % agreed that more than 70 % of people diagnosed with epilepsy can be treated.

3.1.3. *Aetiology*

Asked to select from a list the possible causes of epilepsy, 88 % selected brain injury, 66 % selected brain infections, 52 % selected genetics and 64 % said the causes were unknown. Smaller numbers contributed it to evil spirits (6 %), God (2 %) and Satan (2 %), 6 % to lack of intelligence and none attributed it to witchcraft.

3.1.4. *Seizure description*

Asked to select what a seizure means from a list, the most selected was jerking of the body (82 %), then sudden loss of consciousness (72 %), rigidness of muscles (58 %), tongue biting (54 %), confusion (52 %, froth (48 %), sudden fall (46 %) and incontinence (40 %).

3.2. *Knowledge of social inclusion and exclusion*

Participants were asked questions about their beliefs and perceptions of people with epilepsy focusing on inclusion in society (marriage, school, training and employment) and their responses are recorded in Fig. 1.

3.3. *Practices of managing seizures*

Asked 'what do you do when a person starts having a seizure?', 44 % said they would call an ambulance, 34 % would put an object in the

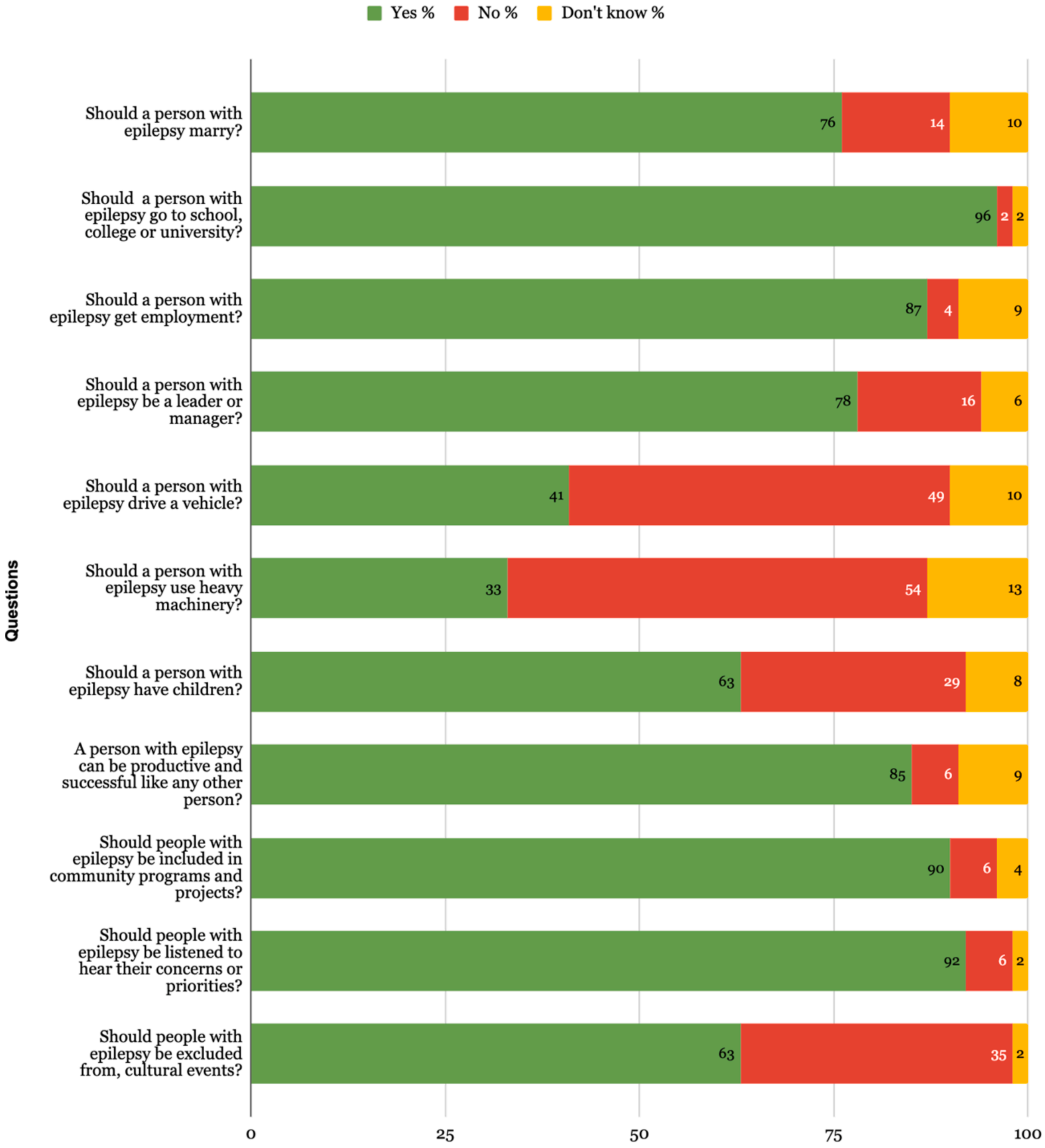

Fig. 1. Knowledge of social inclusion and exclusion (n = 50).

mouth, 28 % would give anti-seizure medicine, 24 % would not touch the person, 18 % would hold them tight, 6 % would wake them up and 4 % would pray for them. Two percent (2 %) said they would give first aid care or protect from falling. None would pour water. Asked ‘what should you do if a person has seizures that last for more than five minutes without stopping?’, 52 % said they would call an ambulance, 48 % would give emergency epilepsy medicines, 26 % would inform the family, 18 % would inform their (health worker’s) manager while 12 % would leave the person.

3.4. *Managing epilepsy: Confidence and quality*

Participants were asked their confidence with knowledge, treating, diagnosing and counselling a person with epilepsy. Responses are shown in Fig. 2.

The survey results show that confidence among healthcare workers regarding epilepsy diagnosis and treatment varies significantly. On a scale of 0 to 10, with 10 being the most confident, only 51 % were confident in the correct diagnostic criteria of two seizures, while the rest displayed varying levels of uncertainty. Similarly, while 90 % expressed confidence that epilepsy is treatable, there were still gaps, with some respondents less sure. Regarding the contagiousness of epilepsy, 82 % were confident that it is not contagious, but a notable portion showed hesitation or incorrect beliefs.

3.5. *Person-centred and African-centred care models*

Person-centred care are techniques used in the management of epilepsy that put the person with epilepsy at the centre of the intervention. Africa-centred care is a collection of practices of managing epilepsy that suit the local African environment, values, ethics of care and resources. Both person-centred and African-centred care prioritise the needs of the person with epilepsy and their family, and values resources available in their community. Used effectively, both person-centred and Africa-centred care improve treatment seeking and compliance behaviour. Fifty-eight percent (58 %) of participants said they did not understand Africa-centred care at all, while 20 % said sometimes, 9 % was average, 4 % used it most of the time while 9 % used it all the time. Those who understood Africa-centred care was said it was treatment appropriate to resource poor communities by 47 %, community inclusion in public awareness by 45 %, cost effective treatment by 23 %, considering needs and priorities of the family by 14 % while 28 % did not know. Asked about use of person-centred care, 15 % said not at all, 32 % used it sometimes, 16 % average, 14 % most of the time and 23 % all the time.

Responses about person-centred care were coded and analysed. The analysis came up with themes, with humanness as the main one, emphasizing kindness, respect, and dignity in treatment. The theme of humanness came from responses that included words like ‘kindness’, ‘good communication’, ‘follow up’, ‘promoting ‘belonging’, ‘respect’, ‘acceptance’ and ‘avoiding harm’ and statements such as ‘when we treat them with dignity and respect they can reach or achieve their goals’ and ‘treating people with sickness compassion’. Patient involvement and capacity building was another crucial theme that came out, as respondents emphasized the need for active patient participation in care decisions, supported by training and counseling. This theme was supported by statements such as ‘on the treatment of epilepsy patient also have the decision on the treatment and care’, ‘understand person’s awareness of their condition (disease)’, ‘a care center working for a client benefit’ and ‘understanding well the person give them individual well counselling’ and ‘attention to the person’. Another theme that came out was the need for quality services. This theme was supported by statements like ‘good history taking’, ‘it is beneficial for patient and it helps the patient to have good prognosis’, ‘positive health behavior’ and ‘to address the clienteles on time and decrease the problem of illness’, ‘care continuity’ and ‘to minimise risk’. However, a significant gap in understanding person-centered care exists, as some respondents lacked knowledge of the concept, as evidenced by statements such as ‘I have no idea about person centred care’ and ‘I have no understanding of person-centred care’ contributed to this theme. Despite this, the benefits of person-centered care, including improved continuity, adherence, and a supportive environment, are clearly recognized. Statements that resulted in this theme included ‘to improve knowledge gap and creates social awareness’, ‘to increase life’, ‘increase the knowledge to our patient by mean of that he can ask anything that he needs to know and understand’,

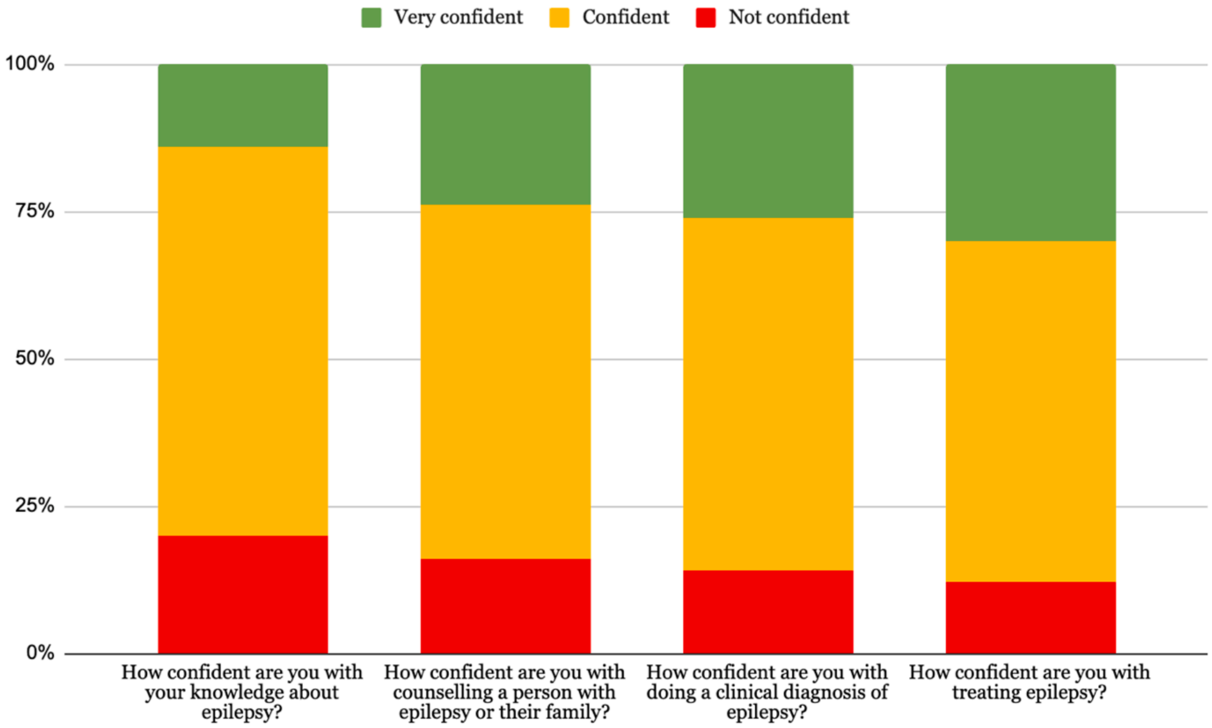

Fig. 2. Confidence with knowledge, treating, diagnosing and counselling a person with epilepsy (n = 50).

'adherence and insight', 'it provides conducive environment top deal with in-depth problem of individual and to address problem, it will for clear understanding between the care giver and the patient, it increases confidentiality' and 'the people who use our services are at the center of everything we do improve insatiably quart cost effectiveness, improvement in patient'.

3.6. Difficulties when managing epilepsy

Participants were asked to describe those things they found difficult when treating epilepsy. Forty-one (41) participants responded. The analysis of participants' responses regarding difficulties in treating epilepsy revealed several key challenges. The most frequently mentioned issue was securing medications, with participants highlighting problems such as medication shortages, high costs, and limited availability in Ethiopia. Another significant challenge identified was the attitudes, behaviors, and knowledge of patients and their families, particularly concerning cultural and spiritual beliefs and resistance to 'lifetime taking of drug'. A participant said 'The relative or family of patient is rejecting the medical treatment because they believe that this problem come from the evil spirit, curse or Satan, so that they can't accept the treatment'. Additionally, respondents pointed out poor outcomes and side effects, particularly with drug-resistant epilepsy, as well as a lack of public awareness about epilepsy. Participants said lack of awareness about epilepsy in the community resulted in patients coming for medical treatment late. They said, even when the wanted to make the community aware, they did not have the resources to do so. Poor management by healthcare workers was mentioned. Participants said some of them had 'poor knowledge of epilepsy', for example 'during the seizure some will put something on their mouth to protect from biting their tongue'. Others did not have knowledge of different types of epilepsy, drug choices, drug interactions and treatment discontinuation. Challenges stemming from hospital and clinic services were mentioned, with some participants saying their hospital was too busy while another said their hospital did not treat epilepsy.

4. Discussion

Our research about knowledge, attitudes, beliefs, and perceptions of epilepsy among health workers in Ethiopia, highlights persistent knowledge gaps. While healthcare workers play a crucial role in epilepsy management, our findings revealed that some health workers' knowledge of epilepsy, attitudes, beliefs, and perceptions were incorrect, for example, a substantial number (41 %) of participants were unsure about the number of seizures required for an epilepsy diagnosis indicating a lack of clarity in the diagnostic process. A significant number (18 %) of participants said epilepsy was contagious or sometimes contagious. Furthermore, a notable proportion of participants (10 %) were unaware or uncertain that epilepsy is treatable. This knowledge gap among trained and practising health workers is a significant concern, as early diagnosis and appropriate treatment are critical for managing epilepsy effectively. Similar knowledge gaps have been observed among healthcare workers in various parts of Africa [4,5]. The survey results align with other studies in African countries, which reported that healthcare workers across often lack a comprehensive understanding of epilepsy, negatively impacting the quality of care provided to individuals living with the condition [6–9].

The survey results indicate a lack of alignment between KAP and evidence-based practices. The belief that epilepsy is contagious or infectious, with some holding the erroneous, though not the majority view, is concerning. Such misconceptions could negatively impact the way patients with epilepsy are treated and further perpetuate social stigma. Research consistently shows that the relationship between healthcare workers' knowledge, attitudes, beliefs, and perceptions of epilepsy and the quality of epilepsy management is a well-documented subject [3]. Previous research from around the world consistently demonstrates that when health workers have a more accurate and empathetic understanding of epilepsy, the management of the condition tends to be more effective, ultimately benefiting patients [11,12].

The responses regarding the management of epilepsy revealed several challenges. This study also highlights several challenges health care workers face in the managing people with epilepsy. Patient and family behaviors, including a lack of awareness and adherence, contribute to these difficulties. However, there is a research gap in Ethiopia [18] and Africa as a whole [10], where the interplay between healthcare workers' knowledge, attitudes, beliefs, and perceptions regarding epilepsy and their subsequent management of the condition remains underexplored [20,22]. Some healthcare workers also indicated inadequacy and difficulties in managing patients with drug-resistant epilepsy and those experiencing severe side effects. These challenges can affect patient adherence and overall health outcomes. Furthermore, the survey findings revealed that some healthcare workers perceived their competence and knowledge about epilepsy management as inadequate. In some cases, poor management practices and a lack of information about specific issues were recognized as impediments to delivering effective care.

A lack of community awareness and knowledge gaps about epilepsy are evident. Several respondents noted that their communities had limited understanding of epilepsy, suggesting the need for comprehensive public awareness campaigns. On a positive note, our survey highlight the recognition of person-centered care as a critical component of epilepsy management, emphasizing kindness, good communication, and patient involvement in treatment decisions. Further, it shows an understanding of Africa-centred care as a model that matches approaches to resources available and respects the priorities of the individual and their family.

4.1. Recommendations

The results of this survey provide valuable insights into the existing gaps in understanding and management of epilepsy in Ethiopia. Based on the findings and discussion, we recommend implementing more targeted and country-specific training programs tailored for healthcare professionals. Health workers should receive ongoing training and updates on epilepsy management and care to keep their knowledge up to date. These programs should focus on improving knowledge, dispelling myths, and addressing stigma related to epilepsy and should be led by the government because it has access to resources, with support from local, regional and global organisations with expertise in epilepsy. Additionally, comprehensive public awareness campaigns about epilepsy should be conducted to dispel misconceptions and increase community understanding. Another key recommendation is the development and implementation of standardized protocols and guidelines for epilepsy management can help ensure consistent and effective care.

Efforts should be prioritized to ensure consistent and affordable access to epilepsy medications, which may necessitate addressing medication shortages and economic constraints. Related to this recommendation, it is imperative to provide patient support and counselling services to bolster adherence and overall health outcomes. Health workers should actively involve patients in their care decisions.

The findings from this survey highlight the critical importance of addressing the knowledge gap and misconceptions surrounding epilepsy among healthcare workers. Implementing these recommendations can facilitate enhancements in the quality of care and support for individuals living with epilepsy in Ethiopia. Furthermore, a deeper understanding of the relationship between knowledge, attitudes, beliefs, and perceptions and management practices can significantly augment healthcare delivery efficacy.

CRediT authorship contribution statement

Enat Yewnetu: Writing – review & editing, Supervision, Resources, Project administration, Methodology, Conceptualization. **Rugare Mugumbate:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis. **Etsegenet F. Tizazu:** Writing – review & editing, Validation, Investigation, Formal analysis. **Mehila Zebenigus:** Writing – review & editing, Visualization, Validation, Supervision, Investigation. **Kindu Woldemichael:** Writing – review & editing, Project administration, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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