



Brief Communication

Perceptions about mental healthcare for people with epilepsy in Africa

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ABSTRACT

Background: Mental illness is commonly comorbid with epilepsy. In sub-Saharan Africa there exists limited access to neurological and psychiatric services predisposing to a “treatment gap” in epilepsy and mental healthcare.

Aims: To understand healthcare providers' knowledge, attitudes, and management practices toward epilepsy and comorbid mental illness in sub-Saharan Africa.

Methods: A cross-sectional online survey following the STROBE guidance was conducted among healthcare providers in sub-Saharan Africa. Eleven questions looking to ascertain clinician demographics, knowledge of epilepsy, and comorbid mental illness as well as management practices were developed.

Findings: Of 203 responses most (92%) respondents recognized a bi-directional relationship between mental health and epilepsy. However, mental illness screening in people newly diagnosed with epilepsy was infrequently performed (14%). Only 1 in 7 (16%) respondents had high confidence in their clinical competence at managing psychiatric comorbidities. Most would value further training (74%) and improvements to be made in current management practices within their local healthcare settings (94%).

Conclusions: This pilot study highlights the need to improve the awareness of management of mental disorders in populations with epilepsy within sub-Saharan Africa in health providers there.

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1. Introduction

Mental disorders are commonly comorbid with epilepsy. In a meta-analysis of population-based studies in people with epilepsy (PWE), the pooled prevalence of anxiety and depressive disorders was 20.2% and 22.9%, respectively [1]. Yet, as reported in a systematic review of 41 publications, deficiencies exist in the psychiatric care of PWE, with estimates for unmet mental healthcare needs ranging from 2.5% to 60.5% in both low-income and high-income countries [2].

In sub-Saharan Africa there is limited access to neurological services. Data from a survey sent to representatives from 53 African

nations showed that the population/neurologist ratio in all African nations far exceeds that of the United States and other developed nations [3]. Similarly, there is a relative scarcity of mental health professionals. The WHO reported that the median number of psychiatrists per 100,000 population in low-income countries, of which most sub-Saharan nations are included, is 0.1, contrasting to 9.2 in high-income countries [4]. The limited access to both neurological and psychiatric services predispose a “treatment gap” in the psychiatric care of PWE in sub-Saharan Africa.

In a systematic review of 23 publications, it was concluded that stigma toward epilepsy is widely prevalent within sub-Saharan Africa [5], but there is a paucity of existing research addressing stigma for mental illness. Nonetheless, the emerging picture from studies conducted in Ethiopia, Nigeria, and Ghana, is that of prevailing stigmatizing attitudes [6]. ‘Double stigma’ is the impact of having two co-occurring stigmatized conditions within the same

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individual, such as epilepsy and mental illness. Ultimately this can result in reduced ability to access healthcare, discrimination, decreased adherence to treatment, poor health outcomes, and poor quality of life [7]. Increasingly, improving the mental health and quality of life of PWE is recognized as a treatment goal in its own right [8].

The views of healthcare providers about mental healthcare provision to PWE in sub-Saharan Africa has not been robustly explored to date. In this study, we sought to understand healthcare provider's knowledge, attitudes, management practices, and barriers to holistic care toward epilepsy and comorbid mental illness in sub-Saharan Africa.

2. Materials & methods

A cross-sectional survey using the STROBE guidance was conducted among healthcare providers from sub-Saharan African countries. A bespoke structured questionnaire was designed by a group of epilepsy and mental health experts (supplementary information 1).

2.1. Ethics

No formal ethics approval was needed for this project. All participants were advised at the start of the study that participation was voluntary and their replies, if they chose to participate, would be anonymized and analyzed. No participant identifier data were collected. Data were pooled prior to analysis. Further, it was to a participant group where consent was implicit by participation.

The survey was undertaken online using the google platform and set to approximately 8–10 minutes to complete. This was felt to be the optimum time to balance response engagement and gain the minimum required information to draw meaningful conclusions. The survey was available online from 19th May to 2nd June 2021. The survey consisted of questions with predetermined answers and questions that allowed for free text comments (supplementary information 1). Of the two sections the first section had four questions that looked primarily at collecting relevant professional demographic information and individual specialism and expertise. The second section had seven questions that aimed to ascertain knowledge about epilepsy and comorbid mental illness among healthcare providers in sub-Saharan Africa, as well as management practices regarding mental health assessment and treatment.

As the different participating countries have different healthcare systems, we approached known clinicians who are in a position of influence in different countries to help develop and disseminate the survey. The survey used an exponential and non-discriminatory snowballing technique. This involves commencing with key personal contacts in professional and charity organizations of the authors in different participating countries and requesting them to forward the request and link within their own professional networks.

This should be considered non-probability sampling, as it does not include complete coverage of services in the field and/or any sector. Descriptive statistical analyses were carried out using Microsoft Excel.

3. Results

3.1. Respondent demographics (see Table 1)

The survey received responses from a total of 203 healthcare professionals in African countries. The initial survey had been sent to 54 people in different sub-Saharan countries known to the

authors as outlined the methodology. A request to the 54 to further disseminate it in their local networks was made resulting in the 203 replies. It is expected they circulated the link further as encouraged. Three countries, Gambia ($n = 58$), Nigeria ($n = 45$), and Cameroon ($n = 27$), made up 64% of all respondents. The sample consisted predominantly of nurses ($n = 72$) and doctors ($n = 95$) who are mainly based in an urban setting and have been working in their role for less than five years.

3.2. Survey results (see Table 2)

Up to 92% of the respondents recognize a bi-directional relationship between mental health and epilepsy. However, screening for mental illness (14%) or provision of education on the risk of developing mental illness (12%) in newly diagnosed PWE is infrequently performed. Similarly, screening at check-ups or review clinics is rarely never performed by approximately half of the respondents (49%).

Nearly three of four respondents (74%) had confidence in their clinical competence at managing psychiatric comorbidities in PWE within their local healthcare settings. Six people of the seven of the study sample responded that they would value further training (84%). Almost all respondents are in favor for improvements to be made in current management practices within their local healthcare settings (94%).

Respondents indicated that the mainstay of treatment for comorbid mental illness in PWE is pharmacological (91%), whereas the remaining minority responded that local community support (6%), patient referral (3%), or religious interventions (1%) are the primary management options available.

The five major themes, identified as challenges to the management of mental health in PWE (up to three themes could be selected of 13 options) were; a lack of confidence in how to assess for mental illness ($n = 104$); people not seeking relevant care from medical doctors – but rather traditional or spiritual sources ($n = 93$); lack of awareness of the heightened risk of mental illness in PWE ($n = 91$); limited access to psychological services ($n = 63$);

Table 1
Respondent demographics.

Answer Given	Number of Respondents (n)	%
Question 1: In which country do you work?		
Kenya	12	5.9
Sierra Leone	16	7.9
The Gambia	58	28.6
Nigeria	45	22.2
Eswatini	12	5.9
Cameroon	27	13.3
Zambia	19	9.4
Uganda	5	2.5
Liberia	3	1.5
Other	6	3
Question 2: What is your role?		
Nurse	72	35.5
Non-neurology doctor	88	43.3
Neurologist	5	2.5
Pharmacist	15	7.4
General practitioner	2	1.0
Midwife	2	1.0
Other	19	9.4
Question 3: What is the main setting for your work?		
Urban / City	116	57.1
Rural	41	20.2
Both urban and rural	46	22.7
Question 4: For how many years have you worked in your field?		
0–5 years	107	52.7
5–10 years	40	19.7
10+	56	27.6

Table 2

Results from our survey addressing understanding of epilepsy with comorbid psychiatric conditions, routine practices regarding mental health education/screening, and perspectives of current management in populations with epilepsy.

Survey Response	Number of Respondents (n)	%
Question 1: Do you think epilepsy is associated with mental illness?		
Yes, strongly associated	62	31.0
Yes, some association	99	49.5
Rarely associated	23	11.5
No association between epilepsy and mental illness	16	8.0
Question 2: Do newly diagnosed people with epilepsy get provided with education (information leaflets/verbal communication) on the risk of developing mental illness?		
Yes, nearly all	25	12.4
Sometimes	78	38.8
Rarely	63	31.3
No	35	17.4
Question 3: Is screening for mental illness performed at diagnosis, check-ups or review clinics of people with a previous diagnosis of epilepsy?		
Yes, nearly always	29	14.4
Sometimes	73	36.3
Rarely	82	40.8
Never	17	8.5
Question 4: Are you confident that you have sufficient knowledge and training to be able to recognize, diagnose and/or refer mental illness in your patients with epilepsy?		
I am highly confident	33	16.4
I am confident but would value further training	116	57.7
I am not confident and would value further training	52	25.8
Question 5: If mental illness was to be identified in a patient who has epilepsy, what treatment would be available?		
Medication	182	90.5
Local community support	11	5.5
Referral	6	3.0
Religious interventions	2	1.0
Question 6: How well do you feel mental illness are managed in patients with epilepsy within your local healthcare setting?		
Very well managed	13	6.5
Well managed but areas for improvements in terms of diagnosis and treatment	59	29.5
Suboptimal management and needs improved	82	41.0
Poorly managed and needs improved significantly	42	21.0
No management of mental illness	4	2.0
Question 7: What is the main challenge to the management of mental health in people with epilepsy within your local healthcare setting? Select up to 3 major relevant reasons		
Lack of training or confidence in how to assess a patient for mental illness	104	
Patients seek treatment for mental illness not from medical doctors, but from others such as faith healers, religious organizations, or witch doctors.	93	
Unaware that there is a heightened risk of mental illness in patients with epilepsy	91	
Limited or no access to psychological services for mental illness	63	
Traditional beliefs that may result in discrimination of patients diagnosed with mental illness	62	
Patients do not want to be diagnosed with a mental illness due to the associated social or cultural stigma	55	
Not enough money / funding for mental health assessment	55	
Aware of a heightened risk of mental illness in patients with epilepsy but it's not my routine practice to perform screening / assessments for them	49	
Patients can't afford the medication / psychological treatment for their mental illness	37	
Not enough time to make an assessment or referral	28	
No one appropriate to refer mentally ill patients to	13	

and patient barriers such as traditional beliefs that may result in discrimination of patients diagnosed with mental illness (n = 62).

4. Discussion

Although international guidelines support screening for mental health problems in PWE [9], the reality of application of this guidance in low- or middle-income is not well known. This study has identified that healthcare providers in sub-Saharan Africa report a lack of awareness, training, and confidence in mental healthcare provision to PWE. This is unsurprising given prior reports by the WHO that over 75% of mental illnesses remain untreated in low-middle-income countries [10]. Similarly, the WHO published that approximately 40% of African countries have no allocated budget for mental health and more than 20% do not have appropriate mental health legislation in place, despite the significant disease burden [11]. The WHO found that psychiatric comorbidities in PWE are associated with poorer health outcomes, greater healthcare needs, reduced quality of life, and higher rates of social exclusion [3]. Ideally, healthcare providers should be familiar with the high rate of psychopathology and should be able to identify mental health needs in PWE [2].

An interesting observation has been that nearly three of four of our respondents expressed confidence in their abilities to manage psychiatric conditions in epilepsy. The possibility of that this confidence is misplaced needs considering especially given that the rest of the results i.e., need for training and resources suggest otherwise. While literature is scant on this matter a recent ILAE task force global survey mainly emerging from economically developed countries has provided much more conservative estimates [13]. Further, other studies in the same region though not focused on the same issues have highlighted significant lack of ability of recognizing core mental health concerns in clinicians working in this field [14,15].

Other challenges generally exist to improve care and understanding on this subject. There is little specific detail on the total number of clinical staff this this region other than knowing it is really very low compared globally. A systematic analysis conducted on 195 countries to evaluate performance on access to and quality of healthcare, including epilepsy, showed that sub-Saharan countries scored at the bottom of the list [16]. As an example, western developed countries have 4.75 neurologists/100,000 while in sub-Saharan Africa this drops to 1 every 3–5 million [17]. Further, estimating available professionals is highly challenging as many trained in the sub-Saharan Africa migrate to more developed economies. An example is the USA where over 7000 physicians were from sub-Saharan Africa including 1.2% (86/6888) were neurologists [18].

There is a pressing need to invest in relevant training to improve health, social, quality of life and economic outcomes in sub-Saharan Africa [19].

The COVID-19 pandemic has showcased how increased use of tele-education offers promising opportunities to enhance quality neurology education for healthcare providers in low-middle-income countries where local or regional healthcare systems are unable to meet the educational needs due to a lack of workforce, or indeed complete absence of workforce in certain regions, and a critical lack of investment/resources [12,20]. One practical recommendation from this study is to call for further provision of accessible training to practicing healthcare providers in different sub-Saharan African countries by way of planned, online medical education programs detailing optimal multidisciplinary care of

comorbid mental illness in PWE. The lack of research on individual characteristics and culture is a current barrier. Local educational needs and culture and resources must be considered in the development of culturally appropriate training. PWE should also participate in the design of curricula as this could add new dimensions, which may not be considered by those providing training from other regions of the world. Another area for future research in the same landscape is the attitudes and clinical approaches toward functional neurological conditions particularly psychogenic nonepileptic seizures. The overlap of psychogenic seizures and mental health in sub-Saharan countries is a under explored subject. Similarly, the engagement with special populations such as intellectual disability is a significant source of interest. Future studies could consider these topics to advance our understanding of the situation better.

Our study has some important limitations. The survey was a pilot survey to inform medical education and formal validation was not employed. It had face validity in that key clinical opinion leaders from the different countries contributed to its development. This has been added to the limitation section.

A significant limitation was the response rate to the survey. It was sent to 54 key individuals across 10 countries with the expectation that it would be forwarded through local professional networks to more contacts who then further cascade it (exponential snowballing technique). The returns from such processes were low when it is considered that 10 countries were involved. We can only speculate on some shortcomings in our work which might have contributed to the reduced returns. Principal concern would be that the survey was in English as it was presumed professionals would have a good working knowledge of English. Many of the sub-Saharan countries have French or German or other languages. This could have negatively influenced engagement with the survey. Secondly, this was an internet-based survey. It could be that access to internet is limited in some of the participating countries and even when available is rationed. Given the lack of institutional email addresses the cascading would have possibly been largely to private email boxes. It might be that they were treated suspiciously as spam. Future such surveys in groups of countries like the sub-Saharan region might benefit from linking in with a local stakeholder organization in each participating country who can advise on the language, implementation strategy and approach.

The strength of the survey rests on the novel data on healthcare providers' perspectives of psychiatric illness management in PWE in sub-Saharan Africa, and the demonstration of several key barriers in the management of mental illness. Our hope for our current research study is to catalyze further assessment of country-specific training and treatment disparities in greater depth to inform more refined education program development, tailored to local needs.

5. Conclusion

While it is recognized that undertreatment of mental illness in PWE occurs both in low- and high-income countries, this pilot study of healthcare providers' perspectives highlights a requirement to improve the awareness and management of mental health in PWE in healthcare providers.

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Conflicts of interest/competing interests

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Availability of data and material

The data that support the findings of this study is available from the corresponding author.

Author's contributions

All substantially contributed to the design, analysis, interpretation of the work, drafting and preparation of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work. All authors meet all four ICMJE criteria for authorship.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2021.108504>.

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