Peninsula Medical School
Faculty of Health

2024-09-20

A cross-sectional study of healthcare provider perceptions of the management of epilepsy in pregnancy in sub-Saharan Africa

Rohit Shankar *UoP RU - Centre for Health Technology*

Let us know how access to this document benefits you

This work is licensed under a Creative Commons Attribution 4.0 International License.
General rights
All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.
Take down policy
If you believe that this document breaches copyright please contact the library providing details, and we will remove access to the work immediately and investigate your claim.
Follow this and additional works at: https://pearl.plymouth.ac.uk/pms-research

Recommended Citation

Shankar, R. (2024) 'A cross-sectional study of healthcare provider perceptions of the management of epilepsy in pregnancy in sub-Saharan Africa', *Epilepsy and Behavior*, 161. Available at: https://doi.org/10.1016/j.yebeh.2024.110048

This Article is brought to you for free and open access by the Faculty of Health at PEARL. It has been accepted for inclusion in Peninsula Medical School by an authorized administrator of PEARL. For more information, please contact openresearch@plymouth.ac.uk.

UNIVERSITY OF PLYMOUTH

PEARL

A cross-sectional study of healthcare provider perceptions of the management of epilepsy in pregnancy in sub-Saharan Africa

Shankar, Rohit

Published in:
Epilepsy and Behavior

DOI:
10.1016/j.yebeh.2024.110048

Publication date:
2024

Document version:
Publisher's PDF, also known as Version of record

Link:
Link to publication in PEARL

Citation for published version (APA):
Shankar, R. (2024). A cross-sectional study of healthcare provider perceptions of the management of epilepsy in pregnancy in sub-Saharan Africa. *Epilepsy and Behavior*, *161*, Article 110048. https://doi.org/10.1016/j.yebeh.2024.110048

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Wherever possible please cite the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content
should be sought from the publisher or author.

Download date: 28. Oct. 2024

Epilepsy & Behavior 161 (2024) 110048

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

A cross-sectional study of healthcare provider perceptions of the management of epilepsy in pregnancy in sub-Saharan Africa

Hannah Kerr [a], Michael Kinney [a,b], Tolu Olaniyan [c,d], Olanrewaju Alani Salako [e], Virginia George [f], Benard Engoru [g], Mary Mbukebam [h], Millie Kumwenda [i], Margaret Sipilon [j], Edward Shabangu [k], Thomas Karway [l], Rohit Shankar [m,n,*]

[a] Queen's University Belfast, School of Medicine, Dentistry and Biomedical Science, Belfast, UK
[b] Belfast Health and Social Care Trust, UK
[c] Pretola Global Health Consulting Limited, Isle of Wight, UK
[d] Medical Assistance Sierra Leone (MASL), Sierra Leone
[e] Department of Pharmacology, Therapeutics and Toxicology, University of Lagos, Nigeria
[f] Lumley Government Hospital, Sierra Leone
[g] Cure Childrens Hospital, Uganda
[h] Nkwen Baptist Hospital, Bamenda, Cameroon
[i] Queen Elizabeth Central Hospital, Malawi
[j] Kajiado County Referral Hospital, Kenya
[k] Mbabane Government Hospital, Eswatini
[l] Safe Haven Community Health Service, Liberia
[m] University of Plymouth, Peninsula School of Medicine, Truro, UK
[n] Cornwall Partnership NHS Foundation Trust, Truro, UK

ARTICLE INFO

Keywords:
Pregnancy
Treatment gap
Low income
Maternal mortality

ABSTRACT

Background: Epilepsy prevalence in sub-Saharan Africa is high with a significant treatment gap. In this context, epilepsy presents substantial challenges to effective and safe reproductive and maternal healthcare. To improve this, it is important to understand the views and perceptions of healthcare professionals delivering epilepsy care to this population.

Methods: This study uses an online questionnaire which asked healthcare professionals (both from nursing and medical backgrounds) who work in sub-Saharan African countries to rate a set of pre-established options designed with the feedback of a local focus group of epilepsy experts from countries targeted. The questionnaire consisted of 21 questions and was a mix of multiple choice and Likert scale questions on managing reproductive health in women in local settings.

Results: Of 203 healthcare professionals respondents from over 10 countries majority were doctors (48%) or nurses (36%). The Gambia (28.6%), Nigeria (22.2%), Cameroon (13.3%) and Zambia (9.4%) accounted for nearly three-quarters of respondents. Over half (54%) felt that they have the necessary training to counsel women with epilepsy on reproductive health and pregnancy. Only 40% reported they regularly discuss family planning. Carbamazepine was reported to be the most used anti-seizure medication (ASM) for childbearing age women. Key challenges outlined were epilepsy awareness among patients and their families, information deficit on ASMs and pregnancy and access to a sufficient range of ASMs.

Conclusion: Understanding the challenges faced by health professionals in sub-Sharan Africa, provides better comprehension of the specific "treatment-education gap" in counselling women with epilepsy on ASM risks and benefits.

* Corresponding author at: FRCPsych, Cornwall Intellectual Disability Equitable Research (CIDER), Threemilestone Industrial Estate, Truro TR 4 9LD, UK.
E-mail address: rohit.shankar@plymouth.ac.uk (R. Shankar).

https://doi.org/10.1016/j.yebeh.2024.110048
Received 26 August 2024; Received in revised form 4 September 2024; Accepted 6 September 2024
Available online 20 September 2024
1525-5050/© 2024 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).

1. Introduction

The global health burden of epilepsy disproportionately affects low- and middle-income countries, with around 80 % of cases occurring in these regions [1]. In sub-Saharan Africa, the prevalence of epilepsy is estimated to be 14.2 per 1000 [2], in comparison to 5.8 per 1000 in developed countries [3]. Despite this high prevalence, there remains a significant treatment gap, defined by the ILAE as "The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage" [4]. It is estimated that around 70 % of people with epilepsy in sub-Saharan Africa do not receive adequate treatment [1].

Epilepsy is a common condition affecting women of reproductive age in Africa given the high prevalence in young adults [5]. Managing epilepsy in women presents significant challenges [1]. Many anti-seizure medications (ASMs) have been linked to adverse effects on the developing foetus [5]. Seizures during pregnancy are associated with poorer outcomes for both mother and infant [6,7]. This includes preterm labour, miscarriage and low birth weight [7]. Certain ASMs, such as carbamazepine and phenytoin, have also been associated with hormonal contraception failure predisposing to unplanned pregnancies [8].. Documented research on the maternal and reproductive health of women with epilepsy in the US and Europe suggest generally poorer outcomes compared to women without epilepsy, with increased risk of hypertensive disorders, pre- and post-partum haemorrhage, miscarriage, and preterm birth [9]. In addition, there is concerns of some ASMs and teratogenicity risk [10]. There is documented increased mortality rate in pregnancy also for women with epilepsy, mostly related to SUDEP risk [10]. Even in developed countries there is a gap in information, education and prompt review when a woman with epilepsy seeks to become pregnant [11]. It is well recognised that treatment plans for women with epilepsy must therefore consider the implications on reproductive health in addition to achieving maximum seizure control [11].

Women with epilepsy living in sub-Saharan Africa face additional difficulties. A lack of neurologists or epilepsy professionals in the region means that diagnostic capacity is reduced, and most women do not have access to specialised care. In 2007, there were an estimated 0.3 neurologists per million people in sub-Saharan Africa, with 11 countries having no qualified neurologists [12]. In comparison, the United States at that time had one neurologist for every 29,200 people [12]. Stigma surrounding epilepsy is also common in sub-Saharan Africa, placing significant psychosocial burden on women with epilepsy [13].

Unlike the economically developed countries there is a lack of data on outcomes for women with epilepsy in sub-Saharan Africa including the knowledge and awareness of key health stakeholders involved in the provision of epilepsy. This study aimed to examine the perceptions and standard practices of healthcare professionals caring for women with epilepsy in sub-Saharan Africa and identify what they believe to be the main challenges affecting this patient group.

2. Methods

2.1. Study design

STROBE guidance for cross sectional studies was adhered to (supplementary information 1) [14]. A questionnaire (supplementary information 2) was developed by an expert group of specialists in epilepsy care, with representative expertise from professionals with knowledge of low- and middle-income countries healthcare systems. The initial questionnaire was designed after a virtual meeting, and all experts agreed to its final content.

The survey was developed on the Google Forms platform with time of completion set to approximately 10 min and was online from 19/5/2021 to 2/6/2021. This was thought to be the optimum time frame to achieve a balance between response engagement and obtaining the minimum information required for drawing meaningful conclusions. The survey consisted of 14 questions aimed at accumulating relevant professional demographic information, individual expertise and perceptions related to the management of reproductive and maternal health in women with epilepsy and the challenges this poses in the low- and middle-income setting. The survey was promoted in a teaching event earlier to when the subject topic was raised in a series of online teaching events and closed prior the topic was discussed. Therefore, we regard this as more of reflection of the baseline of knowledge. Behavioural motivation for participation was not assessed in the questionnaire.

2.2. Study participants

It was offered to the delegates from sub-Saharan African countries attending a popular virtual one-day epilepsy training course for clinicians working with people with epilepsy. The course is a epilepsy teaching course across African nations which is free to attend and participants enrol for a series of weekly teaching sessions led by international experts in the field. Attendance at the first course resulted in the email dissemination of the survey online link, with subsequent dissemination though local experts to their professional networks.

The survey used an exponential and non-discriminatory snowballing technique to recruit participants. Key individuals acted to disseminate the questionnaire in their professional capacity within their profession spheres of influence to their local networks. This should be deemed as non-probability sampling. Microsoft Excel was used to carry out descriptive statistical analyses.

2.3. Ethics and governance

No formal ethics were required for this project. All course attendees were invited to complete the questionnaire. Participants were informed before completing the survey that participation was voluntary, and if deciding to participate, their responses would remain anonymous and be analysed. Participant identifier data was not collected. Consent to the survey completion was implicit by participation and data was pooled prior to analysis. Intention to disseminate by publication and the anonymising of all data was stated at the start of the questionnaire.

3. Results

Two-hundred and three healthcare providers from sub-Saharan Africa regions responded to the survey. Table 1 displays relevant demographic findings of respondents from across the nine countries with the most frequent responses. Sixty-four per cent of replies were from The Gambia, Nigeria and Cameroon. Most responses (97.5 %) were from non-neurology doctors and nurses, with 2.5 % of responses from neurologists. Broadly 48 % were doctors, 36 % were nurses, the rest being other professions such as midwives, pharmacists etc.

Only 20 % of respondents worked exclusively in a rural setting, and just over half (53 %) were in the first five years of their clinical career and 28 % had 10 years and beyond of clinical practice.

Table 2 provides the responses of the respondents to the particular questions asked about epilepsy and maternal health.

Of all participants 40 % reported that they always or often discuss family planning and contraception with females with epilepsy. Reproductive issues influenced ASM choice for 60.6 % of practitioners, with the most used being carbamazepine (37 %), then phenobarbital (10 %) and levetiracetam (9 %).

Just over half (54 %) of participants self-reported that they have the necessary training to counsel women with epilepsy on reproductive health and pregnancy, with 47 % stating they "always" or "often" have access to a multi-disciplinary team to discuss their decisions as needed. A majority of participants (75 %) report that they have intravenous magnesium available for the treatment of eclamptic seizure.

Table 1
Relevant Participant Demographic Information.

Question	Number of Respondents	Percentage
Country of Practice		
The Gambia	58	28.6
Nigeria	45	22.2
Cameroon	27	13.3
Zambia	19	9.4
Sierra Leone	16	7.9
Kenya	12	5.9
Eswatini	12	5.9
Uganda	5	2.5
Liberia	3	1.5
Other	6	3
Profession		
Doctor (Non-Neurology)	92	45.4
Doctor (Neurology)	5	2.5
Nurse	73	36
Midwife	2	1
Pharmacist	15	7.4
Clinical Officer	5	2.5
Other	11	5.2
Work Setting		
Urban/City	116	57.1
Rural	41	20.2
Both urban and rural	46	22.7
Years in Practice		
0–5	107	52.7
5–10	40	19.7
10+	56	27.6

Over half (n = 108, 53 %) stated that the main challenge was a poor understanding among women with epilepsy and their families of management and risk. Other key issues included a lack of information on the effects of ASMs on the foetus (n = 101,50 %) and the lack of access to a wider range of ASMs (n = 99, 49 %). Other concerns include stigma associated with epilepsy (n = 54, 45 %), access to pre-conceptual counselling (n = 81, 40 %), affordability of epilepsy medication (n = 76, 37 %), fear of causing harm to the baby from epilepsy medication (n = 54, 27 %) and inadequate knowledge among healthcare professionals on management of female patients with epilepsy (n = 49, 24 %).

On learning of a pregnancy in a woman with epilepsy, nearly a fifth (n = 37, 18 %) stated they would advise stopping ASMs. Similar numbers (20 %) advise not to breastfeed when the mother is using ASMs. Rates of reported post-partum follow-up were low, with nearly a third of participants (n = 63, 31 %) stating that women with epilepsy were rarely or never followed up.

4. Discussion

This advocacy survey of clinical professionals in sub-Saharan Africa has identified three main barriers in the care of pregnant women with epilepsy. These include patient/family ignorance of epilepsy related safety considerations during pregnancy, a lack of information about the effects of ASMs on the foetus, and a lack of sufficient ASM options to prescribe medications considered safer from a teratogenic perspective. Interlinked to these, stigma associated with epilepsy was a major issue identified as impacting maternal health.

4.1. Ignorance of pregnancy related factors

The surveyed professionals identified that within their own communities there was a lack of awareness of the issues associated with epilepsy. The recent intersectoral report from the ILAE/WHO recommends the importance of healthcare systems considering neurological conditions across the lifespan including during pregnancy [15]. Important issues from an epilepsy perspective have recently been highlighted in a review focused on woman with epilepsy from sub-Saharan Africa to include advice on contraception, the teratogenic potential of certain

Table 2
Participant Responses to Questions Related to Management of Reproductive Health in Women with Epilepsy.

Question	Number of Respondents	Percentage
How often do you discuss family plans and contraception when caring for female patients with epilepsy?		
Always	44	21.7
Often	37	18.2
Sometimes	53	26.1
Rarely	42	20.7
Never	24	11.8
Unsure	3	1.5
Do you consider future family plans when deciding which anti-seizure medication to prescribe?		
Yes	123	60.6
Sometimes	35	17.2
No	41	20.2
Unsure	4	2.0
What is your preferred first-line anti-seizure medication for female patients of child-bearing years with epilepsy?		
Carbamazepine	75	36.9
Phenobarbital	20	9.9
Levetiracetam	19	9.4
Lamotrigine	14	6.9
Sodium Valproate	12	5.9
Phenytoin	5	2.5
Diazepam	2	1
Gabapentin	1	0.5
Other	13	6.4
Unsure/Did not Answer	46	22.7
Would you ever stop anti-seizure medication if a female patient became pregnant?		
Yes	37	18.2
No	163	80.3
Unsure	3	1.5
Are you able to confer with a multi-disciplinary team when making decisions on epilepsy care for women who are pregnant or planning to become pregnant?		
Always	55	27.1
Often	41	20.2
Sometimes	59	29.1
Rarely	30	14.8
Never	11	5.4
Unsure	7	3.4
When counselling female patients with epilepsy, do you feel you have the necessary training and information to discuss issues surrounding maternal health? (e.g. contraception, impact of epilepsy medication on the baby, risk of seizures during pregnancy)		
Yes	109	53.7
No	89	43.8
Unsure	5	2.5
Do you have access to intravenous magnesium for the treatment of eclamptic seizures in pregnancy?		
Yes	152	74.9
No	44	21.7
Unsure	7	3.4
Do you or other healthcare professionals in your practice regularly follow up with new mothers with epilepsy after they have given birth?		
Always	39	19.2
Often	37	18.2
Sometimes	59	29.1
Rarely	41	20.2
Never	22	10.8
Unsure	5	2.5
Is breastfeeding advised for new mothers who are on anti-seizure medication in your practice?		
Yes	156	76.8 %
No	41	20.2 %
Unsure	6	3 %
In your opinion, what are the 3 most significant challenges surrounding maternal health in women with epilepsy? (Please select up to 3 options)		
Poor understanding of epilepsy among patients and their families	108	53.2 %
Lack of information on the effects of epilepsy medication on the foetus	101	49.8 %
Access to a sufficient range of epilepsy medication	99	48.8 %

(*continued on next page*)

Table 2 (*continued*)

Question	Number of Respondents	Percentage
Stigma associated with epilepsy	92	45.3 %
Access to pre-conceptual counselling	81	39.9 %
Affordability of epilepsy medication for the patient	76	37.4 %
Fear of causing harm to the baby when prescribing epilepsy medication	54	26.6 %
Inability to discuss decisions with a multi-disciplinary team	49	24.1 %
Inadequate knowledge among healthcare professionals on management of female patients with epilepsy	1	0.5 %

medications, the risks of seizures during pregnancy and the importance of adherence to treatment [1].

While our study did not explore the reasons for the lack of dissemination of good quality clinical information it highlighted that over 40 % of clinical professionals are not facilitating this due to lack of training or confidence. This is similar to the experiences of reports from childbearing age women with epilepsy in other low-income countries informing on whether they received information or not [16,17].

4.2. Effects of ASMs on the foetus and access to prescribing options

None of the international epilepsy pregnancy registers have recruited from sub-Saharan Africa regions. Data on the major malformation rates of drugs commonly used in sub-Saharan Africa regions is from international studies outside sub-Saharan Africa.

Carbamazepine was the most frequently used ASM by women with epilepsy in our study. Approximately 4–5 % of offspring exposed to carbamazepine in-utero develop major congenital malformations (MCM) compared to 2–3 % among the general population from studies in higher income settings [18]. Phenobarbital was the second most commonly ASM used in our study. Phenobarbital has an MCM rate of 6–7 % after in-utero exposure [18].

Some of the newer ASMs carry comparatively lower risk of MCMs and are generally more tolerable than some of the first generation ASMs [19]. Lamotrigine in particular carries an MCM risk of 2.9 %, comparable to the general population [20]. Unfortunately, newer ASMs are not easily accessible in sub-Saharan Africa [1]. Cost is an important variable and lamotrigine in particular has been identified as being unaffordable [1].

Surveyed healthcare workers felt that they do not have access to a sufficient range of ASMs to allow flexibility in prescribing to accommodate concerns about future malformation risk. Clinicians did not cite their own knowledge as being a barrier.

4.3. Stigma

Poor understanding of epilepsy among patients and their families in sub-Saharan Africa was reported as a significant challenge clinicians face when treating women with epilepsy. Several commonly held misconceptions have been regularly reported in literature, including contagious aetiology and links to witchcraft [21]. These myths lead to significant societal stigma. People with epilepsy in sub-Saharan Africa experience greater difficulties finding employment and educational opportunities compared to peers without epilepsy [21]. Women with epilepsy have fewer years of formal education and experience higher rates of being unmarried or divorced compared to controls with other chronic health conditions. [22]. As epilepsy is classed along with mental illness there is significant double stigma [23,24]. Stigma felt by people with epilepsy in sub-Saharan Africa results in poorer adherence to treatment which is especially important to ensuring good epilepsy control during pregnancy [25].

4.4. Other important public health findings

Magnesium sulphate is listed by the WHO as one of the essential medications which clinicians should have access to [26]. Eclampsia accounts for over 50,000 deaths per year, being more common in developing countries [27]. Hypertensive complications are more common during pregnancy in women with epilepsy [28], so improving access to magnesium to treat these conditions is a necessary step to improving maternal health. The finding that over a fifth of our respondents informed their services did not have access to this life saving drug is an issue of major concern.

Nearly a third of respondents informed that women with epilepsy were not followed up post-partum after child birth, which raises several issues. Women may not have necessary safety advice reiterated, putting them and their child at greater risk of injury [1]. A study of women with active epilepsy found that 32 % of new mothers who had not been provided with appropriate safety advice were involved in serious incidents with their babies, including two near-drownings and six dropped children [29]. In comparison, safety incidents occurred in only 1.6 % of women who received appropriate counselling [29]. Furthermore, research in developed countries has noted that women with epilepsy are at increased risk of perinatal depression and anxiety, particularly in the first 12 weeks post-partum in comparison to women without epilepsy, and so may need additional mental health support [30]. No corresponding data on rates of postpartum mental health conditions has been reported for women in low-income settings but it is reasonable to expect given the significant psycho-social stress similar if not more mental health impact might be an issue. Regular follow-up in the post-partum period can help identify these issues earlier and allow women to access help if needed, as well as promote other initiatives like breast feeding.

Breastfeeding is recommended for most women using ASMs [31]. However, a fifth of respondents reported that breastfeeding is not advised in their practice. Unfortunately, reasons for this were not explored. It may include legitimate concerns about the impact of older medications such as phenobarbital which can render infants drowsier. Provided that there is appropriate monitoring for side effects, most ASMs have been found safe or moderately safe to use while breastfeeding [32,33];.

4.5. Strengths and limitations

The strengths of this study are that it is one of the first attempts to seek clarification around healthcare professionals' opinions on healthcare for childbearing age women with epilepsy in sub-Saharan Africa. The study has considerable limitations. The virtual epilepsy training was offered only in the English language. There was no formal validation for this survey though it was developed by experts from Sub-Saharan Africa. While participants were conversant in English to participate in the course, English skills may have impacted the understanding of aspects of the questionnaire. We sought to minimise this by developing the questionnaire with local experts in the different regions. The study was reliant on self-reporting. The results were from different African countries, however participant numbers from some countries were small. This could potentially skew the results. Almost half of the replies came from The Gambia and Nigeria and the rest of the participating countries had much smaller representation, so it was felt that between state comparisons wouldn't be appropriate from a statistical perspective. Although the sample obtained is large it may not be representative enough to allow robust subgroup analysis. In addition, the uncertain nature of the total number of people the survey was sent to prevents a response rate and, an inability of characterising the non-responders. Whilst examining the views of clinicians is beneficial, obtaining the views of patients, families and carers would be doubly so. The reason for the choice of ASMs was not explored in order to keep the questionnaire short and ensure increased participation. A further study on it would be

helpful.

5. Conclusion

This survey looks to help raise awareness of the concerns of epilepsy in women in sub-Saharan Africa, to advocate for better educational materials and to stimulate discussion on this topic further.

Areas for improvement in the treatment of women with epilepsy in sub-Saharan Africa include more extensive pre-conceptual counselling, improving access to intravenous magnesium, regular post-partum follow-up of women with epilepsy and encouragement of breastfeeding. Attaining these requires investment in healthcare resources. However, online training could offer a valid alternative to achieve some of these by disseminating knowledge to healthcare professionals.

RS has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities all outside this work. No other author has any declared conflict of interest related to this paper.

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.

CRediT authorship contribution statement

Hannah Kerr: Writing – original draft, Investigation, Formal analysis. **Michael Kinney:** Writing – review & editing, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Tolu Olaniyan:** Writing – review & editing, Project administration, Methodology, Conceptualization. **Olanrewaju Alani Salako:** Writing – review & editing, Resources, Project administration, Data curation. **Virginia George:** Writing – review & editing, Resources, Project administration, Data curation. **Benard Engoru:** Writing – review & editing, Resources, Project administration, Data curation. **Mary Mbukebam:** Writing – review & editing, Resources, Project administration, Data curation. **Millie Kumwenda:** Writing – review & editing, Resources, Project administration, Data curation. **Margaret Sipilon:** Writing – review & editing, Resources, Project administration, Data curation. **Edward Shabangu:** Writing – review & editing, Resources, Project administration, Data curation. **Thomas Karway:** Writing – review & editing, Resources, Project administration, Data curation. **Rohit Shankar:** Writing – review & editing, Visualization, Validation, Supervision, Project administration, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: [Tolu Olaniyan is the CEO of Pretola Global Health & Consulting Ltd (GHC) which runs commercial awareness courses on epilepsy and mental health matters. MK has received honoraria to provide talks to peer audiences and for conference travel from UCB, Eisai and Angelini Pharma].

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2024.110048.

References

[1] Menon S, Siewe Fodjo JN, Weckhuysen S, Bhwana D, Njamnshi AK, Dekker M, et al. Women with epilepsy in sub–Saharan Africa: A review of the reproductive health challenges and perspectives for management. Vol. 71, Seizure. W.B. Saunders Ltd; 2019. p. 312–7.

[2] Ba-Diop A, Marin B. Epidemiology, causes, and treatment of epilepsy in sub-Saharan Africa [Internet]. Vol. 13. 2014. Available from: http://www.thelancet.com/neurology.

[3] Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: A meta-analytic approach. Epilepsia 2010 May;51(5):883–90.

[4] World Health Organisation. Epilepsy in the WHO african region: bridging the gap. Geneva; 2004.

[5] Stephen LJ, Harden C, Tomson T, Brodie MJ. Management of epilepsy in women. Vol. 18, The Lancet Neurology. Lancet Publishing Group; 2019. p. 481–91.

[6] Sveberg L, Svalheim S, Taubøll E. The impact of seizures on pregnancy and delivery. Seizure 2015 May;28:35–8.

[7] Hart LA, Sibai BM. Seizures in pregnancy: Epilepsy, eclampsia, and stroke. Semin Perinatol 2013 Aug;37(4):207–24.

[8] Brodie MJ, Mintzer S, Pack AM, Gidal BE, Vecht CJ, Schmidt D. Enzyme induction with antiepileptic drugs: Cause for concern? Epilepsia 2013 Jan;54(1):11–27.

[9] Viale L, Allotey J, Cheong-See F, Arroyo-Manzano D, McCorry D, Bagary M, et al. Epilepsy in pregnancy and reproductive outcomes: A systematic review and meta-analysis. Lancet 2015 Nov 7;386(10006):1845–52.

[10] Angus-Leppan H, Arkell R, Watkins L, Heaney D, Cooper P, Shankar R. New valproate regulations, informed choice and seizure risk. J Neurol 2024;271(8):5671–86. https://doi.org/10.1007/s00415-024-12436-8.

[11] Zhou SM, McLean B, Roberts E, Baines R, Hannon P, Ashby S, et al. Analysing patient-generated data to understand behaviours and characteristics of women with epilepsy of childbearing years: A prospective cohort study. Seizure 2023;108:24–32. https://doi.org/10.1016/j.seizure.2023.04.008.

[12] Owolabi MO, Bower JH. Mapping Africa's Way Into Prominence in the Field of Neurology [Internet]. Vol. 64, Dr Bower). (REPRINTED) ARCH NEUROL. 2007. Available from: https://jamanetwork.com/.

[13] Chomba E, Haworth A, Atadzhanov M, Mbewe E, Birbeck GL. Women's Experiences Living with Epilepsy in Zambia. Am J Trop Med Hyg 2008 Aug 1;79(2):168–72.

[14] von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies. PLoS Med 2007 Oct 16;4(10):e296.

[15] World Health Organisation. Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 – 2031 First Draft. 2021 Jun.

[16] Halani S, Tshering L, Bui E, Clark SJ, Grundy SJ, Pem T, et al. Contraception, pregnancy, and peripartum experiences among women with epilepsy in Bhutan. Epilepsy Res 2017 Dec;138:116–23.

[17] Kochen S. Pregnant Women with Epilepsy in a Developing Country. Open Neurol J 2011 Oct 20;5(1):63–7.

[18] Medicines & Healthcare products Regulatory Agency. Antiepileptic drugs: review of safety of use during pregnancy . 2021.

[19] Sabers A, Dam M, A-Rogvi-Hansen B, Boas J, Sidenius P, Laue Friis M, et al. Epilepsy and pregnancy: lamotrigine as main drug used. Acta Neurol Scand. 2004 Jan;109(1):9–13.

[20] Cunnington M, Tennis P. Lamotrigine and the risk of malformations in pregnancy. Neurology 2005 Mar 22;64(6):955–60.

[21] Kaddumukasa M, Kaddumukasa MN, Buwembo W, Munabi IG, Blixen C, Lhatoo S, et al. Epilepsy misconceptions and stigma reduction interventions in sub-Saharan Africa, a systematic review. Vol. 85, Epilepsy and Behavior. Academic Press Inc.; 2018. p. 21–7.

[22] Komolafe MA, Sunmonu TA, Afolabi OT, Komolafe EO, Fabusiwa FO, Groce N, et al. The social and economic impacts of epilepsy on women in Nigeria. Epilepsy Behav 2012 May;24(1):97–101.

[23] Mula M, Kaufman KR. Double stigma in mental health: epilepsy and mental illness. BJPsych open 2020;6(4):e72.

[24] Gilkinson C, Kinney M, Olaniyan T, Murtala B, Sipilon M, Malunga A, et al. Perceptions about mental healthcare for people with epilepsy in Africa. Epilepsy & behavior : E&B 2022;127:108504. https://doi.org/10.1016/j.yebeh.2021.108504.

[25] Adjei P, Akpalu A, Laryea R, Nkromah K, Sottie C, Ohene S, et al. Beliefs on epilepsy in Northern Ghana. Epilepsy Behav 2013 Nov;29(2):316–21.

[26] World Health Organisation. WHO model list of essential medicines - 22nd list, 2021. Geneva; 2021.

[27] Duley L. The Global Impact of Pre-eclampsia and Eclampsia. Vol. 33, Seminars in Perinatology. 2009. p. 130–7.

[28] Danielsson KC, Borthen I, Morken NH, Gilhus NE. Hypertensive pregnancy complications in women with epilepsy and antiepileptic drugs: A population-based cohort study of first pregnancies in Norway. BMJ Open. 2018 Apr 1;8(4).

[29] Fox C, Betts T. How much risk does a woman with active epilepsy pose to her newborn child in the puerperium? A pilot study.

[30] H. Bjørk M, Veiby G, A. Engelsen B, Gilhus NE. Depression and anxiety during pregnancy and the postpartum period in women with epilepsy: A review of frequency, risks and recommendations for treatment. Vol. 28, Seizure. W.B. Saunders Ltd; 2015. p. 33–9.
[31] https://www.nice.org.uk/guidance/ng217/resources/epilepsies-in-children-young-people-and-adults-pdf-66143780239813.
[32] Veiby G, Bjørk M, Engelsen BA, Gilhus NE. Epilepsy and recommendations for breastfeeding. Vol. 28, Seizure. W.B. Saunders Ltd; 2015. p. 57–65.
[33] Menon S, Siewe Fodjo JN, Weckhuysen S, Bhwana D, Njamnshi AK, Dekker M, et al. Women with epilepsy in sub–Saharan Africa: A review of the reproductive health challenges and perspectives for management. Seizure 2019 Oct;71.