**Epilepsy in Africa: role played by family and community support systems in lessening the burden of epilepsy**

CHISVOKA Tsitsi and NDLOVU Jabulani

***ABSTRACT***

*Epilepsy is a non-communicable condition that affects both males and females, people from all races, children and adults, rich and poor. There are an estimated 10 million people with epilepsy in Africa. Epilepsy can result in numerous social challenges for people with the condition, their families and community. The medication gap and specialist access gap are huge because of financial resources required to buy medicines, consult doctors including specialists and transport. There is also a huge knowledge gap that stands at about 70%. If not attended to, these problems result in long-term challenges, not only for individuals but for the national economy. In this article, authors examined the role played by family and community support systems in lessening the burden of epilepsy. A background and literature was provided on the same. The research was undergirded by Ubuntu research approach (URA) in terms of philosophy, ethics and techniques. We utilized a side-by-side approach or collaborative research with a community-based organisation, where we worked together to identify the problem, design methods, collect, analyse and report data. Data was collected through personal narratives of 16 people with epilepsy and a community indaba that was attended by 18 people. Data were co-analysed, and themes identified: resilience, community potential health philosophies conflict and concept of responsible government. We concluded that where families and communities potential end, government has not taken over more adequately. The implications are, there is inadequate support to families and communities, and this can only change if the current policy is improved or a new policy on non-communicable conditions, including neurological conditions is introduced. We have proposed a new Family-Community-State model to illustrate the pathways of government intervention.*

***KEY TERMS:*** *Africa, epilepsy, experiences, non-communicable, prevalence, stigma, treatment*

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Declarations:

Acknowledgements:

**INTRODUCTION**

Epilepsy is a non-communicable condition that affects both males and females, people from all races, children and adults, rich and poor, educated or not. Epilepsy can result in numerous social challenges for people with the condition, their families and community. If not attended to, these problems result in long-term challenges, not only for individuals but for the national economy. The medication gap and specialist access gap are huge because of financial resources required to buy medicines, consult doctors including specialists and transport. In this article, authors examine the role played by family and community support systems in lessening the burden of epilepsy. A background will be provided first, followed by a review of literature, methodology, results and discussion. Implications and recommendations will be provided.

**BACKGROUND**

There are an estimated 10 million people with epilepsy in Africa, meaning that 0.9% or 1 per 1000 people live with epilepsy on the continent (Awolabi et al, 2020). Of these, only about 25% (2.5 million) are on medical treatment, giving a treatment gap of 75% (7.5 million). Out of those 2,5 million who are on medical treatment, we estimate that only about 25% (625 000) have access to medicines and 5% (125 000) have access to specialist treatment. The major reason behind the huge treatment gap is the knowledge gap, which stands at about 70%, meaning only about 30% view epilepsy as a neurological disorder that can be managed medically or surgically.

Epilepsy can be an annihilating and chronic condition, however, with basic treatment, more than 70% of cases can be controlled with one drug World Health Organization (WHO) (2003). The challenge Africa faces is that of misunderstanding of epilepsy, it’s stigmatized, severely underfunded or even ignored by the healthcare systems. Rural communities suffer more because they are often marginalized with limited health and social support services. Over 75% of people with epilepsy in Africa live in rural and suburban areas where treatment is almost non-existent. People with epilepsy still suffer, even at this time when there is an existence of affordable and effective drugs and low-cost programs (Guyo and Vembe, 2012).

**The problem of epilepsy**

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**Theoretical framework**

This research was grounded in Ubuntu research methodology, specifically African health seeking behaviour…….

**Heading**

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**LITERATURE**

The authors reviewed literature published between 2003 and 2021 that was available in the University of Zimbabwe library and online. For online, we used the database of the Africa Journal Online (AJOL) and the Africa Social Work network (ASWNet). We found 18 relevant articles, summarized in the Table 1. After analysis, we identified four themes as follows: challenges; strategies; responses and conflicts.

**Literature included in the literature review**

*Table 1: Articles included in the review*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Article number** | **Title** | **Authors** | **Year published** | **Brief summary** |
|  |  |  |  |  |
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Over 75% of people with epilepsy in Africa live in rural and suburban areas where treatment is almost non-existent. People with epilepsy still suffer, even at this time when there is an existence of affordable and effective drugs and low-cost programs (Botho, 2012).

**METHODOLOGY**

The research was undergirded by Ubuntu research approach (URA) in terms of philosophy, ethics and techniques. We utilized a side-by-side approach or collaborative research with a community-based organisation, where we worked together to identify the problem, design methods, collect, analyse and report data. Data was collected through personal narratives of 16 people with epilepsy and a community indaba that was attended by 18 people.

**RESULTS**

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**Themes**

***Individual and family resilience***

Type here. If you have a quotation or narrative, put it as follows.

*I find it difficult to inform my employer about my condition. In the past I did, but then my employer started questioning my ability to work and be productive. Most people do not tell their employers actually. And this is understandable* (Kukeza, Interview).

***Community potential***

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***Concept of responsible government***

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***Conflicts of health and well-being philosophies***

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*Conflict at family level*

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*Community at village level*

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*Conflict at community level*

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**DISCUSSION**

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**CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS**

**Conclusions**

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**Implications**

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*Figure 1: Family-Community-State model for epilepsy care*

**Recommendations**

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**CONCLUSION**

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**REFERENCES**

Awolabi L. F., Bappa A., Abubakar M. J., Adamu I. I., Ibrahim D. A. and Okezie O. E. (2020). Prevalence of active epilepsy, life-time epilepsy prevalence, and burden of epilepsy in Sub-Saharan Africa from meta-analysis of door-to-door population-based surveys, *Epilepsy & Behaviour, 103(10),* 68-86.

Epilepsy Alliance Africa (EAA). (2020). About the Alliance. Accessed on 21 March 2021 from http://eaa.neuromarrakech.com/about-eaa/

Guyo V and Vembe N, (2012) Epilepsy in poor regions of the world. *Lancet, 380(9848),* 1193-1201. doi:10.1016/s0140-6736(12)61381-6

Mugumbate J. and Nyanguru A. (2013). Measuring the challenges of people with epilepsy in Harare, Zimbabwe. 2013, *Neurology Asia, 18(1),* 29-33.

Mugumbate J., Riphagenn H. & Gathara R., (2017). The role of social workers in the social management of epilepsy in Africa. In M. Gray (Editor), *The Handbook of Social Work and Social Development in Africa*. London: Routledge.

Obeid T. (2008). Stigma: An aspect of epilepsy not to be ignored. *Saudi Medical Journal, 29(4),* 489-497.

Shona people. ‘Mwana asingachemi anofira mumbereko’ (A baby who does not cry does not get the mother’s attention). *Proverb*. Zimbabwe.

World Health Organization (WHO), (2003). *Bringing Epilepsy out of the shadows in Africa*. Brazzaville, World Health Organization - Regional Office for Africa

Zimba, A. 2004. *Epilepsy in Africa*. Lusaka: Mambo Press.