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Challenges for epilepsy care/treatment in onchocerciasis-endemic regions

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Background

- Epilepsy: highly prevalent in onchocerciasis-endemic zones, with 10% increase in onchocerciasis prevalence → 0.4% increase in epilepsy prevalence (Pion et al, 2009. PloS NTD)
- Strong epidemiological association between oncho and epilepsy ,with compliance to most Bradford-Hill criteria → OAE
- Challenges in epilepsy management due to both the nature of disease and the setting/context in onchocerciasis-endemic areas

Peculiarities of epilepsy in onchocerciasis-endemic areas

- Various seizure types, including nodding seizures
- Frequent misconceptions leading to stigma
- Remote difficult-to-access areas
- Insufficient health infrastructure / personnel for epilepsy care
- Inadequate supplies of anti-seizure medications
- Little engagement from stakeholders

1. Different seizure types

- Epilepsy in oncho areas: Generalized tonic clonic seizures, focal, absences, nodding...
- Treatment protocols vary greatly based on seizure presentation
- Optimal management for nodding seizures still unknown;
 valproate showed promising results (Idro et al. 2014)
- Supportive / adjuvant treatment options rarely implemented

2. Misconceptions and stigma

- Prevailing stigma due to wrong beliefs that epilepsy is a spiritual and/or contagious condition (O'Neill et al. 2019)
- PWE isolation: They eat alone, sleep apart (no mosquito nets...)
- If associated oncho (skin disease): Compounded stigma
- Stigma adversely affects treatment seeking behaviours: Families hide the epilepsy diagnosis, resort to traditional healers...

3. Remoteness of onchocerciasis-endemic areas

- OAE mostly affects remote villages near fast-flowing rivers
- Poor road networks, often unusable during rainy seasons
- Reduced access to healthcare by patients
- Difficulties to procure and deliver medical supplies to such areas
- Situation further complicated by general poverty and sometimes insecurity, reducing access to optimal healthcare

3. Remoteness of onchocerciasis-endemic areas





4. Insufficient health infrastructure and workforce

- Poverty and inaccessibility make oncho areas unattractive for healthcare workers; reluctance to settle in such villages
- Few physicians and even fewer neurologists: Task-shifting++
- Diagnostic equipment (EEG, imaging) often unavailable, hence the development of easy-to-use OAE clinical criteria
- Such areas are also unattractive to researchers ightarrow lack of data

4. Insufficient health infrastructure and workforce





5. Inadequate supplies of anti-seizure medications

- Frequent ASM stockouts: Poor accessibility to deliver the drugs, low economic benefits for ASM suppliers
- Consequence: Many PWE with uncontrolled seizures
- Proliferation of black markets for ASM of doubtful quality at exorbitant costs
- Intermittent treatment → increased risk for rebound seizures

6. Limited stakeholder involvement

- Little or no efforts to adapt national guidelines for epilepsy care to the onchocerciasis-endemic settings
- No attractive policies to encourage extension of the ASM market to remote oncho areas
- No specific incentives to encourage healthcare workers to settle in oncho areas
- It appears epilepsy in oncho areas is not prioritized!



Role of onchocerciasis management in epilepsy care

- Seizure frequency in PWE has been associated with mf load
- Ivermectin treatment improves seizure outcomes in OAE



Ultimately: Synergise brain health and oncho programs



Colebunders et al. 2019

Practically...



Conclusion

- Epilepsy care in onchocerciasis-endemic settings poses several challenges, from stigma and misconceptions to inadequate healthcare services
- Advocacy needed to overcome the inertia in recognizing OAE as a public health problem
- Collaborative management using a comprehensive approach is recommended