High epilepsy prevalence and excess mortality in onchocerciasis-endemic counties of South Sudan: A call for integrated interventions

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Background: Epilepsy poses a significant public health burden in onchocerciasis-endemic regions with intense transmission. This study examined epilepsy prevalence, mortality and the association between onchocerciasis transmission and epilepsy, including probable nodding syndrome (pNS), in five counties of South Sudan.

Methods: House-to-house cross-sectional surveys (2021–2024) identified suspected persons with epilepsy (sPWE) and retrospectively documented mortality among sPWE and individuals without epilepsy (IWE). Epilepsy diagnoses, including pNS, were confirmed by trained clinicians. Ongoing transmission was assessed using anti-Ov16 seroprevalence in children aged 3–9 years. Age- and sex-standardised prevalence rates, mortality rates and standardised mortality ratios (SMRs) were calculated with 95% confidence intervals (95%CIs), using IWE as the reference population. The association between epilepsy and anti-Ov16 prevalence was explored using weighted arcsin-transformed linear regression.

Results: Among 34,345 individuals screened, epilepsy prevalence was 4.1% (range: 2.3–7.1%), and pNS prevalence was 1.5% (range: 0.6–2.2%). Anti-Ov16 seroprevalence among children was 23.3% (range: 1.4–44.1%). Each 1.0% increase in anti-Ov16 seroprevalence was associated with a 0.10 percentage point rise in epilepsy prevalence and a 0.04 percentage point rise in pNS prevalence. Median age at death was lower for sPWE (20 years) than for IWE (39 years; $p<0.0001$). Mortality rates per 1,000 person-years were significantly higher in sPWE (48.4, 95%CI=41.9-55.8) than in IWE (6.1, 95%CI=5.6-6.7). The overall SMR was 6.8 (95%CI=5.8-7.8), indicating sPWE were seven times more likely to die than IWE.

Conclusion: The high epilepsy burden in onchocerciasis-endemic areas is characterised by increased prevalence and mortality. Strengthening integrated onchocerciasis and epilepsy programmes is crucial to reducing epilepsy incidence and ensuring continuous access to antiseizure medication.