

Preventing devastating ‘river epilepsy’

Onchocerciasis is a neglected tropical disease leading to ‘river blindness’, associated with high rates of epilepsy, including nodding syndrome, in sub-Saharan Africa. This study in South Sudan finds that a multi-pronged approach to tackling onchocerciasis could also have a significant impact on epilepsy.

Approach evaluated in South Sudan could be scaled up

A community-based programme in Western Equatoria State, South Sudan, showed that strengthening onchocerciasis elimination efforts can prevent children from developing onchocerciasis-associated epilepsy (river epilepsy). A vector control method to eliminate blackflies (which transmit onchocerciasis to humans) was extremely successful. In addition, a community-based epilepsy treatment programme was able to improve the quality of life of persons with epilepsy and increased schooling of children with epilepsy.



The Naam River, a blackfly breeding site in Mvolo, South Sudan. Credit: Study team

Background

Onchocerciasis, also known as ‘river blindness’, is an eye and skin disease that causes severe discomfort and can lead to permanent blindness. Onchocerciasis, in the absence of an efficient elimination programme is also associated with high rates of epilepsy (onchocerciasis associated epilepsy- OAE- or ‘river epilepsy’). Nodding syndrome and Nakalanga syndrome are two forms of ‘river epilepsy’ which can lead to severe disability and early death. ‘River epilepsy’ is a highly neglected and stigmatised condition affecting millions of people, mostly in sub-Saharan Africa.

How the research was conducted

The study took place in Maridi, Mundri and Mvolo Counties, three onchocerciasis endemic, high transmission areas in Western Equatoria State in South Sudan from 2019 to 2021. In Maridi a community directed treatment with ivermectin (CDTI) programme was switched from annual to bi-annual. A community-based ‘Slash and Clear’ vector control method was also introduced to eliminate blackflies at their breeding site. In Mundri and Mvolo, only annual CDTI was continued, and a community-based epilepsy treatment programme was also established.

Key findings

- There is a high prevalence of epilepsy in the study sites (over 4%). OAE (river epilepsy) is one of the main causes of mortality in areas of high onchocerciasis transmission. Nearly all people with OAE die before the age of 30 years.
- A high prevalence of OAE is linked with severe socio-economic consequences and poverty. In Mundri, 4.8% of persons with epilepsy were severely disabled. Children with epilepsy drop out from or are excluded from school.
- In Maridi, the interventions resulted in an 89.2% reduction in epilepsy incidence. Blackfly biting rates reduced by more than 97%. The improvement of epilepsy treatment and care resulted in over 90% of people receiving treatment reporting reduced seizures and increased quality of life.
- However, while coverage of ivermectin in Maridi increased, the 80% coverage required for onchocerciasis elimination was not achieved.

Implications for humanitarian practitioners and policymakers

CDTI coverage and distribution frequency should be increased wherever OAE is prevalent. Efforts should prioritise children aged 5–15 years. However, it is also clear that CDTI alone is not enough to eradicate onchocerciasis. A multi-pronged approach is needed. Involving local community leaders and community drug distributors (CDDs) and ensuring adequate supervision of CDDs could enhance CDTI distribution effectiveness.

Treatment, care provision and awareness of epilepsy in OAE affected areas must be stepped up, with attention to improving access to education for children with epilepsy.

OAE- river epilepsy- is preventable. The interventions evaluated in South Sudan could be scaled up. Donors, humanitarian actors and governments must increase global awareness and resource mobilisation to strengthen onchocerciasis elimination and epilepsy treatment in endemic regions and develop a holistic cross-sectional governmental response.

Recommendations for future research

More research is needed to identify innovative ways to increase CDTI coverage and to increase the intake of ivermectin among children aged 5–12 years and map the onchocerciasis disease burden in sub-Saharan Africa and to map blackfly breeding sites in areas of high transmission. It is also important to investigate how a community-based "Slash and Clear" vector control method can be scaled up in other ecological settings than in Maridi and identify the most efficient, low-cost anti-seizure treatment for different forms of OAE.

About the study team

The study was conducted by a partnership that included:

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Keywords

Onchocerciasis; epilepsy; nodding syndrome; prevention; treatment; ivermectin, vector control

Articles and further reading

Multiple peer-reviewed journal articles and a policy brief from this study are available on the Elrha project page:

<https://www.elrha.org/project/evaluation-of-a-community-based-comprehensive-epilepsy-prevention-and-treatment-programme-in-onchocerciasis-endemic-villages-in-maridi-state-south-sudan/>



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