BRAIN COMMUNICATIONS

LETTER TO THE EDITOR

Nodding syndrome, many questions remain but we can prevent it by eliminating onchocerciasis

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In their concise review about nodding syndrome, the authors discussed several potential aetiological factors and concluded that the cause is still unknown (Olum *et al.*, 2020). We agree that the pathogenesis of this syndrome remains to be elucidated. However, recent research, not mentioned in the review, showed that nodding syndrome appears in regions with high *Onchocerca volvulus* transmission and disappears when onchocerciasis is eliminated from those areas. This was evidently demonstrated by two recent studies in Uganda. The first study was conducted in an onchocerciasis endemic region in northern Uganda, in the districts Kitgum and Pader. In the early 2000s, these districts experienced a nodding syndrome epidemic in addition to an overall increase of epilepsy. Based on the results of an epilepsy survey performed in 2012 and another in 2017, we showed that new cases of nodding syndrome stopped appearing after consistent implementation of biannual ivermectin distribution and ground larviciding of rivers (Gumisiriza *et al.*, 2020*b*). The second study was performed in Kabende, in western Uganda. In 1991, a high prevalence of epilepsy and cases of nodding syndrome had been reported in this onchocerciasis endemic region (Kaiser *et al.*, 1996). In 2018, during an epilepsy survey in the same area, it was found that nodding syndrome had stopped to appear and that the overall prevalence and incidence of epilepsy also had dropped significantly after the elimination of onchocerciasis in 2004 (Gumisiriza *et al.*, 2020*a*).

It is important to mention that nodding syndrome has now been reported in many other onchocerciasis-endemic areas besides the three countries (Tanzania, South Sudan, and Uganda) where nodding syndrome was initially described. These other countries include Cameroon (Siewe *et al.*, 2019), the Democratic Republic of Congo (Colebunders *et al.*, 2016) and Liberia (Siewe Fodjo *et al.*, 2020).

It is common for persons with nodding syndrome to have siblings correspondingly suffering other forms of epilepsy within the household. This is especially observed among families living near the breeding sites of the blackflies (the vectors of onchocerciasis) (Colebunders *et al.*, 2016). Therefore, nodding syndrome should be considered as one of the phenotypic manifestations of onchocerciasis-associated epilepsy (Colebunders *et al.*, 2019).

The association between onchocerciasis and epilepsy was already reported in 1938 by Casis (1938) in Mexico. The magnitude of the disease burden caused by onchocerciasis-associated epilepsy needs to be internationally recognized. A delay in the implementation of adequate onchocerciasis elimination in hotspot areas will result in the continued development of nodding syndrome and other forms of epilepsy among children.

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Data availability

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Competing interests

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