

Nodding Syndrome

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

[Mike Miller] Hello, I'm Dr. Mike Miller and today I'm talking with Dr. Scott Dowell, a director at the Centers for Disease Control and Prevention. Our conversation is based on his article about nodding syndrome, which appears in CDC's journal, *Emerging Infectious Diseases*. Welcome, Dr. Dowell.

[Scott Dowell] Thanks, Mike.

[Mike Miller] This is an interesting and unusual case. What is nodding syndrome?

[Scott Dowell] Nodding syndrome's a severe neurological disease affecting young children in a few places in Africa.

[Mike Miller] What are the signs and symptoms of it?

[Scott Dowell] These are children who are healthy until about age 5. They get spells of head nodding, and then they have trouble eating, they often lose weight, develop other seizure-like activities, and eventually they drop out of school and can require around-the-clock care.

[Mike Miller] Can people die from it?

[Scott Dowell] Many of the children have died, often from drowning, falling into fires, or malnutrition or other incidental infections. These are common causes of death for children with severe seizure disorders in Africa and elsewhere.

[Mike Miller] Well, who is most affected by it?

[Scott Dowell] These are young children between the ages of 5 and 15 years of age.

[Mike Miller] What countries have the most cases?

[Scott Dowell] The three countries where nodding syndrome's been reported are Uganda, Sudan, and Tanzania.

[Mike Miller] When was nodding syndrome first recognized?

[Scott Dowell] Well, head nodding, as a part of epilepsy, has been described as far back as the 1960s in Africa. But the description of "nodding disease" as a distinctive clinical syndrome really occurred in Sudan in the 1990s and more recently in Uganda.

[Mike Miller] Is this a rare syndrome?

[Scott Dowell] It is rare worldwide, but in affected villages there can be hundreds of cases. In a recent community-wide survey in Northern Uganda, more than a thousand cases were identified.

[Mike Miller] Well, in terms of etiology, have the underlying causes been identified?

[Scott Dowell] No. We don't yet know the underlying cause. We have identified the immediate cause of the head nodding—it's a type of seizure known as an atonic seizure. But what has led to this epidemic of atonic seizure is still being investigated. The most consistent finding in cases is a higher incidence of exposure to a parasite called *Onchocerca volvulus* than in community controls of the same ages.

[Mike Miller] The onchocerciasis parasite is endemic in a lot of areas globally. Why aren't all of these areas affected by nodding syndrome?

[Scott Dowell] We don't know. It may be that there's a second factor is involved, or there's a particular strain of the parasite, or perhaps a reaction to it that's peculiar to these populations. Or it could be that rare cases of nodding syndrome have been missed in areas where onchocerciasis occurs but at lower frequencies than in these areas.

[Mike Miller] Oh, so is there a hypothesis as to why this would be so?

[Scott Dowell] One intriguing idea is that the disease is an autoimmune seizure disorder—caused by auto-antibodies that the body makes against the parasite that, through a process of molecular mimicry, attack its own brain tissue.

[Mike Miller] What are the special circumstances that make this illness so hard to track?

[Scott Dowell] Nodding syndrome's occurring in remote areas with few medical or other resources. Also, we know that unexplained neurologic conditions often take many years to figure out.

[Mike Miller] Well, does the problem seem to be getting worse? Are more children getting it?

[Scott Dowell] It was getting worse for several years in Northern Uganda and in South Sudan. Now, our colleagues tell us that the rise in the number of cases in Northern Uganda is beginning to slow so we have some optimism that the epidemic curve is leveling off.

[Mike Miller] Is there any treatment for it?

[Scott Dowell] The children can be treated for the symptoms—they can be provided with food and vitamins for the malnutrition, and anti-epileptic drugs for the seizures. But there've been no cures that we're aware of.

[Mike Miller] Well, thank you, Dr. Dowell. I've been talking with Dr. Scott Dowell about his article, Nodding Syndrome, which appears in the September 2013 issue of CDC's journal, *Emerging Infectious Diseases*. The article is available at cdc.gov/eid.

If you'd like to comment on this podcast, send an email to eideditor@cdc.gov. I'm Dr. Mike Miller for *Emerging Infectious Diseases*.

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