



## 'These nodding people': Experiences of having a child with nodding syndrome in postconflict Northern Uganda



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### ABSTRACT

**Background:** Nodding syndrome, an epidemic epileptic encephalopathy of unknown etiology, has affected an estimated 1834 children in Northern Uganda. Children are being treated symptomatically but inconsistently with antiepileptic drugs.

**Design:** Ten semistructured interviews with caregivers of affected children and five focus group discussions with 23 relatives, teachers, and religious leaders were conducted to examine the experiences of affected families and communities in Kitgum and Pader districts.

The researcher also did participant observation during MoH outreach clinics. Data collection was carried out from July to September 2012, and data were analyzed through inductive thematic analysis.

**Results:** Nodding syndrome severely affects the children's ability to participate in daily life activities. Daily seizures and physical features such as salivating and stunting make them unable to pass as normal, and mood changes make it difficult for some to interact with others. Caregivers of children with nodding syndrome feel confined to their homes, and economic activities are reduced, which affects entire families, especially the education of healthy siblings. The familial clustering and the unknown etiology made many separate from the affected children when eating, sleeping, and having seizures because of a fear of transmission through saliva. Families struggle to provide care with minimal resources and have experienced a reduction in visitors since their children were affected by nodding syndrome. There were signs of apathy in patterns of care, and, generally, parents felt that antiepileptic medicine had brought only slight improvement in their child's condition because many had begun treatment when developmental milestones had already been lost.

**Conclusions:** A consistent supply of antiepileptic medication is likely to reduce the stigma and fear of transmission, as the affected children's acceptance among others was greatly compromised whenever they had seizures. The loss and suffering involved with nodding syndrome are seen as a continuation of the confinement and trauma once caused by war, and a good regimen of medication is not the whole answer.

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### 1. Introduction

In Northern Uganda, an estimated 1834 children are affected by nodding syndrome [1], a neurological syndrome of unknown pathogenesis. The disease was first described in southern Tanzania in 1962 [2–4], in Liberia in 1983 [5], and in South Sudan in 1991 [6–8]. The syndrome is described as an epidemic epileptic encephalopathy, and clinical studies have shown cerebral atrophy, gliotic lesions, and hippocampal sclerosis [2,9–11].

Affected children, predominantly between 5 and 15 years of age, present with head nodding and seizures. The children gradually lose their cognitive function and become stunted and malnourished partly because the sight of food provokes bouts of head nodding [3,9,10,12].

A large proportion of the affected children are infested with the parasite *Onchocerca volvulus* which is spread by the black fly and causes

river blindness. This parasite has been a central clue in the etiology of the syndrome, but elevated antibodies to the parasite in the cerebrospinal fluid of the affected children have not been found [13]. Onchocerciasis has previously been associated with both seizures and stunting; for every 10% increase in the prevalence of onchocerciasis, epilepsy rates go up by 0.4% [14]. A large proportion of children and adults in the affected areas are infested with this parasite; thus, it is unclear why people living in other endemic regions have not experienced outbreaks of nodding syndrome or why it is occurring in the affected regions at this moment in time [12]. Scientists have examined different theories of causation but have not found any evidence that the disease is caused by dietary practices, chemical exposure during wartime, genetics, viral encephalitis, or vaccines [12,15].

In Northern Uganda, affected children have been treated with antiepileptic medicine since 2012. Many have improved significantly but many continue to have daily seizures and an estimated 200 children have died, mostly from drowning in rivers or falling into fires during seizures [12,16,17]. In order to stop children from getting hurt during

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episodes of confusion, some families have resorted to tying the affected child to a tree [16]. Local reports put the number of affected children at 3000, but some appear to be children with epilepsy [1,17].

While academic literature uses a biomedical discourse to describe nodding syndrome and its effects, locals link the syndrome to social issues [18]. Northern Uganda was the scene of a protracted low-intensity civil war between the Lord's Resistance Army (LRA) and the Ugandan army, which ran from 1986 to 2008 [19]. The LRA abducted as many as 30,000 children, and the conflict altered societal and family structures in the region [20] and resulted in around two million people residing in Internally Displaced Persons (IDP) camps. The crowded conditions of the camps and insufficient access to food and health care led to 1000 excess deaths per week in 2005 [21], and the lack of development during the conflict aggravated the north–south divisions which have existed since independence; the 2009/2010 Uganda national household survey estimated that, in the north, 68.9% live in huts as opposed to 1.8% in Western and 2.4% in Central Uganda [22].

Bukuluki et al. found that nodding syndrome is triggering a reversal in recovery from conflict by diminishing the farming productivity of parents with affected children and that stigma associated with the syndrome was disrupting social networks [23]. A commentary was based on quotes collected by an NGO. It is not declared how the focus groups were analyzed. The participants reportedly felt that food aid or chemicals from bombs caused nodding syndrome but also mentioned spiritual and religious beliefs [24]. Little research had been done, however, of how the children and their families have been affected and of how communities live with the changes brought about by nodding syndrome exists.

In Uganda, nodding syndrome was first found in the districts of Pader and Kitgum where the majority of the affected children are still to be found and, therefore, these were the districts where this study was carried out. Nodding syndrome has since been confirmed in three other districts in Northern Uganda.

Semistructured interviews and focus group discussions were conducted to examine the impact that nodding syndrome has had on affected children, their families, and communities.

## 2. Methods

Participants for this study were identified by key informants and in treatment centers or during outreach clinics through purposive sampling and were asked to identify other possible participants in their area.

All data collections were done in English, the official language of Uganda, and data were triangulated by using multiple methods (focus group discussions, interviews, and participant observations) with different data sources (parents, relatives, community members, and key informants). Triangulation enhances trustworthiness of qualitative research and increases the likelihood of rich descriptions [25]. Data were drawn from ten semistructured, individual qualitative interviews and five focus group interviews consisting of 4–6 individuals each. In total, 33 people were interviewed. An additional nine individuals acted as key informants for the researcher and included hospital staff, a local chief, and a local religious leader. Traditional healers were not interviewed as part of this study as data collected from key informants indicated that they were not significantly involved in the care of children with nodding syndrome (CWNSs). The caregivers were three mothers, three fathers, two older brothers, an older sister, and an aunt, all from different families. The interview guide focused on how it had affected the child, siblings, and parents the child's opportunities of participating in social activities, reactions received from neighbors, and understanding of causation. Participants in the interviews were the primary caregivers of children with nodding syndrome in the age range of 5–17 years, and all had lived in IDP camps during the insurgency. The focus groups consisted of two groups of relatives, two groups of primary school teachers, and one group of religious leaders representing the denominations Anglican, Catholicism, Pentecostal, Seventh Day Adventist, and Islam. The thematic interview

guide focused on their understanding of the disease, why they think it has occurred to the children, and how it has affected their communities. On average, the individual interviews lasted 101 min, and the focus group interviews lasted 122 min. Though saturation was reached at a fairly early stage, data collection was continued in order to ensure that findings were representative also of the next district.

The investigator collected data for a period of ten weeks beginning in Kitgum district, adding field observations to the data trail including participant observation with the MoH Nodding Disease outreach clinics established in June 2012. All data collections were done between July and September 2012, in the districts of Pader and Kitgum, which are neighboring districts, situated about 443 km from the capital, with Kitgum bordering South Sudan. In 2013, the population of Pader district was estimated at 243,200 people, and the population of Kitgum was estimated at 257,600 people [26]. Both districts had a high number of IDP camps.

Interviews were recorded and then transcribed verbatim by the investigator in preparation for analysis. The transcript comprised 263 pages of single space data and five pages of notes from field observations. All of the materials were analyzed through inductive thematic analysis in order to obtain an accurate reflection of the content without interference from theoretical interest or preconceptions of the researcher. Inductive analysis identifies themes directly from interview data instead of using interview data to test whether previously theorized themes are upheld (deductive analysis) [27].

Permission for this study was given by the Institutional Review Board of Gulu University and by the Ugandan National Council for Science and Technology. Participants were given oral as well as written descriptions of the study, and written consent was obtained. A transport refund was provided to all participants since most interviews were carried out in town centers.

## 3. Results

### Themes

- 3.1 Manifestation of the syndrome
- 3.2. Burden of care
- 3.3. Attempts to contain the syndrome
- 3.4. Changes brought by the syndrome
  - Apathy
  - Disruption of education
  - Reduction in social support

### 3.1. Manifestation of the disease

Although all children who are mentioned in this study were, at the time of interviews, on antiepileptic drugs (carbamazepine or sodium valproate), their symptoms were not fully controlled, and some continued to have many episodes of head nodding or seizures daily. This makes the children prone to accidents, making them even more dependent and distressing to people who see them:

“Last week we had a child from our school, a child had fallen in fire and they took her to the hospital and her two arms has been cut from the hospital”.

[Teacher A]

It was observed that children with nodding syndrome often develop features of protruding teeth, salivating, stunting, and a slow gait and thus stand out as impaired. The children also exhibit mood changes

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