

Nutritional Status of Children Living with Nodding Disease Syndrome and Copying Strategies of Their Families in Uganda

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Abstract

In northern Uganda, it is estimated that over 3,541 children in the districts of Kitgum, Pader and Lamwo were affected by nodding disease syndrome (NDS) by December 2013. The nodding Disease syndrome continues to manifest itself in Children in Akwanga, Kitgum and other parts of Northern Uganda causing progressive cognitive dysfunction, neurological deterioration and stunted growth. This study sought to determine the nutritional status of children with NDS in Akwanga Sub County, Kitgum District, identify the factors influencing this nutritional status and delineate the coping strategies at the household level.

Methods: We used mixed methods, Children between 5–18 years with Nodding Disease Syndrome were chosen after their parents consented, and Akwanga HCIII in Akwanga sub county, Kitgum district was considered. This was majorly done for all children registered with the health Centre III and suffering from NDS, 123 children aged (5–18 years) were sampled and their parents/guardians were then traced using the snowballing method to their respective households from where consent was sought. They then participated by way of answering the questionnaire and taking of the anthropometric measurements of the children. We then used SPSS for analyzing quantitative data and Dedoose for qualitative data.

Results: A total of 123 participants took part in the Study. Participants reported that prevalence of malnutrition in the NDS children is very high and this could be attributed to seizures while feeding, religious beliefs and age at weaning. Various coping mechanism include rearing animals, planting different kinds of crops for feeding and rearing cows and goats which are used as food to eat. This would play an important role in fighting malnutrition in NDS children in Northern Uganda.

Conclusion: There is an urgent need to address the through factors that are associated with malnutrition among NDS children, and to strengthen the identified coping mechanisms. Empowering the care takers and prioritizing improvement on economic status could help in fighting malnutrition in NDS children.

Introduction

According to UNICEF state of the world's children's report 2019, Growing well in a changing world, Uganda fact sheet currently, more than 2 million children are stunted in Uganda despite a decline of 4 percentage point reduction in the last 5 years. The absolute number of stunted children in Uganda has increased due to high population growth rate. Three in 10 children under 5 are not growing well due to malnutrition with 280,000 children under 5 are wasted and more than one-third of total number of children who are acutely malnourished were severely malnourished. It is also estimated that 2.2 million children in Uganda suffer from either stunting, wasting or both.

Nodding disease syndrome continues to manifest itself in approximately 3,541 children in Uganda with the highest rates reported in the Districts of Kitgum, Pader and Lamwo in Northern Uganda [1]. Approximately 1000 children in Uganda have succumbed to NDS and many have suffered progressive cognitive dysfunction, neurological deterioration and stunted growth in Northern Uganda.

However, the specific prevalence of malnutrition among NDS children in Kitgum District was not known and this applies to Akwang Sub county too. In addition, the factors associated with the occurrence of malnutrition and coping strategies for the families in Akwang sub county were not clearly known. This study therefore sought to determine the nutritional status of children with NDS in Akwang Sub County, Kitgum District, identify the factors influencing this nutritional status and delineate the coping strategies at the household level.

Methods & Design

We carried out the study using a cross-sectional design and employed both qualitative and quantitative research methods. Using cross- sectional study we estimated the prevalence of malnutrition among NDS in Akwang sub-county in Kitgum district. Drawing from a sample of 124 participants and measuring the characteristics of the sampled members. We examined the situation as it were and identified the characteristics of the observed phenomenon. The participants for this study included children aged 15-18 years living with Nodding disease syndrome, attending NDS clinic at Akwang HCIII at the time of data collection, residing in Akwang for at least 12 months and whose parent/caretaker formally consented to participate in the study. We chose this design to understand the experiences and short-term outcomes in a population that is reachable for easy follow-up.

The choice of application of mixed methods, i.e., both qualitative and quantitative methods was motivated by the desire to achieve triangulation of methods which involved comparison of information obtained from different methods such as anthropometric data, interviews, and Focused group discussions on the same study phenomenon with different participants. The qualitative data was mainly generated from key informant interviews from medical and local government personnel in Akwang HCIII and Kitgum DLG. Also, ten caregivers of children with NDS participated in FGDs. This research design was therefore formulated in such a way that it is complementary and mutually reinforcing; that is, design and implementation was carried out to validate responses from one method by triangulating it with others. The use of both qualitative and quantitative methods has equally been advanced by [2], arguing that quantitative methods alone are not sufficient enough to answer adequately all questions related to the evaluation and assessment of increasingly complex healthcare [2]. All methods were performed in accordance with the relevant guidelines and regulations. Prior to the fieldwork, ethical clearance and approval was sought from Uganda Christian University Research and Ethics Committee-. Informed consent was obtained from all subjects and/or their legal guardian. - The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request.

Presentation of study findings

Table 1: Social demographics of Nodding Disease syndrome children (15-18 years)

Variables		Statistics
Gender	Male	58(47%)
	Female	65(53%)
Mean (Median)		
Age	18(17-18)	
Height	144.82 (139.55-150.08)	
Weight	46.51 (44.32-48.71)	

Data source: Primary data, 2019

Table 1 shows that majority of NDS children 65 (53 %) were females. The average age was 17.85 years, mean height was 144.82 cm and the mean weight was 46.51 kg. The mean age and weight were higher for females (17.94 years, 47Kg) compared to the males (17.64 years, 45.09kgs,), the mean height was higher for males (158.75 cm than females (147.78cm).

Socio-Demographic Characteristics of caretakers of NDS children

Of the 124 screened individuals, 123(99.2%) were enrolled in the study. One participant said they didn't want to continue with the study due to personal reasons. The participant was excluded from the analysis. (Table 2)

Table 2: Distribution of caretakers of NDS children by their Socio-Demographic Characteristics

<i>Variable factors</i>	<i>Frequency (%)</i>
<i>Gender</i>	
<i>Male</i>	25(20%)
<i>Female</i>	98(80%)
<i>Marital status</i>	
<i>Married</i>	3(2.4%)
<i>Single</i>	120(97.6%)
<i>Religion</i>	
<i>Christian</i>	98(98.4%)
<i>Moslems</i>	2(1.6%)
<i>Level of Education</i>	
<i>Non formal</i>	34(27.6%)
<i>Primary</i>	84(68.3%)
<i>Secondary</i>	1(0.8%)
<i>Tertiary/ University</i>	4(3.2%)

Data source: Primary data, 2019

Overall, 124 participants were initially enrolled in this study. Of the 123 participants, 98(80%) were female, Majority belonged to the Christian Faith 98(98.4%) and most care takers didn't go beyond primary school 84(68.3) in the level of education. Majority of the caretakers 120 (98%), were single.

Prevalence of wasting, stunting and underweight among the NDS Children

Table 3: Prevalence of wasting, stunting and underweight among the NDS Children

Variables	Incidence proportion (%)	Acceptable level
Wasting	100 % (95 %CI 95-100)	<5%
Stunting	90 % (95 % CI 81-95)	<5%
Underweight	78% 95 %CI 68-86)	<5%

Data source: primary data, 2019

Of the 123 participants, the overall prevalence rate of wasting was 100 % (95 %CI 95-100), stunting at 90 % (95 % CI 81-95) and Underweight at 78% 95 %CI 68-86) of nodding disease children.

Table 4 shows the factors that influenced stunting, wasting and underweight respectively among NDS children 15-18 years in Akwang sub county in Kitgum district. Animals and food ($p < 0.05$) and seizure at food (p-value < 0.05) during feeding caused stunting among NDS children in Kitgum which was statistically significant. Religion (p-value <0.008), Food run out (p-value < 0.05), Time to complete Meal (p-value <0.0) were factors that caused wasting among NDS children which was statistically significant. Weaning age (p-value <0.05 Animals and food (p-value <0.0128) were factors that caused underweight among NDS children and they were statistically significant. (Table 3)

Table 4: Factors influencing nutritional status among NDS children

Nutritional status N=123	P-Value
Stunting	
Lack of food	0.0212 *
Time to complete meal	- 0.9274
Other foods	0.1681
Seizures	0.0448 *
Wasting	
Religion	- 0.008*
Meals per day	0.924027
Food shortage	0.016259 *
Time to complete meal	0.446252
Seizures at food	0.0005*
Underweight	
Early weaning	0.0386 *
Lack of food	0.0128 *
Rearing animals	0.4542
Other foods	0.3201

**Significant at 5% level Data source: Primary data, 2019

Table 5. Multivariate analysis of factors influencing nutritional status, Copying strategies among Nodding children in Akwang sub county in Kitgum District.

Factor	95% C.I. for EXP(B)			
	P value	Actual QR figure	Lower	Upper
Individual Factors				
Religion				
Christian	0.677	5.245	0.915	9.714
Muslim	0.66	1.266	0.523	2.225
Education level				
Formal Education	0.003*	0.000	2.00	2.00
Primary	0.001*	0.414	1.50	1.50
Secondary	0.007*	2.282	2.00	3.00
University/College				
Spousal support				
Early Weaning	0.0012*	0.433	2.001	5.926
Rearing animals	0.921*	0.707	-6.985	10.985
Nutritional factors				
Stunting				
Time to complete meal	0.6	0.32	4.00	4.00
Meal per day	0.001*	0.00	2.00	2.00
Institutional factors				
Wasting				
Seizures	0.0010*	0.000	1.00	1.00
Meals per day	0.0010*	0.000	2.00	3.00
Food shortage	0.0012*	0.121	1.00	2.00

****Significant at 5% level** Data source: Primary data, 2019

Table 5 shows the standard ratio for likelihood of different factors to influence malnutrition in children living with Nodding Syndrome. The likelihood of religion influencing malnutrition is not there at all and thus not statistically significant. Non formal education is likely to influence nutrition in nodding disease children ($OR=0.000$; 95% CI 2.00-2.00; $p < 0.003$), Spousal support through weaning of these children is also likely to influence their Nutrition Status nutrition ($OR=0.433$, 95%CI 0.00-5.926, $p<0.001$). Underweight through Meals per day ($OR=0.000$, 95%CI 2.00-2.00, $p<0.001$) wasting through seizures ($OR=0.000$,

95%CI1.00-1.00, p<0.001) and Underweight through food shortages (OR=0.0012, 95%CI0.00-5.926, p<0.001. are also among the factors that can influence nutrition in Nodding disease children respectively.

Thus, the static shows that are severe Malnutrition, 100%, Manifesting among NDS Children in Akwang sub county

Table 6: The nutritional coping strategies of families with children with NDS in Akwang Sub County, in Kitgum District

Variables N=123	Nutritional Coping Strategies	
	Yes	No
Rear animals	92(74.8%)	31(25.2%)
Information on nutrition	64(52%)	59(48%)
Own land	119(96.7%)	4(3.3%)

Data source: Primary data, 2019

Table 6: nutritional coping strategies of families with children with NDS in Akwang Sub County

Table shows that most families are rearing animals (74.8%) compared to the 25.2% who don't, 96.7% of the families own land which they use to plant all kinds of crops for feeding and rearing cows on, which is used as food to eat, most families try to get as much information on nutrition (52%) as possible has been among the important strategies of most families to cope up with food and nutrition of NDS children in Kitgum.

Qualitative outputs

This section presents summary findings from the Key informant interviews during the assessments of the study. These findings are summarized into themes. They included caretakers' knowledge on factors influencing stunting, wasting and underweight among NDS children. We used an interview guide to investigate and get in depth information concerning how caretakers understand nodding disease and the different factors that influence stunting, wasting and underweight among NDS children, which would in the end enable us assess the nutritional status and associated factors among children (15- 18 years) with nodding syndrome attending Akwang HCIII. (See Table 7)

Table 7: Understanding the knowledge and factors influencing stunting, wasting and underweight among NDS children.

Theme	Sub-theme	Category	Responses
Factors influencing malnutrition status in nodding disease children	Care takers' knowledge	Common knowledge and perception	-Big problem -abandonment by male spouses - nodding their heads and barely eat their food
	Wasting	Characteristic of Nutritional status	<i>"Failure to eat, mental confusion, the child becomes inactive/dormant especially in the morning, Unconsciousness, Head nodding." (Respondent)</i>
	Stunting	Characteristic of nutritional status	<i>"Poor families may have like one meal a day unlike well to do families this affects the feeding processing terms of frequencies" (Respondent)</i>
	Underweight	Characteristic of nutritional status	<i>"nodding and collapsing, the feeding process is interrupted hence no nutrient entry to the body"(Respondent)</i>

Discussion

Prevalence of malnutrition among children with nodding syndrome in Akwanga Sub County in Kitgum District.

The prevalence of wasting, stunting and underweight was 100%, 90% and 78% respectively. A similar study conducted in 2013 concluded that Nodding disease syndrome appeared to be increasing in Uganda since 2000 with 2009 parish prevalence as high as 46 cases per 1,000 5- to 15-year old children(Foltz et al., 2013). They further stated that as much as many risk factors have been revealed in relation to NDS, there's no supporting evidence, different parameters were examined in their research and they included serologic testing and raised nutritional deficiencies and toxic exposures as possible etiologies. Vitamin B6 deficiency was present in most cases (84%) [3]. This shows that more research should be done in this area.

According to Tumwine (2012),there's evidence that most nodding disease children have severe wasting. In war situations, including Northern Uganda, malnutrition, especially amongst children is very prevalent. This also reported high rates of malnutrition in the Nodding children mainly due to shortage of food in this region. The NDS children of Northern Uganda were severely malnourished and showed Protein-Calorie Malnutrition with severe various vitamin deficiencies. In as much as there has been a treatment interventions for Nodding disease in Northern Uganda, which includes feeding and replacement of the vital nutrients in the affected children with much success, some of these malnourished children may forever remain stunted and wasted as they had already passed the age of maximum [4] bone growth.

A study conducted in 2016 on Data on food availability, rainfall, and prevalent disease temporally related to the NDS reported that the epidemiologic curve of NDS incidence spanned 2000–2013, with peaks in 2003 and 2008. Month of onset of head nodding was non-uniform, with all-year-aggregated peaks in April and June when food availability was low. Families with one or more NDS Cases had been significantly more dependent on emergency food and, immediately prior to head nodding onset in the child, subsistence on moldy plant materials, specifically moldy maize. Medical history revealed a single significant association with NDS, namely prior measles infection.

Similar studies conducted by [4], showed that there's also strong fear that the food distributed might be of poor Quality, expired or poisoned which is because in an environment of distrust, people might also not trust well-intentioned interventions which has also played a role in prevalence of malnutrition or a seen as a theory of causation factor [5], This implies that the interventions made government and NGOs may be rendered ineffective this fears and reservations by the communities.

Some reports compiled by MOH show that the government has tried to solve malnutrition through giving NDS patients fortified foods which are said to have helped in boosting their immunity but despite the above commitments by the Government of Uganda in responding to the problem of Nodding Syndrome, there are still challenges being faced. Regardless of the numerous and extensive investigations, the cause of NDS is yet to be known – implying that the patients will have to remain on treatment and monitoring for unknown period of time. This has instilled anxiety and feeling of hopelessness in the affected children and their families [6] Therefore, there is no prescription medicine for the treatment of NDS to-date. Also, the exact prevalence of Malnutrition sub county in Northern Uganda is un know except for Akwanga Sub county which this study has determined

Factors influencing nutritional status among children with nodding syndrome in Akwanga Sub County in Kitgum District.

The factors found to influence malnutrition status among nodding disease children included Dietary diversity and seizures eating food especially during feeding causing stunting among Nodding disease children in Kitgum which was statistically significant.

Studies show that un-satisfactory food intake is the major cause of the nutritional deficiencies among the children hence, undermining their nutritional status [7]. Also poor nutritional status in children has a long term effect on physical growth and development that lead to high level of illness and disability in adult life [8]. An Environmental, dietary and case-control study conducted in 2016 reported that the maize consumed reportedly smelled bad and induced diarrhea and vomiting which shows a history of difficult diet for nodding disease children thus acute wasting and stunting(Spencer et al., 2016)[9], this shows that Quality assurance and Food safety controls of the food supplied to the NDS children is not adequate, and this calls for established systems of Quality Assurance and Food safety.

Children affected by nodding disease experience a complete and permanent stunting of growth. The growth of the brain is also stunted, leading to mental handicap. The disease is named for the

characteristic, pathological nodding seizure, which often begins when the children begin to eat, or sometimes when they feel cold It was evidenced that bizarrely, the seizures normally occur when the sufferers start to eat, or when it is particularly cold.

Furthermore, a study conducted by [10] in Northern Uganda, showed that NDS children of Northern Uganda were severely malnourished and showed Protein-Calorie Malnutrition with severe various vitamin deficiencies. However, some of these malnourished children may forever remain stunted as they had already passed the age of maximum bone growth [10]. This same study showed that the cases they had dealt with had severe loss of appetite (anorexia), a symptom of depression, as well as total inertia and psychomotor retardation to the point of a staring depressive stupor and/or catatonia [10]. The loss of appetite and chronic food shortages led to severe malnutrition, stunted growth.

Studies have shown that under nutrition/weight is due to inadequate food intake and also low meal frequency [11]. Under nutrition is form of malnutrition that is as a result of a wide range of determinants, most of which relate to unsatisfactory food intake or severe and repeated infections, or a combination of the two during childhood [12, 13].Studies show that features of Nodding disease are nodding attacks with repetitive forward bobbing of the head, frequently associated with other types of epileptic seizures and because of neurological signs, children become underweight and stunted as well [4, 12]

Nutritional coping strategies of families with children with NDS in Akwanga Sub County, in Kitgum District.

As much as most families rear animals, own land which they use to plant all kinds of crops for feeding and rearing cows on, which is used as food to eat, and try to get as much information on nutrition as possible, and even the government coming in to help give fortified food to the patients, there are still challenges. According to Gazda and Kitara,[14]) growth statistics showed steady improvement over time using local nutrition and multivitamin supplementation. Severe and moderate stunting was reduced from a combined total of 54.8–7.7% and 12.8% respectively. Severe and moderate wasting was reduced from 29.1–2.6% and 5.1% respectively. Three groups of NDS children were identified and compared in the review; Low seizure occurrence averaging < 2 seizures/month (28.1%); Moderate averaging 2–4 seizures/month (34.4%) and High averaging > 4 seizures/month (37.5%)[15]. This gives the lowest, moderate and highest average seizures recorded per month respectively.

According to a study conducted in 2019, it showed that also support interventions for both parents, including counselling, household income and nutrition support and improved clinical care and seizure control in affected children, could improve the capacity of whole families to care for their children with NDS and in particular help mothers who are differentially overburdened as care providers [16] Also the treatment interventions for NDS in Northern Uganda has been feeding and replacement of those vital nutrients in the affected children with much success Different stakeholders through the health Ministry through the office of the prime minister have been providing and feeding nodding disease patients fortified foods which are said to have helped in boosting their immunity despite numerous challenges [6]

Conclusion

The prevalence of malnutrition in the NDS children is very high and this was significantly attributed to the presence or occurrence of seizures while feeding, religious beliefs and age at weaning. Various coping mechanism include rearing animals, plant different kinds of crops for feeding and rearing cows are in use by the affected family. Future efforts should focus on more researches on Nodding disease, cost-effectiveness studies on development of affordable Nutrient rich foods like different silver fish products and different milk products.

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