

Stereotypes on Nodding syndrome: responses of health workers in the affected region of northern Uganda

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Abstract

Background: Nodding Syndrome is a debilitating disorder of yet unknown etiology that has affected children and adolescents aged 3 – 18 years in parts of sub Saharan African countries including Uganda, South Sudan, Tanzania and Liberia.

Objective: To identify stereotypes and negative attitudes held by primary care health workers about nodding syndrome.

Method: Of one hundred health workers invited by the Uganda Ministry of Health for training on nodding syndrome from the three most affected districts of Pader, Lamwo and Kitgum forty were interviewed using a predesigned tool. Content and thematic analysis was applied.

Results: There were 22 females. The median age was 33 years (range 23-54 years). The participants included Psychiatric Clinical Officers, Medical Clinical Officers, Laboratory Technicians, Midwives, Registered and Enrolled Nurses. Overall, four broad categories of negative stereotypes were identified; Nodding syndrome is 1) an incurable disease, 2) is associated with evil spirits and curses, 3) is disabling, making the patient a burden to society and 4) is a fatal illness.

Conclusion: Primary health care workers who lead the care of patients with nodding syndrome have several negative stereotypes that may potentially impact negatively on the quality of care they provide.

Key words: Stereotypes, nodding syndrome, northern Uganda

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Introduction

Negative stereotypes towards medical conditions create stigma which can result in major impediments towards provision of medical care. It can directly impact on patients' well-being or the quality of health care they receive¹. Public or social stigma is constituted by attitudes and perceptions which may result in stereotypes i.e. knowledge structures known to most members of a social group. Prejudice and discriminations are the emotional and behavioural responses to these stereotypes²⁻⁴.

Health care professionals are tasked with the treatment and support of patients and it is assumed they are free from negative attitudes associated with the presenting ailments. However, like other members of society, health workers may form positive and negative attitudes which can affect the development

of a therapeutic relationship between a patient and a health worker and, can impact on the quality and range of services offered¹. The expression of these attitudes varies with the individual; in some it is overt while in others, it may be veiled, subtle, or covert. It is also influenced by the direction of the attitude or the strength and intensity with which a particular attitude is held. Particular types of diagnoses or disabilities are more likely to have negative attitudes formed about them leading to poorer treatment, rejection and devaluation of the patients and decline in community participation for the affected group of patients⁵.

Nodding Syndrome is a poorly understood emerging and debilitating disorder of unknown aetiology affecting thousands of children and adolescents in northern Uganda, South Sudan and Southern Tanzania⁶⁻¹¹. It is characterized by epileptiform seizures, neurological and cognitive decline, and stunted growth. The Ministry of health in Uganda developed a comprehensive response plan including training primary care workers to correctly

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identify and effectively manage patients and families affected with the nodding syndrome. The uptake and effectiveness of these interventions will partly depend on beliefs within the community, including that of health workers.

This study aimed to identify common stereotypes and negative attitudes held by health workers about nodding syndrome so as to inform their training and correct any false stereotypes that would hinder health care delivery to affected children and families. The study also serves to inform a more comprehensive evaluation and exploration of stigmatizing experiences of children and families affected by the nodding syndrome.

Methods

Design

This is a qualitative study of perceptions of primary health care workers in the three most affected districts of Pader, Lamwo and Kitgum in Uganda about nodding syndrome.

Participants

Participants were primary health care workers selected by their respective districts to train in and lead the provision of health care services to patients in the proposed nodding syndrome screening and treatment centers. This training was organized by the Uganda Ministry of Health as part of its comprehensive response to nodding syndrome. Participants included doctors, clinical officers, nurses, laboratory technicians and records assistants.

Study area

The study was conducted in Kitgum district which was chosen as the training site for the health workers from the three districts. The main local language spoken in the three districts is Acholi. The study was conducted in March 2012.

Procedures

One hundred health workers from the districts of Pader, Lamwo and Kitgum were invited and trained by the team from the Ministry of Health on the identification, surveillance and symptomatic management of nodding syndrome. All the course participants were asked to brain storm on what stereotypes are and how they may affect health care service provision. One of the trainers (BM) guided discussions on stereotypes and how they contribute to the development of stigma. After this session, participants were informed of the study, its

objectives and benefits. The list of participants was subdivided by their training and qualification categories as doctors, clinical officers, nurses, laboratory technicians and records assistants. We randomly selected the first participant from each category and interviewed using the Internalized Stigma of Mental Illness (ISMI) tool which was designed to measure the subjective experience of stigma, with subscales measuring Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance¹². We also asked the participants to write five negative stereotypes on nodding syndrome. We interviewed participants from each category in turn, one category after the other until point of data saturation when no new information on stereotypes and negative attitudes towards nodding syndrome could be gathered any more. Altogether, we interviewed 40 participants after explaining the purpose and need for the study, and their freedom to participate or decline participation without fear of any negative retribution. Verbal consent was requested and consenting participants were given the study tool which was explained to them further in the process of the interview. In addition, the participants were requested to list five common stereotypes they associated with the illness. Content and thematic approaches were used in the analysis of the responses. Analysis was done manually, and was started during data collection with identification of main emerging themes.

Sample size

In this exploratory qualitative study we included forty participants. Recruitment and interview was continued until point of data saturation was reached.

Results

The forty health workers included Psychiatric Clinical Officers, Medical Clinical Officers, Laboratory Technicians, Midwives, Registered and Enrolled Nurses. The distribution of the participants by district of occupation included; 12 from Lamwo, 18 from Kitgum and 10 from Pader districts. There was similar representation by gender with 22 males and 18 females. The respondents' median duration in the health service was 8 years (ranged from less than a year to 34 years). The median age was 33 years with the youngest and oldest participants as 23 and 54 years of age respectively. The health workers were working at various levels of the health care facilities including Health centre III and IV, District

General and Regional Referral Hospitals and in the offices of the District Health Officers.

No statistical comparisons were done by level of education and age given this was a qualitative study with a small sample size, but there seems to be no variations in response by gender, age and cadre (a proxy to education attainment) of health worker. There were no positive stereotypes about nodding syndrome that emerged from these health workers. Overall, four broad categories of negative stereotypes were identified; Nodding syndrome is 1) an incurable disease, 2) is associated with evil spirits and curses, 3) is disabling and makes the patient a burden to society and 4) is a fatal illness.

Nodding syndrome is an incurable disease

Up to 80 per cent (32/40) of the respondents believed that nodding syndrome has no cure and patients would have to live with it for the rest of their lives. This is typified in a discussion point by one of the health workers; *“children with nodding syndrome cannot get cured because the disease has no treatment...so they stay like that for the rest of their lives”...enrolled nurse from Pader.*

Nodding syndrome is associated with evil spirits and curses

Almost two thirds of the respondents (27/40) believed that the syndrome is brought about by evil spirits and curses following the recently concluded war between the Government of Uganda and the Lord's Resistance Army (LRA) rebels. This has been strongly expressed by health workers, thus; *“...the disease is caused by curses from the gods who are annoyed with the Acholi for the war...” Nursing officer, Kitgum General Hospital.*

Another health worker, a laboratory technician from Lamwo district raised a similar remark; *“This disease is happening because of evil spirits from the people who died during the war and were not buried according to the burial traditions of the Acholi!”*

Nodding syndrome is disabling, and makes the patient a burden to society

A common belief among respondents was that nodding syndrome disables the patients, making them unproductive on their own and therefore a burden to society. This is typified in references such as; *“...children with this disease are useless; they cannot do anything for themselves...” Registered Nurse Pader.*

Another health worker similarly expressed; *“these children are a burden to the community; parents cannot work because of them...” Nursing officer, Kitgum district hospital.*

Nodding syndrome is a fatal illness

Majority of the health workers (33/40) shared the belief that nodding syndrome is invariably a killer disease that has no effective treatment and often left its victim dead. This is found in expressions such as; *“...a child with the disease eventually dies because they cannot be treated” Medical Clinical Officer from Pader district; and “these children will always die because nothing can be done to help them...” Registered nurse, Kitgum district.*

Discussion

This operational exploratory study provides an insight into the perceptions of primary care health workers selected by their district leaders to be trained to manage nodding syndrome and help mitigate the impact of the syndrome in the affected region. The study was performed on the first day of the five days training program of the Ministry of Health of Uganda. The study found no positive but only negative potentially stigmatizing stereotypes: nodding syndrome is an incurable disease; is associated with evil spirits and curses; is disabling and makes the patient a burden to society and, is a fatal illness. Considering the paucity of knowledge on this syndrome in the literature, this study was motivated by the fact that negative perceptions by health workers about a disease or health condition may negatively affect the quality of their services and acceptability of such services by clients. This has been shown in mental illness^{13,14}. Nodding syndrome also presents with mental retardation^{6,15-18} and abnormal behaviours that may be understood as a form of mental illness by a community that has just emerged from a long period of armed conflicts^{16,17}. This is a community that may be sensitive to strange conditions and occurrences (including diseases) in their environment given the traumatic experiences they underwent during the armed conflicts¹⁹⁻²¹. Any negative attitudes of health workers towards a disease condition affecting such communities may adversely affect trust in the health care system and delivery of health care services.

Essence of stereotypes in health care for nodding syndrome

Stereotypes contain collective opinions about particular groups of persons who quickly generate impressions and expectations of persons who belong to a stereotyped group¹³. Though many persons may be aware of these stereotypes, they do not necessarily agree with them. Majority of the health workers who were being trained by the Ministry of Health (MOH) of Uganda to symptomatically manage and mitigate the impact of the nodding syndrome on the affected individuals and their families shared very similar stereotypes on the disease. The stereotypes identified by health workers could be a reflection of those held by the wider community, and are similar to stereotypes that have been associated with highly stigmatized illnesses in the literature.

Most of these stereotypes relate to the outcome of treatment of the disease suggesting that treatment is futile. Such views are very likely to minimize the efforts the health worker would put into the care of the patients with nodding syndrome. The ability of the health workers with such stereotypes to provide health education, encourage treatment compliance and offer family support to the affected children maybe very much curtailed by their own negative attitudes. Similar negative attitudes by health workers were observed in the earlier days of the HIV/AIDS epidemic when antiretroviral treatments were not yet widely available in sub Saharan Africa and were shown to greatly reduce testing and care for the disease^{22, 23}. In addition to lack of effective antiretroviral therapy, it is possible that such negative stereotypes could have contributed to the high mortality rates from HIV/AIDS in the earlier days of the epidemic^{24, 25}. Given this experience, we sought to identify negative stereotypes about nodding syndrome so as to formulate strategies to reverse them particularly among the health workers so that they can competently and without prejudice, provide clinical care, health education, encourage treatment compliance and support families with nodding syndrome.

Stereotypes and community responses

Health workers' views about the causes, course and outcomes of diseases and other health-related conditions can have far reaching implications on communities. When health workers hold causation views such as a disease is caused by "evil spirits" and or "curses from the dead", given their privileged position in society, they may propagate such views

to the community through their communications with the patients and their families and directly through their interactions as members of the affected communities. This may lead to behaviours that may be self-destructive.

The notion of a god or deity being responsible for a disease or ailment and more or less as retribution for an offense stigmatizes the people struggling with the illness by putting the blames for their sickness upon misbehaviours, while presupposing that those without the disease in question are free of the sin that brought forth the disease upon the affected^{26, 27}. In the case of Northern Uganda which is just recovering from more than twenty years of armed conflict and where the community had animosity about the failure of the government of Uganda in protecting them^{19, 20, 28, 29}, such futility and "blame game" views by the health workers working in the public health sector may result in a sense of hopelessness and lack of trust in efforts by the government and development partners in the fight against the syndrome.

For a disease with unknown aetiology and with no proven treatments, the cooperation of the affected communities is very much needed to allow conduct of research to identify effective treatments. It is therefore important that targeted training on stereotypes and stigma associated with the syndrome be provided to the front line health workers. This will help in the management and mitigation of the impact of nodding syndrome on families and communities so that there is more trust, hope and acceptance of health care initiatives, research and other response interventions against the syndrome.

Study limitations

This study is not without limitations. First, the ISMI tool used to guide the formulation of the tool for this study has been validated elsewhere and for use in mental illness but no in this study setting. However, since nodding syndrome is an evolving disorder, there was no validated tool that could specifically be used to measure stereotypes. Future studies could use available data and many children with nodding syndrome now available in the treatment centres to validate stereotypes and stigma tools for use among health professionals, patients and families with nodding syndrome and the community. Second, the use of qualitative design in this study does not provide for estimation of the magnitude of described stereotypes among health workers and therefore judgement of cost effectiveness of interventions to

reverse the identified stereotypes cannot be done based on this study findings.

Implications of this study

Negative stereotypes towards nodding syndrome among health workers may reflect beliefs held by the communities from which the health workers themselves originate and serve. Therefore, the development of strategies to reverse such negative stereotypes among the health workers may have a multiplier effect through the health workers to the communities and improve treatment acceptability, compliance and better outcomes for the disease. Mental models of illness or stereotypes improve with improving knowledge about the illness^{14, 30}. When the identification of negative stereotypes is done early in the course of a disease outbreak and its management and the health workers' knowledge updated as regularly as needed, many lives may be saved and hopelessness reduced in the society. The results of this study will also inform future health worker trainings and community initiatives targeting the management of the syndrome. In terms of research, greater acceptance and participation rates maybe expected and therefore high study power and generalizability of results are more likely.

Conclusion

Primary care health workers in the districts of Kitgum, Pader and Lamwo which are greatly affected by the nodding syndrome have several negative stereotypes against the disorder. These stereotypes may negatively influence their commitment to clinical care of the children with the syndrome, and their ability to provide supportive health education and health promotion activities in the community. The attitudes of the health workers may also negatively influence participation of affected children, families and communities in researches about the disease and this may delay advances of knowledge on the disease, and its proper treatment and prevention strategies. The stereotypes identified could inform the development of stigma assessment tools and anti-stigma messages for the national response towards the Nodding syndrome. Refresher training with particular target of correcting these stereotypes in adding to updating the health workers' knowledge on nodding syndrome as more information becomes available through researches on the syndrome is recommended to help reverse these stereotypes among these health workers and

other health workers in the region and improve delivery of care to the affected children and families.

Author Contribution

BM conceived of the study and drafted the manuscript. ADM participated in the design of the study and helped to draft the manuscript. JM and RI helped coordinate the implementation of the study. CA and RI participated in the drafting of the manuscript. All authors read and approved the final manuscript.

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