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Abstract

Nodding Syndrome (NS) occurs within a wide spectrum of epilepsies seen in onchocerciasis endemic areas of sub-Saharan Africa. It has debilitating consequences on affected individuals and increases the socio-economic, physical and psychological burden on care-givers and their households, diminishing their standing within the community. Social science research on the disproportionate burden of the disease on females is limited. Based on ethnographic research over 3 years in northern Uganda, we explored the burden of being ill and care-giving for persons with NS from a gendered perspective. We found that NS-affected females were at greater risk of physical and psychological abuse, sexual violence, unwanted pregnancies, sexually transmitted infections and stigma, in a context of deteriorating socio-economic conditions. Primary care-givers of the NS-affected, mostly women, struggled to make ends meet and were subjected to stigma and abandonment. Targeted interventions, including legal protection for affected females, stigma reduction, and psycho-social and financial support are needed.

Keywords

nodding syndrome, onchocerciasis, epilepsy, gender, disability, stigma, Uganda, sexual violence, care-giving

Introduction

Nodding Syndrome (NS) is a debilitating form of epilepsy characterized by a unique form of seizure during which the head repeatedly and uncontrollably drops forward (Dowell et al., 2013). NS mostly affects children with symptom onset between 5–15 years of age and occurs only in areas endemic to onchocerciasis (Dowell et al., 2013). Affected individuals often experience other forms of generalized seizures, cognitive decline and growth faltering (Winkler et al., 2008, 2014). Death by drowning and severe burns are frequently reported due to epileptic seizures being triggered by the flickering of open fires or the reflection of sun on water (Olum et al., 2020). Recently, some scientists have argued that NS is a specific form of epilepsy within a spectrum of epilepsies seen in onchocerciasis endemic areas, and should be studied as part of a broader problem of onchocerciasis-associated epilepsy (OAE) (Colebunders et al., 2014). Other scientists have attempted to identify the reason for the association to onchocerciasis by looking

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at whether it is a neuroinflammatory response to onchocerca volvulus (Idro et al., 2016) or an autoimmune reaction to it (T. P. Johnson et al., 2017). To date, the pathophysiology of NS remains unknown and there is no known cure (Colebunders et al., 2016; Pion et al., 2009).

In Northern Uganda, it was estimated that more than 3000 individuals have developed NS without a large variation between the males and females (Iyengar et al., 2014).[1] In highly affected villages, individuals with NS and other forms of epilepsy often cluster at household level (Dowell et al., 2013), which increases the burden on the care-givers and their households (Nakigudde et al., 2016). Furthermore, indicators show that the northern region is badly affected by poverty (UBOS, 2017), a legacy of at least two decades of civil conflict in the area (Branch, 2013), which exacerbates the burden.

In rural areas in Africa, where people predominantly depend on subsistence farming, a person's physical ability to contribute manual labour is highly valued within society (Baskind & Birbeck, 2005). The social standing of a person, whether male or female, is linked to active participation in agrarian activities. An NS-affected person, who is struggling to meet expectations regarding such duties, loses status, which is associated with productivity in society. If unable to perform daily chores, which tend to reflect gendered divisions of labour, a person may be stigmatized and deprived of social and economic opportunities such as marriage (Baskind & Birbeck, 2005). Unmarried adult females with epilepsy find themselves at the bottom of the 'pecking order' regarding education, employment and access to food (Buchmann, 2014, 2015). Anecdotal evidence suggests that women with epilepsy find themselves having to exchange sex for money and shelter more frequently than their healthy counterparts (Baskind & Birbeck, 2005; O'Neill et al., 2019). They become especially vulnerable and easy targets for sexual exploitation and physical abuse (O'Neill et al., 2019). In this article, we show how women subject to such forms of abuse plunge deeper into poverty.

To date, the scientific literature on NS is dominated by biomedical research, except for the social science research undertaken by Buchman (Buchmann, 2014, 2015), Van Bemmel and Van der Weegen (Van Bemmel, 2016a, 2016b; van Bemmel et al., 2014; van Bemmel & van der Weegen, 2017) who addressed disease conceptions regarding NS, the politics of illness and healing, as well as the stigma and poverty that affected families face. There is a need not only for a more holistic understanding of community perceptions and the burden of NS and its social consequences, but also of how hardships are disproportionately distributed according to gender. An understanding of this is imperative for targeted inventions to alleviate the burden of disease. This study therefore used a gendered lens to look at the psycho-social, cultural and economic burden of NS in northern Uganda.

Methods

Study Design

Ethnographic research was carried out between 2015–2017 in northern Uganda, in the regions most heavily affected by NS. Methods including participant observations, informal conversations, in-depth interviews and focus group discussions were used to provide an in-depth understanding of the burden of care which would be difficult to achieve using more standardized approaches such as surveys (R. B. Johnson & Onwuegbuzie, 2004; Quinn, 2002).

Study Site and Population

This study was conducted primarily in Kitgum district and partly in Gulu district in northern Uganda[1], a decade after the Lord's Resistance Army (LRA) war had ended. The region has endured more than two decades of civil conflict, the most recent being the LRA war from 1987–2006 (Branch, 2013) as well as enduring the NS epidemic between 1997–2013 with a peak in the number of cases in 2008 (Spencer et al., 2016). Inhabitants from these villages were mostly of the Acholi ethnic group[2] and most had lived in the area for several generations.

Northern Uganda has the second highest percentage of people living in poverty (32.5%) in the country, substantially larger than the Ugandan average of 21.4% (UBOS, 2017). Literacy in the Acholi region is vastly disproportionate to gender, where 79% of men and only 45.5% of women are literate (UBOS, 2017). The Acholi, residing primarily in the Kitgum, Gulu and Pader districts of Northern Uganda, used to be predominantly cattle herders;[2] however, virtually all of the Acholi cows were stolen from them in the mid-1980s by the Karamajong, who lived in north east Uganda (Doom & Vlassenroot, 1999; Theresa McElroy OT(C) et al. (2012) and later more cows were taken during the LRA war when homes and possessions were indiscriminately used or taken over by both the army and the rebels while – for their safety – the people were eventually moved into 'safe villages' or camps (Theresa McElroy OT(C) et al., 2012). Even in 1997, Kitgum and Gulu districts owned only 2% of their original livestock (Doom & Vlassenroot, 1999). While there have been post-war government efforts to replenish livestock in northern Uganda, herding cattle remains small scale and agragian activities are the main source of income.

Sampling Strategy

Sampling occurred in two stages, first the districts and villages were sampled followed by the respondents in those villages.

Table 1. Respondents for focus group discussions and in-depth interviews.

	Total
Total FGD	**13**
FGD mixed (male/female, affected/unaffected)	6
FGD women only	4
FGD health staff–Village health workers	1
FGD care-givers only	1
FGD teachers	1
Total IDI	**94**
IDI–Care-giver	30
IDI–Community member (unaffected)	22
IDI–Health staff	23
IDI–Politician	4
IDI–Welfare/social worker	2
IDI–Traditional healer	3
IDI–Individuals with NS/epilepsy	8
IDI-Teacher	2

District and village sampling: Kitgum and Gulu districts were purposively selected because (i) they had contrasting villages with low (about 1%) and high (>6%) NS prevalence according to surveillance data from 2012 and (ii) the research team could leverage on contacts made during the 2nd NS conference in Gulu, such as district officials and the NGO 'Hope for Humans' who were working with NS-affected families. Limiting the number of districts allowed us to visit the selected sites repeatedly over the course of 3 years, which helped build community trust and gain a deeper understanding of the context and the experiences people faced regarding NS. 10 villages were sampled in Kitgum from Akwang and Amida subcounties.

Respondent sampling: A mixed-sampling approach was used, driven by both theoretical (based on emergent findings) and snowball sampling techniques (relying on one sampled person to contact the next person in the sample) in order to have maximum variation and representation in the sample. We aimed at including all social groups, regardless of age, gender, persons directly affected/unaffected by NS/epilepsy, occupation, livelihood, local hierarchy or locally perceived expertise. Respondents and interviews conducted are listed in Table 1.

Data Collection

Data collection consisted of participant observations, informal conversations, in-depth interviews and focus group discussions. Participant observation was used to contextualise the understanding of the local context. The field research team, which included the anthropologist and two Acholi research assistants, participated in daily activities in the community setting, observing events in their usual context, while having informal conversations with a maximum variety of research participants. This method was both used to obtain primary data as well as to cross-check the validity of the information obtained in semi-structured interviews by establishing rapport and building trust with community members to reduce response bias. Notes were taken during informal interviews if appropriate, otherwise if necessary, the conversations were written down in detail afterwards. We first investigated what was expected of males and females of different age groups in Acholi society in northern Uganda. Subsequently, we studied how these norms specifically impacted persons with NS and their care-givers. Informal conversations centred around emergent themes such as perceptions of epilepsy, access to and perceptions of public/private health facilities, traditional medicine, religious practices, challenges faced by NS-affected individuals and their care-givers, stigma and coping mechanisms.

In order to inform the villagers about the purpose of the research, we arranged village meetings to introduce ourselves and let people know what we were there to do as well as giving them an opportunity to ask questions. This gesture was very much appreciated by people, who said that they felt respected. Locals complained that such meetings were not common. Due to research fatigue and general scepticism and distrust towards researchers in the area and the politicising of NS (Irani et al., 2019), such meetings were crucial to building relationships of trust. We emphasized that we were interested in speaking with both women and men, elderly and young, as well as households that were affected by NS and those that were not, so as to minimise any potential stigma associated with participation in the study. Overall, 94 semi-structured in-depth interviews were conducted in the local language, Acholi, in a private setting, either at their homes or in settings where respondents felt at ease. 13 group discussions, with a variety of community members, were conducted in market places or outside people's homes. These were either spontaneous discussions with people gathered together socialising in the late afternoons and evenings after their workday or formally organized discussions by the village leader. If formally organized, we specified the desired demographic composition of the group (men, elderly, women, affected households, unaffected households, etc.), a few days in advance.

Due to the sensitive nature of some of our questions, we always respected social hierarchies and discussion of sexual abuse with women and men was done separately and privately throughout the research. Sexual abuse was not directly discussed with the patients themselves as it would have been too sensitive; however, as clinical officers were directly concerned by such issues as part of

their work routine, it was ok to discuss it with them. Many mothers and caretakers volunteered the information themselves without even being asked specifically about it as it was seemingly a common problem. All recordings were transcribed in Acholi and translated into English by the trained field assistants.

Data Analysis

Data analysis was retroductive (combining inductive analysis from field data and theory from existing anthropological literature (Lewis-Beck et al., 2003; Quinn, 2002)) and was carried out concurrently with data collection. Relevant categories for analysis were identified after triangulating data from participant observations, informal conversations, in-depth interviews and focus group discussions. Some of these categories were, for example, care-giver, patient, sexual violence, abandonment and discrimination, economic burden, psycho-social burden and so forth. Through the analytic process, the data were constantly compared and contrasted with existing theories so as to critically question what had been collected, ensure data quality and to ensure the data was analysed using appropriate literature. The data were managed and analysed using NVivo for Mac 11 Qualitative Data Analysis software (QSR International Pty Ltd. Cardigan UK).

Ethical Considerations

The study was reviewed and approved by the Institutional Review Board of the Institute of Tropical Medicine in Antwerp (IRB/AB/ac/036 Ref: 983/14); the Makerere University School of Medicine's Research Ethics Committee (REC REF 2015-079) and the Uganda National Council for Science and Technology (REF: SS 3845). Verbal consent was obtained from all participants with whom we conducted in-depth interviews and group discussions. Informal converations and participant observations took place spontaneously while living and spending time in the village after our initial introductory meeting. The people we engaged with through these informal data collection techniques were thus aware of what we were doing, the purpose of the research and our procedure. They volunteered the information they gave us and generally consented to participation in this research. Confidentiality was maintained by storing all data – including audio recordings – on a password protected computer. In case human right violations were detected, they were reported to local authorities or NGOs who could help the individuals concerned. No respondent names have been used in this manuscript, and exact ages have been excluded to preserve confidentiality.

Results

The narrative below describes the larger gender-based social norms of Acholi society and how these norms impact NS-affected persons and their care-givers. The data shows how females, both NS-affected patients and female care-givers, are disproportionately more affected by the burden of the disease due to the given gender expectations within society. The burden of NS disproportionately falls on females in that they are subject to sexual violence, stigmatization and poverty. Particularly important issues that affected women's well-being that emerged were sexual abuse, under-reporting of the abuse, marriagability and impoverishment.

Gendered Division of Labour and Education

During ethnographic fieldwork, we learned that according to the traditions of Acholi society, important decisions in the family and the community were predominantly made by men or a council of elders. The council of elders consisted of men with one or two elderly women. Younger women contributed to the decision-making indirectly through their husbands who sat in the council of elders; however, men had the last word. In every homestead, the man was typically viewed as the head of the household and deserved ultimate respect especially with regard to decision-making. The Acholi are patrilineal and according to their custom, the children belong to the man and his clan. If a man decided to leave his wife or vice versa, the children usually stayed with him. In rare cases, when a man did not want the children, the woman took them with her, and the children would be commonly referred to as 'bastards' and stigmatized by others in the community for not being in their fathers' clan.

As rural livelihood mostly relied on subsistence farming, agricultural tasks were distributed within the household. These tasks were gendered in that the men in the family were expected to do the more strenuous labour like seasonal digging and preparing the land for planting crops. Women were responsible for the rest of the tasks, which included weeding and harvesting while some also helped with digging. We found that some men and women also worked on other people's land for a wage. Men also engaged in other heavy physical labour like quarrying rocks and building homes. Hunting for subsistence and to sell was also a common income generating activity for men. Men went to the designated hunting grounds in groups and spent a few weeks there accompanied by women who prepared the hunted meat for drying and cooked for the hunters. The preserved meat was brought back and sold to community members.

In addition to agricultural cultivation, women in general were considered responsible for taking care of the

household. According to the social norm, typical tasks included fetching water and firewood, preparing (peeling, drying, pounding, cooking) food, cleaning the home, washing clothes and utensils, and caring for young children, the elderly and the sick. It was also common for women to engage in petty trade by preparing and selling local brews, firewood, harvested grains, fruits and vegetables or snacks. This was done on a local scale, that is, selling to neighbours or on a weekly 'market day'. Every village had a designated area and day of the week for the market where people congregated to sell their produce. This included household items, clothing, foodstuff, drinks and alcoholic beverages.

We observed that task assignments depended on the age, ability and skills of the male or female which was closely tied to social hierarchy. For example, an elder female in the household may delegate certain activities to younger members of the household. Younger boys, who were unable to engage in very strenuous activities, contributed by sweeping the floor around the homestead and assisting with fetching water. Girls took care of younger siblings. In terms of education, boys were generally prioritized over girls, as going to school meant added cost of school fees, supplies and a lack of helping hands at home so often the household could not afford to send all the children to school. It was evident that within this social context, individuals were valued for the gendered duties they fulfilled, which affected women's chances in marriage.

How Gender Norms Impact on Persons With NS and Their Care-Givers

We found that the social standing that came with fulfilling gender roles and being a productive member of society had an impact on how individuals were affected by NS. Epilepsy in the study area presented itself within a wide clinical spectrum. Some individuals were severely affected, both physically and mentally, while the majority appeared to be physically healthy, with some intellectual decline. A few individuals we encountered appeared completely healthy except when suffering from a seizure. The most severely affected individuals were excused from working due to their illness; however, those experiencing sporadic episodes of 'sickness' were expected to continue fulfilling their social obligations and to carry out gender-specific tasks.

Most affected individuals and their care-givers confirmed that fatigue triggered seizures. In the case of affected boys and men, strenuous labour often triggered seizures and when it was evident that they would not be able to continue working on a farm, they were granted reprieve from the task. Furthermore, because most male activities were seasonal, it was not uncommon to see boys and men engaging socially in the daytime during off-season. If the symptoms were not very severe, the affected males could similarly engage socially, which offered some protection against stigmatization and if the family had the means, they would pay for his schooling. Depending on the degree of sickness, schooling was prioritized for the healthy over the sick and boys over girls. Boys of marriageable age without severe symptoms were also encouraged to get married and were assisted by older male relatives with cattle, to pay the bride price.

For affected girls and women, tasks were numerous and social obligations varied. If she could not contribute on the farm, she was expected to at least cook food or fetch water. Females, regardless of illness, were expected to be seen working. Even when socializing during the day, women would engage in household duties such as peeling vegetables or washing clothes. It was acceptable to see elderly women socialising, drinking alcohol and not working during the day; however if a young woman did the same, neighbours would gossip that she was lazy and not a 'good woman'. Females affected by NS with limitations in their ability to carry out responsibilities expected of them would be considered 'unmarriageable'. To avoid this stigma, affected women tried to keep up with the work, which inevitably led to fatigue. Additionally, typical 'female chores' brought women closer to fire (cooking) and water (fetching water, washing clothes and utensils), putting them at a higher risk of severe burns or drowning during seizures. Many affected children's care-givers did not allow children near a fire or river, but this precaution often followed a previous accident and affected individuals frequently had severe burn scars. Despite burns and crippling scarring, women were still seen engaging in chores. We met an NS-affected girl whose hands were severely crippled from a burn. While peeling vegetables, she said,

> "…it pains me (referring to her hands) but if I do not work, they (her family) don't speak well to me and even beat me."– NS-affected female

She was living with her grandmother. Many NS-affected individuals struggled more when their care-givers were not their parents but other relatives or when the household was so poor that the care-giver was financially stretched and overwhelmed with work. In such households, where basic survival was at stake and any amount of help was necessary, it was not an option to let the NS-affected individual sit idle. This increased the risk of accidents giving rise to further debilitating consequences for NS-affected individuals.

Sexual Abuse

Sexual abuse, specifically by men towards females affected by NS, was regularly reported by respondents ranging from the community members, to NGO staff, as well as politicians, administrative district officials and health workers.

> "One challenge that we face, particularly in this area of nodding disease, is that there is too much abuse of human rights especially for the girl child … most of these (NS-affected) girls get sexually abused and get pregnant at their tender age; a child gives birth to a child whose father is not even known and this nodding-diseased girl has to raise the child adding to the burden on their care-giver and when these culprits are identified, the court is also not responsive. It has become common in the community and the culprits are not punished."–clinical officer.

While sexual and physical violence towards women generally was relatively common in this post-conflict area, NS victims were a lot more vulnerable and 'easy targets' for this abuse. This was such a problem, that one of the clinical officers said:

> "Sometimes I wonder if I should start prescribing birth control pills to all females affected by NS to help with this problem."–clinical officer

We probed to find out whether NS-affected males were also subject to sexual abuse and came across one case where the homosexual perpetrator was reportedly persecuted and transferred to the highest security prison. As for NS-affected girls, however, various cases of rape and defilement were repeatedly mentioned with many male perpetrators not being prosecuted. Parents explained that NS-affected girls were often perceived as 'useless', leading men to take advantage of them sexually, but without marriage. As a consequence of the sexual abuse, NS-affected girls were also at a higher risk of contracting sexually transmitted infections (STIs), including HIV (see Case 1).

Sexual Abuse and Reporting

Support services to assist women in case of sexual abuse situations were limited, and often protected the accused man.

> **Case 1:** A clinical officer reported that a teengage girl affected by NS and under her care, was a victim of sexual abuse. Her perpetrator, an HIV positive man on anti-retrovirals persuaded her to have sexual intercourse with him, when she was alone at home while her mother went to work on the farm. He offered her juice and sweets. Then he took her into the bush and forced himself on her. By the time her friends alerted people, he had already raped her and fled. She was brought to the clinic and while she insisted that he had forced himself on her, her mother refused to believe her, saying '*she doesn't understand anything*'. Her mother was initially hesitant and did not want to take her to the clinic, but as the clinical officer knew that the perpetrator was HIV positive, she decided to give the girl post exposure prophylaxis as a precaution, despite the mother's refusal to believe her daughter. The perpetrator was a neighbour and the case was never reported to the police.

The reason for under-reporting is linked to a number of factors explained further below.

Perpetrator Often a Relative or Close Family Friend. In most instances when care-givers and health officials spoke of sexual abuse, if the perpetrator was known, it was usually someone close to the family, such as a relative or a neighbour. Accusing such a perpetrator, particularly without a witness, could tar the accused family's reputation, which in many cases was the same as the accuser's family, or it would make it difficult for neighbours to live amicably alongside each other and cause further tensions in the village. Such disputes typically consisted of loss of trust or blaming the accuser of making false accusations because of jealousy or other past conflicts. Incidents like these could disrupt the, albiet superficial, peaceful and harmonious relationship among neighbours or family members in a post-war context where rebuilt relationships were still fragile. Avoiding such conflicts favoured obfuscation to 'protect' the perpetrator and blame the mentally impaired or weaker female victim. Some health workers suspecting incestuous abuse also hesitated to report the case, fearing loss of support for the victim if the abuser was reported.

Cognitive Decline and so Victim not Believed. Many affected children experienced cognitive decline, and in some cases, even psychosis and hallucinations as symptoms of the illness. As a result of this, a girl who was sexually abused while unconscious after a seizure may not remember her perpetrator. At other times, girls may not be believed, as described in case 1, unless an eye-witness came forward. Sometimes even mothers did not believe their daughters, because the actual or perceived mental impairment reportedly diminished the girl's ability to distinguish fact from fiction.

Girls Perceived as Promiscuous. In one case, a girl was abused at different times and gave birth to two children. Her first child was fathered by an unknown abuser, while

the father of the second child was known and he promised to return to take her with him, as his wife. She waited but he never returned. She was living with her grandmother and often not taken seriously. She also had a reputation of being promiscuous, particularly on market days. It was common for people from neighbouring villages to attend these local markets to sell their produce or merely to socialize, and these would usually evolve into large social gatherings with music, dancing and heavy drinking. Similarly, there were several respondents who asserted that victims of the disease had a higher sexual libido. The clinical officer also gave an example of how two affected individuals started engaging in sexual activity while waiting to be seen by the clinician at the health centre. She added that she did not believe this was a symptom of the disease but that this was normal for teenagers and as their cognitive abilities decline, so do their inhibitions.

Nodding Syndrome affected girls and women seen as unmarriageable. In a society where bearing children raised one's social value as a woman, the life of an NS-affected girl without children was viewed as wasted and they were perceived to be 'useless' and 'unmarriageable'. Therefore, in some cases, if a daughter became pregnant as a result of sexual abuse, it was seen as a blessing that, despite the abuse, at least she got a child even though in most cases, the father of the baby was absent, unknown or bore no responsibility for care-giving or providing financially for the child. This had become the norm and so the culturally enshrined tradition of the father being responsible for the household and for keeping his children ceased to apply to NS-affected individuals and their children. This in turn affected the care-givers, who were often the mothers of these NS-affected children.

Loss of Faith in the Judicial System. Many women expressed frustration about the reporting procedures for sexual abuse. They complained that even when cases were reported, culprits were not punished, and thus, they had lost faith in the judicial system. This discouraged people from reporting cases as this caused social tensions within the village and took away time from their work days, and in most cases, the effort was futile. Parents further feared the accusations of relatives and of neighbours for neglecting or insufficiently protecting their daughters so they preferred to remain quiet to avoid more social tensions.

Marriage and Nodding Syndrome

It was common for married women who became affected by NS, or married women who had children that were affected, to be abandoned by their husband and in-laws. Cases 2 and 3 illustrate this.

Case 2: A woman with NS had progressively become blind since her late 20s. Her husband had remarried and taken their two children with him. She was sent to her brother's home, the closest living relative, as he had benefited from her bride price. When we first met, she had a raw, fleshy, untreated burn wound that covered her entire right forearm. She was sitting under a tree with her head dropped forward. While we greeted each other, she continued to look downwards, visibly in pain as she flicked flies away from her wound. We heard her ask her brother's children for a glass of water but they dismissed her. One child even spat in her direction without any repercussions from the parents. This was unusual to see, as children are not to disrespect their elders in this way in Acholi society. We learned that she slept separately in a poorly maintained shed, without any bedding. Families typically slept together except for teenage boys who were given their own shed to sleep in as a right to adulthood, so this was unusual. She said '*they [brother and sister-in-law] don't guide me to my hut. Sometimes I get lost in the woods on the way to the hut and I spend days without food until someone finds me and brings me back*'. When we offered to arrange for treatment for her burn, she cried and said '*I wish I could just die. I beg you, don't leave me there. He [the brother] will not let me buy the medication and just keep the money*'. The village health worker, a distant relative, agreed to keep her in her home until her wound was healed. A year later, when we returned, the village health worker said that the woman was not doing well. Her burn had healed but she had gotten burned again and she was being raped repeatedly by her cousins, uncles and other men in the village during weekly market days when people socialized and got drunk. Her hut was close to the market, and men would go to her hut and rape her. The woman recognized them by their voices and reported it but they were only reprimanded by the village chief, an uncle, who wanted to resolve things quietly without giving the family a bad reputation. We reported the case to the child protection office and informed a local NGO providing services for persons with NS to try and move her to their health centre. We learned that while a nurse from the NGO had checked on her, no action was taken because the NGO was struggling for funds and eventually shut down.

This case illustrates the rejection often faced by married women who have been affected by NS and their vulnerability at the hands of care-givers. Being mistreated, stigmatized and sexually abused is common for them and they have no way out. This woman was especially vulnerable because her parents were not alive, and she was taken care of by her sister-in-law. It was observed that when biological parents were the caretakers, the treatment of the NS-affected was better.

Poverty Enhancing the Psychological and Physical Neglect, Particularly of Orphans

Living in a post-conflict area which had also been affected by HIV and Ebola epidemics, many NS-affected individuals were orphaned or living with step-mothers, aunts or grandmothers. It was common in such cases, that the NS-affected individual was especially neglected or mistreated as compared to the NS-affected individuals who were living with their biological parents. In some cases, such individuals faced resentment from step-mothers (case 3) or in-laws (case 2), while in most cases it was poverty and the extreme financial burden of caring for children, but also sick, disabled individual(s), that forced relatives to prioritise their own or those who were healthy (case 4). Caring for a NS-affected individual often required dealing with aggressive and disobedient behaviour due to the cognitive effects of the disease. Furthermore, it involved constant cleaning when patients defecated and urinated on themselves during seizures. This was problematic in areas where there were water shortages. Another challenge was keeping watch on affected individuals to protect them from burns, drowning and wandering off while still having to keep up with all the other necessary work for survival. As a response, many care-givers physically separated the affected individual from healthy members of the family by placing them in a shed, detached from the main house. This hut, we learned, was typically without bedding to reduce the cleaning load, usually of poorer quality with several leaks during rains, unclean and infested with insects.

Rejection of Mothers with Nodding Syndrome-Affected Children and the Spiral into Poverty. While we came across some cases where fathers of NS-affected children were supporting their wives by providing care and financial support to the household, there were several men, particularly with multiple NS-affected children, who had left their wives and had settled with or married other women.

Case 3: A woman who had four children, three of whom were affected by NS, was blamed by her husband for their children's illness and accused her of being '*a woman who gives birth to sick children*'. The husband disowned his children and left, leaving the entire burden of caretaking to her. With three sick children, she could not work sufficiently on the farm and take care of them and so was forced to return to her village of birth and stay with her family. Her children were called 'bastards' by the neighbours as they did not live with their father. Her parents also could not afford to keep them and so she married another man. She had to send her children back to their father, as her new husband would not keep another man's children. A health worker and focal person for NS in the area informed us that those children were being mistreated by the ex-husband's new wife.

Furthermore, when NS-affected females got pregnant, the biological fathers were often not there to financially support the children. This added to the economic burden of the care-giver, who spiraled deeper into poverty having to care for and provide for both, the NS-affected child and her offspring.

Physical, Psychological and Economic Burden of Caring for Nodding Syndrome Affected Individuals. In all cases, the primary care-giver of an NS-affected individual was a female. The care-giver would sometimes get assistance from other female family members, neighbours and relatives. There was an unspoken understanding that the kind of assistance that was needed would not be expected from men. Nevertheless, although some men would help, the bulk of the caretaking responsibility was on women and girls. Case 4 illustrates several layers of hardship faced by the carers of NS-affected individuals such as accessing healthcare, having to prioritise funds for subsistence or healthcare and not being able to leave home due to caring duties towards other children. Abject poverty, fatigue and hopelessness about a cure for the condition unfortunately led care-givers to make pragmatic decisions to prioritise the healthy individuals in the household.

Case 4: A young woman was affected by NS when she was 10 years old, while living in the camp during the Lord's Resistance Army war. Her parents died of AIDS when she was 12 after which she lived with her paternal grandparents, an elderly couple, along with her 5 younger cousins. When we visited their home, we found her lying inside the hut, on the floor, unable to speak or standup. Her grandmother explained that she had not taken anti-epileptic medication for the last 5 months as they had not visited the health centre. Her explanation was that she was embarrassed to go as she had lost the treatment booklet in the river while carrying her granddaughter home. We also learned that she had to carry her on her back for several kilometres to the health centre as the local motorbike transporters were too scared to carry an epileptic person. The granddaughter had not been eating properly in weeks and her condition looked grim. So we asked if we could take her to the hospital and the grandmother hesitated saying, '*if she gets admitted to hospital and I have to stay behind with her, who will take care of these children here? […] You know men, they can't take care of children*'. The female village health worker agreed to stay with the girl at the hospital for one night and the grandmother joined her the next day after she had harvested some sweet potatoes to sustain herself while at the hospital. Two days later, we learned that the

girl had passed away at the hospital due to malnutrition and untreated malaria. At her funeral, we paid our respects and sat inside the hut where the body rested. The body was wrapped in 3 layers of cloth and placed on a mat. When the body was being lowered into the grave, the grandmother shouted 'Wait, wait' and she removed two layers of cloth from the body leaving only one thin layer. She did not have much and needed to save the cloth for herself. A year later, we returned to the grandparent's home when the grandmother shared, '*I really suffered with the girl. Sometimes when I went to fetch water, I would return to find that she had an attack and had soiled herself. She didn't know the difference between what is good and bad and would eat anything including her own faeces. Even when I took her to the farm, she could have an attack and I had to carry her home on my back. Then when she became severely ill, she could not move and she would defecate on herself and I had to bathe her; it was really a very difficult time*'. '*Then I started selling firewood in town to get some money*' as she could not grow sufficient produce. '*The granddaughter was eating only once a day… that was when she became severely ill. It became hard for me to cultivate and even the firewood, I could cut just a few, rush to town to sell it so as to get some money to feed the family*'. The grandfather was an elderly man with poor eyesight and heart problems. While his ability to help was limited, his gender removed the expectation for him to help with child rearing. She said, *'There were moments we wished she could just die because she could defecate on herself, take the waste put it in the saucepan, she could not eat by herself, she couldn't feed herself, so we said 'God, if possible, take her life instead of letting her suffer like this', because if you can't eat, it's useless to live*'.

In case 4, the village health worker told us that despite months of encouragement, the grandmother had refused to take the girl to the hospital. Physically and emotionally, the care-giver was exhausted, having to juggle making a living to feed the household and the added responsibilities of a progressively dependent and sick child. These poverty-driven, extreme circumstances also subjected her to judgemental accusations of neglect from her social network, which added to the stigma and to her suffering. Due to the poverty trap, coupled with the gender-imbalanced work load, female care-givers not only faced psychological and emotional stress but also did not have the time or ability to seek healthcare for themselves, affecting their own well-being.

Discussion

It has been shown on a global scale that persons with disability are more vulnerable in society, and that vulnerability disproportionately increases for females (WHO, 2015). Women and girls with disability, experience 'double discrimination' as they are more likely to face gender-based violence and marginalization (WHO, 2015). Additionally, women aged 15–19 years, who do not have financial autonomy and are less educated were found to be at higher risk of sexual abuse (García-Moreno et al., 2005). NS-affected females in Uganda are often psychologically and sometimes physically disabled. They fit several of the factors that increase the risk of being sexually abused, rejected and subjected to psychological and economic hardships (Abbo et al., 2019; Mutamba et al., 2018; O'Neill et al., 2019; Tarzia, 2021).

To interpret these results, it is important to understand the backdrop within which NS first occurred in Uganda. While sexual abuse towards people with disabilities is a growing concern in sub-Saharan Africa in general (Hanass-Hancock, 2009), heterosexual violence against women is even more accentuated in post-conflict countries (Bukuluki et al., 2012; McKay, 2004; Turshen, 2001), including Uganda. Northern Uganda has endured over two decades of war, after which virtually no family remained unaffected by violence, including abduction, mutilation, rape, torture and murder (Atkinson, 2015), undoubtedly leaving people with deep psychological scars. The academic discourse thus far regarding gender-based violence in the area has concentrated on war-related crimes of rape and violence towards women and children (Amone-P'Olak et al., 2016; Atim et al., 2018). The reasons for war crimes against women have been argued to be a symbolic–political form of violence against a specific group or ethnicity, whereby the harm inflicted on women is perceived as harm inflicted on the collective as a whole (Das, 2008; Seifert, 1996). While this is relevant, and sexual abuse towards NS-affected women could be viewed as an act violence over a collective, it is important to understand the systemic gendered inequalities that normalise and exacerbate this behaviour.

Women in northern Uganda are dependent on men for their economic prospects. Socio-economic circumstances and poverty often drive women in vulnerable positions to remarry if divorced, or to stay in violent relationships where children from previous relationships may be mistreated (Fiske & Shackel, 2015). This is common in many African contexts where a woman is forced to tolerate abuse because of her economic dependency on the man (Boyd & Burrill, 2020; Carton, 2020). The economic struggles faced by women caring for NS-affected individuals in this setting are further exacerbated by the high poverty levels in the region. 32.5% of people residing in Northern Uganda live in poverty, which is significantly higher than the national average of 21.4% in the overall population (UBOS, 2017). In fact, it has been shown that NS-affected households have a higher economic burden than those unaffected in the same area (Latio et al., 2020).

Additionally, divorced mothers and their children are more vulnerable to ill health and their children have a significantly higher mortality risk (Smith-Greenaway, 2015). This is also supported by those cases in our findings where orphaned NS-affected children or children of divorced parents dependent on other relatives for their care were mistreated and discriminated.

The negative impact of child sexual abuse on parenting is also an important aspect to consider. Research has shown that mothers who were subject to sexual abuse during their childhood reported that this affected their child-rearing experiences including bonding, intimacy, communication and giving the child room to grow (Lange et al., 2020; Patrice Erdmans & Black, 2008). Most of this research reflected on the effects of sexual abuse on parenting in high and middle income countries and it is likely that such experiences are aggravated in contexts of abject poverty.

Care-giving has been described as a female role in various African contexts including northern Uganda (Kipp et al., 2007; Nakigudde et al., 2016). Care-givers for an NS-affected child expressed emotional agony, burnout, social isolation, rejection and homicidal feelings, coupled with the physical and financial constraints (Nakigudde et al., 2016; Saburi, 2011; Streid et al., 2014) which can also be compared to care-giving of a mentally ill person, (Ganguly et al., 2010) a disabled person or elderly people in need of care (Martz & Morse, 2017), which is supported by our findings as well. While struggling for survival, particularly when burdened with caring for one or more children affected by NS, these households are forced to selectively neglect those with disabilities to assure survival, as also seen in contexts experiencing famine. For example, a 2003 study from southern Zambia revealed that during famine, there was a 'pecking order' for limited food consumption and people with epilepsy were very low on that pecking order as 80% of them suffered from >5 kg weight loss and 20% showed signs of severe malnutrition (Baskind & Birbeck, 2005). Due to the burden of care-giving for NS, even healthy siblings of those affected may suffer in terms of schooling as they are required to contribute more intensively to household work, which makes them more vulnerable to poverty (Buchmann, 2015; O'Neill et al., 2019). Thus, care-givers and their households suffer from deteriorating physical and mental health and spiral deeper into poverty (P. Atim et al., 2016).

Women in Africa have been fighting legally enshrined inequalities against them for decades (Chanock, 1985) and this struggle continues today. The structural inequalities towards females, be it care-givers or those personally affected by disease, result in several poverty-related injustices, especially when corruption within the justice system protects the perpetrators. Social tensions in this post-war context were a paramount concern, and meant that the search for justice for a crime against a woman was often a low priority or simply futile. Health workers hesitated to report abuse towards their patients with NS out of fear that they may lose the limited social support they had. Davies and True (2015) argue that the structural gendered inequalities that perpetuate the abuse of power by men over women is an act of political violence which is informed by discriminatory gender norms and values that entrench male dominance over women and children. Addressing such discrmininatory gendernorms is key to preventing such violence (Davies & True, 2015). Although customary law and traditions did not grant women equal rights and status to men, some used to provide a safety network that took care of women in difficult circumstances and their children. However, in this post-colonial, post-war context, these 'traditional' safety mechanisms have fallen apart, and as in many post-colonial settings, the judicial system of the modern nation-state is not strong enough to provide sufficient support to females in vulnerable circumstances.

Conclusions and Recommendations

Structural and gender inequalities leave women vulnerable to abuse, poverty and discriminationand and NS-affected women and their caretakers are even more vulnerable within this spectrum. One step towards improving this could be female-driven, community-based efforts to stand up for the rights of females, especially females in poverty. The justice system should have mechanisms in place to protect females irrespective of their economic standing. Economic stimulus programs for women are needed for them to gain economic independence that may leverage ways out of abusive dependency relationships. Psychosocial support and counselling are needed to help women deal with trauma and sexual violence. An improved safety network through the support of social workers that are able to refer women to appropriate services may be a good way stop vulnerable women from spiralling deepeer into poverty. While economic stimulus programs and psycho-social support services should be generally available to all women in poverty, additional support should be available for NS-affected individuals and their caretakers so that they do not slip through the cracks. To ensure this, there should also be a stronger focus on monitoring and the evaluation of targeted interventions to determine and keep a check on their quality and efficacy.

Strengths and limitations

The ethnographic study approach over a 3 year period facilitated an in-depth understanding of the NS care context. The qualitative data was triangulated. A limitation of this study is that in-depth research was done in only one region and the quantification of the burden of illness and care-giving was not possible. Additionally, our findings

were based on reported households with NS. Very few patients in the area actually undergo a CT scan, EEG or any other sophisticated form of diagnosis that could confirm whether the patient is affected by NS or a different form of epilepsy. However, as scientists continue to disagree on the definition of NS and whether it is a disease in itself or part of a broader category of OAE, many argue that it is more important to focus on the effects of epilepsy on a larger scale, rather than a precise diagnosis of the disease. The selection of study villages was based on health centre and epidemiological data that showed they were heavily affected and often neighbours and other villagers knew and agreed on which households were affected. Persons affected by the classical symptoms that were commonly known in the study area had often received a clinical diagnosis, but we were not able to link this data to the cases.

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Notes

1. Other regions of Uganda were not known to be affected by Nodding Syndrome. The reasons for this are still unclear
2. The Acholi are patrilineal and speak Acholi, a dialect of a West Nilotic language classified as Luo. The Acholi reside mainly in South Sudan, Northern Uganda and also some parts of Kenya (Acholi/People, n.d.; Atkinson, 2015)

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