



## Impact of COVID-19 on the well-being of children with epilepsy including nodding syndrome in Uganda: A qualitative study



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### ABSTRACT

**Objective:** To investigate the impact of the COVID-19 pandemic and related restrictions on the access and use of health services by children with epilepsy including nodding syndrome in Uganda.

**Methods:** Four focus group discussions (FGD) with parents/caregivers of children with epilepsy and five in-depth interviews with key informants were conducted between April and May 2021 at Butabika National Mental Referral Hospital and Kitgum General Hospital.

**Results:** COVID-19-related restrictions, including the halting of non-essential services and activities, and suspension of public transport, created several challenges not only for children with epilepsy and their parents/caregivers but also for their healthcare providers. Study participants described extreme transport restrictions that reduced their access to healthcare care services, increased food insecurity and shortage or inability to afford essential medicines as consequences of COVID-19-related restrictions. However, parents/caregivers and healthcare workers adopted several coping strategies for these challenges. Parents/caregivers mentioned taking on casual work to earn an income to buy food, medicines, and other necessities. Healthcare workers intensified outreach services to affected communities. A positive impact of lockdown measures described by some FGD participants was that most family members stayed at home and were able to care for children with epilepsy in turn.

**Conclusions:** Our study highlights the significant negative impact of the COVID-19 pandemic and related restrictions on access to health services and the general well-being of children with epilepsy. Decentralized epilepsy treatment services and nutritional support could reduce the suffering of children with epilepsy and their families during the ongoing COVID-19 pandemic and similar future emergencies.

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### 1. Introduction

Epilepsy is a major public health issue in Africa, with severe physical and psychological consequences for persons with epilepsy and their communities [1]. Moreover, it is the second most burdensome neurological disorder worldwide and often starts in childhood [2,3]. An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain [4,5]. Epilepsy has various causes and is characterized by recurring, spontaneous seizures. Seizures are irregular electrical brain activities that cause involuntary changes

in physical movement, function, sensation, consciousness, and behavior [6]. Children with uncontrolled seizures have high rates of psychiatric and cognitive comorbidities and are at risk of injury and death [3,7], and worsened developmental trajectories [8]. Countries with limited resources like Uganda have a chronic irregular supply of antiseizure medication, resulting in poorly controlled seizures and disruption of daily living conditions of children with epilepsy.

At the turn of the 21st century, an epidemic of nodding syndrome appeared in Northern Uganda, in three onchocerciasis-endemic districts of Kitgum, Pader, and Lamwo, where there was no ivermectin distribution [9]. Nodding syndrome is a type of epilepsy that first manifests among children and is characterized by repetitive head nodding (atonic seizures) [10]. Nodding syndrome is often associated with other types of seizures, neuropsychiatric

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disturbances, and growth retardation [11]. In those three districts in Northern Uganda, the increasing number of children with nodding syndrome was accompanied by growing numbers of children with other forms of epilepsy. The onset of these forms of epilepsy occurred in previously healthy children between the ages of three and 18 years, without an obvious cause. These forms of epilepsy are now referred to as onchocerciasis-associated epilepsy and include nodding syndrome [12]. The incidence of onchocerciasis-associated epilepsy started to decrease in northern Uganda after the implementation of mass ivermectin distribution [13]. Furthermore, nodding syndrome ceased to appear in the population after regular bi-annual community-directed treatment with ivermectin was supplemented with vector control by larviciding rivers [13]. Although a strong epidemiological link was established between onchocerciasis and epilepsy, the pathogenesis of onchocerciasis-associated epilepsy remains to be discovered.

Following the 2012 international scientific meeting on nodding syndrome held in Kampala, recommendations for treating and caring for children with nodding syndrome were proposed [14]. These guidelines included treatment of seizures with antiseizure medication and specialized care according to the needs of the affected person, such as speech therapy, physiotherapy, occupational therapy, and ophthalmological, dermatological, and dental care [15].

In 2012, the government opened nodding syndrome treatment centers in the three districts of Kitgum, Lamwo, and Pader. The following year, four additional centers were launched in the Gulu, Lira, Amuru, and Oyam districts [16]. These centers were parallel health facilities within the district health-referral structures run as inter-ministerial collaboration. Their funding also stemmed from supplementary budget allocations by the parliament. When required, specialists would provide consultancy and specialized services to the patients in those centers. Patients and their families also received food rations and supplements from the government [9,14]. Two non-governmental organizations (NGOs) supplemented government efforts in treating and rehabilitating the most debilitated patients, as well as providing social support to their families [17]. However, because the NGOs were unable to raise sufficient funding to continue their activities, the government had to take over the running of these rehabilitation centers in June 2018 [16].

On 21st March 2020, Uganda registered the first case of COVID-19 infection [19]. To combat the spread of the virus, the Ugandan government implemented stringent safeguards and standard operating procedures. These included: closing territorial borders; mandatory institutional quarantine for all returnees from international travels; closure of public and private transportation; halting all non-essential services and businesses such as religious gatherings, retail shops, restaurants, bars, and entertainment centers; closure of all educational institutions; introduction of a night curfew; hand-washing campaigns; and use of facial masks [20]. These measures went into effect immediately at the start of April 2020, leaving most individuals little time to make the required preparations and modifications to their everyday lives, thus disrupting their daily lives [20].

The COVID-19 pandemic undermined the healthcare provision in Uganda, particularly for children with chronic illnesses like epilepsy. Many hospitals converted mental health wards into isolation centers for COVID-19 patients, further disrupting care provision for children with epilepsy. A survey using a standardized questionnaire conducted in the same period in four hospitals spread across the four regions of Uganda linked the COVID-19 lockdown to higher rates of anxiety, depression, as well as increased seizure frequency among children with epilepsy [21].

The possibility of outbreaks of new COVID-19 strains highlights the need to be better prepared for such health emergencies. The initial objective of the study, which was planned before the

COVID-19 restrictive measures were in place, was to “investigate how the specialized and decentralized treatment healthcare models for all forms of epilepsy in Uganda fared in the COVID-19 pandemic”. However, due to stringent movement restrictions, we were compelled to adjust this goal in favor of the objective: “This study aimed to qualitatively investigate the impact of the COVID-19 pandemic on access to and use of healthcare services for children with epilepsy, including nodding syndrome, in Uganda.”

## 2. Material and methods

### 2.1. Study design

This qualitative study was conducted in two of the four reference hospitals included in a recent quantitative study that assessed the impact of the COVID-19 pandemic on persons with epilepsy and their families [21].

### 2.2. Study sites

The study was conducted at Butabika National Mental Health Referral Hospital, located within the capital city of Kampala, and Kitgum General Hospital, which is 435 km north of Kampala. Kampala is a cosmopolitan urban community, while Kitgum and its surroundings are mainly rural. Kitgum General Hospital was selected because it is the major referral, treatment, and research center for nodding syndrome in Uganda [16].

### 2.3. Study procedure and data collection

Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs) were conducted between April and May 2021. Four FGDs (two in each hospital) were carried out among parents and caregivers of children with epilepsy. Five KIIs were carried out among; the District Health Officer (DHO) of Kitgum District, Psychiatric Clinical Officers, and the healthcare workers in charge of the Mental Health Wards in both hospitals. The FGDs aimed to explore the effects of the COVID-19 pandemic on the lives of children with epilepsy and their caregivers. An FGD thematic guide was developed to support the discussions. To recruit participants for the FGDs, we approached parents and caregivers of children with epilepsy who attended the epilepsy outpatient clinic. We informed them about our study and sought written consent to participate in the study. We consecutively recruited eight to 10 parents/caregivers per group. We used the 2014 International League Against Epilepsy (ILAE) practical clinical definition of epilepsy, which defines epilepsy as a brain disorder that is characterized by at least two unprovoked seizures > 24 hours apart [4,18]. Each FGD lasted approximately 60 to 80 minutes and had a moderator and a note-taker who tape-recorded the discussion and made additional remarks. The interviews were conducted in the most spoken local language of the respective study area, which is Luganda in Butabika and Acholi in Kitgum. The groups were homogenous and shared the same social context. Information regarding the participants' demographics, history of epilepsy, and its management was collected. Open-ended questions about the effects of the COVID-19 pandemic on children with epilepsy and their caretakers were used during the FGD (see the guiding questions in Appendix 1). There were follow-up questions to clarify emerging issues. The KIIs were conducted with healthcare workers of the mental health outpatient units. The District Health Officer of Kitgum was interviewed during a scheduled telephone interaction. A semi-structured guide was used during the KII (see Appendix 2). The topics discussed during the KIIs included the impact of the COVID-19 pandemic and its

mitigation measures on the management of epilepsy: accessibility to health services, effects on social support systems, and recommendations on how to improve health services to persons with epilepsy.

The study research assistants were chosen in consideration of the language requirements and experience in conducting FGDs and KIIs. A rigorous supervision process was established to ensure that the data collected was of high quality. The study investigators supervised the data collection and conducted daily de-briefings. Standard operating procedures (SOP) and government guidelines for the prevention of the spread of COVID-19 were adhered to during the conduction of this study, for instance, the FGDs and interviews were conducted in spaces that allowed socially distanced interaction.

#### 2.4. Data analysis

Focus group discussion audio data were transcribed using online software (<https://otranscribe.com/>) and then translated from Acholi and Luganda into English. The transcripts were reviewed, and all unclear words were defined ahead of the actual thematic analysis. Through this process, emerging themes were identified, and follow-up interactions on upcoming issues during the analysis were discussed with the field team interviewers. A thematic analysis approach focused on emerging themes from the discussions to guide the reporting. An analysis session was conducted with a consultant to complete the analysis task. While still in the field, daily de-briefings were conducted with teams to ensure that emerging issues were incorporated into the field notes.

#### 2.5. Ethical considerations

The study followed all the guidelines for performing biomedical research on humans. All participants provided written informed consent. Consent forms were written in English and the local dialect (Luganda or Acholi). Ethics approval was obtained from the local Ugandan Institutional Review Board (TASOREC/081/2020-UG-REC-009) and the Uganda National Council for Science and Technology (HS1156ES).

### 3. Results

#### 3.1. Study participants and themes

A total of 28 females and 05 males participated in the FGDs, and three females and two males in the KIIs (Table 1).

On average, FGD participants had been caring for children with epilepsy for six years, whereas key informant (KI) participants had managed cases of epilepsy for seven years. Codes, categories, and themes generated from FGDs, and KI yielded two major themes and several sub-themes. The two major themes were (i) challenges encountered during the lockdown by children with epilepsy and their caregivers; (ii) coping strategies adopted during lockdowns by healthcare workers and parents/caregivers of children with epilepsy.

#### 3.2. Challenges encountered during the lockdown

Both parents/caregivers of children with epilepsy and KI described how the lockdown restrictions negatively impacted access to and provision of health services for children with epilepsy. The main challenges were increased food insecurity, extreme transport difficulties, and shortage of/inability to afford essential medicines.

**Table 1**  
Characteristics of the study participants.

Characteristic	Number (%)
<b>Caretakers</b>	
Gender	
Males	5 (15.2)
Females	28 (84.8)
Age (years)	Mean 21, range 18–71
Education level	
None	1 (3.0)
Primary	20 (60.6)
Secondary	7 (21.2)
Tertiary	5 (15.2)
Marital status	
Single	0 (0.0)
Married	11 (33.3)
Widowed/Divorced/Separated	22 (66.7)
Relationship with the person with epilepsy	
Child	20 (60.6)
Brother/Sister	5 (15.2)
Other	8 (24.2)
Number of years caring for children with epilepsy	Mean 6, range 1–12
<b>Key informants/Healthcare workers</b>	
Gender	
Males	2 (40)
Females	3 (60)
Age (years)	Mean 42, range 35–68
Type of healthcare worker	
Psychiatric Clinical officer	4 (80)
District Health officer (DHO)	1 (20)
Number of years caring for children with epilepsy	Mean 7, range 4–12

#### 3.2.1. Increased food insecurity

At both Butabika and Kitgum Hospital, FGD participants and KI mentioned increased food insecurity as one of the major challenges encountered by children with epilepsy. Study participants said food insecurity and hunger made it difficult for children with epilepsy to take their medicines as prescribed. The challenge of food insecurity largely arose because many of the caregivers' livelihoods, especially in urban areas, were disrupted by lockdown measures. Also, because of the lockdown, food recommended by health professionals for children with epilepsy was expensive and hardly available in the small markets in the villages. Children with epilepsy depended mainly on cassava, without food rich in proteins and vitamins. One of the FGD participants narrated that health professionals strongly advised her to avoid feeding her child cassava because the medications do not work well with it. She said:

*You buy what you can afford; the doctor tells you not to give it (cassava) to your child. It is not good... let them provide what is good— caregiver of a child with epilepsy, Butabika Referral Hospital.*

Another FGD participant narrated:

*My child had to take fruits daily and eggs. I have been attending seminars about how to take care of these children. There are foodstuffs he must eat and some others he shouldn't. So, since there was a lockdown, I couldn't afford that special feeding anymore. But now, ever since the lockdown was relaxed, the child is back to their original diet" – FGD with parents/caregivers, Butabika Referral Hospital.*

At Kitgum General Hospital, a major challenge encountered while providing mental health services to children with epilepsy was insufficient food for patients and caregivers. A healthcare worker in the Mental Health Department explained:

*During the lockdown, because people were unable to do other economic activities that could generate money, they were unable to get food. This treatment for epilepsy requires food for the patient to function properly. When you are getting side effects because you have not eaten or swallowed drugs on an empty stomach,*

*the patient may not adhere to the treatment plan. So, there was a lot of increase in seizure attacks despite the treatment given to them – KII with a healthcare worker, Kitgum General Hospital.*

An FGD participant mentioned:

*Food has been a problem for most of us, especially last year during the month of June 2020 (. . .) There has been no major challenge of access to drugs, but we are faced with the problem of food – FGD with parents/caregivers, Kitgum General Hospital.*

### 3.2.2. Transportation challenges

Both FGD participants and KI mentioned extreme transportation difficulties as a major challenge created by the lockdown. This made it difficult for many children and their caregivers to access healthcare facilities. As part of the lockdown, a ban on inter-district movement was introduced. This measure resulted in high transport fares and, in some instances, no public transport services to enable children to get to treatment centers. Participants reported that within a short time after the introduction of the lockdown, the transport fares doubled, yet the finances of families had either not changed or worsened. A related challenge was the lengthy procedures to receive authorization from local leaders to transport the children to health facilities.

At Butabika hospital, a healthcare worker pointed out that some caregivers spent all their money on transport, and by the time they arrived at the hospital, they were left with nothing or very little money. At this facility, children with epilepsy were left unattended in the ward by caregivers mainly because of transport difficulties. As narrated by one of the staff of the hospital:

*Here at Butabika, we had increasing numbers of parents who just came and left their children here. They said there was either no transport or transport was too expensive to keep coming to the hospital. These children would sometimes become very aggressive and restless because they could not see their parents.” – KII with a healthcare worker, Butabika Referral Hospital.*

The same healthcare worker further added:

*Some clients come from very far places like Gulu, but the transport has become too expensive. (. . .) When COVID came, many just stayed at home without any access to medication” – KII with a healthcare worker, Butabika Referral Hospital.*

Another FGD participant narrated:

*Before the COVID pandemic hit, we used to travel to the hospital at affordable rates. Now the rates are higher. Then there was a time when even there was no transport at all. – FGD with parents/caregivers, Butabika Referral Hospital.*

A healthcare worker also reported high numbers of children with epilepsy who had to camp at Kitgum hospital and on the church premises because there was no money for transport. Some children with epilepsy traveled from as far as the districts of Agago, Pader, and (Awere in) Omoro. One of the caregivers at Kitgum hospital narrated:

*Because it was clearly stated in the COVID directives that people should not carry one another on motorbikes, so to come here, we used to come on foot and yet in some instances, some of these patients collapsed on the way, so we were left with no option than to carry the patients on our backs, and you know if the patient is an adult it becomes so difficult to carry them. – FGD with parents/caregivers, Kitgum General Hospital.*

### 3.2.3. Shortage of and/or inability to afford essential medicines

Another main challenge for children with epilepsy was the shortage of essential drugs at government health facilities during

the lockdowns. One of the caregivers interviewed from Butabika explained that there were not enough drugs for managing epilepsy:

*I used to still access this place even during lockdown using police assistance with a bike. The challenge has been the insufficiency of drugs. You are only given half of what you are supposed to get, and you are advised to buy the other portion of the dose from the pharmacy. This is because there are so many people who come here for medication. The medical staff tries to divide the little they have with everybody who has come – FGD with parents/caregivers, Butabika Referral Hospital.*

Also, in another FGD, one of the caregivers mentioned that some of the health centers they used to go to no longer had anti-seizure medication:

*We are required to travel to Kitgum General Hospital to access the drugs because it is the only health facility where you can access the medicine properly. – FGD with parents/caregivers, Kitgum General Hospital.*

A healthcare worker at Butabika National Referral Mental Hospital revealed:

*Some of our clients did not have money to buy drugs. Like sodium valproate, they are very expensive. Some poor families couldn't afford that” – KII with a healthcare worker, Butabika Referral Hospital.*

Several FGD participants complained about the quality of drugs obtained from private pharmacies. Most private pharmacies were said to have increased the price of anti-seizure medications. Moreover, some study participants believed that some of these private pharmacies either sold expired or ineffective drugs at a high price. An FGD participant narrated:

*The challenge with the drugs from the private pharmacy is that they are not as effective as the drugs we got from the government health facility.” – FGD with parents/caregivers, Butabika Referral Hospital.*

An FGD participant narrated:

*Pharmacies are different. You may find that a pharmacy that sells genuine drugs whereas other pharmacies have alternative drugs which don't have any effect on epilepsy” – FGD with parents/caregivers, Butabika Referral Hospital.*

### 3.2.4. Coping strategies and support systems

Healthcare workers described several coping strategies to address the challenges children with epilepsy faced during the lockdowns. A coping strategy was to increase outreach services. The district officials and the nodding syndrome task force were reported to have organized outreach services for clients and their families. Community psycho-education activities were conducted to improve awareness and provide epilepsy management tips for caregivers. A healthcare worker mentioned that home visits and psychoeducation improved social cohesion, interrelatedness, and community liaison activities in Kitgum General Hospital operation areas. He said:

*Outreaches have really helped our clients to improve a lot and in our program, you know Kitgum we had a very unique work plan, unique activities since we are trained mental health personnel, so we were using what we learnt from schools to help these clients – KII with a healthcare worker, Kitgum General Hospital.*

At Butabika National Referral Mental Hospital, community outreach services were also strengthened during the lockdown. However, few children with epilepsy collected the available medication because of a lack of money for transport. A healthcare worker at

Butabika Hospital explained that most of these services only helped patients living near the outreach service points. A study participant narrated:

*There has been a program where departments send out community nurses to some areas to reach out for mental illness cases. So, they treat all the clients they get in the community. There are those that have got a mental illness because of the fits. So, they are also treated when the team goes to the community – KII with a healthcare worker, Butabika Referral Hospital.*

To enable clients to cope with the transport challenges to access treatment, healthcare workers of Butabika and Kitgum hospitals referred some patients to health facilities near their homes for medication. This recommendation was made especially in the later stages of the lockdown period. One of the staff explained:

*We have been referring them to the other regional hospitals where they can get drugs from. Like someone coming from Fort Portal can be referred to a nearby facility to them instead of missing getting medication – KII with a healthcare worker, Butabika Referral Hospital.*

Caregivers mentioned they had to walk long distances to health facilities to get drugs during periods when public transport was suspended. An FGD participant said:

*In my case, we used to walk up to here to get the medicine. We had no other choice because the child had to get the medication. – FGD with parents/caregivers, Butabika Referral Hospital.*

To cope with increased food insecurity and declining incomes, caregivers mentioned resorting to casual work to raise money to pay for food and some medications. One of the caregivers at Kitgum Hospital narrated how she took on casual jobs, including bricklaying and collecting water for other community members. She said:

*There are people who have been living through this pandemic by doing activities such as laying bricks or fetching water for others at a fee of 200/= UGX for each jerry can. – FGD with parents/caregivers, Kitgum General Hospital.*

Some participants mentioned they had to rely on occasional food relief support from well-wishers. In addition, some families sold household items and bought food items such as cassava, sweet potatoes, maize, and cereals for family consumption. At Kitgum General Hospital, for instance, a healthcare worker said:

*Some MP (Member of Parliament) donated food to patients so that children can eat something before taking their medications. These children when they are not eating, they will postpone the taking of medication because these drugs have side effects that are so severe they would stop continuing with medication when they always have an empty stomach. So, there was that small donation; actually, it was insufficient for the children. – KII with a healthcare worker, Kitgum General Hospital.*

A positive impact of the lockdown was that it brought family members together, who then worked collaboratively to support children with epilepsy. Every-one in the family shared the responsibility of caring for children with epilepsy, including the father. For instance, at Butabika hospital, an FGD participant narrated how the husband collaborated closely with her to support their epileptic child during the lockdown period:

*Every time I would tell my husband that the OC (Officer in Charge of Police Station) has availed us a motorcycle to go to the hospital, but we need to fuel it, he would gladly fuel it so that I can get medication for the child. I also knew that I had to make it here no matter what because the child cannot miss the doses. – FGD with parents/caregivers, Butabika Referral Hospital.*

Generally, FGD study participants considered that the lead caregivers (usually the mothers) closely monitored the children and requested assistance from close relatives to manage children with epilepsy. During FGDs with caregivers, the majority mentioned that mothers did their best to care for children with epilepsy and were aware that skipping medication was detrimental to their children. At Butabika hospital, one of the caregivers narrated:

*I had to make sacrifices as a mother to make sure the child got medication. I used to be carried on the police motorcycle, but with time, the government banned carrying two people on bikes. Still, I had to look for ways to make sure the child got the medication. I knew this was the life of my child, and I had to fight for it. Every time the child misses medication, the child retards or gets affected negatively – FGD with parents/caregivers, Butabika Referral Hospital.*

#### 4. Discussion

This qualitative study aimed to investigate the impact of the COVID-19 pandemic on access to and utilization of healthcare services among children with epilepsy, including nodding syndrome, in Uganda. Our main findings indicate that children with epilepsy and nodding disease experienced extreme transport difficulties, increased food insecurity, and shortage or inability to afford anti-seizure medication as consequences of COVID-19-related restrictions. Additionally, we found that caregivers and healthcare workers adopted several coping strategies for these challenges, such as taking on casual work to earn an income to buy food, medicines, and other necessities.

Another study in Uganda among children with disabilities showed that the lockdown measures had negative effects on their mental and physical health, social life, finances, education, and food security [22]. Also, the latter study described reduced access to medical services and medication for chronic illness due to restrictions in travel. Yet another study in Uganda highlighted that the COVID-19 lockdown greatly disrupted the living conditions of children by limiting their access to basic needs such as food and health care and increased the incidence of child abuse [23].

Our study revealed that children with epilepsy in Uganda experienced food insecurity and hunger, affecting treatment adherence. These findings are consistent with previous research, such as one conducted in the United States, which found that children in food-insecure households had a lower health-related quality of life and higher medication side effects [24]. A study in Uganda showed that the COVID-19 restrictions severely impacted the lives of children, with many not having enough food to eat due to their meager incomes [25]. Other studies in Uganda and the Democratic Republic of Congo among people living with HIV found that the absence of food led to non-adherence to treatment because of increased medication side effects when the drugs were taken without food [26–28].

During the COVID-19 lockdown, some government-funded health centers had significant shortages of anti-seizure medication. As a result, caregivers of children with epilepsy were advised to buy medicines from private pharmacies, but these medicines were relatively costly for the families and suspected of being of poor quality.

Most of the impediments to epilepsy treatment and care indicated by our study were previously reported in studies conducted in Uganda before the COVID-19 outbreak. Barriers related to transportation, cost of medical care, distance to the healthcare facility, drug stock-outs, and lack of access to anti-seizure medication were the most consistently reported problems [28–30]. A qualitative study conducted in 2019 reported limited knowledge about epi-

lepsy and its treatment, caregiver burden, lack of family support, and poor healthcare access as main barriers to managing epilepsy in Uganda [31]. During the COVID-19 shutdown, these impediments to treatment deteriorated much further.

Strengthening outreach services and providing epilepsy care at lower-level facilities can help bring epilepsy services closer to patients, thus reducing the patient's transport expenses. However, this would require boosting the competency of healthcare workforce personnel as well as maintaining a consistent supply of necessary drugs to these health institutions. A decentralized health service, along with a food and nutrition support mechanism, might significantly lessen the distress of children and adults with epilepsy during the existing COVID-19 pandemic and future epidemics.

A positive impact of the COVID-19 lockdown that emerged from the FGD was that family members, including fathers, stayed at home and were, therefore, able to participate in the care of children with epilepsy. The lead caregivers were usually the mothers, but they usually needed assistance, especially when the children were experiencing seizures. Studies conducted during the pre-COVID-19 period reported that the burden of care for children with epilepsy was usually left largely to mothers, either because the fathers were fed up due to the chronic nature of the illness or busy with work outside the home [32,33]. Our study suggests that other family members, especially the fathers of children with epilepsy, are also willing to actively participate in the daily care of their children with epilepsy.

This study has some limitations. Firstly, there was no control group in our study to evaluate any potential barriers to care before the COVID-19 pandemic. We relied on the research participants' narratives to characterize the disparities in epilepsy care. Second, due to COVID-19 constraints, the study was limited to Kitgum and Butabika Hospitals. Furthermore, only a few KI were interviewed, and only a few parents/caregivers of children with epilepsy took part in the focus groups. Because participants were recruited by convenience sampling and from just two health facilities, research findings may be limited to the scope of our study settings.

Another limitation of the study was that we did not evaluate our data based on the type of epilepsy—one experienced. No one at Butabika Hospital had nodding syndrome (NS), but Kitgum Hospital participants had varied presentations of epilepsy (NS alone; other forms of epilepsy (OFE) alone; or NS plus OFE). It should be highlighted that research in northern Uganda has validated the epidemiological similarities and parallels between NS and OFE [13].

## 5. Conclusion

Our study highlights the significant negative impact that the COVID-19 pandemic had on the general well-being of children with epilepsy, and their access to and use of health services. COVID-19 restrictions exacerbated transport challenges to access health facilities, caused drug shortages at health facilities, and increased food insecurity, thereby making it difficult for children with epilepsy to take drugs when hungry. The distress of children and adults with epilepsy during the current COVID-19 pandemic and future comparable epidemics could be considerably lessened by expanding outreach programs and providing epilepsy care at lower-level facilities, closer to the people.

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## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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### Availability of data and materials

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

### Author contributions

The study was conceptualized by Denis Nono (DN), Nolbert Gumisiriza (NG), and Robert Colebunders (RC.) The data collection was coordinated and implemented by Denis Nono (DN), and analysis and interpretation of data were completed by Denis Nono (DN), Nolbert Gumisiriza (NG), Robert Colebunders (RC), Christopher Tumwine (CT), Luis-Jorge Amaral (LA), Ssegane Musisi (SM) and Herbert Ainamani (HA). The overall paper was written by: DN, NG, RC, CT, LA, SM, and HA. All authors read and approved the final version of this paper.

## Appendix A. Supplementary material

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2022.108992>.

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