

Nodding Syndrome in Uganda: The Detrimental Effect of Gaps in Healthcare, Biotoxins, Epigenetics, and Structural Violence

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ABSTRACT

This research paper is a literary review of the neurodegenerative disease known as Nodding Syndrome which is a form of an epilepsy-related brain disorder found mainly in children from 5-15 years old. The main focus is on Uganda because Nodding Syndrome is most prominent in this area as well as other third world countries in Africa. The primary objectives are to discuss how epigenetics and structural violence, tied in with gaps in healthcare and exposure to biotoxins, interact to shape the progression of this disease. This paper also examines the Ugandan healthcare structure, and the current critical situation in the country regarding the Nodding Syndrome disease. All of this is tied together in the paper to discuss how it affects vulnerable families in Uganda. After this research, this paper arrives at the following major conclusions: First, these findings suggest that social conditions play a large role in furthering the development of Nodding Syndrome. Second, the research highlights structural violence as a main instigator of health disparities. Third, Nodding Syndrome has a lot of biomedical as well as environmental factors that play into it through brain development and biotoxins. Finally, limited access to healthcare and the lack of a well prepared medical system in Uganda makes diseases like Nodding Syndrome much worse due to a multitude of factors such as inadequate treatment, a lack of supplies, and poorly trained doctors.

Keywords: Neurodegenerative; Nodding syndrome; Medical Anthropology; Structural violence; Epigenetics; Uganda; Healthcare access

INTRODUCTION

Certain environmental toxins, poor living conditions, and limited access to adequate medical care may contribute to genetic or neurological changes in children, potentially resulting in severe diseases that substantially affect long-term health and development. Nodding Syndrome, a devastating neurodegenerative disease affecting much of Eastern Africa, lies at the center of this

research question, vital to be answered, which is how do epigenetics and a lack of healthcare affect populations in certain less fortunate parts of Africa (by bringing on neurodegenerative diseases like Nodding Syndrome)? This question has many different aspects to it and it is important to take into account the many different factors that are at play when considering this detrimental syndrome and what contributes to it.

Uganda, a country to the east of Africa is one where this disease, Nodding Syndrome, is very prominent. A neurodegenerative disease such as this affects so many families all over Uganda, which is the main problem that many are trying their best to fight against. Uganda faces a complex problem dealing with dangerous biotoxins, a serious flaw in the healthcare system, and a divide in

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living standards, all of which are a crime against the humanity living there. All these problems together are what induce diseases like Nodding Syndrome which make these families lives so much more difficult on a day to day basis. Now, these issues have a huge tie into the concept of epigenetics, and like it was mentioned before, the lack of healthcare. Both of these topics are extremely vital to understanding how this detrimental disease gets away with so many lives in Uganda daily. To conclude, this paper not only describes but illustrates the reasons for the harsh realities faced in Uganda even today which are factors of structural violence, environmental issues relating with epigenetics, as well as the lack of adequate healthcare provided in this country.

NODDING SYNDROME: A BRIEF REVIEW

Uganda is a landlocked country in the central-eastern region of Africa, bordered to the east by Kenya, to the north by South Sudan, to the west by the Democratic Republic of the Congo, to the

south-west by Rwanda, and to the south by Tanzania. Throughout its history and even in the present day it is unfortunately struggling with one very problematic disease, Nodding Syndrome. Nodding syndrome is a generalized disease disorder which generally affects those who are liable to diseases and health issues often due to inactive vaccinations or malnutrition, especially children (1).

More specifically speaking, this disease is mainly pediatric and some features include head nodding, poor cognitive development, dizziness, and mood change. A lot of the symptoms associated with Nodding Syndrome have to do with internal body processes such as abdominal pain and headaches. This proves to be a very difficult time for kids and families who experience this and these symptoms are some of the many that affect these children (2). Now comes the question, in which kinds of environments does this disease spring up the most and how is it affecting the population today?

To begin, Nodding Syndrome mostly affects children so as one can see, this disease affects very young ages and much uncertainty is spread. So many lives of young children get impacted every day because caregivers feel the need of kids being confined to their homes and this affects entire families.

Families struggle to provide care to these kids due to the minimal resources they have which includes wealth (3). Moreover, wealth does play a minor factor in this as families who are able to afford the highest level of

healthcare available in Uganda may be able to prevent it a bit more than families who cannot afford that. Wealth is one of those many factors that affect how this disease affects this population which are looked at further into this paper.

Lastly, looking at the demographics of the people nodding syndrome has affected and how this disease affects them, one can see that it is a pediatric brain disease so it affects mainly children.

Specifically, as mentioned before, it affects children from the ages 5-15 and seeing that this disease starts at such a small age, it illustrates the impact it has on families for a long time thereafter. (1). In less fortunate parts of Uganda, people are not able to afford healthcare which explains further that these people do not have enough money to afford a reasonably good lifestyle. This inadequate provision of healthcare is also a big part of the lives of people who develop these diseases and it has a lot to do with lifestyles (4). In conclusion, nodding syndrome is not only a devastating neurodegenerative disease that affects just children, it affects so many lives all over Uganda leaving a lasting impact on how the people of Uganda are able to live their lives. It is a reflection of so many economic and social struggles within this population.

EPIGENETICS AND DNA STRUCTURE: BIOTOXINS AND OTHER DANGEROUS FACTORS THAT HAVE AN IMPACT ON NODDING SYNDROME

One thing to take into consideration when discussing how Nodding Syndrome affects the population of Africa is Epigenetics. Epigenetics is how your behaviors and environments can cause changes that affect the way your genes work and this has a big role to play in Uganda. In Africa, among less fortunate populations, there are so many factors within the environment that contribute to this awful disease some of which are biotoxins, neuroinflammatory, and tauopathic conditions. These are all conditions that cause the damage of brain cells and tauopathic conditions specifically, which cause changes and damage to proteins in your neurons, exert a great deal of damage to the human brain allowing these diseases to develop (2).

A big reason why biotoxins and such other toxic conditions induce diseases like Nodding syndrome is because they have profound effects on DNA structure. Biotoxins distort the DNA structure through the breakage of hydrogen bonds which develops an abnormality in

the genome stability which in turn can affect genetic processes, inducing diseases (5).

Biotoxins can be found in unsafe and polluted environments throughout Uganda and it is important to understand that these can severely affect a person's nerves/cells making them much more prone to neurodegenerative diseases like Nodding Syndrome. In addition, it can play into factors such as weakening one's immune system and making their body systems weaker against this type of effect (5).

The consequences of such biotoxins and how much of an impact they can have on Ugandan families' lives is important to recognize as well. With epigenetics coming into play, one person who develops Nodding Syndrome is more than likely to pass it on to their offspring because again, biotoxins affect the genes. Because not everyone is able to get proper access to healthcare, they can't get anything treated and they have to live with Nodding Syndrome in their family line for the rest of their lives.

Children are the ones who mainly get affected by this disease but that is not to say adults don't either. If adults develop Nodding Syndrome, as stated before, they pass it down to their children and because children develop it from a very young age, that family unfortunately isn't able to get that treated early on.

One important thing to note here is that no one can control whether they get affected by biotoxins or not. No one can control whether those biotoxins enter their body and severely damage their DNA structure, leading to disease. It is something controlled by the environment, not so much social class or structural violence, which is discussed further in the next section. This is not to say that things like social class or salary do not affect where people in Uganda are able to live which may contribute to their disease, because these things do absolutely have an impact. More well-off people may be able to live in a more urban area while poorer people unfortunately don't have the opportunity to choose where they live, and again, they can't control that. This is why harmful toxins in the environment or in unclean water can affect people living in Uganda without any health support. This portrays how the environment in certain areas can become a determinant of health, often without any warning or tractability. Certain factors, such as pollution or poor waste management can't even be explained by social class and they still have the ability to make toxins harder to avoid. Overall, many of these factors which contribute to the development of diseases like Nodding Syndrome have profound effects on people's lives even the factors, no one can control.

STRUCTURAL VIOLENCE AND LACK OF HEALTHCARE IN UGANDA

With various different topics in medical anthropology there is one theme that stands out in most social issues seen today, and that is the issue of structural violence. Structural violence can be defined as social structures that put people in harm's way; this can include several factors like social issues, poverty, and gender imbalance. Structural violence prevents people from reaching their full potential and as mentioned before a reason people are not able to afford adequate healthcare is because they are not able to afford it (6). Societal imbalances such as discrimination against those who are not better off in society is an example of how this exact situation can lead to unequal access to healthcare. If people cannot afford healthcare, they may be discriminated against because of that or because of their social class. Modern medicine may be prioritizing the search for new diseases and/or problem solvers to healthcare issues but it doesn't take into account social and political factors, in this case global health funding disparities.

Now, when describing phrases such as "inadequate healthcare" and "lack of provision", it is important to describe what exactly this lack of healthcare in Uganda is. How is this "lack" leaving families in a devastating condition? To start, in Uganda, there is no established legal framework for healthcare which is extremely necessary for a proper healthcare structure in a country (7). This is also another example of structural violence as it is another legal issue preventing people from getting proper healthcare, which some could consider a "lack". In author Kyoko Saito's personal story recalling her visit to an Intensive Care Unit (ICU) ward in Kampala, the capital of Uganda, she explains in detail her account of everything she saw in the ward regarding the implemented medical system. In this ward, there were many hospital beds shoved together in close proximity with family members squeezed tightly together next to beds and nurses moving quickly. Saito recalled her experience talking to one of the doctors who proudly said "this is one of the most spacious ICUs in all of Uganda, and many wealthy patients pay extra to come here" (8). This implies that there unfortunately are worse hospitals than this one and people pay much extra to come here which again relates back to that lack of affordability. According to the statistics she made a note of, in Uganda at the time, there was only 1 doctor for every 25,000 patients which demonstrates a great lack of healthcare professionals and in turn healthcare education for adults

to be licensed. Nurses and doctors don't receive enough training and people who want to become doctors are not able to because of this lack. Connecting all of this back to the basic problem of affordability, the average Ugandan's salary, which is almost \$20 a day, means that hospitalization consumes a big portion of these earnings and can create financial issues for families (8). In addition, the patient is also responsible for paying damages on any medical equipment which further illustrates the bad condition that these ICU units/hospitals are in (8).

When looking at the quick depletion and scarcity of all these extremely necessary resources one can start to see a legal/ethical issue inbuilt in this. Some could say healthcare is a right and that patients should be provided everything they need to live a happy healthy life. Well, the situation in Uganda illustrates the point of structural violence clearly because of this. The scarcity of resources that should be provided to patients such as proper doctors, adequate space, and working medical equipment, are directly inhibiting the delivery of proper healthcare and as, defined before, these "lacks" are putting people in harms way, especially when ties to issues like social classes and demographics of the country. It is immediately an issue in how things are dealt with in Uganda and when looking at Nodding Syndrome, it is clear why people aren't able to cope with that disease.

Finally, when taking a stance on this issue, if healthcare is truly a right, then the lack of infrastructure and resources in Uganda is really a national crisis. This problem exists in many parts of the world, and especially in Uganda, it is a public health issue. As mentioned, the depletion of clean water, affordability issues, and so much more are the cause of many lives lost and so much can be done about it. Structural violence is not just the absence of care or resources in Uganda, it is the deciding factor of who gets to thrive and who must go through horrible situations like getting Nodding Syndrome. As stated previously, social classes and how well-off one is in society is a huge factor of determining whether they get care or not, when looking at things such as salary. This situation should not exist at all and some initiatives that the Ugandan Healthcare Administration could take immediately come to mind: educating and training local healthcare workers, by investing in training programs, and also strengthening the rural healthcare infrastructure such as funding clinics and providing medical resources to poorer areas.

Although it may not be as simple as this, taking small steps toward acting on these initiatives would be a strong

way to get the Ugandan Healthcare System to where it should be for the well-being of its citizens.

HEALTHCARE POLICY AND ACCESS IN UGANDA

Even to this day, Nodding Syndrome continues to affect families in Uganda, specifically kids between the ages 5 and 15 (3). According to a recent study done on the barriers to full healthcare coverage in Uganda, the main reasons and barriers for the poor healthcare go as follows: financial resources, medicines and supply systems, health, human resources, infrastructure and functionality, and finally equity and the Free Healthcare Policy (FHP) implementation (9). The UHC, which is the Universal Health Coverage, aims to achieve equity for access to healthcare in terms of finances. The key to this according to them is to implement Free Healthcare policies in the Ugandan Government (9). These Free Healthcare policies could contribute to many of the problems that were listed previously: a lack of supplies and space in medical facilities and the lack of medical education. These policies would allow more people to have a reach of healthcare as it would be so much more accessible to people of different classes and social backgrounds.

Despite the importance of health policies in healthcare systems, policy creation and implementation is under utilized in healthcare in a few countries such as Uganda. To get to the root of the problem, Namyalo stated that it is vital to conduct a thorough evaluation of Uganda's implementation of the FHP to prioritize things like allocating resources to different parts of the country (9). Finding out whether the Ugandan healthcare system is using this policy or not is extremely important to the overall cause of lowering the numbers of several diseases including Nodding Syndrome. This is largely a part of the reason why Uganda does not have a legal framework for its healthcare sector and by taking these steps, more resources could be given to the healthcare system to solve many problems with diseases. In addition to implementing the FHP, Uganda, in theory, could take a few more steps to ensure healthcare equity for the country. This includes partnerships with nearby countries for provision of more resources they may not have access to. This also includes Uganda needing to utilize their resources completely to ensure maximum benefit (9). By combining all of these efforts, the Ugandan government will be able to set aside more funding for healthcare which will build up that legal framework over time. By

strengthening their policies, implementing meaningful reforms, and forming possible partnerships, Uganda will very likely be able to get its healthcare sector to where it should be, allowing everyone in the country to get free, good quality healthcare.

CONCLUSION

This paper covered the main research question which is, in what ways do epigenetic influences and limited access to healthcare shape the emergence and severity of neurodegenerative diseases such as Nodding Syndrome in underserved African communities? This paper finds that epigenetics influence this disease by means of biotoxins and dangerous chemicals found in the everyday environment of less fortunate people, which can be tied into income and social class as well. This review demonstrates the lack of healthcare in Uganda and the sheer unpreparedness of the medical system is also a large reason why many people are developing this disease.

In this paper, we have specifically touched upon issues such as structural violence which is explained to be something that people can't control such as their social background but still has detrimental effects on the way they receive healthcare. This then relates back to people not being able to afford adequate healthcare which is the reason for proper implementation of the Free Healthcare Policy administered by the Universal Health Coverage. Another issue discussed is biotoxins and how it affects epigenetics which could then be helped through the implementation of the FHP. To sum up, all of these issues do exist today in Uganda and if proper measures are taken, the lack of healthcare in Uganda and the problem of biotoxins may finally be solved.

This paper concludes that it is a crime towards the citizens of Uganda known as structural violence which really cannot be ignored as everyone deserves top notch healthcare. Healthcare is a human right and the fact that the Ugandan people are not receiving proper care for even the worst diseases is not good. In theory, there is so much the Ugandan Government could do to help this issue such as working with the governments of nearby countries, distributing more money to the healthcare sector, and much more. Ultimately, without meaningful reforms, and a true commitment to protect healthcare, Uganda might continue to face the horrible problem of Nodding Syndrome caused through healthcare/

environment, and if nothing is done soon, it might be detrimental for the country.

CONFLICT OF INTEREST

The author declares no conflicts of interest related to this work.

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