Anthropological Study on the Socio-economic Situations of Nodding Syndrome Patients and Their Families in Northern Uganda

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Abstract

Nodding Syndrome (NS), unknown epileptic disease, has been one of serious burdens of eastern Africa. NS is an unexplained disease which affects mostly children between 5 and 15 years old. This disease has so far been reported from southern part of South Sudan, northern Uganda and Tanzania. In spite of extensive medical investigations, its cause remains still unknown.¹

Acholi land in northern Uganda is one of the areas where NS patients are concentrated. The effect of the disease on patients’ families and communities can be devastating because previously healthy young children drop out of school and lose the ability to eat. Constant oversight of the patients is required since they might fall into a cooking fire, wander off, and drown.² This disease has been a burden for individuals and communities in northern Uganda.

The ultimate goal of this research is to clarify everyday-life conditions of NS patients and their family members, and propose an appropriate care-system for them. This field research aimed to describe social and economic situations of NS patients, and explore how local people recognized and coped with NS. From anthropological and sociological perspectives, I examined what kind of attitudes local people had towards NS patients and their family members.

Through this field research, the following three points were revealed;

1) Patients were suffering from various barriers, which were not only epileptic symptoms but also other challenges, including communication disorders and violence to others.

2) Local people tended to suspect NS of an infectious disease. Caregivers used different dishes when serving food to its patients. In other cases, people believed that NS was the aftermath of the conflict involving the use of bombs, and caused by poisoned food provided in the IDP (Internally Displaced Persons) camps. Most patients had experiences of being isolated and bullied by other children at school.

3) Caregivers believed that biomedical care from health centers was the only effective treatment. However, transportation cost for hospital visit had been a difficulty in access to the biomedical treatment.

Caregivers were facing the challenges of the lack of knowledge in appropriate care since no etiology of this disease was developed. Meanwhile, neighbors’ involvement in watching over NS patients were observed. This practice is hoped to be promoted, so that the entire community could perceive and understand the special needs of the families of the patients.


要旨

昨今、さまざまな疾病がアフリカ諸国の人々を脅かしているが、そのひとつに、東アフリカの一部で蔓延しているうなづき症候群がある。うなづき症候群は、主として5〜15歳の子どもにみられる原因不明の神経系の病気である。この病気を発症した患者は、頭を縦に振る症状やけいれん発作をおこし、症状が進行すると死に至る場合もある。近年、症例数が増加するに従って、その原因の究明を目的とした研究報告が相次いでいるが、未だに明確な病因は特定されておらず、治療やケアの方法も確立されていない。ウガンダ政府や国際NGOは、この病気の患者の支援を行っているが、それがどれだけ患者のもとに届いており、いかなる効果をあげているのかに関する報告もほとんどない。この原因不明の疾病について現地住民は、1980年半ばから20年間も続いたウガンダ北部紛争の時代に使われた化学薬品や難民キャンプで配給された食品のほか、現在も調理や水浴びに使っている河川の水など、さまざまな病因を疑っている。また、病気の感染経路も解明されていないため、日常的に不安を感じながらの生活を強いられている。

本研究の最終的な目的は、ウガンダ北部において蔓延しているうなづき症候群の患者とその家族が直面している社会的・経済的な困難を明らかにし、同時に、人々はそれにどのように対処しているのかを、とくに家族や近隣住民による自発的なケアや相互扶助に着目しつつ解明することである。本調査では、各世帯の構成員や世帯間の関係などに関する基本的な情報がわかる村落において、以下の3項目についてデータ収集を行い、一定のデータを得ることができた。

（1）うなづき症候群の患者の病状と生活実態

本調査では、インタビューと参与観察により、患者がいかなる日常生活を送っているのかを検討した。その結果、患者たちの症状を悪化の傾向をたどり、てんかんなど神経系の症状以外にも、患者のコミュニケーション障害や暴力行為、徘徊などがみられ、本人のみならず周囲にも悪影響を及ぼしていることが明らかになった。

（2）うなづき症候群という病気に関する地域住民の認識と対処、および患者とその家族に対する地域住民の対応

今回の調査では、うなづき症候群という病気に対して感染性をもっていると疑っている多くの住民がおり、食器を分けて使用する例もひんぱんにみられた。いったん、紛争の際に使われた火薬や難民キャンプで配給された食事などを原因として疑う例もみられた。うなづき症候群患者は、主として5〜15歳の子どもであるが、学校や遊びの場で同年代の子どもから無視・排斥をされることで病気の感染を恐れることが観察された。そこで、感染を恐れることによる無視・排斥は観察されなかった。

（3）患者とその家族が直面する経済的課題

患者にとって、ヘルスセンターでの抗てんかん薬の処方はもっとも有力な問題解決手段となっている。しかし、通院にかかる交通コストが保護者にとっての大きな負担となっている。今回の調査では、病気の原因が分からない不安を抱え込み、ケアに対する知識不足を嘆いている保護者が多くみられた。いっぱい、地域住民が近隣に住む患者を気遣い、見守るような行為をしていることが観察できた。地域住民の協力的な姿勢を無駄にせず、コミュニティ全体で患者や患者家族のニーズを共有できる仕組みを創出し、情報交換の場を設けることができれば、患者の安全の確保や保護者の負担の軽減を実現できるのではないだろうか。

3 駒澤大佐・齋藤貴志、2014「Nodding Syndromeに関する研究動向：症状・原因・治療」『JANESニュースレター』No.21:7-12。
佐藤靖明、2014「東アフリカにおけるてんか性脳症『頷き症候群（Nodding syndrome）』に対する学際的ネットワークの設定」『JANESニュースレター』No.21:2-6。
Research Activity

1. Introduction

Nodding Syndrome (NS) is an unexplained disease which affects mostly children between 5 and 15 years old. This disease has so far been reported from southern part of South Sudan, northern Uganda and Tanzania. In spite of extensive medical investigations, its cause remains still unknown. Although NS is only observed in Tanzania, Uganda and South Sudan, it is likely to be more widespread than previously thought. This disease is considered as a part of the spectrum of onchocerciasis-associated epileptic disorders, causes varying degrees of mental retardation in growing. In some cases, it occurs considerable growth stunting and failure to develop secondary sexual characteristics.

Acholi land in northern Uganda is one of the areas where NS patients are concentrated. Buchmann (2014) claims that “Nodding syndrome, a disabling epidemic epileptic encephalopathy, has affected an estimated 1,834 children in northern Uganda, with reports of as many as 3,000.” The effect of the disease on patients’ families and communities can be devastating because previously healthy young children drop out of school and lose the ability to eat. Constant oversight of the patients is required since they might fall into a cooking fire, wander off, and drown.

The difficulties NS patients are facing are not only health concerns. NS patients tend to depend on traditional medicine prescribed by local healers, instead of purchasing modern medicines from LC-III health centers. One of the reasons is economic situation of the patients and their families. Most people depend on public transportation for hospital visit. They cannot afford to go to health centers freely, and it is assumed that this is a key factor resorting to the use of traditional medicines. Yet, the details of economic conditions of NS patients and their families are not necessarily unveiled.

Some caregivers were reported to sometimes neglect the health needs, feeding and personal hygiene of their children. These children therefore tend to suffer from other hidden unintended torments and distresses directly related to their NS. However, there is no full investigation of what kind of cares NS patients are receiving from their families and community members.

The burdens on NS patients and their families are not just the suffering of unknown disease as such. Since no etiology of NS is identified, rumors as well as bad reputations on NS patients and their families spread over Acholi land. There is an assumption that NS has something to do with the civil war occurred in the past two decades. Some attribute the cause of NS to foods distributed in wartime, saying that they led to chemical poisoning. Other believe that NS was caused by religious and spiritual reasons.

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My field trip to Acholi land was aimed at revealing how local people were conceiving and coping with NS, with particular interest in their ethnographical background. Participant observations and interviews were conducted to give detailed description of NS symptoms.

2. Study Area
This survey was conducted in Gulu and Kitgum Districts, Uganda where NS patients were seen. Uganda is located in eastern Africa surrounded by Tanzania, Kenya, D.R. Congo, Rwanda, and South Sudan. Its total population is 39,032,383 in 2015.9

Gulu and Kitgum are located in northern part of Uganda, and the majority of their population belong to the ethnic group called Acholi.

Participant observation and interviews were conducted in a village located approximately 60km away from Gulu town. Health centers in Kitgum and Kitgum government hospital were chosen for collecting data on medical treatment and services supply.

This area of northern Uganda was affected by the conflict occurred from 1986 to 2008. Many people experienced and suffered from atrocities of the anti-government Lord’s Resistance Army during the war. Most people in the surveyed village spent their time on being in Acholi land during the war. Some have an experience of being abducted and forced to become child soldiers.

3. Methodology
This research employed the following three study methods.

(1) Literature review:
This research drew mainly on an anthropological approach. A range of the relevant literatures enabled me to fully understand NS and analyze the collected data from a multifaceted perspective. To illustrate the social context of the study area, these literatures were not only cited for summarizing medical elucidations, but also utilized for understanding the ethnographic background of local people.

(2) Interviews with NS patients / their family members / local community members / NGOs / other stakeholders
This research focused on NS patients, their families, their communities, and organizations supporting them. The data collection was carried out mainly in English, while I made maximum efforts to understand their local language, Acholi-Luo.

Informants were NS patients, their family members, local community members, teachers, and community leaders. The interviews with them were designed to explore how NS patients’ families and local members perceived NS, and how they understood and dealt with NS patients.

(3) Participatory observation: everyday-life conditions of NS patients / their care system / their social relationships with local community members.

Data collected through a series of observations of the patients and local community members included their everyday conversations and activities. This allowed me to clarify the social values of local people on NS. During this field survey, I stayed with three patients with different genders and different ages.

4. Research Findings

In this field survey, I investigated socio-economic situations of NS patients and their families. The following three points were revealed.

(1) Symptoms of NS patients and their daily lives:

There are previous studies reporting various symptoms of NS patients; still the details are unknown. The interviews with NS patients and direct observations of their behaviors revealed that the frequency of their symptoms varied according to seasons, weathers, and situations. There were a wide variety of symptoms for the patients. While epileptic seizures were major symptoms as previously reported, the patients were suffering from wandering as well. Caregivers prevented the patients from drowning in water by tying them with ropes.

In general, the majority of patients who have serious epileptic symptoms show aggressive behaviors when they think that their conditions are not well. The accounts of some informants indicates that there is a similar tendency. When their symptoms are serious, NS patients tend to throw stones, and slap and hit others regardless of their wills. Many patients have difficulties of communicating with other family members and friends.

(2) Local people’s recognition of NS, their attitudes towards NS patients and their families, and coping strategies to NS:

Usually, NS children dropped out of school and were kept at home. The patients who had only mild symptoms did heavy every chore, including cultivating crops and collecting firewood, while the risk of wandering did not allow the patients with severe symptoms to go to their farms. Wandering was recognized as a significant issue for caregivers of NS patients since it had the danger of drowning in water and being involved in accidents. Caregivers always needed to pay attention to the patients and worry about their safety.

The interviewees tended to use different dishes when serving foods to NS patients. According to some informants, doctors and nurses of local health centers gave them advice that they must use dishes separately. Local people were already

Figure 2. Patients spending time with their close relatives
informed that NS was not an infectious disease, but most of them were skeptical about this general information. The habit of using different dishes did not echo any intention of isolating the patients, but their willingness of protecting healthy children.

In the interviews, the patients stressed that they experienced cruel bullying from former classmates and neighbors. They tended to be isolated from groups at school, and abused and teased by other children. They spent most of their time on living with their family members and close relatives, so that they would be understood properly and protected.

Most caregivers shared information on the patients’ conditions with community members, especially close neighbors. Information on symptoms as well as characters of each individual patient was shared when community members gathered for events of their social networks, like meetings of money saving groups. This implies that people excluded from such networks and gatherings do not have any chance to obtain this kind of information. Neighbors’ attitudes towards NS patients seemed corporative. The close neighbors always monitored the patients wandering in the bush, and tried to prevent them from going to dangerous areas.

Caregivers criticized that adequate knowledge of proper care for NS patients has not been accumulated yet; in fact, people in this area never experienced this epileptic disease until a few years ago. Also, many interviewees referred to the sense of helplessness caused by the lack of shared information on NS.

3) Economic situations of NS patients and their families:

The majority of the patients were receiving medication from doctors at local health centers. Examination and medication offered by these centers are free in Uganda, but voices of the interviewees indicate that local people have difficulty in securing cost for public transportation from a village to the centers. In the surveyed village, any local health center was not located within working distance. The village was located 9 km away from Health Centre 3, which was the nearest public health center for them. Local people use highway buses and public taxies to go to health centers, but they do not have frequent services. Some caregivers who could not afford to use such public transportations made their patients go to this health center by foot. I frequently observed that the health center was out of service because of the absence of doctors and nurses. When this happened, people needed to visit another health center located 20km away from it.

In Gulu town, there was a regional referral hospital into which patients with serious symptoms, including being violent and wandering, were allowed to be admitted. However, public hospitals in Uganda did not provide patients with meals, clothing and any other additional service. In other words, caregivers should take care of them during the whole hospital stay. This discouraged people fully depending on agriculture in subsistence from getting advanced treatments at public hospitals. Long waiting time and unfamiliar processes at hospitals were also major hindrances to the utilization of their services.

The interviews revealed that NS patients did not necessarily rely upon the traditional medicines. Some caregivers obtained advice from ajuwaka (traditional healer in Acholi land), but most of them failed to find any solution. It was commonly recognized that ajuwaka was no longer effective for NS patients. Some interviewees had some experiences of using local herbs for epileptic seizures, but most local people, including herbalists, believed that these herbs were not necessarily effective for NS patients. Therefore, biomedical care offered by health centers was the only treatment for the patients.
5. Discussion

5-1. Methodology

Through the interviews and observations, I realized that symptoms of NS patients would be affected by the amount and type of daily food. The fieldwork was conducted during the rainy season in which plenty of food were available. What people eat in both quantity and quality is not necessarily constant throughout the year; there are dishes of different kinds in the dry season. This indicates that conditions of NS patients are likely to depend on seasonally varying food intake. It would be explored by conducting a further field survey in different seasons.

5-2. Research Findings

Many caregivers had difficulty in seeking adequate biomedical care. Caregivers stated that they were always afraid of NS symptoms which usually became progressively worse. More and more, the lack of etiology was encouraging their helplessness. Through this field survey, caregivers referred to a sense of anxiety arising from the uncertainty of treatments which have been given to NS patients. These helplessness and uncertainty led to a drop in their motivation for giving adequate care to the patients. The lack of fundamental education on remedy for caregivers diminished therapeutic ideas as well as social integration which could reduce their concerns and stigma.

Meanwhile, most households with affected children were suffering from economic vulnerability. Transportation and hospitalization costs discouraged caregivers from seeking adequate treatments from doctors. This issue regarding the cost for biomedical treatment is considered as a threat to the constructive lives of families with NS patients.

6. Conclusion

My field survey revealed that NS patients’ dependence on caregivers and its various symptoms were the key factors from which they suffered. The absence of etiology resulted in the lowering of their motivation to give better care for the patients. Most caregivers were worried about the uncertainty of their own treatments, thinking that these might be worsening NS symptoms.

Some problems regarding communication between the patients and others could be solved within their community. Neighbors are hoped to be more informed of NS, so that the whole community could create an opportunity to understand and share the special needs of its patients. It is considered that this reduces the burden on NS patients as well as caregivers.

Reflection to the GLTP in Africa

This field survey was my first experience to live in Africa. I spent most of times with local people. I needed to learn to communicate with them in their local language, and I spent most of my free time with children learning their languages and plays. These experiences broadened my perspectives and recognition of diversity and culture. This fieldwork was also a great opportunity to gain skills for becoming a good anthropologist.

There were challenges especially on security because some patients sometime became aggressive when their symptoms were severe. However, I obtained Figure 3. Traditional style of storytelling in Acholi land called “wan-oo”
a valuable experience with safety through participating to the GLTP in Africa thanks to critical advices and encouragement from GLTP staff members.

Also, making presentation at GLTP office was a wonderful chance to spread information on this unknown disease to other researchers. At the same time, I gained precious opportunities to know issues in Africa through learning from other GLTP members. These experiences that I gained through this program would contribute to me becoming a good researcher. I hope Africa will get focused more from researchers. I also hope that I will have an unparalleled opportunity to conduct field survey again.

7. Acknowledgements

Firstly, I would like to express my sincere gratitude to GLTP staff members who gave me continuous support before and after my field survey in Uganda. Advices given by Ms. Kana Miyamoto, a GLTP staff member, was a great help during my stay in rural area with limited resources. Through Global Leadership Training Programme in Africa, I gained a wide range of field experience.

Also, I would like to express my sincere gratitude to Professor Edward Kirumira, the Principal of the College of Humanities and Social Sciences, Makerere University, who gave me all the necessary assistances to conduct research in Uganda. He also gave me advanced and constructive ideas for my field survey.

Finally, I am deeply grateful to every research participants in my research including my research assistant Omony Patrick, nodding syndrome patients, caregivers, village residents, and hospital staff members.

8. References


9. Appendix

CONSENT TO PARTICIPATE IN
RESEARCH ON NODDING SYNDROME PATIENTS

Purpose of this Research
My research aims to describe everyday-life conditions of Nodding Syndrome patients, and to explore how local people recognize and cope with NS, and what kind of attitudes local people have to the patients of NS and their family members, from the anthological and sociological perspectives.

Methodology
I will investigate how local people recognize causes and contagiousness of Nodding Syndrome by conducting intensive interviews to the NS patients, their family members, community members, and staff of local NGOs, which are extending assistance to the NS patients. Group discussions of community members will be conducted as well.

Protecting the Privacy of Participants
I utilize personal information only for academic purposes. All data collected in this research will not identify any individuals. I never allow any data to be released outside this research project.

Rights of Research Participants
Your participation in this research is completely voluntary. It is up to you whether you participate or not. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

If you wish to ask questions, please contact me by telephone or email.
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INTERVIEWS GUIDELINE

Following questions will be asked in interviews:

● Understanding General Information of Individuals
  • What is your name?
  • How old are you?
  • What is your job?
  • What is your academic background?
  • Are you a single or married?
  • Do you have any siblings?
  • How many children do you have?

● About Nodding Syndrome
  1) For Nodding Syndrome Patients
  • How old were you when your symptoms started?
• When is the symptom appear in a day?
• Have you had any dangerous experience when you suffered from NS?
• Are you taking any medicines or herbs?
• Do you feel better when you take medicines?
• Do you go to any clinics? (Have you?)
• How have you know this clinic?
• Why do you stop going to go to clinic?
• Do you have any friends who are nodding syndrome patient?
• Does your symptom seem better when you pray for your god?
• Have you ever visited ajwaka to consult Nodding Syndrome?

2) For Nodding Syndrome Patients’ Families and Other Surroundings
• When did you notice that your family has Nodding Syndrome?
• How do you feel about your family is having Nodding Syndrome?
• Do you feel financial difficulties to support Nodding Syndrome Patients?
• Is there any other problems do you have other than financial problems to support Nodding Syndrome patients?
• Have you suffered from bad reputations about Nodding Syndrome?
• Can he/she(NS patient) work as other family members in daily life?
• Do you think your family is getting proper treatment from other people?
• Do you think your community members are cooperative with nodding syndrome patients?
• What can we do for better understanding for Nodding Syndrome patients?