

Pediatric Epilepsy and Well-Being in Coastal Kenya: Notes from the Fieldⁱ

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Abstract

The following paper presents excerpts of field notes from my dissertation project, which is being conducted over a ten-month period in Kilifi, Kenya. My research examines how cultural and material factors influence the way families seek treatment for pediatric epilepsy, and how these factors and treatment choices affect the concept of family well-being. Field notes are employed to illustrate several important preliminary research findings.

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Introduction

The following paper presents excerpts of field notes from my dissertation project, which is being conducted over a ten-month period in Kilifi, Kenya. My research examines how cultural and material factors influence the way families seek treatment for pediatric epilepsy, and how these factors and treatment choices affect the concept of family well-being. The primary objectives are to: 1) improve the theoretical understanding of how epilepsy, and chronic pediatric disabilities more generally affect the well-being of a family, 2) examine the cultural, social, and material factors that shape how these families seek treatment, and 3) explore how different treatment decisions influence family dynamics and functioning. I am employing a mixed methods approach including surveys, person-centered interviews, participant observation and structured monitoring.

Research Design

In the first phase of the project, I conducted a survey of 111 families with children with epilepsy between the ages of 6 and 11 throughout Kilifi District. These families were identified in a previous project conducted by the district hospital to identify individuals with active epilepsy. My survey covered topics such as resource availability, treatment options accessed, and family spending patterns. There have been several interesting findings from these surveys. Several of these findings pertain to difficulties encountered in employing a survey method in this context, and to the shortcomings of this method in exploring such complex ideas as well-being and treatment seeking.

The second component of my research is a series of interviews and participant observation sessions conducted with traditional healers in the area. I have thus far spent approximately 50 hours with these healers and have learned a tremendous amount about the system they employ to explain illness, the treatments that they administer, and their views and opinions of the causation and effects of epilepsy. I will continue with this line of research until the conclusion of the project.

The final line of research is a series of interviews, informal conversations, and observations of a selected group of families who participated in the initial survey. I have selected eight families, representing the range of treatment options accessed, the degrees to which these various treatments are adhered to, and other demographic factors. This is the primary component of the project and will continue for the duration of the project.

Preliminary Findings

Understanding processes as complex as decision-making and attempting to grasp something as broad as well-being is a tall task which looms even larger when the attempt is made in a context which, at least initially, is foreign to the researcher. While I have yet to begin formal data analysis, there are several findings that have emerged during data collection. In the following article, I present three preliminary findings. First, I discuss views of epilepsy causation held by traditional healers. These findings provide insight into the explanatory model employed in one widely accessed epilepsy treatment option, traditional healing. These are the ideas that individuals are presented with when they seek care for epilepsy from traditional healers. These explanations are

processed and, to varying extents, enter into the patient's own explanatory model, shaping subsequent treatment seeking decisions. Second, I present findings on the payment models employed by traditional healers and biomedical options. The differences between these models serve as a potential barrier to biomedical treatment. Finally, I present findings regarding family goals. These data shed light on possible ways that epilepsy affects the well-being of families with epileptic children. These findings will be presented using notes from the field and direct quotes from participants where possible.

1. Healer explanations of epilepsy causation and different "types" of epilepsy:

A. *Nyagu*: This is a natural spirit that assumes the physical form of a hawk. Nyagu is classified as a "natural spirit" in the spirit system structuring traditional healing and local illness beliefs. It is not sent by witchcraft and cannot be manipulated by humans for revenge or jealousy. Nyagu is believed to be fond of children. SHE (the spirit is believed to be female) likes healthy children and when she comes to a child, the child experiences a seizure. When she leaves, the child's seizure subsides. It is believed that individuals shake and tremor violently during seizures because they are attempting to break away from or shake off the Nyagu. When Nyagu comes to a child under five years of age, the condition is referred to as "Nyagu". This condition is believed to be easily treatable, as the spirit has not been with the child long and has not had sufficient time to mature. An immature Nyagu can be easily pulled from the child and prevented from re-entering. *For this reason early treatment of this condition is believed to be paramount.* If the child continues to be visited by Nyagu (continues to experience seizures), the

spirit will have time mature and become strong, making the condition harder to treat. It is when the child is between 5 and 10 that the Nyagu spirit arrives at full maturity. When this occurs the condition transforms from Nyagu to Kifafa (epilepsy). Though Kifafa is dramatically more difficult to heal, it is still believed to be treatable. Below I present excerpts of field notes on the topic of Nyagu:

Traditional Healer 5, Interview 3, 01/04/07

When I asked Healer 5 about the causes of epilepsy he responded immediately that, "The spirit is what causes people to shake." Seizures are not epilepsy until the child reaches a certain age and is still having the seizures or if they occur for the first time in an individual over the age of ten. Once one of these conditions is met, the individual's status changes and they now have Kifafa (epilepsy). Once an individual has kifafa it is possible that he or she may pass the illness on to his or her children through birth ("when the child is being formed in the mother") or through another means of transmission including breast feeding.

Healer 5 explained that Nyagu is the natural spirit that causes seizures in children (a condition also known as Nyagu) and if she is allowed to become strong, has the power to eventually cause epilepsy. "She is a spirit that occurs in nature. She comes to most children and it is only the ones that she is not attracted to that do not have seizures. It comes to the child as a vision of a hawk, in the child's mind." When the Nyagu comes, the child has a seizure. Once the spirit comes to the child it may come back if it is attracted to the child. Healer 5 made sure that I understood that it is only children that Nyagu likes, that she comes to.

Healer 5 explained that the reason that the fit looks as it does, is that it is the person trying to shake or get rid of the Nyagu that is holding him. "The reason that the person shakes is that he is trying to get free of the Nyagu."

Traditional healer 10, Interview 3, 01/09/07

I started by asking Healer 10 if he has ever treated Kifafa (epilepsy). He said that it is one of the less common illnesses that he treats but he does treat it occasionally. The last case that he treated was a 10 year old child about two months ago. He said that he treated the child and that the child fully recovered after just one treatment. I asked him if this is normal and he said that the spirits that he uses are very powerful Islamic spirits and they are able to do incredible things. "The spirits there (points to a large Baobab tree where the spirits are thought to live) are very powerful. If you can get them to help you, you can heal someone right away." The family has since come back to him twice to thank him and has given him a goat as payment in addition to the small cash payment (500 Ksh, or \$7.00) that they paid him at the time of receiving the treatment.

I then asked what Healer 10 thought were the causes of epilepsy. He said that there is one and only one cause of epilepsy. "That is an easy question. To me there is just one reason that someone can get this condition." He believes epilepsy is caused by an Islamic spirit called Subiani. I asked about the relation of Subiani to Nyagu and Healer 10 said that Subiani is the formal Islamic name for Nyagu and they are actually the same spirit. Healer 10 indicated that he prefers to use the Islamic name for the spirit, as he is a practicing Muslim.

Subiani is an Islamic spirit that is particularly fond of children. "Subiani finds children attractive and is drawn strongly to them," Healer 10 said. Though Subiani likes children, there are several things that she does not like. These include: the words from a specific verse of the Koran ("Resurrection"), the smell of some specific herbs (Mstalafu, Mrori, Mrahsapungu), the roasted and ground powder of a root called Mvuje, pork (people that eat pork are therefore unattractive to her), and the smell of burning elephant dung. It is for this reason that these things are used in treatments for epilepsy.

Subiani is the cause of both Kifafa (which is the advanced and fully matured stage of Nyagu) and the seizures before they have become full blown epilepsy. Healer 10 explained that there are seizures that are not epilepsy. These seizures occur only in small children (under the age of 5). Any seizure in a child over the age of 10 who has never had a seizure before is Kifafa. Also, any continuation of seizures in a child past the age of 5 is Kifafa. Healer 10 explained that the same spirit causes both of these conditions. The main difference is in the treatment of these conditions, Kifafa being much more difficult to treat. Nyagu turns into Kifafa when the Nyagu spirit has had a chance to mature and become strong. "The spirit that comes to an adult that causes a first seizure is already mature because we can see that it is strong enough to cause an adult to fit."

Subiani comes from the beach. Healer 10 believes that she resides in special (haunted) caves along the beach. "She enters the body backwards. She completely enters the person and even gets into the person's blood. It is the strength of the spirit in the blood that causes the person

to fit. The power of the spirit is just too much for the person and they are taken by her power. They shake and lose control and the spirit runs through their body in their blood." The spirit has a body just like a person. When she enters the body her head occupies the person's head, her hands occupy the person's hand and so forth. In this way the spirit is able to control the person like a puppet. When the spirit moves its arm the person is made to move his or her arm as well.

B. *Witchcraft*: There are two forms of witchcraft, which may cause epilepsy. The first is the sending of Majini (Islamic spirits that cause many illnesses and social problems) by a witch. This normally occurs when an individual is jealous or angry with another individual. He then goes to a witch and specifies that he wants the target to be stricken with epilepsy. The witch then uses supernatural powers to send Majini to the target with the specific intention of causing epilepsy. The second way that a witch can cause epilepsy is to leave a curse in the path of the targeted person (in a place that the targeted person will be sure to walk over). Epilepsy caused by witchcraft is easier to deal with than Nyagu as the Majini who cause this variety of the condition are not as strong or persistent as the Nyagu. Below I present an excerpt of field notes on the topic of Witchcraft causing epilepsy:

Traditional Healer 1, Interview 3, 01/02/07

Third time now back to Healer 1. I think he has gotten fairly comfortable with me. Doesn't seem like any big deal when we come anymore. When we came this time, he was making amulets in preparation for a ceremony (on-going) that he is doing with another traditional healer. This other healer is in the process of becoming a

traditional healer. She was sitting on his floor helping him make the beaded amulets that were then wrapped onto to a stick/cane that is one of the symbols of a healer. Every healer must have one and a new healer gets his or her own during the process of becoming a healer.

I started to ask him questions specifically about epilepsy. He said that the last case of epilepsy that he treated was approximately 4 years ago. He said that it was a 12 year old boy who came with both of his parents. He said that the boy's epilepsy was severe and he was actually having fits when he came to seek treatment. Healer 1 treated him once but the boy would not stop fitting. He sent the boy away and then had a dream that night in which Mbingu (an ancestral spirit with whom Healer 1 has a special relationship) came to see him and told him that the boy had not been healed. Mbingu told Healer 1 that he had to do other things in order to heal the boy. He was told that the boy's condition was caused by a very powerful witchcraft. Healer 1 said that Mbingu told him that someone had gone to a witch because he was jealous of the boy's family. The witch had then communicated with the Majini and sent them to the boy who was now suffering from seizures. Mbingu told Healer 1 that he would have to do more work in order to heal the boy and rid him of his problems with fitting.

C. Failure to observe proper behavior when someone with epilepsy has died: A third variety of epilepsy is caused when the family of a person with epilepsy who has died does not observe the proper funeral behavior. When someone with Kifafa (epilepsy) has died, it is paramount that normal funeral rituals *not* be observed. The family is *not* to remain in the village for the normal grieving period

(five days for a woman and seven for a man). They are also *not* supposed to perform the anniversary ceremony for the person. If either of these two rituals *is* performed, the next child born to the family will have this heritable variety of epilepsy. This is thought to be the easiest form to cure, as the remedy requires only that the family appease the spirit of the deceased person (it is the spirit of this individual who is now responsible for the child having epilepsy). It remains unclear as to why the spirit of a person with epilepsy would cause the condition in a living member of his family. Below I present an excerpt of field notes on the subject of epilepsy caused by inheritance:

Traditional Healer 4, Interview 3, 01/11/07

As I arrive at the house, Healer 4 is busy again. She has had a line of people waiting to see her every time that I have visited the home. During our initial discussion, I asked her how many people she saw in an average week. She said "In a week?! I cannot tell you in week because there are many people who come. But in a day I see close to 10." At the time I thought that she was trying to impress me, but I realize now that she was not exaggerating.

I started by asking her to explain why I had gotten different lists of ancestral spirits from each healer. She said that her list is the original one and that the other healers have adopted slightly different names for the same spirits. Part of the reason for having different names is due to small differences between Kigiriama and Kichonyi (two languages of the largest of the coastal tribes) but she said that most of the differences in the names that healers use is because the original names of the spirits have been changed. Some Waganga (traditional healers) have started to use different names to name the same spirits.

When I asked her how she knows that her list is correct she said that she has talked to many people and many other healers and everyone agrees with her. "My list is the common one for all Mijikenda (the name for the grouping of the nine coastal tribes) people. It is the original list." She said that she thought when one healer renames a spirit or calls it by a different name this name can "catch on" and eventually an entire group of healers will be using this name for the spirit.

Later in the interview she explained that sometimes, under very special circumstances, epilepsy can be inherited. When someone with epilepsy dies, the people must not observe the normal funerary ritual. Normally people must stay in the village for seven days (five if it is a woman) and are to observe an anniversary every subsequent year on the date that the person died. However, if the person who has died had epilepsy, these rituals must NOT be observed (the people must leave the village as normal and must not celebrate an anniversary). If these epilepsy-specific funeral behaviors are not observed (in other words if the normal ritual IS observed), a child of the family will get epilepsy. It is actually the spirit of the person who has died with epilepsy that causes the illness in a subsequent child.

There seems to be a slight contradiction here. It seems as if a person would want to be honored by having the traditional funeral customs observed. It seems odd that the spirit of this person would get mad because people have NOT honored him.

2. Models of payment:

Traditional healers employ very flexible models of payment. These models are best described as a "pay if you can" system. Treatment is given regardless of the individual's ability to pay. Payment is not even discussed until after the treatment has been given. However, if the individual is unable to pay at the time of treatment, he/she is expected to come back and provide compensation for the treatment at a later date. However, it is rare that the client is held to the exact amount stipulated during the healing session. In addition, in the traditional system it is not the healer who actually determines the amount of payment. It is instead the spirit(s) that they use in their healing that are responsible for this determination. In biomedical treatment locations, if you do not have the money to pay for anti-epilepsy medication (or any drugs for that matter) you simply do not get them. There is no system of credit or flexibility employed in the district hospital. The difference between a flexible "pay if you can" model and an inflexible "no money- no drugs" model may be significant in the treatment seeking decisions of families with children with epilepsy. Below I present excerpts of field notes dealing with payment methods:

Traditional Healer 1, Interview 3, 01/02/07

In terms of payment, if the condition is caused by a jini, the price is 3,000 ksh (approximately \$40.00), 1,000 of which goes as a gift to the jini. The healer must take the money and leave it in one of a few very evil caves, in which the majini reside, which are inhabited by many odd creatures including snakes and bats. If an Islamic spirit causes the condition, the price is 1,500 ksh (approximately \$20.00). This is because Healer 1 does not have to do the same amount of work here. These prices are incredibly

expensive and would be devastating to almost any family living in the area. Also, in addition to the payment, a sacrifice must be offered to the spirit. In the case of the majini the sacrifice is usually a chicken, and in the case of the Islamic spirits it is usually a goat. I asked Healer 1 how people are able to pay these extremely high prices. He said that these are the prices he "asks for" but that he has never been paid the complete amount he has asked for. In the specific case that Healer 1 mentioned, the family paid him 600 Ksh (approximately \$8.50) and sacrificed a chicken. Furthermore, two years later the family came to Healer 1 and presented him with a goat.

Traditional Healer 5, Interview 2, 12/12/06

He accepts both cash and livestock as payment (no grains or cloths). He is not very strict with his demands for payments. "If someone is unable to pay, I just let them go. If later they get some money, they know that they should come back to pay me a little. This is just how I work. I do not try to make money. I try to make the community healthy. That is what matters to me. I am not after cash, just the good health of the community." It should be noted here that Healer 5 is independently wealthy from a thriving business of producing and selling palm wine throughout the area. He does not rely on his healing practice as his primary source of income.

Healer 5 decides on the amount of payment after the treatment. He makes demands knowing full well that most people will not be able to pay him. He accepts whatever they are able to pay. I find it interesting with all of these healers why they even make demands if they know that the amount they demand will never be paid.

He says his normal fee for a small treatment (one that does not require a lot of time or a lot of medicine) is 50 Ksh (less than \$1.00). More involved treatments, and particularly those that require more expensive medicines that are more difficult to obtain and produce, are more expensive.

Traditional Healer 10, Interview 2, 12/14/06

Healer 10 tells me that the Islamic spirits tell him how much to charge. If he charges more than they tell him, they get mad at him and can make him very sick. His patients are rarely able to pay the amount that he asks for. Healer 10 accepts whatever the person is able to pay, and expects that if they are able to get more money they will come back to him and pay little by little in order to eventually arrive at the amount that the spirit has indicated (although he said later that he almost never gets the full amount that he has asked for).

This is a very different payment model from that employed in biomedical treatment options in three important ways:

- 1. The price is determined by a supernatural agent. This seems to make it difficult for individuals to question the amount of payment. It may also make patients more likely to pay something towards the amount because if no payment is made, it is believed that they may be the victims of supernatural retribution.*
- 2. Bills and fees are settled based completely on trust. This is influenced by the first point, as individuals who think prices have been determined by the supernatural agents who were responsible for their*

cure and still have the power to affect them will be more willing to come back to pay.

- 3. It is not expected that the full amount asked for will be paid. Even in the rare case that the full amount is paid, the payment is made over an extended time period (up to several years later in many cases).*

3. Family goals:

All families have thus far indicated a similar goal progression for their family. They want 1) their children to receive an education so that 2) they will be able to get good jobs so that 3) they will be able to support their family, particularly their parents, later in life. This sequence of goals is significant in understanding how having a child with epilepsy may affect family well-being as the condition can have direct effects on these goals. Children who experience seizures are frequently kept out of school by their parents because of the stigma associated with epilepsy. Also, teachers of these children frequently notify parents that the children are a disruption and should be removed from classes and kept at home. These behaviors, both on the part of parents and teachers, affect the ability of the child and the family to complete the first of the three goals. By inhibiting the completion of the first goal the sequence is disrupted. Below I present excerpts from field notes on family goals:

Family 3. Interview 1. 01/19/07

The grandmother is the primary care giver after the death of the focal child's mother five years ago. The grandmother takes care of the child, but has help from her two grown daughters who live with her at the house with their own children. During the interview the grandmother's son (who lives in Rabai) was also present.

He had come to visit his mother. The son gives the grandmother and his sister support in financial and emotional terms.

We asked what Zawadi's (the eldest daughter who lives at the house with her three children) goals were for her family. Her goals were:

- 1. To get her children educated so that they could*
- 2. Get good jobs so that they could*
- 3. Support her and themselves*

Each goal is dependent on the previous one (again where epilepsy makes the first goal impossible this seems significant). If a child has epilepsy and is not able to go to school, none of these goals can be met.

Family 1, interview 1, 01/20/07

We arrived at the house on Saturday at about 9am. There were about twenty people there who immediately crowded around my research assistant and I. We greeted all of them, which took about a half hour and then we began our interview. Everyone was incredibly curious about what we were doing there. As soon as the tape recorder came out, all of the kids huddled around it to see what it was for and what it was doing. This kept them busy for about a half hour and then they got bored and walked away to play. The focal child sat next to me for the whole interview. She was looking hard at the notes I was taking and could maybe read them as she goes to school, does well, and studies very hard. I tried to write extra illegibly so that she would give up and pay attention to the questions rather than what I was writing in the notebook.

Near the end of the interview, I asked the family what their goals were. The father and mother answered very freely and it was apparent that they had talked about these goals before. This is consistent with my past perceptions that they are a very organized family that communicates and plans very well. The family stated their goals to be:

1. *"Improve the cattle." The father wants the family to increase the number of "graded" cattle that they own (this refers to the quality of animal) as these cattle produce more milk and sell for several times that of "upgraded" cattle. The family plans to do this by selling some of their existing cattle and using the money to buy graded cattle and buying a graded bull to breed with their stock to produce graded cattle. "Even if I sell all of these cattle (points to a herd of about 30 cattle) and buy just three of four cows and one bull I will be better off."*
2. *Clear a path to allow a tractor to get to the shamba (farm plot).*
3. *Improve the plot of land by building a new house which will have a permanent floor.*
4. *Have all his children finish high school and have at least several of them ATTEND UNIVERSITY. This is a very lofty goal but I think that his children do well in school and they appear to work very hard and actually do homework (there is only one other child in one of the focal families who does any school work at home).*
5. *Have ALL of his children get jobs. The mother and the father mentioned that they want one child to become a doctor. This again is a very lofty goal in this remote rural setting. This family sets its goals*

very high but seems to work very hard and these goals seem attainable.

- 6. Have the children come back and support the family after they get jobs.*

Conclusion

Field notes 12/20/06

I have always been intrigued by the different choices that individuals make when confronted with illnesses. I have felt and feel now, as I am immersed in complexities of treatment choice here in Kenya, that understanding how and why these decisions are made is a worthy endeavor. I feel that such knowledge is a topic not only of academic and theoretical importance to many disciplines of the social sciences but of practical importance and promise in its power to be applied to actual people experiencing real illnesses.