NLM Uganda
Makerere University
Medical Student Interviews
Nixon Niyonzima, William Lubega and Nelson Igaba
Interviewed by Julia Royall
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Transcribed by Alison Oppenheim April 29, 2008
* Julia's voice is inaudible in much of the recording.
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NN: My name is Nixon Niyonzima, I am a fourth year medical student at the Faculty of Medicine, Makerere University, and I have been part of this project for the past four years, since its inception.

WL: My name is Lubega William, a fourth year medical student and I've been working on this project, which is a collaboration between the Faculty of Medicine, the National Library of Medicine and other several partners in health, and I've been looking forward to being part in this project and I'd also like to take this opportunity to thank NLM for their support for this project.

NN: I don't look like Nelson, who is the third colleague, but he is coming.

We started four years ago with basic diseases in mind, diseases like malaria, diarrhea, diseases that are treated by using medicines, diseases that are prevented by using the conventional means. We eventually found out that people are not only afflicted by disease and over the past few months, the past four months, we have been able to realize many things.

Among them the fact that if we are to fight disease, we have to fight poverty, we have to fight ??. We have brought on board many companies and organizations to support us. We are planning to devote tools in addition to the malaria tools that we have, the diarrhea tools, and tools in poverty eradication and tools in ??, so that people are able to grow foods and earn a certain amount of money to be able to look after themselves. We believe that this is one of, if you fight poverty and are able to give people some basic level of living, and with improved living comes basic prevention of some of these diseases. And that is some of the things that we have been able to achieve.

And among these collaborators we have had collaborations with the National Agricultural Advisory Services, which is basically an organization charged with improving agriculture in our country. This organization has been trained to spread across the country, but they have not been able to reach everyone. We are going to areas, we are trained to factor in agriculture into our prevention of disease. And this is a whole package which has health, agriculture, and economics. Teach

people to make some money, teach them to buy mosquito nets, to protect themselves, as well as to grow foods and keep healthy. The other partners of ?? was the Makerere University project and the Mifumi project. This is a rural project in Tororo District, that's at the border with Kenya, it's a rural area, where people are so poor, and this tells you why we need to have the three elements. You have to have health, agriculture and poverty eradication. This is a village, you tell them to buy mosquito nets, they can't afford it. You tell them to ?? they cannot ?? because they don't have their crops. So we bring on board the National Agricultural Advisory Services and a tool that's aimed at poverty eradication. Teach people how to make some little money and eventually they will be able to buy a mosquito net because they have some money that they can use.

5:10

And so far we have been able to go out to Mifumi, where we have joined hands with the Mifumi Health Center which is a brainchild of the Mifumi project in Tororo and we have created a corps site there, that is students from Makerere University go there for their community practice and through this they educate the community about disease and take part in the activities of the Mifumi project. Disease prevention and community outreach in all the spheres. School education and those that take part in the youth and women affairs in the area.

And hopefully these projects should grow bigger and we are going to make a change, make a difference in the lives of the people in Mifumi.

JR: What's that you ?? were really keen for the students to be involved in ?? what drove you into it? What made you want to get other people involved?

NN: Well ideally you could say that it was pure coincidence that I joined the Medline Tutorials for Africa group. Coincidence because I met Dr. Ian who interested me in that project and it was a good opportunity to make a difference. To do something for the local people. To give back to the community whose tax money I am using for my education. So yes I joined because I thought I could make a difference in someone's life.

Why did I get other people? I got other people because anything that one person can do, other people can do. And that is, if I could do something small, how much more could three more people do? Four more people do? And the culture was to get people who are self inspired and who have internal motivation to do these things. Seeing as if you can go to rural places. Not everyone can go to Mifumi because it is a rural area, electricity is a luxury. There is piped water. There you have to fight to get these services. Here there is easy access. So you have to get

people who will go to Mifumi and be motivated by the fact that they are making a difference in these people's lives, in the local community.

8:00

JR: When you went into the first villages that you went into ?? in the first villages, what was the reception? Can you tell me what that was like, taking somebody new with you.

NN: In my first year in 2005, the first time I went out to the community we went to Mbara and the expectations there were, as we were first year medical students, just the basic medical knowledge. But in the village, everybody who comes from the medical school, who is wearing a clinical coat is a doctor. So their expectations are very high. And the people expected we would cure their children of all their diseases and basically improve life and health care in that region. So the expectations are very high. The reception was fantastic. Because people had the expectation, the reception was a consequence of the expectations. A very warm welcome, people give you foods, because they expect a lot from you.

And through this project, the NLM tutorials for Africa project, you realize one thing. When we went in there the first year, we went as students to learn, to get from the community. And in the NLM project, we learned as we gave back to the community. We are getting knowledge, we are learning from them, and we are giving them something. We are giving them skills, knowledge to keep themselves healthy, to make some money, to grow crops, to remain alive.

JR: Can you tell me a little bit about the role that traditional medicine plays in the village? Do people go to the clinic or to the shrine or to both?

NN: Traditional medicine is deeply entrenched into African traditions. Almost everybody that I know who is African has a certain amount of belief in traditional medicine. And it is even more with those who have not gone to school. And Uganda has a literacy level of about 35%. That is those who are not educated believe more in traditional medicine than they do in the modern medicine. And this is firstly because of what they believe in about the disease condition. If you get a disease, usually people believe that you are bewitched. And the question is, how can modern medicine help me if I have been bewitched? And it is the traditional healer who can take away this. Of course, that trend is changing. People believe in a bit of both. I go to the hospital and get some medicine, some drugs. But then I will still go to the traditional healer to get a bit of what he has to offer. This is like covering both sides of the coin. You get traditional medicine and you get modern medicines. Whatever works, it will work.

JR: ?? traditional medicine ?? witchcraft ?? ancestry, a sickness might have something to do with an ancestor?

11: 45

NN: That is what I was saying about what people believe about diseases. Some believe that somebody can send you spirits to attack you and cause illness. And these spirits can only be removed from you by ritual cleansing, which is only done by a traditional healer. And the traditional healers have a lot of time to give to their clients, so people feel better received, better treated by the traditional healers.

And this brings in the aspect of the health work frustrations. We are very few trained doctors, very few trained health care workers so the time afforded to the patients who come is very small. Whereas the traditional healer handles you, he can even deal with the whole, so you feel better treated. So psychologically you learn to go back to the traditional healer who treats you better all the time. The one who just rushes you through, even if he helps you, he just rushes you through the system. He just rushes you through so that you don't want to go back. And still the cultural beliefs of course disease causation is not attributed to germs, not attributed to pathogens, microorganisms, but rather to spirits and spells.

JR: What was your major frustration when you first went out with the original draft of the malaria tutorial?

NN: The original draft of course the immediate frustration was that it was tailored by doctors and by medical students that were not culture adapted at that time. And what was put in the draft at that time was what was in the books, not what was on the ground in the community. So you are referring to the condition of malaria and now you want to look at what are the community beliefs. Maybe they believe that the mangoes, as we looked at earlier, causing malaria, you want to look at the spirits. And not just coming to tell them that malaria is caused by mosquitoes, is spread by mosquitoes. You want to get their views, not just tell them what you know.

NI: I am Nelson Igaba and I am a fourth year medical student. I am part of the Mifumi Project, the NLM project and I am proud to be part of it.

JR: I want you to look at what brought you to the project in the beginning and ask has it changed, has it deepened, has it brought you in another direction? What ??

NI: I remember the first time this project was introduced to us. I was in a community called Kirodu, Kirodu Health Centre. It was Dr. Monabi and Dr. Isiagokem, who were already in the field. They brought us paper, they looked like questionnaires. We thought it was someone's research. Only to introduce to us that we could help educating the community about the common diseases that affect them. And we would get the feedback of the community, how did they perceive their diseases, what did they think the causative agents of their diseases are and how do they think the causative agents of their diseases are, and how do they think their diseases affect them, how did they think they could treat their diseases.

15:51

So we picked up an interest that first day because the community was not responding in the way we expected. But when we went down into the community, we found that people really didn't know what caused their diseases. Like people were saying that mangoes caused malaria, instead of knowing it was mosquitoes, people were saying that witchcraft was causing malaria, people associating malaria with cultural practices and the rest. So we really picked a lot of interest. We really knew that we were getting a community that doesn't know. Which we thought the community could benefit.

So basically that's how it all started, that tool was revised from the feedback from the community, because we saw that the tool was a text book tool. It didn't depict what the community understands. Because it was just like notes we were giving to the community. But if you go there and teach them in what they know. If you go there and tell someone to put water in the fridge and he has never seen a fridge, you'd better tell the person, you keep water in a pot. Because they have seen pots. You just teach them how to keep the pot clean. So we really thought of just redrafting the tool, which has helped us fit the culture of the people we talk to, and they understand. Because we are talking to them through what they are used to.

WL: One more thing I would like to talk about in this project of NLM tutorials for Africa is that we consider the cultural aspects. One thing about Africa is that we have a diversity of cultures. And the different cultures understand diseases differently. One thing that is so special about the work that we doing, the education tools that we are developing, is that they take into consideration the different cultural aspects of the different tribes in Uganda. In Africa we love our cultures. And we look to our cultures to find meanings in various things including diseases. For example when somebody gets sick, in most cases they think that they have been bewitched, and you can't explain to them otherwise. So instead you take into consideration the language they speak, what their understanding of disease is, and being able to explain their understanding of disease from their perspective, it will be very difficult to reach out to them. So in most cases what we

do is we go into the community, we collect what their beliefs are, and then also we look at the main information from the medical profession, and then we integrate the two in a multidisciplinary approach to be able to reach out to the people within the communities.

19:37

JR: ? (hard to hear)

WL: OK, one problem that we had with the project is that the initial tools were developed in software form and they were developed as tutorials. But deep down in the villages some of them don't have electricity. Some of them have never seen computers. But when you translate this information into something that is tangible, for example the posters, they can be pinned up in the health centers and anyone who walks into the health center will be able to see the posters. Then also they help us reach out to more people. More people are reached with the posters, we have been able to take some posters to the IDP camps in Gulu and we have also taken some posters to the army. And we also partner with other NGOs who are dealing with health and mainly with malaria and they have been able to use this information in the posters in their campaigns against diseases and malaria.

JR: ?? feedback ???

WL: First of all, we have sent an assortment of posters and booklets to the people in Gulu. They are used in the health shelters and also the women's groups that are being educated by the faith based organizations are able to get the information on malaria. One thing that we are very excited about the posters because they saw things that they could relate to in their own communities. For example the mangoes. They could easily relate to them and identify…. the mangoes are aspects of their culture, aspects of their everyday lives, they could easily relate to them.

And another thing is that the Health Center where they took the posters, the Health Shelter. They are very excited in that they have been telling people about malaria, but they didn't have anything tangible to show the people. Anything tangible that the patients could walk in and see and easily relate to. So it was very beneficial to them in that they could educate the people in the least amount possible and then people will always remember the visuals and learn to associate the vector with the disease, which was very important for us.

JR: ??

WL: The aid becomes in Gulu as a result of the insurgencies, the war in the north between the LRA rebels who are led by Koni and the government forces. So

basically it is the war in the north that has displaced these people from their homes, they live in IDP camps, which are very concentrated. You can find an IDP camp with about 20,000 people and that is really an overpopulated area. So that predisposes them to a lot of diseases such as malaria, diarrhea. They have a lot of diseases, malnutrition, and other diseases. So the IDP camps are so different from normal societies in that there is a lot of pressure on the health care providers at the IDP camps. They have a lot of patients to see and they can't spend so much time to educate each and every patient about diseases, for example malaria. But when you have the posters, the patients can easily get the information when they visit the health shelters.

24:17

NN: The IDP camps are displaced peoples camps and they are ?? for the reasons that William has been explaining. What happens is that because the people can not be easily protected in their individual homes, they are put in one central location where the army can easily protect them. This is basically a refugee camp, only that it is within the country. So the people are crowded. You have one small house, a hut usually, to a family of ten. So the congestion, the overpopulation and the lack of accessibility to services leads to many diseases. I actually visited an IDP camp in Gulu, and the situation is appalling. You have no sanitary facilities, no drainage, no toilets, no latrines, but serving a very big population and the health workers are very few. So the challenges are enormous and there is a great need to prevent disease in such a situation, such an area.

Every year we have medical students going out to the community. And the health system in Uganda is such that in every district we have a district director of health services who is in charge of the health services in that district. He is in charge of the policy implementation in that district. So what we did this time around was we had about 12 groups of students going out to the community who received copies of this malaria tour. And some of these copies are to be given to the district director of health services to enable him in his policies and disease prevention in that district. And also as a tool to enable the students to educate the community.

Twelve groups of students translate into 12 districts. Usually students work at health centers or district hospitals. Health centers serve a population of about 100,000 and if I am taking it to a level of health centers,12 health centers serve a population of about 1.2 million people gaining accessibility to these disease prevention services. And if in one lot you can have 1.2 million people, definitely it goes a long way in preventing disease. Because Uganda has a population of 28 million people, 1.2 million people is quite a good percentage. And I expect subsequently as more groups go out, more people should access these disease

prevention skills and we should do much better in disease prevention in the country.

NI: In addition to what he has said, in Uganda we have over 70 districts. But the Faculty of Medicine at Makerere University has selected a few districts, 40 districts among the 72 districts where we have sites where the students always go every year. And that is where the malaria tools have been distributed in the 40 districts where we have sites where the students go. But in Uganda we have over 70 districts.

27:48

JR: What is the population of Uganda?

NI: We have over 28 million people.

NN: Like I earlier said, one of the partnerships that we have made is with the Mifumi project, in Tororo district, in eastern Uganda, close to the border with Kenya. And it is a diversified project with several areas of involvement. They have the health center, they have the school, they have a legal aid project for women who have been battered by their husbands involved in domestic violence. They have a youth scheme. We have chosen to partner with them because it gives us accessibility to a wide range of vulnerable persons, which William is going to speak about.

WL: As my colleague has said Mifumi is a rural village and it has a wide variety of very many people, children, women and men. Basically what we are doing in Mifumi is we want to see the different media of communicating health information, how effective they are. We carried out a baseline survey on malaria to find out how much the people knew about malaria, their attitudes on malaria, their practices. And we are going to implement the research in January, where we shall go out, educate the people in the different media. We shall be using radio programs, we shall use the poster campaigns, we shall use the booklets, and the electronic versions of the tutorials. And we are going to try and find out which of the different media reaches more people and is more effective in this kind of rural setting, and which one has a greater impact on changing the attitudes of people. And this research is going to be cross sectional research, and we are also going to do it for quite some time, because behavioral changes is not something that you can measure at one instance.

So we are planning to do the research and then do the implementation of the project and then closely monitor it, maybe for one year, two years or three years

and see whether the different media have an effect on the mortalities in general and also the behavior change in the communities.

NI: In the month of November, a bunch of fourth year medical students went to the community to their sites where they were going to do their community activities. These students were given a couple of booklets, the malaria tool, a couple of posters, and they went with them to the community. So basically what they went to do with this tool was that whenever they could go into the community, they would have what we call house visits. This is where they reach one afternoon in their time there, they go house by house asking how they are, how are the diseases affecting them, and teaching them how they can prevent these diseases. So we give them these tools, so that they can reach there and they use these tools to educate people when they go for house visits.

32:05

So me, I went to Igangla district and I went with a couple of these booklets and the posters. And I should say it was a successful journey there because the time I was there we went to primary schools where we were using these pictorial tools, these booklets and the posters to teach the pupils, the primary pupils. Because it is very hard for the primary pupils to understand the English context of these diseases. So when we would raise up a poster that had a picture you would ask them what do you see, then they would tell you what is in the picture. Then you explain what that picture means. Which really helped us to teach students who we called ambassadors in those communities because when they go back home, they will teach their families, their friends, and their relatives.

WL: The research for me was carried out in about 100 households. We visited the households and then we served them with a questionnaire which entailed information about their attitudes, their knowledge, and their practices on malaria. That was done with the aid of a translator who helped us move door to door and to translate the questionnaire into a language that the people in the different households would be able to understand, and they would be able to give us feedback.

JR: Did you find the questionnaire ??

WL: The questionnaire had different aspects it was looking at, for example it had the health data of the household heads and one thing that is in the African culture is that the household heads, who are normally men, have a lot of decisions to make from economic decisions to health seeking criteria. So we wanted to know who is the person who makes the decisions for health in the community.

We also took into consideration the standards of living of the different households by taking into consideration how much the family was earning because the economic income of the family has an impact on where they seek medical attention, which clinics they go to, or which hospitals they go to, where they go to drug shop, whether they can afford a particular medication. That was important information for us.

35:30

Then we also looked at the burden of disease, what the people thought was probably the greatest disease burden in their own community, and we also looked at what they thought was the biggest disease burden in the country at large. And what was interesting was that the different homes had different ideas on what the country's disease burden was. And also the different households had different feelings on what was their own different burden of disease. We also assessed their knowledge of malaria, the prevention and treatment of malaria. And another interesting component of the questionnaire was that we also looked at their health seeking habits. And we found that in our culture there is what we call dual therapy. Not necessarily having two kinds of medicine, or having quinine and panadol, but it's more like having the health seeking habits. Somebody will go to the clinic and at the same time will go to the shrine. That kind of dual therapy. So we also explored that, to know where these people are seeking medical attention. Whether they mix the modern medication with herbs, whether they go to the shrine or to the clinic, whether they go to the church. That was an interesting aspect to look at.

NN: Of course, like William has said, we looked at different aspects of health in the survey. And the aim for example for the head of the households was to find out which household is more affected by disease. Is it the household headed by a father, a household headed by a mother, or by children? So it looks at all of those aspects.

We are in the primary stages of analysis but basically you find the households headed by fathers make on average more income than the other households. The households headed by children suffer more from diseases and this relates to the low levels of income and also knowledge and skills. Then you go to the disease causation.

I imagine that most of the respondents said, sorry not disease causation, but burden of disease. Most of the respondents think that AIDs is the greatest burden of disease that we have. And this is not nearly as true as there has been a lot of media cover up (Nelson might mean 'coverage'?) of HIV/AIDs. The message has

been spread everywhere. And this has been at the expense of the rest of the diseases that kill more. But the only difference is that maybe these diseases are more acute and kill in a shorter time. But AIDs is there for a long time. But most people think that AIDs is the greatest disease burden that we have. And then of course on the causation of the disease, AIDs has been well explored. This is through sexual intercourse, but the rest of the diseases, as I was saying earlier, it is attributed to spells, and of course malaria ranks very high amongst the other diseases. After HIV/AIDs, you have malaria. So it ranks……well, many people think it is the cold weather that brings the malaria, and this is because it goes high during the rainy season. So you can't really blame them for thinking that, since it is the rains that bring malaria.

39:21

Then of course people think that it is the mangoes. When it is the mango season, it is the rainy season. So you can really connect the two. We have malaria highest during the rainy season, we have mosquitoes highest during that time, and people attribute mangoes, malaria and rainfall. And then of course, the other aspects where people give you knowledge which is what you expected, there are people who tell you that malaria is caused by mosquitoes, which to the layman it is true, and this is what we expected people to know. But then there are those who will tell you maybe it is God. You have done something wrong and God is punishing you. So all those aspects are there. And I hope in the final analysis we shall come up with something more much clearer than we do now.

WL: Then we also found another interesting analysis where we are primarily looking at the questionnaires as we were moving from household to household, we found some interesting attitudes and practices. For example, when some people have malaria, they think that they can't do anything about it, that's because they are not economically empowered to be able to go to the drug shop and buy some medication for malaria. So what some people will do is that they will go and use the local herbs or in case that they have their old medication that they had either from their family members or from their children, or from the neighbor next door, they will be able to borrow that medication. And they don't take it until they are ill. Once the symptoms are relieved, they stop the medication. And also something else that we found is that some people use herbs at the same time that they use the modern medicine, so there is some kind of dual therapy.

NI: In our societies we also have discrimination. This is common with women and children. For example in a rural setting, if a woman gets sick, she can't easily come out and say that she is sick immediately. That's why these people always come to the hospital when their conditions are worse. Because she thinks that when she says she is sick, she won't go to dig, go to the plantation to do work, and

the husband might batter her, or the husband might say she is disobeying, plus she might not cook for the children. So she hides the sickness until she is really so down and she can't hold it any longer, that's when she goes. So there is that stigma of proclaiming the disease very early so that they go to the hospital in fear of their husbands.

42:50

But for the husbands, they seek, let's say the husband has a sexually transmitted disease, he will go to the hospital without the notice of the woman, leaving the wife to suffer with the STD. So there are always those discrimination and stigma in families concerning diseases.

NN: Nelson has said, stigma and discrimination is applied to every disease. But is commoner in some diseases more than in others. And if a person has a mental illness, a psychiatric illness, the stigma is higher than if somebody has malaria. And HIV/AIDs, the stigma is higher. Basically because people associate HIV/AIDs with moral degradation. So you are discriminated against because society assumes that you are morally inept, so they discriminate on that basis. For mental illnesses, it's their belief. The belief is that mental illnesses, basically you suffer from mental illnesses because you have been bewitched, it's a spell, so mental illnesses are more commonly associated with the spiritual world than a physical disorder or an organic disease. So people discriminate against you because they believe that you have been bewitched, and if they associate with you, it will probably catch them too.

NI: With the experience that I have had with this project, is that I feel so much for the people of Uganda in that what people here in the medical school really think is not what is on the ground. We think people know what they suffer from, when people don't really know what they suffer from. People associate diseases to weird things, as we have mentioned earlier. So I really feel so bad that if I have been given a way to really help, to change the mind of these people into perceiving diseases with their causative agents than perceiving diseases with their spiritual world, with mangoes, with witchcraft and all the others, then I really feel so, I don't know, about the people. We should really do something so that their minds can be changed to knowing what causes their diseases other than associating their diseases to other things.

JR: So when you are Minister of Health, I will expect that.

NI: Basically I don't doubt that because soon I will be a member of parliament and I will bring that into the house. So that's it.

JR: That's great.

NI: I have political ambitions.

46:04

WL: Working with this project, tutorials for Africa, I have been given a chance to go into the different communities and talk to different people in the communities, from different cultures, different walks of life, and that has inspired me to know more about different people's culture and the impact of their culture on their health. And one thing that I have really noticed is in the African setting when you are speaking the language, the people understand. When you speak their culture, when you know the cultures of the community, it is very easy then to deal with the health issues that come with it. And then sometimes you feel some level of futility of sorts, when you go into the community, you educate someone about malaria prevention and you tell them to use a mosquito net, and yet you can't provide the net. And then when you reach in some areas, for example the IDP camps where you have just a few posters and the demand is so great that you can't meet the demand, it makes you feel a bit sad that you can't reach out to everyone. But one thing is that I always, when I am educating people, I educate them to such a level so that they will always be in a position to educate other people and that way you cause a ripple effect. And in so doing in working with this project, I try as much as possible to inspire the younger medical students and probably the young doctors so that they can be able to incorporate the cultural considerations in administration of their work, in working with people, in bringing health to the people.

Health is about a multisecterial outreach where you need to have the doctors, the social scientists, the educational scientists, so that you are able to reach out to the community. Maybe one day I will be a medical anthropologist and reach out to the different cultures and people.

NN: Being a part of the NLM Tutorials for Africa project translates someone from a position of powerlessness and inability to one of endless possibilities. That is, knowledge is power. And when you get the knowledge you are able to create a difference in somebody's thinking and somebody's actions. We have been able to reach out to several communities to educate them, empower them and give them the ability to change their livelihood. To change their situations in which they are. That is if somebody formally knew that, well they are powerless because they think that malaria is a punishment from God, now they can do something about it, because they are empowered, they have the knowledge. And personally and with my colleagues I think the goal is to make a difference in society. To make a difference in someone's life, to make a difference in health care in Uganda and

Africa. What William just talked about becoming a medical anthropologist and Nelson saying he wants to become a politician, and I want to become a servant. I want to serve the people. I want to become an infectious disease specialist, and serve my community. Make a difference in somebody's life. And my ambition is that I should become a lecturer and maybe dean of the medical school. And continue that project.

50:19

(the three students chat together)

51:20 end of DVD