KAKANDE’S STORY
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By

Rachel Kawuma, Sarah Bernays, Hellen Nakyambadde, Olive Kabajaasi, Sabrina Bakeera-Kitaka, Victor Musiime, Janet Seeley, and Annabelle South
Authors:
Rachel Kawuma, Sarah Bernays, Hellen Nakyambadde, Olive Kabajaasi, Sabrina Bakeera-Kitaka, Victor Musiime, Janet Seeley, and Annabelle South

Contact Address:
Medical Research Council / Uganda Virus Research Institute (MRC/UVRI)
PO Box 49, Entebbe, Uganda. Telephone: +256 417 704000; Fax: +256 414 321137 e-mail: mrc@mrcuganda.org
Joint Clinical Research Centre, Plot 101 Lubowa Estates, Off Entebbe Road, PO Box 10005, Kampala, Uganda Telephone: +256 414 201147/8; Fax: +256 414 342632; e-mail: jcrc@jcrc.org.ug
Baylor College of Medicine, Children’s Foundation – Uganda
PO Box 72052, Kampala, Uganda Telephone: +256 417 119200 / 100 | Fax: +256 417 119166
Website: www.bayloraids.org/uganda

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This book is an output from ARROW Young Lives, which was funded by the Department for International Development for the benefit of developing countries.
This is the story of a young Ugandan boy living with HIV. Kakande is not a real person. His story is based on the stories of the lives of the young people living with HIV who took part in the ARROW Young Lives research project in Uganda and Zimbabwe.

The aim of the ARROW Young Lives project was to find out how young people between the ages of 11 and 13 years managed being HIV-positive. We interviewed 104 young people, their carers and health workers. Some of the young people were interviewed four times, over 18 months.

We hope this story will help people to understand better what it is like being a young person living with HIV.

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Today, Kakande is a happy twelve-year-old, but he has been through a lot in his young life, as a child living with HIV. Here is his story.

Kakande’s grandmother lived in a village. One day her son came home from the city with his bride.

Hello, Mama. This is Nabilingi.

Welcome, welcome. I’ve been waiting to meet you. I hope you are going to stay with me a while.

Just a few days, Mama. Then we have to get back to the city.
Later that year, Granny received a letter from her son, giving her some good news.

Hullo Mama. I hope you are well. We have some good news. Last week our son was born. We have named him Kakande...

But two months later the beautiful dream was shattered and Kakande and his father came to live with his grandmother.

Oh Mama, Nabulungi was very sick. She passed away last week. I don't know what to do. How will I look after Kakande? I don't feel very well myself.

Don't worry, son. You and Kakande come and live with me now. I will look after you. Your brother's children, Kigo, Sunday and Nampuja are already here, keeping me company.
WITHIN A FEW MONTHS KAKANDE’S FATHER BECAME VERY SICK AND DIED. GRANNY TOOK CARE OF HIM TILL THE END. SHE ALSO CARED FOR LITTLE KAKANDE WHO WAS ALWAYS SICK. WHEN HE WAS ABOUT FIVE YEARS OLD KAKANDE’S GRANDMOTHER TOOK HIM TO THE VILLAGE HEALTH CENTRE.

HE OFTEN HAS FEVER AND DIARRHEA AND HE IS NOT INTERESTED IN HIS FOOD. AND LOOK AT THE RASH ALL OVER HIS SKIN.

MY FRIENDS CALL ME GONYA BECAUSE MY SKIN IS ROUGH LIKE A CROCODILE’S.

I WILL PRESCRIBE SOME DRUGS AND YOU WILL FEEL BETTER.

THE DRUGS MADE KAKANDE FEEL BETTER, BUT NOT FOR LONG. THEN ONE DAY A NURSE FROM THEIR NEIGHBOURHOOD TOLD KAKANDE’S GRANDMOTHER TO TAKE HIM TO ANOTHER TOWN WHERE THERE WAS A BIG HOSPITAL. IN THIS HOSPITAL THERE WAS AN ORGANIZATION THAT COULD HELP HER GRANDSON.

OHH GRANNY, THIS IS FUN. THE BUS IS GOING BUMPETY-BUMPETY-BUMP.

WHEN I GROW UP I WILL TAKE YOU TO THE BUS-STOP ON A BICYCLE LIKE KIGO DID TODAY.

YES, KAKANDE THIS IS FUN, BUT MY OLD BONES ARE CREAKING! IT WILL TAKE US THREE HOURS TO GET TO THE HOSPITAL. BUT IT IS ALL FOR THE GOOD.
Soon they reached the hospital. They had to wait for their turn to see the Musawo—the health worker.

Oh, look Kakande! There are so many children here. They are also waiting to see the Musawo. Why don’t you talk to them?

Uh-uh! No. I don’t know them. I don’t feel like talking to any of them.

Kakande and his Granny went in to see the Musawo.

What is he suffering from?

Well, most days he has fever and diarrhea, and he does not want any food. And he has a rash all over his skin.

How long has he been living with you?

His mother died when he was just a few months old. That’s when he came to me.

Oh! Tell me more about his mother. Kakande, will you please wait outside?
Kakande felt left out and unhappy.

Granny came out and took Kakande to the laboratory for some tests. An hour later...

Granny, do come in. I have got the test results. Kakande, I need to speak to your Granny alone. Could you please wait outside?

Why are they talking about my mother? She died many years ago. What's that got to do with me being sick? And why does the Muisawo not talk to me? After all, I am the one who is sick. She has not even asked me how I am feeling!

Why does the Muisawo want to speak to Granny alone? What about me? Why do I always have to wait outside?
The Musawo broke the news to Kakande’s grandmother.

I'm sorry. The tests show that Kakande has HIV. He may have got the illness from his mother.

My little Kakande has HIV? Oh no...

How could he get the illness from his mother? I heard on the radio that a mother can pass on HIV to her child but I don't know how that happens. I must not tell him he has HIV. He will think badly of her.

We have to put him on treatment. I will prescribe some drugs. He must take them twice daily. Please make sure that he is regular in taking the drugs.

Granny only knew that I got HIV from my mother. This is one of the reasons she did not want to tell me that I had HIV. Health workers could help those who take care of us by giving them detailed information about HIV, such as how HIV can be given to a child by the mother. They could offer them support to get over their fears so that they can talk to us about HIV.
Finally, Granny came out of the health worker's room. They collected the drugs from the pharmacy and went home in a bus. But Granny was in deep thought all through the journey.

Oh look, Granny, look ... there's a baby monkey on that tree. Granny, don't look so sad. These drugs will soon make me better.

Granny made sure that Kakande took his drugs regularly every day.

Kigo, Sunday, Nakpilja, your brother Kakande is sick and needs to take his drugs regularly. Whenever I am away I would like you to remind him to take his drugs at seven in the evening and morning. Make sure he doesn't miss.
As they neared the end of each month, Granny took Kakande back to the hospital for a review and got more drugs.

Every month they give me the same drugs and I have to take them every day. Why do I have to wake up early, even during school holidays, to take these drugs? And why do I have to take them again after supper? I hate these drugs, especially the yellow one. Aahh! It smells and tastes really bad.

As Kakande continued to take his drugs, his infections cleared and he felt normal.

Look, Granny, all that rough skin has gone. My friends don't call me Gonya any more. They play with me in school and I'm going with them to graze the cattle tomorrow.
Kakande continued to be reminded to take his drugs but he soon realized that none of the children he played with had to take drugs. One morning Kakande was very excited...

Where are you going so early in the morning, Kakande?

I am going with Akiki and Kizza to fetch water. On the way to the spring, well, we are going to stop by the field and get some sugar cane.

OK, but take your drugs before you go. You know the Mubaso said you have to take your drugs regularly.

Why? Why do I have to take these drugs every day, Granny? I am not feeling sick any more. Akiki and Kizza don't take them. None of my friends takes them.

Granny had still not told Kakande that he had HIV.

Go on Kakande, just take the drugs. They are for your own good.

I don't want to take them. I hate them.

I cannot tell him that he has HIV. Even the Mubaso in the clinic asked if I had told him, but I said, no. He is still too young to be given such bad news. Anyway, I am making sure that he is taking his drugs regularly.
Granny insisted that I take my drugs every day, morning and evening, but I did not see why, since I did not even know that I had HIV. Explain to us why it is important for us to take our drugs every day as prescribed by the Musawo. Talk to us in a positive way. Please don’t use scary words like “you will die”. Involve us in managing our drugs and HIV condition as a whole. That would ensure that we take our drugs regularly.

Kakanpe continued to be an active child at home, helping out with household chores. But when he was about ten years old he started having fevers and losing weight.

Kigo, I am worried about Kakanpe. He is probably working too hard. I think he should stop working in the vegetable garden. Maybe he could continue to fetch water. He enjoys doing that.

OK, Granny.
But there was no improvement in Kakande’s health.

Kakande, have you been taking your drugs everyday?

Of course, Granny. Don’t you see that the tin is half empty?

Good boy. Ok, now get some rest. You still have a fever.

Granny was good at reminding Kakande to take his drugs but she did not actually make sure that he was taking them.

These drugs are horrible. I’m just going to hide them. Granny never checks to see if I am actually taking them. And she never looks under my mattress, so she won’t know.
Sometimes we get tired of taking drugs every day. Some medicines smell bad or make us feel sick in the stomach. But we should not hide the drugs or throw them away when our carers are not looking. That only makes us more sick and we have to take even more drugs.

We children living with HIV can sometimes trick adults into believing we have taken our drugs even though we have not. Adults should closely monitor that we are taking our drugs and not hiding them or throwing them away.

Granny had no idea that Kakande had stopped taking his drugs. She was worried as he was just becoming more sick and weaker. She took him back to the clinic.

Is he taking his drugs well?

Yes, he is.

Continue with his medication. I will also give him some pills to take care of all the infections because I can see he is weak.
But Kakande did not get better. Two months later a health worker visited their home to check on his health.

Has he been taking his drugs regularly?

Yes, he has.

May I please see the drugs?

Here are his drugs. You can count them.

Kakande’s grandmother was very worried and stressed about his health. She often spoke on the phone to her daughter who lived in the city.

Thank you, I got the money you sent me for this month’s needs. I will be buying Kakande’s uniform as well next week. But I am very worried about the boy. He is taking his drugs every day so I cannot understand why he is getting ill.

That would be wonderful.

Well, the numbers are tallying so he must be taking his drugs. But his last test showed that his CD4 count is low. That means the drugs he has been taking are no longer working on him. Please take him back to the clinic. The doctor will have to change his drugs.

Well, Mama, the school holidays will begin soon. Why don’t I come and visit you? We can talk about Kakande’s problem as well.
When the school holidays began, Kakande’s aunt came to visit his Granny. Aunt knew that Kakande had HIV.

Mama, Kakande does not look very healthy. How is he doing in school?

Hmm, that is not good. Why don’t I take Kakande with me to the city? Maybe going to a different place will make him feel better.

Here is his report card. He has not performed well in class. The poor boy missed so many days due to illness.

Kakande was very happy in the city, in his aunt’s house. He could play with his cousins, watch television and there was always a lot of good food to eat.

Eat well, Kakande. I made your favourite chicken.

Thank you Aunt. I love the food here.
Kakande took his drugs regularly in his aunt’s house. He did not hide them or throw them away.

Kakande don’t forget to take your drugs after dinner.

I won’t forget. You saw me have my drugs after breakfast, didn’t you?

Yes, I see you take your drugs after breakfast and dinner every day. That’s very good, Kakande. You seem to be much stronger now. But I think we should visit the children’s clinic. I want to find out why you have been falling sick at Granny’s house, even though you have been taking your drugs regularly.

I was happy in my aunt’s house. I had to take my drugs because they were kept in full view in the dining room. My aunt and cousins reminded me all the time and they made sure I took them every day in their presence. And the delicious and nutritious food made me feel stronger.

Carers – support us children by reminding us to take our drugs and making sure that we take them in your presence.
One evening, during supper, there was a health talk show on TV. They were discussing HIV in the local language.

Media reports that we have run out of ARVs are incorrect.

These are the different daily drugs that are given to children who have HIV. This one is Allivina and this is Eraveri... They are all available in our national medical stores.

Those yellow pills on the chart look exactly like the ones I have to take every day. I must check if it is the same drug that I have.

Kakande was very worried. As soon as he had finished eating, he left the table. He did not even wait for everyone to finish.

They are the same drugs that I just saw on the HIV chart on TV. Does that mean... that means... I have HIV!!
Kakande ran to his bedroom. He climbed into bed and started crying. He was very scared.

Why do I have HIV? How did I get HIV? Am I going to die tonight? During the PIASCY sessions at school they told us that HIV is a very bad disease and if you have it you can die. I must not sleep. If I sleep I will die.

Kakande could not sleep. So many thoughts and questions were going round and round in his head.

Whom can I ask? Granny might beat me if I ask her. Aunt may be upset that I was watching TV while eating. What if she refuses to bring me back to the city again? My cousins are young like me. They probably won't know anything different from what I know. Besides, in PIASCY they said that HIV kills. What if they stop playing with me because I might die anytime?
I found out by accident that I had HIV. I was very scared. I thought I was going to die. I wish some adult had told me that I had HIV and explained it to me. I wish there was someone I could talk to about all my fears. I was told to have my drugs but I did not even know why I had to have them. During the P hazır sessions in school the teachers talked about HIV prevention, but no one talked about all the problems faced by children who already have HIV.

Finally Kakande fell asleep, but the next morning, all the thoughts came back and he became very quiet.

Kakande, why aren’t you outside playing with your cousins?

I don’t feel like playing.

Well, we will be going to the clinic tomorrow. I hope we can find out why you are feeling so poorly.
The next day Aunt took Kakande to the clinic which was near her home. There were many people there, mostly children. Kakande had to go for many tests.

Well, Aunt, the test results show that his CD4 count is still low. Kakande, are you taking your drugs regularly?

Yes Musawo, I am. Aunt, don’t you see me take my drugs every morning after breakfast and every night when we finish supper?

Yes.

Well, OK then, just go on taking your drugs regularly.

When they came home from the clinic, Kakande and his Aunt sat down to chat.

Kakande, what do you think of this clinic?

I liked the Musawo. When I go to the health centre with Granny, the Musawo talks to Granny alone, even though I am the one who is sick. She gives me bitter drugs which I hate. Today the Musawo allowed me to stay while she talked to you. That made me happy. I told her that the drugs made me feel sick in the stomach, so she gave me different drugs. Please can we visit the friendly Musawo again? I would like to ask her some questions.

Yes Kakande, I promise we will go back next Wednesday.
This was a good experience for Kakande as his granny had never asked him about his thoughts and feelings.

I will ask the Musawo if the drugs I am taking are for HIV as they said on television. The Musawo was so polite and kind. I am sure she will not scold me for asking.

When the health workers talked only to my granny I used to wonder what they were talking about. I was confused and worried. Like many of us children who have to take drugs every day, I was going through challenges and wanted to discuss them although I could not say so. Then I found a kind Musawo who was polite and willing to listen to me. I was not afraid of her, so I decided to ask her all the questions that were going around in my mind.
Next Wednesday, when they went back to the clinic, Kakande and his aunt found a health worker giving a talk on health in the waiting area.

Kakande felt cold fear inside. When the Musango invited them into her room he broke down.

As you are the adults who take care of these children, you have to ensure that they take their drugs well, or else they will become weak and get other infections. Here, look at this chart. These are the drugs for HIV that the children have to take.

How are you feeling now, Kakande? What’s the matter? Why are you crying?

Aunt, maybe if you left us alone for a bit I could talk to him and find out what is making him so sad.

Kakande, what happened? Tell me what is upsetting you.
The Musawo let Kakande cry until he stopped.

Can you tell me why you are crying, Kakande?

I have HIV. I saw a chart on TV. It had pictures of drugs they give to children with HIV. The Musawo outside was showing the same chart to people who take care of children with HIV. Those are the same drugs that I take every day. So now I know I have HIV. But how did I get HIV? Am I going to die? How long will I have to take these drugs? Do I have to take drugs even if I don't feel sick?

The Musawo realized that Kakande had not been told that he had HIV. She sent him off to have lunch in the canteen and called his aunt back into the room.

It appears that he does not know that he has HIV. How much have you told him?

I am not the primary carer. His Granny—my mother—takes care of him.

You must tell the boy about his HIV status. He has so many questions that need to be answered. Could you find out how much his Granny has told him? Let us meet on Friday and decide how we are going to break the news to him that he has HIV.
That evening Aunt called Granny and told her what she had discussed with the Musawo.

Oh no, why did you take him to a place where he had to hear such bad news? I think you should bring him back immediately. You are just making him feel bad in the city.

Mama, just calm down and listen to me. The only way we can help Kakande to get better is if we tell him what he is suffering from and how important it is to take his drugs consistently.

I have already lost two sons to this disease. I cannot lose Kakande as well. Kakande will hate me if I give him such bad news. I will convince him to take his drugs but I cannot tell him why he takes them.

Aunt realized that her mother was unhappy, but she understood that Kakande had to be told about his HIV status.

Don’t be so upset, Mama. I will give you all the support you need to make sure that Kakande doesn’t feel sad and continues to take his drugs. He must know why he has to take the drugs. We have a meeting with the Musawo on Friday. I will have you collected so that you can join us for that meeting.
On Friday, Aunt went back with Kakande and his grandmother to meet the Musawo.

Kakande, go to the canteen and have some breakfast while I talk to Granny and Aunt. Then come back and join us.

Indeed she is different. The Musawo back in the village only talks to Granny. This Musawo has said she will call me to talk to the three of them.

My grandmother did not want to tell me that I had HIV. She was worried about hurting me. It was good that Aunt offered to support her, as she could not have done it alone. Sometimes even grown-ups are scared. They may need help to tackle a difficult situation. Then it is good for them to take the support of someone they trust.
When Kakande had left the room, the Musawo spoke to Kakande’s Granny and aunt.

Granny, have you told Kakande that he has HIV?

No, I cannot do it. Kakande’s father also died of HIV. When he was told he had HIV, he stopped taking his drugs and became very sick. I don’t want to lose Kakande as well. If I give him this sad news he will be very upset and will hate me.

Granny, it is very important to tell Kakande that he has HIV and to support him to take his drugs properly. Let me explain to you about HIV and mother to child transmission, or MTCT. Then together we can decide how you will break the news to Kakande that he has HIV.

Mama, I will help you to do this. Don’t worry. We will do this together.

My grandmother did not tell me that I have HIV because she did not want to upset me or hurt me. She could not forget that her son—my father—gave up on life and stopped taking his drugs once he knew he had HIV. We do need to know about our HIV condition. Only then will we see the need to take our drugs, which will keep us well.
After listening to the Musawo’s talk on HIV, Granny finally agreed that they should break the news to Kakande. Aunt said she would also help Granny to support Kakande. The Musawo then called Kakande into the room and broke the news to him.

Kakande, you were right. You do have HIV. But do not worry. Your Granny and Aunt will take care of you. These drugs will keep you well, but only if you take them daily, as the doctor tells you. If you have any worries or questions you must talk to someone you trust. Now, do you have anything to say to us?

Kakande felt sad but relieved. He felt he could talk to the Musawo and even Granny.

Now I understand why I take drugs. I will take them regularly. Can I tell you something? Please don’t be angry with me, Granny. At home I used to remove the day’s dose and put the drugs under my mattress. I was tired of taking them and I did not feel unwell so...

Oh Kakande! After you left I was cleaning up your room and found all the drugs. But I did not say anything to the Musawo because I thought you would hate me.

Kakande, thank you for being honest with us. Now we understand why you were becoming more sick and weak even though we thought that you were taking your drugs regularly.
GRANNY AND OTHER HEALTH WORKERS ONLY ASKED ME IF I HAD TAKEN MY DRUGS. THEY NEVER ASKED ME IF I HAD ANY QUESTIONS OR HOW I FELT. IF THIS MUSANGO HAD ASKED ME, "WHY DID YOU MISS TAKING YOUR DRUGS?" I WOULD HAVE BEEN FRIGHTENED AND NOT ANSWERED HER. BUT SHE WAS SO POLITE AND UNDERSTANDING I WAS NOT AFRAID TO TELL HER THAT I HAD NOT BEEN TAKING THEM.

Look Granny, I've got a good report card.

KAKANDE WENT BACK TO THE VILLAGE WITH HIS GRANNY. HE TOOK HIS DRUGS REGULARLY AND HIS HEALTH IMPROVED A LOT. NOW HE AND HIS GRANNY ARE HAPPY.

YOU ARE DOING WELL IN SCHOOL BECAUSE YOUR HEALTH HAS IMPROVED AND YOU ARE NOT MISSING ANY CLASSES NOW. IT WAS A GOOD IDEA FOR US TO KEEP YOUR DRUGS IN THE CUPBOARD SO THAT I CAN MAKE SURE THAT YOU ARE TAKING THEM REGULARLY. IF YOU CARRY ON LIKE THIS, YOU CAN LOOK FORWARD TO A HAPPY FUTURE.