



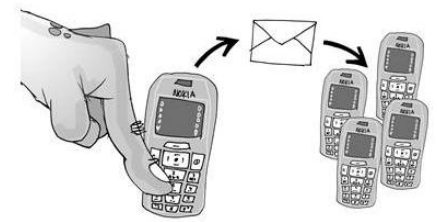
Developing support networks for adolescents living with HIV/AIDS using mobile phone technology

Introduction

This presentation will look to give:

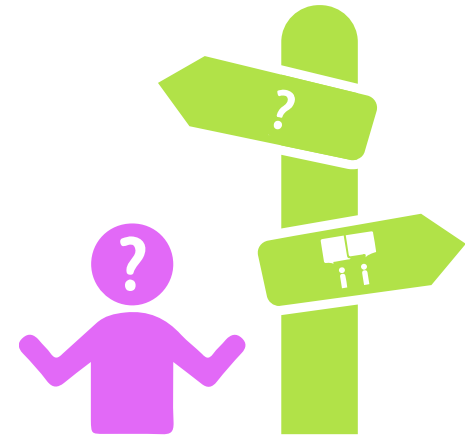
1. Introduction to the mobile phone support group model that we have developed in Mexico that has now been taken to South Africa and Guatemala.
2. An overview of the kind of challenges that HIV positive adolescents are facing and why we have developed a mobile phone support group model.
3. Some of the preliminary findings that we have so far
4. An explanation of why we have used the mobile phone as a tool to set up support groups for HIV positive adolescents
5. Discuss what are plan is going forward

Project Zumbido, Mexico



- High levels of social isolation stigma for those living with HIV in the state of Jalisco, Mexico
- Critical need for support groups but there were a number of barriers:
 - Distance
 - Stigma and discrimination
 - Childcare
- Formed small groups of 10-15 participants where they could communicate amongst themselves simultaneously via SMS about the issues affecting them.
- Over 250,000 SMSs were sent amongst 40 participants over a period of 3 months.
- Levels of anxiety and depression reduced significantly, increased knowledge about HIV and 2 participants reported restarting their medical treatment when they had not been taking them.

Our focus on HIV positive adolescents



The challenges that HIV positive adolescents are facing in South Africa

- Over **15% of young women and 5% of young men aged between 15-24 in South Africa** are infected with HIV (UNAIDS, 2010)
- With the roll out of medical treatment many who acquired HIV through birth are reaching adolescence.
- While this is a success, it raises its own challenges, as, in addition to the general issues associated with adolescence, these young people must navigate their developing sexuality and HIV status.
- Until recently, most of the focus has been on the biomedical outcomes but there is growing awareness many HIV positive adolescents are at increased risk of mental health problems (Abdallah S. Daar, 2014) which in turn leads to issues of treatment adherence.
- In the case of South Africa, HIV positive adolescents have very little support services available. If support groups are available many are infrequent, purely information focussed and cover a large age range.

HIV diagnosis

HIV diagnosis and managing disclosure of HIV status can have a longstanding negative impact on an adolescent's mental health.

I was very scared, I thought I was going to die
(HIV Positive adolescent, 14 years old).

Many of them don't like talking about it. I still struggle to get an answer out of some patients when I ask them why are they here to see me, many won't come out and say that they're HIV positive. There are some who still don't take their treatment because they refuse to accept their diagnosis.
(Doctor, Kalafong Hospital).



Stigma and discrimination

Despite nationwide campaigns to raise awareness of HIV/AIDS and treatment options there are still very high levels of stigma and discrimination. Stigma is a major barrier to accessing prevention, care and treatment services. There are many adolescents who take the decision to travel long hours to go to a clinic outside of their community to receive their treatment as they don't want to go to the nearest clinic for fear of their status being disclosed to family, friends and their community. Levels of social isolation can therefore be very high for HIV positive adolescents, leaving them in the position where they don't feel comfortable sharing their concerns or challenges with others.

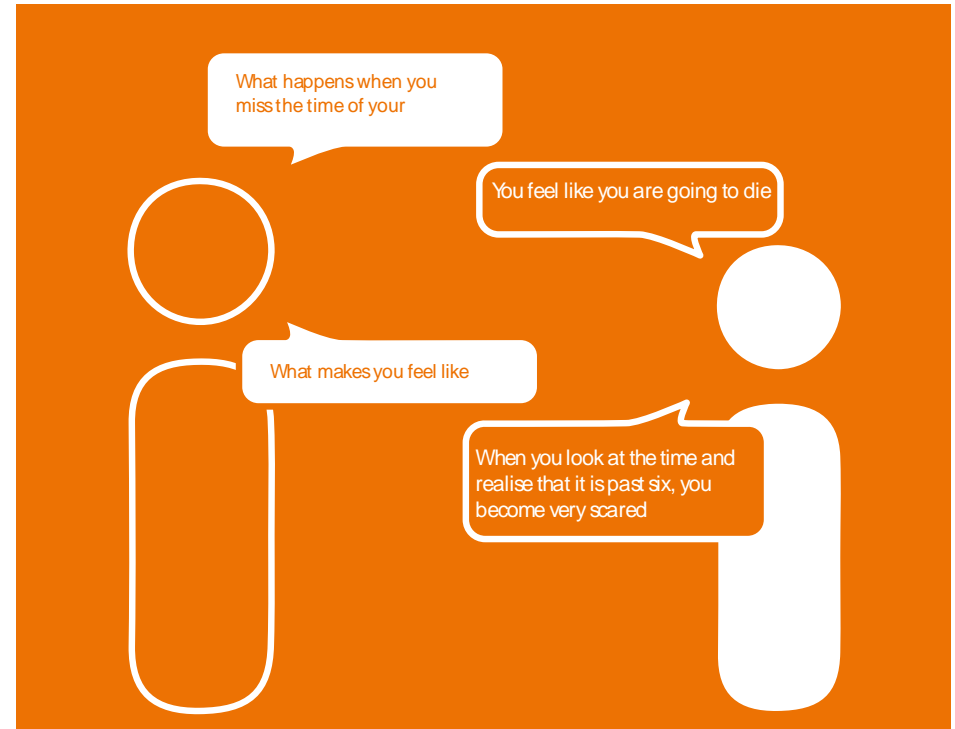
Unfortunately in a lot of cases parents do not want to talk about it they just want to see the adolescents taking their medication and that's it. You can even see the lack of support showing when these adolescents come by themselves to the clinic. They might be having problems as well that not are not related to the illness at all like emotional and social problems at school.

(Counsellor)

I am really scared to tell anyone about my status
(HIV Positive adolescent 13 years old).

Medication

Treatment compliance is an important and complex issue. Adherence to medication is critical if adolescents are going to live healthy lives. There are however many reasons why adhering to medication can be challenging due to emotional issues such as feelings of anger, anxiety and depression.



The need for a space to connect and the challenge of providing support groups

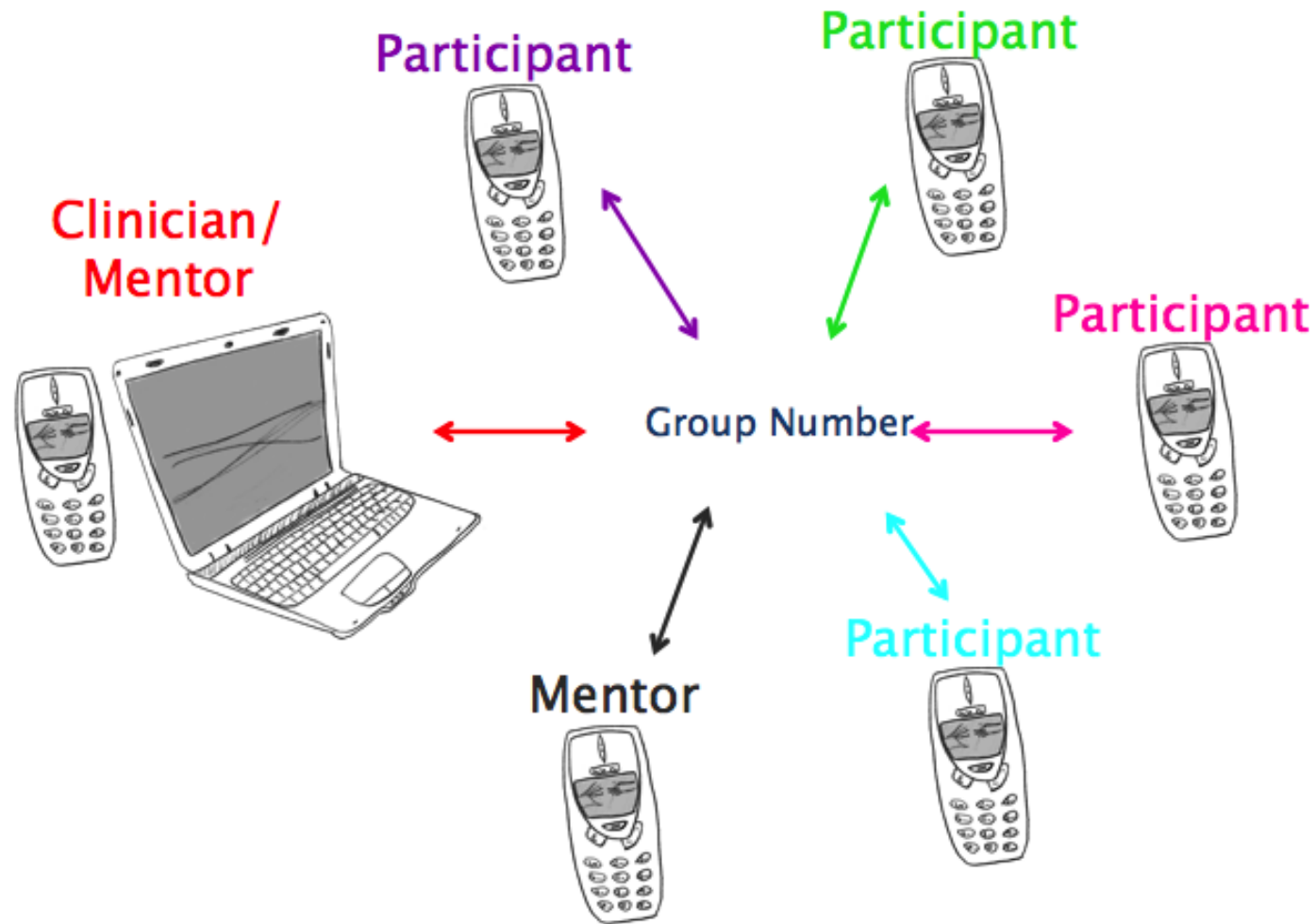
- For reasons of **geographical and especially social isolation**, many of the HIV positive adolescents are confronting these problems alone, either choosing, or being forced to go without any form of emotional or peer group support.
- In 2014 we launched Project Khuluma and have piloted the model so far 55 HIV positive adolescents in Pretoria and we are about to expand to Cape Town with the aim of reaching 150 adolescents by the end of the year.
- In collaboration with Yale School of Medicine and the University of Pretoria we are evaluating the impact of this model.
- The **principal aims of Khuluma are to improve treatment compliance, improve feelings of social support, coping and life skills.**



How Khuluma works

- Much like a physical support group, **Khuluma provides facilitated and interactive support to closed groups of 10 to 15 participants.**
- Participants are able to communicate amongst themselves and with a facilitator via mobile phone about a range of topics that are important to them.
- Guest speakers are also invited into the groups to run facilitated discussions on specific topics such as nutrition, education, careers advice or sexual health.
- HIV positive adolescents who attend the clinics who show interest in taking part can meet with a Khuluma team member to find out more or take part in a Khuluma workshop where they can find out more in a group setting.
- If they then want to take part an interview is conducted as part of the research study and they are then invited to join into a group that is best suited to them.

How the technology works



PRISC

Alternative therapy and substance use:

- Depression is common among people who use substances.
- Screen and monitor when it leads to poor adherence.
- Substance use is often highly sensitive – maintain a high index of suspicion.
- Personalized medicine and substance use.

Prerequisites:

- Encourage a healthy diet
- Flexibility, a target weight should be maintained
- All patients, including TB patients, and pregnant and lactating women should have their diets optimized

At all times:

- Advise patients who cannot access ART facilities to stop all treatment unless their optician with a single drug.
- A quantity of current treatment and medication should be kept by the patient in the case of potential facility or transport issues.

When leaving:

- A supervisor should be given the appropriate information of leaving with appointments made to optimal care.
- Ensure adequate supply of medication is left and scheduled appointments.

3. Oversight within the facilities:

Independent evaluation of the role of providers and performance of all ART programmes within these institutions.

4. Alternative therapies:

Patients with HIV should be warned of side effects, drug interactions and the risk of public health emergencies of their immune systems.

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Know your medicine Ask your pharmacist

health
REPUBLIC OF SOUTH AFRICA

USAID
U.S. Agency for International Development

APS
Agency for Procurement Services

DID YOU GET ALL IF NOT CONTAIN

Do you want to take part in an SMS support group and chat freely with other young people?

If so, contact our Khuluma team on 0722989634, for more details.

Brand Name	Product name	Registration/Reference no.	Active
1			
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What we have found out so far

- Over 21,000 SMSs have been sent amongst 55 participants demonstrating the **huge need to communicate**.
- Topics discussed include health eating, dating, stigma, treatment compliance, problems at school, sexual health, employment and jobs.
- Pre- and-post interviews were conducted with each participant that was underpinned by the IMB model (information-motivation-behavioural skills).
- The interviews were designed to specifically assess changes in the areas of:
 - Adherence motivation
 - Knowledge of HIV
 - Perceptions of internalised stigma
 - Social support
 - Self-efficacy

A conversation about disclosure with a guest speaker

What would u do if ur girl frnd does nt wat to accept ur status Guest speaker: Well sometimes people are afraid of what they don't know. They don't have enough information

So when u disclose to your part ner u need to also be ready for any response from them

But hw abt those who judge us

But than they dont give us that chance to explain,so how wil u respond if xe does not give u a chance??

Firstly you need to have accepted your own status and be comfortable disclosing to others

Do i realy hve tel my partner abt my status if i knw dat i truly trust hm

Let's say this, when you start dating it's important to talk at what u both expect of each other


Trust is great and that means being honest with each other

Medical adherence

- Common response from the adolescents that we have worked with when asked if they have any issues taking their medication is that they have no problems with their treatment.
- However in the mobile phone support groups medication is a very common topic that is discussed within the groups.
 - **Facilitator:** I sometimes find that medication makes me sleepy or feel sick as a side effect, do you ever have side effects from hiv medication
 - **Participant 1:** Nope! B[u]t sum make me sleepy.
 - **Participant 2:** An[d] dizzy
 - **Facilitator:** Oh dear. Sleepy is not so great when you have things to do. And dizzy - ugh that's a horrible feeling!
 - **Participant 2:** That mean[s] [you] ar[e] not dri[n]king the well or u ar[e] going to start [yo]ur madic
 - **Facilitator:** So drinking fluids helps to make the feeling better?
 - **Participant 2:** Ya that is cor[r]ect
- **Direct and indirect messaging**, we have seen that many participants like to remind each other to take their medication and they tailor their messages depending on the participants they are communicating with

What we have found out so far

- While the data sample is small at present there have been some very encouraging findings in the following areas:
 - Decrease in internalised stigma
 - Increase in adherence self-efficacy
 - Increase in perceived social support
- An overwhelming trend in the content of the messages has been the offering and requesting of network support among the participants.
- Having others to connect with on a regular basis who share similar experiences seems to be an extremely valuable aspect of group participation as is the opportunity to connect with others on an emotional level.



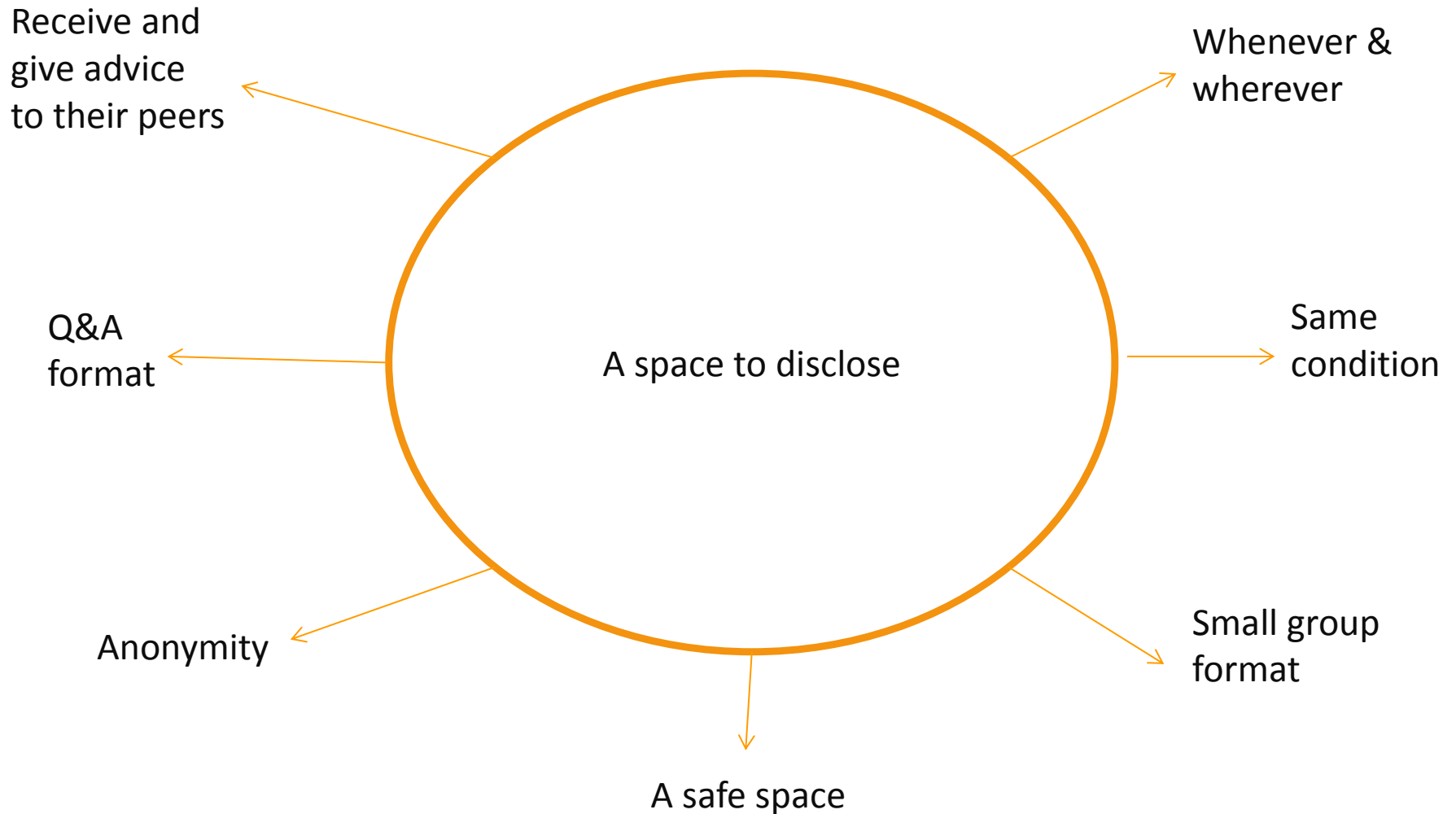
Before I started with the Khuluma group I felt like I am different to other people
(Khuluma participant)

I feel more comfortable talking to people in this group because we all have HIV – I am not the only one
(Khuluma participant)

I learned that I should not be afraid to talk about my feelings
(Khuluma participant)

No one had ever asked me to talk about my feelings in this way before. As I opened up more I learned to trust and could share more.
(Khuluma participant)

Addressing barriers to disclosure



Why the mobile phone?



- Communication is **immediate** helping to respond to questions and concerns when they arise.
- We have found that for many it is **an intimate form of communication** feeling comfortable to communicate about a range of psychological and medical concerns using SMS.
- It is **accessible** for many of the populations that we have been working with in both urban and rural areas. In South Africa over 82% of the population own a mobile phone.
- It helps to **bridge physical distance**. Enables us to have participants in the groups that are diverse with respect to their experiences and backgrounds to living with HIV.
- Particularly for many of the women who are taking part in our support groups in Guatemala communicating via mobile has the benefit of not have to deal with **childcare requirements and travel constraints**.

Some of the challenges of the mHealth model

Challenges to do with the mobile phone:

- Cost, still very high in many countries
- Literacy levels
- Language barriers
- Multiple conversations going on at the same time can be confusing

Other challenges:

- Finding space in clinics where the project can be introduced to participants
- Establishing relationships with health professionals and clinics who can promote the project.

What next

- **Continuing to evaluate the impact of this model** with our research partners as we set up more support groups in different locations.
- Expand our mentoring programme. We have developed a **training tool for participants who want to take on a mentor role** in future groups. It provides accessible information on HIV, tips on how to communicate within small groups via mobile phone and how to deal with tricky group dynamics (www.mykhuluma.org).
- We will be looking to build our next technology platform that can be used for those with WAP enabled phones making it cheaper.
- We are looking to find ways to start working with government agencies as we now have a wealth of messages that if analysed in the right way could inform policy makers and health practitioners on the gaps in information and knowledge and the challenges that HIV positive young people are facing in their-day-to-day lives
- Given the high numbers of HIV positive adolescents in South Africa there is a critical need to come up with new and sustainable models of support particularly in the area of psychosocial support.

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Sizwe's Story

Sizwe is a 15 year old boy living in an urban township near one of the South Africa's major cities. He lives with his grandmother and older brothers, they survive on his grandmother's small pension and any money he or his brothers earn doing odd jobs. Both of his biological parents have died when he was very young, he is not sure what the cause of their death was, but he thinks it might be TB. Every morning for as long as he can remember he has swallowed many different pills, sometimes the pills make him feel sick. Two years ago he finally asked a doctor at the clinic that he visits every three months, what the pills were for, and was told he is HIV positive. **How did this happen? How did he get this?** It was only after much probing that his grandmother told him that his mother had had HIV.

Sizwe's Story cont'd

Sizwe felt very angry, but his grandmother and various other people at the clinic told him that he must not be angry. This made him feel very confused and frightened; he felt like his life was over; but there was no one he could talk to about his feelings. All of this confusion made him feel down, and sometimes, he didn't take his medication, because he did not want to be reminded about his HIV status, and he didn't really feel like he deserved to live. His grandmother didn't talk about HIV at all. He was worried that if he talked to his friends about it, they would hate him and that if members of the community found out it would be bad for him and his family. The nurses at the local clinic live in his neighbourhood, so when he needs to go to the clinic, he travels to a clinic one hour away by taxi.

