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“We’re not all infected, but we’re all affected”.

Nurses’ experiences of preventive work with HIV infected adolescents and adolescents who run the risk of becoming infected.

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HÖGSKOLAN
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Titel: *“We’re not all infected, but we’re all affected”*.
Nurses’ experiences of preventive work with HIV infected adolescents
and adolescents who run the risk of becoming infected.

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Abstract

HIV continues to be a major global health issue and South Africa is reported to have the largest population in the world living with HIV. Adolescents are at high risk to get the infection and are facing many difficulties when growing up from childhood to adulthood. The nurse has an important key role in the preventive work when meeting the adolescents in the health care.

The aim of this study was to investigate nurses’ experiences of preventive work with HIV positive adolescents and the adolescents who run the risk of become infected.

This study is based on semi-structured qualitative interviews with eight nurses, active in the preventive work with adolescents in a suburb in Western Cape, South Africa.

Knowledge of the disease has increased greatly in South Africa in recent years and was thought to be the main issue to reduce transmission. The nurses’ preventive work seems to have many aspects, were information and education takes a great part. Adolescents were reported to be a difficult group to reach especially the young men. Obstacles in the nursing or denial of the disease often stood in the way for the preventive work and since testing for HIV is voluntary in South Africa, many people choose to abstain.

For the preventive work, voluntary testing might not be the most optimal. The wide rifts between rich and poor are a major problem in the country. Poverty among the people might inhibit people not only from the information media provides but also lack of health care, testing and treatment. Adolescents might be in need for a special approach from health care workers.

Keywords: *HIV, prevention, adolescents, nursing, experiences, South Africa.*

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INTRODUCTION

The human immunodeficiency virus (HIV) continues to be a major worldwide health issue, especially in Sub-Saharan Africa where South Africa is situated. One of United Nations eight Millennium Development goals is to halt the spread of the HIV/AIDS. To overcome the problem requires a well-designed preventive work where the nurse has the opportunity to influence the future development.

Since South Africa is reported to have the largest population living with the HIV infection, the authors of this study believe that South African nurses' have a great knowledge and high professional work experience concerning treatments and care related to the disease. Thus, the authors wished to take part of their proven experience and consequently, South Africa was the most optimal country to conduct this study.

BACKGROUND

Population in South Africa

South Africa has a population of approximately 51.2 million inhabitants. The republic of South Africa is the wealthiest economy in Africa but it is a country known for its wide rifts between the rich and the poor. As a remnant from the Apartheid system between the years 1948 and 1990 there is still an enormous difference in the standard of living among the population. Most of the people in South Africa have a very high standard of life but there are some people living in shafts on a Third world country standard. Since the fall of Apartheid, great progresses in mixing ethnicities and equipment of households have occurred. The black middle class increases which contribute to increased consumption in the country, but still the majority in the low incomers is black people (Jonsson, 2013).

South African Healthcare system

The South African health care includes basic primary health care financed by the state, is free for the inhabitants. However, the public sector is under-resourced in places. Also, there is a highly specialized health care available, in the public and private sector. Assets to the private healthcare are crucial depending on your financial status where the majority is middle- and high-income earners. Since 2010 a National Health Insurance (NHI) for all inhabitants in the country has been planned. This has not yet entered (South Africa info, 2012).

The Department of Health Republic of South Africa states that the focus with the NHI and the health care in general is to *prevent diseases and promote health*. When the NHI is accessible for the inhabitants it is thought to have a reduced spread of HIV, AIDS and tuberculosis. There are even stated special targets on the preventive work against HIV, such as behavioral changes from the inhabitants, male circumcision and an early prevention of mother to child transmission (Department of Health Republic of South Africa, 2014).

HIV/AIDS in South Africa

HIV is a disease that continues to be a global public health issue with about 35 million people living with the infection in 2013, according to the World Health Organization (WHO 2014).

The population in South Africa has annually increased but is now threatened by a reduction. This, according to Jonsson (2013), is related to the high amount of deaths in AIDS. According to UNAIDS (2013), 6.3 million South Africans are infected by the HIV/AIDS virus. Their statistics suggests this to be the highest number of any country in the world. HIV and AIDS have the worst economic, social and medical impact for South Africa. In 2007 the country was reported to have the highest number of HIV sufferers in the world (Jonsson, 2013).

South Africa's former president, Thabo Mbeki, blamed the high death numbers of poverty and social inequalities that remained from the Apartheid era, but denied any relation to HIV and AIDS. This resulted in less receives of antiretroviral drugs. Studies have shown that 330.000 people lost their lives during the period 2000-2005 because of this. Mbeki's successor, Barbara Hogan, was against the previous AIDS policy. Hogan argued that HIV resulted in AIDS, such as today's president, Jacob Zuma, also did (Jonsson, 2013).

In 2009 a research institute called Human Sciences Research Council published studies that showed a decreasing number of HIV positive adolescents. The main reason was thought to be an increased usage of condoms. In between 2002 and 2008 the number of HIV infected was reduced from 10.3% to 8.7% among the 15-24 year olds (Jonsson, 2013).

The Chief of the HIV program at UNICEF claims that around 14% of new HIV infections occur during the adolescence. He means that the services to prevent HIV infections need to be more accessible for adolescents, for an AIDS-free generation to up come (WHO, 2013). According to the Director of WHO HIV/AIDS Department, adolescents are facing many difficulties when growing from a child to an adult. This affects their need of support from the health care and they need more support and care to maintain health and stick to their treatment (WHO, 2013).

HIV

HIV affects the human immune system and damages the function of the specific CD4 cells, or T cells. HIV can destroy the T cells and over time, without treatment, increase susceptibility to get infections like tuberculosis, cryptococcal meningitis and a specific type of cancer called Kaposi's sarcoma (WHO, 2014).

HIV is a retrovirus. By reversed transcription the virus transfer its RNAs genetic material in to the host cells' DNA and convert into DNA. By leaving the host cell the HIV is reproduced with every new production of cells which constantly increases the amount of infected cells. This function makes the HIV slowly over take the immune systems T cells (International Partnership for Microbicides, 2011). At this time the body has developed Acquired Immunodeficiency Syndrome (AIDS). AIDS is the most advanced stage of the HIV infection, and depending on the individual, the development of the condition can vary between 2 and 15 years before the condition is confirmed (WHO, 2014).

Symptoms

Depending on the stage of the HIV infection the symptoms are expressed differently. In the acute phase, within two to four weeks after the initial infection, influenza-like symptoms or no symptoms at all occur, but many are unaware that they are infected until later in the development of the disease (WHO, 2014). At this stage the ability to spread the disease is at its highest, as the virus produces itself in very high amounts (Centers for Disease Control and Prevention, 2014).

The next phase, Clinical latency, sometimes also called HIV asymptomatic infection or chronic HIV infection. The virus is still active, but at a very low level. The symptoms may be none or influenza-like. Without treatment this phase can last up to a decade.

The last phase, AIDS, is diagnosed when the amounts of T cells are extremely low, below 200 cells/ μL , compared to a healthy human with levels between 500-1.200 cells/ μL . AIDS can also be diagnosed when one or more diseases are developed regarded to the low amount of T cells. These infections are called opportunistic infections.

As the immune system constantly decomposes, other disease symptoms arise and without treatment the risk of for example tuberculosis or cancer increases (WHO, 2014).

Transmission

The most common transmission of HIV is through unprotected sexual intercourse, vaginal or rectal. Contaminated blood, hypodermic needles and from mother to child during pregnancy, delivery or breastfeeding are other ways of transmission (WHO, 2014). Transmission may occur when contaminated body fluids get in contact with a mucous membrane or damaged tissue, or when it is directly injected in the bloodstream (CDC, 2014).

There is a risk for an already HIV infected person to be reinfected, also known as a superinfection. There have been cases reported of already HIV positive people being reinfected with another type of viral strain, different from the type they already have. This may affect the treatment to be more difficult, as it may result in even lower amounts of T-cells. There is a risk that the new HIV is resistant for the antiviral drugs (AIDS map, 2014).

Treatment

There is no cure for the HIV infection, but the treatment with antiretroviral drugs can slow the process of the disease by controlling the viral replication, strengthening the immune system and assist the body to fight off infections (WHO, 2014). The medical treatment is life long and consists of a combination of drugs, often known as combined therapy, anti-retroviral therapy (ART) or highly active anti-retroviral therapy (HAART-treatment). Adherence to the treatment is important to not risk any resistance development and the side effects might be unpleasant. Diarrheas, headaches and stomachaches are a few examples of adverse effects from the drug use. Lipodystostrophy and cardiovascular diseases are others (Andreassen, Hxgelad and Wilhelmsen 2002, p. 1108).

The increased availability of antiretroviral drugs has reduced the amount of HIV infections worldwide. 6.6 million lives are reported to have been saved. In sub-Saharan Africa, many young people are not aware of their HIV status. Those who were infected at birth are becoming adolescents and it is estimated that only 10% of young men and 15% of young women (15-24 years) know their HIV status. Access to HIV testing and counseling by vulnerable adolescents is consistently reported to be very low (WHO, 2014).

Prevention

The primary preventive act to prohibit spread of the disease is information and education about transmission, mostly the content of safe sex, in particular condom usage (Andreassen et.al, 2002 p. 1105). Therefore, it is important that adequate information about HIV is given in an individualized way for the unique patient. It is also important that the information is repeated several times and given at the right moment while the patient has the ability to

absorb it and understand its content. The main information should involve how to prevent HIV transmission to others. It is also important to support the patient to process and deal with their life situation as a HIV positive. To facilitate this, by respecting the patient's integrity, the patients have to let the nurses' take part of their personal life (Andreassen et. al. 2002 pp. 1107-1108).

According to Andreassen et. al. (2002 p. 1108) the HIV infection is the most stigmatized disease of our time and people with this diagnose is truly likely to experience shame and guilt, from themselves and the society. To deal with this, many people attend to avoid their HIV infection by keeping it a secret for their related or others in their social network. This is one reason that makes the cooperation between the nurse and patient essential. (Anderassen et. al. 2002 p. 1108). Further, Anderassen et. al. (2002, pp. 1108-1109) means that it is important for the HIV positive patient to experience trust in the healthcare. Studies have shown that nurses have a unique and purposeful role to long term ill adolescents and a positive impact on adherence to their treatment (Goode, Harrod, Wales, & Crisp, 2004).

Dahlberg and Segesten (2010, p. 192) describe a relation in the healthcare as they call the relation of caring. The relation is set to create a meeting between the nurse and the patient with a purpose to support the patients' health. Even if the nurse has the responsibility in the meeting, it is of importance that the patient is active and involved and that the relation is based on reciprocity (Dahlberg & Segesten 2010, p. 195).

As a professional, South African nurse one is obligated to provide healthcare in various healthcare settings and to different age groups. Prevention is one of them. This is confirmed in a qualification framework from The South African Nursing Council (2005). There are qualities of nursing care that must be accomplished, such as the preventive, promotive, curative and rehabilitative nursing.

PROBLEMATIZATION

Growing up from childhood to adulthood might be a hard time in life, the Director of WHO HIV/AIDS Department claims that adolescents have particular and individual needs from the health care because of this. South African nurses are obligated by their Nursing Council to provide their patients with preventive work specific to different age groups. This might make the relation of caring essential. How do South African nurses succeed to reach out to the adolescents they meet; the ones who already are HIV infected and those who run the risk of becoming infected?

AIM

The aim of this study was to investigate nurses' experiences of preventive work with HIV positive adolescents and the adolescents who run the risk of become infected.

METHOD

This study was based on qualitative semi-structured interviews with eight nurses. In a science of health care perspective, the authors wished to explore how nurses work preventively and also increase the knowledge of what impact the work has on them.

The purpose of a qualitative study is to get a deeper understanding of a topic. Qualitative studies can contribute to create guidance for an evidence based work, for example in the meeting with a patient. This means that qualitative research might develop the care of a patient when exploring experiences, expectations and needs for example. When the theoretical research is converted to practical actions it might lead to new ways of nursing and open up to new question formulations and further research (Friberg 2006, pp. 105-107).

Sample

The aim was to gather nurses of both sexes and with various years of working experience to get a wider perspective of the topic. Lived experiences of responding to HIV positive adolescents and direct patient care in the daily work were inclusion criteria's for the participants in this study. English as a spoken language is a must for the participants since no interpreter will be used.

All the interviews were held at an AIDS training, information and counseling center in a suburb in Western Cape. The authors got in contact with the clinic with the help from a head nurse at the hospital Groote Schuur in Observatory, Cape Town.

Interview guide

An interview guide with nine questions set the foundation for the semi-structured interviews (Annex B). This was handed out in advance to the interviewed nurses. The questions were formulated after the aim of this study and arranged to stay to its theme. The questions were designed to reach the individual nurses' experiences of the preventive work of HIV with adolescents. The authors strived for an open, first question that would led the conversation in to its topic. Balls (2009, p. 31) also stresses the importance of this. Both of the researchers and the participant had a copy of the interview guide during the conversation. This, according to Balls (2009, p. 31) helps the researchers to make sure that relevant data is collected and if necessary, to guide the interview back to the investigated topic.

Pilot interview

Balls (2009, p. 32) suggests researchers to do a pilot interview with a trusted colleague for learning experience. The authors of this study used the first interviewee as a pilot study in order to discover eventual faults in the questions. Since nothing appeared to be wrong, the authors decided to let the pilot interview be a part of the data.

Ethical considerations

The Swedish law of Ethical reviews that regard the research of mankind (2003:406) states that no permission from an ethical committee is needed when the research is carried out on a university basis. Thus, the authors of this study made some ethical considerations that are presented below.

An informed written consent (Annex A) was distributed to the nurses in advance explaining the purpose of the study, its structure, that their identities will be anonymous and that they have the right to withdraw at any time. The informed consent also provides information about where the study will be published. The information given in the written consent ties with §16 and §17 (2003:406).

Given the prevailing stigmatization around HIV the risk of offending the integrity of a person were considered to be high. The authors have therefore chosen to perform the study through the perspective of the nurses, instead of patients'. This ties with §1 (2003:406) which explains the purpose of the law; to protect the individual and that human dignity needs to be ensured in the research.

This study approved to proceed by the Primary Health Care Manager in the area.

Data collection

Data was collected through interviews. Graneheim and Lundman (2004, p. 105) states that a qualitative method is often used in nursing research. Since the aim of this study was to examine experiences from the nurses, interviewing seemed to be an adequate method. The interviews were held in the participants' office or in the staffroom at the facility. According to Balls (2009, p. 31) a quiet and undisturbed area is ideal. This was hard to evade when interviewing in the staffroom and a few interruptions occurred. One of the interviews that were held at the participant's office put up a sign on the door that stated "Interview in progress". This can be the most optimal solution (Balls 2009, p. 32). Further, an environment where the interviewees feel familiar and relaxed are important.

One of the researchers handled the interviewing part and the other one took notes and handled the recording with the Dictaphone. Both of the researchers took part in asking follow-up questions that seemed necessary to reach a greater understanding.

Consideration of the recording equipment needs to be taken (Balls 2009, p. 31). A recording device that is close to the participants can affect the relaxed conversation. But, in order to remember the interviews, avoid misunderstandings and ensure that the answers are not based on the researchers interpretations a Dictaphone seemed necessary to the researchers.

Data processing

When data were processed all the interviews were transcribed into words. Balls (2009, pp. 32-33) stresses that it is important to type all the spoken words with all its faults, in order to remain integrity to the interview, even if something sounds incorrect or makes the analyzing part hard. The transcription should also be started with as soon as possible after the interviews. Transcription should not be delegated to someone else than the researchers' themselves. The authors of this study started the transcribing the day after the interviews were held and divided the transcription of the interviews to do four transcriptions each. This was a way to save time. Balls (2009, p. 32) also states that one should not underestimate the duration of how long time a transcription can take. With an aim to reach validity of the transcriptions, the authors afterwards sat together to with the transcribed text and interpret emerged ambiguities. When transcribing a text Balls (2009, p. 33) states that the researchers needs to decide whether to type non-verbal aspects or expressions. The authors of this study choose to type any words of hesitation, laughs or such in order to maintain the emotion of the words. This seemed to be important for the authors because many quotations were used to

strengthen credibility of the findings. According to Balls (2009, p. 33) the researchers have a responsibility to stay true to their participants' words.

Data analysis

Data were analyzed with a qualitative content analysis model written by Graneheim and Lundman (2004). A qualitative approach is, according to Graneheim and Lundman (2004, p. 105), often used when data is sampled from interviews, for example when doing nursing research.

The model suggests dividing the text or the whole interview, also called *unit* into meaning units, condensed meaning units, and at last into codes. A meaning unit, according to Graneheim and Lundman (2004, p. 106) refers to words or sentences in the unit that relate to the same context and content. The authors of this study collected sentences from the transcribed text that they interpreted to answer up to the problematization. There after the meaning units were structured and paired up so the ones that related to the same subject assembled. Further, Graneheim and Lundman (2004, p. 106) writes about the next phase in the process of data analysis' as condensing. This is described as a process of shortening a text while still prevents the core of it. Words were erased and restructured in a matter to reach the main sentence of the different meaning units. Several condensed meaning units were created thereafter. Abstraction are described of Graneheim and Lundman (2004, p. 106) as a creation of codes and categories. This means that the condensed text is developed into a higher logical level as it emphasizes descriptions to the different abstracted sentences. This study resulted in eight categories and 37 sub-categories, presented in Figure 2 under *Result*.

Categories are stressed as the core to a qualitative content analysis (Graneheim & Lundman 2004, p. 107). A category is descriptive to the content and compiled after a manifest processing of the text. From the categories different sub-categories can be created, or reversed, sub-categories can create categories. The authors of this study created sub-categories from the categories, which were founded during the analysis process. The condensed meaning units, codes or categories are interpreted and thereby a latent content of the text.

Mening units	Condensed mening units	Code	Sub-Category	Category
”Both boys and girls needs to be protected, so ehm, we will promote condoms, use of condoms, and for girls, there is just that ehm, you need to demonstrate how to use the female condom, and for boys how to use the male condom.”	We demonstrate how to use the female and male condom.	Condom demonstration.	Safe sex/condom usage	Education subjects
“...if they have sex they use a condom, or, yeah it's safe sex, not to sleep with more than one partner”.	If they have sex, it needs to be safe.	Protect yourself and your partner.		

Figure 1 *Examples of meaning units, condensed meaning units, codes, sub-categories and categories from the analyze process.*

RESULTS

The authors have chosen to present the result of the study in a table, presented as Figure 2. Thereafter each category, followed by the associated sub-categories is presented of findings in the text.

Category	Education subjects	Information sources	Work behavior	Individual care	Resources	Facing attitudes	Obstacles in the nursing	Perceptions
Sub-category	Safe sex/condom usage	Media	Self-protection	Own needs	Multidisciplinary teams	Irresponsibility and immaturity	Gender	Stigmatization
	VCT	Pamphlets and posters	Normalize and realize	Support groups	Schools	Ignorance	Parents' attitudes	Fear
	Medication/ART			Home visits			Refuse to VCT	
	Transmission of HIV			Aid the way of thinking			Relate to the private life	Fear of death
	Abstinence of sex	Coping strategies	Autonomy	Leisure activities	Lack of knowledge			
	Wound care			Talks: one on one/group		Relatives		Spite
	Seize the opportunity			Chock				
	Prays		Denial of the disease					

Figure 2

Education subjects

One of the main findings in the preventive work that was raised was to provide the patient with education and information. Six sub-categories led to the category 'Education subjects', and associated under same category as they all got focus in the education of the patients.

Safe sex/condom usage

This involved education about safe sex and condom use, both male and female.

"Both boys and girls needs to be protected, so ehm, we will promote condoms, use of condoms, and for girls, there is just that ehm, you need to demonstrate how to use the female condom, and for boys how to use the male condom." Nurse 3.

"...if they have sex they use a condom, or, yeah it's safe sex, not to sleep with more than one partner". Nurse 5.

VCT

The nurses offered opportunities for Voluntary Counselling and Testing (VCT) but many mentioned the fact that they could not force anyone, since it is voluntary. These findings are further shown under the topic “Obstacles in the nursing”. Importance for the patients of knowing their status was mentioned several times from the interviewees.

“...when patients come in in their hospitals we encourage them to do VCT, yes, even if we're doing family planning, we just educate them about VCT.” Nurse 3.

“To ehm, screen for HIV, you get the person to come for counseling or to be tested, if they want to because it's voluntary.” Nurse 1.

Transmission of HIV

Information that was given involved how to prevent HIV, the treatments with medications, how the patients could protect themselves from the infection and ways of transmission; both sexual and nonsexual.

“If the person is negative then you can even get more information on how to stay negative”.
Nurse 2.

“You can transmit the illness in more than one way, people only think it's through sexual intercourse but it's not, so that is basically what a health worker has to tell the patients, be careful, be on the safe side also, any nips and cuts, you cover it up.” Nurse 8.

Medication/ART

Many of the nurses also informed the adolescents about treatment in a way to let them make a choice to “choose life”. Facts that usually were brought up in the conversations involved consequences of not taking the ARTs. The fact that to not pay adherence to the medicines would cause a sooner death was used by three of the nurses to motivate their patients. Associations were made with the willing to live and the use of medications.

“Just to motivate them- ‘If you don't take the treatment you will die quicker’. That is the reality of it. The easy way through. You don't maybe say it that way but reality is- ‘This is your last resort hey, there is no other tablets after this, so if you want to live you need to take this’.” Nurse 3.

“They must stay on their treatment, and when they got appointments they must come, they must stay on the medication to have a longer life, // if they do not follow their treatments you educate- ‘Stay on your treatment to have a longer life’.” Nurse 6.

Abstinence of sex

Abstinence was stated from one of the nurses. Even the importance of reducing the amount of sex partners was mentioned.

“I'll tell them how to absti..., cause it's abstinence, and if they have sex they use a condom, or not to sleep with more than one partner.” Nurse 5.

Wound care

An example for a nonsexual act that was mentioned from the nurses was education of the handling of wounds, like cover up bleeders.

Further, two of the nurses saw an opportunity in any new facts and progress in research of the HIV disease and used this to motivate the patients.

“I talk about education and education all the time, you know, and any new information that comes up I keep updating the youngsters of any new types of meds. At least that helps them so that they know that they must still take care of themselves.” Nurse 2.

“If they have a injury and it's bleeding, how to treat that and how to handle someone with an exposed bleeder.” Nurse 5.

Information sources

Next findings in the result concerned all the different kind of ways to obtain information about the disease. According to the eight nurses' it appeared that a lot of information has increased for example in the society and in media. The three sub-categories below all belong to the category of 'Information sources' because of this.

Media

Many of the nurses talked about how media had a great impact on the preventive aspect of HIV. One nurse mentioned that TV is a great way to catch an adolescents' attention and in that way get an understanding of the disease.

“Obviously the TV, there is a lot going on on the TV, a lot of information.” Nurse 7.

“...now a days it is even easier because there is a lot of information about HIV on the television, the newspapers, so at least there is a lot of information how to prevent, ya for HIV and AIDS.” Nurse 2.

Pamphlets and posters

The nurses also suggested providing written information such as pamphlets and posters to the adolescents, that they had available at the center.

“We have a lot of pamphlets with information, and now a days it is even easier because there is a lot of information about HIV on the television, the newspapers, so at least there is a lot of information how to prevent for HIV and AIDS.” Nurse 2.

“What we have in this facility we have ehm, a lot of pamphlets, we have booklets, pamphlets, we have posters.” Nurse 1.

Talks: one on one/groups

Another form of verbal information was provided in talks, group talks and support groups or “one-to-one” sessions. This was a way for the patients to share experiences, difficulties and fears with each other and hear from others in their own age group.

“..education, teaching, on one to one, when we get in contact with a person, we ask them about how they are doing, how they coping and things like that. We normally just give information to them.” Nurse 7.

Work behavior

To make sure that the preventive work was working great, it was important according to the nurses that they were aware of their own work behaviors and approach on a daily basis. Five

sub-categories from the findings summarize this category and were affecting the nurses' ways of behaving and relating when meeting the adolescence.

Self-protection

Meeting a HIV positive adolescent requires a professional approach, according to the findings from the interviews. Self-protection in the work, such as wearing protective clothing and gloves and avoid contact with blood and other body fluids was mentioned.

“Preventive is wearing protective clothing, wearing gloves, let's say if there's a contagious disease, then you isolate that patient, so yeah. Then you must wear gloves and avoid touching fluids like bloods and body fluids.” Nurse 4.

Normalize and realize

Findings, in a manner to nurse for the patient, shows that an approach of “normalize” the disease often was taken. Two of the nurses compared HIV with other chronic illnesses, such as diabetes.

“Being HIV positive is not the end of the world. // But like any other people with other chronic diseases, like diabetes, you know, they take their treatment every day”. Nurse 4.

Another aspect of approach was to get the patient to “realize” the disease.

“It is important to give the information, let them know it is the reality. HIV is here, there is not much we can do but prevent. It is the reality.” Nurse 2.

Coping strategies

Also, finding coping strategies for themselves involved their daily work.

“I think you need to be a bit more empathetic, not sympathetic, empathetic. ‘Cause they are still young”. Nurse 8.

Seize the opportunity

The professional behavior was also shown when meeting adolescents with other problems at the clinic. The nurses' seized the opportunity to ask for a HIV test when the patients for example came for family planning or showed symptoms that could relate to an infection. Patients who were unaware of their status were encouraged to take a test. One of the nurses who did the triaging at the clinic had a special strategy. Since there were two departments at the clinic, one basic and one HIV department with different doctors, and in order to get the patient to meet the “right” doctor the nurse took advantage of the situation and in that way got the patient to take a test.

“All my new patients, I just test them. Whether it is a white person or a black person, or whatever, first timers, and especially the ones with all the symptoms, possible symptoms, and after that we get a lot of positive patients, I do it like that.” Nurse 7.

“In order to reach out to them every time they come to the clinic, because they're not scared to come for family planning, 17 year olds, 16 year olds will come to the clinic, I think it's best to just offer them VCT and educate them.” Nurse 4.

Prays

One nurse had a religious aspect of the work. In order to pray for the patients hope for them to succeed and feel better was stated.

"I'm pretty sure that the way that they work, the doctor and the sister, they obviously prays their patients, // cause you know we're all human, the more you been praised by someone, I think the more you would want to succeed in what ever it's you're doing in the moment, you know make you feel like better for yourself, so, yes, I'm pretty sure that they do prays their patients." Nurse 8.

Individual care

The nurses were all agreed that the care must be provided with respect to the individual patient's autonomy, were they described different approaches. Following five sub-categories associated therewith to this category of 'Individual care'.

Own needs

A perspective of focus on the individual patient was seen from the interviewees. The nurses stressed that every patient has their own needs and that motivation comes from inside. In order to reach this they used open-ended questions and let the patients speak up and put words on what they wanted.

"We are not telling people what to do all the time, we are asking them also to tell us how they feel, what their needs are and what they want". Nurse 1.

Support groups

These conversations could be between the nurse and the patient, but also as mentioned earlier, in forms of support groups.

"I think support groups are important where you can share your experiences, your difficulties, your fears, and you'll find out that there is others with the same. So you can actually help and support one another, so, support groups is very important." Nurse 1.

Home visits

One of the nurses mentioned another way of considered patient centered care. Home visits were made of community workers when the patients were seen in their own context. This cooperation gave the nurses information about their patients' home environment. This was stated as a valuable source of information since it helped the nurses to proceed with the care and let them know how they could keep the patient stay motivated by resources from their patients own homes.

"It's a community base service, workers go in to the community to see all the patients who was newly diagnosed and newly put on treatment, so they go out just to monitor and see the use of medication. And then with that information they will come and give feedback on the home visit that was done, and from that, we get information as how to manage that person to stay motivated." Nurse 1.

Aid the way of thinking

To aid the adolescents' way of thinking seemed to be an aspect of the motivating work. The nurses supported the patients in positive thinking by letting them know that being HIV

positive is not the end of the world if compliance to the treatment is taken. The nurses encouraged their patients to have a normal life but simultaneously take care of themselves.

“Okay, what is important to tell them that being HIV positive is not the end, of the world, and it's also important to think positive eh, I tell them that HIV is like any other chronic illnesses because you know I know HIV the stigma, cause it's sexually transmitted, but like any other people with other chronic diseases like diabetes, you know they take their treatment every day.” Nurse 4.

Autonomy

In order to let the adolescents feel involved in their care, they strived for their autonomy. Some of the nurses mentioned that they let the youths know that they had a choice. A mental picture was drawn; on one side there was medication and a longer life, and on the other side there was a young death in AIDS.

“I normally use to motivate them that there is a way out. ‘You can live longer, take the pill. If you don’t want to live, don’t take it’. So most of the time they are up to live longer, and who wouldn’t? Nurse 3.

Resources

All the interviewees mentioned that all the different types of resources must cooperate for the preventive work of HIV. As one nurse mentioned; ‘We must all get onboard and together as one compete against this disease’. Four contiguous sub-categories led to the category of ‘Resources’.

Multidisciplinary teams

Cooperation between different professions was one way of the preventive work. Multidisciplinary teams at the clinic was mentioned as one of them.

“I think there is still a stigma attached to HIV, So ehm, and I'm sure there is a lot of people a lot of adolescents that doesn't know their status, but we mustn't give up hope, we must all as a multidisciplinary team or even the communities must come together, to reach contents and reach out to young people.” Nurse 1.

Schools

Also a cooperation between schools and the school nurses’ was stated as to reach out to the young people.

“Especially at schools, we have more school nurses going out and educates at schools because that’s where the problem starts, when they are small children.” Nurse 7.

Leisure activities

Other communities and organizations like churches and leisure sport activities were suggested to all come together.

“So the churches must come onboard, the schools must come onboard, the colleges and universities, all organizations should, even the sports, the friendly parts like sports, culture, all of those different organizations, we all can make a meaningful difference.” Nurse 1.

Relatives

The nurses' also saw the possibility of informing the patients and let the knowledge be spread with them. The patient was seen in their context and by educating a patient their relatives, families and friends, could also take part of their knowledge. The educated patient contributes in this way to help someone else.

"Any family member, any family friend you know, you're giving them out the education so that they can prove their knowledge at the same time, and they can be able to help someone else." Nurse 8.

Facing attitudes

One of the most difficult things when nursing for a HIV positive adolescent seemed to be the many emotions one has to face, according to the interviewees. Not only the diagnosis itself, but also the aspect of their young age seemed to be one reason for their actions. This five sub-categories as following had this in common.

Irresponsibility and immaturity

When comparing adolescents with adults they spoke in terms of immaturity and irresponsibility from the adolescents.

"I think it will be, because they are young maybe they might not understand, that disease, I think that's the challenge, that you can see when not deal with the adult." Nurse 4.

"There is a difference. Because young people think they are young, they are much more irresponsible, and they think they will live longer, you know." Nurse 3.

"Adolescents they go through life as that's a joke, I mean if they don't they got no care in the world. Yeah so that's the difference between, yeah." Nurse 5.

Ignorance

Some nurses also stressed a way of ignorance from the youths.

"...of course, we still get ignorance some or somehow from people, but those at least knows more about HIV." Nurse 2.

Fear of death

One of the nurses mentioned the chock as associated to the fear of death.

"I think they are in chock. Because hearing HIV and you know what is hanging over there, it is death. So they are in chock." Nurse 6.

Chock

Many of the nurses' mentioned the chock as one of the main inconveniences that they see in the adolescents when receiving their positive test results.

"They don't worry, until, the chock! They get tested maybe and then, they find out. // Mm, I think that's the chocking because they're young, and they don't think that things like that can happen to them, yeah, the chock!" Nurse 5.

Denial of the disease

Further, the denial of the disease was also stated. The nurses' correlated this with the adolescents' young ages. They recognized a behavior of "this can never happen to me, I am young and free".

Obstacles in the nursing

To care for adolescents with HIV or adolescents who run the risk of becoming infected with HIV was not always easy, according to the nurses. Below presents four sub-categories related to this that occurred from the nurses' in the interviews.

Gender

One of the eight respondents was a male nurse. He illustrated the fact of gender as an obstacle when dealing with young teenage girls and the talks about these taboo topics like sex and HIV. He mentioned a feeling of the adolescent being uncomfortable in the conversation since he was of the opposite sex.

"From being a male nurse, yes of course there is differences, sometimes a little bit of challenging you know, when you speak to a girl adolescent and when you speak to a boy adolescent you know. // Because I am a male and now speaking about the sexual things and sometimes they don't feel really comfortable". Nurse 2.

There was another aspect of gender that was brought up from all the interviewees. Differences in responding to boys compared to girls were often experienced. Boys were described as tough, introvert, eager and with an approach of being a stereotype with many girls around them. Girls were further described as more acceptable, responsible, serious and easier to deal with.

"Boys are, they rage up, they ya, they think they are the man, you know. And girls they are like, they will listen and they will understand quicker. The boys they got this man-thing about them, that eager thing you know and the girls are like little mothers, they go in to this little pocket of 'I must be responsible', you know." Nurse 3

"You know with boys they have that attitude thing, because they are boys, they have to have many girls. So I think that's the challenge in providing information to boys compared to girls. It's easier with girls." Nurse 4.

Parents' attitudes

Parents could also sometimes be a hindrance, according to one of the respondents. A form of denial from the parents of their youths being sexually active sometimes inhibited the nurses' chance to reach to the adolescents.

"I do catch some parents who bring their children here, maybe their child is just here for abdominal pain and once you start saying 'Can we also do the pregnancy test?' you find out that the parents are not comfortable. And sometimes people that you speak to say, 'My child is not sexually active'". Nurse 2.

Refuse to VCT

Since testing for HIV is voluntary and, according to the nurses', many of the adolescents' expresses that they do not want to know their status. This is a major problem in their daily work and the nurses' ability to convince them becomes one of their professional challenges.

"Do you know your status?', 'Would you like to know your status?' and a lot of them would say 'No, no, no, I don't want to!', but then I motivate them to. It is better to know than to not to know. Nurse 7.

"Here in South Africa teenage sex and teenage pregnancies, is quite, I would say it's high. It's my personal opinion. So I'm pretty sure that there's a lot that do not know their HIV status// but before they come here I will encourage them to get HIV test. If they say no, I know I can't push them but I do encourage them to go, cause in the end of the day everyone needs to know their HIV status, especially if you have more than one sexual partner, so, yeah we try to get them to, but a lot of them don't want to know." Nurse 8.

Relate to the private life

To maintain professional could sometimes be hard, especially when one starts to relate situations in work to the private life. One of the nurses mentioned the difficulty when meeting the adolescents at the clinic one could sometimes not avoid to relate to their own children at home.

"The difficulty when you facing an adolescent, I think it's especially if you also have adolescents in your home// So it's difficult if you have the same." Nurse 1.

Perceptions

What also appeared from the result were the different perceptions of HIV, from the perspective of society and from patients. This was found to vary among people, but unfortunately, according to the nurses, it remains to be negative attitudes to HIV. The five following sub-categories share this and led to the last category of 'Perceptions'.

Stigmatization

Seen in a perspective from the community many obstacles were spotted from the nurses. Even though the stigmatization about the disease has reduced this problem still maintain to exist, according to the nurses. Negative attitudes of HIV are one cause that makes the preventive work hard to perform.

"I just booked one of the patients this morning, she is positive, and she said to me, 'You know, I get so angry when people talk in taxis, in transports- places, talk negative about it', and then she would make a positive comment, and say 'Look at me, I'm positive' then she would tell them that. People looked at her. They said 'Oh, I don't want to sit next to you' and things like that. And even if there is a talk on the TV, then she said that people would want to turn it off instead of listening. So they don't want to know about the information." Nurse 7.

Fear

Fear was stated to be a common phenomenon among adolescents who did not want to know their status.

"But they are scared to come for the test. And they might um, have the feeling that they might have it but then they won't come for the test." Nurse 7.

Sex trade

Another problem that involves many people in a society is the market of sex trades. Two respondents talked about HIV positive young ladies with “sugar daddies” and foreigners that came to buy sex from these young girls. The sugar daddies often had their own wives and so did also the foreigners. This sexual behavior from these people was also stated to be one of the difficulties in the preventive work for the nurses. The nurses stressed that many of the people who are involved in these sorts of trades were often unaware of their status but still refused to take the HIV test. Fear of the reality and denial was told to be two possible reasons for that.

“Actually, they don’t want to test. // Sometimes they know their husbands or partners or girls are moving around or cheating, they don’t want to face the facts at times. // So ya, there are a lot of people that are unaware because they think it is not gonna happen to them. So it is a thing. Ya. That is sad.” Nurse 3.

Lack of knowledge

Even though the knowledge about the HIV infection has increased, according to the nurses, lack of knowledge still exist and that can also make the preventive work hard to perform.

“Eh, young people they think because- ‘it’s me I’m not going to be infected by HIV’, no they don’t have information.” Nurse 4.

Spite

As mentioned earlier, the nurses’ recognized acts of denial that sometimes occurred from the HIV positive adolescents. In order to act this out one of the nurses reported an associated spitefulness from some adolescents.

“I feel that the young people they sometimes go into a denial state if they hear that they are positive. And then they will go out, and all they would like to do is to spite to other young people, then they won’t protect themselves. // We have those cases were they would go and spread the disease because it is almost like spitefulness. Instead of accepting it, they will rather go out and like ‘Oh no, I am positive now, I might give it to you as well’”. Nurse 7.

DISCUSSION

Method discussion

In the means of Graneheim and Lundman (2004, pp. 109-111) it is important to achieve credibility, dependability and transferability when working with a qualitative content analysis of a text. The terms are therefore further discussed.

This study was based on a qualitative method. Semi-structured interviews with eight nurses were held during one day at their clinic in Western Cape. The purpose of the questions was to gain information about the preventive work of HIV with adolescents in South Africa. The questions were formulated to be open in order to let the nurses speak freely about the topic and avoid receiving answers like “yes” or “no”. Semi-structured, open questions also gave the researchers the ability to ask follow up-questions, which in many times resulted in even more fruitful information from the interviewees. An interview guide with the questions was handed out in advance to the nurses (ANNEX B). Pros and cons with handing out the questions in advance were detected during the data collection. In favor, it eased the nurses’ ability to

prepare for the interview to let them know what would come and get some time to think. This might have contributed the result with more developed answers. A conceivable consequence is that it might have given the interviewees the possibility to discuss the questions with each other before the actual interview, and this aggravates the ability to reach experiences from the individual nurse.

Since the aim of the study was to investigate nurses' experiences the researchers were strict about this when asking for voluntaries at the clinic. A health care worker with a different profession showed interest to participate in the study but was unfortunately excluded. It might have given a wider perspective on the preventive work but not conform to the aim of the study. Further, the participants' practical experiences varied between four months and thirty eight years. The one nurse with four months of experience might have had an influence of the result since it might be considered to be a small grade of job experience. On the other hand, the authors found the answers to be of interest to the study. Both female and male nurses participated in the study. Further, the authors considered that the sample reflects the reality of a health care establishment. It might have been desirable with a more even distribution of men and women, but the one male that was asked to participate also did, and the authors consider this to be sufficiently. Kvale and Brinkmann (2009, p. 156) means that qualitative research based on interviews should involve 5-25 interviews. Further, Kvale and Brinkmann (2009, p. 156) mean that the number of interviews should depend on the purpose of the study. Too many interviews might be hard to analyze and too few might result in narrow findings. This study involved eight participants, enough to answer up to the aim of the study.

Graneheim and Lundman (2014, p. 106) states that reality is in the eyes of the interpreter and understanding depends on the subjective interpretation. Working with a qualitative text based on interviews is therefore an issue to dispute. The transcriptions of the interviews were divided in half between the authors. To make sure that no misunderstandings were made in the transcription the authors also sat together and went through all of the material until agreement were made when emergence of uncertainties.

Quotations from the transcribed text were used to strengthen the different findings. According to Graneheim and Lundman (2004, p. 110) this is a way to approach credibility in the research.

Graneheim and Lundman (2004, p. 110) value the dialogue among co-researchers. To select the most suitable meaning unit, keep the data relevant and judge similarities and differences are all critical issues when achieving credibility. When creating meaning units, categories, sub-categories and codes a discussion between the authors of this study always underlined the outcome. All uncertainties were discussed until clarity emerged. Overall, the authors agreed on the findings.

According to Graneheim and Lundman (2004, p. 110) dependability may be inaccurate when data collection extends over time. Data may change with time and can therefor cause inconsistency. Data for this study was collected during one day at the clinic. The authors suggest that this factor might have caused affections on the result. Stress and workload differ due days and some of the interviews were held late in the afternoon. Posteriori, it might have been wise to spread the interviews on several days to avoid coincidences' like this. To gather information during more than one day might also have given the authors time to get more involved and perhaps get more insights to enricher the interviews with more follow up questions for a greater understanding in some cases.

Transferability lays in the eye of the reader concerning how the study is transferable in other contexts (Graneheim & Lundman 2004, p. 110). This study was implemented at a HIV/AIDS clinic in a residential suburb in Cape Town, South Africa. South Africa has the highest rate of HIV infections in the world (UNAIDS, 2013) and differences in culture may affect the transferability of this study. It might be legit to claim that this study gives a vision of South African nurses' experiences in a small scale.

Graneheim and Lundman (2004, p. 110) states that research findings are hard to apply to a universal context. A qualitative research can answer for one particular perspective but is still a matter of interpretations.

To achieve transferability the authors of this study aimed for a detailed presentation of the results with quotations to strengthen the findings and in that way give the readers the opportunity to interpret in their own ways.

This study took place at a clinic founded by the government in a residential suburb in Western Cape Town. The authors agreed that the results of this study might have had a different outcome depending on where in the country of South Africa the clinic was situated. As mentioned, South Africa is a country known for its wide rifts between the rich and poor and a large part of the inhabitants are living in shafts on a Third world country standard (Jonsson, 2013).

Result discussion

The eight nurses in the study have all contributed an invaluable source of information about how the preventive work of HIV with adolescents works. The results are all consistence of the importance of information and education. Many difficulties in the job were also spotted. Stigmatization in the society and irresponsibility, fear and denial among the youths are all examples that were brought up.

As a nurse to be able to work preventive with adolescents many obstacles were founded. One of the greater findings, according to the authors, was that testing for HIV is voluntary for the patient. The fear and stigmatization that, unfortunately, comes with the disease are two factors that might inhibit persons who are unknown of their status to find out.

WHO (2012) suggests, HIV testing must rely on a foundation of five aspects, named as "the 5 C's". These are Consent, Confidentiality, Counselling, Correct test results and Connection/linkage to prevention, care and treatment. When the aspect of Consent is declared it is stated that a person has the right to refuse testing. Compulsory testing is never to be recommended. This brought the authors minds to the Swedish law of Protection against Contagions (2004:168). A person who is suspected to be infected with a disease classified as a public health hazard, such as HIV, is obligated by Swedish law to get tested and examined by a doctor. This goes against the guidelines from WHO, but could it be an effective way of reducing transmission? An ethical dilemma of autonomy and wellbeing for the individual contra wellbeing for the society may be essential in this context. But if regulation could decrease the numbers of infections, when care and treatment from the health care is offered, may it be wellbeing for the society that is the most pressing?

The nurses in the study also stressed that the adolescents' denial of the reality and spirit of "this can never happen to me" was an obstacle they met in their everyday work and had to overcome in the preventive work. Studies made in a HIV testing clinic in Western Cape have also shown an occurrence of adolescents who comes for HIV testing but never come back for their test results (Patten, Wilkinson, Conradie, Isaakidis, Harries, Edginton, Azevedo & van Cutsem 2013). The researchers of the study suggested this to correlate with the stigma around HIV and fear of disclosure of being positive. They also suggest improving of the support for HIV infected adolescents, as it is known that these are a vulnerable group.

Six out of eight nurses stressed in the study that there is a difference in providing information to boys compared to girls, and they all shared the same opinion that boys are harder to reach to. One of the nurses also stated a gender aspect. If the patient was the opposite sex, difficulties were pointed out of providing information about sex and that it sometimes seemed to be uncomfortable for the patient. In a study of the primary preventive work with adolescents' and their perceptions in receiving comprehensive health risk assessments it is concluded that there is a difference between boys' and girls' preferences (Kadivar, Thompson, Wegman, Chisholm, Khan, Eddleton, Muszynski & Shenkman, 2014). Boys expressed a desire of less parental involvement and had less understanding for the preventive health care. They also valued a professional appearance more than the girls. The girls preferred a face-to-face interaction where they felt that the health care provider really cared for them. Similarities between boys and girls were also found. Interviewees for both sexes valued the relationship with the personnel and stressed that the relationship should be built on trust, confidentiality, and a non-judgmental basis. They also wished for autonomy. It is, according to Kadivar et. al. (2014), important to be aware of the gender differences when providing health care for adolescents.

As seen in our study, many of the nurses worked in a way where they let the adolescents make their own decisions about the treatment. "If you want to live, you take the pill", was stressed from them. At first it might seem harsh but this can also be interpreted as a way of strengthening the adolescents' autonomy and let them feel that they have a choice.

Poverty is thought, by the authors, to might play a large part in the difficulties of controlling the spread of the disease. All of the nurses mentioned information and education as the main factors of the preventive work. But not all people have the assets of newspapers, TV or even schools. 15 % of the children in South Africa are never starting schools and seven million adults are illiterates (Höglund, 2012). It might not be an inadequately thought that if the interviews were held at a clinic nearby a shaft that the answers would be completely different. At least not in the matter on how you provide the patient with information and education. Or, on the other hand, if the interviews were held at a private hospital, the result might again be something different. The private care are, also as mentioned, known to be high specialized but only available for those who can pay for it (South Africa info, 2012).

The Swedish Social Management claims that health care provided by nurses should be evidence based (Socialstyrelsen 2005, p. 8). Evidence based is either scientific proved or proven experience (Dahlberg & Segesten 2010, pp.15-19). The authors of this study claims that the knowledge the nurses' in South Africa possesses is well proven experience since the incidence of HIV infected adolescents is at this high rates. Statistics shows that the number of HIV positive patients is increasing in Sweden. Every year 450 newly infected people are reported (Liljegren, 2009). This might increase the possibility for Swedish nurses to meet these patients in the Swedish healthcare and that might be a motive for the transferability of

this study. The nurses in this study showed much profession in individual education and the creating of a relation to their patients. As mentioned, the relation of caring is something useful for a professional nurse (Dahlberg & Segesten 2010, pp. 192-195). HIV is a global health issue and as long as there is no vaccine or guaranteed cure against the disease, antiretroviral drugs combined with the preventive work is the strongest we got to overcome the disease. Therefore, the South African nurses' knowledge of how to prevent might be useful no matter where in the world you practice nursing.

CONCLUSION

HIV is a major problem in South Africa and adolescents are a vulnerable group that requires a special approach to reach to. To prevent the spread of the infection the work needs to have an overall perspective in the society and where not only the already infected ones are included, but also the non-infected. Health care, schools, researchers, churches and other leisure activity organizations needs all to get onboard so we together as one can compete against this disease. As one of the nurses stated, "*We are not all infected, but we are all affected*".

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INFORMED CONSENT

Request of participation

To whom it may concern

Hello, our names are *Jennifer Palm* and *Malin Rosendahl*, we are nursing students and studying in the University of Borås in Sweden and we have been granted a Minor Field Studies Scholarship to carry out field studies in South Africa, as a part of our bachelor thesis.

The aim of our study is to *investigate experiences of preventive work with HIV positive adolescents*. HIV and AIDS continue to be a global public health issue (WHO, 2014) and according to UNAIDS (2013) adolescents is a high risk group for various reasons.

We believe that you possess a great knowledge about this subject. Therefore, it would be a great honor to get the opportunity to take part of, sample and compile your knowledge in a way to contribute the preventive work.

In this thesis we will use a qualitative method based on semi-structured interview design. To ease the adaption of the result the interviews will, with approval, be recorded with a Dictaphone. The interviews will refer to HIV prevention work. All the participants will be anonymized and answers will be treated privately. To participate is *voluntary* and you are at any time free to defect from the study.

The study will be published on the website of *Minor Field Studies* and examined at the *University of Borås*. If you wish, a copy of the final result can be send to you as well.

Your participation is meaningful and an invaluable source of information for us.

Please feel free to contact us at any time.

**With best regards,
Jennifer & Malin**

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Interview guide

- Can you please describe what preventive work means to you?
- Can you please tell us how the cooperation between health care and HIV positive youths works?
- The number of HIV infected has reduced greatly in recent years, which is amazing. What do you think is the main reason to that?
- Can you please tell us how you inform HIV positive young people about the disease, in a manner to let them understand their importance of reducing the spread of the infection?
- Can you please tell us if there are any differences in responding to adolescents compared to adults?
- Can you please tell us if there is anything you find to be particularly difficult when facing an HIV positive adolescent?
- Are there any differences in providing information to girls compared to boys?
- How do you manage to keep the patient stay motivated for the lifelong treatment that they are facing?
- Do you think there are many adolescents who are unaware of their HIV diagnosis, and if so, can you please tell us how you proceed to reach out to these young people?