



Designing a transition model for young adults living with HIV
followed at University Teaching of Hospital of Kigali

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Designing a transition model for young adults living with HIV followed in University Teaching Hospital of Kigali

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Declaration

This declaration is made on 01 April 2016

I, Dr Febronie Mushimiyimana, pediatric resident, declare that this research entitled “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali” is my original work. I have not copied from anyone’s work and I have referenced any cited text. Acknowledgement was made in the text, especially for my supervisors. The research is a requirement by the University of Rwanda in partial fulfillment of the academic requirement for the award of Master of Medicine in General Pediatrics.

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Signature

Date

Dedication

To Almighty God,

To my husband Jean Claude Nzaramba for his love, care and support

To our children Thalia Ornella Gahozo and Hugo Cesario Nzaramba

To my brother Eugene Rwaswa for his encouragement

To my late parents Bernard Rugerinyange and Nathalie Mukandekezi for their endless love

I dedicate this work.

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ABSTRACT

Background: With introduction of antiretroviral therapy (ART) worldwide, perinatally-infected children are surviving into adulthood, which has created the need to transition HIV-infected youth from pediatric clinics into adult care. Transition readiness involves patients, parents and providers by preparing adolescents and young adults well in advance for moving from pediatric to adult care and preparing adult services to receive them. There are currently no transition programs or protocols in place in any pediatric HIV clinics in Rwanda. In 2014 the pediatric HIV clinic at the University Teaching Hospital in Kigali (CHUK) planned to transfer adolescents and young adults to adult clinics, starting with the oldest. We aimed to assess the transition readiness of the young adults as they would be the first to be transitioned, and then develop a readiness assessment checklist and a transition model.

Objective: This study aimed to assess transition readiness of HIV-infected young adults attending the pediatric HIV clinic of CHUK and to develop a transition protocol.

Methods: This was a qualitative study. An individual, open-ended interview of young adults and health care providers was conducted by the investigator, lasting 20 minutes. Interviews were conducted in Kinyarwanda, audio taped, then transcribed. The transcripts were translated from Kinyarwanda into English by the investigator. We used the grounded theory approach for data analysis; transcripts were coded then codes were grouped into concepts, and then into categories.

Results: We did interviews of 14 participants including 10 young adults and 4 health care providers. The mean age of the young adults was 21 years (range 20-24) and the majority was male. All 4 health care providers were female. We identified 4 major categories: self-management behaviors, readiness to assume responsibility, barriers to transition, and transition readiness. Almost all young adults had gained knowledge about HIV but few were able to name their pills or dosage. Almost all young adults picked up their medications themselves. Identified barriers to transition were: fear of losing the relationship with healthcare providers, fear of new environment and fear of stigma in adult clinic. These results were used to develop a transition readiness assessment checklist and transition model.

Conclusion: We found that even though young adults were taking responsibility in their health care management, they still need additional knowledge related to their drug regimen. We have identified potential barriers to transition that have to be addressed before the transition process is begun. The perceived readiness to transition care among the young adults was low, and this could be addressed by implementing a transition protocol.

KEYWORDS: Young adults, Transition to adult clinic, HIV, readiness to transition care

ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

ART: Antiretroviral Therapy

ARV: Antiretroviral

CD4: Cluster of Differentiation 4

HIV: Human Immunodeficiency Virus

IRB: Institution Review Board

MOH: Ministry of Health

SSA: Sub-Saharan Africa

STD: Sexually Transmitted Disease

TRACK: Transition Readiness Assessment Checklist and model for young adults living with HIV in University Teaching Hospital of Kigali

TRAC: Treatment and Research AIDS Center

TDF: Tenofovir

UK: United Kingdom

UNAIDS: United Nations Programme on HIV/AIDS

US: United States

CHUK: University Teaching Hospital of Kigali

WHO: World Health Organization

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Chapter One: INTRODUCTION

1.1. Background

Introduction of antiretroviral therapy worldwide has significantly decreased pediatric mortality from HIV/AIDS (4). As a result, more HIV-infected children are surviving into adulthood, which has created the need to transition HIV-infected youth from pediatric clinics into adult care (5). Published research on transitioning of HIV-infected youth is limited, particularly in sub-Saharan Africa. There are currently no transition programs or protocols in place in any pediatric HIV clinics in Rwanda. Therefore, there is a gap that needs to be filled as the Rwandan pediatric HIV population matures into adulthood. In our project we aimed to develop a transition model for HIV-infected youth and analyze the outcomes using both qualitative and quantitative research methods. Results from this study will be shared with key stakeholders, including the Ministry of Health, and presented at national and international conferences. If proven successful, we aimed to scale up the transition model to all health care centers offering HIV care to adolescents and young adults.

1.2. Problem statement

According to UNAIDS in 2013, an estimated 2.9 million children under age 15 years were reported to be living with HIV in Sub-Saharan Africa (SSA)(1). In Rwanda in 2014, there were 17,270 children living with HIV (2). During the first two decades of the HIV epidemic, perinatally acquired HIV caused death early in childhood (3), but introduction of antiretroviral therapy (ART) worldwide has significantly decreased pediatric mortality from HIV/AIDS (4). As a result, perinatally-infected children are surviving into adulthood, which has created the need to transition HIV-infected youth from pediatric clinics into adult care (5). Prior studies of transitioning the care of children with chronic illness have focused on other diseases such as diabetes, cystic fibrosis and heart diseases; few have specifically focused on HIV, particularly in SSA (6,7).

According to WHO, adolescence is a period between childhood and adulthood, with age range of 10 to 19 years and is a developmental stage characterized by inability to understand relationship

between behavior and consequences putting them at high risk behaviors like drug abuse or unprotected sex. The young adult stage precedes middle adulthood and according to Erik Erikson's stages of human development, is a person in the age range of 20 to 39 years.

Transition is a planned and purposeful movement of adolescents and young adults with a chronic medical condition from child centered healthcare to adult centered healthcare and is different from transfer, which is a discrete movement to a different health care setting. Transition has to promote responsibility and autonomy and to address concerns of adolescents and young adults for a better success (8)

Transition readiness is how patients, family and healthcare providers plan and begin the transition process by putting in place interventions and/or supports(8,9). Transition readiness involves patients, parents and providers by preparing adolescents and their families well in advance for moving from pediatric to adult care and listening to adolescents' views, and finally preparing adult services to receive them. Any transition assessment and plan should increase the transition readiness over time (8).

Transitioning without preparation to an adult care setting may result in withdrawing from medical care or poor adherence, with measurable consequences in terms of morbidity and mortality and in social and educational outcomes (10). Transitioning to adult care may also cause anxiety and concerns about leaving their current pediatric providers, who are often considered like family. The patients and caregivers often have more trust and faith in the pediatric team members as they helped them to better understand their disease, work through the process of disclosure, and have provided the family with support and guidance to which they have become accustomed (6,11–13).

Most adult clinics are labeled “HIV clinic” or “infectious disease clinic” and have less anonymity and confidentiality, which can cause the adolescents and young adults to worry about stigma, discrimination, marginalization, and social isolation (11,13–15). In adult settings, adolescents and young adults need to have increased independence and autonomy, such as making appointments, arriving on time, and making medical decisions, and some fear such responsibility (6,14,15).

Lack of communication between pediatric and adult providers is another identified barrier, as adolescents and young adults rarely want to retell their HIV medical history and expect that the providers would have talked with each other (16). Difficulty in accessing care that addresses all of their needs, including mental health and reproductive health education, in the adult care setting where services are fragmented, can cause a worsening of sexual risk-taking behaviors and substance abuse (6,12,13).

A dedicated transition service tailored to requirements of every chronic condition can have a positive influence on health care and personal development (16). Successful transition from a child-centered to adult-oriented health care system is dependent on these adolescents and young adults acquiring skills to allow them to manage their health care (17).

1.3. Justification of study

University Teaching Hospital of Kigali (CHUK) is a large tertiary referral hospital based in Kigali, the capital of Rwanda, and is one of the teaching hospitals for the University of Rwanda. As a tertiary hospital, it is responsible for supervising district hospitals in 27 districts of the 42 districts in the country. The pediatric HIV clinic at CHUK currently follows 226 patients, of whom 92 are 15 years and older; and among those 92, 16 (17%) are aged 20 years and above. The pediatric HIV clinic takes place in the Center of Excellence, the pediatric outpatient department, where there are other children coming for other clinical conditions. This may reduce the stigma of attending the clinic as the pediatric HIV clinic is not identified by name, whereas adult HIV clinics in most places tend to be located apart from other clinical activities. The pediatric HIV clinic of CHUK has 4 health care providers taking care of those children. Every patient has to be seen by a doctor once a month for a physical examination and medication refill, and once a year blood is drawn for CD4 and viral load testing. In the clinic they have divided children in groups depending to age: 7 year to 12 years, 13 years to 14 years, and 15 years and above. In these groups they receive education about HIV, ARVs and possible side effects, and the importance of strict adherence. The health care providers also organize home visits for patients with poor follow-up. This is different from how adult clinic works; because for example in CHUK adult HIV clinic, patients are seen by a doctor once every 3 months and they go to the pharmacy monthly for medications refills. Young adults who remain in pediatric clinic may not receive all the appropriate care as warranted by age for example education about reproductive health.

The pediatric HIV clinic intended to transfer the adolescents and young adults to adult clinics starting by the oldest. We aimed to assess the transition readiness of the young adults as they were the first to be transitioned and then to develop a transition checklist and a transition model. There are currently no transition programs or protocols in any pediatric HIV clinic in Rwanda. Therefore, there is a gap that needs to be filled as the Rwandan pediatric HIV population matures into adulthood.

Many studies have tried to identify issues unique to transitioning youth living with HIV to adult care. Mental health, medication adherence, sexual health, insurance, stigma, disclosure, life

planning, communication amongst providers, and the ending of a long-term relationship with the pediatric provider have all been identified by multiple studies as important issues to address when developing a transition plan for adolescents and young adults (5,6,12,18,19). As such, recommendations exist on designing tools and protocols for transitioning these patients in the United States (US) (17,18). Part of this process should involve providing strategies and education about important social issues, such as disclosure in relationships, insurance, education, and employment (14,15,18). The adolescents and young adults should be expected to increase responsibilities in care, such as keeping appointments, coming to get their medications, and making medical decisions (13,15). Having a specific teen/transition clinic with a multidisciplinary team was also identified as being helpful with the process (14,15). This also allows the patient to meet the adult provider and develop a relationship prior to transitioning and allows for communication between the pediatric and adult providers (9,14,15,18). Keeping the pediatric social worker involved for the first 1-2 years after transitioning was also identified as important (14). As described above, little data exists on the ideal transition protocols for youth living with HIV in Sub-Saharan Africa (15).

1.4. Research questions

How ready are the young adults to transition care from pediatric HIV clinic to adult HIV clinic?

1.5. Objectives

1.5.1. General objective:

This study aimed to assess transition readiness of HIV-infected young adults attending the pediatric HIV clinic of CHUK and to develop a transition protocol.

1.5.2. Specific objectives:

- a. To assess the ownership of medical care of the young adults attending the CHUK HIV clinic

- b. To assess the perceptions of the young adults about transition to adult clinic
- c. To assess the views of health care providers about transition of the young adults to the adult clinic
- d. To develop a transition checklist and a transition model

Chapter Two: STUDY METHODS

2.1. Study design

This was a prospective qualitative study.

2.2. Study setting

The study was conducted in CHUK a tertiary referral hospital based in Kigali, the capital of Rwanda, and is one of the teaching hospitals for the University of Rwanda. As a tertiary hospital, it is responsible for supervising district hospitals in 27 districts of the 42 districts in the country. Those district hospitals send to CHUK complicated cases including HIV positive patients and Center of Excellence, the pediatric HIV clinic was created to receive and treat those HIV positive patients. The pediatric HIV clinic at CHUK currently follows 226 children, of whom 92 are 15 years and older; and among those 92, 16 (17%) are aged 20 years and above. A dedicated multidisciplinary team, consisting of trained 4 health care providers including 1 doctor, 1 nurse, 1 social worker and 1 psychologist manage these patients in collaboration with biological parents or relatives.

2.3. Study population

HIV-infected young adults aged 20 years and above attending CHUK pediatric HIV clinic, and health care providers taking care of these young adults. In this study we included young adults as they were the oldest and the first to be transitioned and according to WHO definition the young adulthood age range is 20 to 39 years.

2.4. Selection criteria

Every HIV–infected young adult aged 20 years and above attending the CHUK pediatric HIV clinic was contacted and asked to participate in the study and those who accepted to come on the chosen date was included in the study.

All Healthcare providers involved in the HIV clinic and agreed to participate in the study were included.

2.5. Data collection, processing and analysis

2.5.1. Patient enrollment

Young adults were contacted by telephone to come to a given date for interview; those who did not come were excluded from the study. Health care providers were asked for an appointment for an interview and those who accepted to come were included in the study.

2.5.2. Data collection

An individual, open ended interview of young adults was conducted by the investigator, lasting 20 minutes. Interview questions were focused on their knowledge about their healthcare condition, about their drugs regimen and what they think about transition to adult clinic and were formulated based on literature review. We also conducted interviews of health care providers in 20-minute interviews and focused on what they think about transition of the young adults to adult clinic. Interviews of young adults were conducted during the month of September 2015 and those of healthcare providers were conducted in November 2015.

2.5.3. Data processing and analysis

Interviews were conducted in Kinyarwanda, audio taped, then transcribed. The transcripts were translated from Kinyarwanda into English by the investigator. We used the grounded theory approach for data analysis; we did coding then codes were grouped into concepts, and then into categories.

2.6. Ethical considerations

This study was carried out after receiving Ethical approval from the Institutional Review Board (IRB) from CHUK and the College of Medicine and Health Sciences, University of Rwanda. To participate in the study, all participants were provided verbal and written informed consent. All patient data has been kept confidential and the database has not contained any participant names.

Chapter three: RESULTS

We did interviews of fourteen participants including ten young adults and four health care providers. From the analysis of participants' responses below are our results.

3.1. Demographic characteristics

Ten young adults out of sixteen were available to participate in the study; six others did not attend because they were at the university. The mean age of the young adult patients was 21 years (range 20-24) and the majorities were male (Table 1). Only one participant was living alone and half were living with one or both parents. All the young adults' participants had received antiretroviral therapy for at least 5 years.

Four health care providers from the pediatric HIV clinic participated in the study. All four health care providers were female, including one medical doctor, one nurse and one psychologist and one social worker.

Table 1: Demographic features of young adults

Demographic	Number(percentage)
Mean age in years	21.1 (20-23)
Gender	
Male	6 (60%)
Female	4 (40%)
Living conditions	
With parents	5 (50%)
With family relatives	4 (40%)
Alone	1 (10%)

3.2. Emerged themes

From the responses of the young adults and the health care providers we identified four major categories and eleven subcategories of themes.

The first category was self-management behaviors; the second was readiness to assume responsibility; the third was barriers to transition and the fourth was transition readiness (Table 2).

Table 2: Emerged themes

Major categories	Subcategories
Self-management behaviors	<ul style="list-style-type: none">• Perceived knowledge of the disease• Knowledge of the drug regimen, dosages and possible side effects• Responsibility in the management of his or her clinical condition
Readiness to assume responsibility	<ul style="list-style-type: none">• Participation in the treatment management• Involvement in high-risk behaviors• Fear to lose relationship with health care providers
Barriers to transition	<ul style="list-style-type: none">• Fear of new environment• Fear of stigmatization in the adult clinic
Transition readiness	<ul style="list-style-type: none">• Set up a transition clinic• Visit of adult clinic• Perceived transition readiness

1. Self-management behaviors

Almost all young adults had gained adequate knowledge about HIV and knew that HIV can be sexually transmitted. Few young adults were able to name their pills or tell the dosage. Being in support groups in the pediatric HIV clinic was an advantage as it is in those groups where they are taught about HIV and medications.

a. Perceived knowledge of the disease

The majority of young adults were knowledgeable about their disease by being able to describe what HIV is, tell the mode of transmission and how to prevent it. Only three were unable to tell what viral load is. Healthcare providers told us that many adolescents and young adults had acquired the necessary knowledge from education sessions happening in the clinic.

A 23-year-old male: "HIV is a virus infecting our body and decreases the CD4 cells in charge of defending our body, it is transmitted by sexual intercourse, sharp objects and blood sharing and it can be prevented by abstinence from sex or use condom. CD4 are soldiers in charge of fighting disease, viral load is to check viruses".

A social worker: "Older adolescents have good knowledge especially when they are in support group and I think they can do well in adult clinic and they will be responsible but those who are not in support group will have some difficulties".

Only one young adult was not a member of a support group. Health care providers mentioned that it is during support groups where they teach young adults about HIV, medications, possible side effects and benefits of taking well medications.

A doctor: "...and is in those support groups where we teach them a lot about HIV/AIDS, mode of transmission and prevention; and to be responsible of their medications".

b. Knowledge of the drug regimen, dosages and possible side effects

Only three young adults were able to name their full drug regimen, five remembered one or two of the drugs, and two did not remember any. All were able to tell the dosages and frequency. Only three were able to tell possible side effects of their medications.

A 20-year-old female: “I am on Lamivudine, Kaletra and TDF; and bactrim, three tablets a day at 9 pm, possible side effects is jaundiced eyes”.

2. Readiness to assume responsibility

Almost all young adults picked their medications themselves except for two who at times send their parents for example when they have exams at school. Health care providers had perceived that many young adults are responsible of their medications.

a. Responsibility in the management of his or her clinical condition

Almost all young adults came to get their medications and eight young adults usually remembered to take their medications by themselves. Health care providers have seen that many are responsible about their medications, came to get their medications and do not need someone to remind them to take medications.

A 21-year-old female: “I usually come to get my medications at the clinic myself and I always remember to take them. I am in a support group.”

A social worker: “... many are responsible and able to take medications on their own....”

b. Participation in the treatment management

All young adult participants stated that they know the pediatric health care team, how they can contact them in case of a health question, and were comfortable in asking questions at appointments. The health care providers reported that most of adolescents and young adults are comfortable with them, and that they always come to them when needed.

A 20-year-old female: “I know the healthcare team, I know how to find them as I have their phone number and now I feel comfortable in asking questions but before I was using internet to get answers”.

A doctor: "As we have been following up them, they are comfortable in asking questions even it may happen to be involved in their family problems".

c. Involvement in high-risk behaviors

None of young adults were consuming alcohol and drugs and understood why it is important.

A 23-year-old male: "I am not consuming alcohol, drugs and cigarettes, because it can damage my liver and it is also a sin".

3. Barriers to transition

Some young adults and health care providers stated some barriers to transition like the fear of losing the longstanding relationship and fear of stigma in adult clinic. Health care providers were worried that transition may be too early for some as it requires independence which is not shown by some.

a. Fear to lose relationship with health care providers

Three young adults reported that they do not want to transition care because they fear loss of the relationship with pediatrics healthcare providers and fear to start a new relationship in adult clinic. One of the health care provider expressed fear that some adolescents and young adults will not be comfortable at the adult HIV clinic as they consider pediatric health care workers as parents.

A 21-year-old female: "...it is difficult to change from where you are familiar and go to adult clinic. I don't want to go there because here I am familiar with healthcare providers, so it will be difficult for me to familiarize with others".

A social worker: "... because they are considering health care providers as parents and they are not comfortable with a new one. Moving now will not be easy especially for those who are below 19 years".

b. Fear of new environment

Six young adults reported that it will be difficult for them to transition care because they have been attending pediatric clinic since they were young even though they knew that it would happen one day. Health care providers reported transition will be difficult for some as they may not be comfortable with new health care providers.

A 20-year-male: "I heard about moving to adult clinic but I did not receive it well because moving from a place where you grown up is so difficult".

A nurse: "It is difficult because they are considering health care providers as parents and they are not comfortable with a new one".

c. Fear of stigmatization in the adult clinic

Four young adults were concerned about the privacy in the adult clinic and feared to be stigmatized as they would possibly meet people from their neighborhood in the clinic. Health care providers highlighted the issue of having an adult HIV clinic labeled "HIV clinic", and being separate from other clinics because everyone who will see a person there will immediately know that he/she is HIV positive.

A 21-year-old male: "... I can meet people from my neighborhood and they can start talking about me that is why I want to stay here".

A Doctor: "...as many are living in Kigali, so they will have to go to TRAC the adult HIV clinic. And people outside here when they see you there will immediately think that you are HIV positive. While here in pediatrics they are mixed with others coming for consultation and none will know why there are here".

4. Transition readiness

The majority of young adults showed that they are not ready to transition care. All health care providers agreed on the need of transitioning adolescents especially young adults because they are not able to offer them all needed services tailored to their age. However both the young adults and health care providers suggested that creating a special transitional clinic for adolescents and young adults may be better than immediately transitioning care from pediatrics to adult clinic.

A social worker: "We really want them to transition because us as healthcare providers we are not comfortable in taking care of the adolescents and we need training on how to take care of adolescent. We want MOH to accelerate the process of transition so that adolescent can get the care they need".

a. Set up a transition clinic

Three young adults suggested starting a special clinic for adolescents in the pediatric HIV clinic instead of transitioning care to adult clinic directly. This was also suggested by all health care providers saying that a special clinic can be a transition clinic where adolescents and young adults can become more comfortable with transitioning.

A 22-year-old male: "... being with people you are not in the same category it is difficult to communicate and get involved in whatever they are doing. My wish is to have a clinic for young adults and not to mix us with adult".

A social worker: “We suggest that the move to another place but not adult clinic, because at their age we can’t consider them as adult so we need a special clinic for them”.

b. Visit of adult clinic

A few young adults suggested to start by visiting the adult clinic and see how the clinic functions before transitioning. A nurse also suggested visiting adult clinic before transition because that can help in understanding how adult clinic works and be prepared before transition.

A 21-year-old male: “Health care team can prepare us by letting us visit the adult clinic, see how services are offered and if possible discuss with patients”.

A nurse: “... Another suggestion is to allow them to visit the adult clinic, see how services are offered, and this is really important, someone from pediatrics can accompany them and see how they are received”.

c. Perceived transition readiness

When asked if they were ready to transition, only four reported that they are ready and others said that they want to stay in pediatrics clinic.

A 20-year-old male: “....when I met the adults and we found that they are like us and familiarize with them now no problem of transitioning I am ready to transition and I am waiting them to tell us when to go”.

Two wanted to transition because they were not comfortable being with children in the same clinic and health care providers reported that some adolescents especially young adults are not comfortable being with children.

A 21-year-old female: “Yes I want to transition because here there are children and I am not comfortable in asking questions because of that”.

A social worker: “Here we have patients from 1 year to 25 years, imagine a 25 year old sitting in the waiting room with a 5 year old, so those adolescents are not kids anymore and will be better if there is a place where they can be followed up because we can’t keep calling them children”.

3.3. Transition checklist and model

Based on the participants’ responses we identified areas that health care providers have to focus on before transitioning and developed a checklist which we want to be used in the HIV clinic. The attached checklist (Figure 1) will be in the patient’s file and at each visit the adolescents will be assessed on the skills he/she needs to acquire before transition. The shaded parts mean that the question is not applicable to that particular age group.

From the recommendations of studies done in USA especially the ‘Movin’out” transitional protocol (27), and the results from this study we proposed a transition model. The attached transition model (Figure 2) will be tested in CHUK pediatric HIV clinic and will guide the transitioning care of adolescents and young adults from pediatric clinic to adult clinics.

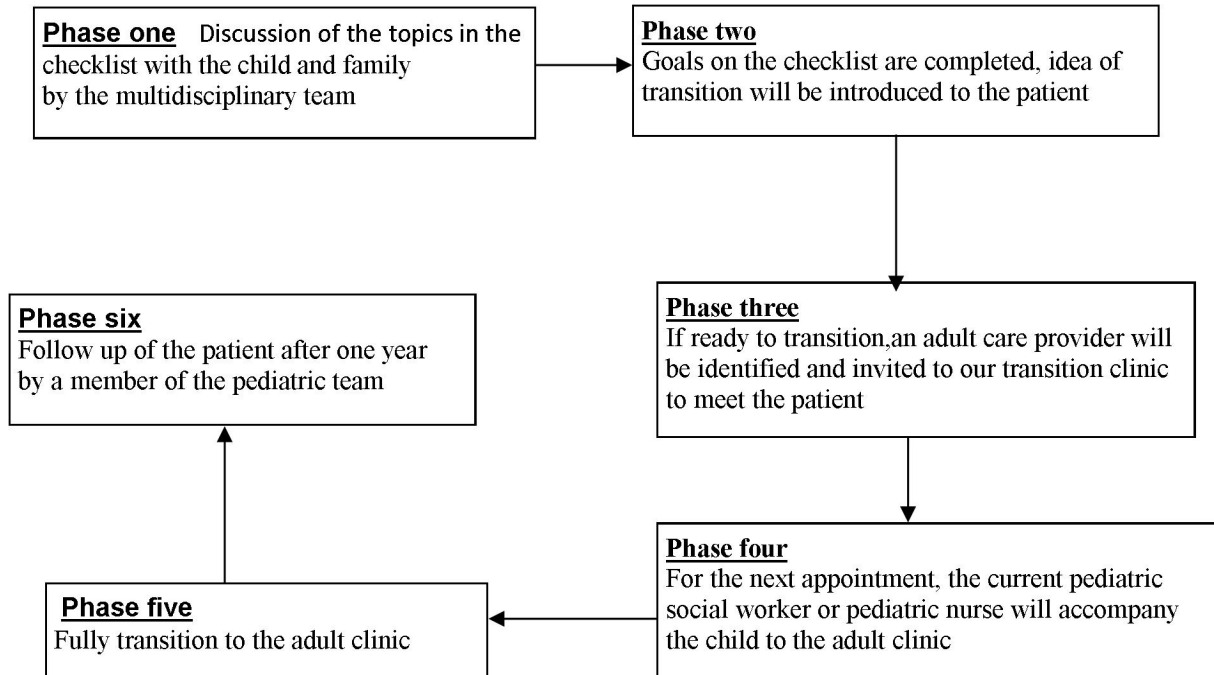
Figure 1: Readiness assessment checklist

Name:	8-11 years of age		12-14 years of age		15-20 years of age	
DOB:						
Date Initiated:	Discussed	Achieved	Discussed	Achieved	Discussed	Achieved
Date of Disclosure:						
Knowledge of Health Condition						
Discuss family readiness regarding disclosure and assist with disclosure.						
What is HIV?						
What are the modes of transmission of HIV?						
How do you prevent the spread of HIV?						
What are T cells and what is your most recent CD4 count?						
What is a viral load? What is your most recent viral load?						
Drug regimen and dosages						
What are the names of your medications?						
What are the dosages (number of tabs) of your medications?						
How do you take your medications (What time of day? Do they need to						

be taken with food?)?						
What are the possible side effects of your medications?						
How do you get more of your medications before you run out?						
How do you get to your appointments?						
How do you deal with problems taking your medications (boarding school, non-disclosure, etc)?						
Health care						
Do you have health insurance?						
Are you able to identify members of your health care team, what their roles are and how to contact them?						
Do you abstain from using alcohol, drugs and cigarettes and understand why this is important?						
Are you in any support groups?						

Communication						
Do you know where to look for answers to your health questions?						
Do you feel comfortable asking questions at your appointments?						
Reproductive health						
Do you know what an STD is and how it can affect you?						
Do you understand how your medical condition affects becoming pregnant or having a child?						
Life Planning						
Do you have parents?						
What do you do?						
Do you know what you want to do when you grow up?						
Have you heard that one day you will move to adult clinic?						
What do you think about this?						

Figure 2: Transition model



Chapter four: DISCUSSION

In our study we had found that young adults had gained autonomy but still needed more education on their medications. We identified some barriers to transition and participants proposed how those barriers can be addressed. Four major themes were identified: self-management behaviors, readiness to assume responsibility, barriers to transition, and transition readiness.

4.1. Self management behaviors

In our study the majority of young adults were knowledgeable about their disease but needed additional knowledge about their medications. This is consistent with findings in other studies done in USA where they have found that adolescents needed additional knowledge about their healthcare (14,15).

The pediatric healthcare providers overestimated what the adolescents were learning in the support groups. In the support groups health care providers discuss with young adults and adolescents about HIV/AIDS, medications and why it is necessary to adhere to ARVs drugs. Without good knowledge especially about their medications young adults will be a risk of poor adherence to their medications in adult clinic. The pediatrics health care providers can improve on this by making sure that everyone is attending those support groups and providing continuous education so that young adults can acquire the skills to allow them to be independent in the management of their own healthcare.

4.2. Readiness to assume responsibility

In our study many young adults regularly came to get their medications and remembered to take them and this is a sign of responsibility and autonomy that is needed in adult clinic. There needs to be individual-centered care where the family will not be involved, such that if he/she is not coming to their appointments parents or guardians will not be called as in pediatric clinic. The acquisition of independence was seen as a benefit in successful transition in a study done at a closing clinic in USA (20). With this finding we have hope that young adults will have good clinical outcomes compared to studies done in USA where the virologic outcomes were poor

among transitioned patients (12,21). Difficulties in adhering to medications may be due to different reasons including social and psychological issues or lack of insurance (12). Our young adults will not have issues in accessing medications due to lack of insurance because antiretroviral treatment is free in Rwanda. Adherence can be maximized by increasing the young adults' disease knowledge and involving them in their healthcare management.

4.3. Barriers to transition

In our study we have identified barriers to transitioning care including fear of loss of the relationship with pediatric health care providers, fear of moving to a new environment, and fear of stigmatization. This is similar to other studies done on adolescents with other chronic diseases like diabetes (22,23). Health care providers can introduce the idea of transition to adult clinic early in adolescence after full disclosure of the HIV infection to the patient and involve the young adults in transition planning. From this study young adults and healthcare providers have identified some interventions which will help in addressing identified barriers like creating a transitional clinic in the pediatric clinic and/or visiting the adult clinic before transition.

Some young adults were not comfortable with transitioning to adult care because they fear loss of the long-term relationship built in pediatric clinic, similar to several studies done in USA where they found that adolescents are concerned about losing the relationship with the pediatric health care providers who have also a difficulty in letting them go (6,7,10,12,19,24). Several studies done in USA and one done in Sub-Saharan Africa have identified that health care providers are considered as family members by the patients they have followed up for many years, sometimes since birth and this can make the transition a challenge for both (6,7,11,12). And because of that strong relationship adolescents were coming back to pediatrics after transition to discuss social issues (6). This barrier can be addressed by starting the transition process early, encouraging the independence through education at each visit and during the group sessions.

Other young adults feared stigmatization in the adult clinic because many adult clinics are labeled "HIV clinic" so people seeing them entering there or even adult patients from their neighborhood may know that he/she is infected. This is similar to findings of a study done in

Uganda where stigma was one of the challenges faced by transitioning young adults (5,25). Stigmatization can have negative impact on follow-up care and medications adherence as shown by a study done on adolescents in Rwanda (2). Fear of stigma was also identified by several studies where young adults and health care providers were concerned about the possible discrimination by other patients or providers which may happen in adult clinic and the young adults may face unwanted disclosure of their status in the adult clinic labeled “HIV clinic” (6,11,12). A possible solution to this is setting up the adult clinic like the pediatric clinic where patient’s confidentiality is kept for example by having the HIV clinic where other consultations are happening and not labeling it “HIV clinic”.

4.4. Transition readiness

All health care providers said that it was really necessary for adolescents and young adults to move to adult clinic because health care in pediatrics is not tailored to the needs of young adults, even though they know it will be difficult for some. Studies have shown that moving to adult services is a normal event for adolescents and young adults as providers recognized that pediatrics may no longer be the best place for them (19,25). There is no specific age at which transition can start but factors to consider in choosing the appropriate age include individual development stage and acquisition of health care skills of each patient (7). Both pediatric and adult health care providers need training on transitioning care for the success of the transition process (26).

The transition readiness assessment needs to be included in the routine care of the adolescents by using the transition readiness tool at each visit. The transition readiness tools can help in identifying areas where health care providers have to focus in the education of the young adults. A transition protocol needs to be created in pediatric clinic to guide the transition process of the adolescents and young adults with HIV to transition to adult care (21).

In our study health care providers and young adults suggested starting a special transitional clinic for adolescents and young adults and this is similar to several studies done in USA where many health care providers recommended starting an adolescent clinic tailored to addressing psychosocial issues related to their developmental stage (14,16,19,23,24,27). In addition,

introduction of an adult health care provider in the adolescent clinic was highlighted as beneficial by the transitioned adolescents in a study done in UK (10).

Young adulthood is a period characterized by engagement in intimate relationships, where many have started thinking about having children but fear possible vertical transmission to their babies. Being in pediatrics clinic may cause those young adults to be uncomfortable in asking questions especially concerning reproductive health as children may be around, but by creating a special clinic in pediatrics clinic which will be a bridge between pediatric and adult clinics, adolescents and young adults can get health care addressing issues related to their development stage (19,20). In the pediatric HIV clinic adolescents and young adults have support group sessions every month - this can be changed to a transition clinic as part of the transition process. Our study also suggests that the pediatric health care providers need additional training in adolescent medicine and sexual health so that they can provide sexual and reproductive health care to those young adults in the adolescent clinic (7).

A few young adults and healthcare providers suggested starting transition by visiting the adult clinic before transitioning care to see how it works and have the opportunity to meet new providers. Furthermore, staying in pediatric clinic was making some uncomfortable as some young adults were not asking questions due to the presence of children. Visiting the adult clinic before transition may be one of the solutions for the feared stigma because young adults can interact with some adult patients and/or adult health care providers and the worries can be allayed (22). Young adults can meet the adult health care provider either in pediatric or adult clinic before transition and this will help in creating a new relationship and decrease the anxiety.

In our study the perceived readiness to transition care was low mainly due to above highlighted barriers - fear of loss of the relationship with pediatric health care providers, anxiety about leaving the familiar environment to go to the unfamiliar adult clinic, and fear of stigmatization they may face due to being seen attending the adult HIV clinic. This is similar to findings in a study done in Australia where young adults considered the transition as a challenge and suggested involvement in the process of transition (20). But it contradicts findings in a study done in UK where transitioned adolescents reported transition as a positive event resulting from

provided transition services including an encouragement to develop adult management skills and treatment as an individual (16).

4.5. Next steps

After identifying barriers to be addressed before transition and from the recommendations of study participants, we want to train the pediatrics health care providers on the transition checklist and transition model developed as a result of this study, which will be used at each adolescent visit. We also plan to work together to develop a transition clinic and to start using the transition model to help in the transition process. After one year we are planning to do another survey and see if there is a difference. Finally, if there are any patients who have been transitioned, we will assess the outcomes in the adult clinics after one year of transition.

4.6. Limitations

Our study had some limitations. We are presenting the preliminary results of our study but the study will continue. The checklist and the transition model will be tested for a possible validation; as our end goal is to develop a transition protocol which will be used by other facilities offering care to HIV infected adolescents and young adults.

There were a small number of participants as all young adults did not participate in the study and those who did not participate could have provided different information.

Lastly, there was the possibility of social desirability bias affecting the participants' responses.

Chapter five: CONCLUSION and RECOMMENDATION

5.1. Conclusion

Although we are presenting the preliminary results of our research we can make some conclusions.

Based on the age of the young adults, it would be expected that they would be ready and wanting to transition to adult clinic. However, transition should not to be age dependent but be based on individual disease management skills, and as well as addressing the possible barriers to transition for it to be successful.

We have found that even though young adults were having responsibility in their health care management, they still needed additional knowledge related to their disease condition and drug regimen. We have identified potential barriers to transition that have to be addressed before transition to adult clinic.

The perceived readiness to transition care among the young adults was low. This may be addressed if there is a transition protocol helping in the process. In addition, health care providers expressed discomfort in caring for young adults and could benefit from additional training in adolescent medicine.

Finally, the readiness assessment checklist and transition model created can be used to guide the transition of the adolescents and young adults to adult HIV clinic.

5.2.Recommendations

From this study we are recommending:

To CHUK

- To train health care providers working in pediatrics and adult HIV clinics on transition for a better success of the process
- To help in creating a transitional clinic for adolescents and young adults

To MOH

- To develop a transitional protocol which can be used by health care providers taking care of adolescents and young adults

To researchers

- To conduct a national study on adolescents and young adults about transitioning care and this will help in retrieving more information.

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Appendices

I. Information form for the study participants – English Version

Dear participant,

Re: Participation in a study “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

I, Febronie Mushimiyimana, am a Masters student in Medicine at University of Rwanda, College of Health Sciences and Medicine, School of Medicine in Department of Pediatrics. As part of the qualification for my program, I am required to do a research project on an area of interest. My study is titled “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**”. This information document aims to inviting you to participate in this study. The objective of this study is to assess transition readiness of HIV-infected young adults attending the pediatric HIV clinic of CHUK and to develop a transition protocol. If you accept to participate in the study we will do an interview to assess your transition readiness. This will help us to develop a transition readiness assessment checklist and a protocol. If proven successful, we aim to scale up the transition model to all health care centers offering HIV care to adolescents and young adults.

You are free to ask any question about the study and the researcher will be available to answer and explain as necessary. Your participation in this study is voluntary; and you are under no obligation to participate. You have right to withdraw any time if you feel uncomfortable to continue. The study data will be coded and will not be linked your name any way, and the questionnaire is anonymous. The anonymity will be maintained by not writing anywhere on the questionnaire and buy using a coding system on the questionnaire, in such way that it will not be possible to connect a participant’s responses to a name or a person. Below is the researcher’s and supervisor’s address that you may contact if there is a need to do so.

Dr Febronie Mushimiyimana, MD,MMED YEAR IV

Principal Investigator

University of Rwanda , College of Medicine and Health Sciences , Pediatrics department ,PG year IV .Email:mushime@gmail.com

Cell:+250 788752779

Dr.Lisine Tuyisenge, MBChB, M.Med. (Paeds), Head of Department of Paediatrics, University Teaching Hospital of a Kigali/CHUK

Supervisor

E- mail tuyisisine@gmail.com

Tel: +250 788411764

II. Information form for the study participants – Kinyarwanda aversion

Ubushakashatsi no:.....

Nshuti bakundwa bitabiriye iki gikorwa,

Impamvu: **Gusaba ko wajya mubushakashatsi** “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

Njyewe,Febronie Mushimiyimana,ndi umunyeshuri uri mucyiciro cya gatatu cya kaminuza mubijyanye n`ubuvuzi bw`abana muri Kaminuza y`u Rwanda. Nsabwa gukora ubushakashatsi kugirango ndangize ayo masomo,ubushakashatsi bwanjye bwitwa “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**”, turashaka kureba uburyo bwiza bwazafasha abangavu n`ingimbi babana n`ubwandu bwa SIDA bakurikiranwa mubana kujya gukurikiranwa mubantu bakuru. Nuramuka wemeye kujya muri ub` ubushakashatsi tuzafata amajwi yawe mugihe uzaba usubiza ibibazo. Nta gihembo uzahabwa kugira ngo ujye murubu bushakashatsi, kubujyamo n` ubwende bwawe,ushobora guhitamo ko atagira uruhare muri iyi nyigo. Turimo gushakisha uburyo abangavu n`ingimbi bazajya bategurwa kugira ngo nibajya gukurikiranirwa muri clinic y`abakuru batazahurirayo nibibazo babashe kuhaguma kandi bakurikiranwe neza. Ugomba kumenyesha niba wifuza kumenya ibisubizo by` ibyavuye muri iri suzuma. icyo gihe uzasiga uburyo bakumenyesha. Uramutse wisubiyeho mu buryo ubwo ari bwo bwose mu gihe cy`iyi nyigo cyangwa se nyuma wamenyesha umuganga ukora kuri iyi nyigo, nawe azagenda ku byifuzo byawe.

Numa y` iyi nyigo y`ingira- kamaro, tuzaba dushobora gutanga amakuru ya ngombwa ku bafata ibyemezo babishinzwe kugira ngobabe babasha guhindura ibyemezo byafatwa by`igihe kirekire mu kwimura abangavu n`ingimbi bajya muri clinic y`abakuru.

Ibisubizo byose uzatanga bizashyirwa mu ibanga rikomeye kandi ntabwo bizashyirwa ku ka rubanda. Ntahantu hazagaragara izina ryawe kandi umuganga n’itsinda rigize ubu bushakashatsi bazakoresha amakuru uzatanga muriyi nyigo gusa. Tuzanatangaza ibyavuye muri ubu bushakashatsi kugira ngo ababyifuza babe bashobora kwigira kuri ubu bushakashatsi bwacu.

Uramutse ugize ikibazo icyo ari cyo cyose wakibaza ubu nonaha cyangwa se nyuma, yewe nanyuma y’uko iyi nyigo izaba yaratangiye gukorwa wabaza aba bakurikira:

Dr Febronie Mushimiyimana, MD,MMED YEAR IV

Umushakashatsi

University of Rwanda , College of Medicine and Health Sciences , Pediatrics department ,PG year IV .Email:mushime@gmail.com

Cell:+250 788752779

Dr.Lisine Tuyisenge, MBChB, M.Med. (Paeds), Head of Department of Paediatrics, Kigali University Teaching Hospital/CHUK

Umugenzuzi

E- mail tuyisline@gmail.com

Tel: +250 788411764

III. Consent form for participants –English version

Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali

Study no.....

I,-----hereby,
fully consent to participate in this study on the “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**”

I agree to participate in this study aiming to assess the readiness for transition care to adult clinic and to develop a transition protocol.

I have been fully informed about the purposes of the assessment that will be done. I have had a chance to ask questions and they have been answered satisfactorily. I also understand that I may withdraw at any time with no adverse consequences whatsoever. I agree that on condition of anonymity, the information obtained from these assessments shall be used for educational and research purposes only. I am also aware that I can contact Dr Febronie Mushimiyimana on Telephone +250 788752779 and Dr Lisine Tuyisenge, on Telephone: +250 788411764 in case of any further clarification or queries.

...../...../.....
Name of the participant	Signature of participant	Date

...../...../.....
Name of the researcher	Signature of the researcher	Date

IV. Consent form for participants -Kinyarwanda version

Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali

Ubushakashatsi no.....

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI

UBUSHAKASHATSI: “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

Jyewe, nemeye kujya mu ubushakashatsi bwitwa “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**”. Ubushakashatsi kukureba uko abangavu n`ingimbi babana n`ubwandu bwa SIDA bakurikiranwa mubana baba biteguye kujya gukurikiranwa mubantu bakuru. Nasobanuriwe ko kujya muri ubu bushakashatsi ari ubushake bwamjye, ko

ntagihembo ntegereje guhabwa, kandi ko nzagirirwa ibanga ku makuru yose nzatanga. Nasobanuriwe uko ibizava muri ubu bushakashatsi bizatangazwa.

Mfite uburenganzira bwo kuva muri ubu bushakashatsi igihe cyose nabishakira kandi ntibingire ingaruka mumivurirwe yanjye. Ikindi kandi, nzi ko nshobora kuba na hamagara Dr. Febronie Mushimiyimana +250788752779 na DrLisine Tuyisenge : +250 788411764 ndamutse ngize ikibazo.

.....

Amazina n`umukono y` ukorerwaho ubushakashatsi

Italiki

.....

Amazina n`umukono y`umushakashatsi

.....

Italiki

V. Consent form for care taker of child-English Version

Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali

Study no.....

I, -----hereby, fully consent Telephone +250 788752779 and Dr Lisine Tuyisenge, on Telephone: +250 788411764 in case on behalf of my child to participate in this study on the “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**” I agree that my child can participate in this study and that any information obtained will be used for the development of the transition protocol.

I understand that I will incur no additional medical costs as a result of participation in this study. I have been fully informed about the purposes of the evaluations that will be done. I have had a chance to ask questions and they have been answered satisfactorily. I also understand that I may withdraw my child at any time with no adverse consequences whatsoever. I agree that on condition of anonymity, the information obtained from these assessments shall be used for educational and research purposes only. I am also aware that I can contact Dr Febronie Mushimiyimana on of any further clarification or queries.

...../...../.....
Name of the participant	Signature of participant	Date

...../...../.....
Name of the researcher	Signature of the researcher	Date

VI. Consent form for care taker of child -Kinyarwanda version

Ubushakashatsi no.....

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI

UBUSHAKASHATSI: “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

Jyewe, nemeye ko umwana wanjye ajya mu ubushakashatsi bwitwa “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**” Ubushakashatsi bwo gufasha abangavu n’ingimbi babana n’ubwandu bwa SIDA bakurikiranwa mubana kujya gukurikiranwa mubantu bakuru. Nasobanuriwe ko kujya muri ubu bushakashatsi ari ubushake bwacu, ko ntagihembo ntegereje guhabwa, kandi ko nzagirirwa ibanga ku makuru yose nzatanga. Nasobanuriwe ko ibizava muri ubu bushakashatsi bizatangazwa.

Mfite uburenganzira bwo kuva muri ubu bushakashatsi igihe cyose nabishakira kandi ntibingire ingaruka mumivurirwe y’umwana wanjye. Ikindi kandi, nzi ko nshobora kuba na hamagara Dr. Febronie Mushimiyimana +250788752779 na DrLisine Tuyisenge : +250 788411764 ndamutse ngize ikibazo.

.....
Amazina n’umukono by’uwasobanuriwe	Icyo apfana n’umurwayi	Italiki
.....
Amazina y’umushakashatsi	Umukono w’umushakashatsi	Italiki

VII. Assent form for a child aged 10 years and above-English Version

Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

Study no.....

I,-----hereby,
fully assent to participate in this study on the “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**” I agree to participate in this study and that any information obtained will be used for the development of the transition protocol.

I understand that I will incur no additional medical costs as a result of participation in this study. I have been fully informed about the purposes of the evaluations that will be done. I have had a chance to ask questions and they have been answered satisfactorily. I also understand that I may withdraw at any time with no adverse consequences whatsoever. I agree that on condition of anonymity, the information obtained from these assessments shall be used for educational and research purposes only. I am also aware that I can contact Dr Febronie Mushimiyimana on Telephone +250 788752779 and Dr Lisine Tuyisenge, on Telephone: +250 788411764 in case of any further clarification or queries.

...../...../.....
Name of the participant	Signature of participant	Date

...../...../.....
Name of the researcher	Signature of the researcher	Date

VIII. Assent form for child aged above 10 years -Kinyarwanda version

Ubushakashatsi no.....

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI

UBUSHAKASHATSI: “Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali”

Jyewe, nemeye kujya mu ubushakashatsi bwitwa “**Designing a transition model for young adults living with HIV followed at University Teaching of Hospital of Kigali**”. Ubushakashatsi bwo gufasha abangavu n`ingimbi babana n`ubwandu bwa SIDA bakurikiranwa mubana kujya gukurikiranwa mubantu bakuru. Nasobanuriwe ko kujya muri ubu bushakashatsi ari ubushake bwamjye, ko ntagihembo ntegereje guhabwa, kandi ko nzagirirwa ibanga ku makuru yose nzatanga. Nasobanuriwe ko ibizava muri ubu bushakashatsi bizatangazwa.

Mfite uburenganzira bwo kuva muri ubu bushakashatsi igihe cyose nabishakira kandi ntibingire ingaruka mumivurirwe yanjye. Ikindi kandi, nzi ko nshobora kuba na hamagara Dr. Febronie Mushimiyimana +250788752779 na DrLisine Tuyisenge : +250 788411764 ndamutse ngize ikibazo.

.....

Amazina n`umukono y` ukorerwaho ubushakashatsi

Italiki

.....

Amazina n`umukono y`umushakashatsi

.....

Italiki

QUESTIONNAIRE

Study number:

DOB:

Knowledge of Health Condition

What is HIV?

What are the modes of transmission of HIV?

How do you prevent the spread of HIV?

What are T cells and?

What is a viral load?

Drug regimen and dosages

What are the names of your medications?

What are the dosages (number of tabs) of your medications?

How do you take your medications (What time of day? Do they need to be taken with food?)?

What are the possible side effects of your medications?

Where do you get your medications?

How do you deal with problems taking your medications (boarding school, non-disclosure, etc)?

Health care

Do you have health insurance?

Who do you live with?

Are you able to identify members of your health care team, what their roles are and how to contact them?

Are you in any support groups?

Do you abstain from using alcohol, drugs and cigarettes and understand why this is important?

Do you know where to look for answers to your health questions?

Do you feel comfortable asking questions at your appointments?

Do you know what a STD is and how it can affect you?

Do you understand how your medical condition affects becoming pregnant or having a child?

As you got older, how did you start to learn that you would have to go to a different clinic as an adult? How did you feel about this when you learned about it?

Do you want to transition to adult clinic?

If not, why?