

# Transition readiness assessment for young adults living with HIV followed at university teaching hospital of Kigali.

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## ABSTRACT

**INTRODUCTION:** Introduction of antiretroviral therapy (ART) worldwide has significantly decreased pediatric mortality from HIV/AIDS. As a result, perinatally-infected children are surviving into adulthood, creating the need to transition of HIV-infected youth from pediatric to adult care.

**Aims:** This study aimed to assess transition readiness of HIV-infected young adults attending a pediatric HIV clinic in Rwanda and then develop a readiness assessment checklist and a transition model.

**METHODS:** This was a qualitative study where in-depth, 20-minute interviews were conducted with 10 HIV-infected young adults (20-24 years) and four healthcare providers. Interviews were conducted in Kinyarwanda, audio taped, transcribed, and then translated into English. The verbatim transcripts were analyzed using content analysis.

**RESULTS:** We undertook 14 interviews - 10 young adults and four HCPs. We identified four major themes: self-management behavior, readiness to assume responsibility, barriers to transition, and transition readiness. All young adults had appropriate knowledge about HIV, but only three were able to name their medications or doses. Almost all young adults (90%) refilled their medications themselves. Identified barriers to transition were: fear of losing the relationship with pediatric 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 identified potential barriers to transition that must be addressed before the transition process begins. The perceived readiness to transition care among the young adults was low, and this could be addressed by implementing a healthcare transition protocol.

**Keywords:** HIV; Transition; readiness; adults; antiretroviral therapy

## INTRODUCTION:

In 2016 there were 16,000 children living with HIV [1] in Rwanda. During the first two decades of the HIV epidemic, perinatally acquired HIV caused death early in childhood [2], but introduction of antiretroviral therapy (ART) worldwide has significantly decreased pediatric mortality from HIV/AIDS [3]. As a result, perinatally-infected children are surviving into adulthood, which has created the need to transition of HIV-infected youth from pediatric clinics into adult care [4].

Prior studies of transitioning the care of children with chronic illness have focused on other diseases such as diabetes, cystic fibrosis, and congenital heart disease; few have specifically focused on HIV, particularly in sub-Saharan Africa [5], [6].

Transition readiness allows patients, family, and healthcare providers to plan and begin the transition process by putting in place interventions and/or supports where health care providers can introduce the idea of transition to the patient, discuss about self-management and involve the adult health care providers. [7], [8]. Schwartz and al. in a study done on patients with chronic health conditions have found that any transition assessment and

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plan should increase transition readiness over time [8]. Transitioning without preparation to an adult care setting may result in a loss of follow up or poor adherence, with measurable consequences in terms of morbidity and mortality and in social and educational outcomes[9].

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 [4], [10]–[12]. In adult settings, adolescents and young adults need to have increased independence and autonomy (such as making appointments on their own, arriving on time, and making medical decisions), and some fear such responsibility [6], [10], [12].

A dedicated transition service tailored to requirements of every chronic condition can have a positive influence on health care and personal development [13]. 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 own health care [14].

There are currently no transition programs or protocols in any pediatric HIV clinic in Rwanda. This study aimed to assess transition readiness of young adults living with HIV attending the pediatric HIV clinic at the University Teaching Hospital of Kigali (CHUK) and then develop a readiness assessment checklist and a transition model.

#### METHODOLOGY:

This was a prospective, qualitative study conducted at CHUK, a tertiary referral hospital located in Kigali, the capital city of Rwanda, and one of the University of Rwanda College of Medicine and Health Sciences teaching hospitals. The pediatric HIV clinic at CHUK currently follows 226 children, 92 (41%) are aged 15 years and older of whom 16 (17%) of are aged 20 years and older. A dedicated, multidisciplinary team consisting of four health care providers – one doctor (a general practitioner), one nurse, one social worker, and one psychologist - manage these patients.

Every young adult living with HIV aged 20 years and above attending the CHUK pediatric HIV clinic was contacted and asked to participate in the study and those who accepted the invitation on the chosen date were included in the study. All healthcare providers involved in the pediatric HIV clinic were included.

In-depth interviews lasting approximately 20 minutes, using semi-structured interview scripts, were conducted with 10 HIV-infected young adults (ages 20-24 years) and four healthcare providers from September till November 2015 by the principal investigator (PI).

Interviews were conducted in Kinyarwanda, audio taped, transcribed, and then translated into English. The verbatim transcripts were analyzed by the Principle Investigator (PI) and a statistician using content analysis. Ethical approval was obtained from the Institutional Review Board (IRB) of CHUK and the University of Rwanda College of Medicine and Health Sciences (Ref:CMHS/IRB/260/2015).

#### RESULTS:

All patients contacted responded but only ten out of 16 young adults were available to participate in the study; six others did not attend because they were away at school and could not attend. The mean age of the young adults was 21 years (range 20-24) and 60% were male. Only one participant was living alone, and half were living with either one or both parents. All of the young adult participants had received antiretroviral therapy for at least 5 years.

From the responses of the young adults and the healthcare providers, we identified four major categories and 11 subcategories of themes (Table 1). The four major categories were self-management behaviors, readiness to assume responsibility, barriers to transition, and transition readiness.

#### 1. Self-management behaviors:

All young adults were knowledgeable about their disease. They could describe HIV, the modes of transmission and how to prevent infection/transmission. Three were unable to explain what viral load is. Healthcare providers (HCPs) stated that many adolescents and young adults had acquired the necessary knowledge from educational sessions conducted regularly 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 of a condom. CD4 cells are soldiers in charge of fighting disease, viral load is to see how many viruses”.

Only one young adult was not a member of a support group. HCPs reported that the young adults were taught about HIV, medications and their possible side effects, and the benefits of strict adherence during support group meetings.

HCP (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 for their medications”.

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 state the 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 effect is jaundiced eyes”.

#### 2. Readiness to assume responsibility

Almost all young adults (90%) refilled their medications themselves. Eight young adults usually remembered to take their medications by themselves. HCPs reported that many are responsible with their medications, came to get their medications on time, 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."

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

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 the internet to get answers".

None of young adults reported consumption of alcohol or drugs and understood how this could impact their health.

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

Three of 10 young adults reported that they did not want to transition care because they feared loss of the relationship with pediatric HCPs and feared starting a new HCP relationship in an adult clinic. One of the HCPs expressed fear that some adolescents and young adults would not be comfortable at the adult HIV clinic because they considered the pediatric healthcare 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".

Six of 10 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. HCPs felt that transition will be difficult for some young adults as they may not be comfortable with new health care providers.

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

Four of ten young adults were concerned about the privacy in the adult clinic and feared stigmatization as they would possibly meet people from their neighborhood in the clinic. HCPs highlighted the issue of the adult HIV clinic being labeled "HIV clinic" and being separate from other clinics because there would be a risk of inadvertent disclosure of HIV status.

HCP (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

Most young adults (six of 10) showed that they were not ready to transition care. All HCPs agreed on the need to transition adolescents and young adults because they are not able to offer them all the needed services tailored to their age. However, both the young adults and HCPs suggested that creating a special transitional clinic for adolescents and young adults may be better than immediately transitioning care from pediatrics to adult care.

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

Three of ten young adults suggested starting a special clinic for young adults in the pediatric HIV clinic instead of transitioning care to adult clinic directly. This was also suggested by all HCPs 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 with, 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 adults".

HCP (social worker): "We suggest that they 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".

Two of 10 young adults suggested starting by visiting the adult clinic and to see how the clinic functions before transitioning. A nurse also suggested visiting adult clinic before transition because that could help in understanding how the adult clinic works and prepares the young adult before transition.

HCP (nurse): "... another suggestion is to allow them to visit the adult clinic, see how services are offered, and, this is really important, that someone from pediatrics accompanies them and sees how they are received".

When asked if they were ready to transition, only four young adults reported that they are ready. The remaining young adults said that they want to stay in pediatrics.

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

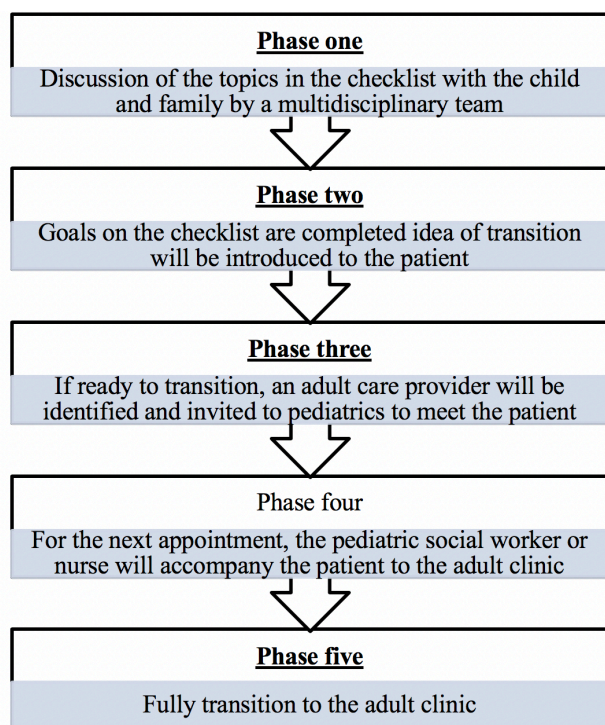
### Transition checklist and model

Based on the participants' responses we identified areas that HCPs should focus on before transitioning adolescents. This was used to develop a transition checklist that will be used in the

pediatric HIV clinic (Figure 1). The checklist will be in the patient's file, and at each visit the adolescent will be assessed on the skills he/she needs to acquire before transition.

We designed a transition model based on the study results considering the four major categories and eleven subcategories of themes (Figure 2). The attached transition model will be tested in the pediatric HIV clinic and will guide the transition of adolescents and young adults from the pediatric clinic to adult clinics.

**Figure 1: Transition model**



## DISCUSSION:

In this study we found that young adults had gained autonomy but still needed more education about their medications. We identified some barriers to transition and participants proposed how those barriers could be addressed. The gaps in the knowledge of medication names and side effects is consistent with findings in US studies where they have found that adolescents needed additional knowledge about their healthcare [10], [12].

The pediatric healthcare providers overestimated what the adolescents were learning in the support groups. In the support groups, HCPs teach about HIV/AIDS, medications and the importance of adherence. Lack of sound knowledge about medications is a potential risk for poor adherence when transitioning to adult care. The pediatric HCPs could improve on this by providing continuous education so that young adults can acquire the knowledge and skills to allow them to be independent in the management of their own healthcare [15].

Most young adults regularly refilled their own medications and remembered to take them without reminders from family members. This is a sign of the responsibility and autonomy that is needed for success in adult care [16]. With these findings we have hope that these young adults will have improved clinical outcomes.

We identified 3 major barriers to transitioning care: 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 [17], [18]. HCPs 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 [10]. The young adults and HCPs identified some interventions to help in addressing the identified barriers, like starting a special transitional clinic for adolescents and young adults and visiting the adult clinic before transition. US studies have also reported this recommendation to start an adolescent clinic tailored to addressing psychosocial issues related to their developmental stage [10], [13], [15], [18]–[20]. A few young adults and HCPs suggested starting transition by visiting the adult clinic before transitioning care to see how it works and to have the opportunity to meet the new providers. Visiting the adult clinic before transition may be one of the solutions for the feared stigma because the young adults could interact with some adult patients and/or adult healthcare providers to alleviate their fears [17].

Fear of the loss of the long-term relationships built in pediatric clinic is similarly reported in several US studies where they found that adolescents were concerned about losing the relationship with the pediatric healthcare providers who also have difficulty in letting their pediatric patients go [5], [6], [15], [20], [21]. Healthcare providers are considered as family members by the patients they have followed up with for many years, sometimes since birth. This can make the transition a challenge for both [5], [6], [11], [21]. In some instances, because of that strong relationship, adolescents were coming back to pediatrics after transition to discuss social issues [6].

Other young adults feared stigmatization in the adult clinic because many adult clinics are labeled “HIV clinic” so people who see them entering there or even adult patients from their neighborhood would now know that they are infected. A study in Uganda similarly found that stigma was one of the challenges faced by transitioning young adults [22], [23]. A Rwandan study found that stigmatization can have a negative impact on follow-up care and medication adherence [1]. Fear of stigma was also identified by several studies where young adults and HCPs were concerned about possible discrimination by other patients or providers adult clinic, and that the young adults may face unwanted disclosure of their status in the adult clinic labeled “HIV clinic” [6], [11], [21]. This is a complex problem to address with no simple solution. Adult HIV clinics could consider having the HIV clinic in similar locations to other internal medicine clinics or remove the HIV word on the name of the clinic.

All HCPs felt that it was necessary for adolescents and young adults to move to adult clinic because healthcare 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 [20], [22]. 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 healthcare [5]. A gap was also identified among the pediatric HCPs in adolescent healthcare, particularly in reproductive and sexual health services. Both pediatric and adult HCPs need training on transitioning care and adolescent medicine for the success of the transition process [24].

The transition readiness assessment needs to be included in the routine care of the adolescents. We seek to address this by using the developed transition readiness tool at each patient visit. The transition readiness tool can help in identifying gaps where HCPs need to focus on the education of the adolescents. 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 [25].

The perceived readiness to transition among our young adults was low. A study undertaken in Australia found that young adults considered the transition as a challenge and suggested involvement in the process of transition [16]. However, transition does not need to be a negative process. In a UK study, 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 [13].

**Table 1: Emerged themes**

Major categories	Subcategories
Self-management behaviors	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	Participation in the treatment management Involvement in high-risk behaviors Fear to lose relationship with health care providers
Barriers to transition	Fear of new environment Fear of stigmatization in the adult clinic
Transition readiness	Set up a transition clinic Visit of adult clinic Perceived transition readiness

In conclusion, we found that even though the young adults were taking responsibility for their healthcare, they still needed additional knowledge related to their drug regimens. We identified potential barriers to transition that must be addressed before the transition process begins. The perceived readiness to

transition care among the young adults was low, and this could be addressed by implementing a transition protocol where the idea of transition will be introduced early and when adolescents and young adults feel ready to transition, an adult health care provider will be introduced to him/her in pediatrics HIV clinic and then the transition process will start.

African healthcare systems need to prepare HIV-infected youth to successfully transition from pediatric to adult care settings. This requires awareness of transition needs and routine assessment of transition readiness by pediatric HIV healthcare providers. The next step of this study is the implementation of the transition checklist and model in the CHUK pediatric HIV clinic, and we plan to follow the clinical outcomes of the transitioned youth.

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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:						
<b>Knowledge of Health Condition</b>						
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?						
<b>Drug regimen and dosages</b>						
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)?						
<b>Health care</b>						
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?						
<b>Communication</b>						
Do you know where to look for answers to your health questions?						
Do you feel comfortable asking questions at your appointments?						
<b>Reproductive health</b>						
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?						
<b>Life Planning</b>						
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?						