

On TRACK to Transition: Designing a Transition Readiness Assessment Checklist and model for young adults living with HIV at the University Teaching Hospital of Kigali

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Introduction

In Rwanda in 2014, there were 17,270 children living with HIV¹. During the first two decades of the HIV epidemic, perinatally acquired HIV caused death early in childhood², but introduction of antiretroviral therapy (ART) worldwide has significantly decreased pediatric mortality from HIV/AIDS³. 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 care⁴. 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 subSaharan Africa^{5, 6}.

Objectives

- To assess the ownership of medical care of young adults attending the University Teaching Hospital of Kigali pediatric HIV clinic.
- To assess the perceptions of the young adults about transition to adult clinic.
- To assess the views of health care providers about transition of the young adults to the adult clinic
- To develop a transition checklist and a transition model.

Setting

- The study was conducted in the pediatric HIV clinic of the University Teaching Hospital of Kigali (UTHK).
- UTHK is located in the capital city of Kigali and is one of the four tertiary referral hospitals in Rwanda.
- The pediatric HIV clinic follows 226 children, of whom 92 (41%) are aged 15 years and older; among these, 16 (17%) are aged 20 years and above.

Methods

This was qualitative study of HIV-infected patients aged ≥ 20, and their healthcare providers (HCPs). Individual 20-minute open-ended interviews were conducted in Kinyarwanda, audio taped and transcribed. The grounded theory approach was used for analysis; transcripts were coded, and then grouped into concepts.

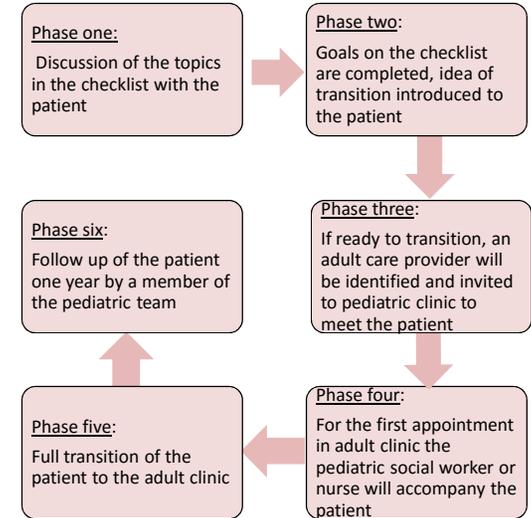
Results

- Ten HIV-infected patients and four HCPs were interviewed.
- The mean age of the patients was 21 years (range 20-24).
- Four major categories of themes were identified from interview responses (Table 1).
- Based on the responses we identified areas that HCPs need to focus on. and developed a transition checklist and model (Figure 1) to be used in the HIV clinic.

Table 1: Emergent themes concerning perception of HIV-infected young adults about transition

Major categories	Subcategories
Self-management behaviors	<ul style="list-style-type: none"> • Knowledge of disease • Knowledge of drug regimen, dosages, and side effects
Readiness to assume responsibility	<ul style="list-style-type: none"> • Responsibility in management of clinical condition • Participation in treatment management • Involvement in high-risk behaviors
Barriers to transition	<ul style="list-style-type: none"> • Fear of loss of relationship with pediatric HCPs • Fear of new environment • Fear of stigmatization in adult clinic
Transition readiness	<ul style="list-style-type: none"> • Create transition clinic • Visit adult clinic prior to transition • Perceived transition readiness

Figure 1. Transition model developed for the UTHK pediatric HIV clinic



Conclusions

The perceived readiness to transition care among the young adults was low. Though the patients had autonomy in their healthcare management, there were knowledge gaps about disease and drug regimen. In addition, HCPs expressed discomfort in caring for young adults and could benefit from additional training in adolescent medicine. In the next steps of this project, the transition checklist and protocol will be implemented and the patients will be followed for outcomes.

References

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