Managing the transition from paediatric to adult care for HIV, Kenya

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Abstract Expansion of access to diagnosis and treatment for human immunodeficiency virus (HIV) and a high incidence of HIV infection in adolescence has resulted in a growing population of adolescents and young adults living with HIV. The prevalence of poor retention in care, insufficient viral suppression and loss to follow-up are higher among adolescents and young adults compared with other age groups. Poor outcomes could be attributed to psychosocial changes during adolescence, but also to poor transitional care from paediatric to adult HIV services. In many countries, transition processes remain poorly defined and unstructured, which may jeopardize treatement adherence and retention. We describe existing definitions of transition and transition frameworks, and key elements of transition as proposed by key national stakeholders in Kenya. Our consensus definition of transition is “a planned process by which adolescents and young adults living with HIV, and their caregivers, are empowered with knowledge and skills to enable them to independently manage their health.” Transition should begin soon after disclosure of HIV status until an adolescent gains the necessary knowledge and skills and is willing to move to adult services, or by 25 years of age. Proposed key elements of transition are: target ages for milestone achievement; readiness assessment; caregiver involvement and communication with adult clinics; flexibility to return to adolescent or paediatric clinics; group transition; and considerations for adolescents with special needs. Retention in care, linkage to care and viral suppression are important markers of transition success. Proposed definitions and key elements could provide a framework for structuring transition programmes in other countries.

Introduction

Expansion of paediatric antiretroviral therapy (ART) and treatment services has improved survival among children living with human immunodeficiency virus (HIV). However, globally, HIV-associated mortality among adolescents 15–19 years of age remains high.1 In addition, adherence to medication is suboptimal2 and loss to follow-up among 15–24-year-olds is twice as high as that of younger adolescents (10–14 years of age) or adults (25 years of age or older).3 Transition from paediatric or adolescent HIV care to adult services is emerging as a critical step for maintaining good outcomes among adolescents and young adults.

Structured transition programmes can support adolescents and young adults living with HIV to successfully transition into adulthood. In high-income countries, transition from paediatric to adult care services usually involves a change of clinic and/or providers, largely because care is provided as a specialized service and transitional models of care are available.4–6 The lack of structured transition programmes reflects a broader gap in bridging from paediatric- and adolescent- to adult-oriented services for chronic illness in general, and for HIV care specifically.7 The model of care in sub-Saharan Africa is predominantly non-specialist, comprising integrated clinics where adults, adolescents and children living with HIV are seen by the same staff in the same place.7,8 However, adolescent-friendly services, usually in the form of a dedicated adolescent clinic day, are increasingly being implemented.7,8 Although specific services that address the unique needs of adolescents may be available, practices remain varied.

The World Health Organization (WHO) defines HIV care transition as purposeful planned movement from paediatric models of care to adult services, the goal of which is to support adolescents gain life skills to independently manage their care.7 However, at a programmatic level, definitions and tracking systems for transition are varied9 and transition-focused services are short-lived, typically occurring in the context of research projects.7

In this article, we describe current definitions of transition, existing transition frameworks and propose transition definitions and key components of transition programmes that could be used in programmatic settings. We outline our team’s experience engaging a broad range of stakeholders, as part of the Adolescent Transition to Adult HIV Care for HIV-infected Adolescents in Kenya study, which has the goal of developing and testing a comprehensive transition package of care. We also describe limitations that may hamper implementation of transition programmes.

Transition definitions

Common definitions of transition in HIV care are based on multiple criteria including: age; completion of a formal transition process; awareness of HIV diagnosis; HIV knowledge; attendance at an adolescent transition clinic; being clinically stable; being pregnant or married; and demonstrating independence.
**Age-based definitions**

Age-based definitions may be used alone or in combination with other criteria that define transition. Three distinct ways of defining the age of transition can be identified in the research literature: (i) by developmental stage; (ii) by achievement of independence; and (iii) by programme categorization.

The first definition is based on expectations of stages in development when the shift to adulthood occurs. Transition programmes are largely designed to prepare 18–25-year-old adolescents for transfer to adult care. Even among adolescents with developmental delay, age is still an important determinant of defining who is prepared for transition. One study reported high numbers of transition failures when transfer to adult care was done at 21 years of age and researchers proposed moving the definition of age of completing transfer to 25 years of age.

The second approach to defining age cut-off for transition is based on society’s expectations of a specific age when individuals achieve independence. Common ages that have been used to define transition include 12, 15 and 18 years, but a wider range exists (from 12 to 22 years of age). The third approach to defining age cut-off for transition is based on an individual attaining the age of re-categorization in data systems within HIV care programmes. Almost a third (57) of 218 health-care facilities across sub-Saharan Africa lack a working definition of adolescents and 80% (174 out of 218) do not disaggregate treatment outcomes by age. Common programmatic age cut-offs for transition are 12, 15 and 18 years of age. These definitions may result in changes in access to certain services, for example access to youth clinics and support groups, or changes in how medical records are handled or stored.

WHO guidelines describe transition in integrated clinics as "adoption of different approaches of care recognizing the child's changing ability and needs." For adolescents in integrated clinics, transition may mean coming to the clinic on their own, making their own clinic appointments and being able to pick their own medications. However, these variables are rarely captured. In the International Epidemiology Database to Evaluate AIDS South African collaboration, where clinics are largely integrated, researchers compared pre- and post-transition retention in care and viral suppression levels using different age thresholds as proxies for when transition might occur. However, although convenient and perhaps the only available approach to analyses of transition given data limitations, using age definitions does not take into account developmental challenges or the family and social circumstances, which adolescents face and that could appropriately influence development and transition.

**Formal processes**

Formal HIV care transition processes are common in high-income countries. Adolescents reach a certain age and then go through a formal transition plan to ensure specific goals are attained. A formal readiness assessment tool or an informal process is used to document readiness to transition. A few programmes in low- to middle-income countries have used readiness assessment tools. The Baylor Kalogo programme in Zimbabwe included two to three readiness assessment questions administered at each clinic visit and training modules on transition in peer support groups. Adolescents were required to meet specific criteria before transfer to adult clinics. The Thailand Happy Teen 1 programme included a multidisciplinary team providing individualized and group-based transition training at clinic visits. In some HIV programmes, training lasting from 90 minutes to 2 days and 6-week transition camps have been conducted. Youth transition clinics to support transition are sometimes used. These clinics are usually in the form of adolescent clinic days, in which a day of the week is dedicated to adolescent care. Activities may include regular clinic care with additional peer-support activities, or only peer-support activities. Ideally, adolescent clinics would fully engage adolescents and have well-trained health-care workers. However, there is evidence of underutilization of these clinics, with only 32% of 379 Ugandan adolescents reported to be regular attendees in one study. In addition, many of these programmes lack policies, guidelines and tools, staff and community support, resulting in poor support for and utilization by adolescents.

**Other definitions of transition**

In Nigeria, individuals’ awareness of their HIV status and HIV knowledge were used to define transition. However, assessment was informal and did not specify what would be regarded as enough knowledge. Including knowledge of HIV status in the transition definition may explain some of the early transition ages reported in sub-Saharan Africa, as disclosure of HIV status tends to occur in early adolescence.

In Nigeria, pregnancy and marriage are used as criteria for transition of adolescents to adult care. Similarly, in Kenya, pregnancy in adolescent girls results in abrupt transfer from paediatric or adolescent clinics to maternal and child health units and these girls may not return to the adolescent clinic after delivery. Adolescent pregnancy, early marriage and HIV infection may be markers of additional vulnerabilities and may result in worse outcomes.

Health-care workers have also described transition as demonstrating independence, either by adolescents attending clinics on their own or collecting their own medication, but this has not been systematically assessed.

In specialized paediatric HIV clinics, particularly in South Africa, transition is defined by reaching 12 years of age and being stable on treatment.

**Transition models of care**

Two distinct groups of models of adolescent care exist. The first model involves a physical transfer, whereby adolescents transition from specialist paediatric or adolescent services to adult services with a change in clinic or provider, or both. In the second model, adolescents remain within comprehensive services and both...
clinic and provider remain the same. For this second group of adolescents, transition definitions are difficult to envision. Adolescent-friendly clinics, may offer some definitions. For example, adolescents who transition from an adolescent clinic day to an adult clinic day may be considered to have transitioned. However, poor utilization of adolescent clinics remains a problem.

### Transition frameworks

Transition frameworks from resource-rich settings may be adapted for use in low-resource settings. The Got Transition tool developed in the United States of America provides a framework for transition services and a transition timeline beginning at 12 years of age and ending at age 26 years that can be adapted by clinics. The tool includes 6 core elements: (i) establishing a transition policy; (ii) tracking transition progress; (iii) assessing transition readiness; (iv) planning for adult care; (v) transferring to adult care; and (vi) integration into an adult practice. The first three core elements may apply to any model of care or setting.

In 2012 and 2014, the United States Agency for International Development released a HIV care transition guide for use in sub-Saharan Africa that includes four of the Got Transition core elements (transition tracking and monitoring; transition readiness; transition planning; and transfer to adult care). However, where the tool was piloted, health-care providers did not fully use the tool due to time challenges and tool complexity. How best to simplify transition tools and motivate providers to use them remain important questions. The International Center for AIDS Care and Treatment Programs at Columbia University, New York, United States, has also published transition guidelines that incorporate HIV care transition readiness, planning, transfer and transfer completion. However, data on utilization and outcomes from the use of these tools are lacking. At a national level, among the five countries with the highest burden of adolescent HIV infection, only the Kenya national guidelines for ART comprehensively address transition, providing age-based transition milestones and a standard data collection tool to act as a reminder to health-care workers to discuss transition during visits.

### Successful transition

Successful transition has previously been described either qualitatively by assessing adolescent experiences after transition or quantitatively by assessing post-transition outcomes including CD4+ T-lymphocyte count, viral load, mortality, adherence to therapy and retention in care. Many of these studies were conducted in resource-rich settings, where there is actual transfer to adult services. In sub-Saharan Africa, few studies have assessed transition readiness and validated tools are lacking. Researchers have developed and validated a transition readiness assessment for adolescents with chronic health-care needs in the United States. While the tool can be used across multiple illnesses, these tools would need to be adapted for the different medical care context in sub-Saharan Africa settings.

### Kenyan experience

Kenya has a generalized HIV epidemic, with over 1.5 million people living with HIV in 2018. Of these, an estimated 105,200 (7%) are children younger than 15 years of age and 184,718 are aged 15–24 years of age. In 2018, there were 8,000 new infections among children younger than 14 years of age. While the Kenya Ministry of Health guidelines for HIV care recognize transition as a key element of successful HIV care, there is little guidance on definitions of transition or how to measure success.

The Adolescent Transition to Adult HIV Care for HIV-infected Adolescents in Kenya study is a cluster-randomized trial aimed at addressing gaps in transition care for adolescents and young adults 10–24 years of age who are living with HIV and attending public HIV care clinics in Kenya. The study aims to (i) understand current transition practices; (ii) develop a transition tool for use in programmatic settings in Kenya; and (iii) test the developed transition tool in a cluster randomized trial. To begin national discussions on transition, the study team has partnered with the Kenya health ministry, HIV care partners, county HIV care directors, implementing partners, mental health experts, health-care providers from pediatric and adult settings, and adolescent representatives.

The first phase of the study included assessment of clinic transition practices and outcomes in a nationally representative sample of 102 HIV clinics representing over 12,000 adolescents and young adults living with HIV. For the second phase, we reviewed existing transition definitions, and adapted and developed transition definitions and frameworks for use in programmatic settings in Kenya. The third phase, the cluster-randomized trial, is planned to begin in 2019. The trial will test the effectiveness of an adolescent transition package of services to improve transition readiness, retention in care and viral suppression among adolescents and young adults living with HIV in clinics randomized to receive the intervention.

### Proposed transition definition

Our consensus definition of transition is “a planned process by which HIV-infected adolescents and young adults, and their caregivers, are empowered with knowledge and skills to enable them to independently manage their health.” The transition process is proposed to begin soon after disclosure of HIV status and not later than 14 years of age. Transition preparation would continue until adolescents gain the knowledge and skills they need, and are ready and willing to move to adult-oriented services (Fig. 1). Transition should be completed by 25 years of age. The currently recommended age at which transition discussions should begin is much earlier than previously documented in the literature from high-income countries, which may allow the desired psychological preparation before transition. Beginning transition preparation earlier may be particularly beneficial in sub-Saharan Africa, as adolescents often present to clinics alone, due to challenges such as transport costs, being orphans, caregiver illness, and not having disclosed their status to others, however, may not necessarily have the knowledge and skills to successfully manage their care.

### Proposed transition framework

For the HIV care transition processes in Kenya, we have proposed the following core elements: transition milestone
over a 12-month period (retention); (ii) three or more visits care, or 25 years of age, whichever is
they have reached the knowledge and
the time at which it is documented that
3 months of attending an adult clinic, or
cessful transition of individuals as fol-
In Kenya, we proposed to define suc-
considerations for adolescents with
transition where possible; and special
with special needs (Fig. 1; Box 1). Other
clinical considerations include patients
transition readiness assessment; care-
giver involvement; communication with
adolescent clinics where necessary; flexibility
to return to adolescent clinics; group
transition where possible; and special
for adolescents with special needs (Fig. 1; Box 1). Other
clinical considerations include patients
being on an optimized ART regimen and clinically stable (vira-
no active opportunistic infections). In clinic settings where adolescent
and adult services are offered separately, communication between providers,
group transition (referring to transition of adolescent cohorts who have been in
care together) and transition support
groups may be key.

Proposed definition of successful transition

In Kenya, we proposed to define suc-
individuals as follows: (i) at least one clinic visit within
3 months of attending an adult clinic, or
the time at which it is documented that
they have reached the knowledge and
skill milestones to navigate autonomous
care, or 25 years of age, whichever is
first (linkage); (ii) three or more visits
over a 12-month period (retention); and
(iii) consistent viral load measure-
ments below the level of detection for
≥12 months (viral suppression). Post-
transition follow-up is recommended to
include contact at 3 months to evaluate
linkage to care and at 6–12 months to
assess retention, viral suppression and
experiences in adult care. These defini-
tions align with existing guidelines for
clinic visits recommended to be at
least every 3 months for adolescents
and young adults living with HIV. In
programmatic settings, retention and
viral suppression are routinely tracked.
In programmes where adult, adolescent
and paediatric clinics are integrated,
documentation of reaching knowl-
edge and skills milestones is available,
achievement of milestones will be used
to define the transition time-point.
If the information is not available, 25
years of age will be used. Retention and
viral suppression following this time
or age will be used to approximate to
post-transition outcomes. Therefore, our
proposed definition of successful transi-
tion fits well into existing programmes,
but will require modification to report
age-disaggregated outcomes.

Benefits of transition programmes

Transition programmes provide a
structured approach for adolescents
and young adults living with HIV to
gain the necessary knowledge and skills
you need for their care in adulthood
and to gain confidence as they enter
adult services. Adult care systems in
many countries have often been de-
scribed as judgemental, depersonalized
and overburdened, and adolescents
have reported feeling afraid, unpre-
pared and alone in adult care. As
a result of the differences in care
in adult and paediatric systems,
health-care workers have expressed
difficulty letting-go of adolescents
and young adults living with HIV
whom they have often looked after
since infancy or childhood. Lack
of effective communication between
adult and paediatric providers is also
seen as a barrier to effective transition
programmes. In clinics where
providers do not change, adolescents
and young adults living with HIV may
face fewer barriers to transition, but
few data are available on the benefits
of these systems. However, qualitative
evidence suggests that transition, if well
planned, could be a positive event. In
addition, while adult clinics may be
unwelcoming, they may foster inde-
pendence and are better placed to ad-
just the biological age-related
realities of care in young adults. Data
on transition experiences is lacking and
more research in this area is needed.

Limitations of transition programmes

Where HIV transition programmes
have been found to be effective, a key
component of these programmes has
been having a dedicated transition
director or team who are respon-
sible for identifying adolescents in
need of transition, and for tracking and
follow-up after transition. An effective
transition programme may require
organisation of staffing to meet
these additional roles. However, many
health-care systems are overburdened
and clinicians may not have enough
time to address transition needs. Inno-
ative models, such as group transition
programmes, peer-led programmes or
programmes and tools that empower
caregivers to support transition, may
be feasible options. The Zimbabwe
Zvandiri programme is perhaps the
most successful peer-led programme.
Zvandiri is heavily invested in com-

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munity adolescent treatment experts; these are 18–24-year-old HIV-infected adolescents who provide support for adolescents who have not attained treatment goals. The strength of the programme seems to lie largely in strong community and health ministry partnerships and collaborations.

Tools for tracking transition are also generally lacking. The Kenya health ministry introduced a standard tool for health-care workers to remind them to address key adolescent needs during clinic visits and a visual poster placed in the clinic that reminds health-care workers what transition milestones to assess by age. Transition preparation is one of the items included in the tool. Tracking individuals’ progress, however, remains challenging. Development of standardized transition tools, such as transition booklets, tracking tools, procedures for assessing successful transition and support systems remain important, as does an understanding of the specific resources needed to support their use. Whether these tools improve transition readiness, translate to better health outcomes or are cost–effective remains unclear.

**Conclusion**

Our definitions and key elements of transition developed in Kenya could be translated to other settings with similar models of care. While identifying a practical way to track and assess transition in programme settings remains challenging, we provide a framework for better understanding transition definitions and processes that can support the development of interventions to improve transition outcomes.

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Transition to adult HIV care, Kenya

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Keywords: HIV care transition; adolescent; young adult; Kenya

Abstract

Transitioning from pediatric to adult HIV care is a critical step for ensuring continued care, linkage to care, and viral suppression. However, transition processes can be challenging for both adolescents and adults, with high rates of clinic attrition and viral suppression failure. This paper reviews the current state of transition processes in Kenya and discusses the key factors that influence successful transition. It also highlights the importance of continued support and engagement with adolescents and young adults as they transition to adult care. The paper concludes with recommendations for improving transition processes in Kenya and other resource-limited settings.

Résumé

Gestion de la transition entre la prise en charge pédiatrique et la prise en charge adulte du VIH, Kenya

L’accès élargi au diagnostic et au traitement du virus de l’immunodéficience humaine (VIH) et l’incidence élevée de l’infection par le VIH à l’adolescence ont entraîné une hausse de la population d’adolescents et de jeunes adultes atteints du VIH. La prévalence de mauvais continuums de soins, de suppressions virales insuffisantes et d’interruptions du suivi est plus élevée chez les adolescents et les jeunes adultes que dans d’autres groupes d’âge. Ces mauvais résultats peuvent être attribués aux changements psychosociaux qui interviennent à l’adolescence, mais aussi à la médiocrité de la transition entre les services de soins pédiatriques et adultes du VIH. L’Afrique subsaharienne, en particulier, a des processus de transition qui sont souvent mal définis et peu structurés, ce qui peut nuire au respect et à la poursuite des traitements. Nous décrivons ici les définitions existantes de la transition et des cadres de transition, ainsi que les éléments clés de la transition proposés par les principales parties prenantes de la transition en Afrique subsaharienne. Notre définition consensuelle de la transition est: « processus planifié qui permet aux adolescents et aux jeunes adultes atteints du VIH, ainsi qu’à leurs aidants, de disposer des connaissances et compétences nécessaires pour gérer leur santé de manière autonome ». La transition devrait débuter peu après le diagnostic de la séropositivité et durer jusqu’au moment où l’adolescent a acquis les connaissances et compétences nécessaires pour gérer son propre processus de soins, et où il est capable de continuer à suivre son traitement et à prendre des décisions concernant sa santé. La transition devrait être mise en place dans toutes les régions africaines où le VIH est endémique, et être soutenue par des politiques et des programmes de santé publique adaptés.
### Resumen

Gestión en la transición de la atención pediátrica a la atención para adultos en relación con el VIH, Kenia

La ampliación del acceso al diagnóstico y tratamiento del virus de la inmunodeficiencia humana (VIH) y la alta incidencia de la infección por el VIH en la adolescencia han dado lugar a una población creciente de adolescentes y adultos jóvenes que viven con el VIH. La prevalencia de una retención inadecuada en la atención, la supresión viral insuficiente y la pérdida de seguimiento son mayores entre los adolescentes y los adultos jóvenes en comparación con otros grupos de edad. Los resultados negativos pueden atribuirse a cambios psicosociales durante la adolescencia, pero también a una transición deficiente de los servicios pediátricos a los servicios para adultos con VIH. En África subsahariana, los procesos de transición siguen siendo mal definidos y desestructurados, lo que puede suponer un riesgo para el cumplimiento y la retención del tratamiento. Describimos las definiciones existentes de transición y los marcos de transición, así como los elementos clave de la transición propuestos por las principales partes interesadas a nivel nacional en Kenia. Nuestra definición consensuada de transición es "un proceso planificado mediante el cual los adolescentes y adultos jóvenes que viven con el VIH, y sus cuidadores, son capacitados con conocimientos y habilidades que les permiten manejar su salud de manera independiente". La transición debe comenzar poco después de la revelación del estado serológico respecto al VIH hasta que el adolescente adquiera el conocimiento y las habilidades necesarias y esté dispuesto a trasladarse a los servicios para adultos, o a la edad de 25 años. Los elementos clave de la transición propuestos son: edades objetivo para el logro de los hitos; evaluación de la preparación; participación de los cuidadores y comunicación con las clínicas para adultos; flexibilidad para regresar a las clínicas para adolescentes o pediátricas; transición de grupos; y consideraciones para los adolescentes con necesidades especiales. La retención en la atención, la vinculación a la atención y la supresión viral son marcadores importantes del éxito de la transición. Las definiciones propuestas y los elementos clave podrían proporcionar un marco para estructurar los programas de transición en otros países.

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