Managing the transition from paediatric to adult care for HIV

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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, 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 sub-Saharan Africa, transition processes remain poorly defined and unstructured, which may jeopardize treatment 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 age 25 years. 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 sub-Saharan Africa and other resource-poor settings.
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 aged 15–19 years remains high. In addition, adherence to medication is suboptimal and loss to follow-up among 15–24-year-olds is twice as high as that of younger adolescents (aged 10–14 years) or adults (aged 25 years or older). 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, a physical transition from paediatric to adult care is common, largely because care is provided as a specialized service and transitional models of care are available. The lack of structured transition programmes in sub-Saharan Africa reflects a broader gap in bridging from paediatric- and adolescent- to adult-oriented services for chronic illness in general, and for HIV care specifically. 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. However, adolescent-friendly services, usually in the form of a dedicated adolescent clinic day, are increasingly being implemented. 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. However, at a programmatic level, definitions and tracking systems for transition in sub-Saharan Africa are varied and transition-focused services are short-lived, typically occurring in the context of research projects.

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 in sub-Saharan Africa. 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 defines 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. This range coincides with the ages at which adolescents are becoming independent. Although the age to begin the process of transition may be defined, the Adolescent Trials Network (an American-based network of HIV clinics participating in adolescent HIV research) has emphasized that adolescents need to have attained sufficient maturity to navigate adult services. 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 old and researchers proposed moving the definition of age of completing transfer to 25 years.

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).

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.\textsuperscript{15} Common programmatic age cut-offs for transition are 12, 15 and 18 years. These definitions may result in changes in access to certain services, for example access to youth clinics and support groups,\textsuperscript{14} 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.”\textsuperscript{9} 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 Databases 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.\textsuperscript{16} 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\textsuperscript{10} 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.\textsuperscript{7} The Thailand Happy Teen 1 programme included a multidisciplinary team providing individualized and group-based transition training at clinic visits.\textsuperscript{17} In some HIV programmes in sub-Saharan Africa, training lasting from 90 minutes to 2 days and 6-week transition camps have been conducted.\textsuperscript{7,18,19}

Youth transition clinics to support transition are sometimes used in sub-Saharan Africa.\textsuperscript{7} 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.\textsuperscript{18} However, there is evidence of underutilization of these clinics,\textsuperscript{20} with only 32\% of 379 Ugandan adolescents reported to be regular attenders 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.\textsuperscript{21,22}

**Other definitions of transition**

In Nigeria, individuals’ awareness of their HIV status and HIV knowledge were used to define transition.\textsuperscript{8} 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,\textsuperscript{7} 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.\textsuperscript{8} Similarly, in Kenya, pregnancy in adolescent girls results in abrupt transfer from paediatric or adolescent clinics to maternal and child health units (Grewal G, dissertation thesis, Department of Paediatrics and Child Health, University of Nairobi, Nairobi, Kenya, 2017) 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.\textsuperscript{23–25}

Health-care workers have also described transition as demonstrating independence, either by adolescents attending clinics on their own or collecting their own medication\textsuperscript{26} 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.\textsuperscript{27}

**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, common in sub-Saharan Africa, 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, common in sub-Saharan Africa, 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.\textsuperscript{7,26} Poor utilization of adolescent clinics remains a problem, however.\textsuperscript{20}

**Transition frameworks**

Transition frameworks from resource-rich settings may be adapted for use in sub-Saharan Africa. The Got Transition tool\textsuperscript{28} developed in the United States of America provides a framework for transition services and a transition timeline beginning at age 12 years 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) transfer 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\textsuperscript{29} 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 the complexity of the tool.\textsuperscript{18} 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 Colombia University has also published transition guidelines that incorporate HIV care transition readiness, planning, transfer and transfer completion.\textsuperscript{30} However, data on utilization and outcomes from the use 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.\textsuperscript{31}

**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.\textsuperscript{17,32–}
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 and 184,718 are aged 15–24 years. There were also 8,000 new infections among children younger than 14 years. 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 transitional care for adolescents and young adults aged 10–24 years 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 paediatric 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 (NCT number: 03574129), is planned to begin in October 2019. The trial will test the effectiveness of an adolescent transition package of services to improve transition readiness, retention in care and
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 independently manage their health.” The transition process is proposed to begin soon after disclosure of HIV status and not later than age 14 years. 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 the age of 25 years. The currently recommended age at which transition discussions should begin is much earlier than previously documented in the literature from high-income countries,\textsuperscript{10} which may allow the desired psychological preparation before transition (Grewal G, dissertation thesis, Department of Paediatrics and Child Health, University of Nairobi, Nairobi, Kenya, 2017).\textsuperscript{39} 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.\textsuperscript{40}

Proposed transition framework

For the HIV care transition processes in Kenya, we have proposed the following core elements: transition milestone achievement in four key areas (HIV treatment literacy; self-management; communication skills; and support); transition readiness assessment; caregiver involvement; communication with adult clinics where necessary; flexibility to return to adolescent clinics; group transition where possible; and special considerations for adolescents with special needs (Fig. 1; Box 1). Other clinical considerations include patients being on an optimized ART regimen and clinically stable (virally suppressed and 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 successful transition of individuals as follows: (i) at least one clinic visit within 3 months of attending adult clinic, or the time at which it is documented that they have reached the knowledge and skill milestones to navigate autonomous care, or age 25 years, whichever is first (linkage); (ii) three or more visits over a 12-month period (retention); and (iii) consistent viral load measurements below the level of detection for \( \geq 12 \) 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 definitions 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, and documentation of reaching knowledge and skills milestones is available, achievement of milestones will be used to define the transition time-point. If the information is not available, an age of 25 years 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 transition 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 they need for their care in adulthood and to gain confidence as they enter adult services. Adult care systems both in sub-Saharan Africa and the United States have often been described as judgemental, depersonalized and overburdened, and adolescents have reported feeling afraid, unprepared and alone in adult care.\textsuperscript{14,41,42} Because of the differences in health-care culture 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.\textsuperscript{14,41,43} Lack of effective communication between adult and paediatric providers is also seen as a barrier to effective transition programmes.\textsuperscript{41} 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.\textsuperscript{33,39} In addition, while adult clinics may be unwelcoming, they may foster independence and are better placed to address some of the biological age-related realities of care in young adults which
paediatric clinic could struggle with. Data on transition experiences is lacking in sub-Saharan Africa, 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 coordinator or team\(^{13}\) who are responsible for identifying adolescents in need of transition and for tracking and follow-up after transition. In sub-Saharan Africa, an effective transition programme may require re-organization of staffing to meet these additional roles. However, many health-care systems in sub-Saharan Africa are overburdened, and clinicians may not have enough time to address transition needs. Innovative models, such as group transition programmes, peer-led programmes or programmes and tools that empower caregivers to support transition, may be feasible options to explore in sub-Saharan Africa. The Zimbabwe Zvandiri programme is perhaps the most successful peer-led programme.\(^{44}\) Zvandiri is heavily invested in community 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.\(^{45}\) 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 sub-Saharan Africa 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 in sub-Saharan Africa that can support the development of interventions to improve transition outcomes.

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Competing interests:
None declared.

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Box 1. **Summary of key elements and definitions of successful transition of children and adolescents to adult HIV care**

**Transition dates**

Transition starts soon after disclosure of HIV status, preferably from age 14 years. Transition ends by age 25 years but with consideration of the individual’s developmental milestones.

**Readiness assessment**

Adolescents are assessed by health-care worker from age 17 years for:

- Transition knowledge and skill milestones; (HIV literacy; self-management; communication and support);
- optimized regimen of antiretroviral therapy (on an oral adult regimen);
- stable on treatment (no new opportunistic infections or active infections);
- holistic approach (addressing school, social and family concerns);
- willingness to transition.

**Caregiver readiness**

Caregivers are willing to allow adolescents to take responsibility for their own health.

**Communication with adult clinic**

Adult clinic staff are aware of the adolescents being transitioned to their clinic.

**Flexibility to return to adolescent services**

At age 18–25 years adolescents can receive services in adolescent clinics if they are uncomfortable in adult clinics.

**Group transition**

Group transition and support groups are available where possible.

**Special considerations**

Transition process can be slower or faster for pregnant adolescents, those with delayed or early milestones and adolescents with disability.

**Definition of successful transition**

Successful transition includes the following:

- linkage to care in adult clinic (at least one clinic visit within 3 months of their last clinic visit in an adolescent or paediatric care system);
- retention in care (three or more visits over a 12-month period);
- viral suppression (consistent viral load measurements below the level of detection for ≥ 12 months).

If clinic is integrated (adult, adolescent and paediatric) successful transition would include retention and viral suppression as above occurring after age 25 years or from the time of achievement of key transition milestones.

**HIV: human immunodeficiency virus.**

**Notes:** Our consensus definition of transition was developed as part of the Adolescent Transition To Adult HIV Care for HIV-infected adolescents in Kenya study, based on a workshop conducted on 17–18 September 2018 with 32 key stakeholders purposively selected from a broad range of HIV care leaders.
Fig. 1. **Overview of a proposed framework for successful transition of children and adolescents to adult HIV care**

- **HIV literacy**
  - Self-management
  - Communication Support

- **Knowledge & skills**
  - Readiness to transition
  - Adult ART regimen

- **Flexibility to return to adolescent care**

**Paediatric- or adolescent-centred care**

- **Age-defined transition milestones**
- **Transition readiness assessment**
- **Pre-transfer communication with adult providers**

**Caregiver readiness**

**Group transition**

**Start:** after disclosure, by age 14 years

**End:** by age 25 years

ART: antiretroviral therapy; HIV: human immunodeficiency virus.