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# What happens at adolescent and young adult HIV clinics? A national survey of models of care, transition and disclosure practices in Kenya

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# **Abstract**

**Objective**—Tailored services for adolescents and young adults (AYA) living with HIV may improve treatment outcomes. We surveyed HIV clinics throughout Kenya to determine AYA clinic practices, disclosure and transition services.

**Methods**—We deployed a mobile team to conduct surveys in a random sample of 102 public HIV clinics with> 300 total clients. Data were collected from healthcare workers offering AYA services who had >6 months of experience delivering AYA care.

**results**—Of 102 surveyed HIV clinics, almost all (101/102) had the same staff to provide services to all age groups. AYA-specific services included dedicated clinic days (91%), the majority being on weekends (57%) and designated clinic spaces (20%). Activities to support AYA retention and adherence were common (support groups [97%] and HIV literacy meetings [93%]). Fewer clinics offered more holistic care, including psychosocial support (16%) and career education (2%), posted additional staff during the AYA day (17%), provided food (17%) or had sporting activities (10%) as incentives. Tracking of disclosure of HIV status to AYA was common (87%). In 40% of clinics, disclosure discussions with caregivers or AYA occurred a median of 2 years later in practice than stated in clinic policy. Transition was not routinely tracked, and definitions were heterogeneous. Median age at transition was reported as 20 years (range: 14–30 years).

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**conclusion**—HIV programmes have implemented varied approaches to enhance AYA services that could be leveraged to support transition to adult services. Research on the impact of these services on health outcomes is needed.

#### **Keywords**

HIV; retention in care; adherence; adolescents and young adults; specific support; Kenya; cross-sectional survey

#### Keywords

Sustainable Development Goals (SDGs): SDG 3 (good health and well-being); SDG 17 (partnerships for the goals)

#### Introduction

Adolescents and young adults (AYA) living with HIV are a high-priority population due to poor health outcomes. Poor adherence and unsuppressed viral loads[1–3], high rates of mortality[4] and loss to follow-up[5,6] remain highest in AYA compared to other age groups. Loss to follow-up is particularly high among 15- to 24-year-olds [5,6], an age group that experiences healthcare transition to adult services. Supporting AYA during the vulnerable period of transition is crucial to optimising health outcomes.

Despite being a critical process, transition from paediatric to adult HIV services in sub-Saharan Africa (SSA) is poorly defined and often unstructured[7]. Data on transition services for chronic non-infectious diseases are similarly lacking in this setting, making it difficult to adapt transition practices for AYA living with HIV. In resource-rich countries, transition programmes have been developed for HIV[8] and chronic non-infectious diseases [9–12]. In these settings, structured transition programmes are associated with improved clinical outcomes [13,14]. These programmes are often multidisciplinary, are individually tailored and support AYA to gain the knowledge and skills they need in adult care systems. Toolkits to support development of transition programmes are also available[15,16]. Key elements considered in these toolkits include defining transition policies, developing systems for individual tracking and monitoring, assessing readiness to transition, planning transition and actual transfer, and monitoring outcomes post-transition[17,18].

There are few data on current transition practices in SSA[7,19]. Adolescent-friendly services are recommended [20], but clinic practices vary[7]. Practices and tools around disclosure of HIV status to adolescents, a prereq-uisite to transition, are also poorly described. Late age at disclosure, partly due to lack of healthcare worker (HCW) guidelines and tools to support disclosure, is one of the common challenges[21–23]. Tools for disclosure are available[24] but may be underutilised.

In Kenya, an estimated 7% of the 1.5 million people living with HIV are adolescents aged 10–19, and AYA contributed to almost 40% of new HIV infections in 2018 [25]. The Kenyan Ministry of Health (MoH) introduced the adolescent package of care (APOC) in 2015[26]. This package includes HCW training on AYA services and a checklist to prompt

and capture services offered. The checklist includes assessment of body mass index, Tanner staging, disclosure, adherence to medication, mental status, school attendance, participation in support groups, transition preparation, and for AYA girls, pregnancy testing, contraception and HPV vaccination. Use of the checklist may be associated with improved viral suppression and better uptake of family planning services among AYA aged 10–19[27]. While the checklist reminds health workers to prepare AYA for transition, and a job aid with a transition algorithm for guidance on age-based transition milestones is available, consensus national definitions of transition, measures of successful transition and tools to track individual progress are lacking. With the growing population of perinatally infected children ageing into adolescence and high numbers of newly infected AYA in SSA, there is a need to better understand current AYA services, models of care and disclosure and transition practices in order to build effective support strategies.

This study aimed to characterise AYA services, HIV disclosure and transition services in a sample of 102 HIV clinics providing services to AYA aged 10–24 years in Kenya.

#### Methods

### Study design and setting

We conducted a cross-sectional study as part of pre-trial clinic assessments to understand transition practices in Kenya in the Adolescent Transition to Adult Care for HIV-infected Adolescents (ATTACH) study (NCT03574129). ATTACH is a cluster-randomised controlled trial (RCT) that aims to test the effectiveness of an adolescent transition package to improve rates of disclosure, transition readiness and successful transition among AYA living with HIV in Kenya.

#### Site selection

Of 2449 HIV clinics, 590 had electronic medical records (EMRs) in 2016. Of these, 300 clinics that had >300 clients in care were selected. The 300 clinics were divided into tertiles based on the total number of clients ever enrolled, and 34 clinics were randomly selected from each tertile for a total of 102 clinics (Figure 1), allowing equal representation of clinics with different patient volumes. Inclusion of clinics with >300 clients assumed that approximately 10% of the population would be adolescents (age 10–19)[25]; therefore, it was expected that each surveyed clinic would have at least 30 adolescents enrolled in care.

#### **Ethical considerations**

The study received approval from the University of Washington (UW) Institutional Review Board (IRB) and the Kenyatta National Hospital (KNH)/University of Nairobi (UoN) Ethical Review Committee (ERC). In addition, the study received approval from the Kenya Ministry of Health National AIDS and STI Control Program (NASCOP), county departments of health in counties of participating clinics, and clinic managers. All surveyed participants provided written informed consent.

# Data collection and analysis

Data collection began in December 2017 and was completed in January 2019. Survey respondents were HCWs aged >18 years currently working with AYA in the HIV clinic, who had worked in the clinic for >6 months. Surveys were conducted in-person or by phone, and questions focused on identifying AYA services, models of care, disclosure services and transition services. Respondents completed a paper-based version of the questionnaire prior to the interview, and reviewed responses with study staff during the interview. Data were then entered into a REDCap[28] database. We used descriptive statistics to describe clinic characteristics, models of care and disclosure and transition services, and chi-square tests and t-tests to compare clinic practices. All data analysis was done using Stata version 14.

# **Results**

The 102 selected clinics were from 27 of the 47 counties in Kenya. The majority of staff interviewed were clinical officers (58%) or nurses (25%). The median duration of time they had worked in AYA HIV care and in their current clinic was 2.7 (interquartile range [IQR]: 1.4, 4.0) and 2 years (IQR: 1.3, 3.4), respectively.

# Clinic demographics: clinic volume and staffing

The majority of clinics (n = 51) were in health centres or dispensaries, 12 were in county hospitals, 37 were in subcounty hospitals and 1 each was in mission and foundation hospitals. Clinics served a median of 51 (IQR: 34, 115) AYA (Table 1). The total number of staff in the HIV clinics was 1745, with a median of 15 staff (IQR: 10, 21).

Patient volume differed by clinic type, with HIV clinics in county and mission/foundation hospitals serving the largest number of AYA (260 [IQR: 120, 365] and 290 [IQR: 182, 398], respectively), whereas subcounty hospitals and health centres/dispensaries served over 4 times fewer AYA (59 [IQR: 38, 115] and 44 [IQR: 28, 68], respectively) (Table 1). Overall, AYA comprised 12% of the total clinic population. The proportion of AYA was slightly lower, but not significantly different, in larger clinics (county/ mission/ foundation hospitals) than smaller clinics (13% vs. 12%, P < 0.001). Clinics in county hospitals had significantly lower AYA-to-staff ratios than clinics in health centres, dispensaries or subcounty hospitals (4:1 vs. 11:1, P < 0.001), as did clinics in mission/foundation hospitals (7:1 vs. 11:1, P < 0.001).

#### **AYA** services

It was rare to have staff who specialised solely on AYA-specific care. Only 7 clinics had specific staff who were designated to work in the AYA clinic; however, these same staff also provided care for adults in six of the seven clinics. Clinic staff distribution was weighted more towards general medical care and general counselling, with few psychosocial specialists and few high-cadre medical specialists. Almost all clinics (98%) had a clinical officer (equivalent to physician assistants in the USA). The majority had counsellors (85%), nurses or nurse counsellors (80%), peer educators (89%) and laboratory technicians (74%). Almost two-thirds had community health workers (65%) or nutritionists (62%), and more

than a third had social workers (38%). Only 10% of clinics had psychologists or psychiatrists, and only 8% had medical doctors (Table 1).

While AYA-specific staffing was uncommon, designating specific times and spaces to AYA-specific care was relatively common. Almost all clinics (91%) had a separate day or days dedicated to provision of AYA services. In 57% of those clinics, the AYA day was on a weekend (Saturday/ Sunday). Only 20% had a separate space in the clinic where AYA services were provided. AYA services were provided all day in the majority of clinics (74%), and did not differ by whether clinics had AYA-specific days (72% in those with AYA-specific days and 89% in those without, P = 0.27). Clinics in smaller hospitals tended to be less likely to have weekend clinic days (36% vs. 55%, P = 0.19) and separate spaces (20% vs. 7%, P = 0.235) than larger clinics, but these differences were not significant.

During AYA-specific days, it was common for AYA to have access to supportive services aimed primarily at treatment adherence. A majority of clinics with an AYA-specific day also held support groups or teen clubs (97%) and treatment literacy meetings (93%) on the dedicated AYA clinic day, and 15% preferentially posted staff with AYA training to the clinic on AYA days. Most facilities (n = 92) had other activities/support including snacks/lunch (13%), games (10%), psychosocial support (16%) or career education (2%). Seventeen per cent of clinics with selected AYA day(s) had extra staff to support additional services, the majority being peer educators or adolescent champions (71%). Other staff who specially attended the AYA-specific days included programme officers, counsellors, psychologists, religious leaders or children officers.

Scheduling AYA visits was generally tailored towards supporting AYA to receive AYA-specific services and to meet their clinical needs. Clinical officers who largely provided medical care were also responsible for scheduling AYA visits in 83% of clinics. Medication adherence (91%) and poor clinical condition (49%) were commonly considered when deciding clinic visit frequency. AYA faring poorly were given shorter intervals between visits. Visit scheduling also took into account the availability of the AYA (81%), availability of the caregiver (23%) or whether the clinic was overbooked (12%). Almost all (94%) clinics with an AYA clinic day informed AYA during their current visit that they were scheduled to attend clinic on the AYA day.

In recognition of the unique AYA needs and risk of poor outcomes, the majority of clinics defined adolescents largely by WHO guidelines (age 10 [78%] to age 19 [72%]), 69% of clinics had started using the Kenyan MoH adolescent package of services including the adolescent checklist (62%), and had developed systems to uniquely identify AYA records (74%).

#### Disclosure and transition services

Most clinics (89%) had age-based policies for guiding when healthcare providers should begin disclosure discussions with caregivers and children. However, there was a gap between policy and practice regarding the age of disclosure initiation discussions. Almost half (44%) of the 91 clinics that specified age to begin disclosure discussions reported that discussions with caregivers began in practice at a median of 2 years (IQR: 2, 4) later than the clinic

policy-recommended ages. Similarly, gaps existed with age to begin disclosure discussions with children, with disclosure occurring at a median of 2 years later in practice versus what was stated in clinic disclosure policy (IQR: 2, 4) reported in 45 clinics (Figure 2). The median typical age at full disclosure was reported by HCW to occur at 12 years (IQR: 10, 15) (Figure 3).

Age was an important component of defining when transition began and was completed. Almost all clinics had policies that specified age at which transition discussions should begin (93%) and end (94%), despite heterogeneous transition definitions. By policy, median age at the start of discussions was 18 years (IQR: 15–19) and completion of transition was at 20 years (IQR: 19–24). Transition occurred at a median age of 21 (IQR: 19–24), with ages 20 and 24 most frequently reported by facilities (Figure 3). In the majority (78%) of clinics, transition was defined by an AYA, demonstrating independence in their own care. Other definitions included the following: reaching a certain age (58%), independently collecting antiretroviral medication (49%), completing an adult clinic visit (27%), completing a formal transition process (25%), becoming pregnant (5%) and switching to adult ART regimens (1%).

Where policies were available, national guidelines were most commonly used, with disclosure guidelines more commonly used than transition guidelines (97% and 69%, respectively) (Table 2). The MoH adolescent checklist was commonly used to track disclosure (67%) and transition (41%). While clinics using the checklist (n = 67) reported to achieve full disclosure slightly earlier (median 12 years [IQR: 10–15]) compared to those not using (n = 34; median 12.5 years [IQR: 12–15]), the difference was not significant (t-test, P = 0.15). A few clinics used additional tools such as disclosure and transition readiness assessment checklists (42% and 19%, respectively) (Table 2). Many staff cadres were involved in initiating disclosure and transition discussions. Disclosure discussions were typically initiated by clinical officers (77%), counsellors (63%), nurses (52%), caregivers (58%) and peer educators (50%), while transition discussions were typically initiated by clinical officers (88%), nurses (60%), counsellors (58%) and peer educators (51%). Only 52% of clinic documented the transfer to adult services, and 66% tracked AYA post-transfer to adult clinics.

# **Discussion**

In this national survey of 102 clinics in Kenya, we found that HIV clinics had adopted models of care to address unique AYA needs. Despite largely utilising the same clinic staff and space for all HIV-positive clients, specific AYA-focused activities, including AYA clinic days, flexible scheduling and weekend clinic days, were common. While national guidelines offered guidance for disclosure and transition, there were delays in offering disclosure services and transition guidelines were less commonly used. Clinics had methods of defining transition, relying mostly on age, though the definitions were heterogeneous. Individualised transition tracking, readiness assessment, planning and monitoring outcomes were uncommon, and use of disclosure and transition tools beyond those in the national guidelines was rare.

Clinic organisation and staffing was as expected[29]; in Kenya, enrolled nurses provide care in dispensaries, 1–3 clinical officers and one medical officer provide care in health centres, while higher level facilities have more medical officers and specialists. We found that clinics in county hospitals had lower staff–AYA ratios, potentially influencing AYA contact time. Future studies to understand differences in outcomes by staff contact time or facility type may be warranted.

Our findings on the models of AYA care reflect those of other settings in SSA, where AYA clinic days are common, with the same staff caring for all age groups [7,19]. In a survey of Nigerian HIV clinics in 2016, only 28% of clinics had an AYA clinic day, which is substantially lower than in Kenya and could be explained by growing interest and focus for AYA-friendly services in Kenya[26]. While AYA clinic days help to focus AYA services, there is evidence of poor utilisation of particularly non-clinical services with only a third of Ugandan AYA regularly utilising the clinics and services offered [30]. This could be a result of conflicting school or work schedules. Indeed, a majority of surveyed clinics reported AYA availability as the most important consideration during scheduling. Understanding barriers to attending AYA clinic days and outcomes of AYA who do not utilise them may be important in developing approaches that meet the needs of all AYA. We found that clinical officers who primarily provided medical care also provided disclosure and transition services in almost all clinics. The median number of clinical officers was 1 per clinic; therefore, task shifting for disclosure and transition services may be beneficial. We noted very few mental health experts – only 10% of clinics had access to a psychologist or psychiatrist despite well-described mental health challenges among AYA[31].

Late age at disclosure is common in SSA[22]. We found that the majority of clinics typically reached full disclosure by age 10–15, which is later than the national target of full disclosure by age 9–12[32]. Inclusion of disclosure guidelines in national HIV guidelines and expanding the use of the APOC may improve age at disclosure[1,32]. While many clinics had disclosure policies, we found a lag in actual practice, with full disclosure typically occurring much later than recommended by clinic policies and national guidelines[32]. Caregiver support for disclosure or task shifting in addition to child-friendly tools to support disclosure may promote planned, early disclosure. Standard toolkits proven to improve outcomes[24] may provide a more comprehensive approach to disclosure.

As in many SSA settings, transition definitions were heterogeneous[19]. There was little time between the typical age at initiation of transition discussion and age at transition, and this may contribute to AYA discomfort in adult services[33]. The goal of transition is to support AYA to gain life skills and knowledge to independently manage their care[34], which could be viewed as a process. Implementing transition services at an earlier age and within existing support services outside clinic services, such as during support groups or treatment education meetings, strategies already implemented in majority of clinics, may be a feasible approach. Task-shifting transition roles may be useful if clinic volumes are high or depending on staffing configurations.

While the Kenya MoH APOC[35] checklist provides a cue to remind healthcare workers to initiate discussions on transition, only one question, 'Has transition preparation discussion

began (yes/no)', is dedicated to transition and one to disclosure, 'Disclosure done (partial/full)'. These questions do not provide tracking of components within the process of transition and disclosure. Clinics did not differentiate perinatally and non-perinatally infected AYA (PHIV), who may require different approaches to care. The WHO and chronic non-infectious literature define transition as 'gaining knowledge and skills to independently manage care' [9,34], which would be difficult to assess with this tool. However, the APOC tool is an excellent start, as it provides a foundation that can be expanded to capture additional transition process milestones. The APOC tool is already widely used in AYA clinics, and its use has been associated with improved viral suppression [36]. Data used in this analysis were self-reported and may be prone to recall and social desirability bias.

Our study is timely with data collected up to January 2019. However, AYA clinic practices are dynamic and are likely to continue to evolve in the coming years. We sampled clinics based on clinic volume and use of electronic medical records. These clinics may more likely be better-resourced and may not generalise to the whole country. However, our results may provide important current evidence of AYA models of care, and disclosure and transition practices in clinics in programme settings in Kenya.

In conclusion, HIV care programmes in SSA have implemented a variety of innovative approaches to address unique AYA needs. However, there is limited evidence regarding the impact of these diverse models. It will be important to understand ideal models of AYA care that result in improved outcomes and the impact of these models on post-transition outcomes. Although there is a lack of standard transition definitions and inadequate information on tracking tools, making it challenging to evaluate transition, there is promising progress in implementing tools to capture disclosure and transition practices. Research to close the policy–practice gap for disclosure, and develop consistent transition definitions, tracking and monitoring systems is urgently needed.

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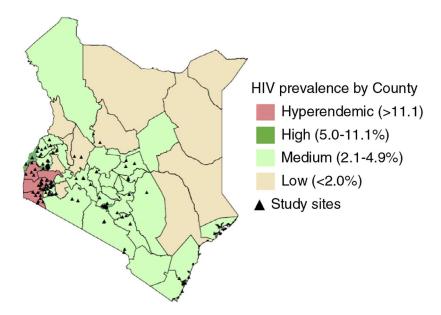
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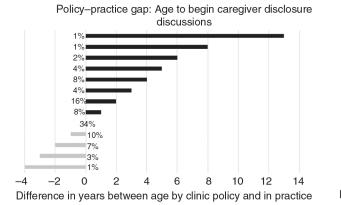
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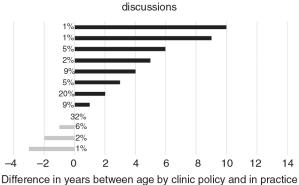
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**Figure 1.**Distribution of study sites and county HIV prevalence. [Colour figure can be viewed at wileyonlinelibrary.com]

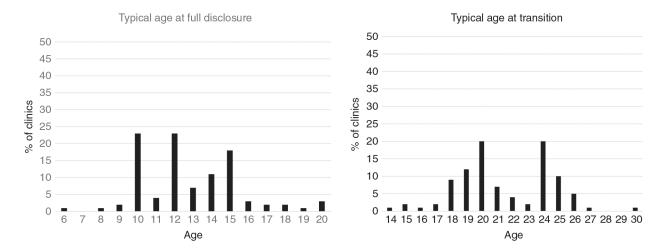




Policy-practice gap: Age to begin child disclosure

% represent proportion of clinics 0 = no difference in policy and practice age

**Figure 2.** Practice—policy gap in age to begin caregiver and child disclosure discussions.



**Figure 3.** Typical age at full disclosure and transition (healthcare worker reported).

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Table 1

Clinic characteristics and AYA services available

Clinic characteristics (N = 102)	n (%)/Median (IQR
Facility characteristics	
Facility type	
County	12 (12)
Subcounty	37 (36)
Health centre/dispensary	51 (50)
Mission/foundation	2 (2)
AYA in active follow-up ( $N = 90$ )	51 (34, 115)
County	260 (120, 365)
Subcounty	59 (38, 115)
Health centre/dispensary	44 (28, 68)
Mission/foundation	290 (182, 398)
Staffing	
Number of staff at HIV clinic	15 (10, 21)
County	19 (16, 23)
Subcounty	15 (11, 20)
Health centre/dispensary	12 (9, 19)
Mission/foundation	40 (24, 55)
Has specific staff for AYA clinic	7 (7)
Has staff who see only children or AYA	1 (1)
Staff type for HIV clinic	
Clinical officers	100 (98)
Counsellors	87 (85)
Nurses/nurse counsellors	82 (80)
Peer educator	91 (89)
Laboratory technician	75 (74)
Nutritionists	63 (62)
Social workers	39 (38)
Community health workers	66 (65)
Psychologists/psychiatrists	10 (10)
Medical officers	8 (8)
Clinic model of care	
AYA day*	93 (91)
Weekend AYA day	53 (57)
In separate AYA clinic	19 (20)
Integrated clinic	9 (9)
Definition of adolescent	.,
Lower limit, 10 years of age	79 (77)
Upper limit, 19 years of age	73 (72)
AYA records	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \

Clinic characteristics (N = 102)	n (%)/Median (IQR)
Has method to identify records	75 (74)

 $<sup>^*</sup>$ Specific day of the week the clinics select that is dedicated to adolescents and young adults.

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Table 2

Disclosure and transition services

Disclosure and transition services $N = 102$	n (%)/Median (IQR)
Disclosure	
Has disclosure guidelines	99 (97)
National guidelines	98 (99)
Has disclosure tools	87 (85)
MoH adolescent checklist	68 (78)
Tracks individual disclosure start	93 (91)
Tracks individual disclosure status	89 (87)
Transition	
Clinic definition of transition	
Shows independence in their own care	80 (78)
Specific age	59 (58)
Picks medication on their own	50 (49)
Has attended adult clinic	28 (27)
Completion of a formal transition ceremony	25 (25)
Becomes pregnant	5(5)
Switch from paediatric to adult ART	1 (1)
regimen	
Has transition guidelines	70 (69)
National guidelines	67 (97)
Has transition tools	50 (49)
MoH adolescent checklist	42 (84)
Readiness assessment tools	19 (38)
Tracking tool	7(14)
Transition booklet	3(6)
Other transition tools	6(12)
Tracks transition completion	61 (60)
Documents transfer to adult services	53 (52)
Tracks AYA post-transfer	67 (66)