

Policy-makers' perspectives on optimizing HIV-infected adolescents' transition from pediatric to
adult care in Kenya

Katherine Shulock

A thesis

submitted in partial fulfillment of the

requirements for the degree of:

Master of Public Health

University of Washington

2020

Committee:

Gabrielle O'Malley

Kristin Beima-Sofie

Program Authorized to Offer Degree:

School of Public Health, Global Health

©Copyright 2020

Katherine Shulock

University of Washington

Abstract

Policy-makers' perspectives on optimizing HIV-infected adolescents' transition from pediatric to adult care in Kenya

Katherine Shulock

Chair of the Supervisory Committee:

Gabrielle O'Malley of Global Health

Abstract

Background: The transition from pediatric to adult care has emerged as a potential contributor to poor clinical outcomes and challenges to retention in care among adolescents living with HIV (ALHIV). While structured processes and tools that bridge the gap between pediatric and adult care can help ensure HIV-infected adolescents and young adults are retained in care and supported through this developmental transition, additional context-specific data are needed to improve the

transition process. This study elicited perspectives of policy-makers regarding barriers and facilitators to successful transition outcomes among ALHIV in Kenya.

Methods: We conducted 20 individual in-depth interviews (IDIs) with a diverse group of policy-makers in Kenya. IDIs were conducted using a semi-structured guide, designed to elicit policy-maker perspectives on current policies, tools and practices for transitioning adolescents from pediatric to adult care. IDIs were conducted in English, audio-recorded and transcribed verbatim. Transcripts were coded using ATLAS.ti, and the socio-ecological model was used to characterize themes related to multilevel optimization of the transition process for ALHIV.

Results: Policy-makers identified multilevel and interrelated factors impacting HIV-infected adolescents' transition from pediatric to adult care. At the interpersonal level, the influence of adolescents' primary caregivers was paramount and contributed to adherence and retention in care throughout the transition trajectory. At the institutional level, key themes related to successful transition included the need for gradual, structured, and inclusive preparation of adolescents, and the pivotal role of healthcare workers (HCWs) in the development of a comprehensive care relationship between HCWs, caregivers and adolescents. Key themes at the structural level were the need for expanded transition guidelines and improved HCW training.

Conclusions: There is an urgent need for expanded transition tools and guidelines focused on strategies to improve caregiver involvement, engage adolescents in illness management, and provide commensurate support and guidance for HCWs. As relatively little research on adolescents' transition from pediatric to adult care has been conducted in SSA, additional context-specific studies are needed to fill this gap and inform regional policy development.

Key Words: Adolescent, transition in care, HIV, Kenya, qualitative research

Introduction

An estimated 1.6 million adolescents live with HIV globally.¹ While many adolescents living with HIV (ALHIV) were perinatally infected, there were 190,000 new infections among adolescents in 2018. The majority of ALHIV (82%) live in sub-Saharan Africa (SSA).¹ Adolescence is recognized as a period of transition from childhood to adulthood² that encompasses a variety of complex physical, neurodevelopmental, psychological, and social changes. Despite effective HIV treatment regimens and improved access to antiretroviral therapy (ART), many ALHIV default from care and treatment during late adolescence.³⁻⁷ Unique stressors, such as understanding and accepting an HIV-positive status, dealing with HIV-related stigma and discrimination, the initiation of sexual relationships and disclosure to others, and taking on increased responsibility for their treatment and care compound this period's normal instability.⁸⁻¹¹

The transition from pediatric to adult care, which generally occurs in late adolescence, has emerged as a potential contributor to poor clinical outcomes and challenges in retention in care during this period.^{3,5} In many settings, adolescents receiving HIV care and treatment services from structured, supportive pediatric care environments transition to more autonomous adult care models, where greater independence and responsibility are required.^{12,13} Research from North America and Europe has shown that not all youth transition successfully into adult care,¹⁴⁻¹⁹ and that many adolescents, particularly in SSA, face challenges with retention in care and experience poor clinical outcomes during this period.^{3-7,20-26}

While evidence is limited, lack of evidence-based tools and guidelines to support healthcare providers, caregivers and adolescents during the transition period may contribute to an increased risk for HIV-related morbidity and mortality in this population.^{12,19,21,27} Poor outcomes in retention in care among HIV-infected adolescents during the transition period has prompted researchers,

healthcare providers and policy-makers to call attention to the need to develop and implement improved adolescent HIV transition tools and practices, particularly in high-HIV prevalence areas.^{6,12,27} Specifically, the Collaborative Initiative for Pediatric HIV Education and Research (CIPHER) of the International AIDS Society and others have outlined the need to (1) understand current transitional care models, (2) assess areas of improvement; and (3) develop and adapt tools and guidelines to better facilitate effective transition to adult care for ALHIV in SSA.^{12,21,27,28}

Although Kenya's guidelines for ALHIV clinical care provide some guidance on preparing and transitioning adolescents to adult care, standardized definitions, measures of successful transition, and reporting tools are lacking.²⁸ Understanding policy-maker experiences and perspectives on current transition practices in Kenya, barriers and facilitators to effective transition, and recommendations for the development of transition tools and processes may contribute to improved transition outcomes among adolescents in Kenya.

Modern socio-ecological theory posits that individuals are inextricably embedded within complex social ecosystems.^{29,30} Applications of the socio-ecological model to a wide range of public health concerns has shown that health outcomes are influenced not only by individual behaviors but also by multilevel and interacting factors across interpersonal, institutional and structural levels.^{30,31} At the interpersonal level, the socio-ecological model shows how an individual's personal relationships, such as those with family and peers, may impact an individual's health behavior and outcomes, while organizations such as healthcare facilities and schools are shown to shape health promotion at the institutional level. The structural level examines how factors such as governing bodies, laws and policies affect community or population health.³⁰ To provide a comprehensive analysis of HIV-infected adolescents' transition from pediatric to adult care, our study employed

the socio-ecological as an organizing framework to identify and assess primary factors at the interpersonal, institutional and structural levels.

Methods

Study Design and Population

We conducted individual in-depth interviews (IDIs) with 20 policy-makers in Kenya as part of the Adolescent Transition To Adult Care for HIV-infected Adolescents in Kenya (ATTACH, NCT03574129) study. The ATTACH study is a randomized control trial (RCT) that aims to improve adolescent transition from pediatric HIV care to autonomous adult HIV care in Kenya.³² The ATTACH study collected qualitative data from key stakeholders (adolescents, adolescents' parents, healthcare providers and policy-makers) in Kenya to develop a healthcare worker intervention to facilitate transition. This qualitative analysis describes policy-maker perspectives on improving the transition process in Kenya.

Data Collection

Participants were purposively selected to represent a broad range of policy-makers involved in the development or implementation of adolescent HIV care and treatment policies and/or services in Kenya. Participants included national and county HIV program heads, chief medical officers and hospital administrators, and HIV program implementing partner leads. IDIs used a semi-structured interview guide with open-ended questions to explore participant perspectives and experiences related to the transition from pediatric or family centered care to adult or independent care. Interview guides were pilot tested prior to use to ensure optimal phrasing and timing of questions. All policy-makers were fluent in English, and all interviews were conducted in English. Interviews were conducted by two trained social scientists.

IDIs were recorded using a digital recorder and transcribed verbatim following each interview. When applicable, phrases in the native language were translated to English in brackets. Transcripts were transcribed by the interviewer in real time within about one week of completing the interview. IDIs lasted an average of 45 minutes. Following each interview, interviewers summarized the interview in a structured debrief report, which provided a subjective impression of the interviewer's experience during the interview and briefly captured the participants' accounts related to key themes.³³

Data Analysis

To effectively characterize and map the network of themes regarding the main topics of discussion, thematic network analysis and descriptive content analysis techniques were used to analyze the data.^{34,35} Analysis employed a combination of deductive and inductive strategies, with an emphasis on inductive methods. Deductive codes were identified from literature review on adolescent transition and the content from the interview guide. Inductive codes were derived directly from the data using open coding. The structure of the codebook was grounded in the socio-ecological model, which provided a platform for simultaneous assessment of multilevel and interrelated factors (Figure 1).^{30,31}

All transcripts were coded by 2 coders (KS, HA) using a final version of the codebook and ATLAS.ti v.8 software (Scientific Software Development GmbH, Berlin, Germany). Definitions for each code category, subcategory, and code were developed to ensure consistent code application. Following codebook development, multiple rounds of consensus coding was conducted to ensure consistent interpretation and application of codes between coders. All transcripts were divided and independently coded. Coded transcripts were then reviewed by a

second coder and disagreements in code application were noted, which were resolved through study team discussions. Upon completion of the coding process, queries were generated to compare coded segments of transcripts and identify divergent and convergent themes. Themes were oriented around the socio-ecological model to characterize policy-maker perspectives on multilevel barriers and facilitators to successful transition of ALHIV from pediatric to adult care and identify novel ideas for the development of new transition tools and guidelines.

Ethical Considerations

This study was reviewed and approved by the University of Washington Institutional Review Board and the Kenyatta National Hospital/University of Nairobi Ethical Review Committee. All participants provided written informed consent prior to participation in IDIs.

Results

Of the 20 policy-makers who participated in this study, fifty-three percent were female (Table 1). The median policy-making experience among participants was 8 years. Participants' primary level of influence varied, with half of all participants operating at the national level, one at the international level, three at the regional level, four at the county level, and one at the community level. Ninety-five percent of participants reported having assisted in the development of HIV treatment and care guidelines or trainings for any population, and seventy-nine percent reported having assisted in the development of HIV treatment and care guidelines or trainings for adolescents and/or youth.

Policy-makers identified barriers and facilitators to adolescents' transition readiness and successful transition at all levels of the socio-ecological model (Figure 1). Five main themes

emerged from our analysis: 1) Caregiver relationships are strong drivers of successful transition, 2) Comprehensive facility-level support, focused on gradual preparation for transition, is crucial, 3) HCWs play a pivotal role in coordinating facility-based support structures necessary for successful adolescent transition, 4) Facility-level engagement of adolescents in their own care is needed for effective transition preparation, and 5) Expanded guidelines and strengthened HCW training will improve transition outcomes.

Caregiver relationships are strong drivers of successful transition.

At the interpersonal level, policy-makers identified the relationship between an adolescent and their primary caregiver as the most powerful relationship shaping adolescents' transition readiness and success.

“[Caregivers] are very, very important and they need to be involved [in transition] because they will be their buddies to do the reminders in terms of taking drugs, the right dosage and the right time, so if they are left behind then we are unlikely to succeed.”

(Participant 5)

Policy-makers noted that although the adolescent developmental stage was often marked by strong desires to establish their independence, adolescents continued to want ongoing caregiver support.

“Adolescents want their independence, yes, but they don't want their parents left out. They really feel that the presence of the parent and the guidance they receive from parents is very important in their health.” (Participant 10)

Policy-makers saw caregivers as providing both positive and negative influence. While supportive caregivers played an invaluable role in effectively preparing adolescents for transition, uninvolved or

stigmatizing caregivers, or caregivers defaulting from treatment themselves, were thought to greatly detract adolescents from care and reduce chances for successful transition.

“But remember again most of our adolescents are with a care giver and most of them will be with a parent. [...] So some of them just default because they don’t have that support from the care giver. If you have a care giver who is a defaulter already and lost to follow up, chances also they will be a lost to follow up.” (Participant 4)

Comprehensive facility-level support, focused on gradual preparation for transition, is crucial.

Policy-makers believed that key to effective preparation of adolescents, was the recognition of transition as a gradual process that occurs over time with structured and staged progression.

“Transition is not an event, like pap! You have transitioned! It’s more like you are weaning a child. Adolescents are going to move from point A to B, and we need to prepare them slowly.” (Participant 1)

Policy-makers believed that the transition process should start early and unfold in response to adolescents’ evolving developmental needs and challenges.

“[T]ransition should begin early, so that when adolescents transition it’s a gradual process, such that they will know that by a certain age I should be moving out of care to access my care in the adult clinic. So this calls for disclosure at the right time, treatment literacy at the right time and life skills empowerment so that they are able to embrace self-care and independence, which are prerequisites for adult care.” (Participant 16)

Policy-makers believed that adolescents’ unique developmental stage required robust, responsive and multilevel support systems galvanized at the facility level. The supportive relationship

between healthcare workers (HCW) and adolescents, including HCW sensitization to adolescent care, was believed to directly impact retention in care, transition readiness and successful transition outcomes.

“Forget about drugs, you know drugs can always be dispensed. The biggest determinant to care is a provider. So if providers are well trained, well sensitized to deal with a young person whether they are seeing them in the adolescent or the adult clinic, I think is always the biggest issue. [...] The providers’ skills, knowledge, how they interact with the young person who is transitioning and actually understanding that this person has their own fears around transitioning.” (Participant 2)

HCWs play a pivotal role in coordinating facility-based support structures necessary for successful adolescent transition.

Policy-makers emphasized the importance of formally engaging caregivers with facility-based transition processes. Many policy-makers noted that HCW’s recalibration of caregivers’ supportive role through the transition process was often needed to effectively support adolescents’ shift towards autonomous care.

“It’s important to have a support system at home. But also remember that adolescents are trying to develop autonomy. So it has to be a balance. So that means even bringing in caregivers, you have to have their session, you have to talk to them about communication with the adolescents, not ordering them around but having just a way to communicate with them so that they understand you from the home front.” (Participant 20)

The development of a triadic care relationship between the HCW, the adolescent, and the caregiver emerged as a key strategy for HCWs to both engage adolescents and to help shape caregiver support to encourage self-efficacy and self-management among transitioning adolescents.

“There are also innovative approaches [where] you align the expectations of the guardian and the adolescent. So you bring them together and actually by having a health care worker there then the triangulation of the expectations makes it much better and easier.”

(Participant 7)

Despite recognized importance of this relationship, policy-makers’ noted that the development of effective triadic relationships was a challenging task for HCWs. Obtaining adolescents’ permission to involve their caregiver was posited as a strategy for HCWs to navigate the complexities of managing an effective triadic care relationship:

“It needs a lot of wisdom. As the health care provider, first discuss everything with the adolescent. They need that privacy. Then, involve the [caregivers], for sure, but with the consent and agreement of the adolescent. Otherwise you’ll lose them completely.”

(Participant 6)

Facility-level engagement of adolescents in their own care is needed for effective transition preparation.

Policy-makers also believed that facilities’ ability to involve adolescents in their own care decisions was a key component to effective preparation of transitioning adolescents, encouraging autonomy, ownership and allowing for customization of the transition process.

“It is very important to actually engage them in their care and part of the transitioning you actually have to empower these adolescent to the point that the adolescent will put

their drugs on the table and they won't feel like it's a problem. [...] You should empower them to the point they can take the drugs themselves.” (Participant 4)

Active involvement of adolescents in care decisions accommodated their growing need for independence and capitalized on their developing capacity for self-management. It was also seen as a strategy to activate resilience and develop self-efficacy.

“Adolescents are very educable; they strive for autonomy and independence. So using that, we have made adolescents in-charge of their health...It's about ‘I am in-charge, if I don't take my medication my virus will shoot to the roof but if I take my medicine, I will crush it. And ultimately I become this hero who is in charge’. And being the people we know want to be cool, adolescents will strive at that.” (Participant 8)

Involving adolescents in their own care decisions was not only a strategy to build ownership, but also foundational to retaining them in care:

“When [adolescents] are not listened to, when they are not given space to make their own decisions, even when they know they are maturing [and] growing up, they will walk out.” (Participant 17)

Expanded guidelines and strengthened HCW training will improve transition outcomes.

At the structural level, many policy-makers felt that existing policy for transitioning adolescents was too narrowly focused on the HCW perspective and lacked clarity on comprehensively addressing adolescents' complex and shifting needs through the transition process.

“At policy level [...] we have mainly focused on providing tools, guidelines for health care providers and we have largely forgotten the adolescent as a stakeholder in their health

care. We have also left behind the caregiver, in a way we can reach them and make them part of the adolescent health program.” (Participant 9)

Policy-makers felt that transition policies should expand to directly address adolescents and their primary caregivers. Policies which structured transition as progressive and staged was posited to aid facilities in adequate preparation and assessment of transitioning adolescents.

“Given that transition is not a one-time event, it’s just putting the right processes in the guidelines and saying what is to be done at what stage; what happens to the 10-15, 15-17 and 17-19? Right now we can have a 14 or 12 year old who is undergoing disclosure. So it’s too varied and broad.” (Participant 8)

Policy-makers also noted the need for improved training for HCWs to appreciate the complexity of caring for HIV-infected adolescents through the transition trajectory. Policy-makers suggested innovative strategies to expand skills-building training for HCWs. When asked how to accomplish comprehensive training at the national level, one policy-maker responded:

“I would think of incorporating adolescent health into nursing and medical school curriculum [because] a one and a half day training doesn’t make you an adolescent specialist. We need to bring this early, build it, and access it more, that way [HCWs] will build real skills in working with adolescents” (Participant 8)

In addition to involving adolescents in their own care the facility level, policy-makers believed that active engagement of adolescents at the policy level was essential to the development of effective transition programming.

“90% of people sitting down to make these policies are policy-makers. There is

something I always say: nothing for us without us. You cannot plan for Uganda when you are a Kenyan. So we need adolescents to be involved at least 70% [to] help Kenya have a policy that will speak to these young people.” (Participant 15)

Discussion

HIV-infected adolescents exist in a complex and dynamic environment where their ability to successfully transition from pediatric to adult care is shaped by interrelated factors across interpersonal, institutional, and structural domains.^{8,21,36,37} Given policy-makers’ comprehensive perspective, the study’s use of the socio-ecological model provides a useful framework for identifying the ecologically layered circumstances impacting adolescent transition at the institutional and policy levels.³ In other studies, the socio-ecological model has been effectively employed to explore HIV-infected adolescents’ experiences, including factors impacting adherence and retention in care^{38–40} as well as barriers and facilitators involved in adolescents’ transition from pediatric to adult care.⁴¹

The current study confirms the significance of transition for HIV-infected adolescents and extends understanding of the importance of comprehensive, responsive, and targeted facility-level transition programming.^{36,42,43} Policy-makers indicated that effective preparation of adolescents for transition to adult care should be gradual and unfold in alignment with developmental needs. Additionally, facilities should enable supportive HCW and caregiver relationships which respond to and capitalize on adolescents’ increasing capabilities. Across diverse contexts, these results reflect other studies’ findings in that transition from pediatric to adult care should be facilitated at the facility-level in a structured, gradual and supportive manner.^{27,36,39,42–46}

Previous studies have shown that HCWs' ability to communicate effectively with the adolescent population, defined by the World Health Organization as adolescent-friendly care,⁴⁷ is an important variable for effective management of adolescents with chronic disease,⁴⁸⁻⁵⁰ including HIV-infected adolescents^{21,39,46,51-54} and transitioning ALHIV in particular.^{36,39,43} For example, Ankrah et al. found that HCW's adolescent-friendly interpersonal skills was the most important facilitator to retention in care among 16-19 year-old HIV-infected study participants in Ghana.⁵¹ Conversely, in an assessment across ten SSA countries, HCW's lack of adolescent-friendly communication skills emerged as a major barrier to retaining ALHIV in care throughout the transition trajectory.⁴⁶ Our study highlights that policy-makers in Kenya also viewed HCW's skilled communication with transitioning adolescents as both essential to ensuring retention in care and a prerequisite to effectively engaging adolescents and caregivers at the facility level.

The triangulation of care between HCWs, caregivers and adolescents provides an important platform for facility-level coordination of adolescents' multilevel protective factors.^{40,43,55,56} Policy-makers in our study and others have identified that by working together, HCWs and caregivers can build self-management skills, activate self-efficacy, and gradually shift responsibility for treatment and care to the adolescent in a supportive environment.^{36,43,57} Although this triadic relationship has been identified as effective for supporting HIV-infected adolescents at all stages,^{36,39} its application to adolescent preparation for transition to adult care may be uniquely essential.⁴³ Interestingly, the socio-ecological theory's earliest author claimed that successful life transitions were best optimized through synergistic triadic relationships.²⁹

The importance of engaging patient populations in their care and as contributors to health policy has long been recognized by the global health community.⁵⁸⁻⁶¹ Emerging understanding of adolescents' unique developmental needs and capacities has likewise prompted widespread

promotion of adolescent participation in the development of adolescent health policy and in individual care decisions.^{62–68} For adolescents managing chronic disease, significant and increasing involvement in care decisions may be especially crucial as they age.⁵⁷ Results from our study and others show that gradual engagement of ALHIV in their care is central to retaining adolescents and building the self-management skills needed for successful transition to autonomous adult care.^{39,46,69–71} As pre-transition retention in care may be the primary predictor of post-transition retention among adolescents in SSA,²² attention to how participatory care models can improve retention outcomes throughout the transition trajectory is needed.⁶⁸

Achieving sustained engagement of patients at the policy level is not straightforward. As noted by Martini et al., political, economic, and cognitive factors significantly impeded the meaningful involvement of people living with HIV (PLHIV) in policy development in Mali.⁷² For ALHIV, who may lack the resources and skills necessary for active engagement beyond their local context, this may be especially true.^{36,68} In the same way that economic assistance has mitigated financial barriers and improved adherence and retention in care among ALHIV in South Africa,⁷³ and leadership development training has ensured adolescents' effective contribution to shaping regional policy in Tanzania,⁷⁴ targeted financing and skills-based measures for effectual engagement of adolescents at the policy level in Kenya may need to be considered.^{36,68} Moreover, identification of viable structural-level opportunities will be required to operationalize effective participation.^{36,64,65,69,72}

While our study used policy-makers' perspectives to explore transition among ALHIV in Kenya, our findings are consistent with studies engaging the perspectives of adolescents, caregivers, and healthcare providers.^{39,40,46} However, transition practices vary considerably across global and regional contexts.^{27,75} As relatively little research on adolescents' transition from pediatric to adult

care has been conducted in SSA,^{21,27} additional context-specific studies are needed to fill this gap and inform regional policy development.²⁷

Limitations

Due to the nature of qualitative research methods, a limited amount of IDIs were conducted, restricting the generalizability of the data collected. Although findings may not be generalizable to a broad audience, we believe this study contributes to knowledge about transition and provides insight into the development of effective transition tools.³²

Conclusion

As a growing cohort of transitioning adolescents mature in Kenya, our study highlights the urgent need for improved transition tools and guidelines for comprehensive preparation of transitioning adolescents. Expanded transition programming, which includes facility-based strategies to shape positive caregiver involvement, engagement of adolescents in their own care, and the provision of commensurate support and guidance for HCWs to facilitate multifaceted management of transitioning adolescents, is needed. At the policy level, research and program development which joins the perspectives of adolescents, caregivers, healthcare providers and policy makers could produce the most comprehensive and effective transition resources.

Acknowledgements

We would like to thank study participants for their time and sharing their experiences, members of the ATTACH study team for assistance in collecting data, and our collaborating partners from the University of Nairobi, Kenyatta National Hospital, and the National AIDS and STI Control Program.

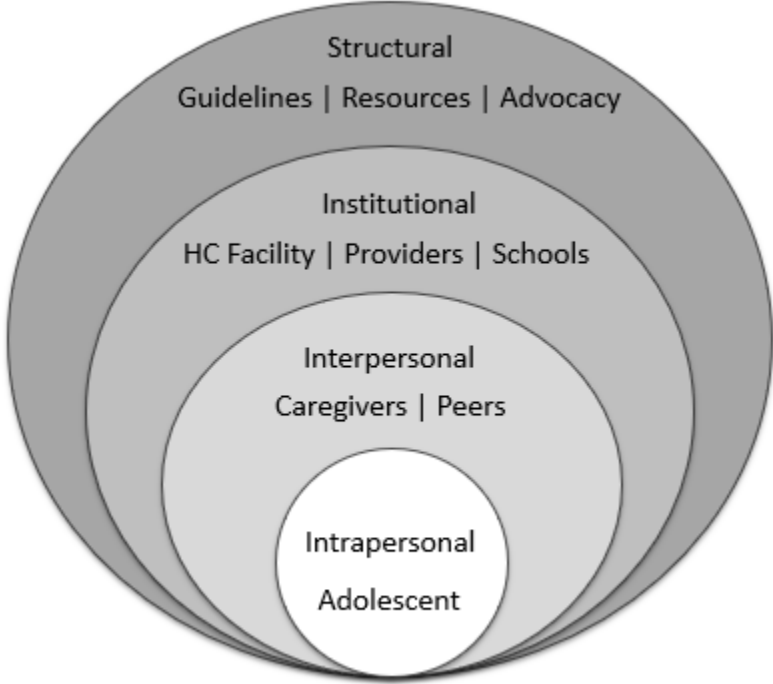
Sponsorship: The Adolescent Transition to Adult Care for HIV-infected Adolescents in Kenya (ATTACH) study was funded by the US National Institutes of Health (Grant Number 1R01HD089850-01).

Table I: Participant Demographics*

Characteristic	n (%) or median (IQR)
Age (years)	39 (25-54)
Female	10 (53%)
Primary level of influence (current)	
International	1 (5%)
National	10 (53%)
Regional	3 (16%)
County	4 (21%)
Community/Clinic	1 (5%)
Experience in policy/supervisory roles (years)	
0-5	8 (42%)
6-10	4 (21%)
11-15	6 (31.5%)
16+	1 (5%)
Number who have assisted in the development of HIV treatment and care guidelines or trainings	18 (95%)
Number who have assisted in the development of HIV treatment and care guidelines or trainings for adolescents and/or youth	15 (79%)

* demographics for one participant were not available.

Figure 1: The adapted Socio-Ecological model



References

1. UNAIDS. AIDSinfo Data Sheet. <http://aidsinfo.unaids.org/> (2018).
2. World Health Organization. Adolescent development. *WHO* (2017).
3. Bekker, L. & Society, S. H. HIV and adolescents: focus on young key populations. *J. Int. AIDS* (2015).
4. Kim, S. H., Gerver, S. M., Fidler, S. & Ward, H. Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. *AIDS* **28**, 1945–1956 (2014).
5. UNAIDS. *The Gap Report*. (2014).
6. Slogrove, A. L., Mahy, M., Armstrong, A. & Davies, M.-A. Living and dying to be counted: What we know about the epidemiology of the global adolescent HIV epidemic. *J. Int. AIDS Soc.* **20**, 21520 (2017).
7. Koech, E. *et al.* Characteristics and outcomes of HIV-infected youth and young adolescents enrolled in HIV care in Kenya. *AIDS* **28**, 2729–2738 (2014).
8. Hazra, R., Siberry, G. K. & Mofenson, L. M. Growing Up with HIV: Children, Adolescents, and Young Adults with Perinatally Acquired HIV Infection. *Annu. Rev. Med.* **61**, 169–185 (2010).
9. Avert. Young people, HIV and AIDS. <https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/young-people> (2019).
10. Busza, J., Besana, G. V., Mapunda, P. & Oliveras, E. ‘I have grown up controlling myself a lot.’ Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania. *Reprod. Health Matters* **21**, 87–96 (2013).
11. Enane, L. A., Vreeman, R. C. & Foster, C. Retention and adherence: Global challenges for the long-term care of adolescents and young adults living with HIV. *Current Opinion in HIV and AIDS* vol. 13 212–219 (2018).
12. International AIDS Society. *The Collaborative Initiative for Paediatric HIV Education and Research (CIPHER)*. https://www.iasociety.org/Web/WebContent/File/CIPHER_Annual_report_2015.pdf (2015).
13. Dowshen, N., Pediatrics, L. D.- & 2011, undefined. Health care transition for youth living with HIV/AIDS. *Am Acad Pediatr.*
14. Abreu-Perez, R. L. N. L., and C. B. ‘Where are they now? Mortality, loss to follow-up and viral suppression in perinatally HIVinfected (PHIV) posttransition young adult antiretroviral therapy (ART) patients in the Dominican Republic (DR): 2004–2015.’ in *21st International AIDS Conference*. (2016).
15. Hope, R. L., Judd, A., Foster, C., Prime, K., Tookey, P., & Jungmann, E. Clinical outcomes in adults with perinatal HIV after transfer from pediatric care. in *Conference on Retroviruses and Opportunistic Infections*. (2016).
16. Hansudewechakul, R. *et al.* Transition of Thai HIV-infected adolescents to adult HIV care. *Journal of the International AIDS Society* vol. 18 (2015).
17. Izzo, I. *et al.* Perinatally HIV-Infected Youths After Transition from Pediatric to Adult Care, a Single-Center Experience from Northern Italy. *AIDS Res. Hum. Retroviruses* **34**, 241–243 (2018).
18. Ryscavage, P., Macharia, T., Patel, D., Palmeiro, R. & Tepper, V. Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. *AIDS Care* **28**, 561–565 (2016).

19. Fish, R., Judd, A., Jungmann, E., O'Leary, C. & Foster, C. Mortality in perinatally HIV-infected young people in England following transition to adult care: an HIV Young Persons Network (HYPNet) audit. *HIV Med.* **15**, 239–244 (2014).
20. Evans, D. *et al.* Treatment outcomes of HIV-infected adolescents attending public-sector HIV clinics across Gauteng and Mpumalanga, South Africa. *AIDS Res. Hum. Retroviruses* **29**, 892–900 (2013).
21. Dahourou, D. L. *et al.* Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: Challenges, youth-friendly models, and outcomes. *Journal of the International AIDS Society* vol. 20 (2017).
22. Tsondai, P. R. *et al.* Characterizing the double-sided cascade of care for adolescents living with HIV transitioning to adulthood across Southern Africa. *J. Int. AIDS Soc.* **23**, (2020).
23. Marcus, R. B. J., and K. K. 'Loss to follow-up in children and adolescents with increasing age in South Africa.' in *9th International Workshop on HIV Pediatrics.* (2017).
24. Weigel, R. *et al.* Mortality and loss to follow-up in the first year of ART: Malawi national ART programme. *AIDS* **26**, 365–373 (2012).
25. Nachega, J. B. *et al.* Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. *J. Acquir. Immune Defic. Syndr.* **51**, 65–71 (2009).
26. Lamb, M. R. *et al.* High attrition before and after ART initiation among youth (15-24 years of age) enrolled in HIV care. *AIDS* **28**, 559–568 (2014).
27. Lee, S. & Hazra, R. Achieving 90-90-90 in paediatric HIV: adolescence as the touchstone for transition success. *J. Int. AIDS Soc.* **18**, 20257 (2015).
28. Njuguna, I. *et al.* Transitioning adolescents to adult HIV care: Health facility models of care and transition practices in Kenya. *Trop. Med. Int. Heal.* (2020).
29. Bronfenbrenner, U. *Toward an Experimental Ecology of Human Development.*
30. Stokols, D. Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion* vol. 10 282–298 (1996).
31. McLaren, L. & Hawe, P. Ecological perspectives in health research. *J. Epidemiol. Community Health* **59**, 6–14 (2005).
32. John-Stewart, G. *Adolescent Transition To Adult Care for HIV-infected adolescents in Kenya (ATTACH).* <http://depts.washington.edu/gwach/wp-content/uploads/2019/04/11.28.17-ATTACH-Protocol-V1.3-Clean.pdf> (2017).
33. Simoni, J. M. *et al.* Debrief Reports to Expedite the Impact of Qualitative Research: Do They Accurately Capture Data from In-depth Interviews? *AIDS Behav.* **23**, 2185–2189 (2019).
34. Hsieh, H.-F. & Shannon, S. E. Three Approaches to Qualitative Content Analysis. *Qual Heal. Res Citations Ebsco Electron. Journals Serv.* **15**, (2005).
35. Attride-Stirling, J. Thematic networks: an analytic tool for qualitative research. *Qual. Res.* **1**, 385–405 (2001).
36. World Health Organization. HIV and Adolescents from Guidance to Action. 2014 https://apps.who.int/adolescent/hiv-testing-treatment/page/Psychosocial_well_being.
37. UNICEF. *Progress for Children.* https://www.unicef.org/publications/files/Progress_for_Children_No._11_22June15.pdf (2015).
38. Ojwang, V. O. *et al.* Loss to follow-up among youth accessing outpatient HIV care and treatment services in Kisumu, Kenya. *AIDS Care - Psychol. Socio-Medical Asp.*

- AIDS/HIV* **28**, 500–507 (2016).
39. Enane, L. A. *et al.* “A problem shared is half solved” – a qualitative assessment of barriers and facilitators to adolescent retention in HIV care in western Kenya. *AIDS Care* **32**, 104–112 (2020).
 40. Mburu, G. *et al.* Responding to adolescents living with HIV in Zambia: A social-ecological approach. *Child. Youth Serv. Rev.* **45**, 9–17 (2014).
 41. Philbin, M. M. *et al.* Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: using adolescent and adult providers’ insights to create multi-level solutions to address transition barriers. *AIDS Care - Psychol. Socio-Medical Asp. AIDS/HIV* **29**, 1227–1234 (2017).
 42. Viner, R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood* vol. 81 271–275 (1999).
 43. Andiman, W. A. Transition from pediatric to adult healthcare services for young adults with chronic illnesses: The special case of human immunodeficiency virus infection. *J. Pediatr.* **159**, 714–719 (2011).
 44. Soeters H, Hatane L, Toska E, Vale B, M. D. Transitioning HIV-infected children and adolescents into adult HIV programmes: barriers and recommendations from frontline HIV healthcare workers in sub-Saharan Africa. in *20th International AIDS Conference* (2014).
 45. Williams, S., Renju, J., Ghilardi, L. & Wringe, A. Scaling a waterfall: A meta-ethnography of adolescent progression through the stages of HIV care in sub-Saharan Africa. *J. Int. AIDS Soc.* **20**, (2017).
 46. Pettit, Edward, Greifinger Rena C., B. Phelps Ryan, B. S. & J. Improving Health Services for Adolescents Living with HIV in Sub-Saharan Africa: A Multi-Country Assessment. *African J. Reprod. Heal.* **Vol. 17**, 17–31 (2013).
 47. World Health Organization. *Adolescent friendly health services*. https://www.who.int/maternal_child_adolescent/documents/fch_cah_02_14/en/ (2002).
 48. Michaud, P. A., Suris, J. C. & Viner, R. The adolescent with a chronic condition. Part II: Healthcare provision. *Archives of Disease in Childhood* vol. 89 943–949 (2004).
 49. Surís, J. C., Michaud, P. A., Akre, C. & Sawyer, S. M. Health risk behaviors in adolescents with chronic conditions. *Pediatrics* **122**, e1113–e1118 (2008).
 50. Young, B., Dixon-Woods, M., Windridge, K. C. & Heney, D. Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *Br. Med. J.* **326**, 305–308 (2003).
 51. Ankrah, D. N. A. *et al.* Facilitators and barriers to antiretroviral therapy adherence among adolescents in Ghana. *Patient Prefer. Adherence* **10**, 329–337 (2016).
 52. Wolf, H. T. *et al.* ‘It is all about the fear of being discriminated [against]…the person suffering from HIV will not be accepted’: A qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. *BMC Public Health* **14**, 1–11 (2014).
 53. Wolf, H. T. *et al.* Health Care Experiences of Youth Living With HIV Who Were Lost to Follow-up in Western Kenya. *J. Assoc. Nurses AIDS Care* **30**, 539–547 (2019).
 54. Hodgson, I., Ross, J., Haamujompa, C. & Gitau-Mburu, D. Living as an adolescent with HIV in Zambia-lived experiences, sexual health and reproductive needs. *AIDS Care - Psychol. Socio-Medical Asp. AIDS/HIV* **24**, 1204–1210 (2012).
 55. Grzywacz, J. G. & Fuqua, J. The social ecology of health: Leverage points and linkages.

- Behavioral Medicine* vol. 26 101–115 (2000).
56. Magnani, R. J. *et al.* Reproductive health risk and protective factors among youth in Lusaka, Zambia. *J. Adolesc. Heal.* **30**, 76–86 (2002).
 57. Kim, B. & White, K. How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review. *International Journal of Adolescence and Youth* vol. 23 198–218 (2018).
 58. World Health Organization. *The Ottawa Charter for Health Promotion*. <https://www.who.int/healthpromotion/conferences/previous/ottawa/en/> (1986).
 59. World Health Organization. *Declaration of Alma-Ata*. <http://www.euro.who.int/en/publications/policy-documents/declaration-of-alma-ata,-1978> (1978).
 60. Brown, P. & Zavestoski, S. Social movements in health: An introduction. *Sociology of Health and Illness* vol. 26 679–694 (2004).
 61. World Health Organization. *Innovative Care for Chronic Conditions: Building Blocks for Action*. www.who.int/chp/knowledge/publications/icccglobalreport.pdf?ua=1 (2002).
 62. World Health Organization. *Global Strategy for Women's, Children's and Adolescent's Health*. (2019).
 63. UNFPA. *Global Strategy on Adolescents and Youth*. [https://www.unfpa.org/sites/default/files/resource-pdf/UNFPA Adolescents and Youth Strategy.pdf](https://www.unfpa.org/sites/default/files/resource-pdf/UNFPA%20Adolescents%20and%20Youth%20Strategy.pdf) (2013).
 64. World Health Organization. *Global Accelerated Action for the Health of Adolescents (AA-HA!) Guidance to Support Country Implementation*. <https://www.who.int/life-course/publications/engaging-young-people-for-health-and-sustainable-development/en/> (2017).
 65. World Health Organization. *Engaging young people for health and sustainable development*. <https://www.who.int/life-course/publications/engaging-young-people-for-health-and-sustainable-development/en/> (2018).
 66. The United Nations. Committee on Population and Development 2012 Resolution on Adolescents and Youth. in (2012).
 67. Gleeson, H. S., Oliveras Rodriguez, C. A., Hatane, L. & Hart, D. Ending AIDS by 2030: the importance of an interlinked approach and meaningful youth leadership. *J. Int. AIDS Soc.* **21**, e25061 (2018).
 68. Oliveras Rodriguez, C. A. Engaging adolescents with HIV to ensure better health and more informed research. *Journal of the International AIDS Society* vol. 20 (2017).
 69. Mburu, G. *et al.* Rights-based services for adolescents living with HIV: adolescent self-efficacy and implications for health systems in Zambia. *Reprod. Health Matters* **21**, 176–185 (2013).
 70. Jao, J., Fairlie, L., Griffith, D. C. & Agwu, A. L. The Challenge of and Opportunities for Transitioning and Maintaining a Continuum of Care Among Adolescents and Young Adults Living with HIV in Resource Limited Settings. *Current Tropical Medicine Reports* vol. 3 149–157 (2016).
 71. Wiener, L. S., Kohrt, B.-A., Battles, H. B. & Pao, M. The HIV Experience: Youth Identified Barriers for Transitioning from Pediatric to Adult Care. *J. Pediatr. Psychol.* **36**, 141 (2011).
 72. Martini, J., Tijou Traoré, A. & Mahieu, C. Chronic patient as intermittent partner for policy-makers: The case of patient participation in the fight against diabetes and

- HIV/AIDS in Mali. *BMC Public Health* **19**, (2019).
73. Cluver, L. D. *et al.* Achieving equity in HIV-treatment outcomes: can social protection improve adolescent ART-adherence in South Africa? *AIDS Care - Psychol. Socio-Medical Asp. AIDS/HIV* **28**, (2016).
 74. Carlson, M., Brennan, R. T. & Earls, F. Enhancing adolescent self-efficacy and collective efficacy through public engagement around HIV/AIDS competence: A multilevel, cluster randomized-controlled trial. *Soc. Sci. Med.* **75**, 1078–1087 (2012).
 75. Bailey, H., Cruz, M. L. S., Songtaweessin, W. N. & Puthanakit, T. Adolescents with HIV and transition to adult care in the Caribbean, Central America and South America, Eastern Europe and Asia and Pacific regions. *J. Int. AIDS Soc.* **20**, 21475 (2017).