

Challenges and Facilitators of Transition from Adolescent to Adult HIV Care among
Youth Living with HIV in Moshi, Tanzania
by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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2018

ABSTRACT

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Abstract

Background: AIDS is the leading killer of adolescents in Africa, the continent most impacted by the AIDS pandemic. The East African nation of Tanzania is one of the top five countries with the highest burden of HIV in the world. Despite these challenges, scale up of anti-retroviral therapy (ART) has enabled millions of children infected with HIV to survive into adolescence and adulthood. These children attend family-centered and adolescent clinics where they not only receive HIV care, but also form close knit bonds with their healthcare providers and peers. As patients age into adulthood, they require to transition to the adult HIV clinic. Failure to transition results in an adolescent treatment bulge and strain on capacity in the family centered and adolescent clinics. This adolescent to adult transition period is a point of frequent loss to follow-up in the HIV care continuum, which may be partially due to fear and anxiety about the change. As clinics seek guidance on how best to manage the transition, few established protocols exist, and those available were primarily written for well-resourced settings. This study examined challenges and facilitators of the transition of care among youth living with HIV in Moshi, Tanzania. **Methods:** Purposive sampling methods were used to recruit youth living with HIV who attended an adolescent specific clinic, Teen Club, and the adult HIV clinic at Kilimanjaro Christian Medical Centre. Two native Swahili speaking research assistants trained in qualitative research conducted in-depth interviews.

Medical records were reviewed retrospectively to collect data on factors associated with HIV outcomes. Preliminary results were presented to key stakeholders. Youth and key stakeholders separately suggested solutions to identified challenges associated with transition of care. **Results:** 19 youth participated in the study. A slight majority were female (53%) and on first-line ART. Participants' age of HIV diagnosis ranged from 5 to 18 years with a mean ART duration of 9.8 years. Barriers and facilitators of transition were categorized into four domains based on the Health Care Transition Research Consortium (HCTRC) framework. **Individual domain:** Barriers included long ART duration and financial constraints due to low socio-economic status. Facilitators to care were a positive perspective on living with HIV, high sense of maturity and responsibility, and good health maintenance. **Family/Social Support Domain:** Barriers were stigma and lack of social events in the adult clinic. Facilitators were family and peer support. **Health care system domain:** Barriers were lack of preparation for transition and concern about the quality of care in the adult clinic which entailed payment for services, few physicians, long waiting times and poor patient-provider communication. **Environment domain:** Barriers were lack of national guidelines for transition and inadequate investment in adolescent health and education by the government. **Conclusion:** Transition is a complex, dynamic process influenced by many factors. With projections indicating that the number of youth living with HIV in Tanzania is likely to increase in the coming years, it is vital to develop a transition

protocol that addresses the challenges identified and is feasible to implement in low resource settings. A strong protocol may influence the use of health system resources, facilitate continuity of care, and improve long term disease outcomes.

Dedication

To my family. For your unwavering support towards my dreams no matter how bold and abstract they may seem at times.

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List of Abbreviations

ART	Antiretroviral Therapy
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HCTRC	Health Care Transition Research Consortium
IDIs	In-depth Interviews
KCMC	Kilimanjaro Christian Medical Centre
PEPFAR	US President's Emergency Plan for AIDS Relief
PMTCT	Prevention of mother to child HIV transmission
SMART	Social-Ecological Model of Adolescent and Young Adult Readiness to Transition
TRAQ	Transition Readiness Assessment Questionnaire

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1. Introduction

1.1 Burden of Disease

AIDS is the leading cause of death among adolescents aged 10 to 19 years in Africa and the second leading cause of death among adolescents globally (UNAIDS 2015). In 2016, approximately 2 million adolescents aged 10 to 19 years old were living with HIV worldwide (UNICEF 2018; UNAIDS 2017). Eighty percent of these youth live in sub-Saharan Africa (UNAIDS 2017). The East African nation of Tanzania is among the top five countries in the world for overall burden of HIV (UNICEF 2018; UNAIDS 2017). Despite these daunting statistics, Tanzania has made significant strides in improving HIV care and treatment services in the last 15 years. Provision of free antiretroviral therapy (ART) in the country began in 2004, with assistance from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and other international and non-governmental agencies (WHO 2005). The resulting scale-up of ART access and use has remarkably reduced the prevalence of HIV among adults. However, the prevalence of HIV among adolescents aged 15-19 years old has remained unchanged since 2008 (UNICEF 2016b). The majority of youth living with HIV acquired the infection perinatally, during birth or breastfeeding, though a growing number acquire HIV behaviorally by having unprotected sex with an infected partner or via intravenous drug use (DHS 2015). In Tanzania, there were approximately 5,500 new HIV infections among adolescents aged 15-19 years old in 2016 (UNICEF 2016c). Only 13% of adolescent boys

and 21% of adolescent girls aged 15-19 years in the country were tested for HIV and received their results in 2016 (UNICEF 2016c). The high rates of new infection and low rates of HIV testing can be attributed to multiple factors, including low levels of HIV knowledge, high levels of stigma and early age of sexual debut with poor utilization of barrier contraception (DHS 2015). A 2016 UNICEF report showed fewer than half of youth aged 15 to 24 years in Tanzania could demonstrate appropriate knowledge on HIV prevention (48.2% and 42.7 % among females and males respectively) (UNICEF 2016b). According to the Tanzania Demographic Health Survey from 2015 to 2016, approximately 60% of women and 51% of men aged 15-24 years reported having sex before they were 15 years old (DHS 2015). Approximately 17% of 15 to 24 year old males reported having two or more sexual partners in the past year (DHS 2015). Only half of these youth used condoms with their most recent sexual partner (DHS 2015).

1.2 Challenges associated with Adolescence and HIV

Adolescence is a transition period between childhood and adulthood that is marked by profound physical, emotional and psychosocial changes. In addition to challenges all youth encounter during this period, youth living with HIV face distinct challenges which include commencement or continuation of lifelong ART, related drug side-effects, retention in care, and disclosure and mental health challenges associated with living with a stigmatizing chronic disease (WHO 2018; Dow et al. 2016; Vreeman, McCoy, and Lee 2017). This long list of challenges has been shown to influence their

quality of life and social relationships making them more prone to high risk behavior and poor ART adherence, increasing their susceptibility to disease complications and mortality (Vreeman, McCoy, and Lee 2017; Ramaiya et al. 2016). Compared to children and adults, youth have worse ART adherence, lower rates of virologic suppression and higher rates of viral rebound after an initial period of suppression (Nglazi et al. 2012). Compared to behaviorally infected youth, perinatally infected youth are more likely to have advanced HIV disease with longer duration of ART. They also demonstrate poorer drug adherence, often with resistance to first and second line therapy complicating their HIV management. AIDS-related adolescent deaths are mostly among perinatally infected youth (Foster and Fidler 2010; Lolekha et al. 2015).

For much of their childhood and adolescence, youth living with HIV attend family-centered and adolescent care clinics where they not only receive HIV care, but also form close-knit bonds with their care providers and peers. The adolescent clinic attempts to mitigate challenges associated with living with HIV through educational seminars and fostering support networks among youth. The supportive care system becomes synonymous to an external 'family' to youth, especially in the context where youth are orphaned (UNICEF 2016c). Adult services, by contrast, frequently lack these supplemental educational and peer-support services. This makes the transition to adult care facilities a daunting task (Pinzón-Iregui et al. 2017).

1.3 Role of Transition

The development of ART and the global push for universal access to medication has shifted the paradigm from HIV being a death sentence to a chronic disease. Scale-up of ART has enabled youth living with HIV to survive into adulthood in large numbers (Meyers et al. 2007). While incredibly encouraging, these large numbers pose a unique challenge to under-resourced health systems in low-and middle-income countries such as Tanzania where more than 56% of HIV-infected children receive ART (UNAIDS 2017). As children 'age out' of adolescent care, there is a need to transfer these emerging adults to the adult care clinics to create space for the increasing cohort of HIV-infected children growing into the adolescent care clinics. This purposeful transfer from adolescent to adult HIV care is referred to as transition of care (Blum 1998). Transition ensures continuity of care in the HIV continuum as youth living with HIV progress on to the adult stage of life. This transition period is frequently met with fear and anxiety, with youth either refusing to transition, transitioning and reverting to the adolescent clinic, or becoming lost to follow up. Failure of transition results in an adolescent treatment bulge, further straining overburdened adolescent care facilities and worse, the fall off of individuals in care (Meyers et al. 2007).

1.4 Transition Practices and Related Interventions

A majority of studies exploring transition models are based in well-resourced settings in North America, Europe and Asia and not in sub-Saharan Africa where the

majority of youth living with HIV live (UNAIDS 2017). Existing transition models involve administration of transition readiness scales and assessments that identify and address anxiety and concerns associated with transition, or encourage creation of separate transition clinics for youth (Tepper, Zaner, and Ryscavage 2017; Acree 2017). Other interventions delay the age of transition with youth moving to the adult care clinics in their mid-twenties with close involvement of caregivers in all aspects of care.

One promising approach for improving the efficacy of transition is the development of individualized transition protocols to assess readiness and identify barriers for each patient. However, this is a resource-intensive approach, often involving several clinic visits with the primary care pediatrician, adult physician and a social worker trained in transition. These protocols also required follow-up visits by the adolescent care providers a year after transfer (Acree 2017). However, even with these protocols in place, transition proved challenging for many youth, with some citing loss of assistance programs and integrated non-medical care such as counselling and social support services in the adult care clinics (Acree 2017). In addition to this challenge, few studies have assessed the outcomes of transition in well-resourced settings limiting the ability to identify specific features of those models that contributed to successful transition (Sohn, Vreeman, and Judd 2017).

Due to the resource-intensive and individualized nature of these interventions requiring several clinic visits with the primary care pediatrician and the adult physician,

feasibility is uncertain in low resource settings in sub-Saharan Africa where clinical personnel are limited, specialists in adolescent medicine are few, and health facilities lack infrastructure (Désiré Lucien Dahourou et al. 2017).

1.5 Theoretical Framework

The Health Care Transition Research Consortium (HCTRC) health care transition model was recently developed as a guiding framework for transition research and practice (Betz 2013). The framework highlights the interaction between various health care processes and variables that influence health care transition outcomes among youth with chronic medical conditions and disabilities (Betz 2013). The framework consists of four main interrelated domains: the individual domain, family/social support domain, the health care system domain, and the environment domain (Figure 1).

The individual domain consists of individual factors that influence attainment of knowledge and skills necessary for successful transition. These factors include demographic characteristics, disease complexity and course, personality attributes, self-management and self-advocacy. The family/social support domain includes the level of family support and level of social support. Family support includes parent-child relationships, family culture, family resources, family composition and level of involvement in care. Social support includes the availability and characteristics of the social support network, and the social environment. The health care system domain includes the pediatric health care system, the adult health care system, patient-provider

relationship and health care insurance access and payment models. Finally, the environment domain includes access to secondary and post-secondary education, community resources and healthcare policy.

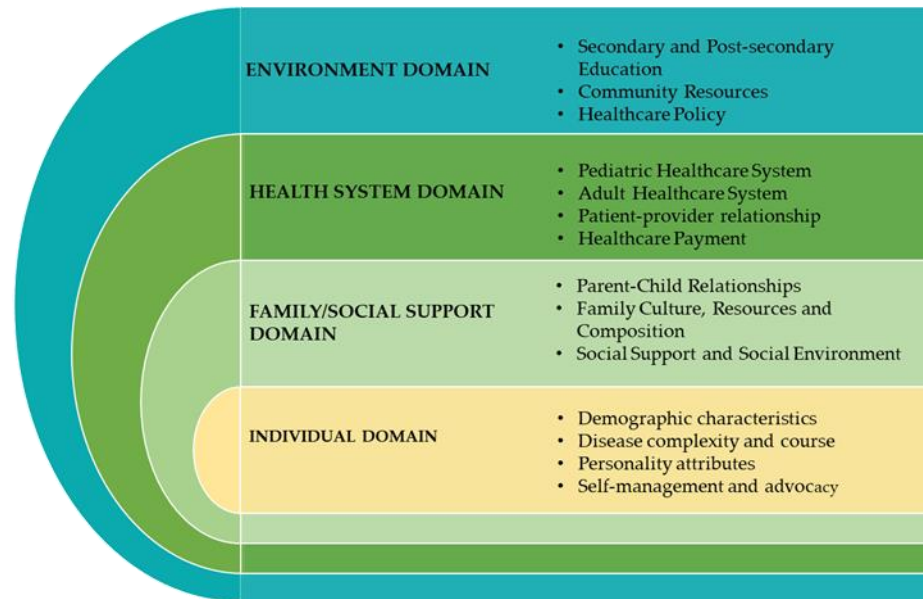


Figure 1: Simplified theoretical framework adapted from the Health Care Transition Research Consortium, Transition Model

1.6 Gaps in knowledge

A recent systematic review of the literature from 2000 to 2017 revealed few studies were conducted on transition models and outcomes for youth living with HIV in Africa (Kordonouri 2017; D. L. Dahourou et al. 2017). A majority of countries in sub-Saharan Africa lack national guidelines or protocols on transition with most institutions tailoring their own policy. There is no standardized age for transition with most health facilities setting a cut off age of between 18-23 years (MacKenzie et al. 2017; Nyabigambo

et al. 2014). The few studies that have explored transition models in sub-Saharan Africa revealed the use of peer counsellors, social media interventions, financial incentives, and provision of a dedicated space for transition (Désiré Lucien Dahourou et al. 2017; Mark et al. 2017; Henwood et al. 2016) . There is a lack of data on transition outcomes of these models, limiting the ability to inform youth-friendly transition policies.

As more youth enter reproductive age, the transition process must account for not only transition to the adult clinic but also the prevention of mother to child HIV transmission (PMTCT) clinic. Female youth who become pregnant are often automatically referred to enroll in the PMTCT clinic, which also serves pregnant adult women living with HIV. In one study, adolescents referred to the PMTCT clinic displayed poor antenatal clinic attendance and poorer adherence to ART compared to adult pregnant women, indicating a need to take into consideration the specific needs of this subgroup as they transition through various clinics (Désiré Lucien Dahourou et al. 2017).

1.7 Rationale and Study Aims

To address this gap in knowledge of the factors that influence the adolescent to adult HIV care transition process in a low resource setting, this study aims to describe the challenges and facilitators of transition from youth who have already transitioned or are soon to transition from the adolescent to the adult HIV clinic in Moshi, Tanzania. These findings may help inform a transition protocol that accommodates youths' and

other stakeholders' perspectives and may facilitate retention of youth living with HIV in the health system, reduce loss to follow-up and improve disease outcomes.

2. Methods

2.1 Summary

Youth living with HIV were purposively recruited from two clinics based on stage of transition: an adolescent-specific HIV clinic, known as Teen Club, and the adult HIV clinic. In-depth interviews (IDIs) were conducted with these participants and their medical records were reviewed. Data collection occurred between April and June 2017. Preliminary results were presented to key stakeholders in September 2017 whereby youth and key stakeholders separately suggested solutions in the local context to address identified challenges associated with transition of care. Findings of the study were discussed in detail by the research team to ascertain the trustworthiness of the interpretations made from the analysis. Qualitative (interview) and quantitative (medical record) data were then combined to provide a full picture of the factors that influence transition of care in the sample population.

2.2 Setting

This study was conducted in Kilimanjaro Christian Medical Centre (KCMC), the third largest hospital in Tanzania with a catchment area of approximately 15 million people. The hospital has an adolescent-specific HIV clinic called Teen Club that meets one Saturday of every month. The target age group is 12-24 years. Teen club activities include education sessions taught by social workers and nurses, and social events such

as soccer, creative arts, keyboard and other games in addition to routine doctor visits and pharmacy refills. Approximately 250 youth attend Teen Club.

Current practice at KCMC encourages youth living with HIV to transition to adult HIV clinic based on the following criteria: reaching age 25, becoming pregnant, marrying, or exhibiting behavior considered to have a bad influence on peers such as substance use or having sex with fellow youth in Teen Club. A majority of youth who have been asked to transition to the adult HIV clinic either refused to transition or returned to Teen Club after an attempted transition. Within the next few years, over 150 youth will meet the criteria for transition to the adult clinic. It will be important to complete these transitions in order to accommodate the next cohort of children entering adolescence and avoid over straining the capacity of Teen Club.

2.3 Participants

Study participants were recruited into the study using purposive sampling methods. Youth were eligible to participate in the study if they were: a) above 18 years, b) currently attending or recently transitioned to the adult clinic from Teen Club, c) were willing to speak about their experiences, and d) were able to understand and provide consent. Youth were recruited from Teen Club and the adult clinic in order to capture youth who had successfully and unsuccessfully transitioned, transitioned early due to pregnancy or due to behavior considered to be inappropriate for Teen Club, and youth in the pre-transition years. Unsuccessful transition was defined as failure to attend three

consecutive adult HIV clinic appointments with reversion to Teen Club. Behavior considered to be inappropriate for Teen Club was defined as substance use or having sex with fellow youth in Teen Club.

2.4 Data Collection

2.4.1 Qualitative Procedures

Two local research assistants who had received extensive training on qualitative methods and were fluent in English and Swahili conducted in-depth interviews (IDIs). Written informed consent was obtained prior to commencing the interview. The IDIs were conducted in Swahili in two separate sessions. Each session lasted approximately one hour. The interval between sessions ranged from 3 days to 1 week. For each session, research assistants utilized a semi-structured interview guide with broad opening questions and more specific follow-up probes based on the participants' response (Morse 2015; Guest 2006). Specific content in the guide included information on youths' perception of health, maturity, living with HIV, stigma, stress-relieving mechanisms, current income generating activities, degree of medical autonomy, transitions in school and clinic care, quality of care in Teen Club and the adult clinic and recommendations on how to improve care (See Appendix A for interview guide).

2.4.2 Quantitative Procedures

Medical records of interviewed participants were obtained from KCMC's medical records unit. Retrospective data were collected from three years prior to the

start of the study to July 31, 2017. Abstracted data included factors associated with transition and disease outcomes such as: date of birth, sex, year of diagnosis of HIV, commencement of ART and any changes in therapy and HIV RNA (viral loads) no more than one year prior to the interview (2016-2017).

2.5 Analysis

2.5.1 Qualitative Data Analysis

All IDIs were audio-recorded, transcribed verbatim in Swahili and translated into English. The interviews were stored in Duke Box, a secure encrypted electronic data storage system administered by Duke University, and analyzed in NVivo 11, a qualitative data analysis software system which was used to code, organize and manage data (Castleberry 2014). Summary memo notes were generated from each interview and discussed in detail by the research team. Codes were developed deductively from topics in the interview guide and inductively from the content in the interview transcripts and were compiled into a codebook with definitions, inclusion and exclusion criteria and examples. The codebook was reviewed by the research team for agreement. Two members of the research team independently coded portions of the interview transcripts, discussed and compared coding decisions. Disagreements were resolved through repeated discussions until consensus was achieved. The codebook was then applied to all texts. After completion of coding, the coded texts were arranged into categories and subcategories based on codes that related to each other. The salience of

particular codes was determined by the frequency of application, similarities and differences among the study participants.

2.5.2 Quantitative Data Analysis

Quantitative data were collected and entered into a computerized database using REDCap (Research Electronic Data Capture) tools hosted at Duke University. REDCap is a secure, web-based application designed to support data capture for research studies. STATA 15 statistical software was utilized to conduct descriptive analyses that determined percentages, mean, standard deviation and interquartile range where appropriate. Viral suppression was defined as a HIV RNA (viral load) of <200 copies/mL (Tabb et al. 2017; Dow et al. 2014).

2.6 Stakeholder Meeting

After preliminary data analysis a stakeholder meeting was held involving health care providers from both the adult and adolescent HIV outpatient clinics including physicians, charge nurses, social workers and other interested personnel including members of the research study team . The meeting was held to describe research findings to date and discuss potential solutions for the challenges reported by youth in the IDIs. The meeting was audio recorded with permission of the stakeholders and extensive meeting notes were documented and stored in Duke Box.

2.7 Ethics Statement

Ethical approval for this study was received from the Institutional Review Boards at KCMC (Protocol ID: 540), Duke University Medical Center (Protocol ID: Pro00069892) and the Tanzania National Institute for Medical Research (Protocol ID: NIMR/HQ/R.8a/Vol IX/2156) prior to participant recruitment and data collection. IDIs were conducted in a private room where participants felt comfortable and safe. The purpose of the study was explained to all participants and written informed consent was obtained prior to the interview. Participants were told they could stop the interview at any point if they felt distressed or overwhelmed. Personal identifying information was not written in the interview transcripts. Participants received reimbursement for lunch (4,000 TZ shillings or approximately 2 USD) and travel costs (2,000-10,000 TZ shillings or 1- 4 USD) depending on the distance travelled to the interview site. No other compensation was provided.

3. Results

3.1 Participant Characteristics

A total of 19 participants were included in the study. Youth represented experiences from three stages of transition: three participants were in the pre-transition years, nine participants had been asked to transition to the adult HIV clinic and seven participants transitioned due to pregnancy. Of the nine participants asked to transition, two successfully transitioned to the adult clinic while seven were unsuccessful. Table 1 summarizes demographic variables of the study participants. Participants ranged in age from 18.8 to 27.4 years (Mean 23.8 years, SD 2.8). Age of HIV diagnosis ranged from 5 years to 18 years. Participants had been receiving ART for a mean of 9.8 years (SD 3.3). The interval from time of HIV diagnosis to time of ART initiation ranged from 1 day to 10 years with a median of 14 months. Slightly more than half of the study participants (53%) were female. A majority of the participants (74%) were virally suppressed.

Table 1: Results of Retrospective Chart Review

	Total (n=19)	Transitioned (n=9)		Due to Pregnancy (n=7)	Pre- transition (n=3)
		Succeeded (n=2)	Failed (n=7)		
Age at time of Study	23.8 (18.8-27.4)	27.1 (26.9-27.3)	23.4 (22.1-24.3)	24.5 (19.2-27.4)	20.9 (18.8-22.2)
Gender					
Female	10 (53)	2 (100)	1 (14)	6 (86)	1 (33)
Age at HIV Diagnosis	11.9 (5.0-18.0)	13.3 (5.0-16.6)	11.1 (5.2-14.6)	13.2 (6.4-18.0)	11.6 (5.6-17.1)
Duration of ART in years	9.8 (2.2-12.9)	10.7 (9.3-12.0)	10.3 (5.8-12.0)	8.1 (2.1-12.9)	8.2 (2.7-12.9)
ART Regimen					
First Line	11 (58)	1 (50)	6 (86)	3 (43)	1 (33)
Second Line	8 (42)	1 (50)	1 (14)	4 (57)	2 (67)
Viral Load <200*	13 (72)	2 (100)	5 (71)	5 (83)*	1 (33)

Mean (Range) or N (%)

*One participant did not have a documented viral load

3.2 Interview Themes

Analysis of transcripts from youth across the different stages of transition revealed similar and overlapping themes. Barriers to transition centered around: the manner in which youth were asked to transition, stigma, financial constraints, and the quality of care in the adult clinic (Table 2). Facilitators of transition included family and social support, high sense of responsibility and maturity, positive perspective on living with HIV and maintenance of good health (Table 2).

3.3 Barriers to Transition

3.3.1 Manner of Transition

Participants knew about transition via an announcement made by the nurses at Teen Club that youth above the age of 25 years were expected to transition to the adult clinic in the coming months. Youth were also told to transition if they had engaged in bad behavior defined as substance use or having sex with fellow youth in Teen Club.

One participant described the process:

“It was announced. It was announced to all youth. There was no one who did not know about it. It was announced publicly and not in secret or via fliers. We were called and told if you have reached a certain age you will move to the adult clinic. And we were given a reason, it’s not like we were not given a reason. We were given more details about the reason for transition after inquiring more about why we were being moved. We were told it’s because of this, this and this. ‘So you mean we are moving because of that?’ We agreed with the decision because we were grown up and those were children and we would have taught them things they weren’t ready for.” (22 years, male)

Youth perceived the purpose for transition as not only age driven, but behavior driven. Youth who did not exhibit bad behavior felt unfairly forced to transition because their colleagues ‘ruined’ Teen Club. Beyond the announcement, there was no formal discussion or effort to prepare youth for transition. The abrupt manner and lack of preparation created anxiety in a majority of youth. Youths’ opinions were also not taken into consideration during the decision making process.

A majority of youth who had to transition at an earlier age due to pregnancy weren’t counselled or given any explanation of their transfer from Teen Club to the

PMTCT clinic. One participant mentioned a sudden switch in her clinic follow-up date and venue as the indication that she was being transitioned:

“Generally as it happened suddenly for me to conceive, I wish during this [pregnancy] to have been told this and this, but I was not told anything apart from being transitioned. Unlike being informed that now you have conceived do this and that, I was just told to come on a certain day and I never knew that was to the maternal clinic.” (25 year old, female)

3.3.2 Stigma

Stigma was a prominent theme among youth. They described experiencing external stigma at various stages of their lives. Youth talked about how people in their communities gossiped and spread rumors about them. When prompted to describe their neighbors, one participant stated:

“It’s really hard for me to answer that because most of them for example in our street, have discriminated me. There is somebody who spreads dirty rumors about me. So I was just alone without anybody to call a friend. When you try talking to somebody they start pointing fingers at you saying that ‘She is like this [HIV-infected].’ You can’t even talk to people in peace so you just stay at home. ‘She is like this [HIV-infected]. She has a problem. She is sick.’ But you find some other people are not fully aware of what this disease means so they stigmatize and discriminate you.” (27 years, female)

Participants identified stigma as a cause of social isolation and poor adherence to ART. One participant mentioned that the only thing that could prevent him from taking medication is if he was in a group discussion with his schoolmates and there was nowhere to take his medication in private. Transitioned youth talked about being stigmatized by patients in the adult clinic. Some youth feared that adult HIV patients

may assume they were behaviorally infected and view them as promiscuous and irresponsible which deterred them from moving to the adult clinic.

“The thing that will stop me going to the adult CTC [clinic], I already told you. You can go there and find your friend or your neighbor so you can’t really know what is in their heart.” (23 years, male)

“Honestly when they were told to move to adult clinic most of them refused. They started saying from there that you will meet people who know you from the street who never knew you are infected and they start stigmatizing you. ‘Even a child of so and so, [...] so from there is when most of the youth started refusing but they told them as per their age, ‘You will go there and receive care as you have been receiving from here.’ They accepted but after some time, the second month, the third, they met and later they got scattered, I don’t know where others went, I don’t know if they are here but they come on different days.” (27 year old, female)

“The benefits of there I mean if you sit with adults, somehow they can educate you on what they understand. May be they can give you the tactics of life so that you may also develop. To the side of weakness, they say the adults gossip. It is the thing that I have heard most youth say about there. Even the male youth say those people from there gossip. When you go there they start saying, ‘A child of so and so is also here.’ So that makes one loose hope and feel bad.” (22 year old, female)

3.3.3 Financial Constraints

Clinic fees: Despite the provision of free ART, patients paid 5,000 TSH (2 USD) for each clinic visit at the adult clinic: the fee specifically covered the cost of opening their medical file and review. This fee was waived for patients in Teen Club due to financial support by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Most youth could not afford the clinic fees and as a result did not successfully transition to the adult clinic.

“It’s hard for me. When we were told [to move], we were told that, for those who don’t have insurance, one has to pay five thousand in the adult clinic. Many people stopped taking medication. They said that if life is a matter of paying five thousand, they would rather stay home.” (22 years, male)

“As youth, we always knew that if we came on Saturday we don’t pay for the file, okay. But when you come to the Monday clinic, there are times when you don’t have cash and when you get there you are told to pay for your file. Imagine there is someone I brought, on Wednesday. This person had been home since February last year. They told me ‘[name redacted] I do not have five thousand,’ I told them, ‘Let us go and see if you will receive care or not.’ By chance they got care. You may be broke for weeks. That’s a challenge. So, it’s better if they went to the Saturday clinic [Teen Club].” (25 year old, female)

Travel costs to clinic: Several participants complained about travel costs to the clinic. Youth preferred travelling to KCMC, a center that was far from their residence to avoid the chance of meeting relatives or neighbors in health facilities near their homes.

“You know I am not employed, I work for myself. If I get two thousand, I thank God. If I get a thousand, I thank God. When the clinic day arrives and I have five thousand shillings I leave Arusha. Let’s say I get on a car, that’s two thousand five hundred one way. Coming back, five thousand will be over. Then I use another bus [from Moshi town to KCMC] total is six thousand. I won’t have money for the file. Shouldn’t I come and get medication? No. They need to look into what arrangement will be right for the weak and for the others who are able. They shouldn’t look at it from one angle only.” (22 year old, male)

Unable to meet basic needs: Study participants reported financial challenges that were compounded by low socioeconomic status, low levels of education and lack of stable income generating activities. Most youth had dropped out of school early, either due to inability to pay school fees or due to an acute illness. Transitioned youth in dire

financial situations reported seeking financial assistance from the hospital's social worker who would stamp their file and waive the clinic fee.

“The costs have been an obstacle to me because I do not have a reliable source of income and my income is low. A patient has to pay five thousand plus some transport fees so you find it’s hard for me because my income is low. I used to find the social worker to stamp my file then I return the file to the clinic. I get medical care. I feel bad, I wish I was able to come and pay for medical care like any other person but it’s not possible because of my income so I have to find the social worker for the stamp. “
(22 year old, female)

3.3.4 Quality of Care in the Adult Clinic

High patient load, long waiting times and limited number of physicians:

Youth stated differences in the quality of care in the adult clinic as compared to Teen Club, which served as a barrier to transition. Youth who transitioned reported high patient load and few physicians which led to long waiting times in the adult clinic.

“Another challenge is sometimes the doctors are very few and so it takes a lot of time to wait for treatment. You can come in the morning but leave in the evening because of the large number of people.” (28 year old, female)

Poor Patient Provider Communication: Participants complained about communication barriers they experienced with care providers in the adult clinic. Physicians were ‘very tired, ‘didn’t listen to problems in detail’ and were in a hurry while nurses lacked empathy and compassion. One participant stated, “You can find a harsh nurse. The one who you may ask to find a lost file for you and she starts shouting

at you, something which becomes a challenge. So you have to open a temporary file until your file is found," (28 year old, female).

A few participants observed nurses favoring some patients, allowing them to 'jump the line.'

"I would like them to treat me the way they treat everyone else. I would not like them to favor me. If I get there first, I should get treated first. Someone who comes after me shouldn't go before me because they gave a something small. I would not like that. Let us follow the order of service where when someone arrives first, they get assisted first. If someone comes and they are worse, they can be excused and be reviewed first then the order is followed." (26 year old, female)

Unfavorable clinic days: The adult clinic days were Mondays, Wednesdays and Fridays while Teen Club clinic day was one Saturday every month. Week day clinic days were a challenge to adhere to among youth who were in school or employed and couldn't take days off work without raising suspicion of their disease. Youth mentioned making excuses and coming up with other creative measures to attend clinic.

Lack of educational seminars: Teen Club had educational seminars led by nurses and counsellors where youth learned about nutrition, benefits of ART and other health maintenance strategies. However, some participants mentioned that sexual and reproductive health education was lacking and requested for more comprehensive educational seminars in Teen Club. The educational seminars provided a platform for youth bonding and formation of peer support networks. Educational seminars didn't occur in the adult clinic. A participant stated:

“The adult CTC [clinic] is different somehow, I mean things that are done in the CTC are different. In the youth clinic there are things that we used to be taught, that used to help, but after transition to the adult clinic you just come give out your card and go to doctor, take your medicines and go home. So there is nothing about seminars, or what. There is none.” (25 year old, female)

Isolation and disconnect from adult patients: Youth mentioned having a hard time sitting and interacting with older adult patients. Culture norms prohibit youth from being ‘free to speak their mind’ with anyone who is older than them. One participant said, “Stories are different so most of the time while you are making stories with an old person you must listen more, I mean you will not be free talking all the things,” (23 year old, male).

Youth unanimously mentioned feeling abandoned and isolated in the adult clinic, which served as a barrier to transition. They were concerned about being alone with ‘no one to talk to’ as they waited to receive care in the adult clinic. They were also discouraged by the possibility of losing their friends from Teen Club. One participant who failed transition stated:

“When I was required to move, meaning there are those who were my friends, who were seventeen [years old], maybe you are used to each other, you have stayed there may be three or four years, and then you are required to move and leave one behind. So the friendship dies. So it could be that there are things that you thought about, you were helping each other, you can’t find them, because they come on Saturdays, you will be coming on Monday and that’s when there is a difference.”(22 years, female)

3.4 Facilitators of Transition

3.4.1 Family and Social Support

Support from family members: Youth in all categories mentioned receiving support from various sources: family, peers, and health care providers. The level and type of support varied among the various sources. Family members were a source of encouragement and motivation especially at times when youth felt overwhelmed or lost hope. Family members helped with ART adherence by reminding youth to take medication.

“My mother [is important to me because], first of all, she knows about my issue because she is the one I am close to. I told her about it [HIV diagnosis] before I told anyone. She gives me solutions to my problems. I can tell her I want to get cash but getting that cash is a struggle and I am unable to take medication [ART]. Maybe, now I am able to get cash. I buy sugar, we add it to the tea.’ But mother you know I haven’t taken medication because of this [HIV]. I don’t know why God created me this way.’ My mother tells me, ‘You are not supposed to talk like that because only God knows [why you are infected]. And don’t make a big deal out of this issue. Now you have this job and at least we are able to drink tea [with sugar]. People have other diseases that prevent them from even drinking tea, so you are not allowed to say such things.’” (23 year old, male)

“They [family] are involved when I am not feeling okay. There are times, like what I went through. I had lots of thoughts so they used to watch carefully for my time for taking medication. This is because there are times you might be thinking, maybe, I have lots of problems they ask me about medicines. If I have taken medicine or not. They help with that,” (25 year old, female).

Youth who successfully transitioned mentioned receiving financial support in the form of insurance or money for transport and clinic fees, which may have contributed to their successful transition to the adult clinic.

“I told them I was required to move [transition] and every month I went I gave out five thousand shillings. They tried, but they could not [sustain it], so they got insurance for me. But how many others don't have insurance?” (27 year old, female)

Peer to peer support: Peer to peer support was common among youth. Youth called each other to make sure they attended the clinic or reminded each other when to take ART. They discussed issues that affected them and advised each other on how to cope with HIV. Youth also met outside of Teen Club for social events such as soccer and hikes.

“I have about three friend who know about this and so when the time reaches, you call your fellow and remind him to take medicine. This is because we are friends. One of us used to forget when to take medicine so we decided to remind each other when to take medicine by calling each other when the time reaches.” (27 year old, female)

“In our life, you might feel like losing hope. You may stop taking medicine or whatever. When you stay there [Teen Club] your fellows advise you that you should not do that.” (23 year old, male)

“What I can say is that the co-operation is enormous in Teen Club, you cannot find your fellow teen sick, then you leave them there. You must help them to some extent. You take them to doctor and tell the doctor may be there is this and this problem. The co-operation is enormous.” (22 year old, female)

Support from healthcare providers: Youth received psychosocial support from the nurses and doctors at KCMC. One participant stated, “At home I have no one to talk

to because I am far from my father. But at the hospital, sister [nurse] and our social [worker] helps me a lot mentally. Maybe when you are stressed out at home. You can call the sister and tell her your problems. She helps you on the phone and if that is not possible she tells you to go to the hospital where you will talk about it and solve it.” (27 year old, female)

Support from the healthcare providers extended beyond the hospital setting in some instances with one participant mentioning how she received assistance in paying school fees. One youth who transitioned due to pregnancy mentioned receiving help with buying food and paying medical bills.

“When I was pregnant, I once had a headache and I was admitted at KCMC. When I was there, some doctors came [to visit me] and they used to bring me food. They also gave me money to buy breakfast in the morning. When I was allowed to go back home, I couldn’t pay my hospital bill so, together with the social worker, they paid for me. The social worker also helped me at the [hospital] gate. The social worker also helped me with transport costs to go home when I was discharged.” (28 year old, female)

3.4.2 High Sense of Responsibility and Maturity

Youth demonstrated a high sense of maturity and responsibility as they grew older. Youth mentioned assuming medical autonomy in their early teen years when they started to go to Teen Club on their own. One participant mentioned, “When I turned 13, I started going to the clinic by myself. When I was 15, my brother used to accompany me to the clinic when he was on break [from school]. He used to give me moral support. He used to wait with me, as I waited to be called to see the doctor. I saw that they were

training me to be independent. If your parent accompanies you [to the clinic] till when you turn 20 years old, then you will even wait for them to instruct you when to take medication. That is not a good thing," (22 year old, female).

Successfully transitioned youth viewed the transfer to the adult HIV clinic as a milestone they could successfully achieve with time. They also viewed it as an opportunity to learn from adult patients. Youth expressed a desire to be self-sufficient and wanted to have a stable source of income without dependence on family members.

"Money is important because I live in the city. There are rent issues, you need to have lunch, you need to have supper. As a human being, you must do these things daily, so to me, money, money only is the only thing that bugs my mind, but other things, I don't know...women,.. Other things to me those don't bug my mind, because that, is just the way I am. If I want a lady, I get one but [I hold back] because I will infect them. So I am aware of myself, I understand myself, I know myself." (22 year old, male)

Youth who transitioned due to pregnancy mentioned having a child as the impetus to assume more responsibility and maturity.

"As in now, I won't only think of myself but also about my children. What are they going to eat? What will they wear? If they get sick how I'll take them to the hospital. The responsibilities as youth are different from the ones now." (28 year old, female)

3.4.3 Positive Perspective on Living with HIV

Successfully transitioned youth demonstrated an understanding and acceptance of their disease and didn't view it as a deterrent to their long-term survival. One participant said, "I see myself as being ok because I take my medication well, I eat well, I exercise so I am not stagnating." Another stated, "If we speak honestly, this disease is

dangerous okay, but once you know you are infected it is not a disease to be scared of though it is difficult to get used to, but the thing to be scared of is for one not to get, but once you are infected it is difficult to accept in the beginning and once you are infected there is no need of being scared, but be scared of being infected," (29 year old, male).

Participants who had a positive outlook on living with HIV also demonstrated high self-esteem, confidence and lack of internal stigma.

"When people point fingers at me saying I have HIV, I am confident about it and I have agreed with the situation. It's important because it helps me have a better life." (28 year old, female)

"I am okay because it is something that I am already confident about. It is just fine. I am already confident that even if they say that so and so has viruses, it's just like any other disease. If malaria can be treated even this can be treated, so long as you continue living, doing your activities as usual, there is no problem. It's saddening when they talk about you and you are bedridden. That is sad. Now I am dying for real. But if I am still living it is not a problem at all." (25 year old , female)

"You see here I am HIV positive, this is not the end. I am not dying. There are accidents, there are those who get cancer, they die but when they adhere to medicine well, they get treated very well, and they live well, as long as you eat food and you check your CD4 on time." (27 year old, female)

3.4.4 Maintenance of Good Health

Youth mentioned good health as a priority in their lives. One participant stated "Good health, first of all, health is everything and you cannot do what you need if you are not healthy. You cannot work. You must have good health," (23 year old, male).

Health was defined as being physically, mentally and spiritually well. A participant said, "Being healthy is that situation whereby you have physical, mental and spiritual

wellbeing. Physically I mean you are strong enough to work. Mentally I mean you can think of something and come out with a decision,” (27 year old, female).

Youth recognized the value of eating a balanced diet, physical exercise, stress relieving mechanisms and good ART adherence as key components to sustaining good health. Youth mentioned using phone alarms or relying on close family members and friends to help them with adherence. Challenges to adherence included unplanned travel, social gatherings, ‘a lot of stress about life,’ with loss of motivation and internal stigma which was expressed as ‘self-guilt.’ Youth experienced psychosocial stress brought on by experiencing the death of a parent or friend due to HIV. Youth who were aware of stress relieving mechanisms had adaptive emotional functioning and were more proactive about dealing with mental and emotional stress. One participant stated:

“I don’t isolate myself. I don’t like isolating myself because when I am by myself sometimes, I think about many things that are hurtful. I cry and stuff but I associate with people. We go exercise together, we play, we do things. That helps me. People also support me.” (27 year old, female)

Table 2: Identified Barriers and Facilitators of Transition

Barriers to Transition	Facilitators of Transition
<p>Transition Process Improper manner of transition Abrupt nature of transition without preparation/ ‘Don’t feel ready’ Negative perception of transition</p>	<p>Family-Social Support Psychosocial support from family members Financial assistance from family members Support in ART adherence and clinic follow-up Psychosocial and adherence support from peers</p>
<p>Stigma Internal Stigma External stigma from HIV infected adults and the community</p>	<p>Maturity and Responsibility High sense of maturity Awareness and desire to assume responsibility Self-reliance and a stable income generating activity</p>
<p>Financial Constraints Clinic fees too expensive Travel costs to clinic Unable to afford school fees and other basic needs</p>	<p>Perspective of HIV Positive illnesses perspective High self-esteem</p>
<p>Quality of care in the Adult Clinic Limited number of physicians High patient volume with long waiting times Poor patient provider communication Unfavorable clinic days</p>	<p>Healthcare Maintenance Good adherence to ART Good clinic follow-up Eating a balanced diet Awareness of stress relieving mechanisms</p>
<p>Isolation Loss of peer network Loneliness and disconnect from adult HIV patients</p>	

3.5 Transition and Pregnancy

Youth who became pregnant had to transition to the PMTCT clinic regardless of age. Youth mentioned that they would hide their pregnancy until they started showing

to delay transition. Youth were hesitant to transition due to unfamiliarity and anticipated stigma in the PMTCT clinic. Despite feeling hesitant, youth reported being received well and receiving good care in the PMTCT clinic. One participant remarked that the nurses were 'compassionate and polite unlike other places where nurses abuse patients.' However, one participant expressed concerned about the continuity of care and the lack of adequate communication among care providers, which in one instance, led to switching of ART with no reported indication of the regimen change.

"I don't know why they change medicines and that is what confuses me. One day I was given yellow tablets. Another day I was given white tablets. They made me very itchy. I went to the pharmacy and I was told that I have to see the doctor and I wasn't at Teen Club, I was at the PMTCT [clinic] and the doctor there didn't know about all this so I had a very hard time and I was given the same tablets. They should improve on medication. They shouldn't tell us to go to doctors without knowing what clinic we are in. They should explain things to us." (20 year old, female)

After childbirth, parents attended the PMTCT clinic for up to two years then moved to the adult HIV clinic. A majority of youth wanted to be transferred back to Teen Club instead of the adult clinic stating 'there are many people there,' 'paying for the file' and 'you will not get lessons like those of youth,' as reasons for not wanting to move on to the adult clinic. These are similar to youth in the other categories.

Participants drew strength from their children and saw them as a source of motivation and brought forth a renewed will to live. They took up responsibility for their health and were more self-reliant which facilitated transition.

"My child gives me hope and motivation when I look at him. He motivates me to keep going. I admire myself because there is nothing that I cannot do, for example, caring for a child. I know how to earn and make sure I have food on the table every day. I have

accepted my condition. You can find some people give up because of having such a condition thinking they will just die sooner or later but that's not how I am.” (27 year old, female)

3.6 Recommendations for Transition

Table 3 summarizes recommendations for a transition protocol provided by youth during the IDIs and other stakeholders during the stakeholder meeting. Youth suggested 25 to 26 years as the ideal ages for transition with flexibility and allowance to transition later if they felt ill prepared. Youth also wanted to be prepared for transition. Another recommendation was to transition youth as a group so that they could maintain mutual support during transition and keep each other company as they waited to receive medical care. Favorable aspects of Teen Club such as creation of social support groups, educational seminars and recreational activities should be adopted in the adult clinic. One participant mentioned, “They should include sports. When we go there we should have our sports and we should get taught. We should cooperate when we are together as groups.” (20 year old, female)

Health care providers mentioned having a one year training and preparation program prior to transition as a group, coupled with exit interviews for youth to obtain youth’s perspectives on transition and allay any anxiety at an individual level. Health care providers also suggested conducting a graduation ceremony prior to transfer to mitigate the abruptness of transition and make it something to celebrate as opposed to dread. Youth could be allowed to visit friends at Teen Club and serve as youth mentors

to pre-transitioned youth as long as they maintained medical follow-up in the adult clinic. Youth who transitioned early due to pregnancy and had their ART combinations switched recommended discussions occur with health care providers on the indications for the change in medication.

“You get the tablets you need, you get the tablets you use every day. They don’t get changed. And if changing is necessary, they get changed and you are told. They don’t do it as a secret, they tell you.” (20 year old, female)

KCMC is a private faith-based organization that requires patients to pay a fee at every clinic visit. The social welfare service could offset that fee in the adult clinic on occasion depending on the availability of donor funds. Health care providers suggested advising youth on how to obtain insurance or refer them to government hospitals where HIV services were free. They also suggested requesting youth to be more willing to adapt to the new adult clinic environment and allow time for application of these recommendations and creation of a transition protocol.

Table 3: Recommendations for Transition

Recommendation	Details
Recommended age for transition	25-26 years with allowance of extension if youth feel ill-prepared.
Transition Activities	<ol style="list-style-type: none"> 1. At least one year of transition preparation. 2. Exit interview to allay anxiety. 3. Graduation ceremony. 4. Transition youth as a group twice a year. 5. Nurse to accompany youth at first adult clinic visit. 6. Youth mentorship in the adult clinic. 7. Permission to transitioned youth to visit friends in Teen Club.
Adoption of certain aspects of Teen Club to the adult clinic	<ol style="list-style-type: none"> 1. Educational seminars on topics such as HIV, ART, sexual and reproductive health. 2. Psychosocial support groups. 3. Group activities such as soccer matches, hikes etc. 4. Increase the number of physicians. 5. Division of the adult clinic into age categories.
Transition to PMTCT clinic	<ol style="list-style-type: none"> 1. Counselling and provision of family planning. 2. Creation of support groups in the PMTCT clinic. 3. Improvement in continuity of care with explanation of reasons for ART changes.
Financial assistance	<ol style="list-style-type: none"> 1. Guide youth on ways to obtain insurance. 2. Referral to government facilities.

3.6 Integrating Thematic Analysis with the Health Care Transition Framework

Barriers and facilitator of transition identified during thematic content analysis were categorized into the four main domains outlined by the HCTRC transition model

(Figure 1). **Individual Domain:** Individual factors that served as barriers to transition included early age of HIV diagnosis with long duration of ART and financial challenges due to low-socioeconomic status. Individual factors that served as facilitators to transition included a high sense of maturity and responsibility, good health maintenance, good ART adherence, awareness of stress relieving mechanism and a positive perspective on living with HIV. **Family/ Social Support Domain:** Identified barriers were stigma from the community and adult HIV patients, and lack of social events such as educational seminars and recreational activities in the adult clinic. Financial and psychosocial support from family was an important facilitator for transition. Peer to peer support promoted good adherence and health maintenance. **Health care system domain:** Payment for services, overburdened adult clinic, unfavorable clinic days, few physicians, poor patient provider relationships, and lack of preparation for transition served as barriers to transition. **Environment Domain:** Barriers were no post-secondary school education and low socioeconomic status with a majority of participants reporting no stable income generating activity.

4. Discussion

Transition of care among youth living with HIV is a complex dynamic process influenced by many factors. The purpose of this study was to understand the barriers and facilitators of health care transition among youth living with HIV in Moshi, Tanzania. The HCTRC framework provides a valuable guide to discuss the factors youth reported as influencing transition (Betz 2013).

4.1 Individual domain

Individual factors that influenced transition in this study included level of HIV care maintenance, maturity, mental wellbeing, and ability to obtain a stable income generating activity. Several studies that explored the preferred age to start discussions on transition had varied results (Nyabigambo et al. 2014; MacKenzie et al. 2017; Pettitt et al. 2013). Start of transition preparation ranged from time of diagnosis to late teen years. The age for transition (25 years) proposed by youth in this study is older than what is reported in most studies where transition occurred during the late teen or early twenties (Nyabigambo et al. 2014; MacKenzie et al. 2017; Pettitt et al. 2013). Other studies proposed initiation of transition according to youth's level of maturity and self-management capability, allowing age adjustments for transition (Wiener et al. 2011). To best meet the needs of youth, the age when transition discussions should begin could be optimized and standardized (Hussen et al. 2015). Early preparation or creation of awareness for transition is essential for successful transfer to adult care.

Youth experience psychosocial stress from HIV and non-HIV related factors (Dow et al. 2016). Studies note that youth living with HIV have higher rates of mental health issues such as anxiety, depression and post-traumatic stress disorder when compared to non-HIV infected youth (Tepper, Zaner, and Ryscavage 2017; Lowenthal et al. 2014). Mental health interventions tailored towards equipping youth with coping and stress relieving mechanisms are likely to be effective in promoting a positive perspective on living with HIV which is linked to good ART adherence and may be associated with improved self-care (Tepper, Zaner, and Ryscavage 2017). Conversely, a negative illness perspective views adherence as a reminder of HIV infection and breeds internal stigma (Tepper, Zaner, and Ryscavage 2017). This interplay of mental health issues, adherence, and health maintenance suggests a critical role for strategies that improve mental resilience for youth living with HIV, which may facilitate transition of care.

There are insufficient data examining potential correlation of disease severity and transition readiness and outcomes post-transition in sub-Saharan Africa. Few studies, based in well-resourced settings have demonstrated poor disease indicators after transition evidenced by high viral loads, and high mortality rates (Tepper, Zaner, and Ryscavage 2017). There is a need for comprehensive surveillance of disease outcomes among youth after transfer to adult care.

Financial constraints are an important barrier to transition in both well and low resourced settings. A systematic review of transition outcomes in North America and

Europe revealed that parental insurance coverage terminated at around the time of transition resulting in gaps in treatment before youth obtained medical coverage (Tepper, Zaner, and Ryscavage 2017). In low resource settings, health insurance may be less common, but similar results may be found showing that direct financial support from parents and others dwindles as patients reach young adulthood, increasing barriers to transition. A majority of youth in this study had low levels of education and were still financially dependent on their families which deterred them from transition to adult care.

4.2 Family Social Support Domain

This study revealed that stigma, both internal and external, was a pervasive barrier to transition. Stigma negatively impacted access to care, and was associated with poor adherence and reluctance to transition. Our results correspond with similar findings by other studies about transitioning youth with HIV (Pettitt et al. 2013; Siu et al. 2012). Interventions tailored towards increasing community awareness and addressing misconceptions about HIV may help mitigate stigma and facilitate social support to youth as they transition into adulthood (Wiener et al. 2011).

This study highlights the importance of family support through financial assistance and psychosocial support. Family involvement in provision of money for clinic fees and advice on transition helped facilitate transition in care. Youth relied on peers from Teen Club, which promoted good healthcare maintenance. However, peer

support that did not extend beyond Teen Club to the adult clinic inhibited successful transition. Youth recommendations for group transition, peer mentors in the adult clinic and permission to visit friends in Teen Club will mitigate the sense of peer loss and ensure continuity of peer support in the adult clinic, thereby facilitating successful transition. Additionally, facilitating spaces for youth with lower levels of internal stigma to empower other youth may lead to increased self-confidence and higher rates of successful transition.

4.3 Healthcare System Domain

Health care system barriers have long been identified in studies of the transition process. In this study, the main health care system barrier to successful transition was the overwhelmed adult clinic with long waiting times and few physicians which is similar to studies in other low resourced settings (Kung et al. 2016; Sharma et al. 2014; Désiré Lucien Dahourou et al. 2017). Health care facilities lack adequate resources to sustainably address structural barriers to transition. Health care providers also lack training on transition which extends to lack of youth preparation for transition despite evidence suggesting that preparation has a significant impact on transition outcomes (Kung et al. 2016; Machado et al. 2016). Several studies in well-resourced settings utilized transition readiness tools such as the Transition Readiness Assessment Questionnaire (TRAQ) and the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) that both measured youth's expectations, motivation,

developmental maturity and other domains to determine if youth were ready for transition (Sharma et al. 2014; Schwatz 2014). However, most of these transition preparation tools are not culturally appropriate or applicable in low resource settings. Further research is required to determine the appropriate transition readiness tool that would be culturally relevant and applicable in low resource settings.

Comprehensive sexual and reproductive health education with provision of family planning was lacking in Teen Club despite youth demonstrating sexual activity with some being transitioned early due to pregnancy or due to engaging in sexual relations with fellow youth in Teen Club. Only seventy percent of the study participants were virally suppressed. Increased sexual activity without barrier contraception and low rates of viral suppression pose an increased risk of disease transmission. The transition process needs to address sexual and reproductive health needs of youth through integration of comprehensive sexual and reproductive health education in a transition protocol and linkage to reproductive health services if requested by youth (Ngilangwa et al. 2016; Lowenthal et al. 2014).

4.4 Environment Domain

Adolescents represent a neglected subgroup in Tanzanian health policy and government expenditure despite adolescents accounting for almost a quarter of the population (UNICEF 2016; UNAIDS 2017). There are no national guidelines that governs transition or training on adolescent health. This reflects a fragmented health care system

similar to most countries in sub Saharan Africa (UNAIDS 2017). Failure to develop and implement transition protocols at the national or hospital level results in arbitrary transfers to the adult clinic with limited feedback about successes and failures (Tanner et al. 2016). The public education system also does not favor youth from low socioeconomic status who have to discontinue school due to lack of funds to pay for school fees. Low levels of education translate to inability to obtain stable income generating activities, perpetuating a vicious cycle of poverty that not only serves as a barrier to transition but impedes overall health care maintenance (Dzimnenani Mbirimtengerenji 2007).

4.5 Implications for practice and further research

Transition of care is a relatively new field of research that is rapidly gaining interest. The number of youth living with HIV growing into adulthood is projected to continue increasing over time, with more youth requiring transition to adult care facilities. There is a need to develop feasible transition protocols that take into account factors outlined in the theoretical framework by the HCTRC while putting in context the available resources in health facilities located in low-and-middle income countries. Further studies are required to assess the outcomes of these transition models and determine the factors influencing their successful implementation. Research on factors influencing transition among distinct subgroups such as perinatally and behaviorally infected youth, particularly in low-and-middle income countries is warranted since

these groups may have different perspectives and needs for successful transition.

Further research is also needed to assess whether identified barriers and facilitators translate to broader health system issues.

4.6 Study strengths and limitations

While this study provides valuable insight on the transition process, there are several important limitations. First, all participants in the study were recruited from Teen Club and the adult HIV clinic in KCMC therefore their experiences may be different from those attending other clinics. This limits generalizability of the results to the entire population of youth living with HIV in Tanzania. Second, the study did not specify which participants were perinatally or behaviorally infected. It is possible that there could have been differences in perceived challenges and facilitators of transition among perinatally and behaviorally infected youth.

Despite these limitations, the study possesses several strengths. The study was the first of its kind in Tanzania that investigated factors influencing transition of care from the youth's perspective. Findings of this study provide valuable information to those conducting research in the field of transition and may help inform a transition protocol that better accommodates youth and other stakeholders' recommendations. This could improve retention in care and improve disease outcomes among youth living with HIV in East Africa and other low resourced settings.

5. Conclusion

This study highlights the challenges youth living with HIV in low resourced settings face as they transition not only in health care but also into adulthood. Since the number of these youth is projected to increase with time, it is necessary to address their challenges in transitioning to adult care. It is imperative that their recommendations for transition are taken into consideration in order to ensure their retention in the HIV treatment cascade. Investment in health infrastructure and policy is also warranted in order to improve disease outcomes not only among youth living with HIV but all people living with HIV.

Appendix A: In-depth interview guide in Swahili and English

KUNDI A SWAHILI, SEHEMU YA KWANZA
SEHEMU YA KWANZA
Asante sana kwa kujiunga na sisi leo kwa ajili ya mahojiano yako ya kwanza kati ya mawili. Wakati wa mahojiano ya leo na mahojiano yako wakati ujao, tunatumaini kuongelea mpito au mabadiliko ya matunzo ya afya na wewe. Mabadiliko ya matunzo ya afya ni maneno yanayotumika kuelezea wakati wagonjwa vijana wadogo kama wewe wanapohamisha matunzo toka Teen Club kwenda CTC ya Watu wazima. Mazungumzo yetu leo yatadumu kati ya dakika 45 hadi saa moja. Ili kujifunza kuhusu vipengele tofauti vya mchakato wa mabadiliko, tutajadili mada kama mabadiliko, msaada wa kijamii, hali ya uchumi-jamii, mahusiano, unyanyapaa, kujitawala, kufuata utaratibu wa ART au dawa za kupunguza makali ya VVU kwa uaminifu, na wajibu. Unachotushirikisha leo kitatumiwa kutengeneza itifaki ya uhamaji, ambayo itawasaidia vijana kwa kipindi chote cha mabadiliko.
KUJENGA MAELEWANO/ KUPELELEZA UTAMBUZI BINAFSI
1. Niambie kidogo kuhusu wewe mwenyewe.
2. Niambie kuhusu shule.
3. Niambie kuhusu shughuli yako ya kuingiza kipato au malengo yako ya kuingiza kipato kama bado hujaanza kufanya hivyo.
HALI YA MAISHA NA HALI YA KIUCHUMI KIJAMII
4. Sasa, ningependa kusikia kuhusu hali yako ya maisha.
KLABU YA VIJANA WADOGO
5. Sasa ningependa kuongelea Klabu ya vijana wadogo. <ul style="list-style-type: none"> Niambie kuhusu Klabu ya Vijana.
MABADILIKO/MPITO
6. Mpito wa matunzo ya afya ni maneno yanayotumiwa kuelezea pale wagonjwa vijana wadogo kama wewe wanahama matunzo/huduma kutoka Klabu ya Vijana kwenda CTC ya Watu wazima. Hebu niambie kuhusu mchakato wako wa mpito.
KLINIKA YA WATU WAZIMA
7. Ungependelea CTC yako iweje?
8. Sasa, nitataka kujua kuhusu afya yako.
KIJAMII
9. Sasa ningetaka kujua kuhusu watu muhimu katika maisha yako.
KUKUA
10. Sasa ningetaka kujua zaidi kuhusu kuwa kwako mtu mzima
KUFUNGA MAHOJIANO
11. Ni kitu gani kingine ambacho sijakuuliza unachofikiri ninahitaji kukijua?
Ninapenda kukushukuru kwa kunishirikisha uzoefu wako leo. Kuna kitu kingine chochote kabla hatujafunga haya mahojiano?

KUNDI A SWAHILI, SEHEMU YA PILI
SEHEMU YA PILI
MABADILIKO/MPITO
1. Mara ya mwisho, tuliongelea kile kilichotokea wakati wa kuhama kwako, nani alihusika, na nini kilikusisimua au kukuogopesha. Leo tungependa kujua kuhusu maoni yako kwa mchakato wa kuhama kwako.
KLINIKA YA WATU WAZIMA
2. Unakumbuka ile CTC bora kabisa ya Watu wazima ambayo uliielezea kwetu kwenye yale mahojiano mara ya mwisho? Leo, tungependa kujua jinsi hiyo CTC halisi ya Watu wazima inavyofanana na ile kliniki yako ya mfano.
3. Unafikiri nini kuhusu Kliniki ya sasa ya CTC ya Watu wazima?
•
4. Nini kinaweza kukuzuia kwenda CTC ya Watu wazima au kumeza dawa zako?
5. Mchakato wa kuhamia CTC ya Watu wazima ulikuwaje?
KUKUA
Unakumbuka wakati tulipoongea mara ya mwisho kuhusu kuwa mtu mzima? Sasa ningependa kujua zaidi kidogo kuhusu kwamba kuwa mtu mzima kuna maana gani kwako.
6. Hebu tuongee kuhusu wajibu.
7. Sasa ningependa kuongelea kujitawala / uhuru binafsi.
MALEZI (kama hana watoto, ruka kipengele hiki cha MALEZI, rejea swali la 4 sehemu ya kwanza)
8. Unaweza kutushirikisha jinsi utaratibu wako wa huduma ya afya ya VVU ilibadilika ulipopata mtoto?
KUDUMISHA HUDUMA YA AFYA
9. Sasa ningependa kujifunza juu ya matunzo yako ya afya juu ya VVU.
KUFUNGA MAHOJIANO
10. Nini kingine sijakuuliza ambacho unafikiri ninatakiwa kujua?
Ningependa kukushukuru kwa kunishirikisha uzoefu wako leo. Je, kuna kitu kingine chochote kabla hatujafunga mahojiano yetu?
GROUP A ENGLISH (HAVE TRANSITIONED), PART 1
IN DEPTH INTERVIEW PART 1
Thank you so much for joining us today for your first of two interviews. During today's interview and your interview in the future, we hope to talk about health care transition with you. Health care transition is a term used to describe when adolescent patients like you transfer care from Teen Club to the Adult CTC. Our conversation today will last between 45 minutes to an hour. In order to learn about different aspects of the transition process, we will discuss topics such as transition, social support, socioeconomic status, relationships, stigma, autonomy, ART adherence, and responsibilities. What you share with us today will be used to create a transition protocol, which will support adolescents throughout their process of transition.
I have a recorder here and I have turned it on. You don't need to pay any attention to it, it will stay here during the interview. The recorder will help me capture all that you share with me today. What we discuss will remain confidential and only the study team will listen to your recording. We ask that you try not to use names during the interview in order to protect your privacy and the privacy of others. Before we begin, is it okay with you if I record this interview?

ESTABLISHING RAPPORT/EXPLORING SELF PERCEPTIONS
1. Tell me a little about yourself.
2. Tell me about school.
3. Tell me about your income generating activity or goals for generating income if you are not already doing so.
LIVING SITUATION AND SOCIOECONOMIC STATUS
4. Now I'd like to hear about your living situation.
TEEN CLUB
5. Now I would like to talk about Teen Club.
TRANSITION
6. Health care transition is a term used to describe when adolescent patients like you transfer care from Teen Club to the Adult CTC. Tell me about your transition process.
PROBES:
ADULT CLINIC
7. What would your ideal Adult CTC look like?
HEALTH
8. Now, I would like to learn about your health.
SOCIAL
9. Now I would like to learn about the important people in your life.
GROWING UP
10. Now I would like to know more about becoming an adult.
CLOSING OF INTERVIEW
11. What else haven't I asked you that you think I should know?
I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?
GROUP A ENGLISH (HAVE TRANSITIONED), PART 2
IN DEPTH INTERVIEW PART 2
1. Last time, we talked about what happened during your transition, who was involved, and what made you excited or scared. Today we would like to learn about your opinion regarding your transition process.
ADULT CLINIC
2. Remember the ideal Adult CTC that you described to us during our interview last time? Today, we would like to learn how the real Adult CTC compares to your ideal clinic.
3. What do you think about the current Adult CTC?
4. What may stop you from going to the Adult CTC or taking your medicine?
5. How was the process of transitioning to the Adult CTC?
GROWING UP
Remember when we talked about becoming an adult last time? Now I would like to learn a bit more about what being an adult means to you.
6. Let's talk about responsibility.
7. Now I would like to talk about autonomy.
PARENTING (If no children, skip PARENTING section, reference Question 4 from Part I)
8. Can you share with us how your HIV health care routine changed when you had a child?
HEALTHCARE MAINTENANCE
9. Lastly, I would like to learn about your HIV health care.
CLOSING OF INTERVIEW

10. What else haven't I asked you that you think I should know?
I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?
KUNDI B SWAHILI, SEHEMU YA KWANZA
SEHEMU YA KWANZA
KUJENGA MAELEWANO/ KUPELELEZA UTAMBUZI BINAFSI
1. Niambie kidogo kuhusu wewe mwenyewe.
2. Niambie kuhusu shule.
3. Niambie kuhusu shughuli yako ya kuingiza kipato au malengo yako ya kuingiza kipato kama bado hujaanza kufanya hivyo.
HALI YA MAISHA NA HALI YA KIUCHUMI KIJAMII
4. Sasa, ningependa kusikia kuhusu hali yako ya maisha.
KLABU YA VIJANA WADOGO
5. Sasa ningependa kuongelea Klabu ya vijana wadogo.
KUHAMIA (PMTCT) – KUZUIA UAMBUKIZO TOKA KWA MAMA KWENDA KWA MTOTO
6. Uhamaji wa huduma ya afya ni maneno yanayotumika kuelezea pale wagonjwa vijana kama wewe wanapohama huduma toka Klabu ya Vijana kwenda kliniki ya Watu wazima. Niambie kuhusu mchakato wako wa kuhama toka Klabu ya Vijana kwenda PMTCT
KUHAMIA CTC YA WATU WAZIMA TOKA PMTCT
7. Unafikiri nini kuhusu kuhama kutoka PMTCT kwenda CTC ya Watu wazima?
UCHUNGUZI:
KLINIKA YA WATU WAZIMA KWA WATU AMBAO HAWAJHAMIA CTC YA WATU WAZIMA
8. Ungependelea CTC yako iweje?
AFYA
9. Sasa, nitataka kujua kuhusu afya yako.
KIJAMII
10. Sasa ningetaka kujua kuhusu watu muhimu katika maisha yako.
KUKUA
11. Sasa ningetaka kujua zaidi kuhusu kuwa kwako mtu mzima
KUFUNGA MAHOJIANO
12. Ni kitu gani kingine ambacho sijakuuliza unachofikiri ninahitaji kukijua?
Ninapenda kukushukuru kwa kunishirikisha uzoefu wako leo. Kuna kitu kingine chochote kabla hatujafunga haya mahojiano?
KUNDI B SWAHILI, SEHEMU YA PILI
SEHEMU YA PILI
KUHAMIA PMTCT
1. Mara ya mwisho, tuliongea kuhusu ni nini kilitokea kipindi cha uhamaji wako kwenda PMTCT, nani alihusika, nini kilikusisimua au kukuogopesha. Leo tungependa kujua kuhusu maoni yako juu ya mchakato wako wa kuhama.
<ul style="list-style-type: none"> Nini mapendekezo yako kwa uhamaji kwenda PMTCT siku za baadaye kwa vijana wanaokuwa na ujuzito?

MABADILIKO/MPITO
2. Mara ya mwisho, pia tuliongea kuhusu uhamaji kwenda Kliniki ya watu Wazima, ni nini umejifunza kuhusu kliniki hii hadi sasa, na ni nini kinakusisimua au kukuogopesha. Leo tungependa kujua kuhusu maoni yako juu ya mchakato wa kuhamia kliniki ya watu wazima.
KLINIKA YA WATU WAZIMA
3. Unakumbuka ile CTC bora ya Watu wazima ambayo ulituelezea kwenye mahojiano mara ya mwisho? Leo tungependa kujua jinsi CTC halisi ya Watu wazima inavyofanana na hiyo kliniki yako ya mfano bora.
KUKUA
Unakumbuka wakati tulipoongea mara ya mwisho kuhusu kuwa mtu mzima? Sasa ningependa kujua zaidi kidogo kuhusu kwamba kuwa mtu mzima kuna maana gani kwako.
4. Hebu tuongee kuhusu wajibu.
5. Sasa ningependa kuongelea kujitawala / uhuru binafsi.
UJAUZITO
6. Unaweza kutuambia jinsi utaratibu wako wa huduma ya VVU ulivyobadilika ulipopata ujauzito?
KUDUMISHA HUDUMA YA AFYA
7. Sasa ningependa kujifunza juu ya matunzo yako ya afya juu ya VVU.
KUFUNGA MAHOJIANO
8. Nini kingine sijakuuliza ambacho unafikiri ninatakiwa kujua? Ningependa kukushukuru kwa kunishirikisha uzoefu wako leo. Je, kuna kitu kingine chochote kabla hatujafunga mahojiano yetu
GROUP B ENGLISH (TRANSITIONED DUE TO PREGNANCY), PART 1
IN DEPTH INTERVIEW PART 1
ESTABLISHING RAPPORT/EXPLORING SELF PERCEPTIONS
1. Tell me a little about yourself.
2. Tell me about school.
3. Tell me about your income generating activity or goals for generating income if you are not already doing so.
LIVING SITUATION AND SOCIOECONOMIC STATUS
4. Now I'd like to hear about your living situation.
TEEN CLUB
5. Now I would like to talk about Teen Club.
PMTCT TRANSITION
6. Health care transition is a term used to describe when adolescent patients like you transfer care from Teen Club to an Adult clinic. Tell me about your transition process from Teen Club to PMTCT.
TRANSITION TO ADULT CTC FROM PMTCT
7. What do you think about transitioning from PMTCT to Adult CTC? PROBES:
ADULT CLINIC FOR THOSE WHO HAVE NOT TRANSITIONED TO ADULT CTC
8. What would your ideal Adult CTC look like? PROBES:
HEALTH
9. Now, I would like to learn about your health.
SOCIAL
10. Now I would like to learn about the important people in your life.
GROWING UP

11. Now I would like to know more about becoming an adult.
CLOSING OF INTERVIEW
12. What else haven't I asked you that you think I should know? I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?
GROUP B ENGLISH (HAVE TRANSITIONED DUE TO PREGNANCY), PART 2
IN DEPTH INTERVIEW PART
PMTCT TRANSITION
1. Last time, we talked about what happened during your transition to PMTCT, who was involved, and what made you excited or scared. Today we would like to learn about your opinion regarding your transition process.
TRANSITION
2. Last time, we also talked about transitioning to the Adult Clinic, what you have learned about it so far, and what makes you excited or scared. Today we would like to learn about your opinion regarding this transition process to adult clinic.
ADULT CLINIC
3. Remember the ideal Adult CTC that you described to us during our interview last time? Today, we would like to learn how the real Adult CTC compares to your ideal clinic.
GROWING UP
Remember when we talked about becoming an adult last time? Now I would like to learn a bit more about what being an adult means to you.
4. Now I would like to talk about responsibility.
5. Now I would like to talk about autonomy.
PREGNANCY
6. Can you share with us how your HIV health care routine changed when you got pregnant?
PROBES:
HEALTHCARE MAINTANENCE
7. Now I would like to learn about your HIV health care.
CLOSING OF INTERVIEW
8. What else haven't I asked you that you think I should know?
I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?
KUNDI C SWAHILI, SEHEMU YA KWANZA
SEHEMU YA KWANZA
KUJENGA MAELEWANO/ KUPELELEZA UTAMBUZI BINAFSI
1. Niambie kidogo kuhusu wewe mwenyewe.
2. Niambie kuhusu shule.
3. Niambie kuhusu shughuli yako ya kuingiza kipato au malengo yako ya kuingiza kipato kama bado hujaanza kufanya hivyo.
HALI YA MAISHA NA HALI YA KIUCHUMI KIJAMII
4. Sasa, ningependa kusikia kuhusu hali yako ya maisha.
KLABU YA VIJANA WADOGO
5. Sasa ningependa kuongelea Klabu ya vijana wadogo.
MABADILIKO/MPITO KWA WATU AMBAO HAWAJAHAMIA CTC YA WATU WAZIMA
6. Huduma ya afya ya mpito/mabadiliko ni maneno yanayotumika kuelezea vijana kama wewe ambao wanatoka kwenye huduma ya klabu ya vijana kwenda Ctc ya watu wazima au kliniki ya watu wazima. Unafikiri nini kuhusu kuhama kutoka PMTCT kwenda CTC ya Watu wazima?

KLINIKA YA WATU WAZIMA KWA WATU AMBAO HAWAJAHAMIA CTC YA WATU WAZIMA
7. Ungependelea CTC yako iweje?
AFYA
8. Sasa, nitataka kujua kuhusu afya yako.
KIJAMII
9. Sasa ningetaka kujua kuhusu watu muhimu katika maisha yako.
KUKUA
10. Sasa ningetaka kujua zaidi kuhusu kuwa kwako mtu mzima
KUFUNGA MAHOJIANO
11. Ni kitu gani kingine ambacho sijakuuliza unachofikiri ninahitaji kukijua?
Ninapenda kukushukuru kwa kunishirikisha uzoefu wako leo. Kuna kitu kingine chochote kabla hatujafunga haya mahojiano?
KUNDI C SWAHILI, SEHEMU YA PILI
SEHEMU YA PILI
MABADILIKO/MPITO
1. Mara ya mwisho, pia tuliongea kuhusu uhamaji kwenda Kliniki ya watu Wazima, ni nini umejifunza kuhusu kliniki hii hadi sasa, na ni nini kinakusisimua au kukuogopesha. Leo tungependa kujua kuhusu maoni yako juu ya mchakato wa kuhamia kliniki ya watu wazima.
KLINIKA YA WATU WAZIMA
2. Unakumbuka ile CTC bora ya Watu wazima ambayo ulituelezea kwenye mahojiano mara ya mwisho? Leo tungependa kujua jinsi CTC halisi ya Watu wazima inavyofanana na hiyo kliniki yako ya mfano bora.
KUKUA
Unakumbuka wakati tulipoongea mara ya mwisho kuhusu kuwa mtu mzima? Sasa ningependa kujua zaidi kidogo kuhusu kwamba kuwa mtu mzima kuna maana gani kwako.
3. Hebu tuongee kuhusu wajibu.
4. Sasa ningependa kuongelea kujitawala / uhuru binafsi.
UCHUNGUZI:
MALEZI (kama hana watoto, ruka kipengele hiki cha MALEZI, rejea swali la 4 sehemu ya kwanza)
5. Unaweza kutushirikisha jinsi utaratibu wako wa huduma ya afya ya VVU ilibadilika ulipopata mtoto?
KUDUMISHA HUDUMA YA AFYA
6. Sasa ningependa kujifunza juu ya matunzo yako ya afya juu ya VVU.
KUFUNGA MAHOJIANO
7. Nini kingine sijakuuliza ambacho unafikiri ninatakiwa kujua?
GROUP C ENGLISH (HAVE NOT YET TRANSITIONED), PART 1
IN DEPTH INTERVIEW PART 1
ESTABLISHING RAPPORT/EXPLORING SELF PERCEPTIONS
1. Tell me a little about yourself.
2. Tell me about school.
3. Tell me about your income generating activity or goals for generating income if you are not already doing so.
LIVING SITUATION AND SOCIOECONOMIC STATUS
4. Now I'd like to hear about your living situation.
TEEN CLUB
5. Now I would like to talk about Teen Club.
TRANSITION FOR THOSE WHO HAVE NOT TRANSITIONED

6. Health care transition is a term used to describe when adolescent patients like you transfer care from Teen Club to the Adult CTC. What do you think about transition?
ADULT CLINIC FOR THOSE WHO HAVE NOT TRANSITIONED TO ADULT CTC
7. What would your ideal Adult CTC look like?
HEALTH
8. Now, I would like to learn about your health.
SOCIAL
9. Now I would like to learn about the important people in your life.
GROWING UP
10. Now I would like to know more about becoming an adult.
CLOSING OF INTERVIEW
11. What else haven't I asked you that you think I should know?
I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?
GROUP C ENGLISH (HAVE NOT YET TRANSITIONED), PART 2
IN DEPTH INTERVIEW PART 2
TRANSITION
1. Last time, we talked about transition, what you have learned so far, and what makes you excited or scared. Today we would like to learn about your opinion regarding the transition process.
ADULT CLINIC
2. Remember the ideal Adult CTC that you described to us during our interview last time? Today, we would like to learn how the real Adult CTC compares to your ideal clinic.
GROWING UP
Remember when we talked about becoming an adult last time? Now I would like to learn a bit more about what being an adult means to you.
3. Let's talk about responsibility.
4. Now I would like to talk about autonomy.
PARENTING (if no children, skip this section).
5. Can you share with us how your HIV health care routine changed when you had a child?
HEALTHCARE MAINTENANCE
6. Lastly, I would like to learn about your HIV health care.
CLOSING OF INTERVIEW
7. What else haven't I asked you that you think I should know?
I would like to thank you for sharing your experiences with me today. Is there anything else before we conclude the interview?

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