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**Moving from Pediatric to Adolescent HIV care in Northern Tanzania: Exploring Transition Services, Perceptions and Self-care during Early Adolescence**

Student:
**Esther David Lisasi**

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**Main Supervisors:**

***Prof. Mary-Ann Davies***
Centre for Infectious Diseases Epidemiology and Research and
Division of Public Health Medicine,
School of Public Health, University of Cape Town

***Prof. Kathleen J Sikkema***
Department of Sociomedical Sciences
Mailman School of Public Health
Columbia University

***Prof. Blandina T Mmbaga***
Pediatrician and Director of Kilimanjaro Christian Research Institute (KCRI)
Kilimanjaro Christian Medical Centre (KCMC)

***Prof. Christopher J Colvin***
Department of Public Health Sciences
University of Virginia

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Declaration

I, Esther David Lisasi, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Date: 2nd February 2024

Signed by candidate

## LIST OF ACRONYMS

| | |
|---|---|
| **AIDS** | Acquired Immunodeficiency Syndrome |
| **ART** | Antiretroviral therapy |
| **ARVs** | Antiretrovirals (i.e. 2 or more drugs) |
| **FGD** | Focus group discussions |
| **CDC** | Centres for Disease Control |
| **CD4** | Cluster of Differentiation |
| **CTC** | Care and Treatment Clinic |
| **CTC2** | Care and Treatment Clinic Database |
| **EFV** | Efavirenz |
| **HIV** | Human Immunodeficiency Virus |
| **HEID** | HIV Early Infant Diagnosis |
| **IDIs** | In-depth interviews |
| **IQR** | Inter Quartile Range |
| **KCMC** | Kilimanjaro Christian Medical Centre |
| **NACP** | National AIDS Control Program |
| **NIMR** | National Institute of Medical Research |
| **NVP** | Nevirapine |
| **PI** | Protease Inhibitors |
| **PMTCT** | Prevention of mother-to-child transmission of HIV |
| **SEM** | Social-ecological Model |
| **SSA** | Sub-Saharan Africa |
| **WHO** | World Health Organization |

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**ABSTRACT**

Given the increased survival of children with perinatally acquired HIV into adolescence due to increased coverage and access to antiretroviral therapy (ART) for children in Sub Saharan Africa (SSA), the pediatric-to-adolescent transition in HIV care is now of public health importance. There is, however, limited information available regarding pediatric-to-adolescent transition practices and how best to transition adolescents with perinatally acquired HIV from pediatric to adolescent HIV care clinics in Tanzania. This study therefore sought to understand how best to move adolescents with perinatally acquired HIV from pediatric to adolescent HIV care in Northern Tanzania during early adolescence. The specific objectives were:

1. To understand the current organization of pediatric-to-adolescent transitional care services and how this organization affects the perceptions and attitudes of transitioning adolescents during early adolescence.
2. To explore contextual factors other than service delivery that affect adolescents' and their caregivers' perceptions and attitudes towards transition before and after the move to adolescent clinics.
3. To understand the immediate effects of the transition from pediatric to adolescent care on medication adherence and clinic attendance management during early adolescence.

**Methods**

This was a mixed methods study that was carried out in three phases at two adolescent clinics in Northern Tanzania (KCMC zonal referral hospital and Mawenzi regional hospital). The first phase of the study was quantitative and used routinely collected clinical data of 345 adolescents aged ten to 18 years who were receiving HIV care in both hospitals. The second phase was a qualitative exploratory study that used in-depth interviews (IDIs) with eight adolescents who had already moved from pediatric to adolescent clinic. The third phase was a one-year longitudinal qualitative study that included repeated IDIs and focus group discussions with eight adolescents who were about to transition to adolescent clinics, eight of the adolescents' caregivers and ten service providers.

**Results**

Findings from the quantitative study show that there was no difference in socio-demographic and clinical characteristics of adolescents between the two hospitals and between transitioned and untransitioned adolescents. However, viral load suppression remained a challenge in many adolescents, regardless of whether they had transitioned to adolescent clinic or not. Despite three years of transitioning adolescents from pediatric to adolescent clinic, a huge backlog persisted,

with 46% of eligible adolescents in the 13-18-year age group still receiving care in pediatric clinic at both hospitals indicating a service gap in the transition process.

Exploration of the organization of pediatric-to-adolescent transition using qualitative methods revealed that disclosure of adolescents' HIV status was the essential factor to the pediatric-to-adolescent transition. All adolescents had to be aware of their HIV status prior moving to the adolescent clinics. Medication adherence, virologic assessment, type of regimen, psychosocial maturity and mental health were also identified as critical aspects of readiness assessment prior to moving to adolescent clinic. High levels of caregiver engagement, interaction, communication, and support were required to guide the transition, particularly for caregivers living with HIV who have been receiving HIV care together with their adolescents since childhood. Overall, there was a well-established transition practice. However, the lack of written protocols/national guidelines and the limited availability of human resources were the limiting factors to the provision of evidence-informed transition practices. Hence, variations in pediatric-to-adolescent transition practices across healthcare facilities in Tanzania are likely to occur given the absence of national guidelines governing this process.

Exploration of influential factors revealed that psychosocial adjustment following disclosure, perceived self-efficacy, perceived stigma as well as feelings of personal responsibility, privacy and confidentiality at the clinic were all individual level factors that affected acceptability of the adolescent clinic and adolescents' continuation with care after transition At caregiver level, caregiver readiness and especially caregivers living with HIV who are also required to transition to adult clinic, fear of stigma and critical events in the family influenced caregivers' decisions regarding the pediatric-to-adolescent transition. At all stages of the transition to adolescent clinic, peer influence and support were important factors. The organization of transition services also affected adolescents' decisions and care continuity, especially in health facility settings where moving to a different clinic could lead to HIV identification. Transition practices requiring adolescents to move to an adult clinic in the event of pregnancy or marriage before age 24 limited pediatric-to-adolescent transition success. Finally, broader structural factors such as the education system where adolescents in grade seven are required to attend classes on Saturdays and the religion where most adolescents attend religious (confirmation and madrassa) classes on Saturdays also influenced adolescents' and caregivers' perceptions towards this transition. Lastly, since many adolescents in Tanzania attend boarding schools, these impacted not only the pediatric-to-adolescent transition process but also continuity with HIV care due to a lack of HIV services in boarding schools and lack of privacy in keeping and taking of one's medicines.

Immediate effects of the pediatric-to-adolescent transition on the level of responsibilities assumed by adolescents were mixed. In some adolescents, the pediatric-to-adolescent transition resulted in an increase in medication adherence and clinic attendance responsibilities, whereas in others, medication adherence and clinic attendance responsibilities decreased or were unaffected. Several factors contributed to these outcomes which include peer influence, peer support, sense of responsibility for one's health, the level of caregivers' engagement in these activities, adolescents' living conditions and fear of stigma. Adolescents appeared to often assume responsibilities for medication adherence and clinic attendance well before the transition period and adolescents of caregivers living with HIV assumed more responsibilities than other adolescents. However, there was no national transition guide to assist healthcare workers in providing systematic and evidence-based support to caregivers in transferring autonomy to adolescents for clinic attendance and medication adherence related tasks. As a result, it may be challenging to ensure smooth transition of responsibilities from caregivers to adolescents in a chronologically, developmentally, behaviorally, clinically, psychologically and culturally appropriate manner for the Tanzanian context.

**Conclusion**

In conclusion, the pediatric-to-adolescent transition of HIV care for adolescents living with perinatally acquired HIV is a bi-faceted (adolescent and caregivers), multi-stage (from disclosure to transition to adult clinic) and ongoing process that needs to attend to the medical, psychosocial, and developmental needs of adolescents at all stages as well as caregivers' needs. This pediatric-to-adolescent transition provides a chance to strengthen adolescents' autonomy and connections to their peers and friends which is an important psychosocial aspect of HIV care and highly valued by adolescents. Therefore, with adequate planning, oversight, and adolescent and caregiver involvement in all transition stages, pediatric-to-adolescent transitional programs can increase adolescents' engagement in care, lead to timely identification of risk factors influencing this transition, and eventually foster self-care to transitioning adolescents.

**DEFINITION OF TERMS**

**An adolescent** is anyone between the ages of 10 – 19 years.

**A young person** is anyone between the ages of 15 -24 years.

**A caregiver** is any adult (aged ≥18 years), usually the parents or anyone who has the responsibility of taking care of children/adolescents.

**Early adolescence** is the period between 10-14 years of age.

**Pediatric-to-adolescent transition** is the move over time from child-centered care to adolescent centered care/Teen clubs.

**Pediatric-to-adult transition** is a "purposive planned movement of adolescents from child centered care to adult centered care" [1].

**Transition experiences is** the "experience of an individual who is confronting, living with and coping with an event/situation/stage of growth or development that requires new skills, goals, behavior or function" [2].

**A successful transition** is the one where "feelings of distress are replaced with a sense of well-being and mastery of a change event" [2].

**A transitioned adolescent** is an adolescent who has already moved to adolescent clinic from pediatric clinic.

**An untransitioned adolescent** is an adolescent who is eligible to move to adolescent clinic but is still attending pediatric clinic.

# CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

## 1.1 Introduction

There is a growing body of literature that recognizes the transition from childhood to adolescence among children living with Human Immunodeficiency Virus (HIV) in developing countries. Due to rapid expansion and uptake of pediatric antiretroviral therapy (ART) during the last two decades, children living with HIV now frequently survive to adolescence thereby contributing to the number of adolescents (10-19 years of age) living with HIV. Globally, it is estimated that there are approximately 1,750,000 adolescents (10-19 years) living with HIV of whom 1,540,000 (88%) are living in Sub Saharan Africa (SSA) [3]. Nearly 60% of these adolescents are currently receiving ART [4]. However, although the number of Acquired Immunodeficiency Syndrome (AIDS) related deaths among adolescents has decreased by 10% since 2003, this is fare lower than the than 74% decrease in AIDS-related fatalities among children aged 0 to 9 years and the 64% decrease in deaths across all age groups[5] Currently, the AIDS related mortality rate among adolescents (10-19 years) globally stands at 2.59 deaths per 100,000 adolescent population with SSA having the highest mortality rate of 11.75 deaths per 100,000 adolescent population [3].

Tanzania is home to 6.3% of all adolescents (10-19 years) living with HIV globally and accounts for 7.1% of adolescents (10-19 years) living with HIV in SSA [3]. It is estimated that there are 96,000 adolescents (10-19 years) living with HIV of whom 75.8% (n=73,000) are currently receiving ART [6]. These adolescents represent 4.9% of all people living with HIV (n=1,500,000) who are receiving ART in Tanzania [7].

The ART program for children in Tanzania started in 2005 and children aged 5–14 years have since then constituted the most predominant group (>50%) with a smaller number of infants and 1- 4 year old children [8, 9]. In 2008, there were 15, 700 children (0-14 years) on ART [10], this increased to 58,047 by December 2021 [6]. Around 60% of children started on ART are still alive and currently receiving ART [11, 12]. AIDS related deaths among children (0-14 years) declined from 10,000 in 2011 to 6,100 in 2021 [7], hence the number of adolescents with perinatally acquired HIV in Tanzania is increasing. Currently, there are 27,000 adolescents (10-14 years) who are receiving ART in Tanzania [6].

*Transition from pediatric to adolescent HIV care*

It is well known that as children grow into early adolescence (10-14 years), receiving HIV care in pediatric settings may not be appropriate according to their developmental needs. Thus, several interventions to address adolescent needs ranging from individual, health facility, community, and policy level have been initiated in Tanzania. Establishment of adolescent clinics is one the initiatives adopted by many hospitals providing HIV care in Tanzania. In most settings, the transition from pediatric to adolescent clinic is done in the same clinic settings, with services provided on Saturdays using the same pediatric providers while pediatric clinics are scheduled once a week, specifically on Tuesdays, to provide clinical care for children and their caregivers who are living with HIV. Currently, adolescent HIV services are mainly provided at hospital level with very few at clinic level in urban areas. Despite the ongoing transition of adolescents from pediatric to adolescent HIV clinics, to our knowledge there are no written guidelines/protocols on how to move adolescents from pediatric care to adolescent care and different transition practices exist depending on the local and international partner implementing HIV care and treatment programs in different regions.

In Northern Tanzania, Kilimanjaro region, two hospitals, Kilimanjaro Christian Medical Centre (KCMC) (the referral hospital in northern Tanzania) and Mawenzi hospital (Kilimanjaro regional referral hospital), are among the hospitals that have established adolescent clinics for all irrespective of the mode of acquisition. The Mawenzi hospital started providing adolescent focused services in 2014 while KCMC established the youth clinic in 2008. Currently there are over 500 adolescents with perinatally and non-perinatally acquired HIV (10-18 years) receiving care in these two hospitals. Transition to adolescent clinic usually begins at the ages of 10-12 years and by 16 years of age, preparations for transition from adolescent to adult HIV care begin. There are no written guidelines about how transition occurs but "full disclosure" of adolescent HIV status is one of the prerequisites for an adolescent to move from pediatric to adolescent care in both hospitals. "Full disclosure" occurs when a child or adolescent knows the name of the disease they have, how they acquired the infection and how they can transmit the infection to others. In Mawenzi and KCMC hospitals, if caregivers have not fully disclosed to the adolescent about their HIV status, then disclosure is done by clinic staff. Full disclosure of adolescents' HIV status has been recommended by WHO [13] while the American Academy of Pediatrics guidelines on disclosure of illness status to children recommend that children of school age should be told their HIV status [14]. Similarly the National HIV and AIDS Control Program (NACP) of Tanzania recommends partial disclosure of HIV status at the age of four years and full disclosure by ten

years [15]. Full disclosure of adolescent HIV status during transition is critical as studies have shown that if adolescents are not fully disclosed about their HIV status, they may get left with partial disclosure without ever knowing the name of their disease, how they became infected or can transmit the disease. Since it is difficult to encourage autonomy for adolescents who do not know their status [16] full disclosure should be one of the primary goals for adolescents before transition to adult care [17].

Central to the entire discipline of transition is the concept of transition experience. Transition experience is an important aspect that reflects how one experiences the passage or movement from one state, condition or place to another[18]. Since adolescence is itself a critical stage and adolescents are at the same time undergoing transition from pediatric to adolescent HIV care, adolescents may be very vulnerable to risks that may affect their health and wellbeing. It is therefore important to understand their transition experiences to be able to develop interventions that will not only help them to regain stability and a sense of wellbeing but also maintain continuity of care. Factors influencing adolescent experiences within the context of the transition to adolescent care are not yet known.

As the adolescents move from pediatric to adolescent HIV care, they at the same time undergo developmental transition where personal growth and development increases while the role of caretakers in ensuring treatment adherence starts to decrease [19]. Further, it is the time when adolescents wish for independence from their caregivers/parents in making choices and decisions [20] and they may no longer wish to be accompanied by their caregivers/parents to HIV clinics. More specifically, early adolescence is an important phase in the development of self-care abilities. It is during this time that children start to develop the ability to think logically and understand the causes and effects of diseases and become aware that the disease that afflicts them requires that they have adequate maintenance of ART medication and regular clinic appointments [21].

Evidence shows that as children grow into adolescence, the role of the caregivers gradually decreases with the adolescents assuming more responsibilities in maintenance of medication adherence and clinic appointments [22, 23]. Questions however remain unanswered specifically in the context of HIV among adolescents with perinatally acquired HIV and include: 1) How does transition to self-care (medication adherence and clinic appointments) occur in the context of early adolescence, (2) What factors influence transition to self-care, (3) Does the move from pediatric to adolescent HIV clinic have any immediate effect on the transition to self-care during

early adolescence?

This study seeks to understand the ways in which transition from pediatric to adolescent HIV care in Northern Tanzania occurs and how adolescents and caregivers feel about and experience the transition practices. It will identify contextual factors influencing their transition perceptions and explore how transition to self-care occurs during early adolescence, focusing on medication adherence and clinic appointment management. Ultimately the study will explore the immediate effects of the move from pediatric to adolescent clinic on the transition to self-care. The two adolescent clinics in Northern Tanzania will provide an opportunity to explore these objectives and hence provide recommendations for successful transition to adolescent care during early adolescence in the Northern Tanzania context and other similar settings.

### 1.2 Literature Review

The literature review on pediatric-to-adolescent transition focuses on three prominent themes; 1) Organization of transition services, 2) Factors influencing perceptions and attitudes towards transition and, 3) Transition to self-care in the context of HIV and other chronic illnesses. A literature search was conducted on databases Medline, Scopus and Web of Science. The search words (transition OR move OR transitional care) AND (pediatric OR child OR adolescent OR youth) AND (HIV or AIDS or antiretroviral) were used. Bibliographies of relevant articles were followed. Studies were included in the review if they included either transition experiences of adolescents, caregivers or services providers or described transition practices and self-care. Thus, the literature review is structured in a cohesive way as follows:

- The organization of transitional services from pediatric to adolescent care.
- Factors influencing adolescents', caregivers' and service providers' perceptions and attitude towards transition.
- Transition to self-care in the context of early adolescence.

#### 1.2.1 Organization of transition services

**The organization of transition services from pediatric-to-adolescent care**

There are differences in defining the term "transition" in health [24]. Most literature in health (not limited to pediatric/adolescent HIV) describes transition as the purposeful and planned movement from childhood/adolescent centered care to adulthood care [1]. However, others have defined transition as the cognitive, behavioral, and interpersonal processes that develop in an

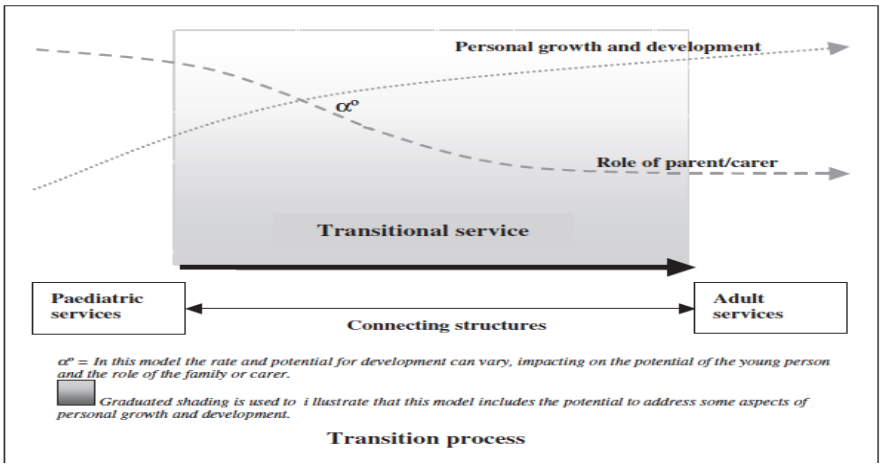
individual during a transition that can either lead to a successful[1] or unsuccessful transition [25]. In other words, the second definition includes the inner reorientation and self-redefining that a person undergoes in order to incorporate change in his/her life.

The majority of research examining transition in the HIV context has used the definition "purposeful and planned movement from childhood/adolescent centered care to adulthood care." Likewise, in the context of other chronic illnesses such as cystic fibrosis, diabetes etc., the focus has been mainly on the transition from pediatric to adult care [26-29]. Thus, there is very limited literature on transition services and perceptions specifically focused on adolescents moving from pediatric to adolescent HIV care in the HIV context. In this study, insights from the transition to adult care have been used in cases where there is no specific research on the transition from pediatric to adolescent HIV care.

**Organization of transition services in the context of chronic illnesses**

When exploring the transition services among children with chronic illness, the situational transition model developed by While et al. (2004) described a transition practice that focuses on personal growth and development of the transitioning client. They proposed that as children with chronic illnesses move from pediatric-to-adolescent/adult care, they at the same time experience developmental transition. Thus the two transitions go hand in hand and it may be difficult to address one type of transition without the other [30]. Figure 1 below explains how the two transitions relate to each other.

Figure 1: Situational transition Model




Source: While et al., 2004

[1] A successful transition is one where feelings of distress are replaced with a sense of well-being and mastery of a change event (Schumacher & Meleis, 1994).

This model further elaborated that as adolescents move from pediatric to adult care, they experience increases in personal growth and their role in self-care while the roles of the caregivers start to decrease. Therefore, the transitioning adolescents require preparation for self-care which the transitional services should be geared towards providing [30]. The caregivers also play critical roles in facilitation of the transition to self-care by redefining their own roles through giving the young people more authority on self-care decisions. Ultimately, provision of adolescent services by connecting structures between the pediatric and adult services are critical intervening steps in the transition from pediatric to adult services.

In practice, transition services to adult care for children with chronic illness and disabilities usually begins by identifying the eligible transition candidates and key areas that need to transition followed by bringing the stakeholders together to identify/discuss transition issues. Transitional planning and agreement then follow with the transitioning candidate being given the necessary resources to facilitate transitioning into adult care. Finally evaluation of the transition is assessed [30]. These practices were identified by While et al. (2004) as recurring themes or core principles of practices that emerged through reviewing 126 articles describing transition practices among children with chronic illnesses or conditions; namely diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy [30]. However, despite the large number of transition practices found, it was not known whether these practices can eventually promote continuity into adult care after transition due to weak or varied evidence from these studies as only three of the articles had strong external validity i.e. findings that could be generalized to other situations or people. Furthermore, very little evidence exists on the outcomes of the adolescents with HIV following transition to adult care from Africa settings [31].

A study carried out by Carrizosa et al. (2014) is a good illustration of how the organization of transition services in the context of epilepsy varies across different places i.e. Canada, France, Germany, UK and Colombia [26]. For example, in Canada, practices included the pediatric epilepsy specialist giving a referral note to the family to attend the adult setting, a pediatric epilepsy specialist going with the client and their family to the adult epilepsy clinic, the adult epilepsy specialist attending pediatric clinic and seeing the clients ready for transfer, or both the adult and the pediatric epilepsy specialists seeing the clients together before the actual transfer. In France, transition of epileptic adolescent/youths to adult care occurred early even if there was no complete control of seizures due to the perception that delayed transition may hinder family acceptance of transfer. In Colombia transition services were offered in private hospitals only with

neither guidelines nor protocols. In the UK there was a dedicated transition service for youth that provided not only adolescent care but also addressed the evolving needs pertaining to adulthood and access to career and employment information in the clinic waiting area [26].

**Organization of transition services in the context of HIV**

Transitioning of care for adolescents living with HIV has been well described in a USAID/PEPFAR technical brief [32] and in the policy statement of The American Academy of Pediatrics [33]. However, these documents mainly focus on the transition to adult care by providing guidance/recommendations for adolescents' preparation for transition to adult care. Similarly, the "Moving on positively guide, 2012" for adolescents, caregivers and service providers provides guidance on preparing adolescents for adult HIV care [34]. Since the focus of these guides is on transition to adult HIV care, little attention has been paid on how to move adolescents from pediatric to adolescent HIV care in these guides. This may be due to fewer logistical issues involved in the pediatric-adolescent transition as it mainly occurs within the same clinical settings with the same service providers when compared to transition to adult care that has more logistical issues.

As stated earlier in this literature section, insights from the transition to adult care have been used where there was no/ limited information on the pediatric-adolescent transition. Nonetheless, the organization of transition to adult care services in the HIV context has mainly been described from developed countries with few publications from developing countries. All these transition practices were developed following the need to link pediatric and adult HIV care services [35, 36] and the high attrition rate of youths following the transition to adult care [35]. The adolescent and young adult population used in developing these models/practices mostly (>90%) had behaviorally acquired HIV while adolescents with perinatally acquired HIV accounted for less than 10% of this population [35, 36].

Despite few articles that describe the organization of transition [43], a recent literature review of transition of youth living with HIV from pediatric to adult care, six core elements of transitional care are identified [37] as follows: (1) availability of a transition and care policy and guide that describe the transition practice and roles of the transitioning adolescents, caregivers and service providers; (2) tracking and monitoring so that transition criteria and the process of identifying eligible youth is established; (3) transition readiness assessment that assesses transition readiness of both caregivers and youths, discusses self-care needs with caregivers and establishes a process to welcome and orient the transitioning youths, (4) transition planning of the optimal

timing of transfer, obtaining consent from caregivers and integration of the transitioning youths to the new environment, (5) actual transfer of care following accomplishment of all arrangements to receive the newcomer and the adolescent being as stable as possible, (6) transfer completion and ongoing care in which support tailored to each youth is provided to connect with the new environment [37].

Gilliam et al. (2011) described the characteristics and practices in transition of adolescents from 14 clinics of the Adolescent Trials Network for HIV/AIDS Interventions in the United States of America (USA). They showed that there is diversity in transition practices and only 6 clinics had written guidelines on transition. Some of the practices included gradual introduction to the adult providers, tours to the adult clinics during transition, having a case manager or peer educator and a member of the adolescent's family or support group that accompanies adolescents during clinic visits, and use of a nurse practitioner or psychiatrist to manage the adolescents care during transition [38].

In a specialized adolescent HIV clinic at the University of Miami, transition to adult care starts when the client is about to reach the transition age (23 years of age) with discussions on the need to transition held on several repeated occasions. When the client has reached the transition age they meet physicians from the setting to which they will transition. If the client is resistant to move to adult clinic, the social workers and peer educators support them during this stage. When the client is ready to move, they start receiving routine HIV care at the adolescent clinic from the adult physician and the social workers assist clients to feel comfortable with the physicians. Once the client is comfortable with the physician, scheduled appointments to be seen by the same physician in the transitioned clinic are made. The last phase is the follow up of the clients in the transitioned clinic by the psychosocial team. Throughout all phases, the medical and psychosocial teams provide support to the clients. This practice, 'the moving out" transition model, was evaluated using 38 adolescents whereby half of the participants were able to successfully transition to adult care. Those who did not transition were mainly lost to follow up, transferred or relocated clients [39]. However, applicability of this model/practice in a resource-limited setting with over-burdened services is limited due to very intense human resources required to implement it.

In Uganda, the transition process for young adults living with HIV from a youth clinic to an adult HIV care clinic was described at the Infectious Disease Institute of Makerere University [36]. No details were however provided on how this practice was developed. Transition begins by identifying an eligible young adult and referring them to the counselor who provides their first

counseling session on transition. The young adult then meets the care provider after the first counseling session who introduces the subject of transition. The young adult then receives a second counseling session from the counselor on transition and the counselor assesses expectation and readiness to transition. If the young adult is not ready for transition, they are retained in the youth clinic and undergo counseling and additional support. If the young adult is ready, they then start attending the adult clinic where there is an annual peer support meeting. However, evaluation of the success of this practice has not been conducted.

In summary, the literature reviewed mainly captured pediatric to adult transition care practices for all children/adolescents with HIV and did not distinguish by likely mode of HIV acquisition. There are limited reports of pediatric-adolescent transition practices. There is also diversity in transition practices in the pediatric-adult transition within different HIV care settings.

### 1.2.2 Factors influencing perceptions and attitudes towards transition

In the past decade, considerable literature has been generated around the theme of transition experiences as children transition to adult care in the context of HIV. Studies have shown that there are many challenges/negative feelings adolescents face during transition that may impair successful transition. These include difficulty letting go of relationships [17, 40, 41], unpreparedness [41, 42], fear of disclosure and confidentiality [16, 17, 43], anxieties [44], disappointments [41], feeling unsupported [36] and negative expectations [40]. As a result of these challenges, transition was either delayed or resisted by the adolescents. On the other hand, preparations for transition [45], feeling comfortable with the new setting and being familiar with the service providers as well as welcoming service providers (i.e. feeling connected) [46] were positive feelings that facilitated adaption to the new setting thus maintaining continuity of care and supporting life style adjustments.

With regard to factors influencing adolescent transition perceptions, these can be categorized into adolescent related, caregiver related, service provider related and health system related which are reviewed below.

#### a) Adolescent related factors

The adolescent related factors influencing adolescents' feelings about transition could either arise from the developmental context of adolescence or outside adolescence. Factors within the adolescent developmental context include the growing desire for privacy and confidentiality, beginning of feeling/expressing embarrassment and shame of their HIV status, fear of being judged by peers and the need for peers' acceptance [47]. There is also a struggle to separate from

parents/caregivers during transfer of responsibilities (this will be reviewed under the transition to self-care section). The following review assesses how these developmental issues have influenced adolescents' perceptions of their transitional journey.

*Privacy and Confidentiality*

There is limited literature on how the desire for privacy and confidentiality plays a role in the transition from pediatric-to-adolescent care during early adolescence. However, in the context of transition to adulthood, studies have shown that older adolescents really value privacy and thus fear being seen to attend an HIV clinic that has an obvious label such an "infectious disease clinic" [38]. Adolescents also value confidentiality and generally do not like re-disclosing their personal and medical histories to new providers [48] and fear that the adult providers will disclose their HIV status to others [44]. When privacy and confidentiality are not assured negative perceptions of transition can result and may impair adolescents' continuity with care.

*Embarrassment and shame*

During adolescence, feeling embarrassed or ashamed of one's HIV status is common. A study in Brazil among adolescents living with HIV showed that shame was a barrier towards continuing with care for fear of disclosure to others of the adolescents' HIV status [49]. Similarly, the experience from the diabetes context shows that as children reach 11 to 12 years old, they also begin feeling embarrassed about their condition preferring not to talk about or perform self-care tasks in front of their peers [50]. Thus, embarrassment and shame during early adolescence can lead to adolescents not wanting to continue with HIV treatment.

*Fear of being judged*

Adolescents fear being judged by their peers or other people, thus when they move to a different care setting, this poses a barrier or negative experience of transition. For example, in the context of transition to adult HIV care, fear of being judged by adult patients and service providers prevailed among adolescents who transitioned. Adolescents feared that adults in the HIV clinic would perceive or judge them to have acquired the disease through their behavior rather than perinatally or through blood transfusion [41]. The fear of being judged is voiced by Kutsiime et al. (2014) where one young adult who was transitioned to the adult setting stated "I don't like the way adult patients look at me in the adult clinic. They look at me in an accusing way…. like I am someone who sleeps around" [36]. Fear of being judged may thus impair adolescents' continuity

with care. On the other hand, adolescents long to be accepted by peers and find it very helpful meeting with them during their transition preparation to adult care [48].

This section has reviewed the three key aspects of early adolescence; desire for privacy and confidentiality, beginning of feeling/expressing embarrassment and shame of HIV status and fear of being judged by their peers. These key aspects play a critical role in the transition to adult care where one is expected to have autonomy. It is not known, however, whether the adolescence related factors prevail during the transition to adolescent care since the transition from pediatric to adolescent clinic is carried out in the same setting and with the same service providers and involves peers living with HIV. Having reviewed the factors arising from adolescence, the next section reviews adolescent factors that do not arise specifically from the adolescent developmental context.

*Motivation/desire to transition*

Not surprisingly, adolescents who are motivated to transition find the process much easier compared to those who do want to move [41]. On the other hand, the desire not to change/move is the most significant barrier to transition among adolescents with a variety of chronic illnesses [51].

*Expectations*

The expectation one has during transition influences one's perceptions and attitudes towards transition. Usually, if one does not know what to expect during transition, the stress associated with transition is greater compared to one with realistic expectations [18]. Fair et al. (2015) explored the expectations of transition to the adult clinic among 18 adolescents (>14 years) still receiving care in the pediatric clinic in the southeast United States [52]. They found that most adolescents were "in the dark"; they did not know what to expect in the adult care environment. They also found negative expectations that included difficulties in adjusting to their new environment. Some adolescents even expected a boring/dull adult environment as stated "adults tend to kind of sit around like they're waiting for death" [52]. Negative expectations were also echoed by Vijayan et al. (2009) who explored challenges to caring for adolescents with perinatally acquired HIV and the barriers to transitioning from pediatric to internal medicine [16].

On the other hand, Miles et al. (2004) showed that when expectations are not met during transition, it reduces progress towards achieving successful transition. For example, one adolescent was made to believe that there would be other adolescents in the adult clinic which

was not the case. This led to stress and disappointment in the transitioned adolescent [41]. Valenzuela et al. (2011) showed that one adolescent opted to discontinue care due to non-availability of counseling sessions in the adult setting which he had expected [53].

*Disclosure of HIV status to the adolescents*

Disclosure of adolescents' HIV status to the adolescents is also seen as an important facilitator towards successful transition and is a pre-requisite for transition to adolescent care in many settings. In the United Kingdom, Miles et al. (2004) showed that among seven adolescents transitioning to an adult HIV outpatient center, the median age at which they were disclosed their HIV status was 15 years (range five to 18 years) [41]. However, non-disclosure still prevails in some settings as Vijayan et al. (2009) reported after interviewing 18 adolescents of whom three adolescents aged 12, 13 and 15 years old respectively did not know their HIV status. There was also limited disease knowledge among most adolescents as most were not able to mention the kind and frequency of their medication [16]. As a result of limited disease knowledge, Vijayan et al. (2009) concluded that it was difficult to encourage autonomy for those adolescents [16]. Other authors recommend that adolescents should be disclosed to as part of transition process from pediatric to adult care [17].

*Attachment with the pediatric providers*

Many emotions have been associated with the moving from a familiar pediatric setting to an unfamiliar adult HIV care setting. These emotions faced by the adolescents, have to some extent delayed transition. For example, a young woman who lost her mother while in pediatric care and was transitioned to adult care felt that leaving the program (pediatric setting) was like losing another member of her family [42]. Other emotions that have been a result of the transition process include difficulties in letting go of important relationships between pediatric providers, families and adolescents [16, 40], anxiety [41], disappointments [36] and loneliness [42]. As a result of these emotions, transition has been delayed or even resisted e.g. adolescents were hesitant to move to the adult clinic [41, 42]. However, these emotions may be less likely to be encountered during pediatric–to-adolescent transition as transition occurs within the same settings without change of service providers.

*Social-economic status*

The effect of socio-economic status during transition has been assessed mainly in studies in USA. As might be expected, two studies have shown that lack of health insurance (which was covered during pediatric care) hindered continuity of care after transition to adult sites [42, 54]. However,

the lack of health insurance in SSA settings may not be relevant as HIV services are mainly offered for free under government subsidization.

*Critical events*

Critical events are events that can influence adolescents' transition experience and perceptions. These include changes in caregivers due to death, illness, exposure to domestic violence, family conflict or family breakdown, living with parents/caregivers who have mental illness, excessive drinking or substance use. Other events include running away from home, suffering from sexual exploitation, being expelled from school, employment or training, and being a teenage parent [55].

**b) Caregiver/family factors**

Caregivers' roles and perceptions are crucial during transition which does not only involve the moving from childhood to adolescent life, but also involves caregivers adjusting to this shift [56]. Caregivers' perceptions of the transition readiness of their adolescents are a critical factor influencing adolescent transition experiences. Caregivers have shown hesitancy in transition due to their perceived lack of preparedness of the adolescents [44]. Hesitancy is also seen in initiating the transition process as some caregivers believe that service providers should initiate the transition discussion while others caregivers believe that they themselves should begin the transition discussion as soon as the adolescent starts to demonstrate readiness for transition [52]. Other caregiver factors include fear of changing significant and trusted relationships formed with the pediatric providers [16, 44], stigma in the adult clinics [16] and confidentiality of the adult care providers [44]. Fear of disclosing the child's HIV status is also presented as a particularly difficult issue for caregivers. Caregivers fear the emotional consequences resulting from children disclosing their HIV status to others, stigma, child rejection, inadequate preparation for disclosure, post-disclosure questions and negative outcomes as well as the perception that children are too young to be disclosed to [57-61].

**c) Service provider factors**

Service providers play a significant role in transition as they assist those undergoing transition to regain stability and a sense of wellbeing. Understanding how service providers perceive the transition services and their clients will therefore enable development of interventions/strategies for service providers that will assist adolescents during transition.

*Preparations of adolescents*

Preparation of adolescents for transition is necessary for a successful transition [18]. Service providers have used several strategies to prepare adolescents for transition which include introducing adult service providers early on in the transition preparation period [41], navigating in the adult clinic [38, 62], use of pediatric social workers who prepare the adolescents for transition [40] and engaging caregivers [62]. Assessing transition readiness as a way to prepare adolescents for transition has also been used to identify possible factors that will influence the transition at an individual level [45].

Pediatric providers have reported concerns about inadequate preparation of the adolescents to face adult care [41, 52, 53]. Adult service providers also feel inadequately prepared for caring for the transitioned youth [56]. As a result of inadequate preparation, some adult service providers face difficulties in disclosing to adolescents [63]. Without adequate preparation, transition can be overwhelming for adolescents who have used phrases such as "being laid off," "a shock," "they threw it on me" and "going from kindergarten straight to high school" to describe their feelings about the transition. Some regretted that they were not given their increased adult responsibilities while they were still in a friendlier pediatric environment [42]. For others, inadequate preparation led to surprises e.g. the new surrounding filled with HIV posters in contrast to the pediatric environment [41], frustrations e.g. long waiting hours [41], inconsistency of service providers [53] and loneliness as there was no one (i.e. no counselors) to talk to [42]. Because of this, adolescents prefer transition to be explained prior to transfer with enough time to discuss problems and perhaps even knowing the names of staff who will provide service for them [46]. These findings have led researchers to recommend that pediatric providers assess readiness and increase adolescents' autonomy during transition [40, 42, 62]. Similarly, it has also been recommended by adolescents, caretakers [44] and service providers [56] that preparations need to occur before transition to support smooth movement towards successful transition.

*Negative perceptions of adolescents*

In general, health care providers perceive that adolescents have difficulties adhering to medication [63] and view adolescents as 'child- like' and not ready for adult life due to their limited skills in managing themselves [41]. The discourse that these adolescents are unprepared for self-management is also reflected by Person and Newman (2012) who explored transition literature from developed countries using critical discourse analysis [64]. Other health care providers in pediatric settings are apprehensive about how the adolescent will fare in an

environment that involves many individual responsibilities [56]. As a consequence of these views, transition is delayed.

*Transition support and coordination*

Support from service providers in both pediatric and adult settings in terms of logistical issues, supportive staff (staff who know how to talk and listen to patients, explain treatment and problems clearly so that patients understand and who treat patients as individuals) [46, 65] and close communication between pediatric and adult care providers [62] were identified as important resources during transition. Support from friends/peers in the adult clinics or in other social gatherings made young people feel connected and relieved knowing that there were others with the same condition [48]. On the other hand, when support was missing during transition, adolescents discontinued care [53].

*Stigma*

Stigma, which has been identified as one of the most difficult issues to address, influences transition experiences regardless of age [32]. Adolescents, health care providers, and the surrounding community are all adversely affected by stigma, making it a major barrier in the transition process [41].

This section has focused on perceptions and attitudes of adolescents, caregivers and service providers towards transition to adult HIV care and factors influencing these perceptions. The literature review has shown that there are more negative perceptions than positive perceptions at adolescent, caregiver and health service level, however most publications to date are based on the transition from pediatric to adult HIV care.

### 1.2.3 Transition to self-care during early adolescence

As stated earlier, as children reach adolescence, they gradually start to assume responsibilities in their medical care as their caregivers start to shift these responsibilities to them. The main aim of shifting these responsibilities is to enhance self-care that is necessary as adolescents will eventually transition into adulthood [66].

Self-care has been defined as “actions people take on their own behalf to maintain life, health and well-being”. In the context of chronic illnesses, self-care is the maintaining of everyday health-related activities by a person afflicted with a disease [67]. However, this study will only focus on

two key aspects of self-care; the shifting of responsibilities of managing medication adherence and continuity in care i.e. keeping up with clinic appointments by the child during adolescence.

Transition to self-care has been recommended by Center for Disease Control (CDC) to begin as early as possible [32]. Similarly, the "Moving on Positively" guide for adolescents, caregivers and service providers recommends that shifting of responsibilities should begin early with the support of caregivers and service providers [34]. By the age of eight to twelve years the transition to self-care should aim at helping the child/adolescent to envision the future. Support should therefore be given to caregivers to disclose to the adolescent, start mapping out the transition timeline after disclosure and explanations of medications and adherence issues should begin. For those aged 13-16 years, the aim of self-care should be to work towards responsibility. Service providers should therefore build a schedule of clinic appointments with the adolescents to strengthen their adherence to medication and continuity in care, discuss any barriers to adherence with medication and clinic appointments and how to seek care for any symptoms arising. The Lancet Commission on adolescent health and wellbeing recommends that consultations with the adolescents can even start without the presence of the caregiver but with their agreement [47].

With regards to these recommendations, studies report that service providers have prepared youth/adolescents using different strategies to enhance the transition to self-care by promoting independence, building skills [62] and adherence to medication [17] as they transition to adult care. These strategies include life skills camps where adolescents learn life-skills [63] assessment of self-care knowledge using tests and checklists, teaching life-skills and health information [34, 38].

Several barriers to transition to self-care management have been identified at different levels. Individual/adolescent factors contributing to creating barriers include age of the adolescents, alcohol use, depression, advanced disease, day-to-day life complications, and inability to continue with school. The environmental factors involved include limited access to clinics while the health facility factors are pill burdens and stock outs. Poverty and stigma cut across all the three categories of barriers [32].

**Shifting of medication adherence responsibilities**

Maintenance of adequate adherence to medication is one of the most critical tasks in promoting the health and well-being of adolescents living with HIV; this unfortunately usually decreases as the child develops into adolescence due to psychological and structural barriers created by related adolescent, provider, medication and disease factors [68, 69]. Among these factors is the fact that

some adolescents are given more responsibility for their own medication management even though they are not ready or have not asked for such responsibility [70-72].

Shifting of medical responsibilities from caregivers to adolescents is a common phenomenon among caregivers of adolescents living with chronic illness/conditions. In order to start shifting these responsibilities, caregivers may assess the level of maturity of their adolescents before giving the adolescents greater responsibility for their medications [20] and/or consider the health and age of the young person [73]. However, resistance from caregivers to give full autonomy of medication management to their adolescents and youth exists [27, 73]. For example, one study reported that caregivers of adolescents felt that their role of parenting was threatened when adolescent consultations were done in the caregivers' absence [74]. Tulloch et al. (2014) reported that caregivers desire to be involved in the transition process and are committed to their responsibility of caring for the adolescents [63].

In an attempt to establish the extent to which children and adolescents assume responsibility in taking medication in the context of asthma, a study was conducted in Michigan in 2016 among 1322 caregivers of children with asthma aged two to 16 years. This study showed that the medication responsibility assumed by children of ages 7, 11, 15 and 19 years is 20%, 50%, 75% and 100%, respectively [22]. In the context of HIV, adolescents also assume responsibilities in taking medication. However, the shifting of medication responsibilities from caregiver to adolescents has been shown to be stressful for caregivers. For instance, in a study examining psychosocial factors related to adherence among adolescents with perinatally acquired HIV aged 10–16 years using a sample of 44 caregivers showed that caregivers were able to work together with the children at the age of 10-12 years in preparing medication and reminding each other of the medication time. As the children grew into adolescence, this strategy could no longer work as they became reluctant to use medication [20]. In another study in Thailand, some caregivers had to use force to make their adolescents take their medications as expressed by one caregiver who used this quote "*I'd even have to hit him to make him take it*" to express his difficulties in ensuring adequate medication adherence [63].

**Shifting of responsibilities in continuity in care (clinic appointments)**

During childhood, the children's involvement with service providers is mainly through caregivers, but as they grow into adolescence, they slowly start to interact with the service providers by themselves even if the caregivers still escort them, and some may no longer be escorted by their caregivers. Some adolescents embrace this shift with enthusiasm. For example, in a study of

transition to adult care among adolescents aged 15-24 who were living with perinatally acquired HIV in Miami, one youth stated, "*Teach me how to do things for myself*" [44]. On the other hand, some adolescents do not conform to this shift in responsibility. For example, one young adult with HIV who was transitioned to community care following closure of an HIV program in the United States of America (USA) felt that transition would have been better if their primary caregiver was also involved in the decision making and treatment planning. He quoted *"I want doctors to listen to my mom and for her to hear what they say*." [42].

The extent to which adolescents living with HIV take responsibilities with their clinic appointments is not clear. However, in the context of chronic diseases, it is clear that transition of responsibilities may be slow. For example, in the case of juvenile idiopathic arthritis, Shaw et al. (2005) showed that among 17-year-old adolescents (n=77), 55% were still visiting the rheumatologist with their caregivers and 20% still received their medications from their caregivers [75].

**The immediate effects of the pediatric-to-adolescent transition on medication adherence and clinic appointment management**

Few studies have directly assessed the immediate effects of the transition to adolescent clinic on self-care among adolescents. Valenzuela et al. (2011) compared experiences of ten youth with non-perinatally acquired HIV (mean age 25 years) with a range of 2.67 to 11 years follow-up post transition to adult care. They found that the transition to adult clinic had a positive impact on the adolescents as most had changed their identity i.e. they made healthier choices and/or had a more positive attitude about their health than when they were younger, took better care of themselves, may have stopped substance abuse, and some self-reported improved adherence to medication. Having successfully transitioned, some clients even wanted to return to adolescent clinics to give back to others by encouraging safe-sex practices among peers, volunteering to tell their story to others, and participating in research [53].

Another study in Canada compared the level of self-management skills among adolescents (11-19 years) with special health care needs who were attending an adolescent transition program with others attending neurology clinic. The study included 32 adolescents attending neurology clinic and 17 in the adolescent transition program at the Alberts Children's hospital and revealed a higher medical self-management score for adolescents in the transition program than to those in a routine care neurology clinic [76]. In contrast, Weiner et al. (2011) found that transitional care

had minimal effect on adolescents' self-care in a telephonic interview study of 59 youth living with HIV, as some wished they were given more responsibilities in their medical care while they were still in pediatric care [42].

The immediate effects of transition on self-care have also been studied in the context of hemophilia whereby Geets et al. (2008) compared adolescents' anxiety and parental concerns between 15 pre-transitioned families (children and their parents) and 14 post-transition families. It was found that there was no difference in the worries about transition or quality of life among the children pre and post-transition. However, fathers of post transitioned children were more worried than the fathers of pre-transitioned children and mothers were more worried than the fathers about the children with medical issues during transition [77].

In summary, literature on the extent to which adolescents assume medication and clinic related tasks in the HIV context is limited. Despite this limitation, the available literature shows that caregivers do transition medication related responsibilities to their adolescents living with HIV. However, this transition can be difficult for caregivers due to both anxieties among caregivers and the need to be involved in these activities as part of parenthood. The transition is also difficult for adolescents who wished for their caregivers to continue with the responsibilities and those who were not ready to assume these responsibilities.

### 1.3 Research gap

The literature review above mainly examined the organization of pediatric-to-adult transition services and how adolescents feel about transition services, as there were very few studies examining pediatric-to-adolescent transition. Results of studies on transition to adult care may not be applicable in the transition from pediatric to adolescent HIV care during early adolescence where children are younger and developmentally at an earlier adolescent stage and there may be fewer logistical issues involved (same providers and clinic settings). Adolescent to adult transition services are also mostly focused on adolescents with non-perinatally acquired HIV whereas adolescents with vertically acquired HIV would predominate in pediatric-to-adolescent transition services. Lastly, most of the research to date has been from developed countries, whose context and HIV prevalence are different from that of the SSA context therefore generalization of these findings is limited.

Factors influencing adolescent transition perceptions and attitudes, may arise from the developmental context of adolescence and or be independent of adolescence. Very few studies have assessed the transition barriers that arise from adolescence during transition, since most

studies have focused on the transition to adulthood of older adolescents and are thus not able to capture the developmental aspect.

Literature has also shown that the shifting of responsibilities in medicine and clinic appointments begins as early as seven years and increases as the child reaches adolescence. Caregivers gradually shift these responsibilities to their growing children using different strategies as their children grow into adolescence, highlighting the importance of their role in the adolescents' transition to self-care. However, there is limited research on how family/caregivers influence adolescents' health and wellbeing [47]. More specifically, much less is known about when and how adolescents' and caregivers' roles in adherence to medication and clinic attendance change over time as the children living with HIV reach early adolescence.

Lastly, few studies have assessed the immediate effect of the transition on self-care. The limited data on the immediate effect of transitional care on self-care has mainly been confined in the transition to adult care with very little known of the move from pediatric to adolescent HIV care in the context of early adolescence.

### 1.4 Research aims

The overall goal of this research is to understand how best to transition adolescents with perinatally acquired HIV from pediatric to adolescent HIV care in Northern Tanzania during early adolescence. The specific objectives are:

1. To understand the current organization of pediatric-to-adolescent transitional care services and how this organization affects the perceptions and attitudes of transitioning adolescents during early adolescence.
2. To explore contextual factors other than service delivery that affect perceptions and attitudes of adolescents and caregivers towards transition before and after the move to adolescent clinics.
3. To understand the immediate effects of the transition from pediatric to adolescent care on medication adherence and clinic attendance management during early adolescence.

### 1.5 Significance of the Study

There are several important areas where this study makes an original contribution to the transition from pediatric to adolescent HIV care during early adolescence. The first area is in the understanding of the organization of pediatric-adolescent HIV transition in Northern Tanzania and how adolescents and caregivers feel about the transition process. Understanding the transition practices and adolescents' perceptions will assist in determining the best practices for

moving adolescents from pediatric HIV care in the context of early adolescence in Northern Tanzania.

This study will also contribute towards understanding of contextual factors besides service delivery, that influence adolescents' and caregivers' perceptions and attitudes towards the transition from pediatric to adolescent clinic in Northern Tanzania. Identification of the contextual factors other than service delivery will assist healthcare providers to understand transition barriers and facilitators and hence provide strategic support to adolescents and their caregivers during transition.

Identification of the level of adolescents' responsibilities in adherence to medication and clinic appointments during early adolescence as they move to adolescent clinic, together with factors associated with taking on such responsibilities and how adolescents perceive these responsibilities will assist in designing targeted support interventions for transition from pediatric to adolescent HIV care. Lastly, it is also important to examine the immediate effects of the move to adolescent care on the shifting of adolescents' responsibilities. The understanding of the immediate effects will lay the framework for future evaluations of long-term effects of pediatric-adolescent transition programs in transition to self-care.

### 1.6 Innovation

This research is innovative in several ways. First of all, the research question is novel. To my knowledge, very few studies in this research area have been conducted to date. All of the identified studies have mainly focused on transition from pediatric to adult care.

Second, the study approach is novel for this area of research. Use of clinical description of adolescents transitioning is combined in a single study with the qualitative IDIs and focus groups. So, it is the combination of the clinical description together with a longitudinal qualitative study that provides a rich picture of the transitioning adolescents and their transition experiences. The understanding is further enhanced by using both IDIs and focus groups, by the longitudinal nature of the study where repeat IDIs allow one to explore changes and confirm previous data collected, and by including a range of stakeholders (adolescents, caregivers and the service providers).

Finally, the use of mixed methods and longitudinal interviews to capture the changes in perceptions and factors and changes in self-care before and after transitioning to adolescent clinic is innovative. Interviews with transitioning adolescents, caregivers and service providers provided important insights about strategies to improve the transitioning of adolescents to adolescent clinic

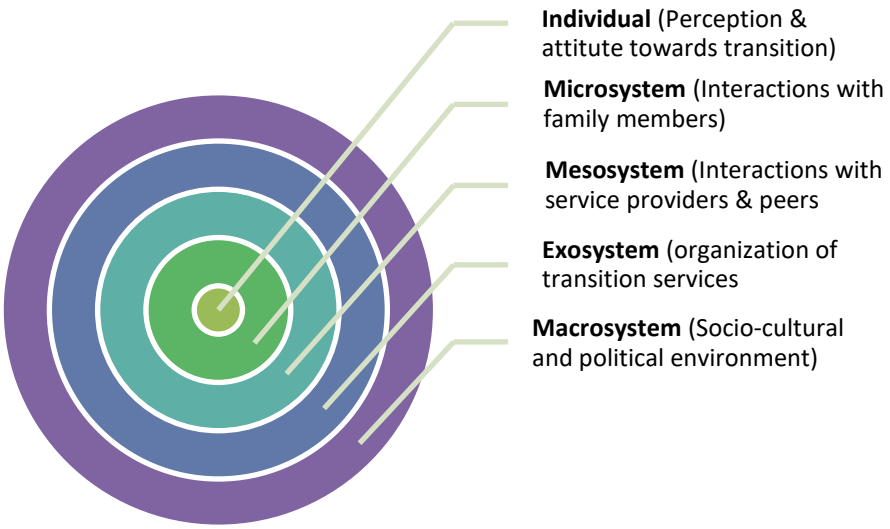
from pediatric clinics. Taken together, this dissertation elucidates factors that future programmatic and policy interventions can use to increase retention to care and medication adherence among adolescents with perinatally acquired HIV.

## CHAPTER 2: METHODS

### 2.1 THE CONCEPTUAL FRAMEWORK

In order to realize the study objectives, the Social-ecological Model (SEM) developed by Urie Bronfenbrenner [78] which conceptualizes the influences on individual behavior was used as a guide. Several researchers have applied this model to explore experiences of health transitions in different contexts [79-81] with the model able to resonate with adolescent transition experiences as it describes influential environments ranging from individual to broader structural factors. The individual factors include how one feels about the transition and actions of adolescents towards transition. The second level (microsystem) involves interactions between the adolescents and other family members while the third level (mesosystem) involves interaction between anyone involved in the transition process such as service providers and peers. The fourth level is the exosystem, which consists of the organization of transition services, and the last level (macrosystem) is the broader socio-cultural or political environment that may influence the transition experiences of adolescents. This model was therefore ideal for this study as it not only describes multiple layers of influence on adolescent perceptions and attitudes towards transition but also describes interactions between adolescents and family, peers, healthcare providers, and the organization of transition services in Northern Tanzania which were the focus of this study. Furthermore, the ecological model places the transitioning adolescents, who were the main focus this study, at the center of attention.

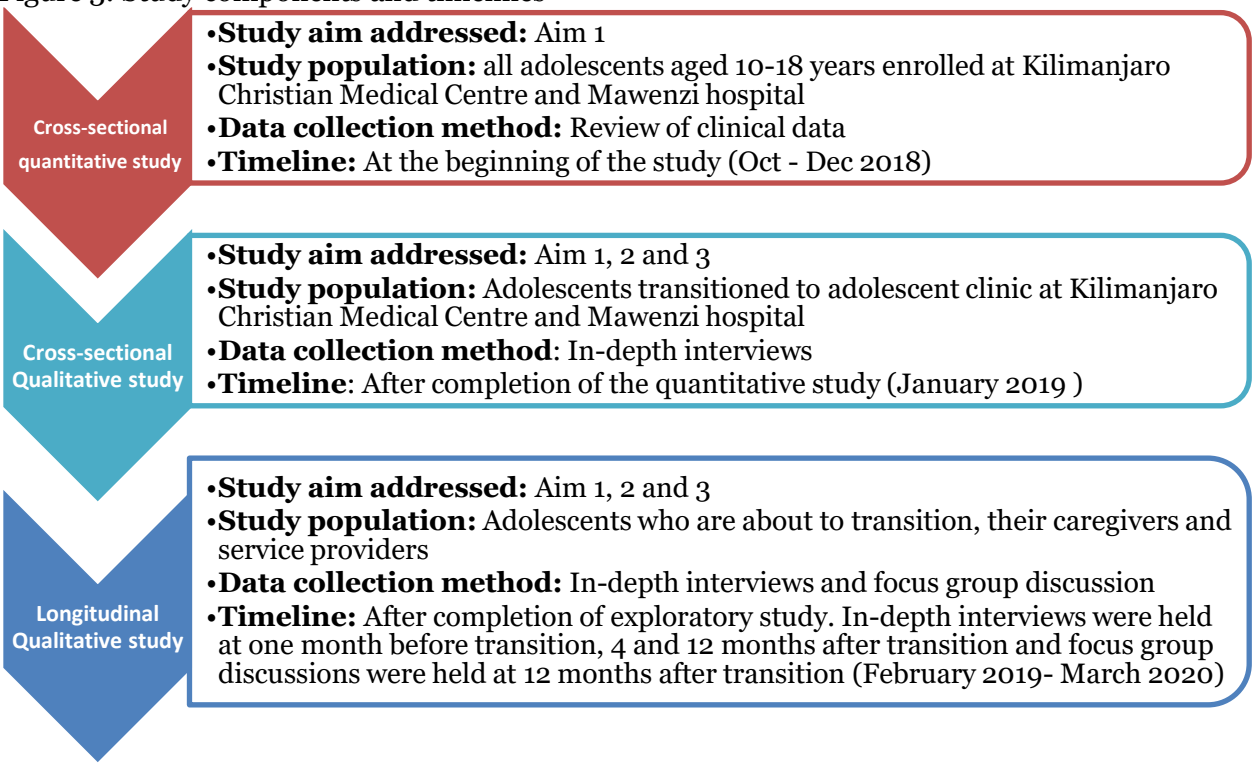
Figure 2: Social-ecological Model for transition experiences among youths



## 2.2 Methods

Mixed methods with complementary qualitative and quantitative components were used in this study and consisted of three phases as shown in the figure three below.

Figure 3: Study components and timelines




- The first phase was a **quantitative study** to describe transitioning adolescents using the routinely collected clinical records of all adolescents aged 10 -18 years in KCMC and Mawenzi hospitals.

- The second phase was a **cross-sectional qualitative exploratory** study that used IDIs with adolescents who had already transitioned to adolescent clinic. Since not much was known about the pediatric-adolescent transition, this qualitative study used phenomenological approach that aimed at highlighting transition practices, perceptions and attitudes towards transition practices and transition to self-care practices.

- The third phase was a **longitudinal qualitative** study that used repeated IDIs building on the previous interviews and FGDs with service providers, adolescents who were about

to transition and their caregivers over a one-year period. These IDIs were held at one-month pre- transition, then at two months post- transition to adolescent clinic and one year after transition. These time points "one month before transition, two months and one year after transition" were purposefully set due to the limited study timelines and to determine the immediate effects of transition on self- care. The repeated IDIs were purposefully selected in order to provide the opportunity to get more in-depth information to describe the transition process when compared with just one or two interviews. It was also deemed necessary to have three consecutive sessions of interviews with adolescents and their caregivers to establish the trust needed for a particular adolescent/caregiver to share with the researcher what they are thinking and feeling as some adolescents may not open up during the initial interviews. Furthermore, repeated IDIs were necessary to explore changes in the perception and attitudes of adolescents and their caregivers towards the transition services and factors influencing their perceptions and attitudes before and after transition. The repeated IDIs also assisted in understanding how adherence to medication and management of clinic appointments as components of self-care evolved during the period of transition hence identifying the immediate effects of the move on self-care.

- After the repeated IDIs, FGDs were conducted with service providers, adolescents and their caregivers separately at one-year post transition to adolescent care. Issues that emerged during the IDIs were discussed in the FGDs and hence provided a different outlook of the transitional practices and experiences at a group level. Findings from the cross-sectional qualitative study were analyzed separately but also considered together with the findings from the longitudinal study in order to strengthen dependability of the study findings. The detailed methodologies used to implement the study and the analysis are discussed in hereunder.

### 2.2.1 Phase 1: Quantitative study

**Study design and data collection:** This was a descriptive cross-sectional study of the clinical characteristics of adolescents who have already transitioned and those not yet transitioned and the study used routinely collected clinical records of all adolescents aged 10 -18 years in KCMC and Mawenzi hospitals who had attended clinic in either November or December 2018. Consent

was waived for the analysis of routinely collected de-identified data extracted from the clinic records.

All adolescents identified in the CTC2 Database (a database designed for HIV/AIDS Care and Treatment Clinics in Tanzania) were included irrespective of their transition status to ensure inclusion of adolescents who were both transitioned and those not yet transitioned. The lower age of 10 years was purposefully selected, as it was the age at which children start being prepared for transition to adolescent clinics and by 18 years most adolescents started to prepare for transition to adult clinics in both hospitals.

The field "transferring to adolescent clinic" was not recorded in the data-base and only a few files had the "transfer to adolescent clinic" written and the date of transfer. Therefore, in order to attain the transfer date in this study, the first clinic attended by the adolescent that fell on a Saturday was assumed to be the date of transfer to adolescent clinic in our study. Data was then extracted from adolescents' files which included demographics, CD4 cell count at start of ART, CD4 cell count within the previous 12 months, the most recent viral loads prior to December 2018, current ART regimen, and WHO stage at enrollment.

**Data analysis**: Descriptive statistics (frequencies and percentages) were used to describe adolescent demographic, clinical and HIV disease characteristics. The variables examined include age, sex, regimen, CD4 testing at start of ART, WHO stage at start of ART, the most recent viral load in the last 12 months. Adolescents were stratified according to hospital and transition status i.e. those transitioned and those not yet transitioned.

Comparisons of adolescents' characteristics were made between the two hospitals and according to the transition status using Chi-square tests for proportions and independent sample median tests. The transitioned and untransitioned adolescents were further stratified into the three age groups: 10–12 years, 13–15 years, and 16–18 years, to describe their clinical characteristics. Lastly, the transitioned adolescents were stratified according to the year of transition by dividing the observation time into three periods: 2016 and the earlier years, 2017, and 2018 to describe the number of adolescents transitioning per year.

### 2.2.2 Phase 2: Qualitative exploratory study

#### Study population

The study population consisted of adolescents with perinatally acquired HIV aged 10-15 years enrolled in ART programs attending either pediatric or adolescent HIV care clinics in KCMC and Mawenzi hospitals. The lower age of 10 years was purposefully selected, as it was the age at which children transition into adolescence and start being prepared for transition to adolescent clinics in Mawenzi and KCMC and by 15 years most adolescents had transitioned to adolescent clinics in both hospitals.

#### Sampling and sample size (transitioned adolescents)

The inclusion criteria that was used to determine whether an adolescent was eligible to participate in the study were: an adolescent with perinatally acquired HIV[2], had been receiving HIV care in the same hospital prior to moving to adolescent care, was receiving ART medication, not older than 15 years and had been fully informed about his/her HIV status in order to avoid inadvertent disclosure during interviews. The sampling criteria used to identify eligible adolescents who are likely to provide rich information was that the adolescent must have transitioned to the adolescent clinic within the last six months. Therefore, a purposive sampling method using homogeneous sampling technique was used to attain a homogeneous sample of transitioned adolescents who provided rich information on transition services, their perceptions on transition services and their experiences in self-care transition. Previous studies that have explored transition perceptions have used sample sizes of minimum seven to ten participants [41] to more than 40 participants [40, 42]. The sample size in this study consisted of eight adolescents i.e. four from each hospital, because this was more than the minimum number included in other studies and was a feasible number to recruit and include in the study period and with available funding.

#### Recruitment

Clinic nurses with good knowledge of transitioning adolescents were used to gain access to the eligible caregivers and adolescents. There were 12 adolescents who met the inclusion criteria of whom eight were purposively selected. All the eight caregivers of the eight purposively selected adolescents were willing for their adolescents to participate in the study. Assent from the adolescents was then sought as children are legally only allowed to give consent for participation in research studies at 18 years of age.

[2] Adolescents with perinatally acquired HIV were determined based on their age at first HIV care visit being <10 years as children under 10 years of age are most likely to have acquired HIV perinatally

**Data collection**

IDIs with the transitioned adolescents were held in a quiet environment outside the hospital environment. Written informed assent was obtained before beginning the interviews as well as assent for recording the interview. The IDIs were conducted in Kiswahili using a semi-structured interview guide that explored the adolescents' perceptions and attitudes towards transition services and self-care. The main theme for the interviews were disclosure, transition practices, adolescents' perceptions of their caregivers, peers and services providers, and clinic appointment and medication adherence management as highlighted in the interview guide (Appendix 1). A nurse counselor was always present in the interview premises (but not in the interview) in case of emotional distress during or after the interview.

The caregivers of adolescents were also invited to the interview venue but not included in the interview process. They were invited to ensure that adolescents get home safely afterwards as interviews were held during afternoons. Each caregiver was compensated for the transport costs they incurred. The viral load tests and medication adherence status of the adolescents were made available to the interviewer prior to the interviews to enhance the discussions on medication adherence management.

**Data analysis**

*The research team*

The research team consisted of the researcher who was responsible for conducting all the interviews and data analysis. The team also consisted of two nurse counselors (one employed in Mawenzi and the other in KCMC to provide routine services) who assisted in explaining the study and getting consent and assent, and provided counselling for any participants with emotional distress. The nurse counselors made it clear to the participating adolescents that their participation in the study was entirely voluntary and completely unrelated to the provision of clinical care. The research team also included a research assistant experienced in qualitative research and the local language who participated in the transcription and coding of the transcripts in order to have multiple coders.

*Transcription and coding*

All IDIs were transcribed and then translated into English as the interviews were held in Kiswahili. All eight transcripts were labeled using the study initials (EL), hospital initials (MZ for

Mawenzi and KC for KCMC hospital), respondent type (AD= adolescent) and each adolescent from Mawenzi were given numbers one to four and KCMC were from five to eight. For example, the first adolescent from Mawenzi hospital to enroll in the exploratory study was labeled "ES-MZ-AD1" while one from KCMC was labelled as "ES-KC-AD5". The codebook was developed both inductively i.e. from the data, and deductively from the Social-ecological Model (SEM). The codebook was developed and refined (collapsing overlapping codes) based on the three first transcripts. The final codebook was then used to ensure uniform use of codes across all transcripts. Routine checks to the research assistant to ensure similar understanding and use of codes were conducted.

*Software & Analytic technique*

The qualitative data analysis software (NVivo) was used to manage and organize the data, and coding as recommended [82] . The eight transcripts were then coded using the codebook whereby all the responses with similar codes were systematically put together to create themes**.** Based on the research questions, "thematic analysis" was the main data analysis technique. The COREQ guideline was used to report the qualitative findings[83]. Further information on data analysis is provided under the longitudinal study section.

### 2.2.3 Phase 3: Longitudinal qualitative study

**Study population**

The longitudinal qualitative study had three distinct but related study populations as shown below:

I. **Health service providers:** The first study population consisted of health service providers including physicians, pediatricians, clinical officers and nurses working in the KCMC and Mawenzi hospitals. The two hospitals were purposefully selected due to the existence of the pediatric and adolescent clinics in this region (Northern Tanzania) and familiarity of the researcher with KCMC and Mawenzi hospitals.

II. **Adolescents:** The second study population consisted of adolescents with perinatally acquired HIV aged 10-15 years enrolled in ART programs attending either pediatric or adolescent HIV care clinics in KCMC and Mawenzi hospitals.

III. **Caregivers**: The third study population consisted of caregivers of adolescents with perinatally acquired HIV who were receiving care in either pediatric or adolescent clinics.

## Sampling and sample size

### Health service providers

The inclusion criteria that were used to determine whether a health service provider was eligible to participate in the study was that the health care worker must be working in Mawenzi or KCMC hospitals and work in either adolescent HIV clinics or pediatric HIV clinics or both clinics. The sampling criteria used to identify health care workers who were eligible and likely to provide rich information were those who were actively working the pediatric/adolescent clinic.

Since the primary goal of this study was to better understand transition practices, Penner & McClement indicate that a sample size of 10-15 people is sufficient to fully understand the pediatric-to-adolescent transition services[84]. As a result, the study sample included ten health care providers (five from each hospital) who were actively delivering HIV care to children and adolescents.

### Adolescents

Inclusion criteria to determine whether an adolescent was eligible to participate in the study were; the adolescent must be receiving HIV care in the pediatric clinic at the same hospital where he/she was about to move to the adolescent clinic, able to speak Kiswahili, have parent/caregiver's permission to participate in the study and has a caregiver participating in this study. The sampling criteria used to identify eligible adolescents who were likely to provide rich information were an adolescent who was about to transition to adolescent clinic with a caregiver involved in the adolescent's well-being. Adolescent-caregiver as a sampling criterion was set in order to attain rich information as well as to enhance our understanding of comparable transition issues from both the perspectives of caregivers and adolescents. Based on previous studies that have explored transition experiences that included 7 -40 participants [40-42] and the aim of understanding adolescents' feelings about transition, the sample size in this study consisted of eight adolescents i.e. four from each hospital, because this was more than the minimum number included in other studies and was a feasible number to recruit and include in the study period and with available funding. Furthermore, given the focused scope of the study, it is was anticipated that saturation would be achieved with eight adolescents, as each would provide detailed accounts that illuminate the research questions and including more adolescents would be unlikely to provide substantial additional insights.

**Caregivers**

Lastly, for caregivers to be eligible to participate in this study, the inclusion criteria were: the caregiver must have an adolescent who was about to transition to adolescent care, provided consent for his/her adolescent to participate in the study and was able to speak Kiswahili. Due to the longitudinal design of this study, sampling criteria were: caregivers and their adolescents who were both accessible geographically and less likely to relocate during the one year of follow up so as to not only provide rich information but also continuation in the flow of information during follow up. A sample size of eight caregivers was included corresponding to the eight adolescents that were included above, with the caregiver of each adolescent being included.

Table 1: Summary of sample sizes for the exploratory and longitudinal study

| | **KCMC** | **Mawenzi** | **TOTAL** |
|---|---|---|---|
| **Exploratory study** | | | |
| Transitioned adolescents | 4 | 4 | 8 |
| **Longitudinal study** | | | |
| Untransitioned adolescents | 4 | 4 | 8 |
| Caregivers | 4 | 4 | 8 |
| Health care providers | 5 | 5 | 10 |
| **Total** | **17** | **17** | **34** |

**Recruitment**

The transition coordinators (clinic nurse) in both hospitals were used to recruit service providers, adolescents and their caregivers for the IDI. The recruitment method for the adolescents was similar to the recruitment in the exploratory study.

**Data collection**

The major instrument for data collection in this study was IDIs complemented by FGD. All IDIs were conducted in the same environment as the exploratory study. The service providers and caregivers were compensated for the transport costs incurred during the days of data collection events.

*In-depth interviews with adolescents*

The procedures for the data collection during the IDIs among adolescents were similar to the exploratory study with themes similar to those in the exploratory study. However, during the

subsequent interviews, only verbal consent from service providers and caregivers, and verbal assent from adolescents was requested. The interviews were conducted in Kiswahili and based on the initial interview guide (Appendix 6) which changed after the subsequent interviews (Appendix 7) in order to provide continuity of the content of issues that arose during the previous interviews.

Three rounds of IDIs with the adolescents and their caregivers were held at one month before transition, at two months after transition and at one year after transition. It was expected that the initial interviews with the adolescents would be the longest (take about 30-45 minutes) with the subsequent interviews being relatively shorter because the interviews would be more focused to prevent question fatigue (Appendix 2-5). However, the initial interviews were actually relatively shorter than the subsequent interviews as the adolescents were more open and more engaging during the subsequent interviews than the initial interview. Summaries of the interviews were made prior to the next interview to recap the previous discussion and keep the focus on changes.

*Focus Group Discussions*

After the three consecutive IDIs, service providers, caregivers and adolescents were invited to FGDs for their relevant group. Written consent for service providers and caregivers and assent for adolescents was again obtained followed by consent and assent to audio record the discussion. In total there were four focus group discussions. The first group consisted of eight adolescents who participated in the IDIs from both hospitals. Similarly, the second group consisted of eight caregivers from both hospitals. The third group consisted of health workers (three nurses and two doctors) from KCMC while the last group had health workers (three nurses and two doctors) from Mawenzi hospital. The FGDs for service providers from the two hospitals were held separately in order to encourage free discussions among the FGD members. An FGD moderator trained and experienced in conducting qualitative data collection conducted the discussions based on themes that emerged as important during the IDIs with service providers, adolescents and caregivers. Refreshments were provided during the FGDs and caregivers as well as service providers were compensated for the transport costs as the FGDs were held on Saturdays outside clinic premises.

*Adherence assessment*

Similar to the exploratory study, viral load test results and medication adherence status of the adolescents (obtained from the clinic records) were also made available to the interviewer prior the interviews to enhance the discussions on medication adherence management.

*Research team*

The same research team in the exploratory study was used in the longitudinal study. Data management was similar to the exploratory study. However, since the aim of using the longitudinal method in this study was to document the transition practices, perceptions and changes over time, the previous interview was summarized before moving onto the current one and the summary was used to recap the previous discussions.

*Transcription and coding*

The transcription, codebook development and the coding process was similar to the exploratory study. However, additional information, namely the IDI round, was added to the transcripts' labels. For example, caregiver number three from the KCMC hospital who participated in the longitudinal study and the second round of IDI was labeled as LS-KC-GC3-IDI2. Another example would be LS-MZ-SP4-IDI1 if service provider number four from Mawenzi Hospital participated in the first round IDIs of the longitudinal study.

*Software and Analytic technique*

For a variety of reasons, NVivo (version 12) was again chosen over a manual approach to qualitative data analysis in this study. Notably, the obtained data consisted of information from three distinct categories of research participants and three distinct time periods, which collectively covered all three qualitative research objectives. Hence, three distinct NVivo projects bearing the names of the three study goals were created in NVivo. Under each project, data was grouped by participant type and timepoint. Then transcripts were coded, enabling the researcher to run multiple queries to address the research objectives and facilitating the identification and extraction of pertinent quotes to support the findings. Furthermore, in order to compare data across timepoints or participants, to provide insights into patterns and changes over time, matrix coding and visualizations were used. Lastly, thematic analysis employed in the exploratory study was also used in the longitudinal study and the emerging themes were compared across different study populations (adolescents, caregivers, health service providers) and time periods[85, 86].

*Rigor*

The Lincoln & Guba (1985) criteria for trustworthiness was used in this study. Dependability, that shows the extent to which findings are a consistent and fair representation of the collected data, was strengthened using multiple sources of data collection that included IDIs and FGDs. Credibility, which refers to the extent to which the information gathered and interpretations made

are correct and accurate, was strengthened using two methods - member checking and participant validation. Member checking among service providers was done during the subsequent IDIs to check truthfulness of the findings from the data collection. In addition, the two nurse counsellors recruited to the study were used to confirm the accuracy of observations and requested to comment on whether the interpretations were true and meaningful. Lastly, transferability which refers to how applicable the findings are in different contexts [87] was addressed through thorough description of the contextual background.

*Reflexivity statement*

As a mother of two adolescents, my personal parenting experiences may have shaped my assumptions about the experiences of adolescents, thereby biasing my data collection and interpretation. I applied reflexivity throughout the data analysis process, from data collection to interpretation of findings, by maintaining a reflective journal. By regularly reflecting on the entries, I was able to remain aware of how my parental experiences might be influencing the study and take steps to address any potential biases. Second, I provided an objective check on my interpretations and ensured that my parental perspective did not unduly influence the analysis by consulting with my colleagues and mentors to review and critique the research process and findings.

## Ethical considerations

*Ethical approval:* This study was approved by University of Cape Town (HREC Ref No 392/2017), National Institute for Medical Research (NIMR) Tanzania (NIMR/HQ/R8a/Vol IX/2445) and Kilimanjaro Christian Medical College Research Ethics Committees (No 2036). Permission to conduct the study was also obtained from the regional authorized official and from the two hospitals (KCMC and Mawenzi) before data collection.

*Consent and assent:* Written informed consent was obtained from adult participants and assent from the adolescents. There were no adolescents who were excluded due to lack of consent from caregivers. Permission to record interviews and FGDs was also obtained prior to the beginning of data collection.

*Confidentiality:* The following measures were taken to protect confidentiality and anonymity. All interviews were digitally recorded; no names were attached to the transcripts, and respondents were identified by their unique identification number and interview round. Participants were assured that they would not be identified by facility or any other identifier in any form of

dissemination, including publications. In light of this, no identities of respondents or health facilities are included in the thesis's results section alongside the quotations or narratives provided by the respondents.

**Risks and mitigation**

*Emotional distress*: One of the major anticipated risks for this study was emotional distress given the fact that disclosure of one's HIV status was among the key in-depth personal experience areas explored among the adolescents. Emotional distress occurred in one interview with an adolescent who had recently learned about their HIV status and had lost their mother a few years previously. The adolescent began crying during the interview because of worrying about not achieving their career goals. The emotional distress was appropriately contained by the interviewer who stopped the interview, counselled the adolescent and gave them time to regroup. The interviewer then asked whether the adolescent would like to continue with the interview, and the adolescent agreed. After the interview, the adolescent met with the nurse counsellor who provided further counselling and followed up the adolescent during the clinic attendance.

*Disrupted adolescent-caregiver relationship*: It was also anticipated that adolescents would express concerns about their caregivers, which might damage the adolescent-caregiver relationship if revealed to caregivers. One disclosed adolescent (in the exploratory research) did not want the caregiver to know that the adolescent was already aware of the HIV status because it was never discussed with the caregiver. The adolescent did not want the caregiver to know because of feeling sorry for the caregiver and the adolescent was concerned that the caregiver would be greatly hurt knowing that the adolescent already knows their HIV status. In order to maintain confidentiality, the researcher thus did not provide this information to the caregiver.

*Drop out of study participants:* Given the longitudinal nature of the study that required follow up of study participants for a period of one year, drop out of study participants due to relocation to another service or death was among the risks identified in this study. Throughout the study period, no participant relocated or died.

### 2.3 Challenges encountered

**Partial disclosure**: Full disclosure of one's HIV status was one of the eligibility criteria for adolescents to participate in this study. However, during adolescent recruitment, one adolescent who was still undergoing disclosure (partial disclosure) was thought to have full disclosure, and so enrolled for the research. As a result, the first-round interview was unable to explore the disclosure experiences of the adolescent.

The adolescent then met with a nurse counsellor, who initiated the full disclosure process together with the caregiver before transferring the adolescent to the adolescent clinic. The follow up interviews were then able to explore the adolescents' disclosure experiences hence provided insights on a recent disclosure experience that occurred shortly before moving to adolescent clinic.

# CHAPTER 3: DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF ADOLESCENTS IN KCMC AND MAWENZI HOSPITAL BY DECEMBER 2018

## Introduction

This chapter presents the findings from the quantitative component of the study that sought to determine the extent of pediatric-to-adolescent transition and clinical characteristics of transitioning adolescents enrolled at KCMC and Mawenzi hospital. This was a descriptive cross-sectional study with waived consent that involved review of routinely collected clinic records of all adolescents aged 10-18 years who were "active in care" at KCMC and Mawenzi hospitals by December 2018 as explained in the methodology section. Adolescents generally are expected to attend the clinic once in a month in both hospitals and to be considered active in care, the adolescents must have attended clinic in either November or December 2018 regardless of whether the adolescent had prior gaps in care or periods of clinic non-attendance. Based on this criterion, a total of 29 adolescents who were previously in care but did not attend clinic in November and December were excluded from the analysis. Specifically, 19 were lost to follow up, 23 had transferred out, and 5 had died. As a result, 435 adolescents were eligible and enrolled this study out of the 464 adolescents who were enrolled in an earlier period (e.g. had been attending clinic previously in 2028).

The chapter starts by describing the clinical characteristics of adolescents who are active in care and compares adolescents' characteristics between the two hospitals. It then describes and compares the clinical characteristic of adolescents according to their transition status i.e. transitioned vs untransitioned adolescents. The 10-12, 13-15 and 16-18 age groups cut-off were chosen to describe the adolescents because the age group 10-12 years was the age at which children start being prepared for transition to adolescent clinics, and by 16-18 years most adolescents have transitioned to adolescent clinic and may even start to prepare for transition to adult clinics in both hospitals. Discussion of key findings, limitations and conclusion of the study are highlighted in the last section.

## Findings

### 3.1 Demographic and clinical characteristics of adolescents who were active in care according to hospital

In December 2018, 435 adolescents (10-18 years) were actively receiving HIV care in KCMC and Mawenzi hospitals with the majority (59.5%, n=259) at KCMC hospital (Table 2). Nearly 50% of

all adolescents were female and there was no difference in the proportion of females between the two hospitals (p=0.880). The median age of all adolescents was 15 years (IQR: 12-16 years) with no significant difference in the median age between the two hospitals (p=0.503). The age group 10-12 years was the smallest (n=128, 29.4%) with the remainder roughly equally spread across the two older age groups (i.e. 13-15 and 16-18 years). No significant difference in age group distribution between the two hospitals was noted (p=0.732).

At the time of ART initiation, the median age of all 435 adolescents included in this analysis was eight years (IQR: 5–12 years) and was similar at both hospitals (p=0.503). The majority of adolescents (93.6%, n=407) started ART below the age of 14 years suggesting likely perinatal acquisition of HIV. Additionally, at the time of ART initiation, 50.0% of the adolescents (n=218) were in advanced clinical stages (WHO clinical stages three and four), 29.7%, (n=129) were either asymptomatic or mildly symptomatic (WHO clinical stages one and two), while the remaining 20.2% (n=88) had no WHO clinical staging data recorded (see Table 3). A higher proportion of adolescents at KCMC (30.5%) had no WHO stage recorded at the start of ART compared to Mawenzi Hospital (5.1%) (p<0.05). A significantly higher proportion of adolescents from Mawenzi (82.0%, n=145) had a CD4 test at the start of ART than adolescents from KCMC hospital (69.0%, n=180) (p<0.01).The median CD4 cell count of all adolescents at the time of ART initiation was 377 cells per µl (IQR: 197.5–661.0) and was higher at KCMC (411 cells per µl; IQR: 217.0–675.8) than Mawenzi (341 cells per µl; IQR: 174.0–648.0) (p=0.02).

More adolescents had a CD4 test done in the 12 months before December 2018 at KCMC (73.8%) vs. Mawenzi (60.3%) (p<0.01). The median CD4 cell count in this period was 695 cells/µL (IQR: 447.5–928.0) and was similar at the two facilities (p=0.936). However, a decreasing trend in the median CD4 is noted with the youngest adolescents (10-12 years) exhibiting the highest median CD4 of 891 cells/ µL; IQR (692.5–1158.0), followed by the age group 12-15 years with 738 cells/ µL; IQR (474.8–930.8), and the oldest adolescents (16-18 years) with the lowest median CD4 of 572.5 µL; IQR (334.0–729.3).

The proportion of adolescents with a viral load result in this period was also higher at KCMC than Mawenzi (99.6% vs. 92.6%; p<0.01). Despite this difference, viral load testing coverage is above 90% in both hospitals. In the Tanzanian context, people with HIV are deemed to be virologically unsuppressed when viral load is 1000 copies/ml or more, and clients are considered virologically suppressed and assumed to be adherent if viral load is less than 1000 copies/ml. With this cut-off point, viral load suppression was attained by almost 70% of those tested (292 of 421 adolescents) with no significant differences in the proportion with viral load suppression KCMC (70.9%) and

Mawenzi (66.9%) (p=0.379). Most (41.9%) of the 292 adolescents with unsuppressed viral load were 16-18 years old with 34.1% in the 13-15-year age group and 24.0% aged 10-12 years. However, older adolescents (16-18 years) contributed disproportionately to those with unsuppressed viral load as 41.9% of adolescents with unsuppressed viral load were aged 16-18 years, whereas the overall proportion of adolescents aged 16-18 years was 35.6%. In contrast, the youngest age group (10-12 years) displayed a relatively lower proportion of unsuppressed viral load, with adolescents aged 10-12 years comprising 24% of those with unsuppressed viral load compared to their proportional representation of 29.4% in this study.

With regards to regimen, 46.7% of adolescents were on efavirenz-based regimens with 27.1% on nevirapine-based and 26.2% on protease inhibitors-based regimens. There were no significant differences in adolescents' regimen type between KCMC and Mawenzi hospital (p=0.152). Most (41.9%) adolescents with unsuppressed viral load were on EFV-based regimens, with 27.9% and 30.2% on NVP-based and PI-based regimens respectively. However, adolescents on PI-based regimen contributed disproportionately more to those with unsuppressed viral load (30.2%) while only comprising 26.2% in the study overall. In contrast, adolescents on EFV-based regimen contributed proportionately less to those with unsuppressed viral (41.9%) although they comprised 46.7% in the study overall.

More than half (56.7%, n=247) of all active in care adolescents were already transitioned from the pediatric to adolescent clinic with the remainder still receiving care in pediatric clinic at the time of the study. There were no significant differences in the proportion of adolescents who had transitioned from pediatric to adolescent clinic between KCMC (54.8%) and Mawenzi hospital (59.7%) (p=0.318). A total of 83, 63 and 101 adolescents were transitioned in year 2016, 2017 and 2018 respectively with an average of 82 adolescents transitioning to adolescent clinic per year across both clinics. However, a smaller proportion of adolescents from Mawenzi (19.1%) were transitioned in 2018 compared to KCMC hospital (44.4%) (p<0.001).

Table 2: Socio-demographic and clinical characteristics of 435 adolescents (aged 10-18 years) who were active in HIV care in KCMC and Mawenzi hospital by December 2018

| | All adolescents (n=435) | KCMC hospital (n=259) | Mawenzi hospital (n=176) | P-value |
|---|---|---|---|---|
| Sex | | | | |
| Female (n, %) | 212 (48.7) | 127 (49.0) | 85 (48.3) | 0.880* |
| Male (n, %) | 223 (51.3) | 132 (51.0) | 91 (51.7) | |
| Age (categorical) by 2018 (n, %) | | | | |
| 10 – 12 years | 128 (29.4) | 76 (29.3) | 52 (29.5) | 0.732* |
| 13 -15 years | 152 (34.9) | 94 (36.3) | 58 (33.0) | |
| 16 – 18 years | 155 (35.6) | 89 (34.4) | 66 (37.5) | |
| Median age by 2018 (years, IQR) | 15 (12-16%) | 15 (12-16) | 15 (12-16) | 0.503^ |
| Age at start of ART | | | | |
| ≤14 years | 407 (93.6%) | 240 (92.7) | 167 (94.9) | 0.354* |
| >14 years | 28 (6.4) | 19 (7.3) | 9 (5.1) | |
| Median age at start of ART (years, IQR) | 8 (5- 12) | 9 (5-12) | 8 (5-11) | 0.323^ |
| Current regimen | | | | |
| EFV-based (n, %) | 203 (46.7) | 111 (42.9) | 92 (52.2) | 0.152* |
| NVP-based (n, %) | 118 (27.1) | 76 (29.3) | 42 (23.9) | |
| PI-based (n, %) | 114 (26.2) | 72 (27.8) | 42 (23.9) | |
| CD4 testing at start of ART | | | | |
| Yes (n, %) | 325 (74.7) | 180 (69.5) | 145 (82.4) | 0.002* |
| No (n, %) | 110 (25.3) | 79 (30.5) | 31 (17.6) | |
| Median CD4 cell count at start of ART (cells/µl, IQR) | 377 (197.5 - 661.0) | 411 (217.0 - 675.8) | 341 (174.0 - 648.0) | 0.022^ |
| WHO stage at start of ART | | | | |

| | | | | |
|---|---|---|---|---|
| Stage 1 & 2 (n, %) | 129 (29.7) | 63 (24.3) | 66 (37.5) | 0.000* |
| Stage 3& 4 (n, %) | 218 (50.1) | 117 (45.2) | 101 (57.4) | |
| Not recorded (n, %) | 88 (20.2) | 79 (30.5) | 9 (5.1) | |
| CD4 result in last 12 months | | | | |
| Yes (n, %) | 305 (70.1) | 202 (73.8) | 103 (60.3) | 0.000* |
| No (n, %) | 130 (29.9) | 57 (22.7) | 73 (39.7) | |
| Median CD4 cell count in last 12 months (cells/µl, IQR) | 695 (447.5-928.0) | 696 (423.3-903.3) | 693 (508.0-990.0) | 0.936^ |
| Median CD4 cell count in last 12 months (cells/µl, IQR) by age category | | | | |
| 10-12 years (n, %) | 891 (692.5-1158.0) | 866 (696.0-1201.0) | 969.5 (676.5 -1130.3) | 0.682^ |
| 13-15 years (n, %) | 738 (474.8 -930.8) | 718 (526.0-923.0) | 803 (392.0-972.5) | 0.580^ |
| 16-18 years (n, %) | 572 (334.0- 729.3) | 515 (300.0 -715.0) | 615.5 (443.8-853.3) | 0.095^ |
| Viral load result in last 12 months | | | | |
| Yes (n, %) | 421 (96.8) | 258 (99.6) | 163 (92.6) | 0.000* |
| No (n, %) | 14 (3.2) | 1 (0.4) | 13 (7.4) | |
| Viral load in last 12 months | | | | |
| <1000 copies/ml (n, %) | 292 (69.4) | 183 (70.9) | 109 (66.9) | 0.379* |
| ≥1000 copies/ml (n, %) | 129 (30.6) | 75 (29.1) | 54 (33.1) | |
| Unsuppressed viral load (≥1000 copies/ml) by age category | | | | |
| 10-12 years (n, %) | 31 (24.0) | 14 (45.2) | 17 (54.8) | 0.236* |
| 13-15 years (n, %) | 44 (34.1) | 28 (63.6) | 16 (36.4) | |
| 16-18 years (n, %) | 54 (41.9) | 33 (61.1) | 21 (38.9) | |
| Unsuppressed viral load (≥1000 copies/ml) by regimen | | | | |
| EFV-based (n, %) | 54 (41.9) | 32 (59.3) | 22 (40.7) | 0.963* |
| NVP-based (n, %) | 36 (27.9) | 21 (58.3) | 15 (41.7) | |

| | | | | |
|---|---|---|---|---|
| PI-based (n, %) | 39 (30.2) | 22 (56.4) | 17 (43.6) | |
| Transition | | | | |
| Yes (n, %) | 247 (56.8) | 142 (54.8) | 105 (59.7) | 0.318* |
| No (n, %) | 188 (43.2) | 117 (45.2) | 71 (40.3) | |
| Transition year | | | | |
| 2018 | 101 (40.9) | 51 (35.9) | 50 (47.6) | |
| 2017 | 63 (25.5) | 28 (19.7) | 35 (33.3) | <0.001* |
| 2016 | 83 (33.6) | 63 (44.4) | 20 (19.1) | |

*Chi-square test
^Independent sample median Test
IQR- Inter Quartile Range
ART- antiretroviral Therapy
NVP- Nevirapine
PI- Protease Inhibitors
EFV- Efavirenz
P-value - compares differences between the two hospitals by the indicated statistical test

### 3.2 Demographic and clinical characteristics of transitioned and untransitioned adolescents who are active in care at KCMC and Mawenzi hospitals

Almost 50% of the transitioned and untransitioned adolescents were female across both sites and there were no gender differences observed between the transitioned and untransitioned adolescents in two hospitals (p=0.850) as shown in Table 3. As expected, the transitioned adolescents had a higher median age of 16 years (IQR=14-17 years) than the untransitioned adolescents whose median age was 12.9 years (IQR=11-15 years) (p<0.01). A similar trend is observed within hospitals where the median age of the transitioned adolescents is higher than that of untransitioned adolescents in KCMC (p<0.01) and Mawenzi hospital (p<0.01). However, transition appeared to occur at a younger age at Mawenzi Hospital where a slightly higher proportion of adolescents aged 10-12 years were transitioned to adolescent clinic (18.1%) compared to KCMC (7.7%) (p=0.04).

A higher proportion of transitioned adolescents (77.3%) had a CD4 test in the last 12 months than untransitioned adolescents (60.6%) (p <0.01). This difference was driven by KCMC where CD4 testing coverage was especially high (89.4%) among transitioned adolescents vs 64.1% among untransitioned adolescents. No significant difference in CD4 testing between the transitioned (61.0%) and untransitioned (54.9%) adolescents in Mawenzi was noted (p= 0.426). There was an expected age-related decline in the median CD4 cell count with older adolescents having lower median CD4 cell counts than younger ones. Despite the overall higher CD4 testing among the transitioned adolescents, the median CD4 count for transitioned adolescents was also lower 625 cells/μ (IQR=402 - 854) than untransitioned adolescents 833 cells/μ (IQR=614 -1113) and this difference was evident at both facilities. Given the normal age-related decline in CD4 cell count, it is difficult to tease out the effects of transition and increased testing completeness with the expected effect of age as older adolescents would be more likely to be in the transitioned group.

Similar to CD4 testing, viral load completeness was higher in the transitioned vs. untransitioned adolescents (98.8% vs. 94.1%; p=0.007). This difference was driven by Mawenzi hospital where 98.1% and 84.5% of transitioned and untransitioned adolescents had a viral load test in the last 12 months respectively (p=0.001), whereas viral load testing coverage at KCMC was >99% irrespective of transition status. There was no significant difference in the proportion of adolescents with unsuppressed viral load (HIV RNA <1000 copies/ml) between the transitioned (66.8%) and untransitioned adolescents (72.9%) (p=0.182) overall or at each facility.

However, when the proportion of adolescents with unsuppressed viral load was compared within each age stratum according to transition status, variations in the proportion of unsuppressed viral load transpired between the transitioned and untransitioned adolescents. For the 10-12 years age group, a slightly higher proportion (33.3%, n=10 out of 30) of the transitioned adolescent had unsuppressed viral loads in comparison to (21.4%, n=21 out of 98) untransitioned adolescents. Similarly, for the age group 16-18 years, a slightly higher proportion of unsuppressed viral load (38.3%, n=49 out of 128) was noted among the transitioned vs 18.5%, (n=5 out of 27) of untransitioned adolescents. On the contrary, for the 13-15 years old, a higher proportion (34.9%, n=22 out of 63) of unsuppressed viral load existed among the untransitioned adolescents compared to transitioned adolescents (24.7%, n=22 out of 89).

Table 3: Socio-demographic and clinical characteristics of 435 adolescents (aged 10-18 years) active in care in KCMC and Mawenzi hospital according to their transition status

| | All adolescents | | | KCMC adolescents (n=259) | | | Mawenzi adolescents (n= 176) | | |
|---|---|---|---|---|---|---|---|---|---|
| | Untransitioned (n=188) | Transitioned (n=247) | p-value | Untransitioned (n=117) | Transitioned (n=142) | p-value | Untransitioned (n=71) | Transitioned (n=105) | p-value |
| Sex | | | | | | | | | |
| Female (n, %) | 90 (47.9) | 122 (49.4) | 0.753* | 59 (50.4) | 68 (47.9) | 0.684* | 31 (43.7) | 54 (51.4) | 0.312* |
| Male (n, %) | 98 (52.1) | 125 (50.6) | | 58 (49.6) | 74 (52.1) | | 40 (56.3) | 51 (48.6) | |
| Median age (years, IQR) | 12.9 (11-15) | 16 (14-17) | <0.001^ | 12 (11-15) | 16(14-17) | <0.001^ | 13 (11-15) | 16 (14-16) | <0.001^ |
| Age (categorical) by 2018 (n, %) | | | | | | | | | |
| 10 - 12 years | 98 (52.1) | 30 (12.1) | <0.001* | 65 (55.5) | 11 (7.7) | <0.001* | 33 (46.5) | 19 (18.1) | <0.001* |
| 13 - 15 years | 63 (33.5) | 89 (36.0) | | 38 (32.5) | 56 (39.4) | | 25 (35.2) | 33 (31.4) | |
| 16 - 18 years | 27 (14.4) | 128 (51.8) | | 14 (12.0) | 75 (52.8) | | 13 (18.3) | 53 (50.5) | |
| CD4 in the last 12 months | | | | | | | | | |
| Yes (n, %) | 114 (60.6) | 191 (77.3) | <0.001* | 75 (64.1) | 127 (89.4) | <0.001 | 39 (54.9) | 64 (61.0) | 0.426* |
| No (n, %) | 74 (39.4) | 56 (22.7) | | 42 (35.9) | 15 (10.6) | | 32 (45.1) | 41 (39.0) | |
| Median CD4 count in the last 12 months (cells/μ, IQR) | 833 (614.5- 1113.3) | 625 (402-854) | <0.001^ | 832 (607-1130) | 610 (368-823) | <0.001^ | 841 (617-1109) | 645 (450- 919) | 0.035^ |
| Viral load in last 12 months | | | | | | | | | |
| Yes (n, %) | 177 (94.1) | 244 (98.8) | <0.001* | 117 (100.0) | 141 (99.3) | 0.363* | 60 (84.5) | 103 (98.1) | 0.001* |
| No (n, %) | 11 (5.9) | 3 (1.2) | | 0 (0.0) | 1 (0.7) | | 11 (15.5) | 2 (1.9) | |
| Viral load suppression (n, %) | | | | | | | | | |
| <1000 copies/ml | 129 (72.9) | 163 (66.8) | 0.182* | 88 (75.2) | 95 (67.4) | 0.168* | 41 (68.3) | 68 (66.0) | 0.762* |
| ≥1000 copies/ml | 48 (27.1) | 81 (33.2) | | 29 (24.8) | 46 (32.6) | | 19 (31.7) | 35 (34.0) | |
| Unsuppressed viral load (≥1000 copies) by age | | | | | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 10-12 years | 21 (67.7) | 10 (32.3) | <0.001* | 10 (71.4) | 4 (28.6) | <0.001** | 11 (64.7) | 6 (35.3) | <0.001** |
| 13-15 years | 22 (50.0) | 22 (50.0) | | 15 (53.6) | 13 (46.4) | | 7 (43.7) | 9 (56.3) | |
| 16-18 years | 5 (9.3) | 49 (90.7) | | 4 (12.1) | 29 (87.9) | | 1 (4.8) | 20 (95.2) | |
| Unsuppressed viral load (≥1000 copies) by duration on ART | | | | | | | | | |
| 0-4 years | 15 (51.7) | 14 (48.3) | 0.089* | 6 (42.9) | 8 (57.1) | 0.766* | 9 (60.0) | 6 (40.0) | 0.038** |
| 5–9 years | 19 (28.8) | 47 (71.2) | | 12 (34.3) | 23 (65.7) | | 7 (22.5) | 24 (77.5) | |
| 10-14 years | 14 (41.2) | 20 (58.8) | | 11 (42.3) | 15 (57.7) | | 3 (37.5) | 5 (62.5) | |

*Chi-square test
** Fishers Exact test
^Independent sample median Test
IQR- Inter Quartile Range
ART- antiretroviral Therapy
NVP- Nevirapine
PI- Protease Inhibitors
EFV- Efavirenz

### 3.3 Discussion

This is one of few studies in sub-Saharan Africa describing the extent to which transition from pediatric to adolescent HIV care occurs and the characteristics of adolescents undergoing transition. Using data from two different facilities in the same geographical and catchment area, adolescents active in care in both facilities were similar in socio-demographic and clinic characteristics. Despite three years since starting to transition adolescents from pediatric to adolescent clinic, there was still a huge back log with 46% of eligible adolescents in the 13 to 18-year age group still receiving care in pediatric clinic in both hospitals, suggesting a service gap in the transition process.

Reassuringly, viral load testing coverage was >90% overall, however at Mawenzi hospital coverage was higher in transitioned vs. untransitioned adolescents which may indicate that higher quality of care is provided to adolescents in the adolescent vs. pediatric clinic. Strengthening viral load testing in pediatric clinics could support transition and promote viral load suppression as health workers may feel more comfortable transitioning a clinically stable virally suppressed adolescent vs one in whom viral load is unknown. Concerningly, nearly a third of adolescents had unsuppressed viral load, and this proportion tended to be higher among transitioned vs. untransitioned adolescents especially at KCMC. While this may be partly due to higher viral load testing coverage in transitioned adolescents (i.e. it is possible that those not tested among the untransitioned adolescents are more likely to have high viral loads than those tested), this finding was unexpected because other studies found that unsuppressed viral load tended to be either lower among adolescents attending adolescent focused care than the standard pediatric clinic [88, 89] or not different between adolescents in teen club and those in standard care [90]. However, interpreting the relationship between transition and viral suppression in a cross-sectional study such as ours is complex as unsuppressed viral load also increases with adolescents' age [68, 74] and the phase of the transition process itself may impact adherence. As adolescents move from pediatric to adolescent clinic where autonomy is encouraged, some adolescents may become less responsible about taking their medicine given less parental/caregiver involvement in their care as evidenced by other studies [70-72]. This observation could also be related to post disclosure coping challenges.

In addition, we found that adolescents aged 13-15 years who were still attending pediatric clinic were more likely to be virally unsuppressed compared to 13-15 years old in adolescent clinics, as

well as compared to younger adolescents aged 10-12 years and older adolescents 16-18 years who were still attending pediatric clinic. It is possible that service providers are reluctant to transition adolescents who are not virally suppressed, so 13-15-year-olds remaining in pediatric clinic may be an unsuppressed subset. Overall, these findings suggest the need to critically address medication adherence throughout the transition process. Exploration of these factors is presented in chapter five of this thesis. These findings also call for careful management by service providers of adolescents still attending pediatric clinic to optimize viral suppression in preparation for the move to adolescent clinic.

### 3.4 Limitations

There are several limitations of this analysis. It was not possible to accurately determine the number of adolescents with perinatally and non-perinatally acquired HIV; therefore, estimates of the number of adolescents with perinatally acquired HIV based on the age at start of ART may under/over represent the true number of adolescents with perinatally acquired HIV involved in this study. We could not report on whether adolescents knew their diagnosis or not as this was not captured by the national CTC2 database at the time of the study.

The transfer status and date of transfer were not recorded in the database and only a few files had transfer status and date of transfer documented. Therefore, adolescents who attended Saturday clinics were inferred to have transferred with the first Saturday clinic attended by the adolescent assumed to be the date of transfer. Therefore, the number reported as transferred may be an under/over representation of the true extent of transition in both hospitals.

While it would have been ideal to compare patient characteristics and outcomes (e.g. viral load, regimen, CD4 cell count) before and after transition, because data collection was done over a very limited period, we did not have longitudinal data on these measures and could only compare among the most recent measures for adolescents who had vs had not yet transitioned.

### 3.5 Conclusion

We found that 54% of adolescents had already transitioned to adolescent clinic by the time of the study and the adolescents at both hospitals have similar socio-demographic and clinical characteristics. However, there was a sizeable backlog of adolescents eligible for transition who were still attending pediatric clinic. Coverage of viral load and CD4 testing was higher at the adolescent clinics of different facilities and may indicate better quality of care for transitioned

adolescents. The high proportion of virally unsuppressed adolescents overall is a challenge, indicating the need for a better understanding of the impact of transition and adolescence itself on adherence to inform targeted medication adherence strategies addressing adolescent subpopulations at greatest risk of unsuppressed viral load.

## CHAPTER 4: THE ORGANIZATION OF PEDIATRIC-TO-ADOLESCENT TRANSITION HIV CARE SERVICES

### Introduction

The previous chapter has provided an overview of the clinical characteristics of "active in care" adolescents age 10-18 years who have and have not yet transitioned and the extent to which the pediatric-to-adolescent transition occurs in both hospitals. Chapter four will describe in detail how pediatric-to-adolescent transition services are organized, as well as the perceptions and experiences of adolescents and caregivers undergoing this transition.

To understand the current organization of pediatric-to-adolescent transitional care services and how it affects the perceptions and attitudes of transitioning adolescents during early adolescence the following research questions were examined:

a. What is the current organization of the pediatric-to-adolescent HIV transition services in Mawenzi and KCMC?
b. What are the perceptions and attitudes of adolescents, caregivers and service providers towards the current pediatric-adolescent transition services over time?
c. How do these transition services affect the perceptions and attitudes of adolescents and caregivers towards pediatric-adolescent transition?

The chapter begins with a description of study participants followed by a brief contextual description of clinic settings of the two hospitals. It then describes in detail the transition practices in both hospitals followed by key themes that emerged from the perceptions and experiences of adolescents and caregivers. The themes are organized according to the three key phases: before, during the actual transfer, and after transition. The last section discusses key issues that emerged from the perceptions of adolescents, caregivers and service providers and the extent to which the transition process addresses the six health care transition elements namely: 1) Transition policy/guide that outlines the transition process and responsibilities of each stakeholder involved in the transition process; 2) Tracking and monitoring including establishment of transition criteria and processes for identifying transitioning youth; 3) Transition readiness assessment; 4) Transition planning on the optimal timing of transfer; 5) The actual transfer of care; 6) Transfer completion and ongoing care support.

## Findings

### 4.1 Description of study participants

Eight service providers (four from each hospital) participated in the IDIs and FGDs. The median age of the service providers was 41 years (range 34 to 55 years). The majority of service providers (six out of eight/) were female (all nurses). The two male service providers were doctors. All of the service providers were serving in both adolescent and pediatric clinic in both hospitals.

### 4.2 Clinics settings

KCMC, being the referral hospital in Northern Tanzania, was among the first hospitals to establish HIV care and treatment services in 2006 for both adults and children living with HIV. By 2008, adolescent-focused HIV care was formally initiated in this hospital and pediatric-to-adolescent transition was put in effect in 2014. By Dec 2018, 299 adolescents aged 10-18 years had already transitioned from pediatric to adolescent clinic. The adolescent HIV clinic is held on Saturdays (once in a month) while the pediatric (family-centered) clinic is on Tuesdays and Thursdays where caregivers who live with HIV receive their HIV care together with their young ones. The pediatric and adolescent clinics are located in the same premises operated by the same service providers. The adult HIV clinic is located in a different premise, with different service providers from the adolescent and pediatric clinic and operates on every week day.

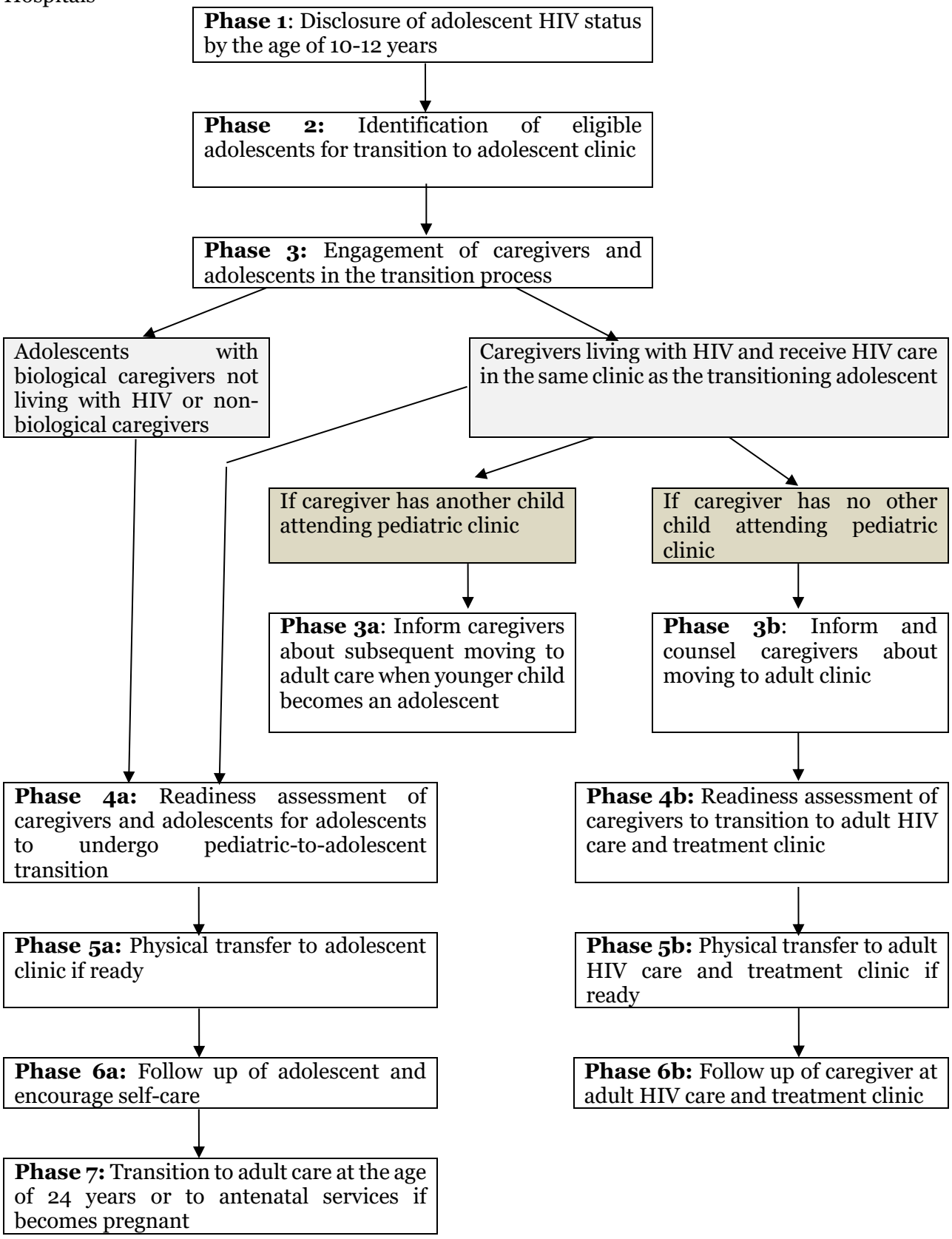
Mawenzi hospital, a regional hospital in the Kilimanjaro region, established HIV care and treatment services in 2008 and adolescent-focused HIV care was established in 2014. The pediatric-to-adolescent transition services were then established in 2016 with assistance and mentorship from KCMC that had initiated pediatric-to-adolescent transition services two years earlier. By Dec 2018, 194 adolescents aged 10-18 years had already transitioned from pediatric to the adolescent clinic. The pediatric, adolescent and adult clinics are located in one building with the same service providers but are operated on different days. Saturdays (one Saturday in a month) are dedicated for adolescent clinic, Thursdays for pediatrics and the remaining days of the week are for adults. With regards to service provision arrangement, caregivers who are living with HIV receive their HIV care together with their children during the pediatric clinic days.

### 4.3 Organization of pediatric-to-adolescent transition services

The transition process at KCMC and Mawenzi hospitals focuses on moving the adolescent from pediatric to adolescent services safely and efficiently within the context of personal growth as well as the wellbeing of the caregiver. Following the mentorship that Mawenzi received from KCMC

to establish pediatric-to-adolescent transition services, the two hospitals have a similar transition program. Figure four below provides an overview of the organization of transition services developed from analysis of IDIs and FGDs of health care providers in both hospitals.

Figure 4: The organization of pediatric-to-adolescent transition services in Mawenzi and KCMC Hospitals



**Phase 1** is the initial preparatory phase of the transition process that involves disclosure of the adolescents' HIV status to the adolescents themselves whereby the caregivers are encouraged and supported to fully disclose the adolescents' HIV status at the age of 10 -12 years together with the service providers. Once the adolescent reaches 10-14 years of age and is fully disclosed to then they are considered eligible for pediatric-to-adolescent transition as the eligibility criteria are based on adolescent age and disclosure status. **Phase 2** is the identification of the eligible adolescents for pediatric-to-adolescent transition that occurs during the normal pediatric clinic procedures which include anthropometric measurements, counseling sessions and consultations with doctors. An eligible adolescent is an adolescent aged 10- 12 years old, fully aware of his/her HIV status and has comprehended with the HIV diagnosis. After identification of eligible adolescents, **Phase 3** involves engagement of caregivers of identified adolescents and adolescents themselves in the transition process. The engagement process is usually coordinated by the transition coordinators (who have many other responsibilities) in both hospitals; hence, other service providers are also involved in providing information and having discussions with the caregivers about the transition process, benefits and expectations of the adolescent clinic, and gaining consent from the caregivers. These engagements are usually held one month before the actual transfer in both hospitals. Caregivers not living with HIV, then move to **Phase 4** of readiness assessment for allowing the adolescent to transition to adolescent clinic. If the caregivers are ready and provide consent, then the adolescents are also assessed for their readiness to move to adolescent clinic and subsequently transferred to adolescent clinic when ready to move **(phase 5).**

If the caregiver is living with HIV and receives HIV care together with the eligible adolescent, then the level of engagement is more intensive as the caregiver will have to undergo two transitions. The first caregiver transition is the transition to attend their HIV clinic in the absence of their child/adolescent with whom they have been receiving HIV care since childhood. The second transition is the transition from the pediatric to adult clinic as the caregiver will be required to move to adult HIV clinic once the adolescent starts attending the adolescent clinic. If the caregiver living with HIV has another child attending the pediatric clinic, they will continue to receive HIV care at the pediatric clinic but will be informed about the forthcoming transitions once the younger sibling grows to adolescence **(phase 3a).** If the caregiver has no other children attending pediatric clinic, the caregiver is informed and supported for their move to adult HIV clinic depending on the clinic logistics/hospital settings **(Phase 3b).** The caregiver is then assessed for their readiness for their adolescent to undergo pediatric-to-adolescent transition

**(Phase 4a)** and at the same time assessed for readiness for their own pediatric-to-adult transition (**Phase 4b).**

**Phase 5** is the actual physical transfer for both adolescents and caregivers living with HIV who were attending the same clinic to their respective new clinics. The actual transfer occurs when the adolescent and caregivers are clinically stable i.e free from opportunistic infections and other HIV-related illnesses, indicating effective immune system functioning. For adolescents, on the day of transfer, each transitioning adolescent is given a warm welcome to the new clinic by the adolescents and given a friend, a relative or any other peer of similar age and sex to support the newcomer in the new clinic **(Phase 5a).** The caregivers (regardless of their HIV status) who have escorted the adolescents on the day of transfer become passive/distant participants so as to allow free participation and discussion of adolescent-related issues in the adolescent clinic. These caregivers will only be involved in clinic issues when the transitioned adolescents show signs of poor adherence to medication and/or clinic appointments.

**Phase 5b** is the actual transfer to adult HIV clinic for caregivers living with HIV whose adolescents have already moved to adolescent clinic. In settings where the service providers in the adult clinic are different from the pediatric clinic, the transitioning caregivers are escorted by a pediatric service provider to the adult HIV clinic and handed over to a service provider who will assist the caregiver with the clinic procedures. However, some caregivers are given prior exposure to the adult clinic to familiarize themselves with the environment prior to the actual day of transfer.

**Phase 6a** is concerned with the follow up of transitioned adolescents in the adolescent clinic as the adolescents continue receiving HIV care there. It is during this phase where self-care initiatives (clinic attendance and medication adherence management) are enhanced as preparations to transition to adult care are instituted. Once the adolescent reaches the age of 18 years, they are consulted by physicians while in the adolescent clinic instead of by pediatricians. Lastly, **phase 7** is when the transition to adult care occurs when the adolescent reaches the age of 24 years. However, if the adolescent marries before that age, they will be gradually moved to the adult HIV clinic despite their age as they are considered as an adult. Furthermore, if an adolescent becomes pregnant before the age of 24 years, they are also moved to the Reproductive and Child Health Clinic (RCH clinic) where they will continue receiving HIV care until delivery. After delivery, the adolescent will then be required to move from the RCH clinic to pediatric HIV

clinic so as to enhance comprehensive follow up the infant for HIV Early Infant Diagnosis (HEID). If the infant is HIV positive, then the adolescent will continue with the pediatric clinic but if the baby is negative, then the adolescent will move to the adult clinic where they will continue to receive HIV care.

Despite these clearly explained pediatric-to-adolescent transition practices, there were no written protocols to guide the organization of pediatric-to-adolescent transition services. Although there are national guidelines regarding adolescent and young people's health [91] including the Tanzanian HIV care and treatment guidelines and adolescent guide [15] , and the "On Track Moving On" guide [34], very little guidance is provided on the process/organization of pediatric-to-adolescent transition services in HIV care.

### 4.4 Perceptions and attitudes of pediatric-to-adolescent transition process

The following section begins with the description of study participants (adolescents and caregivers) that were involved in both the exploratory and longitudinal study. It then describes the perceptions and attitudes of adolescents, caregivers and service providers towards the aforementioned organization of pediatric-to-adolescent transition services over time and how these attitudes and perceptions affect this organization of transition services. The section has been organized based on the seven phases the transition process outlined above.

#### Description of study participants

For the exploratory study, a total of eight adolescents (four from each hospital) who had transitioned to adolescent clinic in the past six months participated in IDIs. The median age of these adolescents was 13 years (range 11-14 years) and the majority (six adolescents) were male. All of the adolescents were schooling with seven adolescents attending at primary school level (grade five to seven) and one in secondary school (form one). Two adolescents were living with their biological mother and father, three with their biological mother alone, two with grandparents and one with an aunt and uncle. All of the adolescents were aware of their HIV status. However, half of them were disclosed to at one to two years before their transition to adolescent clinic, three adolescents at less than one year and one adolescent at two to four years before transition to adolescent clinic. Most of the disclosures (four adolescents) were caregiver led, two service-provider led, one both service provider and caregiver led and one was led by peers.

For the longitudinal study, a total of eight adolescents (four from each hospital) who were about to transition to adolescent clinic participated in the IDIs and FGDs. The median age of the adolescents was 12.6 years (range 11-14 years) and the majority (six adolescents) were female. All of the adolescents were attending primary school (grade two to seven). Three adolescents were living with their grandmother only, two adolescents with both grandparents, two adolescents with a biological father and stepmother and one adolescent with the biological mother. The majority of adolescents (5/8) were disclosed of their HIV status at one to four years before transition, with two adolescents disclosed at zero to six months before transition and one was not yet disclosed at the time of study recruitment (as explained in the methodology section). Of those disclosed, the majority (4/7) of disclosures were caregiver-led while the remaining (3/7) were service provider-led.

A total of eight caregivers (four from each hospital) whose adolescents participated in the longitudinal study participated in the IDIs and FGDs with a median age of 47 years (range 31 to 60 years). Six caregivers were female and two were male. Most of the caregivers had primary school education and the majority of caregivers were grandmothers. Three caregivers were biological parents of whom there were two fathers and one mother. Among the biological parents, only one was living with HIV and was on regular medication, one was not aware of their HIV status and one was not living with HIV.

### 4.4.1 Phase 1 of transition process: Disclosure

#### Adolescents' perceptions

The perceptions and attitudes of adolescents towards pediatric-to-adolescent transition differed depending on how long the adolescent was disclosed to before moving to adolescent clinic. In this study, three adolescents were disclosed to at one month prior to moving to adolescent clinic and five adolescents learned of their diagnosis more than two months ahead. Adolescents who had their HIV status disclosed more than one month before moving to adolescent clinic and had coped with their diagnosis, had positive perceptions of the adolescent clinic and were looking forward to meeting with other adolescents with similar conditions. Adolescents who were disclosed at one month prior moving to adolescent clinic had more difficulties accepting the pediatric-to-adolescent transition despite showing positive reactions to the new clinic. Nonetheless, they had to conform with the caregivers' and service providers' wishes for transition. With eventual exposure to adolescent clinic, however, these adolescents coped with their diagnosis. For example, one caregiver from Mawenzi hospital shared how their adolescent reacted when disclosed at one month prior to moving:

"*He (adolescent) become silent for almost two weeks, not interacting, not as happy as he always was.*" But after going to the adolescent clinic, *"He said that he found many adolescents like him who are also living with HIV/AIDS. He likes that fact that he plays with his friends at the clinic. He liked to meet his fellows and play together. He is fine with it now. He now knows why he uses medicines every day. He has a clear understanding about himself now."*

On the other hand, adolescents who learned of their HIV status and then moved to adolescent clinic less than a month later experienced difficulties in comprehending their HIV status and had negative perceptions of pediatric-to-adolescent transition which resulted in defaulting clinic. During in-depth interviews, one service provider from KCMC hospital shared an example of such a scenario where old age at disclosure also played a role. She said:

*"We had one university girl who had just recently known that she is living with HIV. She became stressed…We had told her that we will take her to adolescent clinic where she will meet with other adolescents of the same age so that she sees that she is not alone. So, we took her there. She looked around and said, 'No. I haven't seen any body of my age. They are all children. I cannot sit with the kids, they only talk about childish stuff.' She never came back to that clinic again."*

Therefore, for adolescents who learned of their HIV status recently and were still experiencing difficulties in comprehending their HIV status, moving to the adolescent clinic resulted into negative perceptions and even clinic default.

**Caregivers' perceptions**

Caregivers whose adolescents were already disclosed to and had coped with their diagnosis had positive perceptions of the pediatric-to-adolescent transition and hence worked together with the adolescents to enhance the transition process. However, among caregivers who had not yet disclosed their adolescents' HIV status, feelings of being under pressure to disclose prevailed with fear that the adolescent is too young to be told. As a result of feeling pressured to disclose, these caregivers felt that they were forced to make quick decisions to comply with the service providers imposed pediatric-to-adolescent transition conditions as evidenced by the following caregivers' quotes:

*"For sure I had to follow the advice of the doctor that my son had to know his HIV status early. I had planned to let him know the truth when he grows up and reaches standard five or six."* (Male caregiver (biological father) from Mawenzi hospital during the initial IDI).

*"I would have waited until when she is grown up then I can tell her…but the doctors know better!"* (Female caregiver (grandmother) from Mawenzi hospital during the initial IDI).

*"Since the doctors knew that it was the right time (to disclose) then I accepted it because the doctors know more than me. I follow what I am told by the doctors. I was waiting until when she reaches standard seven."* (Female caregiver (grandmother) from KCMC hospital during the initial IDI.

As a result of feeling pressured to disclose, caregivers who could not comply with this transition condition (i.e. disclosure) resort to other solutions to relieve this pressure of disclosure such as bypassing the disclosure stage by taking their adolescents directly to the adolescent clinic (without disclosure) or moving their adolescents to another clinic. This was evidenced by the following service providers' quotes:

"*One caregiver of an 11-year boy in grade seven had decided to move her son to the adolescent clinic without telling the service providers. So, she took her son to the clinic and she was greatly shocked because she had not disclosed to her son and they (adolescents) were talking about HIV at the adolescent clinic."* (Service provider from KCMC hospital during the second IDI).

*"One eligible adolescent has not yet moved to adolescent clinic because …his father actually moved this adolescent to another clinic because of the move to adolescent clinic as he does not want his child to be disclosed."* (Service provider from KCMC hospital during the second IDI).

Therefore, putting caregivers under pressure to disclose their adolescents' HIV status when they feel unprepared may predispose caregivers to make poor decisions regarding their adolescents' HIV clinical care.

### 4.4.2 Phase 2: Identification of eligible adolescents for pediatric-to-adolescent transition

From service providers' perspectives, the identification of eligible adolescents for pediatric-to-adolescent transition is usually done during the pediatric clinic routines. However, faced with limited human resources, service providers perceive inefficiencies in identifying eligible adolescents which results in a backlog of older eligible adolescents still attending pediatric clinic. For example, during IDIs, one service provider from Mawenzi hospital said:

> "*If we had more staff, we would have been able to appoint just one person to specifically identify the eligible adolescents so that s/he can talk with and prepare them for the move to adolescent clinic. But we don't have such a specific person, it is any staff who is present at the clinic does that. As a result, we sometimes miss these eligible adolescents. …you may be surprised seeing a 15 years old adolescent and is still attending pediatric clinic…So it means that we missed him due to too much work and limited staff."*

As a result of this inefficiency in identification of eligible adolescents, some adolescents initiate the transition process for themselves as evidenced by one service provider from Mawenzi hospital who said *"…An adolescent comes to you saying, 'Sister, I am 14 years old and I have heard that there is an adolescent clinic. How comes I attend this normal clinic?' So, you assess them and find that they are right. Then you tell them that we have overlooked, and ask them to join that clinic. They agree."* This finding suggests that service providers could increase their efficiency in identifying eligible adolescents for pediatric-to-adolescent transition by raising awareness of the existence of adolescent clinic among adolescents in pediatric clinic.

### 4.4.3 Phase 3: Engagement of caregivers and eligible adolescents in the pediatric-to-adolescent transition process

Following identification of eligible adolescents, engagement of their caregivers and eligible adolescents in the transition process is done by providing the necessary information on the pediatric-to-adolescent transition and having discussions with the caregivers and adolescents about the benefits and expectations of the adolescent clinic. These engagements are usually held 1 month before the actual transfer in both hospitals.

**Adolescents' perceptions**

When adolescents were engaged in the transition process, especially those who have already coped with their HIV diagnosis, positive expectations of meeting with old friends and relatives dominated. Many looked forward to having fun at the clinic, and receiving timely and better quality care than they currently receive at the pediatric clinic. For example, during IDI in the cross-sectional qualitative study, one transitioned adolescent at Mawenzi hospital put it: *"in the pediatric clinic the nurses usually focus on the calling out of the names and serving old people and children. When you go to adolescent clinic, they will follow you closely because the clinic is for adolescents. They shall ask you, how are you? And how are you getting on?"* As a result of these positive perceptions, these adolescents were eagerly looking forward to the day of transfer to the adolescent clinic after being informed by service providers about their pediatric-to-adolescent transition.

Despite the engagement, misinformation about the adolescent clinic was also present resulting in some resistance to this transition as shown in the adolescent quote before moving to the adolescent clinic: "*I feel bad, I want to stay in the pediatric clinic. I will be affected on the use of medicines. There they change the medicines."* This finding suggests the need for service providers to thoroughly engage adolescents and caregivers in the pediatric-to-adolescent transition process by clarifying any adolescent issues or misconceptions that may hinder successful transition.

Interestingly, the thought of friendship dominated among all adolescents after being informed about their move to adolescent clinic. Reunion with former friends or relatives who had moved to adolescent clinic earlier made adolescents want to move to adolescent clinic. For these adolescents, meeting with old friends and reestablishing their friendship was a significant motivator for the move to the adolescent clinic. As a result of the expected friendship/relative reunion, adolescents were eagerly looking forward to the day when they too will be told to move to adolescent clinic or initiated the transition process themselves. For example, one adolescent who was eagerly waiting to reunite with his brother in the adolescent clinic at KCMC hospital said:

> "*My brothers told me that there is an adolescent clinic. Thereafter, I told my brother that I want to join to the adolescent clinic. He then told me that if I want to join the clinic, I have to get permission from the doctor. I was very happy the day I was told that because I will go with my brother."*

Despite the perception of friendship reunion, a sense of friendship breakdown was also felt among adolescents who have strong connections with friends/relatives in the pediatric clinic, with transition perceived as a friendship disruption event. As a result, to maintain the significant friendships in the pediatric clinic, some transitioning adolescents wished for a delayed transition in order to effectively end their friendship in a positive manner while others delayed the transition in order to maintain the friendships formed. For example, during FGDs with adolescents at one year after moving to adolescent clinic, one adolescent when asked on the preferred duration from being told to move to the actual day of transfer, said, "*I prefer one year because you have your friends who are not told to move to adolescent clinic. So, you will have to stay with them until that day when you are moving to adolescent clinic."* One service provider from Mawenzi hospital alluded to this notion during FGDs with service providers by saying: *"There are adolescent who resist moving to adolescent clinic! They are already old enough but because they have made friends in the pediatric clinic, they are resistant to move. We have one old adolescent, he has refused to move."* This finding would suggest that there could be significant benefit in transitioning a group of adolescents to the adolescent clinic together (e.g. a group of friends etc.). This approach has been explored in the pediatric-to-adult transition but has yet been implemented in the pediatric-to-adolescent transition.

**Caregivers' perceptions**

Findings from caregivers' perspectives show that some were content with their level of engagement in the pediatric-to-adolescent transition process while other caregivers felt that they were being left behind. The caregivers who felt that they were well engaged in pediatric-to-adolescent transition actively engaged in the transition process and supported the decisions made to transition their adolescents. For example, one caregiver from Mawenzi hospital said, "*I liked the way they informed me. I have no doubt because she is in safe hands."* On the other hand, caregivers who felt left behind in the transition process, were resistant to the transition process and therefore required more information. As one caregiver from KCMC hospital said, *"I really don't know what is there. I think I require more information"*. Another caregiver from Mawenzi hospital said*, "I don't know why she will be transferred but I hope it's for the best."* Therefore, lack of information about the pediatric-to-adolescent transition appeared to make caregivers resistant to this transition. However, caregivers complied with the transition due to the trust established with the service providers during the pediatric clinic.

**Phase 3a and b: Informing about transfer to adult HIV clinic**

Phase 3a and b are a continuation of further engagement of caregivers about their transition to adult HIV clinic once the adolescent starts attending the adolescent clinic, and separation from their adolescents in receiving their HIV care. Fear of emotional separation prevailed among caregivers living with HIV who were receiving HIV care together with their adolescents. As a result, caregivers resisted the pediatric-to-adolescent transition. For example, one caregiver living with HIV who was attending clinic with her adolescent resisted the pediatric-to-adolescent transition for a period of six months. This caregiver from KCMC hospital reasoned, *"I think I need to prepare myself a bit. I think after three to four months. I would like to continue going to the clinic with my adolescent."*

Fear of moving to adult HIV clinic due to unfamiliarity with the new adult clinic and stigma in the adult HIV clinic also prevailed among these caregivers when informed about their transition to adult clinic who delayed moving to adult HIV clinic and actually attended the adolescent clinic with their adolescents. However, with service providers' support, these caregivers eventually move to adult clinics. The two examples below were shared by service providers to illustrate this observation:

> "*There was one caregiver who cried a lot…That mother didn't want at all to move to the adult clinic because others will see her and so on. We were helping her when she came on Saturdays…. she cried a lot! She was saying, 'How can I go there? How can I go there?' But gradually we took her there, she was given orientation, she was handed over to the nurse in charge so that whenever she attended clinic, the nurse in charge will support and help her…She is now doing fine and happy too. She told me, 'It is just a normal clinic, I am now used to it'."* (Service provider from KCMC during the second IDI).

> *"There was one caregiver who stayed for a long time at pediatric clinic. I even remember her name. She used to come on every Saturday with her adolescent son…We used to talk to her a lot. We asked why she doesn't come during the normal clinic like other adults. She said, 'I don't attend the normal clinic because I have to come with my son to clinic on Saturdays. I have to escort him.' Then we realized that she doesn't want to go to the adult HIV clinic because there are so many people and she doesn't want to be seen. So, she was using that chance as a reason for her not to move to adult HIV clinic. So, from there onwards we talked to her for a long time. Now I think she has agreed as I don't see her*

*anymore, I only see the boy attending clinic alone."* (Service provider from KCMC during FGD).

Therefore, fear of moving to an adult HIV clinic among caregivers living with HIV led to negative perceptions of the pediatric-to-adolescent transition.

### 4.4.4 Phase 4: Caregivers' readiness and adolescents' readiness assessment

**Adolescents' perceptions**

Adolescents' readiness to move to adolescent clinic is assessed by service providers to enhance successful transition and continuation of services after moving to adolescent clinic. Therefore, service providers address adolescents' concerns prior to the actual transfer to ensure smooth and successful transition to adolescent clinic. However, some adolescents felt that their readiness to move to adolescent clinic was not well assessed. Some of the adolescents' concerns that were not addressed included concerns about moving alone to the adolescent clinic. As one adolescent put it: *"I was afraid. I was saying to myself. I am going to adolescent clinic alone? How will it be without a friend and I don't have a friend there! I will be alone."* Other adolescents felt pressured by service providers and caregivers to move to adolescent clinic without addressing their concerns before moving. The following adolescent's quotes illustrate this observation:

"*I wanted to be asked first. I wanted to be asked whether I like to attend the clinic on Saturday or not. I would have told them that I don't want to attend the clinic on Saturday because I will be attending confirmation classes on that day. I was not willing to come to clinic on Saturday."* (Female adolescent from Mawenzi during the third IDI).

"*That doctor had already made arrangements that I had to join the adolescent clinic."* (Female adolescent from KCMC during the second IDI).

*"My mom is the one who used to tell me, 'Go with your brother.' I used to tell her, 'I have not yet been moved.' Then she called the sister (at the clinic) and the sister told her, 'This adolescent should also be coming to the clinic with his brother.' Mom asked me, 'Will you agree?' I had to say, 'Yes.' Then Mom agreed."* (Male adolescent during IDI of the cross-sectional qualitative study.

This finding thus suggests that adolescents' perspectives on pediatric-to-adolescent transition are influenced by factors such as the degree to which the transition disrupts their routines or the reassurance that a friend or relative is also going to the same place.

**Caregivers' perceptions**

Most caregivers felt they were well assessed for their readiness to let their adolescents move to adolescent clinic. For example, one caregiver from Mawenzi hospital said "*Even if they tell me today that child will join the clinic today, I am happy with it. No objections."* However, some caregivers felt that they were not ready to let their adolescents move to adolescent clinic but were forced to comply with either the services providers' wishes or their adolescents' feelings. For example, one caregiver from KCMC hospital said "*I had to agree with the move because there were no more children of her age in the normal clinic that we attend. She was lonely, so I had to let her move her to the adolescent clinic. I had no choice because when I go with her to the normal clinic, she is usually lonely and the doctors told me that she has to move. Now, I am continuing with my usual clinic…I feel lonely but I had no choice.*" Following their unreadiness to let the adolescent move to adolescent clinic, some caregivers wished to be given more time before the transfer so as to prepare themselves and their adolescents for the pediatric-to-adolescent transition. For example, one caregiver from KCMC hospital during the third IDI said *"I would like to be told even two months before so that I can arrange for an escort and prepare adolescent herself."* Hence not all caregivers felt that they were well prepared for letting their adolescents move to adolescent clinic but had to comply with adolescents' or service providers' wishes.

### 4.4.5 Phase 5: Physical transfer to adolescent clinic

**Adolescent perceptions**

For adolescents, Phase five which is the actual day of transfer to adolescent clinic is the most crucial moment during the pediatric-to-adolescent transition as it was recalled by all transitioning adolescents. In this organization of services, each transitioning adolescent is given a warm welcome to the clinic by the adolescents by introducing oneself or being introduced by service providers, and assigning of a friend, a relative or any other peer of similar age and sex to support the newcomer in the new clinic. As a result of this arrangement feelings of enthusiasm dominated the transitioning adolescents' minds on the actual day of transfer. The enthusiasm is augmented by the reunion with old friends who moved earlier as illustrated in the adolescents' quotes:

> "*I saw my friends. I felt very happy. I was the one who saw them and I followed them where they were sitting." (*Female adolescent from Mawenzi hospital during the second IDI).

> "*He (friend) is the one who left me in the pediatric clinic and I found him at this clinic (adolescent clinic). Then he asked me if I have moved to this clinic. We were happy!"* (Male adolescent from KCMC during the second IDI).

Despite the supportive arrangement and the abundance of enthusiasm, anxiety on the day of transfer also prevailed although to a lesser extent than enthusiasm. The anxieties were mainly due to moving alone without being accompanied by a friend and not knowing anybody in the adolescent clinic. For example, one adolescent from Mawenzi hospital who transitioned alone shared her feelings of that day of transfer as follows: "*I didn't know anybody by then, I didn't feel good. I wished I had a friend!"* She further recommended that each transitioning adolescent should be assigned to a friend from the adolescent clinic before the actual day of transfer to assist any transitioning adolescent.

Anxiety was also felt among accompanied adolescents due to being in a new environment with unfamiliar adolescents. This was expressed by one adolescent from KCMC hospital who expressed how she felt on the day of transfer "*I found so many people!!I got scared because there were so many adolescents. I did not know them. The only one I knew was this friend (who escorted her to clinic). I did not know them at all.*" As a result of not knowing anybody in the adolescent clinic, some adolescents find it difficult to interact with other adolescents and adapt to the new surroundings as demonstrated in the following quotes from adolescents:

> "*I used not to have friends at first when I came to the adolescent clinic. I just used to sit. They told me cheer up! I should cheer up. I just used to sit alone. They told me to mix up with others. Then I mixed up then I got friends."* (A transitioned male adolescent from KCMC during IDI of the cross-sectional qualitative study).

> *"I stayed there (adolescent clinic) for a long time until I became friends with Kidoga (pseudonym). I am the one who approached her. I just felt that she was like me. Then I thought she qualifies to be my friend. She was like me then I told her to be my friend."* (A female adolescent from Mawenzi during the third IDI).

Even though some adolescents did not know anyone in the adolescent clinic, peer interaction at the adolescent clinic fostered friendship, thereby reducing anxiety and fears of being alone, resulting in positive perceptions of the adolescents afterward.

**Caregivers' perceptions**

For all caregivers, phase five is the day when they become passive/distant participants in adolescent clinic consultations as they do not participate in clinic consultations together with the adolescents. As a result, some caregivers felt that that they were pushed aside in the adolescent care processes. For example, one caregiver who used to escort her granddaughter from Mawenzi hospital said:

> *"I used to enter to listen and know what the doctors advise her so that I insist the instructions given by the doctor when we are at home. But now doctors have told me not to enter with her anymore. I should wait for her outside the room but my granddaughter is scared to enter to the doctor's room alone. I felt bad but the doctor knows what they are doing."*

For caregivers living with HIV, phase five is the day of moving to the unfamiliar adult HIV clinic. However, this study could not establish how these caregivers feel on their first day of transfer to adult clinic as there was no caregiver among the study participants who transitioned to adult clinic during the study period. Hence this is a potential area for future research.

### 4.4.6 Phase 6: Follow up

**Adolescents' perceptions**

Phase 6a is concerned with the follow up of transitioned adolescents in the adolescent clinic. It is during this phase where self-care (clinic attendance and medication adherence management (explained in chapter six) are enhanced as preparations to transition to adult care are instituted. For adolescents, continued clinic attendance after moving to adolescent clinic was perceived as an opportunity to connect and interact with others thereby expanding their network of friends. For example, some adolescents said:

> *"I want to continue with the adolescent clinic. I will get acquainted to many adolescents and I will get more friends."* (Female adolescent from Mawenzi during FGD with adolescents).

> *"I like the adolescent clinic because it makes you happy. You meet with other children whom you do not know and you become friends with them!"* (Male adolescent from KCMC during the third IDI).

> *"I don't want to go back I really don't want. I will not be seeing my friends. If my friends are going back, then we will go back together. If they are not going back then I am staying."* (Female adolescent at KCMC during the third IDI).

Furthermore, continued clinic attendance after moving to adolescent clinic made adolescents appreciate the adolescent clinic more than the pediatric clinic by giving them a sense of belonging. When asked if they would go back to pediatric clinic, none of the transitioned adolescents in our study wanted to return. The feelings of belonging to the adolescent clinic and wanting to continue with care were also due to adolescents perceiving themselves as unsuitable to receive care in the pediatric clinic. For example, one female adolescent from KCMC hospital said, "*I will not agree to go back because it is called pediatric clinic. It is for the children and not adolescents. I am now an adolescent, I have grown up."* Furthermore, availability of adolescent age-appropriate activities such as singing in the choir, dancing, sports, lectures and availability of food in the adolescent clinic made adolescents feel at home in the adolescent clinic. For example, one male adolescent from KCMC hospital said *"I will remain in this clinic because it is good. We tell stories, we draw."* Another one from Mawenzi hospital said *"I don't want to go back (to pediatric clinic) because we do not eat. We stay hungry until the time we reach home."*

Last, but not least, another reason for adolescents wanting to remain in the adolescent clinic was the perceived greater efficiency in service provision than in pediatric clinics due to fewer people in adolescent clinic and the fact that adolescents spend less time in the adolescent clinic because folders are prepared in advance compared to in pediatric clinic. The following adolescent's quote illustrates this observation:

> *"When I was still in the pediatric clinic, you find that there are many people and if you go late …until you come out! You find files of adult first then children follow. Therefore, when I go there alone, I find myself just sitting there, just sitting there until time passes. But when I come to the adolescent clinic, I just hand in my card, they go fast and they are also few people."* (Male adolescent from KCMC in cross-sectional longitudinal study).

Therefore, the positive perceptions of the adolescent clinic were shaped by the prevailing opportunities to make friends in the adolescent clinic and the greater efficacy of the adolescent

clinic in providing HIV care compared to the normal/pediatric care, which includes adults and other family members.

**Caregivers' perceptions**

As their adolescents continue receiving care in the adolescent clinic, caregivers slowly started to realize the obvious positive changes in their adolescents ranging from increased intellectual capacity, maturity, to adolescents assuming more responsibilities in their clinic attendance and medication adherence management than before moving to adolescent clinic. The following caregivers' quotes shown below illustrate this:

> *"They have grown up. They can reason things."* (Male caregiver from Mawenzi hospital).
>
> *"She has become very active and confident."* (Female caregiver from Mawenzi hospital).
>
> *"He understands all the instructions given by the doctors. When he is told to go to clinic alone he is able to go."* (Male caregiver from KCMC hospital).
>
> *"He now knows why he uses medicines every day. He has a clear understanding about himself now."* (Male caregiver from Mawenzi hospital).

As a result of these positive changes in their adolescents, some caregivers who were resistant wished they had made the decision to move earlier. For example, during FGD with caregivers, one caregiver from Mawenzi hospital said, "*I would have made that decision of moving her to adolescent clinic earlier. There are so many benefits. She has her friends' company, so she is more active than she used to be in the normal clinic."*

**Service providers' perceptions**

From the service providers' perspectives, provision of appropriate individual care to adolescents is perceived as a challenging task due to limited human resources for adolescents and the fact that adolescent clinics are only held once per month. As a result, the number of adolescents per clinic appears excessive compared to the number of service providers. The following service providers' quote from Mawenzi hospital illustrate this challenge, *"Sometimes you find only one doctor attending 80-90 adolescents. It becomes difficult for the adolescents to get the attention they*

*need…. We are at least required to have one person for viral load checking, a nutritionist, counselors present during clinics."* (Transition coordinator from Mawenzi hospital).

Despite the limited availability of human resources, from service providers' perspectives, the availability of adolescent psychosocial services as part of HIV management played a significant role in influencing adolescents before and after transition to adolescent clinic. The psychosocial services in the adolescent clinic not only made adolescents want to move to adolescent clinic, but also continue with clinic. These services such as peer sessions, football bonanza, picnics and provision of refreshments/meals provided the transitioned adolescent with the opportunity to discuss their health conditions with others and encourage one another and promote clinic attendance. When psychosocial services were absent, adolescents were less likely to continue with care. One service provider from Mawenzi hospital described this experience when food was not made available in the adolescent clinic by saying, *"Initially they (adolescents) used to be provided with food and drinks as a way to motivate them to come but I think their sponsor can no longer afford now. So that has affected the clinic attendance. We used to get around 200 adolescents per clinic but now it has decreased to around 70 adolescents in the last adolescent clinic."* Therefore, food is a huge motivator for adolescents to attend clinic.

### 4.4.7 Phase 7: Transition to adult care

It is worth mentioning that in this section, only adolescents' perceptions on transition from adolescent to adult clinic as expressed by service providers are provided as no adolescents themselves in this study transitioned to adult care, and thus there were also no caregivers with adolescents transferring to adult care.

**Adolescents' perceptions (as reported by service providers)**

As stated earlier, once the adolescent reaches the age of 24 years, or when they become married or pregnant before that age, they are transitioned to adult care. With this arrangement, a lot of resistance to move the adult clinic is expressed from adolescents due to connectedness with other adolescents the adolescent clinic. One service provider shared the resistance they experienced from an adolescent who was required to move to adult clinic because she had become pregnant and gave birth. The service providers shared the following two examples:

> *"We have one adolescent who had twins! She was attending adolescent clinic with her twins but we really insisted her to move. She didn't want to move. She was saying that 'I*

*want to meet with my friends.' We counseled her for a long time…She then agreed and now she comes with her two children at the adult clinic. She just needed the company of her friends."* (Female service provider from KCMC hospital during the second IDI).

*"…now we have an adolescent who has a one-year old baby, she had totally refused to move to adult clinic. So, we just let her continue attending adolescent clinic but we treat her differently and consult her individually."* (Female service provider from KCMC hospital during the second IDI).

These results suggest that adolescents who are required to be transferred to an adult clinic view the transition as a break in their friendships with their peers.

### 4.5 Discussion

The initial objective of this study was to understand the organization of pediatric-to-adolescent transition services in HIV care in the two hospitals. The study has shown that there is a transition service that is similar to practices in the transition from pediatric-to-adult HIV care context [30, 36, 92], however there is no formal written process and no job aids such as flow charts or checklists. Nevertheless, there is one major difference which is the greater involvement of caregivers in the transition process compared to adolescent to adult transition where the transitioning adolescents themselves are the major focus.

The current organization of transition services in the two hospitals seems to adequately address the four out of six healthcare transition elements namely: 1) transition readiness assessment; 2) transition planning on the optimal timing of transfer; 3) actual transfer of care 4); transfer completion and ongoing care support [37]. The first transition element that has not been adequately addressed is availability of transition policy/guide. A transition guide/protocol that outlines the transition process and responsibilities of each stakeholder involved in the transition process was not available in either hospital. Lack of written pediatric-to-adolescent transition protocols despite the well-established transition practice is consistent with many sub Saharan Africa countries in the transition to adult care [31, 93-95] and may lead to service providers being less aware of factors influencing the transition process [92]. Although, there are national guidelines developed regarding adolescent and young people's health, including HIV care and treatment guidelines in Tanzania [15, 91] these documents provide very little guidance on the transitioning process from pediatric to adolescent HIV care. Hence, pediatric-to-adolescent transition practices may vary widely across healthcare facilities in Tanzania similar to what

Gilliam et al. found in the USA [38] and Badejo et al. in Nigeria [93]. Given the fact that Tanzania is among the top five countries in sub-Saharan Africa with the highest burden of adolescents living with HIV, there is a need to map the current pediatric-to-adolescent transition practices and services across health facilities in Tanzania and develop/formalize guidelines to ensure well established and evidence-informed pediatric-to-adolescent transition practices in Tanzania.

The second transition component that has been inadequately addressed is the tracking and monitoring component that involves establishment of transition criteria and processes for identifying transitioning youth. This element has been inadequately addressed as it is only age and disclosure status that featured as the main transition criteria while other immunological and virologic markers, regimen type, medication adherence, psychosocial maturity and mental health were given less importance and less assessed during transition. Similar findings have been reported in Kenya in the context of pediatric-to-adult transition [96]. For example, some service providers considered medication adherence to be a criterion for moving to adolescent clinic while others did not concur with this criterion. However, findings from the previous chapter of this study that are consistent with an earlier study done in the same population [68], show high rates of unsuppressed viral loads among untransitioned and transitioned adolescents. These observations together with the fact that poor pre-transition outcomes are predictive of poor post-transition outcomes [97, 98] suggest that virologic response and medication adherence together with the type of regimen should be considered by service providers during transition readiness assessment, as well as being markers of successful transition. However, unsuppressed viral load and suboptimal adherence should not be obstacles to transition as moving to adolescent clinic is needed for their developmental stage and might actually help to support their adherence [62]. Rather, consideration of these criteria could assist service providers to determine and earmark which adolescents need extra support or are at risk of poor medication adherence and virologic failure during and after moving to adolescent clinic.

Pregnancy and marriage were also reported as criteria for moving adolescents from adolescent to adult clinic as married/pregnant adolescents are considered to be adults regardless of their ages. Similar practices have also been reported in some facilities in the Nigerian context [93]. With these transition criteria, some pregnant and married adolescents may be too young or not mature enough to be transferred to adult care. Furthermore, a lot of resistance from these pregnant/married adolescents to move to adult clinic has been portrayed in this study due to the attachment and friendships formed in the adolescent clinic. This finding further highlights the

importance of prolonged individualized support to these adolescents because transition to adult clinic will be an additional transition to their ongoing social transition (marriage or teenage pregnancy) in adolescents who have at the same time to cope with HIV infection. As a result, these adolescents may have psychological distress [99, 100], discontinue with care and may subsequently develop poor transition outcomes clinically, physically and psychosocially [101, 102] and ultimately, for pregnant adolescents, their infants may have greater risk of acquiring HIV perinatally outcomes when compared to older women [103, 104]. This finding thus highlights the continued need of providing a patient-centered approach that focuses on the adolescents' needs rather than what is simplest for the clinic organizationally. Furthermore, the need for providing comprehensive reproductive health education and contraceptive services in the adolescent clinics is highlighted [91, 105, 106].

The perceptions of the adolescents experiencing pediatric-to-adolescent transition are an important lens for evaluating the robustness of transition practices i.e. positive perceptions dominated among most adolescents undergoing transition. The social component of HIV treatment that included peer support and peer interactions, friendship formations, refreshments and extracurricular activities were the major driving factor towards their positivity about this transition. However, feelings of being forced to move, feelings of breaking significant friendships in the pediatric clinic, and worries of moving alone can make this transition process seem like an "abrupt transfer" rather than "transition process". Some adolescents felt like they needed more time so that they end their friendships in the pediatric clinic as was found by Valenzuela et al. 2011 regarding transition to adult care [53]. Therefore, the current transition practice could be improved by providing psychosocial peer support before the actual transfer. This could be done by either assigning a friend from the adolescent clinic prior to transition to reduce the anxieties on the day of transfer or by assessing the adolescent's network of friends in the pediatric clinic so that the eligible adolescents move together with their friends to adolescent clinic. Transitioning adolescents as a group could not only reduce anxieties of moving alone but also sustain the friendships formed in the pediatric clinics which are important developmentally during adolescence and a critical factor in maintaining continuity with care [55].

The perception that the transition process was too abrupt and that the caregivers needed more time to prepare themselves was also a concern among some caregivers. This finding is similar to caregivers' perceptions as their adolescents transitioned to adult care [18, 41, 42, 45, 52, 53]. However, what is different from transition to adult care is the finding that this perception of transition being too abrupt and lack of adequate preparation was only present among caregivers

living with HIV who were receiving care together with their adolescents who were about to transition to adolescent clinic. These caregivers were experiencing 3 transitions simultaneously; attending their own clinic in the absence of the adolescents with whom they have been receiving care since childhood, transitioning to adult clinic in settings where the adult CTC is located on different premises from the pediatric/adolescent clinic, and the emotional separation from their adolescents during HIV care. These caregivers thus needed more time as they had to adjust to these three transitions. Therefore, it is important for service providers to make this transition a "process" rather than "transfer", especially for caregivers living with HIV who were receiving care with their adolescents. Service providers can support these caregivers during the transition readiness assessment phase by giving them more time to adjust to the three transitions, continued counseling and gradual transition to adult clinic. Extending the support time before transition to e.g. four months rather than the current one month as suggested by one caregiver living with HIV could enable these caregivers to adjust to these transitions. However, the adequate timing will also depend on the different situations and needs of individual caregivers.

Feeling pressured to disclose the adolescents' HIV status made some caregivers delay or default this initial phase in the transition process. Caregivers still find it difficult to disclose to their adolescents due to the perception that the adolescents are not ready for disclosure or fear of negative consequences as reported by other studies [57-60]. Faced with the condition that full disclosure of adolescent HIV status must be done before moving to adolescent clinic, some caregivers do feel pressured to disclose to their adolescents but are required to conform to this condition. For those who cannot conform to this condition, some caregivers move their adolescents away from the clinic while others try to skip the disclosure part by moving their adolescents to the adolescent clinic without being disclosed. To prevent this situation and relieve this pressure, service providers need to implement transition as a process rather than a transfer [33] as well as start the disclosure process early rather than making it a single step. This can be achieved by providing continued support to caregivers in the disclosure process and giving more time for caregivers to disclose to their adolescents well before transition is even contemplated rather than insisting on transition and disclosure over a short period which may lead to caregivers defaulting clinic.

Participation in the adolescents' HIV care is one of the caregivers' roles that has been carried out since the adolescent was a child. When children reach adolescence, caregivers still want to be involved in their HIV care as shown in this and other studies [63]. With the current transition practice, as soon as the adolescent moves to the adolescent clinic, caregivers no longer participate

in the clinic consultations unless the adolescent is non-adherent to medicine or clinic attendance. As a result of this practice, some caregivers felt they were pushed aside in their adolescents' care after transition to adolescent clinic. This finding suggests the need for service providers to recognize the caregiver's need for continued but different involvement in their adolescent's care as the presence of caregivers may hinder free discussion of adolescent-related issues in the adolescent clinic. Therefore, during the readiness assessment phase, service providers should prepare caregivers for the fact that their role has not ended but has changed, as they need to be supportive but not directly involved. Furthermore, service providers should discuss the potential areas for caregivers' involvement in the adolescents' care after transition and agree on this role before transition so that caregivers do not feel left out after transition. Setting aside one clinic day in a year for caregivers to participate in the clinic activities and consultations could make caregivers feel involved in their adolescents' care rather than only being involved when the adolescent is non-adherent to medication or clinic attendance as adolescent-adult connectedness is among the key factors for the well-being of the adolescents [107].

Additionally, psychosocial support is one of the major influential factors to this transition. This finding is similar to other studies that assessed factors in transition to adult care [40]. The results of this study showed that adolescents significantly reduced clinic attendance in the adolescent clinic when psychosocial support such as food and refreshments were no longer being provided. Provision of food during clinics has also facilitated adolescent retention in care [108]. Furthermore, psychosocial support from friends/peers in the adolescent clinics made the young people feel connected and relieved knowing that there were others with the same condition. This finding highlights the importance of provision of socio-economic psychosocial support to all children and adolescents [109].

Lastly, the scarcity of human resources has been observed to impact the delivery of services for adolescents, as adolescent clinics are only available on one day per month. This may reduce access to services for adolescents if they are not able to come on that particular day. On the other hand, the adolescent clinic requires providers to work on a Saturday which may be challenging and there may not be sufficient human resources to provide more than one Saturday clinic per month even if this would be preferable for promoting adolescent adherence.

## 4.6 Limitations

This study is limited by its exclusive focus on higher-level health facilities, which results in a lack of diversity of experiences from lower-level health facilities; hence, the results may not be applicable to all health facilities. The small sample size of adolescents and caregivers may limit generalizability of results. Furthermore, due to limited sample size and the focus on the overall transition process rather than only on disclosure, the study could not describe post disclosure challenges with coping and impact on adherence. Despite these limitations, this work offers valuable insights into transition practices in Northern Tanzania and areas for improvement. Future research could usefully explore the applicability of these findings to lower level health facilities in Tanzania.

## 4.7 Conclusion

The aim of this study was to explore the pediatric-to-adolescent transition process in Mawenzi and KCMC hospitals and determine how adolescents and caregivers feel about the transition process. The results show that the transition practices are similar to transition to adult care and address most of the recommended components of youth healthcare transition. However, lack of written protocols and effective monitoring and tracking (transition criteria) are key gaps. Psychosocial support plays a significant role in enhancing this transition among transitioning adolescents. High levels of caregiver engagement, interaction and communication and support are required to guide the transition rather than transfer, especially for caregivers living with HIV who have been receiving care with their adolescents since childhood. Furthermore, medication adherence, virologic assessment, type of regimen, psychosocial maturity and mental health are critical aspects of readiness assessment prior to moving to adolescent clinic to determine and earmark which adolescents are at risk of poor medication adherence and virologic failure after moving to adolescent clinic. Limited availability of human resources in adolescent clinics is one of the limiting factors, which, together with lack of transition national guidelines may lead to lack of evidence-informed transition practices and variation of pediatric-to-adolescent transition practices across healthcare facilities in Tanzania.

# CHAPTER 5. CONTEXTUAL FACTORS INFLUENCING PEDIATRIC-TO-ADOLESCENT TRANSITION IN HIV CARE

## Introduction

The previous chapter has explored the organization of pediatric-to-adolescent transition HIV services and highlighted factors that are influential to this transition at the service provision level. This chapter explores contextual factors besides service delivery that affect perceptions and attitudes of adolescents and their caregivers towards transition before and after the move to adolescent clinics. In order to attain this objective, the following two research questions were put forward:

a. Do concerns about privacy and confidentiality, embarrassment, shame and fear of being judged exist/change among adolescents as they move to adolescent care over time?
b. What are other contextual factors that influence the transition experience over time from the perspectives of adolescents, caregivers and service providers?

As explained in the methodology section, this was a qualitative study that used interview guides that prompted for each level in the Social-ecological Model (SEM). The results are presented following the SEM whereby the first section explores the key individual contextual factors including privacy followed by the second level (microsystem) which is caregiver factors. The third section is concerned with the service providers and peers (mesosystem) and the fourth section highlights the health system factors (exosystem) other than those associated with the organization of transition services. The fifth section presents the findings of the broader socio-cultural or political events that may influence the transition experiences of adolescents (macrosystem).

## Findings

By conducting longitudinal interviews, valuable insights were gained into the perceptions, attitudes, and experiences of adolescents and their caregivers during the paediatric-to-adolescent transition as adolescents and caregivers became more open during the forthcoming interviews due to their trust in the researcher. This enabled me to collect rich information pertaining to the study objectives. I was therefore able to understand the challenges faced by adolescents and caregivers at all stages of transition, i.e., before, during, and after the transition from paediatric to adolescent HIV care. For example, fear of stigma was more pronounced after moving to the adolescent clinic due to adolescents' awareness of their HIV status and the need to keep it a secret

to avoid being stigmatized. I was able to examine changes in attitudes, perceptions, and experiences over time by providing insight into how these changes evolved during the transition to adolescent care. For example, some caregivers had negative perceptions of the paediatric-to-adolescent transition as they were not allowed to participate in clinic consultations with their adolescents so that the adolescents could express themselves freely. However, as the adolescents continued with the adolescent clinic and became used to it, these caregivers' perceptions changed to positive after seeing that the adolescents were able to interact well with service providers and were able to demonstrate what they learned in the adolescent clinic.

By conducting longitudinal interviews, I was also able to assess the immediate impact of the paediatric-to-adolescent transition on clinic attendance and medication-related tasks, as I could identify the extent to which adolescents assumed these tasks before and after moving to the adolescent clinic. Further information on this aspect is explained in chapter six. Furthermore, I was also able to identify gaps in the transition care services and areas where additional support may be needed. For example, adolescents consistently reported the need to have a friend before, during, and after the transition to adolescent care and the need to move along with friends to an adolescent clinic, which indicated the need for additional peer support, especially before and during the actual transfer, to relieve the anxieties faced by adolescents about moving to a new environment.

Lastly, by conducting longitudinal interviews, I was able to identify not only factors that influenced the paediatric-to-adolescent transition but the extent to which these factors persisted during this transition and at what level (adolescent, caregiver, peers, service providers, and broader structural or political events). It is worth noting that the findings of this chapter were based on adolescents, caregivers, and service providers at high-level health facilities (referral and regional hospitals) that are located in urban areas; hence, they may not be applicable to lower-level health facilities or rural locations. Notwithstanding this limitation, the overall representation of the contextual factors related to the paediatric-to-adolescent transition is summarized in Table 4.

Table 4: Contextual factors influencing pediatric-to-adolescent transition in HIV care using Social-ecological Model (SEM)

| SEM Level | Before moving | Around the time of transition | After moving |
|---|---|---|---|
| Individual | - Self-efficacy<br>- Developmental growth | - Self-efficacy | - Self-efficacy<br>- Sense of personal responsibility<br>- Perceived stigma<br>- Privacy and confidentiality |
| Microsystem (Caregivers) | - Parenting style<br>- Financial capacity<br>- Caregiver priorities<br>- Critical events in the family<br>- Fear of stigma | - Financial capacity<br>- Caregiver priorities | - Parenting style<br>- Financial capacity<br>- Caregiver priorities<br>- Critical events in the family<br>- Fear of stigma |
| Mesosystem (Peers) | - Peer influence<br>- Peer support | - Peer influence<br>- Peer support | - Peer influence<br>- Peer support |
| Exosystem (Organization of transition services) | - Setting of health facility | - Setting of health facility | - Setting of health facility |
| Macrosystem | - Education system<br>- Religion<br>- National policies and guidelines<br>- Stigma in the community | - National policies and guidelines<br>- Stigma in the community | - Education system<br>- Religion<br>- National policies and guidelines |

### 5.1 Individual Level (Adolescent)

#### 5.1.2 Privacy and confidentiality

Privacy and confidentiality during early adolescence are among the key factors that affect how adolescents seek and utilize HIV services. In our study, as children became adolescents and moved to adolescent clinic, they began to realize the importance of privacy and confidentiality in concealing their own identity and that of their fellows in the adolescent clinic to avoid the negative consequences of stigma. One male adolescent from KCMC hospital shared his views on confidentiality during the third IDI as follows:

> *"When we go there (adolescent clinic) …we ask each other questions while we did not ask each other questions in the pediatric clinic. We keep each other's secrets even when we go to school we do not say. You don't go and announce to the outside that your colleague is living with HIV. All matters have to be finished in here."*

Hence the importance of privacy and confidentiality in the adolescent clinic usually emerges during the pediatric-to-adolescent transition whereby adolescents become aware of stigma following the disclosure of their HIV status and the peer interaction in the adolescent clinic.

#### 5.1.2 Perceived Stigma

During transition to adolescent clinic, adolescents become aware of their HIV status and they start to realize the stigma attached to the disease. For example, one female adolescent from Mawenzi hospital said, "*…You see, I didn't know what I am suffering from while I was in the pediatric clinic, but now I know."* They then start to fear being identified as living with HIV as they fear being judged, stigmatized and discriminated from their friends or gossiped about by neighbors. For example, one female adolescent from KCMC said, "*You see, it is because they will go and advertise you at the place where we are staying. They will tell people to discriminate me and not to play with me.*" Another one said, "*People will start laughing at you."* Perceived stigma seemed to affect adolescents mainly after knowing their HIV status and subsequent to moving to adolescent clinic. As a result of perceived stigma adolescents come up with different strategies of not being identified as living with HIV during their clinic attendance in the adolescent clinic which they did not do while in they were still in pediatric clinic. For example, adolescents were asked what they would do if they met a person who they know at the entrance of the adolescent clinic but that person doesn't know the adolescents' HIV status. Most of the adolescents were skeptical of entering the clinic. They would pretend not to be entering the clinic or let the person pass by or turn around as shown in the following adolescents' quotes:

*"I will let him/her pass first because I don't want him/her to know. I will either turn around or I will go outside and wait for him/her to leave."* (Female adolescent from KCMC hospital).

*"I saw one young man; he was a bit tall and lives in Barigu (pseudonym). You see he was passing by and we saw him. So, we pretended as if we were not going to the clinic. When he was out of sight, that is when we run fast to our clinic."* (Male adolescent from KCMC).

Therefore, in fear of being stigmatized, adolescents would delay or not seek HIV care at the health facility rather than being identified by someone they know at the health facility. This finding indicates the need to address stigma as part of clinic routines to enhance adolescents' continuity of care after moving to adolescent clinic.

### 5.1.3 Sense of self-efficacy

Self-efficacy refers to how an adolescent perceives their capacity to perform specific activities or behaviors such as clinic attendance unescorted by caregivers. In our study, the major contributing factors to adolescents attaining a sense of self efficacy were the adolescents' need to seek autonomy together with their perceived ability to attend clinic on their own without their caregivers. As result, adolescents who perceived that they could attend adolescent clinic unescorted by their caregivers and could make independent consultations in the clinic were determined to move to adolescent clinic despite the resistance from their caregivers. For example, there was a female adolescent from KCMC hospital whose caregiver was resisting the move to adolescent clinic due to fear that the adolescent could not go to clinic unescorted by caregiver. This adolescent said:

*"…I will go and join the clinic myself. I will go to the hospital to see the doctor and tell him to give me an appointment on the adolescent clinic on Saturday. Now I am used to road crossing because every day I travel from Toru road (pseudonym) to Kijani (pseudonym). I cross the roads every day. I don't want my mother to assist me. She is always busy on Saturday. So, I will go alone."*

Even after transition, adolescent self-efficacy in clinic attendance also played a great role in facilitating adolescents keeping up with clinic attendance in situations where the caregiver was busy or could not afford the bus fare to escort the adolescent to clinic.

### 5.1.4 Sense of personal responsibility

A sense of personal responsibility over one's health and well-being mainly affected pediatric-to-adolescent transition after moving to the adolescent clinic. In this study, when given the autonomy of attending clinic unescorted by caregiver, adolescents with a sense of personal responsibility for their own health made clinic attendance and medication adherence their priority over other social or adolescent valued activities. For example, some adolescents borrowed money from neighbors or other relatives so that they could attend clinic, others reminded their caregivers in advance about their clinic appointment date so that the caregiver could prepare the bus fare before the clinic day. Some adolescents exercised agency and chose to go to the clinic very early in order to be served early as shared by one male adolescent from KCMC hospital: "*In the adolescent clinic you have to go there early. If you go late you will get the last numbers."* On the other hand, when a sense of personal responsibility is missing even though autonomy of unescorted clinic attendance has been granted to the adolescents, clinic attendance and medication adherence was not made a priority by adolescents. As a result, adolescents engaged in other activities that seemed more important to them than clinic attendance. Service providers shared two examples as follows:

> *"The boy was 13 years old…we had transferred that boy …But that boy did not turn up for clinic for like two months after the move. You see, he was a naughty boy! When he was given bus fare, he used to spend it on buying ice-creams. So, the journey ends there and he doesn't go to clinic.*" (Service provider from Mawenzi hospital during the second IDI).

> *"A 12 years boy, very naughty and he was staying with his grandparents. So, he used to lie to them that he was going to clinic while he went to play football…That was like three months after moving to adolescent clinic."* (Service provider from KCMC hospital during the second IDI).

Therefore, a sense of personal responsibility influences adolescents' continuation with clinic attendance and medication adherence after transition to adolescent clinic especially among adolescents who are given autonomy of unescorted clinic visits. This calls for caregivers to be engaged and monitor adolescents who have been given this autonomy and for service providers to reinforce self-care and personal responsibilities among adolescents as they attend clinic unescorted by caregivers.

### 5.2 The microsystem Level (Caregivers & Family level factors)

#### 5.2.1 Parenting style

Parenting style of caregivers has been shown to influence whether the adolescent requiring transition will move and continue with adolescent clinic after transition. If caregivers are supportive of their adolescents assuming responsibilities and preparing them for independence, when informed about pediatric-to-adolescent transition of their adolescents they are likely to support their adolescents in this transition provided there is good communication between the adolescent and the caregivers. For example, one caregiver from KCMC hospital shared their experience during FGD with caregivers by saying:

> *"It depends on the relationship between the parent and the kid. If you have a good relationship, the kid will go straight to the clinic and come back straight home very fast with their medicine. If the kid wants to play, you tell them: 'You first go to the clinic and bring the medicine afterwards you can go to play with your friends.' When my kids come back from the clinic, I usually ask them: `Tell me what is your weight now? What else have you been told at the clinic?' They tell me. So, they enjoy it and they come straight home and I like it too. I tell them 'I am glad that you are doing well, then let me go to my work.' I leave them and go back to work. So, if the parent is really close to the child, I don't think the child will misbehave."*

On the other hand, if the caregivers have different assessment of readiness of their adolescents to attend clinic alone or concerns about girls being unaccompanied, they are likely to face difficulties in preparing the adolescent for independence in activities such as clinic attendance, and hence delay transition for the eligible adolescent. The major reason for caregivers not being ready was the difficulties in letting the adolescents attend clinics on their own, as shown in these quotes shared by service providers:

> *"Sometimes there are those adolescents who are to be moved and are ready to move, but the parent is reluctant to let her come on her own on Saturday just because she is a girl. So, they are being protective, they would rather come with them on the normal clinic days than letting them come on their own on Saturdays."* (Service provider from Mawenzi hospital during FGD with service providers).

> *"One adolescent who was living with his grandma who used to escort him during every visit. We spent a lot of time explaining to the grandmother the benefits of him attending the adolescent clinic but the grandma refused. The grandma was convinced that her grandson cannot cross the roads and he will mix up the buses and won't reach home. Eventually she agreed and the adolescent was moved to adolescent clinic."* (Service provider from KCMC hospital during FGD with service providers).

Therefore, the parenting style of caregivers can have a positive or negative influence on the pediatric-to-adolescent transition, depending on whether the caregiver is ready to transfer medication and clinic attendance responsibilities to their adolescents.

### 5.2.2 Financial capacity

Financial capacity of caregivers is another factor influencing transition at all stages. Most caregivers in this study had limited financial capacity and hence struggled to attain bus fare for clinic attendance. For these caregivers, when they perceived that pediatric-to-adolescent transition would reduce their financial burden, the caregivers supported transition and even advocated for early transition. For example, one caregiver of two adolescents attending KCMC hospital said the following during the third IDI:

> "*When I heard that he will join the clinic with his brother, I was super happy because I knew the burden and cost of going to the family clinic with him will be reduced… I used to carry Chinyemi (pseudonym of the younger adolescent) during the whole journey because I had to go with budget. I did not have money to pay the bus fare for them both."*

On the other hand, if the caregiver perceives that transitioning to adolescent clinic will add financial burden to the family, then the caregiver may resist the transition. For example, one caregiver from KCMC hospital was so concerned about the costs incurred once the adolescent moves to adolescent clinic and she resisted the move. She said, *"So that means that I will be going to clinic twice in a month! And in this Saturday clinic, do you get monthly stock of medicine?"* After being told 'No' she further commented, *"In the normal clinic we take a stock of two months. So, I prefer the normal clinic*."

After transition, if the actual costs incurred by the caregivers are beyond their capacity or increase due to this transition, continuity of clinic attendance may be affected. For example, one service provider from KCMC hospital shared an example of an orphanage center that had children attending pediatric clinic and adolescents in adolescent clinic. She said, *"Some adolescents from*

*an orphanage center were moved to adolescent clinic but were later on moved back to the regular clinic because the owner of the orphanage found it to be too expensive to take them to clinic."* For this orphanage center, it was more cost-effective to take adolescents and children to clinic on one day rather than two separate days in a month. However, the provision of food at the adolescent clinic could encourage transition and clinic attendance.

### 5.2.3 Caregivers' priorities

Caregivers' priorities influence transition before, during and after transition to adolescent clinic. As caregivers face daily life challenges and competing priorities, making decisions based on what they perceive as a priority is crucial in the transitioning of adolescents to adolescent clinic. If the caregivers' priority is maintaining the adolescents' health and well-being, then the caregiver will forfeit all other important issues to ensure that the adolescent health is prioritized, including transition. For example, one caregiver from Mawenzi hospital had prioritized their adolescent's health over all other important issues and said, "*I decided for him to go to clinic because it is his life. If he falls sick, I am the one who suffers. When it is clinic day then he must come to clinic. When it is Saturday and there is no clinic, then he attends school. I told him not to mess up with clinic at all.*"

On the other hand, if the caregivers prioritize other issues such as school demands over adolescents' health, then transition may be delayed or clinic appointments defaulted after transition. One service provider from KCMC hospital shared this observation as follows:

> *"There was a caregiver who came with a child who had very high viral load… I told her mother, "What if we move your child to the adolescent clinic? There are a lot of other adolescents of her age and others who are even older than her'…. She said, 'No. I don't want my child to move to adolescent clinic until next year because she is now in grade seven.' You see she is not the only one to say so. For this month I have had like three caregivers giving the same reason. So, we agree with them."*

Therefore, caregivers' priorities positively or negatively influence the pediatric-to-adolescent transition depending on whether the caregivers prioritize clinic attendance over other issues such as school demands.

### 5.2.4 Stigma experienced by caregivers

Stigma experienced by the caregivers made some caregivers instruct their adolescents to avoid being seen or identified by other people as they enter the clinic premises during the day of transfer and onwards. As a result, caregivers may hinder adolescents seeking HIV care due to fear of being identified by others. For example, one caregiver from KCMC hospital said, *"They have grown up. They can reason things. Sometimes they run away from people who may notice them at the hospital. They use different doors to confuse their enemies who might see them at the clinic and come to gossip them in the street. People are not good sometimes."* Stigma experienced by caregivers has also made caregivers restrict adolescent friends from visiting them *"I don't even want my children to bring their friend at home because when the time to swallow medicines reaches, they might be seen by them and hence the information will spread in the whole street."* Furthermore, as shown earlier in chapter four, that fear of stigma in the adult HIV clinic had also influenced caregivers living with HIV to resist and delay the pediatric-to-adolescent transition for their eligible adolescents.

### 5.2.5 Critical events in the family

Critical events in the family such as family conflict, loss of a caregiver or changes in caregivers during the time of transition influence adolescents before and after moving to adolescent clinic. Family conflicts and change of caregivers before transition can lead to delayed or resisted transition despite the readiness of the adolescent to move to adolescent clinic. One service provider from Mawenzi hospital described this finding as follows:

> "*A 13-year old boy was moved to adolescent clinic but there was a conflict between the mother and in-laws. The in-laws were accusing this adolescent's mother that because she had infected their grandson, so she is not able to take good care of him. Therefore, they were forcing their grandson to live with them (at the grandpa's place). Now, the grannies were living far away in a village while the mother was living near the hospital. So, they decided that the grandson will stay with the mother from Mondays to Fridays because of schooling and he would go to his grannies on Saturdays and Sundays. Now, moving him to clinics on Saturdays became a challenge as he would be with his grannies. So, he went back to the normal clinic. He became less adherent to medications, poor clinic attendance, viral load started increasing, CD4 decreased, he then fell sick for some time. Then we had to call his grandfather to talk to him…So we talked with him and agreed*

*that the adolescent will stay with the mother and visit them during his holidays. He then moved to adolescent clinic and he really liked the move.*"

Furthermore, if the adolescent experiences loss of a biological caregiver during transition and/or moves to a less supportive caregiver, they may be less likely to move to adolescent clinic or maintain clinic attendance after transition. One example was shared by a service provider from KCMC hospital as follows:

> "A *12-year old boy whose parents died while he was still in pediatric clinic. He had stopped taking medication after the death of his parents. He was then counseled and restarted taking his meds and they moved him to adolescent clinic. He was staying in Arusha town with relatives who accompanied him to clinic two to three times then he started going on his own. By the age of 16 years he became lost to follow up for three to four months. His relatives had moved him to a village where he grew up with his mother to live with his grandmother. In that village there were children who knew his mother's history that she died due to HIV and they were saying that to others. This demoralized him and he then stopped attending clinic and taking his medicines."*

Interestingly, in our study change of caregivers during transition positively influenced transition and utilization of adolescent services after transition. If adolescents move from a less supportive to a more supportive caregiver environment, the caregivers will likely support the adolescents' move to adolescent clinic. For example, one adolescent from KCMC hospital shared her experience of moving from an unsupportive caregiver to a supportive caregiver. The adolescent said, "*I used to wake up in the morning, wash utensils, mop, sweep the ground and then I came to clinic. I used to mop, sweep the ground, clean the cows shed…. No one was reminding me to take my medicines."* After moving to a new caregiver, she said *"It is a good place now. No burden of works. I eat food every time. Now I only mop. My aunt washes the utensils. After mopping, I go to bath, drink tea and go to clinic."* Therefore, critical family events can positively or negatively influence transition to adolescent clinic.

### 5.3 The meso-system Level (Peers)

#### 5.3.1 Peer influence

Since adolescence is a time when social belonging and acceptance by peers is important, peer influence plays a significant role in influencing the move to adolescent clinic, and continuation of clinic attendance after moving to adolescent clinic. In this study, peers in the adolescent clinic influenced their peers in the pediatric clinic by informing them about the adolescent clinic, initiating transitions for their peers who are still in the pediatric clinic, and some even negotiated with the resistant caregivers of adolescents who were due to move to the adolescent clinic. For example, one adolescent from KCMC hospital shared how her peer influenced her transition to adolescent clinic as follows: *"Not very long-ago Anu (pseudonym) told me that there is an adolescent clinic. Then I told her that I also want to join. Then Anu went to tell the doctor and we both got transferred, me and Anu together.*"

Furthermore, even peers in pediatric clinic influenced each other by informing each other about the adolescent clinic, telling each other and agreeing to move together to the adolescent clinic. Some adolescents have also initiated transition for their friends who are still in the clinic. e.g. *"Layla (pseudonym) who is my friend advised me to join the adolescent clinic. The doctors said that we have to move to this clinic and later on Layla told me that we should really join the clinic. She gave me advice. I met her here at the hospital."* (Female adolescent from Mawenzi during FGD with adolescents).

After transition, peer influence still played a great role in influencing adolescents to assume more responsibilities in their clinic attendance and medication adherence. For example, one male adolescent from KCMC hospital said. *"I used to copy what my brother does. If I see him keeping his medicine somewhere, I also take mine and arrange them in the wardrobe."* Therefore, peer influence positively affected adolescents' participation in the pediatric-to-adolescent transition at all stages, i.e. before, during, and after the transition.

#### 5.3.2 Peer support

In addition to the peer influence, peer support also played a great role in influencing adolescents towards transition as none of the transitioning adolescents wanted to move alone to the adolescent clinic. When peer support is available before transition as well as during the actual day of transfer and post transition, it enhanced smooth transition and continuity with clinic services as adolescents escorted each other to clinic visits to which the adolescents were not escorted by their caregivers. On the other hand, when peer support is not available before transition,

transition may be delayed by adolescents. For example, during the third IDI, one adolescent from KCMC hospital had resisted moving to adolescent clinic because of not moving together with a friend. The adolescent said: "*They were telling me that I should join the adolescent clinic. I rejected because I thought Chinyemi (pseudonym of her friend) is not moving. ...They told me for a long time but I did not want to join. They even told me that in the adolescent clinic there is food but still I did not want to join. I wanted to move with my friend and when the doctor allowed her that is when we moved together.*" Hence peer support and the desire to be with friends positively influences participation of adolescents in the pediatric-to-adolescent transition.

### 5.4 The exosystem level (Organization of transition services)

#### 5.4.1 The setting of the health facility and clinic schedules

The setting of the health facility together with clinic service arrangement also influences transition both before and after the move to adolescent clinic for both caregivers and adolescents. For caregivers, in a hospital setting where the pediatric, adolescent and adult clinics are located within the same premises with the same service providers, there is usually low resistance to transition from caregivers living with HIV as they will move to the adult clinic that is located in the same building with the same providers, but perhaps on a different clinic day. In settings where the adult HIV clinic is in a different building from the pediatric/adolescent clinic with different service providers, caregivers are usually reluctant to move to adult HIV clinic due to unfamiliarity with the new environment and fear of stigma in the adult HIV clinic. Hence, transition of their adolescents to adolescent clinic may be delayed or resisted due to the health facility setting. For adolescents, settings where the adolescent clinic is in a separate building from the normal clinic building, allowing for someone attending the clinic to be easily identified as living with HIV are an immense challenge for adolescents to use and continue with care as explained in the adolescent level factors.

The adolescent clinics in both hospitals were only being on one day in the month. This may reduce access to services for adolescents if they are not able to come on that particular day. On the other hand, the adolescent clinic requires providers to work on a Saturday which may be challenging and there may not be sufficient human resources to provide more than one Saturday clinic per month even if this would be preferable for promoting adolescent adherence.

### 5.5 Macro-system level (Broader systems)

#### 5.5.1 Education system

In the Tanzanian education system, grade seven is the final primary school grade that is subjected to national examinations and most children in grade seven are usually at the age of 13 – 14 years, the age when transition to adolescent clinic is expected to occur. In this context, most private and government schools require adolescents in grade seven to attend extra classes on Saturdays in preparation for the national exams. As a result, the influence of the education system is mostly felt before transition as many caregivers of grade seven adolescents resist this transition because of Saturday classes. For example, one service provider from KCMC hospital stated:

> "*There was a caregiver who came with a child who had very high viral load… I told her 'What if we move your child to the adolescent clinic?' …. She said, 'No. I don't want my child to move to adolescent clinic until next year because she is now in grade seven.' You see she is not the only one to say so. For this month I have had like three caregivers giving the same reason. So, we agree with them."*

The influence of the education system is also felt after transition to adolescent clinic whereby adolescents who move to boarding secondary school have limited access to adolescent clinics as they are not available in schools and adolescents face difficulties in getting permission from school to attend clinic every month unless they disclose their HIV status to school authorities. As a result, in most instances it is the caregivers who fetch medication for their adolescents and take them to the school and adolescents themselves can only attend the adolescent clinic for clinical monitoring during the holidays. For this reason, some caregivers refuse to let their adolescents enroll in boarding schools. Furthermore, some rules and regulations in boarding schools, such as displaying ones' belongings, have been shown to indirectly influence adolescents' continuation with their medication and clinic attendance after transition. For example, one service provider from Mawenzi hospital shared:

> *"One day there was an ambush in their school whereby they were all told to go to classes while the teachers went to the students' dormitories to inspect their belongings…So the students are required to put all their belongings on their beds. So, they take out everything from their bags and expose them on their beds. Unfortunately, that girl her medicines were also on her bed and she was the last one to go back to the dormitory. When she reached there, she found other students sitting and inspecting her pill boxes. It was the fellow students! They were reading them…The only thing she did was to go to the headmaster ask for permission to go back home…By the time I saw her, she had*

*already stopped going to that school…We then came to know that she got pregnant…I have not seen her personally since then."*

It was also noted that caregivers in this study had negative perceptions of boarding school due to lack of privacy therefore were not willing to let their adolescents go to boarding schools. One caregiver shared his feelings on boarding school as follows:

*"My worry is that they will know his status that he is taking the medicine, so they will be asking him every day what is this? why is this? You know school life, they will start saying, 'Aaah he is living with this' …. I don't like boarding schools."* (Caregiver from KCMC hospital during FGD with caregivers).

Similarly, most of the transitioning adolescents did not like the idea of going to boarding schools due to lack of privacy as evidenced in the following adolescent's quote.

*"Sara (pseudonym of adolescent friend) will never go to a boarding school…Me neither. I want a day school because I want to be reminded of my medicine and if they see me taking my medicine in the boarding school, they will start saying bad things. I don't even want to hear about it*." (Adolescent from Mawenzi hospital during the third IDI).

Therefore, being in seventh grade, which is the age at which most adolescents become eligible for moving to an adolescent clinic, and moving to boarding school are educational factors that hinder the pediatric-to-adolescent transition.

### 5.5.2 Religion

The dominant religions in Tanzania are Christianity and Islam which advocate for religious classes (confirmation and madrassa) among adolescents so as to be confirmed as full members of these religions. These classes are usually held on Saturdays, the day that has been also scheduled for adolescent clinic. As a result, some religious adolescents and caregivers are reluctant to move to adolescent clinic due to scheduling conflicts and not wanting to miss these classes, but not due to religious beliefs being a barrier to transition. For example, one adolescent from Mawenzi hospital when asked how she felt when she was told to move to adolescent clinic replied, "*I wanted to be asked first. I would like to be asked whether I like to attend the clinic on Saturday or not. I would have told them that I don't want to attend the clinic on Saturday because I will be attending confirmation classes on that day."* Another example is seen in comments from a service provider from KCMC hospital: *"Last week I had a transferred in adolescent…But due to his school*

*schedule, he can only come to clinic on Fridays because there are prayer sessions on Saturdays. So, he has a tight schedule on Saturdays."* Hence, religion also influence caregivers and adolescents to participate in the pediatric-to-adolescent transition and continue with care after moving to adolescent clinic.

### 5.5.3 Stigma in the community

Stigma in the community is still high as one caregiver from KCMC hospital said: *"The big problem that I see in our communities is stigma to the people living with HIV/AIDS. People use bad words and point the fingers at people living with AIDS in the street. But if we manage to eradicate stigma, I think we will have a good life".* As a result of stigma caregivers prepare their adolescents to prevent themselves from being identified as living with HIV when attending clinic. For example, one caregiver from KCMC hospital shared how he instructed his children. *"I used to tell them, 'That person knows us. Let us not use this entrance. Let us use the other entrance.' So, we use the other gate. So, I used to tell them, 'If you see anyone you know, don`t let them see you, dodge them because they will find out that you are using medicine.'* As a result, adolescents seeking HIV care take precautions to avoid being seen. For example, one female adolescent from Mawenzi hospital said, *"I hide myself. Many times. I sometimes pretend as if I am not going to the clinic until when they (people whom he knows) are out of sight, then I run fast towards my clinic."* Furthermore, as a result of stigma in the community caregivers resisted moving to adult HIV clinic which delayed pediatric-to-adolescent transition as shown in the earlier examples narrated by service providers in chapter four page 59.

### 5.5.4 Lack of protective safety net for adolescents

In a community where the safety net for orphaned adolescents is inadequate, orphaned children can end up living on the streets and hence miss parental guidance and love, together with experiencing abuse, trauma, and violence in the streets eventually leading to psychological problems. As a result, adolescents in these circumstances may be reluctant not only to seek HIV care but also resistant to pediatric-to-adolescent transition following their past experiences as shown in the following service providers' examples:

> "*A crippled girl around 15-16 years old who was cared for by a certain organization. She was resisting to move to adolescent clinic and going on her own because she was impregnated while going to school on her own. The people who were taking care of her*

*in that organization were also resistant to let her attend on her own seeing that she got pregnant*." (Service provider from KCMC hospital).

"*One adolescent was living in the streets. He was then taken to a center for children. Therefore, the assistants from the center used to escort him to clinic then he started coming on his own. It was at that time we decided to move him to the adolescent clinic because of his age. He was really troublesome, he was not adhering to medication after we moved him, we counseled him and he then started adhering well. He was being tortured in the streets, and him being a boy, they did terrible things to him. After all those tortures, he had lost hope to live. But now he is okay and is my friend too…he has also brought another kid from the center, so we serve them both and they are happy*." (Service provider from Mawenzi hospital).

Hence, inadequate safety nets for orphaned adolescents that predisposes orphaned adolescents to living on the streets and experience of violence, abuse, can negatively affect the pediatric-to-adolescent transition by causing such adolescents to resist moving to an adolescent clinic or maintaining continuity of care in the clinic after transition to adolescent clinic.

### 5.5.5 National protocols and guidelines.

National guidelines and protocols outlining transition practices are a critical factor in ensuring availability and quality of transition services. Lack of integration of transition to adolescent care in the national strategies limits the provision of transition services to adolescent clinic in Tanzania. For example, one service provider from KCMC hospital said "We are transitioning adolescents to adolescent clinic but we don't have a national guideline". Furthermore, the age of consent is 15 years for all health care therefore adolescents cannot move earlier unless caregivers provide consent, thus limiting adolescents' transition to adolescent clinic regardless of their readiness. Lack of provision of HIV care in boarding school settings is another critical area to be assessed by the government of Tanzania so as to provide access to HIV care and confidentiality to adolescents in boarding schools. This could be provided as an integrated adolescent or school health service, to avoid stigma for those with HIV.

### Overlapping of factors

Lastly, it was observed that overlapping of influential factors occur between different SEM layers (the individual, caregivers and broader contextual factors). The narration by the service provider under the critical events in the family demonstrates the overlapping of the factors (Page 71, section

5.2.5). The narration showed that loss of parents, living with non-caring caregivers, and living in a remote village surrounded by stigma made the adolescent less adherent to medication as well as clinic attendance after moving to adolescent clinic.

### 5.6 Discussion

The results of the study demonstrate that most of the contextual factors influencing transition to adolescent HIV care are also features of transition to adult HIV care; however, some notable differences exist. The first difference is the great motivation and desire of adolescents to transition to adolescent clinic due to meeting their peers as opposed to fear and worry exhibited during the transition to adult care [44]. The second difference is the marked resistance to transition from caregivers living with HIV who have been receiving care with their adolescents since childhood due to transition being seen mainly as breaking the caregiver-adolescent bond rather than anxiety about the adolescent-service provider bond when the adult transitions to independent adult care [17, 41, 52]. The third difference is the key role of peer influence on this transition due to adolescents developmentally going through a period when they seek to be accepted by peers and feel belonging to a certain peer group [110].

Transition to adolescent clinic is not a simple process with different actors at different levels influencing this process. Hence it is difficult to determine which factors play the largest role in influencing this transition. However, stigma cuts across most layers (the individual, caregivers as well as service providers and organization of transition services) which concurs with other studies that explored barriers to transition to adult care [16, 32, 41]. Stigma made transitioned adolescents delay or forfeit seeking care in an adolescent clinic that was obviously for people with HIV. This finding suggests the need to make stigma a particularly important factor to address during the process of transition to adolescent clinic. Interventions such as peer support groups have been shown to reduce feelings of stigma by increasing self-efficacy among adolescents living with HIV [109] as well as adults living with HIV [111]. Furthermore, having integrated adolescent clinics for adolescents with a range of health needs that provide contraception, mental health care, pre-exposure prophylaxis and ART could limit the stigma as adolescents might be attending these clinics for a range of reasons, not just because they have HIV.

Additionally, when the factors were compared across different time points, peer support was the most influential factor during all time periods of transition i.e. before, during and after transition to adolescent care. This finding is similar to adult transition where peer support was a critical factor in determining successful transition to adult care [45, 92]. The individual factor “self-

efficacy" also appeared to be influential during all times of this transition. This finding is similar to Barrett et al. (2010) who found that individual variables such as self-efficacy may have a higher influence on successful transition than other logistical variables such as insurance and transportation [65].

The results also show that influential factors exist at all stages of transition but there are more factors that impact after transition than before transition or on the day of transfer. Hence service providers need to continue monitoring these factors after transition to ensure continuity of care among the transitioned adolescents [92]. Furthermore, most of the influential factors at all SEM levels actually stay the same before, during and after moving, except for the individual level factors that seem to evolve over time. This is because these individuals are also growing up (i.e. becoming older). However, the emergence of personal responsibility, stigma and need for privacy are also related to the transition itself (irrespective of the growing up that is happening for the adolescent) and may be more important in this study as the period of follow-up was relatively short and may be too short for major individual developmental changes to occur.

During early adolescence, the desire for privacy and confidentiality at the health facility where adolescents receive HIV care seemed to greatly influence adolescents' decisions and acceptance of transitioning to adolescent clinic. Similar findings have been reported in the transition to adult care [38, 44, 48] and in other health care settings [112]. Furthermore, the Tanzania HIV adolescent service guide acknowledges the importance of ensuring privacy and confidentiality throughout when dealing with adolescents [91]. However, we found that the emerging understanding of the need for confidentiality and stigma appear to be driven by disclosure which may be confounded by transition as disclosure often happened immediately prior to transition. While transition itself may not have been the driver of these factors coming to light, where the adolescent clinic is in a separate building from the normal clinic building making one identifiable as living with HIV, transition may itself threaten privacy for adolescents. This presents an immense challenge for adolescents to use and continue with care. Since most HIV care clinics in lower level health facilities in Tanzania are located in stand-alone buildings which can lead to easy identification of adolescents due to CTC signage, there may be substantial resistance and possible discontinuation with care from adolescents, especially for those who attend clinic unescorted by caregivers. This finding thus supports the recommendations by the USAID [32] to engage adolescents and address their privacy and confidentiality concerns during planning of these transitions before establishing an adolescent clinic in order to enhance adolescents' acceptability and continuation with clinic attendance after transition. It further highlights the importance of

customizing transition protocols depending on the clinic setting for smooth transition while considering the adolescent and caregiver needs and concerns. This finding further supports the previously stated need for having integrated adolescent clinics for adolescents with a range of health needs that provide contraception, mental health care, pre-exposure prophylaxis and ART to limit the stigma.

Critical events in the family have also been shown to be an influential factor in the transition to adolescent clinic similar to transition to adult care. Change of caregivers, loss of caregivers and family conflicts have been identified as factors influencing whether adolescents and caregivers accept transition and continue with care after moving to adolescent clinic. This finding is similar to transition to adult care [55]. Therefore, service providers should work together with adolescents and caregivers to understand the family environment of the adolescent and identify critical events that may make transition difficult or facilitate smooth transition. Assessing transition readiness as a way to prepare adolescents for transition has also been used to identify possible factors that will influence the transition at an individual level [45].

The education system in Tanzania whereby around 5.3% (n=280) of secondary schools (government and private) are boarding schools presents as a barrier to transition. Adolescents enrolled in these boarding schools are less likely to be able to access adolescent HIV care, face difficulties in adhering to medications due to lack of privacy (from boarding school rules or due to the presence of peers all the time) and the fear of being recognized as living with HIV. This finding is common in most East African countries [113, 114] and highlights the continued need for the health sector and education sector to address the limited access to HIV services among adolescents in boarding schools as well as address stigma and discrimination in school settings in Tanzania [91]. Unfortunately, we did not collect information from our study participants about boarding school attendance and so can't comment on its impact in this study.

### 5.7 Conclusion

The aim of this study was to explore contextual factors other than service delivery that influence successful transition from pediatric-to-adolescent HIV clinic. The results show that contextual factors that influence the pediatric-to-adolescent transition exist at all levels of the SEM with overlapping layers of influence. Hence service providers should not only focus on service provision related factors but be aware of the different layers of contextual influence from the adolescents' environment in order to identify and maximize protective factors that will enhance smooth and successful transition as well as identify and address the negative factors.

## CHAPTER 6: IMMEDIATE EFFECTS OF THE PEDIATRIC-TO-ADOLESCENT TRANSITION ON CLINIC ATTENDANCE AND MEDICATION RELATED TASKS.

### Introduction

Chapter four has explored the organization of pediatric-to-adolescent transition HIV services and how adolescents and caregivers feel about the transition process. Then chapter five has highlighted factors influencing the pediatric-to-adolescent transition from individual level to broader structural levels. This chapter now moves to determine the immediate effects of pediatric-to-adolescent transition on medication and clinic attendance related tasks. To further understand how the immediate effects of this transition occur, the following research questions were put forward:

a. Why and how does transition to medication adherence and clinic appointment management occur as children transition into adolescence before and 12 months after moving to adolescent clinics?
b. How do adolescents feel about their own and their caregivers' roles in medication adherence and clinic appointments before and after moving to adolescent clinic?
c. What are the perceptions of caregivers on their adolescents' ability to manage medication adherence and clinic appointments before and after moving to adolescent care?

### Methodology

The study was a qualitative study with adolescents, caregivers and service providers as described in the methods chapter. In order to answer the three key research questions above, an interview guide with questions and prompts was used (Appendix 1 -7). The findings have been organized in two sections; the first section is focused on medication related tasks while the second is on clinic attendance related tasks. In each section, the first part highlights the immediate effects of the pediatric-to-adolescent transition on these tasks. The second section discusses why these effects occurred and the third section highlights processes and strategies used by caregivers and adolescents to achieve these effects. Then section four describes how adolescents feel about the tasks assumed and how caregivers feel about their roles in these tasks during the pediatric-to-adolescent transition. The fifth section discusses the overall findings and provides conclusions of the chapter.

It is worth noting that both hospitals, KCMC and Mawenzi, employ an integrated care model that emphasizes a shared responsibility approach. This approach involves distributing responsibility among adolescents, caregivers, and healthcare providers to establish a network of support.

Therefore, in this study, responsibility for medication adherence refers to the accountability and active role played by adolescents and caregiver to ensure that the adolescent adheres to their ART medication. This study has identified three medication related tasks namely; keeping of medicines, reminding of the time for taking medication and ensuring taking of medicines. On the other hand, "responsibility for clinic appointments" refers to the accountability and active role taken by adolescents and/or caregivers to ensure that the adolescent knows the dates of and attends scheduled clinic visits and interacts with the health care worker at the visit. This study has identified four attendance tasks namely; escorting to clinic, reminding/remembering clinic appointment date, keeping of the clinic card and participation in clinic consultations. The findings reported hereunder are from 16 adolescents i.e. eight from the exploratory study and eight from the longitudinal study.

## Findings

### 6.1 Medication related tasks

#### 6.1.1 The immediate effects of pediatric-to-adolescent transition on medication related tasks

The immediate outcomes of the pediatric-to-adolescent transition was increased adolescents' level of participation in medication related tasks after moving to the adolescent clinic. Before moving to adolescent clinic, only nine adolescents were keeping their medicine and after moving to the adolescent clinic, 15 adolescents were keeping their medicine. All adolescents knew where the medicines were kept before moving to the adolescent clinic. With regards to being reminded by caregivers on the medication time there was no change with nearly all adolescents (15/16) being reminded by caregivers of the time of taking medicine both before and after transition to adolescent clinic. There was a big change in supervision of medicine taking. Before transition 15 adolescents had their caregivers ensuring that medicine was taken (direct supervision), whereas after transition 15 adolescents took their medicine without caregivers watching them. Hence, the most notable effect of the pediatric-to-adolescent transition is in the keeping of medicine and direct supervision of medicine taking while other aspects such as knowing the location of the medicine and reminding of time of taking medicine had little change. This observation was mainly because caregivers are advised by service providers to gradually transfer responsibilities but not leave the entire responsibility to the adolescent as one service provider from Mawenzi hospital said: "*We do tell them not to leave the entire responsibility to the adolescent. They are*

*to remind them and must observe them taking the medications as most children do not like taking medications every day."*

### 6.1.2 Why adolescents assume more or less responsibilities in keeping the medicine?

Several reasons at adolescent (individual), caregiver, peer and service provider levels have been identified that make adolescents assume more responsibilities in keeping the medicine.

**Adolescent-related reasons**

Attaining psychosocial adjustment following full disclosure of adolescent HIV status at the beginning of the transition process was key to adolescents assuming more responsibilities in their care. As adolescents move to adolescent clinic, they meet other adolescents with similar conditions, reuniting with old friends and making new acquaintances which helps adolescents to cope with disclosure. For example, one adolescent from KCMC hospital shared this experience by saying, *"I realized that others (my friends) are doing fine with it (HIV). So, I decided to get used to it. I found them at the adolescent clinic. I said to myself, 'They are already used to their situations; let me also get used to mine'. I used to be sad, I was feeling bad because I have HIV while others don't have."* Therefore, the mere fact of seeing and meeting other adolescents with similar conditions greatly facilitated adolescents' capacity to cope with their HIV status which is essential to assuming more responsibilities in their care.

Adolescents' awareness of their HIV status and the understanding of the need to take medicine regularly influenced adolescents to seek more responsibilities in keeping medicine. For example, one adolescent from Mawenzi hospital said, *"My father was coming home late so I decided to keep them (medicine) myself."* Another adolescent from Mawenzi hospital also said, *"So, I decided to keep the medicine because sometimes my grandmother forgets where she kept them."* Hence, situations that would inhibit the taking of medicine on time acted as a catalyst to adolescents assuming responsibilities in keeping their medicine.

After knowing one's HIV status, fear of accidental disclosure of adolescents' HIV status also made adolescents assume more medication related tasks. For example, one adolescent from Mawenzi hospital shared the reason for keeping the medicine as follows: *"I started to keep my medicines and card when many people came to our home. So, I did not want them to see my medicine and that is why I decided to keep the medicines myself."* Therefore, situations that would trigger

accidental disclosure of adolescents' HIV status made adolescents assume more responsibilities in medication related tasks to conceal their HIV status.

Situations that could lead to identification as one living with HIV made adolescents assume responsibilities in keeping medicine due to fear of stigma. One adolescent from KCMC hospital said, "*My mother was with guests at home, and I had to go to ask her to come and show me the medicines. It was not good with me…. So, I decided to tell my mother to give me the medicines and keep them for myself.*" Another one from Mawenzi hospital also shared "*I was 12 years, I just decided to keep my medicine myself so that people don't find out because they will tell others.*" However, fear of stigma also made adolescents assume less responsibility in medication related tasks to avoid being identified by others thus avoiding accidental disclosures. Some adolescents reverted from being responsible, as one adolescent from KCMC hospital put it: *"Sometimes I keep them and sometimes I ask grandma to keep them for me. If there are other people around, like children who visit and sleep with grandma. I usually take them and keep them in my bag of clothes. If they are not around, I put them back in grandma's room."* Hence, fear of stigma influenced adolescents to assume more responsibilities and less responsibilities making the transfer of responsibilities process fluid rather than sequential.

Lastly, fear of losing a biological caregiver also made adolescents assume more responsibilities in keeping and reminding themselves about the time of medication. For example, one adolescent from KCMC hospital who was living with her biological caregiver when asked about medication related tasks said, *"I just remind myself. When you completely depend on mom…. If you totally depend on mother and what if she dies? Who will you depend on?"* As a result, this adolescent assumed all medication related tasks in the fear of losing the caregiver.

**Peer related reasons**

Peer influence was another critical factor that made adolescents self-initiate medication related tasks and clinic attendance responsibilities. For example, one adolescent from Mawenzi hospital shared how peers influenced their decision to self-initiate medication related tasks by saying, "*My friends in the adolescent clinic told me I should take medicine and never stop. They told me that once I stop taking medications, I will get AIDS."* Another adolescent said, *"I met new friends…They were showing/instructing me how to take medicine and having a balanced diet."* Hence peers influenced adolescents to assume responsibilities in clinic attendance and medication adherence by teaching one another on how assume these responsibilities and the consequences of not assuming these responsibilities.

The need to fit in with other adolescents of similar conditions also made adolescents self-initiate transfer of responsibilities from caregivers. For example, one adolescent started assuming more medication-related responsibilities in order to fit in with other adolescents who were adherent to their medicine. This adolescent from Mawenzi hospital said, *"After joining the clinic I saw one being given the same medicines as mine. I felt that I was not alone. We are many! I said to myself that I will never stop treatment even once."* Therefore, the need for wanting to fit in with others not only triggered adolescents to assume more responsibilities in clinic attendance and keeping of medication but also influenced how responsibilities were to be assumed.

**Service Provider related reasons**

Some adolescents assume more responsibilities in medication related tasks following service providers guidance such as knowing the names of the drugs. In some situations, service providers create fear among non-adherent adolescents so as to make them assume more responsibilities in medication related task as shown in the service providers quotes below:

> *"There was also another adolescent who was naughty too. He used to come to clinic with small pockets of alcohol (viroba). We told him, 'Now if you go on like this we will move you from this clinic to the adult clinic.' From thereon, he stopped and he regularly comes to clinic, he come early, and he said that he will not do it again. He also helped his peers by teaching them about alcohol. He was 15 -16 years."* (Service provider from KCMC hospital).

> *"Our technique for those who are not adhering well to medicine is that we tell them that if you don't take your meds well, we will move you to where they give you many pills. So, when they think about many pills and when they see them, they become like…..oh oh oh!!! So, we use that saying that, 'If you don't take your meds well, we will move you where they give you many pills.' You see Atripla tablets are big! So, they think about it and they adhere to their medicine well."* (Service provider from KCMC hospital).

Additionally, the fear of not moving from pediatric to adolescent clinic among adolescents who were still attending pediatric clinic also played a role in influencing adolescents to assume these responsibilities. For example, during cross-sectional qualitative study, one adolescent from KCMC hospital shared this experience of how service providers used fear to influence him to

assume medication responsibilities as follows: *"I was not taking my medications as required then I tried my best to take them…They (service providers) told me that if I don't take medications well, I will not move to adolescent clinic. Then I started taking them well everyday then I was moved to the adolescent clinic."* Therefore, the mere fact of not moving to adolescent clinic, moving from adolescent to adult clinic, and the increase in pill burden as a consequence of not adhering to medication influenced adolescents to assume responsibilities in medication. It was also noted that there was no national guideline to guide service providers on the appropriate timing and the process of assisting caregivers to transfer medication related tasks to their adolescents.

### 6.1.3 How caregivers transfer keeping of medicines to adolescents and strategies used

The process of caregiver-to-adolescent transfer of keeping of medicine responsibilities is modeled through four discrete phases where caregivers' roles and responsibilities gradually shift from caregivers to adolescents. Table five highlights the phases of caregiver-initiated transfer of keeping of medicine responsibilities to their adolescents. If adolescents self-initiate keeping of medicine, the phases would not explicitly follow the phases described in table five. It is also worth noting that, the process of transferring of responsibilities was mainly determined from the perspectives of supportive caregivers of adolescents who were adherent to their medication. Hence, these findings may not be applicable in situations where caregivers are unsupportive of the shifting medication related tasks to adolescents.

Table 5: The process of caregiver-to-adolescent transfer of medicine keeping

| **Transfer Process** | **Keeping of medicine** |
|---|---|
| **Phase 1** (Caregiver in-charge) | Caregiver keeps medicine and adolescent doesn't know their location |
| **Phase 2** (Adolescent partially in-charge) | Caregiver keeps the medicine but lets the adolescent know their location |
| **Phase 3** (Adolescent mostly in-charge) | Adolescent keeps the medicine but the caregiver is aware of their location |
| **Phase 4** (Adolescent fully in-charge) | Adolescent keeps the medicine and the caregiver is unaware of their location |

**Phase one: Caregiver is fully in-charge of keeping medicine**

In this phase during early adolescence, the caregivers are fully in-charge of keeping the adolescents' medicine in the absence of adolescents' knowledge of their locality to avoid accidental disclosures. Following the influences described earlier in this chapter, caregivers slowly start to transfer the keeping of medicine by first letting the adolescent know where the medicines are kept which is the second phase.

**Phase two. Adolescent partially in-charge of keeping medicine**

Once caregivers have decided to shift medication-related tasks to their adolescents who are adherent to medication, caregivers begin to explore how they would transition these responsibilities. They therefore begin to work together with the adolescent using the **"unknown location"** to a **"known location"** of medicine strategy by letting the adolescent know where the medicines are kept to enhance easy access to medication in the absence of caregivers, as one caregiver (grandmother) from Mawenzi hospital related, "*I keep them but Amina (pseudonym) knows where I keep them so she can access the medicines even at times when I am busy.*" Another caregiver alluded to this strategy by saying, "*I keep them (medicine) and when it is time, I tell her to go and fetch them in the place where I keep them…. So, she knows where we keep her medicine and when it is time she just goes and takes them.*"

During this phase, caregivers can monitor the taking of medicines as they are still in-charge of keeping the medicine and hence reassured as they know that the medications are taken. Adolescents are not fully responsible for finding a safe place for keeping the medicine as the caregivers have already identified the safe place. For example, one caregiver from KCMC hospital said, *"I will only let her keep her medicine only when I am sure that she can stick to the scheduled time or when she will ask me for her medicine."* Caregivers will only move to phase three if the adolescents are adherent to medication and show some sign of interest in or responsibility for their health care.

**Phase three: Adolescent mostly in-charge of keeping medicine**

For caregivers to move adolescents to this phase where adolescents now keep the medicine, adolescents must satisfy one major caregivers' condition which is showing signs of greater responsibility in keeping the medicine such as proper handling of the medicine (taking and returning bottles in the same place). An example of such a condition is illustrated by a caregiver from Mawenzi hospital who said, *"She (adolescent) may take the medicine and not return it back where it is supposed to be kept…it's not good for everyone to see them…It is better for me to continue keep the medicine."* If the caregivers are satisfied with adolescents' handling of medicine,

the caregivers then let their adolescents keep the medicine but under the condition that the caregivers know where the medicines are kept in order to monitor adherence and ensure safety of medicine and hence they retain some control.

To ensure that the adolescent is adhering to their medication after being given the autonomy to keep medicine, caregivers use two main strategies to ensure that the adolescents adhere to their medications. The first strategy is the **"direct" to "indirect" observation** of taking of medicine strategy whereby the caregivers indirectly observe the act of taking medicine without adolescent awareness of being watched or supervised. Some caregivers shared this strategy as follows:

> "*…when I am just sitting at home and it is time for his medication, you see him going to my room to fetch the medicines and swallow them. As soon as it reaches 6:00pm, he always takes his medicine. And in the morning when it is 6:00am.*" (Caregiver from Mawenzi hospital during FGD with service providers).

> "*Even if I am home early, maybe at 20:00hrs and I listen to the news, I just sit quietly, I see him taking his food, taking his plate after eating, he opens the cupboard and takes his medicine, I just watch him. He has no problem.*" (Caregiver from KCMC hospital during FGD with service providers).

As adolescents are mostly in-charge of keeping medicine, the second strategy employed by caregivers is the shift from **"active reminding" to "passive reminding**" of taking the medicine. With this strategy, caregivers only tell the adolescent about taking medicine (because adolescents are aware of the medicine locations) rather than physically taking the medicine to the adolescent. For example, one caregiver from Mawenzi hospital described this strategy by saying, *"The reminding now is just telling him. It is not like it used to be where you have to take them…When he reaches home from clinic, He just puts the medicine where he is supposed to keep them. He has no problem with that*."

Although adolescents are mostly in-charge of keeping their medicine in this phase, most caregivers are still involved in reminding these adolescents about medication time which they view as their responsibility and are concerned that the adolescents may become less adherent to medicines. For example, one caregiver from Mawenzi hospital said, "*How can I forget such an important thing?*"

**Phase four: Adolescent totally in-charge of keeping medicine**

Phase four is when the caregivers hand over full responsibility for keeping the medicine without caregivers knowing where the medicines are kept. This step usually occurs as the adolescents' transition to adulthood which was not a focus of this study.

However, in this study, one adolescent living with a biological caregiver living with HIV had assumed the entire responsibility of keeping medicine and remembering the medication time (phase four). The caregiver from KCMC hospital said, *"Chipegwa (pseudonym) just decided to keep them (medicine) herself and I don't remind her to take them."* This adolescent is the one that decided to assume all responsibilities so that she can depend on herself in the fear of the death of the caregiver. This finding highlights heavy responsibility that might be assumed by some adolescents living with biological caregivers in the fear of losing their caregivers as well as premature transfer of responsibilities i.e. shifting the responsibilities to the adolescent before they are developmentally, emotionally, or practically ready to handle the specified tasks independently

Furthermore, despite structured transfer process related to keeping and taking medicine described above, we also found premature caregiver-to-adolescent transfer of medication-related responsibilities whereby 56% (n=9) of the 16 adolescents in this study (aged 10-14 years) had already assumed the responsibility of keeping their medicine before they transitioned to adolescent clinic. This finding suggests that the transition to adolescent clinic is happening too late whereby the adolescents are ready but the clinic has not identified that they should transition.

### 6.1.4 Adolescents' and caregivers' perceptions on transfer of keeping of medicines

**Adolescents' perceptions**

When given the autonomy of keeping their medicine, initially most adolescents find this a heavy responsibility regardless of whether it was adolescent or caregiver-initiated. This perception was due to the fear of stigma and the need to keep the medications a secret as they (adolescents) are now not only responsible for finding a safe and secure place for keeping their medicine, but also keeping medication hidden from others. Unlike a child with asthma or diabetes who just has to learn to take their own medicines, adolescents with HIV have to both take the medications and make sure they are not found. For example, one adolescent from KCMC hospital shared this responsibility by saying, *"At first time I found it as a heavy responsibility but as the days goes you will used to it. You can keep your medicine and somebody will go and open it. May be when you are outside playing or bathing then someone can open the bag and see the medicine. Nowadays I am keeping under my cloth bag and no one nowadays opens it."* However, with time, adolescents find ways to get used to bearing this responsibility and feel comfortable as one

adolescent from KCMC hospital said, "*I felt good going alone and I feel comfortable because I know the place.*" The need for caregivers to balance between the strategy used and the stage in which the adolescent has assumed responsibilities in medication or clinic attendance was also apparent. When a caregiver's strategy is consistently employed with an adherent adolescent who has already assumed responsibilities for medications, the adolescent tends to view the caregiver's efforts as irrelevant but is forced to comply with their caregiver's approach. One adherent adolescent from KCMC hospital whose caregiver employed excessive direct observation to ensure taking of medicine shared this experience: "*Mom makes sure that I take my medicine. After taking the medicine, I show her then I swallow. If she is not around, there is someone whom she delegates. I show her then she tells mom. She is our neighbor. I am just okay with it although I can do it without being watched.*" This finding signifies the need for caregivers to balance their strategies with the transfer phase since adolescence is a time for seeking autonomy.

**Caregivers' Perceptions**

When adolescents are granted autonomy over medication related tasks, and when they assume this responsibility adequately, caregivers experience a sense of relief. For example, one caregiver from Mawenzi hospital said, *"I used to give her but nowadays she knows their location, how to take them and at what time she should take her medicines. Even when I forget sometimes, she reminds me to show her the watch.***"** As a result, the caregivers may reduce their participation in medication-related tasks to the extent that the adolescents remind them of their roles.

### 6.2 Clinic attendance related tasks

#### 6.2.1 The immediate effects of pediatric-to-adolescent transition on clinic attendance related tasks

This study has identified four clinic attendance related tasks; escorting to clinic, reminding/remembering clinic appointment dates, keeping of the clinic card and participation in clinic consultations. The immediate effects of the pediatric-to-adolescent transition was increased adolescent participation in clinic attendance related tasks. The number of adolescents attending the clinic unescorted by a caregiver nearly doubled from 8 adolescents before transition to 14 after moving to the adolescent clinic. Nonetheless, all adolescents were reminded of the clinic appointment date by the caregivers before transition and this continued for all except one adolescent after transition. Similarly, most caregivers kept the clinic card both before and after transition to avoid accidental disclosures. Lastly, participation in the clinic consultations had the most notable change whereby all transitioned adolescents participated in clinic consultations by

themselves (without caregiver involvement) after moving to the adolescent clinic as this was required by service providers to allow free discussion of adolescent issues in the adolescent clinic.

### 6.2.2 Why adolescents assume more or less responsibility for clinic attendance unescorted by caregivers?

**Adolescent related reasons**

One factor that made adolescents assume more responsibilities in clinic attendance tasks was adolescents' sense of self-efficacy in handling these tasks. For example, one adolescent from Mawenzi hospital who knew the way to clinic decided to start attending clinic unescorted by her caregiver because of knowing the way to clinic. She told her caregiver, "*Grandma, I ask you now to rest, you have carried me a long way. Now I know my way out. You should rest now.*" Therefore, the sense of self-efficacy in situations where the caregivers were facing difficulties in meeting adolescents' need of clinic attendance such as old age or being away, made adolescents self-initiate clinic attendance unescorted by caregivers to relieve caregivers from their burdens of caring for them.

Feelings of being grown up and need for being in control over their lives made some adolescents initiate their own clinic attendance. For example, one adolescent from Mawenzi hospital said, "*I am the one who initiated so that I go early to clinic. If I go with grandma or any other person I leave home late for hospital…If I go with my relatives I come back late from hospital.*" Another adolescent from Mawenzi hospital also said, "*I started after going on Saturday clinic. I felt good going alone. I felt that I have grown up and I feel comfortable because I know the place.*" Hence the adolescents' sense of self-efficacy together with feeling of being grown up made adolescents assume this responsibility.

Lastly, fear of losing biological caregivers also influenced adolescents living with biological caregivers knowing that they may not always be around to assist them with these tasks. For example, one adolescent from KCMC hospital living with biological mother decided to assume all responsibilities in medication management and clinic attendance in the fear that the caregiver may die at any time. She further said, *"Just like I told you before. If you totally depend on your mother and if you depend on her to hold your hand helping you to cross the roads, if she dies you will no longer have anyone to help you cross the roads.*" These comments suggest that adolescents with biological caregivers with HIV assume more responsibilities and carry a heavy burden when compared to adolescents with caregivers without HIV.

On the other hand, adolescent related priorities made adolescents assume less responsibility for clinic attendance when given the autonomy over clinic attendance unescorted by a caregiver. For example, one caregiver from Mawenzi hospital shared this experience by saying, *"…So she missed that appointment and when she went for the following month, she was told to come with her parent…You see, she didn't go there. Instead, she got on a bus and went to Rau to greet her grandmother. She thought that she would come back early but she found the clinic empty."* Another example was shared by service providers of an adolescent who when given the autonomy to attend clinic unescorted by caregivers misused this autonomy at two months after transition to adolescent clinic. The service provider said:

> "*He (adolescent) was 13 years old…we had transferred that boy…But that boy did not turn up for clinic for like two months. His mother started following him up one month after the move and discovered that he doesn't have medicine. So, she started escorting him to clinic…. it was only two months after the move. You see, he was a naughty boy! When he was given bus fare, he used to spend it on buying ice-creams. So, the journey ends there and he doesn't go to clinic!"* (Service provider from Mawenzi hospital).

These findings suggest that although transition to adolescent clinic mostly increased adolescents' responsibilities in unescorted clinic attendance, it may also lead to decreased clinic attendance when adolescents' sense of responsibility is lacking.

**Caregiver related reasons**

For caregivers, everyday activities and life situations in the family influenced them to transfer clinic attendance responsibilities to adolescents. One caregiver from Mawenzi hospital shared this experience by saying, *"I had travelled and delayed coming back meanwhile his mother went to a burial service and also delayed coming back…. he couldn't go to clinic on his own. That incident made me to start building his capacity of going to clinic alone."* Hence, knowing the importance of clinic attendance and medication adherence, situations that made caregivers not able to escort their adolescents to clinic for clinical monitoring and drug refill prompted caregivers to transfer clinic attendance responsibilities unescorted clinic attendance.

Financial constraints were also identified as an influencer towards caregiver-to-adolescent transfer of clinic attendance responsibilities. For example, one adolescent from Mawenzi hospital said, "*There was no bus fare for two people so I had to come alone.*" Another adolescent from Mawenzi hospital said, *"Grandma did not have bus fare and the doctor said that I can come on my own. Then grandma asked me whether I can. She instructed me and I finally managed.*"

Hence, shifting to adolescents attending clinic unescorted by caregivers was a way of relieving the costs incurred during clinic attendance.

**Peer related reasons**

The need to fit in with other adolescents in similar conditions also made adolescents self-initiate transfer of clinic attendance responsibilities from caregivers. For example, one adolescent from KCMC hospital said, *"I saw all of my friends were coming alone with no escort from their parents and then I said to myself that I will start learning go to clinic alone."* The need for wanting to fit in with others not only triggered adolescents to assume more responsibilities in clinic attendance but also influenced how responsibilities were to be assumed.

**Service provider related reasons**

Health service providers have also influenced adolescents to assume responsibilities in clinic related responsibilities to encourage free discussion of adolescents related issues during the adolescent clinic as previously stated in chapter four. Service providers engage caregivers to grant autonomy over clinic attendance-related tasks to their adolescents provided that the adolescents are able to undertake the task. One service provider from Mawenzi hospital shared, *"Once we see that the transitioned adolescent has gotten used to the clinic, we start talking to the caregiver so that they allow the adolescent to come on his/her own depending on the distance from home to clinic."* It was also noted that service providers use various methods to assist caregivers to transfer clinic attendance autonomy, however, there were no standards or guiding documents highlighting how to assist caregivers and adolescents shift these responsibilities and the extent to which adolescents are expected to assume different responsibilities. For example, there was no recommended age by which the adolescent is supposed to start attending the clinic unescorted.

### 6.2.3 How caregivers transfer clinic attendance tasks to adolescents and strategies used

The process of transferring clinic attendance responsibilities follows a similar pattern as for keeping of medication as shown in table 6. Again, the task shifting was mainly determined from the perspectives of supportive caregivers of adolescents who were adherent to clinic attendance. Hence, these findings may not be applicable in situations where the caregivers are shifting clinic attendance management to adolescents who are non-adherent to clinic appointments.

Table 6: The process of caregiver-to-adolescent transfer of clinic attendance tasks

| **Transfer Process** | **Clinic attendance tasks** |
|---|---|
| **Phase 1**<br>(Caregiver in-charge) | Caregiver escorts the adolescent to clinic and the adolescent doesn't know the way to clinic |
| **Phase 2**<br>(Adolescent partially in-charge) | Caregiver partially escorts adolescents (indirect escort) |
| **Phase 3**<br>(Adolescent mostly in-charge) | Adolescent attends clinic unescorted by caregivers but verification of clinic attendance is done by caregivers |
| **Phase 4**<br>(Adolescent fully in-charge) | Adolescent attend clinic unescorted by caregivers without any verification of clinic attendance |

**Phase one: Caregiver in-charge**

In this phase during early adolescence, the caregivers assume all clinic attendance management activities including keeping of the clinic card and escorting their adolescents to ensure their safety on their way to the clinic, to monitor the adolescents' progress in care and as a way of expressing love and care to the adolescents.

**Phase two: Adolescent partially in-charge**

Caregivers will only transfer these responsibilities if the adolescents are adherent to medication and clinic attendance and show some sign of interest or responsibility for their health care. For example, one caregiver from Mawenzi hospital said, *"We will continue escorting her until when she tells us that she can do it on her own.*" However, in some cases, caregivers are forced to skip this second stage because of the adolescents' self-efficacy. For example, one caregiver from KCMC hospital shared her experience, "*One day as I was I escorting her, she told me, 'Today is the last time you are escorting me. I know the way, I know the landmarks…. Don't worry anymore…I am going there myself*."

Therefore, caregivers in this phase of transfer start working together with the adolescents to look for ways to gradually shift clinic attendance responsibilities to adolescents by letting the adolescent know the way to clinic and transition from "**direct escort" to "indirect escort**" to clinic by caregivers. The caregiver may assign someone else to escort the adolescent or may use

mobile phones to guide and monitor their adolescents' clinic attendance. For example, one caregiver shared his experience by saying,

> *"I first started with telling him, 'My friend, tell me, what do you do when your medicine gets finished?' He said, 'I will go to the hospital.' I asked him, 'Do you know where the hospital is?' He said, 'I will just look for someone to escort me, I cross the roads and I go.' I then realized that he has no problem. If only I look for a guy who rides motorcycle to escort him, he will be okay. But then I also had to build his capacity without the motorcycle guy for 1 month because at other times I may not have money."* (Caregiver from Mawenzi hospital during the third IDI).

> *"So, I decided to test him but my heart was really hurting thinking on how he will cross the roads to board buses. So, I gave him a small phone so that we can communicate whether he has arrived. I also gave him bus fare and off he went. When he reached there he called me to tell me that he has arrived safely…I was very happy that he arrived safely. He even told me, 'Now am on my way home, I am through with the clinic.' I was very happy that he came home safely."* (Caregiver from KCMC hospital during the third IDI).

Another strategy used by caregivers in this stage transferring of clinic responsibilities is the shift from **"no responsibilities"** to **"partial responsibilities"** in keeping the clinic card. Some caregivers still keep the clinic cards during early adolescence to avoid accidental disclosure and protect the adolescents from being identified as living with HIV. For example, one caregiver from KCMC hospital described her "no responsibility" strategy as follows: *"I keep it so that it doesn't wear out and secondly I keep it so that others don't know what the card is for. If you just keep it haphazardly, people will know and start stigmatizing her*." However, caregivers who wish to transfer keeping of clinic card responsibility to their adolescents, use the "partial responsibilities" strategy in which caregivers let adolescents handle the clinic card while in a safe place like the clinics where they receive HIV care as one caregiver from KCMC hospital stated, "*When we arrive at the clinic, he takes the number and does everything else. I only hand him the card there because I keep it."* Some responsibilities in keeping the clinic card are given to adolescents only as they leave for the clinic among those who attend clinic unescorted by caregiver. However, most of the caregivers still did not give adolescents full responsibility of keeping the card at home to ensure the safety of the card and avoid accidental disclosures.

Moving from "**active participants**" to becoming **"passive listeners"** during clinic consultations is another strategy that caregivers use to transfer clinic attendance responsibilities

to their adolescents in this second phase. As active participants, caregivers play a greater role in discussions during clinic consultations while as passive listeners caregivers let the adolescent take over clinic consultation and other clinic related tasks. One caregiver from KCMC hospital shared this strategy by saying, *"When we reach there, I just sit and listen and he also sits and listens to what the nurses are telling us. When they tell him to go for meds, he goes!"*.

**Phase three: Adolescent mostly in-charge**

Eventually, when the caregivers are confident with their adolescents' ability to attend clinic on their own, caregivers then move from **"passive reinforcement"** to **"active reinforcement"** of remembering clinic appointment dates**.** In the passive reinforcement strategy, caregivers frequently remind the adolescents about the dates. But to let the adolescent remember the appointment date themselves, caregivers start to use an "active reinforcement" strategy whereby they reinforce the practice of the adolescents looking at/reading their clinic cards to know and remember the clinic dates rather than directly reminding the adolescents of the actual date. For example, one adolescent during cross-sectional qualitative study described the active reinforcement strategy used by caregivers by saying, *"Grandma reminds me: 'Have you checked the clinic card? Do you know when?' I go and check and know the date."* Another adolescent from KCMC hospital repeated this observation by also saying, *"Mom reminds me the clinic day on every day. After every week she asks me about the date. On every Saturday she asks me. Even tomorrow she will ask me. On every Saturday she asks me, 'Is it the date?' So, on every Saturday I look at my card."* Hence, the active reinforcement strategy is used by caregivers to make adolescents remember their clinic appointment dates once the adolescents start to attend clinic unescorted by caregivers.

For adolescents who attend clinic unescorted by caregivers, caregivers do not give all responsibility to the adolescents. Most caregivers in our study verified their adolescents' clinic attendance by getting feedback from the adolescents, checking the clinic card for the date and progress, checking whether the adolescent has returned with medicines, thus making this phase "mostly in-charge." One caregiver from Mawenzi hospital shared how verification of clinic attendance for adolescents given autonomy to attend clinic unescorted is done by saying, "*When she is dropping from boda-boda (motorcycle) I always tell her to give me that bag, then I look at the card, date and medicine."* Another caregiver from KCMC hospital who also verifies clinic attendance said*, "When he comes back, I look at the card and if I see the increase in weight, I know the child is doing well.*" Another caregiver also said, *"I usually check for the next clinic appointment date and whether she has brought back medicine."* Hence verification of clinic

attendance is usually done by caregivers checking whether the adolescent has brought medicines or checking whether the next clinic appointment date has been given to the adolescent.

**Phase four: Adolescent totally in-charge**

Phase four is when the caregivers give full responsibility of clinic attendance management responsibilities to adolescents without caregivers being involved in any clinic attendance related tasks. This step usually occurs during late adolescence as the adolescents' transition to adulthood which was not a focus of this study. However, in this study, the adolescent living with a biological caregiver living with HIV had assumed the entire responsibility of clinic attendance (phase 4). This is the same adolescent described above who decided to assume all responsibilities so that she can depend on herself should her caregiver demise, again highlighting the heavy responsibility that might be assumed by some adolescents who fear losing with the biological caregivers they live with.

Furthermore, despite this structured process, premature caregiver-to-adolescent transfer of clinic attendance responsibilities was observed whereby 50% (n=8) were already given the autonomy of attending clinic unescorted by caregivers before moving to adolescent clinic suggesting that either adolescents seek autonomy early or the caregivers transfer the responsibilities prematurely to their adolescents. This finding also suggests that the transition to adolescent clinic is happening too late whereby the adolescents are ready, but the clinic has not identified that they should transition.

### 6.2.4 Perceptions of caregiver-to-adolescent transfer of clinic attendance tasks

Having discussed the process and strategies used by caregivers and service providers to transfer clinic attendance and medication adherence responsibilities, the following section discusses how adolescents and caregivers feel about these responsibilities during the process of transferring responsibilities.

**Adolescents' perceptions**

There are mixed feelings when the adolescents are granted autonomy over clinic attendance. There are those who are aware of the way to clinic and enjoy this autonomy because they feel comfortable as one adolescent from KCMC hospital said, "*I felt good going alone and I feel comfortable because I know the place.*" On the other hand, some adolescents feel pressured to attend clinic on their own and wish to be escorted by caregivers but are forced to comply with their caregivers' wishes. One adolescent from Mawenzi hospital shared this experience by saying,

"*… dad told me to start going by myself because at times he is too busy at work. I prefer being escorted but I am scared of offending my parents.*" With regards to escorted clinic attendance, some adolescents enjoyed being escorted by caregivers due to quality time spent together but for other adolescents being escorted was viewed as a missed opportunity to interact with other adolescents in the adolescent clinic which is an important social aspect of HIV management. For example, one adolescent from KCMC hospital who was still escorted by their caregiver shared these concerns: "*We are told about lunch but we usually don't have much time as mom has to go to work early. There is food in the afternoon, now mom doesn't have time…If we stay, she will be late for work and she would be scolded for that. I would like to stay and have lunch with my fellows.*" This adolescent therefore had to compromise his opportunities to interact with peers to help the caregiver comply with their work schedule.

**Caregivers' Perceptions**

While caregivers who were highly motivated for their child to assume responsibility were very willing to let adolescents assume clinic attendance responsibilities, some caregivers were not willing to let adolescents attend clinic on their own and resisted granting this autonomy. The resistance is mainly due to the perception that the adolescents cannot go on their own to the clinic due to either long distance to the clinic, unfamiliarity with the route or the fact that the adolescents have never attended clinic on their own. For example, one caregiver from KCMC hospital said, *"Ever since we started going there (clinic), she has never gone there alone. She cannot go alone…I will escort her, it will be inconvenient for me but I will continue escorting her.*" For other caregivers the idea of allowing their adolescents to attend clinic on their own seemed very difficult as one caregiver from KCMC hospital expressed her feelings by saying, *"The day that I allow her to come alone, I will surely be admitted in hospital."*

Some caregivers find the process of adolescents becoming autonomous with clinic visits very stressful especially during the initial days of letting their adolescents attend clinic unescorted. For example, one caregiver from Mawenzi hospital said, *"On the first day I was afraid. I was praying to God then she came back safely. I was even afraid in the next month…I told her, 'When you go to clinic alone, I cannot drink tea, I cannot eat. I only eat when I see you back from the clinic'."* However, with time, the caregivers stress is reduced upon seeing the safe arrival of their adolescents from clinic.

Eventually, caregivers become comfortable not only in their adolescents' ability to attend clinic unescorted, but they also enjoy seeing their adolescents assuming other responsibilities at home

such as doing house chores and preparing beforehand to make sure that they can attend clinic. The following caregivers' quotes illustrate this observation:

> *"He is really enjoying his clinic. …a day before you find them already preparing themselves like ironing their clothes so that they leave very early in the morning on the next day."* (Caregiver from KCMC during the third IDI).

> *"Now she is sharp! She is now a youth…She tells me, `Tomorrow! Wake me up very early tomorrow morning. I am supposed to be there very early in the morning.' So, she wakes up, bathes and leaves. She is grown up!"* (Caregiver from Mawenzi during the third IDI).

> *"After moving from Thursday to Saturday clinic…now if you give him work on Saturday, he will tell you, 'No, today is Saturday I am supposed to go to the clinic'."* (Caregiver from Mawenzi hospital during the third IDI).

Lastly, from caregivers' perspectives, transition to adolescent clinic not only made adolescents take more responsibilities in clinic attendance but also greatly enhanced their growth and independence resulting in reduced caregiver burdens for caring for their adolescents. The following quote from one caregiver summarizes the immediate effects of transition from pediatric-to-adolescent HIV care in Northern Tanzania:

> *"The child is now going alone to clinic and gets medicine and comes back on time…Even if I travel…I don't have to think that it's time to take medicine, who will tell him…I have now passed that hard time. Now he is like a tree which starts to blossom, to toughen the roots and so on."* (Caregiver from Mawenzi hospital during FGD with caregivers).

Hence, the pediatric-to-adolescent transition can increase adolescents' engagement into care, and eventually foster self-care to transitioning adolescents.

### 6.3 Discussion

The main objective of this study was to assess the immediate effects of the pediatric-to-adolescent transition on clinic attendance and medication related tasks assumed by adolescents. Our finding that increased responsibilities in medication related and clinic visit tasks followed transition to adolescent clinic echoes Vijayan et al.'s (2009) findings that redefinement of medication responsibilities was realized after transition to adult care [16]. Despite the increase in medication related and clinic visits tasks, regular clinic attendance and adequate medication adherence was

not always guaranteed after transition and most adolescents still relied on their caregivers to remind them to take their medicines and caregivers also verified clinic visits and taking of medicines. In situations where caregivers were not involved at all, even among mostly adherent adolescents, non-adherence to medications could occur. This finding not only supports that transition must be based on developmental readiness, maturity, and responsibility [38] but also that caregivers' roles are still crucial in ensuring medication adherence and clinic attendance despite the adolescents' autonomy. Hence service providers should continue encouraging caregivers not to leave the entire responsibility to the adolescents.

The second objective of the study was to understand how transition of medication related tasks and clinic attendance tasks are shifted from caregivers to adolescents with perinatally acquired HIV during early adolescence. The study revealed that caregivers gradually transition medication related and clinic attendance responsibilities in phases using strategies ranging from being a passive participant/observer to actively reinforcing the desired self-care behavior. This finding is similar to previous studies that showed caregivers slowly start to transition responsibilities to adolescents during adolescence [20, 22, 71]. Therefore, it is important for service providers to understand the phase of responsibility transfer of each transitioning adolescent to be able to effectively support caregivers and adolescents appropriately to ensure smooth transfer of responsibilities [71, 115, 116].

It is important for adolescents living with HIV to engage in self-care and illness-management skills prior to transition to adult care [45, 117]. However, in this study, we found that adolescents are given greater responsibilities of keeping their medicine and unescorted clinic visits long before the period of transition to adolescent clinic in which self-care support is provided. Previous studies have found that when adolescents are given more responsibility for medication management without proper transition support there is lower adherence in older adolescents [70-72]. Therefore, this finding suggests that transition to adolescent clinic may be happening too late and the need for service providers to guide and assist caregivers to gradually transition medication and clinic attendance responsibilities must be based on developmental readiness, maturity, and responsibility of individual adolescents [38], and not necessarily only occur after transition to adolescent clinic. Consideration should be given to transitioning children to adolescent clinic at an earlier age if developmentally appropriate. Service providers should also provide guidance to the caregivers on the importance of their supervising and monitoring of the shifted clinic attendance and medication related responsibilities [67, 70, 71].

Furthermore, findings from our study show that adolescents whose caregivers are living with HIV assume more responsibilities in medication and clinic attendance tasks than adolescents with caregivers not living with HIV. Caregivers living with HIV may tend to shift these responsibilities to create total independence in the fear of their absence in the future due to their disease status or the adolescents of these caregivers may seek this autonomy to create total independence in the fear of losing their caregivers to HIV disease. While these findings cannot be extrapolated to all biological caregivers living with HIV due to the small ample size, this finding calls for service providers to pay special attention to adolescents of caregivers living with HIV as they may already be carrying heavier responsibilities given their ages and readiness. Transitioning self-care may overburden these adolescents. Furthermore, caregivers living with HIV should be supported and encouraged to continually redefine their family roles, allowing for their adolescents to have the appropriate level of autonomy as they grow and transition to adolescent clinic.

Similar to transition to adult care, fear of stigma was one of the key limiting factors to self-care with adolescents delaying or defaulting seeking HIV care and modification in medication handling such as repackaging of ARVs to avoid accidental disclosure of their diagnosis to others. [32]. Some adolescents even reverted to caregivers keeping medicine in fear of being identified by others who may see the medication as having HIV. This finding highlights the importance of addressing stigma issues as part of the transition package to enhance regular clinic attendance and medication adherence as it is during this time of transition to adolescent clinic when adolescents become aware of perceived stigma and are given autonomy to attend clinic unescorted by caregivers. It supports the USAID recommendations that as part of transition preparations, the service providers should describe stigma and its ill effects to the transitioning adolescents by the age of 11 years and adolescents should participate in peer support groups by 11-14 years [32]. It further supports the Tanzanian Adolescent HIV service guide that calls for service providers to address stigma during follow up visits in adolescent clinic [91].

Despite the well-established transition practices and different approaches to assist caregivers to shift responsibilities and support adolescents to assume more responsibilities as they transition to adolescent clinic, lack of national guidelines for transitioning self-care responsibilities may contribute to non-standardized care and advice provided by service providers to caregivers and adolescents. Furthermore, Hussein et al. (2015) in the review of transition practices stipulated that service providers in health facilities without formalized protocols appeared to be less aware

of factors influencing the transition process [92]. Hence service providers may benefit from self-care guidance so that they are able to identify the caregiver-to-adolescent transfer phase which the transitioning adolescent is in and help the adolescents and caregivers to move to the subsequent phases or revert to a previous phase if the adolescent is not coping. This will ensure that the transition of self-care responsibilities is chronologically, developmentally, behaviorally, clinically, and psychologically appropriate for adolescents transitioning to adolescent clinic.

Lastly, one significant factor that contributed to adolescents assuming more responsibilities in medication related and clinic visit tasks during the transition to adult care was peer support. Peer support was also seen as the key to strengthening adolescent autonomy as they transition to adult care [32]. However, without standardized national guidelines, peer advice provided in the adolescent clinic may be contradictory or sub-optimal. Therefore, providing unified evidence-based guidance on self-care among adolescents in the adolescent clinic will ensure appropriate understanding of the relevant approaches to different self-care challenges adolescents and caregivers face during transition to adolescent care.

### 6.4 Limitations

Task shifting of medication and clinic attendance responsibilities was mainly determined from the perspectives of supportive caregivers of adolescents who were adherent to their medicine. Hence, these findings may not be applicable in unsupportive caregivers and in situations where the caregivers want to shift medication adherence management to adolescent who are not adhering to their medications. Additionally, caregivers of adolescents may be biased to being more involved in adolescents' care hence the results may not be generalizable to populations with less involved caregivers.

### 6.5 Conclusion

We found that caregivers tend to transition medication and clinic attendance related responsibilities to adolescents who are adherent to medication and show some responsibility for these tasks. Shifting of responsibility for medication and clinic attendance occurred well before the transition age and adolescents of caregivers living with HIV tend to assume more responsibilities due to fear of caregiver death. The immediate effects of transition to adolescent clinic include enhanced coping of adolescents with their HIV status following disclosure and increased awareness of perceived stigma that leads to adolescents modifying their clinic attendance and keeping of medicine. At the same time, there is as increased responsibility for clinic attendance and medication adherence with caregiver support. However, increased

responsibility for self-care did not always result in good medication adherence and regular clinic attendance. Other underlying factors such as lack of sense of responsibility for one's health, critical events in the family, lack caregivers' involvement in responsibilities, long distance to health facilities and fear of stigma undermined the pediatric-to-adolescent transition efforts to self-care to improve medication adherence and attendance of clinic appointments among adolescents.

## CHAPTER 7: CONCLUDING DISCUSSION AND RECOMMENDATIONS

### Introduction

This final chapter will discuss the key issues emerging throughout the four chapters and link them back to the central research question: How best do we move adolescents with perinatally acquired HIV from pediatric to adolescent HIV care during early adolescence? The first section summarizes the key findings from the four chapters and the second section discusses the key issues that are critical in the six components of the pediatric-to-adolescent transition in HIV care. The third section makes a conclusion and provides recommendations on how best to move adolescents from pediatric to adolescent care in the Tanzanian context. Areas for future research are presented in the last section of this chapter.

### 7.1 Summary and key issues identified

Chapter three showed that despite three years of transitioning adolescents from pediatric to adolescent clinic, a huge backlog persisted, with 46% of eligible adolescents in the 13-18-year age group still receiving care in pediatric clinic at both hospitals indicating a service gap in the transition process. Furthermore, optimal viral load suppression was a challenge in all adolescents i.e. those who were still attending pediatric clinic and those who have transitioned to adolescent clinic. Chapter four revealed that disclosure of HIV status is the backbone to the pediatric-to-adolescent transition practices whereby all transitioning adolescents must be aware of their HIV status before moving to an adolescent clinic that freely discusses HIV issues. Caregivers' engagement played a significant role in enhancing transition and high levels of caregiver engagement as well as support to biological caregivers who are receiving HIV care together with their adolescents is required. However, lack of written protocols/national guidelines was a limiting factor in provision of evidence-informed transition practices.

Findings from chapter five showed that contextual factors influencing the pediatric-to-adolescent transition exist at all levels of Social-ecological Model with overlapping of the layers of influence. Peer influence and peer support were the most influential factors occurring at all stages of the transition to adolescent clinic. Psychosocial adjustment following disclosure, perceived stigma, and privacy and confidentiality at the clinic were all individual level factors that significantly affected adolescents' acceptability of moving and continuation with care after moving to adolescent clinic. At caregiver level, difficulty in disclosing adolescents' HIV status was the main challenge. Caregivers who were receiving HIV care together with their adolescents feared moving to the adult HIV clinic, and emotional separation from their adolescents was a major challenge for all caregivers. Furthermore, the transition practice that requires moving adolescents from

pediatric to adult clinics in the event of pregnancy or marriage before the age of 24 years had adverse consequences. Lastly, Tanzania's education system, which has 5.3% (n=280) of its secondary school being boarding schools, impacted not only the pediatric-to-adolescent transition process but also continuity with HIV care due to a lack of HIV services and possible limited privacy in boarding schools.

Chapter six showed that caregivers tend to transition medication and clinic attendance related responsibilities to adolescents who are adherent to medication and show responsibility for these tasks. The immediate effects of the pediatric-to-adolescent transition include enhanced adolescents' coping with their HIV status following disclosure and increased awareness of perceived stigma. Increased responsibility for self-care also featured as an immediate effect of the pediatric-to-adolescent transition, however, increased responsibility did not always result in good medication adherence and regular clinic attendance. Other underlying factors such as lack of sense of responsibility for one's health, critical events in the family, lack of caregivers' involvement in responsibilities, fear of stigma and lack of self-care guidelines for service providers undermined the pediatric-to-adolescent transition of self-care responsibilities to improve medication adherence and attendance of clinic appointments.

### 7.2 Key issues that emerged in the six transition components

#### i) Availability of pediatric-to-adolescent transition guide

The key to an effective health care transition in youths is the availability of pediatric-to-adolescent transition guides that outline transition practice and the roles of all stakeholders participating in the transition process. Such a guide was lacking in both hospitals despite the well-established transition practices in these hospitals. Furthermore, the available national guideline on adolescent and young people's health [91], and HIV care and treatment guidelines in Tanzania [15, 91] provide very little guidance on the transitioning process from pediatric-to-adolescent HIV care. As a result, pediatric-to-adolescent transition practices may vary widely across healthcare facilities in Tanzania. There is hence a need to develop/formalize guidelines to ensure standardized and evidence-informed pediatric-to-adolescent transition practices in Tanzania. In addition, this study demonstrate that it is important for the pediatric-to-adolescent guide to address the following crucial components:

a) *The caregiver-to-adolescent transfer of responsibilities during the pediatric-to-adolescent HIV care transition:* Since the pediatric-to-adolescent transition in HIV care occurs in the context of caregiver-to-adolescent shifting of responsibilities, it is important

that the guide covers this transfer process in a way that is developmentally, socially and culturally appropriate for the Tanzanian context. This study identified the need for service providers to guide and assist caregivers to gradually transfer medication and clinic attendance responsibilities given the observation that the majority of adolescents had already assumed these responsibilities before transitioning to adolescent clinic. Therefore, it is crucial for the pediatric-to-adolescent guide to outline what adolescents need to achieve at different stages of transition [115]. The guide should also focus on how to assist adolescents with biological caregivers living with HIV since they seemingly assume more responsibilities than other adolescents living with non-biological caregivers.

b) *The caregiver transition from pediatric-to-adult HIV care:* Evidence from other studies has also shown that transition in health care is more stressful for parents than the patients themselves [77]. This finding has also been portrayed in this study whereby caregivers living with HIV who received care with the adolescent at pediatric clinic found their own transition to adult HIV clinic very stressful. Hence it is important to have a guide highlighting how to transition caregivers from pediatric to adult HIV care settings. In addition to transition to adult care, it is important for the guide to cover issues of emotional separation experienced by these caregivers during the pediatric-to-adolescent transition [118].

c) *Stigma:* In clinic settings where the adolescent clinic is located in a different building even on the same premises, longer time is required to engage and support adolescents especially in the context of high stigma and in situations where the clinic location is likely to lead to one being identified as living with HIV. As adolescents become aware of their HIV status before moving to adolescent clinic, they also start to realize the importance of privacy and the fear of being stigmatized. Therefore, moving them to an obvious HIV clinic may be unacceptable to them. Other studies have shown that adolescents will not enter any obvious HIV clinic [38]. In the Tanzanian context where most HIV clinics are located on different premises from the health facility buildings and have obvious CTC signs, it would be preferable to re-organize HIV services from stand alone to integrated with other out-patient care. In the context of stand-alone HIV facilities, more time is required to engage with adolescents about utilizing these facilities especially after being given the autonomy to attend clinic unescorted by caregivers. Adolescents should be involved in designing the transition process and determining alternative transition practices that are acceptable to them. It is also important for service providers to continue

supporting adolescents by addressing stigma issues so as to ensure continuity of care after transition to adolescent clinic as recommended by the Tanzanian Adolescent HIV services Guide [91].

**ii) Tracking and monitoring**

Planning and establishment of an efficient and effective monitoring and tracking mechanism of adolescents in both pediatric and adolescent clinic before starting any transition program is the second critical transition component to effective transition practices. It is important to have a good monitoring system in the pediatric clinic to assist service providers to identify all pediatric-to-adolescent transition eligible adolescents who are still attending pediatric clinic, facilitate early detection of transitioned adolescents who have reverted back to pediatric or normal clinic and those not keeping their clinic appointments. A comprehensive monitoring and tracking system in the Tanzanian context could include the following:

- ***Clinical monitoring*:**

*The rate of medication adherence of the transitioning adolescent*: Although transition to adolescent clinic did not always guarantee good adherence as an immediate outcome and medication adherence is not a criterion for moving to adolescent clinic, it is important to determine medication adherence status of eligible adolescents before moving them to adolescent clinic. By doing so, all adolescents with poor medication adherence as well as virologic failure will be earmarked for follow up after moving to adolescent clinic. Furthermore medication adherence is one of the key indicators for assessing the success of transition [119].

- ***Self-care responsibilities***

It is important for service providers to assess and monitor the phase of self-care and the strategies used by caregivers to transfer medication and clinic attendance responsibilities in order to support and assist in this transfer of responsibilities in a developmentally appropriate manner.

- ***Contextual factors influential to pediatric-to-adolescent transition***:

It is important to identify and monitor the contextual factors in each transitioning adolescent that are likely to positively influence or hinder the adolescents' medication adherence, clinic attendance and self-care. In order to establish a tracking and monitoring system during health

care transitions, one of the best practices is the use of tools, such as checklists that are placed in the patients' files to aid in the transition process [16]. These checklists can allow service providers to keep track of the clinical monitoring, transfer of responsibilities and contextual factors during transition. However, application of this approach may be challenging in the Tanzanian context that has limited human resources with already overburdened service providers.

**iii) Transition readiness**

Transition readiness of caregivers and adolescents is another crucial component of the pediatric-to-adolescent transition. We found that some caregivers and adolescent perceived themselves as not ready for this transition and were hence resistant. Therefore, it is important for transition readiness assessment for adolescents to not only include adolescents' views on whether they are ready to move, but involve in-depth assessment the following issues:

- **Knowledge:** It is important to assess whether the adolescents are well informed about the adolescent clinic and the transition process as misinformation about the adolescent clinic seemed common and made adolescents resistant to move. Even among caregivers, some caregivers felt they were left behind in the transition process but had to conform with the service providers. If one is aware of the transition process, then one will be more likely to engage [47].

- **Skills:** As adolescents move to adolescent clinic, they require skills to help them with the clinic consultations as their caregivers will no longer be involved once they move to adolescent clinic. The Lancet Commission on adolescent health and well-being suggests that clinic consultations for older adolescents can occur without the presence of the caregiver, provided that the caregivers have given their consent for such arrangements. [47]. Likewise, the USAID technical brief (2012) suggests that adolescents 15 years and above should possess the capability to independently perform tasks such as filling prescriptions, acquiring refills, scheduling clinic appointments, arranging transportation for clinic visits, maintaining a calendar of appointments, and regularly attending appointments. However, it is important to consider cultural factors as well as the cognitive and behavioral development of the individual [32]. Therefore, service providers should inform caregivers beforehand about this transition for consultations and help caregivers to transfer this responsibility so as to relieve caregivers' concerns about their adolescents' ability to speak independently in clinic consultations during the pediatric-to-adolescent

transition. Assessing adolescents' skills/abilities in individual consultations should be one of the pediatric-to-adolescent transition readiness assessment criteria.

- **Friendship assessment:** Peer support on the day of transfer to adolescent clinic was a very important factor for transitioning adolescents. None of them wanted to move alone to the adolescent clinic and anxieties prevailed among adolescents who were not accompanied by a friend on the day of transfer. Group transition may facilitate positive peer interaction and mutual support during transition to adult care [120]. Therefore, it is important to identify the adolescents' networks of friends in the pediatric clinic so that the eligible adolescents ideally move together with their friends to adolescent clinic. For those who do not have friends in the pediatric clinic, assigning a friend from the adolescent clinic prior to transition will allay anxieties on the day of transfer.

**For caregivers living with HIV,** it is important for the transition readiness assessment to capture the following three areas. (1) Readiness to disclose the adolescents' HIV status as studies have shown biological caregivers with HIV face more difficulties with disclosure than non-biological caregivers without HIV due to fear of guilt [61] and secondary disclosure of their own status to their adolescents that often occurs following disclosure of their adolescents' HIV status [121] (2) Readiness to receive their HIV care in the absence of their adolescents together with whom they have been receiving care since childhood and (3) Readiness to move to the adult HIV clinic where they will continue to receive their HIV care and treatment. No study has been done to determine the optimal duration for service providers to assess and support caregivers and there is no guidance for how service providers should support caregivers undergoing such a transition. However, one study participant proposed a period of four months of preparation prior the actual transfer with gradual exposure and assistance of caregivers to attend the adult clinic.

**For non-biological caregivers,** it is important for the readiness assessment to include their readiness to disclose and readiness to allow their adolescents to attend clinic consultations on their own. Our study found that most caregivers proposed a period of one to two months before the actual transfer was adequate to prepare themselves, provided that they are sufficiently well informed about the transition process to make sound decisions.

**iv) The transition planning on the optimal timing of transfer**

Planning of the optimal timing of transition process initiation and the day of transfer is crucial in facilitating successful transition. The following key issues need to be considered when initiating transition and the actual transfer to adolescent clinics;

- **Coping with disclosure:** If pediatric-to-adolescent transfer occurs when the adolescent has coped well with his/her diagnosis after disclosure, then s/he will most likely want to move to adolescent clinic to meet other adolescents with a similar condition. On the other hand, if the adolescent is facing difficulties accepting their diagnosis following disclosure, then the adolescent may not be able to engage in the transition process. Hence attainment of psychosocial adjustment following disclosure is crucial as poor medication adherence due to not accepting the HIV diagnosis has been reported during health care transitions [55, 97].

- **Critical events:** Similar to pediatric-to-adult transition, critical events in the family such as a caregiver's death, their own or caregiver illness, exposure to domestic violence, family conflict or family breakdown, living with parents/caretakers either having mental health problems, excessive drinking or substance misuse can impede successful transition [55]. It is therefore important for service providers to assess the family circumstances and modify the timing of transition and/or provide additional support for adolescents experiencing stressful family events.

- **Ongoing classes**: Pediatric-to-adolescent transition may be more difficult if the adolescent is in grade seven due to national primary school examinations requiring extra Saturday classes which conflict with clinic dates. Likewise, if this transition is initiated when the adolescent is attending religious classes on Saturdays (madrassa or confirmation), transition is likely to be delayed or resisted. Therefore, it is important to plan with the adolescents and caregivers on the appropriate timing that is convenient for them to fully engage in the transition process.

**v) The actual transfer of care**

As already stated in the readiness assessment section, friendship assessment is the key to ensuring that the transitioning adolescents have peer support during the day of the actual transfer to reduce

anxieties of moving alone to adolescent clinics. Furthermore, it is important to have a welcoming environment in the adolescent clinic to reduce anxieties on the day of the transfer.

**vi) Transfer completion & ongoing care**

Continuation with care and maintenance of the necessary skills and behaviors in medication adherence after transfer completion are among the immediate key indicators of a successful pediatric-to-adolescent transition. However, these outcomes are not always attained and pediatric-to-adolescent transition may be an ongoing and sometimes meandering process over time, as an adolescent may periodically intentionally or unintentionally have gaps in clinic attendance and medication adherence. Therefore, the following key issues need to be considered during the ongoing care after transfer completion to maintain continuity with care:

**Adolescent service provision:** Among the reasons that adolescents preferred adolescent clinic over the pediatric clinic was the efficiency in service provision and being valued as adolescents. This finding suggests the importance of adolescent friendly and adolescent focused HIV service providers and providing appropriate clinic days (e.g. that don't conflict with school, religious or social commitments) to sustain the positive perceptions to the adolescent clinic that make adolescents continue with care after transition.

**Importance of addressing stigma:** Fear of stigma emerged during and especially after pediatric-to-adolescent transition and made some adolescents postpone or delay seeking HIV care, take medications in secrecy and sometimes assume less responsibility in medication related tasks. Service providers need to continue addressing stigma during the adherence sessions and incorporate the topic of stigma during the talks, testimony sessions and any other relevant session as recommended by USAID [32] and the Tanzanian adolescent HIV services guide [91] as well as addressing the societal context of stigma for all people through education. Consideration should also be given to integrated adolescent clinics that are not only focused on HIV as a means to reduce stigma of attending an HIV clinic.

**Self-care support**: Ongoing guidance for caregivers who are supporting the development of self-care in their adolescents may be challenging after transition as caregivers no longer participate in clinic consultations after moving to adolescent clinic. This organization can be improved by having opportunities to continue engaging caregivers after adolescent transition.

**Psychosocial support:** Availability of adolescent age-appropriate activities such as singing in the choir, dancing, sports, lectures and availability of food in the adolescent clinic made adolescents feel they belonged in the adolescent clinic. Therefore, this is an important area to assess when establishing pediatric-to-adolescent transition services in any setting as it greatly influences continuation with care after transfer completion.

**Transition to adult care in the context of early marriage or pregnancy:** It is important to review the appropriateness of transitioning pregnant/married adolescents to adult clinic just because they become pregnant as, for example, moving a 15-year-old girl to adult clinic because she is pregnant seems very harsh. Appropriate patient-centered management and psychosocial support should be provided to pregnant adolescents/adolescent mothers to prevent second-generation perinatal HIV transmission [106, 122] and subsequently ensure continuity with care during the appropriate time for transition to adult HIV care.

### 7.3 Conclusion

In conclusion, the pediatric-to-adolescent transition of HIV care for adolescents living with perinatally acquired HIV is a bi-faceted (adolescent and caregivers), multi-stage (from disclosure to transition to adult clinic) and ongoing process that needs to attend to the medical, psychosocial, and developmental needs of adolescents at all stages as well as caregivers' needs. This pediatric-to-adolescent transition provides a chance to strengthen adolescents' autonomy and connections to their peers and friends which is an important psychosocial aspect of HIV care and highly valued by adolescents. Therefore, with adequate planning, oversight, and adolescents' and caregivers' involvement in all transition stages, the pediatric-to-adolescent transitional programs can increase adolescent engagement into care, lead to timely identification of risk factors influencing this transition, and eventually foster self-care to transitioning adolescents.

### 7.4 Recommendations

The study findings and insights point to the following recommendations for National AIDS Control Program (NACP), adolescent transition programs, and the Tanzanian Government on how best move adolescents with perinatally acquired HIV from pediatric to adolescent HIV care in the Tanzanian context. Recommendations for future studies are provided at the end of the chapter.

### 7.4.1 For the National AIDS Control Program (NACP)

a) To develop a national pediatric-to-adolescent transition guide component as part of the adolescent and young people's health guide[91] that outlines the following:

- The key pediatric-to-adolescent transition processes and transition readiness assessment tool to ensure evidence-informed and context-based transition practices across healthcare facilities in Tanzania.
- The caregiver-to-adolescent transfer of responsibilities during the pediatric-to-adolescent HIV care transition to ensure that transfer of autonomy process occurs in a way that is developmentally, socially and culturally appropriate for the Tanzanian context.
- The transition of caregivers living with HIV from pediatric to adult HIV clinics to ensure smooth and successful transition of caregivers to adult HIV care. Specifically, the guide should focus on helping service providers to address the emotional separation, difficulties in disclosure and fear of stigma associated with moving to adult HIV clinics.

b) To review the appropriateness of transitioning pregnant/married adolescents to adult clinic and develop a guide that will ensure appropriate management and psychosocial support to these adolescents to prevent second-generation perinatal HIV transmission and ensure continuity with care until the appropriate time for transition to adult HIV care.

### 7.4.2 For the pediatric-to-adolescent transition programs

- **Tracking and monitoring system:** To develop a comprehensive tracking and monitoring system to track adolescents' clinical aspects (viral loads/medication adherence status and type of regimen), self-care responsibilities and other contextual factors during all stages of pediatric-to-adolescent transition process.

- **Transition readiness assessment:** For transition readiness assessment, transition programs should;
    - Conduct friendship assessment of transitioning adolescents as part of transition readiness assessment to ensure that as far as possible adolescents move together with their friends (group transition).

- Assess the following four key areas for caregivers living with HIV**,** (i) readiness to disclose the adolescents' HIV status (ii) readiness to receive their HIV care in the absence of their adolescents (iii) readiness to move to the adult CTC where they will continue to receive their HIV care and treatment (iv) readiness to allow their adolescents to attend clinic consultations on their own.

- Assess two areas for non-biological caregivers, which include readiness to disclose the adolescents' HIV status and readiness to allow their adolescents to attend clinic consultations on their own.

- **The optimal timing of transfer:** It is recommended that the optimal timing to transfer to adolescent clinic should consider the following:
    - When the adolescents have accepted their HIV diagnosis following disclosure.
    - When adolescents experience critical events in the family then modification in the timing of transition and provision of additional support for adolescents should be considered.
    - Ongoing classes such and religious classes that have greatly influenced adolescents and caregivers' acceptability of pediatric-to-adolescent transition**.**

- **During the actual transfer of care:** It is recommended that peer support should be provided before the actual transfer by either assigning a friend from the adolescent clinic prior transition or by identifying the adolescents' networks of friends in the pediatric clinic so that the eligible adolescents move together with their friends to adolescent clinic (group transition).

- **Transfer completion and ongoing care:** After transfer completion and during ongoing care in the adolescent clinic, it is recommended that**;**
    - Psychosocial support such as sports, creative activities and refreshment should be provided as part of HIV care when establishing pediatric-to-adolescent transition services in any setting in Tanzania.

### 7.4.3 For the Tanzanian government

- To invest in provision of adolescent HIV and other health services in boarding schools to ensure access and continuity with HIV care among adolescents with perinatal HIV infection.
- There is the need for the government to engage secondary schools in addressing stigma and address boarding school rules and procedures that may lead to adolescents' discontinuation with HIV care in fear of being exposed their HIV status**.**
- To provide integrated adolescent friendly health services that provide a range of services and not just HIV care alone so as to address stigma hence encourage adolescent clinic attendance.

## 7.5 Areas for Future Research

- To our knowledge, no study has examined the voices of caregivers living with HIV who themselves transition from pediatric to adult HIV care. Further research to understand this caregiver experience could assist service providers to determine the optimal support for those undergoing this transition.

- Findings from this study were mainly in the context of the higher-level facilities with the same service providers providing both pediatric and adolescent HIV services at the same clinic premises. Hence, pediatric-to-adolescent transition services in the context of lower level facilities and different pediatric and adolescent service providers, and different pediatric and adolescent clinic premises need to be explored.

- Despite the limited timeline, the study has shown that after transitioning to adolescent clinic for one to two years, adolescents may decrease their medication adherence following the fading of the excitement of moving to adolescent clinic. Therefore, further studies with longer duration of follow-up are recommended to assess the trends in medication adherence following transition to adolescent clinics and identify the long-term effects on this transition on medication adherence and clinic attendance management.

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**APPENDIX 1: IN-DEPTH INTERVIEW GUIDE FOR THE EXPLORATORY STUDY**

The sub-questions are only suggested/possible probes

Participant IDNO |__|__|__|__| Gender Male / Female Researcher Initials |__|__|__|

Health facility number |__|__| Date |__|__/__|__/__|__|

**Introduction**

_____

**Opening questions**

- Tell me about yourself

Probes:

- What is your name? How old are you?
- Do you go to school? What class are you in? If not, why?
- Who are you living with now? If s/he is living with non-biological parent/s, how long has s/he been living with the caregiver?
- When did you start receiving care at this clinic? Do you like it or not? Why do you or not like it?

**Now I am going to ask you some questions about your experiences with the transition from paediatric to adolescent clinic.**

| **Theme** | **Topic and Probes** |
|---|---|
| Disclosure | **How did you come to know that you are living with HIV? Tell me…**<br><br>Probes:<br><br>Who told you?<br>When was it (before or after transition),<br>Where were you?<br>Who else was there?<br>How did you feel?<br>Why did you feel that way? |
| Transition practices & | **Moving from the pediatric to adolescent clinic, this experience can vary for individual children and adolescents. Think about your last** |

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| perceptions (adolescents) | **day in the pediatric clinic, can you walk me through that day at the pediatric clinic?**<br><br>Probes:<br><br>**What** was it like?<br>**What** did you do?<br>What did you **like and dislike** most?<br>**How** did you feel knowing that it is your last day at the pediatric clinic?<br>**Why** might you have felt that way?<br><br>**Now think about your first day in the adolescent clinic. Can you walk me through that day at the adolescent clinic?**<br><br>Probes:<br>**What** was it like,<br>**what** did you do<br>What did you **like and dislike** most?<br>**How** did you feel?<br>**Why** did you feel that way?<br><br>**Some adolescents feel that having privacy in the adolescent clinic does matter during their move to the adolescent clinic. Does it matter to you?**<br><br>Probes:<br>**Why** does it/not matter to you?<br><br>**Can you think of what would happen to you if there was or no privacy, peers in the adolescent clinic**?<br><br>**Some adolescents feel that having peers in the adolescent clinic does matter during their move to the adolescent clinic. Does it matter to you?**<br><br>Probes:<br><br>**Why** does it/not matter to you?<br><br>Can you think of what would happen to you if there was or no privacy, peers in the adolescent clinic?<br><br>**What do you think about receiving care in the peds clinic? And the adolescent clinic?**<br><br>Probes:<br>Now **where** do you think you like to receive care? Ped or adolescent? |

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| | Why do you like it there? |
| Transition perceptions (caregivers & other family members) | **Now think about your home, caregivers and other family members during the time you were moving to adolescent clinic. Can you describe your home, parents/caregivers and other family members?**<br><br><u>Probes:</u><br>House arrangement<br>The number of people<br>Who does what<br>**Who knows** the adolescents HIV status<br>**Interactions** with and within family<br><br>What do **you like** most about your caregivers and family members? What do you **dislike** most about them?<br><br>Who do you think was most helpful during your move to adolescent clinic? **How** did they he/she/they help you?<br><br>Who do you think was least **helpful** during your move to adolescent clinic? **Why** do you think so? |
| Transition perceptions (service providers and peers) | **Now think about your friends and peers at the clinic where you receive care. Tell me about your friends in the pediatric and adolescent clinic.**<br><br><u>Probes:</u><br>Were there other children/adolescents in the pediatric clinic that were your friends? If not, how did you relate to others in the clinic?<br>Do you now have any **new friends** at the adolescent clinic?<br>Are there any friends who **moved on to** the adolescent clinic before you?<br>Friends who are still in peds clinic?<br>Any friends that **moved with you** to adolescent clinic?<br>How did you **feel** about it?<br>How did you feel after seeing your peers/friends at the adolescent clinic?<br><br>Did any of your peers/friend **assist** you to get used to the adolescent?<br>Can you tell me an **example** of how your friend helped you?<br><br>**Think about the doctors and nurses at the clinic where you receive care. Tell me a little bit about the person who is your best nurse and/or doctor in the adolescent clinic? (Don't have to mention his/her name)**<br><br><u>Probes:</u> |

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| | Why is he/she the best doctor/nurse? Can you give an example?<br>What do you do together?<br>What about other providers, what do you do together? Tell me more.<br><br>Are there any **changes** in the way the doctors and nurses treat you now that you are in adolescent care when you compare to when you were in the pediatric clinic?<br><br>If yes, can you tell me an **example** of how your doctors and nurses treat you now? |
| Medication adherence management | **Think of the good days when you want to take your medications. Tell me the steps you normally take in order to take your medication at home? What do you do?**<br><br><u>Probes:</u><br><br>Are these steps **similar or different** fromthe steps you took when you were in pediatric clinic? If different, how?<br><br>**Who keeps** the medication?<br><br>If it is you who keeps your medications, when **did you start**? (Probe before or after transition) How do you feel about it?<br><br>Is there **anyone in the family** that ensures/reminds/helps you that you take your medications? How do they do it?<br><br>If no one is involved in ensuring/reminding/helping that you take you medications, how do **you ensure** that you take your medications? How do you **feel** about it? Why do you feel that way?<br><br>**Now think of a day when you don't feel like taking medications. What do you do in order to take your medication?**<br><br><u>Probes</u>:<br>**How** was it like? Can you give an **example**?<br>How did you **handle** it? |
| **Clinic appointment management** | **Think of a good day when you want to the clinic for your appointment. Describe to me what you normally do when you wake up until you reach the clinic?**<br><br><u>Probes:</u> |

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| | How do you **go to** the clinic? Alone or with caregiver? **When** did you start going to clinic on your own?<br><br>**Who keeps** your clinic card? Has this changed since you moved to adolescent clinic?<br><br>How you **know your next clinic** appointment date?<br><br>Is there **anyone else in the family that knows** or reminds you of your next clinic appointment dates? How do they ensure/remind you?<br><br>Has this **changed** since you moved to adolescent clinic?<br><br>If yes, how has it changed?<br><br>How do you feel about you caregiver escorting/not escorting you to clinic? Why do you feel that way? |
| **Ending questions**:<br><br>Was it easy or difficult for you to move from pediatric to adolescent clinic? Why was it easy or difficult for you?<br><br>Do you have any questions or stories you would like to share? | |

**APPENDIX 2: THE INITIAL IN-DEPTH INTERVIEW GUIDE FOR SERVICE PROVIDERS**

The sub-questions are only suggested/possible probes

Participant IDNO |__|__|__|__| Gender Male / Female Researcher Initials |__|__|__|

Health facility number |__|__| Date |__|__/__|__/__|__|

**Introduction**

_____

**Opening questions:** Can you describe to me your position and day-to-day role in the transition of adolescents from pediatric to adolescent HIV care in your hospital?

**Now I am going to ask you some questions about your experiences as a service provider in this facility.**

| **Theme** | **Topic and Probes** |
|---|---|
| Organization of transition services | **Can you walk me through the steps involved during the transition of an adolescent from pediatric to adolescent clinic at your facility?**<br><br>Probes:<br><br>How do you **identify** adolescents who are eligible for transitioning to adolescent care?<br><br>Are there specific **criteria/guidelines** you use? Can you describe these criteria?<br><br>**Who initiates** the transition process and how is it done? Can you describe why it is done that way?<br><br>Are there any **tests or assessments performed** that figure in the decision about whether to transition adolescent clinic? Can you tell me more? Are these done in the presence of caregiver? Why and why not?<br><br>How is the **actual transfer** of care done? Why is it done that way?<br>How do you **track** transitioned adolescents? |
| Disclosure | **Can you tell me more about the process of informing adolescent their HIV status during transition to adolescent care? How is it done?**<br><br>Probes:<br>**Who** does it? **When? How**? **What? Why** is it done that way?<br>What are **your views** on disclosure being a pre-requisite for transition? Does it affect adolescents move? How?<br>What **challenges** do you encounter when disclosing adolescents' HIV status during |

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| | transition? Could you describe an example? |
| Perceptions of transition | **What do you think about the organization of transition services in your hospital? Does it lead to successful transition?**<br><br>Probes:<br><br>**Steps involved** e.g. identification of eligible adolescents, disclosure, preparations, the actual transfer etc.<br><br>Why do you think so?<br>What can be **changed**?<br>What is **missing** or should be added? |
| Transition barriers & facilitators | **Have you had any situations in the adolescent's life and/or at hospital level that made your site reluctant to move an adolescent to adolescent clinic?**<br><br>Probes:<br><br>Can you tell me about that situation with an **example**?<br><br>Do you know any adolescent who has been **lost to follow-up/non adherent** to medication after transition to adolescent care? If you recall, what was the reason for their loss to follow up/non-adherence to medication? Can you provide an example?<br><br>Do you know any adolescent who has been **adhering well to medication &clinic appointments** after transition to adolescent care? If you recall, what was the reason for their good adherence? Can you provide an example? |
| Transition to self-care | **Can you tell me how you assist adolescents and caregivers in medication adherence and clinic appointments management during transition?**<br>Probes:<br>Can you provide an example?<br>Are there any differences in how you assist them before and after transition?<br>Challenges encountered?<br>Are there any written guideline or protocols that you use? |
| **Ending questions**<br><br>Do you have any further questions or stories you would like to share? | |

**APPENDIX 3. SUBSEQUENT INTERVIEWS GUIDE WITH SERVICE PROVIDERS**

The sub-questions are only suggested/possible probes

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|---|---|
| Participant IDNO \|__\|__\|__\|__\| Gender Male / Female Researcher Initials \|__\|__\|__\|<br><br>Health facility number \|__\|__\| Date \|__\|__/__\|__/__\|__\| | |
| **Theme** | **Topic and Probes** |
| Organization of transition services | **Provide a summary of issues/themes identified in the organization of transition service during the last interview.**<br><br>**Probes:**<br>Is this a correct summary?<br>Are these interpretations correct?<br>Can you clarify what you meant by .....?<br>Is there any additional information you would like to add? |
| Disclosure | **Provide a summary of issues/themes identified in the process of informing adolescent their HIV status during transition to adolescent care?**<br><br>**Probes:**<br>Is this a correct summary?<br>Are these interpretations correct?<br>Can you clarify what you meant by .....?<br>Is there any additional information you would like to add?<br>Could you describe another example of another challenge encountered, if you have? |
| Perception of transition | **Provide a summary of issues/themes identified how the service provider thinks about the organization of transition services at his/her hospital whether it leads to successful transitions or not?**<br><br>**Probes:**<br>Is this a correct summary?<br>Are these interpretations correct?<br>Is there any additional information you would like to add?<br>Can you clarify what you meant by .....? |
| Transition barriers & facilitators | **Provide a summary of issues/themes identified on any situations in the adolescent's life or at hospital level that made service providers reluctant to move adolescent to adolescent clinic?**<br><br>**Probes:**<br>Is this a correct summary? |

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| | Are these interpretations correct?<br>Can you clarify what you meant by .....?<br>Is there any additional information you would like to add?<br>Could you describe another example of such situations, if you have? |
| Transition to self-care | **Provide a summary of issues/themes identified on how you assist adolescents and caregivers and in medication adherence and clinic appointments management and challenges encountered during transition?**<br><br>**Probes:**<br><br>Is this a correct summary?<br>Are these interpretations correct?<br>Can you clarify what you meant by .....? (if any clarification is needed)<br>Is there any additional information you would like to add or another example to share? |
| **Ending questions**<br><br>Do you have any further questions or stories you would like to share? | |

**APPENDIX 4. INITIAL INTERVIEW GUIDE WITH CAREGIVERS**

The sub-questions are only suggested/possible probes

Participant IDNO |__|__|__|__| Gender Male / Female Researcher Initials |__|__|__|

Health facility number |__|__| Date |__|__/__|__/__|__|

**Introduction**

_____

**Opening questions**

1. For how long have you been taking care of (adolescent's name)?
2. Are you his/her biological parent? If not biological parent, probe for the relationship (aunt, grandmother, uncle etc.) Do you take medications for the same reason as (adolescent's name) does?
3. Do you have any other children/adolescents receiving care in the pediatric or adolescent clinic? If so, how many and how long have they been in care)

**Now I am going to ask you some questions about you**

| **Theme** | **Topic and Probes** |
|---|---|
| Organization of transition services | **How did you come to know that (adolescent's name) will soon move from the pediatric to adolescent clinic?**<br><br>Probes:<br>**Who**, was involved? **When** was that?<br>**Where**? **What** did they tell you?<br>How did they tell you?<br>What followed?<br>What did you like and dislike? |
| Disclosure | **I understand that your son/daughter was told about his/her HIV status before moving to adolescent clinic. What do you think/feel about this?**<br><br>Probes:<br>Is it a **good or bad** practice? Why do you think so?<br>Do you think that **s/he was ready** to know his/her HIV status?<br>Were **you ready** for him/her to know his/her HIV status?<br>How would you have wanted it to happen? |
| | **Now think about your child/adolescent (_____) during this transition period to adolescent care. What do you think are her thoughts and feelings towards transition?** |

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| Perception (adolescents) | Probes:<br>**Why** do you think that way?<br>Do you think that s/he **wants to move** to adolescent clinic**? Why?**<br>Do you think s/he is **ready to move**? Why do you think so?<br>Where do you think your child **fits best** now? (Pediatric/adolescent clinic), why do you think so? |
| Perception of transition services (caregivers) | **Now think about yourself and other family members at home**. **What were your thoughts and feelings when you/they were first told that (_____) would move to adolescent care?**<br><br>Probes:<br>**Why did you** feel that way?<br>What about other **family members**?<br>Are you **ready** for (_____) to transition? Why?<br>What does this transition **mean** to you?<br>Who do you think will be **most helpful** (_____) during the transition period? **How and why**?<br>Can you think of situations where **you may not be able** to assist (…) with her move to the adolescent clinic? Can you give examples |
| Transition perceptions (service providers & peers) | **Now think about doctors and nurses who take care of your child at the clinic where s/he receives treatment. Can you describe how your son/daughter relates/interacts with the doctors/nurses at the clinic?**<br><br>Probes:<br>E.g.: Making appointments, drug refill, freely interacts with them. Can you give an example?<br>How would you have felt about the transition if your child was to move to adolescent clinic where there are different service providers?<br><br>**Now think about (_____) friends/peers at the clinic where s/he receives treatment,**<br><br>**Can you tell me about his/her friends**?<br><br>Probes:<br>How do they relate/interact at home/school/clinic?<br>Can you give an example of how they relate?<br>**Now think about the government, politics, medical services, education system in Tanzania,**<br><br>Can you think of any example in your life with regards to the above situations or systems that hindered or assisted you and your adolescent in accessing or using the pediatric clinics services? Tell me more. |

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| **Transition to self-care** | **How do you normally manage your son's/daughter's adherence to ART medication?**<br><br>Probes:<br>**How do you do it?**<br>**When, where and why** do you do it?<br>Who keeps medication and why?<br><br>**How do you normally manage keeping up with clinic appointments?**<br>Probes:<br>**How do you do it?**<br>**When, where and why do you do it?**<br>Who **keeps medication** and why?<br>Who **keeps the clinic card** and why?<br>Does the **caregiver escort** the adolescent to the clinic? Why and why not?<br><br>**What do you think about your child's ability to manage medication and clinic attendance on his/her own? Why do you think so?**<br><br>Probes:<br>Medication adherence<br>Making appointments<br>Going to clinic<br>Interaction with service providers |
| Barriers | **Have you in any way not been able to take to keep up your child's clinic appointments?**<br><br>Probes<br>When was it? What happened? Can you give an example?<br>**Have you in any way not been able to assist/ensure that your child adherences to his/her medication**?<br><br>Probes<br>When was it? What happened? Can you give an example? |
| **Closing**<br><br>Is there anything else you think is important that we have not talked about? | |

**APPENDIX 5. SUB-SEQUENT INTERVIEWS GUIDE WITH CAREGIVERS**

The sub-questions are only suggested/possible probes

| | |
|---|---|
| Participant IDNO \|__\|__\|__\|__\| Gender Male / Female Researcher Initials \|__\|__\|__\|<br><br>Health facility number \|__\|__\| Date \|__\|__/__\|__/__\|__\| | |
| **Theme** | **Topic and Probes** |
| Organization of transition services | **Now that (adolescent's name) has moved to adolescent care, what do you think about the transition services in this hospital?**<br><br>Probes:<br>They way service providers **informed you** about the transition, any **preparations**, actual **transfe**r, and assistance from service providers?<br>What did you **like most** and why?<br>What did you **not like** at all, and why?<br>. |
| Disclosure | **In the previous interview, this……. is how you felt about adolescents being told their HIV status before transition.**<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..?( if there is the need)<br><br>**Do you still feel the same or have you changed these feelings/view**?<br><br>If changed, Could you tell me about how your views may have changed? |
| Perception (adolescents) | **Now think about your child/adolescent during this transition period to adolescent care.**<br><br>In the previous interview, these……. were your thoughts on how s/he feels towards transition. Now that s/he has attended adolescent clinic 2 times, do you still hold the same thoughts? Why and why not? |

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| | In the previous interview, you thought that (adolescent's name) fits best in…. (Pediatric or adolescent care), do you still hold the same thoughts now? Why and why not? |
| Perception of transition services (caregivers) | **Now think about yourself and other family members**<br><br>In the previous interview, these…… were your (and/or other family members) thoughts and feelings when initially told that (____) will move to adolescent care.<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Now that your child has had 2 visits in the adolescent care, do you still have the same feelings and thoughts? If changes, how have they changed?<br><br>In the previous interview, you thought that ……..will be most helpful during transition.<br><br>Have she/he/they been helpful? If yes, how? If Not, why? Can you give an example? |
| Transition perceptions (service providers & peers) | **Now think about doctors and nurses who take care of your child at the clinic where s/he receives treatment, this is how……. s/he interacted with the doctors and nurses at the clinic.**<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Has this interaction changed now that s/he has moved to the adolescent clinic? If yes, how has it changed? Can you provide an example?<br><br>**Think about (_____) friends/peers at the clinic where s/he receives treatment.**<br><br>In the previous interview, this is how you daughter/son interacted with his friends/peers at the pediatric clinic.<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed) |

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| | **Now that (……) has attended adolescent clinic twice, can you tell me (if you know) about his/her friends in the adolescent clinic?**<br><br><u>Probes;</u><br>How do they relate/interact at home/school/clinic?<br>Can you give an example of how they relate/interact (if there is)? |
| | **Now think about the government, politics, financial system, medical services, education system in Tanzania,**<br><br>In the previous interview, these…… were your examples of how the government, politics, financial system, medical services, education system had influenced your access and use of pediatric services.<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Can you think of any other example now that you son/daughter is in adolescent clinic? If you have one/ |
| **Transition to self-care** | **During the previous interview, this is how you managed medication adherence. (…….)**<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Have any of these changed since your child has moved to adolescent care? How has it changed?<br><br>**During the previous interview, this is how you do to adhere to clinic appointments. (…….)**<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Have any of these changed since your child has transitioned to adolescent care? How has it changed? |

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| | **In the previous interviews, these (……) were your thoughts about your child ability to manage medication adherence and clinic attendance on her/his own.**<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Do you still have the same thoughts now that your child has moved to adolescent clinic? If changed, how have your thoughts changed? |
| Barriers | During the previous interview, these (…) were the situations that made you or your child not to be able to keep up the clinic appointments/ medication adherence.<br><br>• Are these interpretations correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>**Since your child has moved to adolescent clinic, have you or your child in any way not been able to take to keep up with the clinic appointments or medication adherence?**<br><br><u>Probes</u><br>When was it? What happened? Can you give an example? |
| **Ending questions:**<br><br>After having an adolescent who has moved from pediatric to adolescent clinic, what advice would you give someone who has a child transitioning to adolescent care?<br><br>Is there anything else you think is important that we have not talked about? | |

**APPENDIX 6. INITIAL INTERVIEW GUIDE WITH ADOLESCENTS BEFORE TRANSITION**

The sub-questions are only suggested/possible probes

Participant IDNO |__|__|__|__| Gender Male / Female Researcher Initials |__|__|__|

Health facility number |__|__| Date |__|__/__|__/__|__|

**Introduction**

_____

**Opening questions**

- What is your name? How old are you?
- Do you go to school? What class are you in? If not, why?
- Who are you living with now? If s/he is living with non-biological parent/s, how long has s/he been living with the caregiver?
- When did you start receiving care at this clinic? Do you like it or not? Why do you or not like it?

**Now I am going to ask you some questions about your experiences with this hospital**

| **Theme** | **Topic and Probes** |
|---|---|
| **Disclosure** | **How did you come to know that you are living with HIV?**<br><br>Probes:<br>How<br>When<br>Where,<br>Who,<br>How did you feel? |
| **Transition practices** | **Tell me, how did you come to know that you will be moving to adolescent clinic?** (assuming all adolescents have been told about their move to adolescent clinic)<br><br>Probes:<br>**Who**, if anyone, was involved?<br>**When** was that? What did they tell you?<br>How did you **feel** when you learned that you would move to adolescent care?<br>**Think about your last day at the pediatric clinic. Walk me through that day?**<br><br>Probes: |

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| | **How** was it like, **what** did you do, what did you like/dislike most?<br>**How** did you feel knowing that it is your last day at the pediatric clinic?<br>**Why** did you feel that way? |
| Transition perceptions (adolescents) | **What does moving from pediatric to adolescent clinic mean to you?**<br>Can you tell me more?<br><br>**Can you imagine what the adolescent clinic will be like? Tell me.**<br><br>Probes:<br>clinic area, peers, service providers, services, fun<br>What do you fear most about adolescent clinic?<br><br>**Other adolescents feel that having privacy and peers in the adolescent clinic do matter during their move to the adolescent clinic. Do they matter to you?**<br><br>Probes:<br>Why does it/not matter to you?<br>Can you think of what would happen to you if there was or no privacy, peers in the adolescent clinic?<br><br>**During transition, some adolescents feel that they are ready to move while others feel that they are not ready to move to adolescent clinic. What about you?**<br><br>Probes:<br>How do you **feel**?<br>Are you **ready** or not ready to move? **Why**?<br>**Where** do you like to receive care now? The pediatric or adolescent clinic and why? |
| Caregivers & other family members | **Now think about your home, parents/caregivers and other family members. Can you describe your home, parents/caregivers and other family members?**<br><br>Probes:<br>How **many** people?<br>Who **does what?**<br>**Interaction** with/within family<br>Who **knows** that you are living with HIV?<br>What do you **like most** about your caregivers and other family members? What don't you like most about them? |

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| Peers & service providers | **Now think about your friends and other children in the pediatric clinic where you receive care. Tell me about your friends.**<br><br>Probes:<br>How **many** friends?<br>Who is your **best** friend?<br>What do you **do together**?<br>Can you tell me an **example** of how you interact with your friends/peers?<br>How you feel **leaving** them?<br><br>**Think about the doctors and nurses at the clinic. Can you tell me, who is your best nurse and/or doctor in the pediatric clinic?**<br><br>Probes:<br>**Why** is he/she the best doctor/nurse? Can you give an example?<br>**What** do you do together?<br>What about **other providers**, what do you do together? Tell me more. |
| Medication adherence management | **Think of the good day when you want to take your medications at home. Could you describe the steps you take on that day in order to take your medication? What do you do?**<br><br>Probes:<br>**Who keeps** the medication?<br>How do you feel about it?<br>Is there **anyone in the family** that ensures/reminds/helps you that you take your medications? How do they do it?<br><br>If no one is involved in ensuring/reminding/helping that you take you medications, how do **you ensure** that you take your medications? How do you **feel** about it? Why do you feel that way?<br><br>**Now think of a day when you don't feel like taking medications. What do you do in order to take your medication?**<br><br>Probes:<br>How was it like? Can you give an example?<br>How did you handle it? |
| **Clinic appointment management** | **Think of a good day when you want to the clinic for your appointment. Can you describe to me what you normally do when you wake up until you reach the clinic?**<br><br>Probes:<br>**Who keeps** your clinic card? |

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| | Do you **know** your next clinic appointment date? If yes, How do you know? Is there **anyone else in the family** that knows or reminds you of your next clinic appointment dates? How do they ensure/remind you?<br><br>How do **you go to** the clinic? Alone or with caregiver?<br><br>When did you start going to clinic on your own?<br><br>**Some kids believe that they should/should not be escorted to clinic, what do you think? Why do you think that way?** |
| **Ending questions**:<br><br>Do you have any questions or stories you would like to share? | |

**APPENDIX 7. SUB-SEQUENT INTERVIEW GUIDE WITH ADOLESCENTS AFTER TRANSITION**

The sub-questions are only suggested/possible probes

| | |
|---|---|
| Participant IDNO \|__\|__\|__\|__\| Gender Male / Female Researcher Initials \|__\|__\|__\| <br><br> Health facility number \|__\|__\| Date \|__\|__/__\|__/__\|__\| <br><br> **Now I am going to ask you some questions about your experiences with the transition from paediatric to adolescent clinic.** | |
| **Theme** | **Topic and Probes** |
| **Transition practices** | In the previous interview, this is how your last day at the pediatric clinic was and this is how you felt about it…… <br><br> • Is this correct? <br> • Is there any additional information you would like to add? <br> • Can you clarify what you meant by …..? (if needed) <br><br> **Now that you have attended the adolescent clinic twice, Think about the first day at the adolescent clinic. Walk me through that day?** <br><br> Probes: <br> **How** was it like, **what** did you do, <br> **How** did you feel on that day? **Why** did you feel that way? <br> What did you **like/dislike** most? |
| Transition perceptions (adolescents) | **In the previous interview, this is how you imagined/thought the adolescent clinic to be like…….and this/these …..is/were what you feared most. Now that you have moved to the adolescent clinic, have those imaginations been met? Do you still have these fears?** <br><br> Probes: <br> What has been **met and not met**? <br> How do you **feel** about it? <br> Have the **fears increased or decreased**? Why? <br><br> **In the previous interview you felt that privacy and having peers in the adolescent clinic are important/not important during your move. Now that you have moved, do you still think the same or have your thoughts changed?** <br><br> Probes: <br> How has it changed? Why? <br> If not changed, why? |

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| | **In the previous interview you preferred receiving care in the pediatric/adolescent clinic. Now that you have attended the adolescent clinic twice, where do you like to receive care?**<br><br>Probes:<br>Why?<br>Can you think of what would have happened to you if you didn't move to the adolescent clinic? |
| Caregivers & other family members | **Now think about your home, parents/caregivers and other family members.**<br><br>**In the previous interviews, this is how you described your home…….. and your interactions with caregivers and other family members.**<br><br>• Is this correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>**Now that you have moved to adolescent clinic, has this interaction changed?**<br><br>Probes:<br>How has it changed?<br>Can you give an example?<br>How do you feel about it? |
| service providers and peers) | **Now think about your friends and other children in the clinic where you receive care.**<br><br>**In the previous interview, these were your friends and this is how you interacted with your friends and peers at the pediatric clinic.**<br><br>• Is this correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Now that you have attended the adolescent clinic twice, tell me about your friends/peer at the adolescent clinic<br><br>Probes<br>How **many** friends?<br>How you **feel about meeting** your peers/friends in the adolescent clinic?<br>What did you together with your friends and other peers at the adolescent clinic? Can you tell me an **example**? |

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| | **Now think about the doctors and nurses at the clinic.**<br><br>**In the previous interview, …. and…were your best nurse and/or doctor due to ……..**<br><br>• Is this correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>**Now that you have moved to the adolescent clinic, tell me a little bit about your best doctor/nurse**<br><br><u>Probes:</u><br>Are they the same doctors/nurses? Why?<br>Are there any **changes** in the way the doctors and nurses treat you now when you compare to when you were in the pediatric clinic?<br>If yes, can you tell me an **example** |
| Medication adherence management | **In the previous interview, these are the steps that you normally take in order to you take your medication.**<br><br>• Is this correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br><br>Have any of these steps changed since you moved to adolescent clinic? How has it changed?<br><br>**Since you moved to adolescent clinic, have you had any situations at home or at school or elsewhere that made you delay or not take your medications?**<br><br>**<u>Probes:</u>**<br>**Can you describe with an example?**<br>How was it like?<br>How did you handle it? |
| **Clinic appointment management** | **In the previous interview, this is what you normally do from waking up in the morning until you reach the clinic……**<br><br>• Is this correct?<br>• Is there any additional information you would like to add?<br>• Can you clarify what you meant by …..? (if needed)<br>• Have any of these changed since you moved to adolescent clinic?<br>• How has it changed? |

| | |
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| | • How do you feel about it?<br><br>**Since you moved to adolescent clinic, have you had any situations at home or at school or elsewhere that made it difficult for you to attend clinic?**<br><br><u>Probes:</u><br>How was it like?<br>How did you handle it?<br><br>**Now that you have moved to the adolescent clinic, what are your views? Do you think that you should be escorted or not escorted to the clinic?**<br><br>Why do you think that way? |
| **Ending questions:**<br><br>How easy or hard was it for you to change from pediatric to adolescent clinic? Why did you find it easy or hard to move from pediatric to adolescent clinic?<br><br>Do you have any questions to ask me or stories you would like to share? | |

**Appendix 8: REFLECTION GUIDE**

(To be completed after every data collection event)

Basic data about the data collection event:
Date:
Location:

Participant type:

Name of data collector(s):

Number of people in a group (focus groups only):

Main themes that emerged

……
……

Information that was confusing or contradictory

……
……

Emergent questions that should be added to the subsequent instrument/event/interview

……
……

What has changed in the participant's responses (adolescents, caregivers& service providers)?

……
……

Issues to be followed up in the subsequent interviews

……
……

Suggestions for improving the data collection event (techniques, questions, etc.)

……
……