Transitioning Of HIV-Infected Children From Pediatric To Adult Care: A Jamaican Case Study

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Transitioning of HIV-infected children from pediatric to adult care: A Jamaican Case Study

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine
and
Master of Health Science

by
Flavia DeSouza
2016
TRANSITIONING OF HIV-INFECTED CHILDREN INTO ADULT CARE: A JAMAICAN CASE STUDY. Flavia De Souza, Teisha Brown, Danya Keene, Russell Pierre, Nancy Kim, and Celia Christie. Section of Child and Adolescent Health, Department of Pediatrics, University Hospital of the West Indies, Kingston, Jamaica. (Sponsored by Elijah Paintsil, Department of Pediatrics, Yale University School of Medicine).

Successful public access to antiretroviral therapy in resource-limited settings (RLS) has resulted in survival of HIV perinatally infected children into adulthood. There are few studies on transition of care in RLS, where 90% of HIV-infected children reside. We aimed to characterize the current landscape of the transfer process of HIV-infected adolescents in one such RLS, Jamaica. We conducted in-depth interviews of 18 HIV-infected adolescents in pediatric care and 21 health care providers. We analyzed the data using the grounded theory approach. Five themes emerged: 1. Pediatric clinics were like families who provided care-taking and developmental support in addition to HIV care. 2. Participants felt the quality of care adolescents received in the pediatric clinic was better than it would be in the adult setting. 3. Given the social significance of pediatrics clinics in participants’ lives, alongside the concerns regarding adult care, there was rootedness in the pediatric clinic. 4. In the face of the national policy of transfer to adult care at 13, some physicians sought to bridge the gap between childhood and adulthood by providing adolescent-centered services. 5. Narratives speak to the transfer as a critical juncture in adolescents’ care and a transition as holistic process. We conclude that a formal process of transition is necessary.
ACKNOWLEDGEMENTS

I dedicate this work to Jamaican adolescents living with HIV and those who care for them.

Thank you for sharing your stories with me.

Your resiliency, dedication and compassion, despite all odds, inspire me to become the best physician I can be.

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TABLE OF CONTENTS

Preface .................................................................................................................................................. 1
Introduction .......................................................................................................................................... 3
  Transition of chronically ill children from pediatric to adult care ................................................. 3
  Transition of HIV-infected children in resource-rich settings ......................................................... 5
  Transition of HIV-infected children in resource-limited settings .................................................... 7
HIV epidemic in Jamaica ..................................................................................................................... 9
Jamaica Pediatric Perinatal and Adolescent HIV/AIDS Program .................................................. 10
Pediatric and adult care for HIV-infected patients in our study sites .......................................... 11
Transfer of HIV-infected adolescents from pediatric to adult care in Jamaica ................................ 13
Statement of purpose ....................................................................................................................... 14
Methods ............................................................................................................................................ 15
  Design ........................................................................................................................................... 15
  Data collection ............................................................................................................................... 16
  Analysis ......................................................................................................................................... 18
  Ethics and role of funding sources ................................................................................................. 20
Results ............................................................................................................................................... 21
  Characteristics of the study sample ............................................................................................... 22
  Determinants and description of transfer in Jamaica ........................................................................ 26
  Attitudes to pediatric care and to adult care ............................................................................... 30
  Attitudes and concerns about transfer from pediatric to adult care ........................................... 42
Discussion .......................................................................................................................................... 66
Epilogue ........................................................................................................................................... 72
Tables
  Categories of Data .......................................................................................................................... 79
    Category 1: Determinants of Transfer
      Table C ..................................................................................................................................... 79
    Category 2: Pediatric and Adult care
      Table D ..................................................................................................................................... 80
      Table E ..................................................................................................................................... 81
      Table F ..................................................................................................................................... 83
      Table G ..................................................................................................................................... 84
    Category 3: Caring for HIV infected adolescents in Jamaica
      Table H ..................................................................................................................................... 85
    Category 4: The transition process
      Table I ..................................................................................................................................... 86
Appendix

Appendix I. Health care provider interview script and guide.........................89
Appendix II. Adolescent interview script and guide........................................93
Appendix III. Memo Examples 1 and 2............................................................97
Appendix IV. Codebook..................................................................................100

Bibliography....................................................................................................104
PREFACE

There is an increased risk of loss to follow up during transition of HIV-infected children from pediatric to adult care. HIV-infected adolescents are at an increased risk of virologic treatment failure and are more likely to transmit HIV. In general, HIV-infected individuals must have ≥ 95% adherence to medication to maintain virologic suppression, to avoid the development of resistant virus. Sustained virologic suppression, reduces the risk of HIV transmission in the community. Hence the transition of care from pediatric to adult services must be optimized to maintain adherence to treatment and retention in care.

In an attempt to reduce the risk of dis-engagement of HIV-infected individuals from the health care system, recommendations from bodies such as the New York State Department of Health and American Academy of Pediatrics, have sought to provide guidance to pediatricians and internists on how to overcome barriers and other challenges to the health care transition of HIV-infected adolescents.

The studies examining the process of transition and recommendations on how to conduct this process are predominantly from resource-rich countries. Yet, the majority of HIV-infected youth come from and live in resource-limited countries, such as Jamaica. To date there are no published studies on the transfer process of HIV-infected patients from pediatric to adult care in Jamaica.

Therefore, we used this study to fill this gap in the literature. We used qualitative methodology to characterize the current landscape of the transfer
process of HIV-infected adolescents in Jamaica. We explored the perspectives HIV-infected adolescents in pediatric care had of the transfer to adult care. We also explored the perspectives and experiences of pediatric and adult care providers with this process. In this thesis we share what we learned about the process of transition in Jamaica and present a platform for future work on transition of HIV-infected adolescents from pediatric to adult care.
INTRODUCTION

Transition of chronically ill children from pediatric to adult care

By the late 1980s, children with once life-threatening illnesses such as sickle cell anemia, cystic fibrosis, and diabetes type 1 were surviving to adulthood because of advances in medical treatment. However, their unexpected longevity meant there was limited infrastructure to support these surviving adolescents’ transfer to adult centered services. For example, adolescents, accustomed to seeing a particular caregiver or group of providers at specified and consistent intervals all their lives, had to move sometimes in a sudden and haphazard way to a new environment, where they were expected to be more autonomous than they had been.\(^\text{1, 2}\)

Furthermore, adult care practitioners had limited experience in managing these surviving chronically ill young adults.\(^\text{3, 4}\) Considering that the pediatric and adult chronic care models were different, both pediatricians and adult care practitioners begun to recognize the need for a framework to support patients and providers in the transfer of chronically ill adolescents to adult care.\(^\text{2}\)

Health care providers developed consensus that a gradual and purposeful transition from pediatric to adult care should occur in order to maximize functionality and well-being of these young people.\(^\text{5}\) Recommended transition guidelines with components such as the preparation of the adolescent for the transition, and required pediatric and adult provider training on knowledge and skills needed to provide transition services, were published to help ensure adherence to treatment, high quality care, as well as to maximize life-long functioning and potential of the adolescent. \(^\text{1, 6, 7}\)
Subsequently, there have been several studies and reviews of the process and tenants of health care transition from pediatric to adult care services. In 2014 Fegran et al. published a qualitative metasynthesis of adolescents’ and young adults’ transition experiences from North America, Europe, and Australia. The review showed preparation for transfer involves a loosening of the close relationships developed in the pediatric setting and recommended transfer timing to be dependent on adolescent maturity. Transition has been recommended to be a deliberate process which should consider the adolescent’s practical and psychosocial needs.

Despite the development of transition guidelines and programs, the process of transition continues to pose a challenge to health care professionals, patients, and their families. Scal et al surveyed the types of transition programs existing in the US and argued that barriers to transition included limitations of the health care system, such as inadequate provider training on transition health issues. This includes training on how to facilitate a transition as well as adult provider competency in managing chronically ill adolescents who have transitioned into adult care. In addition to systematic issues, there are social and emotional factors with hinder the transition process. For example, the attachment that exists between the pediatric patient and the pediatrician or adolescent care provider continues to make the transition to adult care challenging. Moreover, chronically ill adolescents face additional challenges which may complicate the adolescent phase.

Additionally, existing transition programs remain underutilized. In 2005, Scal et al assessed the factors associated with addressing the transition from
pediatric to adult care in a first national survey of children with special health care needs.(16) The authors noted few youths received health care transition services, about half of the households interviewed had any transition related discussion and only about 30% discussed how the adolescents’ health care would change upon moving to adult care.

**Transition of HIV-infected children in resource-rich settings**

Transitioning children with special health care needs has been discussed and studied, with transition programs being implemented to varying degrees of success since the late 1980s. However, the success of antiretroviral treatments (ARTs) has made the issue of the health care transition specific to youth with HIV a relatively new area of concern.(17, 18) Perinatally infected adolescents are surviving childhood and adolescence and becoming adults.(19) Furthermore, the incidence of horizontally infected adolescents is climbing, mirroring the increased prevalence of perinatally infected youth.(20) Therefore there are growths in both the populations of perinatally and horizontally infected youth who will be transitioning to adult care.(4)

Several studies have examined various aspects of the process of transition for these youth.(4, 17, 20-39) In their review of the literature, Hussen et al show most studies on the process of transition for HIV-infected adolescents have been qualitative in nature. They categorized the studies as pre-transition barriers and concerns, provider practices during the transition, and retrospective analyses of the process of transition.(40)
Authors have found that HIV-infected youth and youth chronically ill from other causes share similar transition barriers. These challenges include difficulties with the loss of the long-term relationships patients developed with their pediatric clinicians, lack of preparedness for the transition, poor communication and lack of coordination between pediatric and adult providers, and loss to follow up after transfer to adult care. For example, in their study, “Clinical outcomes of adolescents and young adults in HIV care,” Ryscavage compared the outcomes of perinatally and horizontally HIV infected adolescents aged 17 to 24 years to matched HIV infected adults in an adult clinic and showed that adolescents had lower rates of virologic suppression and increased loss to follow up when compared with the adults.(41)

Authors also discuss the unique transitioning challenges HIV infected adolescents face; difficulties that ought to be considered when developing transition protocol specific to that population. For youth living with HIV/AIDS, stigma and disclosure, medication adherence, sexual and reproductive concerns, poor socioeconomic conditions, mental health, and sequelae of HIV infection such as neurocognitive delay, or long-term medication use, are some key issues to be addressed before, during and after the transfer to adult care.(4, 20, 24, 35, 38)

Gaps in the literature include the lack of longitudinal prospective studies assessing the transition process.(40) Furthermore, Persson et al contends the literature needs to address how best to support providers through the transition process.(33)

Several transition strategies, programs, and recommendations for youth with HIV exist.(4, 20, 29) They cite the usage of readiness scales to assess preparedness,
and a coordinated transition approach involving pediatric and adult staff beginning in early adolescence and continuing well after the transfer has taken place. For example, Maturo et al outlined the “Movin’ Out” protocol (29) for behaviorally infected adolescents in a United States urban, university-based, multidisciplinary clinic. “Movin’ Out” uses a five phase approach that is begun in the adolescent’s early twenties and follows the adolescent from the pediatric or adolescent clinic through one year into adult care. A policy statement from the American Academy of Pediatrics recommends the development of a formal transition process, which includes an early introduction to the concept of transition, an individualized transition plan which addresses the adolescent’s social service, health care, and vocational needs, and a formal evaluation of outcome of the transition process for youth with HIV.(38) The New York State Department of Health (NYSDOH) recommends a three-year process of transition. NYSDOH states providers should develop a plan in collaboration with the patient and patient caregiver and transitioning patients should meet their new adult care providers well in advance of the transfer to adult care.(42)

**Transition of HIV-infected children in resource-limited settings**

To date, the transition for adolescents with HIV has been studied mainly in resource-rich countries. There are a limited number of studies from resource-limited countries on the transition from pediatric to adult care for HIV infected children and adolescents.(43, 44) Yet, the greatest prevalence of HIV is in resource-limited areas, first in sub-Saharan Africa and then the Caribbean. UNAIDs reports
there are approximately 37 million people living with HIV worldwide. About 25.8 million of that number live in Sub-Saharan African and 280,000 in the Caribbean. (45) As compared to resource-rich nations, countries within these areas have had an even more recent, steady increase in the population of perinatally infected adolescents who will soon need adult health care services. (4, 46, 47)

The comprehensive technical brief on “Transitioning of Care and Other Services for Adolescents Living with HIV in sub-Saharan Africa” indicated that context and culture must be considered when developing and implementing processes of transitioning to self-management. (44) For example, they asserted secrecy and cultural taboos around HIV, sex, and sexuality are diverse and vary from one cultural context to another. Furthermore, social services and financial support systems may be more limited than in resource rich countries and, therefore compound the challenges HIV-infected adolescents in resource-poor countries experience. Transition programs ought to consider to these unique challenges these adolescents, and their caregivers face.

Sharer et al highlighted adolescent centered programs existing in sub-Saharan Africa and the roles these programs play in assisting with the transition from pediatric to adult care. (44) They focus on training their staff and equipping their adolescents with life skills. The Botswana Baylor Children’s Clinical Centre of Excellence serves over 600 HIV-infected adolescents. They strengthen staff capacity to serve adolescents by conducting bi-monthly multidisciplinary adolescent forums to discuss their most challenging adolescent cases. Moreover, the Zvandiri
Programme in Zimbabwe provides life skills training, vocational training, counseling and adherence support to their HIV-infected adolescents. (44)

However, with the differences in access to comprehensive health, health seeking behaviors, and cultural practices, existing transition processes or guidelines from resource-rich countries or even from sub-Saharan Africa may not be completely applicable to the Caribbean setting. Furthermore, experiences of transition in the Caribbean may be different from those from resource-rich countries and other resource-limited countries. It is therefore crucial to conduct research among adolescents, young adults, and their caregivers in the Caribbean to understand linkage and retention to care in order to facilitate a successful transition process to maintain virologic suppression and to ensure that these individuals get the full benefit of antiretroviral therapy. (4, 48) There are no studies published to date, examining the process of transfer for HIV infected adolescents from pediatric to adult care in Jamaica. We therefore sought to study the transition process in Jamaica.

**HIV epidemic in Jamaica**

Jamaica, measuring 10,991 square kilometers, is the largest English-speaking island in the Caribbean. It has a population of approximately 2.7 million persons and a total HIV prevalence of about 1.8% (30,265). Most of the persons living with HIV reside in and around two largest urban centers; the Southeast city of Kingston and the Northwest city of Montego Bay. Approximately 0.02% (499) of the national population are children aged zero to 13 living with HIV. (49)
Jamaica Pediatric Perinatal and Adolescent HIV/AIDS Program

The Jamaica Pediatric, Perinatal and Adolescent HIV/AIDS program (JaPPAIDS) was launched in 2002. (50) This program provides HIV testing, management of opportunistic infections, and continuing care for HIV-infected children. In its first year there were 110 infected children enrolled from the capital Kingston, and two surrounding parishes, St. Andrew and St. Catherine. At the time the mean age at enrolment was 6 years old, with an age range of 0.9 years to 17.5 years. ART became freely available to HIV-infected individuals by 2005. Through JaPPAIDs, improved surveillance as well improved access to and uptake of ARTs has and continues to increase the survival of perinatally-infected children into adulthood in Jamaica. (51, 52) As of the end of December 2014 there were 303 children in care in the Kingston, St. Andrew and St. Catherine sites, with 170 of them being adolescents and young adults aged 13 to 24 years. Now there are 12 JaPPAIDs treatment sites that offer treatment and care to HIV exposed infants, and 501 HIV-infected infants and children and adolescents islandwide. (See Figure 1 for Treatment sites for HIV-infected youth in Jamaica).
Figure 1: Treatment sites for HIV-infected youth in Jamaica

Pediatric and adult care for HIV-infected patients in our study sites

In the Jamaican public sector, following national policy, children are transferred into adult care at age 13. However, only four of the 12 pediatric treatment sites transfer adolescents at 13 years of age. The other sites wait until the children are older, some instances up to the age of 25 years old. Therefore, the transfer to adult care varies from site to site.

At the University Hospital of the West Indies (UHWI), based on hospital policy, children are kept in pediatric care in the inpatient and outpatient setting until the age of 15 years. The Pediatric Infectious Disease (PID) clinic at the UHWI is one of three sites in the Kingston and St. Andrew area that treat HIV-infected children. Based on clinic policy children are seen up to age 24. As of December 2015, the PID clinic patient load included 144 HIV-infected patients from 0 – 24
years, cared for by two supervising professors and 5 rotating pediatricians. UHWI also houses a fee for service clinic for chronically ill adolescents ages 13 to 21. If the adolescent cannot afford to pay the fee, then the charges are waived. It is run by a pediatrician not affiliated with the PID clinic. She is supported by two rotating pediatrics residents. This is the only formal adolescent clinic for chronically ill adolescents in the island. There is also a Centre for HIV/AIDS research, education and services (CHARRES) which sees approximately 1800 HIV-infected adults as of January 2016. Two physicians care for these patients, one rotating resident and a consultant from the department of medicine who supervises the resident.

Bustamante Hospital for Children (BHC) is the largest pediatric hospital in the English Speaking Caribbean. As a public children's hospital it has a strict cut-off and treats children up to age 13 years. At BHC one pediatrician is assigned to care for approximately 60 HIV-infected children as of December 2015.

Comprehensive Health Clinic is the largest sexually transmitted infections (STI) treatment center in Kingston and St. Andrew and located in a community with one of the highest rates of violent crime in Jamaica. The STI section 3 is one of five clinic sections at Comprehensive. As of January 2016 approximately 4000 HIV-infected patients attend this section of the clinic. One pediatrician cares for about 60 of these patients. Two internists staff each clinic date and take care of the remainder, the HIV-infected adults. Those two internists also see patients with other STIs.

In addition to interviewing providers who worked at PID, CHARRES, BHC and Comprehensive, we also interviewed providers working in the clinics affiliated with
the public hospitals in the parishes of St. Catherine and in Clarendon. The pediatric clinic is situated in the St. Catherine Hospital and is staffed by two physicians who serve 32 HIV-infected children and adolescents. They also care for 108 HIV exposed babies. While two physicians serve approximately 2500 adult patients at the affiliated adult clinic, the St. Jago Park Health Centre. In Clarendon, the public hospital is located in the capital May Pen. The May Pen Hospital Pediatric Special Clinic serves 28 infected children and adolescents. Four physicians, including a supervising pediatric consultant, staff the clinic.

**Transfer of HIV-infected adolescents from pediatric to adult care in Jamaica**

There is one published study on any aspect of the transfer of HIV-infected adolescents from pediatric to adult care in Jamaica. In 2014 Dr. Evans-Gilbert, a pediatrician serving HIV-infected children and adolescents in Montego Bay, investigated the outcomes of patients who transferred to adult care at 13 years as compared to those who remained in pediatric care.(55) That study revealed significantly higher rates of HIV viral suppression in adolescents who remained in pediatric care as compared to adolescents who were transferred to adult care. Their study suggested that adult care was not adequately meeting the needs of patients who transferred. Results of this study also suggested a need for more research on the differences between the pediatric and adult clinics and the process of transfer in Jamaica. In our study, we explore the perspectives and experiences of HIV-infected adolescents and their providers of the process of transfer to better understand the process as well as the challenges of transfer in the Jamaican context.
STATEMENT OF PURPOSE

The aim of this study was to characterize the current landscape of the transfer process of HIV-infected adolescents from the perspectives of both the adolescents and providers in Jamaica.
METHODS

Study Design

We used the qualitative method to explore issues surrounding the transfer of HIV-infected youth from pediatric to adult care. (56-59) Our objectives were to: 1. Explore the perspectives HIV-infected adolescents have of the transfer to adult care; and 2. Explore the perspectives and experiences of providers with the process of transfer. We obtained written and verbal consent from all participants. We gave interested adolescents and their guardians, if the adolescent was under 18 years old, the consent forms to review privately. If they consented to being a part of the study, the interviewer reviewed it a second time with the adolescent and his or her guardian. If both parties consented a second time, the interviewer reviewed the consent form a third time alone with the adolescent. Verbal consent was audio-recorded at the beginning of all the interviews. The same process was completed for the providers who decided to participate in this study.

On the basis of principles of grounded qualitative research we aimed to generate concepts and themes from the data instead of testing pre-specified hypotheses. (60) We used the techniques of purposeful and theoretical sampling to recruit an information rich sample of adolescents. (61) In purposeful sampling individuals who are knowledgeable about or have experience with the topic of interest are chosen. In theoretical sampling, sampling is guided by the objective of developing theory or explanation. For example, analysts collect and analyze data which then guides further data collection. In our study, method of infection, length of time in the pediatric clinic, and experience with adult care services may be factors
which affect the process of transfer and, therefore were chosen as sampling categories for HIV-infected adolescents. Inclusion criteria were: 1. Complete disclosure of HIV status 2. No diagnosis of substantial cognitive limitation or developmental delay 3. Patients between the ages of 13 and 24 being cared for at the pediatric clinic. Eligible adolescents were invited to participate by their health care providers via telephone or when they attended their appointments at the clinic. Providers who cared for HIV-infected patients in the pediatric and adult setting were invited to participate. Eligible providers were recruited in the clinic, over the phone or via email. In addition to purposeful and theoretical sampling, the qualitative technique of snowball sampling was used to recruit additional healthcare providers. We asked providers at the end of each interview to provide the names of other providers who met study criteria and were considered to be information rich, and subsequently invited those named providers to participate in the study. We interviewed patients and providers until thematic saturation was achieved.(62)

**Data Collection**

*Interview guide*

The first author developed a semi-structured script to meet the study objectives. The guide was then modified using input from the research team. The guide included a list of core questions to be explored: introductory demographic questions regarding the respondent’s background, followed by open-ended questions regarding their knowledge, perceptions, and experiences of the transfer process. There were suggested probes for each section. Interviews included the
following broad questions for the adolescent patients: (1) Tell me a little bit about yourself (2) Tell me about the clinic you attend now (3) Tell me about the transfer process to the adult clinic. (4) What do you know about the adult clinic? (5) How do you feel about going to the adult clinic? (See Appendix I for final standard adolescent interview guide). Interviews included the following broad questions for the providers: (1) Tell me about the transfer process from the child clinic to the adult clinic (2) Tell me about your experience with patient transfer from pediatric to adult care. (See Appendix II for final standard provider interview guide). As is typical for qualitative research, we modified questions as the study evolved and as important relationships and directions emerged from the ongoing analysis.

**Interviews**

The first author conducted 39 in-person, in-depth, semi-structured interviews, between February 2015 and August 2015. This researcher had no affiliation with the clinics but was native to Jamaica and fluent in the dialect. Interviews consisted of the interviewer and a single participant. The interviewer conducted interviews in a private room away from exam areas but within the clinic. The average length of the interview was 61.02 minutes (range, 24.67 – 130.18 mins) for the providers and 36.31 minutes (range, 15.28 – 60 mins) for the adolescent patients. Following each interview, participants received the equivalent of US$8.50 for transportation expenses to and from the interview site as well as to compensate them for their time.
During the interviews, the interviewer used probes to encourage participants to clarify and elaborate on their statements. As necessary, the interviewer diverged from the guide to explore emerging ideas in more detail.

All interviews except one were audio-recorded. The interviewer wrote notes during that interview, then immediately following the interview, organized and analyzed the interview notes. Independent local transcriptionists transcribed verbatim all audio-recorded interviews. The interviewer reviewed the transcriptions to ensure accuracy. We used the audio-recorded interviews and the transcripts to reflect on and improve the open-ended interviewing style. Interviews were conducted until no new ideas emerged from transcript analysis, that is, to the point of thematic saturation.

**Analysis**

We used the qualitative analysis software (ATLAS.ti 7.0, Scientific Software Development, Berlin, Germany) to facilitate data organization and retrieval. Using the constant comparative analytic technique, emerging codes, categories, and themes in each transcript were checked iteratively against all other interview transcripts and examined for overall trends throughout and after the interview period until analysis was complete.(63)

The first phase of data analysis involved reviewing transcripts and generating codes. A code is the building block of thematic analysis and is a label, a word, or a brief phrase, which classifies a particular part of the data that might be useful.(64) After the first three interviews were completed and transcribed, the
interviewer and second local analyst, familiar with the health care system and with experience in qualitative research began coding the transcripts and created a list of codes. As the interviewer continued conducting interviews and both the interviewer and a second local analyst continued to review the data. More codes were generated, and existing codes were refined until theoretical saturation was reached and they were in agreement on the coding schema. They assigned these final codes based on the research focus. (See Appendix III for codebook). They re-coded previously reviewed transcripts and coded all new transcripts independently. Throughout the process, the analysts wrote conceptual memos to record and explore ideas and to expand on the codes. (See Appendix IV for conceptual memos) They also met multiple times to discuss the coded transcripts and their memos.

The analysts collated codes and through the continuing iterative process, clustered codes into categories with the aim to capture ideas present in the data. Subsequently, the analysts generated themes. Themes are central organizing concepts which represent a patterned response and are a way to organize meaningful data in relation to the research question.(65) These analysts worked under the supervision of a local Jamaican qualitative researcher, as well as a qualitative researcher affiliated with the Yale School of Public Health. Both those supervisors provided general feedback and guidance. They also collaborated with a third researcher who reviewed, and coded, then generated categories and themes in an iterative fashion from a subset of the transcripts.
Ethics and Role of the funding sources

The research protocol was approved by the Human Investigation Committee of the Yale University School of Medicine, New Haven, CT and the Faculty of Medical Sciences Ethics Committee of the University Hospital of the West Indies, University of the West Indies, Mona Jamaica. The study was funded by the Doris Duke International Clinical Research Fellowship awarded to the first author. The funding sources have no role in the design, analysis, or reporting of the study.
RESULTS

We have divided the results into four sections. Section one describes the characteristics of the study participants. Section two elucidates the timing, the process, and the determinants of transfer for HIV-infected adolescents from pediatric to adult care in Jamaica. In section three, we utilize themes to illustrate attitudes and concerns held by adolescents and providers about pediatric and adult care. In section four, we describe attitudes and concerns held by adolescents and providers about the transfer of HIV-infected adolescents from pediatric to adult care in Jamaica.

We found that adolescents were rooted in their clinics, which were like families. Pediatric clinics provided caretaking and developmental support in addition to HIV care. Both adolescent patients and providers had negative perceptions of adult care services. Given the social significance of pediatrics clinics in the participants’ lives, alongside the negative perceptions of adult centered care, there was apprehension about transfer to the adult clinic. Participants also described adolescence as a challenging phase of life. This is complicated by the biological and psychosocial sequelae of being HIV-infected as well as the lack of national structures and services for chronically ill adolescents in Jamaica.

Throughout provider interviews, a distinction was made between transfer and transition.

Throughout the results section we used participants’ verbatim quotations to illustrate each point. Provider designations are from P1 to P21, each representing a provider. Quotations from the adolescents are likewise labelled with the letter A
and then a number, and go from A1 to A18 since 18 adolescents were interviewed. These designations have been italicized and in parentheses. They follow immediately after each verbatim quotation. We also used pseudonyms to replace participant and clinic names in order to maintain participant confidentiality.

**Section 1: Characteristics of the study sample**

Adolescents ranged from 13 to 24 years old, and had not yet transferred to adult care. All adolescents interviewed were aware of their HIV status. Adolescents were all from one setting, at the Pediatric Infectious Disease (PID) clinic at UHWI and on average had been there for 12 years. However, many of the adolescents had familiarity with other clinic settings. For example, some of the adolescents enrolled in the study had experiences in the adult setting. One adolescent participant had received care in the adult outpatient clinic and was subsequently transferred from the adult clinic to the pediatric clinic at UHWI. Others had accompanied their HIV-infected parents to their appointments in the adult clinic. Several of the participants had been admitted to or sought treatment for illness at an inpatient adult ward. Other adolescents were familiar with pediatric settings outside of the site of the study. Some had been transferred from an outpatient pediatric clinic to the one at UHWI, for example from BHC to PID. (See Table 1) Most invited adolescents chose to participate. Only one of the 18 adolescents who participated in the study did not consent to being audio recorded.
Table A: Characteristics of Adolescents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (total)</td>
<td>14 (18)</td>
</tr>
<tr>
<td>Median Age (range) y</td>
<td>(13 years – 23 years 7 months) 18 years and 8.5 months</td>
</tr>
<tr>
<td>Median years in UHWI pediatric clinic (range) y</td>
<td>(1 year 1 month - 16 years 9 months) 12 years 7.5 months</td>
</tr>
<tr>
<td>Method of infection</td>
<td></td>
</tr>
<tr>
<td>Perinatal</td>
<td>11</td>
</tr>
<tr>
<td>Intercourse (forced or consensual)</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
</tr>
<tr>
<td>CDC Clinical Data</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>2</td>
</tr>
<tr>
<td>B</td>
<td>5</td>
</tr>
<tr>
<td>C</td>
<td>11</td>
</tr>
<tr>
<td>ARVs</td>
<td></td>
</tr>
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<td>Trade/Skills school (only) all</td>
<td>(5) 8</td>
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<td>Remedial school at government state home only</td>
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| Living circumstances                          |       |
| Independent                                   | 1     |
| With biological relatives                    | 10    |
| With non-biological guardian                 | 1     |
| With partner                                  | 3     |
| With friend                                   | 1     |
| State Care                                    | 2     |

All invited providers agreed to participate in the study. Providers represented a range of health care professionals. They included pediatricians, internists, nurses, social workers, adherence counselors and a psychologist. They came from a variety of practice settings. Two of the practice settings were at the UHWI, the Pediatrics Infectious Disease (PID) Clinic and the Centre for HIV/AIDS research, education and services (CHARES). The other providers were affiliated with public Ministry of Health clinics nationwide. These clinics included the Bustamante Hospital for Children, Comprehensive Health Centre, the May Pen Hospital, the Spanish Town Hospital and St. Jago Health Centre. Providers had, on average, over 8 years experience working with HIV infected patients. (See Table 2)
Table B. Characteristics of Providers

<table>
<thead>
<tr>
<th>Characteristic</th>
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<tr>
<td>Median years of service in HIV in Jamaica (range) y</td>
<td>8(2.5 – 23)</td>
</tr>
<tr>
<td>Median number of clinics served (range) y</td>
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<tr>
<td>Women (Total)</td>
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<td><strong>Type of health care professional</strong></td>
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<td><strong>Primary Work Setting</strong></td>
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<td>University Hospital Based Practise</td>
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Section 2: Determinants and description of transfer in Jamaica

National regulations provide a framework for the transfer process of pediatric patients to adult care: “pediatric care stops at 12”

In the Jamaican public sector children are transferred to adult care at age 12. One provider noted “as it currently stands, once you hit twelve for the most part in the public system you’re transferred to an adult facility.” (P7) Another provider elaborated, “whatever the illness because the way how Jamaica is set up is that pediatric care really stops at 12.” (P6)

Description of the process of transfer: “a referral letter and send them to the clinic”

Providers discuss the transfer with the patient and/or the patient’s caregiver, write a referral letter and send the adolescent to adult care at or around the age of 13 years. The topics covered and the length of time over which the conversation about transfer occurs varies from clinic to clinic. At some clinics the conversation is limited and brief. Several providers echoed the statement the transfer “is...a referral letter and send them to the clinic.” (P9) At one site, “normally when we are transferring someone from our clinic what we’ll do is...do a referral...we call the clinics we are going to transfer them to tell them that we actually see them on the day, and that within three month’s time they would need to do their follow-up visit and so forth...we would get the date and give the persons the date along with the referral...and direct them to where they are to go.” (P5) At other sites, the conversation about transfer is lengthy. A provider noted, "we begin the discussion
by saying, they are getting older and you’ll soon have to go to the adults... and we just broach it in a serial manner, so that they are prepared on several visits to know that the time is coming up." (P12)

**Age of transfer “not written in stone”**

Even though it is stipulated that children in the Jamaican public sector are to be transferred to adult care at the age of 12 years, the age of transfer from pediatric to adult care for HIV-infected patients in the outpatient setting tends to be flexible, greater than 12 years, and differs from clinic to clinic. One provider said “it’s (the transfer age) not written in stone...there is some latitude there." (P12)

Age of transfer seemed to be dependent on the clinic cut-off age. Another provider indicated that “our age is much higher than say a government public health HIV clinic where their cut-off for pediatric is twelve." (P9) A pediatric provider remarked, “At Site 1 generally I think they are kinda using the cut off age of 16, so everybody who is newly diagnosed at 16 or under they send to me but the ones newly diagnosed at 17 to in their 20’s generally are just seen there.” (P6) While another said “I have some 18 year olds, I’m not sure if there are plans to send them younger than 18.” (P3) Another pediatric provider noted, “We’ll see them up to about 22 years." (P10) A provider observed “They keep their vertically-transmitted patients almost indefinitely within their clinic.” (P9) Hence, there was variation in the age of transfer from one clinic to the next.
Adolescent readiness for the adult clinic determine timing of transfer to adult care

A few providers indicated that the age of transfer is dependent on the adolescent readiness for the adult clinic. For example, one clinic provider expressed, “we basically keep the adolescents until they are basically ready enough to leave or they express the desire to want to go the adult clinic.” (P16) Another provider elaborated that adolescent readiness or maturity is not solely dependent on age because of differences in the rate of development. She said, “12 to 15 is different from the 16 to 22… somebody who is 16 might be quite okay with going to the adult whereas somebody, who is 22 might still want to cling to, so it’s not just a matter of age it’s also like where the person is and probably trying to find that match.” (P20)

According to the providers, one indication of adolescent readiness is his/her ability to manage his/her own health. This includes the ability to keep appointments and fill prescriptions on one’s own. “We don’t really transfer them until they are about 24, 25…not that they want to keep them, because keeping them kind of just increases our load, but we thought it was pertinent to help them to develop…health literacy skill, because at that point in time they are more or less managing their own, and if you can help them to manage that part of their health like coming to clinic, filling their own prescription, while you doing everything else, working, going to school, whatever then that’s something that we can give them, so that when they go to an adult clinic where they might not necessarily have somebody to following them up peck, peck, peck and asking them all of the
questions that we necessarily ask them, then they can manage." (P17)

Adolescent medical circumstances determine timing of transfer to adult care

Transfer is not solely dependent on adolescent readiness, but also on the adolescent’s medical circumstances. For example, pregnant adolescents who are infected with HIV have to be transferred to the adult setting for treatment and care. “Patients are transferred to adult care when they become pregnant.” (P2) These adolescents may return to the pediatric clinic for follow up and care. The provider continued, “they would be transferred back to us, after they have had their baby. So now mom and baby would be in our care.” (P2) On the other hand, adolescents may remain in adult care after delivering their child. “A child...went to Site 7 for the course of the pregnancy and then after the pregnancy ended up joining the adult clinic rather than coming back to pediatrics.” (P6)

Unanticipated transfers of HIV-infected patients from pediatric to adult care

However, not all transfers are planned. Some adolescent patients end up in adult care after an admission to the adult inpatient unit. One provider explains, “So we’ve had patients who like for one reason or another they were coming to the pediatric section and at some point they may have had an acute illness turned up on a different day of the week than pediatric clinic and then ended up starting to go to the adult clinic so it wasn't a formal transfer....we have had people who have basically inadvertently transferred out of the system rather than formally transferred....so they didn't even have the time to anticipate being transferred
because they were simply transferred after an admission. (P6)

Section 2 summary

Transfer of HIV infected adolescents from pediatric to adult care depends on a number of variables. These include, national policy, clinic policy, adolescent readiness and adolescent medical circumstance. In addition, some transfers occur inadvertently. A provider summarized, “I don’t think that they (pediatric clinics and providers) have a set definition for when they make the transfer or not, I think they do it based on what’s happening with the specific case at the time.” (P9)

Section 3: Attitudes to pediatric care and to adult care

Theme 1: Pediatric clinic as family

Participants perceived the pediatric clinic to be like a home and the pediatric providers and their adolescent patients to be like a family. Health care providers were seen as parents, caregivers, best friends and confidants for the HIV-infected adolescents who were their children. Therefore, in addition to medical care, providers provided social and emotional support to their adolescent patients.

Adolescents

Adolescent patients described their clinicians as second parents, for example using a phrase like “mother and father” (A15) to describe the nurses and physicians on site. Adolescents shared, “Nurse Ruth...she is like my nedda (next/second) mommy.” (A4) They perceived their providers felt the same level of connectedness
saying for example, “Dr. Eve...call me one of her little babies.” (A8)

On average, adolescent patients had been in the pediatric clinic for 12 years. Adolescents had a long history receiving treatment and care from their pediatric providers so they believed their pediatric providers knew their medical history well and could treat them when they became ill. One adolescent phrased it this way; “Nurse Ruth and Nurse Sophia because I was used to them from I was a little girl and so forth and they were the ones who mostly treat me and ensure that...I’m on the right track.” (A12)

Furthermore, pediatric providers cared for these adolescents through their most significant physical and mental health challenges. As such some adolescents considered their pediatric providers to be their family, closest friends, and confidants. Adolescents' shared “they are like family at those times, best friends I ever had” and “dem (they) feel like my personal counselors.” (A10)

This care and provision was more than for the adolescents' health. Providers celebrated the personal successes and achievements of their adolescent patients; “they treat you like actual family. A big family here... they have graduation pictures of some persons...it’s the whole works.” (A8)

The familial atmosphere was enhanced by the friendliness of the clinical staff in the pediatric clinic. Adolescents commented on how easy it was to get along with their providers and how kind their providers were to them saying, “Yuh in di docta room now and docta a gi yuh bare joke,... and if yuh behave yuhselv or if dem a duh blood test and some a dem might bawl, fi di day and like you come and doan bawl and yuh jus duh your own yuh might get sweetie or something.” (A4) (When you are
in the doctor’s room, they make jokes, and if you behave yourself or if they do the blood test, and some of the children might cry, and if you don’t cry you might get a sweetie or something).

Some adolescents suggested this amiable treatment is what distinguishes the PID clinic from other clinics they have attended. Adolescent 12 said, "Nurse Ruth and Nurse Sophia has been very fair and kind, because from I was little I came here and they used to like give me things and so forth, I used to get things and I like this clinic because it’s not like other clinic where you go to doctors where you don’t know and so forth I know and I’m used to Nurse Sophia."(A12)

Regardless of the support they received in the clinic, adolescents described feeling isolated because of their illness. For example, one adolescent who lost both her parents and a sibling to HIV shared, “last night I was feeling very lonely, I was just like crying, crying so sometimes it can be very stressful, when you found out that there is no one around you to really care for you the way you want to be or to love you for who you are."(A18) Moreover, adolescents believed that in the face of stigma associated with HIV they should not or could not disclose their status to others. “I was told not to tell nobody because now people could be very scornful and so forth."(A12) One adolescent posed this inability to disclose as a rhetorical question; “So do you expect me to go and tell people on the road and you know how Jamaican people are?...You have some people out there that just don’t know anything, they are foolish. So some people just, will just start moving differently. You were living so good for five years and then they find out, they say, no way, that boy that we used to be so close to, no way."(A10) Another adolescent echoed that
Jamaicans openly talk about and stigmatize those who they think might be HIV infected. She said, “me live inna di ghetto suh dem more gwaanie gwaanie like dem betta dan di sickness suh, me nah guh tell dem dat...dem nah guh waan talk to somebody who have da sickness deh... as dem hear nuthin everybody start talk and dem watch an si.” *(A17)*  (I live in the ghetto where they act like they are better than the sickness. So I am not going to disclose my status, they are not going to want to talk to someone who has the sickness. As soon as they hear that someone has the sickness, everyone in the community starts to talk about that person and they watch and see).

This isolation was juxtaposed against the sense of security and belonging some adolescents felt by being a part of the clinic where others were like them. One adolescent who had HIV negative siblings at home shared, “Only bredda and sista mi woulda feel seh mi have a dem who come a di clinic along with me...” *(A6)*  (The only brother and sister I would feel like I have are those adolescents who attend the clinic). She explained, “Well the experience here has been fun because...everybody here understand me so when mi come here mi nuh feel incomplete or mi nuh misplaced or anything... So when mi deh here mi nuh feel different or nutn mi just feel complete.” *(A6)*  (Well the experience here has been fun because everyone here understands me so when I come here I don’t feel incomplete or out of place or anything. When I am here I don’t feel different, I just feel complete). Therefore, this feeling of family extended beyond the relationships the adolescents had with the providers, to the secure clinic atmosphere and to the other patients in the clinic.
Providers

Providers echoed similar sentiments, perceiving the pediatric clinic to be like family and their adolescent patients to be like their children. Providers worked hard to develop a “family” – a strong rapport with their patients and made themselves available when their patients needed them. Provider 10 stated, “When they are with us...I think they have a sense of a family sense, because of how we deal with them, is like everybody know you and you know everybody...I don’t just see a client and go through...the paper works...(I) ask them how is their family,...how is school, are you going to school...we try to get a little bit personal with them just so that they can be comfortable with us. We try to be patient with them also.” (P10)

Providers wanted their patients to know they could rely on their health care providers even after adolescents left their clinical home. Providers wanted to give the patients the support they needed even after moving out so adolescents could maximize their function and potential. “If they have any other concerns they will either call or they will come and if we can help them we help them...it’s kinda like family, you know...we have that kind of a rapport, that push come, to shove if they need help, they come...you really want to see your children shine and live.” (P17)

In direct comparison to the adult clinic, one pediatric provider shared “our (pediatric) clinic...it’s more like a family situation,...they feel more comfortable, more open. They feel more that somebody is there for them, maybe because it’s smaller, I don’t know, but they feel more comfortable in the pediatric clinic than the adult situation.” (P19)
Theme 2: Adult care: "No more molly coddle"

Whether or not they had experience in the adult setting, adolescents felt the adult clinic would not have the family feel of the pediatric clinic. Unlike the pediatric clinic, it would be a stern environment where patients would have to fend for themselves. Congruent with the findings in the adolescent interviews, providers felt that adolescents were molly coddled in the pediatric setting. There would be "no more molly coddle" (P4) after they were transferred to adult care.

Adolescents

Negative perceptions of the adult clinic

Adolescents expected less warmth and friendliness than they experienced in the pediatric clinic. One adolescent who had experience in the adult setting stated, "The adult clinic, the overall site, is... so distant you just come, you do what you doing, you leave. Round here (pediatric clinic), it's not like that. Is like, round there (adult clinic) they don't even seem to make little conversations. Is like you just come, they examine you, ask you any problems, give you, your prescription and that's it. There's no conversation and anything...people need to be a bit friendly like, make some conversations than just sit down and look at people." (A8)

Two adolescents who had no prior experience in the adult setting felt they may not be treated as nicely as they were treated in the pediatric clinic. They confided "mi nuh really know nothing bout adult clinic stuff, but dem might a nuh treat yuh like how di pediatrician treat yuh." (A4) (I don't really know anything
about adult clinic stuff but they might not treat you the way the pediatricians treat you).

They anticipated adult care providers would provide less medical attention than providers in pediatric care stating, “Adult Clinic will be like hmmm what it would be like? Rougher, mi nah get dem nice treatment whe yuh get a Paediatric Clinic, some a dem not even really care.” (A4) (Adult clinic, what would it be like? Rougher, I am not going to get the nice treatment I get in the pediatric clinic, some of them don’t even care). Other patients continued this train of thought, “Especially fi di people who a sick, some, when yuh guh places doctor nah look pon yuh, yuh coulda sick till Jesus Christ come. Nuh docta nah look pon yuh.” (A16) (Especially for those who are sick, the doctor is not going to attend to you, even if you are sick to the point to death).

One adolescent remarked the adult clinic environment might even be harmful. He said, “There are many, many teenager who are like probably fretting that if they go to the clinic they probably like inject something that not suppose to be gone into them or so.” (A12)

Adolescents associated the adult clinic with sickness and death and the pediatric clinic with vibrancy and life. For example when describing the adult clinic one adolescent said, “Those older people down there, look like they let themselves get way out a control. Everybody looks dead, seriously. You find people with gross looking stuff on their face, gross looking stuff on their foot, everybody just walking around limping, that’s very depressing.” (A1) And about the pediatric clinic she said, “You have girls and males that come to this clinic specially, they are good to socialize
with none of them alienate thereselect, everybody talk, everybody socialize, everybody smiles.”(A1)

Furthermore, the privacy of the pediatric clinic was juxtaposed against the crowdedness of the adult clinic. This crowdedness resulted in the perception of a clinic atmosphere that was less confidential than the pediatric outpatient clinic for HIV infected patients. So for example, one adolescent said about the pediatric clinic "Mi like da clinic yah it private, di only, di only way people wi know is unless yuh tell dem. Dat mi like wid it, it very private."(A16) (I like this (pediatric) clinic, it’s private. The only way people will know (that it is an HIV clinic) is unless you tell them. I like that about it, it is very private). While another adolescent remarked about the adult clinic, “I don’t like the environment. It’s too crowded...too many faces looking at you.”(A7)

**Neutral Perceptions of the Adult Clinic**

However, not all comments were negative. Some adolescents simply described the adult clinic as an adult version of the pediatric clinic. With statements such as; “It similar to this one di only thing yuh a guh deh around adults not just children.”(A13) (It is similar to this one (the pediatric clinic). The only thing is you will be around adults and not just children).

**Positive Perceptions of the Adult Clinic**

Positive perceptions of the adult care were rare and based on the adolescents’ experiences in the adult setting. Two out of the 18 adolescents
interviewed felt the treatment and care were comparable in the pediatric and adult settings. One commented, “There is not really much difference there only that they are adults down there and they are younger ones up here, nurses and doctors down there, and the nurses and doctors up here they are all the same. They are all affectionate. They don’t make you feel like you created the worst mistake of your life just like others would make you feel, everybody tries to make you feel comfortable everybody just try to tell you just try to be positive if you have aims if you have goals still aim for them.” (A1) Another shared, “Cause down by Site 3 is one adult clinic and up here a children’s clinic. But it’s not really different. Because everyday mi go down a Site 3 oh how you a get prettier and prettier everyday and mi come down yah ah di same ting so it’s not really not it not different.” (A6) (...and I come down here and is the same thing so it’s really not different).

**Providers**

Compared to the pediatric clinic, providers perceived the adult setting to be a place where adolescents would have to take on more responsibility for themselves in their medical treatment and care. “It’s a big difference from when they were dealing with us,...we might baby them or spoon feed them and it’s like you’re just jumping from a...situation where you were being...spoon fed and just thrown into the big open sea and you haffi swim and ketch fi yuhself (akin to swim or sink),...you don’t have anybody there to run you down about your appointment or to run up and down to get your prescription filled for you or to call you when you miss an appointment and be searching for you and you know making extra effort for you to
be seen,…so the fact that they felt that we were interested in their care made a difference…and so in the adult setting they might not have the luxury of that…. Yes somebody is going to call you at some point that you miss your appointment but like us you miss the first appointment we are searching for you, we don't want you to miss a second one.”(P10)

Pediatric providers anticipated their adolescent patients would have to speak up for themselves if they had needs or questions in the adult setting. Those skills might not have been necessary or practiced in the pediatric setting. One provider stated, “you'll (the adolescent) now be expected to show interest in what you want to know and you’ll be expected to take more responsibility for your care.”(P6) She explained, "Many doctors in the adult setting will simply go through doing what they are doing but if you stop and ask them a question they will answer so…We (pediatricians) tend to tell people more information than...they care to know...or ask if they have any questions...pediatricians...works at a...slower pace with more education in there.”(P6)

In summary, providers agreed that though adult patients receive support, it is not the same kind of support the adolescents grew accustomed in the pediatric setting. The adult environment requires the adolescent patient to have greater responsibility for his or her care and to be more autonomous in the adult care environment.
Treatment, care and support in the adult clinic

Even though adolescents are expected to be more responsible for their care, adult care providers assured us of the robust care system that exists for adolescent patients who are being transferred. They shared, “I know that treatment and care and support is there, it’s there, so I know they can look forward to, to getting, proper treatment.” (P11) The providers, especially those providers who work with the adolescents in both the pediatric and the adult outpatient settings, gave these same pledges to the adolescents before they transfer to adult care. “We give them that assurance of us being there and they would have used to you from that age coming up so you being there, is that person that they can always come to, so yes, and if it's a case where I work with the family member also so they know that I'm there not just me but the caregiver is there also, so yes, they yeah they do well.” (P3)

Additionally, adult providers have an open door policy for all their patients. “We talk to them, we let them know that anything they can call us we are here for them, anything, whether, anything they want to talk about the door is always open to them, so feel free to come in.” (P21)

Of note, several adult care providers shared that patients who have transferred, seem to be adjusting well to the adult clinic environment. Providers commented “a lot of the times it was it was the initial ’I don’t know what’s gonna happen’ but once they (the adolescent) came you know it it’s been smooth sailing most of the time after that” (P9) and that “they (the transferred adolescents) are doing fine, they are settling in the clinic find their space just like everybody else.” (P21)
According to the adult care providers we interviewed, there are even patients who prefer to be in the adult setting for one reason or another. So for example, “The one I’m thinking of, he’s a big strapping, he doesn’t want to go to the kiddie clinic any more you know. He's a big man so his preference was to come to the adult clinic.” (P9)
Section 4: Attitudes and concerns about transfer from pediatric to adult care

Theme 3: Rootedness

Another theme that emerged from the interviews was patient rootedness in the pediatric clinic. Rootedness is defined as “not wanting to go,” “not wanting to move,” “not leaving the pediatric clinic,” and “keep coming back” to the pediatric clinic.

Adolescents

Four of the adolescents had clear, strong hesitations about transferring to the adult clinic; they shared they did not want to go, and why they did not want to go. Adolescent patients were happy with the treatment they were receiving at the pediatric clinic, and they trusted the providers they had there. For these reasons adolescents expressed concerns about moving to another clinic. Other providers would not know them as well as the providers they currently had. For example, adolescent 10 explained, "I still don’t want to go over there, Dr. Kevin isn’t over that clinic. That’s why, I don’t want to go over there. I just see Dr. Kevin right here because Dr. Kevin knows everything about me. He knows everything about me." (A10) He also said, “I don’t know what it is like, but I just don’t want to go there. This one is perfect, very fine perfect.” (A10) He was also clear that he would become non-adherent to clinic attendance if he had to go to the adult clinic. He said “I don’t want to see any new doctor, he is alright and if I go over that clinic, I am going to stop coming to clinic, trust me, I don’t want to go over there.” (A10)
Other adolescents were a bit more ambivalent. They would make comments like, “I really don’t want to move, but if it’s a case where I have to …” (A18) they would. When another adolescent was asked how she felt about moving to the adult clinic she responded, “mi nuh feel nuh way” (A6) (I don’t feel any way) adding that she knew she wouldn’t be staying in the pediatric clinic forever.

The remaining adolescent desired to go to the adult clinic as she felt it would be a more suitable environment for her stage of life. She explained, “It’s better you move on….cause is pure child up there and it doesn’t feel good to sitting down with a child. Although they bring up joy and happiness but it’s better you move on to an adult clinic where you learn more from adults and all those things.” (A5)

**Providers**

Providers expressed that after introducing the topic of transferring to the adult clinic the patients “mek up they face (make a face) and the parents don’t want to go and they don’t want to go.” (P12) In fact “there was one little boy who begged to stay.” (P12) Other providers tell us of patients who refuse to participate in the transfer process. “I think she was 22, probably a little older and she say nurse “mi nah guh ova deh (I am not going over there) she just insisted that she wasn’t going over there…and sometimes she would miss her appointments and she would come to us and say, she miss her appointment and she out of medication, so you were forced to see her, you can’t send her home.” (P10) Yet another provider shared that some adolescent patients considered the transfer to adult care to be a kind of punishment and objected to going. “I said to him I said ‘Oh you coming up to being
transferred’ ‘No I don’t want to talk about it cause I’m not leaving this place I take my tablet you and Doc see I take my tablet...so what is the problem. I miss my appointment? I say ‘Well if I don’t miss my appointment why you going to send me over there?’ So they’re seeing it as a problem that they're being sent.”(P4)

According to the providers we interviewed, adolescent rootedness occurred for a variety of reasons. One cause of rootedness was the attachment between the adolescents and the pediatric team. “The children a lot of them are reluctant to go, and will actually cry because...they get very attached to the team.”(P12) Another provider elaborated, “They don’t want to transfer because they have such a good relationship with the physicians here,...they don’t feel comfortable about moving to somewhere else, ...they are not comfortable to talk about themselves in the way that they would, speak to... their physicians who would have been seeing them from childhood.”(P16) For example, a provider quotes her patient as saying, ‘I don’t want to go over there because if I go over there they just gonna be putting me down to sit down and ... I don’t have nobody like...over here.”(P4) Another provider expounded, “but it’s not because he think they’re gonna be horrible to him over there it’s like he’s found his comfort zone...So he doesn’t see why it should be disrupted now to send him to these ones...when he know me and the doctor all his life.”(P13)

The importance of the support adolescents received in pediatric care was magnified because of the perceived lack of support outside of the clinic setting. “All of these things are in place, but when they get back to their little house and their own little area they may not...have a lot of support within their little area, so that is
why they rely very heavily on this support system that we have in place for them and anything that they perceive will change that network makes them a little anxious because they don’t know exactly what they are going to meet.” *P12*

Rootedness was also driven by providers’ perceptions of adolescent concerns about moving to a new environment. For example, one provider evaluated, “I think the barrier really for the patient is uncertainty because the patient and the caregivers,... just not being certain of how this clinic (adult) is run you know, how is it different from the clinic you are in now. Sometimes they, just being uncertain they don’t wish to go.” *(P6)*

Even so, providers assessed that fear of the unknown is not limited to these adolescent patients only; concerns about moving to a new clinic are experienced by all HIV-infected patients and are in part determined by past experiences and a fear of being stigmatized. According to the providers interviewed, adolescents may therefore “like some assurance that where they are going to they will feel comfortable and they will not be ill-treated” *(P15)* “because...there is a stigma attached to the illness, so they not sure if they’re going to be embrace and treated well or stigmatized wherever they go to.” *(P10)* Another provider supported this view and emphasized that adolescents believed “stigma and discrimination is quite rampant in the adult setting, so she doesn’t necessarily want to” go. *(P6)* Yet another echoed that concerns about moving may be the result of negative perceptions of the adult clinic based on experiences that adolescents may have had. “Or the perception of what the adult clinic is like or sometimes...their mom may be in the adult clinic or they may have seen for themselves what the adult clinic is like
and they don’t like what they see.” (P16)

It is important to note that rootedness is a two-sided construct, being supported by the viewpoint and feelings of adolescent patients as well as their providers. For instance, providers’ attachment to the adolescent patient may delay the transfer. “Sometimes the doctors them is really protective, overprotective of their babies so...I think they actually keep them a little longer.” (P5) Secondly, providers are also concerned about the level of service provided. “It’s a worry that new team of physician will take the time out to get to know the patient and not just deal with a problem but have a more holistic approach.” (P7)

Pediatric providers also highlighted that transfer may in some cases disrupt continuity of care and as a result were hesitant to transfer their adolescent and young adult patients to adult care. “We want them to come to clinic we don’t want to give them a reason to not make their clinic visit. If it meant that we had to see them till dem ole and grey (old and grey) they would probably accommodate them just to make sure they came to their clinic visits because people will be afraid to go to adult clinic, and they will just not go you understand...so I wanted to transfer them a lot of the times but then at the same time, you don’t want them to default, so we will accommodate them, we will see them we will treat them, eventually you start preparing them that, hey, you know at some point you will have to be seen in the adult clinic, so you try fi prepare them but at the end of the day a lot of them were not willing to go and so just to make sure that they didn’t default that they continue their care we would see them.” (P5)

Because pediatric providers anticipated their adolescents would be perceived
as adults after entering adult care and would have to have greater responsibility for their care in the adult setting, some were hesitant to transfer before they thought the adolescent would be able to manage that responsibility. “A lot of times the expectation is there for the caregivers, okay because yuh big now, you suppose to can manage, but they don’t manage because that’s not on their mind.”(P17)

Therefore, “we don’t really like to transfer whilst your still in an adolescent developmental age...to an adult clinic because...we figure that somebody has to be sitting down and addressing your issues if you need to talk about relationships, sexuality, school, profession, family life, pediatricians are generally here for you. We want to know what has been happening in terms of all those aspects of your life not just your chronic illness, those things aren’t necessarily addressed in an adult clinic.”(P6)

In summary, rootedness was as a result of the strong relationships between the adolescents and their providers, adolescent fear of moving to a new environment, and their fear of stigma and discrimination outside of the pediatric setting. Providers were also concerned about the level of care that would be provided in the adult setting, and desired to ensure the adolescent remained adherent to treatment and care.
Theme 4: Bridging the health care gap for HIV-infected adolescents

Challenges for the HIV-infected adolescent

Throughout the interviews, the challenges that HIV-infected adolescents in Jamaica face came up repeatedly. These include frequent acute illness, isolation, navigating sexual maturation and subsequent intimate sexual relationships as an HIV-infected adolescent, and issues resulting from lack of disclosure. These challenges are interconnected and exacerbate each other.

One provider explained, “In the normal course of things when you have no chronic illness, the teenage to adolescent period is fraught with difficulties...what you're going to do in the future...your sexuality becomes an issue...how other people treat you in terms of discipline and freedom and then there is the problem of economics, the very meager existence, economics, housing. So those factors alone...the teenager transitioning to adulthood is quite difficult.” (P12)

She continued by saying being HIV-infected complicates adolescence. This is in part because of the health related concerns and health care needs that individuals infected with HIV have. She stated, “You compound that (adolescence) with a chronic illness, that, death is still a feature to reckon with...acute illness intervene more frequently, than the average child.” (P12)

Furthermore, HIV-infected adolescents have minimal social and economic supports. Adolescents were often single orphaned, double orphaned, or living with guardians. Some adolescents who had been perinatally infected were living in state care. They had lost their biological parents to HIV or their extended families or
guardians were not able to care for them. Subsequently, providers describe HIV-infected adolescents as isolated – they were “limited to engage emotional support around,” (P12) had few individuals who could understand what was happening to them, and sometimes no one to rely on. Furthermore, institutionalization carried its own shame, negatively affecting the adolescents’ psyches. “Being institutionalized itself, lends its own psychological impact on an individual,...and you can call it rejection, whether the parents have died or the parents just can’t manage, it can be perceived as rejection. Rejection has its own traumatic effect on any human soul, so they have to override that, some of them might be angry and express it in different ways.”(P17)

The issues that come with being institutionalized, that is, perceived rejection, hurt, shame, and acting out, are complicated by having the stigmatizing and infectious HIV. Providers shared that finding an alternative living arrangements, supportive of their needs as an HIV-infected adolescent may be difficult. All children in special state homes are infected with HIV, so there is early disclosure and staff administers medication daily. “In the homes...somebody pulls out the pills puts it down and you take it.”(P7) However, if adolescents are sent to live with their extended family, their family may not be aware of their HIV status. Lack of disclosure, stigma related to being HIV positive alongside poor living conditions may limit the adolescent’s capacity to adhere to medication. One provider shared, “HIV is hush hush...when you have a room where you are sleeping with five or four cousins, who doesn’t know your status where do you put that tablet when you take it home, you have to hide it, and sometimes when you don’t get to take the morning dose or
you don’t get to take the evening does because of the environment that you are living in.” (P3) Another provider shared, “These people (guardians for HIV-infected adolescents who have left state care) by and large may not know your HIV status...then you going to have adherence issues, adherence to clinic, adherence to taking your medications.” (P17)

Perinatally infected adolescents, also have to navigate sexual exploration and intimacy in the context of being HIV-infected since birth. They may be hesitant to share their status with their partner because they fear of rejection or abandonment. One provider noted about the adolescents, "As you get older you want to engage with the girls or the boys. You want to explore sexually, (but) you cannot disclose to them, so there is a certain amount of deception there, to get what you want, because if you disclose they might leave and abandon you. If you don’t you are hardening yourself, because you are deceiving the other person.” (P12)

Lastly, institutionalized adolescents, especially those who have been set back by the sequelae of HIV, may not be equipped with the skills they need to survive and live on their own when they have to leave the home.

Challenges in the Health Care System: “Like a midget in the land of giants”

Providers spoke at length about the lack of and need for specialized in-patient and outpatient adolescent services, especially because of the unique challenges adolescents with HIV experience. For example, several providers comment on the difficulty of being an ill adolescent on the adult ward. Adolescents
have to cope with the distress of chronically ill and dying adults. “In the Public
Health system they have to go, once they pass 12, they have to go to the adult ward, I
mean I know for a fact not just from HIV but from other situations like even sickle
cell disease, how it must be for an adolescent to be on an adult ward surrounded by
adults who are dying and having severe chronic disease, and having to cope with
that...must be very distressing and difficult for them.” (P16) Adolescents are also out
of place on the adult ward. They are younger and smaller than the other patients
and that may be isolating and intimidating for the teenager. The adolescents are
“like a midget in the land of the giants,...when you go look for them, it's like a child in
an adult environment...they just look lost in an adult world and just the
environment itself might intimidate a child because you're not seeing anybody your
age, that you probably can talk to or play with,...and at 13, 14, 15 you're not an
adult....a lot of time they are probably the only one of that age on the ward and I
think that could be rather intimidating.” (P17) The challenge of being out of place on
the adult ward as a child may be exacerbated by HIV due to the stunting long term
survivors of HIV may experience. “We need to remember that some of the HIV
positive kids especially those who were very sick very early they will end up with
growth retardation, like they are very stunted in their growth so even though by age
they're old, when you look at them they are so small,...and then also you have some
who because of neurological involvement they are not so with it..., mentally and
cognitively and all of that thing.” (P17) A third provider echoed “It’s... just big people
around them and it's just a strange place for them, they don’t like it.” (P19)
Additionally, an adult provider (physician) was uncertain about the ability of the adult outpatient clinicians and other adult providers to address adolescent needs and suggested a clinic specific to the adolescent age range. “It would be nicer if they could have a clinic for adolescent, because there are lots of issues there, that the adult physician is not necessarily, one, have the time or two, attuned to and they themselves, that's a very tumultuous period let's say, much less with HIV.” (P20) For example, “the way you interview an adult say about contacts, might be quite different from the approach of the adolescent.” (P20)

Others felt there were aspects of the adult environment in the outpatient setting that weren’t suitable for adolescents or made delivering care more difficult. One provider objected to the transfer of 13 year olds into adult care. “I don’t agree with the transferring at 13, I don’t think a 13 year old child, should have to be in a clinic with an adult.” (P11) Another provider elaborated that adolescents with HIV may be openly scorned in the adult outpatient setting. When going to the adult STI section in Site 1 “they (the adolescents) get comments from out there “wha dis likkle girl a do in yah so, a man she a tek” (what is this little girl doing here, she is having sex with a man?!) and whatever and they say it loudly you know, they don’t whisper, so the child hears, you understand I’m not saying, necessarily to...but they don’t know whether the child was sexually abused or the child willingly had sex so there are certain things you have to prepare them for, before they come over into the adult clinic, so you know discrimination let them be aware, educate them about they are going to be younger than, the adults here, don’t really pay attention to whatever, you come in, and you come in for treatment, you were born with it, you
didn’t go out there and get it and when you are raped you didn’t go out there and get it so, just come in and get your treatment and leave. Some of them will come in and hear the thing and don’t come back for their visit for the follow-up treatment, they say they “not coming round there because the adult dem a” (not coming around there because the adult them) “yuh know di lady did say this or the di lady did say that” (you know the lady said this or the lady said that) so it’s also and as I said discrimination comes again which is another barrier for them.”(P8)

Bridging the Gap between pediatric and adult care

As a result some providers have sought to bridge this gap in adolescent care and provide services in lieu of structured and formalized adolescent clinics. They emphasize that pediatricians make a personal decision if they choose to take care of adolescents past the age of 13. “Where we find that a little bit difficult is where in terms of adolescent care because while many of the pediatricians in Kingston will retain our patients in our care until 18. It’s a personal decision, it’s not something mandated by the health services, so I can’t tell my colleague in Mandeville to keep a 14 year old, I can’t tell my colleague in St. Mary to do that either, so you know, you may speak to your colleague and say okay fine you have, like I had one of my 12 year olds who use to come here but actually lived in St. Mary didn’t wish to be transferred to Site 1 and had often asked to be transferred to somewhere in St. Mary but you know I didn’t know what to, I didn’t know, I didn’t have somewhere necessarily to transfer her to. The closest treatment site at that time was St. Ann which wasn’t necessarily nearer for her, a colleague of mine graduated and started a
clinic in St. Mary, so when he turned 12 by this time she had established the clinic, so I asked her if she would take him, and she did. So he ended up being transferred to a colleague in St. Mary but not all pediatricians necessarily keep the older ones and some of them will keep the ones that they have from under 11, but they wouldn’t necessarily take a new one under 12.” (P6)

Adolescents face medical concerns that some pediatricians may not feel equipped or have the resources to handle. For example “services like STI management aren’t readily offered in my section of the clinic, so like for those things, management of STI’s, getting Pap Smears, those things I generally have to send them to the adult section.” (P6) These lack of resources and facilities in both the pediatric and adult settings highlight the need for specialized adolescent services.
**Theme 4. Transfer is not a transition**

One of the unifying themes of this study is transfer is not a transition. One provider distinguished between the ideas of transfer and transition. A transfer is one point in time; the movement of the adolescent from the child clinic to the adult clinic. For example, one provider elaborated, “I suspect it (the transfer) is just a referral letter and send them to the clinic…that’s how a lot of the transitions occur in Jamaica. It’s just a letter and it’s down to the patient to make the transfer on their own. I don’t know if there are any special support systems. I haven’t heard of any at least.”(P9)

While a transition is a process, an element of which is the transfer. Another provider clarified the distinction between a transfer and a transition. She commented that although a transfer takes place, there is no transition process for adolescents moving to adult care. She said, “I don't know if we have a process, what normally happens is that we write a summary, we try to make a one-to-one connection with some consultant in a specific adult clinic, update them on the patient, and tell them you know this is who is gonna be coming. If they have any peculiar quirks, the patients that is, we tell the physician about those so that they can kind of pay more attention to that but there is no specific transition process.”(P7)

Providers argued for a holistic approach to the transition process, one which supports, educates, and empowers family, patient, as well as the providers involved. In other words one provider clarifies, “the best thing is a transitioning space...so for the older child or adolescent to see that would help, so you have some time to
prepare them. I think time and as I said before the preparation of the staff on both
side, the parents it’s just everything you know, if as an adolescent now, if the parent,
say it’s a older adolescent now, its 18 year old that the parent don’t need to come,
there is still some other thing that they need to find out though, you not only see the
doctor, you have the long wait at the pharmacy, how do you, you know, it’s
almost...like teaching the children how to take the bus and among all the other
things around the place.” (P20)

Important perceived elements of a transition process in the Jamaican setting
emerged throughout this study. They include an early introduction to the idea of
transfer, patient education and empowerment, the consideration of adolescent
development, expansion of specialized adolescent care services, as well as a clear
plan for the continuity of care of the adolescent during and after the transfer
process.

The transition process: Preparation for transfer

As part of the preparation for the transfer, providers felt adolescents should
be told early on about the transfer to adult care as well as what it might involve.
Providers also suggested a formal introduction to the adult clinic setting, patient
education about the illness, and teaching patients how to take responsibility for
their own care. Providers perceived this as especially important for adolescents
who were rooted in the pediatric clinic.

Because many pediatric patients have strong ties to the pediatric setting,
providers suggest there should be an early introduction to the idea that they would
be transferred in order to ease some of the challenges adolescents may have with the transfer process.

One provider described the inadequacy of the transfer, considering patient rootedness and the pediatric clinic as home, in this way; “Most of the cases you talking about transfer you write a letter and you give it to the parent and the parent just gone over there with it and it stops at that. But I think we forget sometimes that this child has literally been brought up in this little house with us and you just suddenly saying you taking them out of you house but you...never tell them where you gonna take them, you telling them where they take them to but you not really introducing them.”(P4)

Another provider shared a similar perspective. She acknowledged the desire adolescents might have to remain in the pediatric clinic, noted that transfer is inevitable and should be considered a part of growing up, or as a natural part of growth and maturation, and so concluded that adolescents should be prepared for the transfer. “Anybody who goes to pediatric clinic would prefer to stay until they are 20 but that don’t mean that they should, so again this where orientation towards that change, that’s what is lacking we have to start orientating and getting them prepared for moving, to that stage with adults, and you know with adulthood comes responsibilities too and this is one of them and so even though they may want to stay and I can definitely understand why they would want to say, because I tell you the adult environment is completely different, but, they should be prepared for moving into the adult section.”(P11)

Therefore providers also suggested it is important to highlight some of the
differences between pediatric and adult care, in order to teach patients how to advocate for themselves as they move into the adult clinic setting. For example, one provider said, “I think they should start preparing them too for the transition into the adult clinic. Probably to let them know, you won’t have persons around you running behind you saying do this and do that. You are considered an adult now, you are responsible for yourselves they should start, that transition process.” (P14)

In other words, another provider stated, “in preparation for transfer it’s some of what we do is encourage responsibility. So you just don’t talk to the parent about the adolescent, so you have time alone with the adolescent where we talk to them about their concerns and you know tell them their results and expect that they should remember it, ask them questions like, so what do you know about H.I.V,...what do you remember about the last set of results you had, those things begin the preparation for when they should be remembering because nobody is going to check if you know or you don’t know, but you need to know for yourself.” (P6)

In addition adolescents should be introduced to the adult clinic setting. One provider suggested, “we need to bring in more like an introductory service like... if we could get the parent to say I can come another day I will walk over to the adult clinic and introduce the child to make the child feel more into the field of where they going.” (P4)

Patient preparation should extend beyond a conversation about the transfer, and introducing the adolescent patient to the adult clinic setting. Many Jamaican providers believe it should include early education about the illness so the patients
can assume responsibility about their care. "I’m one of those people who believes that an educated patient is a patient who will do better at looking after themselves... so some of things would be educating about the illness itself...whatever complications you have now versus what you could possibly expect, educating them about what a CD4 is, what a viral load is, the routine blood test that we would be doing and why we would be doing it. So that they can keep tabs on their own blood test results and encourage them to ask questions."(P6)

One provider noted that patient empowerment is especially important in the context of Jamaican culture, where patients may not ask many questions of their physicians. She said, “You get a referral you should know where you’re referred to and why. Jamaica culturally is a place where if the Doctor says take this, the people generally do it, we are coming from a culture where people don’t ask a lot of questions. So find that somebody will go to the doctor, get a whole bunch of paper this fat, about you know what they need to get done and when you ask them why they are completely blank."(P6)

The transition process: Adolescent Care/Adolescent Services

As already noted, adolescence can be a challenging time with unique struggles for the HIV positive patients which may cause or exacerbate non-adherence to treatment and care during the adolescent period. Providers suggested that adolescents should be given the support they need throughout the transition process to maintain adherence to treatment and care.

Difficulties with adherence may begin in early adolescence if disclosure is
delayed. “One of the things we realize is that as they get older there is the expectation that they can manage their own medication themselves, that doesn’t really work very well, right, number one disclosure is going to be important for them to be able to manage your medication some of the kids are disclosed to, late for a variety of reasons.” (P17)

Providers spoke to the necessity of an appropriately timed disclosure, before the beginning of adolescence, so formal education about the illness could occur as early as possible. For example, one provider emphasized that informing the patients about their illness is key to better health outcomes including a better transition of care from the pediatric to the adult setting. “That is why I always tell people that it’s very important for the young teenager to understand their illness so that they can make an informed decision, and informed choices about their life. Without proper disclosure and understanding then the decisions are not going to be informed, and that takes time to be developed.” (P16)

Furthermore, separate and a part from delayed disclosure, teenagers may have challenges remaining adherent to their medication regimen for a variety of reasons. One provider explained why non-adherence may occur in the teen years. One reason she gave is the hopelessness some adolescents experience because they have HIV. “Being an adolescent it’s very, it’s very, interesting...one of the regular question is will I be able to have a family and these are some of the issues that they are dealing with and these issues can affect adherence for some of them it’s like why am I here then, and so if they don’t see the reason to be here why take the tablet, you know, so you have to constantly encourage, you know so it’s
Providers felt this means adolescents need special and ongoing support to maintain adherence to treatment and care, especially as they prepare to go to the adult clinic.

Adolescents with HIV also face special challenges in forming and navigating intimate relationships. The same provider explained, “They are having to cope with an adolescent’s life with a adult life, having been HIV positive all their life. Right so they are a lot of stuff that you are going to have to figure out that the other adults who get it horizontally may have figured out or may not have figured out okay, how do I enter into a relationship, you know, how do I get a boyfriend, how do I stay with a boyfriend without giving them HIV, how do I get a girlfriend without giving her HIV, how do I go about having a family, you know, how do I disclose to my partner this person that I see and I like. How do I talk to them you know, um these are real challenges that these kids are going to have, these are real challenges they’re “gonna” have um, by and large now a few of them, the disclosure part not happening, you know, but they’re having sex, don’t know if they have a relationship but they are having sex, you know for whatever reason and not all the partners are knowing you know so.”

The stigma attached to being HIV positive may cause HIV-infected adolescents to keep their status a secret, even from individuals close to them because they feel they won’t be accepted for who they are and what they have. The stigma attached to being HIV positive may also affect the adolescents’ self esteem. Therefore, HIV positive adolescents need special support systems in place to help them navigate through this period. Provider 8 shared, “Alright going over with
them, okay, at this age they are at risk, right, so there are vulnerabilities as in, ... they may feel that, they won’t be accepted out there, alright, they need to know the, the different agencies they can go to for help, right, so...its not just psychological assistance, cause they’ll be getting that through child guidance just the same, but, they need to know their self-worth and need to know that there are other avenues that they can take instead of taking up with a partner or whatever, they need to know, they still have a long life span so, steer them into a career path, right, so basically just how they can cope socially because I think if they can cope socially its it would be easier for them to cope mentally, so the risk and the vulnerability will be lowered, if you understand what I’m talking about.” (P8)

One provider summarized about the current state of affairs, “We don’t have enough capacity to deal with the complex issues that will happen in an adolescent who is HIV positive.” (P9) Therefore, special services for adolescents with HIV are needed and important in the transition from pediatric to adult care.

*The transition process: Continuity of care*

Continuity of care emerged as a critical element in a seamless transition process. Both pediatric and adult providers affirmed the potential for continuity of care that already exists within the HIV care community.

Participants interviewed cited the social workers, and adherence counsellors as staff that might be called on to assist in care continuity during the transition process. A pediatric provider shared “we do have a working relationship with some
of the adult physician and we collaborate the good thing is that the social workers we share, so the same social worker that see adults would also see the children that you may refer sometimes see the families so, having that common person, that common relationship also helps in making that transition."(P16) Another provider reiterated, “what helps for the patient is if they know somebody in the other setting, you know like social, social workers, adherence counsellors tend to go between the groups, not necessarily separate, so if they know the social worker they know the adherence counsellor then a familiar face who knows them, might make them a little more comfortable because there is somebody who knows them, and somebody dem (them) can talk to if anything."(P17)

Providers also noted the effort that is already being made to ensure care continuity. While another stated, “So even though you might be transferred to the adult section, we are a team and we work together, so it’s not just you leaving us and going over there, you know. Yes, you would be leaving us, but you would be going into the same care even though it’s a different place, sort of get prepared in that sense to know that, you know, there will be nothing short from what Nurse Gilmore and Dr. Hanoch has given, and they need to know that it’s a part of a team they are now a part of."(P3) A fourth provider shared that providers who take care of patients with HIV make a greater effort to ensure continuity of care compared with providers who take care of children with other types of disease. She said, "What’s different with HIV is that usually we try to make contact with the physician that they will be going to, or with the health, the clinic site that they will be going to, to that they are expected."(P6)
Even so, a pediatric provider believed it’s necessary to be detailed with the adolescents about referral and care continuity details as that reduces anxiety and manages expectations. In general she felt transitioning adolescents should be given “a specific person that they can go to in case of any questions or whatever, rather than a general referral that you walk into the clinic and it may pass through the hands of three or four different nurses before they figure out which part of the clinic you’re supposed to be at, so giving them a specific person and a specific date to go at a specific time with their referral, I think assist the transfer on both sides and educating the patient as to what to expect. I think is reassuring and minimizes anxiety.”(P6)

Both pediatric and adult practitioners mentioned a transition meeting between providers may be helpful, especially if the transfer is occurring at the same institution; “a case meeting so that you can fully discuss, and really get to know the person or a very detailed referral.”(P20) For example, providers suggested “the team from the pediatric meet with the team from the adult on a given day, ...and we just talk about the cases you know, just to make sure that there is understanding as to what is, as it happens when you have case discussions so that everybody knows that this is who this person is and this is what you’re working with.”(P17)

Continuity of care for adolescents transferring to adult care should also include adult provider education. One provider said “I think we also who are over this side should be informed well in advance that so and so and so will be coming so we also will be able to prepare our mind and have time. Don’t just say ‘Okay today is your clinic’. The first day they come to clinic the will be able to see the members of
the team. Preferably get orientation to a new site. Now...the social worker, the psychologist, the doctor, the contact investigator, the adherence counselor, the nutritionist, everybody... We’re a very big team and we are willing to talk, to reassure them, make them feel comfortable." (P13)

Still, another provider recommended counseling for adolescents to help them navigate this significant change. She advocated for counselling as a part of the transition process as it would help patients cope with the change. She also perceived it as a preventative health care measure as it may identify and allow providers to deal with transfer related signs of emotional distress. It would also assist with continuity of care. The provider argued, “If you have children who are accustomed to a particular routine, and a particular way of going about treatment and the adult clinic is very different, so when the whole environment is different. So there is no orientation provided about the adult clinic and you know sometimes they get lost there and I think in order to get them adjusted, there has to be some counseling provided and that’s not done...Also you can’t wait until these symptoms, of emotional distress to provide these services, the psychologist is there, so that service should be utilized, before anything significant happens, because, the problem is once they start showing signs of depression or/and non-compliance it’s very difficult to keep them there because they don’t want to come back, most times they don’t come back. When they do come back they are very, very ill, and that is not an appropriate time to provide counseling; they are hospitalized, bedridden, it’s really not the best time to provide treatment so, it should be a preventative measure, but as it is now that’s not how it’s been done." (P11)
DISCUSSION

The health care transition (HCT) of HIV-infected adolescents from pediatric to adult care must be optimized to ensure linkage and retention to care, to maximize lifelong functioning and potential of the adolescent or young adult, and to decrease the risk of HIV transmission to the community. HCT has been defined as a purposeful planned process which begins at least a year before the transfer and continues after the adolescent begins receiving treatment and care in the adult clinic. Transition challenges have been well documented through mostly qualitative studies from resource-rich countries. Pre-transfer transition challenges include both patient and provider lack of preparedness for the transition, attachment between pediatric providers and their adolescent patients, and poor communication between pediatric and adult care providers. Post transfer challenges include loss to follow up after the transition. Transition programs and recommendations emphasize considering psychosocial in addition to biomedical aspects of the adolescent’s care throughout the process of transition.

In the Jamaican context, the major pre-transfer challenge which emerged from our study that is already supported by existing literature is the idea of attachment between chronically ill patients in pediatric care and pediatric care providers. Likewise, in our study, patient rootedness and apprehension about transfer to the adult clinic appeared as a two-sided construct, being maintained by both patients and staff in the pediatric clinic. Causes of patient rootedness were variable. They included the strong ties developed over time between pediatric care providers and their patients, belief that no health care provider would be as good as
the providers in the pediatric setting, and negative perceptions of the adult care and the adult clinic. Because rootedness is a two-sided construct, consideration should be given to how to educate and support both pediatric care providers and their patients about and through the transition process.

Of note, perception of adult care influenced feelings about the transfer. These perceptions were sometimes based on actual experiences in the adult setting, but in some instances were not. Pediatricians who had neutral or positive perceptions of the adult clinic wanted to transfer patients at a younger age than those pediatricians who had negative perceptions of adult care. Also, the few adolescents who had neutral or positive perceptions of the adult clinic had fewer concerns about the process of transfer. In general, adult providers had positive perceptions of the adult clinic and believed that patients who transferred to their setting did well – they were adherent to their appointments and expressed no concerns about the adult clinic setting. Adult care providers also believed that patients who transferred were and would be well supported by the systems that were in place for HIV-infected adults who attended the adult clinic.

We learned that both rootedness in the pediatric clinic and apprehension about transfer to the adult clinic are intensified because of the psychosocial significance of pediatrics clinics in the lives of adolescents who are infected with HIV. Given the strong cultural stigma attached to being HIV positive in Jamaica, alongside the limited availability of consistent social and financial supports in the lives of these adolescents, some of who were orphans or without family support,
and from low socioeconomic class in Jamaica, the pediatric clinic became a space where adolescents were given the guidance and support they desired and needed.

Apprehension about the transfer to the adult clinic could be mitigated by creating stepping stones from the pediatric to the adult clinic. These include early and standardized education given to adolescents about the transition process and involvement of providers who interface both with pediatric and adult patients.

In most study sites adherence counsellors, social workers, and psychologists were primarily affiliated with the adult clinic and were called to the pediatric clinic only when they were needed. Staff already working with or available to both adolescents and adults could be utilized in the linkage of patients from pediatric to adult care. For example, social workers, adherence counselors, and psychologists assigned to both the pediatric and adult clinics at one geographical location could help facilitate the transition process starting in the pediatric clinic. Additionally, these staff workers who interface with the pediatric and adult setting could be utilized to provide psychosocial care during this important juncture in a chronically ill adolescent’s life.

In some settings, adherence counsellors work closely with both adolescent and adult patients in both the pediatric and adult care clinics in affiliated pediatric and adult care clinics. These individuals attempted to assure the patients that they would receive high quality care even after their transfer to the adult setting. Even so, there was still apprehension on the part of the patient, because the patient was losing the connection s/he had with their primary medical provider and moving to a new setting.
Two additional major concerns about the process of transition in Jamaica were the lack of formalized adolescent centered services, and a protocol for transitioning adolescents to adult care. Adolescence can be a challenging period. These challenges are exacerbated by being HIV-infected. Challenges include disclosure, exploration of sexuality given HIV status, the development of sexual relationships given HIV status, and transitioning out of school and into work given poor socioeconomic circumstances, and HIV status. Both pediatric and adult health care providers recognized the particular medical needs and psychosocial support these adolescents required. In some instances providers reported a lack of resources and facilities to care for these adolescents. They also expressed the desire for training so they would be better equipped to care for adolescents infected with HIV. Our study implies a need for formalized nationalized adolescent care services, provided by staff equipped to care for HIV-infected adolescents.

A consequence of national policy is that pediatric providers who may not feel equipped or have the resources to take care of adolescents, or who feel they ought to transfer adolescents close to the national cut-off age, may have an age-based cut off early in adolescence for the pediatric clinic they run. An age-based cutoff early in adolescence is a unique issue facing HIV-infected adolescents in Jamaica and other countries with limited formal adolescent services.

Currently in Jamaica, there is a very wide age range for when transfer to adult care occurs. The timing of transfer is dependent on national policy, clinic policy, adolescent readiness and adolescent medical circumstances. In addition
some transfers occur inadvertently. Our results implies the need for flexibility of transfer age depending on the development and readiness of each adolescent.

Our findings are significant because there are no formal guidelines for the process of transition nor are there any nationalized adolescent care services in Jamaica to date. Bearing in mind the concerns reported, in the face of limited resources, consideration should be given to the potential role family care providers or individuals boarded in both internal medicine and pediatrics in caring for chronically ill HIV-infected patients. It would eliminate the need for a transfer or a process of transition from pediatric to adult care, and with it many of the issues presented in this study.

In summary, a process of transition for HIV-infected adolescents should consider the readiness of the adolescent. We have learned that a transition process should ease the challenge of ending the long term relationships developed in the pediatric setting, and incorporate stepping stones to assist with linkage and continuity. Adolescent patient education and empowerment are important to improve adolescent self-management in preparation for the transition out of the pediatric clinic and into adulthood and the adult care setting. Furthermore, supporting providers with the resources and skills they may need to navigate the transition process and support the adolescents they care for may be helpful. A process of transition is holistic and supports, educates and empowers all individuals involved; both the patient and his/her caregiver as well as the providers involved. There may also be a unique role for family medicine practitioners and physicians
who are double boarded in medicine and pediatrics in caring for these chronically ill adolescents.

The validity of our study was enriched because two different researchers utilized the grounded theory approach to conduct analysis of all the transcripts. Furthermore, we interviewed 39 subjects, which in our study was sufficient to arrive at thematic saturation. (62) Limitations of this study include those associated with qualitative interviews. Because we interviewed a modest sample of adolescents from one clinic, and we did not include a post transfer cohort to assess adolescent experiences with the transfer process, the generalizability of our conclusions are limited. However, these interviews provide important information about perceptions and fears adolescents have before they are transferred.

Although the effectiveness of transition programs to date has not been measured, (1, 16) qualitative evidence (40) and retrospective reviews (66) suggest a role for optimization of a formalized transition process. Future studies must assess the transition process of HIV-infected adolescents and effect of transition programs in resource poor countries. Prospective studies are needed to determine if there are significant changes in biological markers, and in retention to care after the transfer and how these might be altered with the implementation of a transition protocol. Studies must also explore the experiences of HIV-infected adolescents living in resource poor countries with the transfer process to adult care in order to better understand the challenges faced by these adolescents and to optimize the process of transition for health care providers, HIV-infected adolescents and their caregivers.
EPILOGUE

I lived in a rural area, about a 20-minute drive away from our metropolis, Kingston. I was able to pick avocados, oranges, soursops and other tropical fruits from the trees in our backyard as they came into season. I often went for walks in the hills. I would almost always pause at one of the lookout points to gaze upon Kingston and her pretty Harbour. Sometimes I went to Falling Edge, a refreshingly cool waterfall, which forms a thin curtain over a cave. It is nestled in the hills near our house. Outside of the swarm of mosquitos that have taken up residence at Falling Edge, it is idyllic.

From the moment I returned home, I was enveloped by the comfort and warmth I seem to only find in Jamaica. Daily, on my way from our house, down Seaview Road to the local town square where I would catch a bus, people in the community greeted me with many easy “Good Mornings” and obligatory, yet welcomed small talk. This daily ritual is a part of country life in Jamaica.

As soon as I arrived at the town square, I would be hustled by a loader1 onto a minibus going in the direction I needed to go – always to town or Half Way Tree. Inevitably he would be competing with several other loaders for prospective passengers. There were always an abundance of loaders, each eking out a living from the few conductors waiting for passengers. Without traffic, it would take me one hour to get from my home to the hospital. I had to take two buses, one from my

1 Loader is the person who finds customers and “loads” them into minibuses or route taxi cabs. This person receives tips from the bus conductor or taxi driver for his/her service.
home to the large bus terminus in Half Way Tree and one from Half Way Tree to the University campus, where the Pediatric Infectious Disease clinic was located. I paid $200 in total, $100 for one buss and $100 for the second. At a conversion rate of JA$120 to US$1 is just over $1.50 for the entire trip. At the hospital I would either shadow in the pediatric infectious disease clinic, interview the participants in the study or extract information from the hospital records. By the time I arrived at the hospital, there were already patients lining the walls of some of the outpatient clinics. Based on what I knew about our clinic patients I knew some of them had travelled for hours to get to the hospital where they might spend much of the day waiting to be seen. I would either bring my lunch or buy food at or near to the hospital. When I bought lunch I would spend between JA$200 and JA$500 for food. Usually, I went home the same way I came, on the bus. If the roads were congested because of the evening rush hour traffic, it could take twice as long – two hours - as it took me to come to work. If I was lucky, a friend might offer me a ride home, and that would considerably decrease my time commuting. A two hour journey would be reduced to 45 minutes in traffic and one hour journey, 20 minutes without traffic.

On my way home, I stopped in Half Way Tree, to catch a connecting bus. There, I savoured the smells of the evening time; freshly roasted pan chicken mixed in with the stale odor of sweat of industrious street vendors blackened by the hot Jamaican sun. Typically, on the bus, passengers were quietened by the vulgar, blaring, dancehall music coming out of the loudspeakers. We could not hear each other or ourselves over the sound. In Kingston, Jamaica’s culture is vibrant, being expressed through uniquely Jamaican sounds, smells, and sights. They are harsher
than those experienced in the countryside. Yet, for me, they represent the hardiness of Jamaican people.

It is a hardiness I cannot fully understand because I am more fortunate than most. I had parents who had some means and who did their best to support me. I went to a good high school in Jamaica and subsequently to an American University. I have had access to opportunities most Jamaicans have not. Now I am at the Yale University School of Medicine. I learn in an environment where it seems patients have access all the social assistance they might need, if they need it, and where doctors can carry out any investigation they may desire. For the most part I live and learn in an environment where resources are plentiful. The only limits I have are those I create for myself.

This is not the case in Jamaica. It is not the case in any other resource-limited setting I have had the privilege of living and working in. When resources are limited it diminishes people’s capacity to thrive. As it relates to medical care, poverty impedes treatment and worsens outcomes. Ethically and personally, when faced with the palpable need in resource-limited settings, it begs the question; as a relatively well resourced individual, how much should I give? And (when) should I draw a line?

The HIV-infected adolescents I met are poor. There were always children who came to the clinic hungry, not having had any food for the day. The nurses or physicians, compelled by compassion, would consistently use the money they had to buy lunch for their hungry adolescent patients.
Then there were those whose poverty affected their adherence to treatment and care. Adolescents would have to take public transportation to come to the clinic. On average it seemed they had to take the same number of buses I took, about two, and it took them the same amount of time, about one hour, that it took me to go from my house to the workplace. Those children and adolescents who were living in a state facility would not have to pay, as the government or the home they lived in had allocated resources for the care and provision of each child. On the other hand, adolescents who were living on their own or with relatives, guardians, or partners bore responsibility for getting to the clinic. Sometimes they had help to do so. Sometimes they didn’t. So, there were times some adolescents could not come up with the approximately US$4 they needed to go to the clinic and return home. Unlike me, they weren’t lucky enough to have a friend who would be able to give them a ride for free. Then there were children who didn’t take their medication because they had nothing to eat with it and it was too difficult to tolerate otherwise. Or others who shared one room with several other extended family members because of financial limitations. Because they had not disclosed to their family members they might miss a dose if they did not have any privacy – a scarce commodity – to take their medication. While I would go home to my beautiful green back yard, or to Falling Edge, many of these adolescents went back to impoverished and miserable living circumstances.

Poverty was pervasive, present at both the individual and systemic levels. Many HIV-infected patients didn’t have enough to take care of their basic needs. Then, the government safety net was inadequate. As one of the participants in the
study succinctly stated, "Jamaica does not have a lot of social agencies...and these programs are already overwhelmed. Most of our clients are from the low socio-economic group (and) will not be able to find food, clothes, funds to go to school, bus fare, lunch...most of the times the issues they have are financial." The only thing patients could rely on, if they had it, was some sort of community and what it could offer to them.

The university and government run hospitals I visited also had financial constraints that restricted the amount and quality of care they could provide. Assessments and plans were often made before investigations were carried out. Either they would not be run unless it was absolutely necessary or the hospital did not have the means or materials to carry them out. This protocol developed the clinical acumen of physicians but meant that sometimes investigations that were needed could not be done. Sometimes inpatients had to source their own medical supplies when the hospital did not have them. Then there was the issue of stock-outs – meaning a line of ART had run out. None was being dispensed by the pharmacy because none was in the island. In a country where options for medication regimens are already limited, providers would substitute, sometimes a line of medication on which the adolescent had already experienced virologic treatment failure. Then, as one participant said, they would "pray that it will work."

Social workers desired to start special programs for adolescents in HIV but there was no government money for it.

This lack came up so often during the course of the study that I had a code labelled “the money is not there.” It was an all-encompassing phrase which
indicated the ubiquitous economic lack sensed or felt by all. It was even evident in the infrastructure. Outside of the University setting, a totally private room was hard to come by for the interviews at other sites. Offices were shared. If there were partitions in a shared space they were not soundproof - they were thin and often did not extend to the ceiling. Despite this lack, the HIV-infected patients were in some sense more fortunate than other patients. All of the three social workers hired at Comprehensive Health Center were dedicated to the 4000 plus HIV-infected patients in part because the funding sources dictate who can be cared for. There were no social workers for the thousands of other patients that went to that clinic. These same funds, subsidize other health care workers dedicated to the care of HIV-infected patients. Likewise, nationally, HIV-infected patients do not have to pay for their medicines and other investigations. Patients with other illnesses often have to find money or do without care.

In a setting like Jamaica, it seems to me, practitioners and administrators have to be sensitive to the unique hurdles poor patients face in a resource-limited context and saavy about developing cost effective options to take care of their patients.

Personally, I was constantly reminded of my relative wealth. I never worried about paying for the bus, or not having enough to buy lunch. I am one of the few who have access, opportunity, and resources. I am reminded to be grateful for what it is I have. And then, my wealth in the midst of lack forces me to acknowledge and consider, in a way I don’t or can more easily avoid when I am on Yale’s campus, the
discomfort and moral force which encourages and obligates me to share what it is I am fortunate to have with those who don’t.


**TABLES**

**Categories of Data**

Tables showing categories of data. Quotes are verbatim and lifted from the transcripts. Spelling is British English and has not been altered here.

Table C. Category 1: In the words of providers: Determinants of Transfer from pediatric to adult care

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Provider Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Regulations</td>
<td>“The way how Jamaica is set up is that paediatric care really stops at 12” 2:13</td>
</tr>
<tr>
<td>Age – not written in stone</td>
<td>“It's (the transfer age) not written in stone...there is some latitude there.” 18:11 and 18:83</td>
</tr>
<tr>
<td>Adolescent Circumstances</td>
<td>“A child...went to Jubilee for a while, which Jubilee is the maternity hospital they went to Victoria Jubilee for the course of the pregnancy and then after the pregnancy ended up joining the Adult Clinic rather than coming back to paediatrics” 2:2</td>
</tr>
<tr>
<td>Adolescent Readiness</td>
<td>“We basically keep the adolescents until they are basically ready enough to leave or they express the desire to want to go to the adult clinic” 20:51</td>
</tr>
<tr>
<td>Inadvertent Transfers</td>
<td>“we have had people who have basically inadvertently transferred out of the system rather than formally transferred.” 2:2</td>
</tr>
<tr>
<td>Thematic Categories</td>
<td>Adolescent Remarks</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Family: My nedda mommy | "Nurse Ruth...she is like my nedda mommy. yeah" 11:18  
"they treat you like actual family. A big family here, like they have graduation pictures of some persons, yeah, it's the whole works" 22:15 |
| Family: Mi know har from mi likkle suh | "mi know har from mi likkle suh, an a she wi always a come tu." 31:21  
"Nurse Ruth and Nurse Sophia because I was used to them from I was a little girl and so forth and they were the ones who mostly treat me and ensure that um, I'm on the right track" 25:22 |
| Family: "No nurse nah go di deh good like Nurse Ruth" | "Cause mi know seh no nurse nah go did deh good like Nurse Ruth" (32:) |
| Family: Mi nuh feel incomplete | "Only bredda and sista mi woulda feel seh mi have a dem who come a di clinic along with me" 15:33  
"Well the experience here has been fun because nobody here everybody here understand me so when mi come here" |
mi nuh feel incomplete or mi nuh misplaced or anything....

So when mi deh here mi nuh feel different or nutn mi just
feel complete.” 15:29

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Adolescent Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rougher</td>
<td>&quot;Adult Clinic will be like .hmmm what it would be like? rougher, mi nah get dem nice treatment whe yuh get a Paediatric Clinic, some a dem not even really care.” 11:21</td>
</tr>
<tr>
<td>Distant</td>
<td>&quot;cause like round there is so distant you just come, you do what you doing, you leave. Round here that, it’s not like that. Is like, round there they don’t even seem to make little conversations. Is like you just come, they examine you, ask you any problems, give you, your prescription and that’s it. There’s no conversation and anything” 22:25</td>
</tr>
<tr>
<td>Harmful</td>
<td>&quot;Because there are many, many teenager who are like probably fretting that if they go to the clinic they probably like inject something that not suppose to be gone into them or so” 25:21</td>
</tr>
<tr>
<td>Crowded</td>
<td>&quot;I don’t like the environment. It’s too crowded...too many faces looking at you” 19:33</td>
</tr>
</tbody>
</table>
Depressing

"Those older people down there, look like they let themselves get way out of control. Everybody looks dead, seriously. You find people with gross looking stuff on their face. gross looking stuff on their foot, everybody just walking around limping, that’s very depressing.” 13:27

Adult

"Site 3 a like adult people, big people, guh dung deh and tek drugs” 29:33

"I would say, I would tell them it similar to this one di only thing yuh a guh deh around adults not just children.” 26:15

"Cause down by Site 3 is one adult clinic and up here a children’s clinic. But it’s not really different. Because everyday mi go down a Site 3 'Oh how you a get prettier and prettier everyday and mi come down yah ah di same ting so it’s not really not it not different” 15:46

"when I looked down there everybody was all adults so I do not know why I was down there really.” 13:14

“There is not really much difference there only that they are adults down there and they are younger ones up here, nurses and doctors down there, and the nurses and doctors up here they are all the same. They are all affectionate. They don’t make you feel like you created the worst mistake of your life just like others would make you feel, everybody tries to make you feel comfortable everybody
just try to tell you just try to be positive if you have aims if you have goals still aim for them. It’s not the end of the world there is stuff that kill you faster than HIV.” 13:17

Table F – Category 2: In the words of providers: Perceptions of and feelings about Pediatric and Adult Care

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Provider Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>“When they are with us,...they have a sense of a family sense, because of how we deal with them, is like everybody know you and you know everybody and we try to, I don’t just see a client and go through...the paper works,...ask them how is their family..., how is school, are you going to school...we try to get a little bit personal with them just so that they can be comfortable with us. We try to be patient with them also.” 17:55</td>
</tr>
<tr>
<td>Rootedness</td>
<td>“I have two or three right now who are like 21 and 22, that I’m sure by now I should really part with, but I know they don’t want to go.” 2:46.</td>
</tr>
<tr>
<td>No more molly coddle</td>
<td>“Being from the baby section they tend to be a little bit more spoilt...We all tend to spoil them rotten with this...molly coddling thing. So it’s...a...shock to go now to an adult clinic...and then to be treated like an adult... that’s what really is...to suddenly then to be told you’re now an adult... No more</td>
</tr>
</tbody>
</table>
Our patients in adult care are happy “Our patients at Site 1 are quite happy actually... I find that the patients take Site 1 like their second home. They will come here whether they have an appointment yes or no, just to sit down and chat, tell us what their kids are doing at school, what is happening in their life or if we can help them with a certain situation and things like that” 38:12, 38:2

Table G – Category 2: In the words of adolescents: Feelings about transfer to the adult clinic

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Adolescent Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rootedness</td>
<td>&quot;I don't want to see any new doctor, he is alright and if I go over that clinic, I am going to stop coming to clinic, trust me, I don't want to go over there” 32:23</td>
</tr>
<tr>
<td>Acceptance of transfer</td>
<td>“Mi nuh feel nuh way... Because mi know mi nah go stay down there for ever” 15:38</td>
</tr>
</tbody>
</table>
It’s better you move on to adult care “It’s better you move on….Cause is pure child up there and it doesn't feel good to sitting down with a child. Although they bring up joy and happiness but it’s better you move on to an adult clinic where you learn more from adults and all those things” 12:26

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Provider Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vulnerable Time period</td>
<td>“adolescent development and the issues that come you know especially early adolescent years,...,there is a lot of peer pressure wanting to belong, wanting to look a certain way, wanting to be like their friends and do what their friends are doing and you will find that the whole issue of,...anti-retroviral adherency become a problem” 20:7</td>
</tr>
<tr>
<td>Inadequate services for adolescents: Like a midget in the land of giants</td>
<td>“like a midget in the land of the giants,...when you go look for them, it's like a child in an adult environment” 37:30</td>
</tr>
<tr>
<td>Bridging the Gap</td>
<td>“the way how Jamaica is set up is that paediatric care really stops at 12....whatever chronic illness...What many</td>
</tr>
</tbody>
</table>
Paediatricians have done like myself to kinda bridge the gap is to keep the out-patient care under our...as in they keep coming to us as Paediatricians for their out-patient care until they get to, in their 20's.” 2:13

<table>
<thead>
<tr>
<th>Thematic categories</th>
<th>Provider Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfer versus transition</td>
<td>“I don’t know if we have a process, what normally happens is that we write a summary we try to make a one-to-one connection with some consultant in a specific adult clinic update them on the patient and tell them you know this is who is gonna be coming. If they have any peculiar quirks, the patients that is, we tell the physician about those so that they can kind of pay more attention to that but there is no specific transition process” 5:104</td>
</tr>
<tr>
<td>Preparation for transfer</td>
<td>“So right now that’s what we discussing now to say how do we get the sixteen year old now and then preparing the fifteen year old so we now in preparation mode to transfer a few across so we actually now thinking about you know the ways and means to go about it” 33:65</td>
</tr>
</tbody>
</table>
“they need proper preparation to know that, okay you
won’t be just going to clinic with just your age group
now...we don't really think we should just throw them out
like that and throw them in with the Adult Clinic” 4:15b

"Well the preparation for transfer is number one telling
them right...that they're going to be going, especially in the
year now, that, is that year of separation... work with them,
which clinic which site would be most suitable for
them”37:16 a...

| Adolescent Care/Adolescent Services | “Even though they are sensitised about the treatment by say, between eight and thirteen so most of them...will know why they are taking their medication, but then there is also the emotional side because...nature will come in as God has made us they'll start having attractions to other you know the opposite sex...and I think they need to be prepared right up until, from even thirteen because they are sexually active even as young as that age, so they need...special guidance right up until say 20, 21...” 4:15a |

| Continuity of Care | “give them (the patient) a specific person that they can go to in case of any questions or whatever, rather than a general |


referral that you walk into the clinic and it may pass through the hands of three or four different nurses before they figure out which part of the clinic you’re supposed to be at, so giving them a specific person and a specific date to go at a specific time with their referral, I think assist the transfer on both sides and educating the patient as to what to expect. I think is reassuring and minimizes anxiety.” 2:36
APPENDIX I

Health care provider interview script – Transitioning HIV-infected adolescents to adult care

Interview Script Introduction

I want to thank you for taking the time to meet with me today. My name is Flavia and I would like to talk to you about your experiences in the clinic especially as it relates to providing care for adolescents/young adult with HIV, especially those who are moving to adult care or who are in adult care.

I am trying to understand more about the transfer process with the hopes of sharing the main findings to help improve the system.

The interview should take about on hour. I will be recording the session because I don’t want to miss any of your comments. Although I will be taking some notes during the session, I can’t possibly write fast enough to get it all down. Because we are being recorded, please be sure to speak up so we don’t miss your comments.

Although the interview is a type of conversation, it is different from regular conversations. I do have a list of questions which I will be asking you, and I am asking you to speak freely in response to each questions. While I will make sure that all of the questions are asked, you are the expert here and I am the student. I hope to gain your knowledge about the transfer process. There are no right or wrong answers; what is most important to me and this study is to learn about your opinion and your experiences.

All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember you don’t have to talk about anything you don’t want to and you may end the interview at any time.

Are there any questions about what I have just explained? Are you willing to participate in this interview?
Interview Guide – Transitioning HIV + adolescents to adult care

Provider

Interview Guide with Field Notes
Provider Interview Guide
Archival #:
Location of Interview:
Date:
Start:
End:

Provider Background

1. Tell me a little bit about yourself professionally speaking
   PROBES include
   a. What is your role and what do you do?
   b. What are some of the challenges that you face in your work?
   c. What are some of the challenges the adolescents who have HIV face?

Providers and the transfer process

Patients can be transferred from one pediatric clinic to another pediatric clinic, from the pediatric to the adult clinic and sometimes from the adult to the pediatric clinic. We will start by looking at the transfer from the pediatric to the adult clinic.

1. Tell me about the transfer process from the child clinic to the adult clinic?
   PROBE: GENERAL KNOWLEDGE
   • Walk me through step-by-step of a patients transfer from adolescent to adult care.
   • At what age does the child begin the transfer process?
   • What does the patient have to do before transfer to the adult clinic?
   • What happens to a patient after he or she is transferred to the adult clinic

2. Tell me about your experience with patient transfer from pediatric to adult care
   • Probe conversations with patients
   • Probe conversations with other providers
   • Probe conversations with caregivers
   • Probe preparation for transfer
   • Probe difference in adult and pediatric clinic and how this is incorporated into the preparation for transfer.
   • Probe providers thoughts and feelings
     • What did you think about this experience? (perspective)
     • What did you feel about this experience? (perspective)
• Do you have any fears or concerns about the transfer process
• What do you look forward to as it relates to your patients going to the adult clinic/receiving new patients from the child clinic?

3. **How does the transfer from pediatric to adult care compare with**
   1. The transfer from pediatric to pediatric care?
   2. The transfer that might occur from adult to pediatric care? Probe specifically around instances of teenage moms being transferred back to the pediatric clinic?
   3. The transfer that might occur from adult to adult care?

   PROBE: experiences, perspectives, sentiments on pediatric to pediatric transfer, pediatric to adult transfer, adult to pediatric transfer

*Adolescents and the transfer process*

1. **Tell me about the barriers for a patient's transfer from pediatric to adult care**
   a. PROBE
   b. Barriers for care team
   c. Barriers for patient
   d. Other Barriers
      i. What barriers exist (if any) in the current/ideal transfer process/transfer system?

2. **What facilitates the transfer process?**

*Adherence to treatment and care throughout the transition process*

3. **Talk to me about adherence to clinic visits and adherence to medications**
   a. throughout adolescence
   b. period before the transfer process
   c. period after the transfer process

4. **What support do you believe recently transferred adolescents need after they transfer to adult care to maintain adherence to clinic visits and adherence to medications?**

*Growing up with HIV and transferring to adult care*
a. Outside of what we have already discussed what other needs does a young adult have during adolescence/transfer process

**Suggestions for the transfer process**

1. **What does the ideal transfer process look like to you?**
   a. PROBE
   b. At what age do you think transfer to adult care should occur and why?
      i. What elements do you think should be included in a transfer process for patients who are HIV positive?
      ii. Do you have any other suggestions for improving the transfer process/transfer system?
      iii. Outside of what we have already discussed, can you think of any issues/problems/concerns that need to be addressed before patients are transferred to adult care?
      iv. Are there any transfer systems in place for other paediatric patients with chronic disease? Are there any models of transition for paediatric patients with other chronic disease that exist here that might work for pediatric HIV patients transferring to adult care?
      v. What do you believe are indicators of a successful transition for HIV positive paediatric patients?
      vi. Is there anything you might change about the transfer process so that these indicators could be met?
   c. How would you go about in implementing this ideal transfer process?

**Closing**

Is there anything else you would like to add? For example, maybe there is a question you think I should have asked that I didn’t.

This is the end of the interview. Thank you for your time.

**After the recorder is turned off**

How was the interview experience for you?
APPENDIX II

Adolescent Interview Script – Transitioning HIV-infected adolescents to adult care

I want to thank you for taking the time to meet with me today. My name is Flavia and I would like to talk to you about your experiences in the clinic especially as it relates to moving to adult care.

I am trying to understand more about the transfer process from the child to the adult clinic.

The interview should take about an hour. I will be recording the session because I don’t want to miss any of your comments. Although I will be taking some notes during the session, I can’t possibly write fast enough to get it all down. Because we are being recorded, please be sure to speak up so we don’t miss your comments.

Although the interview is a type of conversation, it is different from regular conversations. I do have a list of questions which I will be asking you, and I am asking you to speak freely in response to each questions. While I will make sure that all of the questions are asked, you are the expert here and I am the student. I hope to gain your knowledge about the transfer process. There are no right or wrong answers; what is most important to me and this study is to learn about your opinion and your experiences.

All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember you don’t have to talk about anything you don’t want to and you may end the interview at any time.

Are there any questions about what I have just explained? Are you willing to participate in this interview?
Adolescent Interview Guide – Transitioning HIV-infected adolescents to adult care

Interview Guide with Field Notes
Young Adult/Pre- transfer Interview Guide
Archival #: 
Location of Interview: 
Date: 
Start: 
End: 

Keep in mind that this study relates to your experiences at the clinic and your experiences with transfer processes from one clinic to the next.

Open Ended Questions
Pre transfer patients

Background/Warm up questions
1. Tell me a little bit about yourself.
2. Tell me about your day to day life
Probes include
   a. School, how far have you gone in school?
   b. what do you do for work?
   c. Hobbies/what do you do for fun?
   d. where the subject lives, family structure/living arrangement, who knows about HIV at home
   e. Friends and other relationships, who knows about HIV
   f. How do you get to the clinic?
   g. Do you come to the clinic on your own? How do you pay for transport to the clinic? Who picks up your medications?
   h. How long have you been coming to the clinic?
   i. Probe about how subject got HIV
   j. Do you talk to other young people who have HIV?
   k. Most worried about now in life? (what is your life like – what are some of the challenges that you are having – instead of saying teenager, narrow it down to their life)
   l. Most happy about now in life?

Current Care in Paediatric Infectious Disease Clinic
3. Can you tell me about the clinic you attend now?
Probes include
   a. Walk me through your last clinic visit/what does a typical clinic visit looks like?
b. Who do you work with in the clinic? Who do you talk to?
c. What other services does the clinic provide?
d. Tell me about your best experience at the clinic/what do you like best about the clinic?
e. Tell me about your worst experience at the clinic/what do you dislike in the clinic?

Current care/health responsibilities for self for self
4. Tell me about the last time you took your medication? How was that for you?
   a. When do you take them
   b. How often
   c. How do you remember to take your medicine?
   d. Do you take the medicines on your own?/Does anyone else help you with your medicine routine?

Life as an adolescent with HIV
5. What is it like to be living with HIV?

Becoming an adult
1. What does it mean to you to be an adult?
2. What does it mean to be an adult living with HIV?
3. How does being an adult affect your day-to-day life?

Thoughts on the adult clinic
What do you know about the adult clinic?
PROBES include:
How do you know that information? How did you get that information about the adult clinic?

What do you think the adult clinic will be like?
PROBEs include
   a. What are your impressions of the adult clinic?
   b. What will be different as compared to the paediatric clinic?
   c. What will be the same as compared to the paediatric clinic?

1. Tell me about any conversations you have had about going to adult care?
Probes include:
   a. Tell me about that conversation
   b. Tell me about the last conversation you had with your health care provider (doctor, nurse, social worker, adherence counselor) about transferring/going to adult care.
   c. Where and when did it occur?
   d. What did you discuss?
   e. How did you feel during and after the conversation?
2. **How do you feel about going to the adult clinic?**

PROBEs include
  a. What are you looking forward to?
  b. What are you worried about?
  c. Do you know that you will be transferred?

3. **What’s the right age to move on to the adult clinic? Why?**

*Suggestions for transfer*

1. **If you were running this clinic what would you say to a teenager going to adult care? What would you tell them about? How would you prepare that person for the adult clinic?**

*Closing*

Is there anything else you would like to add? For example, maybe there is a question you think I should have asked that I didn’t.

This is the end of the interview. Thank you for your time.

*After the recorder is turned off*

How was the interview for you?
APPENDIX III

Memo Example #1

HIV as a chronic illness

26th April 2015

Transfer of care is now possible because individuals are growing up with HIV, in part because of access and adherence to antiretrovirals.

"that you know parents try their best, utmost best to disclose to them and say okay such and such and it’s not a life, it’s not a death sentence just being considered quote and quote as a chronic illness and can affect anyone.” Provider 1

Could this be potentially a new code/bucket for a code? Individuals are being transferred to adolescent clinics and then later adult care because HIV is a chronic disease. Younger medical professionals as well as older medical professionals have changed the way they think about HIV. Here the social worker uses the phrase “it’s not a death sentence” and goes on to say it is a chronic disease. Another adult provider has stated that if an adult contracts HIV that they can have a full life. But how chronic is chronic? And for those who are born with the illness, if 95% adherence is maintained through life, what is the timeline that we are looking at?

This same adult providers feels like pediatric patients especially those born with the illness should stay in pediatric care, because he is not sure of their lifespan or timeline and feels like they may not be in his care much longer.
How do the patients feel? Providers tell me patients ask about having families and careers and what is it that their providers tell them? Maybe explore with patient, in a careful and delicate way their understanding of their timeline with HIV, what they anticipate their adult life will be like with HIV? How might this relate to wanting to transfer to adult care versus not wanting to transfer to adult care.

Really interesting also that the provider comments on having parents disclose to their children. This provider works with adult patients, so I am not sure here if she is speaking from the parent perspective or based on opinions from other conversations that she has had.
Memo example #2

Nondisclosure creates barriers for adherence

April 26th, 2015

"that you can't really, to ensure that she keeps her medication at a place where you know nobody will have to go and research or you pick up and find out you know and we try to encourage her to encourage her to take her medication and stuff like that."

Provider 1

Patients and patients' parents have a wide variety of reasons why they might not disclose to other family members. These include fear the family members will no longer accept them or allow them to live at home, fear that the family members will not understand, fear that the family members will disclose the patient's status accidentally. Here in the interview I find it interesting that the social work does not talk about disclosing but instead figuring out with the client how the patient can keep her status a secret, including tips on how to hide the medication. In a way this social worker is helping the patient overcome the barrier to adherence that non-disclosure might cause. It might be interesting to explore disclosure and non-disclosure as it relates to HIV stigma and eventual transfer to adolescent and then later adult care. What are providers' stances on disclosure, is there a particular effort that is made to help patient disclose to family members? Stories of how family members react when they find out their relative has HIV? How does this relate to transfer of care if any at all? I suspect it might not.
# APPENDIX IV

## Codes: Code Book

Number of Codes: 28, commented: 28

<table>
<thead>
<tr>
<th>Code Info</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence and nonadherence to clinic visits</td>
<td>Narratives on adherence and non-adherence to clinic visits</td>
</tr>
<tr>
<td>Adherence and nonadherence to medication</td>
<td>Narratives on adherence and non-adherence to medication.</td>
</tr>
<tr>
<td>Adolescent care and development</td>
<td>Narratives of issues specifically related to caring for adolescents and the challenges that exist in caring for this age group. Include narratives about adolescent development, growing up.</td>
</tr>
<tr>
<td>Adult Clinic and Care</td>
<td>Narratives describing patient and provider perceptions and experiences in the adult clinic, including about care received in the clinic.</td>
</tr>
<tr>
<td>Barriers to transfer of care</td>
<td>Narratives about barriers to transfer of care.</td>
</tr>
<tr>
<td>Community Support</td>
<td>Narratives of support systems for HIV-infected adolescents. These exclude narratives about personnel in the medical system (Patient Provider relationship) and the home environment (Patient Family relationship).</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Narratives around issues of confidentiality, as it relates to caring for patients who are infected with HIV.</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Narratives about disclosure or nondisclosure of HIV status. Merged comment from Nondisclosure on 5/9/15, 10:18 PM Disclosure/Nondisclosure can be that of parent to affected child about parents status, parent to infected child about child’s status, adolescent/young adult to partner, adolescent/young adult to friends, adolescent/young adult to family, that of the adherence counsellor to his/her clients.</td>
</tr>
<tr>
<td>Facilitators of Care</td>
<td>Narratives describing various facilitators of care. For example, the use of contact investigators to facilitate care</td>
</tr>
<tr>
<td>Medical Literacy</td>
<td>Narratives on Adolescent knowledge of HIV.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Patient Family Relationship</strong></td>
<td>Narratives about the relationship between the patient and his/her family, this includes family of origin (biological family), as well as other individuals that the patient may be living with. This includes narratives about the home environment, about dynamics between HIV-infected patients and their parents or caregivers as it relates to care and the transfer of care. &quot;I think it have, also have to do with ahm with with ahm with ahm their parent ahm and the caregivers ahm to you know because I mean if they have ahm a positive ahm influence you know and can and is there and they adjust ahm to the settings what they are in then I don't think the child would ahm find it difficult&quot; Pediatric provider</td>
</tr>
<tr>
<td><strong>Patient Patient Relationship</strong></td>
<td>Narratives about dynamics and interactions between and amongst HIV-infected adolescents</td>
</tr>
<tr>
<td><strong>Patient Provider relationship</strong></td>
<td>Narratives about the dynamics and interactions between patients and provider.</td>
</tr>
<tr>
<td><strong>Patient demographics/characteristics</strong></td>
<td>Information about patient's background. This including how s/he contracted HIV, level of schooling, work/work experience, home environment etc.</td>
</tr>
<tr>
<td><strong>Pediatric Clinic and Care</strong></td>
<td>Narratives describing patient and provider perceptions of and experiences in the Pediatric clinic, including care received in the clinic</td>
</tr>
<tr>
<td><strong>Pediatric and adult care</strong></td>
<td>Narratives comparing and contrasting pediatric and adult care including information about the sites. Exclude explicit references to transfer of care. If A represents pediatric care and B represents adult care and the line from A to B is the transfer, then this code only represents conversations comparing and contrasting A and B. Include information about inpatient care. Include stories of when pediatric and adult care teams are involved.</td>
</tr>
<tr>
<td><strong>Provider Provider relationship</strong></td>
<td>Narratives about the dynamic/interactions between two different providers. Include the effects of this dynamic. &quot;What I generally depend on is good interpersonal relationship with the physicians in the adult clinics and essentially I call in a favor to get a fairly soon appointment&quot; Pediatric provider</td>
</tr>
<tr>
<td><strong>Provider demographics/characteristics</strong></td>
<td>Background information about the provider being interviewed. Eg. &quot;I've been working in HIV for over eight years.&quot;</td>
</tr>
</tbody>
</table>
| **Psychosocial challenges**                  | Narratives about psychosocial difficulties. Include 
narratives about psychosocial challenges to care and psychosocial challenges which can cause a barrier to transfer from paediatric to adult care. For example, Provider 5 states the challenge is “trying to get them from one point to the other” and while I assumed this was physically getting them from one point to the other, she could have also meant, getting them from point A to point B in their health. There is the challenge of low finances, “giving up” relational concerns such as difficulties with their parent, “shutting down,” nondisclosure to partner, or other household members secondary to stigma, poor education.

**Transfer from adult to pediatric care**
Narratives on transfer from adult to pediatric care. Eg. "if they get pregnant they would be transferred to an adult site where they would get that care and then they would be transferred back to us"  

**Transfer from pediatric to adult care**
Narratives of transfer from pediatric to adult care including attitudes patients or providers may have of the transfer from pediatric to adult care. Narratives about stopping stones from pediatric to adult care. Narratives about any existing processes or programs that assist in the transfer from a pediatric to adult care facility. Include narratives about reasons for transfer from pediatric to adult care. Eg. "he doesn't want to go to the kiddie clinic any more you know. He's a big man so you know, So his preference was to come to the adult clinic" Eg. "there needs to be like a defined structure and program in place to ensure that this all of the all of the needs of the client are being met once they do make that transition" - Adult Provider Eg. "I try to help them to go to reach that process and we start it from, you know, even before they are transferred to help them understand, that, you’re not going to be in the “peadi clinic” you will have to come to the Adult Clinic" - Provider Eg. "I haven’t prepared myself because there’s no plan or structure" - Adult provider Eg. ‘Will they take care of us the way how you guys \take care’ Provider commenting on patient feeling about moving from one pediatric clinic to another pediatric clinic Eg. because they are very cemented (I:mhm), with um, the nurse in the clinic here (I:mhm) so we introduce them, like I said to the Adherence Counsellors the Psychologists who offer the same telephone contact. Even though they are cemented in the clinic - Dr. is saying they offer the same kinds of services in the adult section.

**Transfer from pediatric to pediatric care**
Narratives of transfer from one pediatric clinic to another pediatric clinic.

**Transfer process**
Narratives on the transfer of care not specific to transfer from pediatric to adult care, pediatric to
pediatric care nor adult to pediatric care. These narratives can be background information; the process of the transfer.

**Understanding HIV**

Narratives of attitudes about HIV. Narratives about living with HIV. Eg. "I know that in your mental state of mind you think that it is something that you can see" - Patient

**Vertical Transmission and Horizontal Transmission**

Narratives comparing and contrasting adolescents who have been infected vertically versus those who have been infected horizontally especially as it relates to transfer of care. Eg. "somebody who is seventeen and had vertical transmission is very different from somebody who is seventeen and had horizontal transmission"

**challenges to care - the money is not there**

Narratives about economic limitations. Include narratives about stock outs, and limited personnel.

**suggestions for care**

Narratives of suggestions for improving the care of HIV positive patients.

**transfer from adult to adult care**

Narratives about the transfer from one adult clinic to another.
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15. Scal P, Evans T, Blozis S, Okinow N, and Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic


60. Bradley EH, Curry LA, and Devers KJ. Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. Health services research. 2007;42(4):1758-72.


