Published in final edited form as:

AIDS Care. 2019 March ; 31(3): 293–297. doi:10.1080/09540121.2018.1533226.

Transfer is not a transition – voices of Jamaican adolescents with HIV and their health care providers

Flavia DeSouza^a, Elijah Paintsil^b, Teisha Brown^c, Russell Pierre^d, Danya Keene^e, Nancy Kim^{a,f}, Celia Christie^d

^aDepartment of Psychiatry, Yale School of Medicine, New Haven, CT, USA;

^bDepartment of Pediatrics, Yale School of Medicine, New Haven, CT, USA;

^cMinistry of Health, South East Regional Health Authority, Kingston, Jamaica;

^dDepartment of Child and Adolescent Health, The University of the West Indies, Kingston, Jamaica;

^eChronic Disease Epidemiology, Social and Behavioral Sciences, Yale School of Public Health, New Haven, CT, USA;

^fDepartment of Internal Medicine, Yale School of Medicine, New Haven, CT, USA

Abstract

Increasing access to antiretroviral therapy in resource-limited settings (RLS) has resulted in the survival of perinatally HIV-infected children into adulthood. We characterized the transition process from pediatric to adult care by conducting semi-structured interviews of HIV-infected adolescents and health care providers in Jamaica. Using an inductive content analytic approach, four themes emerged: (1) Transition should be holistic and a process; (2) Pediatric clinics were like families; (3) Rootedness in the pediatric clinic; and (4) Need for adolescent-centered services to bridge the gap between pediatric and adult-centered services. Adolescent informed- and centered-transition approach may result in better outcomes for HIV-infected adolescents.

Keywords

Transition; adolescent; Jamaica; pediatric HIV; psychology

Introduction

With the advent of effective antiretroviral therapy (ART), children infected perinatally with HIV are surviving into adulthood. Challenges with transitioning from pediatric to adult-centered care have risen to public health significance, particularly in resource-limited

CONTACT Celia Christie celia.christiesamuels@uwimona.edu.jm Department of Child and Adolescent Health, The University of the West Indies, Mona, Kingston 7, Jamaica.

Geolocation Information
Jamaica

Disclosure statement
No potential conflict of interest was reported by the authors.

settings (RLS) (Andiman, 2011; Brady et al., 2010; Dowshen & D'Angelo, 2011; Fish et al., 2014; Foster et al., 2009; Hazra, Siberry, & Mofenson, 2010; Judd, Sohn, & Collins, 2016; Ryscavage, Macharia, Patel, Palmeiro, & Tepper, 2016; Tanner et al., 2016; Westling, Naver, Vesterbacka, & Belfrage, 2016). However, there are few studies on transition of care in RLS (Bailey, Cruz, Song-taweasin, & Puthanakit, 2017; Dahourou et al., 2017; Sharer & Fullem, 2012). In RLS, challenges with transition of care are compounded by lack of adequate infrastructure, providers without expertise in adolescent medicine, and the relatively early age of transfer to adult-centered care (Dahourou et al., 2017; Mark et al., 2017; Pettitt, Greifinger, Phelps, & Bowsky, 2013).

In Jamaica, an RLS, pediatric services are from ages 0 to 13 years; transfer from pediatric to adult-centered care occurs at 13 years. The Jamaica Pediatric, Perinatal and Adolescent HIV/AIDs program (JaPPAIDS) is a unique program which cares for their adolescents up to age 25 (Christie et al., 2008; Christie & Pierre, 2012). Evans Gilbert et al. investigated the outcomes of patients who transferred to adult care at 13 years as compared to those who remained in pediatric care in Western Jamaica (Evans-Gilbert, Reid, & Pierre, 2014). They found that adolescents who remained in pediatric care had a high rate of HIV viral suppression compared with adolescents who were transferred to adult care. The main objective of our study was to characterize the transition process of HIV-infected adolescents from pediatric to adult-centered care in Jamaica.

Methods and materials

Study design

We utilized a qualitative design (Bradley, Curry, & Devers, 2007; Malterud, 2001; Mays & Pope, 1995; Pope & Mays, 1995; Sofaer, 1999; Watling & Lingard, 2012). We explored the perspectives of HIV-infected adolescents and experiences of pediatric and adult care providers with the transfer process. Eligible adolescents were invited to participate by their health care providers. Inclusion criteria were: (1) Complete disclosure of HIV status; (2) No diagnosis of cognitive limitation or developmental delay; and (3) Patients between the ages of 13 and 24 years. Providers who cared for HIV-infected patients in the pediatric and adult setting were invited to participate. We obtained written and verbal consent from all participants.

Interviews

FD conducted 39 semi-structured interviews – 18 HIV-infected adolescents in pediatric care at the University Hospital of the West Indies (UHWI) and 21 health care providers enrolled from UHWI and public Ministry of Health clinics in the South East Regional Health Authority (SERHA) of Jamaica. Participants were asked open-ended questions regarding their knowledge, perceptions, and experiences of the transfer process (Braun & Clarke, 2013; Britten, 1995; Glaser & Strauss, 1967; Miles & Huberman, 1984). Each interview lasted for 30 to 60 minutes.

Analysis

We used the qualitative analysis software (ATLAS.ti 7.0, Scientific Software Development, Berlin, Germany) to facilitate data organization and retrieval. First, we reviewed transcripts and generated codes. We refined codes until we agreed on the coding schema (Miles & Huberman, 1984). Themes were checked iteratively and examined for overall trends through and after the interview period until analysis was completed (Glaser & Strauss, 1967).

Ethics

The study protocol was reviewed and approved by Yale University School of Medicine Institutional Review Board, the University of the West Indies (UWI) Ethics Committee, and The Advisory Panel on Ethics and Medico-legal Affairs, Ministry of Health, Jamaica.

Results

Demographic characteristics of participants

We enrolled adolescents from 13 to 24 years old between February 2015 to August 2015, from the Pediatric Infectious Disease (PID) clinic at UHWI (Table 1). The PID clinic is a part of the JaPPAIDs program. Some of them had received inpatient care at adult wards. Providers represented a range of health care professionals including pediatricians, internists, nurses, social workers, adherence counselors, and a psychologist (Table 2).

We used participants' verbatim quotations to illustrate the themes that emerged. Provider designations are from P1 to P21, with gender, provider type, and location. Adolescent designations for from A1 to A18, with gender and age noted.

Transfer is not a transition

One of the themes was transfer is not a transition.

What normally happens is that we write a summary, we try to make a one-on-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 ... there is no specific transition process. (P7, Female/Pediatrician/UHWI)

Both adolescent participants and providers desired a holistic transition process, including an early introduction to the idea of transfer, patient education and empowerment, as well as a clear plan for the continuity of care of the adolescent during and after the transfer.

Pediatric clinic as family

Pediatric clinics were like families who provided caretaking and developmental support in addition to HIV care. Adolescent patients described their clinicians as second parents and perceived their providers felt the same level of connectedness towards them. One adolescent who had HIV negative siblings at home shared,

The only brother and sister I would feel like I have are those adolescents who attend the clinic ... everyone here understands me so when I come here I don't feel

... out of placeWhen I am here I don't feel different, I just feel complete. (A6, Female/14 years)

Rootedness in pediatric care

Given the social significance of pediatrics clinics in participants' lives, alongside the concerns regarding adult care, there was rootedness in the pediatric clinic and apprehension about transfer to the adult clinic. Four the adolescents had clear, strong hesitations about transferring to the adult clinic. "I don't want to see any new doctor, he (my current doctor) 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, Male/18 years)

Bridging the health care gap for HIV-infected adolescents

Providers spoke about the lack of and need for specialized in-patient and outpatient adolescent services. For example, several providers commented on the difficulty of being an ill adolescent on the adult ward.

In the Public Health system they have to go, once they pass 12 (years), they have to go to the adult ward ... 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, Male/ Pediatrician/UHWI)

Discussion

In this study, we found that HIV-infected adolescents Jamaica had strong opinions and reservation about the current transition process in Jamaica. Four main themes emerged: (1) Transition should be holistic and a process; (2) Pediatric clinics were like families; (3) Rootedness the pediatric clinic; and (4) Need for adolescent-centered services to bridge the gap between pediatric and adult care.

These themes highlight factors that affect the transition process and barriers to the transition of HIV-infected adolescents in Jamaica. Several reported barriers to transition are common to both resource-rich settings and RLS, including issues related to attachment to the pediatric provider (Andiman, 2011; Bailey et al., 2017 Dahourou et al., 2017; Dowshen & D'Angelo, 2011; Hussen et al., 2015; Lam, Fidler, & Foster, 2017). These barriers amplified are in RLS by extreme poverty, as well as the lack of adolescent services and transition infrastructure (Bailey et al., 2017; Dahourou et al., 2017).

In Jamaica, most pediatric providers are not equipped nor have the resources to take care of adolescents, so they transfer care at 13 years according to the national cut-off age for pediatric care. Early transfer of adolescents to adult-centered care is a unique issue facing HIV-infected adolescents in Jamaica and other RLS countries with limited formal adolescent services (Dahourou et al., 2017). Outcomes of transition to adult-centered care in resource-rich countries with structured adolescent care and providers with expertise in adolescent medicine of are much better than in RLS (Bailey et al., 2017; Mark et al., 2017; Tepper, Zaner, & Ryscavage, 2017). Moreover, apprehension about the transfer to the adult clinic

could be mitigated by formalizing adolescent-centered services. These include early and standardized education given to adolescents about the transition process and involvement of providers with expertise in adolescent medicine.

Our study had several strengths. First, the use of two researchers to independently analyze the transcripts improved the validity of the study. Second, we interviewed 39 subjects, which in our study was sufficient to arrive at thematic saturation (Mays & Pope, 1995). Limitations of this study include those associated with qualitative interviews. Because we interviewed a 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 may be limited.

In summary, a successful transition process should take into consideration the views and opinions of HIV-infected adolescents. Adolescent informed- and centered-transition approach may result in better outcomes for HIV-infected adolescents such as linkage to and in retention in care, viral load suppression, and a reduction in new HIV infection in adolescents and young adults (Dahourou et al., 2017; Mark et al., 2017; Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011; Ryscavage et al., 2016).

Acknowledgments

We would like to thank the participants for sharing their stories and the staff of the Pediatric Infectious Diseases Clinic at the University Hospital of the West Indies for their support.

Funding

This work was funded in part by the Doris Duke Charitable Foundation through a grant supporting the Doris Duke International Clinical Research Fellows Program at Yale School of Medicine.

References

- Andiman WA (2011). Transition from pediatric to adult healthcare services for young adults with chronic illnesses: The special case of human immunodeficiency virus infection. *The Journal of Pediatrics*, 159(5), 714–719. doi:10.1016/j.jpeds.2011.06.040. [PubMed: 21868035]
- Bailey H, Cruz MLS, Songtaweasin WN, & Puthanakit T (2017). Adolescents with HIV and transition to adult care in the Caribbean, Central America and South America, Eastern Europe and Asia and Pacific regions. *Journal of The international Aids Society*, 20(Suppl 3), 21475. doi:10.7448/IAS.20.4.21475. [PubMed: 28530040]
- Bradley EH, Curry LA, & Devers KJ (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758–1772. doi:10.1111/j.1475-6773.2006.00684.x. [PubMed: 17286625]
- Brady MT, Oleske JM, Williams PL, Elgie C, Mofenson LM, Dankner WM, ... Pediatric ACTGCT (2010). Declines in mortality rates and changes in causes of death in HIV-1-infected children during the HAART era. *Journal of Acquired Immune Deficiency Syndromes*, 53(1), 86–94. doi:10.1097/QAI.0b013e3181b9869f. [PubMed: 20035164]
- Braun V, & Clarke V (2013). *Successful Qualitative Research: A Practical Guide for Beginners*.
- Britten N (1995). Qualitative interviews in medical research. *BMJ*, 311(6999), 251–253. [PubMed: 7627048]
- Christie CD, & Pierre RB (2012). Eliminating vertically-transmitted HIV/AIDS while improving access to treatment and care for women, children and adolescents in Jamaica. *West Indian Medical Journal*, 61(4), 396–404. [PubMed: 23240475]

- Christie CD, Steel-Duncan J, Palmer P, Pierre R, Harvey K, Johnson N, ... Figueroa JP (2008). Paediatric and perinatal HIV/AIDS in Jamaica an international leadership initiative, 2002–2007. *West Indian Medical Journal*, 57(3), 204–215. [PubMed: 19583118]
- Dahourou DL, Gautier-Lafaye C, Teasdale CA, Renner L, Yotebieng M, Desmonde S, ... Leroy V (2017). Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: Challenges, youth-friendly models, and outcomes. *Journal of The international Aids Society*, 20(Suppl 3), 21528. doi:10.7448/IAS.20.4.21528. [PubMed: 28530039]
- Dowshen N, & D'Angelo L (2011). Health care transition for youth living with HIV/AIDS. *Pediatrics*, 128(4), 762–771. doi:10.1542/peds.2011-0068. [PubMed: 21930548]
- Evans-Gilbert T, Reid G, & Pierre R (2014). G-113 Perinatally HIV infected adolescents and early transition to adult care. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 67(73), doi:10.1097/01.qai.0000456166.66149.ce.
- Fish R, Judd A, Jungmann E, O'Leary C, Foster C, & Network HIVYP (2014). Mortality in perinatally HIV-infected young people in England following transition to adult care: An HIV Young Persons Network (HYPNet) audit. *HIV Medicine*, 15(4), 239–244. doi:10.1111/hiv.12091. [PubMed: 24112550]
- Foster C, Judd A, Tookey P, Tudor-Williams G, Dunn D, Shingadia D, ... Collaborative, H. I. V. P. S. (2009). Young people in the United Kingdom and Ireland with perinatally acquired HIV: The pediatric legacy for adult services. *AIDS Patient Care and STDs*, 23(3), 159–166. doi:10.1089/apc.2008.0153. [PubMed: 19866533]
- Glaser BG, & Strauss AL (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine Publishing Company.
- Hazra R, Siberry GK, & Mofenson LM (2010). Growing up with HIV: Children, adolescents, and young adults with perinatally acquired HIV infection. *Annual Review of Medicine*, 61, 169–185. doi:10.1146/annurev.med.050108.151127.
- Hussen SA, Chahroudi A, Boylan A, Camacho-Gonzalez AF, Hackett S, & Chakraborty R (2015). Transition of youth living with HIV from pediatric to adult-oriented healthcare: A review of the literature. *Future Virology*, 9 (10), 921–929. doi:10.2217/fvl.14.73. [PubMed: 25983853]
- Judd A, Sohn AH, & Collins IJ (2016). Interventions to improve treatment, retention and survival outcomes for adolescents with perinatal HIV-1 transitioning to adult care: Moving on up. *Current Opinion in HIV and Aids*, 11 (5), 477–486. doi:10.1097/COH.0000000000000302. [PubMed: 27272537]
- Lam PK, Fidler S, & Foster C (2017). A review of transition experiences in perinatally and behaviourally acquired HIV-1 infection; same, same but different? *Journal of The international Aids Society*, 20(Suppl 3), 21506. doi:10.7448/IAS.20.4.21506. [PubMed: 28530044]
- Malterud K (2001). The art and science of clinical knowledge: Evidence beyond measures and numbers. *Lancet*, 358 (9279), 397–400. doi:10.1016/S0140-6736(01)05548-9. [PubMed: 11502338]
- Mark D, Armstrong A, Andrade C, Penazzato M, Hatane L, Taing L, ... Ferguson J (2017). HIV treatment and care services for adolescents: A situational analysis of 218 facilities in 23 sub-Saharan African countries. *Journal of The international Aids Society*, 20(Suppl 3), 21591. doi:10.7448/IAS.20.4.21591. [PubMed: 28530038]
- Mays N, & Pope C (1995). Rigour and qualitative research. *BMJ*, 311(6997), 109–112. [PubMed: 7613363]
- Miles M, & Huberman A (1984). *Qualitative data analysis: A sourcebook of new methods*. London, UK: SAGE Publications.
- Pettitt ED, Greifinger RC, Phelps BR, & Bowsky SJ (2013). Improving health services for adolescents living with HIV in sub-Saharan Africa: A multi-country assessment. *African Journal of Reproductive Health*, 17(4 Spec No), 17–31. [PubMed: 24689314]
- Pope C, & Mays N (1995). Reaching the parts other methods cannot reach: An introduction to qualitative methods in health and health services research. *BMJ*, 311(6996), 42–45. [PubMed: 7613329]

- Ryscavage P, Anderson EJ, Sutton SH, Reddy S, & Taiwo B (2011). Clinical outcomes of adolescents and young adults in adult HIV care. *Journal of Acquired Immune Deficiency Syndromes*, 58(2), 193–197. doi:10.1097/QAI.0b013e31822d7564. [PubMed: 21826014]
- Ryscavage P, Macharia T, Patel D, Palmeiro R, & Tepper V (2016). Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. *AIDS Care*, 28(5), 561–565. doi:10.1080/09540121.2015.1131967. [PubMed: 26766017]
- Sharer M, & Fullem A (2012). Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa. Retrieved from http://www.aidstar-one.com/sites/default/files/AIDSTAR-One_TechnicalBrief_ALHIV_Transition.pdf
- Sofaer S (1999). Qualitative methods: What are they and why use them? *Health Services Research*, 34(5 Pt 2), 1101–1118. [PubMed: 10591275]
- Tanner AE, Philbin MM, DuVal A, Ellen J, Kapogiannis B, Fortenberry JD, & Adolescent Trials Network for, H. I. V. A. I. (2016). Transitioning HIV-positive adolescents to adult care: Lessons learned from twelve adolescent medicine clinics. *Journal of Pediatric Nursing*, 31(5), 537–543. doi:10.1016/j.pedn.2016.04.002. [PubMed: 27133767]
- Tepper V, Zaner S, & Ryscavage P (2017). HIV healthcare transition outcomes among youth in North America and Europe: A review. *Journal of The international Aids Society*, 20(Suppl 3), 21490. doi:10.7448/IAS.20.4.21490. [PubMed: 28530041]
- Watling CJ, & Lingard L (2012). Grounded theory in medical education research: AMEE Guide No. 70. *Medical Teacher*, 34(10), 850–861. doi:10.3109/0142159X.2012.704439. [PubMed: 22913519]
- Westling K, Naver L, Vesterbacka J, & Belfrage E (2016). Transition of HIV-infected youths from paediatric to adult care, a Swedish single-centre experience. *Infectious Diseases (London)*, 48(6), 449–452. doi:10.3109/23744235.2016.1143964.

Table 1.

Characteristics of adolescents.

Characteristic	Value
Female <i>N</i> (%)	14 (78)
Median age (range)	18 years and 8.5 months (13 years - 23 years 7 months)
Median years in UHWI pediatric clinic (range)	12 years 7.5 months (1 year 1 month - 16 years 9 months)
<i>Mode of infection</i>	
Perinatal	11
Intercourse (forced or consensual)	3
Unknown	4
<i>CDC Clinical Data</i>	
A	2
B	5
C	11
<i>ARTs</i>	
1st line	7
2nd line	10
Salvage therapy	1
<i>School History</i>	
Some college	0
High school graduate	4
Some high school	8
Trade/Skills school (only) all	(5) 8
Remedial school at government state home only	1
<i>Living circumstances</i>	
Independent	1
With biological relatives	10
With non-biological guardian	1
With partner	3
With friend	1
State Care	2

Table 2.

Characteristics of providers.

Characteristic	Value
Median years of service in HIV in Jamaica (range)	8 (2.5–23)
Median number of clinics served (range)	1 (1–10)
Women <i>N</i> (%)	19 (90)
<i>Type of health care professional</i>	
Physician	6
Nurse	7
Social worker	4
Adherence counselor	3
Psychologist	1
<i>Primary Work Setting</i>	
Public	13
University Hospital based practice	8