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Adolescent and Adult HIV Providers' Definitions of HIV-Infected Youths' Successful Transition to Adult Care in the United States

Morgan M. Philbin, PhD, MHS,[1] Amanda E. Tanner, PhD, MPH,[2] Alice Ma, PhD, MPH,[3]
Brittany D. Chambers, PhD, MPH,[4] Samuella Ware, MPH,[2] Elizabeth N. Kinnard, MS,[1]
Sophia A. Hussen, MD, MPH,[5] Sonia Lee,[6] and J. Dennis Fortenberry, MD, MS[7]

Abstract

It is important for both individual- and population-level health that HIV-infected individuals progress through the Care Continuum. However, HIV-infected youth frequently disengage from care during transition from pediatric/adolescent to adult care; only 50% remain in adult care after 1 year. Understanding how providers define and approach a successful healthcare transition can improve the delivery of HIV-related services during critical years of HIV treatment. We conducted 58 staff interviews across 14 Adolescent Trials Network clinics ($n = 30$) and 20 adult clinics ($n = 28$). We used the constant comparative method to examine how providers defined and approached youths' successful transition. Providers identified four components critical to successful transition: (1) clinical outcomes (e.g., medication adherence and viral suppression); (2) youth knowing how to complete treatment-related activities (e.g., refilling prescriptions and making appointments); (3) youth taking responsibility for treatment-related activities and their overall health (e.g., ''when they stop reaching out to the adolescent [clinic] to solve all their problems.''); and (4) youth feeling a connection and trust toward the adult clinic (e.g., ''they feel safe here''), with some providers even prioritizing connectedness over clinical outcomes (e.g., ''Even if they're not taking meds but are connected [to care], …that's a success.''). The identification of key components of successful transition can guide focused interventions and resources to improve youth maintenance in the HIV Care Continuum as they transition to adult care. Identifying what facilitates successful transitions, and the gaps that interventions can target, will help to ensure HIV-infected youth remain healthy across their lifespan.

Keywords: HIV/AIDS, adolescent health, care transition, transition success, qualitative, barriers to care

Introduction

Contemporary medicine provides many HIV-infected individuals with the possibility of decades of health and wellbeing, making HIV a chronic, manageable condition.[1] Such statements, however, are predicated on assumptions of a streamlined process of care and treatment that is contingent upon care that is accessible, sustainable, and responsive to patients' changing needs over the life course. Such goals of a streamlined process rarely align with clinical realities—particularly at the stage when HIV-infected youth transition from pediatric/adolescent to adult care. This transition is particularly important because in the United States rates of HIV infection are relatively high among young people, particularly men who have sex with men, who will need to successfully complete this transfer to an adult clinic to maintain health across their lifespan.[2]

Healthcare transition (HCT) is the planned and purposeful movement of youth from child-centered to adult-centered care. In the next decade, 25,000 HIV-infected youth in the

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[1] Department of Sociomedical Sciences, Columbia University Mailman School of Public Health, New York, New York.
[2] Department of Public Health Education, University of North Carolina Greensboro, Greensboro, North Carolina.
[3] Department of Applied Health, Southern Illinois University Edwardsville, Edwardsville, Illinois.
[4] Preterm Birth Initiative, University of California San Francisco, San Francisco, California.
[5] Hubert Department of Global Health, Emory University Rollins School of Public Health, Atlanta, Georgia.
[6] Maternal and Pediatric Infectious Disease Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, Bethesda, Maryland.
[7] Department of Pediatrics, Indiana University School of Medicine, Indianapolis, Indiana.

United States will need HCT, although research suggests that only 50% will remain in adult care after 1 year.[3,4] While this transition process in the United States can happen as early as 18 years of age, the majority of youth transition to adult care at 24 years of age and the standard of care is that youth transition by age 25.

This transition often requires that youth access different healthcare systems (e.g., insurance), which is not only complicated but also sometimes forces youth to do without programs to which they have become accustomed. As a result, youths' use of healthcare and support services declines significantly during HCT.[5] To help HIV-infected youth remain healthy, we must better understand what it means to transition successfully and how to facilitate such a transition.

Apart from some notable exceptions,[6–10] HIV-infected youths' HCT process remains understudied, particularly from the perspective of the receiving adult providers. Existing studies have described the process itself and relevant barriers and facilitators to transition,[7,11] but there is little consensus on, or even discussion of, what constitutes a successful transition.[12] To our knowledge, only two studies[12,13] have explicitly examined how providers define transition success for HIV-infected youth, and their findings revealed little consistent definition of ''successful'' transition or consensus regarding specific elements of a transition program.

However, stages along the HIV Care Continuum, such as linkage and engagement, can provide insights about how providers might define success. Linkage and engagement success is often defined by the number of clinic visits within a given time frame—for example, three visits within 1 year—or presence of a biological marker that indicates a clinic visit (e.g., viral load).[14,15] Although some researchers argue that success can be defined based on an individual's viral suppression, the HIV Medicine Association guidelines highlight how the ''emphasis should be placed on the importance of adherence to care rather than focusing solely on adherence to medications.''[16]

Studies of other chronic diseases (e.g., sickle cell and diabetes) define transition success based on functional outcomes such as attending the first posttransition visit.[17,18] More broadly, findings demonstrate the importance of disease self-management by youth,[18] completion of treatment-related activities (e.g., make appointments and fill prescriptions), connection to supportive indivdiuals,[19] and overall care satisfaction.[17]

To address the relative lack of data to help develop integrated clinical services for HIV-infected youths' HCT, there are multiple important perspectives for defining HCT for HIV-infected youth, and this study examined how staff at adult and adolescent HIV clinics defined successful transition and how such definitions informed their approach to youths' HCT. Improvement of such services is particularly important because adolescence is often ambiguously represented in service delivery systems, and divided between pediatric and adult specialties, and it is thus not always clear what is needed for youth to successfully transition to adult care.

Methods

Data for the Comprehensive Assessment of Transition and Coordination for HIV-positive Youth as they Move from Adolescent to Adult Care (CATCH) study were collected from 14 Adolescent Medicine Trials Network (ATN) clinical sites and 20 adult clinics in the United States that received transitioning youth. Two qualitatively trained researchers conducted 58 semistructured interviews from August 2015 to June 2016, with medical and social service providers who transitioned youth from ATN sites ($n = 30$) or received youth at adult clinics ($n = 28$). Providers at the adolescent and adult clinics were contacted via email and/or phone and invited to participate.

Purposive sampling was used to choose individuals whose role included supporting youth as they transitioned from pediatric/adolescent to adult clinical HIV care. Interviews lasted ~45 min (range = 22–78 min) and were conducted over the phone, recorded, and professionally transcribed; all interviewees provided verbal consent and received a $25 Amazon gift card for participating. Interview themes included transition processes and protocols; definitions of success, facilitators, barriers, and solutions to HCT; and interclinic relationships. Institutional Review Boards at the University of North Carolina Greensboro and participating ATN sites approved the study.

Data were analyzed using the constant comparative method[20,21] to examine how providers described and approached HCT, with a focus on their descriptions of what constituted success. In addition to descriptions of transition success arising organically throughout the interview, at the end, we explicitly asked providers how they define a successful transition.

Team members independently read and coded each transcript to create a codebook. We subsequently incorporated thematic codes based on existing literature to ensure that theory-based concepts were included. This codebook was reviewed and amended by other team members.[22] Codes were summarized and refined within a data table,[21] and incorporated into a matrix to compare clinics' descriptions of successful HCT processes. The coders independently applied the finalized codes to all transcripts using Atlas.ti Version 7, resulting in a 90% interrater agreement. Coders then searched transcripts and field notes for negative cases about discussions of transition success, modified the coding matrix as needed, and returned to the transcripts for additional comparisons.[21] Coding disagreements were resolved through consensus of the entire research team.

Results

The majority of clinics in this study developed transition-specific protocols to help youth achieve a successful transition (Table 1). Nine adolescent clinics had formal protocols and 5 had informal protocols; 4 adult clinics had formal protocols, 14 had informal protocols, and two had no protocol. Interestingly, only two protocols explicitly defined transition success—that is, a young person attending two adult medical appointments or having two blood draws. In contrast, when we interviewed providers about transition success, they identified four critical components: (1) clinical outcomes; (2) youth knowing how to complete treatment-related activities; (3) youth taking responsibility for treatment-related activities and their overall health; and (4) youth feeling connection and trust toward the adult clinic.

Clinical outcomes

When discussing what constitutes successful HCT, providers frequently referenced benchmarks outlined in documents such as the National HIV/AIDS Strategy: clinic attendance and viral suppression. Providers uniformly stressed the importance of the initial visit, ''Well, when they actually come to their transition appointments, that's a start'' (adolescent MD, site I1), but made clear that attendance at one visit was insufficient to determine success.

An adolescent pediatrician (site V1) described how successful clinic attendance could only be ensured after a period of time, and should be coupled with medication adherence: ''They're in care a year after transitioning. And I think one indicator is they don't have a gap in obtaining medications. They're just seamlessly able to continue their medications.'' This sentiment was supported by an adult social worker (site Tb1) who shared that, ''Adherence to the appointments, the medications, and very adamant about primary care. That would be a success.''

In addition to adherence, most providers identified viral suppression as imperative to transition success. An adult physician (site Xa1) noted how important it is that youth, ''Not just come…there has to be some clinical outcome also linked to it. So they're coming and they're taking their medicine and continuing to be virologically suppressed. I think you have to put the two together.'' Providers felt that while viral suppression was ideal, it was often challenging to obtain. They therefore described myriad factors that must occur for a young person to successfully transition, nearly all of which involved the following intermediary steps: knowledge, responsibility, and connectedness.

Youth knowing how to complete treatment-related activities

Providers uniformly highlighted the importance of clinical outcomes, but acknowledged that these could not be achieved without youth first knowing how to complete intermediary, logistical treatment-related activities. Specifically, youth had to learn how to complete tasks previously arranged by their adolescent care manager/social worker, such as make their own appointments, refill medication, and maintain insurance coverage. Providers stressed that even this process often involved intermediary steps: youth frequently first learned whom to reach out for help. As one adult clinic social worker (site Xa1) described, it was important that youth, ''Know who to call when they need help…They know the number to the refill line and they will call that refill line or call their nurse and get assistance.''

Another important treatment-related skill youth had to learn was maintaining continuous insurance coverage. An adolescent social worker (site W1) described that success was determined by youths' ''ability to maintain their health insurance on their own without too many lapses.'' Providers believed that youth should know how to renew their insurance, or recertify coverage under the AIDS Drug Assistance Program every 6 months. However, providers acknowledged that even youth who had the necessary knowledge to complete such actions might not take responsibility to actually follow through. As such, they should have the skills to contact their adult provider for help. An adult nurse practitioner (site Wa1) described this as:

> *Patients may miss a mailing and didn't realize that they had to contact their insurance company to keep it. So they may lose their insurance, but I think the indication [of success] would be them notifying us and saying I think my insurance is gone.*

One way to facilitate care engagement was for youth to access ancillary services (e.g., education and housing) that could address some of the upstream factors that help youth improve overall health and maintain adherence. Accessing such services independently might be challenging, and clinic staff stressed that one marker of successful transition was youth recognizing when they needed help accessing necessary services or overcoming barriers that could hinder their HCT, and then reaching out to providers to help them overcome these barriers. Providers then worked to address these challenges to help youth successfully attend that first appointment and then be able to build toward a successful transition. An adult clinical case manager (site Xa1) noted the importance of youth knowing when and how to contact clinic staff if they needed help:

> *Because it's our job to hit those barriers. Like, we do the housing, we do the insurance. We do the transportation. Because if you really work on those social issues, then they honestly have no other excuse to be noncompliant unless they just don't want to…that is a definition of a successful transition.*

Helping youth address these social-structural barriers would allow them to focus on, and take responsibility for, the other challenges associated with transitioning (e.g., new clinic and new staff).

Youth taking responsibility for treatment-related activities and their overall health

Along with the more concrete benchmarks mentioned above—clinical outcomes and youth knowing how to engage in treatment-related activities—providers described a third aspect of successful transition: youth taking responsibility for HIV treatment-related tasks and their overall health and wellbeing. Successful youth were expected not just to know who to reach out to for support, but to independently complete treatment-related tasks. Specifically, they recognized the need for a task (e.g., running low on medication would require requesting a refill) and followed through on their own (e.g., going to the pharmacy to pick up the refill).

Providers routinely described successful HCT as occurring once youth were ''very independent,'' ''on top of everything,'' and ''taking care of everything themselves'' (adult case manager, site Uc1). An adolescent clinic social worker (site W1) described how youth must move from a stage where, ''They're still calling us to say, 'Hey, I need an appointment,' and then we're calling [the adult clinic] across the street'' to a stage where they complete these activities independently. Similarly, an adolescent nurse practitioner (site P1) noted that youth must do more than know whom to reach out for help; they must assume responsibility for their own care: ''They need to show up on time for their appointments. They need to schedule their own appointments, [even though] there may be less services around their appointments.''

In addition to attending appointments, youth should be engaged once they arrive. An adolescent physician described this engagement as, ''They are taking good care of it [HIV], and they know how to use the healthcare system well'' (site U1). A successful transition moved beyond young engagement in HIV-related care and required that youth address their overall health and wellbeing. A nurse practitioner shared how she would also focus on, ''Other health issues like their tobacco use and safe sex'' and expected youth to be equally engaged (site Wa1). Similarly, an adolescent social worker (site W1) asked questions, such as, ''Are you doing the things that we need you to do to remain healthy? Do you feel like you've got everything under control?'' The majority of providers took this holistic approach to transition and expanded their definition of success to include factors beyond viral suppression. As an adult physician (site Xa1) noted:

> *I think the metric is that they really demonstrate that they want to and will engage in the clinic. Then getting their medications, starting them, and some demonstration that they are actually taking them…I'd probably say the most specificity I get is around making the appointments. If out of five appointments they miss one, I'd say that's probably a successful transition.*

In sum, an adult pharmacist (site Na1) described a successful transition as when she ceases to see a young person as a transitioning patient and more like a ''part of the general population.'' This integration into the general population demonstrated that the youth not only knew how to engage in treatment-related activities but they also took the responsibility for actually doing so.

Youth feeling connection and trust toward the adult clinic

The final benchmark of a successful transition, and what providers often described as the most important, was youth feeling connected to the adult clinic. This meant that youth ''stop reaching out to the adolescent program to solve all their problems. When they actually consider this their new clinic, they actually think that this is where they're getting their care'' (pharmacist, site Na1). This was described as particularly important since youth who faced challenges often attempted to reengage at the adolescent clinic instead of reaching out to the adult clinic. As an adult physician (site Wa1) noted, ''The biggest thing, [is] that they come back again. That they talk to us and we get to know them. That they build some trust in the people that they're working with.''

Building this trust was an extended process that could take months or even years, and providers often pushed back against some of the traditional metrics that suggest transition could occur after one or two visits. An adult pharmacist (site Na1) shared how important it is that youth, ''start opening up, and they feel like they can actually ask questions that they feel uncomfortable asking at the beginning…It's not really number of visits. It's when they feel like they're having a conversation and feel comfortable with their doctor.''

Providers also identified youths' honesty as a factor related to successful HCT, specifically around factors like adherence and missed appointments. This ability to feel connected not only facilitated youths' engagement with a clinic but also improved overall health by facilitating challenging conversations. As an adult physician (site Xa1) shared, ''having it be a two-way discussion around their healthcare…when we come to the assessment and plan parts of the visit, can they tell me if it's something that's going to work or if it's something that's not going to work.''

Some providers felt that the goal of achieving connectedness was more important than achieving viral suppression. As an adult physician (site Xa1) noted:

> *They're connected…Even if they're not taking their medicines, they're engaged. They still come in and they still talk about how it's a struggle to not take their medicines, rather than not seeing them for a year…That sort of engagement piece, connected piece, connectedness, is critical. But that to me is a success.*

This focus on connectedness, at times more so than clinical outcomes, aligned with providers' overarching goal to facilitate long-term retention. This approach allowed them to stay connected with youth who were not yet adherent as well as those who were virally suppressed in case they potentially faced challenges that kept them from maintaining suppression.

Discussion

Research and resources have increasingly focused on individuals' progression through the HIV Care Continuum. Although this progression is imperative, we must also focus resources on certain life stages, at which individuals are at high risk of care disengagement. One such stage is youths' transition from pediatric/adolescent to adult care. HCT requires similar resources to the newly infected youths' care linkage and engagement[23] (since HCT is the process of linkage/engagement in a new clinic), although it often has poorer outcomes.

A study of nearly 1700 newly diagnosed youth found that 62% were linked and engaged within 6 months,[24] and that a shorter time to linkage was associated with care engagement.[25] In contrast, ~50% of transitioning youth remain in adult care after 1 year.[3,4] It is imperative to explore multiple perspectives in defining HCT, and this study therefore focused on one of these perspectives, namely providers. This approach helped identify factors critical to transition success for HIV-infected youth to inform how HIV-related healthcare services can be structured in ways that support youths' HCT.

First, providers identified clinic attendance and viral suppression as imperative to transition success. However, they acknowledged that many youth were unprepared or unable to achieve such benchmarks. Indeed, only one-third of HIV-infected adults—and less than 10% of youth—achieve viral suppression.[26] This suggests that youth need additional support to progress through the Care Continuum. This aligns with the second key to transition success: having the knowledge to complete treatment-related activities (e.g., medication refills and appointment scheduling). Research suggests that youth often rely on social workers and case managers at the adolescent clinics to complete many of these tasks, which serves as a barrier when they transition to the adult clinic and must shoulder such responsibilities.[27,28] Clinic protocols could therefore outline how social service providers could collaborate with youth to teach them how to complete such activities themselves and to help them feel empowered to do so.

A third key factor is youth independently completing these treatment-related activities and taking responsibility for their overall health. Research among youth living with a chronic illness demonstrates the important role youth independence has on medical outcomes, and transitioning youth assuming responsibility more generally.[5,18,19] Finally, providers stressed the importance of youth feeling connected to the adult clinic, a factor that is also relevant to newly HIV-infected youth being linked to care.[27,29] Research suggests that generating this connectedness facilitates youths' willingness to attend visits and helps them progress to a place where they were willing and able to maintain viral suppression.[1,5] Adult clinics, however, are often under resource constraints that

Table 1. Adolescent and Adult Clinic Staff Descriptive Statistics

Characteristics and roles	*Adolescent clinic,* n *(%)*	*Adult clinic,* n *(%)*	*Combined,* n
Gender			
Male	4 (13.3)	6 (21.4)	10
Female	26 (86.7)	22 (78.6)	48
Total	30	28	58
Occupation or role in clinic			
MD or MD/professor	7 (23.3)	11 (39.3)	18
NP	7 (23.3)	2 (7.1)	9
Social worker	8 (26.7)	5 (17.9)	13
Case manager	3 (10.0)	3 (10.7)	6
Linkage to care/ patient coordinator or supervisor	3 (10.0)	4 (14.3)	7
Other	2 (6.7)	3 (10.7)	5
Total	30	28	58
Time worked in clinic			
Years	8 (range 1–25)	9 (range 2–25)	

NP, nurse practitioner.

make developing these connections challenging.[30] In addition, how best to evaluate this connectedness, and ameliorate potential problems, remains understudied.

In addition to identifying what constitutes success, adolescent clinics must be able to access adult clinic data to know whether youth have successfully transitioned or if they need additional support.[10,30] However, the development of such a tracking structure frequently depends on outside funding streams. These funding streams are often tenuous and, if eliminated, hinder clinics' ability to support youths' transition. Although the transition process was relatively well-codified among adolescent clinics (nearly all had formal protocols), the same was not true of the adult clinics. This could challenge clinics' ability to help youth meet the key components of a successful transition or to identify where additional support may be needed.

These findings, including issues around data sharing and health insurance, may be somewhat unique to the United States because of the lack of a nationalized healthcare system. The ways in which health insurance is structured in the United States requires that clinic staff spend additional time and resources to ensure that youth are able to access care in existing adult clinics. The lack of a nationalized healthcare system also means that that there is very little infrastructure for transition and what does exist may be fragmented because systemic change cannot happen at a national level. The way providers define transition success may therefore look different Western Europe or Canada, for example, because steps such as ensuring the transfer of a medical records and that a young person knows how to access insurance are not required.

Findings from this study suggest a number of factors crucial to HCT that could be targets for intervention development. The first is the increased need for interclinic data sharing so providers know whether a youth's HCT was successful. Interventions could work to increase collaboration between adolescent and adult clinics, and local health departments,[31] to facilitate the sharing of medical records. This increased data sharing would allow adolescent clinicians to know whether a young person had attended an adult appointment—and whether they were virally suppressed—and for adult clinicians to know whether a youth who missed appointments had fallen out of care or had simply sought care elsewhere. Second, it is important that youth know how to, and are willing to, reach out to their HIV clinic for challenges not directly related to their HIV care. Interventions could work with youth and providers to frame care in a holistic way that ensures youth feel comfortable coming to the clinic for services such as housing, education, reproductive health, and mental health.[32] Accessing these other services will, in turn, increase youths' connectedness to the clinic and support HCT.

Third, it is imperative to increase youths' sense of clinical connectedness by facilitating communication between providers and youth, even youth who are not currently attending clinic visits. One potential intervention is the use of mobile health apps[33] that could support patient–provider contact and increase clinical connectedness. This increased connectedness could, in turn, facilitate youth's willingness to reach out to providers for help addressing additional concerns (e.g., reengaging in care, renewing insurance, helping a partner access preexposure prophylaxis,[34] and so on). Integrating clinical connectedness—which could, for example, be measured by perceived strength of relationships, youths' comfort asking questions of providers, or volume of interactions—with biological measures would also provide a more comprehensive assessment of how engaged a youth is in clinical care.

Limitations

Several limitations should be considered. First, the participating sites represented urban areas with relatively high HIV prevalence among youth. HCT may be affected by different issues in lower prevalence cities, or for youth living in rural areas. Transitioning youth were not interviewed, although some studies have already addressed those perspectives on HCT. In addition, providers had varying clinical roles and experiences in transitioning youth, which could differentially impact their perspectives. Social workers or case managers typically deliver clinic services, thus, it is possible that some providers may not know of all social services offered in their clinic.

Conclusions

The nascent research on HCT for HIV-infected youth has defined success as having a nonpediatric provider, insurance, recent healthcare visit, and no treatment delay.[12] This study, however, identified more nuanced factors that influence HCT success. Although factors commonly touted as markers of success for other chronic diseases—for example, clinic attendance and medication adherence—are critical, they constitute only one aspect of success. In addition, focusing on the ultimate outcome (i.e., viral suppression) may overshadow the intermediary steps that youth must also learn and master.

The identification of these key components of successful transition can guide focused interventions to support adolescent and adult clinics and improve youth maintenance in the HIV Care Continuum as they transition to adult care. Future research must focus on how HIV-infected youth think about and approach transition to better understand what is most important to them and how they choose to exert their own agency throughout the transition process. Identifying what facilitates successful transitions, and the gaps that interventions can target, will help to ensure HIV-infected youth remain healthy across their lifespan.

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Address correspondence to:
Morgan M. Philbin, PhD, MHS
Department of Sociomedical Sciences
Columbia University Mailman School of Public Health
722 West 168th Street, Floor 5, Room 536
New York, NY 10032

E-mail: mp3243@columbia.edu