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Beyond “purposeful and planned”: Varied trajectories of healthcare transition from pediatric to adult-oriented care among youth living with HIV

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Abstract

Healthcare transition (HCT) from pediatric to adult-oriented healthcare is ideally conceptualized as a planned, continuous process characterized by communication between multiple stakeholders. However, empirical data is lacking regarding processes through which youth living with HIV (YLHIV) are actually transitioned to adult care. We conducted a qualitative study to gain a more comprehensive understanding of both pediatric and adult provider perspectives on the HCT process for YLHIV. Our study included focus groups discussions with 24 (11 pediatric and 13 adult) providers at a comprehensive HIV care center in the Southeastern United States. Providers described YLHIV and their HCT trajectories as diverse and complex. They described three distinct HCT trajectories: the Ideal Transition, the Abrupt Transition, and the De Facto Transition. Providers agreed that the most important determinant of successful engagement in adult-oriented care (post-HCT) appeared to be consistent prior engagement while in pediatric care (pre-HCT). In summary, risk for disengagement is not uniform among YLHIV transitioning to adult care, and HCT does not always occur in a seamless or linear fashion. Our data suggest that interventions aiming to improve HCT should be more tailored, focusing intensified efforts on those YLHIV with difficulty maintaining consistent engagement in pediatric care.

Keywords

HIV; transition; adolescent

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INTRODUCTION

As a result of improved treatments and survival among youth living with HIV (YLHIV), virtually all YLHIV in pediatric care will eventually transition their care to adult-oriented care settings. Healthcare transition (HCT) is classically defined as the “purposeful, planned movement of adolescents and adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (Blum et al. 1993). General and disease-specific HCT guidelines building upon this definition have been presented in position papers from a number of leading medical societies, including guidelines specific to HIV (American Academy of Pediatrics, American Association of Family Physicians, & American College of Physicians 2002; Committee on Pediatric AIDS 2013). The HCT literature in HIV has largely focused on characterizing pediatric patient and provider concerns, with comparatively fewer studies that describe actual processes or outcomes (Hussen et al. 2014). We sought to gain an improved understanding of real-world HCT processes from the perspectives of both pediatric and adult-oriented HIV care providers.

METHODS

We qualitatively analyzed the HCT process within a large outpatient HIV care center in the Southeastern United States. The center houses separate clinics for pediatric and adult care; pediatric patients transition to the adult clinic by their 25th birthday. We conducted four focus group discussions (FGDs) with 24 providers – two FGDs each with pediatric and adult providers (Table 1). The Emory IRB and Grady Research Oversight Committee approved the study.

FGDs were conducted by trained research assistants, utilizing semi-structured interview guides. Verbatim transcripts were imported into MaxQDA 12 (VERBI Software, Berlin, Germany) for subsequent thematic analysis. Study team members read through all transcripts for emerging themes, which were then applied to the text as codes. Coded material was analyzed, yielding the descriptions of HCT processes and trajectories below.

RESULTS

Our analysis yielded three closely related themes: (1) YLHIV and their HCT trajectories are diverse; (2) There are distinct HCT trajectory types; and (3) Pre-HCT engagement is critical to shaping the HCT process.

Diversity of YLHIV and their HCT Trajectories.

HCT trajectories varied with respect to the amount of planning and preparation described by the pediatric providers, as well as the level of engagement of YLHIV pre- and post- HCT. Additionally, participants emphasized diversity within the patient population and the need for a tailored, patient-centered approach to HCT, as explained by an adult clinic provider:

It depends. Luckily that portion of patients who are unable to adjust is very small. So the issue is, we need to be able to identify that group during the transition time and work with them. Not everybody is in the same boat... There’s people extremely
well adjusted because they got diagnosed at age 22, they have a job...It’s not 100% of the adolescents…that would end up having problems [with HCT].

**Three Types of HCT Trajectories (Figure 1).**

**Trajectory 1: The Ideal Transition.**—Participants described a smooth well-planned process, in which pediatric providers begin to prepare YLHIV for HCT at least a year in advance. Preparation often included conversations about expectations in adult vs pediatric care, tours of adult clinic, and/or introductions to adult care providers. The Ideal Transition was facilitated when patients were consistently engaged in pediatric care, and such patients were likely to stay continuously engaged once in adult care.

**Trajectory 2: The Abrupt Transition.**—In these cases, medical needs or psychosocial complications led to deferral of HCT discussions until immediately prior to transfer of care – in extreme cases, impending HCT was never broached until the last pediatric appointment. The underlying destabilizing factors that led to erratic engagement in pediatric care often persisted through the time of HCT and into adult care, and these YLHIV were perceived as a high risk for incomplete engagement in adult care as well.

**Trajectory 3: The De Facto Transition.**—Here, YLHIV disengaged from the pediatric clinic before any discussions of HCT took place. When these patients returned to re-register in clinic after age 25, they were enrolled directly in the adult clinic, with no antecedent communication between providers or preparation of patients. This trajectory was a source of significant frustration, particularly for adult providers.

**Importance of Pre-HCT Engagement in Pediatric Care.**

Participants agreed that patients’ healthcare engagement prior to HCT was the most important predictor of outcomes post-HCT. One adult provider summarized this idea:

> In my experience the patients that don’t do well were not doing well [in pediatric clinic]. They were never doing well, and the patients that are doing well were doing well [in pediatric clinic] and they transitioned fine.

Poor engagement in pediatric care was not only a marker for a high-risk patient – it also impeded pediatric providers’ ability to plan a smooth HCT to adult care.

> A lot of times they’re falling out of care, coming back into care, and then we’re transitioning them …when you have a patient who is out of clinic from say, 23 to 24, and they reenroll into our [pediatric] clinic… Then you’re focused on getting them stable, getting them to see some sort of priority in their medical visits to come regularly so that they can get healthy. But then you’re also trying to prepare them to leave [to adult clinic], which [is hard] – you’re trying to address the reason why they left in the first place, all the while kind of pushing them into a system that’s totally different.
DISCUSSION

HCT is typically conceptualized as a smooth, linear process in which stakeholders work collaboratively to create a seamless transfer of care (Blum et al. 1993; Committee on Pediatric AIDS 2013). However, our data show that this ideal is not necessarily reflected in a real world setting. Our participants described diverse HCT patterns, characterized by variable engagement by patients and heterogeneous preparation by providers.

Prior work on HCT in YLHIV has elucidated providers’ definitions of HCT “success”, which primarily focus on YLHIV achieving autonomy for disease management in the adult care setting (Fair, Sullivan and Gatto 2011; Philbin et al. 2017; Tanner et al. 2017). Pathways to this success, or “failures” in the transition process, are understudied to date. Unfortunately, failures in engagement occur frequently among YLHIV; national data show that only 22% of YLHIV are engaged in care (Centers for Disease Control and Prevention 2014), and that only 46% of youth in care achieve the ultimate goal of sustained viral suppression (Beer, Mattson, Bradley, & Shouse 2017). Given this stark reality of suboptimal engagement in care for YLHIV, a more realistic view of HCT that goes beyond planned transfer of perfectly engaged patients is needed. Our findings suggest that HCT-focused interventions should be more personalized, prioritizing medical stabilization of youth prior to transfer and providing special attention to those who are not consistently engaged in pediatric care.

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REFERENCES


Figure 1.
Types of Healthcare Transition (HCT) Trajectories
### Characteristics of Study Participants

<table>
<thead>
<tr>
<th>Primary work setting</th>
<th>N (%)</th>
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</thead>
<tbody>
<tr>
<td>Pediatric clinic</td>
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<tr>
<td>Adult clinic</td>
<td>13 (55%)</td>
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</table>

<table>
<thead>
<tr>
<th>Occupation</th>
<th>N (%)</th>
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<tbody>
<tr>
<td>Medical providers (Physicians and Advanced Practice Providers)</td>
<td>15 (62.5%)</td>
</tr>
<tr>
<td>Nurses</td>
<td>3 (12.5%)</td>
</tr>
<tr>
<td>Social service providers</td>
<td>3 (12.5%)</td>
</tr>
<tr>
<td>Research staff</td>
<td>3 (12.5%)</td>
</tr>
</tbody>
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