

## Transition from Pediatric to Adult Healthcare Services for Young Adults with Chronic Illnesses: The Special Case of Human Immunodeficiency Virus Infection

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The term “healthcare transition” refers to the purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented healthcare systems.<sup>1</sup> Implicitly embedded in this term is the belief that transition should be uninterrupted, comprehensive, integrated, and developmentally appropriate.<sup>2</sup> All young adults eventually must make this move, sometimes after receiving interim care in an adolescent program or a pediatric practice that provides expert care to teenagers and college students, but for those with serious physical and emotional disabilities, the process is complex and often delayed. In particular, youth who were infected with human immunodeficiency virus (HIV) perinatally are beset with some of the most complicated life challenges, and for them the process of transition from pediatric and adolescent to adult medicine practices is daunting, one that requires a response by their healthcare providers (HCPs) that is skillful but time-consuming.

In 1989, the US Surgeon General, C. Everett Koop, convened a national conference with the Maternal and Child Health Bureau (MCHB) to address the issues of transition for youth with special healthcare needs (YSHCN). The conferees, including HCPs caring for youth with chronic conditions, were asked to examine approaches for providing smooth passage and better communication between HCPs as these youth moved from child-centered to adult-centered care. A number of legislative initiatives emerged from this conference, including Omnibus Budget Reconciliation Act 1989, which emphasized that YSHCN must receive support from maternal and child health agencies tasked with implementing family-centered, community-based, comprehensive, coordinated care focused on the total continuum of needs of mothers and children, including adolescents.<sup>3</sup> In the late 1990s, it was estimated that >4 million children in the United States had chronic conditions that affected them daily.<sup>4</sup> Thus, the MCHB has made the implementation

of transition services a core performance outcome for community-based systems of care for YSHCN. The Individuals with Disabilities Education Act also requires that students with disabilities, by age 14 years, must be the recipients of case-managed school transitional services that are integral to their individualized educational plans.<sup>5</sup> However, in a 2005 national survey of YSHCN and their guardians, only approximately half had talked with their HCPs about their healthcare needs and the adult providers who might accept their transfer, and only 15% of YSHCN met the MCHB outcome measures for medical transition.<sup>6</sup>

When discussions with providers do occur, questions are raised about health insurance and the need for the patients’ self-sufficiency. These discussions are less likely to take place with poor African-American and Latino families and with those not speaking English.<sup>7,8</sup> Discussions with providers were associated with older age and connection with a medical home. Ignorance and uneasiness with the mechanics of transition are impediments equally shared by the pediatricians, internists, and family physicians who form the points of contact in the transition process. HCPs feel ill-equipped to initiate discussions about issues for which they have no “scripts” and that they cannot resolve realistically without considerable “outside help.”

Internists vocalize a need for better education on congenital and childhood conditions that afflict YSHCN and more comprehensive programs for a different “breed” of highly skilled subspecialists in the care of older adolescents and young adults (including neurologists, pulmonologists, developmentalists, etc.).<sup>9</sup> Internists also express a need to move toward an untraditional but necessary involvement in care of adult family members and designated friends.

### Youth and Young Adults Living with HIV/AIDS

Astonishing therapeutic and preventive advances of the past 25 years have resulted in improved quality of life and greater survival of children with a wide array of conditions (eg, congenital heart disease, cystic fibrosis [CF], spina bifida, epilepsy, sickle cell anemia, renal disease, etc.).<sup>1</sup> Also, in the developed countries of the world, children infected with HIV peripartum have lifespans 5- to 10-times longer now

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral
ATN	Adolescent Trials Network
CF	Cystic fibrosis
HCP	Healthcare provider
HIV	Human immunodeficiency virus
MCHB	Maternal and Child Health Bureau
NYSDOH	New York State Department of Health
YLHA	Youth living with HIV and AIDS
YSHCN	Youth with special healthcare needs

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than they did in the early years of the epidemic. This remarkable change has resulted from continuing advances in antiretroviral (ARV) discovery and from newer modalities of prophylaxis and treatment of opportunistic infections and other complications.

On the basis of 2007 data collected by the Centers for Disease Control and Prevention, approximately 24 000 youth living with HIV and acquired immunodeficiency syndrome (AIDS; YLHA), ages 13 to 24 years, were living in the United States. This represented a 25% increase from 2004, an increase partly attributed to high-risk adolescent sexual behavior and also to an increasing survival rate in children who were infected perinatally. As time passes, the number of children perinatally infected with HIV in developed countries will continue to fall dramatically and, consequently, will contribute an ever-decreasing proportion to those YLHA. The opposite condition applies in developing countries where, it is hoped, an ever-increasing number of children infected perinatally will survive into adulthood.

Worldwide the numbers are grim. Of the 2.7 million people whose HIV infections were newly recognized in 2008, there were >400 000 children <15 years of age and >1 million young adults, ages 15 to 24 years. In 2009, the Joint United Nations Programme on HIV/AIDS, UNAIDS, estimated that approximately 3000 youth and 1200 children became infected every day. As ARV therapy becomes more widely available in the developing world, we can expect a steady increase in the number of youth and young adults who, 10 or 20 years from now, will be in need of adult forms of healthcare delivery.

Because there is a great disparity in the potential life spans of children infected with HIV in resource-rich versus resource-limited countries, the rich countries are currently encountering the “coming-of-age” of the largest cohort of children infected with HIV in their history, those born between the early 1980s and the late 1990s. Thus, we in the United States currently are confronting a major healthcare transition for youth infected with HIV, one that will become less common as we move into the next decade.

## Goals for Transitional Care

There is consensus among HCPs that developmentally appropriate youth ought to begin to receive their care in adult healthcare settings some time in their early 20s. For these youth, transitioning healthcare is one of several tasks that include: increasing autonomy in all realms of life, developing a personal identity, coming to terms with sexual preferences and practices, planning future educational and vocational goals, etc. Moving into adult healthcare venues changes the locus of communication from the parent to the young adult and provides an atmosphere in which youth can speak more freely about sexual and reproductive issues, illicit drug use, smoking and other risk behaviors, financial issues, intra- and extra-familial social relationships, and emotional upheavals. Transition supports the expectation that young adults must act to take personal control of their own bodies

and illnesses and, in so doing, must see themselves as survivors with a future.

## Challenges to Care and Barriers to Transition of Youth with HIV/AIDS

Vijayan et al identified 3 major challenges in caring for adolescents infected with HIV, their difficulty: (1) adhering to complex medication regimens; (2) negotiating their sexual worlds; and (3) maintaining stable places in their disorganized social environments.<sup>10</sup> Adolescents infected with HIV, their parents, and HCPs all describe poor adherence to ARV therapy that results in failure to achieve low viral loads and the appearance of drug-resistant HIV. In the absence of adequate parental supervision, they sometimes, intentionally or unintentionally, fail to take some or all of their ARV medications. Some of the medicines have unacceptable adverse effects. Additionally, the act of taking medicines is a constant reminder of their disease. Patients neglect to take their pills when they are with their peers, as the act is one that identifies them as being different.

Most adolescents infected with HIV do not know the names of their medicines, although many can describe their colors, shapes, and sizes. Denial of illness is common in all adolescents with chronic conditions, but in those with HIV, despite serious past illnesses, many rationalize their non-adherence by stating that they feel quite well “at present.” Also, many adolescents think concretely and do not recognize the connection between the promised future benefit of their medicines and current actions.<sup>11</sup> Adolescent rebellion manifests itself as refusal to take the medicines as urged by parents and HCPs.

Adolescents infected with HIV freely acknowledge their conflicts surrounding intimate relationships and the difficulties experienced in attempts to disclose their HIV status to their partners. Some feel pressure to have sex, and many fail to use condoms or other forms of risk reduction and birth control. Thus, some young women with HIV become pregnant. Both providers and patients express widespread concern about the insufficient number of resources readily available in the traditional pediatric healthcare setting for comprehensive gynecologic care and for dealing successfully with partner notification.

Most youth infected with HIV live in disorganized homes or are homeless. Some have adoptive parents, and many were placed in foster care at an early age. Some youth have witnessed the complications of AIDS or the deaths of household members and family; others have been exposed to the ravages of mental illness, illicit drug use, the sex trade, and incarceration. The dearth of household routines, the lack of family support, and the stigma associated with their HIV status interferes with the services offered by visiting nurses, social workers, and other HCPs and precipitates medicinal nonadherence.

Stigma intersects with nearly every other factor and, as experienced in social networks, leads many youth to mistrust individuals outside of their closest social circles, sometimes

including their HCPs. Stigma and fear of shunning cause some families to fail to disclose the diagnosis of HIV infection to their children and also cause many patients to fail to share their diagnosis with friends and acquaintances. Thus, they become socially isolated, either by personal choice or by societal disaffection. When adolescents fail to know or share their HIV status, they cannot become autonomous.

Adoptive and foster parents more often than not prohibit discussion of HIV outside the family unit, calling it “a family matter.” However, these parents are more likely than biologic parents to disclose the diagnosis of HIV to their children.<sup>12,13</sup> Biologic parents are oppressed with guilt for having “given” HIV to their children, and the children live with a sense of betrayal and blame their parents for their own illness.

A number of pre-teens and teens reach adolescence never having had their HIV status revealed to them. Disclosure of one's HIV status is difficult, but its benefits include a reduction in the number of behavior problems, improved social and school performance, and better adherence to ARV medication regimens.<sup>14</sup> Disclosure is an issue replete with guilt, denial, acting-out, misconception, and stress. Ideally, disclosure should be a co-operative group activity involving the parents primarily and, when need be, HCPs and social workers. There is no “magical” age at which disclosure should occur, because it depends on the cognitive and emotional maturity of the patient and parent and full acceptance of the biologic mother's HIV infection status. HCPs should work with parents to develop the “script” and the “scenario” for the planned disclosure, both of which must be individualized to mesh with the circumstances of each family.<sup>12</sup>

The barriers to transitioning youth infected with HIV to adult-oriented healthcare systems also include the patients' perceived lack of autonomy and the difficulty “letting go” of their pediatric caregivers.<sup>10</sup> The problem of “letting go” applies equally to the HCPs who feel closely attached emotionally to children for whom they provided care since infancy. The patients and their families regard the HCPs as long-standing allies, even saviors.

School success is a strong predictor of successful transition to adulthood and of performance later in life. Education also is a modulator of the effects of socioeconomic class on adult attainment.<sup>15-17</sup> School absences and poor school performance are frequent in children infected with HIV because of medical appointments, the neurocognitive deficiencies associated with HIV, the adverse effects of medications, anxiety, depression, altered self-image, and chronic fatigue.<sup>18,19</sup> Assessment of psychodevelopmental functioning in children infected with HIV ages 2 to 17 years showed that behavioral problems (eg, psychosomatization, hyperactivity, impulsivity, anxiety) and lower developmental and cognitive scores (eg, mean full-scale IQ score, 86) were more frequent in study subjects infected with HIV compared with established childhood norms.<sup>19</sup>

Finally, because early in the epidemic so many children infected with HIV were not expected to live beyond early childhood, they were not taught many of the life skills that one needs to live successfully and independently.

In addition to the long-term survivors of perinatally acquired HIV infection, sexually active and drug-using teenagers who acquire HIV infection also will face a rite of passage to adult healthcare venues. Behaviorally infected adolescents are different clinically from their similarly aged peers who have been infected since birth. Behaviorally infected adolescents find themselves at much earlier stages of their infection, have sustained fewer complications of their disease, are less treatment-experienced, and are less likely to carry multiple drug-resistance mutations. Also, the prevalence of neurocognitive deficits and dependency on adults for daily care and management is lower in recently infected teens. However, both groups of teens need sexually transmitted infection and pregnancy prevention services, and access to appropriate immunizations and gynecologic care.

### Status of Transitional Care for Patients with Chronic Diseases of Childhood

For at least several decades before the coming-of-age of the “first generation” of youth perinatally infected with HIV, children with other chronic diseases of childhood (eg, asthma, CF, cancer, diabetes mellitus) have benefited from formidable advances in treatment that have resulted in more comfortable and longer lives. Therefore, patients with these ailments and their families have already experienced efforts to design and then execute transition programs. Asthma serves as a paradigm of an increasingly common lifelong chronic medical condition that crosses many demographic boundaries.<sup>20</sup> Practice guidelines emphasize the need for continuous monitoring and management. However, both adolescents and young adults with asthma experience barriers to care that can be attributed to a lack of HCPs and consistent sites of care and insurance and financial barriers.<sup>21</sup> This points to the need to address systemic faults that include the identification of trained adult care providers, the creation of portable medical records, and ensuring continuous insurance coverage.<sup>22</sup>

In 2010, the US Cystic Fibrosis Foundation, having recognized that half of all patients living with CF reached the age of 18 years or older, began by creating a specialized clinical fellowship designed to prepare physicians to care for patients with CF in adult CF programs.<sup>23</sup> The Foundation is developing disease-specific guidelines to facilitate transition and persists in efforts to assess successful outcomes. However, many adults with CF continue their care in pediatric practices, and others, some incompletely prepared, transfer to adult pulmonary practices.

Diabetes mellitus is a chronic lifelong illness that requires constant monitoring. Several studies have been undertaken to understand better the needs of teens with diabetes mellitus as they move into adult medical practices.<sup>24-27</sup> They have shown changes in clinical outcomes and poorer adherence to medical supervision after transfer. Substandard outcomes often were associated with lower socioeconomic status, female sex, poor access to local physicians, and transfer to a new healthcare team.

For childhood cancer survivors, the transition to adult care is an ongoing process, one that includes continuing education and practice innovation.<sup>28</sup> Unlike most other chronic illnesses of childhood in which the underlying disease continues to actively affect the patient, many children previously treated for cancer have been cured. However, many such surviving youth sustain long-term physical and emotional sequelae, which require risk-based care provided by a variety of adult subspecialists. Thus, long-term follow-up programs have been installed in a number of cancer centers.<sup>29</sup>

Two specific transitional care models have been espoused by proponents of those who care for children with chronic medical conditions: case management services and the medical home model.<sup>30</sup> It is generally recognized that nurses, in particular advanced practice nurses with specialty training, are ideally suited to provide comprehensive, coordinated care in a multiplicity of settings. Advanced practice nurses acting as case managers are trained to work with other professionals, such as teachers, social workers, etc. They also act as liaisons among patients, their families, the healthcare and school systems, and a multiplicity of bureaucracies. Case managers often work within the structure of a “medical home,” a virtual compendium of coordinated services that are family-centered, community-based, accessible, and comprehensive.<sup>31,32</sup>

### Current State of Transitional Care Services for Youth Infected with HIV

Several studies have assessed the current state of adolescent survivors of perinatally acquired HIV infection. One report from the United Kingdom found that 26% previously had sustained at least one AIDS-defining illness, 64% were currently receiving ARV therapy, 79% of whom were on highly active antiretroviral therapy and 18% of whom were ARV therapy-naïve.<sup>33</sup> Sixteen percent of young people had already transferred to adult healthcare at a median age of 17 years. At the time of last follow-up, 12% of participants were severely immunocompromised. Of the participants on highly active antiretroviral therapy, >60% of those who had had resistance assays performed carried either dual- or triple-class ARV resistance mutations. These data suggest that access to ARVs is satisfactory, although previous suboptimal regimens and their current use or misuse is sometimes associated with poor viral control or ARV resistance. Hence, HCPs must review ARV regimens and resistance assays and must plan to modify therapy around the time of transition, as needed.

In 2009 to 2010, Rusley et al at Yale undertook an online survey of 631 HCPs and program administrators at 136 pediatric HIV clinical care programs across the United States.<sup>34</sup> The study described program characteristics and transition practices and identified perceived barriers to effective transition of YLHA. Of program respondents, 40% had 10 to 20 years of HIV care experience and had participated in a median of 5 transitions; 81% of programs had a transition coordinator, but few had a formalized process or protocol to guide transitions. Patient- and family-related social and emotional

factors were more frequently rated as significant barriers to transition (eg, patients' lack of autonomy and life skills, difficulty letting go of pediatric program staff) compared with systems-related factors (eg, distance from locus of care or failure to identify a transition coordinator). Most respondents wished for more guidance in smoothing transition.

Another study conducted by the Adolescent Trials Network (ATN), which was limited in the kinds of programs assessed, identified an array of barriers to transitional care for YLHA that included transportation, employment, family support, food, and housing.<sup>35</sup> In contrast to Rusley's study, the ATN study identified “systems issues” as greater barriers to transition than psychosocial issues. These included such elements as insurance problems and the inability to track patients after their transition. HCPs in the ATN clinics proposed a multidisciplinary team approach to the process of transition, which should include education and skills training. It was suggested that a single contact person should assist the adolescent in transition and that psychosocial services be integrated in the patients' care plan before, during, and after the transition event. A more inclusive empiric investigation of transition health services in the United States also identified systems barriers to be the most common, including inadequate funding and access to key staff and a general lack of collaborative, coordinated and integrative services for YSHCN.<sup>2</sup>

### Recommendations for a Successful Transition

Various government organizations, academic institutions, expert panels, and independent investigators have developed guidelines for successful transition of chronically ill youth (including those with HIV/AIDS) from pediatric to adult healthcare venues.<sup>14,36-38</sup> None of these guidelines has evolved from the findings of controlled, experimental interventions in which various models have been tested and their effectiveness subjected to rigorous evaluation. However, there are a number of principles common to all sets of transition guidelines: (1) HCPs should deliver developmentally appropriate (not simply age-appropriate) care; (2) transition is a deliberate, coordinated process, not an event; (3) psychological and case management services should be made available to the patient at all stages of the transition; (4) a transition plan should be developed at least 1 year before the event, and the pediatric provider should arrange for one or more meetings between the adult care provider and the patient before transfer; and (5) the transition process must take into account the educational, housing, and employment needs of the patient.

### Education, Skill Building, and Assessment of Success

During the 10- to 20-year period when the child who is perinatally infected with HIV receives care, he/she is almost always guided by a devoted and deeply involved group of



HCPs, a second family of sorts. They assume protective roles, helping the parent or guardian to successfully comply with appointments and the administration of multiple medicines, while also mediating traumatic events, both social and medical. It is common for HCPs to remind patients about upcoming appointments, to arrange for transportation, and to communicate with teachers, principals, and school nurses about learning difficulties and administration of medicines during the school day. Assistance is provided when families need help negotiating the bureaucracies associated with Social Security, Medicare, Medicaid, private health insurance companies, utility companies, and pharmacies. Much of this assistance diminishes when young adults transition to adult healthcare venues in which there is an implicit assumption that patients can negotiate many of the routine tasks associated with modern healthcare delivery. Children with chronic health conditions (including those with HIV) that impair normal neurologic, cognitive, emotional, and physical function must be taught the skills that accrue naturally in the course of childhood and adolescence in those who are unimpaired.

The New York State Department of Health (NYSDOH) has enumerated a set of skills that are crucial in facilitating healthcare transitions for YLHA.<sup>14</sup> Most of these skills are equally applicable to teens and young adults with other chronic conditions. They include, but are not limited to: (1) making and keeping appointments; (2) learning what symptoms require urgent or emergent care; (3) learning how to fill and re-fill prescriptions; (4) developing daily routines that result in strict adherence to a pharmacologic regimen; and (5) filling gaps in the patients' understanding of their disease. The NYSDOH suggests that success also be gauged on the degree to which patients achieve personal and medical independence. Personal achievements include those associated with education, job training, parenting, and independent decision-making.

At Yale-New Haven Children's Hospital, we have designed a Maturity Index Checklist that provides us with concrete evidence of a patient's level of readiness for transition. In addition to those skills enumerated by the NYSDOH, we have added the ability to: (1) arrange transportation to appointments; (2) know how to apply for available health and income assistance; (3) articulate educational and vocational goals; and (4) know the names of medications.

It will take years of work and analysis to design guidelines for transition of chronically ill youth that are proven successful in resource-rich settings. Unfortunately, in resource-limited settings, the issue of transition for children infected with HIV will continue to exist for an unknown period, as thousands of infants who are newly infected with HIV join the existing pool of infected older children and adolescents. Those of us rich in resources will be obliged to guide our more disadvantaged colleagues in other parts of the world as we learn about healthcare transition for older youth infected with HIV in the decades to come. Furthermore, if current alarming trends continue, ever-increasing numbers of American teenagers will acquire HIV infection, and they

will come to us for counsel, care, and transition to the adult healthcare system.

## Discussion

It is well accepted that adolescents with chronic illnesses find it difficult to transition to the adult healthcare system. Sadly, we have a poor understanding of which transitional practices are most effective and which best match the needs of youth with different underlying illnesses of varying clinical context, severity, and duration. Because prospective studies of transition are rare, we do not know whether transition has a long-term salutary influence on the lives of youth with chronic diseases.<sup>1</sup> However, anecdotal evidence suggests that transition programs better ensure continuity of care, compliance, and self-advocacy.<sup>39,40</sup> To expect that the therapeutic successes of the earlier decades continue to benefit adult lives, transitional models of care must be observed carefully, assessed scientifically, and debated in successive multidisciplinary public forums. ■

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