

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.¹ Implicitly embedded in this term is the belief that transition should be uninterrupted, comprehensive, integrated, and developmentally appropriate.² 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.³ In the late 1990s, it was estimated that >4 million children in the United States had chronic conditions that affected them daily.⁴ 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.⁵ 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.⁶

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.^{7,8} 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.).⁹ 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.).¹ 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.¹⁰ 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.¹¹ 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

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