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Lost in Transition

A Risk Factor for Mortality in Youth Living With HIV

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The main reasons for increased mortality in youth living with HIV (YLHIV) 15–24 years of age are nonadherence to treatment and loss to follow-up during the transfer from pediatric to adult health care.^{1–6} Only 40% of YLHIV in the United States know their diagnosis, and of them, only 6%–13% achieve viral suppression.^{1,3,5} Nonawareness of HIV status combined with a high number of partners and high rates of unprotected sex are a source of continuous spreading of HIV1 in this population.^{1,2,7} A key factor for treatment success in YLHIV is retention in care, which is achieved when the transfer process to adult medicine is guided by health-care professionals, a process termed “transition.” Transition is the purposeful, planned process that addresses

medical, psychosocial and educational needs of YLHIV with chronic physical and medical conditions as they move from child-centered to adult-oriented health-care systems.^{2,4} Different concepts of transition of YLHIV have developed, mainly within the past 10 years.¹ Here we provide a narrative review of the current literature.

Many publications categorize adolescents as 10–19 years and do not accurately discriminate between children (<15 years), youth (15–24 years) and young adults (18–25 years). As do the World Health Organization (WHO), we refer to YLHIV as adolescents and young adults living with HIV 15–24 years of age.

Due to a lack of pediatric treatment programs, transition occurs early—between 12 and 18 years—in resource-limited countries.² In Europe, transition occurs around 18 years with the majority of YLHIV having been perinatally infected.^{1,2,4,6} In the United States, transition happens usually in the mid-twenties and most of the YLHIV are therefore infected behaviorally. In the United States, transition from pediatric to adult health care is bridged by adolescent- and family-care clinics, but in Europe, such clinics are uncommon and transition is direct from child to adult services.^{2,4,6,7}

COMMON PSYCHOSOCIAL CHARACTERISTICS OF THE YLHIV POPULATION

YLHIV are less likely to be retained in health care and have higher rates of non-adherence compared with other age groups living with HIV.^{1,3} Knowledge about the characteristics of the living circumstances of YLHIV is key to understanding their transition problems. Social, economic, medical, psychologic factors and different health-care structures have been identified as barriers to transition in excellent original papers and reviews on the topic (see section “Barriers of transition”). Social and economic factors such as immigrant status, membership of disadvantaged groups (United States: Afro-American, Hispanic/Europe: African origin), under-insurance, poverty and neighborhood-/sexual violence all decrease access to and retention in health care.^{1,3,6} Stigma of HIV, disclosure problems, hiding HIV as a family secret, problems with relationships, physical intimacy and family planning are

EPIDEMIOLOGY

In 2017, the WHO estimated that 3.9 million of the 36.9 million HIV1-infected people worldwide are YLHIV,⁸ of whom two-thirds live in sub-Saharan Africa. In contrast to other age groups, mortality rates in HIV1-infected adolescents continue to rise and have become the second leading cause of death for adolescents worldwide.^{2,5} WHO estimates that worldwide among YLHIV, around half have been infected perinatally and half behaviorally (for characteristics, see Table 1).⁷ All YLHIV will profit from transitional measures. Almost two-thirds of YLHIV worldwide are females^{5,7} reflecting their unequal cultural, social and economic status. In resource-limited countries, most behaviorally acquired HIV infections in YLHIV are heterosexually transmissions in girls,² while men having sex with men is the predominant cause of transmission in resource-rich countries.⁶

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TABLE 1. Differences Between Perinatally and Behaviorally Acquired HIV Infection

	Factors Specific for Perinatally Acquired HIV	Factors Specific for Behaviorally Acquired HIV (via Sex or Intravenous Drug Use)
Medical/health-care factors	Start of treatment in pediatric care (all will experience transition!)	Preferably start of treatment in adult care (only a part will experience transition!)
	Managed in a multidisciplinary team of pediatric health-care providers	Not (or only shortly) treated by pediatric health-care providers
	More advanced HIV disease	Early stage of HIV disease
	More complex ART regimen history	Less complex ART regimen history
	More HIV resistance mutations	Less HIV resistance mutations
Comorbidities	Neurocognitive dysfunctions related to opportunistic infections and/or medication	Normal prior physical and cognitive development
	Chronic psychiatric illnesses like anxiety, depression, behavioral disorders, post-traumatic stress symptoms	Diverse mental health conditions resulting from stress by social and environmental factors according to new HIV diagnosis
Psychologic factors	Loss of (a) parent(s)	Difficulties in accepting the diagnosis and treatment of HIV1 resulting in high-risk behavior
	Lack of coping models	Problems to disclose HIV1-infection
	Lack of social and family support, eg, nonrelated caregivers or in foster care	Additional stigmas like sexual orientation(LGBT = lesbian, gay, bisexual, transgender), sex work, drug/substance abuse

the predominating psychologic factors.^{1,2,4-7} Numerous parallel/coincident social transfers interfere with transition leading to an excessive demand of YLHIV and often result in delay of transition: transfer from school to professional education; transfer from parents/foster home to living alone and change from a close parent relationship to an intensive partnership. While on the one hand moving to another city away from parent responsibility strengthens independence (become familiar with administrations, health insurance, etc), on the other hand, it can lead to the loss of familiar patterns, social network and peers which often results in neglecting one’s own health care.

BARRIERS OF TRANSITION

YLHIV mentioned the following worries and deficits as barriers of transition:^{1,2,4,6,7} First, there is fear to be overstrained by responsibility for their health. In many YLHIV, this fear is strengthened by deficits/lack of autonomy caused by “helicopter parents,” who manage life for their adolescent children and “helicopter medics,” medical staff who take care of all medical problems because of close attachment between adolescents and pediatric health-care providers. Second, YLHIV worry about not to being involved in the timing of transition. Third, there is reluctance to meet and disclose to new health-care providers due to prejudices of YLHIV toward adult health-care providers, regarding reduced flexibility in booking appointments and fear they have not enough time for discussing all problems.

MEASURES TO IMPROVE TRANSITION WHICH HAVE BEEN DOCUMENTED TO RESULT IN VIRAL LOAD SUPPRESSION

In different studies, educational measures improved retention in care and success of antiretroviral therapy: Psychosocial and educational sessions on the knowledge about HIV, barriers of adherence, health knowledge, coping skills, sexual risk reduction and health empowerment applied at an individual level improved knowledge about ART management and risk behavior and resulted in a decreased viral load compared with a control group.^{2,4,5,7} Studies offering motivational interviewing combined with financial incentives to YLHIV off ART resulted in a viral load of <50 copies/mL in 50% of participants 24 months after enrolment (despite multiple prior attempts to restart treatment). In France, regular (once every 6 weeks for 26 months) peer support sessions guided by therapists decreased worries about illness and increased viral suppression compared with a decline group and a control group without these measures.

FACTORS FACILITATING SUCCESS OF TRANSITION

Empower and Engage the Adolescents (YLHIV) in Transition

The discussion about transition should be started early with initiation of transition planning 1-3 years before transition including the creation of an individual transition plan considering common

transition guidelines.^{1,2,4-7,9,10} It is necessary to allow YLHIV to control the timing of transition. The time period during transition can be used to improve knowledge about a range of issues including HIV disease, HIV medication and adverse effects. The pediatric team should check readiness for transition by a transition readiness scale and a knowledge checklist at least on 2 occasions and disclose the results to adult medical staff. Financial and insurance barriers need to be addressed by both pediatric and adult medical staff during the transition process.

Optimize Logistics and Ensure Appropriate Health-care Structures

A multidisciplinary adult health-care provider with the possibility to focus on mental, sexual and reproductive health issues, as well as social support and substance abuse services should be found.¹⁻⁷ Adult health-care providers trained in adolescent care are preferred or alternatively, transfer to an adolescent or family clinic with a multidisciplinary approach. Ideally, the adult health-care provider offers an adolescent friendly waiting area, evening clinic hours and is familiar with teenage communication skills (handy number exchange, WhatsApp etc.). Close communication between pediatric and adult health care including detailed discharge summaries and oral handover to the adult health care should be guaranteed. A patient meeting with the adult provider in the pediatric clinic should be arranged. Peer guidance definitely can promote transition.

It is very useful that the pediatric team organizes a 1-year post-transition follow-up to get a feedback of transition and a chance to lead the YLHIV “lost in transition” back into health care.

CONCLUSION AND FUTURE NEEDS

Lost to follow-up in YLHIV is a daunting problem in the care of HIV infection and an obstacle to the 90-90-90 targets of global HIV response.^{4,6} Most of the publications on transition analyze the situation in Europe and United States with a small sample size and short duration of follow-up. Data on transition in the more prevalent population of female youths with behaviorally acquired HIV in sub-Saharan Africa and Asia are lacking.⁵⁻⁷

To generate reliable transition data, a linkage between pediatric and adult cohorts is essential.^{2,6,7} A strategy for successful transition needs to be based on the understanding of the population characteristics of YLHIV, both perinatally and behaviorally acquired

HIV. A clear population-specific delineation of the barriers is necessary for successful transition. Combining medical and psychologic support as well as Public Health initiatives will provide opportunity to improve transition. New strategies need to account for multiple subgroups (heterosexually vs. men having sex with men, sex work, drug use etc.) and to work in different settings (urban vs. rural and community vs. academic clinics etc.)^{3,7} and in different transitional transfers like in house transition, transition via an adolescent clinic, direct transfer to adult health care.

In summary, there is no “one fits all” transition model and transition remains a strongly individually tailored process.^{2,5} To understand and improve our tools for better transition, the different programs should be evaluated continuously in properly designed clinical trials.

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