Closing the Generation Gap: Increasing Access to Adolescent Treatment and Prevention Across the HIV/AIDS Care Continuum

Adolescent Health & Well-Being

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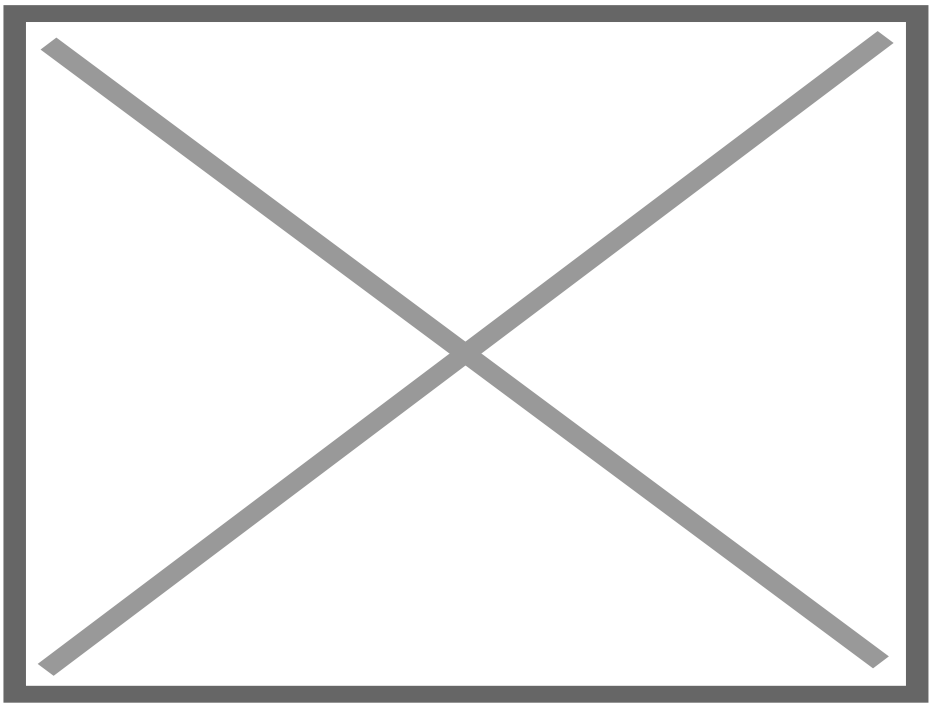
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The day I met Isaiah* was the day he re-engaged in the HIV care continuum. Isaiah had tested positive for HIV at the age of 18 and immediately linked to care at The Children's Hospital of Philadelphia Adolescent Initiative, a program that provides comprehensive multidisciplinary care and psychosocial support to youth living with or at risk for HIV/AIDS. After his first medical visit, feeling overwhelmed by his new diagnosis and in denial, he did not return to clinic for over a year. On the fall day he came back to the office, I was struck both by the warmth of his smile and the shuffle in his step as he walked across the exam room. He reported numbness in his feet, and chalked the sensation up to tight work boots. However, on exam he had evidence of distal sensory neuropathy of his big toes, an inability to feel sensations that was caused by his untreated HIV infection. Isaiah was initially optimistic about starting HIV medicine, saying he was ready to make a positive change for his health. However, over the following month he became homeless. He then lost his job and subsequently his insurance. When I next met him in clinic, he reported that with the chaos in his life he could not consider starting treatment, even understanding the risks of his disease getting worse if untreated. Later that month, he left Philadelphia to re-establish his life elsewhere, again becoming lost to HIV care.

Isaiah's story is not unique. Featured in this month's *JAMA Pediatrics,* the article "Time to Improve the Global HIV/AIDS Care Continuum for Adolescents: A Generation at Stake" (written by myself and colleagues Dr. Elizabeth Lowenthal and Dr. Nadia Dowshen), underscores the need to address discrepancies in care for adolescents living with HIV. The HIV continuum of care model (see Figure) describes the epidemiology of the stages of HIV care needed in order to achieve optimal health outcomes on both individual and population levels. The continuum, which encompasses HIV testing, establishing and staying in care, starting antiretroviral therapy (HIV medication) and achieving suppression of the HIV virus in the blood (viral load), gives us a snapshot of care delivery across health systems, and identifies gaps in treatment delivery and patient engagement in care.



At every stage of the U.S. continuum, youth fare worse than adults. Youth are significantly less likely to be tested, linked to or retained in HIV care, prescribed antiretroviral therapy (ART), or achieve a suppressed viral load. Early initiation of ART and suppression of the HIV viral load improves individual health outcomes and life expectancy, and is 96% effective, according to a recent landmark study in preventing an individual from transmitting HIV to others through unprotected sex. Yet in the U.S., only 18% of youth 18-24 are prescribed HIV medicine by their doctors and only 13% have suppressed virus levels in their blood. Estimates that include younger adolescents report rates as low as 6%. In the global setting, substantial barriers exist for youth with respect to HIV prevention, testing and treatment. In sub-Saharan Africa, where young women are disproportionately affected by HIV, fewer than 1 in 5 young women know their HIV status. HIV is the leading cause of death for adolescents in sub-Saharan Africa, and mortality for youth living with HIV increased by 50% from 2005-2012.

For those of us who work closely with adolescents and young adults, these disparities in care are not surprising. While no phase of life is static, adolescence in particular is a tumultuous time of neurocognitive, psychosocial, physical and sexual development. For youth living with HIV, this often translates to struggles with medication and appointment adherence, as adolescents seek autonomy, separate from traditional family structures and engage in increasing risk behavior. In addition, adolescents are uniquely vulnerable to many of

the known barriers to medication adherence including substance abuse, housing instability, insurance disruption, mental health problems and lack of social support. In most areas of the world, physicians receive little training in the health care needs of adolescents and may be poorly equipped to meet the needs of this unique population. The lack of youth-centered, multidisciplinary medical care and social support services serve as a major barrier to successful engagement in care and optimal health outcomes for this population.

As access to HIV medications expands globally, we must also increase funding for youth-specific HIV treatment and prevention interventions. Achieving an AIDS-free generation will require us to close the equity gap so young people have access to the full complement of health and secondary prevention benefits from antiretroviral treatment. To prevent new infections and sustain youth on treatment, we must invest in interventions to identify new infections, and get youth into care, scale up treatment, and keep them engaged at every step of the HIV care continuum. Rather than focusing solely on the drop-off in numbers of patients represented by the bars on the continuum graph, we need to turn our attention to what supports and interventions can be put in place to ameliorate these gaps in care. In the global setting, this will require a sea change wherein adolescent health is viewed as a priority funding area, and resources are allocated to train a workforce competent in providing adolescent-centered care. Clearly, this is no small feat. However, continuing to fund HIV treatment and prevention at the current level will lead to rising rates of adolescent infections and HIV-related mortality. Without restoring funding cuts to the President's Emergency Plan for AIDS Relief (PEPFAR), the goal of an AIDS-free generation will remain elusive. In addition, continuing to fund the Ryan White HIV/AIDS Program to provide safety net programs and comprehensive HIV care for our most vulnerable patients should be a healthcare priority. Investing now in adolescent HIV treatment, prevention and capacity building is one of few promising strategies that can offset the rising rates of youth mortality from HIV.

More than a year has passed since Isaiah's last visit. He recently reached out asking for his records to be sent to a new HIV care provider. As he again re-enters the HIV care continuum, it will be critical to meet him with an integrated care model that can support his complex psychosocial, medical and developmental needs- clearly just writing a prescription will not be enough. By investing in comprehensive adolescent-centered HIV treatment, we can prevent a generation from disappearing between the stages of the care continuum.

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*Name changed to protect patient privacy

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