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From surviving to thriving: The role of resilience in meeting global HIV goals

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Abstract

Advances in HIV treatment and pioneering public health strategies have yielded remarkable successes in the global fight against HIV. However, attaining UNAIDS Fast Track 90–90–90 global targets will require a renewed focus on the psychosocial aspects of HIV that too often prevent vulnerable individuals from engaging in prevention, testing, and treatment. Each step along the HIV Care Continuum can be viewed as an opportunity for positive adaptation or “resilience”, and the scientific study of resilience among HIV populations continues to grow. This *AIDS* supplement aims to draw attention to current conceptualizations of resilience among HIV-affected populations and to delineate factors that people living with HIV identify as critical for their ability to cope with HIV-related challenges. We also highlight innovative resilience-based interventions that are designed to help people living with HIV not only survive—but also thrive—across psychological, social, and health-related domains.

Keywords

resilience; HIV; psychosocial; coping; behavior; mental health; social support

Opportunities for resilience are created through the experience of adversity, and when considering the history of modern medicine, there have been few adversities that rival the HIV epidemic. Thus the context of HIV infection provides a unique lens through which to better understand the dynamics of human resilience. At each critical juncture—from initial attempts to understand case reports of *Pneumocystis jirovecii* among gay men in Los Angeles [1] to the isolation of the retrovirus in France [2] and the development of the serological test for HIV [3]—medical adversities have been confronted with determination, creativity, and even optimism — characteristics that today are touted as key internal aspects of resilience. Resilience also plays out daily in the lives of people living with HIV (PLHIV) in large and small ways, as well as within the communities of activism and advocacy, agents of assertive change since the early 1980s.

Thanks to concerted scientific and community efforts, we now have highly effective tools for the prevention and treatment of HIV [4–7]. These tools, coupled with strong evidence that viral suppression blocks transmission, offer a clear [8,9], if challenging [10], path forward for ending the epidemic. Still, many individuals fail to achieve favorable clinical outcomes, with nearly 10 million PLHIV still needing to achieve viral suppression in order to meet UNAIDS Fast Track targets of 90–90–90 by 2020 [11]. The barriers to achieving high rates of viral suppression are complex, and include health systems that are inadequate to achieve universal testing, linkage to care, and prompt initiation and continuation of antiretroviral therapy (ART) [12]. Psychosocial factors also contribute to negative HIV clinical and public health outcomes. Too many PLHIV continue to experience profound stigma, discrimination, personal losses, and social isolation. Research is needed to identify ways to enhance psychosocial factors that are associated with treatment success and a good quality of life for people living with HIV. There is much to be gleaned from exploring how people living with or affected by the virus achieve successful life outcomes—not only in the domain of physical health but also in terms of their ability to achieve positive mental health, see meaning and purpose in their lives, develop and maintain positive social relationships, and attain a good standard of living. As more PLHIV reach and maintain viral suppression, these quality of life goals must be given increased research attention.

We assembled this *AIDS* supplement to showcase current lines of resilience research among diverse HIV populations across the globe. We hope that its contributions will draw attention to the active nature of resilience—that resilience is not solely a stable, internal construct, but instead is a dynamic process of positive adaptation to life’s challenges [13,14]. This supplement can be divided into three broad areas: 1) investigations of resilience among HIV-affected women and children; 2) the identification of resilience factors that are associated with successful outcomes for PLHIV; and 3) innovative psychosocial interventions designed to promote resilience and positive adaptation among those living with or affected by HIV.

Conceptualizations of resilience have shifted greatly since the emergence of this psychological construct in the published literature in the 1970s, when resilience research was largely rooted in a belief that certain traits that emerged early in development (e.g., intelligence, agreeableness) offered invulnerability against later hardships [15,16]. Since that time, resilience research has moved through four distinct waves [17]. During the second wave, the concept of resilience became more embedded within an ecological systems framework as scientists tried to understand adaptive processes that enabled individuals (primarily children) to cope with adverse life events [18–20]. During the third wave, researchers became interested in the notion that resilience could be “built”. Efforts began that were intended to translate two decades of research on resilience factors and models of prevention science into applied studies. Frequently, these studies sought to develop positive coping skills for youth that could enable them to overcome challenging circumstances (e.g., impoverished home or school environments) [21–23]. Now, as a fourth wave emerges, resilience research is increasingly incorporating neurobiological and genetic approaches, as well as recognizing that the complexities that are inherent in human development and adaptation will necessitate integrated, transdisciplinary models and approaches [9,24].

Within this *AIDS* supplement, resilience is defined and measured in a number of ways. Building upon a large body of work in using prevention science to strengthen vulnerable families and communities, Rotheram-Borus and colleagues [25] present a new definition of resilience for vulnerable children in South Africa—meeting global standards for physical and cognitive development, as well as displaying typical behavioral functioning across their first five years of life. Using this unique “measuring stick” within a robust cluster randomized controlled design, they show that uninfected children of mothers living with HIV display similar rates of developmental resilience as children born to seronegative mothers.

Malee and her team [26] examine developmental resilience using a longitudinal design, presenting results from the Pediatric Randomized Early versus Deferred Initiation in Cambodia and Thailand (PREDICT) study. Findings show broadly similar emotional and behavioral developmental outcomes among children with perinatal HIV infection, children who were perinatally exposed but did not acquire HIV, and a control group. The findings are promising, particularly given the broad challenges that have been linked with familial HIV in many low- and middle-income countries. Of note, among the ART-naïve Cambodian and Thai children living with HIV ($N=236$), 86% initiated ART over the course of their involvement in the study with 76% achieving viral suppression by the last study visit [26]. This illustrates the continued challenges of reaching 90–90–90, even among populations linked to quality care through externally funded clinical research studies whose resources should enhance local health care expenditures.

Kuo and her colleagues [27] explore the relationships between resilience and behavioral functioning—focusing on adolescents residing in an urban township in South Africa that has been heavily burdened by HIV. Over 40% of the sample was identified as vulnerable because they were either living with HIV, living with an HIV-positive caregiver, or orphaned. Among these adolescents, resilience was associated with positive behavioral health, including fewer conduct problems, fewer symptoms of inattention and hyperactivity, and fewer peer problems. This work is part of a broader effort to develop and evaluate *Our Family, Our Future*, a resilience-oriented family intervention designed to improve behavioral and mental health among South African adolescents; we eagerly await findings from this intervention trial and hope it spurs more interest in using family- and systems-based approaches to enhance outcomes for children affected by HIV.

Two contributions to the *AIDS* supplement focus exclusively on women at-risk for or living with HIV. The qualitative study by Qiao and colleagues [28] explores resilience resources among African-American women living with HIV in the southern United States. A second qualitative study by Bärnighausen and colleagues [29] investigates the role of PrEP in achieving resilience among women at-risk for HIV in Eswatini. These pieces draw attention to the unique socio-cultural contexts that may promote resilience (e.g., sense of community, faith-based support systems) or challenge one’s ability to adapt positively over time (e.g., gender inequality, poverty). Both articles highlight the important roles of autonomy and hope for the future in women’s ability to cope with the daily challenges of HIV.

A qualitative research contribution by Harper and colleagues [30] captures important information about the understudied but high-risk population of trans-feminine youth living with HIV in the United States. Though national surveillance data are not available, the estimated prevalence of HIV among transfeminine populations in the United States is over 20-fold greater than the general population [31]. HIV-related outcomes are particularly poor among transgender individuals of color. Harper [30] documents the experiences of a majority African-American sample of transfeminine youth as they navigate through the HIV Continuum of Care. While a number of well-studied interpersonal resilience assets are identified (e.g., positive affect, psychological well-being, sense of control), the paper also focuses on interpersonal resilience resources—including the critical importance of emotional support and gender affirmation in helping youth overcome HIV-related challenges.

The supplement features studies from China and South Africa that aim to identify resilience factors and examine their relationships with key quality of life and HIV-related outcomes. First, Zhao and colleagues [32] demonstrate that the positive impacts of emotional support on health-related quality of life are mediated through internal resilience—suggesting that supportive interpersonal relationships may strengthen a person's capacity for resilience, which in turn promotes better perceptions of health and well-being (e.g., mental health, energy level). Katz and colleagues [33] employ a Care Continuum framework in their examination of resilience-based predictors of ART initiation among a cohort of eligible PLHIV in South Africa. Within their robust sample, attrition from the cascade was rapid and profound, with 2% dying before ever accessing ART, 62% initiating ART within six months of testing positive, and 25% achieving viral suppression within nine months. This proves fertile ground for examining factors that are associated with increased odds of success across continuum. Investigators found that PLHIV who reported using faith as a coping strategy were more likely to initiate ART, while those who reported coping via substance use were less likely to begin treatment, as one might expect. Interestingly, PLHIV who reported receiving social support from a partner were more likely than those who received support from friends to ultimately achieve viral suppression.

Identifying resilience factors associated with successful HIV prevention or clinical outcomes lays the foundation for the development and evaluation of innovative HIV interventions for PLHIV and other HIV-affected populations. Harrison and colleagues [34] report new findings from the *Child-Caregiver-Advocacy Resilience (ChildCARE)* intervention, a multi-level, resilience-based intervention designed to address the psychosocial needs of children whose parents are living with HIV in central China. Providing strengths-based programming at three levels (i.e., child, caregiver, community), the intervention has displayed modest success in enhancing several key resilience factors among children [35–37]. Findings presented in this supplement represent the first evaluation of intervention efficacy in enhancing mental health and parenting skills among participating caregivers [26].

Vreeman and colleagues [38] examine the concept of resilience within the context of an HIV disclosure intervention (i.e., Helping AMPATH [Academic Model Providing Access to Healthcare] Disclose Information and Talk about HIV Infection or HADITHI). Drawing on the work of Betancourt [39], their study aims to understand the impacts of a supportive and culturally-tailored disclosure intervention on the mental and behavioral health of Kenyan

youth living with HIV. Like many other studies included in this supplement, findings draw attention to global challenges in achieving compliance with clinical recommendations; within their sample [38], only around one-third of children (ages 10–15) living with HIV knew their status at baseline, despite clinical protocols that called for disclosure to be initiated at age 10. Evidence suggests that the HADITHI intervention yielded earlier disclosures, though more efforts are needed to understand apparent spikes in depressive symptoms that occur in the months immediately following disclosure.

As the HIV epidemic moves into a new phase with the Fast Track 90–90–90 goals for 2020 looming before us, addressing the psychological and social challenges that persist for those living with HIV is paramount to ensuring that individuals will be able to reap the benefits of today's potent biomedical tools. Structural improvements in clinic and community services are also needed, but lack of psychosocial interventions will undermine any health systems improvements in HIV testing, care, and treatment. For those who are already virally suppressed, they are surviving—but is there more that can be done to help PLHIV thrive? The demographic tide is turning with longer lifespans thanks to ART. A new generation of PLHIV must grapple with questions of how to attain and maintain a high quality of life throughout aging and older adulthood. The time is right for a renewed commitment to address the psychosocial challenges that remain and for increased efforts to understand how we can foster resilience in homes, communities, and healthcare systems across the globe to enhance the quality of life of PLHIV.

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