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Toward an enhanced understanding of resilience for youth HIV populations

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Abstract

Though mother-to-child HIV transmission has been dramatically reduced in the past decade, there are currently an estimated 1.8 million children living with HIV across the globe, and over 30% of all new HIV infections occur among youth ages 15 to 25. While all youth experience developmental challenges, children and adolescents who are living with HIV must navigate these challenges within the context of high HIV stigma and must cope with a host of psychosocial and health-related challenges. In addition, because HIV disproportionately impacts individuals from minority statuses (e.g., race, ethnicity, gender, sexuality) and people living in poverty, vulnerabilities are often compounded. Resilience frameworks emphasize the capacity for positive adaptation to adversity, and thus provide a useful lens to identify and build upon individual and community strengths. This article introduces a special issue of *AIDS Care* that examines factors associated with resilience among children and adolescents affected by or living with HIV, as well as innovative interventions designed to build resilience among HIV youth populations. The articles highlighted within this issue examine the possibility of building resilience across diverse settings (e.g., schools, communities, healthcare clinics) and with varied populations (e.g., youth living with HIV, AIDS orphans, young men who have sex with men). We also highlight innovative approaches to resilience-building, including a new mobile Health (mHealth) smartphone game that aims to improve adherence among youth living with HIV in the United States.

The global impact of HIV on children and adolescents is immense in scope, ranging from the direct impacts of primary and secondary infections to the indirect effects associated with healthcare costs, caregiving burden, educational impacts, and lost productivity as children age into adulthood. Of the ~36.9 million individuals living with HIV across the globe, an estimated 1.8 million of them are children under the age of 15 (UNAIDS, 2017). The scaling-up of prevention strategies designed to reduce mother-to-child HIV transmission has yielded remarkable success, and thus the number of young children living with HIV has steadily dropped over the past decade (UNICEF, 2017). However, adolescence remains a period of high vulnerability. An estimated 590,000 young people (ages 15-24) acquired HIV in 2017 alone, of whom 250,000 were between the ages of 15 and 19 (UNICEF, 2018). Currently, one out of every seven new HIV infections occurs during adolescence, and thus policy makers and public health experts are increasingly recognizing that targeted efforts are needed to prioritize HIV testing, counseling, treatment, and care for young people around the globe (World Health Organization [WHO], 2013). This is particularly important because, while overall AIDS-related deaths fell by 35% from 2005 to 2013, deaths among adolescents

living with HIV have risen sharply—as much as 50%—over a similar period. Both children and adolescents are currently recognized as key populations in the 90-90-90 goals (UNAIDS, 2014) that seek to have 90% of people living with HIV know their positive status, 90% of diagnosed individuals on antiretroviral treatment, and 90% of people in treatment virally suppressed by 2020.

Extending beyond youth who are living with HIV, millions of children and adolescents around the world have been substantially impacted by parental HIV. Chronic health conditions have been dubbed “a family affair” (Wittenberg & Prosser, 2016), and literature on parental HIV bears this out. Youth affected by parental HIV first and foremost face the potential for orphanhood, with an estimated 17 million children across the globe having already lost one or both parents to AIDS (USAID, 2016). Beyond this, parental HIV is associated with a host of challenges, including parental caregiving, transitions in care arrangements and housing, school disruptions, and negative economic outcomes (Chi & Li, 2013; Foster & Williamson, 2000; Guo, Li, & Sherr, 2012; Shetty & Powell, 2003). These adverse experiences contribute to increased risk for a range of negative psychological, physical, and behavioral health outcomes among HIV-affected children (Cluver, Orkin, Gardner, & Boyes, 2011; Cluver, Orkin, Boyes, Sherr, Makasi, & Nikelo, 2013; Sherr et al., 2008).

Despite these challenges, many youth living with or affected by HIV do not merely survive—but thrive. Many will reach their educational goals, form and maintain healthy romantic relationships, and smoothly transition into adult roles within their community—typical developmental milestones, but ones that are all the more remarkable within the context of having to maintain viral suppression, cope with HIV stigma and discrimination, or care for an HIV-positive parent.

Thus there have been increasing efforts to identify resilience-promoting resources that help such youth adapt to HIV-related adversity (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). For this special issue, we choose to define resilience as the dynamic processes that allow for positive individual adaptation despite the experience of life challenges (American Psychological Association, 2012; Luthar, Cicchetti, & Becker, 2000; Masten & Narayan, 2012). We are particularly interested in resilience processes that help youth endure and bounce back when their stability, sustainability, and/or development are threatened (Masten, 2011) by HIV-related experiences. We also want to draw attention to both resilience processes that occur within an individual and also those that are external, including peer and family support. We wish to highlight characteristics of broader systems (e.g., healthcare systems, school systems) that may increase resilience for vulnerability youth populations and be optimal sights for future resilience-building interventions.

Therefore, we are pleased to present this special collection of papers that examine resilience among a diverse group of HIV-affected youth populations. Work included in this issue spans across the globe—including youth living with HIV in the Southern United States and Tanzania, as well as populations vulnerable for HIV, such as young men who have sex with men in the United States and children orphaned by AIDS-related causes in sub-Saharan Africa. This breadth of coverage was important for us to reflect the diversity of the HIV

epidemic across both place and population. Papers included in this issue also span a wide-range of methodologies, which include modeling studies to elucidate factors associated with positive mental health outcomes and reduction of risk among vulnerable youth, as well as intervention studies that seek to directly increase resilience among youth living with HIV through innovative psychosocial and technology-based interventions.

A wide variety of resilience factors are explored across the studies, which reflect socio-ecological theories of human development, most notably Bronfenbrenner's (1989) ecological systems theory. At the individual level, papers included in this special issue explore factors including positive mental and behavioral health, socioeconomic characteristics (e.g., educational attainment, income), self-efficacy, motivation, and even more nuanced cognitive factors, such as having a positive outlook on life and a belief in one's sense of purpose. A number of factors across the microsystem are examined, including the protective nature of strong familial and social relationships and youths' feelings of school connectedness. At the exosystem, papers explore the role of safe and healthy living environments, as well as economic vulnerabilities that contribute to positive or negative adaptation. Finally, all papers pay due attention to larger cultural attitudes and ideologies (i.e., macrosystem) that shape vulnerability and resilience for HIV-affected youth. A large body of literature has examined links between HIV stigma and negative outcomes (e.g., mental and physical health, quality of life, social support, adherence) (Livingston & Boyd, 2010; Logie & Gadalla, 2009; Smith, Rossetto, & Peterson, 2008)—and the importance of continuing to investigate HIV stigma and develop effective stigma reduction interventions are highlighted throughout this issue. However, authors also add to emerging literature on other ideological constructions that are also critical for improving HIV outcomes among youth, including gender-based power inequities and attitudes and norms regarding sexual agency.

The selected papers identify both challenges encountered by HIV youth populations, as well as unique opportunities to enhance their resilience. Chenneville, Gabbidon, Lynn, and Rodriguez (2018) share findings on associations between reduced anxiety and improved biological and behavioral resilience among youth living with HIV in the Southern United States, and call upon healthcare providers to ensure that mental health screening and treatment is a routine aspect of HIV care for children and adolescents. A recent systematic review (Clucas, Sibley, Harding, Liu, Catalan, & Sherr, 2011) identified 39 separate studies evaluating anxiety-reduction interventions for individuals living with HIV—yet not one of these studies included children or adolescents. Tailored mental health interventions for youth living with HIV are urgently needed. Thus we are pleased to also highlight recent efforts by Dorothy Dow and colleagues (2018) to develop a tailored mental health intervention (i.e., *Sauti ya Vijana* [*"The Voice of Youth"*]) for youth living with HIV in Tanzania. This resilience-based intervention was designed to improve coping skills, promote overall wellbeing, foster strong familial and social relationships, and enhance treatment adherence. Findings suggest high feasibility and acceptability among participants, and the team's efforts to engage youth throughout the intervention development process provide a good model for other research teams.

Whiteley, Brown, Mena, Craker, and Arnold (2018) highlight links between life stressors and adherence for youth living with HIV and present exciting preliminary findings on the effects of BattleViro, a smartphone (i.e., iPhone) game that was also developed with significant input from youth living with HIV (Whiteley, Brown, Lally, Heck, & van den Berg, in press). Their group was able to demonstrate promising improvements in adherence among youth who had recently initiated antiretroviral therapy, and we look forward to future largescale trials and the scaling up of this innovation. We also believe it is an important step toward a greater understanding of how mHealth interventions can boost resilience for HIV youth populations.

The critical role that schools can play in supporting vulnerable children is highlighted by a contribution by Sharp, Penner, Marais, and Skinner (2018), who examine links between mental health and school connectedness among a large sample of vulnerable South African youth, including 224 children orphaned from AIDS-related parental death. School connectedness served as an important buffer for negative mental health outcomes. However, orphans were less likely to report feeling connected to their schools than non-orphans—highlighting the work that remains to be done to ensure that schools have the capacity to fully support both academic and social-emotional needs of HIV-affected youth.

Another contribution to the special issue, by Meanley, Tingler, Chittamuru, and Bauermeister (2018) highlights a very different vulnerable HIV population—young men who have sex with men in the United States. This paper examines economic-dependent partnerships among young men who have sex with men, using a risk and resilience framework. While such relationships are often a means of survival for young men who have sex with men, findings presented here suggest that they are linked with a host of syndemic vulnerabilities, and call attention to understudied area of how to reduce risk for young men in power-imbalanced relationships.

We hope that this issue will contribute to a growing conceptual understanding of resilience for HIV youth populations (Li, Chi, Sherr, Cluvery, & Stanton, 2015) and will aid in the identification of individual and contextual factors that show clear links with positive development for youth affected by HIV. At the same time, the studies highlighted in this article also identify current gaps and provide suggestions for future directions of resilience research. First, while Whitley and colleagues (2018) provide a nice example of partnering with youth living with HIV for intervention development, this is too often not the case in HIV research. Greater involvement is needed by youth themselves in HIV resilience research, and equitable collaborations must be prioritized. Youth are rarely included as meaningful partners in community-based participatory research (Jacquez, Vaughn, & Wagner, 2012). We argue that without involving HIV youth populations at each step of the research process, any impacts will be substantially reduced.

In addition, we also see a greater need for discussion and debate within the field on biological constructs of resilience. In this special issue, viral load is used to represent biological resilience among youth living with HIV (Chenneville, Gabbidon, Lynn, & Rodriguez, 2018; Whiteley et al., 2018). Viral load is certainly a key biological outcome of interest for children and adolescents living with HIV. However, the biology of resilience is

complex, and the studies here do not begin to address biological underpinnings that may shape individuals' responses to adversity. Longitudinal studies are needed to investigate how biological or genetic contributors modify an individual's response to adversity, as well as how environmental events (e.g., loss of a parent to AIDS, disclosure of one's HIV status) impact underlying biological mechanisms (Southwick, Bonnano, Masten, Panter-Brick, & Yehuda, 2014). Such findings could be particularly useful as we move deeper into the era of precision medicine and targeted, individualized therapeutic approaches.

Putting these findings into action will require close collaboration between researchers and practitioners. Innovative practices are being implemented in clinics, communities, and homes around the world to improve outcomes for HIV-affected children and adolescents. Yet there continues to be too little systematic evaluation of these efforts, and when evidence-based practices for youth are identified, they frequently fail to be followed up by the implementation and dissemination work that is critical for effective scale-up. Tremendous progress has been made over the past two decades to slow the spread of HIV. Now is the time to focus our attention on key populations—including youth—to ensure that those who are most vulnerable to HIV are able to reap the benefits of nearly four decades of HIV prevention and intervention science. Resilience-based approaches offer tremendous promise to accomplish this goal and hasten our progress toward an HIV-free generation.

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