Research Brief

Formative HIV Research With Youth in Kenya: Findings From a Psychosocial Needs Assessment

Tiffany Chenneville, PhD*

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HIV is a global disease that affects youth worldwide. Despite medical advances that can significantly reduce the risk of mother-to-child transmission, children continue to be born with HIV (Centers for Disease Control and Prevention, 2016b; World Health Organization [WHO], 2015). In addition, adolescents represent a substantial number of new infections resulting from risky sexual behavior. Globally, AIDS is the second leading cause of death among adolescents (United Nations Children's Fund, 2016).

The mental health toll on people living with HIV is well documented. The most common mental health condition among people living with HIV (PLWH) is depression (Dube, Benton, Cruess, & Evans, 2005), with prevalence estimated at 22% to 81% (Arseniou, Arvaniti, & Samakouri, 2014; Komiti et al., 2003). Youth with HIV are four times more likely to develop depression than their healthy peers and are at increased risk for depression even when compared to youth with other chronic illnesses (Arseniou et al., 2014; Pao et al., 2000). It appears there may be a circular interaction whereby depressive symptoms correlate with behaviors that increase the risk of acquiring HIV to include risky sexual behavior and substance use (Koblin et al., 2006) and then living with HIV increases the risk for depression. As partial evidence of the former, research has suggested that youth with behaviorally acquired HIV are twice as likely to experience mental health symptoms as youth with perinatally acquired HIV (Brown, Whiteley, Harper, Nichols, & Nieves, 2015).

Mental health issues facing youth living with HIV are both influenced and exacerbated by stigma. Because HIV has long been associated with marginalized groups–homosexuals, sex workers, drug users–in the United States and abroad, stigma related to the disease is high and serves as a significant barrier to HIV testing, treatment, and retention in care (Katz et al., 2013; Turan & Nyblade, 2013). Further, HIV stigma is associated with a diminished quality of life (Holzemer et al., 2009). Many people with HIV, including youth, face multiple stigmas (e.g., HIV infection and homosexual orientation). Because mental illness is also a stigmatizing condition, youth with HIV who are experiencing mental health issues may experience stigma related to various aspects of their identities. The intersection between stigma, gender, mental illness, ethnicity, and sexuality has been documented (Collins, von Unger, & Armbrister, 2008; Crowe, Averett, & Glass, 2015), and there is evidence to suggest that mental health stigma negatively affects help-seeking behavior (Clement et al., 2015). This means that youth with, or at risk for, HIV who are most in need of assistance may not access the help they need. Untreated mental health issues may contribute to HIV risk as well as outcomes if infected. Mental health stigma is also associated with decreased resilience (Crowe et al., 2015), which is a factor related to health outcomes for youth with HIV.

*Tiffany Chenneville, PhD, is an Associate Professor of Psychology, Joint Appointment, Department of Pediatrics, University of South Florida St. Petersburg, St. Petersburg, Florida, USA. (*Correspondence to: chennevi@mail.usf.edu).*

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The HIV epidemic has been most devastating in Sub-Saharan Africa, where the number of PLWH represents approximately 70% of the global epidemic and where beliefs related to contamination, sexuality, and religion contribute to HIV-related stigma and discrimination (WHO, 2015). It is, therefore, important to understand the unique psychosocial issues facing youth with or at risk for HIV in the African context. Kenya is one of the countries in Sub-Saharan Africa most affected by HIV. Kenya is tied with Uganda and Mozambique for the highest number of PLWH (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014). As of 2015, there were 1.5 million PLWH in Kenya, including 78,000 new HIV infections (AVERT, 2016). Although 59% of adults with HIV in Kenya received antiretroviral treatment, there were 36,000 HIV-related deaths in 2015 (AVERT, 2016).

Clearly, there is a need in Kenya for individual and structural change efforts designed to improve mental health outcomes for youth living with HIV, to increase rates of HIV testing, and to improve treatment and retention in care. Identifying avenues for HIV prevention and intervention is important not only for Kenyan youth, but also for youth living in other parts of the world who will benefit from cross-cultural research contributing to global efforts to end the HIV epidemic. As a preliminary step to designing a community-based participatory research program involving youth with HIV, the primary objective of our project was to conduct a psychosocial HIV research needs assessment in Kenya by gathering input from primary and secondary stakeholders.

Methods

During an initial visit to Kenya, we conducted a needs assessment via 22 forums involving a convenience sample of 268 stakeholders from five tribes, five communities, and 11 organizations and agencies in Nakuru. Nakuru is located approximately 55 miles northwest of Nairobi and has a population of more than 300,000 people (County Government of Nakuru, 2016; Sphereinfo.com, 2016). People from the Kikuyu and Kalenjin tribes represent nearly 70% of the population, with the remainder comprised of people from the Luo, Luhyia, Kamba, Meru, and Kisii tribes. Christianity is the predominant religion in Nakuru, with a minority of the population representing Muslim or Hindu religions. Languages include Kiswahili, Gikuyu, Kalenjin, and English. The economy is driven, in large part, by small-scale farming, including dairy farming and horticulture.

Primary stakeholders participating in the needs assessment included youth living with HIV, youth orphaned due to parental death from HIV, and parents/caregivers living with HIV. Secondary stakeholders included peers and other community members, orphanage directors and staff, teachers, mental health providers, medical providers, local agency officials, and religious leaders/ministers. Tribes and communities in the city of Nakuru and various organizations including several orphanages, a sewing center for PLWH, the Nakuru Children's Department, the Nakuru Child Protection Unit, the Family AIDS Initiative, the Nakuru Drop In Center, the Comprehensive Care Clinic, local churches, and local ministries were represented in the needs assessment. Participation in forums was completely voluntary.

Forums included 10 individual interviews, nine focus groups, and one community session, as well as a briefing session and a debriefing session with key stakeholders who helped organize activities. Forums were designed to provide HIV education to participants while simultaneously assessing psychosocial and education needs. The provision of HIV education allowed key stakeholders to immediately benefit and, subsequently, increased the likelihood of buy-in to the pending research collaboration. Questions were posed to generate conversations for the purpose of garnering information about HIV misperceptions and factors affecting the lives of children and families affected by HIV. For example, participants across forums were asked about perceived barriers to HIV testing, treatment, and retention in care. Participants also were asked to share experiences and observations related to HIV in the community. Findings were documented through note-taking during and after each forum. In addition, where allowed, forums were videotaped and later reviewed for the purpose of cross-referencing notes. In a debriefing session with key collaborators, notes were reviewed and impressions were shared for the purpose of assessing the reliability