results brief

Youth Living with HIV in Zambia: interpersonal violence, self-stigma, and viral suppression

As adolescents and young adults living with HIV age into adulthood, they must navigate the transition to HIV self-management and adult care. This is a complex process, particularly for young people who must manage a chronic illness like HIV. As a result, many adolescents and young adults living with HIV have incomplete adherence to antiretroviral therapy (ART), leading to poor viral suppression and a greater risk of HIV-related mortality.

Under Project SOAR, Johns Hopkins University in collaboration with Arthur Davison Children's Hospital is refining and testing a peer-mentoring strategy in Zambia (Project YES!) to strengthen the capacity of health systems and families to support youth living with HIV (YLHIV) as they transition to, and engage in, self-management and adult HIV care and treatment. Results will offer evidence-based guidance and refined tools for YLHIV, their families, and their health care providers to improve the care transition process and related HIV outcomes.

A total of 276 YLHIV were enrolled in the study. This brief presents survey and viral load data for 273 participants. The brief also highlights findings from in-depth interviews with a sub-group of 40 YLHIV participating in Project YES! who were selected to provide a range of experiences related to violence and viral suppression.

KEY MESSAGES

- YLHIV participating in this study have experienced high levels of violence.
- Youth often reported experiencing multiple types of violence from multiple perpetrators whom they knew, with high levels for females from a parent/caregiver and intimate partner, and males from a friend/peer.
- Self-stigma, as manifested by feelings of guilt, shame, and worthlessness, is also of concern.
- Many youth are not virally suppressed, and the majority of this group demonstrate resistance to either first or second line treatments.

WHO ARE THE PARTICIPANTS?

60% female

63%
15–19 years
of age

73%
perinatally
infected
(self-report)

49%
currently in
school

50%
receive care in a
pediatric setting

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RESULTS

Interpersonal violence was high in this population.

Nearly three-quarters of males and females reported being a victim of violence (psychological, physical, or sexual) in the past year. Psychological abuse was the most common form of violence, followed by physical violence, followed by forced sex. The overall levels of violence and types of violence reported were similar for male and female YLHIV (Figure 1).

Experiences of physical violence victimization were severe (e.g., kicked, dragged, beaten, choked) for a third of participants experiencing physical violence in the past year. A greater proportion of female than male YLHIV experienced severe past-year physical violence (41 percent vs. 23 percent), although the difference was not statistically significant.

The perpetrators of violence in the past year tended to be different for male compared to female YLHIV.

Among YLHIV reporting any past-year violence, female YLHIV reported significantly higher levels of any past-year violence from an intimate partner (33 percent vs. 5 percent, $p<0.001$), parent/caregiver (32 percent vs. 18 percent, $p<0.05$), and stranger (20 percent vs. 5 percent, $p<0.001$) compared to their male peers. But male participants reported higher levels of any violence from a friend or peer than female participants (74 percent vs. 45 percent, $p<0.001$). Both sexes reported similarly high levels of violence from a family member other than a parent/caregiver (41 percent).

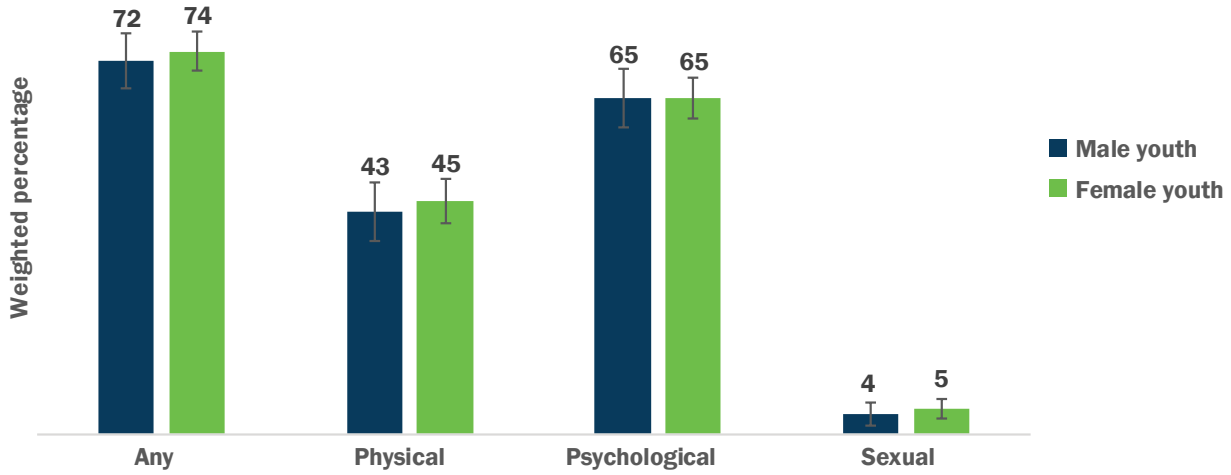
Youth described ways in which their experiences of violence affected their HIV care and treatment.

Some, but not all, youth participating in in-depth interviews recounted how experiences of violence negatively impacted on their mental health, medication regimen, and clinic appointments. Bupe* and Mutale* offer two examples of how violence affected their HIV treatment practices.

While staying with her auntie and cousin, Bupe, age 17, used to experience stigma in the form of constant insults and shouting. Bupe had acquired HIV from a boyfriend, and her auntie would always tell Bupe that it was her fault that she was HIV positive. Because of Bupe's HIV status, her auntie would insult her for not having an appetite and her cousin would refuse to share clothing. As a result, Bupe had thoughts of suicide and her adherence suffered.

*Participants' names have been changed to protect their identity.

Figure 1 Past-year violence victimization, by sex



> *It always breaks my heart…My being HIV positive has brought me trouble at this home…. Each time they tell me [those things], I just think of killing myself. I even had to stop taking my medication…. [I stopped for] two months.*

Over several days, Mutale, age 19, quarreled with his cousin, who did not know his HIV status but would refuse to give him food when he arrived home from school. Mutale started avoiding home, which led him to take his medication late and often on an empty stomach.

> *What happened to my medication particularly was like…'I haven't eaten. Then how am I going to start taking medication?' …I didn't want to see my cousin…. I was coming late so the time taking the medication was quite unbalanced.*

Self-stigma was common among participants.

Two-thirds (66 percent) of youth responded yes to at least one of three questions about feeling guilty, shame, or worthlessness because they are living with HIV. The levels were similar for male and female youth (62 percent vs. 67 percent). Figure 2 shows the breakdown of self-stigma stigma among male and female YLHIV for each of the three items.

Many participants were not virally suppressed.

Only 64 percent of YLHIV were virally suppressed (less than 1,000 RNA copies/ml) at baseline. Thus more than a third of the sample had not achieved this threshold. Figure 3 shows the proportion of youth who had not achieved viral suppression by sex and age.

Figure 3 Proportion of youth not virally suppressed by sex and age

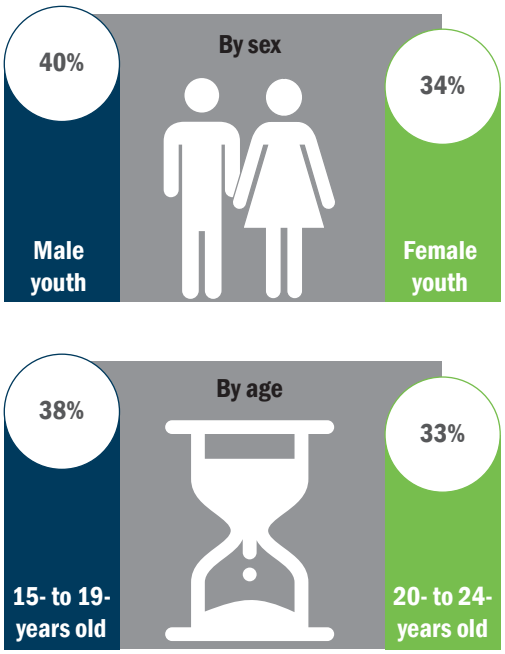
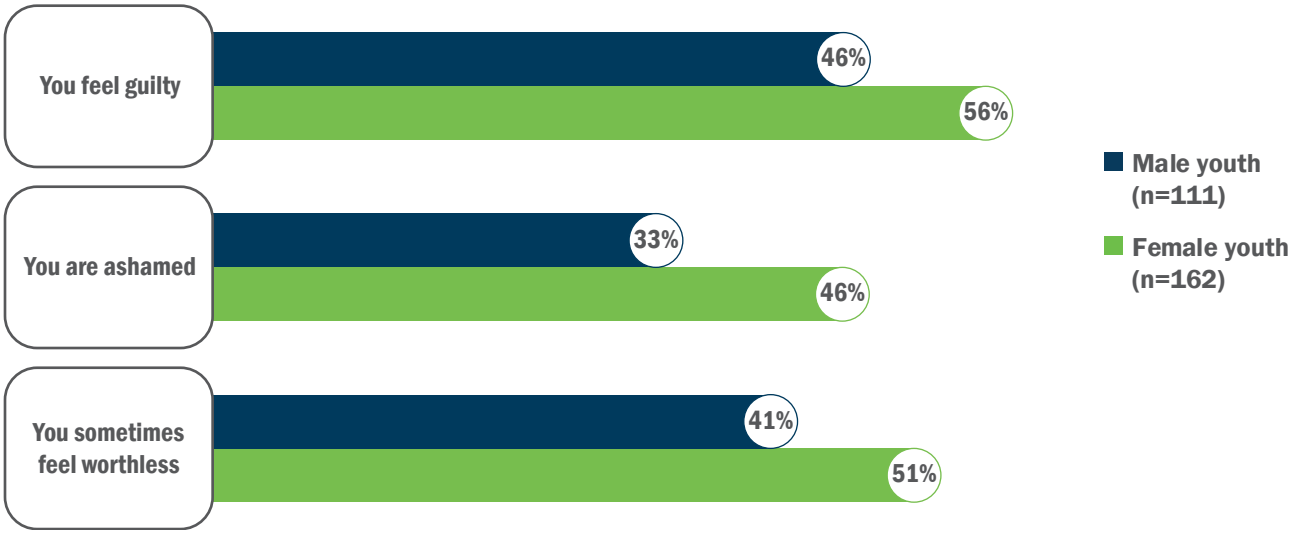


Figure 2 Levels of self-stigma due to HIV-positive status by sex



*N=110; One male participant declined to answer the question about shame.

Most YLHIV not achieving viral suppression had evidence of drug resistance

Drug resistance to at least one antiretroviral drug was detected in 75 percent of YLHIV who were not virally suppressed. YLHIV on both first line and second line treatment exhibited drug resistance, and more than a third of which had Y188C/Y181C mutations. These mutations are of particular concern because they confer resistance to third line therapies, thus limiting treatment options for youth who fail first- or second-line treatment (Figure 4).

CONCLUSIONS

This study found that YLHIV participating in this study have experienced high levels of violence. Youth often reported experiencing multiple types of violence from multiple perpetrators whom they knew, with high levels for females from a parent/caregiver and intimate partner, and males from a friend/peer. Self-stigma, as manifested by feelings of guilt, shame, and worthlessness, is also of concern.

In addition, results highlight that many youth are not virally suppressed, and that the majority of this group demonstrate resistance to either first line or second line treatments.

Project YES! is using these findings to address violence, stigma, and adherence as part of its peer mentoring strategy. Final results on the effectiveness of the strategy will be available in late 2019.

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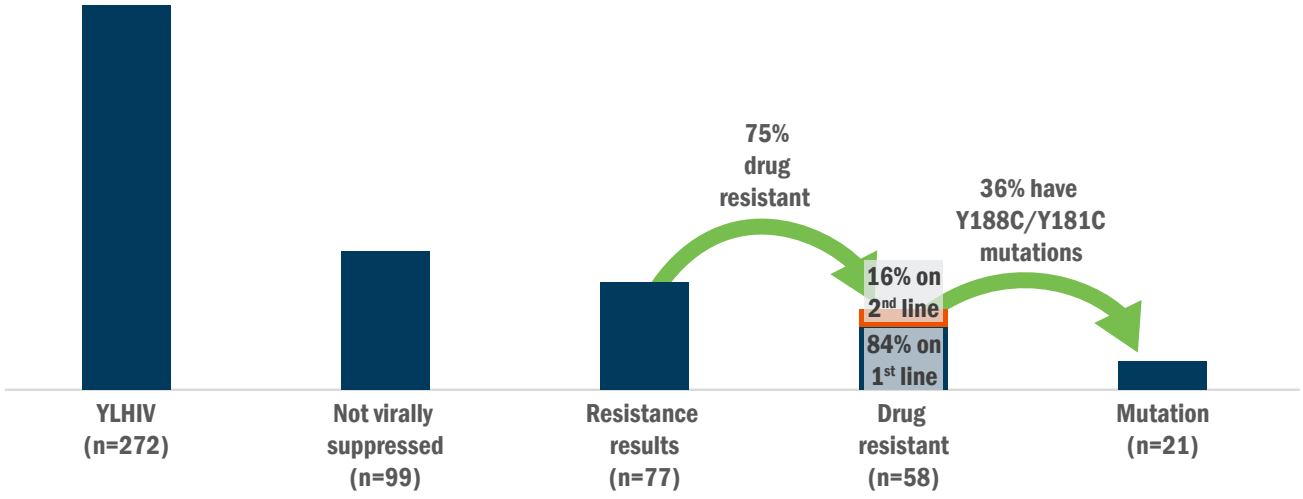
Figure 4 Drug resistance cascade among YLHIV (n=273)



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Population Council leads the Project SOAR consortium in collaboration with Avenir Health, Elizabeth Glaser Pediatric AIDS Foundation, the Johns Hopkins University, Palladium, and The University of North Carolina at Chapel Hill.

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