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Self-disclosure of HIV status by Adolescents and Young Adults is Associated With Higher Levels of Enacted and Internalized Stigma

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Introduction: Disclosure of one’s HIV status to others is encouraged from a public health standpoint in order to prevent onward transmission. On an individual level, disclosure has been associated with both positive and negative impact on antiretroviral therapy (ART) adherence and mental health. We studied patterns of disclosure among adolescents and young adults (AYA) and association between self-disclosure, ART adherence, social support and mental health.

Methods: HIV-infected AYA ages 14-24 were recruited from a peri-urban HIV clinic in Nairobi, Kenya between December 2017 and April 2019. Participants were asked who knew their HIV status and whom they had informed of their status. Number of missed doses of ART in the prior 30 days were self-reported with good adherence defined as a score of >80%. Anticipated, enacted and internalized stigma was assessed using a stigma scale validated among HIV-infected AYA in South Africa. High resilience was defined as a score above the median on the adapted Connor-Davidson Resilience Scale. Depression was defined as a score ≥5 on the Patient Health Questionnaire (PHQ-9). High social support was defined as a score above the median on the abbreviated social support behaviors (SSB) scale. Prevalence ratios (PR) for correlates of self-disclosure, and the associations of self-disclosure with adherence, social support and mental health outcomes were calculated using binomial regression. Age was included as an a priori adjustment in all regressions; gender was additionally included in analysis involving depression, adherence and social support.

Results: Of the 96 enrolled AYA, 76 (78%) were female and 65 (67%) were age 19-24. The HIV status of 87 (91%) AYA was known by a family member or friend, while 63 (66%) AYA reported having self-disclosed their HIV status; 45 (71%) to a family member and 22 (35%) to friends. Older AYA (age 19-24) were 1.75 (95%CI: 1.15-2.65) times more likely to have self-disclosed to someone, 1.96 (1.15-3.33) times more likely to have self-disclosed to family, and 3.00 (1.17-7.68) times more likely to have self-disclosed to friends, than younger adolescents (age 14-18).

Prevalence of good adherence was 73%, high resilience 38%, high social support 31%, depression 48%, anticipated stigma 58%, internalized stigma 40%, and enacted stigma 18%. AYA who had self-disclosed were 2.35 (1.14-4.84) times more likely to report internalized stigma. This association was stronger when self-disclosure was to family (PR=2.80 (1.35-5.82)) than friends (PR=1.60 (0.59-4.36)). AYA were also 11 (1.50-78) times more likely to report enacted stigma than those who had not self-disclosed. This association was stronger when self-disclosure was to family (PR=15.48 (1.96-122)) than friends (PR=4.26 (0.40-46)). There was a trend for higher depressive symptoms among AYA who had self-disclosed, PR=1.76 (0.99-3.12). No significant association was detected between self-disclosure and good adherence PR=1.23 (0.90-1.69), higher resilience PR=1.32 (0.68-2.54), high social support PR=1.60 (0.75-3.42) and anticipated stigma PR=0.93 (0.62-1.39).

Conclusion: AYA had varying disclosure status depending on age. Self-disclosure, while encouraged, should be carefully considered for individual AYA. Disclosure counseling should be accompanied by stigma reduction interventions. Screening for depression should also be prioritized when AYA are undertaking self-disclosure for early detection and management.