

BANTWANA INITIATIVE TECHNICAL BRIEF

Engaging Caregivers in the Health and Resilience of Adolescents Living with HIV



BACKGROUND AND CONTEXT

In Uganda, viral load (VL) suppression rates are lowest among young people under 20 years of age, with only 70% achieving VL suppression compared to 90% of adults over 25 (Uganda Ministry of Health, 2019). Research studies show that heightened stigma, psychosocial difficulties, limited financial resources, and the absence of parental support contribute to poor adherence in adolescents¹.

Under the PEPFAR/USAID-funded Better Outcomes for Children and Youth in Eastern and Northern Uganda (BOCY) project, the Bantwana Initiative of World Education, Inc. (WEI/Bantwana) and local partners² deliver a targeted package of economic strengthening, HIV/health, education and child protection services to mitigate the risk and impacts of HIV and violence on vulnerable children and caregivers. The program also strengthens community to district service delivery systems by developing the capacity of CSO, government and community structures to operate within a clinic-community referral network and case management system.

Services packages for adolescents living with HIV (ALHIV) include Peer Support Groups delivered by trained adults living with HIV ('expert clients') during monthly adolescent ART clinic days. Groups help ALHIV cope with the psychological stresses of living with HIV, support adherence and address adolescent concerns about disclosure, stigma, dating, and other adolescent concerns as they prepare to transition to adulthood.

Family-centered approaches that prioritize the socioeconomic needs of caregivers and their children – beyond HIV and health – should be considered in all efforts to support adolescent adherence and resilience.

¹ Naidoo K, Munsami, et al, S Afr Med J 2015;105(11):953; Hudelson C, et al, AIDS care. 2015 Jul 3;27(7):805-16).

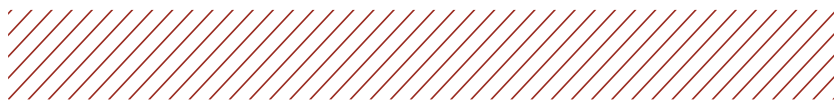
² AVSI, SOS, AIC, m2m and MUCOBADI.

OUR RESPONSE

Research and feedback from ALHIV underscore the importance role their caregivers play in their health and wellbeing. The Peer Support Group model builds mental, physical and social resilience among peers, but misses an important opportunity to engage caregivers in supporting adolescents' broader health and social welfare needs.

Financial stress topped the list of caregiver concerns. Caregivers also faced challenges understanding ART treatment, why adherence is important, and parenting children through adolescence, a time of increased stress due to rapid emotional and physical changes as well as increasing autonomy. With health counterparts across six high volume sites, WEI/Bantwana adapted and integrated BOCY's economic strengthening and parenting supports with ART literacy and adherence information. Together, multidisciplinary clinic³ and community⁴ teams delivered the Peer Support Group Plus package to 138 caregivers and adolescents during ART refill days on weekends, often together to promote cross learning and coordination.

OUR INTERVENTIONS



The holistic package helped families comprehensively address multiple issue impacting adherence and resilience. Community follow up through case management delivered by integrated health, child protection and social welfare cadres helped to strengthen treatment retention and address emerging issues to build a continuum of support around children and families. The intervention package included the following:

A strategic mix of savings groups, financial literacy, and income generating skills

helped families to establish kitchen gardens and start low-cost IGAs using locally available materials . Financial supports motivated caregiver participation and helped households to build a safety net, while backyard gardening supported families to grow their own food, increase overall food security, and enhance nutrition.

Treatment and adherence literacy for better health

helped caregivers and adolescents understand and appreciate the importance of adherence, prepare for disclosure, and address concerns about stigma. Clinic and community teams helped families set up daily medication routines and understand when to seek medical attention for medication side effects.

Positive parenting helped families reshape communication and strengthen emotional bonding, improve parenting confidence in caregivers, open space for adolescents to speak freely about their concerns, and renewed caregivers' commitment to supporting the health and wellbeing of children.

Adolescent sexual and reproductive health (ASRH) and nutrition

delivered during adolescent- and caregiver-only sessions enhanced important knowledge for overall health while creating space for honest and open discussions with peers.

Monthly multi-stakeholder meetings to support broader adherence issues

with clinic, community and school actors sensitized key stakeholders and coordinated action to strengthen disclosure and confidentiality, while reducing stigma in facilities, schools and communities.

³ Clinic teams included nurses, 'expert clients', ART focal leads, Clinic in Charges, Linkage Facilitators

⁴ Community teams included CSO social workers, parasocial workers, parenting and economic strengthening structures.

OUR RESULTS



After my grandmother came to the sessions with me, she gained courage to go with me to disclose my status to the head teacher and the Matron at my school. Now, I can go for refills and swallow my medicine in private, and my viral load has reduced!"

- Adolescent living with HIV, Agago District



After nine months (April 2019-December 2019), findings from a pre- and post-test survey showed important improvements across multiple composites.



25%

INCREASE IN DISCLOSURE OF HIV STATUS BY CAREGIVERS TO ADOLESCENTS



39%

INCREASE IN ART TREATMENT LITERACY BY CAREGIVERS



28%

INCREASE IN CAREGIVER ATTENDANCE ON ADOLESCENT ART CLINIC DAYS



68%

INCREASE IN POSITIVE COMMUNICATION BETWEEN CAREGIVERS AND CHILDREN



23%

IN ADOLESCENT VIRAL LOAD SUPPRESSION

LESSONS LEARNED

Adolescent adherence is a dynamic state

requiring ongoing adaptation and responsiveness to the clinical, psychosocial, and socioeconomic dynamics that impact disclosure, adherence, viral load suppression, and resilience in adolescents.

Family-based approaches that recognize the vital role of caregivers

remain critical to the health and wellbeing of ALHIV. Increased caregiver involvement not only supported adolescents' treatment adherence but helped adolescents better navigate HIV-related stigma, while increasing young people's self-confidence during a period of rapid and complex change.

Practical economic strengthening supports

motivated caregiver and youth participation. Addressing financial concerns upfront built trust and generated greater commitment to participation in treatment literacy and parenting sessions by caregivers.

Strengthening emotional safety between caregivers and adolescents

helped caregivers deal with adolescent shifts towards independence and created openness for discussions on topics around disclosure, stigma, grief, and loss. Beyond caregivers, these exercises also sensitized health workers who often share the responsibility of disclosing status and providing treatment support to ALHIV.

Multi-disciplinary home-visits

through case management helped caregivers to digest and reflect on new learning and information, while enabling a more holistic understanding of complex family-related adherence issues, including neglect, gender-based violence (GBV), nutrition, food insecurity, and poverty.

Monthly multi-sectoral stakeholder meetings

sensitized school administrators and district child protection officers to challenges facing ALHIV reduced stigma and created space for adolescents to safely disclosure to teachers and friends which in turn, strengthened treatment retention and adherence.

OUR CONCLUSIONS

Sustaining and accelerating gains in adolescent adherence require ongoing innovation and rapid adaptation to the fluid dynamics and circumstances facing adolescents living with HIV. Given the right tools, skills, and supports, caregivers can be powerful allies to their children. Family-centered approaches that prioritize the socio-economic, as well as HIV and health needs of caregivers and their children should be considered in efforts to improve adolescent adherence and resilience over the long-term.

