## **Mental Health**

# Strengthening mental health for children, adolescents and young people living with HIV



There is an increasing recognition of the substantial unmet mental health needs of ALHIV, who have higher rates of depression and other common mental health problems than their HIV negative peers<sup>1,2</sup>, as well as a connection being made between mental health and wellbeing with adherence and viral load suppression.<sup>3-6</sup> Depression is the third leading cause of illness and disability among adolescents and suicide is the third leading cause of death in adolescents aged 15–19 years<sup>7</sup>. Several studies in Zimbabwe and elsewhere have found that adolescents living with HIV are at significant risk of depression<sup>8-10</sup> which in turn correlates with poor adherence to ART<sup>11</sup>. Likewise, recent research in Zimbabwe has found high rates of virological failure among adolescents living with HIV<sup>12</sup>. Although the understanding of the relationships between mental health and HIV outcomes is still evolving, there is an increased recognition of the potential effect of attending to mental health as an important outcome in itself, but also tackling the psychological problems that play a role in poor adherence in ALHIV as a means to progress towards achieving the ambitious global target of 95% of those on Anti-retroviral therapy (ART) to be virally supressed.<sup>13-15</sup>

Since 2004, Zvandiri has been integrating psychosocial support and mental health services within the clinical management of children, adolescents and young people living with HIV. In partnership with the Ministry of Health and Child Care (MoHCC), provision of peerled psychosocial support and mental health services within HIV service delivery has been prioritised through scale up of the Zvandiri model in health facilities and their surrounding communities, with the aim of improving both HIV and mental health outcomes.

#### **Strengthening the Evidence**

Over the years, Zvandiri has focused on strengthening the evidence around the prevalence, manifestation, impact and management of mental health conditions in children, adolescents and young people living with HIV. Zvandiri has conducted various studies in partnership with local, regional and international research institutions, the results of which have helped to inform global and national policy, programming and service delivery. Key findings have included:

- Adolescents living with HIV are at high risk of common mental disorders (CMD)
  - 65% ALHIV at risk of CMD in Harare<sup>1</sup>
  - 38% (of 1573) ALHIV at risk of CMD in 10 districts of Zimbabwe<sup>2</sup>
- Depression in ALHIV correlates with poor adherence to ART<sup>1</sup>
- ALHIV and severe depression primarily attribute their poor mental health to the negative relationships in their lives, specifically families, peers and carers<sup>2</sup>
- ALHIV with high viral loads on ART attribute their virological failure to mental health issues<sup>2</sup>
- Poor adherence is considered a form of slow suicide by ALHIV diagnosed with severe depression<sup>2</sup>
- ALHIV consider peer-led interventions, caregiver interventions and supportive health care workers to be critical in preventing and managing depression<sup>2</sup>
- ALHIV diagnosed with depression describe CATS as critical in alleviating feelings of worthlessness, hopelessness, feeling unloved, isolation, depression and suicidality<sup>2</sup>
- Self-stigma is common (100%) among ALHIV including beliefs of worthlessness and hopelessness and negative body image, linked to
  disclosure, relationships and isolation<sup>3</sup>
- HCWs provide psychosocial support services but mental health services are not routinely integrated and capacity strengthening is
  required if they are to effectively manage those with mental health conditions<sup>2</sup>
- CATS are effective at providing a peer-led bereavement intervention for ALHIV<sup>4</sup>
- · Zvandiri is an effective, peer-led, community and clinic based mental health intervention
  - The Gokwe Study: Improved psychosocial well-being among ALHIV receiving Zvandiri compared those receiving standard of care<sup>5</sup>
  - The Zvandiri Trial: Qualitative data confirms improved mental health among ALHIV receiving Zvandiri compared with standard of care<sup>6</sup>
  - The Zvandiri-Friendship bench Trial: Although PST was difficult for young people, ALHIV in both arms (standard CATS and enhanced CATS) has significant improvements in mental health<sup>2</sup>

### **Advocacy**

- CATS-led advocacy for the integration of psychosocial support and mental health service delivery for children, adolescents and young people living with HIV through:
  - · Print and social media, radio, video and television
  - · Regional and international meetings
  - · WHO guidelines development committee and global guidelines on differentiated service delivery for adolescents living with HIV
  - Documentation and sharing of research studies, programmatic data and lessons learned





#### What do ALHIV think?

In October 2020, Zvandiri led a global consultation on behalf of WHO as part of the WHO guidelines development process. 388 ALHIV were consulted across 45 countries. ALHIV unanimously agreed that mental health and psychosocial support services are critical in improving their HIV outcomes and engagement in health services.

Adolescent Voices on the Role of Psychosocial Support in HIV Care

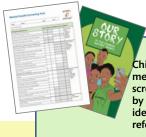
## **Guidelines, Curricula and Tool Development**

The following guidelines, curricula and tools have been developed:

- Validation of the Shona Symptom Questionnaire (SSQ) for adolescents in Zimbabwe in partnership with CeSHHAR, London School of Hygiene and Tropical Medicine (LSHTM) and UNICEF (In press)
- The Zvandiri mental health screening tool for CATS to identify CAYPLHIV at risk of mental health conditions
- · The Zvandiri mental health training curriculum for CATS
- · The Zvandiri mental health training curriculum for health care workers
- Mental health literacy tools for CAYPLHIV and their caregivers
- Zvandiri counselling tools for children and adolescents, including games, videos, books, fact sheets, comics and pamphlets
- · SOPs for Zvandiri Mentors to guide the provision of mental health services for CAYPLHIV
- The CATS Service Delivery Manual and accompanying CATS Guide to guide CATS in promoting mental health among their clients
- · Zvandiri Support Group Curriculum for children and adolescents living with HIV
- Zvandiri Support Group Curriculum for Young Mentor Mothers



The development of age and developmentally appropriate games, books, animations and fact sheets are a key component of the Zvandiri counselling approach



Child and adolescent mental health screening tools are used by CATS to strengthen identification and referral

## Strengthening the workforce

- On-site and virtual training and mentorship for health care workers to strengthen the identification and management of children, adolescents and young people living with HIV and mental health conditions.
- · On site and virtual training, mentorship and supervision of CATS to identify, refer and support CAYPLHIV with mental health conditions
- Emergency capacity strengthening for HCWS providing mental health services for CAYPLHIV affected by Cyclone Idai and COVID-19
- Virtual Enhanced Adherence Counselling (EAC) training for HCWs and Zvandiri Mentors



Zvandiri-ECHO Hub: Virtual capacity strengthening of health care workers, Zvandiri Mentors and CATS to provide mental health services during COVID-19

- · Mental Health training
- · Virtual EAC training for HCWs
- Case Reviews
- · E-mentorship
- Multi-disciplinary case management reviews for ALHIV with mental health conditions

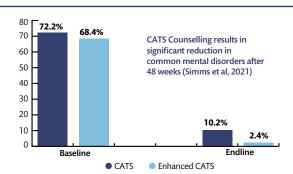
## **Service Delivery**

- Promotion of mental health literacy among children, adolescents and young people, their families and communities
- · CATS-led screening of adolescents living with HIV for mental health conditions
- · Referral of CAYPLHIV at risk of CMD to health facilities and mental health specialists for further assessment and management
- · CATS-led counselling for CAYPLHIV, including cognitive behavioural therapy, problem-solving therapy, narrative therapy
  - · During home visits, clinic visits, MHealth
  - Use of child and adolescent focused counselling approaches and tools
- · CATS-led enhanced adherence monitoring and support for CAYPLHIV facing challenges with adherence to ARVs or psychiatric medication
- Joint case management with clinic nurses, mental health specialists, social welfare officers and CATS for CAYPLHIV with mental health conditions
- Caregiver counselling for caregivers of CAYPLHIV with mental health conditions
- · Group and individual therapy for CAYPLHIV and caregivers affected by emergencies (e.g. Cyclone Idai, Security threats, COVID-19)
- $\bullet \ \ \text{Adherence counselling and monitoring for CAYPLHIV on psychiatric medication}$
- Support groups for CAYPLHIV and their caregivers
- The CATS Lounge and Young Mothers Lounge anonymous, SMS-based groups for CATS and Young Mentor Mothers
- · Adaptation of mental health literacy, screening, counselling, monitoring and support groups to virtual delivery during COVID-19



#### Results

- Research studies have confirmed that Zvandiri is an effective, peer-led mental health intervention.
- Program data confirms 54,764 CAYPLHIV have been engaged in sustained psychosocial support services through home visits, clinic visits, MHealth and support groups, provided by 1,328 CATS and a team of Zvandiri Mentors and clinical psychologists.. This has been adapted to virtual service delivery during COVID-19.
- In 2020, **14,987** mental health screenings were conducted by CATS, ZMs, ZIs both in person and virtually.
- 27% were at risk of CMDs and referred for specialist services



- Among ALHIV receiving standard CATS counselling, common mental disorder (CMD) reduced from 72.2% to 10.3%
- Among ALHIV receiving enhanced CATS counselling, CMD reduced from 68.4% to 2.4%

#### **Lesson learned and Recommendations**

- There is no health without mental health for children, adolescents and young people living with HIV.
- Viral suppression and quality of life for adolescents living with HIV require that mental health services are integrated within HIV care and treatment programmes.
- · There is overwhelming demand for mental health services yet a paucity of mental health specialists to meet the demand
- CATS are perceived by ALHIV to be an effective, acceptable source of counselling and support for the prevention and management of mental health conditions
- · Research and program data confirms CATS are an effective mental health intervention for ALHIV
- · Training, mentorship and supervision is critical for CATS providing mental health services
- · Clinical psychologists and Zvandiri Mentors are an essential component of the Zvandiri mental health response

 $Recommendations \ for \ CATS' \ support: \ Trust \ framework$ 

- **T**raining
- Refferral pathways
- Understanding the remit of their role
- Supervision and Mentorship
- Talking Helps

Zvandiri has drawn on its qualitative and quantitative data, as well as Zvandiri programmatic experience, to establish a framework for supporting CATS-led mental health services.

Wogrin et al (2021) It helps to talk: a guiding framework (TRUST) for peer support in delivering mental health care for adolescents living with HIV, PLoS One 2021









#### Albeto's Story

Africaid Zvandiri
Albeto's Story

Albeto starts his story by describing the depression and suicidal thoughts he was experiencing at the age of 16 years. He was also tested for HIV at that time and when he reached out for support from his mother, she was angry with him for being HIV positive. Albeto describes how he discovered his mother's ARVs but she continued ignoring his requests for more information about his HIV status. Albeto tells us how he felt so lonely and stopped adhering to his treatment. This changed when he was linked to a CATS and joined the local Zvandiri support group. He narrates how he no longer felt alone and realized be would be OK. He describes how he hoped that his mother would be proud of him but instead she turned away CATS when they visited him. He became depressed and the CATS, clinic nurses., psychiatric unit and case care workers all worked together to ensure Albeto received the care and support he needed. This included family therapy sessions with his mother. He describes how his mother came to understand more about Albeto's needs and experiences and has now disclosed her HIV status and apologized for her lack of support. Albeto reminds us of the need to integrate HIV and mental health services if we are to provide the support which young people living with HIV need.

Nyasha's Story

Nyasha is 18 years old. In her film, she narrates the story of the stigma and discrimination she experiences from her aunt's family when growing up. Although her life improved when she began a relationships with her boyfriend, this soon came to an end after she disclosed her HIV status to him. He ended the relationship and told others of her HIV status resulting in further stigma and isolation. Nyasha describes the betrayal, anger and depression she experiences, the way she lost the desire to live and how she stopped taking her ARVs. When the clinic linked Nyasha with a CATS for support, Nyasha did not want to engage, but the CATS continued to check in on Nyasha. Over time, Nyasha highlights the importance of mental health services within HIV care and treatment, and the power of peers in identifying and linking those in need of mental health services and their critical role in the multidisciplinary approach to counselling and support. Nyasha describes how support from the CATS has made her realise that she has a lot to live for and that she too would like to be a CATS so that she can help others like her.

Africaid Zvandiri
Nyasha's Story



#### References

- 1. Lowenthal, E.D., et al., Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. The Lancet Infectious Diseases, 2014. 14(7): p. 627-639.
- 2. Vreeman, R.C., B.M. McCoy, and S. Lee, *Mental health challenges among adolescents living with HIV*. Journal of the International AIDS Society, 2017. 20: p. p.21497.
- 3. Hudelson, C. and L. Cluver, Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low-and middle-income countries: a systematic review. AIDS Care, 2015. 27(7): p. pp.805-816.
- 4. Laurenzi, C.A., et al., Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. Journal of the International AIDS Society, 2020. 23: p. p.e25556.
- 5. Willis, N., et al., Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. PloS one, 2018. 13(1): p. p.e0190423.
- 6. Webster, P., UNAIDS survey aligns with so-called fourth 90 for HIV/AIDS. The Lancet, 2019. 393(10187): p. 2188.
- 7. Global Accelerated Action for the Health of Adolescents (AA-HA!): guidance to support country implementation. Summary. Geneva: World Health Organization; 2017 (WHO/FWC/MCA/17.05).
- 8. Patel V, Flisher AJ, Hetrick S, McGorry P. Mental health of young people: a global public-health challenge. Lancet. 2007; 369(9569):1302–13. Epub 2007/04/17. doi: S0140-6736(07)60368-7 [pii] https://doi.org/10.1016/S0140-6736(07)60368-7 PMID: 17434406.
- 9. Khan R. The prevalence of depression in Adolescents with HIV. 2013.
- 10. Mellins CA, Malee KM. Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. J Int AIDS Soc. 2013; 16:18593. Epub 2013/06/21. doi: 18593 [pii]. https://doi.org/10.7448/IAS.16.1.18593 PMID: 23782478; PubMed Central PMCID: PMC3687078.
- 11. Mavhu, W., et al. (2013) Enhancing Psychosocial Support for HIV Positive Adolescents in Harare, Zimbabwe. PLoS ONE 8 (7): e70254.
- 12. Mavhu W., et al. Evaluating a multi-component, community-based program to improve adherence and retention in care among adolescents living with HIV in Zimbabwe: study protocol for a cluster randomized controlled trial. Trials. 2017 Oct 20;18(1):478. doi: 10.1186/s13063-017-2198-7.
- 13. WHO. Mental Health Atlas 2017. 2018 25 August 2020]; Available from: https://apps.who.int/iris/handle/10665/272735.
- 14. Grimsrud, A.T., C. Pike, and L.G. Bekker, *The power of peers and community in the continuum of HIV care.*, 8(2), . The Lancet Global Health, 2020. 8(2): p. pp.e167-e168.
- 15. Mavhu, W., et al., Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe (Zvandiri): a cluster-randomised controlled trial. The Lancet Global Health, 2020. 8(2): p. pp.e264-e275.
- 16. Willis N., et al. Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. PLoS One. 2018 Jan 3;13(1):e0190423. doi: 10.1371/journal.pone.0190423. eCollection 2018.
- 17. Rich C et al (2020) An exploration of the beliefs and experiences of HIV-related self-stigma amongst young adults living with HIV in Harare, Zimbabwe. Masters thesis submitted to the University of Dublin
- 18. Wogrin C., et al. (2019) Development and piloting of a novel peer-led bereavement intervention for young people living with HIV. Journal of Child and Adolescent Mental Health https://doi.org/10.2989/17280583.2019.1579097
- 19. Willis N., et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. BMC Public Health. 2019 Jan 28;19(1):117. doi: 10.1186/s12889-019-6447-4.
- 20. Mavhu, W., et al. (2020) Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe. Lancet Glob Health 2020; 8: e264-75 https://doi.org/10/1016/S2214-109X(19)30526-1