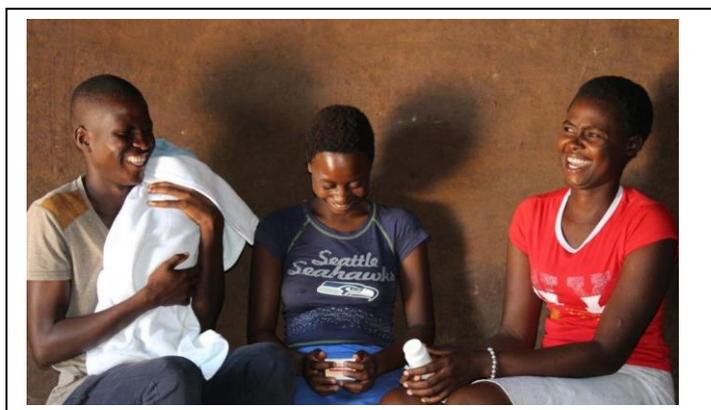

Clinical and Social Outcomes of Adolescent Girls and Young Women Living with HIV Transitioning to Motherhood: an operational research study from Zimbabwe



Background

Young people (10-24 years), especially young women continue to be disproportionately affected by HIV [1, 2]. Despite the improvements in medical treatments, adolescents and young women living with HIV in Zimbabwe face a plurality of risks [3]. In addition to coping with the normal stresses of HIV treatment management, young women living with HIV have to manage an array of issues arising from their sexual and reproductive health (SRH) needs [4, 5]. They confront disclosure of their HIV status, risk of rejection by sexual partners and issues related to pregnancy and childbirth [6]. HIV positive adolescent have higher mother to child transmission rates and lower uptake of PMTCT services compared to older HIV positive women [7] and are more likely to experience attachment disorder [8]. Despite their distinct vulnerabilities little is known about the particular challenges facing these young mothers and their infants

The Young Mentor Mother Model

The Zvandiri programme (run by Africaid) is a model of differentiated service delivery for children, adolescents and young people (0-24 years) living with HIV in Zimbabwe and in eight countries across Africa. Starting in 2018, young mothers, 18-24 years, living with HIV have been trained and supported in 4 districts to act as Young Mentor Mothers (YMM) to provide enhanced care and support to vulnerable mother-baby pairs, within the Zvandiri programme. This holistic model uses peer led counselling, home visits, daily SMS contact, referrals and integration into adolescent friendly mother-baby support groups.

Objectives

Despite their distinct vulnerabilities little has been documented about the challenges facing these young mothers and their infants. This study explored how adolescent girls and young women's transition from childhood to motherhood have shaped their capacity to manage their adherence to HIV medication and disclosure to date. In addition, it sought to understand the clinical and psychosocial status, virological and immunological characteristics and service delivery needs of young mothers (15-24 years) living with HIV (both acquired perinatally and later in life), their children and their partners to further support the content and scale up of the YMM model.

Methodology

This mixed method cross-sectional study was conducted between April and May 2019. Participants were young women aged 15-24 years living with HIV, their infants and their partners from two high HIV burden districts (rural Buhera and urban Hopley (outskirts of Harare). Mothers completed a structured interview, had a full clinical examination including WHO staging and a psychological assessment using three tools; the Shona Symptom Questionnaire (SSQ) for anxiety and depression, the Edinburgh Postnatal Depression Scale (EPDS) which screens for risk of postnatal depression and the Patient Health Questionnaire (PHQ-9) which is diagnostic for depression. Children had a clinical assessment, completed the Malawi Developmental Assessment Tool (MDAT) and those aged 2 years and above were screened for disability (cognitive, motor, vision, hearing and seizure disabilities) using the WHO Ten Question Screen (TQS). All mothers had a finger prick dried blood spot sample for viral load testing. Additionally, a subset of mothers took part in in-depth interviews (n=16), audio diaries (n=10) but only 7 of 35 male partners invited agreed to be interviewed.

Quantitative data were analysed using STATA 15 with descriptive analysis and chi-square tests, and

qualitative data were analysed using thematic analysis.

Key Findings

Demographic characteristics- 177 mothers (15-24 years old) and 176 children (median age of 12 months; range 0-8 years) and 7 male partners participated. 166 mothers were newly enrolled in the YMM programme and 11 were from the “Third generation cohort” first recruited in 2013. 63.3% (n=112) mothers acquired HIV horizontally, 36.0% (n=62) were perinatally infected. 56% were married and staying with their partners, and 76% were unemployed and financially dependent on their partners.

Mothers clinical characteristics - All mothers were on ART (83.6% first line; 16% second line); only 44.6% had been on ART prior to their pregnancy and those were all perinatally infected. There were high rates of self-reported adherence (86% n=152), regardless of how HIV acquired. 86.9% (n=153) were virally suppressed (viral load <1000 copies/ml). Mothers reported a sense of responsibility to their children, described as “wanting to be there for my child” and not wanting to pass HIV to their infants, as motivators for adherence. Few 14%(n=25) said they were struggling with adherence. In-depth interviews highlighted husband not permitting, side effects, food insecurity, stigma and discrimination, lack of sympathy from health workers, drug fatigue as the main causes of non-adherence.

Maternal mental health- more than half (55.9%) of the mothers scored 12 or above on the EPDS indicative of postnatal depression. 13.5% had severe depression. 39.6% (n=70) scored ≥9 on the SSQ-14 indicating risk of common mental disorder. We compared adherence between mothers with high and low scores on the three mental health scales. Mothers who scored above the threshold on the SSQ and EPDS were more likely to report missing any ART pills within the last 7 days than those who reported fewer symptoms (SSQ: $\chi^2=15.4$, $p<0.001$; EPDS: $\chi^2=3.3$, $p=0.07$).

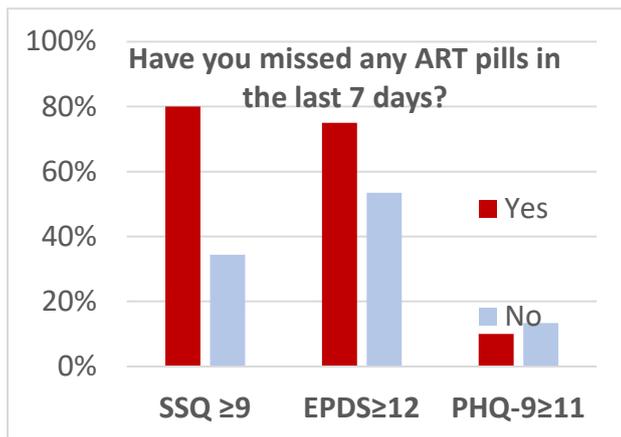


Figure 1: Mental health & ART adherence

Experience of violence and sexual abuse-

Experience of violence was associated with poor mental health regardless of scale (Figure 2). In - depth interviews and audio diaries highlighted that domestic violence was an issue that mothers struggled with.

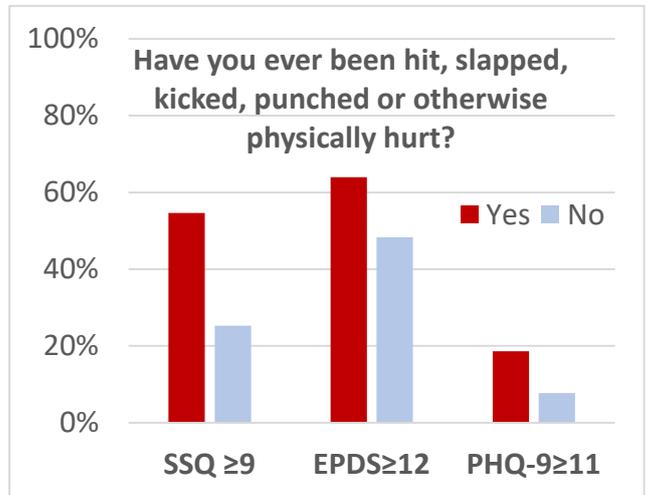


Figure 2: Experience of violence and risk of CMD

HIV Disclosure- 88.1% (n=156) of mothers said they had disclosed their status to someone but only 54.2% (n=78) had disclosed to their male partners. For perinatally infected mothers fear of rejection, stigma/ discrimination and not knowing how to disclose were the most cited reasons for not disclosing. Mothers infected later in life cited fear of being accused of infidelity or of bringing infection into the family.

Partners- 73.5% self-reported that their male partners had had an HIV test, 14.7% had not tested. 11.9% didn't know whether their partners had tested or not. Male partners (n=7) reported in qualitative interviews struggling with status disclosure with some opting to present for HIV testing with their partners as first timers. Five of the seven interviewed also stated encountering adherence challenges. Two stopped treatment after experiencing side effects.

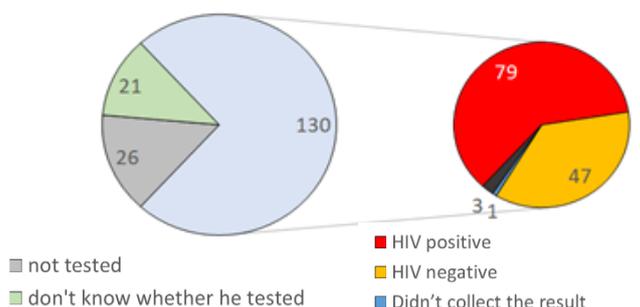


Figure 3: Partners' HIV testing and status

Children clinical characteristics- Eleven mothers self-reported that their infants were HIV positive and on ART. HIV confirmatory tests were conducted as part of the study on all the babies and 5.1% (n=9) were HIV positive. Two infants reported as positive by the mothers and on ART tested negative. Of the nine that were HIV positive five infants were virally suppressed while four were not despite being on ART. Two of the infants not virally suppressed had mothers who were also not suppressed. 126 infants out of 142 eligible for early infant diagnosis (EID) were tested at 6 weeks, 81/115 infants at 6 months, 76/96 infants at 9 months and 45/62 at 18 months.

39.6% (n=70) eligible infants were not on cotrimoxazole prophylaxis. 6.8% (n=12) had not received ARV prophylaxis. In-depth interviews highlighted challenges that resulted from referral and lack of knowledge among mothers about what treatment their infants were supposed to be getting.

95.4% (n=167) of the mothers reported that their infants were up to date with their scheduled vaccinations. However, out of the 159 child health cards that were seen, only 38.4% (61) babies had entries showing they were up to date with their scheduled vaccinations.

176 mothers had ever breastfed. 104 were still breastfeeding. Median duration of breastfeeding was 9 months (interquartile range 5-15 months). 25.3% (n=43) of babies were stunted (height-for-age z-score \leq -2) while 16.1% (n=28) were underweight (weight-for-age z-score \leq -2).

Child development- Out of 173 children who completed the MDAT, 12.7% were not able to do 3 or more items typical for children of their age, on at least 2 of the domain scales of gross motor, fine motor, social and language. A low MDAT score was more common among children with stunting (9/43, 20.9%) than children who were not stunted (13/124, 10.5%). Out of 48 children aged 2 years and above, 62.5% (N=30) had a reported delay or limited function in at least 1 of the 10 areas measured by the TQS. The most common was a serious delay in sitting, standing or walking compared with other children (N=17, 35%), followed by appearing mentally slow, delayed or behind compared to other children (N=13, 27%). Four out of 9 (44.4%) HIV positive children failed 2 or more items compared to 20/162 (12.4%) HIV negative ($\chi^2=7.3$,

p=0.007). HIV positive children had worse cognitive development.

Service delivery needs- All the 16 mothers who took part in the qualitative interviews stated that they require adherence support from their immediate family members and the healthcare workers. Nine were receiving medication reminders, refills reminders and constant support and encouragement from their families.

Lessons learned and recommendations

There were numerous lessons learned during the implementation of this study that may be useful more broadly as country programmes consider scale up of the YMM model. The following recommendations primarily highlight the importance of fostering an enabling environment and investing in comprehensive and integrated package of services to realize the benefits of the YMM:

Recommendations for the YMM

1. Enhance couple counselling to facilitate disclosure and minimise gender-based violence.
2. Provide mental health and parenting services for mothers and fathers, given the high risk of CMD, and the impact of this on maternal adherence (and likely child development as well).
3. Support both the mothers and their partners to adhere to treatment.
4. Support, prepare and encourage mothers and their partners to disclose their HIV status, when safe to do so, within unions to optimise uptake of HIV services.

Recommendations for Ministry of Health and Child Care

1. Strengthen referral systems from local clinics to hospitals and from the hospitals to the clinics to ensure that infants are given the recommended EID, care and prophylaxis.
2. Inform mothers about the HIV care and treatment services they and their infants are supposed to be receiving as a way of plugging gaps in the HIV care cascade.
3. Monitor viral load of infants whose mothers are also failing on ART.
4. Consider early child development interventions and nutritional support for HIV exposed babies.
5. Strengthen male involvement to support mothers and their infants.
6. Disseminate breastfeeding guidelines and messages to include partners and significant

others to avoid early cessation of breastfeeding and to dispel myths and misconceptions.

7. Scale up Mother baby pair register to track and monitor testing of HIV exposed children as per national EID guidelines.

Conclusion

The aim of this cross-sectional study was to explore the clinical and social characteristics of mothers and of their babies. Self-reported adherence and viral suppression suggested good adherence and retention in care. It is important to note that all but 16 of the mothers had recently joined the YMM intervention and started receiving peer support. However, HIV infected young women regardless of mode of transmission confront several challenges which affected their health and social well-being and that of their infants. There was strong evidence of association between experiences of violence and risk of depression. As well, symptoms of poor mental health were associated with poor adherence (and likely had impact on child development). Targeted mental health interventions need to be scaled up.

Male involvement in PMTCT continue to be a challenge which needs to be addressed. As well, YMM should provide information and support mothers and their partners to make informed decisions regarding status disclosure., presuming it is safe to do so. Recent evidence shows that encouraging young women to disclose their HIV status to partners may have deleterious implications for their wellbeing and could potentially derail their adherence efforts [9].

Reassuringly perinatal transmission rates are low and all perinatally infected children are on ART. However, infants have poor clinical outcomes and some missed timely EID. There is need for strengthened support and monitoring to address the bottlenecks and ensure timely EID and commencement on treatment if required. MDAT scores were low among children with stunting. Consideration to prioritising HIV exposed infants for early childhood development interventions should be given.

Of note, although breastfeeding rates were high, food shortages and lack of information on safety of breastfeeding acted as a deterrent to breast feeding for some women.

For more information contact

Zivai Mupambireyi, Centre for Sexual Health & HIV Research Zimbabwe, Children and Adolescents, Harare, Zimbabwe, zietawana@yahoo.co.uk

Acknowledgments

Dr Owen Mugurungi, MoHCC, Director Aids and TB Unit; **Dr Angela Mushavi**, National PMTCT and Pediatric HIV Care and Treatment Coordinator; **Dr Solomon H. Mukungunugwa**, Dep. National Coordinator PMTCT, Paediatric HIV Care Treatment (Aids & TB Unit Ministry of Health & Child Care); **Evelyne Bede Mtetwa**, **Nicola Willis** (AFRICAID Zvandiri); **Chiara Pierotti**, **Beula Senzanje** (UNICEF Zimbabwe); **Frances Cowan** (Liverpool School of Tropical Medicine, Liverpool, UK

References

1. UNICEF. *Turning the tide against AIDS will require more concentrated focus on adolescents and young people*. Adolescent HIV prevention 2019 [cited 2019].
2. Fund, T.G., *Technical Brief Adolescent Girls and Young Women in High-HIV Burden Settings*. 2017, Global Fund Geneva, Switzerland
3. 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. e264-e275.
4. Woollett, N., *Adolescents Living with HIV: Emerging Issues in Public Health in South Africa*, in *Children and Young People Living with HIV/AIDS: A Cross-Cultural Perspective*, P. Liamputtong, Editor. 2016, Springer International Publishing: Cham. p. 65-88.
5. Council., P., *“Sexual and reproductive health and rights among young people living with HIV in Uganda: Findings from the Link Up baseline survey,”* in *Link Up Research Brief*, I. The Population Council, Editor. 2015, Population Council.: Washington, DC.
6. Madiba, S. and M. Putsoane, *Testing Positive and Disclosing in Pregnancy: A Phenomenological Study of the Experiences of Adolescents and Young Women in Maseru, Lesotho*. *AIDS Research and Treatment*, 2020. **2020**: p. 6126210.
7. Callahan, T., et al., *Pregnant adolescents living with HIV: what we know, what we need to know, where we need to go*. *Journal of the International AIDS Society*, 2017. **20**(1): p. 21858.
8. Gelaye, B., et al., *Epidemiology of maternal depression, risk factors, and child outcomes in low-income and middle-income countries*. *The lancet. Psychiatry*, 2016. **3**(10): p. 973-982.

9. Bernays, S., et al., *Scaling the mountain; qualitative findings from the Zvandiri trial.* , in *AIDS Impact*, July 2019. 2019, AIDS Impact: London

