



***Evaluation of GUWHATTA
(Growing-up with HIV and transitioning to
adulthood) intervention***



Prayas Health Group

Amrita Clinic

Athawale Corner,

Karve Road

Pune -411004

www.prayaspune.org

THE CONTEXT	2
THE INTERVENTION	2
METHODOLOGY USED TO EVALUATE THE INTERVENTION	3
OBSERVATIONS	4
IMPRESSIONS	8
CASE STUDY : RESHMA AND VIJAY	9
REFERENCES	10

Evaluation of GUWHATTA (Growing-up with HIV and transitioning to adulthood) intervention

The context

Adolescents and young adults is an important vulnerable group for HIV infections. UNAIDS estimates that, globally, people aged 15 to 24 years account for two out of every five new HIV infections. In India, a country with third highest number of people living with HIV (PLHIV), there are 2.09 million PLHIV. Of these, 7% are children below 15 years of ageⁱ. There are about 120,000 adolescents aged 10-19 years living with HIV (ALHIV)ⁱⁱ. Many of these ALHIV would have contracted the virus through perinatal transmissionⁱⁱⁱ (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2010). The longevity of these children has improved significantly with access to antiretroviral therapy (ART)^{iv} (Collins et al., 2010; Patel, 2008).

ALHIV face multiple risks to their health, education and psycho-social well-being^v (Schenk, 2009). Living with a stigmatised disease such as HIV can put them in a greatly disadvantaged position. Managing disclosure of their HIV status to friends, partners and significant others is challenging for many and can limit access to physical, financial or psychological support. Issues related to sexual needs, marriage and reproductive desires are likely to become more complex in this context^{vi} (Birungi, Mugisha, Obare, & Nyombi, 2009; Brogly et al., 2007; Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006). There is an emerging need to address the concerns related to growing up with HIV and transitioning to adulthood.

ALHIV need support on various levels as they transition to adulthood. It is essential to offer a safe, trustworthy, and professional health care environment during the transitioning^{vii}. In India, provision of clinical and counseling care to HIV infected adolescents takes place mainly at the ART centers. The psycho-social support mechanisms available for these children are deemed to be highly inadequate. There is little evidence regarding a comprehensive/holistic approach that will cater to a wide range of psycho-social and sexuality related needs of ALHIV.

Prayas is a non-governmental organization from India, that provides clinical and counselling care to HIV infected children and adults through its HIV clinic. Through our experience at the clinic, we realized that the children are not open to discussing issues related to growing up, sexuality and transitioning to adulthood. It clearly indicated a need to deploy methods beyond conventional counseling, which would provide an enabling space to these children to freely communicate and draw support through peer interactions.

The Intervention

An intervention was designed for adolescents and young adults living with HIV aged 14 to 24 years which aimed at empowering ALHIV for a smoother transition to adulthood. It is in the form of a 5 days residential workshop and covers a range of topics including HIV transmission, ART, nutrition, growing up, knowing the body, sexuality and reproduction, gender issues, stigma and discrimination, coping with HIV and positive living etc. Sessions using question-answers, low-technology animations, body-mapping etc. are used for building

knowledge beyond information; Participatory methods such as skits, improvisations, group discussions, discussions around stories based on real life situations are used for increasing understanding about sexuality, gender issues, stigma, disclosure, coping with difficult situations and positive living. Participants discuss different facets of difficult situations and debate possible solutions. An active effort is made for application of knowledge in confronting real life situations. After organizing 5 workshops for children staying with families (majority of them were coming to Prayas for treatment) Prayas started conducting similar workshops for children staying at residential institutions.



Till date Prayas has undertaken 10 workshops (5 for institutionalized and 5 for children staying with family) have been held. A total of 119 girls, 140 boys; 144 institutionalized, 115 family based children in the age group 14 to 24 participated in the workshop.

Methodology used to evaluate the intervention

Though a detailed documentation about processes during the workshops, responses and feedback of participants was maintained through all the workshops; we started attempting to evaluate the impact using standardized tools adopted specifically for this group in the first workshop for institutionalized children. Use of these tools was challenging due to limited reading, writing, articulation and comprehension abilities of the participants. Therefore a different method, in the form of action research approach, was adopted to understand the short

term impact of the intervention. This was accrued in the next 4 workshops for institutionalized children.

The evaluation was undertaken in small groups by adopting group discussion approach using a semi-structured questionnaire. The same facilitator conducted discussions with a particular group before and after the workshop. Every participant in the group was encouraged to respond to each question separately. All the questions were open-ended. Many a times, the questions evoked interactive discussions among participants. The responses by each participant in the group were documented in detail. Pre-workshop process identified a range of concerns. Post-workshop process documented the change and also served as intervention to re-emphasize certain issues. We present below our observations before and after the workshop in the form of a table as well as a case study to highlight the process.

Observations

Participant's responses during group assessment and notes of the facilitators Pre-workshop	Post-workshop
What information do you have about HIV and AIDS?	
<p><i>Illness</i> "We don't know what is HIV/AIDS" "There is no difference between HIV & AIDS" "It is an illness, which doesn't have any cure" "It's a serious disease which is denied by society" "Person dies due to this illness. HIV means death." "This virus sucks blood" " Means, our blood is different than others"</p> <p><i>How society behaves?</i> "People make the person stay away from them, keep handkerchief on mouth, behave badly with this person". "In the school they (peers) ask me to stay away from them because of HIV" <i>Different between HIV and AIDS</i> "HIV is an English name and AIDS is a Marathi name", "Person gets AIDS due to bad behaviour", "Person with HIV doesn't have any flaws", "The blood is different in HIV than in AIDS", "There is no difference between HIV and AIDS", "First line medicines means HIV and second line means AIDS", "AIDS can't recover with treatment", "HIV and AIDS are similar but caused by two</p>	<p>"The virus-HIV decrease immunity in the body, it decrease white blood cells and CD4 count", "It can't stay alive in the air but in the human body", "AIDS means a person gets different infections", "If medicines are not taken on time and regularly then the person gets AIDS", "HIV infection spread through sexual relations and through blood."</p>

<p>different viruses, HIV means skin infection” “If you get the infection without any mistake, then it is HIV”</p>	
<p>How is HIV transmitted?</p>	
<p>“If our wound gets touched to other person” “Through mosquito bite”, “Because of rape”, “Unsafe sex” “Marriage, from pregnant woman to her baby”, “Because father’s DNA comes in our body”, “By eating in same plate” “through cough (if there is blood in cough)”, “Through tobacco and cigarette, unsafe sex”, “Through syringe”, “Through carving tattoos”</p> <p>Facilitator’s observations Some of the children were not ready to answer these questions; some got disturbed by the question and started crying while others got angry for asking it to them.</p>	<p>“HIV infection cannot occur due to mosquito bite, with touch, eating together”. “It can occur when the infected blood is given”, “If mother didn’t take medicine during pregnancy then to her baby”, “If the person had sexual intercourse with an infected person without using condom”,</p>
<p>How can we come know if someone is HIV infected or not?</p>	
<p>“If the person get sick”, “low immunity” “Through Haemoglobin (Hb) test” “Through CD4 test” “Through blood & Urine test” “Through sonography” “When taken to hospital” “If the person get TB” “If somebody saw anybody is taking medicines then that person goes and tell others” “If they have worms in stomach” “When the person have vomiting of blood” “If the person has decreased appetite or had bitter taste of food”</p>	<p>Although all of them answered this question as – ‘blood test’, most of them were saying through CD4 test. Some of them were saying through HIV test, but very few could spell out name of the test- i.e. Eliza. One or two participants continued with their answers as ‘through urine test or when the person fall sick’.</p>
<p>What precautions should be taken while taking ART?</p>	
<p>“These tablets should be taken on time/after meal/till the doctor tells to take/for always/till the death” “Don’t drop the medicine on ground, don’t pick the medicine if dropped” “If we throw the medicine then the disease get worse” “Drink lots of water”. “If we take medicine without water then we get allergic reaction of body”</p>	<p>“Take tablet on time, it is lifelong” “Don’t take tablet empty stomach” “One tablet works for 12 hours, so you have to take a tablet every 12 hours, otherwise your immunity goes down and HIV increases” “Don’t take each-others tablets” “Tablets decrease HIV in the blood, that helps our immunity to increase” “Take nutritious and wholesome meal, if you get dizziness due to tablet then take it at times when</p>

<p>“If our CD4 count is high then we have to take more powerful medicines” “Don’t show medicines to kids”, “If we missed a dose then eat bananas as a replacement to the tablet” “Maintain hygiene”</p>	<p>you go to sleep”</p>
<p>Can the baby get HIV infection from mother?</p>	
<p>“Yes, it does, even though elder sibling doesn’t have the younger one gets the infection” “If the mother have wound then the baby gets infection”, “If mother’s blood come in contact with the baby then the baby gets infection” “While cutting the umbilical cord”, “Even if the baby doesn’t have infection right now but it definitely gets it in future”</p> <p>Facilitator’s observations Except one child who said that the baby don’t get HIV infection from mother, all other children knew the mother to child transmission (MTCT) can happen.</p>	<p>Most of them were able to tell about risk of MTCT and how medicines can changes the situation. “If mother doesn’t take medicines then the chances of getting infection to the baby increases to 25% otherwise baby will not get the infection. “</p>
<p>Can girls/women go to temple during menstruation cycle?</p>	
<p>“Can’t go in temple” “God doesn’t accept this, it’s a sin” “God gives punishment or something bad will happen if any girl went in temple during menstruation”</p> <p>Some of them said that they don’t believe in God, and some of them said that it’s fine if anyone goes to temple during menstruation. Most of them, especially boys told that they don’t know anything about menstruation.</p> <p>Facilitator’s observations Almost all participants were feeling shy, smiling, and hiding their faces while answering the question. Boys felt that asking question about menstruation to them is irrelevant. Rather this should be asked to girls.</p>	<p>“Because of tradition, superstitions people don’t go in temples during menstruation but if the God has created menstruation and we all are made through it then we all should clear these misconceptions, we should give correct information about menstruation and should leave superstitions.” Some of girls said that even though it’s not wrong to go in temple during menstruation yet our mind is not prepared for that.</p>
<p>What care should be taken while living with HIV?</p>	
<p>“We must take care that our blood should not come in contact with others” “Take meal on time, do yoga, take medicines”</p>	<p>“Take meals on time, eat eggs, meat, leafy vegetables, eat more quantity (almost double), avoid getting addicted to any drug or alcohol,</p>

<p>“Increase weight, avoid eating oily and spicy food, avoid eating outside” “If we have wound then do not go close to any other person”, “If somebody is caught in an accident then don’t go close to that person” “Take medicines for TB” “Avoid eating with others, avoid stress/tension, eat eggs, meat, milk and properly covered food” “If you miss a tablet then eat banana”</p>	<p>keep checking your CD4 and Hb on time” “Use condom at times of sexual intercourse, even though both are positive use condom” “When you are planning to get married tell your partner about your HIV status (don’t cheat your partner)”</p>
<p>While living with HIV, do you feel that you are different from others? Do you look different?</p>	
<p>“Because of HIV, intelligence decreases, brain functioning is hampered” “The person look different” “There are side effects of medicines, blemishes and boils appear on face” “You always feel weak, don’t feel energetic, height doesn’t increase, feel de-motivated, frequently get sick”</p> <p>Some children felt that there is no difference in them and other due to HIV.</p> <p>Facilitator’s observations While answering this question, participants always referred HIV uninfected children as ‘normal children’.</p>	<p>Post workshop almost everyone said that there is no difference; it’s just that we have the virus in our body. “No difference, except that we can’t donate blood” “There is virus in my blood (HIV), so what?” Its not my fault. “If we don’t take medicines, only then we will look weak, but if we take the medicines properly then we will never get AIDS” “We use to feel that we are less intelligent than others (don’t have brains). Now we don’t have that feeling anymore”</p>
<p>Do you worry about future?</p>	
<p>“Yes, worry a lot, what about marriage?, what about employment?, is there any benefit in getting education?” “Don’t understand what teacher is teaching!, don’t feel like working” “How I will find out HIV positive partner?” “Can’t touch anybody, can’t fall in love, “Society will not accept us, It is a short life, , our dreams will not fulfilled” “If anybody sees us taking medicines and tell other people then they will not allow us to mix with them” “I feel sad due to discrimination, keep worrying about our existence, we fear that if we get a bleeding wound then we might transmit our illness to others, if that happens they will throw us out of the job”.</p>	<p>With proper medicines they can live longer and healthier life. Also can get married and engage in a relationship with HIV negative or positive person. They also mentioned that they will not cheat their life partner; they will not break their partner’s trust.</p>

Impressions

During the pre-workshop assessment, the responses by children clearly showed their lived reality that shaped their perceptions. Most children seemed to have not understood what HIV is, the difference between HIV and AIDS, how HIV is transmitted. The pre-workshop responses reflected the fear related to severe illness and death associated with disease. Post workshop, there was an improved understanding about the disease, the modes of transmission, antiretroviral treatment and how it works. The fear of illness and death appeared to have got addressed during the workshop. Although this change was observed in majority of participants, some children continued to have misconceptions post workshop. Some were unable to correctly recollect the information from the workshop.

Many of the participants were taking ART for a long time. Pre-workshop, they were aware that medicines need to be taken for life-long. However most of them were not aware why it is important to take these medicines regularly. The workshop improved their understanding of how ART works in the body. It appeared to have motivated them and reinforced the intention to adhere to medicines.

Prior to workshop, participants had misconception about MTCT. Some believed that younger siblings get HIV while others believed it's the elder sibling. After the workshop these doubts were cleared. After the workshop all of them knew that if the mother has HIV then she should take medicines as early as possible.

Beyond HIV and its treatment, the workshop also focused on issues related to women's body, birth of child, menstruation. Impact of all these discussions was clearly seen in post workshop assessment. It was possible to address the misconceptions about menstruation among children, especially boys. However, actual change in practice (for girls) will need sustained efforts.

Case Study : Reshma and Vijay

While conducting the pre test, it was obvious from the children's answers that they don't have any information about HIV. Also, they were not informed about what this workshop is about. We could see that they were unhappy about these questions being asked even after knowing that they didn't know the answers. Two of the girls were clueless about how to react to this. They found the questions troublesome and they were shy to answer them. They started crying right at the beginning of the pre test. There was a boy and a girl in the group, who were slightly younger than others. They did not answer at all, nor did they react to anything that was going on. Only one boy was listening to the questions and was trying to respond. He was convinced when told, "This is not an exam. We just want to know, what you all know at the beginning of the workshop." His answers reflected many misunderstandings and a lack of information.

Reshma was not at all ready to answer. She felt very shy to talk about the issues. She hid her face at the time of questions about menstruation. In a while she started crying and did not stop till the end. All attempts to talk to her, to reach out to her, to make her understand the purpose of the pre test were in vein and she did not stop crying. She neither answered, nor listened what others were saying. She completely refused to take part in the session about creating a uterus with human figures. She was crying for the whole day. In the first session, their group needed to answer the question "what do I fear and worry about?" The atmosphere remained very serious throughout. Reshma was not only upset but also angry with us. The care taker from her organization mentioned that she feels that such topics should not be discussed amidst girls and boys together.

Vijay was also very upset during the pre test. "What do you achieve from asking us these questions? How many people would come and ask the same questions and make us cry and feel bad?" he asked. He was not ready to listen to the objective of this questionnaire. "You tell me if there is any complete solution for this otherwise I don't want to listen. You can ask all this just because you don't have this disease," he said, "don't ask me any question. I'll be very nasty to you and I don't want to be nasty to a person older to me."

For each and every question we had this whole dialogue over and over again. The facilitator said, "I understand why you are saying this but if possible give me one percent of benefit of doubt. You will probably feel different at the end of the workshop." Yet, he was not ready to talk.

But in the course of five days, things changed drastically. Children had put many questions in the question box. That session was an important initiation of further dialogue. Vijay asked a lot of questions during this session. 'Is there no medicine to treat this disease completely? If I get married, will my children also be infected?' He also asked whether every child gets this disease if his/her parents are infected. All these questions got answered in detail during the next five days. The heavy minds became lighter and lighter.

We could also see the daily transition in Reshma. The session about 'how a baby is created, where does it grow before being born, knowledge about mother's and father's body, how are the bodies prepared for the creation of babies' was very informative and interesting for the children. It was conducted in a very innovative manner as well. Children started asking more questions, contributing to answers and taking an active part in forming knowledge together. Reshma had opened up till this point. She no more was shy to ask, "Why is it not allowed to go to the temple during menses? Why do people isolate us during that time? Why don't they touch us?"

When all the misconceptions were addressed, the dynamics between girls and boys was totally different. A boy asked, "What can we do for girls when they are menstruating? How can we be of any help?" There were no shameful giggles or crying or uneasiness between them post the session. No one was hiding their faces anymore. By the fourth day, the boys and girls were not even sitting separately. They were trying to be non-discriminative amongst themselves too.

While sharing feedback, Reshma told everyone, what she learnt about uterus and menstruation. She was no more the same girl who was not even ready even to listen these words on the first day and not ready to take part in the session about uterus. On the last day Reshma said, "I was very lost on the first day and was cursing myself for coming here. I cried a lot, wasn't able to answer questions in the pre test but as I started gaining scientific information, reasoning and answers to my questions, I could open up. Our group could not complete the pre-test on time, but today we were the fastest to recap all the knowledge and information during post test."

Reshma and Vijay also lovingly apologized for the first day to their facilitator. The change in them was saying more things than their words. All of us could laugh about the first day.

The pre-workshop responses show how these children had internalized stigma to the disease. A question about care to be taken while living with HIV evoked responses such as ‘we should not go close to other person’. There was a great deal of negativity about their self-image. They not only doubted their physical ability but also intellectual abilities. They perceived themselves different than ‘normal’ (HIV uninfected) children. There was hardly any mention of sexual health during pre-workshop discussions. There was noticeable change in the self-image after the workshop. There was a realization that they are no different than others except for a virus in their blood and that the virus can be kept in control with regular medicines. The workshop helped them to believe that for all practical purposes they should not think less of themselves. After workshop they also talked about importance of disclosure to the partner and safe sex practices. There was positivity and hopefulness towards future, along with a sense of responsibility. However, a more positive and optimistic surroundings are needed for these children to motivate themselves to do and achieve things that others can.

There are so many issues that these children face which results in constant worrying about future. A short intervention in the form of workshop obviously cannot provide answers to everything. However the workshop seemed to have instilled optimism in the children. They often mentioned that after the workshop they feel confident, motivated to understand things. Now they can have dreams in their lives. Through the workshop, they also found a new support system in the form of peers. The perceived peer support mechanism appeared to have positively impacted their outlook towards life and challenges ahead.

References

-
- ⁱ Department of AIDS control (NACO), India, Annual Report, 2014
- ⁱⁱ HIV and AIDS, Datahub for Asia Pacific, 2016
- ⁱⁱⁱ Joint United Nations Programme on HIV/AIDS (UNAIDS). (2010). CHILDREN AND AIDS: FIFTH STOCKTAKING REPORT, 2010. Retrieved from http://www.childinfo.org/files/ChildrenAndAIDS_Fifth_Stocktaking_Report_2010_EN.pdf
- ^{iv} Collins, I. J., Jourdain, G., Hansudewechakul, R., Kanjanavanit, S., Hongsiriwon, S., Ngampiyasakul, C., Program for HIV Prevention Treatment Study Team. (2010). Long-term survival of HIV-infected children receiving antiretroviral therapy in Thailand: a 5-year observational cohort study. *Clin Infect Dis*, 51(12), 1449-1457. doi: 10.1086/657401
- ^v Schenk, K. D. (2009). Community interventions providing care and support to orphans and vulnerable children: a review of evaluation evidence. *AIDS Care*, 21(7), 918-942. doi: 10.1080/09540120802537831
- ^{vi} Birungi, H., Mugisha, J. F., Obare, F., & Nyombi, J. K. (2009). Sexual behavior and desires among adolescents perinatally infected with human immunodeficiency virus in Uganda: implications for programming. *Journal of Adolescent Health*, 44(2), 184-187. doi: 10.1016/j.jadohealth.2008.06.004
- ^{vii} Rydstrom, L. L., Ygge, B. M., Tingberg, B., Naver, L., & Eriksson, L. E. (2013). Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study. *J Adv Nurs*, 69(6), 1357-1365. doi: 10.1111/j.1365-2648.2012.06127.x