

Case Study on
Engagement with Adolescents

Growing with HIV. . . So What!



प्रयास

आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व
या विषयांतील विशेष प्रयत्न

Forum on Child Protection and HIV

Growing with HIV. . .

So what!

Background

Almost 10% of the people living with HIV (PLHIV) worldwide reside in India. Considering the absolute numbers, India ranks 3rd among countries with the largest number of PLHIV. India's HIV epidemic is concentrated mainly in six states, mostly from the south and the north-east, with Maharashtra prominent among these. Children living with HIV (CLHIV) constitute a large proportion among these. If we include persons aged below 18 years under the term children, then a significant proportion of these are adolescents. Adolescents with HIV (ALHIV), constitute two distinct types - a) those with perinatally acquired HIV surviving to adolescence, and b) those acquiring HIV infection due to other risk taking behaviors. Considering that one of the key populations at risk of HIV is the age group of 15 to 25 years, a significant number would belong to the latter category. Though the mode of acquisition of infection may be different, the concerns of the two groups regarding growing up with HIV and transitioning to adulthood are largely similar.

“For many young people HIV infection is the result of neglect, exclusion, and violations that occur with the knowledge of families, communities, social and political leaders.”

Anthony Lake, UNICEF Executive Director

- Young women worldwide make up more than 60 per cent of young people living with HIV; in sub-Saharan Africa, their share jumps to 72 per cent – (See more at: <http://www.unwomen.org/en/what-we-do/hiv-and-aids/facts-and-figures#sthash.Kp9S77af.dpuf>)
- India, where 95,000 adolescents are living with HIV, has been listed along with the sub-Saharan countries for having the highest number of youngsters infected by the virus.
- With 46,000 infected girls and 49,000 infected boys in the age group of 10-19 years in 2009, India was ranked tenth in the list of countries with the most adolescent children with HIV.
- The report says that most of these adolescent girls do not know their infection status.
- There are an estimated, approximately 6300 ALHIV in Maharashtra.

Nurturing them is our responsibility

One of the most effective interventions now available for prevention of HIV transmission is for prevention of parent-to-child transmission of HIV (PPTCT). This can reduce chances of mother-to-child transmission to as low as 2%. Although PPTCT programs are certainly preventing transmission of HIV to thousands of children, there are many children who are already infected; furthermore, there would still be some who could get infected for want of access to PPTCT programs or in spite of these interventions. Earlier, when medicines for treatment of HIV (anti-retroviral treatment-ART) were not available or accessible, it was felt that very few of these children would survive long enough to be adolescents. Almost 60% of children infected at birth would die in the first couple of years of life if not diagnosed and treated early. Among those who would survive these early years, most would succumb before seeing the second decade of life, for want of treatment. After ART became available, the situation has changed rapidly. With treatment, CLHIV are surviving much longer and are doing well. Many among these are now adolescents and some even young adults.

Situation of Adolescents living with HIV

One of the major issues regarding perinatally HIV infected children is late diagnosis. In the case of parents who do not know about their own HIV status, the children have not been tested, hence the late diagnosis. Even when parents or other family members know about the parents' HIV status, testing and diagnosis for the child is delayed. By the time they are diagnosed, these children have faced a lot of illness and bear the brunt of delayed physical as well as neuro-cognitive growth.

The next issue is about disclosure. When parents (or other caregivers) come to know that the child is HIV infected, they are under severe stress. This leads to avoidance of disclosure to the child. When the children are very young, parents feel that they will not be able to understand the meaning and implications of being HIV infected. When the children grow up, caregivers fear that the child might get unduly stressed, might react violently, and that they would not be able to handle the behavior of the child. The most common and pertinent question in their thoughts is associated with stigma – whether the child would get angry with them when s/he comes to know about the parent's infection. Would the child judge the parents for their behavior? Would the child spill the closely guarded secret of the disease to others? There are many aspects to the fear in the minds of parents, and instead of dealing with it, they just keep postponing the inevitable. It is forgotten that it is the basic right of the child to know what is

happening to her/him. Such avoidance has a lot of impact on the child's psyche. It has, however, been shown that timely disclosure has definite medical as well as socio-behavioral advantages, the most important being adherence to ART. This is because it is easier for the children to deal with their situation once they know about it, rather than keeping on guessing about what is wrong with them.

Knowing is but one thing. That brings with it many other questions – such as worries about long term medication, survival, thinking about the future, planning for careers, marriage, intimate sexual relationships, disclosure of one's status to friends, etc. There remain many other hurdles too. Finding no one to share their problems is a major issue, but finding that parents/caregivers do not understand is an even larger issue.

Introduction

PRAYAS (Initiatives in Health, Energy, Learning and Parenthood) is a non-governmental, non-profit organization based in Pune, India. Members of Prayas are professionals working to protect and promote public interest in general and the interests of disadvantaged sections of society in particular.

The health Group of Prayas (PHG) is actively engaged in dealing with issues regarding HIV and sexuality. Various activities of PHG are – increasing awareness regarding HIV/AIDS, training, creation of educational material, information dissemination, counseling, care and support facility for people with HIV, child care, prevention of mother to child transmission (PMTCT), research, advocacy and networking.

ADOLESCENTS AND HIV PROGRAM AT PARAYAS:

The adolescent HIV program at Prayas has evolved over time to address the unprecedented psychological and emotional issues specific to the adolescent group posed by the changing context of the AIDS epidemic.

Many perinatally HIV infected children seeking care at Prayas are now entering adolescence or early adulthood. The clinical and counseling team at Prayas started thinking more on the issues of adolescents because the counselors realized that these adolescents never opened up or asked questions, which other children of their age would routinely ask. Most of them were silent loners, and kept brooding in spite of getting the space to express themselves during one-to-one counseling sessions and an environment where every effort was made to make children comfortable. It was also understood that their issues regarding understanding sexuality and growing up were more complex than other adolescents.

The counselors would have regular interactions with these children whenever they came for their follow-up visits. While parents or care providers accompanied the younger children, the older ones started coming on their own after a particular age. During such interactions, along with pill counts and adherence counseling, the children did discuss several issues. On several occasions, children talked about some stressors like pursuing education/career, responsibility of looking after sick parents, becoming the earning member of the family, becoming independent and so on. However, the counselors felt that in spite of the availability of a space and the comfort level to discuss all issues, these children (adolescent age group) hardly ever talked about issues related to sexuality. This was surprising and caused some concern, since Prayas had prior experience of working with HIV uninfected children, which indicated that children of this age always wanted to discuss issues about sexuality as a prime concern and given the space, they were capable of asking all sorts of questions. Therefore, the team at Prayas wondered why these (HIV infected) adolescents avoided talking about sexuality.

It was discussed within our group and it was felt that there was a need to understand their concerns about growing up, devise appropriate ways to address the concerns, create an even more comfortable space where these children could discuss such issues more openly and also to build a platform for establishing supportive communication with their peers. It was also decided that any intervention would respect the rights of these adolescents: the right to know, the right to understand, the right to decide, the right to life. The intervention was planned for those who were aware of their HIV status and who were facing the challenges of growing up and transitioning to adulthood. So the group had both adolescents and young adults.

Evolution of response by Prayas

Promoting disclosure to HIV infected children -

There is growing evidence indicating that disclosing his/her HIV status to a child has health benefits and carries little or no risk of psychological or emotional harm. The WHO recommends that children of school age (6-12 years) should be told their HIV positive status. Disclosure entails discussion about a condition that is considered to be life-threatening, and which is stigmatized as well as transmissible. It is a common observation that parents delay disclosing its status to the child. In spite of multiple efforts by counselors to encourage disclosure, parents take anywhere between several weeks to even years to talk to the child about his/her status. As children started growing, counselors at the clinic started discussing the issue with caregivers. It was decided that counselors will not enforce disclosure, but would keep working with caregivers. Even if counselors are there for any help and crisis management, ultimately caregivers are the persons who would be required to face the post-disclosure consequences on a day-to-day basis.

Similar challenges to the ones described above were also experienced at Prayas clinic. Parents had several fears and anxiety related to possible negative emotional reactions of the child. They were apprehensive to initiate discussions, and were worried that the child would inadvertently disclose his/her status outside the family. Moreover, it was observed that some parents even avoided visiting the counselor to escape discussion of the topic. The one-to-one, clinic-based counseling support appeared inadequate to facilitate disclosures.

To address these issues, we tried the following approaches that involved group processes and the use of audio-visual tools.

1. **Workshop on disclosure/‘Positive parenting’** – Prayas conducted workshops for parents of HIV infected children, the primary objective being encouraging parents to initiate the process of disclosure.
2. **‘Dhusar’ (The blur)** – A film on the issues of disclosure was created. The target audience was parents and caregivers. It depicted various situations around disclosure in a dramatic manner, with the hope of better engaging viewers. This audio-visual approach could more effectively convey appropriate messages stressing the need of disclosure.
3. **Anavaran’ (Disclosure)** – A booklet in Marathi (the local language) was published that addressed issues around all aspects of disclosure, including disclosure to children.
4. **‘Doctor kakankade gelyawar’ (Visiting the doctor uncle)** – A booklet in Marathi with beautiful illustrations was published. It addressed very young CLHIV (age group 4-8 years), explaining to them the importance of going to a doctor, the significance of repeated investigations, the importance of adherence to medication as well as of other restrictions imposed on them.

During follow-up counseling sessions with the parents who had participated in the workshops and who had watched the film, it was realized that our efforts had increased their urge to disclose. However, one of the drawbacks of the process was that the children of parents who participated in the workshop represented a very wide range of age groups. So, the actual impact, in terms of the total number of disclosures facilitated due to the process, could not be substantiated. Even regarding the older children, it seemed that parents still preferred not talking to their children about the disease till the point when the teenagers were on the verge of transfer to adult care. The average age of disclosure still remained around 14-18 years.

Workshops on Growing up with HIV and Transitioning to adulthood (GUwHaTA)

To create a comfortable space and to provide a platform for supportive communication, Prayas planned a workshop for ALHIV and young adults with HIV, between the ages 14 to 24 years.

During the preparatory phase, when we listed the issues we would eventually like to discuss, the list became so exhaustive that we felt that it would require at least 4 days to cover everything. We also decided that it would be a residential workshop somewhere away from the daily hustle and bustle, so that even during the time apart from the actual sessions there would be free interactions among the children. All these participants were perinatally infected with HIV and were aware of their HIV status. As this was a workshop and as cross disclosure would have been an important issue, Prayas team members individually discussed about the workshop with each adolescent's care giver and then with these children. They obtained consent from caregivers and an ascent from children to participate in the workshop. We approached caregivers of all ALHIV of this age group coming to Prayas for care. Since the care provided at Prayas is irrespective of economic status, the group represented a complete range of backgrounds, spanning socioeconomic statuses as well as urban-rural backgrounds.

The first workshop was organized by PRAYAS and co-facilitated by Aarogya Bhaan (Aa Bha) - a group that uses innovative strategies for health communication.

A total of 15 children (10 boys and 5 girls) and a young adult participated in the workshop. All sessions were combined sessions, without gender-based segregation. The workshop was entirely 'for' and 'of' the children. So as to maintain their privacy, no one except the facilitators from Prayas and Aa Bha was allowed to be present at the venue. All Everyone stayed together throughout the 4 days of the workshop.

The workshop

The specific objectives were:

1. To create an open and free environment so that participants are able to talk and ask questions about sexuality.
2. To help participants understand sexuality positively.
3. To create a platform for communication during and after the workshop.
4. To create an environment where children can think and understand the nuances of evolution of any relationship
5. To demonstrate that the ethos of celebration about sexuality can be maintained even with HIV infection.

Various sessions were planned to fulfill these objectives. The basis for all sessions was the firsthand experience of the children, which was given the highest priority. There was an assurance that children can explore these experiences without any inhibitions.

Any information needed to expand the circumference of the central experience was provided. All contours were touched upon as they came up. There were no restrictions on questions. Children wanted to know about anatomy, physiology, virology, pharmacology, sociology, and many other aspects! At the same time, communication was maintained at an informal level so as to ensure that they were not burdened with information. The tools used for communication were music, singing, drawing, skits, group discussions, story-boards etc.

Increasingly enthusiastic participation from the children and their intense discussions affirmed the need for such intervention.



Information regarding the following topics was provided during the workshop:

- Understanding HIV and HIV disease.
- Understanding the body: vital organs inside the human body and their functioning.
- Defense mechanism of the body.
- Nutrition and its importance.
- Self-hygiene.
- Growing up and changes in body and mind along with the psychological needs and social expectations.

- Stressors generated because of these changes.
- Male and female reproductive systems and their functions.
- Pregnancy and birth: Parent-to-child transmission of HIV and its prevention.
- Realizing about one's own sexuality and different expressions of sexuality.
- Relationships: friendship, infatuation, love, marriage.
- Contraception and positive prevention

The entire workshop was conducted with an ethos of celebrating adolescence. Though the workshop was designed like any other sexuality education workshop, it was made sure that wherever necessary, the issue was linked to HIV infection.



For example,

- The meaning and importance of CD4/CD8 counts were explained during the discussion about defense mechanisms of the body.
- All these children were infected through vertical route. Thus, it was important to explain how it occurs. It was felt necessary to discuss and emphasize that their mothers were not at fault – not only because at the time of their birth, PPTCT interventions were not known, but also because the children should not apply prevalent moral values to their parents.
- As marriage and having children was one of their concerns, PPTCT was discussed.

Observations in the workshop

- It took at least a day for the children to open up
- However, they did get adjusted with each other comfortably
- Space was needed to be provided for catharsis; some situations could be challenging
- Apart from the sessions, children spent the rest of the time sharing with each other
- In spite of varied backgrounds, there were no internal sub-groups
- They were extremely caring for each other
- They all brought up some astonishing issues during discussion
- The stress levels during first two days just started dissolving by the third day. It was a pleasure to watch the transition



Outcomes of the workshop

For children perinatally infected with HIV, the path to achieve adulthood is fraught with several challenges. There are concerns about disclosure of HIV status to friends and the dilemma of

establishing intimate relationships, pushing them to deny their sexuality. Their worldview about relationships reflected their emotional maturity, which probably is acquired due to their confrontation with the difficult life situations such as death of their parent/s, realization of their HIV status, dealing with illnesses etc. For most HIV infected children, it appears that the transition to adulthood is abrupt, and involves a crisis of identity where they have to fulfill the responsibilities of an adult but still retain the status of a child. These youth seem to become less self-oriented and give more priority to the health and wellness of their parents and family. The following could be summarized as the outcome -

- Changed attitudes
- Increased intent to adhere to medicines
- Boost to confidence that they too can try and achieve anything
- Desire to lead a normal, healthy and meaningful life
- Desire to keep on meeting each other and to strengthen the bonds



Changed attitudes of participants:

The workshop was very much appreciated by the children. The realization that they were not alone in this journey was the first comforting point for them. Their feedback reflected their intent to adhere to the medicines, boosted confidence and desire to lead a healthy, meaningful life.

“This workshop has given me immense confidence. I will take my medicines regularly and live healthy.”

A 15 year old girl living with HIV

“I did not have a single friend with whom I could share my issues. In the last four days I have found new friends. When I am with them, I do not have to bother about what would happen if they know of my status.”

A 17 year old boy living with HIV

On the final day of the workshop, the children expressed their desire to keep meeting and to form a group. During post-workshop counseling sessions, they brought up different issues willingly and were keener about adherence to medications. When asked to find a name for this group they came up with a very apt name “So what!”, truly capturing the change in attitudes of these children, who came in for the workshop shy and timid; and went out comfortable and confident.

Objectives ‘So What!’

The group came up with its own charter -

- To work for and with HIV infected adolescents.
- To come together and work for upcoming questions/concerns regarding HIV.
- To create an environment (for other HIV infected adolescents) that is conducive for comfortably talking about their issues.
- To work towards eliminating prevalent misconceptions about HIV.
- To spread more knowledge about HIV.
- To work initially with children coming to Prayas.
- To try and reach out to other adolescents living with HIV all over the world and to join hands with them.

The group started meeting regularly. On an average, 6 to 10 members would meet. After the workshop, the role of Prayas was basically one of providing support and allowing them to set their own course. They decided to help other children like them by sharing their experiences; to help caregivers so that there was timely disclosure; they decided to bring out a book of narrations about their experiences of coming to know about their HIV status.

Expansion and extension of peer support group– ‘So What!’

Initially they met only on specific social occasions. Later they met regularly every month for almost 1.5 years. The camaraderie and increased self-confidence among group members was evident. The Prayas team provided constant support to the group to sustain motivation, streamline its evolution, build capacities, undertake specific activities (e.g. drafting a charter for the group) and transfer ownership.

A second workshop was conducted after 2 years in which 17 ALHIV (11 boys, 6 girls) participated. Five members of the ‘*So What!*’ group volunteered in organizing this workshop and provided constant care and support to the new participants.

During the “*So what!*” group meetings, members raised an issue of delayed and improper disclosure to them. The members narrated their experiences to be compiled as a booklet- ‘*Kalala tevha*’ (When I came to know). They believed that this would motivate caregivers to do early and appropriate disclosure.

“I wish my parents were more open in telling me about the disease earlier. I wish they had talked to me about the tensions and insecurities I am going through. I do not want anyone else to go through this pain and loneliness. I am willing to talk to parents of other children. I think it might help them start the dialogue with their child.”

A 19 year old boy living with HIV

Another issue raised by the members was that of severe psychological stress immediately after disclosure, lasting for around six months. They volunteered to help other children through this period either on a one-on-one basis or through participation in the activities of ‘*So what!*’.

A few members of ‘*So What!*’ participated in a state-level conference called ‘*Children Speak*’, which was organized to give voice to the concerns of children from disadvantaged backgrounds.



Feedback of parents / guardians

A meeting of these children’s caregivers was organized. It was attended by 15 parents. Parents reported that the children were now more responsible, less irritable and more regular with their medicines and showed improved academic performance.

“When my son went for the workshop I was very apprehensive. But I tell you, the one who went for the workshop and the one who came back are entirely different. What magic did you do?”

Father of a 17 year old boy

“I would always feel that my daughter is a slow learner and was worried about her future. After the workshop she has changed a lot. A few days ago, she went to a shop nearby, asked for a salesgirl’s job on her own; she got the job and has been working there for three months. I had never imagined this.”

Mother of a 16 year old girl

A third workshop was organized for ALHIV from Prayas as well as from outside. After undergoing capacity building efforts, 5 members of the group will now be working as facilitators in the workshops. Their involvement in this workshop was even more than that in the previous one.

Some more ALHIV joined “So what!” and the group is expanding.

Lessons learnt and practical implications

There is a need for innovative approaches to understand and address the concerns of HIV infected children entering adolescence and young adulthood. Our experience points out that active involvement of ALHIV and their peer support groups could be a key strategy in interventions aimed at addressing concerns of ALHIV. The ‘Sexuality and Growing Up’ workshops boosted their confidence, induced voluntarism and brought out a desire to contribute. The peer support group increased their self-belief and agency. This approach should be helpful to perinatally infected children as well as those infected through other routes, since many of their concerns would be common. The experiences underline a need to develop a more structured evaluation of the efficacy of the interventions.

Such interventions also need to be aligned to other programs. These should become a part of continuous care. The process is intense and needs to be handled sensitively. The process is resource intensive too. So there could be some questions about replicability and sustainability; however, involving peers, hand holding and capacity building can address these issues.

Plans of ‘So what!’

The group meets regularly to work on its objectives.

- The group wants to work for other children, inside as well as outside Prayas. They want to organize and conduct similar workshops for adolescents and young adults living with HIV, with the help from Prayas in the beginning and then, as they would gain confidence, independently as well.
- Initially, the program would be implemented in 4 high prevalence districts (Pune, Ahmadnagar, Sangli, Solapur). It is estimated that there would be approximately 1200 adolescents with HIV in these districts. The aim is to reach out to at least 25% among them.
- Formation of local “So what!” groups would take the initiative forward.
- The group would be working with various stakeholders from the 4 districts
- The group wants to showcase and give a message to other children that it is possible to live positively even if they are HIV infected and also that coming together does help coping.

Plans of Prayas to take forward this initiative

As the group gets strengthened, Prayas would take a back seat in actually implementing all the activities but would provide support to the group for actual work.

- Prayas would take up a parenting role, to help the group to be on its own.
- Prayas would support the group for strategic planning for expansion without disturbing its existing work.
- Prayas would perform the role of building capacities of the group members (Training of Trainers and other initiatives) so as to equip them to take the initiative forward.

Future directions

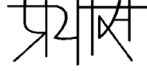
- Organize a state level conference for experience sharing and creating local support structures
- Organize a workshop where at least one uninfected sibling/friend of the same age group joins in (a 'Plus one' workshop)
- Prepare a module for such workshops and disseminate the same
- Plan some scientific research to document the advantages of this approach
- Using this experience for moving into other districts as well as in other states.
- Advocacy for inclusion of such efforts in national HIV/AIDS program as well as internationally

Moving Forward

- The group is working hard with the objective of taking more and more responsibilities in the next workshops.
- The 'So what' group is growing with every workshop.
- Some of its members have started working full time on the issue.
- They all take care of each other.

Conclusion

As children with HIV survived through their childhood and started towards their adolescence, it threw up many questions. There were no readily available answers. There was no precedence. Not only the ALHIV, but we, too, were seeking answers. The case study documents our journey together to find an answer. The development of a peer support group has come up as an effective intervention that not only addresses their concerns but increases self belief, confidence and agency.



आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व
या विषयांतील विशेष प्रयत्न
www.prayas-pune.org

We acknowledge and deeply appreciate the support and inputs of UNICEF Mumbai team, especially, Alpa vora, Specialist, Child Protection, Tushar Rane, Specialist HIV/AIDS and Kamini Kapadia, Consultant, Child Protection, in bringing out this Report.