

Spotlight

The challenges of ART counselling for children and adolescents

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An article from the HDN Key Correspondent Team

The distribution of free antiretroviral drugs (ARVs) in Manipur, India, started on April 5, 2004, and while there are now several government hospitals offering free HIV treatment only 428 Manipuri children have accessed these services as of September 2007.

The lack of paediatric formulations of ARVs and drugs to treat opportunistic infections (OI) used to be a major barrier to children's access in Manipur but with the support of the Clinton Foundation's children's programme, the issue is being addressed.

The Clinton Foundation started supporting diagnostic tests for children and providing paediatric formulations of ARVs and OI drugs. However, several issues related to the treatment of children living with HIV remain, including the need for psychosocial support.

There are a number of adolescents accessing ARV treatment in Manipur, most of whom caught the virus through parent-to-child transmission, and many are at a very delicate stage of development. Some have started to question their status and are no longer satisfied with the simplistic answers provided by carers or their parents.

At this critical juncture in the children's lives, parents and caregivers need to be equipped with the skills to respond to the children's queries and help them understand the reality of their condition.

Interpersonal relations become increasingly important when it comes to child counselling but will the brief interactions that occur between these children and service providers suffice? The time allocation for such interactions is limited and both parents and caregivers can be afraid to share too much information with the child. Often the parents expect the caregivers to be the first to tell a child they have HIV and vice versa.

We need to put ourselves in the shoes of these children and help them make the difficult decisions they face.

There have been cases of children aged between 12 and 13 who have sent their mothers to collect their ARVs for them. We explained to the parents that their child had to be present for follow-ups unless physically unfit and it emerged that the child was too ashamed to come to the centre. The parents didn't discuss the issue further with the child because they didn't feel that they would be able to reassure them. Many caregivers have also reported having a tough time getting children to return to hospital after only being able to offer them partial answers to their questions.

Many skilled parents find themselves at a loss for words when bombarded with queries from their children about the medicines they are asked to take. They sometimes feel that they have to build up a façade to try to get their child take the medicines.

These adolescents have reached an age at which they are prone to risk behavior and are in need of information. But their parents are shying away from even discussing issues surrounding their HIV-positive status. All these factors combine to create stumbling blocks to the counselling process.

Some of the challenges to HIV and ARV counselling for children are:

- Being able to determine how much they know about their status without giving too much away;
- Understanding their abstract mindsets, which are much more dynamic than those of adults;
- Winning their trust and confidence and building up a rapport with them despite having limited interactions;
- Helping them learn to share their concerns over the facts of life and HIV;
- Helping them accept that their HIV-positive status has nothing to do with their own behavior;
- Tackling the fact that most children have no one to talk to about their status except their parents;
- Addressing the fact that they do not have the benefit of peer support systems;
- Tacking the fact that few children seek assistance from child psychologists and professionals;
- Changing the fact that harm reduction, risk elimination, risk reduction principles and behaviour change communication are not things they will readily accept.

To every problem, there must be a solution and parents and service providers need to work together as a cohesive team until children become self-reliant. A multi-level tandem approach needs to be taken in coordination with professionals.

Counsellors need to play a dual professional and personal role when working with a child and they need as much input as possible from caregivers on their personal development and temperament. This is a big ask given the small number of visits a child will make to a centre, but we need to work this out in order to increase the quality and meaning of the work we are doing for children.

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