

## Discrimination rampant at all levels of paediatric HIV/Aids treatment

At night the sounds and shadows grew. The nurses switched off the lights and left the children alone in their beds. Bongi lay awake listening to the click-clack of heels echoing down the corridor. Whenever she thought she saw someone peeking through the open door, she quickly pulled the blanket over her head, waiting for daylight to chase away the shadows.

Bongi is 11 and HIV-positive. Like most children with HIV, she was in and out of hospital in the early years of her life. She fears the darkness and the strange noises in hospital most.

For one boy the word "hospital" evokes the frightening image of baboons staring down at him from a poster next to his bed.

Children's experiences of South Africa's public health system are a composite of dread, boredom and pain, but the experiences of HIV-positive children, who are among its most regular customers, bring sharply into focus the flaws of a system that does not take children's needs adequately into account.

Not all of the children in the support group for young HIV-positive children that Bongi belonged to spent extended periods in hospital or felt frightened by the experience. Not all were taking anti-retroviral drugs and some of those that did had already blocked out the sharp, bitter taste of a syrup they had to take when younger.

They all spoke about the long, dull hours spent in queues during regular visits to clinics, about the pain of having blood drawn from their necks, and about doctors and nurses always talking to adults, never to them.

"Health care for children in the country is not optimal. But kids with HIV have been more disadvantaged than those with other chronic illnesses," says Dr Tammy Meyers, director of the Harriet Shezi Children's Clinic at Chris Hani-Baragwanath Hospital in Soweto.

While there are exemplary health centres with dedicated staff, most children's access to treatment and experience of care are shaped by the reluctance to treat children and by the prejudice towards HIV patients that many doctors and nurses still harbour.

"Discrimination and bad attitude to the disease have hindered access to treatment," says Meyers. The increased availability of anti-retroviral treatment (ART) has led to a shift, she says, but "a lot of bad attitude to HIV-positive kids" still prevails in many facilities.

According to the Medical Research Council, about 37 000 children are born positive in South Africa every year and a further 26 000 are infected through breastfeeding, according to 2004 figures.

A study by Meyers found that at least half of all paediatric medical admissions at Chris Hani-Baragwanath are due to HIV-related illnesses and infections. Without access to anti-retroviral treatment up to 50 percent of HIV-positive children are dead by age 2.

Making the health system more responsive to HIV-positive children, in particular, would seem to be imperative if government is to meet its own and international standards.

Because of the overwhelming numbers of HIV-positive adults, children are not prioritised in the health system. Health-care workers lack confidence and training in treating children and infants. Many admit to being afraid of taking blood from a squirming infant's neck because of the risk of needle-stick exposure to HIV. And it is a long-standing fact that medical professionals tend to talk to adult caregivers rather than directly to children.

Children are also not prioritised in the national anti-retroviral treatment plan, nor are paediatric anti-retrovirals. Paediatric ARVs are less available, more costly and more complicated than for adults - and two of the syrups that form part of the treatment regimen for young children taste "like petrol", as one paediatric HIV specialist says.

According to a 2005 article in *HIV & Aids Treatment in Practice*, which examines children's access to anti-retroviral treatment in sub-Saharan Africa, "the cost for all paediatric formulations are well above the reduced prices achieved for adult anti-retroviral formulations".

As a consequence of the higher price and lower availability, many health workers in the region crush up adult tablets and estimate the dosage for children, risking over- or underdosing.

Meyers says generic manufacturers need to be lobbied to produce child-friendly treatment, including flavoured syrups, chewable tablets and fixed-dose medications.

"The thing that kills me is that children are not seen as economically active, so why bother?"

says Meyers.

The Prevention of Mother to Child Transmission (PMTCT) programme, a key component in halting the spread of HIV to children, "is still a huge problem", Meyers says.

Less than 50 percent of women who need it are getting nevirapine, the drug used in PMTCT.

According to the department of health, by December 2005, 77 percent of public health facilities were offering PMTCT. But even with nevirapine (and without breastfeeding) there is a 12 to 15 percent risk of transmission.

The department of health has included targets in its strategic plan to 2009 to "improve the management of all children under the age of five years presenting with illnesses such as pneumonia, diarrhoea, malaria and HIV" and to "strengthen programmes on women and maternal health".

Recognising that the most common cause of maternal deaths are Aids-related illnesses, saving mothers is a key strategy, says Dr Nonhlanhla Dlamini, technical adviser for the Comprehensive Care, Management and Treatment (CCMT) programme in Gauteng. "Once a child doesn't have a mother, HIV-positive or negative, their chances of survival are slim. Mothers are very compliant [to ART]. It's a great potential we can tap into and use."

The department also wants to put more children on treatment. In the Johannesburg metropolitan area about 22 000 children are HIV-positive, of those approximately 50 percent need anti-retrovirals. As of late last year, about 10 percent were getting them.

"We can see that there are gaps," says Dlamini. "It's not so simple, this rolling out. [We need] a comprehensive ... programme that includes food parcels, grants, linking to social workers, orphan support, STI treatment."

"We see this as a family disease," says Dr Helen Clements, project manager of Enhancing Children's HIV Outcomes (Echo). The organisation seeks to improve the diagnosing of children and the quality of treatment they receive in the public health system

One of the biggest obstacles to getting children on treatment remains adults' reluctance to disclose their or their child's HIV status to the children. "We encourage caregivers to disclose to kids, but it is a difficult thing," says Clements. "They will say that the child is too young to know."

"They are scared that the blame could be passed on to them or that the child might spread it widely and tell friends at school. If a child asks 'what's wrong with me?' you can't lie. If the child is lied to it breaks the trust between the child and the caregiver."

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The opinions expressed are those of the author and do not necessarily reflect the views of the donors. Names have been changed and locations not revealed to protect the identities of the people interviewed

Published on the web by Sunday Independent on May 28, 2006.

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