The international newsletter on HIV/AIDS prevention and care

AIDS action

Asia-Pacific edition

Issue 44-45
July-December
1999

HIV and Children

Many children around the world are affected by HIV – either they have HIV themselves or a close family member is HIV-positive.

More than one million children around the world are estimated to have HIV. Children can be infected with HIV through mother-to-child transmission, infected blood transfusions, unsterile medical equipment or sexual abuse. About four out of every ten HIV-positive children die before they are one year old. However, with good preventive care and early treatment of common infections, many children with HIV can live well beyond their first year. In order to achieve this, their carers need information on how to prevent infections, help on coming to terms with HIV and a supportive environment where people with HIV are not discriminated against.

Dealing with children affected by HIV can be difficult for many health workers due to lack of information or lack of resources to care for sick children and to support their carers.

This special joint issue of *AIDS Action* suggests ways of supporting children and families affected by HIV. In addition, it contains information for health workers and carers on how to diagnose and treat illnesses in HIV-positive children.

Nancy-Amelia Collins/HAIN

One of the most difficult questions is deciding what to do about breastfeeding. An article on infant feeding looks at options to reduce the risk of HIV transmission through breastmilk.

HIV has raised many difficult questions. The Rights of the Child in the Context of HIV/AIDS serves as a framework for promoting children's health and dealing with the difficult issues relating to children and HIV. Also in this issue, a story is used to highlight some of the problems mothers, fathers and carers face when a child is diagnosed with HIV. The sensitive issue of parents disclosing their HIV status to a child is also discussed here.

We hope readers will use this issue to share ideas about how they are responding to the HIV epidemic and involving children and families in their work.

IN THIS ISSUE

Published by

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Children affected by HIV

Geoff Foster outlines the special difficulties faced by children living in communities where HIV/AIDS is common.

During the next 10 years, over 40 million children will lose one or both parents as a result of AIDS, mostly in sub-Saharan Africa. In countries with a high rate of HIV, over one-third of children will be orphaned.

Many children are first affected by HIV when their parents develop HIV-related illnesses. Parents may be too sick to work or they may be too ill to bring their children for immunisation and growth monitoring. Older children often take over caring for younger brothers and sisters at this time, which means that they start to miss school. Children in households affected by HIV face a number of problems:

POVERTY — The AIDS epidemic is leading to increasing poverty and wherever poverty increases, children's health gets worse. When poor children get sick they may not get adequate treatment because their carers cannot afford transport charges, user fees or medicine costs, or because they cannot spare time away from work and family commitments.

Poverty is also associated with increased risk of HIV infection. Orphaned girls from poor households are vulnerable to HIV because of sugar daddies or sexual exploitation by relatives. They may have to work as prostitutes to earn money to feed or educate children in their care. Many orphaned children (boys and girls) end up living on the street.

NUTRITION — Children from HIV-affected families are often at risk of malnutrition. A sick mother will find it hard to provide nutritious food for her children. In Tanzania, in poor families where an adult had died, food consumption fell by 15 per cent. Malnutrition is especially likely when young children are cared for by elderly or adolescent carers who may not be aware of good child feeding practices.

• Substitute Parenting •

Mothers are important primary care workers. Health workers spend time educating mothers about good child health practices. If a young child has no mother, the child's health is often worse. As a result of AIDS, increasing numbers of children are being looked after by grandparents. Often grandparents are unable to care for children adequately. They may be poor, elderly and expected to care for large numbers of grandchildren.

Orphans are often moved from one household to another, sometimes with relatives who neglect, maltreat or abuse them. Increasingly in AIDS-affected communities, relatives are unwilling to foster children, so they are left living alone in child-headed households.

• How To Help •

Health workers and community-based workers can help protect the health of children affected by HIV by:

- encouraging the establishment of community-based orphan programmes to provide support to carers
- recognising HIV-affected families in greatest need, such as large families and those in which children are cared for by single parents or elderly or sick carers
- recognising children at risk, such as those who are orphaned, children under five and those living in child-headed households
- where possible, providing at risk orphans with clothing, housing, food and school fees.

Geoff Foster, Director, FACT, PO Box 970, Mutare, Zimbabwe

Children's Health Indicators

Country	Under-5 mortality, 1998	Infant mortality rate, (under 1), 1998	Annual no. of under-5 deaths (thousands), 1998	Estimated no. of children living w/ HIV/AIDS, 1997	Estimated no. of children (while they were under age 15) who lost parent(s) to AIDS (cumulative), 1997
Bangladesh	106	79	368	270	810
Cambodia	163	104	59	5400	7300
China	47	38	946	1400	720
Fiji	23	19	0	<100	<100
India	105	69	2590	48000	120000
Indonesia	56	40	261	960	1000
Kiribati	74	54	0	-	-
Lao People's Dem. Rep.	116	96	23	<100	150
Malaysia	10	9	5	1400	1500
Nepal	100	72	78	580	750
Pakistan	136	95	722	1800	5000
Papua New Guinea	112	79	16	300	1300
Philippines	44	32	91	620	480
Singapore	5	4	0	<100	<100
Solomon Islands	26	22	0	-	-
Sri Lanka	19	17	6	190	450
Thailand	37	30	37	14000	48000
Vietnam	42	31	71	1100	1900

Source: Downloaded files from http:\\www.unicef.org of the United Nations International Children's Fund (UNICEF) and from http:\\www.unaids.org of the Joint United Nations Programme on HIV/AIDS (UNAIDS)

The Rights of the Child in the Context of HIV/AIDS

HAIN

All children under the age of 18 living in today's world - whether they are themselves are infected with HIV, affected by AIDS in their households or communities, or living in the shadow of HIV risk—are recognised by the United Nations Convention on the Rights of the Child.

In the context of HIV/AIDS, the United Nations Convention on the Rights of the Child has spelled out principles for reducing children's vulnerability to infection and to protect children from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed:

1. *Children's right to life, survival and development should be guaranteed.*

2. *The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.*

3. *Children should have access to HIV/AIDS prevention education, information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.*

4. *Children's right to confidentiality and privacy in regard to their HIV status should be recognised. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.*

5. *All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.*

6. *States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.*

7. *Children should have access to health care services and programmes, and barriers to access encountered by especially vulnerable groups should be removed.*

8. *Children should have access to social benefits, including social security and social insurance.*

9. *Children should enjoy adequate standards of living.*

10. *Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.*

11. *No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.*

12. *Special measures should be taken by governments to prevent and minimise the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.*

Source: The Role of the Committee on the Rights of the Child and its Impact on HIV/AIDS: Problems and Prospects, presentation by the World Health Organization Global Programme at "AIDS and Child Rights: The Impact on the Asia-Pacific Region", Bangkok, Thailand, 21-26 November 1995 UNAIDS Briefing Paper for World AIDS Campaign with Children and Young People "Children and HIV/AIDS". Joint United Nations Programme on HIV/AIDS, 1999.

MANAGING ILLNESS

Dr Grace Ndeezi explains how to manage illness in children with HIV/AIDS.

Most infants infected with HIV show no symptoms at birth. However, children usually develop clinical signs of the disease much sooner after infection than adults. Infants who show symptoms of HIV-related illnesses in the first six months of life are most likely to get sick and die young. Those who show symptoms later (after two to three years), have a better chance of staying healthy for longer. A few children do not show signs of HIV-related illness until they are ten years or older.

Keeping children well

More than half of all children with HIV live beyond five years. It is extremely important that children with HIV lead normal lives. They should be allowed to play with friends, go to school and play sports. Children with HIV infection cannot pass the infection on to others through everyday activities.

In many areas, it is not possible to diagnose a child's HIV status because of lack of counselling and testing facilities. It is not necessary to know HIV status for most infections the child is likely to have. HIV-positive children need the same preventive care as all children including:

- **routine immunisation** – except BCG (the vaccine against tuberculosis) if an infant or child is already showing signs of advanced HIV infection
- **good nutrition** – this is especially important for children with HIV infection. If an HIV-positive mother chooses not to breastfeed this means ensuring adequate and safe replacement feeding for the first six months (see pages 6-7). Appropriate family foods should be started between four to six months. Children with HIV often have a sore mouth due to thrush or other infections such as herpes. This may reduce the amount of food a child takes because it is painful and uncomfortable to eat
- **basic hygiene**, both personal and environmental, helps prevent illness. Advise parents how to prepare the child's food safely and how to dispose of faeces hygienically
- **prompt treatment** of illnesses
- regular **growth monitoring**.

Common illnesses

Infections in children with HIV are similar to the usual common childhood illnesses: acute respiratory infection, diarrhoeal diseases, malaria, measles and malnutrition. The only difference is that these illnesses occur more often and are likely to be more severe or difficult to treat.

The management of illness in HIV-infected children is similar to that in other children. However, if an HIV-positive child does not respond to treatment, he or she needs urgent referral to a hospital. Common illnesses in children with HIV infection include:

CANDIDIASIS (oral thrush)

If a young child has oral thrush (white patches inside the mouth) for more than 30 days and is not having antibiotic treatment, he or she may have HIV infection. Apply 0.25% gentian violet solution (water-based) once a day for seven days or treat with Nystatin oral suspension 100,000 I.U (1ml) four to six hourly for seven days. If there is no response use miconazole oral gel (Daktarin) four hourly for seven days. If there is still no response, use ketoconazole (nizoral).

In children with HIV, thrush sometimes spreads into the child's throat and oesophagus (gullet), causing difficulty or pain on swallowing, reluctance to eat, crying during feeding and weight loss. Oesophageal thrush may occur without signs of oral thrush. Treat with ketoconazole 5mg/kg orally for seven days. If no response, use fluconazole 3mg/kg/day orally for seven days.

RECURRENT FEVER

In endemic areas, malaria is the major cause of fever for all children. If malaria is confirmed by a positive blood slide, treat the child according to national malaria guidelines. If the blood slide is negative for malaria, consider the possibility of a bacterial infection. Encourage the use of insecticide- treated bednets.

RECURRENT BACTERIAL INFECTIONS, such as otitis media (middle ear infection), pneumonia and meningitis, are usually caused by the same organisms that cause infections in children without HIV. Treat with antibiotics according to standard guidelines.

PERSISTENT DIARRHOEA

If the child is dehydrated, give oral rehydration solution, then refer for further care. If there is no dehydration, advise the carer to give the child a diet which contains less animal milk until the diarrhoea stops:

- **if the child is still exclusively breastfed**, give more frequent, longer breastfeeds, day and night
- **if the child is taking other milk**
  - replace the milk with fermented milk products such as yoghurt OR
  - reduce the amount of other milk given by half and replace with nutrient-rich semi-solid foods.

The child should continue to take an appropriate diet for his or her age.

Treat children with dysentery (blood in the stool) with the appropriate antibiotic recommended for *Shigella* in the area.

CHRONIC COUGH

If the child has fast breathing and/or chest indrawing, he or she will need antibiotic treatment for pneumonia. Younger children are particularly at risk from severe pneumonia and should be treated in a hospital where possible.

A child who has a cough lasting for more than 30 days needs referral. Tuberculosis is difficult to diagnose in children, particularly if they have HIV. Consider TB if the child has:

- failure to thrive or weight loss

- fever or persistent cough for more than one month
- an abnormal chest Xray that persists despite adequate antibiotic treatment for two weeks or more
- history of household contact with a person with TB.

Treatment should follow national guidelines. NEVER treat HIV-positive children with thiacetazone because this drug can cause severe and sometimes fatal side effects in people with HIV.

SKIN DISEASES

In many children skin diseases may be the first sign of HIV. It is often difficult to identify the cause of the sore or blister (lesion). Suspect herpes zoster (shingles) if the child has painful blisters spreading over a specific area of skin. Keep the area clean and dry and apply calamine lotion (15% solution). Give paracetamol (10-15mg/kg orally every 4-6 hours) to relieve pain.

If the lesions are scaly or itchy, treat for a fungal infection with miconazole (Daktarin) cream (2%). If not available, apply 1% gentian violet solution or nystatin ointment two times a day for seven days.

If there is pus on the lesions, treat with oral cloxacillin, 50mg/kg every 6 hours until the lesions heal. If not available use erythromycin or trimethoprim-sulfamethoxazole (cotrimoxazole). Creams applied directly to the skin are not effective. For dry lesions provide calamine lotion. Treat scabies with benzyl benzoate 12.5% lotion.

HIV-specific illnesses

Some infections are more common in HIV-positive children than HIV-negative children. These include:

PNEUMOCYSTIS CARINII PNEUMONIA (PCP) suspect if a child presents with fever, fast breathing (which is often severe) and difficulty in breathing; particularly if there is no response to initial antibiotic treatment. It is more common in infants under six months of age, but can occur at any age.

CEREBRAL TOXOPLASMOSIS suspect in a child who is unconscious, has convulsions or weakness down one side of the body.

CRYPTOCOCCAL MENINGITIS suspect if a child fails to respond to standard antibiotic treatment for meningitis. If facilities are available, diagnosis can be made following lumbar puncture, if cryptococcal organisms are found in the child's cerebrospinal fluid.

These conditions are all serious and often difficult to treat. If suspected, the child must be referred to a hospital.

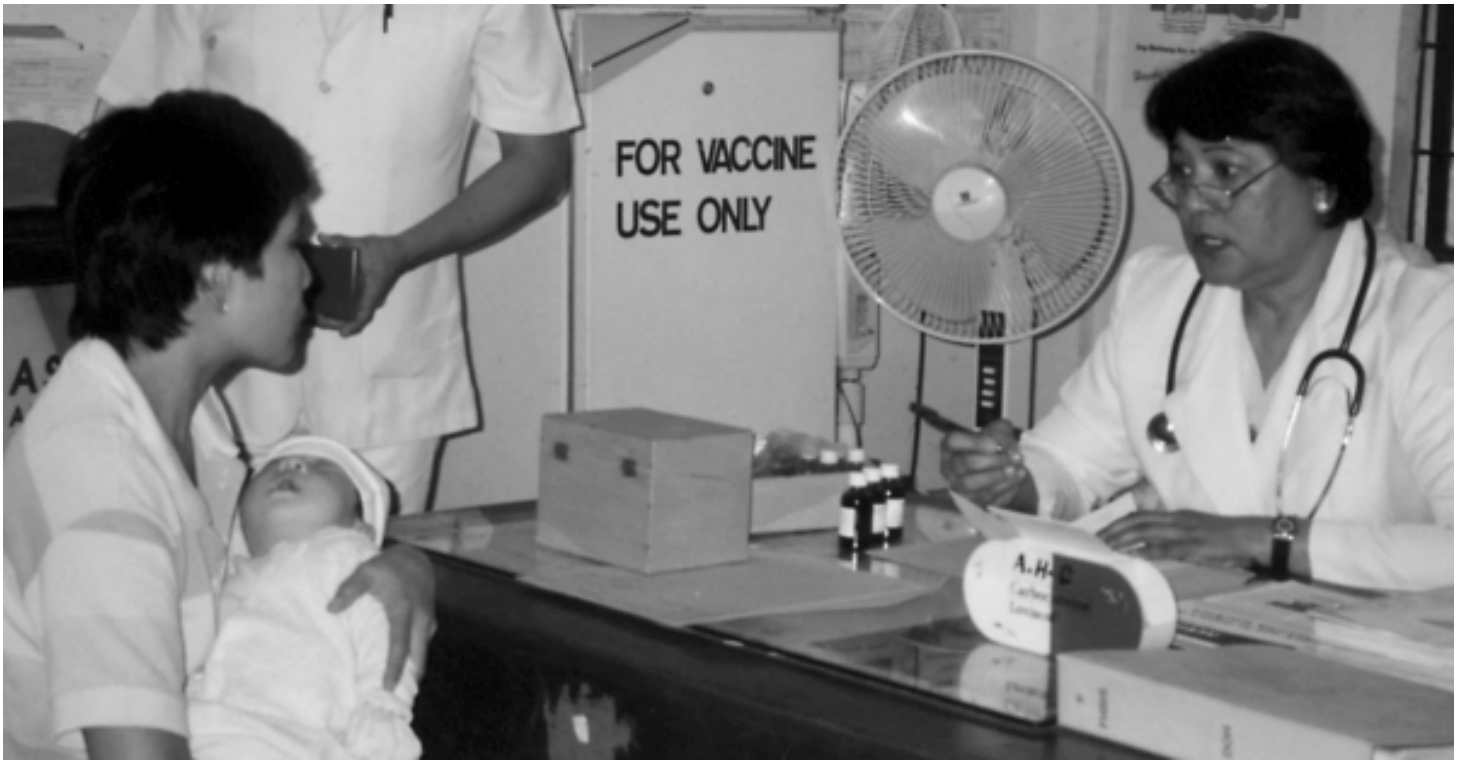
Supportive care

Sick children need supportive care to help relieve symptoms and reduce pain. This includes:

- keeping the child comfortable, warm and dry
- giving plenty of drinks and small, frequent, nourishing meals
- reducing high fever (38.5^{0}c or above) by removing layers of clothing and giving paracetamol
- giving the child love and attention.

Children with HIV who are very sick may also need pain relief. Management of pain follows the same principles as other chronic diseases such as cancer or sickle cell disease. Paracetamol can be used for mild and moderate pain. Stronger drugs such as morphine and codeine are used for moderate and severe pain not responding to paracetamol. They should be given under the supervision of a properly trained health worker. Health workers should find out about local organisations which offer support to HIV-affected families so they can refer families to them.

Dr Grace Ndeezi, Paediatrician and Lecturer, Makere University Medical School, PO Box 7072, Kampala, Uganda



HAIN

Infant feeding and HIV

Mother-to-child transmission of HIV is the main cause of HIV infection in children. About two thirds of these children are infected during pregnancy and around the time of delivery. The other third are infected during breastfeeding.

Breastfeeding is usually the best way to feed an infant, but if a mother is HIV-positive, replacing breastfeeding can reduce the risk of HIV transmission to her infant. However, alternative methods of feeding also have risks. When breastmilk substitutes are used, infants are five times more likely to have bacterial infections than breastfed infants, even where hygiene is good. Where hygiene is poor, artificially-fed infants may be 20 times more likely to die from diarrhoea than breastfed infants.

Women who know they are HIV-positive or feel they are at high risk face difficult decisions about infant feeding.

HIV-positive women need information about the risks and benefits of breastfeeding and of the various alternatives, and support in deciding which method is best. Helping a mother who is HIV-positive decide whether to replace breastfeeding means discussing with her:

- the risk of transmitting HIV to her child through breastfeeding
- all infant feeding options – their risks and benefits
- how she might approach her family, especially her husband and mother, to get their support rather than rejection
- how to get support from other women who have been in her position
- whether she has the resources –water, fuel, utensils, skills and time–to safely prepare replacement feeds
- what effect the cost of buying breastmilk substitutes might have on the rest of the family, if these cannot be subsidised by the health service
- the importance of regular growth monitoring and follow up for her child.

It is also important to remind women that breastfeeding is a natural form of contraception, effective for as long as women continue to practice exclusive breastfeeding and not have periods. Women and their partners should have information about, and access to, family planning methods especially if their child is not breastfeeding.

Some HIV-positive women may decide not to breastfeed. Others may decide to breastfeed. Whatever her choice, a woman needs support and information about the safest way to feed her baby.

INFANT FEEDING OPTIONS

Health workers should continue to encourage breastfeeding by women who are HIV-negative and those who do not know if they have HIV. While it is good to be able to offer access to HIV counselling, and to confidential voluntary testing, in many areas this is not yet available. Women who do not know their status may choose not to breastfeed for fear they are infected. It is important to listen to the woman's reasons why she is choosing not to breastfeed and to explain the value of breastfeeding, while supporting the woman's choice.

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INFANTS OF HIV-POSITIVE MOTHERS

The first six months

Up to about six months, milk in some form is essential. If not breastfed, an infant needs about 150ml of milk per kg of body weight a day. So, for example, an infant weighing 5kg needs about 750 ml per day, which can be given as five 150ml feeds a day. Up to about six months of age, infants do not need other foods if they are gaining weight adequately.

This milk can be supplied by:

• *COMMERCIAL INFANT FORMULA* – feeding an infant for six months requires on average 40 x 500g tins of formula. This provides the best mix of nutrients for infants who cannot have breastmilk but is expensive if bought commercially and therefore not an option for many mothers

• *HOME-PREPARED FORMULA* – made with fresh animal milks, dried whole milk or unsweetened evaporated milk. These milks must be modified to make them suitable for infants. For example, to prepare fresh cow's milk: mix 100mls milk with 50mls of water and two level teaspoons of sugar and boil. Micronutrient supplements should be given because animal milks contain insufficient iron and zinc, and sometimes vitamin A and folic acid

• *EXPRESSED BREASTMILK* – this must be boiled (to kill the virus) and then cooled immediately by putting it in cold water or a refrigerator

• *BREASTMILK BANKS* – in some areas donated breastmilk is used for short periods, for example, to feed sick and low-birth-weight babies in hospital. Donors should be tested for HIV and the milk pasteurised before use

• *ANOTHER WOMAN* who can breastfeed and knows that she does not have HIV. This is often the grandmother. Women who act as wet-nurses must be given information about how to practise safer sex to make sure they remain HIV negative while breastfeeding

Stopping breastfeeding early

This may reduce the risk of HIV transmission by reducing the length of time that an infant is exposed to HIV through breastfeeding. The best time to stop breastfeeding is not known. However, an HIV-positive woman may want to consider stopping breastfeeding as soon as she is able to prepare and give her infant adequate and safe replacement feeding. Stopping breastfeeding early is advisable if an HIV-positive mother develops severe HIV-related illnesses.

After six months

Between 6-12 months infants who are not breastfed should have:

- undiluted cows milk (or a suitable alternative) at least five times a day
- suitably prepared family foods three to four times a day. If milk is not available, give family foods five times a day.

Good meals are those which provide a variety of food. During a day, a child's food should include:

- cereal or starchy roots such as maize, rice or sweet potato
- legumes (beans, peas, lentils or groundnuts)
- small amounts of energy-rich food such as oil, fat, honey or sugar to provide extra calories (energy)
- fruit and vegetables to give extra micronutrients such as vitamins A and C

Where possible include:

- a protein-rich food (such as fish or meat) to provide easy-to-absorb iron and zinc
- other animal foods such as eggs to provide more protein and calcium.

Give micronutrient supplements if the child's diet is likely to be low in iron, vitamin A or other micronutrients.

SAFE FEEDING

To prepare and give milk feeds, carers should:

- wash their hands with soap and water
- wash the mixing and feeding utensils with boiled water or boil to sterilise them before preparing the milk
- carefully measure and prepare the milk. Keep covered until used
- use a cup to feed the infant. Cups are easier to sterilise than bottles and reduce the risk of diarrhoea
- not keep left over milk. Give it to older children.

Other food must also be hygienically prepared and given using a clean bowl and spoon.

Thanks to Caroline Maposhere, Zimbabwe AIDS Prevention Project, 103 Rotten Row, Harare, Zimbabwe, for contributing to this article.

"I pray that my child will be born negative..."

Jyoti, a young girl from Nepal, became involved with a man who was known to be a drug user. It was also rumoured that he had HIV. Despite her family's disapproval, she eloped with him and they got married. She talks about her hopes, worries and life experiences.

"What was I to do? Everyone said he had AIDS, but he said he didn't. He explained that even if I did have HIV, it is curable. It is only AIDS that is incurable.

Only recently did I discover that everyone in his home knew that he was HIV positive. I also found out that it can cause AIDS.

I have always been afraid of death. Now, I am going to die soon. I am only 18 years old and I doubt I will reach 25. But the worst part is that I am now pregnant. It is normal for a woman to be happy when she becomes a mother, but I am also very concerned. I am afraid my baby too has been infected already. I don't want to have an abortion. At least the baby will be my support ... and yet what support? I am going to die soon, and who will support my baby then?

My husband is still irresponsible. He says, "I don't care, no matter what happens." He doesn't inject drugs, but smokes hashish. We fight a lot. His parents and his brother support me too, and, in its own way, it's a pleasant home and time passes as I putter around. I talk and laugh a lot in order to forget my problems. So far, we both remain healthy, thanks to God's grace. Now, I pray that my child will be born negative. Please pray for me, okay?"

Source. Excerpts from Positive Life. The social and cultural roots of the HIV/AIDS epidemic as told by 15 young Nepali men and women. Nepal: Panos South Asia, 1999.

MOTHER-TO-CHILD TRANSMISSION

Facts about mother-to-child HIV transmission

Mother-to-child HIV transmission is also called vertical transmission. Mothers can transmit HIV to their children in three ways:

- during pregnancy
- during childbirth
- through breastfeeding

The risk for vertical transmission ranges from 15 to 25 percent in industrialised countries and from 25 to 45 percent in developing countries.

Mother-to-child HIV transmission in pregnancy and childbirth is also called perinatal transmission.

Mother-to-child HIV transmission can be reduced by:

- reducing the risk of HIV infection in women and their partners by promoting safer sex - before and during pregnancy and during breastfeeding
- providing effective and accessible family planning services to enable women to avoid unwanted pregnancies
- providing anti-HIV drugs to women before and during delivery
- avoiding unnecessary invasive procedures (such as amniocentesis - taking a sample of the fluid surrounding the baby in the womb) during pregnancy and delivery
- avoiding the risk of HIV transmission through breastmilk, where appropriate alternative infant-feeding methods are available
- reducing the risk of HIV transmission through contaminated blood transfusions to women and their children.

Currently, two of these strategies are receiving much attention: providing anti-HIV drugs and avoiding HIV transmission through breastmilk.

In developing countries, mother-to-child transmission of HIV is responsible for 5 to 10 percemt of all new HIV infections. This article looks at the possibilities for reducing mother-to-child HIV transmission, and discusses some of the question that are still unanswered.

Breastfeeding and HIV transmission

The issue of breastfeeding and HIV transmission has been a complicated one. Breastfeeding has many advantages for the child's health: it is free and nutritious, and protects the child against infection. The use of infant formulas, on the other hand, is accompanied by many dangers: malnutrition if the infant formula is not given in the right amounts, diarrhoea if unclean water is used.

Based on different estimates, UNAIDS estimates the following risks for HIV transmission:

Where no anti-HIV drugs are administered and the baby is breastfed by its HIV-positive mother, the risk of infection is generally around 30 to 35 percent

Where no anti-HIV drugs are used, and the baby is not breastfed, the risk of infection is around 20 percent.

It is clear that maternal to child transmission of HIV can be reduced if HIV positive mothers do not breastfeed their babies. However, breastfeeding is still recommended for HIV-positive women who may not have access to appropriate alternatives, that is, safe water supplies with which to prepare infant formula.

Anti-HIV drugs

Several clinical trials have been or are being conducted to evaluate the effectiveness of different anti-HIV drugs in preventing vertical transmission. UNAIDS has summarised these different studies and compared the rates of mother-to-child transmission of HIV under different circumstances:

- Where a one-month course of AZT (zidovudine) is administered and the baby is not breastfed, the risk of infection is around 10 percent.
- Where a one-month short course of AZT is administered, and the baby is breastfed by its HIV-positive mother for up to 8 months, the risk of infection is about 18 percent.
- When two antiretrovirals – AZT and 3TC – are used at the time of labour and to mother and baby for one week following delivery, the risk of infection is around 11 percent. If the drugs are given for approximately one month – from the 36th week of pregnancy, continued in labour and given for a further week after delivery – the chances of the baby being infected is around 9 percent.
- When one oral dose of nevirapine is given to the mother in labour and to the baby within three days of birth, the risk of infection is about 13 percent, even with breastfeeding

The studies are still ongoing and it will take time before definite recommendations can be made about using these anti-HIV drugs.

Unanswered questions

HIV-positive women, HIV support groups, health workers, planners and others still face many unanswered questions. For example:

- Does weaning babies by the age of six months reduce the risk of HIV transmission?
- What effect does antiretroviral therapy have on the risk of HIV transmission through breastfeeding?
- What factors in mothers and babies (such as cracked nipples and mastitis in women and oral thrush in babies) increase the risk of HIV transmission through breastfeeding?
- What can be done in resource-poor settings to reduce the risks associated with not breastfeeding?
- Can cleansing the birth canal with a microbicide (a special type of antiseptic or disinfectant) during labour and delivery reduce HIV transmission?
- Are interventions to prevent HIV-transmission to girls and women, such as voluntary counselling and testing, a more cost-effective way of reducing HIV transmission to children than short-course antiretroviral therapy?

Research is being carried out into a number of these issues.

Practical problems

To put the UNAIDS, UNICEF and WHO recommendations into practice, women will need access to:

- voluntary and confidential HIV counselling and testing
- good antenatal and postnatal services
- safe water and appropriate alternative infant-feeding methods
- community and/or family support.

Health services will also need:

- appropriate laboratory facilities
- skilled staff
- effective drugs supply and distribution.

In many places these requirements cannot be met. Many governments do not have the resources to provide these services and many individuals cannot afford private services. In most parts of sub-Saharan Africa, average spending on public health is less than US$20 per person a year, but short-course zidovudine treatment costs at least US$50 per woman. Pilot projects with external funding and subsidised drugs are unlikely to be sustainable in the long term.

Even if the resources are available, other strategies might be more effective in the long term in reducing mother-to-child HIV transmission - for example, voluntary counselling and testing, and education and condom promotion activities that help prevent men and women getting infected in the first place.

Ethical issues

There is concern that the number of infant infections and deaths may increase if more women choose not to breastfeed. Most women in developing countries do not know whether they have HIV. Many women may choose not to breastfeed if they think that they might be HIV positive, even if they do not have access to appropriate alternative infant-feeding methods.

The recommendations do not address mothers' health needs. HIV-positive women also need ongoing counselling, user-friendly family planning services, treatment for HIV-associated infections and treatment for TB. This is important for HIV-positive women in their own right. It is also important for their children - if the mothers are not supported, it will be harder for them to care for their children.

There is also a fear that women may be pressured to have HIV tests and their HIV status may not be kept confidential. In some communities, choosing not to breastfeed may identify women as being HIV-positive. In many places, women who are known to have HIV are discriminated against within the health services, their communities and families - some have been chased from their homes and even killed because they were known to have HIV.

Adapted by Michael L. Tan for the Asia Pacific edition

What HIV-positive women need to know

Trial results offer hope for HIV-positive women (and their partners) who want to have children. However, women need to know that:

- *There is still a risk that their baby will be born with HIV. That is, of all the children born to HIV-positive mothers who receive zidovudine treatment, about one in ten will still be HIV-positive.*
- *The treatment does not have any benefit for the mother's health, because it only prevents transmission to the child.*
- *The current recommendation is that HIV-positive women should not breast-feed if they can safely use appropriate alternative infant-feeding methods. If they cannot safely use these methods, for example, if they do not have a good supply of clean water, they should continue to breastfeed.*

QUESTIONS TO ASK

These are useful questions to ask before deciding on strategies for reducing the risk of mother-to-child HIV transmission.

(1) HIV-positive women (and their partners)

- *Where can I find confidential counselling?*
- *If I want to be tested, where can I go?*
- *How do I get zidovudine and how do I use it?*
- *What else can I do so that my children have less chance of getting HIV?*
- *Where can I get information and support about alternatives to breastfeeding?*
- *What can I do if it is difficult not to breastfeed?*
- *Are there any support groups for HIV-positive people in my area?*

(2) Health workers

- *What do we tell people who have no access to testing?*
- *What do we tell people who are not able to use appropriate alternatives to breastfeeding?*
- *How do we help people who want antiretroviral treatment?*
- *How do we get access to essential resources such as gloves and disinfectant?*
- *What training and information do we need and where can we get it?*

(3) Women and men who don't know their HIV status

- *Where can I get confidential counselling, and testing?*
- *What about discrimination in my community?*
- *Will my family support me if I test HIV-positive?*
- *Where do I get information about mother-to-child HIV transmission?*

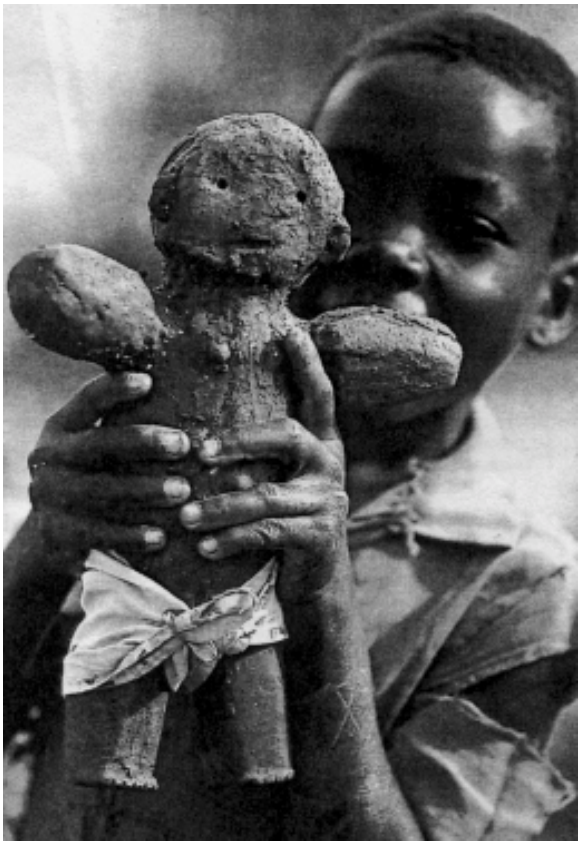
(4) HIV support groups

- *How do we get access to zidovudine?*
- *What about access to services such as confidential testing and counselling?*
- *How do we get more information about what we can do to help ourselves?*
- *What messages will help our members?*

(5) Politicians/governments/health planners

- *Are resources available from other budgets and services, including public health?*
- *Are there more cost-effective ways of reducing mother to child HIV transmission?*
- *Will we be able to afford the drugs and appropriate alternative infant-feeding methods?*
- *Will we be able to distribute and supply them effectively?*
- *What training will staff need?*
- *How will we need to improve HIV testing and counselling services?*
- *How can we improve antenatal services?*
- *How do we decide which group of women has priority, for example, urban or rural?*
- *How do we help prevent stigma and discrimination?*
- *If these strategies lead to more AIDS orphans, how will they be cared for?*

Helping Children Talk



Many children and young people living in our area of London are affected by HIV. Most of the families are from sub-Saharan Africa. Some HIV-positive parents have died, some are ill and some are well. Some older children know that their parents have HIV, but most of the children do not. We felt that these children needed opportunities to understand some of the changes affecting their lives.

Children with a parent or parents who have died or are very sick are invited to six half-days of story telling and play. The sessions are led by a family counsellor and someone who uses drama. Trained volunteers come from local AIDS organisations.

The sessions vary, depending on what the children choose to talk about. The adults' role is to help the children to begin to reflect about their own feelings in a way that is easy for them to express. This allows each child to work at the level that is right for them. The children create the stories, bringing images and themes from their own cultural and spiritual contexts. They know that they share a similar experience of loss, but most do not know that HIV is the cause. Whether, or how, HIV is spoken about depends on the age and understanding of the children, and the wishes of their families and the community.

A session usually begins by making up a story using a toy animal. We all sit in a circle, pass the toy from one child to the next, talking about it. Then we make a story. Everyone in the circle takes it in turn to tell a bit of the story. We go round the circle as many times as the story takes. Anyone who doesn't feel like speaking can say "pass". If it seems appropriate, the adults may use their turn in the story to introduce ideas of family, support, separation, loss and change.

The story in the box was developed by a group of children aged 5-8 years.

After we have made the story together, the children act out the imaginary family in different ways. One example is described below, but there are many other ways that adults can tell stories with children, depending on local traditions.

Story telling and play can help children affected by HIV talk about changes happening in their families.

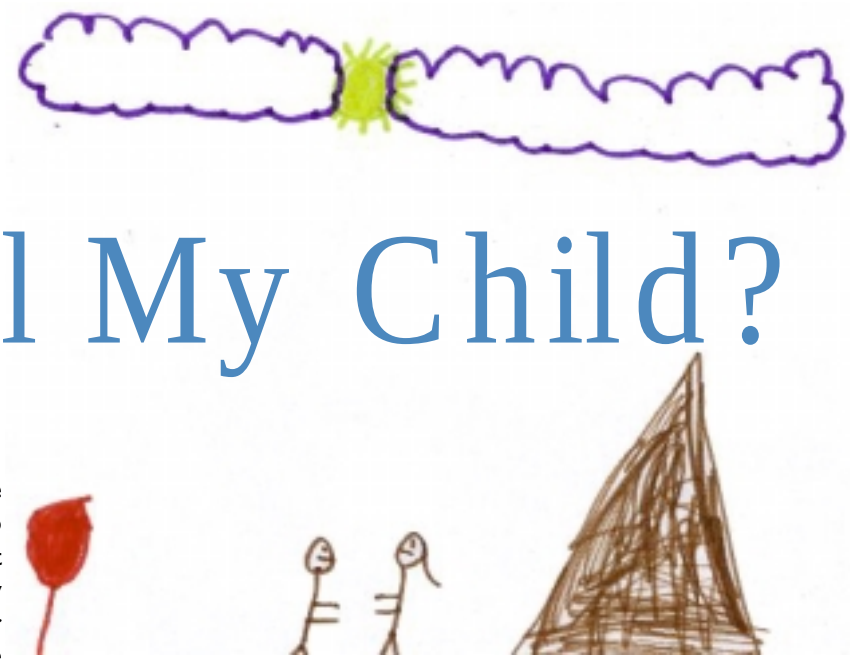
The children chose to build baby cheetah's home out of chairs, branches or bits of cardboard. The adults then ask questions which help the children develop the story. *Where does baby cheetah sleep? Who else is part of her family? What does she like to eat? Who does she play with?* Children weave their own experiences into the story, for example baby cheetah wetting the bed, feeling alone and being comforted by an older animal. Because these experiences happen to baby cheetah not the child, this sometimes make it easier for the child to talk about problems like bed wetting. The story helps children talk about change and the future.

At the end of the sessions, time is set aside for the children to talk freely about what they have been doing and make connections with their own lives. The children say the sessions have helped them feel more confident. They make friends with other children and they give and get support from each other. Families say that their children seem more settled.

Liz Day, HIV Coordinator, Bexley Council, Howbury Centre, Slade Green Road, Kent DA8 2HX, UK and Roya Dooman, Drama Therapist, 8 Harraden Road, London SE3 8BZ, UK

Mummy cheetah and her baby

Mummy cheetah and her baby lived in the plain. Mummy cheetah hunted for food for her baby and sang to her to keep her safe at night. One day mummy cheetah became sick. She was sad and worried about who would look after her baby if she did not get better. Baby cheetah played with her friends in the sun, but sometimes she worried about her mummy. Mummy cheetah became so sick she could not sing any more and after a time she died. Auntie took baby cheetah to live with her and her own children. They had lots of fun together, but sometimes baby cheetah felt sad. When she felt sad, baby cheetah sang the song her mummy used to sing and she felt comforted.



Do I Tell My Child?

Nerida has not told her 9-year-old son that she has HIV infection. The boy lives with Nerida's mother, so they do not spend much time together. Nerida hopes that some day, her son can stay with her. She feels that if they are together, it will be easier for her to tell him about her HIV status, and to give him the emotional support that he needs. She also wants her son to see the work that she is currently doing as a health educator. Nerida used to be a sex worker, and her son does not know about this either.

Kim, a 34-year old HIV-positive woman, has a daughter aged twelve years. Five years ago, Kim started to work as a health educator, and she publicly disclosed her HIV status to help the government's information campaign on HIV/AIDS. Because she is publicly "out", Kim decided to disclose to her daughter, who was then seven years old. Kim wanted her daughter to learn the truth directly from her, rather than hear about it from other people. She also felt that her daughter was mature for her age and could understand the situation. According to Kim, the child has coped well with the knowledge that her mother is HIV-positive. Whenever Kim appears on television, her daughter proudly tells others: "That's my mother."

Disclosing to a Child

Disclosure of a parent's HIV status to his or her child is a very sensitive matter. Parents need to consider how their children will react and cope with the knowledge that their parent is HIV positive.

Many Asian families do not discuss serious family matters with their children. This makes disclosure to one's child even more difficult. Other reasons why parents are reluctant to disclose their HIV status to their children are:

- the effects on the child's emotional and physical well-being
- that children will have less respect for them
- that children would get conflicting information about HIV from the family and from society

Nancy-Amelia Collins/HAIN

• that children might experience discrimination

HIV-positive parents who have disclosed to their children cite a number of advantages about disclosing. They feel that children have a right to know the truth, and that knowing will help the child cope better with the present as well as future situation. Some parents also say that disclosure improves the parent-child relationship, because the child can understand if the parent is ill or worried.

Some factors which influence when and how a person's HIV status is disclosed to a child include gender, HIV status of the child, and most importantly, parenting styles. Other important considerations are:

• how the family copes with difficult situations
• the age of the child
• spirituality
• family circumstances (such as culture, class, family structure)

"Partial truth telling" can be a helpful approach in disclosing to children. Using this approach, children are always told the truth, yet not necessarily using the words "HIV" or "AIDS". The adult talks of infection and its effects on the body in ways that children can understand. The information given to a child will depend on the child's age, maturity and need to know. This will allow gradual revelation of the parent's or child's situation. The child then gains a

gradual understanding of the disease that is affecting his or her family.

Health workers, counsellors, and other care-givers play an important role in helping a parent decide whether or not to disclose to a child. If a parent decides to disclose, the support of care-givers is essential in helping both the child and the parent cope with the situation.

(The Hospital for Sick Children in Toronto, Canada has prepared draft guidelines on how to disclose to children who are HIV-positive. The Guidelines are also helpful for other disclosure situations. See page 16 for information on how to request for reprints.)

References:

Support for Children and Families Living with HIV/AIDS: An Orientation Manual by JR McDonald. Canada: Canadian Hemophilia Society, 1998

"Disclosing HIV Infection to Children: The Paths Families Take to Truth-Telling" by Dale Demaheo, et.al. A paper presented at the AIDS Impact Conference held in Ottawa, Canada, July 15-18, 1999

(Editor's note: The author wishes to thank the HIV-positive parents who shared their insights and experiences on disclosure in this edition of AIDS Action.)

Mercedes B. Apilado (HAIN, Philippines)

Memories Help

When children become separated from their families, important memories quickly fade. Before it is too late they need truthful answers to their urgent questions: Who am I? Where do I belong? Who will take care of me in the future?

In many different countries, parents have helped their children by making memory books which record information about each child. The memory book has pages covering different topics which parents and children can fill in together, such as:

- *My home – where I grew up*
- *Important family traditions*
- *Family trees to show where different relatives are living*
- *Outline maps to show where the family is from.*

Some families have covered the same ideas by making a memory basket for each child. They collect small personal objects from the home which will help children remember the family's life together. Others have made tape recordings of favourite songs and hymns along with spoken messages from individual parents.

Parents say that as well as providing valuable information for their children, these activities have also helped them to remember happier times. When children get involved in helping their parents collect the 'memories' it has been an easy step to go on to talk about the loss and changes ahead. Many parents said this has helped them to talk for the first time about HIV in the family.

Once they broke through the wall of silence, many parents found it was easier to start talking to relatives or friends about plans for their children's future. Open discussion has helped the children to be less afraid of HIV and to learn from their parents about how to avoid risks to their own health in the future.

Many parents have said that by preparing for their children's future, they feel both physically and emotionally stronger. They are no longer wasting energy on hiding the truth.

'You don't need to have AIDS before you start a memory book. We all need to know about our origins. We should all be doing it for our children and for ourselves'.

Carol Lindsay Smith, CLS Development Services, PO Box 4385, Colchester CO6 4UA, UK

Stories can help health workers and other carers learn more about HIV/AIDS and think about ways to improve the care and support they give to families.

The following story can be used and adapted as a training exercise for health workers, counsellors and home-based care workers. Tell the story (or your own variation of it) and then go through it again slowly, asking questions and providing information. You can tell the story in parts (as suggested here), discussing each part in detail before moving on, or you might prefer to tell the whole story right through first. Always change the story to make it familiar to the people you are talking to. For example, change the names to ones that are common in your area.

Ilinanga's Story

1992
Ilinanga Is Born

When Nakala became pregnant for the fourth time, she crossed her fingers that it would be a boy, because that is what her husband wanted. She already had three lovely girls aged 8, 6 and 3 years. She went to the clinic early on in her pregnancy and, as usual, her blood was checked. Nakala had read a lot about HIV in the newspapers and knew that it could be passed on from a woman to her child. She, like most people, had absorbed the facts about HIV but never thought it would affect her family. While waiting to be examined at the clinic Nakala and the other women all agreed that it would be too depressing to discover one was positive when already pregnant.

Ilinanga, a girl, was born healthy and strong. The whole family was happy with the new baby. Nakala happily breastfed her baby. She knew that not only was this best for Ilinanga, but that it would help her not to get pregnant again too soon.

DISCUSSION POINTS

• Most women do not know their HIV status when they get pregnant. Health workers often find it difficult to talk to pregnant women about HIV. In Nakala's case, should the nurse have talked to her about HIV during her clinic visits? Should health talks on HIV and STDs be given routinely at antenatal clinics?

• What information do women like Nakala need about HIV and breastfeeding? How and when should this information be given? For example, is it best to talk to women individually or in a group?

1993
Something Is Wrong

During her first year Ilinanga had many infections. When she was nine months old Ilinanga stopped gaining weight properly. Nakala was surprised and upset as this had not happened with any of her other children. When Ilinanga was 16 months old she developed a bad cough that did not go away. The nurse proposed a HIV test which Nakala and her husband agreed to. They did not think Ilinanga had HIV, but thought that once the nurse knew that their baby was HIV negative, she could start looking for other causes for Ilinanga's frequent infections.

The results came back – Ilinanga tested HIV-positive. Nakala and Samson were shocked. They felt angry and didn't believe it was true. They then both had an HIV test and were also found to be infected with the virus. Nakala asked herself – when did she get infected? Was it before or after her marriage? During her last pregnancy? Or during the time she breastfed Ilinanga? She and Samson had never used condoms in their marriage. Like most couples in their community they started to have sex again one month after the birth of a child. She had not slept with anyone else, but could not say the same for Samson. And when did Ilinanga get HIV? Was this before or during her birth, or from breastmilk?

Nakala worried about Ilinanga's, health, her own health and that of her husband and other children. She worried about how she was going to tell the other children about Ilinanga's illness. Nakala and Samson agreed not to have them tested but they worried that they might get infected through close contact.

For many of their concerns there seemed to be no right or wrong answer. The nurse could only give them the facts about HIV infection and what could be done locally to help them. Nakala and Samson had to make their own decisions. The challenge for

the nurse was how to encourage Nakala and Samson to keep Ilinanga and themselves as healthy as possible. This meant healthy eating, exercise, preventing infections or treating them early and, because they were religious, "putting God first".

DISCUSSION POINTS

• Samson passed HIV to Nakala during sex. What could Nakala have done to prevent herself becoming infected? What could she have done to prevent Ilinanga from getting the infection?

• What do health workers need to consider before they suggest an HIV test to parents? Discuss what facilities for testing there are in your area.

• When Ilinanga tested positive this meant probably either one or both of her parents had the virus too. How might a parent feel knowing she or he has infected his or her child? How can parents be helped to come to terms with this?

• Nakala worried about HIV transmission to her other children through close contact. What do health workers need to do to overcome this fear?

1998
Ilinanga Goes To School

Ilinanga became healthier after she completed treatment for tuberculosis, which was the cause of her chronic cough. She started to grow well again. In November last year, Ilinanga had her sixth birthday. She is a happy, healthy child doing her first year at the local school. The nurse wrote to Ilinanga's teachers explaining that Ilinanga has a chronic medical problem and may sometimes miss school. Ilinanga's sisters now know why Ilinanga was always sick. They asked many questions until Samson and Nakala told them the truth. They are at the same school as Ilinanga and go to the school anti-AIDS club, except the second oldest girl. She will not join the club and avoids any mention of HIV.

So far Ilinanga has not asked any questions about her illness. Everyone in the family is waiting and so is her nurse. No one is sure what they will say to her when the time comes. Nakala reads whatever she can get hold of about HIV and knows about antiretroviral therapy. She also listens for news of traditional remedies. She and Ilinanga's nurse often discuss the different western and traditional therapies. But Nakala, Samson and the nurse all agree that the cost of antiretroviral therapy is too much. They realise as Samson begins to complain that he is tired all the time, that soon they must start thinking more about the future of the family. In the meantime they thank God for each year that passes.

DISCUSSION POINTS

• Who needs to know that a child has HIV infection? Should the teachers be told the real reason why Ilinanga might be sick more often than other children?

• One of Ilinanga's sisters does not want to talk about HIV. Why might this be?

• Ilinanga's three sisters all remain uninfected even though they are living with three other family members who are infected with HIV. Think of all the things they do together but still remain free of the virus.

• When Ilinanga starts to ask about her illness what does she need to know and how should she be told?

• Where do people in the community get information about HIV/AIDS? How can health workers, carers and families find out about the latest information?

With thanks to Dr Connie Osborne, Consultant Paediatrican, University Teaching Hospital, Private Bag RW1X, Lusaka, Zambia, for providing this case study.

Editors' note: The resources on page 16 give you more information to help answer the questions that this story raises.

Tuberculosis and Children: the Missing Diagnosis
Provides detailed information on diagnosis and management
Special supplement to Child Health Dialogue Apr-Jun 1996. *Free from Healthlink Worldwide New Address: Healthlink Worldwide, Cityside, 40 Adler St., London E1 1EE, UK. Tel: +44(0)20 7539 1570, Fax: +44(0)20 7539 1580 Email: info@healthlink.org.uk Web: http://www.healthlink.org.uk*

Caring with Confidence: Practical Information for Health Workers Who Prevent and Treat HIV Infection in Children
Covers all aspects of care including supportive home care measures and talking to children
Single copies free to indigenous organisations in developing countries, US$20/£10 elsewhere. Please write to Healthlink Worldwide

Child Health: a Manual for Health Workers in Health Centres and Rural Hospitals
Covering all aspects of child health
£8+postage. Available from TALC, PO Box 49, St. Albans, Herts AL1 5TX, UK

HIV and Infant Feeding
A set of three manuals comprising: guidelines for decision-makers, a guide for health care managers and supervisors and a review of HIV transmission through breastfeeding
US$8.30 developing countries, US$14.40 elsewhere. Contact your local WHO office or WHO, CH-1211 Geneva 27, Switzerland (WHO/FRH/NUT/CHD 98.1/2/3)

Disclosure Policy
Prepared by The (Toronto) Hospital for Sick Children HIV/AIDS Comprehensive Care Clinic, this policy is a useful reference in disclosing one's HIV/AIDS status particularly to children. **IN** Support for Children and Families Living HIV/AIDS: An Orientation Manual by JR McDonald. Canada: Canadian Hemophilia Society.
Photocopies may be requested from HAIN. Free to developing countries

Recommendations on the Safe and Effective Use of Short-course ZDV for Prevention of Mother-to-Child Transmission of HIV
WHO Weekly Epidemiological Record 41, 9 Oct 1998.
Photocopies may be requested from HAIN. Free to developing countries.

FAQ Sheet: Oct 1998. Frequently Asked Questions on Breastfeeding and AIDS.
Limited free copies from Academy for Educational Development, 1255 23rd St. NW, Washington DC, USA.
Email: linkages@aed.org

Children Living in a World with AIDS: Guidelines for Children's Participation in HIV/AIDS Programmes by J Collings. Geneva: Children and AIDS International NGO Network Publication, 1998
This pamphlet provides a guide to facilitating the involvement of children in activities related to HIV/AIDS education, prevention and care.
Available from UNAIDS: unaids@unaids.org or at www.pedhivaids.org/education/children_living.html

The Impact of HIV/AIDS on Children, Families and Communities: Risks and Realities of Childhood During the HIV Epidemic by M Lyons. NY: UNDP, 1998.
Discusses the impact of HIV/AIDS on childhood, especially for children living in environments where infection rates are high or disregard for children's rights is common.
Full text available at www.undp.org/hiv/issue30E.html

HIV/AIDS and Child Care: Fact Book
Covers frequently asked questions by child care centres on integration of children with HIV. It is important that educators and parents understand that a child infected with HIV does not pose a risk for others when basic hygiene is followed.
The package (Fact Book, Facilitator's Guide, Resource Sheet and Poster) is being distributed to licensed child care centres, institutions which offer training in early childhood education, and public health departments. For more information contact Canadian Child Care Federation, 120 Holland Ave., Suite 306, Ottawa, Ontario K1Y 0x6, Canada.

If you have a specific information request, please contact:
HIV/AIDS Enquiry Services
AIDS Action Asia-Pacific
No.9 Cabanatuan Road
Philam Homes 1104
Quezon City, Philippines
Telephone: (632) 927-6760
Fax: (632) 929-8805
Email: hain@mail.info.com.ph
Website: http://www.hain.org

The international newsletter on HIV/AIDS prevention and care
AIDS action

AIDS Action is published quarterly in seven regional editions in English, French, Portuguese and Spanish. It has a worldwide circulation of 179,000.

The original edition of *AIDS Action* is produced and distributed by Healthlink in London.

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The Asia-Pacific edition of AIDS Action is supported by The Ford Foundation, CAFOD, and Christian Aid

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