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Caring for children

Roberto Villanueva

Children worldwide are affected by HIV - whether or not they, *or members of their families, are infected with the virus.*

The World Health Organisation (WHO) estimates that over one million children are infected with HIV worldwide. Infants can be infected with HIV during pregnancy, birth or breastfeeding. More rarely, children can be infected by contaminated blood products or non-sterile equipment, or through sexual abuse involving vaginal or anal penetrative sex.

More than half the children with HIV infection in developing countries die before they are 12 months old. However they can live beyond their first year with good preventive health care and a supportive environment. This issue provides guidelines on clinical diagnosis of children with HIV infection (see page 4) and on infant feeding and HIV (see page 2).

The lives of many more children who do not have HIV themselves are affected when family members have AIDS. Families face increased poverty and stress because adults have to leave their paid employment or are too sick to farm their land. Women may be ill themselves, as well as caring for other sick family members and looking after young children. Girls in particular often become carers for sick relatives and younger brothers and sisters. Sometimes children have to leave school and look for work.

WHO estimates that more than five million children will have lost their mother or both parents to AIDS by the year 2000. Grandparents, aunts or uncles care for the orphaned children and may be unable to meet costs of extra food and school fees. After their parents' deaths, children can lose their rights to the family land or house. Without education, work skills or family support, children may end up living on the streets. These children are especially vulnerable, often becoming sexually active at an early age and at risk of HIV.

Challenges

AIDS programmes need to address the needs of children, as well as adults, by:

- continuing to stress prevention by promoting safer sex, ensuring blood safety, and avoiding unnecessary blood transfusions
- providing accessible health care for women and children
- supporting children and other family members who are caring for sick relatives
- ensuring that older children receive sex education, and the means to prevent infection
- caring for increasing numbers of children without parents, and elderly people who can no longer depend on their grown-up children

Future issues of AIDS Action will look at innovative ways to tackle these challenges. Please write and share your experiences with other readers.

IN THIS ISSUE

HIV and infant feeding guidelines
Page 2

Imagine being HIV-positive: an exercise
Page 7

NGO staff education in Bangladesh
Page 8

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Risks versus benefits

HIV and safe infant feeding - AIDS Action discusses the key issues for women and their health workers.

HIV can be passed from a mother to an infant during pregnancy, childbirth or breastfeeding. However, worldwide the majority (two thirds) of infants born to mothers with HIV do not become infected with the virus.

It is also important to remember that most babies breastfed by mothers who are infected with HIV do not become infected through breastmilk. However, the virus has been found in the breastmilk of women with HIV.

Breastfeeding when the mother has HIV infection, or drinking infected breastmilk (donated and unscreened/ untreated) does increase the risk to babies, but it is not known by how much. It is not easy to find out if a baby has HIV infection until he or she is between 12 and 18 months old (see page 4). It is therefore difficult to show that a baby has been infected during breastfeeding, rather than in the womb or during birth.

Some factors are known to increase the risk of transmission during breastfeeding. If the woman has only been recently infected, or if she has AIDS-related illnesses, she may have more virus in her body fluids, including breastmilk. The risk to the baby is greater if the mother is:

- infected with HIV through blood transfusions during or shortly after childbirth; or
- infected during unsafe sex with an infected partner when pregnant or breastfeeding; or
- afflicted with AIDS-related illnesses during pregnancy or breastfeeding.

Breastfeeding benefits

- Breastmilk is the most nutritious food for babies, and is very easily digested. For the first 4-6 months, an infant needs breastmilk, and no other food or liquids.
- Breastfeeding helps to prevent common infections, and reduces the risk of death, because:
  - breastmilk contains substances that protect infants against infection; and
  - it is hygienic and avoids babies being exposed to unsafe water and food.
- Breastmilk is thought to contain a substance that helps to protect babies against HIV.
- Exclusive breastfeeding is an important method of child spacing, because it helps to delay return of fertility.

Weighing up pros and cons

Health experts are worried that women may be wrongly advised, or decide themselves, not to breastfeed because of fear of HIV. Breastfeeding is one of the most important ways that a mother can help her infant stay healthy. Infants who are not breastfed are up to 14 times more likely to die of common childhood illnesses than exclusively breastfed infants, especially in low income communities.

Health workers should continue to strongly promote breastfeeding. This is especially important in places where infectious diseases and malnutrition are the main cause of infant deaths, and where poor hygiene and lack of money mean that it is difficult to find safe alternatives to breastmilk.

For many HIV-positive women, the risk of their babies dying if not breastfed will be much greater than the risk of passing on HIV. Where the risks of artificial feeding can be minimised, individual HIV-positive women should have access to counselling to help them decide whether or not to breastfeed, and be supported in safe use of alternative methods.

Advice to all women (whether or not they know their HIV status)

Health workers should discuss breastfeeding and its benefits with all pregnant women. It is also important to talk about HIV and STDs and how to prevent them. Women (and their partners) need to know that having

Breastfeeding is still best for women with HIV, if safe alternatives are not available.

Jonie Arroyo

safer sex, or abstaining from intercourse, are important during pregnancy and breastfeeding. If the woman wishes, talk with her sexual partner as well. Make sure that the couple has access to condoms, and knows how to use them.

If a woman's HIV status is unknown

Most women do not know their HIV status, and in many places are probably not infected with HIV. They should be encouraged and supported to breastfeed.

A woman may be more likely to be HIV-positive if she has illnesses or symptoms often associated with AIDS, or if her sexual partner is HIV-positive or has an AIDS-related illness. In most communities HIV counselling and testing services are not available. However, if such a service is available, a woman may want counselling about the HIV test.

Good counselling is essential, because it helps a woman to consider if she has been at risk of infection, prepare for finding out her HIV status, and to decide whether to have a test, without pressure. Knowing her status may help her make the decision about whether or not to breastfeed, as well as affecting other choices about her life.

The risk of infection before or during pregnancy, or during breastfeeding should *never* be used as a reason to persuade a woman to have an HIV test, or to carry out a test without her consent. Testing without counselling and informed consent is not ethical.

If a woman is HIV-positive

Health workers should discuss the implications of being HIV-positive, and help a woman to make an informed

choice. Find out what the woman already knows about HIV infection and breastfeeding, clarify any misunderstandings, and explain the possible risks and benefits. Reassure her that, whatever choice she makes, she is not to blame if her baby becomes ill.

It is important to help the woman decide if the chance of passing HIV to her baby via breastfeeding is greater than the risks associated with artificial feeding. She needs to be able to assess whether her circumstances allow her to use other feeding methods safely.

However, alternatives may not be easily available or a woman may decide that the benefits of breastfeeding outweigh the possible risk of transmission of HIV. Some women are deciding to breastfeed at first, but to stop if they become ill.

Issues to consider include:

- What does the woman feel about the risk - would she worry and feel guilty about possible infection, or would she prefer to give her child (and herself) all other benefits of breastfeeding?
- Is she afraid of being asked difficult questions about why she is not breastfeeding, and of losing confidentiality about her HIV status?
- Does she have a good support network to help her prepare and give alternative feeds?
- Can she easily obtain affordable animal or formula milk?
- Does she have access to clean water? Can she afford fuel or electricity for sterilising feeding utensils?

Decisions about infant feeding affect the whole family, and joint counselling with other family members may be helpful if the woman agrees. Whether breastfeeding or not, women need support and advice to help them care for themselves and their babies in the best possible way.

Nicoll A and colleagues, Feb 1995. Infant feeding policy and practice in the presence of HIV-I infection. AIDS, vol 9, no 2, pp107-121.

WHO, 1994. HIV and infant feeding: essential issues for decision makers (draft policy guidelines).

Dialogue on Diarrhoea no. 44 covers how to express breastmilk (see back page for details).

Healthy choices

Women with HIV have a right to make their own decisions about pregnancy, childbirth and breastfeeding. They need access to counselling about the risks and benefits of different options, and implications in the long term.

In Tanzania, almost all women breastfeed their babies. This means that most mothers continue to breastfeed even if they have AIDS-related illnesses, and the risk of HIV transmission is high. Because of this risk, and because she may be less able to breastfeed, it is important for the mother to decide herself about other feeding methods, and when it would be best for her to stop breastfeeding.

Some women decide to wean their infants and introduce them to weaning foods before becoming ill.

In 1989 Wakati decided to stop breastfeeding early because her baby was not feeding well, and she was worried about HIV infection. Her husband had just died and she was very ill. She learnt about preparing supplementary foods for the baby and taught her mother how to do it. The baby was fed with a nutritious mixture of powdered maize, finger-millet and beans, with water, milk and fruit or vegetable juices.

Wamata

Positive input: Wakati is an active member of the Tanzania support group.

To Wakati's surprise, her own and the baby's health improved almost immediately. Today, nearly six years on, both mother and child are doing well and Wakati has become a committed peer educator and counsellor.

Theresa Kaijage, WAMATA, PO Box 33279, Dar es Salaam, Tanzania.

Alternatives to breastfeeding

Alternative infant feeding methods require access to a plentiful and clean supply of water to reduce risk of diseases such as diarrhoea. If a baby is not being breastfed, a clean cup or spoon should be used since bottles and teats are difficult to clean.

Infant formula is the most common alternative. However, it is expensive, and hygienic preparation and feeding can be difficult in many households. To feed an infant for the first six months, 44 tins of 500g are needed.

Animal milk, such as cow or buffalo milk, can also be given. It should be diluted and sweetened (one cup of water, three cups of milk, four level teaspoonfuls of sugar), and brought to a boil to reduce the amount of curd and kill harmful germs.

Breastmilk can be expressed by the mother and made safe for the infant by heating it to boiling point, or by pasteurising it - heating to 62.5 C for 30 minutes. In some places, self-help groups for HIV-positive women, or support from health workers, have succeeded in enabling mothers to express and treat their milk. Continuing to express enough breastmilk over a long period may be difficult. Supplementing expressed breastmilk with formula milk and introducing solid foods earlier than usual should be considered.

In some places it may be acceptable for another woman to breastfeed the baby. This option is not advised where this woman might be, or become, HIV-positive herself.

Diagnosing HIV

For a child diagnosed with HIV or AIDS, good care and support help to improve length and quality of life.

A small number of infants with HIV survive frequent infections as an infant, then become healthier, living for over six years. However, globally about four in every ten infants with HIV do not live more than 12 months, and over half die by the age of two, most commonly from dehydration, pneumonia, tuberculosis and malnutrition. Good care and support can increase length and quality of life.

Even if the mother has HIV, her child's illnesses may not be due to the virus. Malnutrition, malaria and anaemia can be similar to HIV symptoms especially if the baby is not breastfed. Congenital syphillis can also resemble HIV infection, with swollen glands and skin rashes.

Diagnosis dilemmas

Health workers need to weigh up the value and disadvantages of diagnosing HIV in a baby or child. HIV can be diagnosed by laboratory testing and/or on the basis of clinical signs (see 'Recognition of symptoms' box).

Diagnosis on the basis of clinical signs is less accurate than HIV testing. However, clinical diagnosis is often used because laboratory testing is expensive and often unavailable. Also, for children under 18 months a positive HIV-antibody test is not reliable. All babies whose mothers have HIV are born with their mother's antibodies, which remain until 12-18 months. If a child is infected with HIV, his or her own antibodies cannot be detected until after this time.

The main advantage of diagnosing HIV in a child is that opportunistic infections such as pneumonia can be identified and treated quickly, and health workers can detect at an early stage childhood infections which are potentially serious, such as persistent diarrhoea.

However, treatment of childhood illnesses is almost always the same whether or not a child has HIV. If a health worker suspects that illnesses are related to HIV, the child should receive close monitoring, good nutrition and appropriate immunisation. It is important to explain to the family that the child will not necessarily die early and that with good care and early treatment of illnesses he or she can survive for a long time.

Felicity Savage

Pneumonia is a common HIV-related infection and needs prompt treatment.

HIV infection in a child often means that the mother, and her sexual partner, may have HIV, but be unaware of the fact. Health workers need to consider the implications of the child's diagnosis for the parents. Whatever the diagnosis method used, the mother (and, with her permission, other family members) need counselling, care and support. The mother may prefer not to know either her own HIV status or that of her child (see letter on page 12).

Older children who may have HIV need special consideration. They may be coping with illness in the family or the distress of sexual abuse as well as the issue of their HIV status.

Common symptoms

Birth to six months

A few babies with HIV are small at birth and do not thrive. At around three or four months, most develop symptoms such as: severe bacterial infections (pneumonia, severe skin infections or rashes, and meningitis); swollen lymph glands; enlarged liver and spleen; failure to thrive; and fungal infections, especially persistent oral thrush.

Six to fifteen months

In children with HIV, growth faltering, often with illnesses like malaria, diarrhoea or ear infections, is common. Growth faltering can be detected by recording changes in weight and length on the child's growth chart. Recent studies suggest that stunting (reduced rate of growth) occurs earlier than wasting (weight loss) in HIV-infected babies. Persistent diarrhoea, when a child has liquid stools (three or more daily) for 14 days or more, and respiratory infections may be frequent. Treatment with standard antibiotics is often unsuccessful.

Tuberculosis is more difficult to diagnose in children than in adults and can produce different symptoms, such as fever without a cough, or swollen glands in the neck and shoulders. A child with a cough for more than one month, recurrent bouts of fever, poor weight gain or loss of weight, should be suspected to have TB and treated appropriately.

Recognition of symptomatic HIV infection in children

WHO has developed guidelines for recognising HIV infection in children. These may be used where a health worker suspects HIV infection and where testing is not available or affordable, or where the child is too young for the test to be accurate. These guidelines may be helpful for clinical management of the child and to alert the health worker to possible needs of the mother for counselling and care.

A diagnosis of symptomatic HIV infection is made if the following are present:

- any **cardinal** finding
- two or more **characteristic** findings
- one characteristic finding plus two or more **associated** findings
- three or more associated findings plus any **epidemiological risk factors**
- two associated findings plus **laboratory evidence** of HIV infection in the child.

Cardinal findings

- pneumocystis carinii pneumonia (PCP)
- lymphoid interstitial pneumonitis (an unusual form of viral pneumonia)
- fungal infection in throat and mouth (candidiasis or thrush)
- Kaposi sarcoma (skin cancer, rare in children)

Characteristic findings

- recurrent bacterial and/or viral infections (such as respiratory and skin infections and meningitis)
- tuberculosis, of the lung or of other organs
- shingles (herpes zoster)
- cytomegalovirus infection
- neurological problems, such as slowness in developing skills in sitting, crawling and talking, fits, microcephaly (reduced head growth)

Associated findings

- oral thrush when the child is not being treated with antibiotics
- failure to thrive (lack of weight gain)
- fever (continuous or intermittent for more than 1 month)
- diarrhoea (persistent or intermittent for more than 14 days)
- generalized lymphadenopathy (swollen lymph glands)
- skin rashes

Epidemiological risk factors

- mother has tested positive for HIV
- history of transfusion of unscreened blood or blood products
- sexual abuse involving penetrative sexual intercourse
- use of contaminated syringes and needles or a history of scarification, ear piercing or circumcision using non-sterile instruments

Over fifteen months

Common symptoms in HIV-infected children include: any conditions listed above; a general itchy rash; swollen glands around the jaw or in other parts of the body; and chronic cough. Some children are slow to develop skills such as walking and talking.

Key points for care

Most HIV-related illness is caused by common infections which can be prevented, or treated at home or a health centre. However, they often last longer than in HIV-negative children, and are more difficult to cure with standard treatments.

- Maintain good nutrition. This includes giving advice on both breastfeeding (see page 2) and other feeding, including feeding a child with poor appetite.
- Treat common childhood infections as early as possible.
- Immunise as usual, except for babies with advanced clinical HIV symptoms, who should not be given tuberculosis vaccine (BCG).
- Emphasise early diagnosis and treatment of suspected TB for all family members (including babies unless HIV illness is suspected).
- Give oral rehydration therapy (ORT) to prevent dehydration during diarrhoea. Antibiotics for other infections can worsen diarrhoea.
- Monitor growth regularly.
- Treat the child as normal, ensuring for example that he or she plays with other children.
- Give comfort when in pain and distress, and relieve pain, with aspirin for example.

Drs. Dennis Tindyebwa and Lawrence Marum, Makerere University Medical school, PO Box 7072, Kampala, Uganda.

Guidelines for the clinical management of HIV infection in children are available in English (French in preparation) for SwF13 (SwF9.10 in developing countries) from WHO/DST, CH- 1211 Geneva 27, Switzerland (order no 1930046).

STD infection in infants

As well as HIV, some other sexually transmitted infections can be passed to the infant during pregnancy or delivery. In infants with HIV, these infections may be more difficult to treat. If these infections are suspected in babies, both parents will need health education about STDs and treatment.

Chlamydia and gonorrhoea cause serious eye infections with pus (known as conjunctivitis or ophthalmia neonaturum) developing within a month after birth. Infections caused by gonorrhoea can lead to permanent damage or blindness if untreated.

Syphilis causes serious conditions in babies and children, such as skin rashes and sores, swollen glands, and long term damage to the nervous and skeletal systems (affecting joints, hearing and sight, for example).

HIV and AIDS: fact not myth

A few scientists have claimed that HIV does not cause AIDS, or that AIDS does not exist, in spite of convincing evidence showing that HIV is responsible for the life-threatening illnesses known as 'AIDS'.

How do we know that HIV exists?

About 15 years ago, researchers recognised that a growing number of adults had severely damaged immune systems and were vulnerable to rare infections and cancers as well as common illnesses. In 1983, a new virus was isolated – now called the Human Immunodeficiency Virus.

Researchers believed that this new virus was responsible for destroying the immune system. However, it was difficult to prove this, especially since some people do not become sick until many years after they are infected. Recent evidence shows that the virus does not remain dormant in the body, but constantly reproduces itself, infecting billions of cells. The immune system fights back – for ten years or longer in some people. However, it is not yet clear how HIV eventually weakens the immune system.

How do we know AIDS exists?

AIDS (Acquired Immune Deficiency Syndrome) is the name given to the collection of illnesses which occur when the body's defence system is weakened. Many of these illnesses – TB, skin rashes and diarrhoea – have always been common, especially among children and malnourished adults in low income communities. Some, such as unusual skin cancers and some pneumonias, were rarely seen in humans before the late 1970s.

During the last ten years, patterns of disease have changed, so that:

- more people, including babies and children, have multiple chronic illnesses, and successful treatment is often difficult
- more middle-aged and young adults are dying from TB and other illnesses, which before affected mainly the elderly or malnourished
- rare illnesses linked with immune deficiency are becoming more common.

How are these illnesses and deaths linked with HIV infection?

Before the 1980s, illness and deaths among people in their 20s, 30s and 40s were uncommon. Studies are now showing that higher mortality rates occur where many people have HIV antibodies in their blood. (The most widely used test for HIV does not react to the virus itself, but to specific antibodies developed by the immune system in response to HIV.)

A study in Uganda found that people between the ages of 13 and 44 years who tested HIV-antibody-positive were up to 60 times more likely to die during the next two years than young people and adults who tested HIV-negative. Being HIV-positive was the only factor that could be related to the greatly increased mortality rate.

Are HIV/AIDS statistics correct?

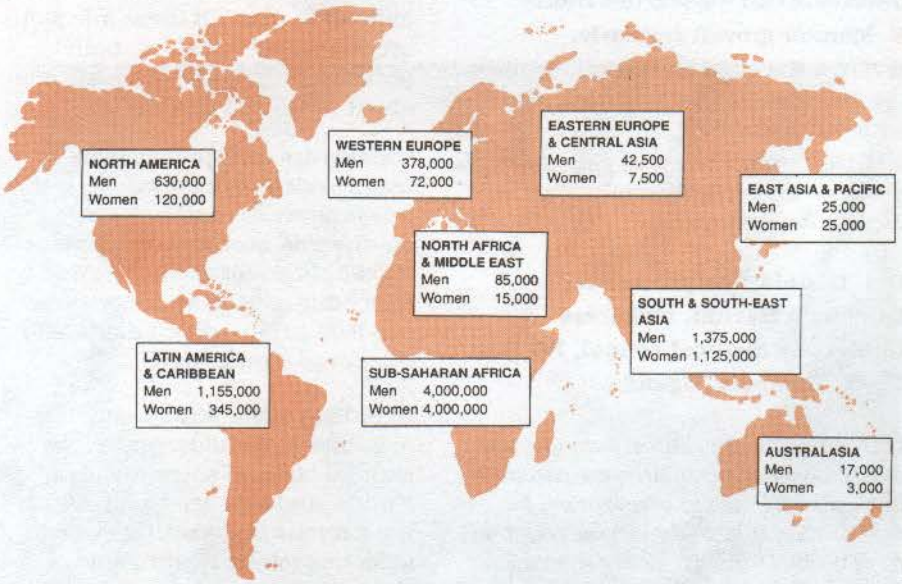
Research into the epidemiology of HIV and AIDS has been difficult. Early HIV tests were less accurate, sometimes giving a positive result if the person had malaria, and infection levels sometimes may have appeared higher than they really were.

Although tests themselves now produce accurate results, many of the statistics are incomplete. Numbers of people with HIV are measured through anonymous surveillance of blood donations, and at STD and antenatal clinics. This can give a biased picture.

In many countries, people with AIDS are unable to visit a health centre or hospital, or seek other types of care. Stigma and fear of discrimination discourage treatment seeking. Clinical case definitions are used to record numbers of people with AIDS, which are not always accurate if HIV testing is unavailable.

WHO's figures are based on the most reliable reports. However, for the reasons above, the numbers are widely considered to be underestimates (see diagram).

Estimated number of HIV-infected adults alive in late 1994



WHO estimates that 13–15 million people are living with HIV or AIDS.

Mulder D and colleagues, 23 April 1994. Two year HIV-I associated mortality in a Uganda rural population, British Medical Journal, vol 343, pp1021-3.

Nicoll A and Brown P, 15 January 1994. HIV: beyond reasonable doubt, New Scientist, vol 141, no 1908, pp24-28.

Understanding HIV

This training exercise can help health workers to understand the risk of HIV, and how it might feel to be infected themselves.


Jonie Arroyo

Number of participants: Minimum 10 and maximum 25.

Time: about 1 hour and 30 minutes.

Needs: Enough floor space for all the participants to stand in a circle.

One card for each participant, half with POSITIVE written on them, and half with NEGATIVE.

The facilitator needs to know the facts about HIV, and be experienced in dealing with sensitive issues. It may be helpful to practise the exercise with a few colleagues before doing it with trainees.

Some people in the group may know that they, or a relative or friend, are HIV-positive. Emphasise that people do not have to talk about their own HIV status or other personal details.

Try to bring up the points in *italic* during discussion. Encourage people to say what they feel rather than simply giving them information, but be careful to answer questions and clarify any confusion.

1 Ask the participants to stand in a circle. Then shake one person's hand, explaining that during this game a handshake means having unprotected sexual intercourse. Scratching the other person lightly on the palm while shaking their hand means that their body has been exposed to HIV. Demonstrate this to the person you are shaking hands with and ask them to pass it round the circle. *Remind participants that, as with all viruses, being exposed to HIV does not always mean that a person becomes infected. However, there is a strong chance that exposure leads to infection.*

2 Ask everyone to close their eyes and explain that you are going to walk around the circle several times, and touch one person on the shoulder. Say that for the rest of the exercise this person 'has HIV infection'. The person who is touched should not tell anyone in the group.

3 After you have touched one person ask everyone to open their eyes and ask them if they know who has HIV. *Remind them that it is not possible to tell who has HIV by looking at them. What did they feel while you walked around them?*

4 The game begins. Explain that participants can walk around and talk to each other, and, if they choose to, shake hands. Each person can shake hands with up to a maximum of three people for a group of 10-15 or four people for a group of 16-25. The person who 'has HIV' has to scratch the palm of everyone they shake hands with. These people should then scratch the palm of every hand they shake.

5 When the handshaking stops ask people to form a circle again. Ask all of those who had their palm scratched and the person whose shoulder was touched to step into the centre of the circle. Anyone who has not had their palm scratched can sit down in an outer circle. *Ask if there was anyone who chose not to shake hands.*

6 Ask people in the inner circle to sit down and remind them that in the game their body has been exposed to HIV but they do not yet know if they are infected. *Ask what it feels like to know that they might be infected. Would they tell anyone? Who? What support would they want? Would they continue to have unprotected sexual intercourse? What do the people in the outer circle think of those in the inner circle? Would they continue to have unprotected sex?*

7 Remind people of the difference between HIV infection and AIDS, about how HIV testing works, and about the need for pre- and post-test counselling. Ask what people feel about having an HIV-antibody test. *Why might they decide to have counselling and be tested or not?*

8 Ask people in the inner circle to imagine that they have chosen to have the test. Make sure they know the facts about local counselling and testing services, such as how many days or weeks people wait for their results. Hand out one card with either POSITIVE or NEGATIVE on it to each person, but ask them not to look at it yet. *How do they feel while waiting for their results?*

9 Ask each person to read their card. Those who have NEGATIVE ones can join the outer circle. *What do the people who have had a negative result feel? Discuss whether it would be possible to reduce their risk, and how they might do this. What support would they need?*

10 Ask the people in the inner circle with POSITIVE cards what they are feeling. *Would they tell anyone? Who? Would they change their behaviour? How easy or difficult would this be? What could they do and what support might they need?*

11 After this discussion, finish by reminding everyone that this was only a training exercise. People often experience strong emotional reactions to this exercise. Ask everyone to say what they felt about the game in a few words. Tell participants where they can get more confidential information or counselling if they wish.

Note: Developed by the Family Planning Association in Australia, this exercise (often called 'Wildfire') is being used very widely with health workers and educators.

Providing basic facts in the workplace

CARE Bangladesh views staff education as the first step towards HIV/AIDS programming

In Bangladesh, the growing threat of HIV/AIDS is just beginning to be addressed, and there is still denial that the disease poses a genuine threat to the country. However, neighboring countries provide examples of how quickly this disease can spread. It is clear that HIV will soon become a serious problem in Bangladesh.

CARE is a large non-sectarian international non-government organization (NGO), with a focus on relief and development programmes worldwide. CARE Bangladesh currently employs over 1,600 employees throughout the country.

Given the growing HIV/AIDS epidemic in Asia, CARE began confronting this issue by developing an internal programme for staff education on HIV/AIDS. The overall purpose of the staff education is to provide all CARE Bangladesh employees with the basic facts about the disease, to dispel common misinformation about HIV/AIDS, and help staff understand the steps they can take to protect themselves and their loved ones from this disease.

CARE differentiates between staff education (i.e., providing employees with basic facts on HIV/AIDS) and staff training (i.e., building specific staff skills to enable them to implement programmes), and views a comprehensive staff education programme as the first step towards actual HIV/AIDS programming. This is the point when staff training would logically take place. The staff education programme is designed to reinforce correct information, and is comprised of participatory workshops, new staff orientation, a system of replying to queries raised by staff, and regular information updates.

With technical assistance from our Asia Regional Technical Advisor/Health (RTA/Health), CARE Bangladesh went through the following process to ensure that the materials fit the Bangladesh context.

- First, we reviewed a wide range of materials, both locally available as well as from other countries, and drafted a first set of staff education materials;
- we involved a wide range of Bangladesh staff in carefully reviewing and adapting each session, transparency, and handout. We went through a number of iterations, and many changes in the initial package of materials resulted from these reviews;
- Bangladesh-specific language, messages, and images were developed and used (e.g., a picture of a water buffalo was used to illustrate the 'iceberg' effect of the epidemic, references to male circumcision, professional blood donors, etc.);
- we pre-tested the materials in several staff education sessions and made technical and editorial revisions. We continue to develop and finetune the materials based on input from different staff education sessions;
- we focused messages and kept the wording precise and simple, to provide very basic facts about HIV/AIDS. We avoided much discussion on testing and counselling because these facilities are very poorly developed in Bangladesh at present;
- since little is known about sexual norms and practices, we also provided general messages on sexual behaviour and prevention; and
- the sessions were designed to promote active participation of the audience. The correct use of a condom was demonstrated through competency-based training sessions, in which each participant is given the chance to examine different brands of condoms, and to experiment with correct use by putting them on suitable vegetables (e.g., eggplant, cucumber).

Observations from the Staff Education Sessions:

This was the first time that CARE Bangladesh staff had attended such a workshop, and also the first time that our trainors were expected to raise such sensitive issues with their colleagues. There were several interesting observations made both from the participants' and facilitators' points of view:

Observation about the Participants:

Within each group (male and female) there was a mix of participants from different backgrounds and levels of seniority within the organisation. Some participants who were senior (i.e., had a higher position within the

CARE Bangladesh

Participatory methods and facilitation skills used during the sessions create an open and enjoyable learning enviroment for the participants.

CARE hierarchy) to the facilitator, had a tendency to take-over the sessions. It was noted that the facilitator would usually defer to this individual, even if this person provided inaccurate information.

- Quite a few participants erroneously believed that the facilitator needed to have a medical background in order to correctly lead sessions on the basic facts about HIV/AIDS. Similarly, medical officers participating in the workshops sometimes spontaneously presented themselves as a reliable reference for information on HIV/AIDS, although they themselves had inadequate information and misconceptions about this disease.

> *'The sessions were designed to promote active participation of the audience.'*

- Sometimes participants would refer to articles they have read which contradicted the information being presented (e.g., that HIV is in saliva therefore kissing may be high-risk behaviour). This created a situation in which other participants became confused because of the conflicting messages they heard.
- Participants often did not think about what was being presented in the workshop in terms of their lives. Instead, they would process the information at an abstract level, not translating it into how they might differently handle potentially risky situations.
- In some cases, unmarried female participants would have benefitted from a basic sex education course, since they were obviously uninformed about sexual issues.
- Some of the women raised the issue that methods to prevent the sexual transmission of HIV/AIDS are male-controlled, and that they can do very little to address this.
- Some participants were quite shy, and resisted participating in the discussions and group exercises.

Observations about the Facilitators:

- Sometimes facilitators became noticeably shy and uncomfortable when discussing certain terms (e.g., anal sex) and would sometimes wrongly substitute words, which made the information being presented confusing and sometimes inaccurate.
- They needed more experience with using the Facilitator's Guide before conducting the actual workshop. Their lack of experience with conducting these sessions also resulted in some being less participatory than expected. The facilitators also needed to be totally familiar with the questions usually raised by participants, and prepared to address them accordingly.
- Facilitators needed to be reassured that they are not expected to be 'instant experts' on the subject of HIV/AIDS; and must only take note of any difficult questions that may come up, so that they can be discussed even after the workshop.
- It was clear that they felt uncomfortable when questioned by participants with medical backgrounds. They had a tendency to defer to those participants more senior to them, and hand over control of the session to these individuals.
- Facilitators benefited from the additional special support made available to help them with some sessions and to answer difficult questions raised by the staff. This support could come from a workshop participant who is well-informed about the basic facts about HIV/AIDS, and can serve as a resource for the facilitator.

We believe that these issues will naturally resolve themselves as the facilitators become more familiar and confident with the subject matter, and with conducting the staff education workshops.

CARE Bangladesh

Participants test the resistance of condoms

Conclusion

The CARE Bangladesh experience with staff education on HIV/AIDS provides an important example for other organisations interested in HIV/AIDS programming. It is crucial that all staff in an organisation be educated as a first step towards designing high-quality HIV/AIDS programmes.

Any staff education initiative must first have support from their senior management, and should fit the needs of the institution and the audience. Messages and materials should be carefully reviewed, pre-tested, and tailored to fit the particular cultural context. Translation of materials should be carefully monitored to ensure a high-quality and acceptable end product. Male and female facilitators should be carefully selected and should feel comfortable discussing sexual issues in front of their colleagues. The number of workshop participants should be manageable (no more than 30 people) and should be segmented by level of education, type of work, and gender, to encourage full participation by everyone.

Staff education should not be viewed as a 'one-time' event. Organisations should consider setting up a comprehensive staff education system for continually providing updated information, answering questions, reaching new staff, etc. Finally, the content and focus of the staff education information should naturally evolve as the organisation's and the staff's needs change. This would also be influenced by developments in HIV/AIDS programmes and services in the country.

Sumana Brahman was formerly the Health and Population Sector Coordinator of CARE Bangladesh. She is now working for CARE Guatemala.

Listening Effectively

'You need to believe that people can be motivated to reduce the risks for HIV, without using fear tactics, without coercion.'

Several AIDS information hotlines have been set up in Asia in response to the HIV epidemic. The hotlines require trained counsellors to provide accurate information about HIV as well as other HIV-related issues.

Two Asian NGOs, both the first to set up AIDS hotlines in their countries, have accumulated vast experience in providing counselling services and the training of volunteers to handle the hotlines. The two NGOs — Pink Triangle in Malaysia and the Remedios AIDS Foundation in the Philippines — share many common approaches.

Pink Triangle, which operates a hotline two hours a night in Kuala Lumpur, requires volunteers to go through 12 training sessions of three hours each, spread out over 6 weeks. Yee Kim Chong, who provides over-all coordination for the volunteers' training, has strong feelings about the approach they use: 'For something like AIDS, you cannot just do a half-day or one-day training seminar.' Yee points out that the technical discussions on AIDS are initiated only during the fifth session.

Yee explains: 'You have to train people to listen effectively and this starts with the prospective volunteers learning to be aware of themselves in relation to others.' Thus, the volunteers' training has topics like 'Self-Awareness' and 'Communicating Sexuality'.

Cesar Natividad

Remedios Hotline volunteers go through a long trainng course.

The Remedios AIDS Foundation also requires volunteers to go through a long training course of 120 hours, with emphasis on interpersonal relationships, sexuality, and gender issues. This Filipino foundation has reason to be sensitive about these issues — their service was actually inherited from another NGO that had to give up because their officials felt uneasy about having to discuss sexual activities.

During their training, the Remedios volunteers process their own sexuality, and the biases they may carry about so-called 'high-risk groups'. Dr. Rene Francia, one of Remedios' educators, observes that the biases are usually directed against sex workers and gay men. Francia observes: 'With such biases you simply cannot be effective in preventing AIDS.'

Maan Balquiedra, Remedios' Executive Director, is concerned about the growing misogyny, or anti-women views, that the AIDS epidemic has generated. 'People think that HIV and sexually-transmitted diseases are mainly transmitted from women to men when it's the other way around. Sometimes, the misconception is propagated even by AIDS educators.'

Both Pink Triangle and Remedios recognise that the hotline volunteers' role extends beyond information since the callers often need counselling. For example, there are callers who may have taken the HIV antibody test without adequate counselling and are therefore anxious about what might happen. Or sex workers and their clients may call in, wondering about their risk for HIV. The hotline volunteers are trained to respond to the question, which may lead into other more complex issues, such as sexual identity problems. Occasionally, there are even callers with problems relating to unwanted pregnancies. The volunteers understand that there are limitations to using the phone to respond to these problems. In such cases, the volunteers will suggest that the caller comes in for one-on-one counselling, or they may be referred to other organisations offering support services.

The two NGOs have also opened their training services to other NGOs, mainly women's organisations, which would like to integrate HIV counselling into existing programs such as those in family planning. This development is inevitable, reflecting the trend toward linking HIV counselling to counselling for a range of sexual concerns.

Both Pink Triangle and Remedios AIDS Foundation require volunteers who have completed the training course to go through a probationary period where they get to work on the hotline, with peer supervision and evaluation. And the learning process continues, with the Malaysian and Filipino NGOs providing refresher courses and updates for volunteers.

Both Pink Triangle and the Remedios AIDS Foundation believe that effective counselling consists of more than technical skills. Pink Triangle's Yee and Remedios' Balquiedra, when asked what area needs to be further strengthened for counselling, zeroed in on ethics. Yee and Balquiedra believe that more emphasis needs to be given to addressing ethical concerns, ranging from the need to provide quality information to preventing the development of dependency relationships between callers and counsellors.

These ethical concerns affect the way Pink Triangle and Remedios screen people applying to become volunteers. Pink Triangle, for example, has questions that evaluate how 'ego-centric' the applicant might be. Both organisations look for people who are team players. Jun, one of the Remedios volunteers, explains: 'If you're too self-centered, you can't be effective in detecting the callers' fears and doubts, which are often unexpressed.' Asked what else it takes to be an effective counsellor, Jun does not hesitate: 'Faith in people. You need to believe that people can be motivated to reduce the risks for HIV, without using fear tactics, without coercion.'

Thailand: Meeting the challenges of children affected by HIV

Rather than singling out children for care, efforts need to be directed toward strengthening the capacity of families to provide for the children.

Among Asian countries, Thailand is currently the most seriously affected by the HIV epidemic. With an estimated 600,000 to 800,000 people with HIV, the children are bound to be affected, either by being infected themselves, or having parents and family members with HIV.

The Institute for Population and Social Research at Mahidol University estimates that by the year 2000, AIDS could account for a quarter of infant deaths in Thailand. Another 86,000 children would have lost their mothers to HIV/AIDS.

As a Buddhist country, Thailand has a long tradition of charity services, including those that care for orphans, street children and other children in difficult circumstances. Western Christian groups have supplemented these efforts with additional institutions. Today, some of these very diverse institutions — Viengping Children's Home in Chiang Mai, Christian Out-reach and the Foundation for Agriculture and Rural Management — are now responding to the new challenges of caring for children affected by the HIV epidemic.

The World Health Organisation (WHO) and the United Nations' Children Fund (UNICEF), in an analysis of programmes in different parts of the world, recommends that children affected by HIV should not be singled out for care since this may only be socially divisive. Efforts need to be directed toward strengthening the capacity of families to provide for the children.

WHO/J. Ling

Village health workers in Thailand meet to share experiences and concerns

For countries like Thailand, the needs will be quite diverse. Street children, for example, no longer have family support and may have to be cared for through drop-in centres and other shelters.

Still another problem is helping HIV-positive women to make decisions about pregnancy and child-bearing. In a study among Thai women with HIV conducted by Mahidol University's Centre for Health Policy Studies, the women spoke about their fears and anxieties of death, of being stigmatized and of the fear that their unborn babies will contract their HIV. Some of the women choose to abort while others carry on the anxiety about the HIV status of their children throughout the pregnancy. After that, the anxieties continue as they raise the child.

Sources:

The WHO and UNICEF have a joint publication, *'Action for Children Affected by AIDS.'* For more information, write to: UNICEF, Programme Publications, DH-49B, 3 UN Plaza, New York, NY 10017, USA. The book includes descriptions of programmes for children affected by HIV and recommendations for policy makers.

The two Thai studies mentioned in this report are:

W. Boonchalaksi and P. Guest, *'AIDS and Children: Prospects for the Year 2000,'* Institute for Population and Social Research, Mahidol University, Thailand, IPSR Publication No. 168 (1993).

P. Pradubmuk (editors). *'Coping with AIDS.'* Center for Health Policy Studies, Mahidol University (1994). (In Thai.)

LETTER

Testing questions on HIV

A woman came to my office last month with her one-year-old daughter. The child was not gaining weight and had had recurrent respiratory infections for three months, with signs of malnutrition and swollen lymph glands. She did not respond to antibiotics and became weaker. After testing for TB, we started treatment. She began to gain weight and is now playing with other children in the hospital.

I suspected HIV infection when I first saw the child, and carefully explained the situation to her mother. I suggested that counselling about HIV and the test might be helpful. After proper counselling, her mother agreed that both she and her child should be tested.

It usually takes two to three weeks for results to return from the laboratory which is over 200 km away. This month there was a technical problem and we had to wait for five weeks for the results. Both mother and daughter had tested HIV-positive.

The situation has made me think again about the benefits of HIV testing. The mother experienced enormous anxiety while waiting for the test results, and is now facing a very difficult future. Her joy at seeing her daughter healthy and happy could be spoilt by worry and a lack of hope. It is very difficult for her to keep up the courage and enthusiasm to look after herself and her family, and work for her daughter's future.

How can knowing her HIV status help the mother? It will not necessarily help her to change her behaviour. Anti-viral treatment and prophylaxis are not available in many countries.

I believe health workers should think twice before suggesting that someone has pre-test counselling. However good the counselling, even mentioning the test means that the person may feel under pressure. Wouldn't it be better to strengthen health education on AIDS and offer anonymous testing with counselling to people who request it themselves?

Dr J Garay, Hospital Medical Officer, Matabeleland South, Zimbabwe.

Editor's note: This letter highlights important and much debated issues - readers are invited to share their thoughts and experiences.

RESOURCES

HIV prevention and care: teaching modules for nurses and midwives includes basic home care and treatment guidelines for children (2nd edition).

Available free in English (single copies) from Global Programme on AIDS, WHO, CH-1211 Geneva 27, Switzerland, French and Portuguese (first edition) available from WHO Regional Office for Africa, PO Box 6, Brazzaville, Congo.

Life First! a practical guide for people with HIV/AIDS and their families is a booklet aimed at people living with HIV and AIDS, and includes sections on how to look after children and talk with them about their parents' HIV status and preparing for the future.

Available free in English and Kiswahili from AMREF Tanzania, PO Box 2773, Dar es Salaam, Tanzania.

HIV infection in children is a set of 48 slides with text aimed at clinicians and health workers and containing information about clinical manifestations of HIV infection in children in Africa.

Available in English for £9.00 (unmounted) from TALC, PO Box 49, St Albans, Herts AL1 4AX, UK.

Dialogue on Diarrhoea and **ARI News** are AHRTAG newsletters covering diarrhoeal diseases and acute respiratory infections in children. In June 1995 they will be replaced by a single child health newsletter, with practical information on these and other issues such as malaria, measles and malnutrition.

Available free to readers in developing countries in English, Chinese, French, Portuguese, Spanish, Tamil and Vietnamese. Write to AHRTAG for details.

The international newsletter on HIV/AIDS prevention and care

AIDS action

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