

The international newsletter on HIV/AIDS prevention and care

AIDS action

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Home and hospital



BMC/HAIN

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In most countries, there are now significant numbers of people with HIV-related illnesses. The burden on health services is growing. In 1992 developing countries spent a total of US\$340 million on health care for people with HIV, up to one third of some national health budgets. One study in Zambia reported that up to half of all patient-days in medical wards of a central hospital were accounted for by people with HIV-related illnesses.

The HIV epidemic in Asia and the Pacific has not quite reached the scale it has in Africa. Thus, many countries in the Asia-Pacific Region still do not have well-planned programs dealing with the care of people with HIV and AIDS. This issue of *AIDS Action* deals more with African experiences, with the hope that we can, this early, adopt whatever is appropriate.

Health services, NGOs and mission hospitals have developed programmes to enable people with chronic illnesses to be cared for at home. Although these programmes can reduce costs and demand on in-patient facilities, saving money is not their main aim. Long-term hospital care is rarely needed for people with

HIV, although it may be necessary for some special investigations and treatments, or intensive nursing care.

Many people prefer to be cared for at home, with adequate resources and support. Most HIV-related infections such as diarrhoea, coughs and fever can be treated at home with support and advice from visiting health workers. People with incurable illnesses often choose to die at home, where they can be with their family and spiritual or religious adviser.

For many people, staying at home is the only option. Hospital care is not always available or accessible — families cannot afford transport or medical costs, or to stay with the sick person while they receive treatment.

'Home-based care' or 'community-based care' programmes aim to:

- ensure that people receive basic nursing care, as well as social and emotional support
- enable health workers to make home visits
- train volunteers, families and people with HIV in basic nursing™ care and infection control

Continued on next page

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Care across the continuum

* Possible home care team members

Home

Person with HIV or other chronic illness
Family
Friends and neighbors



Community

Trained volunteers*
Community health or TB workers*
Traditional healers
Red Cross groups
Local leaders
Teachers
Youth groups

Health centre

Nurse*
other staff



District level

District hospital, e.g. doctors, nurses, counsellors*
Welfare, e.g. social workers*
Education service
Legal



- mobilise other people to provide support
- reach sick people who are not using health services
- provide advice or money for income generation
- integrate care with HIV education
- promote acceptance of people with HIV
- reduce pressure on hospital in-patient facilities.

Providing high quality home care is not easy. At its worst, home care can become 'home neglect'. Pressures on poor families are often immense, health workers are often unable to make frequent visits, and volunteers are inadequately trained or equipped. Sometimes the sick person is neglected due to fear of HIV or a belief that they will die soon.

Close Links

An effective home care service depends on a 'continuum of care' where hospital, clinic and welfare services are linked with the person and their family, as well as members of the wider community.

The home care team, often working with trained volunteers, plays a crucial role in this continuum, and needs committed and well-trained health workers, counsellors and social workers, as well as supplies and equipment. However, it is costly to sustain a programme where hospital staff travel out to people's homes, and better results have been achieved by involving community health workers.

Although many home care

programmes began working only with people with HIV, more are now including anyone with chronic illness, and integrating programmes with other community services. Experience has also shown that health workers' morale remains higher when they care for a wider range of clients, including some with curable conditions.

Prevention and Care

Experience in HIV prevention and care shows that they work best when carried out together, as described in the recent evaluation of TASO in Uganda. Care activities need to include prevention-counselling and education about HIV for both people with HIV and their families. People living with HIV who feel cared for and supported are more likely to take responsibility for protecting others from infection. Family and friends involved in looking after a person with AIDS have opportunities to learn about HIV.

Likewise, prevention programmes need to include care activities, to enable people with HIV to remain involved if they wish, even if they become ill. Integrating care and education also stops barriers from developing between 'them' (the sick) and 'us' (the well), showing the wider community that AIDS does exist, and that people with HIV are just like anyone else.

Confidentiality

Home care programmes need to be sensitive to the need for confidentiality while trying not to 'hide' the illness. Too much secrecy can encourage stigma and discrimination justifiably

feared by people with HIV.

However, it is very difficult to involve the family, and to combine care with education, if the person feels unable to tell anyone why they are ill. Access to counselling, both for individuals and family groups, is essential to help people come to terms with their infection. Telling a few people, with support from a trusted counsellor, can give someone with HIV more confidence, and lead to their involvement in wider education efforts, as described by an AIDS Action reader on page 10.

Involving people with HIV

It is important that the programme meets the needs of people with HIV and their families, and actively involves them. Most studies to assess people's needs show that their greatest problems are poverty and lack of medical care, not HIV illnesses. Fear of rejection by family members is also common. Involving people with HIV means that they can take part as carers and educators, not simply as patients or clients.

Home care relies on the family's ability to provide care, nutritious food and medical treatments. Their capacity to cope needs to be assessed and plans made with family members. Women and older girls are usually the main care providers. Girls are likely to be withdrawn from education before boys when extra hands are needed at home or when there is not enough money for school fees. Home care and prevention programmes need to reduce these

pressures by providing economic, legal and employment support, and promoting equal responsibility for caring in the home.

Community Involvement

Volunteers play a major role in reducing pressures on families in many home care programmes. Increasingly, programmes are encouraging men to volunteer as well as women. In Uganda, both men and women in existing community groups are providing practical support such as bringing food, doing laundry and cultivating land.

The involvement of local people can also stimulate the community to support families affected by HIV, reduce stigma and promote changes in traditions and practices that increase risk. All too often volunteers from church or community groups are

involved simply as an inexpensive way to increase service capacity. But they are essential partners in a comprehensive care service, and maintaining their active involvement and motivation is important. Many programmes provide basic expenses, training certificates or special T-shirts.

Quality and access

Clients for home care are usually referred, with their agreement, from out-patient or STD clinics, or HIV counselling centres. This means that services often fail to reach those in most need because people are unwilling or unable to use the formal health system.

Home-based care is not a cheap option if it is to provide a minimum and sustainable level of service for people. Many hospitals and NGOs have found that programmes cannot

be continued because of lack of funds. Selection and motivation of volunteers is vital to the success of such programmes. The hidden costs to the family of caring for someone at home also need to be considered.

Programmes also need to develop ways to monitor and evaluate the service, in terms of numbers reached, and client feedback. Some suggested methods are summarized on page 5.

Jackson, H, 1994. The benefits of comprehensive care across a continuum (Presentation to WHO/GPA workshop 'Provision of HIV/AIDS care in resource constrained settings')

Foster, S, 1994. 'Care and treatment of HIV disease in developing countries from a socioeconomic perspective.' AIDS, 1994, 8 (supplement), pages S341-S347.

SANASO Home Care Workshop Report, Chikankata Hospital, Zambia, April 1994.

Media Images of AIDS in Asia

The University of Amsterdam's Asian Cinema Centre sponsored a workshop, "Focus on AIDS in Asia" earlier this year. The workshop brought together about 50 representatives from nine countries to discuss the images of AIDS in Asian mass media. The workshop included presentations of various films relating to HIV, ranging from short educational clips to full-length commercial features.

While recognizing mass media as being powerful forces that can help in HIV prevention, workshop participants were also concerned about how the media may in fact reinforce stereotypes that will hinder HIV prevention. In fact, some of the stereotypes have actually been found in educational materials produced either by government or non-government organizations. For example, early information materials in many Asian countries tended to feature western photographs of men with AIDS, usually with lesions of kaposi's sarcoma (purple blotches on the body). This tended to reinforce the idea that one could look for signs and symptoms of HIV infection in a sexual partner.

Another dominant stereotype reinforced by media has been the idea of women transmitting HIV. In most Asian countries, old concepts of sexually-transmitted diseases as "women's diseases" have been transferred to perceptions about HIV/AIDS. Thus, even if a movie tries to sympathetically portray the plight of women with HIV, the movie may in fact reinforce the idea of the woman transmitting the infection, especially when the woman is a sex worker.

Dealing with existing norms was identified as a problem. Generally, Asian societies are said to be conservative about sexual matters. However, other speakers pointed out that many Asian cultures have, in fact, a long history of sexual imagery in the arts and in literature (e.g., the Kama Sutra of India). There was some debate on how much of sexually explicit materials can be used. Suggestions that the materials be as explicit as possible, even through cooperation with pornographers, were hotly debated as women's advocates pointed out how pornography producers in Asia are in fact tied

to criminal syndicates and that they in fact reinforce the very values (e.g., female submission) that block HIV transmission. Generally, the consensus was that culturally-appropriate messages need to be worked out although defining that appropriateness is probably easier said than done. An even more basic question that remained unanswered was the extent to which explicit materials were even needed for HIV prevention messages.

The workshop participants recognized the potential, as well as the limitations, of cinema and media for HIV prevention. More importantly, the participants saw the need to address the ways in which economic, social and cultural forces shape not just the potential for media but, more importantly, the conditions for the HIV epidemic itself.

Copies of the seminar report are available at US\$15 each. A tape has also been compiled and costs US\$15. Prices include postage and handling.

Orders can be sent to Asian Cinema Centre, O. Z. Achterburgwal 185, 1012 D K Amsterdam, the Netherlands.

Steps in setting up home care

Experience in rural South Africa provides useful tips for hospitals or health centres considering a home care programme.

Before starting...

As part of planning a new home care service, it is important to first assess the level and type of need, and what is already being done.

- What are the reported numbers of people with HIV-related illness in the area (with a breakdown by age and sex)? Refer to records in local hospitals, antenatal or STD clinics where HIV testing has been carried out, or national HIV data.

Increasing levels of TB, especially among young adults, are usually associated with HIV. Shingles in adults is another common indicator.

- What are local attitudes towards AIDS? How are people with HIV viewed by their families and in their communities? What do people with HIV and their families need? Talk with hospital patients and their relatives, and contact other organizations working with people with HIV. For example, in KwaZulu, clients' main concerns were about financial and

material support: lack of jobs, money, food, clothing, water, transport and medicines. Other major needs were for medical care, emotional and spiritual support, and education about HIV. People were often afraid of disclosing their HIV status and worried about their children's future.

- What care is already being provided, and what is the impact on health service provision and staff? Examine trends in how hospital services are being used (outpatient attendances, hospital admissions and bed occupancy rates). Assess whether staff are experiencing particular difficulties related to HIV care.

- Are appropriate medicines available for use by health workers making home care visits? What are the most commonly used medicines for treating HIV-related illnesses? Would medicines be free of charge? Is there an adequate supply of condoms?

- Assess how HIV-related infections are treated in the community. Have community-based health care providers, such as community health workers or traditional healers, noticed more people with HIV-related illnesses?

- How is contact maintained with people who have been diagnosed with HIV/AIDS in hospital, and discharged? To what extent are counselling and testing available and being used appropriately?

- What community services already exist? Consider whether they could be expanded to include care for people with HIV/AIDS as well. What are the pros and cons of providing home care for all chronically ill patients, as well as those known to have HIV?

- Could links be improved with STD, family planning, TB or MCH services?

- What other services are there? Are local NGOs providing care or counselling? Could links be improved with health services and organisations doing prevention work?

Responding to needs

The type of home care programme will depend on the needs identified and resources available. In addition to setting up a structure for providing both medical care and other support, the programme's aims will probably include co-ordination with inpatient and clinic services, and access to voluntary and confidential counselling and testing. It may include strategies for appropriate education in the community as well as for patients and their families.

It may be HIV/AIDS specific, and rely only on hospital referrals, or it may target a wider range of people. One evaluation in Central Africa showed that nearly half of people visited by a home-based care programme had illnesses that were not HIV-related. The extent to which other health issues can be tackled will need to be assessed over time as the programme develops.

Referrals for home care

Good referral systems between home clinic and hospital need to be established. In KwaZulu people are referred to the home care team when they arrive at hospital with an HIV-related illness or from the counselling and testing service. They are offered an initial home visit. Traditional healers and community health workers refer people to the team also.

Staff and training

Experience shows that teams made up of hospital-based staff alone are less successful. Treating most HIV-related infections does not require highly trained staff. The presence of uniformed nurses in the community can attract unwanted attention and limit development of informal and supportive relationships. Also, salaries for high grade staff and transport costs are extremely high.

Consider involving community health workers in the team. In KwaZulu, for example, TB field workers were interested in being trained to visit people with AIDS as well. This worked well, because many people had both HIV and TB infection. Strategies for care were developed with the community workers, and strengthened through their knowledge



Traditional healers are involved in the KwaZulu home care programme.

of their communities.

Community health worker training included management of common illnesses such as skin rash and diarrhoea, and how to train family carers in basic nursing and home care. They were provided with essential medicines and other supplies. (see page 7).

Support for staff is very important, through strategies such as developing a team spirit, working in pairs, regular supervision, opportunities to record success, good planning, and refresher training.

The specific roles of health workers, other staff and volunteers need to be developed and understood by everyone on the team. It is important that all team members are included in planning and evaluating the programme and in particular that volunteers' contributions are recognised.

Wider involvement

As part of making stronger community links, organise meetings and workshops with local healers. This gives valuable opportunities for sharing knowledge and perceptions about HIV and AIDS, roles for healers in prevention and care, infection control, and referrals to hospital and clinics.

It is also important to meet with local NGOs and community leaders, including those from religious and traditional organisations, to discuss their perceptions of the epidemic and possible ways to support families and provide community education.

Where it is not possible to include social workers in the team, it is useful to maintain close links with relevant departments.

Counselling

Emphasise the importance of ongoing counselling, not just before and after HIV testing. In KwaZulu, the health workers had difficulty combining care with emotional support and education on HIV prevention and infection control in cases where patients were unwilling to tell close family members that they had AIDS. Counselling helped them to accept the need to talk to relatives.

As part of the care programme, ideally all staff need training in basic



WHO/J-I. Ray

Trained community health workers can be key members of the home care programme.

counselling skills. Referral systems should be maintained with the hospital-based counsellors.

Care at home

Visits by the home care team are often valued by patients and families for medical care and advice. Transport to hospital, emotional support, education and food parcels are also important.

One of the most important issues for the patients and carers is money. Possible sources of income from welfare departments or NGO sources should be investigated. Starter grants for income generation projects should be made available where possible. Continuing access to education for children is often a concern. In KwaZulu the home care team provides advice on government benefit schemes.

Critically ill patients should be referred to a hospital when carers are unable to cope. Many people choose to die at home and counselling and practical support for patients and carers is particularly important at this time. Help after the person dies is also important, not only to provide practical advice about handling the body but to support the family emotionally. Other family members may them-

selves be HIV-positive or already sick.

Care costs

Costs depend on the type of service, but sufficient resources need to be allocated for the programme to be sustainable in the long term. The main costs are likely to be vehicles and staff, together with drugs, equipment, food and other material support. Involving and training community volunteers in planning and giving care can reduce costs and increase people's motivation, although the costs of ongoing training and supervision need to be considered.

Direct costs to the family, such as payment for medical or traditional treatments, extra food and other items should be taken into account. Estimating indirect costs due to loss of earnings or agricultural productivity and additional workloads on women are less easy to measure.

Programme monitoring

Indicators for measuring the success of the programme need to be established at the start of the programme and team members need to keep accurate records. The following indicators may be useful: the number of people with HIV accepting care at home and how many have an identified carer; numbers sharing their diagnosis; number of visits which provide material assistance and referrals; number of drugs and condoms distributed. Changes in hospital attendance should be monitored.

Issues such as quality of care, changes in community attitudes, satisfaction with treatment, adequate support for carers from the home care team and volunteers, evaluation of volunteer training may be considered after the programme has run for some time. Involving people with AIDS, care givers and team members in evaluation is important to ensure that the programme responds to the needs of the community.

Dr Laura Habgood, former AIDS team adviser, and Dr James Stuart, former AIDS programme manager, KwaZulu, South Africa c/o LSHTM, Keppel Street, London, UK.

Caring at home

Family members and volunteers can carry out basic nursing tasks, with support from health workers

Guidelines for carers

Families or other community members can be taught to:

- provide good nutrition
- help the person with hygiene and personal care
- ease pain, fever and discomfort
- assist the person to relieve problems such as diarrhoea, sore mouth or throat, skin sores, or cough
- talk with them if they are afraid, anxious or depressed
- follow simple procedures to prevent infection spread.

Infection control

- Maintain good hygiene in the home. Always wash hands before cooking and eating and after going to the toilet or coughing. Wash dishes, linens and cloths with soap and water. Where soap is not available ashes may be used. Dispose of rubbish in containers or burn.
- Avoid contact with blood and other body fluids and wash hands immediately after handling soiled articles.

Skin problems

- Wash open sores with soap and water, and keep the area dry. Salty water can be used as a disinfectant.
- For rashes, apply local remedies, oils such as coconut oil or calamine lotion.
- Bed sores occur when someone is too weak to move. Continuous pressure on the skin causes sores to develop. The person should get out of bed as much as possible. When a person cannot get out of bed help them to change position every two hours, from one side onto the back, then the other side and so on. Use soft pillows or many layers of cloth. Gently rub skin that is dark, reddened or irritated.

Sore mouth and throat

- Rinse the mouth with warm water mixed with a pinch of salt at least three or four times per day.
- Suck pieces of ripe tomato or a

lemon for thrush if it is not too painful.

- Eat soft foods that are not too spicy.

Fevers and pain

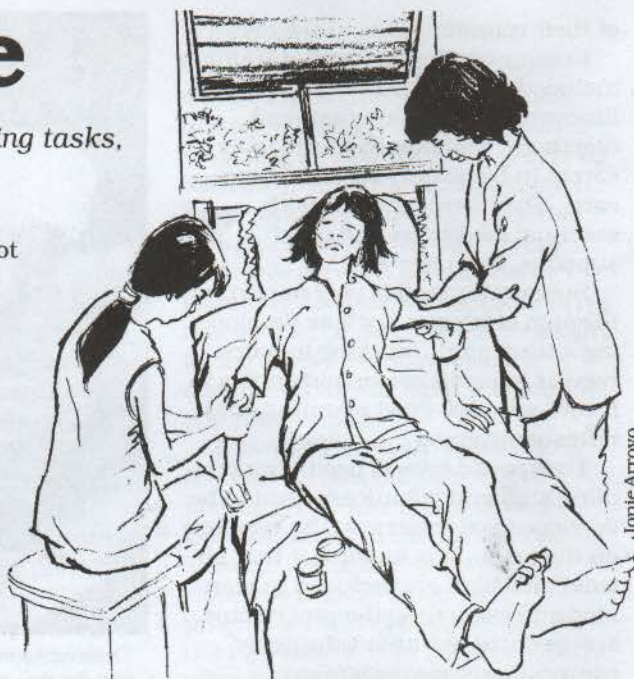
- Rub and gently massage sore muscles using oils.
- For fever wash the body in cool water with a clean cloth or wipe the skin with wet cloths.
- Drink more than usual of water, tea, broth or juice.
- Remove thick clothing and blankets.

Cough, difficulty in breathing

- If someone has a bad cough or a cough lasting more than three weeks they should be seen by a health worker to check for pneumonia or tuberculosis.
- Cover the mouth when coughing. If the person develops a new fever or chest pain, or coughs blood, encourage them to see a health worker.
- Lift the head and upper body on pillows to assist breathing and sit with the person to calm them if they are frightened. Keep windows open to allow fresh air in.
- Sit up when possible. Raise the head on pillows to help the person to breathe.

Diarrhoea

- Treat immediately to avoid dehydration, either using oral rehydration salts or homemade ORS (4 level teaspoons of sugar and 1/2 a level teaspoon of salt mixed with 1 litre of boiled water, or contact the local health facility).
- Ensure that the person drinks more than usual and continues eating frequent regular meals such as porridge or mashed banana.
- Wash the buttocks and anus with warm soap and water after each bowel movement and keep the skin clean and dry.



Family members and friends can do much to help relieve a person's pain and discomforts.

There are often local remedies which alleviate fevers, aches, pains, and coughs, and barks or roots which cleanse sores and abscesses.

For example, abscesses and boils can be drawn using a compress made with sliced onion placed over the boil and then cleaned with salt water. Dry coughs can be relieved by juice made from sliced onion and sugar which is a good expectorant.

In many countries traditional healers and women's associations or home care programmes are collecting information about remedies which alleviate symptoms and discomfort.

Medicine and supplies

Programmes have supplied home care teams with some or all of the medicines needed for carrying out basic treatment of common infections during home visits, or for giving to families.

However, medicine supply lists vary according to national recommendations and availability, and the professional qualification of the health worker or volunteer. Contact the National AIDS Control Programme and Ministry of Health for guidelines. See back page for information resource list.

TREATMENT. CARE AND MEDICINES

Illness	Medicine	Dosage
Diarrhoea: acute	Oral rehydration salts (ORS)	Mix 1 packet with 1 litre of boiled water. Drink 1 cup after each loose stool. Throw the solution away after 24 hours if not used.
Diarrhoea: persistent	Adsorbents e.g. kaolin Antimotility drugs e.g. imodium	Can be used to temporarily reduce cramps and pain but can prolong the illness by delaying the elimination of the organisms causing the diarrhoea. Should never be used with children under 5 years.
Fever and pain	Paracetamol	1 or 2 500mg tablets every 8 hours for adults, 1 for children 8-12 years, 1/2 for children 3-7 years, 1/4 for children 6 months-2 years, 1/8 for children under six months
Skin problems: general e.g. rashes bacterial e.g. open sores	Calamine lotion* Vaseline or oils* Gentian Violet* Potassium Permanganate*	For itching or irritation, rubbed on skin as required For dry skin, rubbed on skin as required 1 teaspoonful of crystals dissolved in half a liter of water A pinch of crystals in 1 litre of clean water, solution painted on sore area
Yeast infections (oral and vaginal)	Gentian violet (mixed as for bacterial infections)* Nystatin*	For oral thrush: as a mouth wash For vaginal thrush: applied to vagina area once daily for three days For oral thrush: oral suspension 2-4 ml daily, held in the mouth for at least 1 minute and then swallowed For vaginal thrush: pessary or cream applied to the vagina area once or twice a day for 5-7 days
Bacterial infections e.g. bacterial pneumonia, salmonella, skin infections	Antibiotics e.g. cotrimoxazole Penicillin or ampicillin	Every 12 hours for 7 days: 960mg for adults, 480mg for children 6-12 years, 360mg for children 12 months-5 years, 240mg for children 2-12 months, 120mg for babies under 2 months Every 6 hours for 7 days: 500mg for adults, 250mg for children 2 months-12 years, 125mg for babies under 2 months
Parasitic infections e.g. giardia	Metronidazole	Every 8 hours for 7 days: 400mg for adults, 200mg for children 6-12 years, 100mg for children 1-5 years
Different antibiotics work for different infections, so they should never be used unless prescribed by a health worker. They have to be used for the full length of time specified to be effective. Check with the Ministry of Health or hospital pharmacy for recommended antibiotics.		
Tuberculosis	Each country should have standard treatment regimens to follow. Commonly used drugs are:	
	Isoniazid	300mg daily, taken orally before the morning meal. Store out of sunlight
	Rifampicin	450-600mg daily, available in tablets of 150-300mg, or in a combined form with isoniazid, taken orally on an empty stomach at least 30 minutes before the morning meal
	Pyrazinamide	1 1/2-2g daily, taken orally in morning with or without food
	Ethambutol	15mg per kilo daily. Not for use in children under 6 years old.
The first 2 months of treatment is based on a combination of these medicines and requires supervised administration. The second phase of treatment is isoniazid with rifampicin for 4 months or isoniazid with ethambutol for 6 months. Thiacetazone should not be prescribed for people known or suspected to be HIV-infected. It can cause severe skin rashes and other side effects which can be fatal.		
Other supplies	Multivitamins Condoms Gloves/plastic bags Soap Dressings Bed pans, urinals	1 tablet daily, when adequate nutrition not available

*Also supplied to volunteers and families

Tapping the potential of collaboration

The focus is on developing guidelines for care to be delivered by both public health care givers and NGOs.

The HIV epidemic in India is estimated to have begun in the mid to late 1980's. Over this period a large number of people have been infected by the virus through several routes. While in most of India, the majority of individuals have acquired the infection through sexual contact. In the Northeast the majority of AIDS cases seen are a result of transmission of HIV through sharing of needles and syringes during intravenous drug use. An increasing number of persons are currently developing symptomatic HIV disease and AIDS and requiring health care and social support. This need is anticipated to be required increasingly in the foreseeable future.

In many African countries the number of persons developing symptomatic HIV disease has increased to a point where bed occupancy for HIV/AIDS in many medical wards in urban hospitals has reached 50 - 70%. This has caused problems in the care of both patients with and without HIV. There are tremendous burdens on the existing health care system. The situation may become similar to that in a number of African countries unless measures are taken to prepare the health care system.

In India there are a number of initiatives that have begun under the direction of the National AIDS Control Organization (NACO). These have focused on care in health care settings with the provision of clinical training and counselling support. Intensive training programmes are being undertaken for the orientation of doctors and paramedical staff in these disciplines. In collaboration with Christian Medical Association of India (CMAI) and Indian Medical Association (IMA), NACO has embarked upon a programme to train physicians in both public and private sectors.

NACO has taken the lead by developing this strategy further to include the care of patients in a continuum that spans hospitals, clinics, communities and homes. The focus is on developing appropriate guidelines for care to be delivered by both public health care givers and NGOs. NACO has instituted a pilot project to test this approach in Manipur in collaboration with NGOs, WHO, OXFAM, British Council and The North East Regional Medical College. The specific objectives of the project are: 1 To stimulate the formation of core inter-disciplinary teams within health facilities responsive to PWA needs for comprehensive care and provide relevant training. 2 To train volunteers from a core group of NGOs to provide emotional and social support to PWAs, prepare families for giving home care, teach prevention techniques for HIV transmission and, when needed, refer PWAs to health facilities. 3 To develop a referral network linking health services with NGOs for the provision of care and prevention across the continuum, by making use of an appropriate resource directory of all care and social support available to PWAs in their environment. 4 To develop and make available an appropriate culture specific AIDS Home Care Handbook for use in local languages, and document the process for replication in other areas. 5 To evaluate the process and compare specified process and outcome indicators before and after the intervention, eg, KABP of volunteers and health personnel, focus group discussions, etc.

Preliminary findings indicate that patients are benefiting from such a service. There is also an indication that attitudes and practices of health staff involved in the care of patients are changing for the better.

Current plans by NACO are to replicate a similar project in other seriously affected states taking into account the specific local needs. There are few integrated care programmes developed in the Maharashtra and Tamil Nadu but there is a potential to build on the good health infrastructure available and NGOs who have been working in the area of community development for many years.

Unfortunately there is still a stigma attached to AIDS and HIV at the community level. This is predominantly due to the fact that the groups most affected by the disease are socially marginalised — mainly injecting drug users, commercial sex workers, the poor, destitute and homeless. In some cases, families have disowned patients because of the shame associated with the disease. In such a climate it is difficult for patients to share their HIV status with the family and are reluctant to consider visits from volunteers in the home, lest they be identified as being affected. It is important that IEC materials and programmes promoting care in the home and community are encouraged to prevent HIV from acquiring the stigma that leprosy and TB has had in some parts of India.

In communities such as Sonagachi in Calcutta and Imphal in Manipur, there is recognition that commercial sex and injecting drug use are a part of life in the respective communities. Acceptance of persons engaging in these practices by community workers has increased and since the two categories are at risk of HIV there may be more acceptance of those who develop illness. This may thus facilitate care in the home.

The visible mortality from AIDS in India is not yet comparable to other diseases and accordingly this is not

perceived by many as a major problem. Consequently, there has been some amount of denial and complacency in some states among key people. A lack of awareness on the part of some health professionals has led to stigmatisation and fear of caring for patients in health institutions.

Despite these difficulties, there are a number of initiatives in both public and NGO institutions focusing on care at various levels. Health Plus, an NGO in Pune, has developed counselling services in the community for patients tested in hospitals and private testing facilities. There are plans to extend the service to community care. Yaogote (YGR) Foundation in Madras has developed plans for a home-based care programme and a day care centre which will assist those in need of short-term care needs. There are counselling services being offered by the same NGO in public hospitals and through a telephone hotline.

Public health facilities are also developing care programmes that have a positive impact on health staff. The AIDS Research and Control Centre (ARCON) project, a collaborative project between the government of Maharashtra and University of Texas, is promoting clinical ward rounds that not only demonstrate signs and symptoms to medical teams but also help them to change their attitudes and overcome fears of caring for patients. At the moment two hospitals are participating in this initiative in Bombay. The project demonstrates, through caring, that the risk of transmission of HIV in health facilities is low.

In Madras, the State AIDS cell is developing initiatives to look at care issues at the state level and promoting NGOs that have drawn up plans for the care of patients. An example of this is an NGO, Udavum Karangal (helping hands), that cares for destitute persons, especially those with psychiatric conditions that have been rejected by the community. Residential care is provided for these persons using whatever resources are available to the NGO. In this way, some people who have HIV are also cared for. This is not seen as a solution to care for AIDS patients as

the numbers will overwhelm the facilities available at present. But in the short run this seems to be the only way to help those without a home.

'The visible mortality from AIDS in India is not yet comparable to other diseases. Consequently, there has been some amount of denial and complacency in some states among key people.'

Another NGO, the Madras Christian Council of Social Services (MCCSS), sees the problem of care for HIV/AIDS patients as part of community development and empowerment of those affected. They have developed peer educators in 200 slums in Madras who are promoting a positive attitude to HIV/AIDS in the community using peer educators. South Indian AIDS Action Project (SIAAP) and Community AIDS Network (CAN) are also utilising peer groups for educating and mobilising communities to help change attitudes to AIDS as an important pre-requisite to care in the affected communities.

The potential for care of those affected by HIV/AIDS in India is great. Unlike a number of African countries which have been beset by economic and manpower problems, India has vast well-trained human resources and a viable growing economy with increasing foreign investments. Workers will have to be re-oriented in the care of HIV/AIDS patients and helped to see the benefit of public health approaches to care. The extension of hospital bed capacity is possible at present but only up to a point. The major limitation will be the rate of population growth. Any new beds created will not only be filled by patients with HIV and AIDS but also with other health problems. The way forward is

clearly to use this potential for community-based public health initiatives that are appropriate to different parts of the country.

India also has a vast capacity to manufacture different types of drugs for the treatment of opportunistic infections cheaply and makes them widely available in the country. This will be useful in the care of affected patients. Herbal and homeopathic remedies that have been used in health care for centuries, may help relieve some symptoms in the home.

Clinical trials have been initiated in several hospitals to assess the efficacy of some of these drugs in curing or relieving symptoms of HIV/AIDS. However, no conclusive comments can be made about the results at the moment.

The care of patients affected by HIV/AIDS will increasingly be a major focus in the next couple of years in India. As we approach the year 2000, the initiative NACO has embarked on by encouraging NGO and government collaboration will provide direction for the development of appropriate care programmes to meet the growing need.

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'I have an important role to play'

If more families were trained in home care, it would help boost the morale of the sick

Experience has taught me that Thai women are expected to follow tradition and behave like ladies. They are expected to be housewives and do all types of household work. By nature they should be soft and gentle, but forebearing. These days, however, AIDS is becoming widespread, especially among men, most of whom are heads of households and important breadwinners. Men tend to die earlier because, even though they are physically stronger, they are emotionally weaker. They have difficulty in coping when faced with problems. They are unable to reason and find solutions. They turn to alcohol, cigarettes and intoxicants which are harmful to health and can end in death. They destroy the body and the mind. Consequently, women find themselves with another role to play in looking after the physical and mental well-being of men. They must do everything they can to help improve the condition of men. I have experienced this myself through looking after my husband. Because of this, women have seriously begun to look for ways to fight this disease. They see the need to set up a project which will provide home-based care in the form of home visits and moral support for people with HIV. Work which has been done in the past has met with a reasonable degree of success.

From home visits I have made and from talks I have given to the public and youth groups, I have come to realize that people infected with HIV have an important role to play. If government, private agencies, or other groups visit the sick in their homes, the sick are not very receptive. However, if people infected with HIV make home visits or give talks, the people are more interested. More and more people suffering from AIDS are beginning to open up and confide

in the people with HIV who visit them. They share their feelings and now the people who visit them are able to understand more about the problems they are facing.

Most of the work I have done is in the form of making home visits, giving moral support, providing education on self-care in the preliminary stages and co-ordinating with hospitals when the sick begin to get opportunistic diseases. I also help coordinate the support from government and private sector regarding vocational training programmes and assist the sick in living happily in society.

Public health services provided by the government these days are improving. Help is mostly in the form of working budgets and support for preliminary treatment. There are, however, some problems with government procedures. AIDS patients cannot afford to go through all those different stages. If the government is able to reduce some of the stages, it will be of great help to the sick and will help to facilitate work. It will also help to reduce the mortality rate among the sick.

I myself had a series of chronic illnesses and have been in and out of hospital many times since I was young. I've received a lot of treatment and have had several operations. This has helped me to understand that life is uncertain. Before I was married I pledged my body and eyes to a hospital. Because I've been practising meditation since I was young I am now able to face any situation.

Consequently, I was not upset when I contracted the AIDS virus from my husband five years ago. I did not criticize my husband but instead tried to give him moral support. I began to study about AIDS and how it progresses. I took my husband to listen to the talks

given at the Thursday Forums. Our purpose was to learn more about AIDS, the advances taking place with research, and about how to look after ourselves. I enrolled in a Home Care Training Programme offered by the Red Cross Society in Chiang Mai and learned how to look after myself at home. In 1994 my husband's health began to fail. He got a lung infection, his small intestine began to malfunction, he had an enlarged liver and his kidney stopped working. The doctors said that he wouldn't last long. I firmly believed that there was some way that he could be cured so I checked him out of the hospital and took him back home where he was cared for with the love and warmth of his relatives who gave him their fullest attention and moral support. His condition improved and eventually the opportunistic diseases disappeared. This made me believe that if the families of other sick people were taught about this disease and the problems that come with it, and were trained in home care, it would help boost the morale of the sick and increase their life span. I began to give talks to the public and to youth groups, and went out to visit the sick whose relatives had come seeking advice. I started visiting people in the district and neighboring areas who were infected with HIV. I soon became known among government and private sector agencies, and decided to draft a proposal seeking support from NAPAC for various activities which I had outlined. I believe the work I'm doing will be successful because more and more people infected with AIDS are beginning to open up about their condition and are winning acceptance from society. I am determined to work in this field so that I can set an example for future generations. The only medicine that AIDS is afraid of is family warmth. I firmly believe that if we know how to use it properly and work together with determination and sincerity, then the mortality rate among people with AIDS will decrease.

Phimchai Inthamun
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Friends for Life

This is a place of refuge, where people who have lost contact with friends and relatives can find solace and peace.

Phra Phongthep Dhammagaruko is a Buddhist monk living on the outskirts of Chiang Mai in northern Thailand. In January 1994, he opened the Friends for Life Centre, in response to the growing number of Thai people with HIV/AIDS (PWA) who have nowhere to go and no money for treatment.

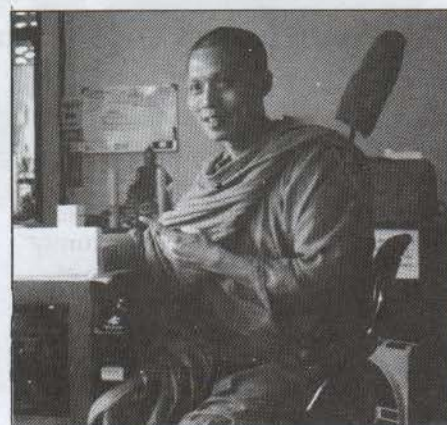
The hospice is simple, with a capacity of 12 beds, which is clearly not enough. Phra Phonthep is assisted by a male nurse, a cook, a driver, and another monk who conducts daily ceremonies. Most of the clients have no relatives. Some are refugees from Burma, or villagers from hill tribes. Many are farmers, labourers, or street children. When we visited, the centre had more male clients than females, but there is no discrimination on grounds of gender or religion. Clients make contact with Friends for Life by telephone, word of mouth, or referral by doctors or hospitals, the hospitals themselves often facing a shortage of beds. The centre also sometimes refers their clients to other like-minded NGOs which may be better equipped to respond to particular circumstances.

After initial contact is made, the centre screens the PWA to identify

his or her needs. If there are relatives who can be identified, the centre looks into the possibilities of home-based care. The centre discusses the issues with the PWA relatives, including their fears. Much of the initial sessions are therefore more of educating relatives about HIV and how it is, and isn't, transmitted. When the relatives visit the hospice, they realize, too, that the centre's conditions are actually quite similar to a home environment. Carers are taught basic skills like identification of symptoms of common opportunistic infections, and administration of drugs.

Herbal medicine is used to supplement western medicine, and a volunteer doctor regularly visits the centre to examine and treat the PWAs. There are various activities for the PWAs' physical and mental health, including gardening, sports, painting. Religious services, chanting and meditation, are also used. If a PWA's family is unable to pay for treatment, the centre assists the relatives to make a claim with the Department of Social Welfare.

Often, PWAs will deny having relatives because they are afraid to tell them about their status. If no



Phra Phongthep orients visitors from the Philippines.

Bernard Tomas/HAIN

relatives can be found, then the PWA is permitted to stay at the centre. If relatives can be contacted, they have to sign a contract stating that they will take responsibility for the PWA upon his or her death.

PWAs often arrive at the centre from hospitals in a critical condition. Phra Phongthep ensures that the hospitals are not shirking their responsibilities before accepting the client, and threatens to go to the police if this is the case. There was a case last year when a hospital was reported for refusing to treat a PWA but generally, hospitals do admit PWAs.

When we asked Phra Phongthep whether religion was a part of peaceful dying, he replied with a question: Even without AIDS, we all die, so do you fear AIDS or death? Is your fear physical or spiritual?

Phra Phongthep has strong views about HIV and AIDS. He sees economic globalization as the dawn of "global disaster" as more people become impoverished. Rural poverty pushes villagers into the cities where they have little social support and access to information and education. This increases vulnerability to HIV infection.

Friends for Life offers a place of refuge, where people who have lost contact with friends and relatives can find peace and solace. What the world has to do is address the root causes of poverty which have made HIV a global pandemic.

Richard Manning works with AHRTAG. He prepared this article following a visit to the Friends for Life Centre.



Bernard Tomas/HAIN

The author, left, with Phra Pongthep, volunteer Dr Tejsit Sukontant and guest Dr Lop Tritan, a veterinarian.

Counselling is important

On the horizon there are few if any rays of hope in the direction of a cure for HIV infection. Naturally, much stress is placed on the preventive aspects with full community participation. We still have the opportunity and time to control HIV infection at an early stage of the epidemic.

As the literacy standards in Kerala are high, it is not that difficult to spread the message of prevention here. Much is being said about safe sex and condom use all over the world. But little attention is being given to the counselling of HIV seropositives. We have been doing this for some time. At our centre in Kerala, India, listening to your

patient is important. Effective counselling gives strength to the HIV seropositives to lead a healthy life, minimize chances of spread of infection, and reduce social distress. We have also observed that even transmission to spouses could be prevented by successful counselling. HIV seropositives have to be followed up periodically through booster counselling.

Time spent on counselling is worthwhile, for counselling is the sharpest weapon in the fight against AIDS.

Dr Laly Jose, Assistant Professor, AIDS Surveillance Centre, Medical College, Trivandrum, Kerala, India

RESOURCES

HIV prevention and care: teaching modules for nurses and midwives includes basic home care and treatment guidelines for children (2nd edition). *Free in English (single copies while stocks last) from WHO/GPA, CH-1211 Geneva 27, Switzerland. French and Portuguese from WHO Regional Office for Africa, PO Box 6, Brazzaville, Congo.*

AIDS home care handbook is a practical handbook for health care workers to help individuals, families and communities to manage AIDS-related problems at home. *In English, French, Portuguese, Kiswahili and Thai for Swiss francs 12.60 from WHO/GPA.*

Caring for people with AIDS at home provides information for Red Cross volunteers to teach families to provide nursing care to people with HIV and other chronic illnesses. *Free supplies in English, French, Portuguese and Spanish (Arabic in preparation) from International Federation of Red Cross and Red Crescent Societies, PO Box 372, CH-1211 Geneva 19, Switzerland.*

Manual of group interview techniques to assess the needs of people with AIDS (WHO/GPA/HCS/95.2) provides guidelines for district level planners on planning services for people with HIV in the community through interviewing people with HIV and their carers. *Available from WHO/GPA.*

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 practical sections on care and support. *Free in English and Kiswahili from AMREF Tanzania, PO Box 2773, Dar es Salaam, Tanzania.*

TASO Uganda: the inside story (WHO/GPA/HCS 95.1) describes the participatory evaluation of their care, counselling and social support services. *Available from WHO/GPA.*

AIDS Action 24 is a special issue on counselling, and includes an article on care for the dying. *Contact HAIN for copies.*

Changing concepts of the family: responses to HIV/AIDS and development documents the emergence of 'families of choice' within the gay community in Australia, and how this has led to a wide range of gay community-based initiatives and responses. *Contact HAIN for free copies to developing countries.*

Assessing and planning home-based care for persons with AIDS was developed to facilitate the design of an AIDS program tailored to local needs. It uses an assessment matrix for systematic community evaluation of the problems and resources with current home care. *Contact HAIN for free copies to developing countries.*

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