The challenge of AIDS home care

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The numbers of people becoming ill as a result of HIV infection will dramatically increase over the next few decades regardless of the effectiveness of efforts at prevention being made today. Since AIDS is a chronic disease lasting months or years, some of the care required is likely to be supplied in hospital, but the home is increasingly considered the option of choice by sick individuals and by health care systems.

Home care relies on two strengths that exist around the world: the family and the community. People with chronic and terminal illnesses have been cared for by families in the home since time immemorial, regardless of the cost. But the AIDS epidemic presents new challenges.

Because home care lends itself to the “ups and downs” of a disease like AIDS, it is tempting to rely heavily on the families to provide care at home. Some countries have set as a target that by the mid-1990s the majority of people living with AIDS will be managed at home. This challenge can only be met if a strategy exists to develop comprehensive care (medical, nursing and counselling) across the continuum from hospital to home.

Once such a mix of services is available the ill person and the carers can jointly decide where the best quality and most cost-effective care is to be found. As with other chronic diseases, the best care depends on a continuity of services, with links and referrals to assist the sick individual to receive care at the right level, i.e. as close to the home as possible while still receiving comprehensive management, including proper diagnostic and therapeutic services for AIDS-related diseases, such as tuberculosis and diarrhoea.

Destigmatizing AIDS

When care is taken out of health care facilities and moved into the community, then community dynamics are added to the picture. People with AIDS and their families suffer from the stigma frequently found in communities and health care facilities. Fear stemming from a lack of knowledge contributes to the rejection of people with AIDS and sometimes their carers too. Without support, communities and families may abandon their traditional caring roles; this can result in despair among carers, and ultimately in the homelessness of family members.
AIDS patients. *Living with AIDS in the community* is a booklet aimed at helping individuals, families and communities to understand AIDS and to live positively in spite of this disease (see box on next page).

The burden of AIDS on the health care system is experienced around the world. Some city hospitals in high prevalence areas have 50–60% of the hospital beds on medical wards occupied by people with AIDS and AIDS-related conditions. However, the impact of HIV/AIDS on households is also enormous: persons with AIDS are economically less productive being able to work fewer hours, so others in the household have to reallocate their time and priorities. And greater spending on caring for the person with AIDS may mean that less is available for the health care of other family members.

Caution is needed, especially to avoid allowing the full burden of home care to fall on females whatever their ages. The distribution of labour within the family should be carefully considered, and communities should develop supportive networks composed of neighbours, religious groups and clubs.

Providing AIDS home care can either bring a family closer together or drive it apart; certainly the family dynamics will be affected. In crowded families struggling with poverty it may be difficult to provide home care. People with AIDS can also experience forgetfulness, confusion and even dementia, which test the coping mechanisms of the family. In contrast, sick individuals who are living alone may be isolated and unskilled in meeting their own nutritional needs and unable to find willing carers and a social support system in nearby surroundings.

### Concerns of carers

Care provided by family, friends or neighbours is not without problems. Very few carers will have had appropriate training. They will be worried about their lack of knowledge and

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**Why home care for AIDS?**

- Good basic care with the most nurturing and flexibility can be given successfully in the home, as it enables the ill person to be as active and productive as the disease allows.
- People who are very sick or dying would often rather stay at home, especially when they know they cannot be cured in hospital.
- Sick people are comforted by being in their homes and communities, with family and friends around.
- Relatives should be able to carry out their other duties more easily while caring for the sick person who is at home.
- Home care is usually less expensive for families, and sometimes hospital care is not possible.
- Home care provides educational opportunities for personal messages about AIDS prevention, both in families and in communities.

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Care at home involves more than a formal visit; it can also mean a sharing of emotions.
skills. They may be especially concerned about catching AIDS themselves, even though HIV is not spread through normal everyday contact or from taking care of a person with AIDS provided the carer covers any cuts or wounds on the patient and is careful not to touch fresh blood. They may be equally frightened about giving emotional support to a person who is terminally ill. WHO's Global Programme on AIDS has recently prepared an AIDS home care handbook (see box) to help health care workers to share their knowledge and to empower families to maintain quality of care at home.

Here are two examples of innovative AIDS home care programmes. The Uganda AIDS Support Organization, TASO, ensures that if its clients are well enough they join together for socialization, counselling, medical care, and recreational and income-generating activities. However, if a client is too ill to come to a centre, a home visit – usually by a nurse – is made to provide direct nursing care in the home, to teach the family how to cope with common ailments, and to refer to a hospital if necessary.

In a situation where severe poverty and overcrowding make it very difficult to provide home care, a care unit has been started in Mashambanzou, Zimbabwe, where a patient and a family member share a small room together. The family member is trained to provide care for common ailments and to give comfort. If no family member is available, seropositive individuals who are well are trained to care for others who need home care but where there is no home available.

AIDS home care has to be developed and supported in the midst of poverty, inequality and discrimination. The ancient tradition of home care faces new challenges in the age of AIDS. Those challenges can be met with compassion and education provided families and communities are seen as partners along the continuum of care.

AIDS: handbooks that will help

How can one cope with AIDS? How can one still get the most from life? What can one do in the home setting or after leaving hospital? How can one accept death? How can people suffering from AIDS be helped practically and emotionally?

There are a great many questions, and straightforward and easy-to-understand answers are difficult to find. This is why WHO has published its AIDS home care handbook, destined for health care workers, to help them teach people with HIV infection or AIDS, their families and communities. It can also be used by social workers, religious leaders, psychologists and companions, and administrators of health programmes.

The first part is a teaching guide for health care workers who have contact with AIDS patients and their families. It describes the evolution of the disease from HIV infection to AIDS, and suggests how to live positively with AIDS as well as how to care for the dying. The second part is a reference guide to the main symptoms of AIDS: fever, diarrhoea, skin problems, etc., and offers advice on what can be done to care for people at home and when to seek expert help. It also offers general advice covering such varied fields as hygiene, nutrition and maternal and child health.

The handbook is fully illustrated with drawings and uses a real life story to present the details of the disease and its impact on individuals, families and communities.

Another illustrated book – written and published jointly by the Ugandan AIDS Control Programme, TASO (Uganda's AIDS Support Organization), UNICEF and WHO – bears the title: Living with AIDS in the community, a book to help people make the best of LIFE.

Both books are available from Distribution and Sales, World Health Organization, 1211 Geneva 27, Switzerland, price Sw.fr. 18.– and Sw.fr. 6.– respectively. Single copies are free of charge to developing countries.

Young men in a hospital of Eastern Europe. AIDS patients have no need to be isolated and ought not to be stigmatized.

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