Community responses to AIDS
Sandra Anderson

Some examples of care in the community for people with HIV/AIDS are reported from Africa. Members of communities committed to fighting the AIDS epidemic cannot do so alone and should be given every possible help. Inadequate care favours the spread of HIV, as does the stigmatization of people with HIV infection and their families.

Communities have certain characteristics that lend themselves to coping with aspects of the AIDS epidemic. Some community responses to AIDS are discussed below.

Integration of home care into district health services

In Uganda the Kaborole and Bundibugyo District Health Teams have started to provide home care for people with AIDS on the following bases.

- Care is provided largely by patients' families, members of which accompany them to hospital and remain with them.
- Much care has traditionally been provided at village level and consequently home care is acceptable to the population.
- Through a programme of home care it is possible to maintain people at the highest possible level of health with minimal interventions by the health care system.
- In general, people wish to recover from illness in their own homes, where they are near their families, friends, neighbours and the community.
- Home care is a grass-roots preventive programme providing guidance to patients and their families as well as giving treatment and palliative care.

In assessing potential clients, staff look for people who are chronically or terminally ill, do not need nursing care for 24 hours a day, and have a care-giver available. A clear statement of service limitations is made: 24-hour-a-day service is not provided, there is no transport facility except for emergency transfer to hospital, and there are no personal supplies such as blankets and food.

The services provided are part of the district health care system and include:

- diagnosis followed by treatment with essential drugs;
- provision of nursing care;
- counselling for individuals and families.

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This programme has been developed in selected areas, and data for evaluation are being collected from families, clients and their standardized charts.

**Trained volunteers**

In Rwanda a home care project supported by the Red Cross is based on the work of volunteers who have been trained by nurses. The volunteers teach families in their communities how to care for people at home with any chronic illness, including AIDS, and give emotional support to the care-givers.

**Spiritual support**

In Kamwokya, Uganda, where 20–30% of the population between the ages of 20 and 45 are HIV-positive, community-based care takes place in a religious context. As well as giving medical and material support the religious community acts to defuse social tensions between neighbours and to demonstrate caring. By reaching out to people it aims to break down unfounded fears and thus encourage the giving of practical help, for instance washing clothes and fetching water.

**Outreach**

In Zambia the Monze District Hospital practises community outreach, including the provision of support for patients and care providers in the home. Home-based care appears to reduce the time spent in hospital by AIDS patients. Specific links are made between people’s homes, the rural health centres and the district hospital, and an effort is made to involve traditional practitioners, community health workers and the staffs of the rural health centres. All available resources are employed and a continuum of care is created between hospital and home.

**Support networks**

The Kitovu home care programme in Uganda has put into effect the concept of community-based support networks, involving lay people, lay leaders and persons trained as community AIDS workers who are supervised by coordinators and a manager. Among other things the network cares for the chronically sick, provides a link with other medical services for people who are acutely ill, helps orphans, and gives community-based counselling and testing. The community AIDS workers are seen as behaviour-change agents.

**Instilling hope**

A nongovernmental organization links orphans in Kiziba, Tanzania, with families and communities in other countries, with the
aim of improving housing and schools and providing day care and food. Young adults, most of whom imagine themselves to be HIV-positive, are trained as community social workers and employed by the organization, which counsels and tests them. When 142 of 150 tested individuals learned that they were in fact HIV-negative they were moved to love and help the orphans, commit themselves to their partners, use condoms, and live with hope. Those who were HIV-positive were given support to remain employed for as long as possible.

**Lessons**

The above examples point to certain general principles of community-based care.

- The care continuum between home and health facility should be strengthened. This requires discharge planning from health facilities, the creation of referral systems, and the establishment of community networks of support services. The nature of AIDS is such that the focus of care shifts back and forth between home and hospital. In the absence of strong links and knowledgeable staffs and families these moves can be badly timed: a chronically ill person remaining in hospital longer than necessary can become depressed and weak while the cost to the family and the health care system mounts; on the other hand a person staying at home may be given medicine and honey for a chronic cough when what is required is a tuberculosis test and, if necessary, the appropriate treatment. Hospital and home are interdependent.

- Organization at the grass roots can be expected to have the largest impact in AIDS care. However, this happens to greatest effect when the political will to tackle AIDS exists at all levels.

- Individuals and communities have the capacity to convert fear into hope, rejection into acceptance, uncertainty into confidence, and risk-taking into risk-preventing. The individual’s capacity can be reinforced by a supportive community.

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- Care-givers have the opportunity to give information on a personal basis about safer sex and other measures for preventing the spread of HIV.

- After counselling and testing, early intervention can bring personal and social benefits – if there is a community commitment to care. Individuals can be empowered by knowing whether they are HIV-negative or HIV-positive – if social support is available. The risks of stigmatization, discrimination and isolation should be challenged, not by denying basic information but by fighting for acceptance, tolerance and solidarity.

- Volunteers with a strong commitment and a generous, nonjudgemental spirit are essential if community-based care is to become a sustainable reality.

- Depression and despair are contagious and lead to inaction; hope, however, is also catching.

**Problems and solutions**

Possible actions for dealing with certain problem areas confronting community-based care are outlined below.
AIDS

Fear and stigma

- Defuse social tension in a religious and cultural context.
- Believe in capacity to change.
- Reward volunteers for their generosity of spirit.
- Distribute information, e.g., WHO/UNICEF document *Living with AIDS in the community*.

Where and when to seek help

- Strengthen the continuum of care.
- Build an alliance between health facilities and communities.
- Use good information sources, e.g., the WHO AIDS home care handbook.

HIV and tuberculosis

- Teach prevention of the transmission of HIV and tuberculosis in all care settings.
  - Any person who has a cough for three weeks or longer should seek early assessment and care.
  - Persons should cover their mouths when coughing.
  - It is advisable to avoid being in an unventilated space with a person who has had a cough for more than three weeks.
  - Homes, health facilities and other places where people meet should be ventilated.

The burden on women

- Improve women’s overall status and thus their options in society.
- Advocate that both sexes provide care and that household tasks be reallocated if necessary.
- Review the domestic distribution of labour, especially in respect of food production.
- Recognize and reward the informal care provided by women in homes.