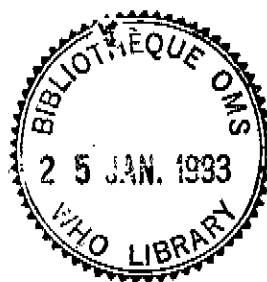

GLOBAL
PROGRAMME
ON **AIDS**

REPORT OF THE
WORLD HEALTH ORGANIZATION/
COMMONWEALTH SECRETARIAT
REGIONAL WORKSHOP ON
HIV/AIDS COMMUNITY-BASED
CARE AND CONTROL

ENTEBBE, UGANDA
6-11 OCTOBER 1991



COMMONWEALTH
SECRETARIAT



WORLD
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1. Introduction

The provision of care for those with HIV-related illnesses and AIDS in the developing world presents new problems with no obvious solutions. However, providing such care does create opportunities for health promotion and disease prevention, which often remain unrecognized unless health care providers and programme managers are prepared to integrate each of these aspects into the whole spectrum of HIV/AIDS-related health care services.

Maintaining the care-prevention balance is very important, especially since there is as yet no cure for AIDS. For example, desperate and hopeless families coping with members who are suffering from the anxiety and multiple symptoms of AIDS need compassionate integrated care, but they also need information which can provide family members with some hope of remaining uninfected.

However, family and community participation in caring for the sick at home still remains an unsupported service in most places, despite overwhelming needs. This problem is now being addressed by both the World Health Organization (WHO) and the Commonwealth Secretariat.

It was in this context that a regional workshop on HIV/AIDS community-based care and control was organized jointly by WHO and the Commonwealth Secretariat, and held at the Lake Victoria Hotel, Entebbe, on 6-11 October 1991, hosted by the Government of Uganda. The proceedings of the workshop are described in this report.

2. Objectives

The objectives of the workshop were to:

- (a) review existing HIV/AIDS community-based care and control, and identify possible future needs in specific African countries;
- (b) discuss various models for the provision of HIV/AIDS care from hospital to home, with particular focus on community participation and home care;
- (c) visit and review several existing models of community-based care and control groups helping people with HIV/AIDS, and their families, in Uganda;
- (d) develop project proposals/plans for HIV/AIDS community-based care and control, and explore potential funding mechanisms;
- (e) identify ways of enhancing collaboration between governments, nongovernmental organizations (NGOs) and professional associations to promote the development and provision of HIV/AIDS community-based care; and
- (f) develop plans for exchange mechanisms within and between countries in order to augment community-based AIDS activities.

3. Background

The WHO Global Programme on AIDS (GPA) was established in 1987, the same year in which several community-based care programmes were initiated in Uganda and Zambia. In 1989 GPA reviewed 6 home care programmes in these 2 countries (reported in document GPA/IDS/HCS/91.3). The WHO Regional Committee for Africa also requested guidelines that would help African countries to address the demand for AIDS-related care. Several meetings were subsequently held on identifying needs, and on planning, and establishing guidelines for, community-based care.

At the Ninth Commonwealth Health Ministers' Meeting in Melbourne, Australia, in October 1989, health ministers from the Western, Eastern, Central and Southern African Regions identified community-based HIV/AIDS management and control as a priority area for further involvement of the Commonwealth Secretariat. They recommended that the Zambian community-based programmes be used as examples of working models.

The Commonwealth Secretariat consequently held a regional workshop in March 1990 in Mwanza, United Republic of Tanzania, an area seriously affected by the AIDS epidemic. The 14 participants included senior health officials and heads of national AIDS committees. A list of recommendations to be acted on by governments, regions and the Commonwealth Secretariat was drawn up and later endorsed by health ministers at their 1990 Pre-World Health Assembly Meeting in Geneva.

In 1991, WHO and the Commonwealth Secretariat decided to complement and coordinate their efforts to promote HIV/AIDS community-based care by holding the joint workshop referred to on page 3 and reported below in full, in order to meet the objectives outlined in Section 2 above.

4. Participants

The workshop was attended by a total of 44 participants from 8 African countries: Ghana, Kenya, Malawi, Nigeria, Uganda, United Republic of Tanzania, Zambia and Zimbabwe. These were largely senior health officials, representatives of nongovernmental organizations (including professional associations), representatives of national AIDS committees and home care implementors.

In addition there were representatives from international and regional organizations, including the International Planned Parenthood Federation (IPPF), the International Development Research Centre (IDRC), WHO Headquarters, WHO Regional Office for Africa and the WHO Sub-Regional Office in Harare, the Commonwealth Secretariat, the Commonwealth Regional Health Secretariat for East, Central and Southern Africa, and the West African Health Community (see Annex 1).

5. Opening session

The workshop was inaugurated by the Honourable Dr James Makumbi, Minister of Health, Uganda, who reminded participants that in managing HIV-infected people and those with AIDS it was necessary to consider the many aspects of the disease which cut across medical, sociocultural and economic status.

Dr Makumbi went on to say that health ministers in the Third World had always relied on hospitals for the care of the sick. These hospitals, however, were never designed to handle massive disease phenomena like AIDS, which partially explains why the infrastructure is now failing to cope with the burden of AIDS.

Between 20 and 40% of hospitalized cases in some hospitals in East Africa were now due to AIDS. In Uganda, about 70% of tuberculosis ward beds are occupied by people with AIDS-associated cases.

To emphasize the importance of preventive measures, including safer sex and condom use, Dr Makumbi outlined the difficulties of funding AIDS care. He compared the amount of gross national product (GNP) available per year for health care spending in Uganda - which was usually less than US\$ 10 per person - to the expenditure per year on an AIDS patient, which was between US\$ 130 and US\$ 1580 per year in the United Republic of Tanzania and between US\$ 100 and US\$ 630 in Zaire.

In Africa, he said, communal efforts were traditionally mobilized, not only in the aftermath of disasters and misfortunes, but also in times of joyful events. In advocating community-based home care, the health services were rekindling this idea and Africans were being reawakened to their traditional values.

The opening session was also addressed by Prof Thairu, Medical Adviser, Commonwealth Secretariat; Dr Fasan, Programme Manager, Global Programme on AIDS, WHO Regional Office for Africa; Dr Naamara, Director, Uganda AIDS Control Programme, Ministry of Health; and Dr Lwanga, Director-General, Uganda AIDS Commission Secretariat.

6. Workshop methodology

The information and theoretical approaches required to achieve the workshop objectives were introduced through plenary sessions and printed material (see Annex 2). These were followed by group work, which resulted in the development of outlines of draft proposals for projects in HIV/AIDS community-based care and control in each country considered. Participants undertook to subsequently finalize their proposals and submit them for consideration to their respective governments, and also to WHO, the Commonwealth Secretariat and other international agencies for possible support. Field visits were arranged to observe community-based programmes in Kampala and in the Masaka and Rakai districts.

7. Workshop presentations

7.1 The consequences of AIDS for health care in Africa

An overview of the AIDS problem and the consequences for health care in Africa was presented by Dr E. van Praag, Chief, Health Care Support Unit, WHO/GPA.

Health care systems find it increasingly difficult to sustain the quality of patient care and a variety of structural, managerial and socioeconomic factors, within and between countries, have been associated with this situation. The AIDS epidemic has been an additional burden, making it even more difficult

to respond with innovative care and preventive activities for HIV/AIDS patients and their families. How well the health care system can cope will depend on two factors.

The first factor is the development of the AIDS epidemic itself, in particular the increasing number of patients. WHO estimates that the number of people developing and already living with HIV-related diseases in sub-Saharan Africa as of 1990 was 200 000, and will increase to 700 000 during 1991. However, these numbers are not equally distributed. One finds more patients in central and south eastern regions than elsewhere in Africa. Even within countries, HIV seroprevalence and disease occurrence is more common in urban and trading areas than in rural areas. Eventually most affected people will utilize a health facility, often in combination with traditional care providers. Hospitals in major cities in central and eastern Africa already report that 50-70% of the adult in-patient beds are occupied by people with HIV-related illnesses (see Table 1).

Table 1. Percentage of hospital beds occupied by patients with HIV-related disease (1991)

HOSPITAL	BED OCCUPANCY (%)	WARD
Mama Yemo, Kinshasa, Zaire	50	Medical Ward
University Teaching Hospital, Lusaka, Zambia	40-60	
Kigali Central Hospital, Rwanda	50 60	Paediatric Medical
Bujumbura Prince Regent Hospital, Burundi	60	Medical
Rural District Hospital, Zambia and Uganda	10-40	

A second limiting factor lies within the health sector itself. Decreasing funding levels from governments and the donor community have left health care services struggling to provide even basic care. For example, treatment of opportunistic infections requires accurate diagnosis, time and expensive drugs (see Table 2).

Table 2. Comparison of drugs costs for HIV+ and HIV- patients in a rural African district

Status of patient	Average length of stay (days)	Drug cost per day (US\$)	Total average drug cost (US\$)
Hospital-based care:			
HIV-, TB-	11	0.76	8.34
HIV+, TB-	17	1.45	24.07
HIV+, TB+	62	0.55	33.90
Home care:			
HIV+ (a)	12 months	NA	5.96

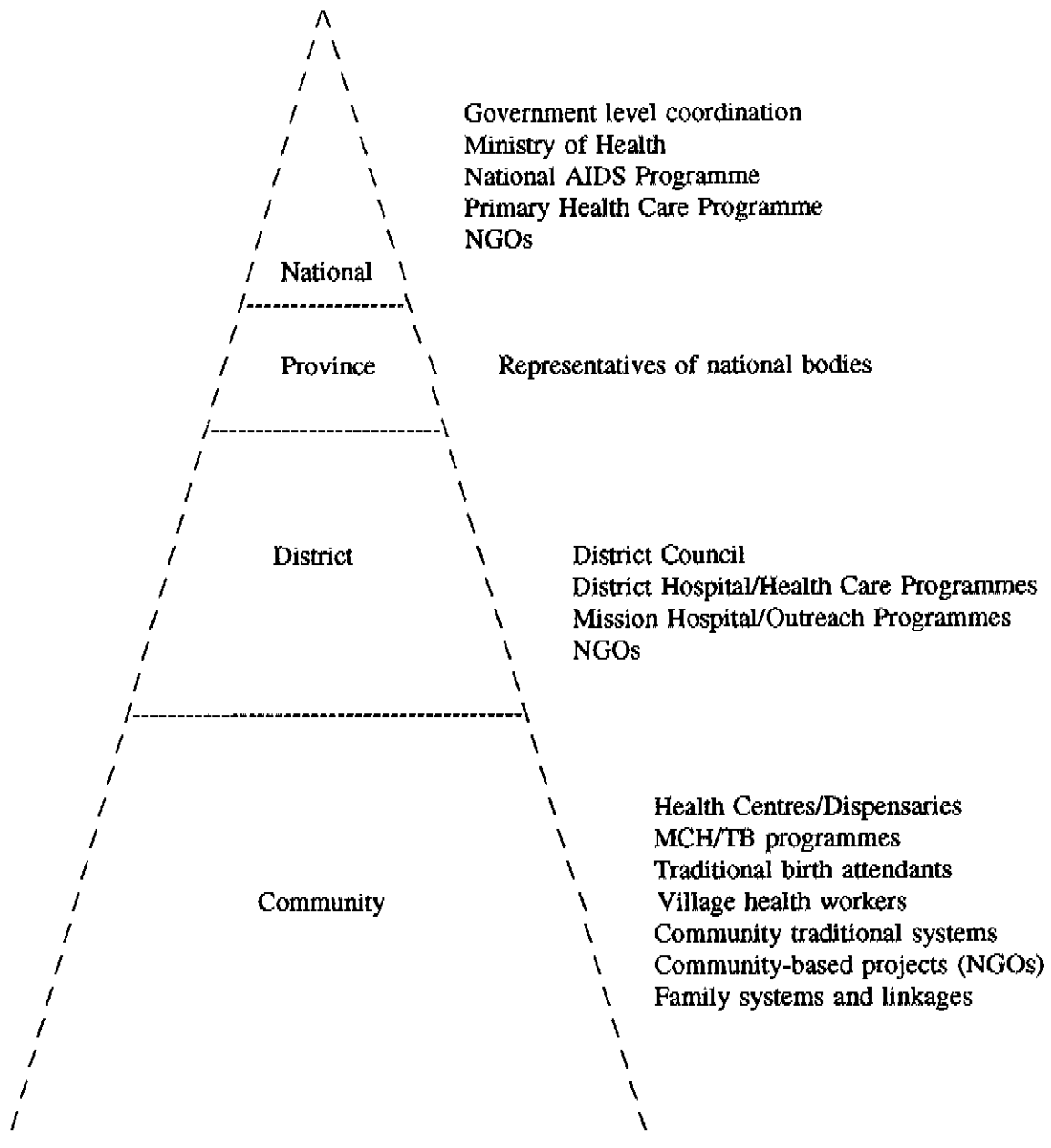
- (a) Home care patients suspected of having TB are admitted to hospital for further investigations. Source: Derived from Chela *et al.*; 1989, Tables 6 and 7, *AIDS Care*, 1(3), S. Foster, 1990, *Tropical Disease Bulletin*, 07,11,2.

In addition, training and allocation of human resources have not as yet resulted in sufficient numbers or optimal distribution of care providers. Career opportunities have not been created for young bright health professionals, leading to a movement to the private sector or abroad.

In a very short time a variety of information campaigns and outreach efforts, clinical and epidemiological research studies, expansion of laboratories, as well as an increase of tuberculosis programme activities and the clinical management of AIDS patients have overwhelmed health workers, and the system itself. Despite these pressures, innovative approaches to the provision of dignified patient care and to overcoming stigmatization have been developed in many places.

These approaches have often been spontaneous and based on principles of decentralization and broad participation. Potential resources at all levels of the health care pyramid have been identified and utilized, with the broadest resources being available at the community level (see Table 3). Decentralization of tasks and authority to district levels in order to generate planning based on local needs has been pursued in some national AIDS programmes. Decentralization can lead to flexible and rapid implementation at the peripheral level. Sharing of responsibilities for care between government and nongovernmental organizations (NGOs), and between the health care providers and family members, has occurred in a very short time.

Table 3. Health care resources for the promotion of community-based care for people with HIV/AIDS



7.2 Issues for consideration in the planning and costing of AIDS patient care management

An outline of resource needs covering categorization of costs, specific capital and recurrent costs, use of cost data and finance was presented by Dr C. Cameron, Health Economist, WHO/GPA.

As the number of people with AIDS increases it will be important to plan how each country will meet their needs. As part of that effort it is necessary to consider how much programmes will cost and who will pay for them. Initially it is necessary to understand the dimensions of the current and projected epidemic. This means estimating the number of HIV-infected people and the number of AIDS cases. It is then necessary to undertake an assessment to determine the medical and welfare needs of those with AIDS.

The type of care to be provided must be defined, and criteria which might be useful in choosing options include the ability to integrate and build on the existing health care delivery system, appropriate access by those in need, the ability to meet the needs most cost-effectively, and the ability to accommodate political and cultural factors.

A vital link between planning and implementation is identification of resource needs and sources of funds. This can be done by categorizing programme elements into broad classes, specifying cost elements within the classes, performing simple analyses and deciding how options will be financed. Cost data are useful for a number of reasons including: accountability, assessing efficiency, and making cost projections and cost-effectiveness analyses.

Many analysts divide programme elements into those which have a useful life of significantly more than one year (capital) and those which are consumed during a year of operation (recurrent). For example, vehicles have a useful life of more than one year and are therefore classified as capital. However, fuel and repair for vehicles are needed continually and are therefore classified as recurrent costs. Calculating the distribution of costs into capital and recurrent categories can address two issues. First, since in developing countries many capital costs are funded by external donors, the analysis indicates how much will be needed from donors. Second, since capital has to be replaced over time, this helps in deciding how it will be replaced and by whom. As a further example, it might also be possible to compare the costs of AIDS-related health care at a central hospital with those of similar services at a community-based setting. This can provide decision-makers with information which can help in planning where to deliver care.

An integral part of evaluating options is finance. This will be a key factor in determining who receives what type of care at different locations. In general, financing directly affects a number of important issues including: equity, accessibility of services, affordability, foreign exchange requirements, local cost requirements and programme sustainability. The entire range of possible financing options should be considered, including government, external donors, community-based income generation, self-pay, and families and friends. Typically, care options will be financed using a mixture of different mechanisms. This both encourages input from many sources and diversifies the funding base, thereby helping to ensure the financial viability of the programme over time.

It is not enough to determine options, evaluate them and choose a programme; they must also be successfully implemented. Over time, it will be important to monitor the programme to determine if it is on schedule and to identify areas which must be further addressed. Indicators which might be useful include: noting types of services offered at different service locations, estimating the number

of people receiving each type of service over time (month or year), determining the number of times per year an individual with AIDS received services and noting how services were financed.

While examination of financing issues can be a daunting task, there are already some encouraging indications concerning community-based care. Initial studies in two African countries indicate that drug delivery and counselling are more cost-effectively delivered through home care, and that people with AIDS prefer home-based care to institutional care.

In summary, it might at first glance appear that planning, costing and financing are complex and difficult to undertake. In most cases, all three can be undertaken with different levels of intensity depending on the questions being asked. In all cases, informative analyses can be done using a pencil and paper and calculating a few ratios. Even simple analyses can empower managers in developing countries by clarifying their thoughts and the planning process. In addition, it can strengthen decision-makers' ability to deal with external donors at a time when donors are asking tough questions about the cost and effects of patient management options.

7.3 Review of three community-based care programmes in Uganda

The AIDS Support Organisation (TASO)

Presentation by Mr E. Maraka, Dr S. Kalibala, Ms R. Bunnell, Mr S. Mulindwa-Sempungu, guest speakers.

TASO is a voluntary, non-profit making, non-denominational, charitable organization founded in Kampala in 1987 by a small group of local people, the majority of whom were themselves infected with HIV. The success accorded to TASO today demonstrates that the active participation of beneficiaries themselves is one of the primary necessities in effectively addressing the problems affecting their lives.

The problems identified by TASO include:

- lack of information among health care providers and laymen about the new "killer disease" - its etiology, mode of transmission and how it could be treated/managed
- stigmatization of people identified as "AIDS victims"
- lack of drugs for the treatment of HIV/AIDS-related diseases
- inability of the economy and social services of the country to meet the cost of medical treatment and to support dependents.

The evolution of TASO has taken place in three phases:

- Development of a hospital-based model of HIV/AIDS care and counselling.
- Extension of the institution to provide medical home care.
- Development of a community-based programme.

TASO now offers counselling on weekdays at the TASO office and at the homes of clients, and twice weekly at the TASO clinics at Mulago Hospital, at the Immuno-Suppressive Syndrome Clinic for adults and the Paediatric Clinic for mothers. The counselling, which is given on a one-to-one basis, includes pre- and post-test counselling and ongoing counselling.

The essence of HIV/AIDS counselling is to empower people to take control of their lives. This presupposes that there are people who have the required skills, positive attitudes and motivation to do the job. Fear of contracting HIV through casual contact affected all professionals, including social workers who had the counselling skills. TASO has trained nearly 300 HIV/AIDS counsellors for its own project needs as well as for other organizations involved in AIDS work. A counsellor's manual has been produced and a training curriculum for counsellors is being developed.

AIDS-related medical care is provided at the TASO and hospital clinics and now also in the homes of clients by government-employed clinicians who work with TASO part-time. Institutionalized care is carried out within the government hospital in a complementary manner.

As the majority of TASO clients are poor, social support is provided, when available, in line with the TASO ideology of living positively with AIDS. TASO runs a day-centre where people with AIDS meet, share a meal and engage in light and productive activities, such as handicrafts. Currently TASO is also supporting the primary education of nearly 800 children whose parents have AIDS.

TASO Mulago model

With external support from Action Aid, a British NGO, TASO established an AIDS Counselling Centre in the government-run Mulago Hospital. The Centre provides a package of services which includes:

- counselling
- medical care
- social support.

Over the last 3 years, the TASO Mulago model has been replicated in 6 other districts - Entebbe, Jinja, Masaka, Mbale, Mbarara and Tororo - along the trans-Africa highway where AIDS was initially high. These centres, which were all established in response to a need expressed by the people of the respective districts, are managed by local committees with back-up support from the TASO head office.

The TASO Mulago model demonstrates a unique approach to the AIDS problem. TASO recognizes that AIDS education and prevention is the best weapon available in the fight against HIV infection and related disease. At the same time TASO recognizes the need to care for those already infected. To meet these very demanding needs, TASO has approached the problem directly through those infected. They are the entry point to the family and community. By involving HIV-infected people and those who are not infected, or who do not know their serostatus, in the care of people with AIDS, TASO is offering not only AIDS care but also AIDS education and prevention.

The hospital-based Mulago model is not without weaknesses. Initially, clients remained stigmatized in their communities because of the lack of community participation. Moreover, the number of patients who sought hospital admission - even for illnesses which could be managed in the community - increased unmanageably.

Medical home care

In response to this situation, TASO strengthened home counselling visits to include home medical care and support for families caring for sick relatives. Family members have been taught how to administer simple treatments, including intravenous feeding. This marked a new phase in the evolution of the TASO service in caring for AIDS patients.

TASO community programme

Despite the support of home medical and counselling visits, TASO clients still experienced stigmatization within their communities. The increasing number of clients made it difficult for TASO staff to offer enough support at the community level. At the same time, a number of communities were approaching TASO for assistance in AIDS education and care. In September 1990, these factors led TASO to initiate a new activity, the TASO community programme, with the aim of building community capacity to respond to the AIDS epidemic.

The results of surveys conducted in pilot sites indicated that most community members felt that there was no one in their community to provide them with facts about AIDS. Over 90% of those surveyed indicated that they would want to care for their relatives with AIDS, but they had never received any training in home care. Many people had fears about how to manage diarrhoea and other symptoms. Most women indicated that they expected to become infected in the future because they could not trust their husbands. Thus, the survey showed the need for more community openness about HIV/AIDS, effective training in home care, accurate information about HIV/AIDS and community counselling.

Following the initial success of activities in the pilot sites, TASO expanded the programme to more communities in the Kampala area as well as to Mbarara, Masaka and Tororo. As a result of the experience gained in these communities, TASO has also developed a conceptual model which serves as a flexible guide for trainers as they establish the programme in new areas.

This model can be clearly illustrated by the example of Saeta-Nazigo. This community of about 4000 people, situated about 25 kilometres from Kampala, has been hit hard by AIDS. On their own initiative, a group of community members formed a drama group which performed plays giving AIDS education. Community members requested TASO to provide training in AIDS education which could help them to improve their plays. They also asked for information on home care, since many families included AIDS patients.

Initially TASO staff conducted a site investigation to ascertain the level of commitment and interest in the community programme. Later, Saeta-Nazigo was selected as a pilot site and a mobilization workshop with community leaders was held. During this workshop, the community members discussed the effect of AIDS on their community and developed an action plan. Later, the community formed the Saeta-Nazigo TASO Committee to oversee and coordinate AIDS activities at the local level. The committee helped the community to define its own objectives for the programme. Saeta-Nazigo, like many other communities, chose to focus on AIDS education, home care and orphans. The community selected 25 TASO community workers (TCWs) who were trained by TASO in AIDS education, home care, basic counselling, referral and prevention information. The TCWs then carried out home visits and AIDS education, using drama in particular. The community also initiated a small butchery project which gives support to the TCWs and the committee. The example of Saeta-Nazigo illustrates the approach TASO has used with many other communities.

Although a participatory evaluation of the community programme has not yet been undertaken, indications of the programme's impact are clear. To date, over 200 community workers have been trained by TASO for its own programmes and for those of other organizations. These community workers have completed a tremendous amount of work. For example, in Muswangali, a densely populated semi-urban community, 14 TCWs conduct an average of 306 home visits per month. The TCWs are encouraged to visit all homes in their area for educational purposes, regardless of whether a patient is present. On the prevention side, TCWs also distribute condoms after training interested people in their correct usage. As a community becomes more aware and more comfortable with its TCWs, the demand for condoms increases. TCWs are trained in basic counselling skills and attitudes and are able to make referrals for HIV-testing in those areas where this is available. This can help some HIV-positive individuals to begin to speak openly about their status.

Challenges for the TASO community programme

Despite these successes, a number of challenges have been encountered in this programme. First, there is an inherent contradiction in the concept of a community-based AIDS programme. By its very nature, a truly community-based programme needs a long time, often years, to develop strong roots, as experience in community-based health care has shown. Yet, with HIV/AIDS as the focus of the programme, time is limited. The high HIV seroprevalence rate in Uganda has meant that communities have felt the impact of AIDS as a crisis in emotional, social and economical terms. However, the urgency of the problem counteracts some of the basic principles of community-based work.

This dilemma has in some ways facilitated demand for the TASO programme from communities themselves and community mobilization has been relatively easy.

One strategy which TASO has used to address both the internal contradictions in a community-based AIDS programme and the large community demand for the programme is to work with existing community-based organizations. TASO has worked with community health workers, traditional birth attendants, women's groups and church groups, as well as with other organizations through a training of trainers approach, which it plans to expand.

Other challenges have been relatively easier to address. The second challenge was to empower community workers with sufficient knowledge about HIV, through new educational approaches. For example, although Ugandans are relatively well-informed about modes of HIV transmission, many surveys have shown that few people understand the progression of HIV/AIDS. Thus, TASO developed a pictorial story as a simple means of teaching community workers about the stages of HIV infection. Drama, song and dance are also used extensively, particularly by the TCWs, in the education of communities. Despite these efforts and the constant development and field-testing of new training modules, one persistent problem is the lack of materials for semi-literate or illiterate people.

A third challenge has been confronting the socio-economic consequences of AIDS. Village committees and TCWs work strictly on a voluntary basis, with TASO providing no allowances or incentives. As a result, a number of the more established communities have opted to initiate income-generating activities so that the community has some funds for supporting patients, orphans and educational seminars. The initiation of these income-generating activities although a positive step in terms of community ownership of the income-programme, has consumed much of the time of the TCWs and the committee which would have otherwise been spent visiting homes and educating.

Additional problems have arisen concerning the TCWs themselves. Not surprisingly, most of the people who are willing to volunteer their time have personal concerns about AIDS. The initial training did not give participants enough time to work through their own personal fears, but focused on helping others. Over time, however, many TCWs have had to cope with the discovery that they themselves are HIV-positive. Although most TCWs have remained committed to the programme, the work is emotionally and physically draining. Although attempts have been made to incorporate more support activities and time in TCW ongoing training, TASO trainers have found it very difficult to provide sufficient support for the TCWs who are dealing with both their own personal concerns about HIV and those of the community.

Finally, a strong referral system is a prerequisite for this model. Unless community workers can refer community members for professional medical treatment and counselling, they will not be able to deal with many of the cases they encounter. For this reason the TASO model is only replicable in those areas where there is a strong referral system. Unfortunately, the need for community-based AIDS care and education is greatest in the more isolated areas where there are often no referral units with staff trained in HIV/AIDS. TASO is trying to overcome this problem by training medical personnel in local referral units in HIV/AIDS care and management.

The TASO community programme is still adapting itself to new parts of the country. New challenges emerge, especially as the number of AIDS patients continues to increase in Uganda. The TASO experience has shown that communities are confronting the problem of AIDS, and that community-based efforts to extend AIDS education and care can be successful. The communities involved in the TASO programme have indicated that their training must be related to care as well as prevention, because people are dying daily and many families feel helpless, unable to cope with the caring of loved ones. Moreover, at the community level, any programme must develop a strategy to cope with the socio-economic consequences of AIDS through an integrated and comprehensive approach.

Given the tragic estimates of HIV prevalence in Uganda, community-based approaches are the only viable option for the future. In order to succeed, however, government and NGOs must work side by side. Donor agencies must look critically at the broad impact of AIDS as it is felt at the community level. If people at the community level are expected to volunteer their time and energy then their efforts must be supported.

Nsambya Hospital, Kampala

Presentation by Dr M. Duggan, Superintendent, Nsambya Hospital, guest speaker.

In 1988, the administration of Nsambya Hospital, a private Catholic hospital, was under pressure to establish more wards for the increasing numbers of AIDS patients. After a review of the situation, it was decided instead to set up a Mobile Home Care Service for AIDS patients for the following reasons:

- Many patients who know they have an incurable disease prefer to die at home.
- People seem happier when cared for at home rather than in a hospital ward with other dying people.

- Follow-up of patients after a clinic visit/hospitalization is important to prevent future hospitalizations.
- Provision of care for orphans is an integral part of community-based care.
- Hospital care is very expensive.

The home care team officers can provide medical/nursing care, counselling, pastoral care, home care kits, protective clothing and where necessary, food and drink. In addition, basic nursing skills are taught to relatives and other carers. The advantages of home care include:

- continuity of treatment
- decrease in demand for hospital beds
- reduction of fear, prejudice and stigma
- participation of family/community in the care of AIDS patients.

However, it was realized that the care of AIDS patients was only one aspect of the problem. The many consequences of AIDS on the whole family became apparent and included:

- severe poverty
- lack of food
- rejection and isolation
- eviction from house (due to non-payment of rent)
- orphans
- both parents sick with children to be cared for.

The needs of the AIDS patients and their families soon overburdened the home care team and a community-based programme with 10 Christian communities in Kamwokya, a poor suburb of Kampala, was therefore started.

The volunteers in the programme assist people with AIDS in the following ways:

- visiting those who are sick or worried
- caring for people without relatives
- assisting in the home, e.g., by washing clothes
- being present, praying, reading the Bible and providing spiritual support
- bringing the community nurse to the sick person
- arranging burials
- collecting money to buy food for those in need.

Owing to the nature of HIV infection and AIDS, many people with HIV-related illnesses were prevented from working on a regular basis, especially those in low-income groups such as labourers. Small income-generating activities were therefore developed for these people, e.g., mounting pictures on wood, lamp-shade making and dressmaking. Small sums of money were also provided to start small trading businesses. These projects enabled people with AIDS to regain their dignity and renew their hope. As a result, their physical health often improved and people found they could still be useful members of society.

One young artist with AIDS was found by a volunteer lying in bed waiting for death. With the assistance of the volunteer, he resumed painting and his quality of life was enhanced and his dignity restored. He was productive for a further two years.

Homelessness is a serious problem for people with AIDS, since many lose their homes with their jobs. Initially, the programme helped people to rent accommodation, but it became too costly. A plot of land was subsequently obtained and every Saturday 40 young volunteers help to build small houses. Single rooms in these houses will be provided to homeless people with AIDS.

A large number of children have lost both parents as a result of the AIDS epidemic and the care of these orphans is an increasing problem. The programme provides material and medical support to many of those caring for orphans, e.g., elderly grandmothers, brothers and sisters. Suitable people are also nominated to take responsibility, with the support of the community, for orphans without remaining family.

Community caring has resulted in a new awareness of the magnitude of the epidemic and of the associated pain and tragedy. This in turn has stimulated a great desire to prevent further spread of the disease.

A programme on community counselling, organized by TASO, was attended by 24 community members who were later able to promote understanding concerning the prevention and control of HIV infection and AIDS.

A programme of behavioural change was also started, covering such topics as education for life and self-awareness. The programme provides education to trainers who in turn initiate groups promoting behavioural change. The programme addresses social needs and alternative lifestyles. For example, bar girls who want alternative work can attend tailoring and craft-making classes. Recreational activities - especially football, volleyball, music and drama - are also encouraged among young people as an alternative to experimenting with sex.

High motivation and a strong commitment is needed to maintain these programmes. Group support is important to ensure the right attitudes. Volunteers divide their time between the programmes for the sick and those for the young to avoid exhausting their motivation and commitment.

The task ahead is great and will require the help and cooperation of everyone in the community.

Kitovu Hospital Mobile AIDS Home Care, Social, Education and Orphans Programme, Rakai and Masaka Districts

Presentation by Sister Ursula Sharpe, Head of the Kitovu Hospital Mobile AIDS Home Care Programme, guest speaker.

Kitovu Hospital is a Catholic, private hospital in Masaka District. The Mobile AIDS Home Care Programme was set up in 1987 and is managed by nurses. The programme provides care to people with AIDS in Masaka and Rakai districts through an integrated approach.

The districts are divided into zones, each of which comprises 2000 to 3000 people. The team visits each zone every two weeks and provides basic medicines, counselling and food supplements. Home visits are no longer possible because of the large number of people with HIV/AIDS. People therefore meet in groups to see the team.

On the positive side, this can provide mutual support for people with AIDS, and by meeting together like this, the stigma of AIDS has largely disappeared. On the negative side, however, the number of people who die between team visits is very apparent.

Despite criticisms that home care is a waste of limited resources, and calls for funds to be used instead to care for orphans, other views stress the importance of home care in helping people with AIDS to retain their dignity.

The home care team found that people with AIDS wanted to return home to die. There they were often cared for by an elderly parent. In some instances grandparents had been left to look after numerous orphans, who were not always attending school. Every family in the district was burdened by AIDS. Apathy is a real problem among people waiting to die. Communities need to learn to support themselves. An education programme has also been set up for community leaders.

Many parents with AIDS are concerned, not so much about dying, but about the future of their children. Grandmothers may be left to care for many orphans, especially in some areas where up to 50% of the population is affected by AIDS. To help the grandmothers, a voluntary programme was started to cultivate crops and help with house repairs etc. To avoid dependency, orphans are encouraged to assist with such projects. The home care team brings children together twice a term to focus on such issues as physical development or behaviour change.

The effect of the increasing numbers of AIDS patients upon staff is also a problem. Moreover, many staff and community workers are themselves infected with HIV and others have already died from AIDS.

7.4 Review of two community-based care programmes in Zambia

AIDS Care and Prevention Department, The Salvation Army Hospital Chikankata, Zambia

Presentation by Dr C. Chela, Medical Officer-in-Charge, AIDS Care and Prevention Department.

Chikankata Hospital is a 240-bed general hospital run by the Salvation Army serving a mainly rural population of 100 000. In May 1986, the first AIDS patient was diagnosed in the hospital. By the end of that year there were 37 more HIV-infected patients.

By March 1987, realizing that HIV had the potential to overwhelm the hospital's limited resources, the administration developed a field-based AIDS Care and Prevention Department.

The setting up of the Department was based on the following four assumptions:

- In rural Zambia the family is the most effective means of supporting people with HIV infection, and of assisting the hospital in the provision of health care.
- As the incidence of HIV infection continues to increase, the decentralization of health care is the key to providing HIV-infected people with medical, nursing, spiritual, social and psychological support.
- Taking care into the community has itself an educational effect on the members of the family and the wider community, thus contributing to behaviour change for the prevention of HIV transmission in the longer term.
- Terminally ill patients prefer to die at home.

The activities of the Department have evolved in three phases:

- Phase I Home-based care and prevention.
- Phase II Hospital intervention.
- Phase III AIDS management training seminars.

Phase I - Home-based care and prevention

Ongoing home-based care is provided to an average of 250 patients, their families and their immediate communities every 3 months.

The objectives of the home-based care team are to:

- (a) visit people with HIV infection in their homes in order to assess their physical, psychological, social and spiritual needs, and to provide for these needs where possible
- (b) trace sexual contacts
- (c) counsel and educate within families and communities, providing personal support, and promoting sustained behaviour change through community counselling

- (d) assess the educational impact of AIDS management on people with HIV/AIDS and their families
- (e) provide material support, giving out HEPS and milk. On occasion the hospital receives donations of blankets and clothes which are distributed.

The team, which includes a clinical officer, a trained counsellor, a nurse, a school educator/trained counsellor and a driver, carry out home visits three days a week and attend to the total needs of five to eight patients each day.

On the remaining two days of the week, a second team goes out to work with the communities - clarifying facts about AIDS, helping communities identify activities which put them at risk, and developing strategies that will prevent them from engaging in high-risk activities. This process is called community counselling and promotes responsibility transfer for behavioural change from people such as health care personnel to the community.

Principles of counselling, as applied to a one-to-one situation have been transferred to counselling a large group or a community. This includes relationship-building, problem exploration, understanding and decision-making, implementation and evaluation.

The team works with different types of communities: kinships based in villages; occupational groups based in industrial towns; commercial farms; religious groups based in churches; and party system based communities. At present 18 communities are involved in the programme.

Some of the strategies for prevention developed by these communities include abolishing ritual cleansing by sexual means, the reinstatement of marriage ceremonies, and selecting a member of the community to carry on the community counselling process in the absence of the hospital community counselling team.

Home care and community counselling teams have been set up at the 4 rural health centres within the catchment area. They will undertake AIDS care and prevention activities, as far as possible, with the transport available, and will continue home-based care and community counselling activities in areas not covered by the 4 rural health centres.

It is planned to train village health workers, and other volunteers who are part of the primary health care structure, so that they will join the AIDS care and prevention network.

Phase II - Hospital care and intervention

The hospital's management plan consists of diagnosis/counselling, planned discharge, home-based care and, when required, hospital admission.

Although the main focus of this plan is to return patients to their homes to be cared for by extended family, the hospital plays a vital part in diagnosis, stabilization and readmission for additional treatment.

Phase III - AIDS management training seminars

Since July 1989, the Chikankata AIDS Care and Prevention Department has been conducting a five-day seminar each month. It is aimed at health professionals and others who are involved in, or need to start, an AIDS care and prevention programme.

The seminar uses an integrative approach covering counselling, clinical care, education, pastoral care and administration. The content is based on the practical experiences of the field-based AIDS care and prevention programmes at Chikankata Hospital.

Community and Home-Based AIDS Care in Monze District

Presentation by Dr V. Mukonka, District Medical Officer, Monze District Hospital.

Monze Mission Hospital is situated in Monze Town, 187 km south of Lusaka on the main Lusaka/Livingstone Road in the Southern Province of the Republic of Zambia. Although a mission hospital and member of the Christian Medical Association of Zambia (CMAZ), it serves as the official district hospital for the Ministry of Health. Monze District covers an area of 6687 sq. km with a population of about 160 000 and 14 rural health centres.

Monze District Hospital introduced community home-based care to help people with HIV/AIDS. This programme is an integral part of the primary health care system which reaches the periphery of the district. An essential emphasis of the programme is the liaison between all the health care facilities available, including the district hospital, rural health care centres, community health workers and trained traditional birth attendants. The family of each patient is also involved in the programme.

The objectives of the programme are to:

- (a) strengthen the facilities available for AIDS care and to integrate AIDS care into the existing facilities
- (b) facilitate relief of the physical, social and psychological suffering associated with HIV infection
- (c) promote educational activities to reduce, through increased public awareness, the progression of the HIV epidemic
- (d) promote the home-based care of patients in such a way as to be acceptable to the family and the community.

Structure of the home-based care programme

The programme's mobile team comprises a social worker, family health nurse and a driver. Other professionals who occasionally accompany the team on outreach activities include the health education officer and a clinical officer from the out-patient department.

The social worker coordinates and assesses the home-based care activities. The health education officer is a part-time member of the home-based care team. He is the co-ordinator of all health education activities and organizes health education sessions and Anti-AIDS Club activities. The family health nurse is involved in nursing HIV/AIDS patients both at home and in hospital. She advises the patients' families on how to deal with illnesses arising as a result of HIV infections. For instance, she demonstrates how to prepare oral rehydration solution (ORS) for HIV/AIDS patients with diarrhoea. The clinical officer is also a part-time member of the team. On the occasional home visits he makes with the mobile team, he deals with complex medical problems and their treatment at home, if possible.

The team is supervised by the district medical officer working closely with the doctors-in-charge of in-patients. The mobile team closely supervises the activities of, and liaises with, the individual institutions in matters relating to the home care of HIV/AIDS patients.

How the programme operates

The programme's operations start within the hospital with the diagnosis of HIV-related illnesses. When a patient is diagnosed as having HIV infection or AIDS, he/she is counselled while in the hospital. Trained counsellors on each ward undertake pre-test counselling. Post-test counselling is carried out by the home-based care team. Counsellors and family health nurses are also available in the antenatal, postnatal and gynaecology clinics. Each of these counselling activities, including planned discharge, is the responsibility of the home-based care team.

Post-test counselling marks the beginning of a purposeful relationship between the patient and the home-based care team. After the patient is informed that they are HIV-positive, the implications and consequences of HIV infection are discussed. The importance of home-based care is also discussed and the patient's active agreement is sought.

Following this, the patient is discharged and taken to their village via the rural health centre. Here the patient is introduced to all the staff and one staff member then accompanies the team to the patient's home via the community health worker (CHW). The CHW or trained traditional birth attendant (TBA) is then introduced to the patient before he/she is finally taken home. The purpose of contacting the rural health centre staff is to make them aware of the presence of each HIV-infected patient within their catchment area. These staff are then expected to visit the family and check on the patient's condition.

During the initial home visit, every effort is made by the health staff to educate family members, and to provide advice on things such as a good diet, continuing with normal life as far as possible and having a positive attitude. The nurse makes sure that a family member knows how to make ORS in case the patient develops diarrhoea. The CHWs or TBAs are also expected to visit the patient frequently in order to deal with the illnesses resulting from HIV infection. If the CHW or TBA cannot cope with the patient's conditions, they refer them to the nearest rural health centre. Hence, the CHW or TBA becomes the first link in the chain of health care for the patient. In this way, community home-based care is integrated into the primary health care programme within the district.

Finally, the home-based care team visits patients to assess their condition and to strengthen the role of the CHWs, TBAs and rural health centre staff.

AIDS education is another aspect of the home-based care programme. In 1990, Headmen and their communities were educated about HIV/AIDS, particularly on the modes of transmission of HIV and the dangers of sexual cleansing rituals.

Of the six Chiefs, five have now passed laws that sexual cleansing rituals should cease. Only one Chief still remains to be convinced.

Problems with community-based care and some solutions

Community level

The following problems and potential solutions have been noted at the community level:

- The CHWs and TBAs form an integral part of AIDS-based care in Monze District. This cadre of staff undergo only a 6-week initial training period. Experience has shown that unless they are supervised by rural health centre and district health management team staff on a regular basis and supported in their community interactions, the quality of their service and commitment decreases. Regular refresher training at the rural health centre on PHC and AIDS-related activities also provide opportunities to monitor and evaluate their work.
- The available information on HIV and AIDS, presented to communities by means of literature, films and slides, is inadequate, especially in areas such as sexual ritual cleansing. District, ward, section and branch leaders are not fully involved in AIDS education.
- The problem of orphans and bereaved aged people is increasing, especially for widows who on the death of their spouse lose their home. Assistance should be provided to orphans to cover school fees, probably for about a year. The law to stop inheritance of property of the deceased should be enforced and the whole property should be left to the widow and children. These issues should be discussed with the Headmen and Chiefs.
- The burden of caring for seriously ill patients falls on the patients themselves, relatives and health care staff. Hence emphasis should be placed on providing practical and material assistance in caring for patients, thereby easing the burden on the family.

Rural health centre level

Most of the rural health centres in the district are in a dilapidated condition and most have only 3 or 4 beds. Linen, blankets, towels and cleaning materials are in short supply. The problem of accommodation for a potentially large number of patients still remains. The staff have to cover very long distances to visit AIDS patients, and they are provided with bicycles.

Hospital level

Problems noted at the hospital level are as follows:

- staff shortages
- HIV test results usually arrive late, sometimes after the patients are discharged from hospital
- delays in receiving funds have disrupted the programme of AIDS-related activities.

Emphasis should be placed not only on the counselling and preventive aspects but also on providing practical help in caring for the patient. This requires careful planning, training of staff and community, and availability of drugs.

7.5 Summary of country presentations

Ghana

AIDS was first recognized and reported as a disease in Ghana in March 1986. By the end of that year 26 cases had been officially reported. Since then, the number of cases has risen rapidly and as of 30 June 1991 a total of 2474 cases have been officially reported from all the regions.

The highest number of HIV/AIDS cases has been reported in the Eastern region of Ghana. One centre in this region that has developed a pioneering programme for people with AIDS is St Martin's clinic, part of the Catholic Mission in the town of Agomanya, 50 miles north of Accra, which serves a population of almost 200 000.

Between April 1988 and December 1990, St Martin's Clinic treated a total of 409 HIV-positive people. The two-person AIDS team also provided care and support to 84 people through home visits during this period.

The objectives of the home-based care project are to:

- (a) provide home-based care for AIDS patients to reduce the stigmatization and rejection of patients
- (b) provide pastoral care and counselling for people with HIV infection and AIDS
- (c) explore the possibility of providing an alternative source of income and employment for patients and young people, particularly women
- (d) educate the family, general community and young people about AIDS, with a view to reducing the number of people placing themselves at high risk of HIV infection.

Patients are referred to the hospital by other patients or they use the facility as one of the health institutions in the district. There is no special AIDS clinic at St Martin's.

HIV-positive patients are seen on an out-patient basis at the hospital and are also visited at home. The drugs and other medical supplies they receive are free of charge. Two days a week an AIDS worker and a community health nurse visit people with AIDS in their homes. During the visit, family members are educated about the transmission of AIDS and the importance of good nutrition and personal hygiene for the patient.

A clinic is held outside the hospital for patients living far away. This enables many people in outlying villages to use the services.

A team of volunteers visits patients and their families on a regular basis. During the visits they provide the needy patients with soap, food and other essential items. The volunteers, many of whom are youth group members of the Catholic Church, also perform plays on AIDS for the community.

Income-generating activities have been set up, including a cassava processing plant run by a cooperative of 4 permanent and 5 casual women workers. The cooperative also makes weaning food from maize, beans and groundnuts.

St Anne's Vocational Institute was set up by the Catholic Diocese in 1963. Girls aged between 11 and 23 are provided with the opportunity to develop various practical skills, e.g., dress-making, cookery and home-management. The aim is to give girls better opportunities for work and marriage.

Most of the support for the programme has come from the Catholic Health Secretariat and the Ministry of Health. However, outside support has been crucial in the setting up of income-generating activities.

The home-based care project will only continue to be beneficial if:

- emphasis is placed on community involvement in the care of AIDS patients
- voluntary service is encouraged
- the AIDS programme is integrated into existing PHC activities, e.g., maternal and child health/family planning
- health workers are educated on a continuing basis in order to change attitudes towards HIV/AIDS patients
- better incentives are given to carers.

As a result of the relative success of this programme and in view of the increasing number of AIDS patients estimated in the future, the National AIDS Programme is reviewing the possibility of replicating and modifying this programme in other districts of the country.

Kenya

In 1984, AIDS was first recognized in Kenya and one year later a National AIDS Committee (NAC) was established by the Ministry of Health. The main responsibility of the NAC was to study

the HIV/AIDS situation and advise the Ministry on all matters relating to the control and prevention of HIV/AIDS.

A national survey of AIDS-related knowledge, attitudes, beliefs and practices (KABP) was conducted. Of the 3120 respondents, 1785 were from rural areas and 1362 from urban areas. The survey revealed a high level of awareness of HIV/AIDS (83%). The majority of respondents felt that AIDS sufferers should not be kept in family homes and advocated specialist hospitals (38%) and isolation (59%). The assured success of HIV/AIDS community-based care therefore depended on changing community attitudes about AIDS and the Ministry of Health started a programme involving community leaders at district level in information, education and communication (IEC) activities.

The programme has currently reached 35 districts in Kenya. As a result of the recommendations of opinion leaders, many training activities for TBAs, traditional practitioners and health care staff at health centres and dispensaries have been started.

The Clinical Subcommittee of the NAC is in the final stages of developing national guidelines for community/home-based care.

Apart from the Ministry of Health, more than 40 NGOs are also involved in the provision of health care services to Kenyans. Some NGOs, e.g., World Vision International, and Crescent Medical AID, are implementing community AIDS care programmes in the slum areas of major urban centres in Kenya.

The Kenya Red Cross Society, AMREF, Amani Counselling Society and many others have been actively involved in the AIDS campaign, through activities such as counselling and training. The Red Cross Society currently runs a day-care centre that also offers counselling services to AIDS patients and their families.

Malawi

The first cases of AIDS in Malawi were diagnosed in mid-1985. Peak incidence is in the 20-49 year-old age group, with about 5% of cases occurring in children under 5 years old. Women predominate among HIV-infected people below the age of 25 years, but about equal numbers of men and women are thought to be infected in the general population.

Although community-based seroprevalence studies have not been undertaken, data based on antenatal clinic attendance, blood donors, patients with sexually transmitted diseases and prostitutes indicate that about 9.6% of the adult, sexually active population may be HIV-infected, i.e., about 300 000 people.

The impact of the AIDS epidemic in Malawi, although still largely borne by the health care services, has begun to be felt in the social and economic/developmental sectors. Increasing numbers of deaths among young adults, a mounting number of orphans and pressure on health care and social services have been forecast.

Currently there is no special management programme for people with AIDS. They are cared for like all other sick people in existing health care units. With the assistance of WHO and other donors, an AIDS Control and Prevention Programme has been in operation, with a combined medium-term plan, since 1989. Emphasis has been placed on information, education and communication, for

both the general public and target groups. Blood safety has been ensured through a vigorous HIV-screening programme involving 53 blood-screening centres. Counselling of both HIV-infected and non-infected individuals is an important component.

The Government of Malawi has recognized the increasing burden which AIDS will become on the use of health care facilities. At present, AIDS accounts for 10% of the admissions to medical wards in urban centres and 30% of the bed occupancy. In order to provide reasonable care for AIDS patients without displacing patients with other needs, a plan for home/community care of AIDS patients has been planned for implementation with effect from January 1992.

Activities relating to the planning of home/community care of people with AIDS include the following:

- A policy of planned, phased introduction of home-based care for people with AIDS has been announced by the government.
- A national core team responsible for the coordination, monitoring and evaluation of home-based care has been established.
- Protocols for the discharge, referral and clinical management of HIV-infected and AIDS patients have been developed.
- A needs assessment for people with AIDS, their care providers and the community at large is under way.
- Formulation of models of home-based care and the selection of pilot sites for the phased introduction of home-based care will take place in October 1991.
- Mobilization of community leaders and women, including political leaders, for home-based care support has already taken place.

As the models of home-based care for people with AIDS are being developed in Malawi, consideration will be given to the lessons learned from programmes in other countries in the region.

Nigeria

Nigeria formally initiated its Primary Health Care (PHC) Programme in 1986. The main strategy of PHC has been mobilization of the communities to obtain their active involvement and participation in their own health and social problems. PHC committees have been formed from the wards and villages, in districts, in the local government areas (LGAs) and up to the national level. These committees, which are multi-sectoral, are linked through an intricate network of representation and feedback mechanisms.

One major achievement of PHC so far has been the provision of a basic, community-based infrastructure for the promotion of health care activities. Furthermore, communities now have a better understanding of their role in the planning, implementation and supervision of their own health care delivery system.

The National AIDS Programme has decided to use the gains accruing from PHC by integrating AIDS-related activities into the PHC system.

Multi-sectoral AIDS Action Committees have been formed by the LGAs and are coordinated by the Health Department. The State PHC coordinator and AIDS coordinator are both members of the State AIDS Committee and each has a supervisory role to play in the LGA activities.

The first case of AIDS was reported in Nigeria in 1986. By June 1991, there were 758 seropositive individuals with 94 AIDS cases reported, which probably indicates under-reporting. Sentinel surveillance sites now show a sustained upward trend in the number of HIV/AIDS cases.

Current management of the relatively few AIDS cases has mainly been institutional and supportive. Patients receive symptomatic treatment and treatment of opportunistic infections. Counselling facilities are also provided on an in-patient and home-visiting basis within the limitations of institution-based care. This care has been limited to a few teaching hospitals where health care providers are trained in the management of HIV/AIDS.

Although the reported number of AIDS cases appears relatively small, estimates indicate a steady future increase. Because of this increase and the high cost of institutional care, the National AIDS Programme has recently appointed a focal person for community/home-based care.

This officer is charged with the responsibility of developing a programme of action that will lead to the establishment of functional and effective community/home-based care in the country. This programme will not only complement institutional care, but will also offer a base for changing personal and community attitudes to HIV infection and AIDS. This in turn should lead to changes in life-style to interrupt and contain the spread of HIV and AIDS.

Uganda

The first cases of AIDS in Uganda were reported towards the end of 1982 when 17 traders from the port of Kasensero in Rakai district died. Initially the disease spread to Rakai town, Masaka and along the trans-Africa highway to Kampala and towns along the eastern border. The disease has continued to spread and almost all districts have now reported cases to the National AIDS Programme; the most affected districts are Kampala, Masaka and Rakai. In Masaka and Rakai districts an estimated 10 000 or more orphans have put a considerable strain on the community.

The AIDS Programme of the Ministry of Health was created in 1987. A national plan was developed with the assistance of WHO/GPA and presented by the government to donors. The emergency plan to reduce the spread and impact of the epidemic was followed by a medium term plan.

The number of AIDS cases has been doubling every 6 months and the cumulative total by 30 June 1991 was 24 977. Adults above 12 years of age accounted for 90% of the cases and children for the remaining 10%. Data show that males and females are affected equally. When stratified by age and sex, female AIDS patients are younger than males. The mean age for females is 27.5 years, while the mean age for males is 32 years. Furthermore, the number of female patients 15-21 years old is four times more than the number of males in the same age group.

The number of HIV-infected people requiring health facilities is obviously increasing. For instance, 30% of medical admissions in Kitovu, Mulago and Rubaga hospitals are AIDS patients.

About 20% of patients in tuberculosis wards are also infected with HIV. It is in this context that the home care policy for HIV-infected/AIDS patients and their families was endorsed in 1987.

During the past three years, several AIDS clinics, some with home care programmes, have been established in various districts. NGOs have taken a lead in this but the National AIDS Programme Patient Care Department has also tried to strengthen the existing AIDS clinics and to establish patient care networks in the community.

Communities should be urged to avoid discrimination and victimization of AIDS patients and those infected with HIV - the human rights of these people must be protected. Moreover, they should be helped by the community to live a decent and dignified life.

In future, the national plan will aim to:

- increase the number of home care programmes through their integration into primary health care approaches in the districts
- strengthen the existing AIDS clinics and establish a good patient care network in the community
- improve the level of care for people with AIDS in hospitals and in homes
- develop, in conjunction with NGOs, national guidelines on home care, counselling and nursing care.

United Republic of Tanzania

The first cases of AIDS in the United Republic of Tanzania were identified in Kagera in 1983. Since then the epidemic has spread very quickly over the whole of the mainland. All 20 regions of the mainland are now reporting increasing numbers of AIDS cases.

The latest report of the National AIDS Programme gives a total of 21 208 reported cases of AIDS and estimates that about 700 000 people are infected with HIV. Data are available on the age and sex of about 5435 cases, and show that the pandemic has affected mainly the sexually active population and children who appear to have contracted the disease from their mothers.

In 1988, in collaboration with WHO, the Ministry of Health established the National AIDS Programme and the Zanzibar AIDS Programme to respond to the escalation of HIV/AIDS-related morbidity and mortality.

With the increased demand for counselling from both the sick and the worried well, and the need for proper coordination of counselling in the country, a unit had to be established to plan, implement and coordinate counselling services for both government and nongovernmental institutions. Home-based care seemed to be a sound strategy to relieve the burden on the overwhelmed health facilities. The care of patients is transferred from the hospital to the patient's own home with assistance from a home-based care team.

So far, in collaboration with Rubya Hospital in Muleba District, the unit has started a one-year pilot home-based care programme to be extended to other parts of the country later. In collaboration

with other units such as the Clinical Unit and NGOs, the intention is to establish a number of home-based care projects throughout the country. NGOs have already established activities aimed at controlling the spread of HIV/AIDS and have provided some regular support services for people with AIDS and their families. However, a strong coordinating mechanism is needed between the National AIDS Programme and NGOs such as the Christian Medical Board of Tanzania (CMBT), WAMATA, etc.

The CMBT is the coordinating body for health activities undertaken by the Christian churches. Its affiliated organizations are the Christian Council of Tanzania (CCT), the Tanzania Episcopal Conference (TEC), and various health centres and dispensaries throughout the country.

Zambia

The number of AIDS patients among all hospital admissions is increasing. In 1986, studies in urban hospitals showed that 13% of all consecutive hospital admissions were HIV-related. By 1989 this figure had increased to 35%. In 1987 the Paediatric Department showed that 5% of consecutive paediatric admissions were for HIV-related illnesses - by 1989 this had increased to 9%.

Responsibility for home-based care in support of the overall objectives is shared by the heads of the following units:

- Counselling.
- Information, Education and Communication.
- Clinical Support.
- NGO Coordinating Committee.

The head of the Clinical Support Unit is ultimately responsible for the overall activities concerning home-based care.

The government has recognized that the basic components of home-based care should be as follows:

- professional nursing/medical care, including the prescription of essential drugs
- counselling, with a focus on problem-solving and decision-making, in the light of the present and anticipated needs of the patient and family members - one aim must be the sharing of the diagnosis and the deeper understanding of the illness and its implications
- practical help in the home - by using trained and supervised volunteers including the young; practical help will include provision of essential supplies for families which lack the means
- pastoral counselling for spiritual needs.

The following principles guide the home-based care programme:

- Maintenance of confidentiality should be a keynote of all activities, although this will not preclude involving members of the family in the full knowledge of the illness, at an appropriate time.
- A central home care liaison officer will take all initial referrals, with necessary details (name, address, diagnosis, whether family is aware, special requirements, etc.) and will communicate this to a designated person (or "unit" at the appropriate health centre). This will only be done after an offer of home care has been made to the patient and permission obtained for a home visit.
- The local health centre clinical counsellor will call upon the patient at home, assess what help will be needed and make the necessary arrangements for all aspects of care. Help which cannot be provided by the local health centre staff or community workers will be sought from the district/provincial/central home care office, which will be in regular communication with each local unit.
- Supplementary supplies, e.g., high-energy protein supplement, may be distributed separately because of the advantages of central storage.
- Regular meetings of team leaders and officials in charge of PHC, urban clinics and so on will take place in order to ensure a high degree of coordination of activities.
- Training will be provided for volunteers selected from the membership of approved organizations, such as churches, the Red Cross Society, and school anti-AIDS clubs. Some communities may consider setting up their own specific organization which should be properly constituted, managed and have the means of proper administration of funds, and maintenance of standards of conduct of its members.
- Close liaison will take place with any local bodies set up to provide care for children, especially orphans.

The concept of home-based care is widely accepted by health providers and communities alike, and the demand for such services is rising.

Models of home care

Widespread experimentation with various models of provision of home care services has occurred, initiated principally by the NGO community.

Model one: hospital-based personnel

Medical and nursing care is provided by hospital-based personnel to patients who are visited in their homes. There is little access to other community resources. This model has now expanded by including trained health workers from urban centres who help in the follow-up of patients within walking distance, and also by involving the community through the training of church leaders in care and counselling. However, there is a potential conflict between respect for confidentiality and the need to involve the community.

Model two: "community counselling"

Hospital care is again taken to patients in their homes, essentially bypassing the established health care system, but at the same time the home care team interact with local community leaders with the aim of preventing some of the traditional practices - such as wife inheritance - which may facilitate the spread of HIV. Even though such "community counselling" is primarily concerned with reducing the spread of HIV by means of changes in community norms of behaviour, the model provides an opportunity to promote the community acceptance of those who are ill, and encourage the provision of appropriate care and support to HIV/AIDS patients and their families.

Model three: PHC system and personnel

This model functions through the existing health care system from the district hospital to the community health workers. TBAs and the family of affected individuals are also involved.

The 1991 National AIDS Programme review identified a number of specific areas of concern for home-based care:

- A home-based care unit should be established, initially to evaluate current models of home-based care, coordinate activities and develop guidelines.
- A unit head and liaison officer should be identified immediately.
- Funds need to be sought for urgently needed supplies and materials, specifically for home-based care services.

In conclusion, several health institutions in Zambia now experiment with home-based care services as an alternative form of care. Although the experiments have been encouraging, financial and other constraints have restrained the process.

Many lessons can be and should be learned from these pioneer home-based care programmes, but models should be adapted to suit each local institution.

Zimbabwe

In 1989, the community/home-based care programme was initiated and a community liaison officer within the National AIDS Programme was employed to address community/home-based care needs.

The main aim of the community/home-based care programme is to promote the care and support of HIV/AIDS patients through a continuous follow-up and supportive system involving the client, family and health services as well as other community support structures.

This concept is receiving more consideration and is being explored as a way of providing continuity of care as well as social support to HIV/AIDS patients and their families. In some provinces, approaches that could be used in initiating this strategy are being discussed, while in other provinces community/home-based care programmes are being established at provincial, district and local level and also through nongovernmental organizations.

Objectives of the community/home-based care programme

- (a) To provide physical, medical and social support to HIV-infected people, AIDS patients and their families.
- (b) To promote the philosophy of providing care to people in their homes.
- (c) To identify and mobilize family and community resources for the care of HIV-related conditions in the home environment and community.
- (d) To provide opportunities for family and community education on HIV/AIDS, thereby promoting a better understanding of the disease.

Why develop community/home-based care services for HIV/AIDS patients?

- The number of people infected with HIV, including those with AIDS, is increasing.
- Hospitals are overcrowded, understaffed and often cannot provide the amount of caring needed by the terminally ill. Therefore, consideration should be given to providing a high standard of supportive care in the home.
- In some communities, family members may find it difficult to visit their sick relatives in hospital because of the long distances.
- Community/home-based care programmes provide the opportunity for education of the sick, the family and the community.

National AIDS Programme

The Ministry of Health, as part of the National AIDS Programme, has taken advantage of many resources to prepare for the extension of community/home-based care programmes into the primary health care system. Various strategies were considered in formulating plans for community home-based programmes.

As part of the medium-term plan, under the section on clinical management and support, consideration was given to providing for the management and treatment of people with AIDS.

Specific issues addressed included:

- Identification of the counselling, social services and community support systems available or necessary for the provision of coordinated services to AIDS patients at all health care levels.
- Formulation of a national policy for the psychosocial management, treatment and counselling of AIDS patients, with particular reference to projecting needs for additional personnel, in-patient/out-patient facilities and financial support required for these.

- Establishment of policies on the medical management and treatment of AIDS patients. Many patients with AIDS are being hospitalized and some of these are receiving expensive medical therapy for opportunistic infections and tumours.
- Closer collaboration with nongovernmental organizations through the NACP-NGO Coordinating Body and Anti-AIDS clubs which are actively involved in providing community/home-based care services.

The National AIDS Programme has also set aside funds for the training of health workers and volunteers in community/home-based care programmes. Such financial assistance is also offered to NGOs.

Zimbabwe has eight provinces of which three have initiated community/home-based care programmes as follows:

- In Manicaland, the programme is run in one district and in the urban area, and covers both low- and high-density populations.
- In Mashonaland West, there are pilot areas in three districts, involving both urban and rural populations.
- In Mashonaland Central, the pilot programme is in a district headed by a mission hospital which primarily serves the rural community.

Nongovernmental organizations

Nongovernmental organizations which work with rural communities are also actively involved in developing community/home-based care. These include, among others, the AIDS Counselling Trust (in both rural and urban areas), and Mashambanzou, which has a terminal care unit in one of the Harare-based hospitals as well as a drop-in centre in a semi low-density area.

Training of AIDS workers covers such areas as:

- management of the patient in the home
- supportive counselling of the patient, family members and care-givers, covering issues such as death and dying
- infection control practices and procedures in the home, involving the supply of materials where appropriate
- education of the patient to avoid the possibility of them unknowingly transmitting the infection, sexually or otherwise
- education of the family members on HIV/AIDS, on care of the patient and on how to cope with the psychosocial issues that might arise.

Constraints

- absence of clear guidelines and appropriate referral procedures within the health care system for AIDS patients, in areas such as the maintenance of confidentiality
- periodic shortages of infection control supplies, such as gloves, disinfectants, etc., and drugs for the treatment of HIV-related illnesses
- lack of transport to carry out home visits on a regular basis
- lack of adequate trained personnel to undertake the programme
- lack of funds specifically allocated to run the programme at local level.

7.6 Reports of field visits

Participants were divided into 4 groups for the field visits to TASO Kampala, TASO Masaka, Nsambya Hospital Community Programme and Kitovu Hospital AIDS Care Programme in Masaka and Rakai districts.

The objectives of the field visits were to:

- (a) identify the methods used by the selected organizations to assess the needs of the community regarding HIV/AIDS care
- (b) describe the planning process used, including the ways in which programme objectives were developed, and to describe service and policy development, and the determination of the existing range of services
- (c) observe organizational and practical aspects of setting, staff, users, services, (medical, counselling, social, day centre, etc.) and administration
- (d) discuss monitoring and evaluation methods used or planned, as well as the results
- (e) explore the main issues in programme implementation, e.g., sustainability, community involvement, coverage, etc.
- (f) identify links between health facilities and other community resources, and to address issues such as systems of referral, mutual support and overlapping of services.

Reports on the field visits, which were presented at a plenary session, are summarized in this section.

Field visit to TASO Kampala

Although an evaluation of the TASO programme has not yet been undertaken, some activities are monitored and an evaluation is being planned for the near future. However, staff were aware of the strengths and weaknesses of the organization.

As regards sustainability, donor agencies (e.g., Action AID) will continue to fund TASO over the next three years. The community did not seem to be sufficiently mobilized to support its activities under the TASO programme. Communities were only able to offer a minimal contribution, e.g., provision of transport and food.

TASO is currently carrying out activities in 4 communities, some of which had an extensive coverage. It is intended that the community outreach programme be extended to a total of 6 communities.

Possible future considerations noted by the group include the following:

- maximize the use of extension workers from other sectors
- integrate activities with the primary health care programme

- strive for total community participation
- evaluate and monitor the programme regularly
- National AIDS Programme to evaluate the programme for possible adaptation in other localities.

Field visit to TASO Masaka

In 1988, as a result of the large number of AIDS cases and lack of support services in the Masaka district, TASO set up another programme in Masaka town, 130 km south-west of Kampala. No formal needs assessment was undertaken when the programme was initiated.

The planning process, programmes objectives, service policy and range of services were modelled on the TASO Kampala programme.

The objectives of the programme were to provide:

- (a) patient care support
- (b) counselling services
- (c) training for counsellors
- (d) income-generating activities
- (c) social support
- (f) supplementary health services.

The organization has 5 sections: administration, medical department, counselling, outreach and day centre.

The staff consist of 2 medical officers, 2 medical assistants, 3 nurses, 3 TASO workers, 6 counsellors and 10 trainee counsellors. However, the staffing level was not considered sufficient for the workload. The clients, who are referred to TASO from the hospital or by other clients, or who drop in on their own initiative, currently number 5000 for medical care and 2000 for other services.

The coverage of the programme is determined by policy. However, any increased coverage would be limited by the available resources, e.g., staff, transport and physical space. A substantial increase in resources (human, material, financial) would be needed to expand the programme.

The programme is totally funded by donors, including Action Aid, USAID, ODA UK, EEC. Nevertheless, the issue of sustainability of the programme has not yet been addressed.

The community participated in the programme by volunteering to be trained as counsellors and by caring for relatives with HIV/AIDS in their homes. In addition, income-generating activities were undertaken by patients and day-care members. However, the small funds obtained were not sufficient even to provide meals for the clients.

The TASO programme maintains close links with the district health facilities (referrals are made to and from the hospitals) and with other nongovernmental organizations in the area, especially regarding training of counsellors.

Field visit to Nsambya Mobile Home Care Programme

The Nsambya Mobile Home Care Programme was started in 1987 to relieve the burden on hospital wards which, as a result of the increasing number of AIDS patients, had become congested.

The programme's management staff perceived that community-based home care services for patients would:

- reduce the strain on hospital management and facilities
- offer an opportunity to educate and involve the community in the care of AIDS patients and the control of HIV infection
- reduce stigmatization of AIDS patients
- ensure the continuity of management of AIDS patients at family level
- reduce expenses both for the hospital management and for the AIDS patients and their families.

The resources and personnel of the programme include: 3 doctors, 4 nurses, 1 social worker, 3 pastoral workers (church), drugs/food/dressings etc., vehicles, counsellor driver, materials for income-generating activities, and the Women Lawyers Association which offers legal advice.

Resources are obtained from the government, church organizations, the hospital, private donors, families, the community, volunteers and from AIDS patients themselves.

The strengths of the programme are based on:

- community involvement
- providing tender loving care
- the use of people with AIDS as educators
- training volunteers as an investment
- providing hope for AIDS patients and the means to support their families
- continuity of the management of AIDS patients at family and community level.

The indicators used to monitor and evaluate the programme are:

- records of income-generating and profits

- the enthusiasm of the patients to involve themselves in an income-generation project; e.g., the Nsambya programme has 200 patients who are involved in such projects
- the level of acceptance of AIDS patients by family and community
- the standard of patient care provided by the families and the community.

The following constraints were identified:

- involvement of other sectors was not being explored
- heavy dependence of the management on donor support.

The group recommended that the programme should:

- maximize the use of extension workers from other sectors
- integrate with the PHC programme
- obtain greater community participation
- evaluate and monitor the programme regularly
- be evaluated by the National AIDS Programme for possible adaptation to other localities and should also sensitize other sectors and the local government to participation in community-based care.

Field visit to Kitovu Mission Hospital, Masaka District

In response to the increasing number of AIDS patients in the district (2000 HIV/AIDS cases have now been reported as of December 1990), Kitovu Hospital created a Mobile Home Care Unit in 1987.

At Kitovu Hospital, people with HIV/AIDS receive care in the following ways:

- in- and out-patient care
- AIDS clinic referral
- social work referral
- outreach activities, e.g., counselling, education and clinical services.

Thus, the planning process starts with an assessment by the hospital social worker of the nature and extent of the problem in the community. He/she conducts interviews with clients both in hospital and at home, and considers the needs of individuals, the community and the programme. The

programme is reviewed at monthly meetings of hospital staff, including all unit heads and field coordinators.

In the field, the coordinators meet with their community workers monthly and activity reports are given. Based on these reports, the best community workers are given a bicycle after one year in the programme.

The hospital has adopted the national AIDS policy. It provides pre- and post-test counselling and follows up people with HIV/AIDS. Diagnosis of AIDS is undertaken using the WHO clinical criteria, due to the lack of testing kits. Assistance is provided not only to AIDS patients but to others in need, e.g., those people who are malnourished or aged.

The hospital has staff based in the hospital and in the field, as follows:

Hospital: 1 programme director, 5 nurses, 2 teachers, 1 secretary and 2 drivers.

In the field: 14 programme coordinators (1 per district), 300 community workers (each worker deals with 10-15 families) and project managers (for fund-raising projects).

The community services are provided to small-scale farmers, traders and visitors to the area. They include: medical care (patient care, home care), counselling, supplies (food, farming inputs) day-care centre, AIDS education, income-generation schemes (sewing, farming) orphan care and support, and house-building.

Monitoring and evaluation (undertaken or planned) include:

- A subjective assessment of the awareness and acceptance of the problem in the community and the status of the people cared for.
- Monthly meetings, held with hospital and field-workers, to discuss the progress of the work.
- Statistics collected and analysed from the laboratory, home visits, patients who died, orphans, etc. Formal research is not undertaken.
- Hospital staff in the unit coordinate their activities with other NGOs at their monthly district meetings.

As regards sustainability of the unit, funding is predominantly from external NGOs, e.g., CAFOD, with some support from local NGOs. Staffing is a problem since many staff leave for better paid jobs elsewhere. Thus, salaries need to be competitive to retain staff. Christian commitment is helpful in retaining staff. However, even without external funding, the work would still continue since many families are self-reliant through income-generation schemes, and the community, as a whole, is able to meet most of its needs.

Community involvement in the work is total. Coordinators and community workers are chosen at community meetings. Volunteers are selected by the community and the churches (of all

denominations). The resistance councils at local level mobilize people to participate in the programme. Close relatives are encouraged to look after the orphans as guardians.

Coverage extends to those patients who are registered in the area. More vehicles (motorcycles and bicycles) are needed to increase coverage.

8. Recommendations

The following recommendations for governments, regions, international agencies and NGOs were generated during the workshop and were adopted by the participants in the final plenary session.

Action by Governments

Programme management

1. Political will should be strengthened in the existing government structure at all levels for the community-based care and control of AIDS in order to ensure that it is a priority area and that adequate resources are provided.
2. Governments should promote multi-sectoral approaches to the prevention and control of AIDS and to the provision of care to people with HIV/AIDS.
3. Governments should have a policy for the establishment of community-based/home care for people with HIV/AIDS.
4. Governments should strengthen health systems, in particular primary health care, to include community-based care activities and the control of sexually transmitted diseases and AIDS.
5. Communities should be involved in the development of future strategies for community-based care and control of AIDS.
6. National AIDS programmes should reflect the multi-sectoral approach by including a representative responsible for home care.
7. Clear policies and guidelines should be established on the management and discharge of AIDS patients from health facilities in preparation for community/home care.
8. The referral system between and among various levels of the health care delivery system should be strengthened where it exists, and established where it does not, as an important element in establishing a community/home care service.
9. Governments should encourage inter-country collaboration on HIV/AIDS community-based care and control.

Patient care management/counselling services

10. Governments should improve the quality of care for HIV-infected people and people with AIDS in hospitals and homes, strengthen existing health facilities for people with HIV/AIDS, and establish effective patient care networks in the community.
11. Governments should adopt strategies to improve counselling services since improvements in counselling can go far towards decreasing the stigmatization of HIV-infection/AIDS.
12. The concept of shared confidentiality should be adopted within the norms of the society concerned in order to destigmatize HIV/AIDS. This will enable better control of the pandemic and facilitate care for people with HIV/AIDS.
13. Planning and procurement of drugs for HIV-associated opportunistic infections should be incorporated into the overall essential drug supply system, and distribution guidelines provided.
14. Governments should support, facilitate, encourage and coordinate the efforts of NGOs, both local and national, working in the community.
15. Governments should involve social workers, teachers, traditional healers and traditional birth attendants, as well as women, young people, community and religious leaders and other relevant people in the planning and implementing of community-based activities.

Community-based home care

16. Governments should empower the community to strengthen its own capability for coping with appropriate aspects of the management and control of AIDS through effective decentralization of activities.
17. Community involvement should be emphasized to ensure sustainability of the programme.
18. Communities should be encouraged to promote or restore positive traditions and discourage those that might promote HIV transmission.
19. Communities should be urged to avoid discrimination and victimization of people with HIV/AIDS and their families.
20. Urgent attention is required to integrate the care and social welfare of orphans into all community-based activities.
21. Condom use should be promoted in communities in the most culturally-acceptable manner with emphasis on their proper use and disposal.
22. Sustainable income-generating activities should be promoted to enhance the quality of life of people with HIV/AIDS and their families.

Information, education and communication

23. Governments should enhance AIDS information, education and communication activities aimed at health workers, people with HIV/AIDS and their families, community leaders and the public, particularly women, young people and those in the labour force or in high-risk groups.
24. Governments should initiate the most effective channels of communication to promote a change to safer social and sexual behaviour.
25. Community health workers should ensure that skin-piercing instruments used in the community are properly sterilized.

Training and capacity building

26. Health workers and community volunteers need to be trained in aspects of counselling and community/home-based care.
27. Governments should train health personnel in the monitoring and evaluation of community programmes.
28. Continuing education for health care workers should be planned and implemented.
29. Governments, in conjunction with NGOs, should produce guidelines, manuals and other training materials on community/home-based care/counselling that are culturally-specific for use by care providers in the field.

Monitoring and evaluation

30. Governments should actively implement monitoring and evaluation activities relating to community-based care and control programmes, with community participation.
31. Needs assessment for people with HIV/AIDS, their families, their care-givers and the community should be undertaken.
32. Community-based studies should be carried out to determine the prevalence of HIV infection; the scope and magnitude of the orphan problem; and the impact of AIDS, for economic planning.
33. Operational research should be promoted and the results communicated to the community.

Action by Regions

1. Mechanisms should be developed to monitor, on a continuing basis, ongoing activities in community/home care and control of HIV/AIDS in African countries. WHO/AFRO could play a catalytic role in such an activity.

2. Mechanisms should be established to exchange information and visits between countries on a continuing basis.
3. Regional training programmes should be organized for selected professionals on the evaluation of community-based care and control programmes.
4. Governments should be helped to identify priorities for research in HIV/AIDS community-based care and control.

Action by International Agencies

1. Technical assistance should be provided to HIV/AIDS community-based care and control programmes.
2. Funds should be provided for training fellowships and study tours as well as exchange visits between countries and regions to share experiences and new approaches.
3. Training materials on community-based care/counselling should be produced.
4. Research to improve community-based care and AIDS control activities should be supported.
5. Follow-up workshops should be held in Africa for the exchange of experience and knowledge on HIV/AIDS community-based care and control.
6. Monitoring and evaluation methodologies and indicators should be included in future workshops at regional and national level.
7. Case-studies of successful community-based projects for the management and control of AIDS should be prepared and distributed to member countries.

Action by Nongovernmental Organizations

1. In view of the limited resources of member governments in the region, nongovernmental organizations should continue to play a major role in supporting communities at the local level.
2. Indigenous NGOs, particularly women's and youth groups, both local and national, should be strongly encouraged to support activities relating to community-based care and control of HIV/AIDS.
3. Nongovernmental organizations should develop a mechanism for coordination and collaboration in order to maximize the use of available resources for community-based care and control of HIV/AIDS.

9. Future activities

Participants were divided into country groups to prepare draft proposals and plans for their respective countries on HIV/AIDS community-based care and control. The need to integrate HIV/AIDS care into the existing health programme areas was emphasized. A framework to assist with the planning of future activities was introduced (see Annex 3).

Although each country prepared a plan to fit its own situation, there were many common elements which are summarized as follows.

- Conduct needs assessment.
- Begin with a pilot project/district.
- Gain consensus on objectives:
 - to increase the level of awareness of HIV/AIDS among the general public
 - to provide psychosocial/counselling services at the grassroots level
 - to develop the capacity of health workers to effectively and efficiently care for people with AIDS and their families
 - to establish a referral system to and from the community health facility using existing primary health care structures
 - to establish a system to tap available community resources to provide physical and psychological support to orphans
 - to coordinate and integrate the different care institutions, of both governmental and nongovernmental organizations
 - to identify and mobilize local resources
 - to identify and mobilize social support to orphans
 - to strengthen facilities available for AIDS care at the community level and achieve integration of AIDS care within the existing facilities
 - to promote educational activities to reduce the progression of the HIV epidemic through increased public awareness
 - to promote home-based care of patients in such a way as to be acceptable to the family and the community.
- Implement plan once resources are available.
- Continuously monitor and evaluate the plan's progress.

10. Closing session

The closing session was chaired by Prof A.M. Nhonoli and addressed by staff of WHO, the Commonwealth Secretariat and other participants.

It was generally agreed that the workshop had achieved its immediate objectives. However, in order to achieve the longer-term objective of strengthening home-based care, proposals drawn up by participants at the workshop would need to be finalized in each respective country and submitted to national authorities for incorporation into existing plans, or for seeking assistance from other sources, such as WHO, the Commonwealth Secretariat and other agencies.

Annex 1

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Annex 2

List of background documents

Ankrah, E. Maxine (1991). AIDS and the Social Side of Health, Social Science and Medicine; Vol. 32(9) pp. 967-980.

Commonwealth Secretariat, Report of the Regional Workshop on Community-Based Approaches to the Management and Control of AIDS, Mwanza, Tanzania, 29 March - 2 April 1990.

Community-Based Care for Persons with HIV Infection and AIDS; Draft/Guide for Administrators, Planners and Managers Implementing Community-Based Services, WHO/GPA, Geneva.

Current and Future Dimensions of the HIV/AIDS Pandemic. A Capsule Summary, WHO/GPA/RES/SFI/91.4, Geneva, April 1991.

Foster, Susan D. Affordable Clinical Care for HIV-Related Illness in Developing Countries (1990). Tropical Diseases Bulletin; Vol. 87(11).

Hauserman, J., Ethical and Social Aspects of AIDS in Africa, Commonwealth Secretariat, London, 1990.

Intercountry cooperation on HIV/AIDS Community-Based Care; Draft Proposal, WHO/GPA/IDS/HCS.

Janovski, Katja, Project Formulation and Proposal Writing, Geneva, 1991. WHO/EDUC(87.187).

Matrix for Planning Community-Based Care at Various Levels in the Health Care System: Draft Proposal, Partnership Programme Grants: Requests for Proposals, WHO/GPA, Geneva.

Patient Management from Home to Hospital; Trends of Events and Country Efforts, WHO/AFRO/GPA, Brazzaville, 1991.

Strategies for Hope: (Action Aid, AMREF, and World in Need).

No. 1. Williams, G. From Fear to Hope; AIDS Care and Prevention at Chikankata Hospital, Zambia.

No. 2. Hampton, J. Living Positively with AIDS: The AIDS Support Organization (TASO), Uganda.

No. 3. Campbell, I.D., and Williams, G. AIDS Management: An Integrated Approach.

No. 4. Hampton, J. Meeting AIDS with Compassion: AIDS Care and Prevention in Agomanya, Ghana.

No. 5. Mukoyogo, M.C. and Williams, G. AIDS Orphans: A Community Perspective from Tanzania.

No. 6. Williams, G. and Tamale, N. The Caring Community: Coping with AIDS in Urban Uganda.

The Care and Support of Children of HIV-Infected Parents, WHO/GPA/CNP/IDS/91.1, Geneva, May 1991.

Traditional Medicine Programme and Global Programme on AIDS. Report of the Consultation on AIDS and Traditional Medicine: Prospects for Involving Traditional Health Practitioners, Francistown, Botswana, 23-27 July 1990, WHO/TRM/GPA/90.1.

UNICEF, Children and AIDS: An Impending Calamity, 1990.

World Health Organization, Review of Six HIV/AIDS Home Care Programmes in Uganda and Zambia, GPA/IDS/HCS/91.3, Geneva, 1991.

