

## Case Study One

### Integrated Community Home-Based Care, Thyolo, Malawi<sup>3</sup>

The study was carried out by the community development advisor of the National Smallholder Farmers' Association of Malawi (NASFAM). Interviews were conducted in September 2003 and February 2004 with HBC volunteers in a smallholder farmer community and with MSF to assess the impact of HIV and AIDS on the communities, and the efforts of the HBC volunteers and MSF to mitigate the impact.

In addition to this, interviews were conducted with representatives from other NGOs working in Thyolo: Zikometso Smallholder Farmers' Association (a member of NASFAM), World Vision Malawi, Family, Life & AIDS Education Ministry (FLAEM) and the Thyolo Active Youth Organisation (TAYO) as well as with representatives from the District AIDS Co-ordinating Committee (DACC) based at Thyolo District Hospital and a Ministry of Health official responsible for Home-Based Care initiatives and the piloting of the MICHBC model.

#### Who (target group)?

Registered, chronically ill patients and their caregivers, orphans and vulnerable children in smallholder farmer communities incorporated in the integrated HIV and AIDS care programme developed by MSF in Thyolo District, Southern Region, Malawi, which was part of the Malawi Integrated Community Home Based Care Model pilot. One of the poorest areas in Malawi, Thyolo District has a population of approximately 500 000

people. Landholdings are small due to population density and the presence of large, private tea estates in the area. Thyolo has a high prevalence of HIV and AIDS due to migrant labour patterns associated with the estates, and to extreme poverty, which leads women to resort to survival sex in order to meet basic food requirements and household needs. Within the district, there are between 30 and 45 per cent of female-headed households, many of them elderly women. As a result, food insecurity is prevalent; according to the Thyolo District Development Plan, 60 per cent of the population has food for six months of the year only.

#### What (the intervention is doing)?

- Training of community HBC volunteers to provide palliative care, medication and information on nutrition to registered AIDS patients and their guardians under the supervision of a nurse, a clinician and HBC co-ordinator. HBC volunteers are supplied with a medical kit every two months containing vitamins, painkillers, medicine for the treatment of simple ailments and malaria, bandages, swabs and condoms. In February 2004, MSF had 340 HBC volunteers supervised by nine nurses and caring for 3 210 registered AIDS patients;
- Monitoring of nutritional status of registered patients and provision of *Likuni Phala*, a nutritional supplement in the form of a porridge prepared from maize meal and fortified with soya and vitamins, to those in need;
- Provision of seeds (cabbage, tomato, onion, rape and soya) and hoes to affected households;

<sup>3</sup> Documented by Lesley Holst, NASFAM.

- Establishment of Voluntary Counselling and Testing (VCT) Centres;
- Treatment of patients with tuberculosis (TB);
- Anti-retroviral treatment;
- Prevention of Mother-to-Child Transmission (PMTCT) programme providing pre-natal counselling;
- Orphan care activities, including establishment of community pre-schools for orphans, psychosocial counselling and vocational training such as carpentry, tin-smithing and tailoring for orphans;
- Community mobilisation and advocacy.

The programme is designed to provide a basket of services aimed at individual, family and community capacity-building to address the problems of illness, vulnerable children and poverty. The ultimate goal is the provision of equitable, quality service, which will lead to an improved quality of life for all citizens. The four essential services are:

- *Counselling* which includes VCT, psychosocial counselling, life skills development targeting youth, peer counselling and ongoing individual and family counselling for positive living;
- *Home Based Care* provided by primary caregivers such as family members or friends assisted by trained, community HBC volunteers. Health surveillance assistants, who are trained health workers, provide support for the caregivers and volunteers. Overall support and supervision is provided by a community health nurse;

- *Income Generation* includes sustainable food production through, for example, communal gardens and income generating projects. These projects are inclusive and village-based, for all vulnerable members of the community and not only people living with HIV and AIDS;
- *Orphan and Vulnerable Child Care* includes child-care and nutrition training for women caring for children under five; multi-purpose children's groups organised on Saturdays offering education, support, a cooked meal and recreation, aimed mainly at school-age children and involving all children, not just vulnerable children; skills training for older children, especially those who are not at school; reading centres or libraries; formal and informal foster care.

In addition to these four essential services, five key elements or 'pillars' have been identified:

- Professional supervision is provided at district level by community health nurses, district development officers, and social workers;
- Improved communication with cell-phones and two-way radios and regular meetings held at different levels;
- Incentives for all categories of workers through career-planning and education and recognition of service;
- Health education and prevention mainstreamed into all activities; and
- Empowerment through capacity-building of all people involved at all levels through a series of training modules.

### With whom (partnerships)?

In order to implement a diverse programme, which includes components outside the core competencies of MSF, a range of partnerships have been established. The model adopts an holistic approach to care, which relies on successful collaboration, rather than simply co-ordination between many partners. MSF works closely with the District Health Services and Thyolo District Hospital and has established a partnership with UNICEF in the PMTCT programme to train health workers in counselling. The services outlined in the model are provided through a partnership between government, the private sector and philanthropic societies, including the Ministry of Health and Population, the Ministry of Gender and Community Services, the National AIDS Commission, Non-Governmental Organisations, Community Based Organisations, Faith Based Organisations and Village Committee Members, who are volunteers and community leaders.

MSF has worked closely with the communities in developing the programme, building on existing community responses where possible. For example, many of the HBC volunteers working within the programme were already caring for the sick in their community prior to being identified and trained by MSF. It is important to identify communities and individuals who are already trying to respond positively to the challenges, even where resources are limited, and to explore ways of supporting their efforts in partnership. Successful examples of such interventions should be widely shared to serve as an inspiration for other communities, organisations and donor agencies. There is a common perception among the latter, and indeed among Malawians themselves, that

community mobilisation is particularly challenging in Malawi due to a widespread dependency syndrome. The MSF intervention counteracts stigma and discrimination against people living with HIV and AIDS through the inclusive, village-based approach, where not only HIV and AIDS-affected households and orphans are targeted, but all vulnerable people and, in the case of the multi-purpose children's groups, all children. Similarly, health education and prevention targets the whole community.

The Malawi model (based on a South African model of community/home-based care initiated by the South Coast Hospice in the 1990s) was developed by a team of consultants from the University of KwaZulu-Natal in consultation with stakeholders. Affiliation with the University will continue throughout the pilot phase for purposes of modification or adjustment of the model and also in the area of further education as part of the career progression element.

### How much (the benefits and impact)?

- Community HBC volunteers highlighted the improved health of AIDS patients receiving home-based care. Individuals who were previously unable to work have, in many cases, recovered sufficiently to be able to cultivate their fields and carry out domestic work;
- The HBC volunteers observed an increase in the number of people approaching them to ask for counselling and for condoms, used by couples for family planning as well as for protection against HIV and sexually-transmitted illnesses (STIs);



- Communities are uniting to address the problems, caused by or compounded by the HIV and AIDS pandemic. Volunteers and community members often provide food to the affected households and in some cases money from their own (usually very limited) supplies, in addition to assisting with the cooking, cleaning and maintenance of patients' houses. Community gardens have been established in some areas and the orphan care activities such as the pre-schools, vocational training and income-generating activities are also community-initiated;
- Awareness of nutritional needs of AIDS patients has improved through information and advice provided by HBC volunteers to the guardians;
- More people are applying to become registered/certified HBC volunteers even though there are no financial benefits involved, and the drop-out rate for trained HBC volunteers is very low;
- Timely referral of patients for treatment of tuberculosis and other opportunistic diseases has improved through regular contact between the HBC volunteers and the patients in their care;
- The number of people, including pregnant women, accessing VCT in Thyolo District has increased. When the PMTCT programme began in 2002, more than 800 women received prenatal counselling in the first month, with 90 per cent accepting voluntary testing for HIV. Thyolo has also seen a significant increase in the number of people joining NAPHAM, the

National Association of People Living with HIV/AIDS, which works to raise awareness of issues of stigma and discrimination and promote information about positive living.

### Timelines?

MSF introduced the training of HBC volunteers in Thyolo in 1999, and has since expanded into more areas within the district, with other components of the integrated HIV and AIDS care programme being added on an ongoing basis.

The MICHBC model was developed in 2003 and presented to stakeholders at a workshop in Lilongwe in August 2003. Three districts were selected for piloting the model: Thyolo in the Southern Region, Salima in the Central Region and Mzimba in the Northern Region. The pilots were run through 2004 and have recently been evaluated.

### Gaps?

The MSF intervention that provides seeds and hoes to affected households has not been monitored adequately and it is therefore not known what the impact has been on the food security and nutritional status. MSF has neither the necessary technical expertise to supervise nor the capacity to monitor a project of this nature as it is primarily a provider of medical services and care, and hoped to collaborate with other organisations specialising in crop production and food security interventions in order to better support the HBC activities.

### How is this different from standard interventions?

Although MSF is primarily a health service provider, it has developed a much broader programme adopting a holistic, multi-sectoral approach to HIV and AIDS care and prevention. MSF has worked closely with the communities involved in the development of their programme, building on existing community responses where possible. The spirit of volunteerism has been successfully retained in the HBC programme. Among the HBC volunteers interviewed, some had 7 to 8 dependants to provide for in their own household, yet they were still willing to care for the sick.

Furthermore,

- The model adopts an holistic approach to care, which relies on successful collaboration rather than simply co-ordination, between a large number of partners involved in the implementation;
- It counteracts stigma and discrimination against people living with HIV and AIDS through the inclusive, village-based approach, where not only HIV and AIDS-affected households and orphans are targeted, but all vulnerable people and, in the case of the multi-purpose children's groups, all children. Similarly, health education and prevention targets the whole community;
- It promotes community ownership through capacity-building of village committees and members and support of existing CBOs;
- It promotes volunteerism, while at the same time introducing incentives for volunteers.

### Enabling factors?

- MSF and the HBC programme are well-established in Thyolo and therefore have a wide experience to draw upon;
- Thyolo now has a cadre of dedicated, self-motivated and experienced HBC volunteers;
- Community leaders actively support the different interventions and community involvement is good;
- There are a number of NGOs operating in Thyolo District in a wide range of programmes relating to food security, crop production and natural resource management.

### Constraining factors?

- Co-ordination has generally been poor in the district with some duplication of efforts and little collaboration between the service providers. The District AIDS Co-ordinating Committee (DACC) which is supposed to facilitate the process of co-ordination does not appear to be fully operational;
- Time is a major constraint. The pilot began before the management structure was properly established, and a one-year period for testing a model involving many different partners is not sufficient if all the elements are to be implemented and evaluated;
- The inter-related problems of poverty, small landholding size and poor soil fertility make food security difficult to achieve. There is a need for promotion of alternatives to inorganic fertilisers as few people can afford to buy these.

### Additional ideas or potential improvements?

There is great potential for collaboration due to the large number of NGOs, CBOs and FBOs operating in the District. Technical expertise on crop production, livestock, labour-saving technologies, soil conservation techniques and income-generating activities would complement the HBC activities and increase the impact of these through improved food security for affected households and communities. Zikometso Smallholder Farmers' Association, World Vision and Oxfam could provide such expertise in collaboration with government departments.

Food diversification should be promoted through awareness-raising and through establishment of kitchen and communal gardens. This would have a significant impact both on food security and nutritional status.

### Implications of scaling up / scaling out?

Changing the Malawian preference for maize is a major challenge, as is encouraging a shift towards organic fertilisers. Establishing communal gardens, school gardens and kitchen gardens as demonstration plots with a wide range of well-adapted plants and fruit trees, vegetables and legumes using compost manure could help to persuade people that it is possible to grow food for a greater part of the year without expensive inputs. Demonstrations and training on preparation of these alternative food sources is also imperative if habits are to change. More testing of labour-saving technologies adapted to Malawian agricultural practices is needed and experiences must be widely shared.

The process of decentralisation of government and development in Malawi takes time and will affect the success of the MICHBC pilots as well as the subsequent implementation process in other districts. The Thyolo District Assembly has drawn up a comprehensive District Development Plan for 2002-2005, outlining the poverty-related issues and the interventions needed to address these. However, the District will need adequate resources if it is to implement the plan.

An improved understanding of the impact of chronic sicknesses on rural livelihoods can influence the future design of practical interventions, as well as inputs for national policy. Building on existing institutional forms implies the preservation and transmission of knowledge. The increasing numbers of orphans and the collapse of extended family networks leads to inadequate transmission and preservation of knowledge. To counteract this trend, the FAO suggests the following strategies ([www.fao.org/sd/ip](http://www.fao.org/sd/ip)):

- ♦ Self-help groups and community mobilisation;
- ♦ Promotion of agricultural training and school gardens;
- ♦ Promotion of youth organisations;
- ♦ Encouragement of farmer-to-farmer knowledge-sharing;
- ♦ Documentation of traditional indigenous knowledge systems;
- ♦ Developing village-based business modules focusing on indigenous products.

Traditional support groups and structures are often under strain as a result of HIV and AIDS, and there is often the need for capacity-building to help strengthen these groups, or even to establish complementary new groups in order to achieve impact.

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### 4.2 Participatory Approaches:

In most of the case studies documented in this paper, interventions were planned in direct response to problems identified through participatory consultation with communities, which revealed the different kinds of impacts that HIV and AIDS has on individuals and communities. In many of these cases the use of participatory methods to design interventions is highlighted, as is working with existing local structures to enhance community involvement. Local political support for projects may be beyond the control of project staff, but where positive relationships are developed this can make a critical difference. Traditional support groups and structures are often under strain as a result of HIV and AIDS, and there is often the need for capacity-building to help strengthen these groups, or even to establish complementary new groups in order to achieve impact.

It is sometimes difficult to bridge the technical side of organisations/aid work (within agencies and local governments) with the community development aspects, which are equally important. Agencies may try to introduce new technologies without proper attention being given to the process, particularly the way they are introduced. Conversely, development approaches need to have something to offer communities with regard to knowledge and/or technology.

Relationships of trust are built through a positive engagement between communities and NGOs around livelihood activities (for example agriculture, credit and loan systems) and through participatory processes can lead to new interventions in more sensitive areas relating to sexual behaviour. For example, farmers' groups that have emerged as a result of new agricultural training may be used as entry points for education and training in HIV prevention. "Farmer to farmer" interactions have worked well as a means of getting farmers to adopt new technologies in many contexts. In Zambia, scaling up some conservation farming activities has been successful through extension services.

This raises the issue of working with people living with HIV and AIDS in the design and implementation of development projects. This should also acknowledge the danger of stigma and the fact that many infected people may not participate within AIDS support groups for fear of being labelled.

### 4.3 Building on local responses

Certain responses have their origin within affected communities and have been used as the basis for interventions by outside agencies such as *Medécins sans Frontières*. It has been widely documented that households under stress from impacts such as hunger, poverty or disease (such as HIV and AIDS, malaria and tuberculosis) adopt a range of strategies to mitigate their impact through complex multiple livelihood strategies. The literature generally suggests that individuals and households go through processes of experimentation and adaptation as they attempt to cope with immediate and long-term household demographic changes. The main source of help and support for the households impacted by chronic sicknesses comes from kinship networks. Neighbours helped those affected with small immediate needs, usually on a reciprocal basis. Parents, children and siblings were the main source of support for the affected households.

A powerful message from a number of the studies was the need to strengthen community- and kinship-based networks to provide more systematic and assured support to the affected households. The role of community AIDS co-ordinating committees in establishing a core of trained community-based volunteers who can provide information and advice, and strengthening the capacity of faith-based institutions to respond to people's needs, can be important measures taken in this regard. Building on existing institutional forms implies the preservation and transmission of knowledge. This message was most clearly articulated in the Tiyambenawo Orphan Care and Self Mobilisation case study in Lilongwe South, Malawi.

#### Orphan Care and Self Mobilisation, Lilongwe South, Malawi

The Tiyambenawo Orphan Care group was formed in March 2003 by three women in response to the growing number of orphans in their community, as a direct result of increased mortality due to HIV and AIDS, and the lack of assistance given to the orphans or the families caring for them. The group raised all funds for the activities through contributions from the group members themselves. All the interventions were entirely self-initiated and were carried out without any external agent or funding. Such examples of self-mobilisation need to be highlighted and shared widely.