Introduction

The HIV/AIDS epidemic was responsible for approximately 2 million deaths in Africa in 1998 and is now the leading cause of death in developing countries. In addition, around 65% of adult medical in-patients are HIV-seropositive in urban hospitals of countries such as Zambia. Home care is the only option available for many HIV/AIDS patients because hospital care is unaffordable and inaccessible. An effective and affordable HIV home care programme can relieve the overload of hospitals with HIV/AIDS patients and also has major health and social benefits for the patients and their families. It can also reduce nosocomial transmission of tuberculosis from tuberculosis infected HIV/AIDS patients. Home care can also be a potentially effective entry point for strengthening HIV prevention and tuberculosis control.

Despite these numerous advantages, currently only a small proportion of people living with HIV and AIDS (PLHA) have access to home care services. An effective home care programme should not only provide high quality services, but it should also have high coverage. Since home care needs are increasing at a rate 5-10 times faster than the growth of home care services, existing home care programmes are unlikely to keep pace with the rising demand. For example, in Zimbabwe home care coverage dropped from 33% to just 6% between mid-1991 and mid-1995. Home care programmes are simply not being expanded and replicated as fast as the demand is increasing. There is therefore an urgent need to expand home care services in order to meet the rapidly increasing needs of PLHA. However, it is not clear how home care programmes should be expanded and replicated. Furthermore, programmes vary as to whether they concentrate on home visiting for the very sick AIDS patients (home care) or have a broader approach. The broader approach involves a ‘continuum of care’ of clinic-based services and care for infections occurring earlier in the course of the disease, such as directly observed treatment (DOT), preventive counselling and condom promotion as well as home care for the very ill (community care).

Methods

Case studies of the Lusaka Family Health Trust HBC Project and the Ndola Catholic Diocese HBC Programme in Zambia were carried out to:

(1) describe the origin and structure of the two HIV/AIDS and TB HBC programmes, so as to illustrate how the origin and structure of HBC programmes may affect their coverage;
to the demands of community volunteers who realized that most patients had TB and that it was a frequent cause of death.

Structure of the home-care programmes

The Family Health Trust HBC Project

Lusaka has a population of about 1.4 million inhabitants, the majority of whom are from the low-income groups or below poverty datum line. As in most parts of Zambia, more than 50% of the population live in households that lack sufficient income to meet their basic daily needs.5 The urban and semi-urban parts of Lusaka are densely populated and consist of a varied mix of nationalities, cultures and ethnic groups.

The FHT HBC is one of the projects of the Family Health Trust. The other two projects are the Anti-AIDS Project, which provides health education to young people, and the Children in Distress Project, which provides support to families and children affected by HIV/AIDS. The HBC project links the University Teaching Hospital with health centres and the community. The project manager (an experienced nurse and counsellor) works with six female senior nurses/counsellors who are in charge of well-defined geographical zones in Lusaka. Since its main office is located in the University Teaching Hospital, most of its patients are referred from the hospital and patients are therefore often received at a late stage of illness (though it also receives patients referred by health centres and the community in general).

Family members are the main and immediate caregivers. However, trained community volunteers or caregivers participate in the daily care of patients, especially in basic nursing care, counselling and the provision of medical advice to patients. Community members are encouraged to form community groups of caregivers. The project works with these community groups to identify patients, support caregivers and manage income generation projects for widows and orphans. The nurse-counsellors support the family carers and volunteers in their activities and provide medical and psychosocial care through home visits. The programme also distributes food supplements to patients and their families free of charge on a monthly basis.

N’dola Catholic Diocese HBC programme

The Ndola Copperbelt is the smallest but most populous province of Zambia. Its large copper mines were a major source of employment; however, the privatization of copper mines and facilities, which were previously owned by the government, has led to the loss of tens of thousands of jobs and consequently high levels of unemployment. High levels of unemployment coupled with inflation have resulted in high levels of poverty. About 80% of Ndola’s 450 000 population live in urban townships. Christian churches play a leading role in community life, with most people belonging to a church.5

The Ndola HBC is run as a partnership. The partnership brings together the Ndola Catholic Diocese, local NGOs and community groups, the District Health Management Team, government and private hospitals, the Victim Support Unit of the Zambian Police, the German HELP Food Project, a small number of local businesses and individual well-wishers within
the Copperbelt Province. It operates in five of the eight towns of the Zambian Copperbelt programme.

Mainly family members provide nursing and medical care with the support of trained community volunteers. Welfare support such as food, clothing and money is also provided. Trained volunteers and religious leaders provide counselling, emotional and spiritual support, while friends, family members or volunteers provide practical help for certain household duties. Community nurses carry out home visits accompanied by community volunteers and provide medical, nursing and psychosocial care. Care is also provided at specialized community clinics or health centres on specific days.

Most of the patients registered with the programme are referred from the community, by the volunteers, and very few from hospitals. Since many patients are referred from the community, most of the patients are registered with the programme before they are severely ill. The programme provides care for all chronically ill patients irrespective of their HIV status.

The AIDS Department of the Catholic Diocese acts as a coordinating body that links the community and donors. It presents the needs of the community through proposals that are understandable to donors and assists the community in accounting for resources spent. Its central offices are located in the community (in contrast to the FHT HBC whose offices are located in the University Teaching Hospital).

The FHT HBC and the Ndola HBC both operate mobile teams of community nurses to provide nursing care and to support community health workers. However, there are fundamental differences in the structure of the programmes. The FHT HBC provides a wide range of services predominantly by networking with other sections of the Family Health Trust, while the Catholic Diocese of Ndola works by networking with NGOs, community groups and government facilities.

### Task analysis of services provided by community nurses and volunteers

The community nurses and volunteers in both programmes perform a wide range of tasks; these are presented in Tables 1 and 2. The tasks with an asterisk indicate tasks that most government, missionary or NGO employed nurses may not be able to provide given the limited means. However, the other tasks may form part of a standard package of care for HIV/AIDS patients in areas with limited or no donor funding, since they appear to be potentially replicable by many government, NGO and missionary services with minimal donor assistance.

In both programmes, consultations are carried out in patient’s homes when they are very sick or bed bound. The nurses of the FHT HBC carry out mainly home visits for patients in their specific zones and counselling of patients at the University Teaching Hospital. On the other hand, the nurses of the Ndola HBC perform home visits and consultations at

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<th>Table 1. Tasks performed by community nurses of two HIV/AIDS home-based care programmes in Zambia, 1999</th>
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<td><strong>Family Health Trust HBC Project and Ndola Catholic Diocese</strong></td>
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<td><strong>HBC Programme</strong></td>
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<tr>
<td>Medical/nursing tasks:</td>
</tr>
<tr>
<td>• Clinical history, examination and preparing care plans for new patients</td>
</tr>
<tr>
<td>• Carrying out home visits and consultations for registered patients*</td>
</tr>
<tr>
<td>• Prescription and provision of drugs free of charge*</td>
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<tr>
<td>• Provision of general nursing care</td>
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<td>• Training of family members concerning care of patients</td>
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<td>• Provision of physiotherapy</td>
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<tr>
<td>Psychosocial and educational tasks:</td>
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<tr>
<td>• Counselling for family members and children</td>
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<td>• Empathizing with patients and family members</td>
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<tr>
<td>• Provision of information and awareness raising</td>
</tr>
<tr>
<td>Welfare tasks:</td>
</tr>
<tr>
<td>• Distribution of food supplements to selected patients in need*</td>
</tr>
<tr>
<td>• Assess the need for food, clothing, etc</td>
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<tr>
<td>Others:</td>
</tr>
<tr>
<td>• Establishing contacts with community members</td>
</tr>
<tr>
<td>• Participate in the training of community volunteers</td>
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</tbody>
</table>

* These are tasks that most government, missionary or NGO employed nurses may not be able to provide given the limited means.

HBC = home-based care.
community clinics. In addition the community nurses in the Ndola HBC are more involved in tuberculosis control. Most of the activities carried out can be done by government-employed nurses working in public health facilities, with the exception of the provision of drugs and food supplies. These health care activities are potentially feasible and could form a basis for the development of community care by government health facilities.

The community volunteers of the Ndola HBC have more responsibilities than those of the FHT HBC. The fact that community volunteers are involved in the provision of DOT for TB appears to be very useful, but it may not be feasible in some settings. In order to reduce the risk of volunteers developing TB, they are trained on how to collect sputum and directly observe TB treatment. In addition, access to care is free if they develop TB.

Coverage of the programmes

The FHT HBC estimates its coverage as a proportion of the programme target figures for the year. The target number for the year is estimated at 600 patients. The estimate is based on the number of patients the FHT HBC can cater for with the available resources while still maintaining good quality services. Since there were about 441 patients on the programme, the estimated coverage is 441/600 or 74%. However, when measured by a population-based method, using the estimated number of AIDS patients and other chronically ill patients who require HBC in the target area, the coverage of the FHT HBC area was 7%. The Project may be small in coverage but it is among the first HBC projects in the country that has made an impact in the care and support for HIV/AIDS patients in the community.

The Ndola HBC used a community survey to estimate its coverage. In 1998, a study was carried out in one of the townships of Ndola, which concluded that 71% of people who had been sick for at least 1 month before death during the previous year had been registered with the Ndola HBC. The coverage of the Ndola HBC is therefore estimated at 71%.

Factors that may affect the expansion and replication of the programmes

Level of community participation

In the FHT HBC, the community participates by forming community groups of caregivers. The caregivers identify patients, provide basic nursing care, supervise care provided by family members, and manage income-generating projects for families in distress. All services are provided free of charge and there is no cost-recovery.

In the Ndola HBC, the community participates by providing community volunteers. Food supplements are provided to community volunteers at half the retail price, while patients pay 10% of the retail price. The money generated is used to provide income generation activities for groups of community volunteers and PLHA. In addition to the time and effort provided by community volunteers, the community also provides infrastructure such as church buildings. Community participation and ownership appears to be greater in the Ndola HBC than with the FHT HBC, as judged by the degree of involvement of volunteers. Volunteers appear to have greater responsibilities and are more active in the Ndola HBC.

Use of support groups

The Family Health Trust uses the existing support groups to give support to other HIV/AIDS clients, and among them some individuals are used to facilitate community training workshops at the HBC Project for families and community volunteers. However, PLHA groups in Lusaka have had difficulties in sustaining their activities.
Support groups of PLHA form an important part of the Ndola HBC. For example, the Chishilano support group for people affected by HIV/AIDS runs a centre where clinic consultations for patients registered with the programme are provided once a week. In addition to peer support and counselling, skills training in income generation activities such as production of greeting cards and clay pots, gardening, production of coffins and the production of high protein supplement meal, are also carried out. Support groups are potentially useful in increasing community awareness of the programme and mobilizing the community but they take time to develop and require continuous support.

**Government support**

In the past, the government provided drug kits to HBC projects through the World Health Organization. Since the introduction of health reforms, this support has ceased. However, the government has provided the enabling environment for HBC programmes in the country, though with minimal support in terms of collaboration, monitoring and logistical support. There is inertia on the part of the government to coordinate the HBC activities in the country.

Government support to the FHT HBC is in the form of drugs (for pain relief) and gloves. The government provides very little financial or material support to the Ndola HBC. This notwithstanding, the government has seconded a few nurses to work on the programme. The Victim Support Unit of the Zambian Police provides legal support to PLHA, widows and orphans in both programmes. The National TB Control Programme provides the tuberculosis drugs, while sputum smears are carried out free of charge at the District Hospital. However, TB drug supply at the district pharmacy is very erratic; hence the Ndola programme procures some TB drugs to supplement the erratic district supply. Some patients receive free consultation when referred to the district hospital, but this has not been formally established. Government support is therefore generally inadequate, and there is little interaction between the community-based programmes and the government institutions.

**Support from foreign donors**

Practically all the financial support for the Family Health Trust is from foreign donors, in particular the Norwegian Agency for international development (NORAD). Food supplements for patients are from the World Food Programme. Other European and American NGOs provide financial and material support for specific components of the programme when possible.

The majority of financial resources in the Ndola HBC are obtained from foreign donors. The World Food Programme originally provided food supplements for free distribution to clients. However the Ndola HBC decided to introduce a fee of 10% of the cost of food and the World Food Programme stopped providing food supplements. The German HELP Food Project now provides the food. The cost-recovery introduced was intended to provide resources for the provision of income-generating activities so as to reduce poverty and avoid dependency on food supplements. It was also thought that payment of this symbolic fee would increase community ownership of the programme. Supplies are currently limited and only about half of patients on the programme receive food supplements.

**Programme costs**

Data were unavailable from the Family Health Trust. The average expenditure per month for Ipusukilo Township of the Ndola HBC was found to be US$2216. The analysis was done over a 24-month period from 1996–98; Ipusukilo has about 400 registered patients. The distribution of expenditure on line items was as follows:

- welfare (food etc.), 37%;
- drugs and equipment, 25%;
- transport, 14%;
- staff, 10%;
- office overheads, 8%;
- volunteers, 4%;
- other, 2%.

The average cost of a nurse consultation for the Ndola HBC is US$3.25. If the cost of welfare is excluded, the cost of a nurse consultation is US$1.85–2.60.

The Ndola HBC believes that these figures are representative of most of the other townships. However, this low cost may only be true for high-density urban areas such as Ndola. The fact that the most costly item of the budget is welfare services contrasts with many other HBC programmes where staff salaries is the most costly item of the budget. An in-depth cost analysis of the programmes is required in order to understand the full cost implications when scaling up programmes. Particular attention should be paid to costing of volunteer time and donated goods. This did not form part of the objectives of this study and we did not have the time and resources to carry out such work.

**Discussion**

This study is based on two of the largest community-care programmes in Zambia. The results are specific to the programmes and not generalizable. Nevertheless, the information obtained provides useful insight on the problems involved in replicating and expanding HBC services.

There is an urgent need to expand and replicate the experiences of community care programmes in Africa in order provide care for the rapidly increasing number of patients. Community care services should be available in all communities and therefore should be planned for as part of district health services. Although the two programmes studied were started spontaneously, communities should be encouraged and supported in developing and initiating community-based care programmes in order to increase coverage of community-care in Africa. Motivation appears to be an important factor to consider in expanding programmes. Since this will vary from area to area and from community to community it is impossible to suggest a formula for developing HBC.
Vices can attract patients to use community-care services and areas with high levels of poverty, such as Zambia. Welfare services are an important component of community care programmes in community organizations appears to be a generalizable and developed programmes that provide services through net-models, as welfare services are often costly. The lack of work are also provided. These welfare services structures exist, such as in the Ndola community. Factors such
as the communities’ prior involvement in projects and the existence of community leaders or structures are also relevant.

The two very different origins and aims of the programmes studied may have influenced the target population and eventually the coverage of the community-based programmes. Community-care programmes that are developed with the primary aim of decongesting hospitals such as the FHT HBC Project tend to care mainly for the severely ill. On the other hand, patients registered with the Ndola HBC Programme tend to be from the primary care clinics and include the relatively less severely ill. Programmes that focus on patients identified in health facilities will tend to have lower coverage and ignore those that are being missed. On the other hand, community-care programmes that are developed with the primary aim of caring for chronically ill patients, such as the Ndola HBC Programme, tend to care for patients at a relatively earlier stage of illness. This appears to be more appropriate as not only is care provided early in the illness, but there is also early access to the care continuum. These types of programmes may also reduce stigma and discrimination related to HIV/AIDS HBC, since many of the patients registered with the programme are not emaciated and so identifiable as AIDS patients.

The programme offices of the two programmes are located in two distinct areas. The offices of the FHT HBC are located in the hospital, which may reduce the capital costs involved in setting up a new programme. On the other hand, the building of new offices in the community, as in the case of the Ndola HBC, may add to the capital costs and therefore feasibility of starting a HBC programme in areas where donor funds are unavailable.

Developing programmes that provide services through networking with other government, non-governmental and community organizations appears to be a generalizable and feasible model of community care. Such models are most likely to be replicable where missionary and NGO community-based care programmes exist. Currently no single organization can pretend to be able to provide all the services needed by PLHA and their families.

The provision of welfare services such as food appears to be an important component of community care programmes in areas with high levels of poverty, such as Zambia. Welfare services can attract patients to use community-care services and can therefore help in increasing coverage. In addition they can contribute to encouraging compliance to TB treatment, since TB patients may discontinue therapy and not regain appetite but do not have food available. However, these welfare services are costly, difficult to sustain and represent a short-term solution to poverty. If the income generation activities are also provided. These welfare services may also limit the expansion and replicability of the HBC models, as welfare services are often costly. The lack of resources has been cited by some authors as being the major limiting factor for expansion of home care programmes. Some authors have also attributed the low coverage rates of HBC programmes to the young age of the programmes. However, it seems too easy to justify low coverage rates in this way.

For HIV/AIDS home care to increase substantially, government health services need to have greater involvement. Government involvement in the past has been predominantly through verbal support and, in some circumstances, through policies. However, greater government involvement in formulating policies, comprehensive plans and coordinating efforts of donors and service providers is required. Apart from the Zambian government’s secondment of government paid nurses to work with the Ndola HBC Programme, there has been very little material, financial or technical support from the Zambian government, and African governments in general. Government involvement and support can have a multiplying effect on HIV/AIDS home care coverage, because of the large number of public health facilities which represent potential outlets for supporting HIV/AIDS home care. The large amounts of resources that are required to increase home care coverage are unlikely to be available through donors; resources will need to be generated by the government. This is particularly so for clinical services as government health facilities are often present in areas where NGO and missionary health facilities are not available.

However, there are a number of factors that may limit government involvement in HIV/AIDS home care. For example, an HIV/AIDS home care model is needed that can be developed, implemented and sustained by government health facilities. The highly funded NGO models of home care that provide high quality services and a wide range of welfare services may not be appropriate for government health facilities. Government staff may also lack the technical expertise or motivation for developing and implementing HIV/AIDS home care. Potentially however, NGOs working in the field of HIV/AIDS home care could provide technical support and training such as community involvement and programme management.

Although the community nurses and volunteers of both community-care programmes studied carry out a wide range of activities, health professionals in government health facilities could carry out most of the tasks. The provision of free drugs may not be feasible through the government health facilities but may be feasible through networking with other...
organizations. Welfare services may be provided through net-
working with other government departments, but are likely to
require strong partnerships between the NGO and govern-
m ent. 10

The integration of HIV/AIDS and TB services appears to be
one of the most important factors that affect the effectiveness
of community-care services. High cure rates through com-
munity DOT are possible, and the detection of other HIV ill-
nesses is facilitated in TB patients and vice versa. Osborne et al. 11 stress the importance of integrating HIV/AIDS home
care to involve all chronic illnesses as a means of reducing
the compliance of patients and hence increasing coverage. Despite the fact that the Ndola HBC is currently implementing a strong DOT
system, it should be recognized that a large amount of time
and effort is required from the volunteers. The fact that
the patients, not the volunteers, keep their drugs and records may
increase the replicability of this model.

There does not seem to be any major threat to the sustain-
ability of these particular community-based care programmes
despite the obvious dependency on external funds. Sustain-
ability appears to be determined by the ability to sustain
funding from donors, which depends on the credibility and
quality of services provided by the programmes. However,
not all community care programmes can be donor funded and
less elaborate community-care models for resource poor
areas should be developed. It is also unrealistic to imagine
that such poverty-stricken communities could one day supply
the amount of financial resources required to sustain these
community-based programmes. The community’s contri-
bution in terms of volunteers and infrastructure is far from
minimal. However, in order to appreciate this, research is
needed to evaluate the community’s contribution in mone-
tary terms.

The coverage of the FHT HBC Project appears to be high
when estimated as a proportion of the programme’s target for
the year. However, this estimate is misleading. The actual
coverage of the programme was low (7%) when coverage is
measured as a proportion of the number of chronically ill
patients in the target area actually receiving care. A number
of reasons may be responsible for the low coverage of this
programme. The immediate reason appears to be the lack of
resources to provide services to the large number of patients
who need care. Another more significant reason may be fact
that most of the Project’s clients are referred from the hospi-
tal wards. They may therefore be preoccupied with patients
who enter the system, rather than with those who are missed. 12

The fact that the Family Health Trust is currently increasing
its use of community volunteers should lead to a change in its
coverage and target population in future. Lastly, like many
NGOs, the Family Health Trust is limited in its ability to
expand. In addition, the high quality of its services may well
be due to the relatively small size of the organization.

The coverage of the Ndola HBC found by community survey
was 71%. This high coverage may well be because the Ndola
HBC is recruiting patients who are not traditionally con-
sidered to need HBC. In addition, the high coverage can be
attributed to its strong community participation and the moti-
vation of the community volunteers working in the pro-
grame. Indeed, volunteers identify most patients registered
with the programme, with case finding by volunteers being a
vital strategy of this programme.

Home-based care programmes that scale-up their services are
likely to be faced with a number of challenges. Although the
motivation of volunteers and caregivers may be high at the
beginning of a programme, it may be difficult to sustain moti-
vation when the programme expands. When workload
increases substantially, Programmes may therefore face sub-
ostantial challenges in maintaining the quality of home-based
care services. Some programmes may even have to trade-off
high quality of services for increased coverage and accessi-
bility. In addition, management structures and systems are
likely to become more bureaucratic, less flexible and respon-
sive, and consequently less efficient. Large home care pro-
grames may therefore develop rigid institutional skeletons,
which allow little flexibility to bring together resources from
a variety of sectors in an efficient way as in smaller home care
programmes.

The main limitation of this study appears to be the lack of
information about the patients’ satisfaction with the services,
and in particular whether the services reflect their felt needs.
Information on patient satisfaction with services provided by
the two HBC programmes was not available at the time of the
study. Surveys are needed to assess this important indicator
of the quality of HBC programmes.

Conclusion

There is an urgent need to expand and replicate the experi-
ences of HBC programmes in Africa. Government involve-
ment in community care has in the past been very limited and
there is much room for improvement. In order to increase
home care coverage significantly, governments must get
involved in providing some form of basic home care for
PLHA. Research and development is needed for affordable,
feasible and sustainable home care programmes that can be
implemented by staff working in government, NGO and mis-
sionary health facilities with limited donor funding. Inno-
vative strategies are also required to establish effective
partnerships between the NGO, missionary and government
health facilities.

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Acknowledgements

Special thanks to the staff of the Family Health Trust, Lusaka and the Ndola Catholic Diocese home care programme for their willingness to share information. This study was made possible through funds provided by the DFID funded Tuberculosis Research and Development Programme of the Nuffield Institute for Health.

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