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How can the community contribute in the fight against HIV/AIDS and tuberculosis? An example from a rural district in Malawi

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Summary This paper describes (a) the experience of initiating community involvement in HIV/AIDS and tuberculosis (TB) activities in a rural district in Malawi and (b) some of the different ways in which the community is contributing in the fight against these two diseases and the outcomes of their involvement. During a 2-year period, a total of 21 358 (41%) of 52 510 HIV tests performed at voluntary counselling and HIV testing (VCT) sites in the district were conducted by lay community counsellors. A team of 465 community volunteers, 1362 trained family caregivers and 9 community nurses provided care and support to 5106 HIV-positive individuals, of whom 2006 (39%) were in WHO stage III or IV. All those in WHO stage III or IV were on co-trimoxazole prophylaxis and 895 (45%) of these were also on antiretroviral treatment. A total of 2714 TB patients, of whom 1627 (60%) were HIV-positive, also received care and support. A total of 1694 orphans were trained in vocational skills. Twelve vegetable gardens and three maize farms were set up, and pre-school activities were organised for 900 orphans. Communities can play an important contributory role in reducing the burden of HIV/AIDS and TB and in mitigating its impact. Despite this, community resources in most settings are often under-exploited and their role remains undefined.

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1. Introduction

At the end of 2003, there were an estimated 900 000 people living with HIV/AIDS in Malawi, of whom approximately 200 000 individuals were thought to require care and support including antiretroviral treatment (ART) (NACP, 2003). The country registers approximately 23 000 new tuberculosis (TB) cases each year, of whom 77% are HIV-positive (Kwanjana et al., 2001). Seventy percent of all medical admissions in some hospitals are HIV-positive (Lewis et al., 2003). An estimated 86 000 AIDS-related deaths occur each year. HIV/AIDS and TB thus constitute a major burden on existing health services in Malawi. In particular, the human resource capacity to cope with this burden is seriously limited for a number of reasons. First, public health facilities face a severe staff shortage, with an estimated 50% of Ministry of Health (MOH) posts currently unfilled (MOH, 1999). Ninety percent of these structures do not even have the capacity to deliver the Essential Health Package (MOH, 2003a) let alone additional interventions linked to TB—HIV. Second, salaries and conditions of service in the MOH are poor and qualified local staff continue to leave the public service for greener pastures elsewhere. Third, among health workers there is a high annual attrition rate of 2.8% due to HIV-related deaths (Harries et al., 2002). Chronic absenteeism due to illness is also a major problem (MOH, 2003b).

In light of this, communities may be considered an 'unexploited resource' that could play an important contributory role. Despite this, in countries such as Malawi, communities have for the large part remained isolated from the public health system and this resource is often under-exploited.

Thyolo, a rural district in southern Malawi, provides an example of the important contributory role that the community is playing in the fight against HIV/AIDS and TB with the support of a non-governmental organisation. This paper describes (a) the experience of initiating community involvement in district-level HIV—TB activities and (b) some of the different activities and outcomes of community involvement.

2. Methods

2.1. Study setting

Thyolo District is a rural region in southern Malawi with 458 976 inhabitants. In 2003, the district had an estimated global HIV prevalence of 9%, with an estimated 41 000 people living with HIV/AIDS, 6000 of whom are thought to be in urgent need of ART (NACP, 2003). The majority of inhabitants in the district are farmers and 80% of all income is from the agricultural sector. The district is divided into seven traditional authorities headed by a traditional chief.

2.2. Voluntary counselling and HIV testing (VCT), co-trimoxazole prophylaxis and ART

Since the year 2000, VCT has been progressively scaled-up from the main district hospital (Thyolo Hospital) to 13 additional peripheral health facilities. VCT is offered to outpatients, patients on the wards, mothers attending antenatal care, patients with TB, blood donors, and to all those who present wishing to know their HIV status. HIV testing is conducted using rapid whole-blood test kits according to the WHO strategy II for HIV antibody testing (UNAIDS/WHO, 1997). All HIV-positive individuals in WHO clinical stage III and IV (including HIV-positive TB patients) are offered co-trimoxazole prophylaxis at a dose of 960 mg daily provided there are no contraindications. ART (a fixed dose combination of stavudine, lamivudine and nevirapine) was initiated in April 2003 and since then has been offered to all patients assessed clinically to be in WHO stage III or IV (MOH, 2003c). HIV-positive individuals are formally linked up with community networks that cover almost half of the district and which provide a continuum of care and support (Zachariah et al., 2004) (Figure 1).

2.3. Steps in initiating, sustaining and monitoring community activities

The following steps were taken over a period covering approximately 3 years (latter part of 2001 to December 2004).

2.3.1. Identify potential community partners

Prior to the involvement of Médecins sans Frontières (MSF), members of some churches had already organised themselves into support groups and were providing spiritual and social support to terminal patients living with HIV/AIDS. Dialogue was initiated with such groups in order to build upon the existing structure. Traditional chiefs, church leaders, representatives of the district services and people living with AIDS were integrated. A community executive committee was conceived and a smaller management committee comprising a president, a co-ordinator (who also acts as a liaison officer with the district health services) and a treasurer were elected.

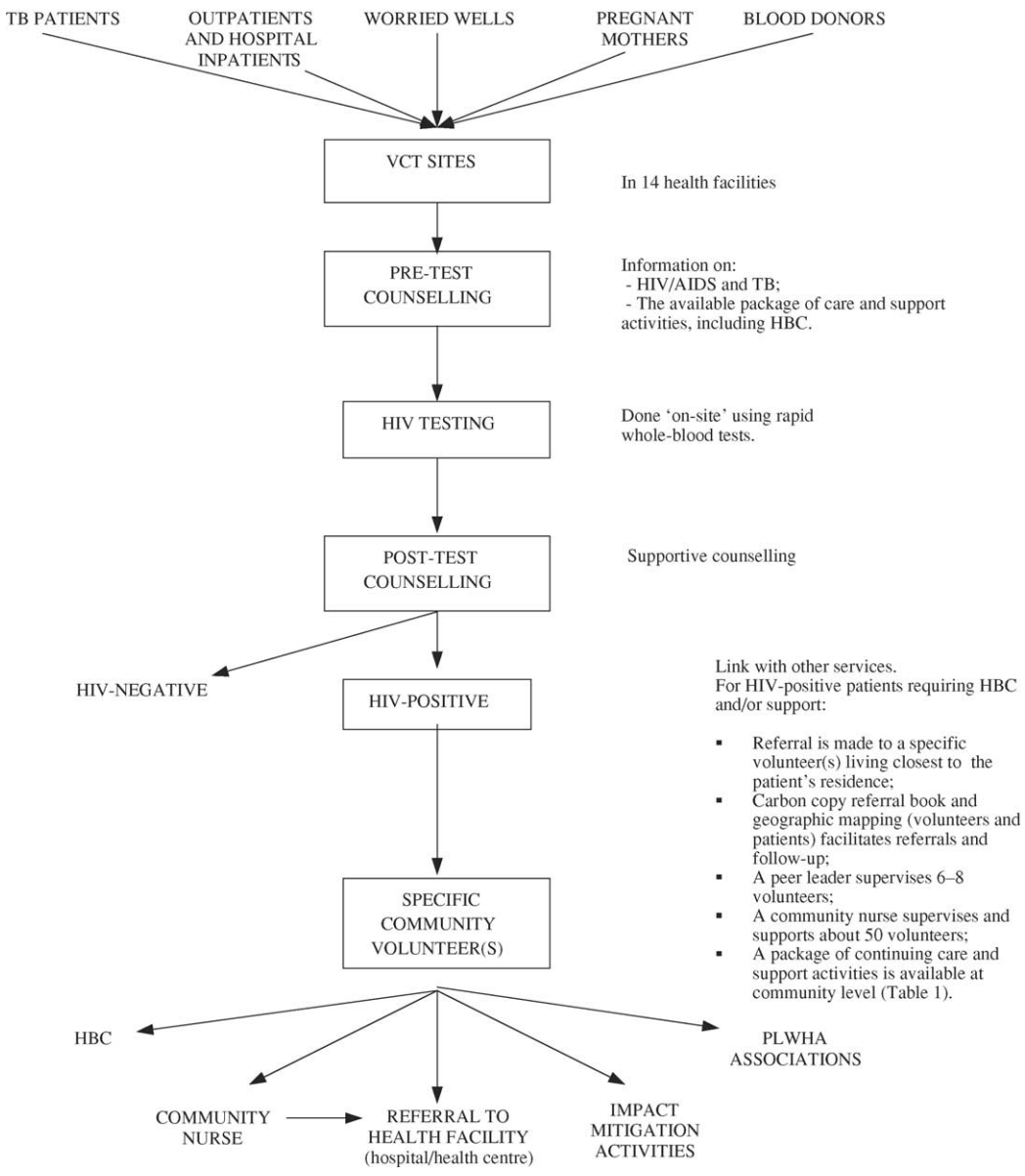

Figure 1 Circuit followed by an individual requiring community care and support from health structures into the community, and vice versa. TB: tuberculosis; VCT: voluntary counselling and HIV testing; HBC: home-based care; PLWHA: people living with HIV/AIDS.

2.3.2. Enhancing the role of the community in the planning and implementation process

Project conception was undertaken in close collaboration with community representatives. Close dialogue, joint decision-making and feedback from the planning stage through to implementation gave all stakeholders the possibility of active participation in decisions and in orienting the overall community health strategy.

2.3.3. Determining the package of activities to be carried out by the community

Table 1 shows the package of HIV/AIDS- and TB-related activities carried out by the community.

2.3.4. Selection and training of volunteers

The main criteria for being eligible to become a volunteer include being resident in the community where the volunteer wishes to work and having expressed a commitment for volunteer work. Volunteers undergo 2 weeks of theoretical training on care and support followed by 'on the job training' with community nurses. The curriculum covers various aspects linked to HIV/AIDS, guardian-based decentralised anti-TB treatment (Salaniponi et al., 2003), adherence counselling, information, education and communication (IEC), and home-based care (HBC) activities. Trained volunteers who undertake house-to-house visits are equipped with

Table 1 Thyolo District, Malawi: community involvement in a comprehensive package of HIV/AIDS- and TB-related activities

Component (prevention, care and support)	Specific activities
VCT	VCT carried out by lay counsellors in 12 of 14 VCT sites. Encourage referral of individuals for VCT.
Link between health facilities and communities	A geographic network of volunteers allows individuals with HIV/AIDS and TB to be referred from health facilities to a specific volunteer(s) for continuing care and support.
Management of opportunistic infections	Decentralised (home-based) diagnosis and management of common opportunistic infections performed by a team of volunteers and community nurses. Monthly supply of co-trimoxazole for prophylaxis for HIV-positive individuals who live far away and are too ill to travel for follow-up. Link with community nurses for further support. Referral of complicated cases to hospital.
Early TB case detection	Systematic chronic cough screening (for TB) in households with an HIV-positive individual or an individual with TB. Sputum collection and transport to health centres for sputum smear microscopy. Link with traditional healers for referral of cases with chronic cough.
Anti-TB treatment	Guardian-based DOTS. Supportive counselling. Defaulter tracing.
Adherence counselling (ART, co-trimoxazole, anti-TB treatment)	Continuing supportive counselling on a one-to-one basis. Support to family caregivers.
Drug-related side effects	Early recognition and referral of individuals having possible drug reactions to ART, co-trimoxazole or anti-TB treatment.
Nutritional support	Distribution and monitoring of supplementary dry rations to malnourished (BMI < 17 kg/m^2) HIV/AIDS and TB patients. Follow-up.
Community mobilisation centres	Support in resource mobilisation (e.g. for clay brick making) for the construction of community centres. Provision of labour for construction.
Vocational training activities for orphans	Carpenters, masons, tailors etc. working in the community provide time for regular vocational training and supervision at community centres or at their own work sites.
Income generation activities	Market sale of products from vocational training activities allows a revolving fund.
Community farms	Mobilisation of labour for community vegetable, rabbit, fish and maize farms that supplement food to destitute individuals living with HIV/AIDS and TB.
Pre-school activities for orphans <5 years old	Day care for orphans <5 years of age who live in single-member households.
PMTCT	Referral of HIV-positive pregnant mothers to PMTCT services.
IEC/behaviour change interventions	IEC at community forums and meetings. PLWHA are actively involved with disclosure and speaking out their experiences at IEC activities to: community groups, teachers, youth in schools, commercial sex workers and leaders (e.g. religious, traditional and political leaders).

TB: tuberculosis; VCT: voluntary counselling and HIV testing; DOTS: directly observed anti-TB treatment; ART: antiretroviral treatment; BMI: body mass index; PMTCT: prevention of mother-to-child transmission; IEC: information, education and communication; PLWHA: people living with HIV/AIDS.

a 'home-based care kit' containing basic drugs and supportive material for first-line care for conditions such as diarrhoea, fever, skin conditions and oral thrush. In families with advanced HIV/AIDS disease, severe malnutrition or debilitated patients, one family member is trained 'on the job' as a 'family caregiver'. This training includes providing information on key issues related to HIV/AIDS and TB, support to adherence, palliative care and nutritional advice. Volunteers and caregivers have also been trained to detect 'risk signs' that merit referral to a health centre or the hospital. These include worsening signs of dehydration despite oral rehydration, persistent difficulty in swallowing despite medication for oral thrush, reducing level of consciousness, progressive worsening of headache, increasing breathlessness despite co-trimoxazole prophylaxis, and focal palsies.

2.3.5. Organisation and supervision of community volunteers

Volunteers involved with care are organised into groups by geographic area and are supervised by teams of peer leaders and community nurses. Geographic mapping of existing patients and volunteers allows visualisation of the network and facilitates planning and supervision. Volunteers are provided with bicycles, and community nurses have motorbikes equipped with an in-built drug box.

2.3.6. Sustaining community groups and volunteers

Regular dialogue, supervision and training are essential to ensure motivation and commitment of the team. In our setting, volunteers are remunerated through incentives. Incentives take different forms and are linked to activity and duration of commitment. They include items such as rain boots, raincoats, seed grain, fertiliser for private or community farms, and bicycles.

2.3.7. Vocational training and income generation activities (Table 1)

A community centre is required to carry out regular co-ordination meetings of community groups, meetings between volunteers and community nurses, vocational training and pre-school activities. MSF provided support for the construction of community centres, with the community participating in providing the necessary labour. Tools and raw materials needed for vocational training and technical support in financial management were also provided by MSF. Land for community farms was provided by traditional chiefs. The products of vocational training and farm produce (Table 1) are sold at a profit margin, which helps to generate revenue and create a revolving fund.

2.3.8. Monitoring and reporting

All patients in HBC have patient cards, which allows a record of diagnosis, treatment and follow-up. A record is kept of the numbers of visits made by volunteers and nurses per week. Peer leaders provide weekly summary statistics. A monthly activity report is collated and made available to the district health office.

2.4. Data collection and analysis

The data presented in this paper cover a 2-year period from January 2003 (from when a monitoring and reporting system for community activities was functional) to December 2004. Patient cards and activity registers as well as monthly reports were used to collate data presented in this paper.

The estimated number of people living with HIV/AIDS in the district was calculated using a global HIV prevalence rate of 9% (NACP, 2003). The proportion of those with advanced stage of HIV/AIDS disease was estimated as 15% of those living with HIV/AIDS.

3. Results

3.1. VCT

A total of 53 379 individuals were offered pre-test counselling at 14 different VCT sites, of whom 52 510 (98%) underwent HIV testing and 15 304 (29%) were found to be HIV-positive. This constitutes a detection rate of 37% of the estimated total number (41 000) of HIV-positive individuals living in the district.

Community members who were trained as lay counsellors were running 12 of the 14 VCT sites in Thyolo, and they conducted 21 358 (41%) of all HIV testing done in the district during the 2-year study period.

3.2. Community care, patients and visits

By the end of December 2004, the community team comprising 465 HBC volunteers, 1362 trained family caregivers and 9 community nurses was taking care of a total of 5106 HIV-positive individuals. Of these, 2006 (39%) were in either WHO clinical stage III or IV, constituting 33% of the estimated 6000 people living in advanced stages of HIV/AIDS in the district. All of these individuals in WHO clinical stage III or IV were on co-trimoxazole preventive prophylaxis,

6 were on fluconazole prophylaxis and 895 (45%) were on ART.

A total of 2714 TB patients, of whom 1627 (60%) were HIV-positive, had also been followed-up on a monthly basis by the community. Ninety-four percent of those who are HIV-positive received co-trimoxazole (Zachariah et al., 2003), and adherence verified during and after anti-TB treatment was 94% and 93%, respectively (Zachariah et al., 2001, 2002). A total of 1899 (70%) of all TB patients were under guardian-based anti-TB treatment where volunteers played a vital role in the community-based implementation strategy (Floyd et al., 2003; Salaniponi et al., 2003).

The average number of monthly entries into the HBC programme was 199 (range 126—276). The average number of monthly exits from HBC owing to deaths, transfer outs or patients being discharged because they no longer required HBC was 33 (range 8—37). There were a total of 794 exits in the study period, comprising 191 patients who improved on ART and were discharged and 603 patients who died. The main reported causes of death were diarrhoea (46%), pneumonia (17%), Kaposi's sarcoma (12%), HIV wasting syndrome with prolonged fever and diarrhoea (12%) and other conditions (13%) (including cryptococcal meningitis, severe vomiting with dehydration, and severe pallor).

There were 23 562 visits made in relation to specific disease conditions (Table 2).

Table 2 Total number of home visits for specific disease or conditions ($N = 23\,562$)

Specific disease or condition	No. (%)
Active WHO defining diseases	
Herpes zoster	249 (1)
Oral candidiasis	1508 (6)
Oesophageal candidiasis	165 (0.7)
Chronic diarrhoea >1 month	2016 (9)
Prolonged fever >1 month	1766 (7)
Severe bacterial infections (pneumonia, pyomyositis)	101 (0.4)
Kaposi's sarcoma	733 (3)
Cryptococcal meningitis	38 (0.2)
Oral hairy leukoplakia	92 (0.4)
Wasting syndrome	452 (2)
Pneumocystis carinii pneumonia	2404 (10)
HIV encephalopathy	42 (0.2)
Non WHO defining disease	
Upper respiratory tract infection	2068 (9)
Urinary tract infection	579 (2)
Vulvovaginal candidiasis	778 (3)
Mucocutaneous herpes simplex infection	101 (0.4)
Severe pallor (? anaemia)	1186 (5)
Others[a]	7913 (34)
Drug side effects (suspected)	
Skin rashes (? drug allergy)	1102 (5)
Peripheral neuropathy	245 (1)
Jaundice	24 (0.1)

[a] Presumed malaria, bloody diarrhoea, skin mycosis, scabies, conjunctivitis.

3.3. Active TB case finding

During house-to-house visits, HBC volunteers systematically screen for a 'chronic cough' (defined as a cough for 3 weeks or more) in households in which there is a known HIV-positive individual or a patient with TB. A total of 806 individuals living in different households were found with a chronic cough and were referred to a health facility. One hundred and sixty-one (20%) of these individuals in our setting have smear-positive TB (Zachariah et al., 2004). Considering an average household size of five (NSO, 1998), this would translate into an estimated annual TB incidence rate of 1997/100 000 in such households where there is a person with a chronic cough compared with the reported annual incidence rate of 265/100 000 within the general population (NTP, 2001).

3.4. Impact mitigation activities

In total, 1694 orphans aged over 12 years from households affected by HIV/AIDS and TB had undergone vocational training in activities such as carpentry, metal work, masonry, tailoring and bicycle repair. There are 12 community vegetable gardens that provide free vegetable supplements for malnourished and destitute individuals. Three maize farms were developed as co-operative schemes. The harvests from these sites provide maize staple for destitute households.

Community groups also organise caretaking and pre-school activities for 900 orphans, which allows foster parents or caretakers to leave their children in safety while they try to earn a livelihood.

3.5. Referrals from the community to health services

Community volunteers referred an average of 422 individuals each month to different services at health facilities. Of these, 67% were referrals to VCT, 12% were referred to the antiretroviral clinic either for possible ART or with complaints related to ART, 11% were referred for complicated

opportunistic infections, 5% were referred to the TB office for complaints related to anti-TB treatment, 3% were referred for sexually transmitted infections and 2% were known HIV-positive mothers who became pregnant and were referred to prevention of mother-to-child transmission (PMTCT) services. Of 34 088 individuals who presented to VCT sites of their free will (labelled worried wells), 5605 (16%) were referred by community volunteers.

4. Discussion

This paper outlines different ways in which the Thyolo community is contributing in the fight against HIV/AIDS and TB. Worthy of particular note are a number of activities. First, Malawi is desperately trying to scale-up HIV/AIDS- and TB-related activities within districts. Community members are playing a major role in the scaling-up process by providing VCT at 12 of the 14 VCT sites in Thyolo and having conducted close to half of all HIV testing done in the district in the 2-year study period.

Second, once diagnosis of HIV/AIDS and TB has been made and treatment has been initiated, the community takes a major responsibility in providing a continuum of care and support at home. The total hospitalisation capacity in Thyolo District is limited to 400 hospital beds. Meanwhile, decentralised community care and support covers a total of 5106 individuals, of whom 39% are in advanced stages of HIV/AIDS disease. Many of these individuals are likely to be bedridden or may require palliative or chronic care. Although this study has not measured the impact of HBC on hospital bed occupancy rates and costs to the health service, decentralised community care is likely to translate into important savings for the health services as well as direct or indirect benefits to patients.

Third, active screening for TB in households as well as early diagnosis and initiation of anti-TB treatment is likely to have an overall impact on TB-related morbidity and mortality. 'One in five' individuals referred with a chronic cough by volunteers have smear-positive TB. This is a rather high yield within this subgroup and, as a strategy for TB control, is thus of public health significance.

Furthermore, among households where volunteers found a person with a chronic cough, the annual TB incidence rate through an active case finding strategy is eight times higher than that in the general population. In other words, it is a worthwhile effort to 'actively' refer individuals with a chronic cough to health facilities (Verver et al., 2004).

Fourth, community volunteers are likely to play an important role in reducing community stigma associated with HIV/AIDS and TB. By interacting frequently with household members as well as religious and traditional leaders, and by being involved with counselling and IEC, they invariably increase community awareness. Through their activities, and particularly by providing care within homes, they are likely to positively influence health-seeking behaviour of individuals under their care and to promote the eventual utilisation of existing services.

Finally, the impact mitigation activities led by the community are an important step towards reducing the psychosocial impact of HIV/AIDS and TB. We continue to see a growing number of communities moving in this direction and have begun to see trained orphans set up their own workshops, earn a livelihood and eventually support others. The results of such activities are very motivating and surely bring dignity and hope to many.

In as much as we have described a number of encouraging aspects of community involvement, and the potential to enhance community involvement in HIV/AIDS- and TB-related activities, there are a number of 'lessons learnt' that organisations wishing to embark on supporting community activities should to consider.

First, many activities taken up and carried out by community members should ideally fall under the responsibility of the public service. Although the public health services do not have the infrastructure or the resources to cope with the current demands, these deficiencies will eventually need to be addressed through greater investment in the public service (Zachariah et al., 2004). By no means should the community be perceived as a group for simple relegation of activities (a dumping ground for responsibilities) that should fall under the mandate of the public service. Otherwise, community resources might end up being abusively exploited on the one hand and, on the other hand, policymakers might tend to disengage themselves unfairly from their responsibilities (Knippenberg et al., 1997).

Second, there is a need to create an environment between stakeholders that enhances 'collective responsibility' and ownership of interventions by all stakeholders. For such a dynamic to work, there have to be forums in which individuals are open to free and transparent dialogue, have an urge to collaborate and are able to find acceptable

compromises in case of disagreements. The skills of the district health representatives and those of collaborating partners in creating such a dynamic are critical for success.

Third, we believe the primary pillar that motivates volunteers in our setting is the religious commitment to their activities. Along with church groups, we have so far managed to maintain the motivation of volunteers and have not yet had dropouts from the volunteer pool. There are, however, rapidly growing numbers of HIV-positive individuals pouring into communities through VCT and an ever-increasing workload on volunteers. A threshold is likely to be reached where volunteers would have to balance the available time that is dedicated to volunteer activity against that required to sustain their livelihood. The current scenario of high commitment and zero dropout rate of volunteers thus might not be sustainable in the longer run.

There might be a way forward in addressing this potential problem. High HIV prevalence countries in sub-Saharan Africa facing serious shortages of human resources in the health sector might need to consider the introduction of a specific 'remunerated' human resource cadre that could be termed the 'community AIDS worker'. Such a profile could be modelled on similar lines as the community health worker profile, and both cadres could work hand-in-hand within the formal public health system. Such an option would seem the most appropriate for sustaining community activities without jeopardising the livelihood of individuals who already live in communities that are on the limits of poverty.

Communities can contribute in different ways to the fight against HIV/AIDS and TB. Health planners in high HIV prevalence settings should take this largely under-exploited human resource on board and endeavour to encourage and enhance their role.

Conflicts of interest statement
The authors have no conflict of interest concerning the work reported in this paper.

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