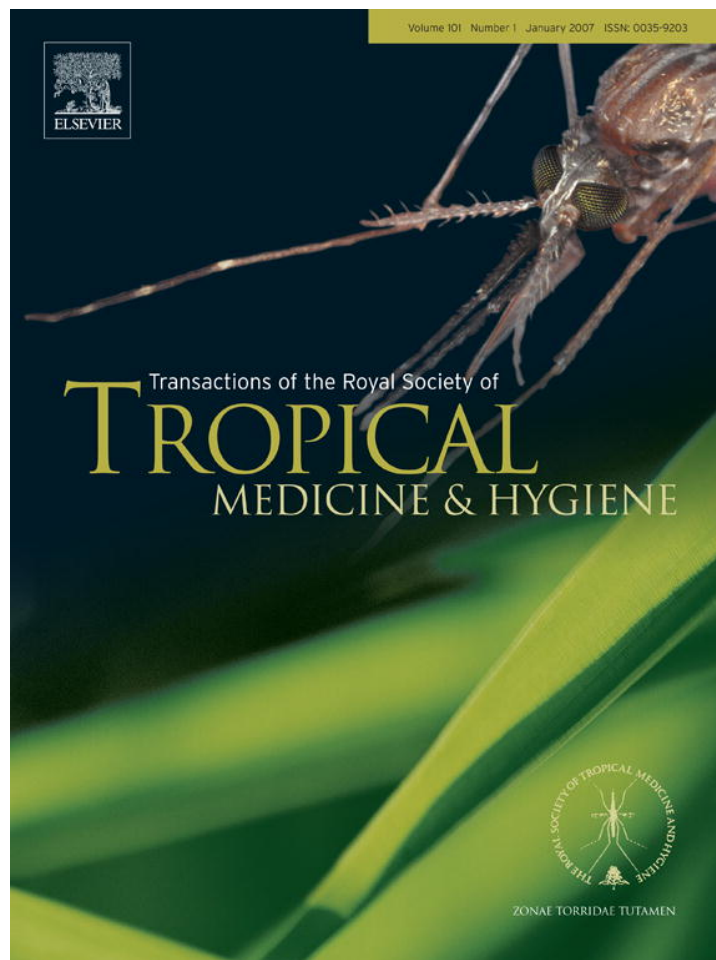


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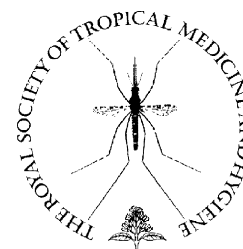
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Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi

R. Zachariah^{a,*}, R. Teck^b, L. Buhendwa^b, M. Fitzerland^b,
S. Labana^c, C. Chinji^c, P. Humblet^a, A.D. Harries^{d,e}

^a Médecins Sans Frontières, Medical Department (Operational Research), Brussels Operational Center, 68 Rue de Gasperich, L-1617, Luxembourg, Belgium

^b Médecins Sans Frontières–Luxembourg, Thyolo District, Malawi

^c Médecins Sans Frontières–Luxembourg & Thyolo District Health Services, Ministry of Health, Thyolo, Malawi

^d National Technical Advisor, HIV Care and Support, Ministry of Health, Lilongwe, Malawi (supported by Family Health International, USA)

^e London School of Hygiene and Tropical Medicine, London, UK

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Summary A study was carried in a rural district in Malawi among HIV-positive individuals placed on antiretroviral treatment (ART) in order to verify if community support influences ART outcomes. Standardized ART outcomes in areas of the district with and without community support were compared. Between April 2003 (when ART was started) and December 2004 a total of 1634 individuals had been placed on ART. Eight hundred and ninety-five (55%) individuals were offered community support, while 739 received no such support. For all patients placed on ART with and without community support, those who were alive and continuing ART were 96 and 76%, respectively ($P < 0.001$); death was 3.5 and 15.5% ($P < 0.001$); loss to follow-up was 0.1 and 5.2% ($P < 0.001$); and stopped ART was 0.8 and 3.3% ($P < 0.001$). The relative risks (with 95% CI) for alive and on ART [1.26 (1.21–1.32)], death [0.22 (0.15–0.33)], loss to follow-up [0.02 (0–0.12)] and stopped ART [0.23 (0.08–0.54)] were all significantly better in those offered community support ($P < 0.001$). Community support is associated with a considerably lower death rate and better overall ART outcomes. The community might be an unrecognized and largely 'unexploited resource' that could play an important contributory role in countries desperately trying to scale up ART with limited resources.

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1. Introduction

Malawi, a small resource-limited country in central southern Africa is faced with one of the highest HIV/AIDS prevalence

* Corresponding author. Tel.: +352 332 515; fax: +352 335 133.
E-mail address: zachariah@internet.lu (R. Zachariah).

rates in the region, with 14% of those aged 15–49 years infected with HIV (NAC, 2003). In 2003, there were an estimated 900 000 people living with HIV/AIDS and 86 000 AIDS-related deaths. An estimated 170 000 people are in need of care and support, including antiretroviral treatment (ART) (MOHP, 2003a).

Thyolo district is a rural region in southern Malawi where Médecins sans Frontières (MSF), an international medical non-governmental organization, has been working closely with the Ministry of Health (MOH) in implementing HIV/AIDS-related interventions. The MSF project, which was launched in 1999, involves the development of a comprehensive package of activities, including community involvement in care and support (Zachariah et al., 2004).

Early in 2003 the district began pioneering ART for eligible HIV-positive individuals in the country. In a number of administrative areas of this district, known as traditional authorities, close links were developed between health services and community networks actively involved in providing care and support to people living with HIV/AIDS, including those receiving ART. Does such community involvement influence ART outcomes in a resource-poor rural setting? In order to answer this question, we conducted a review of ART outcomes among patients living in areas of the district where community support was offered and compared them with outcomes in areas where no such support was available.

2. Materials and methods

2.1. Study setting and population

This study was conducted between April 2003 and April 2005 in Thyolo district, the largest rural district in Malawi, with 452 000 inhabitants. All individuals who started ART between April 2003 and December 2004 were included in the study. The population of this district consists principally of farmers, with 80% of all income coming from the agricultural sector (tea and coffee plantations).

In 1999 voluntary counselling and HIV testing (VCT) was introduced at the main public hospital in the district (Thyolo District Hospital) and progressively extended to other facilities. VCT is offered to patients on the wards, mothers attending antenatal care, patients with tuberculosis (TB) and to all those who wish to know their HIV status. HIV testing is conducted using rapid whole blood test kits: Determine HIV-1/HIV-2 (Abbott Laboratories, Tokyo, Japan) and Uni-Gold™ HIV-1/HIV-2 (Trinity Biotech, Bray, Wicklow, Ireland), according to the WHO strategy II for HIV antibody testing (UNAIDS/WHO, 1997). All HIV-positive individuals undergo a complete medical assessment for HIV-related diseases and are subsequently categorized into different WHO stages on the basis of clinical findings. All HIV-positive individuals are followed up in a specific HIV/AIDS clinic, which also offers ART.

2.2. ART eligibility, regimens and treatment outcomes

All individuals classified in WHO clinical stages III and IV and presenting to the HIV/AIDS clinic are considered eligible for ART. The first-line ART regimen in Malawi (MOHP, 2003b;

WHO, 2004) is a fixed-dose combination of stavudine (d4T), lamivudine (3TC) and nevirapine (NVP) (Triomune®). In the case of d4T- and NVP-related side effects, the respective alternatives are zidovudine (AZT) and efavirenz (EFZ). The second-line regimen in case of failure with the first-line regimen is a combination of AZT, didanosine (ddI) and nelfinavir (NFV).

Treatment outcomes are monitored by cohort analysis, which is carried out retrospectively every quarter by going through patient master cards and the ART patient register, as has been described previously (Harries et al., 2004). Outcomes are standardized and include: alive and on ART; died; lost to follow-up; stopped; and transferred out (Table 1).

2.3. Steps in initiating community activities in Thyolo

Thyolo district is divided into seven traditional authorities, each of which is headed by a traditional chief. The MSF-supported HIV/AIDS programme aimed to enhance the role of the community in a phased and progressive manner throughout the district. In this vein, a number of steps were clearly outlined, for initiating, sustaining and monitoring community activities, as has been described previously (Zachariah et al., 2006). The first step included identifying potential community partners and enhancing their role in the planning and implementation process. In three traditional authorities of the district, members of some churches had already organized themselves into support groups and were providing 'spiritual' support to terminal patients living with HIV/AIDS through a volunteer network. These three traditional authorities, having already made a head start in terms of community initiative, were considered to have a good potential for launching the first operational phase of community activities in the district. Dialogue was then initiated with different stake-holders in these three traditional authorities, which was followed by recruitment, training and organization of a community network of care and support. The progressive extension of community activities to the rest of the traditional authorities in Thyolo is an ongoing process.

Table 1 Standardized monthly treatment outcomes for patients on antiretroviral treatment (ART)

Alive and on ART	Patient who is alive and has collected his/her own 30-day supply of drugs
Dead	Patient who has died for any reason while on ART
Loss to follow-up (defaulted)	Patient who was placed on ART and not seen at all during a period of 3 months thereafter
Stopped	Patient who has stopped treatment completely either because of side effects or because of other reasons
Transfer out	Patient who has transferred out permanently to another treatment unit

2.4. Community support for ART and organization of carers

Table 2 shows the range of community activities linked to HIV/AIDS, some of which (e.g. information, education and communication) were available to a varying extent in different parts of the district.

For the purposes of this study, community support for ART was considered as exposure to a minimum 'care package' comprising all of the following: symptomatic treatment of opportunistic infections at home; support to family carers; referral of patients with possible drug reactions and risk signs; continuing adherence counselling; and defaulter tracing. During the time of the study, such community

Table 2 Thyolo District, Malawi: community involvement in HIV/AIDS activities, including antiretroviral treatment (ART)

Component	Specific activities
Management of opportunistic infections	<ul style="list-style-type: none"> - Decentralized (home-based) diagnosis and management of common opportunistic infections done by a team of volunteers and community nurses - Symptomatic treatment for diarrhoea, fever, oral candida and common skin conditions - Monthly supply of cotrimoxazole for prophylaxis for HIV-positive individuals who live far away and are too ill to travel to follow-up - Link with community nurses for further support
Recognition and referral of individuals with 'risk signs' to community nurses or hospital	<p>Volunteers refer individuals with:</p> <ul style="list-style-type: none"> - 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 cotrimoxazole prophylaxis - focal palsies
Adherence counselling	<ul style="list-style-type: none"> - Continuing supportive counselling on a one-to-one basis for those on cotrimoxazole prophylaxis and ART
Counselling on drug reactions and early referral	<ul style="list-style-type: none"> - Early recognition and referral of individuals having possible drug reactions to ART, cotrimoxazole or anti-TB treatment
Defaulter tracing	<ul style="list-style-type: none"> - Active tracing of individuals who do not show up for scheduled follow-up visits or for drug collection
Nutritional support	<ul style="list-style-type: none"> - Distribution and monitoring of supplementary dry rations to malnourished (BMI < 17 kg/m²) HIV/AIDS patients - Follow-up
Support to family carers	<ul style="list-style-type: none"> - Family carers provide: <ul style="list-style-type: none"> - information on HIV/AIDS and its prevention - counselling and support to ART, cotrimoxazole and anti-TB treatment - support with symptomatic treatment (define) - early recognition of possible drug reactions - nutritional supplementation - palliative care
Community mobilization centres and community farms	<ul style="list-style-type: none"> - Support in resource mobilization (e.g. for clay brick making) for the construction of community centers - Mobilization of labour for community vegetable, rabbit, fish and maize farms that supplement food to destitute individuals living with HIV/AIDS
Vocational training and income generation activities for HIV/AIDS orphans	<ul style="list-style-type: none"> - Carpenters, masons and tailors working in the community provide time for regular vocational training and supervision at community centres or at their own work-sites - Market sale of products from vocational training activities allows a revolving fund
Pre-school activities for HIV/AIDS orphans <5 years	<ul style="list-style-type: none"> - Daycare for orphans <5 years who live in single-member households
IEC/behaviour change interventions	<ul style="list-style-type: none"> - People living with HIV/AIDS are actively involved with disclosure and speaking about their experiences at IEC activities at community forums and meetings, as well as specific groups, such as community leaders (religious, traditional and political), teachers, youth in schools and commercial sex workers

TB: tuberculosis; BMI: body mass index; IEC: information, education and communication.

support was available in three of the seven traditional authorities.

Community activities are run by teams of volunteers and community nurses. In areas where community support exists, every HIV-positive individual is referred to a specific volunteer of the patient's choice living closest to the patient's residence. A carbon copy referral book is available at the hospital level and facilitates referrals as well as follow-up. This process is facilitated by geographical mapping of volunteers and a regularly updated list of available volunteers by villages.

Volunteers involved with care are organized into groups by geographic area and are supervised by teams of peer leaders and community nurses. One volunteer takes care of eight to 12 patients, and a peer leader is responsible for six to eight volunteers. A community nurse supports and supervises about 50 trained volunteers. Volunteers undergo a 2-week formal theoretical training on care and support followed by 'on-the-job training' with community nurses. The curriculum covers various aspects linked to HIV/AIDS, adherence counselling for ART, anti-TB treatment and home-based care (HBC) activities. Trained volunteers who do house-to-house visits are equipped with a 'home-based care kit' containing basic drugs and supportive material for first-line care of conditions including diarrhoea, fever, common skin conditions and oral thrush. Volunteers have also been trained to detect 'risk signs' that merit referral to a community nurse or a health facility (Table 2).

In families with advanced HIV/AIDS disease, at least one family member is trained 'on the job' as a 'family care giver' and this person conducts specific care-related activities at home (Table 2).

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, rain coats, seed grain, fertilizer for private or community farms, and bicycles. Community nurses receive a monthly salary.

2.5. Statistical analysis

Data was analyzed using Excel (Microsoft Corp., Seattle, WA, USA) and EpiInfo 6.04 (CDC, Atlanta, GA, USA). Standardized outcomes between these two groups were compared using the χ^2 test or Student's *t*-test for continuous variables. Relative risks were calculated using the STATCALC function in EpiInfo. All *P*-values are two sided, and the level of significance was set at *P* = 0.05 or less. Ninety-five per cent CI were used throughout.

3. Results

3.1. Characteristics of the study population, community care and support

By the end of December 2004, there were a total of 7062 HIV-positive individuals being followed-up by the HIV/AIDS clinic, of whom 95% were in WHO clinical stage III and IV. A total of 1634 of these individuals had been placed on ART, of whom 1062 (65%) were women and 572 (35%) were men, and whose median age was 33 years (interquartile range 28–42 years). There were a total of 895 (55%) individuals who lived in areas offering community support while 739 were from areas without such support. The characteristics of patients in the two groups are shown in Table 3.

Community care and support were provided by a team of 465 HBC volunteers, nine community nurses and 1362 trained family carers. A total of 60 715 home visits were conducted by the team of volunteers and nurses, of which

Table 3 Characteristics of patients on antiretroviral treatment (ART) in areas with and without community support

Characteristic	Offered community support [<i>n</i> (%)]	Not offered community support [<i>n</i> (%)]	<i>P</i> -value ^a
Gender			
Male	563 (63)	473 (64)	0.6
Female	322 (37)	266 (36)	0.6
Age [mean (SD)]	33 (12)	34 (10)	0.5
WHO clinical stage			
Stage III	680 (76)	539 (73)	0.2
Stage IV	215 (24)	200 (27)	0.1
CD4 count (cells/ μ l)			
0–99	340 (38)	325 (44)	0.01
100–199	269 (30)	214 (29)	0.7
>200	286 (32)	200 (27)	0.03
Body mass index (kg/m ²)			
<17	144 (16)	111(15)	0.5
17.0–18.4	116 (13)	74 (10)	0.06
>18.5	635 (71)	554 (75)	0.06
Active tuberculosis	125 (14)	118 (16)	0.2
Duration on ART [median (IQR)]	199 (87–395)	177 (94–373)	–
Total	895	739	

IQR: interquartile range.

^a χ^2 test or Student's *t*-test for continuous variables.

Table 4 Antiretroviral treatment (ART) outcomes in areas with and without community involvement in HIV/AIDS activities (patients registered April 2003–December 2004)

	Areas with community involvement [n (%)]	Areas without community involvement [n (%)]	P-value ^a
Placed on ART (n = 1634)	895	739	—
Alive and on ART ^b	856 (95.6)	560 (76)	<0.001
Died ^c	31 (3.5)	115 (15.5)	<0.001
Lost to follow-up (defaulted) ^d	1 (0.1)	39 (5.2)	<0.001
Stopped ^e	7 (0.8)	25 (3.3)	<0.001

^a χ^2 test.

^b Alive and has collected his/her monthly supply of drugs for December 2004.

^c Died from any reason while on ART.

^d Patient who was placed on ART and not seen at all during a period of 3 months thereafter.

^e Patient who has stopped ART completely, either because of side effects or for other reasons.

33% were visits made in relation to care-related activities, while the rest were related to raising community awareness, social mobilization, orphan support and defaulter tracing activities. The community team referred an average of 422 individuals each month to community nurses, the hospital, or health centres. Of these, 67% were for first-time VCT; 12% were to the antiretroviral clinic, either for starting ART or with ART-related complaints; 11% were for complicated opportunistic infections; 5% were to the TB office for complaints related to anti-TB treatment; 3% were for sexually transmitted infections; and 2% were known HIV-positive mothers who became pregnant.

3.2. ART outcomes

Table 4 compares ART outcomes among individuals who received community support and those with no such support. Treatment outcomes in all categories were significantly better in areas offering community care and support. The relative risks (RR) for patients who were offered community care and support compared to those without such support were: alive and on ART, RR = 1.26 (1.21–1.32, $P < 0.001$); death, RR = 0.22 (0.15–0.33, $P < 0.001$); loss to follow-up, RR = 0.02 (0.0–0.12, $P < 0.001$); and stopped, RR = 0.23 (0.08–0.54, $P < 0.001$).

4. Discussion

In a resource-limited rural district in Malawi, standardized ART outcomes measured in terms of alive and continuing ART, death, loss to follow-up (defaulters) and stopped ART were significantly better among those that received community support compared with those that did not.

Malawi, like other high HIV-prevalence countries in sub-Saharan Africa, is desperately trying to scale-up ART as a lifesaving intervention for its population. Of particular note from this study was that individuals who had benefited from community support had lower death rates than those who had not received such support.

The strength of this study is that a relatively large number of patients on ART were included in the analysis, outcomes were standardized and thus comparable, and as the data come from a programme setting, the results are likely to

reflect the reality on the ground. This is also one of the first studies that shows a favourable impact of community involvement in ART in a resource-poor, high HIV-prevalence country.

However, one of the main limitations of this study is the fact that, unlike a randomized controlled trial, the analysis is based on simple observational data, and thus it is not possible to know the exact reasons for the differences observed in death rates (or other outcomes) between the two groups.

Are there socio-economic differences or other factors that could have confounded the results? Thyolo district is covered with tea and coffee plantations, and the great majority of inhabitants in all the traditional authorities of the district depend on these plantations for their livelihood. Over 80% of the inhabitants of the district earn less than US\$4 per week and are thus very poor (Zachariah et al., 2002). Although we do not have specific data to support this, we therefore do not think there are significant differences in employment opportunities or earning capacity within the different traditional authorities nor the two groups in this study. The baseline nutritional characteristics of the two groups were similar, and this too favours such reasoning.

Although this study is not designed to show the exact reasons for the differences in outcomes between the two groups, it is reasonable to believe that the 'presence' of an organized and decentralized community network of care might have had a beneficial influence on outcomes for patients who were on ART. For example, individuals living in the three traditional authorities (who received community support) are likely to have benefited from better 'access' to community nurses and home volunteers that managed opportunistic infections. They were also more likely to have benefited from continuing support and referrals viz earlier diagnosis and prompt treatment of episodes of opportunistic infections, earlier referral of complicated cases to community nurses or health structures, earlier recognition and management of side effects to ART or other drugs (by volunteers and trained family carers), better adherence to treatment (through improved treatment literacy and support), and a more favourable home environment fostered through family carers. The cohort might also have been generally better prepared for ART.

These same factors, but also better 'empowerment' of patients and their families, as well as active defaulter

tracing as an integral component of community activity, might explain the fact that only one patient was lost to follow-up in areas with community support compared with 39 in areas without such support (Coetzee et al., 2004). Continuing adherence counselling and family support in areas with community support might also have had a favourable impact on the number of patients stopping ART for any reason (Mocroft et al., 2001).

Whatever the eventual reasons for the differences might be, what this study clearly demonstrates is that the presence of a decentralized community network of care and support significantly influenced overall ART outcomes and particularly death rates among individuals on ART. This information is of relevance for other districts in Malawi that are embarking on scaling up ART in similar circumstances to Thyolo.

HIV/AIDS is a chronic life-long disease, and care and support (including ART) initiated in health facilities needs to be provided over a continuum. However, sub-Saharan African countries, including Malawi, generally face a dire shortage of human resources, and the patient burden on existing health services is extremely high (Kober and Damme, 2004). For instance, public health facilities in Malawi face a severe staff shortage, with an estimated 50% of available MOH posts currently unfilled (MOHP, 2003c). Health workers in such countries are thus understandably unable to take on this added burden of community-based outreach activities.

In this light, communities might be a largely unrecognized and 'unexploited resource' that could play an important contributory role to ART outcomes on a national scale. However, community resources are not unlimited, and although there is a great potential here, it will be important to think of how to sustain it and to reflect on which parts of the community will need support to bear a growing burden. The community should also not be perceived as a group for simple relegation of activities (a dumping ground for responsibilities) that should fall under the mandate of public services or other potential partners (Zachariah et al., 2006).

Communities in countries such as Malawi have for the large part remained isolated from the public health system, and their role is undefined. It is likely to be a worthwhile endeavour to take communities on board in the fight against HIV/AIDS and reinforce efforts to encourage and enhance their role.

Conflicts of interest statement

The authors have no conflicts of interest concerning the work reported in this paper.

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