

Equity in access to ARV drugs in Malawi

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ABSTRACT

This paper discusses the issue of equity in the distribution of ARV drugs in the Malawi health system. Malawi is one of the countries most severely affected by HIV/AIDS in southern Africa. It is also one of the poorest countries in the world. ARV drugs are expensive. The Malawi government, with assistance from the Global Fund on Tuberculosis, Malaria and HIV/AIDS, started providing free ARV drugs to eligible HIV-infected people in September 2004. The provision of free drugs brought the hope that everyone who was eligible would access them. Based on data collected through a qualitative research methodology, it was found that achieving equity in provision would face several challenges including policy, operational and socio-economic considerations. Specifically, the existing policy framework, shortage of medical personnel, access to information and inadequacy of effective community support groups are some of the key issues affecting equity.

Key words: Access, ARV drugs, Malawi, equity

RÉSUMÉ

Cette communication aborde le sujet de l'équité vis-à-vis la distribution des drogues ARV au sein du système de santé du Malawi. Le Malawi est un des pays les plus touchés par le VIH/SIDA dans l'Afrique Australe. Il est également un des pays les plus pauvres du monde. Les drogues ARV sont très chères. Le gouvernement malawien, avec l'aide du Fond Mondial de lutte contre le SIDA, la Tuberculose et le Paludisme, a commencé à gratuitement dispenser des drogues ARV aux personnes séropositives qui remplissent les conditions requises, en septembre 2004. L'approvisionnement gratuit des drogues a donné un espoir que toute personne remplissant les conditions requises en aura accès. D'après les données rassemblées par le biais d'une méthodologie de recherche qualitative, on a constaté qu'il va falloir faire face à des nombreux défis avant d'atteindre l'équité, notamment la politique et les considérations fonctionnelles et socioéconomiques. En particulier, le cadre politique actuel, le manque du personnel médical, l'accès à l'information et l'insuffisance des groupes de soutien efficaces dans la communauté sont entre autres des sujets clés qui touchent à la question d'équité.

Mot clés: Accès, drogues ARV, le Malawi, équité.

INTRODUCTION AND BACKGROUND

Southern Africa continues to be heavily affected by the HIV/AIDS pandemic. Malawi is one of the countries that exhibits high prevalence. According to the Malawi Demographic and Health Survey (MDHS) of 2004, 12% of the population was living with HIV/AIDS (NSO/ ORC Macro, 2005). Urban and rural prevalence were 17.1 % and 10.8 % respectively. However, in terms of absolute numbers more rural than urban people are infected with HIV because 85% of Malawi's population lives in rural areas. Women generally exhibit higher prevalence up to around age

30, while men between the ages of 30 and 39 have higher infection rates. HIV rates also differ across different ethnic groups, educational levels, employment and wealth status and religious denomination and region of residence. There are probably a host of reasons that can explain these differences but it is beyond the scope of this paper to go into the possible explanations.

It is estimated that every year, about 85 000 Malawians die from AIDS. It is further estimated that since 1985, when the first case was diagnosed, more than 641 000

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Equity in access to ARV drugs in Malawi

people have died of AIDS (Office of the President and Cabinet, 2003). To date AIDS has no cure. However, the development of antiretroviral (ARV) drugs offered some hope for AIDS patients by prolonging their lives. In this regard, access to antiretroviral drugs or antiretroviral therapy (ART) is becoming a key health issue in Malawi, as in other countries equally hit by the pandemic. ARVs are not cheap. In Malawi, more than half of the population lives below the poverty line. Consequently, they cannot afford to buy them. The Global Fund for HIV/AIDS, Tuberculosis and Malaria is being used in Malawi to provide free ARVs. In spite of free provision, large numbers of people still do not have access to them. Muula (2004) considered the ethical and programmatic challenges in scaling-up ART, including those related to eligibility criteria, human resources and social eligibility. He concludes that 'the challenges are monumental but surmountable' (p.420), and recommends some of the ways this could be done. This paper discusses some of the same issues in addition to others, focussing on challenges in equitable access to ART.

Equity refers to the state of fairness and reasonableness where everyone is treated equally. With regard to ART, this implies equal opportunity of access. According to the government of Malawi (GOM, 2005), equity comprises elements of an assessment of vulnerability to illness and infection, and disadvantage in terms of access to care and treatment, or ability to cope with the impact of the illness. In addition to this view the government argues that in a health system where resources are severely limited, it is important to consider the impact of ART provision on 'equity' for the provision of essential health services. While ensuring that ARV provision does not discriminate against any group of people on the basis of sex, age, residence and socio-economic status, essential health services should also not be jeopardised. Therefore an assessment of whether there is equity or not in the provision of ART would be judged in terms of practices and conditions that are both unacceptable and avoidable.

Method of study

This paper was produced from a bigger research project that the author conducted on behalf of the Joint Oxfam programme in Malawi. The research adopted a qualitative methodology. Several tools of data

collection were used, including consultative meetings with key stakeholders, review and analysis of documentary sources, key informant interviews and community-level focus group interviews. The main documentary sources used were those published by the World Health Organisation (WHO) on the 3 by 5 strategy, the National HIV/AIDS Policy, ART guidelines and the ARV progress monitoring reports by the Ministry of Health and Population (MoH&P), as well as general reports by the TB Equinet on equity issues. It is recognised that the literature review was not exhaustive because it was in large measure determined by availability and accessibility of documents.

In total, I conducted 28 semi-structured key informant interviews, six focus group discussions and two village meetings. The number of key informants was determined by the number of relevant stakeholders with regard to issues of HIV/AIDS generally and ART specifically. At least one key informant was interviewed in each organisation using a semi-structured questionnaire. Key informants were medical doctors in the Ministry of Health as well as in non-governmental organisations (NGOs), head of missions of medical NGOs, medical personnel and NGO staff running HIV/AIDS programmes. These were selected on the basis of their positions and the likelihood that they were probably best placed in the organisations to provide the required information.

Focus group discussions targeted women and men in selected rural communities. The participants were selected at random with the help of staff from NGOs working in the area, staff of other community based organisations (CBOs) and traditional leaders. Each focus group discussion had between 8 and 12 individuals and took from one hour to one and a half hours. A semi-structured interview guide with open ended questions was used to initiate discussion.

The research covered all the three regions in Malawi, concentrating on the major ARV programmes. All three regions were covered because at the time of the research, there were very few ARV programmes in the country and the major ones were spread across the country's three regions. In this regard, the results of this research could be said to be fairly representative of the whole country.

Equity in access to ARV drugs in Malawi

Context for the provision of ARV Drugs in Malawi (from paying to free drugs)

For a long time, Malawi concentrated its efforts on prevention and the treatment of opportunistic infections (OIs). Public health services in Malawi are free. There is also no health insurance for people who are not formally employed. Antiretroviral therapy was considered very expensive for the government and for many years it failed to become part of the free public health service provision. However, perhaps with the increasing availability of generic drugs and the consequent lowering in cost, the government began to provide a limited service of ARVs. The initial efforts constituted the establishment of an ARV Drug Revolving Fund in the major hospitals of Blantyre and Lilongwe. Drugs were provided to patients at the subsidised cost of K2 500 per month (about US\$25 at that time). Government also encouraged the involvement of the private sector in the provision of ARV drugs (Kawala, 2003).

However, high poverty levels in Malawi (more than 65% of the population live below the poverty line of 1US\$ per day) meant that even with the provision of subsidised ARV drugs, the majority of those in need could not afford to buy them. High poverty levels are coupled with the fact that the large majority of people in Malawi do not have any health insurance or medical cover schemes as pointed out above. It was evident in some studies that purchasing ARV drugs could in fact serve to plunge certain families further into poverty and, in addition, default rates due to failure to continue paying for drugs was found to be high (Ministry of Health and Population, 2005)

It is within this context that in order to move towards equitable provision, as well as guard against the dangers of drug resistance to the virus, government decided to provide free ARV drugs, especially when the Global Fund was introduced, even if earlier consultations with key stakeholders and the general public showed that not everyone favoured free ART for all (Mwansambo and Chizimba, 2004). Free provision was preferred in view of problems of targeting. However, such problems would have appeared only if active, rather than self-targeting was used. Therefore, an opportunity was lost to learn some lessons, if any, that a system with parallel distributions could have generated.

Extent of ARV needs

Health officials estimate that out of about 1 million people infected with the HIV virus in Malawi, 170 000 are eligible for ART. However, at the last ARV provision update by the Ministry of Health and Population in June, 2006, there were 57 366 people who ever started on ART, representing about 34%. As part of the WHO 3 by 5 strategy, Malawi's target was to reach between 36 000 and 40 000 people with ART by December 2005. Evidently, this target has been achieved (WHO/UNAIDS, 2006). Originally, it was ideally thought that 80 000 should have been put on ART by that period, but scaling up that fast has many challenges as will be discussed in later sections of this paper. A summary of ART in Malawi up to June 2006 is presented in the table below.

CUMULATIVE PATIENTS EVER STARTED ON ART UP TO JUNE 30TH, 2006

Total started	Total number of patients started on ART	57 366	
Sex	Number (%) males	22 406	39%
	Number (%) females	34 960	61%
Age	Number (%) adults aged 15 years and above	53 853	94%
	Number (%) children aged 14 years and below	3 513	6%
Occupation	Housewife	10 573	22%
	Farmer	11 544	24%
	Forces	885	2%
	Teacher	2 283	5%
	Business	6 778	14%
	HCW	966	2%
	Student	2 149	5%
	Other	12 557	26%
Reasons for starting ART	Occupation unknown	9 631	
	Number (%) with Stage III	38 122	66%
	Number (%) with Stage IV	13 692	24%
	Number (%) with low CD4 count	5 552	10%
Patient outcomes	Number (%) of patients started on ART due to TB	9 633	17%
	Total number of patients started on ART	57 366	
	Number (%) alive and on ART	41 549	72%
	Number (%) dead	6 576	11%
ART regimen	Number (%) defaulted	4 644	8%
	Number (%) stopped treatment	312	1%
	Number (%) transferred out permanently to another site	4 285	7%
	Of those alive and on ART:-	41 549	
ART regimen	Number (%) on first line regimen	40 064	96%
	Number (%) on alternative first line regimen	1 361	3%
	Number (%) on second line regimen	124	0%

Equity in access to ARV drugs in Malawi

CUMULATIVE PATIENTS EVER STARTED ON ART UP TO JUNE 30TH, 2006 (CONTINUED)

Ambulatory status	Number with ambulatory status known	38 038	
	Number (%) ambulatory	36 276	95%
Work status	Number with work status known	38 038	
	Number (%) at work	35 041	92%
Side effects	Number with side effects counted	30 279	
	Number (%) with significant side effects	1 450	5%
Adherence	Number where pill count has been done	27 422	
	Number (%) with pill count showing 95% adherence	25 078	91%
Death	Of those who died with Date of death recorded	6 519	
	Number (%) dying in the first month	2 248	34%
	Number (%) dying in the second month	1 491	23%
	Number (%) dying in the third month	801	12%
	Number (%) dying after the third month	1 979	30%

Source: Ministry of Health and Population (2006).

When looking at equity it is important to know not only *how many* are accessing ART but also *who* are accessing it. Data on occupation was available for only 47 735 patients. The most common occupations were housewife, farmer and small-scale business people (such as vendors). However, it is not possible from this data to tell with certainty whether ART provision is equitable between the poor and the economically better off. There are strong grounds (some of which will be discussed later in this paper) for believing that ART provision has so far tended to favour the less poor. Such grounds relate to many issues including the policy framework for the provision of ART, the state of the health system and differences in people's socio-economic position in society, which affords different life chances and opportunities. It is to these aspects that we now turn.

Policy and guidelines for provision of ARV drugs

National policies on ART are embedded in the National HIV/AIDS Policy (Office of the President and Cabinet, 2003). With specific reference to ART, the government undertakes, among other things, to provide access to affordable, high quality ART and prophylaxis to prevent opportunistic infections to

eligible individuals. The policy also undertakes to ensure that every person has access to accurate information regarding HIV treatment options as well as information on where and how to access treatment, care and support (p. 21). ART is provided on a first come first served basis.

The overall strategy in Malawi is to provide ART to patients within a 'public health approach', which involves mobilising all existing ARV delivery sites and identifying new ones to provide standardised combination ARV therapy to HIV-positive people who present to health facilities and who are eligible for treatment, using the guardian supported treatment. The guardian supported treatment is a component, which makes it mandatory for patients to have a guardian in order to receive treatment. This helps to ensure adherence to treatment, as well as in monitoring and evaluation of the treatment process (MoH and P, 2004 p. 9).

Eligibility criteria

Voluntary Testing and Counselling (VCT)

Only people who have tested positive with HIV testing and exhibit certain medical conditions are eligible for ARV therapy. This means that testing is the first point of entry into ARV therapy and the Prevention of Mother To Child Transmission (PMTCT) programmes. As such, ensuring that VCT services are accessible to all is a key step in equitable provision. However, although the demand for ARV therapy is high, VCT services are far from reaching everyone. VCT services tend to concentrate in urban areas or rural towns. Just like health facilities in general, government operates a limited number of testing centres, due to resource limitations in infrastructure, health personnel and equipment. Private testing centres are almost non-existent in rural areas, as these prefer to locate in urban areas where they can get paying clients. People from remote areas must travel long distances to access them and many have no money to travel for this purpose, especially when they are not ill. The Malawi AIDS Counselling and Resource Organisation (MACRO) statistics, for example, showed that between 1992 and 2004 there was a cumulative figure of clients of only 48 527. It should also be mentioned that once tested an individual is not given a certificate to indicate that they have been tested. Thus, for the purposes of ART the individual must test again at a testing centre

Equity in access to ARV drugs in Malawi

attached to the health institution where ART will be initiated, doubling the testing burden.

Medical conditions for eligibility

HIV-positive patients who are eligible to start ART are those who fall into WHO clinical stages III and IV, have a CD4 count below 200/mm³ regardless of WHO staging or symptoms, and those who are in WHO stage II but have a total lymphocyte count of less than 1200/mm³ (WHO, 2002; Ministry Of Health, 2003).

The WHO clinical stages detail the medical conditions applicable to each stage of the progression of the disease and offer the best way of expanding the entry point into ART where CD4 count is not possible. Only 17 facilities out of the 94 (18%) who were providing ART in Malawi had CD4 machines. Reagents for tests and for machines were also said to be a problem in some facilities (MoH&P, 2006). In public health facilities CD4 tests are free as part of the free provision of ART, while in private hospitals these are paid for as part of the cost of ART.

Interviews with various stakeholders, however, suggested that the clinical staging procedure was not without problems. Firstly, the process was quite subjective at times, as medical conditions could change dramatically within a short period of time. Secondly, there seemed to be no clear relationship between clinical staging and CD4 count. It was observed by some medical doctors that, depending on a combination of factors, including differences in nutrition and psychological factors among the infected, a CD4 count of less than 200mm³ may not always be confined to stage III and stage IV of infection. For example, in their programme in one of the districts in Malawi (Chiradzulu), Médecins Sans Frontières (MSF) France found that about 30% of WHO clinical stage II patients had a CD4 count of less than 200/mm³ (MSF/MoH&P, 2004). This lack of fit may result in delayed start of ART in some patients, or no start at all for others whose illness might progress quickly to death. This finding points to the crucial role of CD4 machines in equitable ART provision.

Providers of ARV drugs

By the end of June 2006 (MoH&P, 2006) there were 94 facilities in Malawi providing ART free of charge in the public health sector. Several health facilities under

the Christian Hospitals Association of Malawi (CHAM) throughout the country were provided ART free of charge as well. However, at such facilities, patients had to pay for consultation sometimes, depending on the hospital, and for other drugs for treating opportunistic infections. Private providers of ART exist but they are very few and the cost of ART (about US\$50) a month is too high for the majority of patients. In addition, the Ministry of Health and Population also trained a number of small-scale private practitioners, based on their willingness and suitability of their facilities, to provide ART at a subsidised cost of MK500 (about US\$4) for a month's treatment. The subsidy might help to increase the numbers of people who access ART through private providers, thereby easing the burden for the public hospitals. But despite all these various types of facilities, the outlets that reaches the most people are public health facilities with Queen Elizabeth Central Hospital in Blantyre (Southern Region) and The Light House Clinic at Lilongwe Central Hospital (Central Region) having the largest numbers of people on ART. Specific data on provision of ART in private versus public health facilities was, however, not available.

Capacity to distribute drugs

The capacity of the Malawi health system, particularly with regard to the available human resources, to distribute drugs appears to be probably the most important aspect that affects equitable access to ART. Kober and Van Damme (2004), discuss the challenges of scaling up ART in southern Africa (Malawi included): 'We found that financial resources are not regarded as the immediate constraint anymore, but the lack of human resources for health is deplored as the most serious obstacle for implementing the national treatment plans' (p.103). Discussing the many causes of staff shortages in the health sector, the authors conclude that present measures to increase the number of health personnel are not adequate and recommend a number of possibilities for addressing the staff shortages.

It should be said that even when the health system was functioning properly (the current health system is suffering from severe drug, equipment and manpower shortages, partly resulting from Structural Adjustment Programmes during the 80s and 90s), equity to normal health services could not be attained. The geographical distribution of health facilities and their sizes relative to

Equity in access to ARV drugs in Malawi

population, as well as the equipment, numbers and calibre of personnel available at these facilities, generally favour the urban areas, and particularly the large cities. Proximity to major health facilities is a key issue in accessing adequate and good quality health care. Poverty and low educational status place people relatively further away from health services compared with the educated and affluent at similar geographical distances.

ART only complicates the situation further, since it needs specialised personnel who have been properly trained to counsel patients, diagnose the medical conditions, dispense the medicines and monitor and evaluate treatment progress. Another compounding factor is that government's concept of equity for ARV therapy is one that ensures that the other essential health services are not jeopardised. This means that there are severe limits to the extent to which personnel in existing health facilities can be diverted to ART, which has a life of its own. ART is more complicated than conventional treatment. Unlike the latter, it involves many processes, including pre-test counselling, testing and post-test counselling, initial drug disbursement, medical review for side effects, and monthly or bi-monthly collection of drugs. The whole treatment process also involves quite a lot of record keeping to monitor adherence and progress of patients, as well as to assist in monitoring drug stocks. As such, ART requires more (and specially trained) medical personnel than conventional treatment.

At the minimum the following personnel are required for an ARV clinic to operate (Ministry of Health, 2003. p.19):

- 1 clinical officer (full-time) for the time of the clinic
- 1 nurse (full-time) for the time of the clinic
- 1 counsellor (full-time) for the time of the clinic
- 1 ward clerk (full time) for the time of the clinic

With proper training, medical officers and clinical officers can initiate and prescribe drugs, while medical assistants and nurses can be allowed to assist medical and clinical officers to administer and deliver ARV drugs within the clinics. A laboratory that can do quality assured HIV-testing (and if the drug zidovudine is being used, also a Haemoglobin test) is essential for all initiating clinics.

A typical minimum-staff level clinic as described above is referred to as a 'low burden clinic', which means that it can only accept 25 new cases per month. A crude mathematical calculation can help us to appreciate why a clinic with this number of personnel cannot distribute ARV drugs to large numbers of patients.¹ In general, it is evident that not all clinics serve the required numbers of patients since the 94 facilities currently providing ART have managed to accommodate only about a third of those eligible.

The limitations placed on ART scale-up due to capacity problems can also be illustrated by the experience of the MSF-France Chiradzulu programme. The total number of personnel, if we combine decentralised (where ART is provided at health centres, rather than major district hospitals) and the hospital-based teams, included two expatriate doctors, five clinical officers, three ARV nurses, and four counsellors. With an accumulated figure of about 3 500 patients, from Chiradzulu district only, the MSF programme was already beginning to find it difficult to accommodate any more eligible patients.

With regard to capacity issues we could conclude that despite goodwill, and even if funds were available to purchase adequate drugs for all the eligible AIDS patients currently living in Malawi, it would not be possible to distribute such drugs safely and effectively, given the current human resources and physical infrastructure. This realisation should lead practitioners, policy makers, lobbyists, advocates, donors and commentators to refrain, as they have done in some cases, from focussing on the availability of the drugs only, but also to place equal emphasis on the need for adequate numbers of qualified medical personnel as well as adequate physical infrastructure. These aspects are in fact necessary for the health system in general.

Socio-economic issues affecting access and equity

Information and disinformation

Access to correct information is key with regard to the issue of equity. This is particularly so because Malawi has adopted a 'first come first served' strategy in the delivery of ART. Knowledge of issues surrounding ART is undoubtedly the primary aspect of the decision-making process to access the service.

Equity in access to ARV drugs in Malawi

Many people in focus group discussions and village meetings in one of the districts I visited, for example, had not even heard of ARVs. At Bango village I interviewed members of one CBO and ordinary members of the community. Out of 40 people, who included volunteers of a home-based care (HBC) programme, only seven indicated that they had ever heard of ARVs. Out of this number only four were able to provide a description of what they were. Their only source of information appeared to be the radio. In another district, HBC members stated clearly that they did not have adequate information regarding ARVs in public hospitals. For example, they still thought that one had to pay for ARVs. In another focus group discussion in the same district, while four out of nine people knew what ARVs were, none knew anyone in the village who was accessing the drugs. One woman said: *'we don't even know what they look like. So if someone was selling them saying they were malaria drugs, we would buy them'*. The dangers implied in this statement are obvious.

There were many reports that people still associated HIV/AIDS with witchcraft. It is possible that witchcraft could sometimes be mentioned as an easy scapegoat to the fear of stigma as well as a reflection of denial. However, the point remains valid that the more informed people are, the more they are likely to start changing some of their beliefs, attitudes and perhaps even behaviour towards seeking ART.

There was also a general lack of proper understanding of the progression of AIDS, which led to difficulties in understanding the WHO clinical staging system. The whole question of why someone may not need to be on ART even when they had tested positive for HIV was not properly understood. The situation was made worse in cases where a person felt physically weak and unwell but had not exhibited WHO clinical stage III and IV symptoms to be eligible for ART or had not had a CD4 count. This confusion led some people to express doubts regarding the benefits of HIV-testing and the fairness of ART provision. Such doubts could hold people back from seeking treatment.

Home-based care and patient support groups

Home-based care programmes and patient support groups are very good sources of information for ART.

It was clear during the research that, where such organisations were strong, the degree of knowledge about ART was high and the numbers of people accessing ARVs were also high. For example, in contrast to the situation described for one district above, all the people who belonged to a patient support group at a Health Centre in an adjacent district had all the necessary information regarding ART. In the Thyolo MSF HBC programme, out of 5 707 chronically ill patients, 1 007 were accessing ART. Noteworthy about this HBC programme was the fact that it had 465 trained volunteers and nine HBC nurses. However, it was still evident that many factors impinged on access, as demonstrated by the fact that even in this big and well-organised programme, the 1 007 who were accessing ART were a fraction of the 2 183 people who were eligible by falling in WHO clinical stages III and IV.

Beyond merely providing information, HBC programmes are important in many other respects. They are crucial as an element of Information Education and Communication (IEC) on ART; they assist in preparing patients to receive ART through group counselling in the community by the HBC nurse; they help in identifying and referring those who are sick and need to access ART immediately or soon; they sometimes provide food which helps to boost the nutrition of patients who can not afford adequate food; they act as a forum for ongoing counselling and monitoring adherence to treatment; they treat opportunistic infections and they also encourage HIV-positive people to join patient support groups where they can get more knowledge on positive living. Many of them also provide psychological support through pastoral care. In this regard, promoting and supporting HBC groups should be regarded as a key aspect of equitable provision of ART.

It was noted, however, that the effectiveness of HBC groups and patient support groups was greatly compromised by a number of factors. The most important one appeared to be lack of proper training for the staff. As mentioned above, even some HBC volunteers did not have adequate information and knowledge on ART. Most HBC members had attended only 3-day or a week's training at best on health issues, of which ART was only a very small part, or not covered at all.

Equity in access to ARV drugs in Malawi

Volunteers

HBC programmes depend on volunteers. Therefore, the motivation, recruitment and retention of volunteers have been key issues in public health provision in Malawi, as well as elsewhere in the developing world, where governments are not able to meet all the health needs of the population through formally employed staff. The question as to whether volunteers should be given some money in return for their services is still being debated in many circles. There were strong appeals by several of the HBC staff I interviewed for activities that would motivate volunteers who sacrifice their own time, and sometimes money (and thus ultimately livelihood) to support others. Specifically, interviewed HBC staff suggested that appropriate motivating incentives for volunteers could include the provision of bicycles (frequently they walked long distances on foot and this also limited their work apart from eating too much into their time), training support, small amounts of cash to buy food as they did the rounds (sometimes they worked on an empty stomach) and to buy small, but necessary items for patients, particularly soap for bathing and washing, and HBC kits such as gloves, disinfectants and basic drugs for treating opportunistic infections.

Peer counselling

Staff in the MSF programmes indicated that they found peer counsellors (i.e. those already on ART) to be very effective in disseminating information on ART and helping to convince those still held back by fear, shyness, denial and traditional beliefs from accessing the service.

Indeed, where there were no examples of treatment success, (demonstration effect) stories of AIDS being the result of witchcraft and people simply failing to accept the AIDS issue abounded. In these areas, even HBC personnel were afraid to raise the issue of ART to possible eligible people. Said one: *Akutukwana kuti ine ndiye ukuti ndili ndi EDZI* (someone will curse you for accusing them that they have AIDS). In areas where people had many examples of people who were sick but became well because of ART, they had become more open and forthcoming on HIV/AIDS issues.

Religious and traditional leaders, Chambe², and the traditional medicine question

In all the three regions of the country, there were stories of patients who had stopped ART because they

had become born again Christians. This is a difficult question to deal with as it involves a specific definition of faith in supernatural powers.

There were also several reports by medical personnel from all the three regions in Malawi that some patients had stopped their ART in favour of *Chambe* or some other traditional medicine. Some of those patients were reported to have come back to re-start ART after their condition worsened while others had died. While it could be true, as noted in the Ministry of Health report (2005)) that the number of people stopping ART due to either *Chambe* or religious convictions was quite small, the net effect of these influences in terms of preventing people from starting ART altogether could (or could not) yield relatively larger numbers. Lessons need to be learned from countries where there is close collaboration between the health system and traditional healers as regards their role in ART, even if it is just not to discourage people from accessing it.

Geographical location and poverty

Information flows and transport.

Information flows generally favour those who are close to the source of information physically or socially. Physically, those living in remote rural areas generally have poor access to information. There are no newspapers or groups through which information can be obtained. The radio appears to be the only good source of information, but the fact is that not many people in rural areas have working radios. Socially, information flows favour the well to do and the educated. They can travel more widely and can afford to buy printed matter, in addition to accessing audio-visual transmissions and even the Internet. In this regard, while important, the effort made by the Ministry of Health and Population to inform the public regarding health facilities where they can access ARV drugs through the print media, would be regarded as grossly inadequate. More concerted efforts to disseminate information in different ways including social mobilisation campaigns are undoubtedly required.

Health services in Malawi are not evenly distributed. For the poor and for those living far away from VCT centres and ARV clinics, availability and affordability of transport are key issues with regard to accessing the

Equity in access to ARV drugs in Malawi

services. There were many reports of people failing to travel to the district or central hospitals for initiation of ART (which requires at least two visits). In addition, monthly collections of ARV drugs from clinics present transportation cost challenges for the guardians and patients who must visit the clinic together.

For example, one orphan care and HIV/AIDS education centre in Thyolo district conducted a mobilisation campaign through drama for people to test for HIV. After the campaign 60 people came forward for the test. However, most could not afford transport to go for the test at the nearest test centre. In another district (Ntcheu) a CBO was receiving mobile testing services. However, the VCT visits were not adequate to meet the existing demand. Only about 120 people could be tested per month, and at the time of interviews only 600 people had been tested, with a waiting list of 3 000.

Gender and age aspects

Gender inequality, aggravated by imbalances in decision-making power between men and women that exist in Malawian society, surfaces in many aspects of health, including issues of HIV/AIDS. With regard to HIV/AIDS in general, and ART in particular, however, the influence of gender appears to produce mixed outcomes. To begin with, the total cumulative number of patients who ever started on ART up to June 2006 favoured women in the ratio of 61% against 39% for males (MoH&P, 2006). In the MSF France Chiradzulu programme, the proportions accessing ART were 35% males and 65% females.

The key issues centre on the decision to go for VCT and disclosure of status. Most people I interviewed in the medical programmes, including VCT staff, indicated that generally more women went for testing than men, and in addition, women were more likely to reveal their positive status than men. However, for the Malawi AIDS Counselling and Resource Organisation (MACRO), 60% of whose clients are between 15 and 24 years of age, the ratio of VCT was 70% males and 30% females, even though prevalence for HIV was higher among females than males. These data seem to indicate that older, probably married, women are more likely to go for a test than younger girls. The fact that more young men than young women are willing to go for testing may be related to issues of limited levels of assertiveness among girls and other cultural barriers. This is an area that would require further investigation.

Although adult women appeared more willing to test than adult men, village level interviews revealed that women wanting to test usually had to ask for permission from their husbands. In some cases permission was granted. In others, it was denied and it could be a source of family conflict, with men accusing the women, perhaps rather defensively, that the reason the women wanted to go for a test was because they knew that they had not been faithful. On the other hand, women were psychologically troubled and wanted to go for testing because they suspected that their husbands had not been faithful to them.

Revelation of status was sometimes costly for the women as some husbands chased away HIV-positive wives. The result of men hiding themselves was perhaps partly reflected in the higher numbers of women accessing ART. In addition, some NGO personnel stated that this problem also resulted in men coming late into the ARV programme. Men's negative attitudes and behaviour towards women who are found to be HIV positive also affect women's entry into the PMTCT programme. Many pregnant women, while willing to have an HIV test, were afraid to tell their husbands about a positive result and thus frequently either joined the PMTCT programme late or failed to join it altogether.

Ninety three per cent of those accessing ART are aged 15 years and above. Only 7% are children below 15 years. What is not known is the overall proportion of children out of the estimated total number of those eligible for ART. However, there is reason to believe that, because of issues to do with ethical and practical considerations in testing and treating children, particularly orphans and other children living by themselves, fewer children than are eligible could be receiving treatment (Muula, 2004). In addition to these issues, at the treatment level, there are no special formations of ARV drugs for them. Syrups are available from some manufacturers at the international level but the global fund does not have any provision for drugs for children, let alone special formations.³

CONCLUSIONS

Equity and the state of the health system

Equity is undoubtedly an ideal that must be pursued in all aspects of human existence. At the same time it is also important to understand that the issue of equity in access to ART in many developing countries like

Equity in access to ARV drugs in Malawi

Malawi operates within the context of health systems which have severe limitations in human and infrastructure resources. In addition, a range of geographical, economic and socio-cultural reasons does not even ensure 100% equity in normal circumstances. Therefore, the key issues in equity in access as viewed by the government make sense. These are with regard to a) providing ART without jeopardising other essential health services; and b) ensuring that failure to provide ART only happens in situations that cannot be avoided.

Policies on ART provision

In the Malawi context the policy statements with regard to ART are general, indicating government's commitment to ensure that all eligible individuals have access. However, the policy is not specific in terms of specifying the instruments that can ensure that poor and other vulnerable groups have equitable access, considering that the ground for ART provision is not even. On the contrary, the first-come first-served policy, while easy to implement, is unfair, at least by default if not by design, because of the uneven socio-economic or even geographical ground upon which the ART programme is operating. The policy favours those near the ART service either literally or in terms of access to transportation and, perhaps more crucially, information. We argue that both lack of access to information, and within certain limits, transportation, can be avoided and, therefore, should not unnecessarily exert limits on access to ART for poor people.

Information dissemination

The ARV scale up plan states that a comprehensive campaign to inform the general public about the rapid scale up of ARV therapy would need to be prepared. The campaign would involve schools, churches, and civil society, with the National AIDS Commission providing leadership in this regard. This paper argues that there are still critical gaps in information relating to ART. The problems of print media in a poor country with high illiteracy levels where most people do not buy, let alone read, newspapers are obvious. Yet the Ministry of Health and Population has tended to rely on this communication medium to inform people about ART.

Human resources and infrastructure

From the health systems point of view, the main bottlenecks in access are that: a) VCT facilities, which

are the entry point into ART, are inadequate and not equitably accessible, and b) that the initiation of free ART has to be done at the district or the central hospital (where there are properly trained personnel) or equivalent CHAM units. These institutions are not only located far apart, but they also have limited capacity. The experience of some providers show that once initiation has been done, follow up could be done at other decentralised centres, thus easing the burden of the initiating hospitals. We argue that government needs to make special efforts to equip health centres to administer ART if equitable provision is to be enhanced.

Community mobilisation

A vicious cycle seems to perpetuate itself where the absence of cases of successful ART in communities resulting from lack of access, including the unavailability of community mobilisation programmes carried out by properly trained HBC staff, peer educators and others, lead to continued stigmatisation, fear and lack of acceptance and openness about HIV/AIDS issues. This situation provides fertile ground for additional negative influences, such as the voices of some religious leaders and traditional healers, all of which contribute to preventing some people from accessing ART. The supporting of HBC programmes and other CBOs should be seen as crucial in addressing these problems.

Sustainability of ART

Since HIV/AIDS is a global issue, the concern to avoid situations where there is rapid development of resistance by the virus to the ARV drugs is shared internationally. Therefore, it should be expected that no one would be willing to pour more drugs into a health system where the potential for this danger to be realised are high. By the same token it is reasonable to assume that an effective programme would attract continued, and possibly, increased funding. Therefore, effectiveness and accountability in providing ART in a way which does not only address the issue of equitable distribution, but which also has effective follow up and monitoring and evaluation systems, are crucial for sustainability. So far, with 91% of patients showing 95% or more adherence to therapy based on pill counts (MoH&P, 2006), ARV provision appears to be effective and accountable for those already on ART.

However, for the health system to continue to be effective and to include more patients, it needs

Equity in access to ARV drugs in Malawi

adequate and properly trained personnel. Nevertheless, we argue that current experience provides an encouraging indication that it is possible to run an effective programme in the existing circumstances, while continuing to provide training to health workers. But what this also suggests is that caution needs to be exercised in the scale up so that the system is not overwhelmed. This caution could initially appear to be a compromise on equity, but such apparent compromise could be seen as a necessary evil to prevent a greater catastrophe.

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Footnotes

¹If we assume that all patients have no complications, then it would take about five minutes for the patients already on ARV drugs to pass through the ART process of a) reception (records), b) consultation by a nurse or clinician, and c) dispensing of drugs, including the recording of information in the drug book. This translates into 12 patients in one hour. Assuming the clinic operates an eight-hour day, non-stop, it would be able to see a maximum of 96 patients per day. Thus, multiplying 96 by 20 working days in a month, the absolute operating capacity for this clinic would be 1 920 patients. To serve the current estimated 170 000 people who are eligible for ARV therapy, 88 of such clinics would be required.

Many ARV clinics were introducing 'the fast track nurse'. This is the nurse who would administer a checklist of questions to the patient and if the patient has had no complications with the treatment in the period preceding the visit will be allowed to proceed to collect a new consignment of drugs without having to be seen by a clinician or a doctor. However, it would still take a few moments to run down the checklist.

²A current and relatively famous traditional concoction claimed by its producer to cure AIDS.

³Adult ARV drugs are inconvenient for children because the tablets must always be broken for children to be able to swallow. Medically, some have raised questions as to whether the wholeness of the treatment is not affected when tablets are broken compared to pre-produced syrup.

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